The Change You Create
At a time when “change” is in the air, personal involvement must make it happen

oday, right now, where do we stand? We are in the midst of the holiday season. We are on the heels of a historic presidential election. We are basking in a year of legislative successes on Capitol Hill that have given hope to the Alpha-1 community (due in no small part to the efforts of the Alpha-1 Foundation).

We are also in the midst of a new economic reality. It is a time when we take stock and decide what is important and what is mere luxury. We defer luxury for the time being, and we deal squarely with what is vital. And to the Alpha-1 community, increased funding is imperative.

In 2008, we celebrated the passage of the Genetic Information Nondiscrimination Act (GINA). This will prevent health insurance companies and employers from using genetic information unfavorably toward an individual. We cheered a US Department of Transportation ruling that requires all airlines to accept approved portable oxygen concentrators as carry-on items by May of 2009. We also published and distributed the State of the Cure document, reporting on progress made in identifying new therapies and new pathways to a cure. In these and many other ways, change has already begun.

But the economic downturn that has touched us all is threatening to put a stranglehold on promising research. Lack of funding could cause potential cures and therapies to wither and die from neglect at a time when they show great promise.

We believe there is still plenty of room for optimism. Underlying the achievements of the Alpha-1 community is the conviction that change can come if everyone does his or her part to make it happen. The Foundation was founded on the idea that change comes from the grass roots, and that individuals can make a difference. They can make history.

You can help to make history. With your continued contributions, you can see to it that a cure is found. You can help to develop innovative therapies and treatments. Researchers are conducting promising studies. Right now, your contributions are more important than ever before. If funding slows down now, it could set us back significantly. That’s why the Foundation is focusing more research funding to encourage those avenues that lead directly to therapeutic development.

We intend to find a way to make a difference. Through individual contributions, our Building Friends for a Cure program, planned giving — there are so many ways to keep Alpha-1 research going strong.

That’s where we stand right now. We’ve heard a lot about “change” in recent months. But we’ve learned that change is not just something that happens to you. It’s something that happens because of you.

For 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. To learn more about methods of giving, or to make an online donation, visit www.alphaone.org/help/.
Twice the Impact

In the case of the Alpha-1 and COPD Foundations, togetherness has its benefits.

The COPD Foundation produced its first-ever publication, COPD Digest, in time for the American Thoracic Society’s annual conference in May of 2004. It was the first public activity of the then brand-new COPD Foundation.

The COPD Foundation was created with the help of the Alpha-1 Foundation, and to this day the two foundations share several board members and John Walsh is president of both organizations.

In 2004, the COPD community had no central patient advocacy organization to provide support for patients and family members with chronic pulmonary diseases. So the Alpha-1 Foundation (representing only a small percentage of COPD patients) determined to help the larger COPD community by getting the broader community organized.

Four years later, the collaboration between the two — and the efficient working relationship where both organizations overlap — have benefited both organization as well as patients and families from both the Alpha-1 and broader COPD communities.

Board members and staff from the Alpha-1 Foundation helped to develop the new COPD Foundation. This meant that the COPD Foundation, unlike other fledgling organizations, did not have to start from “square one.” This greatly reduced the cost of startup.

“The many things we do at the COPD Foundation, we learned from our experiences in the Alpha-1 Foundation,” said Ab Rees, a member of the boards of both organizations. “There’s a close link between the people of both foundations. If you look at COPD Digest, the magazine of the COPD Foundation, you see ads and support from the Alpha-1 Foundation and AlphaNet.”

The two foundations share senior management and several board members. Because of the inherent structure of the organizations and the ways in which they overlap, decisions are made quickly and communication between the two organizations is natural and easy.

“The NHLBI Learn More, Breathe Better campaign is another way we see the benefit of the collaboration of the two foundations,” said John Walsh. “The campaign reaches the entire COPD sphere, and Alpha-1 is prominently mentioned as the most significant genetic risk factor for COPD. And NHLBI is currently sponsoring the COPD gene study, with the primary objective being to identify five or six genetic predispositions for COPD. That’s huge, especially for an orphan disease like Alpha-1. It greatly extends awareness, both on behalf of the public and researchers.”

The COPD Foundation’s Mobile Spirometry Unit, a part of the Learn More, Breathe Better Campaign, has traveled to health fairs across the country with an attendance of 1.3 million, administered 13,640 lung function tests through June, 2008, and distributed 63,800 brochures.

The COPD Foundation has now launched multiple sources of information and detection.

The COPD Information Line, with a paid manager but otherwise entirely staffed by volunteers with COPD, was created in January, 2007. The volunteers answer up to 80 calls a day; send out information packs for both patients and caregivers; and refer patients to pulmonary rehabilitation and support groups and research studies seeking patients.

The COPD Registry, modeled after the Alpha-1 Research Registry, has more than 2,500 individuals enrolled and creates a growing patient base for research studies.

Circulation of COPD Digest is booming, and calls to the Alpha-1 Foundation’s Information & Referral department increase by an average of 44 percent immediately after each new issue of COPD Digest is published, and all information distributed by the COPD Foundation contains an imbedded message about genetic risk factors for COPD, critical to the goals of the Alpha-1 Foundation.

“As a result of the collaboration,” said Rees, “many more people receive the benefits of our know-how and experience, as well as the research funding we can generate. It’s really a match made in heaven.”
Our Woman in WASHINGTON

Miriam O’Day celebrates a great legislative year for the Foundation — and for Alphas everywhere.

Miriam O’Day doesn’t deserve any credit. Just ask her. O’Day has been Senior Director, Public Policy, of the Alpha-1 Foundation — the Foundation’s Woman in Washington — since July of 2000. And after eight years of hard slogging, 2008 was the best legislative year ever for the Foundation and for Alphas:

- The Genetic Information Nondiscrimination Act (GINA) passed Congress; the US Department of Transportation published its new rule requiring airlines to allow passengers to carry on board any of five approved portable oxygen concentrators; and Congress gave the Centers for Medicare & Medicaid Services (CMS) the authority to make pulmonary rehabilitation a permanent Medicare benefit.

And the credit goes elsewhere.

“We’ve been able to align ourselves on the issues with the professional societies representing physicians and the American Association for Respiratory Care,” O’Day says. “We used the contribution of celebrity wisely — getting help from Grace Anne Dorney Koppel and her husband, Ted Koppel, on pulmonary rehabilitation, and Dr. Francis Collins, former director of the National Human Genome Research Institute, on GINA. Dennis Pollock and the Oklahoma Alphas worked with the genetic counselors in Oklahoma to get action on GINA when Sen. Tom Coburn was blocking the bill in the Senate. And the Foundation contributed financially to a coalition that hired a high-level Democratic strategist, Steve Elmandorf, to help us get pulmonary rehab into the Medicare package.”

