NIH MedlinePlus Magazine

Trusted Health Information from the National Institutes of Health

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Director Collins Promotes NIH Research Advances on Capitol Hill

NIH DIRECTOR FRANCIS COLLINS, M.D., PH.D., talked about the importance of medical research with leaders in Congress this May. He emphasized that NIH-supported basic research helps lead to advances in diagnosing, treating, and preventing disease.

Dr. Collins, who was selected by President Trump to continue leading NIH earlier this year, said “virtually none of the gains in reducing human suffering and extending longevity over the last century would have happened without basic science.” A reflection of this important role: 149 Nobel Prizes have been awarded to NIH scientists and grantees.

But NIH doesn’t work alone. For example, NIH has joined with the public and private sectors to expand understanding of Alzheimer’s disease, the cover story in this issue of NIH MedlinePlus magazine.

Through the Accelerating Medicines Partnership, NIH and its partners are working together to understand the cause of Alzheimer’s disease. They are also working to identify new ways to detect and treat this devastating disease.

“How working with industry and sharing data widely in the scientific community, NIH aims to shorten the time between these discoveries and the development of new strategies,” Dr. Collins noted.

The Friends of the National Library of Medicine is proud to help support the work of NIH scientists by communicating to the public the amazing research they carry out that is improving the lives of patients and their families.

GLEN P. CAMPBELL, CHAIRMAN
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Welcome to NIH MedlinePlus magazine’s new look!

We’ve added new sections and a new design to give you even more of the NIH MedlinePlus magazine content you like to read. Stay tuned for more updates.

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Explore the Montana Wild Virus Hunt
The Eyes Have It

**HEALTH TIPS** Not seeing clearly? Cataracts might be the problem. Like a camera, your eyes rely on a lens—the clear part of the eye that helps to focus light, or an image, on the retina. A cataract is a clouding of the lens in the eye that affects vision. Most cataracts are related to aging. By age 80, more than half of all Americans either have a cataract or have had cataract surgery.

June marks National Cataract Awareness month. The National Eye Institute (NEI) has helpful resources on the condition, symptoms, and potential treatment options, which have been summarized below.

For resources on cataracts from NEI, including an animation on what a cataract looks like, visit NEI's website.

**What are the most common symptoms of a cataract?**
- Cloudy or blurry vision.
- Colors may seem faded.
- Seeing a glare. Headlights, lamps, or sunlight may appear too bright. A halo may appear around lights.
- Poor night vision.
- Double vision or multiple images in one eye. (This symptom may clear as the cataract gets larger.)
- Frequent prescription changes in your eyeglasses or contact lenses.

These symptoms also can signal other eye problems. If you have any of these symptoms, be sure to check with your eye care professional.

**Are there different types of cataracts?**
Yes. Although most cataracts are related to aging, there are other types:

- **Secondary cataract.** Cataracts can form after surgery for other eye problems, such as glaucoma. Cataracts also can develop in people who have other health problems, such as diabetes. Cataracts are sometimes linked to steroid use.
- **Traumatic cataract.** Cataracts can develop after an eye injury, sometimes years later.
- **Congenital cataract.** Some babies are born with cataracts or develop them in childhood, often in both eyes. These cataracts may be so small that they do not affect vision. If they do, the lenses may need to be removed.
Radiation cataract. Cataracts can develop after exposure to some types of radiation.

How is a cataract treated?
The symptoms of an early cataract may improve with new eyeglasses, brighter lighting, anti-glare sunglasses, or magnifying lenses. If these measures do not help, surgery is the only effective treatment. Surgery involves removing the cloudy lens and replacing it with an artificial lens.

What research is being done?
The National Eye Institute is conducting and supporting studies focusing on factors associated with the development of age-related cataracts. These studies include:
- The effect of sunlight exposure, which may be associated with an increased risk of cataracts.
- Vitamin supplements, which have shown varying results in delaying the progression of cataracts.
- Genetic studies, which show promise for better understanding cataract development.

FOR MORE Visit www.nei.nih.gov

Hearing Loss Affects Millions

BY THE NUMBERS
Approximately 15 percent of American adults (37.5 million) aged 18 and over report some trouble hearing. That makes it the third most chronic health condition for older adults (aged 65 to 74).

Below are some interesting facts about hearing loss provided by the National Institute on Deafness and Communications Disorders (NIDCD).

For more information on hearing loss and other communications disorders, visit www.nidcd.nih.gov

One in eight people in the U.S. (13%, or 30 million) aged 12 years or older has hearing loss in both ears, based on standard hearing examinations.

About 28.8 million U.S. adults could benefit from using hearing aids.

Men are almost twice as likely as women to have hearing loss among adults aged 20-69.

Among adults aged 70 and older with hearing loss who could benefit from hearing aids, fewer than one in three (30%) has ever used them.

5 out of 6 children experience ear infection (otitis media) by the time they are 3 years old.

DID YOU KNOW?

50% +

By age 80, more than half of all Americans either have a cataract or have had cataract surgery.

30%
Magic Meets Medicine at NIH

ON EXHIBIT The National Library of Medicine’s traveling banner exhibition, Harry Potter’s World: Renaissance Science, Magic and Medicine, dives into the science behind the books of the wizarding world.

Although “Harry Potter” is a fantasy story, the magic in the books is partially based on Renaissance traditions that played an important role in the development of Western science. Traditions like alchemy, astrology, and natural philosophy, represent the ideas and scientific beliefs of the world in which the “Harry Potter” books take place.

Incorporating the work of several 15th- and 16th-century thinkers, the books look at important ethical topics such as the desire for knowledge, the effects of prejudice, and the responsibility that comes with power.

This traveling banner exhibition, using materials from the National Library of Medicine (NLM), explores Harry Potter’s world and its roots in Renaissance magic, science, and medicine. Check online to see if it’s coming to a city near you.

Additionally, take a look at our interview with one of the curators of the original exhibit at NLM for more info.

