



# ALPHA-1 FOUNDATION RESEARCH REGISTRY UPDATE



Vol. 13 / Issue 1 / Spring 2011

## Celebrating 10,000 Alphas tested



*Letter from  
the Director*

Dear Alpha-1 Foundation Research Registry participants,

WELCOME to our 2011 spring newsletter that I hope you will enjoy. As always, we plan a mix of science and humanity in our work and I believe this newsletter fits the bill.

We are celebrating our 10,000th Alpha-1 test that has been completed through the Alpha Coded Testing (ACT) Study! While this is a nice round number, I am using this public letter to let you know how proud I am of the Registry staff. It is their diligence that ensures that every test is handled correctly and results are returned with

the support you need to handle the important genetic information generated. I also want to thank those of you who have used ACT for confidential testing. I am convinced that the research studies we have done will make a difference in the rare disease community now and for many years to come.

With this letter we are introducing our new Registry Coordinator, Mike Graves. Before joining us, Mike worked in the Department of Surgery at the Medical University of South Carolina (MUSC) for three years in a tumor immunology research laboratory. This means he is smart. He has an M.A. in biology and is currently in pursuit of his MBA part time. If you see him at an Education Day soon, please welcome him into the Alpha-1 community and teach him everything you have taught me about the disease. Mike will be working on



our databases that you will hear more about in the next newsletter. Additionally, we want to publicly thank Rebecca McClure for her three years of service as Registry Coordinator.

As always, please call or email with your great suggestions or any concerns with the Registry. Thank you for all that you do to advance new therapies for Alpha-1 by participating in research studies as they become available. Remember to invite your family members with Alpha-1 to join the Registry. Our new online form takes on average about 15 minutes to complete.

Thank you,

*Charlie Strange*

Charlie Strange, MD  
Director, Alpha-1 Foundation Research Registry  
Professor of Pulmonary and Critical Care Medicine  
Medical University of South Carolina

# ACT Study tests its 10,

“Now, I feel a weight has been lifted



By *Laura Schwarz*  
*ACT Study Coordinator*

The Alpha-1 Coded Testing (ACT) Study tested its first participant in 2001. A few months ago, Rosalie Larson ordered an ACT test, promptly returned it to us, and received her result in the mail a few weeks later.

Little did she know that she would be given the spotlight as the ACT Study's 10,000th participant! Her ACT Study testing found she has a ZZ genotype. Since her diagnosis, she started augmentation therapy and began researching Alpha-1, which she hadn't heard of until recently.

She grew up on a farm in Beavercreek, Oregon, the small town she still lives in today. Her father cleared the land and built their house himself. They had all kinds of animals on the farm, which Rosalie, her brother and two sisters cared for. Other chores she was required to do were picking blackcaps – often called black raspberries – strawberries, and beans every year. One of her favorite memories from her childhood was riding her horse, Patsy, with her siblings and friends. Rosalie and her family also enjoyed fishing, hunting, and camping.

Rosalie developed severe asthma about the time she started grade school. Her mother also had chronic asthma, so debilitating that she could hardly walk, and died at an early age.

**She also met many Alphas, and was amazed at their positive attitude and how they dealt with their illness. When the meeting was over, she told her husband that she had a whole new outlook on life.**

Rosalie married and had a baby daughter. Her daughter was found to have a congenital heart disease when she was three months old. She also developed asthma at age four, requiring allergy shots all the way through high school. Rosalie worked at a paper mill to help pay for her daughter's medical bills before her premature death at just 23.

In recent years, Rosalie began to develop pneumonia every year, sometimes twice. Last May, her primary care doctor diagnosed her with pneumonia and prescribed antibiotics and prednisone that left her still gasping for air. The doctor referred her to a

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You may contact the Alpha-1 Foundation Research Registry staff by email, at [alphaone@muscc.edu](mailto:alphaone@muscc.edu) for additional assistance in locating resources related to Alpha-1 research, to obtain information about current research activities, to participate in the Research Network or Registry, or to receive Foundation publications.

