

## PICTURING DISABILITY

BY DONNA FELLMAN

Twenty years ago, in August 1991, when my children were six, four, and 11 months old, I was diagnosed with MS. My youngest child, Kaija, was taking her first steps while I was losing the ability to walk. I used a cane, but soon needed crutches, and by the time Kaija was two, I was using a wheelchair most of the time.

Last year, in a college photography class, Kaija was given the assignment to do a photographic essay. She chose "Disability" as the subject and framed images that showed her development as a little girl with portrayals showing the progression of my disability. There is a photo of her little shoes with my cane, representing her learning to walk alongside my difficulty walking. Included is a sequence of shoes to illustrate her growing up, my mobility aids, our legs together, her self-portrait in a wheelchair, and other images depicting her memories and perceptions of disability.

We talked about what it was like for her and her brothers growing up. Looking at her little red shoes, I said to Kaija that I had never held her hand and walked with her.

Her reply: "I always had your lap."

*Donna Fellman lives in rural Maine.*



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## PREPARING FOR PREGNANCY



Julie Hammond, diagnosed with MS in 2002, with son Travis. Courtesy of Greater New England Chapter.

The good news about planning a pregnancy when you have MS is that there's no evidence that MS has any effect on fertility; pregnancy usually reduces exacerbations (although flares do tend to increase postpartum); and good outcomes are the norm.

Nevertheless, making the decision to get pregnant can be complicated, primarily because of the physical challenges of MS, says Barbara Green, MD, director of the West County MS Center, St. Louis. "I also suggest women think about and discuss with their partners the emotional and financial challenges of raising a child, which could affect work and managing the disease."

### Meds, pregnancy and MS

None of the disease-modifying drugs (DMDs) are approved for use during pregnancy, and most should not be taken for a few months beforehand. "The risk time is when you're attempting to conceive," noted Dr. Green. Plan a discussion with your neurologist about when to stop DMDs—and when, after delivery, to begin them again.

"Until recently, most studies were neutral about whether breastfeeding was protective in preventing relapses," says Dr. Green. "But a new study quotes a beneficial effect on relapse. People with non-aggressive disease may be able to wait to resume DMDs, which can't be taken while nursing."

Include any symptom-management medications in the discussion with your doctor. From bladder problems to fatigue, pregnancy can make MS symptoms worse, yet many meds are not safe for pregnant women. "We advise people on non-pharmaceutical approaches: getting enough sleep, adjusting work schedules and exercising," says Dr. Green.

"Symptoms during pregnancy are probably not MS—tiredness doesn't mean your symptoms are coming back," says Eileen Davis, APN, who has worked with people with MS for 12 years in New Jersey and New York. Keep exercising, she recommends, "so you aren't carrying unnecessary weight post-pregnancy, which can affect symptoms such as falling."

## Connect the team

Connect your obstetrician and neurologist to coordinate your care. Visit [www.nationalMSSociety.org/pregnancy](http://www.nationalMSSociety.org/pregnancy) for “Pregnancy, Delivery and the Post-Partum Period” to share with health-care professionals. If anesthesia is part of your birth plan, arrange a meeting with the anesthesia team. All forms of anesthesia are considered safe for women with MS.

Don't wait to plan for what happens after delivery. Tap family and friends about helping with housework, food and, of course, watching the baby!



**KNOWLEDGE IS  
POWER**

*Knowledge Is Power* is a six-week, free, at-home educational program for people who are newly diagnosed. Mail or email formats. To register, call 1-800-344-4867, or visit [www.nationalMSSociety.org/knowledge](http://www.nationalMSSociety.org/knowledge).



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## Resources on MS and pregnancy

Check out the Society's collection of videos, books, booklets and Web pages that you can download, or call us for free print copies.

### [www.nationalMSSociety.org/pregnancy](http://www.nationalMSSociety.org/pregnancy)

“MS and Starting a Family”—**Momentum**, Winter 2010-2011

[www.nationalMSSociety.org/Momentum](http://www.nationalMSSociety.org/Momentum) (click “Back Issues”).

Kara's Story – Part I

[www.youtube.com/watch?v=F1-heWHC7jl](http://www.youtube.com/watch?v=F1-heWHC7jl)

The National MS Society follows Kara from her first trimester...

Kara's Story – Part II

[www.youtube.com/watch?v=npgN99NeD1k&feature=channel](http://www.youtube.com/watch?v=npgN99NeD1k&feature=channel)

...all the way through to the birth of her baby boy.

The MS Daily Minute

[www.nationalMSSociety.org/dailyminute](http://www.nationalMSSociety.org/dailyminute)

Sixty-second videos packed with information on

- Beginning MS Therapy after Pregnancy
- Relapses During Pregnancy
- Breastfeeding with MS
- Support During and After the Pregnancy

## MEDICARE DEADLINES

Medicare recipients still have the opportunity to review, renew or replace drug plans during the annual open enrollment period, which began October 15 and runs until December 7 this year. The 2006 drug law imposes a penalty on those who need prescription drug coverage (and who do not have creditable coverage), but do not sign up in time. That penalty grows larger every year.

