How fashion influencer Camila Coelho has gained confidence and connected with others through

**EPILEPSY**

Former U.S. gymnast Shannon Miller on her early ovarian cancer experience

**IN THIS ISSUE**

- The latest on kids and COVID-19
- New MedlinePlus latest test articles for you
- Is it hypothyroidism or something else?
- Research updates on arthritis in children
In this issue

Welcome to the summer 2021 issue of NIH MedlinePlus magazine.

This issue features updates on research from the National Institutes of Health on topics including ovarian cancer, juvenile arthritis, and epilepsy, featuring an interview with fashion star Camila Coelho.

Coelho is no stranger to sharing her story with others. As a fashion blogger and social media star, she has grown a following of more than 9 million people on Instagram alone. But recently, she has opened up about another topic—her health journey with the brain disorder epilepsy, which causes intense, often debilitating seizures.

Though roughly 70% of epileptic seizures can be controlled with medicine and surgery, the other 30% are less straightforward. National Institutes of Health-supported research explores just how epileptic seizures start and spread in the brain to improve diagnosis and treatment for all people with the condition. In this issue, find out how to spot and help someone having a seizure.

September marks Ovarian Cancer Awareness month, which shines light on the 21,000-plus people diagnosed with the disease each year. Olympic gold medalist and gymnast Shannon Miller explains how her ovarian cancer diagnosis showed her the importance of taking a step back and accepting help from others.

Also in this issue, read about ways to help kids and young adults prevent sports injuries as they return to school, recent updates on COVID-19 vaccinations for your family, and where to find comprehensive information on more than 300 medical tests.
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Camila Coelho, who was diagnosed with epilepsy as a child, says sharing her story publicly has made her stronger.
How to keep your family protected from COVID-19

HEALTH TIPS  Though most children and teenagers have had less severe cases of COVID-19 compared with adults, they can still get sick and spread the disease to other people. That’s why COVID-19 vaccines are important for children and teens who are eligible. Currently, the Centers for Disease Control and Prevention (CDC) recommends that everyone age 12 and older be vaccinated against COVID-19. Widespread vaccination is our best hope to prevent COVID-19 from spreading.

How they work
Vaccines help us develop immunity to the virus that causes COVID-19 without needing to get the illness. By getting vaccinated, people of all ages make it harder for the virus to spread from person to person. Much of the science and research behind some of the COVID-19 vaccines started with research that began before the pandemic on other viruses, like those that cause the cold and flu.

The COVID-19 vaccine has mild, temporary side effects and does not cause COVID-19.

Current guidelines for children
Everyone in the U.S., including children who are eligible, can get a free COVID-19 vaccination, regardless of immigration or health insurance status.

Currently, all children ages 12 and older are permitted to get the Pfizer COVID-19 vaccine, which is a two-part vaccine series. People need both doses of this vaccine before they are considered fully vaccinated; they are also not considered fully vaccinated until 14 days after their second dose. Before your child gets their vaccination, check with your local pharmacy to see if appointments are available or if you can just walk in. Your health care provider may also offer COVID-19 vaccines.

How to prepare your child
Talk to your child about what to expect from the vaccination. Side effects such as a sore arm, injection site swelling, tiredness, and headache may affect your child’s ability to do some daily activities. The effects should go away in a few days. Many people have no side effects or reactions.

The CDC does not recommend taking ibuprofen, aspirin, or acetaminophen before vaccination for the purpose of trying to prevent vaccine-related side effects. It’s also good to speak with your child’s health care provider if you have any questions or to confirm any potential allergies.
More than 50% of pregnant women experience sleep issues that may also be insomnia symptoms.

Studies have shown insomnia affects up to 48% of older adults.

More than 50% of pregnant women experience sleep issues that may also be insomnia symptoms.

About 1/3 of U.S. adults report that they don’t get enough sleep.

**What is insomnia?**

*BY THE NUMBERS* Can’t sleep? You’re not alone. Roughly 30% of adults report not getting enough sleep at night. But how can you tell if it’s something more serious?

Insomnia is a sleep disorder which is defined as repeated difficulty getting or staying asleep despite adequate opportunities and circumstances. It also results in daytime impairment. It’s estimated that between 12-20% of adults in the U.S. have insomnia.

Many adults experience short-term insomnia due to stress, pain, an upsetting event, medications, or changes to sleep habits. This can lead to daytime sleepiness, fatigue, and difficulty concentrating. It can also make you more prone to infections, such as colds and viruses. Healthy habits, like incorporating daily exercise and limiting alcohol use, can help some people sleep better.

Long-term (or chronic) insomnia, which lasts for more than three months, may require consultation with your health care professional.

**Back to school this fall**

Vaccines for children under 12 may be available later this year. Clinical trials are now underway in children under 12 and as young as 6 months old. These trials, many of which are supported by the National Institutes of Health, check the safety of medical treatments and vaccines before they are released to the broader public.

Everyone in the U.S., including children who are eligible, can get a free COVID-19 vaccination.

In the meantime, make sure your child is following the schedule for the other vaccinations your pediatrician recommends, such as measles and the flu, and that you follow the latest CDC mask or other guidelines to keep your children protected.

And as children go back to school this fall, check with your school system and local health department for the best information on the spread of COVID-19 and current prevention procedures. They could include masking and social distancing during school and extracurricular activities.

Also, make time to talk to your children about what changes to expect this school year. You may want to prepare for the possibility of virtual learning if school closes or if your child becomes exposed to COVID-19 and needs to stay home.

**SOURCES:** National Institute of Allergy and Infectious Diseases; Centers for Disease Control and Prevention

Experts recommend that adults get 7 or more hours of sleep per night.
275+ medical tests explained: From ADHD to Zika

HEALTH TIPS  Have you ever wondered why your doctor or your child’s doctor ordered a certain blood test? Are you curious about what your blood pressure results really mean? You can find answers to these questions and many more from MedlinePlus.

With information about 278 (and growing) different medical tests, MedlinePlus offers details about everything from routine blood counts and cholesterol checks to tests for tumor markers, cognitive disorders, and rare genetic diseases.

Easy-to-read information
Medical test articles from MedlinePlus give key details and facts in an easy-to-understand Q&A format, using information from leading health experts and organizations. Each article includes:

- A definition or description of the test
- An explanation of why the test is needed
- What to expect before, during, and after testing

Some articles also include information on disease management and prevention.

Test preparation and results
You can also find information on general topics related to testing, such as:

- Preparing for a lab test. Before some tests, you have to take special steps to ensure the most accurate results. This article includes examples of how you may need to prepare, such as fasting or avoiding certain medicines.

- Preparing your child for a lab test. Testing can be especially scary for children. This article includes tips for helping them understand what’s happening so that they’ll feel more at ease before and during testing. It also describes some common tests that children undergo.

- Understanding your lab results. This article explains the different kinds of test results you may get and what they might mean. It also includes information about factors that can affect the accuracy of your results.

Some people get so stressed and worried about medical tests that they won’t take them, which can put their health at risk.

The list of tests is always growing
Medical test articles are updated frequently to ensure they contain the latest information. The list of tests is continually expanding. Recent additions include:

- Coping with medical test anxiety. Some people get so stressed and worried about medical tests that they won’t take them, which can put their health at risk. This article provides helpful information and tips for coping that may help reduce their anxiety.

