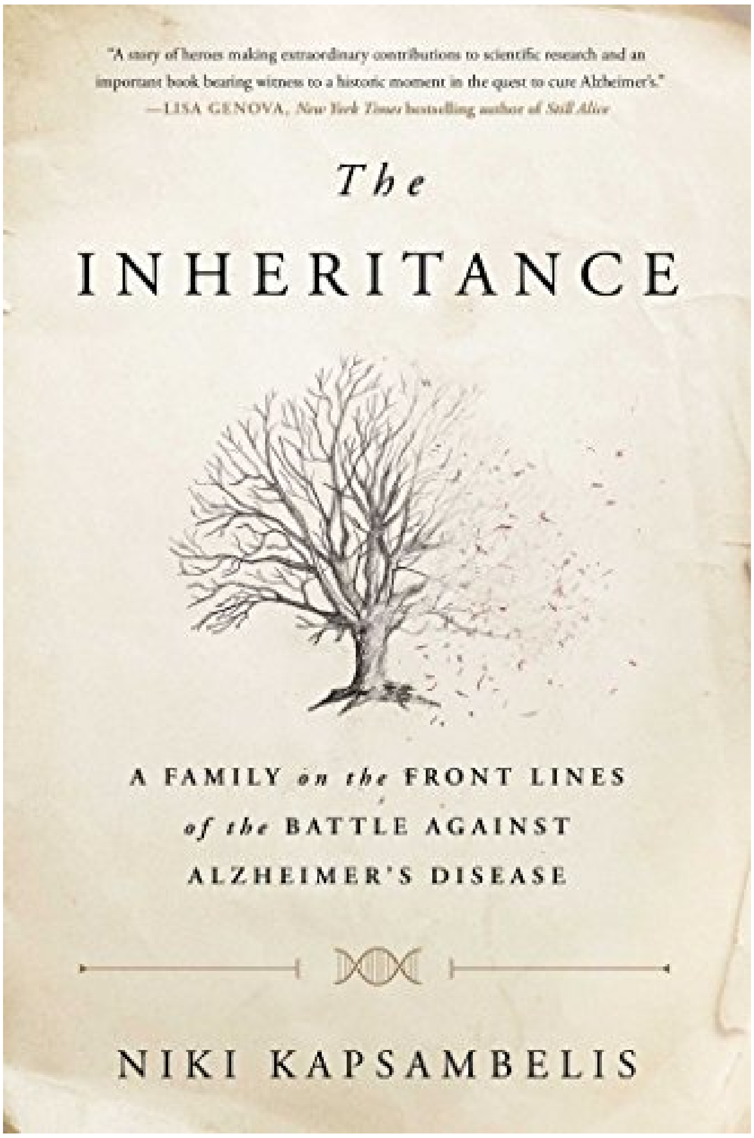
The Inheritance: A Family on the Front Lines of the Battle Against Alzheimer's Disease

Niki Kapsambelis



#56897 in Books SIMON SCHUSTER 2017-03-07 2017-03-07Original language:EnglishPDF # 1 9.00 x 1.40 x 6.00l, .0 #File Name: 1451697228368 pagesSIMON SCHUSTER | File size: 42.Mb

Niki Kapsambelis : The Inheritance: A Family on the Front Lines of the Battle Against Alzheimer's Disease before purchasing it in order to gage whether or not it would be worth my time, and all praised The Inheritance: A Family on the Front Lines of the Battle Against Alzheimer's Disease:

13 of 13 people found the following review helpful. Niki Kapsambelis went above and beyond creating this masterpiece. ...By Jenna ScozzafavaNiki Kapsambelis went above and beyond creating this masterpiece. The research

dedicated to telling the story of such a powerful disease impressed and overwhelmed me. Knowing some members of the family personally made this a very emotional read but I couldn't put it down. Thank you for sharing their story and advocating for them. What a blessing you are and an exceptionally talented author. My prayer is that this book will have a sequel entitled "the cure".22 of 23 people found the following review helpful. I would highly recommend this bookBy Tyler D.Speechless. What a magnificent book that delves deep into the science behind Alzheimer's disease and the search for a cure, and delves even deeper into the story of the incredible DeMoe family. I would highly recommend this book, especially if you have ever witnessed firsthand the devastating impact of Alzheimer's disease.9 of 9 people found the following review helpful. Recmmended without reservationBy David EadingtonFor me for many people few things are as frightening as the loss of self that Alzheimers inflicts on its victims. Writing with clarity, compassion, and insight, Kapsambelis brings us into the DeMoe family, cursed with early-onset Alzheimers, and shows us the damage wrought by the disease, the burden it places on everyone in its orbit, and the courage and strength of the family to give whatever they can to the greater fight against the disease. This powerful book also spells out the history of sciences understanding of the disease, the determined (and seemingly ever more hopeful) efforts of a handful of researchers to find a cure, and how the DeMoes have helped advance their efforts. That said, the book is no hagiography we see the familys flaws, their idiosyncrasies, and their fears and hesitations too but, by showing us their humanity, the author helps us feel their hardships and their hopes more deeply.By the end, I had to fight back tears over the accumulated losses the DeMoes (and others) had suffered, but I was heartened by how far the science of this disease has come, and how important that progress is. Perhaps the authors greatest achievement is making the reader understand, on a visceral level, the human, financial, and societal toll that this disease will take on our society if no cure is found.

