



Challenges to Providing Services in the USA

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The ALS Association- USA

OUR VISION

Create a world without ALS

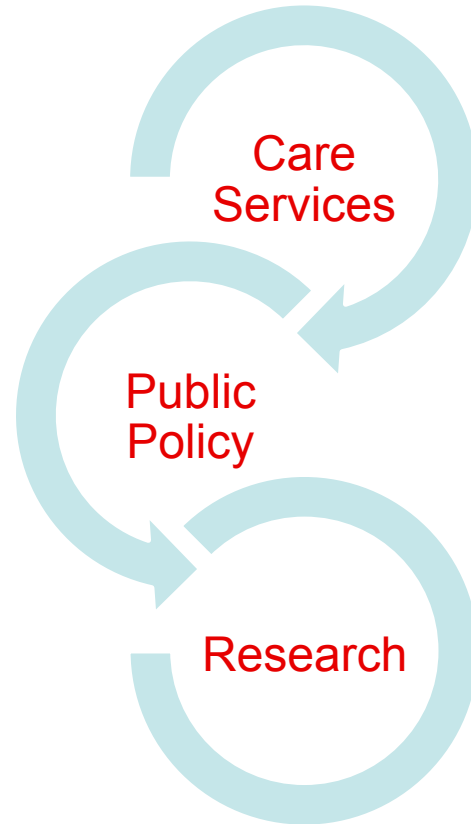
OUR MISSION

Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

Established in 1985

Only national non-profit organization in the USA fighting ALS on every front

Mission Integration

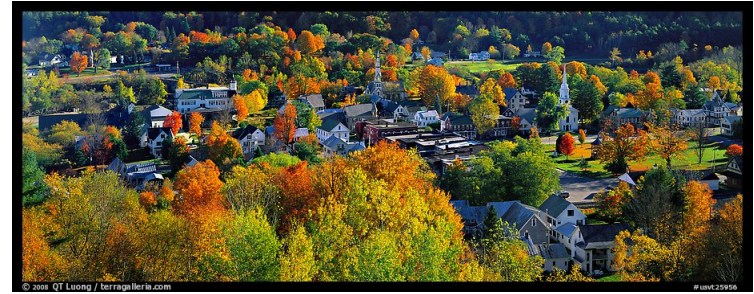


People with ALS and their families come first in everything we do.

Snapshot

- ❑ USA- 3rd most populous country in the world
- ❑ 319 million people
- ❑ 50 States and the District of Columbia
- ❑ Assumed prevalence is 20,000-25,000 people living with ALS in USA
- ❑ 38 ALS Association Chapters
- ❑ Chapter staff= 374
 - ❑ 115 staff dedicated to Care Services
- ❑ 50 National Office staff
 - ❑ 6 staff dedicated Care Services

