

COLLABORATING TO PROVIDE EVIDENCE-BASED, FAMILY-CENTERED CARE



A MESSAGE FROM Sarah Soden, MD

Division Director, Developmental and Behavioral Health

The Division of Developmental and Behavioral Health at Children's Mercy Kansas City is committed to compassionate and evidence-based care. Our team of 62 providers, including psychologists, psychiatrists, developmental pediatricians, advanced practice nurses and behavior analysts, brings their expertise to a wide array of clinical concerns ranging from common behaviors in primary care to high acuity and complex conditions requiring a multidisciplinary team. No matter the setting, we work in an integrated fashion with one another and with clinical staff from across our health care system to care for the whole child.

In 2021, community education was a cornerstone of our efforts to impact the mental well-being of youth and their families. We developed an on-demand behavioral health course for primary care providers offering CME and a wealth of practical advice for managing developmental and mental health conditions. We also offered thousands of hours of live education to families about parenting and caring for children with neurodevelopmental disorders and made recordings of many of these talks available for free in Spanish and English on our website. Another educational highlight is our Prepped and Ready program, which equips parents with tools to curb high-risk behaviors, including self-harm, in teens.

The past year has also been marked by development of a robust mental health strategic plan that seeks to dramatically increase access to care at all acuity levels.

This report highlights some of our division's achievements from the past year. I welcome the opportunity to connect with you regarding any of our programs and initiatives.

2021 HIGHLIGHTS

NATIONAL LEADERS

Children's Mercy is **one of only 15 centers** with membership in the **Developmental Behavioral Pediatrics Research Network**, funded by the federal Health Resources & Services Administration.

Our **Tourette Syndrome Center of Excellence** is the nation's only center of excellence devoted exclusively to kids.

IMPROVEMENT INITIATIVES

We implemented a **Behavioral Health Rapid Improvement Team** to create a unified approach to patient management in the Emergency Department and medical inpatient units in order to deliver the highest possible care in a safe environment for our employees.

LEADING RESEARCH

\$1,233,940 in research funding for **16 active projects** based within Developmental and Behavioral Health.

EDUCATING THE COMMUNITY

We provided over **5,000 hours of free education** to families and professionals in the community, as well as over **1,500 family navigation consultations** to ensure youth can successfully access key clinical services.



Bob Batterson, MD, Child Psychiatry, and patient

FY 2021 By the Numbers

FACULTY

8 developmental and behavioral pediatricians

8 psychiatrists

51 psychologists

2 APRNs

2 dedicated social workers

1 family therapist

13 dedicated clinics

23,102 total outpatient visits

1,970 new patient visits

87 eating disorder visits

174 ADHD visits

1,709 other visits

6,527 follow-up patient visits

1,479 eating disorder visits

1,900 ADHD visits

3,148 other visits

ADVANCING ACCESS TO COMPREHENSIVE DEVELOPMENTAL AND BEHAVIORAL HEALTH CARE

Our Division of Developmental and Behavioral Health is committed to transforming the mental health care continuum. We are focused on reducing barriers to service, addressing social determinants, expanding treatment options for acute care, and conducting research to find better answers to resolve the child and adolescent mental health crisis facing our communities.

Our team offers outpatient clinic visits, parent training programs, individual and group telehealth visits, multidisciplinary team care, and consultation services. Additionally, our team is integrated into Children's Mercy primary care and more than 25 subspecialty programs at all sites, including our nationally recognized Tourette Syndrome Center.

Thrive Program

The Thrive Program is an innovative and comprehensive psychosocial program within the Ward Family Heart Center. **This program utilizes the Heart Center's dedicated psychosocial support team to address needs that arise across the lifespan and across the continuum of care.** This provides families of our complex cardiac patients with a resource to address the social and emotional stressors that come with chronic cardiac conditions. The Thrive Program also serves as a central location to collaborate on cardiac research that focuses upon psychosocial factors, working on program development that benefits patient and family outcomes, and optimizing staff well-being.

On-Demand Behavioral Health CME Course

The Division of Developmental and Behavioral Health developed the On-Demand Behavioral Health Course for primary care practitioners to arm them with up-to-date information on a wide range of behavioral and mental health challenges. **The course features 28 experts who address conditions such as ADHD, autism, depression, eating disorders and many more.** The professionally produced recordings are available through an online educational portal called CloudCME and offer 15 hours of CME for only \$125. The course is available at <https://cmkc.link/BHCourse>.

Prepped and Ready

Prepped and Ready: Experts Edition is a presentation to help equip parents for the transition into parenting teenagers. **Prepped and Ready aims to help parents learn what steps they can take before a crisis develops with their teenager.** We seek to empower parents to address the hard topics that can be very uncomfortable, and we talk about changes each one of us can make within our own homes to make them safer.

