



Sharing Our Unfolding Story

2013-2014 ANNUAL REPORT
FAMILY CENTRED CARE





*nurturing an attitude
of gratitude*

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visioning

The Stollery Children's Hospital strives to be a leader in family centred care (FCC) by placing children and youth at the centre of how we provide care.

We always recognize the family as valued members of their child's care team and in the operations of the hospital.

We aspire to practice family centred care in a collaborative, consistent and continuous way.

thanking

We wish to acknowledge the Stollery Children's Hospital Foundation for their generous funding of family centred care initiatives and the Stollery Leadership for their vision and unwavering support.

A special thank you is extended to the family and staff volunteers who give so much of their time to share their perspectives, experiences and stories to improve the family experience at our hospital.

6 advancing **7** honouring **8** reaching **10** evolving **11** recognizing

reflecting

The Family Centred Care Council draws upon the foundation that was put in place by our original Council, which began in October 2009. The Family Centred Care Council has grown over the past years, and is now a diverse mix of former patients, families, staff, physicians and senior executives. These members provide strong leadership to guide the family centred care initiatives throughout our hospital.

This past year, the Council's work evolved to expand on these core values:

- **Consistency of the Family Voice** – An increasing number of families and former patients are a part of orientations, training sessions, staff interviews and committees.
- **Belief in Collaboration** – Our original commitment to a collaborative Council model continues, as we invite families, staff and physicians to partner together to address common priorities and initiatives.
- **Importance of Relationships** - The first few years, we focused on awareness and knowledge of family centred care at the Stollery. This past year, our relationships have deepened to more fully engage staff, recognize key champions and to nurture relationships based on mutual trust.
- **Championed by Senior Leadership** - The Stollery Senior Leadership group continues to champion family centred care practice at the hospital. Our work has flourished with their ongoing vision and support.
- **Honouring the Unique Perspective of Families** - Family representatives are at the core of this work. They bring new ideas and approaches forward, which propels the practice of family centred care at the Stollery.

NICU FACT Deepens its Roots

The NICU Family Advisory Care Team (FACT) began in the fall of 2009. What started with a small, dedicated group of families, physicians and staff has quickly evolved into an influential, collaborative team with representation from the NICUs at the David Schiff site and the Royal Alexandra Hospital (RAH). The members of FACT are a committed team that is dedicated to ensuring that core family centred care values are upheld in the neonatal intensive care environments.

Looking back, we realize the success of Council and FACT is due to a commitment to true collaboration: both groups feature a partnership of families, staff and physicians who each have an equal voice at the table. Members respect different points of view and share their own unique perspectives through telling their own stories.

Building a Network

We realized that not everyone is able to sit on a formal committee, so we formed the Family Centred Care Network. Building upon the initiatives and direction from the Family Centred Care Council, Network members provide valuable input on policies and educational materials, and share their expertise at presentations and committee meetings.

Becoming a member of the Network is easy and open to any family member, patient, staff, physician or member of the community who is interested in family centred care at the Stollery. Members receive a monthly Primer that keeps them informed of activities at the hospital, and shares opportunities for them to become involved.

We Have Dedicated Staff

We believe that family centred care requires dedicated staff to support the important work of family and staff volunteers.

This past year, our staff included:

- Heather Mattson McCrady – Manager, Family Centred Care
- Marni Panas – Coordinator, Family Centred Care
- Kaitlin Bruner – Administrative Assistant, Family Centred Care

We bid farewell to Family Centred Care Coordinator Marni Panas in September 2014, and warmly welcomed new Coordinator Christie Oswald.

**NUMBER
OF NETWORK
MEMBERS**

128
FAMILY

164
COMMUNITY

284
STAFF

1,500
FAMILY VOLUNTEER HOURS

championing

We've built on our past successes and led new initiatives this past year. Our new work demonstrates the evolution of family centred care at the Stollery. Here's how we've championed our key wins in 2013-2014.

