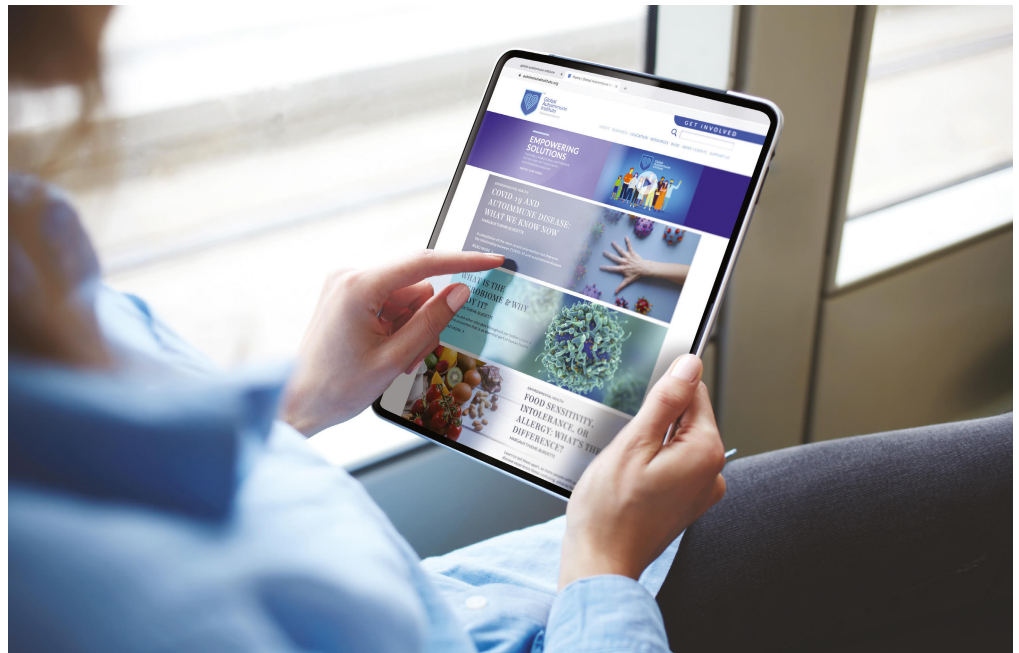


The Global Autoimmune Institute is empowering solutions for auto-immune disease



The Global Autoimmune Institute (GAI) is the product of a non-profit organization founded in the United States in the 1960s. Originally a public health research institute offering postgraduate-level programmes, the GAI mission transitioned in 2014 to directly address the pressing diagnostic and treatment needs of the large population of individuals who live with autoimmune disease. Too often, the 'invisible' yet debilitating aspects of life with autoimmune disease are unrecognized or misunderstood, which has driven GAI's desire to not only help improve the health and well-being of people with an autoimmune disease, but also to raise awareness and promote open communication in the community and between patients and their physicians. GAI strives to ensure complete consideration of unrecognized or mischaracterized symptoms by funding and supporting a multidisciplinary approach to medicine.

GAI set out to improve the landscape in autoimmune disease with a focus on coeliac disease, starting with facilitating the open discussion of the full range of symptoms, to include those considered 'psychological', such as emotional volatility, fatigue, depression, cognitive difficulty, anxiety and pain. We began by collaborating with the dedicated and passionate Coeliac Program of the Department of Gastroenterology at the Children's National Hospital in Washington, D.C., developing educational programming for patients and



The Global Autoimmune Institute (GAI) supports funding of research for better treatment and diagnoses for autoimmune disease.

