



Letter of Intent Invitation

Pervasive needs in neurodegenerative disease: Giving people most impacted more time, money, energy, confidence and connection

ABOUT ADIRA

Adira Foundation was created to counter the unforeseen consequences of siloed, disease-specific approaches that can lead to gaps in seeing and addressing shared systemic barriers, health inequities and day-to-day needs of patients and caregivers across complex health issues. Adira's inaugural focus is on neurodegenerative diseases (ND) including ALS (amyotrophic lateral sclerosis), Alzheimer's and related dementias, Huntington's disease (HD), multiple sclerosis (MS), and Parkinson's disease. This is one of the most complex clusters of ND, which are also among the scariest and costliest. However, targeting these five in one undertaking allows Adira to show that multilateral collaboration and holistic approach among people across disease types, their caregivers, providers and other key stakeholders can achieve a superior response.

With this improved response, Adira gives people back more time, financial resources, energy, confidence, and connection to thrive again as people first. This is achieved both by amplifying their collective voices and through improved and efficient systems. By leading on a sampling of five NDs to start, Adira strives to apply broader lessons to future disease clusters. Life can be very hard when dealing with complex health problems. We can do better. However, doing better will take transformational collaboration.

Through Adira's Pervasive Needs Grants program, we fund programs that offer solutions to problems frequently cited by people living with ND and ND caregivers themselves to improve their quality-of-life by providing:

- More **time** to spend doing the things they enjoy.
- More **money** to live full and rich lives.
- More physical and mental **energy** to take on daily life.
- More **confidence** to navigate systems and make informed decisions.
- More **connection** through opportunities that build shared community.

PROGRAM BACKGROUND

The design of this grants program has been very much "community-driven." We set these priorities explicitly in response to what people most impacted by ALS, Alzheimer's and related dementias, HD, MS and Parkinson's—as well as the organizations that support them—reported to us through interviews, focus groups, convenings and surveys.

The below request for proposals is round three of these grants, following the first round in the spring of 2020, an emergency response to COVID-19, and a second round in Fall 2020, focused on community resources and caregivers.

Adira's approach looks to impact individuals and the systems that serve them. We take on issues that may seem hard to define or are too large to own by one group, applying a bird's-eye view that focuses on the health and social care systems' ability to improve quality-of-life for people living with the most complex diseases.

We believe that when you listen to people living with ND and their caregivers, you can better understand their unique, individual needs and the gaps in the health and social care systems meant to support them that are affecting not only that person, but others with similar experiences.

We look to fund projects that provide immediate benefit to people living with ND and their caregivers while creating, testing, or disseminating a best practice for ND care with the intent to continuously improve and enhance the ability of systems to impact quality-of-life in ND.

Prioritizing focus areas

Insights shared with us directly by people living with ND and their caregivers helped prioritize the three program focus areas. Here are a few:

ON CLINICAL TRIALS

Person with ALS:

I can't dress myself, but aside from that I'm right here, ready, willing and able. You just don't want me. You want a patient that researchers have created. You don't want a real person.

Spousal caregiver for a person living with ALS:

Medicines have different effects on different people and if you're only testing on a certain population then you're only going to get a certain result—and then we all just have to fit in that result and it's not working.

ON NAVIGATION

Spousal caregiver for a person living with Parkinson's:

How to pick the right question. When we moved, if I had known that some of the coverage were affected geographically, we may have chosen another place to live had I known that. But I didn't really know how to ask.

Parental caregiver for a child living with young-onset dementia:

Everything I learned was really like word of mouth and like, check this society they have a list of waivers. Or, go to [another organization], they might have some resources. So everything we did, we had to figure it out on our own. I would say [I could use] something that is comprehensive and that would address kind of overlapping areas.

ON CONNECTION

Person living with ALS on feeling isolated from the community:

People just want to know they're not alone. It doesn't take a lot to make people feel seen. I think with a lot of neurological, people feel unseen. You get put in a chair and you're in a corner, you're unseen, you lose your voice, you're unheard. It's a certain degradation of the soul, of the body. If we could just not make them feel like that. You know, not make people look like they aren't valuable people still. And that's what a lot of the world seems to do, I think. That's what makes me mad is never showing people that have a neurological disease who still have abilities, are still living.

Spousal caregiver for a person living with Parkinson's on the most difficult adjustment since diagnosis:

Providing activities to keep her interested in life is the hardest. If I could change one thing about her disease it would be giving her the ability to do and engage in things she could before.