Top Five Council Priorities

1. Family Talks

Family Talks is our popular presentation program, where families tell their stories with intent to inspire, motivate and educate health professionals. Families often share the podium with staff and physicians. This program has also evolved from lecture-style presentations to dip our toes into a more engaging style with a Pecha Kucha approach (20 slides in 20 minutes), role-playing scenarios created in collaboration with families, simulation and facilitating dialogue-based conversations.

The family voice is now regularly embedded during presentations at Pediatric Nurses' Orientation, NICU New Staff Orientation, PICU New Nurses' Orientation, PICU Fellows Role Playing, NICU Fellows Orientation & Role Playing, and MacEwan University Nursing Students.

We also added new audiences to our roster, including: Wee Wonders Workshop – an education day for NICU Nurses; and Child and Mental Health Grand Rounds at the Glenrose Rehabilitation Hospital (this was the first time a family member has spoken to this group of mental health professionals).

Having actual family members play the roles was helpful and the scenarios were very realistic

— new nurse evaluation

2. Peer Support



Family-to-family support has been a key priority since the inception of the Council. Our unit-based group and individual support continues to grow, thanks to partnerships with social work, child

life and nursing staff. This year, we were involved with peer support research in the Pediatric Cardiac Intensive Care Unit, hosted a sold-out peer support training session in March and continued to host group and one-on-one peer support sessions with families in the NICUs and PICU.

We are thrilled that we were accepted to be part of the *Partnering with Patients and Families for Quality Improvement: a Canadian Foundation for Healthcare Improvement Collaborative*. This grant will fund Family Bedside Orientations – an important new peer support and quality improvement initiative on the Medicine Inpatient Unit to support family engagement with their child's care team.

3. Family Centred Design

Due to growing demand, renovations and expansions continue in our ever-changing physical space. Families are now consistently part of the Capital Project teams. Bringing their family perspective to design discussions has supported our vision of creating family and child-friendly healing spaces in the hospital environment. Our participation in design projects included:



Critical Care Expansion (Pediatric Intensive Care, Neonatal Intensive Care and Pediatric Cardiac Intensive Care), Operative Services Expansion, and the Ambulatory Care Clinic Design.

4. Transitions from Youth to Adult Care

The transition from pediatric care to adult care is a crucial stage in the healthcare journey. The results of a youth to adult transition questionnaire highlighted the importance of successful transitioning, and the gaps we have in our hospital to provide that service.

A team of staff, physicians, previous patients and families started addressing this work by reviewing what resources, tools and processes are currently in place at the Stollery to support teens and their families as they transition to adult care. Next up? A one-day symposium with key stakeholders is being scheduled in early 2015.

advancing

In our quest to embed family centred care throughout the organization, we've planted the seeds in a number of strategic areas. Our visibility has increased throughout the hospital, as more family representatives are more active on an organizational level.

1. Family Involvement in Resuscitation at 23 Weeks Gestation Policy

Families with NICU experience were involved in the review of the 23 Weeks Gestation Policy to influence practice in resuscitating extremely premature babies. This was a significant engagement of families in a sensitive and ethical issue. Family perspective and stories were used in the article written for the Canadian Pediatrics Society Journal, Pediatrics (Volume 134, Number 5, November 2014). This article highlighted the value of parents and NICU FACT participation in this important conversation.

2. Your Baby's Milestones



In partnership with WP Wagner High School Design and Communication classes, we created a calendar with stickers to represent a baby's milestones in NICU. This calendar is for families and staff to recognize

and celebrate the unique and important achievements their babies make in the intensive care environment.

3. Family Representation on Committees

We continue to have family reps provide a strong voice on hospital committees. This year, families have been invited to participate on the new Stollery Quality Council and unit specific quality councils: PICU/PCICU, NICU, Medicine, and Surgery.

4. Research

This year was the first time that families were actively involved (and not only participants) in a research project. True engagement came in the form of Family Mentors participating directly in the Pediatric Cardiac Intensive Care Unit (PCICU) research project.

