

# Diversity, Equity and Inclusion

## 2022 Transparency Report



Diversity, Equity  
and Inclusion 

The icon consists of several overlapping, colorful geometric shapes in shades of purple, blue, green, and yellow, arranged in a way that suggests a group of people or a diverse community.

National  
Multiple Sclerosis  
Society

## Letter from Cyndi

The National Multiple Sclerosis Society is here for every person with multiple sclerosis. As the largest MS organization in the world, we make progress by breaking down barriers and bringing all perspectives to the table.



Together, we have changed what it means to live with MS. What began more than 75 years ago as one woman's vision and commitment is now a nationwide organization leading the global charge to cure MS for every single person as quickly as possible.

But it will take all of us to reach a world free of MS. Everyone must feel seen, valued and welcome in the MS movement.

Our work is evolving as we continue to learn and grow. But we have more to do.

I hope this report inspires you. Please continue to keep in touch and share what's on your mind as we grow together.

Cyndi Zagieboylo (she/her)  
President and CEO



Feedback on how we are doing?  
Share with us at [diversity@nmss.org](mailto:diversity@nmss.org)



Diversity, Equity  
and Inclusion 

## Letter from Neisha

I am thrilled to share the Society's first Diversity Equity and Inclusion (DEI) Transparency Report. Our commitment to DEI is driven by our mission to empower people living with MS to live their best lives. The purpose of this report is to share our progress through the end of fiscal year 2022, which ended September 30, 2022.



Our goal is to create an environment where each person can be their most authentic self, have the tools and resources they need to thrive, and feel valued, respected and a sense of belonging. We are committed to creating an atmosphere where diverse perspectives generate creativity and innovation, and everyone can contribute to our collective efforts to remove the social, systemic and structural barriers to health equity.

To achieve this, we are taking an intentional and integrated approach — focusing on the individual, the team and the organization — and keeping the voices of people living with MS at the center.

In 2020, we established organizational objectives that laid the foundation for this work. Today we have a formal plan with metrics to hold us accountable. Though we have made progress, this work is a journey, and we are on a trajectory of growth and learning.

I hope you will find your space in the MS movement. You are welcome here.

Neisha Fredericks (she/her)  
Vice President, Diversity, Equity and Inclusion

# Mission, Vision and DEI Statement

## Vision:

A world free of MS

## Mission:

We will cure MS while empowering people affected by MS to live their best lives

## DEI Statement:

The National Multiple Sclerosis Society is a movement by and for all people affected by MS. Our voices and actions reflect diversity, equity, and inclusion. We welcome diverse perspectives. We actively seek out and embrace differences. We want everyone to feel respected and be empowered to bring their whole selves to ensure we make the best decisions to achieve our vision.



National  
Multiple Sclerosis  
Society



**NANCY**  
DIAGNOSED IN 1992



**SAMIR**  
DIAGNOSED IN 2005



**DONNA**  
DIAGNOSED IN 1989



**TRACEY (R)**  
DIAGNOSED IN 2009



**ATIBA (L)**  
DIAGNOSED IN 2012



ANGELA  
DIAGNOSED IN 1992



JOSEPH (L)  
DIAGNOSED IN 2008



JOYCE (CENTER)  
DIAGNOSED IN 2011



JOVANY  
DIAGNOSED IN 2016

## How We Define Diversity, Equity and Inclusion

**Diversity:** Diversity encompasses the range of human differences and similarities that make us unique, such as our cognitive skills and personality traits, along with other characteristics that shape our identity, such as:

- Race
- Ethnicity
- Age
- Gender identity and expression
- Disability
- Veteran status
- Religion
- Sexual orientation
- Culture or beliefs
- Education
- Socioeconomic status
- Family or marital status
- Geography

**Equity:** The work of equity seeks to eliminate discriminatory practices, policies, systems and social norms. It acknowledges that underserved and underrepresented populations have experienced unfair treatment and denial of access due to bias or systemic structures.

**Inclusion:** Inclusion is the act of authentically and intentionally bringing traditionally excluded individuals and/or groups into processes, activities and policymaking in a way that shares power.

**The desired outcome of our DEI practice is Belonging, a human, emotional need to feel accepted, valued, seen and supported.**

## Important Terms Used in This Report

We gather and review a range of data — and while some terms may be universal, the understanding of such terms might be varied. To promote a shared understanding, here is how we define terms used throughout this report.

