

Patient Advisory Council (PAC)

Welcome PACket

Created by Michelle Spotts and the ImproveCareNow Patient Advisory Council

Who We Are

The PAC is a working group of patients with IBD (14+) from across the country. We work independently and in partnership with ImproveCareNow (ICN) to improve care and health of pediatric patients with Crohn's disease & ulcerative colitis (also known as Inflammatory Bowel Disease or IBD). We work to bring changes to healthcare that we want and need to happen. We tackle all sorts of different projects and are always evolving and developing new ideas.

Join the PAC and Make a Difference!

Hear what PAC members have to say about their experience. The PAC has....

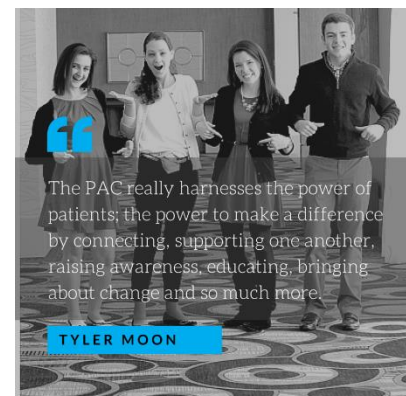
Given me a group of similar-minded people who have allowed for real changes to be made to healthcare in ways patients want change to be made”

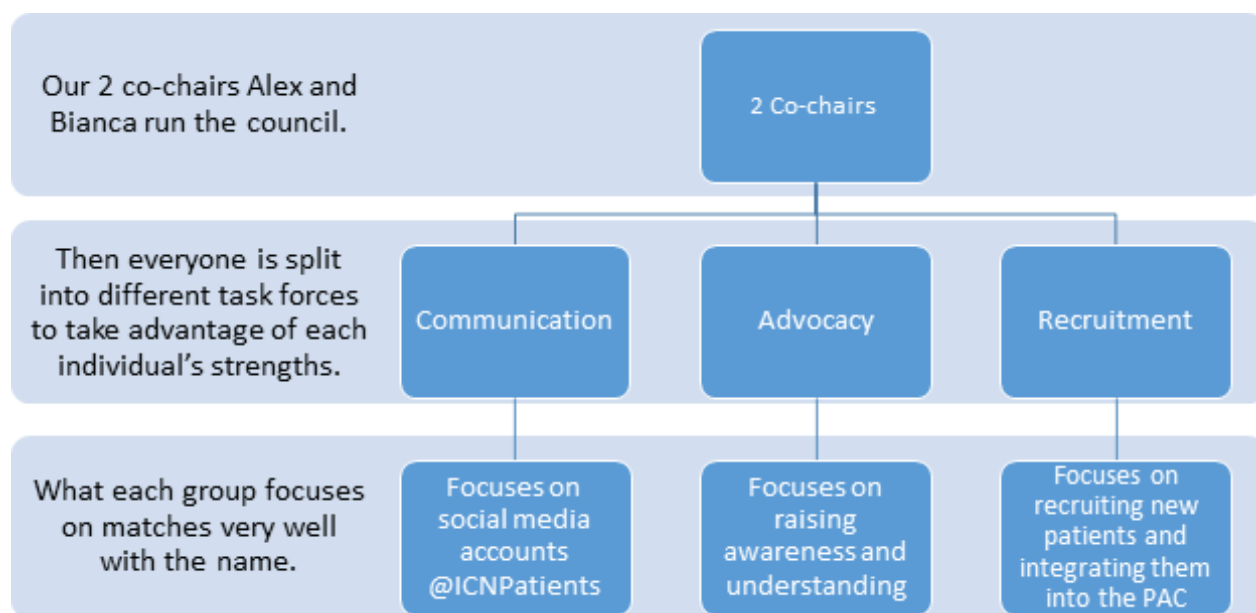
“Allowed me to open up about my disease and has given me the chance to expand my support system”

“Given me the opportunity to raise awareness and educate others about my disease”

PAC Structure

We have a simple, efficient structure:





Important PAC Names & Contact Information

Name	PAC Co-Chair Pac@improvecarenow.org	Name.	Communications Task Force Chairs Pac@improvecarenow.org
Name	PAC Co-Chair Pac@improvecarenow.org	Twitter	@icnpatients
Name	Recruitment Task Force Chairs pac@improvecarenow.org	Instagram	@icnpatients
Name	Advocacy Task Force Chairs Pac@improvecarenow.org	ICN Staff	info@improvecarenow.org

PAC Task Forces

Advocacy Task Force

Description:

Advocacy works on various different projects that serve to raise awareness and support for kids with IBD. These projects often make changes to patient care and patient support.