In 2002, MARLENE BUCHANAN was retired after 35 years as a special education teacher and had become an Alpha-1 support group leader in Pennsylvania after being asked by her AlphaNet coordinator, Kathy Haduck. “So I was accepting some responsibility, but I was not one bit emotionally invested in the Alpha-1 community,” she says.

In June that year she agreed to take part in an Alpha-1 Advocacy Day in Washington, held in conjunction with the Alpha-1 Association National conference. O’Day arranged a daunting eight visits for Buchanan and seven other Pennsylvania Alphas.
that day, and O’Day’s friend and colleague Patrick Collins made that schedule possible by serving as the group’s guide.

“Patrick served as our spokesman for the first meeting, we learned how to lobby, and very quickly we took over,” Buchanan says. “Before each support group meeting, Miriam would get on the phone with me and give me a briefing. Thanks to our support group members, former Pennsylvania Sen. Rick Santorum took the lead as our advocate on this issue in the Senate.

“We were all amazed and felt so empowered when the new Medicare ruling came out in October of 2002 and reversed the cuts in reimbursement. When I went into the room where our support group met that month, it had become a magic place. That day in Washington was a life-changing experience for me, and I think for all the Alphas from my area.”

PATRICK COLLINS is Director of Public Affairs in North America for CSL Behring and he’s known Miriam O’Day for 11 years. They met in 1997, when Collins attended his first government advisory committee meeting as Director of Government Affairs for the National Hemophilia Foundation.

“Miriam took me under her wing, introduced me to the leaders of the other patient groups, and some of them became people I work with to this day,” Collins says. So it was easy for Collins to say yes when O’Day asked him to guide the Pennsylvania Alphas through Congress on that life-changing day in 2002.

CATHEY HORSAK was a support group leader in Austin, TX, in 2002. Her husband Richard had died of Alpha-1 liver disease three years before at age 49. But Horsak never heard of Alpha-1 till she read the report on Richard’s autopsy, weeks after his death. Horsak wanted to work fulltime with the Alpha-1 community. Her chance came the following March, when she was hired to work for the Alpha-1 Association. Her first task: a crash effort, to do all the work involved in planning the 2003 national meeting of the Alpha-1 Association in Oak Brook, IL with Miriam O’Day.

“Our days began at 6 a.m. in Texas, 7 o’clock Eastern, and often ended with an evening phone call at 10 that night. Sometimes it was seven days a week. All our contact was over the phone. I was working with this dynamic, very directed person, and I didn’t know what she looked like. We had to describe ourselves to each other so we’d know who to look for in the hotel lobby on May 29, 2003, the

Continued on page 6
day before the conference began."

It wasn’t till later that Horsak, now Director of Community Programs and Outreach for the Association, got to spend a day with Miriam on her Washington rounds. “She’s like a tornado going through those halls in Congress,” Horsak says. “It’s physically exhausting keeping up with her. She only slows down when she’s actually in the offices. Then you see that she has warm personal relationships with all these people, and yet she’s extremely professional at the same time. She obviously loves what she’s doing. And she takes no credit. She never talks about how much work is involved in setting up opportunities for Alphas to testify on Capitol Hill; she only praises the patients’ efforts.”

JOHN WALSH met Miriam O’Day in the late 1990s, when she was Vice President of the Immune Deficiency Foundation (IDF). Secretary of Health and Human Services (HHS) Donna Shalala had named Walsh to a seat on the Advisory Committee for Blood Safety and Availability.

The Committee was established after a report on HIV in the blood supply suggested that to enhance blood safety and availability, all Federal agencies needed a committee for input from all stakeholders involved. The Committee then made direct recommendations to the Secretary of HHS. The IDF had lobbied hard for a seat on the new committee, without success. When Walsh got the post representing plasma consumers, O’Day looked him up.

“John traveled to Maryland to meet with us. We clicked immediately and we worked together closely for years after that. I was impressed with John’s ability to establish partnerships, get others to join him and raise the issue of Alpha-1 to a level of national concern. One of the first things we did was set up a joint meeting for the Foundation and IDF with the FDA to discuss product shortages in both communities. John became one of the best advocates immune deficient patients ever had in Washington.”

With Patrick Collins (remember him?) of the National Hemophilia Foundation, they formed the Plasma Users Coalition. “Our biggest accomplishment was the national Patient Notification System, which patients could use to keep track of any recalls of blood products they might be using. Industry groups set up the system voluntarily, and we did an education program to teach patients to record lot numbers of their blood product.”

When O’Day finally left the Immune Deficiency Foundation in 2000, Walsh contracted with her to serve as the Alpha-1 Foundation’s Senior Director of Public Policy. It was the beginning of her independent consulting business in communications and government relations. (By the way, O’Day isn’t just our lobbyist; she was the original managing editor of Alpha-1-To-One magazine.) She now represents the Alpha-1 Foundation, Alpha-1 Association, the COPD Foundation, the American Association for Respiratory Care, NTM Info and Research, and the US COPD Coalition.

She is the voice in Washington for pulmonary patients and the allied health professionals who care for them – respiratory therapists. “The most important thing that we can do is to let those who are making policy understand the impact their decisions have on individuals. It is the constituents that we represent who have to remain the focus of all our efforts,” says O’Day. A point that has become obvious with the success of 2008.
New legislation that impacts Alphas calls for celebration — and continued vigilance.

There’s no doubt that 2008 has been a banner year for legislation that affects Alphas. From passage of the Genetic Information Nondiscrimination Act (GINA), to the Department of Transportation ruling on airline oxygen, to Medicare coverage of pulmonary rehabilitation, much has been accomplished.

But while the taste of victory is sweet, there is also no doubt that more work needs to be done.

**Airline Oxygen**

In June, the US Department of Transportation published a rule that will require airlines to allow individuals to bring approved portable oxygen concentrators aboard any flight as carry-on luggage. The effort to win this ruling was spearheaded by the Airline Oxygen Council of America (AOCA), the Ruderman Family Foundation, and the Alpha-1 Foundation.

The rule becomes mandatory in May 2009. While the rule is fairly straightforward, some questions remain. “Will it be mandatory for airlines to provide supplemental oxygen for those who require it?” asks Miriam O’Day, the Foundation’s Senior Director, Public Policy. “Some airlines have stopped providing oxygen and instead are telling people that they may now bring their own.”

