Public Witness Testimony – Fiscal Year 2026 LHHS Appropriations

Submitted by: American Gastroenterological Association and North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

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The American Gastroenterological Association (AGA) and the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) are pleased to submit testimony on the fiscal year (FY) 2026 Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations. We specifically offer testimony on the critical role of the National Institutes of Health (NIH) in digestive disease research.

The AGA is the leading professional society for gastroenterologists and hepatologists, representing members involved in diagnosing, treating, and researching digestive and liver diseases. AGA's vision is a world free of digestive diseases. Federal funding of biomedical research is critical to help us reach this goal.

NASPGHAN represents more than 3,000 pediatric gastroenterologists, pediatric gastroenterology nurses and advanced practice practitioners, and pediatric registered dietitian nutritionists in the United States, Canada, and Mexico and is the only organization singularly dedicated to advocating for children with gastrointestinal, liver and nutrition-related diseases and disorders. NASPGHAN shares the vision of a world free of digestive diseases in children, and sustained federal medical research funding has been—and must remain—critical to achieving this goal.

Federal Investments in the NIH Advance Digestive Disease Research

NIH is pivotal in advancing human health through scientific research. Digestive diseases encompass a wide range of conditions, including gastroesophageal reflux disease (GERD) irritable bowel syndrome, Crohn's disease, ulcerative colitis, obesity, liver disease and gastrointestinal cancers such as colorectal, esophageal, and pancreatic. NIH funding for digestive disease research has provided insights into these conditions' etiology, pathophysiology, and treatment.

Maintaining American dominance in biomedical research requires sustained federal investments. **The AGA and NASPGHAN strongly support the Ad Hoc Group on Medical Research's recommendation to fund the NIH at $51.3 billion in FY 2026, which is the amount necessary to maintain progress and keep pace with medical inflation.**

Medical research supported by the NIH serves as the foundation for nearly every preventive intervention, diagnostic, treatment, and cure in practice today, including those associated with

digestive disease. A cut of 38 percent, as proposed by the current Administration, would have a devastating impact on America's research infrastructure, threaten the future of our nation's best and brightest scientists from pursuing research careers, and cede our economic competitiveness in the life sciences and the industry it creates.

Breakthrough Research in Digestive Diseases

The NIH has funded grants in both basic and translational science that have led to uncovering critical pathways that drive inflammatory bowel disease (IBD) and translating those discoveries into meaningful improvements in patient care. It is estimated 3.1 million Americans have IBD.[1] This condition is often diagnosed in young adults, but pediatric onset is occurring with increasing frequency. IBD, which includes ulcerative colitis and Crohn's disease, has high variability that can impact a patient's productivity and quality of life. When IBD is not effectively managed, serious medical complications can occur.

As examples, an NIH-funded grant in IBD that brought together scientists with expertise in different fields was funded for nearly 30 years and greatly expanded the breadth, depth, and pace of discoveries in IBD. An outgrowth of this research was the ability to define and stratify IBD into distinct subsets, allowing a more targeted approach to developing diagnostics and treatments. NIH-funded research laid the groundwork for precision medicine in these complex diseases that was harnessed by biotechnology companies that have developed novel drugs and diagnostics. Similarly, NIH's transformative investment in ImproveCareNow—a global learning health network of more than 100 care centers and nearly 1,000 pediatric gastroenterologists—has led to dramatic, sustained improvements in remission rates for nearly two-thirds of U.S. children with IBD. With this success, it has become a model for other chronic childhood conditions, benefiting millions of children worldwide. None of this would have been possible without NIH funding.

Another significant milestone in NIH-funded research is the Human Microbiome Project. Launched in 2008, the project aimed to understand the role of the human microbiome in health and disease. NIH funding enabled researchers to map the complex interactions between the gut microbiota and human health, leading to groundbreaking discoveries about how microbial communities influence digestive health.

Companies specializing in microbiome therapies have flourished because of NIH-funded research on the human microbiome. These companies focus on developing probiotics, prebiotics, and other microbial-based treatments aimed at improving digestive health. Similarly, firms dedicated to genetic research have utilized findings from NIH-supported studies to create personalized medicine approaches for digestive diseases.

NIH-funded research also led to the first medication approved by the Food and Drug Administration for eosinophilic gastrointestinal diseases which affect approximately 200,000 patients in the United States. This research was made possible through a NIH grant to the Consortium of Eosinophilic Gastrointestinal Disease Researchers (CEGIR), which is part of the Rare Disease Clinical Research Network. The NIH has funded CEGIR for more than a decade, which includes 18 pediatric and adult clinical centers. Unfortunately, CEGIR's grant renewal application was abruptly dismissed in April due to a technicality. Elimination of NIH funding to

[1] Centers for Disease Control and Prevention; https://www.cdc.gov/inflammatory-bowel-disease/php/facts-stats/index.html Accessed June 1, 2025.

