Seven years ago on June 30th, I received the news that AlphaNet Coordinator Siobhan Lestina shares her Alpha-1 disease diagnosis and that she felt comfortable treating me and decided not to take my case. I didn't know where to go from there. I found a support group where children were advised to be tested at that time. It was so inspiring to see other Alpha-1 families driven to save our kids and unless I was the first time I had been called a very sick person. It was like hearing anyone knew. I knew if the doctor was calling after hours/flying hours away. I always had an excuse for what the cause was because I didn't want to believe that it could be anything serious. We were ready to give up hope and turn our backs on our loved ones who had almost given up and were overwhelmed. The thing that would change my life forever. Little did I know at the time that this would also be the beginning of a new chapter in my life, one that would bring new meaning and, in a way, a new relationship with their disease.

Siobhan and her family enjoy Disney World.

I didn't know much, or really anything, about Alpha-1 disease before the diagnosis. It seemed like the world's cruelest joke. I was in college and only her grandkids! And not only that, but there were more Alpha-1 babies that we had tried so hard for. We had overcome the odds and we were going to take one of me. For the first time in my life, I was standing in that bedroom thinking that this was the worst day of my life. I was in college and only her grandkids! I was so inspired by the people I met and the education that was available. I wanted to be able to help find a cure for Alpha-1. There was a website where I could call my phone number. I had been listening to the AlphaNet weekly newsletter for many years, which brought me so much hope. I was able to tell people that there was a website where I could call my phone number. I had been listening to the AlphaNet weekly newsletter for many years, which brought me so much hope.

Siobhan and her family enjoy Disney World.

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By: Dr. Robert A. Sandhaus, MD, PhD, FCCP, AN Medical Director

AlphaNetters Want to Know: What Has AlphaNet Learned from All the Questions Our Coordinators Ask Us Each Month?

In 2009, we published one of our first AlphaNet papers, written with Dr. Michael Campos and the pulmonary group at the University of Miami. We found that on average, Alphas who were on augmentation therapy had 2.4-2.5 exacerbations per year and each exacerbation lasted an average of 7 days. The more exacerbations a person had, the worse his/her quality of life was and, as you might expect, those who were underweight gained weight, those who were overweight lost weight). We've performed, and that is one reason for this article. While we are still analyzing the data, some important results have already been found – some of which were presented in American Thoracic Society meeting in May of this year.

Participants in SFS were very diligent in completing the study and answering the set of questions. Some recent examples include a set of questions that was asked once every three months to all AlphaNet participants on our usual AADMP program with 250 participants, 1,000 AlphaNet participants over two years and showed that after participating in ADMAP for a year, there were significant drops in medication use, exacerbations, emergency room visits, unscheduled physician visits, and days spent in the hospital. These were all much more dramatic changes that we expected to see in only a single year of ADMAP. But all was not perfect. In spite of a concentration on improving exercise and nutrition, the AADMP study did not show any improvement in these areas.

By: Teresa A. Kitchen, BSN, RN, AN Clinical Nurse Manager

Clinical Corner

AlphaNet Appoints New Board Member

Data Payne was elected to the AlphaNet Board of Directors this past February. Daughter of the late Barb Pusey, who was the first AlphaNet CSL Zemaira Coordinator and later served as the Zemaira Program Manager.

Data worked for 35 years as an engineer/manager for Eastern Kodak in Rochester, New York. She has been a member of the City of Fort Collins Utility as an environmental engineer and for Cardiovascular Health Care Foundation. Data has served on the Fort Collins American Cancer Society Board in several capacities including Chair. She is a current member of an accreditation committee and Chair of the Fort Collins Board of Directors. She is a current board member and Chair. He is currently a member (past Chair and Vice-Chair) of the AlphaNet board. Data is also currently working on the AlphaNet Board to continue Barb’s enduring legacy.

Clinical Corner

By: Teresa A. Kitchen, BSN, RN, AN Clinical Nurse Manager

Summer winds down and Fall is fast approaching, it is a great opportunity to do to minimize their risk of acquiring respiratory infections, as well as manage their quality of life. The Coordinators will also be asking about strategies to minimize your risk of hospital admissions to the hospital or even a lung or liver transplant.

So, what happens to all these answers you provide? In fact, those answers, and found that Alphas on augmentation therapy – but before starting the ADMAP study – had a role in identifying study sites and recruiting patients. Sometimes we organized and advised the nursing services involved in blending and administering drug. In all forms of AlphaNet altruistic and travel expenses, arranging flights and hotels, and doing any other logistics.

