

ALPHA-1 NEWS

The Official Newsletter of the Alpha-1 Association

Volume 13 Issue 3 July 2002

Annual Meeting

Washington, DC- The Alpha-1 Association's 11th Annual Education Conference, held June 6 – 9 in Washington, DC, was without precedent. Nearly 300 people from across the US, Canada and Germany attended the four-day event.

The conference was launched with the first-ever Alpha-1 Advocacy Day on Capitol Hill on June 6. Under the guidance of A1A and the Alpha-1 Foundation, 107 Alphas from nearly 30 states descended on the Hill. People had the opportunity to meet with their members of Congress to discuss Medicare reimbursement, access to care, and funding for rare disorders.

Conference attendees gathered on Friday evening for a town meeting followed by a reception and exhibits. Exhibitors included

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“Not This Again”

By Paul Billings, MD, PhD, Alpha-1 Association Board Chair

Amidst the drumbeat of war and corporate scandal everywhere the essential agenda of the “empowered consumer” and of patient oriented organizations like the Alpha-1 Association may get lost. I, for one, am trying to not let this happen. That is why I am honored to serve as your new Board of Directors Chair.

I was a regular visitor to Washington, DC, ten or more years ago during the first George Bush administration. My research on discriminatory uses of genetic information was gaining some notoriety, and I was asked on several occasions to testify before Congressional Committees.

I was struck at the time with the nasty nature of political life

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Advocacy Day

by Cathey Horsak, Alpha-1 Association Support Group Leader

The original concept for Awareness Day at the Annual Conference was “borrowed” from the Zoo Walk held last year in Ohio. The idea I suggested to the Association was to have each participant come to Washington, DC, with pledges from their own communities, ask the American Lung Association and the American Liver Foundation to match those pledges, and then for the Alpha-1 community to “march” on Washington to make our presence known.

In mid-April, I was asked by the Advocacy Day planning committee to plan the Awareness Day activities. It was suggested that walking would be difficult for some so the concept was diluted

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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 20 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.

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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 You Can Help

Thirty-five percent of the Alpha-1 Association's funding comes from individuals like you. Your donation will enable the Association to continue its work in education, advocacy, support and medical research. Please send your tax deductible contribution to:

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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 insure the accuracy of the information in this newsletter. Material contained here is for informational purposes only. Any changes in your health care should be discussed with your doctor. The opinions expressed here are not necessarily the opinions of the Alpha-1 Association.

ANNUAL MEETING (CONT FROM PAGE 1)

Bayer Corporation, the principal sponsor of the conference, as well as AlphaNet, Aventis Behring, Alpha Therapeutics, Gentiva Health Services, Aerogen Inc., Advanced Respiratory, and Apria.

Attendees also participated that evening in a memorial service during which members could remember, celebrate, and grieve the loss of people who have died from Alpha-1.

Presentations throughout the weekend covered a wide range of subjects. Ira Byock, MD, director of the Palliative Care Service in Missoula, Montana was the recipient of the first annual Bayer Award and presented the Bayer Lectureship on compassionate care at the end of life. The launch of the Association's Compassionate Care Program was also announced, which will provide emotional and economic counseling services to people in the Alpha-1 community.

Experts from around the country spoke on a variety of issues important to Alpha-1, including bioethics, public policy issues, disease management, understanding Alpha-1 alleles, pulmonary rehabilitation, stress management and specific lung and liver disease issues.

Because of the overwhelming response to the Advocacy Day activities, Washington, DC, will be considered as a continuing venue for future annual conferences. At the same time, the Association's Board is reviewing plans to hold regional educational conferences throughout the year for those unable to travel to the annual conference. These conferences would dovetail with the Association's ambitious plans to restructure and expand its support group network, under which regional facilitators would be appointed to guide and provide resources to existing and new Alpha-1 support groups.

The combination of education, camaraderie, and advocacy left most people who attended the four-day conference feeling empowered and ready to take on the issues surrounding all people affected by Alpha-1. The feeling in the air was of rejuvenation and energy for the future of the organization and the Alpha-1 community.



NOT THIS AGAIN (CONT FROM PAGE 1)

inside the Beltway, and with the stalemate that had developed between the Democratic Congress and the Republican President. No legislation was being enacted, and more time was spent pointing fingers—or worse—than doing the public's work.

I fear a similar situation may have already begun to characterize the new Bush Presidency. Caution in legislation is never a bad idea but inaction on topics important to patients and health care at this time could really be disastrous.

Why now more than ever?

