Gene Changes in Type 1 Diabetes

Your genetic code dictates how your genes work. But your environment and behavior can also cause changes in your genes that affect how they function. These are called epigenetic changes. Researchers in Finland, where children have the highest rates of type 1 diabetes, have recently discovered epigenetic changes in some children that indicate that the wheels are already in motion for development of the disease. The new discovery could lead to additional tests to help detect and treat type 1 diabetes in children long before they become sick.

Source: Diabetologia

1 in 7 Number of type 1 diabetes diagnoses that happen in someone who has a family member with the condition.

Source: JDRF

Quickly Aging Cells

Throughout your entire life, your body constantly generates new cells as older ones age and die off. In people with type 1 diabetes, immune cells might age and die off faster. That was the finding of a recent study that examined these cells in people with type 1 diabetes, those of their next of kin, and of people without the disease. The discovery could lead to new ways to monitor the progress of the disease and new targets for specialized treatment.

Source: JCI Insight

Early Detection

Until recently, doctors couldn’t diagnose type 1 diabetes until after a person had all the symptoms of full-blown disease. Tests now in development can detect signs of the disease much earlier in the process. In one new test, T cells—a type of immune cell involved in the development of diabetes—are drawn from people with no symptoms of diabetes. Researchers then provoke the cells with proteins that look like those from the pancreas that T cells attack in type 1 diabetes. If they attack, the person is already on the path to developing diabetes but has time for treatment that could prevent or delay the disease.

Source: Science Translational Medicine
STATS & FACTS

By Sonya Collins
Reviewed by Brunilda Nazario, MD, Chief Physician Editor, Medical Affairs

10 to 14
Most common ages when a child gets a type 1 diabetes diagnosis.

668,000
Number of deaths that could be prevented by 2040 with more prompt diagnosis of type 1 diabetes.

UP TO 1 in 10
Number of people with diabetes who have type 1.

335,000
Expected number of U.S. youths ages 10 to 19 with type 1 diabetes by 2060.

>125 mg/dL
Fasting blood sugar level that indicates diabetes.

1 in 30
Number of U.S. families impacted by type 1 diabetes.

3%
How much type 1 diabetes rates increase every year.

65%
How much type 1 diabetes rates are expected to have increased in U.S. youths ages 10 to 19 by 2060.

SOURCES: JDRF, CDC, Journal of Diabetes
Even if just 1 person in your family has type 1 diabetes, your child is up to 15x more likely to get it too.

You can spot type 1 early with just 1 blood test that looks for diabetes-related autoantibodies. These are proteins that appear in the blood when type 1 begins—even in the early stages.

Sanofi does not provide medical advice, diagnosis, or treatment—information is provided for educational purposes only. Your doctor is the best source of health information. Talk to your doctor if you have any questions about your health or treatment.
Nearly a quarter of a million people in the U.S. under the age of 20 have type 1 diabetes. In this lifelong, autoimmune condition, the immune system, whose job is to attack invading germs that threaten health, mistakenly attacks and destroys the insulin-producing cells of the pancreas. As a result, the pancreas can’t make insulin—a hormone that unlocks the body’s cells to let sugar inside so the cells can turn the sugar into energy.

“Without insulin, the sugar stays in the bloodstream, your blood sugar ends up high, and that is the definition of type 1 diabetes—an autoimmune-driven lack of insulin,” says Nicole M. Sheanon, MD, a pediatric endocrinologist at Cincinnati Children’s in Ohio. There is no cure for type 1 diabetes. People who have it must inject or pump insulin into their bodies in order to survive.

WHO GETS TYPE 1 DIABETES?
Anyone can get type 1 diabetes, but age and genetics play a part. The disease tends to show up most often in childhood or adolescence—that is, in people under age 20. For this reason, it used to be called juvenile diabetes. People who have a next of kin that have the condition are at greater risk than those who don’t.

“But,” Sheanon says, “Really anyone can develop type 1 diabetes. I myself was diagnosed at age 10 and now, over 30 years later, I’m still the only one in my family that has type 1 diabetes.”

HOW IS TYPE 1 DIABETES DIAGNOSED?
Until recently, doctors only diagnosed type 1 diabetes through different tests to determine whether the blood sugar level was abnormally high. This would happen after the person, usually a child, started showing the telltale signs of the condition, which include extreme fatigue, extreme thirst, frequent urination, and eventually weight loss.

But advances in our understanding of the stages of type 1 diabetes have led to screening tests that can detect it before it fully develops and before your child gets sick.

