

United In the Journey

Strategic Plan 2022-2026

United In the Journey: Evolving Care, Support and Access for our Epilepsy Community

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Introduction

The Epilepsy Foundation of Minnesota (EFMN) created a five-year strategic plan for the time period beginning January 1, 2022 and ending December 31, 2026. The result of a year of work and the contributions of approximately 350 people, the strategic plan strives to establish a visionary framework, identify best practices, codify values, and lay a framework to expand organizational capacity and reach to serve people with epilepsy and seizure disorders. The strategic plan will be outcome-driven and will align with industry best practices. The commitment of EFMN to public health philosophies will improve local communities and be widely-recognized for its impact. This document will serve as a detailed roadmap of the strategic plan. It will explain priorities for EFMN, the theories driving those priorities, and address the long-term framework of the work to be pursued.

This visionary framework for the strategic plan can be explained in three statements: the vision statement, the mission statement, and the Center for Disease Control and Prevention's "Managing Epilepsy Well Checklist."¹ EFMN shares its mission statement with the Epilepsy Foundation of America (EF), as well as other EF affiliates.

From 2022 - 2026, EFMN will expand our reach, deepen our relationships, and work towards systems change to increase access to therapies for people with epilepsy and seizures. We are committed to improving the physical, social, and mental wellbeing of people with epilepsy. Strategic and purposeful relationship building with healthcare systems, public officials, community members, and other patient advocacy organizations will be essential to our work. EFMN is committed to being an accessible resource to those living with epilepsy, to ensure that people have their physical, social, and mental needs met.

¹ Center for Disease Control and Prevention (2018). Managing Epilepsy Well Checklist. <https://www.cdc.gov/epilepsy/managing-epilepsy/checklist.htm>

Strategic Planning Process

The strategic planning process began in January 2021. Executive Director Glen Lloyd and Special Assistant for Strategic Planning Sara Goodno formed a Strategic Planning Steering Committee consisting of stakeholders that include EFMN Board members, EFMN Professional Advisory Board (PAB) members, people with epilepsy, EFMN staff, and other community members. The committee met once each month from May through October to provide insights and structure to the strategic plan.

Through strategic planning roundtables and community conversation work that EFMN's Mission Outcomes team has been pursuing since 2020, over 300 stakeholder voices were considered in the process as well. Four strategic planning roundtables were held from May through September 2021. The first three roundtables were specific to the three pillars: to overcome, to accelerate, and to lead. Attendees at these three roundtables were asked open-ended questions about what they saw as the problems and potential solutions concerning the pillars. At the final roundtable, attendees were able to respond to a plan draft. The groups invited to attend the roundtables were:

- To Overcome
 - Regional Advisory Committee Members
 - Former EFMN Winning Kids
- To Accelerate
 - PAB members
 - Non-Staff attendees of 2021 Day at the Capitol
- To Lead
 - All EFMN Staff
- Final Roundtable
 - All individuals subscribed to an EFMN mailing list

Overall, there were 48 unique roundtable attendees, and a few individuals who attended more than one roundtable. Specific Board Members were invited to each roundtable as

well. Information from Community Conversations was also incorporated into the strategic plan. Community Conversations is a Diversity, Equity, and Inclusion (DEI) initiative that EFMN's Mission Outcomes team has been pursuing since 2020. Team members hold one-to-one conversations with members of specific cultural communities over a period of a few months, and at the end of that time, a group conversation is held with that cultural community about experiences with epilepsy and other long-term medical conditions. These conversations are co-hosted by EFMN and organizations relevant to the respective cultural community. Thus far, EFMN has held Community Conversations with the Hmong community, Black Diaspora communities, rural communities, and Latino communities.

As a final check on the strategic planning process, the Red Team, consisting of the Board Executive Leadership team, other EFMN Board members, PAB members, and EFMN staff members came together in early October to review and to provide feedback on any aspects of the plan to improve the final product. The use of the red team comes from a security-based concept of testing vulnerabilities in a system where another group of individuals who had not been working on the project are brought in to test the strength of the defenses.² The 'United In the Journey' plan was unanimously approved by the Epilepsy Foundation of Minnesota's Board of Directors on December 10, 2021.

Mission & Strategic Plan Pillars

We lead the fight to overcome the challenges of living with epilepsy, and to accelerate therapies to stop seizures, find cures, and save lives.

The 2022-2026 EFMN strategic plan has three pillars, each taken explicitly from the language of the mission statement. These foundational imperatives are: To lead, to overcome, and to accelerate. The pillars were flushed out by ideas shared by over 100 individuals who engaged with EFMN at roundtables, community conversations, and other volunteer leadership meetings.

² J. Peters (2021). What is Red Teaming? Methodology and Tools.
<https://www.varonis.com/blog/red-teaming/>

'United In the Journey' Vision

The Epilepsy Foundation of Minnesota will build communities where “*no one journeys through epilepsy alone.*”

We know that epilepsy can be a very difficult journey for people with epilepsy and the people who care about them. EFMN commits to journeying with people with epilepsy and their families through providing tailored support and programming.

Guiding Philosophies

Health

As established by the World Health Organization constitution in 1946, “Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”³ Wellbeing is individual to each person, but EFMN recognizes there are certain aspects of physical, mental, and social well-being that will tend to be relevant to people with epilepsy. EFMN’s focus will be on these epilepsy-specific aspects of health. Many of these topics are covered in the CDC’s Managing Epilepsy Well Checklist, last updated in 2018.⁴ This checklist outlines a number of actions that indicate a person is managing their epilepsy well.

Physical Wellbeing

For people with epilepsy, the primary focus of physical wellbeing is controlling seizures. This comes down to managing seizure triggers. According to the Managing Epilepsy Well Checklist, this includes taking medication as prescribed, eating a balanced diet, exercising regularly, getting sufficient and consistent sleep, lowering stress, and avoiding or limiting recreational substance use. When a person has a seizure, tracking

³ World Health Organization (1946). Constitution of the World Health Organization. https://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf#page=6

⁴ Center for Disease Control and Prevention (2018). Managing Epilepsy Well Checklist. <https://www.cdc.gov/epilepsy/managing-epilepsy/checklist.htm>

the seizure type and triggers is important to know, so those triggers can potentially be avoided in the future, and so doctors can provide better treatment. In addition to these topics addressed by the Managing Epilepsy Well Checklist, EFMN recognizes that the responsibility for achieving physical health for people with epilepsy is not solely on the person with epilepsy: it is important that those around a person with epilepsy know how to perform seizure first aid to limit the chances of injury, and that they have access and knowledge to seizure rescue medications to limit the risk or impact of status epilepticus or SUDEP.

Mental Wellbeing

Mental and cognitive health issues tend to co-occur with epilepsy. Anxiety and Depression are common comorbidities of epilepsy, and having seizures can lead to memory problems. Essential aspects of mental wellbeing are getting help for mental health concerns through working with a mental health professional, and addressing memory issues with memory strategies. In addition to addressing memory and mental health, an essential part of mental wellbeing is knowing about your condition. Knowing about your condition is important because decreasing unknowns in your health makes health conditions feel more manageable, increases ownership of condition, and improves ability to advocate for yourself and your health.

Social Wellbeing

Social isolation is a well known effect of seizures, and the largest aspect of social wellbeing is avoiding social isolation. Two aspects of social wellbeing are addressed in the Managing Epilepsy Well Checklist. The first is having a good relationship with your doctor, so you can speak with them about health concerns and about using other therapies. This connection can improve health outcomes. The second aspect is to keep connected to friends and family. EFMN believes that relationships within the epilepsy community are also essential, so people understand that they are not alone in their journey and experiences with epilepsy.

Intersectional Health Equity

In supporting people with epilepsy to manage their epilepsy well, EFMN will utilize ideas of Health Equity and Intersectionality in our work⁵⁶ to better serve individuals with diverse backgrounds. We recognize that having seizures is not an exclusive identity, and that aspects of race, poverty, age, geographic location, and other facets of a person's identity can make accessing medical care and social support more difficult. As such, EFMN will focus on communities of color, rural communities, and working-poor communities in our efforts to journey together with all persons impacted by epilepsy and seizures. EFMN believes that if we are able to serve the most disadvantaged individuals, we will also be able to provide support for those who are less disadvantaged.

In order to effectively serve intersectional identities, EFMN is pursuing a care and support model to ensure our resources are relevant to the specific people we serve.

EFMN recognizes the following intersectional aspects as essential to providing effective tailored supports to Minnesotans with epilepsy:

- Diagnosis/Seizure Frequency Spectrum
- Life Stage
- Racial/ Ethnic communities
- Poverty
- Geography
- Insurance Status
- Comorbidities

⁵ Center for Disease Control and Prevention (2020). Health Equity.
<https://www.cdc.gov/chronicdisease/healthequity/index.htm>

⁶ N. López, V. Gadsden (2016). Health Inequities, Social Determinants, and Intersectionality.
<https://nam.edu/wp-content/uploads/2016/12/Health-Inequities-Social-Determinants-and-Intersectionality.pdf> (nam.edu)

Diagnosis/ Seizure Frequency Spectrum

There is a wide range of experiences in epilepsy based on the frequency and type of seizure, as well as the response to therapies.⁷

Life Stage

People have different needs at different times of their life, and this is especially true of those who have seizures. Pediatrics (children), young adults, and adults have different needs depending on stage of life. Especially important stages of life to be aware of are the transition from pediatrics to young adulthood, situations like marriage and pregnancy, and retirement.

Poverty

EFMN recognizes that poverty is not only a factor of income, but also standard of living, health, education, economic security, housing quality, and neighborhood quality.⁸ EFMN commits to recognizing barriers to care that stem from poverty, and providing referrals to supports that can better serve non-seizure related needs.