Family Mentors offered peer support to fifteen families who were having a child transferred from PCICU to another unit. We look forward to seeing the published results to find out if families who are present and engaged during Transfer

FAMILY ENGAGEMENT

25 speakers, **46**
speaking engagements

43

Peer Support Interactions

30
Educational Materials and
Policies Reviewed

8 family seats at Sr. Level
Stollery Committees

7
Participation on
Interview Panels

2 previous patients and **14**
family members on FCC Council

14 family members on NICU
Family Advisory Care Team

Rounds decreases parental stress and improve patient safety following transfer from the PICU to the ward.

5. NICU Photo Album

FACT staff members have been scanning photos to place in digital frames in the NICU. Digital frames were installed in locations easily viewed by staff and families both to recognize and honour families who have sent follow-up photos to the unit, and to provide support and hope for current inpatient families.

6. Evaluation

Our Family Centred Care Survey results, which were analyzed in 2013, continue to guide and influence our work going forward. Both the Council and NICU FACT set their priorities based on the results, and our successful Canadian Foundation for Health Care Improvement grant application referenced and built upon the recommendations from this important work.

7. Neonatal Palliative Care Focus and Working Group

Five family members took part in a focus group about supporting palliative care needs in the NICU. A report has been published about this important work, and two family members are now part of the working group moving forward.



honouring

Our work honours the experience of families who are encountering great stress and anxiety from having a sick child. But we also never forget to focus on the strengths of children and families, and believe that the birth and life of every child should be celebrated. We recognize the resiliency of all caregivers, whether they are families, physicians or staff members. We also like having fun while recognizing the good work that's being done!



1. Family Centred Care Week

Our first ever celebration of Family Centred Care Week happened September 30 to October 3, 2013. We joined our partners across Alberta to formally thank our awesome Stollery staff members, and raise awareness about family centred care in the hospital.

2. NICU Fun Run in the Park



To celebrate the 40 year anniversary of the David Schiff NICU last September, the first ever NICU Fun Run featured over 300 NICU grads, families, staff and physicians.

3. World Prematurity Day

For the third year, families and staff participated in World Prematurity Day on November 17, 2013. Highlights included the participation of over 600 people at NICU Graduate Events across Edmonton in honour of babies who are born premature and their families.



4. Family Centred Care Champion Program

To recognize individuals who have provided a significant contribution to family centred care at the Stollery, we established the Family Centred Care Champion program. Nominated individuals are presented with a special Family Centred Care pin and are recognized for their work advancing care at our hospital. Last year, thirteen Champions were acknowledged for their valuable leadership.



5. Appreciation Events

Every year, we host a Fall Barbecue and Christmas Party for Network members. This is a chance to relax, get to know each other and have fun with our children.

**FAMILY
CENTRED
CARE
WEEK**

100

Hours of time contributed by 15 family members to volunteer at the Family Centred Care display booths and to thank staff.

1000

Pieces of cake delivered to every unit, clinic and office at every Stollery site.

3

Participation in three special presentations: NICU Grand Rounds, Pediatric Grand Rounds, and a co-presentation, Pecha Kucha style, with Alberta Children's Hospital.



Don't be afraid to go out on a limb. That's where the fruit is.
— H. Jackson Browne

reaching

We are proud of the work done by our family and staff, and so we've ventured beyond our walls and started sharing our stories with the world. We hope that other family leaders and health professionals can be inspired from learning about our wins, our struggles and our lessons.



National & International Conference Activity

A partnership of families, staff member and physicians presented posters and presentations at these national and international conferences:

- September 2013 - NICU NIDCAP Trainers Meeting, Sharing of FCC Survey, participation in panel of family members, North Carolina.
- October 2013 - Poster Presentation, Family and Service Providers' Perceptions Regarding the Delivery of Family Centred Care at the Stollery Children's Hospital, Canadian Association of Pediatric Health Centres Conference, Toronto.

- October 2013 – Presentation, NICU Fellows Education: When Families are Part of the Story, Canadian Association of Pediatric Health Centres Conference, Toronto.
- August 2014 – Presentation, Empowering Family Members: A Model of Engagement Beyond a Council, Institute of Patient and Family Centered Care International Conference, Vancouver.

