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Winter wellness

COVER STORY
Award-winning “Hidden Figures” and “Empire” actress Taraji P. Henson talks about her work to improve mental health
In this issue

WELCOME TO THE WINTER 2022 ISSUE OF NIH MEDLINEPLUS MAGAZINE. This issue features guidance and research from the National Institutes of Health on topics including rare diseases, asthma, and mental health, featuring an interview with award-winning actress Taraji P. Henson.

Best known for her leading roles in the TV show “Empire” and the movie “Hidden Figures,” Henson recently opened up about her personal struggles with mental health. By sharing her story and starting a Facebook Watch video series about dealing with mental health, Henson is destigmatizing a health issue that affects more Americans than ever.

During the last two years of the pandemic, over 30% of American adults reported experiencing symptoms of anxiety. Isolation, financial strain, and health concerns have had a negative impact on the mental health of many people. Learn how to unwind at home with NIH resources like the guided visualization video highlighted in this issue.

Asthma is another increasingly common health issue. Although 1 in 13 American adults have asthma, most of them lead healthy, active lives with support from their medical providers. Olympic swimmer Dara Torres talks about being diagnosed with asthma at age 25 and explains how figuring out a treatment plan helped her swim faster than ever.

Also in this issue, read about NIH resources that can help you decide when to test for COVID-19, stay healthy in the winter months, and get help for mental health challenges. You can also learn about how COVID-19 has impacted the rare disease community and how NIH-supported researchers are working to find cures for rare diseases.

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

Thanks for reading!
inside

Trusted Health Information from the National Institutes of Health

Taraji P. Henson (right) on the set of “Peace of Mind with Taraji” with co-host Tracie Jade (left).

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*The National Institutes of Health was not involved in the creation of the project and reference to it does not constitute or imply endorsement by any federal agency.
YOUR HEALTH  Even the most seemingly relaxed people deal with stress on a daily basis. Stress includes the feeling of being overwhelmed and your body’s reaction to a challenge or perceived demand. Stress can come from negative life experiences, like dealing with credit card debt, having an overscheduled workday, or getting into a disagreement with a friend. But stress can also come from positive experiences — like an exciting move to a new city or a highly-desired job promotion — that require a lot of planning or extra responsibility.

Dr. Krystal M. Lewis is a licensed clinical psychologist and researcher in the National Institute of Mental Health Intramural Research Program. In this video, Dr. Lewis explains what stress is and the parts of the brain that play a role in how we experience stress. At the end of the video, Dr. Lewis will take you through a guided visualization that you can use to relax when you feel stressed.

Guided Visualization: Dealing with Stress - YouTube
**FISH AND SPINACH BAKE**

- Prep time: 15 minutes
- Cook time: 30 minutes
- Total time: 45 minutes
- Number of Servings: 4

**INGREDIENTS**
- 1 package (10 ounces) frozen spinach, thawed
- ¼ teaspoon each salt and pepper
- 1 pound fish filets (thawed if frozen)
- 1 teaspoon Creole or Cajun seasoning blend
- 1 large tomato, diced
- 4 green onions, sliced

**DIRECTIONS**
- Wash hands with soap and water.
- Preheat oven to 350 °F.
- Squeeze thawed spinach to remove most of the liquid. Spread in the bottom of a 9x13-inch baking dish. Sprinkle with salt and pepper.
- Arrange fish filets over spinach. Sprinkle with seasoning blend. Top fish with tomatoes and green onions.
- Cover the baking dish with foil and bake for 15 minutes. Remove foil and bake for 20 minutes more or until fish flakes easily.
- Refrigerate leftovers within 2 hours.

**NOTES**
- Try any kind of fish or even chicken.
- Change the flavor by adding lemon juice or lemon pepper.
- Try salsa instead of fresh tomato and green onion.
New decision-support tool for COVID-19 testing can help you get back to your life, safely

Find out when to test and how often

**Almost two years into** the COVID-19 pandemic, there’s still so much uncertainty about how to live with this virus. We have safe and effective vaccines, and now masks, social distancing, and testing are normal parts of life. But there’s also a new, more transmissible variant that’s contributing to rising case numbers and breakthrough cases. It’s still hard to know the best ways to use these tools to keep yourself, your loved ones, and your community safe.

**Find out when to test and help slow the spread**

Testing is an important tool to slow the spread of COVID-19 and help us get back to our daily lives and the activities that matter most, safely. A test can tell you if you’re infected (and likely to spread the virus to others) even if you don’t have symptoms.

But when should you test? And how often? Luckily, the *When To Test Calculator for Individuals* from WhenToTest.org can help you decide! This new, state-of-the-art tool is free to use and designed to help you:

- Understand your risk of getting COVID-19
- Understand your risk of spreading COVID-19 to other people
- Decide if you should consider getting tested

The tool was developed with support from the NIH’s *Rapid Acceleration of Diagnostics (RADx®)* initiative and is managed by the National Institute of Biomedical Imaging and Bioengineering.
When To Test Calculator for Individuals calculates your estimated risk of having COVID-19 and spreading it to others.

**How it works**
The tool asks you a series of simple questions and uses your answers to calculate your estimated risk of having COVID-19 and spreading it to others. (It doesn’t collect any personal information.) It uses an algorithm that’s based on the most up-to-date scientific data available, and it asks about things that have the biggest impact on individual risk. The questions are about:

► **Where you live.** If COVID-19 rates are high in your county, your risk will be higher than someone who lives in an area with lower rates.

► **Vaccination status.** If you are fully vaccinated, you’re less likely to get infected with COVID-19 than someone who isn’t vaccinated, and you’re also less likely to spread it to others.

► **Masking.** Wearing a mask around people you don’t live with reduces your risk of getting COVID-19 and spreading it to others (even if you’re fully vaccinated).

► **Social contact.** Being around more people means more opportunities for you to be exposed to the virus and to expose others. That’s why the tool asks about the number of people you’re regularly in close contact with and any social gatherings you’ve attended recently or plan to attend soon.

The When To Test tool doesn’t give medical advice, and it won’t tell you that you absolutely should or shouldn’t get tested. Instead, it tells you your estimated risk of getting COVID-19 and your risk of spreading it to others. If your risk is high, you should think about getting tested as soon as possible. If it’s low, you may not need to test right away.

