

THE OFFICIAL
PATIENT'S SOURCEBOOK

on

WHIPPLE'S
DISEASE



JAMES N. PARKER, M.D.
AND PHILIP M. PARKER, PH.D., EDITORS

ICON Health Publications
ICON Group International, Inc.
4370 La Jolla Village Drive, 4th Floor
San Diego, CA 92122 USA

Copyright ©2002 by ICON Group International, Inc.

Copyright ©2002 by ICON Group International, Inc. All rights reserved. This book is protected by copyright. No part of it may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without written permission from the publisher.

Printed in the United States of America.

Last digit indicates print number: 10 9 8 7 6 4 5 3 2 1

Publisher, Health Care: Tiffany LaRochelle
Editor(s): James Parker, M.D., Philip Parker, Ph.D.

Publisher's note: The ideas, procedures, and suggestions contained in this book are not intended as a substitute for consultation with your physician. All matters regarding your health require medical supervision. As new medical or scientific information becomes available from academic and clinical research, recommended treatments and drug therapies may undergo changes. The authors, editors, and publisher have attempted to make the information in this book up to date and accurate in accord with accepted standards at the time of publication. The authors, editors, and publisher are not responsible for errors or omissions or for consequences from application of the book, and make no warranty, expressed or implied, in regard to the contents of this book. Any practice described in this book should be applied by the reader in accordance with professional standards of care used in regard to the unique circumstances that may apply in each situation, in close consultation with a qualified physician. The reader is advised to always check product information (package inserts) for changes and new information regarding dose and contraindications before taking any drug or pharmacological product. Caution is especially urged when using new or infrequently ordered drugs, herbal remedies, vitamins and supplements, alternative therapies, complementary therapies and medicines, and integrative medical treatments.

Cataloging-in-Publication Data

Parker, James N., 1961-
Parker, Philip M., 1960-

The Official Patient's Sourcebook on Whipple's Disease: A Revised and Updated Directory for the Internet
Age/James N. Parker and Philip M. Parker, editors

p. cm.

Includes bibliographical references, glossary and index.

ISBN: 0-597-83410-5

1. Whipple's Disease-Popular works. I. Title.

Disclaimer

This publication is not intended to be used for the diagnosis or treatment of a health problem or as a substitute for consultation with licensed medical professionals. It is sold with the understanding that the publisher, editors, and authors are not engaging in the rendering of medical, psychological, financial, legal, or other professional services.

References to any entity, product, service, or source of information that may be contained in this publication should not be considered an endorsement, either direct or implied, by the publisher, editors or authors. ICON Group International, Inc., the editors, or the authors are not responsible for the content of any Web pages nor publications referenced in this publication.

Copyright Notice

If a physician wishes to copy limited passages from this sourcebook for patient use, this right is automatically granted without written permission from ICON Group International, Inc. (ICON Group). However, all of ICON Group publications are copyrighted. With exception to the above, copying our publications in whole or in part, for whatever reason, is a violation of copyright laws and can lead to penalties and fines. Should you want to copy tables, graphs or other materials, please contact us to request permission (e-mail: iconedit@san.rr.com). ICON Group often grants permission for very limited reproduction of our publications for internal use, press releases, and academic research. Such reproduction requires confirmed permission from ICON Group International Inc. **The disclaimer above must accompany all reproductions, in whole or in part, of this sourcebook.**

Dedication

To the healthcare professionals dedicating their time and efforts to the study of Whipple's disease.

Acknowledgements

The collective knowledge generated from academic and applied research summarized in various references has been critical in the creation of this sourcebook which is best viewed as a comprehensive compilation and collection of information prepared by various official agencies which directly or indirectly are dedicated to Whipple's disease. All of the *Official Patient's Sourcebooks* draw from various agencies and institutions associated with the United States Department of Health and Human Services, and in particular, the Office of the Secretary of Health and Human Services (OS), the Administration for Children and Families (ACF), the Administration on Aging (AOA), the Agency for Healthcare Research and Quality (AHRQ), the Agency for Toxic Substances and Disease Registry (ATSDR), the Centers for Disease Control and Prevention (CDC), the Food and Drug Administration (FDA), the Healthcare Financing Administration (HCFA), the Health Resources and Services Administration (HRSA), the Indian Health Service (IHS), the institutions of the National Institutes of Health (NIH), the Program Support Center (PSC), and the Substance Abuse and Mental Health Services Administration (SAMHSA). In addition to these sources, information gathered from the National Library of Medicine, the United States Patent Office, the European Union, and their related organizations has been invaluable in the creation of this sourcebook. Some of the work represented was financially supported by the Research and Development Committee at INSEAD. This support is gratefully acknowledged. Finally, special thanks are owed to Tiffany LaRochelle for her excellent editorial support.

About the Editors

James N. Parker, M.D.

Dr. James N. Parker received his Bachelor of Science degree in Psychobiology from the University of California, Riverside and his M.D. from the University of California, San Diego. In addition to authoring numerous research publications, he has lectured at various academic institutions. Dr. Parker is the medical editor for the *Official Patient's Sourcebook* series published by ICON Health Publications.

Philip M. Parker, Ph.D.

Philip M. Parker is the Eli Lilly Chair Professor of Innovation, Business and Society at INSEAD (Fontainebleau, France and Singapore). Dr. Parker has also been Professor at the University of California, San Diego and has taught courses at Harvard University, the Hong Kong University of Science and Technology, the Massachusetts Institute of Technology, Stanford University, and UCLA. Dr. Parker is the associate editor for the *Official Patient's Sourcebook* series published by ICON Health Publications.

About ICON Health Publications

In addition to Whipple's disease, *Official Patient's Sourcebooks* are available for the following related topics:

- The Official Patient's Sourcebook on Appendicitis
- The Official Patient's Sourcebook on Autoimmune Hepatitis
- The Official Patient's Sourcebook on Bacteria and Foorborne Illness
- The Official Patient's Sourcebook on Barrett's Esophagus
- The Official Patient's Sourcebook on Celiac Disease
- The Official Patient's Sourcebook on Cirrhosis of the Liver
- The Official Patient's Sourcebook on Constipation
- The Official Patient's Sourcebook on Crohn Disease
- The Official Patient's Sourcebook on Cyclic Vomiting Syndrome
- The Official Patient's Sourcebook on Diarrhea
- The Official Patient's Sourcebook on Diverticular Disease
- The Official Patient's Sourcebook on Fecal Incontinence
- The Official Patient's Sourcebook on Gallstones
- The Official Patient's Sourcebook on Gas
- The Official Patient's Sourcebook on Gastritis
- The Official Patient's Sourcebook on Gastroparesis
- The Official Patient's Sourcebook on Hemolytic Uremic Syndrome
- The Official Patient's Sourcebook on Hemorrhoids
- The Official Patient's Sourcebook on Hepatitis A
- The Official Patient's Sourcebook on Hepatitis B
- The Official Patient's Sourcebook on Hepatitis C
- The Official Patient's Sourcebook on Hiatal Hernia
- The Official Patient's Sourcebook on Hirschsprung
- The Official Patient's Sourcebook on Indigestion
- The Official Patient's Sourcebook on Inguinal Hernia
- The Official Patient's Sourcebook on Intestinal Pseudo-obstruction
- The Official Patient's Sourcebook on Irritable Bowel Syndrome
- The Official Patient's Sourcebook on Lactose Intolerance
- The Official Patient's Sourcebook on Ménétrier
- The Official Patient's Sourcebook on Pancreatitis
- The Official Patient's Sourcebook on Peptic Ulcer
- The Official Patient's Sourcebook on Porphyria
- The Official Patient's Sourcebook on Primary Biliary Cirrhosis
- The Official Patient's Sourcebook on Primary Sclerosing Cholangitis
- The Official Patient's Sourcebook on Proctitis

- The Official Patient's Sourcebook on Rapid Gastric Emptying
- The Official Patient's Sourcebook on Short Bowel Syndrome
- The Official Patient's Sourcebook on Ulcerative Colitis
- The Official Patient's Sourcebook on Wilson's Disease
- The Official Patient's Sourcebook on Zollinger-ellison Syndrome

To discover more about ICON Health Publications, simply check with your preferred online booksellers, including Barnes & Noble.com and Amazon.com which currently carry all of our titles. Or, feel free to contact us directly for bulk purchases or institutional discounts:

ICON Group International, Inc.
4370 La Jolla Village Drive, Fourth Floor
San Diego, CA 92122 USA
Fax: 858-546-4341
Web site: www.icongrouponline.com/health

Table of Contents

INTRODUCTION.....	1
<i>Overview</i>	1
<i>Organization</i>	3
<i>Scope</i>	3
<i>Moving Forward</i>	4
PART I: THE ESSENTIALS	7
CHAPTER 1. THE ESSENTIALS ON WHIPPLE’S DISEASE: GUIDELINES..	9
<i>Overview</i>	9
<i>What Is Whipple’s Disease?</i>	11
<i>For More Information</i>	12
<i>Additional Information on Whipple’s Disease</i>	12
<i>More Guideline Sources</i>	13
<i>Vocabulary Builder</i>	15
CHAPTER 2. SEEKING GUIDANCE	19
<i>Overview</i>	19
<i>Associations and Whipple’s Disease</i>	19
<i>Finding Doctors</i>	21
<i>Selecting Your Doctor</i>	23
<i>Working with Your Doctor</i>	23
<i>Broader Health-Related Resources</i>	25
PART II: ADDITIONAL RESOURCES AND ADVANCED MATERIAL	27
CHAPTER 3. STUDIES ON WHIPPLE’S DISEASE.....	29
<i>Overview</i>	29
<i>The Combined Health Information Database</i>	29
<i>E-Journals: PubMed Central</i>	31
<i>The National Library of Medicine: PubMed</i>	32
<i>Vocabulary Builder</i>	32
CHAPTER 4. BOOKS ON WHIPPLE’S DISEASE.....	39
<i>Overview</i>	39
<i>Book Summaries: Online Booksellers</i>	39
<i>The National Library of Medicine Book Index</i>	40
<i>Chapters on Whipple’s Disease</i>	40
<i>General Home References</i>	41
<i>Vocabulary Builder</i>	42
CHAPTER 5. MULTIMEDIA ON WHIPPLE’S DISEASE	43
<i>Overview</i>	43
<i>Bibliography: Multimedia on Whipple’s Disease</i>	43
<i>Vocabulary Builder</i>	44

PART III. APPENDICES	45
APPENDIX A. RESEARCHING YOUR MEDICATIONS.....	47
<i>Overview</i>	47
<i>Your Medications: The Basics</i>	48
<i>Learning More about Your Medications</i>	50
<i>Commercial Databases</i>	50
<i>Contraindications and Interactions (Hidden Dangers)</i>	51
<i>A Final Warning</i>	52
<i>General References</i>	53
APPENDIX B. RESEARCHING NUTRITION	55
<i>Overview</i>	55
<i>Food and Nutrition: General Principles</i>	56
<i>Finding Studies on Whipple's Disease</i>	60
<i>Federal Resources on Nutrition</i>	61
<i>Additional Web Resources</i>	62
APPENDIX C. FINDING MEDICAL LIBRARIES	63
<i>Overview</i>	63
<i>Preparation</i>	63
<i>Finding a Local Medical Library</i>	64
<i>Medical Libraries Open to the Public</i>	64
APPENDIX D. YOUR RIGHTS AND INSURANCE	71
<i>Overview</i>	71
<i>Your Rights as a Patient</i>	71
<i>Patient Responsibilities</i>	75
<i>Choosing an Insurance Plan</i>	76
<i>Medicare and Medicaid</i>	78
<i>NORD's Medication Assistance Programs</i>	81
<i>Additional Resources</i>	82
<i>Vocabulary Builder</i>	83
ONLINE GLOSSARIES.....	85
<i>Online Dictionary Directories</i>	86
WHIPPLE'S DISEASE GLOSSARY.....	87
<i>General Dictionaries and Glossaries</i>	96
INDEX.....	98

INTRODUCTION

Overview

Dr. C. Everett Koop, former U.S. Surgeon General, once said, “The best prescription is knowledge.”¹ The Agency for Healthcare Research and Quality (AHRQ) of the National Institutes of Health (NIH) echoes this view and recommends that every patient incorporate education into the treatment process. According to the AHRQ:

Finding out more about your condition is a good place to start. By contacting groups that support your condition, visiting your local library, and searching on the Internet, you can find good information to help guide your treatment decisions. Some information may be hard to find – especially if you don’t know where to look.²

As the AHRQ mentions, finding the right information is not an obvious task. Though many physicians and public officials had thought that the emergence of the Internet would do much to assist patients in obtaining reliable information, in March 2001 the National Institutes of Health issued the following warning:

The number of Web sites offering health-related resources grows every day. Many sites provide valuable information, while others may have information that is unreliable or misleading.³

¹ Quotation from <http://www.drkoop.com>.

² The Agency for Healthcare Research and Quality (AHRQ):
<http://www.ahrq.gov/consumer/diaginfo.htm>.

³ From the NIH, National Cancer Institute (NCI):
<http://cancertrials.nci.nih.gov/beyond/evaluating.html>.

Since the late 1990s, physicians have seen a general increase in patient Internet usage rates. Patients frequently enter their doctor's offices with printed Web pages of home remedies in the guise of latest medical research. This scenario is so common that doctors often spend more time dispelling misleading information than guiding patients through sound therapies. *The Official Patient's Sourcebook on Whipple's Disease* has been created for patients who have decided to make education and research an integral part of the treatment process. The pages that follow will tell you where and how to look for information covering virtually all topics related to Whipple's disease, from the essentials to the most advanced areas of research.

The title of this book includes the word "official." This reflects the fact that the sourcebook draws from public, academic, government, and peer-reviewed research. Selected readings from various agencies are reproduced to give you some of the latest official information available to date on Whipple's disease.

Given patients' increasing sophistication in using the Internet, abundant references to reliable Internet-based resources are provided throughout this sourcebook. Where possible, guidance is provided on how to obtain free-of-charge, primary research results as well as more detailed information via the Internet. E-book and electronic versions of this sourcebook are fully interactive with each of the Internet sites mentioned (clicking on a hyperlink automatically opens your browser to the site indicated). Hard copy users of this sourcebook can type cited Web addresses directly into their browsers to obtain access to the corresponding sites. Since we are working with ICON Health Publications, hard copy *Sourcebooks* are frequently updated and printed on demand to ensure that the information provided is current.

In addition to extensive references accessible via the Internet, every chapter presents a "Vocabulary Builder." Many health guides offer glossaries of technical or uncommon terms in an appendix. In editing this sourcebook, we have decided to place a smaller glossary within each chapter that covers terms used in that chapter. Given the technical nature of some chapters, you may need to revisit many sections. Building one's vocabulary of medical terms in such a gradual manner has been shown to improve the learning process.

We must emphasize that no sourcebook on Whipple's disease should affirm that a specific diagnostic procedure or treatment discussed in a research study, patent, or doctoral dissertation is "correct" or your best option. This sourcebook is no exception. Each patient is unique. Deciding on appropriate

options is always up to the patient in consultation with their physician and healthcare providers.

Organization

This sourcebook is organized into three parts. Part I explores basic techniques to researching Whipple's disease (e.g. finding guidelines on diagnosis, treatments, and prognosis), followed by a number of topics, including information on how to get in touch with organizations, associations, or other patient networks dedicated to Whipple's disease. It also gives you sources of information that can help you find a doctor in your local area specializing in treating Whipple's disease. Collectively, the material presented in Part I is a complete primer on basic research topics for patients with Whipple's disease.

Part II moves on to advanced research dedicated to Whipple's disease. Part II is intended for those willing to invest many hours of hard work and study. It is here that we direct you to the latest scientific and applied research on Whipple's disease. When possible, contact names, links via the Internet, and summaries are provided. It is in Part II where the vocabulary process becomes important as authors publishing advanced research frequently use highly specialized language. In general, every attempt is made to recommend "free-to-use" options.

Part III provides appendices of useful background reading for all patients with Whipple's disease or related disorders. The appendices are dedicated to more pragmatic issues faced by many patients with Whipple's disease. Accessing materials via medical libraries may be the only option for some readers, so a guide is provided for finding local medical libraries which are open to the public. Part III, therefore, focuses on advice that goes beyond the biological and scientific issues facing patients with Whipple's disease.

Scope

While this sourcebook covers Whipple's disease, your doctor, research publications, and specialists may refer to your condition using a variety of terms. Therefore, you should understand that Whipple's disease is often considered a synonym or a condition closely related to the following:

- Intestinal Lipodystrophy
- Intestinal Lipodystrophy (name Used by Dr. Whipple in 1907)

- Intestinal Lipophagic Granulomatosis
- Lipophagic Intestinal Granulomatosis
- Secondary Nontropical Sprue
- Secondary Non-tropical Sprue

In addition to synonyms and related conditions, physicians may refer to Whipple's disease using certain coding systems. The International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) is the most commonly used system of classification for the world's illnesses. Your physician may use this coding system as an administrative or tracking tool. The following classification is commonly used for Whipple's disease:⁴

- 040.2 whipple's disease

For the purposes of this sourcebook, we have attempted to be as inclusive as possible, looking for official information for all of the synonyms relevant to Whipple's disease. You may find it useful to refer to synonyms when accessing databases or interacting with healthcare professionals and medical librarians.

Moving Forward

Since the 1980s, the world has seen a proliferation of healthcare guides covering most illnesses. Some are written by patients or their family members. These generally take a layperson's approach to understanding and coping with an illness or disorder. They can be uplifting, encouraging, and highly supportive. Other guides are authored by physicians or other healthcare providers who have a more clinical outlook. Each of these two styles of guide has its purpose and can be quite useful.

As editors, we have chosen a third route. We have chosen to expose you to as many sources of official and peer-reviewed information as practical, for the purpose of educating you about basic and advanced knowledge as recognized by medical science today. You can think of this sourcebook as your personal Internet age reference librarian.

⁴ This list is based on the official version of the World Health Organization's 9th Revision, International Classification of Diseases (ICD-9). According to the National Technical Information Service, "ICD-9CM extensions, interpretations, modifications, addenda, or errata other than those approved by the U.S. Public Health Service and the Health Care Financing Administration are not to be considered official and should not be utilized. Continuous maintenance of the ICD-9-CM is the responsibility of the federal government."

Why “Internet age”? All too often, patients diagnosed with Whipple’s disease will log on to the Internet, type words into a search engine, and receive several Web site listings which are mostly irrelevant or redundant. These patients are left to wonder where the relevant information is, and how to obtain it. Since only the smallest fraction of information dealing with Whipple’s disease is even indexed in search engines, a non-systematic approach often leads to frustration and disappointment. With this sourcebook, we hope to direct you to the information you need that you would not likely find using popular Web directories. Beyond Web listings, in many cases we will reproduce brief summaries or abstracts of available reference materials. These abstracts often contain distilled information on topics of discussion.

Before beginning your search for information, it is important for you to realize that Whipple’s disease is considered a relatively uncommon condition. Because of this, far less research is conducted on Whipple’s disease compared to other health problems afflicting larger populations, like breast cancer or heart disease. Nevertheless, this sourcebook will prove useful for two reasons. First, if more information does become available on Whipple’s disease, the sources given in this book will be the most likely to report or make such information available. Second, some will find it important to know about patient support, symptom management, or diagnostic procedures that may be relevant to both Whipple’s disease and other conditions. By using the sources listed in the following chapters, self-directed research can be conducted on broader topics that are related to Whipple’s disease but not readily uncovered using general Internet search engines (e.g. www.google.com or www.yahoo.com). In this way, we have designed this sourcebook to complement these general search engines that can provide useful information and access to online patient support groups.⁵

While we focus on the more scientific aspects of Whipple’s disease, there is, of course, the emotional side to consider. Later in the sourcebook, we provide a chapter dedicated to helping you find peer groups and associations that can provide additional support beyond research produced by medical science. We hope that the choices we have made give you the most options available in moving forward. In this way, we wish you the best in your efforts to incorporate this educational approach into your treatment plan.

The Editors

⁵ For example, one can simply go to www.google.com, or other general search engines (e.g. www.yahoo.com, www.aol.com, www.msn.com) and type in “Whipple’s disease support group” to find any active online support groups dedicated to Whipple’s disease.

