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WEALTH MATTERS

# *Bringing Family Wealth to Bear Against a Relentless Illness*

**By Paul Sullivan**
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Alice Anane's father died suddenly of a brutal brain-wasting disease when he was 49. She was 15 at the time and remembers her family thinking that he had contracted mad cow disease on a trip to Britain.

Twenty years later, when she was pregnant with her third child, a routine amniocentesis revealed something different: Her father had most likely died from Creutzfeldt-Jakob disease, a rare illness known as C.J.D. that erases the brain as it ends life, typically within three months.

Unfortunately, she was a carrier. Worse, the disease could manifest at any time after age 30. Ms. Anane, a hospital administrator at the time, was then 35 and had 8-year-old twins. And if the disease did surface, there would be nothing that could be done to slow its progression.

"I couldn't adjust to this information," she said in an interview. "You understand the implication for the whole family? We are nine siblings. Your whole, big family is at risk now."

She started researching the disease, as many people would. But she had an advantage to accelerate her efforts: She and her siblings are part of a family office, a private organization that manages the assets of a single extended family.

Ms. Anane's mother gave the go-ahead for the office to donate to the scientists and clinical trials her daughter had identified. And the office backed Ms. Anane as she traveled to conferences and met carriers of the disease and their families.

Family offices typically serve as investment vehicles, financial managers and charitable advisers. Sometimes, they protect profligate offspring from their worst habits; other times, they are the locus of squabbling among heirs. Financial decisions are guided by a mix of paid staff members and relatives.

Yet when family offices get it right in the field of medical research, they can have a big impact.

"It's not just the money — it's the celebrity that they can leverage to get other people to commit money," said Bill Woodson, who runs the family office group in North America for Citibank's private bank. "It takes real discipline, outreach and a willingness to be public."

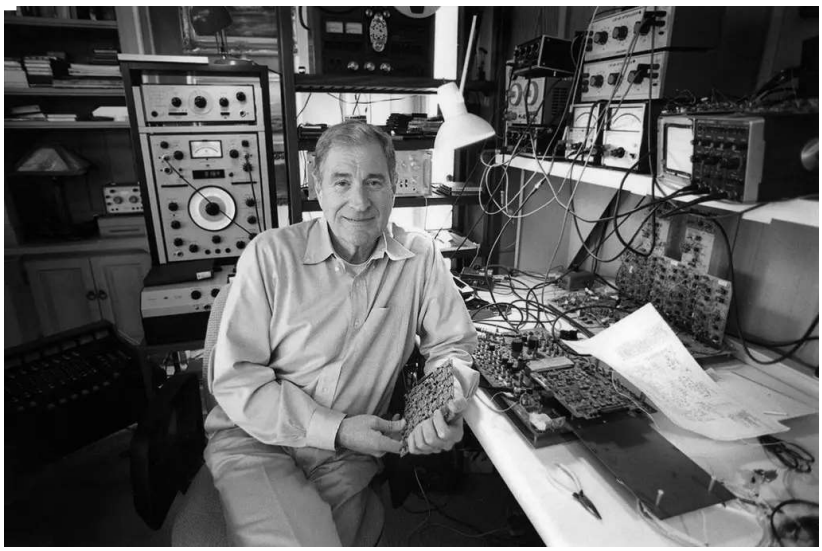
It also takes someone in the family to make sure all members are on board with what the office is doing.

David Dolby, son of Ray Dolby, the sound engineer and founder of Dolby Laboratories, said that when their family first learned their father had Alzheimer's disease, the family made charitable donations to well-known groups supporting research and patients' families.

After his father's death in 2013, Mr. Dolby said, the family office became more disciplined. In addition to its charitable contributions, it is financing basic research on Alzheimer's and investing in companies working on treatments that are on track for regulatory approval. Its board includes doctors and scientists who are at work on treatments for the disease.

"We made a conscious decision as a family that as long as there isn't a silver bullet, we needed to think about personalized interventions and take more of a portfolio approach," Mr. Dolby said.

