



National
Multiple Sclerosis
Society

July 19, 2020

The Honorable Mitch McConnell
U.S. Senate
317 Russell Senate Office Building
Washington, DC 20510

The Honorable Charles Schumer
U.S. Senate
322 Hart Senate Office Building
Washington, DC 20510

The Honorable Nancy Pelosi
U.S. House of Representatives
1236 Longworth House Office Building
Washington, DC 20515

The Honorable Kevin McCarthy
U.S. House of Representatives
2468 Rayburn House Office Building
Washington, DC 20515

Dear Majority Leader McConnell, Minority Leader Schumer, Speaker Pelosi, and Minority Leader McCarthy:

On behalf of the National Multiple Sclerosis Society (Society), thank you for your efforts to date to address the COVID-19 public health emergency and its subsequent economic impacts on Americans. As you work to assess the impact of the Coronavirus Aid, Relief, and Economic Security (CARES) Act, and determine the scope of the next COVID-19 legislative response, we write to inform you of the pandemic's impact on people with multiple sclerosis (MS) and what people with MS need Congress to address in this next legislative response.

MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling, to walking difficulties, fatigue, dizziness, pain, depression, blindness and paralysis. Most people are diagnosed between the ages of 20 and 50, when they are in their prime working years. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS.

Society Response to COVID-19 Pandemic:

The National MS Society just completed a survey of people with MS to better understand the impact of the COVID-19 pandemic on people with MS and to understand their needs. The survey was open from May 1-21st, during the period when the majority of the country was under stay-at-home orders. The survey had 797 respondents and was not limited to individuals who had been diagnosed with COVID-19, but 2% of those who responded to the survey had received a COVID-19 diagnosis.

Key findings from our survey revealed that 70% of respondents had a neutral or negative

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feeling about their economic security. The top impacts reported related to COVID-19 and MS centered on medical questions (risk of contracting COVID-19), concerns about neighborhood and physical environment (access/affordability of housing, social distancing rules, stay at home orders and transportation), and healthcare related questions and concerns (access to health care providers, medication, insurance and telehealth). 17% of respondents had altered their MS therapy due to the COVID-19 pandemic, and 44% had accessed telehealth services for their MS care.

The Society continues to view itself as a strategic partner to the federal government, and we are utilizing the information gained from our COVID-19 impact survey to inform the Society's work to ensure that people with MS are getting what they need during this pandemic. We are committed to continuing our mission to fund innovative MS research, provide services and resources for people affected by MS, and coordinate with MS health care providers to ensure that people with MS have high quality, evidence-based care. Our ability to meet the needs of people with MS through education, resources, financial support, funding research and other needed support has been impacted by the economic impact of COVID-19. However, we continue to be a trusted source of information for both people with MS and MS healthcare providers. We offer weekly live Q&A style "Ask the Experts" sessions so people with MS can get their questions answered right away and offer similar biweekly educational sessions for healthcare providers.

Through the Society's MS Navigator service, every person affected by MS can access a partner to navigate the problems and challenges caused by COVID-19 and MS. Since the beginning of the pandemic, Society Navigators have received hundreds of calls from people affected by MS relating to the pandemic and its impact on the economy. Those calls have centered around informational needs regarding and the impact of COVID-19 on individuals living with MS, employment concerns, financial assistance and resource needs, questions regarding high risk medications (like MS disease modifying therapies), and referrals for chore services and food delivery. Each category reflects the diversity of how the COVID-19 pandemic is impacting those living with MS.

Society Recommendations

The Society's COVID-19 survey and the information that we have received directly from people affected by MS informs the basis of our recommendations on what is needed the next COVID-19 legislative response. We recommend the following provisions be included in the legislation:

- **Ensure access to health coverage and care:**
 - Enact a special enrollment period for the healthcare.gov marketplace, to provide equal access to comprehensive healthcare coverage for all Americans and not just those who lost coverage or live in a state that opened their marketplace.
 - Provide premium subsidies for COBRA continuation of coverage to minimize disruptions in treatment as done in the past.