Racial/Ethnic Communities

Within different racial and ethnic communities, there are differences in access to care, trust in the medical system, and understanding of epilepsy as a condition. For example, in some African immigrant communities, as well as in the Hmong community, many people understand epilepsy to be a spiritual condition rather than a medical condition.^{9,10} This can significantly impact how people in these communities seek care. In addition,

⁷ Epilepsy Foundation of America (2013). Will I always have seizures?.
<https://www.epilepsy.com/learn/about-epilepsy-basics/will-i-always-have-seizures>

⁸ B. Glassman (2017). Multidimensional Deprivation in the United States: 2017.
<https://www.census.gov/content/dam/Census/library/publications/2019/demo/acs-40.pdf>

⁹ Epilepsy Foundation of Minnesota (2020). Hmong Community Conversations Outreach. Appendix A

¹⁰ Epilepsy Foundation of Minnesota (2021). Black Diaspora Community Conversations Outreach. Appendix B.

trust in the medical system is very low, especially in the African American Community.¹¹

¹² Another significant barrier to care is language and cultural barriers.¹³

Geography

There is a significant difference in barriers to services based on geography in Minnesota. Specifically, those living in rural Minnesota have named transportation, food, surgery and rehab centers, childcare, job opportunities, neurology care access, and broadband access as significant barriers due to geography.¹⁴

Insurance Status

Insurance status has many facets, including no insurance, government-funded insurance, employer-based insurance, and the individual market.¹⁵ Inadequate health insurance coverage can prevent patients from accessing care, decreasing health outcomes.¹⁶

Comorbidities

The epilepsy journey is made more complex by the presence of other conditions along with epilepsy. Common comorbidities include mental health conditions like anxiety or depression, neurological conditions like autism and cerebral palsy, and structural cause conditions such as a brain injury, stroke, or tumor.¹⁷ Having comorbid conditions has been linked to worse health outcomes, and more complex clinical management.¹⁸

¹¹ Epilepsy Foundation of Minnesota (2021). Black Diaspora Community Conversations Outreach. Appendix B

¹² H. Washington (2007). Medical Apartheid: The dark history of medical experimentation on black Americans from colonial times to the present. Anchor Publishing.

¹³ Epilepsy Foundation of Minnesota (2021). Latino Community Conversations Outreach. Appendix D

¹⁴ Epilepsy Foundation of Minnesota (2021). Rural Community Conversations Outreach. Appendix C

¹⁵ Minnesota Department of Health (2021). Health Insurance.

https://data.web.health.state.mn.us/insurance_basic#bytype

¹⁶ Office of Disease Prevention and Health Promotion (2021). Access to Health Services.

<https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/access-to-health#3>

¹⁷ Epilepsy Foundation of America (2019). Epilepsy Due to Specific Causes.

<https://www.epilepsy.com/learn/epilepsy-due-specific-causes>

¹⁸ J. Valderas et. al (2009). Defining Comorbidity: Implications for Understanding Health and Human Services. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2713155/>

Epilepsy in Minnesota

The CDC estimates that the epilepsy population is 1.2 percent of the adult population, and 0.6 percent of the pediatric population.¹⁹ Adjusted for the Minnesota population, there are approximately 55,000 individuals living with epilepsy in Minnesota. The table below breaks down the estimated population into pediatrics, young adults, adults, and seniors according to the United States Census.

Epilepsy Population in MN by Life Stage

Life Stage	Percentage of MN Population	Estimated MN Population w Epilepsy
Pediatrics (0-17)	14%	7,500
Young Adults (18-34)	27%	15,000
Adults (35-64)	45%	25,000
Seniors (65+)	18%	10,000

The EFMN database indicates that 5,500 people with epilepsy have had a relationship with EFMN, which is approximately ten percent of the people with epilepsy in Minnesota. Minnesota has a very strong community of epilepsy medical providers, however, these providers are primarily based in the Twin Cities and Rochester, so there is not equal access throughout the state. There are four National Association of Epilepsy Centers (NAEC) accredited level 3 or level 4 centers in the state of Minnesota.

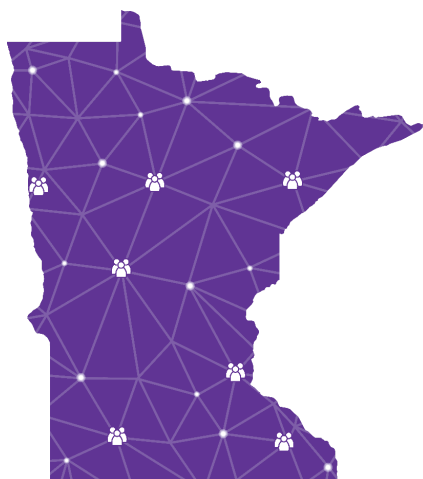
²⁰ Also, the headquarters for both the American Academy of Neurology and the American Brain Foundation are in Minnesota.

¹⁹ Center for Disease Control and Prevention (2020). Epilepsy Fast Facts. <https://www.cdc.gov/epilepsy/about/fast-facts.htm>

²⁰ National Association of Epilepsy Centers (2021). Find an Epilepsy Center: Results in Minnesota. <https://www.naec-epilepsy.org/about-epilepsy-centers/find-an-epilepsy-center/>

Strategic Plan Objectives

To Lead Objective: A Bigger “We”



Increase our community leadership that expands our organizational capacity and reach.

As a patient advocacy organization that represents a large, yet dispersed population, EFMN centers patient voices and priorities in our work,²¹ and supports the connection of the epilepsy community throughout the state of Minnesota. Because we recognize that epilepsy and seizures impact people of all races, incomes, and from all geographic locations, EFMN is committed to ensuring that our volunteer leadership and the individuals that we support are representative of the people who have epilepsy in Minnesota. With the “To Lead” pillar, EFMN envisions an epilepsy community that is representative of and connected within local communities and across the state.

To Lead Goals

EFMN aims to increase the percentage of people in Minnesota with epilepsy with whom we engage from 10 percent to 20 percent by December 31, 2026.²² To achieve this goal EFMN will need to increase the number of people with epilepsy with whom we engage by 15 percent year-over-year. See chart below for specific numbers.

²¹ Epilepsy Foundation of Minnesota (2021). To Lead Roundtable. Appendix E

²² Center for Disease Control and Prevention (2015). Epilepsy data and statistics.
<https://www.cdc.gov/epilepsy/data/index.html>

People with Epilepsy (PWE) Salesforce 2022 - 2026

Year	People with Epilepsy in EFMN Salesforce
2022	5,562
2023	6,325
2024	7,274
2025	8,365
2026	9,620
2027	11,062

To increase EFMN's ability to provide culturally sophisticated support, EFMN commits to continuing its DEI focus through connecting with cultural communities in Minnesota. We will develop a benchmarking process to track relevant outcomes in relationship development with the communities with which EFMN has done outreach under our previous strategic plan: the Hmong community, Black Diaspora communities, rural communities, and Latino communities. Our plan is to continue to outreach to other, yet-to-be determined, cultural communities in Minnesota.

It is essential that our volunteer leadership, including the Board of Directors, PAB, and the Regional Advisory Committees (RAC), is diverse, especially in terms of race, and geographic location so we as an organization are better positioned to serve all people in our community.

To Lead Priorities

As of Q3 2021, EFMN receives referrals to our services through a variety of means, primarily the EFMN website, social media, Google searches, word-of-mouth, and

informal clinic referrals. EFMN believes that a referral system in conjunction with healthcare systems will allow EFMN to provide services to more individuals who are new to EFMN. In 2022, EFMN is planning to create formal referral systems with healthcare systems in Minnesota. The referral system would be based on a combination of the Health Belief Model,²³ and the Buffering Hypothesis²⁴ of social support.

The Buffering Hypothesis is a social support hypothesis that focuses on social support for individuals at high tension points in their journey—in the case of this model, this includes at diagnosis; breakthrough seizures; and, when working towards seizure control, whether in changing medications, preparing for a brain surgery, or the use of another therapy.

The Health Belief model “addresses readiness to act upon a health behavior based upon several individual beliefs.”²⁵ The primary beliefs, assuming the “condition” is epilepsy, and the “behavior” is connecting with EFMN, of this model are perceived susceptibility to the epilepsy, perceived severity of the epilepsy, perceived benefits of a connecting with EFMN, and perceived barriers to the connecting with EFMN.

As we will be pursuing referrals in line with the buffering hypothesis, the perceived susceptibility and severity of the patient's condition is likely to be high. Within perceived benefits and barriers, the benefits will be relayed by healthcare providers, as well as EFMN. The barriers will be minimal, because each healthcare provider system will have access to a referral process that works best for them and their patients.

²³ V. Simpson (2015) Models and Theories to support Health Behavior Intervention and Program Planning. <https://extension.purdue.edu/extmedia/HHS/HHS-792-W.pdf>

²⁴ S. Cohen & T. Wills (1985). Stress, social support, and the buffering hypothesis. <https://psycnet.apa.org/record/1986-01119-001>

²⁵ V. Simpson (2015) Models and Theories to support Health Behavior Intervention and Program Planning. <https://extension.purdue.edu/extmedia/HHS/HHS-792-W.pdf>

Additionally, to increase the relationships we have with people in the epilepsy community, EFMN will pursue relationships with other organizations that serve individuals with co-occurring conditions, such as cerebral palsy, and organizations associated with conditions that can lead to seizures, such as brain injuries, birth injuries, and stroke. These relationships will be productive for both organizations, as EFMN will be able to refer individuals with epilepsy and other co-occurring conditions to other relevant supports, and vice-versa.

To Overcome Objective: Local, Caring, and Supportive



Enhance our care coordination and social support networks that reduce isolation and minimize stigma.

Social support is essential for health,²⁶ and especially for people living with epilepsy and seizures.²⁷ The “To Overcome” pillar focuses on the social support network necessary for people with epilepsy to support physical, social, and mental wellbeing²⁸. For physical wellbeing, people with epilepsy and seizures should feel confident that wherever they have a seizure, they will be physically safe as the people in their network will be aware of how to respond to their seizures. Even though, socially, no one should be limited due to fear of seizures, there is currently fear around social stigma²⁹ and physical safety.³⁰

²⁶ Mayo Clinic (2019). Friendships: Enrich your life and improve your health. <https://www.mayoclinic.org/healthy-lifestyle/adult-health/in-depth/friendships/art-20044860#:~:text=Friends%20can%20also%3A%201%20Increase%20your%20sense%20of,such%20as%20excessive%20drinking%20or%20lack%20of%20exercise>

²⁷ C. Charyton et. al (2009). The impact of social support on health related quality of life in persons with epilepsy. <https://pubmed.ncbi.nlm.nih.gov/18973059/>

²⁸ World Health Organization (1946). Constitution of the World Health Organization. https://apps.who.int/gb/bd/pdf_files/BD_49th-en.pdf#page=6

²⁹ N. Bandstra et. al (2008). Stigma of Epilepsy. [ubmed.ncbi.nlm.nih.gov/18973059/](https://pubmed.ncbi.nlm.nih.gov/18973059/)

³⁰ Epilepsy Foundation of Minnesota (2021). To Overcome Roundtable. Appendix F

This model consists of three concentric circles. The center circle is the person with epilepsy or seizures. The second circle has five aspects: Caregiver, family and personal network, important places, health care team, and the epilepsy community.³¹ The outermost circle is local community systems that impact the lives of people with epilepsy. EFMN will focus first on the center circle and then work outward in providing services and resources for people with epilepsy.