“We do need to keep our eyes on this trend,” adds Foundation President & CEO John Walsh. “Many people cannot afford portable oxygen concentrators. Also, we want to make sure that the FAA and DOT continue to approve new concentrators that meet their specifications. That will give passengers greater choice.”

**Pulmonary Rehabilitation**

Congress has given the Centers for Medicare & Medicaid Services (CMS) authority to make pulmonary rehabilitation a permanent Medicare benefit. While a huge victory, this does not go into effect until 2010. Some pulmonary rehab centers, however, may be in jeopardy from lack of funding before the law takes effect. Other centers may refuse to cover pulmonary rehab under Medicare until it becomes mandatory. The Alpha-1 Foundation will begin an aggressive awareness campaign on this issue, focusing on cardiac rehabilitation facilities and pulmonary rehab centers.

Also, now that CMS has been mandated to set up a permanent pulmonary rehab benefit, CMS needs to come up with a mechanism to make this happen. Coding and billing structures must be in place by January, 2010 when the benefit goes into effect. The Foundation plans to be involved in this area of the legislation, which will ultimately help to determine which healthcare providers will be involved and who is eligible to receive the benefit.

**Home Oxygen Reimbursement**

The problem with this Medicare benefit is that it classifies home oxygen as “durable medical equipment.” Policymakers view home oxygen in the same category as wheelchairs and scooters.

The fact is, home oxygen is more than just medical equipment — it involves an ongoing medical prescription, plus servicing both the equipment and the needs of patients.

The challenge for providers is to contain costs in a distressed economy and still make sure that patients get clinically appropriate care. One possible strategy is to have respiratory therapists who are not employed by the oxygen provider involved in the process of caring for patients using oxygen.

Another challenge: Most reimbursement is geared toward stationary equipment. How can patients who need portable oxygen concentrators be reimbursed fairly?

The Foundation will continue to monitor the home oxygen benefit situation. The main issue for the Alpha-1 community centers around choice and access to care, and that’s where the Foundation’s energies will be focused.
Art of being an Alpha has to do with information and determination. You do what you can to learn about the state of the cure and about treatment options. You do your own research. Then you determine what you can live with and what you can live without. You make the best of a difficult situation and focus on the things in life that you can do, and don’t waste time on things you cannot do.

I have been physically active all my life. I’ve been an avid basketball player and began playing racquetball at about the age of 35. After about 10 years, I noticed that I was being regularly beaten by people with whom I had always been competitive. I noticed I was getting shorter and shorter of breath. My internist initially thought I had asthma. That’s a pretty standard scenario when Alphas first seek a diagnosis of their breathing problems. I went for a cardiac stress test, where they put you on a treadmill and monitor you, and then had a CT scan. The radiologist, Dr. Robert Berlin, was really on the ball. He looked at the lung scan and saw it was consistent with Alpha-1. My internist had not had any experience with Alpha-1, but when he was given the radiologist’s report, he did the blood test and determined that I had Alpha-1. This was about 10 years ago, when I was 50.

My family has been behind me all the way on this. My wife, Cindy, and my daughters, Madison and Grace, have really been champs. They understand what I can and can’t do and are extremely supportive. Of course, one major element in my life right now is that we live in Jackson Hole, Wyoming, at 6,300 feet above sea level. My law practice is here; our life is here. But at this altitude, I need supplemental oxygen all day. If we moved to sea level, I wouldn’t need it during the daytime – least for the near future. So I have to carry an oxygen concentrator with me when I work, when I go to my daughters’ swim meets and dance recitals. It has become a bit of a burden. Now, this is not an insurmountable problem, but because of Alpha-1, we have given serious thought to moving to a lower altitude. Even if you don’t have Alpha-1, it’s not always easy to keep up with your 12- and 17-year-old kids when you’re 60.

Yes, it has started to affect my business. I know I’m starting to slow down. But for the short term, I’m OK. I still work and I still enjoy my work. In fact, I’m litigating on behalf of an Alpha right now. It is alleged that her employer gave her a pre-employment physical exam when she was 30 years old, but did not tell her the results of her spirometry test. So she went to work for the company and continued smoking. Now, she is down to less than 20 percent lung function (FEV1) and is trying to get on a transplant list while dealing with other infection issues. She is a real hero in my book.

In fact, I’m involved in an insurance dispute of my own. It seems that my health insurer doesn’t want to cover my portable oxygen concentrator in addition to the home concentrator. According to them, the POC is for my “personal comfort and convenience” and is therefore not covered. So, my thinking is, I’m not going to put up with that. I believe that portable oxygen is more than just a convenience — that is, it’s only in the discussion stages right now, but I think poker tournaments could be another way to bring much-needed money into the Foundation.
if you like to breathe while away from home, and especially for those who travel for business. We’ll see what happens.

In the last few months, I started an exercise program. I really enjoy it and I feel the benefits. I highly recommend exercise to any Alpha, both for the physical and mental boost it gives you. I got a membership in a gym at a local hospital. When I exercise, the hospital equipment gives me continuous-flow oxygen, which helps me maintain an oxygen saturation level of 90 percent or above. I can do 30 minutes on the treadmill and do many exercises that would be impossible for me otherwise.

I got involved with the Alpha-1 Foundation a couple of years after my diagnosis. I was having my annual exam with Dr. Robert Sandhaus in Denver. It happened that there was a national Alpha-1 meeting in Denver that year, and Dr. Sandhaus introduced me to John Walsh. They asked me to join the Board of Directors and I was happy to accept. I try to go to as many meetings as I can. The Foundation board members and executives spend so much of their time trying to fund research to find a cure, generate dollars for research and awareness, and help other Alphas maintain their quality of life. Sometimes I can’t do as much as I would like because of the demands of my law practice, but I try to keep up on issues like early detection programs and the need for Alphas to get as much exercise as they can.

I’m also on the Foundation’s Development Committee. That involves looking for new and innovative ways to raise funds for the Foundation so it can fund scientific endeavors, achieve its goals and ultimately find a cure. Everyone on the committee brings their own life experiences to the group. For instance, one of my interests is poker. I play in a weekly game of dealer’s choice here in Jackson Hole with eight or nine friends. I’ve also participated in a few World Series of Poker events — with only marginal success.

So, naturally, I thought that poker might be a good way to raise funds for the Foundation! It would be great to have a tournament in, say, Miami, and find a high-profile celebrity or sponsor to help promote the event. It’s only in the discussion stages right now, but I think poker tournaments could be another way to bring much-needed money into the Foundation.

