



Family Advisory Council ANNUAL REPORT

FAC Members 2007-2008

Mark Abrams
 Jo-Ann Angelucci
 Julia Barugel
 Debbie Benefeld
 Karen Bergan
 Paul Brown
 Michael Craig
 Masumi Goldman
 Matt Goldman
 Asher Haft
 Josh Itzkowitz
 Rachel Itzkowitz
 Karen Kaiser
 Shevy Kahan
 Jackie Katon
 Ellen Lee
 Michelle Morea
 Ann O'Connor
 Maria Reyes
 Gary Wartenberg
 Rose Winton

Executive Committee:

Ann O'Connor
 Parent Leader, Chairperson
Michelle Morea
 Parent Leader, Membership Officer
Julia Barugel
 Parent Leader,
 Communications Officer
Karen Bergan
 Parent Leader,
 Immediate Past Chairperson
Lori Armstrong, RN
 Hospital Liaison
Pat Hametz, MD
 Faculty Advisor
Aliza Koenigsberg
 Operations Advisor

Message From Our Chairperson

Back in 2005, when I joined the Family Advisory Council (FAC) in our inaugural year, I had never heard the terms "Family-Centered Care" or "Family Advisory Council." I did not know about Family-Centered Rounds and did not understand the full meaning of the term "Patient Safety." I was not even sure what the FAC would do or how we would do it and I certainly didn't expect to be the Chairperson two years later. What I did know at that time was that my family's life was forever changed by the eye-opening and humbling experience of having a child in the hospital. So, as I sat with twenty or so other parents at our very first meeting I wondered, "What could we, a group of parents, do at a big hospital like MSCHONY? Would it make a difference? Would people stay interested and committed? Would the hospital support the efforts of a group of parents?"



Reflecting on our accomplishments over the past three years, and specifically during this 2007-8 term, the answers to these questions are now quite clear. **What could we do?** **We could do a lot:** Not only to give families more information during their stay, but also to help doctors and nurses change the way they interact with

families. **Would it make a difference? Yes.** We have received feedback from both families and hospital staff that the impact of the FAC is making a positive difference here. **Would people stay interested and committed? Definitely.** More than half of our membership is comprised of "veteran parents"; and half of that number has been with us since 2005. **Would the hospital support the efforts of a group of parents? Absolutely.** In fact, each year our number of hospital advisors has grown and at the heart of each success is close collaboration with, and support from, the hospital.

On behalf of the entire membership of the Family Advisory Council, we are pleased to share some of our accomplishments in this, our first Annual Report. Thank you to our members, our advisors and all the hospital staff and faculty who have worked with us to achieve these successes.

Sincerely,

Ann O'Connor
 Chairperson, Family Advisory Council
 Morgan Stanley Children's Hospital of New York-Presbyterian



Overview of the 2007-2008 Term

The September 2007 to June 2008 term was a busy and highly productive one. During our first few years we made great strides bringing our message to different committees, areas and employees of the hospital. This year, many of our projects reached completion and we impacted the patients and families of MSCHONY more than ever before. Our significant accomplishments for the year are summarized below. Please feel free to contact us for more information about any of our projects, committee participation or other collaborations.

Reaching Out to Patients and Families

One of our goals this year was to bring more information into the hands of families who currently have children admitted to the hospital. As part of this goal we:

- Developed and launched the **On-line Family Guide** on the MSCHONY website! This comprehensive guide covers everything a family needs to know when admitted to MSCHONY – from what to bring to where to eat to when and why to wash your hands. This represents two years of planning and information gathering based on our collective experiences as parents of MSCHONY patients. The Guide is currently available at: <http://www.childrensnyp.org/mschony/patients/family-guide.html>. An in-print version is soon to follow.
- Collaborated with the hospital to create the content for the new **Welcome and Orientation DVD** that all families will view upon admission to the hospital.
- Partnered with the Excellence at Children's Committee to plan the implementation of **Family-Centered Rounds** at MSCHONY. This approach to rounding underscores the hospital's commitment to Family-Centered Care by recognizing the role the family plays in the care of their child – both at home and in the hospital. To educate parents about Family-Centered Rounds – what it is, why and how it is done - we also worked with the committee to create the Family-Centered Rounds DVD. This DVD is a training tool for parents so they can make an informed choice about if and how to participate in the rounds. The next step is to create a training DVD for clinicians to make Family-Centered Rounding as effective as possible.

- Collaborated with the residents to develop the **Bedside Communication Sheet** so that family members can remain informed on their child's Care Plan for the day.

- Provided extensive feedback regarding the **hospital website** pages intended for patients and families. This information is targeted to families of both current and prospective patients.