EFMN is committed to working at the pace desired by the person with epilepsy. We recognize that everyone has different needs, and everyone has different comfort levels with whom they want to share their epilepsy journeys, and when. We firmly respect these boundaries, and are committed to supporting people with epilepsy where they want our support, and stepping back where they do not.

Person with Epilepsy/Seizures

Our primary focus as the Epilepsy Foundation of Minnesota will always be the person with epilepsy--supporting them in their epilepsy journey is the reason we exist as an organization. As such, our first priority is to ensure that people with epilepsy receive support tailored to their needs and wants. When appropriate, EFMN will provide necessary support through the Managing Epilepsy Well Network.³²

Caregiver

The caregiver is a complex role for people with epilepsy, because the involvement of the caregiver experience depends on the seizure frequency and age of the person with epilepsy: if for example, the person with epilepsy has had two seizures in their life, and have been seizure-free for a number of years, the role as caregiver is much less intensive than the caregiver of someone who has multiple seizures per day.

³¹ E. Tracy & J. Whittaker (1990). The social network map: Assessing social support in clinical practice. https://www.researchgate.net/publication/232542443_The_Social_Network_Map_Assessing_Social_Support_in_Clinical_Practice

³² Managing Epilepsy Well Network (2021). Managing Epilepsy Well Network. <https://managingepilepsywell.org/>

EFMN will focus on the caregivers who must be more involved: Caregivers of pediatrics, and caregivers of those with no or limited seizure control. In these cases, the caregiver is an essential part of the social support network, both because they are likely to be the people reaching out for resources from EFMN, and because they will need support themselves.

Health Care Team

Receiving care is an essential part of the epilepsy journey. However, many individuals do not know what options there are for epilepsy-specific care, including general practitioners, neurologists, and epileptologists. Many also may not be aware of other health care providers that could be valuable in their journey, including nutritionists, chiropractors, and therapists, among others.

EFMN will work with our PAB to establish a list of care providers that may be valuable within the epilepsy journey, and EFMN information services staff will help provide location-relevant referrals.

Important Places

An important part of living life is being able to go places and trust that you will be physically safe and socially supported. The important places aspect of the social support model is different for all individuals as where people spend a lot of time varies with each individual. For example, a senior in high school would likely spend a lot of time in their classroom, but also may spend time in the gym, their place of worship, and their favorite coffee shop. EFMN aims to ensure this individual is supported physically and socially in all these places, and any other place where they spend a lot of time.

Epilepsy Community

Connections to the broader epilepsy community can be essential for individuals living with epilepsy.³³ While each epilepsy journey is different, the only people who can truly understand what someone with seizures is going through is another person with seizures. These connections provide not only social support, but also practical advice for things like starting a new medication, talking about seizures with friends, or sharing how “coconut oil is also good for getting the glue off when you have an EEG!” as one Camp Oz camper shared with the rest of the group on day 4 of Camp Oz, 2021.³⁴ These connections are comforting, informative, and lets people with epilepsy know they are not alone. EFMN is ideally positioned to facilitate these connections due to our relationships in the epilepsy community.

Important People

Important people include family, friends, coworkers, and others in your personal network. According to the “Managing Epilepsy Well Checklist” from the CDC, one of the indicators that you are managing your epilepsy well is if you stay in contact with friends and family for support.³⁵ In addition, studies have found that social support can minimize the negative impact of chronic health conditions such as epilepsy.³⁶

Local Community Systems

Local Community Systems include First Responders, age-specific locations, and vulnerable spaces. First responders, including Emergency Medical Services (EMS), Fire Departments, Police Departments, and Emergency Rooms (ER) are important because oftentimes, they are the first professionals to respond to a seizure. However, these

³³ Mayo Clinic (2020). Support Groups: Make Connections, Get Help. <https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655>

³⁴ E. Williams (2021). Camp Oz Day 4 Update. <https://www.epilepsyfoundationmn.org/2021/06/24/camp-oz-day-4-marshmallows-over-construction-paper-campfires/>

³⁵ Centers for Disease Control and Prevention (2018). Managing Epilepsy Well Checklist. <https://www.cdc.gov/epilepsy/managing-epilepsy/checklist.htm>

³⁶ C. Charyton et al (2009). The impact of social support on health related quality of life in persons with epilepsy. [https://www.epilepsybehavior.com/article/S1525-5050\(09\)00511-3/fulltext](https://www.epilepsybehavior.com/article/S1525-5050(09)00511-3/fulltext)

groups are not always well trained in seizure response, and may not carry seizure rescue medication, which can decrease the safety of those living with seizures.

Age-Specific Locations are extensions of important places: A classroom is an important place that should provide physical and social safety before, during, and after a seizure, but the broader school, with its policies and norms, is also important to influence on a broader scale so more people with epilepsy can be supported by the system, now and in the future, with limited intervention from EFMN.

Vulnerable places, including homeless shelters³⁷, group homes, and prisons³⁸ and jails are also important systems to influence because they are statistically more likely to have people impacted by seizures, and are less likely to have the resources to access supports--specifically seizure-related supports. Thus, EFMN should stand in the gap to support the most disadvantaged populations.

To Overcome Goals

The goal of the “To Overcome” pillar is to increase depth of relationships. The end goal of these relationships is to support each person living with epilepsy in Minnesota to fill out their social support circle, described above. However, we understand that the epilepsy journey can be extremely personal, and people may not want to share with everyone in their networks. We fully respect that desire, and want to be supportive even if people are not ready to share with their full networks.

There are two primary metrics that will be used to analyze the depth of relationships. The first is EFMN active participants. As discussed on page 7, EFMN uses a database to track the relationships we have with people with epilepsy, along with contact information. To track active participants, EFMN will continue to track people who

³⁷ A.Laporte et. al (2006). Epilepsy among the homeless: Prevalence and characteristics.<https://academic.oup.com/eurpub/article/16/5/484/590420>

³⁸ S. Whitman et. al (1984). Epilepsy in Prison: Elevated prevalence and no relationship to violence. <https://n.neurology.org/content/34/6/775>

participate in events, as well as donors, but will also track successful connections. These connections will be tracked as EFMN receiving a first communication or a response to their communication. This can occur over the phone, email, texting, social media, or another form of communication. The goal is to have 20% of the database PWE number to be active over the course of the year. The chart below gives estimated numbers of our goal of 15 percent growth year-over-year within our “To Lead” pillar,

Active People with Epilepsy Goals January 1, 2022 through January 1, 2027

Jan 1, Year	PWE in Salesforce	Active PWE
2022	5,500	1,200
2023	6,325	1,265
2024	7,274	1,455
2025	8,365	1,673
2026	9,620	1,924
2027	11,062	2,212

The secondary metric is based specifically on the “To Overcome” Model by sending out surveys that will track people’s feelings and perception of their social network in terms of their seizures and epilepsy.

To Overcome Priorities

Our top two priorities within the “To Overcome Model” are focused on the person with epilepsy—making sure they have needed support; and, the epilepsy community—connecting people with epilepsy with other people with epilepsy. The other aspects of our model will be built out through 2022, to be prioritized and implemented

throughout the remainder of the plan. To operationalize, much of the work within this pillar will be completed by outreach and information services staff in one-to-one conversations and individualized support.

In order for the Regional Outreach team to effectively support the mental health, cognitive, and behavioral needs of people with epilepsy, EFMN will work to develop mental health referral systems in the state, and will work to integrate the CDC's Managing Epilepsy Well Network programs into EFMN's offerings. When the systems are in place, the Regional Outreach team will implement.

The Regional Outreach team, in addition to one-to-one connections, will hold gatherings in the communities they serve, which will provide casual connections to the local epilepsy community. This is important for two reasons: first, it increases the number of "weak ties"³⁹ within the epilepsy community; and second, it promotes the development of stronger relationships with others with similar life experiences.⁴⁰ Although strong ties are important, "weak ties" can also be very important for those who need support in their epilepsy journey because it will expose them to new people and ideas.⁴¹ Creating ties with people who have experiences with epilepsy can make it easier to talk about their own experiences with epilepsy; for example, talking about how you feel when you have a seizure is much easier with someone who also knows how it feels to have a seizure than another person who does not have that experience.⁴²

In addition, the Regional Outreach team will develop a more formal mentorship program that can be in place in local communities, the region, or the state. This initiative

³⁹ M. Granovetter (1973). The Strength of Weak Ties.

<https://www.cs.umd.edu/~golbeck/INST633o/granovetterTies.pdf>

⁴⁰ Mayo Clinic (2020). Support Groups: Make Connections, Get Help.

<https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655>

⁴¹ B. Powers et al (2016). Remembering the Strength of Weak Ties.

