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INSIDE THIS ISSUE

PAGE 1

Remembering Ed Brailey

PAGE 2

Alpha-1 News

PAGE 3

Staying active in the spring with a smart design to gardening

PAGE 4

Shaping a plan for a safe and effective exercise routine

PAGE 6

Gain insurance insight through research and resources

Alpha sees hope in improving the health of insurance

PAGE 8

Video uses animation to explain health reform

Remembering Ed Brailey

A leader who strengthened the Alpha-1 community



Photo courtesy of
Alpha-1 Association

In January of this year, the Alpha-1 community lost one of its most passionate and energetic supporters with the passing of Ed Brailey. Dedicated to Alphas and their families since his own diagnosis in 1992, Ed was Chairman of the Alpha-1 Association Board of Directors and served on its Board for five years. His tireless work to raise awareness about the condition and the need for increased access to education and support included advocacy trips to Washington, D.C. He was 58.

Ed enjoyed a long career as a firefighter and Vice President of Shipman's Fire Equipment Company in his hometown of East Lyme, CT. Once he was diagnosed with Alpha-1, his involvement with numerous community and civic organizations expanded to include Alpha initiatives on a local level. He served as a Support Group Leader to the Alpha

Nutmeggers of Connecticut for more than a decade. When he began to emerge as a national advocate for Alpha-related issues, his wife JoAnne stepped up to become Support Group Leader.

After undergoing a single lung transplant in May 2002, at age 50, Ed became an ardent supporter and, ultimately, a long-time volunteer for the New England Organ Bank. His transplant also spurred his fundraising and fun raising efforts as bike team leader for the American Lung Association Bike Trek on Cape Cod, MA. Cycling as "Team Brailey," the firefighters, police officers, and lifelong friends who joined Ed raised funds for the Alpha-1 Foundation. Ed also organized fund raising events for the Alpha-1 Association that ranged from spaghetti dinners to silent auctions and raffles.

When profiled in the Alpha-1 Foundation's magazine in 2004, Ed talked about his fundraising dinners. "People don't come for the spaghetti," he said. "They come for the cause. I can't tell you how much that moves me."

As that sentiment reflects, Ed found his greatest fulfillment in his many interactions with the Alpha community and the long-term relationships that he formed throughout the years. He often spoke on a weekly basis to an Alpha-related group or community organization. "Ed was constantly interacting with people and seemed to bring a smile to everyone he met," said Marlene Erven, Executive Director of the Alpha-1 Association. "He lived a true life of service to others and helped to create the fabric of the Alpha-1 community. Ed's goal was to ensure that every Alpha had access to support and education. His leadership in this area was tremendous on behalf of the Alpha-1 Association. He will be missed by many." ●

He lived a true life of service to others and helped to create the fabric of the Alpha-1 community.

ALPHA-1 NEWS

Alpha-1 explained on Dr. Oz Show

Last December, an episode of the Dr. Oz Show, hosted by Dr. Mehmet Oz, featured three top cancer experts who answered questions about cancer and explained the environmental and genetic risk factors for developing cancer. At the beginning of the show, Dr. Oz brought up Alpha-1 Antitrypsin Deficiency as a risk factor for developing lung cancer, and he then used two trays of coals to demonstrate exactly how the alpha-1 protein works in the body. If you missed this show and are interested in Oz's demonstration, you can view it on the show's website, at www.doctoroz.com/videos/ask-dr-oz-cancer-edition-pt-1.



New video promotes the importance and process of plasma donation

While plasma protein therapies are used to treat rare, chronic diseases and disorders such as Alpha-1, there are many people unaware of how they can personally contribute to the development of these lifesaving medicines. In an effort to raise awareness about plasma donation and outline the process of donating plasma, the Plasma Protein Therapeutics Association (PPTA) has produced "Becoming a Plasma Donor," a DVD that can help those living with Alpha-1, as well as their family and friends, encourage others to consider becoming a committed plasma donor.¹

The 10 minute video illustrates how critically important plasma donors are to the production of safe and effective therapies and details the safety and eligibility steps required to become a plasma donor at one of the 400-plus U.S. Food and Drug Administration-licensed and International Quality Plasma Program-certified plasma collection centers in the United States.

