



# Autoimmune Registry

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

# 2022 Annual Report

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Using data to reduce time to **diagnosis**, discover  
new **treatments**, and improve **quality of life**

[www.autoimmuneregistry.org](http://www.autoimmuneregistry.org)





## Growth

2021-2022  
Registry increased from 3,100 to  
over **3,700** registrants



## Target

2022-2023  
Aim to reach **10,000** registrants  
by the end of 2023



## Citation

April 2022  
ARI's Disease List and  
classification was **cited in the  
National Academy of Sciences**

## Research Recruitment

- Accomplished* ➤ **Successfully placed 15 lupus patients** in a 2-month trial on symptom management. ARI helped the researchers identify eligible participants and provided support until 15 participants successfully enrolled in the trial.
- Participated* ➤ **Sent representatives, sponsored patients, and presented** at a number of Global Genes' events for rare diseases. ARI represented and engaged with patients with rare autoimmune diseases, of which there are more than 70 different types. ARI also presented its recruitment efforts during a Global Genes' Lunch & Learn session.
- Collaborated* ➤ **Set up an Autoimmune Registry Network** and reached out to individual disease advocacy and research groups to collaborate with our registry. These groups include the Pernicious Anaemia Society in the UK, MyPATH's StoryBooth research program, and the IndoUSRare Patients Alliance.
- Initiated* ➤ **Initiated discussions with a number of medical centers** to set up recruitment pipelines in order to assist with the placement of participants in clinical trials.

## People

### Director of Research

Ingrid He, Esq. joined ARI this year as its Director of Research. Ingrid has the autoimmune disease Sjogren's and was building a symptom-tracking app for the condition when she connected with ARI. As the Director of Research, she has been instrumental in setting up ARI's clinical trial recruitment program. With her 10 years of experience practicing law, she is familiar with negotiating contracts and addressing privacy and security concerns from sponsors. With Ingrid's help, we are preparing our largest and most promising clinical trial with a global pharmaceutical company.

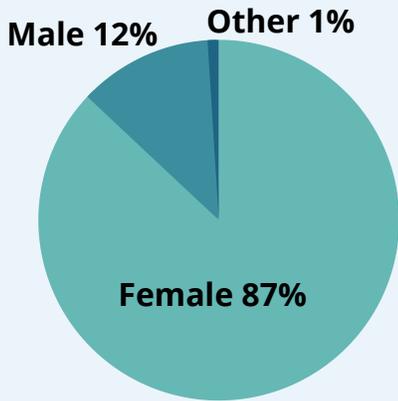


### Patient Navigators

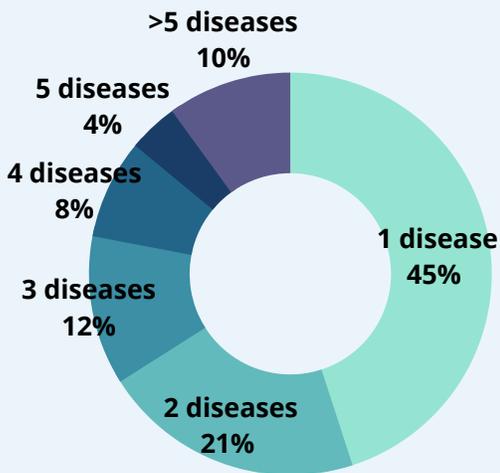
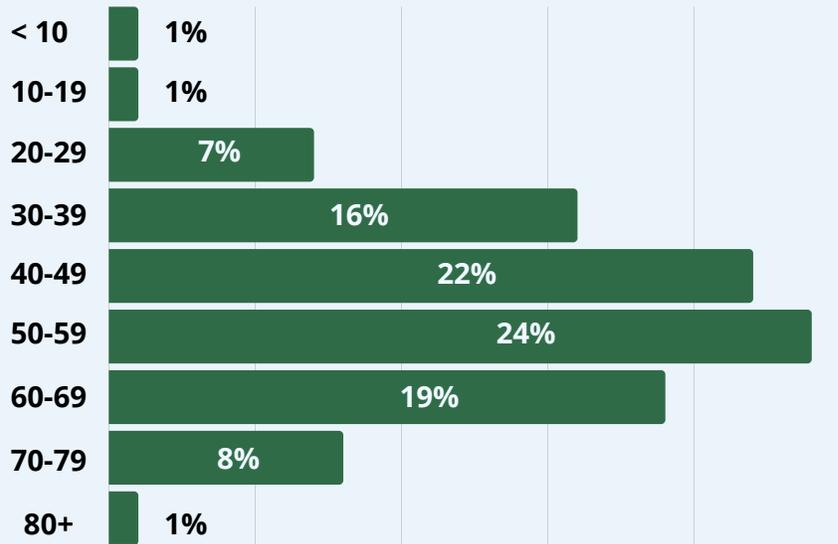
We have begun training registrants with autoimmune diseases to serve as Patient Navigators during clinical trials. Our goal is to provide patient-to-patient support during the trial process in order to increase enrollment and retention of participants. This will aid researchers in completing clinical trials, allowing new treatments to enter the market for autoimmune disease patients.

