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

Grant funds are generously provided by Bristol-Myers Squibb Foundation (BMSF)

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
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<tr>
<th>Virginia Target Counties</th>
<th>Maryland Target Counties</th>
<th>North Carolina Target Counties</th>
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**Rural Access**

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

Health-related barriers persistent in rural areas

Lack of awareness of MS risk factors, symptoms and treatments

Lack of providers living / practicing in rural areas

**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

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<th>Completed Work</th>
<th>Active Work</th>
<th>Future Work</th>
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| **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