Children's Mercy KANSAS CITY

RESEARCH-DRIVEN PEDIATRIC ENDOCRINOLOGY CLINICAL CARE

A MESSAGE FROM Francesco De Luca, MD

Division Director, Pediatric Endocrinology and Diabetes

Despite the many difficulties related to the COVID-19 pandemic, in 2021 the Division of Pediatric Endocrinology and Diabetes at Children's Mercy Kansas City continued to achieve numerous and outstanding accomplishments. With respect to patient care, we were able to provide endocrine and diabetes care to a higher number of children than in 2020. We also implemented a new multidisciplinary program offering specialized care to children with Prader-Willi syndrome. Last year, we began to develop a standardized, stepwise process to assist our adolescent patients with diabetes as they transition to adult care providers.

The efforts of our team to improve the quality of care provided to our patients with diabetes were recognized at the national level by the T1D Exchange network with the T1D Exchange Best Quality Improvement Team 2021 Award. In 2021 many faculty members and trainees in our division excelled in their academic efforts: their scholarly activities, often supported by significant external funding, led to numerous scientific publications and presentations at national and international meetings.

Lastly, our Diabetes Research Team received the Children's Mercy Department of Pediatrics 2021 Annual Research Team Achievement Award for its exceptional productivity, leadership and scientific accomplishments in the field of Type 1 Diabetes.

We are very proud and grateful for all of these accomplishments, and they motivate us to reach new and exciting goals in the future.

2021 HIGHLIGHTS

The diabetes team was recently awarded the **T1D Exchange Best QI Team 2021 Award**. This important award is granted to recognize "a well-rounded team with diverse team roles, good camaraderie, and the ability to scale QI work within your organization."

Together with the Children's Mercy Genomic Medicine Center, **our researchers continue to explore the relationship between hormones and genetics** to better understand factors that play a role in a child's growth and their risk of developing a number of endocrine disorders.

BEST CHILDREN'S HOSPITALS U.S.News & WORLD REPORT DIABETES & ENDOCRINOLOGY 2021-22

Ranked #38 in Pediatric Diabetes and Endocrinology by U.S. News & World Report.

The program's endocrinologists offer a variety of multidisciplinary clinics not typically available at other pediatric hospitals, such as **22q11.2 Deletion Syndrome, Turner Syndrome** and **Gender Pathway Services**.

Additional multidisciplinary clinics: Prader-Willi Syndrome (PWS), GUIDE Clinic for Children with Differences of Sexual Development, Endocrine Disorders in Cancer Survivors (EDICS), Polycystic Ovary Syndrome Clinic (PCOS), Thyroid Nodule and Carcinoma Clinic.

Endocrinology fellow Erica Zarse, MD, and patient

FY 2021 By the Numbers

24,519 patients seen in FY 2021*

2,400 unique patients seen with type 1 diabetes and **229** unique patients seen with type 2 diabetes in 2021**

29 board-certified or board-eligible endocrinologists

4 advanced practice nurse practitioners

3 social workers

17 certified diabetes educators

9 multidisciplinary clinics

*Fiscal Year 2021 (July 1, 2020 to June 30, 2021)
**Calendar Year 2021 (January to December 2021)

Our providers participate in an average of **6** outreach clinic visits per month.

Our Diabetes Center has had approximately **1,200** kids go through our LAND program since it started in Jan. 2016. We have been able to save more than **1,500** inpatient days with this program, which will expand to Wichita, Kan. later this year.

Percentage of all primary diabetes care patients who have had a face-to-face visit of the following type in the last calendar year:

97.8% medical nutrition therapy with nutritionist or a certified diabetes educator