- **Population** — a complete set of a group being referred to.
- **Representation** — someone from the population who might be in a position to amplify the voices and needs of the population they represent. “A representative sample is a subset of a population that seeks to accurately reflect the characteristics of the larger group,” according to Investopedia.
- Race and ethnic data referenced in this report reflect numbers voluntarily collected and reported to the U.S. Equal Employment Opportunity Commission based on these categories:
  - » **Asian** —A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, India, China, the Philippine Islands, Japan, Korea, or Vietnam.
  - » **Black or African American** —A person having origins in any of the Black racial groups of Africa.
  - » **Hispanic or Latinx**<sup>7</sup>—A person of Cuban, Mexican, Puerto Rican, South or Central American or other Spanish-speaking culture or origin regardless of race.
  - » **American Indian and Alaska Native** —A person having origins in any of the original peoples of North and South America (including Central America).
  - » **Native Hawaiian and Other Pacific Islander** —A person having origins in any of the original peoples of Hawaii, Guam, Samoa or other Pacific Islands.
  - » **White** —A person having origins in any of the original peoples of Europe, the Middle East or North Africa.
  - » **Two or more races** —A person who identifies with more than one of the above races or ethnicities.

<sup>7</sup>Latinx — in this report we use this gender inclusive term as an alternative to Latino or Latina, referring to anyone born in or with ancestors from Latin America, regardless of whether that person speaks Spanish. We recognize this is not a term everyone favors for themselves. The way each person describes theirs is personal, and we encourage everyone to use the terms that most effectively capture their own identities, experiences and cultures.

# Our Journey

2017

August: CEO Diversity Advisory Committee established

2019

Signed Memorandum of Agreement between the U.S. Department of Veterans Affairs, Veterans Health Administration and the Society

2020

- Publicly confirmed commitment to being an anti-racist organization, eliminating healthcare inequities
- Established practice to recite DEI statement to kick-off all meetings
- Created Racial Equity Sprint Team and plan to build a more diverse, equitable and inclusive culture
- Launched two Employee Resource Groups (ERG): Inclusive Voices for racially and ethnically underrepresented staff and Society Pride for LGBTQ+ staff
- Juneteenth and Election Day established as paid Society holidays; Columbus Day holiday removed
- Delivered first nationwide virtual Black MS Experience Summit
- Delivered Courageous Conversations and Unconscious Bias staff training
- Included Maternity/Parental Leave Policy for Fellows funded by Society training grants to provide support for fellows at a critical stage in their career
- Began collecting demographic information in research and training grant applications so that we may better understand who is applying to our programs

2021

- Joined CEO Action for Diversity & Inclusion, the largest (over 2,2400 signatories) CEO-driven commitment to advance DEI in the workplace
- Began requiring an outreach plan for grant proposals to expand engagement of underrepresented groups in research and clinical trials
- Added pronoun options to standard email signature template
- Launched Workability ERG for staff living with a disability
- Delivered second nationwide virtual Black MS Experience Summit
- Hired VP, Diversity, Equity and Inclusion to develop a strategic action plan

2022

- Created Health Equity Initiatives team within the Healthcare Access team
- Updated All Staff Calendar to include Monthly cultural, religious + identity observances to increase org-wide cultural competency
- Launched Military Community Network ERG for Veteran staff
- Paid internships to increase representation and expand opportunities
- Inaugural Hispanic/Latinx MS Experience Summit
- Established DEI Work Team to advise and execute DEI plan
- Created an Inclusion Policy (zero tolerance), an extension of our anti-harrasment policy
- Announced a Dependent Care for Early Career Growth award for fellows attending the 2022 Tykeson Fellows Conference, to provide financial support for fellows with dependent care responsibility and so they can participate fully in the Tykeson Fellows Conference at a critical stage in their career
- Established inclusive leadership goals for our VPs and supervisors

# Our Approach to Diversity, Equity and Inclusion

DEI is central to everything we do (see **FY2022-2024 Strategic Plan** and **FY2022-2024 Implementation Plan**). To see real change and make the greatest organizational impact, we must take a comprehensive approach to DEI and make bold, systemic and structural changes.



