ADIRA'S BIG IDEA

Integrating a response to five communities with complex conditions

In the end, a more complete response for all of us
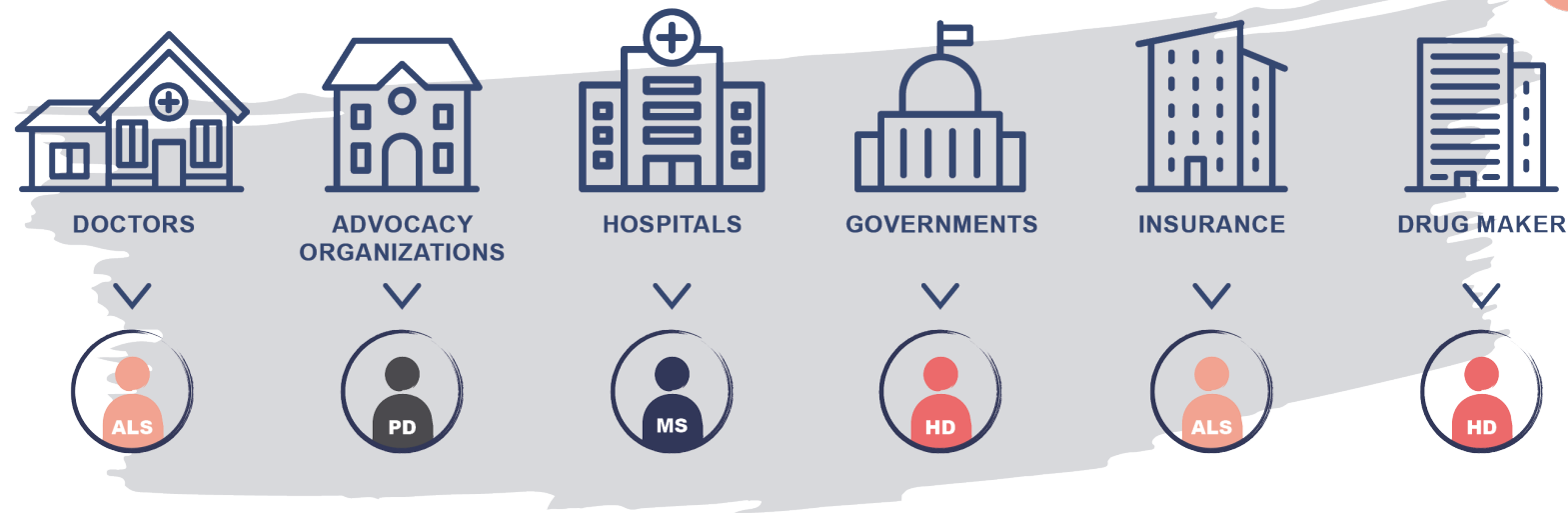
Adira Foundation – Uniting in Care for the Common Good

Greg Smiley, Founder and CEO

*Adira Foundation dissolved in late 2022. Legacy website found here

Problem: Silos isolate and crush us

Life has grown isolating for all of us—people who are ill feel it most.

Service providers can't solve everything at once. Many take on one population, point-of-view, or service at a time. While designed in good faith, each additional program ironically can compound the burden on a person. **Finding 17 paths for 17 problems would shut anyone down.**

DOCTORS

ADVOCACY ORGANIZATIONS

HOSPITALS

GOVERNMENTS

INSURANCE

DRUG MAKER

ALS

PD

MS

HD

ALS

HD

> 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

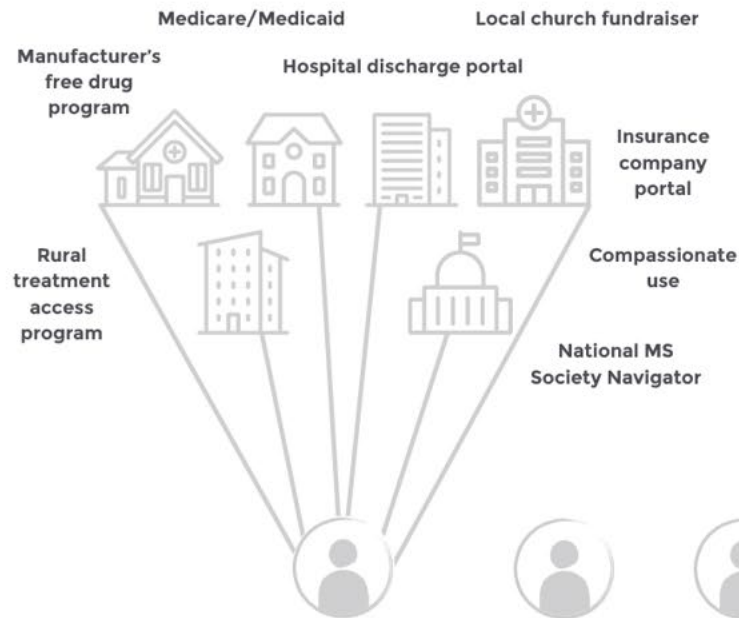# Turning the Vertical Health Care Model on its Side

Problem
Asking for help feels like climbing a rope alone.

Manufacturer's free drug program
Medicare/Medicaid
Hospital discharge portal
Local church fundraiser
Insurance company portal
Compassionate use
Rural treatment access program
National MS Society Navigator

Solution
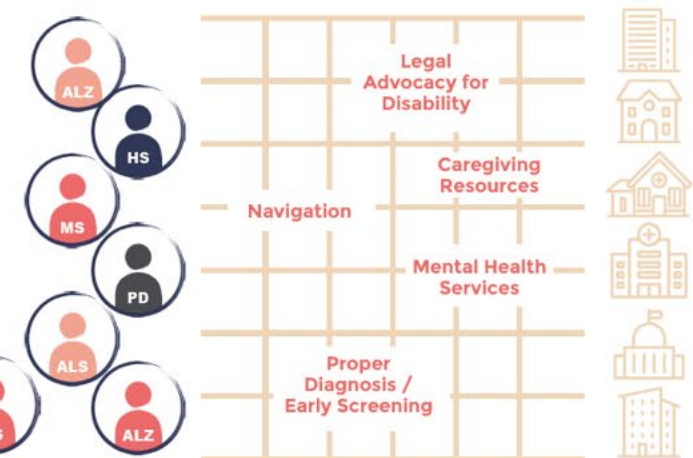### Addressing the urgent, common needs of five populations as one.

▶ We gather and assemble voices from five populations as one—focusing on their many urgent common needs.

▶ Together, this group is 10+ million and can act with more equal footing to providers.

Common needs of the five populations:

- Navigation
- Mental health
- Caregiver burnout
- Stigma
- More collaboration
- Clinical trials

MS HD ALS PD MS

Adira's Result
To bridge across silos!