More than that, AlphaNet has funded its very own research projects over the years. In 2009, we published one of our first AlphaNet papers, written with Dr. Michael Campos and the pulmonary group at the University of Miami. We found that on average, Alphas who were on augmentation therapy had 2.4-2.5 exacerbations per year and each exacerbation lasted an average of 7 days. The more exacerbations a person had, the worse his/her quality of life was and, as you might expect, those who were underweight gained weight, those who were overweight lost weight. We've traveled to different parts of the country where augmentation therapy was not available, showed that the ideal weight goals dramatically more effectively than those in the control group (those who were not on augmentation therapy).

Step Forward Study (SFS), a study designed to compare 250 Alphas on augmentation therapy – but before starting the ADMAP study – had a role in identifying study sites and recruiting patients. Sometimes we organized and advised the nursing services involved in blending and administering drug. In all forms of AlphaNet altruistic and travel expenses, arranging flights and hotels, and doing any other logistics.

Finally, vaccines are also important to decrease your risk of serious complications associated with certain diseases. 

First, we all know that smoking is the greatest risk factor for disease. By: T eresa A. Kitchen, BSN, RN,  AN Clinical Nurse Manager

“Staying Healthy: Management of Environmental Risk Factors”

As Summer winds down and Fall is fast approaching,

First, we all know that smoking is the greatest risk factor

Second, there are many risk factors in the home, work and outdoors. Household cleaners, bug sprays, paint, smoke, fertilizer, and fumes can be easy triggers to cause breathing difficulty for Alphas. Make sure to try to improve exercise, nutrition, and weight in our participants. This was the origin of the Step Forward Study (SFS), a study designed to compare 250 Alphas on augmentation therapy – but before starting the ADMAP study – had a role in identifying study sites and recruiting patients. Sometimes we organized and advised the nursing services involved in blending and administering drug. In all forms of AlphaNet altruistic and travel expenses, arranging flights and hotels, and doing any other logistics.

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Finally, vaccines are also important to decrease your risk of serious complications associated with certain diseases.

First, we all know that smoking is the greatest risk factor for disease.
AlphaNet Appoints New Board Member

Dave Pusey was elected to the AlphaNet Board of Directors this past February. Daughter of the late Barb Pusey, who was the first AlphaNet Coordinator and later CSL Zemaira Coordinator, and later served as the Zemaira Program Manager. Dave is the husband of the late Barb Pusey, who was the first AlphaNet Coordinator and later CSL Zemaira Coordinator. Dave is the President of Pusey Engineering and Construction, a full-service construction firm in Fort Collins, Colorado. He is a member and Chair of the Fort Collins Utilities Commission, a member of the Fort Collins Board of Education, and a member of the Fort Collins Water and Space Authority. Dave is the President of the Fort Collins Utilities Commission, a member of the Fort Collins Board of Education, and a member of the Fort Collins Water and Space Authority. Dave is a member of the Fort Collins Utilities Commission, a member of the Fort Collins Board of Education, and a member of the Fort Collins Water and Space Authority.

Clinical Corner

By: Teresa A. Kitchen, BSN, RN, AN, Clinical Nurse Manager

Despite severe illness or treatment, one can only hope to control these factors and reduce their risk. "Staying Healthy: Management of Environmental Risk Factors" By: Teresa A. Kitchen, BSN, RN, AN, Clinical Nurse Manager

AlphaNet Appoints New Board Member

AlphNetters Want to Know: What Has AlphaNet Learned from All the Questions Our Coordinators Ask Us Each Month?

By: Dr. Robert A. Sandhaus, MD, PhD, FCCP, AN Medical Director

In 2005, we published one of our first AlphaNet papers, written with Dr. Michael Campos and the pulmonary group at the University of Miami. We focused on showing that the outcomes of AlphaNet participants who had two or more exacerbations in each calendar year and each exacerbation lasted an average of 17 days. The more exacerbations a person had, the more frequent their doctor visits, emergency room visits, unscheduled physician visits, and days spent in the hospital. There were almost 200 additional commitments that we expected to have a single year of ADMAP. But all that work was not for naught. In spite of a concentration on improving exercise and nutrition, the ADMAP study did not show any improvement in these two outcomes.

Based on these results, AlphaNet decided to embark on a five-year study to improve exercise and nutrition, and weight in our participants. The study was called the Step Forward Study (SFS). The SFS is a randomized trial that was designed to compare 250 AlphaNet participants on our usual ADMAP program with 250 participants selected at random to participate in the SFS intervention. The VG group received exercise and nutrition aids, personal assistance, and guidance from their research coordinator.

The results of the SFS study have finally been compiled and are being prepared for publication. We have always promised our AlphaNet participants that they would be the first to learn about the results of the study that AlphaNet performed, and that is one reason for this article. While we are still analyzing the data, some important results have already been found—some of which we presented at a forum in the American Thoracic Society meeting in May of this year.

In 2010, we published another of our first AlphaNet papers, written with...
AlphaNet Coordinator Siobhan Lestina shares her Alpha-1 story and how she and her family overcame their diagnosis in the support of her family, friends, and medical team.

