

MANAGING

Governance and Regulation

A Think Tank Seeks to Accelerate Medical Science's Search for Cures

By Michael Anft

FIVE YEARS AGO when Josh Sommer was a freshman at Duke University, doctors discovered a troublesome growth in his skull. They diagnosed him with chordoma, a rare disease marked by incurable tumors of the spine and head that typically kill an affected person in seven years.

When he received the bad news, Mr. Sommer was forced to quit school, but he maintained his Duke ties, and for good reason: One of the country's leading chordoma researchers works in a lab at Duke.

Mr. Sommer, an engineering major, eventually learned enough microbiology to help the researcher determine which chordoma cell lines might be used to find a cure. But the painstaking pace of the work made him realize that new treatments, if they were to be found at all, were many, many years away.

"I realized that one person working in the lab wasn't going to cure the disease," he says. "We needed to find a way to speed up and expand the research."

Since 2007, when he founded the nonprofit Chordoma Foundation with his mother's help, Mr. Sommer has raised \$1.5-million to fight the disease. But he has needed some assistance, he says, getting other players to help devise new treatments.

He found it through FasterCures, a nonprofit think tank in Washington created to speed up the pace of medical research into deadly and debilitat-



SARA D. DAVIS/AP IMAGES

Josh Sommer, who suffers from the rare ailment chordoma, not only started a charity but learned microbiology to help aid researchers.

ing diseases by strengthening connections between the people who can make it happen.

At annual meetings of FasterCures the past two years, Mr. Sommer has rubbed elbows with donors, drug-industry representatives, leaders of organizations with similar aims, patients, and venture-philanthropy groups.

He has also taken part in discussions about how drug companies and

research groups investigating a range of diseases can pool their resources and stop duplicating their efforts, with the aim of accelerating the rate of medical discoveries and reducing the cost of achieving them.

And he got a chance to tell people about chordoma and the hurdles that he and others like him face in living with the disease.

"It's been an enormously valuable

experience to meet all these people I wouldn't meet otherwise," says Mr. Sommer. "FasterCures acts a bit like a Chamber of Commerce in that they do a lot of matchmaking and broadcasting of best practices. They've been a big help to us."

Working Across Boundaries

Started in 2003 by Michael Milken as part of the Milken Institute, an economic think tank in Santa Monica, Calif., FasterCures encourages philanthropists to take bigger risks when supporting research in the name of people who, like Mr. Sommer, often don't have the time to wait for new treatments to drip from the research pipeline.

Mr. Milken originally got involved in supporting medical research through philanthropy back in the 1970s. Later, not long after he was released from prison following his role in the 1980s "junk-bond" scandal, he was diagnosed with prostate cancer. When he started the Prostate Cancer Foundation in 1993, he streamlined the process for getting grants to top researchers.

In starting FasterCures, he expanded that approach to support research on a roster of diseases that affect more than 100 million Americans, including Alzheimer's, cancer, and Parkinson's, says Margaret A. Anderson, the group's executive director.

With an annual budget of \$3.5-million—raised with support from individuals as well as grant makers like the Bill & Melinda Gates Foundation, the Sumner M. Redstone Charitable Foundation, and the Robert Wood Johnson Foundation,—FasterCures has devoted much of its effort to understanding the players on the medical-research scene and getting them together.

"Our original board's idea was that we should work across disciplines and sectors to see how we can make organizations more efficient and better funded," says Ms. Anderson. "Because we don't represent one particular patient group, we can play a strong role in coming up with solutions across the sector without facing the pressures they're facing. There are a lot of passionate, smart people who want to cut through what's holding them back, and we try to help them."

Broader Collaboration

FasterCures does not make grants to groups working to develop new therapies. Instead, according to those who have benefited, its main role is as a networker. By bringing together various groups involved in the search for new treatments—patient groups, pharmaceutical companies, prospective donors, research scientists, and venture philanthropists—FasterCures encourages them to take the financial and strategic risks involved in developing those treatments.

"For a long time, people who have had

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Through Advocacy and Networks, FasterCures Helps Groups Seek Money to Step Up Medical Progress

FASTERCURES, a Washington think tank that works to speed up medical progress on a host of diseases, has begun a big advocacy push to encourage Congress to boost spending on projects that could help researchers convert scientific discoveries into treatments.