Both educational and inspirational, it outlines what to expect, from the physical examination to the donation process itself, and offers a clear understanding of the safety measures in place to support protect the health of the donor and the patients who rely on therapies made from plasma. To view the DVD online, visit www.pptaglobal.org/news/videos/plasma-donation.aspx. To obtain a copy of the new DVD, please contact Diana Krueger at dkrueger@pptaglobal.org or (443) 433-1107.¹ ●

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Staying active in spring with a smart design to gardening



For people living with Alpha-1, springtime offers opportunities to be more active. As the weather warms up and the flowers begin to bud, you might balance your outdoor walks with time spent cultivating a beautiful garden. It's important to consider your health, however, when digging into such a project.

To begin, settle on a place and a plan that will ease your effort, conserve your energy, and enhance your enjoyment. This may involve reducing the size of a previous garden site and designing flowerbeds that are easier to reach. If necessary, relocate your garden tools and hose closer to your garden. When it comes to tools, lighten your load by trading in your traditional hoe and rake for smaller versions with extendable handles. Use a stool or small bench to eliminate excessive kneeling and bending.¹

It's all about preparation and moderation. Always stretch your muscles before you begin working, do a little at a time, and take a break whenever you feel fatigued. Be aware of the weather and the pollen. Garden during the cooler times of the day (early morning and late afternoon) and avoid working outside when allergen, pollen and pollutant levels are high.^{1,2}

When you are choosing flowers, remember that plants that are pollinated by insects or birds rather than by the wind produce heavier pollen that are less likely to be inhaled because they stick to the flowers. These flowers also tend to be larger and brighter than other varieties. Weeds are usually wind pollinating, so be sure to get rid of them early before they have a chance to mature. Inorganic mulch can help to control them.²

By doing a little homework and making a plan that emphasizes moderation and relaxation, you can plant the seeds of a healthy spring and beautiful summer. ●



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Shaping a plan for a safe and effective exercise routine

We all know that exercise, if performed consistently and appropriately, is beneficial to the health of people of all ages. A chronic obstructive pulmonary disease (COPD) such as Alpha-1, however, can limit how you exercise and how often you exercise. Yet, it is through exercise that you can reduce shortness of breath and build the muscle strength and endurance that will allow you to be more active in your everyday life.¹

Many people with COPD integrate exercise into their lives by participating in a physician supported or physician prescribed pulmonary rehabilitation program. A primary aspect of such programs is to develop appropriate exercise plans tailored to individual needs, abilities, and conditions. In fact, an article in the March 2009 issue of the *New England Journal of Medicine* addressed those with COPD who complain that exercise is too exhausting and leaves them breathless by reporting that supervised exercise through pulmonary rehabilitation can actually reduce their feelings of breathlessness, increase their tolerance for exercise, and improve their quality of life.²

While entering pulmonary rehabilitation involves gaining a physician's consent, it is vital that you always consult with a physician before doing any exercises, starting any exercise program, or following any exercise guidelines you may find on a website. This also applies to the exercises described below. These are examples of general exercises for people with COPD. As every Alpha-1 patient is different, your doctor can help you determine the exercises that best suit you, how often and how long to do your exercises, and how to set your long-term goals.¹



Common exercises

Aerobic exercises are typically a centerpiece of pulmonary rehabilitation programs, but they include exercises common to all people. Walking and bicycling, whether in a park or on a treadmill, are aerobic exercises, and swimming is as well. Any exercise that raises your heart rate and keeps it up for an extended time improves your aerobic fitness because it increases the amount of oxygen to your muscles, which allows them to work longer.¹

Walking to work, walking your dog, or even vacuuming your house at an increased pace can be a beneficial aerobic exercise. If you can't talk while you exercise, you are exercising too hard.¹ This is another example of why it is important to involve your doctor in your exercise plan.

Sitting exercises

There are many exercises that can be done while sitting, including knee extensions and leg lifts that develop lower body muscles. Elbow breathing can help develop arm and shoulder muscles that support the rib cage and can help improve your breathing.

Knee extensions

Sit in a chair with your feet slightly apart. Breathe out as you straighten your knee and raise your lower leg. Breathe in as you bend your knee and return your foot to the floor.

Leg lifts

Sit in a chair with your feet slightly apart. Breathe out as you lift one leg straight up so that the knee rises toward your shoulder. Breathe in as you return your foot to the floor.

Elbow breathing

Sit with your feet slightly apart. Lift your elbows to shoulder level and touch your fingertips in front of your chest. Breathe in as you pull your elbows back so that your fingertips separate. Breathe out as you return your elbows and fingertips to the original position.¹

Breathing exercises

Another exercise that can be done either sitting or standing is known as pursed-lip breathing, and it is designed to help you control your breathing rate and shortness of breath by getting more air into your lungs.³ It's a simple inhale-exhale process, and breathing out slowly, as if into a straw, should take twice as long as breathing in.

