

The Global Autoimmune Institute (GAI) empowers research at Children's National Hospital to unlock the mysteries of celiac disease. You give voice to kids with this complex condition by enabling our exploration into new and innovative ways to treat it. Your partnership allows us to take a holistic view of celiac disease so children living with it can have brighter futures. We are pleased to share the impact of your generosity.

The Celiac Disease Program at Children's National



Through our partnership, we continue to investigate the gut's link to the brain. Your support of our research database, biorepository and clinic drives our work and enables Dr. Vahe Badalyan, Medical Director of the Celiac Disease Program and the celiac and neurology teams to make significant research progress.

Because of you, we know that a multidisciplinary approach is not only needed, but feasible and sustainable. Our research shows that headaches are the most prevalent neurologic symptom and Attention Deficit Hyperactivity Disorder (ADHD) is the most prevalent neuropsychological symptom of pediatric celiac disease. GAI helped us learn that parents and providers often overlook headaches, and that early identification could speed the process of getting kids the help they need through school accommodation services. Our enhanced preclinic survey strives to provide that flag.

The following aims guided the team through this work:

AIM 1: Identify neurological issues experienced in relation to celiac disease

AIM 2: Evaluate their mechanisms

AIM 3: Develop evidence-based prevention and intervention programs that have lasting benefits for families

Below are findings based on data the team gathered and analyzed through biorepository data, preclinical surveys, questionnaires and more.

Aim 1: Identify neurological issues experienced in relation to celiac disease

The neurologic, neuropsychological and psychological problems that children with celiac disease and their families experience can have a significant impact on their well-being. Our team identified ways to make a difference.

PRECLINIC SCREENING

We identified key findings through screenings in the hopes of flagging potential issues for children as early as possible. To do that, we updated a preclinic survey (our REDCap tools) to include neurological and neuropsychological questions. The new headache-related section uses branching logic to tag patients for referral. We ask patients to describe the duration, position, associated symptoms and time of

day and frequency, among other symptom details. Patients who screen positive for neurological issues are referred to our headache clinic.

Also, we began actively looking through our clinic data to flag any potentially related autoimmune-diseases. This data could prove important for making connections between celiac disease and other conditions.

We remain committed to identifying children who need follow-up or referrals. Our updated preclinical survey will benefit not only our patients; we hope to distribute our survey widely to help gastroenterologists at other pediatric institutions screen patients.

[Mental Health Disorders and Psychosocial Distress in Pediatric Celiac Disease. \[pubmed.ncbi.nlm.nih.gov\]](https://pubmed.ncbi.nlm.nih.gov/)

Using our pre-clinic survey in REDCap, we published an article in the *Journal of Pediatric Gastroenterology and Nutrition* reporting that our clinic population had higher rates of anxiety disorders and ADHD compared to national population rates for children. We emphasized the importance of including mental health screenings in medical care for celiac disease.

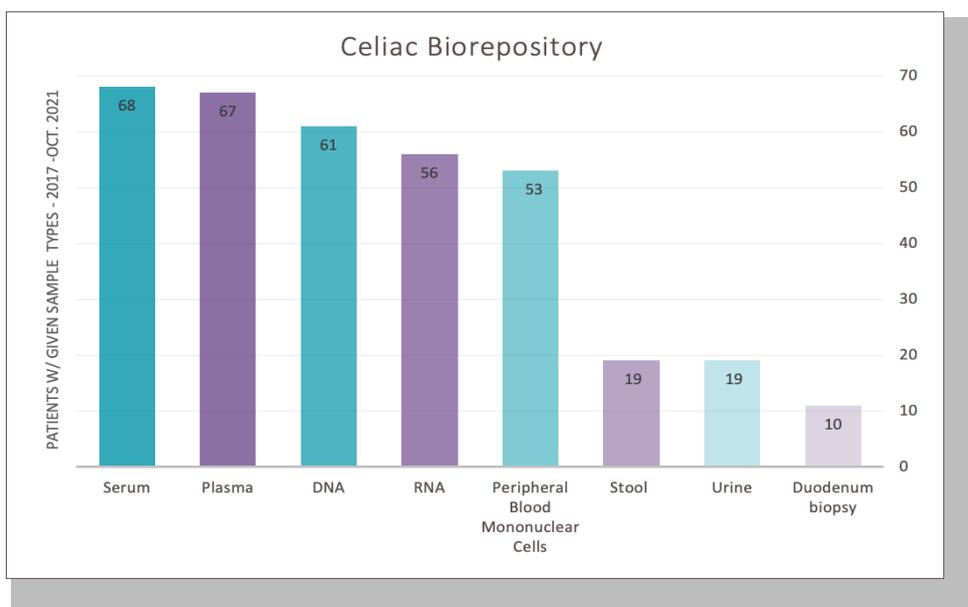
Aim 2: Evaluate their mechanisms

We examined the longitudinal trajectories of patients' illnesses, assessing the risk and protective factors that affect the course of a child's disease.

