



MassGeneral Hospital
for Children™



Pediatric Inflammatory Bowel Disease Center

PARENT / PATIENT ENGAGEMENT MANUAL

Jill Horan, Nicole Steeves, Mike Steeves, Dan Horan, Em Horan, Esther Israel, MD, Jess Kaplan, MD,
Christopher Moran, MD, Harland Winter, MD, Hailee Reeves



This manual is made possible through the generous support of the ImproveCareNow (ICN) Parent Innovation Grant. The MassGeneral Hospital for Children (MGHfC) Inflammatory Bowel Disease Parent / Patient & Physician team is grateful for the financial support and guidance provided by ICN throughout this project. A special thank you to Michelle Spotts who has worked directly with our team and has helped facilitate the process since the grant inception.

MGHfC IBD Center Parent /Patient Advisory Team (PPAT) and ICN core physician team gratefully acknowledge the work done by the ICN Co-Production Team. Through our ICN Parent Innovation Grant project, we are picking up the baton where the ICN Co-Production Team left off. Our manual adds our experiences with the hope that it will help other centers redefine their relationships with families and patients ultimately leading to greater partnering, improved care, and better outcomes for pediatric IBD patients.

Acknowledgements:

ImproveCareNow Co-Production Team:

Carrie Fritz (Project Manager)
Alex Jofriet (ImproveCareNow Patient Partner)
Lauren Moore (Project Coordinator)
Liz Monti (Project Specialist)
Sarah Myers (ImproveCareNow Executive Improvement Director)
Sarah Nocito (ImproveCareNow Strategic Communications Manager)
Lisa Oipari-Arrigan (Team Leader)
Jen Powell (Quality Improvement Consultant)
Tifini Ray (Project Specialist)
Rita Siedlaczek (ImproveCareNow Parent Partner)

We would like to acknowledge the following individuals who contributed ideas and expertise in the development of the Co-Production Change package:

Laura Eshee
Carrie Frost
Cindy Gessouroun
Shawna Ricks
Diane Russell
Michael Seid

Frederique Verly

Adapted v2.1: By PPAT and ICN Provider Team

Jill Horan (PPAT Co-Lead-Parent Partner)

Nicole Steeves (PPAT Co-Lead- Parent Partner)

Mike Steeves (PPAT- Parent Partner)

Dan Horan (PPAT- Parent Partner)

Em Horan (PPAT – Patient Partner)

Esther Israel, MD (ICN Core physician Co-Lead)

Jess Kaplan, MD (ICN Core physician Co-Lead)

Christopher Moran, MD – (ICN Core physician)

Harland Winter, MD – (ICN Core physician)

Hailee Reeves – (ICN Research Coordinator)



Table of Contents

Redefining Co-Production Together

Setting the Stage: Creating Conditions for Collaboration

- The Care Team
- Identify a Champion
- Incorporating partners into Your QI Work
- Calibrating Care Team Attitudes and Expectations

The Parent/Patient Partner

- Think About Characteristics That Are Important to Your Team
- Identify Potential Partners
- Reach Out with the Goal of Finding 1 or 2 Partners
- Should We Interview Parents?

The “Big Ask”

- 1st MGHfC Parent / Physician Engagement Meeting: January 2016
- We Have Engaged Parents - Now What??? *Lessons Learned*

Creating Expectations

How to Grow Your Community While Navigating in a HIPAA World

Blueprint for Success – Annual Plan

Event Planning Tips and Strategies

Collecting Data

Funding

Database and Patient /Family Recruitment

Final Thoughts

Redefining Co-Production Together

At the inception of our Co-Production journey, the focus was trying to determine what tasks needed to be accomplished to produce programs that would result in improved care. It was the beginning of building workflows that would help coordinate our efforts. At this stage, less thought was given to the type of relationship we were building.

What has grown out of our early co-production efforts is the emergence of an equal and reciprocal partnership that redefines the relationship between healthcare providers and healthcare recipients. By empowering families and patients to take an active and equal role in determining how care is delivered, it has indeed improved care. Patients and families are no longer passive recipients of care but rather equal partners in a collaborative team. This collaboration has been transformative in the way that quality improvement is thought about and achieved. It has been a defining achievement in our partnership.

Building the Future of Collaboration Together



Core ICN Providers - Dr. Harland Winter, Dr. Jess Kaplan, Dr. Esther Israel, Dr. Christopher Moran and ICN Former Research Coordinator, Jeff Savarino (Current Research Coordinator Hailee Reeves – not pictured)



Center for Inflammatory Bowel Disease

- Located in Boston, MA with 13 satellite centers in MA, NH, and ME
- Target pediatric IBD population of ~700
- Large Pedi GI staff
 - 23 attending physicians
 - **4 core ICN providers**
 - 3 nurse practitioners

- 4 outpatient nurses
- 6 fellows
- 7 clinical research coordinators
(**1 ICN coordinator**)
- 4 dieticians

MGHfC Inflammatory Bowel Disease Center joined ICN in 2009 but still had no parent partners...until January 2016

Setting the Stage: Creating Conditions for Collaboration

STEP 1. The Care Team

Successfully launching a new way of working together requires preparation, not only around practical issues such as finding appropriate meeting times and determining the types of projects on which to collaborate, but also around being ready—and receptive—to working in new ways and with new kinds of contributors. As members of the care team consider involving parent and patient partners in their improvement work, “some will embrace the idea without reservation; others will need to be convinced of the significant value to be found in redesigning care in partnership with parents and patients.”¹ Likewise, parents and patients will vary greatly in their comfort and receptivity to co-designing and co-producing care delivery improvements. However, our early experiences with co-production in ICN suggest that, when asked, most people will be willing to be a part of making improvement happen.

Before parents or patients are recruited to work with the quality improvement (QI) team, the team should be ready for this new way of working. Creating conditions that enable all contributors (clinicians, staff, patients, parents, researchers) to be effective and remain engaged is an important first step. ***Evidence and anecdotal information indicate that if there is not enough structure to support collaboration at the center, everyone will struggle to focus and effectively contribute to care center improvements.***

Setting the Stage: Creating Conditions for Collaboration

As centers begin to identify potential parent or patient contributors, it is important to have in place an infrastructure that will support this new way of working.

1. Identify a Champion

First, it can be very helpful to identify a champion—someone who will help you overcome barriers to this work, help identify new opportunities to leverage your new partnerships,

¹Source: Center for Medical Home Improvement (CMHI), A Guide for Parent and Practice “Partners” Working to Build Medical Homes for Children with Special Health Care Needs

and spread the word about your achievements. Like most of the improvements that are tested and implemented through the network, identifying a team champion for this work will increase your likelihood of success.

2. Incorporate into Your QI Work

Collaboration should become “part of the woodwork” of the quality improvement work at your center. Building the groundwork for collaboration into your existing improvement infrastructure, (such as by incorporating parent and patient partners into your existing QI team), will also help increase the likelihood of success.

3. Calibrating Care Team Attitudes and Expectations

Most clinicians and patients have not been trained to work as equal partners. Learning to collaborate in this way does not happen overnight – it takes time, trust, dedication, practice, and experience. ***It is important to recognize that collaboration is much more than assessing opinions or letting parents/patients ‘help’.*** Collaboration requires a shift in how patients, parents, and professionals view their roles in creating health and healthcare – it involves a new way of people relating to each other.

It’s normal for staff and clinicians to be both excited and anxious about involving parents and patients in their improvement work. Change is hard, no matter how obvious the potential benefits might be. Setting aside time to identify, acknowledge, and address team member concerns early in the process is critical to developing meaningful collaboration at your center.

