

Alpha 101: Board Member Gets the Facts for Video Production

By Dawn McGee

Remember how hungry for information you were when you learned you had Alpha-1? Maybe your hometown doctor did not know much about the disorder and you were left to scour the Internet for facts, or you could not figure out how to pronounce Alpha-1 Antitrypsin Deficiency, let alone spell it? Now imagine what it would have been like if you had been given one-on-one access to experts and patients from across the country. Well Dell Witcher, who was diagnosed in 2007, just had this opportunity recently when the Alpha-1 Association asked her to produce a DVD for Alphas and their families.

Like most Alphas, Dell's diagnosis didn't come immediately. She had elevated liver enzymes and the cause was unknown. Finally she was tested for Alpha-1.

"My doctor said that he had called a colleague who was more familiar with Alpha-1," Dell recalls. "Basically, he said it was a rare diagnosis, but that as long as I don't smoke I didn't need to worry about it."

Dell drove home from that appointment and contacted the Alpha-1 Association. She learned there was much more to the diagnosis than her doctor had led her to believe. That is when Dell became an empowered patient and joined the Alpha-1 Association.

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Dell Witcher and Jim Bolton





Dear Friends,

We expect a record number of Alphas and their families in attendance at our National Conference kicking-off June 11, 2010 in Orlando. What setting could be more appropriate than Disney World, the home of Mickey Mouse! The conference is entitled "Unlocking the Family Genes, a Key to a Healthier Life" and will focus on creating awareness and detection among Alpha families. It is also a time that the

Association conducts its Town Hall meeting to report on its activities for the year to our members and to report on the Board election results. In addition, our Board of Directors will convene and elect its officers for the next two-year term.

I would like to recognize and thank **Jan Petersen, Esq.**, from St. Cloud, MN, our Chair for the last two terms. Together, we have worked as a team for four years and he has been a source of guidance and inspiration to me. As an attorney, Jan's legal expertise has helped the Association immensely and his vast knowledge and personal experience have strengthened our organization. He has also worked diligently with me to foster relationships with industry and other Alpha organizations. Jan has been an involved and active Chair, and I thank him for his leadership of our Board of Directors and dedication to the Alpha-1 Community.



I am delighted to announce that our incoming Chair is **Ed Brailey**, from East Lyme, CT. Ed is an Alpha and a single lung-transplant recipient who has been extremely active in the Association. He started as the Support Group Leader for the Connecticut Nutmeggers, served on the Board of Directors for 6 years, and served on numerous Board committees. His wife Jo Anne, a strong Alpha-1 advocate herself, encourages and supports Ed's active participation in the community. Being a professional

firefighter, it is a part of Ed's DNA to help his community in any way he can. Ed serves as a peer guide through the Alpha-1 Association and Brigham & Women's Hospital in Boston for those waiting for a lung transplant. He continues to volunteer for the New England Organ Bank, knowing that many are not as fortunate as him to receive the gift of a second chance at life. While serving as Chairman of the Association, Ed promises to be available to everyone in the Alpha-1 community, meeting with and listening to their suggestions and ideas. Please welcome him as our new leader!

Best regards to all!

Marlene Erven
Executive Director

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Due to her background in medical video production, the Alpha-1 Association asked Dell to help with a new project to create videos explaining Alpha-1 to patients and their families.

Dell went to work to create four short videos that would explain the genetics of Alpha-1, liver and lung issues, family considerations and Alpha-1 in children. The project took her to Clinical Resource Centers around the country where she spoke to dozens of people in the Alpha-1 community.

“One of the first things I noticed was the mutual respect between doctors and patients,” Dell says. “Over and over again, Alpha docs told me how much they admire their patients for being proactive about making the best possible lives for themselves. The patients told me their doctors had saved their lives.”

Dell also learned how much patients can and do help each other. She had always heard about the value of support groups, but this message really hit home when she began talking to Alphas.

“So many people told me how much easier it is to cope with the diagnosis when you are involved with an Association Support Group,” Dell says. “The Support Groups help people stay on the right track by living healthy lifestyles. People also say they get valuable advice from their peers who have experience in dealing with Alpha-1.”