People impacted drive solutions built from equal standing with services providers. The result is inventive programs that address common problems:

ALZ
HS
MS
PD
ALS
ALZ

Legal Advocacy for Disability

Caregiving Resources

Navigation

Mental Health Services

Proper Diagnosis / Early Screening

We turn the model on its side to help supplement this help

Why Neurodegenerative Diseases?

Illness is overwhelming; enduring multiple silos can make it worse.
Five resources are threatened: time, money, energy, confidence, and relationships.

- **Urgency:** Rapidly climbing incidence and prevalence

- **Universality:** These diseases touch nearly everyone.
  - Adira focusing first principally, though not exclusively, on 5 to start: ALS, Alzheimer's and related dementias, Huntington's, multiple sclerosis, and Parkinson's.

- **Cost:** Expensive and worsening,

- **It's personal:** Adira team and board are dealing with these, including the Founder/ CEO dealing with MS and Alzheimer's in direct family
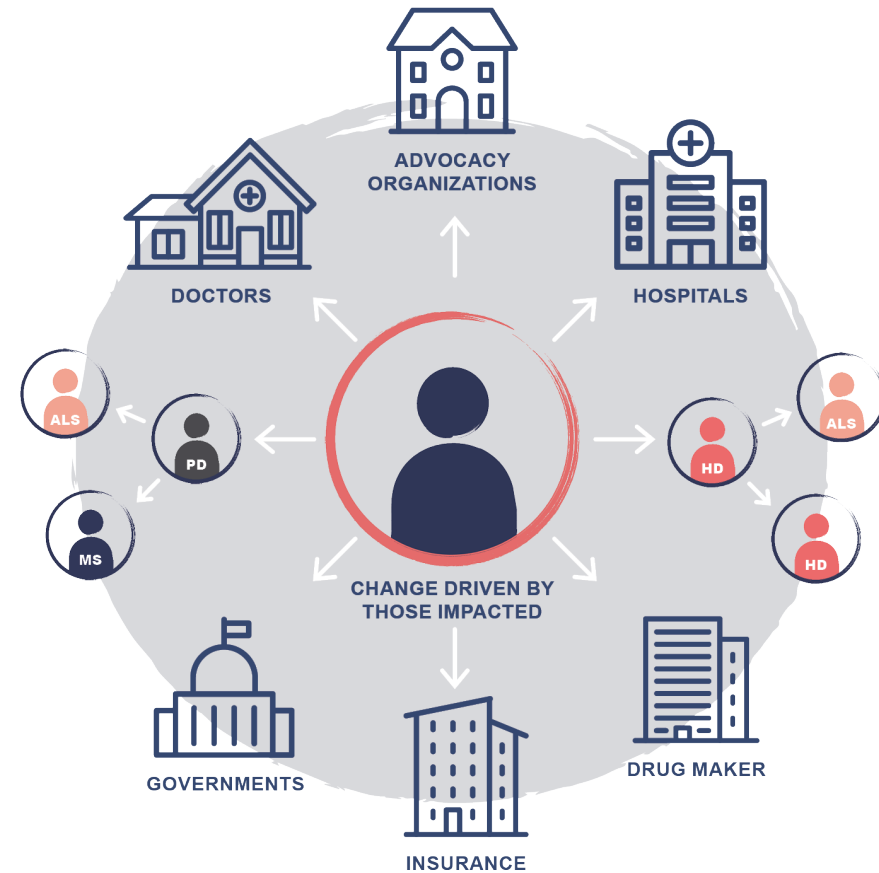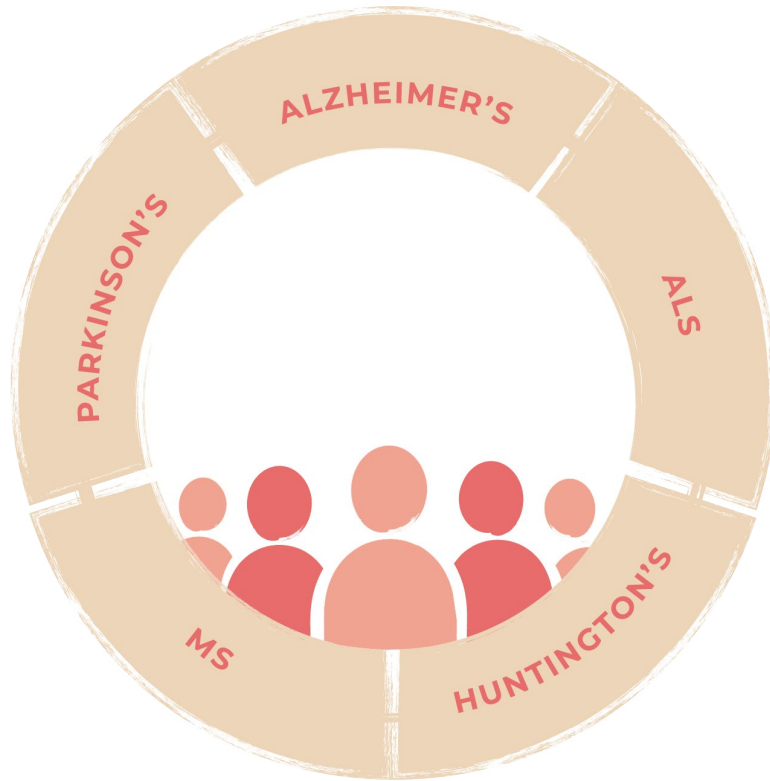
8M 38% ▲INCREASE 11M

2020   2030

The total who live with these five diseases is expected to grow from 8 million to 11 million by 2030, a 38% increase.

Adira's response: Build Bridges Across Silos

We ask people what they still urgently need and what help looks like.
Then we leverage $$ to fund nonprofit grants for a common, integrated response

This model has worked before:

Adira is inspired by the ambition, scale, and scope of current successful integrated responses to other health challenges.

