MS AND PREGNANCY

A Special Reprint

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MS AND PREGNANCY

SURPRISE! SURPRISE!

MS and pregnancy ... for thousands of people, they do go together

by Mary Elizabeth McNary

Mary Elizabeth, it’s good to hear your voice,” declared my neurologist. We hadn’t spoken in six months. My neurologist is wonderful. I went through five doctors before finding her, and she has become the friend and partner who helps me see my MS as an inconvenience rather than a tragedy. “How are you?” she demanded.

“Well ... pregnant!” I blurted in disbelief. I’d never expected to say the “p” word about myself, but true love leads one down unexpected trails. Fatherhood was the dearest dream of my healthy, strap-
Keith’s sibling is on the way!

I am currently five-and-a-half months pregnant with my second child since my diagnosis in 1991.

My husband, Philip, has been key in my ability to keep going while being a pregnant mom. He takes over when he comes home from work.

I still make dinner, but retire to the couch afterwards to rest. Philip cleans up, plays with Keith, gets him ready for bed, and sings him to sleep. I couldn’t get through this without my wonderful husband.

—Pamela Meyer, Illinois

over the nine months. An expectant mother with MS should be able to count on her two most important health-care providers to work well together while she does the life-changing task of carrying a baby. My physicians got me through it swimmingly.

The first trimester brought few physical changes. No weight gain, no morning sickness, and no more than my usual fatigue, weakness, and ataxia. The emotional changes, however, were something else entirely. The entire trimester was like a bad bout of PMS.

For twelve weeks, I was horrible company. Life seemed overwhelming. Everything either infuriated or depressed me. After snapping at my bewildered husband for some imagined transgression, I would burst into tears and apologize for being unfit as a wife, friend, or mother-to-be. What a case of hormone poisoning!

As if my emotional state weren’t indignity enough, the first sonogram revealed something more. As the radiologist extracted the vaginal probe that had captured the image of a healthy fetus, she suddenly exclaimed, “Uh-oh! What’s that?!” It appeared that the baby was not alone. Patrick later told me he’d awakened that morning with the eerie feeling that we’d be having twins. To his credit, he’d refrained from telling me.

I lost it. “You’re the one who wanted a kid, now this is what you get!” I sobbed. “How will I ever do it? What about my life, my job, my ambitions? What about my MS?” Patrick was

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somber. “We’ll manage,” he whispered, hugging me.

If MS has taught Patrick and me anything, it’s to keep a sense of humor. After the shock wore off, we joked about our win-win situation: “You get to be a father, and I only have to be pregnant once. It’s a ‘Mc-Family’,” I quipped. We left the hospital laughing.

We continued laughing as I grew to be nearly as wide as I am tall. We chuckled as I started craving red meat instead of my usual vegetarian fare. We giggled as I started urinating every five minutes instead of just every half-hour. We told everybody I was having trouble making the transition from sex kitten to Earth Mother, and they all laughed with us.

By the third trimester, the twins were making a constant fuss. When I sang, they’d dance inside of me, keeping time with the song. When I drank seltzer water, they’d keep me up all night with their hiccups. If I put a paper cup on my belly, they’d kick it off.

I lived through a muggy Washington, D.C., summer without an exacerbation of my MS, but I got no third-trimester break from symptoms. Pregnancy, not MS, hampered my mobility in the end. My legs and feet swelled up with edema until only bedroom slippers fit. My gait, long since robbed of any grace, became a blundering lurch. As the due date (“D-Day,” I called it) approached, I felt as if twin parasites were sucking the energy out of me.

The babies arrived safely, by planned C-section, two weeks before D-day. They weighed nearly 7 pounds each, and the obstetrician praised me for being one of her “healthiest” patients.

They are three years old now, and I remain well, gainfully employed, and happily married. Not bad for a woman living with MS, is it?

Mary Elizabeth McNary wants to thank Heidi Crayton, MD, and Michele Wylen, MD, her neurologist and her OB. Both practice at Georgetown University Hospital, Washington, D.C. The twins are on p. 11.
Pregnancy is a special time in a woman’s life, but pregnancy with multiple sclerosis can make the nine months perhaps a bit more special than desired. MS does not rob women of motherhood, but the disease does require extra attention to ensure that the pregnancy is safe, comfortable, and as happy as possible.