95.6% diabetes education with a certified diabetes educator or equivalent

53.3% social worker or psychologist assessment

CLINICAL EXCELLENCE SETTING NEW STANDARDS OF CARE IN PEDIATRIC ENDOCRINOLOGY

Prader-Willi Syndrome (PWS) Clinic

In March 2021, the Division of Endocrinology began seeing patients in its new multidisciplinary Prader-Willi Syndrome (PWS) Clinic, created by Kelsee Halpin, MD, MPH, and Emily Paprocki, DO. In recent years, there has been an increased need for improved comprehensive care for these patients. Early diagnosis and multidisciplinary care are key to improving the quality of life for PWS patients. Also important is growth hormone therapy, a medication approved by the FDA for use in PWS from infancy through adulthood. One of the clinic's goals is better coordination of care to ensure timely initiation of growth hormone in infants. Children's Mercy is also participating in clinical trials exploring other PWS treatment options. In addition to Endocrinology, other specialties involved in the clinic include Genetics, Nutritional Services, Orthopedics, Psychology, Sleep Medicine, Social Work, and Weight Management. The clinic is attracting patients not only from Kansas and Missouri but also surrounding states, including Iowa, Arkansas and Nebraska.

Kelsee Halpin, MD, MPH, and Emily Paprocki, DO, lead the Prader-Willi Syndrome Clinic.

MAPP (Multispecialty Adolescent PCOS Program)

Polycystic ovary syndrome (PCOS) is a prevalent endocrine condition which manifests in a tendency toward ovulation dysregulation, insulin resistance and hormonal imbalance favoring androgen production. Clinical expression is compounded by environmental, nutritional and lifestyle factors. To address the constellation of symptoms and to provide individualized and optimized care for each adolescent, the Children's Mercy MAPP (Multispecialty Adolescent PCOS Program) was established in early 2016 by Tania S. Burgert, MD. While excellence in clinical care remains at the heart of the program, the clinic has also become a rich resource for clinical research and its team delivered several presentations at this year's annual Pediatric Endocrine Society meeting. Recently the clinic joined a multicenter collaborative across the United States, looking at the response to treatment and the development of comorbidities in adolescents with PCOS.

New Faculty

Michelle Knoll, MD, and Melissa Litao, MD, joined the Pediatric Endocrinology and Diabetes Division in 2021.

The MAPP is one of the few multispecialty programs in the nation focused on research and clinical care for adolescents affected by PCOS.

Members of the Pediatric Endocrinology and Diabetes team after receiving the T1D Exchange Best QI Team 2021 award

ENDOCRINOLOGY RECEIVES AWARD FROM T1D EXCHANGE QUALITY IMPROVEMENT COLLABORATIVE

The Division of Pediatric Endocrinology and Diabetes has been honored with the QI Team award from the T1D Exchange Quality Improvement Collaborative (QIC).

QIC brings together 41 clinics across the U.S. that treat over 55,000 individuals with type 1 diabetes. QIC member clinics share data via the T1D Quality Improvement platform to measurably improve the lives of individuals with type 1 diabetes. Once a year the organization recognizes members of the collaborative with an award to celebrate their accomplishments and contributions.

> Congratulations on receiving the T1D Exchange Best QI Team 2021 award," said Dr. Osagie Ebekozien, Chief Medical Officer and EVP of the T1D Exchange. "We are thrilled to present this award to Children's Mercy to continue working at its highest capacity, supporting peer sites and inspiring others to track necessary diabetes device measures that support better diabetes outcomes. We reviewed multiple criteria in evaluating the most outstanding team this year. Children's Mercy undoubtedly was exceptional in all of the categories we evaluated and from our conversations with your peers.
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> The award was presented Nov. 9, 2021 at the organization's virtual learning session.