WHO SHOULD GET A TYPE 1 DIABETES SCREENING?
The American Diabetes Association and researchers around the country and the world are working to determine who would benefit from a type 1 diabetes screening. For now, general recommendations include people who have next of kin with the condition, but that only captures about 15% of people with type 1 diabetes.

If others would benefit from early screening and detection, experts want to know. An early diagnosis could allow doctors to start treatment that could prevent the disease or greatly delay it.

“There are drugs in development that may one day prevent the onset of type 1 diabetes,” Sheanon says. “We are not quite there yet, but that’s the hope.”
A new diagnosis of type 1 diabetes comes with a lot of new information to absorb. “It’s a big diagnosis, and it can be overwhelming,” says Nicole M. Sheanon, MD, a pediatric endocrinologist at Cincinnati Children’s in Ohio. “You’re going to have a lot of questions. There’s a big learning curve. I always tell parents, ‘Diabetes isn’t easy, but it is possible.’”

As you begin the journey of caring for a child with type 1 diabetes or just want a refresher, here are some terms you might hear.

**A1c.** A blood test that shows what your blood sugar level has averaged over the past 2 to 3 months.

**Antibodies.** Proteins that the immune system creates to fight off germs and illnesses. In type 1 diabetes, the body mistakenly makes antibodies that fight the insulin-producing cells of the pancreas. Diabetes screenings test for these antibodies.

**Blood glucose.** The medical term for blood sugar. It’s your body’s main source of energy taken from food. In type 1 diabetes, too much of this accumulates in the bloodstream because the body lacks the hormone insulin that breaks it down.

**Continuous glucose monitor.** A device that uses a sensor attached to the body to measure blood glucose levels every few minutes throughout the day and night without the need to prick a finger every time. The monitor sends the readings to a wireless device such as a smartphone or smartwatch.

**Diabetic ketoacidosis.** An emergency condition in which blood sugar becomes extremely high in the absence of insulin to break it down. Without sugar for energy, the body breaks down fat and leaves behind chemicals called ketones, which show up in your urine and also cause vomiting, stomach pain, a fruity breath odor, and rapid breathing. This is an emergency that can cause coma or death without treatment.

**Hyperglycemia.** High blood sugar that is over your target number.

**Hypoglycemia.** Low blood sugar that is under your target number. You must treat it with a high-carbohydrate food like fruit juice. Untreated, you can pass out and become unconscious. At this point, you need an injection of glucagon, a substance that prompts the liver to release glucose and restore healthy blood sugar levels.

**Insulin.** A hormone, produced in the pancreas, that helps the body break down sugar. Specifically, it opens cells to let sugar inside where it is burned for energy. Type 1 diabetes destroys certain cells in the pancreas so that they can no longer produce the critical hormone.

**Insulin pump.** A device that can deliver insulin as needed through a thin, flexible tube and into your body and avoid the need to inject insulin manually every time. Tethered pumps may be carried in your pocket or clipped to a belt. Patch pumps or micropumps are stuck directly onto the skin, usually on the stomach.
If a screening shows your child is in stage 2 of type 1 diabetes (T1D), you’re bound to have many questions about what it means and what comes next. Questions like the ones below can help you better understand what your child is dealing with and how to manage what comes next.

**Q. WHAT DOES IT MEAN TO BE IN STAGE 2 OF T1D?**

Type 1 diabetes happens when insulin-producing cells in the pancreas called beta cells stop working correctly, or when the immune system incorrectly attacks and destroys them as if they are foreign invaders.

T1D has three stages. Your doctor knows which stage your child is in by looking at a sample of their blood under a microscope for specific antibodies. These antibodies, called autoantibodies, are made by your child’s immune system in response to their body’s own proteins. They’re responsible for destroying insulin-producing beta cells.

“Stage 1 is determined once a person tests positive for two or more autoantibodies [while] the person’s blood sugar continues to be normal,” says Nicole M. Bereolos, PhD, MPH, a clinical psychologist in McKinney, TX, and spokesperson for the Association of Diabetes Care & Education Specialists.

When your child’s blood sugar starts to become abnormal, that’s a marker that they’ve moved on to what doctors call stage 2 T1D.

“[At this stage] blood sugar levels aren’t high enough to be diabetes, but high enough to not be normal,” says Kimber Simmons, MD, MPH, associate professor of pediatrics at the Barbara Davis Center for Diabetes at the University of Colorado Anschutz Medical Campus in Aurora.

In stages 1 and 2, your child will not show any symptoms of diabetes, and they aren’t considered to be diagnosed with T1D. Once your child is showing symptoms, they’ve moved to stage 3, which is when a doctor would give them a clinical diagnosis.

