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May 2006

# CFAN

# Connector

**THE CANADIAN FAMILY ADVISORY NETWORK**  
BUILDING BRIDGES ACROSS THE NATION BY LINKING  
PEDIATRIC PATIENT & FAMILY ADVISORY GROUPS

## ~ Spring ~

### A Time of Growth, Rebuilding, Renewal

As the trees and flowers begin a new cycle, vibrant colours appear and fresh life is abundant. The CFAN Steering Committee hopes that this newsletter will similarly provide you with new energy and some fresh ideas for the season. Family Advisories throughout Canada have also made much progress over the winter, news of which fills most of this newsletter.

As we send this newsletter out across the country, we're continuing work on the agenda for the CFAN workshop on October 15th. We'll be focusing on issues related to making sure our advisory groups function well (recruitment, especially of younger parents, retention of members, and strategies for making real differences) and on a few issues of great interest and

relevance to all of us, such as transitions within the pediatric "system" and between the pediatric and adult systems as well as the roles families and family advisory bodies can play to make transitions better in every way.. There will also be an opportunity for all groups represented to share information and experiences about common issues. The steering committee is also considering making a reservation at a local restaurant for all CFAN members on the evening of the 16<sup>th</sup> after the Hospital Tour from 5:30-7:30pm.

Susan reports that the majority of the CAPHC Conference Program has been confirmed-this information can now be viewed on the CAPHC website. The Vancouver Social events committee is planning several fabulous evenings which will feature great West Coast Food and Entertainment.



Once again, Frank is writing a grant application asking for renewed support from the Sick Kids Foundation. This will help as many groups as possible to send at least one representative to Vancouver. News about the grant should come in June.

Just as rebuilding, and renewal are an integral part of spring, sharing ideas will enable us to continue to evolve as we all seek to grow and learn from one another.



### CFAN Steering Committee: Who Are We?

Frank Gavin, Family Advisory Committee-The Hospital for Sick Children  
Susan Greig, Partners in Care Family Liaison-BC Children's Hospital  
Erin Pearson, Family Advisory Council Liaison-Children's Hospital of Western Ontario  
Lisa Rosati-White, Family Advisory Forum-Montreal Children's Hospital  
Sherri Wuetherick, Chair, Family Liaison Council-Alberta Children's Hospital



# FAC's Across the Country- Committee News & Updates

## Alberta Children's Hospital Calgary, AB

*Family Liaison Council*



The Family Liaison Council (FLC) at the Alberta Children's Hospital currently has 8 parents and 1 staff member. Parents are involved in several sub-committees within the hospital. Some of the initiatives we have been involved in this year include:

- Involvement in preparing for the 2007 Family Centred Conference to be held in Calgary
- Providing feedback on hospital policies
- Providing feedback on Regional Patient Safety Policies and having a parent join that committee
- Participation in the planning of the new ACH which will be opening September 2006
- Several presentations have been made at the FLC meetings for information purposes and for feedback
- Participation in vignettes to be used for teaching purposes
- Participation in patient interviews for an inter-professional project

An area that continues to be a struggle is recruitment of new members.

I know that this is a struggle for many groups. If anyone has had some recent success I would be interested in hearing about your successes. I am also interested in hearing about what initiatives other groups have been involved in and what projects are upcoming. I would like to hear what others are doing so that I can approach Administration about opportunities for our group. There has been a lot of involvement in the planning for the new ACH this past year and when the new facility opens in September we will need to focus our energy in different areas.

**Contact:**

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## BC Children's Hospital Vancouver, BC

*Family Advisory Committee*

It's hard to believe but as of March 7<sup>th</sup> I have been in the Family Liaison position here at BCCH for one year. It has been an extremely busy year wherein our Family Advisory Committee has grown up so to speak.