Key Characteristics of Teams Who Are Successful partnering with Parents/Families

One way for teams to calibrate their views and expectations about collaboration is to discuss their readiness as part of a standing team meeting. Reflecting on the following characteristics of teams that are ready for collaboration may help get you started:

- Recognize people are service users and are valuable resources
- Develop people’s existing capabilities
- Promote mutual aid and reciprocity
- Break down barriers between professionals and parents/patients
- Facilitate rather than deliver healthcare
- Listen well

STEP 2. The Parent/Patient Partner

Think About Characteristics That Are Important to Your Team

When beginning their collaboration journey, many improvement teams focus on finding the ‘right’ parent or patient contributor(s). While it is certainly important to identify parents or patients who have the time, energy, and enthusiasm to collaborate and who are generally compatible with the rest of the team, there is no single right set of characteristics. Teams that have been successful in identifying potential parents and patient partners have described the following as potentially important characteristics:

- Proactive and engaged in their own healthcare
- Respect and acceptance of the HIPAA process
- Clear about their values and aware that others may feel differently
- See beyond their own experiences
- Able to build consensus, collaborate on solutions, and accept compromises
- Have resources – including time, relationships, knowledge, and experience
- Have a learning orientation and are willing to take risks
- Listen well
- Ask questions
- Respect diversity and different opinions

Identify Potential Partners

When you are ready to formally build parent and patient partners into your work, begin by asking team members to **identify 2-3 individuals** who might be willing and able to work with your team (see above list of parent and patient attributes as guidance). If it’s difficult to come up with these names, try posting a flyer in the clinic or sharing the opportunity via your clinic’s social media channels to see if those you may not have originally considered approach you to share their interest.

Reach Out with the Goal of Finding 1 or 2 Partners

Once you have identified potential partners, reach out in person or by other means to tell them about your needs and plans and to assess their interest. Here’s a basic way to describe Collaboration:

“Our care center is working to improve the way we provide IBD care by involving parents and patients in new ways of working with us. We believe that the best way to improve our care center is to work together with our families to improve the patient & family experience and create better care. I’d like to tell you about our efforts, find out about your interests, and see if you would be interested in playing a role. We want to make a new kind of healthcare where everyone – patients, parents, staff, and clinicians – contributes to making care better.”

Should We Interview Parents?

Some teams may want to ‘interview’ a potential contributor to find out about their experiences, story, expertise, and interests – other teams may not find this step necessary or appropriate.

Whether or not you formally interview a potential contributor, take the time early on to ask about

his/her story and share your own. **Relationship building is an important part of successful collaboration.** An alternative to formally interviewing all potential contributors (which would involve a good deal of time and effort from current members of the team and the potential contributors) is to observe potential contributors in the initial engagement meetings. Key things to observe are not only the participation but also how contributors interact with others. This is also a good way to find out many of the things you might learn about during a formal interview.

Explain what is involved (hospital or clinic onboarding requirements and training, possible roles/types of activities, meeting expectations, time commitment) and assess the parent's/patient's interest in moving forward together. Remember that sometimes the best way to assess interest is to just get started and test a joint project together. Some ICN teams have successfully used surveys when trying to reach a larger number of families.

Collaboration:

***It's Not About Attending
Support Groups...***

Inviting parents or patients to attend a support groups or asking for their help with a project, is not the same thing as collaboration. While both of those things are worthwhile, collaboration is about parents and patients partnering on equal footing with the care team to address gaps in care and opportunities for improvement. It also involves each stakeholder assuming a shared responsibility to ensure the success of those efforts.



The Big Ask...

*"At this time, we would like you to join us for a parent focus group meeting on **January 31, 2016** at **Newton-Wellesley Hospital – Bowles 1 Conference Room** from **4 PM – 6 PM**. Dinner will be provided. We encourage you to consider partnering with the IBD team at MGHfC to improve care for our children with Inflammatory Bowel Disease. We value your experience and ideas, and we look forward to working with you.*

Sincerely,

The IBD Team:

MassGeneral Hospital for Children

Pediatric Gastroenterology & Nutrition"

In general, working together to identify gaps in services or ideas for improvement that fit with the parent/patient's interest and expertise is a great way to start. This approach makes it easier to find a role in enhancing current improvement efforts that are already underway. The bottom line is that **starting small** works. If the project goes well, it can be a launching board into a long-term relationship or commitment.

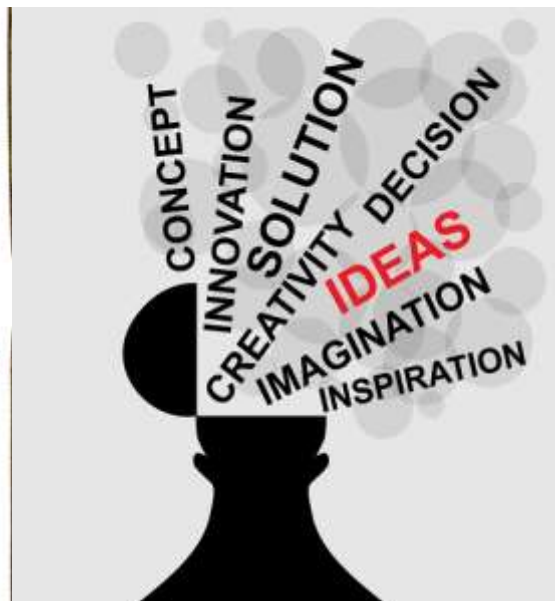
1st MGHfC Parent / Physician Engagement Meeting: January 2016

Approximately 18 parents responded to the "Big Ask" and gathered at Newton Wellesley Hospital for the first parent/ provider engagement meeting. It was a great meeting with sharing and brainstorming of ideas to improve services and address needs. The physicians facilitated the breakout session, "Through the Eyes of a Parent". Participants were broken into smaller groups with a provider. They were given the question, "If you had the opportunity to start from scratch and build a brand new MGHfC Center for Inflammatory Bowel Disease, how would it look?" Each group generated ideas and then the entire group came back together. The results were shared and organized. Colored dots were used to signify the most important ideas for improvement and engagement opportunities. The top four areas became the basis of our sub-committees.

- **Breakout Session: "Through the Eyes of a Parent"**
 - If you had the opportunity to start from scratch and build a brand new MGHfC Center for Inflammatory Bowel Disease, what would it look like?
 - Be creative! No idea is too big, too small, or too far-fetched!
 - Feel free to comment on existing systems, too!



1. Newsletter
2. Parent Blog
3. Parent-to-Parent Networking
4. Attend Improve Care Now Community Conference
5. Lead MGHfC CCFA Walk
6. Design Learning Opportunities for parents/patients
7. Design Annual "IBD Center" visit
8. Serve on Patient/Family Advisory Council



Collaboration is not a linear process...

It has many twists and turns and evolves over time – that's okay! It's part of the process to find just the right fit for your individual center. The important part is that the team stays steadfastly committed to the overarching goal of improving care for patients and families. The rest can be negotiated and overcome with open, honest, and constructive feedback.

We Have Engaged Parents - Now What??? Lessons Learned:

It cannot be overstated that if there is not enough structure in place at the center to support collaboration, everyone will struggle to focus and effectively contribute to care center improvements.

Despite everyone's best efforts, our collaboration efforts struggled and never quite reached the level of enthusiasm that was generated at the first parent engagement meeting.

As time passed, smaller projects were attempted. Two parents emerged as champions to work on improving care at MGHfC. They attended ICN Community Conferences and came back energized and committed to help facilitate improvement. This time around, there was a much better sense of what they wanted to accomplish and more center structure to support it.



Building a Culture of Improvement

"Is a long journey that requires commitment, patience, long-term thinking, positive mindset and continuous improvement which are merged together as operational excellence for strategic advantage."