LEADING THE WAY Through Research

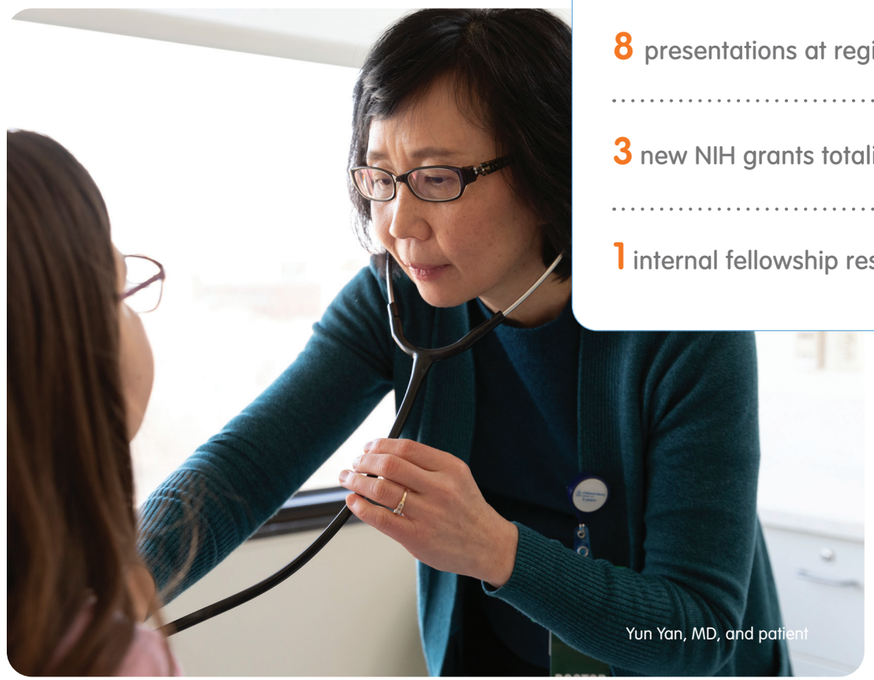
The Division of Endocrinology and Diabetes, along with the Genomic Medicine Center, is working to diagnose pediatric conditions quickly and accurately at the genetic level. Children's Mercy, in partnership with the University of Kansas Medical Center, is also involved in collaborative projects funded by the National Institutes of Health (NIH). These initiatives are exploring how technology and the principles of family-centered design can improve outcomes for children and their families dealing with type 1 diabetes.

2021 Annual Research Team Achievement Award

Our Diabetes Research Team received the Children's Mercy Department of Pediatrics 2021 Annual Research Team Achievement Award for its exceptional productivity, leadership and scientific accomplishments in the field of Type 1 Diabetes.

By the Numbers

- **21** published manuscripts
- **3** book chapters
- Participation in **17** clinical trials
- **23** presentations at national/international meetings
- **8** presentations at regional meetings
- **3** new NIH grants totaling **$433,950**
- **1** internal fellowship research grant



Yun Yan, MD, and patient

RESEARCH HIGHLIGHTS

Dr. Kelsee Halpin Awarded an NICHD RO1 Subcontract

Kelsee Halpin, MD, MPH

Kelsee Halpin, MD, MPH, was recently awarded the subcontract for a project led by Bhagwhat Prasad, MS (Pharm), PhD, at Washington State University. The overarching aim of the project is to develop and validate a biomarker panel of renal transporters that will be incorporated into physiologically based pharmacokinetic (PBPK) models to help predict age-dependent drug disposition. As a subcontract PI, Dr. Halpin will collect random one-time and 12-hour time course blood and urine samples from Children's Mercy patients treated with metformin, a substrate for the renal transporters under study by Dr. Prasad. The samples will be used to help develop the renal transporter biomarker panel and PBPK model to predict metformin disposition in pediatric patients.

Dr. Mark Clements and Team Awarded Two NIH Grants

Mark Clements, MD, PhD

Mark Clements, MD, PhD, received two NIH grants to support his research on type 1 diabetes in children and adolescents. The first, titled Remedy to Diabetes Distress (R2D2), aims to establish a scalable program for school-age families. His objectives are to identify a clinically relevant level of diabetes distress among children with type 1 diabetes and their parents, implement a clinic-wide screening program, and develop and test an intervention to treat diabetes distress. With his second grant, Dr. Clements will develop and pilot test a novel intervention called COIN2DOSE that uses principles of behavioral economics theory to increase daily insulin BOLUS activities and improve glycated hemoglobin in adolescents with type 1 diabetes.

Turner Syndrome Transition Initiative

Benjamin Hoag, MD

The Turner Syndrome Transition Initiative is an online program for young women with Turner syndrome to help them prepare for the transition from pediatric to adult medical care. The program features an interactive audio/video module with surveys and multiple-choice questions designed to help assess and improve transition of care knowledge, readiness and confidence. The pilot for this study is set to start in early 2022 and Benjamin Hoag, MD, is focused on recruitment.

