



2022 Year End
Update on
The APS Type 1
(APECED) Registry

How to Register

Click link below or paste web address into your browser:

<https://apstype1.iamrare.org/>

The APS Type 1 (APECED) Registry

Welcome to The APS Type 1 (APECED) Registry! Together we will jumpstart research in Autoimmune Polyglandular Syndrome Type 1.

[Learn more »](#)

Rare Disease Research

This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

[Researchers »](#)

Participating in This Study

Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.

[Patients »](#)

Join the Registry

Please create an account and provide consent to participate in the study.

[Register »](#)

Who has enrolled in the Registry?

106 Enrolled

(our initial goal was 100 so congratulations to all of us!)

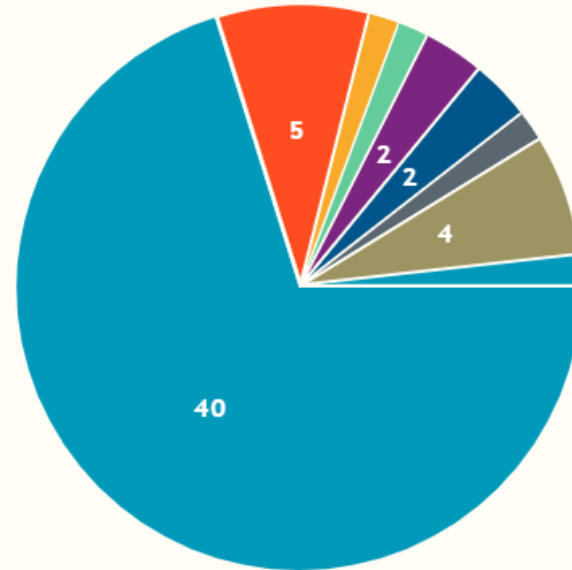
84 Consented

(if this is you, please let us know how we can help)



Our Global Reach

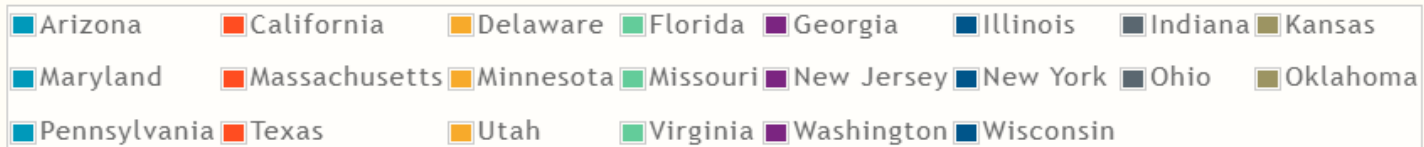
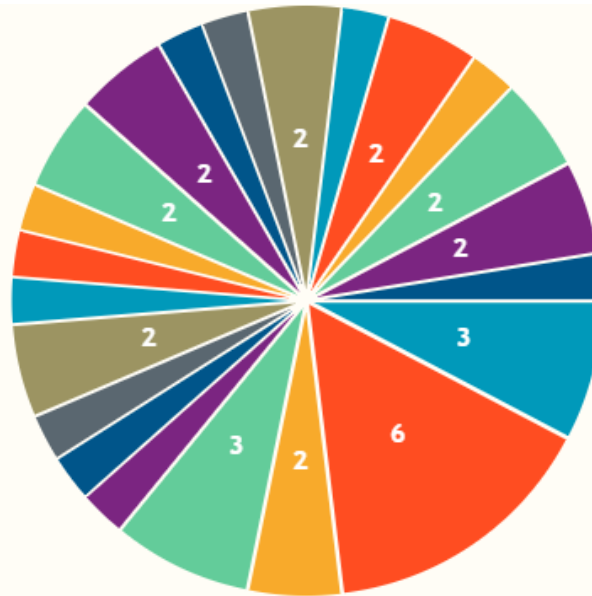
57 Patients from 9 Countries



■ United States ■ Canada ■ Croatia ■ France ■ Greece ■ Ireland ■ Isle of Man ■ United Kingdom of Great Britain and Northern Ireland (the) ■ Vanuatu

