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SPRING 2017

the magazine

Performer

NICK JONAS

talks about life with
type 1 diabetes
and how he's
spreading awareness
about the chronic
disease.

TYPE 1 DIABETES

+

- Miracle of an Artificial Pancreas
- Hope for Aphasia Patients
- What's new in Psoriasis Treatment?

ALSO INSIDE

Tick Bite
Prevention

Kids and
Concussions

Latest
NIH Research
Highlights

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From left to right, NLM Director Patricia Flatley Brennan, R.N., Ph.D., NIH Director Francis S. Collins, M.D., Ph.D., and Kathy Bates are pictured at the Research!America awards dinner.

Kathy Bates' *NIH MedlinePlus* magazine cover is featured at the Research!America awards dinner in Washington, D.C.

Academy Award-winning Actress and Patient Advocate Kathy Bates Raises Awareness of NLM and NIH

ON MARCH 14, 2017, FORMER NIH MEDLINEPLUS MAGAZINE COVER celebrity and actress Kathy Bates was honored at a Washington, D.C.-based Research!America awards dinner for her advocacy on behalf of lymphedema and the research of the National Institutes of Health (NIH).

After developing lymphedema following a double mastectomy due to breast cancer, the award-winning actress and director has been a strong advocate for those with the disease, which is a type of swelling that can develop after cancer treatment, certain infections, and other causes. A national spokesperson for the patient community, Bates shared her story with *NIH MedlinePlus* magazine.

During the awards dinner, Bates distributed copies of *NIH MedlinePlus* magazine to audience attendees, urging them to read it and pass it along to their family and friends. She also emphasized the importance of federal funding for research at NIH, saying, "I don't plead for this funding for myself, but for the invisible millions standing behind me tonight and I accept this extraordinary award on their behalf."

Bates continues to raise awareness about lymphedema. She remains active with the Lymphatic Education and Research Network.

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Special Assistant to the Director, NLM

Fedora Braverman
MedlinePlus and MedlinePlus en español
teams, NLM

Kathryn McKay
Writer-Editor, NLM

Elliot Siegel, PhD
Outreach Consultant, NLM

Selby Bateman
Senior Editor

Peter Reinecke
Strategic Advisor

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NIH MedlinePlus magazine is published by
Friends of the NLM in conjunction with



24 Prime Park Way, Suite 103, Natick, MA 01760
(508) 907-7000

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Cover photo: Andrew Zaeh.
Photos this page, clockwise from top: Island Records, Jane Galyean, Audrey Marchionni

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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BREAKING NEW GROUND: NIH RESEARCH HIGHLIGHTS

With NIH support, scientists across the U.S. and the world conduct research to improve the health of our nation. Here is a small sample of the research accomplishments made by NIH-supported scientists in 2016.

Preventing peanut allergy

RECENT CLINICAL guidelines recommend introducing peanut-containing foods to infants between four and 11 months of age. Prior to introduction, infants should be evaluated by their health-care provider to assess the risk of developing a peanut allergy. These new guidelines show great promise in reducing the number of cases of peanut allergy in children.



Experimental malaria vaccine protects adults for more than a year

ABOUT HALF OF THE world's population is at risk for malaria, despite better prevention and control efforts. Scientists have been working to develop a vaccine that provides long-term, reliable protection from malaria. An experimental vaccine, PfSPZ, protected healthy adults from infection for more than a year.



Long-term benefits of age-related macular degeneration treatments

AGE-RELATED macular degeneration (AMD) is the leading cause of vision loss among older Americans. AMD often has few symptoms in its early stages, but causes loss of central vision in later stages. Researchers examined the five-year outcomes of using the drugs Avastin and Lucentis to treat AMD. The results showed that almost half of the participants had 20/40 vision or better, confirming the long-term benefits of the therapy.

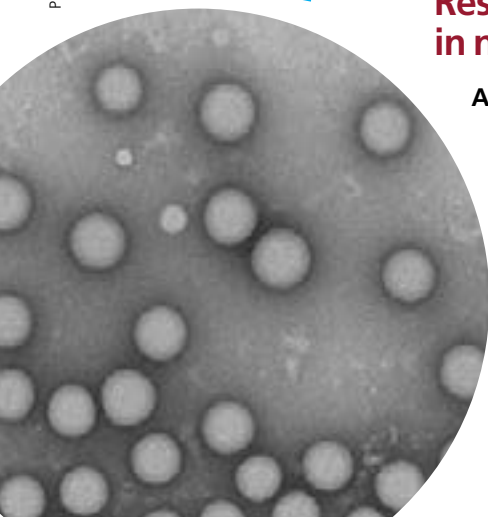


Biomarker signatures of prostate cancer

PROSTATE CANCER is the second most common cancer in men in the U.S. While more than half of prostate cancers don't become life threatening, doctors don't have a way to reliably predict which will likely cause problems. Researchers have discovered biomarkers in urine samples that were unique to two different prostate cancer stages. The findings suggest a noninvasive way to diagnose prostate cancer and assess tumor progression.

Research to treat obesity in new ways

ADULTS HAVE TWO TYPES OF FAT: white fat to store excess calories and brown fat, which can burn energy to create heat and help maintain body temperature. Scientists recently designed nanoparticles to target white fat and convert it to calorie-burning brown fat. The nanoparticles slowed weight gain in obese mice without affecting food intake. This proof-of-concept work could lead to new therapies to treat obesity.





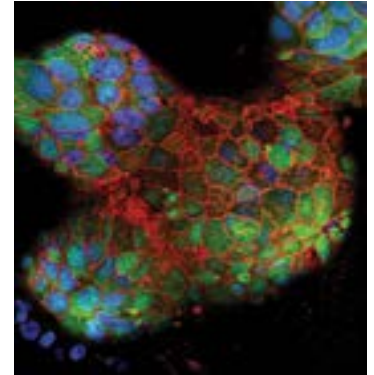
Gene editing shows promise in different disease models

GENE-EDITING techniques like CRISPR/Cas9 can successfully replace faulty genes, and scientists have been exploring their therapeutic potential. In 2016, NIH-funded scientists showed the approach holds promise as a gene therapy for three diseases in animal or cell models: Duchenne muscular dystrophy (in mice); sickle cell disease (in blood stem cells from affected people); and the inherited eye disorder retinitis pigmentosa (in rats).



Placenta's role in preventing disease

THE PLACENTA SERVES as a barrier to protect the developing fetus from toxins and infectious microbes, but some viruses can cross the placenta and potentially harm the unborn fetus. In 2016, researchers developed a 3D cell culture system that mimics aspects of placental development and microbial resistance. The system may help researchers understand how pathogens, such as herpes, HIV, and Zika, pass from a pregnant woman to her developing fetus.



Blood pressure management for seniors

HIGH BLOOD PRESSURE, or hypertension, affects one in three American adults. In a large clinical study, researchers found that seniors who aimed for a target systolic blood pressure level lower than commonly recommended (less than 120 mm Hg compared to less

than 140 mm Hg) had a reduced risk of heart disease and death. The findings will help older adults with hypertension and their health-care providers make more informed decisions about blood pressure goals.

Meditation and cognitive-behavioral therapy ease low back pain

MOST PEOPLE EXPERIENCE low back pain at some point in their lives. Treatment choices include over-the-counter and prescription drugs, cold and hot compresses, exercise, and in some cases, surgery. Researchers have found that both mindfulness-based stress reduction and cognitive-behavioral therapy improved chronic low back pain in adults. This means more treatment options are available for those suffering from the condition.



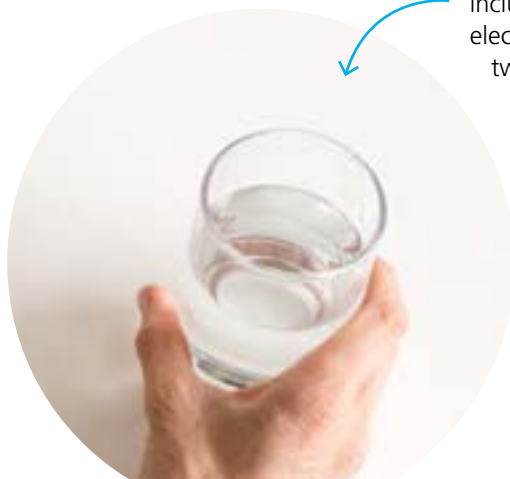
Research to help male infertility

MANY DIFFERENT FACTORS can affect a couple's ability to conceive. One is sperm motility. Inside the female reproductive tract, sperm use their tail-like appendages to swim for the egg. Researchers have identified a molecular pathway that activates sperm. The findings may lead to new approaches for male contraception and treatments for infertility that result from problems with sperm mobility.