- Reduce regulatory barriers that inhibit access to treatments and medications, therefore freeing up providers from unnecessary utilization management requirements.
- Include the bipartisan and bicameral agreement to end surprise billing from the House Energy and Commerce Committee and the Senate Committee on Health, Education, Labor and Pensions; and ensure that surprise billing protections apply to all providers within a facility if that facility accepts Public Health and Social Services Emergency funds.
- Provide an additional 10% FMAP increase specifically dedicated to Medicaid home and community-based services (HCBS) to strengthen the readiness and capacity of providers.
- **Ensure economic security:**
 - Implement automatic stabilizers to keep expanded critical safety-net programs (including unemployment insurance, food assistance, and Medicaid assistance, among others) available to those who need it for the duration of the public health and economic crisis.
 - Prohibit states from weakening Medicaid Maintenance of Effort or dropping HCBS. To address budget challenges, the Federal Medical Assistance Percentages (FMAP) should be increased to 14%.
 - Provide state and local governments the financial resources necessary to address exponentially expanding health coverage and care needs including the ability to ensure accessible voting in time for the 2020 election.
- **Protect charitable non-profit organizations:**
 - Enable non-profit organizations to continue their life-changing work by ensuring they are eligible for forgivable loans regardless of size and increase incentives for charitable giving to these organizations.
 - Provide at least \$2 billion in emergency bridge-funding to ensure that non-profit funded research that is currently stalled due to COVID-19 can resume once researchers can return to their lab.

Ensure health care coverage and access

Create a Special Enrollment Period for Marketplace Coverage

The Kaiser Family Foundation estimates that at least 25 million in the US currently insured through employer-sponsored insurance (ESI) are likely to lose their current source of comprehensive and affordable health coverage.ⁱ While current law assures these individuals the option of purchasing a Marketplace plan *or* electing COBRA to maintain their current coverage, the Society is concerned that many are unaware that they only have 60 days to select the coverage option most suitable to their needs, secure the financial means to pay the premium and submit all necessary paperwork to assure they are enrolled in a plan through one of these routes.

Due to the expected surge in uninsured and under-insured, we urge Congress to direct the Administration to open a special enrollment period for Marketplace coverage nation-wide, so that un-insured or under-insured individuals and their families can pursue Marketplace coverage, including tax credits for those eligible, to assure their access to affordable and comprehensive coverage and care. Truly appropriate coverage will be critically necessary for individuals and families currently enrolled in plans with minimal benefits and safeguards, such as short-term limitation duration (STLD) and Association Health Plans (AHPs), which may not cover inpatient services, prescription drugs or other benefits that will be essential to any individual impacted by COVID-19.

Already, eleven states and the District of Columbia have opened their marketplaces, and thousands of residents in these states have already benefited from this opportunity. At present, residents of the remaining states do not have equal opportunities to obtain comprehensive coverage. All but one of the remaining states do not have the authority to open their own marketplace enrollment and must rely on the federal system. The Society believes equitable access to quality health coverage must be a priority, especially during a pandemic. Further, we recommend Congress fund public education and outreach programs to raise awareness of these opportunities and their implications. Enabling individuals and families to access treatment and care, raising awareness, and assuring insurance benefits will aid in the stabilization for Marketplace health plans and continued viability of hospitals and health care providers.

The Society believes that continuing existing coverage under COBRA and assuring uninterrupted access to treatment and known providers is often the best option for people with MS: however, too many households cannot afford to pay the full premium for employer-sponsored insurance plans on their own. For these reasons, we also support a provision to subsidize COBRA premiums, as has been done in the past for certain populations.

End Surprise Billing

We are pleased that the Administration is prohibiting providers that use the Public Health and Social Services Emergency fund from sending surprise bills to patients related to COVID-19. We believe this is a positive first step and will curb surprise billing practices more broadly but remain concerned that individuals are still receiving surprise bills resulting from their COVID-19 treatment. We urge Congress to ensure that if a facility accepts these funds, the surprise billing protections apply to all providers (contracted or facility-employed) that deliver services within that facility. For example, this should include a contracted physician who is not employed by the hospital that receives those funds. Currently, this surprise billing protection only applies if the contracted provider also accepts those funds.