In 2012, the “donut hole,” or gap in prescription drug coverage, still exists, but the Affordable Care Act requires insurers to give Medicare Part D participants a 50% discount on most brand-name drugs, including the MS disease-modifiers, while they are in the coverage gap. Drugs prescribed “off label” for MS symptoms are still excluded from coverage and exempt from the discount.

Visit [www.medicare.gov](http://www.medicare.gov) for general information, publications and to compare the drug plans available in your area. Call an MS Navigator® at 1-800-344-4867 for free health-insurance counseling.

People with a Medicare private health plan, also known as a Medicare Advantage plan, (but not including a Medicare Medical Savings Account plan), can switch to Original Medicare during the Medicare Advantage Disenrollment Period from January 1, 2012, to February 14, 2012.

### The “Extra Help” program

People who receive SSI (Supplemental Security Income) benefits, or who get help from the state Medicaid program to pay Part B premiums (Medicare Savings Plan), automatically qualify for “Extra Help,” which

means no donut hole for prescription drugs as well as lower coinsurance and copayment costs. People with low incomes also qualify. Apply directly through the Social Security Administration at [www.socialsecurity.gov/i1020](http://www.socialsecurity.gov/i1020).

## FLU SHOT, OR NOT?



Flu season brings not just coughs and sniffles, but the question: Get a flu shot, or not?

Because there is a much higher risk of an MS relapse due to flu than to the flu vaccine, the Society generally recommends that people with MS get the shot. “Don’t wait for flu season to catch up with you. Discuss getting the flu shot with your doctor to protect yourself this year,” says Rosalind Kalb, PhD, vice president of the Society’s Professional Resource Center.

The injectable flu vaccine—which is an “inactivated” vaccine—has been studied extensively in people with MS and is considered quite safe. It may be taken by

people on an interferon medication, glatiramer acetate, or mitoxantrone. It is not yet clear if the vaccine is as effective for those taking natalizumab or fingolimod.

It's best to delay vaccination for four to six weeks after the onset of any serious exacerbations. People with MS should avoid FluMist, a live-virus flu vaccine (sometimes called LAIV for "live attenuated influenza vaccine") delivered via nasal spray. For more information, go to [www.nationalMSSociety.org/vaccinations](http://www.nationalMSSociety.org/vaccinations).

## TAX DEDUCTIONS BEYOND MEDICINE

Many of the expenses associated with managing MS might be tax deductible, beyond medicines. (Keep in mind that only unreimbursed medical expenses that exceed 7.5% of your adjusted gross income are deductible.) Here are additional possibilities:

- **Equipment and extras**, such as service dogs (and dog food!) and transportation to doctor appointments via car service or taxi if you can no longer drive.
- **Home modifications** that don't increase a home's value. "Get a doctor's prescription for ramps, wider doorways, grab bars, even a swimming pool, as well as a letter from a real estate agent stating that these changes don't make your home more valuable," suggests Anne Davis, program director of Legal Services for the Society's New York City and Southern New York Chapter.

For people receiving SSI or disability benefits, impairment-related work expenses may be



deducted from their earnings, if their income might otherwise jeopardize their government benefits.

Two IRS Publications—907, Tax Highlights for Persons with Disabilities ([www.irs.gov/pub/irs-pdf/p907.pdf](http://www.irs.gov/pub/irs-pdf/p907.pdf)) and 502, Medical and Dental Expenses ([www.irs.gov/pub/irs-pdf/p502.pdf](http://www.irs.gov/pub/irs-pdf/p502.pdf))—may be helpful.

Consult an accountant to make sure your particular situation is in line with current IRS regulations.

### Scholarship Opportunity

High school seniors who have been diagnosed with MS or who have a parent with MS are eligible for the Society's scholarship program. Awards range from \$1,000—\$3,000; a small number of four-year awards are offered. Applications for 2012 scholarships will be accepted (online only) between October 1, 2011, and January 13, 2012. For more info, visit [www.nationalMSSociety.org/scholarship](http://www.nationalMSSociety.org/scholarship) or call us at 1-800-344-4867.

## 52 MS GENES IDENTIFIED



In the largest MS genetics study ever, researchers have documented 29 new genetic variants associated with MS, and confirmed 23 others previously implicated in the disease.

Most of the genes were related to immune function, and more than a third have already been linked to autoimmune diseases. A large number were related to T-cell function; T cells, a type of white blood cell, play a major role in the immune system's attack against the nervous system in MS. Also, two genes linked to vitamin D were found: research increasingly suggests that low vitamin D levels are a risk factor for developing MS. (The Society is funding a new clinical trial of vitamin D supplementation.)

