

US Disability Info for Travelers

The U.S. Department of Transportation is calling on all disability organizations to promote public education about its Toll Free Hotline for air travelers with disabilities through their organization newsletters, list-serves and sponsored events.

The Toll Free Hotline for disabled air travelers has been in operation since August 2002 and is available for callers from 7 a.m. to 11 p.m. Eastern Time, seven days a week. It is currently not being fully utilized. The Hotline serves two main purposes: (1) education and (2) assistance in resolving disability-related air travel problems.

*Call the Toll Free Hotline 7 a.m. to 11 p.m. EST
1-800-778-4838 (Voice) • 1-800-455-9880 (TTY)*

Many disabled air travelers are not aware of their rights and the Hotline, in part, exists as an educational service to inform air travelers with disabilities about their rights under the Air Carrier Access Act and the Department's implementing regulations 14 CFR Part 382 (Part 382). Hotline operators are well versed in the ACAA and Part 382 and can provide callers with on the spot general information about the rights of air travelers with disabilities. The Hotline operators also respond to requests for printed consumer information about air travel rights of the disabled.

The Hotline can also assist air travelers with disabilities in resolving real time or upcoming issues with air carriers. The purpose of "real-time" assistance is to facilitate airline

compliance with DOT's rules by suggesting to the passenger and the airline involved alternative customer-service solutions to the problem. The airline remains responsible for deciding what action will be taken to resolve the issue in accordance with the ACAA and Part 382. Generally, if a caller has a real time problem or an upcoming issue with an air carrier, a Hotline Duty Officer will contact that air carrier and attempt to resolve the issue. For example, there have been a number of incidents in which Hotline Duty Officers have contacted air carriers and convinced them to accept service animals and electric wheelchairs on board flights, to stow folding wheelchairs in the cabin, and to provide requested wheelchair assistance.

Air travelers who want information about the rights of persons with disabilities in air travel or who experience disability-related air travel service problems may call the Hotline to obtain assistance.

Air travelers who want DOT to investigate a complaint about a disability-related issue still must submit their complaint in writing via e-mail at airconsumer@ost.dot.gov or postal mail to:

Aviation Consumer Protection Division
U.S. Department of Transportation
400 7th Street, S.W., Washington, D.C. 20590 ■



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ALPHA-1 NEWS

The Official Newsletter of the Alpha-1 Association

VOL. 14 ISSUE 1

August 2003

NATIONAL SURVEY OF PATIENTS WITH ALPHA-1 ANTITRYPSIN DEFICIENCY IN THE UNITED STATES: 2003

Conducted for the Alpha-1 Association, the Alpha-1 Foundation, and AlphaNet

by Schulman, Ronca & Bucuvalas, Inc. June 2003

Overview

The Alpha-1 Association, the Alpha-1 Foundation and AlphaNet commissioned a joint National Survey of Patients with Alpha-1 Antitrypsin Deficiency in the United States in the spring of 2003. The survey was conducted by mail by Schulman, Ronca and Bucuvalas, Inc. (SRBI), an international research organization, which had previously conducted Confronting COPD in the United States and Confronting COPD in North America and Europe. The survey organization signed a confidentiality agreement with each of the three sponsoring organizations so that they could construct a single sampling frame for Alpha-1 patients from the mailing lists of the three organizations. After eliminating duplications based on address, there were a total of 5,222 unique Alpha-1 patients or probable patients from these lists.

A four page self-administered questionnaire was sent to these approximately 5,000 patients, along with a cover letter explaining the purpose of the survey, a toll-free number to call at SRBI for questions, and a business reply envelope. The questionnaires were mailed out beginning April 14, 2003. Some additional questionnaires were sent out at the request of survey participants to patients who were not in the sampling frame. Reminder postcards were mailed to non-respondents on May 7, 2003. By June 11, a total of 1,953 completed questionnaires had been returned to SRBI. After eliminating non-patients, deceased

and bad addresses, the 1,953 completed interviews at the end of the field period represented a response rate of 40% to the survey. **This response rate substantially exceeds industry standards for single mailing and single reminder mail survey.**

Characteristics of the Patient Population

The patient survey was designed to include those who had been diagnosed with Alpha-1 Antitrypsin Deficiency or as a carrier of the Alpha-1 condition. If the patient was too young or too ill to complete the questionnaire, a caregiver could participate on behalf of the patient. Caregivers were asked to answer survey questions with reference to the patient, not themselves. Approximately 93% of the survey participants were patients. Another 2% were caregivers answering on behalf of a patient. Only 5% were carriers of the Alpha-1 condition. The status of the survey respondent was not identified in less than one percent of completed interviews.

The National Survey of Alpha-1 Patients confirms that these patients are significantly older than the general U.S. population. Only 9% of Alpha-1 patients are under 40 years of age, compared to 55% of the U.S. population. Nonetheless, only 17% of Alpha-1 patients are aged 65 or older, compared to 12% of the U.S. population. The majority of the Alpha-1 patients are found in the 45-49 (16%), 50-54 (17%), and 55-59 (18%) year age ranges. Indeed, the average age of the Alpha-1 patients who responded to the survey was 53 years old. Unlike Chronic Obstructive Pulmonary Disease (COPD), which is usually characterized as a disease of the aging population, this survey finds that Alpha-1 Antitrypsin Deficiency could be more properly described as a disease of the middle-aged population.

The gender distribution of persons with Alpha-1 Antitrypsin deficiency is similar to that of the general population. Among the national sample of Alpha-1 patients, 51% were male and 49% were female. This is the reverse of the slight bias in gender distribution between males (48%) and females (52%) in the general adult population of the United States.

Diagnosis and Treatment

The distinction between Chronic Obstructive Pulmonary Disease, as a whole, and Alpha-1 Antitrypsin Deficiency, in particular, is even more striking when looking at the age at first diagnosis. Many specialists maintain that patients younger than 50, or at least 40, cannot have COPD. However, a third of Alpha-1 patients (33%) were diagnosed before age 40. Another 36% were

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NATIONAL CONFERENCE ISSUE

Read about the 12th Annual National Education Conference in this issue—who attended, the lively Town Hall meeting, an “open-mic” question and answer session and much more. Complete with photos of conference attendees and award recipients, you'll find the complete story on pages 4, 5 and 6.

Content for the Alpha-1 News is gathered from a wide variety of sources, including professionals, staff and members. All ideas are welcomed. The editor reserves the right to screen and edit all submitted materials. Every effort is made to assure the accuracy of the information in this newsletter. Material contained here is for informational purposes only.

What is Alpha-1 Antitrypsin Deficiency?

Alpha-1 Antitrypsin Deficiency, also referred to as Alpha-1, is a relatively common genetic disorder characterized by low or no levels of the protein Alpha-1 Antitrypsin (AAT) in the blood. AAT is primarily made in the liver. The function of AAT is to protect the tissues of the body, primarily the lungs. When there is a deficiency of AAT, severe lung damage can occur. Less commonly, the liver itself is damaged, and rarely Alpha-1 causes a skin condition called panniculitis. There is no cure for Alpha-1. There are treatments available to lessen symptoms, but organ transplantation is often needed when the disease advances. It is estimated that up to 100,000 adults and children in the U.S. have severe Alpha-1, and potentially 23 million people nationwide are carriers. Given this high prevalence, it is surprising that many medical professionals perceive Alpha-1 to be rare, and it is often misdiagnosed. An alarming 95% of people estimated to have Alpha-1 have not been identified.

