

**Report of the**  
**Missouri Multiple Sclerosis**  
**Task Force**



**May 8, 2017**

May 8, 2017

The Honorable Ron Richard  
The Honorable Todd Richardson  
State Capitol  
Jefferson City, Missouri 65101

Dear Mr. President and Mr. Speaker:



The Missouri Multiple Sclerosis Task Force, acting according to its charge, has met, deliberated, and concluded its study on issues relating to multiple sclerosis in Missouri. The Task Force now presents to the Missouri General Assembly a report of its activities and actions to date.



Darnetta Clinkscale, Chair



Senator Brian Munzlinger

  
Representative Travis Fitzwater  
Representative Clem Smith  
Dr. Mark Tullman

Myles Goble MD  
Dr. Myles Goble

Robin Slater  
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Florian P. Thomas  
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Jenelle Lee  
Jenelle Lee

May 8, 2017

Members of the Missouri Legislature  
Missouri State Capitol  
#201 W. Capitol Avenue  
Jefferson City, Missouri 65101

Dear Members of the Missouri Legislature:

Multiple Sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system, which is comprised of the brain, spinal cord, and optic nerves. MS damages the nerve-insulating myelin sheath that surrounds and protects the brain. The damage to the myelin sheath slows down or blocks messages between the brain and the body. The cause of MS remains unknown; however, having a first-degree relative, such as a parent or sibling, with MS significantly increases a person's risk of developing the disease.

According to the National Institute of Neurological Disorders and Stroke, it is estimated that there are approximately 250,000 to 350,000 persons in the United States who are diagnosed with MS. This estimate suggests that approximately 200 new cases are diagnosed each week. In 2015, Senate Concurrent Resolution 12 established the Missouri MS Task force, which was made up of the following members:

- Senator Brian Munzlinger, 18<sup>th</sup>
- Senator Gina Walsh, 13<sup>th</sup>
- Representative Travis Fitzwater, 49<sup>th</sup>
- Representative Clem Smith, 85<sup>th</sup>
- Dr. Florian Thomas, Neurologist, St. Louis University
- Robin Slater, MS Society
- Darnetta Clinkscale, Barnes-Jewish Hospital
- Karen Minch, Person with MS
- Dr. Myles Goble, MS Specialist at Neurology, Inc.
- Dr. Mark Tullman, Missouri Baptist Medical Center
- Kerri Bowes, Former National Multiple Sclerosis Society employee
- Jenelle Lee, Occupational Therapists, Rehabilitation Institute of Kansas City

The purpose of the MS Task force was to develop strategies to identify and address the unmet needs of persons with MS in order to enhance the quality of life of persons living with MS by maximizing productivity and independence, and addressing the emotional, social and vocational challenges of persons with MS; and to develop strategies to provide persons with MS greater access to various treatments and other therapeutic options that may be available.

The MS Task Force met several times during 2016 in Jefferson City or by teleconference to develop recommendations to address the charge to the MS Task Force. The task force divided into three workgroups to address its charge. The Independence Workgroup consisted of Senator Brian Munzlinger, Robin Slater and Kerri Bowes. The Access to Care Workgroup consisted of

Representative Clem Smith, Dr. Florian Thomas, and Jenelle Lee. The Insurance Reform Workgroup consisted of Representative Travis Fitzwater, Darnetta Clinkscale, and Dr. Myles Goble.

The attached workgroup reports describe some of the main issues that persons with MS struggle with daily and strategies and recommendations to address these critical issues. The issues are categorized as follows:

1. Access to Quality Health Care:
  - a) Isolation and Mental Health
  - b) Connections and Awareness
  - c) Rural Health Care Access
  - d) Telehealth/Telemedicine
2. Insurance Reform:
  - a) Barriers to Medication Access: Administrative Burdens, High Cost and inadequate Information, a perspective from the National MS Society, a perspective from a neurologist and a pharmacist
3. Needs and Barriers to Persons with MS being able to be Independent:
  - a) Transportation
  - b) Housing: Affordable and Accessible
  - c) Public Housing
  - d) Home and Community-bases Services

We, the MS Task Force, urge you to act expeditiously to address the needs and barriers for persons with MS living to their fullest potentials. The members of this task force are willing to work with your members to assure that these actions and recommendations are addressed. We look forward to your response.

Respectfully submitted,



Darnetta Clinkscale, Chair  
Missouri MS Task Force

## ACCESS TO QUALITY HEALTH CARE WORKGROUP REPORT

Access to affordable, high quality healthcare is essential for people with multiple sclerosis (MS) to live their best lives. The MS Society's Access to Care Principles guide the work the MS Society accomplishes related to access to quality health care for people with MS. The principles are listed below and additional information to realize the principles can be found on the MS Society's website: <http://www.nationalmssociety.org/Get-Involved/Advocate-for-Change/Take-Action/Access-to-High-Quality-Healthcare/Access-to-High-Quality-MS-Healthcare-Principles>

- People with MS are at the center of their health care decision-making.
- People with MS have access to a comprehensive network of providers and healthcare services focused on producing the best outcomes at affordable costs.
- People with MS have access to comprehensive health insurance plans with affordable premiums, deductibles and other out-of-pocket costs.
- Health care providers have greater awareness, resources and tools to enable the timely diagnosis, treatment and symptom management of MS.
- People with MS have access to and receive high quality MS care regardless of disparities, including but not limited to: disease progression, level of disability, geographic location, socioeconomic status, gender, sexual orientation, race/ethnicity, cultural background, age and care setting (home- and community-based or residential).
- People with MS have access to high-quality long-term supports and services in settings that best meet their needs and prevent financial hardship for the individual and family.

### **A. Isolation and Mental Health**

A. In FY2015, the National MS Society convened a work team to identify the groups of isolated individuals that the MS Society is not currently serving well and to make a plan to better connect them to current Society programs who could offer information, resources and connection to others living with MS. In June 2015, the National MS Society also convened a group that included people with MS and support partners, health care professionals in the fields of neurology and mental health, and researchers and Society staff, to address the depression-related issues including mood disorders. The work team defined isolation as an individualized experience caused by a perceived or actual lack of meaningful connections that may prevent people from living their best life physically, emotionally and socially and that mood disorders may manifest with major depression, mania, grief, disordered sleep, change in appetite, pain, lack of energy, inability to experience joy, anxiety, suicidal thoughts and attempts, and mood swings. The access to quality health care work group reviewed these summary documents and provided recommendations for improved programs and services for people with MS who live with emotional disorders and isolation.

Isolation and mood disorders are interdependent. Isolation contributes to mood disorders and mood disorders may lead to isolation. Both alone and in combination, they compromise quality of life, may simultaneously increase utilization of health care resources, and prevent access to health care resources (including preventive care).

**Several subgroups of patients at high risk have been identified:<sup>1</sup>**

#### **1. People with Progressive/Advanced MS**

People with MS who are isolated as a result of progressive or advanced disease, have little or no recovery from major symptoms and/or symptoms that interfere with daily activities.

People with progressive MS have less access to MS treatment, more permanent major symptoms, greater risk of anxiety and depression, and less access to peer support, greater caregiver needs such as respite or home care, and more barriers to mobility within the home and community, technology, and accessible transportation, creating a greater risk of isolation as a result of reduced access to meaningful connections.