First, recently our investment in the life sciences and biomedical technologies has increased enormously. The NIH budget has grown dramatically and it is dwarfed by private sector funds being applied. While the "market" will identify winners and losers in this high stakes game, those in need may wish other values and factors to

influence and at least partially govern such an important effort.

Second, with weakness in the New Economy apparent (telecommunications and software, for instance), our economy is becoming more dependent on the impact of health care spending and productivity. We currently spend about 8 percent of the GNP on health matters (around 2 billion dollars) annually.

Some experts now suggest that we should up that amount to twenty percent of the GNP and properly fund basic/clinical research and technology development, finance health care for the uninsured, improve the situation for the chronically ill and disabled, and assure needed long term care with the monies.

If health care's vitality will be to the future economy of the United States what the performance of General Motors was to the

old manufacturing world, it would make me more optimistic to think we had effective public policy processes to oversee it.

In its absence, patients, sick people and those at risk for illnesses—the primary beneficiaries of good policies and our best intentions—may not have their needs met or voices properly heard.

Therefore, as A1A enters an exciting new period of outreach and growth, it is crucial that we keep our eye on public policy developments, and intervene as appropriate to represent the interests of the Alpha-1 community. The outstanding representation of our community at our first Advocacy Day on June 6 bodes well for the Association's future role in voicing the concerns of the community. I look forward to working with the members of our organization as we move ahead in this and other important areas.

Did You Know?

AlphaNet, a non-profit health management organization, gives back to the community through donations to Alpha-1 Support Groups, scholarships to Advocacy Day and the Association Annual Education Conference, support of the Alpha-1 News, and contributions to other publications that reach the majority of the extended Alpha-1 community.

MEMBER VOICES

Dear Editor:

I really enjoy all the information I learn from the Alpha-1 News. I'm especially interested in some of the questions in the February issue (what are the worst and best things about having Alpha-1?).

The worst thing about having Alpha-1 is pretending to your family and friends it's ok to be sick and not to worry about it. You sometimes have to pretend you're not sick, so the loved ones around you don't feel guilty. I'm very good at that, because if I say I'm not feeling well, they all worry.

I can't think of a great thing about this disease, although it does make you think about being educated about what you can do to make the best out of it, and this is a good thing.

What really ticks me off, is I don't look sick! So everyone thinks I can keep up with the every day chores, and they ask me what I do all day. Well, I do what everybody else does, but it takes me at least twice as long as it takes everybody else!

What matters most to me is being thankful for every day I get to spend, and not to obsess over things I can't control. One of the positive things about this disease is being connected with the Alpha-1 Organization.

Sincerely,
Kathy Lewis

Dear Editor:

In reference to the *Alpha-1 News* February 02, page 20, I noticed an ad for the AARP Pharmacy. A short time ago I made my own survey by having the same prescription filled at four different local places, with no significant price difference from the AARP. This drove me to explore having my prescriptions filled in Canada by www.canadarx.net. This resulted in approximately 50% savings.

Now I realize the AARP is a fine organization and must have paid for the ad that appears. Since the main goal of Alpha-1 is helping people, they should give equal space and effort to teach their subscribers how to buy their medications over the internet in Canada. Every city has a computer on line and a librarian to help. The complete instructions and prices are on the web site.

John Fickett

Editor's note the *Alpha-1 News* does not accept paid advertisements. The piece regarding the AARP Pharmacy was for informational purposes only. The Alpha-1 Association does not endorse individual pharmacies or prescription websites, and we encourage you to do your own research when looking for a pharmacy.

Advocacy Day (cont from page 1)

down to a "gathering" to coincide with Advocacy Day. The Awareness Day activities committee consisted of Ken Richmond (local to the area and a big, big help!) Elena Halford, Pam VanScoy and myself. Prior to the day, several posts were made to multiple lists about the Awareness Day activities, and we had 25 plus people who e-mailed me that they would be attending. Ken secured a location under the trees in Union Plaza, directly across the street from the Capitol, with a park permit from the Capitol police department.

After the Advocacy Day training session that morning, Ken, Elena and I made a mad dash to Ken's car parked at Union Station, and proceeded to set up two tables draped with Alpha-1 banners and stocked with literature. We had two ice chests full of cold water, colas, and juice available for any Alpha participating. Ken then made

another mad dash back to rejoin his group from Virginia. Elena and I settled into the park setting watching all the people scurry about Washington DC, and anxiously awaited our first visitors.

