At 65, Warren Babcock, a lifelong resident of Scranton, Pennsylvania, started missing words. When his family began to notice these subtle changes they consulted a doctor in Scranton to search for an answer. A year later, the answer was clear: early onset dementia caused by Alzheimer’s disease.

But for Warren Babcock’s son, Dean, this answer was just the beginning. His family’s journey to find a cure had just begun.

Warren Babcock grew up in Scranton and lived there his entire life. A small business entrepreneur, he owned and ran Northeast Data Search, Inc., a title abstracting company where he was responsible for researching deeds that came through any bank in all of Lackawanna County. As a keeper of information, Warren’s symptoms stood out in stark contrast to his former self.

The Babcocks began investigating clinical research trials, and their search led them to the Penn Memory Center in Philadelphia and into the care of Dr. Steven Arnold, director of the center. Warren was enrolled into the bapineuzumab—nicknamed “Bapi”—study. For the family, this was a step forward.

“I was interested in whatever he would qualify for that would be a cure for Alzheimer’s disease,” said Dean Babcock.

The long journey of Alzheimer’s disease

Warren’s son Dean was a man of many cities. After living in New York, Baltimore and most recently Chicago, he made the move home to settle continued on page 2
In Wilkes-Barre, Pennsylvania to be closer to family. Shortly after this move, his father’s symptoms began.

Wilkes-Barre is a two and a half hour drive from the Penn Memory Center. But the family’s long journey to participate in research was made easier by a supportive group—Warren and Dean made each trip with Warren’s partner of 26 years, Kathy Abdalla, and his twin sister, Dale.

“All four of us came to the visits. It was ‘Team Babcock,’” said Dean.

In the early stages of the research visits, the trips were positive and hope was high. But hope to see an improvement in Warren’s condition was not the only reason they made their journey. Kathy Abdalla, Warren’s longtime partner, saw their participation as serving a greater purpose.

“We definitely hoped that there would be an improvement in his mental status and his illness, but we also felt that we were contributing to society and helping out in the research for Alzheimer’s. We wanted to do whatever we could to help future Alzheimer’s patients,” she explained.

After a year at the Penn Memory Center, Warren Babcock’s decline became significant. He had begun to show more and more Parkinson’s-like symptoms, including stiffness and a slowed gait, and it became apparent that he likely had Lewy Body dementia in addition to Alzheimer’s disease. In April 2011, just two months before his last scheduled visit for the research trial, he withdrew from the Bapi study.

“Towards the end, he certainly didn’t know why he was making the trip to the Penn Memory Center. Dr. Arnold and I talked, and we agreed to withdraw. It was a tough decision to give up the fight. That was the last trip we made,” Dean said. Warren passed away several months later.

“The end of the Bapi trials

In July 2012, just months after the Babcocks stopped their visits, Pfizer and Janssen, the manufacturers of bapineuzumab, announced that the drug showed no positive improvements on cognitive testing and functional scales of research participants with a gene believed to be connected with Alzheimer’s disease, ApoE4. Research trials on Bapi in ApoE4 carriers were ceased.

One month later, Pfizer released another announcement. The drug had also failed to show positive effects

“Initially looking into the study it was selfish… I wanted to cure my father. Toward the end it was really to better the advancement of the science. I feel strongly that if the drug is proven not to work, which it has been, that it’s still beneficial. It’s still positive because it allowed experts to rule out Bapi and move on to the next thing.”

— Dean Babcock
in the larger subset of non-ApoE4 carriers. With this news the trials were halted completely, a decision that brought to an end research into what was hoped to be a breakthrough drug in Alzheimer’s disease. The trials were declared “negative.”

For Dean Babcock, though, the Bapi trial and the journey that he, his father and his family made to participate in the study was far from a failure. “Initially looking into the study it was selfish… I wanted to cure my father. Toward the end it was really to better the advancement of the science. I feel strongly that if the drug is proven not to work, which it has been, that it’s still beneficial. It’s still positive because it allowed experts to rule out Bapi and move on to the next thing,” said Dean Babcock.

Despite the failure of the Bapi trials, the data collected remain useful. Researchers are reviewing data gathered from participants across the country to search for answers that will continue to inform and improve the progress of Alzheimer’s disease research.

