Nutrition and Alpha-1

Jacob Primera: Becoming a Part of the Family

Exercising Tips for COPD Patients

Vaccinations for Those Living with Alpha-1
A Letter from Dan Greenleaf

Nutrition and Alpha-1
Maintaining optimal weight and eating a balanced diet can actually help people living with Alpha-1 breathe better. Learn how you can incorporate good nutrition into your diet.

Jacob Primera: Becoming a Part of the Family
A 17-year veteran Coram nurse, Jacob Primera helps all kinds of Coram patients. Read about how he becomes part of his patients’ families.

Exercising Tips for COPD Patients
Exercise, at almost any level, improves the oxygen utilization, work capacity, and state of mind of COPD patients. These tips can help you enjoy exercise at the level that’s right for you.

Vaccinations for Those Living with Alpha-1
If you have Alpha-1, your lungs — and possibly your liver — are vulnerable to infection. Learn about how vaccines can help prevent lung and liver problems.

Healthy Living
Read the latest news and updates regarding Alpha-1 Antitrypsin Deficiency.

Breathe Easy
Learn about Breathe Easy, Coram’s Alpha-1 program that provides support and information.

2012 Alpha-1 Consumer Educational Series
Find out about our 2012 educational conference call series.

Your Advocate Resources
Our primary focus at Coram is our patients: their health and well-being, as well as the quality of the clinical and personal care that we provide for them.

In this issue of *The Advocate*, we profile Jacob Primera, a nurse who has worked for Coram for 17 years. Jacob works with all types of patients, from children with hemophilia to adults with Alpha-1. Our article describes Jacob's weekly visits into the homes of his patients, where he helps with questions ranging in topic from their infusion therapy to the quality of their daily life. Jacob doesn't just provide infusion therapy — he becomes a part of his patients' lives. Jacob represents the best of what we offer at Coram — caring, knowledgeable clinicians who provide excellence in home infusion therapy.

In addition to clinicians who provide high-quality care, another priority for us is patient education. This issue contains valuable lifestyle guidance for Alpha-1 and other COPD patients. Our main feature provides nutrition information that can help patients breathe better and feel more energetic. Another article describes the benefits of exercise for COPD patients, and provides tips to help make working out fun, healthy and safe. And as always, we provide a listing of current news items about Alpha-1 and related topics.

I am honored to introduce this issue of *The Advocate*. I enjoy communicating with you and hope that you will reciprocate. Feel free to email me at dan.greenleaf@coramhc.com — I'd love to hear about your experiences with Coram.

In the meantime, I hope you enjoy this issue of *The Advocate*!

Take care,

Dan Greenleaf
CEO, Coram
Nutrition and Alpha-1

By Valerie Hansen, Contributing Writer, and
Carol Ireton-Jones, PhD, RD, LD, CNSD, FACN, Consultant Director, Nutrition
Maintaining optimal weight and eating a balanced diet can actually help people living with Alpha-1 breathe better. On the one hand, if you are overweight, your stomach is pushing against your diaphragm, making it harder to breathe. Any woman who has gone through pregnancy can attest to that! At the opposite end of the spectrum are those who find it difficult to gain or maintain weight because they expend so much energy just breathing. According to the American Lung Association, people with COPD need ten times more calories than those without lung disease.

If you have Alpha-1, talk to your doctor and/or a registered dietitian (RD) about a nutrition plan that can help you breathe better and feel more energetic. Coram can connect you with an RD who can help you design a food plan based on your likes and dislikes, teach you how to read labels and provide guidelines for grocery shopping, and give you tips on what foods to choose when eating out. An RD can also review what medications you are taking and let you know about any possible interactions they might cause with certain foods.

In the meantime, here are some tips that can help you make more informed food choices on your own.

**Nutrients You Need**

Nutrients are needed by the body to provide energy as well as to maintain normal body functions. The main source of calories, or energy, are the “macronutrients” — protein, carbohydrates and fat. Additionally, vitamins, mineral and trace elements, or “micronutrients,” are needed in very small amounts. And one more important “nutrient” is water! Although water provides no calories or nutrition per se, water is an excellent fluid source and it’s important to ensure that adequate fluids are taken in daily.