Here’s the bottom line from MS experts: Pregnancy, labor, delivery, and the incidence of complications for the baby are no different for women who have MS than for women without the disease. There is no evidence that MS impairs fertility or leads to an increased number of spontaneous abortions, stillbirths, or birth defects.

Thankfully, decades of research have also overturned the myth that pregnancy makes MS worse over the long term. There are even some published studies suggesting that pregnancy is associated with a better long-term course. That said, it’s still essential to guard the health of mother and baby.

Factors to consider during the “trying” time

Talk to your MS physician first! Women who take any of the disease-modifying therapies (Copaxone, Betaseron, Rebif, or Avonex) and men or women who take immune suppressants (such as Novantrone or Cytoxan) should discuss their plans to become pregnant with their MS doctor.

“The Food and Drug Administration (FDA) recommendation is clear on disease-modifying drugs. Women with MS who are actively trying to become pregnant should not be on these therapies,” said Patricia K. Coyle, MD, of the State University of New York at Stony Brook’s Health Sciences Center. She is also a member of the Society’s Medical Advisory Board. The main concern is damage to the developing fetus, especially during the first weeks, followed by concern that the medication might increase the risk of miscarriage.

“Most doctors recommend that women discontinue disease-modifying drugs one month, or one cycle, prior to conception,” Lael Stone, MD, noted. She is with the Edward J. and Louise E. Mellen Center for MS Treatment and Research at the Cleveland Clinic. “I always find this conversation a good time to remind a woman to start on pregnancy vitamins to increase her folic acid intake. All women should do this; folic acid prevents neural tube defects.”

Men with MS who want to become dads don’t have to discontinue disease-
modifiers, but Dr. Coyle would consider taking a man off any MS drug known to be a cytotoxic (or cell-killing) agent. “I would want to reduce the risk of chromosomal damage,” she said.

Dr. Stone is also cautious about chemotherapeutic agents, such as Imuran (azathioprine) or methotrexate: “Both men and women should discontinue chemotherapeutic drugs for a minimum of one month prior to attempting conception. Two to three months would be better. For people using these medications,” Dr. Stone added, “contraception is an absolute must.”

To help women minimize the length of time they need to be off their disease-modifying drug—a question of heightened significance to older women, who may need more time to conceive—Dr. Stone recommends using ovulation kits and other non-medical methods to beef up the odds. “Theoretically,” she observed, “most fertility treatments are safe in MS, but there are virtually no data on this.”

These can be “trying” times indeed.

Suppose a woman’s symptoms intensify? Despite the FDA recommendation, which is also the recommendation of the National MS Society’s Medical Board, there might be a situation in which a physician would suggest staying on a disease modifier. The safety profile of Copaxone (glatiramer acetate) is somewhat better than the interferon drugs in such a circumstance. In animal studies, high-dose interferons caused increased rates of miscarriage, while nothing similar has yet shown up in animal studies of glatiramer acetate.

“And sometimes women must put conception on hold, to get the disease under control,” said Barbara Green, MD, a member of the Society’s Medical Advisory board and director of the West County MS Center in St. Louis. For how long? “That depends on the pattern of that person’s disease,” she said. “If the MS is out of control, the MS needs treatment. Attempting pregnancy must be delayed so the woman can remain on medication.”

Dr. Green sounded a note of concern for men as well: “When young men have erectile dysfunction due to MS, it’s often hard for them to discuss it with their doctor. Neurologists need to help their male patients talk, because ED makes life so difficult for couples who want to conceive.”

Did someone say triplets?
I was diagnosed in 1997. It was a big blow to my marriage—we had also had two miscarriages. But in 2000, I went the extra mile: triplets!

—Nicole Thiroux, via e-mail
Despite all these worries, most couples who want to become parents eventually find themselves pregnant.

**Being pregnant: staying safe and comfortable**

A neurologist knowledgeable about MS is probably comfortable with pregnancy. (If not, the Society’s Professional Resource Center has citations to the professional literature for physicians.) The next task is finding an understanding obstetrician who is willing to collaborate with the MS physician.

“Make sure your OB knows you have MS,” Dr. Coyle stressed. “You don’t want it coming up as a surprise. It’s most helpful if your two doctors are at the same center, or in the same referral network, so you might start your search for an OB with your neurologist. She or he probably knows some OBs. Ask the two to e-mail or speak to each other.”