PART I: THE ESSENTIALS

ABOUT PART I

Part I has been edited to give you access to what we feel are “the essentials” on Whipple’s disease. The essentials of a disease typically include the definition or description of the disease, a discussion of who it affects, the signs or symptoms associated with the disease, tests or diagnostic procedures that might be specific to the disease, and treatments for the disease. Your doctor or healthcare provider may have already explained the essentials of Whipple’s disease to you or even given you a pamphlet or brochure describing Whipple’s disease. Now you are searching for more in-depth information. As editors, we have decided, nevertheless, to include a discussion on where to find essential information that can complement what your doctor has already told you. In this section we recommend a process, not a particular Web site or reference book. The process ensures that, as you search the Web, you gain background information in such a way as to maximize your understanding.

CHAPTER 1. THE ESSENTIALS ON WHIPPLE'S DISEASE: GUIDELINES

Overview

Official agencies, as well as federally-funded institutions supported by national grants, frequently publish a variety of guidelines on Whipple's disease. These are typically called "Fact Sheets" or "Guidelines." They can take the form of a brochure, information kit, pamphlet, or flyer. Often they are only a few pages in length. The great advantage of guidelines over other sources is that they are often written with the patient in mind. Since new guidelines on Whipple's disease can appear at any moment and be published by a number of sources, the best approach to finding guidelines is to systematically scan the Internet-based services that post them.

The National Institutes of Health (NIH)⁶

The National Institutes of Health (NIH) is the first place to search for relatively current patient guidelines and fact sheets on Whipple's disease. Originally founded in 1887, the NIH is one of the world's foremost medical research centers and the federal focal point for medical research in the United States. At any given time, the NIH supports some 35,000 research grants at universities, medical schools, and other research and training institutions, both nationally and internationally. The rosters of those who have conducted research or who have received NIH support over the years include the world's most illustrious scientists and physicians. Among them are 97 scientists who have won the Nobel Prize for achievement in medicine.

⁶ Adapted from the NIH: <http://www.nih.gov/about/NIHoverview.html>.

There is no guarantee that any one Institute will have a guideline on a specific disease, though the National Institutes of Health collectively publish over 600 guidelines for both common and rare diseases. The best way to access NIH guidelines is via the Internet. Although the NIH is organized into many different Institutes and Offices, the following is a list of key Web sites where you are most likely to find NIH clinical guidelines and publications dealing with Whipple's disease and associated conditions:

- Office of the Director (OD); guidelines consolidated across agencies available at <http://www.nih.gov/health/consumer/conkey.htm>
- National Library of Medicine (NLM); extensive encyclopedia (A.D.A.M., Inc.) with guidelines available at <http://www.nlm.nih.gov/medlineplus/healthtopics.html>
- National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); guidelines available at <http://www.niddk.nih.gov/health/health.htm>

Among these, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is particularly noteworthy. The NIDDK's mission is to conduct and support research on many of the most serious diseases affecting public health.⁷ The Institute supports much of the clinical research on the diseases of internal medicine and related subspecialty fields as well as many basic science disciplines. The NIDDK's Division of Intramural Research encompasses the broad spectrum of metabolic diseases such as diabetes, inborn errors of metabolism, endocrine disorders, mineral metabolism, digestive diseases, nutrition, urology and renal disease, and hematology. Basic research studies include biochemistry, nutrition, pathology, histochemistry, chemistry, physical, chemical, and molecular biology, pharmacology, and toxicology. NIDDK extramural research is organized into divisions of program areas:

- Division of Diabetes, Endocrinology, and Metabolic Diseases
- Division of Digestive Diseases and Nutrition
- Division of Kidney, Urologic, and Hematologic Diseases

The Division of Extramural Activities provides administrative support and overall coordination. A fifth division, the Division of Nutrition Research Coordination, coordinates government nutrition research efforts. The Institute supports basic and clinical research through investigator-initiated

⁷ This paragraph has been adapted from the NIDDK: <http://www.niddk.nih.gov/welcome/mission.htm>. "Adapted" signifies that a passage is reproduced exactly or slightly edited for this book.

grants, program project and center grants, and career development and training awards. The Institute also supports research and development projects and large-scale clinical trials through contracts. The following patient guideline was recently published by the NIDDK on Whipple's disease.

What Is Whipple's Disease?⁸

Whipple's disease is a malabsorption disease. It interferes with the body's ability to absorb certain nutrients. The disease causes weight loss, irregular breakdown of carbohydrates and fats, resistance to insulin, and malfunctions of the immune system. When recognized and treated, Whipple's disease can be cured. Untreated, the disease is usually fatal.

Whipple's disease is caused by bacteria. It can affect any system of the body, but occurs most often in the small intestine. The disease causes lesions on the wall of the small intestine and thickening of the tissue. The villi--tiny, finger-like protrusions from the wall that help absorb nutrients--are destroyed.

Symptoms include diarrhea, intestinal bleeding, abdominal bloating and cramps, loss of appetite, weight loss, fatigue, and weakness. Arthritis and fever often occur several years before intestinal symptoms develop. Diagnosis is based on symptoms and results of a biopsy of tissue from the small intestine.

Whipple's disease is treated with antibiotics to destroy the bacteria that cause the disease. The physician may use a number of different types, doses, and schedules of antibiotics to find the best treatment. Depending on the seriousness of the disease, treatment may also include fluid and electrolyte replacement. Electrolytes are salts and other substances in body fluid that the heart and brain need to function properly. Extra iron, folate, vitamin D, calcium, and magnesium may also be given to help compensate for the vitamins and minerals the body is not absorbing on its own.

Symptoms usually disappear after 1 to 3 months of treatment. Because relapse is common even after successful treatment, the health care team may continue to observe patients for some time.

⁸ Adapted from the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK): <http://www.niddk.nih.gov/health/digest/summary/whipple/whipple.htm>.

For More Information

More information is available from:

National Organization for Rare Disorders Inc.

P.O. Box 8923

New Fairfield, CT 06812-8923

Tel: (800) 999-6673 or (203) 746-6518

E-mail: orphan@nord-rdb.com

Home page: www.rarediseases.org

Additional Information on Whipple's Disease

The National Digestive Diseases Information Clearinghouse collects resource information on digestive diseases for the Combined Health Information Database (CHID). CHID is a database produced by health-related agencies of the Federal Government. This database provides titles, abstracts, and availability information for health information and health education resources.

To provide you with the most up-to-date resources, information specialists at the clearinghouse created an automatic search of CHID. To obtain this information you may view the results of the automatic search on Whipple's Disease.

Or, if you wish to perform your own search of the database, you may access the CHID Online web site and search CHID yourself.

National Digestive Diseases Information Clearinghouse

2 Information Way

Bethesda, MD 20892-3570

E-mail: National Digestive Diseases Information Clearinghouse

The National Digestive Diseases Information Clearinghouse (NDDIC) is a service of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). NIDDK is part of the National Institutes of Health under the U.S. Department of Health and Human Services. Established in 1980, the clearinghouse provides information about digestive diseases to people with digestive disorders and to their families, health care professionals, and the public. NDDIC answers inquiries; develops, reviews, and distributes publications; and works closely with professional and patient organizations and Government agencies to coordinate resources about digestive diseases. Publications produced by

the clearinghouse are carefully reviewed for scientific accuracy, content, and readability.

More Guideline Sources

The guideline above on Whipple's disease is only one example of the kind of material that you can find online and free of charge. The remainder of this chapter will direct you to other sources which either publish or can help you find additional guidelines on topics related to Whipple's disease. Many of the guidelines listed below address topics that may be of particular relevance to your specific situation or of special interest to only some patients with Whipple's disease. Due to space limitations these sources are listed in a concise manner. Do not hesitate to consult the following sources by either using the Internet hyperlink provided, or, in cases where the contact information is provided, contacting the publisher or author directly.

Topic Pages: MEDLINEplus

For patients wishing to go beyond guidelines published by specific Institutes of the NIH, the National Library of Medicine has created a vast and patient-oriented healthcare information portal called MEDLINEplus. Within this Internet-based system are "health topic pages." You can think of a health topic page as a guide to patient guides. To access this system, log on to <http://www.nlm.nih.gov/medlineplus/healthtopics.html>. From there you can either search using the alphabetical index or browse by broad topic areas.

If you do not find topics of interest when browsing health topic pages, then you can choose to use the advanced search utility of MEDLINEplus at <http://www.nlm.nih.gov/medlineplus/advancedsearch.html>. This utility is similar to the NIH Search Utility, with the exception that it only includes material linked within the MEDLINEplus system (mostly patient-oriented information). It also has the disadvantage of generating unstructured results. We recommend, therefore, that you use this method only if you have a very targeted search.

The National Guideline Clearinghouse™

The National Guideline Clearinghouse™ offers hundreds of evidence-based clinical practice guidelines published in the United States and other countries. You can search their site located at <http://www.guideline.gov> by using the keyword "Whipple's disease" or synonyms.

Healthfinder™

Healthfinder™ is an additional source sponsored by the U.S. Department of Health and Human Services which offers links to hundreds of other sites that contain healthcare information. This Web site is located at <http://www.healthfinder.gov>. Again, keyword searches can be used to find guidelines.

The NIH Search Utility

After browsing the references listed at the beginning of this chapter, you may want to explore the NIH Search Utility. This allows you to search for documents on over 100 selected Web sites that comprise the NIH-WEB-SPACE. Each of these servers is "crawled" and indexed on an ongoing basis. Your search will produce a list of various documents, all of which will relate in some way to Whipple's disease. The drawbacks of this approach are that the information is not organized by theme and that the references are often a mix of information for professionals and patients. Nevertheless, a large number of the listed Web sites provide useful background information. We can only recommend this route, therefore, for relatively rare or specific disorders, or when using highly targeted searches. To use the NIH search utility, visit the following Web page: <http://search.nih.gov/index.html>.

Additional Web Sources

A number of Web sites that often link to government sites are available to the public. These can also point you in the direction of essential information. The following is a representative sample:

- AOL: <http://search.aol.com/cat.adp?id=168&layer=&from=subcats>
- drkoop.com®: <http://www.drkoop.com/conditions/ency/index.html>
- Family Village: <http://www.familyvillage.wisc.edu/specific.htm>

- Google: http://directory.google.com/Top/Health/Conditions_and_Diseases/
- Med Help International: <http://www.medhelp.org/HealthTopics/A.html>
- Open Directory Project: http://dmoz.org/Health/Conditions_and_Diseases/
- Yahoo.com: http://dir.yahoo.com/Health/Diseases_and_Conditions/
- WebMD[®]Health: http://my.webmd.com/health_topics

Vocabulary Builder

The material in this chapter may have contained a number of unfamiliar words. The following Vocabulary Builder introduces you to terms used in this chapter that have not been covered in the previous chapter:

Alimentary: Pertaining to food or nutritive material, or to the organs of digestion. [EU]

Antibiotic: A chemical substance produced by a microorganism which has the capacity, in dilute solutions, to inhibit the growth of or to kill other microorganisms. Antibiotics that are sufficiently nontoxic to the host are used as chemotherapeutic agents in the treatment of infectious diseases of man, animals and plants. [EU]

Bacteria: Unicellular prokaryotic microorganisms which generally possess rigid cell walls, multiply by cell division, and exhibit three principal forms: round or coccid, rodlike or bacillary, and spiral or spirochetal. [NIH]

Biopsy: The removal and examination, usually microscopic, of tissue from the living body, performed to establish precise diagnosis. [EU]

Carbohydrate: An aldehyde or ketone derivative of a polyhydric alcohol, particularly of the pentahydric and hexahydric alcohols. They are so named because the hydrogen and oxygen are usually in the proportion to form water, (CH₂O)_n. The most important carbohydrates are the starches, sugars, celluloses, and gums. They are classified into mono-, di-, tri-, poly- and heterosaccharides. [EU]

Chronic: Persisting over a long period of time. [EU]

Diarrhea: Passage of excessively liquid or excessively frequent stools. [NIH]

Electrolyte: A substance that dissociates into ions when fused or in solution, and thus becomes capable of conducting electricity; an ionic solute. [EU]

Endocrinology: A subspecialty of internal medicine concerned with the metabolism, physiology, and disorders of the endocrine system. [NIH]

Fatal: Causing death, deadly; mortal; lethal. [EU]

Fatigue: The state of weariness following a period of exertion, mental or physical, characterized by a decreased capacity for work and reduced efficiency to respond to stimuli. [NIH]

Fats: One of the three main classes of foods and a source of energy in the body. Fats help the body use some vitamins and keep the skin healthy. They also serve as energy stores for the body. In food, there are two types of fats: saturated and unsaturated. [NIH]

Hematology: A subspecialty of internal medicine concerned with morphology, physiology, and pathology of the blood and blood-forming tissues. [NIH]

Immunization: The induction of immunity. [EU]

Influenza: An acute viral infection involving the respiratory tract. It is marked by inflammation of the nasal mucosa, the pharynx, and conjunctiva, and by headache and severe, often generalized, myalgia. [NIH]

Insulin: A protein hormone secreted by beta cells of the pancreas. Insulin plays a major role in the regulation of glucose metabolism, generally promoting the cellular utilization of glucose. It is also an important regulator of protein and lipid metabolism. Insulin is used as a drug to control insulin-dependent diabetes mellitus. [NIH]

Lesion: Any pathological or traumatic discontinuity of tissue or loss of function of a part. [EU]

Malabsorption: Impaired intestinal absorption of nutrients. [EU]

Mental: Pertaining to the mind; psychic. 2. (L. mentum chin) pertaining to the chin. [EU]

Molecular: Of, pertaining to, or composed of molecules : a very small mass of matter. [EU]

Pancreatitis: Inflammation (pain, tenderness) of the pancreas; it can make the pancreas stop working. It is caused by drinking too much alcohol, by disease in the gallbladder, or by a virus. [NIH]

Spectrum: A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. By extension, a measurable range of activity, such as the range of bacteria affected by an antibiotic (antibacterial s.) or the complete range of manifestations of a disease. [EU]

Toxicology: The science concerned with the detection, chemical composition, and pharmacologic action of toxic substances or poisons and the treatment and prevention of toxic manifestations. [NIH]

Urology: A surgical specialty concerned with the study, diagnosis, and treatment of diseases of the urinary tract in both sexes and the genital tract in

the male. It includes the specialty of andrology which addresses both male genital diseases and male infertility. [NIH]

Vaccine: A suspension of attenuated or killed microorganisms (bacteria, viruses, or rickettsiae), administered for the prevention, amelioration or treatment of infectious diseases. [EU]

CHAPTER 2. SEEKING GUIDANCE

Overview

Some patients are comforted by the knowledge that a number of organizations dedicate their resources to helping people with Whipple's disease. These associations can become invaluable sources of information and advice. Many associations offer aftercare support, financial assistance, and other important services. Furthermore, healthcare research has shown that support groups often help people to better cope with their conditions.⁹ In addition to support groups, your physician can be a valuable source of guidance and support. Therefore, finding a physician that can work with your unique situation is a very important aspect of your care.

In this chapter, we direct you to resources that can help you find patient organizations and medical specialists. We begin by describing how to find associations and peer groups that can help you better understand and cope with Whipple's disease. The chapter ends with a discussion on how to find a doctor that is right for you.

Associations and Whipple's Disease

As mentioned by the Agency for Healthcare Research and Quality, sometimes the emotional side of an illness can be as taxing as the physical side.¹⁰ You may have fears or feel overwhelmed by your situation. Everyone has different ways of dealing with disease or physical injury. Your attitude, your expectations, and how well you cope with your condition can all

⁹ Churches, synagogues, and other houses of worship might also have groups that can offer you the social support you need.

¹⁰ This section has been adapted from <http://www.ahcpr.gov/consumer/diagin5.htm>.

influence your well-being. This is true for both minor conditions and serious illnesses. For example, a study on female breast cancer survivors revealed that women who participated in support groups lived longer and experienced better quality of life when compared with women who did not participate. In the support group, women learned coping skills and had the opportunity to share their feelings with other women in the same situation. There are a number of directories that list additional medical associations that you may find useful. While not all of these directories will provide different information, by consulting all of them, you will have nearly exhausted all sources for patient associations.

The National Health Information Center (NHIC)

The National Health Information Center (NHIC) offers a free referral service to help people find organizations that provide information about Whipple's disease. For more information, see the NHIC's Web site at <http://www.health.gov/NHIC/> or contact an information specialist by calling 1-800-336-4797.

DIRLINE

A comprehensive source of information on associations is the DIRLINE database maintained by the National Library of Medicine. The database comprises some 10,000 records of organizations, research centers, and government institutes and associations which primarily focus on health and biomedicine. DIRLINE is available via the Internet at the following Web site: <http://dirline.nlm.nih.gov/>. Simply type in "Whipple's disease" (or a synonym) or the name of a topic, and the site will list information contained in the database on all relevant organizations.

The Combined Health Information Database

Another comprehensive source of information on healthcare associations is the Combined Health Information Database. Using the "Detailed Search" option, you will need to limit your search to "Organizations" and "Whipple's disease". Type the following hyperlink into your Web browser: <http://chid.nih.gov/detail/detail.html>. To find associations, use the drop boxes at the bottom of the search page where "You may refine your search by." For publication date, select "All Years." Then, select your preferred language and the format option "Organization Resource Sheet." By making

these selections and typing in “Whipple’s disease” (or synonyms) into the “For these words:” box, you will only receive results on organizations dealing with Whipple’s disease. You should check back periodically with this database since it is updated every 3 months.

The National Organization for Rare Disorders, Inc.

The National Organization for Rare Disorders, Inc. has prepared a Web site that provides, at no charge, lists of associations organized by specific diseases. You can access this database at the following Web site: <http://www.rarediseases.org/cgi-bin/nord/searchpage>. Select the option called “Organizational Database (ODB)” and type “Whipple’s disease” (or a synonym) in the search box.

Online Support Groups

In addition to support groups, commercial Internet service providers offer forums and chat rooms for people with different illnesses and conditions. WebMD[®], for example, offers such a service at their Web site: <http://boards.webmd.com/roundtable>. These online self-help communities can help you connect with a network of people whose concerns are similar to yours. Online support groups are places where people can talk informally. If you read about a novel approach, consult with your doctor or other healthcare providers, as the treatments or discoveries you hear about may not be scientifically proven to be safe and effective.

Finding Doctors

One of the most important aspects of your treatment will be the relationship between you and your doctor or specialist. All patients with Whipple’s disease must go through the process of selecting a physician. While this process will vary from person to person, the Agency for Healthcare Research and Quality makes a number of suggestions, including the following:¹¹

- If you are in a managed care plan, check the plan’s list of doctors first.
- Ask doctors or other health professionals who work with doctors, such as hospital nurses, for referrals.

¹¹ This section is adapted from the AHRQ: www.ahrq.gov/consumer/qntascii/qntdr.htm.

- Call a hospital's doctor referral service, but keep in mind that these services usually refer you to doctors on staff at that particular hospital. The services do not have information on the quality of care that these doctors provide.
- Some local medical societies offer lists of member doctors. Again, these lists do not have information on the quality of care that these doctors provide.

Additional steps you can take to locate doctors include the following:

- Check with the associations listed earlier in this chapter.
- Information on doctors in some states is available on the Internet at <http://www.docboard.org>. This Web site is run by "Administrators in Medicine," a group of state medical board directors.
- The American Board of Medical Specialties can tell you if your doctor is board certified. "Certified" means that the doctor has completed a training program in a specialty and has passed an exam, or "board," to assess his or her knowledge, skills, and experience to provide quality patient care in that specialty. Primary care doctors may also be certified as specialists. The AMBS Web site is located at <http://www.abms.org/newsearch.asp>.¹² You can also contact the ABMS by phone at 1-866-ASK-ABMS.
- You can call the American Medical Association (AMA) at 800-665-2882 for information on training, specialties, and board certification for many licensed doctors in the United States. This information also can be found in "Physician Select" at the AMA's Web site: <http://www.ama-assn.org/aps/amahg.htm>.

If the previous sources did not meet your needs, you may want to log on to the Web site of the National Organization for Rare Disorders (NORD) at <http://www.rarediseases.org/>. NORD maintains a database of doctors with expertise in various rare diseases. The Metabolic Information Network (MIN), 800-945-2188, also maintains a database of physicians with expertise in various metabolic diseases.

