

## Alpha-1 Antitrypsin Deficiency and Caregivers by Cheryl Ellis

Once nicknamed "The Viking Disease" because it was prevalent in geographic areas where the Vikings traveled, Alpha-1 is a protein that is manufactured in the liver, and balances the enzyme that helps with keeping the lungs "clean." The deficiency can result in the enzyme attacking the lungs.

Because this deficiency is genetic, it is passed on through generations. Most people have normal genes. Others have one gene, and one with a defect. When it comes to genes, there are variations that contribute to abnormalities being passed on.

In general, doctors test for Alpha-1 when they see lung disease and no obvious cause. The smoker or secondhand smoker may be diagnosed with one condition (bronchitis, for example), with the "clues" pointing toward smoking. The Alpha-1 test will differentiate whether the patient was predisposed to lung problems because of a genetic, rather than environmental or behavioral cause.

Individuals with Alpha-1 are susceptible to lung infections, regardless of age. The young person with Alpha-1 may be diagnosed with asthma, and treated with medications that don't correct the problem sufficiently.

Knowing the Alpha-1 status

helps caregivers and loved ones understand the limitations of certain treatments. It also helps the physician properly guide the course of treatment, sending the person to the appropriate specialist.

The liver is another organ Alpha-1 can attack. Individuals may be diagnosed with cirrhosis of the liver, and lifestyle activities be branded the cause. Even infants with Alpha-1 can have liver damage, and while early intervention helps with management, liver transplantation is the only "cure."

Lungs and liver are not the only organs Alpha-1 can affect. Panniculitis is inflammation of the fatty tissue under the skin. The skin is the largest organ in the body, although it is not thought of as an organ by many without medical training (or good trivia skills).

Since more than one organ can be affected, doctors and Alpha-1 patients and caregivers refer to the primary organ affected when histories are given.

### Diagnosis and Research

The Alpha-1 Association has made diagnosis and participation in research efforts easy for those interested. While the majority of Alpha-1 testing by doctors is done when there are problems noted (lung dis-

ease without an apparent cause or history), anyone can be tested and be guaranteed of confidential results.

### Caring for the Alpha -1

With any lung imbalance, it is important to follow common sense. Cessation of smoking and staying away from secondhand smoke and other pollutants is primary. Talk to the doctor about physical exercise instruction from a licensed physical therapist to determine how to build lung capacity without sapping endurance.

Monitoring allergies and exposure to other allergens is a "given." Yet, caregivers and loved ones often ignore subtle allergens such as mild food allergies, soaps and colognes and cleaning solutions that do the job but leave one gasping for air. Exposure to these allergens may be eliminated within the home, but visits to the doctor, grocery or shopping center are difficult to control. When encountering these possible irritants, move away quickly to reduce the effect.

If your loved one qualifies for treatment by augmentation therapy (IV infusion of human plasma contain Alpha-1 antitrypsin protein), caregivers may be trained to administer therapy. Knowing how much you and your loved one are capable of handling at home

will make for better therapy. Proper nursing instruction and supervision are required. If you cannot envision being able to handle at-home therapy, be frank with staff and continue treatment at a professional center.

Administering any medications must be done as the doctor directs. As with any medical decisions, if your loved one is diagnosed with Alpha-1, find a doctor who recognizes the significance of diagnosis, regardless of smoking history.

### One Diagnosis Helps Many

Within your own family, having a member diagnosed with Alpha-1 can assist other family members should problems crop up. Since diagnosis can be confidential, testing can be done as a family health project. The goal is to help and receive treatment appropriate to their situation. The Alpha-1 Association has support groups, advocacy efforts and information that bring power to patient and caregiver.

Information can be frightening to some people. Some worry that if the insurance company is aware, they will be dropped. Alpha-1 seeks to advocate on behalf of people who may be disabled. (con't. pg. 4 top)

## Enlightening News About Insomnia in the Elderly By: Alice Abler

Insomnia can be a serious problem for older adults. A lack of sleep can cause difficulties that mimic symptoms of Alzheimer's disease: slower response time, increased falls, decreased memory, attention and cognitive performance. Depression and dementia sometimes follow insomnia. All too often, people respond to such difficulties by staying indoors, resting more and sleeping during daytime hours. This results in a decreased ability to sleep at night, and the cycle repeats.

