Welcome to the winter edition of the Alpha-1 Advocate.

I hope that you will find the Advocate helpful as an alpha-1 patient or care partner for an alpha-1 patient. Please let me know if you have any questions or comments about the information in this newsletter. I will be more than happy to address them.

Nancye Buelow
National Director of Consumer Advocacy and Program Development, Coram Alpha-1 Services

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Dear Friends,

As CEO of Coram, Inc., I am proud to announce that we have recently completed a merger with Apria Healthcare. In doing so, we have greatly enhanced our level of integrated home care services, and have become the largest specialty infusion service provider in the nation. This means that as a Coram alpha-1 patient or caregiver, you’ll have access to new resources and expanded support services along with a seamless continuation of your current care plan.

We now have greater resources with which to serve you. Benefits include a more extensive network of branch offices, and a combined total of 84 infusion sites to support you when you travel. Of course, you will continue to have access to the advocates, consumer resources and expert clinical support you’ve come to expect and trust. From personalized care and delivery of your therapy, to the availability of a broad range of new products and services, our goal is to be the provider of choice for all of your alpha-1 needs by giving you a level of service, responsiveness and care that is second to none. Coram’s merger with Apria also adds the benefits of inhalation therapy pharmacies and a broad range of respiratory services such as home oxygen therapy, CPAP/BiPAP for treating sleep disordered breathing, home-delivered diabetic supplies and home medical equipment.

If you have any questions, please contact your local branch, consumer advocate or our consumer resource line at 866.for.A1Pi (866.367.2174). Thank you once again for the trust you place in us to deliver the expert care you need to stay healthy and live your life to the fullest.

Sincerely,

John J. Arlotta
Chief Executive Officer
Coram Inc.
An Apria Healthcare Company
Making a Difference – A Nurse’s Story

Susan Gregory, RN, BSN, has been infusing alpha-1 patients since 1990 in the physician’s office, as well as in home and ambulatory infusion suite (AIS) settings. Susan was first introduced to alpha-1 while working with Asheville Pulmonary Associates in Asheville, N.C.

In fact, Susan was with Asheville Pulmonary when they diagnosed their first alpha-1 patient. Shortly after the diagnosis, Susan started performing the patient’s weekly augmentation therapy in the pulmonary physician’s office due to his Medicare status. As time went on, Asheville diagnosed several more cases of alpha-1, and Susan would treat them weekly, coordinating their care. If they were hospitalized, Susan would also assist them with their care programs.

After five years of working at Asheville Pulmonary, Susan returned to cardiovascular ICU nursing but continued to get calls from the pulmonologists at Asheville, asking for her assistance. Eventually, Susan began infusing patients at the request of home specialty infusion pharmacies.

Susan now speaks at support group meetings and national events about treatment of alpha-1. In addition, she is asked by manufacturers to participate on advisory boards. Susan has been generous with her time, and volunteers a large portion of it to the alpha-1 community.

She finds it rewarding to help patients manage their chronic conditions, enabling them to increase their quality of life by optimizing their health. Susan believes that if a primary nurse or physician’s office can guide a patient for an extended length of time, it can make a huge difference in outcomes.

Susan, currently a per diem nurse for Coram, is married and lives in the mountains of western North Carolina. She enjoys running with her black lab, Fred, and has recently begun running marathons with her daughter.
Facts about MRSA
The following is courtesy of the National Institutes of Health

There has been a great deal of media coverage recently about Methicillin-resistant staphylococcus aureus, or MRSA. Learn what the National Institutes of Health has to say about MRSA, its treatment and its prevention.

What is MRSA and How is it Acquired?
MRSA, community-acquired MRSA (CA-MRSA) and hospital-acquired MRSA (HA-MRSA), are all an infection caused by a strain of staphylococcus aureus bacteria that is resistant to antibiotics known as beta-lactams. These antibiotics include methicillin, amoxicillin and penicillin.

