

FALL 2017

NIH MedlinePlus

MAGAZINE

Trusted Health
Information from the
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of Health

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NIH MedlinePlus Magazine Cover Star Nick Jonas Recognized for Diabetes Advocacy

Performer Nick Jonas received the “2017 Hero Award” at this year’s Radio Disney Music Awards show for his work fighting for type 1 diabetes research advances and patient care. Jonas was featured on the cover of this spring’s NIH MedlinePlus magazine, in which he discussed his experiences with the disease.

Jonas was diagnosed at age 13 and has translated his battle fighting type 1 diabetes into advocacy. He has spoken out in favor of NIH research as an advocate for the Juvenile Diabetes Research Foundation (JDRF) and in 2015 founded Beyond Type 1, an organization focused on raising awareness and support for diabetes.

During his acceptance speech, the entertainer asked children with type 1 diabetes to come onto the stage to help him receive the award. Jonas told the audience, “Every day can be an opportunity to be a hero if you’re kind to someone who needs it or you find a cause you’re passionate about.”

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NEWS,
NOTES,
& TIPS
FROM NIH

The ABCs of GERD

HEALTH TIPS Gastroesophageal reflux (GER) causes your stomach contents to come back up into your esophagus, causing heartburn or acid reflux. Gastroesophageal reflux disease (GERD) is a long-lasting and more serious form of GER.

GERD Awareness Week 2017 takes place from Nov. 19 through 25. This fall, as you sit down to eat turkey or open your Halloween candy, watch out for potential GERD symptoms and contact a provider if you are concerned.

For more information, visit the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) website and read the overview below.

Symptoms

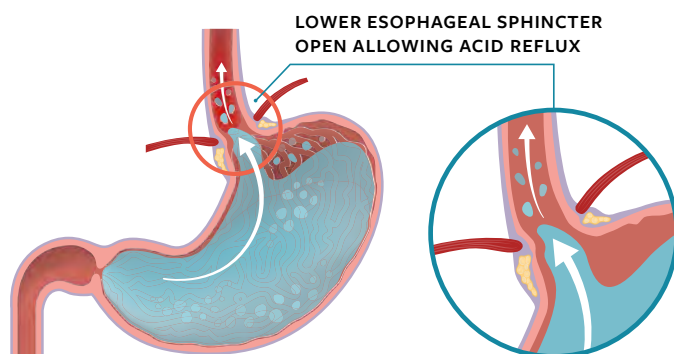
The most common symptom of GERD is regular heartburn, a painful, burning feeling in the middle of your chest, specifically behind your breastbone and in the middle of your abdomen. Not all adults with GERD have heartburn. Other common GERD symptoms include:

- Bad breath
- Nausea
- Pain in your chest or the upper part of your abdomen
- Problems swallowing or painful swallowing
- Respiratory problems
- Vomiting
- The wearing away of your teeth

Causes

GERD happens when your lower esophageal sphincter becomes weak or relaxes when it shouldn't. This in turn causes stomach contents to rise up into the esophagus. The lower esophageal sphincter can become weak or relax from things such as:

- Increased pressure on your abdomen from being overweight, obese, or pregnant



- Smoking, or inhaling secondhand smoke
- Certain medicines:
 - Those that doctors use to treat asthma
 - Medicines that treat high blood pressure
 - Antihistamines: medicines that treat allergy symptoms
 - Painkillers
 - Sedatives: medicines that help put you to sleep
 - Antidepressants: medicines that treat depression

Treatment

Anyone, including infants and children, can have GERD. If not treated, it can lead to more serious health problems. In some cases, you might need medicine or surgery. However, many people can improve their symptoms by:

- Avoiding alcohol and spicy, fatty, or acidic foods that trigger heartburn
- Eating smaller meals
- Not eating close to bedtime
- Losing weight if needed
- Wearing loose-fitting clothes
- Quitting smoking



When to see a provider

See a provider if your gastroesophageal reflux symptoms do not get better with over-the-counter medicines or changing your diet.

If your symptoms don't improve with lifestyle changes and medicine, you may need testing and may be referred to a specialist.

Tests to diagnose GERD

- **Upper gastrointestinal (GI) endoscopy and biopsy:** A provider uses an endoscope to see inside your upper GI tract. This procedure takes place at a hospital or an outpatient center.
- **Upper GI series:** An upper GI series looks at the shape of your upper GI tract using x-rays.
- **Esophageal pH impedance monitoring:** Measures the amount of acid in your esophagus while you do normal things, such as eating and sleeping.
- **Esophageal manometry:** Measures muscle contractions in your esophagus. A gastroenterologist may order this procedure if you're thinking about anti-reflux surgery. ■

SOURCE: National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) www.niddk.nih.gov

The Opioid Crisis

BY THE NUMBERS Opioid misuse and addiction is a major public health crisis. Opioids, sometimes called narcotics, are a type of drug. They include strong prescription pain relievers and the illegal drug heroin. Millions of Americans suffer from opioid use disorder. Millions more suffer from chronic pain.

Earlier this year, NIH Director Francis S. Collins, M.D., Ph.D., met with research and development leaders from the world's leading biopharmaceutical companies to discuss the opioid crisis.

The meeting highlighted new ways for government and private industry to work together to address the opioid crisis and find better ways to manage pain.

Stay tuned for updates on this important initiative from NIH.

An estimated **2.1 million Americans** used prescription drugs nonmedically for the first time within the past year.



Among those who reported past-year nonmedical use of a prescription drug, nearly **12%** met criteria for prescription drug use disorder.

More than **1.2 million** emergency department visits in 2011 were the result of nonmedical use of prescription drugs.



+72%
2002 → 2012

There was a **72%** increase in hospitalizations related to opioid use from 2002 to 2012.

SOURCE: National Institute on Drug Abuse

What Happens at the 'House of Hope'?



"FIRST IN HUMAN," a new documentary series from the Discovery Channel, follows four patients at NIH's Clinical Center, also known as the "House of Hope." Two of the patients have cancer and two have rare, inherited diseases.

The three-part documentary is named for the "first in human" trials, or trials in which new, innovative medical therapies are tested on patients for the first time. Viewers can step behind hospital doors and learn about these courageous patients, their caregivers, and the dedicated NIH staff treating them.

Many NIH Clinical Center patients have rare diseases or diseases that don't respond to other available treatments. For these patients, the Clinical Center is often their last hope.

The moving series highlights the human impact of NIH's research and scientific work. "Big Bang Theory" and "Hidden Figures" actor Jim Parsons narrates the series, which was filmed over a one-year period.

A history of hope

For more than 60 years, the NIH Clinical Center—the world's largest hospital dedicated to clinical research—has been at the forefront of developing treatments for deadly and damaging diseases.

Located in Bethesda, Maryland, on the main NIH campus, the center has seen many medical firsts. These include chemotherapy first used to treat cancerous tumors, gene therapy undergoing its first human tests, and the first antiviral drug for HIV/AIDS meeting with early success.

More Americans needed

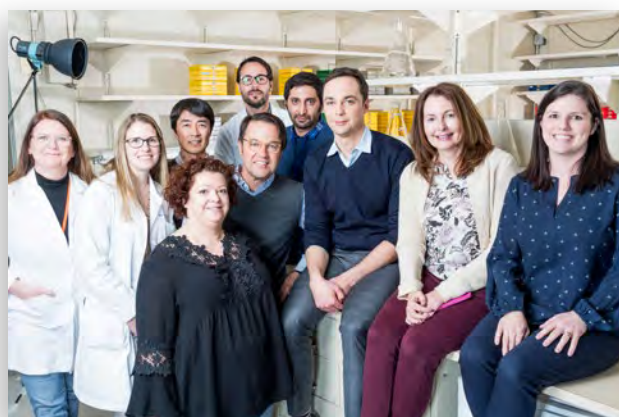
"With the attention now being drawn to the value of clinical research by 'First in Human' and other outreach efforts, I hope we can begin to build momentum to encourage more

Americans to take part in clinical trials," said NIH Director Francis Collins.

"Not only do clinical trials offer sick people who have no other options a chance to receive experimental treatments that may extend or save their lives, such work is essential for advancing scientific knowledge in ways that will benefit the health of future generations," he added.

FOR MORE INFORMATION ABOUT CLINICAL TRIALS, visit <https://www.nih.gov/health-information/nih-clinical-research-trials-you>.

Actor Jim Parsons is pictured with NIH Clinical Center staff.



VIEW "FIRST IN HUMAN"

For more information about "First in Human," including where to view it, visit www.cc.nih.gov/ocmr/firstinhuman.