Being an Alpha is an up-and-down thing. Sometimes, you think about the bad things. Like when you first heard of the disease, and looked it up on the Internet. That’s where you read prognosis after prognosis, and it’s never positive. But then you notice the good things. In my case, the upside has been that I’ve met absolutely wonderful people like John Walsh and Dr. Sandhaus, Janis Berend at National Jewish Health and all the great people at the Alpha-1 Foundation. You meet the researchers, the physicians and the scientists who are so committed and so generous with their time and talent. And you do get the feeling that you are not in it alone. Not by a long shot — and there are lots of good things happening.
I was diagnosed with Alpha-1 and moderate emphysema in January, 1993. For the next five years, I didn’t use oxygen. Then, after testing my oxygen saturation levels, my doctor prescribed oxygen for me to use during exercise. Shortly thereafter, he also prescribed it for sleep and for airline travel. For the next 10 years, I was pretty careful to use oxygen when I slept, traveled on airplanes and exercised on a treadmill. But that was all.

I ignored my doctor’s recommendation to use it when I had a lot of walking to do. For me, oxygen was a necessary nuisance. I avoided using it more than I absolutely had to. I convinced myself I really didn’t need it.

Then, early this year, my doctor had me take an echocardiogram. This was a test that I had taken routinely every two or three years, but this time it showed substantial pulmonary hypertension. I knew immediately that my life would have to change. My doctor and I agreed that I would go on oxygen 24/7.

But the psychological transition to oxygen 24 hours a day wasn’t easy. Knowing that oxygen was and is my best hope to prolong my life is one thing; accepting it is another. For me, this was a major life transition. I had a few rough days. Thanks to a number of Alpha friends who had experience with oxygen, however, I was back on track pretty quickly and considering my options.

I am a pretty active person, so I needed a portable oxygen system. My regular daily needs are only two to three liters per minute, using a pulse-dose during the day and continuous flow at night. But when I exercise on the treadmill and rowing machine, I need at least four liters.

I also wanted to be able to carry my oxygen on my shoulder. I know that others carry their oxygen in backpacks and around their waist, but for me, the shoulder is most comfortable.

Before making my decision, I not only talked to friends, but also consulted a number of helpful websites. Two of the best I found:

1. The American Thoracic Society site http://www.thoracic.org/ Go to the site and type “oxygen” into the search box at left. A wealth of articles appears. You might start with this one near the top: “Why Do I Need Oxygen Therapy?”

I ultimately decided on the Helios system and ordered one from my oxygen supplier. At the same time, I asked to have my home concentrator replaced. I used it at night, and it had been behaving erratically. The very next day, a respiratory therapist came out to test whether or not I would be able to maintain normal oxygen levels while using the Helios. She explained its use briefly, confirmed that my oxygen levels were appropriate on this system, and left the Helios with me. The following day, a driver showed up with a tank of liquid oxygen and a new concentrator. He gave me a quick lesson in how to fill the Helios and left me on my own.

I used the Helios without incident for the rest of the day. Then, after supper, I turned on my new concentrator. I immediately smelled something funny, but chalked it up to the smell that one sometimes gets when using a brand-new product. I left the room and came back about five minutes later. The room smelled unmistakably like cigarette smoke. My “new” concentrator obviously wasn’t.

What could I do? It was time for bed. I couldn’t sleep with the pulse-dose Helios and my liquid oxygen tank had no setup for connecting my oxygen tubing. I could wait up in the hope that my oxygen company would deliver another concentrator later that night, or sleep
with the window open and put the concentrator on the far side of the room. I chose the latter, even though I knew that it was likely that the cigarette smoke had also contaminated the oxygen I would be breathing. I did not sleep well.

I called my oxygen company first thing in the morning. I also sent off an e-mail letter to corporate headquarters. The good news is that I got an almost immediate response. I got an apology and was told that, by company policy, my concentrator should have been discarded, and would be. I was also given an actual, brand-new concentrator and my liquid oxygen tank was set up so that I could use it at night in emergencies.

I realized that, for almost 10 years, I had been almost completely oblivious to the operation and servicing of the oxygen equipment upon which my life depended. I needed to educate myself. In order to do so, I turned again to friends, my oxygen company and the Internet. Over the next week or so, I gathered books and pamphlets on the operation and servicing of all my equipment. My oxygen company provided some written information and also sent a supervisor out to train me. I downloaded information from the websites of the companies that manufactured each piece of equipment that I use. Now I have a basic working knowledge of how each piece of equipment works – and when and how it should be serviced. I intend to make sure that servicing is done. I also know how to operate my emergency backup systems.

Lessons learned:

First, if your doctor says you need to use oxygen, use it! It’s the only intervention proven to extend the lives of people with emphysema. If your doctor says you need it, you need it -- even if you don’t feel short of breath.

Second, if you use oxygen, educate yourself! Learn the different types of oxygen systems. Learn about your oxygen equipment. Ask questions of your oxygen company. Check manufacturers’ websites. Insist that all of your equipment be in tiptop condition. Be sure you have emergency backup systems – and know how to operate them.

Your life depends on it!

The Doctors’ View

From Robert A. Sandhaus, MD, PhD, the Foundation’s Clinical Director:

• For many, especially with Alpha-1 because of their younger average age, wearing oxygen amounts to wearing a big sign that shouts, “Look at me, I have bad lungs!” Needing oxygen and wearing oxygen are two distinct steps in dealing with your lung disease. Practical issues like whether oxygen will affect your ability to continue in your present job often weigh heavily on someone new to oxygen use.

• The body has no “sensor” that detects your oxygen level. If you’re sitting in a chair and your oxygen level drops dangerously, you won’t notice. You don’t even feel short of breath. Where you might notice low oxygen is with exercise or any physical work. When your muscles become starved for oxygen, they switch to a type of metabolism that can generate energy without oxygen (anaerobic metabolism). This generates a lot of carbon dioxide and lactic acid. Your body does have sensors for carbon dioxide and acid in the blood; this makes you breathe harder and faster. When you get short of breath, you are actually feeling the effects of high carbon dioxide and lactic acid rather than low oxygen.

• If you need oxygen at night, with exercise, and at rest during the day, the closer you come to using it a full 24 hours a day, the better the health effects will be.