**Q. CAN I PREVENT A T1D DIAGNOSIS FOR MY CHILD?**

When it comes to your child moving to stage 3 T1D, Bereolos says it’s not a matter of if, but when.

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**SPECIALISTS TO KNOW**

Kimber Simmons, MD, MPH, lists some of the health care professionals who will care for your child’s T1D needs.

+ **Primary care physician** to help keep tabs on overall health.
+ **Pediatric endocrinologist** for diabetes treatment.
+ **Dietitian** who specializes in diabetes to help with nutrition.
+ **Certified diabetes educator** to teach you and your child diabetes management skills.
“We know that 100% of people who are in stage 2 will eventually move onto stage 3,” she says.

Children typically move through the stages of T1D at a faster pace than adults, but researchers are working on holding that movement off as long as possible.

“A medication for those 8 years of age and older has recently been approved that can help slow the progress from someone going from stage 2 to 3 type 1 diabetes,” Bereolos says. “This medication is not a cure to type 1 diabetes; movement to stage 3 is inevitable, based on the treatment that we have at this time.”

Q. WHAT ARE THE NEXT STEPS FOR MY CHILD?

It can feel overwhelming to absorb all the information about T1D. Now is the time to lock in your child’s health care team and commit to regular follow-up visits to monitor your child’s health. It’s important to know the symptoms of T1D, such as being very thirsty, very tired, weight loss, and frequent urination, so you can alert your doctor if you see these signs in your child.

“Watch for things like your child getting up at night to pee or having wet diapers when they didn’t before,” Simmons says. “That’s usually one of the very earliest signs.”

Above all, know that although your child’s journey with T1D will be lifelong, it is manageable.

“There are amazing medications and technology for kids with T1D to help their bodies work almost as if they are still making insulin on their own,” Simmons says. “As long as your child takes insulin, they should be able to live a completely normal, healthy, happy life.”

SUPPORT FOR THE ROAD AHEAD

These organizations can connect you to other type 1 diabetes (T1D) families and resources.

+ The JDRF funds T1D research and provides online forums, clinical trial information, and education about T1D.

+ Beyond Type 1 is a nonprofit group that supports people with diabetes with programs, grants, and an online community, plus an app.

+ The American Diabetes Association works to prevent and cure diabetes and improve the well-being of people with diabetes and their families.
Before 2016, the way doctors checked for the development of diabetes was by testing blood sugar levels. Then researchers created a way to screen for certain diabetes-related markers in your body. They can see these markers long before blood sugar starts to be abnormal and the symptoms of type 1 diabetes (T1D) start.

With this screening technology, doctors can intervene sooner, can learn more about how T1D progresses, and hope one day to be able to use the information to help prevent the disease.

HOW DO DOCTORS SCREEN FOR T1D?
T1D screening involves drawing about half a teaspoon of your blood that goes to a lab for analysis. The process is incredibly easy and free, says Zoe M. González-García, MD, pediatric endocrinology specialist at Children’s Hospital & Medical Center in Omaha, NE.

“TrialNet [the National Institutes of Health-sponsored type 1 diabetes clinical trials network] has several locations in the country where you can go get tested, and it also has a home test kit that they can deliver to your home,” she says. “In addition to finding important information about your family, it helps the medical community get closer to finding a cure for type 1 diabetes.”

Your results come in about 4 to 6 weeks.
HOW DOES SCREENING HELP?

If your blood has one or more of five specific pancreatic autoantibodies, your doctor will know that you may have started down the path toward T1D.

“There’s a big need for education about the stages of diabetes,” says Emily K. Sims, MD, pediatric endocrinologist at Riley Hospital for Children in Indianapolis, IN. “A lot of people aren’t familiar with it, but now we know that type 1 progresses in three stages.”

Screening results that are positive for two or more autoantibodies mean you’re at stage 1 of T1D. Two or more autoantibodies plus abnormal blood sugar puts you at stage 2. These two stages happen before any symptoms show up and before an official diagnosis.

“The risk for developing type 1 diabetes increases with an increase in the number of positive antibodies,” González-García says. For example, having one positive antibody means you have around a 3% risk of developing T1D within 2 to 3 years. Having four positive antibodies increases your risk to about 50% in 2 years and 80% in 6 years.

The earlier in the stages of T1D doctors can make a diagnosis, the sooner they can start treatment and the fewer beta cells (the cells in your pancreas that make insulin) will be destroyed. More beta cells may lead to better blood sugar control and may lower your risk of long-term diabetes complications.

WHO SHOULD GET A T1D SCREENING?

Anyone can benefit from the information a diabetes screening provides, but it’s most helpful for certain people who are at higher risk of getting T1D.