~ Jeffrey Liker - The Toyota Way

CREATING EXPECTATIONS:

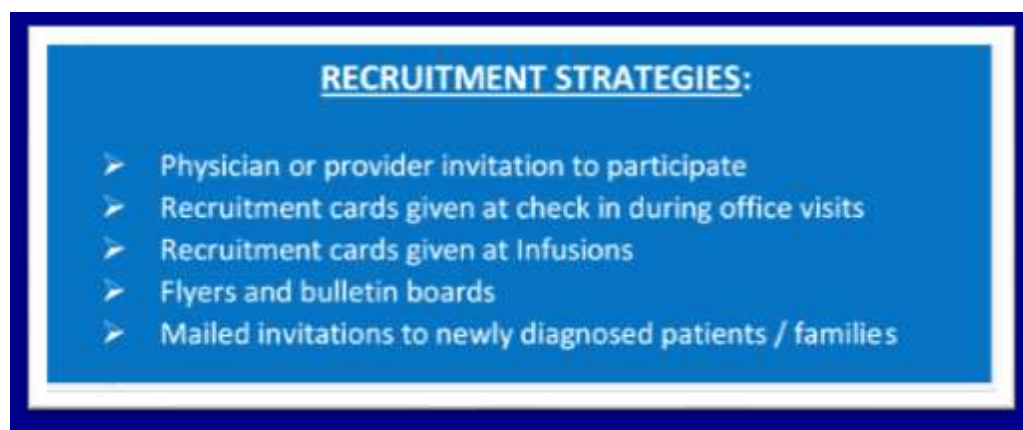
Once a cohesive team is created, it's important to set expectations. Consideration should be given to the team's bandwidth and ability to work together and under what circumstances. The following are examples of some standards to determine:

- Best way for the team to communicate
- What tools will be used - Email, virtual, or in-person meetings?

- How often will the team meet?
- How will projects be determined?
- Attendance and support of programming

HOW TO GROW YOUR COMMUNITY WHILE NAVIGATING IN A HIPAA WORLD:

- Most hospitals have annual training requirements for volunteers. It is important to consult with the hospital's privacy office (or equivalent) regarding their HIPAA and training requirements.
- Confidentiality can be tricky when recruiting families. Physicians cannot share any patient information with a parent/patient engagement group. They can help facilitate the engagement group's recruitment effort by giving out sign-up cards and inviting patients and families to participate in events.
- Patients and families expect a degree of confidentiality within the engagement community. It's important to respect patient and family confidentiality. If you are concerned about a patient or family, encourage them to speak with their provider. Always ask if it is okay to share information with a provider or others.
- Social media resources, like Facebook and other online communities, are a great way to build your engagement community. A word of caution if you chose to an online community option – be sure to verify the security of the information that is being shared.
- As the community grows, there may be other people (such as other health care providers, patients/parents from other medical centers, and other people that find the topic intellectually interesting) that show reasonable interest in attending some of your group events. While there is no easy answer, you should certainly consider that the core of your community is patients and parents that may want to discuss sensitive matters.



BLUEPRINT FOR SUCCESS:

- Creating an annual programming plan is a great way to keep your team on track and to ensure that programs align with the center's goals and meet the needs of the patients and families.
- It's important to think about providing both educational and social opportunities

that bring patients, families, and providers together to create a real sense of community.

- Events scheduled to allow adequate time for preparation.
- Allows every team member the opportunity to be involved with master planning and time sensitive tasks.

EXAMPLE OF ANNUAL PLANNING CALENDAR: *The calendar serves as a working document and includes tasks, ideas and concepts to act upon or revisit in the future.*

MGHfC PPAT PLANNING Calendar: 2017/18

<u>Date</u>	<u>Event description</u>	<u>Tasks</u>
<u>August 16th – Back to school</u>	<ul style="list-style-type: none"> • Psycho-social - Anxiety – Back to school (pair with mentoring program, try and recruit mentees); • Review of 504 plans • In-Service / Networking opportunity • August 16th 6:30 pm in Boston - Wang 023 • Presentation of the Joy of Childhood Foundation Grant to Chris. 	<u>Completed</u> <u>Completed</u>
<u>September</u>	<u>September - ICN Fall Community Conference (Chicago)</u> <u>PPAT – Social Networking event – “Fall Funfest” (End of September)</u>	<u>Completed</u>
<u>November</u>	<u>Fall Newsletter</u> <u>CCF’s MGHfC Take Steps Team registration for 2018 team</u> <u>CCF Event – November 16th – Take Steps Recap event</u>	<u>In progress</u> <u>Completed</u>
<u>December 3rd.</u>	<u>“Kindness Rocks” Paint party – NWH AR Living room. 2:30-4:30. Community building Event</u>	<u>Completed</u>
<u>January 18th</u>	<u>PPAT EVENT: - Winter Blues - Judy</u> <ul style="list-style-type: none"> • Psycho-social well being <ul style="list-style-type: none"> ▪ Family Stress ▪ Anxiety / Depression – Chronic Disease? Something more? ▪ Healthy strategies to cope ▪ Where to find help and support • In-Service / Networking opportunity 	<u>Tabled due to weather</u>

<u>March 8th</u>	<u>PPAT Event: Sports and IBD – Chris NWH 7:00-8:30 P.M.</u>	<u>Completed</u>
<u>April</u>	<u>ICN Spring Community Conference – Dallas</u>	<u>Completed</u>
	<u>Dr.Baldassano – Guest Speaker from CHOP</u>	<u>Completed</u>
	<u>NE Symposium</u>	<u>Completed</u>
<u>April/ May</u>	<u>Spring Newsletter</u>	<u>Completed</u>
<u>PPAT EVENT: May</u>	<u>Changes and Transitions Em and Judy</u> <ul style="list-style-type: none"> • Review recommended transition timeline • Transition considerations for each age group • Moving up and out...High school to College and beyond– college transition - work in progress • Transitioning to Adult care • In-Service / Networking opportunity 	<u>Tabled /In development</u>
<u>June</u>	<u>CCF Take Steps Walk</u>	<u>Completed</u>
<u>July</u>	<u>New IBD Dx. Orientation</u>	<u>Completed</u>
<u>August</u>	<u>Back to school & IBD – Separate breakout session for patients w/ Child Life & Social worker</u>	<u>Completed</u>
<u>September</u>	<u>ICN CC</u>	<u>Completed</u>

Ongoing Domain Projects:

Patient Experience: Infusion Room Improvements:

- Received grant funding from DD for improvements
- Have estimates for construction / painting improvements
- Chris, Jill, Nicole, Mike, Esther have toured Pedi Oncology to see how they updated their infusion space.

Mentor Program:

- Three mentors have been vetted and trained.
- Waiting on referrals from GI physicians
- One mentor / mentee have been paired
- Separate mentoring webpage; (Pending)

Education:

- Website redesign – Dr. Winter, Dr. Kaplan, Dr. Israel, Dr. Moran, Dr. Biller, Jill, Nicole, PR and computer teams.
- IBD Newly Diagnosis manual – online – Pending section format Done
- Vetted IBD online resources - Pending
- Brainstorming sessions
- Work with the PR department to see if we can record and upload videos of our education events

Outreach: Social Opportunities / Networking / Support – goal of quarterly or every other month (Ideas)

- Targeted Gateway (Patient portal) Emails – ongoing
- Continued recruitment for new parents and families to sign up for the parent database – In progress
- Picnic in the park (Spring)
- Ice Skating – Patriots place / Boston Frog Pond (Winter)
- Take Steps Walk; Paw Sox, Lowell Spinners, CC Baseball league (Summer)
- Houghton's Pond (Fall)
- Fundraising for Take Steps walk combined with a social event – bowling, etc....
- Support Groups
- Collaborative programs with other Boston ICN centers

ICN / MGHfC

- **Parent /Patient Innovation Grant** – Implementation
- **PWG**: Nicole
- **Membership PWG**: Jill
- **Presenting at Spring ICN CC** – Expectation that we will share info at the spring CC regarding our proposal and our goal to spread other PPATs to other centers throughout the network.

PPAT Involvement with QI –Attendance at QI meetings (Ongoing discussion regarding PVP meetings)

- Goals for continued collaboration and goal setting for upcoming year
- Future of ICN and MGHfC – Strategic planning





EVENT PLANNING TIPS AND STRATEGIES:

Event planning Tips and Strategies Remember the following are *suggestions*.

