



# IMPROVECARENOW™

*improving lives through collaborative medicine*

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I'm happy to report that 2018 was an excellent year for ImproveCareNow, which now includes 109 centers with 30,000 patients and 1,200 clinicians, including 950 pediatric gastroenterologists. There are 97 centers in the US and the District of Columbia, 2 in England, 1 in Qatar and 9 in Belgium. We are the largest and fastest growing pediatric improvement and research community in the world. Currently 55% of children and youth cared for by pediatric gastroenterologists in the US are at participating ImproveCareNow centers. Centers range from small private practices to the largest and highest-ranked children's hospitals: 90% of the top children's gastroenterology centers including 9 of 10 of the top children's hospitals.

ImproveCareNow has had enormous success since it began 12 years ago, including increasing remission rates for thousands of youth with IBD, transforming how care is being provided, enlightening and exciting clinicians and other care providers, and engaging patients and parents in a common mission and work. Partnering with Cincinnati Children's Hospital, ImproveCareNow has been involved in over \$35 million of grant projects, built a research infrastructure, initiated industry-sponsored research and formed fruitful relationships with foundations and funding agencies. Our work is widely acclaimed, as epitomized by receipt of the 2016 Drucker Prize for innovation. Most importantly, we have transformed how people think about and take action to improve the health, care and cost of children and youth with IBD.

Our mission is to have all children and youth with Crohn's disease and ulcerative colitis cared for at an ImproveCareNow center, where 82% of patients are in clinical remission (feeling well, fully active, and able to do the activities they enjoy), 90% have satisfactory nutrition, 94% have satisfactory growth and 96% are not taking steroids.

In 2018 we continued important work supported by a \$1 million grant from the Clare Foundation to study and implement methods to empower patients, and an award of \$2.5 million from the Patient Centered Outcomes Research Center Institute (PCORI), for a study of the effectiveness of the Specific Carbohydrate Diet in Crohn's disease (called PRODUCE), using a novel investigative method called "n of 1" or personalized trials. PCORI previously awarded over \$9 million to projects involving ImproveCareNow. In one project ImproveCareNow is creating a Patient Powered Research Network (PPRN), increasing the role of patients and parents in the governance of ImproveCareNow, setting research priorities, participating in clinical research, and providing reports of their health (patient reported outcomes, or PRO). This grant also funded an Engagement Campaign to make patients and parents aware of, and connect them with ways to participate in and contribute to ImproveCareNow and its network of participating care centers. In another PCORI-funded project, eight ImproveCareNow centers are leading a Clinical Data Research Network (CDRN) called "PEDSnet", in which children's hospitals develop the infrastructure to share data to facilitate novel approaches and large scale pediatric research. Finally, with funding from PCORI to the University of North Carolina at Chapel Hill, ImproveCareNow continues to conduct its first clinical trial (called COMBINE) to evaluate whether, for children and adolescents with Crohn's disease who need to start Remicade or Humira medication, adding another medication called methotrexate leads to better outcomes.

Other research funding, from AbbVie, Takeda and Celgene, supported collaborative studies using data from ImproveCareNow centers that have been entered into the ImproveCareNow registry. These studies examined the effectiveness of adalimumab in Crohn's disease and ulcerative colitis, the use of sequential biological agents and the impact of Crohn's disease and ulcerative colitis on growth.

ImproveCareNow is uniquely capable of facilitating clinical trials of new drugs developed by pharmaceutical companies to make them more rapidly and readily available to pediatric patients: As an enduring learning health network, ImproveCareNow has the communications and collaboration infrastructure to facilitate clinical trials, and can perform data queries of the registry to determine how many patients at each center are potentially eligible for a study. In 2018 ImproveCareNow launched ENROLL in Hubble, a collaboration with Takeda to facilitate their pediatric trial of vedolizumab (Entyvio), and began collaborations with Eli Lilly and Genentech. In addition, ImproveCareNow has formed an alliance with IQVIA (one of the largest global Contract Research Organizations and provider of data information, services and technology for the healthcare industry) to begin creating the ICN-IQVIA RESPECT (Rapid Engagement, Startup & Precision Enrollment Clinical Trials) Network, with a goal of 25 trials-ready ImproveCareNow centers by July 2019.

ImproveCareNow, Inc., a 501(c)3 with its central office at the University of Vermont, continues to work closely with its strategic partner, the Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center. Each year more than \$10 million is invested in ImproveCareNow activities, from center participation fees, planned giving, grants and in-kind contributions of participating centers (including physician and staff time and attendance at twice-yearly Community Conferences). More than ten years after its founding, ImproveCareNow is a robust sustainable organization with 25 staff (14.5 full time equivalent staff). In addition there are 100 researchers and volunteers, and 200 staff at participating centers who also contribute to ImproveCareNow.

As we continue to keep our primary focus on improvement, we have also developed and expanded our research activities. With data from almost 40,000 patients and 275,000 visits, the ImproveCareNow registry is a great resource for advancing our knowledge about pediatric Crohn's disease and ulcerative colitis. In 2018, the ImproveCareNow Research Committee received an additional 6 proposals for research—26 studies are underway or have been completed and another 1 is under consideration. In addition, there were 4 ImproveCareNow research publications in medical journals, 15 published abstracts, 8 oral presentations at a national or international research meeting and 11 poster presentations.

ImproveCareNow twice-yearly Community Conferences are highlights of our year. Held in the spring and fall, they are attended by members of the center QI teams, staff and guests so we can put our mottoes into action: *We all teach, we all learn; we steal shamelessly and share seamlessly; we know that to go fast you go alone, but to go far we go together*. Attendance at our 2018 conferences included a total of 529 registrants, including 54 parents and patients. We look forward to lively, stimulating and fun Community Conferences in 2019 (on March 29 - 31 in Dallas, TX and September 19 – 21 in Chicago, IL).

The year 2019 promises to be full of exciting discovery, improvement and innovation, as we pursue support to develop or expand important programs:

- Develop a program to meet the needs of families when they first learn their child has Crohn's disease or ulcerative colitis
- Expand our research program to learn more about pediatric inflammatory bowel disease
- Explore how we could begin to include pediatric surgeons and pediatric liver specialists in the ICN community
- Increase our collaborations to facilitate the development of new drugs

- Enhance our communications program for more effective engagement of patients and parents.

We invite you to visit our website [improvecarenow.org](http://improvecarenow.org); [sign up](#) to receive our community newsletter (CIRCLE); follow us on [Facebook](#), [Instagram](#) and [Twitter](#); [get in the LOOP](#) with #myICN stories on our blog; watch us on [YouTube](#)—be aware of, participate in and contribute to the ImproveCareNow mission. We are eager to have you join us as we work together to improve the care and health of children and youth with Crohn’s disease and ulcerative colitis. For additional information please feel welcome to [contact me](#).

Sincerely,

*Richard B. Colletti*

Richard B. Colletti, MD  
Executive Network Director, ImproveCareNow  
President, ImproveCareNow, Inc.  
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