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Fund-Raising on Borrowed Time

**Diagnosed With the Rare Disease
 He Studied for Years, Dr. Olney
 Struggles to Find Donors for ALS**

By **AMY DOCKSER MARCUS**
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Like many patients who get diagnosed with a rare disease, Richard K. Olney set out to raise awareness and money after learning in 2004 that he has amyotrophic lateral sclerosis, or ALS.

Few people seemed better poised than Dr. Olney to draw attention to the fatal neurological disease, which attacks the nerves that control movement. Dr. Olney, a neurologist, was already a prominent researcher on ALS, also known as Lou Gehrig's disease. In 1993 he founded the ALS Treatment and Research Center at the University of California, San Francisco, and turned it into one of the top ALS research facilities in the country. After his diagnosis, he enrolled in a clinical trial that he himself had designed -- testing whether two drugs used to treat AIDS and cancer patients might also benefit people with ALS.



Dr. David Cutsforth

Richard K. Olney (center) with his wife, Paula, and children, Nicholas and Amy, in a family photo taken in October 2005.


The poignancy of being afflicted with the same disease he had studied and treated all his professional life generated high-profile stories in newspapers and magazines, and appearances on national television. Dr. Olney and his family set up the Richard Olney Endowment with the hope of raising \$10 million to find a cure and to support the ALS center, which had a \$500,000 debt when he was diagnosed.

Despite the widespread publicity and outpouring of sympathy, Dr. Olney says he has raised only \$200,000. Some of the money went to pay down the center's debt, leaving around \$100,000. Since the endowment follows a practice of spending only 5% of total funding each year, this means just \$5,000 is available for spending.

"I was a little disappointed at first," Dr. Olney, age 58, wrote in an email from his home in Corte Madera, Calif. He no longer can speak, due to the progression of the disease. "But I now accept that \$200,000 is a good, realistic result."

Dr. Olney's efforts highlight one of the big difficulties for patients with rare and lethal diseases, particularly ones such as ALS, which usually leads to death within five years of diagnosis. With a tightening economic climate and so many other competing and worthy fund-raising causes; with only around 5,600 people diagnosed with ALS each year; and with the devastating toll the disease takes on families who frequently help as caregivers, even people who can put a prominent face on a disease often have trouble raising money.

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When it comes to fund raising, many patient advocates point to the success of breast-cancer and AIDS groups as role models. But these diseases have a large pool of patients -- many of whom are relatively healthy as a result of advances in treatment and early detection -- to help drive fund-raising efforts. Breast cancer is expected to kill 41,430 people in 2006, but death rates from breast cancer declined by an average 2.3% per year from 1990 to 2002 in all women, according to the American Cancer Society, increasing the ranks of survivors.

In diseases that are highly lethal, such as ALS or pancreatic cancer and ovarian cancer, patients often have little time to stump for cash. In 2006, there will be an estimated 33,730 new cases of pancreatic cancer, according to the American Cancer Society, and 32,300 estimated deaths. Also, families and the patients who do survive can feel isolated by the lack of a large community. "It's like a bad nightmare and they want to move on, not start fund raising," says Paula Kim, who helped found a patient-advocacy group focused on pancreatic cancer after her father died of the disease.

Uncommon Causes

Some groups raising money for rare diseases.

- **Alpha-1 Foundation/** www.alphaone.org
For a hereditary condition that can result in serious lung and/or liver disease.
- **The ALS Association/** www.alsa.org
Funds patient services and research into amyotrophic lateral sclerosis.
- **National Organization for Rare Disorders/** www.rarediseases.org
Fundraises for "orphan" diseases that affect fewer than 200,000 people in the U.S.

There are, of course, instances of success in fund raising for rare illnesses. Project A.L.S., founded in 1998 by Jennifer Estess, who died of ALS, and her family and friends, raised \$3.77 million in fiscal 2006, \$1.46 million of which came from an annual benefit. The Lustgarten Foundation for Pancreatic Cancer Research, created in 1998, has awarded more than \$15 million in research grants. But these efforts generally pale in comparison to the money that major foundations for diseases such as breast cancer are able to give out.

Dr. Olney's fund-raising efforts have largely been driven by his desire to put the ALS clinic he built on solid

financial ground. The \$500,000 debt has been cut by a \$250,000 contribution from a philanthropist and by the \$100,000 Dr. Olney has managed to raise. But the center, which treats 350 patients, still has an annual operating budget of roughly \$400,000, says Catherine Lomen-Hoerth, the center's current director. Insurance reimbursements pay for just 10% of the operating costs, she says, in part because the center offers services such as dieticians and social workers that often aren't covered.

The clinic has made cutbacks over the years, including the loss of its full-time nurse and speech therapist. Just recently, a patient at the clinic worked with the local Amyotrophic Lateral Sclerosis Association chapter to run a letter-writing campaign that raised enough money to hire a part-time nurse, a part-time speech pathologist, and four hours of respiratory therapy for the clinic, Dr. Lomen-Hoerth says.

Ryan Randall, a member of the center's board of advisers whose father died of ALS, raised \$20,000 last year through an email campaign, which amounted to a significant chunk of the clinic's total donations for that year. "This is the brutal dilemma of raising money for an orphan disease," he says. The ALS center still relies heavily on \$25 and \$100 checks sent by families and friends of current and former patients.

In assessing his own fund-raising strategy, Dr. Olney wrote that "there is not much I could have done differently, except mail more letters more quickly." He said many people who knew him personally gave money before he even wrote to them. "If they had known that the main reason ALS is rare compared to multiple sclerosis is that people with ALS die so much more quickly, they may have given more," he wrote.

Dr. Olney also feels that as his disability has worsened, and his ability to speak and meet with potential donors has deteriorated, fund-raising efforts have been harder to sustain. The timetable for raising the

money originally had been five years. Now, the timetable is "whenever," he wrote. "I am becoming less involved as my disability increases and my death becomes closer," added Dr. Olney, who is in the end stages of the disease and is receiving hospice care.

For the Olney endowment, there have been two main fund-raising events, the first a symposium that included the announcement of the endowment at a reception with Dr. Olney's patients in August 2004, two months after his own diagnosis. The other was Rock ALS, run by Dr. Olney's daughter, Amy, a 25-year-old occupational therapist who wrote a manual for ALS patients about making daily living easier. Rock ALS, held in 2005, raised \$22,000, the most successful fund raiser for the endowment.

Ms. Olney says she and her father had always gone to rock concerts together, and she wanted him to have the opportunity to see one of her favorite bands, Stephen Kellogg & The Sixers. She wore a T-shirt printed with the lyrics of one of the band's songs to a concert in Seattle and waited by the refreshment stand, where band members were known to stop by after playing. Once she got their attention, she told them about her father and convinced them to play at a fund-raising benefit for his endowment in San Francisco. Dr. Olney came up with the name for the benefit, which also included a silent auction. It was an enormous undertaking, however. "I see it as a one-time event for now," Ms. Olney says.

She said her own family's experiences reflected many of the challenges involved in fund raising for devastating rare diseases. "We have the ideal situation in every way for coping with this disease," she said. "My dad is an expert on it, my mom is a nurse, I am an occupational therapist, my dad has two grown children who could move home to help him, we are financially stable." Her 28-year-old brother, Nicholas, is a medical student who also helps care for their father. "But even with all this, it's still tiring and exhausting and hard coping with ALS," Ms. Olney says.

Well-meaning families can find that the disease "maxes out favors from your friends," she adds. "It's hard on top of that to say, 'By the way, you've been so kind in making us dinner once a month, do you also want to donate to ALS?'"

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