**2. People with MS who live in Rural Areas/Geographically Isolated Communities**  
*(See Rural Health Care Access section)*

People with MS who live in a rural area (open countryside, towns with a population of less than 2,500, those living 1 hour (50 m) or more from an urban center with a population of at least 50,000) are at high risk due to limited access to quality mental health care, respite care, MS specialty care and treatment, transportation, peer support, home care, rehabilitation, housing and support resources. In addition, rural residents are more significantly affected by disability in terms of employment, independence, and quality of life.

**3. People with MS from Diverse Cultures/Ethnic Backgrounds**

People with MS from a variety of ethnic, racial, or national backgrounds may face barriers due to differences in customs, attitudes, practices, languages, and behaviors.

Cultural diversity goes beyond the values, beliefs, practices and customs of African Americans, Asians, Hispanics/Latinos, Native Americans/Alaskan Natives, and Pacific Islanders. Religious affiliation, language, physical size, gender, sexual orientation, gender identity, age, physical and mental disability, political orientation, socio-economic status, occupational status and geographical location are additional factors.

For instance, Hispanics/Latinos with MS report more pain, fatigue, cognitive problems, mental health problems, and dissatisfaction with their access to mental health care than the general MS population. Ethnic minorities are at greater risk for depression and poor mental health, and are less likely to receive adequate care for these problems. Language barriers further compromise access to care.

*\*\*Note: This section excerpted from the MS Society's Isolation Work Team Summary FY15.*

**General issues persons with MS struggling with mental health issues and isolation include (per the MS Society's Mental Health Issues Task Force):**

- Access to mental health professionals who understand the impact of life with a chronic and unpredictable neurological disease
- Access to mental health services in long-term care facilities
  - Per the Missouri Department of Social Services, a Medicaid recipient in a nursing home who receives behavioral health services in the nursing home will not have

those services paid for by Medicaid. This is state policy. The position of the Department is that these services should be covered under the monthly fee paid to the nursing home by Medicaid. Medicaid will cover behavioral health services for a recipient in a nursing home if those services are provided outside of the nursing home, so a recipient can be driven to an off-site psychologist and those services will be covered. Below is an excerpt from the department's policy manual regarding this issue:

○ **13.26.B BEHAVIORAL HEALTH SERVICES IN A NURSING HOME**

- MHD does *not* cover Behavioral Health services provided by a Psychologist, LCSW, LMSW, LPC, or PLPC, with the exception of 90791 and 90792 (see Section 13.14), to nursing facility residents when those services are provided in the nursing home setting. This is the policy regardless of any arrangement a provider may have with a nursing facility concerning the leasing of office space within the nursing home. If Behavioral Health services are provided in the long-term facility itself, there is no MHD coverage afforded a patient. Any costs incurred by a facility for the provision of these services are *not* allowable costs on the nursing facility's MHD cost report.
- MHD will allow a Psychiatric Diagnostic Evaluation (procedure codes 90791 and 90792) for participants in a Skilled Nursing Facility (nursing home) when performed by a Psychiatrist, PCNS, or PMHNP. The Psychiatric Diagnostic Evaluation includes a history, mental status, and a disposition, and may include communication with family or other sources, ordering and medical interpretation of laboratory or other medical diagnostic studies. Please see Section 13.4 for documentation requirements and content of a Psychiatric Diagnostic Evaluation.
- Per Missouri Legislative Research Office, their interpretation is that Missouri Medicaid (MO HealthNet) did at one time cover such services in a nursing home with an additional payment; however, due the drastic increase in utilization as well as the inappropriate utilization of the services, it was determined that the cost of behavioral health services in a nursing home should be included in the monthly fee rather than as an additional charge. It is assumed that once the policy was changed, nursing homes decided to stop providing the services.
- Stigma of accessing mental health services in small towns

**Recent Missouri Legislation related to mental health issues:**

2016

- (Passed) Provision in SB 607 and SB 608 that allowed for MO HealthNet reimbursement for behavioral, social, and psychophysiological services for the treatment, prevention, or management of physical health problems
- (Did not pass) SCR 49 – May as Mental Health Awareness Month



- (Passed) SCR 50 – September as Suicide Prevention Month
- (Did not pass) HB 1428 – expands definition of service dog to include a psychiatric service dog or mental health service dog (filed in previous years as well)

2015

- (Passed) HB 343 – Establishes a committee to assess the continuation of the Money Follows the Person program (designed to assist transition of disabled or elderly persons from facilities to community settings)
- (Did not pass) SB 226 – permits certain counselors and social workers to provide behavioral health services to MO HealthNet managed care participants

### **The Role of Community Mental Health Organizations**

The Missouri Coalition for Community Behavioral Healthcare (formerly Missouri Coalition of Community Mental Health Centers), founded in 1978, represents Missouri’s not-for-profit community mental health centers, as well as alcohol and addiction treatment agencies, affiliated community psychiatric rehabilitation service providers, and a clinical call center.

<http://www.mocoalition.org/>

In Missouri, community mental health centers (CMHCs), designated as administrative agents by the Department of Mental Health, are the primary treatment providers for both adults and children in the Department of Mental Health’s Comprehensive Psychiatric Services Division. In accordance with Section 632.050 RSMo, these designated centers serve as entry and exit points in each geographic area, into and from the state mental health delivery system, and offer a continuum of comprehensive mental health services.

Additionally, the CMHCs must be responsive to their respective communities and thus function in the private as well as the public sector. Through the years, CMHCs have consistently worked with the business community, the schools, the juvenile justice system, disaster response teams, special populations, and numerous government and private agencies in developing a variety of innovative, outcome-based, mode programs that have been implemented both locally and statewide.

Society staff met with Christine Patterson, Community Integration Manager of the Missouri Coalition for Community Behavioral Healthcare in June 2015 to discuss services of organization and opportunities to support them/collaborate. The Coalition works with 31 mental health liaisons across the state, including law enforcement agencies who have clients with behavioral health issues, many with substance abuse disorders or suicidal thoughts. MS has not come up in their work, but they also do not identify other diagnoses. They follow their clients for 30 days. Opportunities for future outreach may include an MS informational briefing at the quarterly meetings and having an information table at their annual conference in September.

### **MS Society Outreach Survey Results**

Related to access to health care issues, MS Society interns interviewed a random sample of 25 individuals with MS in Missouri who have registered with the National MS Society to better understand the issues and barriers they face related to access to health care. We asked individuals

questions related to access to health care (i.e., do they see a neurologist regularly for their MS care, do they access mental health services in their community, do they even know who to call for mental health services, do they go to see an occupational and/or a physical therapist (OT/PT) when they need to, and does their insurance cover OT/PT therapy?).

Many of the individuals with MS had no idea if they had mental health resources in their area. Among those individuals who did know about mental health services, they had not personally taken advantage of services. Some individuals knew that their insurance would cover the cost, but they decided not to go because “it wasn’t needed”. Others never really thought about it, and had not asked their insurance provider if mental health services were covered. Many individuals were not going to occupational or physical therapy because they did not think they needed these services. Instead, they would do their exercises on their own, within their homes. The individuals who did go said they went for a short time, learned the exercises and continued them at home. A majority of the individuals visited their neurologist every six months or at least once a year.

Note: Eighty-eight percent of the individuals contacted had access to Internet.