# 1000th patient – an Alpha

“Off my shoulders, knowing I can live longer...”

pulmonologist. The pulmonologist noticed that her X-ray showed emphysema predominant in the lower lung. That made the pulmonologist suspect that she might have Alpha-1. He ran a blood test that showed Rosalie had a low Alpha-1 level. He also ordered home oxygen.

Her pulmonologist recommended that she attend a support group meeting at Oregon Health and Science University. At the meeting she met Dr. Alan Barker, who heads the Clinical Resource Center in Portland.

She also met many Alphas, and was amazed at their positive attitude and how they dealt with their illness. When the meeting was over, she told her husband that she had a whole new outlook on life.

“Having pneumonia and shortness of breath made me terrified that my life would be cut short,” she says. “Now, I feel a weight has been lifted off my shoulders, knowing I can live longer than I feared.”

She picked up the Alpha-1 Foundation’s brochure about the ACT Study and ordered a test kit for a second opinion. And following a suggestion she was given at the meeting, she recommended the ACT testing to her father and siblings. Her ACT results matched her previous test with a ZZ genotype. Her father, brother, and one sister tested as MZ carriers, while her younger sister was ZZ like Rosalie.

In September 2010, her pulmonologist started her on augmentation infusions once a week. He ordered a sleep study,

then a CPAP machine to wear at night. She uses a portable oxygen tank during the day when she is mobile.

Rosalie and her husband LeeRoy will celebrate their 30th anniversary this September. They have three healthy grandchildren.

Alpha-1 has not kept Rosalie and LeeRoy from riding their all-terrain vehicles up in the mountains at Mt. Hood National Forest. Rosalie calls LeeRoy and herself “putters,” meaning they don’t go over 25 miles an hour! She says that at their age they can’t afford any broken bones.

Rosalie feels that her pulmonologist saved her life. With her current therapy she can exhale easier and her lungs don’t burn the way they used to. She tries to maintain a normal lifestyle. “The portable oxygen gets a little tiresome but I deal with it,” she says. “I know there are many people out there a lot worse off than I am.”



*Rosalie Larson*



**Featured Clinical Resource Center:**

# University of Iowa teaches young doctors to recognize Alpha-1 early

By Jeff S. Wilson, MD

Professor

Director, Pulmonary Fellowship Program

University of Iowa

The University of Iowa's involvement as a clinical resource center for patients with Alpha-1 Antitrypsin Deficiency began in the late 1980s, when we were one of the clinical centers in the National Heart, Lung and Blood Institute (NHLBI) registry of patients with severe Alpha-1. We were able to contribute data from 30-35 individuals to the NHLBI Registry.

The expertise developed through our participation has allowed the University of Iowa to serve our state and surrounding area as a referral center for clinical care. Those with pulmonary disease benefit from a state-of-the-art lung function lab, an outstanding pulmonary rehabilitation program and a very successful lung transplant program.

We also have expertise in liver disease for both children and adults.

Dawn Ebach, MD, in the Department of Pediatrics, trained at Washington University in Saint Louis where she worked with well-known Alpha-1 researchers David Perlmutter and Jeffrey Teckman. She has a special interest in metabolic liver disease.

Michael D. Voigt, MD, is Medical Director of Liver Failure and Transplantation. He has a special interest in Alpha-1 related liver disease. His areas of research interest include autonomic function in portal hypertension and its effects on hemodynamics, pulmonary vascular and renal function.

A primary goal at the University of Iowa is the education of young physicians in the recognition and treatment of Alpha-1. The physician knowledge gap in this condition is well known and persists today. It frequently leads to a delay in diagnosis and institution of optimal treatment.

This delay in diagnosis in the United States was first described by James Stoller, MD, and colleagues in the Cleveland Clinic Journal of Medicine in 1994. One of my Alpha-1 patients, Judy Spray, PhD, was a contributing author to this study. Judy and I had several conversations about this problem of delayed diagnosis, which helped me better understand its severity.



*Dawn Ebach, MD*

**SMALL GROUP LEARNING** – In the mid-1990s the curriculum at the University of Iowa Carver College of Medicine was revised to include an increased emphasis on case-based small group learning. In the first year of medical school, the cases are paper-based. Small groups of students (usually six or fewer) work their way through

these cases identifying areas they need to learn about, actively researching these “learning issues,” and reporting back on what they have learned to their colleagues. Faculty facilitators help to keep the students on track. This emphasis on active learning teaches students what questions are important, where to find the answers and promotes better retention of knowledge.

