Improving Access to Diagnostic and Support Resources for Rural Populations Impacted by Multiple Sclerosis in MD, NC, VA, and WV

Why MS?

- MS is a leading cause of disability in people aged 35 and under
  - Diminishes workforce capacity
  - Reduces individual financial security
- There is no cure for MS, it is a disease persisting through lifespan
  - Evolving needs
  - Evolving responsibilities, including dual patient / caregiver roles
- MS impacts physical, mental, and emotional wellbeing
  - Requires a team of healthcare providers
  - Requires a holistic network of social support services
- Similarities to many other neurological diseases

Grant Funds

Year 1

$265,430

Year 2

$267,685

Year 3

$214,390

= **$747,505** total

Purpose

- To improve access, delivery, and utilization of specialty care for people living with multiple sclerosis (MS) in rural areas of Maryland, North Carolina, Virginia, and West Virginia

Project period
November 1, 2021
–
December 31, 2024

Methods

To promote health equity and improve the health outcomes of populations disproportionately affected by serious disease and conditions by

1. Strengthening community-based healthcare worker capacity
2. Integrating medical care and community-based supportive services
3. Mobilizing communities in the fight against disease

Maryland Target Counties

Maryland Target Counties
Caroline
Garrett

North Carolina Target Counties

North Carolina Target Counties	
Caswell	Lenoir
Duplin	Montgomery
Greene	Surry
Jones	Wilkes

Virginia Target Counties

Virginia Target Counties		
Brunswick	Henry	Orange
Buckingham	Louisa	Patrick
Charlotte	Lunenburg	Pittsylvania
Cumberland	Nottoway	Prince Edward

West Virginia Target Counties

West Virginia Target Counties				
Fayette	McDowell	Monroe	Raleigh	Wetzel
Marion	Mercer	Preston	Summers	Wyoming

Rural Access

Lack of providers living / practicing in rural areas

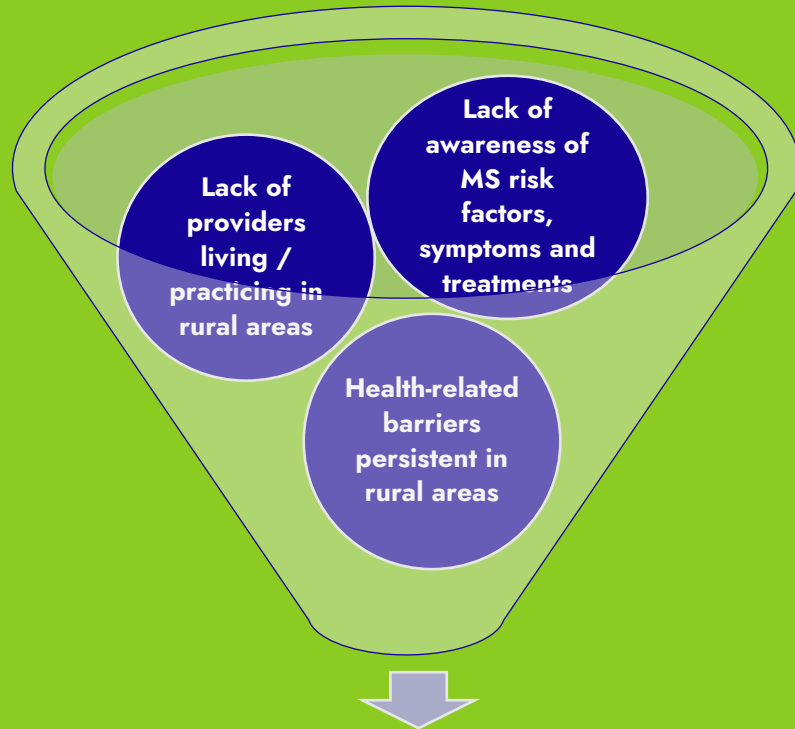**Lack of awareness of MS risk factors, symptoms and treatments**

Health-related barriers persistent in rural areas

Delayed diagnoses, delayed / inconsistent treatment, provider mistrust, reduced quality-of-life, increased disability / employment issues

Most needed support services -

- Transportation
- Financial support to pay caretakers
- SUPPORT GROUPS
- Durable medical equipment access
- Home treatment options
- Healthy lifestyle support
- Pain management
- Emotional support
- Exercise support
- More localized healthcare services

Participants reported that currently they rely on word of mouth to find community services.

Strengthening Community-based Healthcare Worker Capacity

Fill the gaps in:

Awareness

- Community-based events
- Convenings & surveys

Education & Training

- ECHO curriculum for non-specialty healthcare providers and community workers delivering health-related services

Access

- Network mapping tool
- Technology assistance
- Navigation centers

Integrating Medical Care and Community-based Supportive Services

Utilizing approaches like:

