



NAF Community Survey Initial Results

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NAF
National Ataxia
Foundation

March 27-29, 2025
Planet Hollywood
Las Vegas, NV

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PRESENTER DISCLOSURES

I am a full-time employee of the National Ataxia Foundation. I have no other conflicts to disclose.



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What is the NAF Community Survey?

- Online survey in English
- Open to all NAF members over the age of 18 diagnosed with ataxia or family members
- Feedback collected from January 6-20, 2025
- Advertised through email and social media



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Why did we conduct a survey?



**Get To Know Our
Members**



**Feedback On NAF
Programs & Services**



Access Pattern Analysis



**Learn About The
Experiences Of People
With Ataxia**



Initial Findings

We are still doing data analysis!

Full findings will be shared later this year.

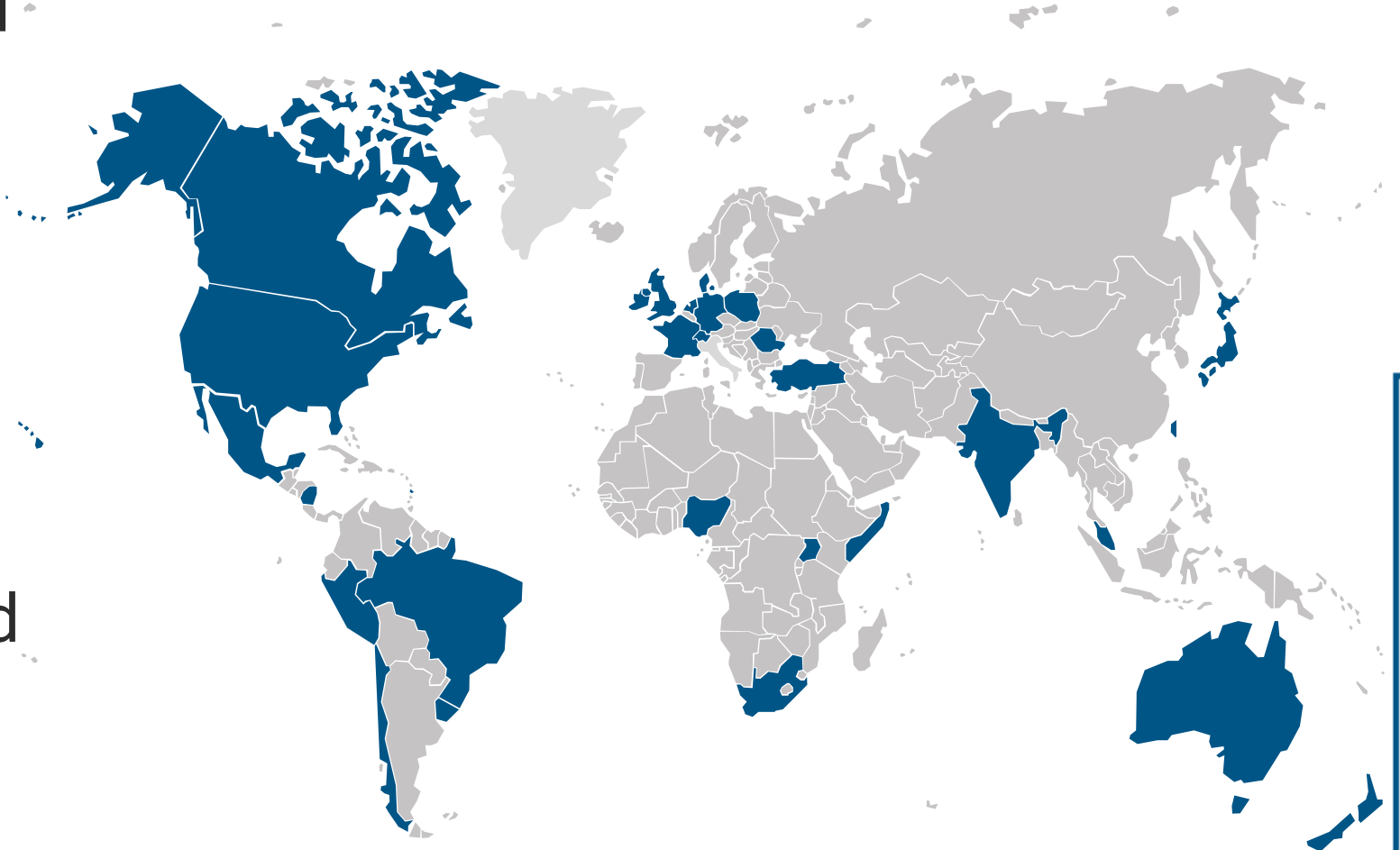


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Who Answered the Survey?

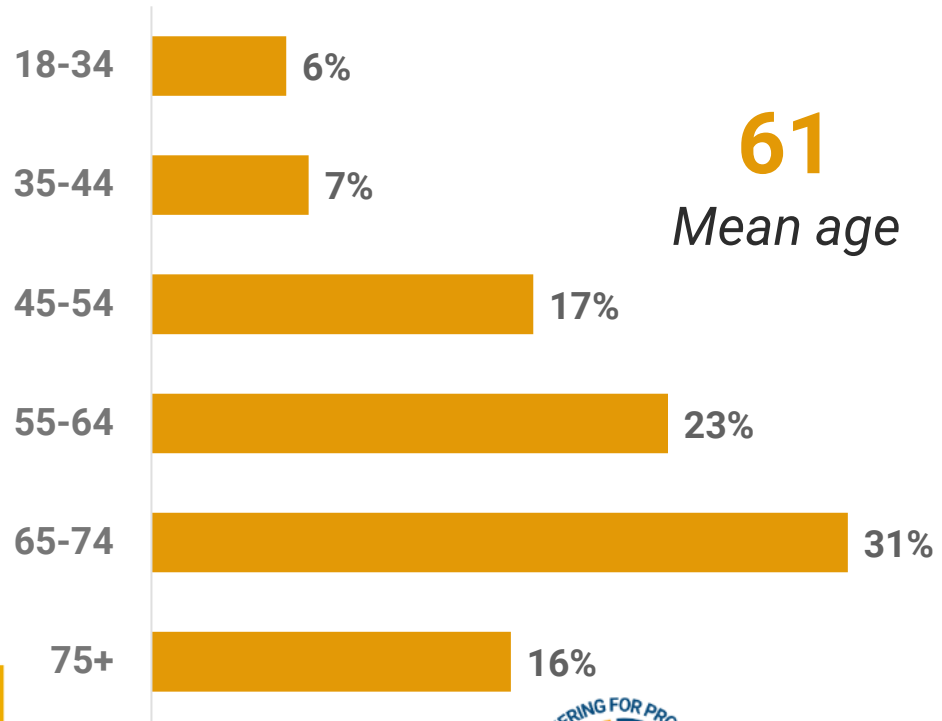
- 680 NAF members
 - 587 people with ataxia
 - 93 caregivers
- 81% from the United States
- 63% women



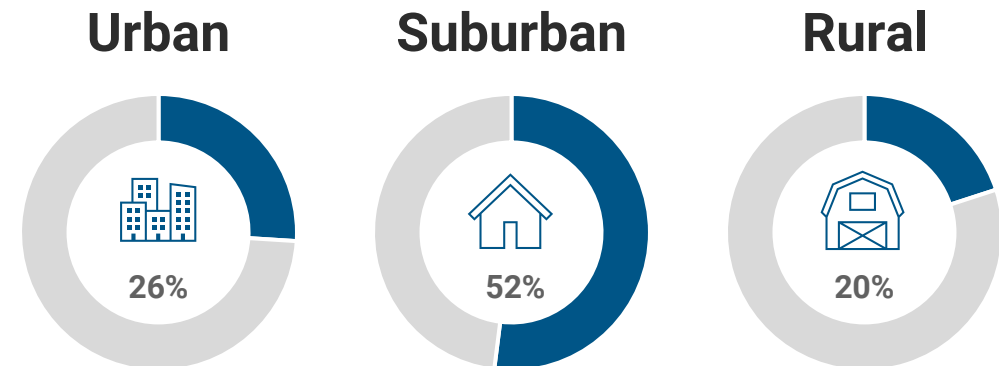
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Who Answered the Survey?

