Welcome!

August 17, 2020
2:00 pm ET/11:00 am PT

ALS FOCUS SURVEY: LEARNING WHAT MATTERS MOST FOR PEOPLE WITH ALS AND CAREGIVERS

Guest Speaker:
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The ALS Association
Director, ALS Focus Program

The ALS Association
National Office-Care Services
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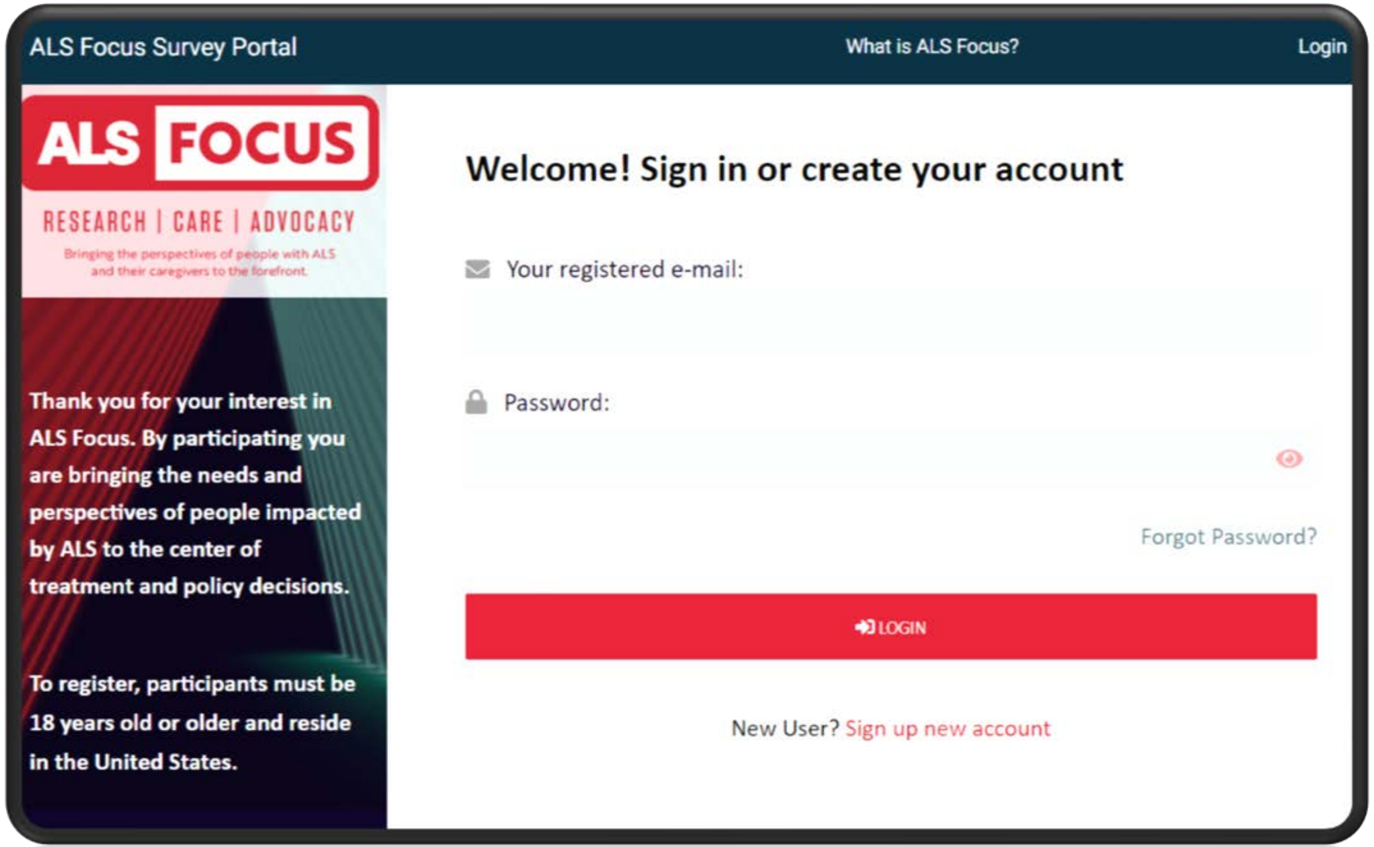
Refresher on ALS Focus

- ALS Focus is an online survey program.
- For people with ALS, current and past caregivers (18+ years old and living in the U.S.).
- Surveys ask about symptoms, burdens, and everyday impacts of ALS on daily life.
- Goal is to use survey results to improve drug development, clinical trial design, clinical care, and home health for people with ALS and their caregivers.



Thank you for your interest in ALS Focus. By participating you are bringing the needs and perspectives of people impacted by ALS to the center of treatment and policy decisions.

To register, participants must be 18 years old or older and reside in the United States.

