



The Parent Connection

March 1, 2017

Volume 1, Issue 1



Parent Highlight

We are so excited to bring you the first edition of the quarterly Parent Working Group newsletter. We have partnered with Improve Care Now (ICN) and recently started a Parent Working Group at Phoenix Children's Hospital. We are committed to enhancing the quality of life for children and their families who live with IBD. If you want to join the Parent Working Group please send an email with your name and best contact info to:
dg_ibd_program@phoenixchildrens.com

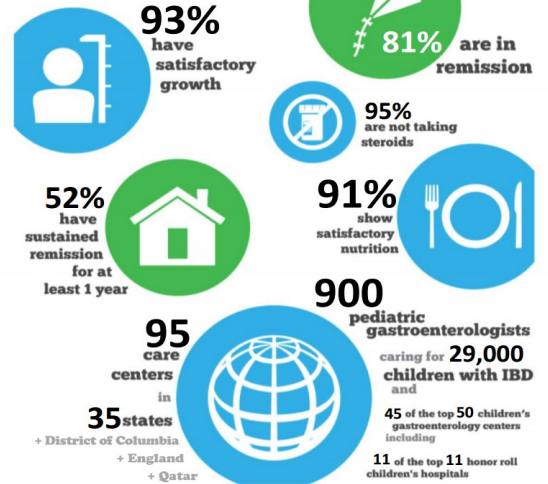
Improve Care Now (ICN)

Most of you probably remember being asked to sign a consent form for Improve Care Now (ICN) and some of you are likely wondering what this really is. ICN is a "Learning Health System" dedicated to all stakeholders—patients, parents, providers, researchers, dietitians, etc.—working together to improve care for all children with inflammatory bowel disease (Ulcerative Colitis or Crohn's Disease.) Because you are at an ICN center, data from your visits are entered into a database and we can then use that data to develop strategies to improve remission and quality of care. Phoenix Children's Hospital is the only ICN center in Arizona and we are working hard to improve quality of care. The network strongly encourages parental involvement. The graphic on the right shows National Data.

Phoenix Children's Hospital is proud to say we have also maintained nearly 80% of our patients with IBD in clinical remission since 2015.



Our Success



Data from ImproveCareNow centers with greater than 75% registration of eligible IBD patients

updated 6 February 2017

Figures include National Data

CCFA Take Steps Walk

"Take Steps for Crohn's & Colitis" is CCFA's largest fundraising event dedicated to raising awareness and funds for the 1.6 million American adults and children affected by [Crohn's disease](#) and [ulcerative colitis](#)—that's one out of every 200 people!

The funds you raise through Take Steps will help support patient programs, enhance professional education efforts, and propel critical research for cures. Since its inception, Take Steps has successfully connected more than 120,000 patients, families, and businesses in the community and raised more than \$75,000,000 to support CCFA.

Join us Saturday, **April 8th** at the Phoenix Zoo. Registration starts at 7:00 am and the walk begins at 8:00 am.

Register online at:
www.cctakesteps.org/phoenix2017

Inside this issue:

- Improve Care Now
- CCFA Take Steps Walk
- Upcoming Educational Events
- CCFA Monthly Support Group
- Physician Corner

Educational Events Coming!

Mark your calendars for **Thursday, March 30th from 6:00-8:00 p.m.!** We will be sponsoring a **“Meet your IBD Team”** Educational Event at PCH in the Main Building, 2nd Floor, Rooms 22110—22112. You will have the opportunity to meet with GI Doctors, Surgeon, Dietician, Psychologist, GI Nurse, GI Research Coordinator and CCFA. Network with other parents and children with IBD. Information on CCFA Take Steps Walk, Camp Oasis and mentoring programs will also be available. Snacks & beverages will be provided.

Please RVSP for this event at:

dg_ibd_program@phoenixchildrens.com

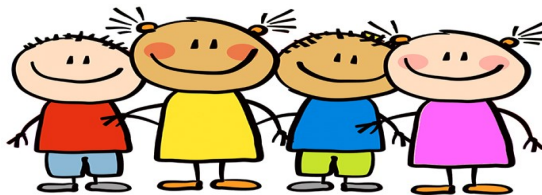
Due to limited space we ask that only the parents and children with IBD attend.



Courageous Kids Event

On May 20th, CCFA is bringing you a Courageous Kids Half-Day Educational Event for Families Dealing with IBD in Phoenix. You won't want to miss this one! Dr. Marla Dubinsky will be speaking on current and upcoming research on IBD. Dr. Dubinsky is the Chief of Pediatric Gastroenterology and Hepatology at the Kravis Children's Hospital at Mount Sinai, New York.

Stay tuned for time and place!



Did you know you can meet up with other parents and kids that have IBD? Join our CCFA Support Group that meets the second Tuesday of every month on the 2nd Floor at Phoenix Children's Hospital. For more information on this group please contact Emily Curtis at 602-734-1392 or email

ecurtis@crohnscolitisfoundation.org

Physician Corner

Dr. Gary Silber, is the Head of the Pediatric Gastroenterology Department at Phoenix Children's Hospital. Dr. Silber has been a Pediatric GI Doctor with PCH since 1987. He became interested in GI during his first year of

residency at the University of Connecticut Medical Center. "I was able to see it provided a balance of general pediatric problems, nutritional problems, and diseases that required long term management, as well as the ability to do procedures." Dr. Silber has been married for 35 years and has two grown daughters. He has two dogs, Pepper a border collie mix and Macy a Golden Retriever. In his free time Dr. Silber likes to golf, go to the gym and read mysteries and political novels. He is also an avid sports fan. Dr. Silber's favorite team is the New York

Yankees. Thank you Dr. Silber for taking care of our kids!