One of our most major projects has been a revision of the committee structure including new member

categories and guidelines. For example we now have:

- PiC Family Members-who we ask to commit to attend at least 5 meetings a year.
- PiC Family Email Members-who are limited in the number of meetings they can attend but can participate in "Virtual working groups"

## FAC'S ACROSS THE COUNTRY/BC CHILDREN'S HOSPITAL, VANCOUVER, BC.....CONTINUED

(PiC Hospital Website Review) and 5 & 10 minute email projects (giving input on hospital documents) and they are invited to attend through teleconference.

- PiC Regional Family Members-who live far from the hospital and are not able to attend meetings at all. They serve as ambassadors for family centred care in their communities and function similar to the Email Members. If we hold a Regional Meeting at some point during the year they are invited to attend and/or they can attend meetings via teleconference.

We are also currently working on recruitment by:

- Hosting a "Bring a Friend" meeting in April. Each FAC member was asked to bring a "friend" whether it was a staff person or a family member. It was successful, as we have had two new members join because of this day.
- Creating a new Recruitment pamphlet which contains an application form-these are being printed as we speak and will be put out in pamphlet holders throughout the hospital within the next few weeks.
- Creating a new Recruitment poster with a photo of the PiC. It asks two question: What does the PiC do? which details the great work that has been going on and specific projects. The second question is Why should I join Partners in Care? The answers are: to provide your experience, knowledge and expertise; to help other families; to add to your resume and to give back to the hospital. These are at the printer and will be put up on notice boards around the hospital.
- Emailing application forms to all family members who have submitted Family Centred Care Award Nominations in the past; all family members who have submitted comments through our comment card box system and/or written letters of thanks/constructive criticism to the hospital.
- Contacting all current family members asking for them to review the commitment along with new guidelines and orientation sessions to start in September.
- Putting our application form on the BCCH website so that families can fill it out electronically.

This fall we will be celebrating our 5<sup>th</sup> Annual Family Centred Care Awards. This has been a wonderful way to recognize those hospital staff members who weave family centred care throughout their practice. However, since this event is only once a year we started looking for ways to increase opportunities to recognize staff for family centred care on a more regular basis. PiC has developed the Bravo

Star which is an award that the committee gives out if we receive a complimentary comment card (from our comment card box system), a complimentary letter from a family or when a department/individual goes the extra mile in working with the PiC. This has generated a huge amount of interest and enthusiasm among staff and everyone who received one has so far has indicated how honored they have been to receive recognition from the people they are serving.

When it comes to education we currently have two projects underway. The first is entitled Parents coping with the Chronically Ill Child which is an 8 week course for parents to help them develop the skills in caring for their child. It covers things such as helping your family cope with stress; managing your child's day to day care; caring for the needs of other family members; managing your families emotions as well as other topics. Our first session is training PiC staff and family members so that the course can be offered to hospital families starting this fall. We hope to expand the course into various communities as well so that families do not have to travel to the hospital to attend.

We were also recently approached by Dr. Elizabeth Mickelson who has been working at setting up Project Doc, a Family Faculty program created by the Hospital of Vermont. The funding for training sessions is next on our agenda and we're hoping to start training the first 12 families in Sept/October of this year. Our goal is to have the program up and running in January 2007.

We recently received some funding that must be used to support family members of children in the hospital. Currently, we have one organization that sets up appointments at their spa for family members for facials and/or manicures/pedicures so they can get away for an hour or two of refreshment; another great thing going on is a yoga instructor who puts on weekly relaxation sessions for family members in our parent lounges. We are looking for other initiatives that specifically support and "give breaks" to families. I'd be interested to hear if you have any ideas for other programs that we could initiate.

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# Bloorview Macmillan Children's Centre Toronto, ON

*Family Advisory Council*



Here are some thoughts on what we'd most like others to know about the work of our group:

- Youth members play a significant role on the FAC.
- Senior administration ( C.E.O., V.P. of Program and Services ) as well as Board members attend meetings regularly.
- Programs and services consult with FAC on a regular basis bringing new learning and new initiatives for discussion and input.
- We have the respect of senior administration, for FAC as a group and as individuals.
- Senior management is accessible; values, listens and responds to the FAC voice.

