Focus: Neurodegenerative disease

Adira is a national, tax-exempt foundation whose mission is to invest in better lives for people with neurodegenerative diseases.

We work by bringing disease communities together, listening and learning from their point-of-view, naming and setting priorities for grants, co-financing and funding programs. We monitor, evaluate, and learn from the work to improve over time.

Adira Foundation will focus first on people living with five neurodegenerative diseases:

- Alzheimer’s disease
- ALS
- Huntington’s disease
- Multiple sclerosis
- Parkinson’s disease

Neurodegenerative disease is a national public health priority.

Research shows these conditions: (1) are more prevalent and costly (2) constitute high-needs, complex conditions, and (3) are placing significant financial and other burdens on families and caregivers.

GROWING POPULATION, COSTS

- The total number who live with these five diseases is expected to grow from 8 million to 11 million by 2030, a 38% increase.
- Neurodegenerative diseases are more common in people over 85—a group expected to grow from 5.8 million to 18 million by 2050, a 210% increase.

Costs to U.S. systems

- Alzheimer’s disease: $186 billion
  Annual cost to Medicare and Medicaid systems
- ALS: $256-433 million
  Annual cost to commercial and Medicare systems
- Huntington’s disease: $603 million*
- Parkinson’s disease: $14.4 billion*
- Multiple sclerosis: $28 billion*

*Annual cost to U.S. health systems
HIGH-NEEDS, COMPLEX CONDITIONS

Neurodegenerative diseases are among the most complex and life-altering diagnoses. Current programs addressing just one or two needs aren’t enough for people with dozens of needs.

Neurons deteriorate in the brain and spinal cord, causing physical, mental and emotional symptoms to progressively worsen.

Secondary diagnoses or complications can cause a wide range of additional symptoms, requiring complex and coordinated care.

The severity and complexity of these needs require expensive treatment, specialists and medical equipment—very costly to the health systems.

 Symptoms impact how well a person thinks and moves, make independence increasingly difficult, and even affect personality.

 Depression rates are significantly higher among each of these five communities, ranging from 30-50%, compared to the national average of 7%.

 On top of medical care, everyday needs—social/emotional support, childcare, household chores, administrative help, etc.—grow more complex.

BOTTOM LINE: People end up taking on a great deal at a time when they have less ability to do it. The system needs to change.

FAMILY/CAREGIVER BURDEN

U.S. OUT-OF-POCKET CAREGIVING COSTS

$232 billion
the value of unpaid care provided by Alzheimer’s disease caregivers in 2017.

$2.36 billion
the value of annual unpaid care provided by Parkinson’s disease caregivers.

PER FAMILY/CAREGIVER COSTS

$129,059 per family
spent on average out of pocket throughout the duration of ALS.

$1,284 per caregiver
spent by Huntington’s disease caregivers out-of-pocket per year.

$14,000-$24,483 per family
the range of annual MS-related costs.

SOURCES:
https://census.gov/
https://alzimpact.org/
http://www.alsa.org/
https://www.nationalmssociety.org/