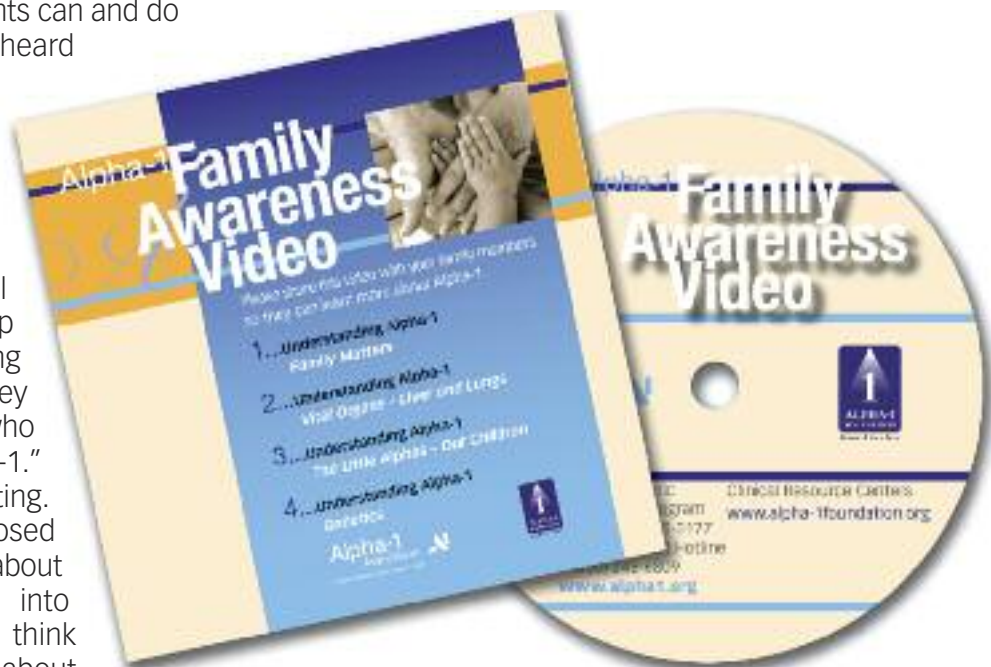
Another hot topic was family testing. All too often, when newly diagnosed individuals tell their family members about the diagnosis, they run into reluctance to test. Often, relatives think Alpha-1 is nothing to worry about, especially if they are healthy. This reluctance to test can be very frustrating for the Alpha because one of the most important things about being diagnosed is learning the things you can do to stay healthy. Dell says this attitude made her eager to give Alphas new tools, like the DVD, to help them communicate with family.

During the production process, Dell learned that Alpha-1 is never stagnant and that her own condition

“So many people told me how much easier it is to cope with the diagnosis when you are involved with an Association Support Group,” Dell says.

might progress over time. “Right now I am so lucky that I don’t require augmentation therapy or oxygen,” she explains. “But even though I am healthy, this project reminded me that Alpha-1 isn’t something I can just forget. I received a lot of lectures on healthy eating and exercise from the Alphas I met!”

Dell says that she wants the Alpha-1 community to know how much she appreciates everyone’s help during the production process. “We did these videos in a news-style; that means the interviews were long and very thorough,” Dell explains. “We didn’t write scripts and put words in people’s mouths to tell them what to say. Instead, we did the interviews and learned the things that were most important to Alphas and their doctors. It was a lot of work for the people I interviewed and I am incredibly grateful for everyone’s help.”



- 1... **Understanding Alpha-1 Family Matters**
- 2... **Understanding Alpha-1 Vital Organs – Liver and Lungs**
- 3... **Understanding Alpha-1 The Little Alphas – Our Children**
- 4... **Understanding Alpha-1 Genetics**



Public Policy Update

Celebrating Spring with Advocacy Partnerships

By **Miriam O'Day**

Healthcare Reform Update

IN MARCH, the Health Care Reform legislation was signed into law. The goals of covering uninsured individuals and improving health care quality will take time to evaluate and the implementation timeline will be long. The Association did not take a position on the legislation, but we did work hard with our partners to ensure that provisions beneficial to those living with chronic diseases such as Alpha-1 were considered during the ongoing negotiations. To that end, we are happy to report that many provisions within the legislation will:

1. Protect from discrimination based on preexisting conditions,
2. Phase out lifetime and annual insurance caps, and
3. Guarantee issue of health insurance policies.