This approach has allowed the family to find small markers of success — say, a treatment that works for 25 percent of the people in a clinical trial — and avoid getting discouraged.



Ray Dolby, the sound engineer and founder of Dolby Laboratories, in the mid-1980s. Mr. Dolby, who had Alzheimer's disease, died in 2013. The Dolby family office finances basic research on Alzheimer's and invests in companies working on treatments.

As Mr. Dolby put it, "I've crafted a portfolio that has this emotional hedge in it, that if we fail miserably in every one of our targeted therapies, perhaps that disappointment is offset in the tools we're supporting."

He added, "Any failure has to be learned from."

For medical ethicists, wealthy people coming in and funding research to benefit their children or relatives is a complicated proposition. David Wendler, who heads the research ethics section in the bioethics department at the National Institutes of Health Clinical Center, said nongovernment funding of research was nothing new, with some 70 percent of the money coming from private, for-profit companies.

He said he welcomed the charitable and investment dollars of these family offices. "These things are hard," Dr. Wendler said. "It's not like someone knows how to do this and says, 'I just need money to do it.' We need to try different approaches."

But he had some concerns that in their haste to help family members some family offices might not follow the proper protocols. "You want to protect the validity of the studies and you want to make sure you protect the subjects participating in these clinical trials," he said. "I'm imagining what happens if I have my billion dollars and I fund a clinical trial for some disease my son has. And then we screen my son and he's not eligible for it. I say, 'Hey, I want my son in.'"

He added that there were also public policy implications to wealthy people's funding research for certain diseases over others. "There's a significant value in having the American public funding these diseases," he said. "These philanthropists are doing great things, but their targets are going to be a function of what their daughter got. Sometimes that's going to overlap with what the public needs. Sometimes that's just not going to match up with the priorities that come out of the diseases other people get."

Professional wealth managers suggest that people seeking to make progress against a disease cast a wide net. Judy Spalthoff, head of family advisory services for UBS Wealth Management in the Americas, said she worked with a client to expand her network beyond her hometown, Houston.

"From her perspective, she wasn't networked at all, but she had the dollars," Ms. Spalthoff said. "Now she has this crazy network. That's highly effective."

Billy and Jennifer Frist, whose wealth comes from the Hospital Corporation of America (founded by Billy's grandfather), have a 16-year-old son with autism. Despite the resources of their family office — and of their relatives, who include former Senator Bill Frist of Tennessee, a physician — they said they struggled for ways to help both their own son and the cause of autism research.

"It was hard for us to figure out how to get involved, where to get involved, how to be effective," Ms. Frist said. "The autism community is large but very fragmented. Everyone has these opinions and is trying to make a difference, but people are living in their silos."

Another challenge — for those who choose to take it on — is going public about what would normally be a private battle with a disease. Ms. Anane said she initially wanted to keep her family's condition secret, but then decided to speak out to draw attention to the disease.

She spoke at a conference at Harvard Medical School this month under the auspices of its Personal Genetics Education Project. After the conference, she said, she was hopeful that some Alzheimer's research might be applicable to C.J.D.

"I try in as many ways as I can to make progress," Ms. Anane said. "I don't want to rely on one option and say, 'We'll keep our faith in this.' I'm trying to get everywhere I can, to try to connect and see."

The Frists said that when it came to investing their money, they had focused on companies working on treatments in the later stages of approval. For instance, the Frists have made a $20 million investment in a biopharmaceutical company called Curemark, which is testing an enzyme replacement therapy that had shown promise in reducing the symptoms of autism. Ms. Frist said the drug worked best with younger children, and was thus unlikely to help their son. They remain hopeful for other advances.

Many families have no idea if they have time on their side. At 46, Ms. Anane remains healthy — as do her siblings, nieces and nephews. But Creutzfeldt-Jakob is mercurial: She had a cousin with the gene mutation who was healthy at 93, but who had watched her daughter and granddaughter die from the disease. Then the cousin's 86-year-old brother died from it.

"I want to find a solution," Ms. Anane said. "I have a greater mission to bring some new revelation to the world."