Q+A

With NLM’s Jill Newmark, who helped curate the original Harry Potter exhibit, along with Elizabeth Bland and Stephen Greenberg.

How did you come up with the idea to feature the Harry Potter exhibit at NLM?
In 2007, our colleague Stephen J. Greenberg, Ph.D., told the NLM exhibition program about the book “La Metallique Transformation,” written by Nicolas Flamel. Dr. Greenberg’s action fueled the idea for an exhibition. As any Harry Potter fan will know, Nicolas Flamel is referenced several times in the “Harry Potter” series as the creator of the philosopher’s stone. At the same time, a new “Harry Potter” movie was about to be released. The Exhibition Program thought it would be a great idea to create a special display exhibition that focused on the real Renaissance scientists who were referenced in Harry Potter.

What are some interesting facts you learned?
We learned about the extensive materials that are held within
the History of Medicine Division collections from the 16th and 17th centuries. Many are beautifully illustrated, provide interesting revelations about the scientific beliefs and medical practices at that time. They help illuminate the science, medicine, and magic of the Renaissance.

Can you tell us more about the traveling portion of the exhibit? The traveling exhibition has been touring around the U.S. and abroad since 2009. It is booked through 2018 and is free and open to the public. The exhibition will also be on display at the National Library of Medicine this June to celebrate the 20th anniversary of the publication of the first “Harry Potter” book.

BLAKE WIEDENHEFT is a researcher at Montana State University who launched his virology lab (which studies viruses) with help from a grant from the National Institute of General Medical Sciences. He spoke to us about a workshop that helps high schoolers explore their passion for health and science.

What is the focus of your research? Viruses that infect bacteria (i.e., bacteriophages) are the most abundant biological entities on earth. In my lab, we rely on a combination of techniques from bioinformatics, genetics, biochemistry, and structural biology to understand the mechanisms that bacteria use to defend themselves from viral infection.

What is the Montana Wild Virus Hunt? The aim of this project is to engage high school students and their instructors in a three-day basic virology workshop at Montana State University. Like me, many of these students come from rural parts of the state. For some, this is their first opportunity to visit a college campus. We tour the local wastewater treatment facility with expert speakers. We then collect wastewater samples, bring them to the lab and perform plaque assays, isolate viral clones, purify bacteriophages, and visualize the bacteriophages using transmission electron microscopy.

What advice do you have for young scientists? Above everything, I recommend finding a topic that captivates your curiosity. Then, incorporate ideas and techniques from other disciplines, identify and communicate with scientists that you respect (i.e., mentors), striking a productive balance between healthy skepticism and blind optimism (i.e., know when to walk away). Pursue your research with vigor and never stop asking questions.

FOR MORE visit www.nlm.nih.gov/exhibition/harrypottersworld
UNDERSTANDING FOOD ALLERGY

Latest updates from NIH
Understanding Food Allergy

FOOD ALLERGIES are often misunderstood. “This disease is common and it has a dramatic impact not only on the lives of people who have the allergy but on the lives of anyone who cares about them,” says Pamela Guerrero, M.D., Ph.D. She is chief of the Food Allergy Research Unit of the Laboratory of Allergic Diseases at NIH’s National Institute of Allergy and Infectious Diseases (NIAID).

Dr. Guerrero spoke to NIH MedlinePlus magazine about food allergies and research to help understand and potentially prevent them.

Allergic reactions

Allergic reactions can be scary if you’ve never had one before. If you have a mild allergic reaction, which could include hives, itching, sneezing, or a runny nose, you should take an antihistamine if it’s available and monitor for more severe symptoms, Dr. Guerrero said.

If you have a more severe reaction, you should seek immediate medical attention at an emergency room or call 911. Severe reactions include difficulty breathing or low blood pressure, which can cause confusion, paleness, a weak pulse, or a lack of consciousness. Dr. Guerrero said if the reaction is severe or if it involves multiple organ systems—for example the person has hives and is also vomiting—you should administer an EpiPen if you have one and call 911.

Once the initial reaction has been treated, you should see an allergist to get tested for a food allergy and discuss a course of action.

Development and diagnosis

Blood and skin tests can be helpful but are not enough to determine a food allergy. You must also have clinical symptoms when you eat the food. Since these tests can result in false positives, “It’s important that they are interpreted within the context of the patient’s entire health picture,” said Dr. Guerrero.

Most allergies develop early in life, Dr. Guerrero said, and food allergy development peaks around age 1.

It is uncommon for an allergy to develop later in life, though there are exceptions. The most common food allergies in adults include shellfish and nuts.

As people with a food allergy get older, they have increased chances of developing other allergic diseases or allergies. Sometimes people grow out of an allergy.

Food allergy studies

With so many unanswered questions surrounding food allergies, it’s important that researchers continue to study them. “It’s really only with more research into food allergy that we’re going to find better ways to diagnose, prevent, and treat the disease,” Dr. Guerrero said.

A major, NIAID-funded study on peanut allergy prevention recently took place in the United Kingdom. This led to changes in food allergy guidelines from NIH. The study, Learning Early About Peanut Allergy (LEAP), looked at early exposure to peanuts in infants at high risk of developing a peanut allergy.

The study looked at 640 infants under the age of 1 who had either eczema, an egg allergy, or both. These conditions indicate a child is at high risk of developing a peanut allergy.

The children were split into two groups. The
parents of the first group of children were told to have their child avoid peanut-containing foods completely until age 5. Parents of the second group were told to introduce peanuts into their child’s diet immediately and children were to eat peanut-containing foods at least three times a week.

At age 5, the children had a peanut oral food challenge to see if they had developed a peanut allergy.

“The remarkable result was that the rate of peanut allergy was almost 80 percent lower in the group that had eaten peanut-containing products compared to the group that had avoided them,” Dr. Guerrerio said.

