

FINANCIAL WELLNESS AMONG INDIVIDUALS LIVING WITH MULTIPLE SCLEROSIS (MS)



A REPORT ON FINDINGS FROM NDI AND
MSAA'S ONLINE SURVEY AND FOCUS GROUPS



SUPPORTED BY A GRANT FROM:



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AND FOCUS GROUPS

Survey Conducted by:

National Disability Institute
Multiple Sclerosis Association of America

Survey and Report Supported Through a Grant by:

Acorda Therapeutics

Report Written by:

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I. Introduction

A 2010 Harris Poll found that a majority (58%) of people with disabilities report that they are **struggling to get by, going further into debt each month or living paycheck to paycheck, not going into debt but not gaining much either**, compared to only one-third (34%) of people without disabilities. Current US Census data reveals that nationally, nearly one in three or 28 percent of individuals with disabilities live in poverty, nearly double the national poverty rate. Less known, is the impact of specific diseases, such as Multiple Sclerosis (MS), on the financial wellness of those individuals living with a disability. National Disability Institute in collaboration with the Multiple Sclerosis Association of America (MSAA) developed questions for an online survey to learn more about the financial wellbeing of individuals living with MS. The survey, which was responded to by 3,011 individuals living with multiple sclerosis, was supported by Acorda Therapeutics as part of a multi-pronged strategy to educate the national MS community about opportunities to increase financial wellness and advance economic self-sufficiency. The survey was broken down into three key parts: demographics (age, marital status, living arrangements, educational history, geographic location, employment status), MS diagnosis status and medical care (year of diagnosis, type of support system, access to medical care), and financial status (income, ability to cover expenses, trusted points of contact, types of accounts and investments). The results present an unprecedented picture of the challenges of financial stability for individuals living with MS nationwide.

II. Demographics

The 3,011 survey respondents represent the diverse group of individuals who live with multiple sclerosis in the United States. Respondents were from all fifty states, Washington, D.C. and Puerto Rico. They responded to the online survey voluntarily.

Age of Survey Respondents

Survey respondents range in age from 21 years to over 70 years with the highest percentage being between ages 41 and 60.

Figure 1: Age		
Answer Options	Response Percent	Response Count
21-30	4.3%	130
31-40	15.6%	468
41-50	31.2%	935
51-60	34.4%	1031
61-70	12.4%	372
71+	1.9%	57

Gender and Marital Status of Survey Respondents

The majority of respondents are female and just over half are married.

Figure 2: Gender		
Answer Options	Response Percent	Response Count
Male	22.1%	661
Female	77.9%	2327

Figure 3: Marital status		
Answer Options	Response Percent	Response Count
Married	58.8%	1757
Widowed	3.1%	93
Divorced	19.7%	588
Separated	2.6%	79
Never Married	15.7%	469

Living Arrangements of Survey Respondents

The living arrangements of respondents corresponded with the reported marital status: the majority live with a partner, while 22% are the only adult in household and 19% live with parents, friends, or other family.

Figure 4: Living arrangements

Answer Options	Response Percent	Response Count
I am the only adult in the household.	21.9%	647
I live in my parents' home.	5.8%	170
I live with my significant other.	59.1%	1743
I live with other friends/family/roommates.	13.2%	389

Educational History of Survey Respondents

In terms of highest level of educational achievement, results indicate survey respondents are highly educated. 98% of respondents graduated high school, 81% attended college and 15% have a graduate or professional degree. Higher levels of educational attainment are linked to higher incomes, less unemployment, less poverty, and less reliance on public assistance¹, indicating that this population should experience low incidence rates. Survey results discussed in Section III will identify the impact MS has on this cohort and the corresponding rate of income, unemployment and receipt of public benefits.

Figure 5: Educational history

Answer Options	Response Percent	Response Count
Less than 9th grade	0.3%	8
9th to 12th grade, no diploma	1.7%	52
High School graduate/equivalency	16.8%	502
Some college	31.9%	952
Associate's degree	12.8%	383
Bachelor's degree	21.7%	648
Graduate/Professional degree	14.6%	436

¹ Burd-Sharps, Sarah, Elder, Jeff, Lewis, Kristen and Martins, Eduardo (2009) *Goals For The Common Good: Exploring The Impact Of Education*

Current Employment Status of Survey Respondents

Significantly, only one-third of respondents reported being employed (23% full-time, 6.5% part-time and 4% self-employed). Of consequence, almost 50% reported they were unemployed or unable to work. Work is an important component of financial stability and an aspect of life that many individuals with MS fear will be impacted by the physical and cognitive implications of the disease. Individuals may experience diminished productivity and be forced to limit their employment from full-time to part-time to unemployed/unable to work. Survey results discussed later note that a high percentage of respondents receive Social Security Disability Insurance (SSDI) and accompanying Medicare Health insurance. To receive SSDI, individuals are required to prove that their medical diagnosis prevents them from working at a substantial level (\$1,000 in gross monthly wages in 2011). This is often viewed as proving you are unable to work. In supplemental focus groups held to draw additional information from individuals with MS, individuals reporting they were unable to work also reported wanting to work but unsure of their ability and fearful of the impact of work on critically needed public health care benefits.

Figure 6: Which of the following best describes your current employment or work status?