<https://www.ajmc.com/view/remembering-the-strength-of-weak-ties>

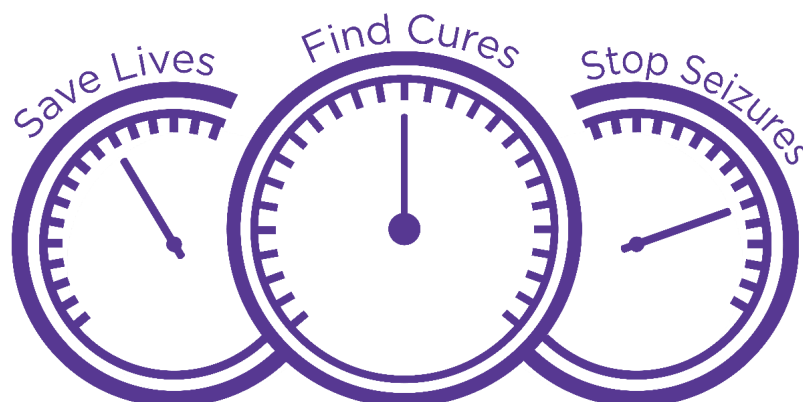
⁴² United States National Library of Medicine: Medline Plus (2020). Living with a chronic illness - reaching out to others. <https://medlineplus.gov/ency/patientinstructions/000602.htm>

is based on feedback from the “To Overcome” roundtable, where numerous participants discussed that at the beginning of their journey with epilepsy, they wished they had a connection with someone who had been through the same thing they were going through, who could give them support and advice in their journey. Now, those same people would also like to be able to share their experiences with people who are new to epilepsy, and be a part of that support system.⁴³

Important places and local community systems are an extension of seizure smart schools programming. Due to the Seizure Smart Schools legislation that was enacted during the 2021 Minnesota legislative session our Seizure Smart School programming will be able to expand into other areas that will need to be further determined.

⁴³ Epilepsy Foundation of Minnesota (2021). To Overcome Roundtable. Appendix F

To Accelerate Objective: More Access



Improve access to essential specialty care, vital community resources, and life-saving therapies.

The “To Accelerate” pillar is focused on the imperatives written into the mission statement: Stop Seizures, Find Cures, and Save Lives. “To Accelerate” focuses more on systems impacting people with epilepsy, rather than the individual journey.

Access to Therapies

“Access to Therapies” means access to the appropriate level of medical care, rescue medications, daily medications, and specialized therapies such as medications, devices, surgeries. Access to Therapies also includes access to neurology professionals who are knowledgeable about epilepsy and its treatments. We narrow down “Access to Therapies” to three topics: transportation, telehealth, and the full therapeutic toolkit.

Lack of access to transportation is a barrier for people with epilepsy and seizures to leading a full life. It impedes people with epilepsy from receiving seizure care and accessing non-medical services such as food and employment.⁴⁴ While many people with epilepsy are able to drive safely, some are not. If a person’s seizures can cause loss of consciousness or voluntary control, their driver’s license will be revoked until the

⁴⁴ Epilepsy Foundation of Minnesota (2021). Rural Community Conversations Outreach. Appendix C

person is seizure-free for three months.⁴⁵ As neurology care in Minnesota is available in the Twin Cities, lack of access to transportation is especially impactful for those who live in rural areas, where services are not easily accessible by walking or public transportation.

Telehealth has made great strides in increasing access to care, especially during the COVID-19 pandemic.⁴⁶ While telehealth is a great tool, it also has its obstacles. For example, not all appointments can be done virtually as some require tests or interactions that are only able to take place in-person. Another challenge in certain areas of Minnesota limited broadband access makes telehealth inefficient or unusable. Additionally, for some individuals, even if broadband is available in their area it may not be accessible to them if it is unaffordable.

Accessing the full therapeutic toolkit promotes quality and effective treatments that are financially accessible. Education of health care professionals is the first required aspect that is key to improving the quality of treatments by increasing the knowledge of health care providers to effective new and old therapies, including medications, surgeries, and other supports such as devices or animals. This education will introduce new ideas, but also overcome historical biases against certain therapies, such as surgery.⁴⁷⁴⁸

The second aspect is to ensure that people with epilepsy do not face undue financial barriers to accessing needed therapies to treat their epilepsy. Reducing barriers includes helping people access health insurance and also making needed therapies accessible for those who do have insurance by addressing barriers such as prior authorization, step therapy, restrictive coverages.

⁴⁵ Epilepsy Foundation of Minnesota (2019). Driving with Epilepsy. Driving-with-Epilepsy-Brochure-English.pdf (www.efmn.org)

⁴⁶ Epilepsy Foundation of Minnesota (2021). To Accelerate Roundtable. Appendix G

⁴⁷ Epilepsy Foundation of Minnesota (2021). To Accelerate Roundtable. Appendix G

⁴⁸ D. Samanta (2021). Underutilization of epilepsy surgeries: Part 1: A scoping review of the barriers. [https://www.epilepsybehavior.com/article/S1525-5050\(21\)00071-8/fulltext](https://www.epilepsybehavior.com/article/S1525-5050(21)00071-8/fulltext)

These access to therapies projects will require significant investment in research, time, and money. It will also require significant coalition building that will extend beyond the term of this strategic plan.

Seizure Safety Education

Seizure safety education is essential for maintaining life for people with epilepsy. Seizure safety education focuses on three topics: Sudden Unexpected Death in Epilepsy (SUDEP) , rescue from an epilepsy medical emergency, and general safety for those living with epilepsy.

SUDEP refers to deaths in people with epilepsy that are not caused by injury, drowning, or other known causes. Although the exact cause of SUDEP may be unknown, risk factors for SUDEP and precautions to reduce the risk of SUDEP are known. It is important that those with epilepsy know that SUDEP is a risk with epilepsy, and to be educated about how to decrease the risk of SUDEP.

Rescue from an epilepsy medical emergency is knowing how to respond to status epilepticus. Status epilepticus is a medical emergency that starts when a seizure that lasts longer than expected. Rescue medications can be used to treat status epilepticus. Educating caregivers and other people in your network on how to react when you have a seizure, when to call emergency services, know how to use and have access to your rescue medication are vital to seizure management and reducing the impact of uncontrolled seizures. In addition, emergency services must know how to use and have access to seizure rescue medication.

General Safety ensures being able to live your life safely regardless of where you have a seizure. This requires education of the person with epilepsy and members of their network. Knowing how to keep a person from injury or death when having a generalized

tonic clonic seizure while walking on the sidewalk, or if they have a seizure while swimming is essential.

Epilepsy Self-Management and Prevention

Epilepsy self-management is one of the most important aspects of maintaining health for those living with epilepsy. According to the CDC, there are three aspects to epilepsy self-management: treatment management, seizure management, and lifestyle management.⁴⁹ These categories include subjects like adhering to your medication regimen, tracking when your seizures happen, and reducing stress.⁵⁰ According to a 2012 study, “Support for self-management can be an important component in managing epilepsy.”⁵¹ As such, EFMN must support the people in our community by providing one-to-one services in the areas of self-management that the people we serve want and need.

In addition, EFMN will pursue prevention initiatives. While the large majority of seizures have no known cause, there are some specific conditions, such as brain injury, birth injury, and stroke, that can lead to seizures.⁵² Our “To Lead” pillar (pg 7), includes working with other organizations who deal with these conditions on a referral system. But ideally, EFMN will be able to work with other organizations on initiatives to prevent these conditions in the first place: for example, wearing helmets to reduce brain injuries, expansion of neonatal care to reduce birth injuries, and promoting healthy eating to reduce stroke.

⁴⁹ Center for Disease Control and Prevention (2019). Epilepsy Self-Management: The Importance of Epilepsy Self-Management. <https://www.cdc.gov/epilepsy/communications/features/self-management.htm>

⁵⁰ Center for Disease Control and Prevention (2019). Epilepsy Self-Management: The Importance of Epilepsy Self-Management. <https://www.cdc.gov/epilepsy/communications/features/self-management.htm>

⁵¹ E.R. Walker et. al (2012). Social support for self-management behaviors among people with epilepsy: A content analysis of the WebEase program.

[https://www.epilepsybehavior.com/article/S1525-5050\(12\)00021-2/fulltext](https://www.epilepsybehavior.com/article/S1525-5050(12)00021-2/fulltext)

⁵² Epilepsy Foundation of America (2013). What Causes Epilepsy and Seizures? <https://www.epilepsy.com/learn/about-epilepsy-basics/what-causes-epilepsy-and-seizures>

Epilepsy Learning Healthcare System (ELHS)

According to EFA, the purpose of ELHS is to “connec[t] epilepsy centers with each other, community services providers, and people with epilepsy and their families... [As a result] ELHS will empower all people with epilepsy to live their highest quality of life, striving for freedom from seizures and side effects.”⁵³ Essentially, data will be shared among clinics in the system, with additional data input from patients, to improve treatment outcomes for people with epilepsy. As of Q2 2021, six centers across the United States were contributing data. Minnesota is home to four NAEC systems: Mayo Clinic, Gillette Children’s, the Minnesota Epilepsy Group, and MINCEP. EFMN will encourage the Minnesota NAECs to join ELHS because we believe this system will be effective in improving treatment outcomes for those living with seizures, thereby stopping seizures and saving lives.

Medical Research

There is currently no known cure for epilepsy.⁵⁴ According to EFA, 6 in 10 of those who have seizures have idiopathic seizures, which means their seizures have no known cause.⁵⁵ While we believe EFMN’s primary role is in supporting people with epilepsy physically, socially, and mentally, we also believe that finding an epidemiological cause of and/or cure for epilepsy would make the ultimate difference in the lives of the people we serve. As the brain is a still-untapped field, we support interdisciplinary research with the same thoughts as the American Brain Foundation, the philanthropic arm of the American Academy of Neurology: That if we cure one brain disease, we will cure many.

⁵⁶

⁵³ Epilepsy Foundation of America (2021). ELHS Clinical Handout.
https://www.epilepsy.com/sites/core/files/atoms/files/ELHS_Clinical%20handout.pdf

⁵⁴ E. Wyllie & L. Jehi (2018). Is there a cure for Epilepsy?
<https://health.usnews.com/health-care/for-better/articles/2018-03-26/is-there-a-cure-for-epilepsy>

⁵⁵ Epilepsy Foundation of America (2013). What Causes Epilepsy and Seizures?
<https://www.epilepsy.com/learn/about-epilepsy-basics/what-causes-epilepsy-and-seizures>

⁵⁶ American Brain Foundation (2021). Who We Are.
<https://www.americanbrainfoundation.org/who-we-are/>

In addition to epidemiological research around the brain itself, there is also an opportunity to invest in the Epilepsy Ventures Fund, led by EFA, where EFMN would need to commit to a funding at a certain level to get an equity stake, and that money would go to fund epilepsy therapies research, and EFMN would have a possibility of getting the initial investment back to reinvest.⁵⁷

Public Health Epilepsy Research

While epidemiological research in ending epilepsy is essential in the long term, in the shorter term, we should also be investing in research around psycho-social interventions in which Epilepsy Foundations across the country have been participating. Easily accessible research about effective interventions for different age groups, seizure types, and race is essential to effectively improving quality of life for the people we serve.