We developed a case for Alpha-1 involving a young man presenting with severe obstructive lung disease. The case provides a wide spectrum of possible learning issues encompassing patient history, physical exam skills, interpretation of lung function and other laboratory tests, pharmacology, physiology, genetics, nicotine addiction, transplantation and many others.

It is exciting to see how interested many of the students become during the case discussions. When the case is finished there is a wrap-up session with the entire class. This year, Peg Iverson – the Iowa Alpha-1 patient support group founder and leader – came to this session with me and spoke with the students about her experiences living with this condition. The students were rapt in their attention while she spoke and had many questions. She received more applause at the end than I ever have!

From working with third-year students in the pulmonary clinic, I know this case is very effective in promoting lasting knowledge about Alpha-1. Any institution interested in using this case for student teaching, please contact [jeff-wilson@uiowa.edu](mailto:jeff-wilson@uiowa.edu).



*Michael Voigt, MD*



# Ask the Alpha Doc

By Jeff S. Wilson, MD

## **Q: When should I use oxygen for my Alpha-1 lung disease?**

**A:** Oxygen can be a very important part of the treatment of those with lung disease from Alpha-1-Antitrypsin Deficiency. In the right setting, it can lessen shortness of breath, improve exercise capacity and prolong life.

It is important to recognize that shortness of breath is often not a good indicator of the amount of oxygen in your blood. The best way to determine whether oxygen can help you is to have your oxygen level measured. Measurement of your arterial blood oxygen level is the most accurate – this is usually taken from the radial artery in your wrist.

Chronic long-term oxygen therapy is recommended if the resting arterial partial pressure of oxygen is < 55 torr, or if you have evidence that the right side of your heart is strained - < 60 torr.

Measurement of oxygen saturation with a pulse oximeter probe placed on the finger, forehead or ear is another common way to measure oxygen levels. It is easier to perform, but less accurate, than an arterial blood oxygen test. An oxygen saturation value equal to or less than 88% (or less than 90% with right heart strain) is an indication for chronic oxygen therapy. If chronic long-term oxygen is indicated, it should be used at least 18 or more hours per day.

Some people may not meet the above criteria when awake and at rest, but do when they exert themselves and/or are asleep. The value of using oxygen in these settings is not as clear-cut.

Wearing oxygen with exercise/exertion can improve your oxygen levels. However, I hear quite frequently from my patients that the energy needed to carry or pull the portable oxygen cylinder seems to offset the benefit of more oxygen in the blood. (Modern lightweight portable oxygen units might reduce or eliminate this problem.) Using oxygen during stationary exercise on a treadmill or bicycle is easier because the oxygen source does not have to be carried.

Wearing oxygen at night in the setting of poor sleep or evidence of right heart strain can also be beneficial in selected individuals. Every person's situation is unique; discuss the use of oxygen with your physician.

## **Q: When should a patient with Alpha-1 lung disease consider a lung transplant?**

**A:** For carefully selected individuals with severe lung disease, lung transplantation can improve both quality and length of life.

Lung transplantation is generally considered in individuals who are very limited and symptomatic in their activities of daily life. Most are using oxygen, either chronically or with exertion. Their lung function tests are severely abnormal -- typically FEV1 or diffusing capacity below 20-30% of the normal value. Basic requirements for being considered for lung transplantation include not currently smoking, exercising regularly, having a near normal weight, compliance with taking medications and having a strong social support system. These requirements increase the likelihood of success of the procedure.

Having a lung transplant is a rigorous process that requires careful long-term follow-up – including the long-term use of immune-suppressing medications to prevent rejection, and regular bronchoscopic examination of the airways with lung biopsy to monitor for evidence of rejection or infection.

If successful, most individuals have significant improvement in their quality of life and are able to do more activity with less shortness of breath after transplant. The average 5-year survival after lung transplant is 50 – 55%.