### **Summary/Recommendations:**

- Increase awareness of mental health issues impacting persons with MS (general public, people with MS and their families, health care professionals). Invite MO HealthNet to provide a link to the National MS Society’s website specific to mental health issues for people with MS and resources for mental health providers. Support future legislation designating Mental Health Awareness month (see SCR 49 from 2016 legislation);
- Identify mental health providers interested in treating persons with MS including providing training for mental health professionals, as well as other community mental health resources. Also, ensure that persons with MS can access the mental health providers (i.e., insurance covers mental health services, access to transportation to see mental health professional or access through telehealth);
- Explore collaborative strategies with other disease groups (e.g., Parkinson’s disease, rheumatoid arthritis, inflammatory bowel disease) for promoting awareness of mood disorders and isolation in chronic illness;
- Learn more about the impact of mental health services not covered by MO HealthNet in long-term care communities. Study the impact of mental health services no longer being reimbursed separately within long-term care communities and explore a possible legislative solution; and
- Create opportunities for collaborating with community mental health centers to enhance care for people with MS-related depression.

### **B. Connections & Awareness - Awareness of MS in all areas of Missouri and connecting people with MS to each other**

Legislative solution:

- Missouri Revised Statute 9.045. The first full week of March is hereby designated as "Multiple Sclerosis Awareness Week" in the state of Missouri. The citizens of this state are encouraged to participate in appropriate activities and events to increase awareness of

multiple sclerosis. MS week 1<sup>st</sup> week of March: set in place to raise awareness of MS and its implications

Expand awareness of the following sources for improving MS awareness and connections:

- National MS Society: website, print publications, emails, online learning and social media
- National MS Society Advocacy: - Individuals with MS are credible experts about how MS has impacted their lives. Sharing their story with the right people raises awareness and can drive change by influencing federal, state, and local government.
- Various medical websites including Consortium of MS Centers at [mscare.org](http://mscare.org)

Enhancing resources already in place, increasing funding for supports and services, and creating new programs and educational opportunities will assist in improving awareness of MS and bolstering connections between people with MS, the community, and medical professionals. The National MS Society already offers a variety of opportunities to connect individuals with MS to others with similar life experiences. Opportunities include:

- MSFriends – a telephone-based program for people living with MS.
- Peer Connections – connect individuals with peer volunteers via phone or email through [MSconnection.org](http://MSconnection.org)
- Self-help groups and clubs focus on support, advocacy or education, or socialization
- Everyday Matters – the National MS Society offers this educational program based on the principles of positive psychology

**Existing barriers and challenges related to raising awareness of MS and improving connections in Missouri include:**

- Lack of Internet access in rural areas.
- Decreased community education opportunities for people with MS, caregivers, medical professionals, and the general population.
- Lack of networking opportunities for persons with MS to ensure proper disease management throughout the course of the disease progression.
- Proper follow through post diagnosis to provide the person diagnosed and their family with current resources and opportunities for engagement/connection.

Raising awareness and improving connections between people with MS is important in order to improve their social and medical support systems. Connections should be made specifically between persons with MS in a face-to-face manner and through Internet based options. Missourians with MS would also benefit from awareness of disease management tools provided by MS specialized neurologists, therapy programs, and existing technologies such as smart phone apps. This increased connection and awareness of MS across populations would provide improvement in continuity of care. Improvements in continuity of care allow for proper therapeutic positioning and safety for functional mobility and transportation; for follow-ups by doctors or nurses to ensure medication follow through and medical management of new or worsening symptoms; for an increase in social networking between persons with MS to decrease isolation and assist in improving overall mental health through connecting to others with like symptoms.

### **Summary/Recommendations:**

- Ensure that National MS Society MS Awareness Week activities are implemented throughout Missouri;
- Apply for grants for National MS Society chapter in Missouri to set in place public education classes at local hospitals, libraries, and city halls for persons with MS to connect and for people in the community to learn about MS that are in line with the National MS Society's strategic priorities;
- Utilize self-help groups through the National MS Society to assist in increasing awareness and as an opportunity for individuals with MS to connect with each other as they provide a medium for individuals to meet in their community and provide opportunities for education;
- Encourage point of service registration with National MS Society to allow patients to be immediately connected with an MS community after being diagnosed with MS by their neurologist;
- Explore funding for local rehabilitation facilities to provide ongoing YouTube or other social media "online" education for people with MS, their caregivers, family, and community members regarding MS, its physical implications and ways to keep health optimum through stretching programs and proper mechanics with transfers, etc.;
- Explore funding to hospitals to initiate MS Achievement Center programs for continuity of care and connections with people who have MS, maintaining status and ensuring proper care during disease progression; and
- Link to the MS Society's website on Department of Health and Senior Services and Department of Social Services, MO HealthNet Division.

### **C. Rural Health Care Access**

Of the approximately 11,200 persons with MS living in Missouri and registered with the MS Society, 21 % (2,364) live in rural communities. Ages of people with MS living in rural Missouri: 20-40 y.o. (10 %), 41-60 y.o. (39 %), 61-100 y.o. (32 %), unknown (19 %). Additional demographic information was requested from Missouri's Department of Health and Senior Services (DHSS). Because MS is not a reportable condition, DHSS's knowledge is limited. Only information on the number of inpatient hospitalizations, emergency room visits, and outpatient hospitalizations for MS was available.

Per undocumented patient self-report and self-report of neurologists at Centers for Comprehensive MS Care in St. Louis, patients often travel long distances to receive a medical evaluation and treatment from a neurologist. With an estimated primary care underserved population of over 35 million (August 2012), the U.S. currently has a significant shortage of health care practitioners. Missouri has a similar problem, with close to 1.5 million primary care underserved Missourians and an estimated 643 practitioners needed to achieve the target population-to-practitioner ratio of 2,000:1. According to the 2010 U.S. Census, 29.6 % of Missourians live in a rural area, but only 18 % of the primary care physicians in Missouri are located in rural areas.<sup>2</sup> Specific to providing care to people with MS, the workforce in neurological care is significantly declining, and more specifically, there is a looming shortage of neurologists who specialize in multiple sclerosis. There are several factors contributing to this: 1) health care policies and reimbursement strategies favor

procedural specialties (such as orthopedics and radiology) over so-called ‘cognitive’ specialties such as neurology,<sup>3</sup> and 2) negative perceptions about clinical care of people with MS<sup>4</sup>.

Dr. Robert Buchanan was a professor of health policy at Ohio State University (Columbus, OH). Highlights from Dr. Buchanan’s research findings in “Living with MS in Rural America” is published in the National MS Society’s Health Policy Fact Sheet. Specific issues to rural health care access we know from Dr. Buchanan’s studies:

People with MS (PwMS) living in more remote rural areas were....

