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NIH MedlinePlus

FALL 2016

the magazine

Kathy Bates

American Horror Story actress
copes with lymphedema and
speaks out on behalf of those
with the disease.

Living With **Lymphedema**

**Understanding the Opioid
Overdose Epidemic**

**Myths and Facts for
Future Moms and Dads**

**Finding Good Health
Information Online**

Dr. Patricia Flatley Brennan Takes Oath as New NLM Director



Photo: Ernie Branson, NIH

NIH Director Francis Collins, MD, swears in Patricia Flatley Brennan, RN, PhD, as the Director of the NLM. Her sister, Jean Flatley McGuire, is holding the Constitution for her.

On September 12, Patricia Flatley Brennan, RN, PhD, raised her right hand and became the first nurse and first woman to be sworn in as director of the 180-year-old U.S. National Library of Medicine (NLM).

Hundreds gathered in person with hundreds more tuned in online to witness the historic occasion that NIH Director Francis Collins, MD, called a “great day for NIH.” Deputy Director and former Acting Director of NLM Betsy Humphreys called Dr. Brennan the right choice at the right time.

Dr. Brennan, a nurse and an industrial engineer, joined the Library from the University of Wisconsin-Madison, where she was the Lillian S. Moehlman-Bascom Professor, School of Nursing and College of Engineering.

The U.S. National Library of Medicine is the largest biomedical library in the world. The Library is dedicated to accelerating scientific discovery, delivering information, and improving health. The Library is supported and promoted by the Friends of the National Library of Medicine, which publishes *NIH MedlinePlus* magazine.

**Glen P. Campbell, Chairman
Friends of the National Library
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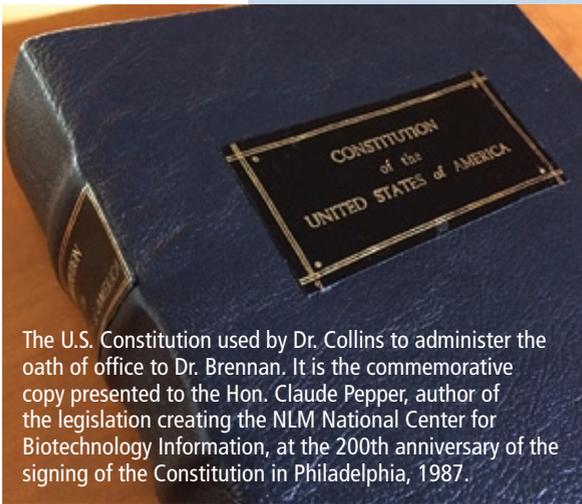


Photo: Kathy Cravedi, NLM

The U.S. Constitution used by Dr. Collins to administer the oath of office to Dr. Brennan. It is the commemorative copy presented to the Hon. Claude Pepper, author of the legislation creating the NLM National Center for Biotechnology Information, at the 200th anniversary of the signing of the Constitution in Philadelphia, 1987.



Photo: Caffeine Photography

Dr. Brennan makes remarks at her swearing-in ceremony at the Lister Hill Center Auditorium.



Photo: Caffeine Photography

Dr. Brennan outside of NLM’s Lister Hill Center with members of her family who attended the event.



Photo: Caffeine Photography

Dr. Brennan greets well-wishers following her swearing-in.

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4

▲ Actress Kathy Bates has lymphedema and urges those with the disease to be seen and heard.

12 **Understanding the Opioid Overdose Epidemic**

16 **Clinical Trials and You**

20 **Healthy Pregnancy**



20

▲ The Human Placenta Project is part of research efforts to promote healthy pregnancies.

2 **Cancer Moonshot Aims to Double Pace of Research**

4 **Living With Lymphedema**

9 **Vasculitis**



▲ The START study on arthritis is just one example of NIH-supported clinical trials.

24 **Finding Good Health Information Online**

28 **HealthLines: Research News**

29 **Contact Us**

Photos: (cover and top) Keith Munyan; (center) Mike Shaw, Wake Forest University; (bottom) NICHD

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

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Cancer Moonshot

Aims to Double Pace of Research

During his State of the Union address in January, President Obama announced the “Cancer Moonshot” initiative to speed up cancer research. The initiative aims to make more therapies available to more patients sooner. It also seeks to improve our ability to prevent cancer and detect it at an early stage.

NIH MedlinePlus magazine sat down with Dinah Singer, PhD, one of the three co-chairs of the Cancer Moonshot Initiative’s Blue Ribbon Panel and Director of the National Cancer Institute’s Division of Cancer Biology, to learn about its progress.



Dr. Dinah Singer, co-chair of the National Cancer Moonshot Initiative Blue Ribbon Panel

Photo: Bill Branson, NIH

What should the public know about the goals of the Moonshot?

The President’s memo outlined three goals. One is to speed up progress regarding cancer. Number two is to help all parts of the cancer community join forces—from academics to the private sector and government agencies. The third goal is to increase data sharing across these sectors.

We have been charged with speeding up our knowledge of cancer—the basis of the disease and how it progresses. This will depend on expanding and supporting new research. The President’s memo says we should do in five years what we’d normally do in 10.

We ended up having more than 150 people from the cancer community involved in making an action plan of research options that would benefit cancer patients to better prevent, diagnose, and treat cancer.

What areas have been identified for early research under this new initiative?

Rather than look at specific types of cancer, we're looking more broadly at global barriers. For instance, we're looking at access to clinical trials. Today, only about five percent of all cancer patients are enrolled in clinical trials. One of the recommended actions is to develop a network that will engage patients directly and increase their access to studies.

That way, any patient anywhere in the country can register, have their tumor genotyped, and be pre-registered for a clinical trial for which they are eligible. This creates a database of research and clinical information to help us learn more about the different kinds of cancers.

“It takes all cancer patients to cure one patient.”

—Dr. Dinah Singer, co-chair,
Cancer Moonshot Initiative Blue Ribbon Panel

Another recommendation proposes to screen cancer patients for the presence of genes that predispose them to cancer. If the patient is a carrier, we could offer their close relatives a chance to be screened for that gene and allow early detection of a cancer. This has the potential to save hundreds of thousands of lives.

Other cancers that we focus on are those in people who don't have a cancer-related gene. In many cases, those cancers can be prevented through means that we know work. For instance, we know cervical cancer can be prevented with HPV shots. Quitting smoking reduces lung cancer and early screening reduces colon cancer.

Most people think, “We've already done huge amounts with tobacco cessation,” but there are huge gaps. For instance, one gap is in people who have been diagnosed with lung cancer. There are very few programs to help those patients stop smoking.

Enhanced data sharing is a theme running through all these actions. To paraphrase, it takes all cancer patients to cure one patient. What I mean is that in order to understand any one tumor, we have to look at thousands to predict how the one will respond. To do that, we have to be able to share data.

What are some approaches that could boost data sharing?

What I've found is there is a lot more interest in sharing data than people presume. The difficulties are more technical. Different researchers use different formats. This is what we'll need to address.

An incentive is that if I share my data, you'll share your data. Together, we'll accomplish a lot more. Drug

companies will want to share some of their data to be able to work with scientists. The idea is to link everyone up and promote data sharing.

What else can you tell us about clinical trials?

The idea is to have a network where cancer patients can register. In terms of clinical trials, immunotherapy is an exciting new tool in the treatment of cancer. Immunotherapy is a treatment designed to boost the body's natural defenses to fight cancer.

I've been watching its development for 30 or 40 years. It has had a quantum leap in the past few years. We'll need a lot of clinical trials to understand the tumors that respond and the tumors that don't respond to this treatment.

Many times, patients respond well to a standard of care. Other times, they'll respond and then relapse. The question again is why? Can we predict who will respond and benefit from therapy and who will not? The action here is having tumors biopsied, storing those samples, and analyzing them in future research. These would be small clinical trials because they would be very focused. But they would be very good at helping us find which patients are going to benefit from what therapy.

As someone who has been in cancer research for more than four decades, what does the Cancer Moonshot mean to you?

The way our knowledge has exploded has offered so many new opportunities for people with creative ideas to move the field forward. What we're limited by at this point is our resources. The passion and commitment of the research community is amazing and inspiring.

