



# Begin with **HOPE**

Your Guide to Living Confidently  
with Type 1 Diabetes

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# You Are Not Alone

Living with the burden of type 1 diabetes (T1D) can be overwhelming. But you're never alone. It may feel scary at times as you begin the journey, but we're here to guide you, and help you and your family to move forward with confidence and support.



## We Are Here to Help

At JDRF, our commitment is to provide you with a compassionate community and valuable resources as you navigate the challenges that life with T1D presents. Our Begin with Hope guide was created with care by people living with T1D, their families, and medical experts. You will learn T1D basics, what you should know about blood sugar and insulin, how to educate others about T1D, and where to find more information.



## Who We Are

JDRF was created in 1970 by parents of children with T1D who were committed to finding cures through research. Today, JDRF is the leading global organization funding T1D research. Our strength lies in our exclusive focus on the worldwide effort to end T1D. Our mission is improving lives today and tomorrow by accelerating life-changing breakthroughs to cure, prevent and treat T1D and its complications. You can find out more about our mission and initiatives at [jdrf.org](http://jdrf.org).



## Be Who You Want to Be

T1D is often described as a "hidden disease." Your next-door neighbor, teacher, colleague — anyone can have T1D and you may not know it. Some people with T1D are rock stars, actors, and heads of state. Others have successfully completed World Marathon Challenges and Ironman Triathlons, participated on American Ninja Warriors and have become NASCAR drivers. T1D does not have to stop anyone from achieving their dreams. Whether your dream is to become a parent, pilot, scientist or anything you want, T1D does not define you or limit you!

We hope you find the information in this guide useful. Visit us at [jdrf.org](http://jdrf.org) to learn more about our impact, initiatives and resources.

# Type 1 Diabetes Basics

Type 1 diabetes (T1D) is a chronic autoimmune disease in which insulin-producing beta cells in the pancreas are mistakenly destroyed by the body's immune system. The body stops producing insulin, a critical hormone made by the pancreas that allows the body to use sugar (glucose) from carbohydrates in food consumed for energy. People with T1D monitor their blood sugar throughout the day and take insulin via multiple daily injections (MDI) or continuous subcutaneous insulin infusion (CSII) also known as an insulin pump.

T1D is diagnosed in both children and adults, and its causes are not fully known. It is an autoimmune disease and factors such as diet, lifestyle, or exercise aren't considered causes of T1D.



**T1D is NOT** a lifestyle disease, it isn't contagious or something you can outgrow, and it's not preventable, curable or caused by eating too much sugar.

## Signs of T1D



Extreme Thirst



Unexplained Weight Loss



Dry Mouth



Frequent Urination



Fruity Odor on the Breath



Drowsiness or Lethargy



Increased Appetite



Heavy or Labored Breathing



Sudden Vision Changes

## Day-to-day with T1D

Learning how to manage T1D means balancing insulin, food, exercise and stress to keep blood sugar levels in a target range as much as possible. Living with T1D isn't always convenient, but thanks to advances in medical science and technology, now more than ever before, T1D is a manageable disease.

You will notice that each day may be different and you'll need to carefully plan and make adjustments to your or your child's routine to stay on track and live well with T1D. Daily management of T1D involves checking blood sugar levels regularly throughout the day to avoid severe high or low blood sugar levels and related complications. If your or your child's blood sugar levels are out of your/their target range, you will need to respond with insulin or carbohydrates. Even with careful attention, people with T1D may still experience dangerously high or low blood sugar levels. We're here to help you know the signs, what action to take and when.

## Blood Sugar 101

For people without diabetes, a typical blood sugar range is 70 to 125 mg/dL when fasting. The goal for people with diabetes is to try to stay between 70 to 180 mg/dL (commonly referred to as in-range); however, your target range should be discussed with your diabetes care provider.

Visit [jdrf.org/living-with-t1d](https://www.jdrf.org/living-with-t1d) for more information, including how to manage blood sugar and downloadable resources on recognizing and treating high and low blood sugar levels.



### Caring for Insulin:

- Unopened insulin needs to be refrigerated.
- Store open insulin at room temperature, never near extreme heat or extreme cold.
- Check the expiration date before using, and discard expired insulin.
- Examine the bottle and discard if you notice particles or discoloration.



