



Dear Friend of ImproveCareNow –

ImproveCareNow (ICN) has had extraordinary success since it began 19 years ago, [increasing remission rates](#) for thousands of young people with IBD, transforming how pediatric IBD care is provided, enlightening and exciting clinicians and other care providers, and engaging patients and parents in a shared purpose and effort. We are pleased to share our ImproveCareNow **2025 Annual Update**, which includes highlights and achievements from 2025 and plans for our continued work to improve health, care, and costs for young people with IBD in 2026 and beyond.

In 2025 ImproveCareNow continued work on the [FY 2025-2028 Strategic Plan](#), which includes goals in the following domains: Outcomes; Health Equity; Sustainability & Leadership; Engagement & Community Building; Technology; and Research & Innovation. This strategic plan was developed using a new process to gather more comprehensive feedback and participation from every stakeholder group in the network.

Outcomes

- **Reported various centerline shifts in key process measures**, including percent of patient visits in the last 200 days, a direct result of the hard work care center teams have achieved in reliable data entry and improved processes leading to improve outcomes for kids.
- **Added two new depression-screening measures to *Outcomes Registry*** to gather more reliable data on whole-person measures now included in the Model Care Guidelines.
- **Completed and shared the [2024 Data Report](#)** which aims to present a brief summary of patient data captured in the [ICN Outcomes Registry](#) and represents the breadth of knowledge gathered by the network so that new learnings are possible.
- **Led three Learning Labs in our Pathway to Mastery quality improvement framework.** The *Foundations Learning Lab* partnered with new and established care center teams to focus on processes and opportunities to improve patient registration rates and establish multidisciplinary teams to support ICN initiatives. The *Pre-Visit Planning and Population Management Learning Lab* continued work with care centers to standardize and improve Pre-Visit Planning and Population Management processes focusing on the importance and complexity of clinic visits within the model care guidelines and tools to improve care in increasing the number of patients in remission. The *Clinical Standardization / Personalized Care Learning Lab* re-established its partnership with care center teams with three new innovative projects aimed at standardizing care for patients in remission and increasing sustained remission rates.
- **Supported the improvement work of the Autoimmune Liver Disease Network for Kids ([A-LiNK](#)).** Now in its fifth year, A-LiNK has 12 participating centers and counting. Sites continued efforts to standardize and improve data capture via REDCAP registry, leading to an improved understanding of the current state of care for patients with Auto Immune Liver Disease (AILD) and identification of gaps and opportunities to improve both outcomes and Health Related Quality of Life (HRQoL) measures. In collaboration with patients and caregivers, A-LiNK leadership established a 5-year Strategic Plan, with goals focused on Outcomes; Inclusive Access; Leadership, Growth & Sustainability; Engagement & Community Building; Technology; and Research & Innovation. Community members have made progress on finalizing the AILD Model Care Guidelines, to guide a standard approach





to patient care for all pediatric AILD patients. The team is also submitting grants and manuscripts highlighting their learnings and natural history with improved outcomes for patients with AILD.

- **Chartered an intestinal ultrasound in IBD committee and hosted the first iUSCAN Training course** so ImproveCareNow physicians could learn more about using intestinal ultrasound (IUS) for managing IBD. Held after our in-person conference in Orlando, Florida, this course engaged clinicians to take the next step on this innovative path of care. We are developing IUS data collection capabilities in *Outcomes* registry and looking forward to sharing best practices in IUS care across the network.

Health Equity

- **Translated and shared two co-produced resources** - the [Accommodations Highlight](#) and the [Finding a Mental Health Care Provider Guide](#). Additional resources are slated to be translated and shared in 2026.
- **Developed a Social Drivers of Health (SDoH) toolkit** that was shared with care center teams to help implement a consistent and effective SDoH screening process. By identifying and addressing social factors that influence patient outcomes, this toolkit empowers centers to deliver more equitable and targeted care.
- **Published The Social Factors with Racial Disparities in Pediatric IBD study (SaFR Kids)** in the April 2025 issue of [Clinical Gastroenterology and Hepatology](#), which highlights differences in travel time leading to delays in diagnosis for Crohn's disease

Sustainability & Leadership

- **Welcomed new Executive Director Becky Johnson Rescola** to ImproveCareNow. Becky's 15 years of experience at the Crohn's & Colitis Foundation brought new connections and energy to the team and her expertise and vision will help guide the network forward.
- **Sustained active participation** across our network of [100+ care centers](#) and welcomed 3 new centers. ICN serves more than 33,000 patients and their families, with nearly 1,900 healthcare professionals, including 1,180 pediatric gastroenterologists.
- **Initiated a new term of ICN's Board of Directors in July**, and welcomed Ashish Patel, MD to the board, while [continuing their goals](#) to build our network's leadership and financial sustainability.
- **Celebrated ImproveCareNow Care Centers** ranked in the [U.S. News & World Report Best Children's Hospitals of 2025-2026](#) with 9 out of 10 Honor Roll hospitals, and 43 out of 50 best hospitals for Gastroenterology & GI Surgery, belonging to the network.





