Putting the Boogeyman to Bed:

Asking the Hard Questions

by Heather Boerner photos by Gary Landsman

Annie Scamman refuses to come to terms with her MS. She fears that to do so—and to do the planning that would follow—would be like inviting a boogeyman into her home. It doesn't matter that her symptoms have been increasing, or that her lack of planning has resulted in a few concussions from falling down the small flight of stairs in her Maine bungalow.

What's ahead? This article lays out a framework for asking some big questions.

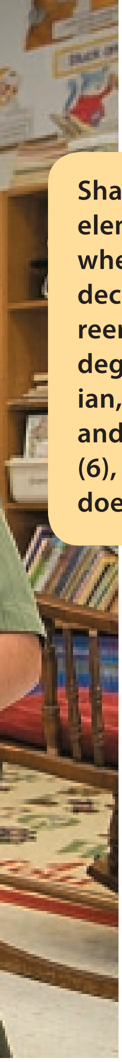
What matters to Scamman is her conviction that not planning is saving her stress and anxiety.

"Having MS is like living with a feeling of a ghost behind a door," said the 57-year-old, who was diagnosed at age 29. "I'm the anxious type and I didn't want to surround myself with lots of things that remind me that I could really get whomped by this thing. I really thought my best tactic was to resist."

But according to experts, Scamman's resistance isn't helping her. Leaving the big questions, "Can I keep my job?" "What if I go blind?" or "Who can help me?" unasked is prolonging her anxiety.

"Change is scary for everyone—whether they have MS or not," said Dr. Rosalind Kalb, a clinical psychologist and vice president of the Professional Resource Center at the National MS Society. But if you can deal with fear for a short time early on in your disease, you'll save yourself countless sleepless nights worrying about what could happen.

"None of us do our most creative problem-solving when we're in a crisis," Dr. Kalb said. "The earlier you



Shannon Kerr was an elementary school teacher when Jeff's MS arrived. She decided to enhance her career by getting advanced degrees. As a school librarian, she'll net higher pay and more time for Carson (6), Mallory (4) and "all she does for my life," Jeff said.

can allow yourself to think about the unpredictability of the future, the sooner you'll put into place the kind of safety nets we all need."

The first thing to do is to allow your MS diagnosis to sink in, she suggested. Then you'll have the mental space to think about the implications of your symptoms and be able to start planning accordingly.

The next step is to set aside time on a good day to gently probe those big questions.

"Think about your finances and how you might do things a little differently, just to build up a bit of security," Dr. Kalb said. "If you do a certain kind of work, and that work might be vulnerable to changes in MS, think about how you could tweak it."

Next, take some small actions: Make an appointment to talk to a financial advisor. Explore job training that might allow you to continue using some of the skills you already have. An MS Navigator® at your chapter can point you to resources in your state.

Shannon, Jeff, Carson and Mallory; Kaitie (18) from Jeff's previous marriage is away at college.

Even if you're very anxious like Annie Scamman, you can still ask the big questions, said Dr. Marla Chalnick, a North Carolina therapist in private practice who has had MS for 27 years.

The trick is to work first on changing your perspective on the disease. As long as MS is a boogeyman out to get you, opening yourself up to thinking about hard questions will only allow the catastrophic thoughts already running through your head to deluge you. If you can change those awful thoughts, then planning won't be so scary.

"Thoughts like, 'I'm going to lose my job,' 'My husband is going to leave me,' 'I can't play tennis anymore'—these are all negative messages, not positive or creative," Dr. Chalnick said. "They aren't messages that allow me to figure out how to get things done today. They're messages about what I can't get done today."

Dr. Chalnick recommends thinking of your MS as a dependent child. After all, she explained, MS isn't a boogeyman. It shares your body. You can't leave home without it, even though you'd like to. You do lose some spontaneity by taking your MS into account, but you'll gain greater clarity and calm.

"I have to care for my MS in the same way I care for my animals," she said. "Before I leave the house, I know I have to prepare for them. MS is the same. It's a dependent—it's a very independent dependent, but it's still something I'm responsible for."

