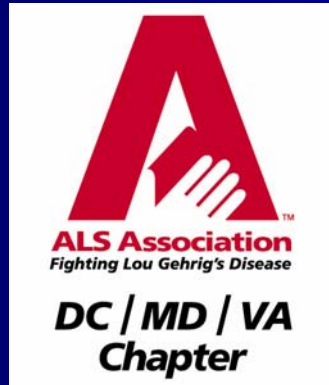


*Fighting on every front to
improve living with ALS™*



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www.ALSinfo.org

- Ken Nicholls
Executive Director
ALS Association—DC/MD/VA Chapter
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Facts about ALS

- Progressive, always fatal, neurodegenerative disease; attacks nerve cells and pathways in brain and spinal cord
- About 30,000 Americans have ALS at any given time; 5,000+ new cases each year
- Average age of onset is 55
- Commonly known as Lou Gehrig's Disease



Facts about ALS

- Average life expectancy 2 – 5 years
- Incidence same as MS and Huntingdon's



- Not just Lou Gehrig's disease—ALS occurs throughout the world with no racial, ethnic or socioeconomic boundaries
- NO KNOWN CAUSE OR CURE

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Factors Linked to ALS

- Aging
- Genetic predisposition
- Military Service
- Other potential factors:
 - Smoking
 - Exposure to environmental toxins
 - Athletic activities



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The ALS Association: Who we are

- The ALS Association's mission is to lead the fight to cure and treat ALS through global, cutting edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

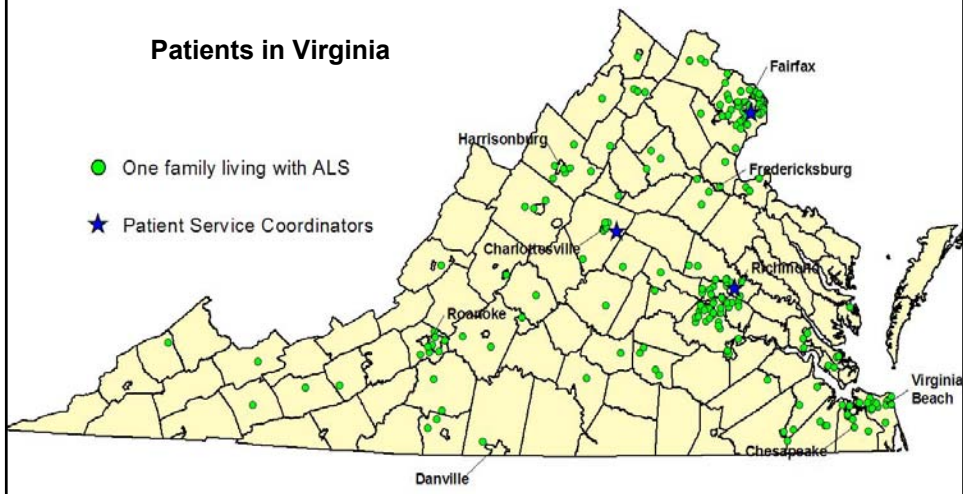


The ALS Association— DC/MD/VA Chapter



- Part of a national organization with over 40 chapters across the country; serving all of Virginia, Maryland, and DC
- Founded in 1991 by volunteers to respond to the unmet needs of patients & families

The ALS Association— DC/MD/VA Chapter



The ALS Association— DC/MD/VA Chapter

- Over the past 18 months, provided support to more than 300 Virginia families
- We identify and address the needs of the ALS community on multiple fronts
- Raise awareness and understanding about ALS through Advocacy, research, fundraising

DC/MD/VA Chapter Services

- All of our services are offered free of charge:
 - Individual support/home visits
 - Information & referral
 - Support groups
 - Medical equipment loan closet
 - Respite care grants
 - Transportation grants
 - Augmentative communication/assistive technology services
 - Multidisciplinary ALS clinic

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Needs of the ALS Community are Great



- Cost of care for an ALS patient can cost the family upwards of \$200,000 per year
- Custodial care disease—most patients remain at home and are cared for by family
- Insurance and Medicare do not cover cost of home care for assistance with most activities of daily living



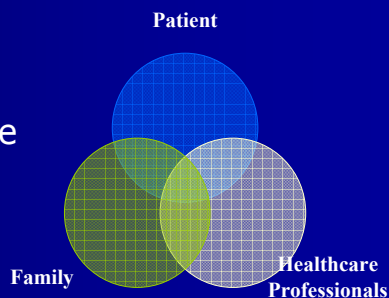
DC/MD/VA Chapter Services

- Also provide support to the entire community:
 - In-services
 - Information & referral
 - Support for healthcare professionals
 - Research & clinical update information
 - Advocacy efforts, both state and federal

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How the ALS Association is unique

- The only organization in Virginia dedicated solely to helping the ALS community
- All services offered free of charge regardless of income
- Live and work in the communities we serve
- 100% privately funded



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How the Commonwealth can support families living with ALS

- Home based care program
- Assistive Technology Program
- Multidisciplinary ALS Clinic at UVA
- Transportation Program
- Medical Equipment Loan Program

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How the Commonwealth can support families living with ALS

- Home-based care—funding would help expansion into underserved areas and potentially reach an additional 100 families affected by ALS

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How the Commonwealth can support families living with ALS



- Assistive Technology—funding would allow us to provide additional grants to help pay for communication devices and purchase additional equipment not provided through VATS or DRS

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How the Commonwealth can support families living with ALS

- Richard Dart ALS Clinic at UVA—funding would allow the only multidisciplinary ALS clinic in Virginia to expand their clinic hours and services



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How the Commonwealth can support families living with ALS

- Transportation—funding would allow for additional grants for wheelchair accessible transportation to medical appointments

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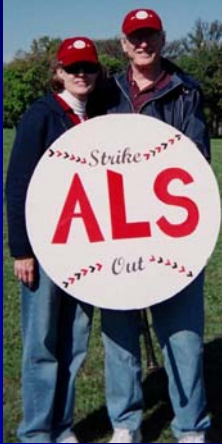
How the Commonwealth can support families living with ALS

- Medical Equipment Loan—funding would allow for expansion of program which provides medical equipment not covered by insurance



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The ALS Association



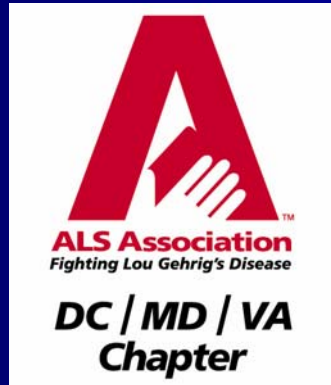
- “There is a great deal that can be done to treat the symptoms of ALS, to improve the quality of life of a patient, and to help caregivers and the family cope with the disease”

– *Mitsumoto and Norris 1994*

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