- Basic metabolic panel. This article briefly describes the types of tests included in a basic metabolic panel. It also explains why the test is given and what you can expect when you take it.

- Measuring blood pressure. This article describes why you might need a blood pressure test and how it works. It also mentions at-home tests as well as steps you can take to reduce your blood pressure.

- Coming soon. Articles on sleep studies and more.
5 questions for NIH’s Dr. Marie A. Bernard

INSIDE NIH  Formerly with the National Institute on Aging, Marie Bernard, M.D., transitioned to the role of chief officer for scientific workforce diversity at the National Institutes of Health (NIH) earlier this year. She was previously acting director and though she only started recently in her permanent role, has already hit the ground running.

Dr. Bernard separately co-chairs the UNITE Initiative at NIH which aims to promote diversity throughout all of NIH and the greater scientific community.

“We know that diverse groups lead to better creativity and innovation.”
– Marie Bernard, M.D.

She talked about her office’s priorities over the next few months and how she stays healthy when she’s not on the job.

What does diversity mean in your role and at NIH?
When we say diversity, we’re thinking broadly. The NIH definition of diversity, that includes women, people who are underrepresented in the sciences by race/ethnicity, people living with disabilities, and other groups that don’t have equal representation at the table. My office’s goal is to facilitate scientific workforce diversity within and beyond NIH. We know that diverse groups lead to better creativity and innovation. So, you want to get as many of those diverse perspectives as possible.

What are some of your team’s priorities this year going into next?
One of the first things we’ve done is offer NIH institutes and centers the opportunity to go further in paying for diversity supplements than they have in the past. We’re also really interested in developing programs that will incentivize external institutions [universities or hospitals that conduct research with support from NIH] to focus more on what their culture is like and what sort of things can enhance a culture of inclusivity and excellence. Internally, we’ve been looking at our policies and procedures, and we have a policy that will make it much more evident to NIH staff how they can report incidences of racial discrimination, something that we think is really important. We will be announcing that this fall.

Can you give a brief summary of UNITE?
UNITE is an ambitious agenda to end structural racism led by NIH Director Francis S. Collins, M.D., Ph.D. It is something that came about as a result of intense discussions from June 2020 onward. We determined that we are at a tipping point, and we cannot let this moment pass. For example, making sure there aren’t barriers based on race/ethnicity, within the NIH workforce and beyond. I’m very privileged to co-chair that initiative.

What’s your advice to other women and particularly women of color pursuing scientific leadership positions?
You just need to know you can do it. Having that self-confidence is almost like being an actor or actress; you have a lot of things that won’t go your way, but you have to believe in yourself going forward. You can have it all, but not necessarily all at one time. Take advantage and get help with various roles in your life. And, along those lines, make sure that you have a robust network, both personally and professionally.

What’s something people may not know about you?
What people generally don’t know about me is that I’m just short of my black belt in taekwondo. I used to keep all the broken boards in my office so I could point at them and tell people, don’t mess with me! But in all seriousness, I’ve found that with physical activity, which lately has been more yoga and going to the gym, that it is important to have that time for oneself in order to be centered.
Ali Palmer has always been active. She has a small, athletic build and even worked at a fitness studio during college.

In 2019, when Ali was 22, she gained about 10 to 15 pounds within a year. She was confused and concerned. As an actress living in Los Angeles, Ali had the pressure of Hollywood on her shoulders as well.

“L.A. is the city of perfection,” Ali says. She felt uncomfortable about her body and what others might think. She also felt incredibly tired. Even seemingly low-energy activities, such as going to the movies, were too much for her.

“I couldn’t have any form of social life because I didn’t have the energy to go through it, to talk to people,” she says.

In March 2020, at the beginning of the COVID-19 crisis, she decided to move back home with her parents and focus on getting healthy again. She and her mom worked together to build a diet and exercise regimen. Between March and June, Ali gained another 2 pounds. She was feeling sluggish and depressed, and she could hardly get out of bed in the morning.

It was then that Ali contacted her doctor. After a number of blood tests, her doctor diagnosed Ali with Hashimoto’s disease, an autoimmune disease that causes hypothyroidism. Hypothyroidism is a condition where the thyroid is underactive and does not make enough hormones for your body, according to the National Institute of Diabetes and Digestive and Kidney Diseases. It can cause fatigue and weight gain over time, along with a list of other symptoms.

“In that moment, I felt relieved and excited to have some answers,” she says.

Ali is now taking thyroid medication to regulate her hormones. She also has prioritized staying healthy above looking a certain way.

“After my diagnosis, I realized my beauty is not defined by my weight,” Ali says.

She recommends checking in with your own body and talking to a health professional if you think something isn’t right.

“Say to yourself, ‘I deserve to figure out what this is so I can feel right.’ It will change every aspect of your life,” she says.
HYPOTHYROIDISM

“After my diagnosis, I realized my beauty is not defined by my weight.”
– Ali Palmer

Fast facts about hypothyroidism

Underactive thyroid most common in women, people over 60

- Nearly 5% of Americans over the age of 12 have hypothyroidism.
- It is most common in women.
- Hashimoto’s disease is a common cause of hypothyroidism. When someone has Hashimoto’s disease, their immune system attacks the thyroid, which then can’t produce enough hormones.
- People with celiac disease, Sjögren’s syndrome, diabetes, rheumatoid arthritis, or lupus are more likely to have an underactive thyroid.
- If an underactive thyroid is not treated during pregnancy, women can experience high blood pressure in late pregnancy, anemia, miscarriage, low birth weight, or stillbirth.
- Infants can also have an underactive thyroid. All newborns in the United States are tested for congenital hypothyroidism.

SOURCE: National Institute of Diabetes and Digestive and Kidney Diseases
Hypothyroidism research: A long-term effort

New study looks at patients with kidney disease and underactive thyroid

HYPOTHYROIDISM CAN BE A COMPLICATED DISEASE on its own and require daily medication in most cases and surgery in more serious cases. But many people with hypothyroidism have other conditions as well. Some of those include diabetes, celiac disease, lupus, anemia, and Sjögren’s syndrome.

Another one is chronic kidney disease, which can be associated with hypothyroidism in some patients. Chronic kidney disease causes the kidneys to fail, which makes it hard to filter waste and water from your blood. People with the disease often need medication or more advanced treatment to help them filter out this waste.

A current National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)-supported study is investigating patients with both chronic kidney disease and hypothyroidism.

The five-year study started in 2019 and has 336 participants. It is looking at whether levothyroxine, a medication that treats hypothyroidism by increasing thyroid hormones, helps hemodialysis patients’ overall health and quality of life. Hemodialysis is a treatment for people with chronic kidney disease. During hemodialysis, waste and water are filtered from a person’s blood by a machine called a dialyzer. The blood is then returned into your body. Researchers also want to learn whether levothyroxine improves these patients’ cardiovascular health.

In addition to studying chronic kidney disease, NIDDK has ongoing studies that track hypothyroidism patients over time. One such study, which has been active since 1977, focuses on people with all types of thyroid issues, including hypothyroidism. Participants go through regular checkups and testing. Researchers use that data to improve how to best manage thyroid issues and better understand the genetics of the thyroid conditions.