We had five Alphas come by, share a cola or water with us, and then they were on their way back to visit their Congressmen. We had a school health nurse come by and ask what we were all about. She took literature and vowed to share it with her School Health Nurse Conference being held in Washington, DC. That was the extent of participants in the Awareness Day activities. Elena and I sat there until about 4:00 p.m. when the skies over DC opened wide and a huge rainstorm drenched us!

All in all, we made the best of a bad situation, but I was disappointed in the lack of participation in the Awareness Day activities. However, several factors

contributed to this. The day was overcast so I think the weather may have convinced some people to stay at the hotel. It was extremely hot and humid! The time required to see a congressman was lengthy. And then the rain came! And, although the Awareness Day activities spot was located on the maps distributed to all participating in Advocacy Day, I do not think an announcement was made about the Awareness activities at the Advocacy Day training, and many people did not understand that they were TWO SEPARATE EVENTS. Though I was disappointed, I am even more determined to create an AWARENESS EVENT in the future that will be more in alignment with the original idea. It needs the backing of the whole Alpha-1 community and I feel it can be an excellent fund-raiser for the community.

HEALTH NEWS

Tips for Low Salt Eating

By Nancy Cropper

First, let's get one thing straight: I am not the Martha Stewart of low sodium cooking, any more than my cooking resembled Martha's in the old days. However, when my husband, Leigh, (a liver-affected Alpha-1) was instructed by his doctor to cut his sodium to 2000 mg per day, I did learn some new tricks. Maybe they will help someone else.

So how do you reduce your sodium intake? You don't have to learn to cook all over again, but if your two favorite ingredients are dried onion soup mix and cream of mushroom soup, you'll have to make a few changes. I started with my family's favorite foods. There's no point searching for salt-free meat loaf recipes if your husband (like mine) never liked meat loaf made with salt! Whatever your particular favorites may be, try modifying them slightly. That way the person who must reduce sodium won't feel deprived while everyone eats in front of him.

As an example, I often bake chunks of potatoes (with skins) that have been coated in melted margarine and sprinkled with seasoning salt and parmesan cheese. For Leigh I use unsalted butter and sprinkle them with lemon pepper and a little garlic or onion powder instead. You will find you can modify many favorites that way.

There are a lot of good salt-free cookbooks out there as well. We bought one called *No Salt Cooking*, by David C. Anderson and Thomas D. Anderson. It has the best from-scratch brownie recipe I've ever tried, including all the ones with salt. When you try to reduce sodium, you have to learn to shop all over again. The best advice is to ALWAYS READ THE LABELS. I never used to need my glasses for grocery shopping, but now I can't shop without them! Here are just a few things we've learned:

Watch meats carefully. Don't assume that boneless, skinless chicken breasts are created equal. One store brand had 190 mg of sodium in a four-ounce serving. That statement on the label "enhanced with up to 15% chicken broth" also means a lot of salt was added. Tyson chicken breasts, on the other hand, contain 40 mg in four ounces. The same thing is true of vegetables. Canned peas always seem to have some sodium, but I bought Pictsweet at 105 mg. per serving instead of Kroger's store brand at 200 mg. Many frozen vegetables contain no salt, or you can buy fresh and cook them yourself.

Eating out is the biggest challenge of all. Try a good restaurant and see if they will broil you a steak or some fish without any seasoning. Order a baked potato. (Sour cream is lower in sodium than butter, but you can bring your own salt-free butter or margarine from home as well). Bring your own salad dressing - and good luck! We certainly miss our favorite Mexican, Italian, and Chinese restaurants.

The best way to deal with the whole low-sodium thing, I think, is not to approach it by looking at all the things you can't have. A more positive approach is to think, "I am allowed 2000 mg of

sodium today. How am I going to 'spend' them?" With a little effort and a lot of label reading, it is possible to eat reasonably well even on a low salt diet. I wonder if Martha Stewart has ever tried it?

Gardening With Allergies

From the American Academy of Allergy, Asthma and Immunology

As people start to work on their lawns and gardens, the American Academy of Allergy, Asthma and Immunology (AAAAI) recommends they take short- and long-term precautions to control allergy symptoms.

To avoid the worst allergens, the best bet for your garden are "natural" plants, according to Mary Jelks, MD. "The trend in smart gardening now is to avoid large areas of turf and use natural plants," Jelks said. "Lawns require a good deal of attention, and mowing is a hazard to grass and mold sensitive people." Native plants are best for people with allergies because they require little effort, withstand climate extremes and do not need fertilizers, water or pesticides.

