



Established Roots, Growing Strong, Branching Out

2014–15 ANNUAL REPORT
FAMILY CENTRED CARE



"If we didn't have families involved like we do through the Stollery Family Centred Care Network, it would be like having a hospital without surgeons!"

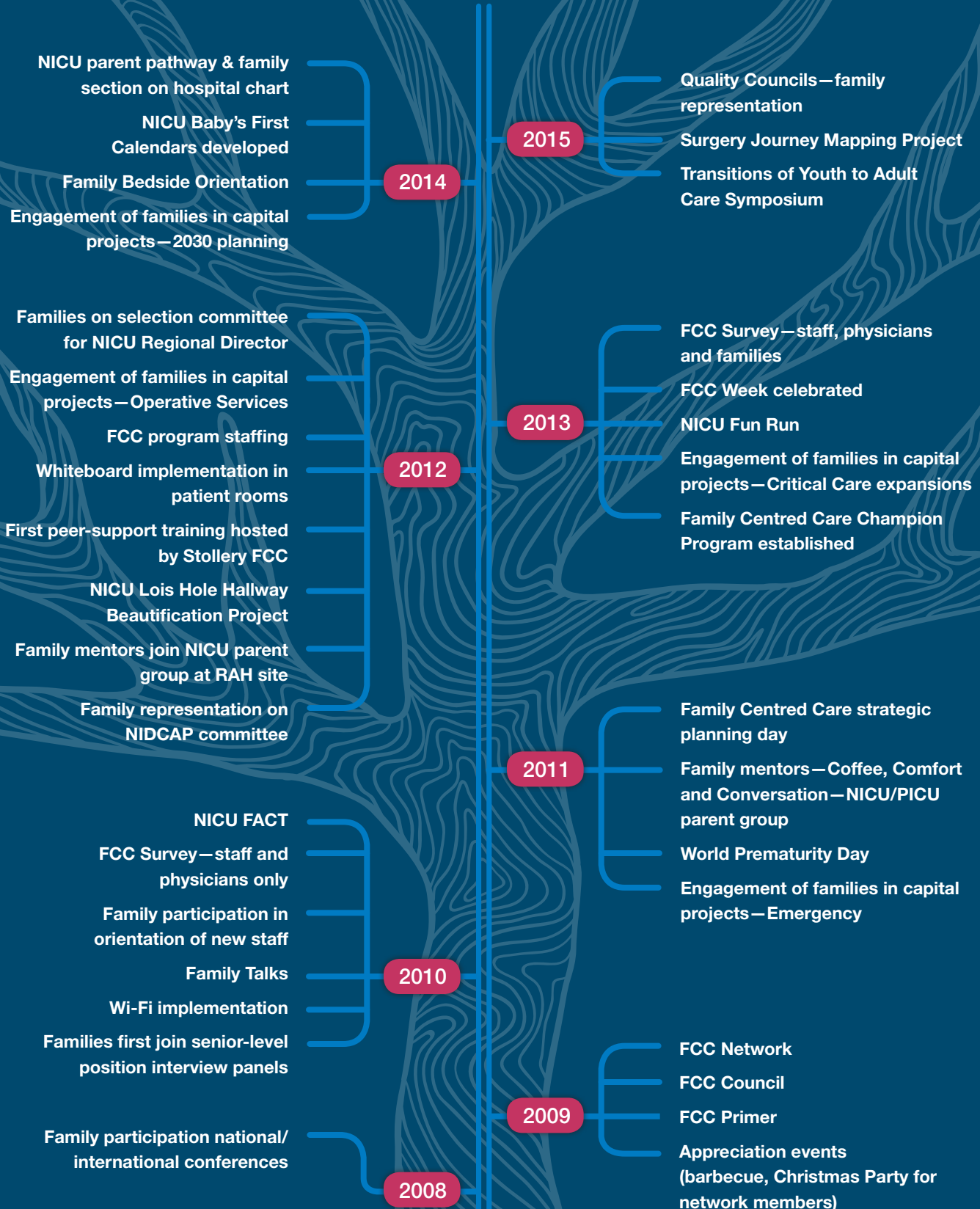
— Dr. Alf Conradi, MD, FRCPC, Pediatric Intensivist

