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Dear Friends,

I’m proud to present our newest Working Mother Research Institute survey, *Women and MS: The Working Mother Report*. Multiple sclerosis, which affects some 400,000 people in the United States, is usually diagnosed between the ages of 20 and 50—right at the moment when many women are revving their careers up into high gear and raising families.

With the support of Novartis and help from the National Multiple Sclerosis Society, we surveyed more than 1,200 women who are coping with MS to learn how they handle the pressures of health concerns, medication adjustments and worries for the future along with the typical stresses of parenthood and work. We found that they’re doing what women have been doing for millennia in the face of difficult situations: They’re keeping proactive about their treatment options. They’re adapting their work and home routines to accommodate their condition. And they’re making sure to prioritize how they spend their own energy so that they can keep their loved ones, meaningful work and healthy-living activities front and center.

I want to thank Novartis for sponsoring this important research study and for supporting our efforts to disseminate the findings broadly among HR leaders, the medical community and the general public.

I also want to thank the National Multiple Sclerosis Society for helping us reach so many working women with MS. Together, we have revealed new attitudinal information that will better help not only working women with MS but their employers as well.

I invite you to study and share this report. For more on this and other Working Mother Research Institute reports, please visit workingmother.com/wmri.

All the best,

Jennifer Owens
Director
Working Mother Research Institute
Novartis Pharmaceuticals Corporation is proud to partner with the Working Mother Research Institute to release the Women and MS report to help raise awareness of the unparalleled challenges that women with multiple sclerosis face on a daily basis. Three quarters of the 400,000 people diagnosed with MS in the United States are women, and the results of this report emphasize where this crucial population needs the most support—both at work and at home. Through our work with WMRI, our goal is to continue to foster an open dialogue and help patients become more active in managing their MS to live their best lives.

At Novartis, we’re committed to driving innovation that redefines the future of MS treatment. We recognize that each person living with MS is unique and has individual needs. Novartis is committed to ensuring high-quality support throughout the patient journey, including support programs, patient education, co-pay support, research and development, and investment in new therapies. We will remain focused on empowering those living with MS to become their own advocates, facilitate conversations with their health care professionals and build relationships with others in the MS community.

Novartis is privileged to partner with the Working Mother Research Institute to bring forward this information so there is a greater understanding of the tremendous impact this disease has on all aspects of a person’s life.
Women and MS

The Working Mother Report

“*The most challenging part of this disease is that it’s unpredictable. Sometimes my outlook is the only thing I can control. What falls in my lap between sunrise and sunset each day, I try to look at in the most positive manner I can.*” —KRISTIE SALERNO KENT

Multiple sclerosis, a chronic, unpredictable disease that attacks the brain and spinal cord, exacts a heavy toll on women. Nearly four times as many women as men develop the disease, which affects at least 400,000 people in the U.S.¹ The disease is most commonly diagnosed between the ages of 20 and 50, striking women just as they are building careers and families. Living with it is a roller coaster: the disease can appear nearly invisible or flare into an acute attack in which a woman experiences mild to severe impairment of vision, mobility or cognitive function. Though there is no cure for MS, huge advances have been made in the last two decades, says Nicholas LaRocca, PhD, vice president of health care delivery and policy research for the National Multiple Sclerosis Society. “Not long ago, doctors often felt that there was little they could do for a woman diagnosed with MS—sometimes the patient wasn’t even told directly,” he says. “Now, the trend is to be open about the diagnosis and proactive in treatment.”

For these reasons, the Working Mother Research Institute (WMRI), together with sponsor Novartis and our knowledge partner, the National Multiple Sclerosis Society, set out to discover how living with MS affects women’s work and personal lives today. For our study, we surveyed 1,248 women between ages 20 and 50 who have been told by a health professional that they have MS.

Our survey shows that most women cope with the impact of MS daily. Eight in 10 women surveyed say they’re currently experiencing symptoms or have in the past three months. (The most common symptoms are fatigue, numbness and tingling; about 60 percent report difficulty with thinking or memory.) Our data reveal how tough it is to juggle a career, family and MS: Three quarters of respondents are concerned about their future, 70 percent wonder if they will be able to continue working, and half say they worry constantly about relapsing.