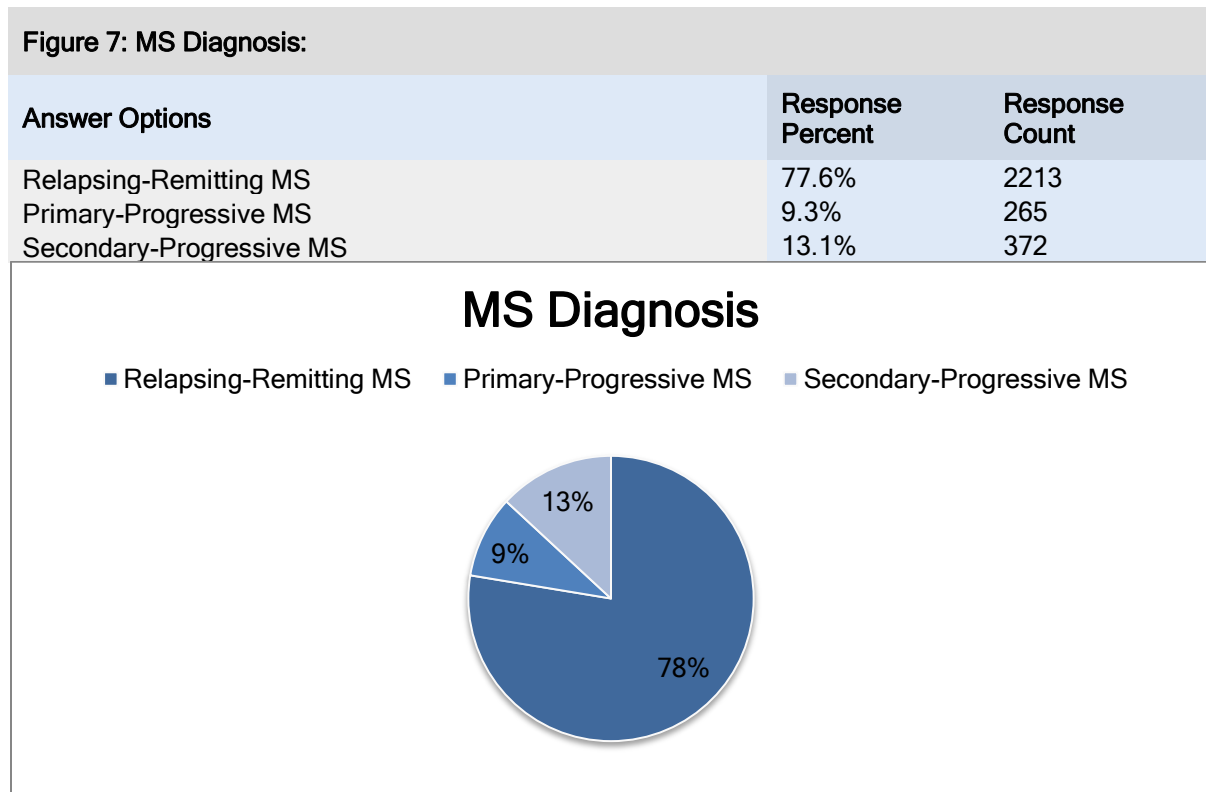
Answer Options	Response Percent	Response Count
Self Employed	4.0%	108
Work full-time for an employer	23.0%	624
Work part-time for an employer	6.5%	176
Homemaker	4.8%	131
Full-time student	1.1%	30
Unable to work	39.5%	1072
Unemployed	7.7%	208
Retired	13.4%	362

Based on these survey results, the average respondent is a middle-aged married female who lives with her partner, attended college and is most likely not working.

III. MS Diagnosis Status and Access to Medical Care

MS Diagnosis

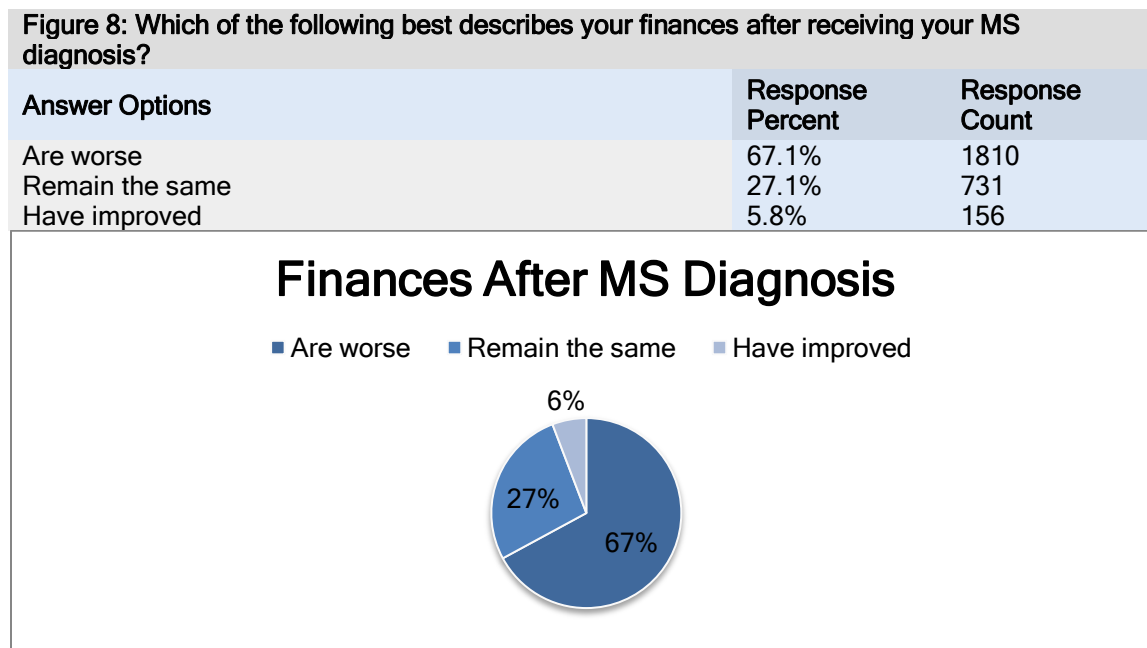
Survey respondents reported varying MS diagnoses. 77.6% of the respondents have relapsing-remitting MS (RRMS), 9.3% have primary-progressive MS (PPMS), and 13.1% have secondary-progressive MS (SPMS). RRMS is characterized by symptom flare-ups followed by recovery. Individuals are often stable between attacks. PPMS is characterized by a gradual but steady accumulation of neurological problems from onset. SPMS (the second phase of RRMS) is characterized by a progressive worsening of symptoms with or without superimposed relapses.² Treatments may delay disease progression but varied and complex symptoms persist, making access to medical care paramount.



² Multiple Sclerosis Association of America, Types of Multiple Sclerosis, downloaded from http://www.msassociation.org/about_multiple_sclerosis/commontypes/.