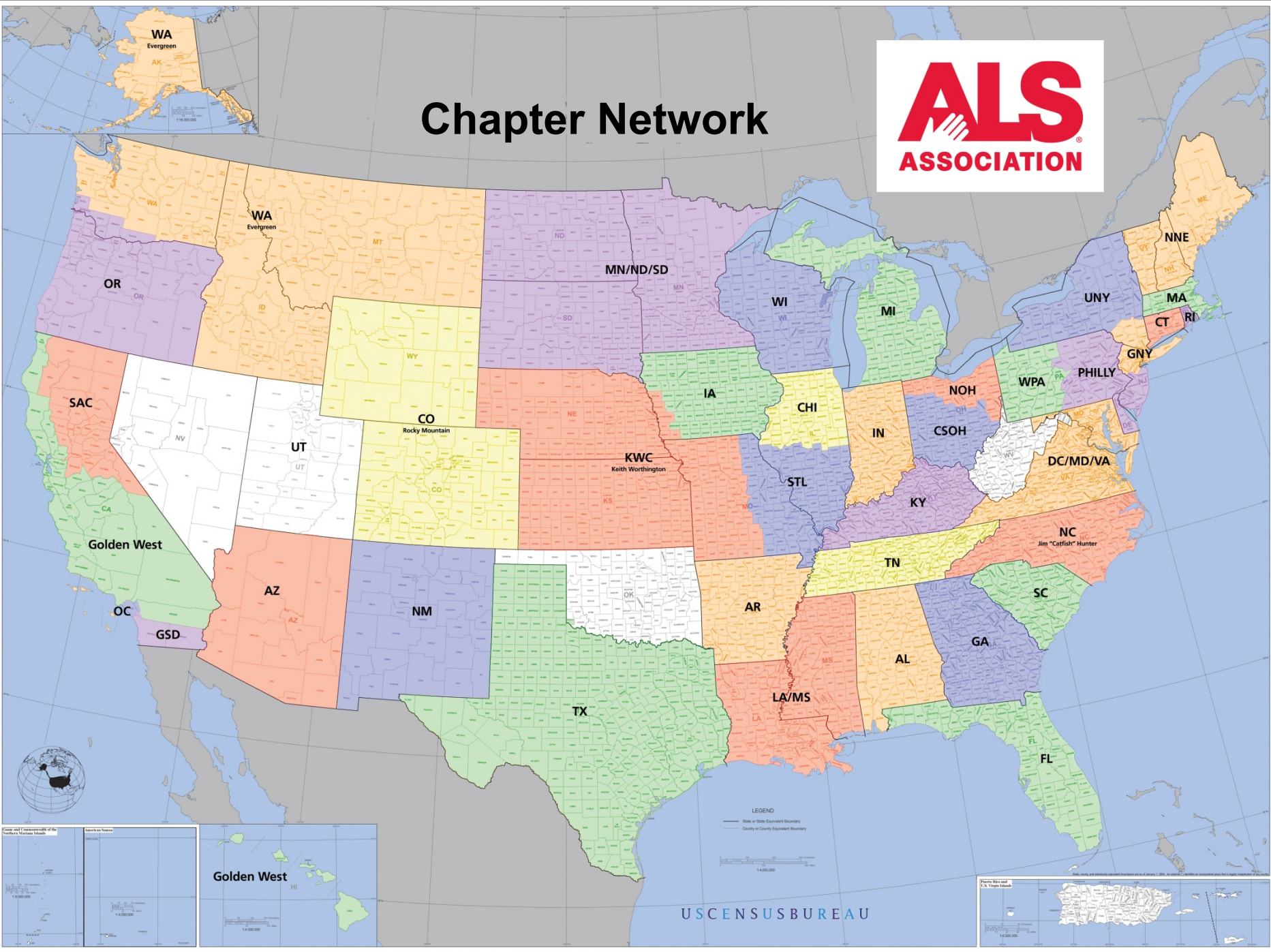
Across the USA: A vastly different landscape



Challenges

- Geographic
- General resources
- Federal, state and private insurance coverage
- Providers

