

Kids & Type 1 Diabetes

Although the disease is on the rise, doctors say it can be managed with care and discipline

By **SUSAN BLOOM**

For 9-year-old Ally Carman of Barnegat, it started with extreme thirst. “When she was 3, we noticed she was chugging water or juice before bed,” says her mother, Candice. “Then, she grew more lethargic and wanted to nap a lot.”

Rutherford High School sophomore Sarah Kirkpatrick, 16, recalls a similar experience when she was 12.

“I would drink three full bottles of water at lunch without even thinking about it,” she says. “I was playing basketball at school that year, so I just thought it was related to that.”

But there were other telltale signs.

“I generally didn’t feel well, lost 20 pounds and noticed the blackboard in class became very blurry, even though I sat right up front.”

After seeing a doctor, Kirkpatrick was sent to the emergency room, the same thing that happened to Ally Carman. The diagnosis in both cases: Type 1 diabetes.

“At the time, I’d never even heard of it,” says Candice Carman. “I thought it was something older or overweight people got. They stabilized Ally and I was okay until they told me they had a room for her in the ICU. Then I realized how dangerous this was.” Ally’s 8-year-old sister, Emma, was also diagnosed last fall.

Type 1 diabetes, which affects more than 250,000 young people in the United States, is increasing at an annual rate of about 3 percent and impacts one in every 300 to 400 children by age 18, according to Andrew Calabria, attending physician at the Children’s Hospital of Philadelphia and CHOP at Virtua in Voorhees.

“It’s one of the most common chronic diseases in childhood,” he says. “The majority of cases are diagnosed prior to age 18, with peaks usually between ages 4 to 6, and in early puberty between 10 and 14. Interestingly, we’re now seeing more and more children under 5 developing Type 1 — that’s where the biggest rise has been,” he says.

Why Type 1 is on the rise remains unknown, though theories range from susceptibility due to decreased exposure

to allergens (hygiene hypothesis) to changes in the environment that encourage kids to grow faster and gain more weight earlier (accelerator hypothesis).

“Type 1 patients have suffered an autoimmune insult on their pancreas which specifically targets the insulin-producing cells and results in a gradual process of insulin decline,” says Margarita Smotkin-Tangorra, pediatric endocrinologist at Jersey Shore University Medical Center in Neptune.

Patients with Type 2 diabetes, often associated with obesity, suffer from insulin resistance, which prevents the body from processing insulin effectively, leading to a build up of glucose.

Insulin is a protein hormone produced in the pancreas and secreted into the bloodstream that delivers glucose, the body’s main source of energy, to all cells in the body.

For Type 1 patients, for whom there’s a deficiency of insulin, glucose isn’t getting into the cells and builds up in the bloodstream, says Smotkin-Tangorra, precipitating the telltale signs of uncontrolled diabetes — thirst, frequent urination, lethargy, weight loss and

dehydration.

“The cells are essentially starving for glucose and the body begins to break down fat for energy, causing weight loss and potentially life-threatening diabetic ketoacidosis,” she says.

Once tests reveal high glucose levels in the bloodstream (the norm is 80 to 120 milligrams per deciliter), along with clinical symptoms for Type 1 diabetes, patients are rehydrated and started on an IV insulin drip.

“Once they’re stabilized, they begin receiving subcutaneous insulin injections in two different forms — long-acting, basal insulin, typically administered once a day, and short-acting bolus insulin, which needs to be administered whenever the patient eats carbohydrates or has hyperglycemia, anywhere from three to seven times a day,” Smotkin-Tangorra says.



At left, Emma Carman uses an insulin pump to help control her Type 1 diabetes. At right, pediatric endocrinologist Margarita Smotkin-Tangorra calibrates the device so that Emma can regulate their insulin while avoiding frequent injections.

While she recommends patients remain on daily injections for a brief time after diagnosis so they understand the mechanics of insulin delivery, “they can opt for an insulin pump, which can be programmed to deliver appropriate amounts of insulin through a catheter inserted under the skin,” she says. “It reduces the frequency of injections required and has been a wonderful addition to the arsenal of treatments for Type 1.”

While genes and family history can play a strong part in the development of Type 2 diabetes, this isn’t necessarily the case with Type 1.

“A patient has a 5 percent to 15 percent chance of having a relative with Type 1, which can make the diagnosis more of a shock for many parents and kids because no one else they know of in their family has it,” says Calabria with CHOP at Virtua.

“One of the first things I always say to families affected by Type 1 is that it’s nothing you or your child did wrong,” says Steven Ghanny, attending physician and pediatric endocrinologist at the Joseph M. Sanzari Children’s

Hospital at Hackensack University Medical Center.