Finances After a Diagnosis of MS

Although there are differences in the type of MS respondents experience and differences in their diagnosis history, 67% of respondents indicated that their finances were worse after receiving their MS diagnosis. Several common factors influence individual finances, particularly once a disease, such as MS, impacts an individual's activities of daily living and ability to work to the point that the disease becomes a disability. Factors include costs associated with co-pays and prescriptions, non-medical equipment costs and decreased income due to reduced productivity. Individuals who are no longer able to work typically apply for Social Security Disability Insurance (SSDI). SSDI has a mandatory 24-month waiting period for accompanying Medicare health insurance. The cost of health coverage while individuals wait for Medicare can have a devastating impact on finances. In 2008, the average SSDI payment was \$12,050 and the average cost of COBRA (for individual coverage) was \$4,820; approximately 40% of an individual's SSDI income went toward paying for health insurance³.



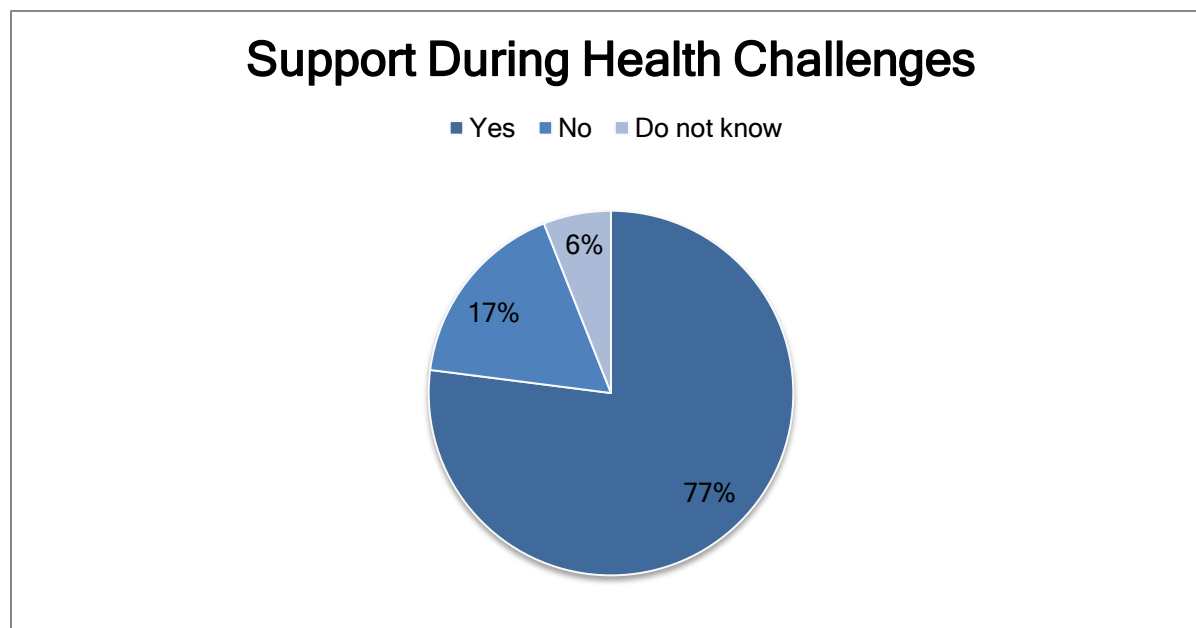
³ Schwartz, Karyn and Claxton, Gary (2009). *Spending To Survive*.

Support During Health Challenges

Living with an unpredictable disease such as MS lends to periods of time when more assistance is needed than others. When asked if a network of friends or families are available to provide support or assistance when faced with a health challenge, 77% of respondents answered “yes”. However, of concern, the remaining quarter of respondents did not have or did not know whether they would have a network of friends or family available to provide support. Given their MS diagnosis, these individuals will likely face periods of time where additional support/assistance is necessary. Friend and families provide in-kind caregiving valued at \$360 billion annually (\$10,400 per caregiver per year)⁴. In the absence of a network, individuals will likely incur additional costs of care.

Figure 9: When you face a health challenge, do you have a network of friends or family who are available to provide support or assistance?

Answer Options	Response Percent	Response Count
Yes	77.1%	2264
No	17.0%	499
Do not know	6.0%	175



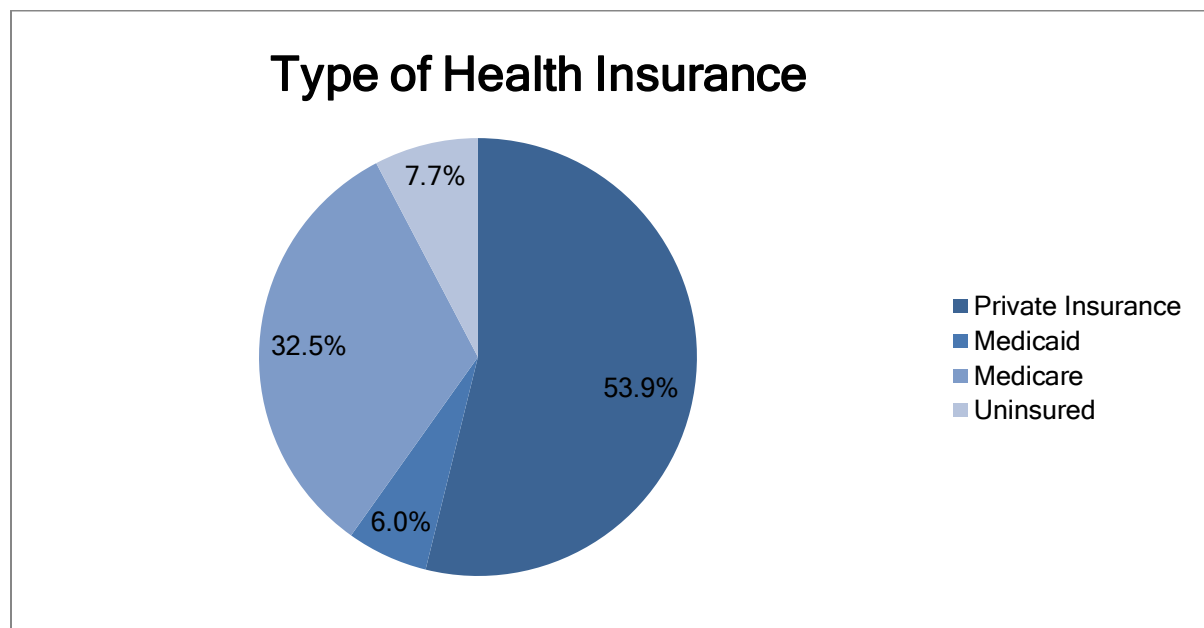
⁴ Gibson, Mary Jo and Houser, Ari (2007). *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving*

