

Virginia MS Alliance – Informing the Need

The Virginia MS Alliance converged on October 27, 2022, to welcome 65 participants most impacted by multiple sclerosis to the first rural healthcare convening at the Salem Civic Center in Salem Virginia. We engaged in discussion for over two hours about what mattered most to those living with and caring for those with MS. The participants discussed the barriers to diagnosis and what needed to change to improve outcomes. The themes from the event will inform the collaborative project to improve access, delivery, and utilization of MS specialty care in rural areas.

Themes / Discussions:

Barriers to diagnosis

Participants shared personal experiences about the various challenges that delayed diagnosis. Many expressed the important role of self-advocacy to get to a diagnosis as many of their symptoms were dismissed. Others credited their primary care physician as pushing for a diagnosis after observing their progressive symptoms. There was a general feeling that a visit to neurologist does not necessarily lead to a proper diagnosis and sometimes caused further delays. Some participants reported that it took over a year to get the diagnosis from a neurologist. One participant stated she had symptoms for 17 years before diagnosis. Others discussed the number of misdiagnoses, typically around 4 before finally getting the correct MS diagnosis. Most expressed a willingness and acceptance to travel to a specialist but were frustrated that despite their efforts to get the care they needed they were misdiagnosed or had to return several times. All expressed a sense of relief with the diagnosis so they could finally get treatment and understand what was happening to them. A participant spoke about her depression improving after she finally received a diagnosis. Others discussed their insurance providers preventing them from seeing specialists early on as well as the barriers they experienced uninsured. One participant reported that it was her mother's ophthalmologist who recognized her symptoms and sent her to a neurologist. Another reported having an unnecessary surgery to treat symptoms before his diagnosis.

Few Neurologists / Limited Access

The local neurologists are generally viewed as trusted professionals and known by name and reputation. There was often a disconnect between neurologists at hospitals/clinics further away from their home. However,

	<p>the most advanced treatments are sometimes inaccessible at the local level. Participants saw a need for more neurologists, but neurologists that were also culturally sensitive. Many participants expressed a need for advocates to help at diagnosis to ensure they are given options and access to treatments.</p>
<p>Advocacy - Reducing Stigma & Increasing Understanding.</p> <p>“We need to bring it out of the darkness”</p> <p>“Who knows how we feel better than we do”</p> <p>“You look fine”</p>	<p>The group expressed frustration around the common misconceptions about MS and feelings of isolation. They wished for more exposure about the disease, so they didn’t have to keep explaining it to their family, those in the community, and at times their own physicians. Participants stated that they often feel judged for their symptoms or that their providers feel as though they are exaggerating. The participants at this convening are from a support group and many stated that there needs to be more support groups as their participation has had a significantly positive impact on their outlook and access. Others expressed that because MS looks so different on everyone, there is no one size fits all and they are sometimes not believed, or their experience is minimized. A participant wished for an outspoken celebrity to take the role as advocate for the MS Community and to raise awareness. Caretakers discussed their own stages of grief and the lack of understanding and support.</p>
<p>Navigating Community & Support Services</p>	<p>Most needed support services -</p> <ul style="list-style-type: none"> • 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 <p>Participants reported that currently they rely on word of mouth to find community services.</p>
<p>Telehealth</p> <p>“This is a good step to reaching the unreachable”</p>	<p>Pros - Most participants spoke highly of the increased access to healthcare through telehealth. Many stated that telehealth access helps to ensure they attend their appointments even when battling fatigue. Others stated that it increased access to new medications and made accessing medication faster. Others stated that they felt telehealth improved the amount of time the physician had</p>

to listen to their symptoms and concerns. Participants stated that telehealth is most beneficial during times when their health feels more stable.

Cons – For the more isolated patients, sometimes healthcare appointments are the only time some patients leave their homes, and it encourages mobility. Access to out of state physicians is a challenge due to legislative regulations. There are still long wait times to see a specialist. Participants felt concerned that negative drug interactions would go undetected during telehealth visits. In addition, other mobility symptoms would be harder to assess. The lack of reliable internet impaired the visits and interactions with healthcare providers. Participants complained of regular interruptions during their visits.

Increasing Awareness

Healthcare Providers – the participants wished they had pamphlets to give to their doctors about MS to reduce time they spend educating their providers

Community awareness needs to start early. One participant remembered a film she saw in her high school about MS that pushed her to address her symptoms.