An inspiring race against time: The courageous, hopeful story of the one family who may hold the key to finding a cure for Alzheimers disease.Every sixty-nine seconds, someone is diagnosed with Alzheimers disease. Of the top ten killers, it is the only disease for which there is no cure or treatment. For most people, there is nothing that they can do to fight back. But one family is doing all they can. The DeMoe family has the most devastating form of the disease that there is: early onset Alzheimers, an inherited genetic mutation that causes the disease in 100 percent of cases, and has a 50 percent chance of being passed onto the next generation. Of the six DeMoe children whose father had it, five have inherited the gene; the sixth, Karla, has inherited responsibility for all of them. But rather than give up in the face of such news, the DeMoes have agreed to spend their precious, abbreviated years as part of a worldwide study that could utterly change the landscape of Alzheimers research and offers the brightest hope for future treatmentsand possibly a cure. Drawing from several years of in-depth research with this charming and upbeat family, journalist Niki Kapsambelis tells the story of Alzheimers through the humanizing lens of these ordinary people made extraordinary by both their terrible circumstances and their bravery. Their tale is intertwined with the dramatic narrative history of the disease, the cutting-edge research that brings us ever closer to a possible cure, and the accounts of the extraordinary doctors spearheading these groundbreaking studies. From the oil fields of North Dakota to the jungles of Colombia, this incredible narrative redefines courage in the face of one of the most pervasive and mysterious pandemics of our time.

"Kapsambelis skillfully interweaves the quest to conquer Alzheimers with the saga of a few families at the center of the latest research....At its most compelling, The Inheritanceis a portrait of the DeMoes experience as both Alzheimers sufferers and research subjects." Wall Street Journal "A model of immersion journalism, it is especially notable for its specificity and author Niki Kapsambelis' empathy. The DeMoes laid bare their lives, and Kapsambelis repays their candor with a warts-and-all portrait softened by fondness and respect." Chicago Tribune "In sometimes heartbreaking detail, The Inheritance describes the impact of the disease on individual family members." Pittsburgh Post-Gazette "Excellent, accessible....A science text that reads like a mystery and treats its subjects with humanity and sympathy, this volume should be of interest to everyone, as Alzheimer's is now known to be a major cause of dementia in the elderly and because we are facing a potential epidemic as the baby boomgeneration ages." Library Journal,starred review "Kapsambelis, an empathetic reporter and storyteller, obviously cares deeply for the DeMoes... With its ethical quandaries and likeable characters, this absorbing story will be of interest to medically curious readers." Booklist "In her debut, journalist Kapsambelis builds a compelling narrative about Alzheimer's disease around one North Dakota extended family.... In addition to clear discussions of the disease's history and research, Kapsambelis successfully portrays Gail, Galen, and their extended family as fully fleshed individuals. An educational and emotional chronicle that should resonate with a wide variety of readers." Kirkus s, starred review "The Inheritance is the story of the DeMoe family, plagued by familial, early onset Alzheimer's disease. It is a story of heroes making extraordinary contributions to scientific research, of crusaders driven to change the course of this disease for the sake of their children, the next generation, all of us. I felt honored to read this important book, bearing witness to a historic moment in the quest to cure Alzheimer's." Lisa Genova,New York Times bestselling author of STILL ALICE? "Niki Kapsambelis has produced an unflinching narrative of a family in an unfathomable situation, seamlessly weaving in the history of the disease and neuroscience's ongoing race against the clock to find a cure. This is a truly important book." Susannah Cahalan, New York Times bestselling author of BRAIN ON FIRE: My Month of Madness "Kapsambelis is a beautiful writer whose storytelling transports you. I fell in love with the big, loud, awesome DeMoe family and was inspired by the doctors on their long, strange journey into Alzheimer's research.The Inheritanceoffers a rare, human glimpse at this harrowing disease." Jeanne Marie Laskas,New York Timesbestselling author ofCONCUSSION "Science is people. Niki Kapsambelis doesnt let you forget that for one moment in this very human story.The Alzheimers community is so lucky to have this first-rate storyteller. Her book tackles the disease from every possible angle." David Shenk, author of THE FORGETTING: Alzheimers, Portrait of an Epidemic "Niki Kapsambelis adroitly weaves the saga of a family with the stories of the scientists,who are working