Dr. Green suggests that women ask each doctor being consulted, “Would you mind sending my other doctors copies of your notes?”

If the woman has little to no disability from her MS, she can be considered a routine obstetric patient. MS experts think a “high-risk” designation is generally not warranted, unless there are other medical problems, or the woman has significant difficulty with sensation or ambulation.

As for what to expect symptom-wise, there’s a shiny silver lining: Pregnancy appears to have a protective effect on women with MS, perhaps because of the way pregnancy changes immune response. The number of relapses or exacerbations goes down during pregnancy, especially in the second and third trimesters.

“If an MS relapse does occur, the use of the steroid methylprednisolone is OK, especially after the first trimester,” Dr. Stone said. “But some neurologists are uncomfortable treating a relapse during pregnancy with steroids.” Dr. Coyle sees nothing to indicate that it is dangerous to use steroids to shorten MS relapses. If treatment is advised and delivery is near, Dr. Green wants the woman to inform the third member of her medical team: the baby’s pediatrician.

Pediatricians have changed their perception of steroid use, Dr. Stone pointed out. Today, steroids are sometimes ordered for a woman who has to deliver early because they help mature a pre-term infant’s lungs.

In other words, while a severe MS relapse during pregnancy is trying for everyone, there are safe and effective treatment options.

“Mostly we just recommend rest
and taking extra care of health concerns—adequate sleep, nutritious food, gentle exercise, stress reduction,” Dr. Stone said. “The same things every woman needs. We do need to make sure that any symptoms are truly due to MS and not to pregnancy-related changes.” The neurologist and the OB should discuss which drugs for symptoms such as bladder problems, depression, or spasticity are safe to take during pregnancy.

For the final phase, an expectant couple needs to plan for the fatigue of late pregnancy. Will the mother be able to work? Will the family need extra help at home, especially if there are other children?

That last trimester makes all pregnant women uncomfortable, and women with MS may expect problems with bladder and bowels to intensify. “Women need to take particular care to drink plenty of fluids and not become dehydrated, despite the increase in bladder symptoms,” Dr. Green said.

As women become heavier, their center of gravity shifts, turning occasional unsteady gait or loss of balance into a much bigger problem. It may be time to install grab bars, especially in the bathroom, and to leave a few sturdy chairs in strategic locations. For maximum safety, some women use a cane or forearm crutches in the third trimester—or they go mobile in a wheelchair.

The possibility of urinary infections also increases. Some doctors take monthly urine cultures from all pregnant women with MS. “Urinary infections must be medicated during and after pregnancy, as they could threaten the lives of baby and mother,” said Dr. Stone. “Most antibiotics are considered

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**Against all odds**

At 25 years old I was diagnosed with endometriosis, fibroids, ovarian cysts, and the onset of cervical cancer. After five years of surgeries and treatments, I was told that I couldn’t have children.

In 1999 I was diagnosed with MS. “See, it’s good you can’t have kids,” some well-meaning folks were saying. But in early 2000, I discovered I was pregnant. At the 10th week I started bleeding. My husband and I went to the ER. They did an ultrasound to see if there was an injury, and discovered my baby’s heartbeat. The ER doctor said there was a 75% chance that I would miscarry. John was born on October 7, 2000, after an hour-and-a-half labor. He is now two, and he’s still a little ball of energy. It hasn’t been easy, but I would do it all again.

—Judy Blochowitz, Illinois
OK. Treatment is best facilitated when there is communication between the OB and neurologist,” said Dr. Green.

**Special Delivery: It’s baby time!**

Long or short, labor and delivery are usually the same for a woman with MS as for other women, with no special management needed. For everyone, childbirth classes help reduce stress by teaching valuable relaxation techniques.

The parents-to-be should make sure the MS doctor and the OB discuss pain management well before the due date. A hospital anesthesiologist is probably not up on the latest MS research literature, and could be gun-shy about an acceptable option.

“Even women who are numb are going to experience labor pain,” Dr. Green noted. “MS is not like spinal cord trauma.”

General anesthesia is known to be safe. This is the tube-in-the-throat anesthesia that renders a person completely unconscious. It may be required for a C-section, or requested as a matter of preference, but more often women opt for anesthesia that leaves them awake and aware.