Despite the fact that they live with unknowns about how far and fast the disease will progress, our survey finds that today’s women with MS are proactive about treatment. The majority of respondents (85 percent) describe themselves as knowledgeable about treatment options, and 79 percent say they’re on disease-modifying medication for symptoms.

“When people find out I have MS, I see their faces fall. Automatically, they imagine I’m headed for a wheelchair,” says Andrea Sparkman Lindsley, a senior vice president for an advertising and public relations firm and mom of one daughter. “I tell them the statistics of MS are changing. I’m taking good care of myself. I’m partnering with my doctor on the right treatment plan.”

**PARTICIPANT SNAPSHOT**

**WHO:**

1,248 total respondents, all of whom have MS

Average age: 40

Average age of diagnosis: 32

**EDUCATION:**

61% have a 4-year degree or higher level of education

**HOME LIFE:**

67% have children under age 18

73% are married or partnered

$86,700 is the average household income

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¹ National MS Society: www.nationalmssociety.org/About-the-Society/MS-Prevalence
**WHAT IS MS?**

*Multiple Sclerosis is a disease of the central nervous system.* In MS, an abnormal response of the body’s immune system permanently damages myelin—the protective covering on nerve fibers—so that nerves can’t transmit messages from the brain. Symptoms can include cognitive impairment and memory loss, bladder and bowel control problems, paralysis, seizures, vision loss and mobility problems.

No one knows for certain why women are at higher risk for MS, says J. Theodore Phillips, MD, PhD, FAAN, clinical professor and member of the Multiple Sclerosis Comprehensive Treatment Training Program at the University of Texas Southwestern Medical Center in Dallas. “It’s an important question with still unclear answers,” he says. “In MS, it is increasingly likely that female (and possibly male) hormones play an important role in the disease.”

Beyond a hormonal connection, other MS risk factors include low vitamin D levels (women raised in northern latitudes are significantly more likely to develop MS) and high blood levels of antibodies to the Epstein-Barr virus (which causes mononucleosis). A high salt diet, obesity and smoking may also raise a woman’s risk of developing MS.

Sources: [www.nlm.nih.gov/medlineplus/ency/article/000737.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000737.htm); Nicholas LaRocca, PhD, National MS Society

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**WORK LIFE:**

- **95%** are employed
- **77%** work full-time
- **18%** work part-time

**DISEASE PROFILE:**

- **86%** were diagnosed between ages 16 and 40
- **71%** were diagnosed within 6 months of seeing a doctor for symptoms
- **95%** have relapsing-remitting MS, in which symptoms flare up between periods when they abate (for about half of MS patients, the disease evolves to a progressive form, says Nicholas LaRocca, PhD, vice president of health care delivery and policy research for the National Multiple Sclerosis Society)

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**MOTHER AND DAUGHTERS: ONE FAMILY’S MS STORY**

*When Janelle Camacho was 9,* her mother went blind at work one day. Her mom’s MS diagnosis changed every aspect of the family’s life. Racked with seizures, her mother could no longer work; money was tight, and Janelle and her brother spent lots of time with relatives while her mom was in and out of the hospital. These memories returned in a rush when Janelle, a mom of four, began having shoulder numbness each time she breastfed her youngest daughter. Eventually she went to the doctor, and he confirmed her fears. “To say I was scared to death doesn’t even cover it,” she says. “I was worried about being able to work and take care of my kids and about what my husband’s reaction was going to be because he had seen what happened with my mother.” Janelle’s experience, though “no walk in the park,” has been much better than her mom’s. Medicines have alleviated her worst symptoms (she works two jobs and is an active runner), and support groups have helped the whole family navigate their new normal.
The Diagnosis

MS is diagnosed by the combination of symptoms coupled with an MRI scan that's positive for brain and spinal cord lesions, says Kathy Zackowski, PhD, OTR, MSCS, a Johns Hopkins University School of Medicine researcher specializing in MS. In our survey, 43 percent of women got diagnosed less than a year after first experiencing symptoms. “Often, persons with MS have actually been relatively healthy individuals until dramatic symptoms occur ‘out of the blue’ that result in medical evaluation,” says Dr. Phillips.