Alpha-1 Association Board of Directors



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Who is the Alpha-1 Association?

The Alpha-1 Association is a member-based nonprofit organization founded to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education, advocacy and research. We believe in treating the whole patient and all the issues facing individuals and families affected by this disorder. The Alpha-1 Association receives funding from a variety of places. We receive about 10% of our overall funding from our membership. An additional 25% comes from individual gifts, memorials, and Association-sponsored events and products. The remainder comes from gifts or grants from foundations and corporations.

How To Contact Us

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Visit our web site at

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NATIONAL SURVEY CONTINUED FROM PAGE 12 . . .

Foundation as excellent (34%) or good (50%). About the same proportion of patients rates the job done by the Alpha-1 Association for their community as excellent (33%) or good (49%). A majority of Alpha-1 patients rate the job done by American Lung Association in meeting the needs of the Alpha-1 community as excellent (14%) or very good (39%). The survey suggests that there is some halo affect in patient ratings of patient health organizations, since the proportion of Alpha-1 patients who rate the job done by the American Liver Foundation (43%) and the National Organization for Rare Disorders (37%) as excellent or good is greater than the proportion who were at least somewhat familiar with these organizations.

The patients who responded to the survey were asked if they had any comments about the activities or performance of the organizations serving the Alpha-1 community. Less than one in five patients (18%) had any additional comments about these organizations. Among those who did

have comments, there was a mixture of positive and negative comments. On the one hand, some volunteered that the organizations were doing a great job and keep up the good work (19%).

On the other hand, some of those who had comments said that more communication with patients was needed (13%), they were not doing enough and needed to do more (12%), there were problems inside of the organizations (9%), or they were doing a poor or bad job (7%).

At the end of the survey, the patients were also asked in an open-ended fashion what they personally felt should be the priority issues of the organizations serving the Alpha-1 patients and families in the next few years. Nearly seven out of ten patients had recommendations for priorities for the next few years. Among those with suggestions, the most commonly cited priorities were: availability and access to treatment (15%), research (15%), physician awareness and education (13%), new treatments and therapies (13%),

public awareness and education (13%), affordable treatments and medications (12%), more information (10%), early detection and screening (10%), and finding a cure (10%).

This National Survey of Patients with Alpha-1 Antitrypsin Deficiency in the United States conducted in 2003, provides the first comprehensive assessment of patient opinion about the needs and priorities for this community. The high participation rate in the survey suggests that Alpha-1 patients are interested and engaged in the issues facing Alpha-1 patients and their families. The survey suggests that patients are generally supportive and appreciative of the organizations serving the Alpha-1 community. Nonetheless, some of the gaps between activity importance and organizational performance and comments about better communication with patients suggest that there is still room for improvement in the future. ■

ALPHA-1 EDUCATION DAYS CONTINUED FROM PAGE 14**Upcoming Alpha-1 Education Days**

Date	Name/Location	Contact/Organizer	States Invited
August 16, 2003	3rd Annual New England Alpha-1 Education Day Dartmouth Hitchcock Hospital Lebanon, NH	Shirley Dennis (877) 662-4774 sdennis1963@attbi.com	RI, ME, VT, CT, MA
October 4, 2003	Virginia Alpha-1 Education Day Lewis-Gale Foundation, Salem Virginia	Linda Richardson (540) 380-3022 lbdrieh@aol.com	NC, WV, VA, DC
October 18, 2003	Texas Alpha-1 Education Day University of Texas at Tyler, Dallas, TX	Lou Glenn (817) 477-5430 e.lou.glenn@worldnet.att.net	TX, OK, AR, LA, NM
October 11, 2003	The Jean Bennett Conference on Alpha-1 Cleveland Clinic Foundation, Cleveland, OH	Marlene Erven (305) 567-9888 ext 211 mserven@alphaone.org	MI, IN, VA, PA & Ontario
October 17-18, 2003	COPD and Alpha-1 Education Conference The James P. Mara Center St. Luke's Hospital Roosevelt Center, New York, NY	Lori Tartell (212) 523-2828 ext 2566 LTartell@chpnet.org	NY, PA, NJ, CT, DL, MD

Alpha-1 Education Days “A GREAT DAY IN SIOUX FALLS”

By Bob Haggerty

I was recently asked to be a presenter at the 1st Upper Midwest Alpha-1 Education Day held in Sioux Falls, South Dakota on Saturday June, 27th. This was my first time at one of the Education Day events, and I was asked to update the attendees on the status of the Alpha-1 Association. The last time I was in Sioux Falls was in 1974, and I stayed in the same Holiday Inn, which at that time had a delightful revolving restaurant on the top floor. I was looking forward to enjoying a dinner at the Top Floor Club until the van driver informed me that the equipment failed, and was removed in 1979. So much for ancient history.

I settled for a wonderful Welcome BBQ that was sponsored by Bayer, and allowed almost 70 attendees the chance to get to know the speakers and one another. Rain forced us inside, but it didn't dampen the mood, as Alphas always seem to find a way to start a conversation.

I was extremely impressed with the effort that went into putting the event together. The Alpha-1 Association, Alpha-1 Foundation and AlphaNet sponsored it with support from Corporate Sponsors. Kay Kinsel-Swift, the Midwest AlphaNet coordinator took the lead role in putting together the agenda and ensuring attendance. I would be remiss however, if I failed to mention the coordination that Denise Schoolmeester and Sandy Melstad from Care Trends Health Education & Research Institute put into the speaker development and support. Their effort behind the scenes made for a very successful day that went on without a hitch.

“Dr. Sandy” Sandhaus once again was the lead off speaker who covered the “Alpha-1 Basics”. Marshall Hertz MD, from the U of MN whose topic was “Lung Transplantation for Alpha-1”, followed him. Dr. Tim McCashland from the University of Nebraska did a very interesting presentation on the issues surrounding a “Liver Transplant”. Next we were fortunate to have Peg Canal Wittler, MS, RD, from Brattleboro Memorial Hospital in Vermont, speak to us about proper “Diet &

Nutrition”. Our last morning speaker was Rick Carter, PhD, a Professor of Medicine & Physiology at the University of Texas Health Center. He delivered an outstanding presentation covering “Strategies for Functional Restoration in Patients with Alpha-1”.

I continue to be impressed by the talent that we have offered to us by the medical profession, who willingly avail themselves and their knowledge to our community.

The afternoon featured Alpha-1 speakers, so you might say we left the audience ‘breathless’. Ed Schuck, a Board member from the Foundation gave an excellent presentation on the “Alpha-1 Foundation Partnership For A Cure”. I then followed with an “Overview of the Alpha-1 Association”. I covered what we have been through; our strategic priorities; and recent information we obtained from our members through the first National Survey of patients with Alpha-1. I discussed the Survey results and how they will help guide the Association to improve our services. The day ended with

“Dr. Sandy” chairing a very lively question and answer session.

It was a great meeting, and everyone left with some new ‘nuggets’ of information about how to cope with Alpha-1. The Education Day Calendar is included in this newsletter, do yourself a favor and find a way to go and participate.