Health Insurance

Access to health insurance is not a major barrier experienced by survey respondents. The majority, 54%, have private insurance and an additional 39% receive federally funded healthcare (Medicare/Medicaid). It is important to note that respondents, who receive Medicare and/or Medicaid based on their MS diagnosis, have earning limits, which impact their ongoing eligibility. Additionally, individuals receiving Medicaid must also remain below asset limits that vary from state to state but are as low as \$2,000 for an individual/ \$3,000 for a couple under Social Security's Supplemental Security Income (SSI) program. These concerns are evidenced by responses to survey questions discussed later in this report.

Figure 10: What type of Health Insurance do you have?

Answer Options	Response Percent	Response Count
Private Insurance	53.9%	1585
Medicaid	6.0%	175
Medicare	32.5%	956
Uninsured	7.7%	225

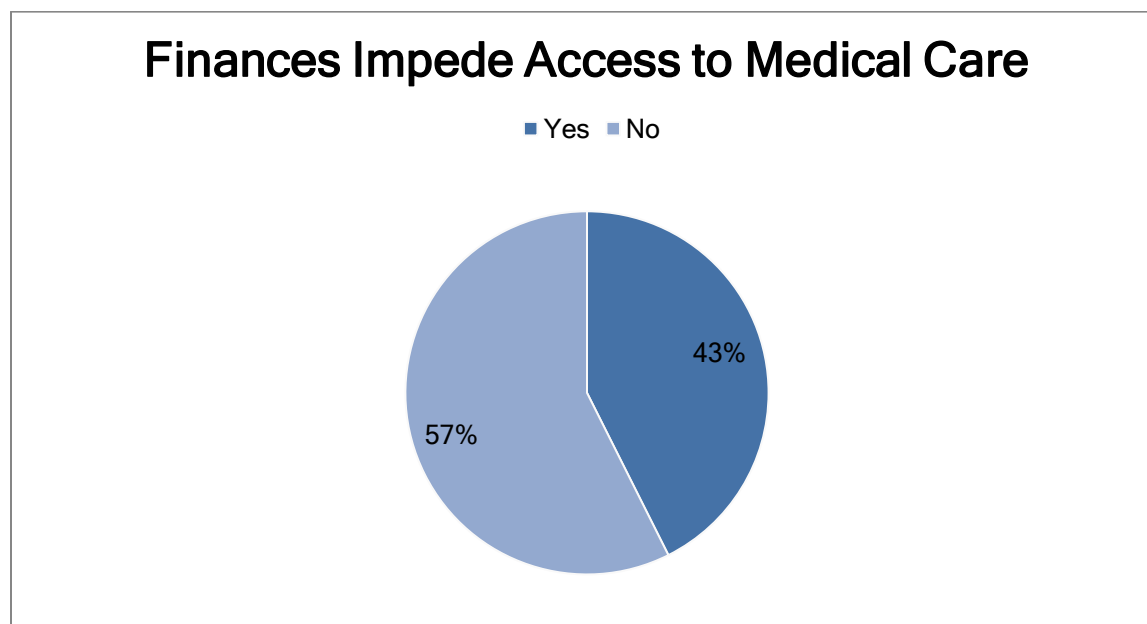


Financial Status and Access to Medical Care

Although the majority of survey respondents currently have access to medical care, 43% of respondents reported that their financial status has affected their ability to access medical care at some point. Accessing medical care is not solely about having insurance. Access is impacted by the services available and the related out of pocket costs. Estimates suggest that prescription therapies to slow MS progression can range from \$34,000 to \$48,000 per year or upwards of \$1,200 per month out of pocket and a report by the Multiple Sclerosis International Federation (MSIF) “estimates that the total average lifetime costs of the disease to the person affected and society as a whole, is \$1.2 million.”⁵

Figure 11: Has your financial status ever affected your ability to access medical care?

Answer Options	Response Percent	Response Count
Yes	42.6%	1143
No	57.4%	1539



⁵ Michael Trisolini, PhD, MBA, et al., *Global Economic Impact of Multiple Sclerosis*, downloaded from http://www.msif.org/en/news/msif_news/countingthecost.html.