Nicole Lemelle was 29 and attending nursing school when she suddenly went blind in her left eye. A neurologist ordered an MRI. “They were surprised at the lesion burden they saw compared to the ability I had and how I looked in person,” she says. Nicole’s illness has progressed to the point where she uses a wheelchair, has difficulty speaking at times and has experienced bouts of paralysis. Though dramatic symptoms often trigger an MS diagnosis, it’s not uncommon for women to experience mild symptoms (such as numbness, tingling or vertigo) for an extended period of time without realizing they have MS. Nearly a quarter of survey respondents said they had symptoms for more than four years before they were diagnosed. “The more I learn about this disease and the more I look back, the more I realize I’ve had this a lot longer than I first thought,” says Kristie Salerno Kent, an Atlanta-based mom of two children, who believes she had her first MS symptoms in adolescence. Like Kristie, nearly 80 percent of women are taking a disease-modifying medication, and of those, 61 percent are taking it by injection. Their most common goals are to slow disease progression and reduce relapses.

How Women Learn About MS

“When you’re first told you have a chronic, progressive illness, it’s jaw-dropping. You almost don’t know what to ask.”

—KRISTIE SALERNO KENT

When women have questions about MS, 95 percent are likely to consult their doctors, and 99 percent use websites dedicated to MS. Eight out of 10 respondents say they are satisfied with information they’ve gathered. Yet there are opportunities to provide more information about how MS affects fertility, pregnancy, childbirth and breastfeeding. Women in our survey—particularly those under age 30—express low levels of satisfaction with information about these areas of women’s health. As well, women ages 20 to 30 appear to want a more “conversational” approach to learning about the disease. They are more likely than older women to seek information from blogs, social media, friends or family.

Kristie regularly searches for MS-related news on medical websites, blogs and social media outlets. She compiles an ongoing list of questions to ask her doctor. “Having a strong partnership with your health care team is really important,” she says. “You want to communicate often and be proactive, not reactive.”

MS and Motherhood

In our survey, having MS doesn’t appear to affect a woman’s decision to marry or have a relationship, but it does cause women to worry about raising children. More than three quarters of participants under age 31 are afraid the disease will prevent them from being a good mom. (It may be fear of the unknown: 63 percent of respondents did not yet have children when they were diagnosed.) “I was afraid at first to have children,” says Kristie. “I had so many questions about how I would take care of myself, let alone children.” She and her doctor talked about her family goals and made a plan for going off medication before conceiving.

As it turned out, Kristie’s MS symptoms disappeared during both her pregnancies. “I loved every moment. It felt like freedom,” she says. For reasons not fully understood, studies have shown that MS symptoms can abate during pregnancy (particularly in the third trimester). In our survey, 20 percent of respondents say their symptoms were milder during pregnancy.
Raising Children

“Everyone living with MS knows that some days are better than others. Every day that I wake up and am able to see, talk, walk and use my arms is a gift, and I try to make it count.”

—JANELLE CAMACHO

Getting through a pregnancy is one thing—raising children while battling a chronic illness is a much larger challenge, according to moms with MS.

“Fatigue is really a common symptom that most patients experience. It’s difficult to quantify and treat and can be disabling,” says Bonnie Gerecke, MD, chief of neurology at Mercy Medical Center in Baltimore, MD.

“I wake up feeling tired and I haven’t even done anything yet,” says Nicole. Andrea describes the fatigue as “like a wave that washes over you. When I have that feeling, I know I need to sit or lie down immediately.”

In our survey, 85 percent of women say they are currently experiencing MS-related fatigue. (Only 3 percent say they’ve never felt tired because of MS.) Fatigue curtails some aspects of family life. A majority (64 percent) of respondents say the disease or symptoms prevent participation in activities with children. Half of women say that fatigue hurts their family’s ability to be spontaneous. About a third worry their child will feel embarrassed or nervous about bringing friends home because of Mom’s disabilities.