Following the LEAP study and a follow-up study, LEAP-ON, an expert panel led by NIAID reviewed the available evidence and recommended that infants with a high risk of developing a peanut allergy be exposed to peanut-containing foods as early as 4 to 6 months old. The goal is to reduce the development of a peanut allergy.

Dr. Guerrerio said it’s important that parents of children with a high risk for developing a peanut allergy speak to a provider before introducing peanuts into a child’s diet. The provider can help determine if the child should first see an allergist for a food allergy test.

NIAID is also conducting research at the NIH Clinical Center in Bethesda, Maryland. The Institute is looking for participants for a study called “Natural History and Genetics of Food Allergy and Related Conditions.”

The 10-year study aims to better understand the development of a food allergy and look at nutrition and growth in children with food allergies.

“Most of the major food allergens—such as milk, eggs, peanuts, soy, and wheat—are nutritionally dense. The concern is that children who have to avoid those foods because of their allergies will be at high risk for not getting enough nutrition. So we wanted to ask whether children with food allergy are indeed susceptible to nutritional deficiencies,” Dr. Guerrerio said.

Eligible participants include anyone between the ages of 2 and 99 who has a food allergy confirmed by a doctor’s testing. NIAID is also looking for healthy individuals (who do not have a food allergy) for the control group.

What is a food allergy? In a person with a food allergy, the immune system reacts abnormally to a part of a food. Sometimes the response can be life-threatening.

What foods commonly cause an allergy? Foods that often cause allergic reactions in adults include fish, shellfish, peanuts, and tree nuts, such as walnuts. Problem foods for children can include eggs, milk, peanuts, tree nuts, soy, and wheat.

What are symptoms? The allergic reaction may be mild. In some cases, foods can cause a severe reaction called anaphylaxis. Symptoms of a food allergy include:

- Itching or swelling in your mouth
- Vomiting, diarrhea, or abdominal cramps and pain
- Hives or eczema
- Tightening of the throat and trouble breathing
- Drop in blood pressure

What types of treatment are there? Health care providers can help manage patients’ food allergies by encouraging them to avoid foods that may cause an allergic reaction and by treating severe reactions when they happen. Additionally, the National Institute of Allergy and Infectious Diseases (NIAID) is researching new ways to help treat and manage food allergies.

For more information, visit the NIAID website.

FOOD ALLERGY 101

Food allergies affect 5 percent of children and 4 percent of adults in the U.S. The number of people with food allergies is rising without a known cause.

FOOD ALLERGY

Pamela Guerrerio, M.D., Ph.D., discusses research in her office at NIH in Bethesda, Maryland.

INFORMATION PROVIDED BY THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIONOUS DISEASES (NIAID), MEDLINEPLUS.GOV, AND THE CENTERS FOR DISEASE CONTROL AND PREVENTION.
Don’t Sweat the Small Stuff

Food allergy sufferer lives a cautious but normal life

ANTHONY TERLIZZI was just 16 months old when he had his first allergic reaction to peanuts.

His mother, Lisa Terlizzi, was introducing solid foods into his diet. She gave him a peanut butter and jelly sandwich. His reaction was immediate.

“He rubbed his eyes, and his whole face blew up,” Lisa said. She quickly took the sandwich away before Anthony had a chance to eat it.

Lisa had just watched a morning news show that warned of possible allergic reactions to bee stings. The show recommended giving your child a small dose of antihistamine if you feared an allergic reaction. That’s exactly what she did.

After that, Lisa called her son’s pediatrician for guidance. “His pediatrician told me to watch his breathing, and that if his breathing became labored, to get him to an emergency room,” she said.

Thankfully, Anthony got better and they didn’t need to visit the ER.

Lisa had her son tested by an allergist to confirm the peanut allergy. She didn’t know anyone with a peanut allergy, so she learned a lot quickly.

“I started reading labels a little bit more. But I never got crazy with it. If something had peanuts in it, I just didn’t buy it,” Lisa said.

Lisa’s older daughter didn’t have a peanut allergy. Sometimes, she wanted food with peanuts. Lisa found the best way to handle this was to carefully prepare food and make her son’s food first to avoid cross-contamination. Some children’s allergies are more severe and may warrant extra precautions to avoid cross-contamination with allergens.

She also stocked up on EpiPens. She kept them in the house, car, and in her purse. She did this until Anthony was old enough to carry and use the EpiPen himself.

“It was about being vigilant and making sure we were prepared if anything happened,” Lisa said. She recognized that children should be aware of their allergies and know the dangers, but “they can’t be afraid to live either.”

That philosophy made an impact on Anthony, who doesn’t let his food allergy stop him from enjoying life.

Anthony is now 23 years old. “The same way that you wake up knowing you have to brush your teeth in the morning is the same way I wake up every day knowing I’m allergic to peanuts,” Anthony said.

For those facing a food allergy diagnosis, Anthony has a simple message: “Don’t live your life being scared.”

Anthony knows how easy it is for allergies to negatively affect your life. That’s why he is always prepared.

“As long as I have my EpiPen on me, I try to live as normal a life as possible,” he said. In the decades he’s had this food allergy, he’s never had to use his EpiPen.

Anthony also wants those without food allergies to understand their danger.

“Ask questions and don’t be uncomfortable,” Anthony said. He would rather someone ask for more information than risk someone’s safety. ■

Find Out More

- National Institute of Allergy and Infectious Diseases
  www.niaid.nih.gov/diseases-conditions/food-allergy
- Food Allergy: MedlinePlus
  www.medlineplus.gov/foodallergy.html
- Clinical Trials
  www.clinicaltrials.gov/ NCT02504853
- LEAP Study
  www.leapstudy.co.uk/
“NIH is key because it supports crucial work to find answers and drive advances for Alzheimer’s.”
– Liz Hernandez

for my mom
Fighting for a Cure

ELEVISION PERSONALITY and journalist Liz Hernandez brings the world’s top celebrities into our homes as a news correspondent for NBC’s “Access Hollywood.” An award-winning Latina voice in entertainment news, Hernandez is also a leading advocate for those living with Alzheimer’s disease. Her mother was diagnosed with the condition in 2014.

