

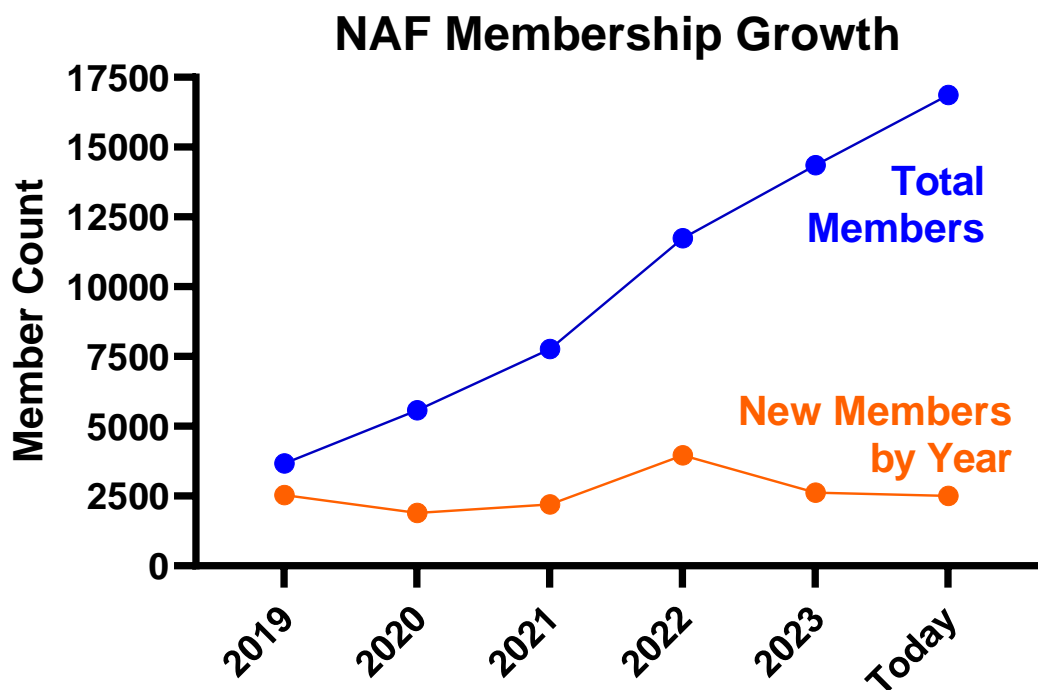
National Ataxia Foundation: Expanding Our Impact