There are a lot of good nutrition and healthy eating tips that apply to everyone, including individuals with COPD or other lung diseases. To start, pay attention to the main food groups. The new My Plate campaign...
from the U.S. Department of Agriculture makes it easy to choose the right foods in the right proportions (www.choosemyplate.gov/food-groups). Divide your “plate” into quarters and choose carefully from the main food groups:

- **Fruits and vegetables** should take up at least half of your plate. Try for five or more servings* of fruits and veggies daily, using fresh produce as often as possible.

- **Proteins** should fill only one-quarter of your plate. Proteins help to maintain cellular function and build muscle. Beef or pork (choose lean cuts of meat), poultry, fish, eggs, nuts, legumes (such as beans or lentils) and soy products are all sources of protein.

- **Grains and starchy vegetables** should make up the other quarter of your plate. These are sources of complex carbohydrates and provide energy as well as many nutrients such as B vitamins and minerals. Choose whole-grain breads and cereals. Also try some new grains, such as quinoa and brown rice, to provide enhanced nutrients and fiber.

- **Dairy products** don’t actually “fit” on your plate, but be sure to include two or more servings daily. These items contain calcium, magnesium and protein as well as other vitamins and minerals for bone and heart health. Choose low-fat milk, cheeses and yogurts for the nutrition they provide without the excess fat.

- **Fats** should be limited on your plate, even if you are trying to gain weight. Fats provide the most energy per gram of weight compared to carbohydrates and protein, and they come in various forms. Healthy fats include mono- and poly-unsaturated fats such as olive oil and canola oil. Less healthy are saturated fats, which are those that become solid at room temperature. These include lard, margarine, butter, cheese and animal fats. Processed foods are more likely to contain additional fats, including saturated fat; so, whenever possible, prepare your foods at home using the healthy oils.

By eating a variety of foods — fruits, vegetables, grains, dairy and healthy oils — and avoiding processed foods, you can improve your nutritional health. The choices within these groups range widely, and selections should be made based on whether you are trying to lose weight, or gain and maintain weight. Your registered dietitian can help you determine your goal weight and the calories you need.

### Other Things to Consider

Sodium, fluid intake, and supplements can be confusing topics. You may wonder: How much salt should I eat? How much water should I drink each day? Do I need to take a supplement? Here are some pointers to help you make healthy choices.

- **Sodium.** Sodium is most commonly thought of as table salt, but it is also found in processed and canned foods. Read food labels when you are shopping. If the sodium content for an item is more than 300 milligrams per serving, leave it on the shelf. Recent recommendations for sodium intake have been to limit it to around 2,500 mg/day, which can be difficult to do. If you have been told to limit sodium, try to manage at that level. Otherwise, a 4,000-mg (4-gram) sodium diet is more realistic. If you are sodium-sensitive, you’ll need to pay extra attention to your sodium intake. This is because sodium will make your body retain fluids, which can make it harder for you to breathe. Cooking fresh, whole foods and using spices rather than salt is the best option, whether you are trying to gain or lose weight.

- **Fluids.** Drinking plenty of non-caffeinated liquids each day will help keep mucus thin and easier to cough up. A standard goal is to drink six to eight glasses of water daily, spread out over the span of the day. If drinking liquid with your meal makes you feel too full to eat, try drinking less with the meal. Then, wait an hour or so before you drink another glass of water or other non-caffeinated beverage. All non-caffeinated beverages count toward the daily goal of fluid intake.
**Supplements.** Many people find that taking a daily multivitamin helps them feel secure that they are getting the micronutrients they need. In general, a multivitamin that contains ~100% of the RDA for all vitamins and minerals is adequate. (RDA is the Recommended Dietary Allowance, which is determined by the Food and Nutrition Board of the National Academy of Sciences.) If you have certain health considerations — for instance, if you have anemia or liver disease, or are taking steroids — you may have different vitamin or mineral requirements. Talk with your doctor or RD about this.

If you find that you are sometimes too tired to eat, there are medical nutritional products available that can help you get the calories you need to maintain energy. Again, discuss these with your doctor or RD.

**Additional Tips**

Here are some tips to help you maintain your optimal body weight while getting the nutrients you need:

- **Monitor your weight.** Weigh yourself at least once a week (more often if you are taking diuretics or steroids). If you have a weight gain or loss of two pounds in a day or five pounds in a week, contact your doctor.

- **Select foods that are easy to prepare.** This helps you avoid using all your energy to make the meal — but this doesn’t mean turning to processed foods!

- **Avoid foods that cause gas and bloating.** When your stomach is bloated, it’s more difficult to breathe. Gas-producing foods include cauliflower, cabbage and beans. Carbonated beverages also cause bloating.