Welcome! Sign in or create your account

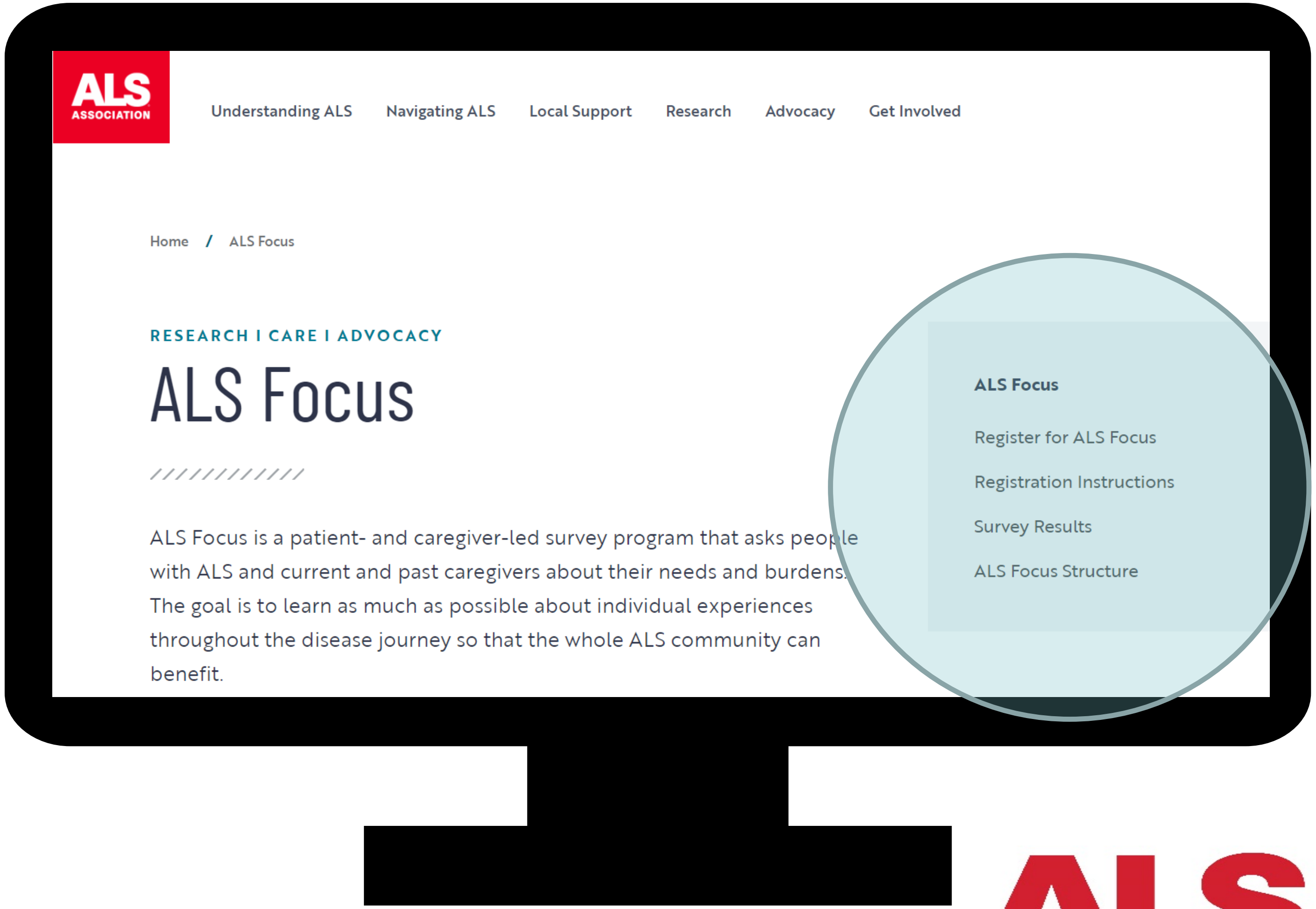
Your registered e-mail:

Password:

Where to participate

www.als.org/als-focus

- First-time participants can learn more information, sign up and register
- Several steps will get you started