"Plants that cause allergies usually have flowers that are small and insignificant looking and have no color or attracting nectar. They are usually wind pollinated and produce great amounts of pollen. Conversely, plants with bright, showy flowers are better for people who have allergies. Their pollen is large and because they are pollinated by insects, the pollen is seldom airborne," says Jelks.

The following trees, shrubs, and plants have been found to be better for people with allergies: fruit trees such as pear, apple and cherry; flowering annuals and perennials like crocus, hydrangea, azaleas, roses, impatiens, daisies, tulips and others with bright flowers; shrubs and vines such as hostas, cacti and clematis.

If you are considering adding trees to your landscape, you should avoid planting the following: alder, cottonwood, olive, ash, cypress, palm, aspen, elm, pecan, beech, hickory, poplar, birch, juniper, sycamore, box elder, mulberry, walnut, cedar, oak, and willow. For more information, go to www.aaaai.org/springallergy.

California Air Worst for Lungs

FRESNO, Calif. The four smoggiest areas in the nation are in California, according to a new American Lung Association report. The Los Angeles area tops the list for the third straight year, followed by Bakersfield, Fresno and the Visalia-Tulare-Porterville areas. The Houston metro area was fifth.

"This report is really focused on ozone pollution as a national problem, but we're most famous for it in California," said Dr. John Balmes, president of the association's medical section. The report is based on Environmental Protection Agency data from 1998-2000 measuring the number of days that pollution exceeds the EPA's air quality index for ozone. It did not take into account improvements in the past year.

Smog has been reduced by two-thirds in California during the past two decades, but much work remains. The Los Angeles area has made the most progress, cutting smog by 75% since 1985, but officials still do not foresee the city meeting federal standards until 2010. California's smog is worsened by the state's dense population and a topography that traps air pollution.

"There has been progress, but it's a tough battle," said Richard Varenchik, communications director for the California Air Resources Board.

Can Wine Help your Lungs?

Reprinted from *Science Daily Magazine*

Drinking white wine appears to be good for the lungs, a University at Buffalo study has shown. In research presented at a May meeting of the American Thoracic Society, Holger Schunemann, M.D., Ph.D., assistant professor of medicine and social and preventive medicine in the UB School of Medicine, reported that drinking white wine recently and over a lifetime was associated with better lung function.

"This finding may indicate that nutrients in wine are responsible for the positive effect of alcohol on lung function," said Schunemann. "Red wine in moderation has been shown to be beneficial for the heart, but in this case the relationship was stronger for white wine."

UB researchers conducted the study in a random sample of 1,555 white and African-American residents of Western New York. Wine drinkers had the highest levels of protective antioxidants in their blood. Analysis of all of the alcohol consumption variables with lung function showed that both recent and lifetime intake of wine had the strongest association with FEV1 and FVC, Schunemann said, an effect likely linked to wine's antioxidant properties.

"We think that the antioxidants in wine account for our current findings."

Note: the medical community has differing opinions on alcohol consumption for patients with Alpha-1. Do not make any changes in diet or lifestyle without first checking with your doctor.

Keep the Pests Away, Naturally

From *The Green Guide*

Summer is here, and along with it summer pests. This can mean the use of pesticides around the home, but natural approaches to pest control can be as effective as chemicals and much healthier for our bodies.

Herbs and essential oils are vital weapons in the war on bugs. Here are some common indoor pests and natural materials you can use to chase them away: Ants can be defeated with borax powder or ground cloves, and boric acid keeps cockroaches at bay. Fleas are repelled by rosemary oil and orange oil. Flies will avoid areas scented with basil, pine oil, or cloves. Fruit flies will flee from areas sprayed with a solution of basil oil and water. Moths can be discouraged with lavender, cloves, camphor, or cedar.

There are a number of natural solutions to outdoor pests as well: In the garden use an all purpose pest spray made from water and a head of mashed and boiled garlic. You can also raise beneficial bugs that eat the bad bugs. Ladybugs, for example, feast on aphids. Nematodes (tiny worms) feed on the larvae of many garden pests. And praying mantises will feast on many pests. These and other healthy scavengers can be obtained from garden supply companies. For protection from biting insects, replace synthetic DEET sprays with gentle oils of lavender, bergamot, or lemon balm. In a pinch, vanilla extract can even be used. Ticks are repelled by essential oils of rose geranium or palmerosa.

These are but a few of the time-tested, natural pest control strategies available if you want to avoid the dangers of conventional chemical pesticides. They'll help keep the bugs at bay and your home a safer, healthier place to play.