¹² While board certification is a good measure of a doctor's knowledge, it is possible to receive quality care from doctors who are not board certified.

Selecting Your Doctor¹³

When you have compiled a list of prospective doctors, call each of their offices. First, ask if the doctor accepts your health insurance plan and if he or she is taking new patients. If the doctor is not covered by your plan, ask yourself if you are prepared to pay the extra costs. The next step is to schedule a visit with your chosen physician. During the first visit you will have the opportunity to evaluate your doctor and to find out if you feel comfortable with him or her. Ask yourself, did the doctor:

- Give me a chance to ask questions about Whipple's disease?
- Really listen to my questions?
- Answer in terms I understood?
- Show respect for me?
- Ask me questions?
- Make me feel comfortable?
- Address the health problem(s) I came with?
- Ask me my preferences about different kinds of treatments for Whipple's disease?
- Spend enough time with me?

Trust your instincts when deciding if the doctor is right for you. But remember, it might take time for the relationship to develop. It takes more than one visit for you and your doctor to get to know each other.

Working with Your Doctor¹⁴

Research has shown that patients who have good relationships with their doctors tend to be more satisfied with their care and have better results. Here are some tips to help you and your doctor become partners:

- You know important things about your symptoms and your health history. Tell your doctor what you think he or she needs to know.
- It is important to tell your doctor personal information, even if it makes you feel embarrassed or uncomfortable.

¹³ This section has been adapted from the AHRQ:
www.ahrq.gov/consumer/qntascii/qntdr.htm.

¹⁴ This section has been adapted from the AHRQ:
www.ahrq.gov/consumer/qntascii/qntdr.htm.

- Bring a "health history" list with you (and keep it up to date).
- Always bring any medications you are currently taking with you to the appointment, or you can bring a list of your medications including dosage and frequency information. Talk about any allergies or reactions you have had to your medications.
- Tell your doctor about any natural or alternative medicines you are taking.
- Bring other medical information, such as x-ray films, test results, and medical records.
- Ask questions. If you don't, your doctor will assume that you understood everything that was said.
- Write down your questions before your visit. List the most important ones first to make sure that they are addressed.
- Consider bringing a friend with you to the appointment to help you ask questions. This person can also help you understand and/or remember the answers.
- Ask your doctor to draw pictures if you think that this would help you understand.
- Take notes. Some doctors do not mind if you bring a tape recorder to help you remember things, but always ask first.
- Let your doctor know if you need more time. If there is not time that day, perhaps you can speak to a nurse or physician assistant on staff or schedule a telephone appointment.
- Take information home. Ask for written instructions. Your doctor may also have brochures and audio and videotapes that can help you.
- After leaving the doctor's office, take responsibility for your care. If you have questions, call. If your symptoms get worse or if you have problems with your medication, call. If you had tests and do not hear from your doctor, call for your test results. If your doctor recommended that you have certain tests, schedule an appointment to get them done. If your doctor said you should see an additional specialist, make an appointment.

By following these steps, you will enhance the relationship you will have with your physician.

Broader Health-Related Resources

In addition to the references above, the NIH has set up guidance Web sites that can help patients find healthcare professionals. These include:¹⁵

- Caregivers:
<http://www.nlm.nih.gov/medlineplus/caregivers.html>
- Choosing a Doctor or Healthcare Service:
<http://www.nlm.nih.gov/medlineplus/choosingadoctororhealthcareservice.html>
- Hospitals and Health Facilities:
<http://www.nlm.nih.gov/medlineplus/healthfacilities.html>

¹⁵ You can access this information at:

<http://www.nlm.nih.gov/medlineplus/healthsystem.html>.

PART II: ADDITIONAL RESOURCES AND ADVANCED MATERIAL

ABOUT PART II

In Part II, we introduce you to additional resources and advanced research on Whipple's disease. All too often, patients who conduct their own research are overwhelmed by the difficulty in finding and organizing information. The purpose of the following chapters is to provide you an organized and structured format to help you find additional information resources on Whipple's disease. In Part II, as in Part I, our objective is not to interpret the latest advances on Whipple's disease or render an opinion. Rather, our goal is to give you access to original research and to increase your awareness of sources you may not have already considered. In this way, you will come across the advanced materials often referred to in pamphlets, books, or other general works. Once again, some of this material is technical in nature, so consultation with a professional familiar with Whipple's disease is suggested.

CHAPTER 3. STUDIES ON WHIPPLE'S DISEASE

Overview

Every year, academic studies are published on Whipple's disease or related conditions. Broadly speaking, there are two types of studies. The first are peer reviewed. Generally, the content of these studies has been reviewed by scientists or physicians. Peer-reviewed studies are typically published in scientific journals and are usually available at medical libraries. The second type of studies is non-peer reviewed. These works include summary articles that do not use or report scientific results. These often appear in the popular press, newsletters, or similar periodicals.

In this chapter, we will show you how to locate peer-reviewed references and studies on Whipple's disease. We will begin by discussing research that has been summarized and is free to view by the public via the Internet. We then show you how to generate a bibliography on Whipple's disease and teach you how to keep current on new studies as they are published or undertaken by the scientific community.

The Combined Health Information Database

The Combined Health Information Database summarizes studies across numerous federal agencies. To limit your investigation to research studies and Whipple's disease, you will need to use the advanced search options. First, go to <http://chid.nih.gov/index.html>. From there, select the "Detailed Search" option (or go directly to that page with the following hyperlink: <http://chid.nih.gov/detail/detail.html>). The trick in extracting studies is found in the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the

format option "Journal Article." At the top of the search form, select the number of records you would like to see (we recommend 100) and check the box to display "whole records." We recommend that you type in "Whipple's disease" (or synonyms) into the "For these words:" box. Consider using the option "anywhere in record" to make your search as broad as possible. If you want to limit the search to only a particular field, such as the title of the journal, then select this option in the "Search in these fields" drop box. The following is a sample of what you can expect from this type of search:

- **Diagnosis and Monitoring of Whipple Disease by Polymerase Chain Reaction**

Source: *Annals of Internal Medicine*. 126(7): 520-527. April 1997.

Summary: Whipple disease is a chronic, multisystem disorder associated with infection with *Tropheryma whippelii*, an organism that has not yet been grown on artificial media. In some cases, the diagnosis of Whipple disease is uncertain if it is based on histology alone. Although antibiotic regimens of various durations have been used, the disease recurs in about one third of cases. This article reports on research undertaken to develop a test that is more sensitive and specific than histologic examination to diagnose Whipple disease and monitor the effects of antibiotic therapy. The authors performed retrospective, laboratory-based evaluations of stored tissue specimens of 30 patients with clinically diagnosed, histologically confirmed Whipple disease and 8 patients in whom Whipple disease was clinically suspected but who did not have definitive histologic evidence. Pretreatment and posttreatment biopsy specimens of the small bowel and lymph node were tested by polymerase chain reaction (PCR) for the presence of *T. whippelii* DNA. Results on PCR were positive in 29 of the 30 specimens from patients with histologically confirmed disease and in 7 of the 8 specimens from patients in whom disease was clinically suspected. The authors conclude that PCR is highly sensitive and specific when used to confirm the diagnosis of Whipple disease, to identify inconclusive and suspicious cases, and to monitor response to therapy. A negative result on PCR may predict a low likelihood of clinical relapse; a positive test result that remains positive despite therapy may be associated with a poor clinical outcome. 5 tables. 25 references. (AA-M).

E-Journals: PubMed Central¹⁶

PubMed Central (PMC) is a digital archive of life sciences journal literature developed and managed by the National Center for Biotechnology Information (NCBI) at the U.S. National Library of Medicine (NLM).¹⁷ Access to this growing archive of e-journals is free and unrestricted.¹⁸ To search, go to <http://www.pubmedcentral.nih.gov/index.html#search>, and type "Whipple's disease" (or synonyms) into the search box. This search gives you access to full-text articles. The following is a sample of items found for Whipple's disease in the PubMed Central database:

- **Cloning and Sequencing of a Part of the Heat Shock Protein 65 Gene (hsp65) of "Tropheryma whippelii" and Its Use for Detection of "T. whippelii" in Clinical Specimens by PCR** by Silvia Morgenegg, Fabrizio Dutly, and Martin Altwegg; 2000 June
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=86774&rendertype=external>
- **Evaluation of a Specific Nested PCR Targeting Domain III of the 23S rRNA Gene of "Tropheryma whippelii" and Proposal of a Classification System for Its Molecular Variants** by Hans Peter Hinrikson, Fabrizio Dutly, and Martin Altwegg; 2000 February
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=86155&rendertype=external>
- **Homogeneity of 16S-23S Ribosomal Intergenic Spacer Regions of Tropheryma whippelii in Swiss Patients with Whipple's Disease** by Hans Peter Hinrikson, Fabrizio Dutly, and Martin Altwegg; 1999 January
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=84193&rendertype=external>
- **rpoB Sequence Analysis of Cultured Tropheryma whippelii** by Michel Drancourt, Antoine Carlouz, and Didier Raoult; 2001 July
<http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=88165&rendertype=external>

¹⁶ Adapted from the National Library of Medicine:
<http://www.pubmedcentral.nih.gov/about/intro.html>.

¹⁷ With PubMed Central, NCBI is taking the lead in preservation and maintenance of open access to electronic literature, just as NLM has done for decades with printed biomedical literature. PubMed Central aims to become a world-class library of the digital age.

¹⁸ The value of PubMed Central, in addition to its role as an archive, lies the availability of data from diverse sources stored in a common format in a single repository. Many journals already have online publishing operations, and there is a growing tendency to publish material online only, to the exclusion of print.

The National Library of Medicine: PubMed

One of the quickest and most comprehensive ways to find academic studies in both English and other languages is to use PubMed, maintained by the National Library of Medicine. The advantage of PubMed over previously mentioned sources is that it covers a greater number of domestic and foreign references. It is also free to the public.¹⁹ If the publisher has a Web site that offers full text of its journals, PubMed will provide links to that site, as well as to sites offering other related data. User registration, a subscription fee, or some other type of fee may be required to access the full text of articles in some journals.

To generate your own bibliography of studies dealing with Whipple's disease, simply go to the PubMed Web site at www.ncbi.nlm.nih.gov/pubmed. Type "Whipple's disease" (or synonyms) into the search box, and click "Go." The following is the type of output you can expect from PubMed for "Whipple's disease" (hyperlinks lead to article summaries):

Vocabulary Builder

Aberrant: Wandering or deviating from the usual or normal course. [EU]

Alleles: Mutually exclusive forms of the same gene, occupying the same locus on homologous chromosomes, and governing the same biochemical and developmental process. [NIH]

Anemia: A reduction in the number of circulating erythrocytes or in the quantity of hemoglobin. [NIH]

Antibodies: Proteins that the body makes to protect itself from foreign substances. In diabetes, the body sometimes makes antibodies to work against pork or beef insulins because they are not exactly the same as human insulin or because they have impurities. The antibodies can keep the insulin from working well and may even cause the person with diabetes to have an allergic or bad reaction to the beef or pork insulins. [NIH]

Antigens: Substances that cause an immune response in the body. The body

¹⁹ PubMed was developed by the National Center for Biotechnology Information (NCBI) at the National Library of Medicine (NLM) at the National Institutes of Health (NIH). The PubMed database was developed in conjunction with publishers of biomedical literature as a search tool for accessing literature citations and linking to full-text journal articles at Web sites of participating publishers. Publishers that participate in PubMed supply NLM with their citations electronically prior to or at the time of publication.

"sees" the antigens as harmful or foreign. To fight them, the body produces antibodies, which attack and try to eliminate the antigens. [NIH]

Biliary: Pertaining to the bile, to the bile ducts, or to the gallbladder. [EU]

Capillary: Any one of the minute vessels that connect the arterioles and venules, forming a network in nearly all parts of the body. Their walls act as semipermeable membranes for the interchange of various substances, including fluids, between the blood and tissue fluid; called also vas capillare. [EU]

Collagen: The protein substance of the white fibres (collagenous fibres) of skin, tendon, bone, cartilage, and all other connective tissue; composed of molecules of tropocollagen (q.v.), it is converted into gelatin by boiling. collagenous pertaining to collagen; forming or producing collagen. [EU]

Colorectal: Pertaining to or affecting the colon and rectum. [EU]

Contracture: A condition of fixed high resistance to passive stretch of a muscle, resulting from fibrosis of the tissues supporting the muscles or the joints, or from disorders of the muscle fibres. [EU]

Cytokines: Non-antibody proteins secreted by inflammatory leukocytes and some non-leukocytic cells, that act as intercellular mediators. They differ from classical hormones in that they are produced by a number of tissue or cell types rather than by specialized glands. They generally act locally in a paracrine or autocrine rather than endocrine manner. [NIH]

Digestion: The process of breakdown of food for metabolism and use by the body. [NIH]

Dysplasia: Abnormality of development; in pathology, alteration in size, shape, and organization of adult cells. [EU]

Endocarditis: Exudative and proliferative inflammatory alterations of the endocardium, characterized by the presence of vegetations on the surface of the endocardium or in the endocardium itself, and most commonly involving a heart valve, but sometimes affecting the inner lining of the cardiac chambers or the endocardium elsewhere. It may occur as a primary disorder or as a complication of or in association with another disease. [EU]

Enzyme: A protein molecule that catalyses chemical reactions of other substances without itself being destroyed or altered upon completion of the reactions. Enzymes are classified according to the recommendations of the Nomenclature Committee of the International Union of Biochemistry. Each enzyme is assigned a recommended name and an Enzyme Commission (EC) number. They are divided into six main groups; oxidoreductases, transferases, hydrolases, lyases, isomerases, and ligases. [EU]

Epithelium: The covering of internal and external surfaces of the body, including the lining of vessels and other small cavities. It consists of cells

joined by small amounts of cementing substances. Epithelium is classified into types on the basis of the number of layers deep and the shape of the superficial cells. [EU]

Exogenous: Developed or originating outside the organism, as exogenous disease. [EU]

Fluorescence: The property of emitting radiation while being irradiated. The radiation emitted is usually of longer wavelength than that incident or absorbed, e.g., a substance can be irradiated with invisible radiation and emit visible light. X-ray fluorescence is used in diagnosis. [NIH]

Gastrointestinal: Pertaining to or communicating with the stomach and intestine, as a gastrointestinal fistula. [EU]

Helicobacter: A genus of gram-negative, spiral-shaped bacteria that is pathogenic and has been isolated from the intestinal tract of mammals, including humans. [NIH]

Hemorrhage: Bleeding or escape of blood from a vessel. [NIH]

Heparin: Heparinic acid. A highly acidic mucopolysaccharide formed of equal parts of sulfated D-glucosamine and D-glucuronic acid with sulfaminic bridges. The molecular weight ranges from six to twenty thousand. Heparin occurs in and is obtained from liver, lung, mast cells, etc., of vertebrates. Its function is unknown, but it is used to prevent blood clotting in vivo and vitro, in the form of many different salts. [NIH]

Hormones: Chemical substances having a specific regulatory effect on the activity of a certain organ or organs. The term was originally applied to substances secreted by various endocrine glands and transported in the bloodstream to the target organs. It is sometimes extended to include those substances that are not produced by the endocrine glands but that have similar effects. [NIH]

Hybridization: The genetic process of crossbreeding to produce a hybrid. Hybrid nucleic acids can be formed by nucleic acid hybridization of DNA and RNA molecules. Protein hybridization allows for hybrid proteins to be formed from polypeptide chains. [NIH]

Hyperbaric: Characterized by greater than normal pressure or weight; applied to gases under greater than atmospheric pressure, as hyperbaric oxygen, or to a solution of greater specific gravity than another taken as a standard of reference. [EU]

Immunohistochemistry: Histochemical localization of immunoreactive substances using labeled antibodies as reagents. [NIH]

Induction: The act or process of inducing or causing to occur, especially the production of a specific morphogenetic effect in the developing embryo through the influence of evocators or organizers, or the production of

anaesthesia or unconsciousness by use of appropriate agents. [EU]

Inflammation: A pathological process characterized by injury or destruction of tissues caused by a variety of cytologic and chemical reactions. It is usually manifested by typical signs of pain, heat, redness, swelling, and loss of function. [NIH]

Intermittent: Occurring at separated intervals; having periods of cessation of activity. [EU]

Lactobacillus: A genus of gram-positive, microaerophilic, rod-shaped bacteria occurring widely in nature. Its species are also part of the many normal flora of the mouth, intestinal tract, and vagina of many mammals, including humans. Pathogenicity from this genus is rare. [NIH]

Lectins: Protein or glycoprotein substances, usually of plant origin, that bind to sugar moieties in cell walls or membranes and thereby change the physiology of the membrane to cause agglutination, mitosis, or other biochemical changes in the cell. [NIH]

Lipophilic: Having an affinity for fat; pertaining to or characterized by lipophilia. [EU]

Lupus: A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

Methotrexate: An antineoplastic antimetabolite with immunosuppressant properties. It is an inhibitor of dihydrofolate reductase and prevents the formation of tetrahydrofolate, necessary for synthesis of thymidylate, an essential component of DNA. [NIH]

Microbiological: Pertaining to microbiology : the science that deals with microorganisms, including algae, bacteria, fungi, protozoa and viruses. [EU]

Microorganism: A microscopic organism; those of medical interest include bacteria, viruses, fungi and protozoa. [EU]

Motility: The ability to move spontaneously. [EU]

Mutagenesis: Process of generating genetic mutations. It may occur spontaneously or be induced by mutagens. [NIH]

Neoplastic: Pertaining to or like a neoplasm (= any new and abnormal growth); pertaining to neoplasia (= the formation of a neoplasm). [EU]

Occult: Obscure; concealed from observation, difficult to understand. [EU]

Pediatrics: A medical specialty concerned with maintaining health and providing medical care to children from birth to adolescence. [NIH]

Perforation: 1. the act of boring or piercing through a part. 2. a hole made through a part or substance. [EU]

Pharmacokinetics: The action of drugs in the body over a period of time,

including the processes of absorption, distribution, localization in tissues, biotransformation, and excretion. [EU]

Phenotype: The outward appearance of the individual. It is the product of interactions between genes and between the genotype and the environment. This includes the killer phenotype, characteristic of yeasts. [NIH]

Precursor: Something that precedes. In biological processes, a substance from which another, usually more active or mature substance is formed. In clinical medicine, a sign or symptom that heralds another. [EU]

Prednisone: A synthetic anti-inflammatory glucocorticoid derived from cortisone. It is biologically inert and converted to prednisolone in the liver. [NIH]

Procollagen: A biosynthetic precursor of collagen containing additional amino acid sequences at the amino-terminal ends of the three polypeptide chains. Protocollagen, a precursor of procollagen consists of procollagen peptide chains in which proline and lysine have not yet been hydroxylated. [NIH]

Protease: Proteinase (= any enzyme that catalyses the splitting of interior peptide bonds in a protein). [EU]

Receptor: 1. a molecular structure within a cell or on the surface characterized by (1) selective binding of a specific substance and (2) a specific physiologic effect that accompanies the binding, e.g., cell-surface receptors for peptide hormones, neurotransmitters, antigens, complement fragments, and immunoglobulins and cytoplasmic receptors for steroid hormones. 2. a sensory nerve terminal that responds to stimuli of various kinds. [EU]

Recombinant: 1. a cell or an individual with a new combination of genes not found together in either parent; usually applied to linked genes. [EU]

Rectal: Pertaining to the rectum (= distal portion of the large intestine). [EU]

Refractory: Not readily yielding to treatment. [EU]

Remission: A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

Serum: The clear portion of any body fluid; the clear fluid moistening serous membranes. 2. blood serum; the clear liquid that separates from blood on clotting. 3. immune serum; blood serum from an immunized animal used for passive immunization; an antiserum; antitoxin, or antivenin. [EU]

Species: A taxonomic category subordinate to a genus (or subgenus) and superior to a subspecies or variety, composed of individuals possessing common characters distinguishing them from other categories of individuals of the same taxonomic level. In taxonomic nomenclature, species are designated by the genus name followed by a Latin or Latinized adjective or

noun. [EU]

Stomach: An organ of digestion situated in the left upper quadrant of the abdomen between the termination of the esophagus and the beginning of the duodenum. [NIH]

Streptococcus: A genus of gram-positive, coccoid bacteria whose organisms occur in pairs or chains. No endospores are produced. Many species exist as commensals or parasites on man or animals with some being highly pathogenic. A few species are saprophytes and occur in the natural environment. [NIH]

Synergistic: Acting together; enhancing the effect of another force or agent. [EU]

Syphilis: A contagious venereal disease caused by the spirochete *treponema pallidum*. [NIH]

Systemic: Pertaining to or affecting the body as a whole. [EU]

Telomere: A terminal section of a chromosome which has a specialized structure and which is involved in chromosomal replication and stability. Its length is believed to be a few hundred base pairs. [NIH]

Tolerance: 1. the ability to endure unusually large doses of a drug or toxin. 2. acquired drug tolerance; a decreasing response to repeated constant doses of a drug or the need for increasing doses to maintain a constant response. [EU]

Topical: Pertaining to a particular surface area, as a topical anti-infective applied to a certain area of the skin and affecting only the area to which it is applied. [EU]

Toxicity: The quality of being poisonous, especially the degree of virulence of a toxic microbe or of a poison. [EU]

Tropomyosin: A protein found in the thin filaments of muscle fibers. It inhibits contraction of the muscle unless its position is modified by troponin. [NIH]

Tuberculosis: Any of the infectious diseases of man and other animals caused by species of mycobacterium. [NIH]

Ulceration: 1. the formation or development of an ulcer. 2. an ulcer. [EU]

Viral: Pertaining to, caused by, or of the nature of virus. [EU]

CHAPTER 4. BOOKS ON WHIPPLE'S DISEASE

Overview

This chapter provides bibliographic book references relating to Whipple's disease. You have many options to locate books on Whipple's disease. The simplest method is to go to your local bookseller and inquire about titles that they have in stock or can special order for you. Some patients, however, feel uncomfortable approaching their local booksellers and prefer online sources (e.g. www.amazon.com and www.bn.com). In addition to online booksellers, excellent sources for book titles on Whipple's disease include the Combined Health Information Database and the National Library of Medicine. Once you have found a title that interests you, visit your local public or medical library to see if it is available for loan.

