Adira’s mission is to invest in better lives for people with neurodegenerative diseases.

ADIRA AT A GLANCE

Adira is creating one unified community to deliver transformational change driven by people impacted by neurodegenerative diseases.

A COMPLEX NETWORK

WE ALL USE HEALTHCARE.

But navigating the complex network that makes up our healthcare system is so often a struggle. One solution to one problem here and there is manageable.

But people dealing with neurodegenerative diseases have dozens of problems to navigate and solve at one time. That divided focus can lead to fragmented care, isolation, feelings of defeat, and missed chances for better, fuller lives.

The costs and impact of that is faced on a personal level and a national level.

SYSTEMIC REALITY

Many groups are already working on solutions to this growing crisis. But:

1. They rarely work together.
2. They often work on only one issue or diagnosis at a time.

Adira’s approach wants to create connections and community where there are divisions and borders.

COSTS AND IMPACT

Neurodegenerative disease symptoms impact every part of a person’s life: physical, emotional, cognitive. As a result they, their loved ones and caregivers face tremendous burden.

“...it’s so little time left together, and yet our system forces us to waste it dealing with bills and bureaucracy.”

Ady Barkan
ALS patient, Congressional hearing

ADIRA’S APPROACH

FIVE COMMUNITIES WORKING AS ONE TO ADDRESS COMMONALITIES.

We are starting with neurodegenerative diseases: Alzheimer’s disease, ALS, Huntington’s disease, multiple sclerosis, Parkinson’s disease.

By addressing multiple issues and disease communities at a time, and working collectively from a neutral platform with multiple sectors and funders, resources will stretch further. What’s working in one group or sector can be applied to overlapping needs among the five diseases.

The total 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.

The costs and impact of that is faced on a personal level and a national level.

We have so little time left together, and yet our system forces us to waste it dealing with bills and bureaucracy.”

Ady Barkan
ALS patient, Congressional hearing

1.877.426.0712  |  adirafoundation.org
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HOW WE WORK

We work by developing strong funding and programming partnerships that enable us to bring together people impacted by neurodegenerative diseases to discover pain points we can work on with others—and have lasting impact on the day-to-day lives of people with neurodegenerative diseases.

LISTEN

Adira talks to people with neurodegenerative diseases to hear not only what living with their diagnosis is like from their perspective, but also who they are as people. We will help them share their stories, changing the narrative around neurodegenerative disease, while informing our own priorities for impacting change.

**Projects underway:**
- Visiting and surveying support groups
- Moderating conversation with first round of grantees
- Collecting stories through StoryCorps™ partnership

LEARN

Partnering with and studying groups working on solutions will teach us how other approaches are working and where they are falling short. What we learn helps us further set and test priorities.

**Projects underway:**
- Research project with George Washington University
- Creating a digital map as a resource to visualize the network of organizations in our community

ACT

To address the priorities we’ve discovered, we offer grants, and use our neutral vantage point to co-fund with groups working on solutions. We will support existing programs created by nonprofits working towards building inventive solutions for people living with neurodegenerative diseases. We will co-finance and fund these programs and launch new projects on our own.

**Projects underway:**
- Fast-track grants program in response to COVID-19
- Online hub for neurodegenerative disease resources and tools
- 2020 Adira grants program

Together we can deliver transformational change driven by people impacted by neurodegenerative diseases.

WHAT’S NEXT

We are looking for like-minded partners in three categories:

**PROVIDERS**
Medical and nonprofit providers can help build unity and confidence within the healthcare system.

**SUPPORTERS**
We need selfless individuals with a passion for change who can confund and cocreate solutions with us.

**INFLUENCERS**
We need people impacted by neurodegenerative diseases to speak from real-life experience, prioritize needs, and be the voice of Adira.

We want to build a health ecosystem where all stakeholders—advocacy organizations, drug companies, hospitals, doctors, governments, insurance providers, and more—are moderated by one strong, unified voice:

Adira.

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