

Annual Report

2010-2011 FAC Members

Jo-Ann Angelucci
Julia Barugel
Regene Best-Prescott
Erica Blit
Patricia Byron-Kimball
Janet Caro
Denise Carsten
Michael Craig
Patti DiSanto
Masumi Goldman
Ellen Goldstein
Asher Haft
Josh Itzkowitz
Rachel Itzkowitz
Shevy Kahan
Karen Kaiser
Marni Lane
Ellen Lee
Lauren McGeough
Ann O'Connor
Maria Aller Reyes
Lanier Saperstein
Gary Wartenberg
Rose Winton-Quintero

2010-2011

Executive Committee

Ann O'Connor, Parent Leader,
Chairperson
Ellen Lee, Parent Leader,
Membership Officer
Julia Barugel, Parent Leader,
Communications Officer
Lori Armstrong, RN,
Hospital Liaison
Pat Hametz, MD, Faculty Advisor
Aliza Koenigsberg,
Operations Advisor

Message From Our Chairperson

Since the Family Advisory Council (FAC) began six years ago, our partnership with the hospital has become well established and our level of collaboration has increased significantly in terms of the number of projects, as well as the breadth and depth of our involvement in areas all around the hospital. At this point it is not uncommon to find FAC members in regular hospital meetings, ranging from Ethics to Event Planning. In fact, about half of our Council now serve as standing members of nine hospital committees.

Looking back at the work we have done this term, a common theme has emerged. Whether our objective was to help improve Patient Satisfaction, produce a video for families or provide training to staff, much of our work revolved around "Sharing Our Stories." What became clear is that these stories – our stories – not only contain teachable moments, but can be powerful tools that highlight real-life, first-hand examples of the everyday hospital experience.



In fact, many parents join the Family Advisory Council for this purpose – to share the story of their child's journey and their hospital experiences with the hope of benefiting others. However, this is not always easy to do. Many times, these stories are from the most difficult times in our lives. Even as listeners, we might also be touched or moved by other parents' stories because we can relate to a specific element in the story, or to the general experience of parenting a child in the hospital. But we continue to share these stories because we want to make a change that makes a difference. As the FAC Chair, I want to use this space to personally thank our members for sharing their experiences to further our mission and help make the hospital the best possible place for all children and their families.

The entire Family Advisory Council also gratefully acknowledges the time and efforts of our committed advisors, our supportive administration, the dedicated Patient Care Directors (PCDs) and all of the physicians and hospital staff who worked with us this year to promote family-centered care, listen to our stories and collaborate to "make it better."

Sincerely,

Ann O'Connor

Chair, Family Advisory Council
Morgan Stanley Children's Hospital of NewYork-Presbyterian



Overview of the 2010-2011 Term: “Sharing Our Stories”

This year, our Council members were called upon to share their stories and experiences with the goal of promoting Family Centered Care across all areas of the hospital. The audiences for these stories varied widely and included families of patients preparing for surgery, Patient Care Directors of every inpatient unit, physician residents at MSCHONY as well as representatives from all five NYP campuses. We even shared our stories with architects, designers, and construction managers to ensure that the new spaces being built reflected the needs of the patients and families. Some of our key projects and initiatives of this past term are highlighted below.

SHARING OUR STORIES: To Inform Other Families

Many of our members hope to use their experiences to help other families facing similar situations. A powerful example of this can be viewed in the series of pre-surgical videos created in partnership with the hospital and the FAC. The **“What to Expect When Your Child Has Surgery”** video series takes parents and patients through the surgical experience - from registration and reception to the operating room and recovery - so they can prepare for what will happen at each step along the way. There are four videos in the series: three are targeted toward specific patient age groups (pre-school age, elementary school age and pre-teen/teenage patients) and the fourth features seven FAC members addressing questions that parents may have or should ask when preparing for a child's surgery. This last video is truly a parent-to-parent educational tool. We are very proud of and grateful to our FAC members for sharing their insights and experiences for this video. **The videos can be found on the hospital website at: <http://childrensnyp.org/mschony/patients/what-to-expect.html>**

SHARING OUR STORIES: To Educate the Care Team

Our stories have increasingly been used as an element of teaching and training sessions for hospital staff and physicians. Recently, NYP implemented a **Pain Resource Nurse (“PRN”)** program across all five NewYork-Presbyterian campuses as part of the efforts to improve the patient experience in terms of pain management. During the multi-campus training sessions, several FAC members shared their personal stories about how their children's pain was managed during their hospital stays. Hearing these first hand accounts was a powerful and effective component of these sessions and was very well received by those attending the training.