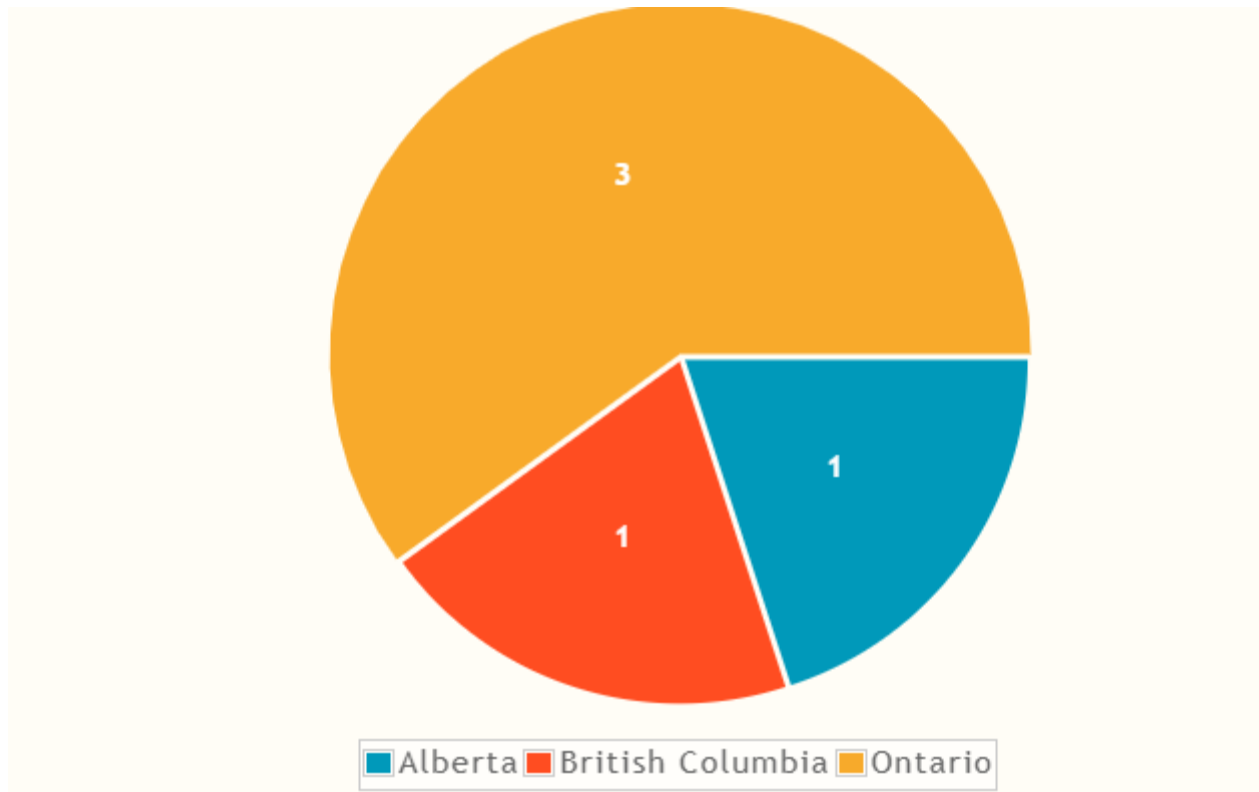
Our U.S. Reach

39 Patients from 22 States



Our Canadian Reach

5 Patients from 4 Provinces



Registry Goals

Achieve earlier
diagnosis

Find new,
undiagnosed
patients

Learn about the
disease course
over time

Inform research
priorities

Unite patients
with the
research
community

Improve quality
of care

Attract new
researchers

Attract
investment in
the field

Plans for 2023



Publish article using de-identified data.

Update your surveys today to be included!



Create more relevant surveys.

What do you want us to know?
What questions do you want the researchers to answer?

