

Volume 2, 2020

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**Cohen Children's
Medical Center**
Northwell Health®

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Our patients, our inspiration



The coronavirus pandemic has compelled all of us at Cohen Children’s Medical Center to face up to unexpected challenges. But we consider ourselves fortunate because our patients inspire us. Walking into an exam room or patient room brings us face-to-face with hope and resilience during hardship.

For example, Violet Alexander is only five years old, but she brings a maturity and focus to her diabetes management that many adults strive for. Our diabetes specialists and educators devote their time to helping kids like Violet live normal lives with diabetes — not in spite of it.

Sam Lipskin went to the doctor for a simple teen complaint — acne — and walked away with a diagnosis of chronic autoimmune hepatitis.

Treatment got tough, but Sam didn’t give up, and neither did his clinicians and caregivers at Cohen Children’s. The team didn’t just tend to his liver, but they also focused on improving his overall quality of life.

And our pediatric hematology/oncology team brought all of their therapeutic tools to treat Max Berlin’s leukemia. That meant dozens of procedures and months in the hospital for Max, but “he never cried once,” his parents said. Max inspired his care team through years of treatment, which ultimately led to the bone marrow transplant that healed him.

Our patients’ strength makes us stronger. They motivate us every day, even in the toughest times. I hope their stories, plus other helpful information in the following pages, will do the same for you and your family.

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Get ready for some fall family fun

Feeling restless this fall? It's no wonder. Even though most kids are back in school at least part time, this season isn't very "normal."

But restrictions on some activities and altered schedules don't have to prevent new adventures this fall! Many autumn-friendly outings are available and offer physically distant, Covid-safe fun. Give one of these activities a go:



Pick produce

Fall is apple- and pumpkin-picking season. A few hours at an orchard or pumpkin patch make social distancing a snap. Take your haul home and bake a pie or carve jack-o-lanterns.

Leaf peep

In the Northeast, you don't have to travel far to see fantastic fall foliage. Hop in the car and head to the Hudson Valley for some spectacular colors. Pack a picnic and stop in one of the many parks in the area to enjoy some fresh air and sunshine.



Take a hike

Take advantage of crisp weather to get in some final family hikes before winter sets in.

Wave to the animals

Zoos and aquariums are now open in New York. All follow social-distancing rules, and many exhibits are completely outside. Autumn's cooler months make strolling around more comfortable. Just check in advance if you will need timed tickets.



Make your own fall festival

Don't let canceled fall fairs and festivals get you down — try a smaller version with your family out in the yard or a nearby park. Make a scarecrow from old clothes, have a pumpkin painting competition or put some field day activities together, and then top it all off with some festive treats.





Living and learning with diabetes

Violet's Type 1 diabetes diagnosis was overwhelming at first, but she and her family are now thriving with support and know-how

When then-four-year-old Violet Alexander wet the bed one night last fall, her mother's heart sank. Stephanie Castro wasn't worried about a potty training regression. Her concerns were more serious. "Violet's half-brother has Type 1 diabetes," she explained. "I was always on alert for signs that Violet would develop it too, so that one bedwetting incident was a big red flag."

Violet's pediatrician wasn't concerned at first. But after more nighttime accidents, Violet had a blood glucose test during her five-year wellness check last November.

"It confirmed diabetes," said Ms. Castro. "Very early, but that was it. Everyone was pretty shocked because she had no other symptoms."

Constantly adapting

Additional testing at Cohen Children's Medical Center confirmed the diagnosis. Then came a whirlwind week of diabetes education for Violet and her mom. The nurses and nutritionists on the Cohen Children's diabetes education team provided blood sugar control strategies — small lifestyle changes to incorporate at home that were almost second nature.

Ms. Castro, who always kept an eye on Violet's half-brother's Type 1 diabetes, watched portion control and provided water as the only beverage at home. Still, testing Violet's blood glucose and constantly adjusting her insulin dose was stressful.

"In the beginning, I paid attention to those numbers like they were a test grade. If her numbers weren't good, I felt like I was failing or doing something wrong," she said.

