

NIH MedlinePlus

Trusted Health
Information from the
National Institutes
of Health

MAGAZINE

IN THIS ISSUE

NIH program to prevent
childhood obesity

CNN's John King isn't letting
MS slow him down

Multisystem inflammatory
syndrome in children

Kathy Bates is figuring
out how to live with
lymphedema



Meet NIH Directors
Dr. Jon R. Lorsch, Ph.D., from NIGMS
Dr. Nora Volkow, M.D., from NIDA

COVER STORY

Fitness trainer and
entrepreneur **Cassey Ho**
shares advice on how to
maintain a balanced and
healthy lifestyle

FITNESS AND WELLNESS

In this issue

WELCOME TO THE SPRING 2022 ISSUE OF NIH MEDLINEPLUS MAGAZINE.

This issue features information from NIH on fitness and wellness including an interview with social media fitness trainer and entrepreneur Cassey Ho.

Cassey talks with us about fitness and nutrition as the keys to a balanced, healthy lifestyle and speaks about the importance of having a healthy body image. She also shares advice for improving fitness and overall wellness.

Also in this issue, CNN's John King talked with us about his experience living with multiple sclerosis, which is a chronic disease that affects the central nervous system. In this article you can find out more about his journey and why he's decided to speak out 13 years after his diagnosis.

In 2016, award-winning actress Kathy Bates was featured in the magazine and shared her experience with lymphedema following breast cancer surgery. We catch up with her to learn more about her lymphedema journey and where she is today.

In this issue we also kick off our new "Meet the Director" series in which we feature interviews with directors from across NIH. This quarter we sat down



with Jon Lorsch, Ph.D., from the National Institute of General Medical Sciences and Nora Volkow, M.D., from the National Institute of Drug Abuse.

Have you or someone you know been experiencing lasting COVID-19 symptoms? We explain in this issue what we know about long COVID, which is a collection of symptoms and health problems that some people experience for weeks or even months after the initial COVID-19 infection is over.

Are you a new parent? We would like to introduce you to responsive feeding, which is a practice that helps parents establish healthy eating patterns in their children from an early age. MedlinePlus magazine sat down with NIH-funded researchers to learn more! ■

NIH MedlinePlus MAGAZINE

WHO WE ARE

The National Institutes of Health (NIH) is the **nation's premier medical research agency**, with 27 different institutes and centers. The National Library of Medicine (NLM) at NIH is a leader in biomedical informatics and data science research and the world's largest medical library.

NLM provides **free, trusted health information** to you at medlineplus.gov and in this magazine. Visit us at magazine.medlineplus.gov

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inside

SPRING 2022
Volume 17
Number 1



Fitness trainer and entrepreneur Cassey Ho shares advice on how to maintain a balanced and healthy lifestyle.

FEATURES

06 Cassey Ho is staying fit while loving herself

The social media fitness entrepreneur talks about the importance of loving your body and keeping healthy

12 The long haul: When COVID-19 symptoms don't go away

Some patients struggle with brain fog, fatigue, headaches, dizziness, and trouble breathing for months after initial infection

18 CNN's John King isn't letting multiple sclerosis slow him down

The long-time news anchor talks about dealing with his disease through the pandemic

22 Preventing childhood obesity

Program for first-time parents promotes healthy growth in firstborn babies and their siblings

DEPARTMENTS

04 NIH on the web

Find it all in one place!

Meet the directors

Dr. Jon R. Lorsch, Ph.D., NIGMS, p. 20

Dr. Nora Volkow, M.D., NIDA, p. 32

34 Tech in medicine

Learn about new technologies

37 Contact us

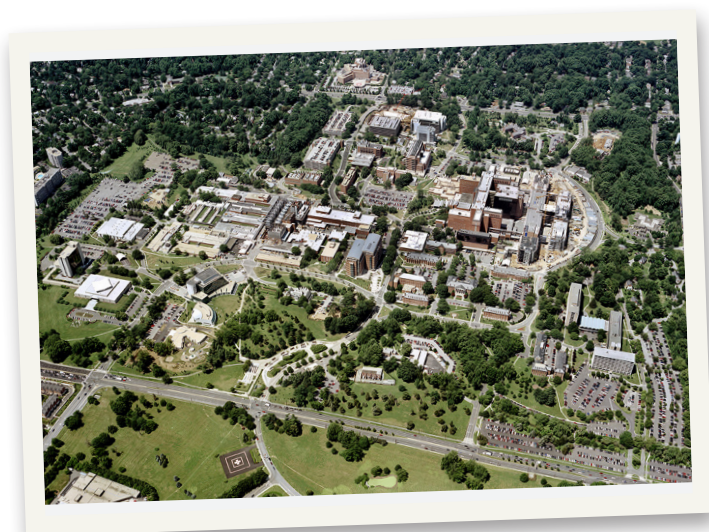
NIH is here to help



Kathy Bates is figuring out how to live with lymphedema.

26

NIH on the web



Can you find your way around the National Institutes of health?

➡ A RESOURCE FROM THE NATIONAL LIBRARY OF MEDICINE

asks just that question. Developed as an activity for the 7th Annual Science Day for Students at NIH, “Virtual Escape Room: An Intern’s First Day at NIH” introduces users to various NIH institutes, centers, and key figures.

To get through the escape room, you’ll have to find secret codes and messages hidden among NIH resources like the National Library of Medicine’s digital gallery of women physicians. Learn more about NIH’s campus and research as well as NIH leaders’ musical talents.

You can enter the virtual escape room on-demand here: <https://www.nlm.nih.gov/oet/exhibits/virtualescaperoom/ver-welcome>.

Find it all in one place!

magazine.medlineplus.gov/otw



MedlinePlus healthy recipes: Bell pepper nachos

Prep time: 5 minutes

Cook time: 15 minutes

Total time: 20 minutes

Number of servings: 8

INGREDIENTS

- 4 bell peppers
- 1 cup salsa
- 2 teaspoons seasoning (try a mixture-chili powder, garlic powder, ground cumin, pepper)
- 2 cups cooked meat (chopped or shredded), beans or tofu
- 1 cup reduced fat shredded cheese

DIRECTIONS

1. Preheat oven to 350 °F.
2. Wash bell peppers, remove seeds and cut into bite-sized pieces. Arrange pieces close together in a single layer on a large foil-lined baking sheet.
3. In a medium bowl, combine salsa, seasonings and meat, beans or tofu. Spoon the mixture evenly over pepper pieces then top with cheese.
4. Bake for 15 minutes, or until peppers are heated through and cheese is melted. Serve warm.
5. Refrigerate leftovers within 2 hours.

NOTES

- For added flavor, top with chopped cilantro, green onions or black olives!

Find more healthy recipes online at [MedlinePlus Healthy Recipes](https://www.nlm.nih.gov/medlineplus/healthyrecipes/).



Find clinical studies on the updated ClinicalTrials.gov

➔ **INTERESTED IN LEARNING** about clinical trials? Want to find research that's happening on a specific health topic? On ClinicalTrials.gov you can do all that and more! It's an online database from the National Library of Medicine that has current, up-to-date information about more than 400,000 research studies from all over the world.

ClinicalTrials.gov is free to use and doesn't collect any personal information. Anyone can access it online from a computer or mobile phone. You can find information about specific research studies that are happening now, will happen soon, or have happened in the past, including:

- The study name and its purpose
- Who is conducting the study
- When and where it's happening
- Who can join and how to get involved
- What researchers learned (the study results)

New updates will make it easier to find and learn about the studies that are relevant to you and the people in your life. The updated ClinicalTrials.gov website will include a new, more modern look and user-friendly features, like:

- **Improved search and new filters** to help you find the right information
- **Plain language information** about clinical research that's clear and easy to understand
- **A responsive web experience** that adjusts web pages automatically to fit different screen sizes

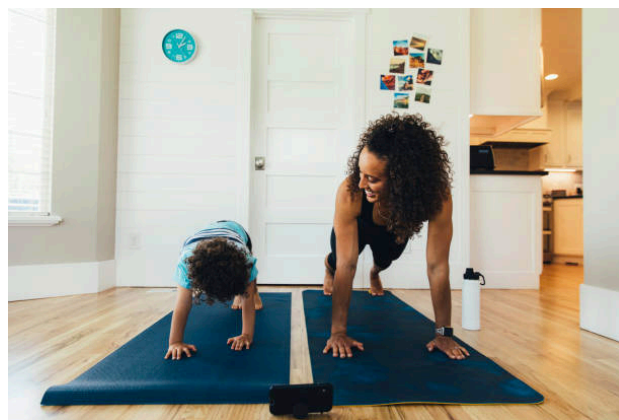
The updated site hasn't officially released, but you can try it out by visiting Beta.ClinicalTrials.gov. The ClinicalTrials.gov team plans to keep adding new features, based on feedback from users like you.

Yoga for Health: Learn about the science and practice of yoga

➔ **CURIOUS ABOUT THE EFFECTS OF YOGA** on physical and mental well-being? Find out about the science of yoga with [Yoga for Health](#), a free downloadable e-book from the [National Center for Complementary and Integrative Health](#) (NCCIH).

Yoga is an ancient practice with modern benefits. More Americans than ever before are practicing yoga for their health and well-being. With NCCIH's [Yoga for Health](#), you can learn about the practice of yoga.

Yoga combines physical postures with breathing techniques and relaxation or meditation, which research shows can promote physical and mental health in people of all ages and backgrounds. You'll find specific information about yoga for children, older adults, pregnant people, and people with health conditions, as well as tips for practicing yoga safely (such as discussing your health needs with your doctor and yoga instructor before starting a new program).



Learn what science says about yoga in the free downloadable e-book.

Cassey Ho

is staying fit while loving herself

The social media fitness entrepreneur talks about the importance of loving your body and keeping healthy.

Fitness trainer and entrepreneur Cassey Ho has won a large audience through her online fitness videos and social media presence. She sees fitness and nutrition as the keys to a balanced and healthy lifestyle. She is also outspoken about the importance of having a healthy, positive body image. Cassey spoke to NIH MedlinePlus magazine about her work and shared advice for others looking to improve their fitness and overall wellness.

Research has clearly shown that regular exercise has many health benefits. How do you view the relationship between physical fitness and overall health and well-being?

Fitness is all about building mental, emotional, and physical strength. When you're able to find the joy in your daily movement—like finding a workout that makes you smile—that is when you will find consistency. And guess what? Consistency is the key to seeing real changes in your body and your life.

What's your take on individual differences when it comes to having a healthy, balanced lifestyle?

Everyone is different. We each have a different genetic makeup, we come from different ethnicities, and we have different needs and wants. So how can we possibly be prescribed the same eating plan and workout regimen? It is important to understand that what works for one person may not work for another. It took me many years to finally realize that.



IMAGE: COURTESY OF CASSEY HO

“Trying something new and failing? That’s the ultimate gift. Why? Because you become your strongest self when you have to get up and try again.”

For a long time, I would compare my body to others and get frustrated that someone could eat burgers and pizza all day and have six-pack abs while I would consistently eat salads and still have a soft belly. Understanding that not all bodies are created equal helped me find peace with my body instead of always fighting it.

Why is it important to be willing to try new things?

