



Autoimmune Registry

Annual Report of the Autoimmune Registry

December 2021

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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Third Annual Report of the Autoimmune Registry – 2021

Summary of Progress

The Autoimmune Registry Inc (ARI) is pleased to present the results of our third full year of operation. This year, we continued to grow enrollment in the registry from 2000 participants to more than 3,100. Details can be found in the Registry Profile section below.

Most notably we raised significant revenue from 2 clinical trial recruitments this year, and have several new recruitments in the works.

Plans for 2022

The coming year will see an emphasis on recruiting, and a focus on collaboration to engage with disease-specific patient groups to expedite recruitment and speed research and development that will improve the lives of people with any autoimmune disease.

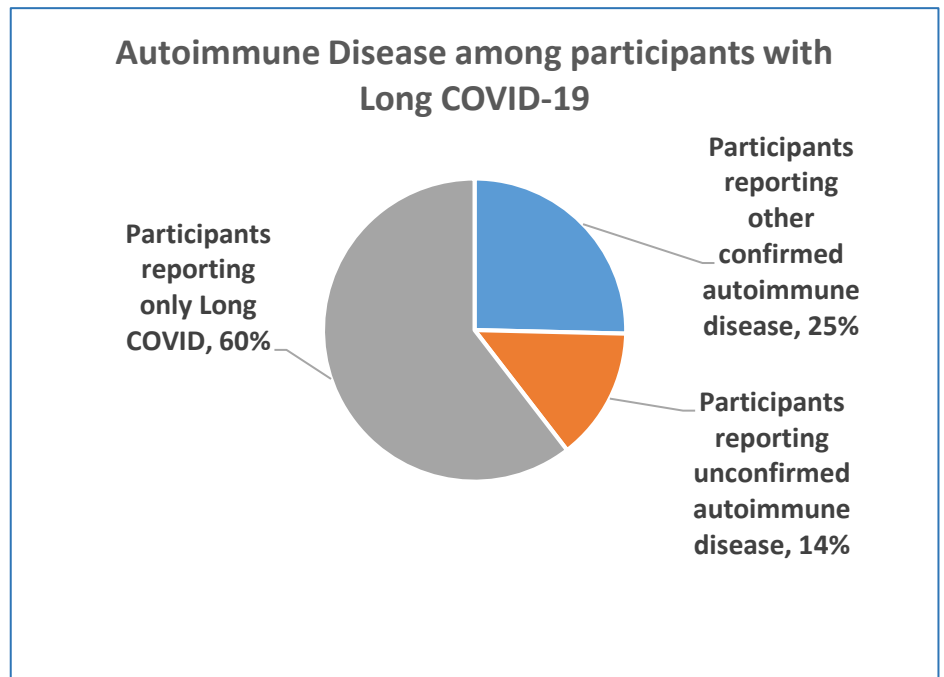
Registry Profile

The Registry grew steadily through the year. After the release of the full list of diseases in 2020, we received emails offering corrections and improvements, and have spent time improving content on the site.

Long COVID-19

In October, we added Long COVID to the list of diseases. Also known by the scientific name “Post-Acute Sequelae of COVID-19”, or PASC, Long COVID appears to involve inflammation similar to that seen in autoimmune and autoinflammatory disease patients. The decision to include PASC was made with advice from our scientific board, but it is still classified as an unconfirmed autoimmune disease since there is limited research and further study is needed. The addition of Long COVID saw the enrollment of over 100 participants, many of whom reported confirmed and unconfirmed autoimmune diseases, as seen in the chart to the right.

