New pediatric wheelchairs
listening to the
voice of our patients
with a little help from
the Pediatric Oncology
Patient-Family
Advisory Committee
(See story on page 5)

10-year-old patient, Javertle Pezos, is a perfect fit for these new pediatric wheelchairs, the culmination of an idea brought forward by a parent at a meeting of the Pediatric Oncology Patient-Family Advisory Committee.

“At the needs of our patients and their families…”
OUR MISSION

“GUIDED BY THE NEEDS OF OUR PATIENTS AND THEIR FAMILIES, we aim to deliver the very best healthcare in a safe, compassionate environment; to advance that care through innovative research and education; and, to improve the health and well-being of the diverse communities we serve.”
Founded in 1811, Mass General is the third oldest general hospital in the United States and the oldest and largest in New England. Mass General continues its tradition of excellence today. Massachusetts General Hospital has been ranked among the top five hospitals in the United States by U.S. News & World Report since the rankings began. In 2017, Mass General is recognized as #4 out of nearly 5,000 hospitals considered in the ranking; Mass General is the only hospital ranked in all 16 specialties considered by U.S. News & World Report, a testament to the breadth and depth of our expertise. Mass General patients rate their experiences highly, with nearly all indicating they would be very likely to recommend Mass General to others. The hospital consistently achieves high ratings from professional organizations, including the American Nurses Credentialing Center, the Society of Thoracic Surgeons, The Joint Commission, and the Leapfrog Group. In addition, our clinicians and researchers are recognized at home and internationally for their contributions to the field.

Patients at Mass General have access to a vast network of physicians, nearly all of whom are Harvard Medical School faculty and many of whom are leaders within their fields. Our many multidisciplinary care teams—known worldwide for innovations in cancer, digestive disorders, the neurosciences, heart disease, orthopaedics, transplantation, urologic diseases and trauma care—unite specialists across the hospital to offer comprehensive, state-of-the-art medical care. In addition, Mass General Hospital for Children provides a full range of pediatric health care services, from primary care to leading-edge treatment of complex and rare disorders.

Mass General is a 999-bed academic medical center that offers sophisticated diagnostic and therapeutic care in virtually every specialty and subspecialty of medicine and surgery. The hospital’s five multidisciplinary care centers—known worldwide for
innovations in cancer, digestive disorders, heart disease, transplantation and vascular medicine—unite specialists across the hospital to offer patients comprehensive, state-of-the-art medical care. In addition, the hospital provides care and services in multiple health centers located within neighboring communities, including Back Bay, downtown Boston, Chelsea, Charlestown, Danvers, Everett, North End and Revere, as well as at MGH West and the North Shore Medical Center. The hospital also holds concurrent Level 1 verification for adult and pediatric trauma and burn care. The MassGeneral Hospital for Children, Mass General provides a full range of pediatric health care services, from primary care to leading-edge treatments of complex and rare disorders. The hospital holds concurrent Level 1 verification for adult and pediatric trauma and burn care.

Mass General annually:

- Admits approximately 48,000 inpatients
- Handles nearly 1.5 million outpatient visits
- Records more than 100,000 emergency room visits
- Performs more than 42,000 operations

Mass General and Brigham and Women’s Hospital are the founding members of Partners HealthCare, an integrated health care delivery system that includes community hospitals, primary care and specialty physicians, specialty facilities, community health centers and other health-related entities.

Mass General has long been a leader in successfully bridging innovative science with state-of-the-art clinical medicine. Mass General conducts the largest hospital-based research program in the United States, with an annual research budget of more than $781 million. This funding drives discoveries and breakthroughs in basic and clinical research, which translate into new and better treatments that transform medical practice and patient care. In addition, Mass General is the original and largest teaching hospital of Harvard Medical School, where nearly all Mass General staff physicians have faculty appointments. Since the hospital’s founding, Mass General has been committed to training and mentoring the next generation of international leaders in science and medicine, providing a wealth of opportunities for physicians, nurses, and other health professionals. These clinicians, in turn, lend fresh and innovative perspectives on how to treat and care for patients.
Patient and Family Advisory Councils

a valuable mechanism for tapping into the suggestions and ideas of patients and families

Sometimes, some of the most important work in the hospital takes place behind the scenes with no fanfare or recognition, but it’s nonetheless crucial to our ability to achieve our goals and fulfill our mission. Certainly, the work of our dedicated patient and family advisory councils (PFACs) falls into that category. These councils are comprised of patients, family members, and staff who give generously of their time and ideas to help us improve care and refine systems.