RESEARCH I CARE I ADVOCACY

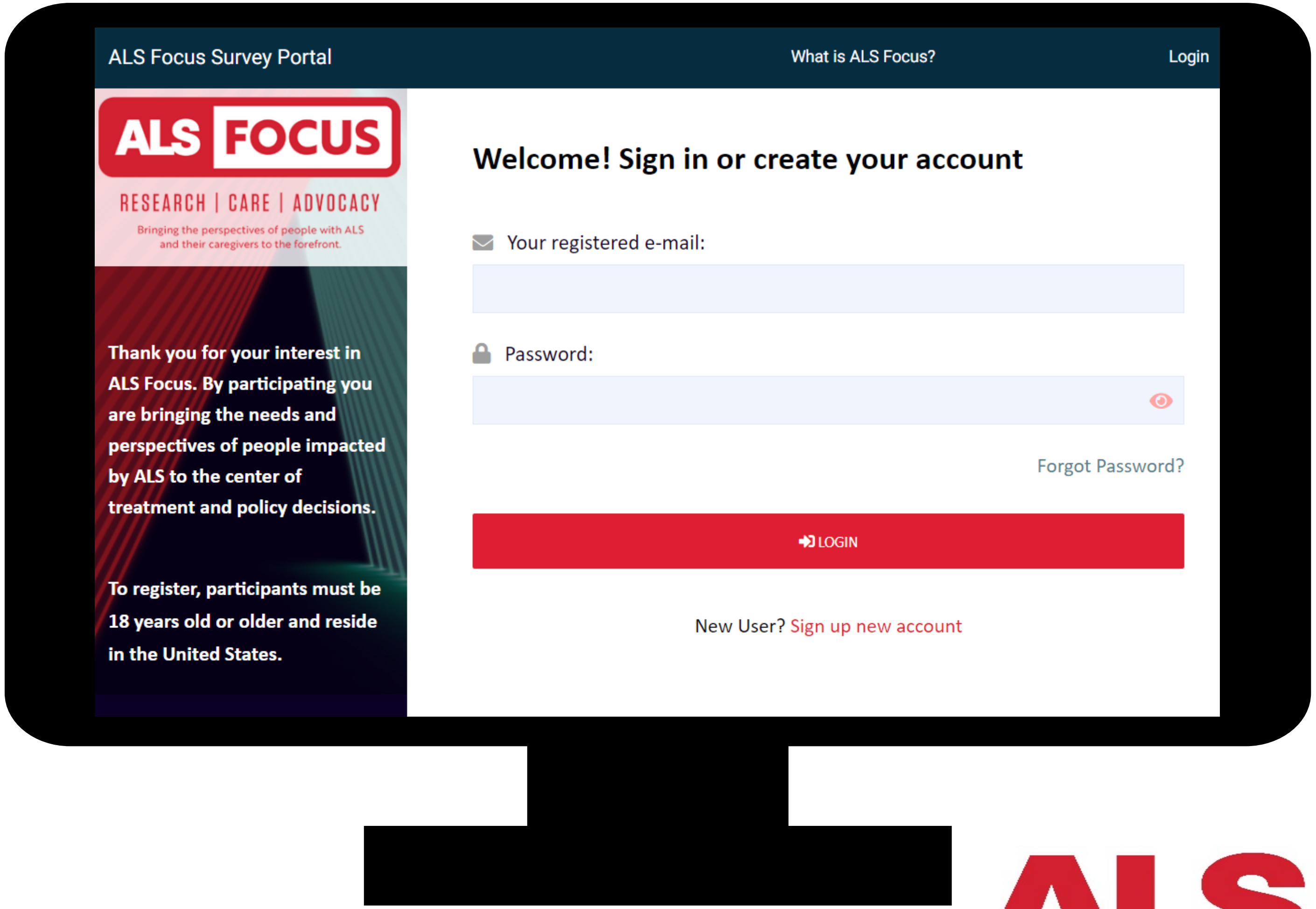
ALS Focus

ALS Focus is a patient- and caregiver-led survey program that asks people with ALS and current and past caregivers about their needs and burdens. The goal is to learn as much as possible about individual experiences throughout the disease journey so that the whole ALS community can benefit.

Where to participate

www.alsfocus.org

- Returning participants can login and take surveys



ALS Focus Survey Portal

Bringing the perspectives of people with ALS and their caregivers to the forefront.