to develop therapies for this disease. Her insightful reporting makes it impossible not to marvel at the courage of the DeMoe family." Kathleen Gallagher, author of ONE IN A BILLION: The Story of Nic Volker and the Dawn of Genomic MedicineAbout the AuthorNiki Kapsambelis was born and raised in Boston, Massachusetts. She worked for several years as a newswoman for the Associated Press in New England, Los Angeles, and Pittsburgh. Her work has appeared in publications around the world, including The Washington Post, Los Angeles Times, and People magazine. She lives in Pennsylvania. The Inheritance is her first book.Excerpt. Reprinted by permission. All rights reserved.The Inheritance One THE ENEMY WITHIN WALK INTO A shopping mall. An amusement park. An auditorium of parents gathered for a school play. Within this crowd, there will be someonein fact, several peoplewho are directly and irreversibly affected by Alzheimers disease. In the United States, Alzheimers is the sixth-leading cause of death. Next to cancer, there is no condition more feared by human beings than Alzheimers, for it means more than a slow death; it robs its victims of the key components of their humanity. They lose shared experiences; they fail to recognize their most cherished loved ones; they forget even their proudest accomplishments. The stress of caring for an Alzheimers patient has decimated close-knit families, ended happy marriages, snapped the tensile bond between parents and children. And the disease is as baffling as it is unforgiving. An estimated 24 to 36 million people worldwide5.3 million in the United States alonesuffer from the disease or similar dementias. But Alzheimers is the least understood of all major fatal illnesses, frequently mistaken for other conditions, especially depression if the patient is young. Only one in four people who have the disease are actually diagnosed. None of them can be cured. Once thought to be relatively rare, Alzheimers is now known to be the leading cause of age-related dementia, and science is only beginning to grasp how commonand how lethalit really is. For it is always fatal: If patients do not die from secondary causes, such as pneumonia, the disease will eventually move from erasing memory and language to shutting down involuntary functions, such as breathing and swallowing. In the developed world, most major causes of deathincluding cancer, heart disease, and AIDShave undergone great strides in treatment across the past quarter century. People do sometimes survive these diseases. But to date, science has been unable to make any kind of dent in Alzheimers. In fact, the problem is actually growing, due to the population bubble created by aging baby boomers. It is a disease that ignores celebrity, income, character, and gender. President Ronald Reagan had it, and so did one of his most controversial allies, British Prime Minister Margaret Thatcher. So have movie stars, literary figures, sports heroes, criminals, humanitarians, geniuses, and dullards. It has claimed victims among the most wealthy, powerful, and famous: Rita Hayworth, Norman Rockwell, E. B. White, Sugar Ray Robinson, Charlton Heston, Glen Campbell. For such a formidable enemy, Alzheimers managed to keep a low profile for a surprisingly long time. The disease was first identified in 1906 by its namesake, Alois Alzheimer, a German psychiatrist who was also a neuropathologist, meaning he specialized in diseases of the brain and nervous system. But descriptions of similar symptoms have appeared in literature dating back to ancient times. In the second century, Roman emperor Marcus Aurelius employed a Greek-born physician who used the term morosis to describe dementia. He described people afflicted with this condition as some in whom the knowledge of letters and other arts are totally obliterated; indeed they cant even remember their own names. In recent years, better diagnostic tools have allowed doctors to understand two sobering facts about the way they have approached Alzheimers disease: First, that senility is not a normal part of the aging process; people who were once generally described as senile often actually had Alzheimers, meaning it is a much more widespread disease than anyone realized. And the second fact, which is more frightening, is that no current medical intervention can reverse it, or even slow it down, because for most of the time science has known about Alzheimers, there has been no way to see it coming until it has already wreaked havoc within the walls of the brain. From 1906, when Alois Alzheimer first described the disease, until well into the twenty-first century, diagnosing Alzheimers disease in living patients was little more than an educated guess. Doctors relied on clinical tests, asking questions about the patients memory and ability to function. Though these tests depended on the patients honesty, doctors might separately verify answers with close friends or family members. There really werent objective physical tests, although there were some telltale physical signs, such as