As a research scientist running a lab, it's been exciting to see the cancer community come together because of this initiative. There's lots of hope that the Moonshot will take off. We've outlined goals and begun strategizing to guide NCI's planning going forward.

We had a website called Cancer Research Ideas at cancerresearchideas.cancer.gov. Anyone could submit thoughts and ideas about cancer research. Between that, email, and other outreach, we had 1,600 responses, all of which we read and considered in our deliberations. Although the Cancer Research Ideas site is not accepting new ideas, the ideas that were posted still can be viewed.

Find Out More

- ✓ **National Cancer Institute:**
cancer.gov/research/key-initiatives/moonshot-cancer-initiative

A Leading Role

Actress and director **Kathy Bates** is a fan favorite thanks to her wide variety of stage and screen roles. She is perhaps best known for her Academy Award-winning performance in the movie *Misery*, playing an obsessed fan who holds her favorite author captive. Since 2013, she has starred in the *American Horror Story* series on the FX television network.

Photo: Keith Munyan

FastFacts

- ✓ Lymphedema is a disease in which the lymph fluid does not drain properly. It may build up in the tissues and cause swelling.
- ✓ It can happen when part of the lymph system is damaged or blocked, such as during surgery to remove lymph nodes or radiation therapy. Cancers that invade lymph vessels can cause lymphedema. It can also be hereditary.
- ✓ Lymphedema usually affects an arm or leg, but it can affect other parts of the body, such as the head and neck.

in Lymphedema Awareness

After developing lymphedema following a double mastectomy due to breast cancer, Bates has been a strong advocate for those with the disease. A national spokesperson for the Lymphatic Education & Research Network, she shared her story with *NIH MedlinePlus* magazine.

You developed lymphedema after surgery for breast cancer. When did you first experience symptoms? Was it diagnosed quickly?

I started feeling symptoms right away in the hospital. It was a strange kind of pain that moved around in my hands sort of like lightning. I knew all about lymphedema. A man I knew had it and never took care of it. He never had therapy. His arm was heavy like wood. It was so painful he took drugs to manage that and became addicted.

I was terrified of getting it. I had seen my mother's arm swell when she had a radical mastectomy many years ago. I didn't know what it was then.

What was your reaction when you got the diagnosis?

My reaction? I flipped out. I was being examined for the first time since my surgery. I was in a lot of pain. When my surgeon told me he removed 19 lymph nodes from my left armpit and three from my right, I went crazy in the examining room and ran out of the building.

How do you manage your lymphedema? How often do you get treatment?

I try to get treatment at least once a month or every six weeks. When I work out of town I have to find a therapist there. I am lucky in that my lymphedema is barely recognizable. Also I have lost 30 pounds and that has helped immensely. I manage it by wearing compression sleeves when my arms hurt. Sometimes being on the computer irritates the crook of my arm. So I self-massage and put my sleeves on. Swimming is excellent. I have to wear my sleeves on airplanes. Sometimes I have to wear them while shooting, but it's difficult given the style of the costume.

"Lymphatic disease is a life sentence," Kathy Bates told attendees last year at the NIH Lymphatics Symposium.

Photo: Ernie Branson, NIH

You have called lymphatic disease a “life sentence.” What do you mean by that?

Many doctors think that since lymphedema is rarely fatal that it's merely a cosmetic issue. They haven't a clue of how many millions of people suffer in this country—10 million. More than MS, muscular dystrophy, ALS, Parkinson's, and AIDS combined. Those millions suffer far worse than I. They suffer in silence, in shame, and may be ridiculed. It can be fatal. People have lost loved ones due to complications brought on by untreated lymphedema.

This disease affects not only quality of life, but in some cases whether a person can have a life. Infections like cellulitis—which I have had in my arm—can be serious if untreated, requiring frequent hospital stays. And the psychological damage cannot be measured. That is a life sentence in my opinion.

I asked Dr. Stan Rockson of Stanford University, who consults with Lymphatic Education & Research Network (LE&RN), why so few general practitioners know about lymphatic diseases. He said very little time is spent on it in medical school—it's glossed over in a couple of hours.

Why did you become an advocate for people with lymphedema?

When I discovered that breast cancer survivors who develop lymphedema are just the tip of the iceberg, that there are many different kinds of lymphedema, it was an eye-opener. It is congenital. Sometimes it appears when people are in their 20s and just beginning their lives. When you are about to embark on the best years of your life, your aspirations to become someone wonderful in this world, all of that can end. Can you imagine?



Kathy Bates in character as Iris, manager of the Hotel Cortez, during the third season of *American Horror Story*.

Photo: Frank Ockenfels/FX Network

What advice do you have for others who are facing lymphedema?

Get the best care you can find immediately. You must see a doctor who is trained to diagnose and treat lymphedema specifically. Persevere. Go online and research for yourself. Find a treatment center near you. Unfortunately, it may have a long waiting list. There are not enough trained therapists. Most importantly, a doctor must properly diagnose you before using compression sleeves. Don't just go out and buy them. If they don't fit just right for you, you risk worsening your lymphedema.

Many people with lymphedema are afraid to “come out,” so to speak. We want them to come out. To us, to each other, to band together and create their own support groups. At LE&RN, we are encouraging people to send us brief videos just giving their names and that they have lymphedema. We are hoping to create a kind of AIDS quilt, only with videos of the faces of those who suffer. All of this will raise awareness. That is key.

With Lymphedema, Early Treatment is Key

You may notice symptoms of lymphedema at the part of your body where you had surgery or received radiation therapy. Swelling associated with lymphedema usually happens slowly, over time. It may develop during treatment or it may start years after treatment.

At first, lymphedema in an arm or leg may cause symptoms such as:

- swelling and a heavy or achy feeling in your arms or legs that may spread to your fingers and toes
- a dent when you press on the swollen area
- swelling that is soft to the touch and usually not painful at first

Lymphedema that is not controlled may cause:

- more swelling, weakness, and difficulty moving your arm or leg
- itchy, red, warm skin, and sometimes a rash
- wounds that don't heal, and an increased risk of skin infections that may cause pain, redness, and swelling
- thickening or hardening of the skin
- tight feeling in the skin; pressing on the swollen area does not leave a dent
- hair loss

Lymphedema in the head or neck may cause:

- swelling and a tight uncomfortable feeling on your face, neck, or under your chin
- difficulty moving your head or neck

Tell your health care team as soon as you notice symptoms. Early treatment may prevent or reduce the severity of problems caused by lymphedema.

Managing the Condition

Steps you may be advised to take to prevent lymphedema or to keep it from getting worse:

- **Protect your skin.** Use lotion to avoid dry skin. Use sunscreen. Wear plastic gloves with cotton lining when working to

prevent scratches, cuts, or burns. Keep your feet clean and dry. Keep your nails clean and short to prevent ingrown nails and infection. Avoid tight shoes and tight jewelry.

- **Exercise.** Work to keep body fluids moving, especially in places where lymphedema has developed. Start with gentle exercises that help you to move and contract your muscles. Ask your doctor or nurse what exercises are best for you.
- **Manual lymph drainage.** See a trained specialist (a certified lymphedema therapist) to receive a type of therapeutic massage called manual lymph drainage. Therapeutic massage works best to lower lymphedema when given early, before symptoms progress.

Treatment Options

Your doctor or nurse may advise you to take these and other steps to treat lymphedema:

- **Wear compression garments or bandages.** Wear special garments, such as sleeves, stockings, bras, compression shorts, gloves, bandages, and face or neck compression wear. Some garments are meant to be worn during the day, while others are to be worn at night.
- **Other practices.** Your health care team may advise you to use compression devices (special pumps that apply pressure periodically) or have laser therapy or other treatments.

Talking With Your Health Care Team

Prepare for your visit by making a list of questions. Consider adding these questions to your list:

- What can I do to prevent these problems?
- What symptoms should I call you about?
- What steps can I take to feel better?
- Would you recommend that I see a certified lymphedema therapist?
- If lymphedema advances, what special garments should I wear during the day? During the night?

Source: National Cancer Institute

Lymphedema: What We Know

Ann O'Mara, PhD, RN, MPH, Head of Palliative Research at the National Cancer Institute's Division of Cancer Prevention, explains.