### Check blood sugar levels frequently, using one of these options:

- Place a small drop of blood (usually from the fingertip) on a test strip in a glucometer or glucose meter.
- Use a continuous glucose monitor (CGM), which checks blood sugar via a sensor placed just under the skin that measures tissue-glucose levels in real time and relays them to a receiver.

### Feeling under the weather?

Make sure to monitor blood sugar more frequently and closely as illness can make blood sugar levels fluctuate unexpectedly.

## Insulin 101

There are five main types of insulin: rapid acting, regular or short-acting, intermediate-acting, long-acting, and ultra long-acting. These types are categorized by how quickly they begin to work in the blood stream and how long their effects will last.

Insulin can be administered through several ways: injections, pumps, inhalers or automated insulin delivery systems. Work with your physician and diabetes care team to figure out the right insulin therapy for your needs.

**Insulin is not a cure for diabetes: it is a treatment that keeps people with diabetes alive.**

For more information on different types of insulin and how to administer them, visit [jdrf.org/insulin](https://www.jdrf.org/insulin).

## Why is Counting Carbohydrates so Important?

Carbohydrates, or “carbs,” are nutrients in the food we eat and drink. The body uses insulin to break down carbs and turn them into glucose for the body to use as energy.

For people with T1D, it’s important to know how many carbs they consume so they can determine how much insulin they need based on their insulin-to-carb ratio. Your diabetes support team will help you calculate your carb ratio. This will give you a good place to start, but there will be times when extra carbs are needed to treat a low blood sugar, or extra insulin is needed to correct a high blood sugar.

A “correction factor” or “insulin sensitivity factor” helps you figure out how much extra insulin is needed to bring blood sugar down to your or your child’s target range when it is high. Insulin takes a little while to work and will continue to work for several hours. Everyone’s sensitivity to insulin is different, so your diabetes support team will figure out your correction factor with you.

This might feel overwhelming at first, and it will take time for you and your family to adjust. But with a little extra preparation and thoughtful planning as well as with encouragement and affirmation from your T1D community, this will soon become second nature to you. Have patience with yourself.

### A few tips you may find helpful as you learn to count carbs:

- ➔ **Read nutrition labels on packaged goods to determine the total grams of carbs per serving size.**
- ➔ **Use measuring cups and spoons or food scales to count carbs more accurately.**
- ➔ **Use smartphone apps and websites that make it convenient to calculate carbs.**
- ➔ **Create your own personal database of frequently consumed foods and their carb counts as an easy reference.**



For more information on food facts and recipes, including newly-diagnosed meal ideas and parent’s guide on counting carbs like a pro, visit [www.beyondtype1.org/food](https://www.beyondtype1.org/food).

## Putting Together Your Diabetes Support Team

People with T1D often need input from different kinds of healthcare professionals.

Members of your diabetes support team typically include:

### **Doctor | Primary Care Physician | Endocrinologist:**

Manages the medical aspects of T1D including insulin dosing and caring for complications.

### **Nurse | Diabetes Care and Education Specialists:**

Educates on diabetes management.

### **Registered Dietitian:**

Helps with carb counting and meal planning.

Other members of your support team might include, Mental Health Professional, Social Worker, Obstetrician, Ophthalmologist, Podiatrist, and School Nurse.



### **Remember:**

- Regular medical checkups and adjusting your diabetes management routine with your healthcare team can help to improve glucose management, which may reduce complications and will allow you to tackle T1D with confidence.
- Healthcare professionals and clinics may vary substantially in their experience with and approach to T1D. Choose the team that best suits your needs and lifestyle.

For tips on how to choose your diabetes support team, visit [jdrf.org/supportteam](https://jdrf.org/supportteam).



### **Learn to Speak T1D:**

Wondering what is meant by bolus, HbA1c or DKA? You'll come across a lot of words and phrases that are frequently used by the T1D community and your diabetes care providers when discussing the treatment and management of T1D. Visit [jdrf.org/T1Dictionary](https://jdrf.org/T1Dictionary) to get up to speed on T1D language.

## Low Blood Sugar or Hypoglycemia

A blood sugar of 70 mg/dL or lower is usually considered low blood sugar or hypoglycemia. This can occur for many reasons including when a person with T1D takes too much insulin, the type of food consumed and/or the timing of insulin administration, and during or after physical activity.

Common signs of a low blood sugar may include sweating, shaking, dizziness, poor coordination, blurry vision, difficulty concentrating, anxiety, irritability, hunger, nausea, or erratic behavior. If you notice any of these symptoms, check blood sugar and treat accordingly.