SOURCE: National Institute of Diabetes and Digestive and Kidney Diseases

For more information on the latest hypothyroidism clinical trials from both NIDDK and others, visit ClinicalTrials.gov.
Why the internet can’t diagnose your thyroid problem

Weight gain, fatigue can stem from other health concerns

NEARLY FIVE OUT OF 100 AMERICANS over the age of 12 have hypothyroidism, or an underactive thyroid. Because the condition is common, people often think they have hypothyroidism when they actually don’t.

In fact, many symptoms that result from hypothyroidism can be caused by something unrelated. For instance, they can result from a medication, separate hormonal issue, or gastrointestinal disorder.

Symptoms of an underactive thyroid

- Fatigue
- Weight gain
- Feeling cold
- Joint and muscle pain
- Dry skin or hair
- Irregular menstrual periods
- Slower than usual heart rate
- Depression

Diagnosis

“Many patients refer to the internet for information related to their symptoms and incorrectly assume that these nonspecific symptoms indicate a thyroid problem,” said Henry B. Burch, M.D., a program director at the National Institute of Diabetes and Digestive and Kidney Diseases.

The only accurate way to diagnose an underactive thyroid is to consult a doctor or other health professional. They will review your medical history and do a physical exam. Your doctor may also run blood tests and imaging tests. The tests will detect if your thyroid is underactive, and if so, why.

Treatment

Dr. Burch says people who are diagnosed with thyroid problems like hypothyroidism often find misinformation about treatment online too.

“The only accurate way to diagnose an underactive thyroid is to consult a doctor or other health professional.”

Dr. Burch encourages people who think they may have a thyroid issue to meet with their doctor. They should discuss their symptoms and get the appropriate tests. He said it’s important to remember that the thyroid might not be the issue. Be open to the fact that if the thyroid lab test results are normal, the doctor will need to seek other causes for your symptoms.
Camila Coelho is among today’s most influential voices in social media with millions of followers on Instagram, TikTok, and Twitter. She has also built successful cosmetics and fashion businesses. Now she is speaking out about accepting differences, overcoming challenges, and her life with the seizure disorder epilepsy. There are many forms of both epilepsy and seizures, ranging from mild to severe. This is Camila’s story.

What were your early experiences with epilepsy like?
I was only 9 when I had my first seizure. I don’t remember much about it, but I do remember thinking I had just fainted and being scared since I didn’t know what had just happened. I was taken to the hospital and the doctors told me I had epilepsy. Thankfully, after my diagnosis, medication worked to control my epilepsy, and I had pretty much a normal childhood without more seizures or hospital visits.

Tell us about the turning point you had as a teenager.
When I was 14, my family moved from Brazil to Scranton, Pennsylvania, and everything was different. I started struggling when I was around 16 or 17. I was a teenager trying to fit in in a new world. At the same time, I was very much afraid that I could have a seizure in front of new friends. I found myself in situations that made me feel insecure and uncertain. I responded by trying to reject my epilepsy because I couldn’t accept it. I stopped taking my medications and, after a few months, I had a seizure at my high school in front of all my friends.

I remember waking up in the hospital in tears. I knew I had done something wrong and had risked my life. I was so ashamed. But then I had an amazing conversation with my mom and opened up my heart to her. She said, “Camila, there are people fighting for their lives every day for many different reasons. There are many with epilepsy who can’t control their seizures. You can control yours if you take your medicine. How lucky are you?” That was a real turning point for me. After that talk, I started to see life in a different way. Instead of complaining and feeling different, I started to feel blessed and lucky. I began to accept myself as I was.
Why did you decide to speak out?
I came to that decision recently when I started thinking about pregnancy and starting a family. That is when epilepsy came back into my life as a challenge. I knew it could impact my ability to get pregnant and have a healthy pregnancy. My doctor said that if I got pregnant without being on medicine, I could have a seizure and quickly lose the baby. I decided that I needed to share this big struggle I was going through. I came to realize that telling my story would make me stronger and could help others.

Going public was very scary. Only my family and closest friends knew about my epilepsy. There is still a huge stigma and lack of understanding about the condition. But it is the best thing I have ever done. I received so many messages from women who had epilepsy and had successful pregnancies while on their medicine. That gave me hope and strength. By sharing, I was able to help others. So many of my social media followers shared their own stories about living with epilepsy.

What healthy habits help you manage your epilepsy?
Getting enough sleep and controlling stress are really important for me. I try to sleep eight or nine hours a night. Also, getting outside, walking, biking, and playing volleyball relieve stress and get me more connected to myself.

What is your message to others who have epilepsy or other challenges?
Never lose hope. See yourself as someone strong. If you believe in the beautiful inner light that all of us are born with, you can be whoever you want to be. Don’t ever let anyone bring you down or stop you. It is up to you to let your life shine and to go after your dreams. No matter what your condition is, believe in yourself and love yourself.

Why is it important to promote that message on social media?
Many people look at social media and see everyone else’s life as perfect. They compare themselves to this and think their lives are not good. They need to understand that social media is a filter. I see sharing my struggles as an important part of my role, to show people that we all go through challenges and that life is never perfect.

What’s next for you and your health?
I’m changing my epilepsy medicines now, with the help of my doctor, to prepare for potentially getting pregnant. I hope that 2021 will be the year that I get pregnant!

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70%
For roughly 70% of people with epilepsy, seizures can be controlled with modern medicines and surgery.

SOURCE: National Institute of Neurological Disorders and Stroke

“For roughly 70% of people with epilepsy, seizures can be controlled with modern medicines and surgery.”

“I came to realize that telling my story would make me stronger and could help others.”

– Camila Coelho

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IMAGES: LEFT, COURTESY OF KRIZIA LOECHLE; ABOVE, COURTESY OF ICARO COELHO
Of the roughly 3 million people with epilepsy in the U.S., about 30% still have seizures despite being on medication. That’s where research like that from the National Institutes of Health comes in. Kareem Zaghloul, M.D., Ph.D., is a principal scientist at the National Institute of Neurological Disorders and Stroke in Bethesda, Maryland. He has focused much of his research on epilepsy and how advanced surgery techniques can help treat patients when medication isn’t enough. Dr. Zaghloul provided a glimpse into this technique and his work to improve the lives of patients with more advanced treatment needs.

**What is the focus of recent epilepsy research?**

There are still some very big questions about epilepsy, including how it starts in the brain. For people who have seizures that continue despite the best medication that doctors provide, surgery is an option. The only way that surgery can be useful, though, is if we can identify the exact spot in the brain that’s causing the seizures. Our research has been focused on trying to pinpoint those spots and identify which areas are most likely to be involved in seizure activity.

**How do you do that?**

When we don’t know exactly where a patient’s seizures are coming from, we surgically implant electrodes in and around the brain. These electrodes collect data on seizure activity. Some can be placed deep in the brain. Others are placed on the surface of it. These electrodes record brain activity for a week or two.

This data gives doctors a much more detailed view of what’s happening in the brain. We combine this data with models we’ve developed to help identify where those seizures are coming from and how they’re spreading. Beyond the individual patient, this data is used to identify an “epilepsy network.” For example, one part of the brain might start seizing, and then it spreads to another part. We want to know why that happens.