“My daughters understand sometimes Mommy needs a time-out,” says Janelle. “It frustrates them sometimes. It frustrates me, too.”

When you live with MS, you learn to simplify and conserve energy, says Janet Perry, a mom of three who left a high-pressure sales job after her MS diagnosis and now runs an at-home needlepoint business in Napa, CA. “If I know I have to take the kids places after school, I make sure to sit down and rest before they come home. I look for ways to reduce stress—when it’s my turn at the carpool, I will take the closest driving location or someplace familiar.”

Moms overwhelmingly say (95 percent) that MS hasn’t prevented them from developing a strong bond with their children.

“I think I am a more thoughtful parent because of MS,” says Kristie. “I really savor the simple moments of cuddling, singing and reading books. I don’t know if I would be that way if I wasn’t dealing with MS.”

Many agree that watching Mom cope with MS-related difficulties has made their children more resilient: 66 percent say their children have learned how to deal with unexpected things, and 41 percent say their kids take on more responsibility around the house.

MS AND FAMILY LIFE

Many women with multiple sclerosis say symptoms hinder their spontaneity and participation in activities, but those with mobility issues are more likely to have such difficulties.

- I can still have a strong relationship with my child/children despite my MS. 95% agree, 3% disagree.
- Having MS shows my child/children how to face challenges and succeed. 71% agree, 21% neither, 6% disagree.
- Having MS helps show my child/children how to deal with the unexpected. 66% agree, 23% neither, 8% disagree.
- MS symptoms or relapses prevent me from participating in activities with my child/children. 64% agree, 16% neither, 28% disagree.
- There is less spontaneity in our family activities because of my fatigue. 51% agree, 18% neither, 29% disagree.
- My child/children have additional responsibilities around the house because of my MS. 41% agree, 18% neither, 37% disagree.
- I am concerned my child/children will feel different, embarrassed or apprehensive about bringing friends home because of my MS. 31% agree, 16% neither, 50% disagree.

- 83% of those with mobility issues agree.
- 47% of those with mobility issues agree.
THOUGH THE MAJORITY OF SURVEY PARTICIPANTS ARE EMPLOYED FULL-TIME, THE DATA SHOW THAT MANY FIND IT DIFFICULT TO WORK AND DEAL WITH CHRONIC ILLNESS.

“The unpredictability is hard,” says Dr. Gerecke, of Baltimore’s Mercy Medical Center. “It’s difficult for a patient to know how much she can exert herself.” In our survey, 71 percent of women are worried about becoming unable to work. And the fear seems well founded: 60 percent missed work in the last 12 months due to MS. Of these, 23 percent missed one or two days, 29 percent were absent 3 to 5 days, and 21 percent were out 6 to 10 days.

When MS flares up, “it takes me out of commission,” says Andrea.

Even though 60 percent of respondents say they try to hide their symptoms at work, our survey shows they don’t believe they can do so indefinitely. “Imagine you have to stand and give a presentation, but your sense of balance is off,” says Johns Hopkins’s Dr. Zackowski. Or you have a spastic bladder, and the bathroom is far away. (Forty percent of women surveyed report having bladder and/or bowel problems, a common source of anxiety and discomfort for working moms with MS, says Dr. Zackowski.) MS suffers may also have difficult walking long distances, navigating uneven surfaces or attending work events in the evening. Certain kinds of lighting can trigger double vision and vertigo.

The challenge isn’t just physical; it’s mental, too. Because MS affects the brain, mood and cognitive changes are part of the disease. Sixty percent of respondents say they’ve had difficulty with thinking or memory.

“I know my memory isn’t as sharp as it used to be,” says Janelle. “Sometimes it’s hard—MS can look like nothing is wrong with you, but inside you are really struggling.”

For the women in our survey who are not currently employed but were within the past two years, 56 percent cite MS as the reason. Twenty-one percent plan to return to work.

MS and Work

“There isn’t a day that I don’t think about the what-ifs or whether I will be able to continue to work and take care of my children.”