- **Control acid reflux.** Try limiting caffeine, fat, alcohol and spicy foods, and avoid eating just before bedtime.

- **Conserve your energy.** Rest just before eating, and eat your bigger meals earlier in the day when you have more energy to prepare them.

- **Eat smaller, more frequent meals throughout the day.** This will help you feel less full and make it easier for you to breathe.

- **Eat between 20 and 35 grams of fiber per day.** Fresh fruits and vegetables and whole grains — which contain lots of fiber — aid digestion, as well as provide important nutrients.

- **Use safe food preparation practices.** Wash all fruits and vegetables before eating. Also, always use one cutting board for meat or poultry, and a separate one for vegetables.

- **Consider developing a food plan with your RD.** An individualized plan can help you breathe better and feel more energetic. It doesn’t have to be a matter of feeling deprived if you are trying to lose weight, or all-consuming if you are trying to gain weight. It is more about making the best choices among the foods you like to eat.

*For information on serving sizes, go to www.heart.org and search for “serving.”*

**References:**

As a 17-year veteran Coram nurse, Jacob Primera has helped children grow up and transition to college; he has reassured newly diagnosed Alpha-1 patients and their loved ones; and he has become a confidant to patients from all walks of life. Although he came to Coram as a pediatric nurse and still finds working with young patients quite fulfilling, Jacob’s experience ranges far beyond those parameters.
“I treat people with all the conditions covered by Coram,” he explains, “whether it’s administering IV nutrition, antibiotics for kids with cystic fibrosis, factor for our hemophilia kids, or therapy for our Alpha-1 patients. I also change dressings and adjust medication for people on hospice care.”

Jacob began his career as an emergency room nurse and then received training as a pediatric nurse in the intensive care unit. During his hospital years, Jacob discovered that he had a talent for relating to his young patients and soothing their fears. He still brings that quality to his Coram kids, but his compassion has no age limitation. All of his patients benefit from Jacob's calm demeanor and empathy.

Coram nurses like Jacob become a part of their patients’ lives. A few years ago, for example, one of Jacob’s Alpha-1 patients invited him to be part of an Extreme Makeover Home Edition episode. The patient was the foreman for the builder involved in the episode.

“He knew I had renovated some properties and would enjoy being part of the show,” Jacob says. “I told him that I would probably ruin the deadline because it might take me six months to do something they do in six hours. But he invited me to come along and be a ‘go-fer’ for the guys.”

Jacob has that kind of relationship with his patients. He began treating some of his young patients as children and later helped them transition to college. He has worked with parents to help them make the change from providing all of their child’s hemophilia care to allowing the child to take control of his own care. He has also taught young people to follow through with the treatment protocols he sets for them.

Jacob’s relationships don’t end with the patients — they typically involve the patient’s family. For instance, when he meets with newly diagnosed Alpha-1 patients, he often meets the whole gang.

When Jacob and other Coram nurses go into their patients’ homes every week, a comfort level develops... Jacob plans his home visits around his patients’ schedules. He sees his youngsters before they head to school. He treats his working adults in the evening after they get home. In between, he treats those who are at home during the day, such as patients under hospice care.

“My visits usually include some socializing: ‘How’s the family? How was your day?’ And my patients may have questions that they feel more comfortable asking me than their doctor. If it becomes a pattern, we involve the physician, but often the patients just want to talk.”

When Jacob and other Coram nurses go into their patients’ homes every week, a comfort level develops that is lacking in a ten-minute doctor visit every three to six months, no matter how caring or knowledgeable the physician.

“We see them every week,” Jacob says. “We become part of the family.”

The first visit will involve the spouse, caregivers, siblings who are close to them, and parents. Everyone is interested and wants to know what to expect. They have a million questions. To start, I reassure them that the diagnosis won’t change the way they are living their lives. It’s just something they have to live with, like a diabetic learning to live with diabetes.”

When patients and family members want to know how having Alpha-1 will affect their daily lives, Jason’s response is: “Not much.” Whatever their condition was when they were diagnosed is likely to remain the same.

“I explain that the progression of the disease will slow down due to the medication we’ll be giving them. Wherever they are now — on oxygen or not, able to work or not, getting short of breath with exertion or not — it won’t change much,” he says. “All the patients I have were working when they were diagnosed and continue to do so. They still go camping. They go on vacation. They do everything they were doing but with less difficulty and more assurance that they aren’t going to get worse.”