For more information, log on to www.thegreenguide.com.

ASK THE DOC

By Jeff Teckman, MD

Dear Doctor:

Q: I am a lung-affected ZZ adult with normal liver enzymes. Should I be worried that I may have Alpha-1 related liver problems and not know it?

A: There has been some recent information about ZZ liver disease in adults, but we still don't have definite, conclusive answers. Reports from Dr. Eriksson in Sweden, who has followed up on autopsies of ZZ patients who died of various causes, suggest that many Alpha-1 patients have "silent" liver problems that develop later in adulthood/old age. Many of these people died in their 70s and 80s not knowing they had liver problems, but when their livers were examined significant damage was seen. In many of these cases, the patients died of something else. Since the study was based on autopsies, we don't really know when or how fast the damage occurred.

If you are asymptomatic and healthy from the liver standpoint, and there is no current treatment, then do you really need a liver biopsy to look for slow, silent changes? I'm not so sure. I'll let you know as we learn more.

Dr. Teckman is a professor at Washington University School of Medicine in St. Louis and sits on the A1A Board of Directors.

A SPECIAL FAREWELL

As Sandy Brandley leaves the Association, we would like to thank her and remember her for all she has done for the Association. Below is a small sampling of the people whose lives have been touched by her and how much she will be missed.



Sandy is bid farewell by the Association's Midwest Chapter. Left to right: Peggy Paul, Sandy, Shirley Marnett, Julie Swanson, Dick Bueker.

Dear Sandy,

What a special person you have been to the Cline household for these past 13 years! Your encouragement to us as we accepted and dealt with Alpha-1 was from a caring and nurturing soul who instinctively knew what we needed and when to suggest it. The emotional support and medical knowledge was tremendous.

You also supported, with hard work, Jay's dreams, visions and hopes for the future of an Alpha-1 organization on the local, national, and later, international level. With great courage and intelligence, you tackled the adventure of uncharted waters and led a small group of Alphas to greater heights. That group of Alphas swelled to the thousands!

Your abilities and willingness to lead the cause gave Jay the energy, focus and dedication to keep on fighting for Alphas at all levels. Our whole family is thankful for that gift. He devoted countless hours to the organization, as he knew that you were the one who could make a huge impact for Alpha-1. Because of your leadership, energy and enthusiasm, Jay maintained his excitement and hopes for a brighter future for Alphas and their families. You were generous with your time, intellect, creativity and spirit to further the mission of Alpha-1... and always with a cheerful countenance and a wonderful sense of humor. What an amazing example for us all!

This is not "good-bye", but a bon voyage as you venture forth to other life experiences. Thank you for your years of dedication to the Alpha-1 family. It has been an amazing journey.

May you go in love, good health and peace,

Jeanne Cline, Todd, Cathryn and A.J. Quast, Ryan and Allyson Guttormson

Dear Sandy,

It has been a pleasure doing business with you throughout the years and I know personally that the National Association will suffer a gigantic loss with your departure. Thank you so much for all that you have done for the Association and thank you mostly for being there as an in charge, or should I say, take charge, Executive Director, who never left my side when I requested your help or assistance.

I can remember the first time meeting you in Framingham, Massachusetts at the National Alpha-1 Convention. We had a very invigorating conversation and I thanked you then for helping me to organize funding for our first ever Alpha-1 Atlas. You helped me to get the seed money so I could get the presses running on this valuable contribution for Alphas.

I called on you that night again when I leaned over the table and said, "Sandy, I have a case going on against the Veterans Administration. I was wondering if you could help me out with a written letter of support to be used as evidence?" You never hesitated and stated that you would be glad to help me out in any way that you could. I was truly impressed that someone whom I had just met would go to such lengths to help. Thank you for that.

I remember calling you from Syracuse at another National Alpha-1 Convention, pleading for help for a young girl who was having trouble getting Prolastin. Her condition was critical and her medical staff was frustrated. You cut corners and the red tape and made some calls that helped to get her on Prolastin. That patient still thanks you and I thank you for taking the time to help out with this even though I know that you were up to your neck in things to do at the convention.

I can account for many things you have unselfishly done for me. Each time, you never hesitated or gave the impression that I was knocking on your door too many times for help. I appreciate that. Thank you so much for all you have done for me, for others, and most noticeably A1A. As they say in the trade, "your shoes will be hard to fill!"