Cone snail reveals insulin insights

MANY PEOPLE WITH DIABETES rely on injections of synthetic insulin to keep their blood sugar levels in check. However, human insulin molecules take time to act on blood glucose levels. Researchers have found that a fast-acting insulin from the cone snail can bind and activate the human insulin receptor. The 3-D structure and other findings from the study provide insights for designing rapid-acting insulins to better manage diabetes.



Designing more effective opioids

OPIOIDS ARE A CLASS of powerful pain-relieving drugs that are generally safe when taken for a short period of time and prescribed by a doctor. However, they're frequently misused because they also produce euphoria. Researchers used computer simulations to screen millions of molecules for opioid-like, pain-relieving properties. The analyses allowed them to create a molecule that effectively alleviates pain in mice, but with fewer side effects than the opioid morphine.



Spinal cord stimulation helps paralyzed people move hands

MORE THAN A QUARTER of a million Americans live with spinal cord injuries. Spinal cord damage can lead to serious disabilities, including paralysis. In a proof-of-concept study, electrical stimulation of the spinal cord helped two people with quadriplegia improve voluntary movement and use of their hands. The study represents the first step in using this approach to improve hand function for people with cervical spinal cord injuries.

Find Out More

- ✓ **NIH Research Matters:** nih.gov/news-events/nih-research-matters

Former
Auctioneer
Finds Voice
After

Aphasia

Speech impairment changed his life

ONE UNREMARKABLE

September morning in 2011, Mark Vail had trouble getting dressed. Then, he poured milk across the kitchen counter instead of into his cereal bowl. Thinking he was just overly tired from conducting a long, tedious auction the day before, he decided to lie down on the sofa.

When he responded to a question in nonsensical language, his wife, Jane Galyean, realized something was wrong and called 911. Vail, a healthy 58-year-old, had suffered a stroke during the night that left him with aphasia—an inability to communicate caused by damage to specific brain areas.

Immediate effects

"I felt foggy, like I was in a bubble," Mark says. "I'd lost my peripheral vision and remember thinking that maybe I'd died and was just observing the chaos in the emergency room around me."

The effects of Vail's aphasia were immediate and devastating for Vail and Galyean. "Overnight, Mark's work as an auctioneer ended," says Galyean. "It was devastating for both of us as our lives changed so dramatically. Suddenly, Mark's career ended and the demands of his aphasia became all consuming."

Luckily, Vail and Galyean had recently moved to John's



Pictured with his dogs, Lucy and Henry, Mark Vail has rekindled his former talent as a master potter. Last winter he taught his first class.

Island, S.C., near the Medical University of South Carolina—one of the few hospitals in the country with a language and aphasia clinic and a dedicated aphasia research program.

Follow-up therapy

"This is an important service that's not available in many regions," explains Leonardo Bonilha, M.D., Ph.D., associate

professor of neurology and clinic director. "It allows patients with chronic language problems to receive appropriate follow-up therapy and access to clinical trials."

When Galyean called to find a stroke support group, she was directed to the clinic where a phase II trial of Transcranial Direct Current Stimulation to Treat Aphasia was under way, funded by the National Institute on Deafness and Other Communication Disorders (NIDCD). "This study evaluates whether speech therapy coupled with brain stimulation through the scalp improves recovery for patients with chronic aphasia like Mark," Bonilha says.

But Vail wasn't sure. "Initially, I was hesitant because the study involved repeated MRIs and I know how claustrophobic and uncomfortable they are," he says. Vail eventually enrolled and soon found the benefits were worth it.

"The MRI technician was great at helping me relax and it was really good to have so much daily stimulation. I enjoyed challenging myself to get the answers right to the language tests they gave me. Everything helped."

Social benefits

Bonilha agrees that patients benefit even if they receive placebo. "First, they're helping others. I can't stress enough what a huge service participants do for everyone else with similar conditions. Plus, they get extensive speech therapy that is not available to many stroke survivors. And, people in trials also benefit from the social interaction. They become part of our group and we try to create an enjoyable, welcoming, and supportive environment."

Now, five years post-stroke, Vail would say to others in a similar situation, "Even though it may be uncomfortable, try to get into as many programs, studies, and support groups as you can to help re-fire your brain. It made me feel less isolated and more self-confident."

What Is Aphasia?

Aphasia makes it hard to read, write, say what you mean to say, and, sometimes, to understand what others say. It is most common in adults who have had a stroke. Brain tumors, infections, injuries, and dementia can also cause it.

APHASIA OCCURS

when parts of the brain that are responsible for language processing are damaged. For most people, these areas are on the left side of the brain. It may be temporary or long-term, depending on the cause and other factors.

Aphasia affects about one million Americans, and about 180,000 are newly diagnosed each year. There is no cure for aphasia. But it can be treated. Research shows that treatment for aphasia improves language abilities.

Who is at risk?

Most aphasia cases result suddenly from a stroke or head injury. However, they may also develop slowly from a brain tumor or disease that affects brain tissue.

Preventing aphasia

One way to prevent aphasia is to lower your chance of a stroke by improving your cardiovascular health. Another is to protect your head from injury, such as by wearing a helmet when you ride a bike.

Symptoms

The symptoms of aphasia vary according to where damage has occurred in the brain and the type of aphasia. For aphasia caused by stroke, the types are fluent and non-fluent. The most common type of fluent aphasia is called Wernicke's aphasia. It results from damage to the temporal lobe and surrounding areas in the brain. People with Wernicke's aphasia may speak in complete sentences that are often long but have little meaning. They also often have trouble understanding speech.

Broca's aphasia is the most common type of non-fluent aphasia. People with Broca's aphasia have damage primarily to the frontal lobe of the brain. This can cause weakness or even paralysis on the right side of the body. They typically understand speech, although they may experience difficulty understanding complex sentences. People with



Dr. Leonardo Bonilha and speech-language pathologist Kikki Thayer talk about a patient as they review her scans.

Broca's aphasia know what they want to say, but have trouble saying it or writing it.

Diagnosis

Often the clinician is the first person to recognize the symptoms of aphasia while treating the patient for a brain injury. To diagnose aphasia, the clinician will usually order a magnetic resonance imaging (MRI) scan or a computed tomography (CT) scan to locate a brain injury.

In addition to the scans, the clinician usually tests the abilities to understand language and speak, often by asking the patient to follow commands, answer questions, name objects, and carry on a conversation. If aphasia is suspected, the clinician should refer the patient to a speech-language pathologist, who conducts further tests of the patient's communication skills.

Treating aphasia

A brain injury produces tremendous changes in the area of the brain directly affected by the injury and also in distant brain regions. During the first few months following the injury, the brain heals and language ability often improves, even without treatment.

Even so, for most people with aphasia, language difficulty remains after this initial recovery period. For these people, speech-language therapy improves their ability to understand and use language. This therapy aims to help the patient make use of remaining language abilities, restore language abilities to the extent possible, and learn other ways to communicate, such as by using gestures, pictures, or smartphones and other electronic devices.

Outlook for people with aphasia

How much a person recovers from aphasia depends on many factors, including what caused the brain injury, what part of the brain was injured, the degree to which the brain was injured, and the age and health of the patient. Participating in individual and group therapy improves recovery outcomes.

Aphasia research

Researchers are developing new and more effective behavioral treatment types of speech-language therapy to see which work best in helping patients recover aspects of understanding and using speech and language.

Drug therapy is another avenue of research in treating aphasia. Researchers are studying drugs that affect the chemical neurotransmitters in the brain and are investigating whether these drugs can be used in combination with speech-language therapy.

10 Tips for Communicating with Someone who has Aphasia

1. Talk to them in a quiet, calm, relaxed way.
2. Be patient and give the person with aphasia time to respond.
3. Encourage social situations and continue normal activities.
4. Limit your conversation if the person is tired.
5. Avoid correcting speech and/or grammatical errors.
6. Understand that abilities may change from day to day.
7. Treat the person as an adult; don't talk down.
8. Use simple yes/no questions, rather than open-ended questions.
9. Do not speak for the person with aphasia unless it's absolutely necessary.
10. Try not to interrupt or supply words unless requested.

