

Giving Hope

for a **BRIGHTER** future



2023 Impact Report

Dear Friends,

I am pleased to share our 2023 Impact Report, a testament to the progress the Autoimmune Association has made in advancing our mission and creating hope for the autoimmune community. I am immensely proud of all we have achieved together. We are making a lasting difference in the lives of those we serve.

Within these pages, you'll read about the work we've done over the last year in the areas of advocacy, awareness, education, and research. Through our advocacy work, we fight for equitable and sustainable access to care. We are active at the federal and state levels, pushing for policies that put patients first. Through public awareness campaigns, we have increased visibility and understanding about autoimmune diseases and mobilized a network of supporters to take action and drive positive change. We have relentlessly worked to educate and empower patients with the knowledge they need to navigate their autoimmune journey, from working with their healthcare team to managing symptoms and everything in between. Through collaborative efforts with leading research experts and institutions, we continue to push the boundaries of knowledge, seeking innovative treatments and scientific advancements that hold the promise of a world without autoimmune disease.

Thank you for being an integral part of our journey. Your support, whether as a donor, sponsor, partner, or volunteer, has been the driving force behind our success. Together, we have forged meaningful connections, fostered positive change, and laid the foundation for a brighter future for the autoimmune community.



With gratitude,

A stylized, handwritten signature of Molly Murray in a vibrant pink color. The script is fluid and elegant, with the first letters of 'Molly' and 'Murray' being capitalized and prominent.

Molly Murray
President and CEO

BY THE NUMBERS

IN 2023...



137K+

people followed the Autoimmune Association on social media

32,300+

people were in our online support community at inspire.com



13K+

people received "Research Roundup," our monthly newsletter with research and clinical trial information

64K+

people received "Autoimmune News," our general monthly newsletter



500+

people benefited from our resources and services by calling in or emailing for support

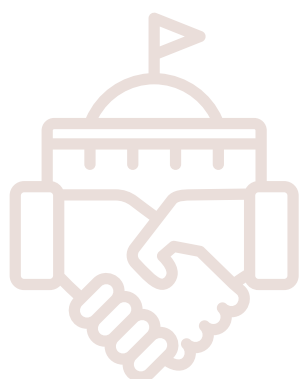
92

Autoimmune Expressions were submitted



2,500+

people registered for the 2023 Autoimmune Community Summit



50+

people participated in the 2023 Virtual Legislative Fly-In day

72

meetings were held with federal legislators' offices at the 2023 Virtual Legislative Fly-In day

12K+

patients were registered on our ARNet patient registry

ADVOCACY

SPEARHEADING COLLABORATION WITH NIH'S OFFICE OF AUTOIMMUNE DISEASE RESEARCH

In March, we led the first National Coalition of Autoimmune Patient Groups (NCAPG) Legislative Virtual Fly-In. With more than 50 advocates representing 17 states and a variety of diseases, we made great strides in increasing the visibility of the autoimmune patient community among legislators and staff. The fly-in addressed issues important to the community, including support for the newly created National Institutes of Health (NIH) Office of Autoimmune Disease Research (OADR) within the Office of Research of Women's Health (ORWH).

OADR is working with NIH leadership, other Institutes and Centers (ICs), researchers, clinicians, patient advocacy groups, and the public to ensure that plans for the new office synergize with other NIH efforts, observe congressional directives, address research gaps, harmonize research, and serve patients with autoimmune disorders. The new office's mission is: To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

We're uniting leaders from various autoimmune advocacy groups to bring expertise and resources to support the newly formed office as it establishes an operating plan, defines goals, and begins undertaking the tasks that Congress has established for the office.



TAKING ACTION TO IMPROVE PATIENT ACCESS TO CARE

We continue to urge Congress and the Administration to prioritize policy reforms that directly address the rising patient burden, access challenges, and out-of-pocket expenses.

