



IMPROVECARENOW

improving lives through collaborative medicine

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Dear Friend of ImproveCareNow:

I'm happy to report that 2016 was an excellent year for ImproveCareNow, a year in which ImproveCareNow was selected from among 495 candidates as the winner of the prestigious Drucker Prize for innovation. In addition, 10 new centers joined ImproveCareNow, expanding our network to include 95 centers with 27,000 patients and 1,200 clinicians, including 900 pediatric gastroenterologists. 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, and at our current rate of growth we will have 75% by the year 2020. ImproveCareNow centers range from small private practices to the largest and best children's hospitals: 90% of the top children's gastroenterology centers including all 11 of the top children's hospitals.

ImproveCareNow has had enormous success since it began 10 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. ImproveCareNow has been involved in over \$30 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 the 2016 Drucker Prize. Most importantly, we have transformed how people think about how to improve the health, care and cost of children and youth with IBD.

But this has been just the first decade. This is just the beginning.

Our mission is to have all children and youth with Crohn's disease and ulcerative colitis cared for at an ImproveCareNow center, where 81% of patients are in clinical remission (feeling well and fully active), 90% have satisfactory nutrition, 93% have satisfactory growth and 94% are not taking steroids.

In 2016 we received good news from the Clare Foundation, which will provide \$1 million over the next 4 years to study and implement methods to empower patients. There was also 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 and providing reports of their health (patient reported outcomes, or PRO). In a second PCORI-funded project, eight ImproveCareNow centers will be leading a Clinical Data Research Network (CDRN) called "PEDIStnet", 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, ImproveCareNow is conducting its first clinical trial 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, is supporting collaborative studies using data from ImproveCareNow centers that have been entered into the ImproveCareNow registry. These studies are examining 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, 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 \$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). Ten years after its founding, ImproveCareNow is a robust sustainable organization with 46 staff (17 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 27,000 patients and 185,000 visits, the ImproveCareNow registry is a great resource for advancing our knowledge about pediatric Crohn's disease and ulcerative colitis. In 2016, the ImproveCareNow Research Committee received an additional 17 proposals for research—9 studies are underway or have been completed and another 8 are under consideration. In addition there were 5 ImproveCareNow research publications in medical journals, 5 published abstracts, one oral presentation at a national research meeting and 5 poster presentations.

The ImproveCareNow twice-yearly Community Conferences are the 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 2016 conferences included a total of 595 registrants, a 13% increase over 2015. We look forward to lively, stimulating and fun Community Conferences in 2017 (on April 28-27 in Dallas, TX and September 7-9 in Chicago, IL).

The year 2017 promises to be full of exciting discovery, improvement and innovation, as we pursue support to develop or expand important programs:

- Develop a program to determine the risk of cancer for current and new medications
- 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 inflammatory bowel disease
- Enhance our communications program for more effective sharing including patients and parents.

We invite you to visit our website improvecarenow.org, [join our CIRCLE](#), like us on [Facebook](#), follow us on [Twitter](#), read our blog ([LOOP](#)), see us on [YouTube](#)—be aware, participate 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 us](#).

Sincerely,

Richard B. Colletti, MD

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