FAC members' experiences were also shared in a unique and powerful way during **Grand Rounds** this past June. The topic – Bereavement - was a sensitive and difficult one for both families and providers. Keynote speaker Dr. Stephen Sands spoke about the challenges physicians and staff may have communicating with bereaved families. Several FAC members were able to share their

first-hand experiences in these difficult situations and help shed light on what may be appreciated by families during these times. The FAC members' stories were read aloud by the residents during the Grand Rounds. Many attendees expressed gratitude for the opportunity to hear these stories and appreciation of the families taking time to share them.

The **Family Faculty Program** provides an educational forum for residents to hear directly from parents of patients about their experiences related to a specific topic. During these interactive sessions FAC members provide real-life, in-person examples about a topic and then the residents can react and engage with them to discuss ways to handle different situations related to that topic. Under the leadership of Dr. Patricia Hametz, we have created a repeatable three-year curriculum of family-presented topics. This year we conducted three sessions with residents:

- **“Introduction to Patient and Family Centered Care”** – Families describe core concepts of Family Centered Care and provide real-life examples of how it can best be delivered.
- **“Physician as Parent/Parent as Physician”** - Parents discuss the unique situation when a parent is also a physician and how this may impact the parent/resident relationship and experience.
- **“Delivering Bad News”** – Parents share what it is like to receive bad news about their child's health – whether it be a new diagnosis or the result of a test or study. Parents describe what might help in that situation.

SHARING OUR STORIES: To “Make It Better”

Improving Patient Satisfaction is an important goal for both the hospital and the Family Advisory Council. This is the second year that the FAC partnered with the hospital in the development of the annual **“Making It Better”** plans which target specific improvements in Patient Satisfaction for each unit. FAC members were assigned to units based on their personal experiences and they were able to collaborate with the Patient Care Directors to help formulate specific improvement plans. To further this effort, ten FAC members were involved in the mid-year **Patient Satisfaction Summit** where targets were reviewed against actual results and plans adjusted as necessary. The Family Advisory Council and MSCHONY plan to continue this highly interactive and collaborative approach to evaluating and improving Patient Satisfaction.

Through discussions with the FAC, we learned that information was not flowing from the clinical team to our NICU families in the most effective manner. We collaboratively developed a solution for how best to update the families. As a result... we have seen a significant increase in the patient satisfaction score of these indicators.”
–NICU Staff Member

SHARING OUR STORIES: To Build It Right

On a hot day this past June, physicians and nurses, staff and administrators, patients and families, donors and supporters and members of the local community gathered for the long-awaited ribbon-cutting for the beautiful, state-of-the-art **Alexandra and Stephen Cohen Emergency Department**. For FAC members, touring this space was like seeing a dream come to life. Discussions we had many months - even years ago - are now reflected in this new facility. It is gratifying to think about the tremendous impact this will have on the patient and family experience during acute and stressful times. It is truly a 'game changer' as Dr. Lee Goldman stated during the ribbon cutting ceremony. The FAC thanks and recognizes Meri Sonnet, MD, Joan Bregstein, MD and Bonnie Corbett, RN for their dedicated partnership with us during the ED design effort. We also congratulate Kevin Hammeran and Bernadette O'Brien, RN for their leadership on this tremendous effort and for including the patient and family voices every step of the way.

SHARING OUR STORIES: Beyond MSCHONY

This past March, Lori Armstrong, VP Nursing and Patient Care Services and Ann O'Connor, FAC Chair, had the opportunity to attend and present at the **Creating Connections Conference hosted by NACHRI** (National Association of Children's Hospitals and Related Institutions). The topic of their presentation was **"Family Matters in Quality and Patient Safety"** which gave an overview of how MSCHONY has partnered with families since 2006 in the area of Quality and how this partnership has grown over the years. Lori and Ann also shared advice and tips on how other institutions could begin or enhance their own partnerships in this area. The packed room very enthusiastically received the presentation and it became clear that MSCHONY has distinguished itself as a national leader in partnering with families in the area of Quality and Patient Safety.

FAC members currently serve on:

- Quality Council
- Children's Advisory Council
- Ethics Committee
- Palliative Care Committee
- Patient Centered Care Cabinet
- OB Experience
- End of Life Task Force
- Spirituality Committee
- Bereavement Committee

SPOTLIGHT ON:

The Family Resource Center

It has long been a goal of the FAC to establish a **Family Resource Center** at MSCHONY. A Family Resource Center is truly about making care more patient-centered by providing a "one-stop-shopping" experience for information pertaining to the hospital as well as to a clinical diagnosis or procedure. This summer, the goal of opening a Family Resource Center at MSCHONY became a reality.



