Many diagnosed with Alpha-1 are often mistakenly under the impression they will not live a long and productive life. This notion is often a result of misinformed physicians who don’t have a complete up-to-date understanding of Alpha-1.

“So many of us were not expecting to live into our 70’s and 80’s and some not even to our 60’s,” explained AlphaNet Coordinator Judy Rose. “It’s just not the case, we seem a many patients living long and productive lives.”

One example is Maryland resident, Isabel Baynes. Isabel, a very active 78, hasn’t let living with Alpha-1 slow her down. She recently painted her barn and frequently can be found working her expansive property, weeding, planting, cutting down trees for her curly willow business, even jumping on her tractor to pull up tree stumps.

She keeps busy with a wide variety of activities and has learned to work around her Alpha-1. A lover of woodwork ing, Isabel “set off a chain of events” breathing the dust it produced by taking her mask off too soon. She still loves to make things, but has learned not to overdo it. Isabel’s efforts have won scores of ribbons at state and county fairs for her wood carving, as well as for her embroidery, baking and painted gourd birdhouses.

“I believe in the Lord and when I have a hard job, His strength always sees me through,” said Isabel.

Her craftwork has also helped her cope in times of grief, such as the recent tragic death of her beloved grandson, Robert, whom she memorialized with a beautiful hand-carved letter to serve as a lasting tribute.

(continued inside)
Mother of four, Jenny Faull, started training to run her first marathon, while Reverend Kurt Gamlin learned to swim at age 51 to prepare for his first triathlon.

She had initially started a walking program to help build natural painkillers and help her cope with the symptoms of fibromyalgia. Her shortness of breath curtailed her walking program until after her Alpha-1 diagnosis and attendance at an Alpha meeting. The program featured a speaker who had written a study on the benefits of exercise for pulmonary rehab and she decided to start walking again. Her pace improved and she advanced to running, with her kids riding along on their bikes to give her support and encouragement.

An interesting fact, after just three months on her infusion therapy, Jenny’s symptoms of fibromyalgia disappeared. Her physicians are not sure why this has occurred, but at 41, Jenny is not going to let up on any of her therapeutic regimens.

Jenny recently had a setback when she tore a cartilage in her knee, but pledges to be back to training in time for the spring races. In the meantime, she philosophically pronounces it “a good day for a walk.”

Kurt has always exercised and, after his diagnosis as an Alpha two years ago, has been having infusions, closely monitoring his progress, and gradually building his fitness regimen with slow jogging and now, running.

A Methodist pastor in Wheaton, Illinois, he and his wife have also reared their three children to have a focus on athletics. His current goal of becoming a triathlete (running, biking and swimming) pushed him to take swimming lessons twice a week to learn to swim.

Exercise has always helped Kurt start his day and he feels strongly that “exercise helps mentally as well as physically.” “It gets those endorphins going and sharpens the mind,” he explains.
During her weekly infusions, Isabel started crocheting slippers for other patients and the nurses, and getting a great response. “I made Boo-Boo Bunnies with a message inside that always makes my fellow patients laugh,” explained Isabel. “Then in about one minute I teach them how to make them for others.” She discovered that teaching the other patients how to make crafts opened them up to conversation, helped them unwind, relax and ultimately, feel better.

She describes her latest “prank” as tossing a handful of gourd seeds over the fence to her son’s property onto an unplanted plot of land. She’s having fun watching the gourds multiply “as they almost double overnight” and wondering what she can do with all those gourds for her next project.

Joyce Martyn knows how to party. The festivities for her 80th birthday turned into a weeklong celebration, involving her family, church, infusion nurses, and friends at her Tucson, Arizona retirement center. Members of her Alpha-1 support group even showed up with a home-baked cake for a special visit.

After a busy career working in hospital admissions, Joyce volunteered as her church secretary for many years. She keeps busy and is on the go, still driving and getting out on her own regularly (with a lift on her car for her scooter).

When asked about how she stays so active and limber, Joyce reports, “determination has a great deal to do with it, I don’t just sit back and relax.” She enjoys reading and keeps fit with daily exercises, which she now does lying on her bed since walking does tire her.