The care team at Cohen Children's and parents Ms. Castro met at a support group quickly told her she wasn't failing. "I learned it's an art as much as a science," Ms. Castro said. "We're constantly adapting to what her body does. It's not wrong. It's not good. It's not bad. It's more like, let's move forward and see how we can fix it."

Let kids be kids

Flexibility is key to managing kids with Type 1 diabetes, said Paula Kreitzer, MD, Violet's endocrinologist. "We want children to lead normal lives. And on a normal basis, none of us eat exactly the same thing at the same time every day. So we try to tailor diabetes management to the patient's life so eating patterns and activity are age appropriate."

In practice, this means that Violet can eat what other kids eat. Ms. Castro just needs to know about anything unusual so she can adjust Violet's food intake and sugar levels with insulin. If she wants cake at a birthday party, she can have it. If she wants Chinese food, that's okay too. As they continue on this journey together, Violet and her mother are learning how different foods affect her and how to deal with them.

"It's a never-ending cycle of learning and reacting to changes," said Ms. Castro. "If she's stressed out, her blood sugar is affected. If she's sick, her blood sugar is affected. There's just never a perfect plan that will last forever. And that's okay. I have the tools I need to keep her healthy."

New rules for kids with Type 1 diabetes

Decades ago, care for children with Type 1 diabetes meant a lot of rules. Kids were told to eat specific combinations of carbohydrates and proteins at certain times of day. Blood glucose testing happened on a set schedule, and the goal was tight control of sugars.

That has changed recently, said Dr. Kreitzer. “Diabetes is very different from many other chronic illnesses, because the management is ongoing, all day every day. So there are constant decisions to make, and that is up to the family.”

The family of every child diagnosed with Type 1 receives extensive education at Cohen Children’s. Nurses and nutritionists, who are trained as diabetes educators, teach families the ins and outs of monitoring blood sugar, how to calculate insulin dosages and healthy eating tips for the whole family.

Education doesn’t stop after the family goes home — it develops with each child. For example, a diagnosis at age five may require learning how to recognize low blood sugar and to tell their parents whenever they eat something. As that child grows, they gradually learn to give themselves injections or operate their pump. “Then we get to the point when they’re 17 or 18 and going to college,” said Dr. Kreitzer. “So what we teach really has to change along with the needs of the patient. It’s a lifelong education process, and we’re here for them the whole way.”



We’re ranked among the nation’s top hospitals for superior pediatric endocrinology care by *US News & World Report*. To learn more or make an appointment, call **(516) 636-7202**.



“He never cried once”

Multiple rare diagnoses couldn't bring Max down

March 2014 was the start of a long and sometimes scary journey for then-seven-year-old Max Berlin. First, one side of his face was suddenly weak and droopy, a condition called Bell's Palsy that can come on suddenly. His pediatrician said it was likely viral and prescribed steroids. A few days later, Max developed “a huge lump, the size of a softball,” on the back of his neck, said his parents, Abbie and Nils Berlin. Still, several doctors diagnosed a viral infection and said it would go away.

It didn't. After several weeks of feeling unwell ("He looked like hell," the Berlins recalled), the family took him to the local emergency department, where doctors discovered a mass in Max's chest.

"We decided immediately to transfer him to Cohen Children's Medical Center," said Mr. Berlin.

A tough battle

At Cohen Children's, Max was diagnosed with leukemia and began an intense treatment journey. At first, he spent about three weeks in the intensive care unit and on the oncology floor. Then, for the next nine months, he endured rounds of chemotherapy and radiation therapy. With support from extended family and friends, Mr. and Mrs. Berlin switched off in 24-hour shifts so one of them was always in the hospital with Max and one was always at home with his then-six-year-old brother, Jake, and their dog, Daisy.

Despite treatment, Max's leukemia relapsed three times. At one point, he even temporarily lost sight in one eye during a relapse. After the third relapse, doctors told the Berlins that Max's best chance at complete remission was a bone marrow transplant. Back at Cohen Children's, he was cared for by the bone marrow transplant team and pediatric hematologists Joel Brochstein, MD, and Indira Sahdev, MD. No one in Max's family was a bone marrow match, but he got lucky with an unrelated donor from Germany.