# Enrollment

ARI has increased its global enrollment from 3,100 to over 3,700, with the majority of registrants located in the US. We continue to have a significantly greater number of women compared to men, 87% female and 12% male.



Below is a breakdown of the registrants by age:



We continue to see significant comorbidity among patients with autoimmune diseases. As in the past, the majority of our registrants have two or more autoimmune diseases. The percentage of patients with two or more autoimmune diseases increased from 52% in 2021 to 55% in 2022.

We expect the number of comorbidities to increase over time as many autoimmune diseases are underdiagnosed or misdiagnosed and comorbid conditions can develop over time. With enough data, we can one day forecast likely outcomes and comorbid conditions for autoimmune disease patients.

For 2022, the top 10 diseases in our registry with strong level of evidence for autoimmunity are listed on the right. Our most common autoimmune disease is autoimmune thyroiditis (Hashimoto's disease), followed by rheumatoid arthritis, and Sjogren's.

Rank	Disease	Percent
1	Autoimmune thyroiditis	16%
2	Rheumatoid arthritis	12%
3	Sjogren's disease	12%
4	Mixed connective tissue disease	9%
5	Systemic lupus erythematosus	8%
6	Psoriasis	6%
7	Autoimmune gastritis	5%
8	Celiac disease	5%
9	Ulcerative colitis	5%
10	Antiphospholipid syndrome	4%

## Reach and Expansion



54K

WEBSITE  
VISITORS



158K

PAGE VIEWS



20,341

SOCIAL MEDIA  
REACH

We have been using third-party vendors and volunteers to increase our social media presence. In addition, we have been sending out weekly newsletters, increasing engagement with our existing registrants and encouraging them to refer friends and family to our registry.

## Year-end Highlights



### *Prevalence Paper*

The prevalence of autoimmune diseases as a class of disease was one of the first questions ARI sought to answer. In April, the “Assessment of NIH Research on Autoimmune Diseases” was released by the [National Academy of Sciences](#), citing ARI’s statistics and list of diseases.

Recognizing the importance of accurate epidemiological data, we collaborated this past year with the University of Southern California to assess the prevalence of autoimmune diseases using a novel algorithmic approach. The final draft of the paper is being prepared for publication early next year. Thank you to everyone on our Scientific Advisory Board for your input and support.

### *All of Us Spotlight*

In June, the NIH’s *All of Us* program [put the spotlight](#) on ARI, publishing a profile on our work using the *All of Us* database (with 500,000 participants) to report statistics on autoimmune diseases to the public. We are honored to be part of this program and believe our publication of statistics on these diseases can help those with any autoimmune disease.

### *NIH Genetic and Rare Diseases Collaboration*

The NIH Genetic and Rare Diseases Information Center (GARD) is a source of information for patients with rare diseases, almost 100 of which are autoimmune. We have established a collaboration with GARD, and ARI will soon be listed as a resource for patients. In addition, GARD anticipates referencing disease prevalence data published on ARI’s website, demonstrating the value of the data we provide to the public.

### *Rare Autoimmune Diseases*

We are extending our representation of rare autoimmune diseases by engaging registrants with those diseases to represent ARI at advocacy conferences like those hosted by Global Genes and the EveryLife Foundation for Rare Diseases.

## Thank You!

We want to extend a heartfelt appreciation to our generous donors, registrants, volunteers, Scientific Advisors and Board members. Without you, our registry would not be where it is today.