



PROVIDING CARE ACROSS THE SPECTRUM OF ENDOCRINE DISORDERS

DIVISION OF PEDIATRIC ENDOCRINOLOGY AND DIABETES

The Division of Pediatric Endocrinology and Diabetes at Children's Mercy Kansas City is one of the busiest full-service endocrinology and diabetes programs in the country. The first pediatric program in the U.S. to be accredited by the American Diabetes Association, it cares for nearly 2,400 children diagnosed with type 1 and type 2 diabetes. Research and quality improvement efforts through initiatives such as TrialNet and the T1D Exchange Quality Improvement Collaborative are helping Children's Mercy improve outcomes for patients with diabetes. The division also provides a wide range of care and support services to help children with endocrine disorders lead healthy lives today and into adulthood.

SPECIALTY CLINICS

The program's endocrinologists offer a variety of multidisciplinary clinics not typically available at other pediatric hospitals:

- 22q11.2 Clinic
- Endocrine Disorders in Cancer Survivors Clinic (EDICS Clinic)
- Cystic Fibrosis Endocrine Clinic
- Thyroid Nodule and Carcinoma Clinic
- GUIDE Clinic (Gynecology/Genetics, Urology, Integrated, Developmental and Endocrine)
- Great HeightTS Clinic for Turner Syndrome
- Gender Pathway Services Clinic
- Multispecialty Adolescent Polycystic Ovary Syndrome Clinic



TOP-RANKED PROGRAM

Recognized as one of the nation's top 20 endocrinology programs by *U.S. News & World Report*.

BY THE NUMBERS

PATIENT VISITS

24,065	Patients seen in FY 2018
2,400	Patients seen with type 1 and type 2 diabetes

CLINICAL STAFF

4	Advanced practice nurses
6	Dedicated social workers
15	Certified diabetes educators
20+	Board-certified or board-eligible endocrinologists

BY THE NUMBERS

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Percentage of all primary diabetes care patients who have had a face-to-face visit of the following type in the last calendar year:	
Medical nutrition therapy with nutritionist or a CDE	98.60%
Diabetes education with a CDE or equivalent	96.90%
Social worker or psychologist assessment	62.54%

IMPROVING ENDOCRINOLOGY CARE THROUGH RESEARCH AND MULTIDISCIPLINARY CLINICS

Together with the Genomic Medicine Center at Children's Mercy, the endocrinology team is working to quickly and accurately diagnose pediatric conditions at the genetic level. Researchers continue to explore the relationship between hormones and genetics to better understand the factors that play a role in children's growth.

In partnership with Susana Patton, PhD, Pediatric Psychologist at The University of Kansas Medical Center, Children's Mercy also is involved in collaborative projects funded by the National Institutes of Health (NIH). These initiatives are exploring how technology and the principles of family-centered design can be used to develop interventions that improve outcomes for children and their families dealing with type 1 diabetes.

In addition, the Children's Mercy Diabetes Center has made a significant change to the way it cares for its type 1 and type 2 diabetes patients newly diagnosed each year. Patients age 5 or older and their families begin receiving the education and training needed to maintain healthy blood glucose levels in three outpatient visits. Regular clinic follow-up visits are scheduled. The team has tracked more than 200 children who have been a part of the program's inaugural year. Initial results show promise. To date, they've saved more than 300 inpatient hospital days by shifting from inpatient to outpatient care.

USING MACHINE LEARNING TO IMPROVE OUTCOMES IN T1D

In mid-2017, a project was launched to find out whether it was possible to predict which type 1 diabetes patients are at risk of poor outcomes so interventions can begin sooner.

Children's Mercy, under the direction of Mark Clements, MD, PhD, endocrinologist, Director of endocrine/diabetes research, and Joslin Diabetes Center in Boston teamed up with the machine learning-powered performance improvement company Cyft, Inc., to address this challenge. The research team began collecting data and looking for opportunities to turn data into insights that could be provided to clinical staff at the point of treatment.

A number of variables were deemed significant in predicting those patients who would have the highest rise in HbA1c in the next 90 days. Based on these predictions, the team has been able to implement quality improvement projects in an effort to improve these outcomes, offering immediate alternate pathways of care for those at high risk of negative outcomes.

TRIALNET CLINICAL CENTER FOCUSES ON T1D PREVENTION

Children's Mercy is one of 18 designated TrialNet Clinical Centers, the National Institutes of Health's network dedicated to the study, prevention and early treatment of type 1 diabetes. TrialNet Centers are working with more than 200 screening sites to identify people at risk for developing T1D. Centers also are performing clinical trials of medicines that have the potential to prevent T1D from occurring. TrialNet's work has also helped shift our understanding of the diagnosis of T1D. Previously, diagnosis was considered to be the time when patients developed abnormal blood sugars; now the disease is thought to begin at the time when individuals first develop antibodies against the pancreas.