Solving the Undiagnosed Disease Puzzle at NIH

Q AND A Mystery illnesses are not just fodder for television. There are real, undiagnosed illnesses that are important to solve for public health.

One way that NIH tackles mystery diseases is through its Undiagnosed Diseases Program. The program focuses on the most puzzling medical cases referred to the NIH Clinical Center in Bethesda, Maryland. It was founded in 2008.

NIH leaders, including William Gahl, M.D., Ph.D., National Human Genome Research Institute's (NHGRI) clinical director and head of the program, recently did an "Ask Me Anything" discussion on Reddit.

We thought we'd provide our own question and answer overview for readers on the unique program.

Who leads the program?

The program is organized by the National Human Genome Research Institute, the NIH Office of Rare Diseases Research, and the NIH Clinical Center.

While the program started at the NIH Clinical Center in 2008, it expanded into a network of seven clinical sites throughout the U.S. in 2012. These sites are collectively known as the Undiagnosed Disease Network.

What happens to a patient in the program?

The patient visits one of the Undiagnosed Disease Network centers for about a week. During their visits, a large medical team—with a deep base of knowledge about rare and common diseases—examines them. This team of NIH



experts studies a patient's clinical and laboratory results for important clues following the patient's visit.

What are some of the program's goals?

The program offers patients the hope of a diagnosis and the possibility of treatment strategies. In return, patients provide researchers the opportunity to learn more about diseases and what causes them.

How many patients are seen each year?

As of 2014, the annual patient visit rate was 130.

How many cases are solved?

The number of cases closed with no diagnosis is approximately 25 percent. However, the number of cases that are pending diagnosis with strong leads is 60 percent. ■

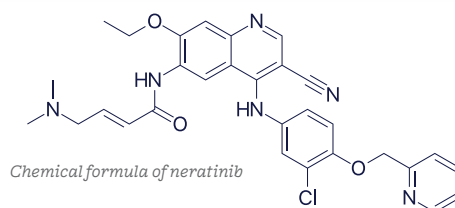
SOURCE: National Human Genome Research Institute: www.genome.gov/27543155/udp-background/

www.genome.gov/27568204/2017-news-feature-reddit-ask-me-anything-recap-the-undiagnosed-diseases-network/

New Breast Cancer Treatment Approved

IN THE NEWS Breast cancer is the most common form of cancer in the U.S. According to the National Cancer Institute (NCI), approximately 15 percent of patients with breast cancer have tumors that are HER2-positive.

This summer, the U.S. Food and Drug Administration approved a new breast cancer treatment that aims to reduce the risk of the cancer returning. The drug, neratinib, is intended for patients with early-stage, HER2-positive breast cancer.



NCI estimates approximately 252,710 women will be diagnosed with breast cancer this year, and 40,610 will die of the disease. This approval is a major step forward in helping to improve survival rates in some breast cancer patients. ■

SOURCE: National Cancer Institute/Food and Drug Administration



Gluten-free flours can be good alternative options for celiac patients, as long as they do not come boxed with seasonings. Make sure to check with a provider before making any dietary changes.

SOURCE: MEDLINEPLUS

Going **Gluten-Free**

Life with *Celiac Disease*

Celiac disease is a digestive condition and autoimmune disorder that affects the small intestine.

Celiac disease can also affect the body outside the intestine. If a person with celiac disease eats food with gluten, a protein found naturally in wheat, barley, and rye, his or her body creates an immune response that attacks the small intestine. Celiac disease can cause long-term medical problems, such as malnutrition or osteoporosis.

Some adults with celiac disease have digestive problems such as intestinal discomfort or pain after consuming gluten, but they are more likely to have headaches, depression or anxiety, and other symptoms. Some people feel tired, have sore joints, or even get a rash. This skin rash, called dermatitis herpetiformis, causes itchy bumps and blisters.

Digestive symptoms are more common in children and can include bloating, chronic diarrhea, constipation, gas, nausea, fatty stools that float, stomach pain, and vomiting.

To treat celiac disease, a provider must first diagnose it. Diagnosis can often be difficult, as celiac disease symptoms are often similar to those of other conditions. Diagnosing celiac disease often begins with a review of family history and a physical exam. If your provider

suspects you have dermatitis herpetiformis, a blood test and intestinal or skin biopsy is needed to diagnose celiac disease. If these tests do not clearly confirm celiac disease, a genetic test can help rule it out.

If you have celiac disease, you must follow a strict gluten-free diet. This can include more than you would expect. You should avoid all foods that contain gluten, such as most cereal, grains, and pasta, and many processed foods. You can eat gluten-free bread, pasta, and other foods that are now easier to find in stores, restaurants, and at special food companies. You also can eat potato, rice, soy, amaranth, quinoa, buckwheat, or bean flour instead of wheat flour.

You also must consider the products you use.

For example, if a lip balm contains gluten, you are at risk of consuming it. Some soaps or lotions also contain gluten, which could transfer from your hands to your mouth.

A gluten-free diet is the only treatment for celiac disease that has been approved and is safe and effective. ■

SOURCE: National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Celiac Disease or Gluten Sensitivity?

Some of the symptoms of gluten sensitivity (also known as gluten intolerance) are similar to those of celiac disease. They include feeling tired and stomachaches. It can cause other symptoms including muscle cramps and leg numbness. But gluten sensitivity does not damage the small intestine like celiac disease.

Researchers are still learning more about gluten sensitivity. If your provider thinks you have it, he or she may suggest that you stop eating gluten to see if your symptoms go away. However, you should first be tested to rule out celiac disease.



Muscle Cramps



Fatigue



Numbness



Stomach ache

SOURCE: MedlinePlus and Dept. of Health and Human Services Office on Women's Health



Tips for Following a Gluten-Free Diet

Eating a gluten-free diet can be overwhelming for newly diagnosed celiac patients. We've combined some fun gluten-free eating tips from Rose Perry and Jack Gottschalk, as well as helpful advice from Joseph Murray, M.D., a gastroenterologist and internist.

Serving Size: 6 great tips

Amount Per Serving

	% Daily Value
Isolate New Foods	100%

When you try new foods, do it with one food at a time. This way, if you have a negative reaction, you can pinpoint what food caused it.

Check Labels	100%
--------------	------

Be sure to check food and product labels thoroughly. A food or product may be labeled "gluten-free" but be sure to read the ingredient list, and look for any warnings about how and where the product was produced.

Try Different Brands	100%
----------------------	------

Explore different brands. There are many gluten-free offerings today, and you won't know what you like until you try it.

Explore Cooking at Home	100%
-------------------------	------

Put on an apron and try some new recipes at home. It can be easier to avoid cross-contamination at home since you have more control over the environment.

Ask Questions	100%
---------------	------

Stay aware when eating at restaurants, friends' houses, or unfamiliar environments. If someone has made food you're unsure of, ask what ingredients were used and what kind of environment it was made in.

Keep Nutritious	100%
-----------------	------

Be sure to check for other nutritional information. Often, gluten-free foods can be high in sugar and other fats, and lack important nutrients like fiber.

Love and Life without Gluten: Rose and Jack

Partners Rose and Jack approach celiac disease together

Rose's story

When Rose Perry was in high school, she developed a skin rash and didn't know why. It was a complete mystery to her and her family.

After six months, she finally knew what was wrong. A skin biopsy revealed she had dermatitis herpetiformis, which then led to the diagnosis of celiac disease.

She and her mom had to make a number of changes. Their work started in the kitchen.

They got rid of all foods containing gluten in their house. They also threw away food that had come into contact with gluten-containing foods.

Then Rose had to go through her beauty products and toss any soap, shampoo, or other products that contained gluten. Since those products could come in contact with her mouth, they could cause accidental gluten exposure.

"The idea was to eliminate everything that you could from things that you could touch, so that you wouldn't have to worry about it," she said.

Living at home, she had control. College was going to be different. As a student at Iowa State University, Rose had to learn about the school's resources for students living gluten-free. She adapted to her new lifestyle.

Jack's story

For some people, college is the best time of life. It wasn't for Jack Gottschalk. He felt too sick to enjoy himself.

