Dear Friend of ImproveCareNow:

I’m happy to report that 2017 was an excellent year for ImproveCareNow, a year in which 14 new centers joined ImproveCareNow, including all 9 pediatric IBD programs in Belgium. ImproveCareNow has expanded our network to include 106 centers with 29,400 patients and 1,200 clinicians, including 945 pediatric gastroenterologists. There are 94 centers in the US and the District of Columbia, 2 in England, 1 in Qatar and now 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, and we continue to grow towards a reach of 75%. ImproveCareNow centers range from small private practices to the largest and highest-ranked children’s hospitals: 90% of the top children’s gastroenterology centers including 10 of 11 of the top children’s hospitals.

ImproveCareNow has had enormous success since it began 11 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 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 2017 we were carrying out 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 is also funding 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. Finally, with funding from PCORI to the University of North Carolina at Chapel Hill, ImproveCareNow is conducting 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 also benefited from valuable funding from the Crohn’s and Colitis Foundation, to enable patients and parents to attend our Community Conferences and to reduce the cost for centers to attend.

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 33,000 patients and 225,000 visits, the ImproveCareNow
registry is a great resource for advancing our knowledge about pediatric Crohn’s disease and ulcerative colitis. In 2017, the ImproveCareNow Research Committee received an additional 8 proposals for research—29 studies are underway or have been completed and another 4 are under consideration. In addition, there were 4 ImproveCareNow research publications in medical journals, 7 published abstracts, 3 oral presentations at a national research meeting and 3 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 2017 conferences included at total of 634 registrants, a 6% increase over 2016 despite a major hurricane in September that kept our friends and colleagues in Florida from attending. We look forward to lively, stimulating and fun Community Conferences in 2018 (on April 26 – 28 in Dallas TX and September 13 – 15 in Chicago).

The year 2018 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 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

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