Our plan was developed and informed by reviewing staff and volunteer data across multiple dimensions of diverse identities with an inclusive lens, to better understand both our opportunities and impediments to growth and change. We will approach this work through the pillars:

**Foundation and Structure:** We develop leaders to be change agents who model inclusive leadership practices and influence workplace culture.

**People:** People are our greatest strength and most valuable resource. We focus on attracting, hiring, developing and advancing our workforce to reflect the many dimensions of diversity.

### **Consistency and Accountability:**

We integrate DEI into all learning for staff and key external stakeholders in support of our strategic goals and respective of different learning styles and modalities. Organizational assessments and measurement tools are comprehensive and allow us to make data-driven decisions and hold ourselves accountable to metrics.

### **Community, Marketing and Supplier Diversity:**

We cultivate partnerships that help us achieve our mission, amplify the voices of all people affected by MS and increase the cultural awareness and professional expertise of physicians and other care partners and researchers. We develop practices to ensure our organizational brand is culturally sensitive and accessible. We source vendors responsibly, ethically and intentionally and engage underrepresented suppliers.



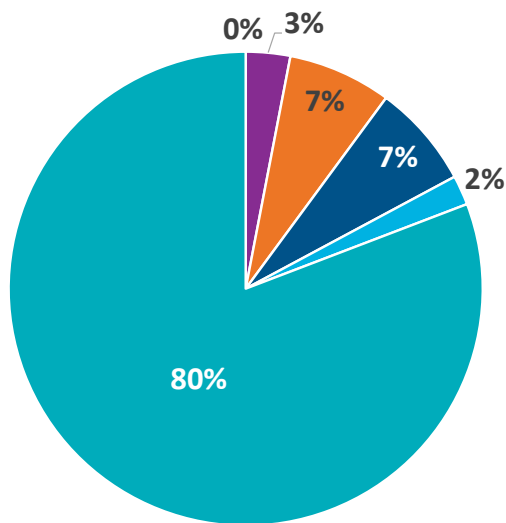
## 2022 Staff Composition

To build upon our commitment to accountability through transparency, we are providing the following demographic<sup>2</sup> data to establish a benchmark for how we will measure progress over time; which we intend to be both quantitative and qualitative and focused on the issues that are most important to our staff and volunteers to ensure that people can see themselves in our goals and progress.

### Overall Staff Representation (total staff: 798<sup>3</sup>)

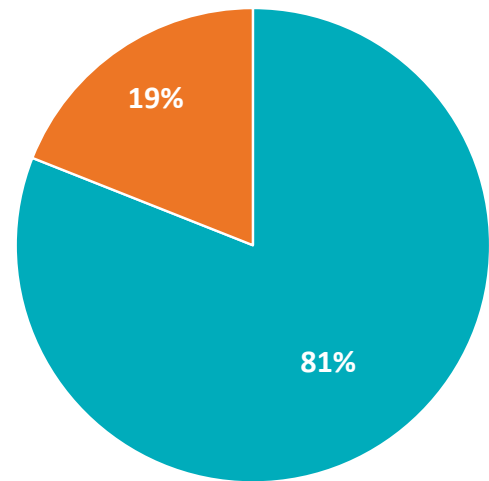
Percentages are calculated to the 1/100th but rounded and published to the nearest 1/10th; therefore, totals may not equal 100% and there might be variances due to the number of people who chose not to disclose.

Overall Representation Race/Ethnicity<sup>4</sup>



- American Indian/Alaska Native
- Asian
- Black or African American
- Hispanic or Latinx
- Two or More Races
- White