Each year New York Presbyterian awards **Patient-Centered Care Grants**. Hospital employees can apply for these grants to support the implementation of projects that promote Patient-Centered Care. In 2008, FAC Members suggested topics and wrote or helped write applications for the Patient-Centered Care Grant Awards. Two of these applications were selected as winners and, over the next year, we expect to see these winning proposals implemented to improve the experience of patients and families:

- Purchase and installation of a **Starlight Fun Center** for the ED. This is a portable video entertainment system which includes a flat screen TV, DVD player and a Nintendo Wii™ system. The Fun Center helps children cope with difficult situations, long waits or nervousness by providing entertainment and distraction.

- Creation of a **"Comfort Cart"** or "Cocoon Cart" with soothing items to help provide some physical comfort to parents facing end-of-life situations.

"I think so much of medical education is focused on disease and how the disease process affects the body but little time is spent thinking about how diseases affect children and their families emotionally. The FAC provides insight into these important areas."

– Dr. Deena Blanchard,
second year resident

Reaching Out to Staff and Faculty

Our **Family Faculty** program continues to thrive and receive rave reviews from the residents. This program encompasses the development and delivery of a three year curriculum of family-led training sessions for residents. There are two sessions conducted each year resulting in a repeatable program of six sessions. In 2007-8 we conducted the following Family Faculty sessions:

- **Fall:** *The Physician as Parent*
- **Spring:** *The Angry Parent*

Beginning this summer, FAC members participated in the monthly **MSCHONY New Employee**

Orientation Day. The feedback from staff indicates that the presence of family members at their orientation helps drive home the hospital's commitment to Family-Centered Care. This new effort has been very well received by the FAC, the hospital and the new employees.

We have also participated as advisors to other hospital-led projects to incorporate family feedback to these efforts:

- **Emergency Department Patient Experience**
- **Discharge Planning Collaborative on 6T**
- **Food and Nutrition Menu updates and changes**
- **NICU Orientation CD which will soon be ready in both English and Spanish**

These advisory roles are in addition to the committee member roles some of our members serve. We have FAC members serving alongside hospital staff as regular members on the following committees:

- **Quality Council**
- **Excellence at Children's**
- **Ethics Committee**
- **Bereavement Committee**

Reaching Out Beyond MSCHONY

The MSCHONY Family Advisory Council has also made contributions "off-campus." Over the past year our members attended:

- **Advocacy Day** – in Albany to share family perspectives with members of the State Legislature
- **MSCHONY Annual Leadership Retreat** – Seven parents participated in three of the breakout sessions which are used to formulate key strategic goals for the coming year. Thank you to MSCHONY Executive Director, Cynthia Sparer, for our third invitation to this important event.
- **WCBS 880AM "It's All About the Kids"** radio promotion – The MSCHONY Marketing team asked our FAC members to participate in this three week radio-based campaign where CBS News radio 880AM dedicates on-air time and resources to educate listeners on topics relevant to children's health. Interviews with our members will be aired as part of this program.
- **NICHQ Conference** – In addition to having two members attend this conference, MSCHONY FAC partnered with other FAC leaders to conduct a full-day session where FAC members from around the country could share ideas, learn from each other and explore ways to bring the family perspective to future agendas of this national conference. The MSCHONY FAC is clearly taking a lead role in developing a platform for a national dialogue about Family-Centered Care among family advisory groups at other hospitals and national organizations.

These accomplishments would not be possible without the dedication of many parent volunteers and our committed hospital partners. Thank you all for your tremendous efforts. ■



SPOTLIGHT ON: FAC Shining Star Award

This year we presented the **First Annual Award for Excellence in Family-Centered Care**, also known as the Shining Star Award. This is the first award at MSCHONY where patients and families can recognize any outstanding staff member – physician, nurse, social worker, housekeeper, administrator, etc. – for exemplifying the delivery of Family-Centered Care. This requires that not only the staff member be compassionate and helpful, but also take measures to include the family in all aspects of their child's care.

Since launching the award in February 2008, we have received over 140 nominations from almost every department in MSCHONY. Three awards were granted at the Patient-Centered Care Awards ceremony in February 2008 to:

Dr. Cherise Rowan, Fellow,
Pulmonary Hypertension/Cardiac Dept.;

Sylvia Villaraza, RN, NICU; and

Joyce Po, RN, Cardiac ICU.

We again, extend our congratulations to these recipients for making a positive difference in the experience of a child and family during their stay at MSCHONY. The next awards will be announced in September 2008 in conjunction with the hospital's regularly scheduled employee recognition program. Applications can be found on every inpatient floor. Please see your nurse or unit assistant if you cannot locate one.

Honorable Mentions

For the past two years the FAC has hosted a **"Thank You Luncheon"** in the Wintergarden to thank our members, advisors and their families. Each year we recognize a staff member and family member for their exceptional contributions, as decided by a membership vote. *Congratulations to this year's winners:*

Rose Winton-Quintero, the FAC Member of the Year and **Aliza Koenigsberg**, FAC Staff Advisor of the Year.



