



# Family Advisory Council ANNUAL REPORT

## FAC Members 2008-2009

Mark Abrams  
Jo-Ann Angelucci  
Julia Barugel  
Alberto Barugel  
Karen Bergan  
Michael Craig  
Crista DeStefano  
Patti Di Santo  
Masumi Goldman  
Matt Goldman  
Ellen Goldstein  
Asher Haft  
Josh Itzkowitz  
Rachel Itzkowitz  
Karen Kaiser  
Shevy Kahan  
Marni Lane  
Ellen Lee  
Marcel Messing  
Colleen Messing  
Michelle Morea  
Ann O'Connor  
Wendy Polanco  
Luis Ramirez  
Maria Reyes  
Carole Stroll  
Gary Wartenberg  
Rose Winton

## Message From Our Chairperson

Each year our partnership with the hospital grows, and this past year we enjoyed an even greater level of recognition than before. We have always enjoyed much support by many individuals throughout the Hospital and Department. I believe a hallmark of this past term, however, has been an even greater level of collaboration around topics that will truly impact the delivery of care. For example, this year we were very excited to be made a standing member of the MSCHONY Patient-Centered Care Cabinet. Our continued presence on the Cabinet will bring the family perspective and a collaborative approach to implementing Family-Centered Care solutions to

improve Patient Satisfaction.

This past spring, we had a record number of ten parents attend the MSCHONY Annual Leadership Retreat. There was FAC representation in all four Retreat Breakout groups and the output of these sessions helps set the priorities for MSCHONY for the months ahead. Much of the work of this past year



has laid the foundation for collaboration in areas that are important to us as parents, as well as critical to our mission of supporting the delivery of Family-Centered Care at MSCHONY.

## 2008-2009 Executive Committee:

**Ann O'Connor**, Parent Leader  
*Chairperson*

**Karen Bergan**, Parent Leader  
*Founding Chair*

**Michelle Morea**, Parent Leader  
*Membership Officer*

**Julia Barugel**, Parent Leader  
*Communications Officer*

**Ellen Lee**, Parent Leader  
*Incoming Membership Leader*

**Lori Armstrong, RN**  
*Hospital Liaison*

**Pat Hametz, MD**  
*Faculty Advisor*

**Aliza Koenigsberg**  
*Operations Advisor*

**Sharon Madden**  
*Family Centered Care Advisor*

As we begin this new session, we are pleased to announce that FAC member Ellen Lee will be taking over the role of Membership Officer. Ellen will have overall responsibility for recruiting and orienting new members, as well as helping identify opportunities for all members to participate in FAC and hospital programming. Welcome and thank you, Ellen! At this time, we must also say farewell to Karen Bergan, our Founding Chair, and Michelle Morea, our first-ever Membership Chair, as they relocate with their families out of the area. We thank them for their four years of dedicated service and commitment to the FAC and MSCHONY. Best of luck to both our incoming and outgoing Parent Leaders!

On behalf of the entire membership of the Family Advisory Council, we are pleased to share this Annual Report. Thank you to our members, our advisors and all the hospital staff who have worked this year to make this level of collaboration possible.

Sincerely,

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



## Overview of the 2008-2009 Term

This year we were joined by eight new members with broad and diverse hospital experiences. We welcome their spirit of determination to improve the experiences of patients and families. Most of these new members were referred to us by physicians or nurses who had cared for their children. We have had great success with recruiting members from physician and nurse referrals. We thank our hospital and department partners for spreading the word about the FAC.

### Providing the Family Perspective

One of the most important ways the Family Advisory Council serves MSCHONY is by sharing our “real-life” patient and family experiences at the moments when decisions are being made about hospital policies, programming, patient services, amenities, facility renovations, etc. In addition to serving as standing members on hospital committees, we set aside time at each monthly meeting to serve as a “focus group” for various hospital and department initiatives. During the past year, we have served in this advisory capacity on topics ranging from ‘behind the scenes’ initiatives such as Electronic Medical Records to initiatives at the bedside, such as Hourly Rounding. *If you are currently working on a project or program that would benefit from input from family members with experience at MSCHONY, please do not hesitate to contact us at [familyadvisorycouncil@nyp.org](mailto:familyadvisorycouncil@nyp.org).*

The **MSCHONY Annual Leadership Retreat** provided another opportunity to share our “real life” experiences and perspectives on a variety of topics and issues identified as priorities for MSCHONY. Ten FAC members were in attendance and they were divided among the four working groups at the retreat: Quality and Patient Safety, Family Centered Care, Subspecialty Outpatient Experience, Medically Complex inpatient and Outpatient Care. The group leaders each commented on the value the family perspective brought to their discussions and planning. Each work group created an action plan for implementing its priority items over the next year. The FAC will continue to collaborate with each of these groups as they move forward with their action plans.