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THE 'FAMILY CENTRED CARE' TREE



established roots

Development of the family-centred care philosophy and practice at the Stollery Children's Hospital over nearly a decade could not have happened without the dedication, persistence and support of staff, patients, family members and senior executive leadership. The Stollery now radiates the essence of family-centred care, with firmly rooted programs, services and practices that recognize family members as a valued part of a child's care team, and that family members and past patients can make important contributions to hospital operations and decision-making.

The core roots of family-centred care at the Stollery are secured in the

- Family Centred Care Council
- NICU Family Advisory Care Team (NICU FACT), and
- Family Centred Care Network

With quiet determination and long-term dedication, the Council, NICU FACT and the Network have provided nourishment and found fertile ground in pockets of the health-care system to feed and build the foundation of family-centred care at the Stollery. These programs have grown over the years and currently include a diverse mix of patients, family members including siblings, staff, physicians and people in senior leadership positions. These influential groups are now firmly rooted in family-centred care initiatives and practices at the Stollery and are beginning to branch out.

Supported and strengthened by the Alberta Health Services Patient First Strategy 2015, the family centred care programs focused this year on transitions of youth to adult care, youth engagement and greater patient and family involvement in areas including planning, design, peer support and quality.

Trust and credibility have been gained; families' voices are now genuinely welcomed and valued at all levels of practice and operations. A testament to this is the addition of 10 family members to six Quality Councils this past year.

Family Centred Care Council

The Family Centred Care Council sets Stollery-wide strategic priorities and initiatives through an active membership of young adults, family members, staff, physicians and senior leadership totalling 24 people.

The value of engaging the patient and family voice was demonstrated by the spirit of collaboration, partnership and leadership shown by this group in:

- Establishing family positions on Quality Councils

- Forging partnerships with adult care providers to aid in transitions of youth to adult care, and
- Implementing the Family Bedside Orientation project

The families' commitment to furthering family-centred care by using their personal stories to promote positive change [is one of the strengths of the FCC Council]

— Physician

NICU Family Advisory Care Team (NICU FACT)

This 24-member team—made up of staff, family members, physicians and NICU leadership—is very active in family-centred care projects and initiatives. NICU FACT supports the NICU Care Team in promoting the values, perspective and practices of family-centred care, effective communication, and facilitated learning among all members of the care team.

This past year, NICU FACT focused on the following key initiatives:

- Creating a family section in the permanent hospital chart
- Improving the transfer process between units and hospitals
- Baby's Journey: a unit-wide quality-improvement initiative
- Family representation on the NIDCAP Committee
- Family representation on the Regional NICU Operations Committee
- Family input/review of research projects

- NeoPal working group
- Royal Alexandra Hospital 2030 planning

Family Centred Care Network

The Family Centred Care Network is made up of a large number of patients, family members and staff who want to stay informed about family-centred care initiatives and opportunities to get involved at the Stollery. Some actively participate on councils; share their stories at staff orientations and other speaking engagements; review and provide input on policies, procedures and educational materials; participate in peer-support initiatives; and participate in senior-level interview panels—to name just a few. Yet another way members stay informed is through the monthly email newsletter, the Family Centred Care Primer. The fluidity of this network allows members to stay engaged to the degree to which they want to be at any given time. There are many reasons families want to be involved:

“Whether it be in research, family involvement at bedside, hospital development and planning or councils, the parents have a vital and very important role. Our voice matters!”

—a family member describing the network

“Lived out, these ideas have the power to bring empowerment, encouragement and transformation out of anxiety, suffering and fear.”

—a family member describing the network

“Our children have already paid; let’s make sure we honour them and use these experiences to bless as many families, children, caregivers and health-care professionals as we possibly can. Our kids are worth it.”

