

New Vaccines, New Questions



By: Robert A. Sandhaus, MD, PhD, AlphaNet Medical Director

With the development of new vaccines and the rise in popularity of others, Alphas may benefit from getting some of these vaccines in order to protect themselves against certain illnesses. Vaccines, also called immunizations or simply 'shots', are usually injections that raise your immunity against specific infections. Most of us received a series of immunizations as children. Currently, children should be immunized against polio, tetanus, diphtheria, whooping cough, meningococcal infection, measles, mumps, chickenpox, German measles (rubella), hepatitis and others.

Alphas are at risk for lung and liver disease and a number of infections can increase the risk of such diseases or make an existing disease worse. Therefore, many Alphas are recommended to receive immunizations as adults. Annual flu shots are one such recommendation, as is immunization against common bugs that cause pneumonia.

Pneumonia vaccine
For the past several decades, the pneumonia vaccine in wide use has been Pneumovax. There is now a new vaccine called Prevnar 13 or PCV13. It prevents a more current spectrum of bugs that cause pneumonia and meningitis and should probably be used the next time you are due for a pneumonia vaccine, about once every 5 years. There is currently no specific recommendation about whether everyone who has had a Pneumovax injection less than 5 years ago should receive the PCV13 vaccination sooner than 5 years after the Pneumovax. It has been recommended that immunocompromised individuals (such as transplant recipients) receive both Pneumovax and PCV13, however it was recommended that if you've received Pneumovax in the recent past, you shouldn't receive PCV13 sooner than 1 year after the Pneumovax.

Shingles vaccine
A shingles vaccine has recently become available. It immunizes people against the virus Herpes Zoster. This virus causes chickenpox in people who have never been infected with this virus before and can cause shingles (a very painful, blistering skin rash) in people who have had chickenpox in the past (often the distant past). The Herpes Zoster virus lives in the nerves of people who have had chickenpox in the past and, as you get older or develop certain chronic illnesses, can reactivate as shingles. The shingles vaccine is an injection that builds up your immunity to the shingles-causing virus and prevents shingles or, if shingles occurs, can minimize the effects of this infection. In people who have already had an episode of shingles, the vaccine can prevent or minimize recurrence.

The shingles vaccine is a live virus vaccine. It is recommended for all adults over 50 years of age or any adult who has had a shingles infection in the past. Because the vaccine is a live virus, it should not be given to someone who is immunosuppressed, such as people who have had a lung or liver transplant. In fact, family members of transplant recipients should speak to their doctors before being immunized as they can infect their transplanted relative if they receive the vaccine.

Whooping cough (pertussis) vaccine
Most of us were immunized against whooping cough or pertussis when we were children. We now know that the immunity to the bacteria that causes whooping cough rarely extends to adults. In addition, there is a growing epidemic of whooping cough in the U.S. Therefore, it is recommended that all adults 65 years old and above be revaccinated against pertussis. This is usually done with a Tdap vaccine which covers tetanus, diphtheria and pertussis. You only need this vaccination once as an adult. If you have Alpha-1, especially if you have lung disease, your doctor may well recommend immunization even if you are younger than age 65. Immunization for adults younger than age 65 is also recommended if you are regularly exposed to infants or young children.

There are a number of other vaccinations recommended for patients with Alpha-1, including hepatitis immunizations. It is recommended that you consult your doctor to find out if your vaccinations are up-to-date.

Community Calendars

Alpha-1 Association Education Days

co-sponsored by the Alpha-1 Foundation

June 7-9 - National Education Conference
Washington, DC

August 10 - Education Day
Denver, CO

September 21 - Education Day
Chicago, IL

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

Alpha-1 Foundation Event Calendar

August 11 - Alpha-1 Morning Walk
Denver, CO

Sept. 26 - Escape to the Cape Bike Trek
Cape Cod, MA

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



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CONGRATULATIONS!

