“Friends” Campaign Turns Two

As Building Friends for a Cure enters its second year, the Foundation has much to celebrate and more to look forward to.

According to studies of charitable giving, donors have a remarkably simple reason for supporting a particular cause: because someone asked them. Asking is usually all it takes for most Americans to open their hearts. That simple truth underlies the Alpha-1 Foundation’s one-year-old fundraising effort, Building Friends for a Cure. The Foundation’s campaign has mobilized Alphas everywhere to enlist friends and family members in raising awareness of the disorder and generating more funds for research.

During its first year, Building Friends for a Cure far exceeded expectations. Dedicated, energetic Alphas raised more than $200,000 for research, surpassing the campaign’s initial goal of $150,000. They organized 59 fundraising events coast to coast, ranging from a wine-tasting in Northern California to an old-fashioned sock hop in the Midwest to a whale-watching expedition in Massachusetts.

But we aim to do even better in our second year, and we’re already off to a great start. At the Alpha-1 Association’s 2006 Annual Education Conference in San Diego, nearly 60 enthusiastic Alphas attended a full-day, in-depth training seminar on event organizing. They learned about choosing an event, recruiting a committee to help organize, setting a workable budget, dealing with the media, and more. They also received firsthand tips from fellow Alphas who successfully organized theme dinners, garage sales, golf tournaments, and other events.

Above all, they heard the message, “Do what you love.” Are you an art aficionado? Then consider an auction of paintings, drawings, sculptures, and other works to benefit Alpha-1 research. Are you interested in athletic activities? Walk-a-thons, bike-a-thons, charity horseback riding, raffles, dinner cruises, and even letter-writing campaigns are just a few examples of fun and successful fundraising events organized by Alphas last year. The only thing missing is you. Building Friends for a Cure offers you the opportunity to take an active role in supporting Alpha-1 research. Although the Alpha-1 Foundation cannot help with administrative chores, the staff has compiled an easy-to-follow, step-by-step guide for organizing and publicizing fundraising events. It provides practical, hands-on advice about soliciting sponsors, raising awareness through local media interviews, using the Web, and even submitting IRS forms. Foundation staff can offer over-the-phone training for you and your volunteers, provide updated educational materials and sample press releases, and answer any questions that you might have along the way.

With your energy and commitment in the coming year, Foundation-funded researchers can move closer to new therapies and, ultimately, to a cure. You can help by enlisting friends and family members. Sometimes, all you have to do is ask.

For more information about organizing a fundraising event to benefit Alpha-1 research, contact Angela McBride at 1.888.825.7421, ext. 233, or amcbride@alphaone.org.
Bridge Builder

William J. Martin leads NIEHS effort to connect research with clinical practice.

In March, Dr. William J. Martin II, vice-chair of the Alpha-1 Foundation’s board of directors, assumed a new post as associate director for translational biomedicine at the National Institute of Environmental Health Sciences (NIEHS). In his new position, Martin oversees the Institute’s efforts to translate research results into practical improvements in patient care.

Part of the National Institutes of Health, NIEHS focuses on how the environment affects human health. It created the Office of Translational Biomedicine to explore innovative ways in which research findings might apply to clinical practice. “I am very excited about the new office and the opportunity to work with the in-house and grant-supported researchers as we work together to develop new approaches to clinical research,” says Martin.

Martin has long worked to strengthen the connection between researchers and patients. As president of the prestigious American Thoracic Society (ATS), he led the formation of the organization’s Public Advisory Roundtable, which gave patient groups a voice in ATS research. Martin has also served as dean of the University of Cincinnati College of Medicine. He will continue to serve on the Foundation’s board in his new NIEHS position.

Alpha-1 & Beyond

February 2007 conference will examine the protein that defines Alpha-1.

As you probably know, Alpha-1 takes its name from the protective protein alpha-1 antitrypsin (AAT). In Alphas, the protein folds incorrectly and accumulates in the liver, which may lead to disease in that organ. Also, the resultant deficiency in the bloodstream may lead to lung disease. But what other roles does AAT play—not only in Alphas, but also in non-Alphas? Does it offer clues to new treatments for other diseases?

Those questions will become the focus of an international scientific conference, “New Insights into the Biology of AAT,” on Feb. 8-10 in Miami, Fla., organized by the Alpha-1 Foundation. The subtitle of the conference says it all: “The Expanded Role of AAT in the Treatment of AAT-Deficient Individuals and Other Diseases.”