Book Summaries: Online Booksellers

Commercial Internet-based booksellers, such as Amazon.com and Barnes & Noble.com, offer summaries which have been supplied by each title's publisher. Some summaries also include customer reviews. Your local bookseller may have access to in-house and commercial databases that index all published books (e.g. Books in Print®). The following have been recently listed with online booksellers as relating to Whipple's disease (sorted alphabetically by title; follow the hyperlink to view more details at Amazon.com):

- **Whipple's Disease** by William O., III Dobbins; ISBN: b>Publishe;
<http://www.amazon.com/exec/obidos/ASIN/b>Publishe/icongroupinterna>

The National Library of Medicine Book Index

The National Library of Medicine at the National Institutes of Health has a massive database of books published on healthcare and biomedicine. Go to the following Internet site, <http://locatorplus.gov/>, and then select "Search LOCATORplus." Once you are in the search area, simply type "Whipple's disease" (or synonyms) into the search box, and select "books only." From there, results can be sorted by publication date, author, or relevance.²⁰

Chapters on Whipple's Disease

Frequently, Whipple's disease will be discussed within a book, perhaps within a specific chapter. In order to find chapters that are specifically dealing with Whipple's disease, an excellent source of abstracts is the Combined Health Information Database. You will need to limit your search to book chapters and Whipple's disease using the "Detailed Search" option. Go to the following hyperlink: <http://chid.nih.gov/detail/detail.html>. To find book chapters, use the drop boxes at the bottom of the search page where "You may refine your search by." Select the dates and language you prefer, and the format option "Book Chapter." By making these selections and typing in "Whipple's disease" (or synonyms) into the "For these words:" box, you will only receive results on chapters in books. The following is a typical result when searching for book chapters on Whipple's disease:

- **Whipple Disease**

Source: in Feigin, R.D. and Cherry, J.D., eds. Textbook of Pediatric Infectious Diseases. 4th ed. Volume 1. Philadelphia, PA: W.B. Saunders Company. 1998. p. 606-611.

Contact: Available from W.B. Saunders Company. Order Fulfillment, 6277 Sea Harbor Drive, Orlando, FL 32887. (800) 545-2522. Fax (800) 874-6418 or (407) 352-3445. Price: \$315.00. ISBN: 0721664482.

²⁰ In addition to LOCATORPlus, in collaboration with authors and publishers, the National Center for Biotechnology Information (NCBI) is adapting biomedical books for the Web. The books may be accessed in two ways: (1) by searching directly using any search term or phrase (in the same way as the bibliographic database PubMed), or (2) by following the links to PubMed abstracts. Each PubMed abstract has a "Books" button that displays a facsimile of the abstract in which some phrases are hypertext links. These phrases are also found in the books available at NCBI. Click on hyperlinked results in the list of books in which the phrase is found. Currently, the majority of the links are between the books and PubMed. In the future, more links will be created between the books and other types of information, such as gene and protein sequences and macromolecular structures. See <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=Books>.

Summary: Whipple disease is a rare, systemic bacterial infection that until recently was uniformly fatal. This chapter on Whipple disease is from a textbook on pediatric infectious diseases. In its most common form, Whipple disease affects white, middle-aged men with diarrhea, weight loss, abdominal pain, arthralgias, and fever. Although it is extraordinarily rare in children, its recognition may be critical. Simple treatment with appropriate antibiotics may be both curative and lifesaving. The authors consider the disease's history, epidemiology, etiology and pathogenesis, clinical manifestations (symptoms), diagnosis, and treatment. The authors conclude that Whipple disease, despite its rarity in children, deserves diagnostic consideration in any child with failure to thrive, malnutrition, and chronic diarrhea. Such findings, especially with central nervous system symptoms or arthralgias (painful joints), should raise Whipple disease as a consideration. Diagnosis of Whipple disease can be made using molecular tests, such as polymerase chain reaction. The preferred treatment in both adults and children is trimethoprim-sulfamethoxazole (antibiotic) given orally twice a day for 1 year. 3 figures. 3 tables. 60 references. (AA-M).

General Home References

In addition to references for Whipple's disease, you may want a general home medical guide that spans all aspects of home healthcare. The following list is a recent sample of such guides (sorted alphabetically by title; hyperlinks provide rankings, information, and reviews at Amazon.com):

- **The Digestive System (21st Century Health and Wellness)** by Regina Avraham; Library Binding (February 2000), Chelsea House Publishing (Library); ISBN: 0791055264;
<http://www.amazon.com/exec/obidos/ASIN/0791055264/icongroupinterna>
- **American College of Physicians Complete Home Medical Guide (with Interactive Human Anatomy CD-ROM)** by David R. Goldmann (Editor), American College of Physicians; Hardcover - 1104 pages, Book & CD-Rom edition (1999), DK Publishing; ISBN: 0789444127;
<http://www.amazon.com/exec/obidos/ASIN/0789444127/icongroupinterna>
- **The American Medical Association Guide to Home Caregiving** by the American Medical Association (Editor); Paperback - 256 pages 1 edition (2001), John Wiley & Sons; ISBN: 0471414093;
<http://www.amazon.com/exec/obidos/ASIN/0471414093/icongroupinterna>

- **Anatomica : The Complete Home Medical Reference** by Peter Forrestal (Editor); Hardcover (2000), Book Sales; ISBN: 1740480309;
<http://www.amazon.com/exec/obidos/ASIN/1740480309/icongroupinterna>
- **The HarperCollins Illustrated Medical Dictionary : The Complete Home Medical Dictionary** by Ida G. Dox, et al; Paperback - 656 pages 4th edition (2001), Harper Resource; ISBN: 0062736469;
<http://www.amazon.com/exec/obidos/ASIN/0062736469/icongroupinterna>
- **Mayo Clinic Guide to Self-Care: Answers for Everyday Health Problems** by Philip Hagen, M.D. (Editor), et al; Paperback - 279 pages, 2nd edition (December 15, 1999), Kensington Publishing Corp.; ISBN: 0962786578;
<http://www.amazon.com/exec/obidos/ASIN/0962786578/icongroupinterna>
- **The Merck Manual of Medical Information : Home Edition (Merck Manual of Medical Information Home Edition (Trade Paper))** by Robert Berkow (Editor), Mark H. Beers, M.D. (Editor); Paperback - 1536 pages (2000), Pocket Books; ISBN: 0671027263;
<http://www.amazon.com/exec/obidos/ASIN/0671027263/icongroupinterna>

Vocabulary Builder

Ankle: That part of the lower limb directly above the foot. [NIH]

Arthralgia: Pain in a joint. [EU]

Curative: Tending to overcome disease and promote recovery. [EU]

CHAPTER 5. MULTIMEDIA ON WHIPPLE'S DISEASE

Overview

Information on Whipple's disease can come in a variety of formats. Among multimedia sources, video productions, slides, audiotapes, and computer databases are often available. In this chapter, we show you how to keep current on multimedia sources of information on Whipple's disease. We start with sources that have been summarized by federal agencies, and then show you how to find bibliographic information catalogued by the National Library of Medicine. If you see an interesting item, visit your local medical library to check on the availability of the title.

Bibliography: Multimedia on Whipple's Disease

The National Library of Medicine is a rich source of information on healthcare-related multimedia productions including slides, computer software, and databases. To access the multimedia database, go to the following Web site: <http://locatorplus.gov/>. Select "Search LOCATORplus." Once in the search area, simply type in Whipple's disease (or synonyms). Then, in the option box provided below the search box, select "Audiovisuals and Computer Files." From there, you can choose to sort results by publication date, author, or relevance. The following multimedia has been indexed on Whipple's disease. For more information, follow the hyperlink indicated:

- **Infections aren't forever : a guide to isolation precaution.** Source: LexCom Productions; Year: 1986; Format: Videorecording; [W. Columbia, S.C.]: LexCom, c1986

- **Tools for genetic research in the next century.** Source: Marshfield Clinic, Saint Joseph's Hospital; a presentation of the Marshfield Video Network; Year: 1998; Format: Videorecording; Marshfield, WI: The Network, c1998

Vocabulary Builder

Artery: A large blood vessel that carries blood from the heart to other parts of the body. Arteries are thicker and have walls that are stronger and more elastic than the walls of veins. [NIH]

Carcinoma: A malignant new growth made up of epithelial cells tending to infiltrate the surrounding tissues and give rise to metastases. [EU]

Cardiology: The study of the heart, its physiology, and its functions. [NIH]

Coronary: Encircling in the manner of a crown; a term applied to vessels; nerves, ligaments, etc. The term usually denotes the arteries that supply the heart muscle and, by extension, a pathologic involvement of them. [EU]

Lipid: Any of a heterogeneous group of fats and fatlike substances characterized by being water-insoluble and being extractable by nonpolar (or fat) solvents such as alcohol, ether, chloroform, benzene, etc. All contain as a major constituent aliphatic hydrocarbons. The lipids, which are easily stored in the body, serve as a source of fuel, are an important constituent of cell structure, and serve other biological functions. Lipids may be considered to include fatty acids, neutral fats, waxes, and steroids. Compound lipids comprise the glycolipids, lipoproteins, and phospholipids. [EU]

Lipoprotein: Any of the lipid-protein complexes in which lipids are transported in the blood; lipoprotein particles consist of a spherical hydrophobic core of triglycerides or cholesterol esters surrounded by an amphipathic monolayer of phospholipids, cholesterol, and apolipoproteins; the four principal classes are high-density, low-density, and very-low-density lipoproteins and chylomicrons. [EU]

Orthopaedic: Pertaining to the correction of deformities of the musculoskeletal system; pertaining to orthopaedics. [EU]

Transfusion: The introduction of whole blood or blood component directly into the blood stream. [EU]

PART III. APPENDICES

ABOUT PART III

Part III is a collection of appendices on general medical topics which may be of interest to patients with Whipple's disease and related conditions.

APPENDIX A. RESEARCHING YOUR MEDICATIONS

Overview

There are a number of sources available on new or existing medications which could be prescribed to patients with Whipple's disease. While a number of hard copy or CD-Rom resources are available to patients and physicians for research purposes, a more flexible method is to use Internet-based databases. In this chapter, we will begin with a general overview of medications. We will then proceed to outline official recommendations on how you should view your medications. You may also want to research medications that you are currently taking for other conditions as they may interact with medications for Whipple's disease. Research can give you information on the side effects, interactions, and limitations of prescription drugs used in the treatment of Whipple's disease. Broadly speaking, there are two sources of information on approved medications: public sources and private sources. We will emphasize free-to-use public sources.

Your Medications: The Basics²¹

The Agency for Health Care Research and Quality has published extremely useful guidelines on how you can best participate in the medication aspects of Whipple's disease. Taking medicines is not always as simple as swallowing a pill. It can involve many steps and decisions each day. The AHCQRQ recommends that patients with Whipple's disease take part in treatment decisions. Do not be afraid to ask questions and talk about your concerns. By taking a moment to ask questions early, you may avoid problems later. Here are some points to cover each time a new medicine is prescribed:

- Ask about all parts of your treatment, including diet changes, exercise, and medicines.
- Ask about the risks and benefits of each medicine or other treatment you might receive.
- Ask how often you or your doctor will check for side effects from a given medication.

Do not hesitate to ask what is important to you about your medicines. You may want a medicine with the fewest side effects, or the fewest doses to take each day. You may care most about cost, or how the medicine might affect how you live or work. Or, you may want the medicine your doctor believes will work the best. Telling your doctor will help him or her select the best treatment for you.

Do not be afraid to "bother" your doctor with your concerns and questions about medications for Whipple's disease. You can also talk to a nurse or a pharmacist. They can help you better understand your treatment plan. Feel free to bring a friend or family member with you when you visit your doctor. Talking over your options with someone you trust can help you make better choices, especially if you are not feeling well. Specifically, ask your doctor the following:

- The name of the medicine and what it is supposed to do.
- How and when to take the medicine, how much to take, and for how long.
- What food, drinks, other medicines, or activities you should avoid while taking the medicine.
- What side effects the medicine may have, and what to do if they occur.

²¹ This section is adapted from AHCQRQ: <http://www.ahcpr.gov/consumer/ncpiebro.htm>.

- If you can get a refill, and how often.
- About any terms or directions you do not understand.
- What to do if you miss a dose.
- If there is written information you can take home (most pharmacies have information sheets on your prescription medicines; some even offer large-print or Spanish versions).

Do not forget to tell your doctor about all the medicines you are currently taking (not just those for Whipple's disease). This includes prescription medicines and the medicines that you buy over the counter. Then your doctor can avoid giving you a new medicine that may not work well with the medications you take now. When talking to your doctor, you may wish to prepare a list of medicines you currently take, the reason you take them, and how you take them. Be sure to include the following information for each:

- Name of medicine
- Reason taken
- Dosage
- Time(s) of day

Also include any over-the-counter medicines, such as:

- Laxatives
- Diet pills
- Vitamins
- Cold medicine
- Aspirin or other pain, headache, or fever medicine
- Cough medicine
- Allergy relief medicine
- Antacids
- Sleeping pills
- Others (include names)

Learning More about Your Medications

Because of historical investments by various organizations and the emergence of the Internet, it has become rather simple to learn about the medications your doctor has recommended for Whipple's disease. One such source is the United States Pharmacopeia. In 1820, eleven physicians met in Washington, D.C. to establish the first compendium of standard drugs for the United States. They called this compendium the "U.S. Pharmacopeia (USP)." Today, the USP is a non-profit organization consisting of 800 volunteer scientists, eleven elected officials, and 400 representatives of state associations and colleges of medicine and pharmacy. The USP is located in Rockville, Maryland, and its home page is located at www.usp.org. The USP currently provides standards for over 3,700 medications. The resulting USP DI® Advice for the Patient® can be accessed through the National Library of Medicine of the National Institutes of Health. The database is partially derived from lists of federally approved medications in the Food and Drug Administration's (FDA) Drug Approvals database.²²

While the FDA database is rather large and difficult to navigate, the Pharmacopeia is both user-friendly and free to use. It covers more than 9,000 prescription and over-the-counter medications. To access this database, simply type the following hyperlink into your Web browser: <http://www.nlm.nih.gov/medlineplus/druginformation.html>. To view examples of a given medication (brand names, category, description, preparation, proper use, precautions, side effects, etc.), simply follow the hyperlinks indicated within the United States Pharmacopoeia (USP). It is important to read the disclaimer by the USP (<http://www.nlm.nih.gov/medlineplus/drugdisclaimer.html>) before using the information provided.

Commercial Databases

In addition to the medications listed in the USP above, a number of commercial sites are available by subscription to physicians and their institutions. You may be able to access these sources from your local medical library or your doctor's office.

²² Though cumbersome, the FDA database can be freely browsed at the following site: www.fda.gov/cder/da/da.htm.

Reuters Health Drug Database

The Reuters Health Drug Database can be searched by keyword at the hyperlink: <http://www.reutershealth.com/frame2/drug.html>.

Mosby's GenRx

Mosby's GenRx database (also available on CD-Rom and book format) covers 45,000 drug products including generics and international brands. It provides prescribing information, drug interactions, and patient information. Information can be obtained at the following hyperlink: <http://www.genrx.com/Mosby/PhyGenRx/group.html>.

Physicians Desk Reference

The Physicians Desk Reference database (also available in CD-Rom and book format) is a full-text drug database. The database is searchable by brand name, generic name or by indication. It features multiple drug interactions reports. Information can be obtained at the following hyperlink: http://physician.pdr.net/physician/templates/en/acl/psuser_t.htm.

Other Web Sites

A number of additional Web sites discuss drug information. As an example, you may like to look at www.drugs.com which reproduces the information in the Pharmacopeia as well as commercial information. You may also want to consider the Web site of the Medical Letter, Inc. which allows users to download articles on various drugs and therapeutics for a nominal fee: <http://www.medletter.com/>.

Contraindications and Interactions (Hidden Dangers)

Some of the medications mentioned in the previous discussions can be problematic for patients with Whipple's disease--not because they are used in the treatment process, but because of contraindications, or side effects. Medications with contraindications are those that could react with drugs used to treat Whipple's disease or potentially create deleterious side effects in patients with Whipple's disease. You should ask your physician about any

contraindications, especially as these might apply to other medications that you may be taking for common ailments.

Drug-drug interactions occur when two or more drugs react with each other. This drug-drug interaction may cause you to experience an unexpected side effect. Drug interactions may make your medications less effective, cause unexpected side effects, or increase the action of a particular drug. Some drug interactions can even be harmful to you.

Be sure to read the label every time you use a nonprescription or prescription drug, and take the time to learn about drug interactions. These precautions may be critical to your health. You can reduce the risk of potentially harmful drug interactions and side effects with a little bit of knowledge and common sense.

Drug labels contain important information about ingredients, uses, warnings, and directions which you should take the time to read and understand. Labels also include warnings about possible drug interactions. Further, drug labels may change as new information becomes available. This is why it's especially important to read the label every time you use a medication. When your doctor prescribes a new drug, discuss all over-the-counter and prescription medications, dietary supplements, vitamins, botanicals, minerals and herbals you take as well as the foods you eat. Ask your pharmacist for the package insert for each prescription drug you take. The package insert provides more information about potential drug interactions.

A Final Warning

At some point, you may hear of alternative medications from friends, relatives, or in the news media. Advertisements may suggest that certain alternative drugs can produce positive results for patients with Whipple's disease. Exercise caution--some of these drugs may have fraudulent claims, and others may actually hurt you. The Food and Drug Administration (FDA) is the official U.S. agency charged with discovering which medications are likely to improve the health of patients with Whipple's disease. The FDA warns patients to watch out for²³:

- Secret formulas (real scientists share what they know)

²³ This section has been adapted from <http://www.fda.gov/opacom/lowlit/medfraud.html>.

- Amazing breakthroughs or miracle cures (real breakthroughs don't happen very often; when they do, real scientists do not call them amazing or miracles)
- Quick, painless, or guaranteed cures
- If it sounds too good to be true, it probably isn't true.

If you have any questions about any kind of medical treatment, the FDA may have an office near you. Look for their number in the blue pages of the phone book. You can also contact the FDA through its toll-free number, 1-888-INFO-FDA (1-888-463-6332), or on the World Wide Web at www.fda.gov.