—a family member describing the network

Staff Supporting Family-Centred Care

Supporting patients, families and staff volunteers in the work of family-centred care requires a strong foundation and dedicated staff. This past year, staff included the following people:

- Heather McCrady, Manager, Family Centred Care
- Michelle Childs, Coordinator, Family Centred Care
- Christie Oswald, Coordinator, Family Centred Care
- Jasmine Rosentreter, Social Worker, Family Centred Care

As well, we bid farewell to Kaitlin Bruner in October 2015 after over eight years supporting families and children in the Family Room, and we welcomed Chrystal Plante as the new Secretary.



Heather McCrady



Michelle Childs



Christie Oswald



Chrystal Plante

NUMBER OF
FAMILY CENTRED
CARE NETWORK
MEMBERS

120
FAMILY

240
COMMUNITY

269
STAFF

1,844
FAMILY VOLUNTEER HOURS

growing strong

The seeds of the Family Centred Care program at the Stollery were planted a decade ago. With time and persistence, the program has become well established at the Stollery as a culture and a “way of being.” The founding projects of the Family Centred Care (FCC) Council and NICU Family Advisory Care Team (NICU FACT) have become firmly established as prominent and necessary to family-centred care at the Stollery. These foundational programs and groups provided a strong basis from which new initiatives emerged in 2014–15. Here are some of our key highlights of the year.

Transitions of Youth to Adult Care Symposium

The Family Centred Care Council held a Transitions of Youth to Adult Care Symposium in March 2015. The purpose of the symposium was to discuss a strategy for building and implementing an effective approach to transitioning youth with chronic health conditions to adult care in northern Alberta. Attendees learned about other Canadian youth-to-adult-care transition programs from speakers who shared their expertise from Sick Kids’ Good to Go transition program in Toronto, BC Children’s Hospital’s ONTRAC transition program and Alberta Children’s Hospital’s Well on Your Way transition program. One hundred pediatric- and adult-care providers attended, along with 13 young adults and parents, plus 60 participants via video conference.

Following discussions at the symposium, the Steering Committee expanded its membership to include representatives from the Glenrose Rehabilitation Hospital, Family Medicine and Primary Care in an effort to further collaborate with adult care. A “transitions framework” document and other tools for health-care providers, parents, teens and young adults is currently being developed by this group.

Other Recommendations from the Symposium

- Aligning the regional transition focus with provincial and national initiatives.
- Increasing awareness and collaboration with pediatric and adult health-care providers, young adults and parents across the health system.
- Identifying champions who can support the transition implementation process.
- Supporting the transition process in beginning as early as 12 years of age and continuing until the early 20s.
- Building relationships between youth, specialists and family physicians early in the transition process, including tours of adult clinics and early education on how to prepare for adult care.

- Adaptation of existing resources for youth and parents from other established Canadian transition programs to meet the needs of our program.
- Developing a shared regional model, including transition principles, clinical pathways and guidelines.
- Utilization of technology, online resources, apps etc. for the transition model rollout.
- Conducting research to build on current knowledge and determine the effectiveness of transition processes and tools.
- Securing funding for sustained and dedicated staff, resources and tools for standardized transition processes.
- Piloting the transition model and building capacity to bring other clinics on board.



Family Member Simone Chalifoux and Young Adult Lacey Haddon presenting at the symposium.



Symposium attendees in small working groups.

Engagement of Families in Capital Projects

Families were included in the planning committees and focus groups for capital projects such as Operative Services, Critical Care Expansions, and Stollery RAH Site 2030 Planning Focus Groups. The inclusion of families in these planning sessions has ensured that the viewpoints of pediatric patients’ families are represented and incorporated. Family members participated in “mock-up” patient rooms and were able to provide valuable input on room design that accommodates the needs of both staff and families.

“From an architect’s perspective, the Family Users brought invaluable insights during the design process as they shared crucial values and personal experiences.”

— John Lee, Architect, Associate, HFKS Architects Inc.