Drs. Mark Brantly of the University of Florida College of Medicine, Robert A. Stockley of Queen Elizabeth Hospital (Birmingham, England), and Charlie Strange of the Medical University of South Carolina will co-chair the three-day event. Investigators from around the world will share their most recent discoveries into the workings of AAT and exchange ideas about possible new therapies for Alpha-1 and other liver and lung diseases. In organizing the event, the Foundation hopes to stimulate research into non-intravenous therapies in particular.

In 1999, the Foundation organized its first international scientific conference, which also focused on AAT. Eight years later, the Miami conference will offer researchers the opportunity to share updated findings and discuss broader applications for the protein from which Alpha-1 takes its name.
Since 2002, Bruce Trapnell has steered the Foundation on its scientific course.

He best scientists don’t have all the answers, but they do know the right questions. As the scientific director of the Alpha-1 Foundation, Dr. Bruce Trapnell has been asking those questions since 2002. Which studies will yield the most valuable results? How can the Foundation get the most knowledge from its investment? In short, how can the organization ensure that every dollar it spends on research will improve the health and well-being of Alphas and take them one step closer to a cure?

This year, Trapnell—professor of medicine and pediatrics at Cincinnati Children’s Hospital Medical Center—ends his second consecutive two-year term as scientific director. During his tenure, he has organized scientific meetings and conferences, managed the annual review of grant programs, and assembled a group of Alpha-1 experts to revise and update the Foundation’s scientific agenda. Essentially, he has steered the organization’s scientific course for the past four years.

Looking back, Trapnell likens the role of directing a multi-million-dollar research effort to managing a portfolio of financial investments. “You never know which investments are going to earn the best returns, so you have to keep evaluating them,” he says. “Do you diversify, and spread your investments over a range of vehicles? Or do you put your money on only a few horses and take your chances?”

Under Trapnell’s guidance, the Foundation has adopted a strategy of diversification, investing in research that not only explores the mechanisms of Alpha-1-related liver and lung disease and targets possible therapies for the future, but also evaluates potential clinical breakthroughs closer at hand. Other Foundation-funded projects examine the ethical, legal, and social issues raised by genetic disorders, identify Alphas among the undiagnosed, and create scientifically accurate, up-to-date educational materials for the newly diagnosed.

Setting an Agenda

Trapnell’s background made him a perfect candidate to captain the Foundation’s scientific ship. He has worked in government (as a fellow and senior investigator at the National Heart Lung & Blood Institute), industry (at the biotech firm Genetic Therapy, Inc.), and academia (in his current position at a teaching hospital). And he served on the Cystic Fibrosis Foundation’s grant review committee before joining the Alpha-1 Foundation’s Medical and Scientific Advisory Committee in 2002. As chair of the Foundation’s Grants Review Working Group, he set up a system to evaluate, review, and administer grant applications, based on a model developed at the National Institutes of Health.

Among his many accomplishments as scientific director, Trapnell takes particular pride in refining, extending, and formalizing the Foundation’s scientific agenda. “Gordon Snider initiated that work before me,” he explains. “We collected a group of experts in different aspects of Alpha-1, and then coordinated their opinions and recommendations to create a scientific agenda. We identified specific, focused research questions that needed to be answered.”

That effort led to the Foundation’s diversified research portfolio, distributing funding among “pilot and feasibility grants” for high-risk/high-reward studies, research grants for longer-term investigations, and clinical trial grants for studies that might bring imminent benefits. The Foundation has also funded postdoctoral fellowships to train next-generation researchers. “We wanted to encourage smart young investigators to come into the field of Alpha-1 research,” explains Trapnell.

In fact, the number of grant applications received by the Foundation exploded during Trapnell’s tenure, increasing from about seven per year to nearly 50. “We wanted to stimulate interest and get more investigators to apply so that we could pick the best ones,” he notes.