I love feeling challenged. If I am not working towards a goal, learning a new skill, solving a problem, or just doing something outside my comfort zone, then I feel stagnant. New experiences allow you to find out new things about yourself, and that is such a gift! Trying something new and failing? That’s the ultimate gift. Why? Because you become your strongest self when you have to get up and try again.

What is your advice to someone who is just getting started or thinking about getting started?

It’s always nice to follow a calendar or routine of some sort, as it takes the thinking and decision-making out of doing a hard thing. I schedule time in my calendar for my workout. It gets the same importance and urgency as an event, a meeting, an appointment, or a date because it is a commitment to myself, my health, and my happiness. Try to find someone to do it with you, someone to keep you accountable.

A lot of your fitness focus has been on Pilates. What is it and what do you like most about it?

Pilates is a low-impact, mind-body exercise that focuses on strengthening your muscles while improving flexibility through beautiful, graceful, controlled movements. What I love most about it is that it feels like a dance on the mat and can be done without any equipment.

How do you think about food and healthy eating as part of a healthy, balanced lifestyle?

Food is fuel. If you don’t give your body the food and beverages to help you meet your goals, you may not feel energized enough for an intense cardio routine or be able to build the muscle you want in your weightlifting regimen. I like to keep a food journal so I can take notes on what foods make me feel good and those that do not work for me.

What are some ways to stay motivated with good exercise and nutrition habits?

Ask yourself why: “Why am I doing this?” If you have a strong “why,” it will take you through the toughest of times. This works for anything in life.

What is your message to others about the importance of maintaining a positive body image?

The way your body looks in the mirror does not determine your worth. Same thing with the number on the scale. Your body is simply a vessel for you to carry out all the amazing things you are meant to do on this earth. Focus on reaching your potential, following your passion, and letting your body be your body, not your obsession. ■



Cassey Ho and her husband, Sam Livits, enjoy a healthy meal.

Physical fitness and nutrition: Know your terms



Make the most of your exercise and eat a healthy and balanced diet.

Staying healthy includes exercising, eating nutritious food, getting enough sleep, and caring for your overall well-being. Understanding these terms can help you make the most of your exercise routine and eat a healthy and balanced diet. Always consult your doctor before beginning any exercise program.

Physical activity terms

Physical activity is any body movement that works your muscles and takes more energy than resting. Walking, running, dancing, swimming, yoga, and gardening are a few examples of physical activity.

- **Aerobic exercise** is activity that requires moving your large muscles, such as those in your arms and legs. It makes you breathe harder and makes your heart beat faster than usual. Over time, regular aerobic activity makes your heart and lungs stronger. Running, swimming, walking, and biking are a few examples of aerobic exercise.
- **Flexibility training** is exercise that stretches and lengthens your muscles. It can improve your joints and muscle flexibility, which can

help prevent injuries. Some examples are yoga, tai chi, and Pilates.

- **Resistance/strength training** is exercise that firms and tones your muscles. It can improve your bone strength, balance, and coordination. Some examples are push-ups, lunges, and bicep curls.
- **Warm-ups** are exercises or movements that get your body and muscles ready to be physically active—for example, walking or jogging for 5 to 10 minutes before a run.
- **Cool-downs** are light activities that help your body relax and recover after you've been physically active—for example, slowing down gradually at the end of a workout or switching to a less-intense activity for a few minutes.

Heart rate (or pulse) is the number of times your heart beats in a certain amount of time—usually a minute. The typical resting heart rate for an adult is 60 to 100 beats per minute.

- **Maximum heart rate** is the fastest your heart can healthily beat based on your age.
- **Target heart rate** is how fast your heart should beat when you exercise based on your age. Your target heart rate should be about 50–75% of your maximum heart rate.

Perspiration (sweat) is a clear, salty liquid produced by glands in your skin. Sweat evaporates when it hits the air, which cools your body down.

Nutrition terms

Food and drinks provide the energy and nutrients you need to be healthy. Nutrients include proteins, carbohydrates, fats, vitamins, minerals, and water.

Basal metabolic rate is the number of calories your body needs to maintain basic functions such as breathing, heart rate, and digestion.

Body mass index (BMI) is an estimate of your body fat percentage based on your height and weight. BMI is a tool for screening for weight categories that are associated with health concerns such as heart disease.

Blood glucose is the main sugar found in your blood. It is a source of energy for your body, including your cells, tissues, and organs. During the digestion process, carbohydrates break down, releasing glucose. A hormone called insulin regulates glucose and moves it through the body.

Calories are a unit of energy in food. Calories come from carbohydrates, fats, protein, and alcohol in food and drinks.

Carbohydrates are sugar molecules and one of the main types of nutrients in food and drinks. Your body breaks carbohydrates down into glucose.

- **Dietary fiber** is a type of complex carbohydrate that's important for gut health. Fiber is found in plants like fruits, vegetables, and whole grains. Fiber makes you feel full faster and for a longer time. It also helps to lower cholesterol levels and can prevent constipation.

- **Sugar** is a type of simple carbohydrate that tastes sweet. Your digestive system breaks down sugar into glucose, and your cells use the glucose for energy. Sugars can be found naturally in fruits, vegetables, milk, and milk products. They are also added to many foods and drinks during preparation or processing. Foods with added sugars have lots of calories but few nutrients, so aim to only eat these foods in moderation.



Simple carbohydrates are found in food and beverages like table sugar, fruits, and milk and in processed foods like candy and soda.



Complex carbohydrates include whole grain breads and cereals, vegetables, beans, and foods that are high in fiber.

Cholesterol is a waxy, fat-like substance that's found in all the cells in your body. Your body needs the right amounts of cholesterol to stay healthy. Your body makes all the cholesterol it needs, but there's also cholesterol in foods that come from animals. High levels of cholesterol in the blood can increase your risk of heart disease.

- **HDL** stands for high-density lipoproteins. It is also known as "good" cholesterol. HDL carries cholesterol from other parts of your body to your liver, where it can be flushed out of your body. Foods that contain healthy fats, such as fish oils, avocados, and nuts, can increase HDL cholesterol.
- **LDL** stands for low-density lipoproteins. It is also known as "bad" cholesterol. Too much LDL causes plaque (fatty deposits) to build up in your blood vessels, which can cause health problems. Foods that contain trans fats, saturated fats, and cholesterol can increase LDL.

Dietary fats are a type of nutrient. You need a certain amount of fat in your diet—but not too much—to stay healthy. Fats give you energy, insulate your body to help keep you warm, and help your body absorb vitamins. Fat stored in the body can also be used for energy. Dietary fat also plays a major role in your cholesterol levels. Not all fats are the same, but they all have the same number of calories per serving.

- **Saturated fat** is a type of dietary fat that is found in animal products and some oils, including dairy products (like butter, cheese, and cream), coconut and palm oils, and some meats. Saturated fatty acids can raise blood cholesterol and the risk of heart disease.
- **Monounsaturated fat** is a type of healthy dietary fat that is found in avocados, canola oil, nuts, olives and olive oil, and seeds. Replacing saturated fats with monounsaturated fats may help lower cholesterol and reduce the risk of heart disease.
- **Polyunsaturated fat** is a type of healthy dietary fat that is found in plant and animal foods such as salmon, vegetable oils, and some nuts and seeds. You need polyunsaturated fatty acids for proper brain function and cell growth, but since our bodies don't make them, you need to get them from other sources.
- **Trans fat** is a type of dietary fat that is created when liquid oils like shortening are changed into solid fat. It may be found in crackers, cookies, and snack foods. Trans fat raises your LDL (bad) cholesterol and lowers your HDL (good) cholesterol.

Digestion is the process your body uses to break down food into nutrients. Your body uses these nutrients for energy, growth, and cell repair.

Electrolytes are minerals in your body—like sodium, magnesium, and chloride—that you get from the food you eat and the fluids you drink. When you are dehydrated, your body does not have enough fluid, nor does it have enough electrolytes.

- **Sodium** is a mineral that helps your nerves and muscles function properly and keeps the right balance of fluids in your body. Table salt is a sodium

compound made up of the minerals sodium and chloride. Diets high in sodium can raise your blood pressure.

Energy balance is the balance between the calories you get from eating and drinking (energy you take in) and the calories you use up through activity, growth, and daily living (energy you burn).

Glycemic index is a measure of how a carbohydrate-containing food raises your blood sugar.

Metabolism is the process that your body uses to get or make energy from the food you eat.

Protein is in every living cell in the body. Your body needs it to build and maintain bones, muscles, organs, skin, blood, and immune cells. Your body doesn't store protein, so you need to get it from the foods you eat, like meat, dairy products, nuts, and certain grains and beans.

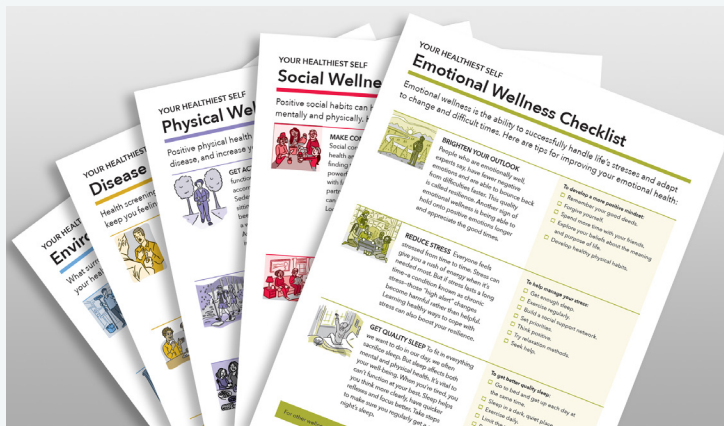
- **Amino acids** are the molecules that make up protein. Some amino acids are made by the body, and others come from food. It's important to get a balance of amino acids every day.

Triglycerides are a type of fat found in your blood. Your body makes triglycerides or gets them from the foods you eat and from broken-down, stored body fat. High levels of triglycerides may increase your risk of heart disease and stroke.

Water intake is the amount of water we all need to drink. How much you need depends on your body type, your activity level, and the weather where you live. Your intake includes fluids that you drink and fluids that you get from food. ■



Make the most of your exercise and eat a healthy and balanced diet.



Improve your well-being with NIH's *Your Healthiest Self: Wellness Toolkits*

Become your healthiest self with NIH's Wellness Toolkits

When you want to become the best version of yourself but aren't sure where to start

There's a lot of information out there about the best ways to stay healthy, but health and wellness mean different things to different people. We each come from diverse backgrounds and have different minds, bodies, relationships, and living situations, so it makes sense that we all have different health needs.

NIH's [Your Healthiest Self: Wellness Toolkits](#), available in English and Spanish, have evidence-based tips and resources to help you improve your well-being in different areas. Well-being includes your physical, emotional, and social health; your relationships; and the environments where you live, work, and play.

Looking to improve your physical health? Check out the [Physical Wellness Toolkit](#) for tips on:

- Getting active
- Building muscle
- Finding and staying at a healthy weight
- Eating a healthy diet
- Building healthy habits
- Keeping your metabolism healthy as you age

Need support with a different area of your health? NIH has you covered with toolkits to help you:

- [Stay safe and healthy in different environments](#)
- [Support your emotional health](#)
- [Develop and maintain strong relationships](#)
- [Prevent disease](#)

Your “healthiest self” will look a little different from that of others in your life. With NIH's *Your Healthiest Self: Wellness Toolkits*, you can focus on what's most important to you right now.