Age



Urbanicity



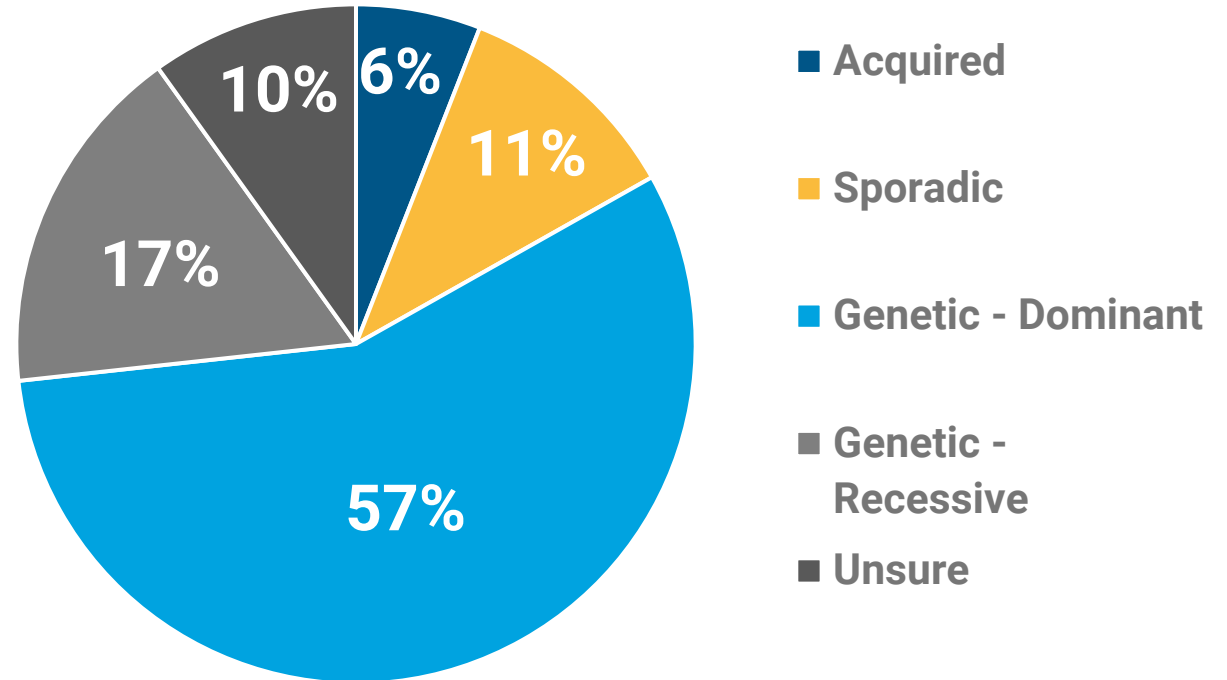
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Who Answered the Survey?

