Harmonica Instrumental in Breathing Tune-Up

Making music is making breathing easier for Alpha John members of the Harmonikatz, harmonica aficionados in the Florida Celebration rehabilitation program.

"Initially, we were trying to do something to build up our diaphragms and intercostal muscles, which you need for proper breathing. Our diaphragms were kind of sluggish," John says. "Our instructor, Patricia Ross, recognized that some musical instruments can help us practice proper breathing. She outfitted our group with $4 harmonicas from Cracker Barrel and brought in an instructor to show us how to use them."

"According to respiratory therapist, Jeff Fraser, the breathing techniques used to play the harmonica are very similar to some standard exercises used in pulmonary rehabilitation programs for COPD patients. For example, COPD patients tend to get air trapped in their overextended air sacs, causing shortness of breath. Purse lip breathing helps patients to keep their airways open, to exhale longer and to expel air from their lungs with their abdominal muscles. A similar type of resistance is created when exhaling through pursed lips to produce notes on the harmonica."

"Many COPD patients also develop flattened diaphragms, which do not constrict as efficiently and cause patients to use accessory muscles in the chest, neck, arms and shoulders to help them breathe. Harmonica play requires diaphragmatic breathing which strengthens the diaphragm by inhaling through a restricted space. During inhalation, the diaphragm contracts, creating pressure that allows more air to be drawn into the lungs."

"To teach our patients breath control, we have them focus on playing a single note and trying to fine tune it much like they would tune in a radio station," Patricia Ross, lead respiratory therapist, explains. "When patients utilize their diaphragms properly, they will hear a rich, strong sound. Although most of our patients have never played an instrument, they have become proficient in a variety of harmonica songs ranging from 'Mary Had a Little Lamb' to 'The Battle Hymn of the Republic'."

"One of the program's goals is to train patients in proper breathing technique and the harmonica has been an excellent learning tool," Jeff adds. "It helps patients to see improvement and provides an incentive to stick with the breathing pattern."

"Our breathing has improved and our mutual enjoyment has helped us to develop a strong support community," John says. "We are eager to share what we've learned with others."

The Harmonikatz have performed for pulmonary rehabilitation programs, for COPD support groups, at parades and at other events in South Florida. Their goal in these performances is to entertain, encourage and educate other COPD patients.

Pick up your FREE HARMONICA from the AlphaNet booth at the Alpha-1 Association National Education Conference.

Harmonikatz member John Shook plays his harmonica.
If an individual has a genotype of ZZ, is the alpha-1 antitrypsin that escapes the liver able to protect the lungs at all since the protein is mis-folded?

The Z alpha-1 antitrypsin protein functions very well as an inhibitor of the neutrophil elastase that is thought to cause the lung disease of Alpha-1. Out of the 394 amino acids that make up the alpha-1 antitrypsin molecule, there is only one amino acid that is different in the Z protein compared with the M protein (normal alpha-1 antitrypsin). That one amino acid difference does allow the molecules of Z protein to stick together inside the liver cells, but the Z protein that makes it into the circulation seems to work quite well. That’s why some people with ZZ Alpha-1 never get any lung disease at all.

Since the body makes small amounts of alpha-1 antitrypsin in places other than the liver, why not target those places for making more of the protein when trying gene therapy?

The vast majority of the alpha-1 antitrypsin in the circulation and the tissues comes from the liver. That’s why, when an individual with Alpha-1 gets a liver transplant, their blood will have only normal alpha-1 antitrypsin in their circulation. There is good evidence that the cells that have been shown to make alpha-1 antitrypsin get clogged with abnormal protein just like the cells in the liver. Having said all this, it is interesting to note that the current gene therapy studies going on in Alpha-1 are aiming to turn muscle cells into alpha-1 antitrypsin secreting cells.
Those willing to participate in research studies and clinical trials related to Alpha-1 Antitrypsin Deficiency may want to consider signing up for the Alpha-1 Research Registry.

The Alpha-1 Research Registry is a confidential database of individuals with Alpha-1 Antitrypsin Deficiency (Alpha-1) or a carrier phenotype located at the Medical University of South Carolina in Charleston, SC. The goal of the Registry is to facilitate Alpha-1 research by providing investigators with a group of Alphas and carriers willing to consider participation in research.