Not everyone has these or the same symptoms every time or notices them in time to prevent low blood sugar from getting lower. It is a good idea to wear medical ID at all times to make sure caregivers and people around you are aware of your diabetes. For children with T1D, make sure that their school has the information they need to treat lows. Visit [jdrf.org/school](https://jdrf.org/school) to learn more.

### **Treating low blood sugar**

- Low blood sugar should be treated immediately. Build an easily accessible supply of fast-acting low blood sugar treatments, including fruit snacks, juice boxes and/or glucose tabs/gels.
- Glucagon is a hormone used to raise blood sugar and can be administered via injection, auto-injection pen or nasal spray. Have a glucagon kit on hand in case of an emergency and make sure others (especially caregivers of children with T1D) know where to access glucagon and how to use it. This is especially important if you or your child are unable to treat low blood sugar or are unconscious.
- After administering glucagon, turn the treated individual on their side and call 911.

## High Blood Sugar or Hyperglycemia

A blood sugar of 180 mg/dL or higher is usually considered hyperglycemia or high blood sugar. It can occur when too little insulin is taken for carbs consumed, but also due to other unpredictable factors such as illness, stress and hormonal changes.

Signs of high blood sugar may include extreme thirst, frequent urination, or increased hunger. If you notice any of these symptoms, check blood sugar and treat accordingly.

### **Treating high blood sugar**

- Take insulin to bring blood sugar levels down.
- Stay hydrated by drinking plenty of water or other carbohydrate-free beverages.



For people with T1D, careful management of blood sugar is important to help prevent long-term complications to the eyes, heart, kidneys, and nerves. Visit [jdrf.org/newly-diagnosed](https://jdrf.org/newly-diagnosed) to learn more about how to get the right support.

# Diabetic Ketoacidosis (DKA)

Diabetic Ketoacidosis (DKA) is a serious and potentially life-threatening condition. Ketones are caused by the breakdown of fat when there isn't enough insulin to allow the glucose (sugar) into your cells for energy. When ketones build up, the result is acidosis (too much acid in the blood). Often blood glucose levels are elevated (above 240 mg/dL) but not always.

DKA develops slowly. Early symptoms of DKA include thirst or a very dry mouth, frequent urination, high blood sugar level (above 240 mg/DL), and high levels of ketones in urine or blood. Later symptoms of DKA include extreme exhaustion, dry or flushed skin, nausea, vomiting or abdominal pain, difficulty breathing, chest pain, fruity breath, confusion and/or difficulty paying attention.



## How to check for ketones?

- Many experts advise to check your urine or blood for ketones when the blood glucose remains higher than 240 mg/dl for an extended period of time or DKA symptoms are present.
- Keep a blood or urine ketone test kit handy and read the package to learn how to check for ketones.
- Do a sample check when ketones are not present, in consultation with your diabetes care team, to make sure you understand the instructions.
- Check expiration dates on kits and discard expired strips.



It is a good idea to wear medical identification at all times to make sure caregivers and people around you are aware of your diabetes.

**Diabetic ketoacidosis (DKA) is a medical emergency and must be treated immediately. If your or your child's blood sugar is above 240 mg/dL and ketones are present in the blood, please contact a member of your diabetes healthcare team immediately for instructions on what to do or seek emergency care.**

## Processing News of a T1D Diagnosis

T1D's presence in a family often affects people's social, behavioral and emotional well-being, often known collectively as psychosocial health. We know, because many JDRF volunteers and staff are living with T1D. We've also conducted extensive research that has prepared us to lead the dialogue about identifying and addressing the psychosocial impact of this disease.

## How to Get Help

If you feel like you need help to cope with the mental and emotional challenges that come with T1D, don't hesitate to seek help. You or your child may need some extra support if you experience:

- ➔ **No motivation to check blood sugar or take insulin and it feels like you or your child's mental health is getting in the way of diabetes management.**
- ➔ **Trouble navigating relationships with family and friends.**
- ➔ **No desire to spend time with loved ones.**
- ➔ **No interest in pursuing hobbies or activities that were previously enjoyable.**
- ➔ **Constant feelings of being stressed out, overwhelmed, anxious, having trouble sleeping or changes in appetite.**



If you or your child is feeling this way, we want you to know that you are not alone. If you are unsure whether seeking help is the right option, talk with your family's healthcare team or visit the American Diabetes Association Mental Health Provider Directory at **[professional.diabetes.org/mhp\\_listing](https://professional.diabetes.org/mhp_listing)**.