**One more tool in the toolkit**
Even though you don’t have much control over where the virus is, the When To Test team wants to empower people with the latest data and support to help them get back to the things that matter most to them, safely. Testing is one important tool in the toolkit to help you get back to a more normal life. But the tool can also help you evaluate and make decisions about other behaviors that can impact risk. For example, you might choose to skip the live concert before or after visiting with family or friends from out of town.

When To Test also has a tool for organizations like schools and workplaces and resources to help them develop and implement testing programs for COVID-19.

Visit [WhenToTest.org](https://www.when totest.org) and get the information you need to get back to your life, safely.
Taraji P. Henson
Starting the conversation to improve mental health
Taraji P. Henson won the hearts of millions with her acting, singing, and writing. The award-winning star of the hit TV series “Empire” and acclaimed movie “Hidden Figures” has now taken on a bigger challenge. She’s a leading advocate for improved mental health care, particularly for people of color. Henson talked with NIH MedlinePlus Magazine about her own mental health challenges and her efforts to bring about change.

What led you to use your voice and platform in this way?
As a privileged woman who can afford good health care, I found it really difficult to find a therapist for myself and my son. I called my best friend who has battled anxiety her entire life and said to her, “This is a problem. How can we improve the culture and community in a major way?” We came up with the idea of starting the Boris Lawrence Henson Foundation*, which focuses on improved mental health care. It’s named for my father who was a Vietnam veteran and suffered from mental health challenges following his service.

The first thing is to get people to talk about mental health. That is why I decided to share my own mental health struggles. The community has seen my work as an actress for a long time. I have a rapport with them, and they trust me. So, I started to speak out, and, sure enough, we started to see more and more people talking about needing to take care of their mental health. Now we have people motivated to talk about mental health in a major way. It is a great thing, but we have a long way to go.

You have been especially vocal about the stigma associated with mental health and mental illness.
Yes. We need to combat the stigma. And the first thing we need to do is to make it normal to talk about our mental health and how to work on our mental health struggles. Especially coming off a pandemic that seems to never end, we all have issues.

Seeing mental health issues addressed on TV and in movies is also very helpful in reducing stigma. I love the TV show “Dave.” In one episode, they talked about the character living with and managing bipolar disorder. Someone who has been suffering in silence can see a show like that and go, “Oh my God, I’m not alone.” That is how you end the stigma. You normalize it.

Your Facebook Watch series “Peace of Mind with Taraji”* takes on the issue of stigma among women of color.
I love the series. After we launched the Foundation*, I felt we weren’t reaching enough people. We needed a show to reach people. We set up the show in a format where each episode has a celebrity, another woman of color, and a mental health professional. A health care professional is also there to make sure we can give the audience information on what they can do and where they can go for help. We wanted to show people how therapy really looks. It is just a conversation. I’m really proud of the show because people are watching it and being touched by it. To me, this is the most important work that I’m doing in my career.

Are you concerned people cannot afford the care they need?
Mental health care should be affordable and easier to access. We also need to improve mental health care services for those who are going through drug rehabilitation. A lot of people who are addicted to drugs and/or alcohol have underlying mental health challenges. They need help addressing those challenges.

“You are not alone.
There is no need for you to suffer in silence. There is help.”
—Taraji P. Henson

Taraji P. Henson and her best friend Tracie Jade work to bring mental health out of the shadows by highlighting personal stories from the African American community.

* Images courtesy of Facebook Watch
“To me, this is the most important work that I’m doing in my career.”

—Taraji P. Henson

You also have talked about the importance of access to culturally competent mental health professionals.

Yes, one reason a lot of Black people don’t go to therapy is they don’t feel safe. A lot of mental health challenges come from racism. So, when you have to bring that up in a room with someone who can’t relate, it’s uncomfortable. And a big reason why there’s a lack of African American mental health professionals out there is that we don’t even talk about mental health issues in our homes. We’ve got to change that.

Millions of us have struggled during the pandemic. You have talked about your own struggles during COVID-19, including suicidal ideation.

I think during the pandemic many people toyed with the idea of “should I live anymore?” It’s called suicidal ideation or thoughts of suicide. It doesn’t mean you are going to go through with it. It is just a thought. Because I’m in therapy, and I have a psychiatrist, I have the tools. I knew that saying it, getting it out of my head, and talking about how to address it would make me feel better. If you keep those thoughts in, that thought might turn into a plan. And that’s why I felt the need to share my experience. I don’t want people to suffer alone. I had so many people reach out to me after I shared my story to say that they had the same thoughts. And I had the opportunity to show them they could get help. Humans need humans, and if you have a story to tell, tell it.

What is your message to others who are struggling with mental health challenges?

You are not alone. There is no need for you to suffer in silence. There is help. There is always hope. The sun will always come out after the storm. I don’t care how bad things may look right now. If you can hold on for just another day, things will get better. There are people out there who can help and want to help.

What’s next for Taraji P. Henson, the actress?

I’m about to film the musical version of “The Color Purple.” I’m very excited about that!

Find Out More

- MedlinePlus: Mental Health
  https://medlineplus.gov/mentalhealth.html
- National Institute of Mental Health: Mental Health Information
  https://www.nimh.nih.gov/health
- Boris Lawrence Henson Foundation*
  https://borislhensonfoundation.org

*The National Institutes of Health was not involved in the creation of the project and reference to it does not constitute or imply endorsement by any federal agency.
Getting help for mental health

About one in five Americans live with a mental health condition. If you or someone you know is struggling, it’s important to know that help is available.

Your mental health matters
Mental health is your overall mental well-being. It’s shaped by your life experiences, relationships, physical health, family health history, and environment.

Mental illnesses, including depression, anxiety, and post-traumatic stress disorder, can affect how you feel and think and can make it hard to complete everyday tasks. If you’re dealing with mental health issues or illness, you are not alone.

Getting help in an emergency
If you or someone you know needs help right away, call 9-1-1. You can also reach out to:

- National Suicide Prevention Lifeline. Call 1-800-273-TALK (8255) or use the Lifeline Chat online at suicidepreventionlifeline.org.
- Crisis Text Line. Text “HOME” to 741741 to connect with a trained crisis counselor.

How to get help
Talk to your healthcare provider. Mention your mental health concerns at your next health care visit or call to schedule an appointment. Your healthcare provider knows you and your medical history and can help you find a mental health professional.