As a follow up to the meeting I received a special phone call from Ed Schuck, who was on the agenda on behalf of the Alpha One Foundation. Ed has been on the list for a lung transplant for a while, and he was called on July 3rd to get to the University of Minn. Hospital to receive his new lung. Ed called me from the hospital four days after the transplant to share his good news. I didn't even recognize him at first, because there was no shortness of breath. And by the way, Marshall Hertz MD, who was also a speaker at the June 27th event is Ed Schuck's doctor. So you see it really all started with a “Great Day in Sioux Falls” with our Education Day for Alphas. ■

THANK YOU TO ALL OUR SPONSORS

Alpha-1 Association

12th Annual Education Conference



August 2003

Alpha-1 Association and AlphaNet Hit the Ground Running

Dear Friends:

Thank you for the incredible amount of patience and kindness you have extended to the Alpha-1 Association and its Board of Directors over the past months. The Board has been working diligently for the past nine months to address the legal and financial challenges facing our organization. This period of reassessment and reorganization has allowed us to begin development of operational plans that will, among other things, conserve our limited resources and enhanced services to the Alpha-1 community. In the interest of keeping you fully informed, I am writing to provide an update on the current status and future outlook for the Alpha-1 Association.

Our lawsuit has been settled on the same terms we discussed at the Town Hall Meeting in Oak Brook, IL. If you would like copies of this agreement, I will be happy to forward them to you.

With regard to our structure, the following has been established:

The Executive Committee is made up of:

John Morton, Chairman • **Bettina Irvine, Immediate Past Chair** • **Judy Reid, Vice Chairman** •
Lou Glenn, Secretary • **Dr. Bob Fallat, Advisor** • **Bob Haggerty, Treasurer**

The Audit Committee is made up of:

John Morton • **Dr. Fallat** • **Bob Haggerty**

The Nomination/Election Committee is made up of:

Bettina Irvine • **Lou Glenn**

The By-Laws Committee is still gathering its members.

AlphaNet

As many of you know, the Association recently executed an administrative services agreement with AlphaNet whereby they will be providing operational and financial support for our organization. We are excited about our new relationship and believe this collaboration will bring the best of both worlds together to serve you.

Operations Update

Some of you have expressed concern that we have not been carrying on with our usual communications and operations, such as producing a newsletter or mailing membership renewal notices. Please know that we are getting these activities back on track quickly, as evidenced by this issue of Alpha-1 News. If you are due for membership renewal, we'll be getting those notices out to you soon, too. Your patience and understanding is appreciated.

Accounting Audit

I am pleased to tell you that the audit process resulted in the publication of complete, audited financial statements through June 30, 2002. We published those results in the a 'Building Our Community' Annual National Education Conference Booklet, distributed at the three day conference, in Oak Brook, Illinois, May 30, 31 and June 1, 2003. As it is audit time once again we look forward to sharing the results of the June 30, 2003 audit with you. We are currently in a better position to address your legal and financial questions regarding the previous Association administration.

What do YOU need?

Thank you to all who completed the National Needs Assessment Survey. We are happy to share the results in this newsletter. You will find an Executive Summary of the survey on pages 1, 11 and 15 in this issue of Alpha-1 News.

National Education Conference

The Alpha-1 Association and AlphaNet worked together to plan and execute the very successful 2003 National Education Conference in Oak Brook, Illinois on May 30, 31 and June 1, 2003. I hope you were able to attend. Photographs and a recap can be found on pages 10 and 11 in this issue. You can find more details at our website www.alpha1.org

In Closing ...

We are here to provide services and support to the Alpha-1 Community through programs, education and advocacy. All our efforts over the past several months have been aimed at ensuring that our mission will be served. I know I speak for the community at large when I express our Association's deep appreciation for AlphaNet's commitment to the Association and the Alpha-1 community.

I wish you the best of health and look forward to seeing you at an upcoming Education Day Series event.

Sincerely,
John P. Morton
Chairman, Board of Directors
Alpha-1 Association

NATIONAL CONFERENCE

“Building Our Community” May 30, 31 and June 1, 2003

A resounding success

Attended by nearly 300 people, the 12th Annual Alpha-1 Association National Education Conference was an extremely successful event, resulting in enhanced community leadership, empowered participants seeking to advocate for their insurance and public policy rights, and a stronger community base.

Participants were made up of Alphas, family members, industry leaders, health care providers and included international guests, one third of whom were first time participants. Bayer, Baxter, Aventis Behring, AlphaNet, Express Scripts, and Coram graciously provided sponsorship for this year’s conference.

Planned and coordinated by an enthusiastic and diligent group of volunteers and staff, the committee selected the theme of “Building Our Community” and the agenda, speakers and panelists focused on the Association’s Support Group Network. To promote camaraderie whenever possible, presentations and participation by Alphas and their family members were incorporated. The planning committee was comprised primarily of individuals personally affected by Alpha-1, ensuring that the meeting format and logistics were comfortable for Alphas.

A lively Town Hall Meeting kicked off the Conference, where the preliminary data from the 2003 National Patient Survey was presented. Additionally, a frank discussion took place regarding the Association’s financial position and legal matters and all documents presented at the Town Hall meeting were made public to members.

In addition to reinvigorating the Support Group Network through special education sessions, the conference featured many Alpha-1 experts and health care professionals. Conference attendees participated in sessions for Alphas, family members and caregivers, on subjects from the basics of Alpha-1 lung and liver disease to the importance of participating in clinical trials. Saturday’s session ended with a



Our conference sponsors.



(l) John Morton, Chairman of Alpha-1 Association, with Greg Hules, Conference Moderator and Chairman of the Alpha-1 Foundation.



Conference speakers (l to r) Theo Wagner and Fred Walsh.



Bob Campbell, AlphaNet coordinator with Susan Kelbaugh.



Bob Haggerty with John Morton.



Dr. Sandy Sanhaus (center) and family with Sally Everett, (left) John Walsh, and Joe Zuraw, Bayer (far right).



Conference participants.



The AlphaNet staff.

Continued on page 6

Support Group Leader Training in Chicago

By Cathy Horsak

The 12th Annual Educational Conference in Chicago focused on Building Our Community. Our tireless and dedicated volunteers build this community each and every day. One especially hard working group of volunteers is our support group leaders. I am proud to say that we had 30 support groups represented at our meeting in Chicago. These community builders deliver 110% to their fellow Alphas.

Prior to the start of the Education Conference this group toured the Aventis Behring Kankakee manufacturing facility. Everyone was truly amazed and impressed with the Alpha-1 facility. Aventis Behring tended our every need—from water to oxygen and wheel chairs to ensure that all were able to participate. What wonderful hosts they were and the message they delivered was good news for the Alpha-1 Community. Zemaira™ will be on the market soon, as the product licensure was granted shortly after our Conference.

