FORGOTTEN PEOPLE, FORGOTTEN DISEASES
Dedicated to my youngest daughter,
Rachel Kate Hotez,
who teaches me every day about disabilities

To the memory of my brother,
Richard Eric Hotes, M.D.

And to the Bill and Melinda Gates Foundation
for the opportunity to devote my
life to the Neglected Tropical Diseases
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Foreword

Like a great general mustering his forces, Prof. Peter Hotez is gathering the forces of the world community to the fight against mankind’s most ancient scourges: leprosy, worm infections, blinding trachoma, and other harrowing tropical diseases. Hotez is an able leader in this great battle. His crystal clear and powerful text displays the mind of a great scientist and humanist, one who knows every technical detail about the diseases which afflict billions of people and kill millions each decade. But Hotez never overlooks the afflicted themselves, the poor people of Africa, Asia, and Latin America among whom he’s worked throughout his path-breaking career. Most importantly of all, he provides not only facts but also solutions, how we can finally triumph in an age-old struggle by deploying the best of modern public health and medical science.

In recent years, Hotez and several other world leaders in public health, including David Molyneux (Liverpool School of Medicine), Alan Fenwick (Imperial College London), and Lorenzo Savioli (World Health Organization), have been alerting the world to new possibilities to confront crippling diseases that have been long out of the limelight—indeed, often stigmatized to the point of systematic neglect, but taking a huge and devastating toll nonetheless. These leaders have christened these diseases the Neglected Tropical Diseases, or NTDs, and, in a crusade that combines elegant science with public education on a global scale, have created a new awareness of the possibility of making decisive advances in disease control. In essence, Hotez aims to take the “N” out of NTDs and to replace it with an “F,” so that these become the Former Tropical Diseases, at least in the sense of being brought decisively under control if not fully eliminated.

This book is an amazing and invaluable primer. It can be read by the general reader but also by the Infectious Diseases specialist. The general reader will no doubt feel stretched by the countless disease pathways, pathogenic agents, types of controls, and variations around the world. Yet at the same time, the
reader will feel exhilarated by seeing this complex and fascinating world presented with the utmost clarity, historical insight, and optimism. For this is a tale not only of harrowing suffering, but also of largely, and sometimes wholly, remediable suffering. As shocking and devastating are some of the stories, figures, and pictures, there is no gloom, only the steely determination to do all that we can as a global society to get these diseases under control.

The book is organized in a compelling manner. After a powerful overview showing that these diseases, despite their relative neglect, carry a combined disease burden on the same order of magnitude as AIDS, tuberculosis, and malaria, Hotez takes us on a remarkable tour of the world of worms and other pathogens, the disease vectors (such as mosquitoes and flies) which transmit them, and the state of public health and medical science. The agenda is daunting, with no fewer than thirteen killers playing a leading role and countless lesser infections also making cameo appearances. Yet the writing is so clear and compelling that, instead of jumble, Hotez provides us with an intellectual framework to keep the big picture even as we tour the water holes, lymph nodes, intestines, and mosquito salivary glands which constitute the settings of Hotez’s dramatic stories.

After explaining clearly and compellingly, but never condescendingly, the complexities of these tropical infections—including the pathogens which cause them, their transmission routes, the links to poverty, the pharmacology, and the history of control methods, right up to the present—Hotez rounds off the text with four crucial chapters. In chapter 9 he reminds us, forcefully but not alarmingly, that these are not only diseases of the tropical nations but also of the United States (at least in some cases). We have to care, not only for what these diseases mean for global suffering and for global political stability, but also for what they mean right at home in the U.S. In chapter 10 he describes the heroic efforts of many leaders, such as former President Jimmy Carter, and countless organizations and the new hopes for a stronger global leadership pulled together by a new Global Network for NTD Control, an effort in which Hotez has played a decisive role. In chapter 11 he reminds us that all effective public health programs, including the comprehensive control of the NTDs, must combine the comprehensive use of our existing tools—medicines, bed nets, surveillance, and others—with the research and development of new and more powerful tools, including vaccines against many of the NTDs. Characteristically, Hotez himself is a pioneer in research and development of a hookworm vaccine.