Photo: NCI

Dr. Ann O'Mara, National Cancer Institute

Who is at risk for getting lymphedema?

Having lymph nodes removed during breast cancer surgery can put you at risk. Women who have this along with chemotherapy are at highest risk. Patients with head and neck cancer, which is primarily men, who have radiation and lymph nodes removed also can get lymphedema. Women having lymph nodes removed for cervical cancer are also at risk.

On the other hand, head and neck cancer patients who don't have lymph nodes removed but do receive radiation can develop lymphedema. So it's not just the removal of lymph nodes.

Not everyone who has lymph nodes removed gets lymphedema. That's the puzzle—who is and who is not going to get it? Right now, we don't know, and that's where the research is.

Can you be born with lymphedema?

There is a lymphedema that people are born with. They have weak lymphatic drainage and it may be very subtle. Then it can become full blown. We do believe there likely are women with certain genes who are at higher risk.

How can patients make sure they get timely lymphedema diagnosis and treatment?

Women will report a feeling of heaviness in their arms. They are not able to get their rings off, and then their fingers start getting stiff. Don't ignore it! Get back to your surgeon because that's the best time to treat it. Massage from physical therapists who specialize in lymphedema, wearing compression garments, and exercise are great ways to help control lymphedema.

Besides painful swelling, what are other complications of lymphedema?

The swelling of lymphedema disrupts blood flow. That can keep wounds from healing. It's important to protect the affected arm. Infection is the major problem. Also, women with cancer of the vagina, uterus, or ovaries who have surgery are at risk for blood clots in the deep veins of the legs, known as deep vein thrombosis.

Trends in Lymphedema Research

- **Lymphedema and Breast Cancer:** Christine Miaskowski, RN, PhD, FAAN, of the University of California San Francisco is leading a study of a large group of women with breast cancer who received the same surgery and the same treatment after surgery. It aims to find out if genes cause lymphedema.
- **Lymphedema and Gynecologic Cancer:** Richard R. Barakat, MD, FACS, of Memorial Sloan Kettering Cancer Center, recently completed a study of women with gynecologic cancer. The study seeks to find why patients get lymphedema.
- **Regenerating Lymphatic Tissue:** Research funded by NCI is examining the possibility of reviving lymphatic tissue and restoring lymphatic flow. "That's now being studied in animal models," Dr. O'Mara says. "But if we can find a way to regenerate lymphatic tissue, that would be huge progress."

Find Out More

- ✓ **National Cancer Institute:** nlm.nih.gov/medlineplus/lymphedema.html
- ✓ **MedlinePlus:** medlineplus.gov/lymphedema.html
- ✓ **Clinical Trials:** medlineplus.gov/lymphedema.html#cat27
- ✓ **Lymphatic Education & Research Network:** lymphaticnetwork.org

Vasculitis

A rare-but-serious family of diseases you may never have heard of



Dr. Peter Grayson (left), principal investigator of NIH's Vasculitis Translational Research Program, reviews diagnostic images with Dr. Mark Ahlman at the NIH Clinical Center.

Photos: Ernie Branson, NIH

When there is swelling or inflammation in the body's blood vessels, the cause may be vasculitis. That's an umbrella term for more than 30 uncommon conditions—some of them life-threatening.

What Is Vasculitis?

It is a condition that involves inflammation in the blood vessels. It can result in poor blood flow to the body's organs and tissues. Vasculitis occurs when your immune system attacks your blood vessels. This can happen due to infection, reaction to a medicine, or another disease or condition.

Blood vessels include:

- Arteries that carry blood from your heart to your body's organs
- Veins that carry blood from your organs and limbs back to your heart
- Capillaries that connect your small arteries and veins

"There are well over 30 different types of vasculitis," notes Dr. Peter Grayson. He is founder and principal investigator of the Vasculitis Translational Research Program (VTRP) at the NIH's National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). "We group them predominantly based on the size of the blood vessels that are affected."

Vasculitis is believed to be an autoimmune disease. This is where the immune system is dysfunctional or confused. The immune system, rather than fighting off infections, actually starts to attack blood vessels.



Dr. Peter Grayson, principal investigator, VTRP

Diagnosis

“There is no single test for diagnosing vasculitis,” Dr. Grayson says. “Diagnosing comes down to pattern recognition. But even within individual conditions, there are variations.”

This can make diagnosis a challenge for health care providers.

Photo: Ernie Branson, NIH



Imaging technology can help diagnose some types of vasculitis. Posing with a PET-CT scanner used in NIH research are, from left, Elaine Novakovich, RN, Peter Grayson, MD, Kathleen Marinelli, Mark Ahlman, MD, and Sara Alehashemi, MD.

Treatment

“Thirty years ago, many of these diseases were fatal. Today, we try to find out what drug will be right for each person,” Dr. Grayson says. “Treatment often works well if it’s started early. In most cases, vasculitis can go into remission with treatment. This means the condition isn’t active, but it can come back, or ‘flare,’ at any time.”

Sometimes vasculitis is chronic, or ongoing, and never goes into remission. Long-term treatment with medicines often can control vasculitis.

Much is still unknown about vasculitis. But researchers, including Dr. Grayson and his team, continue to learn more about the condition and its various types, causes, and treatments.

Research

Although most patients with vasculitis achieve remission with treatment, many experience at least one relapse. A major focus of Dr. Grayson and his team is to identify when a relapse might occur. Markers in the blood and tissues can guide treatment decisions for people with the disease.

The VTRP also collaborates with the NIH-supported Vasculitis Clinical Research Consortium. It is a network of academic medical centers, patient support organizations, and clinical research resources. Fifteen participating clinical centers throughout the United States and Canada currently conduct studies.

NIH-supported researchers are working to identify the genetic and biologic structures of the various forms of vasculitis. Their goal is to develop more targeted and less toxic therapies for people with the disease.

Coping with Vasculitis and Contributing to Research

A Personal Journey for Ida Hakkarinen

For two-and-a-half years—May 2009 to November 2011—Ida Hakkarinen felt like a walking catalog of disease symptoms: reflux, joint aches, bronchitis, night sweats, elevated body temperature, extreme fatigue, sinus congestion, trouble breathing, wheezing, chronic cough. Some came and went; some came and stayed.

“Now that I look back at those episodes,” Hakkarinen says, “I wonder if they were signs of GPA waiting to break forth.”

The GPA she mentions is *granulomatosis with polyangiitis* (GPA, formerly *Wegener’s granulomatosis*), one of more than 30 rare diseases that fall under the umbrella of vasculitis—a condition that involves inflammation in the blood vessels.

“I did not know what vasculitis was, prior to my diagnosis,” says Hakkarinen, a meteorologist with the National Oceanic and Atmospheric Administration. After undergoing surgery at MedStar Georgetown University Hospital in December 2011 to widen her airway, which had narrowed due to inflammation, Ida was referred by her surgeon to Dr. Thomas Cupps, chief of the division of rheumatology, immunology, and allergy at Georgetown University Medical School. He diagnosed her in early 2012 with GPA and became her treating physician. Over the next two years, she was hospitalized twice for relapses.

NIH Clinical Trials

In 2014, Dr. Cupps, told her about a vasculitis research trial at the National Institutes of Health (NIH) by Dr. Peter Grayson, founder of the Vasculitis Translational Research Program in the NIH’s National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

“Having a rare disease, I wanted to contribute to the research being done in vasculitis through the use of my personal health data,” she says. “I also hoped that through a clinical trial, I could benefit from having a ‘second opinion’ from a medical professional researching the disease, which might help my treatment.”

Meteorologist Ida Hakkarinen, shown with a weather satellite being prepared for launch, has a form of vasculitis. She takes part in NIH-supported clinical research.