—JANELLE CAMACHO

The majority of women surveyed say they worry about their ability to continue working with multiple sclerosis, while 60% of those with jobs try to hide their symptoms.
"People avoid me sometimes. Even my sister can barely stand to see me this way, in a wheelchair, but I want to say, ‘Please come and see me. Social visits are really important.’"

—NICOLE LEMELLE

When an MS patient can’t move freely, it affects her life and outlook profoundly.

The social stigma of using a wheelchair or walking aid can’t be overstated, says Johns Hopkins’s Dr. Zackowski. “I have one patient not using a cane because her husband doesn’t want anyone to know.” Another woman has been hiding her disease progression by working from home. “When she is on video-conference calls, she focuses the camera so that no one can see she’s in a wheelchair,” Dr. Zackowski says.

On nearly every measure, we see that lack of mobility damages confidence and self-esteem. Women who have mobility problems are likely to worry about their ability to continue working (82 percent), feel they aren’t performing their best at work (69 percent), have passed up a more demanding role (56 percent) and dread going to work (51 percent).

“There was a period of time when my walking was slowing down, my balance was worse,” Kristie recalls. “Instead of acknowledging that, I started withdrawing and changing my routines so it was less noticeable.”

**Satisfaction depends on mobility**

Women with mobility issues worry more and have more difficulty managing symptoms.
So how do women cope with MS at work? Forty percent of our respondents say they adjust their schedules. Of those, 38 percent reduce their hours, about a third opt for a flexible schedule, and 19 percent have taken a less demanding job. Nine percent admit they do not adjust their schedules because they do not want anyone to know they are struggling. (Only 39 percent of women in our survey agree with the statement “My supervisor is interested in helping me manage my MS symptoms in the workplace.”)

In terms of physical accommodations for MS, most respondents do not receive special treatment. Of those who do, the most common accommodations are an ergonomic workstation (9 percent), parking close to the worksite (15 percent) and temperature adjustments (18 percent). (Temperature is important because too much warmth can trigger weakness, fatigue and double vision in MS patients, says Dr. LaRocca.)

MS symptoms can be subtle, which may account for the overall low level of physical accommodations. A person “may have mental slowing, fatigue, and pain, but their peers and co-workers may not be sympathetic because they don’t see the physical signs of disease,” says Dr. Gerecke.

In fact, when women do have obvious impairment, they get more accommodations. Women with mobility problems, for instance, are twice as likely to get a dedicated, close parking spot as women without.

Certainly, our survey shows more openness is needed. A majority of women say they try to hide their symptoms at work.

Kristie, who spent years “hiding my symptoms and working a desk job,” says that “denial has been the most damaging symptom of MS for me. For three years after diagnosis, I went on no treatment. Things would pop up and I would dismiss them. Hiding and pretending only hurts you.”

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FLEX HELP AT WORK

Many respondents aren’t offered workplace flexibility options that they say would help them manage their symptoms while they work.

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<th>CURRENT EMPLOYER OFFERS</th>
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<td>Access to resources/info on MS</td>
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Moms with MS: What They Need

Our survey shows clearly that women with MS need more help in the workplace. More than half admit they are not performing their best at work. Roughly a third dread going to work because of MS. Here’s what employers can do:

Provide flexibility on when, where and how work is done. Flexibility tops respondents’ wish list. They want flexibility to take time off during the day for doctors’ appointments, to change their work schedule and/or to work from home. This kind of flexibility may help women better manage their energy and daily responsibilities, with the goal of preventing stress or exhaustion-triggered disease flare-ups. We see large gaps in the desire for flexibility versus access to it. (For instance, 95 percent say flexibility to take time off for doctors’ appointments is important, but only 43 percent are able to do so; 76 percent want to work occasionally from home, but only 26 percent say they can.)

Discuss career planning. Beyond daily flexibility, MS moms need career pacing options as well. People with MS might need time off or a reduced schedule to manage a relapse, recover from one or try a new drug therapy—some of which are administered intravenously. “Over the past decade, there has been a shift from treating the condition with medications that are low risk with mild side effects ... to treating it with more potent, immune-modulating drugs that may end up altering the course of the disease in a grander way,” says Mercy Medical Center’s Dr. Gerecke. “I would say that treating multiple sclerosis these days is in some ways almost tantamount to treating cancer with chemotherapy in that the risk is higher, but the reward can be, too, potentially.” Nearly three quarters of respondents want the ability to take a sabbatical or switch to part-time work, while two thirds want to be able to step off the fast track.