In full admiration,
Peter Lyon Duttweiler



Sandy Brandley accepted a new award named in her honor, the *Sandra K. Brandley Leadership Award*. The award signifies the leadership Sandy brought to the Association in her decade of service, and it will be awarded annually to a person in the Alpha-1 community who shows outstanding leadership. Dennis Barbour presented the award.

ANNUAL CONFERENCE & ADVOCACY DAY

A Photographic Journal of the 11th Annual Education Conference in Washington, DC

Despite 90 degree heat and the occasional downpour, over 100 people met with their members of Congress, shaking hands, telling their stories, and educating our politicians about Alpha-1.



Advocacy Day a Huge Success

The first Alpha-1 Advocacy Day was a huge success. Well over one hundred people from the Alpha-1 community made visits to their members in the Senate and House of Representatives, with primary focuses on Medicare reimbursement issues and increased funding for the Office of Rare Diseases at the National Institutes of Health.

This was a collaborative effort between the Association and the Alpha-1 Foundation. Planning started many months ago, and through regular teleconferences members of the planning committee handled the logistics of Advocacy Day as a team.

Most participants visited between two and three offices, which added up to extensive coverage of Capitol Hill. By all standards, this was an amazing success for our first advocacy effort. Participants will be kept informed of follow up efforts and what they can do to keep the momentum going.



A Photographic Journal of the 11th Annual Education Conference in Washington DC Photographs by Peg Callihan and Cate Tyynela

ASSOCIATION NEWS

Awards Program a Highlight of Weekend

A banquet and awards program was held Saturday evening of the conference. A new award was created this year in honor of our outgoing executive director, the *Sandra K. Brandley Leadership Award*. Other awards were given to those who have made significant contributions to the Alpha-1 community. Other awards not pictured: *Advancement of Research Award* - Symma Finn; *Inspirational Award* - Skyler Haynes; *Special Appreciation Award* - Rick Perry; - Len Geiger; and the *Community Dedication Award* - Evelyn Heering.



Dr. Robert Sandhaus (center) was the recipient of this year's *Physician Appreciation Award*.



The *Peter Smith Achievement Award* was given to Joe Reidy (in jacket) surrounded here by family and friends.



The first *Bayer Lectureship Award* was presented to Dr. Ira Byock (center) by Bayer and Association representatives.



Dennis Barbour presented the *Alpha-1 Explorers Award* to Fred deSerres, PhD.



Bob Haggerty presented fellow Board member Lou Glenn with the Board's *Dedication Award*.

Dennis Barbour—The First Four Months

By Cathy Valenti

There have been many changes at the Alpha-1 Association over the past four months. On the first of April the Association welcomed a new President and CEO, Dennis Barbour. Even before Dennis officially started, he engaged in regular communications with board and staff to determine needs, assess talents, and listen to thoughts and ideas.

During the first week in April Dennis had mapped out a list of possible programs for the community, assessed the needs of current ones, and identified new funding sources. He continued on with this very steep Alpha-1 learning curve as he traveled across the country, meeting with key people in industry, government, and partnering organizations.

Always flexible, Dennis continued to revise and refine ideas for programs and special projects, even while dealing with two major events; the first-ever Alpha-1 Advocacy Day (co-sponsored by the Alpha-1 Foundation) and the Association Annual Education Conference, both held in the Washington, DC area. At the conference, he kicked off one of his new ideas, the Compassionate Care Program, by inviting the renowned Ira Byock, MD for the Sunday morning keynote. The overwhelmingly positive response Dr. Byock received from the attendees ensured the need to include end-of-life issues and grief counseling as important components of the program.

Dennis brought together a small number of individuals to Washington DC in July, forming the Alpha-1 Community Advisory Committee, with each member uniquely committed to the needs of the extended Alpha community. The result of this intensive weekend of discussion, probing questions, and brainstorming was a clear, concise plan for program implementation.

These programs included membership development, a revitalized public policy program, restructuring of both the support network system and the community assistance program, a new compassionate care program, physician and provider awareness and education, public awareness, a planned summit on orphan biologics, a professional quarterly publication, a speaker's bureau, and a media/public relations campaign.

A few of Dennis' accomplishments since April include: the opening of a Washington, DC Association office for additional public and legislative exposure, outreach and collaboration with related organizations, businesses, and government, an improved website with an interactive advocacy page, a well-developed strategic plan, and restructuring staff to make the best use of limited resources.

Dennis has the vision and energy to strengthen the Association, and is passionate about fulfilling the Association mission to improve the quality of life for all those affected by Alpha-1 through support, education, advocacy, and research.