‘More Access’ Priorities

EFMN’s primary focus in the “to accelerate” space is increasing access to therapies. EFMN will increase access to therapies through increasing the size and impact of our funding initiatives such as the Bridge Fund. These funds will allow more people to access therapies and social determinants of health needs in the short term.

To increase access to therapies in the long term, EFMN will participate in advocacy and public policy work to work towards increased access to therapies for people with epilepsy in Minnesota. EFMN will pursue lobbying activities, both legislative and administrative; as well as coalition work and grassroots advocacy to work towards our short and long term priorities, listed below.

⁵⁷ Epilepsy Foundation of America (2021). Epilepsy Ventures Fund. <https://www.epilepsy.com/about-us/research-and-new-therapies/epilepsy-ventures-fund#:~:text=Epilepsy%20Ventures%20Fund%20The%20Epilepsy%20Ventures%20Fund%20%28EVF%29,quality%20of%20life%20for%20people%20with%20epilepsy%20now.>

Short-Term Priorities (1-2 years)

- **Epilepsy recognized by the Minnesota Department of Health (MDH)**
Epilepsy is not currently listed as a condition on the MDH website. EFMN would like Epilepsy to be a named condition on the MDH website.
- **Seizure Detection Devices covered by Medicaid.** Seizure detection devices decrease the risk of SUDEP. EFMN believes that these devices should be covered by Medicaid so life saving devices have a greater chance of getting in the hands of people who need them.
- **Health Policy Reform.** There are a number of overarching health policy reforms EFMN will pursue in partnership with coalitions. This includes, but is not limited to telehealth equity, copay reform, prior authorization, mental health access, and Medicaid access.

Long-Term Priorities (3-5 years)

- **Seizure Nasal Rescue Medication Coverage and Equity.** Rescue medications bring people out of status epilepticus. The nasal rescue medication is newly on the Medicaid Drug Formulary--before, only a rectally applied rescue medication was the only available rescue medication. There is not equal coverage of the nasal rescue medication, and EFMN aims to boost coverage and equity.
- **First Responders/EMS Carry Nasal Rescue Medication.** EMS should carry nasal rescue medication in their supplies to treat people in status epilepticus immediately.
- **Transportation.** Transportation to neurology care is a large barrier to care in the epilepsy community. EFMN will pursue policy solutions to these barriers.
- **Epilepsy Data.** EFMN supports initiatives that will track epilepsy data in Minnesota.
- **Seizure Smart Schools Policy Evaluation.** Seizure Smart Schools passed in the 2021 Special Session. EFMN will monitor any challenges families have with the school district's compliance with the law, and pursue changes to the law if relevant.

- **Health Policy Reform.** EFMN recognizes that health policy reform will be a constant overarching priority in the long, as well as short term. As with our short term health policy reform priorities, EFMN will focus on mental health access, telehealth equity, Medicaid access, and insurance reforms.

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Appendix A

FINAL REPORT **2020 Hmong Community Outreach** **Community Conversation** **October 28, 2020** **One-to-One Conversations** **September – November 2020**

As one of the stated goals in its 2018-2020 Strategic Plan, *Rise Beyond*, the Epilepsy Foundation of Minnesota (EFMN) identified “we will connect with more communities” as one of four strategic pillars. To help achieve this goal, EFMN partnered with Minnesota Association for Community Health Centers (MNACHC) and Hmong Early Childhood Coalition (HECC) to facilitate a Community Conversation with members of Minnesota’s Hmong community on October 28, 2020. EFMN staff also conducted one-to-one conversations with twenty-nine individuals from Minnesota’s Hmong community during the months of September, October, and November. The stated goal of the Community Conversation and individual conversations was:

To engage members of the Hmong community in a well-designed and inclusive conversation about what EFMN does and how EFMN can better serve the Hmong community. The primary goal is to create connection and community, and to lay the foundation for long-term, meaningful relationships.

Fourteen participants gathered virtually on October 28 to talk in small groups about community health and significant medical conditions such as epilepsy. During the individual conversations, discussion focused on personal knowledge of and experience with epilepsy and how EFMN can engage the Hmong community in their work. The following report sums up key takeaways from those conversations, as well as offering all the specific notes gathered from the participants.

EFMN understands that this Community Conversation and the individual conversations are only the first step in a long-term commitment to engaging with the Hmong community, and EFMN is committed to using the knowledge and insights from the conversations to create a strategy for engagement with the Hmong community.

We know that hearing directly from individuals in the Hmong community is an important part of serving the community and that listening is a vital step forward in creating connection. EFMN’s entire Mission Outcomes team is grateful to the forty-three individuals who took the time to talk with us, sharing personal perspectives and wisdom. We hope each participant found the experience meaningful.

Summary

The following general conversation areas were posed during the Community Conversation and one-to-one conversations:

- Hmong community health needs around epilepsy and other major medical conditions.
- Approach for seeking help for epilepsy and other major medical conditions.

From the discussion of these questions, clear themes emerged:

There's no monolithic view of epilepsy in the Hmong community. Epilepsy is seen both as a blessing and a curse, and it is seen as both a spiritual and a medical condition. **Participants identified the stigma, shame, fear, and misunderstanding that exists in the Hmong community around epilepsy.**

Participants stressed the intersection of Western medicine, spiritual healing, and family involvement in treatment plans. Many in the Hmong community believe shamans are an integral part of treatment and several participants stressed that spiritual healing has a place in treatment conversations. There is opportunity for medical providers to build trust and bridge the cultural gap through holistic treatment.

Family relationships and roles are extremely important. **Participants often discussed the differences between generations as well as gender roles. Several individuals mentioned that younger people are more likely to view epilepsy as a medical condition.** As with all communities, EFMN needs to recognize the complexities of faith, culture, and family structure.

There is ongoing opportunity for EFMN to be a convener for those impacted by epilepsy in the Hmong community. **Participants shared that epilepsy can be a scary topic and that there often isn't a safe space to talk about epilepsy.**

Participants found value in having one-to-one conversations with EFMN staff. This speaks not only to the importance of community outreach but also to longer term engagement that creates partnerships and relationships.

Participants encouraged EFMN to meet individuals where they are at. How will EFMN approach a conversation with a person who believes epilepsy is a spiritual condition? How will EFMN bridge language barriers?

Radio, YouTube and social media are all significant news and community sources for individuals in the Hmong community. **Participants suggested using these channels to increase epilepsy awareness and decrease stigma.**

Opportunities:

At the Epilepsy Foundation of Minnesota, we embrace community outreach efforts as ongoing, integral parts of our mission to overcome the challenges of living with epilepsy and to accelerate therapies by engaging communities, government, the medical field, and others in developing a shared agenda that strives for the goal of a healthier community.

Over the first several months of 2021, our team will conduct a second round of outreach, revisiting conversations with organizations that serve the Hmong community and initiating conversations with organizations that we didn't connect with in 2020.

Across our service area there are over 63,000 people who speak Hmong at home and among residents who speak a language other than English, Hmong, Somali and Spanish are the most common languages. We are expanding the materials available in these languages to include our epilepsy fact sheet, which will be available in early 2021. Existing materials include a seizure recognition and response chart, talking with your doctor brochure, and driving with epilepsy brochure.

Also in 2021, we will introduce multiple language options on the EFMN website and additional storytelling on EFMN's blog. We will work with program participants to share their stories in an effort to show the impact that epilepsy has on different demographics. From our conversations with the Hmong community, it is apparent that hearing about individuals and families who look like you is an important piece in not feeling alone when dealing with epilepsy. It also can encourage individuals to reach out to EFMN if they can see that EFMN has worked with someone like them in the past.

We continue to explore opportunities to expand our awareness efforts to include Hmong radio, YouTube, and other social media channels. Many individuals expressed not knowing about EFMN and our services so it is important to become more aware about what channels to use to connect to the Hmong community.

Appendix B

FINAL REPORT **2021 Black Diaspora Community Outreach** **Community Conversations** **March 24, 2021** **April 7, 2021** **Individual Dialogues** **January - March 2021**

As one of the stated goals in its 2018-2020 Strategic Plan, *Rise Beyond*, the Epilepsy Foundation of Minnesota (EFMN) identified “we will connect with more communities” as one of four strategic pillars. To help achieve this goal, EFMN staff conducted individual dialogues with 51 individuals from Minnesota’s Black Diaspora communities during late 2020 and early 2021. In addition, EFMN partnered with Black Nurses Rock, Family Rise Together, and Project for Change to facilitate Community Conversations with members of Minnesota’s Black Diaspora community in early 2021. The stated goal of the Community Conversations and individual dialogues was:

To engage members of the Black Diaspora in a well-designed and inclusive conversation about what EFMN does and how EFMN can better serve the Black Diaspora community. The primary goal is to create connection and community, and to lay the foundation for long-term, meaningful relationships.

In the spring of 2021, 45 participants gathered virtually at two Community Conversations to talk in small groups about community health and chronic health conditions such as epilepsy. In addition, staff and individuals completed individual dialogues focused on personal knowledge of and experience with epilepsy and how EFMN can engage the Black Diaspora in its work. The following report sums up key takeaways from those conversations.

EFMN understands that Community Conversations and the individual dialogues are only the first step in a long-term commitment to engaging with the Black Diaspora community, and EFMN is committed to using the knowledge and insights from the conversations to create a strategy for engagement with members of the Black Diaspora.

Hearing directly from individuals in the Black Diaspora is an important part of serving the community and listening is a vital step forward in creating connection. EFMN’s entire Mission Outcomes team is grateful to the individuals who took the time to talk with us, sharing personal perspectives and wisdom, and we hope each participant found the experience meaningful.

Summary

The following general conversation areas were posed during the Community Conversations and individual dialogues:

- Black Diaspora health needs around epilepsy and other chronic health conditions.
- Approach for seeking support for epilepsy and other chronic health conditions.