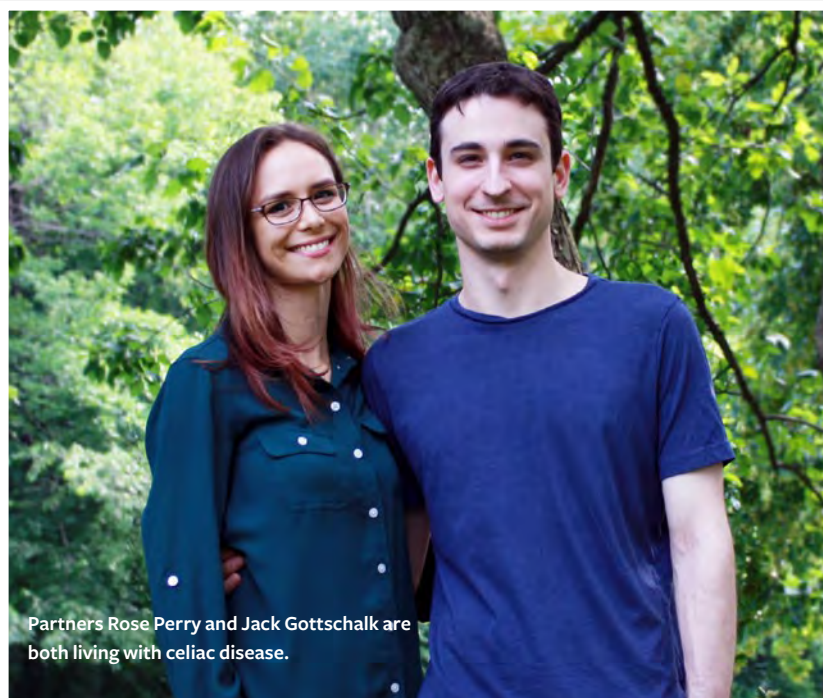
"I felt sick all the time. I couldn't eat anything and feel good afterwards," said Jack.

As a swimmer at York College in Pennsylvania, Jack often had pasta parties with his teammates. He never guessed

“The awareness of celiac disease and gluten-free diets has been both a blessing and a curse.”

— Rose Perry





Partners Rose Perry and Jack Gottschalk are both living with celiac disease.

that the delicious pasta was causing him trouble.

The summer before his senior year, Jack was diagnosed with celiac disease. It turns out that most pasta is primarily made with gluten.

He was surprised to learn that there was only one treatment: Jack had to follow a strict gluten-free diet. “There isn’t really anything you can do for this,” he said. “You’re going to have to live differently and that’s kind of a shock.”

Rose and Jack’s story

Rose and Jack met in 2015. She was attending grad school in Maryland, where he lived.

In addition to their Maryland residency, it turns out they had one more thing in common. They both have celiac disease.

“It’s a huge advantage to have a partner with the same dietary restrictions,” Rose said. “Knowing that you have somebody who is going through something similar and understands how serious it is, you’re not going to get questions all the time

like, ‘Is that really necessary? Do you have to do that?’”

Jack says it makes things easy to have an entirely gluten-free home. Both he and Rose say they never have to worry about grabbing something out of the pantry to snack on.

“I can live a totally normal life within the confines of our home,” Jack said. “It fades into the background and you don’t even remember it half the time when you’re at home because it’s not something you have to worry about actively.”

The two have found, as so many with celiac disease have, both benefits and frustrations with the rise in people choosing a gluten-free lifestyle. “The awareness of celiac disease and gluten-free diets has been both a blessing and a curse,” Rose said.

Since they were diagnosed, there are many more foods they can eat. They are both happy with the expanded gluten-free offerings and accommodations they’ve found, but food labels can still be challenging.

Rose explained that often they will find a product labeled gluten-free, only to turn the package over and read that it was made in a facility that processes wheat.

“It does lead to a lot more accidental exposures,” Rose said. “People will try something new thinking that it will be okay and it isn’t.”

Over time, Rose and Jack have become used to their gluten-free lives. They hope others faced with the same diagnosis will not be too worried about the adjustment. “It’s not as bad as you think it is,” Rose said.

Jack recommends that those who are newly diagnosed take time to explore new food options and be prepared for things like social gatherings. He says you should still go to parties and get together—just bring your own food.

“It’s really not a big deal, especially compared to the peace of mind you’ll have knowing your food is safe,” Jack said.

Rose and Jack enjoy busy lives. Rose is a medical and scientific illustrator and Jack is a retail professional.

Dealing with celiac disease is just one aspect of their lives. ■

Find Out More

- ▶ **MedlinePlus:**
Celiac Disease: medlineplus.gov/ceciacdisease.html
- ▶ **MedlinePlus Gluten Sensitivity:**
medlineplus.gov/glutensensitivity.html
- ▶ **NIDDK:**
www.niddk.nih.gov/health-information/digestive-diseases/ceciac-disease
- ▶ **NHANES Study:**
<https://www.cdc.gov/nchs/nhanes/index.htm>

Exploring the Celiac Disease Mystery

Research looks at what's causing the rise of this autoimmune disorder

MOST OF US KNOW SOMEONE on a gluten-free diet. But not all of us know someone who has no choice but to be on one. This is the case for those with celiac disease. It causes the immune system to attack a person's small intestine if they eat gluten.

"Patients who have celiac disease must avoid all gluten," said Joseph Murray, M.D. "It's not a choice. It's a matter of medical need." Dr. Murray is an internist and gastroenterologist at Mayo Clinic in Rochester, Minnesota. He receives funding support from the National Institute of Diabetes and Digestive and Kidney Diseases.

A person with celiac disease who does not eat an entirely gluten-free diet could experience many medical issues, including abdominal pain, rashes, and even death.

Choice vs. celiac disease

Dr. Murray said there are pros and cons to the rise in popularity of a gluten-free diet for celiac disease patients.

On the positive side, patients tend to have more gluten-free options at restaurants and in grocery stores. They also don't feel as strange about living gluten-free since it's no longer rare.

However, it's also caused some people to take gluten-free diets less seriously.

"The biggest problem is the fashion of the gluten-free diet, because you might lose weight, for example," Dr. Murray said. "In that fashion or fad is loss of the real disease of celiac disease, which is a serious illness that causes damage in the intestines."

One industry that can be particularly problematic is the food service industry. "They feel that they have been barraged with demands for lots of diets, many of which are not medically justified or necessary," Dr. Murray explained. "And one of those is a gluten-free diet. When they're faced with a patient with celiac disease, they don't often recognize that that patient is facing a real medical need."

The problems with the rise of gluten-free by choice don't end with those with celiac disease either.

Dr. Murray warned that many people who eat an unnecessarily gluten-free diet are missing out on important nutrients like fiber and whole grains. Additionally, they may



Joseph Murray, M.D., is a gastroenterologist and NIH-supported researcher working to answer critical questions about celiac disease.

be consuming unnecessary calories and significantly more added sugar when eating prepackaged, gluten-free foods.

Solving celiac mysteries

"Living gluten-free in our world is difficult," Dr. Murray explained, which is why studies about celiac disease are so important. Dr. Murray is working to answer some critical questions about celiac disease. Who gets it? Why do they get it? Why has celiac disease become more common in our country and around the world?

His work studying the Centers for Disease Control and Prevention's National Health and Nutrition Examination Survey and its data are starting to answer some of those questions.

For example, they have found that **one in 141 Americans has celiac disease.**

Celiac disease is also more common in northern states in the U.S. and occurs more often in Caucasians.

Dr. Murray also learned that a significant number of people who have celiac disease have

not been diagnosed. However, the number of diagnoses has gone up in recent years.

"The efforts that have been made to increase medical awareness and testing for celiac disease are working," he said.

He is also working on a study focused on refractory celiac disease, which is when the small intestine continues to be damaged despite the individual going on a gluten-free diet. "That's at the very sharp point of the worst of celiac disease and consequences," Dr. Murray said. ■

"The efforts that have been made to increase medical awareness and testing for celiac disease are working."

— Joseph Murray, M.D.

EXPANDING Hearing Health Care

Addressing an urgent public health need

“What’s that you said?”

Perhaps you’ve heard yourself say those words more often than you’d like to admit. Or maybe you, a family member, or a friend is consistently turning up the TV volume or can’t follow simple conversations in restaurants.

If you are age 70 or older, this is common. Mild- to-moderate hearing loss affects more than 60 percent of 70-year-olds, and more than 80 percent of 80-year-olds have hearing loss, according to NIH’s National Institute on Deafness and

Other Communication Disorders (NIDCD).

Hearing health care affordability and accessibility is an urgent public health problem. Nearly 37.5 million adults in the U.S. report hearing loss in one or both ears. This number is rising as the number of senior citizens increases.

“Hearing loss is a hidden disability that usually occurs gradually over time, so it’s often hard to know how much hearing loss you have or how much you’re missing,” says

Debara Tucci, M.D., of Duke University.