The Association partnered with the Plasma Users Coalition (PUC), a group of national patient organizations organized around the principal that individuals who require plasma based therapies have unique needs that can be best addressed with one voice during the national health reform debate. The PUC includes individuals with Alpha-1 Antitrypsin deficiency, primary immunodeficiency diseases, hemophilia and other bleeding disorders, Guillain-



Miriam O'Day

Barré, CIDP, platelet disorders, all of which represent patients whose lives depend on plasma derived therapies. The PUC advocated for affordable and quality coverage for all Americans and for all of the provisions mentioned above. As with all legislation, once passed, it is the responsibility of the federal agencies of jurisdiction to go through regulatory rule making. The Association will continue to work on behalf of Alphas and with our partners to ensure that we are not disadvantaged during the rulemaking process.

Understanding Genetic COPD: Alpha-1 Antitrypsin Deficiency Congressional Briefing

The Alpha-1 Association and Alpha-1 Foundation hosted their first Alpha-1 Congressional Briefing on Capitol Hill on Monday, March 8th. Speakers at the Congressional Briefing included John Walsh (CEO and President of

the Alpha-1 Foundation), Karen Erickson (Board Member of the Alpha-1 Association), and Julie Birkofer (Senior Vice President of the Plasma Protein Therapeutics Association). Karen gave a moving testimony that helped us all understand the personal struggles of living with lung disease. Various Legislative Aides visited, listened to, and met with the Alphas as well.

Alphas Storm the Hill

On March 8th and 9th, Patient Advocates from the Alpha-1 Community and respiratory therapists who are members of the American Association for Respiratory Care's (AARC) Political Advocacy Contact Team (PACT) converged in Washington, DC, for the AARC's annual Capitol Hill lobbying event. Together, they worked tirelessly to bring a cohesive message to their members of Congress through nearly 300 scheduled appointments. Twenty Alphas partnered with respiratory therapists and were able to enhance awareness on the importance of allowing qualified respiratory therapists to provide care outside the hospital setting— which will reduce costs and improve the quality of life for lung affected individuals. They also assisted our legislators in understanding the need to increase the Federal response to COPD— as this serious health issue is the 4th leading cause of death in the U.S.

American Association for the Study of Liver Disease (AASLD)

Father Jack Gentleman, a liver transplant recipient, and Vergene Schmidt, grandmother of an Alpha-1 patient, represented the Alpha-1 Community by participating in the AASLD's 3rd Annual Capitol Hill Day. They were paired with physicians to ask for increased funding for the National Institutes of Health and other legislative requests that will benefit those living with liver disease.

In Their Own Words

By Helen A. Nichols

"I saw the Washington trip as an opportunity to plant seeds of knowledge about Alpha-1 into what could be very fertile ground. My assigned respiratory therapist and I were able to successfully discuss with our legislators the benefits of allowing a



qualified Respiratory Therapist

to provide care outside the hospital setting and the need to increase the Federal response to COPD. Indeed, the AARC and Alpha-1 are a match made heaven!!!"

In Their Own Words

By Vergene Schmidt

"I would like to thank the Alpha 1 Association for giving me the opportunity to visit Washington, DC during the Liver Capitol Day event. Every office that we visited seemed very receptive of our request for continued and increased funding for research and treatment of liver diseases. We visited the offices of Senator Grassley, Senator Harkin, Congressman Boswell, and Congressman Loeb sack. We were unable to talk with the members themselves, however, we did talk



with staffers in all 4 offices who took notes and assured us that their members were all supportive of research, etc. The group that I was with included Miriam O'Day, and Douglas LaBreque, MD, Director of Liver Services at University of Iowa Hospital & Clinics at Iowa City. Dr. LaBreque is an impressive advocate for liver research and presented our case very well."



1/1/10-4/15/10

These donations help to advance the mission of the Alpha-1 Association. If you would like to post a memorial statement, please visit the Memorial Garden on the Discussion Forum on our website at www.alpha1.org. If you would like to make a donation, please visit the Donate section on our website or contact us in any of the following ways: Phone: 1-800-521-3025 or (305) 648-0088. Email: info@alpha1.org; Mail: 2937 SW 27th Avenue, Suite 106, Miami, FL 33133.