Overall Gender Representation



- Female
- Male

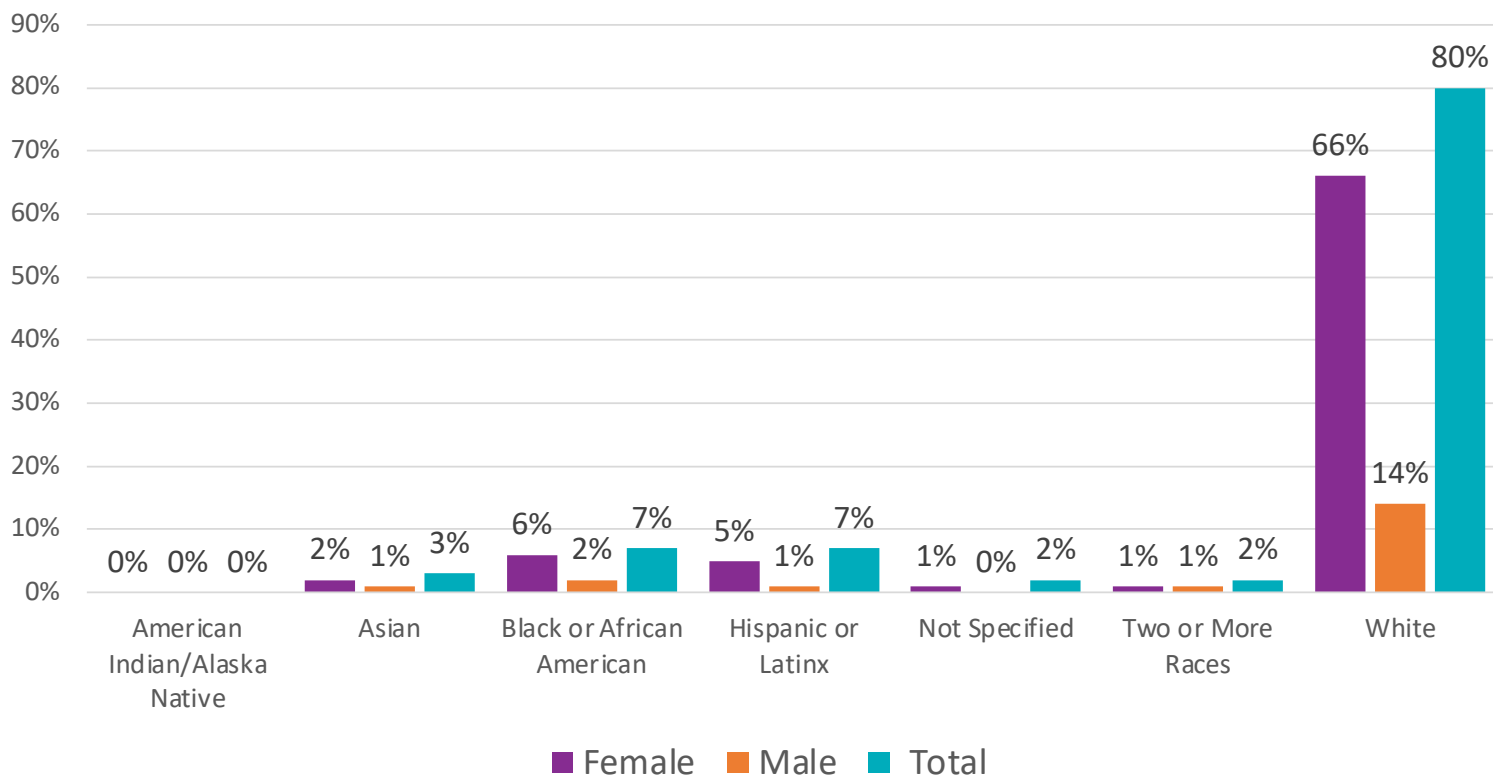
<sup>2</sup>All gender, race/ethnicity, veteran and disability data are self-reported and collected at the time of hiring for compliance related reporting. Additional self-identification data was collected via our 2022 Inclusion Survey and is used here as a baseline to enable us to measure employee trust and confidence in providing the data through future efforts. We are focusing attention on methods to increase our post-hiring self ID collection efforts to gather and review intersectional data that cuts across multiple identities to understand needs and inform strategies and tactics to ensure a welcoming and inclusive MS movement.

<sup>3</sup>Total workforce as of November 9, 2022, the Society fiscal year is September – October.

<sup>4</sup>Staff who opted to not disclose are excluded from the above figures. As of November 2022, Race not disclosed is 2%

## Intersection of Race and Gender

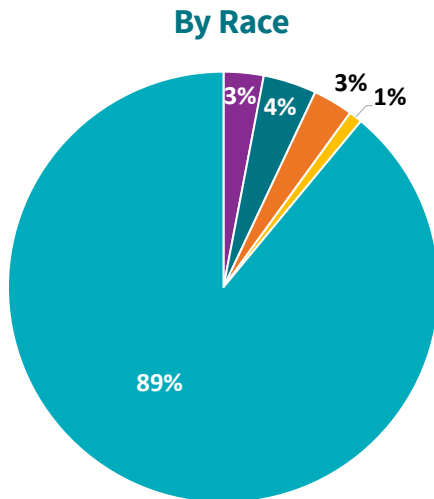
We know various social identities can overlap to influence the amount of type of bias or disadvantages they may face. As we begin to collect more data about the identities of our staff, we will begin to look at correlations in experiential data and dimensions of diversity. The data below is being published to establish a benchmark and monitor changes in these percentages and experiences over time.