In addition to serving in an advisory capacity, our members also speak directly to the hospital community as part of education and orientation programs. A FAC member participates in the monthly **MSCHONY New Employee Orientation Day**, explaining the tenets of Family-Centered Care and how it impacts the overall hospital experience. This program has tremendous reach as all new hospital employees attend this orientation. Our **Family Faculty**

program is recognized an important element of the overall resident education experience. The program provides a unique opportunity for residents to hear directly from families about “what worked and what didn’t” in specific situations. Dr. Pat Hametz, who heads the program with a FAC member explains, “Hearing directly from families as part of the curriculum is critical to teaching residents how to deal with difficult, emotional situations.”

FAC members have presented the following topics to the resident community:

- Bereavement
- The Physician Parent
- The Angry Parent
- Disclosure/Delivering Unexpected News

### Providing Information to Families

The Family Advisory Council is committed to educating and empowering patients and families through the timely delivery of information. We are working on several projects to support this goal. FAC members Jo-Ann Angelucci and Gary Wartenberg led a group of dedicated FAC parents to develop a comprehensive **Family Guide** which is available online on the MSCHONY website at <http://childrensnyp.org/mschony/patients/family-guide.html>. The Family Guide includes information ranging from where to eat to when and why to wash your hands.

Now we are working with the hospital to incorporate the pediatric-specific and Family-Centered Care information into printed version of the NYP Guidebook for MSCHONY.

FAC members, led by Michael Craig, are also working closely with the hospital to customize the information that will be provided in the **new interactive television and entertainment system**. This system will also include the **Family Orientation Video** that the FAC helped develop last year.

We are also collaborating with the hospital to explore creating a **Family Resource Center** which would serve as a hub of all available information.

### NYP Patient-Centered Care Grants

This year the FAC was extremely pleased to receive another **Patient Centered Care Grant Award**. This is the fifth time a FAC proposal was chosen to receive money from this grant program. This year’s Award money will be used in a way that will impact a great many of the children cared for at MSCHONY – with a particular focus on outpatients. Many of the FAC families have children with chronic conditions, many of whom require regular blood draws as part of their outpatient care. These “frequent fliers” felt that the waiting area of the outpatient Phlebotomy Lab was not as

“FAC members currently serve on the following committees:

- Quality Council
- Bereavement
- Excellence at Children’s
- Ethics Committee
- Events Committee
- Patient-Centered Care Cabinet

“At this point, I can't imagine starting any major initiative or making any major changes in our provision of care without family member's input.”

– Dr. Philip Graham

comfortable or patient-friendly as other areas of the hospital, and yet it is an area that many children wait in many times a year. With the money awarded, new, updated furniture and child-friendly entertainment elements will be available in a

freshly painted waiting area. Thank you to FAC members Patti Disanto and Michelle Morea and all who contributed ideas for the grant. We also thank Toni Millar, Director of Child Life, for your support in completing the application. We look forward to seeing the completed results!

## Leading the Way in Family-Centered Care

We are very proud that the MSCHONY Family Advisory Council continues to receive national recognition for some of our efforts. This past March, FAC Chairperson Ann O'Connor joined Dr. Philip Graham at the **NACHRI Conference** in Nashville, TN to present their experiences of partnering with families in the area of Quality and Patient Safety. Although MSCHONY has had parents as active members of the Quality Council since 2006, few hospitals have engaged parents at this level of collaboration and MSCHONY is seen as a leader in this area.

Also in March, Karen Bergan attended the **NICHQ Annual Forum** in Texas where she received the **Family Leader Achievement Award** for her roles as co-leader of the NICHQ Family Leaders group and co-founder of the Patient and Family Advisory Council (PFAC) Listserv which currently has over 300 family and staff members sharing their FAC experiences in their hospitals. Karen's work in these areas has not only raised MSCHONY's profile as a leader in Family-Centered Care, but it has helped FACs from around the country help each other.

## A Special Program for Parents: Rejuvenate You

This past January we launched a very special: the “Rejuvenate You Wellness Program.” This program is the brainchild of one of our founding parents, Jennifer Gault, and it dedicated to helping parents find some rest and respite during one of the most stressful experiences for a family – the hospitalization of a child. Jennifer and other FAC parents recognized that parents and caregivers must take care of themselves in order to take the best possible care of their hospitalized children. The Rejuvenate You program runs weekly in the 7th floor Family Lounge and provides light refreshments, complimentary 10-minute chair massages, soothing music, pet therapy, and access to a meditation room. Judging by the number of parents coming to these weekly sessions, the program has been an immediate and overwhelming success!

## SPOTLIGHT ON: NICU Orientation

More than half of our FAC parents are veteran NICU parents. In fact, together we have had 17 babies cared for in the NICU with a cumulative length of stay in the NICU exceeding 1400 days, or almost four years. These parents know first-hand that the NICU experience can be overwhelming and stressful and they share a strong desire to ease this transition for other parents, and help them be the best possible advocates for their children.