Shallow non-REM (rapid eye movement) sleep is typical in older adults. When sleep is disrupted, as is common with the elderly, the deep stage 3 and 4 slow-wave sleep cycles (SWS) are difficult to achieve and maintain. It takes time for the body to shift into SWS, and any disturbance, whether the sleeper actually wakes or not, throws the body back into a lighter sleep phase. Current scientific evidence indicates that these SWS cycles are the most restorative phase of sleep and are necessary for proper daytime brain functioning, as well as hormones affect glucose regulation, a lack



of SWS sleep may affect glucose homeostasis and could therefore be a contributing factor to the development of type 2 diabetes, which is an increasing problem for older adults.

This type of diabetes, sometimes called adult-onset diabetes, is exacerbated by obesity. Since sleep deprivation results in weight gain due to an effect on appetite-controlling hormones like leptin and ghrelin and increased cortisol levels, quality sleep is doubly important: SWS affects both glucose regulation and weight. This important connection has gone unnoticed in the past, and may be part of the reason for the alarming upsurge in prevalence of type 2 diabetes in our aging population. Recent research shows simple, non-pharmacological methods are helpful for improving their sleep and thereby improving their health.

A visit to a stereotypical nursing home or other habitation of the elderly will usually find attendants wheeling residents through darkened hallways and parking them in dimly lit rooms. It seems uncommon to see the elderly in brightly lit rooms or outside enjoying the sunshine and fresh air. But according to studies published in the Journal of Sleep Research, an official publication of the European Sleep Research Society, exposure to adequate light is exactly what will help the elderly achieve a higher activity level and bet-

ter sleep, resulting in better health and improved quality of life.

A study published in the February 2006 American Journal of Geriatric Psychiatry showed that 69% of 492 observed nursing home residents were sleeping during the day and 60% of those had disturbed nighttime sleep as well. Neither condition was well documented in their medical records, indicating that daytime sleeping and poor nighttime sleep were considered by the caregivers to be the norm. But the causal factors may be more than just normal aging. Light—in particular the broad spectrum light found in bright sunshine—is essential for the regulation of wakefulness and sleep cycles by the internal circadian clock. Researchers found that residents spend about 1/3 of the day in their rooms, usually in bed, and were rarely exposed to bright light or sunshine. The more time spent in bed and less time spent in social activities, the sleepier the residents were during the day. It should not come as a surprise that 97% of these residents had weak or abnormal circadian rhythms. The authors of the study state that "More daytime sleeping and less nighttime sleep were associated with weaker circadian activity rhythm acrophase (peak

was associated with more bright light exposure." We already know this to be true for children and adults. It is therefore logical that especially for the elderly who may have cataracts or impaired vision, brighter light during the day makes for better sleep at night.

As part of a panel speaking at a satellite symposium at the American Geriatrics Society meeting, Dr. Sonia Ancoli-Israel of the University of California School of Medicine in San Diego, assured the audience that sleep disorders are not an unavoidable part of aging: "Don't think it's normal because they are older; don't think it's normal because they are sick."

In this study the observation was made that "on average residents never sleep for a full hour and never awake for a full hour over 24 hrs." This pattern insures that they never have the opportunity to enter the rejuvenating SWS cycle. Several suggestions to improve the sleep of the elderly, included, limiting daytime sleeping to one-hour naps in the early afternoon, avoiding all caffeine (including chocolate), and improving the environment by keeping it bright during the day and dark and quiet at night. Research shows that for optimal health and quality of life, we still need to follow and abide by the natural cycle of daylight and night, no matter what our age.

www.vision.org  
(see pg. 4 for definitions)

# Delaware County

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Visit us on the web:  
[www.co.delaware.ny.us/depts/ofa/ofa.htm](http://www.co.delaware.ny.us/depts/ofa/ofa.htm)

The Delaware County Legacy Corps is operated by Delaware Support & Services, under contract to the Delaware County Office for the Aging with funding from Delaware County, NYS Office for the Aging and the Older Americans Act, and donations provided by program participants.



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(con't. from Page 2, col. 4)  
criminated against because of genetic conditions. The more people who supply the organization with information, the greater the chances of understanding this (and other) genetic processes.

### Where To Find Help

The website:  
[www.alphaoneregistry.org](http://www.alphaoneregistry.org)  
not only houses confidential information on those who carry the gene, but those who are living with Alpha-1. By registering, you begin the first stage in learning your ge-

netic predisposition, and helping in research. The DNA and Tissue Bank at University of Florida accepts blood and tissue donations to further research links between Alpha-1 and other processes. You do not have to be diagnosed with Alpha-1 to donate, but you will be helping research efforts. Contact them toll free at 1.866.284.2708 to see what research can offer you, and vice versa.