An NIDCD-funded researcher, Dr. Tucci

specializes in ear surgery and health care for people with hearing disorders. She says that if hearing loss is not treated, it can result in serious health, social, and financial problems.

“People with hearing loss have a higher risk of falls, depression, and hospitalization. They also have more difficulties accessing health care,” Dr. Tucci says. Hearing loss has also been associated with a higher risk of social withdrawal and dementia in older adults.

Of the millions of adults who could benefit from hearing aids, only 25 percent has actually used one, according to NIDCD.





Dr. Debara Tucci, M.D., examines a patient's ear.

Social stigma

There are many reasons why people with hearing loss don't use hearing aids. One reason is that there is a stigma associated with them.

"People often see hearing aids as a sign of being old, so they avoid getting the help they need," Dr. Tucci says. Before seeking medical treatment, most hearing aid users have lived with hearing loss for more than 10 years, and their hearing has become worse over time.

Hearing aids, provider visits, and other hearing care treatment can also be very expensive. Medicare and Medicaid offer limited to no coverage for hearing aids, which can cost up to \$3,000 per aid.

Affordability and accessibility

Why the high cost? In most cases, the price of the hearing aid includes the services of a hearing health professional.

Currently, if you think you need hearing aids, you must first visit an audiologist or hearing instrument specialist to be tested. You would then

purchase the devices from one of these hearing health providers, who would fit you for the hearing aids and adjust them for your needs. They might also counsel you and family members about how to adjust to hearing loss.

Audiologists are health care providers with advanced degrees who have special training in hearing and balance disorders. Hearing instrument specialists are state-licensed professionals. The requirements vary among states; most states require completing a two-year apprenticeship.

As hearing aids have moved from analog to digital components, the options for different settings have expanded substantially. In addition, the settings on the hearing aids can be adjusted more easily. In some cases, the user can adjust the settings.

Researchers have been exploring why many people don't get the help they need and whether there are ways to ensure that more adults with mild-to-moderate hearing loss get hearing health care.

"The NIDCD has a long history of research and discovery in hearing health," says NIDCD Director James

F. Battey, Jr., M.D., Ph.D. "We support studies not only on how we hear, but also on technologies to help people hear better and on delivery models to get hearing loss interventions into the hands of the people who need them."

"Over the counter is a good option for people who think they have hearing loss"

— Larry Humes, PH.D.

One study recently found that participants who selected pre-programmed hearing aids using an over-the-counter delivery model reported a similar level of benefit as participants who purchased the same hearing aids through an audiologist following best practices.

The audiology services included fitting the hearing aids and counseling the consumers on how to use them. The study is the first randomized, double-blind, controlled clinical trial to compare the effectiveness of two

service-delivery models of hearing aids.

Larry Humes, Ph.D., professor of speech and hearing sciences at the University of Indiana, is the lead researcher on the study. “I’m excited about the research results,” Dr. Humes says. “I’d like more hearing aids to be available to consumers.”

On August 18, 2017, a new law was established that will provide more options for some adults with hearing loss. The law gives the Food and Drug Administration (FDA) three years to create standards for safety, effectiveness, and labeling of over-the-counter hearing aids. This new law was a provision in the FDA Reauthorization Act of 2017.

Over-the-counter hearing aids would be FDA-approved for adults with perceived mild-to-moderate hearing loss. Consumers would not need to see licensed hearing professional to purchase certain hearing aids.

Advocates of the law expect the cost of the hearing aids will be much lower than hearing aids sold through current service delivery models.

FDA is developing language to help consumers determine if they are a good candidate for these devices, or if they have symptoms that suggest that they should see a health care professional.

“Over the counter is a good option for people who think they have hearing loss,” says Dr. Humes. “It’s an affordable

way for people to try out the hearing aids at low cost. As their hearing needs become more complex, they may then go to a professional to get more assistance.”

Beyond hearing loss

Using hearing aids to improve hearing is not as simple as putting on a pair of reading glasses to see better.

“People think they can just use a hearing aid and they will have 20-20 hearing, like they do with eyeglasses,” says Dr. Humes. “The problem with older adults and hearing loss is a little more complex.”

It takes weeks or months to get used to the louder sound from hearing aids. And treating a hearing problem involves adjustments for the inner ear and the brain. “The convenience of over-the-counter hearing aids is good, but older people must not have expectations that they will hear like a 20-year-old again as soon as they put on their

hearing aids,” Dr. Humes says.

Adults with perceived mild- to-moderate hearing loss are encouraged to check out low-cost hearing care options when they become available. And, if you are over 65, a visit with an audiologist should be within reach.

“I encourage everyone over age 65 to see their primary care doctor and get a referral to an audiologist for a hearing test, which is covered by Medicare,” advises Dr. Tucci. “This is the best way to determine if you have hearing loss and to prevent other health issues related to hearing loss.” ■

“We support studies not only on how we hear, but also on technologies to help people hear better.”

— NIDCD Director James F. Battey, Jr.

Hearing aids come in many shapes and sizes.



What are Over-the-Counter Hearing Aids?

- Consumers will be able to purchase them at a store or online, with or without the assistance of a licensed provider.
- Will provide a new, affordable, and easily accessible option for adults with perceived mild- to moderate hearing loss.
- Will be regulated by the Food and Drug Administration with clear labeling for usage, safety, and effectiveness.

Helping others hear better

Turning first-hand experience into hearing loss advocacy

Lise Hamlin was born with hearing loss in one ear, though she was able to communicate adequately for 30 years.

That changed overnight.

One morning, when she was in her mid-30s, Lise woke up and suddenly realized she couldn't hear at all.

She was scared but didn't panic. "I thought that if I lost my hearing overnight, it would come back overnight," she says.

But her hearing didn't come back. The only way she was able to hear people was if they yelled.

Six months later, she got a hearing aid.

When Lise suddenly lost her ability to hear, she faced new challenges. "I wanted to be with my family and be social. But I was missing the jokes," says Lise.

She recalls feeling self-conscious in social situations while wearing her hearing aid, which was "brown and ugly."

"There was a stigma with having a hearing aid, but now

I know it was more of a self-esteem issue," she says. "Now I tell people that I have hearing loss, and they are almost always willing to work with me."

Lise sought help at the Hearing Loss Association of

America. The Association has many resources and opportunities for people with hearing loss to help one another.

"I realized that people actually like talking about their disabilities if they admit they have one," she says. She started volunteering for the association and eventually was offered her dream job there.

Lise is now the director of public policy at the Hearing Loss Association of America. She works with Congress and federal communications agencies to make communication accessible and affordable for people with hearing loss.

Lise says she receives nearly 10 calls a day from people looking for affordable hearing aids.

"It's heartbreaking," she says. "We are social people. We need to communicate. Everyone should have access to hearing care."

Lise recently had surgery and now has a cochlear implant in one ear and a hearing aid in the other ear. "I live a full life now," she says. "If you know you have hearing loss, don't bluff, do something about it. Once you deal with it, your life will be so much easier." ■



Lise Hamlin's hearing loss experience led her into a career of advocacy.

"We are social people. We need to communicate. Everyone should have access to hearing care."

— Lise Hamlin

Signs of Mild-to-Moderate Hearing Loss

Here are some signs that you may have mild-to-moderate hearing loss:



Muffling of speech and other sounds



Needing to turn up the volume of television, radio, or music



Trouble hearing in groups or noisy places, or when you can't see who is talking



Asking others to speak more slowly, clearly, and loudly, or to repeat what they said

If you experience any of these, you may want to see an audiologist or otolaryngologist (an ear, nose, and throat specialist) or an audiologist for a hearing evaluation.

For more information on signs of hearing loss and treatments, visit <https://www.nidcd.nih.gov/>.

A Journey with Mid-life Hearing Loss

Don't wait to seek help for hearing issues

STEPHEN FERRANTI knew he had to address his hearing loss issues when he realized it could affect his job. As a product strategy manager in his mid 50s working for a financial software company in New Hampshire, Stephen found himself nodding in agreement with colleagues, but not knowing what they were actually saying.

"I work with a lot of startup companies and with 20-something-

"I was tired of apologizing for my age and my hearing."

— Stephen Ferranti

year-old millennials who tend to have a lot of social and business gatherings in noisy restaurants and cocktail bars," he says.

When presenting at conferences or talking with colleagues and clients in busy restaurants, he found himself agreeing to do tasks for colleagues or saying "yes" to high-end customers who had not asked a 'yes' or 'no' question. "It was embarrassing," he says.

