

First Annual Report of the Autoimmune Registry

December 2019

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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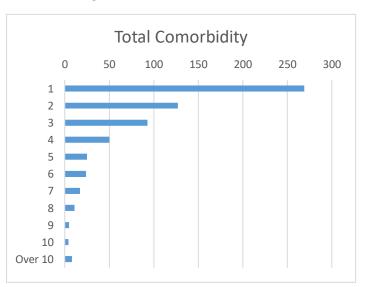
The Autoimmune Registry is pleased to present the results of our first full year of operation.

Over 600 participants have registered to date, representing over 100 different diseases. The most common are shown here:

		Number of	Percent of
Rank	Disease	Participants	Participants
1	Rheumatoid arthritis	178	28.1%
2	Fibromyalgia	121	19.1%
3	Sjogren's syndrome	111	17.5%
4	Raynaud phenomenon	99	15.6%
5	Mixed connective tissue disease	92	14.5%
6	Autoimmune thyroiditis	86	13.6%
7	Systemic Lupus Erythematosus	66	10.4%
8	Celiac disease	60	9.5%
9	Chronic fatigue syndrome	55	8.7%
10	Psoriatic arthritis	52	8.2%

Comorbidity is an important fact for our community. A total of 360 (56.8%) of our participants suffer from more than one autoimmune disease. In the table below, the left column is the number of diseases reported by the participants, and on the right is the number of participants reporting that number of diseases. So, 269 participants reported they suffered from one disease, 127 reported 2 different diseases, etc. A graphic representation is shown to the right of the table.

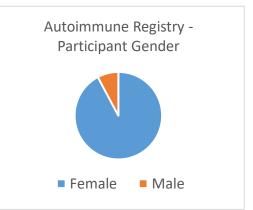
Number of Diseases	Number of Participants
1	269
2	127
3	93
4	50
5	25
6	24
7	17
8	11
9	5
10	4
12	4
13+	4



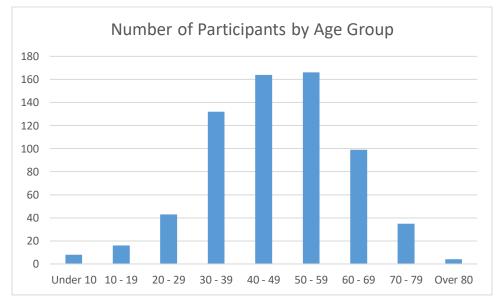
As expected, most of our participants are female:

Sex	Participants	Percent
Female	585	92%
Male	48	8%
Total	633	100%

Since studies indicate that about 70% of people with autoimmune disease are female, our data suggests we should make an effort to reach out to men to get a more representative sample.



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.



The full table of all diseases, sorted by prevalence, starts on the following page.

Summary

The Autoimmune Registry has collected data from over 600 participants. Their contribution of data is beginning to allow us to paint a picture of those who suffer from these diseases. We need more participants willing to share their data so we can stimulate research on the underlying cause of all autoimmune diseases and develop ways to prevent and even cure them.

<u>We thank every participant for taking the time to contribute their data</u>, and hope their effort inspires others to join the registry. To register, please go to <u>www.autoimmuneregistry.org/register</u>.

In addition to donations of data, financial contributions make it possible for us to reach more participants and support more research. Please go to <u>www.autoimmuneregistry.org/donate</u> to donate.

For more information, contact Aaron Abend, Executive Director, at aaron@autoimmuneregistry.org.