The Annual Education Day Conference featured special interactive sessions designed specifically for the support group leaders. And who better to share their Alpha experiences than a group of our very own successful leaders. Support group leaders Gayle Allison (West Virginia) and Linda Richardson (Virginia) presented Building Leadership Skills, and discussed the very important issue of confidentiality and trust among our support group members. Marlene Buchanan (Pennsylvania) then enthusiastically shared her group's total sense of empowerment as they relentlessly pursued advocacy issues on a state and national level. The Pennsylvania support group was instrumental in ensuring that the entire Alpha community benefited from a November 1, 2002 ruling removing the threat of deeply reduced Medicare reimbursement rates for the hospital outpatient setting. Joe Reidy (New Jersey) and Barbee Bennington (Arizona) followed with Communication for Support Groups, providing examples of newsletters distributed regionally to their support group members. Our final session of the day, presented by Fred Walsh (Massachusetts), focused on Building a Local Reference Network. Fred challenged each support group leader to use the Massachusetts reference list as a guide to create their own comprehensive local guide, specific to their support group's needs.

Each attendee left with a two-inch binder entitled "Support Group Leader's Handbook—A Work In Progress." Binders have also been sent to those support group leaders who did not attend the conference. As Director of Field Services, I will provide you with updates to this book periodically. It will become our Volume of Best Practices. I have asked all support group leaders to share their successes with me. I will share these successes with all support group leaders for the benefit of Alphas in their local communities.

Note: Please do not hesitate to contact me at any time. Together we will achieve our mission of improving the day-to-day lives of individuals with Alpha-1 and achieve our mission of Support, Education, Advocacy and Research.

Cathy Horsak can be reached at 877-346-3212 or horsak@alpha1.org. As Director of Field Services, Ms. Horsak assists regional Support Groups with meeting locations, speakers, agendas and maintains a current list of volunteers around the country assisting the Association in achieving its mission. ■

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Bobbie Stafford	559.673-3948	alpha1bobbie@aol.com	3rdSat, monthly
Gene Johnson	818.362-5018	lnewlung@hitech.networks.net	quarterly
Karalee Karp	DO NOT LIST	kjkarp@aol.com	quarterly
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Willa Long	865.995-2986	pjlong@icx.net	1st Sat, monthly
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NATIONAL SURVEY CONTINUED FROM PAGE 11 . . .

Survey respondents put a lot of importance on promoting a number of types of activities for Alpha-1 patients. Promoting access to treatment (88%) and development of new therapies (87%) are rated as “very important” by nearly nine out of ten Alpha-1 patients surveyed.

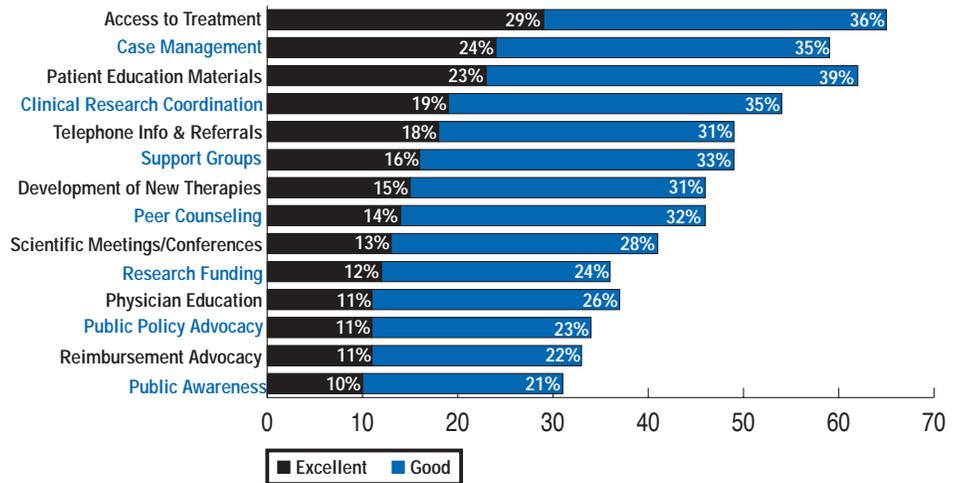
Two thirds rate public awareness (69%), patient education materials (67%), and reimbursement advocacy (66%) as very important. More than half consider public policy advocacy (57%) and transplant information and advocacy (56%) as very important for Alpha-1 patients. Somewhat fewer consider support groups (47%), telephone information and referrals (46%) and peer counseling (38%) as “very important” activities to be promoted for Alpha-1 patients.

Unfortunately, the majority of patients rate the job that organizations for Alpha-1 patients are doing as “excellent” or “good” in less than half of these areas. Nearly two thirds (65%) of patients rate the job Alpha-1 organizations are doing in access to treatment as excellent or good. About six out of ten patients rate organizations as excellent or good in patient education materials (62%). About half say these organizations are doing an excellent or good job in support groups (49%), and telephone information and referrals (49%). Slightly less than half rate these organizations as excellent or good in peer counseling (46%). By contrast, a third or fewer patients rate organizations for Alpha-1 patients as

doing a good job or better in public policy advocacy (34%), reimbursement advocacy (33%) and public awareness (31%). (Figure 11)

report that reimbursement advocacy is very important while only one-third (33%) feel the organizations are doing at least a good job. Public policy advocacy

Figure 11 **How Well Organizations are Currently Doing**



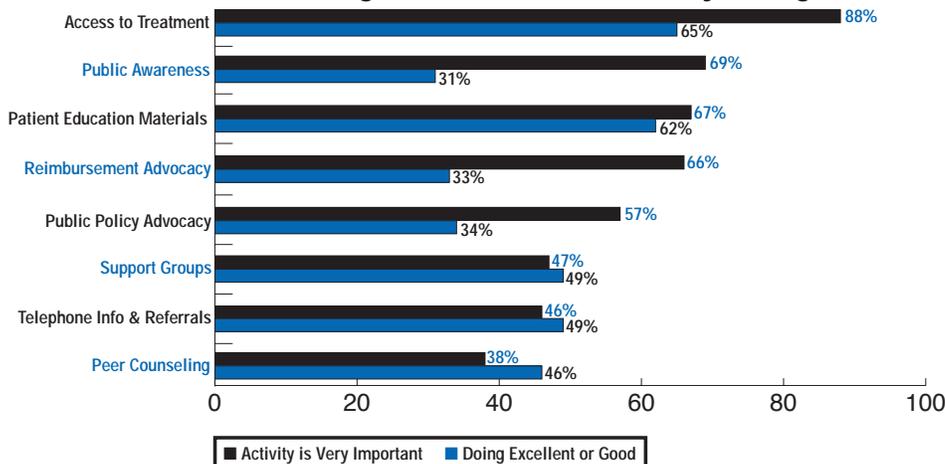
There is a reasonably good correspondence between the importance of an activity to Alpha-1 patients and the performance rating of the organizations in this area for most of the activities evaluated in the survey. However, there are three activities in which the importance rating is much higher than the performance rating. More than two-thirds (69%) of Alpha-1 patients report that public awareness promotion is very important, but only 31% report that the organizations are doing a good or excellent job at public awareness promotion. Similarly, 66% of respondents

is another area that a majority of patients (57%) report as being very important but only a third (34%) report the organizations doing a good or excellent job (Figure 12).