Before your visit:

- Think about what you want to talk about, including the specific symptoms you’ve been having.
- Bring a list of any medications you’re taking.
- Find out about your family’s mental health history if you can.

If it makes you more comfortable, you can ask someone you trust to come with you to the appointment. The National Institute of Mental Health (NIMH) has tips for talking to your provider about your mental health concerns.

Find treatment near you. You don’t need to have health insurance to get support. There are federal resources and local organizations in your community that can help you find qualified providers and services.

- Contact the HHS Substance Abuse and Mental Health Services Administration. Call 1-800-662-HELP (4357), text 435748 (HELP4U), call TTY 1-800-487-4889, or visit findtreatment.samhsa.gov to find local treatment facilities, support groups, and community-based organizations.
- Find a health center. Health centers offer community-based primary health care, including mental health treatment. Your local health center can help you find services and treatment. Find a Health Center near you.
- Check out FindTreatment.gov. Visit FindTreatment.gov to learn about different kinds of treatment options and find a treatment facility in your area.

For more resources and information about getting help for mental illness, visit the NIMH Find Help page.
Different kinds of treatment

When it comes to mental health, there’s no “one size fits all” treatment. A trained mental health professional can help you address your mental health concerns and improve your mental well-being. There are different kinds of mental health professionals, and it’s important to find someone who has the right expertise and helps you feel comfortable. You and your provider should work together to find the treatment or combination of treatments that will work best for you.

Depending on your situation, history, biology, and preferences, your treatment plan might include:

- **Psychotherapy.** Psychotherapy (or talk therapy) is a kind of treatment that helps you identify harmful emotions, thoughts, and behaviors, and learn how to change them. To find out more about talk therapy, visit [Psychotherapies](https://www.nimh.nih.gov/health/topics/psychotherapies/index.shtml) from NIMH.
- **Medication.** Medications may help you manage some symptoms and can be an important part of the overall treatment plan. Medications sometimes work best in combination with therapy. To find out more, visit [Mental Health Medications](https://www.nimh.nih.gov/health/topics/medication-therapy/index.shtml) from NIMH.
- **Brain stimulation therapy.** Brain stimulation therapies use electricity to change how the brain works. Read more about [Brain Stimulation Therapies](https://www.nimh.nih.gov/health/topics/brain-stimulation-therapies/index.shtml) from NIMH.

Mental health care providers may offer services in person or online (telemental health). Check out [Telemental Health](https://www.nimh.nih.gov/health/topics/telemental-health/index.shtml) from NIMH to learn more about telemental health and how to find a virtual provider.

Get support

Support groups can be a great way to connect with other people who are dealing with similar issues. You can find support groups online or join one in your local community.

- **Contact the NAMI HelpLine.** Call 800-950-NAMI (6264) or visit [www.nami.org/help](https://www.nami.org/help) to connect with volunteers across the country and get support, information, and resources.
- **Visit Mental Health America.** Visit [www.mhanational.org/find-support-groups](https://www.mhanational.org/find-support-groups) for a directory of mental health peer support programs.

Remember, you’re not in this alone. Help is available.
Virtual Rare Disease Day at NIH

Event brings people together to raise awareness, highlight research, and promote collaboration

In the United States, diseases that each affect less than 200,000 people are called “rare diseases.” There are about 7,000 – 10,000 rare diseases, and more than half of them are diagnosed in children. Many rare diseases are caused by genetic mutations. Most of them are complicated and hard to diagnose, and only a few have any effective treatment options. Rare diseases can cause serious, chronic, and long-term health problems, and many of them are fatal.

Individually rare, collectively common

The diseases themselves are each rare, but as a group they have a large impact. Each rare disease might only affect a few hundred to several thousand people, but all together there are about 30 million people in the United States living with a rare disease.

Annual events raise awareness

Every year, the National Center for Advancing Translational Sciences (NCATS) and the NIH Clinical Center host Rare Disease Day at NIH to raise awareness about rare diseases and the people living with them.

Rare Disease Day 2022 was held on February 28th with events to support and raise awareness for rare disease patients, their families, and caregivers.

The event’s goals were to:

- **Bring together** groups of people affected by rare diseases – including patients, caregivers, patient advocates, health care providers, and researchers.
- **Increase awareness** about rare diseases and the people living with them.
- **Share information** about how the NIH advances rare disease research and highlights patients’ voices and experiences.

The virtual event was free and open to the public. It featured rare disease patient stories, scientific posters, panel discussions, and an art exhibit.

Topics included:

- Diversity in rare disease research
- Individualized therapies
- Telehealth during the COVID-19 pandemic
- The diagnostic odyssey (the long, complicated journey that many rare disease patients go through to get diagnosed)
COVID-19 makes living with a rare disease even harder

But there are silver linings

Ongoing uncertainty, being alone, and not being able to get treatment. In many ways, the widespread challenges the COVID-19 pandemic created were already too familiar to members of the rare disease community. Now there was a new concern for people with rare diseases: how would COVID impact their specific disorder?

The pandemic has dramatically changed the world we live in. For people with a rare disease, many of the things that have been hard in the past have become even more difficult, and new challenges have appeared. Despite this, the pandemic has led to promising developments in rare disease research – a silver lining of this difficult time.

Working together on rare disease research

The Rare Diseases Clinical Research Network (RDCRN), led by the National Center for Advancing Translational Sciences (NCATS), is made up of 9 NIH Institutes and Centers along with rare disease patient advocacy groups. Together the RDCRN group studies over 200 rare diseases to learn more about how they start, progress, and how to improve diagnoses and treatments.
Telehealth makes it easier for some people with rare diseases to access medical care.

The pandemic affects access to care
To learn about how COVID-19 has impacted rare disease patients and provide better support for this community, RDCRN surveyed rare disease patients, their families, and caregivers about their experiences. They found this community has been deeply affected by the pandemic.

Between cancelled and delayed appointments, long waitlists, and concerns about getting infected, the pandemic has made it harder for people to get medical care, which is especially important for the rare disease community. It’s not always easy to know when to seek medical care — especially if you’re immunocompromised (which means your body can’t fight disease) — and the pandemic made it even harder for people with rare diseases to get access to:

- Routine (regular) and preventive health care
- Treatments to help manage their disease – including special diets, medications, and therapies
- Testing and medical help for COVID-19 — which means that many rare disease patients aren’t sure if they’ve been infected or not

Although most people who were infected with COVID-19 only had mild symptoms, some in the rare disease community said the virus made some symptoms of their rare disease worse.