Trapnell also led the effort to leverage the Foundation’s resources in collaborative efforts with other organizations. For example, he was instrumental in forming the Rare Lung Disease Consortium, a group that includes the Alpha-1 Foundation and organizations interested in LAM (lymphangioleiomyomatosis), pulmonary alveolar proteinosis, and hereditary interstitial lung disease. Currently, the collaboration is funding research into computed tomography (CT) scans as a method of measuring lung improvement. If successful, CT scans could replace old-fashioned, long-term FEV1 measurements in clinical trials and make new treatments available much faster.
Making Accidents Happen
Now, Trapnell will devote more time to his primary research interest—the biomechanics of lung defenses, especially alveolar macrophages (roving cells that originate in the bone marrow and attack invasive organisms in the airways). He plans to delve deeper into the molecular controls for these cells, focusing in particular on GM-CSF (granulocyte-macrophage colony-stimulating factor). When macrophages attack an invader, they secrete the GM-CSF protein as a way of stimulating the body to produce even more macrophages, thereby regulating lung defense.

As for the Foundation, Trapnell will continue to chair the Grants Advisory Committee. Trapnell continues to believe that the organization’s greatest challenge remains the ongoing assessment of its scientific investment. “Are we getting what we intended or need from these studies?” he says. “How can we best allocate resources? These are the questions that are important, and we have to continue to ask them.”

“The fact is, most great scientific discoveries are accidents,” continues Trapnell. “They’re not complete accidents, of course. You have bright people working on a problem who happen to notice something.” As scientific director for the last four years, Trapnell has assembled the best minds and ensured that they focus on the right questions with the right resources. In that sense, he has created the ideal conditions for accidents to happen.

We collected a group of experts... and then coordinated their opinions and recommendations to create a scientific agenda. We identified specific, focused research questions that needed to be answered.

PHOTO: ©2006 RICK BRADY
lenis lives on a sheep station in Omarama, deep in the mountains of New Zealand’s South Island. Diagnosed with Alpha-1 in 1999, she’s been trying to launch a support group in her remote corner of the world for nearly two years.

Henry, a cancer survivor, lives in Kenosha, Wis. When he received a double lung transplant, he prayed for just one more year to spend with his fiancée and their blended family of seven children. That was back in February 2005, and he’s still going strong.

Michael lives in Alabama. Diagnosed two years ago, he longed to recover enough breath to rejoin his church choir. This summer, after a regimen of augmentation therapy, regular exercise, oxygen, and other medications, he sang a solo in Sunday service.

You can meet these Alphas and dozens more on www.spiderspun.net—the brainchild of Noreen James, an artist, Web hostess, and Alpha-1 support group leader in Wisconsin. Since going online in October 2000, Spiderspun has become a haven for Alphas all over the world looking for information, resources, support, encouragement, or just a place to share their stories. “I feel blessed and lucky,” says James of the website’s success. “To tell you the truth, it makes the world seem smaller, a lot closer. You don’t feel so alone facing this disease.” With the website drawing about 4,000 hits a month, she and the more than 60 other Alphas who blog there are far from alone.

Asthma from Hell
James launched Spiderspun partly out of creative expression and partly out of desperation. A successful artist who has painted in a variety of media and illustrated several children’s books, she began to have trouble breathing in 1992 at the age of 30. Doctors prescribed inhalers to no avail, and James started calling her condition “asthma from hell.” Eventually, it forced her to give up working in acrylics and oils; she switched to pen and ink drawing to avoid the fumes. After her diagnosis with Alpha-1 in 1999, she had trouble learning about the genetic disorder. “I especially couldn’t find any information on a personal level,” she says. “I wanted to find other people with this condition, read about their background, and learn from their stories, but I couldn’t find anything. I couldn’t believe it.”

Then, inspiration struck. She told her husband, Larry, “Y’know, I could do one of those Web logs that are getting so popular.” With her husband’s wholehearted encouragement, she threw herself into the project. As an artist, she already knew about design and visual expression, but she took a crash course to learn the more technical aspects of the Web. James borrowed the name “Spiderspun” from her artistic enterprise. Her husband had always called her Spider (a corruption of a childhood nickname), so she naturally called her work Spiderspun. On the Web, she adopted the handle Spider Queen.
Spiderspun’s links quickly became one of its most important features. “I was Googling everything—social security information, insurance questions, disability,” James recalls, “but oxygen deprivation caused me to forget things.” Her new website became a handy spot to store the links she had accumulated and to share them with others. Since then, regular visitors have contributed finds of their own, and Spiderspun’s links now number well over 200. They’re organized sensibly into four broad categories and several subcategories, making the site an easy-to-use, practical starting point for anyone interested in Alpha-1.

