

About the Division

The Division of Pediatric Endocrinology, Diabetes, and Metabolism at UPMC Children's Hospital of Pittsburgh provides diagnostic and therapeutic services for children with diabetes mellitus, hypoglycemia, and disorders of physical growth, sexual maturation, thyroid function, pituitary function, and calcium and phosphorous metabolism, as well as other gender disorders. Patients are evaluated in collaboration with multidisciplinary teams to come to a unifying diagnosis and provide the best outcomes for patients and families.

For a referral or consultation, please contact us at 412-692-5170. Visit us online at CHP.edu/diabetes.

Clinical Innovation: Improving Outcomes in Children With Type 1 Diabetes

The Division of Pediatric Endocrinology, Diabetes, and Metabolism at UPMC Children's Hospital of Pittsburgh follows more than 2,000 children and youth with type 1 diabetes (T1D). Between 250 and 300 new cases are diagnosed every year.

These children and their families face numerous challenges that compromise adherence to treatment and their well-being. In 2018, the Division received funding for and began the process of implementation of a new pilot program to improve diabetes management and outcomes in high-risk children and adolescents who have T1D.

Dubbed the "Adapted Wraparound to Improve Type 1 Diabetes Management in Youth," this pilot project is designed to test the adaptation of an evidence-based High Fidelity Wraparound (HFW) process initially developed and used in the behavioral health community to teach and empower patients and families to better self-manage their behavioral health conditions through a comprehensive, holistic, patient-centric approach.

UPMC Children's is partnering with the Youth and Family Training Institute (YFTI) at UPMC Western Psychiatric Hospital to adapt and refine its HFW, developed for its behavioral health patients, for use in children and youth with T1D followed at UPMC Children's Hospital.

The pilot project is co-directed by Ingrid Libman, MD, PhD, associate professor in the Division of Pediatric Endocrinology, Diabetes, and Metabolism and Justin W. Schreiber, DO, assistant professor of psychiatry and pediatrics in the Department of Psychiatry at the University of Pittsburgh School of Medicine. The HFW team also includes Amy Nevin, MD, who serves as a

coach/supervisor helping to coordinate the project and oversee compliance with HFW processes in collaboration with Lauren Jones and her team from YFTI; facilitators who will work directly with families to develop individualized management plans; and youth with T1D and family peer support partners who can provide support, assistance, and mentorship to the entire family unit.

The management of T1D in children and adolescents continues to prove to be challenging for patients, families, and the providers who treat them. The reasons for this are well documented in the literature and are multifactorial, but stress and associated behavioral health issues are significant contributors to struggles with adherence and poor control. The implications of having diabetes extend far beyond the individual and the family, and they also extend well beyond good glucose control. In essence, T1D is a community disease for young patients and their families. Schools must become involved and understand the needs of the individual. Essentially anywhere the child spends time must be equipped to understand and deal with the needs of managing the condition.

"Given that only about 21 percent of children and adolescents meet the American Diabetes Association (ADA) guidelines for HbA1c targets, and given that short- and long-term complications are associated with suboptimal control, it is clear

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that new models of care are critical to empowering youth and families to improve adherence, self-confidence, quality of life, and ultimately outcomes,” says Dr. Libman.

Psychosocial Aspects of T1D

Depression and anxiety are commonly associated with having T1D. The effects of these comorbidities derive from, and at the same time exacerbate, poor management in a kind of negative feedback loop.

“Depression and anxiety make it hard for children and families to control their diabetes, and these comorbidities make it difficult to engage in activities of daily living. In most of the current models of diabetes care, the psychosocial aspects are pushed to the periphery. Many times individuals and families who need this kind of support the most can struggle to find it. Our model places special emphasis on managing this aspect of diabetes with the peer support staff being the primary foundation,” says Dr. Schreiber.

Pilot Project Details

The UPMC Children’s T1D HFW project is a two-year pilot that targets the intervention at youth between the ages of 12 and 15 years who have been diagnosed with T1D for at least two years. These youth also will have had a more than two-point change in their HbA1c levels during a six-month period, or two or more hospital admissions during a year related to their underlying diabetes.

“Our goal is to enroll 20 to 25 children and families in the pilot project during the first year and continuously monitor and collect data in a rigorous and standardized way throughout the intervention. This preliminary data, if we are successful in our efforts, will support the development of a much larger clinical trial in the future,” says Dr. Libman.

The process of enrollment will begin with the initial step of a comprehensive family evaluation to assess their needs for all aspects of care — medical, social, behavioral, financial, and the like — and where the challenges or barriers to successful management may lie.