It is important to recognize that the time from your initial transplant evaluation to receiving a new lung or lungs may be over one year. You should talk earlier, rather than later, with your lung doctor if you would like to explore the option of lung transplantation.

# An Alpha-1 diagnosis can lead to em

Being a part of the Alpha-1 community opened my eyes to the importance of health literacy for managing disease.

By Symma Finn, PhD  
University of Florida



My interest in patient empowerment in the Alpha-1 community began when I started working for the Alpha-1 Foundation. There I had the opportunity to meet many diagnosed individuals and their families, and to work with organizational leaders. These people impressed me with their dedication to finding a cure for Alpha-1, and their support for each other. Being a part of the Alpha-1 community opened my eyes to the importance of health literacy for managing disease. I saw that many

**Being a part of the Alpha-1 community opened my eyes to the importance of health literacy for managing disease.**

excellent efforts were already underway to increase knowledge about Alpha-1, and the strength of the support network for Alphas and their families.

I began research on empowerment and conducted interviews and focus group sessions to find out what empowerment meant to those affected by Alpha-1. My preliminary conclusions were that key elements of empowerment in Alpha-1 included health literacy

(knowledge), support, disease self-management, and proper treatment. I then designed a survey to test the extent of empowerment among Alphas.

After analyzing the information from the focus group sessions and interviews, I read a great many articles about empowerment and how to measure feelings and attitudes among patients. I found that there were existing survey instruments that had proven useful and adapted several of these for my survey. I also re-interviewed “key informants” to help me develop survey questions so that they would be understandable. Key informants are people who I came to know well over time and who were able to help me understand the views and perspectives of Alphas. I then tested selected questions with individuals attending an Alpha-1 Association national educational conference, and revised the questions to make them more understandable.

The survey was sent to 2,476 individuals enrolled in the Alpha-1 Research Registry. The results were analyzed to understand empowerment in Alpha-1. Additionally, I asked if promoting empowerment in the Alpha-1 community could improve people’s lives.

## THE DIAGNOSIS EXPERIENCE

After analyzing all the survey responses, it became clear that having a favorable experience at diagnosis jump-started the empowerment process. Unfortunately, many Alphas have an unfavorable diagnosis experience.

### Examples of an unfavorable diagnosis experience:

- Alphas are not diagnosed quickly after the onset of symptoms;
- or Alphas are told they have a fatal disease with no effective treatment.

**A favorable experience at diagnosis**, on the other hand, would be being told you have Alpha-1 and immediately being told about support groups and the Alpha-1 organizations. This favorable diagnosis experiences also included being given educational materials, or being counseled by a genetic counselor about how to deal with having Alpha-1 and about your family’s risks.

Other important elements of being empowered were being married (which was interpreted as having some support at home); being less ill on overall health score; spending fewer symptomatic years before diagnosis; and having the ability to work.



## Is a webcam better than the telephone for genetic counseling?



*By Dawn McGee  
Program Director, Alpha-1 Association  
Genetic Counseling Program*

The most important element leading to empowerment was years to diagnosis, which was interpreted as getting the proper diagnosis in a timely manner and getting the right kind of treatment and information.

The survey responses showed that many members of the Alpha-1 community are empowered – the majority who answered the survey improved their awareness over time, and although many had negative feelings at diagnosis, they had increasingly positive feelings and chose more positive actions over time.

My overall conclusions are that empowerment begins with a favorable diagnosis experience. This experience requires family and community support, and enough education about Alpha-1 for patients, families and caregivers to manage illness episodes and maintain health. The research shows that the Alpha-1 organizations are providing the right type of information and support to empower Alphas, families and caregivers, but this information must be made available when people are first diagnosed. Lastly, after Alphas understand the essentials of their disease, there is an additional need to provide more advanced information to understand how to best manage Alpha-1.

The Alpha-1 Association Genetic Counseling Program has been providing confidential genetic counseling for over three years by telephone. Now, a new research study has been approved by the Medical University of South Carolina to provide genetic counseling

by video conferencing (on a computer screen) in addition to telephone.

This method of delivering service is called telemedicine – using electronic technology to connect a health care provider with the patient.