• If you need oxygen and you don’t use it, the health effects can be devastating, including pulmonary hypertension [high blood pressure in the circulation of the lungs], congestive heart failure of the right ventricle also known as cor pulmonale, and even irregularities of your heart’s rhythm. And you’ll find it difficult to maintain your fitness – because exercise is so difficult.

Adds Thomas L. Petty, MD, a pioneer in oxygen use for COPD patients: “All ambulatory patients should use an oximeter to insure they are getting adequate oxygen saturation, and adjust their device accordingly.”
The Alpha-1 Foundation grant recipients for the current year are doing widely-varied research. Here are the grantees and their current work funded by Foundation grants.

Alpha-1 in African Americans
Marilyn Foreman, MD, of Morehouse School of Medicine in Atlanta, will test 400 African Americans with COPD for Alpha-1, as well as another 400 who do not have COPD. The study will also test for genes previously found to be associated with COPD in more than one study. Foreman hopes that finding the genetic causes of COPD in African Americans will help to uncover the reasons for the currently increasing rates of emergency room visits, hospitalizations and death from COPD among African Americans.

Designing Drugs
Anne Gershenson, PhD, of Brandeis University will use a microscopic measuring technique to study the makeup of alpha-1 antitrypsin (AAT) polymers. Alpha-1 liver disease occurs when single AAT proteins link together in long chains called polymers. The polymers get stuck inside the liver cells and can sicken the cells, leading to liver disease. In order to link together, AAT molecules must be more flexible than normal AAT. The abnormally flexible part of the molecule is a good target for “small molecule drugs” aimed at preventing the formation of polymers — and theoretically, preventing both Alpha-1 lung and liver disease.

Cells Eating Themselves
Autophagy (self-eat) is a process by which a cell digests a part of itself with enzymes from the cell itself. This process is involved in the removal of faulty AAT from the body. The research program at Baylor College of Medicine recently discovered that autophagy is also involved in removing pathogens from the cells. In an Alpha during an infection, autophagy might be forced to do double duty, removing both faulty AAT and infection pathogens. Tony Eissa, MD, of Baylor will study autophagy in AAT cells under conditions that mimic infection, hoping to better understand how liver disease develops in Alpha-1 and how to treat it.

The Snip
According to Rick Sifers, PhD, of Baylor College of Medicine, Alpha-1 liver disease is accelerated by a mutation called a single nucleotide polymorphism (SNP, pronounced “snip”) in the gene for an enzyme called ER Mannosidase 1 (or ERMan1). “ERMan1 is the key regulator in the protein degradation process,” Sifers was quoted as saying in this past spring’s edition of Alpha-1-To-One. Shujuan Pan, PhD, who is working with Sifers’ research team, has received a two-year postdoctoral fellowship to study the mechanism by which the SNP hinders the breakdown of AAT in Alphas with the ZZ genotype.

Smoke Damage
Cigarette smoke damages the lungs by causing inflammation. Tracy Adair-Kirk, PhD, of the Washington University School of Medicine in St. Louis, believes that smoke also impairs the lung’s ability to repair itself — especially the lung’s ability to make elastic fibers that are crucial for lung function. This research to identify the factors that interfere with lung repair could lead to interventions that help prevent the problem.
Alpha-1 Mice
Sihong Song, PhD, of the University of Florida plans to develop a transgenic mouse line that will express only mutant human AAT (or Alpha-1 mice). The mice will be studied to see if they develop COPD and liver disease, and may reveal previously unknown functions of AAT.

Empowered Alphas
Symma Finn, PhD, of the University of Florida will survey members of the Alpha-1 Foundation Research Registry to measure how empowered people are in the Alpha-1 community. The results will be compared to standard measurements of quality of life, to see if there is a connection between empowerment and quality of life. The study will also address the question of whether a rise in patient empowerment changes the relationship between patients and doctors. The study results may help Alpha-1 organizations promote empowerment and may help individuals better manage their health condition.

A Combination Gene Therapy
Terence Flotte, MD, of the University of Massachusetts School of Medicine, plans to use adeno-associated viral vector (AAV) to deliver microRNAs (single-stranded molecules of RNA, carrying genetic instructions) into the livers of mice with Alpha-1-type liver disease. In the process, he hopes to both increase the secretion of normal AAT protein and reduce the production of mutated AAT protein which can damage the liver. The ultimate goal is to alleviate or reverse Alpha-1 liver disease and provide normal AAT protection for the lungs.
It's that time of year. Holiday decorations fill store shelves and dangle in window displays. You may be thinking, "What will I add to my holiday wish list this year?"

For an Alpha, that might not be the typical list. An Alpha's wish list might be about wanting to breathe better, without the use of supplemental oxygen. It might be a wish for a long, healthy life – or just the ability to celebrate one more holiday with loved ones. Some with severe disease might even hope for the gift of life.

"As a caregiver, I wish for at least 10 more years of good health," says Larry Angell, who cares for his wife Diane.

Diane was diagnosed with Alpha-1 in 1996. She and Larry began to do their own research on Alpha-1 and the two decided to be their own advocates. She is the co-founder and president of the Idaho Alpha-1 Community Outreach Inc, a nonprofit group that provides support to people diagnosed with Alpha-1.

Larry is an engineering technician for Micron Technologies. Last year, while attending the annual company children's Christmas party, a woman asked him to play Santa Claus for the children. After a bit of persuasion, he agreed.

"I've always grown my beard out every winter and shaved it in the summer. Last year, my beard came in a little whiter, so I'm sure that was the reason she asked me."

But it was the look on the first two children's faces that got him hooked.

He decided to get serious about being Santa Claus. He enrolled in the International University of Santa Claus (yes, it exists!), where he learned the history of Santa, the reindeer and the magical sleigh. He passed the exam and took the Santa Claus Oath. He received a Bachelor of Santa Claus degree and became a registered Santa. He also listed his beard in the National Beard Registry, making him a 100% authentic Santa Claus. [This is all true.]

While he likes to get dressed up and hear the secret wishes of a child, Angell is serious about remembering "the true meaning of Christmas." It's not about getting gadgets and toys, he points out, it's about being thankful for your family and for what you have. "We have to count our blessings. I've been blessed with a supportive wife and a terrific family."

With today's troubled economy, more people are finding it harder to manage their finances. The uninsured and unemployed are wishing for lower prescription drug costs and better healthcare coverage.

So when you are making out your wish list this holiday season, you might think to yourself, "What is it that really matters to me?"

You might take a look at the Wish List on the following page, and add your own!
Dear Santa,

All we want for the holidays is...
More research on Alpha-1
Liquid oxygen that doesn't freeze
A liver/lung transplant...