“We wanted to do whatever we could to help future Alzheimer’s patients.”

— Kathy Abdalla

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— Kathy Abdalla

Looking back on the negative trials, Dean Babcock remains a strong supporter of Alzheimer’s disease research and is positive about his family’s participation in the Bapi study. A father of three, Dean Babcock hopes—for himself and his family—that advances in drug treatments for Alzheimer’s disease will be made by the time he reaches his sixties.

“I think that when you’re faced with something without a cure, A—you want to fight because it’s the right decision. And B—having some degree of hope helps manage the process. If you’re not in a research trial and there’s no cure, there is no hope. The hope that it gives is huge,” Dean Babcock said. “Now that my father is no longer with us, it feels good that it enhanced the science.”

A supportive team. Above, top: Warren Babcock before taking a ride on a hot air balloon sponsored by his company, Northeast Data Search, Inc. circa 1994. Seventeen years later, in 2011, Warren would take another journey in search of data at the Penn Memory Center.
I love desolate film settings for murder mysteries, especially the rainy, gray terrain typical of BBC miniseries and British films. These foggy, empty fields frame narratives to feel open-ended, even when they are resolved within 90 minutes. Here in a Philadelphia suburb I live with an unsolved mystery set closer to home. I am not sure of the cause of my father’s death and, as a result, I am not sure if his story will one day be mine.

The mystery of my father’s illness began on a farm in Mercersburg, Pennsylvania, where as a boy my dad swung on a rope over Conococheague Creek, fell and split his head on a rock. It continued south to an army camp in Oklahoma, where he took up boxing; traveled east to Obbach, Germany, where a land mine left him infinitely broken; and then returned to Pennsylvania, where for decades he struggled to control pain and anxiety. After these years of trauma to his body and mind, the story came to an end in a VA hospital in Altoona in 1997 where, beaten by a squadron of diagnoses—coronary artery disease, carotid artery disease, old infarcts, Parkinson's with dementia and probable Alzheimer’s—he died of septic shock at 78.

Fifteen years later, I am still trying to identify his assailant. Was it some single missed diagnosis, maybe Lewy Body dementia? Or the cumulative effects of lifestyle choices? Was he predisposed by genetics, or doomed by a series of traumas? Will the same fate be waiting for me, my sister or my daughter?

Medical science has made great progress in defining the diseases that cause dementia. Alzheimer’s disease, for example, shows a stereotypical pattern of cognitive problems, neurological findings and functional losses that interfere with a person’s ability to perform their usual daily activities. Yet not all cases of dementia fit into a clear diagnostic category. Patients often have a history of past traumas, complicating conditions like vascular disease, unexpected physical findings, prominent psychiatric symptoms or ambiguous brain imaging. This complicated set of evidence drives clinical research on dementia, but it also describes the real experiences of families who struggle to make sense of this uncertainty.

Deborah Fries, a writer and editor living in Elkins Park, Pennsylvania, lived such a story. After her father’s death at 78, she thought she would learn the final answer to explain his years of cognitive problems. Instead, she was presented with a mixture of diagnoses: probable Alzheimer’s disease, Parkinson’s with dementia, and coronary artery disease. She reflects on the sparse medical evidence at her disposal to connect her with this mystery of the past.

Deborah Fries’ parents, Harold and Reinette Fries, circa 1942 before her father was sent to serve in central Germany during WWII.
Parkinson’s disease and began to sundown. Sometimes he would leave the house in pajamas, even on a snowy night. He began to hallucinate, and on one occasion he thought a silver candelabra was my face, turned dead cold.

Solving a mystery like this usually requires the introduction of a flawed but passionate detective—a role I’m willing to play. My body contains evidence of my own medical vulnerability: I’ve been on blood pressure medications since the age of 28, at 34 I had meningitis and at 46 I was diagnosed with pseudoexfoliation syndrome, a systemic disease characterized by the buildup of amyloid-like protein fibers in my eyes. This road map of medical history and my own genetic makeup means I carry clues that forecast my future and could possibly reveal what killed my father.