Stephen realized that not being able to hear people would affect his job and career. He needed to do something about his hearing before it became a big problem.



Stephen Ferranti addressed hearing loss early.

"What triggered it for me was that I was working in an environment where 50-year-olds are not the majority," he says. "Most of the people I work with are young, and they have perfect hearing."

His doctor suggested that Stephen see an audiologist. Audiologists are health care providers who focus on hearing and balance disorders. His audiologist told him he had typical hearing loss of people in their early 70s, although most people don't address the issue until they are much older.

"He told me I was one of the lucky ones, because I addressed my hearing issues 15 years earlier than most people do," Stephen says.

The audiologist report gave Stephen two options: do nothing or get hearing aids. After much research, Stephen found a few options available for the type of hearing aids he needed.

"Unfortunately, the type of hearing aids I needed were not covered by my medical insurance," he says. "They were expensive. I am fortunate that I can pay for them, but I know many people can't afford them."

The new normal

Stephen has been wearing his hearing aids for almost three years now, and is very happy with his choice. He says it took a couple of months to

get used to the hearing aids, because the devices allowed him to hear high frequency sounds that he hadn't heard in a long time. "Your brain needs to adjust to the new normal," he says.

Social situations became easier. "I was tired of apologizing for my age and my hearing. I'm not afraid to point out that I wear hearing aids and eyeglasses," says Stephen. Best of all, he keeps up with conversations in noisy places.

Stephen's advice to anyone with perceived mild-to-moderate hearing loss is to seek help immediately: "Own it. It's not 100 percent like your old hearing, but it's much better than before." ■

Find Out More

► **MedlinePlus: Hearing Loss:**
medlineplus.gov/ency/article/003044.htm

► **NIDCD Hearing Loss:**
www.nidcd.nih.gov/health/statistics/quick-statistics-hearing

► **NIDCD Hearing Aids Fact Sheet:**
<https://www.nidcd.nih.gov/health/hearing-aids>

► **Hearing Loss Association of America:**
hearingloss.org



Breathtaking

Managing a COPD Diagnosis

Chronic obstructive pulmonary disease (COPD) is a serious lung disease that makes it hard to breathe. It's also known as emphysema or chronic bronchitis.

In people who have COPD, the airways—tubes that carry air in and out of your lungs—are partially blocked. This makes it hard for air to get in and out. COPD causes symptoms such as coughing, mucus, wheezing, shortness of breath, and chest tightness. These symptoms tend to worsen over time.

Severe COPD may prevent you from doing even basic activities like walking, cooking, or taking care of yourself.

Cigarette smoking is the leading cause of COPD. However, up to 25 percent of people with COPD never smoked. Exposure to other lung irritants—such as air pollution, chemical fumes, or dust—may contribute to COPD. A rare genetic condition called alpha-1 antitrypsin deficiency can also cause the disease—but it is rare.

Most of the time, COPD affects middle-aged or older adults. Some COPD patients wait to seek help as symptoms such as increased shortness of breath may seem like a natural part of aging. If you are or a loved one suspects that you have COPD symptoms, make sure to see a health care provider.

There is no cure and doctors do not know how to reverse the damage to the lungs. But treatments and lifestyle changes can help patients feel better, stay active, and slow the progression of the disease. ■

SOURCE: National Heart, Lung, and Blood Institute (NHLBI) and MedlinePlus

NIH Launches National COPD Action Plan

James P. Kiley, Ph.D., is the director of the Division of Lung Diseases at NIH's National Heart, Lung, and Blood Institute (NHLBI). In 2017, NHLBI launched a national action plan on COPD to empower patients and support COPD research and education. Dr. Kiley, who helped lead the launch, answered questions for NIH MedlinePlus magazine.

Why was the COPD National Action Plan created?

The staggering numbers associated with COPD highlight the need for a coordinated national approach to deal with the critical issues around this chronic disease. This is the first-ever blueprint for a multipart, unified fight against the disease. It was developed at the request of Congress, with input from the COPD community.

Eight of 10 cases of COPD are caused by smoking. Why hasn't that statistic changed in a while?

Cigarette smoking rates have been going down, but COPD takes 20 to 30 years to show its symptoms. We are now seeing the effects of smoking that go back two or three decades ago, when smoking rates were much higher.

Women make up 56 percent of COPD cases, while men make up 44 percent. Why is that?

We know that more women die from COPD than men. Several factors could be responsible. Men and women are biologically different. They may respond differently to the toxic substances that cause COPD. Also, women survive longer with COPD than men.

Have the genetic research efforts on COPD improved in recent years?

Understanding the causes of COPD is complex. Genetic research efforts—for example in the NHLBI COPD Gene program—are highlighting specific traits associated with COPD. These approaches are becoming more powerful as more studies are included in the analyses.

More needs to be done to understand how these genes interact with the toxicants, like cigarette smoke, that cause COPD.

The most direct connection remains with the deficiency of the protein alpha-1 antitrypsin, a blood protein that limits inflammation in the lungs. People who lack a functional alpha-1 antitrypsin protein are at greater risk of developing COPD—with and without exposure to cigarette smoking.

“While there is no cure for COPD, optimal medical therapy can improve the symptoms and the quality of life for patients.”

— James P. Kiley, Ph.D.

Beyond genetics, have there been any other important NIH-supported research studies or findings on COPD in recent years?

NHLBI funds a wide range of research directed toward the reduction of COPD cases and COPD-related death:

- Some additional research is looking at the causes of COPD on the molecular level. For example, recent data suggest that the lengths of telomeres, the DNA sequences at the ends of our chromosomes that shorten with aging, might be associated with COPD.
- Cohort studies such as COPDgene and SPIROMICS, which follow COPD patients as they age and their disease progresses, are helping us to understand the complexities and possible pathways of the disease. Investigators recently found that there is a large group of smokers and ex-smokers who do not have lung obstruction, and therefore are not diagnosed with COPD, but nevertheless suffer from respiratory symptoms.



In May, the first COPD National Action Plan was announced by (left to right) Grace Anne Dorney Koppel, president of the COPD Foundation; MeiLan K. Han, M.D., M.S., medical director of the Women's Respiratory Health Program at the University of Michigan Health System; and James P. Kiley, Ph.D., director of the Division of Lung Diseases at the NIH's National Heart, Lung, and Blood Institute.

- We are supporting clinical trials through the NHLBI Pulmonary Trials Cooperative. These will determine whether drug treatment helps COPD patients who do not have lung obstruction. They will also test interventions in COPD patients who are overweight and those with prevalent emphysema.
- NHLBI, as part of the Tobacco Regulatory Science Program, is supporting research to understand whether other tobacco products (cigars, hookah, e-cigarettes) lead to chronic lung diseases.
- NHLBI-funded investigators are looking at diseases that can happen at the same time as COPD, like cardiovascular disease, high blood pressure, arthritis, depression, and asthma. They are trying to understand how these diseases associate with and influence COPD.

Why is it important to tell your primary-care health provider about tobacco use, either by you or by someone you live with?

Cigarette smoke is the best-known cause of COPD. In addition to COPD, cigarette smoking is a known cause of other conditions such as heart disease and lung cancer. Quitting smoking is known to slow the progression of COPD and reduce your risk of death.

Like all chronic addictions, quitting smoking usually requires teamwork between the patient and the primary-care health professional. Medical and behavioral support are often needed together for a successful outcome. Primary-care health professionals can direct the patient to helpful resources.

What is pulmonary rehabilitation and why is it important for COPD patients?

Pulmonary rehabilitation is a treatment for patients with chronic lung diseases like COPD. It provides patients with exercise, education, and support.

The primary goal is to help patients achieve their maximum level of independence and functioning. It benefits exercise tolerance, symptoms, and quality of life, with a reduction in the use of health care resources.

Pulmonary rehabilitation involves a long-term commitment from the patient and a team of health care providers. The team may include respiratory therapists, physical and occupational therapists, dietitians or nutritionists, and psychologists or social workers. Patients usually receive care at an outpatient program in a hospital or clinic. ■

COPD by the Numbers

Chronic obstructive pulmonary disease (COPD) is the **third** leading cause of death in the U.S., behind heart disease and cancer.

150
THOUSAND

In 2014, **COPD killed more than 150,000** Americans.

16
MILLION

16 million Americans have been **diagnosed with COPD**. Millions more have the disease but don't know it.

#4

The disease is the **fourth leading cause of disability** in the U.S.

\$49
BILLION

The cost of COPD-related **patient care** is projected to hit **\$49 billion by 2020**.

