



The Parent Connection

August 2018



Parent Working Group

Would you like to be a part of advocating for your children both locally and nationally? Would you like to help with educational or family support programs? Are you good at fundraising to help build resources and programs in GI? We would love to have you on our team! Please visit our website for more information on how you can help!

<https://phoenixchildrensfoundation.org/giving-groups/find/inflammatory-bowel-disease-ibd-parent-working-group/>

Patient Advisory Council (PAC)

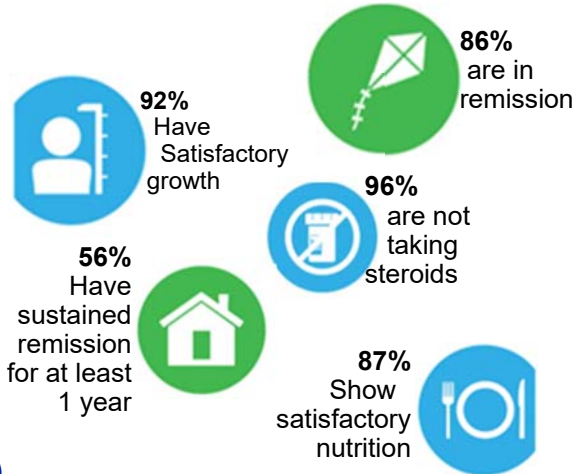
The Patient Advisory Council is made up of young (14 years and up) passionate and motivated patients with IDB. Together, the PAC is a voice for all patients in ImproveCareNow. They contribute to research studies and the development of health care innovations; they share valuable experiences with healthcare professionals, researchers and others; and they raise awareness of IBD and ICN via social media like LOOP, Twitter, and Instagram. Do you have a child 14 and older who would be interested in joining the PAC? Please see a member of your care team to learn how!

Read the first post to PAC from one of our own PCH kids!

https://www.improvecarenow.org/deal-ing-with-a-chronic-illness-can-really-make-a-person-grow-up?utm_campaign=8918_circlevcc&utm_medium=email&utm_source=improvecarenow



Improve Care Now (ICN)



As a member of the Improve Care Now Network, Phoenix Children's Hospital is improving the outcomes for kids with IBD. Above are some measures of care we track for our patients with IBD.

To learn more, and ensure your child is participating in Improve Care Now, we invite you to ask a member of your care team today.

Did you know...

Eye problems can occur as a result of having IBD? Sometimes inflammation can occur in your eye. As many as 13% of IBD patients can develop inflammatory disease of the eye. The most common eye problems are Episcleritis (inflammation of the surface tissue of the eye) and Uveitis (inflammation of the inside the eye). If left untreated these eye problems can develop into something more serious.

It is recommended that you see an eye doctor to have an eye exam once a year. PCH has ophthalmologists on staff, please ask a member of your care team if you need a referral.

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Upcoming Educational Events

Do you have questions about other health issues that can arise with your child that has IBD?

Please join us on **Thursday, November 1st, from 6:00—8:00** and get your questions answered from our panel of specialist! The IBD Parent Working Group will be hosting this free educational event.

We will be discussing how IBD can affect you in other ways besides your intestines. Our panel of doctors include:

Dr. Harper Price—Dermatologist

Dr. Mittun Patel—Diagnostic Radiology

Dr. Rick Golub—Ophthalmology

Dr. Micah Olson—Endocrinologist

This event is being held in the **Mel Cohen Conference Center** located in the Rosenberg Building on the PCH campus. Access and parking provided for free at the Cambridge Garage located off Cambridge Ave. Light appetizers and refreshments will be served.

Please register for this free event at:

<https://phoenixchildrensfoundation.org/giving-groups/find/inflammatory-bowel-disease-ibd-parent-working-group/>

Crohn's & Colitis Foundation

Join the CCF for **Patient Education day on Saturday, November 3rd from 8:30am—12:30pm** at the Desert Willow Conference center located at 4340 E. Cotton Center Blvd., Phoenix AZ 85040. Ticket price is \$5 and you can purchase your tickets online at: <http://online.ccf.org/siteCalendar?id=145255&view=Detail>

Financial assistance is available if needed. For more information feel free to email Karishma at kpur-sel@crohnscolitisfoundation.org

This year the CCF will be hosting a **Night of Champions gala on Friday, November 16th** at the Clayton House in Scottsdale. This semi-formal event will honor community leaders who impact patient lives, and will raise critical dollars to fund local programs and research in support of the estimated 34,000 Arizona children and adults living with Crohn's disease or ulcerative colitis. Our very own *Shannon Groppenbacher* will be honored as the 2018 "Humanitarian of the Year"!!

Visit <http://noc18.auction-big.org> to purchase tickets or a table.

PCH Staff Corner



Jamie Smith is the Senior Clinical Research Coordinator for the Gastroenterology & Rheumatology Departments at PCH.

"After graduating from UofA (Go Wildcats!), I started my research experience working in Phase I research. A little over 8 years ago, the opportunity came up to work at PCH as a research coordinator for GI and Rheumatology. I still work in the same departments and love it! I have transitioned into doing quality improvement and research in both departments which has been a very rewarding experience".

So what does a Research Coordinator do? Check out Jamie's work on the 1st page! Jamie tracks the percentages of improvement that are shown on this graphic. Currently PCH is involved in a research study through Improve Care Now, called COMBINE. This is a study for kids with Crohn's disease who need to start an anti-TNF medications (such as Remicade or Humira). This study is looking to answer the important question of "Does adding another medication called Methotrexate lead to better outcomes?"

Jamie has been involved in the ICN since PCH joined in 2014. "ICN has had a huge impact on my work at PCH. I truly enjoy working on quality improvement projects and seeing the positive impact it has on our patients. ICN is full of physicians, nurses, researchers, parents and patients all coming together in a way that I've never seen to improve the care the patient with IBD receives".

When Jamie is not busy doing research, she has 2 children ages 9 and 5. She keeps busy being a Girl Scout troop leader and playing with her large English Mastiff, Primus!

Thank you Jamie for your hard work in the research of IBD. We appreciate you!!