Telegenetics is providing genetic services by telemedicine. This alternative to traditional genetic counseling was created so that patients in rural areas could have access to genetic counseling. In general, genetic counselors are available at larger medical centers in cities. For patients who live hours away from the nearest medical center, it is difficult to see a genetic counselor in person. By providing services by telephone or video conference, patients can benefit from genetic counseling regardless of how far they live from the medical center. The Alpha-1 Association Genetic Counseling Program was created to allow patients all over the country, as well as Canada, access to disease-specific genetic counseling for Alpha-1.

A disadvantage of telephone-based services is that the caller and the genetic counselor cannot see each other; therefore, they are not able to communicate through visual cues. In video conferencing, the caller and the genetic counselor can see each other. The most common video conferencing software today is Skype. Skype is currently a freely downloaded software program that requires a web-compatible camera (webcam). Webcams are built into many current computers.

The new research study will examine caller satisfaction from genetic counseling provided by telephone compared to video conferencing through Skype.

When someone calls the Genetic Counseling Program requesting genetic counseling, they will be invited to participate in the study. If they agree and have access to Skype, they will be randomized to receive the services by either Skype or the telephone. If the caller wants to participate but does not have access to Skype, they will still be able to participate and will receive genetic counseling by telephone. The results of the study should give us a good idea whether telephone or video conferencing is a better way to convey complicated genetic information.

The perfect study – to see if in-person counseling is superior to either the telephone or the computer – will need to wait for another day.

Regardless of whether a caller participates in the study or not, the Genetic Counseling Program is available to everyone in the Alpha-1 community that wants genetic counseling for Alpha-1. If you have questions about the study, or want to talk confidentially to a certified genetic counselor about Alpha-1, just call 1-800-785-3177.

# ACT Joins the 21st Century! Test kits now

More than 700 people have ordered free, confidential test kits through ACT's new electronic system, replacing paper forms



By *Laura Schwarz*  
ACT Study Coordinator

If you requested a free confidential Alpha-1 test through the Medical University of South Carolina in the last few months, you may have been directed to our web site at [www.alphaoneregistry.org](http://www.alphaoneregistry.org) where our new electronic Alpha-1 Coded Testing (ACT) Study consent form and research questionnaire are now found. If so, congratulations for filling out your online forms correctly!

Yes, in September 2010, the ACT Study entered the 21st century by doing away with paper forms and introducing online forms.

To make this transition as easy as possible for our ACT participants and ourselves, we obtained a new computer program called REDCap or Research Electronic Data Capture. This program was discussed in the last issue of the Registry Update, because the same program is used for the Research Registry application and survey.

REDCap offers secure, web-based applications designed to gather data for research studies. Vanderbilt University initiated the REDCap program, which is currently used by about 110 medical universities, hospitals, and other medical research groups. REDCap consortium partners include Harvard, Stanford, Yale, the Mayo Clinic and the Cleveland Clinic.

Here at MUSC, the ACT Study is one of 30 active studies using REDCap. We store all data collected through REDCap on secure, firewall-protected university servers.

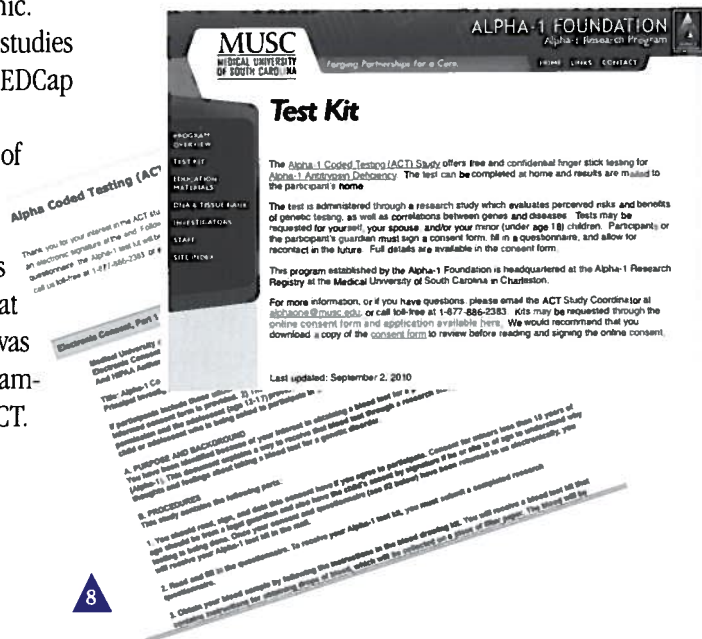
**They like it:** We are pleased to report that most of the feedback has been positive since this transition occurred. There have been a few complaints, however, from those who either are not familiar with computers or do not have Internet access. It is important to us that the Alpha-1 community understands why this change was necessary so that you will continue to encourage your family members and friends to test for Alpha-1 through ACT.