SOURCE: National Heart, Lung, and Blood Institute (NHLBI)

Too 'Stubborn' to Give in to COPD

Jim Nelson fights COPD with determination and advocacy

"I was blessed with a fine case of the 'stubborns'" says Jim Nelson, a 77-year-old retired accountant living in Arizona with his wife of 50 years, Mary.

It was his stubbornness and Mary's support that got him through withdrawal from cigarettes and helped him deal with his COPD. His commitment to exercise and good health helped him qualify for a double lung transplant at the age of 71.

Jim provided a first-hand account of his experience with NIH MedlinePlus magazine. It has been edited for space.

Even though I smoked for 20 years, I was active when I was younger. I enjoyed hunting and fishing in the Colorado mountains and boating on nearby lakes. But that changed when I was in my 50s.

After I had repeated lung infections over the years, the Veterans Administration hospital in Grand Junction, Colorado, gave me my first pulmonary function test. I was diagnosed with severe COPD, the third of four stages of the disease. The doctors told me I'd continue to lose lung function. They also told me I should begin using supplemental oxygen for sleeping and exercising.

"I set out to learn all that I could about my disease to better deal with it."

— Jim Nelson

I was 55 years old by this time and hadn't smoked in 20 years. But my lung function was dismal: 33 percent of what it should have been.

Predictably, my lungs continued to get weaker and my breathing became more labored. But the "stubborns" took over again. I learned all that I could about my disease to better deal with it. I vowed to become the rare

COPD patient who exercises religiously, talks about COPD to anyone who will listen, and who anticipates dying with the disease, rather than because of it.

I became involved with the American Lung Association

as a teacher and inspirational speaker. Mary and I also work with the national COPD Foundation as Arizona Advocacy Captains. We have developed classes on living with and dealing with lung disease for patients and caregivers.

We help spread awareness and work to improve communication between the medical community and the COPD community. And we were recently invited to participate in the COPD Town Hall at the NIH campus

in Bethesda, Maryland.

We are trying our best to give back. We are helping a lot of people by spreading awareness about lung disorders to help people with COPD get through their days. However, we would be less than honest if we didn't admit that it still helps us, too. ■



Jim and Mary Nelson are pictured on a recent trip to Stonehenge in the United Kingdom.

Find Out **More**

- ▶ **MedlinePlus:**
medlineplus.gov/copd.html
- ▶ **National Heart, Lung, and Blood Institute—COPD:**
www.nhlbi.nih.gov/health/health-topics/topics/copd/
- ▶ **COPD National Action Plan:**
<https://www.nhlbi.nih.gov/health-pro/resources/lung/copd-national-action-plan>
- ▶ **National Heart, Lung, and Blood Institute—Clinical Trials:**
www.nhlbi.nih.gov/health/health-topics/topics/copd/trials
- ▶ **American Lung Association:**
www.lung.org
- ▶ **COPD Foundation:**
www.copdfoundation.org



OUTRUNNING ASTHMA

Football player Rashad Jennings battled childhood asthma with exercise and determination

National Football League (NFL) running back and reigning “Dancing with the Stars” champion Rashad Jennings battled childhood asthma with grit and determination. He has partnered with the Allergy and Asthma Foundation of America to raise awareness about the widespread condition.

**You developed asthma as a child.
Tell us about your experience.**

It was something that I struggled with throughout my childhood. I was 10 years old when I had my first asthma attack. I’ll never forget it—I was playing on the monkey bars with my friends, and I fell to the ground. I was dependent on an inhaler daily. And it prevented me from running and other activities. After my second major asthma attack, when I was 13, I was hospitalized and nearly died. I couldn’t breathe.



Rashad Jennings with his “Dancing with the Stars” partner, Emma Slater, in 2017.

“It’s hard to raise our kids up to their full potential if they are struggling to breathe.”

— Rashad Jennings



You overcame asthma to play professional football in the NFL and win “Dancing with the Stars.” How did you educate yourself and gradually strengthen your lungs?

The doctor suggested that I not play sports. But I was hard-headed. I strengthened my lungs little by little by running. I also improved my diet.

For the past 10 years, I haven’t had any asthma symptoms. I haven’t had to use inhalers. I live a very healthy life.

Did you have any environmental factors at home that impacted your asthma?

My dad smoked heavily. That was part of the reason my asthma was so bad. To this day, I hate the smell of smoke and I stay away from places where I could encounter it.

What is your message to others with asthma?

I have a special message for kids. I want them to know that because you have asthma doesn’t mean you *are* asthma. It is something you can overcome. It is something you can live with. I am a living example of that. By taking the proper measures you will get strong; you will get better.

I also encourage you to exercise. If you put in the right work ethic about anything, you will succeed.

I’m proud that the Rashad Jennings Foundation promotes health and fitness and reading and education as well as mentorship for kids.

How important is additional research, like that supported by NIH, to help those with asthma?

Research is critical. The number of people who suffer from asthma is astronomical. We also need to do more to educate people about asthma. It’s hard to raise our kids up to their full potential if they are struggling to breathe. ■

The Future of Asthma Monitoring

With so many pollutants indoors and outdoors, determining what triggers asthma in children is not easy. Now, NIH-supported researchers are developing technology to help identify those triggers more easily.

New research supported by the National Institute of Biomedical Imaging and Bioengineering (NIBIB) uses biosensors to gather data about environmental and other factors involved in childhood asthma. Biosensors are devices that detect and measure biochemical changes within the body. Technology then turns those signals into helpful data, which experts can analyze to learn about our health.

These asthma biosensor systems monitor what children are exposed to and their body’s reactions. Zhenyu Li, Ph.D., a biomedical engineer at George Washington University, is engaged in the research.

He and his team are developing a sensor that can be worn on a child’s wrist to detect formaldehyde, an air pollutant that can trigger asthma.

“Researchers don’t have tools at the moment that can monitor environmental triggers, physiological responses, and behavior without interrupting normal activities,” Dr. Li said. He expects to have a wearable sensor prototype that can be tested soon.

Dr. Li’s team is also working on a device that can be placed in a child’s home to detect multiple air pollutants, like those found in tobacco smoke and some manufactured wood products, such as flooring and furniture. ■

SOURCES: NIH News in Health and National Institute of Biomedical Imaging and Bioengineering (NIBIB)



Stavros Garantziotis, M.D., is the lead researcher on NIH's Natural History of Asthma with Longitudinal Environmental Sampling study.

Understanding Asthma from the Inside Out

NIH study looks at the microbiome's role

Three NIH institutes fund asthma studies to improve treatment and learn more about what causes this widespread illness: the National Institute of Allergy and Infectious Diseases (NIAID); the National Heart, Lung, and Blood Institute (NHLBI); and the National Institute of Environmental Health Sciences (NIEHS).

NIH MedlinePlus magazine sat down with pulmonologist Stavros Garantziotis, M.D. to discuss one such study. He is a lead researcher on the Natural History of Asthma with Longitudinal Environmental Sampling (NHALES) trial. The trial is supported by NIEHS. Dr. Garantziotis and his team still need people to participate in this study, which is based in North Carolina. To learn more, visit clinicaltrials.gov and search "NHALES."

What are the goals of the NHALES study?

There are two goals, both scientific and community-based. The scientific side is to try to understand the microbiome, or the microbial makeup of our environment and our

"The time to get worried is if you start feeling wheezy, have a cough, chest heaviness, or shortness of breath that prevents you from doing normal activities."

- STAVROS GARANTZIOTIS, M.D.

bodies, and how that affects asthma activity. We gather samples from participants' homes and their bodies, including phlegm, saliva, and stool samples. We are following asthma patients over a long period of time, five years at the minimum. These patients include those who have recurrent symptoms and have moderate to severe asthma. We offer free care and free medications for study participants. In that way, we can also give back to the community through the study.

How can patients tell if it's just allergies or asthma?

There is certainly an overlap. The immune system response that causes you to have allergies plays a role in getting asthma. But while most patients with asthma have allergies, most patients with allergies don't have asthma. The time to get worried is if you start feeling wheezy, have a cough, chest heaviness, or shortness of breath that prevents you from doing normal activities. These are signs that it is not just a simple allergy.

How do you suggest approaching potential triggers with children?

In terms of medication, you should use as much as necessary and as little as possible. When you can influence asthma symptoms by changing something in the environment that's always the preferred way. Some scientists think that keeping our children's environment too clean may prevent their immune system from learning to discriminate what is harmful and what is an innocent exposure. That may be a reason why allergies have become more common. I encourage my own children to play outdoors and that's especially important when they're young.

