



Dear Friend of ImproveCareNow -

ImproveCareNow has had enormous success since it began 14 years ago, including increasing remission rates for thousands of young people with IBD, transforming how pediatric IBD care is being provided, enlightening and exciting clinicians and other care providers, and engaging patients and parents in a shared purpose and work. We are pleased to share our [ImproveCareNow Annual Update](#), which includes highlights and achievements from 2020 and plans for our continued work to improve health, care, and costs for young people with IBD in 2021 and beyond.

In 2020 ImproveCareNow:

- Sustained active participation across our network of [100+ care centers](#) serving 30,400 patients and their families, and with 1,200 clinicians, including 974 pediatric gastroenterologists
- Continued important work supported by a grants from the David R. Clare and Margaret C. Clare Foundation to study and implement methods to empower patients, and 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
- Completed recruitment for its first pediatric clinical trial (called [COMBINE](#)), with 306 randomized patients, to evaluate whether children and adolescents with Crohn's disease, who need to start Remicade® or Humira® medication, would see better outcomes by also adding another medication called methotrexate
- Shared a [Research Change Package](#) to help care center teams progress more efficiently and effectively through their research projects, which includes best practices on all phases of research, including legal and IRB approval, recruitment, communications and other key topics
- Continued developing our improvement infrastructure (called [Pathway to Mastery](#)), launching innovation teams called "Trailblazer Learning Labs", increasing our community to 10 learning labs, including a short-term learning lab formed to address needs specific to the [COVID-19 pandemic](#) and resuming care
- Approved 13 new proposals for research; the ICN Research Committee reports that 44 studies are underway, and another 4 studies are currently under consideration
- Recorded [5 ImproveCareNow research publications](#) in medical journals, 4 published abstracts, and 4 poster presentations
- Celebrated virtually with our community of learners by living our mottoes (*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*) during two Live Online Community Conferences, which brought together a total of 1,243 registrants, including 148 patients and parents
- Partnered with pediatric liver specialists to host the first Auto-immune Liver Network for Kids (A-LiNK) Community Conference and kicked off the A-LiNK Learning Lab with 11 participating sites
- Transitioned to new [Executive Leadership](#) with the recruitment and successful onboarding of a new Executive Director and Clinical Director for the network



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improving lives through collaborative medicine

- Implemented changes that will enable the network to respond to shifts in data based on interventions and trends over time, including updating data analytic guidelines for assessing improvement using statistical process rules and basing outcome measure control limits on the initial 20 data points in the registry
- Improved clinical remission (from 81% to 82%) and sustained clinical remission (from 54% to 56%) for patients cared for in our network. This translates into 1844 more patients in clinical remission and 1665 more patients in sustained remission.

As the ImproveCareNow community continues to work together through 2021 and beyond, the journey promises to be full of exciting discovery, improvement, and innovation, as we:

- Finalize a successful strategic planning period with the new Executive Leadership, which will outline areas of focus for the next three years (outcomes, diversity/equity, financial sustainability, engagement, and technology)
- Continue to develop the *myICNhome*® online platform to meet the needs of patients and families when they first receive a diagnosis of Crohn's disease or ulcerative colitis, fulfilling another of our guiding principles, [WINWIN](#) (What I Need, When I Need it)
- Launch the ICN Hub, an online collaboration platform to facilitate bidirectional sharing of knowledge and information in real time
- Expand our research program to continue learning together about pediatric inflammatory bowel disease and its treatment and management
- Develop our Diversity, Equity and Inclusion Committee with a goal of exploring and closing gaps in outcomes across racial and socioeconomic factors
- Enhance our communications program for more effective and timely engagement of patients and families
- Migrate our health registry to a new, more nimble platform that will enhance continuous improvement, increase efficiencies and enable more accurate data collection to allow providers to better understand and address patient needs

Currently, half the children and youth cared for by pediatric gastroenterologists in the US are at participating ImproveCareNow centers. 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), 91% have satisfactory nutrition, 95% have satisfactory growth and 97% are not taking steroids. We are eager to have you [join us](#) as we work together to pursue our mission *to transform the health, care and costs for all children and adolescents with Crohn's disease and ulcerative colitis (Inflammatory Bowel Disease or IBD) by building a sustainable collaborative chronic care network.*

Thank you for your support,

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