IV. Financial Status

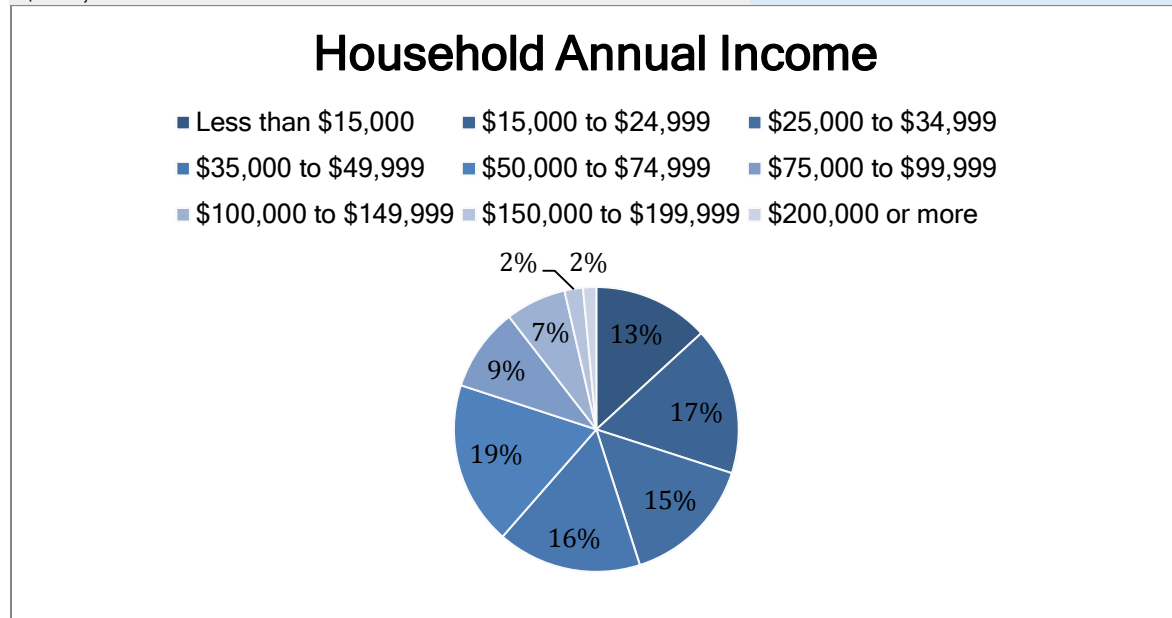
The financial status of the respondents reflects the profound influence MS may have on financial wellness and the need to increase information and access to tools that increase financial wellness among individuals living with MS.

Household Income

Survey respondents spanned the economic spectrum with the majority, 61%, with household income below \$50,000 per year and almost half of those households with income below \$25,000 per year.

Figure 12: What is your (household's) approximate annual income from all sources (wages, tips, investment income, public assistance, retirement benefits, etc.)?

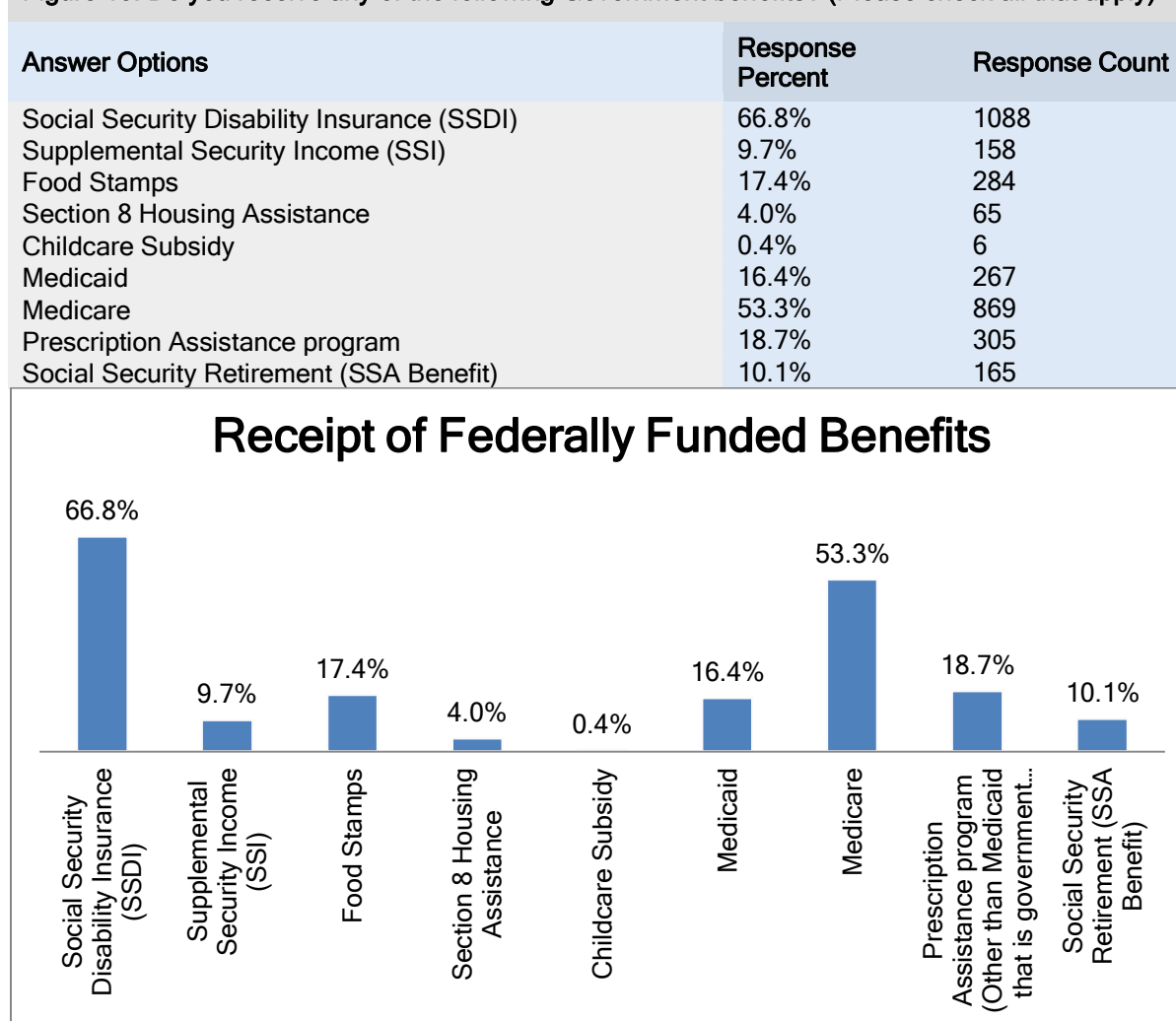
Answer Options	Response Percent	Response Count
Less than \$15,000	13.2%	381
\$15,000 to \$24,999	16.8%	483
\$25,000 to \$34,999	15.1%	435
\$35,000 to \$49,999	16.4%	471
\$50,000 to \$74,999	18.6%	535
\$75,000 to \$99,999	9.5%	273
\$100,000 to \$149,999	6.9%	200
\$150,000 to \$199,999	2.1%	60
\$200,000 or more	1.5%	42



Government Benefits

The majority of survey respondents receive government benefits in the form of Social Security Disability Insurance (SSDI) and Medicare. These benefits are based on Social Security rules that affirm the individual has a disabling condition that prevents them from working at a significant level. The average SSDI cash benefit in 2011 was \$1,110.50⁶ per month. This benefit is not based on income but does require gross earnings below \$1,000 per month to maintain full eligibility.