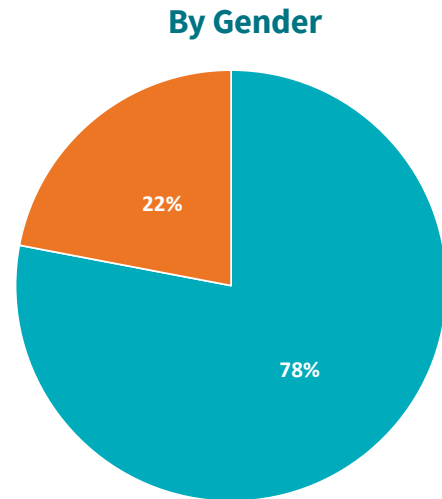
- Additional self-identification (percentages calculated out of total # of staff responding to our Inclusion Survey March 2022: N=529)
  - » Identify as a veteran: 1%
  - » Identify as a person with a disability: 11%
  - » Identify as LGBTQ+: 10%
  - » Identify as transgender: 1%
  - » Identify as nonbinary: 1%

## Leadership Representation

### Society Leadership and Management Team “SLMT”<sup>5</sup> (N= 74)

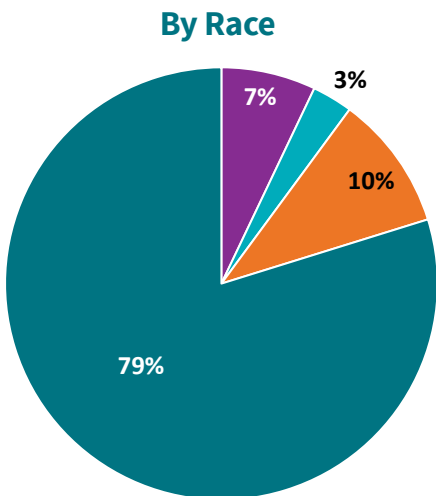


- Asian
- Black or African American
- Hispanic or Latinx
- Two or More Races
- White

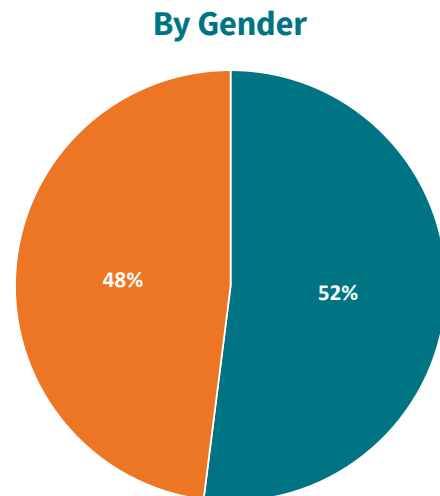


- Female
- Male

### National Board of Directors (N= 29<sup>6</sup>)



- Asian
- Black or African American
- Hispanic or Latinx
- White



- Female
- Male

<sup>5</sup> SLMT are persons with the title of Vice President or above.  
<sup>6</sup>This number represents the number of members of National Board of Director that responded to the DEI Leadership Volunteer Survey March 28 – April 11, 2022, at the time there were 38 total members.

## Employee Resource Groups

Employee Resource Groups, commonly known as “ERGs”, are voluntary, employee-led groups designed to foster a diverse and inclusive workplace which encourages all staff members to bring their authentic selves to work. ERGs are integral to advancing diversity, equity and inclusion Society-wide and are aligned with the Society’s vision, mission, strategic plan and DEI goals.

### The benefits of ERGs:

- Provide opportunities for career development, enabling members to highlight and showcase their skills, while developing their own brand and are a great way to identify emerging talent
- Create safe and accountable spaces for connection, support and celebration
- Executive sponsor support
- Allow for the diversity of voices which strengthens the MS movement

### The Society’s ERGs



**Inclusive Voices** amplifies the voices of those underrepresented and ensures community inclusion, develops and seeks opportunities for professional growth and educates about the unique needs of the community.