Re-Humanization
Most of all, James saw Spiderspun as much-needed therapy. “It made me feel human again,” she says simply. “Unless you have a terrific doctor, you end up feeling dehumanized—treated more like a medical curiosity than a real person. I felt that way. The doctors just didn’t know what to do with me. Working on the website and connecting with other Alphas made me feel whole again.”

In fact, just days after Spiderspun made its debut, James underwent lung volume reduction surgery (LVRS) in an attempt to ease her breathing. A controversial procedure not appropriate for all lung-affected Alphas, LVRS removes damaged portions of the lung, relieving pressure on the diaphragm and improving breathing. In James’ case, the surgery removed large bullae—voids created by damaged tissue—at the base of her lungs. “Up until then, a root canal was the worst surgery I had ever had,” she says. “The only way for me to prepare was to keep myself upbeat.”

Since then, James has undergone two more LVRS procedures. “It has been a godsend to me,” she says. “Before, I could barely get from the bed to the bathroom, I was so short of breath. Now, my lung function is at 23 to 24 percent. LVRS doesn’t increase your FEV1, but it does make it easier to breathe.”

Throughout her surgeries, James enjoyed the unqualified support of her husband and her cyberfriends. “The people I’ve connected with online have always been positive, always kind, and always true to their hearts,” she says. This summer, for instance, when James organized a fundraising art auction at the first Alpha-1 Education Day in Wisconsin, some of those cyberfriends traveled from as far away as Florida to attend. “People would come up to me and say, ‘Oh, you must be Spider Queen,’” says James. “And I’d say, ‘Yeah, that’s me.’ I knew them only through their blogs, but we sat for hours and talked. It was great to connect with them in person.”

After all, making connections is what the Spider Queen does best.

...It makes the world seem smaller, a lot closer. You don’t feel so alone facing this disease... Working on the website and connecting with other Alphas made me feel whole again.

Is it COPD or Alpha-1?

Call 1-888-825-7421, ext. 217 or 246 for more information.

www.alphaone.org
In a manner of speaking, medicine has already found a cure for Alpha-1. Unfortunately, it involves a liver transplant, which isn’t terribly practical. Because the liver produces (and traps) most of the body’s abnormal alpha-1 antitrypsin, transplanting the organ from an unaffected donor provides a steady supply of normal protein to the bloodstream—protecting the lungs and eliminating the buildup of abnormal protein in the liver. But the chronic shortage of donors puts the “cure” out of reach for most patients, and the dangers associated with transplantation make it risky for others.

Dr. Mark Zern and his colleagues at the Transplant Research Institute of the University of California Davis Medical Center aim to change all that. “We’re taking a gene therapy approach that might inhibit the production of abnormal alpha-1 antitrypsin in the liver,” explains Zern. Supported by grants from the Alpha-1 Foundation and American Liver Foundation, their research attempts to accomplish through gene therapy what only a liver transplant can do now.

Zern’s interest in Alpha-1 as a research area grew out of his concern for people and his fascination with a physiological puzzle. “As a liver physician, I’ve seen patients with Alpha-1 for a number of years,” says Zern, a former member of the Foundation’s Medical and Scientific Advisory Committee. “The pathology of the disease presented an interesting challenge. It seemed as though a gene therapy approach had potential.”

Attacking Abnormal RNA
Currently, Zern and his colleagues are exploring the potential on two fronts. The first involves a ribozyme—an RNA molecule that initiates a chemical reaction which degrades RNA in liver cells. “We wanted to make it specific for the messenger RNA that encodes the production of abnormal alpha-1 protein,” he explains. “It had to decrease the abnormal alpha-1

We’re taking a gene therapy approach that might inhibit the production of abnormal alpha-1 antitrypsin in the liver, if the approach succeeds, they may be able to accomplish through gene therapy what only a liver transplant can do now.
mRNA without affecting other RNA species in the liver cell.”

Theoretically, when injected into liver cells via a viral vector, the ribozyme would hit only its target and decrease the production of abnormal protein. “Then, we put in a modified gene that produced normal alpha-1 antitrypsin, but would not be affected by the ribozyme,” continues Zern. That would increase the levels of normal protein—and halt the progression of the disease.

