

# Needham Times

## Determined doctor seeks to solve ALS



*Dr. Robert Brown discusses his work at the Day Lab for Neuromuscular Research in Charlestown on Friday.*

*- PHOTO BY ZARA TZANEV*

By Amanda McGregor / Staff Writer  
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Dr. Robert Brown has a mission.

Brown, 55, is leading the charge of stamping out ALS, and he won't slow down until he finds a cure.

The Oakland Avenue resident has been called a hero and a pioneer, especially by those families affected by Amyotrophic Lateral Sclerosis, or Lou Gehrig's disease, a neuromuscular disorder that leads to muscle atrophy, paralysis and eventual death.

In 1983, the now world-renowned Dr. Brown founded the first research institute for ALS, and has since been rallying the world to find a cure for one of the most devastating muscular diseases.

Though the prognosis does vary, on average people afflicted with ALS survive only four years, at which point respiratory paralysis kills the disease's victim.

"It's a very aggressive disease, as a rule. I became interested in Lou Gehrig's disease because it was completely untreatable and hopeless," said the Oxford- and Harvard-educated neurologist. "And now I have enormous hope. Thanks to these genes and understanding them, we're studying aspects of the disease we didn't even know about before."

Though the disease has long existed, said Brown, it was first documented by the mid-1800s. Current statistics show about four per 100,000 people suffering from the disease worldwide. Massachusetts alone presently has 250 cases.

The Day Laboratory for Neuromuscular Research at Massachusetts General Hospital in Charlestown is where Brown and his crew of 42 researchers and doctors have been chipping away at a cure for the past 20 years.

The Day Lab works with families with hereditary ALS to conduct clinical trials, for though the vast majority of cases aren't genetic, Brown and his fellow researchers feel they can better understand the disease if they can harness the genes that trigger it, and study gene defects that can cause paralysis.

In the past decade, they have discovered three ALS genes.

"Without being a Pollyanna, I think ALS has a very optimistic future," said Brown.

At the Day Lab, the researchers harness nerve cells to

which they administer the "sick protein" triggered by ALS that causes nerve cell death, at which point the researchers administer drugs that will hopefully halt the cell death. Thousands of drugs have been tested at the Day Lab.

Several drugs, such as for acne and arthritis, have been found to prolong life by about three months in some cases, but no panacea has yet been discovered.

"It's like leukemia in the 1950s. Minor progress was important because they knew nothing about the disease. We use the model of leukemia and cancer because those diseases were completely lethal 50 years ago, and they're treatable now," said Brown. "They're good models for curing diseases. There are plenty of precedents of people succeeding in what seemed like daunting tasks."

ALS research and treatment faces some major challenges in that it victimizes a small portion of the population, relative to diseases like cancer and diabetes, and therefore does not get the funding or big interest from the drug companies.

"Funding is the crucial issue," said Brown. "I spend the majority of my time fretting over that."

ALS is considered an "orphan disease," meaning it affects fewer than 100,000 people in the United States, so federal and corporate funding for research is very limited. The Day Lab, like other ALS research institutions, relies mainly on educational and private funding, for which it is extremely grateful.

"It's an orphan disease, so no big drug companies have worked on it because there's no money in it. We could never be [one of the big drug companies], but for people like Joyce Edelman we can try to get things going," said Brown, referring to the fellow Needham resident who has ALS.

A worldwide research network provides crucial collaboration, according to Brown.

"There's a wonderful world community that appreciates the direness of ALS," said Brown. "There are no more than 300 of us in all of the world working on it. We don't have a legion, like in cancer."

The group convenes two to three times annually, and the lines of communication flow freely in the meantime. This week, Brown is in London, England, and Sevilla, Spain.

"It's terribly important that we meet because the exciting ideas are exchanged at these meetings," Brown. "Published research comes out later. We can for that. All the cutting-edge stuff comes out at meetings."

"My mission is to trick the best scientists to work on it, Brown. "I don't care who finds the answer as long as someone does soon."

Once - not if, emphasized Brown - the cure is found, the whole other challenge will be repairing the damage done by a disease like ALS, for those people already ravaged would need a way to rebuild the nerve cells killed by the disease.

"We also work on stem cell theory [the replacement of damaged or dead nerve cells]," said Brown. "Stem offers at least formally the prospect of rebuilding neurons, but this is miles away from a reality yet."

It's a wonder Dr. Brown can do all that he does, be seeing his patients, teaching at Harvard Medical School, overseeing research, grant writing for research, traveling around the world to collaborate and information with other ALS specialists.

"Indirectly, he's everyone's doctor. We all share the fact that we're so glad and lucky he's working for us," Christine Joy of Framingham, whose mother is suffering from ALS. "He does amazing work for us, amazing research for ALS, and has such a kind, human side to him."

Brown has also published around 140 articles, as well as contributed chapters in books.

"I think of myself as a reporter because I go home and write every night," said Brown. "Grant writing and article research would die without that."

He continues to push for the cure and though "it's a long road and there are no quick answers, it's incredibly motivating," said Brown.

Brown resides in Needham with his wife, Elaine Beilir, is a professor at Framingham State College. They have daughters, Rachel and Hannah, who are 19 and 23.

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