



Autoimmune Registry

A hub for **research, statistics, and data** on all
autoimmune diseases

2023 ANNUAL REPORT

USING DATA TO REDUCE TIME TO **DIAGNOSIS**, TO DISCOVER NEW
TREATMENTS, AND IMPROVE **QUALITY OF LIFE**



www.autoimmuneregistry.org



GROWTH

2022-2023

Registry increased from 3,700
to over 4,000 registrants



TARGET

2023-2024

Aim to reach 10,000
registrants by the end of 2024



CITATION

August 2023

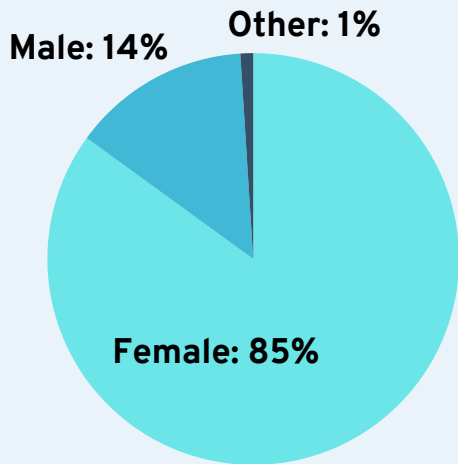
ARI wrote a blog post on
autoinflammatory diseases for
Global Genes

Research Recruitment

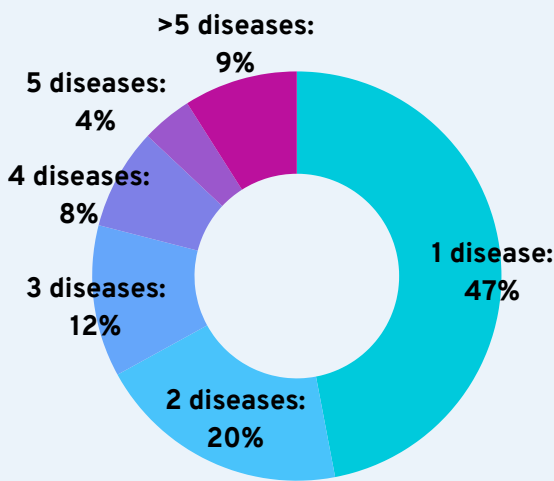
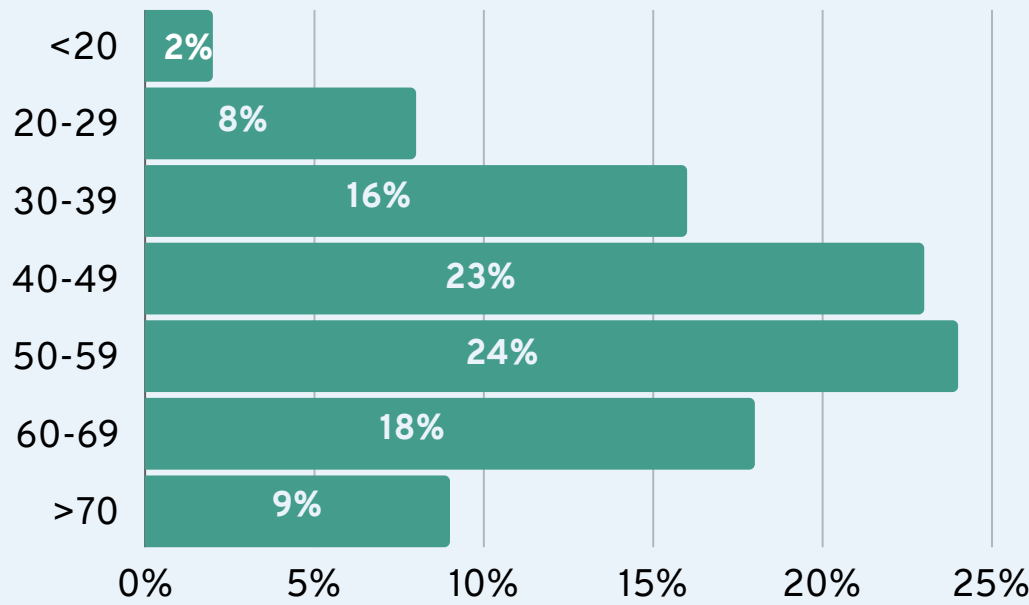
- Accomplished*** → **Recruited 8 registrants with warm autoimmune hemolytic anemia** to participate in a phone or virtual interview. ARI promoted the study on all social media pages and helped identify eligible participants. ARI also received two contracts with two pharmaceutical companies to help recruit for their clinical trials, one for warm autoimmune hemolytic anemia and the other for dermatomyositis. Although we weren't able to enroll any participants in these two trials, these two recruitments were a great learning experience for future recruitment efforts.
- Participated*** → **Sent representatives to national events** including PCORI, Global Genes, and Milken's Future of Health to network and raise awareness on autoimmune diseases. ARI also organized an event that complemented the Global Genes Summit which brought together autoimmune-focused patient advocacy groups.
- Collaborated*** → **Continued to expand our Autoimmune Registry Network** by reaching out to individual disease advocacy and research groups to collaborate with our registry. We have 5 new members in our network including Male Lupus Warriors, Brain Inflammation Collaborative, Encephalitis411, and more.
- Initiated*** → **Initiated discussions with several medical centers** to set up recruitment pipelines to assist with the placement of participants in clinical trials. We are currently working on creating a network with various academic medical centers to make recruitment efforts easier.

