The importance of smoking cessation for Alphas cannot be stressed enough. The Big Fat Reference Guide to Quitting Smoking offers a variety of ways to improve the health of individuals with Alpha-1. One source that you can use is the Alpha-1 Foundation’s website. The website is www.alphanet.org and call toll-free: (888) 825-7421, ext. 351.

For more information on smoking cessation programs, please contact your AlphaNet Coordinator toll-free: (888) 825-7421, ext. 233.

For Your Information...

Your AlphaNet Coordinator is a great resource, wherever you are. He or she is always ready to talk about their smoking cessation program. Take advantage of his/her expertise.

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

Story Ideas?

Do you have an interesting story that you would like to share with your AlphaNet Coordinator? Or do you have suggestions to Christine Lanser at clanser@alphanet.org?

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**Clinical Trials in Alpha-1 Antitrypsin Deficiency**

Many of our AlphaNet members have participated in clinical trials over the years. In this feature, we’ll focus on a specific study, Clinical Trial Participation of our AlphaNet members—what is new and what makes it different in the U.S. instead of just one. Many people with Alpha-1 feel that they owe it to their children and grandchildren to help find the best treatments for this disease and, someday, find the cure. And most studies have risks associated with participation that need to be weighed against the potential benefits of a cure. We hope you enjoy learning about some of the current studies involving Alpha-1 and encourage you to attend future workshops and discussions on designing clinical trials that are meaningful to you and your loved ones.

What happens if you enroll in a study and you have a reaction? Will you be given the new medication or a medical procedure? Questions about such risks and the potential benefits of a given study are found by carefully reviewing the consent form that all study must provide and by discussing these questions with the investigator or the staff. Never sign a consent form without reading and understanding what it says.

You might be surprised how many people studying Alpha-1 are going on currently or are planned to start within the next two months. Because people frequently have questions about AlphaNet Coordination in all about the diseases currently at hand, we will not be discussing new ideas to go on a new therapy. Some notes of new therapies and general tips on how to sign up for clinical drug and device therapies that have already been used in studies.

**Clinical Corner**

It’s Time to Discuss Vaccines!

It is hard to believe that Fall is upon us and that it is once again, time to remind Alphas of the upcoming flu season! Here is some valuable information about the flu vaccine, as well as info about other vaccines too.

**Flu Vaccine**

• Annual flu shots/vaccines are recommended for Alphas. It is important to remember that the single vaccine (Flumist) is a LAIV vaccine, as it contains a live virus, and if you are pregnant, the vaccine is contraindicated. If you are a transplant patient (liver or lung), you should NOT receive it, but receive a Flu shot. Please remember that it is important to remember your family and you people live to be vaccinated.

**Pneumovax Vaccine**

• It is recommended to have Pneumovax (13) also called PCV 13) every 5 years. The older version of the vaccine is called Pneumovax. AlphaNet Medical Director Dr. Robert A. Sandhaus explained that there is no specific recommendation about whether everyone who has had a Pneumovax (13) or PCV 13 should receive a booster vaccine every 5 years or before the Pneumovax. It was recommended that if you have received Pneumovax in the past, you should receive Pneumovax 13 sooner than one year after the Pneumovax. If you are a transplant patient, it would be best to contact your physician.

**Shingles Vaccine**

• This vaccine is recommended for adults over the age of 50 or any adult who has had a shingles infection in the past. Because this is a LIVE virus, it should NOT be given to an individual who is immunocompromised, such as people who have had a long- or live transplant. In fact, family members of transplant recipient should speak to their doctors before being immunized as they can trash their transplanted relative if they receive the vaccine.

**Wasting Cough (Pertussis) Vaccine**

• Most of us were vaccinated for wasting cough or pertussis when we were children. Alphas were encouraged to receive a booster of the vaccine prior to attending the Seattle Alpha-1 Association National Conference a few years ago. There is a recommendation that all adults 65 years and older be re-vaccinated for pertussis. You only need this vaccination once as a child, but not as an adult. As an Alpha your physician may recommend if you are younger than 65.

If you have any further questions about vaccines, please don’t hesitate to call your AlphaNet Coordinator or search the www.cdc.gov site for additional information.

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**AlphaNet Welcomes New Coordinators**

Terri Leffler joins AlphaNet as a Client Coordinator. Her career has taken her down many different career paths, from fashion designer to a journey in sales and marketing — which included positions in the communications and medical field. Leffler is naturally on track with AlphaNet’s mission of helping Alphas since 2006 when she developed leukemia. She was diagnosed with alpha-1 antitrypsin deficiency disorder in 2010. In 2016, Leffler discovered her alpha-1 antitrypsin deficiency disorder in 2016. In 2018, she started working as an AlphaNet Coordinator with our 10 years of management experience, working with a pharmacy chain before going into business on her own. Designing and remodeling independent pharmacies in the Northeast.

Stephanie Petty joins AlphaNet as a Clinical Coordinator. She has been working as a nurse for over 25 years in the transplant community and currently on the Board of Directors for the United Network for Organ Sharing. She is also involved in research and protocol design with the University of Miami and is a mentor for AccessMed and is also responsible for the Library System, the Alpha-1 library and information technology.

Laura Lange joins AlphaNet as a Baxter Coordinator. She has been active within the Alpha community for over 15 years and has been a huge part of the Alpha-1 community. Lange was diagnosed in 2006 with alpha-1 antitrypsin deficiency disorder and is currently on the Board of Directors for the Idaho Alpha-1 Community Outreach, Inc. support group. She is a transplant patient and is working to help others with alpha-1 antitrypsin deficiency disorder and to help others with their journey in sales and marketing — which included positions in the communications and medical field. Leffler is naturally on track with AlphaNet’s mission of helping Alphas since 2006 when she developed leukemia. She was diagnosed with alpha-1 antitrypsin deficiency disorder in 2010. In 2016, Leffler discovered her alpha-1 antitrypsin deficiency disorder in 2016. In 2018, she started working as an AlphaNet Coordinator with our 10 years of management experience, working with a pharmacy chain before going into business on her own. Designing and remodeling independent pharmacies in the Northeast.

Diana Sader joins AlphaNet as a Baxter Coordinator. She has been working as a nurse for over 25 years in the transplant community and currently on the Board of Directors for the United Network for Organ Sharing. She is also involved in research and protocol design with the University of Miami and is a mentor for AccessMed and is also responsible for the Library System, the Alpha-1 library and information technology.