Figure 13: Do you receive any of the following Government benefits? (Please check all that apply)



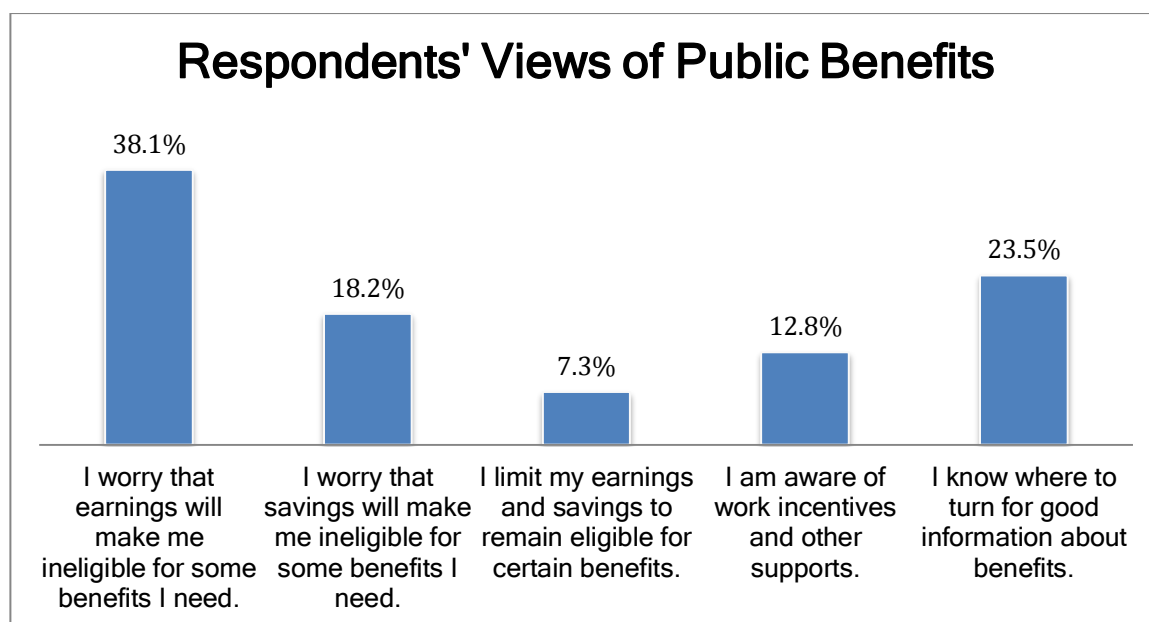
⁶ SSA, *Monthly Statistical Snapshot, December 2011*, downloaded from http://www.ssa.gov/policy/docs/quickfacts/stat_snapshot/index.html?qs.

Views of Public Benefits

More than half of respondents worry that their earnings or savings will make them ineligible for public benefits, and only about 24% of respondents know where to turn for accurate information about public benefits. Accurate information on benefits is critically important for those individuals who receive benefits and seek to improve their financial stability through work. As evidenced by responses, individuals may be unaware of provisions within public benefits programs that allow for earnings and savings at levels that increase finances while protecting critical healthcare. In the absence of good information, individuals may limit earnings and/or savings unnecessarily.

Figure 14: Which of the following statements do you agree with regarding your public benefits?

Answer Options	Response Percent	Response Count
I worry that earnings will make me ineligible for some benefits I need.	38.1%	1101
I worry that savings will make me ineligible for some benefits I need.	18.2%	525
I limit my earnings and savings to remain eligible for certain benefits.	7.3%	211
I am aware of work incentives and other supports.	12.8%	370
I know where to turn for good information about benefits.	23.5%	679

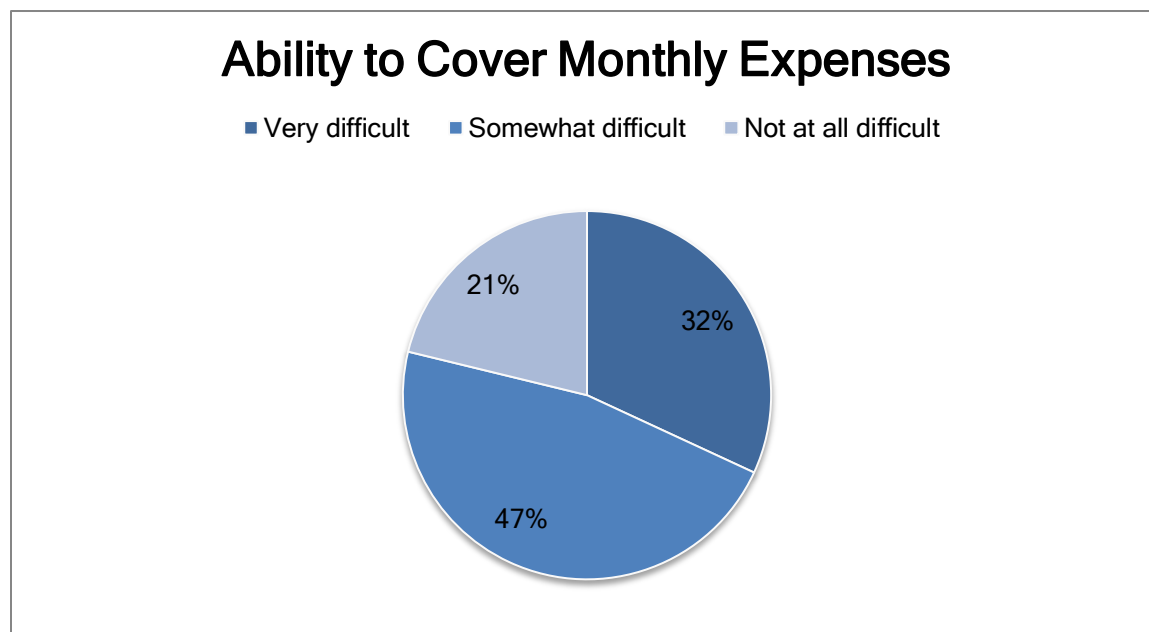


Difficulty Covering Expenses

When asked about the ability to pay all of their bills in a typical month, 32% of survey respondent reported having a “very difficult time” and 46.9% reported a “somewhat difficult time.” Difficulty covering expenses exemplifies the need for a focus on financial stability for individuals with MS and their families. Particularly as the ability to increase income through work may be limited among this population due to MS-related barriers and/or the need to maintain eligibility for public benefits, specifically healthcare (SSDI-Medicare and/or Medicaid). Increased income is not the only way to meet expenses. Budgeting, utilizing community supports and securing available benefits should also be employed.