- Start small. You will make a difference.
- You and your care center may have other great ideas or resources.
- If you get stuck, reach out to ICN engagement members, the PWG or the PAC.
- Some of the simplest things had the greatest impact with attendees.
- Repeat the motto- “Share seamlessly and steal shamelessly!”
- Organize thoughts in online folders or a physical binder.
- Keep track of ideas and plans. Once you complete an event, keep copies of flyers or handouts so it can happen again.
- Write down your lessons learned, what could you do differently next time.
- Take photos of events. Most care centers have photo release consent forms. If you aren’t sure, take photos from behind and don’t show faces or a picture of the room before attendees come in. Then use the photos in future flyers. After a few events you’ll have enough pictures to make a mini slide show of all the great events you have co-produced. It can be played on a loop at the beginning of an event, while folks are signing in and getting settled. Storing all photos on a google drive is helpful for team

members to share as well.

- Schedule specific time to work on projects.
- When hosting events, you will need some common office supplies. Does a budget exist? Discuss with your team how to obtain materials.
 - Pens, stick on name tags, tape or thumbtacks to hang direction signs, paper and ink for copies of materials.
 - Discuss how photocopies will be acquired. If there is an event with many handouts, it may be useful and professional to have folders.
 - The care center may be able to obtain branded items from the department.
- Discuss a refreshment budget with your care center team. Keep in mind food allergies, special diets and food sensitivities.
- Keeping all office supplies, paper goods, etc., together in a bin will be helpful when you are setting up an event.
- Utilize the hospital's Public Relations department and social media team to help promote events. Often a hospital will have various announcement mechanisms, social media pages and accounts. They can help promote your events. Another strategy is a Parent / Patient center Facebook page. Again, if you decide to go this route, keep in mind confidentiality and security of family information. Facebook pages can be made a 'closed group' where access to the page is controlled by an administrator.

Educational Events

Educational events are a great way to partner with your provider team. Providers are experts when it comes to Inflammatory Bowel Disease. Partnering with them to provide educational programs is a great way to collaborate on a project. Choose members who are willing to assist and share their wealth of knowledge.

Educational Ideas for programming:



- View PWG videos or Community Conference sessions
- IBD and Nutrition-
 - Ask a MD, Resident, GI Fellow, Registered Dietician speak about enteral nutritional therapies

- ICN and PWG has individuals who are very passionate about SCD and the PRODUCE study. See if they would be willing to do a webinar or in person program.
- Have the hospital nutritionist/dietitian speak and offer small tastings of recommended foods.
- Reach out to the hospital food service provider, local culinary schools, high school vocational schools, or a local grocery store. Many are already equipped to do a cooking demo. Set up a small smoothie bar where patients can make their own concoction with yogurt, ice, and precut fruit and veggies.
- IBD 101 - for newly diagnosed families
 - Invite a GI MD, Resident or Fellow trainee speak. In addition, include the experience of an experienced patient or parent.
 - Distribute information through patient portal regarding 504 plans.
 - Provide links to ICN newsletters or LOOP articles.
 - Visual aids “when to call the GI” usually seen as a green/yellow/red traffic light sign with symptoms and actions.
 - Include specifics on how your care center handles a 2 a.m. call from a family.
 - What should they expect?
 - Give a template for a medication list that allows for families to update changes and for patients to learn what they are taking.
 - Teaching a small step in self advocacy at the same time.
- Back to School - Ask a principal or 504 Coordinator to speak about 504 plans and a counselor or therapist to explore stress reduction strategies. Role play speaking with teachers or coaches.

Community Building Events:

- Organize a cooking demo at a local grocery store, college or restaurant.
- Kindness Rock painting party
- CCF Take Steps Walk are great to meet other center families and build a sense of community.
- Host the Virtual Community Conference while eating a potluck dinner or a bring your own dinner. Kids can have their own party with supervision from Child Life Specialists.
- If a YMCA like center will host, kids could use gym, pool or other space as the location provides.
- ‘Picnic in the Park’- Families bring their lunch and spend time supporting each other while playing lawn games like corn hole, golf toss, maybe Giant Jenga or local favorite game. Low to no cost and low to no stress. Just find a location and give good directions.



Additional QI Ideas from the ICN Exchange to Help Facilitate a Dialog and Planning at Individual Centers: *Engaging parent and patients: Collaboration wish list & brainstorming session (Generated by parents / patient at the ICN Community Conference Fall- 2015)*

- Psychosocial help & awareness for patients
- Mentoring options in every hospital within the network
 - New diagnosis mentoring
 - Parent mentoring
 - Peer mentoring
- ICN welcome package
 - ICN training
 - Parent handbook
- Buzzy's for all patients
- Ability to have infusions outside of the hospital or at home
 - Extended infusion and clinic hours
 - More comfortable infusions
- Navigating insurance help
- Dietitian to focus on IBD
- IBD newsletter
- IBD and non-related issues: colds, puberty, allergies, mental health, vaccinations
- IBD nurse line for parents to call

- Patient / parent rewards for their time & contributions
- Open and willingness of clinical team to learn and participate with IBD/ICN data and initiatives
- Acknowledgment of department engagement efforts by the hospital
- Electronic data transfer so that time can be spent on other efforts
- Soft toilet paper for hospital and clinic bathrooms
- Bathroom access
- More effective medications
- Better hospital beds and food
- Netflix options for inpatient tv
- Greater visibility and understanding about IBD
- More nursing support
- Funding ideas to support parent and patient efforts
- Physician training on using parent and patients
- Parent access / training to other parents for engagement
- Inside look to inpatient floor and care experience
- Education packages: IBD >Empowerment>Engagement
- More help to centers on how to create an engagement model that works for that center
- 504 plan information

Top Priorities

- ***Newly diagnosed program***
- ***Transition tool***
- ***Tips and tricks managing IBD***
- ***Q & A for doctors***
- ***Ostomy care took kit***
- ***New diagnosis welcome package***
- ***Parent / patient acceptance as participating partners***
- ***Scheduled meetings to provide consistency for team***
- ***Each center to have at least 2 to 3 driven and passionate parents***
- ***Parent / patient led initiatives***
- ***More child life specialist for IBD patients***

Choosing a Date - There will never be a perfect date or time for an event but when you are starting, make sure the date works for those planning the event and of course a guest speaker if you have one. It's a good idea to factor the time of year (if weather could be a challenge), long weekends and holidays are typically not good. Location and time should be convenient to participants. Give yourself enough lead time to get the event planned. A month and a half is a good guide to allow for enough time to finalize arrangements and market the program. Sometimes additional lead time is necessary if the care center is sending out email invitations. After planning 2-3 events, the lead time needed will become clearer.

Time – Part of building community is being able to spend time together as a group to network and socialize. Schedule unstructured networking opportunities into the events. One strategy to get

participants to mingle is during a program, set up chairs in rows. Have the first row turn around and meet the second row and the third row turn around and meet the fourth row and so on.

When determining the length of a program, ask or suggest how long speakers think they need to cover the information. Will they take questions from the audience? Don't forget to allow time for set up and clean up.

Location - Ask if your care center has some space for use. Sometimes a date is set by the availability of the location. Families are comfortable driving and parking someplace they have already been. Conference rooms, small auditoriums, even cafe space off hours can work. Other options include Public Libraries, Rotary/Lions/Veterans Clubs, YMCA's, even some banks have community rooms for use. Watch your local papers for other community events. See where these events are held, inquire if it is rented or available for community use. Many "clubs" have charter/bylaws that encourage enriching and supporting their community and will allow these types of events to be held at their facility. If you're considering an outdoor event, factor in a back-up plan if the weather does not cooperate. Some outdoor locations may require a permit for groups of a particular size.