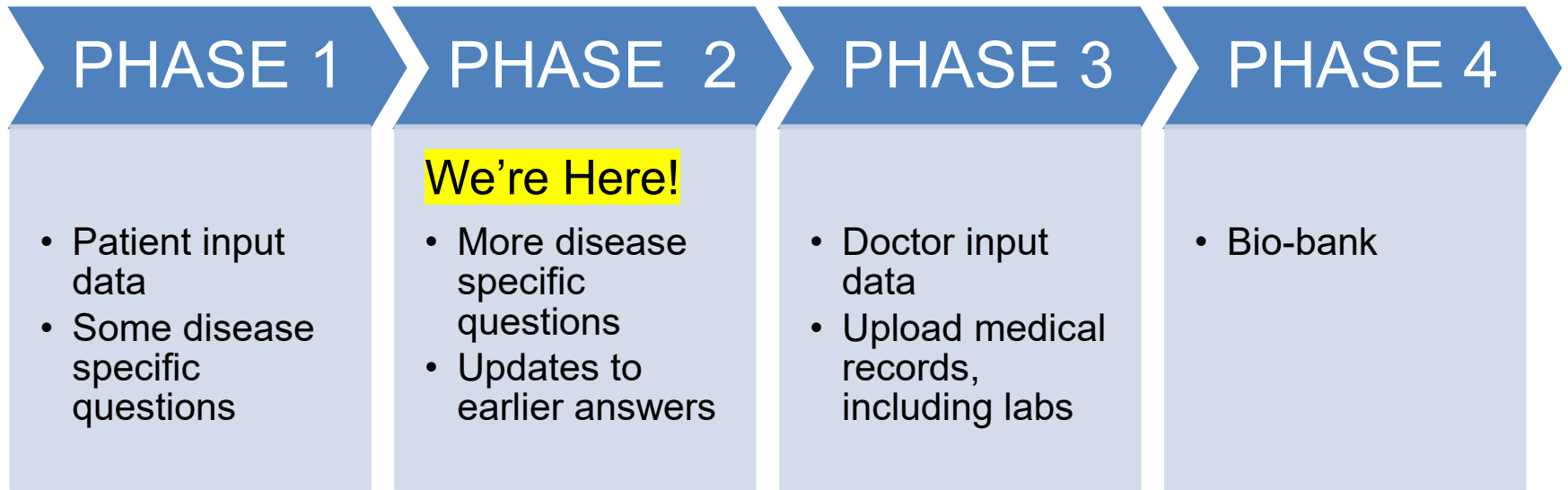


Improve user experience with existing surveys and platform.



Add additional language capabilities.

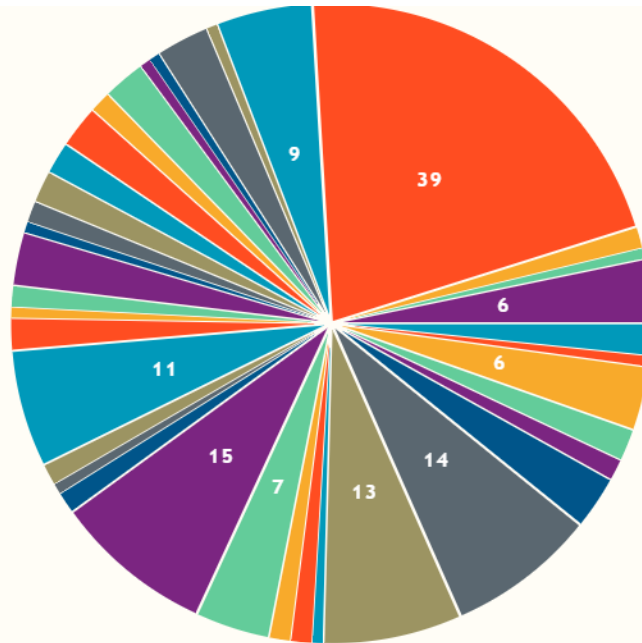
(Hopeful) Evolution of our Registry



What have we learned from the Registry?



Medications (185 Responses)



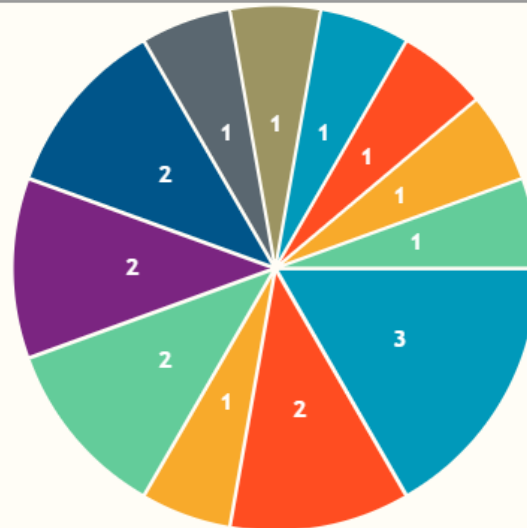
Albuterol inhaler	Amphotericin solution (oral)	Antibiotic	Antifungal cream	Artificial tears
Azathioprine (Imuran)	Calcitriol	Calcium supplement	Cholecalciferol	Contraceptive pill or injection
Cyclosporine	Fluconazole (Diflucan)	Fludrocortisone	Forteo	Growth hormone supplementation
High blood pressure medication	Hydrocortisone (Cortef, oral)	Insulin	Itraconazole (Sporanox)	Levothyroxine
Magnesium	Methotrexate	Miralax	Multivitamin	Omeprazole (Prilosec)
Nystatin solution (oral)	Potassium	Prednisone	Ranitidine (Zantac)	Rituximab
Vitamin B12 (intramuscular)	Vitamin B12 (oral)	Vitamin D	Other	Iron
Alrex (eye drops)	Hydrocortisone (Solu-Cortef, injection)			

Time to Diagnosis

44% @ 7 years +

We still have a lot work to do to shorten the time to proper diagnosis!

How long was it from the Participant's first symptom of APS Type 1 (APECED) until the diagnosis of APS Type 1 (APECED)? (Responses: 18)



■ Less than one month ■ Less than six months ■ Six to 11 months ■ 1 year ■ 2 years ■ 7 years ■ 9 years ■ 13 years
■ 14 years ■ 22 years ■ 23 years ■ More than 25 years

How can you help?

1

Let us know
what you want
to learn about

2

Enroll and
consent today

3

Update your
survey
responses
annually

Thank you for your support!



Register at:

<https://apstype1.iamrare.org/>



Email us:

registry@apstype1.org