So far, the results show promise. The technique works exactly as planned in mouse models. In one series of experiments recently published in the journal *Gastroenterology*, a group of mice treated with the ribozyme reduced their production of abnormal alpha-1 antitrypsin by half. A similar reduction in humans might significantly improve the condition of patients with liver disease. Zern and his colleagues expect to reduce the levels of abnormal protein even further as they refine their techniques. Furthermore, the ribozyme-treated liver cells seem to grow quite well in the experimental mice and maintain their properties for a long time.

Zern emphasizes that these experiments are still in very preliminary stages. “We still have to do much more detailed studies on the possible side effects of the gene products,” he notes. And, of course, the jump from mice to larger animals—and eventually humans—presents a big challenge.

**Cultivating New Cells**

On the second front, Zern and his colleagues are trying to cultivate liver cells from human embryonic stem cells. “Human embryonic stem cells have the ability to differentiate into any kind of cell in the human body,” he says. “We’re looking at the best combination of growth factors and sera to get them to act like liver cells.”

To date, the UC Davis research team has had a 1 percent success rate. “We need to do much better than that,” says Zern. “We need 50 percent or more—ideally, 100 percent—of the stem cells to start acting like liver cells.” They’ve improved their harvest by labeling the liver cells with a genetic marker and then using a technique called “laser micro-dissection pressure catapulting” to separate the marked cells. A laser severs the incipient liver cells from the rest of the cell mass and slings them into a tube. With laser catapulting, Zern and his team have managed to reap 20 times more liver cells than before.

Either of these gene therapies could lead to valuable new treatments for Alpha-1 within the next decade. “If we succeed in growing liver cells from human embryonic stem cells, we could transplant them into a patient’s liver,” says Zern. “As the cells producing abnormal protein die out, the liver would repopulate itself with cells producing normal protein.” Essentially, that means “growing” a new liver. It would eliminate the long waiting lists for donors, the risk and expense of transplantation surgery, and the need for immunosuppressant drugs to ward off possible rejection. Such an advance would signal a breakthrough not only for Alphas, but also for all patients with liver disease.

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**Upcoming Events & Sponsor Thanks**

In 1996, the Alpha-1 Foundation began organizing Education Days throughout the United States. These events offer programs geared to patients, their families, and caregivers. Many also include a medical track for health care professionals and are accredited through the American Thoracic Society (ATS) or American Association for Respiratory Care (AARC).

The Alpha-1 Foundation gratefully recognizes the following companies as **2006 COPD and Alpha-1 Education Series Sponsors:** AlphaNet, Boehringer Ingleheim & Pfizer, Centric Health Resources, Talecris Biotherapeutics and ZLB Behring, and **Series Exhibitors:** Accredo Therapeutics and Baxter Healthcare.

For a complete listing of Alpha-1 educational programs next year, please go to [www.alphaone.org](http://www.alphaone.org) and search for Education Days.

**Team Alpha-1 – Looking for Members**

The Alpha-1 Foundation gratefully acknowledges Talecris Biotherapeutics as anchor sponsor for **Team Alpha-1.** The team has participated in 80 U.S. events and five international events, logged over 100,000 miles, and fielded over 500 volunteer riders, walkers, and runners.

For information on joining Team Alpha-1, please contact Mary Pierce at 888.883.2991 or mpierce@alphanet.org.
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With the BFRG, you can understand, manage, and live with Alpha-1. It has detailed information on genetics and on understanding lung disease, discussions on environmental risk factors, suggestions on diet, nutrition, activity and fitness, and much, much more. Plus there is practical information about insurance and disability, and explanations about key terms and the various diagnostic tests.

This invaluable resource, available on-line at no cost, was developed by AlphaNet, a not-for-profit health management organization dedicated to improving the lives of patients with Alpha-1. Written by patients and healthcare professionals, it is part of AlphaNet’s Disease Management and Prevention Program (ADMAPP), a key service staffed by Alphas to serve Alphas.

Use the Big Fat Reference Guide, written in language that you can understand, to learn more and share the insight with your family.

Register at www.alphenet.org to access the BFRG today.
Even if you follow Alpha-1 research closely, you've probably never heard of Dr. Adam Wanner. A former president of the prestigious American Thoracic Society (ATS) and current Joseph Weintraub Professor of Medicine at the University of Miami’s Miller School of Medicine, Wanner has spent more than three decades researching asthma, emphysema, and other lung diseases, looking for new therapies, and treating patients. But he’ll readily admit that he doesn’t count Alpha-1 as his specialty.