a shuffling walk. Mood changes could occur, too; aggression, hallucinations, and depression were common. But all of these symptoms can also point to other afflictions: meningitis, brain trauma, stroke, syphilis, and medication side effects can produce similar results. Even sleep apnea and urinary tract infections can cause confusion. And while Alzheimers disease is the leading cause of dementia, accounting for 60 to 80 percent of all cases, other causes exist, too, such as Parkinsons and Huntingtons diseases. The word dementia is a general catch-all term encompassing many abnormalities. A study of 852 men diagnosed with Alzheimers disease from 1991 through 2012 found that the diagnosis was wrong one-third of the time, correct one-third of the time, and partially wrongin other words, the patient had a mixture of diseasesone-third of the time. And in situations where a patient is young or a doctor has limited experience with memory disorders, the diagnosis becomes even more elusive. For most of the time science has known about the disease, a true, definitive diagnosis of Alzheimersnot probable Alzheimerscould only happen after death, when a neuropathologist examined brain samples under a microscope to confirm the presence of amyloid plaques and tau tangles, the abnormal proteins that are the diseases grim signature. Plaques are sticky, microscopic clumps of stray amyloid proteins that form outside the brain cells and possibly prevent the cells from signaling each other. Tangles occur inside the brain cell. They are twisted fibers of the tau protein, whichin its normal statehelps transport nutrients. When its strands begin to twist, they choke the transport system and the cell dies. Current consensus within the Alzheimers research field holds that early intervention is key; by the time a person shows what we think of as mild symptoms, such as occasional forgetfulness, the brain may have reached a tipping point from which it will not return. But just how far in advance a doctor would need to give a treatment isnt known. Is ten years before the onset of symptoms soon enough? Should it be sooner? Can it be later? If scientists were working with a patient who knew that he would develop Alzheimers at a specific age, they could answer these questions faster. So even as they search for a viable treatment, researchers also continue to seek out ways to predict who the disease will strike. If they know who will someday get Alzheimers, they want to treat that person before he begins to slip away, much the way possible cardiac patients are now given cholesterol-lowering medication to help them avoid heart attacks. But to find such a treatment, doctors need a patient who is guaranteed, with 100 percent certainty, to get the diseaseonly then will they know if an experimental treatment was successful, by testing it out on that person and then measuring its effect. Those perfect patients do exist, as one tiny sliver of the population who stand distinctly apart from the rest. They are the people living with one of three known genetic mutations that guarantee they will be stricken. Only about 1 percent of all Alzheimers patients fall into this category. They are hit young: Their average age of onset is between thirty and fifty years old. Often, they have children, not knowing they stand a 50 percent chance of passing on the mutation; so the disease has raged silently through generations of families. For as little as science has known about Alzheimers, its known even less about these mutations. But in nature, curses are often a double-edged sword. As tragic as mutations are, they may well hold the key to preventingor at least delayingAlzheimers. Doctors can diagnose patients with mutations years before symptoms appear, even in childhood. By testing preventative drugs in this population, researchers hopeand the rest of the world praysthat they will be able to translate a successful treatment to the rest of humanity before another generation is lost. To get to that point, quiet sacrifices have been made by the most ordinary of people. They could be your neighbor, your coworker, your high-school classmate. Their lives were sometimes colorful, sometimes simple; but in their mutations, they have become exceptional. For it is their courage, often driven by desperationsometimes tempered by fear or frustrationthat has fueled the science that hopes to beget the solution. These are the people future generations will thank when Alzheimers itself becomes a distant memory. Alois Alzheimer was a bespectacled, cigar-loving, robustly built man. He took a job in 1888 at the Frankfurt Asylum for the Insane and the Epileptica facility housed in a fairy-tale Gothic revival building known colloquially as the Castle of the Insane. A few years before Alzheimer joined the staff, the assistant medical director of the Frankfurt asylum, Franz Nissl, had invented a method for staining brain cells, turning their components a vivid shade of methylene blue that made them easier for researchers to analyze. The process, known simply as the Nissl