The study, a collaboration between the International MS Genetics Consortium and the Wellcome Trust Case Control Consortium 2, was published in the August 11, 2011, issue of **Nature**, and involved nearly 10,000 people with MS and more than 17,000 who do not have the disease. While the results of genetics studies haven't so far resulted in the ability to do individual genetic counseling, these and further findings should help uncover

what causes MS and improve treatments. The Society is funding a second large study to confirm and expand these results.

## NEW MS THERAPY MOVES FORWARD

The first phase III study of alemtuzumab (proposed brand name Lemtrada) for relapsing-remitting MS found that the drug met one of two primary endpoints. Researchers found that people treated with the drug had 55% fewer relapses over two years compared to those taking the interferon Rebif. However, results of the trial's other goal, to delay disability, were not statistically better than Rebif. The study, called CARE-MS I, involved 581 people with relapsing-remitting MS. Another trial, called CARE-MS II, is still underway.

Alemtuzumab is a monoclonal antibody that attacks the cells in the immune system that contribute to myelin damage. It is presently approved by the FDA to treat B-cell chronic lymphocytic leukemia. Sanofi and Genzyme, the drug's sponsor, plan to seek approval of this intravenous drug for MS in the U.S. in early 2012. In June 2010, the FDA designated alemtuzumab a "Fast Track Product," which should expedite its future review after results of the phase III trials are submitted.

## BONE HEALTH MAY BEGIN EARLY

People with MS have long been known to be at risk for bone loss, but a study published in the July 12, 2011, issue of **Neurology** suggests that it can occur very early, even before MS has been diagnosed.

## MS RESEARCH TAKES CENTER STAGE



In October, **About.com** blogger Dr. Julie Stachowiak and producer/director Kate Milliken—both of whom live with MS—reported live from the world’s largest MS conference at the Society’s blog.

At the fifth joint meeting ofECTRIMS andACTRIMS (the European and Americas Committees for Treatment and Research in MS), over 5,000 of the world’s leading scientists and clinicians gathered October 19-22 in Amsterdam. Results from four phase III studies on MS therapies were presented, along with the latest research on MS risk factors, treatments and diagnosis.

Join the conversation at **blog.nationalMSsociety.org**, and connect with people with MS, the people who care about them and MS experts.

According to the study, low bone mass is more widespread among people newly diagnosed with MS, or those with clinically isolated syndrome (or CIS, a single episode of MS-like symptoms), than among people without MS. Study researchers measured bone density in 99 people newly diagnosed with MS or CIS, compared to 159 people without MS. More than half of the people with MS or CIS had low bone mass, compared to 37% of controls.

Previously, scientists had speculated that people with MS are at greater risk of low bone density and broken bones due to factors such as lack of exercise stemming from mobility issues, medications or low levels of vitamin D (which plays a significant role in building bone). The researchers suggested that even early in MS, people should pay attention to good bone health by getting adequate vitamin D and calcium, as well as by performing weight-bearing activities. For more ideas on promoting bone health, go to **www.nationalMSsociety.org** and search for “You Can Build Healthier Bones.”



## SIX TIPS FOR YEAR-END GIVING



Give to a cause you believe in while making your tax bite smaller by donating to the Society before December 31. These suggestions can help your gift be a successful one.

### Talk to your accountant

Charitable gifts made now may reduce what you owe for 2011. Talk to an accountant or financial advisor who can help you determine the full impact of your gift.

### Don't wait

Get started now to make the best of 2011 tax legislation. For example, the extended charitable IRA legislation allows people aged 70½ or older to transfer lifetime gifts of up to \$100,000 tax free using funds from their IRAs. This opportunity is only available through December 31, 2011.

### Review your portfolio

If you have held appreciated stocks for more than a year, avoid the capital gains tax by giving the stock to the Society—and get a deduction for the full value of the stock. Stock gifts need to be transferred into the Society's account by close of business December 31 for them to count in the tax year. For details, visit [www.nationalMSsociety.org/giftsofstock](http://www.nationalMSsociety.org/giftsofstock).

### Consider an annuity

A charitable gift annuity provides you with current tax benefits and guaranteed payments for life, but it also allows you to provide for meaningful future gifts to support people living with MS. Call the Society's National Individual Giving Office at 1-800-923-7727 or email [giftplanning@nmss.org](mailto:giftplanning@nmss.org) for more information. We make it very easy to weigh the options.

### Stick with organizations you support—like the Society!

According to [www.charitynavigator.com](http://www.charitynavigator.com), dividing money among many nonprofits diminishes its impact as each charity will spend a percentage on fundraising and overhead expenses. An easy way to make a lasting impact is to name the Society as a full or partial beneficiary of your retirement plan or life insurance policy.

### Make a long-term commitment

Be a partner in the Society's efforts to end MS. Please consider a gift in your living will or living trust, which will help to support our mission well into the future. We can only succeed with your continuing support.

For more information on ways to give to the Society, call us at 1-800-344-4867.