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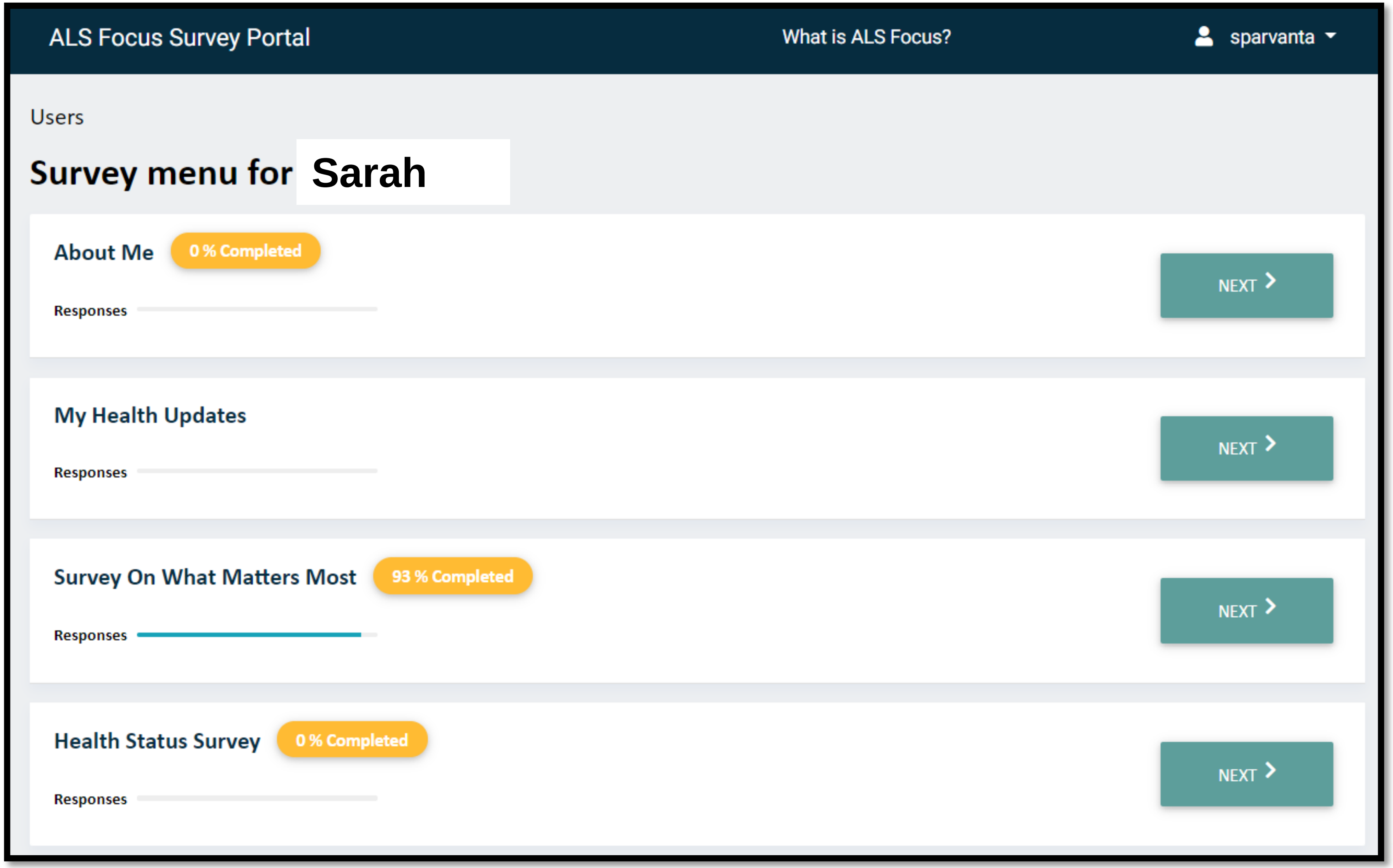
Welcome! Sign in or create your account

Your registered e-mail:

Password:

New User? Sign up new account

ALS Focus Survey Portal



Users

Survey menu for Sarah

About Me 0 % Completed

Responses

My Health Updates

Responses

Survey On What Matters Most 93 % Completed

Responses

Health Status Survey 0 % Completed

Responses

Summer 2020 Survey – Open now!

- **Topic: What matters most to people with ALS**
- How do ALS symptoms impact the lives of people living with ALS?
- Perspectives from people with ALS and caregivers are important!
- Your opinions will help the community create ways to improve quality of life

Spring 2020 Survey Results:
Understanding Insurance Needs and Financial Burdens

444 participants

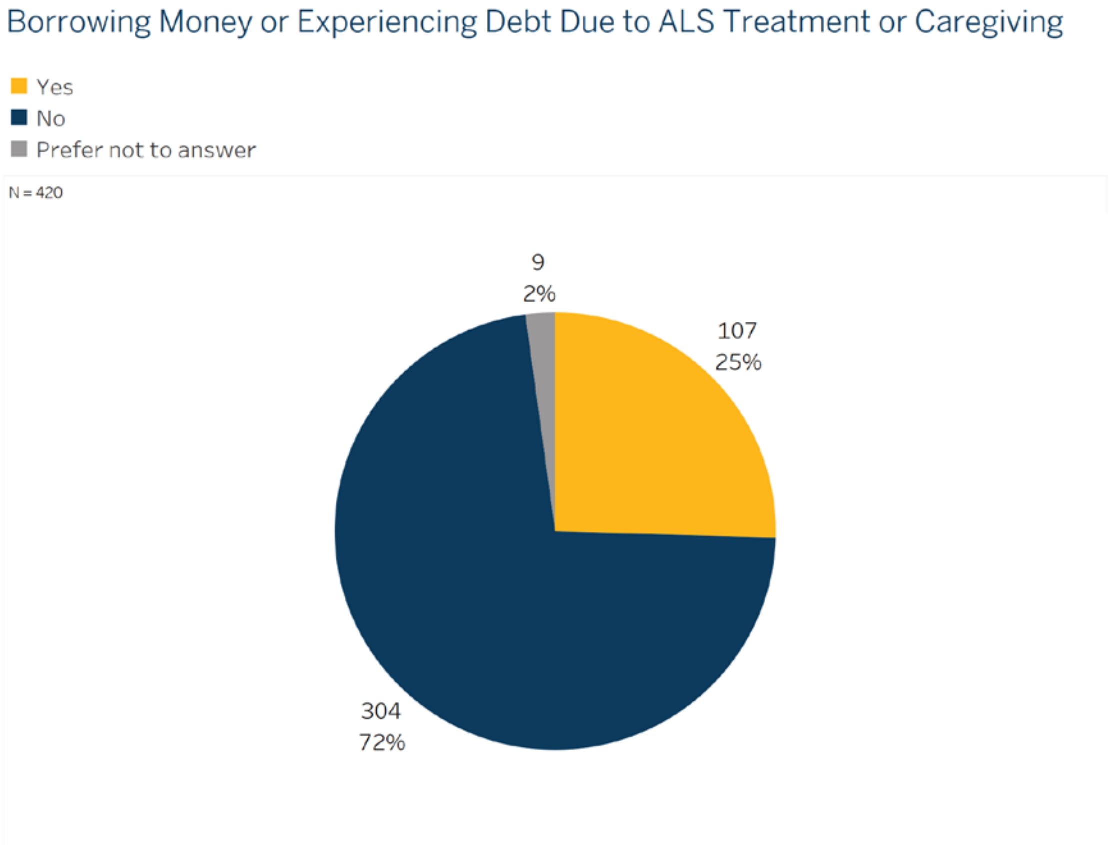
204 people with ALS
118 current caregivers
122 past caregivers