Meeting People Where They Are

- Mobile health units & faith-based nurses
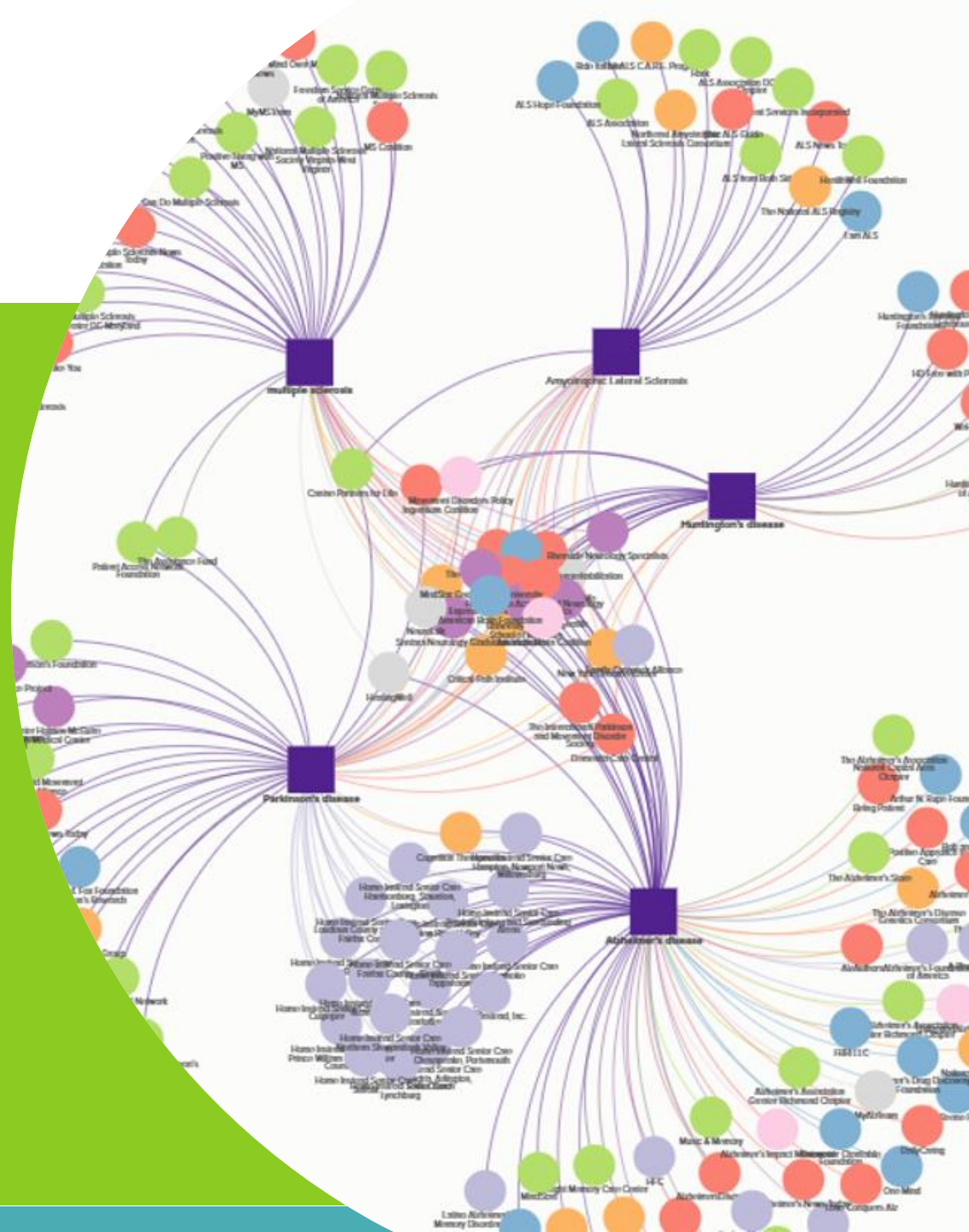- Community-based events

Filling Technology Gaps

- Navigation tool browsable offline
- Tablets and mobile hotspots
- Telehealth sites

Providing Holistic Health & Social Service Navigation Support

Network Mapping

- Pilot map *"Health and Social Support Resources for People Most Impacted by Neurodegenerative Disease in Virginia"*
  - Organizations located in or serving residents of Virginia
  - Organizations have specialized knowledge of ND support and a mission to serve ND communities

Network Map Uses

Individual

- Resource identification
- Resource vetting
- Increased information and referral services
- Increased time, money, energy, confidence, and connection

Systems

- Maximize community resources
- Reduce replication of services
- Increase collaboration
- Improve network effectiveness

Mobilizing Communities in the Fight Against Disease

Engage with rural communities to:

Inform

- Raise awareness
- Co-design solutions

Involve

- Implement solutions
- Connect to research, education, and support opportunities

Inspire

- Evaluate impact

Project Timeline, Summary

	Completed Work	Active Work	Future Work
Provider education & training	Established partnerships with ECHO and PBRN programs Identified partners for curriculum development	Curriculum development and program session design Provider recruitment	Research Question Expand activity to more providers with more neurologic health conditions
Public awareness & education	Established partnerships with mobile health units and community-based programs	Risk-factor awareness tool Educational materials development	Host community-based events Community leaders training
Community engagement	Established partnerships for PMI recruitment and management	Host additional convening events	Continued community engagement
Network Mapping	Identified existing resource information	Collaborating with VANAV to create resource directory	Establish Navigator Centers

Impact

- Increase access to healthcare providers with knowledge of MS risk factors, early signs and symptoms, and treatment options in rural areas
- Increase public awareness of MS risk factors, early signs and symptoms, and support resources including treatment options
- Improve the health and social service navigation experience for people most impacted by MS living in rural areas
- Decrease time from symptoms to diagnosis (undiagnosed) and increase treatment compliance (diagnosed)
- Improve the quality-of-life of people most impacted by MS