FAC parents, led by Rachel Itzkowitz, worked closely with Norene Dove, RN (Patient Care Director, 7T) and other NICU staff to develop and launch the NICU Orientation Program. This program combines existing materials – the NICU Guidebook and the FAC's Patient Safety Tip Sheets – with a personal touch to help understand and absorb the information. This past spring, Rachel began meeting with newly admitted NICU moms and dads to personally present these materials. The feedback on this program has been extremely positive from families, physicians and NICU staff.

“When Rachel came in on the day of our sons surgery, I can't describe the way it made us feel. Someone who had been through this, who really understood our feelings.”

– Mrs. B

To supplement these efforts, the FAC, with the support of Norene Dove and Lori Armstrong, R.N. (VP Nursing and Patient Care Services), developed the Transitional Nursery (TN) Booklet. The booklet is intentionally kept simple, so as not to overwhelm, and focuses on just a few key Patient Safety and general TN information. Both the NICU Orientation and TN Booklet programs are wonderful examples of FAC parents leveraging their personal experiences to support and empower other families.



TN Booklet

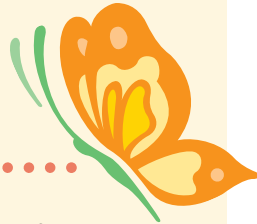
“We have been waiting for an innovative, non-threatening way to inform parents about the situation their babies are in,” said Norene Dove, Patient Care Director, NICU. “The TN Booklet will enhance what our nurses have to offer greatly. We are pleased to be working with the FAC.”

## Honorable Mentions

The FAC Award for **Excellence in Family-Centered Care** was developed to give patients and families the opportunity to recognize anyone – physician, nurse, social worker, housekeeper, administrator, etc. – for exemplifying the delivery of Family-Centered Care. Recognizing excellence in Family-Centered Care directly corresponds to the Mission of the hospital and FAC. This requires more than compassion and helpfulness; this requires a dedication to include the family in all aspects of the child's care. Last year the FAC was pleased to present nine Excellence in Family Centered Care awards. The FAC recognizes, however, that families are the best judge of the delivery of Family-Centered Care and for that reason a letter of recognition is placed in the personnel file of each nominee for this award.

Congratulations to this year's winners of the Award for Excellence in Family-Centered Care:

- Keith Kuenzler, M.D., Pediatric Surgery
- Susie Burdine-Ward, Interventional Radiology
- Lizzy Olsen, Child Life
- Peter Fair, R.N., NICU
- Mary Osuch-Wilson, R.N., NICU
- Abby Hodges, R.N., CICU
- Amanda Barile, R.N., 6 Tower
- Patricia Burnham, R.N., 6 Tower
- Mark Richmond, M.D., Cardiology



Each year, FAC members vote to honor one of our members and one of our advisors for their exceptional contributions to our mission. This year we are pleased to award Dr. Pat Hametz as our FAC Advisor of the Year. Dr. Hametz has worked tirelessly with and for the FAC since 2006. She directs our Family Faculty program and as our Faculty Advisor provides valuable insight and advice on our progress.

This year's vote resulted in our first ever "tie" for the FAC Member of the Year Award. Both Rachel Itzkowitz and Ellen Lee have shown tremendous commitment to the FAC and our mission.

**Congratulations to all and thank you for your dedication!**



(from left to right) Rachel Itzkowitz, Ellen Lee and Ann O'Connor

**Find us on the web:**

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

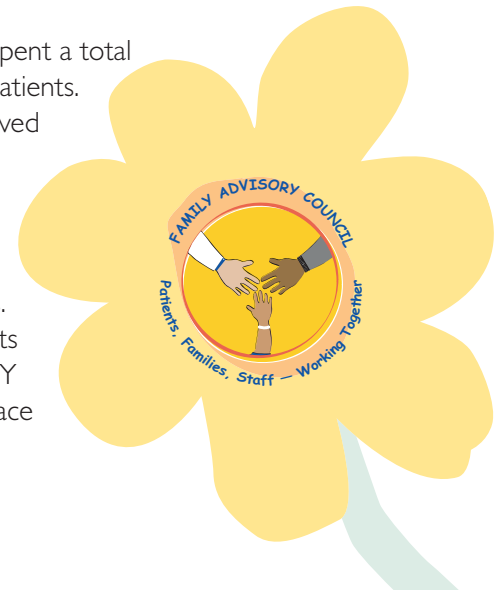
**Email us at: [familyadvisorycouncil@nyp.org](mailto:familyadvisorycouncil@nyp.org)**

## Family Advisory Council: Who Are We?

### 2009-2010 Impact Statement

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.



## 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 family member** or parent 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 who we are 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.

- 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](mailto:familyadvisorycouncil@nyp.org).