The Alpha-1 Association gratefully acknowledges those who have generously made a contribution in memory or honor of someone special in their lives:

In Memory

In Memory of True Chapin

Cheryl Pecorella
Shelby & Louise Sliker

In Memory of James Dege

Renee Barrett

In Memory of Larry Enklemann

Kurt Enklemann

In Memory of Chris Ennis

Maureen Ennis

In Memory of George E. Hodge

Barberie Radanovich

In Memory of Dr. David Pogue

Mrs. Georgia Pogue

In Memory of James "Vick" Shea

Robert Labonte

In Memory of Karen Simonini

Hon. & Mrs. Gene Nottolini

In Memory of Richard Smith

Betty Smith

In Memory of Lisa Stevens

Ivan Carroll

In Memory of Stewart Windham

Marlene Erven
Carl & Mary Vinson

In Honor

In Honor of Tom Corron

Alan Adams
Barbara Alvard
Dorothy Corron
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Bob Meyer
Terry & Linda Meyer
Patricia R. Perrozzi
Amy Plymat
Gregory Ruble
Sarah Corron Toms

In Honor of Jean McCathern & Kathy Haduck

Shirley Yarnall

In Honor of Dana Jones

Ralph Jones

In Honor of Nancy Klinghoffer

Karen Cook

In Honor of Julie Knutson

Norris & Doris Knutson

In Honor of Barb & Ed Lamping

Bernard & Renee Lustick

In Honor of Hannah Lloyd

Catherine Lloyd

In Honor of Barbara Stuart

Beth Karjala

Support Group News

By Cathey Horsak

What an exciting spring it has been for the Association's Support Group Network! The Support Group Network of volunteers continued their steadfast path of providing **support, education and advocacy** to their local support group members. In the last few months, some wonderfully eager people, dedicated to creating support and awareness in their community, have decided to become Support Group Leaders.

Let me introduce you to **Brian Travis** from Ft. Wayne, Indiana. Brian's goal is to help Alphas in the Ft. Wayne area. He says *"I did all my own research on Alpha-1, because my doctor did not have any information about it. All he knew was to test for Alpha-1 and nothing else. I felt so alone like most Alphas I have been talking to on Facebook."*

Motivated and inspired by the Education Day held in Ann Arbor, Michigan, **Jeannette Therrian**, stepped up to start a new group. This group will meet in the Clarkston, Michigan area. Jeannette is starting the group because *"we all have something in common but there is a lot that makes us different. . .and we can learn so much from each other*



Alabama Support Group Meeting

. . .there is no better way to learn through experience, or by someone we actually know going through the same thing."



Oklahoma Support Group Meeting

It's been awhile since North Dakota has had a support group, but thanks to **Roger Hanes**, they do now. He just signed on as a new Support Group Leader. Roger was inspired to start a group after attending the San Francisco National Education Conference last year. One of his goals is *"to get other Alphas together and involved to help identify more Alphas in the state."*

Robert Metcalf, a former police officer, is stepping up as the new Support Group Leader for the Orlando, FL group. Robert lost his father to Alpha-1 in 1998. He says, *"I have received a great deal of help in*

the past and it is my mission to give back to the Alpha-1 Community."

The Hershey, Pennsylvania area is also getting a new Support Group Leader. **Laura Austin** and her husband, Arthur, are teaming up to help Alphas in their area. Laura says *"I love to help people. I know what my support group did for me, helping me to realize that I could live with Alpha-1 and that I was at the beginning of a new journey."*

The Association thanks **Patty Tew** in Orlando and **Jean McCathern** in Hershey for their dedicated service as Support Group Leaders and wish them well in their new endeavors as AlphaNet coordinators.

If you love helping others, want to give back, share experiences and educate other Alphas, then maybe you really want to become an Alpha-1 Association Support Group Leader. As a Support Group Leader, you can help find other Alphas and provide them with support. If you are interested in starting a new support group in your area, please contact **Cathey Horsak**, chorsak@alpha1.org or **877.346-3212**.



South Florida Support Group

Ask A Nutritionist



Heather Driscoll, RD, MBA is a Registered Dietitian and Manager of Clinical Nutrition at the University of Colorado Hospital. She has both a Bachelor of Science in Nutrition and an MBA from the University of Colorado. Her specialties include nutrition and aging, eternal nutrition, nutrition advancement with neurosurgery, and nutrition in respiratory disease.