Luckily, telehealth has become more available because of the pandemic, which means it’s becoming easier to get care without needing to worry about getting exposed to COVID-19. It also means many rare disease patients won’t need to travel such long distances to see rare disease specialists.

COVID-19 innovations benefit rare disease research
Only about 5% of rare diseases have a treatment that’s approved by the Food and Drug Administration (FDA). Research and development for new treatments can be painfully slow.

The pandemic caused delays and shutdowns for clinical studies and laboratories – including those studying and developing treatments for rare diseases. Figuring out how to research in these uncertain times has led to innovative changes in the research world that could have a lasting benefit for rare disease patients:

- **Virtual research.** Research institutions are moving towards virtual clinical trials, and the FDA has introduced new, more flexible guidelines. Virtual research means more rare disease patients will be able to take part in clinical trials and get new, promising treatments.
- **Learning more about the biology of COVID-19.** Studying COVID-19’s biology is also helping researchers find better ways to treat COVID-19 in rare disease patients.
- **Using old drugs in new ways.** Finding new uses for approved drugs (called “drug repurposing”) cuts down on FDA approval time, so as part of their pandemic response, the NCATS team developed a new resource for scientists called OpenData Portal to share information about COVID-19 drugs. Drug repurposing and data sharing platforms like this help to overcome some of the challenges of developing new treatments for rare diseases – like time, resources, and logistics – and get new, safe treatments to patients, faster.

**HEALTH FAST FACT**
People with underlying conditions are at greater risk of severe illness from COVID-19.

**SOURCE:** Centers for Disease Control and Prevention
When there’s research, there’s hope

Living with a rare disease called relapsing polychondritis

The first sign Meredith Winchell noticed was trouble breathing. At the time, she worked as an analyst at NIH. First, she started losing her breath just walking down a hallway at work. Then new symptoms started showing up, and they kept getting worse. Five years later, after countless doctor’s visits, diagnostic tests, and trips to the emergency room, she was diagnosed with a rare disease called relapsing polychondritis.

Relapsing polychondritis — “RP” for short — causes widespread inflammation (pain and swelling). It also breaks down cartilage (the tissue that protects your bones and joints) in certain parts of the body.

Common symptoms include:

- Pain and swelling in cartilage (especially in ears and nose)
- Pain, redness, and swelling in joints
- Sore throat, neck pain, and hoarseness
- Hearing loss, tinnitus (ringing), and dizziness

Most people don’t know about RP, so Meredith has learned to ask, “do you know what that is?” when she meets someone new.

An invisible disease

RP is extremely rare, and like many rare diseases, RP is an invisible disease. Doctors don’t know what causes RP, and getting the right diagnosis and treatment is one of the biggest challenges for people who have it.

Without a biomarker (biological material that can measure and identify diseases), there’s no way to test for RP. This means that doctors need to rely on patients’ symptoms to diagnose it. Unfortunately, RP can cause different kinds of symptoms in different people. Symptoms also don’t always seem related to each other, and they can come and go. For example, Meredith said her ear isn’t inflamed right now, but that doesn’t mean it won’t be in the next few hours or days.
Classical symptoms led to diagnosis
When Meredith first went to the doctor about her breathing problems, doctors told her she had asthma and gave her albuterol (an inhaler that relaxes and opens the airways to the lungs). When that didn’t work, they tried a steroid inhaler, which helped a little.

Along with trouble breathing, Meredith had extreme pain and inflammation in her stomach area, colon, and digestive tract and in her skin, joints, and sternum (the cartilage that connects the ribs). She took tests to find out what was wrong, but the tests didn’t give enough information to either diagnose or rule out any disease. One doctor told her it must be anxiety.

Meanwhile, her symptoms became so bad that she had to stop working. During an especially painful flare-up, she went to the emergency room four times in a month. Luckily, a doctor there recognized the most common and visible RP symptoms – ear, nose, eye, and joint inflammation – and sent her to a rheumatologist (a doctor who specializes in joint, muscle, and bone diseases). The rheumatologist took one look at her and knew it was RP.

Disease impacts every part of life
Meredith considers herself lucky. She knows other people with RP whose diagnoses took even longer than hers. But getting diagnosed was just one part of her journey. Because there aren’t any treatments designed specifically for RP, doctors typically try giving RP patients therapies that work for other rheumatic and autoimmune diseases with similar symptoms. Sometimes they work, but not always.

Meredith’s RP and the side effects from its treatment impacts every part of her life. Her work was an important part of her identity before she got RP, and it’s hard not being able to work full time anymore. The medications she takes to help with inflammation suppress her immune system, which makes her more likely to get infections.

In each moment, she’s constantly adjusting her breath, her body, and her interactions to help her stay within her limits. “There’s never a time I’m not thinking about my disease,” she says.

Support from people who know what it’s like
Meredith joined her first RP Awareness support group on Facebook a few days after her diagnosis. Now she’s part of several Facebook groups for RP patients, doctors, researchers, and caregivers from countries around the world. They talk about research and raising awareness about RP. For Meredith, these groups are a way to stay informed about what’s happening in RP research and advocacy in other countries. But they also look out for each other, and Meredith says there’s nothing like the understanding and support from people who know what it’s like to live with RP.

“Anything I can do to get more information and more data to get answers I consider a good day.”
—MEREDITH WINCHELL

Offline, Meredith’s biggest supports are her family and friends, her husband Dillon who she calls her “rock and caregiver,” and the talented doctors who work together to plan her care. She’s especially grateful for her rheumatologist Dr. Paola Pinto and NIH RP researcher Dr. Marcela Ferrada.

When there’s research, there’s hope
On the days when her symptoms are the worst, Meredith reminds herself of something Dr. Ferrada often says: “where there’s research, there’s hope.”

When Meredith was first diagnosed, most of what we knew about RP was based on old research from the 1970s. Luckily, that’s changing. Today, we know much more about who gets RP and its symptoms. Meredith says it’s easier now to find good, clear information on RP.