What we would most like to hear about from other groups:

- Strategies implemented by other FAC's to enhance the representation of diverse cultures.
- Strategies of engagement and recruitment.
- How concerns are responded to in a timely manner; are they heard by staff?

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## Children's Hospital of Western Ontario London, ON

*Family Advisory Council*

2006 has brought many new and exciting opportunities for the FAC at CHWO, beginning in January with the development of a new executive. After founding the group in 2002, Marc Garson resigned from the Chair position leading the way for Bonnie Pierotti, previous Vice-Chair and long time FAC member to fulfill this role. Linda Shanahan, also an experienced member then began her role as Vice-Chair. Over the winter months, the group has focused on a few prominent projects and began work on some new initiatives.

- ❖ Some of our members actively planned and participated in the recently held 2<sup>nd</sup> annual Family Centred Care Conference – “Celebrating the Care of Children.” This collaborative event, hosted by CHWO and community agencies featured several guest speakers, child and youth presenters, as well as parents and families who all shared their personal stories.
- ❖ The FAC have long advocated for a Children and Youth Advisory Council at CHWO. In 2006, this goal came to fruition as nominations for this newly

approved council began. Since January, 11 members have joined the council ranging in age from 9-17. Two meetings have already occurred and the children and youth have all offered many great design ideas for our new hospital. The two councils will operate as separate entities, but will report to, and refer members to one another.

- ❖ LHSC Visitor Policies – FAC members were invited to sit on the committee for redefining London Health Sciences Centre visitor guidelines. This committee was eager to have the first hand expertise on visiting hours that only the family can provide.
- ❖ Medical School Interviews – The FAC was recently invited to sit on panels for the second time, to interview medical school students at the University of Western Ontario's Schulich School of Medicine. The family centred perspective is highly valued by the school and members enjoy this opportunity.

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## FAC'S ACROSS THE COUNTRY/CHILDREN'S HOSPITAL OF WESTERN ONT.....CONTINUED

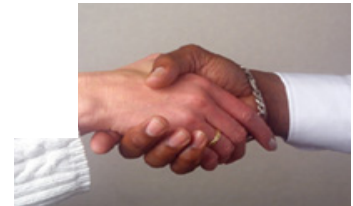
- ❖ Design Teams – One major focus of the FAC's work continues to be the design of the new Children's Hospital of Western Ontario. The exterior shell was recently completed and the detail on the interior will soon commence. FAC members will sit on all of the design teams alongside multi disciplinary professionals, to provide a family perspective.

As opportunities for this group continue to arise, the need for enhanced membership is always at the forefront. We welcome any recruitment tips that other advisory bodies have to offer.

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## Hospital for Sick Children Toronto, ON

*Family Advisory Committee*



Sick Kids went through a “strategic directions” process in the last year, and FAC was happy to be involved early and to have had some influence in shaping the final document. We formed a focus group for one of the consultants last June and provided many ideas and identified what we thought should be hospital priorities. In September Mary Jo Haddad, the Hospital's CEO, came to an FAC meeting, presented a draft document, and asked for our response. We urged her and the hospital to make the commitment to family-centred care and to working in partnership with families more explicit. This happened.

Our education sessions with residents, nurses, and medical students continue to be well received. Recently three of our members met with thirty residents for two hours; all of the residents indicated on their evaluations that they would make changes in their practices as a result of the session. We've also begun working with the Hospital's family-centred care consultant about the hospital assuming more administrative responsibility for the program and integrating the sessions within its own inter-professional education activities. The intended result: we'll reach more staff, staff in “mixed” groups, and staff from areas our program has never reached.

Two FAC members, Valerie McDonald and I, made presentations at the Ontario Hospital Association's first family-centred care conference in April. Valerie, one of FAC's co-chairs, is receiving the Sick Kids Foundation's

Volunteer Humanitarian Award in May for her work with FAC and on the hospital's palliative care team.