- 74% with a genetic form of ataxia
- 45% waited over 5 years for an ataxia diagnosis
- 51% report impaired balance as their first symptom

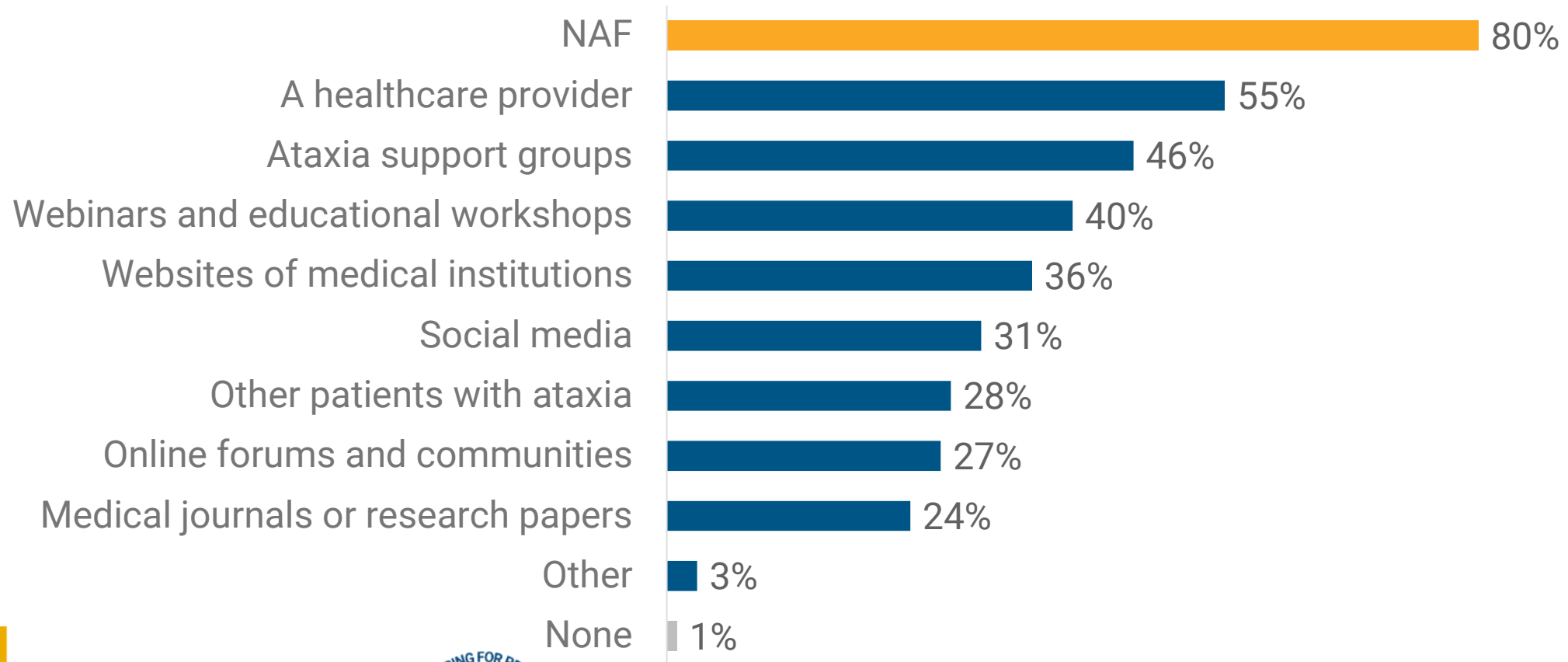
Ataxia Types Represented



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NAF is the top resource relied on for ataxia information, followed by HCPs and support groups

