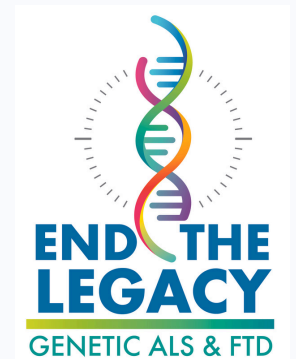


Centers of Compassion Initiative



End the Legacy Genetic ALS & FTD At Risk Care Centers of Compassion

End the Legacy proudly announces a new initiative to drive innovation in clinical care for individuals at great risk of genetic ALS and FTD. Through resource sharing and financial support, we aim to encourage clinics to adopt measures that ensure competent and compassionate care for our vulnerable community.

Criteria for Centers of Compassion

Clinics striving to meet the vision of this initiative will need to fulfill the following criteria:

1. **Cultural Competency** : Acknowledging both the risks associated with carrying a pathogenic gene and the likelihood of many years of functional health. This includes understanding the evolving knowledge of disease likelihood (penetrance).
2. **Dedicated Time for At-Risk Individuals**: Rather than ad-hoc inclusion, clinics should dedicate regular time to see these individuals. Initially, monthly or even quarterly focus days may suffice.
3. **Commitment to Staying Informed**: Clinics must stay updated on the latest developments in the management of at-risk individuals, especially through periodic communications from End the Legacy, and be open to patient preferences in monitoring methods.
4. **Connection to Resources and Peer Supports**: Clinics should commit to connecting individuals to relevant resources and peer supports, as such as those offered by End the Legacy.

Future Directions

As we advance and discover best practices, we expect these criteria to evolve. One area of active exploration is how a non-profit model can support genetic counseling costs and the education of at-risk individuals about the importance of documenting risk in medical records. This step is crucial before they engage with a clinic and generate those records.