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# Cure Alzheimer's Fund

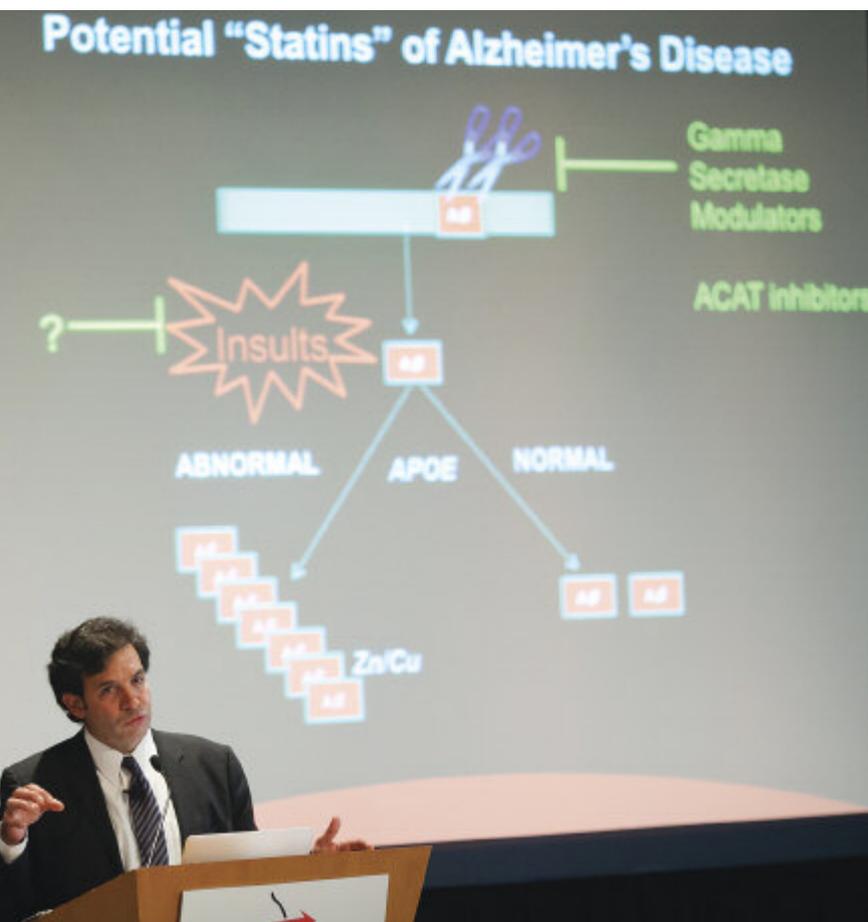
JANET MENDELSON **writer**



NIR LANDAU

**if philanthropists** think like venture capitalists, can they help medical researchers solve the riddles of Alzheimer's disease? Frustrated by decades of slow progress to curb the devastating illness, in 2005 four families decided to try. Most had a loved one who suffered from the disease. Each was willing to commit financial support and entrepreneurial expertise to help find its causes, prevention, and cure. In 2005 they founded the Cure Alzheimer's Fund (CAF) to support the work of leading researchers in Boston and beyond. By late last year, the founding families had donated nearly \$11.1 million, including \$4.4 million to cover 100 percent of CAF's operating expenses. Overall, more than \$20 million has gone directly to support the kind of promising but scientifically risky, large-scale research that big, traditional fundraising organizations shy away from. With CAF's support, new scientific breakthroughs have been made and new therapies are being explored.

*left to right: Cure Alzheimer's Fund Founder and Chair Jeff Morby, Senior Vice President and Wellesley resident Sally Rosenfield, Founder Henry McCance, Founder Phyllis Rappaport, President and CEO Tim Armour, Founder Jacquie Morby, and Senior Vice President Mike Curren*



Dr. Rudolph Tanzi, Ph.D., explains his research at the Cure Alzheimer's Fund annual symposium

ing on a book about the brain which led me to consult with someone at Harvard Medical School who recommended I meet Rudy Tanzi, who knows more about the brain than anyone else.” Rudolph Tanzi, Ph.D., professor of neurology at Harvard Medical School and Director of Genetics and Aging Research at Massachusetts General Hospital (MGH), has authored more than 340 papers and received several prominent awards for his Alzheimer’s research.

