



Autoimmune Registry

Annual Report of the Autoimmune Registry

December 2020

Prepared by the Autoimmune Registry Inc.

The Autoimmune Registry Inc. is a 501(c)(3) nonprofit that serves as a hub for research, statistics, and patient data on all autoimmune diseases.


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Second Annual Report of the Autoimmune Registry – 2020

The Autoimmune Registry Inc (ARI) is pleased to present the results of our second full year of operation. This year, we tripled enrollment in the registry from 600 participants to more than 2000. Our goal for 2021 is 5,000 participants. We also participated in three clinical trial recruitments and received compensation for our recruiting efforts, pointing the way to a sustainable business model that can support increased research on the underlying causes of all autoimmune diseases.

The List of Autoimmune Diseases

In November, ARI published the first complete list of autoimmune diseases:



Filter criteria [\[Reset Filters\]](#)
[Guide to the list](#)
[Hide Filters](#)

Level of Evidence [\[Reset\]](#)

Strong evidence it is autoimmune

Moderate evidence it is autoimmune

Not Autoimmune:

Immune related - not autoimmune

Unconfirmed - more research needed

Symptom - not an autoimmune disease

Category [\[Reset\]](#)

Blood Digestive System

Glands Major organs (except skin)

Nervous System Skin

Systemic and connective tissue Vascular System

Hide Synonyms

US Prevalence [\[Reset\]](#)

Extremely rare (under 100,000 cases)

Rare (100,000-200,000 cases)

Uncommon (200,001-500,000 cases)

Common (500,000+ cases)

Filters based on US Cases Min

Disease Search:

Total US Cases for the diseases listed: **60,860,670** - **190,065,773**

(Note: US Case count is **higher than the actual number of people with autoimmune disease** because this computation does not account for patients with more than one disease, who are counted more than once). Synonyms & subtypes are shown but not counted.

Rows to show:

Showing **154** of **154** diseases

Category	Disease (click to see disease profile. Hover over disease name to see reference details)	Level of Evidence [Edit]	US Prevalence (%)	US Cases Min	US Cases Max
Blood	Acquired hemophilia	Moderate	0.00%	480	480
Blood	Antiphospholipid syndrome	Strong	0.04%	128,000	160,000
Blood	Anticardiolipin antibody syndrome (Synonym)	Strong	0.04%	128,000	160,000
Blood	Hughes syndrome (Synonym)	Strong	0.04%	128,000	160,000
Blood	Aplastic anemia	Strong	0.00%	752	752
Blood	Autoimmune lymphoproliferative syndrome	Strong	0.00%	200	200
Blood	Autoimmune neutropenia	Strong	0.00%	1,600	1,600

The list is not included in this report due to its size, but you can find it here:

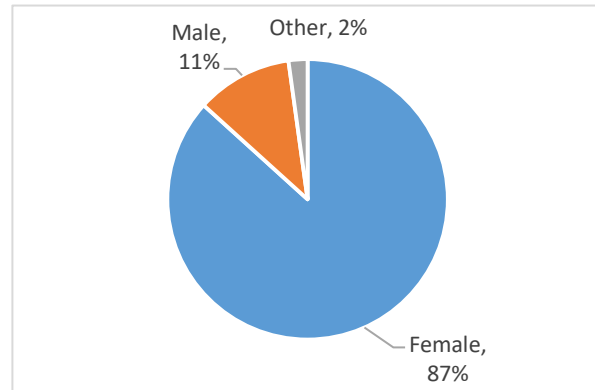
<https://www.autoimmuneregistry.org/autoimmune-diseases>.

The list can be filtered by several criteria, and is the first to include synonyms, subtypes and published prevalence data on every disease. This new list also characterizes the level of evidence for each disease based on data from *“The Autoimmune Diseases”* by Noel Rose and Ian Mackay. Strong and Moderate evidence constitute our definition of “Autoimmune disease”. Diseases suspected of being autoimmune are included as “Unconfirmed” if no cause has been determined and autoimmunity is currently being evaluated. There are also a number of diseases caused by a malfunctioning immune system, but that are not autoimmune. These diseases are classified as “Immune related”.

Note that we are currently researching the role of autoinflammation in diseases like psoriasis and will add filtering and classification based on that research once it is complete.

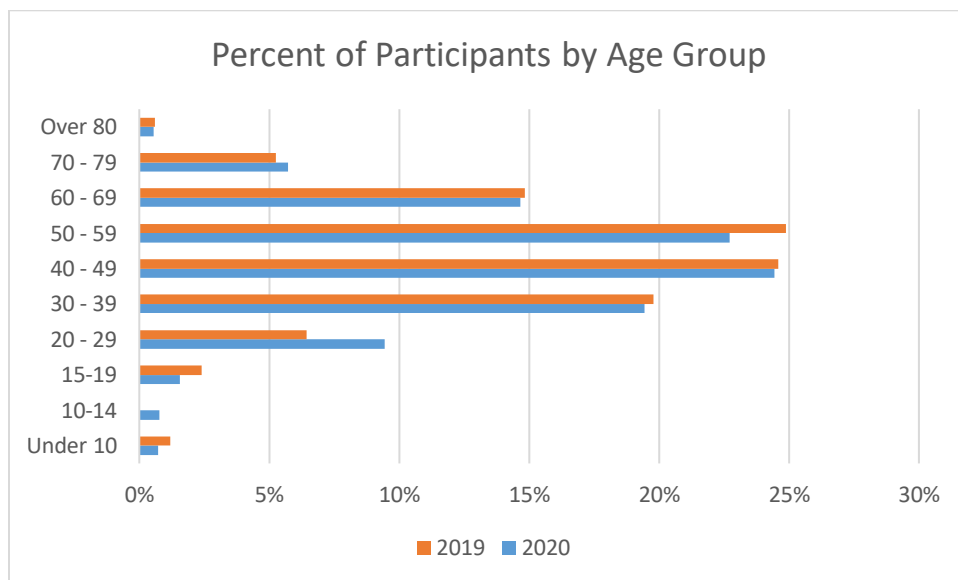
Demographics

As expected, women continue to dominate the ARI database, as the pie chart shows, 87% of our participants are female. Our new data collection system includes a response for patients who do not report being biologically simply male or female.