The long haul: When COVID-19 symptoms don't go away

While most people who get COVID-19 bounce back after a few weeks, some struggle with symptoms and health problems like brain fog, fatigue, headaches, dizziness, and trouble breathing, even months after the initial infection is over.

**This article is an update to the original article, published on July 6, 2021. It was updated on July 2022 to reflect new information.*

Doctors and scientists are working to understand these mysterious symptoms, sometimes called “long COVID.” Who gets them? Why? How long do they usually last? To help answer these questions and more, NIH is funding research on the long-term health effects of COVID-19, including long COVID and other post-COVID conditions.

What is long COVID?

The term “long COVID” is commonly used to describe a collection of symptoms and health problems that some people who had COVID-19 experience after the initial infection is over.

There are a few different terms to describe long-term health effects of COVID-19. Long COVID is one, but you may also hear terms like “post-COVID syndrome,” “post-COVID conditions,” “chronic COVID,” or “post-acute sequelae of SARS-CoV-2 (PASC).” People with long COVID are sometimes called “long-haulers.”

What causes long COVID?

It's not clear what specific biological process causes long COVID, but researchers have uncovered a few clues that could shed light on this mysterious condition.

One clue is the way that different people's immune systems respond to COVID-19 infection. Research shows that people with the most severe COVID-19 symptoms and people with long COVID are more likely to have higher levels of harmful antibodies called “autoantibodies.” Autoantibodies are proteins in the immune system that attack and damage healthy tissue, and they are involved in many autoimmune diseases.

There may be multiple causes of long COVID, which could help explain the wide range of symptoms. Some of the current theories are:

- **Autoimmune response.** A healthy immune system helps protect us by fighting a virus or infection. Sometimes it mistakenly attacks healthy cells, tissues, and organs. This is called an “autoimmune response,” and it's what happens in autoimmune diseases like lupus, multiple sclerosis, and rheumatoid arthritis. The COVID-19 virus may stress the immune system so much that it triggers an extreme autoimmune response that

continues after the patient has recovered from the initial infection.

- **Persistent virus.** The virus could hide and continue to multiply in the body for months or even years. This means it doesn't immediately cause symptoms and isn't necessarily infectious, but it could cause symptoms down the road.
- **Dormant virus.** Long COVID could be symptoms of a completely different dormant (or inactive) virus like the Epstein-Barr virus, the virus which causes mononucleosis, or “mono.” This theory proposes that COVID-19 infection could reactivate—or wake up—the dormant virus.
- **Organ damage.** COVID-19 may cause long-term damage to the body's organs or blood vessels, which may cause long COVID symptoms.

Who can get it?

Current estimates on how common long COVID is among people who have had COVID-19 vary widely. Researchers are working to better understand who is most likely to experience long-term complications from COVID-19, but research on who gets long COVID is also mixed and complex. People who had severe cases of COVID-19 seem more likely to get long COVID—especially if they were hospitalized or admitted to an intensive care unit. But some people with long COVID didn't have any symptoms from COVID-19 or only had mild or moderate symptoms.

Other groups who may be at greater risk include women, African Americans, people who had certain health issues before getting COVID-19, and people who did not get a COVID-19 vaccine.

How is it diagnosed and treated?

There isn't a specific test for diagnosing long COVID. If you are experiencing long COVID symptoms, you should talk to your doctor. If you know you've had COVID-19 in the past, you and your doctor can work together to rule out other possible causes for your symptoms.

Until we know more about the biological processes behind long COVID, treatment for people with long COVID focuses on managing individual symptoms.

How is it being studied?

In December 2020, Congress approved \$1.15 billion in funding over four years for NIH research into long COVID and other long-term health effects of COVID-19.

In February 2021, NIH launched a new program to identify the risk factors and causes of long COVID and to help understand how it can be prevented or treated.

Want to get involved?

There are lots of ways you can contribute to long COVID research. You can:

- **Connect with the RECOVER Initiative.** The [NIH RECOVER Initiative](#) brings together research teams, people with long COVID, caregivers, clinicians, and community leaders. They are working on multiple studies at different sites across the nation to better understand, prevent, and treat long COVID and other post-COVID-19 conditions in adults and children [Find a RECOVER study site and join a study.](#)

- **Learn about patient-led research.** [The Patient-led Research Collaborative](#) is a group of citizen scientists and researchers, many of whom also have long COVID. This group is conducting research to define and better understand the long-term effects of COVID-19, with a strong focus on the patient experience.
- **Join a clinical trial.** Go to [ClinicalTrials.gov](#) to find out about [long COVID studies happening around the world](#) and sign up to participate.
- **Join a study at the NIH Clinical Center.** Learn about how to get involved in [COVID-19 studies happening at NIH.](#) ■

Long COVID can be considered a disability under the Americans with Disabilities Act (ADA).
Find out more at [HHS.gov](#).

SOURCE: Department of Health and Human Services

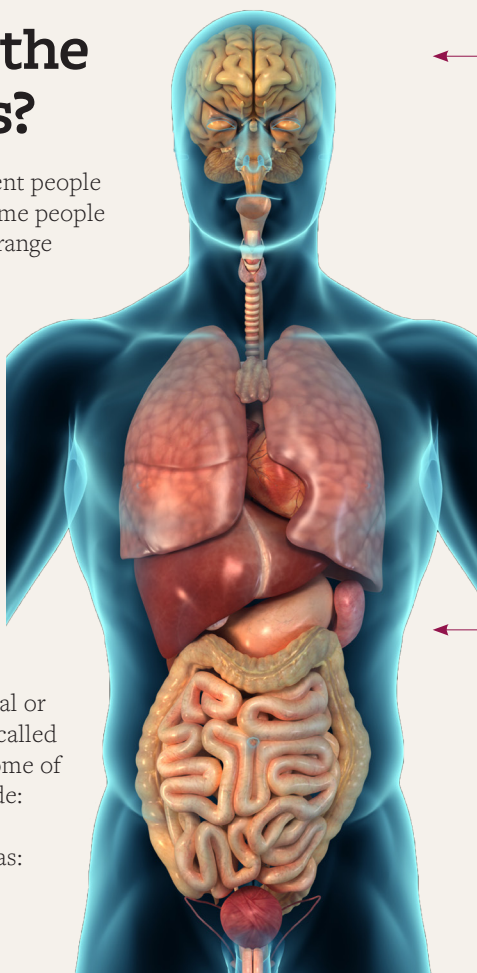
What are the symptoms?

Long COVID affects different people in different ways. While some people with long COVID notice strange symptoms when they first start recovering from COVID-19, others don't notice anything is wrong until well after the infection has cleared.

People have reported a wide range of symptoms that impact their ability to move and think, as well as their mood. The symptoms often get worse after doing mental or physical work, sometimes called post-exertional malaise. Some of these symptoms can include:

General symptoms such as:

- Fever
- Fatigue
- Joint or muscle pain



Neurological symptoms (related to the brain and nervous system) such as:

- Difficulty thinking or concentrating (sometimes called brain fog)
- Headaches
- Sleep problems
- Anxiety and depression
- Dizziness or lightheadedness upon standing up

Breathing and heart-related symptoms such as:

- Trouble breathing
- Cough
- Chest pain
- Pounding heart

Digestive symptoms such as:

- Stomach pain
- Diarrhea

Symptoms can last for weeks or even months after COVID infection. They can range from relatively mild to severe, and they can change, disappear, and reappear over time.



Multisystem inflammatory syndrome in children

Most children who get infected with the virus that causes COVID-19 have mild or no symptoms and some may also experience severe illness, especially if they have underlying medical conditions. A very small group of these kids go on to develop a serious set of symptoms—an extremely rare condition called multisystem inflammatory syndrome in children, or MIS-C. NIH-funded researchers are working to learn more about this condition, including how it differs from other diseases and COVID-related complications like long COVID and the best ways to diagnose and treat it.

What is multisystem inflammatory syndrome?

Multisystem inflammatory syndrome (MIS) is a set of symptoms associated with an extreme immune response to COVID-19. It causes inflammation in multiple organs, including the heart, lungs, kidneys, brain, stomach, and intestines. It's a very rare condition—only 2 out of 100,000 children develop it—but it's serious and can be deadly.

What are the symptoms?

Children with MIS-C usually experience their first symptoms a few weeks after getting COVID-19. The most common symptoms are inflammation in more than two organs and a high fever (more than 100.4 degrees Fahrenheit) for 24 hours or longer. Other symptoms can include:

- Diarrhea, vomiting, or stomach pain
- Skin rash
- Bloodshot (red) eyes
- Dizziness or lightheadedness, which are signs of low blood pressure

If a child has any of these symptoms, they need emergency medical care right away:

- Trouble breathing
- Pain or pressure in the chest that doesn't go away
- Confusion or unusual behavior
- Severe pain in the abdomen (stomach area)
- Inability to wake up or stay awake
- Discolored lips, skin, or nail beds (pale, blue, or gray depending on skin tone)

Who can get it?

Although there have been cases in adults and teenagers, most people who get MIS-C are children between ages 1 and 15. Boys are slightly more likely to get MIS-C than girls, and it seems to disproportionately affect Black and Hispanic/Latino children.

Multisystem inflammatory syndrome in adults is called MIS-A. It also causes inflammation in different organs, but it's even less common than MIS-C.

What's the best way to prevent MIS-C?

The best way to keep children safe from MIS-C is to protect them from getting infected with the virus that causes COVID-19. Getting vaccinated is the most effective way to prevent COVID-19 and MIS-C, and vaccines are currently available for children ages 6 months and older. Research shows that vaccines are safe for kids who have already had MIS-C, and everyone who is eligible should get vaccinated. Other steps you and your child can take are:

- Wearing masks in public
- Staying away from people who are sick
- Practicing social distancing
- Avoiding touching your eyes, nose, and mouth

How is MIS-C being studied?

Researchers across NIH are collaborating on research to determine how the COVID-19 virus behaves in children and how it can lead to long-term conditions like long COVID and MIS-C.

The CARING for Children with COVID Initiative.

The [Collaboration to Assess Risk and Identify Long-term Outcomes \(CARING\) for Children with COVID study](#) is led by the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) and the National Heart, Lung, and Blood Institute (NHLBI), in collaboration with the National Institute of Allergy and Infectious Diseases (NIAID). Research studies at multiple sites across the country aim to answer important questions like:

- Which children are most likely to get COVID-19 and why?
- Why is there such a range of symptoms in kids who get COVID-19?
- Which children who get COVID-19 are most likely to develop conditions like MIS-C?
- What are the best ways to treat these conditions in children?