On Wednesday, September 7, 2016, I had the opportunity to attend a meeting of the General Patient and Family Advisory Council (see Fielding the Issues on page 11 for more information about the G-PFAC) to get their feedback on our plans to implement Partners 2.0. As you may know, Partners 2.0 is the initiative led by Partners president and CEO, David Torchiana, MD, along with MGH president, Peter Slavin, MD, and BWH president, Elizabeth Nabel, MD, to ensure collaboration, efficiency, and coordination of services across all Partners entities. The G-PFAC was one of the first groups to provide feedback on the ‘big opportunity’ statement for this initiative. It was so helpful and instructive to hear their comments and get a sense of the MGH experience from the patient and family perspective. I can’t thank them enough for sharing their insights and impressions.

My visit to the G-PFAC meeting was a wonderful reminder of the good work being done by all our patient and family advisory councils. So I thought I’d use this week’s column to share some of that work with you. What follows is a partial summary of some of the projects that are benefiting from the input of our general, cardiology, cancer, pediatric oncology, and MGH General Hospital for Children patient and family advisory councils.

The General PFAC:

This past year, the G-PFAC participated in the MGH volunteer’s orientation and training program to enhance their understanding of hospital culture and policies. They provided feedback on a number of activities and initiatives, including:

- The Kitty Hawk Project, an initiative geared toward reducing physician burden while optimizing patient care, such as the use of medical scribes to document patient-physician encounters

continued on next page
MISSION DRIVEN

Within this large, complex environment of care, it is our mission that guides our individual and collective beliefs, decisions and actions—our work. Rewritten in recent years with direct input from patients and families, this statement of purpose provides the foundation for the hospital’s patient- and family-centered approach to care:

“GUIDED BY THE NEEDS OF OUR PATIENTS AND THEIR FAMILIES, we aim to deliver the very best healthcare in a safe, compassionate environment; to advance that care through innovative research and education; and, to improve the health and well-being of the diverse communities we serve.”

The hospital’s Patient and Family Advisory Councils (PFACs) serve as a primary vehicle for incorporating the patient and family care experience into our planning and day-to-day hospital operations.

PFACs at MASS GENERAL

Mass General formed its first Patient and Family Advisory Council seventeen years ago, with the launch of the MassGeneral Hospital for Children (MGHfC) Family Advisory Council in 1999. Following their lead, other high-volume specialty areas launched their own service-specific PFACs: MGH Cancer Center in 2001 and the MGH Heart Center in 2007, and the hospital formed a General PFAC in 2011. In addition, the hospital’s Ambulatory Practice of the Future operates a Care Alliance. These PFACs represent the hospital’s most widely used clinical services and represent a large proportion of the care provided at Mass General.

The hospital, patients and families have found it beneficial to operate multiple, targeted PFACs, each bringing voice to a specific patient and family experience, environment of care, and/or priority area for the hospital. These PFACs are optimally situated to impact the delivery of care for their respective and unique patient populations. Collectively, they are positioned to influence hospitalwide initiatives, with the added benefit of bringing multiple, authentic and highly relevant perspectives to the table, and ultimately, to the hospital’s governing body, the Board of Trustees.

The PFACs continue to direct and shape the patient experience at Mass General by participating on key service-based and hospitalwide committees, reviewing educational and other materials for patients and families, lending their wisdom and voice to staff orientation sessions and educational offerings, bringing forward new ideas for services and service enhancements, reviewing blueprints and plans for new patient facilities, and so much more. Above all, they bring an experience and perspective to the table that no others can replicate, and for that we are all the better.
The MGHfC FAC continues to foster partnerships between patients, parents and professionals to improve the hospital and enhance patient and family-centered care. In 2016-2017 it attained its goals of supporting parent to parent efforts by participating in a NICU peer mentor program, increased parent member participation on hospital committees, developed patient and staff education most notably in the form of a video to help reduce stress for children who are waiting in the Emergency Department and aligned with the hospital’s Patient Experience efforts with parents helping to develop and facilitate staff trainings.

**PRESENTATIONS and FEEDBACK**

- Provided feedback to Kevin Callans, NP, who presented about the Parent to Parent program she developed for parents whose children have undergone tracheostomies.