Similarly, diaphragmatic breathing can help your lungs expand and take in more air. It can be done many times a day.

As breathing techniques should be incorporated into any strenuous exercise, and oxygen is sometimes recommended for those with Alpha-1 when exercising, it is again imperative that your doctor be aware of your exercise activities. In fact, the many online sites offering products not beneficial to you include those promoting Oxygen Supplements over Oxygen prescribed by the physician. In addition to talking with your doctor, review reputable resources about appropriate exercise and pulmonary rehabilitation, including more in-depth sources such as:

The American College of Chest Physicians, www.chestnet.org.

American Thoracic Society, www.thoracic.org.

American Association of Cardiovascular and Pulmonary Rehabilitation, www.aacvpr.org/. ●

Pursed-lip breathing

1. Inhale slowly through your nose until your lungs are full of air.
2. Purse your lips as if you are going to whistle. Now exhale slowly. Do not force your lungs to become empty.

Diaphragmatic breathing

1. Sit comfortably and relax your shoulders.
2. Put one hand on your abdomen. Now inhale slowly through your nose (push your abdomen out while you breathe in).
3. Repeat the above maneuver three times and then take a little rest.³

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Gain insurance insight through research and resources

For many Americans living with Alpha-1, navigating the landscape of health insurance can be a complex and frustrating challenge. With distinct elements of health care reform being planned for implementation over the next four years, staying informed of change through personal research and by making the most of knowledgeable resources is a way of taking control of your own health care.

For example, many Alphas may benefit from the new pre-existing condition insurance plans (PCIP) designed to make health insurance available to Americans denied coverage by private insurance companies because of a pre-existing condition. This and other key provisions contained in the Patient Protection and Affordable Care Act were outlined in the Summer 2010 issue of *Airwaves*. The PCIP program began accepting applications for enrollment in the Federal program in July of 2010 (dates for the 27 states that have chosen to run their own programs varied). According to the Department of Health and Human Services (HHS), the total enrollment in the PCIPs has jumped by over 50 percent since lower premiums and new plan options were introduced on January 1st.^{1,2}

Those covered by Medicare are likely aware that keeping up with change is essential to keeping up with benefits. Administered by the Centers for Medicare & Medicaid Services (CMS), the Medicare program is for people age 65 or older, some disabled people under age 65, and people of all ages with End-Stage Renal Disease (permanent kidney failure treated with dialysis or a transplant). In covering nearly 40 Million Americans, including those with Alpha-1, it is the nation's largest health insurance program.³

Alpha sees hope in improving the health of insurance



Although Ray Baumann had rarely been sick in his adult life, the severe stomach pains that prompted him to see his doctor in February of 2009, when he was 62, eventually led to him being diagnosed with Alpha-1. The surprise of learning he had been living with this genetic disorder all of his life was amplified by the challenge of pursuing treatment while now being categorized, in the eyes of the nation's

health care system, as a patient with a pre-existing condition.

With his wife Cathy, Baumann is the owner of Baumann's Bakery, which for decades has been an institution in the Chicago suburb of Palos Heights. As the depth of his sickness included liver cancer, he had discontinued working and was ineligible for Social Security disability support by the time physicians determined he was in need of a liver transplant. The contradiction of paying the full costs of prescribed medications meant to improve his health, while waiting to become sick enough to rise to the top of the transplant waiting list, were among the frustrations that surrounded Baumann's struggle to survive.



There are two ways to get Medicare prescription drug coverage. Those who have Original Medicare can choose to join a Medicare Prescription Drug Plan or can choose to join a Medicare Advantage Plan (like an HMO or PPO) that includes Medicare drug coverage. In either case, it is important to know that prescription drug coverage can vary by cost, coverage, and convenience.⁴

In fact, as of 2011, most Medicare Prescription Drug Plans (Part D) have a temporary limit on what they cover for prescription drugs. This limit is called the “coverage gap” or the “donut hole”. The coverage gap starts after you and your plan have spent a certain amount of money for covered drugs. Because all Medicare drug plans are different, it is wise to call your plan if you have questions about how the coverage gap will work for you.⁵ It is also important to note that if you or your prescriber feel that your medications should be covered by your plan but claims are being denied, or that a specific drug should be added to the plan’s formulary, you have a right to appeal the denial of coverage.

