

ALS Better Care Act

(S.3258 & H.R.5663)

A law to fund ALS Clinics

ALS is a financially, physically, and emotionally devastating disease that is currently 100% fatal. Most people living with ALS will die within two to five years after diagnosis. Unfortunately, there are few treatments and no cures. However, treatment at an ALS multidisciplinary clinic has been shown proven to extend survival and improve quality of life while living with ALS. This provides people living with ALS (PLWALS) and their loved ones with more quality time together.

What is an ALS multidisciplinary clinic? There are more than 200 of them around the US. These clinics bring together teams of specially trained health care professionals to address the many needs of PLWALS. This approach allows health care professionals to communicate with each other more easily and PLWALS to receive comprehensive care during a single visit. These evidence-based multidisciplinary clinics help ALS patients and their families avoid the need to have multiple, separate appointments in different locations. Additionally, some multidisciplinary ALS clinics are involved in ALS-specific research, thereby providing PLWALS with opportunities to participate in research and clinical trials.

While multidisciplinary clinics provide much needed support and resources to people living with ALS, clinics are often burdened by financial constraints. This bipartisan bill seeks to rectify these challenges by increasing the amount ALS providers at multidisciplinary clinics receive from Medicare for seeing PLWALS. This allows the clinics to focus on patient care and quality of life without the added stress of excessive costs and bureaucracy.

In addition, the ALS Better Care Act directs the National Institute of Neurological Disorders and Stroke (NINDS) to submit a report to Congress on the challenges facing ALS clinical trial sites and solutions to these challenges. This could lead to faster clinical trial enrollment, which will speed up the science and get us closer to a cure.

Rationale

ALS multidisciplinary clinics provide much needed resources and support to people living with ALS. However, these clinics are often burdened with financial constraints. These clinics not only provide excellent care, but help PLWALS and their families by having them attend one appointment, instead of many. This saves PLWALS' and their loved ones' time and money. This bipartisan bill seeks to correct these challenges, allowing people living with ALS, and the clinics that treat them, to focus on patient care and quality of life without the added stress of excessive costs and bureaucracy.

Ultimately, this bill will improve the lives of people living with ALS and their families, loved ones, and their caregivers. It will reduce burdens on them so that they can focus on enjoying their time together while knowing that they are receiving the best care available.

Bill Components

- Creates a supplemental, facility-based payment in Medicare for ALS-related services.
- Directs the Government Accountability Office to submit a report to the Department of Health & Human Services recommending a single payment amount for ALS-related services.
- Directs the National Institute of Health's National Institute of Neurological Disorders and Stroke (NINDS) to submit a report to Congress and publish it on their agency website. The report must address the (1) challenges in administering and staffing clinical trials, (2) actions to address the challenges, and (3) legislative recommendations.

About ALS

ALS is a 100% fatal disease that makes the brain stop talking to the muscles, causing increased paralysis over time. Ultimately, ALS patients become prisoners within their own bodies: slowly losing the ability to eat, talk, move or breathe on their own. Their minds, however, often remain sharp so they are aware of what's happening to them. ALS will affect 1 in 300 people (military veterans are more than twice as likely to be diagnosed), and life expectancy after diagnosis is typically 2-5 years.

Contact to Support

Rep. Jan Schakowsky (D-IL) & Rep. Brian Fitzpatrick (R-PA)
Sen. Chris Coons (D-DE) & Lisa Murkowski (R-AK)