The COVID MUSIC Study. The [Long-term Outcomes after the Multisystem Inflammatory Syndrome In Children \(MUSIC\) study](#) is looking at how MIS-C affects children's health—both in the short term and over time. This study, which is happening through the NHLBI-funded [Pediatric Heart Network](#), is taking place at multiple hospitals and

medical centers across the country and has recruited more than 1,200 children and adolescents in little more than a year. The study has a specific focus on health disparities (when certain groups of people have worse health outcomes than others) and aims to:

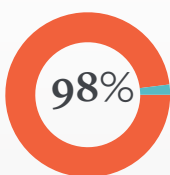
- Learn how MIS-C affects children's organs over the long term
- Improve treatment and care for people with MIS-C and other similar conditions
- Understand who gets MIS-C and why

PreVAIL kIds. [Predicting Viral-associated Inflammatory Disease Severity in Children with Laboratory Diagnostics and Artificial Intelligence \(PreVAIL kIds\)](#) is a study being led by NICHD as part of NIH's [Rapid Acceleration of Diagnostics \(RADx\)](#) initiative. Its goal is to develop innovative approaches to understanding the underlying factors that influence the spectrum of conditions that may occur in children infected with the COVID-19 virus. The study explores which factors in a child's genes, immune system, and environment can affect:

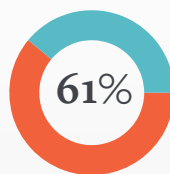
- Who gets COVID-19
- How severe their symptoms are
- Who goes on to develop severe COVID-19 and MIS-C

Visit ClinicalTrials.gov to find more [clinical research studies about MIS-C](#). ■

MIS-C: By the numbers



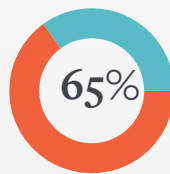
Out of all MIS-C patients, **98% tested positive for the COVID-19 virus.**



61% of MIS-C patients **are male.**



90% of MIS-C patients are between ages **1 and 15.**



Of all reported MIS-C cases, **65% have been in non-white children**, and children who are Black (non-Hispanic), and Hispanic/Latino are disproportionately affected.

SOURCE: Centers for Disease Control and Prevention

Navigating long COVID

Mark Elliott was vaccinated and boosted when he was exposed to COVID-19. A year later, he's still struggling with long COVID symptoms.

Mark Elliott, Ph.D., is a 66-year-old associate professor in the department of biochemistry and molecular medicine at George Washington University who has been struggling with long COVID for the past year. Long COVID occurs when someone infected with COVID-19 has symptoms that last for months or years. There can be a wide range of symptoms, which can include fatigue, brain fog, and respiratory issues.

Though Mark has been able to manage some of his symptoms by working with his health care providers, treatments for other ailments—particularly brain fog—remain elusive. Mark chatted with MedlinePlus magazine about his experience.

When did you first test positive for COVID-19?

I actually never tested positive. I was exposed to COVID-19 in August 2021 and started having minor symptoms shortly after that—just coughing and

respiratory issues for about a week. Within five days, my wife got it, and her symptoms were worse. We isolated and stayed home, but even though we took tests, neither of us tested positive. So many people with long COVID never actually have a positive test. I had been vaccinated and boosted before I got sick.

It sounds like your COVID-19 experience was fairly mild. When did you first start to feel like something was off?

About four weeks after getting sick. I was getting better, then one day I woke up and I could barely stand up; I could barely walk. I was in such

extreme pain that I was almost crying. But if I walked more than 50 yards, it started to loosen up. So I'd go to class, I'd give my lecture, and I'd be completely capable of doing that. Within two to three hours, though, the pain would come back, and I would be a complete basket case.

In the year before he died at 93, my dad had severe mobility issues. I suddenly felt like my dad, and I kept thinking, "Am I really that old? I should still be able to move, should still be able to cut the yard."

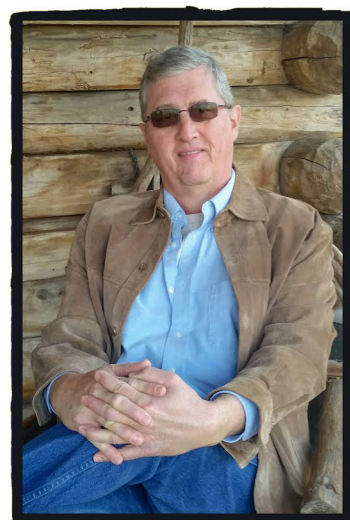
When did you decide to seek care?

I called my primary care physician after three days of this pain. He initially told me to do Tai Chi. Which is cool, but if I can't get out of a chair and walk, that's not going to work. After two weeks, I called my primary care doctor back, and he started me on a 10-day course of steroids. The second they gave me prednisone, everything went back to normal. But it was only a 10-day course, and once I was done with the steroids, everything hurt again and I couldn't move.

It took another five weeks to get an appointment with a rheumatologist. I was diagnosed with polymyalgia rheumatica, which is a type of arthritis. I have no history of that disease or any kind of autoimmune disease in my family, so I thought it was weird. My wife went into NIH's PubMed and found a number of articles that show respiratory viruses can trigger reactive arthritis, and there was a case study that suggested COVID-19 could also do that.

How different is your current state compared to your prior health?

I've had two knee replacements and one shoulder replacement from



Mark was able to treat some of his long COVID symptoms but still deals with severe brain fog.

years of football and basketball, but otherwise, I had no health issues.

Now I'm taking a few drugs to treat my long COVID symptoms. I have to keep an eye on the side effects, but they are helping dramatically. As long as I'm on my regimen of drugs, my pain management and physical lifestyle are just fine. But it took months to get here.

Where I'm struggling is with my brain fog, which started with the COVID-19 and never really went away. I'll be in the middle of a class giving a lecture I've given many times, and I'll just get lost right there in the middle of a sentence. I finally had to stop class because I was staggering and stammering. I said, "Look, kids, this is what's going on." Remembering the simplest of things can be hard—like, right now, there's a complete mental block on what my next-door neighbor's wife's name is.

How have you learned to cope with that?

I've appreciated my students' patience and their willingness to help play the brain-fog game. I'll be in the middle of a sentence, and I'll forget where I was going. I'll look at the class, and they'll remind me, and then we go on together. It's been a nice team-building effort on their part. ■



Multiple sclerosis: What you need to know

What is it?

Multiple sclerosis (MS) is a nervous system disease that affects the brain, optic nerve (which helps you see), and spinal cord. The immune system attacks myelin—the coating on nerve fibers—and makes it harder for those cells to send signals across the body. The exact cause of MS is unknown, but it's linked to a number of infectious diseases like the Epstein-Barr virus, which can cause the disease commonly experienced by teenagers or young adults known as mononucleosis or mono. Environmental factors like low levels of vitamin D and genetic factors also play a role. People typically experience their first symptoms between ages 20 and 40.

Symptoms of an MS attack develop and peak within a few days, and then slowly resolve over the next several days or weeks. In the early stages of the disease, symptom attacks happen about once a year. As the disease progresses, symptoms can arrive more frequently and resolve less completely. MS is different for everyone, and in its most severe forms it can impair walking or standing, and it can even lead to partial or complete inability to move.

Symptoms and diagnosis

Different people have different experiences with MS. Some cases can be less severe, and others can be disabling. Symptoms can include:

- Double vision
- Blurred vision or blindness in one eye
- Colors looking different
- Muscle weakness
- Dizziness
- Difficulty with balance
- Numbness, prickling, or a “pins and needles” sensation
- Pain
- Tremors

Many people experience mental symptoms as well, such as:

- Difficulty speaking
- Impaired concentration, attention, and memory
- Depression

Because MS has so many different symptoms, it can be difficult to diagnose. People with MS might be diagnosed soon after developing

symptoms, while others might spend years with confusing symptoms and multiple diagnoses. An MRI to look for scars in the brain and spine can help medical professionals make an accurate diagnosis.

Treatment

There is currently no cure for MS. Treatment plans depend on the severity of the disease and can include:

- Steroids to improve symptoms of an attack
- FDA-approved drugs that reduce the number of relapses, change how the body responds to inflammation, and improve mobility
- Muscle relaxants and tranquilizers that reduce stiffness
- Drugs that decrease fatigue ■

By the numbers:

2.5M

The number of people
worldwide with MS

60%

The amount of people with
MS who **can walk without
assistance**

1878

**The year MS was first
recognized** as a specific
disease in the United States

300%

How much more likely it is
for **women to develop MS**
compared to men

CNN'S JOHN KING ISN'T LETTING MULTIPLE SCLEROSIS SLOW HIM DOWN

The longtime news anchor talks about dealing with his disease through the pandemic.



CNN host John King has covered American politics for decades. Millions of Americans have tuned in to watch him provide poll updates via a high-tech U.S. map on election nights. Recently, King shared the personal news that he's living with multiple sclerosis (MS), a chronic disease that affects the central nervous system. King talked to NIH MedlinePlus magazine about his MS journey and why he decided to speak out 13 years after his diagnosis.

How did you discover you had MS?

It's now clear I was experiencing MS symptoms for a decade before my diagnosis. They were mostly in my legs—numbness, tingling, the feeling my legs were heavy like lead or nonresponsive. Every now and then I would drop things or have trouble with my grip. But I always wrote this off as inattention or fatigue or random stupidity. Also, doctors thought early on these issues were possibly related to damage I have in a couple discs in my low back.

While covering a presidential convention in the summer of 2008, I had numbness and loss of control that spread to my hands and most of my upper body. A paramedic at the convention site pulled me aside and said, "My bet is you have MS." It took me a while to get all of the proper testing, but late that fall I finally had a series of tests that confirmed I have MS.

What was going through your head when you received the MS diagnosis?

I was full of fear when I heard the words multiple sclerosis, even more so when I read about it and realized how cruel this disease is to many people. But my doctors were reassuring from the beginning.

Because we knew some of my symptoms dated back a decade before diagnosis, they were fairly optimistic I had the "relapsing-remitting" type of MS. While there were no guarantees, the hope was that with medication, this form of MS could be managed.

How are you doing now?

The "how are you" question is always a funny one. I'm great and I know I'm lucky, but MS is with me every day. I haven't had full sensation in my legs since Bill Clinton was president.

Recently, my right side and especially my right hand are having issues. I fall sometimes. Some days, every waking moment has to be planned. I have to think about and focus on things that for most are second nature—things like standing up or holding the coffee mug.

Do I need the railing on the stairs? Are there headaches, and how bad are they? But I have learned how to snowboard even though I can't really feel my feet. And just once in 13 years since diagnosis have I had to miss a day of work because of MS.

What led you to speak out?

I kept my diagnosis secret from most people for 13 years and had no plans to speak out. But mounting frustration with some of the country's COVID-19 conversations pushed me over the line. The medications I take to treat

“I’m lucky,
but multiple
sclerosis
is with me
every day.”

– John King

my MS compromise my immune system, so I’m at higher risk from COVID-19. I allowed CNN’s medical experts to deal with the “freedom” versus “science” debate about wearing masks, but this was obviously an issue I was thinking about a lot because of my MS.

One day, our conversation on the air included a particularly outrageous statement from a media personality about wearing masks, and I just talked about my MS diagnosis on the fly. I said I wanted to share this personal information because I was grateful for those who get vaccinated and wear a mask. They are not only protecting themselves; they are protecting me and so many others around them.



John King working the 2020 presidential election at CNN.

What is your message for others who are dealing with MS?

Remember the gifts we get from the challenges. Many days are frustrating or worse. But the human brain and body are remarkable in how they adapt to the fight. The resilience and tenacity it takes to fight MS are great skills for other challenges.

What do you want others to know about MS?

One thing MS quickly teaches you is that there are so many things that are invisible to us. If you have a friend or family member with MS, please know there are things you can’t see and

things that these loved ones might not want to share all the time. This can cause tension in relationships, which is another giant piece of the challenge.

For others who don’t have any direct experience with MS, please know that some of the things that come easy to you might be really hard for the person at the next desk or the stranger in front of you in line who maybe isn’t moving as quickly as you would like. Everyone has challenges. Remember some are invisible.