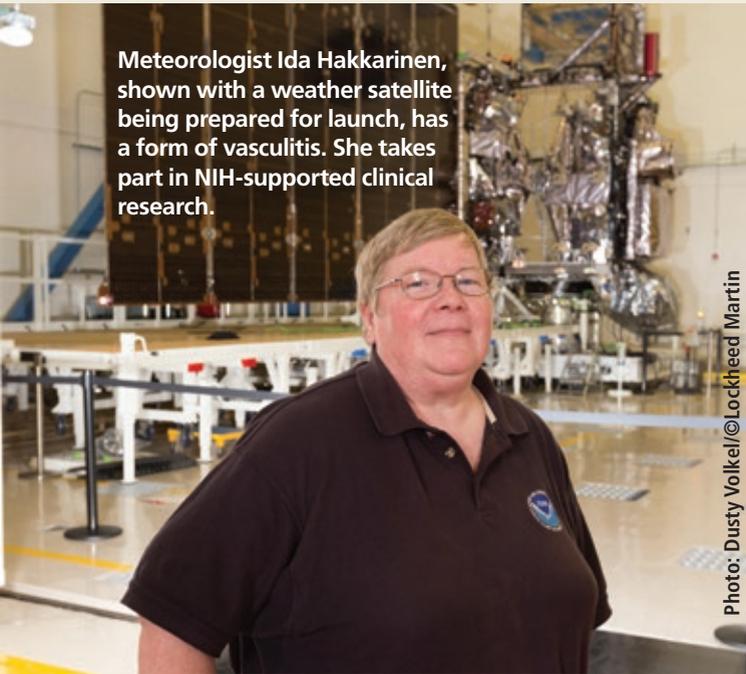


Photo: Dusty Volkel/©Lockheed Martin

“I knew from my Internet searches about GPA that the research conducted by Drs. Sheldon Wolff and Anthony Fauci at the NIH from 1968-1971 was fundamental to the discovery of a treatment for the disease, leading to the use of cyclophosphamide in combination with prednisone for bringing GPA into remission. Through their clinical trials, GPA was transformed from a nearly uniformly fatal disease to a chronic one,” says Hakkarinen.

Hakkarinen was accepted as a participant in Dr. Grayson’s research at the NIH Clinical Center. She felt confident that Dr. Grayson and his colleagues would provide an additional medical opinion regarding her diagnosis and the current state of her disease, as well as recommendations for treatment.

Dr. Cupps suggested this study to Hakkarinen because, as he told her, one of the benefits of being in a research study is gaining information about the newest ideas in treatment options.

“In the beginning, I went to the NIH in Bethesda, Maryland, four times a year for routine lab work, including blood samples, totaling 18 vials each time, and a urine sample,” she says. “Beginning in 2016, my appointments changed to every six months. A variety of tests are

performed on my blood. My understanding is that, while clinicians and researchers look at a variety of measurements to assess the state of a patient’s disease, there are no clear biomarkers identified at this time.

“That’s one goal of the study Dr. Grayson is performing,” she adds, “to gather a cohort of patients with vasculitis (both adult and pediatric) to evaluate the signs and symptoms, imaging findings, and blood and tissue biomarkers associated with pathogenesis and disease outcomes. Another goal is to identify, from this group, patients for possible entry into future protocols of treatment studies.

“Having a rare disease, I wanted to contribute to the research being done in vasculitis through the use of my personal health data.”

—Ida Hakkarinen

“After each of my research visits, Dr. Grayson provides input to Dr. Cupps regarding recommendations for my treatment. I appreciate having another set of data and the insight from a second medical team on the status of my disease and treatment options.

“The NIH patient data portal is being updated to enable results from NIH laboratory findings to be available electronically to a patient’s clinicians. This connectivity of electronic health records will be an important step in data sharing between the research physicians and the patient’s treatment physicians.

“As a patient with a rare disease that is often complex and not easily diagnosed in its beginning states,” she adds, “I feel a duty to help educate young medical professionals about granulomatosis with polyangiitis, and the importance of gathering accurate medical histories that include often subtle signs and symptoms that, when pieced together, outline a framework suggestive of a diagnosis of vasculitis.”

Find Out More

- ✓ **National Institute of Arthritis and Musculoskeletal and Skin Diseases:** niams.nih.gov/research/ongoing_research/Branch_Lab/Systemic_Autoimmunity_Branch/vtrp.asp
- ✓ **MedlinePlus:** medlineplus.gov/vasculitis.html
- ✓ **Clinical Trials on Vasculitis:** <https://medlineplus.gov/vasculitis.html#cat27>

Understanding The Opioid Overdose Epidemic

Responding to the crisis.

Prescription opioids are powerful drugs commonly used to reduce pain after surgery or injury. They are also used for pain from health conditions like cancer. However, opioids can produce harmful side effects, including drowsiness, mental fog, nausea, constipation, and respiratory depression (slowed breathing) that can lead to overdose deaths. Continued use can lead to addiction, making it hard to stop using opioids even after the cause of pain is gone.

An estimated 1.9 million people in the United States have a prescription opioid use disorder. Another 586,000 have a heroin use disorder. Heroin is an opioid drug that is produced from morphine and sold illegally. Although most people who use heroin (80 percent) started by misusing prescription opioids, most people who abuse pain relievers (96 percent) do NOT go on to use heroin.

Anyone taking an opioid can suffer an overdose, which slows a person's breathing so much that the person passes out and is at risk for death. This can happen when someone takes more than prescribed, combines opioids with depressants (such as Xanax®) or alcohol, or has a medical condition that makes them more sensitive. In 2014, more than 28,000 people died from an opioid overdose, and more than half of those deaths involved a prescription opioid.



Wilson Compton, MD, deputy director of the National Institute on Drug Abuse (NIDA)

“There is a very complex set of issues leading to this public health crisis,” says Wilson Compton, MD, deputy director of the National Institute on Drug Abuse (NIDA).

“We can’t just stop treating pain,” Compton says. “But now that we’re discerning some of the risks, we must balance the need for pain treatment with the abuse potential. The goal is to minimize the risk for this substance use disorder while discovering better ways of treating pain.”

The U.S. Department of Health and Human Services (HHS) launched the **Opioid Initiative**. It focuses on three priority areas to tackle the opioid crisis.

1. Improve Opioid Prescribing

Pain is one of the most common reasons for health care visits. A doctor who wants to alleviate a patient’s pain may be thinking, “You’ve got pain; I’ve got a pain reliever.” But opioids are not always the best treatment option for pain.

Part of the National Pain Strategy is providing pain education for health professionals and pain management care for patients. Because it’s not always covered in clinical training, more than a dozen NIH Institutes and Centers are working together to improve the quality of education about pain treatment for medical, nursing, dental, and pharmaceutical schools.

Health care providers wrote nearly a quarter of a billion opioid prescriptions in 2013—enough for every American adult to have his or her own bottle of pills.

New Prescribing Guidelines

In 2016, the Centers for Disease Control and Prevention (CDC) released new guidelines suggesting that long-term opioid therapy for chronic pain, outside of end-of-life or cancer care, remains limited. The risks for misuse and overdose remain high. The checklist when considering long-term opioid use includes:

- Setting realistic goals for pain and function based on diagnosis
- Checking that non-opioid therapies (such as anti-inflammatories) and non-pharmacologic therapies (such as exercise and cognitive behavioral therapy) have been tried



- Discussing benefits and risks for harm or misuse
- Setting criteria for stopping or continuing opioids
- Assessing baseline pain and function
- Scheduling reassessment within one to four weeks
- Prescribing short-acting opioids using the lowest dosage

Improving the way opioids are prescribed can ensure patients have access to safer, more effective chronic pain treatment options while reducing the number of people who misuse or overdose on these drugs.

Compton says, “We have started to see prescribing patterns change with modest reductions in opioid prescriptions.”

2. Expand Access to Medication-Assisted Treatments

There are three approved medications to help treat opioid addiction. All are designed to help patients stop their opioid drug use and improve their overall health and functioning.

- **Methadone** is a liquid that is taken daily. It reaches the brain slowly, and is long-acting, preventing withdrawal symptoms and reducing opioid craving. It requires that you go to a special clinic every day to receive it.
- **Naltrexone** blocks the action of opioids and is not addictive or sedating. The Food and Drug Administration (FDA) approved an injectable, long-acting formula in 2010, which can be taken once a month.

- **Buprenorphine**, a daily tablet that can be prescribed by a doctor, prevents withdrawal in patients with opioid use disorder and helps these patients manage cravings so they can return to their daily routines. An implantable formulation of buprenorphine was recently approved that provides six months of continuous medication for patients stabilized on buprenorphine and eliminates the need for daily dosing.

What the Research Tells Us

Research suggests that medication-assisted treatment is much more effective than behavioral therapies alone.