“Your chance of getting type 1 diabetes without a positive family history is about 1 in 300,” González-García says. “But if you have a positive family history, that risk increases to 1 in 20.”

That means siblings of children with T1D are 15 times more likely to develop T1D themselves.

“It’s a no-brainer for family members because they can get screened for free through TrialNet,” Sims says. “But if it’s someone who doesn’t have a family history, that’s more complicated. Some states have screening programs available.”

Screening should be an ongoing process if your child is at high risk but tests negative. Siblings of kids with T1D who don’t test positive for diabetes-related autoantibodies should continue to get screened every year until age 18.
HAVING A CHILD WITH TYPE 1

MY JOURNEY AS A CAREGIVER

By Dominick Esposito
Reviewed by Brunilda Nazario, MD, WebMD Chief Physician Editor, Medical Affairs

You’d think I would be prepared for diabetes in our home after watching my father cope with it for many years. But when it’s your own child—or in my case, children—it’s a different story. You can have an idea of what’s involved, but you’re never ready to hear “your child has diabetes.”

ALL IN THE FAMILY

I have twin sons who are 12 and a daughter who is 10. When my sons were 9, one of them, Raff, started getting up a lot at night to use the bathroom, and he was always tired. His doctor suggested we test his blood sugar and then confirmed early stages of type 1 diabetes. My wife and I went online immediately—finding resources and all we could research. The Juvenile Diabetes Research Foundation (JDRF) has a helpful starter kit and other things for both the child and parents. It also comes with Rufus the teddy bear—a symbol of comfort for the entire family. While my wife and I devoured information about what would be our new normal, Raff took it all in stride. He told us, “I’m ready for my new adventure.” It meant a lot to see him have such a positive attitude about it all.

GADGETS ARE GOOD

My son uses an insulin pump to control how much insulin he receives. It also includes a continuous glucose monitor. These are relatively new devices that track your blood sugar. It can be a lot to keep up with, especially for a kid, so these gadgets are very helpful. We’re also careful about what he eats and where it’s from. We watch for hidden sugars and carbs. We don’t treat him much differently than our other two. All of our kids are active—Raff in baseball, Sev in camping and fencing, and our daughter, Carabella, is a gymnast.

With doctor appointments, Raff goes every 6 months. His twin, Sev, goes more regularly since we’re watching his antibodies for diabetes and he’s in a clinical trial. He goes every 3 months for a glucose tolerance test. He’s also been positive about being on the brink of full-stage type 1. For now, he’s doing his part to help others. He donated his money from the trial ($50) to the JDRF One Walk.
THE FUTURE IS BRIGHT

One of the biggest myths many parents have is that it’s their fault. They often think it’s their fault or that they did something to cause it. I’ve met so many children who are perfectly healthy, not overweight, and eating nutritious food and they still develop type 1 diabetes.

Another misconception is that it’s going to be difficult to manage. I try to help parents I meet understand that life isn’t over because they have a child with diabetes. There are so many amazing resources. Other parents are great support also. They’ve walked the road you’re on and can shed some light on ways to manage. Science and technology have come a long way since my father had diabetes. It’s not always easy. We are careful about what our children eat. We’re cautious about helping Raff to avoid catching a cold, which can throw off his blood sugar. We are vigilant about handwashing and staying healthy, especially during cold and flu season. We’re watching our other son closely, and while my daughter has tested negative, she’s not out of the woods yet. Still, we remain a family that has fun, stays close, and keeps our eyes on the silver linings.

DOMINICK’S TIPS

+ Try to stay calm. You are not in this alone.
+ Learn a lot and teach your kids, too.
+ Get your other children tested. It’s easy and provides peace of mind.
When your child has type 1 diabetes (T1D), you'll want a care team you trust. Your child will benefit from having people on their team with the expertise and experience to help in different ways, says Anuradha Viswanathan, MD, a pediatric endocrinologist at Cleveland Clinic in Ohio. “We treat [T1D] by replacing insulin, but it depends on what the child eats, how active the child is going to be, and what happens when the child is sleeping overnight,” Viswanathan says. Because various aspects of your child’s day-to-day life will affect their blood sugar levels, she notes, it’s not as simple as taking a set dose of insulin each day.

A TEAM APPROACH
An endocrinologist who specializes in diabetes care like Viswanathan will help you manage your child’s treatment with insulin. They also will look for and help with any health complications or other challenges related to type 1 diabetes. Depending on your specific needs, your endocrinologist can refer you to other doctors that specialize in conditions that may affect your child’s eyes (ophthalmologists), kidneys (nephrologists), or skin (dermatologists).