Scamman has been working on her perspective and while she is no more fond of her MS now than she was before, she thinks she'd do things differently today. She'd try to plan a little better.

"If you've just been diagnosed and you're making big life decisions like buying a house, don't do what I did," she said. "I should have bought a house on one floor. I should have taken the MS into account." ■

Heather Boerner is a San Francisco–based health writer.

Did you find this article helpful?
✉ **editor@nmss.org**.

Get the Facts

Before you can deal with life changes, you have to know your options. And how you decipher those options largely depends on how you learn, said Dr. Rosalind Kalb, a clinical psychologist and vice president of the Professional Resource Center at the National MS Society.

How much information do you need?

Do you like to become an expert? Some people want an encyclopedic knowledge of challenges they might face. For others, that much information would leave them stuck in their tracks. Which are you?

What medium works best for you?

"Some people like books that they can mark up," Dr. Kalb said. "Others are more comfortable with a five-minute podcast. Others want to go to a public meeting. Still others want to post questions on an Internet bulletin board. What works for you?"

What information should you trust?

Not all facts are created equal. Find out if the information being provided is part of a moneymaking enterprise or if the facts are designed to get you to take a position on a controversy. It's not that such sources can't be useful, but you have to temper your expectations with the reality that they are pushing an agenda.

Non-biased Web sites like the National MS Society (**nationalMSsociety.org**) or the MS Coalition (**multiplesclerosiscoalition.org**) are good bets. Books from Demos Medical Publishing (**demosmedpub.com**) have a long record of reliability. MS World (**msworld.org**), which offers chat groups and bulletin boards, is a partner of the Society.

Are the facts out of date?

"Things are changing so fast these days that even a book two or three years old could be obsolete," Dr. Kalb said. Check the publication date. Check dates on Web sites, too. Find the most current MS information you can.—*HB*

What's Ahead

Planning to Plan

Imagine your future. Now imagine having the guesswork taken out of it. Feel that relief? That's what happens when you have a plan, according to research by Harvard psychologist Dr. Daniel Gilbert.

Worries about what will happen if you can't work, if your mobility changes, or if you lose your financial support or your primary caregiver can rob you of sleep and serenity. But a study published in the November 2003 issue of **Personality and Social Psychology Bulletin** found that people often overestimate the emotional impact of future events. Add to that improvements in MS care and medications, promising research and a growing support system for people with MS, and there's plenty of hope for the future.

Even so, the greatest salve for the anxiety of MS isn't research or medication—it's planning. So we've gathered together some experts to show you how you can keep living your best life today.

Work in progress: Planning for workplace changes

Emily Fodor isn't one to shrink from a challenge, especially at work. Now 26, the North Carolina resident has already supported herself for a decade. As a banker, she's used to long hours, hard work and giving her full attention to perplexing problems.

When her MS announced itself in 2006, she found a new use for all that on-the-job experience. Her long hours now apply to researching reasonable accommodations and new jobs. Her hard work goes to both her job and self-monitoring her symptoms. And her

for You?

by Heather Boerner

This article offers planning basics on the job, at the bank, in the community and at home.

focus on perplexing problems is tailor-made for dealing with the uncertain future that comes with MS.

Focus on now

“I think I may be one of the unlucky ones eventually and I’ll have to stop working,” Fodor said. After two stints on temporary disability, she chose to move away from Florida and the heat that magnifies her symptoms. “The name of the game for me now is to do as much as I can today,” she said.

“She’s right,” said Dr. Marla Chalnick, a North Carolina therapist who has lived with MS for 27 years. “You can’t stop your symptoms from progressing.” Instead, Dr. Chalnick changed the way she practices her profession. She obtained post-graduate training and now has a private practice so she can control her working hours and continue using her skills.

MS made the Kerrs serious about saving. They use payroll deductions to build their accounts. They also discovered they can ask their chapter financial insurance questions. “Really nice having that resource,” Jeff said.