**How do you hope this research will help people with epilepsy?**

We have a couple of goals. First, we want to improve treatment for the patients. Agreeing to surgery is a big step for people with epilepsy, and we want to make sure it’s going to be very successful. Identifying the areas of the brain involved in the seizures will help us develop a surgical strategy to target those regions.

The second goal is to learn more about how seizures affect the actual neurons and the cells surrounding them. When we perform the surgery, we remove a sample of brain tissue to examine.

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**Having a seizure does not mean someone has epilepsy.**

Other causes can include very high blood sugar in diabetics or eclampsia during or after pregnancy.

**SOURCE:** National Institute of Neurological Disorders and Stroke
“For people who have seizures that continue despite the best medication that doctors provide, surgery is an option.”

– Kareem Zaghloul, M.D., Ph.D.

We look at the neurons and compare them to regular neurons from other parts of the brain. This has allowed us to ask questions about what’s happening in the fundamental biology of the brain during a seizure. We think seizures may develop from disruptions in metabolism and inflammation.

What do you wish more people knew about epilepsy?

Epilepsy is quite a common disorder. It affects about 1% of the population, or about 3 million people in the U.S. The first approach to treating it is to use medication, but about a third of those people still have seizures despite the best medical therapy.

Having epilepsy can be frustrating, especially for someone who feels like they’ve made no progress controlling it. But there’s a lot of support out there, and groups are constantly working on new treatments. Don’t be shy about reaching out to see what other options are available.

How to help someone who is having a seizure

Try to remain calm and don’t stop their movements

If a person is having a seizure, it’s important to know how to help. Some signs of seizure, according to the National Institute of Neurological Disorders and Stroke, include staring, jerking movements, falling, or even loss of consciousness.

1. Remain calm
   Check to see if the person is wearing a medical ID bracelet or necklace. Time the length of the seizure using your watch or phone.

2. Keep the person safe
   Move or guide them away from harmful or sharp objects. If a person wanders, guide them away from dangerous situations.

3. Turn them onto their side
   Turn the person onto their side if they are not awake or aware. Loosen tight clothing around their neck, and place something soft and small under their head. If they are aware, help them to sit down.

4. Do not stop their movements
   Do not try to stop the person’s movements or hold the person down. This can lead to injuries and cause the person to feel distressed.

5. Stay with them
   Stay with the person until they are fully awake and alert after the seizure. Most seizures last a few minutes. Call 911 if a seizure lasts more than five minutes.

Sources: Epilepsy Foundation; Centers for Disease Control and Prevention
One family’s journey to find epilepsy answers

Rare gene mutation caused up to 10 seizures per hour

As an infant, Kai Johnson struggled to reach developmental milestones on time. He sat up and crawled late, and he had difficulty chewing and swallowing solid foods, says his mother, Jessica.

She talked about her concerns with Kai’s pediatrician. After that, Kai began receiving developmental therapy through early intervention, which is a program for young children who have developmental delays or disabilities.

About one year later, Kai’s day care closed due to the COVID-19 pandemic. That’s when Jessica noticed something else—unusual movement patterns in his face.

“He was home with me all the time, and that’s when I noticed some eye fluttering. At first, I just thought that he was tired and ready to fall asleep,” she says. “But about a month into it, I knew something wasn’t right.”

Finding the cause

His pediatrician requested overnight monitoring of Kai’s brain to determine whether it was experiencing seizure activity. But just five minutes into the monitoring, they detected significant seizure activity, Jessica says. Kai was soon diagnosed with epilepsy, a disorder in which nerve cell activity in the brain is disturbed, causing seizures.

“It was kind of scary because other than one family member who had one seizure once, I didn’t know anything about epilepsy,” she says.

Kai’s doctors quickly started him on anti-seizure medication. Meanwhile, they ordered genetic testing and imaging of his brain to better pinpoint why he was having seizures. The results of the imaging showed normal brain development. Genetic testing, however, revealed SYNGAP1—a rare gene mutation discovered in 2009. SYNGAP1 causes developmental delays and recurrent seizures.

“That diagnosis was devastating,” Jessica says. “It’s a spectrum disorder, and kids can have mild to severe symptoms.” Those medical issues include developmental and verbal delays, sensory processing disorder, low muscle tone, autism, sleep disturbances, and epilepsy.

Kai is now 3 years old, and Jessica says treating his epilepsy with medication has been difficult. Finding the correct combination and dosages takes time. Kai currently takes four anti-seizure medications. They have reduced his seizures from up to 10 an hour to about five an hour.

“It’s frustrating because we see him making so much progress with speech, for example, and then seizures set him back,” Jessica says. “But he has the best attitude considering how many seizures he’s had. He blows my mind every day.”

“An epilepsy diagnosis might change things and life will look different, but it will still be great.”

– Jessica Johnson

Building a team

Jessica says Kai’s experiences have taught her a lot about working with the medical community and advocating for her son.

“You need to be your child’s advocate,” she says. “Be the squeaky wheel, and don’t stop until your child is getting what they need. Build a good team for your child.”

She has also learned how important it is to educate others about epilepsy.
“Teach the people around you about epilepsy so that they’re not scared of seizures, know how to recognize one, and how to help when one happens,” she says. “People think seizures are when someone drops to the ground and violently shakes, but some seizures aren’t like that. So many people suffer from epilepsy, and awareness of this disorder is so important.”

Above all, she says, keeping a positive attitude is essential. “There’s a lot that Kai won’t be able to do because of his seizures, like drive a car,” Jessica says. “But I read something that put it into perspective. Your whole life you may have dreamed of visiting Italy. You learn the language and buy the tickets. When the plane lands, you’re actually in Amsterdam. You’ll need to learn a new language and you’ll always think about Italy, but Amsterdam is still beautiful. An epilepsy diagnosis might change things and life will look different, but it will still be great. It’s important for people to remember that.”

**Understanding different kinds of seizures**

*More than 30 types have been reported*

How do you know if someone is having a seizure? It’s not always obvious, and symptoms can vary widely. For example, some seizures cause a person to fall and shake, while others cause them to stare off and look confused.

There are two different categories of seizures, based on where they start in the brain. Under those categories, there are many different types. According to the National Institute of Neurological Disorders and Stroke (NINDS), doctors have discovered more than 30 different types of seizures. Here’s a rundown of a few.

**Generalized seizures** affect both sides of the brain at the same time. Some types include:
- **Tonic-clonic seizures** may cause a person to lose consciousness. This may cause them to fall to the ground, have muscle jerks or spasms, and cry out. They are also called grand mal seizures.
- **Absence seizures** cause rapid blinking or staring into space for a few seconds. They are also called petit mal seizures.

**Focal seizures**, also called partial seizures, happen in just one area of the brain. Some types include:
- **Simple focal seizures** affect a small part of the brain. They may cause twitching or a change in sensation, such as a strange taste or smell.
- **Complex focal seizures** may make an individual feel confused or dazed. Someone with a complex focal seizure won’t be able to respond to questions or directions for up to a few minutes.
- **Secondary generalized seizures** begin in one part of the brain, then spread to both sides of the brain. This causes a focal seizure first, followed by a generalized seizure.
- **Unknown onset seizures** may later be diagnosed as focal or generalized seizures. A seizure is initially termed unknown onset if no one else witnesses it. For example, if it happens at night or to someone who lives alone.