What Causes MRSA?
Staphylococcus aureus, also known as staph, is a common strain of bacteria that typically lives on the skin. This bacteria also lives harmlessly in the nasal passages of roughly 30 percent of the U.S. population. Staph can cause infection when it enters the skin through a cut or sore. Infection can also occur when the bacteria moves inside of the body through a catheter or breathing tube. The infection can be minor and local (for example, a pimple), or more serious.

Most staph infections occur in people with weak immune systems, usually patients in hospitals and long-term care facilities. People who have been hospitalized or had surgery within the past year are at high risk for HA-MRSA. People receiving certain treatments, such as dialysis, are also at high risk. MRSA bacteria account for a large percentage of hospital-acquired staph infections.

Over the past several years, MRSA infections in people not considered high-risk have increased. These CA-MRSA infections occur in otherwise healthy people who have no history of hospitalization in the last year. Many such infections have occurred among athletes who share equipment or personal items, such as towels or razors, and children in daycare facilities.

For those who have contracted a local skin MRSA infection, draining the abscess at the doctor’s office is usually the only treatment needed. Few antibiotics

An Ounce of Prevention Keeps the Germs Away
Each year, infectious diseases cost the U.S. $120 billion. Worse yet, more than 160,000 people in the U.S. die from an infectious disease each year. Therefore, staying healthy is important for you and your entire family. Washing your hands is an easy, low-cost step to help stop infectious diseases before they happen!

How to Wash Your Hands
• Wet your hands and apply liquid, bar or powder soap.
• Rub hands together vigorously to create a lather. Scrub all surfaces.
• Continue for 20 seconds! It takes that long for the soap and scrubbing action to dislodge and remove stubborn germs. Need a timer? Imagine singing “Happy Birthday” all the way through twice!
• Rinse hands well under running water.
• Dry your hands using a paper towel or air dryer.
• If possible, use your paper towel to turn off the faucet.
are available to treat more serious MRSA infections. These include vancomycin (Vancocin®, Vancoled), trimethoprim-sulfamethoxazole (Bactrim, Bactrim DS, Septra, Septra DS) and linezolid (Zyvox®).

If you are prescribed one of these antibiotics, finish all doses you have been given, even if you feel better before the final dose. Unfinished doses can lead to development of drug resistance in the bacteria.

Other treatments may be given in the hospital for more serious infections. These treatments may include supplemental oxygen and intravenous medication. In cases of kidney failure, dialysis may be needed.

**What is the Prognosis?**
The outcome varies with the severity of the infection and the general condition of the person who has the infection. Although uncommon, MRSA pneumonia and blood poisoning have high death rates.

**Are There Possible Complications?**
Serious staph infections may include cellulitis, endocarditis, toxic shock syndrome, pneumonia and blood poisoning. Organ failure and death may result from untreated MRSA infections.

**When Should I Contact a Medical Professional?**
You should contact your healthcare provider if a wound gets worse and fails to heal. You also should seek medical assistance if any other symptoms of staph infection are present.

**How Can I Prevent MRSA?**
Careful attention to personal hygiene is key to avoiding MRSA infections. Wash your hands frequently, especially if visiting someone in a hospital or long-term care facility. Do not share personal items such as towels or razors with another person — MRSA can be transmitted through contaminated items. Cover all wounds with a clean bandage and avoid contact with other people's soiled bandages. If you share sporting equipment with others, clean it first with antiseptic solution. ♦

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**Whenever possible, wash your hands:**
- Before eating
- Before, during and after handling or preparing food
- After contact with blood or body fluids, such as vomit, nasal secretions or saliva
- After changing a diaper
- After you use the bathroom
- After handling animals, their toys, leashes or waste
- After touching something that could be contaminated, such as a trash can, cleaning cloth, drain or soil
- Before dressing a wound, giving medicine or inserting contact lenses
- More often when someone in your home is sick
- Whenever they look dirty

If soap and water are not available, use an alcohol-based wipe or hand gel. Keeping your hands clean is one of the best ways to keep from getting sick and spreading illnesses. Cleaning your hands gets rid of germs you pick up from other people, from the surfaces you touch and from the animals you come in contact with.