Marketing / Promotion of Events: Get the word out! Use a variety of methods to market your program. Below are some examples:

- Emails – For potential families (patient portal) as well as families in current database
- Permanent PPAT Sandwich Board Sign that is displayed at all events co-branded with our care center name and logo
- Flyers – Given at appointment check in or given by the provider
- Community bulletin boards at the care center

- Social media – Hospital FB pages, Twitter account, hospital publications, etc.
- MD invitation to patients/ families by having them hand parent/patients the flyer at the end of appointment.
- Targeted snail mail for a specific group.
- Someone in your ICN team may be able to use your registry to identify patients who were recently (in the last year) added to the network.
- Always ask for a RSVP to track interest and capture email addresses.
- Ask people who do reply, where they heard about the event.



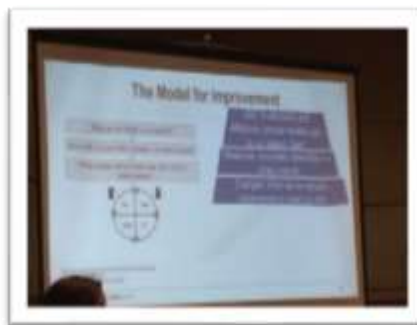
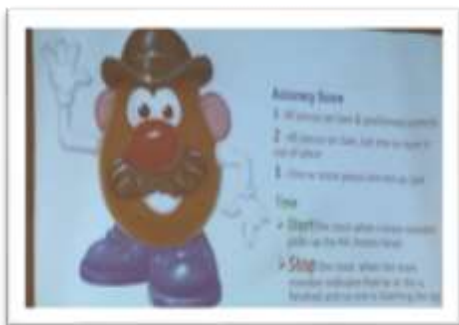
Day of event - Breathe and repeat!

- Branding is important. Hang directions and signs with arrows. Be consistent with a logo used on emails.
- Set up a 'Welcome Table' with a dedicated person to handle whatever paperwork you have or your care center requires. (sign in/registration/photo consent forms/parking validation if available)
- Ask attendees to wear name badges
- Distribute handouts and printed materials
- CCF offers no-cost pamphlets and ICN has pages that can be reproduced and included for many events
- Refreshments- water, appropriate small snacks, utensils and trash receptacles
- Begin on time. Say a few words to kick off the event. Suggestions - Greet with an official welcome, thank you for coming and indicate restroom locations.
- This event would not have been possible without support from "X,Y,Z" and the ImproveCareNow network. *We are not just one Pedi GI center with 20 people in this room but over 100 Pedi GI centers & 20,000 patients, parents & care providers from all over the world. We all have the same goal in mind for your patient...To improve care NOW.*
- Introduce the first speaker with 2-3 sentences. Who they are and what they do. If you have more than one speaker, repeat.

- Networking - Encourage families to mingle. Choose an ice breaker so families can meet one another. Families want to share their stories and hear others. They want to make connections and validate that they are not alone.
- Closing comments - Fill out surveys of what attendees learned during the event, thank everyone for coming and thank speakers for their time and expertise. A hand written thank you note is a nice way to thank speakers for their time.
- Remind attendees this is their group and suggestions for programming, events, etc. are always welcome.
- Encourage parents to sign up for the ICN PWG ALL CALLS and the LOOP. One-hour phone call or listening to the recording, can be informative for parents and patients.
- Follow up with those that RSVP'd and did not attend by short and sweet email along the lines of "hope everyone is okay & we missed you at the event. We would love to see you at our next event on_____."
- Remember to record any lessoned learned in your files. ***Congrats - You did it!***



PDSAs – PDSAs are a great way to identify what worked well and where improvements can be made. As an example, we use various types of media to invite families to events. The most successful method of inviting families and patients to attend is when the physician hands the invitation at the end of an appointment. We had a low turnout at an event that had been previously very successful. After analyzing our process, we realized three of the MD's who typically invite patients were on vacations in the weeks before the event. Lesson learned - process improved for next time.



MGHfC PPAT Post-Event Survey Example

- 1) Did tonight's program improve your understanding of 504 plans and how they can benefit your child? (1 being not at all and 5 being significantly improve)

1 2 3 4 5

- 2) Did tonight's program improve your knowledge about resources to help with the 504 plan process?

1 2 3 4 5

- 3) Did tonight's program improve your understanding of how mindfulness programs can be incorporated into IBD care?

1 2 3 4 5

- 4) Did tonight's program help you meet supportive families/individuals that can help my family (for 504 plans or anything else)?

1 2 3 4 5

- 5) Was it helpful to have a break-out section for your child?

Yes No N/A (My child did not go to the breakout session)

- 6) What future programs would you like to hear?

- 7) Would you like to participate more in the PPAT activities and planning? (If so, please leave name/contact information)

COLLECTING DATA:

Data collection is a critical part of quality improvement work and helpful when asking for support and funding from an institution. There are several methods for data collection.

Data Collection Examples:

- Survey Monkey
- Paper evaluations
- Live polling

Survey Monkey (www.surveymonkey.com) – This website offers a free resource for conducting polls. Access to polls is possible by sharing the hyperlink to the poll in an online newsletter or email. The results of these polls can be useful if associated with the theme of an upcoming event, and can be shared at the event itself. Broadening your scope by sending surveys and results to the entire engagement group allows you to include families who might not be available to attend the event.

Paper Evaluations – Feedback following events is key for not only improving your events but also engaging families that attend. Keeping the survey brief can be helpful to maximize completed surveys since many events may occur at night.

Live polling –(<https://www.polleverywhere.com/>) We used an online program called *Poll Everywhere*. The app allows for participants of a program to use their smartphones to text answers to various polling questions. It is another way for participants to interact during a presentation and to gather data. The free version lets you collect up to 40 responses per question. The website has instructions on how to set it up, and there are also some YouTube videos that show how to do it as well.

With the free app, there are some limitations to keep in mind. If you are polling a large number of people, it will only allow a certain number of responses. This will skew your data results. Also, it's important to see if the WiFi and internet connections are sufficient ahead of time. Software compatibility can also be a challenge. There are options to pay for an upgraded version of the program if you decide to move forward with more extensive polling.



LIVE Polling questions used for our IBD 101 Program

Polling Question #1

- Do you have anyone in your family with Inflammatory bowel disease (IBD)? (Choose 1)
 1. Yes
 2. No



Polling Question #2

- Do you know anyone (family or friend) that you would consider using as a support to discuss IBD-related issues? (Choose 1)
 1. Yes
 2. No



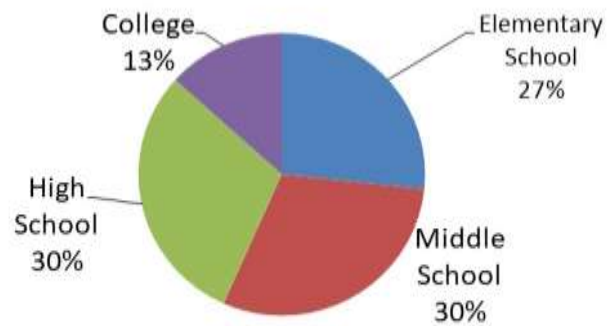
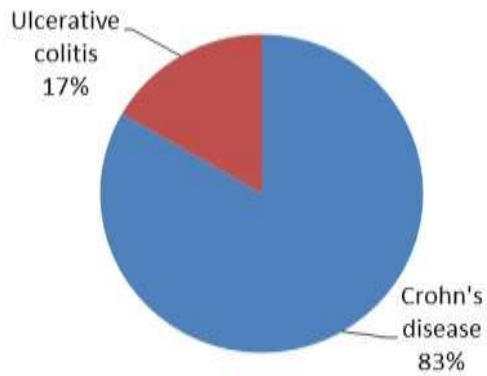
Polling Question #3

- Where have you gone for information regarding IBD? (May have multiple choices)
 1. GI physician (and that group)
 2. Websites like Crohn's and Colitis Foundation (or other foundations)
 3. Independent Blogs or Internet sources like Twitter or Facebook groups related to IBD
 4. Ordered books and other print materials
 5. Have not looked



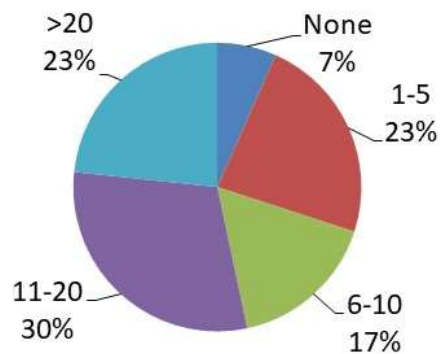
504 Survey Results

What type of IBD does your child have? What type of school does your child attend?