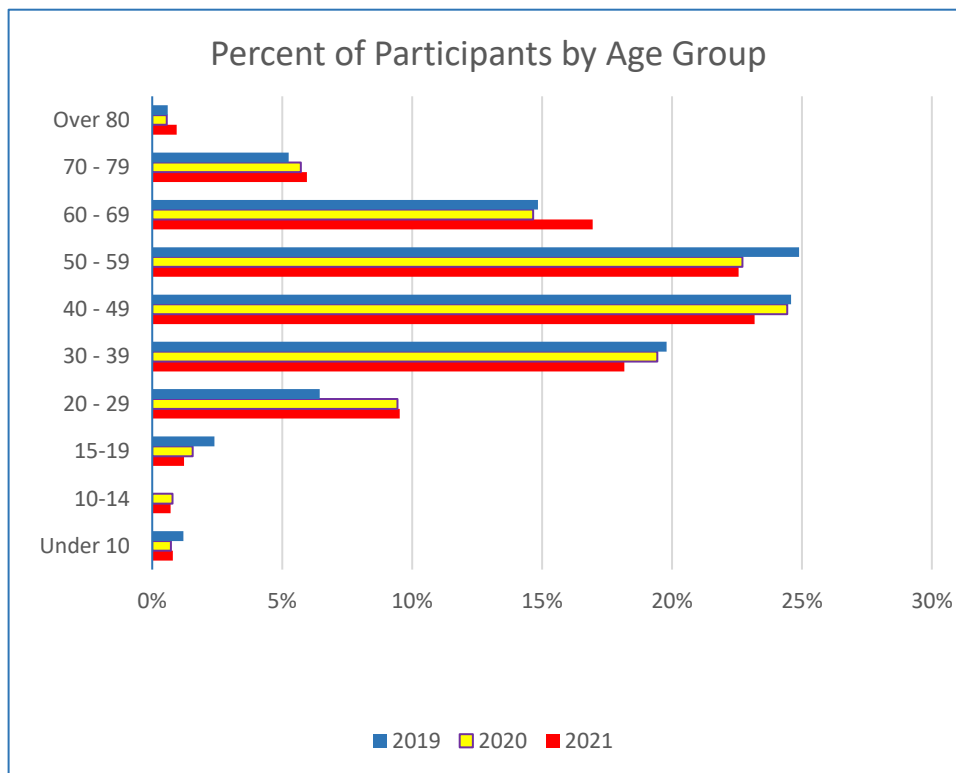
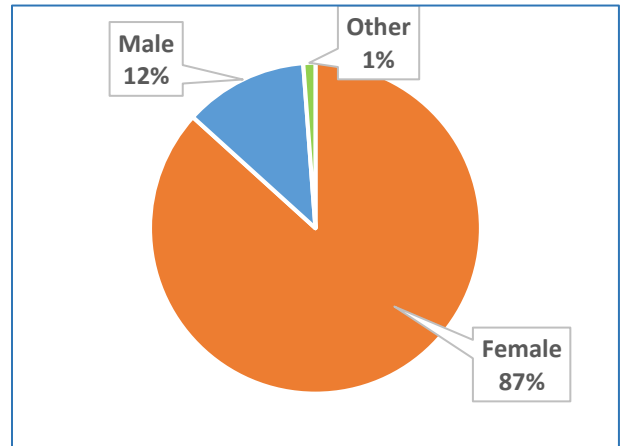
We believe research on Long COVID-19 will provide additional insights into autoimmune and autoinflammatory diseases.



Demographics

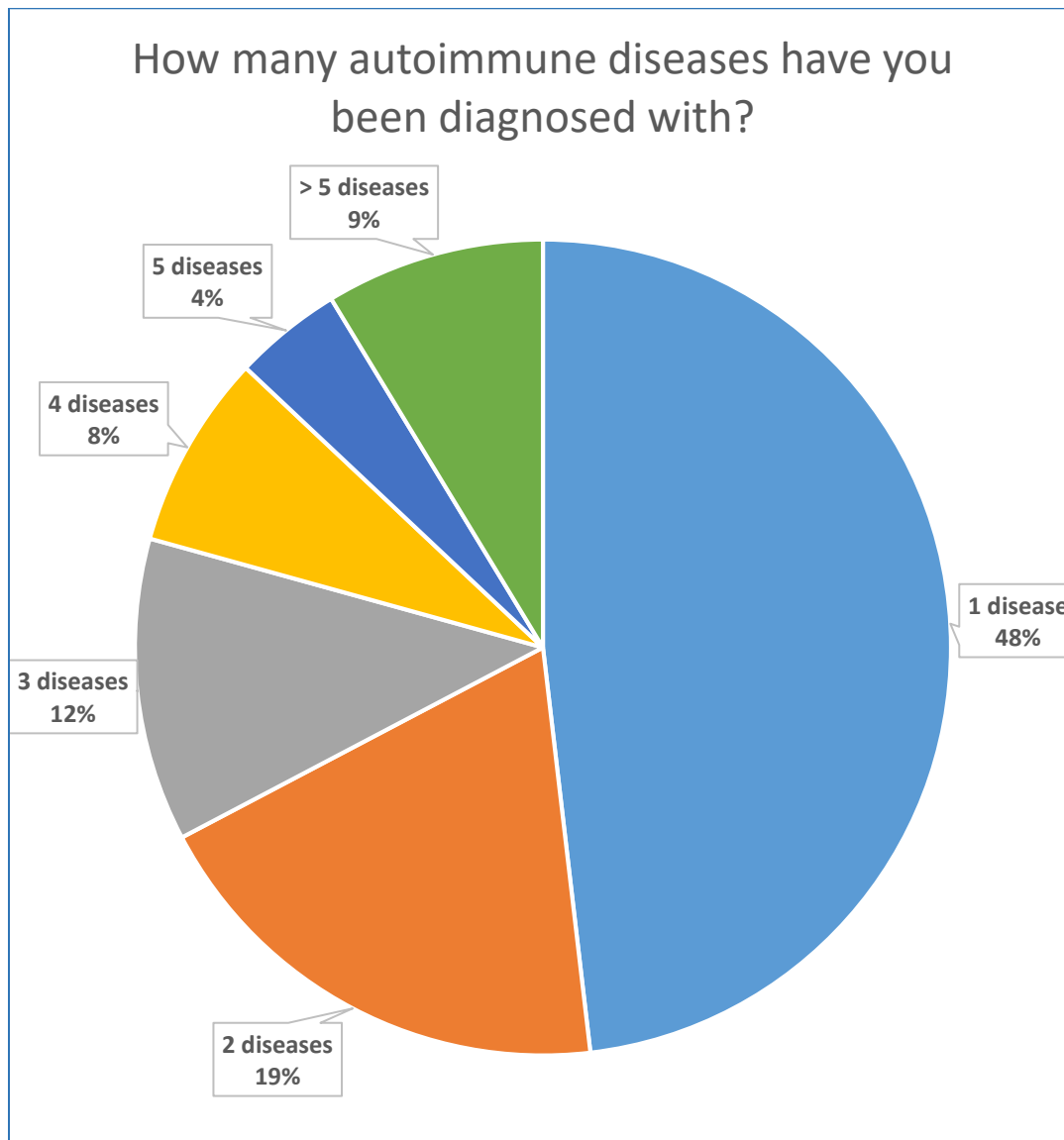
Women continue to dominate the ARI database, as the pie chart to the right shows, but we did increase male enrollment slightly, from 11% in 2020 to 12% in 2021.