# Life with T1D

## Explaining T1D to Family, Friends and Those Who Need to Know

T1D can be complicated to manage and when you're trying to explain it to someone else like a teacher, coach or family member, you may wonder where to start. On [jdrf.org/living-with-t1d](https://jdrf.org/living-with-t1d) you'll find all the information that you'll need when talking about T1D to others.

Additionally, *The Teaching Type 1 Diabetes to Others Guides by Beyond Type 1* available at [beyondtype1.org/understanding-type-1-diabetes](https://beyondtype1.org/understanding-type-1-diabetes) are great resources for newly diagnosed children and adults.



## For Parents

### Educating Caregivers

For children with T1D, educating caregivers and ensuring they have the necessary supplies (including low blood sugar treatments and glucagon) is critical to successful diabetes management. Meet with the individuals responsible for caring for your child and explain: how to check blood sugar, spot signs of high or low blood sugar and how to treat it, how to count carbs before meals and snacks and administer an insulin dose as well as how to administer glucagon in case of severe hypoglycemia. Communication is key, so reassure them that if they have questions or concerns you are just a phone call or text away.

### Going Back to School

Returning to school after a diagnosis of T1D requires paperwork, planning and perhaps multiple conversations with teachers, school nurses and sometimes other students about T1D and how it's managed at school. The good news is that with JDRF's help, you don't have to feel overwhelmed. Available resources include:

- **Back to School Checklist.**
- **A video explaining life with T1D to extended family, caregivers, teachers and fellow students.**
- **Tips for teachers on keeping their student with T1D safe and helping them succeed.**



For more information on these resources, as well as 504 plans (a legal written document specifying what modifications and accommodations the school must make for your child) and Diabetes Medical Management Plans (or doctor's orders) visit [jdrf.org/school](https://jdrf.org/school).

### Empowering Your Teen

It's only natural to want to ensure your teen is safe and empowered to make healthy decisions for themselves when they are away from you. Make diabetes management discussions with your teen a collaborative process. Hear out their concerns or objections and discuss solutions that help you reach common ground. For tips on handling conversations with your teen successfully (including driving), visit [jdrf.org/living-with-t1d](https://jdrf.org/living-with-t1d).

### Living Independently

If you have a young adult with T1D who lives away from home or on a college campus, discuss a plan for communicating their diabetes with their roommate, Resident Advisor (RA) and Dorm Director. For more resources on living independently, visit [jdrf.org/teens](https://jdrf.org/teens).

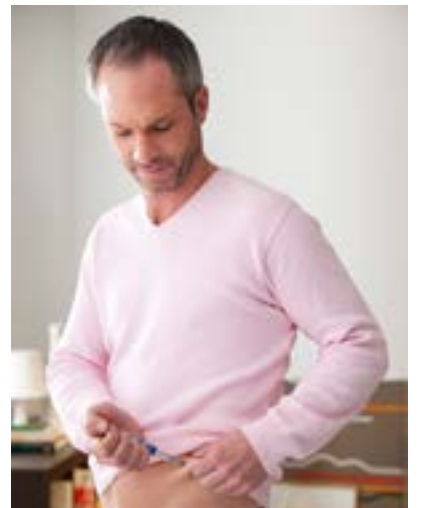
If your young adult attends college, encourage them to become familiar with disability services offered on the university's campus and discuss if they would like to register for accommodations. The College Diabetes Network (CDN) offers helpful resources that enable college students with T1D to have a safe and enjoyable college experience, and an opportunity to connect with other college students living with T1D. Learn more at [collegediabetesnetwork.org](https://collegediabetesnetwork.org).

## T1D Diagnosis as an Adult

As an adult with T1D, you are your number one health advocate. You'll have a lot to process and you'll need to make adjustments to your routine. You may want to create a diabetes management plan that allows you to have a system in place to aid in managing your diabetes no matter what new or stressful situations you encounter.

### The Workplace

Unless your diabetes could have safety implications for your colleagues or the general public (for example, if you drive public transportation or are a police officer), your medical information is confidential from your coworkers. It's your decision whether to talk about it or not. If you choose not to officially talk about your diabetes to your team or office, telling a trusted colleague is a good idea so there is someone at work who can respond if you experience severe hypoglycemia and need assistance. If you do share information about your diagnosis with your employer, they are required to take reasonable steps to accommodate your needs.