An epidural involves injecting medication on top of the “dura”, which is a thick outer layer protecting the spinal cord. Dr. Stone reports that a large-scale study in France, published two or three years ago, showed that epidurals are safe in women with MS. Spinal anesthesia, on the other hand, is usually not recommended. “Anecdotally, there have been cases of MS relapses following spinal anesthesia,” Dr. Coyle noted.

Does prior treatment with steroids require a “steroid prep” for labor? Dr. Coyle strongly feels this is erroneous. “Only chronic or continuous steroid use might prompt the steroid prep—and that’s not how steroids are used in MS,” she observed.

On one point the MS specialists all agree: The overwhelming majority of women with MS who become pregnant are in early stages of the disease. Most are ambulatory. In between relapses, they are generally healthy. It’s extraordinarily rare that a pregnant woman has so many sensory deficits that she won’t know when labor begins or can’t cooperate with the contractions. If that should be the case, Dr. Coyle advises women to discuss the situation with their OB. “They may elect to induce labor or to have a C-section,” she said.

**Starting out: Breastfeeding and other issues**

The first six months after delivery may be difficult. Relapse rates rise; in fact, there is an estimated 20 to 40% risk of a relapse during this postpartum period. Knowing this, parents are wise to plan how they would handle the situation. Happily, a large body of evidence shows that the rise in relapse rate is temporary.

Many MS experts favor restarting
“… but it was worth it!”

During my fourth pregnancy, I was struck with a severe kidney infection, followed by insatiable itching and numbness on one side of my abdomen. The numbness and itching spread down my leg and eventually to my toes. Eight years prior I had had optic neuritis, and couldn’t emotionally bear the thought of an MS diagnosis.

By the seventh month of pregnancy, I was weak, experiencing severe pain, and numbness from the waist down. Now, I asked for a brain scan. I wasn’t willing to just sit there and do nothing. I had to know. My MS diagnosis finally came eight months into my pregnancy. I convinced the doctors to induce labor four weeks early. I delivered a healthy, eight-pound, one-ounce baby boy named Simon. A true miracle and blessing.

I would tell anyone wondering if it was worth it that I can look at Simon and know that I am still able to be what I want to be and do what I want to do as a mother.

—Rebecca Gardner, Utah
will be the best guide, but MS experts have some insight, too.

“T’d be wary of the fatigue medications,” Dr. Coyle said. She would also prefer not to use steroids during breastfeeding. “But a woman could stop breastfeeding temporarily and just use steroids for a couple of days.”

“Zoloft (sertraline) is known to be safe for nursing mothers, and the implication is that other antidepressants in this class can also be used,” Dr. Stone said. Dr. Stone also mentioned an encouraging preliminary study on the use of IV immunoglobulin in the postpartum period to help prevent relapses for women who are off their disease-modifying drug while breastfeeding.

MS experts decried the “pump and toss” solution that can be heard through the grapevine. Some women who take Avonex, the once-a-week interferon, simply skip breastfeeding the day and day after their injection. They pump and dispose of the milk on those days.

There is no evidence that this is safe. “Once you start taking the drug, it is in your system,” Dr. Green explained.

The family way

Stepping back from talk of drugs and symptoms, Dr. Green urges people who are contemplating parenthood to think beyond pregnancy or the immediate health of their baby to what happens 10 years down the road. “MS is a lifelong disease, and it influences what pace you can take,” she said. Couples who are willing to take a clear-eyed look at the long term are more likely to cope well with future challenges.

That said, MS presents no proven medical risk for a healthy, normal pregnancy. A little family planning can go a long and happy way.

Miraculous

My neurologist and obstetrician were very supportive of my pregnancy. Since my general health was good, they felt I was a fine mother-to-be. Childbirth, as I know it, was a miraculous and memorable part of my life!

—Ann B. McKee, Kentucky

Rachel Adelson wrote about bathrooms in the January–March 2003 issue of InsideMS.

More on pregnancy can be found in the Society’s MS Information Sourcebook, at www.nationalmssociety.org/Sourcebook-Pregnancy.asp. Readers without Internet access can get a copy by calling 1-800-FIGHT-MS.
The motherhood decision (the choice to forgo, start, or enlarge a family—whether by adoption or by pregnancy) is one of the most important that a woman ever makes. When the woman has MS, that decision becomes more complicated.