Still active with her church, Joyce sings in the choir, “breathing when I have to” and enjoys giving the congregation’s kids rides on her scooter, an activity that has made her extremely popular.

She was 56 when she was finally diagnosed after 20 years of “doctors getting it wrong.” “I thought I had a mental problem because they could never find anything wrong with me,” explained Joyce.

She finally asked to be tested when her brother (also an Alpha), told her about a new theory involving a missing protein. Two of her grandsons are Alphas as well. Joyce has a very rare Alpha gene (ZMheerlen) that has been traced back to her Dutch heredity. She is one of a few identified in the U.S. with this specific gene that can be traced back to a small town in the Netherlands.

“The (Alpha-1) Registry has been a blessing, helping my family find out this information,” said Joyce.

**New Year’s Resolution:**
Try something you’ve always wanted to do!
ALPHAS
IN THE NEWS

AN ADVOCATE
IS BORN
Richard Fallstich, who was featured in the AlphaNetter, Spring ‘07, about his double lung/liver transplant, has decided to take on a more activist role to raise awareness of organ donation. An opinion piece, written by Richard about his experience and the importance of organ donation, was recently featured in The Morning Call, the leading newspaper serving the Lehigh Valley, PA communities.

AN ALPHA’S STORY
IS CHRONICLED
The Star Press, in Muncie, Indiana, is running a series on Alpha, Judi Crouch, who is waiting for a double lung transplant at the Cleveland Clinic. Several other Alphas have logged on to the newspaper’s on-line Readers Forum to express support for Judi. Although Judi has hit a few snags, she is now awaiting her transplant and plans to stay in Cleveland, with her 17-year-old son Zach, during her recovery. To follow Judi’s story, log on to www.thestarpress.com, go to archives and put “Fighting the Good Fight” in the search field (there is a $2.95 charge to access the full text).

WHERE IN THE
WORLD?
Hal Nordwall, and his wife Hope, from Mooresville, NC, appeared in The Charlotte Observer in a group photo of their recent trip to Peru. The story of their trip was featured in the Summer ‘07 AlphaNetter.

NEWSPAPER HELPS
ALPHA FIND
TRANSPLANT
DONOR FAMILY
The Arizona Republic featured a heart-wrenching transplant story that focused on a family who donated their daughter’s liver to a child with liver failure due to Alpha-1. Mary Jo Morris was diagnosed before age 3 and received the transplant at age 10, after her parents were told she had just four weeks to live. Now 33, she wanted to find the family that had made this special gift. For the full story, log on to the www.azcentral.com/arizonarepublic/news and type "Mary Jo Morris" in the search field. There you will be able to read all the stories including how The Arizona Republic helped her find her donor-family (there are access charges from $2.50 an article).

NEW BINGHAMTON,
NY SUPPORT
GROUP FORMED
The new Binghamton, NY Support Group was recently started by group leader Katherine Arnaldi and AlphaNet Patient Services Coordinator Pat MacInnes. Pat reports everyone enjoyed a “delicious lunch” supplied by Talecris Rep Mitch Ling. Guest speaker Donovan Quill, who works for Centric, spoke about how Alpha-1 has affected his family. “It was a great meeting for our first time and I was very proud of everyone for coming,” said MacInnes. “I was so glad to meet Alphas that I hadn’t met before; they are wonderful people.”

Regular meetings will be held throughout 2008. For more information call Pat MacInnes toll-free at 1-877-277-7931 or e-mail pmacinnes@alphanet.org

Two significant issues have compelled AlphaNet to provide education for the medical community specific to Alpha-1. First, there is a general lack of awareness about Alpha-1 in the population at large, as well as among members of the medical community. Clinical research studies have shown that, once a patient with Alpha-1 develops symptoms, it takes an average of seven years and visits to five different doctors before the diagnosis of Alpha-1 is made.

Are you aware that Alpha-1 is one of the most common serious genetic disorders and it is believed that only 7,000 of the estimated 100,000 Americans with severe Alpha-1 have been diagnosed to date? An additional 20 million Americans are estimated to be genetic carriers of this disorder. Alpha-1 can cause severe liver disease in children or severe liver and lung disease in adults, presenting as cirrhosis or early emphysema.