Open a dialogue about needs. No two people with MS are alike. “Go to any MS conference and you’ll see such a range—from people running marathons to people who are quadriplegic but maintain full cognitive function,” says the MS Society’s Dr. LaRocca. Encourage openness so teams understand what an individual is dealing with and what specific adjustments will be meaningful—such as holding critical meetings in the morning, when energy level is high, or providing a podium for presentations.

Offer counseling. MS can be a lonely disease; roughly half the women surveyed say they often feel overwhelmed, and more than a third say they feel isolated. “MS-related brain damage may directly result in depression,” says Dr. Phillips. “Dealing with the life challenges imposed by MS can significantly contribute to depression also.” Only 5 percent of survey participants have access to a support group, but 36 percent say it’s an important resource.

Evaluate accessibility. In our survey, we see surprisingly few physical accommodations for women with MS. (Even among those with mobility issues, only a third have parking close to the worksite.) “Things to consider include architectural barriers like steps, the thickness of carpeting if someone is using a wheelchair, transition surfaces and distance to bathrooms,” says Dr. LaRocca. Consider not just physical access but other environmental factors. For example, can someone control the temperature of her office, adjust lighting or keep her work zone quiet?

Enable activity. Current advice to people with MS is “be as active as you can.” Nearly half say they exercise regularly. “Many different studies support the idea that regular exercise up to the individual’s ability yields benefits in many different arenas including physical, cognitive and emotional realms,” says UT Southwestern Medical Center’s Dr. Phillips. Offer health savings accounts that can be used for gym memberships, create an office walking trail, plan fun incentives, and reward individuals who meet personal Fitbit goals.

The National MS Society, our knowledge partner on this survey, also offers resources to support people with employment and parenting issues, ranging from publications for the children of parents with MS to peer support groups to brochures on workplace topics (nationalmssociety.org).

Methodology
The Working Mother Research Institute, with sponsorship from Novartis and guidance from our knowledge partner, the National Multiple Sclerosis Society, developed a national survey about how MS affects women. The online questionnaire was hosted by Bonnier Custom Insights (a division of Bonnier Corporation), and respondents were recruited through communications (email blasts, Facebook posts and website information) from the National Multiple Sclerosis Society between August and October 2014. A total of 1,248 qualified respondents (women aged 20 to 50 who had been diagnosed with multiple sclerosis) completed the questionnaire. Bonnier Custom Insights received and tabulated the responses, which were analyzed by Maria S. Ferris Consulting LLC. The final results are documented in this report, which was written by the Working Mother Research Institute.
Located in East Hanover, New Jersey, Novartis Pharmaceuticals Corporation researches, develops, manufactures and markets innovative medicines aimed at improving patients’ lives. It offers a broad range of medicines for cancer, cardiovascular disease, endocrine disease, inflammatory disease, infectious disease, neurological disease, organ transplantation, psychiatric disease, respiratory disease and skin conditions. The company’s mission is to improve people’s lives by pioneering novel health care solutions.

The Working Mother Research Institute, a division of Working Mother Media, is home to the Working Mother 100 Best Companies, the Best Companies for Multicultural Women and the National Association for Female Executives Top 50 Companies for Executive Women, among other initiatives. WMRI produces insightful benchmarking reports and important research papers on work life and the advancement of women and conducts surveys, such as Women and MS: The Working Mother Report, to further culture change nationwide.

The Society mobilizes people and resources to drive research for a cure and to address the challenges of everyone affected by MS. In 2014, the Society invested $50.6 million to advance more than 380 research projects around the world in order to stop MS in its tracks, restore what has been lost and end MS forever. Through its comprehensive nationwide network of programs and services, it also helped more than one million people affected by MS connect to the people, information and resources needed to live their best lives.