“In the process of our conversations about his research in genetics leading to potential cures, Rudy told me there was no money for research, while Alzheimer’s disease was decimating our society,” says Morby. “My wife, Jacqui, and I have been fortunate and able to be philanthropic, supporting many causes. But we had been thinking that if we concentrated our full resources in one area, we could make a real impact on society. Maybe this was what we were looking for.”

Morby set up a foundation in Pittsburgh, where he and his wife live. Part of the deal, he says, was that Tanzi would put together and lead a research consortium of the best scientists in the world working on research with highest probability of finding a cure. But realizing that the task was more than one family’s foundation could support alone, Morby spoke with others. Phyllis Rappaport, who lives with her husband, Jerry, in Lincoln; Henry McCance of Dover; and later Joshua and Anita

Alzheimer’s disease is a progressive, degenerative disorder that attacks nerve cells in the brain. It gradually deprives patients of their memory and ability to think or speak, and significantly alters behavior. Although not a normal part of aging, it is the most common cause of dementia among people age 65 and older, and its incidence is rising as our population ages. According to the Alzheimer’s Foundation of America, as many as 5.1 million Americans may have Alzheimer’s today. It is estimated that about 500,000 Americans younger than age 65 have some form of dementia, including early-onset Alzheimer’s disease.

Jeffrey Morby, former vice chairman of Mellon Bank, took the first steps towards founding CAF. “One of my lifelong hobbies is an interest in the human brain and how it manifests itself in human behavior,” Morby said recently. “After retiring from Mellon Bank, I began work-

At a White House briefing in September 2010, Rudy Tanzi, Ph.D., and Tim Armour, CEO and president of Cure Alzheimer's Fund, were among panelists presenting the current state of Alzheimer's research to senior staffers of the White House, Department of Health and Human Services, National Institutes of Health, and Alzheimer's advocacy groups.



Dr. Rudolph Tanzi, Chair of the Research Consortium

fitness & health “every dollar raised goes immediately into research”

Bekenstein of Wayland, became co-founders of CAF. Phyllis Rappaport is director of New Boston Fund, a provider of real estate, development, and management services. McCance is a venture capitalist. His wife, Allison, was diagnosed more than ten years ago with early-onset Alzheimer’s.

In their no-frills office suite in Wellesley, a short distance from Tanzi’s lab at MGH, I met with Tim Armour, President and CEO, of Weston; and two Wellesley residents, Sally Rosenfield, Senior Vice President, and Laurel Lyle, Director of Fundraising Programs, from the six-person (plus intern) staff. They described CAF’s approach, known as venture philanthropy.

“We don’t seek any financial return for ourselves or our investors,” says Armour. “The return is in the cure of the disease. But we try to apply venture capital principles in terms of seeking the best people to do this research, running a very lean operation, and focusing on big changes, not incremental ones. None of the funding and no proceeds from any of the research go back into the organization because the founders pay for all expenses.” There is no endowment. Every dollar raised goes immediately into research.

The founders remain heavily involved in daily operations and provide about 40 percent of support. About 50 percent comes from their friends and family, and 10 percent from others.

Lyle’s husband is a cancer researcher, so she knows first-hand the frustrations of trying to get funding from regular institutions, like the National Institutes of Health (NIH). When she lost her mother to Alzheimer’s, her work became her passion. “There’s so little money out there,” Lyle says. “Pursuing grants takes so much time away from their actual work that a lot of scientists in virtually every field are leaving research because it is so frustrating. One of the ways CAF is making a difference is to make funding accessible for important projects quickly and without the nightmare of an 18-month grant application process.”

