

CHEO Family Forum – Putting Families First

By Julie Drury
CHEO Family Forum Member
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In 1994 a group of parents and CHEO staff met for the first time to form an advisory committee to the CHEO Board of Trustees. Their goal was to represent the perspective of families with a vision to foster, promote and support the highest quality patient/family centered care at CHEO.

Today CHEO's Family Forum is still going strong. Approximately 18 parents/caregivers/former patients and 8 CHEO resource staff meet monthly to review, discuss and provide advice to administration, staff and physicians on priority issues for families who use CHEO's services.

Where We Are

In addition to providing an advisory role to the CHEO Board of Trustees, Family Forum also provides an annual report to CHEO's Quality Management Council. Family Forum members sit on various committees and task forces at CHEO including; Partnership Councils, the Pain Committee, Multiculturalism Committee, Bilingualism Committee, and the Coordination of Complex Care Committee.

A few Family Forum members are trained as 'Family Faculty', and in this role they provide regular presentations to CHEO staff and medical students about patient/family-centered care, while representing the diverse needs and perspectives of families served by CHEO. These Family Faculty members share their personal stories about their child's journey at CHEO in order to highlight the important messages they share with staff and medical students.

CHEO's Family Forum are also active participants in the Canadian Family Advisory Network (http://www.caphc.org/partnerships_cfan.html), an organization that links family advisory groups that are involved with pediatric acute care, rehabilitation, regions and hospices across Canada. CHEO's Family Forum were proud to host CFAN during the recent *Canadian Association of Pediatric Health Care Centres Conference* held in Ottawa this past October (2011).

What We Do

CHEO's Family Forum is proud of the many successes they have achieved in collaboration with CHEO administration, staff and physicians over the past several years. A few of these successes include:

- ✓ *The Kaitlin Atkinson Resource Library*
This library is located on the first floor of CHEO and provides a collection of books and resources for parents and families who would like more information about a medical condition or diagnosis their child might have. The library is supported by trained librarians who are ready to help.

- ✓ *Parent Sleep Rooms (ICU/NICU)*
With the new PICU and NICU facilities as part of the Gary Cardiff Wing of CHEO, Family Forum provided much needed perspective and advice about the need for parents to have a place to stay in order to be close to their critically ill child. The parent sleep rooms allow for a parent to stay in comfort during this difficult time.
- ✓ *Family Forum Lounge*
The fifth floor Family Forum Lounge provides an area for parents and family members to regroup during a child's stay at CHEO. The Family Lounge offers shower facilities, laundry, a small kitchenette, internet/computer service, a TV and a quiet area to lounge and rest.
- ✓ *Peri-operative Parental Presence*
This is a wonderfully successful initiative which allows parents to enter the operating room with their child to be with them while they undergo sedation for their procedure, and be there when they awaken, reducing anxiety for the parent and providing reassurance for the child during recovery.
- ✓ *Coordination of Care Pilot Program*
Many children who come to CHEO have complicated medical conditions and are considered medically fragile. They have several specialists involved in their case and are often hospitalized or at the Emergency Department. This pilot program, Coordination of Complex Care, provides improved medical coordination, support, and care for these children and their families. It recently won the Innovation Prize at the Canadian Association of Pediatric Health Care Centres Conference.

As a parent of a child who frequents CHEO and a Family Forum member myself, I am inspired by the work that has been achieved and by the initiatives we have planned for the upcoming year. This year, Family Forum has identified six priorities on which to focus their attention. These include:

- Youth Transition to the Adult Health Care Sector
- Continuation of the Coordination of Complex Care Program
- Mental Health for Children and Youth
- Family Friendly Environment
- Child Life Services
- Parent to Parent Support

If you would like more information about CHEO's Family Forum, please feel free to contact CHEO's Patient/Family Representative & Coordinator for Patient/Family Centred Care at 613-737-7600 ext.2203.