stain, is still in use today. In Nissl, Alzheimer found a lifelong friend. They shared a professional interest in linking symptoms of mental illness to physical causes through a microscopic analysis of the brain. Better imaging, they reasoned, would allow doctors to more clearly define and treat the disorders. In those early years, Nissl and Alzheimer worked as clinicians by day and conducted their research by night, frequenting pubs when time permitted. Nissl served as a witness when Alzheimer married his wife, Cecilie, the widow of a wealthy diamond dealer who had briefly been his patient. But in 1901, Alzheimer suffered a devastating personal loss when Cecilie died months after giving birth to their third child. Grief-stricken, he buried himself in his work, personally seeing virtually all newly admitted patients and committing his findings to an extensive written record. Cecilies fortune would later allow Alzheimer to devote all his time to research, a rarity for that era. The same year that Alzheimer lost his wife, a Frankfurt railroad worker named Karl Deter was also losing his. Auguste Deter was a wife and a mother, hardworking and orderly. In school, she may have been a student of Alzheimers grandfather, Johann. She married her husband, Karl, in 1873, and together they had a daughter, Thekla. In March 1901, just before her fifty-first birthday, Auguste began developing the bizarre symptoms that would mark her rapid decline into dementia. Although shed always had a somewhat excitable personality, she became inexplicably and irretrievably jealous, accusing Karl of having an affair with their neighbor. She began blundering through the cooking and the laundry, and she started squirreling objects away in their home. She cried constantly. She was convinced that a courier who frequently stopped by was plotting to hurt her. She lives in a world of the moon, Karl Deter reportedly said to a work colleague. Even my jackets are badly cared for. Things continued to roll downhill in the Deters home. Unable to sleep, Auguste sometimes wandered at night, or worse, woke up screaming uncontrollably. She deteriorated to the point where she could not handle any type of work. She busied herself with plans to visit her mother, who had been dead for more than ten years. She accused her husband of hiding jewelry she had inherited from her grandmother. Auguste was admitted to the Castle of the Insane, where Alzheimer took notes on his first visit with the new patient on November 26, 1901: She sits on the bed with a helpless expression. What is your name? Auguste. Last name? Auguste. What is your husbands name? Auguste, I think. All told, Auguste spent close to five years at the asylum, and by any account, it was hard time. Moody and anxious, she alternated between calling for her husband and daughter and failing to remember parts of her own name. Sometimes she withdrew or whined; she continued to hoard objects, this time under her bed, and dragged the bedclothes around or buried herself under them. She was not allowed to wander freely because she would become aggressive with other patients and grab their faces, although sometimes she was also kind and courteous. Most of her days were spent in the bathtub, a common remedy that was intended to soothe agitated patients. Her nights were spent in the wards isolation room. I have lost myself, she confided to her doctor. Although Alzheimer had seen patients with similar cognitive deterioration, most of them had been much older than Auguste Deterin their seventies, not early fifties. He attributed their dementia to atherosclerosis, a thickening of the brains blood vessels. He continued to study his unusual and otherwise healthy patient, calling her malady the disease of forgetfulness, never realizing that her affliction and those of the older patients were likely one and the same. Are you sad? Alzheimer asked her on a visit in early December 1901. Oh always, mostly not, she answered. It happens that one sometimes has courage. In 1902, Alzheimer left the asylum to take a new job working with the most respected German psychiatrist of the day, Emil Kraepelin. He hadnt been able to cure or even successfully diagnose Auguste, but his fascination with the weeping, lost woman never waned; he kept track of her condition with the help of his former boss. Augustes husband, who struggled to pay her medical bills, also visited her when he could. By 1905, she was bedridden and incontinent, unable to feed herself. Her weight dropped to sixty-eight pounds, and she lay curled in the fetal position. Her agitation stopped responding to sedatives. A bedsore festered into sepsis and pneumonia, and she died on the morning of April 8, 1906, a month shy of her fifty-sixth birthday. Twenty days later, Alzheimers former clinical director at the Castle of the Insane sent a box containing Augustes brain, brainstem, spinal cord, and medical records on a train to him in Munich, 190 miles away, where Alzheimer spent the next six months analyzing her disease. At his disposal was a laboratory