Currently, the World Health Organization, the American Thoracic Society, and the European Respiratory Society recommend that all adults with the following conditions be tested for Alpha-1/COPD: chronic bronchitis and emphysema, chronic asthma, unexplained bronchiectasis, family history of Alpha-1 and chronic liver disease.

Equally important is the second issue; the recognition that significant variations in the care and treatment of Alpha-1 exist in the medical community and that these variations may adversely affect the health of individuals with Alpha-1.

FREE EDUCATION PROGRAMS AVAILABLE FOR MEDICAL PROFESSIONALS
In an effort to address these two issues, AlphaNet provides two professional education programs for the medical community. Each program is approved for continuing education credits by its respective medical specialty.

One program is for physicians and respiratory therapists and offers Continuing Medical Education (CME) credit for physicians and/or Continuing Respiratory Care Education (CRCE) for respiratory therapists. The program reviews the recently published “Standards for the Diagnosis and Management of Individuals with Alpha-1 Antitrypsin Deficiency.”

The other program is for nurses and is approved for 3 contact hours by CNE-Net, an accredited approver by the American Nurse Credentialing Center’s Commission on Accreditation. It includes an instructional DVD. The video, along with supplemental written materials, comprises an educational program titled “Alpha-1 Antitrypsin Deficiency and Augmentation Therapy.”

HOW NURSING PROGRAM GOALS BENEFIT ALPHAS:
1. Upon completion of this program the nurse will have a better understanding of the disorder and its treatment.
2. Enhance the care of individuals receiving IV augmentation therapy by providing specific and detailed instructions regarding the drugs preparation and infusion.
3. Provide the nurse and the patients they serve with access to resources in the community for further information and support.

Instructions for this program are included with the accompanying materials. Upon successful completion of the Post Test with a grade of at least 80%, along with the submission of the Registration and Evaluation Forms, each participant will receive a certificate and 3 contact hours.

AlphaNet provides this program free to all nurses. I encourage you to ask your nurse to become certified as an “Alpha Nurse” by completing this program. If your nurse has not viewed this video and taken the exam, please have them call me at 877-553-0093; I will make sure he or she receives a copy.

NOW AVAILABLE: The Nursing Education Program is on the AlphaNet website, www.alphanet.org
**ALPHA-1 FOUNDATION & TEAM ALPHA EVENT CALENDAR**

**February** – Yoga Grove’s Class for Alpha-1
Coconut Grove, FL

**February 2** – Race up Boston Place
Boston, MA

**February 15** – Eaton’s Alpha-1 Awareness Across the USA
St. Augustine, FL

**MAY 2** – Celebration of Life
Key Largo, FL

**MAY 17** – First Annual Trek for Alpha-1
East Lyme, CT

**ONGOING** – Alpha-1 Awareness Wristbands.
Alpha-1 Scarf, Tie & Car Magnet Campaign
USA & Abroad

To find out more about these or other events in your area, log on to www.alphaone.org or call toll-free: 1-888-825-7421, ext. 248.

**ALPHA-1 ASSOCIATION PROGRAMS & ACTIVITIES**

**Education Days & Regional Support Group Meetings**

**MARCH 9** –
Alpha-1 Education Day
Phoenix, AZ

**MARCH 29** –
Regional Support Group Meeting
Jackson, MS

**JUNE 20-22**
Alpha-1 Association National Conference
St. Louis, MO

To find out more about conferences and support groups, visit the Alpha-1 Association website at www.alpha1.org or call toll-free: 1-800-521-3025.

**SPECIAL TOPIC REFERENCE GUIDES AVAILABLE**

New brochures offer focused information on single topics and have both included and expanded on the material in the Big Fat Reference Guide™.

For copies, call AlphaNet at 1-800-577-2638, and ask for extension 243.

Titles include: *Traveling with Alpha-1, Oxygen Therapy, Understanding Pulmonary Exacerbations* and *Staying Healthy/Management of Environmental Risk Factors.*