I have had multiple sclerosis since 1987. The motherhood decision was so difficult for me that I ended up spending several years in graduate school conducting research on the subject. The results of my study were published in a special, MS-focused issue of the Journal of Vocational Rehabilitation [“Themes arising in the motherhood decision for women with multiple sclerosis: an exploratory study,” 12 (1999), 93–102]. InsideMS asked me to summarize my findings here, and I hope that the discussion will be helpful to any reader who is currently struggling with these questions. I wish you all the best, whatever you decide.

We are more like other women than not

As I began researching the professional literature on MS, I found that nobody had identified the themes that actually accompany the life-changing choice of whether to have a child when the potential mother has MS. I interviewed a small group of women with MS. I identified 27 themes that the women in the sample had considered as they made their personal decisions. Twelve of them arose in the motherhood decision of every woman in the study. I found it very interesting that of these twelve, only four were specifically related to MS. The professional literature had neglected to mention that women with MS are more like other women than we are different from them.

For example, every woman thought about how having a child would affect her life’s work, be it inside or outside the home. Every woman with a partner considered that partner’s role in...
parenting a child. Everyone thought about the demands and responsibilities that motherhood imposes and about the people and organizations that could help. Almost everyone in this study expressed concerns about financial resources, justice, equity, stress, and burn-out.

**What MS added**

What did MS add? Each woman I interviewed had considered the possible effects of MS on the members of her family, and on the family dynamics. Each had reviewed her own physical and cognitive capacities and all had considered the negative changes caused by MS. All expressed concerns about their future abilities to perform tasks. Some, but not all, worried about the effect of future disability on their children’s emotional health. Because this was a small, qualitative study, it is difficult to draw any firm conclusions.

What issues do women with MS explore? What issues do they tend to avoid? A much larger study is needed to answer these questions.

One important concern that might arise in the motherhood decision of a woman with MS is the question of whether she risks passing the disease on to her child (see page 15). This did not happen in my study, possibly because the women in my sample were well educated about the disease and probably knew that the risk is low.

**Creating a climate of respect**

Examining the themes that arise—or fail to arise—in the course of making this choice would have implications for the doctor-patient relationship, family counseling, rehabilitation, and creating a climate of respect for the decision regardless of whether a person decides to become a parent or not.

For some people, life without children is a viable choice that should be respected—not condemned or pitied. For others, life without children is literally unlivable. Can support be found to make parenthood possible for each man or woman who desires it regardless of any potentially disabling condition that person may have?

*Mary Elizabeth McNary’s story of her own pregnancy and its outcome starts on page 1.*

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The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual therapeutic recommendations or prescription. For specific information and advice, consult your personal physician.
Pregnant women with MS may have done the larger MS community a big favor, simply by feeling pretty good. Noting how exacerbations are rare during the last two trimesters, MS researchers, notably UCLA’s Rhonda Voskuhl, MD, wondered what caused the protective effect of pregnancy.

Dr. Voskuhl’s team focused on estriol, a form of the hormone estrogen that rises to high levels during pregnancy. Estriol is known to alter the immune system. “There’s a natural shift,” Dr. Voskuhl explained, “so the mother’s immune system won’t reject the ‘foreign’ baby. This shift also means the immune system is not as likely to attack the mother’s central nervous system.”

In a pilot study funded by the National MS Society, Dr. Voskuhl gave six months of estriol—which can be taken orally—to 12 non-pregnant women, half with relapsing-remitting and half with secondary-progressive MS. The trial had a “crossover” design, so all 12 received the treatment. MRI images revealed a striking 80% drop in inflammatory lesions in the six women with relapsing-remitting MS while they were on the active treatment. “This is within the realm of the beta interferon and glatiramer acetate drugs,” said Dr. Voskuhl. Inflammatory protein levels also went down. The six women with secondary-progressive MS did not improve significantly.

Dr. Voskuhl plans a longer trial for 70 women, starting this summer. If the results confirm estriol’s benefit on MRI results and immune responses, then researchers will conduct still larger studies for three to five years. Only longer studies can establish whether estriol can also reduce relapse rates and whether or not it is safe for long-term use. If it proves both effective and safe, it would be an oral treatment for MS.