Hernandez shared her thoughts with NIH MedlinePlus magazine.

Why did you decide to share your story with us?
I think it is vital that we raise awareness about Alzheimer’s disease.

What were the first signs that your mom may have had Alzheimer’s?
We started seeing signs in my mom a few years before she was diagnosed, but they were really subtle. We wrote them off as just a part of getting older. Then it became more consistent. My dad would call me and say, ‘Your mom lost her car keys again today and I found them in the refrigerator.’ Or he would say, ‘Today she accused me of stealing her jewelry.’

One day my mom called me and asked for directions to get home. Then I knew we had to get her help.

How did your family deal with the news?
My mom is the heart and soul of our family, so it hit us very hard. My initial focus was stepping up to take care of my mom and make sure she felt loved and supported. Once we found our bearings and adjusted to this new reality, I realized that I didn’t want to sit on the sidelines while this disease devastated our family.

I made the decision to share my story and get involved with the Alzheimer’s Association. We have to use this pain to build awareness.

What advice do you have for others whose loved ones have Alzheimer’s?
I’ve learned that loved ones living with dementia and Alzheimer’s are still who they are, and we shouldn’t treat them any differently. In fact, this is a time when they especially need us to make them feel included, loved, and cared for. In the beginning, I was so worried about what my mom was losing that I didn’t appreciate what she still had left to give.

FAST FACTS

For people aged 65 and older, estimates indicate that Alzheimer’s may rank third as cause of death.
“On a personal level, this disease is devastating. But it is also a national health crisis.”

What message do you want to send to the public about Alzheimer’s?
This is a disease that could impact anyone. I thought Alzheimer’s happened to other people. But then I realized, why not us?

Knowing the warning signs is important. If I had known the signs sooner, I could have given my mom more options and let her make her caregiving decisions before the disease took over. The Alzheimer’s Association has a very helpful resource that outlines the 10 warning signs.

Why did you decide to become an advocate?
I believe that we need to use the pain that comes from this disease to build awareness and get families the resources that they need. On a personal level, this disease is devastating. But it is also a national health crisis. More than 5 million Americans live with the disease.

Alzheimer’s is already the most expensive disease in the country.

I attended this year’s Alzheimer’s Association Advocacy Forum in Washington, D.C. and was inspired by the advocates from across the country who are fighting with everything they have to end this disease.

And I recently met with Richard Hodes, M.D., director of the NIH’s National Institute on Aging (NIA). NIH is key because it supports research to find answers and drive advances for Alzheimer’s.

Alzheimer’s can be very isolating, but being surrounded by so many individuals and families going through the same thing was energizing. I hope that I can continue to do my part to make Alzheimer’s a thing of the past.

Alzheimer’s and Dementia: An Overview

What is Dementia?
Dementia is the loss of cognitive functioning—or thinking, remembering, and reasoning. It also includes the loss of behavioral abilities that interfere with a person’s daily life and activities. Dementia ranges in severity. In its most severe stage, dementia could cause a person to depend completely on others for basic activities and daily living.

What is Alzheimer’s disease?
Alzheimer’s disease is the most common cause of dementia. It is an illness of the brain that begins slowly and gets worse over time. Abnormal deposits of proteins form plaques and tangles in the brain, and once-healthy neurons stop working, lose connections with other neurons, and die. It affects a person’s ability to remember things, think clearly, and use good judgment.

Phases of Alzheimer’s disease
In Alzheimer’s disease, toxic changes to the brain likely start a decade or more before problems appear.

Early: The first symptoms of Alzheimer’s can be different in each person. They may include memory problems and nonmemory problems. Some symptoms include word-finding, vision/spatial issues, and impaired reasoning or judgment.

Mild: As memory loss and other cognitive problems increase, people may have a number of issues. These include wandering and getting lost; issues with handling money and paying bills; repeating questions; taking longer to complete normal daily tasks; and personality and behavior changes. People are often diagnosed in this stage.

Moderate: Damage occurs in areas of the brain that control language, reasoning, sensory processing (relating to sensation or the physical senses), and conscious thought. People in this stage begin to have problems recognizing family and friends. They may also have trouble doing tasks such as getting dressed. Some may have hallucinations, delusions, and paranoia.

Severe: People in the final stages of the disease cannot communicate and are completely dependent on others for their care. Near the end, the person may be in bed most or all of the time as the body shuts down.

For more information on the diagnosis and treatment of Alzheimer’s, visit the National Institute on Aging’s website: www.nia.nih.gov/alzheimers.
From Caring to Commitment

During her sister’s battle with Alzheimer’s, Anne Murphy stayed by her side and continues to help fight the disease today.

Anne Murphy and her sister Jean did nearly everything together from childhood to adulthood. As adults, they often started the day bringing coffee to each other’s houses, located directly next door in Concord, Massachusetts. Then they set out for yard sales, museums, or the beach. They both worked as nurses, volunteered, took care of each other’s children, and also looked after each other. “Jean was always taking care of me and telling me what to do from the earliest age,” Anne recalls.

But that all changed in 2011, when Jean started losing her memory. “She had a hard time remembering things and finding her way,” recalls Anne. She could no longer write out checks at yard sales.

They both were already aware of Alzheimer’s and dementia. Their older brother died of dementia and complications related to Parkinson’s disease at age 62. Jean agreed to be evaluated at age 64 and was understandably upset when she heard the results.

Staying Active and Engaged

As Jean’s Alzheimer’s progressed, Anne says she did her best to talk to Jean as much as possible and keep her active. “Jean, my sister Mary, and I would do ‘girls’ day’ once a week. We played cards and brain games,” Anne says.

As time went on, Anne focused on talking to Jean and letting her know she was still by her side. “I’d say to her, ‘I still see you, you are right here,’” says Anne.