Our main challenge has been determining, even after nearly twenty years of existence, where we fit within the Hospital's complex and changing structures and processes. Our bylaws, for instance, state we are advisory to the hospital board as well as to the administration, but there's no regular reporting mechanism to the board. We're also trying to identify ways of ensuring that families can participate meaningfully in the work of hospital committees that do important work affecting patient care but that do this work at times of the day family members find it very hard to attend. Any suggestions?

Finally, our annual report for 2005 should be up on our website ([www.sickkids.ca/fac](http://www.sickkids.ca/fac)) sometime in May.

### **Contact:**

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Family Advisory Committee  
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## IWK Health Centre Halifax, NS

*Family Advisory Committee*

What we would most like others to know about the work of our group:

### Ronald McDonald Family Room

(I believe Chuck Livingstone has already provided background on this project. I was on the original planning committee, coordinated surveys to determine room requirements and needs analysis from the family perspective, and am available to provide information as well.)

### Redevelopment Advisory Project

To ensure patient and family input is a key part of the design process, we have developed five advisory opportunities that will be in the works over the next five years of the Project. The following describes two of these initiatives.

### Youth Advisory Team

The team consists of over 20 youth ages 12 and up, representing all three provinces, a variety of backgrounds and IWK experiences ranging from inpatient to surgical to ambulatory. An email is sent out biweekly asking a value-added design/space question and members have two weeks to respond with their input, and enter their name to win the biweekly prize. Their input will be regularly submitted to the Architect and design team, who will in turn report back to the Team what they are doing with their ideas. Each team has a commitment of six months, ending with a Summit where Team members have an opportunity to meet each other and the Design Team in person or by videoconferencing, and one Member will win a grand prize.

### Child Life Advisory Project

The IWK Health Centre's Child Life Team are engaging inpatient children and youth in design input through the use of games, drawings, picture taking (what I like, what I don't), story telling, survey questions, and lots more.

### Stay Tuned!

Presently the IWK Health Centre has two Family

Advisory committees in place: the Mental Health Advisory Committee – including representation by community partners, and the Emergency Family Advisory Committee. Representatives from both recently joined a centre-wide team for Patient and Family Centred Care training by the Institute for Family Centered Care, and exciting developments for both committees out of this training are in the works. More advisory committees are on the near horizon, including one dedicated to Inpatient Mental Health – Patient and Family Centred Care, one for Children and Youth Addictions, and another potentially for our Birth Unit.

What we would most like to hear from other groups about a topic or problem our group has been dealing with:

- How to establish a two-way reporting relationship: "The Loop"  
Advisory Committees receiving opportunities for meaningful input on policies, etc., from the beginning stages, having communication throughout, and feedback that is answerable to how the input was used in final decision-making.
- How to sensitively retire Advisory Members.
- How to get the word out about Advisory Committees: communication and advertising strategies!
- How to create meaningful advisory opportunities where there is not an overall Advisory Committee.
- Staff, Patient and Family education: advice to share, and lessons learned.
- What you would most like to see included on the agenda for the next CFAN Workshop.
- The above!

### **Contact:**

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# McMaster Children's Hospital Hamilton, ON

*Family Advisory Council*



The Family Advisory Council at McMaster Children's Hospital has been very busy this year. We have several projects in the process right now. We are focusing on the four key areas at this time and hope to wrap up some of these projects by the end of 2006.

We have been working on developing a **Family Centered Care video** that would help families better understand the philosophy of Family centered care. The video will welcome families and give a brief history of our hospital. Several vignettes of families in hospital for different reasons will illustrate the application of Family-Centered Care. The video concludes with thoughts from doctors, nurses and support staff about the importance of having family involved in the care of their child. We hope to have the video complete around September 2006 with footage from our Celebration 2006 and additional footage specific to this project if necessary.