1 The Ryan White Program

2 The U.S. President's Emergency Plan for AIDS Relief (PEPFAR)

3 Global Fund to Fight AIDS, Tuberculosis, and Malaria

Adira applies their best practices:
Funded by many, steered by results, complemented by other good programs, and informed *by what people say they need.*
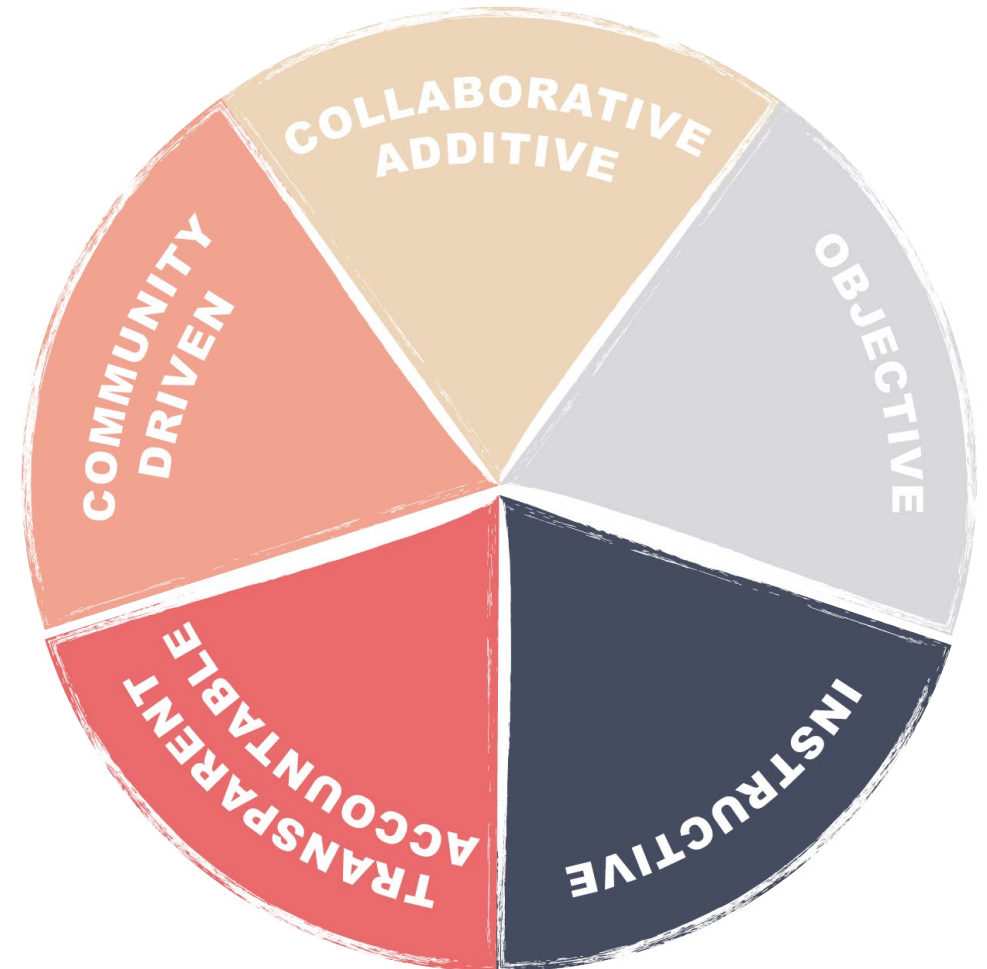
Adira programs: Taking on the big issues

Round 1, April **COVID-19 response**: **Funded 12 U.S. nonprofits.**
Round 2, Fall 2020: **Convened R1 grantees to help set R2 priorities. Funded five large national projects.**
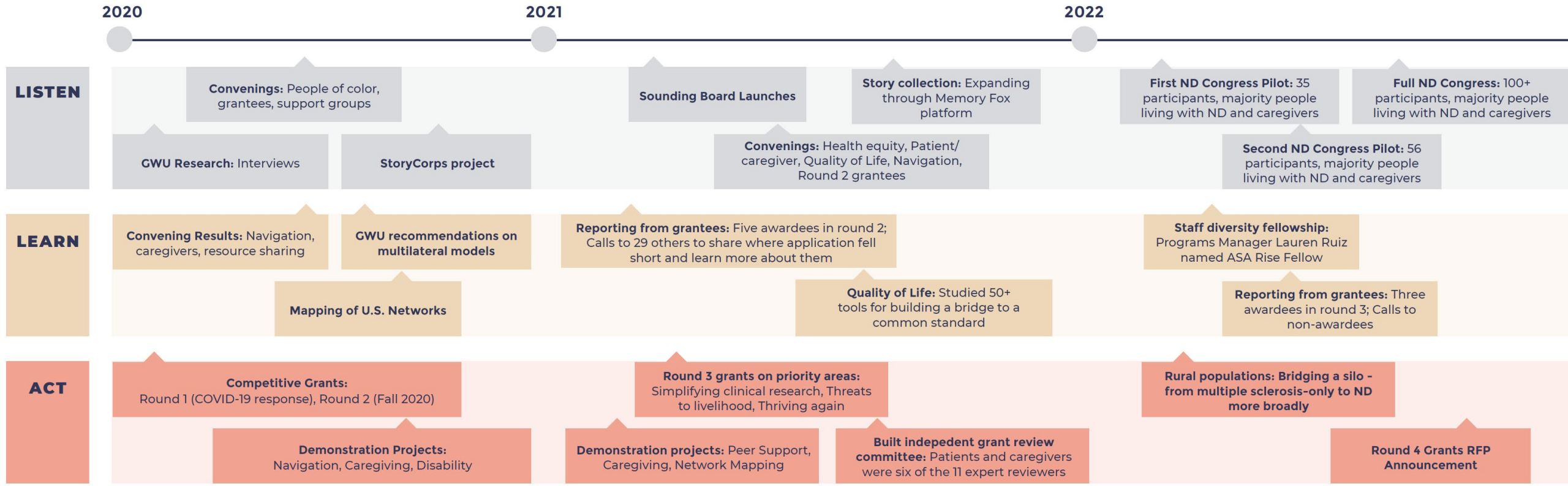   Launched demonstration projects off other listening
Round 3, Fall 2021: Cycle continues only larger

1. Finding good neurologist/specialty care
2. Access to medicine
3. Education about my disease
4. Access to clinical trials
5. Mental health and well-being
6. Racism/classism
7. Durable medical equipment
8. **Navigation**
9. **Care coordination**
10. Managing disease-modifying therapies
11. Home modifications
12. Finding and keeping good health coverage
13. Transportation
14. **Stigma/Discrimination**
15. Long-term care/housing
16. **Telling my story from my point of view (POV)**
17. Palliative care