The Prepped and Ready presentation was developed after Shayla Sullivant, MD, spent many hours with families in crisis at Children's Mercy. After providing advice to parents on the next steps to take, many parents asked an important question: why didn't anyone ever tell me this sooner? The Prepped and Ready presentation provides a brief overview on the following topics: Eating disorder prevention; Home safety (including storage of firearms, medications, etc.); Screen time; Self-care; Substance use (including vaping); and Suicide prevention.

Telehealth Parent Coaching

Children's Mercy is a national leader in telehealth group parent coaching to support youth with autism and developmental disabilities. Developed prior to the COVID-19 pandemic, these evidence-based service lines (available in both English and Spanish) have provided **over 1,800 hours of evidence-based service in the last 18 months alone, with high family satisfaction and consistent improvements in child behavior.** The Children's Mercy team has shared this success at scientific meetings (International Society for Autism Research, Society for Developmental & Behavioral Pediatrics, Dream Integrated Primary Care Conference, Association for Behavioral and Cognitive Therapies) as well as through capacity-building consultation with regional and national partners.

Eating Disorders

Our eating disorder program has a **unique transdisciplinary service delivery model.** All medical, therapeutic, and support service disciplines are maintained in one location with robust care coordination, joint treatment planning, and progress monitoring. It is rare to find both family-based treatment and cognitive-behavioral therapy, offered in an eating disorder program, but by doing so we are able to individualize each patient's treatment to their individual needs and presentation.



By the Numbers

57 published peer-reviewed manuscripts

41 national-level board member/
leader/co-chair positions

BEHAVIORAL HEALTH RAPID INTERVENTION TEAMS ADDRESS HIGH-PRIORITY MENTAL HEALTH ISSUES

A critical piece of the Children's Mercy five-year Strategic Plan is mental and behavioral health. We are enthusiastic about embracing the continuum of care and creating a unified approach to patient management in order to deliver the highest possible care in a safe environment for patients and employees.

In March 2021, we developed Behavioral Health Rapid Intervention Teams to address a surge in behavioral health-related incidents in our medical units and Emergency Department. Three work groups were formed on high-priority issues as part of a 90-day sprint. Initiatives included widespread de-escalation education and certification, use of personal protective equipment for bedside staff, creation of soothing carts to provide patients with activities and methods to self-calm, two

observation and communication tools for bedside staff, and an Escalation Assessment and Prevention process for admitted patients.

A Team Member Safety Council, launched in Feb. 2021, continues to monitor, evaluate and support initiatives involving team member safety.

A Behavioral Health Advisory Council was launched in Jan. 2022, comprised of diverse representatives from across Children's Mercy who impact behavioral health services and projects. The council will be responsible for monitoring, evaluating and supporting initiatives and groups that involve managing patients with mental and behavioral health conditions.

TRANSFORMING CARE Through Research

Our team is integrated into pediatric subspecialty programs throughout the Children's Mercy health system. What we see in patient care leads to research initiatives to advance treatments and therapies. This past year, our team led or participated with Children's Mercy colleagues on research not only in developmental and behavioral health issues, but in areas such as gender dysphoria, abdominal pain, weight management, heart disease and cancer treatment.

Rates of Positive Suicide Screens

Prior research has suggested that rates and acuity of suicidality are elevated among patients seen in EDs and in certain clinics. However, the occurrence and severity of suicide risk has rarely been studied in the pediatric clinic populations due in part to unsystematic screening. We examined suicidality across different pediatric clinical care settings based on data from our newly implemented hospital-wide suicide risk screening program to determine a) which patient populations presented with the highest rates of suicidality; and b) the percentage of patients who had current thoughts of suicide and were thus deemed "acute."¹

Out of the 101,732 screenings completed during this time, 11,460 (11.3%) were positive, and 734 were at acute suicide risk. **We found suicidality among pediatric patients is highest among adolescents seen in the inpatient unit and those seen in the ED.** Some pediatric outpatient clinics also have high rates of suicidality, but the rate of acuity appears to be lower in this setting relative to the inpatient and ED setting. Data on the acuity of risk and on the prevalence of acute risk in different clinical settings can be used to plan for allocation of mental health resources to follow-up on positive screens.



ADHD and Accidental Injuries in Preschoolers

Children with attention-deficit/hyperactivity disorder (ADHD) are at risk for accidental injuries, but little is known about age-related changes in early childhood. We predicted that ADHD would be associated with greater frequency and volume of accidental injuries.

This study explored associations between ADHD and injury types and examined age-related changes within the preschool period.² **Our study found early identification and treatment of preschool ADHD following accidental injury may prevent subsequent injuries.** Clinical implications and future directions are discussed with emphasis on the maintenance of parental monitoring into the older preschool years.