The Family Resource Center is conveniently located on the first floor near the central elevators. At approximately 900 square feet, it is a welcoming, comfortable space and includes computers, Internet access, fax/copy capability, a coffee machine, a flat screen television and comfortable seating. FAC members were heavily involved in the creation of this Center every step along the way from space design and furniture selection to resource planning and hiring our new full-time, bilingual Resource Librarian, Carol Evans! Special thanks to Kevin Hammeran for his early support and to Bernadette O'Brien, RN, VP, Operations for her ability to get the job done, Alex Curran, Director, Clinical Services for his commitment to partnering with the FAC and Toni Millar, Director, Child Life who ran the project and will oversee the Family Resource Center now that it is operational.

Thanks also to the rest of our team members who helped make this dream a reality.



Hats Off!

NYP Patient-Centered Care Grants

Once again, the NYP Volunteer Department awarded \$100,000 to fund projects throughout the NYP organization that improved the patient and family experience. This year, they collected, read and evaluated **152 submissions** from all **five campuses** for the annual Patient Centered Care (PCC) Grant Awards. In total, **22 grants** were awarded across the five campuses, **three to MSCHONY**. We are extremely pleased to announce that a submission by the Family Advisory Council, under the leadership of Toni Millar, Director, Child Life, was one of the three awarded to the MSCHONY campus! This \$5000 grant will be used to purchase research materials and other convenience items to make the new Family Resource Center (FRC) as effective and family-centered as possible. Specifically, the grant will be used to purchase medical resources, classic children's books in several languages, USB ports as a "green" alternative to paper copies for families' medical research, a coffee maker and information cards that detail available Center services.

Since 2007, the Family Advisory Council, in partnership with our advisors, has submitted applications to the NYP Patient-Centered Care Grant program. We are extremely proud of our track record – we have been awarded at least one grant each year, which has been used to make the hospital experience more family-friendly and patient-centered. Thank you to the NYP Volunteer Department for this empowering program, which has enabled us to provide:

- Rejuvenate You Program (2007)
- "Starlight Fun Center" for the ED (2008)
- Comfort Cart (2008)
- Phlebotomy Lab Facelift (2009)
- Technology for Text Message Reminders for Heart Transplant Patients (2010)
- Family Resource Center Materials (2011)

FAC Advisor and Member of the Year Awards

At the close of each term, FAC members vote to recognize one member and one advisor for exceptional contributions to our mission. This year it was no surprise that **Lori Armstrong**, VP Nursing and Patient Care Services was named our **FAC Advisor of the Year**. In addition to serving tirelessly as our official Hospital Liaison, Lori, is a staunch advocate for not only the FAC and Patient Centered Care, but for all the patients and families treated at MSCHONY. She truly puts patients first in her everyday work and challenges those around her to do the same. And when it comes to partnering with patients and families, Lori never hesitates to suggest Patient and Family involvement in a committee or hospital project. Lori has been a wonderful partner to the FAC and we are thrilled to recognize her with this award.



FAC Members Karen Kaiser and Michael Craig

This year our **FAC Member of the Year Award** was awarded to two of our long-time members **Michael Craig and Karen Kaiser**. Michael and Karen joined the FAC in 2006 at the start of our second term. Since then, they have worked as a team on many important initiatives and are both active standing members of the Ethics

Committee. Their extraordinary dedication to the Emergency Department Experience Committee was made evident as we saw in the new ED the many suggestions and ideas that Michael and Karen brought forth from their own and the other FAC members' experiences. Thank you Michael and Karen for all you have done as FAC members.

Congratulations to all our members for another great year. Thank you for your dedication!

Family Advisory Council: Who Are We?

We are the MSCHONY Family Advisory Council. We are 24 parents representing 29 children's hospital experiences. Together, our members have over 106 years of experience parenting a sick or hospitalized child.

We have spent 1,401 days in the NICU and 597 days in the PICU. We represent our children's 103 surgeries and 144 Emergency Department visits.

Our children have spent a total of 2,716 days as inpatients. Five of us are bereaved parents; two of our children have been treated for cancer; five others have received transplants. Each one of us wants to make MSCHONY the best possible place for all children.

Parents, Physicians and Staff: We Need You!

- Do you know of a family member that would enjoy contributing to these efforts?
- Are you involved in a project or committee would benefit from family input and support?
- Are you interested in Family Centered Care and would like to learn more about what we do and how we can help?

**If so, please contact us at
familyadvisorycouncil@nyp.org.**

Contact Info:

Find us on the web:

<http://www.childrensnyp.org/mschony/family-advisory-council.html>

Email us at: familyadvisorycouncil@nyp.org