Is there anything else you’d like to share with our magazine’s readership?

First and foremost, I would like to share a giant thank you to the scientists and other professionals on the front lines of the COVID-19 pandemic. As a journalist, you have helped me learn. As a parent, you have fought to help those I hold most dear.

I would also pose a challenge of sorts. Debates about vaccines and mandates are the American way, and we should welcome and cherish them. But the explosion of misinformation, disinformation, and conspiracy are a threat to public health and public support for critical work. So we need to think about how we communicate and how we get our feet on the ground where these things take root. ■



What are the different types of multiple sclerosis?

Relapsing-remitting

This is the most common type of MS—approximately 85% of people are initially diagnosed with relapsing-remitting MS. Symptoms flare up for a period of time then go away. Most people make a full or partial recovery at the end of symptom flares. During symptom-free times, any related disability does not worsen.

Secondary-progressive

After experiencing relatively stable levels of disability between symptom flares, many people with relapsing-remitting MS may develop secondary-progressive MS and start to see their symptoms and in-between periods worsen. Individuals with this type of MS may experience more debilitating symptom flares. They may not recover from these flares, or their disability may get worse even when they’re not flaring.

Primary-progressive

A small percentage of people with MS—approximately 10-15%—have primary-progressive MS. They feel their symptoms worsen over time from the very beginning, usually in the absence of flares.

Meet the director:



National Institute of
General Medical Sciences



Jon R. Lorsch, Ph.D.

Jon R. Lorsch, Ph.D., has been the director of the National Institute of General Medical Sciences (NIGMS) since August 2013. In his position, Dr. Lorsch oversees a \$3 billion budget that supports more than 5,500 investigators through roughly 5,000 research grants. One in 10 research grants from NIH comes from NIGMS, so Dr. Lorsch's work is crucial to NIH's goal of advancing research across the country. Dr. Lorsch chatted with us about his work with NIGMS, his reasons for pursuing science, and his passion for helping up-and-coming researchers.

How would you describe the mission and focus of NIGMS?

We have a few areas of focus. We perform basic scientific research, looking at how life processes work. That includes research on things as small as molecules and cells and as large as whole organisms and entire populations and ecosystems. We fund research in specific clinical areas that involve multiple organ systems—things like sepsis, anesthesiology, burns, and trauma. We also have a major focus on training new scientists, developing a diverse workforce, and increasing research capacity throughout the country. We're trying to invest in places that historically haven't had much funding to conduct research and support researcher training and career development so we can create a more diverse and inclusive scientific workforce.

What is NIGMS doing to help foster that diversity?

Our programs span the entire pathway of science career development, starting with early childhood education and going all the way to helping early career scientists establish independent research.

Tell us about the scientific research you fund: What is basic science research, and why is it so important?

We lay the foundation for all the other research that NIH supports. It's crucial to understand the basics of how different organisms work because if you know that, then you understand how breakdowns in those processes

cause diseases. That gives you the needed information to eventually develop treatments. It's like when there's something wrong with your car. If you don't understand the basics of how the car *should* work, then it's going to be really hard to figure out what's wrong with it and how to fix it.

We support research that investigates how basic life processes—which covers a wide range of approaches and topics—work at different levels. That research could look like anything from scientists working with test tubes and solutions to researchers using computers to simulate biological processes. We think it's really important to support investigator-initiated research, meaning we don't tell researchers what they should be working on. We don't know where discoveries will arise, and big breakthroughs often come from surprising places, so we need to invest in a broad range of research.

What are some things NIGMS does to support early career scientists?

We have programs that support research training, career development, and increased diversity at the undergraduate, graduate, and post-doctorate levels. One of our new programs called [MOSAIC](#) (which stands for Maximizing Opportunities for Scientific and Academic Independent Careers) helps post-doctorate research fellows establish faculty careers at research institutions. We really invest in networking and mentorship—a good network and mentors can “make or break” someone's interest and success in science.

And what about for kids, how do you get them interested in STEM?

Our [SEPA](#) (Science Education Partnership Award) Program, which funds new, innovative education projects in scientific areas that young people might be interested in, has programs in almost every state. Some help support after-school science clubs that focus on students from underserved communities. We have a program that makes science-focused apps for online games. A program in West Virginia supports students who are pursuing biomedical research activities in high school, and graduates of the program get college tuition from the state at colleges and universities in West Virginia. A superhero-themed program in Indiana gets kids interested in veterinary research, and a program in Utah helps train teachers to give them the skills to make genetics engaging for kids.

What are some NIGMS-funded research projects that you're really excited about?

There are so many things! We're supporting research that uses data science, artificial intelligence, and machine learning to better understand biological systems. We're investing in research related to synthetic chemistry—basically, making molecules. This is super important for drug development, and one of our researchers recently won the Nobel Prize in chemistry for their work in “molecular carpentry.” They essentially created a better way to stick different molecules together to make new ones.

We're also funding research on organisms that might give us new insights into biological processes in surprising ways. For example, the African spiny mouse is the only mammal that can heal its wounds without scarring. By studying that, we're hoping to learn more about why humans form scars and whether we could make a molecule that could let us heal without scarring. This could be huge for heart disease since heart attacks cause scarring on the heart, which makes it weaker than before the attack.

What led you to a career in science?

I actually remember the exact moment I knew I wanted to be a scientist. I was 4 years old, and a teacher brought a cow heart into the classroom. Most of the other kids were freaked out, but I thought it was the coolest thing. I was looking at all the channels and flaps and thinking, “How did this work? Where did it come from?” It made me want to be a scientist.

I also had really great science teachers throughout my education who helped me get and stay interested in science.



Though his background is in biochemistry, Dr. Jon Lorsch is just as passionate about education and supporting the next generation of scientists.

How did you get to your current position?

After completing a post-doctorate fellowship, I joined the faculty at the Johns Hopkins School of Medicine, where I was really thrown into the deep end of teaching. I had this pressure to focus on research, but I found I really enjoyed teaching the medical students and got more involved in that. I wanted to find the best ways to teach them and ended up leading the first-year curriculum for medical students and working on some curriculum reform efforts.

My experience there made me realize I wanted to move towards scientific leadership and management—spaces where I felt like I could have a bigger impact. The NIGMS director opportunity came along, and I decided to apply in the spirit of “opportunity knocks only once.” It's the greatest job in the world.

What's the best thing about working in science?

The young people. It's amazing to have the opportunity to help people's careers get started and sustain them throughout those careers. Funding an early career investigator to get their lab up and running, then watching what they do over the next few years and thinking, “Maybe they'll be the one to win the Nobel Prize”—that's what motivates me.

What do you like to do when you're not working?

I really enjoy gardening, and the pandemic helped reinvestigate that hobby. Planting a seed, watching it grow, and getting to manage all that is just astonishing. It's a lot like promoting careers in science! ■



Teaching parents how to recognize and respond to their baby's cues can help promote healthy growth.

PREVENTING CHILDHOOD OBESITY:

Program for first-time parents promotes healthy growth in firstborn babies and their siblings

An NIH-funded study called Intervention Nurses Start Infants Growing on Healthy Trajectories (INSIGHT), has been shown to support healthy weight in babies and lay the groundwork for positive eating habits and growing patterns later in life. The program teaches first-time parents how to recognize and respond to their baby's cues around things like hunger, sleep, feeding, and emotional regulation. It helped protect against infant weight concerns and promoted healthy growth in firstborn children. A follow-up study called SIBSIGHT discovered that siblings benefit, too.

Childhood obesity, which affects 1 in 5 children in the United States, is a complicated issue without a single clear solution. When a child is overweight, there are almost always multiple factors at play including genetics; behavior; or access to healthy, affordable food and safe places to exercise.

One approach to preventing obesity in children is a practice called “responsive feeding,” which includes teaching new parents strategies for recognizing their baby's food needs and responding to them immediately, and in a nurturing way. It includes:

- Making sure the feeding experience is pleasant and free from distractions.
- Noticing signs from the child that they are hungry or full.
- Responding quickly and appropriately to those signs (for example, not using food to quiet a crying infant who is full).

Responsive feeding also helps babies notice their own feelings of hunger and fullness, which can encourage self-regulation (the ability to eat or stop eating based on those cues) throughout their lives.

Promoting healthy growth in children

A promising intervention program that was found to promote healthy growth in firstborn babies appears to also benefit their siblings. INSIGHT is an ongoing study funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) that teaches responsive skills and strategies to help first-time parents recognize and respond to their infant's cues.

Firstborn babies in the program had healthier growth rates—including slower weight gain through the first six months, lower rates of being overweight at age 1, and lower BMI (body mass index) at age 3—compared to babies whose parents didn't get this training.

“We saw many positive outcomes... but most striking was the impact on weight gain: Compared to the control group, the babies whose parents got the responsive parenting intervention grew healthily but more slowly in the first six months, were less likely to be overweight at age 1, and had lower BMI at age 3.”

– Ian Paul, M.D., M.Sc.



Ian Paul, M.D., M.Sc.

Recently, the research team found that these benefits spill over to second children even without more training for their parents.

NIH MedlinePlus magazine spoke with two Pennsylvania State University researchers who led this work. Ian Paul, M.D., M.Sc., is a practicing pediatrician at Penn State Children's Hospital and a professor of Pediatrics and Public Health Sciences at Penn State's College of Medicine. Jennifer Savage Williams, Ph.D., is the director of Penn State's Center for Childhood Obesity Research and an associate professor in Nutritional Sciences.

What is responsive feeding? What is its relationship to responsive parenting?

Dr. Williams: Responsive feeding builds on responsive parenting, which has been around for a long time. It's about picking up on a child's signs and reacting quickly in a way that's developmentally appropriate for the child and is associated with lots of positive outcomes for children.

About 10 years ago, researchers started looking at how feeding specifically fits into this framework. Instead of focusing on what and how much children are eating, responsive feeding takes a developmental perspective, which looks at *how* they're eating. This includes parents giving kids foods that are age-appropriate (in terms of texture, portion size, and so on) and being able to identify when a child is hungry versus when they are full. The [responsive] parenting literature laid the foundation for thinking about feeding responsively, and we looked at all the positive outcomes around parenting and wondered if responsive feeding would also protect against weight gain and help young children learn how to regulate their energy intake by paying close attention to their feelings of hunger and fullness.

Dr. Paul: That's right. Responsive feeding is all about teaching parents how to recognize their child's cues that they are hungry or full—especially during infancy—and how to respond in a developmentally appropriate and productive way. For example, infants cry for many reasons, and feeding them can seem like an effective

response in the moment, even if hunger isn't the cause of the child's fussiness. That's why it's important to give parents other strategies for responding to their child's fussiness that don't involve feeding.

What questions were you trying to answer with INSIGHT? How did you go about answering them, and what did you find?

Dr. Paul: INSIGHT looked at whether a responsive parenting intervention for first-time parents could reduce rapid infant weight gain and improve weight status in their babies. It was a randomized controlled trial (a kind of research study where participants are randomly assigned to different groups to compare the effects of different treatments or interventions) with almost 300 mothers and firstborn infant children. In the responsive parenting group, we taught parents strategies for responding to their babies' needs around sleep, feeding, interactive play, and emotional regulation, then followed them over the next three years. The control group (the group of study participants that didn't get the responsive parenting intervention) learned about home safety. We saw many positive outcomes around sleep, feeding, and nutrition, but the most striking was the impact on weight gain: Compared to the control group, the babies whose parents got the responsive parenting intervention grew healthily but more slowly in the first six months, were less likely to be overweight at age 1, and had lower BMI at age 3.