But there’s still so much we don’t know. Most importantly, what causes RP, and how it evolves. That’s one reason Meredith became involved in an NIH study led by Dr. Ferrada that follows people with RP over time. “ Anything I can do to get more information and more data to get answers,” she says, “I consider a good day.”

Only about 3 people out of a million are diagnosed with relapsing polychondritis each year.
SOURCE: National Center for Advancing Translational Sciences
Gene therapies are a promising path to treating rare diseases

Researching and developing new treatments for rare diseases is time consuming, complex, and often expensive. Most rare diseases (almost 80%) are caused by a defect in a single gene. Because of this, gene therapies – treatments where certain genes are adjusted to treat someone’s disease — are a promising approach for some diseases. These treatments “fix” the genetic mutations (harmful changes) that cause some diseases by replacing or changing a gene that doesn’t work with one that does.

Because specific rare diseases generally only affect a few hundred people, pharmaceutical companies aren’t usually interested in developing treatments for them.

That’s where NIH research comes in. This article describes two rare diseases – spinal muscular atrophy and Duchenne muscular dystrophy – and how NIH supports research and development on gene therapies to treat them.

**Spinal muscular atrophy: Genetic therapies to improve movement**

A medication called nusinersen was one of the first genetic therapies approved for a rare disease. It treats a group of rare genetic disorders called spinal muscular atrophies (SMAs) that cause loss of nerve cells that control skeletal muscles (muscles that allow us to move) leading to weakness.

SMAs start in infancy or early childhood and are a leading cause of death in infants and toddlers. There are a few different SMAs, and all of them are caused by a mutation in a gene called SMN1 (which stands for “survival motor neuron”). SMN1 helps the body make an important protein that keeps the nerves that control muscle movement healthy. Because people with SMAs don’t make enough SMN proteins, some of their muscles (like the ones that help us move, breathe, and swallow), don’t work correctly. In the most severe cases, this can cause paralysis and death. There’s no cure for SMA, but there are treatments to help prevent and manage its symptoms.

In some rare diseases, DNA mutations cause a gene or protein to work incorrectly. The National Institute of Neurological Disorders and Stroke (NINDS) supports research and development on therapies that work at the genetic level to “fix” those problems in children and adults with SMA.

Nusinersen targets another gene called SMN2 that also makes a small amount of the SMN protein. It helps muscles and nerves work properly by changing the SMN2 gene product to make more of the SMN protein than it usually would.

There’s another gene-based therapy for children under age 2 that uses a safe virus to deliver a new copy of the SMN gene into specific neurons to improve muscle movement.

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**Health Fast Fact**

There are about 7,000 known rare diseases, but only a few have treatments approved by the Food and Drug Administration.

**Source:** National Center for Advancing Translational Sciences.
Duchenne muscular dystrophy: Genetic therapies to improve muscle weakness

Muscular dystrophies are a group of inherited diseases that cause muscle wasting and weakness. Duchenne muscular dystrophy (or DMD) is the most common muscular dystrophy in children, and it mostly affects boys in early childhood. Children with DMD usually notice their first symptoms before they turn six, and those symptoms get worse quickly.

Early symptoms of DMD include:

- Fatigue
- Weak muscles (especially in the legs and groin area)
- Problems with movement (like running, hopping, or jumping)

By age 12, most children with DMD can’t walk anymore. By age 20, they usually start having problems with their heart and lungs and may need support to help them breathe. Tragically, most people with DMD don't live past age 30.

Some muscular dystrophies are caused by mutations in genes that make important muscle proteins. In this case, it’s a protein called “dystrophin” that keeps muscle membranes stable and strong. Without it, damage to muscle cells build up causing the muscles to get weaker and break down.

There’s no cure for DMD, but there are treatments that can help with the symptoms, including gene-based therapies that help the muscles make more dystrophin. One promising approach uses an injection of small, harmless viruses to deliver therapeutic dystrophin-producing genes directly into cells in the muscle. These kinds of treatments have potential, but they're still being studied to make sure that they are safe and effective. Because muscles make up a large portion of our body mass, the dose of viral gene-based therapy needs to be very high to be effective, which can cause unwanted side effects.

NIH-supported researchers have been studying ways to deliver dystrophin genes to affected muscles with fewer side effects. So far, they’ve only tested the new approaches in animals, but their findings are promising for the future of gene therapies for humans.
Dara Torres’ remarkable swimming career has inspired generations of Americans. She broke her first world record at age 14 and went on to win 12 Olympic medals between 1984 and 2008. She won her last two medals at age 41 as the oldest swimmer ever to earn a spot on a U.S. Olympic team. And she did this as one of the more than 25 million Americans living with asthma, a chronic lung disease that can make it difficult to breathe. Dara shared her asthma journey and advice for others with NIH MedlinePlus Magazine.

Tell us how you were diagnosed with asthma.

Until I was 25, I actually had no idea I had asthma. I began swimming at an early age, and I was always known as a “drop dead” swimmer. I would swim my races and always slow down at the end. And I wasn’t sure why that happened. This happened no matter what training I did, so I just thought it was the way I was built.

In 1992, after my third Olympics, I was running with a friend in Gainesville, Florida on a hot summer day with very thick, humid air. My friend told me I was wheezing. And I said, “Oh yeah, I always do that!” She works in the medical profession and asked if I had ever been checked for asthma. I said I no, I had not. I told her I didn’t think I had asthma but would get checked. Shortly after that I went to the doctor and, sure enough, I was diagnosed with asthma.

After taking seven years off from competitive swimming, I decided to make a comeback and swim in the 2000 Olympics. Since I was in my 30s at that point - pretty old for swimmers - the coach wanted to know how my body was holding up and if I had any ailments. I told him that everything was fine, but I did have asthma. He urged me to see a doctor who specialized in helping underwater athletes who have asthma. That doctor evaluated me, and it was a turning point because they put me on a much better treatment regimen. From that point on, I was able to hold my breath more and not slow down at the end of my races.
What were your thoughts after receiving your asthma diagnosis? Did you wish you had been diagnosed earlier?

Yes, I thought to myself, “What could I have done? Would I have been faster? Would I have won other races? What would have been different for me if I had been diagnosed earlier in life?” It definitely made me scratch my head. But I’m one of those people who feel like things happen for a reason, and I was able to come back and compete and have success later in life.

What was the improved treatment regimen you started in 2000?