Another promising area of research is the use of advanced imaging methods, including functional magnetic resonance imaging (fMRI), to see how healthy and damaged brains process language to better understand the recovery process. This research could result in better diagnosis and treatment of aphasia and other neurological disorders.

Noninvasive brain stimulation techniques are also receiving research attention. Researchers hope to identify whether techniques such as transcranial magnetic stimulation (TMS) and transcranial direct current stimulation (tDCS) can be used with speech-language therapy to improve recovery.

Clinical trials funded by the National Institute on Deafness and Other Communication Disorders (NIDCD) are looking closely at these technologies.

Find Out More

- ✓ **National Institute on Deafness and Other Communication Disorders (NIDCD):** nidcd.nih.gov/health/aphasia
- ✓ **National Institute of Neurological Disorders and Stroke (NINDS):** ninds.nih.gov/disorders/aphasia/aphasia.htm
- ✓ **MedlinePlus:** medlineplus.gov/aphasia.html
- ✓ **National Aphasia Association:** aphasia.org
- ✓ **Clinical Trials:** clinicaltrials.gov

Hope for Aphasia Patients

New research, better outcomes

Cynthia K. Thompson, Ph.D., is a top researcher on language recovery from brain damage. Her research is funded in part by the National Institute on Deafness and Other Communication Disorders (NIDCD).

NIH MedlinePlus magazine caught up with the Ralph and Jean Sundin Professor of Communication Sciences at Northwestern University's School of Communication, where she leads the Center for the Neurobiology of Language Recovery.

What led you to your current research?

The first patient with aphasia I saw was a very well-educated, World War II veteran, and former attorney, who clearly had difficulty expressing himself. He appeared to understand most of what was said to him, but his sentences were ungrammatical. On testing, he was able to name nouns (pictured objects), but not verbs (pictured actions). This was shocking, yet intriguing, and it has guided much of my research ever since.

My work is focused on understanding the brain and language (primarily verb and sentence) processing.

What do people need to know about aphasia?

Aphasia is a language disorder that affects the ability to understand and produce language. It's a common result of stroke and other problems that affect the brain.

Treatment improves communication ability, resulting in gains in language processing as well as changes in the neural networks for language.

What have been some recent findings developed through research?

My team has made several important discoveries. Think about learning and how our brains are wired. We learn simple things first, and then build on them as language develops. In people with aphasia, damage has occurred to an already built language system; therefore, stimulating access to more complex forms results in access to simpler, related forms.

We used to think that once a brain heals from the stroke

itself (swelling of the brain subsides, etc.) recovery is no longer possible or is limited. Research shows that people with aphasia can continue to recover up to 10 years post stroke and beyond. We have learned that factors, such as cerebral blood flow, are affected even in parts of the brain not directly damaged by stroke.

Other parts of the brain may be recruited to

support language recovery. We know we can change the brain, we know people learn, but we want to understand which patients have the potential to recover most.



Dr. Cynthia K. Thompson's work is focused on understanding the brain and language processing.

“Research shows that people with aphasia can continue to recover up to 10 years post stroke and beyond.”

What sorts of therapies are available and proven to be effective?

The most effective treatments target specific language problems, such as naming and word retrieval, spelling, and sentence processing. There is a “use it or lose it” truth when it comes to recovery.

Thus, intense language treatment focused on impaired processes is important. But, the schedule of treatment is also important. In chronic stages of recovery, treatment spread out over a longer period may be better than a great deal of treatment provided within a shorter time period in terms of learning and recovery of some aspects of language, like spelling and sentence processing, in aphasia.

One of our next projects will attempt to “boost” recovery. Based on what we have learned about regions of the brain that are recruited to help in recovering language, we plan to apply magnetic stimulation to activate those regions.

Finally, we know being involved in communication-based activities also improves outcomes. We recently opened the Northwestern Center for Aphasia, focused on communication and community for people with the condition.

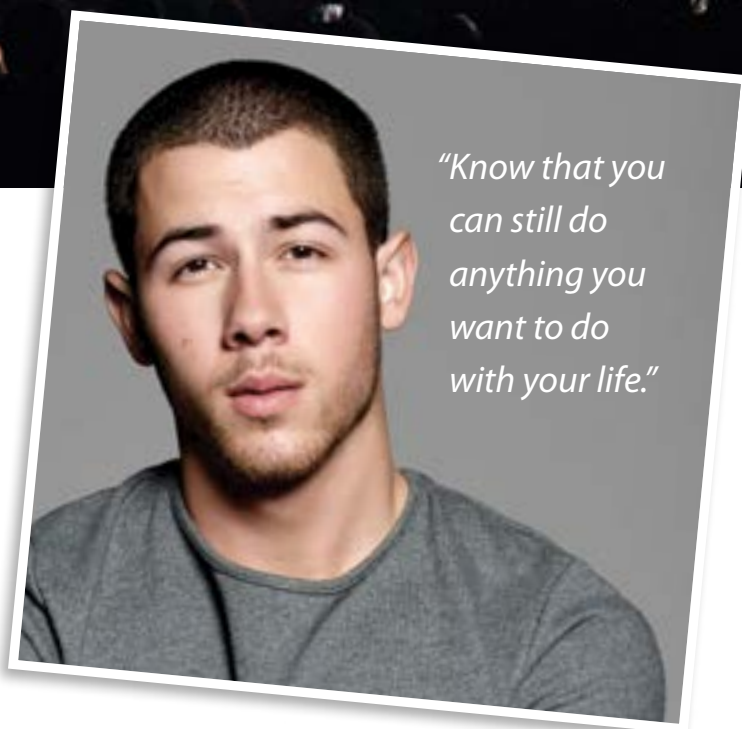
Nick Jonas performs in Kansas City, MO, as part of the 2016 Future Now Tour.

Nick Jonas

Talks Life On Stage and Off
with Type 1 Diabetes

ENTERTAINMENT SUPERSTAR NICK JONAS IS A hit singer, songwriter, producer, and actor. He's also one of the approximately 1.25 million Americans living with type 1 diabetes. Jonas, now 24, was diagnosed at age 13 and has emerged as a leading voice in raising awareness about the disease.

In 2015, he helped found *Beyond Type 1*, a philanthropy that aims to empower people with type 1 diabetes "to both live well today and to fund a better tomorrow."



"Know that you can still do anything you want to do with your life."

NIH MedlinePlus magazine interviewed him about his experience with type 1 diabetes and his message for others with the disease.

Would you share the circumstances of your type 1 diabetes diagnosis? What were your initial thoughts?

My thoughts when I was diagnosed were real concern for my future, first of all as a performer, and also not knowing anything about the disease. I think I was initially just thinking that it was going to limit my ability to follow my dreams.

How do you manage your type 1 diabetes? Do you use an insulin pump?

I use an insulin pump to help manage my diabetes, check my blood sugar frequently, and do my best to get to know my body and get to feel out if I am high or low. More than anything, it's trusting my doctor and following all of her advice.

You lead a very active and busy life with your type 1 diabetes. What do you do to manage your diet and exercise?

I choose to live a pretty healthy life as far as my eating habits go. But I love physical exercise and pushing my body. I think it's just about being honest and vocal with the people who you are working with, or trainers and friends who you might be training with, about the disease and how to take care of situations should they arise.

How has your family supported you in all this?

My family has been an incredible support from the time I was diagnosed to now. I became very independent and chose to be independent when it came to the disease, but I am never afraid to rely on them when certain situations come up.

What message do you have for others living with type 1 diabetes?

Know that you can still do anything you want to do with your life. I didn't let it slow me down, and you don't have to either. Also, don't become discouraged. It's tough, because it is such an unpredictable disease from day to day. Even when you think you have a really solid grip on how to manage it, there are times that your body just does what it wants. So be patient and don't get frustrated.

What is Diabetes?

Diabetes means your blood glucose, or blood sugar, levels are too high.

WITH TYPE 1 DIABETES, your pancreas does not make insulin. Insulin is a hormone that helps glucose get into your cells to give them energy. Without insulin, too much glucose stays in your blood. Over time, high blood glucose can lead to serious problems with your heart, eyes, kidneys, nerves, gums and teeth.

Symptoms of diabetes may include:

- Being very thirsty
- Urinating often
- Feeling very hungry or tired
- Losing weight without trying
- Having sores that heal slowly
- Having dry, itchy skin
- Losing the feeling in your feet or having tingling in your feet
- Having blurry eyesight

Types of diabetes

Type 1 diabetes

If you have type 1 diabetes, your body does not make insulin. Your immune system attacks and destroys the cells in your pancreas that make insulin. Type 1 diabetes is usually diagnosed in children and young adults, although it can appear at any age. It is a lifelong disease and people with type 1 diabetes need to take insulin every day to stay alive.

