

WELCOME !

August 28, 2023



**ALS Focus Survey:
Sharing Experiences with Mobility at Home**

**Guest Speakers:
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ALS Association

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RESEARCH | CARE | ADVOCACY

ALS Focus Survey: Sharing Experiences with Mobility at Home

Amanda Lee & Ron Faretra

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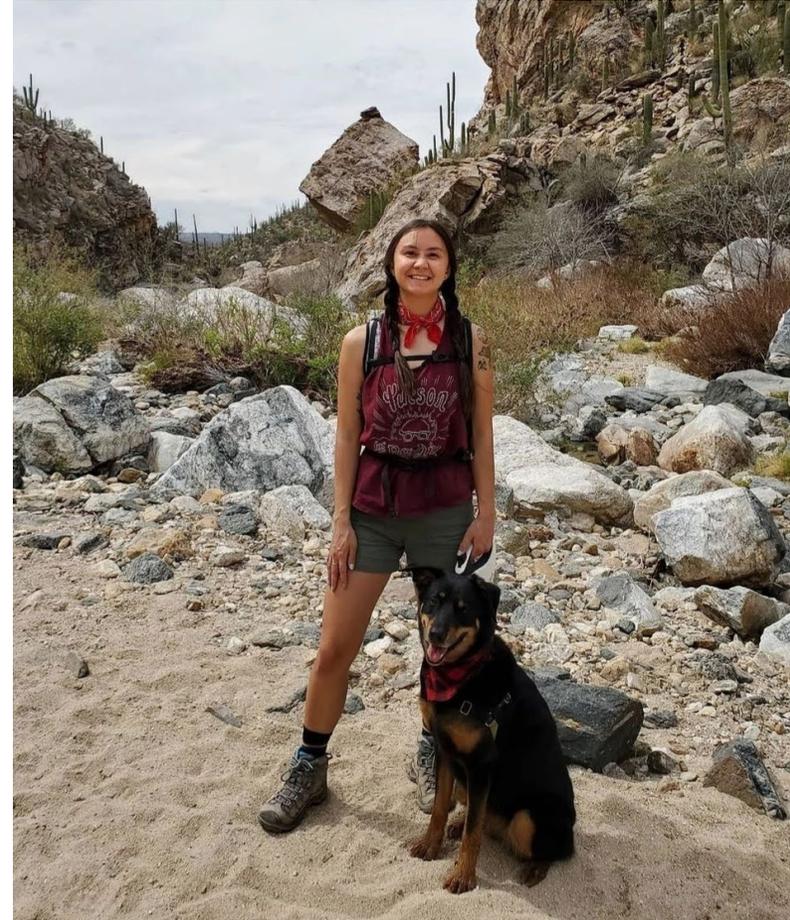
About Me – Ron Faretra

- 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

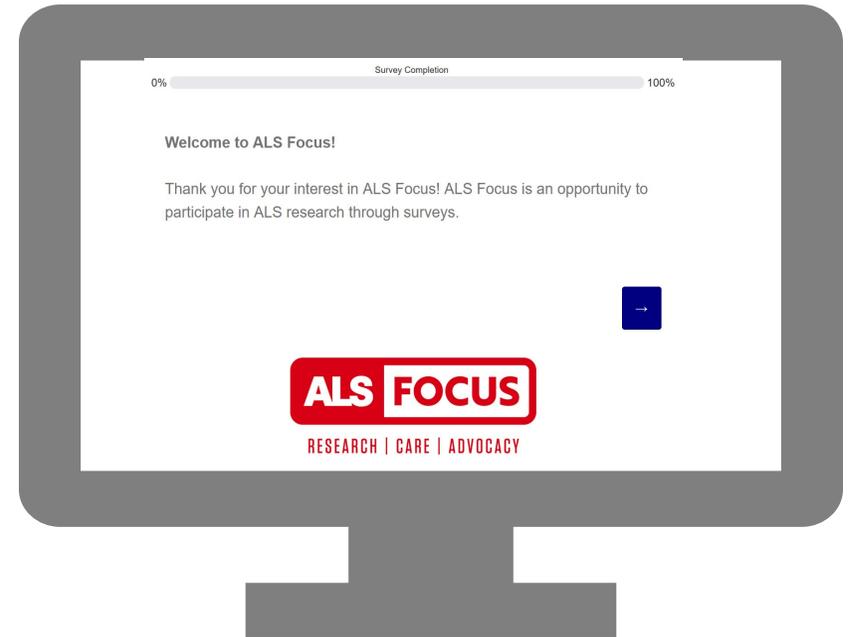
- Associate Director of ALS Focus since June 2022
- Experience in public health research and community engagement



