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
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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.
Where to participate

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

www.als.org/als-focus
Where to participate

- Returning participants can login and take surveys

www.alsfocus.org
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
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.
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

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

• 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 your 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
THANK YOU! QUESTIONS?

Contact:
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