As many of you know, we previously sent the ACT fingerstick kits with the consent and research questionnaire included in the package. This method required excessive amounts of time and paper. For example, sometimes a kit was returned without the required consent form or questionnaire. We had to hold the test kit until we received these documents. That required telephone calls, usually multiple times, asking the participant to return their forms. More often than not, the forms had been misplaced, which meant they had to be resent. We don't like calling and bothering people any more than people like having to complete our paperwork.

These problems described are eliminated with the new online system.

The REDCap program is designed so that participants "sign" the consent (by typing their full name into the space provided) as the first step in study participation. They cannot fill out the questionnaire until the consent is signed. Once signed, they are directed to the survey, which must be completed entirely before the SUBMIT button can be clicked successfully. Again, the system doesn't allow anyone to skip sections. Once the questionnaire is complete, the participant can click the SUBMIT button and both forms are sent to us. The test kit is then shipped within one week.

Please be assured that we still keep the results confidential by mailing them to the participant. We never fax, email, or give results over the phone.





ordered online

# How to donate your body tissues – or your body – for Alpha-1 research

*By Michael Graves  
Research Registry Coordinator*

This new system is very beneficial to us because we receive the information we need, which is easily exported to a database. We don't waste time tracking down unreturned consents and unfinished questionnaires. There are also benefits to the participant. One is the "Save and Return Later" option.

This allows anyone to save their survey and return later to exactly where they left off. Also, we can hide questions if they do not apply because of a previously answered question.

**Here at MUSC, the ACT Study is one of 30 active studies using REDCap. We store all data collected through REDCap on secure, firewall-protected university servers.**

The new system saves time and resources as well as reducing waste.

So far, more than 700 participants have requested an online ACT test kit and have successfully sent their online forms to us. We are very pleased with the success of the new ACT online system. If a member of your family wishes to test and does not have computer skills, you can assist them in navigating to [www.alphaoneregistry.org](http://www.alphaoneregistry.org).

We are always happy to talk to your family members and friends at our toll free number, 877-886-2383, or our email, [alphaone@musc.edu](mailto:alphaone@musc.edu) to request an ACT kit to test for Alpha-1.

At least monthly, the staff at the Alpha-1 Foundation Research Registry receives requests to accept lungs, livers, or whole bodies as a donation to benefit Alpha-1 Research. Human tissue is extremely valuable to researchers, providing them with samples they can use for experimentation.

While this is a good thing to do, tissue must be collected quickly within minutes after removal (a diseased lung removed during a transplant, for example) or after death for them to be any good for researchers. It would not be practical for the Registry staff to travel around the country to collect tissues or having them collected and mailed.

To accommodate these requests, the Alpha-1 Foundation, following the lead of many other rare diseases, has joined forces with The National Disease Research Interchange (NDRI) Rare Disease Registry.

The mission of the NDRI is to receive donated tissue and organs and distribute them for research. NDRI is a federally funded organization designed for the preservation and distribution of human cells, tissues and organs for research and transplant.

The NDRI is the nation's leader in providing human tissue and organs to NIH-funded and university based investigators. The organization has developed a meticulous process for receiving aged and diseased tissue. NDRI representatives travel to pick up tissue and distribute samples to medical centers all across the country.

Alphas can participate in this program by going to the NDRI website ([www.ndriresource.org](http://www.ndriresource.org)) and filling out a consent form. Lung and liver tissue can be donated after transplant or death. The consent form must be filled out well in advance to ensure the necessary arrangements can be made in order to preserve the tissue as well as possible. Once the NDRI has received the specimen, they will allocate the viable tissue to investigators around the country. A donated liver or lungs, regardless of disease state, can be used to help further research in the Alpha-1 community.