“The idea is to think creatively to find work that uses your talents,” she said. “That might mean you only work 40 hours a week instead of 70. It might mean a job or career change. It may not be whether you need to go on disability or not. The creative part may be about how to use your talents in a way that enhances the preservation of your health.”

One of the most important things to do is ask yourself what you like best about your job and what skills you’ve acquired that you’d like to keep using—whether you keep working in the exact same profession or not.

Staying employed

Make your new goal staying in the workforce as long as possible, whatever that looks like, said Dr. Phillip Rumrill, director of the Center for Disability Studies at Kent State University in Ohio.

“The majority of people with MS are employed at the time of diagnosis,” Dr. Rumrill continued. “MS doesn’t affect people’s desire to work or their vocational interests—just their ability to do certain work.”

He suggests considering these points:

✓ Check out your options.

Once you’ve asked yourself what you like about your job and what skills you’d like to keep using no matter what, start brainstorming about changes you could make today—and research retraining so you have information about your alternatives.

✓ Log your symptoms.

The sooner you know a symptom is interfering with your job functions the better. The easiest way to keep track isn’t to keep a tally in your head. Log interfering symptoms in a notebook. Once you’ve made a note, you’re free to think about other things. And there's a side benefit: You may discover patterns. Perhaps you'll find you work best in the early morning, or at home or after a nap.

✓ Solve the problem, then ask for help.

Once you've figured out what works best for you, tell your boss. That's right: Tell. Don't ask, advised Dr. Rumrill.

"Your job is to bring your boss an offer he or she can't refuse," he explained. "So don't start with the problem—say, heat sensitivity. Instead, come up with an answer. It may be as simple as a $9 fan from the local variety store. Then the problem is a footnote instead of the central issue. The focus should always be on how these changes will allow you to continue to be a good, effective worker," he said.

✓ Know your rights.

The good news is that the law is on your side. The trick is to know what it says and to wield it properly. Start by researching reasonable accommodations under the Americans with Disabilities Act and the provisions of the Family Medical Leave Act and Health Insurance Portability and Accountability Act.

Then talk to an MS Navigator® at a Society chapter about your concerns. And contact JAN, the Job Accommodation Network of the U.S. Department of Labor, at 800-526-7234 or **jan.wvu.edu**. JAN tracks the accommodations people with disabilities have used to solve job problems.

✓ At work, keep your diagnosis private.

While everyone's different, Dr. Rumrill said it's best to keep mum on your MS—not because it's something to be ashamed of, but because it's a personal issue.

"I tell people to focus on function, on doing their job and knowing their rights—not their diagnosis," he concluded.

For Fodor, the bewildering onset of symptoms and subsequent life changes have ushered in a new sense of accomplishment. "I was nervous to ask for accommodations," she recalled. "I wasn't sure what to expect—if I would be faced with animosity from my manager because my problems make a difficulty for someone else. But now I'm so glad I did it. It wasn't hard at all. It ended up being very easy."

She's fallen behind where she was in her career when she was diagnosed, but she believes she's learned a lot about facing her fears. Dr. Rumrill isn't surprised at her new attitude. "No one looks back on life and says, 'I wish I'd spent more time at the office,'" he said.

Planning to put money where your future is: Insurance and savings

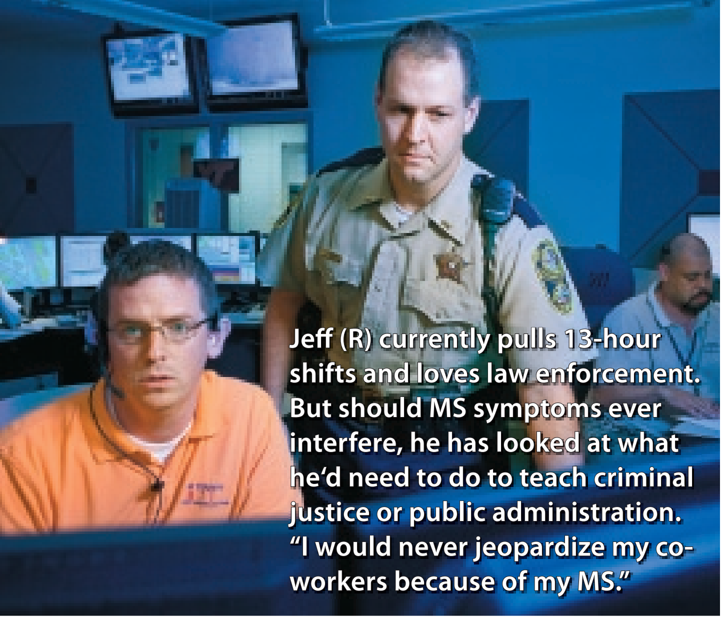
For Lisa Emrich, $325 a month is a small price to pay for ensuring her insurance.