1. Less likely to have a neurologist as their primary care physician;
2. Less likely to have seen several types of health care providers during the past year, including neurologists;
3. Report that services were too far away or they had problems getting a referral;
4. Traveled an average of 103 miles to see a physician who provided MS-focused care;
5. Reported difficulty receiving MS care due to lack of money, level of impairment, lack of or no nearby facilities;
6. Were less likely to report the need to utilize mental health services and were less likely to receive medicine and counseling for their mental health issues.<sup>5</sup>

Rural areas face challenges that contribute to the shortage of health professionals. They include:

1. An aging workforce;
2. Lack of educational and training opportunities;
3. Difficulty in recruiting and retaining health care providers;
4. High turnover and vacancy rates;
5. Lack of opportunities for career advancement;
6. Increased work load demand;
7. Lack of necessary health resources (e.g., specialty services); and
8. Inability for rural towns to financially support full-time health care professionals.<sup>6</sup>

**Summary/Recommendations:**

- Outreach to mental health, rehabilitation and neurology providers in health care professional practices serving rural communities to increase awareness of services and resources available to their patients with MS. Also, connect health care professionals to MS specialists at Partners in MS Care practices as a resource or a mentor.
- Provide training opportunities focusing on MS and/or autoimmune/chronic illnesses for health care professionals serving rural communities – general neurologists, physician assistants, primary care physicians, mental health providers, nurse practitioners, rehab providers (*See Telehealth Section – Project Echo program*).
- Develop a framework of innovative partnerships with already established rural health care providers including: Veterans Health Administration, health systems that serve rural communities, rural health clinics; rural health association, local universities with

programs focusing on rural health and rural health providers (See Health Policy Fact Sheet – Living with MS in Rural America)

#### **D. Telehealth/Telemedicine**

In 2016, Missouri Foundation for Health wrote a comprehensive health policy publication on *Health Care Transformation – Telemedicine: Implications for Missouri*. Telemedicine is the use of electronic communications and technology remotely to deliver health care services. The term “telehealth” is used interchangeably with “telemedicine”, though it often has a broader definition relating to more than the delivery of clinical services. Telemedicine is used, in certain cases, as a substitute for in-person consultations to improve access to geographic regions or particular providers. One major advantage of telemedicine is that it allows people with MS to access quality, specialized MS care. Telemedicine overcomes other potential limitations such as the travel costs and the lack of transportation options available to individuals in rural areas.<sup>7</sup>

Services delivered through telemedicine can be done through a number of models:

- **Interactive videoconferencing:** The use of shared technology with both audio and visual capabilities to allow for real-time consultations.
- **Asynchronous store-and-forward technology:** The transfer of patient information from one provider to another.
- **Remote patient monitoring:** The use of digital technology to transfer medical information directly from patients to providers in another location.<sup>8</sup>

#### **Reimbursement Policy Issues**

**Medicare:** <http://heartlandtrc.org/billing-reimbursement/medicare/>

Medicare only reimburses for a select number of health care services provided through interactive videoconferencing and does not currently cover store-and-forward telemedicine. Qualifying originating sites for telemedicine include physician offices, hospitals, critical access hospitals, rural health clinics, federally qualified health centers, certain renal dialyses centers, skilled nursing facilities, and CMHCs. Telemedicine is only allowed for those eligible beneficiaries who come to an originating site that is located either in a rural health professional shortage area or in a county that is located outside of a metropolitan statistical area.<sup>9</sup>

#### **Private Payers**

In 2013, Missouri passed legislation mandating coverage by private insurers.

**Policy Changes in Missouri:** <http://heartlandtrc.org/billing-reimbursement/missouri/>

During the 2016 legislative session the Missouri General Assembly passed SB 579, and in June of 2016, Governor Nixon signed this legislation into law. SB 579 includes language that expands the use of telemedicine within the state of Missouri.

**Until this legislation passed, Missouri did not reimburse for asynchronous telehealth services.**

The Department of Social Services (DSS) is charged with the duty of creating rules that govern the use of store-and-forward telemedicine in the MO HealthNet Program.

The providers eligible to receive payment for asynchronous store-and-forward services under the MO HealthNet program include any provider of mental, medical, optometric, or dental health services and “all other medical disciplines”. The law later designates which providers may use all telehealth services under the MO HealthNet program, which includes a comprehensive list of providers with all licensure levels. Under previous rules, many providers, such as *licensed professional counselors*, providers in rural health clinics, optometrists, and podiatrists were ineligible for reimbursement under MO HealthNet. The law expands the list of eligible providers to include the aforementioned clinicians, as well as other mid-level practitioners.

One of the most significant provisions in the law is the extended list of authorized originating sites where a MO HealthNet enrollee may receive services. Prior to this legislation, a patient could only receive telehealth services if they were located in a clinical setting such as a hospital, clinic, nursing home, or rehabilitation center. The statutory language added schools, patient homes, clinical areas in pharmacies, and child assessment centers to the list of authorized originating sites. The broader list of originating sites, especially the inclusion of schools and homes, helps to increase access points to care by minimizing barriers that create disruption and inconvenience.

The final major revision established by the new law is the creation of a home telemonitoring program for certain MO HealthNet beneficiaries. **The viability of this program depends on the legislature allocating funds to support it.** If such funding exists, the DSS must develop the program to allow physicians to monitor patient data from the patients’ homes. Clinical information would be gathered by a home health agency or hospital and shared with the patient’s physician. Only individuals who have certain health conditions and exhibit two or more delineated risk factors are eligible to receive care via home telemonitoring. These patients are those that are the most vulnerable, but whose conditions can be managed through remote monitoring. After implementation, the Department must assess whether the program is cost-effective and whether it achieves any cost savings for either MO HealthNet or the Medicare program.<sup>10</sup>

**Project ECHO (Extension for Community Healthcare Outcomes)** is a collaborative model of medical education and care management that empowers clinicians everywhere to provide better care to more people, right where they live.

The ECHO model™ does not actually “provide” care to patients. Instead, it dramatically increases access to specialty treatment in rural and underserved areas by providing front-line clinicians with the knowledge and support they need to manage patients with complex conditions such as Hepatitis C, HIV, tuberculosis, chronic pain, endocrinology, behavioral health disorders, and many others. It does this by engaging clinicians in a continuous learning system and collaborating them with specialist mentors at an academic medical

center or hub. As the ECHO model expands, it is helping to address some of the health care system's most intractable problems, including inadequate or disparate access to care, rising costs, systemic inefficiencies, and unequal or slow diffusion of best practices.

In Missouri, **Show-Me ECHO (Extension for Community Healthcare Outcomes)** uses videoconferencing technology to connect a team of interdisciplinary experts with primary care providers.

In 2015, Missouri became the first state to publicly fund a telehealth project that uses videoconferencing to educate primary care providers around the state through receipt of \$1.5 million to create the ECHO program. MS Society staff met with Missouri Telehealth Network (MTN) Director in September 2016 to learn more about the state of telehealth/telemedicine/Project ECHO in Missouri. Project ECHO is showing good outcomes. Project ECHO is designed as case-based learning. Attendees receive CME credits. An interdisciplinary group of health care professionals provides education to primary care physicians and other health care professionals practicing in rural communities. Project ECHO builds relationships and creates of "community of learning". Education provided is based on evidence-based practice. **Project ECHO is funded through state appropriation. Additional funding was approved, but was withheld.** Cost to provide education to healthcare providers is considered minimal (approx. \$250,000 for experts, operations, technology). **MTN needs additional funding to roll out all the Project ECHO projects they have planned.** MTN is interested in considering opportunities to collaborate with the MS Society for future Project ECHO projects related to managing chronic illnesses such as MS, Parkinson's disease, and more.