Full Table of Diseases

#	Disease	Participants	Percent
1	Rheumatoid arthritis	178	28.1%
2	Fibromyalgia	121	19.1%
3	Sjogren's syndrome	111	17.5%
4	Raynaud phenomenon	99	15.6%
5	Mixed connective tissue disease	92	14.5%
6	Autoimmune thyroiditis	86	13.6%
7	Systemic Lupus Erythematosus	66	10.4%
8	Celiac disease	60	9.5%
9	Chronic fatigue syndrome	55	8.7%
10	Psoriatic arthritis	52	8.2%
11	Psoriasis	47	7.4%
12	Restless leg syndrome	37	5.8%
13	Inflamatory Bowel Disease (IBD)	34	5.4%
14	Hashimoto's encephalopathy	29	4.6%
15	Scleroderma	26	4.1%
16	Ankylosing Spondylitis	24	3.8%
17	Dermatomyositis	23	3.6%
18	Endometriosis	23	3.6%
19	Graves' disease	22	3.5%
20	Gastritis	21	3.3%
21	Juvenile Arthritis	21	3.3%
22	Ulcerative colitis	21	3.3%
23	Palindromic rheumatism	19	3.0%
24	Urticaria	18	2.8%
25	Alopecia areata	16	2.5%
26	Multiple sclerosis	16	2.5%
27	Antiphospholipid syndrome	14	2.2%
28	Ménière's disease	13	2.1%
29	Polymyositis	13	2.1%
30	Undifferentiated connective tissue disease	13	2.1%
31	Diabetes mellitus type 1	12	1.9%
32	Vasculitis	12	1.9%
33	Autoimmune urticaria	11	1.7%
34	Crohn's disease	10	1.6%
35	Autoimmune hepatitis	9	1.4%
36	Chronic inflammatory demyelinating polyneuropathy	9	1.4%
37	Polymyalgia rheumatica	9	1.4%
38	Vitiligo	9	1.4%
39	Addison's disease	8	1.3%

#	Disease	Participants	Percent
40	Angioedema	8	1.3%
41	Interstitial cystitis	8	1.3%
42	Systemic scleroderma	8	1.3%
43	Behçet's disease	7	1.1%
44	Lichen sclerosus	7	1.1%
45	Lyme disease (Chronic)	7	1.1%
46	Myositis	7	1.1%
47	Primary immunodeficiency	7	1.1%
48	Hidradenitis suppurativa	6	0.9%
49	Inclusion body myositis	6	0.9%
50	Lupus nephritis	6	0.9%
51	Lupus vasculitis	6	0.9%
52	Pernicious anemia	6	0.9%
53	Sarcoidosis	6	0.9%
54	Complex regional pain syndrome	5	0.8%
55	CREST syndrome	5	0.8%
56	Discoid lupus erythematosus	5	0.8%
57	Lichen planus	5	0.8%
58	Myasthenia gravis	5	0.8%
59	Thrombocytopenia	5	0.8%
60	Adiposis dolorosa	4	0.6%
61	Antisynthetase syndrome	4	0.6%
62	Autoimmune hemolytic anemia	4	0.6%
63	Autoimmune uveitis	4	0.6%
64	Guillain–Barré syndrome	4	0.6%
65	Rheumatic fever	4	0.6%
66	Autoimmune Angioedema	3	0.5%
67	Autoimmune inner ear disease	3	0.5%
68	Microscopic colitis	3	0.5%
69	Morphea	3	0.5%
70	Primary biliary cirrhosis	3	0.5%
71	Urticarial vasculitis	3	0.5%
72	Autoimmune neutropenia	2	0.3%
73	Autoimmune polyendocrine syndrome	2	0.3%
74	Autoimmune polyendocrine syndrome type 2	2	0.3%
75	Churg-Strauss syndrome	2	0.3%
76	Enthesitis	2	0.3%
77	Eosinophilic esophagitis	2	0.3%
78	Giant cell arteritis	2	0.3%
79	Pemphigus vulgaris	2	0.3%

#	Disease	Participants	Percent
80	Reactive arthritis	2	0.3%
81	Relapsing polychondritis	2	0.3%
82	Acute disseminated encephalomyelitis	1	0.2%
83	Adult-onset Still's disease	1	0.2%
84	Anti-neutrophil cytoplasmic antibody-associated vasculitis	1	0.2%
85	Autoimmune pancreatitis	1	0.2%
86	Autoimmune polyendocrine syndrome type 3	1	0.2%
87	Autoimmune thrombocytopenic purpura	1	0.2%
88	Dermatitis herpetiformis	1	0.2%
89	Drug-induced lupus	1	0.2%
90	Enthesitis-related arthritis	1	0.2%
91	Erythema nodosum	1	0.2%
92	Felty syndrome	1	0.2%
93	Henoch-Schonlein purpura	1	0.2%
94	Intermediate uveitis	1	0.2%
95	Leukocytoclastic vasculitis	1	0.2%
96	Microscopic polyangiitis	1	0.2%
97	Optic neuritis	1	0.2%
98	Parry Romberg syndrome	1	0.2%
	Pediatric Autoimmune Neuropsychiatric Disorder		
99	Associated with Streptococcus	1	0.2%
100	Polyarteritis nodosa	1	0.2%
101	Pyoderma gangrenosum	1	0.2%
102	Rheumatoid vasculitis	1	0.2%
103	Sympathetic ophthalmia	1	0.2%