ALS ASSOCIATION

Understanding Insurance Needs and Financial Burdens

Debt from ALS

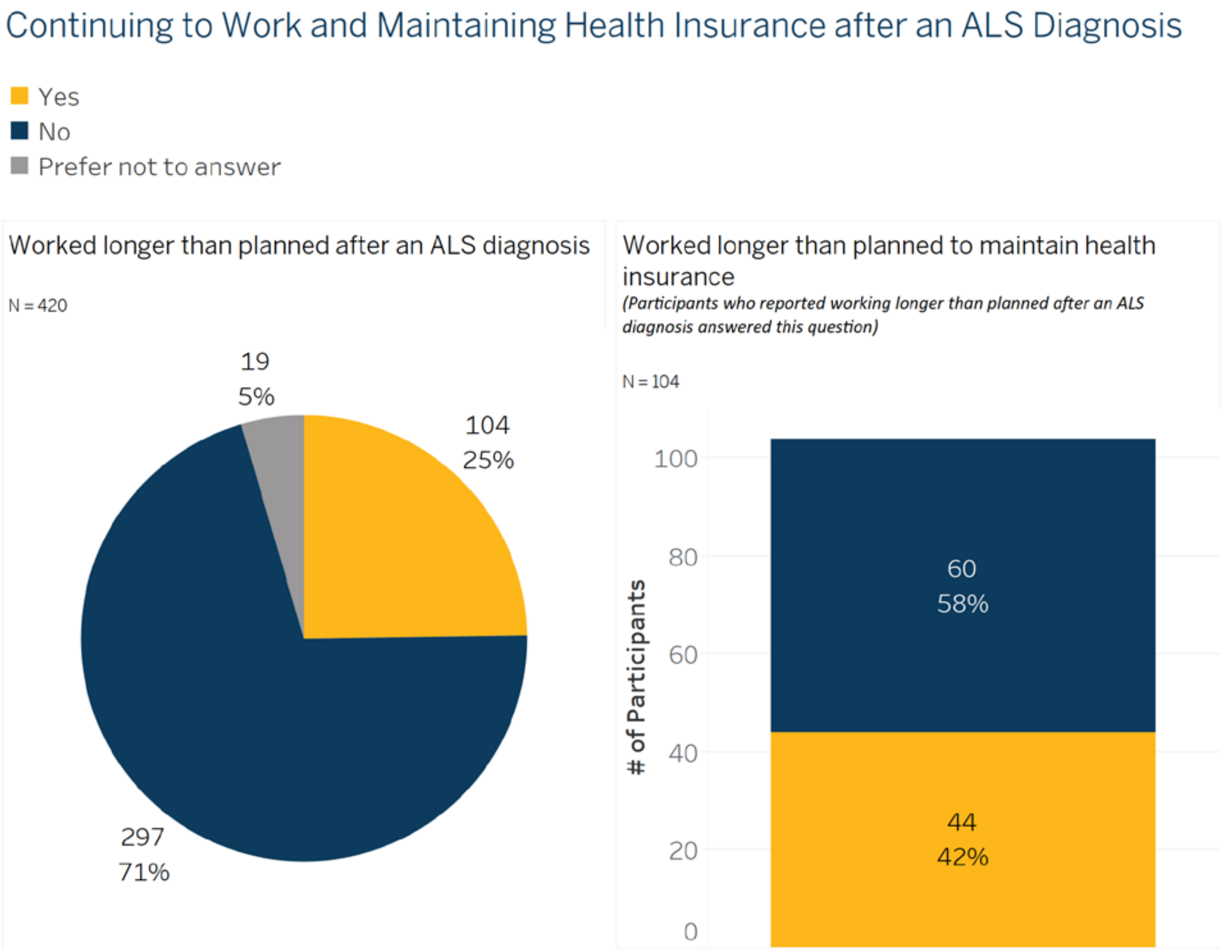
- **25%** had to borrow money or go into debt because of their ALS treatment or needing to provide caregiving.