Engagement & Community Building

- **Partnered with Cincinnati Children's Hospital and the David R. Clare and Margaret C Clare Foundation** to further study the link between patient engagement and improved outcomes. This partnership resulted in the addition of Patient Reported Outcomes in *Outcomes* Registry. Additionally, those measures were implemented for the first time with patients enrolled in the [CLARE study](#).
- **Supported the Patient Advisory Council (PAC)** as they onboarded two new co-chairs and five new leads, progressed and revised their Insurance Toolkit (expected to be published in 2026), and promoted the [imPACt podcast](#), including an episode featuring an interview with Grayson Murphy, a professional runner with IBD.
- **Supported the Parent/Family Advisory Council (PFAC)** as they continued to grow, connecting with 52 new parents/caregivers. The PFAC created and shared The [Caregiver Coping Resource](#) in collaboration with A-LiNK and the Social Workers & Psychologist workgroup. This resource is the culmination of years of co-production and their work was highlighted in [Learning Health Systems](#) in 2026.
- **Exhibited for the first time at Advances in Inflammatory Bowel Disease (AIBD)** and connected with thought leaders and innovators in attendance.

Technology

- **Released the new Medication & Lab forms** to *Outcomes* Registry that increased efficiency of data entry, updated entry options and allows us to add new medications and labs in a matter of a few months. This was a significant and much needed system upgrade to the registry that has long been requested by our network.
- **Released new population management reports** that allow care center teams to gain deeper insight into their patient population, spotting gaps and planning next steps more effectively.

Research & Innovation

- **Launched a Shared Decision Making pilot with ICN care centers** to [study best practices](#) for dissemination and implementation using the [COMBINE study](#) results. This work is funded by The Leona M. and Harry B. Helmsley Charitable Trust.
- **Finalized and submitted a manuscript for 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.
- **Approved 8 new proposals for research; 25 total studies** are currently underway, with another one under consideration.
- **Published 8 new manuscripts in peer-reviewed journals.** As of August 2025, ICN research had been cited 1251 times.





IMPROVECARENOW™

Additionally, ImproveCareNow continues to strengthen learning and connection through a [variety of events](#), webinars, and educational courses throughout the year, including:

- **A successful in-person Fall Community Conference** in Orlando, Florida which energized our community as attendees from 66 care centers gathered to learn from 74 speakers, which included patients, caregivers, researchers, and healthcare professionals sharing rich insights and powerful personal stories.
- **A full slate of virtual opportunities**, such as the *Live Online Community Conference*, topic-focused *Community Wide Webinars*, and *Immersion* for new ICN care center staff.
- **The launch of the fifth cohort of the Introduction to Quality Improvement (IQI) series** which [teaches participants](#) to apply the Model for Improvement tools and methodology in a QI project specific to their center and its needs, while providing a unique leadership training opportunity to our community.
- **Overall, our educational and community programs have reached over 1500 attendees virtually and over 240 in person participants!**

Thank you for being part of this extraordinary community and for helping us improve care for all kids & youth living with IBD.

Becky Johnson Rescola– President & Executive Director for ImproveCareNow

Shehzad Saeed, MD, FAAP, AGAF, NASPGHAN-F – Clinical Director for ImproveCareNow





Our Success



94%
show
satisfactory
GROWTH



82%

are in
REMISSION



98%
are not taking
PREDNISONE

59%
have
**SUSTAINED
REMISSION**
for at least
one year



91%
show
satisfactory
NUTRITION



100
care centers
participating across:
37 states
+ the District of Columbia
+ England
+ Qatar
+ Belgium



1180 pediatric
gastroenterologists
caring for **33,000+**
children with IBD
at care centers that include:
43 of the top **50** pediatric
GI & GI surgery programs
and **9** of the **10** honor roll
children's hospitals



SCAN ME!

Source: centerline data for select QI measures from the ImproveCareNow Outcomes registry

November 2025

Visit improvecarenow.org/purpose-success for the most up to date infographic