And if you can fit it in your big, black sack... a cure for Alpha-1!

Love,
The Alpha-1 Community

What is on your Alpha-1 holiday wish list? Share your stories with us... we would love to hear them. Send your stories to rcampbell@alpahone.org by Dec. 19. The best story will win a $500 gift card. We will try to include as many as we can in an upcoming story.

Alpha News on the Web

When Indiana Alpha John Grammer took to the skies in his ultralight aircraft to rescue Maude, with him here, and her pups, we told you about it in our website news. Grammer volunteers with Animal Rescue Flights, transporting animals from overcrowded shelters to qualified families willing to adopt them. Keep up with Alpha news and features every day by clicking the "NEWS" button at the top of our Home page, or go directly to http://www.alpahone.org/news/.
Dan Martini knew exactly why he was short of breath: "I was overweight, lazy and smoked two packs of cigarettes a day." But in 1997, seven years after he quit smoking and after several years of severe asthma and recurring bronchitis, he was finally diagnosed with Alpha-1. He had an FEV1 of 27 percent at age 45; his doctor told him a lung transplant was his only hope for survival.

He began "shopping around" for a lung transplant. He applied for the transplant list at the Veteran’s Administration Medical Center in Madison, WI. While awaiting a decision, he changed his behavior. "I exercised, I went to my rehab center and I continued to call the transplant center to check in."

Martini has worked his way through two pulmonary rehabilitation courses. He says it’s the best way to gain exercise tolerance and build healthy muscle. He even created his own set of exercises.

"If you have problems with your lungs, you should exhale on the exertion — which is the most difficult part of the exercise — and inhale as you come out of it," he says.

Martini has worked his way through two pulmonary rehabilitation courses. He says it’s the best way to gain exercise tolerance and build healthy muscle. He even created his own set of exercises.

For example, if you are raising your hands over your head, you breathe out as your arms go up, and breathe in as they come back down. Often, you have to start out doing small exercises like this to build tolerance. When he started lifting weights, he used a can of beans. Now he can curl 15 pounds.

"You exercise as much as you can tolerate, for as long as you can tolerate it," he said. "If you can only do two curls, then do those two curls every day until you can do more. But his best advice is to find something that interests you. If you don’t enjoy doing it, then you’ll find every reason not to."

For Martini, it’s the stationary bike. Sometimes he pedals seven or eight miles without even knowing it. His secret? Video games. As long as he’s focused on his video games, he isn’t aware of what his feet are doing.

On the morning of Jan 8, 2001, Martini made his routine call to the hospital to find out where he was on the list. "There were some movements, but you’re still only fourth,” the nurse told him. That evening, at dinner with his family, he got The Call: incredibly, four lungs had become available at the same time. He received his new lung the next day. Now, he gets 60% more lung function out of that one lung than he did from both of his damaged lungs combined.

After breathing easy for the first time in years, he decided to go to school and become a respiratory therapist. In 2004, he began taking prerequisite courses at the local community college. Then he transferred to Nebraska Methodist College where he received a degree in Respiratory Care this past July. "I passed my boards in August, and now I’m a Registered Respiratory Therapist."

Martini believes his experience as a patient helps him motivate others. He’s been in their footsteps and he knows what works. "Anyone who has lung problems should remember that the more you do, the more you can do," he said. "It’s like they always say – use it, or lose it. It’s just that simple."

For Dan Martini, respiratory therapy has become both a lifestyle and a living.

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Dan Martini
### Calendar of Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Description</th>
<th>Location</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>January 15</td>
<td>Casino Night for Alpha-1</td>
<td>Allentown, PA</td>
<td>Donovan Quill 610.597.4221 <a href="http://www.firstgiving.com/quillfamily">www.firstgiving.com/quillfamily</a></td>
</tr>
<tr>
<td>March 17</td>
<td>Celtic Challenge [Contact The Alpha-1 Foundation for more information.]</td>
<td>USA</td>
<td>Yiomara Perry <a href="mailto:yperry@alphaone.org">yperry@alphaone.org</a></td>
</tr>
<tr>
<td>March 30</td>
<td>Alpha-1 Jeans for Genes</td>
<td>Mansfield, MA</td>
<td>Donna Tucker <a href="mailto:hdtuck4@yahoo.com">hdtuck4@yahoo.com</a></td>
</tr>
<tr>
<td>May 1</td>
<td>Alpha-1 Jeans for Genes</td>
<td>Montclair, NJ</td>
<td>Nancy Smith <a href="mailto:nsmith1029@aol.com">nsmith1029@aol.com</a></td>
</tr>
<tr>
<td>May 9</td>
<td>New York and New Jersey George Washington Bridge Walk</td>
<td>New York, NY</td>
<td>Joe Reidy <a href="mailto:joereidy@verizon.net">joereidy@verizon.net</a></td>
</tr>
<tr>
<td>May 15</td>
<td>Get the Scoop on Alpha-1 Ice Cream Event</td>
<td>Denver, CO</td>
<td>Judy Simon <a href="mailto:saidsimon@comcast.net">saidsimon@comcast.net</a></td>
</tr>
</tbody>
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For fundraising event information, contact Angela McBride at 888.825.7421 ext. 233 or amcbride@alphaone.org, for an application. Talecris Biotherapeutics is the anchor sponsor for the Team Alpha-1 Program.

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### Are we on your wish list?

This holiday season, put the Alpha-1 Foundation at the top of your wish list by asking friends & family to make a charitable donation that will advance research for a cure for Alpha-1.

Or, commemorate the life of a loved one by giving in their honor or memory.

Donate Online at [www.alphaone.org/help](http://www.alphaone.org/help)

Or mail a donation to
2937 SW 27 Ave., Ste. 302
Miami, FL 33133
Finishing the Race

AlphaNet coordinator Roger Bray believes in reaching for more.

When Roger Bray was diagnosed with Alpha-1 in 1998, he couldn’t find much information. Most doctors he talked with didn’t even know about Alpha-1. In fact, it took several years of breathing symptoms before he was diagnosed correctly.

After numerous trips to different doctors, his primary doctor gave him a pulmonary function test. He was referred to a pulmonologist who diagnosed him with Alpha-1. But he was still unclear about what Alpha-1 was, or what it meant for his future. And he didn’t know anyone who could give more insight, or even the voice of experience.

That’s why he enjoys being an AlphaNet coordinator. He wants to make sure that others are more informed. “I can remember how I felt when I was diagnosed. There’s so much uncertainty. Because of that experience, I can talk them through it and reassure them.”

