Say hello again to Hollie…

We met Hollie in our last Child Watch story. She told us a compelling story about her work as a diabetes navigator in southeast Ohio where she meets with families and children to help educate them on how to successfully manage their diabetes.

But her work as a diabetes navigator is only half of her story. One reason Hollie is so passionate about her work is because she has a 20-year-old son affected by this chronic disease, which is also expensive to manage.

Diabetes is a chronic disease in which the body does not properly break down food for energy. Most of the food we eat is broken down into sugar, or glucose, for the body to use as energy. When a person has diabetes, the body’s pancreas either physically cannot produce insulin (as in Type 1 diabetes) or it cannot use insulin as well as it should (as in Type 2). When the pancreas is not working properly, insulin cannot be utilized to get glucose into the cells of the body, and this causes a buildup of glucose that leads to a high blood sugar.

When diabetes is not managed properly, it can cause complications such as blindness, kidney failure, heart disease, nerve damage, and loss of toes, feet and even legs. Diabetes can be controlled by working with a healthcare professional to keep blood glucose levels within a normal range and by practicing healthy habits like eating well and being physically active.

When diabetes develops in children or young adults, it is known as juvenile onset diabetes. Diabetes diagnosed in children or adolescents is most often Type 1 diabetes. There is no known way to prevent Type 1 diabetes, but the disease can be managed through daily insulin injections, blood glucose monitoring, healthy eating, and adequate exercise.

Diabetes is growing at an epidemic rate in the United States. According to the National Diabetes Statistics Report 2020, in 2018, 210,000 children and adolescents younger than age 20 years had been diagnosed with diabetes. This includes 187,000 with Type 1 diabetes. The Centers for Disease Control have found that diabetes is more common in Appalachia than in the nation as a whole. According to A Summary of the Regional Diabetes Needs Assessment Study published in 2017 by the Diabetes Institute
at Ohio University, in Athens and the seven surrounding counties, nearly 1 in 5 adults had been diagnosed with Type 1 or Type 2 diabetes. This area includes all six of the counties Hollie covers as a diabetes navigator. Diabetes also has a significant financial impact on the Ohio Medicaid program. Nearly $76 million was spent on diabetes-related hospital admissions and emergency department visits for Medicaid beneficiaries in 2015.

The Regional Diabetes Needs Assessment Study also highlighted that social determinants of health such as income, education levels, housing, food insecurity, transportation, and a shortage of diabetes specialists in the region present challenges to people who suffer from diabetes. Of the people interviewed for the study, 41% reported delaying care for their diabetes because they lacked transportation to get to their appointment.

For Hollie and her son, the COVID-19 pandemic has added another layer of struggle on top of what is already a daily battle with an expensive and devastating disease. As a result of COVID-19, Hollie’s husband was furloughed from his job and lost his health coverage which also provided health coverage for their son. For many of the more than one million families in Ohio who experienced job loss because of the pandemic, the loss of their health insurance was another major blow, but when you or a member of your family suffer from a chronic disease that requires lifesaving medication, the loss of insurance is terrifying.

Hollie’s son’s diabetes medication costs $7,000 a month. Due to the cost of her son’s medication, Hollie immediately attempted to enroll her son in Medicaid. She uploaded all of the requested documentation into the system but continued to receive letters requesting the same documentation she already submitted. She attempted to contact someone at the county JFS office five times in two weeks, but was not able to speak to a live person or get a return call, and she was not able to go into the JFS office due to the COVID shutdown and state stay-at-home order. This is a perfect example of the public health emergency highlighting weaknesses in our social services system and by no means an isolated incident.

Beyond the COVID crisis, Hollie has seen parents challenged in trying to secure the medication and testing strips needed by their children to manage their diabetes – a need that could be eased if Ohio adopted more flexible eligibility procedures and higher income guidelines for children. Families with health insurance are not eligible for CHIP Medicaid if their income exceeds 156% of the federal poverty level (FPL), or $33,888 for a family of three. Raising the Medicaid eligibility to 200% of FPL would allow more children to qualify for critical healthcare coverage.

Encouraging more pharmacists to participate in making presumptive eligibility decisions is another flexibility that could make a difference to families struggling to pay for life-saving medications like insulin. When Medicaid eligibility determinations get bogged down and lag behind, and insulin (that can cost over $1,000 for a 30-day supply) is needed, a child with juvenile diabetes runs the risk of going without medication while the Medicaid application is processed. This is particularly problematic at a time like the present when demand is heavy on the system. A pharmacist could quickly apply presumptive eligibility to the patient and ensure the child goes home with the needed medication.
Hollie also wanted to highlight that there are additional resources out there to help families who have children with chronic conditions such as the Bureau of Children with Medical Handicaps, a health care program in the Ohio Department of Health (ODH), that links families of children with special health care needs to a network of quality providers and helps families obtain payment for the services their children need.

Diabetes is a chronic disease that affects thousands of children around Ohio. Many of these children depend on Medicaid for the healthcare and medication that keeps them alive, healthy and allows them to thrive. Children’s Defense Fund-Ohio has the following recommendations to help families like Hollie’s.

CDF- Ohio Recommends:

- **Provide inclusive educational opportunities tailored to youth as it is a critical component of a child diabetes management program.** Education materials should be culturally sensitive and geared toward local communities. Using the lens of health equity, education efforts must recognize the unique challenges different populations face trying to attain their best health. These challenges may include social, economic, and environmental disadvantages of where individuals live, learn, work and play.

- **Allow providers to bill for recognizing and mitigating social determinants of health.** This would allow providers to be more proactive in documenting issues and referring patients to services and resources to help with things like food and housing insecurity, employment, healthcare coverage, lack of transportation, and access to affordable utilities.

- **Mandate stricter standards of care that Medicaid managed care organizations are required to meet to improve child outcomes.** According to the **2019 Ohio Department of Medicaid Annual Report**, only 52 percent of Ohio children get their Healthcheks completed, and only 60 percent of Medicaid enrolled children have had a blood test reported. Ohio is below the 50th percentile in managing diabetes and below the national 25th percentile for Comprehensive Diabetes Care—HbA1c Poor Control. Medicaid managed care organizations are responsible for the health of the members they cover and they should be held accountable for poor health outcomes.

- **Fund greater broadband connectivity in underserved areas.** HB 13 and HB 190 are positive steps in this effort. Greater connectivity would allow the region to realize the full potential that telehealth offers in healthcare shortage areas, and mitigate the problem of missed appointments due to lack of transportation.

- **Increase CHIP eligibility to 200% of the Federal Poverty Line (FPL).** This would allow more children to qualify for critical healthcare coverage.

Children’s Defense Fund-Ohio thanks the individuals, families, and health practitioners who have shared their stories for the Child Watch Ohio series and the funders of the Ohio Finish Line project for their support. For more information, please contact Kelly Vyzral, Senior Health Policy Associate at kvyzral@childrensdefense.org.