18. Nutrition/Access to stable food sources
19. Legal assistance
20. **More collaboration among clinic and community**
21. Estate planning
22. Social Security Disability Insurance appeals
23. **Caregiver burnout/respite**
24. Isolation and loneliness
25. Symptoms and co-morbidities
26. **Central home for caregiving resources**
27. Parenting children while also caring for elder parents
28. Building confidence for informed care decisions
29. Pain management
30. Building identity beyond being a patient
31. **COVID-19 adjustments**
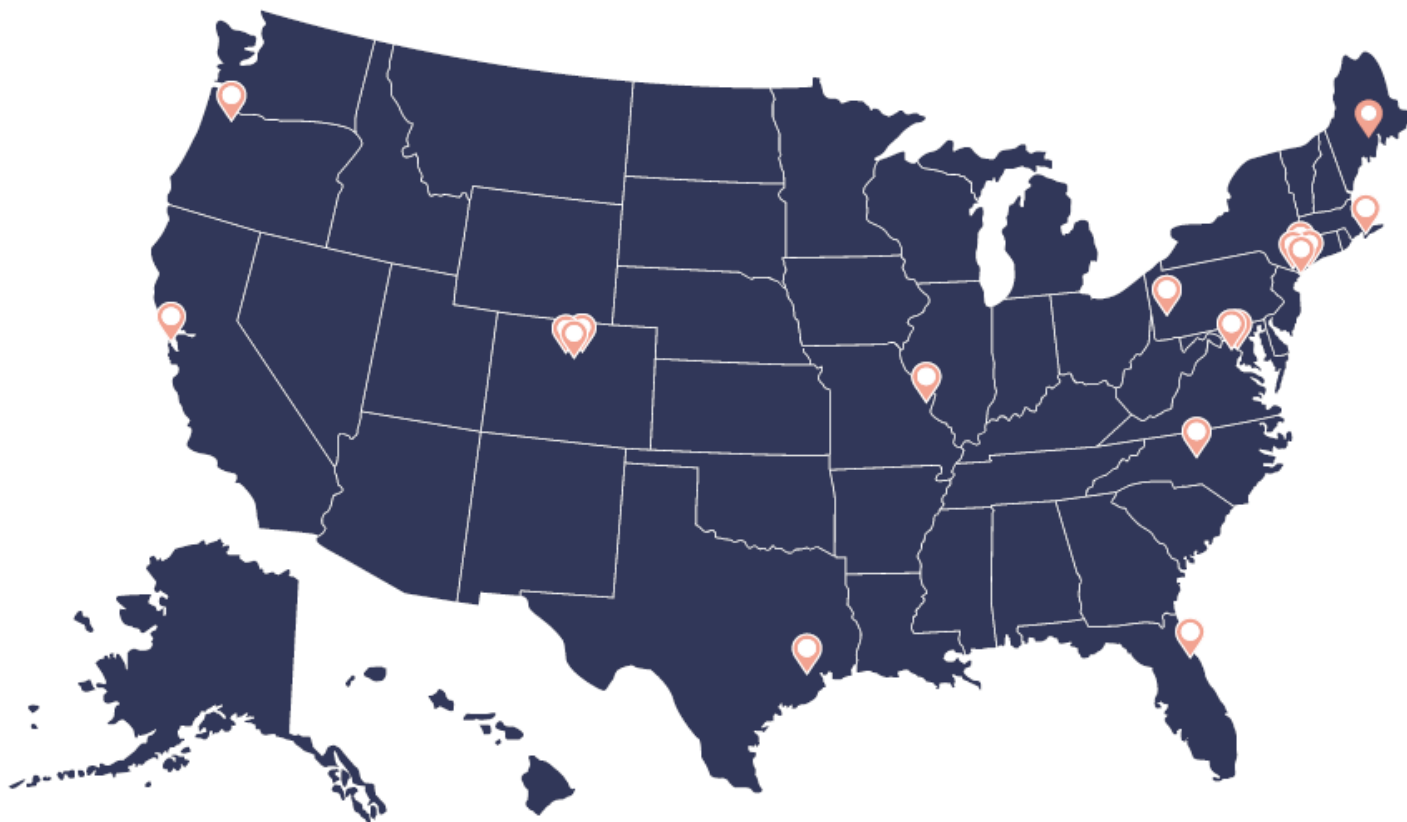32. Biomedical research
33. Advocacy

■ = Round 2 priorities

■ = Demonstration project priorities

Adira's Timeline

2020   **2021**   **2022**

LISTEN

Convenings: People of color, grantees, support groups

GWU Research: Interviews

StoryCorps project

Sounding Board Launches

Convenings: Health equity, Patient/caregiver, Quality of Life, Navigation, Round 2 grantees

Story collection: Expanding through Memory Fox platform

First ND Congress Pilot: 35 participants, majority people living with ND and caregivers

Second ND Congress Pilot: 56 participants, majority people living with ND and caregivers

Full ND Congress: 100+ participants, majority people living with ND and caregivers

LEARN

Convening Results: Navigation, caregivers, resource sharing

Mapping of U.S. Networks

GWU recommendations on multilateral models

Reporting from grantees: Five awardees in round 2; Calls to 29 others to share where application fell short and learn more about them

Quality of Life: Studied 50+ tools for building a bridge to a common standard

Staff diversity fellowship: Programs Manager Lauren Ruiz named ASA Rise Fellow

Reporting from grantees: Three awardees in round 3; Calls to non-awardees

ACT

Competitive Grants: Round 1 (COVID-19 response), Round 2 (Fall 2020)

Demonstration Projects: Navigation, Caregiving, Disability

Round 3 grants on priority areas: Simplifying clinical research, Threats to livelihood, Thriving again

Demonstration projects: Peer Support, Caregiving, Network Mapping

Built indepedent grant review committee: Patients and caregivers were six of the 11 expert reviewers

Rural populations: Bridging a silo - from multiple sclerosis-only to ND more broadly

Round 4 Grants RFP Announcement

What We Have Done: Adira grant recipients

Round 2

Bangor Region YMCA
Bangor, ME

Chronic Care Collaborative
Denver, CO

Compassionate Care ALS
West Falmouth, MA

Family Caregiver Alliance
San Francisco, CA

I AM ALS
Washington, DC

Round 3

Mark Morris Dance Co.
New York, NY

Memory Home Care Solutions
St. Louis, MO

University of Pittsburgh, School of Nursing
Pittsburgh, PA

Round 1

ALS Association
DC/MD/VA Chapters

American Parkinson Disease Association
Staten Island, NY

Baker Ripley
Houston, TX

Chronic Care Collaborative
Denver, CO

HD Reach
Cary, NC

Huntington's Disease Society of America
New York, NY

National MS Society
New York, NY

New Horizon Service Dogs
Orange City, FL

Parkinson's Resources of Oregon
Beaverton, OR

Rocky Mountain MS Center
Denver, CO

University of Anschutz Med Center
Aurora, CO

The result

- **Communities drive the change** (51% of people in the room**)**
- People are **more connected** (Sounding Board, ND Congress)
- Programs and **services are easier to find** (Network Map)
- **Greater understanding, mutual respect** (among those getting the help and those providing it)
- **More attention to those larger problems too big for anyone to own**
- **Economies of scale:** what's working for one could be scaled to 5+ (Legal Advocacy for Disability; Quality of Life metrics)
- Both people and systems **reinforce** we are moving in the right direction.

"As a person who has lived with multiple sclerosis since 2002, I've become knowledgeable in navigating our healthcare system. I would like to assist people like myself who are living with a chronic neurodegenerative condition, navigate the healthcare system and streamline their journey. Adira's listening sessions give me insight on how other patients cope with everyday living. It's an exchange of patient advice. Most importantly, it's validating for myself and other patients to know that we're not alone in this fight and that there are other people in the same situations."