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Exercising Tips for COPD Patients

Chronic obstructive pulmonary disease (COPD) is a common occurrence in the United States today. People who suffer from COPD are usually debilitated as a result of poor mucociliary clearance, increased secretions, and frequent infections. Furthermore, these patients often experience anxiety, depression, and social isolation due to the limitations placed on their lifestyles.

Exercise, at most any level, improves the oxygen utilization, work capacity, and the state of mind of COPD patients. Low-impact activities place minimum stress on joints and are easier to perform than high-intensity activities. Some COPD patients may also benefit from exercise programs that target the upper body and are designed to increase the strength of respiratory muscles.

If you are a COPD patient, you already know that you expend extra energy to breathe. If you can use your energy more efficiently for breathing, you will have more energy left for performing routine activities of daily life or participating in new activities. Actively practicing some form of exercise, along with proper nutrition, can significantly improve your quality of life. In this article, you will find some general tips for exercising. Of course, before delving into any exercise program, be sure to consult your physician.

Warm up before exercising.

Warm-up exercises include plenty of stretching. If you have chosen walking as your aerobic exercise, you can warm up by starting out at a slow pace for five or ten minutes.

Set attainable goals.

Begin your exercise regimen by setting a goal that you know you can achieve. Then gradually set your goals higher as you progress. It’s good to work up to sustaining your activity for 20 to 30 minutes, two to four times a week. If you can comfortably do five minutes of exercise your first week and then increase it to ten minutes the next, you will probably be able to attain this 20-minute goal. As you achieve each goal, however small, you are more likely to continue your exercise program.

Vary your activities.

Alternate exercise activities such as swimming, walking, upper-body weight training and low-impact aerobics. If you get bored, you are less likely to stick with it.

Choose activities you enjoy.

Exercise shouldn’t be something you dread — have some fun with it! You may need to try a number of activities before you find the one(s) best suited to your lifestyle.
Exercise with a friend.

Not only will you motivate each other, you should always be able to carry on a comfortable conversation while exercising. And what better way to make sure you don’t overdo it?

Don’t make excuses — just do it.

If your physician approves your chosen low-impact activity, don’t make excuses for why you can’t begin — just do it! You can perform plenty of activities while wearing a supplemental oxygen setup. Any exercise is better than no exercise at all. Start slowly, and as you begin to reap the benefits of exercise, you will soon find you want to do more.

Take time to cool down.

Cool-down activities, such as stretching or walking/swimming at a slower pace, will round out your exercise period and bring your heart rate back to normal.

Stop if you experience a problem.

If you become nauseous or dizzy, feel weak, have palpitations, become short of breath, or experience pain, stop exercising immediately. You may want to consult your doctor, depending on the degree of pain or discomfort.

Set your own pace.

Proceed at a pace that is comfortable for you. You’re not in competition with anyone but yourself.

Reward yourself.

As you reach each of your goals, however small, reward yourself in some way. You deserve it!

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For more information, please call:
(800) APRIA-88
www.apria.com
VACCINATIONS FOR THOSE LIVING WITH ALPHA-1

By Jackie Leverson, RN, BSN, PHN, CRNI, Infusion Clinical Manager
If you have Alpha-1, your lungs are vulnerable to infection. In fact, the lung damage that can be caused by Alpha-1 can be triggered by inflammation from a bacterial or viral infection. Fortunately, vaccines can help protect your lungs from infection. They can also help protect your liver. If you are living with Alpha-1, it is recommended that you receive a flu vaccine every year and a pneumococcal vaccine every five to six years. If you have established liver disease, your doctor may also recommend vaccinations for hepatitis A and B.

**Influenza**

Influenza is a viral infection in the nose, throat and lungs. About 10–20% of Americans get the flu each year. Of those, about 200,000 people go to a hospital, and 36,000 people die from the flu and complications.

Influenza may cause fever and chills, cough, sore throat, a runny or stuffy nose, headache, muscle aches and tiredness. Most people feel better after one or two weeks; for some, however, the flu leads to serious diseases, such as pneumonia. The best way to protect yourself and your family is to get the influenza vaccine.