Questions in this column represent the most frequently asked questions from Association members. This column is not intended to provide specific medical advice, which can only be obtained from a health care provider who has knowledge of the details of your particular health situation. The opinions expressed in this column represent those of the author.

Q Is it necessary, and why, to take a magnesium supplement if you are taking calcium and vitamin D supplements?

A Yes, magnesium has been shown in studies to improve lung function in asthmatics, up to 6% in 6 months. It acts as a bronchiodilator. Calcium and Vitamin D have similar pathways, though, to absorption, so it is important to space supplements out over the day. Calcium is vital for the ionic exchange in the muscles during contraction in breathing. Vitamin D is essential for the body to absorb calcium and it is also thought to be able to repair lung tissues.

Q Are there certain foods that cause shortness of breath?

A Certain foods are classified as "gassy foods": broccoli, cauliflower, beans, and cabbage are some. Carbonated beverages also produce excess gas. These gasses are not helpful for breathing and can cause bloating. High sodium foods are also to be avoided, as they cause bloating and pressure on the lungs as well. Avoid large meals. Instead space small ones throughout the day for adequate nutrition.

Q Are there specific foods or drinks that should be avoided to prevent fluid overload with augmentation therapy infusions?

A As stated previously, sodium should be avoided. Sodium is highest in processed foods, unfortunately. Look for easy to prepare "healthy" meals that list sodium. A rule of thumb is try to stick to less than 2000 mg sodium per day. Food manufacturers are beginning to improve their sodium and sugar content to meet the health demands of consumers.

Q Are there certain foods that cause reflux problems for Alphas?

A Fluid overload with augmentation therapy can be complicated by several factors. Malnutrition or poor protein intake puts patients at higher risk. Sodium and other electrolyte balance should be monitored if there is suspected liver, kidney, or congestive heart failure. Other medications like steroids can contribute to these imbalances. Also, stress and hormones are factors to consider.

Q What can an Alpha incorporate in their diet to help reduce inflammation?

A Inflammation can be reduced by eating foods closest to their natural state. Fried foods, processed, refined sugar and

white flour, candy, sugary cereal, soft drinks, pastries, and junk foods are all implicated in inflammation. The exception to the whole foods is the nightshade family: potatoes, tomatoes, and eggplant. Saturated fat also has a component that triggers inflammation: the fatty acid arachidonic acid.

Q Why do carbohydrates make breathing more difficult? Are there "good" carbohydrates for Alphas?

A Simple carbohydrates are the least desirable source of energy: white flour, white rice, white pasta, sugary pastries and cereals. The way the grain came off the plant is the best carbohydrate: whole grain flour, brown rice, whole grain pasta, whole grain baking mixes. Whole grains are a complete package of nutrition: the fiber in the hull, the starch in the endosperm, and the oil and protein packed into the bran. The vitamins and minerals are included in the grain, rather than sprayed on in the enrichment process of refined starches.

As with any nutrition advice, a Registered Dietitian is the best resource to customize a program based on physician recommendations, labs, and anthropometrics.

Turning Limitations

By Cathey Horsak and Jonathan Welsh

A

SICK LUNGS DON'T SHOW, sometimes friends, colleagues, and family members may be unaware of the difficulties that Alphas face. As a result, many Alphas extend themselves further than they should and are forced to make choices between their health and the people they care about. This elevates fear, anxiety, and stress.

Here are some examples of challenges that Alphas have faced:

Tom Corron- IOWA

"There are many activities or events that I feel an obligation to attend or participate in but in so doing,



I am really overextending myself. For example, I perform weekly with the Senior Radio Theater Group. Half of the group members are women and a few men well into their seventies. At age 55, I am definitely the youngest, yet I probably have the worst lung function in the entire ensemble. We have a number of heavy and large items that we cart around to each performance. Our Director asks everyone to help and I feel badly if I don't help, but when I do it is really difficult and strenuous. I

get winded and out of breath tying my shoes nowadays due to my condition, however, I am perceived as one who should carry, load, and unload our heavy equipment. I don't carry around an oxygen bottle yet so they can't see my disability, my sick lungs!"