In 2015, the National MS Society, Greater Washington Chapter, collaborated with the University of Washington for MS Project ECHO offering a 41 CME weekly videoconference sessions. As a result of the sessions, provider confidence in MS practice increased, case consultation influenced practice habits, and connection to information and resources from the MS Society increased.

### **Summary/Recommendations:**

- For the new Missouri law established through SB 579 related to the creation of a home telemonitoring program for certain MO HealthNet beneficiaries, request that multiple sclerosis be considered as one of the health conditions to receive care via home telemonitoring;
- Educate healthcare professionals about the different ways telemedicine can be provided and identify coverage gaps for appropriate MS specialties; and
- Explore collaborative opportunities and funding sources with MTN to offer education program on MS, chronic illnesses, and/or autoimmune diseases from disease-specific specialists to rural healthcare providers.



## REFERENCES

- 1 Isolation Work Team FY15 Summary (2015).
- 2 Office of Primary Care and Rural Health. 2010-2011. Missouri Rural Health Biennial Report 2010-2011. Available:  
<http://health.mo.gov/living/families/ruralhealth/pdf/biennial2011.pdf> .
- 3 AAN Neurology Workforce Report (10/26/12).
- 4 Research Triangle Institute study for the National Multiple Sclerosis Society (2013) *Analysis of the MS Physician Workforce* (Michael Halpern, PhD, Principle Investigator).
- 5 *Health Policy Fact Sheet, Living with Multiple Sclerosis in Rural America*,  
www.nmss.org.
- 6 Missouri Foundation for Health (2013), *Issues in Missouri Health Care, Assuring an Adequate Health Care Workforce in Missouri's Medically Underserved Areas*, p. 13.4, 13.5.
- 7 *Report of Recommendations to Address the Needs of Persons with Multiple Sclerosis* (December 2015). Illinois Department of Public Health.
- 8 Policy Option Series, *Health Care Transformation – Telemedicine: Implications for Missouri* (2016), p. 1.
- 9 Policy Option Series, *Health Care Transformation – Telemedicine: Implications for Missouri* (2016), p. 2.
- 10 Policy Option Series, *Health Care Transformation – Telemedicine: Implications for Missouri* (2016), p. 4-5.

## **INSURANCE REFORM WORK GROUP**

### ***I. Barriers to Medication Access: Administrative Burdens, High Costs and Inadequate Information Perspective from the National MS Society***

The initiation of the use of an FDA-approved disease-modifying treatment (DMT) is recommended as soon as possible following a diagnosis of relapsing MS. While no DMT is currently available to treat progressive MS, symptom management medications are often prescribed to allow for pain management and to improve quality of life. The average price of an MS DMT in 2016 is \$70,000 per year, increasing 400% since 2004. A recent National MS Society survey reported that more than 75% of respondents mentioned the high cost of medications.

Pharmacologic access and high drug costs present significant and ongoing challenges for people who receive an MS diagnosis. Those who have insurance often face hurdles with a lack of transparency, discriminatory formulary designs, high co-pays and co-insurance, limited access to drug assistance programs, cumbersome insurance authorization practices, and step therapy or first-fail drug protocols. The challenges for the uninsured are even greater, as access to affordable neurology care, other necessary specialty care (physical therapists, ophthalmologists, urologists), and prescription drugs often remains elusive.

The delay in receiving recommended care caused by these barriers to prescription drug access can result in adverse health effects, disease progression, relapse, and even hospitalization.

#### **Transparency and Insurance Plan Structure:**

Transparency in insurance plan pricing should include premiums, deductibles, co-pays and co-insurance. Patients should have access to complete information about formulary coverage and cost-sharing when choosing a plan with substantial notification of any changes. The costs of purchasing MS medications is shrouded in secrecy and makes it impossible for people with MS and their medical care providers to make informed decisions. Medications on co-insurance should not be subject to the plan's deductible. MS medications are not interchangeable. However, formulary decisions frequently do not consider this and are based on factors such as rebate negotiations rather than medical decision-making. Missouri should work toward the elimination of discriminatory practices in formulary design. All available medications for a particular condition, such as MS, must not be on a specialty tier with co-insurance. In recent study of people living with MS and health insurance, those who reported a negative insurance change in the previous 12 months had greater odds of not taking their MS medications.\*

#### **Prior Authorization:**

People with MS would benefit from the simplification of prior authorization processes at the point of prescribing and at the point of renewal. With the current prior authorization process, valuable resources in physicians' offices are spent navigating and securing insurance approvals. Insurance companies have created overly complex systems that are time-consuming to navigate,

something extremely challenging for a person managing a potentially debilitating chronic disease. People with MS often interact with an employer, their provider, an insurer, a specialty pharmacy, and a patient assistance program to get their medication, each often having different requirements and paperwork for patients to complete.

### **Step Therapy:**

Step therapy policies vary in terms of their requirements. Some plans require patients to go through the step therapy process again if the drug they are currently on is moved to a non-preferred status. Some step therapy protocols allow patients to stay on their prescribed treatment as long as they are stable, while others impose step requirements on stable patients. Step therapy requirements may require patients to not only fail one treatment, but several. The time delay before a patient can access their preferred treatment may be relatively lengthy (e.g. 90 days). People with MS would benefit from the elimination of medication changes that are not based on medical benefit. It is suggested that pharmacological determinations be made based upon clinical criteria, high quality research, and medical expertise.

### **Drug Assistance Programs:**

Drug assistance programs are usually offered, with funding provided by pharmaceutical companies. They are often the only gateway to affordable medication for people living with MS. Access to these programs is limited however. Patients must reapply yearly and access is not guaranteed long-term. Funding for these programs runs out quickly and can even fluctuate on a daily basis. In fact, the past year has signaled a very significant increase in times when all drug assistance programs offering help to people with MS are completely out of funds. A poll of MS patients in 2015 indicated approximately 40% of people using DMTs rely on these programs. Multi-year approvals would be an improvement over current processes.

*The following “Barriers to Drug Access Narratives” are true MS patient stories provided to the National MS Society by a Missouri neurologist. They present a snapshot of the prevalent and varying scenarios that patients and providers encounter in their quest to obtain the appropriate pharmacological care.*

#### **Scenario #1- 56-year-old female with private insurance.**

Patient was taking an MS drug, but had to discontinue use due to complications from the medication. The patient’s physician went on to prescribe a new medication. The copayment for this medication was going to be \$1,500 per month. The patient contacted the MS Society to assist with the copayment. The patient could not afford the cost, but was in need of this new medication. The patient received financial assistance through an outside agency, but could not access the medication due to a clause in her insurance. The insurance carrier did not allow their patients to have co-pay assistance. According to the nurse, “They felt the patient should be able to afford their medication and should not have to use assistance.”

*The copayment for this medication was going to be \$1,500 per month. The patient contacted the MS Society to assist with the copayment. The patient could not afford the cost, but was in need of this new medication.*

**Scenario #2- A 63-year-old female with private insurance.**

Patient's MRI showed increased MS activity, indicating her current medication regimen was ineffective. This patient also suffered from injection fatigue and issues with dexterity. Her physician prescribed a different MS drug to adapt to these changes in condition. The patient received a denial from the insurance company. The insurance company stated a preauthorization form was not completed within 72 hours of the request and the patient would have to appeal the denial. The company offered the patient and the doctor's office the opportunity to submit a prior authorization form. The nurse was able to submit the correct form, but later the insurance company stating, "The PA had already been denied," canceled the request. The patient and the nurse tried other attempts to get the medication paid for prior to completing the appeal process, but were unsuccessful. The patient then filed an appeal with the insurance company and was successful in this attempt. After almost 3 months of trying to obtain the medication, the patient was successful in completing medication pre-testing and was able to start the medication.

