THE PARKINSON'S PLAN

A NEW PATH TO PREVENTION AND TREATMENT

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AUTHORS OF *ENDING PARKINSON'S DISEASE*

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New York

PublicAffairs
Hachette Book Group
1290 Avenue of the Americas, New York, NY 10104
www.publicaffairsbooks.com
@Public_Affairs

First Edition: August 2025

Published by PublicAffairs, an imprint of Hachette Book Group, Inc. The PublicAffairs name and logo is a registered trademark of the Hachette Book Group.

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Illustrations and photographs created and provided by authors unless otherwise noted.

Print book interior design by Amy Quinn.

Library of Congress Cataloging-in-Publication Data has been applied for.

ISBNs: 9781541705388 (hardcover), 9781541705401 (ebook)

E3-20250701-JV-NF-ORI

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Explore book giveaways, sneak peeks, deals, and more.

Tap here to learn more.

NOTE TO READERS

Dozens of individuals have shared their stories with us and you. In most cases, these amazing individuals have agreed to have their names shared. In some cases, we have changed their names and identities to protect their privacy. We are thankful to all.

GLOSSARY

alpha-synuclein—A small protein found in nerve cells that is misfolded (assembled improperly) in Parkinson's disease.

Alzheimer's disease—A brain disease that commonly affects memory, mood, and behavior.

animal model—The use of a laboratory animal to mimic a disease. The animal model is used to learn about the disease and to test new treatments.

biomarker—Chemicals, often in the blood or spinal fluid, that can be used to measure a disease. Cholesterol is a biomarker of heart disease, for example.

deep brain stimulation (DBS)—A surgical treatment for Parkinson's disease in which wire electrodes are inserted into the brain and connected to a battery-powered device to reduce symptoms and improve function.

dopamine—A chemical produced by some nerve cells that allows them to communicate with one another. In Parkinson's disease, many of the nerve cells that produce dopamine are lost.

dopamine pump—A device that can be inserted into the intestine or under the skin to provide a more continuous flow of levodopa.

gene editing—Altering DNA, often to prevent or treat a disease.

gene therapy—Inserting normal genes to replace or enhance missing or defective ones.

growth factors—Chemicals that help (brain) cells grow, develop, and survive. Scientists squirt growth factors on the brain like we put Miracle-Gro® on plants.

HIV/AIDS—The human immunodeficiency virus (HIV) attacks the immune system and at advanced stages can cause people to have the acquired immunodeficiency syndrome (AIDS).

homeostasis—The stable balance that your body and brain maintain. Your body tries to keep this balance as a way to fight off disease.

incidence—The number of new cases of a disease during a particular period (e.g., a year).

Lewy bodies—Clumps of a misfolded protein (alpha-synuclein) that are found in the brains of most individuals with Parkinson's disease.

microbiome—All the microorganisms (e.g., bacteria) living in a particular environment, such as the gut.

mitochondria—The energy-producing parts of cells, which are often damaged in Parkinson's disease.

MRI—Magnetic resonance imaging creates pictures of the brain and body using a large magnet and radio waves.

nanoparticles—Very tiny particles that are invisible to the human eye and slip easily into the brain. Nanoparticles can help deliver drugs to the brain.

neuron—A nerve cell.

organoid—A three-dimensional mini-brain in a dish that is usually made from growing stem cells.

particulate matter—Tiny pieces of dirt and soot that are suspended in the air. The smallest are less than one-thirtieth the width of a hair and may be an important risk factor for Parkinson's and Alzheimer's diseases.

perchloroethylene (PCE)—A chemical, closely related to trichloroethylene, that is widely used in degreasing and dry-cleaning.

PET scan—A sophisticated imaging test that reveals the chemicals in your brain.

prevalence—The proportion of individuals having a disease at any point in time (e.g., today).

proteins—Large molecules that carry out the functions of a cell.

RNAi therapy—Treatment that interferes with or destroys the instructions that genes give to make different proteins. It can be a "silencing therapy" for Parkinson's disease.

substantia nigra—Latin for "black substance"; the black area of the brain where nerve cells that produce dopamine are lost in Parkinson's disease.