Type 2 diabetes

If you have type 2 diabetes, your body does not make or use insulin well. You can develop type 2 diabetes at any age, even during childhood. This type of diabetes occurs most often in middle-aged and older people. Type 2 is the most common type of diabetes.

Gestational diabetes

Gestational diabetes develops in some women when they are pregnant. Most of the time, this type of diabetes goes away after the baby is born. However, if you've had gestational diabetes, you have a greater chance of developing type 2 diabetes later in life. Sometimes diabetes diagnosed during pregnancy is actually type 2 diabetes.

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



NIH MedlinePlus Magazine Remembers Mary Tyler Moore

A LITTLE MORE THAN 10 YEARS AGO, Mary Tyler Moore helped launch the first issue of *NIH MedlinePlus* magazine on Capitol Hill. The award-winning actress and diabetes research advocate was also featured on the first cover of the magazine. She passed away this January at the age of 80.

Moore, who was diagnosed with type 1 diabetes at age 33, advocated for the advancement of diabetes research throughout her life. In addition to working with the National Library of Medicine and NIH, Moore also worked with the JDRF (formerly known as the Juvenile Diabetes Research Foundation). She served as the international chair for the organization.

“Mary Tyler Moore was an inspiration for so many of us in the diabetes community. Her decades of service raised the voice of all people with type 1 diabetes, and her tireless work behind the scenes will accelerate research progress for years to come. Mary Tyler Moore is proof that one person can make a positive difference for all, and she will be much missed,” said Griffin P. Rodgers,

“Mary Tyler Moore was an inspiration for so many of us in the diabetes community.”

M.D., M.A.C.P., Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

In 2006, Moore met on Capitol Hill with House and Senate lawmakers, former NIH director Elias Zerhouni, M.D., NLM leadership, and the Friends of the National Library of Medicine to give even more visibility for MedlinePlus.gov and its diabetes resources.

MSNBC, *Self* magazine, *Health* magazine, and other media featured Moore’s role as an advocate by citing, linking to, or using images from *NIH MedlinePlus*.

“I champion the efforts that are being made through *NIH MedlinePlus* to provide easily understandable and reliable information on behalf of all people and their families affected with diabetes,” Moore told the magazine in 2006. “I am honored to be part of the launch of this new publication.”



(From left to right), Mary Tyler Moore, Griffin Rodgers, M.D., M.A.C.P., Sugar Ray Leonard, and Nick Jonas advocate for type 1 diabetes funding in front of a congressional panel on Capitol Hill in 2009.

The Miracle of an Artificial Pancreas

Four NIH-funded Artificial Pancreas Research Efforts Underway

THANKS TO INVESTMENTS IN RESEARCH, new and improved methods for managing type 1 diabetes are on the horizon, including the artificial pancreas. The artificial pancreas is an integrated system that monitors blood glucose (sugar) levels automatically and provides insulin or a combination of insulin and a second hormone to people with type 1 diabetes.

A successful artificial pancreas would be a life-changing advance for many people with type 1 diabetes. This closed-loop system would replace reliance on testing by

“These studies aim to collect the data necessary to bring artificial pancreas technology to the people who need it.”

fingerstick or continuous monitoring systems and separate, non-integrated delivery of insulin by shots or a pump.

The first of several major research efforts to test and refine artificial pancreas systems is now underway. Four separate projects,

funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), are designed to be the potential last steps between testing the automated devices and requesting regulatory approval for permanent use.

“These studies aim to collect the data necessary to bring artificial pancreas technology to the people who need it,” said Guillermo Arreaza-Rubín, M.D., director of NIDDK’s Diabetes Technology Program. “Results from these studies could change and save lives.”

Previously, researchers and participants worked together to test artificial pancreas devices in short-term trials, with varying levels of patient supervision. In 2016, the U.S. Food and Drug Administration approved a hybrid model of an artificial pancreas, an automated system that requires users to adjust insulin intake at mealtimes. A fully automated system will sense rising glucose levels, including at mealtimes, and adjust insulin automatically.

In addition to easing the burden of management for people with type 1 diabetes or their caregivers, in shorter studies, the devices brought glucose levels closer to normal

than traditional management. NIH research has found that early, tight control of blood glucose helps reduce diabetes complications including nerve, eye, and kidney diseases.

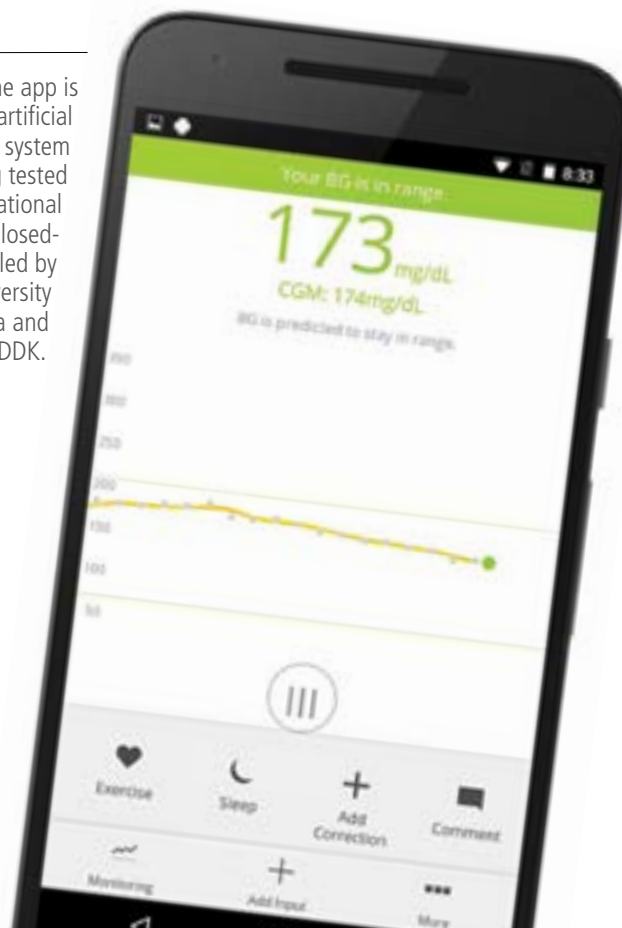
The four research projects begin this year and in 2018. They will be conducted in larger groups over longer periods of time than the earlier trials, and in largely unrestricted conditions. The participants will live at home and monitor themselves, going about their normal lives, with remote monitoring by study staff.

“Managing type 1 diabetes currently requires a constant juggling act between checking blood glucose levels frequently and delivering just the right amount of insulin while taking into account meals, physical activity, and other aspects of daily life, where a missed or wrong delivery could lead to potential complications,” said Andrew Bremer, M.D., Ph.D., the NIDDK program official overseeing the studies. “Unifying the management of type 1 diabetes into a single, integrated system could lift so much of that burden.”

Studies will look at factors including safety, efficacy, user-friendliness, physical and emotional health of the participants, and cost. The Jaeb Center for Health Research in Tampa, Florida, will serve as coordinating center for all of the trials.

“For many people with type 1 diabetes, the realization of a successful, fully automated artificial pancreas is a dearly held

A smartphone app is part of an artificial pancreas system now being tested in the International Diabetes Closed-Loop trial, led by the University of Virginia and funded by NIDDK.



dream. It signifies a life freer from nightly wake-up calls to check blood glucose or deliver insulin, a life freer from dangerous swings of blood glucose," said NIDDK director Griffin P. Rodgers, M.D., M.A.C.P. "Nearly 100 years since the discovery of insulin, a successful artificial pancreas would mark another huge step toward better health for people with type 1 diabetes."

The studies include:

- Now recruiting, the International Diabetes Closed-Loop trial, led by Boris Kovatchev, Ph.D., and Stacey Anderson, M.D., of the University of Virginia, Charlottesville, will test an automated insulin delivery system called inControl. The trial, which uses smartphones, will follow 240 people age 14 and up with type 1 diabetes for six months. A second, six-month study will recruit from the 180 U.S. participants of the first trial to test an alternative algorithm. (NIH grant DK108483) Learn more at Clinicaltrials.gov: NCT02985866 and NCT02844517.