CAF’s Research Consortium, drawn from scientists at Stanford, UPenn, California (UC) at Irvine, UC San Diego, University of Pittsburgh, Northwestern, Washington University in St. Louis, University of Chicago, and Mount Sinai School of Medicine, worked with Tanzi to design a “roadmap for research” to stop Alzheimer’s before it begins:

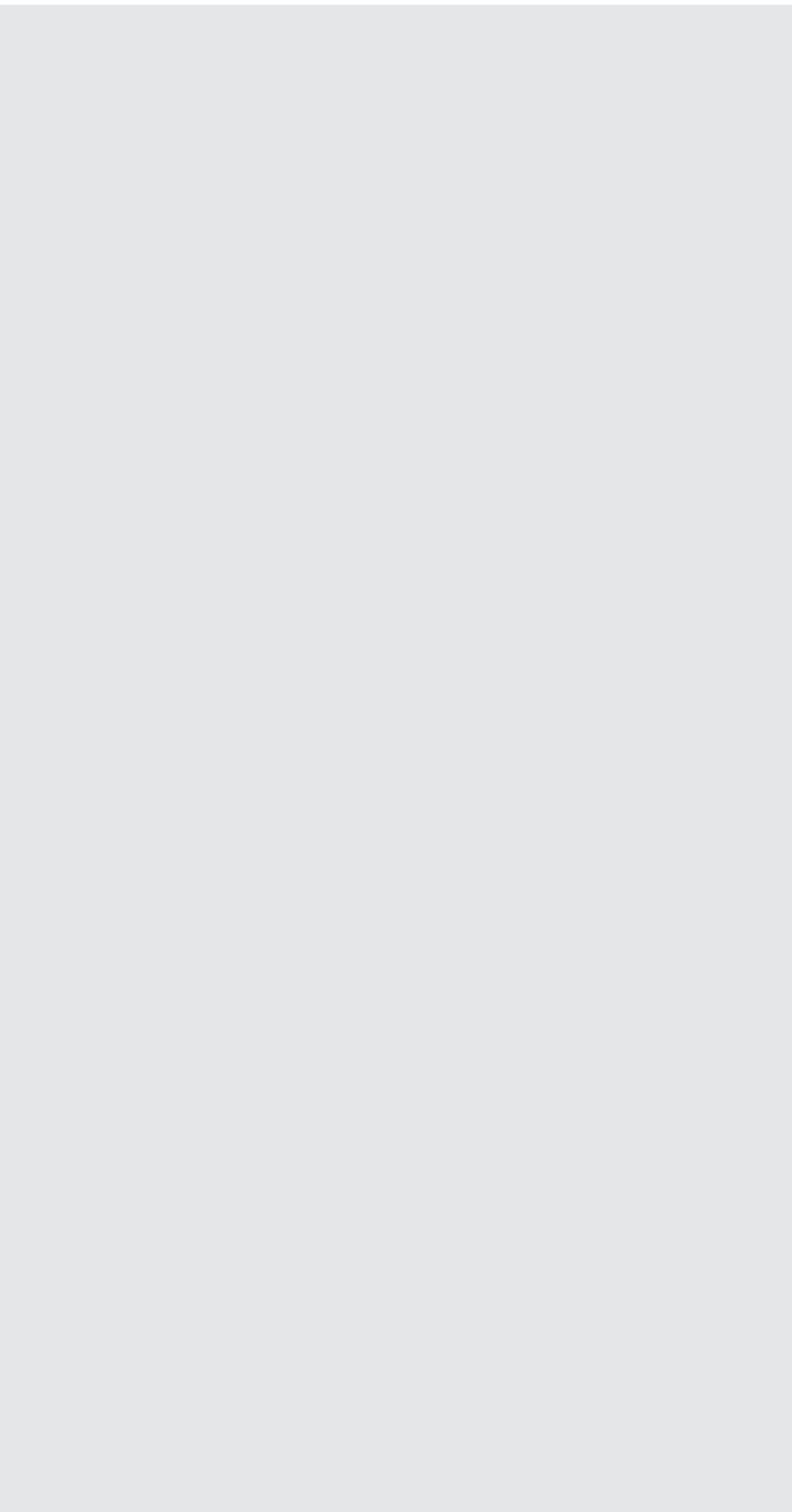
- **FIND ALL GENES** that contribute to risk or protect against the disease, prioritizing those with the greatest impact.
- **LEARN EVERYTHING POSSIBLE** about the role of those genes.
- **DETERMINE WHICH DRUGS** or newly developed chemical compounds can safely disrupt Alzheimer’s pathology generated by the highest priority genes.
- **FACILITATE CLINICAL TRIALS** of the most effective drugs by partnering with biotech

firms or pharmaceutical companies to hasten development and approval.