Policies from insurance companies and pharmacy benefit managers (PBMs) often create barriers that hinder a patient's ability to access necessary medications. We have been working with Congress on various PBM reform packages, including coordinating our grassroots advocate network to support various bills that require PBMs to report on patient costs, utilization methods, and formulary tiers, as well as other bills that impede access to necessary medications or increase burden for patients.



Our National Coalition of Autoimmune Patient Groups hosted Conor Sheehey, Senior Health Policy Advisor on the Minority Staff of the U.S. Senate Committee on Finance, for a discussion on an updated bipartisan package and the committee's work to engage with the Senate Health, Education, Labor and Pensions (HELP) Committee for a fall 2023 release. We also led a grassroots letter-writing campaign to support this legislation.

"I HAVE FOUR AUTOIMMUNE DISEASES
AND I SUSPECT I HAVE A FIFTH. THE
AUTOIMMUNE ASSOCIATION FIGHTS
FOR ALL OF THEM."

Cynthia



FIGHTING FOR PATIENT-FIRST POLICIES IN HEALTH CARE PLANS

Together with Let My Doctors Decide (LMDD), a national patient-provider initiative led by the Autoimmune Association, we continue to raise awareness about unnecessary, costly access barriers that hinder autoimmune patients' access to medication and treatments as prescribed by their provider. We are committed to achieving patient-centered health care coverage to improve health outcomes, lower costs, and protect the patient-provider relationship. We continue to advocate for meaningful reforms and strongly encourage the adoption of principles that address the barriers that prevent patients and their providers from making treatment decisions.

LMDD's national scorecard study found that three out of four health care insurance plans scored a "C" or an "F" for treatment accessibility under their medical benefit for several autoimmune diseases. Results of recent national polling found health care consumers are extremely worried about these restrictions. Seventy-five percent are concerned that prior authorization, for example, can delay or block access to treatment, and 72% said they are worried that these practices can override doctors' recommendations by allowing insurance companies to control treatment decisions. Additional research found that 90% of rheumatology providers said prior authorization decisions were delayed sometimes or most of the time, and nearly half the cases are denied by insurance companies and must go through an appeal process.

THE AUTOIMMUNE ASSOCIATION FORMS NEW 501(C)(4)

As part of an expanded effort to level the playing field for autoimmune patients, the Autoimmune Association has established a new 501(c)(4) organization to allow for direct and public opinion lobbying on legislative and regulatory reforms to improve patient access and affordability.

This organization will play a critical role in convening conversations on patient access issues and will lead the opposition on several insurance companies and PBM utilization management practices. As new access barriers emerge, it is strategically positioned to augment its advocacy success with enhanced public policy and legislative strategies.



CELEBRATING OUR PARTNERS AND ADVOCATES

In March, we hosted a reception in Washington, D.C. for our Autoimmune Partnership Council and friends in the autoimmune patient advocacy community. Monique Gore-Massy was honored with the 2023 Autoimmune Advocacy Leadership Award, given each year to an outstanding autoimmune advocate who through dedication and commitment improves the lives of those affected by autoimmune disease. Monique is a tireless advocate for the autoimmune community. She provided invaluable insight throughout the launch of a series of roundtables bringing together underrepresented patients that have become foundational for the Association.





AWARENESS

RAISING AWARENESS THROUGH ART

In March, we recognized Autoimmune Awareness Month with Autoimmune Expressions, a virtual art gallery featuring drawings, paintings, poetry, essays, videos, and more created by people living with autoimmune disease. For many living with chronic illness, art is a healthy form of self-expression and self-care, as evidenced by the many unique submissions. View the creative expressions in our virtual [Autoimmune Expressions gallery](#). Additionally, we featured a series of videos with autoimmune champions sharing their personal autoimmune stories.

INCREASING PUBLIC AWARENESS THROUGH MEDIA COVERAGE

The Autoimmune Association bylined an op-ed in the *Virginian-Pilot* drawing attention to the “pervasiveness of health care payer practices that delay essential care to Americans with life-altering diseases.”

Another op-ed in *Scientific American* highlighted the rise of autoimmunity worldwide and proposing a comprehensive strategy to address this epidemic.