Using tablet-based technology, Children's Mercy has expanded the ability of physicians in the region to help its TrialNet Clinical Center identify participants at risk for T1D.

Children's Mercy is also participating in TrialNet studies that are focused on the development of three new medications for T1D: abatacept, hydroxychloroquine and teplizumab. These drugs seek to delay or prevent progression of early-stage T1D and prevent clinical diagnosis.

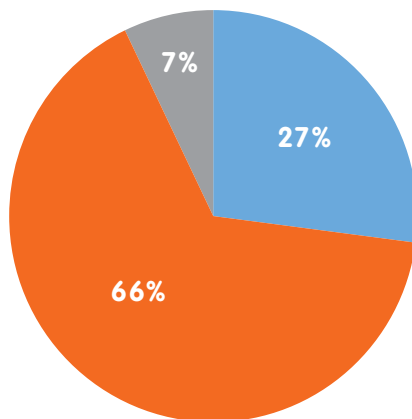
TELEMEDICINE EXPANDS PATIENT REACH

The Endocrinology and Diabetes Programs are continuing to increase their presence throughout the Children's Mercy region via telemedicine. Using

technology, the team is able to provide care for patients who live hundreds of miles from Kansas City. This approach lets the team see new patients when circumstances are appropriate. They also can see established patients more regularly, ensuring these patients receive the care they need, when they need it.

TELEMEDICINE SATISFACTION*

- 93% of patients are more or equally satisfied with telemedicine appointment
- Number of telehealth visits offered in 2018: 60



- More satisfied with the appointment by TM
- Equally satisfied with the appointment by TM
- Less satisfied with the appointment by TM

*2018 Endocrinology telemedicine patient satisfaction

OUTREACH CLINICS

The Endocrinology Division participates in an average of 10 outreach clinic visits a month, allowing patients across the region to receive care. Outreach services bring the quality and comprehensive medical care found in the Kansas City facilities to families in neighboring and distant communities. The outreach team is composed of physicians, nurses, certified diabetes educators and nutritionists to provide pediatric endocrinology care to patients from western Kansas to south central Missouri.

TAKING CARE TO GREAT HEIGHTS FOR GIRLS WITH TURNER SYNDROME

The Great HeightTS Clinic at Children’s Mercy was created in 2010 to provide answers for these girls and their families. Children’s Mercy has one of the largest Turner Syndrome

programs in the nation, providing care to more than 90 patients from a six-state region.

The clinic provides patients and families access to a multidisciplinary team of specialists in one convenient location during a daylong event offered three times a year.

Between lab tests and doctor visits, many activities also keep the girls busy, including the popular “Pink Party,” coordinated by Children’s Mercy Child Life. During the party, wives of local sports celebrities, along with students from cosmetology programs, visit with the girls, do their hair and nails, and provide crafts.

GENDER PATHWAY SERVICES (GPS) CLINIC

In 2014, Children’s Mercy developed one of the few clinics in the nation to help manage gender nonconforming (GNC) behavior, a condition that, if left untreated, has a 40 to 50 percent attempted suicide rate.

The Gender Pathway Services (GPS) Clinic team provides interdisciplinary family-centered services for transgender, gender-variant and gender-questioning patients. This is the only center of its kind in the Midwest and one of only a handful in the country.

The GPS Clinic cares for approximately 250 patients ages 5 to 21. Approximately 70 percent are female to male, and 30 percent are male to female.

CHILDREN’S RESEARCH INSTITUTE

The Children’s Research Institute (CRI) at Children’s Mercy Kansas City is an integrated research environment where no boundaries exist between science and medicine. Here physicians, scientists, academic colleagues and philanthropic partners are collaborating to change the future for children. Research areas include genomics, precision therapeutics, immunotherapy and health outcomes, among many others. To enhance its research endeavors, a new building, future home to the CRI, is under construction. This building has been carefully designed so research and clinical care work as cross-functional teams, aligned together, to find answers to pediatric medicine’s most challenging questions.

STAFF

LEADERSHIP

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Division Director

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ENDOCRINE NURSE PRACTITIONERS

The division's four nurse practitioners have an average of 10 years of advanced practice experience and an average of 25 years of combined RN and APRN experience, including an average of 10 years with Children's Mercy. They see all endocrine diagnoses and participate in a wide range of clinical quality improvement and education initiatives.

Lisa Bennett, MSN, BC-FNP, CDE, BC-ADM

Amy Gab, MSN, FNP

Terri Luetjen, RN, MS, CPNP, CCRD

Taryn Vaeth, MSN, CPNP, CDE



LEARN MORE ABOUT THE DIVISION OF PEDIATRIC ENDOCRINOLOGY AND DIABETES.

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April 2019