General References

In addition to the resources provided earlier in this chapter, the following general references describe medications (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **Drug Development: Molecular Targets for Gi Diseases** by Timothy S. Gaginella (Editor), Antonio Guglietta (Editor); Hardcover - 288 pages (December 1999), Humana Press; ISBN: 0896035891;
<http://www.amazon.com/exec/obidos/ASIN/0896035891/icongroupinterna>
- **Drug Therapy for Gastrointestinal and Liver Diseases** by Michael J.G. Farthing, M.D. (Editor), Anne B. Ballinger (Editor); Hardcover - 346 pages, 1st edition (August 15, 2001), Martin Dunitz Ltd.; ISBN: 1853177334;
<http://www.amazon.com/exec/obidos/ASIN/1853177334/icongroupinterna>
- **Immunopharmacology of the Gastrointestinal System (Handbook of Immunopharmacology)** by John L. Wallace (Editor); Hardcover (October 1997), Academic Press; ISBN: 0127328602;
<http://www.amazon.com/exec/obidos/ASIN/0127328602/icongroupinterna>
- **A Pharmacologic Approach to Gastrointestinal Disorders** by James H. Lewis, M.D. (Editor); Hardcover - (February 1994), Lippincott, Williams & Wilkins; ISBN: 0683049704;
<http://www.amazon.com/exec/obidos/ASIN/0683049704/icongroupinterna>

APPENDIX B. RESEARCHING NUTRITION

Overview

Since the time of Hippocrates, doctors have understood the importance of diet and nutrition to patients' health and well-being. Since then, they have accumulated an impressive archive of studies and knowledge dedicated to this subject. Based on their experience, doctors and healthcare providers may recommend particular dietary supplements to patients with Whipple's disease. Any dietary recommendation is based on a patient's age, body mass, gender, lifestyle, eating habits, food preferences, and health condition. It is therefore likely that different patients with Whipple's disease may be given different recommendations. Some recommendations may be directly related to Whipple's disease, while others may be more related to the patient's general health. These recommendations, themselves, may differ from what official sources recommend for the average person.

In this chapter we will begin by briefly reviewing the essentials of diet and nutrition that will broadly frame more detailed discussions of Whipple's disease. We will then show you how to find studies dedicated specifically to nutrition and Whipple's disease.

Food and Nutrition: General Principles

What Are Essential Foods?

Food is generally viewed by official sources as consisting of six basic elements: (1) fluids, (2) carbohydrates, (3) protein, (4) fats, (5) vitamins, and (6) minerals. Consuming a combination of these elements is considered to be a healthy diet:

- **Fluids** are essential to human life as 80-percent of the body is composed of water. Water is lost via urination, sweating, diarrhea, vomiting, diuretics (drugs that increase urination), caffeine, and physical exertion.
- **Carbohydrates** are the main source for human energy (thermoregulation) and the bulk of typical diets. They are mostly classified as being either simple or complex. Simple carbohydrates include sugars which are often consumed in the form of cookies, candies, or cakes. Complex carbohydrates consist of starches and dietary fibers. Starches are consumed in the form of pastas, breads, potatoes, rice, and other foods. Soluble fibers can be eaten in the form of certain vegetables, fruits, oats, and legumes. Insoluble fibers include brown rice, whole grains, certain fruits, wheat bran and legumes.
- **Proteins** are eaten to build and repair human tissues. Some foods that are high in protein are also high in fat and calories. Food sources for protein include nuts, meat, fish, cheese, and other dairy products.
- **Fats** are consumed for both energy and the absorption of certain vitamins. There are many types of fats, with many general publications recommending the intake of unsaturated fats or those low in cholesterol.

Vitamins and minerals are fundamental to human health, growth, and, in some cases, disease prevention. Most are consumed in your diet (exceptions being vitamins K and D which are produced by intestinal bacteria and sunlight on the skin, respectively). Each vitamin and mineral plays a different role in health. The following outlines essential vitamins:

- **Vitamin A** is important to the health of your eyes, hair, bones, and skin; sources of vitamin A include foods such as eggs, carrots, and cantaloupe.
- **Vitamin B¹**, also known as thiamine, is important for your nervous system and energy production; food sources for thiamine include meat, peas, fortified cereals, bread, and whole grains.
- **Vitamin B²**, also known as riboflavin, is important for your nervous system and muscles, but is also involved in the release of proteins from

nutrients; food sources for riboflavin include dairy products, leafy vegetables, meat, and eggs.

- **Vitamin B³**, also known as niacin, is important for healthy skin and helps the body use energy; food sources for niacin include peas, peanuts, fish, and whole grains
- **Vitamin B⁶**, also known as pyridoxine, is important for the regulation of cells in the nervous system and is vital for blood formation; food sources for pyridoxine include bananas, whole grains, meat, and fish.
- **Vitamin B¹²** is vital for a healthy nervous system and for the growth of red blood cells in bone marrow; food sources for vitamin B¹² include yeast, milk, fish, eggs, and meat.
- **Vitamin C** allows the body's immune system to fight various diseases, strengthens body tissue, and improves the body's use of iron; food sources for vitamin C include a wide variety of fruits and vegetables.
- **Vitamin D** helps the body absorb calcium which strengthens bones and teeth; food sources for vitamin D include oily fish and dairy products.
- **Vitamin E** can help protect certain organs and tissues from various degenerative diseases; food sources for vitamin E include margarine, vegetables, eggs, and fish.
- **Vitamin K** is essential for bone formation and blood clotting; common food sources for vitamin K include leafy green vegetables.
- **Folic Acid** maintains healthy cells and blood and, when taken by a pregnant woman, can prevent her fetus from developing neural tube defects; food sources for folic acid include nuts, fortified breads, leafy green vegetables, and whole grains.

It should be noted that one can overdose on certain vitamins which become toxic if consumed in excess (e.g. vitamin A, D, E and K).

Like vitamins, minerals are chemicals that are required by the body to remain in good health. Because the human body does not manufacture these chemicals internally, we obtain them from food and other dietary sources. The more important minerals include:

- **Calcium** is needed for healthy bones, teeth, and muscles, but also helps the nervous system function; food sources for calcium include dry beans, peas, eggs, and dairy products.
- **Chromium** is helpful in regulating sugar levels in blood; food sources for chromium include egg yolks, raw sugar, cheese, nuts, beets, whole grains, and meat.

- **Fluoride** is used by the body to help prevent tooth decay and to reinforce bone strength; sources of fluoride include drinking water and certain brands of toothpaste.
- **Iodine** helps regulate the body's use of energy by synthesizing into the hormone thyroxine; food sources include leafy green vegetables, nuts, egg yolks, and red meat.
- **Iron** helps maintain muscles and the formation of red blood cells and certain proteins; food sources for iron include meat, dairy products, eggs, and leafy green vegetables.
- **Magnesium** is important for the production of DNA, as well as for healthy teeth, bones, muscles, and nerves; food sources for magnesium include dried fruit, dark green vegetables, nuts, and seafood.
- **Phosphorous** is used by the body to work with calcium to form bones and teeth; food sources for phosphorous include eggs, meat, cereals, and dairy products.
- **Selenium** primarily helps maintain normal heart and liver functions; food sources for selenium include wholegrain cereals, fish, meat, and dairy products.
- **Zinc** helps wounds heal, the formation of sperm, and encourage rapid growth and energy; food sources include dried beans, shellfish, eggs, and nuts.

The United States government periodically publishes recommended diets and consumption levels of the various elements of food. Again, your doctor may encourage deviations from the average official recommendation based on your specific condition. To learn more about basic dietary guidelines, visit the Web site: <http://www.health.gov/dietaryguidelines/>. Based on these guidelines, many foods are required to list the nutrition levels on the food's packaging. Labeling Requirements are listed at the following site maintained by the Food and Drug Administration: <http://www.cfsan.fda.gov/~dms/lab-cons.html>. When interpreting these requirements, the government recommends that consumers become familiar with the following abbreviations before reading FDA literature:²⁴

- **DVs (Daily Values):** A new dietary reference term that will appear on the food label. It is made up of two sets of references, DRVs and RDIs.
- **DRVs (Daily Reference Values):** A set of dietary references that applies to fat, saturated fat, cholesterol, carbohydrate, protein, fiber, sodium, and potassium.

²⁴ Adapted from the FDA: <http://www.fda.gov/fdac/special/foodlabel/dvs.html>.

- **RDIs (Reference Daily Intakes):** A set of dietary references based on the Recommended Dietary Allowances for essential vitamins and minerals and, in selected groups, protein. The name “RDI” replaces the term “U.S. RDA.”
- **RDAs (Recommended Dietary Allowances):** A set of estimated nutrient allowances established by the National Academy of Sciences. It is updated periodically to reflect current scientific knowledge.

What Are Dietary Supplements?²⁵

Dietary supplements are widely available through many commercial sources, including health food stores, grocery stores, pharmacies, and by mail. Dietary supplements are provided in many forms including tablets, capsules, powders, gel-tabs, extracts, and liquids. Historically in the United States, the most prevalent type of dietary supplement was a multivitamin/mineral tablet or capsule that was available in pharmacies, either by prescription or “over the counter.” Supplements containing strictly herbal preparations were less widely available. Currently in the United States, a wide array of supplement products are available, including vitamin, mineral, other nutrients, and botanical supplements as well as ingredients and extracts of animal and plant origin.

The Office of Dietary Supplements (ODS) of the National Institutes of Health is the official agency of the United States which has the expressed goal of acquiring “new knowledge to help prevent, detect, diagnose, and treat disease and disability, from the rarest genetic disorder to the common cold.”²⁶ According to the ODS, dietary supplements can have an important impact on the prevention and management of disease and on the maintenance of health.²⁷ The ODS notes that considerable research on the effects of dietary supplements has been conducted in Asia and Europe where the use of plant products, in particular, has a long tradition. However, the

²⁵ This discussion has been adapted from the NIH:

<http://ods.od.nih.gov/whatare/whatare.html>.

²⁶ Contact: The Office of Dietary Supplements, National Institutes of Health, Building 31, Room 1B29, 31 Center Drive, MSC 2086, Bethesda, Maryland 20892-2086, Tel: (301) 435-2920, Fax: (301) 480-1845, E-mail: ods@nih.gov.

²⁷ Adapted from <http://ods.od.nih.gov/about/about.html>. The Dietary Supplement Health and Education Act defines dietary supplements as “a product (other than tobacco) intended to supplement the diet that bears or contains one or more of the following dietary ingredients: a vitamin, mineral, amino acid, herb or other botanical; or a dietary substance for use to supplement the diet by increasing the total dietary intake; or a concentrate, metabolite, constituent, extract, or combination of any ingredient described above; and intended for ingestion in the form of a capsule, powder, softgel, or gelcap, and not represented as a conventional food or as a sole item of a meal or the diet.”

overwhelming majority of supplements have not been studied scientifically. To explore the role of dietary supplements in the improvement of health care, the ODS plans, organizes, and supports conferences, workshops, and symposia on scientific topics related to dietary supplements. The ODS often works in conjunction with other NIH Institutes and Centers, other government agencies, professional organizations, and public advocacy groups.

To learn more about official information on dietary supplements, visit the ODS site at <http://ods.od.nih.gov/whatare/whatare.html>. Or contact:

The Office of Dietary Supplements
National Institutes of Health
Building 31, Room 1B29
31 Center Drive, MSC 2086
Bethesda, Maryland 20892-2086
Tel: (301) 435-2920
Fax: (301) 480-1845
E-mail: ods@nih.gov

Finding Studies on Whipple's Disease

The NIH maintains an office dedicated to patient nutrition and diet. The National Institutes of Health's Office of Dietary Supplements (ODS) offers a searchable bibliographic database called the IBIDS (International Bibliographic Information on Dietary Supplements). The IBIDS contains over 460,000 scientific citations and summaries about dietary supplements and nutrition as well as references to published international, scientific literature on dietary supplements such as vitamins, minerals, and botanicals.²⁸ IBIDS is available to the public free of charge through the ODS Internet page: <http://ods.od.nih.gov/databases/ibids.html>.

After entering the search area, you have three choices: (1) IBIDS Consumer Database, (2) Full IBIDS Database, or (3) Peer Reviewed Citations Only. We recommend that you start with the Consumer Database. While you may not find references for the topics that are of most interest to you, check back periodically as this database is frequently updated. More studies can be

²⁸ Adapted from <http://ods.od.nih.gov>. IBIDS is produced by the Office of Dietary Supplements (ODS) at the National Institutes of Health to assist the public, healthcare providers, educators, and researchers in locating credible, scientific information on dietary supplements. IBIDS was developed and will be maintained through an interagency partnership with the Food and Nutrition Information Center of the National Agricultural Library, U.S. Department of Agriculture.

found by searching the Full IBIDS Database. Healthcare professionals and researchers generally use the third option, which lists peer-reviewed citations. In all cases, we suggest that you take advantage of the “Advanced Search” option that allows you to retrieve up to 100 fully explained references in a comprehensive format. Type “Whipple’s disease” (or synonyms) into the search box. To narrow the search, you can also select the “Title” field.

Federal Resources on Nutrition

In addition to the IBIDS, the United States Department of Health and Human Services (HHS) and the United States Department of Agriculture (USDA) provide many sources of information on general nutrition and health. Recommended resources include:

- healthfinder®, HHS’s gateway to health information, including diet and nutrition:
<http://www.healthfinder.gov/scripts/SearchContext.asp?topic=238&page=0>
- The United States Department of Agriculture’s Web site dedicated to nutrition information: **www.nutrition.gov**
- The Food and Drug Administration’s Web site for federal food safety information: **www.foodsafety.gov**
- The National Action Plan on Overweight and Obesity sponsored by the United States Surgeon General:
<http://www.surgeongeneral.gov/topics/obesity/>
- The Center for Food Safety and Applied Nutrition has an Internet site sponsored by the Food and Drug Administration and the Department of Health and Human Services: **<http://vm.cfsan.fda.gov/>**
- Center for Nutrition Policy and Promotion sponsored by the United States Department of Agriculture: **<http://www.usda.gov/cnpp/>**
- Food and Nutrition Information Center, National Agricultural Library sponsored by the United States Department of Agriculture: **<http://www.nal.usda.gov/fnic/>**
- Food and Nutrition Service sponsored by the United States Department of Agriculture: **<http://www.fns.usda.gov/fns/>**

Additional Web Resources

A number of additional Web sites offer encyclopedic information covering food and nutrition. The following is a representative sample:

- AOL: <http://search.aol.com/cat.adp?id=174&layer=&from=subcats>
- Family Village: http://www.familyvillage.wisc.edu/med_nutrition.html
- Google: <http://directory.google.com/Top/Health/Nutrition/>
- Healthnotes: <http://www.thedacare.org/healthnotes/>
- Open Directory Project: <http://dmoz.org/Health/Nutrition/>
- Yahoo.com: <http://dir.yahoo.com/Health/Nutrition/>
- WebMD[®] Health: <http://my.webmd.com/nutrition>
- WholeHealthMD.com:
<http://www.wholehealthmd.com/reflib/0,1529,,00.html>

APPENDIX C. FINDING MEDICAL LIBRARIES

Overview

At a medical library you can find medical texts and reference books, consumer health publications, specialty newspapers and magazines, as well as medical journals. In this Appendix, we show you how to quickly find a medical library in your area.

Preparation

Before going to the library, highlight the references mentioned in this sourcebook that you find interesting. Focus on those items that are not available via the Internet, and ask the reference librarian for help with your search. He or she may know of additional resources that could be helpful to you. Most importantly, your local public library and medical libraries have Interlibrary Loan programs with the National Library of Medicine (NLM), one of the largest medical collections in the world. According to the NLM, most of the literature in the general and historical collections of the National Library of Medicine is available on interlibrary loan to any library. NLM's interlibrary loan services are only available to libraries. If you would like to access NLM medical literature, then visit a library in your area that can request the publications for you.²⁹

²⁹ Adapted from the NLM: <http://www.nlm.nih.gov/psd/cas/interlibrary.html>.

Finding a Local Medical Library

The quickest method to locate medical libraries is to use the Internet-based directory published by the National Network of Libraries of Medicine (NN/LM). This network includes 4626 members and affiliates that provide many services to librarians, health professionals, and the public. To find a library in your area, simply visit <http://nnlm.gov/members/adv.html> or call 1-800-338-7657.

Medical Libraries Open to the Public

In addition to the NN/LM, the National Library of Medicine (NLM) lists a number of libraries that are generally open to the public and have reference facilities. The following is the NLM's list plus hyperlinks to each library Web site. These Web pages can provide information on hours of operation and other restrictions. The list below is a small sample of libraries recommended by the National Library of Medicine (sorted alphabetically by name of the U.S. state or Canadian province where the library is located):³⁰

- **Alabama:** Health InfoNet of Jefferson County (Jefferson County Library Cooperative, Lister Hill Library of the Health Sciences), <http://www.uab.edu/infonet/>
- **Alabama:** Richard M. Scrushy Library (American Sports Medicine Institute), <http://www.asmi.org/LIBRARY.HTM>
- **Arizona:** Samaritan Regional Medical Center: The Learning Center (Samaritan Health System, Phoenix, Arizona), <http://www.samaritan.edu/library/bannerlibs.htm>
- **California:** Kris Kelly Health Information Center (St. Joseph Health System), <http://www.humboldt1.com/~kkhic/index.html>
- **California:** Community Health Library of Los Gatos (Community Health Library of Los Gatos), <http://www.healthlib.org/orgresources.html>
- **California:** Consumer Health Program and Services (CHIPS) (County of Los Angeles Public Library, Los Angeles County Harbor-UCLA Medical Center Library) - Carson, CA, <http://www.colapublib.org/services/chips.html>
- **California:** Gateway Health Library (Sutter Gould Medical Foundation)
- **California:** Health Library (Stanford University Medical Center), <http://www-med.stanford.edu/healthlibrary/>

³⁰ Abstracted from <http://www.nlm.nih.gov/medlineplus/libraries.html>.