Most patients who responded to the survey were at least somewhat familiar with the three Alpha-1 organizations. Four out of five patients say that they are very familiar (32%) or somewhat familiar (48%) with the Alpha-1 Association. Three out of four patients are very familiar (37%) or somewhat familiar (38%) with AlphaNet. Nearly three quarters are very familiar (27%) or somewhat familiar (47%) with the Alpha-1 Foundation. About half of Alpha-1 patients say that they are very familiar (14%) or somewhat familiar (37%) with the American Lung Association. By contrast, only a small proportion of Alpha-1 patients are very or somewhat familiar with the American Liver Foundation (17%) or the National Organization for Rare Disorders (12%).

The patients give high marks to the three Alpha-1 organizations on the job they have done in meeting the needs of the Alpha-1 community. Almost nine out of ten patients rate the job done by AlphaNet as excellent (47%) or good (40%). Six out of seven rate the job done by the Alpha-1

Figure 12 **Importance of Activity Promotion and How Organizations are Currently Doing**



NATIONAL CONFERENCE CONTINUED . . .

one-hour panel discussion between participants and the physicians who had presented on the agenda. This “open-mic” was very successful and proved to be popular with participants because it allowed people to ask the questions they wanted answered. Saturday evening featured an awards and recognition dinner (see page 6) moderated by Bob Haggerty and sponsored by Bayer.

The Sunday agenda began with a memorial service planned by Joe Reidy and Fred Walsh to remember and grieve the loss of those who have died from Alpha-1. Advocacy training, featuring the stories of three Alphas who have successfully advocated for reimbursement, transplantation rights and federal research funding was part of Sunday’s agenda. The final session informed participants about disability insurance.

Conference participants had plenty of time to engage in fellowship, which is often the most important benefit of attending a national conference. We are grateful to all those who participated on the agenda and especially thank Greg Hules for moderating the education sessions.

We achieved our goal of enhancing our community leadership in their assistance to fellow Alphas. We achieved our goal of empowering individuals to advocate on their behalf for insurance reimbursement and public policy issues. We achieved our goal of Building our Community. We hope to see you at the 13th Annual National Education Conference.

Continued on page 6

“Thank You”

to Alphanet for their sponsorship of Travel Grants to 39 conference participants.

National Conference Agenda:

The agenda included presentations by 16 Alphas; 3 Caregivers; 8 MD’s; 3 professionals; 1 RN and 1 staff member.

Planning Committee Members Included:

Gayle Allison, Sandy Brandley, Lou Glenn, Greg Hules, Cathey Horsak, John Morton, Miriam O’Day, Ed Schuck, Liz Veronda, and Fred Walsh.

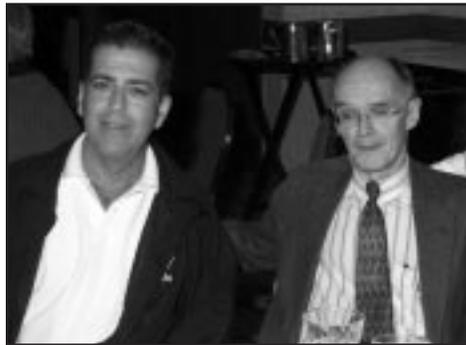
In addition, **Liz Veronda** joined the group to represent the local Chicago region as coordinator of hosts, greeters and volunteers. We are especially indebted to **Sandy Brandley** for her participation in the planning the Conference. Sandy joined us on our weekly teleconference and gave us the expertise and institutional memory, which helped us overcome tremendous hurdles.



Alpha-1’s evening entertainment.



Terry Young, Dave Courtney and Dave’s brother, Dan.



(l) Darrell Nall, Bob Campbell.



Miriam A. O’Day. and Dr. Campos



Alpha-1 Association Board of Directors.



The Moore sisters.



Carla Moore receives recognition for raising \$1000 for the Alpha-1 Association. Carla and her family sold raffle tickets for a beautiful piece of glass art to raise the money for the Peter Smith Scholarship Fund.

NATIONAL CONFERENCE CONTINUED . . .



Award recipient, Marlene Buchanan.



Award recipient, Judi Reid.



Award recipient, Miriam O'Day.



Award recipient, John Morton.



Community Appreciation Award being accepted by Joe Zuraw, presented by (L to R) Bob Barrett, AlphaNet, John Walsh, Alpha-1 Foundation and Bob Haggerty, Alpha-1 Association.



Fred Walsh, Jack Walsh and John Walsh presenting the Helen Chase Walsh Memorial Award to Sally Everett.



(l) Martha Waldron, from The American Lung Association with John and Fred Walsh and Ed Brailey.

**ALPHA-1 ASSOCIATION CONFERENCE
2003 AWARDS and RECOGNITION**

Peter Smith Achievement Award

Bobbie Stafford

*In appreciation and recognition
For many years of dedicated volunteer service
To the Alpha-1 Community
Accepted on behalf of Bobbie Stafford
by Greg Hules*

.....

Inspirational Award

Marlene Buchanan

*Thank you for your leadership and excellence
in advocacy*

.....

Special Appreciation Award

Miriam A. O'Day

*With Sincere Gratitude for
Your Dedicated Leadership and Service
In Public Policy and Advocacy for Our Causes.
The Alpha-1 Community is Stronger Because of You.*

.....

Sandra K. Brandley Leadership Award

Jack and Judi Reid

*In gratitude for improving access to care
Through Advocacy and Public Policy*

.....

Alpha-1 Community Appreciation Award

Bayer Corporation

*In deep appreciation for your sustained commitment and
support of Alpha-1 Community Programs and Services*

Presented by:

Bob Haggerty, Treasurer, Alpha-1 Association
Board of Directors

Robert C. Barrett, CEO, AlphaNet

John W. Walsh, President and CEO,
Alpha-1 Foundation

.....

**Alpha-1 Board of Directors
Dedication Award**

John P. Morton

*For taking the bull by the horns
Weathering the storm
Sticking your head above the sand
And offering tireless commitment to the
Alpha-1 Community*

.....

Helen Chase Walsh Memorial Award—

presented by the Walsh Family to Sally Everett

.....

Special Fundraising Award

Presented to Ed Brailey

.....

**Alpha-1 Association Board of
Directors Special Recognition**

given to Robert C. Barrett ■

NATIONAL SURVEY CONTINUED FROM PAGE 1 . . .

diagnosed between age 40 and 49. Less than one third (31%) were first diagnosed with Alpha-1 at age 50 or older. The average age at first diagnosis as Alpha-1 Antitrypsin deficient was 43.6 years of age.

The survey finds that the majority of patients with Alpha-1 Antitrypsin are diagnosed within a fairly short period after first seeking treatment for symptoms. Nearly a third (32%) said that they were seeing a physician for symptoms less than a year before they were accurately diagnosed. Another 20% were seeing a physician for symptoms for 1 to 2 years before being diagnosed with Alpha-1. At the other extreme, 16% of Alpha-1 patients had been seeing a physician for more than ten years before being accurately diagnosed. The average time to diagnosis after seeing a physician for symptoms was 5.6 years for all Alpha-1 patients.

The National Survey of Patients with Alpha-1 Antitrypsin suggests that the time to diagnosis has been improving for these patients. The average number of years between seeking treatment for symptoms and diagnosis was 7.0 years for those born before 1950. The average time to diagnosis declined to 4.5 years for those born in the 1950s and to 4.0 years for those born in the 1960s. The average time to diagnosis from seeking treatment for symptoms among Alpha-1 patients further declined to 3.0 years for those born in the 1970s. Finally, among the relatively small proportion of patients born in 1980 or later, the average time to diagnosis had declined to 1.2 years.