ALS Focus results page

ALS Focus results blog

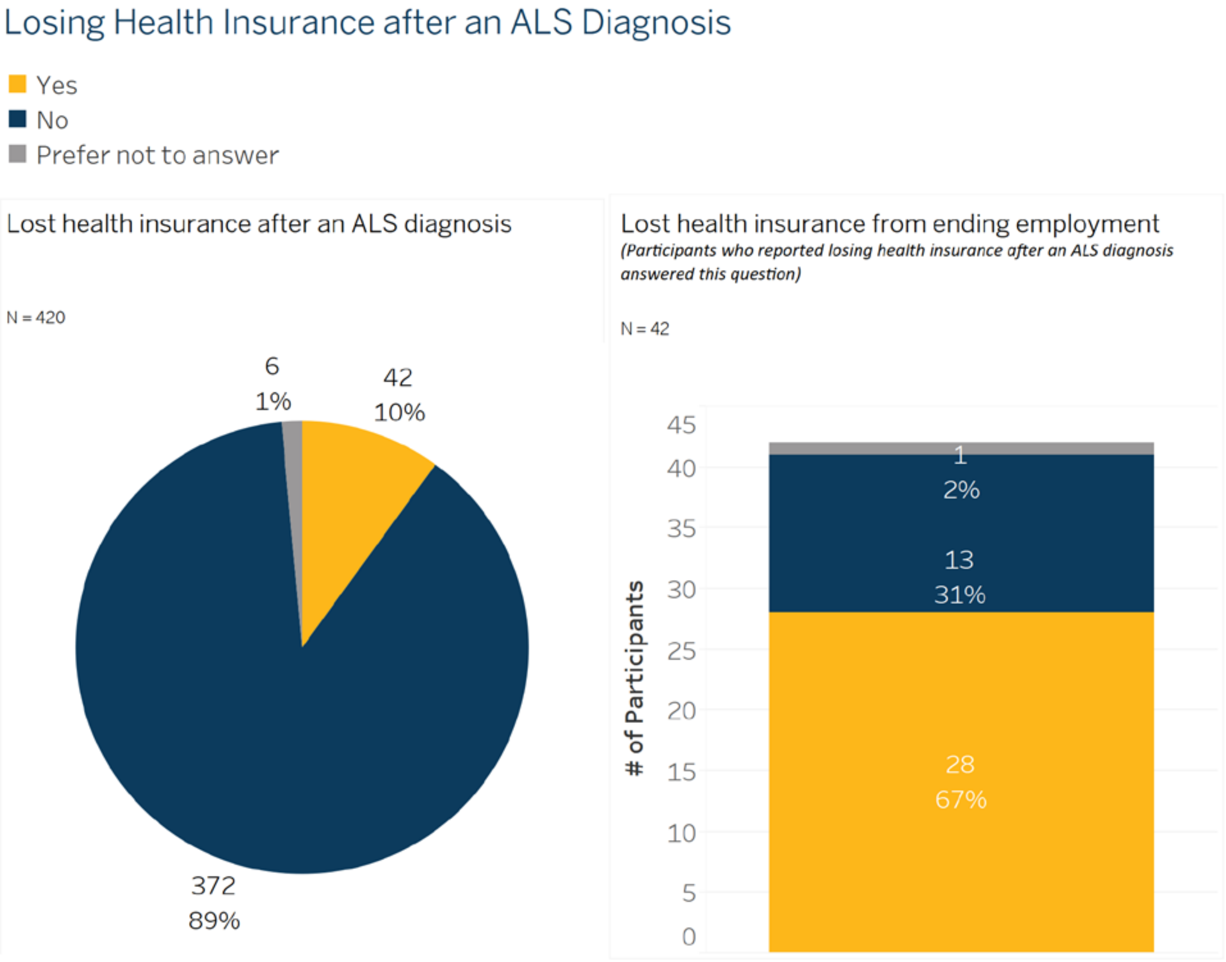
Understanding Insurance Needs and Financial Burdens



Work Burden from ALS

- **25%** continued working beyond originally planned after their ALS diagnosis or the diagnosis of the person they care(d) for.
- **42%** of those who continued to work did so to maintain health insurance, either for themselves as they live with ALS or the person they care(d) for.

