

The Morris ALS Principles

ALS, a devastating neurodegenerative disease discovered in the middle of the 19th century, has killed millions of people across the globe. Yet more than 150 years later, there are no cures, no effective treatments, no urgency. This is unacceptable.

Today, we unite as leaders to end ALS. We take ownership of our disease so that the road to cures is faster, equitable and more humane. We are not *subjects* or *victims*, and are only occasionally *patients*, a term which implies passivity. We are a relentless community working alongside researchers, policy-makers and clinicians to identify and cure this heterogeneous disease. We demand a seat at the table *before* decisions are made in drug trial design, research, healthcare policy or anything that affects our care. From this point forward, we will not tolerate siloes, disorganization or lack of urgency by any agency or organization that serves us. There will be *Nothing About Us Without Us*.

We live on the ALS Clock.* ALS is stunningly brutal and kills us quickly. Our political leaders must make ALS research and therapy development a national priority. Our nation has rallied to confront HIV/AIDS, cancers, multiple sclerosis and now COVID-19. We demand that the United States leaders make a commitment to end ALS.

We will:

1. **Protect** our intellectual, physical, and financial dignity.
2. **Be global stewards** of our disease and respected partners in the science of treatments and cures.
3. **Act as trusted peers** with clinicians, researchers, and policy-makers.
4. **Fight** for equity in decision-making.
5. **Lead** to end ALS.

This impacts you!

Healthcare professionals

- Communicate with us and about us as though we are *living* with ALS. We are partners with you in our own care.
- Encourage every Person Living with ALS to consider clinical research by providing timely, comprehensive information about approved and investigational therapies. We are experts in our own disease and deserve to be informed.
- Provide accessible clinical and research options, including telehealth.
- Give options for genetic counseling and testing, even for those with no known family history of ALS.

Scientific community & ALS research community

- Provide virtual and in-person access to all ALS/MND conferences and scientific meetings for People Living with ALS.
- Include People Living with ALS on all clinical trial protocol teams, on advisory bodies to the National Institutes of Health, the Food & Drug Administration, Centers for Disease Control & Prevention.
- Build Expanded Access Programs (EAPs) into drug development plans. EAPs for other diseases were key routes to extend experimental therapies to those not eligible for trials and to learn more about the therapies and the disease. Sponsors must design trials that adhere to the Patient-Centric Trial Design (PaCTD) rating criteria.
- Share your data, designs, failures, and best practices. Your duplication of work is deadly.

ALS policy community, legislators & regulators

- Prioritize finding treatments and cures as if your loved one was living with ALS. You must move as aggressively as the disease itself.
- Execute *real* pathways to access experimental treatments through EAPs or a national ALS clinical trials network.
- Mandate a reliable census of People Living with ALS with an annual report that uses modern technology and information science as the current epidemiology in the US is poorly understood.
- Create policies that provide coverage for care and caregivers.
- Treat ALS as the non-partisan issue that it is.

ALS nonprofits

- Amplify and serve the diverse People Living with ALS.
- Focus on your core competencies and celebrate the successful efforts & results across the Community. Work together to address the critical gaps that are preventing real progress.
- Don't treat us as mere fundraising opportunities for your organization. We are the people you serve and must be involved in every facet of operations, including your board of directors.

*** The ALS Clock**

This disease will kill 50% of us within 3 years, it will kill 90% of us within 5 years.

Our lives are worth saving. Work with that kind of urgency.

This document was created by those living with and impacted by ALS