*This patient also suffered from injection fatigue and issues with dexterity. Her physician prescribed a different MS drug to adapt to these changes in condition. The patient received a denial from the insurance company.*

**Scenario #3- A 52-year-old female with private insurance.**

This patient had a severe post-injection reaction to her MS medication. After meeting with her neurologist, it was determined she should be placed on an alternate medication. Her neurologist sent the medication request to the insurance company for prior authorization. Four days later the insurance company sent a denial letter stating, "The prior authorization form was not completed within 24 hours from the date it was sent to the doctor's office," and the decision could be appealed. Along with the letter, there was also a medical condition alert form. The insurance company stated that they had a diagnosis of chronic liver failure for the patient. The nurse contacted the insurance company and the specialty pharmacy where the prescription was sent to

inform them that their office did not provide the incorrect diagnosis code and the patient does not have liver failure. The pharmacist stated that it may have been an error on their part and to verify the information with the patient. The patient shared she had never stated she had liver failure and denies history of this as well. The nurse completed and submitted the medical condition alert form to correct the patient's health information. Eleven days later the medication was approved. Total time from request to medication approval = two weeks.

*Over a month and a half later, the original prior authorization was finally approved. Total time from request to medication approval = five weeks.*

**Scenario #4- A 53-year-old female patient with private insurance.**

The patient tried several injection medications without success and stopped due to various reasons and reactions. Some of the reasons for ceasing medications included tolerance issues, breakthrough disease, personal financial burdens, and cost of the multiple medications. She participated in a randomized study and began treatment with a new medication as a part of that study. Upon the closure of the study, she alongside her doctor made the decision to continue the medication. A prior authorization form was sent to her insurance to request the medication. It was denied over a week later due to no documentation of pre-testing. An appeal was completed with the pre-testing information included and mailed via US Mail. The insurance company denied the receipt of the appeal that was sent by US mail. An employee at the pharmacy followed up, requesting to fax the appeal that originally had been declined. At this point, the appeal was allowed to be faxed. The employee at the pharmacy received a fax receipt confirmation that day. Almost a week later, the insurance company denied receiving the faxed appeal despite the pharmacy employee having received a fax receipt confirmation. The appeal was re-faxed and the pharmacy employee again received notice that fax had been received. At this point, the insurance company is allowed 15 calendar days to respond. On 3/23/16, over a month and a half later, the original prior authorization was finally approved. Total time from request to medication approval = five weeks.

**Scenario #5- A 62-year-old male with private insurance.**

For many years, the patient declined disease-modifying therapies. He felt the medications were not needed and was uncomfortable with the idea of injections. After a significant relapse in March 2016, he was hospitalized and received IV steroids. He now experiences residual numbness and tingling to his hands, balance impairment, bladder issues, and new cognitive issues. He agreed to take oral medication, which he received approval through prior

authorization. A significant amount of time was spent on patient's behalf trying to clarify if this prior authorization covered maintenance medication in addition to the starter medication. During this time, several barriers were encountered regarding with whom to communicate in order to get this question answered. After talking to several different people and getting conflicting answers, a supervisor intervened and clarified that the prior authorization was for both the starter and maintenance medication. It took 3 weeks from the original order to receive prior authorization and clarification due to communication barriers and misinformation. After the concerns were addressed, the patient was able to start the medication the following day.

### **In Summary:**

Different entities involved in working with the patient must work together to navigate a complex web of paperwork and administration (insurer, specialty pharmacy, patient assistance program). There is also an overall lack of clarity on the role of each entity. Medication should make people better, not add to the challenges of living with a chronic illness. Insurance should make medication access affordable, simple, and transparent. Broadening access to insurance, reducing drug prices and out-of-pocket expenses for patients will allow more people to access these life-changing medications and remain on them.

\* Wang G, Marrie RA, Salter A, Fox R, Cofield S, Tyry T, Cutter G. Health insurance affects the use of disease modifying therapy in multiple sclerosis. *Neurology* 2016;87:1-10

## ***II. Barriers to Medication Access: Perspective from a Neurologist***

Choosing a MS disease-modifying therapy (DMT) is a personalized decision, best made through careful consideration of the relative risks and benefits of each treatment in the context of the values in health goals of the patients and their loved ones. Relapsing MS varies considerably among patients with disease severity ranging between those with mild, indolent disease to those with highly active and rapidly disabling disease. In the United States, there are now 14 FDA-approved therapies in seven different classes of medication for relapsing MS. These medications differ in route of administration, mechanisms of action, side effects profiles, and efficacy, and are not interchangeable. The high variability in the disease course among patients coupled with the large number of FDA-approved therapies render selection of a MS DMT for a given patient highly complex. Decisions about MS DMTs are also complex as they involve consideration of the attitudes of the patients about their MS, their lifestyle, and trade-offs between the risks and benefits of the various therapies. To complicate the process further, there is uncertainty about the comparative efficacy and safety of MS therapies because there are few head-to-head clinical trials. Given the large number of treatment options, neurologists and their patients can usually find an approach that will control the patient's MS while meeting the patient's personal goals and preferences. This is best accomplished through shared decision making between patients and their neurologist.

Despite the large number of MS DMTs and the complexity of the decision-making, insurance companies commonly limit treatment options. The costs of MS DMs have skyrocketed in recent years and because of this, insurance company seek to manage costs by placing restrictions on their use and establishing tiers of therapy that govern what they will cover. Opaque deals between pharmaceutical companies and insurers result in preferred pricing and rebate arrangements that drive these restrictions on access. Policies concerning which MS DMTs are available to any given patient vary from company to company, creating a confusing and frustrating environment for the patient and the neurologist.

Insurers often claim that they base their coverage policies on the analysis of efficacy and safety data of the available treatments. However, if this were the complete story, major differences in criteria for approval of MS DMTs among insurance company should not occur. Instead, wide differences do exist between the insurers, again driven by the opaque financial arrangements made between insurers and pharmaceutical companies.

It is well established that a MS DMT should be started as soon as possible to help provide for the best possible outcome. Unfortunately, neurologists encounter daily a myriad of obstacles to timely and appropriate treatment of their patients with MS. The first DMT chosen by the patient and the neurologist after a lengthy discussion can be denied. Step therapy programs are often illogical, sometimes requiring trials of several different interferons or a trial of a second injectable DMT in a person who cannot perform self-injections, before approving an oral drug. There are major obstacles to communication between the prescribing neurologist and decision-makers at the insurance company with a lack of timely response or any response to appeal letters and an unreasonable expectation of the time that her neurologist can spend contacting multiple insurance carriers for multiple patients. These delays in initiating appropriate treatment are not merely inconveniences for the neurologists and the patient, but can result in irreparable harm. Any given MS treatment is most effective when initiated early, and delays in MS treatment approval with resulting gaps in therapy can result in an exacerbation in MS disease activity. Trying several ineffective therapies when the preferred therapy has been denied can result in poor MS disease control and permanent disability. Short-term and long-term toxicity of MS DMTs can vary considerably depending on the patient's comorbidities, and a poor drug choice, dictated by the insurer, may result in permanent harm. Forcing patients to use an MS DMT with a side effect profile unacceptable to them results in poor adherence to therapy, which can lead to increased MS disease activity and disability. Many patients, especially those who have never given themselves an injection of any sort, prefer an oral DMT to an injectable DMT, and forcing patients to take an injectable medication is unjustified. The intrusion of insurance companies into the complex decision-making needed to select the prior MS DMT for any given patient and the resulting delays put patients at risk of harm from continued disease activity or side effects.