Program focus areas

1. SIMPLIFYING CLINICAL RESEARCH

For people dealing with an incurable disease, advancements in treatment and research can offer hope. But too often the process of learning about or participating in these opportunities brings stress, access barriers and disappointment. These challenges not only effect people impacted by ND, but the effectiveness of the research produced.

A more diverse group of people, accurately reflecting the ND populations they represent, need to have information and access to clinical trials and research. We look to support programs that remove barriers affecting time, money and confidence for people most impacted by ND.

EXAMPLE

Provide education, navigation, or direct support services to people living with ND and ND caregivers to facilitate the removal of participation barriers in clinical research.

2. PREPARING FOR FUTURE THREATS TO LIVELIHOOD

“Sidewalks help the blind see.” People navigating an ND need a path forward, to know what's next, and to feel more prepared. Information often gets to people too late, resulting in severe physical, mental, emotional, and financial consequences.

It is too much to ask someone navigating an ND to do it blind. We look to support programs that offer comprehensive and clear guidance to people most impacted by ND, giving them the information and

EXAMPLE

Provide education, navigation, and skill-building activities to people living with ND and ND caregivers to support their ability to implement a planned, phased approach to their disease journey.

tools to know and tackle what's next and ultimately give them more time, money, energy, and confidence through their disease journey.

3. THRIVING AGAIN IN COMMON PURSUITS

People most impacted by ND felt isolated at home long before pandemic quarantines. The world feels uninviting and dismissive when events, spaces and attitudes work against the needs of people living with an ND and caregivers. People are already uniquely complex in their lives, those navigating the incredible intricacies of an ND even more so, yet they so often feel reduced to nothing more than the disease itself.

We look to support programs that reduce stigma and give people most impacted more opportunities to do the things they enjoy and live full, rich lives.

EXAMPLE

Provide opportunities for people living with ND and ND caregivers to easily access and enjoy community-based spaces and resources through inclusive social and recreational programs.

Eligibility

Applicants must meet the following criteria:

- 501(c)(3) nonprofit in good standing.
- Currently serving people with ALS (amyotrophic lateral sclerosis), Alzheimer's disease and related dementias, Huntington's disease, multiple sclerosis, or Parkinson's disease and/or their caregivers.

Smaller, community-based organizations are encouraged to apply.

Individuals and private corporations are not eligible to apply.

PREFERRED ELIGIBILITY

We are hoping to build shared community around areas of common concern, driven by the points-of-view of all people living with ND and ND caregivers. Priority will be given to projects that include these elements:

Aggregating

Project serves people from two or more of the five neurodegenerative diseases.

Our intent is to expand the reach of programs to help foster a larger shared identity among the five NDs and seek potential efficiencies in delivery.

Convening

Project includes convening activities seeking the collective input of multiple people living with one of the five NDs, caregivers, or related stakeholders to improve the design, delivery, or measurement of the project. Bringing together individuals with different perspectives, such as people living with NDs and caregivers, is a plus.

Our intent is to ensure that those being helped have a say in how a program is built and/or evaluated.

Health Equity

Project includes activities that serve groups historically experiencing less power and privilege by addressing an evidence-based health disparity or health inequity. Additional consideration will be given to projects that address a specific health inequity.

Our intent is to elevate the voices of those less often heard and ensure all people have the same ability to access programs that support their quality of life.

See the “[Fall 2021 FAQ](#)” for more details.

Funding and project period

Adira is awarding at least **\$250,000** and seeks proposals for a 12-month project period.

The average grant amount is **\$60,000**.

We anticipate funding at least 3-5 projects. The project period begins in February 2022.

Application instructions

IMPORTANT DATES

Informational conference call Q&A

Mon., Sept. 27, 1 p.m. ET

Adira staff will answer questions from 1-2:30 p.m. ET. Please submit questions in advance of the call, as possible, to programs@adirafoundation.org

Submit a Letter of Intent

Due: Mon., Oct. 18, 5 p.m. ET

Use the LOI template provided.

Submit the cover sheet and LOI in a single PDF to Lauren Ruiz, programs@adirafoundation.org no later than 5 p.m. ET on Oct. 18.

We will confirm receipt of all submissions.

INFO CALL | Sept. 27, 1 p.m. ET

Join the call:

<https://us02web.zoom.us/j/86597551986>

SUBMISSION INFO

Submit PDF to:

Lauren Ruiz,
programs@adirafoundation.org

No later than: 5 p.m. ET, Oct. 18