The National Institutes of Health has asked lawmakers to pour \$1-billion into such efforts, starting in the new federal fiscal year that begins in October.

The agency made the move after the White House expressed concern about the slow pace of drug development.

The cost of getting one treatment from a drug company's lab to the pharmacist's shelf—about \$1-billion per drug, on average—has slowed the quest for new therapies.

Pharmaceutical companies, frustrated by a lack of new and profitable breakthroughs, have cut back on research in recent years as many promising developments in areas of science such as stem cells and the mapping

of the human genome have not led to new remedies with wide applications, as many scientists had hoped.

Raising 'Every Dollar'

Private donations have yet to fill the breach. Philanthropy for medical causes makes up about 3 percent of the total dollar amount poured into research in the United States each year. The rest comes from federal agencies or from biotech and drug companies.

So far, FasterCures has not succeeded in pushing the percentage of philanthropic dollars higher, concedes Margaret A. Anderson, the organization's executive director.

"It's been static for the last five years," she says. "Our groups have to fund raise for every dollar they get."

But FasterCures has helped other groups make new connections to donors, she adds.

For example: During last year's "Partnering for Cures" conference, which the organization presents each year in New York, Matthias Bowman

was seated next to Cat Oyler, senior director of emerging technologies at Johnson & Johnson, the medical- and hygiene-products company in New Brunswick, N.J.

Mr. Bowman, a board member of the International Mental Health Research Organization, in Rutherford, Calif., had placed himself at a "mental-health round table" to get ideas on how his group's grants could best promote more research on brain diseases such as depression and schizophrenia.

"I explained to Ms. Oyler what we're about, and before I knew it, she told me that Johnson & Johnson would entertain making a grant with us," Mr. Bowman says. "I had no idea that they could do something like that."

The result is the Johnson & Johnson/International Mental Health Research Organization Rising Star award: two \$250,000 grants, to be announced this spring, to researchers who are performing promising work.

—MICHAEL ANFT

Charity's Push for Quicker Cures Adds New Dimension to Philanthropy

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success financially have written checks to Nobel Prize winners and other scientists," says Katie Hood, chief executive officer of the Michael J. Fox Foundation for Parkinson's Research, in New York. "But there may be more to finding a cure than dealing with a scientist or two. FasterCures recognizes that broadening the spectrum means getting all the players involved in trying to find answers."

The group also has worked to create ways to evaluate the effectiveness of medical charities, and to help connect funding to worthy projects. Its leaders travel to conferences run by venture capitalists to explain the state of research and how more money would help, Ms. Anderson says. So far, the group has worked with 150 donors, ad-

visers, and wealth managers.

FasterCures also provides advocacy: Ms. Anderson frequently testifies on Capitol Hill in favor of increasing the budgets of the National Institutes of Health and the U.S. Food and Drug Administration. More money would speed up reviews of drugs and discoveries in basic research that can lead to treatments and cures, she says.

Model Methods

In promoting greater collaboration between nonprofit groups and companies, FasterCures has advised organizations, for example, about the best way to pool their resources to start "biobanks"—archives of patients' DNA and other biological research material—and to support speedier clinical trials.

"They take effective models

and spread the word, sharing information and helping other organizations understand how the model works, why it's successful, and how they might be adapted for different purposes and goals," says Robert Beall, president of the Cystic Fibrosis Foundation, in Bethesda, Md. By doing so, FasterCures amplifies the work of groups that have taken risks and been successful, he says.

By getting organizations and companies that are used to competing to instead work together, FasterCures hopes to break down walls that may slow the achievement of medical discoveries that could save lives. Matthias Bowman, a board member of the International Mental Health Research Organization, in Rutherford, Calif., touts FasterCures' ability to quickly link

groups with information from the 50 to 60 other organizations that it deals with regularly. Such groups, says Ms. Anderson, "are groups known for innovative research and funding approaches that we'd like to see adopted as best practices." Leaders at some of them serve on investigatory committees that explore ways to get research projects moving more rapidly.

"You can download other organizations' profiles using [FasterCures'] software and get in touch with them weeks in advance of a conference to set up meetings," says Mr. Bowman. "It's almost like an Internet dating service."