- **California:** Patient Education Resource Center - Health Information and Resources (University of California, San Francisco), <http://sfghdean.ucsf.edu/barnett/PERC/default.asp>
- **California:** Redwood Health Library (Petaluma Health Care District), <http://www.phcd.org/rdwplib.html>
- **California:** San José PlaneTree Health Library, <http://planetreesanjose.org/>
- **California:** Sutter Resource Library (Sutter Hospitals Foundation), <http://go.sutterhealth.org/comm/resc-library/sac-resources.html>
- **California:** University of California, Davis. Health Sciences Libraries
- **California:** ValleyCare Health Library & Ryan Comer Cancer Resource Center (ValleyCare Health System), <http://www.valleycare.com/library.html>
- **California:** Washington Community Health Resource Library (Washington Community Health Resource Library), <http://www.healthlibrary.org/>
- **Colorado:** William V. Gervasini Memorial Library (Exempla Healthcare), <http://www.exempla.org/conslib.htm>
- **Connecticut:** Hartford Hospital Health Science Libraries (Hartford Hospital), <http://www.harthosp.org/library/>
- **Connecticut:** Healthnet: Connecticut Consumer Health Information Center (University of Connecticut Health Center, Lyman Maynard Stowe Library), <http://library.uchc.edu/departm/hnet/>
- **Connecticut:** Waterbury Hospital Health Center Library (Waterbury Hospital), <http://www.waterburyhospital.com/library/consumer.shtml>
- **Delaware:** Consumer Health Library (Christiana Care Health System, Eugene du Pont Preventive Medicine & Rehabilitation Institute), http://www.christianacare.org/health_guide/health_guide_pmri_health_info.cfm
- **Delaware:** Lewis B. Flinn Library (Delaware Academy of Medicine), <http://www.delamed.org/chls.html>
- **Georgia:** Family Resource Library (Medical College of Georgia), http://cmc.mcg.edu/kids_families/fam_resources/fam_res_lib/frl.htm
- **Georgia:** Health Resource Center (Medical Center of Central Georgia), <http://www.mccg.org/hrc/hrchome.asp>
- **Hawaii:** Hawaii Medical Library: Consumer Health Information Service (Hawaii Medical Library), <http://hml.org/CHIS/>

- **Idaho:** DeArmond Consumer Health Library (Kootenai Medical Center), <http://www.nicon.org/DeArmond/index.htm>
- **Illinois:** Health Learning Center of Northwestern Memorial Hospital (Northwestern Memorial Hospital, Health Learning Center), http://www.nmh.org/health_info/hlc.html
- **Illinois:** Medical Library (OSF Saint Francis Medical Center), <http://www.osfsaintfrancis.org/general/library/>
- **Kentucky:** Medical Library - Services for Patients, Families, Students & the Public (Central Baptist Hospital), <http://www.centralbap.com/education/community/library.htm>
- **Kentucky:** University of Kentucky - Health Information Library (University of Kentucky, Chandler Medical Center, Health Information Library), <http://www.mc.uky.edu/PatientEd/>
- **Louisiana:** Alton Ochsner Medical Foundation Library (Alton Ochsner Medical Foundation), <http://www.ochsner.org/library/>
- **Louisiana:** Louisiana State University Health Sciences Center Medical Library-Shreveport, <http://lib-sh.lsuhscc.edu/>
- **Maine:** Franklin Memorial Hospital Medical Library (Franklin Memorial Hospital), <http://www.fchn.org/fmh/lib.htm>
- **Maine:** Gerrish-True Health Sciences Library (Central Maine Medical Center), <http://www.cmmc.org/library/library.html>
- **Maine:** Hadley Parrot Health Science Library (Eastern Maine Healthcare), <http://www.emh.org/hll/hpl/guide.htm>
- **Maine:** Maine Medical Center Library (Maine Medical Center), <http://www.mmc.org/library/>
- **Maine:** Parkview Hospital, <http://www.parkviewhospital.org/communit.htm#Library>
- **Maine:** Southern Maine Medical Center Health Sciences Library (Southern Maine Medical Center), <http://www.smmc.org/services/service.php3?choice=10>
- **Maine:** Stephens Memorial Hospital Health Information Library (Western Maine Health), http://www.wmhcc.com/hil_frame.html
- **Manitoba, Canada:** Consumer & Patient Health Information Service (University of Manitoba Libraries), <http://www.umanitoba.ca/libraries/units/health/reference/chis.html>
- **Manitoba, Canada:** J.W. Crane Memorial Library (Deer Lodge Centre), <http://www.deerlodge.mb.ca/library/libraryservices.shtml>

- **Maryland:** Health Information Center at the Wheaton Regional Library (Montgomery County, Md., Dept. of Public Libraries, Wheaton Regional Library), <http://www.mont.lib.md.us/healthinfo/hic.asp>
- **Massachusetts:** Baystate Medical Center Library (Baystate Health System), <http://www.baystatehealth.com/1024/>
- **Massachusetts:** Boston University Medical Center Alumni Medical Library (Boston University Medical Center), <http://med-libwww.bu.edu/library/lib.html>
- **Massachusetts:** Lowell General Hospital Health Sciences Library (Lowell General Hospital), <http://www.lowellgeneral.org/library/HomePageLinks/WWW.htm>
- **Massachusetts:** Paul E. Woodard Health Sciences Library (New England Baptist Hospital), http://www.nebh.org/health_lib.asp
- **Massachusetts:** St. Luke's Hospital Health Sciences Library (St. Luke's Hospital), <http://www.southcoast.org/library/>
- **Massachusetts:** Treadwell Library Consumer Health Reference Center (Massachusetts General Hospital), <http://www.mgh.harvard.edu/library/chrcindex.html>
- **Massachusetts:** UMass HealthNet (University of Massachusetts Medical School), <http://healthnet.umassmed.edu/>
- **Michigan:** Botsford General Hospital Library - Consumer Health (Botsford General Hospital, Library & Internet Services), <http://www.botsfordlibrary.org/consumer.htm>
- **Michigan:** Helen DeRoy Medical Library (Providence Hospital and Medical Centers), <http://www.providence-hospital.org/library/>
- **Michigan:** Marquette General Hospital - Consumer Health Library (Marquette General Hospital, Health Information Center), <http://www.mgh.org/center.html>
- **Michigan:** Patient Education Resource Center - University of Michigan Cancer Center (University of Michigan Comprehensive Cancer Center), <http://www.cancer.med.umich.edu/learn/leares.htm>
- **Michigan:** Sladen Library & Center for Health Information Resources - Consumer Health Information, <http://www.sladen.hfhs.org/library/consumer/index.html>
- **Montana:** Center for Health Information (St. Patrick Hospital and Health Sciences Center), <http://www.saintpatrick.org/chi/librarydetail.php3?ID=41>

- **National:** Consumer Health Library Directory (Medical Library Association, Consumer and Patient Health Information Section), <http://caphis.mlanet.org/directory/index.html>
- **National:** National Network of Libraries of Medicine (National Library of Medicine) - provides library services for health professionals in the United States who do not have access to a medical library, <http://nmlm.gov/>
- **National:** NN/LM List of Libraries Serving the Public (National Network of Libraries of Medicine), <http://nmlm.gov/members/>
- **Nevada:** Health Science Library, West Charleston Library (Las Vegas Clark County Library District), http://www.lvccld.org/special_collections/medical/index.htm
- **New Hampshire:** Dartmouth Biomedical Libraries (Dartmouth College Library), http://www.dartmouth.edu/~biomed/resources.html#conshealth.html#
- **New Jersey:** Consumer Health Library (Rahway Hospital), <http://www.rahwayhospital.com/library.htm>
- **New Jersey:** Dr. Walter Phillips Health Sciences Library (Englewood Hospital and Medical Center), <http://www.englewoodhospital.com/links/index.htm>
- **New Jersey:** Meland Foundation (Englewood Hospital and Medical Center), <http://www.geocities.com/ResearchTriangle/9360/>
- **New York:** Choices in Health Information (New York Public Library) - NLM Consumer Pilot Project participant, <http://www.nypl.org/branch/health/links.html>
- **New York:** Health Information Center (Upstate Medical University, State University of New York), <http://www.upstate.edu/library/hic/>
- **New York:** Health Sciences Library (Long Island Jewish Medical Center), <http://www.lij.edu/library/library.html>
- **New York:** ViaHealth Medical Library (Rochester General Hospital), <http://www.nyam.org/library/>
- **Ohio:** Consumer Health Library (Akron General Medical Center, Medical & Consumer Health Library), <http://www.akrongeneral.org/hwlibrary.htm>
- **Oklahoma:** Saint Francis Health System Patient/Family Resource Center (Saint Francis Health System), <http://www.sfh-tulsa.com/patientfamilycenter/default.asp>

- **Oregon:** Planetree Health Resource Center (Mid-Columbia Medical Center), <http://www.mcmc.net/phrc/>
- **Pennsylvania:** Community Health Information Library (Milton S. Hershey Medical Center), <http://www.hmc.psu.edu/commhealth/>
- **Pennsylvania:** Community Health Resource Library (Geisinger Medical Center), <http://www.geisinger.edu/education/commlib.shtml>
- **Pennsylvania:** HealthInfo Library (Moses Taylor Hospital), <http://www.mth.org/healthwellness.html>
- **Pennsylvania:** Hopwood Library (University of Pittsburgh, Health Sciences Library System), <http://www.hsls.pitt.edu/chi/hhrcinfo.html>
- **Pennsylvania:** Koop Community Health Information Center (College of Physicians of Philadelphia), <http://www.collphyphil.org/koopp1.shtml>
- **Pennsylvania:** Learning Resources Center - Medical Library (Susquehanna Health System), <http://www.shscare.org/services/lrc/index.asp>
- **Pennsylvania:** Medical Library (UPMC Health System), <http://www.upmc.edu/passavant/library.htm>
- **Quebec, Canada:** Medical Library (Montreal General Hospital), <http://ww2.mcgill.ca/mghlib/>
- **South Dakota:** Rapid City Regional Hospital - Health Information Center (Rapid City Regional Hospital, Health Information Center), <http://www.rcrh.org/education/LibraryResourcesConsumers.htm>
- **Texas:** Houston HealthWays (Houston Academy of Medicine-Texas Medical Center Library), <http://hwh.library.tmc.edu/>
- **Texas:** Matustik Family Resource Center (Cook Children's Health Care System), http://www.cookchildrens.com/Matustik_Library.html
- **Washington:** Community Health Library (Kittitas Valley Community Hospital), <http://www.kvch.com/>
- **Washington:** Southwest Washington Medical Center Library (Southwest Washington Medical Center), <http://www.swmedctr.com/Home/>

APPENDIX D. YOUR RIGHTS AND INSURANCE

Overview

Any patient with Whipple's disease faces a series of issues related more to the healthcare industry than to the medical condition itself. This appendix covers two important topics in this regard: your rights and responsibilities as a patient, and how to get the most out of your medical insurance plan.

Your Rights as a Patient

The President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry has created the following summary of your rights as a patient.³¹

Information Disclosure

Consumers have the right to receive accurate, easily understood information. Some consumers require assistance in making informed decisions about health plans, health professionals, and healthcare facilities. Such information includes:

- **Health plans.** Covered benefits, cost-sharing, and procedures for resolving complaints, licensure, certification, and accreditation status, comparable measures of quality and consumer satisfaction, provider network composition, the procedures that govern access to specialists and emergency services, and care management information.

³¹Adapted from Consumer Bill of Rights and Responsibilities:
<http://www.hcqualitycommission.gov/press/cbor.html#head1>.

- **Health professionals.** Education, board certification, and recertification, years of practice, experience performing certain procedures, and comparable measures of quality and consumer satisfaction.
- **Healthcare facilities.** Experience in performing certain procedures and services, accreditation status, comparable measures of quality, worker, and consumer satisfaction, and procedures for resolving complaints.
- **Consumer assistance programs.** Programs must be carefully structured to promote consumer confidence and to work cooperatively with health plans, providers, payers, and regulators. Desirable characteristics of such programs are sponsorship that ensures accountability to the interests of consumers and stable, adequate funding.

Choice of Providers and Plans

Consumers have the right to a choice of healthcare providers that is sufficient to ensure access to appropriate high-quality healthcare. To ensure such choice, the Commission recommends the following:

- **Provider network adequacy.** All health plan networks should provide access to sufficient numbers and types of providers to assure that all covered services will be accessible without unreasonable delay -- including access to emergency services 24 hours a day and 7 days a week. If a health plan has an insufficient number or type of providers to provide a covered benefit with the appropriate degree of specialization, the plan should ensure that the consumer obtains the benefit outside the network at no greater cost than if the benefit were obtained from participating providers.
- **Women's health services.** Women should be able to choose a qualified provider offered by a plan -- such as gynecologists, certified nurse midwives, and other qualified healthcare providers -- for the provision of covered care necessary to provide routine and preventative women's healthcare services.
- **Access to specialists.** Consumers with complex or serious medical conditions who require frequent specialty care should have direct access to a qualified specialist of their choice within a plan's network of providers. Authorizations, when required, should be for an adequate number of direct access visits under an approved treatment plan.
- **Transitional care.** Consumers who are undergoing a course of treatment for a chronic or disabling condition (or who are in the second or third trimester of a pregnancy) at the time they involuntarily change health

plans or at a time when a provider is terminated by a plan for other than cause should be able to continue seeing their current specialty providers for up to 90 days (or through completion of postpartum care) to allow for transition of care.

- ***Choice of health plans.*** Public and private group purchasers should, wherever feasible, offer consumers a choice of high-quality health insurance plans.

Access to Emergency Services

Consumers have the right to access emergency healthcare services when and where the need arises. Health plans should provide payment when a consumer presents to an emergency department with acute symptoms of sufficient severity--including severe pain--such that a "prudent layperson" could reasonably expect the absence of medical attention to result in placing that consumer's health in serious jeopardy, serious impairment to bodily functions, or serious dysfunction of any bodily organ or part.

Participation in Treatment Decisions

Consumers have the right and responsibility to fully participate in all decisions related to their healthcare. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators. Physicians and other health professionals should:

- Provide patients with sufficient information and opportunity to decide among treatment options consistent with the informed consent process.
- Discuss all treatment options with a patient in a culturally competent manner, including the option of no treatment at all.
- Ensure that persons with disabilities have effective communications with members of the health system in making such decisions.
- Discuss all current treatments a consumer may be undergoing.
- Discuss all risks, benefits, and consequences to treatment or nontreatment.
- Give patients the opportunity to refuse treatment and to express preferences about future treatment decisions.

- Discuss the use of advance directives -- both living wills and durable powers of attorney for healthcare -- with patients and their designated family members.
- Abide by the decisions made by their patients and/or their designated representatives consistent with the informed consent process.

Health plans, health providers, and healthcare facilities should:

- Disclose to consumers factors -- such as methods of compensation, ownership of or interest in healthcare facilities, or matters of conscience -- that could influence advice or treatment decisions.
- Assure that provider contracts do not contain any so-called "gag clauses" or other contractual mechanisms that restrict healthcare providers' ability to communicate with and advise patients about medically necessary treatment options.
- Be prohibited from penalizing or seeking retribution against healthcare professionals or other health workers for advocating on behalf of their patients.

Respect and Nondiscrimination

Consumers have the right to considerate, respectful care from all members of the healthcare industry at all times and under all circumstances. An environment of mutual respect is essential to maintain a quality healthcare system. To assure that right, the Commission recommends the following:

- Consumers must not be discriminated against in the delivery of healthcare services consistent with the benefits covered in their policy, or as required by law, based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.
- Consumers eligible for coverage under the terms and conditions of a health plan or program, or as required by law, must not be discriminated against in marketing and enrollment practices based on race, ethnicity, national origin, religion, sex, age, mental or physical disability, sexual orientation, genetic information, or source of payment.

Confidentiality of Health Information

Consumers have the right to communicate with healthcare providers in confidence and to have the confidentiality of their individually identifiable

healthcare information protected. Consumers also have the right to review and copy their own medical records and request amendments to their records.

Complaints and Appeals

Consumers have the right to a fair and efficient process for resolving differences with their health plans, healthcare providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review. A free copy of the Patient's Bill of Rights is available from the American Hospital Association.³²

Patient Responsibilities

Treatment is a two-way street between you and your healthcare providers. To underscore the importance of finance in modern healthcare as well as your responsibility for the financial aspects of your care, the President's Advisory Commission on Consumer Protection and Quality in the Healthcare Industry has proposed that patients understand the following "Consumer Responsibilities."³³ In a healthcare system that protects consumers' rights, it is reasonable to expect and encourage consumers to assume certain responsibilities. Greater individual involvement by the consumer in his or her care increases the likelihood of achieving the best outcome and helps support a quality-oriented, cost-conscious environment. Such responsibilities include:

- Take responsibility for maximizing healthy habits such as exercising, not smoking, and eating a healthy diet.
- Work collaboratively with healthcare providers in developing and carrying out agreed-upon treatment plans.
- Disclose relevant information and clearly communicate wants and needs.
- Use your health insurance plan's internal complaint and appeal processes to address your concerns.
- Avoid knowingly spreading disease.

³² To order your free copy of the Patient's Bill of Rights, telephone 312-422-3000 or visit the American Hospital Association's Web site: <http://www.aha.org>. Click on "Resource Center," go to "Search" at bottom of page, and then type in "Patient's Bill of Rights." The Patient's Bill of Rights is also available from Fax on Demand, at 312-422-2020, document number 471124.

³³ Adapted from <http://www.hcqualitycommission.gov/press/cbor.html#head1>.

- Recognize the reality of risks, the limits of the medical science, and the human fallibility of the healthcare professional.
- Be aware of a healthcare provider's obligation to be reasonably efficient and equitable in providing care to other patients and the community.
- Become knowledgeable about your health plan's coverage and options (when available) including all covered benefits, limitations, and exclusions, rules regarding use of network providers, coverage and referral rules, appropriate processes to secure additional information, and the process to appeal coverage decisions.
- Show respect for other patients and health workers.
- Make a good-faith effort to meet financial obligations.
- Abide by administrative and operational procedures of health plans, healthcare providers, and Government health benefit programs.

Choosing an Insurance Plan

There are a number of official government agencies that help consumers understand their healthcare insurance choices.³⁴ The U.S. Department of Labor, in particular, recommends ten ways to make your health benefits choices work best for you.³⁵

1. Your options are important. There are many different types of health benefit plans. Find out which one your employer offers, then check out the plan, or plans, offered. Your employer's human resource office, the health plan administrator, or your union can provide information to help you match your needs and preferences with the available plans. The more information you have, the better your healthcare decisions will be.

2. Reviewing the benefits available. Do the plans offered cover preventive care, well-baby care, vision or dental care? Are there deductibles? Answers to these questions can help determine the out-of-pocket expenses you may face. Matching your needs and those of your family members will result in the best possible benefits. Cheapest may not always be best. Your goal is high quality health benefits.

³⁴ More information about quality across programs is provided at the following AHRQ Web site:

<http://www.ahrq.gov/consumer/qntascii/qnthplan.htm>.

³⁵ Adapted from the Department of Labor:

<http://www.dol.gov/dol/pwba/public/pubs/health/top10-text.html>.

3. Look for quality. The quality of healthcare services varies, but quality can be measured. You should consider the quality of healthcare in deciding among the healthcare plans or options available to you. Not all health plans, doctors, hospitals and other providers give the highest quality care. Fortunately, there is quality information you can use right now to help you compare your healthcare choices. Find out how you can measure quality. Consult the U.S. Department of Health and Human Services publication “Your Guide to Choosing Quality Health Care” on the Internet at www.ahcpr.gov/consumer.

4. Your plan’s summary plan description (SPD) provides a wealth of information. Your health plan administrator can provide you with a copy of your plan’s SPD. It outlines your benefits and your legal rights under the Employee Retirement Income Security Act (ERISA), the federal law that protects your health benefits. It should contain information about the coverage of dependents, what services will require a co-pay, and the circumstances under which your employer can change or terminate a health benefits plan. Save the SPD and all other health plan brochures and documents, along with memos or correspondence from your employer relating to health benefits.

5. Assess your benefit coverage as your family status changes. Marriage, divorce, childbirth or adoption, and the death of a spouse are all life events that may signal a need to change your health benefits. You, your spouse and dependent children may be eligible for a special enrollment period under provisions of the Health Insurance Portability and Accountability Act (HIPAA). Even without life-changing events, the information provided by your employer should tell you how you can change benefits or switch plans, if more than one plan is offered. If your spouse’s employer also offers a health benefits package, consider coordinating both plans for maximum coverage.

6. Changing jobs and other life events can affect your health benefits. Under the Consolidated Omnibus Budget Reconciliation Act (COBRA), you, your covered spouse, and your dependent children may be eligible to purchase extended health coverage under your employer’s plan if you lose your job, change employers, get divorced, or upon occurrence of certain other events. Coverage can range from 18 to 36 months depending on your situation. COBRA applies to most employers with 20 or more workers and requires your plan to notify you of your rights. Most plans require eligible individuals to make their COBRA election within 60 days of the plan’s notice. Be sure to follow up with your plan sponsor if you don’t receive notice, and make sure you respond within the allotted time.

7. HIPAA can also help if you are changing jobs, particularly if you have a medical condition. HIPAA generally limits pre-existing condition exclusions to a maximum of 12 months (18 months for late enrollees). HIPAA also requires this maximum period to be reduced by the length of time you had prior "creditable coverage." You should receive a certificate documenting your prior creditable coverage from your old plan when coverage ends.

8. Plan for retirement. Before you retire, find out what health benefits, if any, extend to you and your spouse during your retirement years. Consult with your employer's human resources office, your union, the plan administrator, and check your SPD. Make sure there is no conflicting information among these sources about the benefits you will receive or the circumstances under which they can change or be eliminated. With this information in hand, you can make other important choices, like finding out if you are eligible for Medicare and Medigap insurance coverage.

9. Know how to file an appeal if your health benefits claim is denied. Understand how your plan handles grievances and where to make appeals of the plan's decisions. Keep records and copies of correspondence. Check your health benefits package and your SPD to determine who is responsible for handling problems with benefit claims. Contact PWBA for customer service assistance if you are unable to obtain a response to your complaint.