Quality Councils: Engagement of Families in Senior Level Committees

A new initiative this past year has been to engage families with the newly formed Stollery Quality Councils. Family members bring new ideas and creative solutions, help clarify possible assumptions, contribute expertise from their careers and experiences, share stories and help communicate issues and results to other patients and families.

The goal of the Quality Councils is to deliver better quality, better outcomes and better value to patients at the Stollery. Quality Councils throughout the hospital are a venue for front-line teams to participate in quality planning, quality monitoring and quality improvement.

This past year, we were able to have 10 family representatives on six Quality Councils.

Having families at the table on these important quality-improvement initiatives is key to ensuring the patient and family voice remains at the centre of care at the Stollery.

“Families have the ability to convey their personal experiences in such a way that it leaves a lasting impression with our staff. This fresh perspective enhances the care we provide to our patients and their families.”

— Kristy Cunningham, Co-chair PC IC U and PIC U Quality Council

“The role-playing component of the ‘Family Talks’ program means the physician trainees can work through difficult scenarios with parents; receive valuable feedback; and reflect; all before they are faced with a similar situation in clinical practice.”

— Dr. Chloe Joynt, Neonatologist

Family Talks

Engaging young adults and families in sharing their stories helps to further the understanding and integration of patient- and family-centred care practices at the Stollery. Family Talks are now part of new-staff orientation, nursing classes at post-secondary institutions, staff meetings, national and international conferences, visioning and strategic-planning days and more. Family presentations are built around key messages, helping staff recognize how they make a difference in care and reconnecting them with patients and why they chose this career path in the first place.

Peer Support



Family Bedside Orientation Leadership Team of staff and one parent, Nicole Lyste (front right)

Family Mentors offer peer support in a number of family-centred care initiatives at the Stollery, providing parents with a unique and valuable perspective on coping within the health-care system. Mentors attend a two-day training to learn how to

provide peer support to inpatient families. Peer support programs include the following:

- PICU/NICU Parent Coffee Hour
- NICU—RAH Site Parent Group
- Family Bedside Orientation



Family Bedside Orientation—Unit 5G4

In December 2014, a Stollery Children's Hospital and Family Centred Care Council initiative, made possible by the Canadian Foundation for Healthcare Improvement, introduced a peer-support presence for families on the 5G4 medicine inpatient unit. The goals of the Family Bedside Orientations initiative, were to improve patient safety and encourage families to become involved in their child's care and care team.

This initiative invites former patient families back to the unit as volunteer peer mentors responsible for orienting current families to hospital surroundings and providing information on how they can participate in patient care practices.

The success of the project is evident in its acceptance by staff and the support and accolades it has received from families. "It's always nice to talk to someone who has been there. [It] takes stress off of what's happening with our kid" said one family member.

Validating a family's feelings and experiences around their child's care provides encouragement and support. Families have indicated that the practical information provided to them by mentors, including parking information and the use of the patient bedside whiteboards for communication with the care team, has made their hospital stay much easier.

As one staff member commented, "Calming one stressed family down through a Family Mentor visit means calming the whole unit down."

Peer mentors have noted that the goals of the project are being met and that they are able to be a listening presence, assist with health-system navigation, empower caregivers to be advocates in their child's care, and support caregivers in transitioning a child home or to another unit.

Surgical Journey Mapping Project

A huge quality-improvement initiative for the Stollery was to map the surgical journey of patients and families from the point of referral all the way to follow-up, and the numerous touch points in between. Every step of the process was reviewed and discussed to understand where the process might be improved. A multi-disciplinary team was involved in the process, including consultants, physicians, surgeons, medical-device reprocessing technicians, environmental services, nurses, bed managers, management, quality-improvement professionals, a family member and many others.

From the consultative mapping day sessions, six quality-improvement working groups were established including Discharge Practices, Pre-Admission Clinic/Surgical Clinics, Operating Room Booking, Operating Room and Dayward Processes, Inpatient Practices, and Medical Device Reprocessing. These working groups report back to the Stollery Surgical Quality Council on progress and change.

One of the highlights of the project was that the key family member involved was able to directly speak with staff about what incredible work they are doing and how proud they should be of what they do for patients and families. She shared how she tells many families she meets about how hard the staff work to improve care for children.