- This year, recruitment will begin for youths between the ages of six and 18 for a full-year trial of an artificial pancreas. Led by Roman Hovorka, Ph.D., of the University of Cambridge, England, the study seeks to enroll 130 youths for a full year of use of an artificial pancreas system that uses a smartphone as one component. (NIH grant DK108520) Learn more: NCT02925299.

- Starting in late 2017, research led by Richard Bergenstal, M.D., of International Diabetes Center, Minneapolis, Minnesota, and Moshe Phillip, M.D., of Schneider Children's Medical Center, Petah Tikva, Israel, will compare the FDA-approved hybrid artificial pancreas to a next-generation system to further improve glucose control, particularly around mealtime. (NIH grant DK108611) Learn more: NCT03040414.

- In mid-2018, a study led by Steven Russell, M.D., Ph.D., of the Massachusetts General Hospital, Boston, and Ed Damiano, M.D., of Boston University will enroll 312 people ages 18 and older. The six-month study will use a bionic pancreas system, with a dual-chamber pump to deliver both insulin and its counteracting hormone, glucagon, using tested algorithms for automated dual-hormone delivery. (NIH grant DK108612) Learn more at www.bionicpancreas.org.

The trials are made possible through the *Special Statutory Funding Program for Type 1 Diabetes*, a Congressional appropriation administered by NIDDK to support research to prevent and cure type 1 diabetes and its complications. Together, the grants total about \$41 million.

Other NIDDK Research on Type 1 Diabetes

TEDDY

TEDDY (short for **T**he **E**nvironmental **D**eterminants of **D**iabetes in the **Y**oung) is a long-term study that started in 2002 and is led by *National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)*. It aims to understand what environmental factors cause type 1 diabetes in children. TEDDY researchers from across the U.S. and Europe are following more than 6,000 newborns until they are 15 years old. Researchers collect samples from TEDDY participants to create a unique database that will give new insight into type 1 diabetes and children's health.

TEDDY

By the numbers

Number of children screened for TEDDY

▶ **425,104**

over

Number of children enrolled in TEDDY

▶ **8,677**

over

Number of children currently followed:

▶ **6,000**

Number of samples collected for analysis

▶ **3 million and counting**

Expected length of the TEDDY study

▶ **23 years**

Expected TEDDY completion date

▶ **2025**

SOURCE: NIDDK



“An Incredible Burden has Been Lifted”

KADY HELME CAN'T REMEMBER A

time in her life when she didn't take care of her own type 1 diabetes. Diagnosed at the age of five, she quickly began checking her blood sugar levels and giving herself insulin shots. For most type 1 diabetes patients, self-monitoring is a lifelong endeavor.

Now, at the age of 26, Helme is taking part in a field test of an artificial pancreas, the first ever approved by the U.S. Food and Drug Administration (FDA).

The pancreas is an organ located behind the lower part of your stomach. The pancreas makes the hormone insulin to control blood glucose and also makes enzymes and fluids for digestion.

The artificial pancreas isn't a replacement organ, but does replace some of the function of a pancreas. The model that Helme wears tests her glucose level every five minutes throughout the day and night, automatically giving her the right amount of insulin. It manages her electronic insulin pump that actually releases the insulin.

“I've always been the manager of my diabetes,” says Helme, who uses a hybrid closed loop system. “But since I began using the artificial pancreas,

it's like an incredible burden has been lifted, since I no longer have to manage my levels as closely night and day.”

A Chicago-area native who today calls New York City home, Helme volunteered at the JDRF (formerly known as the Juvenile Diabetes Research Foundation) since she was a child. Now, she works at the Foundation. She's also been a regular volunteer in type 1 diabetes clinical trials. Those experiences led, in part, to her being selected to help in tests of the artificial pancreas.

Until she began using the artificial pancreas, Helme didn't realize how many episodes of low blood sugar she was experiencing, despite her best efforts. With the new device, she said, the overnight control is wonderful.

“Instead of having to wake up two or three times a night to test my sugar level, the artificial pancreas keeps my level

steady. I sleep through the night and wake up refreshed, with my sugar level where it should be.”

As important as her own relief has been with the artificial pancreas, the ripple effect to her parents, fiancé, family, and friends has been equally dramatic. “They don't worry about me like they used to,” Helme says. “The stress for them has been largely taken away.”

Kady Helme speaks to an audience at the JDRF Children's Congress.



Find Out More

- ✓ **National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**
niddk.nih.gov/health-information/diabetes/overview/what-is-diabetes
- ✓ **MedlinePlus—Type 1 Diabetes**
medlineplus.gov/diabetestype1.html
- ✓ **Beyond Type 1** beyondtype1.org
- ✓ **JDRF** jdrf.org
- ✓ **FDA Approval of First Automated Insulin Device for Type 1 Diabetes**
fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm522974.htm

Psoriasis:

On the road to discovery



Research
advances are
resulting
in improved
treatments.



ADVANCES IN GENETIC KNOWLEDGE

are providing the keys to unlock new treatments. NIH-supported researcher **James T. Elder, M.D., Ph.D.** (left), from the Department of Dermatology at the

University of Michigan, is a leader in psoriasis research. He recently shared his insights with *NIH MedlinePlus* magazine.

How is psoriasis different from other skin conditions?

Psoriasis is quite a distinctive skin disease. It features a thick scale and a dark redness to the spots, and typically shows up on the scalp, elbows, and knees, but can be on other parts of the body. Psoriasis affects about 6.7 million Americans.

A common skin disease that can be confused with psoriasis is atopic dermatitis, also called atopic eczema. In its chronic phase, that disease can look a lot like psoriasis. Another skin disease that looks like psoriasis is common dandruff. Dandruff can be caused by seborrheic dermatitis, which produces dry scaly skin, especially on the scalp and face. In one form of psoriasis, called seborrheic dermatitis, patients have both conditions.

One of the defining characteristics of psoriasis is how fast the skin cells are growing. They grow about 10 times as fast as normal skin. Instead of taking a month for the skin cells to turn over, it happens in a week or less. The rapid growth seems to be stimulated by the immune system.

It comes on most typically around the age of 20 to 25. It affects men and women equally and tends to persist throughout life. About 25 percent of people with psoriasis develop psoriatic arthritis, which is important to diagnose early because it's one of the more destructive forms of arthritis.

What's new in psoriasis treatment?

A lot. All you have to do is turn on your TV and see all of the advertisements for psoriasis medications to know that.

Biologic medications, or proteins made by living cells, are especially promising. Some of the earliest biologics have been on the market now for almost 15 years.

These medications inhibit cytokines, which are proteins that promote inflammation. Recently we've discovered

cytokine pathways important in psoriasis. We have found antibodies against these cytokine receptors that are especially good in treating psoriasis.

I've been in dermatology for almost 30 years, and there have been tremendous advances in knowledge compared to where we were when I arrived. It's very gratifying to be a part of it.

What is the future of psoriasis treatment?

In the area of biologics, one concern is that many of these antibodies are quite expensive to buy because they're patent protected, and pharmaceutical companies are trying to recoup their investment. Yet it sometimes might not seem very fair that not everyone has access to them.

One movement that's really coming on is called biosimilars, which is where companies can produce an antibody that's not exactly like the one that is being marketed. But it's similar in structure and they're capable of making it and showing that it works. It's expected that biosimilars will substantially reduce the price of biologics over time.

There are [traditional] medications also. I've spent a lot of time talking about antibodies that require a shot, but there are two kinds of oral medications. One targets an enzyme with a long name, phosphodiesterase-4. The other family of medications targets an intracellular signaling molecule that is a tyrosine kinase.

While the antibodies I mentioned function on the outside of the cell, these oral agents don't need to be a shot.

Because they function inside the cell, they're much smaller molecules and that's why they can be taken as a pill and don't have to be given as a shot.

The new measure for when a drug is really more effective has become a 90 to 100 percent improvement in skin lesion severity. In the past, even with the best treatments, not everybody got to 75 percent improvement. This is all an indication that we're on the right track.

What's the takeaway message for people with psoriasis?

It's very exciting how the drugs that work in psoriasis line up very well with the genes that all of our patient volunteers helped us identify over the years, as we discovered the sometimes-subtle genetic differences that predispose someone to psoriasis.

We're seeking more ways to take advantage of the approved new medications, which oftentimes don't get prescribed either because the psoriasis is relatively mild, the doctors don't have experience, or it costs too much.

Instead of looking at this as the end of the road of discovery, we're looking at it as the beginning, with even more advances and improved understanding that should lead to improved treatment.