The distribution by age, as seen below, shows consistent data over the past 3 years of operation.



Comorbidity

Comorbidity is a major problem for patients with autoimmune disease. As in 2020, more than half of our participants reported having more than one autoimmune disease.



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.

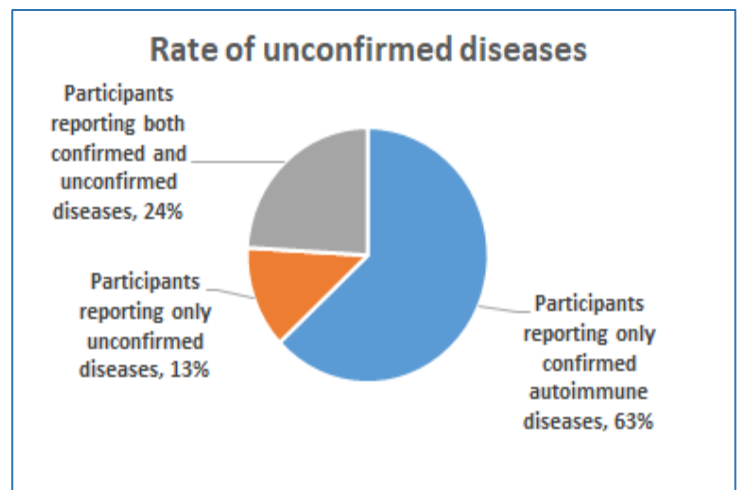
The Top 20

This year's Top 20 includes diseases with moderate to strong evidence that autoimmunity is responsible for the disease. There were a few changes from 2020, with Alopecia and Pernicious Anemia joining the top 20.

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

Unconfirmed diseases: More work is needed

One of the most striking and frustrating facts we have collected are the numbers of people reporting diseases that are suspected, but not confirmed, as autoimmune. This year, we analyzed the number of participants who reported unconfirmed diseases, like fibromyalgia, and classified them by whether they also reported a “confirmed” autoimmune disease. The results are shown in the pie chart below. More than half of the participants reporting an unconfirmed disease reported a “confirmed” autoimmune disease. More study is needed on the connection between these unconfirmed diseases and the “confirmed” autoimmune diseases for which there are biomarkers like antibodies and other evidence of immune system activity.



This year, we are also listing the top 10 “unconfirmed” diseases. It is important to note that a disease that is “unconfirmed” means it is a **real disease** that has **not been confirmed as autoimmune**. The classification does not mean the disease is not real.

Fibromyalgia is our leading unconfirmed disease. At 14%, we have almost as many participants as we have for rheumatoid arthritis.

Summary

The past year was marked by significant progress in recruitment, one of ARI’s 3 major programs. We are hoping 2022 will see even more clinical trial work that furthers the development of treatments and diagnostic tools for autoimmune disease.

Our goal of 5,000 for participation in 2021 is again on target for 2022. You can help by sharing 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 Aaron Abend, Executive Director, at aabend@autoimmuneregistry.org.

Rank	Unconfirmed Diseases	Percent of Participants
1	Fibromyalgia	14%
2	Myalgic encephalomyelitis	6%
3	Endometriosis	5%
4	Hidradenitis suppurativa	1%
5	Lichen planus	1%
6	Long COVID	1%
7	Complex regional pain syndrome	1%
8	Chronic Lyme disease	1%
9	Microscopic colitis	1%
10	Sarcoidosis	1%