

Program priorities

Adira Foundation's 2020 programs are based on three interwoven priorities: patient engagement, program grants and flagship projects.

Three Priorities for Investing in Communities

The Three 2020 Priorities

1. Patient listening and convening
2. Grants to nonprofits with inventive ideas
3. Our flagship projects

Adira has three interwoven priorities for investing in communities. These priorities each influence the others and strengthen the foundation's overall work.



PATIENT ENGAGEMENT

PATIENT INTERVIEWS

Adira will talk to people with neurodegenerative diseases and 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 with audio and video as possible.

SMALL GROUPS

Adira has begun visiting support groups and other gatherings to hear from the point of view of patients, their families and caregivers about their experiences and unmet needs. This presents small, familiar settings from which patients can share their stories.

LARGER, REGIONAL CONVENINGS

Adira will convene a wide range of stakeholders regionally, in a neutral space, to have open and honest conversations, and commit to an objective approach not aligned with any one industry or perspective.

People living with one of the five target diseases or their caregivers will make up more than half of attendees. Other participants will include representatives from patient-focused organizations, public and private payors, life sciences, research institutions, clinicians, and hospitals, among others.



PROGRAM GRANTS

Adira Foundation knows that phenomenal organizations provide critical services to people living with neurodegenerative diseases. Adira plans to enhance that work in 2020 through small grants to charitable nonprofits.

Priorities for funding will be for inventive ideas that help **aggregate, collaborate or navigate**.

Examples may include:

- Joining ALS and Parkinson's disease communities for travel to movement disorders clinics.
- Assembling a three-person team from a hospital, patient group, and undergraduate volunteer program to provide a limited series of in-home visits to help caregivers manage time and space better.
- Grants that find surviving spouses of people lost to neurodegenerative disease that will agree to link up and buddy with newly diagnosed people to speak together about navigating care.

Advantage of Approach

1. **Joining communities helps build a shared identity to supplement current identities.**
2. **As an independent foundation, unaffiliated with existing services, we can provide a relatively neutral platform.**
3. **We learn from our experience with domestic and global health successes.**



FLAGSHIP PROJECTS

Adira will invest in several internal flagship projects in 2020. A sampling:

- **Networking map** of organizations and services across the five diseases to identify joint efforts to echo and enhance.
- A **shared virtual hub** to share resources, communication and tools among people from each of our five neurodegenerative disease communities.
- Examining ways to **convene in a post-coronavirus world** bringing together representatives from all five communities to share best practices, hear about innovative services and create connections.

- An awareness campaign, **#SquirmSessions** to spark conversations and action on topics important to people in the neurodegenerative disease community that are often avoided as they are considered too controversial or taboo.



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PATIENT ENGAGEMENT



PROGRAM GRANTS



FLAGSHIP PROJECTS