ALS Focus Survey:
Sharing Experiences with Mobility at Home

Guest Speakers:
Amanda Lee, Associate Director - ALS Focus Program
Ron Faretra, Chair - ALS Focus PCAC
About Me – Ron Faretra

- Chairman - ALS Association PCAC committee
- Assist in the development of the ALS Focus Surveys
- Mid Atlantic Advisory Council & South Carolina Advisory Council
- Retired USAF Chief Master Sergeant November 1995
- Retired Finance Director City of Goose Creek July 2017
- Diagnosed by Dr. Jeffrey Rothstein October 2016
About Me – Amanda Lee

• Associate Director of ALS Focus since June 2022
• Experience in public health research and community engagement
What is ALS Focus?

- Online surveys for people living with ALS and their caregivers that ask about life experiences
- Our goal is to learn as much as possible about individual experiences throughout the disease journey so that the whole ALS community can benefit
About ALS Focus

Patient- and caregiver-led
The Patient and Caregiver Advisory Committee (PCAC) drives Focus survey topics, survey questions, and other research components.

Experience and preference data
Focus surveys measure the experiences, needs, and preferences of people with ALS and their caregivers as they face this disease.

Informing research, policy, & care
Focus surveys are designed to inform patient-focused drug development, payment and reimbursement models, care services, and caregiver programs.
What happens to my data?

Anonymous
Data shared from ALS Focus surveys is confidential and anonymous.

NeuroSTAmP™
Each participant receives unique identifier to ensure participant privacy and enable combined ALS data across studies.

Data is free to use
De-identified Focus data files are free for the public and ALS researchers.

Regional ALS data
Analyses of Focus data by U.S. region, demographics, and disease progression are possible.
Why is ALS Focus important?

• Participating in ALS Focus brings the needs and perspectives of people impacted by ALS to the center of the conversation

• Robust data collected from ALS Focus surveys:
  o Impact decisions of ALS key opinion leaders
  o Shape ALS public policy
  o Inform clinical trial design
  o Strengthen care and service programs for our community
A few key findings...

1 out of 4 people with ALS and caregivers have experienced debt or had to borrow money due to ALS treatment or caregiving.

The inability to do activities and limitations with mobility or walking mattered most to people with ALS.

Nearly half (47%) of people with ALS and caregivers said insurance refused to cover their electronic seat elevation.

1 in 3 people who submitted a prior authorization or claim for ALS care had experienced an insurance denial, most commonly for medications.
Impacts of ALS Focus

• ALS Focus data used in **Centers for Medicare & Medicaid Services** decision to cover the cost of power seat elevation

• ALS Focus data was used to inform an **evidence-based resource guide** for educating insurance providers on the importance of covering the costs of ALS care early and often

• All survey results and public data files were shared with the National Academies of Sciences, Engineering, and Medicine Committee for their study on **Accelerating Treatments and Improving Quality of Life in ALS**

• …and more!
How do I participate in ALS Focus surveys?

Go to www.ALSFocus.org!
# ALS Focus and CDC Registry: What’s the difference?

<table>
<thead>
<tr>
<th>Similarities</th>
<th>Unique to Focus</th>
<th>Unique to Registry</th>
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</thead>
<tbody>
<tr>
<td>Both online survey programs</td>
<td>New surveys launched throughout the year</td>
<td>Same surveys for all participants (one and done)</td>
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<tr>
<td>Both ask about life experiences</td>
<td>Goal is to measure the needs and preferences of people with ALS and their caregivers</td>
<td>Goal is to identify risk factors for ALS</td>
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<tr>
<td>Anonymous data shared with researchers</td>
<td>Open and free to anyone</td>
<td>CDC requires a request process</td>
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<tr>
<td>Eligibility: Adults with ALS in the US (and proxies)</td>
<td>Eligibility also includes current and past caregivers</td>
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<td>IRB reviewed</td>
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<tr>
<td>NeuroSTaMPs</td>
<td>Run through ALS Association, driven by PCAC</td>
<td>Run through CDC, includes the National ALS Biorepository</td>
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Mobility Survey Results

Results from ALS Mobility Survey, 2021

The ALS Mobility survey focused on access to mobility equipment for getting around outside the home. 352 people with ALS and ALS caregivers answered questions about using and paying for power wheelchairs, portable ramps, and rollators.

Costs of Mobility Equipment

1 in 4 respondents said they paid at least some of their power wheelchair cost out of pocket.

47% said insurance refused to pay for their power wheelchair seat elevation.

1/2 said they paid out of pocket for their portable ramp or rollator.

Use of Mobility Equipment

16-26% thought the person with ALS should have started using their power wheelchair, portable ramp, or rollator sooner.

80% agreed their equipment adequately met their needs, but 11-18% disagreed.

Delayed delivery

Malfunctioning equipment

Lack of Knowledge

and other barriers were reasons respondents cited for not using equipment.

The ALS Association, 2023
OPEN NOW: Mobility at Home Survey

• Survey is open: **August 23 – October 23**

• People with ALS, current caregivers, and past caregivers are eligible to participate

• This survey takes about 20 minutes to complete

• Sign up at [www.ALSFocus.org](http://www.ALSFocus.org) or check for an email from [ALSFocus@als.org](mailto:ALSFocus@als.org)
What topics does this survey cover?

• Types of equipment used at home
• Home modifications and renovations
• Access, costs, and quality

www.ALSFocus.org
Thank You!

Acknowledgements

• ALS Focus Participants
• Patient and Caregiver Advisory Committee
• Steering Committee
• Working Groups

• Massachusetts General Hospital Neurological Clinical Research Institute
• Current Industry Sponsors

Contact

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Register Today!
www.ALSFocus.org