With his background, why would Wanner take on the job as scientific director of the Alpha-1 Foundation? “Without question, the Foundation is highly-regarded in the scientific community for its organization and professionalism,” he explains. “In fact, it has become a model—not only for organizations specializing in rare diseases, but also for any type of research organization. I feel honored to be a part of it. Having been a researcher in lung disease for 30 years and having played a leadership role in the ATS, I believe that I can use some of my experience and apply it a new way. I believe that there’s a lot to be gained by opening up the Alpha-1 research community to a wider audience.”

The Foundation’s scientific director usually serves for a two-year term. Assuming the post in July of this year, Wanner will manage the Foundation’s research efforts, organize scientific meetings and conferences, and provide guidance on scientific, clinical, and public policy issues. He comes to the job with bold, imaginative ideas to accelerate the pace of discovery not only in the basic science that might lead to a cure in the future, but also in the development of new therapies for the present.

Broadening the Funding Base

Wanner sees one of his most important long-term goals as helping to broaden the funding base for Foundation-sponsored research. “The Foundation’s research budget increased very rapidly during the first several years of its existence,” he notes. “But for the past few years, it has leveled at about $4.5 million per year. If we want to grow the program, we have to find more financial support.”

Of course, finding funds for rare-disease research has always proved difficult, but Wanner wants to explore opportunities with the pharmaceutical industry. “I believe that pharmaceutical companies understand that an investment in Alpha-1 research will benefit the understanding of COPD [chronic obstructive pulmonary disease] in general, which will lead to a broader market for new pulmonary drugs,” explains Wanner. As a past president of ATS, the Foundation’s new scientific director seems ideally suited to take this message to the industry. “As long as we clearly define the terms of engagement in keeping with the Foundation’s policies and guidelines, it deserves exploration,” he says.

By exploring this channel—as well as persuading the National Institutes of Health to...
explore Alpha-1 as a model for more general COPD therapies—Wanner hopes to increase the Foundation’s grants by 20 percent each year over the next four years, effectively doubling the total awards by 2011.

A Bigger Tent
Along with increasing funding for research, Wanner plans to increase the opportunities for generating new ideas and new therapies. Rather than focusing exclusively on the rather small circle of Alpha-1 specialists, he wants the Foundation to reach out to other researchers and pitch a bigger tent in the scientific community.

“The Foundation’s current research program is extremely well organized, and it has come a long way since its inception,” he says. “I think there’s much to be gained by opening up opportunities to a larger audience. I would like the Foundation to support investigators with established technical expertise in other fields that can be applied to Alpha-1. In that way, the Foundation can become more of a research network rather than a collection of research opportunities.”

After only a few weeks on the job, Wanner has already begun to cast a wider net for new ideas. He has included Foundation-funded opportunities on the SMARTS program—an e-mail system that automatically alerts lung and liver researchers by delivering announcements of funding opportunities directly to their electronic inboxes. He also plans to announce requests for applications on websites of the ATS, the American Association for the Study of Liver Disease, and other professional societies.

Thinking of Today’s Patients
Perhaps most important, Wanner would like to broaden the nature of the research as well. “I think we need to focus not only on basic research that could lead to a cure in the future, but also on developing newer, more effective treatments now. In that regard, I would like to see a broader clinical research effort and I support fast-track research in this area. We have to think not only of the Alpha-1 patients tomorrow, but also of Alpha-1 patients today.”

The key to this strategy lies in showing how a better understanding of Alpha-1 can shed new light on other types of lung and liver diseases that affect far larger numbers of people. “There are compelling parallels between COPD in general and Alpha-1 in particular,” says Wanner. “Alpha-1 research can benefit from this link.”

And he believes that Alpha-1 patients can benefit as well—both now and in the future.
Alphas scored one big victory on Capitol Hill in 2006, but other health initiatives must wait.

This year, Congress took an important step to stimulate federal funding for the Alpha-1 National Targeted Detection Program and expand research into chronic obstructive pulmonary disease (COPD) in general and Alpha-1 in particular. Aside from that big victory, however, many other bills to improve health care, expand research, and ensure patients’ rights either failed to become law or went into limbo as Congress prepared to adjourn for the fall election campaigns.