Spotlight on Media

We were pleased to receive media attention about some of our important initiatives. We shared our stories with television and print media to spread our family centred care message with our local community.

We had two family members speak at a Human Milk Bank event in the spring. They were interviewed for various media outlets.

Shift in Focus article: this was a story about the Stollery's leadership in family centred care in Canada, and featured interviews with staff and family members. Heroes Magazine, Stollery Children's Hospital Foundation, Spring 2014.

A story about Baby Milestones in the NICU was featured on Global Edmonton (Health Matters) in June and was published in the July Alberta Health Services Zone News.

Heather Chinnery, a Clinical Nurse Specialist in the NICU, was honored as a Hero in Nursing for the Hospital News



*Your hospital is the gold standard to which
all other hospitals should aspire to be.*

—Dr. Gretchen Lawhon, NIDCAP Federation International President

and AHS Zone news. A family perspective was shared in the nomination and the story.

Reaching Out to Others



To honour our commitment to having diverse family representation, we now have Council and NICU FACT members participate from their homes outside of Edmonton area. We have members in Winnipeg, Calgary and Grande Prairie, and utilize our virtual technology to include them in our meetings.

In April 2014, we participated in an Alberta Health Services Patients First Consultation session, in partnership with the Glenrose Family Advisory Network. This Consultation was part of a broad series of consultations that included patients and families, AHS staff and physicians, and the community at large. Participants shared their experiences and opinions about how to work together toward patient and family centred health care.

We had a joint Presentation with Alberta Children’s Hospital Family Centred Care staff in Calgary in celebration of Family Centred Care week. We used Pecha Kucha’s style, and shared 20 slides in 20 minutes, leading to a fun and engaging presentation.

Nationally, we are proud of our representation on the Canadian Family Advisory Network (CFAN). The Stollery Children’s Hospital Foundation sponsored four family members to

*What is essential is
invisible to the eye.*

—The Little Prince

attend the CFAN and Canadian Association of Pediatric Health Centres (CAPHC) Conference in Toronto in October 2013. We were also invited as speakers to present at CAPHC to discuss the integration of families into role-playing and training of NICU Fellows.

We continue to nurture close relationships with our colleagues at Alberta Health Services (AHS) Patient Engagement, Alberta Children’s Hospital, the Glenrose Rehabilitation Hospital and South Health Campus in Calgary. We also participate in the Child Health Patient and Family Centred Care Working Group, with our colleagues in Red Deer, Grande Prairie, Lethbridge and Medicine Hat.

We are happy to respond to requests for information about our work from all over the world. Our reach has expanded as far away as Australia and Israel.

evolving

Looking into our future

New ideas to improve the family experience flow from our Council, FACT, Network members and more informal lively conversations in the hospital hallways. We also intentionally meet regularly with the Stollery Senior Leadership to identify priorities and solidify ideas that come from multiple discussions, meetings and requests. Our staff are constantly gathering ideas and categorizing them into strategic priorities, which are chosen by our formal committees each year.

The Family Centred Care Council has identified the following strategic priorities for the upcoming year:

1. Capital Planning

- Critical Care Expansion and Design
- Operative Services Expansion and Design

2. Peer Support

- Family Bedside Orientations
- Coffee Comfort and Conversation

3. Transitions of Youth to Adult Care

4. Quality Councils

- Stollery Quality Council
- PICU/PCICU Quality Council
- Medicine Quality Council
- NICU Quality Council
- Surgery Quality Council

The NICU FACT Priorities for 2014-2015 include:

1. Information Sheets for Different Units and Hospitals
2. Generic Toolkit – to explain the transfer and discharge process to families
3. Prototype of Parent Section in the baby's chart
4. Peer Support
 - Coffee Hour at the David Schiff Site
 - Parent Group at RAH
 - Perinatal Peer Support (new)
5. Inspirational Sayings for Staff Members
6. NICU Collaborative Practice Quality Improvement (CPQI)
7. Continued Participation in Family Talks, on regional and unit-specific committees.