As the AlphaNet coordinator for Kentucky and Indiana since 2003, Bray has developed his own philosophy to help motivate his Alphas. It’s called, “just out of reach,” and it’s as easy as finding something that you would like to do — that you can’t quite do now.

“I was so afraid when I got diagnosed, and after a while I just got over the fear,” Bray said. “Now, I don’t want to take a single day for granted.”

Not long after getting over his fears, he decided to venture out to try new things. So far, he’s gone sky diving and even took up auto racing.

His newest goal: “To finish a race without getting short of breath.” (It’s stressful, driving those fast cars.)

The goal after that? “Finishing without being last.”

For more information about AlphaNet, call 800.577.2638 or visit www.alphanet.org.

Newborn Screening Reborn

Has there been a paradigm shift in newborn screening?

A panel of national and international experts has recommended that multiple pilot studies be initiated to assess the benefits and practicality of newborn screening for Alpha-1 Antitrypsin Deficiency (Alpha-1).

The panel said that adding Alpha-1 to newborn screening would be “a new paradigm” — focusing on benefits resulting not only from immediate medical treatment, but also on avoiding risk factors including parental and personal smoking and environmental exposures, both in the workplace and at home.

Given that the currently available information on the benefits of newborn testing for this condition is limited, the panel recommended that multiple pilot studies be initiated to assess the practicality and clinical impact of early diagnosis.


The workshop was chaired by R. Rodney Howell, MD, Special Assistant to the Director, National Institute of Child Health and Human Development, National Institutes of Health.

Howell, also the Chair of the Advisory Committee on Heritable Disorders in Newborn and Children (ACHDNC), explained the procedures and guidelines for adding a condition to the recommended panel of diseases typically screened for in all newborns.
**CONTRAINDICATIONS**

Individuals with selective IgA deficiencies who have known antibody against IgA (anti-IgA antibody) should not receive Prolastin, since these patients may experience severe reactions, including anaphylaxis, to IgA which may be present.

**WARNINGS**

Because this product is made from human blood, it may carry a risk of transmitting infectious agents, e.g., viruses, and, theoretically, the Creutzfeldt-Jakob (CJD) agent. The risk that such agents will transmit an infectious agent has been reduced by screening plasma donors for prior exposure to certain viruses, by testing for the presence of certain current virus infections, and by inactivating or removing certain viruses. Despite these measures, such pathways may still potentially transmit an infectious agent. There is also the possibility that unknown infectious agents may be present in such products. Individuals who receive infusions of these plasma products may develop signs and/or symptoms of some viral infections, particularly hepatitis C. All infections thought by a physician possibly have been transmitted by this product should be reported by the physician or other healthcare provider to Telecris Biotherapeutics, Inc. [1-800-520-2807].

The physician should discuss the risks and benefits of this product with the patient, before prescribing or administering it to a patient.

Alpha-1-Proteinase Inhibitor (Human), Prolastin® is heat-treated in solution at 60°C for 10 hours in order to reduce the potential for transmission of infectious agents. No cases of hepatitis, either hepatitis B or hepatitis C, have been recorded to date in individuals receiving Prolastin. However, as all individuals received prophylaxis against hepatitis B, no conclusion can be drawn at this time regarding potential transmission of hepatitis B virus.

**PRECAUTIONS**

**General**

1. Administer within 3 hours after reconstitution. Do not refrigerate after reconstitution.

2. Administer only by the intravenous route.

3. As with any colloid solution, there will be an increase in plasma volume following intravenous administration of Prolastin. Caution should therefore be used in patients at risk for circulatory overload.

4. Prolastin should be given alone, without mixing with other agents or diluting solutions.

5. Product administration and handling of the needles must be done with caution. Percutaneous puncture with a needle contaminated with blood can transmit infectious virus including HIV and hepatitis. Obtain appropriate medical attention if injury occurs. Place needles in sharps container after single use. Discard all equipment including any reconstituted Prolastin product in accordance with biohazard procedures.

**Carcinogenesis, Mutagenesis, Impairment of Fertility**

Long-term studies in animals to evaluate carcinogenicity, mutagenesis, or impairment of fertility have not been conducted.

**Pregnancy Category C**

Animal reproduction studies have not been conducted with Prolastin. It is also not known whether Prolastin can cause fetal harm when administered to a pregnant woman or can affect reproductive capacity. Prolastin should be given to a pregnant woman only if clearly needed.

**Nursing Mothers**

It is not known whether Prolastin is excreted in human milk. Because many drugs are excreted in human milk, caution should be exercised when Prolastin is administered to a nursing woman.

**Pediatric Use**

Safety and effectiveness in the pediatric population have not been established.

**ADVERSE REACTIONS**

Therapeutic administration of Prolastin, 60 mg/kg weekly, has been demonstrated to be well tolerated. In clinical studies, six reactions were observed with 517 infusions of Prolastin, or 1.16%. None of the reactions was severe. The adverse reactions reported included delayed fever (maximum temperature rise was 38.9°C, resolving spontaneously over 24 hours) occurring up to 12 hours following treatment (0.77%), light-headedness (0.19%), and dizziness (0.19%). Mild transient leukocytosis and dilutional anemia several hours after infusion have also been noted. Since market entry, occasional reports of urticarial, urticarial, or other serum protein. Long-term controlled clinical trials to evaluate the effect of chronic replacement therapy with Prolastin on the development of or progression of emphysema in patients with congenital alpha-1-antitrypsin deficiency have not been performed. Estimates of the sample size required for such a trial have not been met. In one study, the median survival of patients with severe panacinar emphysema that most often manifests itself in the third to fourth decades of life. Although no other steps were taken to prevent cross-contamination, it is possible that this product may carry a risk of transmitting viral, bacterial, or fungal agents, even though these agents may not be present in Prolastin.

**DOSE AND ADMINISTRATION**

Each bottle of Prolastin has the functional activity, as determined by inhibition of porcine pancreatic elastase. The “threshold” level of alpha-1-proteinase inhibitor in the serum believed to provide adequate anti-elastase activity in the lung of individuals with alpha-1-antitrypsin deficiency is 80 mg/dL (based on commercial standards for alpha-1-proteinase inhibitor assay).

**STORAGE**

Prolastin should be stored at temperatures not to exceed 25°C (77°F). Freezing should be avoided as breakage of the diluent bottle might occur.