The victory came in the Subcommittee on Labor, Health and Human Services, Education and Related Agencies of the House Appropriations Committee. After hearing testimony from Alpha-1 advocate Stuart Windham of Tupelo, Miss., and Dr. Gerard Turino, chair of the COPD Foundation, the subcommittee issued a report urging the Centers for Disease Control (CDC) “to develop a partnership with appropriate patient and professional organizations to actively support Alpha-1 targeted detection efforts.” According to Miriam O’Day, the Alpha-1 Foundation’s senior director of public policy, the report “opens the door to have additional meetings with CDC officials to work out the specifics of our partnership.”

The subcommittee also recommended that the National Institutes of Health “enhance [its] research portfolio, encourage targeted detection, raise public awareness about Alpha-1, and provide appropriate information to health professionals.” This recommendation comes on the heels of last year’s generous grant from the National Institute of Diabetes & Digestive and Kidney Diseases for Alpha-1-related liver research.

Meanwhile, due largely to tighter budget constraints, most other health initiatives didn’t fare as well in the 109th Congress. These include:

**Stem cell research**
In July, President Bush vetoed the Stem Cell Research Enhancement Act of 2005. Introduced last year by Rep. Michael Castle (R-Del.) and Diana DeGette (D-Colo.), it would have permitted funding for research using any stem cell line produced under clearly specified ethical guidelines.

The veto surprised some observers. Five years ago, Bush had issued an executive order banning federal funds for research on all but a few stem cell lines, most of which have since proved unusable for biological reasons or unavailable for intellectual property reasons. But, as O’Day explains, “The advocacy community believed that the administration would step back and not veto the bill after it had passed both houses of Congress, because the legislative branch was expressing the will of the people.” Despite the bill’s bipartisan support, Bush confounded those expectations and used the first veto of his presidency.

**Cardiac and pulmonary rehab coverage**
Two companion bills—one introduced by Sens. Mike Crapo (R-Idaho) and Blanche Lincoln (D-Ark.), the other by Reps. Chip Pickering (R-Miss.) and John Lewis (D-Ga.)—would have clarified Medicare coverage for cardiac and pulmonary rehabilitation nationally. The Centers for Medicare and Medicaid Services determined coverage for cardiac rehabilitation earlier this year, but the pulmonary rehabilitation portion of the bills have languished.

**In-home RT coverage**
H.R. 964, which would have provided Medicare coverage for the services of respiratory therapists as part of home health care, also appears unlikely to pass.

**Rent-to-own oxygen**
Under the Deficit Reduction Act of 2005 and beginning in January of 2006, Medicare recipients who require home oxygen will own their equipment and assume responsibility for it after the first 36 months of rental. First-term Rep. Joe Schwartz (R-Mich.) introduced a bill that would rescind those provisions and return Medicare coverage for home oxygen to its former terms. However, Schwartz lost in his district’s Republican primary this year. With his lame-duck status, the bill doesn’t face a promising future, despite its 60-plus co-sponsors. However, original co-sponsor Rep. Tom Price (R-Ga.) remains committed to the bill.

**Genetic discrimination**
The Genetic Information Nondiscrimination Act would encourage early detection and treatment of genetic conditions by prohibiting discrimination in employment and insurance. Although the House version (H.R. 1227) has won more than 200 co-sponsors, the proposal’s fate remains unclear. The Genetic Alliance—an advocacy consortium that includes the Alpha-1 Foundation—organized a late-September advocacy day on Capitol Hill to marshal support.

The reintroduction of these health care initiatives—and their ultimate fate—awaits the 110th Congress, which will convene in January 2007.
Four on the Board

The Foundation’s board of directors welcomes four new members.

With three-year terms beginning on July 1, 2006, four new members have joined the Alpha-1 Foundation’s board of directors. They include:

- **Gordon E. Cadwgan, Jr., Ph.D.** (West Palm Beach, FL), a retired DuPont scientist who also serves as a trustee of the board of directors of his family’s charitable foundation. An Alpha, Cadwgan has served on the Foundation’s Ethical, Legal, and Social Issues Working Group and serves on the Board’s Development Committee. He and his wife, Ruth, are also members of the Foundation’s Community In-Reach Program. Dr. Cadwgan recently established the Gordon E. Cadwgan Jr. Family Research Initiative through the Alpha-1 Foundation.