What should you do if you think you may have asthma?

Discuss your symptoms with a provider. Not every type of asthma needs intensive treatment.

We always try to improve asthma both by changing the immune response (through medications, diet, etc.) and by identifying and removing the environmental triggers that cause the immune response. ■

A Lifelong Asthma Struggle

NIH study helps Jeff Long battle illness

Jeff Long, Ph.D., can hardly remember a time when he didn't suffer from serious asthma. Jeff, who is now in his 50s, started experiencing symptoms when he was just a child.

"I remember participating in sports in elementary school and being very short of breath. It got worse and worse over time," he said.

While some people have one or two asthma triggers, Jeff had many. In addition to pollen, cold and dry weather, cat dander, and exercise were all potential triggers for Jeff. His hometown also had factories and with them, pollution.

Jeff's symptoms included shortness of breath and difficulty breathing. He often had major attacks that could last as long as an hour or two, usually after exercising.

"In the fall, my asthma would start to flare up and then I got other things, like secondary bronchitis. One time, in high school, I even got pneumonia," Jeff said.

Jeff's family struggled with how to treat his condition. He grew up in a small town in Illinois, where his parents didn't have many choices for his medical care.

"I think I was prescribed some sort of inhaler, but many of the symptoms were managed with over-the-counter medicines," he said. He also tried pushing through the symptoms, by running and staying active, but he kept experiencing asthma symptoms.

As an adult, he tried to treat his attacks as they happened, but he never felt like he had a handle on his asthma. That changed when he moved to San Antonio, Texas.

"Probably the worst place for my asthma was south Texas, where there were live oaks and cedar trees," Jeff said. "I got very ill. It got to the point where I was taking a couple of Benadryl pills a day."

Ultimately, though, San Antonio had a positive effect on Jeff's allergy treatment though. It was there that he met his now wife, Deb. She is a pulmonologist, a doctor who treats asthma. Even though Deb didn't treat Jeff herself, he



Jeff Long with his son Noah, wife Deb, and daughter Gabi.

"As part of the study, my understanding of asthma has had a major shift."

— Jeff Long, Ph.D.

started seeing a doctor regularly thanks to her suggestion.

"When I did have a flare-up, my physician would treat things more quickly than I did trying to treat it myself," Jeff said. "The intervention was much earlier."

Jeff is now participating in an NIH study. NIH's NHALES, or Natural History of Asthma with Longitudinal Environmental Sampling, is helping Jeff learn more about his condition and help others with asthma.

"My experience with the study has been fantastic," Jeff said. "It has been helpful for many different reasons." Until this year, Jeff had been on and off antibiotics for 15 years due to asthma. Now, he takes a combination of an inhaled steroid and an inhaled bronchodilator, which helps relax tightened air passageways during an attack.

His doctor and the study's lead researcher, Stavros Garantziotis, M.D., also diagnosed another condition. Jeff has

bronchiectasis, a condition in which the lungs' airways become damaged. This makes it hard to get rid of mucus. The condition was a result of scar tissue from pneumonia Jeff had when he was 2.

"This explained some odd flare-ups I had in the past," Jeff said. "It has also changed, to some degree, the management of my asthma flare-ups going forward."

Jeff has strengthened his approach to treating asthma as a chronic illness through participating in the NHALES study. "As part of the study, my understanding of asthma has had a major shift. Instead of looking at this as a problem that surfaces a couple of times of year, I'm seeing and treating it as a chronic condition," he said. ■

Asthma: What You Need to Know

Asthma is now the most common chronic disorder in childhood. In the U.S., nearly 24 million people have asthma. Asthma often occurs early in life, but it can also occur for the first time in adulthood. Some patients can also “outgrow” asthma at first, but then develop symptoms again later in life.

What is asthma?

Asthma is an inflammatory disease of the lung. It can occur along the entire airway from the nose to the lung. Once the airway becomes swollen and inflamed, it becomes narrower, and less air gets through to the lung tissue. The exact cause of asthma is not known. Researchers think some genetic and environmental factors interact to cause asthma, usually before the age of 5.

What are the symptoms of asthma?

Wheezing, coughing, chest tightness, and trouble breathing. During an asthma attack, the muscles around the airways tighten up, more mucus is produced, and asthma symptoms become worse.

Are allergies related to asthma?

Yes. Asthma can be triggered by substances in the environment called allergens. Some indoor allergens come from dust mites, cockroaches, dogs, cats, rodents, molds, and fungi. Outdoor allergens include pollen from many trees, weeds, and grass. Even food allergies can cause asthma symptoms.

What about air pollution outside?

Outdoor pollution plays a major role, as does cigarette smoke. Children exposed to pollution are more likely to develop asthma. Asthma patients are more likely to have their asthma flare up when they are exposed to pollution. This is why asthma patients should not exercise outdoors during high-pollution days, for example when there is a code-orange ozone day.

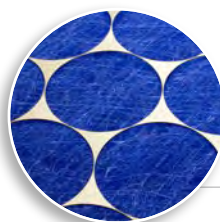
How is asthma treated?

Treatment plans can include taking prescribed medicine and avoiding your asthma triggers. You can breathe in some medicines and take other medicines as a pill. Asthma medicines come in two types—quick-relief and long-term control. Quick-relief medicines control the symptoms of an asthma attack. Long-term control medicines help you have fewer and milder attacks, but they don’t help during an asthma attack. ■

SOURCES: National Institute of Environmental Health Sciences; National Heart, Lung, and Blood Institute; National Institute of Allergy and Infectious Diseases; and the Centers for Disease Control and Prevention

Indoor Allergens & Asthma

What steps can you take to reduce indoor allergens and prevent asthma attacks?



Use HEPA air filtration devices

to reduce airborne allergens. Change HVAC filters at least once every quarter, or more frequently if your home has a lot of dust.

Wash sheets and blankets in hot water every week.



Put mattresses, pillows, and box springs in allergen-proof covers.

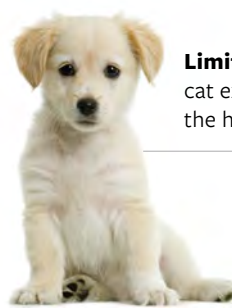
Vacuum carpets and upholstered furniture every week.



Eliminate pest infestations

to reduce cockroach or mouse allergen exposure.

Reduce humidity to under 50% and check for leaks/water damage to reduce mold.



Limit dog and cat exposure in the home.

Don't Let Asthma Define You

Sylvia Granados-Maready uses her competitive edge against condition



Sylvia Granados-Maready, right, is pictured with her newborn son, Peter Ernesto, and her sister, Sandra.

When Sylvia Granados-Maready was born, she was diagnosed with asthma. To this day, Sylvia lives with asthma without letting it define her.

"All my life, I've had asthma," she said. "If you've got that competitive edge, accept it but know your limits."

She let her competitive ambitions shine in middle school and high school by participating in sports.

"You have to learn to love yourself with asthma and realize that there is still a future, with or without it."

- Sylvia Granados-Maready

Though her asthma was less severe when Sylvia was in her teens, there were times when it was tough. Sometimes she needed to stop playing sports or slow down to use her inhaler during gym class.

An avid swimmer, Sylvia once stopped in the middle of the pool lane during a swim meet because she was having difficulty breathing. Having asthma was emotionally difficult.

"I hated having asthma," she said. "People don't see asthma, but you know you have it."

Sylvia's asthma symptoms have worsened, making some physical

activities far more challenging than they were. She finds herself feeling motivated just to keep up at the gym.

"Some people might be super self-conscious about their bodies when they're going to the gym," she said. "For me, it's wondering if I can keep up with the person next to me that's running."

To treat her symptoms, which worsen in the spring and winter, she uses two medications. The first is a bronchodilator, which opens breathing passages and relaxes muscles. She administers it with a nebulizer and an inhaler, as needed. She also takes a steroid through an inhaler every day.

Sylvia gave birth to her first child this April and asthma caused some issues during her pregnancy. In her third trimester, she experienced shortness of breath doing day-to-day activities such as walking up stairs. Asthma made it worse.

Giving birth was also more complicated. Luckily, Sylvia's doctors knew that she had asthma and were ready for any possible issues. "During labor, I was having an asthma attack," she said. "It was so much exertion and so much pressure." She ended up needing a breathing mask to ensure she got enough oxygen.

While asthma has impacted

some life milestones, like giving birth, Sylvia stays positive.