Superfund—A US federal program that allows for cleanup of the most toxic sites in the country, often at the cost of the responsible parties.

toxicant—A synthetic (human-made) chemical that is harmful to health.

toxin—A naturally occurring substance that is hazardous to health. For example, some plants produce toxins that protect them from being eaten by insects.

trichloroethylene (TCE)—A common chemical that has been used to dry-clean clothes, decaffeinate coffee, and degrease metal.

vaccine—A medicine used to stimulate the body's own immune response against a disease. Vaccines have been typically aimed at infectious diseases (like Covid-19) but may also help treat diseases such as Parkinson's.

ABBREVIATIONS

AI Artificial intelligence

ALS Amyotrophic lateral sclerosis, a neurological disorder that leads to weakness; also known as Lou Gehrig's disease in the United States or motor neuron disease in the United Kingdom.

DBS Deep brain stimulation

DDT Dichloro-diphenyl-trichloroethane, one of the first modern synthetic pesticides

EPA US Environmental Protection Agency

FDA US Food and Drug Administration

NIH US National Institutes of Health

PCE Perchloroethylene

TCE Trichloroethylene

WHO World Health Organization

FOREWORD

FOR US, PARKINSON'S IS PERSONAL.

For Gus, Parkinson's has affected multiple generations. My parents' families emigrated from Greece in the early twentieth century. Both families settled in Tarpon Springs, Florida, known as the "Sponge Capital of the World." When my dad was an infant, his family moved to western Pennsylvania, where my dad's dad worked at local steel mills for forty years.

At an early age, my dad, Michael Bilirakis, sold newspapers and worked every night until 1:00 a.m. as an usher at the local movie theater. After graduating high school, my dad worked at local steel mills before serving in the US Air Force during the Korean War. Following his service, he attended the University of Pittsburgh and received a degree in chemical engineering while working forty-eight hours a week at Westinghouse. He then moved back to Florida and graduated with a JD from the University of Florida. He ultimately returned to Tarpon Springs, resided near a Superfund site, practiced law, and served in the US Congress for twenty-four years. Michael Bilirakis lived the American dream until Parkinson's robbed him of his retirement.

Like our father, my brother Emmanuel attended the University of Florida. He became a successful family practice doctor serving those in need in our community. He was diagnosed with Parkinson's in his forties and died at age sixty-one. Parkinson's robbed him of his life.

For Jennifer, the disease was a shock and a surprise. I explained away my earliest symptoms as everything but Parkinson's—like the stress of this new job in Congress, walking tens of thousands of steps around the Capitol, or just simply getting older. I couldn't believe someone like me could get a disease like this. But in 2022, when my clenching toes and shuffling gait progressed and a tremor in my voice emerged, I sought medical advice and was diagnosed at age fifty-four with Parkinson's disease. On World Parkinson's Day in 2023, I shared that diagnosis publicly.

Unfortunately, my symptoms progressed much faster than expected. My doctors revisited their diagnosis and changed it to a different parkinsonian disorder—progressive supranuclear palsy (PSP)—a kind of Parkinson's on

steroids. PSP has robbed me of my speech. But it has not taken away my voice, a voice that I am determined to use to help end these terrible diseases.

Both of us realized that our efforts to address these awful conditions required a plan. And surprisingly, the federal government did not have one. Every six minutes, an American is diagnosed with Parkinson's; yet we had no plan. Every day, one hundred Americans die from the disease, but we had no plan. Every year, the country spends $50 billion on Parkinson's and still no plan.

So with our wonderful colleague, Congressman Paul Tonko from New York, and great supporters in the Senate and beyond, we drafted the National Plan to End Parkinson's Act. The bill directs the secretary of the Department of Health and Human Services to work with experts from the public and private sector to develop a national plan to prevent and to cure Parkinson's disease. On December 14, 2023, the US House of Representatives passed the bipartisan bill 407–9. Six months later, the Senate passed it unanimously. With our families and us at his side, President Joe Biden signed the bill into law.