**Source:** National Institute of Neurological Disorders and Stroke
Gymnast Shannon Miller captivated the world on her way to Olympic gold. Now the seven-time Olympic medalist and women’s health advocate holds another title: long-term cancer survivor. Miller says that though cancer treatment was one of the hardest parts of her life, her family and health teams helped her reach recovery and stay positive along the way.

**When were you diagnosed with ovarian cancer?**
In the fall of 2010, my doctor found a baseball-sized cyst on my left ovary. On January 13, 2011, I woke up from surgery to remove the tumor to news that I had a rare form of ovarian cancer. I was only 33.

**Had you experienced any symptoms prior to finding the cyst?**
It wasn’t until after the diagnosis that I rethought my symptoms prior to that initial doctor’s visit. My husband reminded me that I had called him at work a couple of weeks before because I was doubled over on the floor with stomach pain and wasn’t sure I could get our 1-year-old son out of his crib.

I also realized that I had three of the four primary symptoms of ovarian cancer: bloating, weight loss, and pain. But I had completely written them off. I didn’t even remember them. That is why it is so important for me to talk about this to women. As women, as moms, we need to listen to our bodies.

**How did your skills and experience as a world-class gymnast help you approach your cancer recovery?**
As an athlete, I learned the importance of setting and sticking to goals and keeping a positive attitude. Going through chemotherapy was the toughest thing I have ever had to do. Being in that positive mindset was so critical. That doesn’t mean being cheery 24/7. But I was trying to look to the positive and tell myself that I could do this. I started setting achievable goals for myself. Even if it was as basic as walking around the dining room table twice. If I could do that, it was a win for the day. Little by little, I was able to do more and get stronger.

Even with this, I hit my low. I was having horrible nausea at one point and couldn’t keep anything down. I ended up back in the hospital. As I sat alone in my hospital room, I thought, “I can’t do this. I don’t know how to do this.” Then a nurse came in to check on me. It brought back to me my experience from gymnastics of the importance of having a team. From that moment forward, I knew I had a team of health professionals, family, and friends working with me to get through this.

**How did you manage being a mom of a young child and recovery from cancer?**
It does take a village when going through a health crisis. I had to learn a tough lesson: I can’t do it all. And it’s OK that I can’t do it all. I think, naturally, as parents, we do everything. And I couldn’t. After talking with friends, I realized that if I didn’t focus on my own health and recovery, I was not going to be any good to my son. One of the hardest and most important things we have to learn is to ask for help and accept help when it is offered.

**What are your thoughts about research like that supported by the National Institutes of Health?**
Research is so vital. We need a better test to identify ovarian cancer earlier. We need to be better educated.

**As a 10-year cancer survivor, what is your message to other women with cancer or those who may be at risk for it?**
It is so important to be aware of your body and look out for signs and symptoms. Educate yourself and ask questions. You are your own best health care advocate. Take stock of your body. I paid attention to my body as an athlete, but I have paid much more attention to my health in the last 10 years. I took good health for granted.

Finally, don’t be afraid to speak up about it. Try to find others who have gone through this. When I heard from other survivors, it made me feel less alone, and that is really important.
“One of the hardest and most important things we have to learn is to ask for help and accept help when it is offered.”

– Shannon Miller

Shannon Miller won seven Olympic medals during her gymnastics career.
Triathlete on winning the cancer race

Persistence and self-education pay off

In 2018, Leslie Heffernan, then 58, was training for a triathlon. The Massachusetts resident has always been active and ran, swam, and biked in her spare time to prepare for the event. “I was very in tune with my body at that time, and very aware of how I was feeling and moving,” she says. When she began experiencing abdominal discomfort during training runs, she knew something wasn’t right. “I felt like I needed to hold my belly when I ran,” she says. “I started to feel something in my lower abdomen that I could push and move around. It didn’t hurt, but I had no idea what it was.”

Seeking professional advice

Leslie made an appointment with her primary care doctor to have it checked out. The doctor, she says, felt her abdomen but didn’t find anything unusual. She sent Leslie on her way. But she still felt like something was wrong. “I made an appointment with a gastroenterologist [a doctor who helps manage intestinal and liver diseases] figuring it might be something intestinal,” she says.

Two months later, at the appointment, Leslie described the mass she felt. The gastroenterologist ordered an ultrasound. Three days after that, the doctor said the ultrasound had revealed a mass. It was so large that it was difficult to determine exactly where it was coming from. A subsequent MRI determined that the mass was on her ovary. “Even at that point I never thought that this could be cancer,” she says. “After all, I wasn’t feeling sick, and I was still running. I thought it could be a number of things, like a large cyst.”

Surgery and recovery

Later that month, during surgery to remove her ovaries, the surgeons also removed a mass the size of a soccer ball that was shaped like a figure eight, she says. “It was squishy, like a water balloon. It moved when you pushed it, which might have been why it was hard for people to feel,” she says. They sent the mass to a lab to check it for cancer cells. They also removed tissue from her stomach and lymph nodes for additional testing.

After the surgery, when Leslie was in recovery, her doctor explained that the ovarian mass was cancerous,
but that the cancer was contained. She then had six rounds of chemotherapy. Leslie was declared cancer-free three years later.

“I know how extremely lucky I was that the cancer was contained, and I know that not all people with ovarian cancer get that same news,” she says. “I’m not sure I would have known that anything was wrong if I wasn’t in tune with my body and training for a triathlon.”

Leslie’s experience with ovarian cancer taught her the value of advocating for yourself, she says. She implores others to do the same.

“You know your body best. If you think something is wrong, see other doctors until you get an answer.”

– Leslie Heffernan

“By the Numbers”

A woman’s risk of getting ovarian cancer during her lifetime is about 1 in 78. Here are more quick facts about ovarian cancer, prevention, and causes.

- **63 and older**
  Half of all ovarian cancers are found in women aged 63 and older.

- **25%**
  Up to 25% of ovarian cancers result from inherited mutations in certain genes.

- **Age 35**
  Women who give birth after age 35 or who have never carried a pregnancy to term have a higher risk.

- **5 or more years**
  Using birth control pills for five or more years has been associated with a lower chance of getting ovarian cancer.

- **1 year or more**
  Some studies suggest that women who breastfeed for one year or more may have a reduced risk.

- **21,410**
  About 21,410 women will receive a new diagnosis in 2021.

**SOURCE:** National Cancer Institute
OVARIAN CANCER

IMMUNOTHERAPIES SHOW PROMISE

‘Innate’ immune system is key to managing cancer

Christina Annunziata, M.D., Ph.D., has dedicated most of her career to studying ovarian cancer with the aim of discovering new treatments for women. She works at the Center for Cancer Research at the National Cancer Institute. She shares updates on new immunotherapy research and what it could mean for ovarian cancer treatment in the next few years.

Tell us about some of your recent research on ovarian cancer.

My research focuses on the intraperitoneal environment—or the area inside of the abdominal cavity lining. We are looking at therapies we could use there to treat ovarian cancer. One of the approaches we’re taking is looking at the immune system cells in this area. We’re also looking at why these immune system cells aren’t killing ovarian cancer cells.