The Autoimmune Association was featured in *USA Today's* special issue on rare diseases, sharing Nika Beamon's story of living with a mystery disease and receiving countless inaccurate diagnoses for 17 years before being diagnosed with the autoimmune disease IgG4-related sclerosing disease.

Autoimmune Association leaders participated in several radio and podcast interviews throughout the year, and the Autoimmune Association was mentioned in various media stories covering autoimmune issues including diet and nutrition, disease spotlights, legislation, and more.

The Virginian-Pilot

Friday, June 16, 2023

opinion

Opinion: Health insurance too often fails to make the grade

Harry Gewanter & Molly Murray, Guest Columnists

Movies and TV programs showing insurance companies denying care to critically ill patients to save money are thought to be episodic in nature — exceptions rather than the rule. We now know more about the pervasiveness of health care payer practices that delay essential care to Americans with life-altering diseases.

Research shows how our health insurance system often fails the more than 50 million people with autoimmune diseases. A national scorecard examined insurance plans from some of the most recognized companies including AARP, Aetna, Cigna, Elevance Health, Humana and United Health Group. These plans cover more than 100 million people, and this report found that insurers have erected barriers making it

This scorecard comp benefit managers (P autoimmune disease insurer-preferred m specialty tiering whi and prior authorizat treatment.

Three out of four pla their doctors prescri to 17% of exchange authorization decis Rheumatologists no company or PBM ev. It's not just a matter treatments are disea organ systems can b joint replacements, i ability to work. Fortunately, we are Mark Warner is a m accountable. Virgini

SCIENTIFIC AMERICAN

OPINION

DECEMBER 1, 2023 | 4 MIN READ

Autoimmunity Has Reached Epidemic Levels. We Need Urgent Action to Address It

Environment and lifestyle changes have increased the prevalence of autoimmune diseases. If we want to address this epidemic, let's start acting like it

BY OLIVIA CASEY & FREDERICK W. MILLER

At some point in your life, you could have about a one in five chance of developing an autoimmune disease. The odds are greater if you are a woman, you have a genetic predisposition to autoimmunity, or you are exposed to certain pollutants. These diseases include more than 100 lifelong and costly illnesses such as type 1 diabetes, rheumatoid arthritis, lupus and multiple sclerosis. They are often difficult to diagnose and currently impossible to cure.

The effects of autoimmune disease are devastating. As a person's own immune system attacks their body instead of microbes or cancerous cells, they can experience chronic fatigue, chronic pain, drug dependency, depression and social isolation. These symptoms annihilate mental health, wreck promising careers, destroy lives and, often, ruin families. For too many, these illnesses result in early death. As a patient advocate and a physician researcher, we have seen people search for decades to identify the source of their illness, and continue to suffer after receiving a diagnosis that leaves them with few effective treatments.

Autoimmunity is an epidemic. To keep it from destroying so many lives, we urgently need to understand these diseases better and find more effective ways

FORGING CONNECTIONS AND PARTNERSHIPS

Throughout the year, we connected with patient advocacy groups, the medical and research communities, and industry organizations. Through these collaborations, we've fostered an idea exchange and continued to bring together a strong community.

In April, we attended the Lupus and Allied Diseases Association, Inc.'s "Enhancing Lives by Empowering the Lupus Community" Education Symposium & Luncheon. There, we met with lupus patients and advocates and shared our resources and materials.

In May, we attended Women 4 Wellness, an event focused on increasing health awareness and healthy behaviors among women of the Flathead Indian Reservation and Lake County, Montana. This was an incredible opportunity to connect with their patient and provider community, and we are planning a roundtable to dig deeper into the unique needs of autoimmune patients, care partners, and providers in this community.

In September, we attended the Coalition of State Rheumatology Organizations (CSRO) State Society Advocacy Conference and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition Outreach and Education Meeting.

In October, we continued to exchange best advocacy practices and tools and connected with fellow patient groups at the National Organization for Rare Disorders (NORD) Breakthrough Summit and the BIO Patient & Health Advocacy Summit.