Joe Sparkman
Music Producer, MS Activist and Professional Volunteer

"What a gift it was for Family Caregiver Alliance to receive an Adira Pervasive Needs Grant. It allowed us to double down in our critical work with caregivers of individuals living with neurodegenerative disease. Information from our 10 caregiver and local provider listening sessions is informing us of new important topics to address and to design more effective ways to deliver caregiver education, which we will be sharing with local ND organizations. We anticipate delivering improved education and support to the 1,300 ND caregivers FCA currently serves, plus to the many caregivers our peers serve."

Leah Eskanazi
Director of Operations and Planning, Family Caregiver Alliance

Working for the Common Good:

Adira focuses first principally, though not exclusively, on five diseases to start

Parkinson's Disease

Alzheimer's and Related Dementias

ALS

Multiple Sclerosis

Huntington's Disease

Common Concerns

- Multiple systems
- Legal needs
- Cognition
- Depression, anxiety, fear
- Caregiving
- Mobility
- Housing security
- Life after work
- Financial security
- Risk of misdiagnosis or late diagnosis
- Grief
- Disability
- Apathy
- Search for cures
- Isolation/Shift in relationships

Each diagnosis demands unique attention for what makes that diagnosis special.

Yet, from a birds-eye view, they share far more in common than not.

We take on those problems that are too big for anyone to own.

Yet people dealing with these diseases persistently name these common issues as typically left behind

Adira asks people to name and describe which problems stay most urgent, then ask them what better help would look like.

We fund that additional help that makes people typical to supplement the help on what makes them unique.

Grants life cycle: How this works over time

Addressing those cross-cutting, common problems that are often underfunded or unowned, but will help both people as well as systems.

E.g. Caregiving, navigation, resource sharing.

VERTICAL IMPACT

One service for one population. Siloed.

E.g. A transportation program for people with ALS or medication cost-reduction programs for people with MS.

06. REPORTING

04. GRANTING

07. EVOLVING

02. CONVENING

05. EVALUATING

03. PRIORITIZING
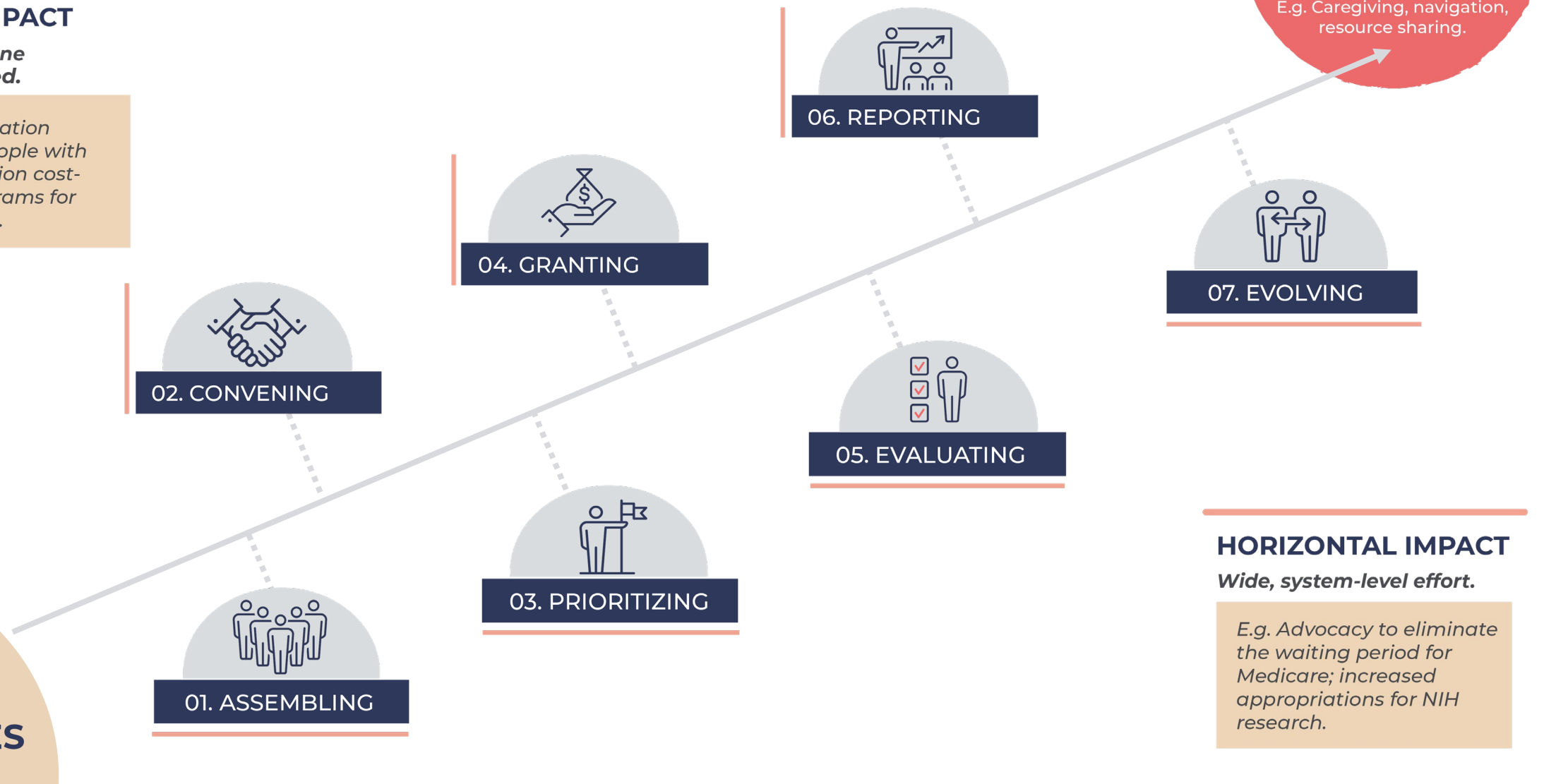
HORIZONTAL IMPACT

Wide, system-level effort.

E.g. Advocacy to eliminate the waiting period for Medicare; increased appropriations for NIH research.

01. ASSEMBLING

OUR RESOURCES

Beyond the bullseye

Transformational movement builders

Sports, entertainment, faith-based, B-corps, venture philanthropists
We aim to reach potential influencers unlikely to stand with one singular disease, but who may be more likely to help 8 million people with five diseases for a larger purpose of collaborative reform.

Singular disease efforts trend in the inner layers of the bullseye.

Adira is focused on reaching the outer layers to supplement the inner layers.