“Parents often blame themselves, but Type 1 diabetes has nothing to do with what you did or didn’t give your kids to eat or drink, and no one is at fault. Still, diabetes is a serious condition and we discuss the gravity of it,” he says.

“It shouldn’t change the child’s life, but if it’s not managed properly, it could result in long-term complications in the form of kidney failure, vision problems, heart attacks, stroke and nerve damage in the extremities. Good care and a responsible, disciplined approach are critical.”

“It’s a difficult discussion with families at the beginning because it’s something that’s not going to go away,” Calabria says. “We also have to clarify the differences between Type 1 and Type 2 and dispel some misconceptions they have based on their experiences with other relatives. It helps to educate families right up front and surround them with a solid support network. It’s a complicated process, but it’s critical to establish a solid foundation and expand those building blocks over the

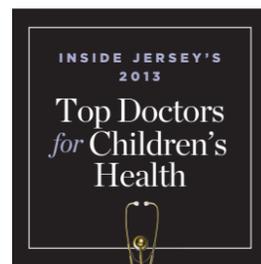
child’s lifetime.”

Sarah Kirkpatrick, whose older brother was found to have Type 1 Diabetes a year before her own diagnosis, was at least familiar with the disease.

“After watching my brother go through it, I kind of saw it coming. I wasn’t upset about my diagnosis, just sick of being sick,” she says. While she admits to being nervous the first time she had to give herself an injection, she ultimately got a pump and is open about her condition with her friends and teachers. She even participates in online support groups and helps other teens manage their diagnoses through a peer program at HackensackUMC.

“Feeling sorry for yourself won’t make it go away, and if you don’t stay on top of it, you’ll end up back where you started, in the emergency room,” she says. “Some days are tougher than others, but it becomes a lifestyle. Checking your blood sugar every day becomes routine, like brushing your teeth.”

“It becomes like breathing,” says 18-year-old Rutgers student Andrew Davis, who has been managing his



diabetes since he was 5 years old.

But when the Willingboro teen left home to become a Rutgers freshman, the lifestyle change landed him in the hospital in May when his blood sugar level jumped to more than 300 and he was unable to bring it down for nine hours.

"I lived in a nice bubble at home, with my parents always checking up on me," says Davis. "So, I'd never had this kind of pure responsibility all on me. It's been more tricky and a real learning experience."

College can indeed present a challenge for kids with Type 1 diabetes, which is a 24/7 condition, experts say.

"As kids get older, they become more independent and may feel it's not cool to have diabetes anymore or to stay on top of it as vigilantly as they once did," says Ghanny at HackensackUMC. "But the more compliant kids can be early on, the greater discipline and success they'll have as adults."

"Type 1 is a very manageable condition and kids can enjoy a happy, healthy and long life as long as they're providing for their body what it's unable to provide for itself," says Smotkin-Tangorra. Calabria strongly recommends that kids with Type 1 attend special diabetes camps, "where they can be themselves and make friends that they may keep for life. Diabetes can be a very isolating disease, but at camp everyone's checking their blood sugar and living with the same reality, so there's no stigma. It's amazing to see the confidence that many kids gain over time."

As for athletic and outgoing Ally Carman, she said, "Type 1 makes me feel unique," and though a little scared at first, she admits she's fine with it now. She even hopes to become a pediatric endocrinologist when she gets older "so I can help kids like me get through it because I know how they feel."

Davis, the Rutgers student, says that while he doesn't want the condition, it has helped shape

his personality. "It's made me fight back and push to be number one," he says. "I've learned you can't wallow in this disease. It keeps some people down, but it's propelled me forward and made me more outgoing and confident."

Kirkpatrick says that having Type 1 diabetes has "presented me with some amazing opportunities." Like Carman, she dreams of being a doctor one day.

"It's not the end of the world," she says. "It's manageable if you manage it." @

Possible Advances on the Way

Will there ever be a cure for Type 1 diabetes?

"Yes, but probably not in the immediate future," says Steven Ghanny, attending physician and pediatric endocrinologist at the Joseph M. Sanzari Children's Hospital at Hackensack University Medical Center.

Research and development efforts are primarily focused on treatment, such as developing an artificial pancreas that will use a continuous glucose monitoring system to read blood sugar measurements at multiple intervals and intelligently adjust the amounts of insulin administered through an integrated pump.

Other recent studies have centered on longer-acting insulin that can last 36 to 48 hours. This would lower the frequency of injections, according to Andrew Calabria, attending physician at the Children's Hospital of Philadelphia and CHOP at Virtua in Voorhees. Also, early intervention studies are attempting to extend the brief recovery or "honeymoon period" that patients often experience within 6 months to 2 years after diagnosis, he says.