ASSOCIATION NEWS

Visit CapVoice—A1A's Voice on Capitol Hill

If you have web access, you have an easy way to be an advocate for issues associated with Alpha-1. Contact your legislators, individuals within government agencies, the executive branch of the government, and local and national media with a few clicks of your mouse. Simply visit www.alpha1.org/advocacy and enter into *CapVoice*, our interactive website.

Please take a few moments to read the Issues and Legislation within the interactive site. There you will find specific Action Alerts for current concerns, as well as general information on other legislation pertinent to the Alpha-1 community. Follow a few easy steps to send your message. You can either read and sign the letter provided, adding your personal message to it before you send it, or compose your own letter. With a few simple clicks of the mouse, your message will be on its way to your designated legislative, administrative, or media contacts.

You can also send your comments to most government agencies and even the White House. Use the Media search to find contact information for your local media and ensure your mail is sent to the right people for optimum exposure.

If you have any questions about this site, please email advocacy@alpha1.org or call Cathy Valenti at (800) 365-9014. Thank you for making your voice heard!

New Patient Services Programs

Three new programs will be offered to the Alpha-1 Extended Community, which is comprised of patients, caregivers, family members, friends, providers, and significant others.

Patient Information Program was established to provide telephone assistance on a daily basis in order to offer education, support and resource information to the extended Alpha-1 community.

- Answer questions for newly diagnosed Alphas, listen to concerns regarding

A1AD, provide patient information Packets and testing kits.

- Talk with established Alpha patients or family members helping to answer questions, meet needs and encourage Peer Guide or Support Group involvement.
- Provide professional information packets to physicians, nurses, case managers and other health professionals needing information on A1AD.
- Patient Advocate for Benevolent Needs and Services.

Health Insurance Support Program was designed to educate, assist, and equip Alpha-1 affected community on how to identify and resolve health insurance concerns.

- Provide direction with health insurance questions or concerns for the extended Alpha-1 Community that are considering testing of A1AD.
- Provide assistance with resolving questionable billing claims and/or duplicate billing problems.
- Offer advice and guidance on Medicare and provide reimbursement information on Medicare Durable Medical Equipment (DME) products.
- Assistance with locating High Risk Insurance Plans, Medicare Supplemental Policies, electing COBRA/COBRA conversion policies and understanding HIPPA compliance.
- Patient advocate and referral resource for information on benevolent insurance and RX needs.

Compassionate Care Program is in the planning stage, and will serve to support the extended Alpha-1 Community on loss, grief, and end-of-life issues, including emotional and economic support.

- Short-term Grief/Loss Counseling services for the extended Alpha-1 Community provided by the Alpha-1 staff, Peer Guides and Support Group Leaders, supported by a team of trained and certified grief and loss counselors.
- Links to community resources, including long-term grief counseling.

- Advocate for Alpha-1 patient services which include hospice, hospital, physicians, funeral service provider, etc.
- On-line Guest Book to memorialize loved ones.

Alpha-1 Community Advisory Committee (ACAC) Meets in DC

A new advisory panel met July 20 and 21 in Washington, DC, to discuss programs and future direction of the Alpha-1 Association. The group's focused discussion over the weekend resulted in a clear plan for the design and implementation of new A1A programs as well as the restructure of the existing support system network. The A1A's Board of Directors approved the appointment of this panel as a standing committee of the A1A, named the Alpha-1 Community Advisory Committee (ACAC.) Members of this committee include Sue Landers, Committee Chair, Dennis Barbour, A1A president and CEO, Diane Angell, Evelyn Heering, Cathey Horsak, Mark Louser, Dennis Pollock, Ken Richmond, Pam VanScoy, Pam Harris, Greg Smiley, and Cathy Valenti.

A1A Backs Coalition Moves on BPAC, HOPPS

On July 24, Dennis Barbour and Greg Smiley, A1A public policy associate, met with the Plasma Users Coalition (PUC) in Chicago to discuss coalition efforts on a number of public policy issues of interest to the Alpha-1 community. Among other things, A1A rededicated itself to working within Congress and the Administration to insure that the recent CMS provisional ruling limiting reimbursement for Prolastin® treatment is overturned. A1A also backed an effort of the coalition to insure that the tenure of the DHHS Blood Products Advisory Committee (BPAC) is extended beyond its planned expiration this year.