“T1D is a highly heterogeneous disease requiring individualized plans of care that extend into virtually every area of a patient’s life. I do not think you can create a program or protocol for managing this condition that treats everyone in a similar manner. Diabetes is a pervasive disease, but its pervasiveness is highly variable,” says Dr. Schreiber.

Project Progress and Upcoming Milestones

The advisory board for the T1D HFW pilot has been established and consists of a multidisciplinary group of clinicians from UPMC Children’s and UPMC Western Psychiatric Hospital, along with patients with T1D, family members and members of community organizations essential in T1D management, such as insurers, primary care providers, and support agencies.

The implementation team currently is adapting the behavioral health HFW model for application to youth with T1D. At the same time, they are creating the necessary support, educational, and training materials that will be used by team members and enrolled patients.

This phase of the project will be completed by spring 2019, at which time patient and family enrollment into the pilot project will commence.

While the goal of this program is to address a high-risk population of patients with T1D to improve outcomes, reduce disease burdens, and limit adverse health-related events, the bigger picture speaks to how the program may be able to empower and train children and adolescents to successfully manage their condition as they transition into becoming independent adults responsible for their own decisions and health care needs. Instilling the behaviors and support networks that will be needed for successful T1D management early in life should allow more individuals to carry forward their successes into adulthood.

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CME Courses, News, and Events for Physicians

Visit UPMCPhysicianResources.com/Pediatrics for the latest CME courses, news, and upcoming events available for physicians from UPMC Children’s Hospital of Pittsburgh.

Current CME Courses in Endocrinology include:

Polycystic Ovary Syndrome

Presented by Kara Hughan, MD

Dr. Hughan gives a presentation on identifying the diagnostic criteria for PCOS and the risk factors for cardiometabolic disturbance that women face.

The Drive for Quality Diabetes Care and Outcomes

Presented by Linda Siminerio, RN, CDE, PhD

Dr. Siminerio gives a presentation on the key elements of the quality of diabetes care and the importance of self-management.

Center of Excellence for Pediatric Thyroid Disease

Presented by Pushpa Viswanathan, MD

Dr. Viswanathan provides an update on pediatric thyroid cancer, reviews the ATA pediatric guidelines on the management of thyroid nodules and differentiated thyroid cancers in children, and shares the collaborative efforts and multidisciplinary approaches to the care of children with pediatric thyroid diseases.

Video Rounds

Clinical Approach to Treating Disorders of Sex Development

Selma Witchel, MD

New Initiative to Improve Dietary Education for Diabetes Patients

In November 2018, members of the Division of Pediatric Endocrinology, Diabetes, and Metabolism were awarded a grant from the Children's Trust of the Children's Hospital of Pittsburgh Foundation to develop and implement a pop-up Teaching Kitchen initiative to create dietary education and support for patients and families with diabetes and other chronic conditions for which dietary control and education are critical to establishing long-term positive outcomes.

Dorothy Becker, MD, Christine March, MD, and **John Weidinger, PA-C,** all members of the Division who have a focus on diabetes treatment, were awarded a \$15,000 grant to procure a pop-up, portable Teaching Kitchen and develop curricula for its use. The pop-up Teaching Kitchen will initially be used by diabetes patients, but then will likely be used over time by other clinical divisions, such as cardiology, gastroenterology, and others.

The pop-up Teaching Kitchen is designed to be highly portable and allows for interactive, hands-on learning experiences for children and families. It is designed to teach basic kitchen skills to educate and promote the lifestyle, as well as reinforce behavioral modifications necessary for managing a chronic condition such as diabetes.

"The pop-up kitchen is designed to be used in partnership with one of our chefs and dietitians to demonstrate healthy meals while at the same time emphasizing nutritional benefits of different foods to complement the care for patients with diabetes," says Dr. March.

Teaching Kitchen sessions can be set up for 12 children or adolescents at a time. Patients are led through a session by the chef, following his or her instructions to prepare their own meal/snack. Throughout the process, a dietitian provides nutrition information and guidance



about the ingredients being used, as well as broader nutrition information. The format of the Teaching Kitchen is designed to engage the patient and family in a fun, hands-on learning experience, empowering the family to learn healthy food preparation techniques and, in return, healthier lifestyle habits.

"We receive frequent requests from our patients for cooking classes and healthy recipes. The Teaching Kitchen will be an innovative format to provide them practical information, hopefully leading to sustained dietary improvements," says Mr. Weidinger.

Age-appropriate programs and developmentally appropriate cooking and dietary demonstrations will be developed to target important nutritional aspects of diabetes care — be it carbohydrate

counting skills, low cholesterol and low fat food preparation, and the fundamentals of balanced nutritional intake.