Questions & Answers About Psoriasis

PSORIASIS IS A CHRONIC (long-lasting) skin disease of scaling and inflammation that affects more than three percent of the U.S. population. Although the disease occurs in all ages, it mostly affects adults. It appears about equally in males and females.

Psoriasis occurs when skin cells quickly rise from below the surface of the skin and pile up on the surface before they can mature. Usually this process (also called turnover) takes about a month, but in psoriasis it may occur in only a few days.

In its typical form, psoriasis results in patches of thick, red (inflamed) skin covered with silvery scales. These patches, which are sometimes referred to as plaques, are usually itchy or sore. Plaques often occur on the elbows, knees, other parts of the legs, scalp, lower back, face, palms, and soles of the feet. But they can occur on skin anywhere on the body.

“Researchers who have studied a large number of families affected by psoriasis have identified genes linked to the disease.”

How does psoriasis affect quality of life?

People with psoriasis may experience significant physical discomfort and some disability. Itching and pain can interfere with basic functions, such as caring for oneself, walking, and sleeping. Plaques on hands and feet can make it difficult to work in certain physical occupations, play some sports, and care for family members. People with moderate to severe psoriasis may also feel self-conscious about their appearance.

How is psoriasis diagnosed?

Because psoriasis can resemble other skin diseases, doctors sometimes find it difficult to diagnose it. Health care providers may need to use a microscope to examine a small skin sample before confirming a diagnosis.



Psoriasis patches (or plaques) often occur on the legs and the scalp, as pictured above. But they can occur on skin anywhere on the body.

In many cases, there is a family history of psoriasis. Researchers who have studied a large number of families affected by psoriasis have identified genes linked to the disease.

People with psoriasis may notice times when their skin worsens, called flares, before improving. Infections, stress, and weather changes can cause flares. Also, certain medicines may trigger an outbreak or worsen the disease.

How is psoriasis treated?

Doctors generally treat psoriasis in steps based on the severity of the disease, size of the areas involved, type of psoriasis, and where the psoriasis is located. Options can include:

- Medicines applied to the skin (topical treatment)
- Light treatment (phototherapy)
- Medicines by mouth or injection (systemic therapy)

Over time, affected skin can become resistant to treatment, especially when topical corticosteroids are used. Also, a treatment that works well in one person may have little effect in another. Thus, doctors often use a trial-and-error approach to find an option that works.

TOPICAL TREATMENT

Treatments applied directly to the skin may improve its condition. Doctors find that some patients respond well to ointment or cream forms of corticosteroids, vitamin D3, retinoids, coal tar, or anthralin. Bath solutions and lubricants may be soothing, but they are seldom strong enough to improve the condition of the skin. Therefore, they usually are combined with stronger remedies.

LIGHT THERAPY

Natural ultraviolet (UV) light from the sun and controlled delivery of artificial UV light are used to treat psoriasis. It is important that a doctor administers light therapy. Spending too much time in the sun or a tanning bed can cause skin damage, increase the risk of skin cancer, and worsen symptoms.

SYSTEMIC TREATMENT

For more severe forms of psoriasis, doctors sometimes prescribe medicines that are taken by pill or injection.

- **Cyclosporine.** Taken orally, cyclosporine acts by suppressing the immune system to slow the rapid turnover of skin cells. It may provide a quick relief of symptoms, but the improvement stops when treatment is discontinued. Cyclosporine may impair kidney function or cause high blood pressure (hypertension). Therefore, a doctor's supervision is important.
- **Methotrexate.** Like cyclosporine, methotrexate suppresses the immune system to slow cell turnover. It can be taken by pill or injection. Patients taking methotrexate must be closely monitored because it can cause liver damage and decrease the production of oxygen-carrying red blood cells, infection-fighting white blood cells, and clot-enhancing platelets.
- **Retinoids.** Oral retinoids are compounds with vitamin A-like properties that may be prescribed for severe cases of psoriasis that do not respond to other therapies. Because these medications may cause birth defects, women must consult with their health-care provider if they plan to become pregnant.
- **Biologics.** Biologics are made from proteins produced by living cells instead of chemicals. They interfere with specific immune system processes, which cause the overproduction of skin cells and inflammation. These drugs are injected (sometimes by the patient). Patients need their doctors to carefully monitor these treatments.
- **PDE4 inhibitors.** Taken orally, phosphodiesterase 4 (PDE4) inhibitors target molecules inside immune cells to suppress the rapid turnover of skin cells and inflammation.

COMBINATION THERAPY

Combining various topical, light, and systemic treatments often permits lower doses of each and can result in greater improvements. There are many approaches for treating psoriasis. Ask your doctor about the best options for you.

Psoriasis Doesn't Slow Down Texan Brian LaFoy

BRIAN LAFOY HAS BEEN around psoriasis his whole life. His father has it and his father's mother has it. Then, when he was in his mid-20s, he saw the signs and symptoms on his own body.

"It started as plaque psoriasis in my navel and then some plaques on my scalp," recalls LaFoy, 46, a civil engineer from Plano, Texas. "I wasn't diagnosed with psoriasis at first. It was diagnosed as dandruff and other things." A year went by before he got an accurate diagnosis.

Considering treatment options

His father's experiences with earlier psoriasis treatments led LaFoy to be wary about his own treatment options.

"They didn't know as much back then as they do now," he says. "My dad went through some medications that affected his health quite a bit, and for a period of time, almost killed him.

"That led to me stay away from anything that I would take internally, orally, or a shot," LaFoy recalls. "Everything I did for years and years was only skin creams. That's the only thing I would touch, just having seen what happened to my father. I pretty much tried every topical there was."

Quality of life issue

By the time he reached his mid-30s, LaFoy's condition had advanced to severe plaque psoriasis. He had it in his ears and on his scalp, chest, knees, feet, and other places on his body. He also started to develop symptoms of psoriatic arthritis. That is a form of arthritis that produces the joint inflammation common in arthritis and the lesions common in psoriasis.

"It became a quality of life issue for me," LaFoy says. "I'd lost the use of my right hand because the arthritis was so bad. That's the point where I decided to go on biologics. I've been taking etanercept for about eight years. It's a once-a-week injection for me.

"I have cleared up approximately 95 percent and am living manageably with my psoriasis now. It still hurts every day



Brian LaFoy, center, stands with his wife, Jennifer, and children, Micah (left) and Bethany (right).

and I still have plaques on certain parts of my body. But I'm much better than I was before I started on biologics."

Today, LaFoy is active with the National Psoriasis Foundation and a national mentor for psoriasis patients.

What advice does he offer to those with the disease?

"Understand your body and try to get the right help at the right time as early as you can," he advises. "It can be such a long time for a lot of patients to be able to get the proper diagnosis. There's a limited number of doctors who really specialize in it. Fortunately, I'm with one now."

LaFoy, who has his own family now, has not allowed psoriasis to slow down his active lifestyle. He plays soccer and ice hockey, and enjoys snowboarding, wakeboarding, and scuba diving. However he says his true passion is surfing and he spends as much time as he can on the Florida and California coasts.

"The key is to not let the disease get you. Part of who I am is being active and doing things I like to do. Whatever it takes, that's what I'm willing to do. I'm one of the lucky ones."

Find Out More

- ✓ **National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS):** niams.nih.gov/Health_Info/Psoriasis
- ✓ **MedlinePlus:** medlineplus.gov/psoriasis.html
- ✓ **ClinicalTrials.gov:** Search "psoriasis"



Bruce Davidson paints a picture of lavender in Maynard, Massachusetts.

FROM
LYME DISEASE
TO
ART &
ADVOCACY

Photo center: Catherine Anderson, background photo: Adobe Stock

BRUCE DAVIDSON always enjoyed the outdoors.

He owned and operated a landscape contracting business in the early 2000s in Boxborough, Massachusetts. It was this job and location that put him exactly in many ticks' paths.

"My work was certainly making me vulnerable to tick bites. I was always outside in high grass, low grass, thickets, brush," Davidson said. It was a "high-risk environment."

In the spring of 2005, Davidson first suspected he had Lyme disease. He went to his general physician with flu-like symptoms, including headaches and sore muscles. During the visit, Davidson mentioned his symptoms sounded familiar to those of many friends who had Lyme disease.

Unfortunately, Davidson's primary physician at the time did not consider a potential Lyme disease diagnosis and instead gave him a round of general antibiotics. He began to feel better, but his symptoms appeared again and worsened by August of that year.

