

Cystic Fibrosis clinic focuses on family centred care



The Robinson family is pictured sitting on the couch with mom Nicole holding Kiana and dad Matt holding Alysa, surrounded by CF team members, from left: Natasha Nunes, Jill Tosswill, Dr. April Price, Erin Fleischer, and Amanda Finnie.

Alysa is four years old and Kiana is 19 months. They live in London with their mom and dad, Nicole and Matt Robinson. Alysa has crazy curly brown hair and loves to read books, watch cartoons and is very excited about starting soccer this spring. Kiana is the daredevil of the two girls, and loves to boogie to music. Nicole is due with her third daughter in June and they are a busy, active family.

You might see Nicole, her baby belly and her two little girls in the halls of Children’s Hospital as they are at the hospital at least once every three months for their regular check-up at the CF Clinic, and they’ve had six inpatient admissions. Both girls were diagnosed with Cystic Fibrosis – Alysa when she was 18 months old, and Kiana prenatally. Their third daughter has been tested prenatally and no CF gene has been detected.

The multidisciplinary staff at the CF Clinic has children like Nicole in mind when they plan their programs and work one-on-one with families.

“It is our job to see the child within the context of the whole family, to make sure a family’s questions are answered, and to look beyond the medical to make sure families have the supports that they need,” says Jill Tosswill, social worker with the CF Clinic.

The kids at the CF Clinic can see up to six clinicians (physician, nurse case manager, RPN, dietician, physiotherapist and social worker) during their visit every three months, and the appointment can be up to three hours. Nicole’s appointments are even longer, because she has two kids with CF.

“The CF team is so awesome,” says Nicole. “Everybody smiles at us, and makes an effort

to stop in and say hi when we are waiting at the clinic. The nurses blow bubbles when they take blood, and the girls look forward to stickers after their appointments.

“The team also does a fabulous job of responding to questions. I really feel like I’m a part of my girls’ team, and everyone is very careful to include Matt and I in our children's plans of treatment.”

Tosswill confirms this philosophy. “We ensure the CF team is very available to families, including by e-mail and pager. We never want a family to think their question is not important. They know their kids. They are the experts.”

When a new baby is diagnosed with CF, parents are given a Parent Handbook for CF as a resource and are encouraged to connect with the local CF Foundation.

At the CF clinic, parents fill out a questionnaire for staff to share so they don’t have to repeat their updates or family history over and over again. Families are also given a copy of a report that is written and printed off while they are in clinic that helps them remember the variety of information that is shared with them when they are at the hospital.

Family centred care is about culture change—from a one-on-one interaction in clinic, to a voice at a boardroom table, and parents are speaking up about their family needs in the health system.

Nicole is a new member on LHSC’s Family Advisory Council (FAC). She joined in December 2008 to share her experiences and to provide a voice of parents who have direct input and influence on policies, programs, and practices that impact the care and services children and families receive.

“I applied to join the FAC because I work with Leslie Meredith, the Chair of the Council. She encouraged me to join to help improve the way the things are at the hospital,” says Nicole.

Nicole’s girls have daily puffers and nebulizer treatments as well as take enzyme medications before they eat or drink. They also have a half hour of chest percussions each three to four times a day. And while it is hard work and stressful to worry about health and shortened life expectancies, the Robinsons still feel like a regular family.

“My girls are regular kids who happen to have CF,” says Nicole. “CF is not who they are, but it is part of who they are.” The CF team understands this, and imparting this concept to health providers is important to families, and is a cornerstone to building family centred care.

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