Chapter Network

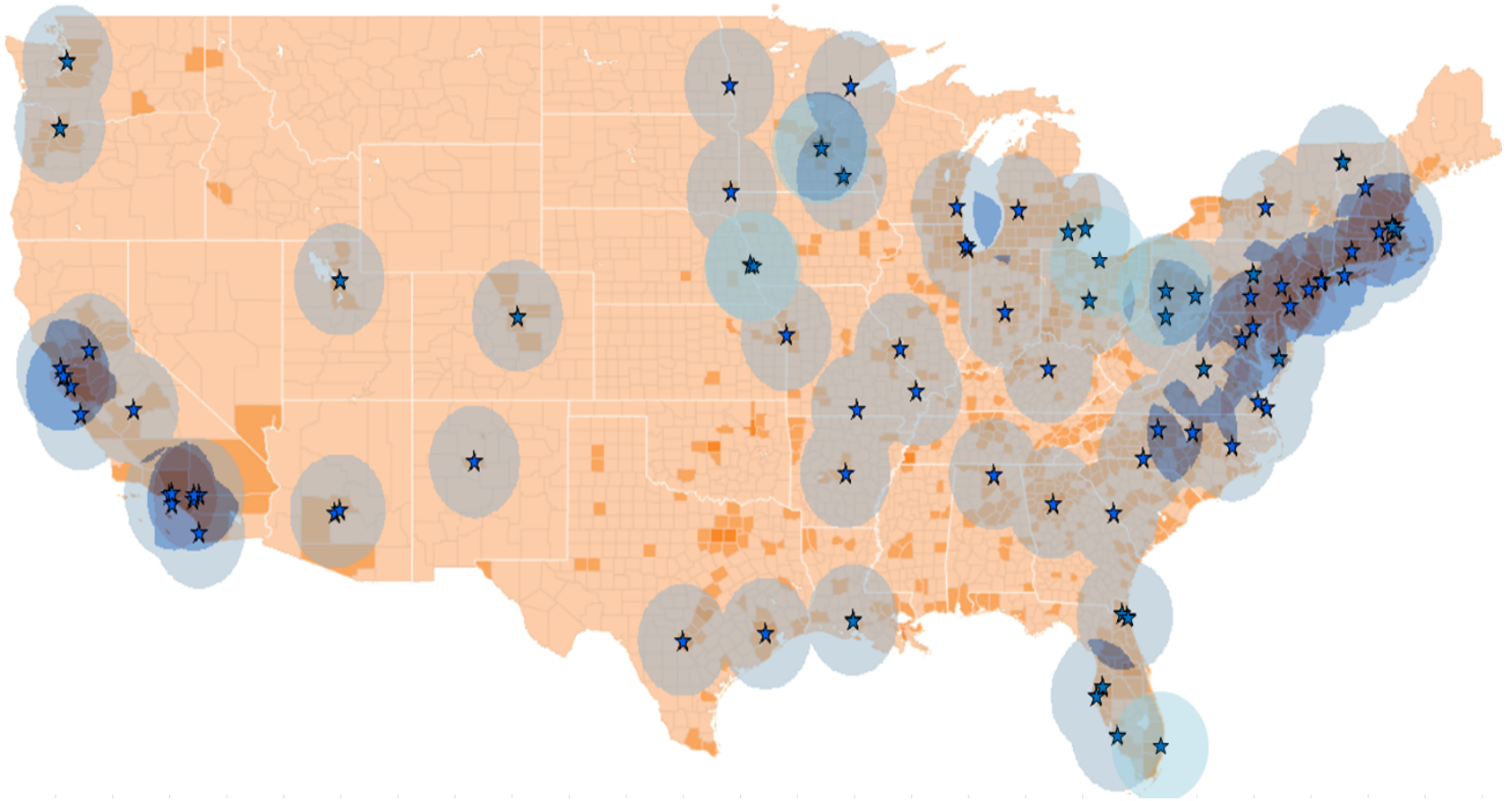


USCENSUSBUREAU

The ALS Association Chapter Network

- ❑ 38 Chapters
- ❑ (FY13)-provided care services and support to over 15,000 people living with ALS
 - ❑ Reaching approximately 60%, based on prevalence estimates
- ❑ Chapter Care Services may include:
 - ❑ Resource and Referral
 - ❑ Support groups
 - ❑ Home visits
 - ❑ Care Connection
 - ❑ Transportation programs
 - ❑ Bereavement programs
 - ❑ Respite grant programs

Geographical Distribution of Current ALS Association Clinical Collaborations



Circles show a 150 mile radius
The Booz Allen
Fusion Center – 10/2014

Utilizing Clinical Collaborations

- ❑ Partnerships with our network of 43 Certified Treatment Centers of Excellence
 - ❑ Provide highest quality multidisciplinary ALS care rooted in best practices
 - ❑ Actively engaged in ALS research
- ❑ Partnerships with over 50 affiliated multidisciplinary ALS clinics
- ❑ **7,328** people with ALS were seen through a Center of Excellence or affiliated ALS clinic (2013)

Questions We Ask Ourselves

- Are these locations supporting our overall achievement of our mission priorities?
- Are we serving people living with ALS equally across the United States?
- Are we in the right place, at the right time, delivering the right services?
- Are there opportunities we have now that we haven't had in the past?

How Can We Be Successful and Sustainable?

- ❑ By defining the scope of the services offered and aligning them with our mission and community needs
- ❑ By engaging in creative uses of resources to fund, staff and create demand for services for the long term
- ❑ By engaging in a continuous improvement process
- ❑ By always remembering our core values:

People with ALS and their families come first in everything we do

Maximizing Current Relationships and Creating New Ones

- ❑ Cultivation of new clinic partnerships and other models of care
- ❑ Relationships with national and state health service, home health and hospice agencies and veterans administration

Developing and Building Upon Existing Collaborations

- Other ALS-related organizations
- Foundations and other funding sources
- Governmental agencies
- Researchers

Providing ALS Education and Outreach

- Educational webinars for people living with ALS and their caregivers/families
- Educational webinars for professionals
- Association website and educational materials
- Regional ALS Educational Symposiums
- National Clinical Conferences for Professionals

Growing and Deepening All Relationships within The ALS Association

- ❑ Partnering with our Public Policy Department
 - ❑ Advocating in our nation's capital and at the state level
- ❑ Research
 - ❑ Educating the public
 - ❑ Supporting and identifying research opportunities
- ❑ Communications
 - ❑ Sharing our vision and education and allowing for constructive feedback to our organization
- ❑ Development
 - ❑ Identifying one-time and ongoing financial resources
- ❑ Finance
 - ❑ Being good stewards of our donors contributions in order to provide sustainable services

Thank you to my ALS Association colleagues:

- ❑ Barb Newhouse, President & CEO
- ❑ Kim Maginnis, Chief Care Services Officer
- ❑ Other members of our executive team:
 - ❑ Lance Slaughter, Chief Chapter Relations and Development Officer
 - ❑ Lucie Bruijn, PhD, Chief Scientist
 - ❑ Steve Gibson, Chief Public Policy Officer
 - ❑ Carrie Martin Munk, Chief Communications & Marketing Officer
 - ❑ Gregory L. Mitchell, Chief Financial Officer
- ❑ Our 38 Chapters- Executives and Staff across the USA

Questions?



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