Opioid use disorders change the way the brain works, causing alterations in the brain circuits responsible for reward, habit, and decision making. All three of these medications directly target opioid receptors and either stabilize these circuits or block the action of illicit opioids.

Studies have shown that methadone, naltrexone, and buprenorphine are all effective treatments that significantly reduce opioid use and help patients stay in recovery.

“Opioid addiction is a long-standing problem,” Compton says. “But we’re working hard to engage the medical community, using research to convince them, and working with our health care partners to help shape prescribing practices.”

3. Increase Access to and Use of Naloxone for Overdose

More than 28,000 deaths in 2014 were linked to opioid overdose. In 1971, the FDA approved the drug naloxone to prevent overdose death or to reverse overdose, which has since become a standard of care for emergency medical personnel.

However, in the past two years, the FDA has approved both a naloxone auto-injector and a nasal spray, which make the drug easier for families and loved ones to administer. This will prevent opioid-related deaths and give patients a second chance to enter into long-term treatment.

Compton describes the auto-injector for naloxone, which is the size of a pack of cards. “You can simply take the cap off and it will start talking, giving step-by-step instructions on administering the opioid antidote,” Compton says. “It’s a very easy way for non-medical people to save a person’s life.”

He also sees promise with the nasal spray. “It’s inexpensive and very easy to use, so there are broader implications for getting the drug into the hands of those on the front lines in an overdose—family members, friends, or first responders.”

U.S. Surgeon General Dr. Vivek Murthy

sent a direct plea in late August to 2.3 million doctors and other health care workers to help fight the opioid epidemic by treating pain “safely and effectively.” A website for his “Turn the Tide” campaign highlights alternative, nonaddictive treatments for pain at turnthetidex.org.



Photo: Office of the Surgeon General

Co-Prescribing Provides Better Results

NIDA funded research suggests that co-prescribing naloxone may reduce opioid overdose. “Prescribing naloxone along with an opioid is one way of making sure this life-saving drug is in the hands of people who may overdose or be around someone who may overdose,” Compton says.

Research shows that even if the naloxone prescription is not filled, the health care provider has educated the patient using opioid pain relievers about the potential dangers of opioids, and fewer patients end up in the ER with adverse side effects.

NIDA and its partner institutes in the search for solutions to the opioid crisis continue to look for different approaches to treat pain. “Certainly, there are some people who are responding well to opioids, but all too often, patients become addicted without achieving long-term pain relief,” Compton says. “As long as that’s the case, we will continue to look for other treatment options to improve the lives of those suffering with chronic pain.”

Safe Disposal of Opioid Medications

Opioids may be especially harmful and, in some cases, fatal in a single dose if they are used improperly. Once you no longer need them, dispose of them promptly to avoid harm to others and the environment.

If you properly dispose of these medicines, they cannot be stolen and misused, or accidentally taken or ingested by children, pets, or anybody else.

Safely dispose of opioid medications by mixing them with something unappealing like kitty litter or used coffee grounds in a sealed plastic bag before throwing them into your household trash.

Beyond Opioids: Mind and Body Practices

A Personal Story

When asked recently by her doctor, “How would you rate your daily pain,” Diana Gray answered quickly, “What pain?” She breaks into laughter just talking about the exchange.

At 73, Gray has battled chronic pain—that is, pain that lasts a long time and can be hard to treat—for nearly 20 years. She was first diagnosed with osteoarthritis of the hip after a car accident left her feeling really old at age 55. A retired student affairs administrator, Gray longed for the days when she walked a mile to work every morning at the University of Chicago.

Research suggests that mindfulness meditation—paying close attention to the breath and body movements—reduces stress and produces a sense of well-being.

Along her pain journey, doctors prescribed opioids after two hip surgeries and a wrist surgery after a fall. “I can understand how people get addicted. It’s hard being in chronic pain,” Gray says. “It affects every part of your life. You can’t sleep. You gain weight. You get depressed.”

Recent research shows that some non-drug approaches—including mind and body practices such as tai chi and mindfulness meditation—can help some people with chronic pain feel better.

For example, a study funded by the National Center for Complementary and Integrative Health (NCCIH) found that tai chi, a traditional Chinese practice that combines meditation with deep breathing, relaxation, and gentle movements, was as effective as physical therapy. Tai chi may also lessen pain in people with fibromyalgia, a disorder that causes widespread pain, fatigue, and other symptoms.

Four mornings each week, Gray walks to a local park near her house to a tai chi class. On the other three mornings each week, she practices tai chi at home. She says she feels younger today than she did 10 years ago. “I was lucky that I didn’t like the way opioids made me feel,” Gray says. “Once the pain moved into my knees, it forced me to find another way to treat my pain.”

If, like Gray, you have chronic pain, you may want to talk with your health care provider about adding a mind and body approach to your treatment plan.



Diana Gray, a 73-year-old grandmother, practices the ancient Chinese practice of tai chi to reduce her chronic pain.

Photo: Terri Poindexter Smith

For low-back pain, several techniques—including mindfulness-based stress reduction, spinal manipulation, massage therapy, and yoga—have shown promise in NCCIH-sponsored research studies.

“I know that the slow and gentle movements of tai chi keep me feeling pain free,” Gray says. “I highly recommend it to anyone suffering from chronic pain.”

Find Out More

- ✓ **National Institute on Drug Abuse:** drugabuse.gov/drugs-abuse/opioids
- ✓ **National Center for Complementary and Integrative Health:** nccih.nih.gov/health/pain
- ✓ **MedlinePlus:** medlineplus.gov/painrelievers.html
- ✓ **NIH Pain Consortium:** painconsortium.nih.gov
- ✓ **U.S. Department of Health and Human Services:** hhs.gov/opioids
- ✓ **Turn the Tide Rx:** turnthetiderx.org

CLINICAL TRIALS

A Healthier Future for All

Did you know that most anyone can get involved with clinical research? No matter if you're healthy, sick, young, or old, you may be able to help scientists find treatments or cures. Clinical trials, also known as clinical research or clinical studies, offer hope for many people with a health condition or illness.

Helping Yourself and Helping Others

If you or a loved one has a condition, you may be able to help test a new drug, device, or intervention. While participating in a clinical trial may not result in direct benefits to your health, the knowledge developed may help others. If you're a healthy volunteer, you can help scientists learn more about how the body works or how to prevent an illness. Either way, it's a chance to potentially help yourself and help others.



Medical care is better today thanks to clinical trials from the past. It will be better tomorrow as a result of clinical trials going on today.

There are different types of clinical trials:

- **Natural history studies** provide valuable information about how disease and health progress.
- **Screening trials** test the best way to detect certain diseases or health conditions.
- **Diagnostic trials** determine better tests or procedures for diagnosing a particular disease or condition.
- **Treatment trials** test new treatments, new combinations of drugs, or new approaches to surgery or radiation therapy.
- **Quality of life trials** (or supportive care trials) explore and measure ways to improve the comfort and quality of life of people with a chronic illness.

Before a new medical treatment or medication can be given to the public, it has to pass through clinical research studies. These are designed to test if it works and if it is safe.

Participation by many people is important because medical treatments may affect different racial or ethnic groups in different ways.

The Process

A clinical trial closely follows a protocol—the process that will be followed throughout the trial. The protocol clearly defines who can participate, how long the study will last, and what information will be collected. It also tells the research team, and you, what tests, procedures, medications, and dosages are involved.

Clinical trials are conducted in “phases.” Each phase has a different purpose and helps researchers answer different questions.

The first phase of a clinical trial involves a smaller group of people, usually less than 100. If no major problems occur at this stage, the treatment is tested on larger groups of people in Phase II and Phase III trials, usually including patients with the condition.

After a trial, the information is analyzed to see if the treatment, intervention, or medication is better, worse, or about the same as

Find a Clinical Trial Near You

Health research takes place at hospitals, universities, doctor’s offices, and community clinics across the country. Much of the research is conducted through the National Institutes of Health, which currently supports nearly 224,000 studies in all 50 states and in 192 countries.

If you are interested in participating in a clinical trial, visit **ClinicalTrials.gov** to see what is being studied in your area and regarding your condition. Your doctor can help you decide if a trial makes sense for you.

what is currently available. Once the Food and Drug Administration rules on the safety and effectiveness of a treatment drug, it is made available to the public.