In the closing chapter 12, Hotez again raises the stakes. Controlling the NTDs is nothing less than “healing the world.” The control of the NTDs is a matter not only of disease control, but also of global security. Hotez argues persuasively that the NTDs, together with other killers such as AIDS, tuberculosis, and malaria, not only are exacerbated by upheavals of violence and conflict, but also are causes of conflict through their devastating effects of poverty, hunger, and despair, all precursors to violence in the poorest countries.

This book is thrilling on all levels. It is a unique opportunity for a wide readership to understand the science behind many of the world’s leading afflictions.
It is an opportunity to draw hope from countless examples of how science is contributing to solutions and the chances for comprehensive control of these killer diseases. And it is an invitation to all of us to engage personally with one of the greatest challenges of our time: using our heads and our hearts to help solve some of the longest-standing scourges facing humanity, and thereby building a world of greater justice, shared prosperity, and security.

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Foreword

In my humanitarian missions to Angola and elsewhere in developing countries, I am always struck by the devastation wrought by disease and malnutrition. Watching children and young women fall ill or fail to reach their full potential because of circumstances beyond their control has imprinted many indelible images in my mind. Although I have tried to capture some of this human suffering in my black and white photography, I also know there is so much more hidden misery that cannot be captured through pictures.

In my role as Lead Ambassador for the Global Network for Neglected Tropical Diseases, I have learned firsthand about the largely silent suffering that results from these terrible afffections. Hookworms rob children of their daily iron and protein requirements and prevent them from growing and learning. Elephantiasis, Buruli ulcer, and leprosy cause disfigurement. River blindness and trachoma cause permanent vision loss. African sleeping sickness results in a slow and agonizing death.

Forgotten People, Forgotten Diseases explains in straightforward language where these neglected tropical diseases occur and how they have become the most common diseases among the world’s poorest people. It also highlights the chronic and debilitating aspects of these diseases and their poverty-promoting features. Of particular importance to me, the book illustrates how people afflicted with neglected tropical diseases suffer from stigma in their communities, especially young women, who are often abandoned by their husbands and prevented from holding their children. Portrayed here is human suffering on an almost unimaginable scale.

Finally, Forgotten People, Forgotten Diseases teaches us about an incredible opportunity we have to control these neglected tropical diseases on a massive scale, with both existing drugs and new vaccines being developed in nonprofit research laboratories. I am excited by the possibility of witnessing the elimination of some of these terrible scourges in my lifetime. For all of these reasons, I am hopeful that this book will inspire you and stimulate you to get involved
in stamping out the neglected tropical diseases, thereby taking an important step to reaching out in a very tangible way to the world’s poorest and most vulnerable people.

Alyssa Milano

Lead Ambassador, Global Network for Neglected Tropical Diseases
Preface

Ever since junior high school, I have been fascinated by the application of scientific knowledge for solving tropical public health problems of global importance. Starting with an M.D.-Ph.D. dissertation begun in 1980, my adult life has been a quest to develop experimental vaccines for human hookworm infection. Now, after more than 25 years of laboratory investigation and thanks to the support of the Bill and Melinda Gates Foundation, I have the opportunity and good fortune to head a multidisciplinary team that is developing and manufacturing these vaccines and then testing them in an area of Brazil where hookworm is endemic. While reaching this goal has been intensely satisfying at both a professional and personal level, I have also come to realize that completing early-stage development of a new product for a disease such as hookworm has in many ways been the easy part! Hookworm infects approximately 600 million people worldwide, but they almost all live on less than US$2 per day and only in the poorest regions of sub-Saharan Africa, Asia, and the tropical regions of the Americas. Because the people at risk for hookworm infection cannot afford to pay for a vaccine, unless there is greater general awareness about the public health and economic importance of hookworm and other parasitic infections there will never be the political will and large-scale financial investment necessary to ensure the global access of a hookworm vaccine, or indeed any other product for the diseases of poverty. Simultaneously, as it becomes evident to me that vaccine development is a decades-long process, I feel a need to do more in order to reach out to the world’s poor and provide them with better access to the existing treatments for hookworm, even if our currently available anti-hookworm drugs are imperfect.

