At Risk Care Center Recognition

Background

With progress occuring in therapies for some forms of genetic ALS and endorsements of prompt diagnosis for all forms of ALS and FTD, guidance has emerged detailing what clinical care may be offered to those at risk of genetic ALS / FTD. To encourage centers to offer this care and to make sure the care on offer is responsive to community needs, End the Legacy established a recognition program for Centers of At Risk Care in 2024.

Recognition Criteria

Centers seeking recognition are asked to strive to meet certain criteria

Framework

- [ ] Centers will strive to provide culturally competent care for those at genetic risk of ALS and FTD - acknowledging both the risks associated with carrying a pathogenic gene and the likelihood of many years of functional health and possibility of incomplete penetrance.
- [ ] Centers will consider establishing, when practical, specific days or times of at risk care.
- [ ] Centers will stay up to date on the evolving best practices for at risk monitoring in ALS and FTD and will adhere to the practices outlined in the forthcoming At Risk Care Guidelines currently being developed by End the Legacy and leading clinicians.
- [ ] Centers will offer community resources to at-risk patients including information on research participation, educational resources, and community organizations all available at EndtheLegacy.org.

Current Recognized Centers

We cheer the centers who have sought and achieved recognition to date. If you are interested in being recognized email info@endthelegacy.org to learn more.

UCSF ALS Center	**Nova Southeastern ALS Center**
Temple Neurology ALS Center	**Motor Neuron Disease Risk Assessment Clinic , Massachusetts General Hospital**
University of Minnesota ALS Center	**Northwestern University ALS Center**