As you find your new normal, be sure to visit [jdrf.org](https://jdrf.org) for answers to questions on everything from dating with T1D, to driving safely to planning for a night out with friends.



## Exercise

People of all ages living with T1D can and should reap the benefits of exercise (whether playing a game of golf or tag) — it just may take a bit of planning. In addition to the benefits everyone gets from exercise, like improved heart health, positive impacts on the brain and enhanced muscle mass, people with T1D enjoy additional benefits like lowering blood sugar and improving their insulin sensitivity. So stay active and reap the benefits, but also keep an eye on your blood sugar which may rise or fall with different types of activities.

Visit [jdrf.org/exercise](https://jdrf.org/exercise) to learn how to incorporate exercise into your life and understand how blood sugar is affected by physical activity.



## Navigating Health Insurance

When you have health needs due to a chronic condition like T1D, having health insurance is critical in helping you manage and treat it. Visit [jdrf.org/insurance](https://jdrf.org/insurance) for JDRF's Health Insurance Guide to help you answer questions like:

- How do I choose a health plan and get help with my costs?
- My claim was denied, what do I do now?
- My employer is changing insurance plans, what are my options?

The guide also includes tips for advocating for your needs, sample letters and a glossary that breaks down complicated insurance terms in plain language.



## Clinical Trials

Clinical trials are research studies in humans to determine if possible medical treatments and technologies are safe and effective. Without clinical trials, new preventions and treatments would not be available. They are essential if we are to achieve success in finding better treatments for our T1D community. Currently, there are more than 300 clinical trials underway for people living with T1D and T1D-related complications. Participants may receive some, or all, of the following benefits:

- Access to new treatments and technologies that are not available to the wider public.
- Health care not covered by your insurance when enrolled in the clinical trial.
- A feeling of empowerment knowing your contribution to clinical research will help advance the development of medical treatments and technologies.

For more information visit [jdrf.org/clinical-trials](https://jdrf.org/clinical-trials).

## Connecting with the T1D Community

From the day of diagnosis to daily life decades later, we know that connecting with others who have been impacted by T1D makes a huge difference. We want you to know that JDRF is with you every step of the way, actively supporting and connecting people in the T1D community. Whether you're interested in finding a local chapter, in need of advice from someone who's been there, are looking to connect online or in search of educational tools to help you or your loved one manage the disease, we have the resources you need.

### Chapters

JDRF has chapters across the United States. Your nearest chapter serves as the hub of JDRF information and events in your area. To find support, community and ways to join the fight to end T1D, visit [jdrf.org/chapters](https://jdrf.org/chapters).

### T1D Connections Program

JDRF Outreach Volunteers have a personal connection to T1D. They are caregivers, spouses and other adults who either have T1D themselves, or have a loved one affected by the disease. Our volunteers understand how overwhelming it can be to adapt to the daily demands of managing T1D, and they are here to help get you through it. Visit [jdrf.org/t1d-connections](https://jdrf.org/t1d-connections) to request to be paired with an Outreach Volunteer.

*"When I found JDRF and was connected with parents who had been through what I had been through, it changed my life. I found my new normal, my source of hope — and strength — to face my son's disease. I wanted to become an Outreach Volunteer so that I could do that for others. I want to be someone's light through all that darkness."*

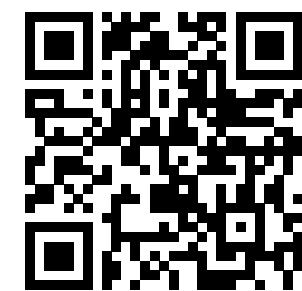
— Alexis Newell, whose son Justice was diagnosed at age 7

### TypeOneNation Summits | Educational Events

**The TypeOneNation Summit** is an all-day educational and networking opportunity for the T1D community hosted by JDRF chapters. The event features a research update, keynote address, and multiple workshops, as well as opportunities to meet other attendees to exchange ideas and participate in discussions important to you and your loved ones.

**TypeOneNation Educational Events** are shorter, topic-specific gatherings hosted periodically throughout the year by chapters. Featured content may focus on preparing to go back to school or learning more about the latest in diabetes technology.

Visit [jdrf.org/typeonenationsummit](https://jdrf.org/typeonenationsummit) for more information.