She said, "You have to learn to love yourself with asthma and realize that there is still a future, with or without it." ■

Find Out **More**

- ▶ **MedlinePlus:**
medlineplus.gov/asthma.html
- ▶ **National Institute of Environmental Health Sciences:**
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- ▶ **Allergy and Asthma Foundation of America:**
www.aafa.org

Predicting Autism in High-Risk Infants

AN NIH-SUPPORTED STUDY

has found a tool that may be able to predict which high-risk, 6-month-old infants will develop autism spectrum disorder by age 2. Such a tool would be significant because it could lead to earlier treatment of the condition. Researchers looked at how regions of the brain work together during different tasks and during rest. The study used scanning technology called functional magnetic resonance imaging (functional MRI or fMRI). It measures brain activity by looking at changes in blood flow.

The study is funded by NIH's Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Institute of Mental Health (NIMH).

Using fMRI technology, the researchers scanned 6-month-old infants while they slept. The children in the study were labeled as high-risk because they have older siblings with autism. At age 2 years, 11 of the 59 infants in the group were diagnosed with autism.



Study researchers looked at how regions of the brain work together.

“Although the findings are early-stage, the study suggests that in the future, neuroimaging may be a useful tool to diagnose autism or help health care providers evaluate a child’s risk of developing the disorder,” said Joshua Gordon, M.D., Ph.D., NIMH director.

One study analysis predicted each infant’s future diagnosis by using the other infants’ data. This method identified 82 percent of the infants who would go on to have autism (9 out of 11). It also correctly identified all of the infants who did not go on to develop autism.

Another study analysis that tested how well the results could apply to other cases had an accuracy rate of 93 percent.

“Previous findings suggest that brain-related changes occur in autism before behavioral symptoms emerge,” said Diana Bianchi, M.D., NICHD director. “If future studies confirm these results, detecting brain differences may enable physicians to diagnose and treat autism earlier than they do today.” ■

SOURCE NIH News and Events <https://www.nih.gov/news-events/news-releases/neuroimaging-technique-may-help-predict-autism-among-high-risk-infants>

Rare Gene Mutation May Have Link to Common Cold

COLDS SEEM HARDER

to escape as the temperature drops and people spend more time indoors. They are also not well understood by doctors and scientists. Recently though, NIH-supported research found a new piece of information about this common infection.

Researchers at the National Institute of Allergy and Infectious Diseases (NIAID) identified a rare genetic mutation earlier this year. It can result in a person being more prone to infection by human rhinoviruses (HRVs), the main cause of the common cold.

The study looked at the case of a young child who had respiratory infections, including colds, influenza, and bacterial pneumonia, within only a few weeks of birth. The genetic analysis of the child found a mutation in the IFIH1 gene. The gene mutation created problems with proteins in her respiratory tract.

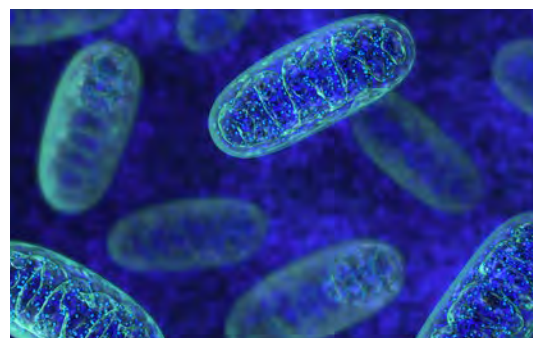
"The human immune response to common cold viruses is poorly understood," said NIAID Director Anthony S. Fauci, M.D. "By

investigating this unique case, our researchers not only helped this child but also helped answer some important scientific questions about these widespread infections that affect nearly everyone."

Researchers then analyzed a database of more than 60,000 volunteers' genomes. While the genetic mutation was rare, they found multiple variations in the IFIH1 gene that could lead to these dysfunctional proteins in the respiratory tract.

Insights from the study may lead to new strategies for treating patients with severe complications from colds. ■

SOURCE: NIH Research Matters <https://www.nih.gov/news-events/nih-research-matters/genetic-alteration-child-reveals-immune-response-pathway-common-cold>



DNA-PK activity lowers the number of mitochondria, shown here, which turn fat into energy to fuel the body.

New Discovery About Middle-Age Weight Gain

A TEAM OF SCIENTISTS has identified an enzyme that promotes weight gain and the loss of exercise capacity starting in midlife. Enzymes increase the rate of chemical reactions. Through animal studies, the team found a drug that inhibits the enzyme to prevent weight gain in mice, increase fitness levels, and reduce the incidence of obesity and type 2 diabetes.

The particular enzyme is activated by a specific kind of DNA damage. But it also may affect the metabolism, which controls digestion and waste elimination.

The researchers thought reducing DNA-PK activity could cause fat burning. They tested their theory with a drug that inhibits DNA-PK. Mice that took the drug had a 40 percent decrease in weight gain when fed a high-fat diet.

The team is led by Jay H. Chung, an endocrinologist at the National Heart, Lung, and Blood Institute. It also included researchers from the National Institute of Diabetes and Digestive and Kidney Diseases, and five universities.

The findings could lead to the development of a new type of weight-loss medication. ■

SOURCE NIH Research Matters/The NIH Catalyst <https://www.nih.gov/news-events/nih-research-matters/enzyme-drives-middle-age-weight-fitness-changes>



NIH on the web

NIH MedlinePlus is Now Animated!

➔ **NIH MEDLINEPLUS** magazine is now on YouTube. Check out our bonus animated videos on medical topics featured in the magazine.

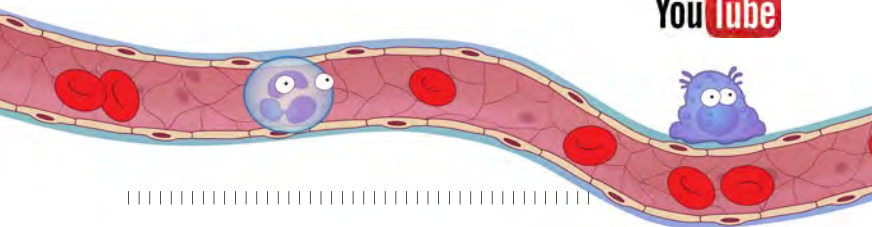
The videos feature fun information that supplements our articles.

Our first animation is titled “Histamine: Friend or Foe...or Frenemy?” Why do our bodies make a chemical that causes allergies? Find out in this video.

We plan to feature more videos in the coming months. We'll look at topics such as celiac disease and antibiotic-resistant infections. The videos break down medical conditions, provide interesting facts, and introduce NIH research.

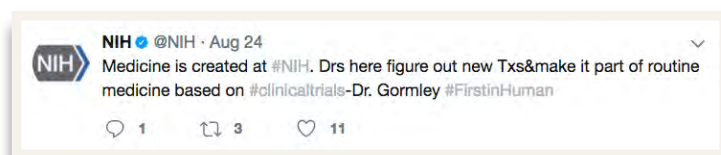
You can find our animations on the NIH MedlinePlus magazine playlist within the NLM YouTube Channel. Search for “histamine” to see the first animation.

Please leave comments on the videos telling us what topics you'd like to see next.



Social Media Corner: Chemotherapy

➔ **Did you know** that the development of chemotherapy happened at the NIH Clinical Center? Follow @NIH on Twitter to learn more cool facts and see the latest updates from NIH and its 27 institutes and centers.



Find it all in one place!
medlineplus.gov/magazine



ClinicalTrials.gov

➔ **INTERESTED IN JOINING A CLINICAL TRIAL** but not sure where to start? ClinicalTrials.gov, a service of NIH, allows you to search for studies by condition or disease, location, study phase, and more.

The database currently lists 249,566 studies with locations in all 50 states and in 201 countries. Of those, more than 40,000 studies are recruiting volunteers.

The listing of a study on ClinicalTrials.gov does not reflect endorsement by NIH. So make sure to talk with a trusted health care professional before volunteering for a study.

To see if a study is NIH-supported, make sure to select “NIH” under the “Funder Type” drop-down menu.



Three New Topics on MedlinePlus

➔ **MEDLINEPLUS.GOV**, your resource for trusted health information, hit the 1,000 topic mark this year. Now, it's added three more topics. Those include tanning, mosquito bites, and the risks of an inactive lifestyle.

Check out MedlinePlus' pages on these conditions and more. Each disease topic page links to information on symptoms, treatment options, diagnostics tests, medical journal articles, and latest news.

NIH Is Here to Help

The National Institutes of Health (NIH)—the nation’s medical research agency—includes 27 Institutes and Centers and is a part of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

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