Since studies indicate that about 70% of people with autoimmune disease are female, our data continue to show we should make an effort to reach out to men to get a more representative sample. Last year females were 92% of our participants, so we have achieved a 5% improvement in the male participation rate.

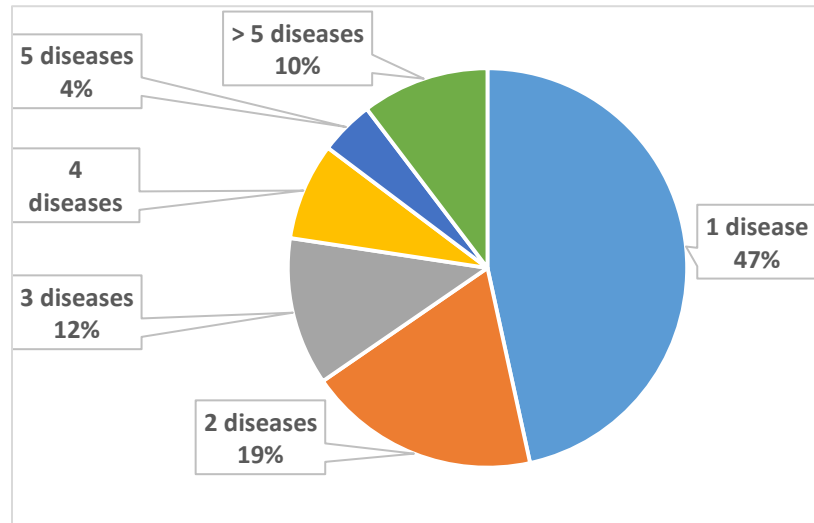
The distribution by age shows what we would expect, with a significant number of participants under age 60. We believe it is important for the public to understand that autoimmune disease is not a disease of the old, but has a significant impact on relatively young individuals.



Comorbidity: More is not merrier

Comorbidity is a major problem for patients with autoimmune disease. More than half of our participants reported having more than one autoimmune disease.

The pie chart to the right shows that 53% of participants report suffering from more than one autoimmune disease, with 10% suffering from over five. And, given the time it takes for a correct diagnosis, it is likely that these patients waited many years for correct diagnoses for their multiple conditions. Diagnostic speed is a key goal of the Autoimmune Registry, and we are starting to collaborate with several biotech companies to develop new diagnostic tools to accomplish this.



The comorbidity data in 2020 is similar to the 2019 data. In the table to the right, the first column is the number of diseases reported by the participants, and the second column is the percent of participants reporting that number of diseases for 2019 and 2020.

We believe the data shows that comorbidities for each disease contain patterns of disease that could be used to speed diagnosis. If a first diagnosis of autoimmune disease takes five years, diagnosis of a second disease could be expedited – and treatment started – if comorbid conditions are understood and properly diagnosed.

Number of diseases I have been diagnosed with	Percent of patients	
	2019	2020
1 disease	38%	47%
2 diseases	18%	19%
3 diseases	13%	12%
4 diseases	7%	8%
5 diseases	4%	4%
More than 5 diseases	10%	10%

The Top 20

This year's Top 20 includes diseases with moderate to strong evidence that autoimmunity is responsible for the disease:

Rank	Disease	Percent of Participants
1	Rheumatoid arthritis	16%
2	Autoimmune thyroiditis	15%
3	Sjogren's syndrome	13%
4	Mixed connective tissue disease	10%
5	Systemic Lupus Erythematosus	8%
6	Undifferentiated connective tissue disease	7%
7	Ulcerative colitis	7%
8	Celiac disease	6%
9	Psoriasis	6%
10	Psoriatic arthritis	5%
11	Multiple sclerosis	5%
12	Autoimmune Gastritis	4%
13	Systemic scleroderma	4%
14	Ankylosing Spondylitis	4%
15	Antiphospholipid syndrome	4%
16	Lichen sclerosus	3%
17	Graves' disease	3%
18	Dermatomyositis	3%
19	Autoimmune urticaria	2%
20	Alopecia	2%

Summary

In 2020, we increased our enrollment more than three-fold and we are targeting a goal of 5,000 participants by the end of 2021. The contribution of data by these participants helped ARI recruit potential participants for three clinical trials for drugs that are being developed for autoimmune diseases.

Please share this report with someone who suffers from autoimmune disease and ask them to consider participating in the Registry!

We thank every participant for taking the time to enroll in the Registry, and hope their effort inspires others to join. To enroll, please go to www.autoimmuneregistry.org/register.

Thank you to our generous donors

In addition to donations of data, financial contributions make it possible for us to reach more participants and support more research. Please go to www.autoimmuneregistry.org/donate to donate, or contact the Aaron Abend, Executive Director, at aabend@autoimmuneregistry.org.