Although lung or liver transplantation represents a prominent form of treatment for Alpha-1 Antitrypsin Deficiency, the survey finds that only about one in ten Alpha-1 patients have had such a transplant. This includes 3% who have had a single lung transplant, 4% who have had a double lung

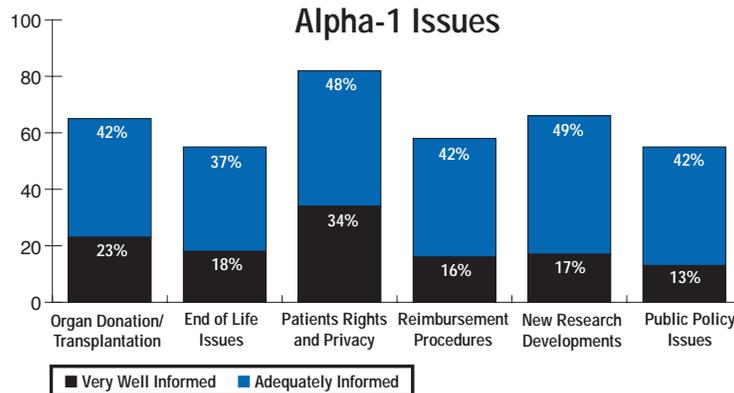
transplant, and 2% who have had a liver transplant. Another 7% of Alpha-1 patients report that they are currently on a transplant list. By contrast, 84% of Alpha-1 patients have never had a transplant nor are they on a transplant list.

Nearly half (43%) of Alpha-1 patients have used oxygen therapy outside a hospital on a regular basis in the past 12 months. The prevalence of oxygen therapy among Alpha-1 patients is another distinction from COPD patients in the United States, as a whole. In *Confronting COPD in America*, only 22% of COPD patients in the U.S. reported using home oxygen therapy in the past year.

Most persons with Alpha-1 Antitrypsin Deficiency have some form of health insurance coverage. The majority (54%) has insurance through an employer or work group policy. Another 10% have their health insurance from a non-employer group policy, while 9% have an individual policy. More than a third of Alpha-1 patients (36%) have Medicare coverage, compared to 14% with Medicare coverage in the general population (14%). Nearly one in ten Alpha-1 patients (9%) has Medicaid coverage, 2% are covered by a state or county health program, and 4% have their health care coverage through COBRA. Only 2% of Alpha-1 patients report no insurance coverage.

Figure 7

How Well Informed Patient Feels about Alpha-1 Issues



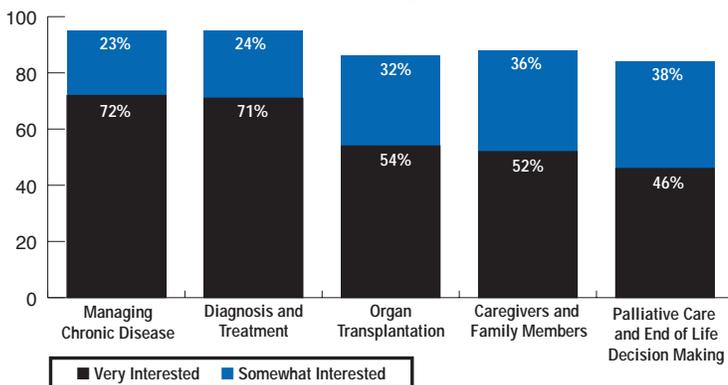
Needs, Programs and Services

The majority of Alpha-1 patients feel at least adequately informed about six key issues related to their condition and treatment. Patients seem to feel best informed about patient rights and privacy with 34% saying they are very well informed, and another 48% saying that they are adequately informed. Two thirds of Alpha-1 patients feel that they are either very well informed (17%) or at least adequately informed (49%) about new research developments. About two thirds of Alpha-1 patients feel that they are either very well informed (23%) or at least adequately informed (42%) about organ donation/transplantation. Better than half of Alpha-1 patients feel that they are at least adequately informed about reimbursement procedures (58%), public policy issues (55%) and end of life issues (55%). (See Figure 7)

There is a high level of interest among Alpha-1 patients and caregivers in new programs and services for patients and families in this population. The vast majority of patients say they are “very interested” in new programs and services aimed at managing chronic disease (72%) and diagnosis and treatment (71%). The majority are “very interested” in new programs and services related to organ transplantation (54%) and caregivers and family members (52%). Nearly half (46%) are “very interested” in new programs and services in the areas of palliative care and end of life decision-making. Six out of seven patients or more are at least somewhat interested in new programs and services in each of these areas. (See Figure 9)

Figure 9

Interest in New Programs and Services



Public Policy Update

By: Miriam A. O'Day

As Senior Director of Public Policy for the Alpha-1 Association my responsibility is to monitor and influence Federal Legislation and regulations that impact individuals and families living with Alpha-1; and to ensure that the mission of the organization is implemented by identifying legislative opportunities to include Alpha-1 specific references or provisions. There are many issues of concern to the Alpha-1 Community that were left hanging in the balance as Congress recessed in August, such as the Medicare Reform bill and prescription drug benefit. Therefore, I am providing a summary of those issues that are Alpha-1 specific and where your participation is essential.

Chronic Obstructive Pulmonary Disease (COPD) Resolution passes the U.S. House of Representatives and moves on to the Senate

On July 16, 2003, Congressman Cliff Stearns (R-FL) Sponsor of H. Con. Res. 6—the National COPD Awareness Resolution—brought this legislation to the House floor for a successful vote. The Resolution designates November 2003 as National COPD Awareness Month in order to raise public awareness about the prevalence of chronic obstructive pulmonary disease and the serious problems associated with it. While making his floor speech, Congressman Stearns referenced Alpha-1 and the need for early screening and detection to improve health outcomes. Proudly promoting the Alpha-1 Screening Lab

which resides in his district, Congressman Stearns stated “It is their hope that this program will serve to not only detect potential Alpha -1 deficient individuals but also to impress upon health care professionals the importance of simply screening for this Alpha-1 deficiency.” Senator Michael Crapo (R-ID) has introduced S. Con. Res. 59 an identical bill in the Senate. Please write to your Senators expressing your support.

Supplemental Oxygen for Airline Travel

We are pleased to report to you that we were able to convince Congress that air travelers who require supplemental oxygen during flight face significant barriers to accessing air travel and that this is therefore discriminatory. On July 24, 2003, The House of Representatives included legislative language requesting that the Federal Aviation Administration (FAA), the Transportation Security Administration (TSA) and the Research and Special Projects Administration (RSPA) enter into discussions with the National Council on Disabilities (NCD) to review, and where appropriate, revise policy to improve access to air travel for patrons requiring supplemental oxygen. These agencies were encouraged to work swiftly to review, and where appropriate, approve new technologies and procedures that will improve the ability of patients needing supplemental oxygen to use during air travel. With 44% of the Alpha-1



Alpha-1 delegation recognizes Congressman Cliff Stearns (R-FL) for his leadership in raising awareness about COPD and Alpha-1.

population requiring supplemental oxygen this initiative is critical to our community.