That's how much she spends now on her individual health insurance. As a self-employed musician and music teacher, she was shopping for a policy that would pay for her MS needs. Insurance brokers advised her to hold onto her current insurance for dear life. So even though she could have been added to her boyfriend's insurance policy when the couple moved in together, she said she's unlikely to let her own insurance go. You know, just in case.

"It's sort of an insurance policy for an insurance policy," said Emrich, 40, who lives in Washington, DC. "If anything did happen—if he changed jobs—paying an extra $325 a month might be a good investment."

Since her diagnosis in 2005, Emrich has made several other good investments: She opened a Self-Employed Pension account and an Individual Retirement Account.

She's lucky. She's always been a good saver. But even if you don't have that advantage, you should still think about how you can protect yourself financially. Some people with MS work without much interruption in their earning power for decades. For others,



Jeff (R) currently pulls 13-hour shifts and loves law enforcement. But should MS symptoms ever interfere, he has looked at what he'd need to do to teach criminal justice or public administration. "I would never jeopardize my co-workers because of my MS."

sudden symptom progression leaves them without work—and without health insurance. For everyone, financial planning is one of the most important tools to protect against the unpredictable.

An emergency fund

"How do you spell financial disaster?" Michael Elder likes to ask. He's a Pennsylvania-based social worker who provides financial advice to people with MS through the Foundation for Financial Service Professionals. (The foundation has a special partnership with the Society connecting people with MS to skilled financial counselors in every chapter—free!) "For some it's the loss of a spouse through divorce or death or it's major home repairs," Elder continued. "For others it's as simple as a battery in their car stopped working and they just can't buy a new battery."

No matter where you are on that spectrum, there are a few small changes you can make now to create a more secure financial future.

This is no time to rely on credit cards for financial security, said Elder. Instead, your job is to cut up your credit cards, perhaps keeping one in a drawer just in case. Then start your own emergency fund. Use Social Security as your guide for how much to save.

Serious money

It takes at least five months for Social Security to gather your facts and approve you for Social Security Disability Income or SSDI—and that's in the best-case scenario, Elder said. It can take far longer.

If you do lose your job and your health insurance goes with it, you will also need money to pay for COBRA health coverage. Medicare doesn't kick in for 24 months. That's right. Two years. The National MS Society is trying to change that but a personal emergency fund should cover what's real right now.

While COBRA health coverage is pricey, it's actually a great way to protect yourself during any life transition. COBRA coverage ensures that you will be able to continue to get the same level of coverage for 29 months—often enough time to figure out what to do next, said Kim Calder, manager of the National MS Society's Health Insurance Initiative.

Once an emergency fund is paid up, you'll be in a saving mode. Start contributing to a 401(k) or a retirement account, Elder advised.

Beyond emergency: staying covered

Get your insurance facts, both experts agree. It's always hard to tell if health insurance will cover a new test or treatment. The best way to find out is to ask—in writing, Calder said. "For general information, calling is fine," she explained, "but when you need very detailed and exact information on what your benefits are, I would only trust an answer in writing. This is not because the company wants to lie to you, but because they have so much wiggle room in terms of how much is covered or under what circumstances."