Past Projects:

Ostomy Toolkit: PAC members assembled a compilation of resources for those patients with ostomies. Each member who contributed had some kind of experience with an ostomy which

made for a valuable perspective. The resources included things like: what to wear; playing sports with an ostomy; and choosing the right type of bag for you.

PAC Profiles: In an effort to create a virtual mentoring system for patients at ICN centers who do not have mentoring or for those centers that cannot find a proper mentoring match, the Advocacy task force has assembled profiles for each PAC member. The profiles include information about medications taken; IBD experiences; and hobbies.

Job Responsibilities:

Responsibilities vary depending on what toolkit the team is working on. Most responsibilities surround the toolkit topics. A list of potential responsibilities are listed below:

1. Write a spark sheet to help potential mentors have a solid conversation with mentees (mentoring toolkit).
2. Summarize your experience with a particular medication to help patients going through a medication change (medication toolkit).
3. Help patients going through ostomy surgery by writing about the clothes to wear and how to play sports post ostomy surgery (ostomy toolkit).

Communications Task Force

Description:

Communications works to raise awareness for PAC and ImproveCareNow via social media. The idea is that if the PAC is visible on social media it will allow more people to see who the PAC is and get interested in joining. Their main avenue for awareness is via @ICNPatients on Twitter & Instagram. ImproveCareNow also has a blog called [LOOP](#) which PAC members contribute to.

Past Projects:

Flat Jennie: It started as a joke, but this project became a way to connect centers and report those connections using [social media](#). The idea behind it was that Flat Jennie, named after a past PAC co-chair, would visit centers and team members would take photos as they showed her around their offices and clinics. This would document each center in the network and raise awareness about ImproveCareNow on social media.

@ICNPatients: The PAC is on [Twitter](#) and [Instagram](#) to raise awareness. This started because ImproveCareNow is very active on social media so having accounts really allows us to interact with the Network and with staff at each of the centers nationally. It also helps increase our visibility, which extends our reach and impact.

Job Responsibilities:

1. Posting once a day on Twitter and two times a week on Instagram; and posting live during Community Conferences and IBD Twitter Chats
2. Sourcing, writing and editing patient posts for [LOOP](#)
3. Making sure the GroupMe (group text message) keeps on task
4. Updating the PAC infographic
5. Submitting PAC updates for the [ICN Digest](#)
6. Curating materials on the [icnpatients board](#) on the ICN Exchange

Recruitment Task Force

Description:

The Recruitment Task Force works to recruit new members and support their transition into the PAC. The responsibilities include sending welcome emails to the new members and helping them to decide on a task force to join. They also write blogs about the PAC in order to raise awareness about the PAC and get new members to join.

Past Projects:

New member and Year in Review Blogs: When new members join the PAC, a blog is written to highlight who they are and to introduce them to the network. There are also blogs written at the end of the year to summarize what the PAC has accomplished during the year. This is a good recruitment tool for the PAC as it can be sent to prospective members so they know exactly what the PAC is capable of doing.

High School Program: In order to create a sustainable flow of members into the PAC, recruitment is working on a brochure to put in clinics and high school nurse offices to get new members to join.

Job Responsibilities:

1. Following up with new prospective PAC members who have provided their contact info
2. Writing year in review & new member posts on LOOP
3. Continually finding ways to build connections with other IBD patients to recruit more people to the PAC
4. Developing and testing materials to enable ICN centers to communicate with their patients about the PAC

PAC Meeting Schedule

Monthly Calls

When

The second Thursday of every month at 7 PM ET

Why

Calls allow for us as a group to keep updated on other task force projects as well as give feedback to centers doing a variety of projects.

How

Call-in info will be in the meeting reminder emails. This includes a phone number as well as computer log in information if you want to see documents that could be shared during the call use the computer log in info.