Medicare Reimbursement—Proposed Rule

In Federal rulemaking a three-step process is followed: 1. Proposed Rule is published in the Federal Register with an open public comment period 2. Final Rule is published with a slight time lapse until 3. The Regulation is implemented. On August 6, 2003, the Centers for Medicare and Medicaid Services (CMS) released a proposed rule regarding the hospital outpatient prospective payment system (HOPPS) reimbursement for 2004.

The proposed rule reverses the special carve-out for Alpha-1 augmentation therapy and places it back into the larger pool, subjecting us to cuts and reimbursement based on data that is averaged. This proposal is not acceptable for Alpha-1 and will impact access to care. It is a shame we have to fight this battle again – please stay alert for the call to arms. We will issue a Legislative Alert with a specific action plan once a full technical review has been completed.

ACTION ALERT

Congressman Christopher Cox (R-CA) introduces legislation to ensure coverage for orphan drugs

The National Organization for Rare Disorders (NORD) Task Force on HOPPS was formed to seek legislative relief from the proposed CMS reductions in outpatient benefits. Last month, NORD was instrumental in the introduction of legislation by Congressman Cox; “The Medicare Patient Access to Drugs for Rare Diseases Act of 2003” (H.R. 2700).

What does H.R. 2700 do?

H.R. 2700 will address the need for adequate reimbursement for Alpha-1 and all orphan drugs within CMS and compensate for the lack of data regarding the cost of these therapies by

modeling reimbursement on other sites of services. H.R. 2700 will solve the administrative merry-go-round of CMS rule making by amending the social security act. H.R. 2700 will counter the current CMS proposal that Alpha-1 return to the HOPPS pool and be subject to reimbursement based on 2002 hospital claims data.

What can I do?

Write, call or fax your member of Congress, educate them about the need for H.R. 2700 and urge them to become a co-sponsor. **Please copy me on the action you take: Miriam A. O'Day—moday@alpha1.org or via mail at the Alpha-1 Association.**

His Day To Win

By: Ann M. Dassing

*If you can imagine it, you can achieve it.
If you can dream it, you can become it.*

—William Arthur Ward

Since 1994, Len Geiger has dreamed of conquering his Alpha-1 diagnosis. In his dream, he is running in The Peachtree 10K, the most sought-after road race in the world, alongside 60,000 runners, in front of 150,000 spectators. It is this dream that served as a motivator for Len. To achieve it, he faced ten years of deteriorating health, hip replacement surgery, and recovered from a life-threatening bicycle accident.

This is a story of a man who, through sheer grit and determination improved his health and is living his dream.

For the first five years after receiving his lung diagnosis, Len fought his declining lung power with augmentation therapy, supplemental oxygen and larger and larger doses of the anti-inflammatory drug, prednisone. While this regimen helped him to continue to breathe, it also led to the development of prednisone-induced avascular necrosis (AVN), and resulted in double hip surgery. Despite these operations and the pain involved, he continued to work out at the gym, walking on the treadmill, in order to stay in shape for a possible lung transplant.

By May of 2002, Len's lung function had dropped to about 18% of normal and he could not walk and talk at the same time. He did not have much longer to live. He finally got the call that a donor had been found. Through the decision one family made, resolving that something positive might come from the tragedy of the loss of their loved one, Len received a double lung transplant at the University of Virginia, on May 27th, Memorial Day, 2002.

After his lung transplant, he needed to increase his aerobic activity to get his new lungs into the best shape possible.



Alpha Len Geiger completes the Peachtree 10K Road Race!

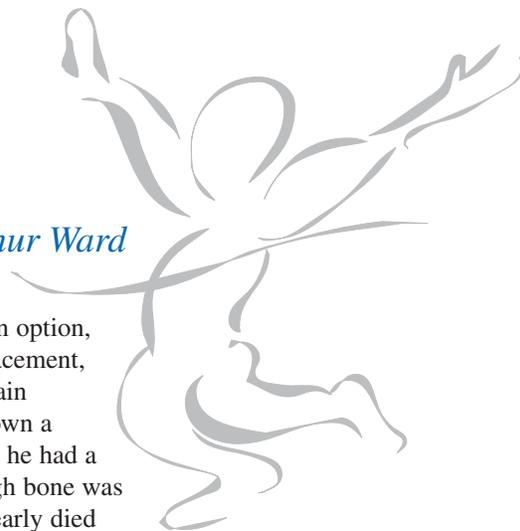
Running was not an option, due to his hip replacement, so he chose mountain biking. Heading down a trail one afternoon, he had a wreck. His left thigh bone was shattered and he nearly died from the trauma of the accident and the 5 hours of orthopedic surgery needed to repair his leg. He developed Adult Respiratory Distress Syndrome (ARDS)—total respiratory failure. He was put on life support, and, in an induced coma, was airlifted back to UVA where he awoke almost three weeks later.

When he finally got home to Georgia, mid-September, it was in a wheelchair with two steel plates and assorted hardware in his leg. He could breathe, but now, could not walk.

It was during those most troubled times that he decided whatever it took, he would make a full recovery. Not just by surviving, but by thriving. He knew he needed to set a goal—an impossible dream. Dare he consider competing in the Peachtree 10K? Yes, that was it. He'd do Peachtree again, even if he only had 10 months to get ready. Ten months sounds like a long time to train, but for Len, who could not bend his left leg at the knee or put any weight on that leg for the next three months, ten months would go by very quickly.

His training plan included working his way from a wheelchair to a walker, to crutches to a cane and finally, walking without assistance. By then it was January 2003. Keeping his dream in the forefront, he began the cardiovascular and weight training programs, gaining much needed muscle mass. In mid June, with his training nearly complete, he successfully competed in two local 5K races. Unbelievably, his lung capacity tested well over 140%, partly due to his dedication to the exercise regimen.

On July 4, 2003, Len became the first known lung transplant recipient to enter the Peachtree Road Race. He says he didn't come in first, but DID finish the race and this pleased him. He considers himself fortunate to have been driven by the wonderful gift of life and feels blessed to be living such a unique existence. That said, it certainly was - his day to win! ■



Your Choice First!

Presumed Consent Policy for Organ Donation

By: Dave Courtney



Gene therapy and other cures for Alpha-1 Antitrypsin Deficiency are being researched, but organ transplant remains the only lifesaving treatment for end stage liver and lung disease. With transplants from animals, cloned organs, and true artificial organs also many years away, we currently have an organ donation crisis in the US! The waiting list for organ transplant is

over 82,400* and more than 17 people** are dying every day waiting for a transplant.

Many people when faced with a decision at the time of a tragic event do not consent to donation of their loved one's organs or tissue simply because they don't know their loved one's choice. Our current "opt-in" system requires people to state they want to be a donor by signing a donor card, marking their Driver License as a donor, or registering with an Organ Donor Registry. Federal "Required Referral" law requires hospitals to routinely refer to the Organ Procurement Organization (OPO) any patients that face impending death. There are many states with "First Person Consent" or "Donor Designation" laws requiring acceptance of completed donor cards or donor designation on a driver license as all the proof of consent needed for donation. Our state and federal government have spent billions of dollars on educating our public about the need for donation. Our current system has failed!