A few years ago I pursued mitochondrial DNA testing to address an ethnicity question, but that micro-universe of information could not answer the big questions that haunt me. This testing revealed that I am a member of Haplogroup I, a small tribe whose prevalence peaked in the Iron and Viking ages. Epidemiological research suggests a lower incidence of Parkinson’s for my haplogroup, but without further sequencing I have only an impressionistic glimpse into my maternal genetics and no clue about genes I inherited from my father. It is unsettling to live without knowing why something happened to a loved one or what it means to his descendents—a kind of real life cold case file shelved by my father’s passing.

My favorite fictional detectives must at some point turn to the clinical report of a medical examiner to solve their cases. The report confirms or redirects their intuitive understanding of the evidence they’ve collected, and clinical results eliminate the detectives’ need to keep knocking on doors in the fog. Hard medical evidence is the missing piece that speaks to causation with certainty and allows the law to apprehend the criminal.

For this reason my investigation has been indefinitely stalled: I’m left waiting for a definitive medical report on my father’s illness that will never be released. In place of concrete documentation of my father’s medical history I have scraps of evidence that scarcely aid my search. I have a doctor’s handwritten note from 1956 that attributes my 37-year-old father’s complaints to “Segmentive Neurologic Syndrome.” A neurologist’s report from 1986, thirty years later, says my 67-year-old father’s EEG report and spectral analysis “demonstrate slow wave abnormalities consistent with a destructive process.” A note by that same neurologist from 1993 says she will not discuss my 74-year-old father’s illness with me without his permission. These notes became available to me only after it was too late to ask questions.

I moved back to Pennsylvania in the fall of 1993, not knowing my father’s diagnosis, prognosis or if my presence could be helpful. I knew that something had been set in motion that my parents were ill equipped to handle. As my father slipped away from us, my mother, whose own brain health had been undermined during a cardiac arrest in her sixties, became a less reliable source of information and judgment.

Pride and their own limitations kept my parents from gathering and sharing information with their daughters. They guarded their privacy and left us chasing disjointed clues, finding only potential witnesses who won’t talk.

My sister and I experienced our father’s illness without the armature of knowledge. Not sure of when it began, what it was or how it has changed our trajectories, today we are left with questions and our own bodies as evidence.

Lost, then found, in a good book
Shared stories help one daughter make sense of Alzheimer’s

by Colette Cassidy

Families experiencing a loved one’s Alzheimer’s disease understand the wisdom of C.S. Lewis’ observation, “We read to know we are not alone.” Shared stories can be a powerful means to make sense of the world and even to heal.

When my mother was diagnosed with early onset Alzheimer’s disease I went searching for those stories. As an avid reader I hoped to find a book that would answer my questions about Alzheimer’s and provide first hand accounts from people who have been through it.

Bookstores I visited had few choices so I continued my search at home online. I googled, tweeted and searched until I found what I was looking for: shared stories that would become my greatest resource in the world that is Alzheimer’s. The following six books are some of my top titles. For those on an Alzheimer’s journey, my best advice is this: read, read, read as much as possible. And then read some more.

Jan’s Story: Love Lost to the Long Goodbye of Alzheimer’s
by Barry Petersen
Behler Publications, 206 pages

This is the first book I bought. It is the story of former TV anchor and reporter Jan Chorlton, who, like my mother, was diagnosed with early onset Alzheimer’s disease. Written by her husband, CBS correspondent Barry Petersen, it’s a good resource not only for early onset families but, I believe, for any Alzheimer’s family. Petersen does something that is particularly helpful—he divides the chapters by the seven stages of the disease defined by the Alzheimer’s Association. He gives the “official” description of each stage but then describes how it actually looked in real life by detailing the cognitive and behavioral changes he saw in his wife as the disease progressed. I found that the book helped my family and I make sense of the stages by identifying where we had been and where we were likely going. Petersen also discusses the often controversial topic of marriage and Alzheimer’s and reveals a very personal decision he made about his own relationship.

