



Stanford
MEDICINE

Children's Health

CF Family Advisory Council: A Partnership

Kirsten McGowan

Lead Parent
Family Centered Care

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Our Mission

- To work in *partnership* with the pediatric CF clinic care team to provide the highest quality of care and service to patients and families.

Who Are We

Parents:

Kirsten McGowan

Arek Puzia

Rohini Thukral

Team:

Carlos Milla, MD

Mary Helmers, RN, BSN PHN

Jake Brockmeyer, PharmD, BCPS, BCPPS

Jessica King, RRT-NPS, CPFT

Debbie Menet, LCSW

Cathy Hernandez

CF Research Team (Tina Conti, Sophie Fuller, Lani Demchak)



Children's Health



Family Centered Care promotes partnerships between patients, families and health care providers to help navigate patient care.



What We Do: Projects And Duties

Been in practice since 2003

- Develop support materials: *Transition guides, binder inserts, help with school, life during COVID, etc.*
- Enhance communication between Care Team and families
- Serve as a **voice** for families receiving care at Stanford.



- CF Newsletter
- Website Feedback: <http://med.stanford.edu/cfcenter>
- Social Media updates/content
- Sit on hospital-wide FAC and Patient Safety committees to provide feedback that will impact CF patients/families

Current Projects

Milestones for the Toddler (2-4 years) with CF & Parent/Support Person

PROVIDING & TEACHING	DEPENDING
<p>ROLE OF PARENT/SUPPORT PERSON</p> <p>CF TREATMENTS & MEDICATIONS</p> <ul style="list-style-type: none"> - Setup: Responsible for setting up all equipment and medicine - Taking Treatments: Responsible for day-to-day management <ul style="list-style-type: none"> o Being in the room while child does treatments o Ensuring proper technique is used o Having a plan/system for doing treatment away from home (vacation, daycare, etc.) - Cleaning & Disinfecting: Responsible for cleaning and disinfecting all equipment - Medication Management: Responsible for tracking, sorting and storing all medicines and identifying needs for refills. <p>MANAGING CF CARE & DAILY LIFE</p> <ul style="list-style-type: none"> - Leads all aspects of clinic visits (ask/answer questions, health status, insurance, knowing medications, etc.) - Identify and report changes to care team - Maintain appropriate sleep schedule for child (12-14hrs/day) - Maintain proper diet & nutrition plan for child - Educate all new caregivers (example: extended family, daycare, nanny) about CF care - Remembers to take/carry all medicines (example: enzymes) - Parent/caregiver also needs time for self-care (support system, exercise, sleep, meditation, etc.) 	<p>ROLE OF PERSON WITH CF</p> <p>CF TREATMENTS & MEDICATIONS</p> <ul style="list-style-type: none"> - Child can choose activity for treatments (screen time, book, music, game, etc.) - Child can assist in setting up equipment - With close oversight from parent/support person, child takes and participates in all treatments. - Child takes medicines as prescribed under the direct supervision of parent/support person. - SOME children can learn to swallow enzymes whole at this stage. Start by practicing with something smaller (like a tic-tac). Do not force the child if they are not ready, just try again when they are older. <p>MANAGING CF CARE & DAILY LIFE</p> <ul style="list-style-type: none"> - Can identify if they don't feel good (example: my tummy hurts) - Can wash their own hands or use hand sanitizer - Visit the dentist for the first time for a cleaning - By 4 years old, typically your child can: <ul style="list-style-type: none"> o Talks about what they like or don't like o Follow simple 3-step instructions (example: point to the cat, the horse and the pig) o Can sing songs like "Itsy Bitsy Spider"

- Collaboration with Adult Clinic to promote transition success for teens/young adults
- Providing feedback for CF specialty pharmacy
- Collaborate with LatinX FAC to discuss support for Spanish-speaking families and their needs
- Partner with MyChart team for improved communication for CF familie
- Provide feedback at department-wide summits on Peripheral IVs, Sedation Program and Pain Management

COME JOIN US! BECOME A PARENT ADVISOR!

kmcgowan@stanfordchildrens.org

Thank You