The Centers for Disease Control and Prevention (CDC) recommends that all people over six months of age get the annual flu vaccine. It is especially important for those who may have a higher risk of flu complications, such as:

- Children aged six months up to 19 years
- Adults aged 50 years and older
- Women who are or will become pregnant during the flu season
- People living in nursing homes or long-term care facilities
- Individuals with chronic health problems (such as Alpha-1)
- Healthcare workers who have direct contact with patients
- Caregivers and household contacts of children less than six months old

*continued*
Streptococcus pneumoniae bacteria are becoming more resistant to antibiotics, making immunization increasingly important.

Pneumococcal pneumonia is the most common type of bacterial pneumonia. It is especially severe in adults over age 65 and in people who have chronic medical problems such as Alpha-1, asthma, emphysema, COPD, heart disease, diabetes, alcohol abuse, kidney failure, cancers, and weakened immune systems from disease or drug treatments.

Pneumococcal meningitis is the leading cause of bacterial meningitis in the U.S. Death rates from this condition are approximately 20–50% in adults. Pneumococcal meningitis can also result in permanent damage to the brain and nervous system, learning deficits, and deafness.

The pneumococcal vaccine is recommended for all adults aged 65 and older, and people aged two through 64 who smoke or have any of the following:

- Chronic cardiovascular disease
- Chronic lung disease
- Chronic liver disease, including persons with long-term alcoholism
- Diabetes mellitus
- CSF (cerebrospinal fluid) leaks
- Functional or anatomic asplenia (when the spleen doesn’t work properly or is absent)
- Immunosuppressive conditions
- Organ or bone marrow transplantation
- Therapy with alkylating agents, antimetabolites, or systemic corticosteroids (used to treat cancer)
- Chronic kidney failure or nephrotic syndrome
- Cochlear (hearing) implants

A second dose (revaccination) of the pneumococcal vaccine is recommended for people aged two through 64 who smoke or have any of the following:

- Functional or anatomic asplenia
- Immunosuppression
- Transplant
- Chronic kidney failure or nephritic syndrome

If you are pregnant during flu season, you cannot get the nasal-spray vaccine. However, it is recommended that women who will be pregnant during flu season get the flu shot. Pregnancy can increase your risk for complications from the flu.

Vaccination is recommended each year because influenza vaccines are always changing. The flu vaccine approved for the 2011–12 season protects against three strains of influenza, including the H1N1 pandemic flu strain. Protection against the H1N1 strain has been incorporated into both the nasal spray and injection vaccines. For all strains of the flu, it may take up to two weeks to be fully protected after receiving the vaccination.

Some people should not get the flu shot. If you fall into one of these categories, you should talk to your doctor before being vaccinated:

- People who have had an allergic reaction to a flu shot in the past
- People with an allergy to eggs
- People who previously developed Guillain-Barré syndrome within six weeks of getting a flu shot
- Children younger than six months of age
- People who have a moderate or severe illness with a fever (these people should wait until symptoms subside before receiving the flu shot)

You can also reduce your risk of catching the flu by washing your hands frequently, which helps stop the spread of germs. Eating a healthy diet, exercising and getting enough sleep also play a part in preventing the flu because these activities help boost your immune system. If you are sick, cough into your elbow and wash your hands often to help prevent giving the flu to others.

Pneumococcal Disease

Pneumococcal disease is an infection caused by the bacteria Streptococcus pneumoniae. Types of pneumococcal disease include pneumonia, bloodstream infections and meningitis (infection in the brain or spinal cord). Pneumococcal disease kills more people in the United States each year than all other vaccine-preventable diseases combined. Antibiotics used to be an effective treatment, but
Adults age 65 years or older who received the first dose prior to age 65 should also be revaccinated. For children aged two to nine years, revaccination is recommended every three years; for people aged ten years and up, it is recommended every five years.

Hepatitis A and B

The liver is one of the largest organs in your body. It is very important to your health because of its many functions. Some of its functions are to clean your blood, help digest food, make chemicals your body needs, and help fight infections. A normal liver removes a yellow substance called bilirubin that builds up in the blood in many liver diseases.

Approximately 1 in 20 people born with two abnormal Alpha-1 genes (ZZ or SZ) will get liver disease in the first year of life. Adults with Alpha-1 can also get liver disease, usually involving cirrhosis (scarring of the liver). During their lifetime, people with Alpha-1 have up to a 30–40% chance of developing a liver problem, including cirrhosis and liver cancer.