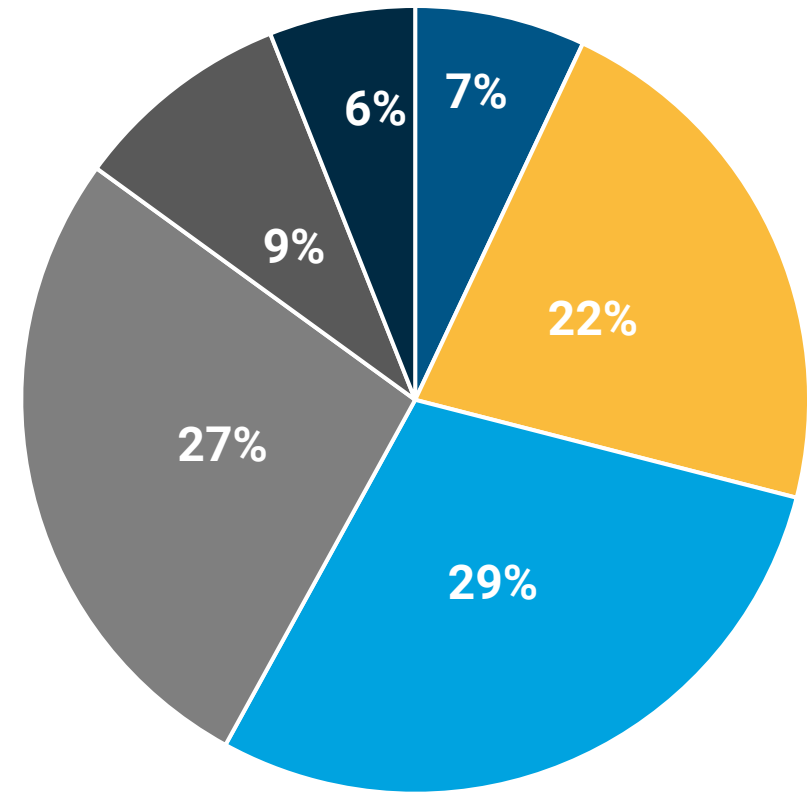


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58% of survey respondents access NAF services & programming at least monthly

- Daily
- Weekly
- Monthly
- Every few months
- Annually or less frequently
- Never

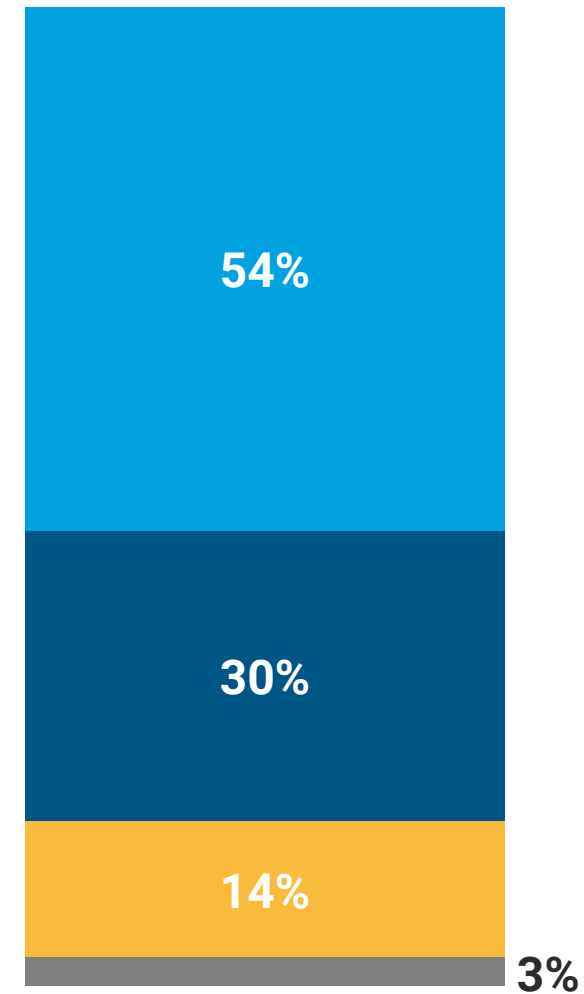


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84% of survey respondents have a positive overall opinion of the National Ataxia Foundation

- Very positive
- Somewhat positive
- Neutral
- Very/ somewhat negative



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Next Steps

- **We will continue to analyze the survey data**
 - Feedback on specific NAF service area
 - Barriers to accessing NAF services & programs
 - Healthcare experiences of NAF members
- **Discuss internally how to incorporate your feedback into the work we do**
 - We will share findings publicly once analysis is completed



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Thanks for Listening!

Questions? Please come chat with me,
or email celeste@ataxia.org



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