What is the role of the immune system in fighting ovarian cancer?

People have two types of immune systems. There’s the adaptive immune system, which is what most people think of when they get sick. This immune system is activated by exposure to pathogens. Those are the viruses, bacteria, or other microorganisms that can cause disease. It builds a memory about these threats in order to improve the immune response.

There’s also the innate immune system. It works to prevent the spread and movement of foreign pathogens throughout the body. This is the first line of defense against invading pathogens, and it’s what we’re focusing our research on.

What we’ve found is that the innate immune system is very important in controlling ovarian cancer. We’ve also discovered that it can be controlled by ovarian cancer. The cancer is finding ways to escape the innate immune system cells, which are designed to fight it. Our goal is to make the innate immune system work better so that we can better contain ovarian cancer.

How are you doing that?

We are currently performing a clinical trial in which we take the innate immune cells, called monocytes, out of the patient’s blood. We use a process calledapheresis that separates the plasma from the cells. We stimulate the monocytes, which activates them to kill cancer cells. Once they’re activated, we put the cells back inside the abdominal cavity lining.

We’re optimistic about this potential treatment, but it’s just a starting point for resetting the immune system. It could be used as a platform to build more complex immune therapies, but by itself, it probably won’t be a cure for ovarian cancer.

What do you want people to know about ovarian cancer research?

People with ovarian cancer should have hope because researchers are working on new therapies all the time. To speed up the discovery of new and effective treatments, I encourage patients to participate in clinical trials.

It’s also important to know that ovarian cancer is not one disease, and the way doctors are treating it is becoming more individualized. For example, we are learning how certain gene mutations and features of different ovarian cancers make them react differently to specific therapies. In the next five or 10 years, I think we will be developing therapies that target these specific molecular abnormalities, which we’ll be able to identify using diagnostic tests.
Could genetic screening help catch ovarian cancer earlier?

Researchers look at broad range of detection, prevention tactics

Scientists like Christina Annunziata, M.D., Ph.D., at the Center for Cancer Research and others at the National Cancer Institute (NCI) are working hard to understand the ins and outs of ovarian cancer better to help women and save lives.

They have learned more about the risk factors and causes of the disease, and new ways of treating the cancer through advanced imaging and improved early detection.

Here are a few other key areas scientists at NCI and beyond are studying:

**Genetic risk factors**

One area of study involves the genes responsible for ovarian cancer that family members pass on. This research has already led to better ways to detect high-risk genes and assess a woman’s risk of developing ovarian cancer. Scientists hope this research will also lead to new drugs that can prevent and treat it.

Researchers have developed mathematical models that help estimate how many years of life an average woman with a BRCA, or BReast CAncer gene mutation, might gain if she has her ovaries and fallopian tubes removed.

**Early detection and prevention**

Scientists are testing new ways to screen women for ovarian cancer with imaging techniques like functional MRIs and PET/CT scans, as well as how drug and lifestyle changes may alter the risk of ovarian cancer.

**Other treatment areas**

In addition to immunotherapy treatment work like that by Dr. Annunziata, cancer researchers are exploring new chemotherapy drugs and drug combinations that could result in more effective treatment for ovarian cancer patients.

**How you can help future research**

If you have or know someone with ovarian cancer or someone who is at risk, consider joining an NCI-supported trial near you. Learn more at NCI.gov.

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3 types of ovarian cancer, explained

90% of cases involve outer surface of ovary

All ovarian cancers involve one or both ovaries, or the nearby tissue that covers organs in the abdomen (belly area). There are three types of ovarian cancers: epithelial ovarian carcinomas, germ cell tumors, and stromal cell tumors. Each has different characteristics and traits:

1) **Epithelial ovarian carcinomas**

These are the most common type of ovarian cancer. About 85% to 90% of these cancers involve the cells that cover the outer surface of the ovary. They commonly spread first to the lining and organs of the pelvis and abdomen, then to other parts of the body. Nearly 70% of women with this type of ovarian cancer are diagnosed in the advanced stages.

2) **Germ cell tumors**

These make up less than 2% of all ovarian cancers. They begin in the reproductive cells that are a woman’s “eggs.” Ninety percent of patients with germ cell tumors survive five years after diagnosis. Teenagers and women in their 20s are more likely to develop this type of ovarian cancer.

3) **Stromal cell tumors**

These represent about 1% of all ovarian cancers. They form in the tissues that support the ovaries. This type of cancer is often found in the early stages. Vaginal bleeding is one of the most common symptoms.

**SOURCE:** National Cancer Institute
Sports injury? Finding a specialist can improve recovery

Growing bodies face unique risks

Many children and young athletes rival grown-ups with their skill and strength in the sports they play competitively. That makes it easy to forget how different they are from adults.

You might assume that any sports injuries they get are just smaller versions of the same injury in an adult, but they aren’t, says Miho Tanaka, M.D., a sports medicine surgeon at Massachusetts General Hospital and Harvard Medical School.

“One misconception is that children and young athletes are just small adults, and that’s just not the case,” Dr. Tanaka adds. “The types of injuries they get, and the recommended treatments for them, are often very different.”

Injuries to growth plates, for example, can only happen to children and young people, she said. Growth plates are the area of tissue at the end of the long bones in growing children and teens, according to the National Institutes of Health.

Young athletes’ muscle control is also constantly changing due to growth. That might lead to differences in how they train for or play a sport, which can require specific preventative measures.

Emphasizing prevention

Dr. Tanaka began to study youth sports injuries after her own experience as a young athlete.

“I not only became fascinated with the process of healing, but with the potential for predicting recovery and sports performance,” she says. “Much of my research is focused on being able to better identify risk factors that can be used to predict injury or surgical outcomes.”

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One of Dr. Tanaka’s recent studies focuses on anterior cruciate ligament (ACL) injuries. Dr. Tanaka said about 80% of ACL injuries in women happen because the knee gives out during a pivoting movement when playing a sport.

“It’s been shown that with preventative exercises, you can reduce that rate by about 75%,” she said. “But not a lot of athletes and parents know this.”

In fact, her research team learned that almost 70% of respondents in the study didn’t know about specific prevention training programs (PTPs) that could help them avoid ACL injuries.

**Sports injuries are first treated with R-I-C-E:**

Rest, Ice, Compression (pressure on the injury), Elevation (raise the injured area above the heart).

**SOURCE:** National Institute of Arthritis and Musculoskeletal and Skin Diseases
4 tips for keeping young athletes safe

Variety, rest are important to injury prevention

To prevent sports injuries, kids need to get plenty of rest, play a variety of sports, and follow the rules and regulations, says Miho Tanaka, M.D., a sports medicine surgeon at Massachusetts General Hospital. Coaches and parents can help. Here's a breakdown:

**Promote rest**
The most important thing a young person can do to avoid a sports injury is take time off. “You need rest,” Dr. Tanaka says. “Have an offseason.” Taking a break allows bones and joints to rest and grow without the constant strain of a sport.

**Follow safety guidelines**
Warm-up sessions before and cool-down sessions after games and practices are key. Kids should wear the correct equipment and gear for the sport they are playing. They also need to follow the rules of the sport and take regular water and rest breaks.