TRANSFORMATIONAL DONORS

HEALTH-ADJACENT DONORS

BOUNDARY SPANNERS

SUPPORTERS, DONORS, PROVIDERS

PEOPLE IMPACTED BY NDs

National associations & nonprofits

Other private sector, churches, sports

Adira
FOUNDATION
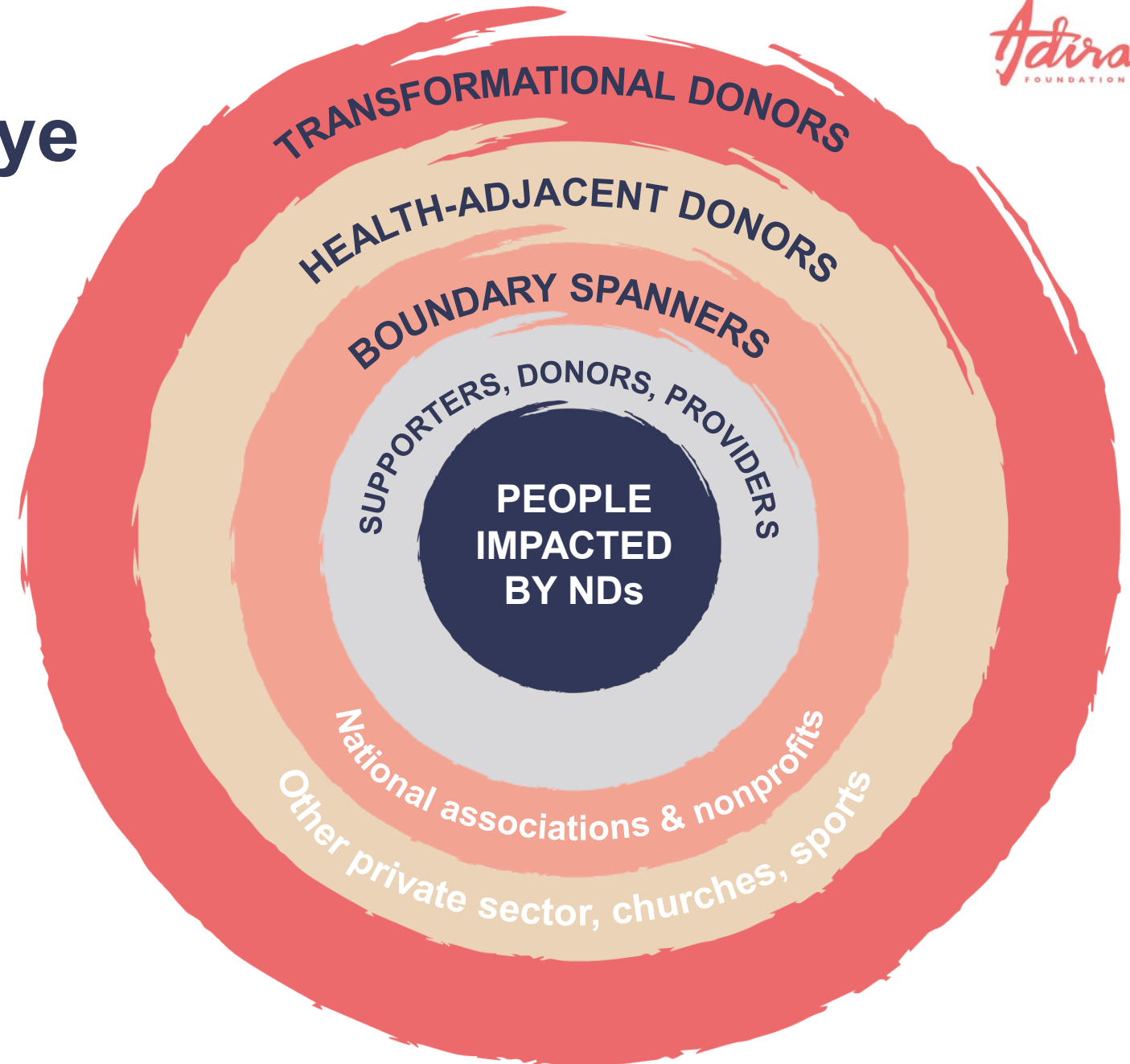
Introducing our $2.5 million campaign

Contributions will unlock the *Brave Transformational Fund*

First $1 million will go to needs named by people with ND and caregivers

- When we reach $1m, we will invest it in the fourth round of grants revealed through the ND Congress finale

Additional investments will:

- Assemble and connect 100+ people to cocreate solutions that they think will make a difference in their own lives
- Support nonprofits like Family Caregiver Alliance with inventive, effective programming that takes on those solutions
- Bring more and more diverse voices into the conversation
- Provide technology that makes it easier for people with ND/caregivers to access support (Sounding Board, navigation platform, etc.)

Sampling of Potential Benefits

- You provide welcoming remarks at ND Congress
- You facilitate an ND Congress breakout session
- Invitations to attend ND Congress
- Space in Adira's Resource Exchange
- Name and logo on ND Congress banners
- Recognition in our annual report
- Spotlight article recognizing your sponsorship
- Adira presents a "Lunch and Learn" at your event

ND Congress Series Timeline

LISTEN

Pilot
Virtual | 1/20 - 1/21
Discover Needs

LEARN

Extended Pilot
Denver, CO | 6/16 - 6/17
Finalize Solutions

ACT

ND Congress
Washington, D.C. | 11/17 - 11/18
Implement Solutions

Teams Form | February - June
Teams create viable grants

• Build teams to volley potential solutions and use evidence to build and grow these informed solutions

• Invite and recruit an evergreen alliance of people living with ND, caregivers and professionals to participate in part two of the ND Congress series and beyond

Teams Advance | June - November
Teams finalize grants and impact metrics

• Prioritize between three and five programmatic ideas for funding

• Set markers and metrics to best monitor and evaluate impact

• Ask people to bring forth their best strengths to see this plan of action through

- Life sciences
- Foundations
- Government
- Private payers
- Patient organizations
- Clinicians
- Hospital systems
- Other nonprofits

