An introduction

Greg Smiley, CEO
gsmiley@adirafoundation.org
Adira’s mission is to invest in better lives for people with neurodegenerative diseases. We want to solve the isolating nature of navigating care for these “high needs” populations.

Many are working on solutions:

- Patients
- Doctors
- Legislators
- Manufacturers
- Advocacy organizations, patient groups, other nonprofits
- Insurance companies
- Federal and state payors

But often separately—addressing one issue or one diagnosis at a time.

“\[
\text{“We have so little time left together, and yet our system forces us to waste it dealing with bills and bureaucracy.”} \\
\text{– Ady Barkan, ALS patient, Congressional hearing}
\]
Adira’s big idea:

Best of both domestic and global health practices.

Five communities working as one family to address commonalities. Starting with neurodegenerative diseases: Alzheimer’s disease, ALS, Huntington’s disease, multiple sclerosis, Parkinson’s disease.

- Neutral platforms to convene full range of stakeholders
- Community-driven action and priority setting
- Movement building
- Larger financing mechanisms:
  - Results-based financing
  - Accountability and oversight
  - Leverage funding from other sectors
  - Economies of scale
Why neurodegenerative disease?

Neurodegenerative diseases have much in common—symptoms impact how well a person thinks and moves, they make independence increasingly difficult, and they even affect personality. In addition, caregivers face tremendous burden.

High costs, growing population

- 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.

- Caregiving costs for Alzheimer’s disease and Parkinson’s disease are $232 billion and $2.36 billion, respectively.
How?

Model:

Prioritizing the patient point of view.

Funding grants to nonprofits for inventive projects.

Priorities for investing in communities:

Supporting efforts that aggregate, collaborate and navigate.
What impact will Adira have? How will we measure it?

Prioritizing patients’ points of view:
- Diversity, distribution of stakeholders convened
- Report published and disseminated

Supporting aggregation, collaboration, and navigation efforts:
- Build network map of services available in the space
- Track and measure user data/feedback

Grantmaking:
- Funding and tracking results around:
  - Patient engagement
  - Aggregating disease communities
  - Navigation, collaboration

Vision: All sectors working more fully together on community-led priorities.
Who is Adira?

- Adira Foundation embodies the meaning of its name, strength and power.
- The founder and CEO is the survivor of a multi-trauma accident and knows firsthand the challenges of navigating multiple streams.
- CEO was most recently with a health nonprofit that ceased operations. Adira received some seed funding from the nonprofit.
- The inaugural board is comprised of eight accomplished experts from a range of disciplines. All have cared for or devoted their careers to those in need.
- Small but committed team experienced in health nonprofits.