If you are interested in donating, please contact a Rare Disease Coordinator at the NDRI by email at [raredisease@ndriresource.org](mailto:raredisease@ndriresource.org), or toll free at 800-222-6374.

# The scoop on raising Alpha-1

By Angela McBride  
Director of Development,  
Alpha-1 Foundation

**B**uilding 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.

How many ways could you help to raise research funds and awareness for Alpha-1?

This year, an amazing number. We haven't counted, but here are just a few:

- **Walking**
- **Irish step-dancing**
- **Belly dancing**
- **Running the Boston Marathon**
- **Enjoying ice cream**
- **Playing golf**
- **Riding a bicycle**
- **Playing trivia games**



*Celtic Connection chair Bob Healy and his sister Patti Murphy, also a Celtic Connection committee member.*

At the Alpha-1 Foundation, we call our community fundraisers

**Building Friends for a Cure (BFC)** – a grassroots program that includes our Team Alpha-1.

Don't see anything you like to do on that list? You're welcome to pick your own favorite. As you can tell from all that variety, we're open to ideas. We'll help you get organized. If you don't have much fundraising experience, feel free to build on someone else's experience.

An example of that is Julie Liljenquist, who organized a "**Get the Scoop on Alpha-1**" fundraiser in Fairmont, MN, that raised more than \$4,000 for research. She was following in the footsteps of two other established "Get the Scoop on Alpha-1" events in Des Moines, IA, and Denver, CO.



after year at this event. He had organized many other fundraising events and became Chair of the Alpha-1 Association in 2010.

You can also help by taking part in a long-standing event, such as riding a bike for any distance you are comfortable with as part of Team Alpha-1's participation in the annual **Escape to the Cape**, Sept. 30-Oct. 2 on Cape Cod, MA.

If you live in New England, you might want to pitch in and help to organize one of the most successful BFC events of recent years, the **Celtic Connection**. Bob Healy again this year chaired the Celtic Connection dinner dance in Needham, MA, held

in March. Long-time researcher and clinician Gordon Snider, MD, was honored with the Irish Shillelagh Award. And as always, there was the traditional Irish boiled dinner, an Irish step-dancing performance, and live music for dancing.

This year, Team Alpha-1 will salute the late Ed Brailey at the autumn bike trek. Brailey, who had a lung transplant in 2002, became an Alpha-1 activist almost immediately afterward, and led "Team Brailey" year



*Ed Brailey*



# awareness and research funds

Walking.  
Eating an ice cream  
cone.  
Riding a bicycle.  
Playing trivia games.  
Belly dancing.  
Irish step dancing.  
Running a marathon.

The ways to help are  
endless.

#### Some of this year's coming events:

Pam Van Scoy will lead the 5K "**Hero Walk**" in Byrd Park, Richmond, VA, on Saturday, April 9. "That's right around cherry blossom time," says Van Scoy. "So if you're from out of town, it's the best time of the year to be visiting Virginia and Washington, DC.

Denise Carrara will hold a **Belly Dancing for Breath** evening April 17 in Arlington, MA.

Eric Hogleund will be "**Running for a Reason**" in the Boston Marathon (that's 26.2 miles) April 18. The reason is his little boy Sam, who was born with symptoms of Alpha-1 liver disease. "While Sam is doing well," says Hogleund, "we hope to see the day that a cure is found."

On April 29, the Foundation will hold its signature event, the **Celebration of Life at Indian Creek Country Club**, with a golf tournament during the day, dinner and dancing under the stars that evening.

See our calendar on page 12 for contact information on these and many more events, including "Get the Scoop" events, the 4th annual George Washington Bridge Walk, and the Alpha-1 golf event at Greenwich Country Club in Greenwich, CT.



**ALPHA-1 5K "HERO" WALK**  
**JOIN THE FIGHT AGAINST ALPHA-1!**



For for the most up-to-date listings, check our website at [www.alpha-1foundation.org](http://www.alpha-1foundation.org).