Liz Veronda- ILLINOIS

"Recently my family had been trying to encourage me to visit my grandmother every two weeks since I have some free time. It's not that I do not want to see Grandma...it's three hours of driving to and from along with the two hour visit which makes for an exhausting day. So I try to visit at least once every six weeks. I also used to make incredible fruit

tray displays for special events. One business owner begged me to make some trays for his function, but I had to refuse as it just takes too much out of me. It feels bad to tell friends and family that you are not able to help them. But when I see the positive results of taking care of myself, I know in the long run I am doing the right thing for everyone. The more I take care of myself, the longer I will stay independent and the less I will have to rely on others to do things for me."



into Opportunities

Bonnie Chakravorty, PhD, MSW, CHES, TENNESSEE

"This is my advice to those who may be uncomfortable with saying no..."

1. First and foremost– be honest with yourself– are you actually unable to give help or otherwise comply with a request? Sometimes we do need to push ourselves a little to stay in the game. For example, I just wanted to rest one day. I was a little tired but not debilitated. My visiting adult daughter wanted me to play Scrabble with her. At first I begged off saying I was too tired but after a little cajoling I did force myself to play and it was fun- in fact it perked me up. Be honest with yourself– don't use your condition as an excuse for things that you can and should do (such as exercising, socializing, etc.). Talk with your doctor about things that you should avoid (e.g., crowds during the holidays; smoky nightclubs, sick grandchildren, etc.) and know when there is an actual medical reason not to participate. You can refer to AlphaNet's Big Fat Reference Guide online for detailed explanations about why you cannot participate in certain activities. This brings me to my next point.

2. Does the person asking for help already know the nature of your condition? If not, you need to put it out there. At work I had to explain to co-workers why I actually couldn't just run over to another building and be back in five minutes. I like to use the analogy of breathing through a pinched straw– try doing that and walking around a large campus! Explain why it is that you are unable to do what you have been asked.

3. Ask yourself, would you really have wanted to do something for the person making the request if you were able? If yes, explain that you are unable to help those at this time and include an offer to do something you can do, or something you could do at a later time. For example, you might really want to help out with your grandchild but can't at this time. You might offer to help in



some other way, such as paying for a babysitter, or making something for your grandchild when you feel up to. Clearing up after dinner? Perhaps you can scrape the plates after they have been collected, or ask your hosts what else you can do."

MANY ALPHAS are faced with similar situations. It is okay to advocate for yourself with family and friends and let them know that you have a lung disorder that prevents you from doing some activities but that you can do your part in other ways. Communication and honesty are important to those around you. Let them know about both your feelings and limitations. Also, if you are in a situation where you feel physically pushed beyond your limits, don't be shy to ask your family and friends for support and assistance. It may not be easy to ask for help. Nevertheless, getting help from others will not only benefit you, but it will also be an opportunity to educate others about Alpha 1-Antitrypsin Deficiency too.

BUILDING FRIENDS FOR A CURE

By Angela McBride



BUILDING FRIENDS FOR A CURE (BFC) is a grassroots initiative to raise funds through community fundraisers, including our Team Alpha-1 Program, and to foster an even more involved community.

A key part of the Alpha-1 Foundation's reason for being is research for better health and ultimately a cure for Alpha-1. Every year, these fundraisers play a greater part in funding our research programs.

That's why we believe in training our volunteer fundraisers.

This spring, Alphas, their family members and friends learned the details of raising both awareness of Alpha-1 and funds for Alpha-1 research at our Building Friends for Cure training in Needham, MA.

The trainees learned the best and easiest ways to get involved. At the end of the program, they walked away with the tools they need to raise funds for Alpha-1 research in their communities.

We outlined event organizing, including how to choose an event (make sure it's something you're comfortable with!), recruiting friends,

Spring training for volunteer fundraiser's

family and others to help, how to get donations and find sponsors, budgeting, paperwork, and getting help from the Foundation staff.

Two experienced volunteers talked to the group about their experiences. Sheila Favazza discussed the Celtic Connection fundraising dinner and organizing its silent auction; Fred Walsh talked about the annual Escape to the Cape bike ride on Cape Cod.

Foundation President & CEO John Walsh presented the new BFC trainees with their graduation certificates and spoke to the group about the importance of their work in both getting out the Alpha-1 message and helping to support Alpha-1 research programs.

Then the new BFC training graduates teamed up with committee members for one of our most successful events for the past two years – the Celtic Connection.

They watched the organizers in action, assisted with preparations and the event itself, and enjoyed an evening of Irish music,

dancing and a traditional St. Patrick's Day dinner.