Cleaning and disinfecting are not the same thing. Cleaning removes germs from surfaces, whereas disinfecting actually destroys them. Cleaning with soap and water to remove dirt and most of the germs is usually enough. But sometimes, you may want to disinfect for an extra level of protection from germs.

*Courtesy of the Centers for Disease Control and Prevention*
Changes Ahead for Medicare Drug Program

Nearly two million low-income Medicare participants could be switched to different insurance plans for their prescription drug coverage this year. Millions more will have to shop around if they want to avoid double-digit increases in their monthly premiums.

Reassignment of benefits to the country’s lowest-income beneficiaries and an increase in premiums for many others are just two reasons why seniors and the disabled may want to look at other options as the Medicare drug benefit plan enters its third year. The shopping season runs annually from Nov. 15 through Dec. 31. It is never too early to start looking at a plan for next year. *

Advocacy groups warn the benefit’s 24.5 million participants to take nothing for granted, even if they are happy with their current coverage. “Everybody needs to shop around every year,” said Patricia Nemore, senior policy attorney at the Center for Medicare Advocacy. “Just because you like your plan this year doesn’t mean that plan will work the same next year.”

Under the current drug benefit program, Medicare subsidizes insurance plans that cover an enrollee’s prescription drug buys. The government pays insurers extra for covering the very poor. However, plans covered under Medicare regularly adjust their coverage to reflect the changing marketplace, as well as which drugs they will cover for safety and financial reasons. These plans also make adjustments to the monthly premiums they charge customers, trying to maximize demand for their product and profitability.

On average, Medicare Part D plans will charge a monthly premium of $28 in 2008, but the premiums vary widely across the nearly 1,800 plans around the country. The premiums range from $9.80 for a basic benefit to $107.50 for enhanced coverage.

About a quarter of the poorest beneficiaries don’t pay any monthly premium, and they are entitled to the extra benefit next year, but they will have to get their coverage though other plans meeting Medicare’s requirements for offering coverage to low-income beneficiaries. Medicare officials sent letters to nearly two million people to inform them that they will be moved to new plans.

Kerry Weems, administrator for the Centers for Medicare and Medicaid Services, said those beneficiaries can opt to stay with their current coverage if they like, but would have to start paying. He anticipates that the government will make changes to the drug benefit in future years to reduce the number of people “ping-ponging” from insurer to insurer with each new year of coverage.

“It’s not good for them,” Weems said. “There are some things we could have done this year to avoid that, but it would have meant changing the business rules after companies had bid. That didn’t seem like the right thing to do.”

* A Coram Advocate can assist you in navigating the Medicare plan selections.
Most of the low-income beneficiaries being reassigned participate in plans offered through UnitedHealthcare and Humana, according to an analysis from Avalere Health, a consulting firm based in Washington. Two companies, Silverscript and Medco, should pick up many of the reassignments.

The most underprivileged participants can switch their drug plans at any time; so if they get a reassignment notice from the government, they should make sure their new plan covers all their medicine. For more information, call 1.800.Medicare (1.800.633.4227) or contact the State Health Insurance Assistance Program, which has counselors in every state.

Low-income beneficiaries are not the only ones facing major changes, officials note. Enrollment in the drug benefit is highly concentrated, and some of the most popular plans will charge considerably higher monthly premiums next year. For example, the most popular plan, the AARP Medicare RX Preferred Plan, will increase its monthly premium by 16 percent. Humana will increase the premium for its standard plan by 71 percent. In addition, the AARP Medicare RX Save Plan will jump 65 percent, according to Avalere Health. Silverscript, the ninth largest plan, lowered its monthly premium by 24 percent.

Weems said he had not seen Avalere’s analysis, but he pointed out that beneficiaries have a wide array of choices and more than 90 percent of participants can move into a plan with a lower premium than they are currently paying. “They just need to shop around,” Weems adds.