Protections

If you’re thinking about joining a clinical trial, the research team will tell you about the details of the study and what your involvement would mean before getting your informed consent. This is a signed document that details the study, it’s purpose, length, processes, risks, and who to contact for more information. You should be well informed and feel confident and secure about participating.

Before you enroll in a clinical trial, you may have to take screening tests to see if you are able to participate. These tests are designed to exclude those who may not benefit from, or may be harmed by, the treatment.

Most, but not all, clinical trials in the U.S. are approved and monitored by an Institutional Review Board (IRB). An IRB is an independent committee that consists of physicians, statisticians, and members of the community who ensure that the trials are ethical and that your rights are protected. Ask the sponsor or research coordinator whether the trial you want to participate in was reviewed by an IRB.

Need for Inclusion

More members of minority groups are needed to participate. For example, African Americans make up about 12 percent of the U.S. population, but only five percent of clinical trial participants. Hispanic/Latino Americans make up 16 percent of the population, but less than one percent of participants in clinical trials.

Participation by many people is important because medical treatments may affect different racial or ethnic groups in different ways. Clinical trials are designed to measure these variations, so it’s very important to have diversity.

Meet Clinical Trial Participants

People just like you from all walks of life and living in many places across the country participate in NIH-funded clinical trials. Some have a medical condition. Others are part of healthy control groups—people who are willing to lend a hand to ensure that science can move forward. They are helping to improve the health of future generations.



HIV-AIDS

Zenovia's uncle died of complications due to AIDS when she was a senior in college, and she wondered how many other families were going through the same loss and anguish. She began to think about ways she could make a difference for people living with HIV. In addition to pursuing a master's degree in public health and joining the DC HIV Prevention Community Planning Group, Zenovia has participated in clinical trials to promote HIV vaccine research with the Vaccine Research Center at the National Institute of Allergy and Infectious Diseases.



Asthma

Allison, a public affairs specialist with NIH, is enrolled in an ongoing clinical trial as a healthy volunteer. She's paired with a patient who has asthma and is of similar gender, age, height, and weight. She goes to the NIH Clinical Center once a year for breathing tests, DEXA scans, blood draws, and chest X-rays. While Allison doesn't have asthma, she knows how important her participation is in finding better treatment options for those with this condition.



Alzheimer's

Dewayne, a retired doctor, has a strong family history of Alzheimer's disease. He volunteered for a study at UT Southwestern's Alzheimer's Disease Center, where he could contribute to research efforts and be monitored for signs of cognitive impairment. His decision to volunteer changed his life and set him on a new course to educate and reach out to those facing this disease.



Crohn's

On the surface, Holden looks like a typical boy. But he deals with a chronic illness, Crohn's disease, which makes his life anything but ordinary. He is participating in a clinical trial led by UNC-Chapel Hill researchers. UNC-Chapel Hill is home to one of more than 60 institutions participating in NIH's Clinical and Translational Science Awards (CTSA) program. His mother says, "He feels so much better and we're getting a different level of care. They go way beyond treating his Crohn's disease."



Sickle Cell

Afia once struggled to walk even a few blocks anytime she had a flare-up due to her sickle cell disease. In 2010, she arrived at the National Institutes of Health to undergo an experimental treatment. Doctors removed her bone marrow and replaced it with specially treated marrow from her brother. Today, Afia works as a lawyer and can do things she once only dreamed of, including running to stay fit. Her fatigue and pain have all but disappeared, and she offers a glimpse of what results might take place in the future for other sickle cell patients.

Photos: (from top to bottom) Zenovia Wright, Allison Fisher, Dr. Dewayne Nash, NIH Clinical Center, and NIH Clinical Center

North Carolinians Volunteer for Knee Pain Study

Three times a week, thousands of people with knee osteoarthritis lift weights, have their blood pressure checked, and walk around a track at gyms in central and western North Carolina.

Some of them also take nutrition classes and listen to lifestyle lectures. Others count their calories.

But everyone has their blood work done, has their leg strength tested, gets bone density scans, and fills out quality-of-life questionnaires.

These North Carolinians are part of clinical trials led by Stephen Messier, PhD. He is the director of the J.B. Snow Biomechanics Laboratory at Wake Forest University.

Addressing a Rising Problem

For more than 30 years, Messier has been searching for ways to reduce knee pain from osteoarthritis without taking medicine.

An estimated 27 million people in the U.S. have osteoarthritis, and this number is on the rise. Osteoarthritis can be painful and have a negative impact on quality of life. It often affects joints, especially the knees.

"Randomized clinical trials are the gold standard of clinical research," Messier says. "We're looking for ways to reduce pain and improve function and quality of life."

What We've Learned

"Forty years ago, doctors told patients to sit down and take it easy. Gradually, we figured out that moving helps," Messier says.

"We thought a little movement was good, then maybe a little more is even better, and now we know that long-term exercise and weight loss produce excellent results. They aren't a magic pill, but they come close."

The clinical trials at Wake Forest last for 18 months or longer. About 88 percent of participants stick with a study for the entire time. Danny Hamm, an exercise and diet interventionist for one of the studies, the Strength Training for Arthritis Trial (START), believes it's because participants gain so much from participating.



Photo: Mike Shaw, Wake Forest University

Ishman Woodard volunteers for START in Winston-Salem, North Carolina. Daniel Hamm and Jovita Newman monitor his progress.

"I love hearing that the people I work with are getting up the stairs better, or they are better able to play with their grandchildren," Hamm says. "I'm hoping the results of our work will help more people do the same."

"We're reducing pain by as much as half," Messier says. "And that's a lot more than you get by taking pain medicine."

The National Institute of Arthritis and Musculoskeletal and Skin Diseases funds the research for START and other clinical trials at Wake Forest.



The Human Placenta Project is a long-term research initiative to develop new ways to study the placenta, the organ in a woman's uterus that nourishes and maintains the fetus during pregnancy.

The Mystery and Miracle of the Placenta

*Understanding its
role in health and
disease*

Dr. David Weinberg, the project lead, says his work has been a personal calling. The Human Placenta Project was launched in 2014 by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD).

“The placenta influences not just the health of a mother and her baby during pregnancy, but also the lifelong health of both.”

—Catherine Spong, MD, acting director, NICHD

“After a simple first pregnancy, my wife Cynthia and I thought we were in for an easy second pregnancy,” says Weinberg.

“She began bleeding at about 20 weeks. We were scared and fully unprepared.” That was 25 years ago.

“We Were Worried”

“Of course, we were worried that our baby would not survive or would have long-term health problems,” continues Weinberg. “I also worried about Cynthia, whether her life was at risk.”

Courtesy David Weinberg



In 1991, Weinberg was relieved and happy when son Evan was born healthy after a scare during Cynthia’s pregnancy.

Bleeding during the second trimester of pregnancy has many causes, including problems with the placenta, early delivery, infection, or cancer. “Our doctor couldn’t tell us why she was bleeding, the ultrasound didn’t show anything wrong, and the tests turned up negative,” continues Weinberg. “But that feeling of uncertainty and helplessness is one I think back on and can feel again as if it were yesterday.”

Drawn to Placenta Research

This experience helped lay the foundation for Weinberg’s current role as the project lead for NICHD’s Human Placenta Project (HPP), which aims to bring together researchers from several different disciplines to improve the understanding of the placenta and its role in health and disease.

“I see many times where pregnancy outcomes go poorly because the placenta hasn’t formed correctly,” says Catherine Spong, MD, acting director of NICHD. “Yet we still don’t have all the tools we need to understand why that happens. We want to make placenta outcomes better so pregnancy outcomes will be better.”

The mystery and miracle of placenta development is fascinating. “The placenta is perhaps the least understood human organ,



In 2014, Weinberg celebrated Evan’s college graduation with wife, Cynthia, and son, Michael.

even though it’s one of the most important,” Spong says. “It influences not just the health of a mother and her baby during pregnancy, but also the lifelong health of both.”

Until birth, the placenta provides the fetus with nutrients and acts as its lungs, kidneys, liver, and endocrine system (hormones), and it is essential for its immune defense. It is the platform for life.