If it turns out your insurance doesn't cover everything you need, consider buying supplemental or new insurance. Visit **healthinsuranceinfo.net**, a site run by Georgetown University. It lists every health insurance program by state. Call your state's department of insurance or phone the National MS Society for more help.

Get disability insurance while you are employed. Though it's hard to get after you've been diagnosed, it may be offered through your own or your spouse's employer, Calder said. Often, there's a limited open enrollment window during which you can apply for it without having to disclose your health history.

The bottom line is the bottom line

Set yourself up well financially and you'll experience less anxiety. Mindy Alpert from New York knows this personally. When she worked full time in the financial industry, she purchased disability insurance as part of her benefits package. Today, she's grateful. She keeps active by volunteering and her disability insurance benefits are essential to her financial well-being.

"I had to stop working at 38," said the 46-year-old. "Now I have to make sure I'm saving and investing appropriately so financial issues don't become a problem for me in the future."

Planning to give your life life support

In the 27 years since she was diagnosed with MS, Louise Greenleaf has gone from limping to using a wheelchair. Fatigue eventually led her to stop driving and she's mostly at home these days. Her love of piano hasn't disappeared, but her ability to play has. Instead, she sings in her church choir.

Despite this, Greenleaf believes she is blessed. She says her MS symptoms are no match for all the love and support she has in her life.

"I have a really wonderful life," said the Florida resident. "I knew someday I'd need to rely on good friends to support me and they really do—not because I have MS but because they are my friends."

Friends help with groceries, drive her around town and chat with her on the phone. She volunteers at her church. Her husband is a constant source of love and affection. The clerks at her local grocery store hug her when she arrives, and tell her they've missed her.

A safety network

This may be obvious, but Greenleaf isn't alone. Her support network has seen her through many difficult changes. Studies show that people who surround themselves with good relationships can weather even big life changes like divorce, career change, or the death of a loved one.

"When big changes occur, a support network will be key in helping you navigate your options," said David Rintell, EdD, a clinical psychologist at the MS Clinical Center at Brigham and Women's Hospital in Boston. "You don't have to do it alone.

"A support network is just a fancy way to say relationships," he said. "In essence, we do better when we have people in our lives with whom we can discuss what's happening. It tempers our stress."

How's your safety net?

"There are three types of support we need to feel in order to make the best decisions and live our best lives," said Dr. Alexa Stuifbergen, a PhD nurse and researcher at the University of Texas at Austin School of Nursing who has studied wellness in people with MS for more than 20 years. "The types are emotional, practical and informational."

Chances are you already have the informational level covered. (See sidebar, "Get the Facts," p. 24). But you may be lacking in people who are able to lend an ear when you want to talk out a concern or just chat. You may also lack some practical support for getting around town, and getting your work done when your symptoms flare.

Not everyone has to be capable of all three types, Dr. Stuifbergen pointed out, but if you don't have someone who can support you in each of them, it's time to look for that now, when you don't need it. Practice asking your friends for the support you need, and see who's best at what and who seems to enjoy helping the most.

Finding new network members

If you can't find the supporters you need among your friends and family, call in your reserves. "We all have relatives and friends we're out of touch with," Dr. Rintell said. "That's a bank account of support."

"I'd rather not have MS but it brought some positive changes. It really expanded our social life, especially cycling. The Bike MS Team we started now has 58 members. We've met people who were immediately supportive, and we go out a lot more than we used to."—Jeff Kerr

If your reserves are tapped out, start looking elsewhere. Spiritual communities may fill that niche, he suggested, even if you aren't particularly religious. So can people you meet taking a class or volunteering. (Your chapter of the National MS Society probably needs volunteers.) Moreover, any good support network should include other people with MS.

"But having MS is not the be-all and end-all qualification," said Dr. Rosalind Kalb, a clinical psychologist and vice president of the Society's Professional Resource Center. "The biggest qualification is being nonjudgmental and friendly. If the other person constantly bombards you with advice, tells you what treatments to take or doesn't listen well, find someone else!