Minnesota's Black Diaspora is not a monolith. The second-largest population group in the state, it is composed of multiple cultures, and members of the Black Diaspora have different lived experiences and perspectives. This diversity is reflected in the themes that emerged.

The overarching message across conversations was that there is a lack of understanding about what epilepsy is, with the majority of participants saying they have a limited understanding of epilepsy. **Participants shared that the term 'seizures' is more recognizable and understood within the Black Diaspora than the term 'epilepsy'.**

Participants identified the stigma of epilepsy within the Black Diaspora as well as the stigma around mental health conditions, and that neurological conditions such as epilepsy are often associated with mental health conditions. Because epilepsy and mental health conditions, including depression and anxiety, often co-occur, there is opportunity for EFMN to work simultaneously to destigmatize epilepsy, seizures, and mental health conditions.

Depending on their cultural community within the Black Diaspora, some participants identified their community's perception of epilepsy as a medical condition, while others identified it as a spiritual condition. **Participants made clear that beliefs around epilepsy are intrinsically linked to the cultural community that they are part of.**

Participants, particularly African Americans, identified current and historical trauma associated with the medical system as a significant barrier to receiving care. Historical trauma, including the Tuskegee Syphilis Study, has caused African Americans to be wary of the medical system, and negative incidents many have experienced while seeking care have reinforced that wariness.

EFMN must meet the community where they are at, adjusting for barriers of language, understanding, and past experiences. Recognizing language, cultural, and knowledge barriers is essential for creating positive relationships in the community. African American participants also shared that the white savior mentality is harmful, that there is a long history of talk with no action, and that building trust is essential. Participants discussed the importance of being able to see themselves in communications materials.

EFMN should focus on outreach to Black Diaspora community leaders, have open and honest conversations, and give grace in our interactions, as community leaders have expressed that they are overwhelmed with what is going on in the world.

Opportunities:

At the Epilepsy Foundation of Minnesota, we embrace community outreach efforts as ongoing, integral parts of our mission to overcome the challenges of living with epilepsy and to accelerate therapies by engaging communities, government, the medical field, and others in developing a shared agenda that strives for the goal of a healthier community.

We plan to update our photo repository in 2021. We will ensure that these photoshoots are diverse, so all Minnesotans with epilepsy can see themselves in our communication materials.

EFMN's advocacy program is pursuing a first-person storytelling focus for the remainder of 2021 and into 2022. This initiative will focus on encouraging those with epilepsy to embrace their stories to shape the way Minnesota serves people with epilepsy, which will be a step toward decreasing stigma in communities across Minnesota.

Also within EFMN's advocacy program we are committed to supporting Black Diaspora leaders already doing great work in the policy space. The Legislative People of Color and Indigenous (POCI) Caucus puts out a list of legislative priorities, and we will use these legislative priorities to inform our policy work.

In 2021, EFMN's Information Services is strategically running ads and utilizing email distribution lists tied directly to specific audiences, which will expand the communities we will be able to serve.

Hmong, Somali, and Spanish are the most common languages among Minnesota residents who speak a language other than English. We are continuing to expand materials available in these languages to improve access. This includes our seizure action plan in addition to existing materials, which include a seizure recognition and response chart, talking with your doctor brochure, epilepsy fact sheet, and driving with epilepsy brochure.

By the end of 2021, we will introduce multiple language options on the EFMN website and additional storytelling on EFMN's blog. The new blog content will focus on the diverse stories of those living with epilepsy in Minnesota, and will be published in the storyteller's preferred language, with a translation to English option.

Appendix C

FINAL REPORT **2021 Rural Community Outreach** **Community Conversations** **June 17, 2021/July 7, 2021** **Individual Dialogues** **April - June 2021**

As one of the stated goals in its 2018-2020 Strategic Plan, *Rise Beyond*, the Epilepsy Foundation of Minnesota (EFMN) identified “We will connect with more communities” as one of four strategic pillars. To help achieve this goal, EFMN staff conducted individual dialogues with 54 individuals from Minnesota’s rural communities during early 2021. In addition to connecting with individuals, EFMN partnered with Kids Kare Fund, Greater Northwest Emergency Medical Services, Dancing Sky Area Agency on Aging, Unite Us, and Centracare to facilitate Community Conversations with members of Minnesota’s rural communities in summer 2021. The stated goal of the Community Conversations and individual dialogues was:

To engage members of rural communities in a well-designed and inclusive conversation about what EFMN does and how EFMN can better serve individuals and families within rural communities. The primary goal is to create connection and community, and to lay the foundation for long-term, meaningful relationships.

In the summer of 2021, 44 participants gathered virtually at two Community Conversations to talk in small groups about community health and significant medical conditions, including epilepsy. The individual dialogues with 62 individuals and families focused on personal knowledge of and experience with epilepsy, the impact of living in a rural community, and how EFMN can engage rural communities in its work.

EFMN understands that Community Conversations and individual dialogues are only the first steps in a long-term commitment to engaging with rural communities. EFMN is committed to using the knowledge and insights from the conversations to create a strategy for furthering our engagement with rural communities.

Engaging directly with individuals impacted by epilepsy living in rural areas is an important part of serving the epilepsy community in Minnesota. Listening is a vital step forward in creating connections. EFMN’s entire programs and services team is grateful to the individuals who took the time to speak with us to share their personal perspectives and wisdom. We hope each participant found the experience meaningful.

Benefits of Living In Rural Areas

During the individual conversations, the common theme was the importance of smaller communities, compared to a large city, and the close-knit sense of community it brought to an

individual or family. Some referred to this as a benefit of living in a rural community. Participants discussed that it is easier to build relationships, described the sense of safety and peacefulness of living in their communities as a large benefit, and affordability in rural areas. In addition, many believe that the pace is slower, which is helpful for families managing a chronic illness.

Challenges of Living in Rural Areas

The biggest challenge facing the participants EFMN spoke to was access to services. These services include, but are not limited to:

- Access to medications
- Neurology care access
- Broadband/reliable internet access
- Pure travel time to appropriate healthcare
- Transportation
- Food
- Surgery and rehab centers
- Childcare
- Job opportunities

Due to the lack of access to specialists and the significant physical distances between families and medical care in rural areas, participants mentioned that they often have to take a half or full day off work for an appointment due to travel time. In addition, many individuals with epilepsy are unable to drive due to seizure risk. Rural areas provide few options for travel for those who cannot drive, and other options can be expensive.

Further, access to good emergency care in rural areas can be difficult because Emergency Medical Services (EMS) in rural areas may not be trained to respond to seizures, in the experience of some of our participants. As such, local care can not be entirely sufficient. As a result, the patient may be transported to a larger city such as St. Cloud, Fargo/Moorhead, or Rochester for substantial care at a high cost.

Access to neurology healthcare services can also be a challenge due to a lack of specialty or comprehensive providers in rural areas. Service navigation and care coordination are especially difficult yet vital to many families managing an epilepsy diagnosis. It is crucial to find reliable and

effective ways to coordinate care between primary care physicians and specialists, as needed. While the COVID-19 pandemic has made telehealth services more accessible, multiple issues still play a role. First, obtaining reliable Internet access can be an obstacle in rural areas. Second, telehealth visits can be difficult and ineffective depending on the healthcare needs to be addressed per patient. While some check-ins can take place virtually, some require a patient and healthcare provider to interact face to face to ensure proper healthcare and communication. Telehealth has allowed for a new and innovative approach to providing healthcare however does not always align with all individuals with epilepsy and their support network.

Individuals also commented that rural areas tend to have a fear of change, and language

barriers are an issue for those who are non-native English speakers. In addition, though some parts of life are more affordable, as previously discussed, certain products and services are more expensive in rural areas due to limited options and supplies.

Understanding of Epilepsy

The understanding of epilepsy in rural communities is limited, based on the conversations with our participants. Participants shared that people with epilepsy are “hard to see.” Many people also do not want to talk about epilepsy, leading to a limited knowledge base in rural communities. While some people are open to learning more about epilepsy, there continues to be ignorance, taboo, and misperceptions surrounding epilepsy. However, one participant mentioned that there seems to be greater awareness now than in years past, which is a good indication that things can change.

The rural community conversations reinforced an insight from other community outreach work --mental health and neurological conditions are perceived as connected or the same in the minds of many individuals, and the stigma surrounding one overlaps the other.

The word “epilepsy” was a key topic in both conversations. Rural doctors don’t always use “epilepsy” when speaking with someone with epilepsy or a seizure disorder, which may cause confusion and add to the stigma of epilepsy. Participants also said there is a fear of the word “epilepsy,” much more than the “seizure” or “seizure disorder.” A participant specifically shared that one of the traumas associated with epilepsy is the historical information of individuals who were institutionalized because they had epilepsy.

What should EFMN know to better understand the needs?

EFMN needs to be proactive in building relationships, awareness, and trust with rural communities. In addition, support networks are essential to basic needs, especially in rural areas. It is vital to address the value of social connection versus the previously discussed toll of traveling to an event. Understanding the other obstacles that impact a person’s life, such as lack of access to food, housing, childcare, and having co-occurring conditions, is important in EFMN’s work in supporting people with epilepsy.

Transportation is a significant challenge to those living with epilepsy, especially those unable to drive to meet their basic needs and go to the doctor. Telehealth is an improvement for those who cannot physically get to the doctor, though there are still gaps in care.

Opportunities

Though there are no easy solutions to the challenges discussed in individual conversations and community roundtables, there are many subjects that EFMN can address in the coming years.

EFMN plans to continue raising awareness regarding epilepsy to increase knowledge and decrease stigma. Raising awareness includes educating individuals on epilepsy, seizures, and seizure disorders. In addition, while raising awareness, EFMN will be mindful of sharing stories

and journeys from the rural communities.

In terms of Mission Outcomes initiatives, the Mission Outcomes team will embrace the support of social determinants of health by connecting people to needed resources. Our care and support model, which emphasizes tailored, one-on-one support, will improve the quality of care in rural communities, including increasing staff presence in rural areas. EFMN also continues outreach to rural organizations, including local Chambers of Commerce, to better communicate and provide services to people with epilepsy and seizures. Future policy priorities will focus on minimizing barriers to care while considering the impacts of geographic location.