I had an inhaler that I used every morning when I woke up. And I had a rescue inhaler that [I would take two puffs of] 30 minutes before I started my swimming training. I would also use that before a swimming meet.

In 2008, at my fifth Olympics, I was 41, and it seemed like everything was questioned because of my age. Some had the gall to suggest that I didn’t actually have asthma and was taking the asthma medication just to gain a competitive advantage. At the time I responded by saying my advantage is trying to breathe like everyone else.

What message do you have for young swimmers and athletes with asthma?

If you feel yourself having a hard time breathing or you hear a wheezing in your lungs, definitely go get it checked out by a health care professional. I wish I had when I was younger. It is nothing to be ashamed of. Just know you are trying to have the same breathing capacity as everyone else.

What do you do now to stay healthy and fit?

I had an eating disorder when I was in college, so I would say I eat reasonably and nutritionally. I eat in moderation, and still work out every day. I actually haven’t been swimming a lot lately, but I do a lot of other things. I go for a run twice a week. I like to box. I do Pilates. I do a great work out called Solid Core as well as a Total Body Resistance Exercise class. I really mix it up now, because I used to do the same routine all the time. But I found that your body can plateau and get used to that and not see improvement.

Has your fitness routine changed as you have gotten older?

You do feel your aches and pains more! I’ll get a good night’s sleep and wake up feeling like my back is killing me. My advice is to listen to your body, and allow yourself time to recover. I see some women working out three or four times a day. They are not getting anything extra out of this. Do one good workout and give your body a chance to rest and recover.

What projects are you working on now?

I’m excited about a new venture partnering with Mariel Hemingway to give motivational talks about women our age. I also work on an all-women’s sports talk show on CBS Sports Network called “We Need to Talk.”

“I’m one of those people who feel like things happen for a reason, and I was able to come back and compete and have success later in life.”

—Dara Torres

Dara Torres made an olympic comeback to the sport of swimming after her asthma diagnosis.
Eczema: What is it?
Also known as “atopic dermatitis,” eczema is an inflammatory skin condition that affects roughly 30% of Americans, mostly children and adolescents. Those with eczema experience dry, itchy skin that can leak clear fluid when scratched. Eczema is not contagious, but those who have eczema may be particularly at risk for bacterial, viral, and fungal skin infections. Flare-ups can arise unexpectedly, and oftentimes frequent treatments are needed. Trying to manage this condition can be quite hard and emotional for patients and caregivers.

The exact cause of eczema is unclear, but environment, genetics, and the immune system can all be causes. Eczema often is associated with allergic diseases like asthma, hay fever, and food allergies. Children with siblings are less likely to develop eczema than only children. People who live in urban areas and those with higher socioeconomic status also appear more likely to develop the disease.

Eczema in young children, especially in infants, is a major risk factor for the development of food allergies, particularly allergies to peanuts.

The Food and Drug Administration (FDA) has recently approved new treatments for eczema. Speak with your dermatologist to learn more about what treatment options might be available for you.

30% Percentage of children with eczema who also have a food allergy.

SOURCE: National Institute of Allergy and Infectious Diseases

Winter and eczema
Though eczema flare-ups can occur at any time of year, many experience flare-ups in the winter. Cold air, wind, and a decrease in humidity dry out everybody’s skin, which can trigger a flare-up for those with eczema. Here are some tips to beat back those winter flares.

- Use a humidifier
- Moisturize right after you get out of the shower—petroleum jelly or thicker creams are better
- Avoid scented lotions or laundry detergents
- Avoid very hot showers
- Cover up as much skin as possible when going outside in the cold, dry air
- If you know you’re going to sweat, wear quick-drying fabric
- Avoid wearing wool, nylon, polyester, or spandex
- Ask your doctor about prescription therapy if symptoms persist
Heart attacks
What to do and how to prevent them

A heart attack occurs when the flow of oxygenated blood suddenly becomes blocked, and a section of the heart can’t get oxygen. If blood flow isn’t restored quickly, that section of heart muscle begins to die. Here’s what to look for and what to do in the case of a heart attack.

**Symptoms**
- Chest pain or discomfort, often on the left side of the chest
- Light-headedness or dizziness
- Pain or discomfort in the jaw, neck, or back
- Pain or discomfort in one or both arms or shoulders
- Shortness of breath
- Unexplained tiredness
- Indigestion or heartburn
- Nausea or vomiting
- Sweating

**What to do**
Call 9-1-1 immediately. The sooner the individual can get to an emergency room, the better their chances for reducing damage to the heart. If the individual is unconscious and not breathing or without a pulse, begin CPR. Push down hard on the center of the person’s chest at about 100 to 120 compressions a minute – about the same tempo as the Bee Gees’ “Staying Alive” or the Spice Girls’ “Wannabe.”

**Cardiovascular disease**
Cardiovascular diseases affect the heart and blood vessels. Some cardiovascular diseases include coronary artery disease (where the arteries to the heart are blocked or narrowed), congestive heart failure (where the heart doesn’t pump as efficiently as it should), and heart rhythm problems.

Heart disease is the leading cause of death for men, women, and people of most racial and ethnic groups in the United States.

**SOURCE:** Centers for Disease Control and Prevention

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**By the numbers**

90 — The number of people in the United States who suffer from a heart attack every hour.

659,000 — The number of people in the United States who die from heart disease every year.

$363 billion — The annual cost of heart disease in the United States.

80% — The amount of all heart disease that can be prevented by keeping a healthy lifestyle and managing risk factors.

**SOURCE:** Centers for Disease Control and Prevention
Winter viruses
Steps to take to stay healthy this winter

Winter and viruses: A dangerous combination
Though a cold, flu, or COVID-19 can strike at any time, you’re more likely to pick up a viral disease in the winter than at other times of the year. The cold, dry air in the winter months provides optimal conditions for the spread of viruses. People are also more likely to gather indoors to avoid the cold weather, creating ideal situations for viruses to spread in large numbers.

Prevention best practices
The best prevention for any kind of virus is to get a vaccine if available. As we’ve seen with breakthrough COVID-19 cases, though, vaccines aren’t perfect. Even if you’re vaccinated, you should take the following steps to avoid contracting a virus this winter.