Because of their increased chances of having liver problems, it is important for people with Alpha-1 to get vaccinated against infections that can damage the liver, such as hepatitis A and B. Hepatitis is irritation and swelling of the liver. Hepatitis A often resolves on its own, but can cause serious problems for those with existing liver damage. Hepatitis B can cause cirrhosis and, in some cases, can lead to liver failure. If you have Alpha-1, and especially if you have established liver disease, it’s very important for you to talk to your doctor about the hepatitis A and B vaccines. They can be an easy way to prevent serious liver problems.

Symptoms of Liver Problems

Parents, caregivers, or significant others of people with Alpha-1 need to be aware of any indication of possible complications related to liver disease. Signs and symptoms include:

- Increased abdominal swelling or swelling of the extremities
- Coughing up or vomiting bright red blood
- Blackish, purplish or dark-colored stools
- Confusion, irritability, disorientation, lethargy
- Lack of appetite
- Little or no urine, or dark (cola- or tea-colored) urine
- Itching or increased itching
- Change in appearance of jaundice (yellowish skin color)

Summary

If you have Alpha-1, it is important to receive a flu shot annually and the pneumococcal vaccine every five to six years. Because your lungs are vulnerable to infections, the use of these preventive vaccines is vital. If you have liver disease, you should also talk to your doctor about the hepatitis vaccines. The right preventive care plan that includes vaccinations can help you avoid these serious health complications.

References

- www.cdc.gov
- www.alphanet.org
- www.alpha-1foundation.org/files/Recently_Diagnosed.pdf
Healthy Living

Toolkit Helps RTs with Rehab Information

3/26/2012 — Although a permanent pulmonary rehabilitation (PR) benefit is available for Medicare beneficiaries, reimbursement for this benefit by Medicare is not enough to sustain many PR programs. The Medicare data reveals that much of the reimbursement problem is due to improper billing of the benefit by PR centers.

In an effort to combat this problem and help the provider community, the American Association for Respiratory Care (AARC) announced the “Pulmonary Rehabilitation Toolkit” last week, an educational resource developed by experienced PR clinicians from AARC and the American Association of Cardiovascular and Pulmonary Rehabilitation, American College of Chest Physicians, American Thoracic Society and National Association for Medical Direction of Respiratory Care.

The toolkit is designed to aid respiratory therapists, PR program directors, hospital charge masters and financial directors with the information they need to accurately establish the charges for their PR programs when they bill Medicare.

The Toolkit can be accessed at www.aarc.org/resources/pulmonary_rehab_toolkit/

Source:
www.copdfoundation.org/PressRoom/ArticlesPressReleases/News/180.aspx
**More States Receive Funding for Insurance Exchanges**

5/16/2012 — Health and Human Services (HHS) Secretary Kathleen Sebelius announced that Illinois, Nevada, Oregon, South Dakota, Tennessee and Washington would receive more than $181 million in grants to help implement the Patient Protection and Affordable Care Act. The grants will help those states establish Affordable Insurance Exchanges. Starting in 2014, Affordable Insurance Exchanges will help consumers and small businesses in every state choose a private health insurance plan. These comprehensive health plans will ensure consumers have the same kinds of insurance choices as members of Congress. Including today’s awards, 34 states and the District of Columbia have received Establishment grants to fund their progress toward building Exchanges.

To see a detailed state-by-state breakdown of grant awards and what each state plans to do with its Exchange funding, visit the map tool on HealthCare.gov at www.healthcare.gov/news/factsheets/2011/05/exchanges052320115232011a.html.

**Source:**
www.hhs.gov/news/press/2012pres/05/20120516a.html

**Study Finds that Genetic Testing Does Not Spur Use of Costly Medical Services**

5/25/2012 — A study released by the National Institutes of Health found that most people do not seek costly follow-up medical services after genetic tests indicate they are at risk for specific diseases.

The research, published in the journal Genetics in Medicine, compared the amount of services that 217 healthy people (aged 25–40 years) received in the 12 months before and the 12 months after they received genetic testing results. It also compared these care patterns with those of a group of about 400 people who had not been tested.

The testing determined whether the participants carried any of 15 different genes that would slightly increase their risk for eight common health conditions. These conditions included diabetes, coronary heart disease, high cholesterol, lung cancer, colorectal cancer and skin cancer.

Since the human genome was mapped in 2003, genetic tests have become increasingly available to consumers. Critics have speculated that knowing this type of information would lead people to seek further diagnostic tests or additional medical care. However, the NIH study appears to refute that notion, as the participants did not change their overall use of healthcare services as compared to those participants not tested.