Partly as a means to increase access to essential medicines and innovation, I have begun a concerted effort to raise public awareness of hookworm and other parasitic infections and to advocate for the largely voiceless poor people living in remote and rural regions of endemicity. However, it was only after I met three scientific “soul mates,” medical parasitologists who were simultaneously
launching their own advocacy efforts, that I felt an important breakthrough was achieved in terms of placing parasitic diseases on the global radar screen. Since 2003 I have engaged in intense colloquy with Professor David H. Molyneux of the Liverpool School of Tropical Medicine (David is also the Director of the Global Alliance to Eliminate Lymphatic Filariasis), Professor Alan Fenwick from Imperial College, London (Alan is also the Director of the Schistosomiasis Control Initiative), and Dr. Lorenzo Savioli from the World Health Organization (as well as some of his close colleagues there, including Drs. Denis Daumerie, Dirk Engels, and Jean Jannin) about some of the common features of all parasitic infections affecting poor people. During these long and detailed but also joyful conversations, which took place in Washington, DC, Atlanta, New York, London, Liverpool, Glasgow, Geneva, Berlin, and Stockholm, we soon realized that the major parasitic infections, as well as some selected bacterial and viral infections, could be thought of in aggregate as a group under the banner of the neglected tropical diseases, or NTDs for short. The NTDs are the most common infections of poor people, and also among the most important in terms of their health and economic impact. In many respects, their burden of disease rivals those of better-known conditions including HIV/AIDS, even though most people have never heard about the NTDs. This lack of recognition continues to surprise us given that the NTDs are ancient conditions that have plagued humankind for centuries (as documented in many of our earliest writings such as Egyptian medical papyri and religious texts, including the Bible), and they represent one of the most important reasons why the populations living in low-income countries of Africa, Asia, and Central and South America remain mired in a vicious cycle of poverty, destitution, and despair. The continued presence of NTDs in North America represents that region’s most striking health disparity and a sad legacy of the Middle Passage, the Atlantic slave trade between the 15th and 19th centuries.

Professor Jeffrey Sachs and Dr. Sonia Ehrlich Sachs of Columbia’s Earth Institute and Dr. Eric Ottesen (then at Emory University) subsequently joined our informal NTD working group, and in a series of policy papers published in PLoS (Public Library of Science) and the New England Journal of Medicine, we were able to articulate the concept of the NTDs and how we can control or eliminate them through a global scale-up of access to essential medicines. These policy documents also provided a rationale for us to establish a new Global Network for NTDs, which is working to coordinate global advocacy and resource mobilization efforts for these conditions.

Forgotten People, Forgotten Diseases summarizes in mostly nontechnical language the major concepts about the NTDs and how they cause human suffering, as well as their global importance and the unique and unusual opportunity we now have to lift the world’s poorest people out of poverty through low-cost and highly cost-effective control measures.

Peter Hotez
Washington, DC
The idea for this book’s title came from a 2002 paper on helminth infections written by David Crompton and Michael Nesheim in the Annual Review of Nutrition, in which they quoted the phrase “forgotten diseases of forgotten people” (attributed to M. G. Schultz). I was inspired to write an “NTD Manifesto” in part from Jeff Sachs’s success in educating the general public about poverty in low-income countries in his landmark book, The End of Poverty, and also because of a very accessible book entitled Essentials of Global Health, written by my friend and colleague Richard Skolnik.