AlphaNet would like to acknowledge the following SFS Monthly Sweepstakes Drawing Winners:

March 2012: **Monica Lee Barrett**
Forest Grove, OR

April 2012: **Rose Grice**
Globe, AZ

May 2012: **Marion Richards**
Thornton, CO

June 2012: **Edgar Croom**
Greenville, SC

July 2012: **Albert Cooke**
Glen Rock, NJ

Aug. 2012: **Lloyd Herlocker**
Dunnellon, FL

Sept. 2012: **Nancy Feuerbach**
Blacksburg, VA

Oct. 2012: **Bob Healy**
Whitman, MA

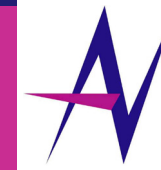
Nov. 2012: **Denny Knight**
Cleveland, TN

Dec. 2012: **Caroline Zeigler**
The Dalles, OR

Jan. 2013: **Ted Hill**
Coeur D' Alene, ID

Feb. 2013: **Kevin Butikofer**
Idaho Falls, ID

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The AlphaNetter

AlphaNet Launches Alpha-1 App

AlphaNet is proud to announce the release of the AlphaNet Alpha-1 App now available as a free download exclusively on iTunes. The App is compatible for use on iPhones, iPads and iPods — 3rd generation and above.

The App provides easy access to the searchable version of AlphaNet's *Big Fat Reference Guide* (BFRG), as well as the 13 *Skinny Little Reference Guides* — the specialty medical brochures on specific topics of interest. Furthermore, the App allows users to identify nearby Alpha-1 Support Groups and Alpha-1 physicians.

The Alpha-1 App delivers pertinent information regarding Alpha-1 Antitrypsin Deficiency directly to the public community and gives users the unique advantage of being able to access information while on-the-go.

AlphaNet Medical Director Robert A. Sandhaus, MD, PhD, points out that "the App gives tech-savvy Alphas an easy way to get in-depth Alpha-1 info at their fingertips. Furthermore, it helps Alphas find local Alpha doctors when they are out and about. Beyond that, it allows the public to learn about the condition."

"This App is part of AlphaNet's efforts to reach out to patients' family members, physicians and even the general public who may be interested in learning more about the condition. As we know, education is key," Dr. Sandhaus notes.

An App for physicians who treat patients with Alpha-1 is currently in development.



Pictured: (far left) Screenshot of AlphaNet Alpha-1 App Main Page.

(right) Screenshot of Augmentation Therapy Skinny Little Reference Guide.

Scan QR code to download AlphaNet Alpha-1 App

Frequently Asked Questions

Can Alphas Donate Blood?

According to *The Big Fat Reference Guide* (BFRG), "Individuals with Alpha-1 may donate blood as long as they do not have emphysema or liver disease and are not receiving augmentation therapy. Plasma donation may be made by Alphas; however, that decision will be made by the physician at the particular plasma site where you wish to make your donation. Your plasma may be used for other plasma products not related to making Alpha-1 augmentation therapies. Carriers of Alpha-1 may donate both blood and plasma. Your local blood donation center may be able to provide more information."

Can Exercise Reverse Alpha-1 COPD?

The BFRG states that while exercise cannot reverse Alpha-1, it can change the way you feel and function. "In Alphas with moderate to severe COPD, exercise can reduce disability by improving endurance, breathing efficiency and dyspnea (shortness of breath) tolerance." You should begin with a light exercise routine and then slowly work up to more moderate exercise over time, which should then be followed on a consistent basis. Consult your doctor before starting any exercise routine to ensure that you are healthy enough to do so.

Why Are Diet and Nutrition So Important to the Health of Alphas?

While nutritional needs and dietary recommendations for Alphas are similar to those for individuals without Alpha-1, there is an additional incentive for Alphas to follow healthy diet and nutrition guidelines. According to the BFRG, "Good nutrition may help Alphas to protect lung function and improve breathing by providing the energy and muscle tone needed to maintain effective respiratory effort. A poor diet can complicate Alpha-1 by imposing additional problems associated with diseases such as hypertension, coronary artery disease, diabetes and others."

What's the Best Philosophy for Fighting Pulmonary Exacerbations?

The BFRG notes that "The best philosophy for fighting exacerbations is to hit them hard and early. Know your own disease, know how your lungs react during an exacerbation. Continue with your usual medications, and consult your own physician to see if you should start a regimen of steroids and/or antibiotics."

Step Forward Study Updates

- We have entered the last year of the 5 year-long clinical trial, with the conclusion being May 1, 2014.
- The Daily Diary Sweepstakes is on-going so we encourage you to continue entering your data either online or using the mail-in postcards in order to qualify for the monthly drawing.
- If you have any SFS-related questions, please contact Ashley Chase at achase@alphanet.org.