Jean was taken care of by her husband, who is also a nurse, her children, and Anne in her own home. “It’s difficult for anyone dealing with a loved one who has Alzheimer’s disease,” Anne says. “She was older than me, always fixing my hair, always fussing with me. After she lost her speech I knew she was still fussing with me, as her forehead would become wrinkled, but she couldn’t say what was on her mind.”

Jean had lost her speech, but like many people with the disease, she could still sing or hum tunes.

“I feel like I am contributing to finding an answer to the big brain puzzle.”

Advice for Other Families

When Jean died at age 69, Anne was devastated, despite knowing the day would come.

Since then, Anne has decided to enroll in clinical studies to help Alzheimer’s research. “At first I was hesitant to sign up, but now I’m glad that I did,” Anne says. “I feel like I am contributing to finding an answer to the big brain puzzle.”

Anne’s advice to those who care for loved ones with Alzheimer’s: don’t give up.

“Never stop being present with them. Never think for a minute they are gone. Enjoy them wherever they are.” She suggests talking about family memories or pointing out surroundings.

“Most of all, be able to sit and deal with silence,” Anne adds.
NIH-supported research aims to better understand Alzheimer’s disease.

By taking images of the brain and using biomarkers, researchers can track the brain’s structure and see how it works over four disease phases. These include memory issues, ability to process thoughts, losing control of moods and senses, and slowing of the heart and breathing.

The overall goal is to find a treatment and a cure for Alzheimer’s. Our newest phase of research, called ADNI3, is conducting clinical trials for brain imaging. By taking images of the brain, we can see changes that happen up to 10 years before actual Alzheimer’s symptoms appear. If we wait until symptoms appear, there is already too much damage to the brain. Brain scans, lumbar punctures (spinal taps), and biomarkers help us study brains over time and predict Alzheimer’s growth.

How does this research differ from other Alzheimer’s research?
A lot of research has been done on animals or from human autopsies. Live humans are needed to study the brain over time, before symptoms appear. Alzheimer’s research now uses various brain tests such as positron emission tomography (PET) scans, magnetic resonance imaging (MRIs), and spinal fluid from people who volunteer, and we can study how their brains change over time, rather than study brains that already have damage.

Another difference is ADNI immediately shares all the data collected from clinical trials and posts it on the ADNI website. The information is available to any scientist in the world at no cost. As a result, more than 1,200 Alzheimer’s research papers have been published worldwide, which helps spread awareness and ultimately, find a cure more quickly.

What are some of the challenges of the study?
The biggest challenge is getting more volunteers. The volunteers can range from people who have no symptoms and are in good health to people with mild memory loss or a diagnosis of early Alzheimer’s. They even include people who may
be at risk if they have a history of Alzheimer’s in their family. The more people who volunteer, the faster we may be able to prevent, treat, and cure the disease.

Are risks involved with volunteering for the clinical study?
Like most clinical trials, there are some risks, but they are minor. Privacy may be a concern to some, although all health information is locked up. Lumbar punctures involve inserting a needle in your lower back to get spinal fluid. It’s a routine procedure but still has some risks. PET scans have the risk of slight radiation exposure. Unlike many other clinical trials, this one does not involve any experimental pills or infusions. We are taking images of brains to study them over time.

What have you learned after 10 years?
We can now diagnose Alzheimer’s on a much larger scale and in multiple locations nationwide, not at just one lab. With PET scans and lumbar punctures, we’ve also learned that some people who may appear to have Alzheimer’s on the outside don’t seem to have enough of it in their brains to be qualified as having the disease. Most importantly, having biomarkers is an important way to predict Alzheimer’s growth in the brain. This helps us understand what might happen to a brain in advance and whether it can be treated early.

How do I volunteer for the ADNI3 study?

EXERT Yourself and Help in the Search for an Alzheimer’s Cure

CAN EXERCISE SLOW or prevent cognitive decline in older people who are at increased risk for Alzheimer’s disease? The EXERT Study: Building Memories Through Exercise is a national clinical trial to test whether aerobic training or other exercises can improve memory and thinking skills in people with mild memory loss.

How to qualify:
The EXERT Study is enrolling adults who:
- Are between the ages of 65-89
- Are experiencing mild memory loss or are diagnosed with Mild Cognitive Impairment
- Have not been exercising regularly
- Are in good health

After completing a variety of tests during the screening phase, eligible adults will enroll in the EXERT Study. All trial participants will receive a free membership at a participating YMCA, where they will work closely with a personal trainer for one year. They will then exercise on their own for an additional six months. The trainers will ensure participants’ physical safety and encourage them to stick with the EXERT exercise program.

How to enroll:
There are many academic medical centers and specialty clinics across North America participating in the EXERT Study. To learn more, visit www.exertstudy.org/locations.
Is Genetic Testing Right For You?

Understanding the basics of your genetic code

What is genetic testing?
Genetic testing looks at your genes. Genes are the DNA instructions you receive from your mother and father. Genetic tests may identify risks of health problems. This can help people choose treatments or to understand how they may respond to treatments.

What can I learn from testing?
Genetic testing tells you information about your DNA. Genetic test results can be hard to understand. Specialists like geneticists and genetic counselors can help explain information.

What types of genetic tests are there?
Diagnostic testing can identify the disease that is making a person sick. The results of a diagnostic test may help you make choices about your health.

Predictive and presymptomatic genetic tests find gene changes that increase a person’s chance of developing diseases. This information could be useful in decisions about your lifestyle and health care.

Carrier testing is used to find people who carry a change in a gene that is linked to disease. Carriers may show no signs of the disease. However, they can pass on the gene change to their children, who may develop the disease or become carriers themselves.

Prenatal testing is offered during pregnancy to help identify fetuses that have certain diseases.

Newborn screening tests babies one or two days after birth to find out if they have certain diseases known to cause problems with health and development.

Pharmacogenomic testing gives information about how certain medicines are processed by an individual’s body. This type of testing can help your health care provider choose the medicines that work best for you.