Like this book, the plan calls for us to **prevent** the disease, **amplify** the voices of patients and caregivers, and **navigate** the frontier of new treatments. However, one element was still missing, and that was to **learn** why people are developing these diseases in record numbers. Unlike many other conditions, like seizures and strokes, which date to biblical times, these diseases are relatively new. The first major description of Parkinson's disease did not happen until 1817. ALS, which causes paralysis, was first observed in 1869. PSP was not described until 1964, just sixty years ago. Dementia with Lewy bodies, another parkinsonian disorder that affected the late actor Robin Williams, was not noticed until 1976. All these diseases are increasingly common. Why?

To answer that question, we have drafted the Healthy Brains Act. The bill instructs the director of the National Institutes of Health to establish research, training, and education programs to identify the underlying environmental causes of neurodegenerative diseases. We have spent a generation studying the genetics of many different diseases, which has advanced our understanding of these conditions. Investigating the environmental causes is long overdue.

The heritability of many of these diseases is modest or low. Most people, like Jennifer, do not have a family history of the disease. They do not carry a genetic risk factor. The prevalences of these diseases vary by geography, and

clusters abound. Many are tied to chemicals in our food, water, and air. And many victims, including our families, have lived near polluted sites.

We need to learn why for three reasons. First, the initial step to curing any disease is to determine its cause. This approach has helped us cure hepatitis C and stomach ulcers. Second, once we know its cause, we can slow its progression or at least prevent it from getting worse. This has worked with Covid-19, where early treatment decreases the risk of hospitalization, and with many cancers, where early detection can save lives. Third, and perhaps most powerfully, when we learn why, we can prevent diseases. Textbooks are filled with diseases that no longer exist (e.g., smallpox), are very rare (e.g., polio), or may even one day disappear (e.g., HIV). This all happened because we learned why. And it will happen again for Parkinson's, PSP, and many other brain diseases, but only if we identify and eliminate their root causes.

Parkinsonian disorders do not respect political party or national boundaries. They affect all of us—our neighbors, our friends, and our families. We have experienced far too much of these diseases. To prevent and end this suffering, we helped pass a bill that calls for a national plan. Ray and Michael, two compassionate and thoughtful neurologists, have now taken the first step toward providing one.

Congressman Gus Bilirakis
Congresswoman Jennifer Wexton
October 28, 2024

INTRODUCTION

It takes as much energy to wish as it does to plan.

—Eleanor Roosevelt

ATHLETICS, MILITARY SERVICE, MEDICINE, AND PARKINSON'S DISEASE HAVE connected the lives of Jana Reed and Sara Whittingham. Thirty years ago, as young, talented, ambitious cadets, they met on the US Air Force Academy's idyllic track at the foot of the Rocky Mountains in Colorado Springs. Jana was from the California coastal town of San Luis Obispo, and Sara came from Steamboat Springs, Colorado. Jana, who was a year older, was a hurdler and long jumper for the Academy, while Sara ran long distances. Both women majored in biochemistry and were accepted to top medical schools, Jana at Georgetown and Sara at Tulane. Jana's ability to navigate obstacles made emergency medicine a natural fit, and Sara's stamina sent her into anesthesiology. After completing their medical training, they served throughout the United States and around the world, including in Afghanistan.

In 2016, Jana noticed something strange. When she propped up her feet, her left toes would shake. She thought it was a leftover symptom from an old injury, so, like many physicians, she just blew it off. However, over the next two years, while she was working nights in the emergency room, other symptoms began to emerge, and nurses started to notice. They came to her, almost apologetically, with their concerns. One whispered, "I noticed your arm was really shaking when you put on your gown." Another sidelined her and said, "Hey! I noticed you are moving really slow and stiff. Are you injured?" One more said, "You're walking funny, like shuffling. Are you OK?" The nurses were not the only ones concerned. Her friends thought she was sad because her face seldom produced a smile.

Jana blamed fatigue, exhaustion, and menopause. Anything but Parkinson's. Eventually, she saw a neurologist via telemedicine who diagnosed her with the disabling disease. She was forty-seven. Jana decided