Grant proposals primarily come from the Consortium members' own or complementary projects. To reduce lag time between application and implementation, proposals are much briefer than traditional formats and decisions by CAF's independent Scientific Advisory Board are often reached within two weeks. Most projects are funded for one year, typically with a grant of \$100,000, although that varies. CAF is also guided by a Strategic Advisory Board made up primarily of venture capitalists.

Since its inception, CAF has funded 36 researchers in 25 labs, including several at MGH and one at the Max Planck Institute in Germany.

In 1983, as a young lab technician, Rudy Tanzi worked with Dr. James Gusella's team at MGH on the first use of genetic methods to localize a gene linked to a particular disease, which was Huntington's disease. That pioneering discovery is credited as a lead-up to the groundbreaking Human Genome Project which mapped roughly 25,000 genes. Since 1984, Tanzi has focused on Alzheimer's. His laboratory at MGH co-discovered the three known genes that can carry mutations causing early-onset familial Alzheimer's (younger than age 60). A fourth known gene, identified at Duke University in 1993, is among those responsible for its late-onset form.





*above: Harold and Janet Ginsburg, with Senior Vice President Sally Rosenfield, at the annual fall symposium, Taking Control of Alzheimer’s Through Research. top right: (left to right) Founders Henry McCance and Phyllis Rappaport with Alzheimer’s patient Charlie Collier, the former senior philanthropic advisor at Harvard University. bottom right: (front row, left to right) Karen Peterson, bookkeeper; Laurel Lyle, Director of Fundraising Programs; Julie Winton, previous office manager; (back row, left to right) Mike Curren, Senior Vice President; Rachel Weinstein, intern; Sally Rosenfield, Senior Vice President; and Tim Armour, President and CEO.*



PHOTOS BY NIR LANDAU

Seeking to identify the remaining 70 percent of genes contributing to risk for Alzheimer’s, with CAF support, Tanzi has headed the Alzheimer’s Genome Project. Working at MGH, his team has studied 5,000 families in which multiple members were afflicted with Alzheimer’s. Tanzi says it is the world’s first large-scale study of the human genome on the world’s largest collection of families affected by the disease. The project discovered four new genes, and was cited by TIME/CNN as among the Top 10 Medical Breakthroughs of 2008.

When one of those genes, ATXN1, is inactive, they found there is a dramatic increase in levels of a fatty protein called A-beta, which for 27 years has been identified as the leading cause of Alzheimer’s. In a related study, also funded by CAF, the team determined that too much A-beta creates plaques and tangles, killing brain cells and leading to Alzheimer’s, while not enough A-beta interferes with the body’s immune system. Suddenly researchers realized if a drug could be developed that would control the level of A-beta, the incidence of Alzheimer’s might be lowered, much like statins lower cholesterol production.

CAF’s venture philanthropists hope their risk-taking will give Tanzi and many others the means to convince larger funding organizations to provide major support. Recently, Steve Wagner, a neuroscientist at UC San Diego and past recipient of two CAF grants, was awarded a \$1 million, five-year NIH “Blueprint” grant for the fast-track development of a new Alzheimer’s drug therapy.

“I don’t think there’s any doubt we’ll find a preventive, and maybe a cure,” says Jeff Morby. “Alzheimer’s disease costs the US close to \$150 billion a year when Medicare, Medicaid, and additional miscellaneous funds are combined. The Afghanistan, Iran, and Iraq wars cost this country less. And it has a huge impact on individual families. I don’t think we can wait the ten years that others predict to find preventions.” He wants that breakthrough in five. [W W](#)

For more information, contact the **CURE ALZHEIMER’S FUND** at 877.287.3800, e-mail [info@curealz.org](mailto:info@curealz.org), or visit their Web site at [www.curealz.org](http://www.curealz.org).