FAMILY BEDSIDE ORIENTATION PROJECT – RESULTS FROM 2014/15

114
peer-support visits with
103 families

80%
of families rated the visit as
"very important or extremely
important" to them

Celebrations

The Family Centred Care Council is always looking for ways to recognize the important volunteer work of families and youth, as well as staff dedication to this work. Many annual events are hosted or supported by the FCC Council as a way of thanking people and showing appreciation.

CELEBRATIONS HELD SEPTEMBER 2014 TO AUGUST 2015

September	FCC Network Fall Family Barbecue
September	Second annual NICU Fun Run/Walk
October	Family Centred Care Week
November	World Prematurity Day
December	FCC Network Christmas Party
May	Parents of Premies Day
June	FCC Network Summer Party Barbecue

FAMILY ENGAGEMENT

25 speakers, **37**
speaking engagements

198
peer-support interactions

14
volunteer Family Mentors
in all peer-support
initiatives

17
policies and educational
materials reviewed

4 families on corporate planning
16 committees and
families in focus groups

20 family seats at senior-level
Stollery committees

10 family members on **6**
Quality Councils

11 family member and **3**
past-patient/youth positions on
FCC Council

14
family members on NICU FACT



Participants enjoying FCC Summer Party Barbecue



Participants enjoying FCC Summer Party Barbecue



FCC Network Christmas Party



Participants warming up at NICU Fun Run/Walk

branching out

Our initiatives and family involvement opportunities are branching out and becoming far-reaching in the health system, demonstrated by the focus on transitions of youth to adult care; family representation on Quality Councils; and the visioning, planning and design of future capital projects for pediatric care.

We are literally branching out beyond the walls of the main Stollery Children's Hospital site, touching spaces in other buildings where Stollery programs and units reside; reaching into the adult world of patient care to smooth transitions; participating in provincial initiatives like the First Patient Advisory Conference and national events with the Canadian Family Advisory Network (CFAN) and at the Canadian Association of Paediatric Health Centres (CAPHC) conference and stretching patient- and family-centred care into the community as with the Awesome Project (see sidebar).

The future is bright, and we are excited that the priorities of the Family Centred Care Council and NICU FACT for 2015–16 include the following:

- Strengthening the membership and infrastructure of the FCC Network
- Enhancing the engagement of youth and young adults in network initiatives
- Establishing a Cardiology Family Advisory Care Team
- Enhancing awareness about the Stollery at the Royal Alexandra Hospital NICU

- Participating in the Regional NICU Visioning Day and the Walter C. Mackenzie Campus 2030 Planning and Visioning Day
- Augmenting the FCC team with an Aboriginal Child Health Nurse Coordinator position

The Awesome Project is a campaign aiming to bring to light the damaging effects of using the word “retarded.” Fifteen-year-old Karleen Rutter first presented her initiative to her junior high-school leadership conference, and with the assistance of Qi Creative, she created an inspiring video using her family's story as an example of how a person can “embrace and learn from diversity.”

Karleen and her family are active members of the Stollery Family Centred Care Network, having presented their story numerous times. Though not a project of the network, it's an indication of how this work extends beyond the walls of the Stollery.

“Not only should we respect people with differences, we should realize how they enlighten everyone.”—Karleen Rutter

gratitude

We are grateful for everyone who plays a role in nurturing the family-centred care philosophy that has taken root at the Stollery Children's Hospital.

Family-centred care would be nothing without the following:

- The Stollery Children's Hospital Foundation, which generously funds family-centred care initiatives
- Stollery leadership, who provide vision and support
- Patient and family volunteers, who generously tell their stories, work to improve the system, and mentor other families
- Staff and physicians, who champion this work in their everyday practice and beyond

WE GROW STRONGER WITH MEMBERS

JOIN US:

**Call 780-407-7255 or email
stolleryfcc@albertahealthservices.ca.
You can complete an online application form
at <http://bit.ly/stolleryfcc>**

strength in members

Through the ongoing commitment and dedication of the Family Centred Care Champions, members of the Family Centred Care Network, Family Centred Care Council, and NICU FACT, the Family Centred Care program has established a permanent foothold in programming at the Stollery, and our tree is growing and branching out.