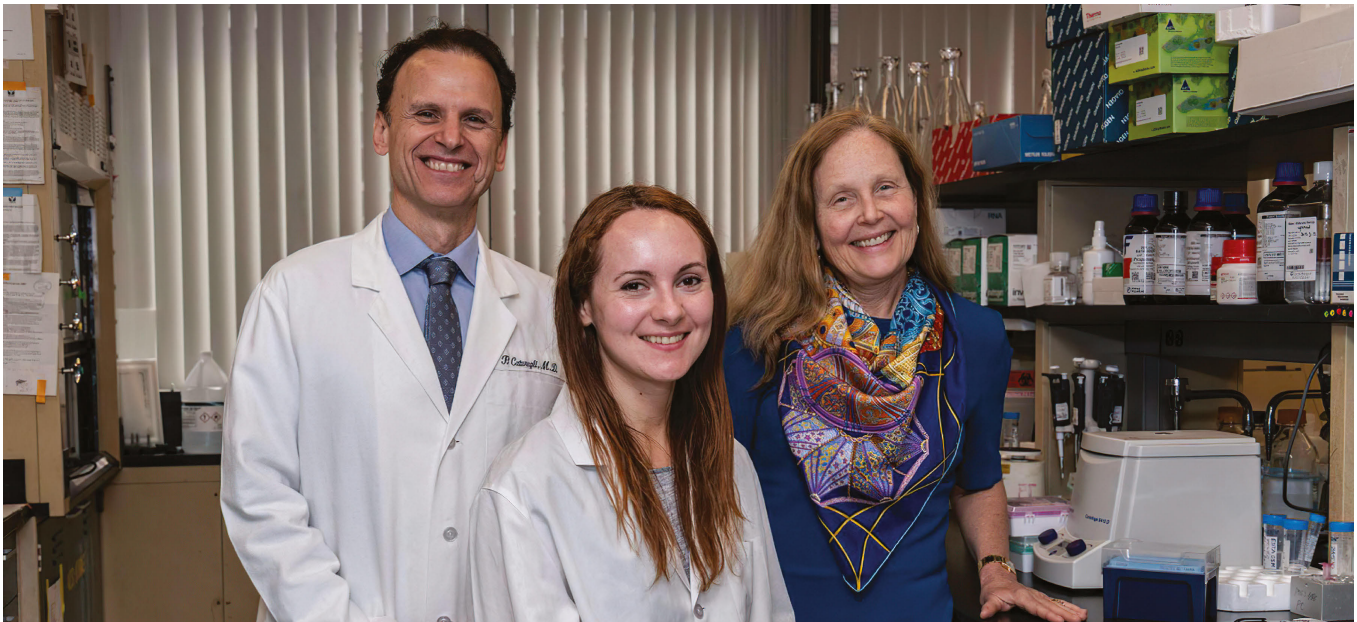
families, bringing together experts from across the US, funding an innovative and effective method of diagnosis and treatment, the Multidisciplinary Clinic for Coeliac Disease, which developed a robust model of comprehensive patient care, cementing Children's National Hospital and GAI's role as a powerful moving force in the advancement of care and scientific investigation in coeliac disease. The effects of these many initiatives continue to grow, impacting the health and happiness of many patients with coeliac disease and their families. Our research has helped to establish the importance of addressing the psychosocial needs of the individual, delivering comprehensive education about diet, nutrition

and the complexities of food ingredients, and the necessity of thorough examination to determine whether the individual has co-existing autoimmune disease(s) or conditions, and/or neurological disorder(s). Our efforts have contributed to the marked increase in knowledge and awareness of physicians internationally.

Coeliac disease is a productive focus for clinicians and researchers. The condition is caused by genetic and environmental factors and affects more than 1% of the world's population. Coeliac disease is underdiagnosed and misunderstood, lifelong, well defined, easily detected and known to co-exist with certain other common autoimmune

diseases with significant frequency. GAI alleviates suffering by helping to dispel the mysteries and shame clouding this disease, providing essential information and guidance, and furthering clinical and scientific studies. We have expanded our reach to fund investigations of other diseases to help unlock the complex process that leads to autoimmune disease, including a new discovery in lupus. GAI has funded research at several institutions, including Johns Hopkins Medicine, Baltimore, Maryland; Washington University Medical Center, St. Louis, Missouri; the Children's National Hospital in Washington, D.C.^{1,2} and The CUNY School of Medicine, New York³.

Viral pathogens such as the Epstein-Barr virus (EBV)



Left to right: Patrizio Caturegli, M.D., M.P.H., director of The Autoimmune Research Center, Johns Hopkins Medicine; Paulina Chalan, PhD, autoimmune research fellow, Division of Immunology, Johns Hopkins Medicine; Sandra Boek Werness, executive director, Global Autoimmune Institute.

have long been associated with autoimmune diseases such as systemic lupus erythematosus (SLE). One mechanism by which EBV has been linked to SLE is molecular mimicry. Research shows that some antibodies to Epstein-Barr nuclear antigen 1 (EBNA-1), an EBV protein, cross-react with double-stranded DNA (dsDNA). A study funded by GAI demonstrates that these anti-EBNA-1/dsDNA antibodies have pathogenic potential and can deposit in the kidney where they can induce proteinuria and can elicit histopathologic changes consistent with glomerulonephritis. These results highlight the significance of antibodies that cross-react with a viral protein in the aetiology of lupus nephritis³.

POTENTIAL RISK FACTORS

Autoimmune disease research is a rapidly evolving area in science and medicine, yet many questions remain. Autoimmune diseases are characterized by inappropriate activation of the immune system against the patient's own tissues, resulting in a wide spectrum of possible symptoms and

severity. Autoimmune disease is believed to be caused by genetic predisposition and environmental factors. Potential environmental triggers include viral or bacterial infections, vitamin D status, or exposure to toxic chemicals in the environment. There are many important theories of causation, supported by thorough investigation. However, there is much to uncover.

We do not know enough about how genetic differences, including gender, may or may not factor in autoimmune disease and why symptoms are so variable, why some individuals are afflicted and in varying severity and duration, and others are not, and why some recover completely. Why do some individuals experience flareups and what is the cause? What is the interplay of genetic and environmental causes that manifest in autoimmune disease development? Is the incidence of autoimmune disease on the rise overall, and if so, what is the potential cause? Does autoimmune disease affect young people more frequently now than in previous decades, and if so, why?