Additionally, the Society urges Congress to include the bipartisan and bicameral surprise billing agreement from the House Energy and Commerce Committee and Senate Committee on Health, Education, Labor and Pensions in the next COVID-19 response package. In a time when

many patients may see unpredictable treatment costs, we believe it is time that Congress end the practice of surprise billing once and for all.

Telehealth

The Society appreciates the flexibility provided by the CARES Act and the Centers of Medicare and Medicaid Services (CMS) to expand the use and reimbursement of telehealth visits during this public health emergency. As noted above, 44% of those who responded to the Society's survey had utilized telemedicine during the pandemic and most were satisfied with the care they received.

We remain concerned that there is not parity with the telehealth services that can be provided to Medicare beneficiaries. We recommend that Congress include language in the next COVID-19 response package that expands Medicare coverage of audio only services and clarifies the intent of reimbursement parity around video visit and telephone visits for commercial health plans. We realize that many people with MS across the country who live in rural areas, minority populations, or who are lower income may not have access to video services (or broadband support to utilize such services) and can only use their telephone. While telehealth and telemedicine may not be appropriate for every medical appointment, we urge Congress to continue supporting telehealth appointments for the duration of the pandemic and urge you to look at data on access, adherence, and patient outcomes to help guide conversations on what elements should remain permanent after the pandemic.

Continuation of Medicaid Maintenance of Effort from Families

The Society has a robust state advocacy program, and through our on-the-groundwork we have recognized that states will face unprecedented budgetary constraints in the coming months. We supported the enhanced Federal Medical Assistance Percentage (FMAP) provided through the Families First Coronavirus Response Act, to make it possible for states to realize the goal of continuous Medicaid coverage. We also applauded the Families First Coronavirus Response Act's maintenance of effort requirements, which mean that since states are getting additional funding, they will not be allowed to impose more restrictive eligibility standards, increase cost-sharing during the public health emergency, or disenroll current or newly enrolled members in most circumstances. These protections are critical to ensuring that patients with serious and chronic conditions, such as MS, continue to receive care during a period in which there will be enormous pressure on states to reduce costs. We know the states will require flexibility in the coming months, even though they have been given this additional funding. We strongly urge Congress to preserve these protections in any future COVID-related legislation, while enhancing payments to states to continue to offer vital Medicaid services.

Additional Increase in State Funding for Medicaid and Home and Community Based Services

To make it possible for states to meet expanding coverage needs, the Society appreciated the 6.2 percent increase in the Federal Medical Assistance Percentage (FMAP) for states in the Families First Coronavirus Response Act. Given the unprecedented level of need that exists across the country and the increasing Medicaid population due to unemployment, we urge

Congress to raise the FMAP increase at least 14% percent. We are concerned that anything less than this amount will result in further reductions of already reduced workforce capacity at the state level and thus impact patient access to care.

Additionally, we urge Congress to provide an additional increase of 10% FMAP increase specifically for Home and Community-Based Services (HCBS). Increased funding for these essential services allows Medicaid beneficiaries to receive services within their homes and communities, rather than within institutions or live-in residential facilities. Investments in these services specifically will allow states to maintain coverage, benefits, services, and preserve quality of care—all of which are particularly important for people living with MS and their families.

Meaningful investments in HCBS are one of the most important steps Congress can take to safeguard the health and well-being of people with disabilities, including many living with MS, and the cost efficiency of supporting home and community-based care compared to institutional care is well established. Investment in HCBS and flexibility for HCBS Waivers to be used to quickly meet the needs of a community's population is key. We propose that with the additional funding, states are given the flexibility to utilize these funds for home modifications that would allow for people to stay in their homes or transfer from a live in facility to their homes if that is their preference. The CDC estimates that falls are the most preventable cause of nursing facility placementⁱⁱ. When people can remain in their home independently, savings accrue to the healthcare system (by preventing falls/injury and premature residential nursing care), and the economy overall.

The COVID-19 pandemic has exposed the increased infection risk associated with live-in residential and other long-term care facilities, and dedicated funding to ensure that services that help people with MS remain in their own homes should be a primary focus on any COVID-19 response. The enhanced FMAP approach builds on existing Medicaid infrastructure to allow states to the flexibility to quickly transfer resources to HCBS programs and providers that desperately need it.