- **Kenneth A. Irvine** (New York, NY), portfolio manager of the Bank of Nova Scotia and head of investor relations for Citadel Hill Advisors, a U.S. investment advisory firm. As a former managing director at Chase Investment Banking, Robert Fleming Securities, Wertheim and Lehman Brothers, Irvine has over 40 years of expertise in financial engineering, corporate finance, private placements, securitization, and portfolio management. Irvine’s wife, Bettina, is an Alpha and past president of the Alpha-1 Association.

- **Joseph Reidy** (Waldwick, NJ), a retired electrical engineer from Avionics, a defense contractor. Diagnosed with COPD in 1988 and with Alpha-1 in 1991, he has coordinated an active Alpha-1 support group in Northern New Jersey. He has also served on the Foundation’s Medical and Scientific Advisory Committee, Research Registry Working Group, and the Educational Materials Working Group. He currently serves on the Alpha-1 Patient Needs Advisory Committee and is a member of the Board’s Budget, Program and Nominating Committee.

- **Stephen I. Rennard, M.D.** (Omaha, NE), the Larson Professor of Medicine in the pulmonary and critical care medicine section of the Department of Internal Medicine at the University of Nebraska Medical Center in Omaha. He also directs the Nebraska Office of Tobacco Control and Research and is a member of the board of the COPD Foundation. Rennard’s research interests include the mechanisms of lung tissue repair and remodeling, and he maintains an active program of clinical investigation in COPD and smoking cessation. He also serves as courtesy professor in the Department of Pathology and Microbiology at the University of Nebraska.

The four join Wayne E. “Chip” Withers, Jr. (chair), William J. Martin, II, M.D., (vice-chair), Robert Williams, Esq. (secretary), Ab Rees (treasurer), Greg Hules (immediate past chair), William A. Brenner, M.D., Elaine Alfonzo, Marilina Fernández, Holly Miller, M.D., Edward A. Schuck, and Edwin K. Silverman, M.D., Ph.D. to complete the 15-member board. According to the Foundation’s bylaws, Alphas, Alpha carriers or their immediate family members must constitute a majority of the board.
A Friend to All

Alphas everywhere mourn the passing of Buddy Golder.

Lasttime Alpha activist Preston "Buddy" Golder passed away on June 1, 2006, at the age of 61. Since his diagnosis with Alpha-1 in 1985, he devoted himself to furthering Alpha-1 education and awareness, especially among pre- and post-transplant patients.

Many people met Golder through his website, www.transplantbuddies.net, where he recounted his eventual diagnosis, his lung transplant in 1993, and its aftermath.

Others met him through his tireless work in the Alpha community, especially with the Foundation's Screening and Detection Program in the state of Florida. "If there was any event that he was physically able to attend, Buddy would be there. In his own quiet, unpublicized way, he helped many, many people. He was an extraordinary person in the Alpha community."

Before relocating to Florida in his retirement, Golder worked for the Santa Clara County Transit Authority and operated a satellite TV business in San Jose, Calif. After his diagnosis, he steeped himself in Alpha-1 literature and websites and eagerly shared his knowledge with others. "When Dad would meet someone online or through a friend of a friend, he would reach out to them," says his elder daughter, Kelly LoFrese. He was open to anyone with any type of lung disease."

"Whenever he talked to people awaiting transplants, Buddy would always tell it to them straight," notes Motsinger. "Sometimes, he'd admit that you really exchange one set of problems for another." In addition to persistent migraines and other ailments, Golder suffered slow rejection after his transplant and took a variety of immunosuppressants. But he always remained upbeat and thankful for his "second chance" at life, and he encouraged other transplant candidates to seize theirs.

In fact, Golder never allowed his illness to stop him from enjoying life. He remained an enthusiastic boater and fisherman, and he even threw himself into jet-skiing and parasailing. "Dad was crazy about flea markets, too," recalls his younger daughter, Kimberly Golder. "Whenever he'd visit us in the summers, he'd walk the flea markets from top to bottom by himself in the New York humidity. I couldn't keep up with him, and I'm 31 years old! He always stayed strong and never complained." He was particularly devoted to his grandchildren.

Even in death, Golder continues to help Alphas and others with lung diseases. His website remains up, though not necessarily updated. His children hope that an equally knowledgeable volunteer will step forward to keep it going as a resource and inspiration for others. "Dad was such a fighter," says daughter Kelly. "He showed everyone that you have to live every day to its fullest. It's all about staying positive. His memory will always inspire Alphas everywhere."