51% of attendees are people with 1 of the 5 target diseases and/or their caregivers
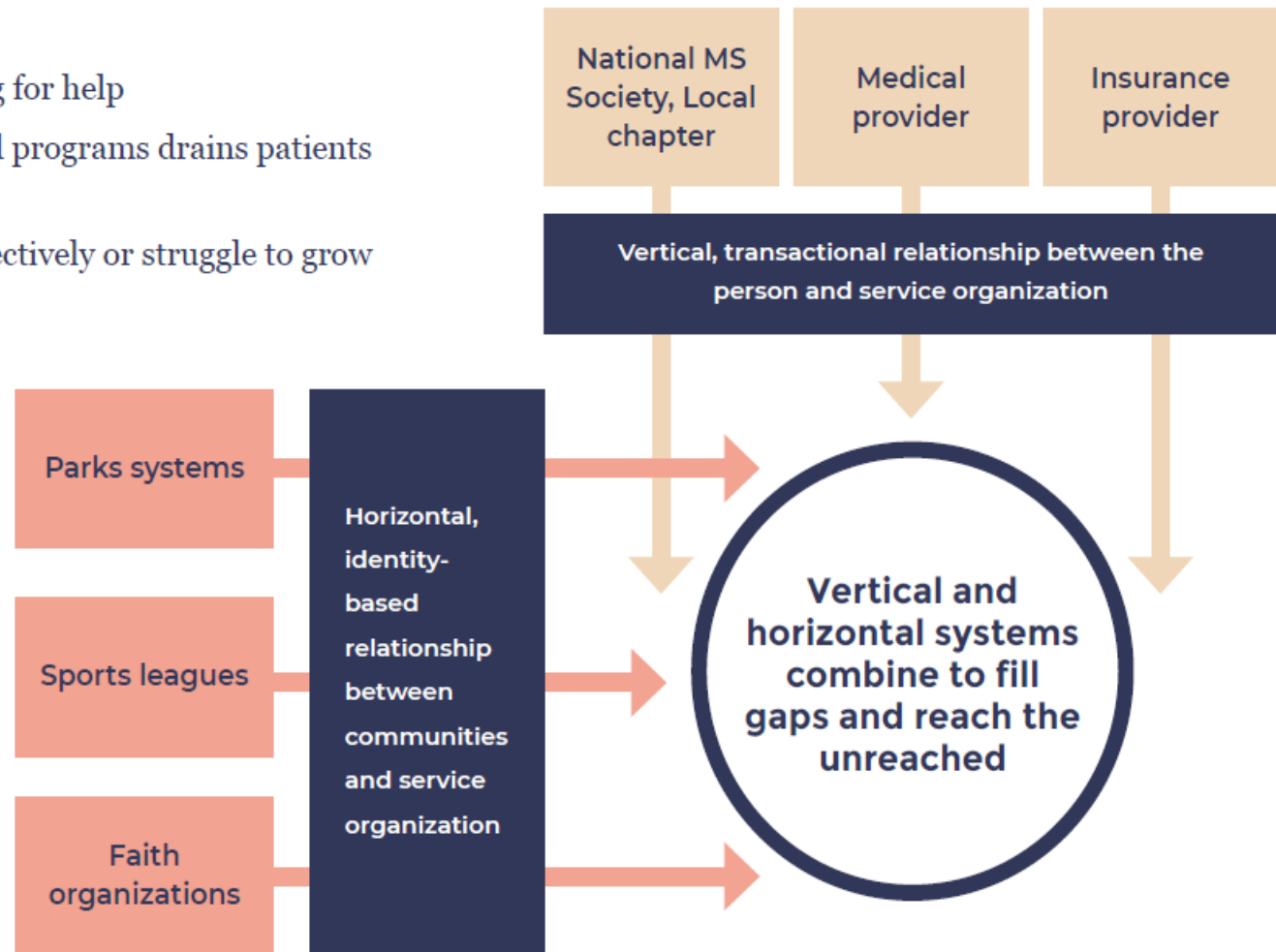
Adira in miniature: Not just MS but other neurodegenerative diseases in rural areas

Current Approach

- Siloed programs leave out many people looking for help
- Finding, understanding, and using many siloed programs drains patients and caregivers of time, energy, and confidence
- Donors and providers utilize resources less effectively or struggle to grow and reach more people

Adira's Fortified Approach

- Services expand to serve common needs of 5 populations instead of 1
- Existing health and health-adjacent networks are utilized to create more entry points to care
- Scale and replicate effective programs economically
- Convene PMI by MS at the earliest stages of the project to provide insight and leadership to our intervention

National MS Society, Local chapter

Medical provider

Insurance provider

Vertical, transactional relationship between the person and service organization

Parks systems

Sports leagues

Faith organizations

Horizontal, identity-based relationship between communities and service organization

Vertical and horizontal systems combine to fill gaps and reach the unreached

Samples of other Adira funding:

In addition to competitive grants, we funded other urgent priorities we heard:

8. Navigation	**23. Caregiver burnout/respite**

Funding VirginiaNavigator to build a searchable online resource directory.

Co-launching "Take Care," a crowdsourced website to share and find family caregiver support resources.

A PARTNERSHIP OF

6. Racism/Classism	**16. Telling my story from my point of view (POV)**

Convening people of color to hear about their experiences with ND, with GOODSTOCK Consulting.

Partnering with StoryCorps to record conversations featuring people impacted by ND.

Network Map

The network map gathers all the organizations serving one or more of our five disease communities and plots them into an interactive, searchable web-based data visualization. The visualized data informs decisions around:

▶ Underfunded communities   ▶ Underserved geographic areas
▶ Programming gaps   ▶ Collaboration opportunities
▶ Networking gaps

Parkinson's Disease

If an organization has programming for more than one disease, it lands in between those diagnoses.

Alzheimer's and related dementia

Multiple Sclerosis

Huntington's Disease

ALS
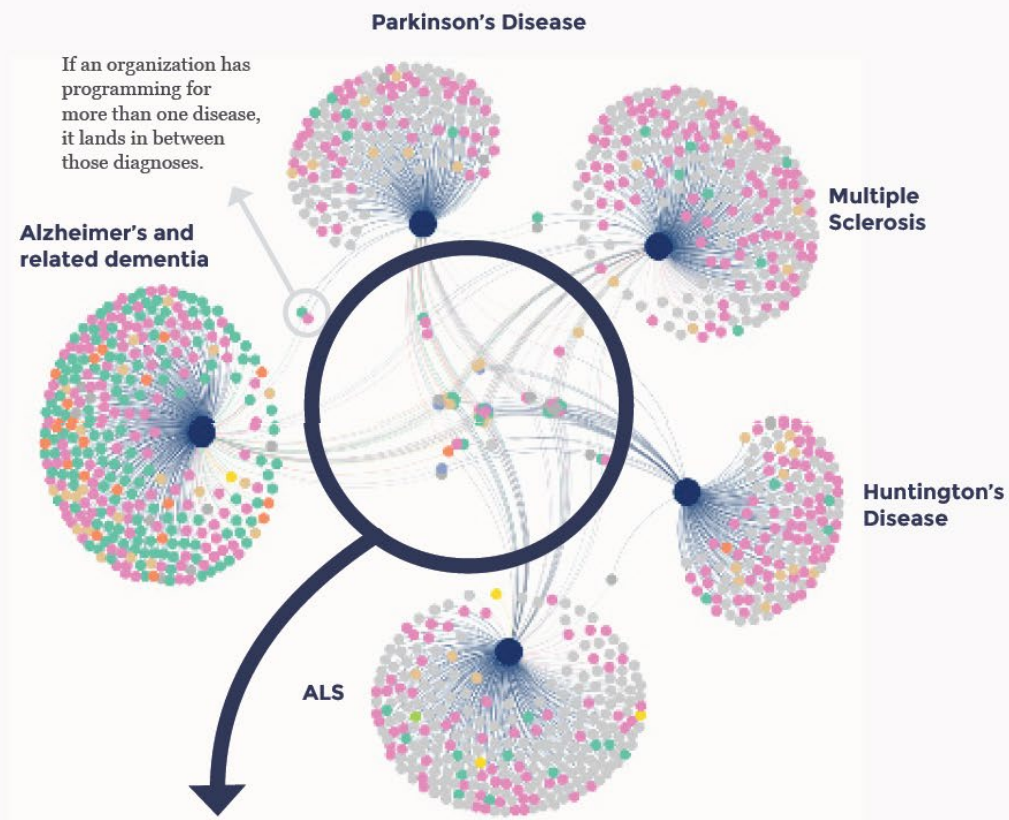
Very few organizations work in all five disease communities. **Adira wants to fill this white space** — bridging these five communities around their shared needs and experiences.
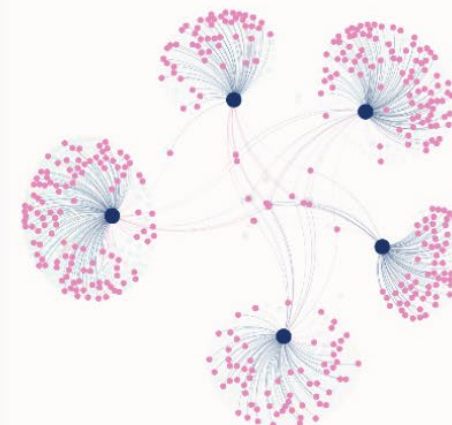
Filter: Organizations that provide **'Patient Support'** programs
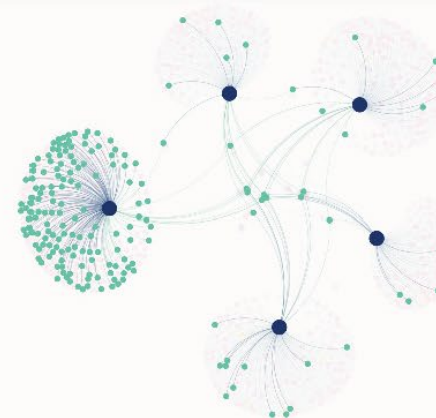
Filter: Organizations that conduct **'Clinical Research'** in ND populations