Research genetic testing is used to learn more about how genes affect health and disease.
“The last few decades have brought profound advances in our understanding of how the human genome works; with this has come exciting opportunities to use genetic testing for a wide range of medical applications.”

– Eric Green, M.D., Ph.D.
Director of the National Human Genome Research Institute
What are the pros and cons of genetic testing?

Benefits: Genetic testing may be helpful whether the test identifies a mutation or not. For some people, test results remove some of the uncertainty surrounding their health. These results may also help doctors and give people more information to make decisions about their health, as well as their family’s health, allowing them to take steps to lower the chance of developing a disease.

Drawbacks: Genetic testing is relatively safe for your body. However, it can be hard to find out your results. Sometimes, testing can be costly.

Emotional: Learning that you or someone in your family has or is at risk for a disease can be scary. Some people also feel guilty, angry, anxious, or depressed when they learn their results.

Financial: Genetic testing can cost anywhere from less than $100 to more than $2,000. Health insurance companies may cover part or all the cost of testing.

Many people are worried about discrimination based on their genetic test results. In 2008, Congress enacted the Genetic Information Nondiscrimination Act to protect people from discrimination by their health insurance provider or employer.

How do I decide if I should be tested?

There are many reasons why people might get genetic testing. A test could help doctors learn if you or your family have certain patterns of disease. You can decide if a genetic test will be helpful for you.

A geneticist or genetic counselor can help families decide if a particular genetic test will be helpful.

SOURCE NHGRI

An Inside Look at Genetic Counseling

Katie Lewis is a genetic counselor and research coordinator at NIH’s National Human Genome Research Institute (NHGRI). She counsels people who volunteer for genetic clinical research. She spoke to NIH MedlinePlus magazine.

What kind of genetic research do you direct at NHGRI?

I work on a project called the ClinSeq® study. This study offers people from the Washington, D.C., area the opportunity to have a type of genetic testing called exome sequencing. Exome sequencing looks at almost all of a person’s genes. The basic idea is that the sequencing can identify variants in a person’s genes. These variants are places where their genetic sequence differs from an expected sequence.

We try to find out whether those variants have health
implications. If we think that they do, we offer participants the option to hear about them. The participants in the study agree to have this kind of testing and to return from time to time over many years to hear results of their genetic testing. They also give us more information about their health.

**What are the goals of this research?**

We want to learn as much as we can about this new type of genetic testing. We also want to serve as a resource so other researchers can learn about our participants and their genetic information. Specifically, we are interested in learning about exome sequencing in several ways:

Along with other researchers, we are working to develop and refine systems for interpreting a person’s exome sequencing results. This is a complex process because genetics is still a relatively new field, and we have a lot to learn about how variants in a person’s genes might affect their health.

We are also researching what participants think about this testing. For example, we want to learn how much participants want to know about their genetic makeup. Some participants may only want to hear about genetic variants that put them at risk for health problems that they can prevent. Other participants may want to know about risks for diseases even if we can’t prevent them. We’re also doing research on the best ways to share genetic testing results with individual participants with an eye toward finding a system that is efficient but also maintains an excellent quality of care.

**What exactly does a genetic counselor do?**

We provide people with education and information about genetics that is relevant to their personal or family history, advise them about screening recommendations, and may offer genetic testing. We also provide our patients with support in the face of this type of information and help them adapt to it.

**Why do people take part in these studies?**

We asked participants, “What are your reasons for wanting to participate in this study?” The two most common reasons that participants said they joined the study were that they wanted to support research and hoped they would learn more about their personal health risks.

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Genetic Tests Can Help to:

- **Diagnose Your Disease**
- **Pinpoint Genetic Factors That Caused Your Disease**
- **Predict How Severe Your Disease Might Be**
- **Choose the Best Medicine and Correct Dose**
- **Discover Genetic Factors That Increase Your Disease Risk**
- **Find Genetic Factors That Could Be Passed to Your Children**
- **Screen Newborns for Certain Treatable Conditions**

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**Why else do people seek genetic screening?**

There are many reasons why a person might have genetic testing or screening. One of the most common reasons for seeking genetic counseling is if a couple is concerned about their risk of having a child with a genetic condition. These couples might have genetic testing and counseling ahead of or during a pregnancy.

Another common reason to have genetic counseling is if you have a health problem that runs in your family and want to know more about your risk of developing the condition. Other times people who have a personal history of a health problem—like heart disease or cancer—seek genetic counseling for more information about the chance that their genes put them at risk for the condition. This may help them understand why they developed the health problem. It could also show if their family members have a similar risk.

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“We want to learn as much as we can about this new type of genetic testing.”

- Katie Lewis
A Diagnosis of Lynch Syndrome

*Genetic testing identifies a potentially deadly hereditary disease*

**JACK C. REMEMBERS**

that day well. The seemingly healthy 65-year-old suddenly had chest pains. But, he had a busy day ahead. So he pushed himself through the pain and kept working.

However, the chest pain continued. Before he knew it, Jack was in the emergency room and doctors were running tests on him. He started asking questions.

“Be quiet. I’m working here,” one of the doctors said. “We’re trying to decide whether or not to crack you open. You’ve got a 90 percent blockage in one of your arteries.”

Jack stopped talking. After more tests, Jack’s doctors inserted a stent—a short tube to help relieve the obstruction—into his blocked artery. Jack was soon released to go home.

The next day, though, he was still bleeding. The bleeding didn’t stop, so he called an ambulance and went back to the hospital.

Doctors soon found out why he was so sick. He had a large cancerous tumor growing in his colon.

Jack, who had seldom seen a doctor through his adult life, found out that the tumor had been growing for about 10 years. Jack’s oncologist said, “We’ve got to operate to get that tumor out now.”

However, Jack’s cardiologist, who had inserted the stent, said, “You’re not touching him for at least 30 days.”