10. You can take steps to improve the quality of the healthcare and the health benefits you receive. Look for and use things like Quality Reports and Accreditation Reports whenever you can. Quality reports may contain consumer ratings -- how satisfied consumers are with the doctors in their plan, for instance-- and clinical performance measures -- how well a healthcare organization prevents and treats illness. Accreditation reports provide information on how accredited organizations meet national standards, and often include clinical performance measures. Look for these quality measures whenever possible. Consult "Your Guide to Choosing Quality Health Care" on the Internet at www.ahcpr.gov/consumer.

Medicare and Medicaid

Illness strikes both rich and poor families. For low-income families, Medicaid is available to defer the costs of treatment. The Health Care Financing Administration (HCFA) administers Medicare, the nation's largest health insurance program, which covers 39 million Americans. In the following pages, you will learn the basics about Medicare insurance as well as useful

contact information on how to find more in-depth information about Medicaid.³⁶

Who is Eligible for Medicare?

Generally, you are eligible for Medicare if you or your spouse worked for at least 10 years in Medicare-covered employment and you are 65 years old and a citizen or permanent resident of the United States. You might also qualify for coverage if you are under age 65 but have a disability or End-Stage Renal disease (permanent kidney failure requiring dialysis or transplant). Here are some simple guidelines:

You can get Part A at age 65 without having to pay premiums if:

- You are already receiving retirement benefits from Social Security or the Railroad Retirement Board.
- You are eligible to receive Social Security or Railroad benefits but have not yet filed for them.
- You or your spouse had Medicare-covered government employment.

If you are under 65, you can get Part A without having to pay premiums if:

- You have received Social Security or Railroad Retirement Board disability benefit for 24 months.
- You are a kidney dialysis or kidney transplant patient.

Medicare has two parts:

- Part A (Hospital Insurance). Most people do not have to pay for Part A.
- Part B (Medical Insurance). Most people pay monthly for Part B.

Part A (Hospital Insurance)

Helps Pay For: Inpatient hospital care, care in critical access hospitals (small facilities that give limited outpatient and inpatient services to people in rural areas) and skilled nursing facilities, hospice care, and some home healthcare.

³⁶ This section has been adapted from the Official U.S. Site for Medicare Information: <http://www.medicare.gov/Basics/Overview.asp>.

Cost: Most people get Part A automatically when they turn age 65. You do not have to pay a monthly payment called a premium for Part A because you or a spouse paid Medicare taxes while you were working.

If you (or your spouse) did not pay Medicare taxes while you were working and you are age 65 or older, you still may be able to buy Part A. If you are not sure you have Part A, look on your red, white, and blue Medicare card. It will show "Hospital Part A" on the lower left corner of the card. You can also call the Social Security Administration toll free at 1-800-772-1213 or call your local Social Security office for more information about buying Part A. If you get benefits from the Railroad Retirement Board, call your local RRB office or 1-800-808-0772. For more information, call your Fiscal Intermediary about Part A bills and services. The phone number for the Fiscal Intermediary office in your area can be obtained from the following Web site: <http://www.medicare.gov/Contacts/home.asp>.

Part B (Medical Insurance)

Helps Pay For: Doctors, services, outpatient hospital care, and some other medical services that Part A does not cover, such as the services of physical and occupational therapists, and some home healthcare. Part B helps pay for covered services and supplies when they are medically necessary.

Cost: As of 2001, you pay the Medicare Part B premium of \$50.00 per month. In some cases this amount may be higher if you did not choose Part B when you first became eligible at age 65. The cost of Part B may go up 10% for each 12-month period that you were eligible for Part B but declined coverage, except in special cases. You will have to pay the extra 10% cost for the rest of your life.

Enrolling in Part B is your choice. You can sign up for Part B anytime during a 7-month period that begins 3 months before you turn 65. Visit your local Social Security office, or call the Social Security Administration at 1-800-772-1213 to sign up. If you choose to enroll in Part B, the premium is usually taken out of your monthly Social Security, Railroad Retirement, or Civil Service Retirement payment. If you do not receive any of the above payments, Medicare sends you a bill for your part B premium every 3 months. You should receive your Medicare premium bill in the mail by the 10th of the month. If you do not, call the Social Security Administration at 1-800-772-1213, or your local Social Security office. If you get benefits from the Railroad Retirement Board, call your local RRB office or 1-800-808-0772. For more information, call your Medicare carrier about bills and services. The

phone number for the Medicare carrier in your area can be found at the following Web site: <http://www.medicare.gov/Contacts/home.asp>. You may have choices in how you get your healthcare including the Original Medicare Plan, Medicare Managed Care Plans (like HMOs), and Medicare Private Fee-for-Service Plans.

Medicaid

Medicaid is a joint federal and state program that helps pay medical costs for some people with low incomes and limited resources. Medicaid programs vary from state to state. People on Medicaid may also get coverage for nursing home care and outpatient prescription drugs which are not covered by Medicare. You can find more information about Medicaid on the HCFA.gov Web site at <http://www.hcfa.gov/medicaid/medicaid.htm>.

States also have programs that pay some or all of Medicare's premiums and may also pay Medicare deductibles and coinsurance for certain people who have Medicare and a low income. To qualify, you must have:

- Part A (Hospital Insurance),
- Assets, such as bank accounts, stocks, and bonds that are not more than \$4,000 for a single person, or \$6,000 for a couple, and
- A monthly income that is below certain limits.

For more information on these programs, look at the Medicare Savings Programs brochure, <http://www.medicare.gov/Library/PDFNavigation/PDFInterim.asp?Language=English&Type=Pub&PubID=10126>. There are also Prescription Drug Assistance Programs available. Find information on these programs which offer discounts or free medications to individuals in need at <http://www.medicare.gov/Prescription/Home.asp>.

NORD's Medication Assistance Programs

Finally, the National Organization for Rare Disorders, Inc. (NORD) administers medication programs sponsored by humanitarian-minded pharmaceutical and biotechnology companies to help uninsured or under-insured individuals secure life-saving or life-sustaining drugs.³⁷ NORD

³⁷ Adapted from NORD: http://www.rarediseases.org/cgi-bin/nord/progserv#patient?id=rPIzL9oD&mv_pc=30.

programs ensure that certain vital drugs are available “to those individuals whose income is too high to qualify for Medicaid but too low to pay for their prescribed medications.” The program has standards for fairness, equity, and unbiased eligibility. It currently covers some 14 programs for nine pharmaceutical companies. NORD also offers early access programs for investigational new drugs (IND) under the approved “Treatment INDs” programs of the Food and Drug Administration (FDA). In these programs, a limited number of individuals can receive investigational drugs that have yet to be approved by the FDA. These programs are generally designed for rare diseases or disorders. For more information, visit www.rarediseases.org.

Additional Resources

In addition to the references already listed in this chapter, you may need more information on health insurance, hospitals, or the healthcare system in general. The NIH has set up an excellent guidance Web site that addresses these and other issues. Topics include:³⁸

- Health Insurance:
<http://www.nlm.nih.gov/medlineplus/healthinsurance.html>
- Health Statistics:
<http://www.nlm.nih.gov/medlineplus/healthstatistics.html>
- HMO and Managed Care:
<http://www.nlm.nih.gov/medlineplus/managedcare.html>
- Hospice Care: <http://www.nlm.nih.gov/medlineplus/hospicecare.html>
- Medicaid: <http://www.nlm.nih.gov/medlineplus/medicaid.html>
- Medicare: <http://www.nlm.nih.gov/medlineplus/medicare.html>
- Nursing Homes and Long-term Care:
<http://www.nlm.nih.gov/medlineplus/nursinghomes.html>
- Patient's Rights, Confidentiality, Informed Consent, Ombudsman Programs, Privacy and Patient Issues:
<http://www.nlm.nih.gov/medlineplus/patientissues.html>
- Veteran's Health, Persian Gulf War, Gulf War Syndrome, Agent Orange:
<http://www.nlm.nih.gov/medlineplus/veteranshealth.html>

³⁸ You can access this information at:

<http://www.nlm.nih.gov/medlineplus/healthsystem.html>.

Vocabulary Builder

Capsules: Hard or soft soluble containers used for the oral administration of medicine. [NIH]

Cholesterol: The principal sterol of all higher animals, distributed in body tissues, especially the brain and spinal cord, and in animal fats and oils. [NIH]

Degenerative: Undergoing degeneration : tending to degenerate; having the character of or involving degeneration; causing or tending to cause degeneration. [EU]

Iodine: A nonmetallic element of the halogen group that is represented by the atomic symbol I, atomic number 53, and atomic weight of 126.90. It is a nutritionally essential element, especially important in thyroid hormone synthesis. In solution, it has anti-infective properties and is used topically. [NIH]

Levothyroxine: Levo isomer of the thyroid hormone thyroxine. It is used for replacement therapy in reduced or absent thyroid function. [NIH]

Neural: 1. pertaining to a nerve or to the nerves. 2. situated in the region of the spinal axis, as the neutral arch. [EU]

Niacin: Water-soluble vitamin of the B complex occurring in various animal and plant tissues. Required by the body for the formation of coenzymes NAD and NADP. Has pellagra-curative, vasodilating, and antilipemic properties. [NIH]

Overdose: 1. to administer an excessive dose. 2. an excessive dose. [EU]

Pancreas: An organ behind the lower part of the stomach that is about the size of a hand. It makes insulin so that the body can use glucose (sugar) for energy. It also makes enzymes that help the body digest food. Spread all over the pancreas are areas called the islets of Langerhans. The cells in these areas each have a special purpose. The alpha cells make glucagon, which raises the level of glucose in the blood; the beta cells make insulin; the delta cells make somatostatin. There are also the PP cells and the D1 cells, about which little is known. [NIH]

Potassium: An element that is in the alkali group of metals. It has an atomic symbol K, atomic number 19, and atomic weight 39.10. It is the chief cation in the intracellular fluid of muscle and other cells. Potassium ion is a strong electrolyte and it plays a significant role in the regulation of fluid volume and maintenance of the water-electrolyte balance. [NIH]

Proteins: Polymers of amino acids linked by peptide bonds. The specific sequence of amino acids determines the shape and function of the protein. [NIH]

Riboflavin: Nutritional factor found in milk, eggs, malted barley, liver,

kidney, heart, and leafy vegetables. The richest natural source is yeast. It occurs in the free form only in the retina of the eye, in whey, and in urine; its principal forms in tissues and cells are as FMN and FAD. [NIH]

Secretion: 1. the process of elaborating a specific product as a result of the activity of a gland; this activity may range from separating a specific substance of the blood to the elaboration of a new chemical substance. 2. any substance produced by secretion. [EU]

Selenium: An element with the atomic symbol Se, atomic number 34, and atomic weight 78.96. It is an essential micronutrient for mammals and other animals but is toxic in large amounts. Selenium protects intracellular structures against oxidative damage. It is an essential component of glutathione peroxidase. [NIH]

Somatostatin: A polypeptide hormone produced in the hypothalamus, and other tissues and organs. It inhibits the release of human growth hormone, and also modulates important physiological functions of the kidney, pancreas, and gastrointestinal tract. Somatostatin receptors are widely expressed throughout the body. Somatostatin also acts as a neurotransmitter in the central and peripheral nervous systems. [NIH]

Sphincter: A ringlike band of muscle fibres that constricts a passage or closes a natural orifice; called also musculus sphincter. [EU]

Thyroxine: An amino acid of the thyroid gland which exerts a stimulating effect on thyroid metabolism. [NIH]

ONLINE GLOSSARIES

The Internet provides access to a number of free-to-use medical dictionaries and glossaries. The National Library of Medicine has compiled the following list of online dictionaries:

- ADAM Medical Encyclopedia (A.D.A.M., Inc.), comprehensive medical reference: <http://www.nlm.nih.gov/medlineplus/encyclopedia.html>
- MedicineNet.com Medical Dictionary (MedicineNet, Inc.):
<http://www.medterms.com/Script/Main/hp.asp>
- Merriam-Webster Medical Dictionary (Inteli-Health, Inc.):
<http://www.intelihealth.com/IH/>
- Multilingual Glossary of Technical and Popular Medical Terms in Eight European Languages (European Commission) - Danish, Dutch, English, French, German, Italian, Portuguese, and Spanish:
<http://allserv.rug.ac.be/~rvdstich/eugloss/welcome.html>
- On-line Medical Dictionary (CancerWEB):
<http://www.graylab.ac.uk/omd/>
- Technology Glossary (National Library of Medicine) - Health Care Technology: <http://www.nlm.nih.gov/nichsr/ta101/ta10108.htm>
- Terms and Definitions (Office of Rare Diseases):
http://rarediseases.info.nih.gov/ord/glossary_a-e.html

Beyond these, MEDLINEplus contains a very user-friendly encyclopedia covering every aspect of medicine (licensed from A.D.A.M., Inc.). The ADAM Medical Encyclopedia Web site address is <http://www.nlm.nih.gov/medlineplus/encyclopedia.html>. ADAM is also available on commercial Web sites such as Web MD (http://my.webmd.com/adam/asset/adam_disease_articles/a_to_z/a) and drkoop.com (<http://www.drkoop.com/>). Topics of interest can be researched by using keywords before continuing elsewhere, as these basic definitions and concepts will be useful in more advanced areas of research. You may choose to print various pages specifically relating to Whipple's disease and keep them on file.

Online Dictionary Directories

The following are additional online directories compiled by the National Library of Medicine, including a number of specialized medical dictionaries and glossaries:

- Medical Dictionaries: Medical & Biological (World Health Organization):
<http://www.who.int/hlt/virtuallibrary/English/diction.htm#Medical>
- MEL-Michigan Electronic Library List of Online Health and Medical Dictionaries (Michigan Electronic Library):
<http://mel.lib.mi.us/health/health-dictionaries.html>
- Patient Education: Glossaries (DMOZ Open Directory Project):
http://dmoz.org/Health/Education/Patient_Education/Glossaries/
- Web of Online Dictionaries (Bucknell University):
<http://www.yourdictionary.com/diction5.html#medicine>

WHIPPLE'S DISEASE GLOSSARY

The following is a complete glossary of terms used in this sourcebook. The definitions are derived from official public sources including the National Institutes of Health [NIH] and the European Union [EU]. After this glossary, we list a number of additional hardbound and electronic glossaries and dictionaries that you may wish to consult.

Aberrant: Wandering or deviating from the usual or normal course. [EU]

Alimentary: Pertaining to food or nutritive material, or to the organs of digestion. [EU]

Alleles: Mutually exclusive forms of the same gene, occupying the same locus on homologous chromosomes, and governing the same biochemical and developmental process. [NIH]

Anemia: A reduction in the number of circulating erythrocytes or in the quantity of hemoglobin. [NIH]

Antibiotic: A chemical substance produced by a microorganism which has the capacity, in dilute solutions, to inhibit the growth of or to kill other microorganisms. Antibiotics that are sufficiently nontoxic to the host are used as chemotherapeutic agents in the treatment of infectious diseases of man, animals and plants. [EU]

Antibodies: Proteins that the body makes to protect itself from foreign substances. In diabetes, the body sometimes makes antibodies to work against pork or beef insulins because they are not exactly the same as human insulin or because they have impurities. The antibodies can keep the insulin from working well and may even cause the person with diabetes to have an allergic or bad reaction to the beef or pork insulins. [NIH]

Antigens: Substances that cause an immune response in the body. The body "sees" the antigens as harmful or foreign. To fight them, the body produces antibodies, which attack and try to eliminate the antigens. [NIH]

Artery: A large blood vessel that carries blood from the heart to other parts of the body. Arteries are thicker and have walls that are stronger and more elastic than the walls of veins. [NIH]

Arthroplasty: Surgical reconstruction of a joint to relieve pain or restore motion. [NIH]

Bacteria: Unicellular prokaryotic microorganisms which generally possess rigid cell walls, multiply by cell division, and exhibit three principal forms: round or coccid, rodlike or bacillary, and spiral or spirochetal. [NIH]

Biliary: Pertaining to the bile, to the bile ducts, or to the gallbladder. [EU]

Biopsy: The removal and examination, usually microscopic, of tissue from the living body, performed to establish precise diagnosis. [EU]

Cadaver: A dead body, usually a human body. [NIH]

Capillary: Any one of the minute vessels that connect the arterioles and venules, forming a network in nearly all parts of the body. Their walls act as semipermeable membranes for the interchange of various substances, including fluids, between the blood and tissue fluid; called also vas capillare. [EU]

Capsules: Hard or soft soluble containers used for the oral administration of medicine. [NIH]

Carbohydrate: An aldehyde or ketone derivative of a polyhydric alcohol, particularly of the pentahydric and hexahydric alcohols. They are so named because the hydrogen and oxygen are usually in the proportion to form water, $(CH_2O)_n$. The most important carbohydrates are the starches, sugars, celluloses, and gums. They are classified into mono-, di-, tri-, poly- and heterosaccharides. [EU]

Carcinoma: A malignant new growth made up of epithelial cells tending to infiltrate the surrounding tissues and give rise to metastases. [EU]

Cardiology: The study of the heart, its physiology, and its functions. [NIH]

Cholecystectomy: Surgical removal of the gallbladder. [NIH]

Cholesterol: The principal sterol of all higher animals, distributed in body tissues, especially the brain and spinal cord, and in animal fats and oils. [NIH]

Chronic: Persisting over a long period of time. [EU]

Collagen: The protein substance of the white fibres (collagenous fibres) of skin, tendon, bone, cartilage, and all other connective tissue; composed of molecules of tropocollagen (q.v.), it is converted into gelatin by boiling. collagenous pertaining to collagen; forming or producing collagen. [EU]

Colorectal: Pertaining to or affecting the colon and rectum. [EU]

Contracture: A condition of fixed high resistance to passive stretch of a muscle, resulting from fibrosis of the tissues supporting the muscles or the joints, or from disorders of the muscle fibres. [EU]

Coronary: Encircling in the manner of a crown; a term applied to vessels; nerves, ligaments, etc. The term usually denotes the arteries that supply the heart muscle and, by extension, a pathologic involvement of them. [EU]

Curative: Tending to overcome disease and promote recovery. [EU]

Cyst: Any closed cavity or sac; normal or abnormal, lined by epithelium, and especially one that contains a liquid or semisolid material. [EU]

Cytokines: Non-antibody proteins secreted by inflammatory leukocytes and some non-leukocytic cells, that act as intercellular mediators. They differ

from classical hormones in that they are produced by a number of tissue or cell types rather than by specialized glands. They generally act locally in a paracrine or autocrine rather than endocrine manner. [NIH]

Degenerative: Undergoing degeneration : tending to degenerate; having the character of or involving degeneration; causing or tending to cause degeneration. [EU]

Diarrhea: Passage of excessively liquid or excessively frequent stools. [NIH]

Digestion: The process of breakdown of food for metabolism and use by the body. [NIH]

Dysplasia: Abnormality of development; in pathology, alteration in size, shape, and organization of adult cells. [EU]

Electrolyte: A substance that dissociates into ions when fused or in solution, and thus becomes capable of conducting electricity; an ionic solute. [EU]

Endocarditis: Exudative and proliferative inflammatory alterations of the endocardium, characterized by the presence of vegetations on the surface of the endocardium or in the endocardium itself, and most commonly involving a heart valve, but sometimes affecting the inner lining of the cardiac chambers or the endocardium elsewhere. It may occur as a primary disorder or as a complication of or in association with another disease. [EU]

Endocrinology: A subspecialty of internal medicine concerned with the metabolism, physiology, and disorders of the endocrine system. [NIH]

Enzyme: A protein molecule that catalyses chemical reactions of other substances without itself being destroyed or altered upon completion of the reactions. Enzymes are classified according to the recommendations of the Nomenclature Committee of the International Union of Biochemistry. Each enzyme is assigned a recommended name and an Enzyme Commission (EC) number. They are divided into six main groups; oxidoreductases, transferases, hydrolases, lyases, isomerases, and ligases. [EU]

Epithelium: The covering of internal and external surfaces of the body, including the lining of vessels and other small cavities. It consists of cells joined by small amounts of cementing substances. Epithelium is classified into types on the basis of the number of layers deep and the shape of the superficial cells. [EU]

Exogenous: Developed or originating outside the organism, as exogenous disease. [EU]

Fatigue: The state of weariness following a period of exertion, mental or physical, characterized by a decreased capacity for work and reduced efficiency to respond to stimuli. [NIH]