The transplant required 37 additional days in the hospital and more grueling treatments. "I tell people all the time that I don't know of a person alive or dead who's had more done to them than Max," said his father. "Well over 10 kinds of surgical procedures, over a dozen spinal taps and bone marrow biopsies, chemotherapy, radiation therapy, and an actual bone marrow transplant. And he never cried once."



The risk paid off, and the bone marrow transplant worked. Max's parents were told that if he relapsed within the first two to three months, it would most likely be fatal, so when Max got sick a few months after his transplant, everyone was nervous.

Not over yet

But it wasn't a relapse. Instead, and remarkably, Max was diagnosed with a condition even more rare than leukemia. As a complication of cancer treatment, he has hemolytic uremic syndrome (HUS), a condition in which damaged blood vessels in the kidneys cause blood clots. Untreated, HUS can lead to kidney failure.

Max ended up back at Cohen Children's for 36 more days, this time in the nephrology department, where he received dialysis and blood transfusions. Max's doctors also found the right medications to control his HUS.

Today, Max is looking forward to starting high school. In the fall he will celebrate six years cancer-free. He's a high honor roll student who plays basketball, tennis and flag football. "He's always been a kid who could make everyone around him laugh and smile, even during the hardest times," said his mother. "He's still that way, and for that we thank everyone who cared for him and helped us beat the odds."

Blood disorders and cancer in children

Just a few years ago, chemotherapy, radiation therapy and bone marrow transplants were among the only options for kids like Max. But advances in technology have led to a number of groundbreaking options for blood cancers and disorders, said Dr. Brochstein.

"Today we can offer bone marrow transplantation to just about every

patient who needs one, regardless of whether or not they have a perfectly matched donor. We're also pursuing immunotherapy treatments for leukemia and gene therapy for other blood disorders."

Those treatments include:

Haploidentical bone marrow transplantation: This "half matched" transplant usually comes from a patient's parent. Unlike traditional bone marrow transplantation, which requires that the donor be a perfect match for the recipient, a haploidentical transplant works just as effectively with only a 50 percent match.

CAR-T cell immunotherapy: Chimeric antigen receptor T cells (CAR-T cells) utilize the patient's own immune cells that have been genetically engineered to recognize and eliminate the patient's leukemia cells. This therapy recently received FDA approval to treat the most

common form of leukemia in kids if a relapse occurs.

Gene therapy: Cohen Children's doctors, in collaboration with biotechnology company bluebird bio, recently inserted a normal hemoglobin gene into the bone marrow stem cells of a patient with sickle cell anemia (Sickle cell disease causes abnormal hemoglobin and distorts the shape of red blood cells, leading to frequent episodes of severe pain throughout the body). The patient is now showing signs of making normal hemoglobin for the first time in his life and remains free of any symptoms of his underlying condition.

"We've come a long way since Max's transplant," says Dr. Brochstein. "We have a lot of treatment options for kids with these diseases at Cohen Children's. It's very exciting."




We're ranked among the nation's top hospitals for pediatric hematology/oncology. To learn more or make an appointment, call (917) 472-9779.

Nils and Abbie Berlin with their sons, Jake and Max.







Clearing up a medical mystery

Sam just wanted his skin to clear up, but he ended up on an unexpected path

Acne is a familiar woe for many tweens and teens. In 2017, Sam Lipskin of Melville, then 13, had his turn with skin troubles.

When the usual home remedies didn't help, Sam's mother, Lesley, took him to a dermatologist, who suggested the acne-clearing prescription medication Accutane. Because the medicine is processed through the liver, dermatologists make sure patients aren't at risk. Sam soon underwent liver enzyme testing to confirm that Accutane would be safe for him.

"A few days later, I got a call from the dermatologist, who asked if Sam was drinking heavily," said Ms. Lipskin. "His liver enzymes were so high that they looked like someone who has cirrhosis."

A bigger problem...and a solution

The Lipskins' search for answers brought them to Cohen Children's Medical Center's new Pediatric Liver Disease Section and its head, Shari Sheflin-Findling, DO.