There seems to be a consensus that 5-8% of the US population is living with autoimmune disease, and the incidence is increasing. There is a growing awareness in the general public and medical community that people often have more than one autoimmune disease. Science is just beginning to explore the co-existence of combinations of autoimmune diseases.

RESEARCH ADVANCES

This is an exciting time in science. Attention has turned to the composition and function of the microbiome and how it influences the immune system. Scientists are exploring how the microbiome is influenced by, for example, circadian rhythms, the food we eat, the medicines we take, our cultural practices and genetics. The microbiome may be pivotal in the development and/or the cure of autoimmune disease, thus it is crucial to uncover whether autoimmune disease originates in the gut, and if so, how?

Nutrition and lifestyle changes can help some people with autoimmune diseases, but we do not know enough about who, how, why, or in what

variations and combinations. We do know the effects of certain foods, such as simple carbohydrates, in relation to diabetes, and of medicines, such as antibiotics. Many individuals with autoimmune diseases are trying supplements and diets to improve their health. What has worked for them, and why? We need systematic reliable tools to track and evaluate interventions.

These and many other questions remain to be answered. Intricate methodologies and analytical systems are needed to connect existing research to create frameworks allowing us to grasp the autoimmune disease complexity in a new era of research.

Autoimmune disease research is a complex multidisciplinary practice of medicine. Increased awareness of autoimmune diseases within medical subspecialties is necessary to ensure the highest standards and quality of care. With the goal of helping to improve awareness and diagnosis, GAI began its work with coeliac disease in 2014. Coeliac disease is a common autoimmune disease and is better understood and easier to diagnose than many others, but



Linda Spatz (fourth from the left), Ph.D., and colleagues in their lab, CUNY School of Medicine at The City College of New York researching antibodies to an Epstein-Barr virus protein.

a few years ago it was virtually unknown or unrecognized by many physicians, including paediatricians. Many of its symptoms can be misunderstood, discounted and dismissed to the detriment of patients. A desperate need exists for a better understanding of this disease in the clinical setting, including the detection of other autoimmune diseases and neurological disorders that can co-exist with coeliac disease.

In addition to developing and instituting its excellent patient care model, the GAI-funded Multidisciplinary Clinic for Celiac Disease conducted a study on the incidence of headaches among patients. This was done because of the known high incidence of headaches in coeliac patients. In addition, patients were screened for a range of neurological disorders. Patient bio-samples were taken during the first two years and preserved for future research. Psychological testing is administered to determine need for psychological support services, and a survey is given to measure quality of life in patients following a gluten-free diet.

The clinic developed a plan to deliver telemedicine to far-

ranging, underserved populations allowing a seamless transition to overall reliance on telehealth during the COVID-19 pandemic. The staff provide training, education and support in the community to nurses, physicians, patients and their families.

PATIENT GUIDANCE AND LONG-TERM SUPPORT

GAI supports the autoimmune disease community through its website, autoimmuneinstitute.org, which provides:

- continually updated information about many autoimmune diseases and conditions;
- comprehensive and timely articles to address the most pressing and significant topics;
- educational programming including webcasts and over 70 podcasts;
- lists of supportive websites, organizations and medical institutions;
- books, apps and other resources reviewed by the GAI team;
- an essential, uniquely tailored guide for individuals in their search for solutions as they navigate the medical system to seek ways to improve their

health and relationships, with useful tools to assist them.

We bridge the gap between science, medicine and the autoimmune disease community to create understanding and awareness of important scientific developments and to dispel confusion and clarify common terms, labels and concepts. GAI provides valuable answers to pressing concerns for our community about COVID-19, quickly bringing newly published studies, evidence and facts to their attention. GAI actively engages with the autoimmune disease community to understand and address their needs and concerns on several social media platforms.

Moving forward, GAI plans to stay abreast in key areas of science to fund scientific investigations and encourage researchers to explore the many important issues that remain.

GAI will provide essential information, tools, resources, education, inspiration and hope to those with autoimmune disease. We will continue to promote and support the multidisciplinary practice of medicine as it relates to autoimmune disease.

GAI supports the scientific and medical communities as they turn their focus to these serious and complex diseases. We will continue to raise awareness and serve as a force for bringing the global community together to solve the puzzle that will one day lead to a cure for autoimmune disease.

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Global Autoimmune Institute Empowering Solutions



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The Global Autoimmune Institute funds research to further scientific discovery and clinical efforts to improve diagnosis and understanding of autoimmune disease. We are deeply committed to helping those whose lives are affected by autoimmune disease.

Funding for 2020 included the following institutions: Johns Hopkins Medicine; CUNY School of Medicine at The City College of New York, Washington University School of Medicine in St. Louis; and the Children's National Hospital in Washington, D.C.

We approach autoimmune disease from many angles to assist our community in its search for improved quality of life; see autoimmuneinstitute.org for current articles, educational resources and unique tools.