### Online T1D Volunteers

Staffed by compassionate volunteers from across the United States who know firsthand the ever-changing demands of living with T1D, this team uses its collective expertise to answer questions and provide support on a variety of T1D-related topics. Contact JDRF's online T1D volunteers with your questions at [jdrf.org/personal-support](https://jdrf.org/personal-support).

### Online Community Forum

TypeOneNation is JDRF's social network for people with T1D, their families and friends. The site is created for and powered by the T1D community. Members of this diverse community exchange information, answers and support. Anyone over 13 can sign up, connect with others and join the conversation. Learn more at [jdrf.org/community/typeonenation](https://jdrf.org/community/typeonenation).

### JDRF Social Channels

Connect with us on Instagram, Facebook and LinkedIn to stay up to date about what's new at JDRF, including the latest resources available online at [jdrf.org](https://jdrf.org) and updates from JDRF Advocacy and JDRF Research.

### Additional Resources

We hope you find the information in this guide useful and timely. We have more resources and in-depth information about T1D and how to navigate all ages and stages of your life with this disease online, including educational tools and printable resources.

Find the following and much more on [jdrf.org](https://jdrf.org):

- Videos on how to exercise safely with T1D.
- Information on insulin pumps, CGMs and other technology.
- An overview of the three trimesters of pregnancy for women with T1D.

Through our partnership with Beyond Type 1, we are pleased to offer these additional resources which you can find at [beyondtypeone.org](https://beyondtypeone.org):

**Safe Sitings** - a resource for families to search for a sitter who understands the details of T1D, and for sitters to post availability and search for families who are looking for knowledgeable sitters.

**Snail Mail Club** - a pen pal program for kids and teens (adults are welcome too) with T1D around the world. Sign up to be matched with a pen pal based on your unique interests.



# Make a Difference!

We know this isn't a journey you would have chosen to be on, but we're glad to be able to provide you with support as you find your way. We want you to know that there is not a more passionate and effective group of people when it comes to changing the world for people with T1D than the JDRF community. If you want to be part of creating a world without T1D, join us!

### Tell Your Story and Strengthen the T1D Community Voice

JDRF Advocates use the most powerful tools they have — their own personal stories — to communicate the financial, medical and emotional costs of T1D to our nation's leaders. We'd love to have you on our side! Use your voice to help secure federal funding for important diabetes research, inform health and regulatory policy, and improve the quality of life for those affected by T1D until we find cures. Sign-up today at [jdrf.org/advocacy](https://jdrf.org/advocacy).

### Turn Your Passion into Action

Join volunteers around the globe and make a profound difference for people with T1D. You can volunteer for events with your JDRF chapter, for a national program, through our online channels and more.

- **Ask friends and family to support your JDRF One Walk. More than 900,000 people participate in one of 200 One Walks each year.**
- **Celebrate progress toward a cure alongside generous community leaders at a JDRF Gala.**
- **Want to go the distance? JDRF Ride to Cure Diabetes challenges cyclists of all skills at several destination rides.**
- **Raise awareness about diabetes at your child's school. Give kids a chance to educate and empower their peers.**

Whatever your interests, there are no limits. Whether it's a marathon or a ride, a spaghetti dinner or a social media campaign, a tribute to a friend or trek across a mountain, JDRF provides fundraising tips and tools to create your own successful fundraiser to fuel our shared mission of cures for the T1D community.

Connect with your nearest chapter for information on their educational programs and fundraising events. Learn more at [jdrf.org/volunteer](https://jdrf.org/volunteer).



## **Disclaimer**

JDRF does not provide medical advice. Any content accessed through "Begin with Hope" is for informational purposes only and is not intended to be a substitute for professional medical advice.

JDRF's mission is to improve lives today and tomorrow by accelerating life-changing breakthroughs to cure, prevent and treat T1D and its complications. We also want to support you in living your best life with diabetes. As such, our content is intended to provide support and tips for living well with diabetes.

The information we provide is not intended to cover all possible uses, directions, precautions, drug interactions, or adverse effects. Please contact your doctor or other qualified health provider with any questions you may have regarding your diabetes or any medical condition.

Do not disregard professional medical advice because of something you have read on JDRF.org, any 3rd party site or any non-medical literature. If you think you may have a medical emergency, call your doctor or 911 immediately.

JDRF does not recommend or endorse any specific tests, providers, products, procedures, opinions, or other information that may be mentioned on our website or by one of our sponsors.

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