In November, we engaged with the rheumatology community and heard about the latest developments in treating rheumatic autoimmune diseases at ACR Convergence 2023, where we were invited to participate in the movement to study and understand the role of climate change on autoimmune disease.



EDUCATION

PROVIDING CRITICAL SUPPORT FOR UNDER-RESOURCED COMMUNITIES

In recent roundtable discussions held with people living with autoimmune disease from unique demographics, we learned that the need for better mental health resources and support systems is a critical concern. In response to this valuable feedback, we developed a Pilot Support Group program. Our first pilot program began with 15 remarkable women of color. In these virtual group sessions, they shared their symptoms, coping strategies, and crisis management techniques. These sessions offered patients a platform to discuss their challenges, share their successes, and contribute to the growth of future support groups.



ENGAGING WITH PATIENTS IN RURAL AREAS

In 2023, we continued holding roundtable discussions with unique demographic groups to better understand their experiences throughout the diagnostic process. During a roundtable discussion with patients who live in rural areas, we learned that they face unique challenges not only in obtaining a diagnosis, but also managing their disease and communicating with friends and family the severity of their illness. Patients shared their obstacles in simply identifying a provider capable of providing care; in fact, in some areas, local hospital closures are creating a void in access to care as patients need to travel even greater distances for specialty treatment. Additionally, participants strongly indicated a need for mental health support services. With the insight gained from this and other roundtables, we plan to create and offer much-needed patient education and support resources.

"THE AUTOIMMUNE ASSOCIATION HAS BEEN LIKE A GUIDING LIGHT. I'VE FINALLY FOUND SUPPORT AND A COMMUNITY THAT UNDERSTANDS AND EMPOWERS ME TO NAVIGATE LIFE WITH AUTOIMMUNE DISEASES."

Sarah

RESEARCH

SUPPORTING SCIENCE & RESEARCH

We participated in the Annual Meeting of the Federation of Clinical Immunology Societies (FOCIS), including co-sponsoring a course in basic immunology and sponsoring a networking event that featured a juried poster session showcasing breakthroughs in immunological research. Additionally, we awarded travel grants to two early-career investigators to attend FOCIS. In November, we supported the Cell Therapy for Autoimmune Disease Summit to help advance pre-clinical, translational, and clinical applications of cell-based therapies.



SHARING RESEARCH AND CLINICAL TRIAL NEWS

Our “Autoimmune Research Roundup” newsletter continued to educate more than 11,000 community members about advancements in autoimmune disease research. We’ve shared news articles and educational tools to help people better understand the clinical trial participation process.

We’ve worked with more than a dozen health industry leaders to share information about more than 80 open enrollment research studies and clinical trials for diseases such as: Addison’s disease, alopecia areata, chronic fatigue syndrome, dermatomyositis, eosinophilic granulomatosis polyangiitis, fibromyalgia, Goodpasture’s syndrome, granulomatosis with polyangiitis/Wegener’s granulomatosis, Graves’ disease, hypereosinophilic syndrome, IBD, IgG4-RD, myasthenia gravis, primary progressive MS, psoriasis, psoriatic arthritis, pyoderma gangrenosum, relapsing remitting MS, rheumatoid arthritis, sarcoidosis, scleroderma, Sjögren’s, thyroid eye disease (TED), warm autoimmune hemolytic anemia, and many more.



Looking Ahead

We celebrate a year of incredible accomplishments and meaningful impact in 2023. In 2024, we will carry this passion and momentum forward as we continue serving autoimmune patients, promoting research, advocating for access to healthcare, and fostering collaboration to identify and explore the common threads that link autoimmune diseases.

We invite you to join us on our mission: To lead the fight against autoimmune disease by advocating and collaborating to improve healthcare, advance research, and empower the community through every step of the journey.

Your partnership and support fuels our determination, and together, we will make an even greater impact in creating positive change.

Thank you for being an integral part of our journey.