**Encourage variety**
“We’re seeing this increasing tendency to do what we call single-sport specialization earlier on,” Dr. Tanaka said. In single-sport specialization, a young athlete will focus just on one sport, even during offseasons. The repeated use of specific bones, muscles, and joints can cause injuries. To prevent that, Dr. Tanaka recommends that young athletes participate in a variety of sports and training exercises.

**Monitor overuse**
Many sports that require repetitive and consistent motion have regulations that help kids avoid injuries. “There are things like pitch counts that little leagues have. Those are guidelines on how many pitches a pitcher can throw,” Dr. Tanaka says. Coaches or other adults may monitor these numbers at games and practices, especially if their child plays for multiple teams (for example, a school team and a club team).

Injuries. Many also expressed interest in participating in PTPs in the future.

“I feel very fortunate to be able to work with young athletes while continuing to seek ways to optimize their treatment and recovery. I want to help them remain healthy and succeed in their goals,” says Dr. Tanaka.

**Find the right care**
When it comes to treating sports injuries in young adults, Dr. Tanaka emphasizes that parents should seek out specialized providers.

“Even their X-rays can look different,” Dr. Tanaka said. “Knowing what normal X-rays look like for a given stage of growth, as well as the specific injuries and treatments associated with them, is important when treating young athletes.”

That’s why finding a doctor in sports medicine who specializes in treating young people is crucial. And if surgery is needed, the surgeon should know how to perform modified surgeries to accommodate open growth plates.

**Take time to recover**
Dr. Tanaka says that a young person who has experienced a sports injury can often recover fully—it just might take a while.

“It’s important to appropriately manage an injury to full recovery, not only to be able to perform at your best, but also for long-term health of the joint,” Dr. Tanaka said.

In addition to parents and guardians, she encourages athletes to be educated about their injury and treatment. That can help them keep up with their treatment and stay motivated while they recover.
In addition to researching joint and bone health in young athletes, the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) also studies specific joint conditions in young people.

One of those conditions, juvenile idiopathic arthritis (JIA), is the most common form of arthritis in children and teens. In some forms of JIA, the body’s immune system mistakenly attacks some of its own healthy cells and tissues, resulting in joint swelling, pain, stiffness, and loss of motion.

There are several types of JIA, each with distinct features. Right now, scientists don’t fully understand why certain kids get JIA.

That’s where researchers at NIAMS come in. Michael Ombrello, M.D., is a principal investigator at NIAMS who is leading a study to better understand a rare form of JIA known as systemic juvenile idiopathic arthritis (sJIA) and related conditions. The primary goal of this research is to understand the causes and improve treatments for children and adults with the disease.

The study, which started in 2018, seeks to involve over 1,000 participants.

“To succeed, we must examine large populations of people with systemic juvenile idiopathic arthritis,” Dr. Ombrello notes.

Juvenile idiopathic arthritis, or juvenile rheumatoid arthritis, begins in children and adolescents before they turn 16.

**SOURCE:** National Institute of Arthritis and Musculoskeletal and Skin Diseases
Participants share their medical history with researchers and go through a series of exams. Researchers might take pictures of their skin and joints, as well as X-rays and biopsies. Some family members of the participants may be asked to give blood or saliva samples.

The researchers will use those for genetic testing, which could reveal genetic factors that contribute to the disease.

““My team’s motivation comes from the severe nature of sJIA, which drives us to overcome the challenges of translational research [research in which scientists, health care providers, and other experts work together],” Dr. Ombrello says.

He hopes to use what the team learns to create more personalized treatment for kids who have the disease.

“How to support kids with juvenile arthritis

Stay positive and educate school health care staff

Juvenile idiopathic arthritis (JIA) can be difficult for children to live with. That’s why it is important for parents and guardians to learn about JIA and how to help. We’ve rounded up a few tips for how to best support a child with JIA.

■ **LEARN:** Learn about the condition and treatment, and find a health care provider who specializes in treating JIA. Usually, that is a pediatric rheumatologist. Physical therapists can help with pain management.

■ **PREPARE:** Have cold packs and heat treatments, like a heating pad, at the ready for joint pain and stiff muscles. Sometimes your child may need a splint (a piece of hard material, usually wrapped in fabric) to help reduce pain and swelling. Make sure to talk to your child’s health care provider before using a splint.

■ **EDUCATE:** Work with your child’s school and school health care provider to educate them on your child’s needs and how to best support them if they are experiencing pain.

■ **FIND BALANCE:** Find a good balance with rest and exercise for your child. Sometimes they may need more rest or more activity. Generally, short rest breaks are better than long periods in bed.

■ **SUPPORT HEALTH:** It’s important that your child has a balanced diet full of whole grains, lean protein, fruits, and vegetables. Children also need a good night’s sleep, which can range from nine to 13 hours depending on their age.

■ **STAY POSITIVE:** Keep a positive mindset and help your child understand that they are supported. Help answer any questions they have about JIA, and if you can’t answer them, check with a health care provider.

**SOURCE:** National Institute of Arthritis and Musculoskeletal and Skin Diseases
Eat fruit and vegetables, live longer

MOST OF US KNOW that eating fruits and vegetables is good for our health. But a new study from the National Institutes of Health says it may even help us live longer.

The study found that eating an average of five servings of fruits and vegetables a day is linked to a reduced risk of death from heart and respiratory diseases. Eating more fruit is also associated with a lower risk of cancer.

Researchers gathered data from more than 100,000 people starting in the mid-1980s until 2014. Participants included people who didn’t have diabetes, heart disease, or cancer when the study began. All participants were asked questions about their diets every two to four years.

The results showed that eating about two servings of fruit and three servings of vegetables a day was associated with lower risk of death from chronic disease. Most types of fruits and vegetables led to these results, except fruit juices and starchy vegetables such as peas, corn, and potatoes. Although it is often recommended to eat 5 cups of fruits and vegetables a day, eating more than five servings per day wasn’t associated with further reduction in risk of death.

Researchers in this study added their findings to data from 26 other studies. The combined findings support current daily recommendations for eating fruits and vegetables. For adults, the recommended daily amount is 1.5 to 2 cups of fruit and 2 to 3 cups of vegetables.

However, the average American adult only eats about one serving of fruit and 1.5 servings of vegetables a day. So, the next time you head to a grocery store, make sure to add some apples, broccoli, or whatever healthy options you like to your cart!

SOURCES: National Cancer Institute; National Heart, Lung, and Blood Institute; National Institute of Diabetes and Digestive and Kidney Diseases
New drug may slow or prevent type 1 diabetes

**A RECENT STUDY HAS FOUND** that a drug may delay the start of type 1 diabetes in people who are high risk, such as people who have a family member with the disease.

Type 1 diabetes is a serious lifelong condition in which the body makes little or no insulin. Insulin is a hormone that manages your blood sugar to give you energy. People with type 1 diabetes have to take insulin every day to stay alive.

Type 1 diabetes is usually diagnosed in kids and teens, but it can develop at any age.

The National Institutes of Health-supported clinical trial followed 76 people at high risk of developing type 1 diabetes. Half of the people in the study were given the drug, teplizumab, and half took a placebo, which doesn't have any medicine. Researchers followed the participants for several years.

Participants who took the drug were diagnosed with type 1 diabetes more than two-and-a-half years later than the placebo group. Also, 50% of the people treated with the drug didn't develop the disease at all during the study; 22% of the people in the placebo group did not develop it.