"You need a medical team you feel confident in. You need family and friends because they're the ones who know you best and are with you on a day-to-day basis. And you need people from the MS community. Plan on having them all," Dr. Kalb summed up, "and you're likely to feel far less burdened by your disease."

Planning to house your future

"This house makes me feel good about the future," said Wes Reissing, 42, a Georgia resident who was diagnosed with MS in 2001. "I want to live here forever."

There's a good chance he'll be able to. Reissing and his wife Juanita built the house in 2005. It's one story with wide doors, big bathrooms and an open floor plan designed to accommodate a wheelchair should his symptoms ever require that.

And now they do. Just a few years after breaking ground, Reissing can walk through his house, but for labor-intensive tasks like housework, he prefers his wheelchair. Since his house is designed with mobility in mind, it's no strain.

The surprise is the house is no strain on the eyes either. Built in mid-century modern design, it draws compliments from their neighbors in more traditional houses. They say it looks more spacious than their homes, even though it's one of the smaller houses in the development at 1,800 square feet.

Reissing has discovered what experts and some developers already know. Accessible housing is not only convenient, it can also be very attractive. No longer does accommodating mobility changes mean slapping on some medical-looking ramps and grab bars. It means creating floor plans that are appealing to buyers and convenient for users.

Susan Lasoff, OTR/L, a Minneapolis-based occupational therapist, accessibility specialist and co-author of **The Accessible Home**, put it this way: "A lot of people think that if they put modifications in their home, it won't be good for resale values. That's not true anymore. If a home is as comfortable, functional and safe as possible, the resale value is going to be OK."

As it happens, some of the more important renovations for people with mobility limitations are also some of the most sought-after design features today. They include curbless showers, hardwood floors and open floor plans.

Many small changes, such as choosing a single-lever faucet or levers instead of doorknobs, don't cost an arm or a leg either. Offset door hinges allow a door to swing completely out of the way, adding an inch and a half for maneuver space, Lasoff said. The cost of tearing out carpet and installing hardwoods or linoleum can range from modest to expensive, depending on the materials.

The important thing is to make sure the home changes you make are the ones that are most important for your needs, said Wendy Jordan, author of **Universal Design for the Home: Great Looking, Great Living Design for All Ages, Abilities and Circumstances**. Walk through your house looking for things that can and do trip you up, like bulky rugs. Make a list of these problem areas, Jordan said.

"If you think your shower needs to change, don't just guess at your needs. Get in there and do a dry run. Pretend you're showering," she advised. "Stand or sit where you would in the shower stall and note where the bench, faucets, grab bars and showerhead should be and where to place the lighting to provide good, unobstructed illumination."

When you're ready for a big renovation—installing a curbless shower or widening doorways or hallways—choose a contractor with experience in accessible design, advised Lasoff. Consult your National MS Society chapter or the nearest Center for Independent Living. Look for "Aging In Place" certification from the National Association of Home Builders and AARP, or "EasyLiving Home" certification from EasyLiving Homes.

Some places aren't worth renovating, Lasoff noted. If you plan to move, your job is to look at how your potential new home could serve your need to save energy (sitting to work is a key tactic), as well as accommodate a range of aids from crutches to a wheelchair. Always remember, this might not be for you but for a friend or family member who wants to visit.

Look for these features:
Accessible front door. Can the front entrance be made accessible with a wider door and a ramp?

Single-floor living. If you're looking at a multistory home, is there a bathroom, kitchen and bedroom on the first floor?

Open floor plan. It isn't just a fad. Open floor plans, with fewer hallways, make it easier to get around.

Easy-to-reach appliances. Are appliances like refrigerators tucked in corners that would be hard to reach if you were sitting in a wheelchair? A front-loading washer is easy to use while sitting. A stacked washer-dryer can be impossible.

Most of all, don't feel bad about having to think about these things. "The truth is, if we live long enough, everyone will need mobility accommodations," said Jordan. "We all need to be thinking about making life easier, not harder," she said. ■

Planning Resources

Take charge of your future—with help.