Ms. Anderson points to the annual conferences as an indicator of FasterCures' effectiveness in forging connections. "When we bring people togeth-

er, we see this kinetic energy," she says. "It's almost like a religious experience for some. They see that there are like-minded people who can help them get where they need to go."

Risk and Safety

The way in which FasterCures has expanded the focus on donors—including people who may never have made donations to medical causes as well as others who tend to limit their giving to programs supporting one disease or one researcher—adds a new dimension to medical philanthropy, some observers say.

FasterCures' work has yet to yield a new lifesaving drug or therapy. But its efforts might ultimately prove to be a boon for organizations fighting a variety of deadly diseases, says Ms. Anderson. She points to the successful nationwide mobilization of politicians and researchers, spurred on by activists, to find treatments for HIV/AIDS as an example of how far collaboration, energy, and passion can push science.

But others say that science can only be moved so far so fast. "It's legitimate to say we can't wait seven years for a potentially lifesaving drug to go from animal trials to the pharmacy," says Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania, in Philadelphia. "On the other hand, we keep hearing about all these drugs, like Vioxx, being recalled because they're harmful. These are drugs that were approved by regulators, but we end up needing to be protected from them. We want to speed up the pendulum of the pace of research—until someone in a study dies. As a society, we have a split personality on this."

But FasterCures' advocacy work may lead to more needed research money, he adds. Currently, the National Institutes of Health budget is \$30-billion per year. "We spend trillions on health care in the meantime," he says. "It seems out of whack."

For organizations that represent the 25 million Americans with one of the 7,000 known diseases that are considered rare—each of which has fewer than 200,000 people who are diagnosed each year—FasterCures offers a glimmer of hope. Mr. Sommer, one of 2,000 people across the nation diagnosed with chordoma, says that the sharing of information among competitive companies is now being discussed—a strong sign that FasterCures' methods are working.

"Getting people in a room and on the same page can have a tipping effect," he says. "In a few years, we might see favorable outcomes, like development of new drugs, because those people were encouraged to meet."

International Education Group Announces Plans to Close

By Debra E. Blum and Maria Di Mento

The Academy for Educational Development, a nearly 50-year-old group in Washington whose financial problems are forcing it to close, is seeking a single buyer to which it can transfer its programs and employees.

Gregory R. Niblett, who has served as president and chief executive officer of the group since January, said that many for-profit and nonprofit organizations are interested in acquiring the group's assets, which include contracts with the U.S. Agency for International Development worth hundreds of millions of dollars.

The move comes in the wake

of a decision in December by USAID to cut off new contracts to the charity after the agency's inspector general accused the group of financial mismanagement.

With 250 programs in the United States and 150 countries, the charity has worked internationally to improve civil society, economic development, education, and health. In March 2009, the nonprofit was awarded a five-year, \$76-million grant from the Bill & Melinda Gates Foundation, in Seattle, to support a new program meant to improve child nutrition in developing African and Asian countries.

In all, the organization

raised \$48.6-million from private sources last year, up from 2009's total of \$42.9-million but down from \$56.1-million in 2008, as reported by *The Chronicle's* Philanthropy 400, an annual ranking of the charities that raise the most from private sources.

Selling Assets

Mr. Niblett said the academy is assessing the value of its assets and will accept bids from potential buyers—he declined to name any interested parties—in the next few months. He expects the transfer to occur by the end of June.

In addition to the contracts, grants, and cooperative agreements to run its many programs, Mr. Niblett said the group's assets include its employees (as many as 2,700 people in the United States and abroad) and such items as the furniture and computers in its offices. Bidders could also offer to take over the academy's office leases.

Money from the sale would be put into an escrow account, Mr. Niblett said, and used "to wind down affairs, close the organization, and pay off any liabilities." Any excess funds, he said, would be transferred to a nonprofit group to be spent for charitable purposes.

Continuing Support

Mr. Niblett said the sale will have to be approved by all the organizations that finance the academy, including the federal government, which he expects will endorse the move. One private foundation has already decided to pull its support for an academy-run program and will move the project and grant to another organization, Mr. Niblett noted, though he declined to name the foundation or the project.

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