Provide 100% Matching Rate for States Expanding Medicaid for the First Time

With states continuing to face large budget shortfalls due to the impacts of the COVID-19 pandemic, it is more important than ever for Congress to help states close existing coverage gaps that leave too many uninsured or underinsured. Several states are considering possibilities to improve access to Medicaid and enacting provisions to help people stay enrolled. However, non-expansion states would benefit from additional funding to help make it possible for them to expand coverage. Therefore, the Society urges Congress to provide 100 percent FMAP for the first three years that states expand their Medicaid programs, a financial incentive that was available to states that expanded their programs in 2013, to help additional states expand their programs at this critical time. As noted above, Kaiser Family Foundation estimates that more than 20 million people who have lost job-based health coverage will become eligible for Affordable Care Act Coverage through Medicaid or marketplace tax credits—including people affected by MS, who may have previously relied on private coverage.

Curb the Use of Substandard Health Plans

The Society has voiced concern at both the state and federal level about the proliferation of substandard insurance products. Our key concern is that consumers are too often unaware of the limited protections available through these plans, and how exposed they are not only to lack of coverage, but to extreme out-of-pocket costs if they enroll in them. The Administration has opened the floodgates and increased the availability of insurance products such as short-term, limited-duration plans and association health plans, which are not required to meet federal coverage standards or comply with federal patient protections. These products are too often marketed in misleading ways, meaning consumers may purchase them and not realize how limited they are until they need them most. We encourage Congress to prohibit the Administration from implementing or enforcing final rules that expand availability of short-term, limited-duration plans or association health plans during this public health emergency. During the COVID-19 pandemic, it is unwise to allow substandard health plans to enroll more people.

Additionally, for those individuals who are already covered by these plans, Congress must ensure they have a mechanism to purchase comprehensive, affordable coverage that meets their and their families' needs.

Economic Security

As noted from our survey, people with MS overwhelmingly reported that they felt neutral or negative about their economic security. People with MS reported challenges affording their medications, groceries, and housing. Based on this feedback, the Society recommends that Congress provides another round of stimulus payments to ensure that all Americans can meet their basic needs as the economic consequences of the COVID-19 remain.

Additionally, we recommend that Congress extend the enhanced unemployment benefits, food assistance, paid sick and family and medical leave provisions, and Medicaid assistance included in the CARES Act until December 30, 2020 and implement automatic stabilizers, mechanisms that are tied to economic conditions rather than calendar dates, that keep these expanded benefits available to those who need it for the duration of the public health and economic crisis. Even when the public health emergency ends, many sectors of the U.S. economy will not be ready to hire workers immediately and parts of the country will have to manage through subsequent resurgence of COVID-19 until a vaccine is approved and readily available. Implementing automatic stabilizers tied to the economy will create automated benchmarks for the availability of these benefits and support to be available to those who need it until the pandemic runs its course and the economy rebounds.

The Society urges Congress to revisit the emergency paid sick days and paid family and medical leave provisions, by expanding this coverage to larger employers, and expanding the paid leave beyond only allowing leave for child care coverage. Additionally, we urge Congress to increase funding to ensure safe housing for those who need it, particularly those who may be

experiencing domestic violence. At the beginning of the pandemic, the Society saw an increase in calls from people living with MS who were experiencing incidents of violence due to their living circumstances and the social distancing measures put in place across the country. Increases in unemployment and other stressors tend to trigger increases in violence, and we urge Congress to provide needed funding to ensure state and local governments can meet the increased need.

Further, we ask that Congress expand leave provisions that would protect individuals with chronic diseases and health conditions, who are uncomfortable going back to their places of employment. Through the Society's Navigator calls and COVID-19 impact survey, we found that people with MS need guidance on returning to work, questions about disclosing their MS to their employer and fears of discriminatory actions if they are deemed to be in a "high-risk" group. In fact, we heard directly from a respondent to the Society's survey that they were "let go from their job due to being a high-risk employee." No one should face this type of discrimination, and we strongly recommend Congress include a provision in the next COVID-19 package that prevents this type of discrimination.