PERSONAL FINANCE

The **Society** offers a free 72-page brochure: **Adapting: Financial Planning for a Life with MS** at **nationalMSsociety.org/financialplanning**. Free one-on-one financial counseling is available through the Society's **Financial Education Partners** program. Call 1-800-344-4867.

The **National Foundation for Credit Counseling** works with you to get credit card companies to reduce your debt. Call 800-388-2227 or go to **nfcc.org**.

EMPLOYMENT

The **Society** offers a range of brochures, webcasts, and programs for people making decisions about work at **nationalMSsociety.org/employment**. For full explanations of your legal protections on the job, click on **Knowing Your Rights**.

The **Job Accommodation Network** is a free consulting service that offers workplace solutions

What Will Genes Tell Us?

by Gary Sullivan

Can genes predict individual futures? Will they reveal who will do well and who won't? There are already some partial answers.

In a study of more than 200 people taking interferon-beta, world-renowned genetics experts Jorge Oksenberg, PhD, Esther Byun, MD, and their colleagues at the University of California-San Francisco, working with European collaborators, found an important pattern. Specific gene variations influenced the response to interferon-beta therapy as assessed by the number of relapses the participants had over two years. The results of their study were published in the March 2008 issue of **Archives of Neurology**.

Dr. Oksenberg, who is a member of the strategy group of the Society-funded International Multiple Sclerosis Genetics Consortium (IMSGC), is convinced that genetics will lead to more personalized treatments.

"We are in the infancy of 'pharmicogenomics'—

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for people with disabilities. Go to **jan.wvu.edu** or call 800-526-7234.

The global job search service **Monster.com** has teamed up with the National MS Society to create MS Workplace, the first MS-dedicated job-posting Web site at **MSWorkplace.com**.

INSURANCE

The **Society** has free downloadable brochures, webcasts and podcasts that explain in depth HIPAA, COBRA, Medicare and private health insurance. Go to **nationalMSsociety.org/healthinsurance**.

The **National Endowment for Financial Education** in collaboration with **Georgetown University's Health Policy Institute** offers three free guides on how to navigate the health insurance system: **Understanding Health Insurance**; **Medicare and Medicaid**; and **Options for Avoiding and Managing Medical Debt**. Visit **healthinsuranceinfo.net/nefe**.

Got a complaint about health insurance? Your state insurance department can help. Go to **naic.org/cis/fileComplaintMap.do** and click on your state.

HOUSING

The Society publishes **At Home with MS: Adapting your Environment**. Call 1-800-344-4867 or go to **nationalMSsociety.org/athome**.

The Paralyzed Veterans of America (PVA) offers free articles on how to make your house accessible. Visit **pva.org** and click on **Accessible Design**.

The **U.S. Department of Housing and Urban Environment (HUD)** offers information on how to get a home and loans for accessible improvements. Call 202-708-1112 or go to **www.hud.gov** and type "people with disabilities" in the search bar.

Do you know of other important planning resources? ✉ us at **editor@nmss.org**. If they check out, we'll add them to our resource lists for others.

the study of genetic variation that gives rise to differing responses to drugs," Dr. Oksenberg told **Momentum**.

He explained that the current MS drugs, including the beta interferons, have very complex modes of action. "There are probably many genes involved in the response to these drugs, each contributing modestly to the overall response," he said. "It's more complicated than we had thought. Still our great hope is that gene research will inform a new generation of drugs that are far more targeted."

The role of clinical trials

The best way to discover which genes might be responsible for positive (or negative) drug responses is to study the genetic profiles of people in clinical trials testing these drugs, and to correlate genetic profiles with objective measures of response—for instance, the appearance of new brain lesions. But the companies that make drugs, and who set up the clinical trials, sometimes resist the expense of adding on a genetics arm to a trial.

Giving DNA is easy—and important

If you or a member of your family has been diagnosed with MS, the UCSF MS Genetics Group invites you to participate in their genetics study. Large numbers of participants are needed to accelerate their work.