- Two FAC members reported back to the group after presenting a poster at the Institute of Family-Centered Care’s International Conference that outlined a staff training in courtesy and helpfulness in which FAC parents had participated. The staff training resulted in higher hospital C-GCAP scores in courtesy and helpfulness.

- Provided input to Karen Turner, MGH Patient Navigator, who plans for and accompanies patients who carry a diagnosis of autism during their appointments and in-patient stays.

- Eve Megargel, a parent member of FAC, gave a presentation to our group on her newly published book titled ‘Learning to Kiss’ about her son who is a young adult with autism treated at MGH.

- Learned about the work of Annie Brewster, MD, MGH physician and founder of the Health Stories Collaborative who discussed her work on the importance of storytelling around illness.
PATIENT and STAFF EDUCATION

- Provided the parent perspective to Dr. Jeanne MacDonald and Sandra Stokes, LICSW who spoke about their work developing a Perinatal Bereavement Program at MGH.

- Developed a Grand Rounds that was presented on April 11, 2017 titled ‘So Your Child is Going to Need a Trach: Reflections on Good Communication Around Difficult Decisions’ featuring an ENT Surgeon, Nurse Practitioner, and parents whose infant underwent a tracheostomy discussing their decision-making process before the procedure.

- Three parent members spoke to pediatric interns in a session titled “Introduction to Bedside Rounding” explaining that bedside rounding is an important way for them to ask questions and partner in their child’s care.

- Sandra Clancy, Co-Chair of the Family Advisory Council, co-presented a workshop titled ‘Harnessing the Power of the Patient Voice’ at the annual conference of the Association of Pediatric Program Directors that demonstrated how video of patient presentations is a powerful tool in medical education and used video of pediatric patients speaking at FAC Grand Rounds in 2016.

- Darcy Daniels, FAC Co-Chair, was a panel speaker at the Partners Patient Experience Summit and noted the importance of her work on the FAC as a way to improve the hospital.

- Two parent members and their children who are pediatric patients at MGHfC spoke about their experiences to a dinner hosted by the MGHfC Advisory Board. The two teenage patients provided insight into what they learned when they were patients and shared advice for clinicians treating children.

- Wendy’s Welcome, a video developed by a pediatric patient and her mother who is a FAC member was featured on several news outlets. Its purpose is to introduce pediatric patients to the Emergency Department and help them to relieve anxiety about what will come next. The video was featured in news stories on WCVB, CBS Boston (Malika Marshall), Boston Magazine, Patients’ View Institute, Chronicle, STAT News, and Healthcare Design Magazine.
OTHER ACTIVITIES

- Voted in a new parent Co-Chair.
- Added 5 new parent members.
- Updated the website to include committees on which parent members serve, staff members and activities.
- Discussed and finalized a list of priorities for the upcoming year. Analyzed progress made on priorities for the previous year. They are, in order of priority:
  - Support parent to parent networks throughout MGHfC
  - More FAC parents on hospital committees
  - Patient and staff education efforts
  - Further alignment with patient experience efforts
  - Organize a family-centered hero award
  - Focus on transition to adult care
  - Relationship with Office of Patient Advocacy
  - Outreach to MGH healthcare centers for recruitment
  - Create language for parents around patient safety
- In response to parent member’s observation that pediatric patients do not fit properly in MGH’s adult wheelchairs, FAC and the Pediatric Cancer Center PFAC spearheaded an effort and the hospital purchased 12 pediatric wheelchairs.
- Initiated a parent member recruitment drive. Steps taken include creation and putting up recruitment posters, providing letters to each Unit Chief at MGHfC so that they could target 5 to 10 families and educate them about the FAC, and having the FAC Co-Chair make a presentation to the monthly Unit Chief’s meeting.
- FAC Co-Chairs participated in conference call with members of a new MGHfC Parent to Parent group whose mission is to provide support to families whose children have Irritable Bowel Disease and gave information about our group’s formation, development and mission.
- Several members participated in the hospital’s annual Santa’s Workshop gift wrapping event that provides gifts for families of children whose hospital stays take place over the holidays.