Enrollment

ARI has increased its global enrollment from 3,700 to over 4,000, with the majority of registrants located in the U.S. We continue to have a significantly greater number of women compared to men, 85% female and 14% male.



Below is a breakdown of the registrants by age:



Compared to the data last year on comorbidity, the number of comorbidities has stayed relatively the same. We hope to receive more data in hopes of forecasting likely outcomes and comorbid conditions for autoimmune disease patients.

For 2023, the top 10 diseases in our registry with strong levels of evidence for autoimmunity are listed on the right. As in 2022, our most common autoimmune disease continues to be Autoimmune thyroiditis, followed by Rheumatoid arthritis, and Sjogren’s syndrome.

Rank	Disease	Percent
1	Autoimmune thyroiditis	15%
2	Rheumatoid arthritis	12%
3	Sjogren's syndrome	11%
4	Mixed connective tissue disease	8%
5	Systemic Lupus Erythematosus	7%
6	Undifferentiated connective tissue disease	7%
7	Psoriasis	5%
8	Celiac disease	5%
9	Autoimmune Gastritis	4%
10	Ulcerative colitis	4%

Reach and Expansion



51K

**WEBSITE
VISITORS**



93K

PAGE VIEWS



74,478

**SOCIAL MEDIA
REACH**

We have been using Facebook ads and volunteers to increase our social media presence. In addition, we have been sending our weekly newsletters, increasing engagement with our existing registrants to make videos through a collaboration with Soapboxx, and encouraging them to refer friends and family to our registry. We hope to continue to increase our numbers in 2024.

Year-end Highlights

Prevalence Paper

Work on the prevalence paper was delayed because one reviewer suggested that getting data from multiple sites would provide more compelling support for the results. In addition to the University of Southern California, we have collaborated with Mass General Brigham and the University of Florida. We have completed our final draft and we are submitting to publications at this time.

Welcoming Reggie Barnes to the Team

Reggie Barnes joined ARI as a volunteer in late 2022. By early 2023, he demonstrated his capabilities in relationship-building. He has engaged with dozens of disease-specific patient groups this year, building our Autoimmune Registry Network to over 12 organizations. In June, Reggie accepted our invitation to join our Board. Reggie has represented ARI at numerous events this past year, including as an Advisory Board member at the Partnership for Quality Measurement, a non-profit that advises Medicare on quality health measures.

Patient Centered Outcomes Research Institute (PCORI)

Ingrid He was invited to serve on PCORI's Advisory Panel on Clinical Trials this year. Ingrid has been responsible for ARI's clinical trial recruitment activities and has handled our relationships with the pharmaceutical companies and market research organizations that sponsor these studies. The 3-year appointment gives autoimmune patients a voice at this leading research organization.

FINANCIAL REPORT

Financial Report	2023	2022	2021	2020
Revenue				
Donations	20,046	8,379	13,669	5,942
Program Activities	53,070	5,000	5,100	-
Total Revenue	73,116	13,379	18,769	5,942
Expenses				
Salaries & Related Expenses	18,000	1,925	8,089	2,617
Administrative Expenses	11,009	8,268	4,848	2,214
Marketing	16,350	12,033	3,862	175
Total Expenses	45,359	22,226	16,799	5,007
Change in Net Assets	27,757	-8,847	1,970	935

Donations

ARI received a little over \$20,000 in donations, our biggest donor being Goldman Sachs, which donated \$10,000. Our second biggest donation was from a Facebook fundraiser organized by Mike Calabrese who helped raise \$5,000 to honor his sister who passed away from her autoimmune disease.

Program Activities

Ingrid He negotiated our first 2 contracts to recruit patients for clinical trials of new treatments, one for warm autoimmune hemolytic anemia and the other for dermatomyositis. These two recruitments allowed ARI to pass the \$50,000 threshold.

Expenses

The increased revenues allowed ARI to start compensating key members of our team in 2023. While compensation remains very low, the goal is to lay the groundwork for ARI to hire a professional management team.

Thank you!

We extend a heartfelt “THANK YOU!” to our generous donors, registrants, volunteers, Scientific Advisors, and Board members. Without your support, our registry would not be where it is today.