Family Centred Care Champions

Congratulations to the champions of family-centred care in 2014–15 who received our prestigious Family Centred Care Champion pin. This award recognizes network members who have demonstrated exceptional service to the FCC Council, have incorporated the principles of family-centred care into their own practice, or have had a significant impact on the development and facilitation of such initiatives in Edmonton. The NICU FACT and FCC Council members recognized have volunteered their time for more than two years. We would like to thank these volunteers for their continuing leadership, dedication and support.

Jodie Craven,
family member

Kevin George,
family member

Nicole Lyste,
family member

Shannon Robertson,
family member

Mary Ellen Hawkins,
Stollery Program
Coordinator

Valerie Levesque,
NICU Transport Nurse

Tracy MacDonald,
Stollery Senior
Operating Officer

Family Centred Care Council Members

Current Members

Family Members

Simone Chalifoux

Jodie Craven, past chair

Donald Lepp

Poonam Maddan

Ali Martens

Amanda Moon

Anne-Marie Paquin

Daniel Paquin

Amanda Proctor

Shannon Robertson

Shelley Wywal

Previous Stollery Patient/ Sibling

Erin Cripps-Woods

Andrew Hendricks

Tristan Pidner, Co-Chair

Physicians

Natalie Anton

Rehana Chatur

Dawn Davies

Staff

Janice Belyea, Co-Chair

Lynett Kane

Deb Olmstead

Stollery Leadership

Bridget Smith

Christine Westerlund

Completed Service on FCC Council

Family Members

Monica Sneath

Staff

Kaitlin Bruner

Myrna Landers

Jasmine Rosentreter

Stollery Leadership

Tracy Macdonald

Tim Tsounis

NICU FACT Members

Current Members

Family Members

Stephanie Amoah

Jodie Craven

Samantha Figueroa
Garcia

Kevin George

Jennifer Hanrahan

Leah Johnson-Coyle

Nicole Lyste, Co-Chair

Allan Macdairmid

Natasha Martin

Ian Mathieson

Raya Owen

Amanda Proctor

Sarah Topilko

Kristy Wolfe

Physicians

Amber Reichert

Jennifer Toye

Juzer Tyebkhan

Staff

Revee Agyepong

Barb Davis

Amanda Eccleston

Tara Follett

Bev Rennie

Amanda Schroeder

Cathy Ward

Stollery Leadership

Kristy Cunningham

Karen Pelletier

Bridget Smith

Completed Service on NICU FACT

Family Members

Joyce Tang

Kim George

Physicians

Dr. Sandra Escoredo

Staff

Chantal Balash

Kaitlin Bruner

Jacqueline Cook

Doryta Foote

Diandra Yates

Valerie Levesque

Stollery Leadership

Carol-Anne Middleton

Daisy Garvey

Christine Westerlund

Stollery Quality Council Family Representatives

Child Health Quality Assurance, Improvement, and Patient Safety Collaborative (CHIPS)

Amanda Moon

Ambulatory Care

Anne-Marie Paquin

Ashley Volkerink

Surgery

Karen Calhoun

Medicine

Chad Herbers

Nicole Lyste

Blessie Mathew

PICU/PCICU

Donald Lepp

Rosella Trulli

Monica Sneath,
past representative

NICU (CPQI)

Caitlin Nicholson

Ian Mathieson,
past representative

Family Room and Family Centred Care Staff

Current

Michelle Childs

Heather McCrady

Christie Oswald

Chrystal Plante

Family Room Casual Evening and Weekend

Alexandra Dixon

Jasmine Minhas

Louise Sevigny

Completed Service with FCC Staff

Kaitlin Bruner

Brianne Smith

Katie Wilkes



From a small seed a mighty trunk may grow.

— Aeschylus