At about this time, two doctors stopped by his hospital bedside and asked if he would like to join an NIH genetic research study to help uncover the foundation of his medical makeup and potentially help others.

Jack said yes. His father died from heart disease and his mother from liver cancer that started in her colon.

He joined an exome sequencing study that looks at most of a person’s genes. “The basic idea is that the sequencing can identify variants in a person’s genes—places where their genetic sequence differs from an expected sequence,” says Katie Lewis, a research coordinator at NIH’s National Human Genome Research Institute.

“We try to determine whether those variants have health implications. If we think that they do, we offer our participants the option to hear about them. The participants in the study agree to have this kind of testing and to come back from time to time over many years to hear about any results of their genetic testing and to give us more information about their health.”

Over the next several years, Jack had 10 months of chemotherapy. He had an operation that removed two feet of his colon (large intestine) and 12 lymph nodes. His doctors took a total of 18 vials of his blood for the research.

The NIH research helped Jack learn what was wrong. Jack had Lynch Syndrome—an inherited disorder. Lynch Syndrome increases the risk of many types of cancer, particularly cancers of the colon and rectum, which are together referred to as colorectal cancer.

“The NIH research study has been a big deal for me,” he says. “I’d be dead without it.”

Jack, a motorcycle enthusiast, turns 72 in June. For his birthday, he plans to take a long trip with his wife on their matching motorcycles.
A Missing Ancestry

Filling in a genetic background

Many adopted children don’t know very much about their biological family. That was the case for David Hale. He didn’t know any of his biological family’s health.

All Hale knew from his adoption papers was that he was part Native American and Portuguese.

That knowledge launched his interest in Native American culture, medicine, and history. As a staff member with the NIH’s National Library of Medicine (NLM), he regularly participated in NLM outreach programs dealing with Native American health. He attended many powwows, which are social gatherings in American Indian communities, with tribes throughout the U.S.

When genetic testing became available, Hale decided to have ancestry-focused genetic testing to learn more about his heritage. He used a popular genetic ancestry-tracking company to do this.

The result? He learned he has no Native American ancestry whatsoever. “The information the adoption agency gave my parents was wrong,” he says. “It turns out I’m largely of Portuguese descent.”

Hale was initially shocked by this revelation but says, “It helped me understand the importance of health information that is accessible and accurate.”

In addition to Native American culture, Hale also has personal and professional interests in technology and music. He helped create NLM’s Pillbox program, which was developed to identify unknown pills. It combines images of pills with appearance and other information to visually search for and identify medications. As for music, when Hale was a small boy he told his adoptive parents that he wanted to play an instrument. Although they weren’t musical, they supported him. Today, Hale is a musician who performs, composes, and plays the ukulele.

Through his genetic testing, Hale also found some of his birth mother’s relatives. He was in for another surprise.

His birth mother played the guitar and sang, and his grandmother played the ukulele.
In the not-too-distant future, operating rooms will feature devices that will revolutionize surgery for patients and doctors. You can get a sneak peek at these tools in a new mobile app.

The Surgery of the Future app provides a 3D virtual tour of the operating room of the future. This app is provided by the National Institute of Biomedical Imaging and Bioengineering (NIBIB).

More than a dozen surgical technologies are featured in the app. You can download it on iOS and Android devices. All of the featured technologies are still in development and are funded by NIBIB.
“NIBIB funds a wide range of advanced technologies, including tools for imaging the body, biomaterials, and robotics,” says Margot Kern, who led the development of the app. “One arena where all of these technologies come into play is in the operating room, in surgery.”

“When people think about the types of research NIH supports, they don’t necessarily think of surgery,” she adds. “But surgery is a critical part of our health care system, and advances in surgical technologies have the potential to greatly improve patient care. We thought showcasing some of the technologies NIBIB is funding in a virtual surgical operating room would be an exciting way for the public to learn how their tax dollars are being used to make surgery safer and more effective.”

In the app, users can view a number of NIH-funded technologies. These include robots that can stitch tissues by themselves, biomaterials that change shape or dissolve inside the body, and a tool that reduces a surgeon’s natural hand tremor.

“This project demonstrates ways that patients and surgeons may benefit from the next generation of technologies.”
Silk Screws
Silk has been used to stitch up wounds for centuries. Now, researchers have created silk screws and plates to repair fractured bones. Unlike metal, silk can safely break down in the body. This means that patients who receive temporary silk devices to hold their bones in place wouldn't need a second surgery to remove them. Developer: David Kaplan, Tufts University.

Biopsy Guidance
The Clear Guide ONE is a device that helps target tumors for biopsy. The tool attaches to an ultrasound probe, which produces images of the inside of the body. It helps the physician see the path the needle would take if inserted at that spot. Developer: Clear Guide Medical.

High-Intensity Focused Ultrasound
High-intensity focused ultrasound lets surgeons operate deep within the body without making a cut. In a procedure that uses this technology, multiple beams of ultrasound focus on a target in the body. At the focal point, the energy from the ultrasound beam causes the temperature of the tissue to rise and then destroy it. It does this while leaving surrounding tissue unharmed. Developer: Kullervo Hynynen, Sunnybrook Research Institute.

Flexible Endoscope with Fluorescent Capabilities
Researchers have developed a flexible endoscope that can help spot precancerous growths in the colon. The endoscope has a single optical fiber that uses laser light and shows images of fluorescent molecules, which stick to the precancerous growths. Developers: Eric Seibel, University of Washington, and Thomas D. Wang, University of Michigan.

Minimally Invasive Neurosurgical Intracranial Robot
Researchers are creating robots to use inside an MRI (magnetic resonance imaging) machine so surgeons can more easily see tumors. One researcher is developing a worm-like robot that could be directed inside the brain while a patient has an MRI scan. Developer: Jaydev Desai, Georgia Institute of Technology.
Self-Stitching Surgical Robot
This robot can stitch soft tissues all by itself. It has 3D and special light cameras to keep track of tissue position. Developers: Axel Krieger and Peter Kim, Children’s National Health System.