An Inside Look

Past studies of the placenta have focused on the organ after delivery because it has been challenging to access during pregnancy. The HPP aims to look at safe and non-invasive technologies that might someday allow researchers to study the placenta during pregnancy, while it’s still doing its job. “The goal is to monitor the placenta in real time so we can understand how it develops and functions,” Weinberg says.

Funding for the project currently supports 19 projects around the country, involving diverse research teams with expertise in imaging, biotechnology, obstetrics, placental biology, and other fields.

“I expect that what we learn will benefit other areas of science and medicine as well,” Weinberg says.

Steps for Maintaining Baby's Health

What's the safest sleeping position for babies? What steps can help women achieve healthy pregnancies? What's the latest word on NIH's Zika-related pregnancy initiatives? Dr. Catherine Spong, acting director of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), shares the answers with *NIH MedlinePlus* magazine.



Dr. Catherine Spong

What is the latest research on pregnancy and parenting?

Full-Term Pregnancy: We used to think that outcomes for babies were the same if they were born any time between 37 weeks and 40 weeks of pregnancy—once called “term.” But research has shown that babies born at 39 weeks or 40 weeks of pregnancy are healthier than babies born at 37 or 38 weeks.

Safe Infant Sleep: Always placing babies on their backs to sleep, for naps and at night, is one way parents and caregivers can greatly reduce baby's risk for sudden infant death syndrome (SIDS) and other sleep-related causes of infant death.

Research shows that babies who are used to sleeping on their backs, but who are then placed to sleep on their stomachs or sides—even for just a nap—are at very high risk for SIDS. Anyone who cares for baby—babysitters, childcare providers, and grandparents—should learn safe sleep strategies.

What research-proven steps should women take to avoid problems during pregnancy?

Get early and regular prenatal care while you're pregnant. Your health care provider will probably talk to you about the following steps you can take:



Babies who are used to sleeping on their backs are at risk for SIDS if a grandparent or other caregiver puts them down for sleep on their stomachs or sides.

- **Take 400 micrograms of folic acid** to help prevent spina bifida and other problems that can affect how the fetal brain and spinal cord develop.
- **Maintain a healthy weight and safe diet.** These can prevent gestational diabetes, a type of diabetes that only pregnant women get. Research suggests that what a woman eats and how active she is before she gets pregnant affect her risk. Gestational diabetes may cause both short- and long-term health risks for mom and baby.
- **Avoid alcohol, tobacco, and marijuana,** as all can cause problems. In some cases, these can lead to stillbirth, which is death of the fetus after 20 weeks of pregnancy. In other cases, babies bear long-term effects in the form of fetal alcohol spectrum disorders and asthma.
- **Avoid toxic substances** and discuss your medications with your health care provider.
- **Limit caffeine.** Even though we don't yet know the full effects of caffeine, it's best to limit its use.
- **Get regular dental checkups.** There may be a link between oral disease and preterm and low birthweight in pregnancy.

What about the latest Zika-related pregnancy initiatives and warnings?

NICHD, together with other institutes at NIH, announced support earlier this year to review research to explore the effects of Zika virus infection on pregnancy and babies. NIH has funded several studies as a result, including an NICHD-supported study that monitored potential Zika virus exposure among athletes, coaches, and others attending the 2016 Summer Olympics in Brazil.

NIH also launched the Zika in Infants and Pregnancy (ZIP) study, working with the Brazilian Ministry of Health. The study will evaluate the health risks that Zika virus poses to pregnant women and their babies.

What about mental health issues and pregnancy?

Historically, much of the research has been on depression that occurs after the birth of a baby. But we know now that some women have depression and anxiety, as well as other mental health conditions, during pregnancy and after the baby is born.

NICHD designed the Moms' Mental Health Matters initiative to help explain who is at risk, the signs of these problems, and how to get help.

NICHD supports research on maternal mental health, which covers a number of areas, including:

- Postpartum depression and how it affects maternal and infant health
- Ways to treat or prevent depression during or after pregnancy
- Biology of maternal mood disorders, anxiety, and stress, and how they may affect pregnancy and outcomes

Find Out More

- ✓ *Eunice Kennedy Shriver* National Institute of Child Health & Human Development (NICHD) Human Placenta Project: go.usa.gov/xDhym
- ✓ NICHD Promoting a Healthy Pregnancy: go.usa.gov/xDhyA
- ✓ NICHD Know Your Terms: go.usa.gov/xDhyJ
- ✓ NICHD Moms' Mental Health Matters: go.usa.gov/xDhVB
- ✓ Growing up After Zika Infographic: bit.ly/2bUPxRH
- ✓ MedlinePlus: medlineplus.gov/pregnancy.html
- ✓ Safe to Sleep®: go.usa.gov/xDhVY

For Future Moms & Dads The Facts on Healthy Pregnancy

All pregnancies are different. If you have questions about how the facts outlined below affect you, talk with your health care provider.

Myth: I'm eating for two.

Fact: Pregnant women only need about 300 extra calories per day. Gaining too much weight during pregnancy increases the risk for short- and long-term health problems for both mom and baby.

Myth: I can have an occasional alcoholic drink during pregnancy without harming my baby.

Fact: There is no known "safe" level of alcohol intake for pregnant women. Even less than one drink per week can lead to serious birth defects. Drinking alcohol also increases the risk for learning and growth problems and for sudden infant death syndrome (SIDS). Avoiding alcohol altogether is the best way to keep baby safe.

Myth: I can't take medications while I'm pregnant.

Fact: Many medications can be used during pregnancy, even though some medications and nutritional supplements should be avoided during pregnancy. It's best to talk with your health care provider.

Myth: I shouldn't get a flu shot while I'm pregnant.

Fact: Actually, a flu shot is more important for pregnant women than for non-pregnant women. The flu can cause severe illness and pregnancy problems for mom and increase the risk of serious health problems for baby. Getting a flu shot during pregnancy is a safe and effective way to protect yourself and your baby.

Myth: Pregnancy is nine months, so babies can be born any time after 36 weeks of pregnancy.

Fact: A healthy pregnancy usually lasts about 40 weeks, close to 10 months. Research shows that babies born at or after 39 weeks of pregnancy are, on average, healthier than babies born at 37 or 38 weeks.

Finding Good Health Information on the Internet

Some online health information is reliable and up to date, some not. How can you tell the good from the bad?

If you use the web, look for an “about us” page. Check to see who runs the site. Focus on quality. Be skeptical. Things that sound too good to be true often are. You want current, unbiased information based on research. Quite often, the best information is found at **MedlinePlus.gov**, the National Institute of Health’s website for patients and their families.

Follow these **7** steps:

1 Consider the source.

—Use recognized, responsible authorities.

“You wouldn’t drink from an unmarked bottle, right? Instead you’d look for clues about what’s inside,” says Stephanie Dennis, head of the MedlinePlus team. “The same is true for health information on the web.”

Ask some key questions:

- Who is providing the content?
- What do they know about the topic?
- Why are they providing this information?
- Where does it come from?
- Is it up-to-date?
- How is the site funded?
- Is there advertising on the site, and, if so, is it clearly labeled?

Make sure the information is from reliable medical experts.



Photo: Tamzin Smith

Stephanie Dennis leads the MedlinePlus initiative and team for the National Library of Medicine.

2

Focus on quality.

—All websites are not created equal.

Does the site have an editorial board? Is information reviewed before it is posted?

“This information is often on the ‘about us’ page,” says Dennis.

- Are the board members experts in the subject of the site? A site on osteoporosis with a medical advisory board composed of attorneys and accountants is not medically authoritative.
- Look for a description of the process for selecting or approving information on the site. It is usually in the “about us” section and may be called “editorial policy,” “selection policy,” or “review policy.”

3

Be a cyber-skeptic.

—If it sounds too good to be true, it probably is.

“We’re often looking for health information when we’re vulnerable and seeking answers for comfort,” says Dennis. “Once you understand why a site was created, you can more easily pick up on any bias.”

- Beware of remedies that claim to cure a variety of illnesses, are “breakthroughs,” or rely on “secret ingredients.”
- Use caution if the site uses a sensational writing style (lots of exclamation points, for example).



4

Look for the evidence.

—Rely on medical research, not opinion.