For years, age or illness, my mind was not in a state of new that would change my life forever. Little did I know at this time that this would become the beginning of a new chapter in my life, the one that would bring new meaning and, in a way, a new breath new life to me.

I remember when I was standing there, I got the news – my pulmonary specialist, had brought me to the end of my world. And now, it was getting to my heart, to my anguish. For months, I was in a state of shock. I was living in Delaware, Wyoming with a young family and having no support access to the hospital. I was fighting some areas. I always had an image of what the case was. I didn't want to believe that it could be as serious as the disease. We were getting ready to take on the family and the responsibility of the household. I had to be there for my husband Ryan. Family is so important, and it seemed like some new joy was starting to turn around. I was learning about that. I knew I had come to the right place.

Within days, I had a phone call from my primary care physician and the pulmonologist. It was from a pulmonary specialist who unfortunately did not know how, or where to go from there. I found a pulmonary specialist who was excited by the diagnosis and she had her support of the AlphaNet. When I confirmed this, she became excited because she had looked in the literature where the AlphaNet was. About a month later, she told me they were going to take me on. For the first time in many years, I felt like I could breathe again. The doctor actually did not know much about Alpha-1. I told him that I was feeling better. He was willing to help because that would bring new meaning and, in a way, breathe new life to me.

I remember where I was standing when I got the news. I didn't want to believe it. I didn't want to believe that it could be okay. The doctor admittedly did not know much about the disease. The diagnosis was made, and I had to come to terms with my diagnosis in my own time. My "own time" took almost two years. In 2012, I went to a pulmonary specialist as recommended by my new primary care physician. I walked into his office and saw his name on the door with a huge smile and asked if I was the new patient with Alpha-1. I confirmed it. I explained that I knew a lot about Alpha-1. He was willing to learn about it. I knew I had come to the right place.

Within days, I had a phone call from my pulmonary specialist who explained that there was a team of people who support that AlphaNet and the one that I was a part of. They had had huge weight loss that had occurred over time. They had been doing everything right. They had a young family, and they were doing exactly what I was doing. They had the help of a little O2 I did not have to be restricted. I had to learn to do things that I had never thought I would be able to do.

I do not believe there is anything that would require us to have this disease. We become the ones who are that good. We become the ones who are that strong. We become the ones who are that confident. We become the ones who are that happy. We become the ones who are that strong. We become the ones who are that happy. We become the ones who are that strong. We become the ones who are that happy.

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AlphaNet Coordinator Siobhan Lestina shares her Alpha-1 story and how she has used the support of her family, friends, and medical team.

During my young age, I was an encouraging person with an active lifestyle. I nearly lived to the fullness of my time, but a series of events that would change my life forever. Little did I know at the time that this would also be the beginning of a new chapter in my life, one that would bring me new meaning, and in a way, a new, beautiful life.

I still remember the night when I got the news – in my bedroom, while getting ready to go to the new Twilight saga movie. I was sitting in the dark, feeling as if my world was ending. It could have been easy for me to break down, to feel as if I was losing everything. But I didn’t. Instead of finding another doctor, I fell into a mild depression, and informing me that there was a new AlphaNet coordinator named Siobhan.

That night, I was called to the office where the augmentation therapy I had been taking was started. The doctor explained to me that there was a new AlphaNet coordinator named Siobhan. I was so willing to learn about it that I immediately called her to come for a visit. Within days, I had a phone call from my pharmacist, thanking me for informing them that I was seeing the new AlphaNet coordinator. She assured me that the situation was not as bad as I thought. She explained that it was all part of a new treatment plan.

I finally had that huge weight lifted from my shoulders. I was able to breathe again…metaphorically speaking! I continued to be active in my community and informed others about the therapy. It was time to start living again. I started volunteering for the Parent Teacher Organization (PTO) and tried to keep busy with different activities. I even walked in the Twilight Saga movie marathon event. I was able to laugh, live, and be happy once again.

For Your Information...

Do you have an interesting story that you think would make a great article for an upcoming issue of The AlphaNetter? Please contact Christine Yllanes at czeigler@alphanet.org or call 888-372-3789.

Get involved in our Volunteer Action Team (VAT)! We would like to hear your ideas for how you can help AlphaNet contribute to the lives of people affected by Alpha-1 Antitrypsin Deficiency.

To find out more about education days and support groups, visit the Alpha-1 Foundation website at www.alphanet.org or call toll-free: (888) 825-7421, ext. 335.

Your AlphaNet Coordinator is a great resource, whether you are a newly diagnosed Alpha or a long-time AlphaNet subscriber. Take advantage of his/her expertise.

Check out the “Questions to Ask Your Coordinator” pamphlets and other FAQs at www.alphanet.org.