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## NOT FOR PROFIT — JUST FOR HOPE

**Charitable foundation  
gears up for biotech  
road show, seeking  
help for its MS  
treatments**

*By Bernadette Tansley*  
CHRONICLE STAFF WRITER

After four years of research with Silicon Valley backing, Scott Johnson's outfit is preparing for the trial by fire faced by most biotechnology startups. It's time for the road show.

Young companies routinely go on the road to present their best ideas for new drugs to big pharmaceutical and biotech companies. They hope to land a rich licensing deal.

But Johnson's organization is not a biotech startup. It's a nonprofit charitable foundation with a uniquely hands-on scientific program. And its upcoming road show will be a key test of Johnson's theory that a small charity with the right rules can be a formidable force to bring new treatments to the world — and speed up the process of drug development.

The Myelin Repair Foundation, which Johnson founded in 2004, is part of a growing phenomenon in the nonprofit arena that some call "venture philanthropy" or "social entrepreneurship." Business veterans like Johnson put grant-making organizations at the helm, and adopt business methods such as precise goal-setting and performance standards. A more traditional philanthropy would solicit proposals from scientists and fund the best ones, even if the different projects had no coordinated goal.

Nonprofits including the Bill & Melinda Gates Foundation are gathering at a UCSF forum next week to discuss methods of collaborating with industry to provide new therapies faster for infectious diseases that



MICHAEL MALONEY / *The Chronicle*

**Scott Johnson** stands in front of team members Russell Rydel (left) and Russell "Rusty" Bromley in their Saratoga office.

plague the developing world.

Charities can help bridge the funding gap that often prevents promising early stage science from being developed into medicines, said Johnson. The Myelin Repair Foundation wants to advance studies to the point where it makes financial sense for drugmakers to pick it up, he said.

The Saratoga foundation zeroed in on one possible route to create treatments for multiple sclerosis, a disabling disease that strips the insulation away from nerve fibers by damaging a fatty substance called myelin that encases the fibers. Johnson, a former civil engineer and consultant, recruited top scientists at rival universities to work together on the discovery of possible myelin repair drugs.

The group raised \$20 million from foundations and individual donors, such as Intuit founder Scott Cook. With \$10 million spent on research so far, the team has found 18

leads. The two strongest so far will be unveiled by summer to big drugmakers.

"We're very confident," Johnson said. Drug companies are hungry for new products, he said. The nonprofit will accept leaner licensing fees from the drugmaker in favor of quick medical advances. Its projects have been vetted to professional pharmaceutical standards.

"Maybe we sound cocky," Johnson said cheerily.

His urge to create a model for disease research arose the same way many experienced business people get involved in similar ventures. They, or family members, need new treatments quickly for life-threatening diseases. Johnson has multiple sclerosis, and he saw a discouraging mismatch of incentives among the traditional institutions that contribute to medical progress: academic research centers, government funding agencies, traditional nonprofits and the drug industry.

# Biotech nonprofit takes show on road

"It was just so inefficient and crazy," he said. Drug companies are doing less of the basic research that can lead to novel drugs, because it's expensive and risky. Those who conduct basic university research could tackle big medical problems if they worked in collaboration, Johnson said. But they compete with each other for government grants, so they keep their work under wraps until they can publish in scientific journals, he found. Only then do they hear comments from other experts.

## Quick brainstorming

By contrast, members of his collaborative group of university researchers recently brainstormed on a proposed experiment during a conference call. "In four minutes the experiment was completely redesigned," Johnson said.

Other nonprofits have directed research and licensed discoveries. Notably, scientists supported by the Cystic Fibrosis Foundation discovered the faulty gene for the disease in 1989. The Myelin Repair Foundation has tried to expand the grantmaker's scope, bringing a scientific project clos-

er to the stage where a drugmaker would take over, Johnson said.

The teamwork so far has produced two research avenues ready for drug company consideration, said the foundation's chief operating officer, Russell "Rusty" Bromley. The scientists identified a possible way to defeat immune system cells in the blood called T-cells that sometimes attack myelin. Multiple sclerosis is an autoimmune disease in which the immune system, which normally fends off foreign invaders such as bacteria, mistakenly turns on the body's own tissues.

The foundation team also discovered that certain types of stem cells migrate to the site of injuries to the myelin-packed sheath around nerve fibers. The stem cells don't directly repair the sheath, but they release a large biological factor that appears to have a role in myelin repair, Bromley said.

## Many have interest

The foundation will seek audiences with companies that already have an interest in multiple sclerosis, including Eli Lilly, Biogen-Idec, Novartis and Genentech Inc. of South San Francisco.

Genentech's senior vice president of development, Hal Barron, said Johnson has duplicated the collaborative environment Genentech and other science-driven companies try to create for their in-house researchers. Barron said Genentech wouldn't hesitate to hear proposals from the nonprofit.

"Genentech is reasonably agnostic on where the great science comes from," said Barron, who is also Genentech's chief medical officer. "If this is better than what we've developed in-house, we'd transfer the resources."

Mike Pleiss, a consultant who is helping the foundation prepare its road show, said the charitable foundation will accept lower licensing fees than a VC-backed biotech because its main goal is to get new therapies on the market quickly. "That's the beauty of the foundation — you're not worried about making big profits."

Bromley, the chief operating officer, said the foundation would seek royalties on approved products, and share them with the university scientists. The foundation's revenue would be plowed back into research.

## A huge market

The worldwide market for MS drugs is \$5.85 billion, and could increase to \$11.85 billion by 2011, according to Kalorama Information. A novel drug for multiple sclerosis could reach \$1 billion in sales, Bromley said. "A 1 percent royalty on that ends up being a lot of money," he said.

Camille Samuels, a managing director at the Menlo Park venture capital firm Versant Ventures, said the Myelin Repair Foundation will at least get a foot in the door at many companies by offering to take lower payments initially and waiting to recoup its investment. But she said there aren't many companies that take on early stage work from outside groups. "There's an enormous amount of time, risk and capital between here and what they really want, which is drugs for patients," Samuels said.

That said, Samuels sees the venture philanthropy strategy as promising. "I am convinced the nonprofits are going to make a lot more progress by taking this more proactive and applied approach," she said.