



# The Parent Connection

August 2017

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## Parent Working Group

If you want to join the Parent Working Group (PWG) please send an email with your name and best contact info to: [dg\\_ibd\\_program@phoenixchildrens.com](mailto:dg_ibd_program@phoenixchildrens.com)

**There are many ways you can help! This group is made up of parents who have different talents. Our goal is to work together for the benefit our kids.**

If you are interested in donating to help support initiatives through the Parent Working Group like our social or educational events, you can donate to the GI Department through the PCH Foundation website or by check. Make your check out to Phoenix Children's Hospital Foundation GI Dept/IBD Center/PWG or online at <http://www.phoenixchildrens.org/ways-to-help/donate>. Be sure to note your online donation for the GI Dept/IBD Clinic/PWG. Thanks!

## Improve Care Now (ICN)



### Our Success



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 ImproveCareNow, we invite you to ask a member of your care team today.

## Research Corner

Did you know that PCH takes part in IBD research projects? For more information please talk to your GI Doctor.

### MICROBIOME

The microbiome is defined by the organisms that reside within our intestinal tract. In fact, there are more bacteria in our colon than cells in our body. IBD is likely caused by an aberrant immune response to the normal gut bacteria. With advances in research, we are now able to identify these bacteria and study the important roles they play in our body. This has led to identifying the different populations existing between healthy and diseased individuals. This is currently being investigated in IBD and clear differences are being seen. Armed with this information, we are now better positioned to develop strategies that manipulate the microbiota for therapeutic purposes. The potential exists to optimize microbial-based therapies of IBDs if we continue efforts to identify individual microbes and functions that play roles in IBDs and then design methods to modulate the concentrations and functions of these microbes to suppress. Such microbial-targeted treatments offer more physiologic approaches to treating IBD patients compared with lifelong potent immunosuppression, though may also be used as adjuncts to immunosuppressive treatments. Furthermore, potential exists for nontoxic approaches to prevent onset of disease in individuals at high risk of developing CD and UC, such as offspring and siblings of IBD patients.

We currently perform Fecal Transplants at PCH and studies are being performed at many centers on its role in IBD; but there is no clear consensus or benefit that has been identified to date.

Sartor B. Curr Treat Options Gastroenterol. 2015 Mar; 13(1): 105–120.

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## Picnic in the Park!

IBD Parent Working Group will be hosting a family pot-luck picnic at **McCormick Railroad Park—Papago Ramada** on **Sunday, October 22nd, from 12:00-3:00 p.m.**

Please join us for an afternoon of fun and food! Dr. Gary Silber has generously offered to be our “chef” for the afternoon and will be showing off his BBQ skills at the grill! We are looking for assistant chefs so if you are willing to step up to help BBQ please let us know. The PWG will provide the main course and picnic supplies, you bring your favorite side dish!

**All IBD families and kids are invited! RSVP is required. Please send an email to: [dg\\_ibd\\_program@phoenixchildrens.com](mailto:dg_ibd_program@phoenixchildrens.com)**

with the subject line **RSVP– FAMILY PICNIC** and let us know the ages of your children, how many will be attending and if you would like to help!

## ICN Virtual Community Conference

ICN will be holding a virtual community conference webinar on October 11 from 4-8 pm (Eastern Time). Agenda and RSVP coming in early September.

## CCF Take Steps Walk—Update

On Saturday, April 8, 2017 over 1,000 people participated in the Phoenix Take Steps walk and raised more than \$113,000 to fund critical research and patient programs! The Giving Tree was the top team raising \$10,687 and our own PWG leader Shannon Groppenbacher was the top individual fundraiser with \$5,675 in donations. It takes a village and the Foundation is so grateful to our sponsors, honored heroes, team captains, walkers and volunteers for making this a special day!

## CCF Future Events

The “Courageous Kids” event has been postponed. Stay tuned for a future date!

*This newsletter is put together by parents of children who have IBD. We are here to help educate and support one another. If you would like to see any topic of interest on IBD, please reach out to Shannon Groppenbacher at [sgroppen@yahoo.com](mailto:sgroppen@yahoo.com). We are accepting donations for the GI Department. To donate please make your check out to Phoenix Children's Hospital Foundation GI Dept/IBD Center or online at <http://www.phoenixchildrens.org/ways-to-help/donate>. Thank you!*

## Physician Corner

Dr. Brad Pasternak completed his fellowship at Cincinnati Children's Hospital in 2008 and then joined Phoenix Children's Hospital. Dr. Pasternak became a GI doctor because he suffers from GI issues, including IBD and this spurred his interest in helping kids that suffer from the same conditions. He is very interested in research to help understand the causes and treatments of IBD. Dr. Pasternak grew up in New Jersey and his parents have now become snow birds in the Valley. He has 2 children ages 6 and 4 and his younger sister is an occupational therapist in Cape Cod. In his spare time, Dr. Pasternak loves to swim and is an avid runner. He also enjoys live music and our valley's restaurant scene.



“When PCH joined the ICN Network in 2014 it allowed PCH to monitor their progress and remissions rates in comparison to other centers in the network. Most importantly, it has resulted in the creation of the Parent Working Group which has been a fruitful experience to date.” Dr. Pasternak is committed to seeing the GI Department create a multi-disciplinary clinic and in addition creating a social network for the kids. Quality improvement and fundraising activities are all goals of the clinic.

Thank you Dr. Pasternak for taking care of our kids!

