

PATIENT AND FAMILY HANDBOOK

For The Primary Immune Deficiency Diseases

PRODUCED FOR PATIENTS AND FAMILIES BY



IMMUNE DEFICIENCY FOUNDATION

Dedicated To Research And Education For The Primary Immune Deficiency Diseases

This publication has been made possible
through a generous grant from

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This book contains general medical information which cannot be applied safely to any individual case.
Medical knowledge and practice can change rapidly. Therefore, this book should not be used
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THIRD EDITION

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PREFACE

The first edition of the Patient and Family Handbook was written over a decade ago in response to requests from patients with primary immune deficiency diseases, their families, and their physicians. We hoped that it would help patients and their families to learn more about the immune system, the primary immune deficiency diseases, currently available therapies and possible future treatments. Since then, tens of thousands of copies have been distributed to patients and their families!

This third edition has been stimulated by the many new and exciting advances in the diagnosis and therapy of the primary immune deficiency diseases. Many chapters in this edition are new and all of the old chapters have been revised to include important new information. The first chapter entitled "The Immune System and Primary Immune Deficiency Diseases" explains the immune system and how it functions and should be useful to all readers. Chapters on specific primary immune deficiencies follow. We have included chapters on disorders that were not covered in the previous two editions and updated chapters on specific disorders to include information on new diagnostic tools, more precise clinical information, and new therapies. The chapter entitled "Inheritance" has been rewritten to not only explain how some of the specific disorders can be passed from generation to generation, but also to provide new information on prenatal diagnosis and carrier testing. The "General Care" chapter conveys "common sense" guidelines that the patient and family may find useful. The "Specific Medical Therapy" chapter has been revised to reflect recent advances in treatments available to the immune deficient individual. In the last edition we included a chapter on "Adults and Primary Immune Deficiency Diseases" that dealt with issues that have special significance to adults with primary immune deficiency diseases. In response to suggestions from a number of patients and their families, we have added another new chapter on "Children, Teenager, and Primary Immune Deficiency Diseases" that deals with the issues that are relevant to children. The "Resources" chapter includes additional information available both in printed form and on the "Internet". Finally, the "Glossary" includes definitions of the more common, and possibly confusing, medical terms.

A few words on how to use this book! This book is not a substitute for a dialogue between the patient, his/her family, their physician, and other members of the health care team. Rather, it is intended to provide the patient and family with tools to enhance the communication process and to understand the information they receive from the health care team. Most importantly, this book is not intended to suggest diagnostic approaches or to recommend specific therapy for a specific patient. Each patient's illness and treatment is unique and the management of their illness should be customized to their individual medical needs.

We thank all those individuals who contributed to this book: those who wrote specific chapters, the members of the Medical Advisory Committee who reviewed the chapters, the Board of Trustees and the Staff of the Immune Deficiency Foundation who made this book a high priority, and finally, the patients and their families whose suggestions will make this edition even better than the last two!

*The Editors
Baltimore 2001*

TABLE OF CONTENTS

| | | |
|--------------|---|-----|
| CHAPTER I | THE IMMUNE SYSTEM AND PRIMARY IMMUNE DEFICIENCY DISEASES | 1 |
| CHAPTER II | X-LINKED AGAMMAGLOBULINEMIA | 11 |
| CHAPTER III | COMMON VARIABLE IMMUNE DEFICIENCY DISEASE | 15 |
| CHAPTER IV | SELECTIVE IGA DEFICIENCY | 19 |
| CHAPTER V | SEVERE COMBINED IMMUNE DEFICIENCY | 23 |
| CHAPTER VI | CHRONIC GRANULOMATOUS DISEASE | 31 |
| CHAPTER VII | THE WISKOTT-ALDRICH SYNDROME | 35 |
| CHAPTER VIII | THE X-LINKED HYPER IGM SYNDROME | 41 |
| CHAPTER IX | THE DIGEORGE SYNDROME | 45 |
| CHAPTER X | IGG SUBCLASS DEFICIENCY | 49 |
| CHAPTER XI | ATAXIA TELANGIECTASIA | 53 |
| CHAPTER XII | INHERITANCE | 57 |
| CHAPTER XIII | GENERAL CARE | 65 |
| CHAPTER XIV | SPECIFIC MEDICAL THERAPY | 75 |
| CHAPTER XV | CHILDREN, TEENAGERS AND PRIMARY IMMUNE DEFICIENCY DISEASES | 87 |
| CHAPTER XVI | ADULTS AND PRIMARY IMMUNE DEFICIENCY DISEASES | 95 |
| CHAPTER XVII | INSURANCE | 103 |
| | GLOSSARY | 113 |
| | RESOURCES | 119 |
| | READING LIST | 125 |