The FAC has also been involved with the academic part of the hospital proposing and providing curriculum for a **Family Faculty program**. This program will allow medical, nursing and allied health staff to receive information from families who have been in our hospital. This will also provide an opportunity for current staff to receive in-service training on the needs of families when they are hospitalized. This project blends nicely with the belief of Family Centered care held by our hospital and will help implement the belief in all disciplines.

The FAC has worked closely with the Early Autism Initiative in redeveloping the **information package for newly diagnosed children and families**. Through this project new information packages and delivery system have been designed and volunteers are currently being recruited and trained to deliver the needed services.

Another issue we have debated at length has been the **parking policies at McMaster Children's Hospital**. This proved to be a very useful look into the policies as they relate to the Children's Hospital and the effect parking has on the care of children and stress levels of families. Through this discussion, the FAC recognized other factors affecting the stress levels of families and proposed an Emergency Care kit to give to every family. The FAC offered to provide a letter of support to management who has also been looking into Emergency Care kits. Hopefully, Emergency Care kits will be implemented in 2007.

The McMaster Family Advisory Council has had a very busy, productive first year and looks forward to the addition of new members, new challenges and the completion of other tasks in the coming year.

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## Montreal Children's Hospital Montreal, PQ

*Family Advisory Forum*

The MCH Family Advisory Forum has, in collaboration with hospital Quality Management and the Ombudsman has undergone a period of committee soul searching review of its mandate and list of priorities for parents and children and whether the FAF was properly addressing the needs of parents and children of the MCH. Perhaps a very useful exercise for committees to undergo from time-to-time...

The committee has decided to focus on comprehensive and

important patient safety and security issues for parents and children in various physical areas/aspects impacting on children's health and parental understanding and compliance to treatment within the hospital, working with staff to monitor for users the meeting of these MCH patient safety accreditation requirements.

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## FAC'S ACROSS THE COUNTRY/MONTREAL CHILDREN'S HOSPITAL.....CONTINUED

We thought that the positive results obtained by the FAF from our having a more focused approach to advocating for the smaller and more tangible issues that are part of the puzzle pieces making up the bigger picture, would be in themselves an effective recruitment tool. And, to otherwise use staff contact people to get things done quickly as much as possible. (ie housekeeping issues) This, as opposed to expending our energy solely on recruitment as we had initially focused on as being The Priority.

A concern from a parent was emailed to our FAF account. She was asking for our assistance in obtaining a paediatrician for her 2 small children, since paediatricians in her area were either unavailable or not accepting new patients. This rather simple request was initially a bit of a stumper for members and staff alike! It was a valid concern, one that we had not encountered -- what should be suggested to parents in similar situations, and what resources for such existed in the hospital, if any? A temporary in-hospital ambulatory solution was found. However, it might be an important issue for parents to be

addressed at the 'Paediatricians in the 21<sup>st</sup> century' symposium this Fall.

The FAF has been asked to participate in the newly-formed committee looking at seamless transition care for long-term paediatric patients to adult care, within our McGill University Health Centre (MUHC) organization having both paediatric and adult missions.

As always we welcome input from other paediatric advisory groups to anything mentioned here for which you have experiences/advice to share!

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## Winnipeg Children's Hospital Winnipeg, MB

*Family Advisory Committee*



Susan Brelsford-Shallcross, co-chair of the Family Advisory Committee reports that she recently took part in two patient safety conference, one in San Francisco. She's very excited about an addition she and others are working on to the statement below and hopes it will soon be available to all.

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### London Declaration Patients for Patient Safety

#### WHO World Alliance for Patient Safety

We, Patients for Patient Safety, pledge to help create a world in which health care errors harm fewer people. We, gathered in London from 27-30 November 2005 to join together in partnership in an effort to reduce the massive burden of avoidable harm in health care. Risk and uncertainty are constant companions. So we come together in dialogue, participating in care with providers. We unite our strength as advocates for care with less harm in the developing as well as the developed world.