That delivery method is crucial. “The beauty of this is that it’s not given as a shot. It’s a pill a day,” Dr. Voskuhl said. A pill could be more readily accepted by more patients, more quickly—meaning more would begin treatment right after diagnosis. “Ultimately, earlier treatment would be expected to lead to less disability,” Dr. Voskuhl said.
Nothing compares to the joy (and relief) of welcoming a newborn family member. But the weeks after delivery are daunting—and hold some special pitfalls when MS is in the mix.

The breastfeeding decision: Whether yes or no, don’t let anyone guilt you

Women differ and so does their MS! Have a thorough discussion about nursing with your own MS doctor. Healthy, well-adjusted babies can be raised on bottles. Today’s formulas are easy and nutritionally superior to those of old. On the other hand, the advantages of breastfeeding to an infant are real. A breastfeeding consultant may pave the way to a good adjustment.

Inexperience: Get smart

The “mother instinct” is a myth. Parenting is learned. Make time for classes in infant care—and connect with friends who have young kids. (A good pediatrician is vital, but you need another parent for heart-to-hearts about the weird stuff.)

Fatigue: Absolutely plan to have help

“How can one little baby take up so much time?” You’ll believe it only after you’ve lived it. It takes weeks for a new mother to regain her normal strength. Meanwhile, even the most easy-going infant shreds sleep, disrupts meal-times, and produces laundry in Alp-like dimensions. Add the unique fatigue of MS and be assured you will need help. Whether help comes from family members, volunteers, paid houseworkers, baby-care professionals, or a combination of all four, create a schedule with a division of labor and realistic limits.

Depression: MS might increase the odds

The risk of depression is high in MS. Plus, depression goes hand-in-hand with post-pregnancy hormonal shifts. An estimated 70% of new mothers without MS have bouts of feeling blue, angry, and anxious within a few days of birth. One out of 10 moms who do not have MS develops serious postpartum depression. Persistent feelings of inadequacy, irritability, lack of interest in the baby, or over-concern about the baby are among the signs that your hormones have hit you up. If negative emotions fill your space, call your MS health-care provider. Untreated depression can be deadly. Treatment can restore balance and joy.

A PRE-PARTUM CHECKLIST

Plan now, and avoid some bumps.

by Rose Cohen
What about breastfeeding?

I was diagnosed in 1994 when I was 28 and had to make a decision about having kids. Long story short, they are now 3 1/2 and 1. I saw how “official” recommendations changed over the few short years between my two pregnancies.

My neurologist was really cool and told me there will never be hard evidence about pregnancy and medications because no one would subject herself to that kind of research. He paired me with another woman treated in the same clinic who was pregnant when I was. We had totally different views on breastfeeding. I decided not to. I went back on Betaseron about two days after delivering. My friend has kind of lied about it. She breastfeeds and doesn’t take her prescription. Maybe the Society can get some discussion going on this.

Name withheld, via e-mail

Dr. Rosalind Kalb of the Professional Resource Center replied:

Clear-cut answers that apply equally to everyone are not likely. We hope your friend will discuss her decision with her doctor. She should expect to be listened to respectfully and not criticized. She should also expect to listen to reasonable advice. If there is no give-and-take, she may need another doctor.

Will our baby have MS?

Dr. Stephen Hauser, who heads research on MS and genetics at the MS Center, University of California, San Francisco, answered:

Simple risk estimates are oversimplifications which can easily be misinterpreted. The reality is that risk estimates may be very different depending upon family structure. We now know that risks are much higher for families in which MS occurs in multiple relatives than for families in which there is only one affected individual. Risk is also moderated by ethnicity and by other factors we haven’t yet pinned down.

Only one study indicated that fathers transmit their family MS risk to children less often than mothers do. Although the National MS Society previously published that information, we should now consider this unconfirmed.

Please remember that individual situations will override these general rules:

- The risk of eventually developing MS for any baby in the general population: approximately 1:750
- The risk for a baby when one parent has MS: approximately 1:40

In other words, the MS risk is increased and yet 1 out 40 is generally considered to be a relatively low risk.
The National Multiple Sclerosis Society is dedicated to ending the devastating effects of multiple sclerosis.

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