In addition to the individuals mentioned above and in the Preface, there are also many others who inspired me to write this book. They include my colleagues from the Global Network, including my associates at the Sabin Vaccine Institute, Kari Stoever (who provided leadership in helping to launch the Global Network, as well as her “A team”), Azalea Kim, Karen Palacio, Colin Burke, and Lindsay Wheeler; Kathy Spahn and Chad MacArthur from Helen Keller International; Jacob Kumaresan and Ibrahim Jabr from the International Trachoma Initiative; Mark Rosenberg, Eric Ottesen, and Nana Twum-Danso from the Task Force for Child Survival and Development; Joanna Rubinstein and Josh Ruxun from the Earth Institute at Columbia University; and John McCullough from Liverpool Associates in Tropical Health. I also want to acknowledge the leadership of the WHO, including Margaret Chan (Director-General), Anarfi Asamaoah Baah (Deputy Director-General), and David Heymann (Assistant Director-General, Communicable Diseases); the leadership of the Carter Center, including Donald Hopkins, Frank O. Richards, and former President Jimmy Carter and Rosalynn Carter; the Division of Parasitic Diseases of the CDC; Marcel Tanner, Juerg Utzinger, and Jennifer Kaiser at the Swiss Tropical Institute; Michael Katz at the March of Dimes Birth Defects Foundation; and Mirta Roses Periago, Director-General, Steven Ault, and the NTD group at the Pan American Health Organization for their exemplary dedication to NTDs, as well as the leadership at Merck & Co., Pfizer Inc., GlaxoSmithKline, Johnson
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Of enormous importance to the NTD enterprise is the Sabin Vaccine Institute Board Chairman, Philip K. Russell, who is my very important mentor on all things vaccines and global health, as well as his wife, Connie Russell. Ciro de Quadros, one of the giants of vaccinology and global health, has also been a source of inspiration and much-needed advice and wisdom. I also want to extend my deepest appreciation to my close friends and colleagues at the Human Hookworm Vaccine Initiative (HHVI) based at the Sabin Vaccine Institute, H. R. Shepherd, the Founding Chair, and his wife, Carol Ruth; Heloisa Sabin; Mort and Chris Hyman for their particular commitment to NTDs and their very important early support for schistosomiasis vaccine development; and to the rest of the Sabin Board members: Mary Ann Chaffee, Lou Cooper, Brian Davis, Jeffrey Fuisz, Lance Gordon, Nancy Gardner Hargrave, Axel Hoos, Michael and Jacqueline Kempner, Clark McFadden, Walter Orenstein, Ciro de Quadros, Kevin L. Reilly, Adan Rios, and Michael Whitham. I acknowledge the support of some very important people at The George Washington University Medical Center, including Jim Scott, Allan Goldstein, Richard Skolnik, Richard Southby, Ruth Katz, George Davis, Victor Barbiero, Gary Simon, Alan Wasserman, and John F. “Skip” Williams, past GWU President Stephen Joel Trachtenberg, and the new GWU president, Steven Knapp.

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I want to express deepest gratitude to the program officers of the Gates Foundation, who advocated for us and made it possible for me to pursue a dream and have a career devoted to hookworm vaccine development and NTD control. They include David Brandling-Bennett, Julie Jacobson, Gordon Perkin,
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Based on his personal experiences in the Democratic Republic of Congo and elsewhere in developing countries, Dikembe Mutombo of the Houston Rockets has been a powerful force behind the movement to raise awareness of the NTDs. I also thank the comedian Jill-Michele Meleán.

Beloved everywhere, Alyssa Milano, our Global Network for NTDs Ambassador, has given a fresh and beautiful face to these conditions and new hope to people everywhere who suffer from the stigma and disfigurement of the NTDs. She has been an eloquent and passionate spokesperson for these conditions.

Finally, I want to thank my loving family, Ann, Matthew, Emy, Rachel, and Daniel Hotez, as well as Larry and Linda Hotes, Liz and Warren Kirshenbaum, Andrea Hotes, and parents Ed and Jean Hotez; nephews and nieces Gennifer, Josh, Todd, Andrew, Alyssa, Marissa, Sammy, and Julia; in-laws Don, Marsha, Julia, and David Frifield, Mark and Judy Conway, and Irv and Peggy Goldberg; Daniel and Nancy Goldberg and their families, and all of the others in my extended family and circle of friends for putting up with me all of these years!
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