All the graduates plan to organize their own community event within the next year, using their newly acquired knowledge.

The training graduates came from all over the country: Julia Torres Barden from Ohio; Sarah Bradly from Iowa; Mindy and Neal Catron from South Carolina; Tom Corron from Iowa; Judi Kaplan Elkin from Massachusetts; Peg and Peter Iverson from Iowa; Ken Richmond from Virginia; Sandy Ringgard from Massachusetts; Lucinda Shore from Tennessee; Troy Sutherland from Iowa; Timothy and Desiree Truett from Arizona; Pam Vanscoy from Virginia; and Jay Whitmore from Georgia.

Would you like to take advantage of our next BFC training? Contact **Angela McBride** at **(888) 825 7421, Ext. 233**, or **amcbride@alpha-1foundation.org**.

July 18	Second Annual Get the Scoop on Alpha-1	Johnston, IA	Peg Iverson
Aug. 9	2nd Annual Memorial Paul (PJ) Healy Golf Tournament	Halifax, MA	Bob Healy
Sept. 9	Alpha-1 Golf Tournament	Greenwich, CT	Ken Irvine
Oct. 1-3	Team Alpha-1 Escape to the Cape	Cape Cod, MA	Sue Binnall
Nov. 20	2nd Annual Alpha-1 Ocean Walk Miami	Miami, FL	Angela McBride

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Phone: 800-521-3025 ext 14
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Alpha-1 News is the magazine of the Alpha-1 Association. It provides pertinent news and information for individuals diagnosed with Alpha-1, their family, friends, caregivers, medical professionals and all people touched by Alpha-1.

The Alpha-1 Association gratefully recognizes the advertiser of this issue: Talecris Biotherapeutics and CSL Behring.

No part of the promotional materials inserted in the newsletter implies that the Alpha-1 Association supports or endorses any of these products or services. Individuals should consult with a physician and other qualified professionals for medical advice concerning their treatments.

ALPHA-1 ANTITRYPSIN DEFICIENCY (Alpha-1)



Association at www.alpha1.org.

ALPHA-1 is a genetic/hereditary condition passed through genes from parents to their children. It may lead to liver disease in infancy or adulthood and/or lung disease, especially when there is exposure to cigarette smoke, dust or inhaled irritants. For more information on Alpha-1, please visit the Alpha-1

Alpha-1 Association provides an array of programs and services for patients and families:

Support Group Network

- 75 Support Groups
- Virtual Support Groups for Alpha-1 Families, Caregivers, Transplant Group and Phone Buddies

National Support Programs

- Patient Information Hotline: **1-800-245-6809**
- Peer Guide Program: **1-877-346-3212**
- Genetic Counseling Call Center: **1-800-785-3177**

Education

- Annual National Education Conference
- National Patient Education Series
- E-Education

Advocacy

- Grassroots Advocacy Network

**The Alpha-1 Association recognizes our
2010 Core Program Sponsors:**

Baxter
CSL Behring
Talecris Biotherapeutics

Core Program Sponsors are the highest level of contributors to the Alpha-1 Association providing major support to our 19th Annual National Education Conference, 2010 National Education Series and Support Network.

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We apologize if you have received more than one copy of this newsletter, and encourage you to share it with your healthcare providers, family members and friends.

2010 Calendar of Upcoming Events

Date	Event	Location
June 24, 2010	Massachusetts Support Group Meeting	Needham, MA
July 17, 2010	Connecticut Nutmeggers Support Group Meeting	Wallingford, CT
July 24, 2010	Oklahoma Alpha Okies Support Group Meeting	Oklahoma City
August 7, 2010	Missouri Support Group Meeting	Springfield, MO
August 8, 2010	Denver Support Group Meeting	Denver, CO
August 12, 2010	Massachusetts Support Group Meeting	Needham, MA
August 14, 2010	South Florida Alphagators Support Group Meeting	Miami, FL
August 28, 2010	Alpha-1 Education Day	Des Moines, IA
September 25, 2010	Alpha-1 Education Day	Las Vegas, NV
September 25, 2010	Oklahoma Alpha Okies Support Group Meeting	Oklahoma City

Please visit the Alpha-1 Association Calendar at www.alpha1.org for more information on Alpha-1 Association and Support Group Meetings and Conferences.