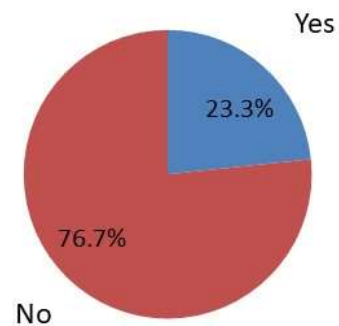


Total of 31 respondents

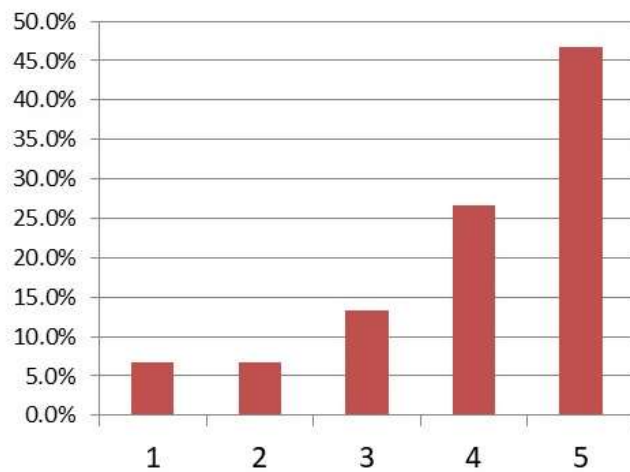
How many days of school has your child missed this year?



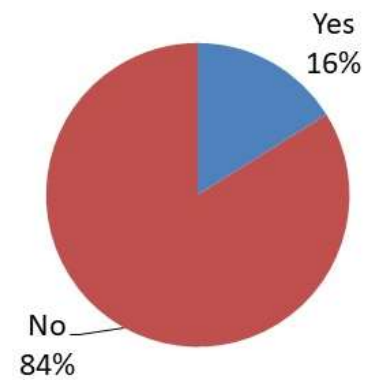
Has your child been hospitalized this year?



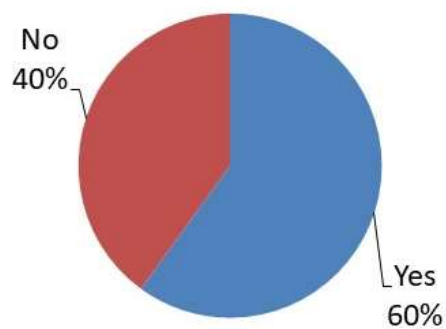
How comfortable are you with your knowledge about 504 plans?



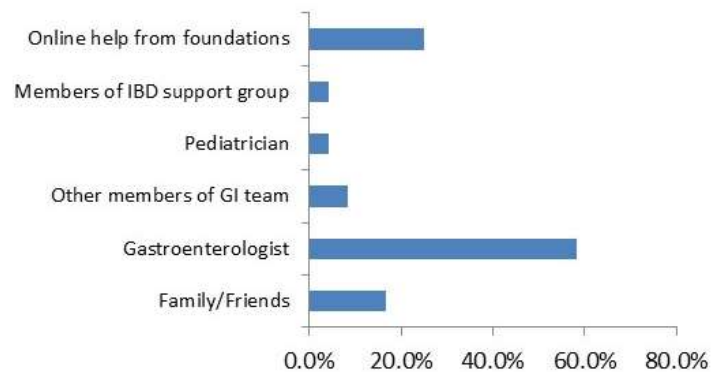
Does anyone work in K-12 education in your immediate family?



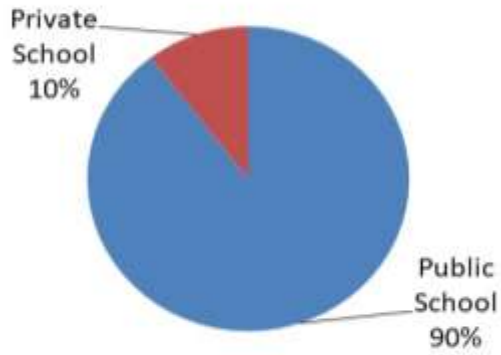
Does your child have a 504 plan?



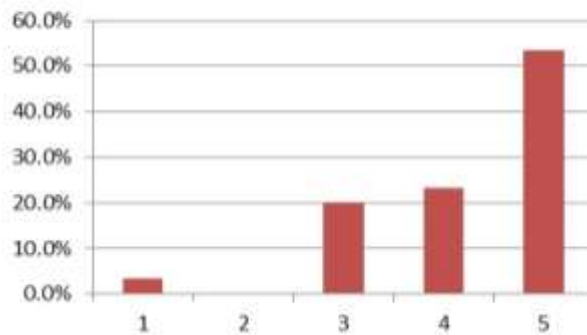
Who helped you develop it?



What type of school does your child attend?



On a scale from 1-5, how understanding has your school been about IBD?



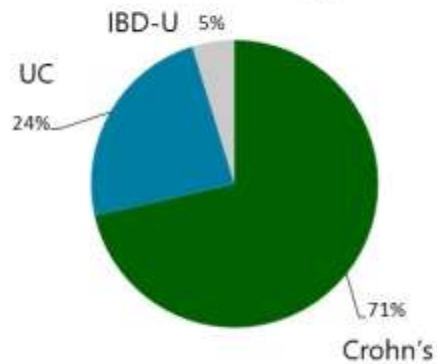
SPORTS & IBD SURVEY RESULTS

What about us?

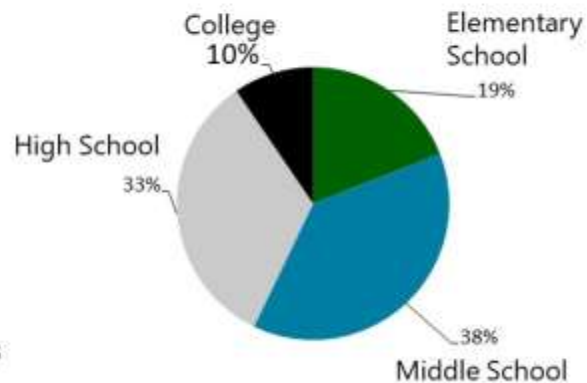


- We had a total of 21 responders
- Thanks to everyone that completed the survey!

IBD Subtype



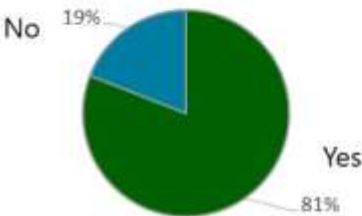
Grade Level



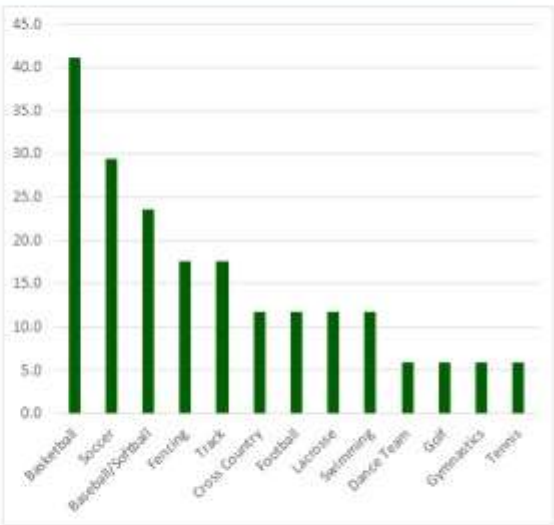
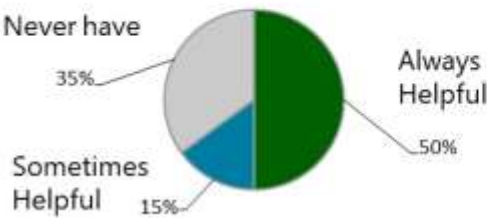
Our Survey



Do you participate in sports?