The All-Weather Friend’s Guide to Alzheimer’s Disease by Mary M. Cail
True Wind Press, 208 pages

This is a fantastic read and resource that starts with a brief history of Alois Alzheimer and an introduction to the disease. Like Petersen’s book, it’s also divided by the stages of the disease and offers real life cases from families affected by Alzheimer’s. As the title implies, the book is intended as a guide for extended family members and friends, and it provides great advice on how to be supportive through the most difficult stages of Alzheimer’s. Caregivers will find it helpful not only for care issues but also for learning how best to present their needs to loved ones. I found Cail’s writing deeply touching and compassionate. She constantly reiterates how much assistance an Alzheimer’s family requires and how best to offer it. The subtitle of the book is “Staying Connected to Loved Ones with Dementia and their Caregivers,” and after reading it I had a better understanding of how to do just that.
A Pocket Guide for the Alzheimer’s Caregiver
by Dr. Daniel Potts and Ellen Woodward Potts
Dementia Dynamics, LLC, 200 pages

This was a practical and terrific aid during a very difficult time with my mother. It’s an easy read—I read it cover to cover the first night, then again two days later—with direct tips that caregivers can start trying right away. Dealing with Alzheimer’s is overwhelming, confusing and exhausting, so a book that provides information that is quick, easy to understand and straightforward is essential. This book fits the bill perfectly, and it is especially good for dealing with the unpredictable behavior issues that come with Alzheimer’s. This is a pocket guide to refer back to again and again.

Still Alice by Lisa Genova
Gallery Books, 292 pages

This is a work of fiction that tells the story of Alice, a 50-something Harvard professor who is diagnosed with early onset Alzheimer’s disease. The story is told from Alice’s point of view, which to me didn’t always work as a literary device, and details of her diagnosis and life seemed a little implausible. That being said, the book’s devoted following is what first persuaded me to read it, and presenting the characteristics of Alzheimer’s in a fictional setting may be a preferable way for some readers to absorb the information.

The 36-Hour Day by Nancy L. Mace and Peter V. Rabins
The Johns Hopkins University Press, 384 pages

Considered “the bible” for many Alzheimer’s families, this is certainly an in-depth and exhaustive presentation of everything caregivers and family members may face with Alzheimer’s disease. It covers every challenge of daily care, driving issues, financial and legal issues, respite for the caregiver and too many more topics to mention. However, the sheer depth of the book means that for busy caregivers in the center of the storm it can be too much to read and absorb cover to cover. I still recommend purchasing it to keep as a reference because the index and chapter guides make it easy to jump through sections of the book as needed.

Tuesdays with Morrie by Mitch Albom
Broadway, 192 pages

This longtime best seller is not a book about Alzheimer’s, but it is an excellent true story of a professor sharing final life lessons with his former student. I re-read it when my mother was dying. It gives great perspective on terminal illness and dealing with end of life issues, which brought great comfort in that difficult time.

Colette Cassidy is a passionate advocate for Alzheimer’s patients and their families after losing her mother and grandfather to the disease. She is a writer and journalist, a former anchor and reporter with KYW-TV and MSNBC. She can be reached at ccalz@hotmail.com and on Twitter @cc4alz. For more book suggestions visit her on Twitter @AlzBooks.
Please consider supporting the vital research at the Penn Memory Center. We rely on your gifts to advance.

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“It is better to light a single candle than to curse the darkness.”
Eleanor Roosevelt

A

I Alzheimer’s disease threatens to become the largest and most costly public health crisis ever faced by our nation. Yet federal and other funding for our efforts continues to be cut back.

This hard reality makes your tax-deductible gifts and bequests even more vital now to aid our research and nurture our advances.

We are especially appreciative of those who have made gifts in these harsh economic times. We recognize donors here and on our website at www.pennadc.org. To view the list, click on “Gifts” and then “Our Proud Donors.”

Planned giving, matching gift programs and a range of tax-advantageous structured giving approaches are also available. To learn more about how your support can strengthen and advance the work of the Penn Memory Center, please contact Irene Lukoff at (215) 573-0187 or ilukoff@upenn.edu. Thank you.

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• Chris Clark
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In lieu of flowers...