outfitted with the most modern equipment available, including the first distortion-free microscopes. Alzheimers assistants prepared more than 250 slices of Augustes brain and spinal cord into slides stained with several different techniques, including the one invented by his old friend Nissl, to help him better examine the intricacies of the cells. There, Alzheimer got his first glimpse of Auguste Deters enemy within. As he studied her cortex, the brains largest section and the one that controls higher functions such as thought and action, he saw that it had been taken hostage by brown clumps of plaque, sticky blotches resembling tumbleweeds that had landed in the space between neurons. A different stain revealed all manner of tangled fibrilsdark, twisted bundles resembling balls of twine, crescents, and baskets, growing out of control and wiping out a third of the neurons in her cortex. In short, Augustes brain, like her body, had atrophied, apparently thanks to normal cell components that had somehow turned traitorous. With so much cellular death, Alzheimer felt certain the lesions had to be the key to Augustes bizarre behavior. What surprised him most was how extensively the brain had changedmore than people in their seventies and eighties, who typically experience a loss in brain volume as part of the aging processeven though she was just fifty-six. It was not like any illness he had ever seen before. Excited by his discovery of what seemed to be a new disease, Alzheimer carefully prepared a lecture on his findings for the 37th Assembly of Southwest German Psychiatrists in Tbingen. Eighty-eight respected colleagues were in attendance, including Nissl and the child psychologist C. G. Jung. When Alzheimer concluded his remarks, he expected an avalanche of questions. Instead, he was met with deafening silence. The conference chairman, who was acting as moderator, repeated himself: Did anyone have a response? They did not. He thanked Alzheimer for his presentation and moved on. In hindsight, its difficult to imagine a lack of interest in the discovery of such a widespread disease. Yet within the context of early twentieth-century psychiatry, the collective shrug was not surprising. The field generally did not believe in a correlation between mental illness and biological causes. (One notable exception was general paresis of the insane, a form of dementia caused by syphilis.) Alzheimer hoped his discovery might help underscore the connection between brain and behavior. But Auguste Deters case seemed too rare to be of clinical importance, given that no link had been established between her disease and the more common senility of older patients. The audience was eager to move on to the presentations that followed, which delved into the sexier issues of hypnosis, childhood trauma, and Sigmund Freuds new field of psychoanalysis. Disappointed, Alzheimer packed up his slides and left the stage. The local newspaper devoted one sentence to his talk. The disinterest of the psychiatrists at the conference would prove an unfortunate foreshadowing for the way the field treated Alzheimers disease for the next several decades. Scientists simply didnt understand that they were dealing with a disease that was affecting people all around them; it would remain an invisible predatorits power unchallenged. Although Alzheimers presentation flopped at the conference, he retained the enthusiastic support of his boss, Emil Kraepelin, who shared the radical theory that mental disorders had physical causes and was pleased to promote the discovery. Four years after the Tbingen conference, Kraepelin coined the term Alzheimers disease in the eighth edition of his book Psychiatrie, or Handbook of Psychiatry. Ironically, Kraepelinwho valued classificationunwittingly worsened a key confusion over Alzheimers disease by defining it as a dementia that occurred in patients before the age of sixty-five. After that arbitrary milestone, it was the much more common senile dementia, he said. And senility was so common that it was thought to be a standard part of aging, like graying hair or sagging skin. Alzheimer himself didnt dispute this. In 1911, he wrote that while the two diseases were similar, he could not be certain they were identical. Yet the only difference was that the dementia happened to some people earlier than others. This misperception would muddy the waters for decades, allowing this widespread disease to go largely unexplored. Unfortunately, neither man would live to see the discovery vindicated. During the next fifty years, little public fanfare was given to Alzheimers findings, which were thought to be interesting but too rare to be of larger significance. Plagued by heart and kidney problems, Alois Alzheimer died in late 1915. The slides he made from slices of Augustes brain, as well as his notes, clinical materials, and case histories in both Latin and German, were added to blue cardboard files and left to collect dust deep within Johann Wolfgang Goethe Frankfurt University Hospital, where they lay until 1995.