

Network Map

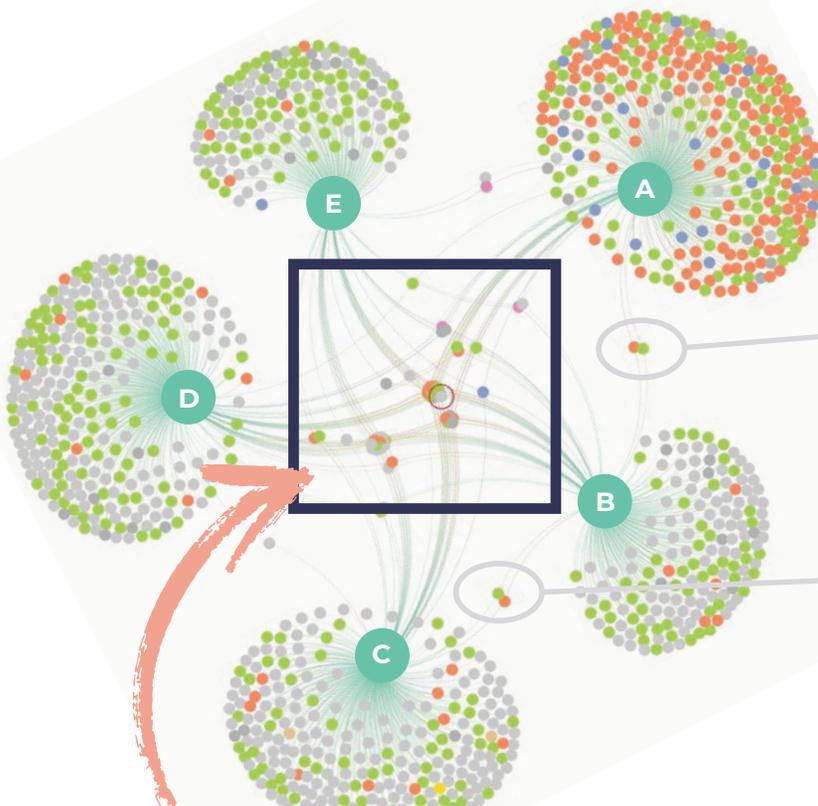
Mapping organizations in neurodegenerative disease communities

WHAT IS IT?

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. We'll publish a basic map in addition to partnering with organizations to implement the same tool customized for them, first in Virginia then expanding nationally.

THE PROTOTYPE

Here's a static glimpse of the web-based prototype, where each dot is an organization grouped based on the diagnosis it serves.



Initial Map

The **Basic Network Map** can be sorted by disease, nine major service types and major categories within each service type.

The visualized data can inform decisions around:

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

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

The green dot represents Canine Partners for Life, an organization with programming for ALS and Parkinson's.

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.**

LEGEND

- | | |
|--|-----------------------------------|
| A Alzheimer's disease | ● Diagnosis |
| B Parkinson's disease | ● Clinical Research |
| C Amyotrophic lateral sclerosis | ● Caregiver |
| D Multiple sclerosis | ● Legislative Advocacy |
| E Huntington's disease | ● Patient Support |
| | ● Disease Forum |
| | ● Technology |
| | ● Disease Education & News |

As people interact with the map, we will use their feedback to decide what features to add to the map next.

FUTURE MAP VERSIONS

A map where you can search for organizations by location is underway. Other possible maps include:

- **Patient support:** Serves as a directory for patients and providers, and highlights whether any services are particularly rare or duplicative
- **Financial influence map:** Highlights where money flows from, to whom, and how it can be leveraged for joint projects
- **Policy influence:** Maps proposed local, state, or federal legislation
- **Collaboration networking:** Identifies who is working with who behind the scenes, where expertise lies, and how network collaboration can be improved
- **Organizational volunteer openings:** Leverages the large group of individuals interested in impacting people with neurodegenerative diseases by connecting them with organizations seeking volunteers

PROJECT PHASES



ONE

September — Chart Basic Network Map

TWO

October — Complete Geographic Map, searchable by location

THREE

November — Ask users (convene them) to hear what features would be most useful in future maps

FOUR

Early 2021 — Amplify and celebrate the best bridges amongst disease communities

FIVE

Mid-2021 — Design new features/maps based on what we hear from users

ABOUT ADIRA, OUR ROLE, AND WHAT WE HOPE TO ACHIEVE

Adira Foundation is bringing five neurodegenerative disease communities to work together to address commonalities: Alzheimer's disease, ALS, Huntington's disease, multiple sclerosis, and Parkinson's disease. This map shows us where these efforts may be most effective.

In sharing it with people and partners, we can explore ways to mend the fragments of our care systems—improving collaboration, communication, public policy, financing, and intersection among the five communities. Adira serves as a relatively neutral platform to host these cross conversations. Here, Adira will research and map programs and will host the ultimate platform for shared use. Adira will also convene stakeholders to discuss uses and future iterations.

OUR NEXT STEPS

We are seeking diverse funding and partners to help validate the data, develop the technology for wide-spread dissemination, and to feed the expansion of key intersections of programming among multiple, if not all five, communities.