Implementing an "opt-out" system of Presumed Consent is the fastest and least expensive way to lessen the shortage of organs for transplantation with no harm to anyone. This policy is currently being explored for adoption in many countries including the United States, United Kingdom, and Australia. Presumed Consent is already in place in Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, France, Greece, Hungary, Italy, Latvia, Luxembourg, Norway, Poland, Portugal, Singapore, Slovak Republic, Slovenia, Spain, Sweden, and Switzerland***. The way Presumed Consent works is that everyone is considered to be an organ donor unless they "opt out" of the system. Our current system with the United Network for Organ Sharing (UNOS), our regionally located OPO's, and the existing transplant centers can be utilized continuing their current roles.

We would still need the OPO's to provide procurement coordination and donor family services and UNOS could be utilized to maintain a confidential Opt-out Registry to verify a potential donor's wishes while continuing their current mission. Making a choice remains the most important part of this policy as no one should be ridiculed for his or her choice and every one is entitled to have his or her choice honored.

Presumed Consent Policy in the US should be implemented with these four areas of integral capabilities:

1) *Notification, Education, and Awareness- Every adult will need to be formally notified of the law and given an opportunity to state their choice. We have to have a mechanism ongoing to notify and educate our people, as they become adults. We have to be able to verify that people have been made aware of the law. We certainly don't want anyone to be forced to be a donor just as much as we want everyone to be a donor.*

We have to educate the general public, our lawyers, our doctors and all medical staff. Why can't we have a required course in every high school, every college, and every medical school? It should be part of every nurse, doctor, lawyer, public servant/clerk/official's training or certification program. That's why we have the myths and the misinformation now- lack of education.

We need ongoing awareness programs- secondary schools, churches, and all public facilities and activities.

2) *A Central Registry- The most reasonable is a national "opt-out" registry. In Europe only 2% opt out of the program, so it would be easier and less expensive to track those that opt-out than those that opt-in. This registry would have to be able to maintain 100% accuracy, 100% confidentiality, and 24/7 accessibility. UNOS already maintains the transplant candidate list and they could be adapted for this purpose also. Or, at state level, existing Organ Donor Registries could be used, or we can create registries in states that don't have them.*

3) *Program management- As an extension of the OPO's, we need a Dr. or at least a nurse in every hospital over 150 beds to coordinate and manage the program. This person would be responsible for monitoring the patient population so they can identify in a timely manner a potential donor, provide donor family services, coordinate procurement actions, and administer the education program in their hospital as well as their local community. We have to have a system that provides legal protections for all involved. I believe that's a major failure of the program we have now- Doctors, hospitals, and OPO's are afraid of being sued if someone takes offense.*

4) *Oversight- We would have to guard against abuses. We don't want a system that promotes "death mongers" and we don't want a system that allows any one person or part to be ignored or fail. ■*

*As reported by the United Network for Organ Sharing (UNOS), www.unos.org

**6,439 in 2001, as reported by the Organ Procurement and Transplantation Network (OPTN) www.optn.org

***from *Presumed Consent and Other Predictors of Cadaveric Organ Donation in Europe*; 04/16/03, North American Transplant Coordinators Association
Dave Courtney was diagnosed with COPD in 1997, identified as having Alpha-1 in 1998, and is currently pursuing lung transplant at the University of Texas Health Science Center at San Antonio, Texas. He is the Vice President and Director of Public Relations for The Presumed Consent Foundation, Inc. (www.presumedconsent.org). Both Dave and his wife Jo are A-1 Association Peer Guides and they coordinate the West Texas Alpha-1 Self Support Group.

Peter Smith Scholarship

A tribute to his memory

The seeds of a national organization for those with Alpha-1 were sown at the National Institutes of Health in the 1980's. A small group of Alphas began receiving augmentation therapy in the first clinical trial. Inspired by meeting others with the same disorder, they created an informal network of communication to share issues of common concern. Peter Smith from Neenah, Wisconsin learned of these efforts and offered to create a newsletter to link Alphas across the United States. Pete was a major influence in formalizing the Alpha-1 network into an advocacy and educational organization and served on the first board of directors. He was a tireless spokesperson for the organization until his death in December 1992 due to complications following lung transplantation. His creativity, energy and wisdom were respected and admired by those privileged to know him. To honor his memory the Alpha-1 Association board of directors instituted the Peter Smith Achievement Award for remarkable lifetime contributions to the Alpha-1 community. Additionally a scholarship fund was named in his honor to provide support for post high school education for the children or spouses of those with Alpha-1.



Engine of Discovery

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Alpha-1-to-One a quarterly magazine
of the Alpha-1 Foundation

The Alpha-1 DNA & Tissue Bank needs you to fuel future breakthroughs.

Mark Brantly, M.D. sets ambitious goals. As program director of the Alpha-1 Foundation's Alpha-1 DNA & Tissue Bank at the University of Florida College of Medicine, he expects to quadruple the number of DNA deposits by the end of the year. With about 250 samples now, the bank is already the world's largest research repository for Alpha-1 DNA available to the international research community. But Brantly wants it to grow to over 1,000 by 2004.

"One of the biggest barriers to the development of new therapies is that no one physician has access to enough tissue or DNA to make reasonable judgements about the pathology of the disease," he says. The bank aims to overcome that barrier by serving as a source for research samples. That's why Brantly refers to it as "an engine for discovery."

You provide the energy to drive this engine, though. Anyone affected by Alpha-1 can donate two small vials of blood as DNA samples and answer a questionnaire, which takes 45 minutes or less. That's all.

By donating your DNA, you do more than contribute the raw material for research. "When an Alpha donates to a centralized source, run by a foundation, the Alpha-1 community gets a voice larger than one person," explains Brantly. "The Alpha-1 community gets a seat at the table to decide how the material is taken care of and how it will be used. It becomes a stakeholder to guide research."

How does the Alpha-1 community make its voice heard? The Alpha-1 DNA & Tissue Bank collects and maintains the samples for the Alpha-1 community. As a not-for-profit foundation, it provides free samples to researchers who apply; the bank's advisory committee—comprising ethicists, Alphas, scientists, physicians, and others—must approve each research application. Currently, the bank makes samples available only to academics engaged in primary research.

In addition to scientific merit, the advisory committee carefully considers the patient confidentiality protocols in each research application. As for the bank itself, "the data are kept in the most secure environment possible," says Brantly. The clinical data and identification data are housed separately, and only the program director holds the key to match one with the other. The data are stored in secure servers, protected by firewalls.

In donating to the bank, you'll also sign an informed consent document, which broadly outlines how the samples will be used, as well as the practical and theoretical risks involved. Any questions will be answered fully before you donate.

To get more information or to request a donation kit, call the DNA & Tissue Bank's toll-free number (800.559.5706) or e-mail alpha1lab@alphaone.ufl.edu.

The DNA & Tissue Bank also accepts donated lung and liver tissue from Alphas undergoing transplants. Currently, only candidates for transplants at the University of Florida's center can donate their organs. Brantly hopes to add one more transplant center as a source for donations before the end of the year.

"Numbers are so important in answering the critical questions behind Alpha-1," says Brantly. The more donations to the bank, the better the genetic composite available to researchers. Yours can bring the bank one step closer to its 1,000-sample goal. ■