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:
 - Impact decisions of ALS key opinion leaders
 - Shape ALS public policy
 - Inform clinical trial design
 - 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



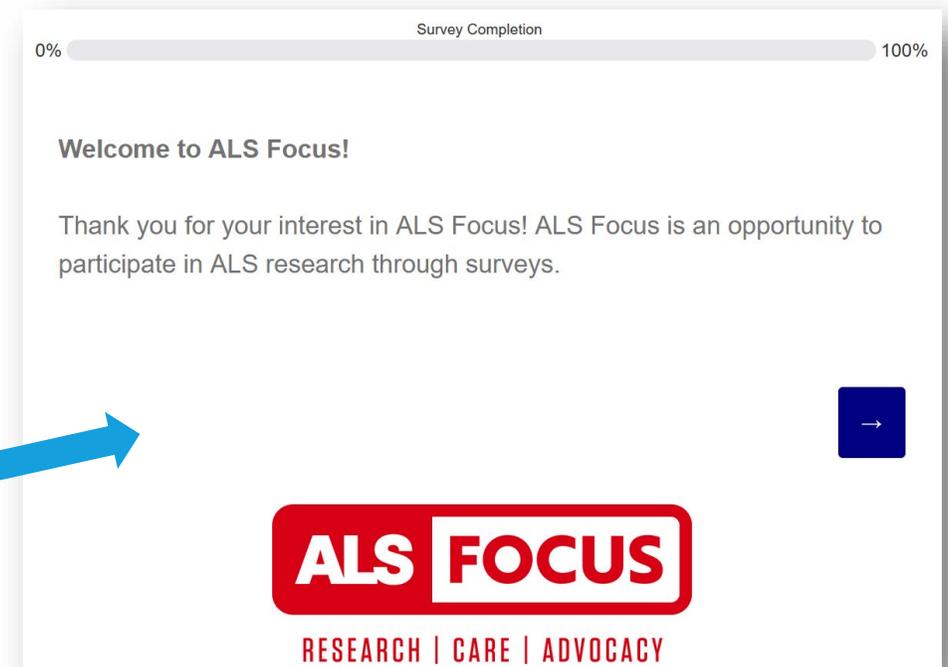
- ALS Focus data used in **Centers for Medicare & Medicaid Services** decision to cover the cost of power seat elevation
- ALS Focus data was used to inform an **evidence-based resource guide** for educating insurance providers on the importance of covering the costs of ALS care early and often
- All 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!



The screenshot shows the ALS Focus landing page. At the top left is the ALS Association logo. The navigation menu includes 'Understanding ALS', 'Navigating ALS', 'Local Support', 'Research' (highlighted), 'Advocacy', and 'Get Involved'. Below the navigation is a breadcrumb trail: 'Home / Research / Participate in Research / ALS Focus Survey Program'. The main heading is 'ALS Focus' under the sub-header 'RESEARCH | CARE | ADVOCACY'. A paragraph describes the program: 'ALS Focus™ is a patient- and caregiver-led survey program that asks people with ALS and current and past caregivers about their needs and challenges. The goal is to learn as much as possible about individual experiences throughout the disease journey so that the whole ALS community can benefit. All data collected is de-identified and shared free of charge with the entire ALS community.' At the bottom, there is a red button that says 'CLICK HERE TO TAKE ALS FOCUS SURVEYS →'. A blue arrow points from this button towards the survey completion screen on the right.



The screenshot shows the survey completion screen. At the top, there is a progress bar labeled 'Survey Completion' with '0%' on the left and '100%' on the right. Below the progress bar, the text reads: 'Welcome to ALS Focus!' followed by 'Thank you for your interest in ALS Focus! ALS Focus is an opportunity to participate in ALS research through surveys.' At the bottom right, there is a blue button with a white right-pointing arrow. Below the button is the 'ALS FOCUS' logo in a red rounded rectangle, with 'RESEARCH | CARE | ADVOCACY' written below it.

ALS Focus and CDC Registry: What's the difference?

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

Mobility Survey Results

ALS FOCUS

Results from ALS Mobility Survey, 2021

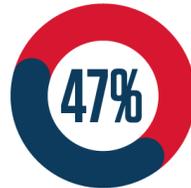
The ALS Mobility survey focused on access to mobility equipment for getting around outside the home. 352 people with ALS and ALS caregivers answered questions about using and paying for power wheelchairs, portable ramps, and rollators.

Costs of Mobility Equipment



1 in 4

respondents said they paid at least some of their power wheelchair cost out of pocket



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

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 or check for an email from 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

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- Steering Committee
- Working Groups
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- Current Industry Sponsors

Contact

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