Lauren Moore, PhD
Chief Scientific Officer

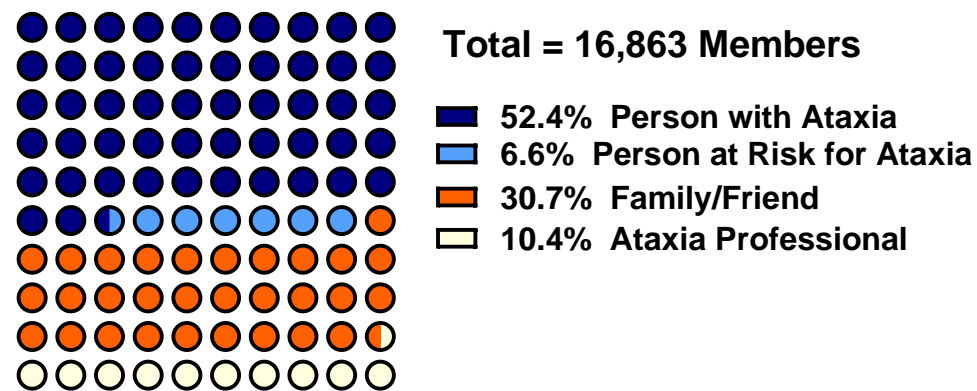
Euro-Ataxia Meeting
November 16, 2024



NAF Membership is Rapidly Growing

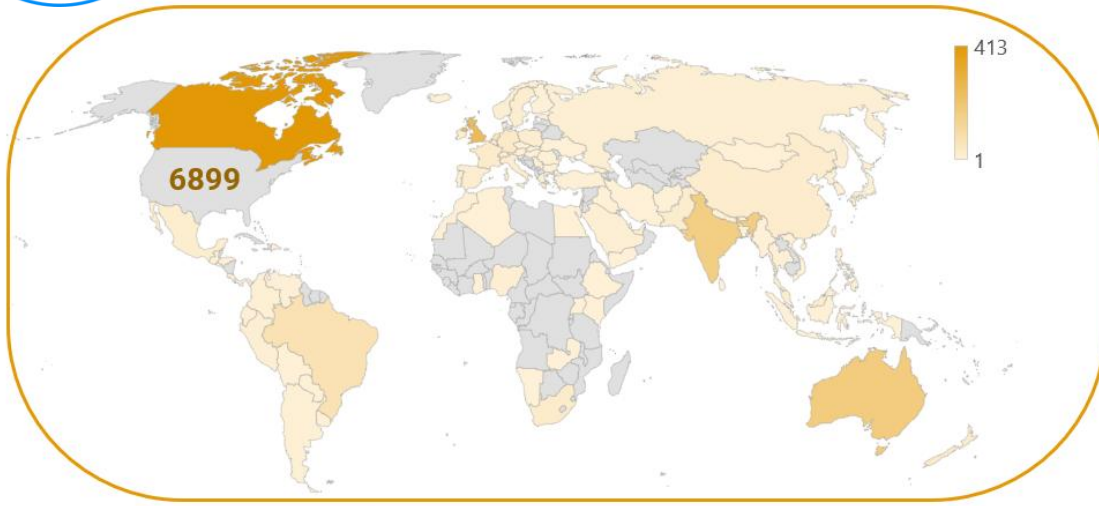


NAF Membership by Affiliation to Ataxia

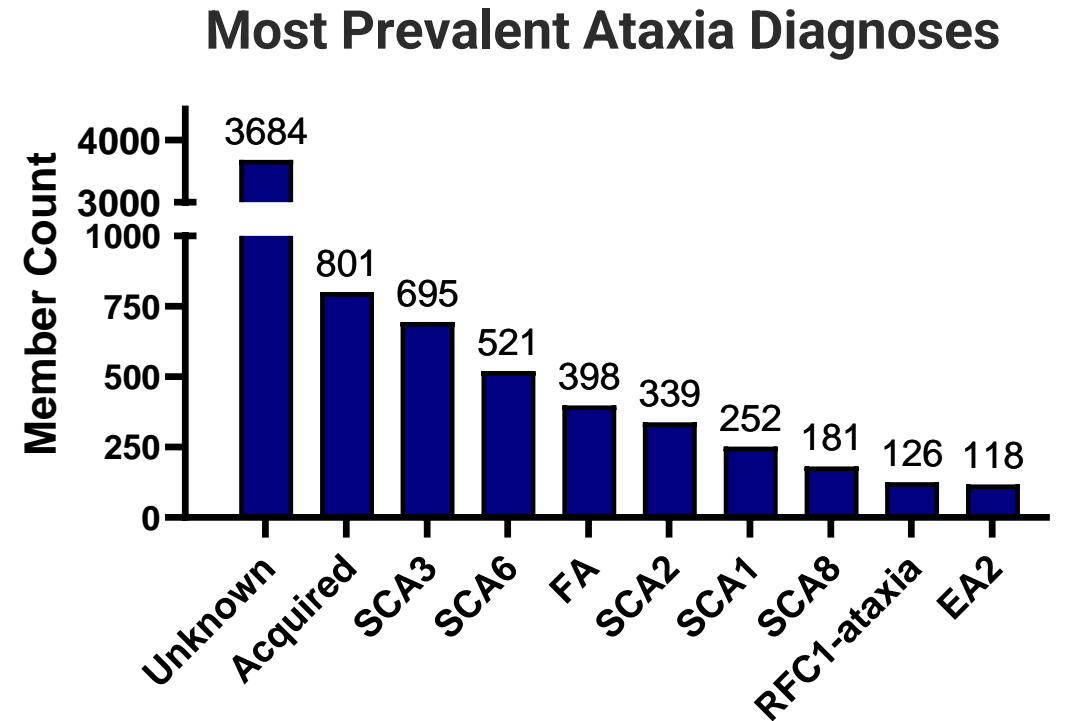


- Gaining ~2500 new members each year
- >8800 members self-reporting an ataxia diagnosis

NAF Membership is Global and Spans Ataxia-Related Disorders



Global Distribution of NAF Members with Ataxia



- NAF members span 109 countries.
 - Largest ex-USA ataxia populations in Canada (413), UK (247), Australia (174), India (164), Brazil (69) and Netherlands (61).
- >70 hereditary, sporadic, and acquired ataxia subtypes represented.