Dr. Williams: The team was really thoughtful about setting up the intervention. It was delivered by nurses who focused on teaching parenting skills. This helped the parents feel like they were getting unique and tailored support and guidance, which can be really powerful—especially for new parents who don't always have good support. Instead of talking explicitly about obesity prevention, we really focused on the kinds of outcomes that parents are invested in. What kind of 3-year-old do most parents want? They want a kid who isn't a picky eater, sleeps through the night, and is good at regulating their emotions.



Jennifer Savage Williams, Ph.D.

“Like their older siblings, the younger, secondborn siblings in the intervention group had significantly lower body weight than those in the control group, even without more training for their parents. That tells us that this intervention has an incredible return on investment.”

– Jennifer Savage Williams, Ph.D.

How did the SIBSIGHT study build on these findings?

Dr. Paul: Across cultures around the world, firstborn children and only children are more likely to be overweight than their siblings. This is a bit of a paradox because women who get pregnant later in life are more likely to be heavier during pregnancy, which puts the child at risk for obesity.

We know that children turn out differently than their siblings; the question is why. How much of this difference is due to genes, how much is behavior, and how do each of these contribute to obesity? We hypothesized that experienced parents may be more responsive to a second child’s cues after going through it with their firstborn.

Dr. Williams: We had collected so much good information about the firstborn children in the study, and now we wanted to answer these questions by looking at their younger siblings. When we analyzed the sibling data, we were pretty floored by what we found. Like their older siblings, the younger secondborn siblings in the intervention group had significantly lower body weight than those in the control group, even without more training for their parents. That tells us that this intervention has an incredible return on investment.

Truly a team effort

Dr. Williams and Dr. Paul are grateful for all the dedicated, talented people who have contributed to—and in turn have been touched by—the program over the years.

None of this work would have been possible without their mentor, Leann Birch, Ph.D. Dr. Birch was a developmental psychologist and a pioneer in both

childhood eating behaviors and early-life obesity prevention until her passing in 2019, and her research and work around childhood feeding laid the groundwork for the intervention and its curriculum. “She was absolutely brilliant, innovative, and collaborative,” said Dr. Williams.

There was also the team that developed the curriculum and intervention—including their colleague Stephanie Anzman-Frasca, Ph.D., who Dr. Williams and Dr. Paul credited as a key player—they also credited the nurses who delivered it and the entire research team, including students, statisticians, and project coordinators.

And of course, the ongoing dedication and involvement of the families in the program—some of them traveling from out of state—over the 9 years. Without them, Dr. Paul noted, “we wouldn’t be able to do the study.”

The positive impacts of the study went beyond the intervention outcomes. The many, many students—undergraduate, graduate, and post-doctoral—who trained in this interdisciplinary, collaborative program represent a new generation of researchers, many of whom have since gone on to envision and lead research of their own.

What’s next?

Thanks to NIDDK funding, the INSIGHT study will continue to follow the firstborn children through age 9. The team is also focusing on delivering education on nutrition and responsive parenting in community-based settings. That includes the National Heart Lung and Blood Institute’s Early Intervention to Promote Cardiovascular Health of Mothers and Children (ENRICH) program, which engages with communities to bring evidence-based interventions like INSIGHT to new parents and their children. ■



Leann Birch, Ph.D.

Childhood obesity affects **1 in 5** children in the United States.

SOURCE: Centers for Disease Control and Prevention

Healthy habits that last a lifetime: How to practice responsive feeding

Feeding time can be hard for new parents, especially since babies can't use words to tell you when they're hungry and when they're full. Luckily, they use nonverbal signs and cues to communicate when they need to eat and when they've had enough. It's important for parents to recognize these signs and respond to them quickly, warmly, and consistently—a strategy that's called “responsive feeding.”

Healthy eating habits that last a lifetime

Practicing responsive feeding when your child is a baby teaches positive eating habits and skills that keep them healthy as they get older. That's because responsive feeding teaches children to:

- Recognize when their bodies are hungry and when they're full (and to trust those feelings).
- Clearly communicate their needs to others.
- Eat when they are hungry and stop when they are full (instead of when someone tells them to).

How to practice responsive feeding with your child



Learn to recognize when your child is hungry and when they are full. Babies need to eat when they are hungry, but they shouldn't eat more than they need. Watch your baby carefully for signs that they are ready to eat and signs that they are full.

Signs your baby may be hungry include:

- Opening and closing their mouth, moving their hands to their mouth, or putting things in their mouth.
- Making sucking noises.
- Putting their hands on their belly.
- “Rooting” (opening the mouth and turning to look for food).

Signs your baby may be full include:

- Starting and stopping feeding often.
- Slowing down or falling asleep while feeding.
- Closing their mouth or turning away from food.
- Spitting food out, pushing it away, or ignoring it.

Fussiness and crying don't always mean your baby is hungry. Babies cry for many reasons—for example, when they are tired, uncomfortable, teething, or cold. A baby who is crying because they're hungry usually shows some other signs of hunger first.



Respond quickly and appropriately.

Respond right away when your baby shows signs of hunger and fullness. Acknowledge your baby's cues and attend to them promptly and warmly.

Do:

- Start feeding when your baby shows signs of hunger.
- Make sure your baby is comfortable and remove distractions (turn off the TV, put away your phone) so you can both focus on feeding.
- Use eye contact and touch to engage with your baby during feeding.
- Let them stop eating when they show signs of being full.

Don't:

- Ignore your baby's cues.
- Force your baby to eat after they are full.
- Give your baby food to make them stop crying if they haven't showed other hunger cues.



Be predictable. Establish a consistent schedule, structure, and routine for meals and snacks. This will help your baby know what to expect. ■



Kathy Bates joins other lymphedema advocates at the steps of the Lincoln Memorial in Washington, DC.

Kathy Bates is figuring out how to live with lymphedema

MedlinePlus magazine caught up with the actress to see how she's been managing her diagnosis

When award-winning actress Kathy Bates was featured on the cover of NIH MedlinePlus magazine in [2016](#), she spoke about her experience with lymphedema following her breast cancer surgery and her advocacy for those with lymphatic diseases as a national spokesperson for the Lymphatic Education & Research

Network. NIH MedlinePlus magazine recently caught up with her to learn more about her lymphedema journey.

How are you doing?

My lymphedema (LE) is under control. I've lost about 80 pounds over the last few years, which has helped a lot with the swelling in my arms, but I still wear my

compression sleeves if I'm flying or if I'm doing strenuous tasks. I like to be self-sufficient, so before I know it, my arms are inflamed and painful. However, I'm luckier than most who have LE. I can afford the doctor's visits, compression garments, and therapy. Many people can't.

“Other people’s stares may hurt at first, but they have no power to define us as people. We **have** lymphedema. We’re not lymphedema.”

– Kathy Bates

How did the pandemic impact you?

Like many, I was in quarantine for almost two years. My niece brought me food and helped me take care of the house. She took care of the whole family. I don’t know what we would have done without her. I managed to keep my weight off, which was a miracle. I worked very hard at it.

What do you do to maintain your health and energy?

I try to pace myself so I don’t get too stressed. If I can stop rushing, relax my shoulders, straighten my spine, breathe deeply, and focus on each little moment of completing a task, I have more confidence in my ability to live with LE. The pandemic forced me to slow down.

I also started raising miniature and full-size violets. I found working with plants, digging my hands into bags of soil... it centers me. I love coming downstairs in the morning to see the new buds. My little dog is jealous that they get attention before she gets her breakfast!

Looking back over the course of your experience with lymphedema, what is your message to others who have been diagnosed more recently?

That’s a very difficult question to answer. To give someone meaningful comfort without physical connection

is hard. The platitudes like “don’t lose hope” or “try not to get depressed” seem so cliché. For the day-to-day battle, I would advise gathering the courage to get out and live your life no matter the severity of your disease.

Going out in public wearing a compression garment, especially when people aren’t educated about LE, can sometimes be more painful than the disease itself. However, hiding at home and living a sedentary life will only make things worse for your body and brain. As my other niece says, “Motion is lotion.” Other people’s stares may hurt at first, but they have no power to define us as people. We *have* lymphedema. We’re not lymphedema. Reclaim your life. Get used to being in public so you can live your life to the fullest. Most of all, don’t withdraw from your family and friends. Keep them close. We’re all dealing with something, especially these days.

Has there been progress made through your advocacy?

Absolutely! NIH is working on a new, broader way of advancing lymphatics science and research by establishing a [National Commission on Lymphatic Diseases](#). And NIH is now creating research categories specifically for lymphedema and for lymphatic diseases. Those of us with lymphedema have succeeded in making our case and being recognized, but there is still work to be done to get us to our ultimate goals of new treatments and eventual cures.

What are you doing in your entertainment career now? Any plans for new shows or movies?

Last June, I had an opportunity to do a lovely role in the film adaptation of Judy Blume’s acclaimed novel, “Are You There God? It’s Me, Margaret,”

which will be released in September. I’m getting ready to fly to Dublin to do a film with Maggie Smith and Laura Linney. I’ve been working with a dialect coach for the past few weeks to perfect the working-class Irish dialect. I love poetry and literature, and I think Irish writers are the greatest who ever laid a pen to paper. Also, my middle name is Doyle. My great-great-grandfather came from Dublin during the Irish Potato Famine, so in a way, I’m going home. ■



Kathy Bates testifies before Congress as an advocate for those with lymphatic diseases.

Find Out More

- ▶ **MedlinePlus:**
<https://medlineplus.gov/lymphedema.html>
- ▶ **National Heart, Lung and Blood Institute:**
<https://www.nhlbi.nih.gov>
- ▶ **National Cancer Institute:**
<https://www.cancer.gov>
- ▶ **Lymphatic Education & Research Network:**
<https://lymphaticnetwork.org>

Lymphedema: Living with swelling and stiffness

Lymphedema can be painful, but many have learned how to live with it

What is lymphedema?

Lymphedema is chronic swelling that happens when something upsets the lymphatic system. The lymphatic system is part of the body's immune system and includes tissues like bone marrow and bowel lining; blood vessels; and organs like your tonsils, spleen, and lymph nodes.

The lymphatic system works to move a clear, watery, protein-rich fluid called lymph into your bloodstream. Lymph contains lymphocytes, or white blood cells, which attack viruses and bacteria when they enter your body. If you've ever been sick and felt a swelling or tenderness in your neck or armpits (where some of your major lymph nodes are), you've felt your lymphatic system at work.

Sometimes, though, the lymphatic system gets blocked due to obesity, serious injuries, or genetic problems. When this happens, lymph draining from body tissues has nowhere to go and gets stuck in the tissue. When enough lymph builds up, you swell up. This swelling can negatively affect your quality of life.

What does that swelling look and feel like?

Lymphedema swelling typically occurs in the arms or legs. Symptoms can include:

- An arm or leg feeling heavy or full
- Skin in the swollen area feeling tight
- Difficulty moving a joint in the arm or leg, including those in the hands and feet
- Skin becoming thicker
- Itching in the legs or toes
- A burning feeling in the legs



Lymphedema causes swelling and stiffness.