**So, Your Child is Going to Need a Trach:**
Reflections on Good Communication Around Difficult Decision Making

- Christopher Hartnick, MD
- Kevin Callans, RN
- Katherine and Michael Catapano (parents)

In this Grand Rounds, a medical team consisting of a pediatric surgeon and nurse will discuss how they approached discussing the need for a tracheostomy with a pediatric patient’s parents. The patient’s parents will explain their questions and concerns around this difficult medical decision, highlighting what they see as the components of good communication. This Grand Rounds, sponsored by the Family Advisory Council, will feature a positive partnership between medical providers and parents around challenging medical conversations.

This event is sponsored by the MGHfC Family Advisory Council.
• Created a binder for new members that contains photographs of all members of the group and brief biographical statements, copy of the bylaws, yearly list of accomplishments, and the committees on which parents serve.

• Collaborated with the Director of Volunteer Services to enable parent members to undergo volunteer orientation on-line. Now members receive HIPPA training, safety instruction, and orientation on-line.

• The Co-Chairs interviewed candidates for the position of Nursing Director on Ellison 17 and 18 and provided their feedback to the group directing the hiring process.

• Committee formed with the goal of improving the parent experience in the PICU when a child has a long stay in the Unit and has reviewed existing patient education material in the PICU and is developing more comprehensive material that will be prominently displayed.

• Collaborated with MGHfC’s Ambulatory Patient Experience Committee which developing a ‘Secret Shopper’ form enabling parents to complete an on-line survey immediately after an appointment with a provider at MGHfC. FAC parents will pilot the form when it is complete.

• Planned with the Ambulatory Patient Experience Committee that is preparing training material for staff around improved courtesy and helpfulness and will engage FAC parents in the trainings.

• FAC will participate in MGHfC Day at the Massachusetts Statehouse on November 14, 2017. This is an opportunity for members of the Massachusetts delegation to learn more about the hospital.

• FAC member who is a PICU nurse initiated a program in the Unit in which the medical team rounds on adolescent patients, allowing adolescent patients to discuss their care with the entire team.
PARENT PARTICIPATION IN HOSPITAL COMMITTEES and TASK FORCES

- MGH Quality Oversight Committee
- MGH Gun Violence Prevention Committee
- MGHfC Ambulatory Patient Experience Committee
- MGHfC In-Patient Experience Committee
- MGHfC Ethics Committee
- MGHfC Advisory Board
- MGHfC Pediatric Wheelchair Committee
- MGHfC PICU Parent Life Committee
MASS GENERAL HOSPITAL FOR CHILDREN FAC MEMBERS

**Parent Members**

Seta Atamian  
Debby Cartisser  
Lisa Cimino  
Darcy Daniels *(Co-Chair)*  
Michael Doiron  
Charlene Harper  
Roxanne Hoke-Chandler  
Cindy Matuszewski  
Matthew McGuinness  
Janice Morris  
Eve Megargel  
Erin Quinney  
Randi Stempler

**Staff Members**

Sharon Badgett-Lichten  
Debra Burke  
Monic Chardin  
Sandra Clancy *(Co-Chair)*  
Anne Fonseca  
Kate Gerne  
Peter Greenspan  
Esther Israel  
Karen Manning  
Jessica Mascola  
Sandra Dodge McGee  
Eleanor McLaughlin  
Anne Pizzano  
Alexandra Sobran  
Kim Whalen
1. **Mission Statement:**

The MassGeneral Hospital for Children’s Family Advisory Council (FAC) is dedicated to fostering the partnership of parents, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within Massachusetts General Hospital.

2. **Purpose:**

2.1. Work together with the administration and staff of MassGeneral Hospital for Children (MGHfC) to promote Family-Centered Care;

2.2. Collaborate with the MGHfC staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings;

2.3. Improve patient, family and staff satisfaction;

2.4. Ensure an attractive environment that is responsive to the needs of children and their families;

2.5. Act as an advisory resource to MGHfC leadership on issues of planning, evaluation of programs and services, policies and new facilities;

2.6. Act as an advisory resource to MGHfC giving input to teaching documents generated by the hospital regarding families;

2.7. Promote a positive relationship between MGHfC and the community; and serve as a vital link between community at large;

2.8. Contribute to the educational process of new professionals as positive resources and teachers contributing to the mission of the MGHfC.