FAC Advisor of the Year, Aliza Koenigsberg



FAC Member of the Year, Rose Winton-Quintero and her son



Looking Ahead

We are currently planning for the kick-off of the 2008-9 term and it promises to be another busy and hopefully equally successful year. As always, we are looking forward to welcoming our new FAC members and hearing the suggestions of our membership and advisors. Some of the many plans we already have include broadening our membership, deepening our presence into different areas at the hospital, reaching out more to our current inpatient population, and addressing the needs of outpatient and emergency room patients.

Broadening Our Membership

To ensure we reach and address the needs of all patients and families, we need to hear the voices of all patient and family experiences. We are pleased and proud to have made a significant step in broadening our own range of voices. We are currently in the process of establishing the **Grupo de Familias**, a group of primarily Spanish-speaking parents that will help ensure our efforts are reflective of their specific experiences and cultures.

Deepening our Presence

Because many of our parents have NICU experience, we are assembling a group dedicated to collaborating with NICU staff to bring even more Family-Centered Care initiatives to the NICU. One of our first projects will be creating additional orientation materials for NICU parents. We hope to expand these unit or department specific "teams" of parents to other areas of the hospital.

Helping Inpatient Families

We are also exploring different ways to reach out to the current in patient population, such as establishing a Family Welcome and Information Desk in the MSCHONY lobby.

Supporting Outpatient Families

Many of our parents have children who are chronically ill and spend much of their time as outpatients. We are working with the hospital to bring family perspectives to issues related to the outpatient and emergency department experiences.

Family Advisory Council: Who Are We?

2007-2008 Impact Statement

We are the **MSCHONY Family Advisory Council**. We are 20 parents representing 24 children's hospital experiences. Together, our members have over 58 years of experience parenting a sick or hospitalized child. We have spent 897 days in the NICU and 297 days in the PICU. We represent our children's 77 surgeries and 173 Emergency Department visits.

Our children have spent a total of 1,974 days as inpatients. Four of us are bereaved parents; three 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.



Focus on Patient Safety

As a result of our member participation on the Quality Council, the FAC has created a series of **Patient Safety**

Tips - For Parents

by Parents. We have Tip Sheets to educate family members on important safety topics such as:

- Hand Hygiene
- Medicine Reconciliation
- Patient Verification and
- Keeping a Notebook of your child's care while in the hospital.

Meagan Henry Children's Hospital of New York Presbyterian

TIPS for Parents by parents

THE PATIENT IDENTIFICATION BAND

Every patient is given an Identification Band when admitted to the hospital. The ID Band contains your child's name, date of birth, hospital number and a unique identification number assigned at the time of admission. The ID Band is used as an important safety measure in many aspects of your child's care and the hospital staff is trained to check the ID Band prior to certain activities. It is required that each patient's ID Band is checked when hospitalized. You can help keep your child safe while in the hospital by remembering these tips:

Do not remove the ID Band.

- If the band falls off, loses or becomes uncomfortable for your child, notify your child's nurse immediately.

Make sure hospital staff checks the ID Band before:

- Giving medication – before every dose, every time
- Drawing blood
- Performing any test (e.g. X-ray, ultrasound) or procedure
- Transporting your child by hospital staff

Remember, even if the staff member is familiar to your child, they should compare the ID Band to the medication or physician's order every time.

If your child has allergies...

- If your child has food or drug allergies, an additional red allergy band will be placed on the same arm as the ID Band.
- If your child is allergic to latex, an additional purple allergy band will be placed on the same arm as the ID Band.
- Correct allergy information is important for your child's safety. Some medications contain allergies such as egg products.
- When your child is admitted, be sure the admitting nurse is aware of your child's allergies. Check to see that the ID Band includes important allergy information.

These tip sheets were developed by the parents of the Family Advisory Council at the Meagan Henry Children's Hospital of New York Presbyterian. For more information on the Family Advisory Council please email FamilyAdvisoryCouncil@nyp.org. V1.12/05/07

To view these, please visit: <http://www.childrensnyp.org/mschony/family-advisory-council.html>.



We Need You!

To make MSCHONY the best possible place for our children we need the support of family members and hospital faculty and staff.

If you are a parent or family member of a child treated at MSCHONY and are interested in

learning more about the Family Advisory Council, please contact us at [familyadvisorycouncil @nyp.org](mailto:familyadvisorycouncil@nyp.org). You can read more about us and what we do on the web: <http://www.childrensnyp.org/mschony/family-advisory-council.html>.

If you are a member of hospital staff or faculty, you can help us too. How? Do you know of a family member that you think would enjoy contributing to these efforts? Are you involved in a project or committee that would benefit from family input and support? Are you interested in the topic of Family-Centered Care and would like to learn more about what we do and how we can help your area of the hospital? If so, please contact us at familyadvisorycouncil@nyp.org.

Find us on the web:

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

Email us at: familyadvisorycouncil@nyp.org

Morgan Stanley
Children's Hospital
of NewYork-Presbyterian
Columbia University Medical Center

3959 Broadway
New York, NY 10032