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### Spring 2009 Issue 3

### May 2009 Legacy Corps

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*Legacy Corps*

#### Note from the Editor

I have found that throughout some of my initial assessments, people have been diagnosed with an illness that is just not something you would have expected that person would be diagnosed with given their normal living behaviors and habits. Two that comes to mind are cirrhosis of the liver and lung disease.

When I found this article about Alpha-1 Antitrypsin Deficiency I thought it could be the cause of some of these diagnoses in peo-

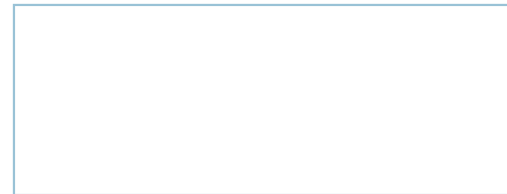
ple that just didn't fit those pre-requisite type habits in life. It also shows just how important genetic testing is even in spite of it's expense. That knowledge can help direct your future generations as to what they need to be aware of while planning to have families or have a health problem that they just don't understand.

The other article is about insomnia which I don't know but I find to be so debilitating. Sleep deprivation just does not lend

itself to a good quality of life in either the care recipient or the caregiver. Though the studies are from nursing home settings, I am happy to see that nursing homes are beginning to make their facilities much more lively in selections of color, activities and other environmental facets. For caregivers with home based caregiving, there are a few suggestions that may assist you and how to plan the daily régime of events and activities. Enjoy the beautiful season. Don't forget your sun block!

*Kit*

But now I have learned to listen to silence. TO hear its choirs singing the song of ages, changing the hymns of space, and disclosing the secrets of eternity. ~Kahlil Gibran



### Definitions for Insomnia article

**Circadian rhythm:** a pattern based on a 24-hour cycle, especially the repetition of certain physiologic phenomena, as sleeping and eating.

**Shallow non-REM:** (NREM) The first three of four stages of typical sleep. Rapid eye movement (REM) is detected with electrodes placed on the skin around the eyes so that tiny electric discharges from contractions of the eye muscles are transmitted to recording equipment. The REM sleep period, lasting from a few mins. to half an hour, alternated with the NREM periods. Dreaming occurs during REM time.

**Glucose homeostatis:** The ability or tendency of an organism or cell to maintain internal equilibrium by adjusting its physiological processes.

### Bedtime Relax Tea

Serves 2

- 2 cups water
- 1/2 tsp. Dried or fresh chamomile
- 1/2 tsp. Dried lavender
- 1/2 tsp. Dried mint
- 1/2 tsp. Fennel seeds
- 1/2 tsp. Dried lemon balm



- In a pot, bring the water to a boil. Remove from heat.
- Add the chamomile, lavender, mint, fennel & lemon balm. Steep for 5-10 minutes.
- Strain and drink before going to bed.



### Books available to borrow:

**The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent**  
By: *Barry J. Jacobs*

**The House on Bear Town Road: A Memoir of Love and Courage**  
By: *Elizabeth Cohen-Van Pelt*

and others....

### Up and Coming!

**May 28-**There will be a Vol. Training Mtg. from 10:00-noon in Rm. A at the Public Safety Building. Our subject will be on lung disorders and Ken Gracey from **LINCARE** will be coming in to show us the proper way to switch nasal cannulas or masks, oxygen cylinders, regulators and handle transport with someone using oxygen.

**June 25-** There will be a **recertification** class for CPR and AED trained individuals. If you've been trained more than 2 yrs. ago you may **still** be eligible to take the class.

Call Kit for details. Please make sure you state your intentions as the space is limited.

**July 30-** venue changed to the Community Room at the Senior Housing Community, 7 Main Street, Delhi. **Please park in spots facing Rt. 10.** The training subject to be announced. 10:00-noon.

**There will not be any August meeting.** We will try and get back to the Public Safety Building (PSB) for September.

### Did you know?

**Anger harms the heart.** Researchers recently measured heart instability in 62 people with implantable cardioverter-defibrillators while they were thinking about an event that had made them angry. Those who had a strong reaction were 11 times more likely to experience dangerous heart-rhythm problems over the next two to four years.



Consumer Reports  
On Health June '09