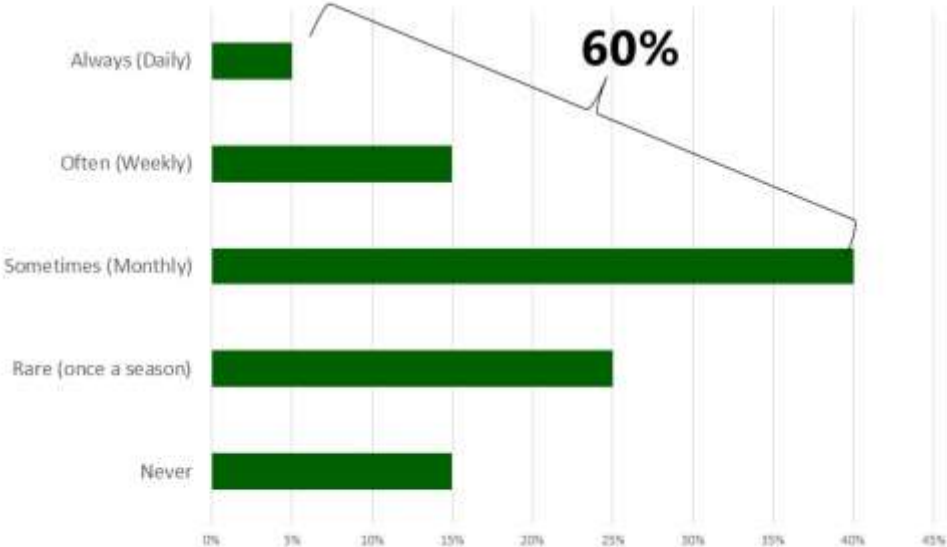
Have you Talked with your Coach about it?



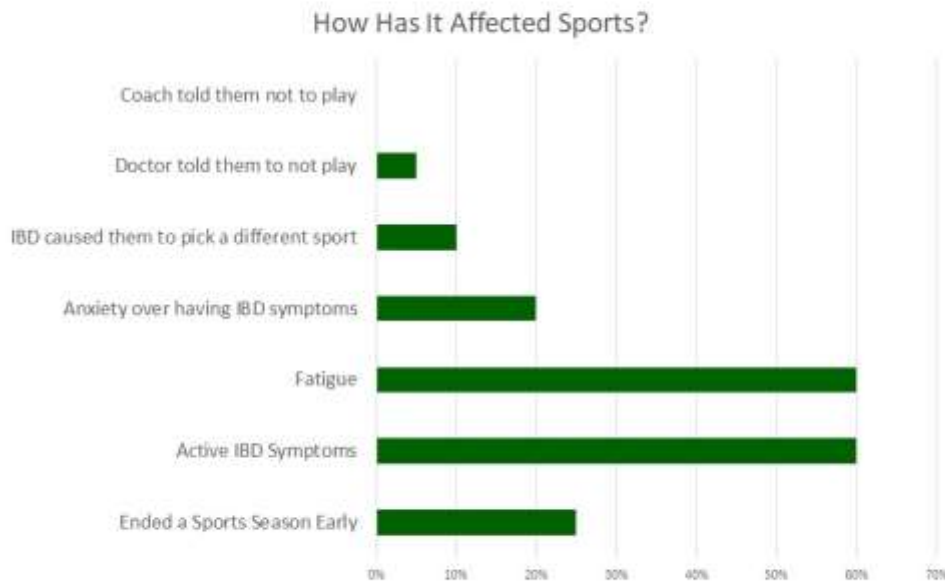
Our Survey



How Often Does IBD Affect Your Sports?



Our Survey



FUNDING

Securing funding to support your programming efforts can be a challenge. Many care centers do not have funding allocated for a Parent/Patient engagement group. Working with your hospital's development office may be helpful. If your hospital is a non-profit institution, they might be able to provide you with a 501(c)(3) organization letter along with their tax ID number. This letter can be used to help secure donations, office supplies, services, refreshments, etc. The development office may also be helpful in applying for Grants or have toolkits to help with fundraising efforts. Many companies will offer donations for specific organizations and have information on their company website. Costco is one example of a company that will provide charitable donations for organizations. Costco's donations are organized by regions of the country.

Example of letter from the MGH Development Office:

October 3, 2017

To Whom It May Concern:

The Massachusetts General Hospital is pleased to be named the beneficiary of funds raised by the Patient/Parent Advisory Team (PPAT). Funds raised by this effort will be used to support the Inflammatory Bowel Disease Center at Massachusetts General Hospital for Children.

Our tax identification number is XXXXXXXXX for your reference, and while we are not sponsoring, endorsing, providing financial support to or assuming any liability for the PPAT, we want you to know that we are aware of the organization's efforts and that Jill Horan is proceeding with our consent.

We appreciate any support you can provide to contribute to the success of this event. On behalf of Massachusetts General Hospital, we offer our many thanks. Please do not hesitate to contact us with any questions.

Beth Anthony
Associate Director

Leslie Ruchala
Development Officer

Massachusetts General Hospital Community Fundraising Team 617-726-2200 (office)
mghcommunityfundraising@partners.org www.giving.massgeneral.org/cfp

DATABASE AND PATIENT/FAMILY RECRUITMENT:

There are a number of online Database programs that can be utilized as you build your center's community. Our experience has been with MailChimp. Mailchimp allows customization of email communication. There is a free version of the program that is quite generous with the number of names it stores.



PROS / CONS:


- **PROS:**
 - Able to customize the data you would like to collect.
 - Allows tracking of emails including when it is opened and how many times.
 - If your email contains a link, it will also register how many times the link has been accessed.
 - You can segment your database and target specific email addresses as well.
 - Templates can be created to make it easier to send out email campaigns.
- **CON:**
 - One of the downsides of the program is that it is quite cumbersome to create campaigns and can be a bit limiting. One of the ways around this is to create a document on Publisher and save it as a JPG file and import it into Mailchimp document.

Example of recruitment cards



The recruitment card features a decorative header with a blue sky, a yellow wavy line, and colorful abstract shapes. The text is centered and uses bold, underlined fonts for emphasis. Logos for Mass General Hospital for Children and the Pediatric Inflammatory Bowel Disease Center are on the left and right respectively. The bottom of the card has a blue and yellow gradient bar.

DON'T MISS ANOTHER PPAT EVENT...
REGISTER TO
RECEIVE UPDATES AND
ANNOUNCEMENTS!!!

**Patient/Parent Advisory Team (PPAT)
for MGHfC Pediatric Inflammatory Bowel Disease Center
invites you to register with PPAT:**
IBDMGHPARENTS@GMAIL.COM
or
Complete & return this card


What is PPAT???	
<p>PPAT- Parent/Patient Advisory Team, is a volunteer organization comprised of both parents and patients dedicated to complementing the care that is provided at MGHfC Pediatric Inflammatory Bowel Disease Center. This mission is accomplished through working in partnership with MGHfC Pediatric IBD physicians and providers. Our goal is to build a supportive IBD community and offer educational programming opportunities for more in depth learning about topics related to advances in care, treatment and management of pediatric inflammatory bowel disease.</p>	
<p>REGISTRATION (Please Print)</p>	
Name of Parent/Guardian: _____	
Name & Age of patient: _____	
City/Town, State: _____	
Email address: _____	
MGHfC Physician: _____	
Please add me to the PPAT email list: <input type="checkbox"/> (please check)	
<p><i>I grant permission for my information to be shared with PPAT and to be added to their email list. I may revoke this permission at any time by emailing PPAT at IBDMGHPARENTS@GMAIL.COM</i></p>	
Parent/Guardian/Patient 18+ Signature: _____ Date: _____	

Examples of Programs & Flyers


BACK TO SCHOOL & IBD

Believe it or not, school is just around the corner!
Please join
MGHfC Pedi IBD Center Physicians & PPAT
as our expert panel discusses tips & strategies for a
successful school year!
We all teach...We all learn - Time will be provided to
meet & network with other patients / families, too!