Behavioral Economics Intervention Aims to Improve Mealtime Insulin Dosing Engagement in Adolescents with T1D

Sarah Tsai, MD, FRCPC

Sarah Tsai, MD, FRCPC, and Co-Investigators Mark Clements, MD, PhD, and Ryan McDonough, DO, will evaluate two behavioral economic interventions called COIN2DOSE (Cash-Only INcentive to promote mealtime insulin DOSE Engagement) and LOAN2DOSE, a concept that uses an economic loss aversion approach to promote mealtime insulin dose engagement. These interventions are designed to improve glycemic control by decreasing the number of missed mealtime boluses. Subjects will be identified using an AI algorithm to predict those at risk for rising A1C. The outcomes for this study include change in A1C trajectory, time in range, mealtime bolusing engagement, quality of life and patient satisfaction. Funding for this study is provided by the Helmsley Charitable Trust.

NOTABLE PUBLICATIONS

Study Demonstrates That Fingerstick Blood Collection Kits Provide Results Comparable to Venous Specimens for Measuring HbA1c

Mark Clements, PhD, MD, in collaboration with Roy Beck, MD, PhD, et al., demonstrated that blood collection kits designed for home use provide HbA1c measurements comparable to venous blood draws done in clinics or laboratories. The easy-to-use kits, from the University of Minnesota Advanced Research and Diagnostic Laboratory and Children's Mercy Laboratory, can provide a critical tool for the management of diabetes.

Beck RW, Bocchino LE, Lum JW, et al. An evaluation of two capillary sample collection kits for laboratory measurement of HbA1c. *Diabetes Technol Ther.* 2021;23(8):537-545. doi:10.1089/dia.2021.0023

Research Confirms That Boys With 45,X Mosaicism Have Features Consistent with Turner Syndrome

Michelle Knoll, MD, and colleagues published a study that determined that patients with 45,X mosaicism with Y chromosome material raised as boys had features consistent with Turner syndrome, a label restricted to phenotypic females. The research recommends routine screening of boys following the Turner Syndrome Clinical Practice Guidelines.

Knoll MM, Strickland J, Jacobson JD. Can boys have Turner syndrome? More than a question of semantics. *Sex Dev.* 2022;16(1):19-26. doi:10.1159/000518092

Researchers Share Protocol for Reducing Emotional Distress for Childhood Hypoglycemia in Caregivers

Mark Clements, PhD, MD, in collaboration with Susana Patton, PhD, et al., conducted a clinical trial of an innovative, video-based telehealth intervention to treat a fear of hypoglycemia in caregivers of young children with type 1 diabetes, which can improve a family's quality of life. The intervention merges education and behavioral parenting strategies with cognitive behavioral therapy strategies.

Patton SR, McConville A, Marker AM, Monzon AD, Driscoll KA, Clements MA. Reducing emotional distress for childhood hypoglycemia in parents (REDCHiP): Protocol for a randomized clinical trial to test a video-based telehealth intervention. *JMIR Res Protoc*. 2020;9(8):e17877. Published 2020 Aug 18. doi:10.2196/17877

Genomic Answers for Kids Advances Rare Disease Research

The Children's Mercy Research Institute has released more than 2,300 pediatric rare disease genomes through its Genomic Answers for Kids (GA4K) program, which makes it one of the largest pediatric rare disease whole genomic datasets ever publicly shared.

To date, more than 3,700 patients have enrolled in the program, which has resulted in more than 18,000 new genomic analyses and more than 600 genetic diagnoses. In addition, the program has advanced research genomic analyses for children of 350 families with more common childhood diseases: cerebral palsy and Down syndrome.

The full pediatric data repository is shared in a real-time web interface through a comprehensive process, which gives researchers and clinicians low-barrier access to processed data with disease prioritized genetic changes.

"Giving access to our data allows researchers to link their own genetic findings so they can accept or reject hypotheses on their gene discoveries," said Tomi Pastinen, MD, PhD, Director, Genomic Medicine Center, Children's Mercy Kansas City. "Data sharing is the only way we'll make headway in the quicker delivery of results that are non-diagnostic today."

The GA4K program has helped hundreds of kids, like Celia, find a genetic diagnosis.

MEET THE TEAM

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Division Director, Pediatric Endocrinology and Diabetes

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LEARN MORE ABOUT THE DIVISION OF PEDIATRIC ENDOCRINOLOGY AND DIABETES.

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