"With its built-in flexibility, we have the option to move the Teaching Kitchen around easily and integrate its teaching capabilities into a number of our existing clinical and educational programs to provide a deeper level of education and interactivity," says Mr. Weidinger.

"For example, we will likely use the pop-up Teaching Kitchen for young adults who are learning to cook for themselves. We can also help families with picky eaters by introducing the kids to new foods that are tasty and healthy," says Dr. March.

Managing type 1 diabetes comes down to a combination of good nutrition, healthy exercise, and insulin use. While all three aspects are critical to successful management, food is the key.

"Dr. Becker, when discussing diabetes management with patients and families, specifically mentions insulin last, because a healthy diet is crucial. Of course, monitoring blood sugars and giving insulin are important, but we can't forget the importance of how what we eat affects our health, too. This new initiative will give us another tool to use in our work to help build healthy eating habits for kids," says Dr. March.

New Faculty and ELECT Clinic Expansion



Sripriya Raman, MD, joined the Division of Pediatric Endocrinology, Diabetes, and Metabolism in December 2017 after having served previously at Children's Mercy Kansas City in Missouri as an associate professor and co-director of the Endocrine Disorders in Cancer Survivors clinic. Joining UPMC Children's Hospital as an associate professor of medicine, Dr. Raman also serves as co-director

of the Endocrine Late Effects After Cancer Therapy (ELECT) clinic alongside clinic founder Nursen Gurtunca, MD (see article on Page 4).

A fellowship-trained pediatric endocrinologist with a special focus on managing and studying endocrine late effects from cancer therapies, Dr. Raman sits on many national and international committees and

consortiums, including the Children's Oncology Group Endocrine Task Force, the International Guideline Harmonization Group for Late Effects of Childhood Cancer (IGHG), and the Pediatric Endocrine Scientific Committee (current chair) of the American Association of Clinical Endocrinologists, among many others.

Dr. Raman also has a focus on helping pediatric cancer survivors navigate and prepare for issues involving fertility and fertility preservation related to their cancer therapies, and the process of transition from the pediatric to adult endocrine clinic. Since joining the faculty at UPMC Children's, Dr. Raman has joined the Oncofertility Consortium that was developed by UPMC Magee-Womens Hospital to better tackle these issues of fertility preservation for pediatric cancer patients.

The ELECT Clinic — Endocrine Late Effects After Cancer Therapy



Upwards of 50 percent of pediatric cancer survivors are at risk for one or more endocrine late effects due to their cancer therapies. There is a broad spectrum of effects that these children can suffer

from — years or even decades post-treatment. The ELECT clinic, founded by **Nursen Gurtunca, MD**, is designed specifically to assist these patients in the long-term management of endocrine late effects and to help them transition from pediatric to adult care when they are ready.

Drs. Gurtunca and Sripriya Raman, MD (see article on Page 3), are positioned to expand

the scope of the ELECT clinic and work to better identify the patients within UPMC Children's who may be good candidates for referral to ELECT. They will also be working to establish formalized transitional plans of care as pediatric patients move to adult care — both aspects of which are of primary importance for Dr. Raman. Prior to joining the faculty at UPMC Children's, Dr. Raman had six years of experience establishing and running an endocrine late-effects clinic in Kansas City with a robust patient census.

Since arriving at UPMC Children's, Dr. Raman has been working with the cancer registry and IT staff to build a comprehensive database that will include 10 years of data on all patients

who were, or are, being served by the hospital. "We will obtain very granular data on what kind of treatment they received — for example radiotherapy or chemotherapy — and very relevant details about the doses, administration sites, and frequency of treatment," says Dr. Raman.

The database will also capture other critical care and demographic data such as the last time they were seen in clinic, where, and what provider saw them. "Once we have the database established, we'll be well-positioned to use the data as a base for future research composition, health outcomes research, and quality metrics."

UPMC Children's Hospital of Pittsburgh is affiliated with the University of Pittsburgh School of Medicine and nationally ranked in nine clinical specialties by *U.S. News & World Report*.



About UPMC Children's Hospital of Pittsburgh

Regionally, nationally, and globally, UPMC Children's Hospital of Pittsburgh is a leader in the treatment of childhood conditions and diseases, a pioneer in the development of new and improved therapies, and a top educator of the next generation of pediatricians and pediatric subspecialists. With generous community support, UPMC Children's Hospital has fulfilled this mission since its founding in 1890. UPMC Children's is recognized consistently for its clinical, research, educational, and advocacy-related accomplishments, including ranking 13th among children's hospitals and schools of medicine in funding for pediatric research provided by the National Institutes of Health (FY2017).