3. **Membership Committee:**

3.1. Members of the Membership Committee will be appointed by the MGHfC Associate Chief, Department of Pediatrics;

3.2. The Membership Committee will consist of three current FAC members and two MGHfC Council members;

3.3. Members of the Membership Committee will track membership terms and actively recruit new members.

4. **Membership:**

4.1. Membership is by application to the Membership Committee;

4.2. Membership consists of fifteen people whose children have received care at MGHfC or are patients sixteen years or older who have received care at MGHfC;

4.3. Family members will serve as the Council Co-Chairs;

4.4. The MGHfC ‘s Medical Director, Associate Chief Nurse of Pediatrics, Executive Director, and Inpatient Director of Quality and Safety will be ex-officio members;

4.5. The MGHfC Inpatient Director of Quality and Safety will be allowed to vote in times where a tie-breaking vote is required.

4.6. The MGHfC will have four rotating staff members of the Council;

4.7. Other MGHfC staff will attend meetings as needed and receive meeting minutes approved by the Council to have knowledge regarding the agenda and on-going work.
5. **Membership Terms:**

5.1. Each year in September, the Council will seek to appoint three family members to serve a three-year term to the Council;

(Beginning with the Council in 2007, the 9 appointed family members will be appointed to one, two, and three year terms, the same with the 3 MGHfC staff);

5.2. Members can re-apply for appointment for up to six years. After this time, members can still be active on committees but must wait three years before reapplication to be a member of the Council;

5.3. Membership will elect in March a Council Co-Chair for a two-year term with co-chair election to follow six months later.

5.4. Any Council member that misses four consecutive meetings will be considered an inactive member unless the absence has been approved by the Membership Committee;

5.5. If a Council member cannot fulfill his/her commitment to the Council, they can resign in writing and a new member will be chosen to serve the balance of his/her term.

6. **Membership Responsibilities:**

6.1. Participate in the formation and evaluation of FAC yearly goals and objectives and be an active participant in Council activities;

6.2. Prepare for and attend meetings;

6.3. Be an advocate for all patients and families by identifying and representing their needs and concerns;

6.4. Maintain patient confidentiality according to HIPPA guidelines at all times;

6.5. Consider serving on other MGHfC committees when requested;

6.6. Support the MGHfC publicly;

6.7. Notify the Co-Chairs if unable to attend meetings;

6.8. Agree to attend the Volunteer Program Initiation and Training as well as participate in the Volunteer Program;

6.9. MGHfC staff members will act as the hospital liaisons to the Council.

7. **Co-Chair Responsibilities:**

7.1. Establish goals and objectives of the Council with the Membership in September;

7.2. Complete an annual progress report to be submitted in January to the Chief of Service, Department of Pediatrics, Chief of Pediatric Surgery, Vice-President of Pediatrics, MGH, Vice-President, Chief Nurse, MGH, Storybook Ball Committee Chair;

7.3. Set meeting agendas and schedules;

7.4. Represent the goals and objectives of the FAC with any correspondence approved by the Membership with hospital administration and staff;

7.5. Appoint subcommittee chairs, who will be responsible for:

- updates of the subcommittee work to the Council at regular intervals;
- goals and objectives for the subcommittee;
- annual reports of the subcommittee.
8. MassGeneral Hospital for Children Responsibilities:

8.1. Work collaboratively with the FAC to promote the best possible family-centered practice at the MGHfC;

8.2. Work together with the FAC in policy-making, planning and evaluating of programs and services;

8.3. Review and respond to recommendations of the FAC in a timely manner;

8.4. Offer new member orientation to the MGHfC structure, decision-making process, committee structure, and HIPPA regulations;

8.5. Provide meeting space and refreshments;

8.6. Provide free parking for FAC meetings and work in hospital;

8.7. Provide financial support for approved FAC activities based on submitted proposals.

8.8. Provide staff support person to:
• take meeting minutes;
• notify members of upcoming meetings with agendas;
• distribute meeting minutes to the Council and others on the distribution list;
• keep the FAC distribution list up to date;

9. Quorum:

9.1. A quorum represents 7 members, one of whom must be a staff member, needed for any official meeting.

10. Amendments:

10.1. The process to amend the FAC By-Laws is as follows:
• Council member submits suggested revision in writing.
• Revisions are sent out to members and discussed at a Council meeting.

10.2. The Council will vote on the amendments and approve through majority vote.
The Pediatric Oncology Family Advisory Committee (FAC) has continued to remain integral to the Pediatric Oncology clinical service, providing input around clinical practice and program planning. This has been a long standing, active group since 2003 with a changing membership to reflect the needs of the parents and practice. Parents of children receiving cancer treatment and parents of those children who have completed treatment join with members of the multidisciplinary team of clinical professionals to collaborate with the common goal of providing excellence in pediatric oncology care and enhancing the patient experience.