So what can be done to improve this flawed approval process for MS DMTs?

First, neurologists and patients with MS need to be engaged in the process of policy creation by insurance companies. These policies cannot be rigidly applied to all patients and need to acknowledge the variability in disease severity and patient preference. Additionally, final determinations regarding MS DMT coverage need to be made in a timely and efficient manner to

avoid harm to patients. Step therapy or tiered structuring of MS DMT availability is inappropriate in a disease state, such as multiple sclerosis, where the wrong therapy may result in permanent disability.

Second, legislation providing transparency regarding financial arrangements between insurance and pharmaceutical companies needs to be lobbied for to ensure fair access to all MS DMTs. MS advocacy groups should collaborate with other medical specialty groups to maintain access to life-altering drugs for all patients since interference of insurance companies with medical decision-making and the resulting limitations to medication access are not unique to MS drugs.

Third, the costs of MS drugs need to be lowered. The root cause of the conflict between neurologists and insurance companies over approval of MS therapies is the high cost of the treatments that have risen dramatically in recent years without good explanations.

### ***III. Barriers to Medication Access: The Pharmacist Perspective***

1. Step Therapy: Pharmacies across the state struggle on a daily basis with allowing patients, including patients with MS, to access the proper medication for their disease states due to the onerous step therapy processes. Pharmacists dislike that they cannot provide patients with the drugs that they and their doctors have agreed to be the necessary and best treatment plan for their individual cases. It is also a massive waste of time for pharmacies to sit on the phone for long periods fighting insurance companies to accept a therapy for a patient and ensure that those pharmacies are paid as a result.
  - a. Action: Continue to work on updating step therapy laws to gain access to much needed medications without having to go through multiple steps in their therapy program to “save money”.
  - b. Legislative Updates: This year, the MO legislature updated the laws regarding step therapy to be more patient friendly, however the law was changed dramatically from its original form. There will have to be a continued push to update those laws to be patient friendly.
2. Prior Authorization (PA): Another incredibly complex issue that will take hard work to inform decision makers on. Prior authorization puts the onerous task of fighting through insurance and pharmacy benefit managers red tape to allow a patient to use a specific drug on doctors and pharmacists. It also provides patients with the drug, covered by insurance, provided they can get prior authorization from the insurance company.
  - a. Action: The issue of PA needs to be reformed to allow doctors and patients to be the final decision makers on health care needs, not insurance bureaucrats. Pharmacists agree.

### ***IV. Insurance Reform Work Group Legislative Recommendations:***

Prior Authorization-

Legislation proposing a standardized prior authorization form to be utilized by all health carriers offering policies of insurance in Missouri was considered by the Legislature in 2015 and 2016.



The legislation proposed that the Missouri Department of Insurance be responsible for the creation of the form and that it be made available in both electronic and paper format. The MS Task Force supports the passage of legislation creating a standardized prior authorization form and specifically recommends the following additional provisions relating to such legislation:

1. 72-hour response for initial determination of prescription drug benefits, 24-hour for emergent requests;
2. Failure to comply with specified timeline will result in automatic approval of physician recommended medication; and
3. Current and accessible drug specific prior authorization requirements, including a query function for each drug with a link to prior authorization criteria for each drug and the clinical criteria or peer-reviewed evidence corresponding with said protocol.

#### Step Therapy-

HB 2029 was passed by the 2016 Missouri Legislature and signed into law by Governor Nixon. Provisions of the legislation include a) insurance carrier establishment of a clear, convenient, readily accessible physician exception process, b) carrier approval of the exception request if the patient has already tried and failed medication in their previous medical history and d) Missouri Department of Insurance enforcement of the legislation after its January 2018 implementation.

This legislation represents a good baseline for insurance transparency in the interest of consumer access to information. However, further patient protections are recommended in order to allow for a reduction of the administrative burden currently imposed upon health care providers and to provide greater access to MS disease modifying therapies and other drugs.

1. 72-hour response for step therapy exception request, 24-hour for emergent requests. Failure to comply with timeline will result in automatic approval of physician recommended medication;
2. Publication of step therapy protocols with corresponding clinical criteria or peer reviewed evidence on web;
3. Exceptions should be granted under the following circumstances. a) if physician determines that it will cause an adverse patient reaction, b) if patient has failed medication in same pharmacological class or mechanism of action, c) if patient is currently stable on another MS drug, and d) patient be required to fail only once on any one single MS drug; and
4. Require that the use of step therapy for any prescribed drug for be limited to sixty days. At the expiration of such time period, if the prescribing healthcare provider deems such step therapy drug ineffective for the insured an exception shall be granted.

## INDEPENDENCE WORK GROUP

### **I. Transportation**

#### **a. Need:**

- i.** People living with MS often experience impairment in their mobility, which as the disease progresses can lead to intense isolation. They can also have difficulties obtaining accessible and affordable transportation, which allows them to live an independent life. People living with MS often have more health care appointments, including primary physicians, neurologists, physical therapists, occupational therapists, and many more. Other life activities that require transportation can include grocery shopping, leisure activities to stay connected to the community, and employment, to name a few. People living with MS who do not have family available to assist them need affordable and accessible transportation to lead a full and rewarding life, maintain their health and prevent isolation.

#### **b. Barrier:**

- i.** Current organizations providing transportation services often operate under policy guidelines that restrict their service areas within the confines of county lines. This creates an inefficient system of transportation, with multiple drivers servicing duplicative routes to fulfill the transportation needs of a limited number of riders living with disabilities in any given area;
- ii.** The cost of transportation creates a financial burden, leading to stress and poor health outcomes, as the cost of living with MS is high. It is estimated that the lifetime financial cost of living with MS is around \$1.2 million, which is disconcerting as the MS diagnosis often occurs during the most lucrative and productive working years of one's life (age 30-50); and
- iii.** Many transportation services are restricted to curbside pick up, which makes it difficult for people living with more aggressive forms of MS, as it severely limits their mobility.

#### **c. Recommendation:**

- i.** Update the Missouri Department of Transportation website to include a visual Mobility Management map of the counties, similar to what Iowa has created, to increase ease of access and user-friendliness. This will help identify transportation options more clearly and identify service providers specific to the counties;
- ii.** Clearly identify transportation companies that have wheelchair accessible vans;
- iii.** Coordinate transport efforts across services areas, increase utilization or information available for mobility coordinators; and

- iv. Through committees, like the Mid-Missouri Regional Planning Committee, identify further options and solutions for accessible transportation for constituents living with an aggressive form of MS.