Additional money to states and local governments

While the Labor Department's May jobs report provided decreases in unemployment, the economy remains in a recession and the impact on state and local governments cannot be overstated. The Center for Budget and Policy Priorities projects that state budget shortfalls expected from COVID-19 economic impacts will total \$615 billion over the current state fiscal year ending on June 30th, the new state fiscal year (beginning July 1st) and the subsequent state fiscal year.ⁱⁱⁱ States have laid off more than 1.5 million workers, and states will under pressure to cut more workers to balance their budgets, unless Congress provides substantially more aid. We have recommended that Congress provide substantial FMAP increases to increase the federal share of Medicaid costs to preserve access to services at a time when the Medicaid population is increasing, but we also urge Congress to provide substantial state and local fiscal relief. The aid provided will help states avoid making more dramatic cuts that will have a direct impact on those living with MS and other chronic health conditions which rely on state provided programs.

States are also currently enacting plans for the 2020 election. The COVID-19 impact on the election complicates an already complicated system and the resurgence of COVID-19 in certain parts of the country are increasing concerns about ensuring accessible voting. Currently more than 1 out of 7 eligible American voters lives with a disability. In recent presidential election years, only about 60% of the eligible U.S. population has voted; however It is widely recognized that the COVID-19 pandemic will present a series of challenges to the 2020 general election, from both an administrative and public health standpoint. One of the CDC's key recommendations to mitigate COVID-19 spread is by avoiding large-scale social contact. The Society urges Congress to include provisions for increased infrastructure to support mail-in voting, online voter registration, and support for people with disabilities. These provisions will protect the ability of those with disabilities or chronic health conditions like MS to vote in the

2020 election. States will require funding specifically for this, and we urge Congress to include that funding in the next COVID-19 legislative package.

Allowing states to implement infrastructure to support mail-in voting is reliant on having a healthy and strong U.S. Postal Service (USPS). The USPS employs thousands of Americans across the country, and Americans are more reliant than ever on its ability to deliver medicines, food, and essential goods and supplies. Further, the USPS plays a key role in supporting charitable non-profits and for-profit business across the country. We urge Congress to include at least \$50 billion in funding for the postal service to continue its important work.

Non-profit protections

Ensure Nonprofit organizations can continue their life-changing work

The Society believes Congress must ensure that mid-sized nonprofits have equitable access to loan programs for the business sector, including the availability of loan forgiveness. While we appreciate the Federal Reserve making its Main Street lending program available to some nonprofits, this assistance does not address what is most needed by nonprofit organizations – a provision that makes these loans forgivable.

In this critical time, nonprofits have stepped up to meet the unprecedented level of need in our country due to the COVID-19 pandemic. Even though they face many of the same economic challenges as other industries, nonprofits are not shutting down. Rather, they are straining to meet increasing demands in our communities on the frontlines, caring for the sick, feeding families, and keeping our communities connected. Further, they will play an integral role as our nation recovers – providing childcare and job training, funding research and other core supports.

Charitable nonprofits of all sizes and focus areas are struggling to maintain mission-critical operations despite enormous economic challenges. Data released by Independent Sector shows that nonprofits with between 500 to 5,000 employees, who have been key to scaling relief efforts across the nation, have also been severely impacted by this health and economic crisis. When asked “What types of additional assistance would be most helpful to your organization?” organizations overwhelmingly (92% of responses) suggested government support in the form of forgivable loans.

Nonprofit organizations need support to continue to meet the needs of their communities. Many charitable organizations do not have steady streams of commercial income and have little capacity for loan and interest repayment. Nonprofits are the third largest employment sector and the fourth largest contributor for U.S. medical and health research. America cannot afford to leave out such a vital part of the economy.

As Congress remains balancing addressing the needs of the public health emergency and focusing on supporting the country’s economic recovery, we urge you to include provisions that incentivize charitable giving in this time of need for the nonprofit sector like the Legacy IRA Act,

which would expand the charitable IRA rollover to treat donations made by retirees to gift annuity programs as pre-tax income. Additionally, we support the Universal Giving Pandemic Response Act from Senators Lankford, Coons, Lee, Shaheen, Scott and Klobuchar. The bill would expand the current above-the-line deduction in tax years 2019 and 2020 for charitable giving made available by (CARES) Act and ensure that Americans who donate to nonprofits are able to deduct up to one-third of the standard deduction (around \$4,000 for an individual filer and \$8,000 for married joint filers) from their federal taxes.