**OBJECTIVES**

- Build a consistent and committed membership
  - Initiate a vigorous recruitment process, including promoting diversity amongst members
  - Develop an orientation program in collaboration with Mass General’s Volunteer Services program for all members joining the Committee
  - Increase awareness of the value of the Advisory Committee’s role within the clinic’s operations and programs
  - Enhance the Advisory Committee member’s role as a change agent within the practice
- Collaborate with other PFAC’s and integrate into the already establish infrastructure of Advisory Groups at Mass General
  - Co-chairperson (Mass General staff member) will attend Chairpersons Council
  - Advisory Committee members will have opportunities to participate in professional conferences within the region for education and collaboration
- Document initiatives and successes to organizational leadership
  - Provide periodic reports to practice leadership
  - Compile a yearly report detailing annual activities
  - Identify opportunities for collecting additional data for evaluation and action
The Pediatric Oncology FAC holds meetings five times annually, with additional meetings scheduled when the group or a subgroup is working on a specific project. There is a clear understanding of the competing demands of families when a child has cancer—family, other children, work and of course, treatment, all impact the ability of any member to attend in person meetings of the Advisory Committee. Opportunities to call into meetings or Facetime have been made available to members, so to offer flexibility and promote members’ participation.

This year the Committee honored 4 members of the Committee who departed after several years of service. Another Committee member took a hiatus from the FAC to care for her ill child. Subsequently, the Family Advisory Committee also welcomed 5 new enthusiastic parents to the membership of the Committee. Clinical staff participation remained constant.
• Family Advisory Committee members initiated a meeting with MGH Nursing Leadership to discuss concerns related to port-a-cath access in the Emergency Department for pediatric oncology patients. Members of the Emergency Department leadership and staff along with multiple stakeholders within MGHfC convened in ongoing problem solving to address this issue. New ED nursing now staff participate in training within the Pediatric Oncology clinic where they learn approaches and techniques for port access with young patients. Standards of practice and care have been revised and tools for communication between the Pediatric Oncology clinic and ED have been put into place. Continued planning within nursing administration about improving the competencies of the ED nurses in this arena.

• Completion of a Patient/Family Education Center within the clinic’s waiting area. This area includes dedicated space for our Adolescent and Young Adult patient population. Resource materials, technology and a quiet space are offered for researching and learning about childhood cancer, coping with treatment and optimizing support and care for children during their therapy. The Family Advisory Committee provided guidance throughout the development of this center.

• The Family Advisory Committee met with David Ekrem, Web site developer to discuss enhancements to the Pediatric Oncology web site. Goals and timeliness were established for the Pediatric Oncology team to implement changes to enhance the site and better reflect the achievements of the team and programs available within the clinic’s practice. Clinical staff continued to consult with the FAC as changes continue to be made.
• Continued implementation of the Mass General Pediatric Oncology POPS – Parents offering Parents Support program. The Committee has offered guidance in marketing the program and how best to engage families’ participation. Promotional materials were created with the input of the FAC (see photo attached), which are now added to new family information provided at the time of a child’s cancer diagnosis.

• Development of the Pediatric Wheelchair initiative. One Committee member who brought the concern forward participated in all the planning meetings and reported back to the FAC for their input and guidance. In July 2017, 11 customized Pediatric Wheelchairs were made available in the outpatient pediatric practices as a pilot project to enhance the comfort and safety of pediatric patients.

• Collaboration with Cancer Center Administration to extend the hours of the Healing Garden to offer a place of respite and comfort both later in the day and on the weekends for pediatric patients and their families who are in the hospital. Reviewed policies which limit patients and families from having access to the Healing Garden when other programs are utilizing the space. Development of more inclusive policies to support patient and families.

• Dr. Howard Weinstein, Chief of the Pediatric Hematology-Oncology unit joined the April 2017 meeting of this Committee providing updates around pediatric cancer research, growth and operations of the clinic practice. Dr. Weinstein’s participation in the Committee validated the importance of the Committee within the practice and provided an opportunity for face to face communication around issues of parents’ concerns.

• Tracking of Patient Experience Data and input offered by the Committee around clinical improvements
• Continued review of eCare implementation and impact on patient/family’s perceptions of care.