“Ask yourself if you’re being persuaded or manipulated,” suggests Dennis. “A site supported by public funds is less likely to support a particular perspective and is obliged to provide sound, unbiased information based on research.”

- Look for the author of the information, either an individual or an organization, such as “By Jane Smith, RN,” or “Copyright 2016, American Cancer Society.”



5

Look for timeliness.

—Is the information current?

“Look for dates on the research,” says Dennis. “You want to be sure you are seeing current information on things like treatment.”

- Click on a few links on the site. If a number are broken, the site may not be kept up-to-date.

6

Beware of bias.

—Who pays for the site? What is the purpose?

“What if a page about a skin condition is paid for by a company making medicine that treats this condition?” asks Dennis. “Ask yourself if it’s possible that the website’s purpose is to encourage use of a sponsored product instead of using other options.”

- For example, if a page about treatment of depression recommends a drug by name, is the information from the drug’s manufacturer?



7

Protect your privacy.

—Health information should be confidential.

Dennis suggests you should be aware of what information you share about yourself. “If a site requires personal information, consider how it may be used. Read the privacy policy, and beware of sites without one.”

- There should be a link saying “Privacy” or “Privacy Policy.” Read the policy to verify your privacy is protected. For example, if it says “we share information with companies that can provide you with useful products,” then your information isn’t private.

The MedlinePlus Advantage

MedlinePlus is the National Institutes of Health’s website for patients and their families and friends. Produced by the National Library of Medicine, it brings you information about diseases, conditions, and wellness issues in language you can understand. **MedlinePlus** offers reliable, up-to-date health information, anytime, anywhere—for free.

“We provide **MedlinePlus.gov**, and our Spanish sister site **MedlinePlus en Español**, so that you can quickly find reliable health information,” says Stephanie Dennis, head of the MedlinePlus.gov team. “It’s your perfect starting point for information on diseases, conditions, medications, and wellness issues. Our site provides access to information produced by the National Library of Medicine and the National Institutes of Health, such as searches of **PubMed** and **MEDLINE**, our database that indexes medical research literature, and **ClinicalTrials.gov**, a database of research studies conducted around the world.”

You can use **MedlinePlus.gov** to learn about the latest treatments, look up information on a drug or supplement, find out the meanings of words, and view medical videos or illustrations.

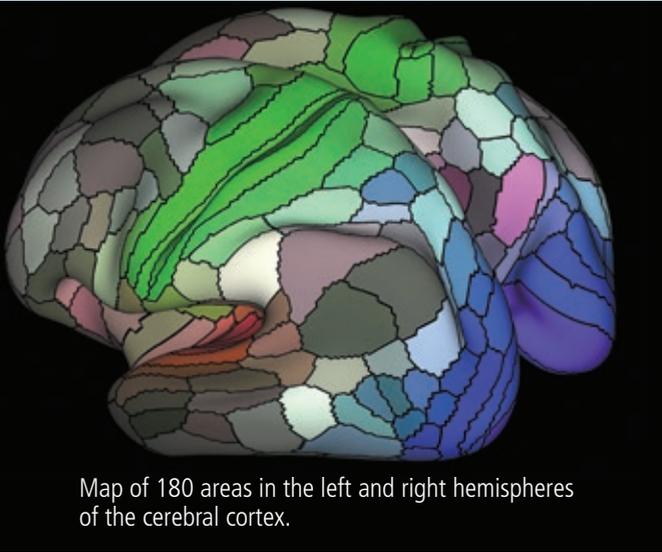
“We also have a database of full-text drug and supplement information, an encyclopedia, a medical dictionary, and health news,” says Dennis. Plus, you can click through to thousands of pages provided by the NIH Institutes, federal government sites, and other trusted providers of information. We review the content on **MedlinePlus** on a daily basis, and you can trust that it is up-to-date and reliable.”

Visit **MedlinePlus.gov** for comprehensive health information from the world’s largest medical library, NIH’s National Library of Medicine.

Illustration: iStock

A Better Map of One of the Most Important Places in the World

Illustration: Matthew F. Glasser, David C. Van Essen, Washington University Medical School, St. Louis



Map of 180 areas in the left and right hemispheres of the cerebral cortex.

researchers is bringing a map of the human brain into sharper focus.

The team started with cutting-edge brain images from hundreds of healthy young men and women. They subdivided the brain's outer layer called the cerebral cortex into 180 specific areas in each hemisphere.

This is remarkable because before this, almost 100 of those areas had never been described.

To create the map, Drs. Matthew Glasser and David Van Essen of the Washington University Medical School, St. Louis, and their colleagues used information from the National Institutes of Health's Human Connectome Project.

This new high-resolution brain map will help increase our understanding of the human brain. In the future, a better map of the brain will also help with the diagnosis and treatment of many brain disorders.

For more scientific information on the project, neuroscienceblueprint.nih.gov.

NIH Support: National Institute of Mental Health; NIH Blueprint for Neuroscience Research

When you want to learn more about a place, it helps to have a detailed map. This is true for scientists who study the brain.

Fortunately, a better map of the brain is now available.

As reported in the journal *Nature*, an NIH-funded team of

Physical Activity May Reduce Risk of 13 Types of Cancer

New research has shown that greater levels of leisure-time physical activity were associated with a lower risk of developing 13 types of cancer.

The risk of developing seven of the 13 cancer types was as much as 20 percent lower among the most active participants in the study, compared to the least active participants. The most active people did the equivalent of seven hours of brisk walking or two and a half hours of jogging each week. Examples of physical activity included walking, running, swimming, and other fitness activities.

This research from the National Cancer Institute and the American Cancer Society supports the importance of physical activity in cancer prevention.

Researchers used information from 1.44 million people, ages 19 to 98, from the United States and Europe. The study's participants reported on their own physical activity.

The risk of developing the first seven cancer types was 20 percent or lower among the most active people as compared with the least active people.

1. **Esophageal adenocarcinoma**
2. **Liver cancer**
3. **Lung cancer**

4. **Kidney cancer**
5. **Gastric cardia (stomach) cancer**
6. **Endometrial cancer**
7. **Myeloid leukemia**
8. **Myeloma**
9. **Colon cancer**
10. **Head and neck cancer**
11. **Rectal cancer**
12. **Bladder cancer**
13. **Breast cancer**

For the remaining six, risk was 10 percent to 20 percent lower among the most active people.

The lesson? No matter what type of body you have or your smoking history, physical activity is important.

For more information about cancer and this study, visit cancer.gov or call NCI's Cancer Information Service at 1-800-4-CANCER.

NIH Is Here to Help

Institutes

- **National Library of Medicine (NLM)**
www.nlm.nih.gov
1-888-FIND-NLM (1-888-346-3656)
- **National Cancer Institute (NCI)**
www.cancer.gov
1-800-4-CANCER (1-800-422-6237)
- **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 1-800-222-2225
Alzheimer's information 1-800-438-4380
- **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
1-877-22NIAMS (1-877-226-4267)
- **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 | 1-800-370-2943
- **National Institute on Deafness and Other Communication Disorders (NIDCD)**
www.nidcd.nih.gov
1-800-241-1044 (voice)
1-800-241-1055 (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
Diabetes 1-800-860-8747
Digestive disorders 1-800-891-5389
Overweight and obesity 1-877-946-4627
Kidney and urologic diseases
1-800-891-5390
- **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 | 1-866-615-6464
- **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 | 1-800-352-9424
- **National Institute of Nursing Research (NINR)**
www.ninr.nih.gov | (301) 496-0207

Centers & Offices

- **Fogarty International Center (FIC)**
www.fic.nih.gov | (301) 402-8614
- **National Center for Complementary and Integrative Health (NCCIH)**
www.nccih.nih.gov | 1-888-644-6226
- **National Center for Advancing Translational Sciences (NCATS)**
www.ncats.nih.gov | (301) 435-0888
- **NIH Clinical Center (CC)**
<http://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)**
obssr.od.nih.gov | (301) 402-1146
- **Office of Rare Diseases Research (ORDR)**
rarediseases.info.nih.gov
Genetic and Rare Disease Information Center
1-888-205-2311
- **Office of Research on Women's Health (ORWH)**
orwh.od.nih.gov | (301) 402-1770

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Dr. Griffin Rodgers