Invited

Available PAC members as well as occasional guests asking for PAC feedback

Sample Agenda

7:00-7:15: Task force updates and new member introductions

7:15-7:36: Review of welcome materials

7:36-7:45: Unveiling of new PAC infographic

Sample Call Audio

<https://youtu.be/c4HSI4t9gd0>

PAC Social Media

The PAC has both [Instagram](#) and [Twitter](#) accounts that we use to raise awareness about ImproveCareNow, IBD and the PAC. Our username for both is @icnpatients

PAC & ImproveCareNow

The PAC is a part of ImproveCareNow, but what exactly is ImproveCareNow?

The purpose of ImproveCareNow (ICN) is to:

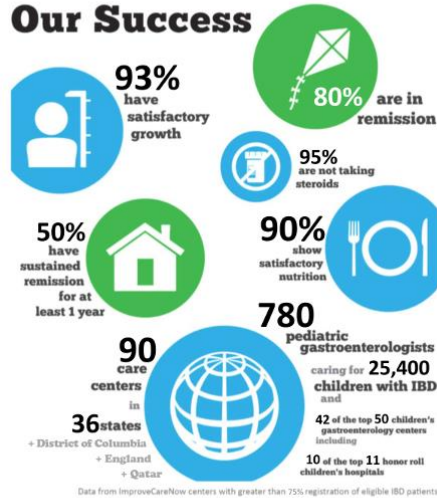
Transform the health, care and costs for all children and adolescents with Crohn's disease and ulcerative colitis by building a sustainable collaborative chronic care network, enabling patients, families, clinicians and researchers to work together in a learning healthcare system to accelerate innovation, discovery and the application of new knowledge.

But from a patient's point of view what does that mean?

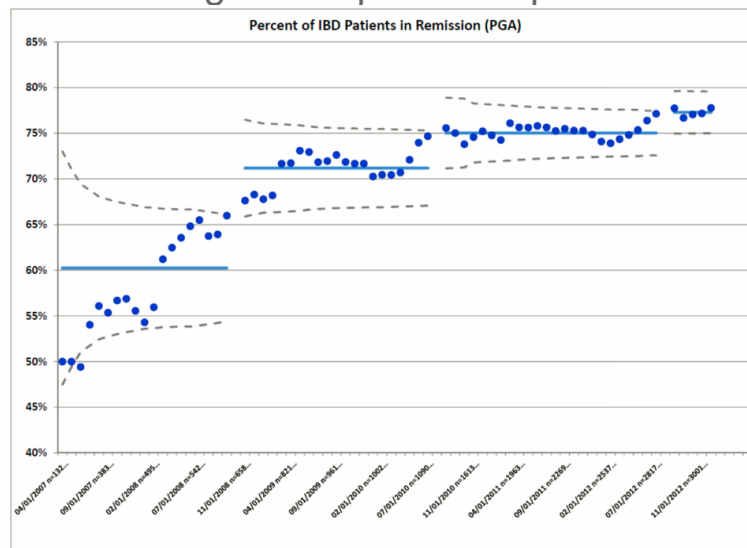
It means that ICN was created to improve your quality of life by sharing information between team members at participating hospitals; to accelerate pediatric IBD research and standardize what has been learned. And they want your help in doing that because a patient & family perspective is valuable and underutilized.

Their impact is proven:

Our Success



Currently 90+ centers, up from 16 centers in 2009, and remission rate for registered patients up from 60% in



2007 to 80% in 2016.

PAC & Community Conferences

This document is meant to clear up initial confusion about what ImproveCareNow Community Conferences are and why we talk about them so much.

Community Conferences

Community Conferences (formerly called learning sessions) are twice-yearly conferences held by ImproveCareNow. Since ICN is so large these conferences serve as a time for representatives from [participating care centers](#) to come together; to all teach and learn from and with each other in person. The virtual learning that happens across ICN, through tools like

monthly webinars and on the ICN Exchange, is amazing, but bringing people together for a couple days makes the collaboration even more powerful.

Some patients and parents are invited to attend and we are encouraged to develop and submit proposals for sessions at community conferences. This represents an opportunity to be a strong voice for the 25,000 patients being cared for across ICN; to share our perspectives, knowledge and experience with hundreds of providers: nurses, doctors, dieticians, psychologists and so many more. Sharing our experiences with them is valued to the point where when we speak everyone listens because our perspective is something that is rarely heard at big conferences like this. Here's what one of our PAC member's has to say about the conference.