**Source:**

**Study of Rats Shows Mature Liver Cells Better than Stem Cells for Liver Cell Transplantation Therapy**

6/10/2012 — A study from researchers in Sapporo, Japan compared how well immature liver stem cells versus mature liver cells grow when transplanted into rats with liver damage. The research concluded that the mature liver cells performed better than the stem cells.

Until day 14 post-transplantation, the growth of the stem cells was faster than that of the mature liver cells. However, after two weeks most of the stem cells had died, while the mature liver cells continued to survive and proliferate one year after their implantation. The study is published in the journal Cell Transplantation.

The researchers noted that the shortage of cell sources and the difficulties of preserving the cells have limited the clinical application of cell-based therapies. Stem cells have been considered candidate cells because they can expand in vitro and can be preserved for a long time.

**Source:**
www.medicalnewstoday.com/releases/246198.php
Through the *Breathe Easy* program, one of our team members — either a Consumer Advocate (some of whom are Alphas themselves) or a Patient Relations Specialist — will follow up periodically to check on your therapy and service experience, as well as address any questions you may have. Additionally, the *Breathe Easy* program will provide you with routine educational opportunities, such as our Alpha-1 toll-free teleconference series and our quarterly magazine, *Alpha-1 Advocate* — all to aid you in learning more about living with Alpha-1 Antitrypsin Deficiency.

With Coram, you can breathe easy knowing we are committed to you and your care. As one of the longest-serving home care providers to the Alpha-1 community, Coram understands the multitude of questions, concerns and challenges you may face.

Coram’s *Breathe Easy* support program is designed to provide you with the individualized resources, information and advocacy that you need to achieve success with your augmentation therapy. Through the *Breathe Easy* program, you have the advantage of a coordinated team that will assist you in making vital lifestyle adjustments, finding answers to disease and therapy questions, locating community resources, addressing financial and insurance coverage issues, and even having your infusion or oxygen therapy managed while you travel. The *Breathe Easy* program provides:

**Customer Service**  
Ongoing contact from a Customer Relations Specialist to answer questions and address therapy or service-related issues.

**Peer Mentoring Program**  
On-demand counseling and educational support by a specially trained Alpha-1 Consumer Advocate.

**Alpha-1 Resource Network**  
Customized Alpha-1 information, tools and support items sent to your home.

**Insurance and Financial Support**
- Information about premium assistance programs
- Information about nonprofit organizations for state high-risk insurance pools
- COBRA counseling and assistance
- Enrollment in manufacturer assistance programs as applicable

**The Alpha-1 Advocate Quarterly Magazine**  
A free informational magazine for the Alpha-1 community.

**Alpha-1 Consumer Teleconference Series**  
A monthly, toll-free Alpha-1 community conference call series for consumers and their caregivers, provided free of charge.

**Alpha1Source.com**  
A website devoted exclusively to providing helpful information and resources to Alpha-1 consumers and healthcare providers.

For any questions regarding the *Breathe Easy* program, please contact Coram’s Alpha-1 hotline at **866.FOR.A1Pi** (866.367.2174).
Coram is pleased to offer this insightful series to help you learn more about the subjects that affect Alpha-1 consumers today. These educational calls are available at no cost to you. We hope you attend and feel free to ask questions.

**How to Join a Call**

**Call:** Call toll-free **877.60CORAM (877.602.6726)**
Enter option **9** when prompted.

**Time:** Tuesdays, 7:00 pm EST / 4:00 pm PST

**2012 Conference Call Calendar**

*No calls in August — enjoy the rest of your summer!*  

**SEPTEMBER 25**

**Influenza**  
Speaker: Jackie Leiverson, RN, BSN, PHN, CRNI, Coram

**OCTOBER 23**

**Understanding Your Insurance Policy, Major Medical and Prescription Benefits**  
Speaker: Thomas A. Lamondra, Senior Manager - Reimbursement & Advocacy, Baxter BioScience

**NOVEMBER 27**

**Caregivers: Steps to Guide You**  
Speaker: Aaron Holderby, Consumer Advocate, Coram

*No call in December — have a great holiday season!*

For more information or to listen to past conference calls, please visit our website [alpha1source.com](http://alpha1source.com)
Your Advocate Resources

To learn more about our Alpha-1 services and the Breathe Easy program, please contact one of our Alpha-1 Advocates listed below.

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