Cathy Valenti promoted to Vice President of A1A

Dennis Barbour has announced that Cathy Valenti, A1A director of education and public policy, has been promoted to become A1A's first vice president. As vice president for programs, Cathy will be working with Dennis in developing and overseeing all of A1A's programs. "The Alpha-1 community is fortunate to have someone with Cathy's competence and skill at work on their behalf," said Dennis. "As an Alpha herself, Cathy brings a unique and important perspective to her new job as one of my primary partners in our efforts. I am grateful to have her as a member of our team." Cathy can be reached at (800) 365-9014, or at valenti@alpha1.org.

Member of White House Policy Team Joins A1A

Greg Smiley, former member of the White House Office on AIDS who served as its acting executive director earlier this year, has joined A1A as its first director of public policy and development. Smiley, who received his MPH from George Washington University and his undergraduate degree from Duke University, will be responsible for coordinating the Association's public policy activities in Washington, DC. "We're thrilled to have someone with Greg's experience on board as we move ahead aggressively on public policy matters," said Dennis Barbour, A1A president and CEO. Greg can be reached at (800) 251-0175, or at smiley@alpha1.org.

Harris joins A1A team as Patient Advisor

In June, Pam Harris joined A1A as its director of comprehensive patient services. In her role, Pam will oversee A1A's recently restructured Patient Services program and will oversee development and implementation of A1A's new Compassionate Care Program. Pam has had extensive previous experience with the Alpha-1 community as a part of a national service to provide direct patient assistance on insurance reimbursement matters. "Pam is an infusion of new thinking and strength into our A1A team," said Dennis Barbour. "We're pleased to have been able to harness her seemingly limitless energy on behalf of the A1A community." Pam can be reached at (800) 425-7421 or at harris@alpha1.org.

Landers to Oversee Restructuring of Support Group Effort

Sue Landers has recently been named A1A Director of Community Services to inaugurate the launch of A1A's restructured support group network. Under the restructuring, A1A regional facilitators will coordinate the Association's new regional support network, designed to provide direct services to local support groups and expand their numbers throughout the country. "I've learned rather quickly that Alphas oftentimes exude more energy than ordinary mortals," said Dennis Barbour. "Sue is a prime example. I can't imagine anyone better suited to take on this huge new responsibility." Sue can be reached at (800) 245-6809 or at landers@alpha1.org.

DC Based Consultant Joins A1A Team

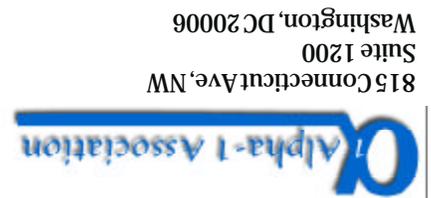
In May, Liz Callihan joined A1A as its principal consultant on publications and website design and management. Liz has had over 12 years' experience in senior level management positions with non profit health organizations. She has also had extensive experience developing and managing physician continuing medical education (CME) programs, a skill that will prove invaluable to A1A as it expands its efforts in the CME arena. "Having worked with Liz for over twelve years, I am delighted that she has joined us at A1A," said Dennis Barbour. "Liz is extraordinarily competent and efficient, and well understands the needs of small non profits like A1A." Liz can be reached at (301) 320-8995 or at callihan@alpha1.org.

Spotlight on A1A Consultants: Peg Callihan and Bernie Pobiak

For attendees at the A1A Annual Conference, the names Peg and Bernie will be familiar. The pair were ubiquitous over the course of the four-day program. Their photo shoots were displayed throughout the meeting on a giant screen in one of the main meeting rooms, are shown on the A1A website, and have been compiled in a series of CDs that are available from the A1A office. The team is also responsible for the complete redesign and reposting of A1A's website, accomplished in a mere five days of non-stop effort in April. "Peg and Bernie are a miracle," said Dennis Barbour, "their work is not only outstanding, but responsive and quick. We're very happy to have them as a part of our effort to project a new image for the Association." Peg can be reached at peg@pubcomm.com. Bernie can be reached at bernie@pubcomm.com.

Alpha-1 Foundation—www.alphaone.org—Alpha-1 research organization
Alpha Net—www.alphanet.org—non-profit health management
Espanol web site—www.alfa1.org
United Kingdom web site—www.alpha1.org.uk
Canadian registry site—www.alpha1canadianregistry.com
Alpha 2 Alpha—www.alpha2alpha.net—provides peer-to-peer support

be sure to visit alpha-1's new
website: www.alpha1.org



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The Alpha-1 News is dedicated to supporting our mission “to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education, advocacy and research.” The Alpha-1 Association is a member-focused organization, and we encourage you to participate in this publication.