The significance of cost, coverage, and convenience factors in Medicare plans depends on individual situations and prescription drug needs.⁴ For example, for some who are covered

continued on page 8

“The great frustration is in understanding and navigating the insurance process, especially while you are sick” he said. “In fact, if I had even caused my own health issues rather than having been born with them, I would have been better covered by insurance.”

To be clear, Baumann puts these frustrations in proper perspective. He is lucky to be alive. Two hours after being placed at the top of the transplant list, on March 17th of last year, he received a cadaver-donor liver and underwent a successful liver transplant at the University of Illinois Medical Center’s Walter Payton Liver Center. “The doctors saved my life,” he said. A year later, his prognosis is good.

With the transplant, however, Baumann’s total medical costs surged to approximately \$500,000. His health insurance paid only about \$5,000 toward that cost and he will be on anti-rejection drugs for life and will routinely need follow-up doctor visits and blood work. To help defray costs of the transplant, the Baumann’s agreed to pledge to the hospital money they raised from a fundraiser organized in their community. As Baumann said, anything will help, and that has included the passage of health care reform.

The Health Care Reform Act, which was enacted in the same week of Baumann’s transplant, included a provision that prohibits insurers from dropping customers

with pre-existing conditions. “For one of my medications, we were paying \$1,700 a month,” Baumann said. “With health reform, it now costs \$450 a month.”

At 64, Baumann is furthered helped by his upcoming eligibility for Medicare. “When you’re basically told to hang on until you’re able to be covered by Medicare so you can receive the effective treatments you need, you know there is a problem with our health care system,” he said. “I feel sorry for those who come behind me, but I do think we are finally beginning to deal with those problems. I really think there is hope for the future.” ●

continued from page 7

by Medicare, their plans may include a Medicare Secondary Payer (MSP) or a Medicare Supplement (Medigap) policy. Medicare Secondary Payer is the term used by Medicare when Medicare is not responsible for paying first. (The private insurance industry generally talks about “Coordination of Benefits” when assigning responsibility for first and second payment.) A Medicare Supplement (Medigap) policy is a private health insurance policy designed specifically to fill in some of the “gaps” in Medicare’s coverage when Medicare is the primary payer. Medicare supplement policies typically pay for expenses that Medicare does not pay because of deductible or coinsurance amounts or other limits under the Medicare program.⁶ Each fall Medicare participants receive information about changes to their Medicare plan. This is an opportune time for them to review their prescription drug needs and compare Medicare drug plans.⁴

In assessing the personal impact of changes to Medicare or the impending changes in the broader insurance market through health reform, people living with Alpha-1 and their families should take advantage of the many resources that provide insight on these issues as well as organizations that make a priority of addressing individual needs.

Baxter Healthcare Corporation offers the Alpha-1 community educational support and resources designed to help them answer questions about insurance coverage and discover insurance options. Baxter also provides those who benefit from its therapies with access to a channel

Resources for more information:

Baxter’s Alpha1Health: www.alpha1health.com

Patient Services Incorporated (PSI): www.uneedpsi.org

HealthCare.gov: www.healthcare.gov

Medicare: www.medicare.gov

of experts and advocates dedicated to supporting this and other aspects of their journey of living with Alpha-1.

Through its Department of Healthcare Economics, Baxter assists patients as well as healthcare providers and payors with a variety of economic, insurance, and reimbursement-related issues, including:

- Providing coverage, support, and assistance with challenging issues
- Coordinating patient assistance programs
- Offering patient education programs and advocacy for insurance-related concerns
- Facilitating the gathering of technical and clinical information for medical professionals
- Analyzing and disseminating healthcare economics information to customers upon request

While supporting the work of Patient Services Incorporated (PSI), a non-profit organization that helps patients with billing and reimbursement issues, Baxter also operates the Alpha-1 Security Program, a way for eligible users of augmentation therapy to continue to receive their therapy without charge in the event of a lapse in private insurance.

Video uses animation to explain health reform

A new video written and produced by the Kaiser Family Foundation uses clever animation to help explain the new health reform law and how changes in the health care system could affect you. Narrated by Cokie Roberts, a news commentator for ABC News and NPR and a member of Kaiser’s Board of Trustees, “Health Reform Hits Main Street” can be viewed at the Kaiser Family Foundation website, at <http://healthreform.kff.org/The-Animation.aspx>. ●

It is through these and other initiatives that Baxter will continue to communicate with the Alpha-1 community about the progress in health care reform and how specific changes may affect them today and in the future. ●

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