Appendix D

FINAL REPORT **2021 Latino Community Outreach** **Community Conversation** **10/20/2021** **Individual Dialogues** **July - November 2021**

As one of the stated goals in its 2018-2020 Strategic Plan, *Rise Beyond*, the Epilepsy Foundation of Minnesota (EFMN) identified “we will connect with more communities” as one of four strategic pillars. To help achieve this goal, EFMN staff conducted individual dialogues with 43 individuals from Minnesota’s Latino communities during 2021. These individual dialogues focused on personal knowledge of and experience with epilepsy, and how EFMN can engage Latino communities in its work. In addition, EFMN partnered with Dávila Diversity, Equity & Inclusion Consulting, Ventanilla de Salud, Susana Pelayo-Woodward, HACER, Lifehouse, Oasis del Norte, and Centro Tyrone Guzman to facilitate a Community Conversation with 14 members of Minnesota’s Latino communities in late 2021 to discuss community health and chronic health conditions such as epilepsy. The following report sums up key takeaways from those conversations.

The stated goal of the Community Conversations and individual dialogues was:

To engage members of Latino communities in a well-designed and inclusive conversation about what EFMN does and how EFMN can better serve Latino communities. The primary goal is to create connection and community, and to lay the foundation for long-term, meaningful relationships.

EFMN understands that Community Conversations and the individual dialogues are only the first step in a long-term commitment to engaging with Latino communities. EFMN is committed to using the knowledge and insights from the conversations to create a strategy for engagement with members of Latino Communities

Hearing directly from individuals in Latino communities is an important part of serving the community and listening is a vital step in creating connection. EFMN’s entire Mission Outcomes team is grateful to the individuals who took the time to talk with us and shared personal perspectives and wisdom. We hope each participant found the experience meaningful.

Latino Communities

In Latino communities, identity and the language used to define identity are complex and diverse. Different people within the individual conversations said that they identify with a broader term, such as Latino or Hispanic, while others prefer to identify specifically with their community of origin, with terms such as Chicano, Tejano, Mexicano, or Peruvian. EFMN uses the phrase

“Latino communities” because it is currently the most accepted term for individuals of Latin American heritage and we acknowledge that there is no one specific Latino community.

People who identify as part of a Latino community, referred to in this report as community members, in Minnesota have many countries of origin. There can be significant cultural and language differences between individuals of different countries of origin. In addition, recent immigrants tend to have different needs than families who have lived in the United States for multiple generations.

Due to the broad spectrum of identities and experiences within Latino communities, there is not one unified experience that can be attributed to those in Latino communities. This document acknowledges some of the understandings of epilepsy among those EFMN spoke with, as well as common themes in barriers to care.

Understanding of Epilepsy

Overall, the understanding of epilepsy among the participants was limited mainly because the condition is not widely discussed unless the participant had an individual with epilepsy in their family. Epilepsy may be perceived as weakness or as a punishment in some cultural or spiritual contexts. There is an acknowledged stigma around neurological and mental health conditions. Participants also discussed a tendency to lump conditions together, not understanding a specific diagnosis, such as describing a child with autism as “sick.” In addition, homeopathic remedies are a common aspect of care for those in Latino communities.

Barriers to Healthcare

Language barriers, cultural norms, and insurance complications were commonly discussed concepts in the individual and community conversations.

Language Barriers

Language barriers in healthcare, in both written and verbal communication, was the most discussed barrier to care in Latino communities. Some community members speak Spanish as their primary or preferred language, and it can be difficult to access medical resources in languages other than English. The lack of access to medical resources in the preferred language of the patient includes hospital discharge papers, as well as resources for supports like the Epilepsy Foundation, among many others. Verbal communication between patient and provider can also be difficult. Even when there are interpreters available, medical interpretation is complicated, and there is often confusion. Confusion is especially apparent in specialty diseases and conditions, such as epilepsy, where there are nuances within the condition that are important, such as the various types of focal and generalized seizures. There are also a variety of phrases that are used to describe one type of seizure, and with so many nuances in the condition, it is important to have medical interpretation that is accurate and accessible to all parties involved.

Cultural Barriers

One cultural barrier community members mentioned is that many people do not seek preventative care, which can cause conditions to become more serious before they are treated. While participants provided many possible reasons for this, some attributed it to having not gone

to the doctor much growing up and that mindset caring over into adulthood. Others mentioned that traditional gender roles for both men and women and concerns about appearing “weak” in Latino cultures may discourage individuals from going to the doctor, especially if there is no visible issue such as a broken bone.

An additional large cultural barrier to care occurs within the doctor's office-- culturally, some participants shared a hesitancy among community members to question authority, especially face-to-face. Thus, community members may agree with the doctor when the doctor is in the room, even if the doctor did not fully understand or address the issue the patient brought up. As such, participants discussed the need for cultural brokers as well as language translators in health care settings to ensure concerns and treatments are fully understood by both the physician and patient.

Insurance

Insurance access is a complicating factor for community members due to how complex and challenging the US Health and Insurance systems can be to understand and use. Additionally, for the large majority of Americans, insurance is tied to employment, so job security is also a factor in using insurance for community members. Some community members said they or their family members would sometimes seek care outside of the United States, for example in Mexico. Affordability of care and a less complex system that allows for more recovery time were reasons participants said they or someone they knew sought care outside the United States.

Other Barriers

Other barriers to care discussed include limited transportation and childcare options. These barriers limit the ability to access care, as well as the perceived worth of accessing care. If transportation and childcare are too expensive or inaccessible, it may not be perceived as worth it to go to the doctor. Another significant barrier to care is immigration status. Immigration status can impact access to government aid programs, which in turn can limit access to care.

Opportunities

Based on the barriers discussed, as well as other comments made by participants, there are a number of opportunities EFMN can pursue. The first opportunity discussed is encouraging peer-to-peer connections among community members. According to participants, this will encourage community members with epilepsy to try new therapies they may not have been willing to try without a direct connection with someone from their community who tried it. EFMN can pursue this opportunity through a mentorship program pilot.

Another large opportunity for EFMN is to lessen the language gap, specifically when it comes to resources about living with epilepsy. EFMN will review materials and provide more translated documents, as well as focus on distributing materials to the community. In addition, EFMN has started providing one-to-one phone and in-person support for Spanish speaking individuals. EFMN will also monitor any policy initiatives aimed at improving access to medical interpreters, and support the initiatives as relevant.

In addition to the opportunities listed above, EFMN is committed to staying in communication with our partners in this work, to seek further ways EFMN can support community members. EFMN has also presented a number of Spanish language trainings and is looking forward to

presenting more in the future. EFMN also has an option on our company phone line that will transfer individuals who prefer to speak Spanish to an EFMN Spanish speaking staff member. EFMN staff is also regularly present at the Ventanilla de Salud through St. Mary's Health Clinics at the Mexican Consulate. We will continue to seek community partnerships to better serve Latino communities in Minnesota.

Appendix E

FINAL REPORT

To Lead Roundtable

The Epilepsy Foundation of Minnesota (EFMN) held a virtual roundtable on July 28 for all staff. Unfortunately, drivers were unable to attend due to their routes. Twenty staff were able to attend to provide insight into how EFMN can lead as an organization, and how EFMN can support our staff to lead in their roles. The roundtables were split into two groups. One group consisted of supervisors, and the other group was the remainder of the staff members who are not in a supervisory position. At the end of our scheduled time together, both groups came together to harvest the information. Sara Goodno has had additional 1:1 conversations with individuals who were unable to attend the larger roundtable. The four questions that were asked were:

- What does it mean to lead as an organization?
- What can we do to better lead as an organization?
- What does it mean to lead in your role?
- How can you be better supported to lead in your role?

The third and fourth questions were combined in one of the groups due to time constraints.

There are two aspects of community that were brought up in both groups: being a leader, and being led. In terms of being a leader, EFMN should be recognized as a go-to resource in the epilepsy community, and a leader in the nonprofit world. More importantly, however, was the idea that EFMN must be community led to be a top organization. EFMN must be enveloped in communities, learn from the community what the needs are, recognize those needs and provide those services.

Internally, one point that was consistently discussed was change. While many employees were supportive of change, the pace of that change, and the lack of institutional knowledge involved in making those changes were difficult on EFMN staff. These issues are especially visible during this time of change occurring outside the organization with Covid-19, in addition to internal change, which could be overwhelming. To address these conflicts between desiring change and being overwhelmed by it, the strategic planning team proposes a culture of evolution, which encompasses reasonably paced change, based on institutional knowledge and the desires of the community. As one roundtable participant put it, changes should be regarded with a “hell yeah” attitude by our community, instead of apprehension--buy-in to any changes is paramount.

The suggestions brought up in the strategic planning roundtables to address the pace of change come down to internal infrastructure. For example, having a stable knowledge base of epilepsy and programming across the organization and having stable procedures for onboarding and offboarding across the organization that include transferring relationships to improve continuity

of care for people we serve would increase stability and staff knowledge, which would make changes easier. In addition, communication about initiatives between staff is very important in all directions-- from the top-down, bottom-up, side-to-side, and out, so implementation staff is not cut out of the decision making process by leadership, which can make their jobs much harder; so leadership knows what is going on on the ground and is able to make informed decisions; so departments know what other departments are working on to decrease overlap and provide insight; so our community understands and is excited about new initiatives and changes.

One other point that was consistently made regarding change was that planning and executing cannot happen simultaneously. EFMN must be conscious of timelines and staff capacity in order to be effective in creating and following through on programming.

In terms of workplace benefits, work-life balance was an important topic that arose in the conversations that took place. Ensuring that all staff at all levels of the organization have a healthy work-life balance is important to avoid burnout and provide services to the best of EFMN's abilities. In addition, a strong benefits package and professional development opportunities are integral to supporting employees at EFMN.

Appendix F

FINAL REPORT To Overcome Roundtable

EFMN hosted roundtables on Wednesday, May 26 surrounding the To Overcome Pillar of the Strategic Plan. Members of the Regional Advisory Committees, as well as former Winning Kids were invited to attend. There were 13 attendees over two roundtables. We are very appreciative to the attendees for their insight.