Understanding Insurance Needs and Financial Burdens

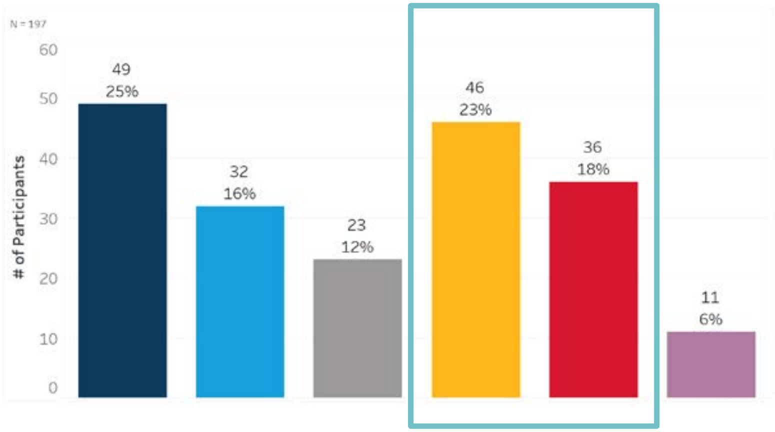


Losing health insurance

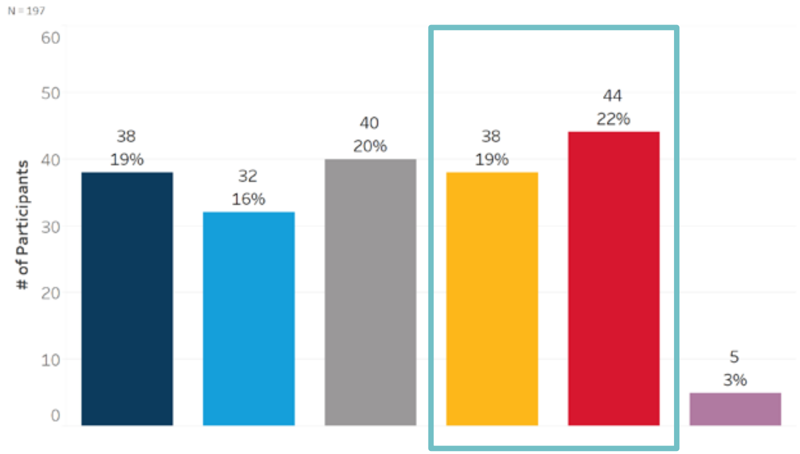
- **10%** lost health insurance after their ALS diagnosis or the diagnosis of the person they care(d) for.
- **67%** in this group said they lost their health insurance in part because they needed to stop working due to their ALS or to provide ALS care.

Financial stress from ALS

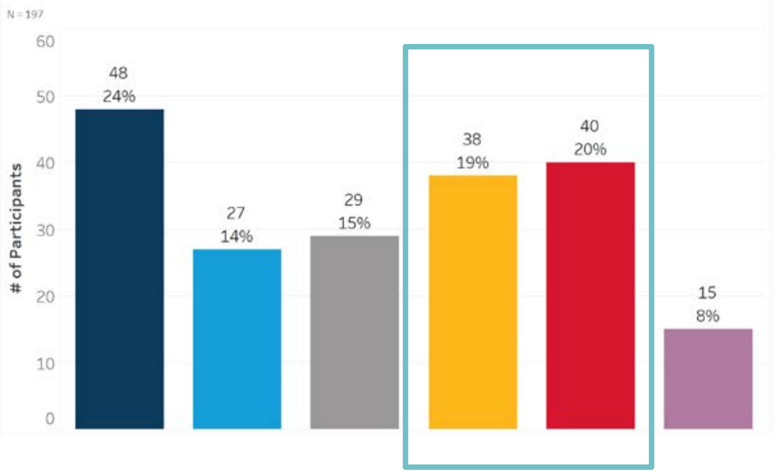
- 🟦 1 - Not stressful to me
- 🟦 2
- ⬜ 3
- 🟨 4
- 🟥 5 - Very stressful to me
- 🟪 Not Applicable



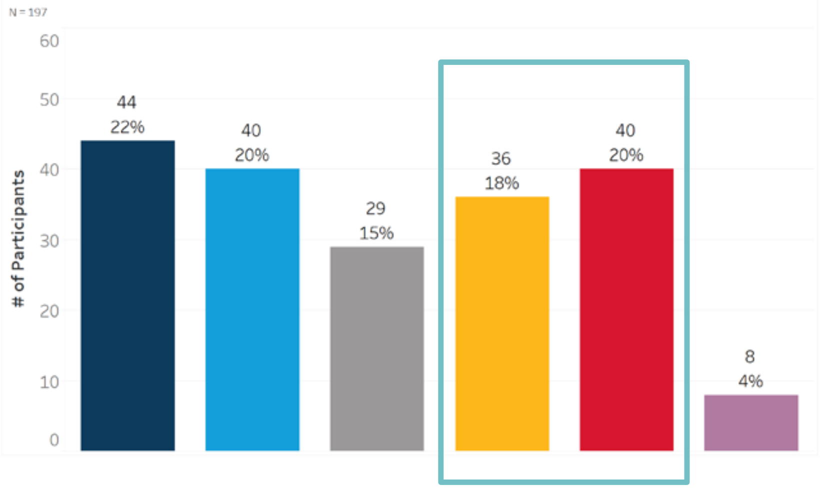
Covering costs of medical treatments



Understanding health insurance coverage



Covering costs of medical services



Managing medical bill paperwork

How will survey results be used?

- Financial burdens warrant attention
  - Borrowing money
  - Working longer than planned
  - Financial stressors

- Participants can see how their own experiences compare to others.
- The ALS Association assesses these results to improve care and advocacy.
- Use results to improve Chapter programs.
- Publish research papers to expand ALS knowledge and support policy change.

Why participate in ALS Focus?