We are committed to continuing to solidify the work we've started, while seeking new opportunities to provide collaborative family centred care in a continuous and consistent way throughout the family journey.

The future belongs to those who believe in their dreams

— Eleanor Roosevelt

HOW TO JOIN US

As our stories unfold, we welcome you to join us on our journey.

PLEASE CALL OR EMAIL

780.407.8822

**stolleryfcc@albertahealthservices.ca
and we will send you a Network application.**



recognizing

Family centred care is a culture and a philosophy. Here's to our awarded Family Centred Care Champions, and the hard-working members of the Family Centred Care Council and NICU FACT groups. These influential families, staff and physicians led the direction for family centred care at the Stollery.

Family Centred Care Champions

Congratulations to our 2013-2014 Family Centred Care Champions. These individuals were recognized last year for their tremendous commitment to advancing family centred care practice at the Stollery:

Andrew Hendricks,
Previous Stollery Patient

Simone Chalifoux,
Family Member

Sue Robins,
Family Member

Dee Ann Schwanke,
Family Member

Katharina Staub,
Family Member

Sharon Drury,
Clinical Unit Manager,
Emergency

Gerri St. Jean,
Clinical Nurse
Educator, Emergency

Karen Latoszek,
Patient Care Manager,
Emergency

Kim Boyko,
Clinical Nurse
Educator, PICU

Lorraine Hodson,
Clinical Nurse
Educator, PICU

Dr. Cloe Joynt,
Neonatologist

Sarah Southon,
Nurse Practitioner

Lynett Kane,
Manager, Social Work

Family Centred Care Council Members

Current Members

Previous Stollery Patients

Tristan Pidner

Andrew Hendricks
Family Members

Monica Sneath

Erin Cripps-Wood,
Sibling

Amanda Moon

Shelley Wywall

Anne-Marie Paquin

Daniel Paquin

Simone Chalifoux

Shannon Robertson

Donald Lepp

Allan MacDairmid

Jodie Craven,
Co-Chair

Ali Martens

Amanda Proctor

Poonam Madan

Physicians

Natalie Anton

Dawn Davies

Rehana Chatur

Salma Bahreinian,
Resident

Staff

Lynett Kane

Misty Reis

Janice Belyea,
Co-Chair

Deb Olmstead

Myrna Landers

Stollery Leadership

Tracy Macdonald

Tim Tsounis

Completed Service on Council

Karen Calhoun

Dee Ann Schwanke

James Coughlan

Dr. Ian Adatia

Dr. Karen Forbes

Gayle Parks Krupa

Marni Panas,
Staff Liaison

NICU Family Advisory Care Team Members

Current Members

Family Members

Stephanie Amoah

Jodie Craven

Samantha Figueroa
Garcia

Kevin George

Kim George

Jennifer Hanrahan

Leah Johnson-Coyle

Nichole Lyste

Allan MacDairmid,
Co-Chair

Ian Mathieson

Raya Owen

Sarah Topilko

Amanda Proctor

Kristy Wolfe

Staff

Tara Follett, Co-Chair

Chantal Balash

Jacqueline Cook

Kristy Cunningham

Barb Davis

Doryta Foote

Daisy Garvey

Shelley Jakubec

Lisa Leniuk

Valerie Levesque

Carol-Anne Middleton

Karen Pelletier

Amanda Schroeder

Cathy Ward

Diandra Yates

Physicians

Juzer Tyebkhan

Sandra Escoredo

Amber Reichert

Stollery Leadership

Christine Westerlund

Completed Service on FACT

Roberta Davis

Joyce Tang

Dr. Michael VanManen

Denise Clarke

Karen Long

Laura Townsend

Cathy Hill

Angela Templar

Marie Hambly

Elsa Fiedrich

Marni Panas,
Staff Liaison

*Dear past: Thank you for the lessons.
Dear future: We are ready.*