BIOREPOSITORY SAMPLE COLLECTION

Our biorepository of specimens includes blood, stool and urine in patients with celiac disease that provide key data points and can inform future treatment strategies. As of October 2021, 160 patients participated in the research. We collected RNA samples from 56 patients; peripheral blood mononuclear cells samples from 53 patients; serum samples from 68 patients; plasma samples from 67 patients; and 10 duodenum samples. We also collected stool and urine longitudinally from a subset of 19 patients.

This data is a potential starting point for new research utilizing artificial intelligence to look for pattern recognition across biopsies of patients with celiac disease and co-existing autoimmune diseases.



Aim 3: Develop evidence-based prevention and intervention programs that have lasting benefits for families

We consistently work to pinpoint interventions that will better serve patients.

CELIAC DISEASE STUDY

The team is drafting a paper for publication about research findings from the Global Autoimmune Institute's partnership with Children's National highlighting potential neurological links to pediatric celiac disease using data from 160 patients. The study looks at the connection between neurology, diet and celiac disease. As a multidisciplinary clinic, we have a unique take on this issue. We plan to publish in neurology and/or gastrointestinal journals this winter.

QUALITY OF LIFE SURVEY

Team psychologist Dr. Shayna Coburn is finalizing an important survey that assesses quality of life for children of all ages with celiac disease. This Quality-of-Life study looks at the burden a strict gluten-free diet can have on kids.

The survey was developed through interviews with children and their parents. This work, pending final data analysis, examined how celiac disease affects a child and their management of it. In the early development phases, five children, five parents and eight expert clinicians gave interviews and later feedback related to the survey questions.

The final validation phase included answers from 100 kids, ages 8 to 18, and 100 parents of newborns up through 18-year-olds regarding quality of life in areas such as daily activities, physical health and social and emotional well-being. Children and parents did not necessarily belong to the same family. Participants were drawn from celiac clinic populations at Children's National and Children's Hospital Colorado. Themes that arose included challenges at school, medical treatment experiences and the emotional impact of the COVID-19 pandemic.

We plan to make the survey widely available for clinical and research purposes to help identify at-risk families and recommend interventions for them. It could have broader applications beyond celiac disease for children who require other medically necessary diets.

Questions and responses about the COVID-19 pandemic spurred an additional study that examines the combined impact of the pandemic and celiac disease. The manuscript, written by Dr. Coburn, is under peer review. Findings include that the circumstances of being at home led to better control over food, but also to stressors possibly due to less access to certain foods. Another of Dr. Coburn's research manuscripts under review looks at links between ADHD-related symptoms and celiac disease management using data mined from our project with the GAI.

[Psychological Needs and Services in a Pediatric Multidisciplinary Celiac Disease Clinic.](https://pubmed.ncbi.nlm.nih.gov/)
[\[pubmed.ncbi.nlm.nih.gov\]](https://pubmed.ncbi.nlm.nih.gov/)

Our multidisciplinary clinic offers psychological consultations to all patients, which has provided us with the opportunity to understand the psychological needs of our clinic population. We published an article in a special issue on Psychogastroenterology in the *Journal of Clinical Psychology in Medical Settings* reporting that 49% of our patients needed follow-up mental health services. This paper further established the significant psychosocial burden that many families experience and highlighted the importance of continuing to provide psychological services in a multidisciplinary clinic.

BEHAVIORAL COPING SKILLS GROUP:

Thanks to the data and opportunities provided by GAI, team psychologist Dr. Shayna Coburn received a prestigious career development "K" award from the National Institutes of Health to develop the first evidence-based program to support quality of life and gluten-free diet management for teens with celiac disease and their parents. The initial telehealth-based group program was piloted in Spring 2021, and a 5-year study is now underway to refine the program and test it using a randomized controlled trial. To our knowledge, this is the first ever behavioral study on celiac disease funded by the National Institutes of Health.

Celiac Program Highlights

Over the years, we have served families in many ways.



Telehealth - The clinic found enormous success in pivoting to telemedicine, which has enabled us to continue to serve patients during COVID-19. The shift was well-received by families who find it time-saving and convenient.



Multidisciplinary approach - We continue to deepen the clinic's unique approach of treating kids holistically through GI care, nutrition, education and psychology services. Our celiac program cared for 406 patients since its inception in 2017.



Advocacy - The program continues to care for the whole family by providing many other resources, including podcasts, videos and four parent support groups. We supported kids in our communities through 504 services that help them thrive in school. In 2021, 29 celiac patients were placed on 504 education plans.



Partnerships - Our participation in the Celiac Learning Health Network helps us build brighter futures for patients and families living with celiac disease. We are sharing resources and knowledge with the 12 other national hospitals in the network listed below. We aim to utilize our GAI-fueled research, including the biorepository, in other studies being conducted across the country.



Children's National



Where the world comes for answers



Our Heartfelt Appreciation

Children's National is deeply grateful to the Global Autoimmune Institute for its longstanding commitment to children living with autoimmune diseases and for its support for this research project in particular. Your partnership has been critical to uncovering neurological issues often not associated with celiac disease. This work will enable the dissemination of important findings to help providers identify and care for kids with celiac disease who have such symptoms earlier. Thank you for your vision and support to help these children lead healthier lives.