Ataxia Centers of Excellence



Launched in 2023 to recognize exceptional centers that:

1. Provide expert, comprehensive care and services
2. Are actively engaged in clinical research & trials
3. Demonstrate commitment to patient community

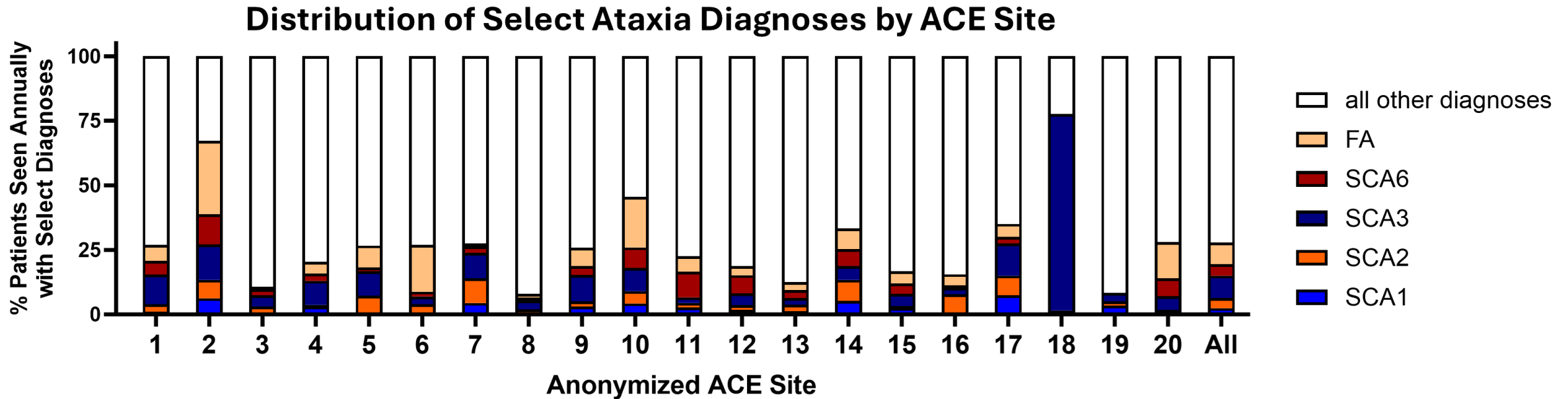
Centers selected through application and competitive review process that includes leading neurologists, industry and patient representatives

34 Centers have been designated:

- 25 centers across 17 states designated in US
- Other countries represented: Canada (2), UK (1), Australia (3), Peru (1), Italy (1), Germany (1)



ACEs are Required to Submit Annual Reports Detailing Infrastructure, Research Engagement & Population Served



Required ACE annual reporting to aid in:

1. Understanding ataxia epidemiology
2. Connecting pharmaceutical partners with clinical trial ready sites

Ataxia Clinical Training Program



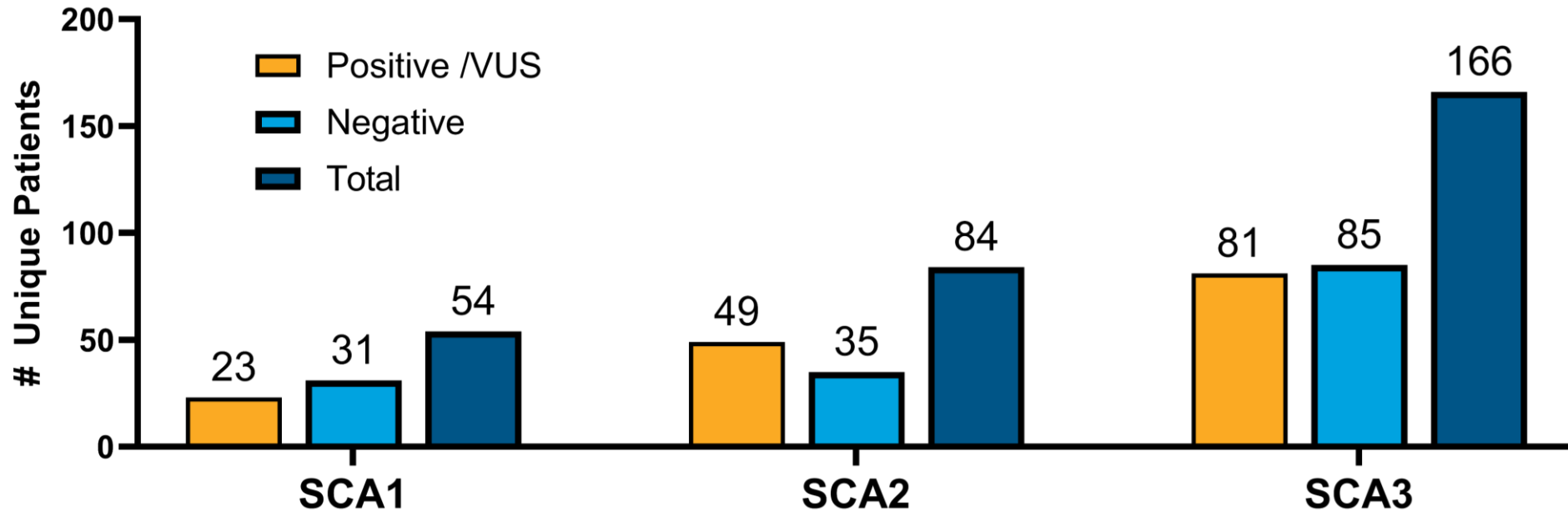
Goal: Preparing the next generation of ataxia clinical care and research leaders

- Annual 3-day ataxia-intensive education program for movement fellows led by 10+ ataxia clinical experts
 - Live SARA training and direct patient engagement in course
 - Have expanded registration to all HCPs & industry representatives



Over 3 years, we will provide advanced training for >120 movement disorder fellows from 25+ fellowship programs.

No-Cost Genetic Counseling & Testing Initiative



Over 2.5 Years, NAF has sponsored:

- 653 genetic counseling visits
- Return of 304 genetic test results for those at-risk for SCA1, 2, and 3

Recently launched expanded program for suspected RFC1 or SCA27b



Greatly Expanding Accessible Education Across Ataxia Types

Expert Webinars for Patients over past 2 years:

Unknown Ataxia without family history
Ataxia caused by traumatic brain injury
Autoimmune Ataxia
X-Linked Cerebellar Ataxias
Ataxia Caused by Stroke
MSA-C
SCA1
SCA2
SCA3
SCA5
SCA6
SCA7
SCA8

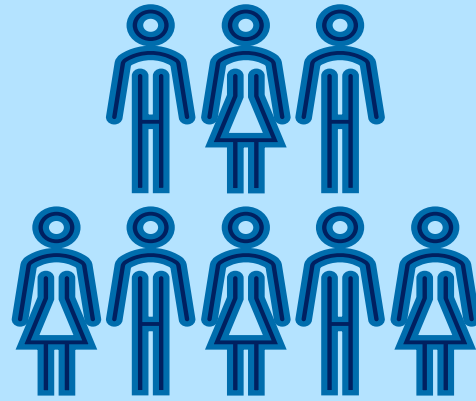
SCA10
SCA12
SCA14
SCA27B
Episodic Ataxia
FA
AOA
CANVAS/RFC1 Ataxia
SYNE1 Ataxia
FXTAS
HOD
SPG7
ARSACS

Building your clinical trial resume
intro to drug development
What are Natural History Studies?
All about Imaging: CT, MRI, PET
Finding Ataxia Information Online
Drug Development from a Biotech Perspective
Finding Clinical Trials
Safety in Clinical Trials
All about DBS
All about Gene Therapy
CRC-SCA Natural History Study Panel (bilingual)
Todo Sobre la Ataxia
All about Troriluzole
All about the Cerebellum
All about Mouse Models in Ataxia Research
All about ctDCS

Most watched webinar recordings: All About MSA-C (4.9k),
Todo Sobre la Ataxia (4.5k), All About Unknown Ataxia
(4.1k), All About FA (3.4k)



**Improving
Clinical Care**



**Engagement &
Empowerment**



**Partnering with
Pharma**

Expanding Areas of Impact