



# IMPROVECARENOW™

*improving lives through collaborative medicine*

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Dear Friend of ImproveCareNow,

I'm happy to report that 2019 was an excellent year for ImproveCareNow™, which now includes [110 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 pediatric improvement and research community in the world. Currently half the 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 13 years ago. ImproveCareNow has [increased remission rates](#) for thousands of youth with IBD, transformed how care is being provided, enlightened and excited clinicians and other care providers, and engaged 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 how to improve the health, care and cost of children and youth with IBD.

Our goal 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 and fully active), 90% have satisfactory nutrition, 94% have satisfactory growth and 96% are not taking steroids.

In 2019 we continued the 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](#), 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, providing reports of their health (patient reported outcomes, or PRO). This grant also funded an Engagement Campaign to make patients and parents aware of, participate in and contribute to ImproveCareNow and its participating 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. 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. Finally, in 2019 the Patient Centered Outcomes Research Institute gave a new award that will allow ImproveCareNow centers to more efficiently perform clinical research.

ImproveCareNow has previously also received research funding from pharmaceutical companies, including AbbVie, Takeda, Celgene, Lilly and Genentech, to support collaborative studies using data from ImproveCareNow centers that have been entered into the ImproveCareNow registry. Research included studies of the effectiveness of adalimumab in Crohn’s disease and ulcerative colitis and the use of sequential biological agents. A study of the impact of Crohn’s disease and ulcerative colitis on growth in over 10,000 adolescents and young adults in the ImproveCareNow registry is about to be published in the prestigious journal *Inflammatory Bowel Diseases*.

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 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); the trial was completed successfully in 2019 due in part to the contributions of ImproveCareNow to enable its centers to enroll patients at higher rates than non-ImproveCareNow centers. In addition, ImproveCareNow continues its alliance with IQVIA (one of the largest global Contract Research

Organizations and provider of data information, services and technology for the healthcare industry) in creating the ICN-IQVIA RESPECT (Rapid Engagement, Startup & Precision Enrollment Clinical Trials) Network, with a goal of 25 trials-ready ImproveCareNow centers.

In 2019 ImproveCareNow also launched the [Pathway to Mastery](#), an exciting new program for ImproveCareNow centers to drive an energetic focus on mastering and applying improvement science skills and tools to improve outcomes. The program provides coaching geared to the needs and achievements of individual centers. While new and reorganizing centers focus on mastering the fundamentals of quality improvement, more advanced centers focus on achieving higher rates of clinical remission and higher rates of sustained clinical remission. In addition, Trailblazer centers are collaborating to develop processes to customize care and to improve patient adherence to treatment plans.

While we keep our primary focus on improvement, we also continue to expand our research activities. With data from over 45,000 patients and 330,000 visits, the ImproveCareNow registry is a great resource for advancing our knowledge about pediatric Crohn's disease and ulcerative colitis. In 2019, the ImproveCareNow Research Committee received an additional 10 proposals for research—45 studies are underway or have been completed and another 2 are under consideration. In addition, there were 9 ImproveCareNow research publications in medical journals, 5 published abstracts and 5 poster presentations at a national research meeting.

The ImproveCareNow twice-yearly Community Conferences are highlights of the 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 mottos 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 2019 conferences included a total of 462 registrants, including 58 parents and patients. We look forward to lively, stimulating and fun [Community Conferences in 2020](#) (on April 2 – 4 in Orlando FL and September 24 – 26 in Denver CO).

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.

The year 2020 promises to be full of exciting discovery, improvement and innovation, as we pursue support to develop or expand important programs:

- Develop the *myICNhome*<sup>®</sup> online platform to meet the needs of families when they first learn their child has Crohn's disease or ulcerative colitis
- Develop an enhanced *ICN Exchange* for easier better sharing and communication among the ImproveCareNow center team participants
- Expand our research program to learn more about inflammatory bowel disease and its treatment and management
- Explore how we could begin to include pediatric surgeons and pediatric liver specialists in the ICN community
- Strengthen our collaborations to facilitate the development of new drugs, and
- Enhance our communications program for more effective and timely engagement of patients and families.

On behalf of all the outstanding hardworking [staff, leadership and Board of Directors](#) of ImproveCareNow; and the patients, parents, clinicians and researchers dedicated to improve the care and health of children with Crohn's disease and ulcerative colitis—I invite you to visit our website [improvecarenow.org](http://improvecarenow.org), sign up to receive our [CIRCLE eNewsletter](#), like us on [Facebook](#), follow us on [Twitter](#) and [Instagram](#), get in the LOOP with community stories on [our blog](#)—be aware of, participate in and contribute to the ongoing success of ImproveCareNow. 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*

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