Other high-tech procedures on the horizon are pancreas or islet cell transplantation and stem-cell therapy.

Either way, "Type 1 patients need to be in good health for when a cure becomes available," says Margarita Smotkin-Tangorra, pediatric endocrinologist at Jersey Shore University Medical Center in Neptune.

Adolescent Medicine

Barbara K. Snyder
Eating Disorders, Pediatric Gynecology
New Brunswick
(732) 235-7896
Robert Wood Johnson University Hospital - New Brunswick

Allergy & Immunology

Theodore Falk
Asthma, Immune Deficiency, Chronic Fatigue Syndrome, Pediatric Allergy & Immunology
River Edge
(201) 487-2900
Holy Name Medical Center, Englewood Hospital & Medical Center

David A. Fost
Asthma & Allergy-Pediatric
Sparta
(973) 726-8850
Clara Maass Medical Center, Hackensack University Medical Center-Mountainside

Patrick Perin
Allergy, Asthma, Pediatric Allergy & Immunology
Teaneck
(201) 836-6400
Holy Name Medical Center

Child & Adolescent Psychiatry

Jacqueline Bartlett
Stress Management, ADD/ADHD, Mood Disorders
Newark
(973) 972-2977
University Hospital-UMDNJ-Newark

Rosalie Greenberg
Bipolar/Mood Disorders, ADD/ADHD
Summit
(908) 598-0200
Overlook Medical Center

Lisa A. Kotler
Eating Disorders, ADD/ADHD, Depression, Anxiety Disorders
Hackensack
(201) 465-8111
NYU Langone Medical Center

Emile I. Pincus
Substance Abuse, Suicide
River Edge
(201) 615-1352
St. Clare's Hospital - Denville

Lawrence R. Shampain
Trauma Psychiatry, Anxiety Disorders
Metuchen
(732) 548-1600
Somerset Medical Center, University Behavioral Healthcare-Univ of Med/Dentistry of NJ

Child Neurology

Ronald Barabas
Pediatric Neurology, Developmental Disorders, Neurogenetics, Metabolic Disorders
Wall
(732) 556-0200
Monmouth Medical Center

Harvey S. Bennett
Concussion, Tourette's Syndrome, Cerebral Palsy
Morristown
(973) 971-5700
Morristown Medical Center, Overlook Medical Center

Trevor Desouza
Epilepsy
Sparta
(973) 993-8777
St. Clare's Hospital at Sussex, St. Clare's Hospital - Denville

Olga Goldfarb
Developmental Disorders, Neuromuscular Disorders
Voorhees
(856) 751-9339
Cooper University Hospital

Michael H. Goodman
Brain Injury, Concussion Management, Seizure Disorders
Camden
(856) 968-7965
Cooper University Hospital

Elliot A. Grossman
Migraine, ADD/ADHD, Tourette's Syndrome, Epilepsy
Florham Park
(973) 966-6333
Saint Barnabas Medical Center, Morristown Medical Center

Gary N. McAbee
Autism, Epilepsy, Headache
Edison
(732) 321-7010
JFK Medical Center - Edison

Jayoung Pak
Epilepsy/Seizure Disorders
Newark
(973) 972-2922
University Hospital-UMDNJ-Newark

Rolando Sousa
Epilepsy, Autism, Neurofibromatosis
Morristown
(973) 326-9000
NYU Langone Medical Center

Eveline C. Traeger
Autism, ADD/ADHD, Learning Disorders
Mountainside
(908) 233-3720
Children's Specialized Hospital

Jan B. Wollack
Epilepsy/Seizure Disorders
New Brunswick
(732) 235-7875
Robert Wood Johnson University Hospital - New Brunswick

Clinical Genetics

Rhonda E. Schnur
Medical Genetics, Dysmorphology, Genetic Skin Disease, Vision Disorders in Children
Camden
(856) 968-7255
Cooper University Hospital

Dermatology

Miriam Fishman
Pediatric Dermatology, Skin Cancer
Englewood
(201) 569-5678
Englewood Hospital & Medical Center

Warren R. Heymann
Dermatopathology, Pediatric Dermatology
Marlton
(856) 596-0111
Cooper University Hospital, Virtua West Jersey Hospital-Marlton

Steven M. Manders
Pediatric Dermatology, Cosmetic Dermatology, Dermatologic Surgery
Marlton
(856) 596-0111
Cooper University Hospital, Virtua West Jersey Hospital-Marlton