



IMPROVECARENOW

improving lives through collaborative medicine

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Dear Friend of ImproveCareNow:

I'm happy to report that 2015 was an excellent year for ImproveCareNow: 14 new centers joined ImproveCareNow, expanding our network to include 86 centers with 23,000 patients and 950 clinicians, including 750 pediatric gastroenterologists. We are the largest and fastest growing pediatric improvement and research community in the world. Currently 50% 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: 11 of the 12 top children's hospitals and 39 of the top 50 children's gastroenterology centers.

Our mission is to have all children and youth with Crohn's disease and ulcerative colitis cared for at an ImproveCareNow center, where 80% 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.

The extraordinary achievements of the ImproveCareNow Network are the result of proven quality improvement training and tools that center QI team members use to improve the care and health of their patients. ImproveCareNow performance reports show each center how healthy its patients are, and how well it is providing care. Robust ImproveCareNow population management and pre-visit planning reports help teams identify and respond to the needs of their individual patients. And, most importantly, ImproveCareNow has created a collaborative community where clinicians, researchers, parents and patients work together to bring about more reliable proactive care and healthier children and youth.

In 2015 we received good news from the Patient Centered Outcomes Research Center Institute (PCORI), which 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 "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, ImproveCareNow will be conducting its first clinical trial to evaluate whether, for kids 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, is supporting collaborative studies using data from ImproveCareNow centers that have been entered into the ImproveCareNow registry. One study of thousands of ImproveCareNow patients examines the frequency and variation in the use of immunomodulator therapy (azathioprine, 6-MP and methotrexate) with adalimumab (Humira). A second study will examine the effectiveness of adalimumab in the treatment of pediatric Crohn's disease.

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, philanthropy, grants and in-kind contributions of participating centers (including physician and staff time and attendance at twice-yearly Community Conferences). Nine 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 22,000 patients and 145,000 visits, the ImproveCareNow registry is a great resource for advancing our knowledge about pediatric Crohn's disease and ulcerative colitis. In 2015, the ImproveCareNow Research Committee received an additional 10 proposals for research—13 studies are underway or have been completed and another 13 are under consideration. In addition there were 4 ImproveCareNow research publications in medical journals, 7 published abstracts, one oral presentation at a national research meeting and 7 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 2015 conferences included a total of 525 registrants, a 20% increase over 2014. We look forward to lively, stimulating and fun Community Conferences in 2016 (on April 7-9 in Dallas TX and September 15-17 in Chicago).

The year 2016 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, receive our eNewsletter ([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 me.

Sincerely,



Richard B. Colletti, MD
Executive Network Director, ImproveCareNow
President, ImproveCareNow, Inc.
Professor of Pediatrics, University of Vermont