The conference really helps you see what you can do to help in the world of healthcare. I also learned way more about doctors and other providers. I did not realize how limited their time was and how much they actually have to do in a day. But I also got to see their other sides. So few patients get to see doctors outside of the clinic where their guards are down and their real personalities come out. It was so rewarding!

Why We Talk About Community Conferences

If you couldn't tell from all of the above information, the conferences are awesome for us because:

1. You learn more about clinician's personal sides.
2. You see how and where your help is needed and you feel empowered to do more.
3. You make deeper connections with PAC members that you work with on PAC projects.

PAC Attendance at Community Conferences

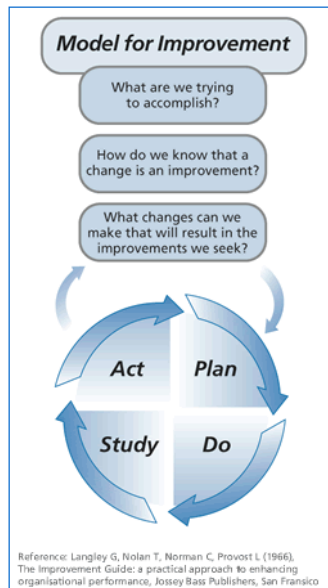
Currently, funding for patients is limited. Typically, the PAC co-chairs and most of the task force chairs are able to attend each conference. Sometimes we are lucky enough to be able to invite even more patients! Even though we aren't able to bring the entire PAC to the conferences, there are several ways in which all PAC members can participate:

1. If you can afford to pay your own way personally or through fundraising, or your center has funding and would like to pay for your attendance, you can register and join us!
2. If you are not able to attend in person, you are always invited and encouraged to join the conversation online by following and interacting with [@improvecarenow](#) and [@icnpatients](#)

PAC Role at Community Conferences

Patients attend talks on various topics that range from social media in healthcare, to Quality Improvement skills, to what kind of research ICN is doing. The entire ICN Community takes part in preparing and presenting sessions at Community Conferences; including the PAC. At the last conference the PAC led talks about mentoring, transition, and recruiting PAC members. The PAC also sets aside time for patient attendees at Community Conferences to get together and work on various PAC projects. Starting in Fall 2016 the PAC will also dedicate one day of the conference to doing team building activities.

QI Cheat Sheet for ImproveCareNow



Parent & Patient Partners

The Model for Improvement

1. What do we want to accomplish (our aim)
2. How will we know if a change is an improvement (our measures)
3. What changes can we make that will result in improvement? (our changes)

About AIMS

- Keep it **SMART**: Specific, measureable, actionable, realistic, time-bound
 - *Not this*: We will help more patients get pre-visit planning.
 - *This*: 60% of scheduled IBD patient visits will have pre-visit planning by June 30, 2015
- Develop your aim **as a team** so all are aligned around what you are trying to accomplish

About Changes

In ImproveCareNow, improvement teams get ideas for changes to test from other teams (on webinars or at Community Conferences), via group brainstorming, talking to patients and families, and from the [ICN Exchange](#).

A Practical Example

- Aim: 60% of scheduled IBD patient visits will have pre-visit planning by June 30, 2015
- Measure: % of visits with pre-visit planning—keep track weekly
- Changes to test: Build pre-visit planning (PVP) into existing pre-clinic meeting; test teams' process for reviewing PVP form; assign initial PVP review to clinic nurse.

Testing is Important

1. What works in Ohio won't necessarily work in Wisconsin.
2. Don't want to upset the system if the change does not lead to improvement.

In our example: Test new changes related to pre-visit planning with one physician's patients for 2 weeks. Then reflect and decide whether and how to spread.

Resources

1. A great (and entertaining!) video primer on applying QI to healthcare: <http://www.ihl.org/resources/Pages/AudioandVideo/MikeEvansVideoQIHealthCare.aspx>
2. A slightly less exciting (but thorough) overview of the Model for Improvement: <http://www.ihl.org/resources/Pages/HowtoImprove/default.aspx>
3. Staff Inbox: info@improvecarenow.org