The roundtables were structured in the world cafe model with two primary questions. They are:

- What are the challenges you've faced in your epilepsy journey?
- What could EFMN do to support your epilepsy journey?

All of the points brought up in the next few pages were brought up by attendees at the roundtables--they are valuable opinions that will inform our work, but please keep in mind that they are reflections of other's epilepsy journeys, and you may have different experiences.

Life Transitions

Life transitions are difficult. The transition from being school age to a young adult is especially difficult, not only socially, but also in the healthcare system, for example switching from a pediatric doctor to an adult doctor. Another transition that was described as difficult was finding a job, specifically the interview process. In addition, transitioning to college is difficult, especially with medication, because schedules change dramatically from day-to-day, so taking medication consistently is more difficult.

Seizure Smart

Multiple attendees described a lack of school engagement when it came to their children's epilepsy. One attendee mentioned that there was a lack of engagement, where the school nurse was just going to call 911 every time there was a tonic clonic seizure, which was unnecessary for the child's needs, as well as embarrassing. Another attendee mentioned there was pushback from her child's Pre-K class from learning about seizures at an age appropriate level--the school insisted on sending letters home to student's guardians to confirm it was okay for them to learn about seizures. In the workplace, there is a lack of workplace-specific seizure smart training, and how different people in the workplace need different information. For example, Human Resources may need different resources than a supervisor, than other coworkers. Finally, an attendee said that people should be seizure smart wherever people gather.

Care

Care is a very important part of a person's epilepsy journey--it includes medication, therapies, specialty care, surgeries, and more. The subjects brought up in the roundtables focused on

medication and specialty care. In terms of medication, attendees have run into logistical problems getting their medications--for example, pills being backordered, getting the wrong sized pills, and needing multiple prescriptions in order to make sure they can take the correct dosage with pharmacy logistical problems. In addition, controlled substances are controlled in such a way that a person can only get a refill the day before their prescription runs out, which is inconvenient and stressful.

Medication management and side effects are also challenges for people living with epilepsy, and there is a lack of training for families of people with seizures on the use of rescue medication. In addition, medication for children has the additional complication of frequent growth in weight and inches, which often requires updating medications.

Specialty care also is an area where there are a number of issues. There is often a waitlist to get into a subspecialty, and if a person does not like the care or provider at the subspecialty they get into, it is very difficult to get into a different specialty care facility.

There is also a geographic access to care issue in terms of specialty care, as well as monitoring care such as EEGs--one attendee mentioned they either had to go the cities or Fargo for access to an EEG.

Stigma/ Mental Health

Stigma and Mental Health are issues that often impact people with epilepsy. Stigma surrounding seizures and the resulting isolation can make people feel alone. One attendee mentioned that this may be a benefit of the past year and a half with the COVID pandemic--the general public has a greater understanding of the anxiety of having a medical risk of leaving your house, and having a greater understanding of not being able to leave your house. Within the sphere of mental health, it is important for people with epilepsy and their caregivers to have access to mental health professionals that understand the complexity of epilepsy, and advocate more resiliency strategies in mental health.

Epilepsy Community/ Autonomy

The roundtable attendees discussed the idea of having more autonomy in their epilepsy journey. To paraphrase using language used in our community outreach work, the attendees discussed wanting more ownership of their epilepsy journey. For example, some mentioned that they would like EFMN to provide a 15-20 minute resource about seizures and seizure safety that the person with epilepsy or caregiver can share directly with schools or workplaces, themselves. If this is unsuccessful, they would like to be able to tap into EFMN as an advocate. Essentially, the point was that EFMN does not need to do all the work of making Minnesota Seizure Smart--the community can contribute to that as well.

A One-to-One mentorship network is another point that was discussed at length. At different difficult points during their epilepsy journeys, attendees wanted to connect with people who had

gone through similar issues they were going through—for example, brain surgery, trying a 4th medication, going off medication, trying to have a baby, and a child entering elementary school. Multiple of the attendees also said not only did they want someone to talk to when they were going through specific times of their lives, but they would now like to share their experiences with others.

One additional insight into increasing people's autonomy within their epilepsy journey is it would be valuable for EFMN to create customizable toolkits for those living with epilepsy, specifically allowing for more customization for those with rare epilepsies.

EFMN

The final category of insight was things that EFMN could do better in the programs and services it already provides. The first is more recognition and recommendations from doctors—one family only found out about EFMN a year into their diagnosis from their third doctor.

Connect groups were another topic discussed. The parent support groups are not ideal because for them to go, they need to find childcare for their high-needs child, which is not easy. This resulted in them essentially creating their own parent support group where they could bring their children as well. Additionally, there are limited connection opportunities for teens and young adults—they can connect at Camp Oz, but there are not many opportunities outside of that for teens, and age-appropriate connections drop off entirely for young adults.

Some attendees really appreciated having a “face of epilepsy” in Coach Kill, but think that it may be valuable to have an ambassador who is an average Minnesotan who has epilepsy.

Appendix G

FINAL REPORT To Accelerate Roundtable

On June 23, 2021, EFMN hosted two roundtables about the strategic planning pillar of to accelerate therapies to stop seizures, find cures, and save lives.

There were four questions asked at each of the roundtables. They were:

- What are the challenges/barriers to access to current therapies?
- What are the solutions?
- What are the challenges/barriers around not-yet invented therapies?
- What are the solutions?

Those invited include current and former PAB members, as well as people who are involved with advocacy at EFMN. We are very grateful to all attendees for taking the time to share their insights with us.

The topics discussed can be narrowed down to three primary categories: Access, Research, and Education.

Access

Difficulty with transportation to appointments, telehealth as an effective alternative, and insurance as a barrier to treatment were the primary points discussed in regards to access. Access to in-person or telehealth appointments was a subject that was a surprise to EFMN staff, as we originally had been thinking about therapies as specific treatments such as medication, surgery, or tech wearables. However, the needs according to our roundtable participants were much simpler than that--they simply needed support attending and travelling to appointments. Transportation barriers are an important aspect of life for those with uncontrolled seizures, as seizures can limit their ability to drive. Transportation can be even more difficult if a person lives in a more rural area with few neurologists and limited public transportation.

Many doctors and patients at the roundtable noted that the increase of telehealth services during the pandemic has benefited them greatly. Though not all appointments can be virtual, many can, and this is an important aspect to health equity according to roundtable participants. While telehealth was praised, potential issues with access to devices and broadband, as well as unclear insurance policies on telehealth.

Insurance policies also pose difficulties to access to therapies. Specifically, prior authorization⁵⁸ is a barrier to access because it slows down the process of finding seizure control, and in some cases can put certain therapies out of reach entirely.

⁵⁸ [What is prior authorization? | Cigna](#);
[What is Prior Authorization? - Prior Authorization Training \(priorauthtraining.org\)](#)

A few potential solutions to access were discussed. They are:

- Work with potential transportation partners (Metro transit, metro mobility, Day Training and Habilitation organizations with transportation, other private partners) to provide more consistent transportation to treatment
- Invest in getting the technology needed for telehealth visits into the hands of the people we serve.
- Commit to pursuing policy solutions to prior authorization issues

Education

Participants discussed that there is limited education for patients and providers about epilepsy, which can make getting treatments and attaining seizure control difficult. The most important point that was brought up within this category is the idea that there is limited education about the hope and risks of having epilepsy. In terms of hope, many patients have limited knowledge about therapies alternative to medication, such as surgery. As such, these patients either do not know that surgery is a potential option, or they are scared of surgery as it is portrayed as a last resort therapy. Because of this lack of education about the options outside of medication, options for seizure control therapies become more limited.

In terms of risk education, SUDEP is an important topic for people with epilepsy and their families to know about. Approximately 1 in 1000 people living with epilepsy pass away from SUDEP each year, and it is not a subject that is discussed often, and patients often do not know about the risks. While SUDEP is still not well understood, there are some technologies and non-tech devices that can mitigate the risk of SUDEP through monitoring seizure activity and making certain objects, such as pillows and placemats more friendly to seizures. An organization based in Chicago, the Danny Did Foundation⁵⁹ is a leader in SUDEP awareness and providing access to seizure detection and prevention devices.⁶⁰

Roundtable participants discussed a full therapeutic toolkit as an important aspect of treatment and seizure control. A full therapeutic toolkit is when a provider has the knowledge and access to prescribe treatments including the newest medications, old medications that may not be common anymore, but still may provide seizure relief, surgeries, and tech and non-tech therapies. Because everyone's epilepsy is different, some may respond best to what can be termed as outdated medication, and some may respond best to surgery or a brand new medication. Because there is such a wide range of therapies that may work for a specific person, it is important for providers to have as much of that knowledge as possible, and the ability to prescribe those therapies based on their knowledge and experience.

⁵⁹ [Advancing Awareness of Epilepsy & SUDEP | Danny Did Foundation](#)

⁶⁰ [Devices & Technology - Devices | Danny Did Foundation](#)

Proposed solutions to these issues include:

- Emphasize the variety and acceptability of therapies in our outreach and communication with people we connect with
- Connect individuals considering certain therapies with others who had used that treatment
- Put a focus on educating doctors and patients about SUDEP
- Provide access to seizure trackers through a fund
- Education library for patients
- Education library for providers

Research

Scientists still don't understand the brain. This is the biggest issue discussed by roundtable participants. Because the brain is still an unknown, research about understanding the brain has a number of opportunities to pursue. Specifically, participants mentioned that a focus on interdisciplinary brain research has the potential for many opportunities to find a cure for epilepsy. The other research discipline discussed was Epileptogenesis research, which is the research of how epilepsy begins, which would likely have benefits for preventing and curing epilepsy. In other areas of research, the drug development to market pipeline is slow and expensive.

To address the gap in research, EFMN can:

- Commit finances to research
- Invest in the Epilepsy Ventures fund with National
- Invest in the ELHS data system at National by encouraging Minnesota's NAEC's to become members

The roundtable discussions provided a large amount of information that has been developed into a model draft, which we will be discussing during the steering committee meeting on July 16, 2021. The model, which centers on the mission imperatives of stop seizures, find cures, and save lives, is drafted below for your review.