CEGIR would disrupt care[2] to roughly 1,000 patients benefitting from ground-breaking care. Researchers received some good news on June 6, 2025 when the NIH released the Notice of Funding Opportunity for Rare Diseases Clinical Research Consortia for the Rare Diseases Clinical Research Network,[3] which allows for re-submission of CEGIR's grant renewal application. While the opportunity to reapply for this funding is welcome news, this process will likely lead to interruption in the important work of CEGIR. While the focus of this statement is on the importance of FY 2026 NIH funding, disruptions such as this to NIH-funded research require Congress 'attention and intervention.

NIH support has also been instrumental in the advancement of the treatment of liver disease. A recent amazing gene therapy breakthrough led to an infant being rescued with CRISPR-Cas9 technology to cure an inborn error of liver metabolism carbamoyl phosphate synthetase 1 (CPS1) deficiency.[4] This deficiency was previously only amenable to cure through liver transplantation, which came with all the potential complications and morbidities of major invasive surgery and life-long immunosuppression. This advancement would not have been possible without support from the NIH.

Clinical Trials and Treatments

Clinical trials funded by NIH have played a critical role in assessing the efficacy and safety of new treatments for digestive diseases. These trials have led to the approval of various medications and interventions that have improved the quality of life for patients. Examples include biologic therapies for IBD and innovative surgical techniques for gastrointestinal cancers. NIH funding not only advances scientific knowledge but facilitates the translation of research findings into practical applications that improve the lives of patients.

The NIDDK Deserves to be Upheld as a Stand-alone Institute within the NIH

Roughly 60 to 70 million people in the United States are affected by digestive diseases.[5] In 2021, GI health care expenditures totaled $111.8 billion. A GI diagnosis or symptom led to 14.5 million emergency department visits and 2.9 million hospital admissions.[6]

The Administration's budget proposes to consolidate the current 25 institutes and centers to just eight. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) would be consolidated with the National Heart, Lung, and Blood Institute (NHLBI), and the National Institute of Arthritis and Musculoskeletal and Skin Diseases into a new National Institute on

[2] Kim, E. Parents of child with rare disease worry after NIH cuts grant that provides him treatment; Cincinnati Enquirer. May 28, 2025. https://www.cincinnati.com/story/news/2025/05/28/as-nih-pulls-funding-for-rare-disease-research-families-speak-out/83677582007/
[3] https://grants.gov/search-results-detail/358818 Accessed June 6, 2025.
[4] https://www.nih.gov/news-events/news-releases/infant-rare-incurable-disease-first-successfully-receive-personalized-gene-therapy-treatment. Accessed June 9, 2025
[5] Opportunities & Challenges in Digestive Diseases Research: Recommendations of the National Commission on Digestive Diseases, 2009. https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/opportunities-challenges-digestive-diseases-research-recommendations-national-commission
[6] Anne F Peery, Caitlin C Murphy, Chelsea Anderson, Sasha Deutsch-Link, et al. Burden and Cost of Gastrointestinal, Liver, and Pancreatic Diseases in the United States: Update 2024. Gastroenterology 2025; May;168(5):1000-1024; doi: 10.1053/j.gastro.2024.12.029. Epub 2025 Feb 4.

Body Systems funded at $4.31 billion — an amount that reflects almost the entirety of the FY 2025 NHLBI budget alone.

While our organizations appreciate the goals of ensuring the efficient use of federal resources, fundamentally, it is unclear what would be accomplished by consolidating these institutes. We fear consolidating the NIDDK into a new institute would diminish the priority and visibility of digestive diseases research within the NIH. We are also concerned the new institute would offer fewer funding opportunities for digestive diseases research, as it would have to compete with other research areas within the same institute. **The proposed structural reform would likely disrupt existing research programs, networks, research training pathways, and infrastructure that the NIDDK has established and maintained over the years.**

Simply put, **the burden of digestive disease requires more, not fewer, federal resources and deserves to be upheld as separate and independent institute within the NIH.** This preservation is essential to sustain and enhance research on and funding of digestive diseases. **The FY 2026 Labor-HHS-Education spending bill is not the right vehicle for major NIH structural changes. We ask that the authorizing committees hold hearings and engage with the public to review these reorganization ideas.**

Conclusion

Federal funding of the NIH has been instrumental in advancing human health in digestive diseases. **NIH funding is not just about advancing science but transforming lives.** Cutting NIH-funded research, including capping facilities and administrative (indirect) costs at an arbitrary 15 percent, doesn't just slow research – it stalls groundbreaking discoveries that have the potential to change the future of medicine and improve the lives of millions of Americans. **It is critical Congress protect NIH and provide for meaningful investments that will continue to drive innovation, create economic opportunities for Americans, and improve patient lives.**