Participants will be asked to:
- Fill out a family information form
- Sign a form to release medical records (people with MS only)
- Read and sign a consent and authorization form
- Donate a blood sample (about five tablespoons)

For more information visit **neurology.ucsf.edu/msdb**. To participate call **866-MS-GENES** (866-674-7637).

The institutional review board

An institutional review board, or IRB, is an oversight committee that is formally designated to approve, monitor and review research involving humans in order to protect their rights and welfare. The U.S. Food and Drug Administration (FDA) and Department of Health and Human Services (HHS) empower IRBs to approve or disapprove research—or to require modifications.

"We are trying to identify people who are prone to responding well or poorly, as well as people who may be prone to developing dangerous side effects," Dr. Oksenberg continued. "This can be seen as infringing on the potential market. But, on the other hand, the promise is so great—if genes can identify people who will respond well, that data should facilitate marketing."

Getting pharma, academia, patient groups and oversight committees on board

In fact, Dr. Oksenberg believes the time will come when informed consent for clinical trials will routinely include a request for a genetic profile. "We'll need pharma interest—and I think that will happen. And we'll also need trial participants to be willing," he said.

The first step is to convince institutional review boards that genetic profiles are an important part of trials. (See "The institutional review board," above.)

"All the stars need to be aligned," Dr. Oksenberg added. "We need to partner with industry, patient groups and academia—and we're just beginning that process. When clinical trials involving both standard and experimental drugs have a genetics component to them, our work in understanding the relationships among gene variation, gene function and drug response will speed up." ■

Gary Sullivan is managing editor of **Momentum**.

What's in Store for Me?

Medical Prognosis Now and to Come

by Gary Sullivan

"Whether someone comes to me for a second opinion or it's their first visit, everyone wants to know: 'What's in store for me?'" said Minnesota-based neurologist Gary Birnbaum, MD.

Dr. Birnbaum, who directs the MS Treatment and Research Center at the Minneapolis Clinic of Neurology, sees four to 10 new MS patients every week and confirms that there are no hard-and-fast rules. But there are signs that he considers.

"When someone experiences an attack that involves multiple areas—vision, numbness, weakness, tremors, and bowel or bladder issues, for instance—there is a relatively greater chance that person will go on to have a more aggressive pattern to their illness," Dr. Birnbaum explained. "If the MRI shows evidence of a more destructive disease process—for example the presence of many lesions that are "black holes," or there is a more general loss of brain tissue (atrophy)—these also may indicate an increased risk for more significant progression."

Doctors can't yet predict the course of an individual's MS. But there are some important signs now—and new technology is poised to do more.

Dr. Birnbaum also pays attention to how quickly or fully a person recovers from an initial attack.

"If a person's first attack was fairly mild with only a single system involved, and if the person returned to normal fairly quickly and their MRI scan showed few if any changes, I would want to follow that person with additional exams and MRIs. Since there is no cure for MS, and a person can stay in remission for years, there may not be a benefit to such an individual by starting treatment. However, if there is evidence of new disease activity in follow-up evaluations, either by history, exam, or MRI, I would not wait."

Six more months may tell

Though a person's prognosis will not be crystal clear after a first attack, a period of time can help sharpen the picture. For Dr. Birnbaum, an increase in MRI activity in the next six months is a good indication that the disease may be more aggressive.

"Right now, we're able to successfully modify the disease, if not stop it, in most people. Early intervention in active MS is important for successfully slowing it down. Defining 'active' exactly is a matter of some discussion," he explained.

The prognosis for prognosis

Dr. Birnbaum is confident that newer MRI techniques, such as "magnetic resonance spectroscopy" and "magnetization transfer," will soon sharpen predictions. In addition, as gene research progresses, "biologic markers" may well be identified. "They will allow us to better predict who will do well and what therapies are best for which individual." he said.

That day may not be too far away. ■

The National MS Society's National Clinical Advisory Board Consensus Statement recommends the use of a disease-modifying therapy as soon as possible after diagnosis of MS, and in select cases after a single attack in people at high risk to develop the disease, as many neurologists agree that these drugs are most effective when started early, before MS has had the opportunity to cause significant damage.