



Dear Friend of ImproveCareNow -

ImproveCareNow (ICN) has had enormous success since it began 15 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 2021 and plans for our continued work to improve health, care, and costs for young people with IBD in 2022 and beyond.

In 2021 ImproveCareNow:

- **Sustained active participation** across our network of [100+ care centers](#) serving nearly 30,000 patients and their families, and with 1,200 clinicians, including 965 pediatric gastroenterologists
- **Completed a successful strategic planning period** with the new Executive Leadership, outlining the following domains for the next three years: Outcomes; Diversity, Equity, and Inclusion or “DEI”; Sustainability; Engagement; Technology
- **Launched [REALITI](#), an innovative research study** that will shift clinical research and drug approval paradigms by collecting real world data about the efficacy of a biologic agent for regulatory approval
- **Launched *Social Factors with Racial Disparities in Pediatric IBD*** (called [SaFR Kids](#)) with 23 participating ICN care centers and over 660 patients enrolled
- **Approved eight new proposals for research**; the ICN Research Committee reports that 43 studies are underway, and another five studies are currently under consideration
- **Recorded [seven new research publications](#)** in medical journals, and one poster presentation
- **Continued important work** supported by 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) **to study 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
- **Reached our goal of sharing IBD resources** by connecting with more than 10,000 patients and families through our [CIRCLE community](#)
- **Continued growing our quality improvement (QI) infrastructure** (called [Pathway to Mastery](#)), entering year three with seven learning labs and a total of 20 care centers advancing to the next pathway
- **Launched the Autoimmune Liver Disease Network for Kids** Learning Lab (called [A-LiNK](#)), which has catalyzed partnerships with pediatric hepatologists from 11 participating ICN care centers
- **Celebrated virtually with our community of improvers** during two [Live Online Community Conferences](#), which brought together a total of 627 registrants, including 182 patients and parents. Of the total presentations, 64% were proposed by our community and 19% included patient and parent speakers



- **Shifted our ICN Community Conference content structure** in Fall 2021 to align and focus our offerings across the five domains of our Strategic Plan, including:
 - *Outcomes*: 15 sessions
 - *DEI*: 3 sessions
 - *Engagement*: 3 sessions
 - *Sustainability*: 1 leadership panel
 - *Technology*: 1 session
 - We also continued to share overall progress of the network and offer role specific collaboration
- **Developed our DEI Committee** with a goal of exploring and closing gaps in outcomes across racial and socioeconomic groups within our network
- **Launched the ICN Hub**, our online collaboration platform to facilitate real time, multidirectional sharing of information, knowledge, and know-how. To date, more than 600 ICN network participants have joined.
- **Migrated our health registry to a new, more robust, and nimble platform** (called *Outcomes*) that will enhance continuous improvement, increase our efficiency, and enable more accurate data collection to allow providers to better understand and address patient needs
- **Integrated use of our Data Quality Scorecard** to drive data integrity at the care center level to ensure accurate, timely, and complete data capture

The ICN community continues to work together through 2022 and beyond, and our journey promises to be full of exciting discovery, improvement, and innovation, as we:

- **Continue to organize and advance work in the five domains of our Strategic Plan**
- **Welcome new members to the ICN Board of Directors**, manifesting a multi-stakeholder configuration that incorporates recommendations from our [2019-2020 Digital Asset Governance project](#)
- **Expand our research program** to continue learning together about pediatric inflammatory bowel disease and its treatment and management
- **Continue to support the [COMBINE](#) study** as it enters its seventh year of data collection. The study is the largest randomized trial ever conducted in pediatric Crohn's disease and results will be published soon
- **Launch an Introduction to Quality Improvement series** to encourage participants to apply the Model for Improvement tools and methodology in QI projects
- **Update our Model Care Guidelines** based on clinical processes and current approaches to care
- **Welcome and onboard surgical representatives across key ICN network committees**
- **Continue enhancing our *Outcomes* registry** to harness ICN data more accurately to drive real time improvement, innovation, and discovery in pediatric IBD
- **Learn best practices to enhance our current consenting process** that enables patient data shared in the *Outcomes* registry to be used for research
- **Enhance our communications program** for more effective and timely engagement of patients and families



IMPROVECARENOW™

improving lives through collaborative medicine

- **Continue to support the development of and share IBD resources** co-produced by the ICN community, including resources created *for patients by patients* through work led by our Patient Advisory Council
- **Support our Parent Working Group as they redesign, rename, and restructure** their group to better engage parents and caregivers across the community

Currently, half the children and youth cared for by pediatric gastroenterologists in the U.S. are at participating ImproveCareNow centers. **Our goal is to improve outcomes for children and youth with Crohn's disease and ulcerative colitis who are 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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