Ensure your opinions contribute to your community

Survey data create strength in numbers

Shape care, clinical trials, advocacy, policy

ALS FOCUS

RESEARCH | CARE | ADVOCACY

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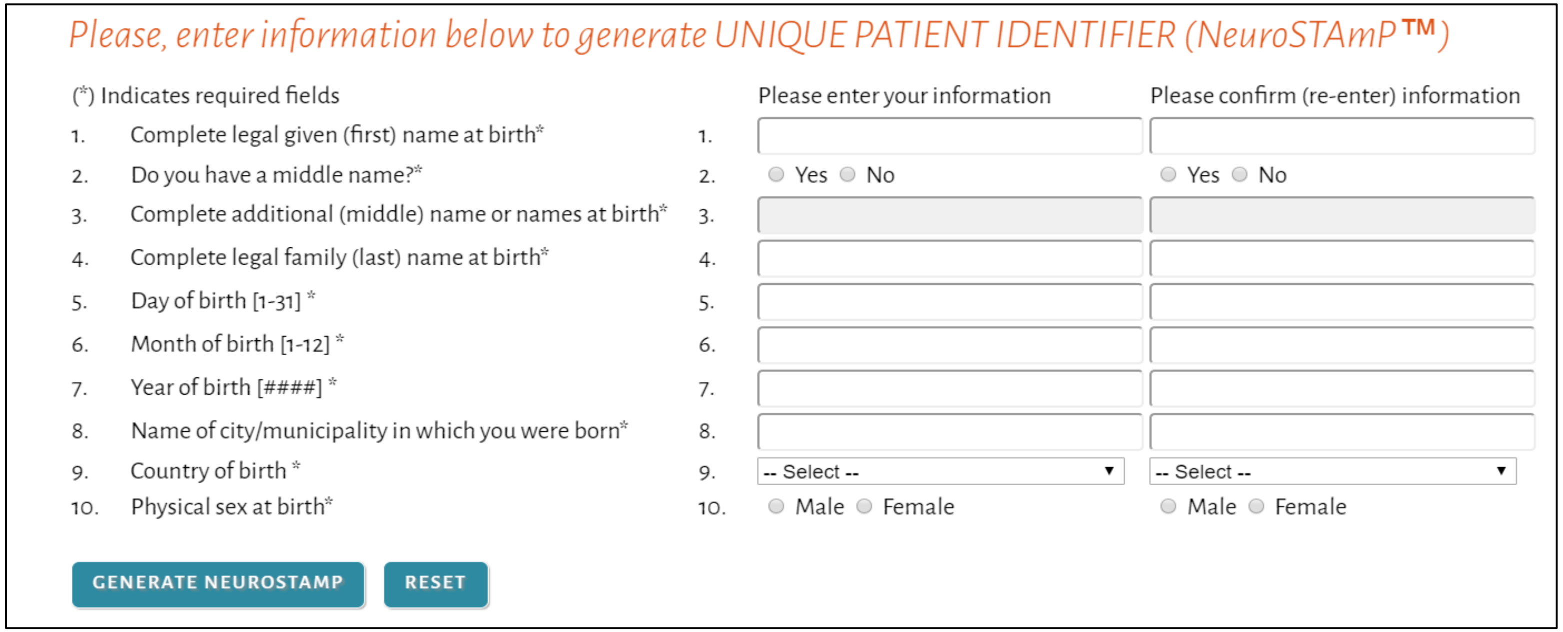
- www.als.org/als-focus
- www.alsfocus.org

Registration Steps
www.als.org/als-focus/als-focus-registration-instructions

1. Sign up using your email address and select a secure password
2. Click on the confirmation email
3. Sign into you account
4. Add yourself as a **USER** on your account
5. Complete a consent form
6. Create your NeuroGUID
7. Add any other USERS on your account
8. Complete demographics
9. Take surveys!
10. Need help? ALSFocus@alsa-national.org

Privacy

- Neurological Global Unique Identifier (NeuroGUID)
  - NeuroSTAmP
  - Random code of letters and numbers
  - Used to DEIDENTIFY participants' responses



Please, enter information below to generate UNIQUE PATIENT IDENTIFIER (NeuroSTAmP™)

	(*) Indicates required fields		Please enter your information	Please confirm (re-enter) information
1.	Complete legal given (first) name at birth*	1.		
2.	Do you have a middle name?*	2.	○ Yes ○ No	○ Yes ○ No
3.	Complete additional (middle) name or names at birth*	3.		
4.	Complete legal family (last) name at birth*	4.		
5.	Day of birth [1-31] *	5.		
6.	Month of birth [1-12] *	6.		
7.	Year of birth [####] *	7.		
8.	Name of city/municipality in which you were born*	8.		
9.	Country of birth *	9.	-- Select -- ▾	-- Select -- ▾
10.	Physical sex at birth*	10.	○ Male ○ Female	○ Male ○ Female

THANK YOU! QUESTIONS?

Contact:

Sarah Parvanta, Ph.D.
Director, ALS Focus Program
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