"I immediately felt good about Dr. Sheflin-Findling," said Ms. Lipskin. "I knew we were in good hands and she would figure out what was going on with Sam."

Dr. Sheflin-Findling suspected that Sam had autoimmune (AI) hepatitis, a chronic condition that causes the body to attack the liver. She ordered a liver biopsy, and the results confirmed the diagnosis. Patients like Sam can go undiagnosed for years because early

symptoms of AI hepatitis are vague and subtle. Untreated, it can cause serious complications, including cirrhosis.

Sam immediately started a three-month course of steroids to control the inflammation in his liver. The treatment is not easy, especially for a teen who didn't even feel sick. High-dose steroids cause weight gain and other side effects.

Autoimmune (AI) hepatitis in children and teens

AI hepatitis happens when the liver becomes inflamed as the body's immune system attacks liver cells. Girls and young women are more likely to develop the condition, but as Sam's story shows, boys are also affected.

Many symptoms of AI hepatitis can be mistaken for other conditions and may go unnoticed. They include:

- Fatigue
- Aching joints
- Nausea and abdominal discomfort
- Itching
- Jaundice (a yellowing of the skin)
- Spider angiomas (swollen blood vessels just beneath the skin surface that look like a spider's web)

Whole-person care

Ms. Lipskin and her husband, Danny, appreciate how Dr. Sheflin-Findling helped their son physically and emotionally throughout his course of high-dose steroids.

"She is so nurturing," said Ms. Lipskin. "She wanted to fix Sam's liver, but she also wanted to fix his spirit."

Sam responded well to treatment. After a few months, his liver function recovered enough so that



Cohen Children's Medical Center's Liver Disease program is part of our extraordinary pediatric gastroenterology program, recognized by *US News & World Report*. Learn more or make an appointment: **(516) 712-2268**.

Dr. Sheflin-Findling recommended working with a dermatologist to start him on Accutane.

Today, Sam is a "typical high school junior, living his best life. A normal life," said Ms. Lipskin. He plays soccer, basketball and flag football. The side effects are long gone. Dr. Sheflin-Findling prescribed immunosuppressive drugs that Sam will take until he turns 18, and hopes that he won't need treatment at all after that.

"I forget that there's anything wrong with me," Sam said. "I feel completely fine. I am so glad we have Dr. Sheflin-Findling."

Although there's no known cure for AI hepatitis, physicians can control it with medications that suppress the immune reaction. Kids with AI hepatitis will have to manage the condition for the rest of their lives, so it's important to find an expert care team from the start, said Dr. Sheflin-Findling.

"You want a specialist — a pediatric hepatologist," she said, adding that a comprehensive program like the one at Cohen Children's allows the care team to collaborate with other specialists to manage side effects or other potential conditions. "Working as a team, we manage whatever the disease throws at your child."



The Cohen Foundation's most recent gift benefited staff members and patients of Cohen Children's Medical Center and Long Island Jewish Medical Center.

Cohen Foundation supports Covid-19 clinicians and patients

Longtime supporters, Steven and Alexandra Cohen helped those in the fight against the coronavirus

During the emergence and surge of Covid-19, we were heartened to witness the expression of humanity at its best and the steadfast support of Northwell Health partners such as Steven and Alexandra Cohen.

Mr. and Ms. Cohen have a long tradition of philanthropy and are the benefactors that Cohen Children's Medical Center is named for. The Steven and Alexandra Cohen Foundation recently stepped up to support not only frontline Covid

caregivers, but also many families who couldn't be with loved ones recuperating at Northwell hospitals.

"Steven and Alexandra Cohen were among the very first to support our frontline caregivers at the start of this health care crisis," said Michael Dowling, the health system's president and CEO. "We're extraordinarily grateful that the Cohens helped us give back to these critical teams when they needed it most."

The Cohen Foundation purchased meals for a week for all staff at Cohen Children's Medical Center and Long Island Jewish Medical Center — 8,000 meals in all. The Cohen Foundation's gift also included 30 iPads for the hospitals' patient experience teams, which they used to help keep patients connected with loved ones.