Gender Dysphoria, General Well-Being and Weight-Related Behaviors

Gender dysphoria is associated with body-dissatisfaction, abnormal weight and weight-related behaviors. This study sought to describe the association of gender dysphoria severity and general well-being with Body Mass Index (BMI) and weight-related behaviors among transgender males.³

A retrospective review of 118 transgender male patients presenting to initiate gender-affirming medical care in 2017-2020 was conducted. We found lower parent PedsQL scores were associated with higher BMI Z-scores and more patient reports of perceiving themselves to be overweight and fasting to lose weight. Patient PedsQL General Well Being Scores were not associated with any of our outcomes. **There is a non-linear relationship between gender dysphoria and BMI.** Further research is needed to determine if the non-linear relationship between dysphoria and BMI is present in other transgender youth and associated with differences in weight-related behaviors.

RESEARCH HIGHLIGHTS

Characterization of Comorbidities in Patients with Down Syndrome and ASD

Up to 19% of patients with Down syndrome (DS) meet diagnostic criteria for autism spectrum disorder (ASD) (Channell, et al., 2019). While the medical and psychological comorbidities for patients with DS or ASD are well characterized, outcomes for patients with a dual diagnosis (DS-ASD) are poorly understood.

Utilizing Cerner Health Facts, we identified large populations with DS, ASD, and DS-ASD, allowing for characterization and comparison of their ICD9/10 diagnoses.⁴ A secondary objective was the development of a higher order classification system based on ICD9/10 diagnoses to allow for identification of meaningful differences in body system dysfunction across populations.

1,087 patients with DS-ASD, 22,862 patients with DS, and 98,979 patients with ASD were identified. Thirty-three compound phecode groupings were developed from 1,886 phecodes. Patients with DS-ASD had higher rates of a wide range of medical and psychological diagnoses compared to those with DS or ASD alone. The compound phenotype classification scheme is a viable method for comparing diagnoses between distinct populations, as well as aggregating differences to produce interpretable phenotypic trends. These trends can both inform clinical practice and provide the basis for future work, such as investigating the link between mortality and comorbidities in those with DS-ASD.

Family, Routines, and Caregiver Distress During the First Year of Pediatric Cancer Treatment

A new diagnosis of pediatric cancer may disrupt family functioning. This study found that during the first year of pediatric cancer treatment, caregivers reported changes in bedtime, mealtime, and school routines; relaxed behavioral expectations and rules around screen time; and new rules and routines around treatment, medications, and infection control.⁵ Caregivers with elevated levels of psychosocial distress reported more changed routines than caregivers with low levels of psychosocial distress. Caregivers who endorsed more cancer-related stressors reported more new rules and routines than those who reported fewer cancer-related stressors.



Families may relax rules and routines during the first several months of diagnosis, and this may be related to side effects of treatment and limited caregiver capacity. The long-term impact of changes in family rules and routines during cancer treatment warrants further study given that accommodating parenting strategies have been associated with adverse short- and long-term child health and behavior outcomes.

An Update on the Assessment and Management of Pediatric Abdominal Pain

Chronic abdominal pain is very common in children and adolescents and results in high personal and social costs. Most youth with chronic abdominal pain fulfil criteria for a functional abdominal pain disorder (FAPD) as defined by Rome criteria. These are complex conditions with a wide array of biological, psychological and social factors contributing to the experience of pain. The purpose of this review was to provide an overview of the pathophysiology of FAPDs and an up-to-date summary of the literature related to FAPDs in children and adolescents, with additional focus on several areas (e.g., diet and probiotics) where patients and families frequently have questions or implement self-directed care.⁶ We also provide an approach to the assessment and treatment of pediatric FAPDs focusing on the robust literature regarding psychological interventions and much sparser literature regarding medication treatment.

Parent Experience During the Single Ventricle Congenital Heart Disease Interstage Period

To explore parents’ experience of transition in the period between the palliative cardiac surgeries (i.e., the interstage period) of an infant with single ventricle congenital heart disease, we conducted an exploratory naturalistic inquiry using a qualitative descriptive approach.⁷

Parents described the experience of transition in interstage as striving for normality, a theme that was clustered in subthemes of home, self and infant. Parents’ experiences of striving for normality indicated a need for more targeted efforts to address parents’ psychosocial needs during the highly stressful interstage transition. This research underscored the complexity of parents’ psychosocial support needs on returning home after their child’s first palliative surgery. The findings also suggest need for examination of the transition following the second palliative heart surgery, when the home monitoring program is withdrawn. Understanding parent needs will help guide health care teams in developing ways to support parents as they adjust to home, self and child.

Weight Status, Medication Use, and Recreational Activities of Treatment-Naïve Transgender Youth

Studies of transgender/gender diverse (TGD) youth indicate a high prevalence of overweight/obesity and concern for unhealthy weight management behavior. This study describes the association of weight status with medication use and recreational activities among treatment-naïve, pediatric TGD patients.⁸

Overweight/obesity is a common problem among TGD youth. TGD youth should be considered a high-risk group and targeted in obesity prevention and treatment efforts. Interventions to decrease sedentary activities and improve connections with friends and family are promising strategies to address overweight and obesity among TGD youth.

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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