Dietitians play an essential role, Viswanathan says, especially when you and your child are new to a type 1 diabetes diagnosis. The amount of insulin your child needs will depend on how many carbohydrates they’re eating, which will vary. Your dietitian will help you learn how to count carbs. They’ll also help you learn how fat and protein affect blood sugar levels.

GET AN EDUCATION
When your child has T1D, there’s lots to learn. Certified diabetes care and education specialists are specially trained to help you learn how to manage type 1 diabetes in a way that works for you. They can help you learn what to do when your child’s blood sugar gets too high or too low. They’ll explain the pros and cons of an insulin pump and teach you how to use one. They’ll prepare you for when your child gets sick and answer any questions you may have.

“Diabetes educators are the backbone of a lot of the education that we do,” Viswanathan says.

ROUND OUT YOUR TEAM
A social worker will make sure you’ve got all the supplies you’ll need at home, Viswanathan adds. They’ll also help you to ensure your child will have the needed supports in place at school. Mental and behavioral health professionals can help the whole family prepare and adjust to the ongoing challenges and feelings that come with life with diabetes.

“It is quite a significant change in lifestyle when [a child is] diagnosed and going forward for the rest of their lives,” Viswanathan says. “Behavioral psychologists play a big role.”
NAVIGATING SPORTS AND ACTIVITIES

EXERCISING IS KEY TO A HEALTHY, HAPPY LIFE

By Kendall K. Morgan
Reviewed by Brunilda Nazario, MD,
WebMD Chief Physician Editor, Medical Affairs

Kids with type 1 diabetes (T1D) can play actively and compete in sports just like other kids do. You should aim for your child to get at least 30 to 60 minutes of exercise or active time each day.

“We know from a fair amount of published data that kids with T1D who achieve around 200 minutes a week of accumulated exercise are a lot healthier in terms of physical health and mental health,” says Michael C. Riddell, MD, a kinesiologist who studies the effects of exercise on diabetes at York University in Toronto, Canada. “There’s good evidence it delays diabetes complications and gives them a better overall state of well-being.”

EXERCISING SAFELY

You will need to take steps to ensure your child can exercise safely with T1D. While it might seem challenging at first, Riddell says, the “health and fitness benefits of exercise will more than pay off.”

Riddell advises to check your child’s blood sugar level about an hour before planned exercise. That will give your child time for a snack if they need one. Check blood sugar again at the start of exercise.

When possible, it’s nice to check again at the end of the sports practice or exercise session. If your child is exercising for a longer period—more than an hour—check it in the middle, too.

HANDLING LOWS

Exercise may cause blood sugar levels to drop, Riddell says. On active days, kids with T1D often spend less time with high blood sugar but more time with low blood sugar.

Over time, you’ll learn your child’s patterns and how to fine-tune blood sugar levels by adjusting insulin or eating the right snack. Simple carbs are good for a quick blood sugar boost. Before a long bike ride or hike, Riddell says that a complex carb may help sustain your child’s blood sugar levels longer even without any changes to insulin.

TAKE A BREAK

After an active day, be aware that your child may be at risk for low blood sugar overnight. It’s even more likely, according to Riddell, if they had low blood sugar during exercise. Combat this with a healthy bedtime snack. He suggests yogurt or a peanut butter sandwich on pumpernickel bread.

Be sure your child takes it easy sometimes, too. “It’s OK to have play and activity every day, but if your child is training as an athlete, they need recovery days with light exercise only,” Riddell says. “That’s really important.”

EXERCISE TIPS

+ Get advice from your child’s doctor first.
+ Talk to your child’s gym teacher and coach.
+ Have an exercise plan your child understands.
+ Check blood sugar before, during, and after exercise.
+ Have a snack and plenty of water at the ready.
Like so many families, when my son Peter was diagnosed in 2014, we missed many of the warning signs and had a very scary experience with DKA (diabetic ketoacidosis). Because of the increased risk for siblings to develop T1D, we decided to screen ourselves and our younger three children for type 1 diabetes. Fortunately, none of our other children have been diagnosed with T1D, but screening led to a diagnosis of Celiac disease for our younger daughter and her early diagnosis helped to avoid further health complications.

—Meredith, JDRF’s Clinical Trial Education Volunteer

Screening and Monitoring for Type 1 Diabetes:

- Helps avoid serious complications both during diagnosis and in the long term
- Gives families time to plan and prepare and discuss treatment options with their doctor
- Opens the opportunity to participate in clinical trials that can lead to new treatments and therapies

T1Detect is JDRF’s education and awareness program for type 1 diabetes risk screening. We help people understand why screening matters, how to get screened, and what to do after they are screened.