Further, we ask that you clarify language used in the CARES Act that allows taxpayers that do not itemize to deduct up to \$300 of charitable donations to non-profits. Language used in the CARES Act refers to an “eligible individual”. This language is problematic as the term “individual” is referred to in a different context in the U.S. tax code. We recommend that the next COVID-19 response package include language that clarifies Congressional intent and aligns with U.S. tax code’s interpretation of the term “individual”.

Research Protections for Non-profit Organizations

The Society is the largest private funder of MS research in the world and has committed over \$1 billion dollars to date to research and treatment to stop disease progression, restore function and end MS forever. As detailed above, the Society has experienced a significant decrease in revenue due to the economic fallout of the COVID-19 pandemic. This decrease will significantly impact our ability to fund new research and our team is focusing on honoring the research funding commitments that we have made to date. We are deeply concerned about the impact on MS research and the research pipeline broadly. Non-profit and foundational research dollars are critical for young and mid-level career researchers in retaining a strong research work force.

Nonprofit organizations like the Society are being extremely flexible in how our grantees can utilize the funds that we have provided but we are not able to offer additional money as well as extensions. In a survey of Society-funded researchers, 93% reported that their Society-funded research had been impacted by the COVID-19 pandemic. Almost 85% expected a delay to their research, with over half of those anticipating a moderate delay of at least 1-3 months. Over 44% of researchers anticipated requiring at least an additional 6 months to complete their projects, and 35% reported they expect to need an additional year. When asked what barriers they anticipated to restarting the projects, researchers reported anticipated challenges to replenishing or re-establishing animal colonies, re-engaging patient participants, loss of staff, continuing COVID-19 related restrictions and difficulty replenishing supplies.

These barriers will require additional funds, and unfortunately nonprofits are not in a place to be able to provide these funds. We estimate that the nonprofit research sector will need at least \$2 billion to restart research impacted by COVID-19. We urge Congress to provide at least \$2 billion in funding to cover costs associated with stalled research and costs for restarting research once researchers can return to their labs. This will enable researchers to finish critical research proposals, help get researchers and their institutions back to work, and keep the scientific and medical research pipeline robust.

We appreciate your attention and actions to date in response to the COVID-19 pandemic and urge you to include our recommended policies and provisions as you consider the scope and scale of the next COVID-19 response package. If you have any questions about our letter, please contact me at Bari.Talente@nmss.org.

Sincerely,



Bari Talente, Esq.
Executive Vice President, Advocacy
National MS Society

CC: Congressional MS Caucus, Senate Finance Committee, Senate Health Education, Labor, and Pensions Committee, Senate Committee on Commerce, Science, and Transportation, House Energy and Commerce Committee, House Ways and Means Committee, House Science Committee.

ⁱ Garfield, Rachel, Claxton, Gary. Damico Anthony, Levitt Larry. t al. Kaiser Family Foundation. "Eligibility for ACA Health Coverage Following Job Loss." https://www.kff.org/coronavirus-covid-19/issue-brief/eligibility-for-aca-health-coverage-following-job-loss/?utm_campaign=KFF-2020-Health-Reform&utm_source=hs_email&utm_medium=email&utm_content=2&hsenc=p2ANqtz-9tOXMMbsyXN8XAnoxfSqHNAKSU9xNdXDuAx4HQzNcqcAqWGOsslrkkw5WK6pl2Ct3pF3bl76RVrXWeRockDAF7m0N0DQ&hsmi=2. May 13, 2020. (Accessed June 18, 2020).

ⁱⁱ "Important Facts About Falls". Centers for Disease Control and Prevention. <https://www.cdc.gov/homeandrecreationalsafety/falls/adultfalls.html> (accessed June 28, 2020).

ⁱⁱⁱ McNichol, Elizabeth and Leachman, Michael. States Continue to Face Large Shortfalls Due to COVID-19 Effects. Center on Budget and Policy Priorities. June 15, 2020. <https://www.cbpp.org/sites/default/files/atoms/files/6-15-20sfp.pdf>. (Accessed June 23, 2020).