Fluorescent Tumor Paint
Researchers created fluorescent molecules that cause cancer cells to glow. The molecules can be injected before surgery and are just taken up by cancer cells. Surgeons can see the glowing cancer tissue or tumors using a special camera. Researchers are also developing molecules to light up nerves, which can get wrapped up in tumors. Developer: Quyen Nguyen, University of California, San Diego.

Tremor-Reducing Instrument
This hand-held tool reduces a surgeon’s shaking when operating on small structures such as the eye. It estimates the tremor of the surgeon and then adjusts to provide smooth control. Developer: Cameron Riviere, Carnegie Mellon University.

Biodegradable Stent
Each year, approximately half a million Americans receive a stent to hold open an artery in their heart that has been unclogged during a procedure called angioplasty. A stent is a small wire-mesh tube. It is usually made of stainless steel or another metal. NIBIB-funded researchers have invented a new material that makes a stent dissolve over time. This new solution could eliminate some of the disadvantages of metal stents. Developer: Joachim Kohn, Rutgers University.

Find Out More
- National Institute of Biomedical Imaging and Bioengineering (NIBIB): www.nibib.nih.gov
Progress Against Zika

FROM 2015 TO 2016, THE World Health Organization declared the Zika virus a world health crisis. The U.S. National Institute of Allergy and Infectious Diseases (NIAID) has been leading the search for a vaccine, and has progress to report.

The Zika vaccine trial entered the next stage of clinical testing in March 2017. As reported by NIH MedlinePlus magazine, it entered early-stage human testing in 2016, following extensive testing in animal models.

The trial is testing an experimental DNA vaccine designed to protect against disease caused by the Zika infection, which usually does not cause symptoms or causes mild ones such as fever, rash, joint pain, and conjunctivitis (red eyes).

However, when Zika infection occurs during pregnancy, the pregnant woman can pass the virus to her fetus, which can result in a range of fetal defects known as congenital Zika syndrome.

This phase of the trial aims to gain more safety and immune response data and find out if this immune response protects against disease caused by natural Zika infection.

“We are pleased to have advanced rapidly one of NIAID’s experimental Zika vaccines into this next stage of testing in volunteers. We expect this study will give valuable insight into the vaccine’s safety and ability to prevent disease caused by Zika infection,” said NIAID Director Anthony S. Fauci, M.D.

The study aims to enroll more than 2,000 healthy participants in areas of confirmed or potential active mosquito-transmitted Zika infection, including the continental U.S. and Puerto Rico, Brazil, Peru, Costa Rica, Panama, and Mexico. It is expected to finish in 2019.

Stay tuned to NIH MedlinePlus magazine and NIAID’s website.

SOURCE www.niaid.nih.gov
Diet’s Role in Disease Risk

RESEARCH SUPPORTED in part by NIH’s National Heart, Lung, and Blood Institute (NHLBI) that was released earlier this year examined how different dietary components affect the risk of dying from the major cardiometabolic diseases. These include heart disease, stroke, and type 2 diabetes.

Researchers found that nearly half of all the deaths in the U.S. in 2012 that were caused by cardiometabolic diseases were associated with poor eating habits.

The researchers investigated the relationships of 10 different foods and nutrients with deaths related to these three diseases. They also compared data on participants’ age, sex, ethnicity, and education.

These results suggest ways to change eating habits that may help improve health.


A TEAM OF SCIENTISTS, supported in part by the National Cancer Institute (NCI), found changes that were similar between the nose and lung samples of patients with lung cancer.

Studies have shown that the activity of certain genes of lung cells of current or former smokers can distinguish people with lung cancer from people with benign (noncancerous) lung tumors. However, collecting lung cell samples is an invasive procedure.

These new findings suggest that smoking may cause similar genetic changes throughout the entire airway, which means that there may be a noninvasive way to screen for lung cancer (through swabbing the nose, as opposed to the lung, for cells).


CHATTER

“Somewhere, something incredible is waiting to be known.”

CARL SAGAN
An Inside Look

**EVER WANT TO** pick the brain of NIH Director Francis Collins, M.D., Ph.D.? Look no further than the NIH Director’s Blog. Dr. Collins pens multiple updates a month on topics ranging from new findings to featured researchers and NIH events. Check out directorsblog.nih.gov, where you can subscribe to the blog’s RSS feed, and also be sure to follow Dr. Collins on Twitter at @NIHDirector.

The Beautiful Brain

**NIH’S YOUTUBE CHANNEL**, NIHOD, recently featured a data visualization of a magnetic resonance imaging (MRI) scan of the human brain. An MRI is a medical imaging procedure used to help examine the inside of the human body. This eye-catching video shows greater detail of the hippocampus, a brain region that helps you create new memories. The data visualization helps researchers map out entire brainwide circuits, and provides a new, cool way to look at the human brain.

Medical Research 101

**NEW RESEARCH** findings can be hard to understand and evaluate, especially with so many coming out so often. In addition to their 1,000 health topic pages, medlineplus.gov features a dedicated resource page on evaluating medical research and findings. The info, including a list of helpful questions and a video, can help you identify trusted findings and better understand results.

A Peek into the Past

**EVER WONDERED** about important dates in NIH’s history? The NIH Almanac timeline goes all the way back to the 1800s and includes important dates throughout NIH’s history.

What happened 80 years ago this month? The National Cancer Institute Act was signed into law by President Franklin Delano Roosevelt on July 23, 1937, establishing the National Cancer Institute (NCI) as part of NIH.
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.

Institutes
National Library of Medicine (NLM)
www.nlm.nih.gov
888-FIND-NLM 888-346-3656
National Cancer Institute (NCI)
www.cancer.gov
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Office of Behavioral and Social Sciences Research (OBSSR)
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301-402-1146
Office of Rare Diseases Research (ORDR)
www.rarediseases.info.nih.gov
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