- Mask up: Even if you’re fully vaccinated, you should wear a mask in public in areas where viruses are spreading quickly.
- Wash your hands frequently: Even if you don’t see any dirt or grime on your hands, that doesn’t mean germs aren’t there. Hand sanitizer is good in a pinch, but washing with soap and water is still the best way to keep clean.
- Disinfect surfaces: Wiping down surfaces you touch a lot with just soap and water does remove some germs, but to make sure you’re reducing germs to a safe level, consider using disinfectants like bleach or antibacterial wipes when cleaning. Some germy items to look out for include counters, doorknobs, faucet and toilet handles, light switches, remotes, and toys.
- Avoid close contact with people who are sick: If someone you’re living with comes down with a viral disease, try to stay in different rooms as much as possible, use separate dishware, and wipe down shared spaces like bathrooms. If you have to be in the same room, try to be at least six feet apart and consider wearing a mask. Air purifiers are great if you have one, and, if the weather’s warm enough, a cracked window can help new air flow into the room, lowering the risk of infection.
- Try not to touch your eyes, nose, and mouth: Though the virus that causes COVID-19 has been shown to mainly spread through the air, many viruses spread when someone touches a surface with the virus on it and then touches their eyes, nose, or mouth, where the virus can enter the body.
Steps to recover quickly from an illness
Should you come down with COVID-19, the flu, or another respiratory virus, here are some tips on how to help care for yourself.

- Stay home, and stay away from those you live with as much as possible.
- Get tested – knowing what’s causing the infection can help inform treatment decisions.
- Rest, drink lots of liquids, and take pain relievers as needed for aches, pains, and fever.
- Speak with your doctor. Prescription antiviral drugs might be an option if you test positive for the flu. If you’ve tested positive for COVID-19, ask your doctor if you’re eligible for an FDA-authorized or -approved COVID-19 antiviral medication.
- Older individuals and those with existing medical conditions who have symptoms should call their doctor if they test positive for COVID-19.
- If symptoms get much worse, consider going to the hospital.
- Try using a humidifier or steam to relieve congestion.
- Gargling with salt water can help get rid of mucus that collects at the back of the throat.
- Cough drops and hard candy can help ease a cough or sore throat.

Vaccine news
Vaccines not only provide protection for yourself but help prevent the spread of disease to vulnerable populations. The FDA-authorized and approved COVID-19 vaccines are safe, highly effective at preventing hospitalization and death, free, and widely available. The Centers for Disease Control and Prevention advises everyone age 5 and older to get the first two COVID-19 vaccine shots, and everyone age twelve and older to get a booster shot. People can find a local COVID-19 vaccination site by going to vaccines.gov or texting their zip code to GETVAX (438829) or VACUNA (822862).

Today’s flu vaccines are developed to prevent what scientists believe will be the most widespread flu strain each winter. In June 2021, the NIH launched a clinical trial of a universal flu vaccine developed by scientists from the National Institute of Allergy and Infectious Diseases. If it works, the vaccine would provide long-lasting protection against multiple flu virus strains and could one day get rid of the need to get vaccinated every year. Until then, be sure to get your flu shot every year as well as the COVID-19 vaccine and any boosters.

If you have a virus, and especially if you’re not wearing a mask, be sure to stay away from others.
COLD-WEATHER WELLNESS

HYPOTHERMIA AND FROSTBITE

Tips to prevent and treat cold-related health problems

Hypothermia: Easier to develop than you might think

Cold temperatures can cause hypothermia, which occurs when body temperature drops below 95 degrees Fahrenheit. Warning signs include shivering, exhaustion, confusion, memory loss, and fumbling hands. Infants and older adults are especially at risk for hypothermia, as they have a harder time regulating their body temperature. Medical conditions in older adults can also make that problem worse. Hypothermia can lead to health problems like heart attacks, kidney problems, liver damage, or death.

Even a small drop in temperature or a short time spent outside can cause a large drop in body temperature in infants and older adults. And according to the National Institute on Aging, living in a poorly heated home can cause hypothermia. To avoid developing hypothermia indoors, place a rolled towel in front of doors to keep out drafts, make sure windows are weather stripped or caulked if they have gaps, and keep indoor temperatures above 68 degrees Fahrenheit.

Frostbite: What to look for

Frostbite occurs when temperatures get cold enough that flesh begins freezing. Though frostbite can occur anywhere on the body, it typically affects exposed areas like the nose, ears, cheeks, chin, fingers, and toes. During early stages, you’ll likely feel pins and needles in the affected areas, which will turn white. True frostbite causes the skin to appear waxy, hard, and cold to the touch.

Hypothermia doesn’t just occur in frigid weather. Living in a poorly-heated home kept below 68 degrees F can be a risk for older populations.

SOURCE: National Institute on Aging
How to prevent hypothermia

To avoid hypothermia or frostbite when going outside:

- Dress in layers
- Wear warm clothing to protect your hands, feet, neck and face
- Get plenty of food and fluids
- Avoid alcoholic drinks

To prepare your car for a cold-weather emergency:
Make sure to have an emergency car kit with supplies like:

- Extra warm clothing and blankets
- An ice scraper
- A snow shovel
- Cat litter or sand to help tires grip on snow and ice
- Water and non-perishable food
- Jumper cables
- First aid kit with any necessary medicines and a pocketknife
- A battery-powered radio, a flashlight, and extra batteries
- Emergency flares or distress flags
- Waterproof matches and a can to melt snow for water

To prepare your home for a cold-weather emergency:
Make a disaster plan and prep your home for any winter weather by doing the following:

- Make sure you have important phone numbers — such as for your doctor and pharmacy — written down
- Prepare your home to keep out the cold with insulation, caulking, and weather stripping
- Gather supplies in case you need to stay home for several days without power
- If you plan to use your fireplace or wood stove for emergency heating, have your chimney or flue inspected each year

How to treat

Seek medical care as soon as possible and take the following steps:

Frostbite

- Get into a warm car or room
- Try not to walk on frostbitten feet or toes
- Put the frostbitten area in warm (not hot) water
- Use body heat, such as an armpit, to warm the frostbitten area
- Cover the area with a clean cloth - if your fingers or toes are frostbitten, wrap each one individually and keep them separated
- Don’t rub the frostbitten area
- Avoid touching hot surfaces with the frostbitten area, as frostbite makes the area numb

Hypothermia

- Get to a warm car or room
- Remove any wet clothing
- Warm the core of the person’s body (chest, neck, head, and groin) using an electric blanket or skin-to-skin contact under loose, dry layers of blankets
- Serve warm, non-alcoholic drinks
- Once body temperature has increased, wrap the individual in a warm blanket to help increase body temperature

SOURCE: National Library of Medicine
**Physical exercise**

**What should you be doing, and how much is enough?**

When you hear the word “exercise” you might think about lifting weights or hitting the treadmill to try to lose a few pounds. Weight loss can be one benefit of getting enough physical activity, but there are other important ways that exercise helps you stay healthy – including physical, emotional, and mental benefits.