Figure 15: In a typical month, how difficult is it for you to cover your expenses and pay all your bills?

Answer Options	Response Percent	Response Count
Very difficult	31.9%	856
Somewhat difficult	46.9%	1257
Not at all difficult	21.2%	569

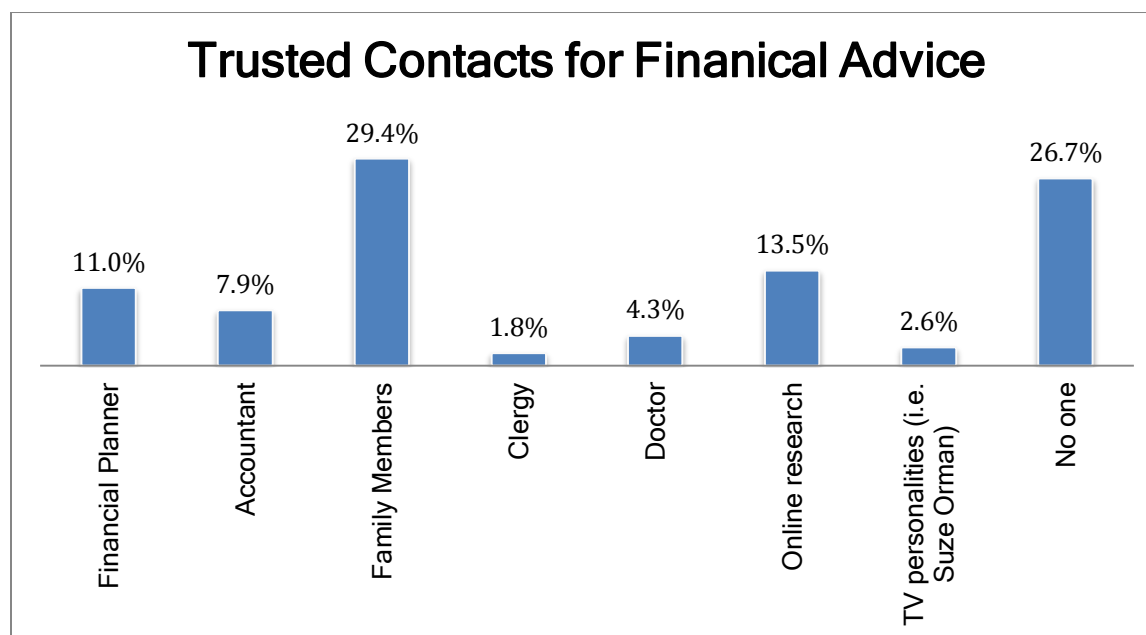


Trusted Contacts for Financial Advice

Individuals with MS lack access to accurate and reliable financial advice. The majority of respondents do not have trusted points of contact or simply rely on family members. Less than 20% of respondents turn to financial planners or accountants for financial advice. Trusted financial advice can support three important goals, (1) open conversations about money choices and needs (the good and the bad), (2) getting an objective view of debt and how to formulate a plan to reduce debt, and (3) developing a budget to meet costs, current and future, and savings goals (short-term and long-term).

Figure 16: Who are your trusted points of contact for financial information and financial advice?

Answer Options	Response Percent	Response Count
Financial Planner	11.0%	292
Accountant	7.9%	209
Family Members	29.4%	778
Clergy	1.8%	48
Doctor	4.3%	113
Online research	13.5%	358
TV personalities (i.e. Suze Orman)	2.6%	69
No one	26.7%	705
		59