• Family Advisory Committee members provided guidance about the development of psychosocial care programs for patients and families throughout the year. Programs including parent education/support, creating connections between families and honoring patients for their participation in arts programming were planned with FAC input.
PEDIATRIC ONCOLOGY FAC MEMBERS

**Parent Members**

Mary Cincotta  
Michael Doiron  
Patricia Flaherty (on leave)  
Susan Jacobson  
Kim Kayajan  
Mary Koperski  
Michelle McKiernan  
Peter Palamidis  
Sabrina Pettinicchio  
Dawn Regan (Co-Chair)  
Jerry Schindler  
Janice Theriaque  
Tarrah Zedower

**Staff Members**

Mary Huang, MD  
Heidi Jupp, RN  
Elyse Levin-Russman, LICSW, OSW-C *(Co-Chair)*  
Ellen Silvius, RN, BSN
PEDIATRIC ONCOLOGY FAC BY-LAWS

OVERVIEW

In 2003, the Massachusetts General Hospital for Children’s Cancer Center launched its' initial Advisory Committee. Parents of children both currently receiving cancer treatment, as well as parents of children who had completed treatment joined with a multidisciplinary team of pediatric oncology providers to develop a framework for collaboration to inform clinic operations and program development. The committee quickly became an important voice in meeting the center’s expressed goal of providing family centered care. Since its’ inception, the Family Advisory Committee has seen changes in membership, as parents typically move off the Committee after several years of service. This has afforded the Committee the opportunity to move forward with new input while building upon past accomplishments.

MISSION STATEMENT

Massachusetts General Hospital for Children’s Cancer Center Family Advisory Committee (FAC) is committed to fostering a partnership between families and caregivers to promote excellence in the care of children with cancer.

PURPOSE

- Parents, patients and health care providers work together to improve the quality of care for children and their families during and after cancer treatment.
- Promote Family Centered Care as a central principle within the Pediatric Oncology practice.
- Optimize the patient and family experience.
- Provide guidance and input on family education and the development of resources to support patients and families.
- Act as an advisory resource on issues of planning and evaluation of programs, services and clinic operations.
- Contribute to ensuring that the physical environment of the clinical areas is responsive to the needs of children and their families.

MEMBERSHIP

- The goal of membership is to have more than 50% of all committee members be parents of patients either currently in treatment for cancer, or those who have completed treatment. The remainder of the membership will include clinicians of the Pediatric Oncology health care team. The Clinical Social Worker will serve as the Co-Chair of the Committee. A Pediatric Oncologist and representative of the Nursing staff will maintain membership in the Advisory Committee. Other MGH Pediatric Oncology staff may attend a FAC meeting as needed.
- Adolescents and young adults cared for within the Pediatric Oncology practice will be invited to participate in the FAC as needed. Specifically, patients will be included as ad hoc committee members, serving as subject experts and advisors on projects and new program development.

MEMBERSHIP QUALIFICATIONS

- There will be an open enrollment process for participation in the Family Advisory Committee. Parents who are interested in joining should speak with the Clinical Social Worker who can provide information about the Committee. Additionally, parents can be recommended by staff for participation. In those cases, the Clinical Social Worker will contact the identified family member to discuss membership in the FAC. Information about the Committee will remain available in the Pediatric Oncology waiting area.
• Parents should have a child currently in treatment or be followed in the Pediatric Oncology practice for ongoing follow up care.

• Individuals participating should possess the ability to represent the perspective of the patients and family members and can consider issues beyond one’s own cancer experience.

• Ability to work collaboratively amongst a team of parents and clinical staff members.

• Ability to make a time commitment for meetings and special projects, as they arise.

• Represent diverse perspectives and backgrounds to reflect the clinic’s population.

**Membership Terms/Responsibilities**

• Members will be expected to make a two-year commitment with the option to renew after that time.

• No specific term limits have been set.

• Meetings will be held 5 times a year, with a schedule provided at the beginning of each year.

• Additional meetings, either in person or via conference calls, may be added to address special projects or input from the Committee that needs to be obtained before the next scheduled meeting.

• Members are expected to attend the meetings, and make a reasonable attempt to participate in meetings outside the usual schedule.

• Participate in MGH Pediatric Oncology community programs to provide a presence for the Committee and serve as a point of contact for other parents.

• Members will maintain patient confidentiality according HIPPA guidelines at all times.