"As someone with the dual experiences of being an ICU intensivist and also being hospitalized with Covid-19 pneumonia, I know firsthand the tremendous toll this virus takes on our sickest patients and their families," said Charles Schleien, MD, executive director of Cohen Children's Medical Center. "The Steven and Alexandra Cohen Foundation facilitated the purchase of crucial technology to help these patients remain connected to their loved ones, giving them tremendous hope while they battled the virus. I am indebted to Steve and Alex for their generosity."



Little kids, little masks

Teens and children over the age of two should wear a face covering to prevent the spread of Covid-19 — just like adults. The American Academy of Pediatrics (AAP) recommends that all children over two wear masks when they can't be at least six feet from others — including at school or daycare. Even very young children can learn basic infection-control skills like mask use and proper hand-washing. Babies and toddlers under age two should not wear or sleep in masks because they pose a suffocation risk.

Here's how to encourage your kids over age two to mask up for safety:

Practice

Start slowly at home, having your child wear a mask for short periods of time while doing things they enjoy (watching TV, playing a game). Then take short trips to places where masks are required. Work up to wearing the mask more often.

Make it fun

Does your kid love superheroes? Unicorns? Find masks in patterns or colors they're drawn to. They're more likely to wear something they choose.

Make it fit

The AAP recommends masks made of multiple layers of cloth, without vents. Put one on by first placing it over your child's nose and mouth, then securing it around the ears. It should fit snugly, without gaps. You may need to try a few different child-sized masks to find the right fit. Always remove a mask from behind; don't grab it from the front.

Be a model

When kids see their parents and other trusted adults wearing masks appropriately, they're more likely to follow. Make a point of talking about masks, too ("We're going in the store! Time to put on our masks!") and wear yours properly.

Keep it clean

Wash cloth masks after every wearing. They can be machine- or hand-washed and hung to dry. Have several for each family member.

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Kids First is published by Northwell Health Public Relations. The information herein is intended to educate readers about subjects pertinent to their health and is not meant as a substitute for consultation with a personal physician. Produced by **Onward Publishing, Inc.**, Port Jefferson, NY 11777, (631) 757-8300. Printed in the USA.

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- Huntington Hospital
- Lenox Hill Hospital
- Long Island Jewish (LIJ) Forest Hills
- LIJ Medical Center
- LIJ Valley Stream
- Mather Hospital
- North Shore University Hospital
- Northern Westchester Hospital
- Peconic Bay Medical Center
- Phelps Hospital
- Plainview Hospital
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- Southside Hospital
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- Nassau University Medical Center
- Western Connecticut Health Network

Do your kids need an outlet? Look outside.

Science and medicine agree: Kids don't get enough physical activity. Most don't come close to the 60 minutes of daily exercise recommended by the American Academy of Pediatrics. And with sports and activities canceled due to Covid-19, many families are struggling to keep kids moving.



Nature to the rescue! Stepping into the great outdoors (which could be as modest as your own back yard) for exercise and entertainment is a better idea now than it ever was. Plus research shows that kids who engage with nature tend to be less anxious and more creative. They also do better in school and have more confidence.

Even if you don't think of your family as "outdoorsy," there are easy ways to get kids out in nature and reaping the benefits:

1. Take a hike or a walk in an open space, park or on the beach. While you're there, keep an eye out for bugs, birds or plants you've never seen before. To add to the fun,

you can download Seek, a free phone app that uses your camera to identify animals, bugs and plants while you earn badges for what you discover.

2. Plan a scavenger hunt, giving kids age-appropriate items to find and collect (like rocks or leaves) or to check off a list (a yellow house, a person with a dog).

You'll get exercise and encourage kids to focus and learn new things.

3. Plant a garden in a sunny window or backyard. Autumn is the perfect time to plant carrots, bok choy, peas, lettuce, garlic or scallions. Weeding and planting is great exercise and teaches kids about life cycles.

4. Encourage kids to play with what they find right outside — building things out of sticks, making sculptures from rocks and leaves, or drawing in the dirt or sand gets them moving to find materials and encourages creativity.

Visit [kohlshealthykidsny.com](https://www.kohlshealthykidsny.com) for kid-friendly, healthy recipes and activities.