When contemplating your own final arrangements or those of a loved one, please consider an obituary request that, instead of flowers, donations for Alzheimer’s research at the Penn Memory Center be made to:

“Trustees of the University of Pennsylvania”
(write “ADC-PMC” on the memo line)

And mailed to: Penn Memory Center (Attn: Chelsea Brandt)
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Questions? Call Chelsea at (215) 615-0975

Make a gift online

It’s easy, quick and secure. Visit our website at www.pennadc.org and click on “Gifts.” You’ll be directed to the online donation form.
The Marian S. Ware Alzheimer Disease Program International Summit took place on June 21-22, 2012 at the University of Pennsylvania. National and international leaders in Alzheimer’s disease research gathered on the Penn campus to identify challenges, opportunities and solutions in the field. The results of the Ware summit were compiled into a strategic road map that was published in the September issue of Alzheimer’s & Dementia: The Journal of the Alzheimer’s Association. The plan aims at bringing various stakeholder groups—patients, researchers, policy makers, pharmaceutical companies and more—together behind a set of prioritized goals.

Roy Hamilton, MD, Penn Memory Center clinician and Assistant Professor of Neurology at the University of Pennsylvania, was named to the newly created Faculty Council on Diversity and Inclusion at Penn. The Council will work closely with the Office of Admissions and Financial Aid and the Office of Student Affairs to promote and strengthen diversity and inclusion efforts at the Perelman School of Medicine.

Penn Medicine researchers presented new findings at the 2012 Alzheimer’s Association International Conference (AAIC) in Vancouver showing that an anti-tau treatment called epothilone D (EpoD) was effective in preventing and intervening in the progress of Alzheimer’s disease in animal models. The results showed that EpoD improved neuron function and cognition and decreased tau tangles. “This drug effectively hits a tau target by correcting tau loss of function,” said John Trojanowski, MD, PhD, professor of Pathology and Laboratory Medicine at the University of Pennsylvania. EpoD is now in a clinical trial at the Penn Memory Center.

A new study co-authored by Penn Memory Center researchers has found that biomarkers in blood may detect Alzheimer’s disease and mild cognitive impairment (MCI). The results of this multi-center study showed that levels of four different biomarkers detected in blood plasma were different in people with Alzheimer’s disease and MCI when compared to healthy controls. These findings stand apart from other diagnostic tests for Alzheimer’s, which have until now mainly included biomarkers present in spinal fluid and tests like MRIs and PET scans. Penn researchers included Steven Arnold, MD, Jason Karlawish, MD, Virginia M.Y. Lee, PhD, MBA, and John Trojanowski, MD, PhD.

Tonya joined the PMC front desk staff in November 2011. She assists in patient scheduling and appointment check-in/check-out. She is currently pursuing her bachelor’s in Health Care Administration at Pierce College.

David Wolk, MD, Assistant Director of the Penn Memory Center, was elected to the Memory Disorders Research Society (MDRS).

A warm welcome from the Penn Memory Center front desk

Barbara Sharpe-Latham
Barbara, our Front Office Manager, has been with the PMC since 1998. She oversees medical record management and patient visit scheduling and supervises patient intake staff.

Tonya Farmer
Tonya joined the PMC front desk staff in November 2011. She assists in patient scheduling and appointment check-in/check-out. She is currently pursuing her bachelor’s in Health Care Administration at Pierce College.

Katrina White
Katrina White joined the PMC in August 2012 as a Clinical Receptionist. She assists patients with checking in and out for appointments. She is currently pursuing a M.S. in psychology from Capella University.
 Started in Boston in 1989, the MDRS is a professional society dedicated to the study of memory and memory disorders. Invitation to the society is extended only to individuals with a faculty appointment and international prominence in memory disorders research.

Florbetapir, a substance that helps indicate the presence of amyloid plaques in the brain helpful in diagnosing Alzheimer’s disease, was approved in Europe by the European Medicines Agency. In conjunction with a PET scan, florbetapir can help clinicians more effectively diagnose neurodegenerative dementias including Alzheimer’s disease by allowing them to see the presence of beta amyloid plaques in the brain in real time. Florbetapir, discovered at the University of Pennsylvania, was approved by the Food and Drug Administration in April and is currently being evaluated for Medicare reimbursement by the Centers for Medicare and Medicaid Services (CMS).