**Military Community Network** supports and encourages Veterans and their loved ones through shared experiences and external engagement with the MS Veteran Community.



**Society Pride** provides support within the Society’s LGBTQ+ community, creating a network of common experience focused on developing resilience and professional courage and ensures all Society communications reflect LGBTQ+ voices.



**Workability** supports people with a chronic mental or physically disabling condition.

### IN THEIR OWN WORDS...

“My experience with the group is that the support is paramount to anything I’ve ever experienced in my working career. Workability is such an important safe space for employees who are working with chronic conditions, where they can connect with others trying to juggle all of these difficult aspects of their lives. Knowing they aren’t alone in these experiences and being able to bring issues forward to HR and other departments to influence decision making and come to solutions is incredibly empowering. It has given us a format to have difficult conversations and deep learnings in a respectful way. We have never had an issue where staff did not support each other emotionally — they always jump in to share kind words and guide one another through hard diagnoses and treatments. Dealing with all of this while working full time and acting as caregivers to others can be overwhelming but knowing there is that one hour a month where they can share difficulties is everything.

I’ve seen individuals start to grow their leadership skills, whether they are helping put together content or presenting to peers. Workability has the potential for mentorship opportunities in the future as well – so this is just another route to define career paths for internal staff who might not have had other opportunities to build supervisory skills.”

— **Abigail Vacca, MSW**

Senior Manager, MS Navigator Services Delivery  
Co-Founder of National MS Society Workability  
Employee Resource Group

## Health Equity for the MS Movement

As a movement by and for people affected by MS, the National MS Society is committed to creating a world where everyone can live a life free of MS. While more life-changing treatments and solutions are available to people affected by MS than ever before, stark inequities in our healthcare system, medical mistrust, and gaps in our organizational reach are keeping people, particularly people from Black and Hispanic/Latinx communities, from receiving what they need to live their best lives today and benefit from tomorrow's cure.

### Health Equity Initiatives Targeted to Healthcare Professionals

Our goal is to improve access to personalized, affordable, high-quality healthcare for everyone affected by MS. We will measure success by reducing disparities in treatment among ethnically diverse, low socioeconomic, and rural populations.

#### FY22 Successes

The passage of the **Inflation Reduction Act** includes meaningful provisions to lower the cost of prescription drugs and health insurance for people on Medicare. MS Activists played a key role in the passage of this historic legislation.

We launched the **General Neurologist outreach campaign** to expand the number of healthcare professionals caring for people with MS. As a result, 409 general neurologists became newly engaged with the Society, who provided care for more than 17,034 people with MS, 391 of whom were newly diagnosed.

**ECHO MS**, a peer-to-peer tele-mentoring and knowledge sharing program, increases the capacity of neurologists and other healthcare professionals to diagnose and manage MS, with the goal of improving overall health outcomes for people with MS.

- **More than 150 participating clinicians** provided care to **5,291 people living with MS**, 83 of whom were newly diagnosed.

- The Society implemented the first **International Pediatric ECHO MS**, to increase international pediatric MS expertise through sharing evidence-based best practices and contemporary research.

We promoted **MS-specific workforce development programs** providing financial assistance and support to clinicians caring for people with MS.

- Twenty-five Society-funded medical students were placed at 23 different MS Centers nationwide. 96% of program graduates said this **clinical mentorship** inspired them to pursue a career in neurology, MS or related field.
- The Society funded 16 fellows through the **MS Clinical Care Physician Fellowship** at 14 training locations and two new five-year **Institutional Clinician Training Awards**.
  - » The Society hosted nine **MS Clinical Fellows Complex Case Webinars** where fellows presented challenging

cases of MS and received feedback from distinguished faculty. A post-cohort survey of fellows showed:

- 100% are likely to attend another webinar sponsored by the National MS Society
  - 100% agreed or strongly agreed webinar content will enhance professional practice and competence in treating and caring for people with MS
  - 100% felt feedback and discussion contributed to overall learning
  - 93% (7% neutral) felt the webinar environment was inclusive and diverse perspectives felt respected
- To build capacity in medically underserved areas, the Society awarded **Health Equity Scholarships** to healthcare professionals caring for people with MS from systematically disadvantaged populations. Eleven healthcare professionals attended the Consortium of MS Centers (CMSC) Annual Meeting. As a result, Robin Mack, a nurse practitioner at the VA medical clinic in Jackson, Mississippi, an area with a shortage of healthcare providers, became an MS Certified Nurse. Robin said: “Thank you so much for the awesome opportunity to network and learn with the GIANTS in the field of multiple sclerosis. It was a priceless experience for me. CMSC increased my confidence and competence in caring for people with MS. After attending

the conference, I completed the MSCN (MS Certified Nurse). I could not have afforded to attend CMSC if I had not received the scholarship from the Society”.