"I was starting to feel a slow eroding," Davidson explained. "My energy was going. I'm typically high-energy and fit." He had difficulty breathing and would at times hear a high-pitched white noise. He initially thought he had a summer cold, but as his symptoms worsened, he went to the Emerson Hospital emergency room in Concord, Massachusetts.

"I was surrounded by lots of doctors and I think they were giving me an electrocardiogram, which tests for electrical activity in the heart, and I heard somebody say in a chilling way, 'Look at the P waves on the screen. Is the machine broken?'" Those waves were signaling a complete heart block, something only a small percentage of Lyme disease patients' experience.

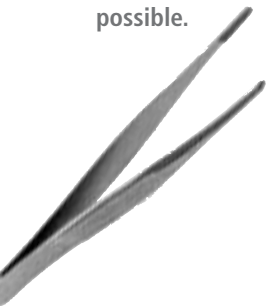
Davidson was quickly admitted to the intensive care unit (ICU) where he was treated by Dr. Scott Paparello of the infectious diseases unit. Dr. Paparello confirmed Davidson's initial suspicion of Lyme disease and began treatment immediately. Intravenous antibiotics treatment began to resolve the atrioventricular block (AV block) and a planned pacemaker operation was canceled. Davidson spent the next three days in the ICU.

When Davidson was released from the hospital, Dr. Paparello said he believed Davidson was cured and would experience no long-term effects. He has since had tick bites that have resulted in a tell-tale bullseye rash, and each time he received a course of doxycycline antibiotics from his doctor. He hasn't had any relapses.

How to remove a tick

1

USE FINE-TIPPED tweezers to grasp the tick as close to the skin's surface as possible.



2

PULL UPWARD WITH steady, even pressure. Don't twist or jerk the tick; this can cause the mouthparts to break off and remain in the skin. If this happens, remove the mouthparts with tweezers. If you are unable to remove the mouth easily with clean tweezers, leave it alone and let the skin heal.

3

AFTER REMOVING the tick, thoroughly clean the bite area and your hands with rubbing alcohol, an iodine scrub, or soap and water.

4

DISPOSE OF A LIVE tick by putting it in rubbing alcohol, placing it in a sealed bag/container, wrapping it tightly in tape, or flushing it down the toilet. Never crush a tick with your fingers.

5

FOLLOW-UP. IF YOU develop a rash or fever within several weeks of removing a tick, see your doctor. Be sure to tell the doctor about your recent tick bite, when the bite occurred, and where you were.



Since his recovery, Davidson has become “hyper-focused” on art and uses these talents to help others. “I decided I’m going to aggressively improve my artistic skills and bring them to a point where I’m going to represent the things that I love in art,” he explained. In addition to producing art and teaching, he works with the Make-a-Wish foundation creating pieces for those in need.

“In 2007, I started painting murals for people,” he explained. “The first one I did was for my 99-year-old neighbor at the nursing home.” The piece was a landscape of the area she lived in, complete with images of the flowers that bordered the yards.

Davidson considers himself a patient advocate, offering information about Lyme disease to anyone who needs it. His biggest suggestion to those with Lyme disease is to keep learning, questioning, and sharing information. “Get all the

information you can from lots of different sources,” Davidson said.

“Do be an

advocate for yourself and don’t always take one opinion,” he said. “I wouldn’t have been at such a risk if I had not waited until I was in peril.”

Understanding and preventing tick bites

As people spend more time outdoors, so do many insects and pests. Among them are ticks, which are small bloodsucking parasites and arthropods. Some diseases you can get from a tick bite are Lyme disease, ehrlichiosis, Rocky Mountain spotted fever, and tularemia. To find about more about these conditions, visit medlineplus.gov.

One of the biggest things to keep in mind when thinking about the risk of tick bites is your location. Different regions in the U.S. are home to various types of ticks. The type or species of a tick determines what diseases it may carry.

NIH MedlinePlus magazine spoke with two officials at the National Institute of Allergy and Infectious Diseases (NIAID) to find out more about tick bites, how to avoid them, and new research that could increase our understanding of how to treat tick-related conditions.

Tick bite symptoms

The most common symptoms of tick-related illnesses are:

Fever/chills

With all tick-borne diseases, patients can experience fever at varying degrees and time of onset.

Aches and pains

Tick-borne disease symptoms include headache, fatigue, and muscle aches. With Lyme disease you may also experience joint pain. The severity and time of onset of these symptoms can depend on the disease and your personal tolerance level.

Rash

Lyme disease, southern tick-associated rash illness, Rocky Mountain spotted fever, ehrlichiosis, and tularemia can result in distinctive rashes.



Types of ticks

THE DEER TICK

(Ixodes scapularis) is found mainly in the Eastern and upper Midwestern regions of the U.S. It can cause conditions like Lyme disease and babesiosis.



THE DOG TICK

(Dermacentor variabilis) is found in the Eastern half of the U.S. and can cause diseases such as Rocky Mountain spotted fever and tularemia. There have been reports of dog ticks as far west as California.



THE LONE STAR TICK

(Amblyomma americanum) lives in the Northeast and Midwest regions of the U.S. It carries diseases such as ehrlichiosis and Southern tick-associated rash illness.



Ticks are smaller than you think.



The average deer tick is 2.75 mm long.



An engorged tick may be up to 10 mm long.

Location, location, location

“The east coast here in the U.S., parts of the south and Midwest, and even in California you have the major [tick-borne] disease, which is Lyme disease,” said José Ribeiro, M.D., Ph.D., chief of the Vector Biology Section of the Laboratory of Malaria and Vector Research in NIAID’s Division of Intramural Research. “People should be aware of ticks and where they can encounter them. In other parts of the country you have other diseases, like Rocky Mountain Spotted Fever in the Rocky Mountains, and so on.”

Online maps that show tick activity in different regions of the country can be helpful in understanding the risk in your region.

Prevention is a top priority

Maliha Ilias, Ph.D., Lyme Disease Research Program Officer in NIAID’s Division of Microbiology and Infectious Diseases, said it is important to prevent ticks from coming into contact with your skin.

Dr. Ilias discussed that there are ways to prevent exposure to ticks. She noted that the best way to do this is wear clothing that covers your arms and legs; tuck your pants into your socks or even put tape around openings in clothing so ticks have no access; and wear light-colored clothing to also help you see if a tick is on you.

When you are in the woods, keep to the center of the trail, where ticks are less likely to be (ticks tend to stay in shrubs and bushes).

As soon as you are home, check yourself or have a family member help check you for ticks. Use a fine-tooth comb through your hair and check folds of the skin. You should also shower and wash your clothes at a high heat so any ticks on you are killed.

Stay calm

If you do find a tick on yourself or a family member, be sure to stay calm.

“I think the most important thing for folks to know is that if they find the tick on themselves, don’t panic,” Dr. Ilias said, noting that it typically takes 36 hours for the bacteria that causes Lyme diseases to travel from the tick gut to its salivary glands and into the host.

It is also important to remove the tick properly. “There is a lot of folklore about how to take a tick out of your skin. Some people even talk about having a lighted cigarette close by, things like that,” Dr. Ribeiro said. “The most important thing is just to use appropriate forceps such as tweezers. Grab the whole tick and pull it out.”

Tick bite prevention

Tick-borne diseases occur worldwide, including in your own backyard. To help protect yourself and your family, you should:

- Use a chemical repellent with DEET, permethrin or picaridin.
- Wear light-colored protective clothing
- Tuck pant legs into socks
- Avoid tick-infested areas
- Check yourself, your children, and your pets daily for ticks and carefully remove any ticks



Saliva is a tick's best friend

A tick's saliva (or spit) is important in its ability to feed. A combination of compounds in a tick's saliva stops human blood from clotting while the tick feeds.

"What we're seeing now is ticks change the composition of their saliva every few days. So the cocktail that they're showing on Monday will be completely different from the cocktail that will be showing up on Friday," Dr. Ribeiro said.

Researchers at the National Institutes of Health are studying the saliva of arthropods to see if there is a way to create a vaccine that will affect the saliva. A current study is looking at a vaccine that works against the saliva of sand flies, so the parasite cannot establish itself at the site of the initial bite. This sort of vaccine will be harder to develop for ticks, as the tick is constantly changing the composition of its saliva.

Early removal is key

The sooner you remove a tick, the better. It takes time for infections to reach a person's blood stream, especially Lyme disease. A tick needs to remain attached for 36 hours before Lyme disease can be transmitted, so remove any ticks as quickly as you can.