Fats: One of the three main classes of foods and a source of energy in the body. Fats help the body use some vitamins and keep the skin healthy. They

also serve as energy stores for the body. In food, there are two types of fats: saturated and unsaturated. [NIH]

Fluorescence: The property of emitting radiation while being irradiated. The radiation emitted is usually of longer wavelength than that incident or absorbed, e.g., a substance can be irradiated with invisible radiation and emit visible light. X-ray fluorescence is used in diagnosis. [NIH]

Gastrointestinal: Pertaining to or communicating with the stomach and intestine, as a gastrointestinal fistula. [EU]

Helicobacter: A genus of gram-negative, spiral-shaped bacteria that is pathogenic and has been isolated from the intestinal tract of mammals, including humans. [NIH]

Hematology: A subspecialty of internal medicine concerned with morphology, physiology, and pathology of the blood and blood-forming tissues. [NIH]

Hemorrhage: Bleeding or escape of blood from a vessel. [NIH]

Heparin: Heparinic acid. A highly acidic mucopolysaccharide formed of equal parts of sulfated D-glucosamine and D-glucuronic acid with sulfaminic bridges. The molecular weight ranges from six to twenty thousand. Heparin occurs in and is obtained from liver, lung, mast cells, etc., of vertebrates. Its function is unknown, but it is used to prevent blood clotting in vivo and vitro, in the form of many different salts. [NIH]

Hormones: Chemical substances having a specific regulatory effect on the activity of a certain organ or organs. The term was originally applied to substances secreted by various endocrine glands and transported in the bloodstream to the target organs. It is sometimes extended to include those substances that are not produced by the endocrine glands but that have similar effects. [NIH]

Hybridization: The genetic process of crossbreeding to produce a hybrid. Hybrid nucleic acids can be formed by nucleic acid hybridization of DNA and RNA molecules. Protein hybridization allows for hybrid proteins to be formed from polypeptide chains. [NIH]

Hyperbaric: Characterized by greater than normal pressure or weight; applied to gases under greater than atmospheric pressure, as hyperbaric oxygen, or to a solution of greater specific gravity than another taken as a standard of reference. [EU]

Immunization: The induction of immunity. [EU]

Immunohistochemistry: Histochemical localization of immunoreactive substances using labeled antibodies as reagents. [NIH]

Induction: The act or process of inducing or causing to occur, especially the production of a specific morphogenetic effect in the developing embryo

through the influence of evocators or organizers, or the production of anaesthesia or unconsciousness by use of appropriate agents. [EU]

Inflammation: A pathological process characterized by injury or destruction of tissues caused by a variety of cytologic and chemical reactions. It is usually manifested by typical signs of pain, heat, redness, swelling, and loss of function. [NIH]

Influenza: An acute viral infection involving the respiratory tract. It is marked by inflammation of the nasal mucosa, the pharynx, and conjunctiva, and by headache and severe, often generalized, myalgia. [NIH]

Insulin: A protein hormone secreted by beta cells of the pancreas. Insulin plays a major role in the regulation of glucose metabolism, generally promoting the cellular utilization of glucose. It is also an important regulator of protein and lipid metabolism. Insulin is used as a drug to control insulin-dependent diabetes mellitus. [NIH]

Intermittent: Occurring at separated intervals; having periods of cessation of activity. [EU]

Iodine: A nonmetallic element of the halogen group that is represented by the atomic symbol I, atomic number 53, and atomic weight of 126.90. It is a nutritionally essential element, especially important in thyroid hormone synthesis. In solution, it has anti-infective properties and is used topically. [NIH]

Lactobacillus: A genus of gram-positive, microaerophilic, rod-shaped bacteria occurring widely in nature. Its species are also part of the many normal flora of the mouth, intestinal tract, and vagina of many mammals, including humans. Pathogenicity from this genus is rare. [NIH]

Lectins: Protein or glycoprotein substances, usually of plant origin, that bind to sugar moieties in cell walls or membranes and thereby change the physiology of the membrane to cause agglutination, mitosis, or other biochemical changes in the cell. [NIH]

Lesion: Any pathological or traumatic discontinuity of tissue or loss of function of a part. [EU]

Levothyroxine: Levo isomer of the thyroid hormone thyroxine. It is used for replacement therapy in reduced or absent thyroid function. [NIH]

Lipid: Any of a heterogeneous group of fats and fatlike substances characterized by being water-insoluble and being extractable by nonpolar (or fat) solvents such as alcohol, ether, chloroform, benzene, etc. All contain as a major constituent aliphatic hydrocarbons. The lipids, which are easily stored in the body, serve as a source of fuel, are an important constituent of cell structure, and serve other biological functions. Lipids may be considered to include fatty acids, neutral fats, waxes, and steroids. Compound lipids comprise the glycolipids, lipoproteins, and phospholipids. [EU]

Lipophilic: Having an affinity for fat; pertaining to or characterized by lipophilia. [EU]

Lipoprotein: Any of the lipid-protein complexes in which lipids are transported in the blood; lipoprotein particles consist of a spherical hydrophobic core of triglycerides or cholesterol esters surrounded by an amphipathic monolayer of phospholipids, cholesterol, and apolipoproteins; the four principal classes are high-density, low-density, and very-low-density lipoproteins and chylomicrons. [EU]

Lupus: A form of cutaneous tuberculosis. It is seen predominantly in women and typically involves the nasal, buccal, and conjunctival mucosa. [NIH]

Malabsorption: Impaired intestinal absorption of nutrients. [EU]

Mental: Pertaining to the mind; psychic. 2. (L. mentum chin) pertaining to the chin. [EU]

Methotrexate: An antineoplastic antimetabolite with immunosuppressant properties. It is an inhibitor of dihydrofolate reductase and prevents the formation of tetrahydrofolate, necessary for synthesis of thymidylate, an essential component of DNA. [NIH]

Microbiological: Pertaining to microbiology : the science that deals with microorganisms, including algae, bacteria, fungi, protozoa and viruses. [EU]

Microorganism: A microscopic organism; those of medical interest include bacteria, viruses, fungi and protozoa. [EU]

Molecular: Of, pertaining to, or composed of molecules : a very small mass of matter. [EU]

Motility: The ability to move spontaneously. [EU]

Mutagenesis: Process of generating genetic mutations. It may occur spontaneously or be induced by mutagens. [NIH]

Neoplastic: Pertaining to or like a neoplasm (= any new and abnormal growth); pertaining to neoplasia (= the formation of a neoplasm). [EU]

Neural: 1. pertaining to a nerve or to the nerves. 2. situated in the region of the spinal axis, as the neutral arch. [EU]

Niacin: Water-soluble vitamin of the B complex occurring in various animal and plant tissues. Required by the body for the formation of coenzymes NAD and NADP. Has pellagra-curative, vasodilating, and antilipemic properties. [NIH]

Occult: Obscure; concealed from observation, difficult to understand. [EU]

Orthopaedic: Pertaining to the correction of deformities of the musculoskeletal system; pertaining to orthopaedics. [EU]

Overdose: 1. to administer an excessive dose. 2. an excessive dose. [EU]

Pancreas: An organ behind the lower part of the stomach that is about the size of a hand. It makes insulin so that the body can use glucose (sugar) for energy. It also makes enzymes that help the body digest food. Spread all over the pancreas are areas called the islets of Langerhans. The cells in these areas each have a special purpose. The alpha cells make glucagon, which raises the level of glucose in the blood; the beta cells make insulin; the delta cells make somatostatin. There are also the PP cells and the D1 cells, about which little is known. [NIH]

Pancreaticoduodenectomy: The excision of the head of the pancreas and the encircling loop of the duodenum to which it is connected. [NIH]

Pancreatitis: Inflammation (pain, tenderness) of the pancreas; it can make the pancreas stop working. It is caused by drinking too much alcohol, by disease in the gallbladder, or by a virus. [NIH]

Pediatrics: A medical specialty concerned with maintaining health and providing medical care to children from birth to adolescence. [NIH]

Perforation: 1. the act of boring or piercing through a part. 2. a hole made through a part or substance. [EU]

Phenotype: The outward appearance of the individual. It is the product of interactions between genes and between the genotype and the environment. This includes the killer phenotype, characteristic of YEASTS. [NIH]

Potassium: An element that is in the alkali group of metals. It has an atomic symbol K, atomic number 19, and atomic weight 39.10. It is the chief cation in the intracellular fluid of muscle and other cells. Potassium ion is a strong electrolyte and it plays a significant role in the regulation of fluid volume and maintenance of the water-electrolyte balance. [NIH]

Precursor: Something that precedes. In biological processes, a substance from which another, usually more active or mature substance is formed. In clinical medicine, a sign or symptom that heralds another. [EU]

Prednisone: A synthetic anti-inflammatory glucocorticoid derived from cortisone. It is biologically inert and converted to prednisolone in the liver. [NIH]

Procollagen: A biosynthetic precursor of collagen containing additional amino acid sequences at the amino-terminal ends of the three polypeptide chains. Protocollagen, a precursor of procollagen consists of procollagen peptide chains in which proline and lysine have not yet been hydroxylated. [NIH]

Protease: Proteinase (= any enzyme that catalyses the splitting of interior peptide bonds in a protein). [EU]

Proteins: Polymers of amino acids linked by peptide bonds. The specific sequence of amino acids determines the shape and function of the protein. [NIH]

Receptor: 1. a molecular structure within a cell or on the surface characterized by (1) selective binding of a specific substance and (2) a specific physiologic effect that accompanies the binding, e.g., cell-surface receptors for peptide hormones, neurotransmitters, antigens, complement fragments, and immunoglobulins and cytoplasmic receptors for steroid hormones. 2. a sensory nerve terminal that responds to stimuli of various kinds. [EU]

Recombinant: 1. a cell or an individual with a new combination of genes not found together in either parent; usually applied to linked genes. [EU]

Rectal: Pertaining to the rectum (= distal portion of the large intestine). [EU]

Refractory: Not readily yielding to treatment. [EU]

Remission: A diminution or abatement of the symptoms of a disease; also the period during which such diminution occurs. [EU]

Rheumatoid: Resembling rheumatism. [EU]

Riboflavin: Nutritional factor found in milk, eggs, malted barley, liver, kidney, heart, and leafy vegetables. The richest natural source is yeast. It occurs in the free form only in the retina of the eye, in whey, and in urine; its principal forms in tissues and cells are as FMN and FAD. [NIH]

Secretion: 1. the process of elaborating a specific product as a result of the activity of a gland; this activity may range from separating a specific substance of the blood to the elaboration of a new chemical substance. 2. any substance produced by secretion. [EU]

Selenium: An element with the atomic symbol Se, atomic number 34, and atomic weight 78.96. It is an essential micronutrient for mammals and other animals but is toxic in large amounts. Selenium protects intracellular structures against oxidative damage. It is an essential component of glutathione peroxidase. [NIH]

Serum: The clear portion of any body fluid; the clear fluid moistening serous membranes. 2. blood serum; the clear liquid that separates from blood on clotting. 3. immune serum; blood serum from an immunized animal used for passive immunization; an antiserum; antitoxin, or antivenin. [EU]

Somatostatin: A polypeptide hormone produced in the hypothalamus, and other tissues and organs. It inhibits the release of human growth hormone, and also modulates important physiological functions of the kidney, pancreas, and gastrointestinal tract. Somatostatin receptors are widely expressed throughout the body. Somatostatin also acts as a neurotransmitter in the central and peripheral nervous systems. [NIH]

Species: A taxonomic category subordinate to a genus (or subgenus) and superior to a subspecies or variety, composed of individuals possessing common characters distinguishing them from other categories of individuals

of the same taxonomic level. In taxonomic nomenclature, species are designated by the genus name followed by a Latin or Latinized adjective or noun. [EU]

Spectrum: A charted band of wavelengths of electromagnetic vibrations obtained by refraction and diffraction. By extension, a measurable range of activity, such as the range of bacteria affected by an antibiotic (antibacterial s.) or the complete range of manifestations of a disease. [EU]

Sphincter: A ringlike band of muscle fibres that constricts a passage or closes a natural orifice; called also musculus sphincter. [EU]

Stomach: An organ of digestion situated in the left upper quadrant of the abdomen between the termination of the esophagus and the beginning of the duodenum. [NIH]

Streptococcus: A genus of gram-positive, coccoid bacteria whose organisms occur in pairs or chains. No endospores are produced. Many species exist as commensals or parasites on man or animals with some being highly pathogenic. A few species are saprophytes and occur in the natural environment. [NIH]

Synergistic: Acting together; enhancing the effect of another force or agent. [EU]

Systemic: Pertaining to or affecting the body as a whole. [EU]

Telomere: A terminal section of a chromosome which has a specialized structure and which is involved in chromosomal replication and stability. Its length is believed to be a few hundred base pairs. [NIH]

Thermoregulation: Heat regulation. [EU]

Thyroxine: An amino acid of the thyroid gland which exerts a stimulating effect on thyroid metabolism. [NIH]

Tolerance: 1. the ability to endure unusually large doses of a drug or toxin. 2. acquired drug tolerance; a decreasing response to repeated constant doses of a drug or the need for increasing doses to maintain a constant response. [EU]

Topical: Pertaining to a particular surface area, as a topical anti-infective applied to a certain area of the skin and affecting only the area to which it is applied. [EU]

Toxicity: The quality of being poisonous, especially the degree of virulence of a toxic microbe or of a poison. [EU]

Toxicology: The science concerned with the detection, chemical composition, and pharmacologic action of toxic substances or poisons and the treatment and prevention of toxic manifestations. [NIH]

Transfusion: The introduction of whole blood or blood component directly into the blood stream. [EU]

Tropomyosin: A protein found in the thin filaments of muscle fibers. It inhibits contraction of the muscle unless its position is modified by troponin. [NIH]

Tuberculosis: Any of the infectious diseases of man and other animals caused by species of mycobacterium. [NIH]

Ulceration: 1. the formation or development of an ulcer. 2. an ulcer. [EU]

Urology: A surgical specialty concerned with the study, diagnosis, and treatment of diseases of the urinary tract in both sexes and the genital tract in the male. It includes the specialty of andrology which addresses both male genital diseases and male infertility. [NIH]

Vaccine: A suspension of attenuated or killed microorganisms (bacteria, viruses, or rickettsiae), administered for the prevention, amelioration or treatment of infectious diseases. [EU]

Viral: Pertaining to, caused by, or of the nature of virus. [EU]

General Dictionaries and Glossaries

While the above glossary is essentially complete, the dictionaries listed here cover virtually all aspects of medicine, from basic words and phrases to more advanced terms (sorted alphabetically by title; hyperlinks provide rankings, information and reviews at Amazon.com):

- **Dictionary of Medical Acronyms & Abbreviations** by Stanley Jablonski (Editor), Paperback, 4th edition (2001), Lippincott Williams & Wilkins Publishers, ISBN: 1560534605, <http://www.amazon.com/exec/obidos/ASIN/1560534605/icongroupinterna>
- **Dictionary of Medical Terms : For the Nonmedical Person (Dictionary of Medical Terms for the Nonmedical Person, Ed 4)** by Mikel A. Rothenberg, M.D, et al, Paperback - 544 pages, 4th edition (2000), Barrons Educational Series, ISBN: 0764112015, <http://www.amazon.com/exec/obidos/ASIN/0764112015/icongroupinterna>
- **A Dictionary of the History of Medicine** by A. Sebastian, CD-Rom edition (2001), CRC Press-Parthenon Publishers, ISBN: 185070368X, <http://www.amazon.com/exec/obidos/ASIN/185070368X/icongroupinterna>
- **Dorland's Illustrated Medical Dictionary (Standard Version)** by Dorland, et al, Hardcover - 2088 pages, 29th edition (2000), W B Saunders Co, ISBN: 0721662544, <http://www.amazon.com/exec/obidos/ASIN/0721662544/icongroupinterna>
- **Dorland's Electronic Medical Dictionary** by Dorland, et al, Software, 29th Book & CD-Rom edition (2000), Harcourt Health Sciences, ISBN:

0721694934,

<http://www.amazon.com/exec/obidos/ASIN/0721694934/icongroupinterna>

- **Dorland's Pocket Medical Dictionary (Dorland's Pocket Medical Dictionary, 26th Ed)** Hardcover - 912 pages, 26th edition (2001), W B Saunders Co, ISBN: 0721682812,
<http://www.amazon.com/exec/obidos/ASIN/0721682812/icongroupinterna/103-4193558-7304618>
- **Melloni's Illustrated Medical Dictionary (Melloni's Illustrated Medical Dictionary, 4th Ed)** by Melloni, Hardcover, 4th edition (2001), CRC Press-Parthenon Publishers, ISBN: 85070094X,
<http://www.amazon.com/exec/obidos/ASIN/85070094X/icongroupinterna>
- **Stedman's Electronic Medical Dictionary Version 5.0 (CD-ROM for Windows and Macintosh, Individual)** by Stedmans, CD-ROM edition (2000), Lippincott Williams & Wilkins Publishers, ISBN: 0781726328,
<http://www.amazon.com/exec/obidos/ASIN/0781726328/icongroupinterna>
- **Stedman's Medical Dictionary** by Thomas Lathrop Stedman, Hardcover - 2098 pages, 27th edition (2000), Lippincott, Williams & Wilkins, ISBN: 068340007X,
<http://www.amazon.com/exec/obidos/ASIN/068340007X/icongroupinterna>
- **Tabers Cyclopedic Medical Dictionary (Thumb Index)** by Donald Venes (Editor), et al, Hardcover - 2439 pages, 19th edition (2001), F A Davis Co, ISBN: 0803606540,
<http://www.amazon.com/exec/obidos/ASIN/0803606540/icongroupinterna>

INDEX

- A**
 Abdominal..... 11, 41
 Antibiotic 16, 30, 41, 95
 Antibodies..... 32, 33, 34, 87, 90
 Antigens..... 33, 36, 87, 94
- B**
 Bacteria 11, 16, 17, 34, 35, 37, 56, 90,
 91, 92, 95, 96
 Biopsy..... 11, 30
- C**
 Capsules..... 59
 Carbohydrate..... 58
 Cholesterol 44, 56, 58, 92
 Chromosomal 37, 95
 Chronic 30, 41, 72
 Collagen 33, 36, 88, 93
 Curative 41, 83, 92
- D**
 Degenerative 57
 Diarrhea 11, 41, 56
 Digestion..... 15, 37, 87, 95
- E**
 Electrolyte..... 11, 83, 93
 Enzyme..... 33, 36, 89, 93
 Epithelium..... 88
 Exogenous..... 34, 89
- F**
 Fatal..... 11, 41
 Fatigue..... 11
 Fats..... 11, 16, 44, 56, 83, 88, 90, 91
 Fluorescence 34, 90
- G**
 Gastrointestinal..... 34, 84, 90, 94
- H**
 Hematology 10
 Hormones 33, 36, 89, 94
 Hyperbaric 34, 90
- I**
 Immunization 36, 94
 Induction 16, 90
 Inflammation 16, 91
 Insulin 11, 16, 32, 83, 87, 91, 93
 Intestinal 11, 16, 34, 35, 56, 90, 91, 92
- L**
 Lipid 16, 44, 91, 92
 Lipoprotein 44, 92
- M**
 Mental 16, 74, 89
 Microorganism 15, 87
 Molecular 10, 34, 36, 41, 90, 94
- N**
 Neural 57
 Niacin 57
- O**
 Overdose 57
- P**
 Pancreas..... 16, 83, 84, 91, 93, 94
 Pharmacologic 16, 95
 Phenotype..... 36, 93
 Potassium 58
 Precursor 36, 93
 Procollagen..... 36, 93
 Proteins..... 33, 34, 56, 58, 88, 90
- R**
 Riboflavin 56
- S**
 Selenium 58
 Serum 36, 94
 Somatostatin 83, 93
 Species 35, 36, 37, 91, 95, 96
 Spectrum..... 10
 Sphincter..... 84, 95
 Stomach..... 34, 83, 90, 93
 Surgical 16, 96
 Systemic 41
- T**
 Thermoregulation..... 56
 Thyroxine 58
 Tolerance 37, 95
 Topical 37, 95
 Toxicology..... 10
 Tuberculosis..... 35, 92
- U**
 Urology..... 10
- V**
 Viral..... 16, 91

