

**Statement of Jim Barber Before the  
California State Assembly Health Committee  
Presented on January 29, 2013**

Chairman Pan, committee members: Good afternoon. My name is Jim Barber. I have ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's disease). I am accompanied today by my wife of 45 years, and now my full-time caregiver, Cheryl, without whom I literally could not do anything anymore. I am here today to speak about multi-disciplinary ALS centers and clinics – the established system of care for patients with ALS.

ALS is a degenerative neuromuscular disease in which the nerves die and the muscles, in turn, atrophy and die. Patients live, on average, only two to five years from diagnosis. ALS patients never get better. In the late stages of the disease, they are completely paralyzed, unable to walk, talk, eat, or breathe. In the 150 years since ALS was discovered, there is still no known cause, prevention, treatment, or cure. The disease can strike anyone at any time. There is only one FDA approved drug that gives only some ALS patients an extra month or two of life.

Presently, treatment consists solely of symptom management. From a patient's perspective, the medical landscape is ever-changing, sometimes quite rapidly – and it can be overwhelming. How can I prolong the use of my arms and legs? When will I need a wheelchair? When should I get a stomach tube? How quickly will my breathing deteriorate and how do I cope with that? How can I communicate when I can no longer talk? How do you find caregivers? What diet is most helpful? How can I prepare myself and my family to navigate all that is to come? How can I travel to an ALS center or clinic when I can no longer walk or drive? What benefits are available to help pay for all of this?

All of these questions, and more, require answers from different medical experts. Left to their own devices, ALS patients must seek different medical providers at different locations at different times to get answers and treatments – a daunting and sometimes insurmountable challenge for people with ALS. The answer lies in multi-disciplinary ALS clinics and centers that afford ALS patients and their families "one stop shops" for all of their ALS-related medical needs. At these centers and clinics, patients and their families can spend 3 to 4 hours in one place at one time consulting every medical specialist and expert they need during the progression of the disease, including:

- Neurological diagnosis, care and treatment
- Physical therapy
- Occupational therapy
- Respiratory therapy
- Nursing care
- Registered dietitian services
- Psychology or psychiatry
- Speech and language pathology
- Medical social work services

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Research has shown that attendance at ALS centers and clinics can extend life 10 months or more – which is more than three times that of the only FDA-approved drug. This multi-disciplinary treatment regimen also reduces hospital visits and increases the quality of life significantly for both patients and their families.

In addition, where possible, the ALS centers and clinics provide wrap-around services such as respite care, home care and telemedicine — services that are crucial to ALS patients, particularly those who are unable or cannot afford to travel to one of these ALS centers and clinics. Any comprehensive program also should include the provision of durable medical equipment to patients, for which the Veterans Administration program is a good model.

The foregoing multi-disciplinary standard of care for ALS patients is embodied in Section 104323 of the California Health & Safety Code. As you move forward to implement the Affordable Care Act in California, I urge you to look closely at established models of care, such as the ALS centers and clinics which are true medical homes for patients with ALS and their families.

I would like to introduce my friend and colleague, Fred Fisher, the President and CEO of the Golden West Chapter of the ALS Association. With your permission, Fred will elaborate on the key elements of the ALS centers and clinics.

Thank you again for the opportunity to speak to you today.