People who took the drug also showed improved insulin production.

If it is approved, teplizumab would be the first drug to delay or even prevent the development of type 1 diabetes. It has the potential to offer significant benefits to many people at risk for type 1 diabetes, especially “for those children who might have a chance to grow up without it,” according to study author Kevan Herold, M.D.

**SOURCES:** National Institute of Diabetes and Digestive and Kidney Diseases; National Cancer Institute; National Heart, Lung, and Blood Institute

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Small patch can diagnose cystic fibrosis earlier

**EARLY DIAGNOSIS** for cystic fibrosis (CF) can make a big difference in improving the quality of life for people with CF. It can also help them live longer. That's why a recent study from the National Institutes of Health is important to potentially providing an earlier and more reliable diagnosis.

CF is a chronic genetic disorder that creates a mucus buildup in the lungs and other organs. Usually, CF is diagnosed with a sweat test, which measures the amount of chloride in sweat. People with CF have high levels of chloride in their sweat.

The current sweat test, which is most often done in infants, uses a device strapped to the wrist to make a child sweat. The sweat is collected for 30 minutes and then measured.

But this approach often produces too little sweat for a reliable measurement.

Now researchers have developed a wearable device they’ve dubbed the “sweat sticker.” It sticks to the skin using an adhesive that’s safe for newborn babies, since that’s often when children are tested for the condition.

Measuring only about 1 millimeter thick—about the width of the point on a pencil—the sticker collected 33% more sweat on average than the current sweat test in one study.

More research is needed before the sticker can be used in clinical settings. But it could make future cystic fibrosis testing more reliable, especially in infants.

**SOURCES:** NIH Research Matters; National Institute of General Medical Sciences; National Institute on Aging

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Children and adults with type 1 diabetes have to measure their blood sugar multiple times a day.

The “sweat sticker” collected 33% more sweat than the current test in a recent study.
NIH on the web

Become a citizen scientist today

**ARE YOU CURIOUS** about how our world works? Are you motivated to make a difference? You can be the eyes and ears for researchers by becoming a citizen scientist.

Researchers like those at the National Institutes of Health create a project and then they give citizen scientists—or members of the public—steps to gather and share data. For example, researchers may want to track flu outbreaks and ask people to share their symptoms (without personal information or data).

The National Library of Medicine has a tutorial in English and Spanish where you can learn more about citizen science and how you can get started. There is no minimum age requirement, as kids under 13 can participate with an adult.

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MedlinePlus healthy recipes: Sautéed zucchini

**Prep time:** 10 minutes  
**Cook time:** 10 minutes  
**Total time:** 20 minutes  
**Number of Servings:** 4

**Ingredients**
- 2 medium zucchini, cut into 1/4-inch thick rounds or sticks
- 2 teaspoons vegetable oil
- 1 clove garlic minced or 1/4 teaspoon garlic powder
- 1/8 teaspoon each salt and pepper
- 1/4 teaspoon oregano (optional)

**Directions**
Wash hands with soap and water. In a medium skillet, heat oil over medium high heat (350°F in an electric skillet).
Add garlic and zucchini, then sprinkle with salt, pepper, and oregano, if desired. Cook, stirring occasionally, until zucchini is soft, about 5 to 7 minutes.
Refrigerate leftovers within 2 hours.
Find more healthy recipes online at MedlinePlus Recipes.

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Breathe better with NIH’s asthma management videos

**SUMMER FLOWERS AND FALL LEAVES:** They look pretty, but they can trigger asthma. Asthma narrows your airways, which are the tubes that carry air into your lungs. A series of videos from the National Heart, Lung, and Blood Institute (NHLBI) can help you understand what happens during an asthma attack.

Watch these three videos to learn how to prevent attacks and the best ways to manage and control asthma. In addition to videos, you’ll find asthma guides, tip sheets, and other resources through NHLBI’s Learn More Breathe Better® program.

Work with your health care provider to develop an asthma action plan to help you take your medicines safely and avoid irritants that cause attacks. You’ll also learn what to do if your asthma symptoms are getting worse.
The National Institutes of Health (NIH)—the nation’s medical research agency—includes 27 Institutes and Centers and is a part of the U.S. Department of Health and Human Services. It is the primary federal agency for conducting and supporting basic, clinical, and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases. For more information about NIH and its programs, visit www.nih.gov.

Institutes

**National Library of Medicine (NLM)**
www.nlm.nih.gov   888-FIND-NLM   888-346-3656

**National Cancer Institute (NCI)**
www.cancer.gov   800-4-CANCER   800-422-6237

**National Eye Institute (NEI)**
www.nei.nih.gov   301-496-5248

**National Heart, Lung, and Blood Institute (NHLBI)**
www.nhlbi.nih.gov   301-592-8573

**National Human Genome Research Institute (NHGRI)**
www.genome.gov   301-402-0911

**National Institute on Aging (NIA)**
www.nia.nih.gov   Aging information 800-222-2225   Alzheimer’s information 800-438-4380

**National Institute on Alcohol Abuse and Alcoholism (NIAAA)**
www.niaaa.nih.gov   301-443-3860

**National Institute of Allergy and Infectious Diseases (NIAID)**
www.niaid.nih.gov   301-496-5717

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

**National Institute of Biomedical Imaging and Bioengineering (NIBIB)**
www.nibib.nih.gov   301-451-6772

**Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)**
www.nichd.nih.gov   800-370-2943

**National Institute on Deafness and Other Communication Disorders (NIDCD)**
www.nidcd.nih.gov   800-241-1044 (voice)   800-241-1055 (TTY)

**National Institute of Dental and Craniofacial Research (NIDCR)**
www.nidcr.nih.gov   301-480-4098

**National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**
NIDDK Health Information Center 1-800-860-8747

**National Institute on Drug Abuse (NIDA)**
www.nida.nih.gov   301-443-1124

**National Institute of Environmental Health Sciences (NIEHS)**
www.niehs.nih.gov   919-541-3345

**National Institute of General Medical Sciences (NIGMS)**
www.nigms.nih.gov   301-496-7301

**National Institute of Mental Health (NIMH)**
www.nimh.nih.gov   866-615-6464

**National Institute on Minority Health and Health Disparities (NIMHD)**
www.nimhd.nih.gov   301-402-1366

**National Institute of Neurological Disorders and Stroke (NINDS)**
www.ninds.nih.gov   800-352-9424

**National Institute of Nursing Research (NINR)**
www.ninr.nih.gov   301-496-0207

Centers & Offices

**Fogarty International Center (IFIC)**
www.fic.nih.gov   301-496-2075

**National Center for Complementary and Integrative Health (NCCIH)**
www.nccih.nih.gov   888-644-6226

**National Center for Advancing Translational Sciences (NCATS)**
www.ncats.nih.gov   301-435-0888

**NIH Clinical Center (CC)**
clinicalcenter.nih.gov   301-496-2563

**Office of AIDS Research (OAR)**
www.oar.nih.gov   301-496-0357

**Office of Behavioral and Social Sciences Research (OBSSR)**
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**Office of Communications & Public Liaison (OCPL)**

**Office of Rare Diseases Research (ORDR)**
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