We are committed to spreading the word from person to person, town to town, country to country. There is a right to safe health care and we will not let the current culture of error and denial continue. We call for honesty, openness and transparency. We will make the reduction of health-care errors a basic human right that protects human life around the world.

Continued on next page...

We, Patients for Patient Safety, will be the voice of all patients, but especially of those who are now unheard. Together, as partners, we will collaborate in:

- Devising and promoting programmes for patient safety and patient empowerment.
- Developing and driving a constructive dialogue with all partners concerned with patient safety.
- Establishing systems for reporting and dealing with health-care harm on a worldwide basis.
- Defining best practices that deal with health-care harm of all kinds and promote those practices throughout the world.

In honor of those who have died, those who have been left disabled and our loved ones today, we will strive for excellence, so that all people receiving health care are as safe as possible, as soon as possible. This is our pledge of partnership.

January 17, 2006



## Paediatricians in the 21<sup>st</sup> Century-FAC members help needed

This November in Toronto there will be a symposium with a very long title: “Child Health in the 21<sup>st</sup> Century: The Role of the Paediatrician in an Inter-Professional Environment.” That’s more than a mouthful, and I know the very name “symposium” might make some people think of sleep. But the event (which is being supported by CAPHC, the Canadian Paediatric Society, and by many other groups representing family physicians, nurses, ministries of health, etc. from across the country) has the potential to make a real difference for children, youth, and families, and everyone reading this can help make that difference.

I’ve been asked, as a representative of CFAN, to join the planning committee and to make a presentation at the symposium about what families most value in paediatricians, about the roles paediatricians can and should play in working with others, including families. I’ve circulated a survey that many of you have seen and that a number of you have completed. Thank you. The responses so far have been both enlightening and (mostly) inspiring. What’s most helpful are specific comments about the experiences and expectations of families and children. (I will, of course, maintain confidentiality in making the presentation.)

I’ve also met with the Children’s Council at Sick Kids and asked them to complete a modified survey with five questions. (What do you like most about your doctor(s)? What do they do that is most important and helpful to you? What do you wish your doctor(s) would change? Is your main doctor part of a team? If so, who else is on it? One child wrote this in response to those last questions: “My doctor is on my team.”) If you have a children’s council and think the members might like to complete such a survey, please let me know or just go ahead and look after the administration of it yourself.

Please let me know if you would like me to send you the survey for parents (again). I know there’s nothing scientific about the methodology, but I won’t be pretending that there is either. I’d like to have most of them returned by the end of June, but I can make good use of any returned by October 15<sup>th</sup>.

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# Upcoming Conferences

## May 30-June 1, 2007

12<sup>th</sup> Annual Building on Family Strengths Conference  
Hilton Portland, Portland, Oregon, USA  
Research & Training Center on Family Support and  
Children's Mental Health  
<http://www.rtc.pdx.edu/>

## October 15-18, 2006

CAPHC-Canadian Association for Pediatric Health Centres  
The Fairmont Hotel Vancouver, Vancouver, BC CANADA  
<http://www.caphc.org/>

## November 2-4, 2006

Collaborative Family Healthcare Association Conference  
Hyatt Regency Newport Hotel and Spa, Newport, Rhode  
Island USA  
<http://www.cfha.net/>

## December 7, 2006

16th Partners In Care Conference  
Sheraton Hotel, Burlington, WA USA  
<http://www.partoparvt.org/PIC.html>

## April 29-May 1, 2007

Family Centred Care in Context  
Hyatt Regency Hotel, Calgary, AB  
Southern Alberta Child & Youth Health Network and  
the Central and Northern Network for Child Health  
<http://www.sacyhn.ca/pages/fccbackground.html>

# CFAN Logo Needed

Win \$10.00 in Telephone Cards for designing the CFAN Logo! Please submit any ideas/drawings/digital images to any member of the steering committee. The winner will receive not only our accolades but our small gift and recognition across the country through the logos use on our future webpages and in our newsletters!

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