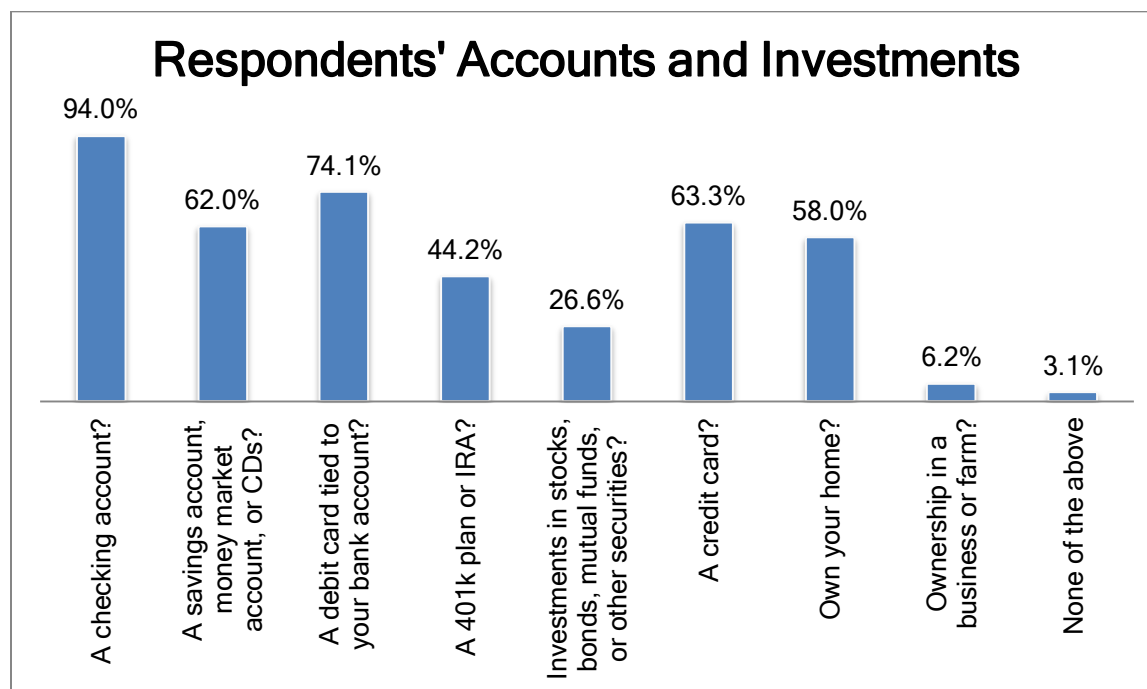


Accounts and Investments

A very high percentage of respondents (94%) report having a checking account (94%) although almost four in ten did not possess a savings account, money market account or CD. Additionally, less than half invest in a 401(k) or IRA and only 26% have investments in stocks, bonds, mutual funds, or other securities. Given the long-term costs associated with MS, long-term savings and investments are important to the ongoing financial stability of individuals with MS.

Figure 17: Do you (or does your household) have any of the following accounts or investments? (Please check all that apply)

Answer Options	Response Percent	Response Count
A checking account?	94.0%	2521
A savings account, money market account, or CDs?	62.0%	1663
A debit card tied to your bank account?	74.1%	1986
A 401k plan or IRA?	44.2%	1186
Investments in stocks, bonds, mutual funds, or other securities?	26.6%	714

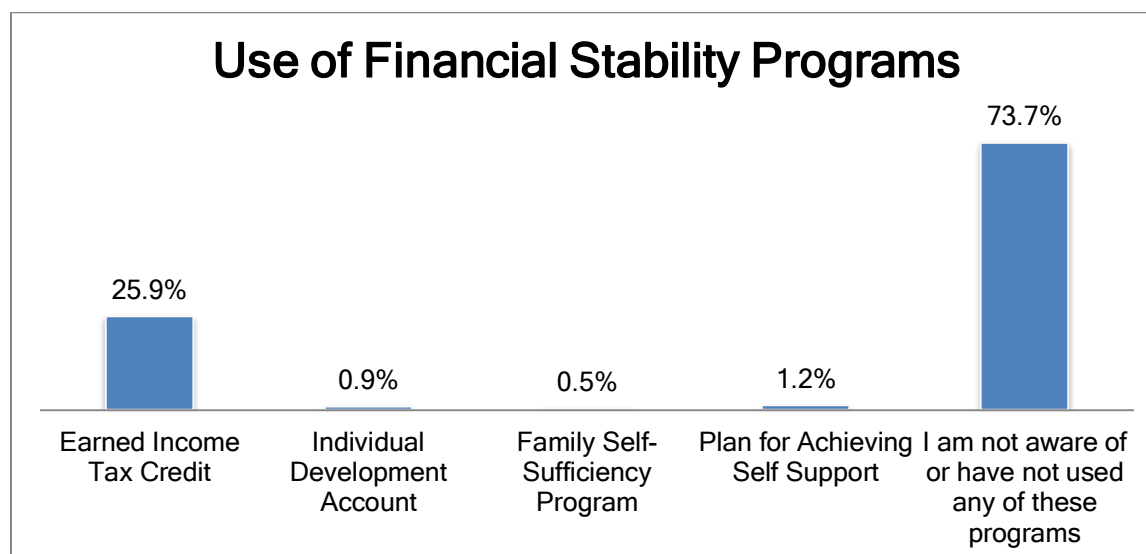


Use of Financial Stability Programs

One of the first steps in improving financial well-being for individuals living with MS is to increase awareness about financial stability strategies and financial education programs. According to the survey, there is a general lack of awareness about financial tools and strategies to help stabilize one’s financial position and advance one’s economic self-sufficiency. About three-quarters of the respondents were not familiar with or did not use any of the noted financial stability and mobility programs; Earned Income Tax Credit, Individual Development Accounts (IDAs), Family Self-Sufficiency Program, and Plan for Achieving Self-Support. Each of these programs provides opportunities to secure additional funds to support an individual’s financial stability goals. These programs are available in local communities and, importantly, provide opportunities to build assets while preserving eligibility to Federally-funded public benefits.

Figure 18: Are you aware of or have you ever used any of the following financial stability programs? (Please check all that apply)

Answer Options	Response Percent	Response Count
Earned Income Tax Credit	25.9%	667
Individual Development Account	0.9%	22
Family Self-Sufficiency Program	0.5%	13
Plan for Achieving Self Support	1.2%	32
I am not aware of or have not used any of these programs	73.7%	1900



V. Conclusion

The survey results provide a comprehensive overview of the financial challenges that people living with MS in the United States are currently facing. Disability diagnoses, medical care, and financial status are complexly intertwined and because poverty and disability do not discriminate, individuals who incur a disability, such as MS, frequently encounter a formula for poverty. Disability-related changes in employment status jeopardize income, access to employer-sponsored benefits and, ultimately, long-term financial stability. Significantly, a decline in wages due to disability-related underemployment and/or unemployment often leads to increased medical costs without insurance coverage. Access to public benefits (Social Security, Medicaid, food assistance, rent assistance) provides a safety net but continued eligibility is coupled with income and asset limitations that create powerful disincentives to income production and saving. Additional new costs related to home modifications for accessibility and technology-related assistance to live independently further create material hardship. The survey results reflect this difficult cycle and the impact on finances often experienced by individuals with disabilities and their families.

The survey results provide important documentation of the need to promote greater awareness of these financial challenges and available tools and strategies to improve the financial wellness of individuals living with MS. Informed by the survey results' documentation of the complex connections between disability diagnoses, medical care, long-term services and support needs, and financial status, the design and implementation of a financial wellness program for the MS community should be an important priority. A financial wellness education program for individuals with MS could lead to improvements in all aspects of the quality of their lives and serve to advance a better economic future for individuals living with MS.



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