On October 27, 2012, Steven Arnold, MD, Director of the Penn Memory Center, presented a lecture titled “New Diagnostic Studies for Mild Cognitive Impairment and Early Alzheimer’s Disease” at the First Alzheimer Caribbean Conference in San Juan, Puerto Rico. The conference provided a forum for education and discussion not only for physicians and researchers in the field but also for health care professionals and caregivers. Topics including early diagnosis, cognition and judgment, neuropsychological testing and non-pharmacological approaches related to mild cognitive impairment and Alzheimer’s disease were discussed.

Virginia M.Y. Lee, PhD, MBA, and John Q. Trojanowski, MD, PhD, both professors of Pathology and Laboratory Medicine at Penn, were given the John Scott Award, Philadelphia’s most prestigious scientific award, for their contribution to research in the treatment of neurodegenerative diseases. Established in the early 1800s, the award is given to “ingenious men or women who make useful inventions.” Recipients are awarded with an inscribed copper medal that “shall not exceed twenty dollars” and an accompanying prize that has since been increased to $12,000. Early awards were given for the invention of the knitting machine and door lock, and notable recipients include Marie Curie, Orville Wright, Thomas Edison, Jonas Salk, Alexander Fleming and Nikola Tesla.

Giving thanks to our research partners

The 6th Annual Penn Memory Center Thank You Breakfast drew a packed crowd to the Inn at Penn’s Woodlands Ballroom on October 20, 2012. Over 200 research participants along with their family members and guests gathered to enjoy a breakfast buffet before attending presentations on the latest updates in Alzheimer’s disease and the results of Alzheimer’s disease research done at the Penn Memory Center.

Jason Karlawish, MD, Associate Director of the Penn Memory Center, presented this year’s Turken Lecture at the Mary S. Easton Center for Alzheimer’s Disease Research at UCLA. Turken Award Day is an annual event that includes internationally renowned guest lectures, tours of UCLA’s School of Medicine and the awarding of the Turken Day Researcher Award. Dr. Karlawish spoke on “Why do patients with Alzheimer’s disease enroll in research? The science and ethics of recruitment.”

All event photos by Megan Healy.
If you remember Jack LaLanne as the height of physical fitness...
Then you might be the perfect age to improve your brain fitness in the Cognitive Fitness program

Cognitive Fitness is an educational program specially designed for older adults with normal memory, those with concerns about their memory, or for people with mild cognitive impairment (MCI) who want to improve their memory and thinking.

The 12-week program is based on empirical research and is designed to help people change habits and behaviors in order to optimize brain health. The course provides education on lifestyle choices, strategies to compensate for memory loss and individualized wellness plans—all of which are known to be beneficial for successful aging. Goals of the program include increased independence, improved communication in relationships, sharpened focus and memory and the practice of effective coping mechanisms.

“In addition to the skills and strategies learned in class, participants seem to find a real benefit from having the opportunity to participate in a group with others going through a shared experience,” said Felicia Greenfield, LCSW, Penn Memory Center Associate Director for Clinical and Research Operations.

Early enrollment is now open for Spring 2013. Two classes will be offered: one at the Perelman Center for Advanced Medicine at the University of Pennsylvania and another at Waverly Heights, a retirement community in Gladwyne, Pennsylvania.

• Perelman Center classes take place from 9:00 a.m. to noon on Tuesdays and Thursdays starting January 15, 2013.
• Waverly Heights classes will take place from 1:30 p.m. to 4:30 p.m. on Tuesdays and Thursdays starting February 12, 2013.

For more information or to register, contact Felicia Greenfield at (215) 614-1828 or felicia.greenfield@uphs.upenn.edu.

InSight
On people and efforts that bring the knowledge we seek on Alzheimer’s disease and life-long brain health ever closer in sight.

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Phone: 215-615-0975

• The Penn Memory Center is a National Institute on Aging-designated Alzheimer’s Disease Center (ADC), one of only 30 such centers in the United States, and the only one in our tri-state region.
• Our staff and programs are dedicated to research in Alzheimer’s disease, age-related cognitive problems and life-long brain health and improving the well-being of our patients and their families.
• Produced by the Penn Memory Center, a part of Penn Medicine. We welcome and encourage your questions, comments, suggestions and gifts.
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