## Building Friends for a Cure 2011 Calendar of Events

April 9	Alpha-1 5K "Hero" Walk	Richmond, VA	Pam Van Scoy: <a href="mailto:pamvs2000@yahoo.com">pamvs2000@yahoo.com</a>
April 17	Belly Dancing for Breath	Arlington, MA	Denise Carrara: <a href="mailto:desertrose4022@yahoo.com">desertrose4022@yahoo.com</a>
April 18	Boston Marathon	Boston, MA	Eric Hogleund: <a href="mailto:e-hogleund@hotmail.com">e-hogleund@hotmail.com</a>
April 29	Celebration of Life	Miami, FL	Angela McBride: <a href="mailto:amcbride@alphaone.org">amcbride@alphaone.org</a>
May TBD	"Get the Scoop on Alpha-1"	Denver, CO	Judy Simon: <a href="mailto:saidsimon@comcast.net">saidsimon@comcast.net</a>
May 7	4th Annual George Washington Bridge Walk	NY	Joe Reidy: <a href="mailto:joereidy@verizon.net">joereidy@verizon.net</a>
July TBD	All Aboard for Alpha-1	Connecticut River	Sandy Ringgard: <a href="mailto:oakhamsix@yahoo.com">oakhamsix@yahoo.com</a>
July TBD	"Get the Scoop on Alpha-1"	Des Moines, IA	Peg Iverson: <a href="mailto:pegiver@mchsi.com">pegiver@mchsi.com</a>
August 9	2nd Annual Memorial Paul (PJ) Healy Golf Tournament	Halifax, MA	Bob Healy: <a href="mailto:Bobhealy125@msn.com">Bobhealy125@msn.com</a>
September 8	Greenwich Golf Event	Greenwich, CT	Ken Irvine: <a href="mailto:Airvine3@optonline.net">Airvine3@optonline.net</a>
Sept. 30 – Oct. 2	Team Alpha-1 Escape to the Cape	Cape Cod, MA	Angela McBride: <a href="mailto:amcbride@alphaone.org">amcbride@alphaone.org</a>
October 6	Trivia Night	MO	Amber Behrendt: <a href="mailto:rtalbatr@hotmail.com">rtalbatr@hotmail.com</a>
November TBD	3rd Annual Alpha-1 5k Walk Miami	Miami, FL	Angela McBride: <a href="mailto:amcbride@alphaone.org">amcbride@alphaone.org</a>

## 2011 Education Days

April 16	Alpha-1 Education Day	Oklahoma City, OK
August 6	Alpha-1 Education Day	Portland, OR
September 17	Alpha-1 Education Day	Syracuse, NY
October 15	Alpha-1 Education Day	Indianapolis, IN
November 5	Alpha-1 Education Day	Charleston SC
June 10-12	20th Annual Alpha-1 Association National Education Conference	St. Paul, MN

The National Education Series is co-sponsored by the Alpha-1 Foundation and Alpha-1 Association. For information on education programs, contact Marlene Erven at 1-800-521-3025 or [mserven@alpha1.org](mailto:mserven@alpha1.org). For information on Building Friends for a Cure, contact Angela McBride at 1-888-825-7421 Ext. 233 or [amcbride@alphaone.org](mailto:amcbride@alphaone.org). Commitments and dates are subject to change.

## Alpha-1 Foundation

The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1). The Foundation has invested nearly \$39 million to support Alpha-1 Antitrypsin (AAT) research and programs in more than 70 institutions in North America, Europe and Australia.

## Alpha-1 Association

The Alpha-1 Association is a member-based not-for-profit organization founded in 1991 to identify those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education and advocacy. The Association has a network of more than 70 volunteer-led support groups around the U.S.

## AlphaNet

AlphaNet, Inc. is a unique disease management organization. Through its medical and operations staff, AlphaNet provides a wide range of integrated support services to individuals with Alpha-1 Antitrypsin Deficiency who require augmentation therapy, oversees and sponsors clinical trials involving Alpha-1 therapies, and makes available a comprehensive disease management and prevention program to improve the quality of life of those affected by Alpha-1.

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