Our values

Alliance
Agreement to work together towards common goals.

Dignity
Our right as human beings to be loved, valued and held in high regard.

Integrity
Having strong ethical principles that are followed at all times.

Courage
The quality that enables one to face danger, fear, or change with self possession, confidence and resolution; bravery. It fosters creativity and innovation.

Respect
Admiration for others for simply who they are, but also for what they have done and what they do. Treating others as we would want to be treated.

Inclusivity
The practice of including and integrating all people and all groups.

Typical response	Adira response
Looks to what makes people "unique"	Looks to what makes people "typical"
Person affected as end user	Person affected as co-collaborator
Small but mighty communities swimming upstream	Larger community turning the tide
Designed from POV of donor /provider	Led by POV of person impacted first, then with donor
Helpful but limited	Supplementing what already works
Ground level: what's easier to count, get funding for	Bird's-eye view for more perspective and impact
Either designed for the individual OR for the system	Straddling both (diagonal)
More pressure on any one donor	Diffusion of donor influence and pressure
Targeted to the needs of the few	Targeted to the needs of the many
Person as their sick self	Person as their best self
Costly	Economies of scale
Categorical identity	Shared identity
Traditional donors	Transformational donors plus traditional donors

We welcome partnership, support and point of view

Together we can invest in the day-to-day lives of people most impacted by:

IMPROVING WELL-BEING

- For people living with, or loved by those with serious, challenging diseases like ALS, Alzheimer's and related dementias, Huntington's, MS and Parkinson's.

COLLABORATING ON WHAT PEOPLE NAME MOST

- Naming and addressing common cross-cutting unmet needs that may be too big for anyone to own or do alone.

- Assembling traditional and non-traditional donors for co-financing work on those precise unowned issues.

ACCELERATING EQUITY, INCLUSION

- Assembling voices of vulnerable populations—so that *together* their points of view are not so easily dismissed.

- Reducing both inequities as well as disparities across and among populations: ethnicity, color, primary diagnoses, income status, urban/rural.
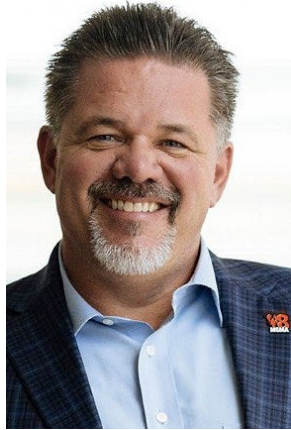
ACCESSING NEW POINTS OF VIEW

- Amplifying the voice of people most impacted through storytelling and fluid conversations over different points in time.

- Convening people and their care partners alongside providers—then crowdsourcing priorities for funding.

Adira
FOUNDATION

Board of Directors

Alan Abramson

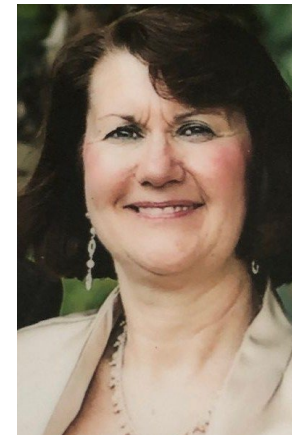Todd Evenson

Kandy Ferree

Cynthia A. Gómez

Laura Hanen

Alan Hutson

Ian Kremer

Zenawit Melesse

Cheryl Sullivan Staveley

Leadership

GREG SMILEY, Founder/CEO

Greg brings more than 20 years' experience in both U.S. domestic and global public health policy and management. Career highlights begin with managing the U.S. Presidential Advisory Council on HIV/AIDS at President Clinton's White House Office of National AIDS Policy and shepherding the council into former President George W. Bush's first year. He later inaugurated government affairs programs for two national health nonprofits before joining the United Nations Joint Program on HIV/AIDS in 2008 with duty stations in Washington, D.C., South Africa and Switzerland. In 2017, he separated from the U.N. to return to the U.S. to lead nonprofit work and launched Adira Foundation in 2019. Greg leads Adira from both professional but also personal experience with complex health needs. Living in Johannesburg in 2013, he sustained multiple traumatic injuries to his face and mouth in a high-speed cycling accident on a nearby mountain road. In the wake of 12 surgeries and multiple complications, he has lived the challenges of health navigation, isolation, and understands the urgency for new approaches to supplement current good work.

CYNTHIA GÓMEZ, Board Chair

Gómez has demonstrated leadership and contribution to U.S. and international health policy, and over 25 years of experience as a behavioral health scientist. She has been a pioneer in the integration of social determinants of health in research and in the development of community-based health interventions. Gómez has helped build strong and diverse health-focused organizations, including a community mental health center, a global HIV research center, and a broad-based health equity institute. Currently, she consults around health equity, health policy, and community-informed science. She serves as the ETR, Inc. board chair, and the board of the San Francisco Community Health Center. She served on the federal advisory committee of the Department of Health & Human Services' Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2030 (Healthy People 2030). She has over 100 scientific publications.