The open enrollment season doesn’t begin until Nov. 15, 2008; however, officials warn beneficiaries that it’s safer to make a decision sooner rather than later — especially if they want to be sure their new coverage is in effect when they pick up their first prescriptions in January of the following year.

While the drug benefit affects people differently depending upon their incomes, their health and where they live, the standard benefit looks like this: Participants pay the first $275 in drug costs, after which the plan pays 75 percent of the tab until total drug costs reach $2,510. That’s when beneficiaries hit the so-called “doughnut hole,” where they pick up all cost until they’ve paid $4,050 out of pocket. After the doughnut hole has been covered, they only have to pay five percent of the tab for their medicine. About a quarter of the plans offering the drug benefit do cover generic drugs when customers hit the doughnut hole.

For more information, visit the Medicare website at www.medicare.gov, and the Center for Medicare Advocacy Inc. at www.medicareadvocacy.org.
Coram’s Alpha-1 Advocacy Programs

The goal of Coram’s Alpha-1 Advocacy program is to provide better educational materials for alpha-1 patients and their families, and to provide resources and support to all those affected by the condition. These goals are met by highly trained Alpha-1 Advocates who are hired from within the alpha-1 community. These resources are outlined in more detail below.

♦ Health Insurance Issues
  - Referrals to nonprofits for premium assistance
  - Referrals to nonprofits for state high-risk pool insurance
  - COBRA counseling and assistance

♦ Peer Mentoring Program
  One-to-one support for alpha-1 consumers and family members by specially trained Alpha-1 Advocates.

♦ The Alpha-1 Advocate Quarterly Newsletter
  The Advocate is provided free of charge to the alpha-1 community.

♦ Aralast™ Users’ Resource Network
  - Monthly teleconference support meetings for Aralast users
  - Educational professionals for physicians and nurses

♦ Conference Call Series
  Monthly, toll-free educational conference call series for consumers and their families.

♦ Quality of Life Patient Outcomes Study
  In an effort to learn more about the quality of life (QOL) and outcomes of Aralast users, Coram is conducting a QOL patient outcomes study. We are currently enrolling Coram Aralast patients to participate in the study. If you are interested in participating, please call 866.367.2174.

♦ Increasing Awareness
  Coram’s 130-plus field representatives are aggressively educating physicians and nurses about the need to test for alpha-1 and early detection of alpha-1 antitrypsin deficiency.
Who to Contact for Help

If you have any questions or need help with any issues, please feel free to contact any of the individuals listed below.

Melodie Beck
Southern States  Alpha-1 Consumer Advocate
Toll-Free  877.288.2003
Tel  336.294.3992
Email  beckm@coramhc.com

Barbee Bennington
Midwestern and Western States
Alpha-1 Consumer Advocate
Toll-Free  800.355.5180 x50
Tel  480.429.1715
Email  benningtonb@coramhc.com

Aaron Holderby
Mid-Atlantic States Alpha-1 Consumer Advocate
Toll-Free  866.760.5670
Tel  304.768.1241
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Kathy Johnson, RN
Supervisor, Northeastern States
Alpha-1 Consumer Advocate
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Loretta Kristofek, RN
Investigator for Coram Alpha-1 Quality of Life Study
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Nancye Buelow
National Director of Consumer Advocacy and Program Development, Coram Alpha-1 Services
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Tel  828.627.1205
Cell  828.246.4541
Email  buelown@coramhc.com
Who Should be Tested for Alpha-1 Antitrypsin Deficiency?

According to the World Health Organization, “all patients with COPD, and adults and adolescents with asthma should be screened once for [alpha-1 antitrypsin deficiency] using a quantitative test (immunoassay).”

People who are at risk for alpha-1 antitrypsin deficiency include:

- Anyone with COPD
- Anyone with asthma or who experiences shortness of breath
- Anyone under the age of 50 with symptoms of emphysema
- Anyone with decreased exercise tolerance in the third or fourth decade of life
- Anyone with recurring infections that don’t respond to antibiotics

For more information about testing and alpha-1 treatment options, call 866.for.A1Pi (866.367.2174).