However, you may not always know if you've been bitten by a tick, and therefore won't know to keep an eye out for symptoms of tickborne disease.

Looking forward, Dr. Ilias noted the importance of a sensitive and specific diagnostic test for Lyme disease, particularly to detect it early. She added that Lyme disease can be effectively treated if it is diagnosed early.

Find Out More

- ✓ **National Institute of Allergy and Infectious Diseases:** niaid.nih.gov/diseases-conditions/tickborne-diseases
- ✓ **MedlinePlus:** medlineplus.gov/tickbites.html and medlineplus.gov/lymedisease.html
- ✓ **Clinical Trials:** clinicaltrials.gov/search/open/condition=%22Tick-Borne+Diseases%22
- ✓ **Centers for Disease Control and Prevention:** d.gov/ticks/removing_a_tick.html



Kids and Concussions

What the experts think

EVERY YEAR, HUNDREDS OF THOUSANDS OF school-aged children get concussions, a mild form of traumatic brain injury. But the after effects of a concussion can be serious. Experts from the National Institute of Neurological Disorders and Stroke (NINDS) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), share what you can do to protect your child from this injury and its consequences.

What is a concussion?

A concussion is a type of brain injury caused by a bump or blow to the head. During a concussion, the brain literally bounces inside the skull. It causes chemical changes in the brain and temporary changes in normal brain function. Health-care providers often describe a concussion as a

“mild” traumatic brain injury (TBI). While other TBIs may be more severe and even life-threatening, any brain injury can be serious and should be treated promptly.

How does a concussion impact a child differently than an adult?

“There’s a huge gap in our knowledge about childhood concussions,” says Patrick Bellgowan, Ph.D., program director at NINDS. But because there is so much growth and development in the brain during childhood, we do believe that concussions may have a different impact on a younger brain.”

However, he notes, “we don’t know the extent of that impact,” if it’s short-term, long-term, temporary or permanent.

NIH neuropsychologist Alison Cernich, Ph.D., who is the director of the National Center for Medical Rehabilitation Research at NICHD, adds that treating concussion in children can be challenging.

“Unlike adults, children don’t or can’t always articulate their symptoms,” she says. “They may not be able to say where it hurts or how they feel.”

What are the signs and symptoms of a concussion?

“One of the biggest misconceptions about concussions is that there needs to be a loss of consciousness,” Dr. Cernich says. While loss of consciousness happens sometimes, you also need to look for other symptoms including nausea, vomiting, sensitivity to light, dizziness, and blurred vision.

In addition, concussion symptoms may not appear right away. NIH pediatric trauma specialist Valerie Maholmes, Ph.D., who serves as the chief of the Pediatric Trauma and Critical Illness Branch at the Eunice Kennedy Shriver National Institute of Child Health and Human Development, says, “Your child may seem fine immediately after injury, but symptoms can appear hours, days, even weeks later.”

Post-concussion symptoms include difficulty concentrating, headaches, memory problems, confusion, changes in movement or gait, changes in behavior, and trouble with schoolwork.

Dr. Maholmes says to “watch out for anything that seems out of the ordinary, changes in movement, mood, or trouble concentrating.”

How are concussions treated?

Immediately After Injury

- Remove the child from play or other activity that caused the injury
- Seek medical attention as soon as possible
- Keep the child still, lying face up, with head and

shoulders slightly raised; do not move the child unless absolutely necessary.

- Stop any bleeding, applying firm pressure to the wound with sterile gauze or clean cloth; do not apply direct pressure if you think there could be a skull fracture.
- Monitor breathing and alertness; if breathing or movement ceases, immediately begin CPR.

Follow-up care

Concussions take time to heal. Returning to activities too soon while the brain is still healing can increase the risk of another concussion and possible brain damage. But total rest and isolation for several days or more is no longer recommended.

Dr. Bellgowan says it’s better to “reintroduce physical and mental activities slowly.” But treatments for children have not been studied extensively.

Questions remain on exactly how long a child should rest after injury and what other steps should be taken. If you have questions about your child’s care, talk to your health-care provider.

Can concussions be prevented?

You can’t prevent kids from getting hurt, but you can reduce the risk of brain injury with a few simple precautions. The National Institute of Neurological Disorders and Stroke (NINDS) and the Centers for Disease Control and Prevention (CDC) recommend all children:

- **Wear a seatbelt or use a safety seat when riding in a car**
- **Wear a helmet when:**
 - Riding a bike or motorcycle
 - Playing football, ice hockey, or any contact sport
 - Roller skating or skateboarding
 - Horseback riding
 - Skiing or snowboarding

Recommendations for parents include:

- **Storing firearms and ammunition in a locked cabinet or safe**
- **Avoiding falls by installing:**
 - A step-stool with grab bar when reaching for high objects
 - Handrails on stairways
 - Window guards
 - Safety gates at the top and bottom of stairs



A Head Start on Concussion Recovery

Life lessons after three pediatric concussions

“IT WOULD HAVE BEEN EASIER IF HE HAD broken a limb,” Michelle Marchionni says about her son Sam’s first concussion.

In the fall of 2012, 8-year-old Sam fell backward and hit his head on the grass when he was playing touch football.

The school nurse called Marchionni and said it was nothing to worry about. “When Sam came home, he seemed fine. I didn’t think it was anything serious. A day later, he complained of a mild headache, but nothing more,” Marchionni says. “We didn’t take any special precautions.”

On the following Sunday, while playing in the yard at home, Sam hit his head again. The injury seemed minor, but it turned out to have a major impact. “Kids get bumps and bruises all the time. We had no idea the first injury was a concussion,” Marchionni says.

Presumably, because his brain didn’t have enough time to heal after the first injury, the second hit caused more problems for Sam. His mother noticed it right away. “He’d get a headache after any kind of mental activity, even just watching TV,” she says.

It got so bad, he needed to stay home from school. From the time of his injury in November until early January, Marchionni

“If we had let Sam rest after his first concussion, that second hit wouldn’t have happened,” said Michelle Marchionni, pictured at home with Sam in April 2017.

had her son limit his activities. “No sports, no screen time, no reading. He couldn’t even have friends over, because we were afraid of the physical activity,” she says. “It was really tough on him.” Fortunately, by mid-January, Sam was back to his old self.

One year later, Sam fell again during a touch football game at recess.

This time, Marchionni knew more.

“We pulled him out of sports for three weeks. We made sure he took it easy,” says Marchionni. “Recovery was faster, and Sam didn’t miss any school.”

Three years later, when Sam was 12, he got a concussion during a school hockey game. “Sam immediately benched himself. He didn’t forget what happened to him when he was younger,” says Marchionni.

Once again, Marchionni consulted with a pediatric concussion specialist. But this time was different.

The specialist told them about new research on treating concussions. “He said mild physical activity was actually good for recovery. We took his advice, going on walks together, getting fresh air. I think it helped Sam get better faster,” Marchionni noted.

“The most important thing to remember is to pay attention,” Marchionni says. “If we had let Sam rest after his first concussion, that second hit and its repercussions wouldn’t have happened.”

She knows Sam was lucky. “Some kids that get concussions are never the same.” But it wasn’t luck that kept Sam healthy after his subsequent concussions. “Taking steps right away made all the difference.” Today Sam is an active and happy seventh grader. Marchionni says, “He’s the happiest kid I know.”

Find Out More

- ✓ **National Institute of Neurological Disorders and Stroke (NINDS)**
ninds.nih.gov/
- ✓ **Eunice Kennedy Shriver National Institute of Child Health and Development (NICHD)**
nichd.nih.gov/Pages/index.aspx
- ✓ **Centers for Disease Control and Prevention: CDC Heads Up**
cdc.gov/HeadsUp/

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- **National Heart, Lung, and Blood Institute (NHLBI)**
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- **National Institute on Aging (NIA)**
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www.nibib.nih.gov | 301-451-6772
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- **National Institute of Dental and Craniofacial Research (NIDCR)**
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- **National Institute on Minority Health and Health Disparities (NIMHD)**
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- **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

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- **National Center for Complementary and Integrative Health (NCCIH)**
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- **National Center for Advancing Translational Sciences (NCATS)**
www.ncats.nih.gov | 301-435-0888
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<http://clinicalcenter.nih.gov> | 301-496-2563
- **Office of AIDS Research (OAR)**
www.oar.nih.gov | 301-496-0357
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obssr.od.nih.gov | 301-402-1146
- **Office of Rare Diseases Research (ORDR)**
rarediseases.info.nih.gov
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