Regular exercise can help you stay physically healthy by:

- Building strength – stronger muscles help with performing everyday activities
- Helping to manage and even prevent some diseases like arthritis, heart disease, stroke, and type 2 diabetes
- Helping you lose weight or keeping you from gaining weight
- Giving you more energy and making you feel less tired
- Enabling you to sleep better
- Helping with balance and preventing falls

**Emotional and mental benefits of exercise include:**

- Less stress, anxiety, and depression
- Feeling more in control
- Improved self-esteem
- Finding it easier to plan, focus, and shift between tasks
- Enhanced reasoning and thinking
- Possibly lowered risk of developing Alzheimer’s disease

**Being active: How much is enough?**

Guidance from your health care provider can help determine how much activity is right for you based on your lifestyle. Here are some general suggestions:

- **60 minutes**
  - The amount of daily moderate to vigorous activity children and teens should get. This includes activities like walking, running, and sports that make the heart beat faster. Adults who want to lose or want to maintain weight should aim for this amount as well.

- **150 minutes**
  - The minimum amount of weekly moderate activity adults should get to stay healthy. Strengthening activities should also be included two or more days a week.

- **Moderate activity**
  - Some activities include walking, biking, jogging, volleyball, climbing stairs, gardening, raking leaves, and dancing. A good test is to try to talk while doing the activity. Making conversation might be a little more difficult, but you shouldn’t be gasping for air.

- **Vigorous activity**
  - Some activities include hiking, running, shoveling snow, carrying heavy loads, basketball, soccer, bicycling, and singles tennis. Making conversation should be difficult at this level.

- **Strength exercises**
  - Some activities include lifting weights using large muscles like in the arms or thighs, using resistance bands, and using your body weight by doing push-ups, pull-ups, crunches, and squats. These exercises strengthen large muscles or make your muscles work harder than usual. Doing these activities at least two days a week can help build strength and keep or increase muscle mass.
The four types of exercise

The best way to get enough physical exercise is to find activities you enjoy doing. Finding different ways to exercise is an important part of staying healthy. Your health care provider might recommend some of the below activities.

**Endurance exercises**

*What it does:* Endurance exercises increase your breathing and heartbeat, which improves the health of your heart and lungs.

*What to do in the gym:* Use the treadmill, stationary bike, rowing machine, or stair climber. If a pool is available, swimming is a great option for individuals worried about their joints.

*What to do at home:* Go for a brisk walk, jog, bike ride, or hike. Play tennis or basketball with friends. Even routine yard work like mowing or raking can be beneficial. Watch and follow along to a dance workout video online. Climb up and down stairs if available.

**Strength exercises**

*What it does:* Strength exercises use body weight or physical weights to improve muscle strength and make everyday activity easier.

*What to do in the gym:* Find a buddy in the gym to help you safely lift free weights, use weight machines as directed (using machines improperly can cause back injury), or perform body weight exercises.

*What to do at home:* Get creative. Find exercises that use your own body weight, like squats, push-ups, and crunches. Use resistance bands and weights if available.

**Balance exercises**

*What it does:* Balance exercises strengthen the muscles that help keep you upright such as your legs and core. They are especially important for older adults as working on balance helps prevent falls.

*What to do in the gym:* Join a Tai Chi class or use a balance board, if available.

*What to do at home:* Stand on one foot or practice walking heel-to-toe.

**Flexibility exercises**

*What it does:* Stretching improves the flexibility needed for everyday activities like bending over to pick something up or looking over your shoulder to back your car out of the driveway.

*What to do at the gym:* Take a yoga class, and use stretching devices like boards and resistance bands.

*What to do at home:* Do stretches commonly found in yoga or those found online from trusted sources like the Mayo Clinic.

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**Health Hack**

Daily activity can help you get enough physical exercise. Try making little changes like walking when running an errand that’s close to you, parking farther away from your destination, and using the stairs instead of the escalator or elevator when possible.
Burns: How to treat and prevent

Stay safe when using fires or hot liquids

Ouch! I burned my skin, now what?

First Degree
- Put the affected area in cool water or apply a cold, wet compress
- Apply petroleum jelly a few times each day
- Consider taking over-the-counter pain medicine like acetaminophen or ibuprofen to ease pain
- Protect the affected area from the sun

Second Degree
- Follow all first degree burn treatment recommendations
- Don’t break any blisters
- Apply a bandage if the skin or blisters are likely to become irritated by clothing or daily activity, or if the blisters have broken open

Third Degree
- Seek immediate medical attention
- While waiting for medical help to arrive, cover the affected area in a clean bandage and attempt to raise the affected area above the heart

How to avoid betting burned
It’s likely you’ll experience a burn at some point. Accidents happen! However, there are some steps you can take to reduce the risk of injuring you or those around you.

- Keep hot foods and beverages away from table edges
- Don’t leave hot beverages or cooking pots and pans unattended around children or pets
- If using a travel mug be sure to use a spill-proof lid
- Don’t overfill cups or bowls
- Warn others when a hot liquid or dish is being served
- Use oven mitts when cooking or handling hot food and drinks
- Warn others when household appliances such as a stove or iron may be hot

Getting warm gone wrong: How bad is my burn?

First Degree

What it means: Only the top layer of skin is affected
What it looks like: The top layer of skin is red and painful
What might have caused it: Splashing a cup of hot tea

Second Degree

What it means: The first and second layers of the skin are affected
What it looks like: Skin looks wet or moist and blisters may form
What might have caused it: Making contact with a hot stove burner

Third Degree

What it means: All three layers of skin are affected
What it looks like: Skin is black, white, or red with a leathery appearance
What might have caused it: Being caught in a fire

SOURCE: National Institute of General Medical Sciences
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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