SFS Sweepstakes Winner Steps Up to the Challenge

Alpha Kevin Butikofer of Idaho Falls, Idaho was selected as the Step Forward Study Sweepstakes yearly grand prize winner for 2012. As a reward for his hard work and commitment to the SFS study—a 5 year-long clinical trial which began in September 2009 that tracks the effects of diet and exercise on the health of Alphas—Kevin selected an Apple iPad as his prize. He was one of the SFS participants who had at least 85 percent compliance with daily diaries and spirometry testing and 100 percent compliance with spirometry flash drive exchanges. Because Kevin fulfilled these qualification requirements, he was entered into a computerized drawing for the grand prize and was selected at random from amongst other eligible SFS participants.

As far as his Alpha-1 diagnosis is concerned, Kevin discovered he was a ZZ in August 2002. He was due to have surgery for an injured shoulder, but just prior to surgery, he informed the anesthesiologist of long-standing breathing issues he had been experiencing. Upon hearing this news, the doctor canceled the surgery and sent Kevin to a pulmonologist to get tests done, which confirmed that he had Alpha-1. "I had previously had breathing problems and I was driving trucks for work. Whenever I would go over the mountains, my breathing would get worse but I didn't exactly know why." With his diagnosis, the breathing issues he had been experiencing now made sense.

After discovering he was an Alpha, Kevin sought out ways to lend a hand to research efforts related to

Alpha-1. One of the main reasons Kevin was inspired to get involved with the SFS study was because he felt as though it was his duty to help out those with Alpha-1. "I have always felt like it was my job to do what I could for society, which is why I participate in studies. So, when the SFS study came along, it seemed like a good idea for me to be involved in it."

Furthermore, Kevin saw an opportunity to motivate himself to stay active. He has had a long-standing back problem and, in order to prevent further strain on it, he exercises regularly. "The only way I can keep walking every day is by doing my exercises and stretching. I do it to stay active and because I want to be able to go to the grocery store without pain. I have lost so much weight that my muscles have deteriorated so I stay active by focusing on a routine of walking and stretching to maintain my range of motion."

Kevin credits exercise with keeping his body working properly and he encourages Alphas to stay active in order to maintain proper health. He notes, "I believe that the more active Alphas are, the healthier they will be overall."

Depending on the weather and on environmental factors, Kevin tends to maintain an exercise routine that includes daily full body stretches and walking 6000-7000 steps several days a week. Recently, he won the February 2013 monthly drawing sweepstakes, which shows Kevin's continued commitment to SFS.



Kevin Butikofer and his family.

Clinical Corner

By: Teresa Kitchen, BSN, RN, AlphaNet Clinical Nurse Manager

Medication Management After a Natural Disaster

During the upcoming summer months, it is not uncommon to hear news of unpredictable weather occurring throughout the country (hurricanes, wildfires, tornadoes and flooding). Would you know what to do with your medications in the event of a natural disaster? Most Alphas are on a wide range of medications including inhalers, pills and temperature-sensitive IV medicine.

With this in mind, the Food and Drug Administration (FDA) offers valuable information detailing the important steps every Alpha should know in order to safeguard their medications in the event of a natural disaster. The following is the link to the FDA website: <http://www.fda.gov/drugs/EmergencyPreparedness>.

This website includes information about what to do if your drug is exposed to excessive heat (fire), unsafe water (flooding) and concerns about drugs that need to be refrigerated. Contamination of your medicines can lead to diseases that could cause serious health issues for an Alpha.

If the unthinkable happens to you, please call your AlphaNet Coordinator for assistance, as AlphaNet has many resources available to assist you. Also, a call to your healthcare provider/pharmacy is important to notify them of the issue that is occurring.

Don't forget to stop by the AlphaNet Booth at the National Education Conference to pick up your complimentary digital thermometer!



AlphaNet Welcomes You to Alphaville!

Get the most comprehensive Alpha-1 information available by accessing our *Big Fat Reference Guide* and *Skinny Little Reference Guide* collection.

Visit www.alphanet.org and click on the BFRG link to register.