How is it diagnosed?

Many things, like infection or blood clots, can cause swelling in the limbs. Only a medical provider can give an official lymphedema diagnosis. When a medical provider looks at a swollen limb to see if it's lymphedema, they might do the following to rule out other possibilities:

- **A physical exam and medical history.** A medical provider might measure your swollen limb to compare it to the other limb; look for lumps or other signs of disease; and ask about your health habits, past illnesses, and treatments.
- **Lymphoscintigraphy.** A medical provider will inject a small amount of radioactive substance into the body and observe how it flows through the lymph nodes.
- **Magnetic resonance imaging (MRI).** A medical provider will use a magnet, radio waves, and a computer to take detailed pictures of areas inside the body.
- **Indocyanine green (ICG) lymphography.** A medical provider will inject a small amount of ICG—a medical dye used for [diagnostic imaging](#)—into the body and observe how it flows through the lymphatic system.

How is it treated?

Some early stages of lymphedema can go away without treatment. There is no cure for later stages of the condition—once the lymph system is damaged, it cannot be repaired. However, that does not mean that lymphedema symptoms can't be managed. A medical provider might suggest a plan that includes:

- **Weight loss and exercise** to help lymphatic vessels move trapped lymph fluid.
- **Compression of the area** through things like special physical therapy or compression garments to help move lymph fluid and keep it from building up in your body.
- **Physical therapy** like special massage and skin care to help reduce swelling and protect the skin.
- **Some newer treatment options** like lasers and stem cells, which have been shown in small studies to be an effective treatment for lymphedema.



Wuchereria bancrofti, the causative agent of lymphatic filariasis.

Who is at risk for lymphedema?

There are two types of lymphedema:

- **Primary lymphedema** occurs when the lymphatic system doesn't develop properly and is extremely rare, affecting roughly 1 out of every 8,000 individuals worldwide.
- **Secondary lymphedema** occurs when the lymphatic system is damaged by something else, often through cancer treatment or parasite infections, and is the most common type of lymphedema. Roughly 1 in 1,000 Americans have secondary lymphedema, and it's believed to affect as many as 140 million to 250 million people worldwide.

Secondary lymphedema is often associated with cancer and cancer treatment. Tumors that press against lymph nodes can create blockages, and radiation can affect lymph nodes and create scar tissue that blocks the flow of fluids. Surgery that removes organs or tissues affected by cancer can sometimes remove lymph nodes as well. ■



NIH research to end lymphatic filariasis

- Parasitology is a field of medicine that focuses on the study of parasites—small organisms that survive by living off the human body. The Parasitology and International Programs Branch and the [Laboratory of Parasitic Diseases](#) at the National Institute of Allergy and Infectious Diseases (NIAID) are supporting and conducting multiple research projects aimed at treating and ending a kind of lymphedema called lymphatic filariasis. This disease is a form of secondary lymphedema caused by microscopic worms entering the lymph system via an infected mosquito bite.
- Lymphatic filariasis affects more than 120 million people in tropical areas across 72 countries and is considered a [neglected tropical disease](#) (NTD). Because NTDs generally affect some of the world's poorest communities, they historically haven't gotten the same amount of attention or research funding as other diseases. The at-risk population for lymphatic filariasis includes 1.2 billion people worldwide.
- NIAID-supported researchers are working to make lymphatic filariasis a problem of the past. Some labs are working to develop better treatments for people who have lymphatic filariasis, and other labs are working on tests to detect the disease and help curb its spread. A vaccine for the disease is currently in early stages of development.

Meet the director:



National Institute
on Drug Abuse



Dr. Nora Volkow, M.D.

Nora Volkow, M.D., has been the director of the National Institute on Drug Abuse (NIDA) since May 2003. NIDA supports research on the health aspects of drug use and addiction. As a research psychiatrist, Dr. Volkow uses brain imaging to study how substance use affects the brain. Her work has helped show how addiction is a chronic disease best addressed with prevention and treatment rather than judgment and punishment.

What made you want to study addiction and substance use disorders?

I was born in Mexico. My father is a chemist, and I always liked medicine and science—I was particularly fascinated by the brain. My family had a tragic history related to discrimination and shame around alcoholism. My favorite uncle had a problem with alcoholism, but this was a secret in the family that nobody spoke about. That silence was hard for me to understand. I didn't know until later, but my mother's father was also an alcoholic who had tried to stop drinking and ended up killing himself.

When I was in medical school, I was frustrated to see substance use issues ignored. The curriculum addressed the physical impacts of alcoholism but not the causes of addiction. Individuals with both mental illness and addiction have worse outcomes than those with one or the other, but resources to take care of people struggling with both of these issues were not prioritized.

I went into psychiatry because I was fascinated by the brain. If someone has a neurological problem like Alzheimer's disease, you can see the disease in the brain. But that's not true for mental health issues, and I wanted to understand that.

During addiction, there's a disconnect between what you want to do and what you're able to do. The need for the drug becomes as strong as the need for food or oxygen,

and you can't stop taking the substance even though consciously, you may not want it. I wanted to understand how something this powerful gets imprinted in the brain and what's happening in the brain when someone loses control over their behavior, even if their brain looks normal on a scan.

I saw how addiction affected my family and the vulnerabilities we all had because of it. I wanted to understand how genetic vulnerabilities affect the brain and what factors drive behavior in addiction scientifically—but also personally.

What brought you to NIDA?

When NIH asked me to apply for the [NIDA director] position, they said I would have the opportunity to develop impactful policies. This was appealing because I wanted to address the ways that our society and health care systems neglect addiction and to work to change the criminalization of people who take drugs. Research shows that when people end up in jail or prison, they have a much higher chance of overdosing, dying, or relapsing. Criminalizing people who use drugs has created a structurally racist system that allows us to treat certain people, particularly Black Americans, worse than others.

Could you describe some of NIDA's primary research initiatives and studies?

We are conducting [two large longitudinal studies](#) that use neuroimaging [scans of the brain] to learn about child brain development, behavior, and health. The [HEALthy Brain and Child Development Study](#) (HBCD) follows a large group of pregnant women and their children across the country, from pregnancy through early childhood, and the [Adolescent Brain Cognitive Development Study](#) (ABCD) follows more than 11,000 children of different racial and ethnic backgrounds across the United States, from ages 9 to 10 through early adulthood. Both studies are looking at what factors in a child's environment, genes, biology, and social relationships—including exposure to harmful substances and stressors— affect brain development and behavior. This will give us a better understanding of the things that make it more likely—or less likely—for someone to develop a substance use disorder so we can intervene early on and prevent and treat harmful outcomes like addiction later in life.

We support research to identify and develop new treatments, including research on the pharmacological effects of different drugs—what they do in the brain, in the cells, to the genes—to find ways to tailor personalized therapies. We're also studying ways to implement effective treatments *and* get them covered by insurance.

And we're very involved in policy and translational research so we can [bring interventions into different communities](#). How do we learn from what other diverse groups are doing to address this crisis in their communities? What works well? What doesn't?



Dr. Nora Volkow, a pioneer in addiction science, uses brain imaging to study how substance use affects the brain.

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"I saw how addiction affected my family and the vulnerabilities we all had because of it. I wanted to understand how genetic vulnerabilities affect the brain and what factors drive behavior in addiction—scientifically, but also personally."

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How do health disparities play into substance use and addiction, and how is NIDA addressing the needs of people affected by these issues in underserved communities?

There are health disparities in all areas of health, especially around substance use. What's unique to addiction is how it relates to criminalization. Being in jail or prison interferes with physical and emotional health, makes it hard to get a job, disrupts families, and destroys self-confidence. We're trying to tackle these issues at NIDA.

For one, we have [the Justice Community Opioid Innovation Network](#) (JCOIN), which is part of NIH's broader [Helping to End Addiction Long-term](#) (HEAL) Initiative. JCOIN tests strategies for improving access to high-quality treatment and care for people with opioid use disorder in justice settings.

Another of our research priorities to help address health disparities is to conduct large-scale studies like ABCD that allow us to look at brain development and health outcomes over time in children who come from disadvantaged backgrounds. We know that income is a key factor, and on average, people of color have lower incomes than White Americans. These families are less likely to have access to good health care and nutritious foods, and the parents often work extra shifts, which can affect sleep quality.

Understanding how stressful environments and experiences like discrimination in school or unsteady home lives impact differences in children's brains and health will allow us to develop more effective interventions for preventing and treating substance use and addiction. We want to push the envelope in our research, but we also want to promote treatments that are sustainable and accessible for the people who need them.

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“The people who are the most vulnerable can be those who are socially deprived, and it’s narrow-minded to believe that people take drugs because they choose to.”

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How does stigma affect the health, treatment, and well-being of people with substance use disorders? How does it affect their networks and communities?

Stigma seeps in at every level, affecting individual and community suffering, the health care system, and health insurance coverage.

Individuals, families, and communities internalize stigma around substance use. It is something that everyone is ashamed to talk about, and that gets in the way of people getting the help they need. This has created a health care system that doesn’t provide the resources to treat addiction and insurance companies that won’t pay for effective treatments.

Why are you trying to change the institute’s name to the National Institute on Drugs and Addiction?

Language is the most unique advantage humans have over animals because it allows us to build. We use language to build shared realities and to build identities. It’s how we communicate with each other, and the words themselves

are powerful. You respond emotionally to a word based on your association with it, and you can actually see this in the brain, where certain words activate the amygdala [the part of the brain that prepares us to respond to threats].

We call people who use drugs “abusers,” but the word “abuse” has very negative associations. So our brains connect that term with other terms like “sexual abuse” and “physical abuse,” which creates a negative opinion of that person.

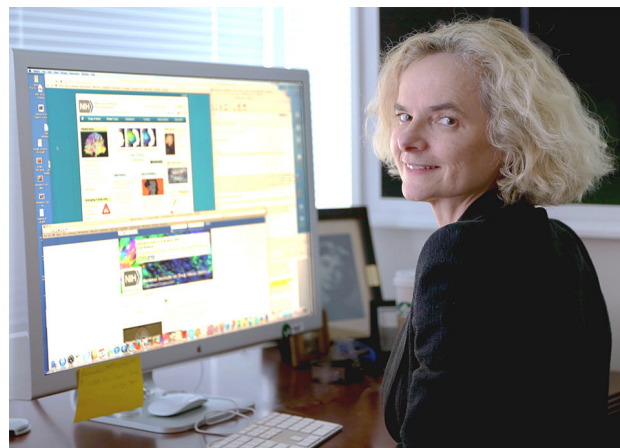
We will still be NIDA, but it’s important to change the “A” to “addiction” instead of “abuse.”

How has the COVID-19 pandemic contributed to increased substance use, overdoses, and deaths, and what other factors are at play?

The pandemic has caused enormous stress and uncertainty for people—people have lost homes, jobs, and loved ones, and this stress contributed to increased drug use. It also stressed the health care system. Community services, emergency departments, and methadone treatment programs became overwhelmed or were shut down, which made it harder for people to get services and treatment.

On top of this, [synthetic opioids like fentanyl became far more widely available](#). Fentanyl is 50 times more potent than heroin and can be fatal even at low doses. Originally, it was used to contaminate heroin, but now it is showing up in drugs like cocaine, methamphetamines, and illegal counterfeit prescription pills, which puts more people at risk of overdosing from it.