## **II. Housing- Affordable and Accessible; Public Housing**

### **a. Need:**

- i. According to Census data, over 846,000 Missourians experience disabilities. That equates to 14% of the state population. Statewide, there is a gap between the need and the supply of affordable housing. A study by Mass Mutual found that the average cost of a one-year nursing home stay is \$75,000. This creates a financial incentive to finding a solution to Missouri's disabled housing shortage. MoHousing, a nonprofit agency, explains the philosophy of utilizing universal design as follows: "It is not the person with the disability who has limitations, but it is the design of our programs, policies, procedures, and our environments that have limitations. The limitations do not reside in the individual but in our society, how we perceive disability, and how we design things." The need for accessible housing exists, the ability to create accessible housing exists, and yet many people living with disabilities or a chronic disease that inhibits mobility, like MS, find themselves in unsafe and inaccessible homes or residing in nursing homes sometimes decades before necessity would require.

### **b. Barrier:**

- i. The current "Baby Boomer" population in Missouri is approximately 1,171,000 citizens 60 years and older, which makes up 20% of the population. As this generation continues to age, the available market for universal and accessible housing decreases for other populations;
- ii. Accessibility for affordable housing for persons living with disabilities under the age of 60 can be limited or unfavorable; and
- iii. Knowledge and development of universal homes remains siloed, making it difficult for a person living with disabilities to locate or access.

### **c. Recommendation:**

- i. MoHousing has identified several recommendations that would be appropriate and advantageous for constituents living with MS:
  - 1. Implementation of a unified housing plan to guide the development of subsidized housing in Missouri to best meet the individual needs of citizens requiring housing support;
  - 2. Creation of a multi-demographic approach to housing development to ensure the full integration of citizens with disabilities into society;

3. Development of regional housing teams made up of citizens in need of subsidized housing, agencies that support them and the private and public housing development communities; and
  4. Bring together the disability support systems in Missouri to create a multi-demographic partnership with all aspects of the disability communities and their support networks.
- ii. The National MS Society recommends the following:
1. Improving awareness of the Missouri Tax Credit for Renovations for Disability Access (Section 135.562.1), which allows for a tax credit equaling 100% of the costs incurred for modifications to make a taxpayer's principle dwelling accessible, up to \$2,500. This credit is available for taxpayers earning up to \$30,000 gross yearly income.

### **III. Home and Community-based Services**

#### **a. Need:**

- i. The need identified is to complete a study demonstrating cost saving for expanding home and community based waiver to people with disabilities under age 63. The hypothesis is that providing in-home services will prove to be less costly than Medicaid costs for long-term care in skilled nursing facilities and would allow many persons living with disabilities to remain in their own homes.

#### **b. Barrier:**

- i. Individuals living with MS require more assistance as their disease worsens. To remain in their homes, many individuals will need home modifications to insure a safe long-term living environment. The amount of home modifications is costly ranging from \$150 to \$50,000. Income levels are often too low to allow enough disposable income to pay for these necessary modifications or to carry additional loans. Additionally, the cost of monthly in home care services can range from \$18.00 to \$25.00 an hour or higher depending on the amount of care needed. Individuals do not have enough income or insurance to cover the cost of in home care providers.

#### **c. Recommendation:**

- i. Develop a grant program to assist individuals living with disabilities afford the cost of home modifications; and
- ii. The state of Missouri should offer tax exemptions or deductions to provide financial assistance for families with at home caregivers that are unable to work outside the home due to family caregiving responsibilities.

## APPENDIX A

### SENATE CONCURRENT RESOLUTION NO. 12

Whereas, Multiple Sclerosis (MS) is a chronic, often disabling disease that attacks the central nervous system, which is comprised of the brain, spinal cord, and optic nerves. MS damages the nerve-insulating myelin sheath that surrounds and protects the brain. The damage to the myelin sheath slows down or blocks messages between the brain and the body; and

Whereas, the cause of MS remains unknown; however, having a first-degree relative, such as a parent or sibling, with MS significantly increases a person's risk of developing the disease. According to the National Institute of Neurological Disorders and Stroke, it is estimated that there are approximately 250,000 to 350,000 persons in the United States who are diagnosed with MS. This estimate suggests that approximately 200 new cases are diagnosed each week; and

Whereas, it is in the public interest for the state to establish a Multiple Sclerosis Task Force in order to identify and address the unmet needs of persons with MS, and develop ways to enhance their quality of life:

Now Therefore Be It Resolved that the members of the Missouri Senate, Ninety-eighth General Assembly, First Regular Session, the House of Representatives concurring therein, hereby create the Missouri Multiple Sclerosis Task Force; and

Be It Further Resolved that the mission of the Task Force shall be to fully consider and make recommendations in a report to the General Assembly on:

(1) Developing strategies to identify and address the unmet needs of persons with MS in order to enhance the quality of life of persons with MS by maximizing productivity and independence, and addressing the emotional, social, and vocational challenges of persons with MS; and

(2) Developing strategies to provide persons with MS greater access to various treatments and other therapeutic options that may be available; and

Be It Further Resolved that the Task Force shall consist of the following members:

(1) Two members of the Senate, one to be appointed by the President Pro Tempore of the Senate and one to be appointed by the Minority Leader of the Senate;

(2) Two members of the House of Representatives, one to be appointed by the Speaker of the House of Representatives and one to be appointed by the Minority Leader of the House of Representatives;

(3) The Director of the Department of Health and Senior Services, or his or her designee, to serve as a member and provide technical assistance to the task force;

(4) Two neurologists licensed to practice in this state, with one appointed by the President Pro Tempore of the Senate and one appointed by the Speaker of the House of Representatives, from a list of recommendations by the Department of Health and Senior Services;

(5) Two Missouri regional members of a national organization with experience in helping people affected by MS through funding cutting-edge research, driving change through advocacy, facilitating professional education and providing programs and services that help people and the families living with MS, with one appointed by the President Pro Tempore of the Senate and one appointed by the Speaker of the House of Representatives, from a list of recommendations by the Department of Health and Senior Services;

(6) Two persons who represent agencies that provide services or supports to individuals with MS in this state, with one appointed by the President Pro Tempore of the Senate and one appointed by the Speaker of the House of Representatives, from a list of recommendations by the Department of Health and Senior Services;

(7) Two persons who have MS, with one appointed by the President Pro Tempore of the Senate and one appointed by the Speaker of the House of Representatives, from a list of recommendations by the Department of Health and Senior Services; and

Be It Further Resolved that the staffs of Senate Research, House Research, and the Joint Committee on Legislative Research shall provide such legal, research, clerical, technical, and bill drafting services as the Task Force may require in the performance of its duties; and

Be It Further Resolved that the Task Force will report its recommendations and findings to the Missouri General Assembly by January 1, 2017; and

Be It Further Resolved that the Task Force shall terminate by either a majority of members voting for termination, or by January 1, 2017, whichever occurs first; and

Be It Further Resolved that the Multiple Sclerosis Task Force is authorized to function during the legislative interim between the First Regular Session of the Ninety-eighth General Assembly and the Second Regular Session of the Ninety-eighth General Assembly through January 1, 2017, as authorized by State v. Atterburry, 300 S.W.2d 806 (Mo. 1957); and

Be It Further Resolved that the Secretary of the Missouri Senate be instructed to prepare properly inscribed copies of this resolution for the Director of the Department of Health and Senior Services.