For more information visit www.alphaoneregistry.org
How much do you appreciate the flexibility that comes with driving your car, walking with a friend or spouse, preparing meals, traveling to visit family, and managing your personal care? All of these activities require a degree of personal mobility and increase your opportunities to interact with others and maintain independence. Personal mobility can play a significant role in improving your quality of life. And the choices you make now can influence your quality of life down the road. As the saying goes “if you don’t use it, you lose it”. Here are a few ideas to help you be proactive about maintaining and increasing your mobility.

- Make a list of the activities you enjoy and want to continue to be able to perform. Next to that list write what you need to do to maintain the ability to do them. If you don’t know, consult your doctor.

- The best way to maintain or increase your ability to do an activity is to do it on a regular basis. Alphas need to be as physically active as possible, because the stronger your muscles are, the less oxygen you need to use.

- Identify tools that will help you monitor and increase your activity. The use of a pedometer (a device that measures your steps) or therabands (exercise bands) are both great ways to improve your strength and endurance and therefore increase mobility.

- Utilize medical equipment that can help you get around and perform daily activities. Wheelchairs, walkers and scooters can help Alphas maintain a more active lifestyle.

- Identify roadblocks that prevent you from participating in the activities you enjoy and create solutions by modifying the activity with support tools. Those using oxygen may consider a portable oxygen concentrator. There are many equipment options to choose from and it is best to speak with your home medical equipment company or oxygen supplier for their advice.

- Remember, for a medical support device to be covered in part or in whole by Medicare or private insurance, you should obtain a prescription from your doctor.

If you have a topic you think that all Alphas should learn about in the next issue of the AlphaNetter, please contact Lindsey Griffin at lgriffin@alphanet.org or 800-577-2638 ext.243

50 SCREENED AT ALPHA-1 TESTING DAY

In April, the American Lung Association, Pennsylvania State Hershey Medical Center and the Central Pennsylvania Alpha Support Group provided information about COPD and Alpha-1 and provided free testing for asthma, COPD and Alpha-1 Antitrypsin Deficiency at the Friendship Center in Harrisburg, Pennsylvania. Hershey Medical Center doctors, led by Dr. Timothy Craig, screened over 50 individuals. The screening consisted of spirometry testing and Alpha-1 testing using kits provided by CSL Behring and Talecris Biotherapeutics. CSL Behring and Talecris Biotherapeutics also provided beverages and breakfast snacks for the participants.

(Pictured right) Amy Czech of the American Lung Association and Jean McCathern, AlphaNet Coordinator (ME, VT, NH, CT, MD), work the information and check-in table at the Alpha-1 Testing Day in Harrisburg, Pennsylvania.
The Big Fat Reference Guide, the most comprehensive guide to living with Alpha-1, is now available in a new USB drive format. This up-to-date version of the BFRG is easy to transport and can be used on any computer with a USB port. The Skinny Little Reference Guide collection of 13 topic-specific guides is also included on the drive. Stop by the AlphaNet booth at the Alpha-1 Association National Education Conference in Orlando for your free copy. The BFRG and SLRG’s can also be accessed online at www.alphanet.org.

AlphaNet is proud to support members of the Alpha-1 community with its unique focus on individualized needs, specialized health management programs and outcomes research.

For the tenth consecutive year, AlphaNet is pleased to provide scholarships for 40 participants to attend the Alpha-1 Association National Education Conference.
Community Calendars

Alpha-1 Association Education Days
co-sponsored by the Alpha-1 Foundation

August 28
Des Moines, Iowa

September 25
Las Vegas, Nevada

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.

AlphaNet Employment Opportunity
Do You Have What It Takes?

Applications are currently being accepted for employment as AlphaNet Patient Service Coordinators. Interested Alphas should be dedicated, organized professionals who are able to travel and demonstrate strong computer and communication skills.

Send resumes to humanresources@alphanet.org

Alpha-1 Foundation Event Calendar

June 5 - Alpha Bike Run:
Mohawk Ramblers Motorcycle Club
Greenfield, Massachusetts

July 18 - Second Annual
Get the Scoop on Alpha-1
Johnston, Iowa

August 9 - Paul Healy Golf Tournament
Halifax Country Club
Halifax, Massachusetts

September 9 - Alpha-1 Golf Tournament
Greenwich, Connecticut

October 1 - 3 - Team Alpha-1
Escape to the Cape
Cape Cod, Massachusetts

November 20 - Alpha-1 5k Walk
Miami, Florida

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.

Alpha-1 Association National Education Conference

June 11 - 13
Orlando, Florida

Alpha-1 Association
co-sponsored by the Alpha-1 Foundation

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