Thursday, August 23rd
6:30 p.m. - 8:30 p.m.
Shipley Auditorium Newton - Wellesley Hospital
Please RSVP: IBDMGHPARENTS@GMAIL.COM



Ellen Hagerty is a Special Education Lawyer and Partner at the law firm Kottin, Crabtree & Strong. She was chosen as one of Boston's Top Rated Lawyers in education law (Boston Globe, 2012). In addition to receiving numerous other honors, She will discuss legal rights and protections for IBD patients provided by the 504 Plan for all levels of school including college.



Dr. Mark Salvatore is an Attending Pediatric Gastroenterologist at MGHfC and instructor of the SMART (Stress Management and Resiliency Training) program. He will discuss the effect of stress and anxiety on the body. Dr. Salvatore's presentation will include information on the 8 week SMART program, which he will lead starting Sept 26th.



Christopher Gerschl is the Principal of the Richardson Elementary School in Falmouth, MA. In 2017, he was awarded the Thomas C. Payson Outstanding Principal Award from the Massachusetts Elementary School Principals' Association. He holds a B.A. in psychology and a M.Ed. in school administration. He is highly regarded by both educators and students alike. He will discuss tips and strategies for a successful school year.



**Kindness Rocks Paint
Party Reminder...**

Sunday, December 3rd
2:30 p.m. - 4:30 p.m.
Newton Wellesley Hospital
Allen-Riddle Building
All are welcome!



Your child has
been diagnosed
with
Inflammatory Bowel Disease (IBD)...
Now what???



**MGHfC Pediatric IBD Center Physicians
&
Parent / Patient Advisory Team (PPAT)**
Invite you to an evening of learning & networking
with other IBD families.

Topics included:

- IBD 101- Physician led introduction to IBD
- Mark Salvatore, MD - 'Mind Body - (SMART) Stress Management and Resiliency Training for teens
- Parent/Patient tips and strategies to cope & thrive
- Small group networking and discussion

Thursday, July 19th

6:45p.m. - 8:45 p.m.

Allen Riddle Bld. / Newton Wellesley Hospital

RSVP: IBDMGHPARENTS@gmail.com



MassGeneral Hospital for Children
IBD Patient and Parent Advisory Group
Pediatric Inflammatory Bowel Disease Community

**FREE
EVENT**

You're Invited!
FALL FUN FEST
Houghtons Pond Recreation Area



Games Fishing Swimming Friends Hiking Field Games Playground

SUNDAY SEPTEMBER 24
FROM 1-3 PM 840 Hillside St., Milton, MA 02186
Houghton's Pond is located within Blue Hills Reservation.

Connection can be a powerful resource.
Join us for an afternoon of fun with other MGHfC IBD families and kids!
Lots of activities: hiking, fishing, playground, field games and so much more...
Restrooms and Free Parking available.
Well behaved dogs on a leash welcome

For questions, please email us at IBDMGHParents@gmail.com



**Patient/Parent Advisory Team
for MGHfC IBD Center
Newsletter**

CCF honors 2017 MGHfC Take Steps Team for fundraising efforts

The MGHfC Take Steps Team was honored at the Calderwood Theater in Boston on Thursday, November 16th. Take Steps honorees gathered to connect with fellow participants, vendors, IBD patients, their loved ones and the Take Steps support team. The Crohn's and Colitis Foundation (CCF) shared their accomplishments, vision and mission for research and advocacy for those with IBD.

The evening capped off with awards and recognition for top fundraisers. The MGHfC 2017 Take Steps team received the Top Hospital Fundraising team award. In recognition of this prestigious honor, the team was presented with the coveted "Golden Plunger". It will be proudly displayed in the Infusion Room at MGH West - Waltham campus. Don't miss out on the fun... Join our 2018 MGHfC Take Steps Team today!



Members of the 2017 MGHfC Take Steps Team present for the award ceremony: Keith Melton, Emma Li, Dr. Chris Moran, Jill Horan, Em Horan and Kris Farrar

FALL / WINTER 2017



In This Issue

- CCF honors 2017 MGHfC Take Steps Team
- Back to School & IBD
- Jig in Childhood Foundation Grant
- ICN Parent Innovation Grant Award
- PPAT Fall Family Fun Fest
- UPCOMING EVENTS

NEXT PPAT EVENT: DEC. 3rd



Sunday, December 3rd
2:30-4:30 p.m.
Newton Wellesley Hospital/ Allen Riddle Room
PLEASE RSVP:
IBDMGHPARENTS@gmail.com

STAY CONNECTED WITH ICN PARENT WORKING GROUP:
<http://www.icnparents.com/>

SAVE THE DATE:

January 18th -

Winter Blues: Depression, Anxiety & IBD w/ MGHfC IBD Social worker, Judy Burrows

March 8th -

Sports & IBD w/ MGHfC Pedi GI - Dr. Christopher Moran

Save the Date!



Flu season is upon us, call your PCP and get your flu shot today!!!



Questions, suggestions, comments...

Let us know!

IBDMGHPARENTS@gmail.com

FINAL THOUGHTS:

In Isaac Serwanga's motivational talk, *What makes you come alive?* he talks about **"Who's your why?"** Who motivates you to do what you do? When reflecting on my motivation at the beginning of this collaboration, the answer to the question "Who is your why" was easy; it was my two children and niece with IBD. A year later, my "why" has changed and expanded. My "why" now includes the families and patients I've had the honor to get to know over the past year and cherished friendships that I've made. These patients and families inspire me with their resilience, strength, and tenacity. They not only cope but thrive and push through any challenges or adversity they may face with a warrior spirit.

Serwanga goes on to ask us to ***look around at the people in your life; those who you can say because of YOU, I will do more, be more, and become more.*** Our team of providers are that for me. I am inspired by their passion and selfless dedication to their patients, their families, and our team. Despite their unyielding commitments and crazy schedules, they are committed to ensuring patients receive exceptional care and have the best experience possible. They look holistically at each patient and understand their well-being isn't limited to their disease.

Starting a collaborative team is not easy. It will take a significant amount of time (that likely you don't think you can spare), perseverance, determination, and commitment on the part of all of the team members. Like most relationships in life, sometimes you can contribute a great deal and other times you are only able to contribute a little. Life happens and priorities may need to shift. Understand that this is an ongoing part of the process. Recognize and respect your own limitations and those of your teammates. It will go a long way in having a healthy and positive team dynamic. It is important to keep the lines of communication open and discuss any challenges you may be facing in a respectful and candid manner. There will be times of frustration and moments when you feel like you'll never get the program off the ground. This is to be expected. You may even need to reboot and start again. That's okay!

Don't give up! Push through those moments of frustration because once you're on the other side, you'll reap the rewards of seeing families connect, friendships forged, and kids 'finding their people'. You will be part of building an incredible, supportive community bound by friendships and common experiences. Our strength and resiliency often lies in the connections we make with others. Look around and be inspired by those who make you want to **do more, be more, and become more.** Your life will be enriched beyond measure and you will receive far more than you give. This manual will hopefully serve as a catalyst and roadmap to help you on your way. Best of luck and in the words of our fearless leader Dr. Richard Colletti, *Happy trails!* Remember you are one of thousands in the ICN network and we have your back!





MassGeneral Hospital
for Children™



IMPROVECARENOW