So as people are using more drugs, the drugs themselves are much stronger and more dangerous than in the past.



Dr. Nora Volkow has been the director of the National Institute on Drug Abuse since 2003.

What are the most important next steps to address the overdose crisis?

This crisis is not going to go away by itself. It requires a multipronged, tailored approach to interventions that's targeted at different stages.

First, we need to educate the public about fentanyl. This includes tailored education that's factual and relevant to specific communities.

We also need to provide treatments and interventions that protect people from overdoses. This includes prioritizing behavioral health and training clinicians to screen for substance use.

Finally, we need to make overdose reversal medication available for any individual who uses drugs. [Naloxone](#) is a safe medication that can save lives, and it should be widely available, including in schools.

“I wanted to address the ways that our society and health care systems neglect addiction and to work to change the criminalization of people who take drugs.”

What are the most important things that you think people need to know about substance use and addiction that they may not already know?

Substance use disorders are both a chronic brain disease and a social problem. Societal factors [things like access to food and transportation, housing security, education, violence, and social support] have the power to create conditions that make people vulnerable to substance use and addiction, and they also have the power to facilitate recovery. But this doesn't erase the fact that addiction is a chronic disease of the brain.

For more information on using language to reduce stigma when talking about addiction and substance abuse, **check out NIDA's [Words Matter](#) webpage.**

Addiction is treatable, but we need to treat it as a chronic condition. It causes long-term changes to the brain that are compounded by changes in behavior. These changes don't reverse when you stop taking drugs. The longer someone is in treatment, the less likely they are to relapse; eventually, most people will achieve remission [when you are no longer dependent on the substance].

The people who are the most vulnerable can be those who are socially deprived, and it's narrow-minded to believe that people take drugs because they choose to. For example, you see people experiencing homelessness with high rates of smoking and alcohol use and with high overdose rates. These individuals don't have anything else, and many of them take drugs as a way to escape, to feel better, because they have no other options. And many are struggling with other mental illnesses. Instead of stigmatizing people by saying that this behavior is a choice, we need to ask what we can do to [provide alternative behaviors, resources, and support](#) so that everyone has *actual* choices.

What do you like to do when you're not working?

I love to explore the world. I love to run and hike. And I love to read. Books let you get into someone else's brain and explore the uniqueness that's there. ■

TECH IN MEDICINE

PregSource: Using input from pregnant people to uncover the secrets of pregnancy



What is PregSource?

[PregSource®: Crowdsourcing to Understand Pregnancy](#) is a research project that collects data about pregnancy from the early stages through birth directly from pregnant people. Participants are invited to share information such as their health history, changes in weight and sleep patterns, and labor and delivery experiences using confidential online surveys. [The PregSource resource library](#) provides information from NIH and other trustworthy sources to answer pregnancy-related questions.

The project is led by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). Since its launch in 2017, the project has received data from more than 2,000 pregnant people.

Why was it created?

Even though many people across the globe experience a pregnancy in their lifetimes, there's still a lot scientists don't know about what a typical pregnancy looks like. For example:

- How many people experience morning sickness? When in their pregnancy does it start or stop?
- How does pregnancy affect sleep and energy levels?
- Are there warning signs for pregnancy complications? If so, when are they detectable?

"Very little is known about what a typical person in the 21st century can expect from a pregnancy," says NICHD's [Caroline Signore](#), M.D., M.P.H., who leads the PregSource project. "Much of pregnancy research focuses on problems. While we have learned a great

deal about preventing and treating certain pregnancy complications, we know comparatively little about the everyday, lived experiences of pregnant people.

The PregSource project aims to fill these knowledge gaps and provide data that informs guidance and recommendations for maintaining a healthy pregnancy.

The PregSource project incorporates newer crowdsourcing techniques to gather information about pregnancy experiences from pregnant people, rather than relying on health care providers to collect the data. The study's confidential, secure online platform allows participants to add their information from any place, at any time.

IMAGE: COURTESY OF PREGSOURCE

PregSource resource library: Answers to pregnancy questions at your fingertips

Who can join PregSource?

Any pregnant person between ages 18 and 70 can participate in the PregSource research project. It's free to join, participants can decide which questions they want to answer, and they can opt out at any time. Users can input information on their own schedules, preferably at least once a month.

How are the data used?

Right now, the study is in a data collection stage. After this stage of the study ends next year, the dataset will be made freely available to researchers through NICHD's [Data and Specimen Hub](#). Researchers will be able to use the grouped data to look for trends, similarities, and differences in people's pregnancy experiences.

To protect users' privacy, all data has names and other identifying information removed. Only PregSource coordinators see personal information, and they are trained to protect user privacy and keep data secure.

What's next for PregSource?

As of December 2021, PregSource is available as an [app](#) for Apple devices as well as in an online format. Having PregSource easily available on a smart device makes it easier for pregnant people to give updates on their own schedules. An "award" system, in which users earn badges for making a certain number of entries in a week, is also new in the app. ■

[PregSource®: Crowdsourcing to Understand Pregnancy](#) includes a resource library where users can search keywords and find answers to their pregnancy questions from trusted health resources like NIH; CDC; the American College of Obstetricians and Gynecologists; and the Association of Women's Health, Obstetric, and Neonatal Nurses. Here are some of the topics you can learn more about through the library:

Morning sickness

[One article](#) from the National Center for Complementary and Integrative Health explains that ginger helps reduce mild nausea and vomiting associated with pregnancy.

Eating for two

Although the Institute of Medicine recommends that expectant mothers need to eat more during pregnancy, most women only need [roughly 300 extra calories](#) a day—about the same caloric content as a plain bagel with cream cheese.

Breastfeeding

Breastfeeding is beneficial for babies and can reduce the risk of [sudden infant death syndrome](#) (SIDS), as well as [obesity in childhood and adulthood](#). But the [Eunice Kennedy Shriver National Institute of Child Health and Human Development](#) says it benefits moms, too. Breastfeeding can help the uterus heal and reduce the risk of postpartum depression.



POWERED BY NIH EXTRAMURAL FUNDING

SPOTLIGHT: NATIONAL LIBRARY OF MEDICINE

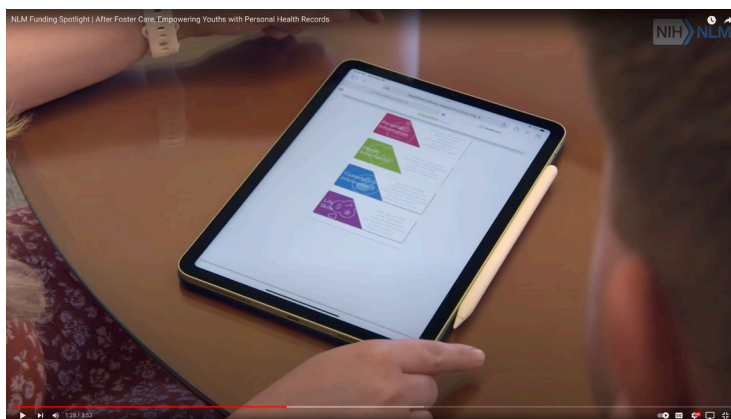
NIH funding powers research and programs that improve health and lead to new scientific findings. While intramural research happens within NIH's labs and clinics, extramural research grants provide support for programs outside of NIH.

MedlinePlus magazine explores how funding from NIH's institutes and centers is making a difference in communities across the country. This month, we're putting the spotlight on extramural research supported by the National Library of Medicine (NLM). Each year, NLM awards more than 80% of its budget to universities, medical schools, and other research institutions to support research and training in biomedical informatics and data science.

Ohio: Empowering youth aging out of foster care with personal health records



There are about 470,000 children in the foster care system in the United States, and every year more than 5,000 of them age out of the system. With support from an NLM extramural grant, Judith Dexheimer, Ph.D., of Cincinnati Children's Hospital Medical Center built an application called Health Hero, which helps youth who are aging out of foster care access and use their medical records. [Learn about how Health Hero empowers these young people to take charge of their healthcare.](#) ■



NIH funding powers extramural research programs.

IMAGE: COURTESY OF THE NATIONAL INSTITUTES OF HEALTH

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.

National Institutes of Health (NIH)

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Institutes

National Library of Medicine (NLM)

www.nlm.nih.gov

888-FIND-NLM 888-346-3656

National Cancer Institute (NCI)

www.cancer.gov

800-4-CANCER 800-422-6237

National Eye Institute (NEI)

www.nei.nih.gov

301-496-5248

National Heart, Lung, and Blood Institute (NHLBI)

www.nhlbi.nih.gov

301-592-8573

National Human Genome Research Institute (NHGRI)

www.genome.gov

301-402-0911

National Institute on Aging (NIA)

www.nia.nih.gov

Aging information 800-222-2225

Alzheimer’s information 800-438-4380

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

www.niaaa.nih.gov

301-443-3860

National Institute of Allergy and Infectious Diseases (NIAID)

www.niaid.nih.gov

301-496-5717

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

www.niams.nih.gov

877-22-NIAMS 877-226-4267

National Institute of Biomedical Imaging and Bioengineering (NIBIB)

www.nibib.nih.gov

301-451-6772

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

www.nichd.nih.gov

800-370-2943

National Institute on Deafness and Other Communication Disorders (NIDCD)

www.nidcd.nih.gov

800-241-1044 (voice)

800-241-1055 (TTY)

National Institute of Dental and Craniofacial Research (NIDCR)

www.nidcr.nih.gov

301-480-4098

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

www.niddk.nih.gov

NIDDK Health Information Center

800-860-8747

National Institute on Drug Abuse (NIDA)

www.nida.nih.gov

301-443-1124

National Institute of Environmental Health Sciences (NIEHS)

www.niehs.nih.gov

919-541-3345

National Institute of General Medical Sciences (NIGMS)

www.nigms.nih.gov

301-496-7301

National Institute of Mental Health (NIMH)

www.nimh.nih.gov

866-615-6464

National Institute on Minority Health and Health Disparities (NIMHD)

www.nimhd.nih.gov

301-402-1366

National Institute of Neurological Disorders and Stroke (NINDS)

www.ninds.nih.gov

800-352-9424

National Institute of Nursing Research (NINR)

www.ninr.nih.gov

301-496-0207

Centers & Offices

Fogarty International Center (FIC)

www.fic.nih.gov

301-496-2075

National Center for Complementary and Integrative Health (NCCIH)

www.nccih.nih.gov

888-644-6226

National Center for Advancing Translational Sciences (NCATS)

www.ncats.nih.gov

301-435-0888

NIH Clinical Center (CC)

clinicalcenter.nih.gov

301-496-2563

Office of AIDS Research (OAR)

www.oar.nih.gov

301-496-0357

Office of Behavioral and Social Sciences Research (OBSSR)

www.obssr.od.nih.gov

301-402-1146

Office of Communications & Public Liaison (OCPL)

[www.nih.gov/institutes-nih/nih-office-director/](http://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison)

office-communications-public-liaison

301-496-5787

Office of Rare Diseases Research (ORDR)

www.rarediseases.info.nih.gov

Genetic and Rare Disease

Information Center

888-205-2311

Office of Research on Women’s Health (ORWH)

orwh.od.nih.gov

301-402-1770




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