**CONSULT PACKAGE INSERT FOR FULL PRESCRIBING INFORMATION FOR INTRAVENTRICAL USE ONLY**

**DESCRIPTION**

Alpha-1-Proteinase Inhibitor (Human), Prolastin® is a sterile, stable, lyophilized preparation of purified human alpha-1-Proteinase Inhibitor (alpha-1-PI) (Human), also known as alpha-1-antitrypsin. Prolastin is intended for chronic replacement therapy of individuals having congenital deficiency of alpha-1-proteinase inhibitor (alpha-1-PI) (Human) on entry into the investigation. Although no other steps were taken to prevent cross-contamination, it is possible that this product may carry a risk of transmitting viral, bacterial, or fungal agents, even though these agents may not be present in Prolastin. Alpha-1-antitrypsin deficiency is a chronic, hereditary, usually fatal, autosomal recessive disorder in which a low concentration of alpha-1-PI (alpha-1-proteinase inhibitor) is associated with slowly progressive, severe panacinar emphysema that most often manifests itself in the third to fourth decades of life. Although the terms “Alpha-1-Proteinase Inhibitor” and “alpha-1-antitrypsin” are used interchangeably in the scientific literature, the hereditary disorder associated with a reduced serum level of alpha-1-proteinase inhibitor is referred to as “alpha-1-antitrypsin deficiency.” The emphysema is typically worse in the lower lung zones. The pathogenesis of development of emphysema in alpha-1-antitrypsin deficiency is not well understood. It is well established, however, that alpha-1-antitrypsin, a serine protease inhibitor, is present between elastase (an enzyme capable of degrading elastin tissues, released by inflammatory cells, primarily neutrophils, in the lungs of individuals with emphysema), and alpha-1-antitrypsin deficiency is associated with decreased elastase (the principal enzyme responsible for degradation of elastin tissues). The eventual outcome is the development of emphysema. Neonatal hepatitis with cholesletic jaundice appears in approximately 10% of newborns with alpha-1-antitrypsin deficiency. In some adults, alpha-1-antitrypsin deficiency is complicated by cirrhosis. A large number of phenotypic variants of alpha-1-antitrypsin deficiency exist. The most severely affected individuals are those with the PiZZ variant, typically characterized by alpha-1-PI serum levels <35% normal. Epidemiologic studies of individuals with various phenotypes of alpha-1-antitrypsin deficiency have demonstrated that individuals with endogenous serum levels of alpha-1-PI <50 mg/dL (based on commercial standards) have a risk of >80% of developing emphysema over a lifetime. However, in a number of individuals, alpha-1-PI levels >50 mg/dL, in general, do not manifest an increased risk for development of emphysema above the general population background risk. From these observations, it is believed that the “threshold” level of alpha-1-proteinase inhibitor in the serum required to provide adequate anti-elastase activity with alpha-1-antitrypsin deficiency is about 80 mg/dL (based on commercial standards for immunologic assay of alpha-1-PI).

In clinical studies of Prolastin, 23 subjects with the PiZZ variant of congenital deficiency of alpha-1-antitrypsin deficiency participated in a study of acute and/or chronic replacement therapy with Prolastin. The mean in vivo recovery of alpha-1-PI was 42.2 mg (immunologic) or 44 mg (functional) kg body weight administered. The half-life of alpha-1-PI in vivo was 13 hours. Based on these findings, a protocol for chronic replacement therapy was developed. Nineteen of the subjects in these studies received Prolastin replacement therapy over a period of 12 weeks (average of 16 weeks). With this schedule of replacement therapy, blood levels of alpha-1-PI were maintained above 80 mg/dL (based on the commercial standards for alpha-1-proteinase inhibitor immunologic assay). Within a few weeks of commencement of chronic replacement therapy, all patients demonstrated increased, consistently increased levels of alpha-1-PI and functional anti-elastase activity, both of which were present in the lower respiratory tract of the lung, as compared to levels prior to commencing the program of chronic replacement therapy in 19 patients. A 51% reduction in the rate of decline of alpha-1-antitrypsin deficiency was noted in all individuals received prophylaxis against hepatitis B, no conclusion can be drawn at this time regarding potential transmission of hepatitis B virus.

**INDICATIONS AND USAGE**

Prolastin is indicated for chronic replacement therapy of individuals having congenital deficiency of alpha-1-proteinase inhibitor (alpha-1-PI deficiency) with clinically significant emphysema. Clinical and biochemical studies have demonstrated that with such therapy, it is possible to increase plasma levels of alpha-1-PI, and that levels of functionally active alpha-1-PI in the lung epithelial lining fluid are increased. As some individuals with alpha-1-antitrypsin deficiency will not go on to develop panacinar emphysema, only those with evidence of such disease should be considered for chronic replacement therapy. Studies with the PiMZ or PiMZ phenotypes of alpha-1-antitrypsin deficiency should not be considered for such treatment as they appear to be at small risk for panacinar emphysema. Clinical data are not available as to the long-term effects derived from chronic replacement therapy of individuals with alpha-1-antitrypsin deficiency with Prolastin. Only adult subjects have received Prolastin to date.

Prolastin is not indicated for use in patients other than those with PiZZ, PiZ(null) or PiN(null) null phenotypes.

**CONTRAINDICATIONS**

Individuals with selective IgA deficiencies who have known antibody against IgA (anti-IgA antibody) should not receive Prolastin, since these patients may experience severe reactions, including anaphylaxis, to IgA which may be present.
We’ve got you covered

With PROLASTIN, you get more than just a leading alpha-1 treatment. You also get the leader in alpha-1 care—PROLASTIN DIRECT.*

1.800.305.7881

One simple call provides easy access to:

• Health management from AlphaNet
• Insurance reimbursement help
• Customized drug delivery and home infusion
• Prompt answers to questions about PROLASTIN therapy

Plus, PROLASTIN DIRECT is fully staffed by alpha-1 specialists, many of whom are alphas themselves, so they understand firsthand that there’s more to successful treatment than first-rate infusions.

IMPORTANT SAFETY INFORMATION
PROLASTIN is for people who have emphysema caused by inherited alpha-1-antitrypsin deficiency. In clinical trials of PROLASTIN, side effects were not common and occurred in 1.16% of weekly infusions. Side effects were generally mild with the most common being fever, light-headedness, and dizziness. Individuals with selective IgA deficiencies should not receive PROLASTIN. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088. As with all plasma-derived products, the potential to transmit infectious diseases cannot be totally eliminated.

Please see brief summary of PROLASTIN full Prescribing Information on adjacent page.

*Formerly known as Talecris Direct®.

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www.prolastin.com