- In 2019, the Society signed a **Memorandum of Agreement with the U.S. Department of Veterans Affairs, Veterans Health Administration** (“VA”) with the goal to improve care and outcomes for Veterans living with MS.
  - » During the four-year agreement, **1,468 Veterans were assisted by an MS Navigator**. As a result:
    - 73% felt more prepared to advocate for what they need
    - 77% felt more confident in addressing the challenges of MS
    - 59% felt optimistic about the future
  - » Through a collaborative initiative to provide opportunities for continuing MS education for established MS healthcare professional, we delivered **21 educational webinars for clinicians**, with a total of 1400 on-demand views, and 84% clinicians reported learning new knowledge and skills.
  - » We engaged with **357 VA clinicians**, representing 19,079 Veterans living with MS.
  - » The Society is entering a new agreement with the VA in 2023. This will replace and expand an existing agreement in effect from 2019–2023.

## Health Equity Initiatives to Increase Diversity in Clinical Trials, Scientific Inquiry and Research Workforce

Our goal is to deepen our understanding of health disparities through research to develop health equity solutions. In March 2021, we began requiring that grant proposals for clinical research describe the planned composition of the study population in terms of sex/gender and racial/ethnic diversity. Additionally, grant proposals must include an outreach plan for recruiting and retaining diverse study participants and annual reporting must include subject accrual broken down by group.

We will measure progress by collecting baseline data to understand the research grant and fellowship applicants we are reaching now, as a starting point for determining success of engagement activities and increasing the number of people from systematically disadvantaged populations participating in clinical trials.

### 2020-2022 Race/Ethnicity of Research and Clinical Grant Applicants (N= 729<sup>1</sup>)





Research Grants	
Asian	19%
Hispanic or Latina, Latino, Latinx	5%
White	61%
Black; Native American or Native Alaskan; Native Hawaiian or Other Pacific Islander; or My race is not listed here	1%
From multiple races	3%
I prefer not to say	10%

Fellowship and Training Awards	
Asian	24%
Black	1%
Hispanic or Latina, Latino, Latinx	8%
Native American or Native Alaskan	0%
Native Hawaiian or Other Pacific Islander	0%
White	47%
From multiple races	3%
My race is not listed here	6%
I prefer not to say	11%

<sup>1</sup>This number represents the number of applications from grant deadlines Summer 2020 – Summer 2022.

## Moving Forward: Our FY2023–2027 Priorities

Our commitment to transparency and accountability is vital to our diversity, equity and inclusion objectives and we will advance our work with the following initiatives:

 <p><b>Foundation and Structure</b></p>	<p>Leaders are change agents and champions who proactively take actions to increase DEI in the workforce and an inclusive workplace.</p> <p>DEI is integrated into core organizational structures, policies, systems and practices.</p>
 <p><b>People</b></p>	<p>Double the representation of all staff in the category of race and ethnicity from 19.1% to 40% by the end of FY27.</p> <p>Improve representation of Society Leadership Management in the category of race and ethnicity by 60%, from 25% to 40% by the end of FY27.</p> <p>Double the representation of the National Board of Directors in the category of race and ethnicity from 20% to 40% by the end of FY27.</p>
 <p><b>Consistency and Accountability</b></p>	<p>Integrate DEI into professional development, performance management, and advancement and retention efforts by the end of FY24.</p> <p>Develop an understanding of anti-racism concepts and cultivate allyship through education.</p>
 <p><b>Community, Marketing and Supplier Diversity</b></p>	<p>Increase engagement and feelings of inclusion amongst underrepresented/underserved people affected by MS.</p> <p>Establish principles and a framework of execution related to social responsibility by the end of FY23.</p> <p>Expand and diversify the MS research workforce.</p>