Assisting people living with foot drop associated with Multiple Sclerosis. To find out if the L300 is right for you, please contact us at 800.211.9136.

www.bioness.com

THE NESS L300™ FOOT DROP SYSTEM

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Welcome

A very successful pop-psychology book out a few years ago was called All I Really Need To Know I Learned In Kindergarten. My version of that book would be, All I Really Need To Know About The National Multiple Sclerosis Society I Learned On My First Bike Ms. Ride.

Joyce Nelson
President and CEO
The National Multiple Sclerosis Society

The year was 1985. Sometimes around Memorial Day I was pro-
moted to executive director of the Mid America Chapter, based in the Kansas City area. I learned to love, in just a little time, to begin plans for the chapter’s second ever bike ride. To say there was one of the Society’s largest athletic fundraising endeavors, that year, was an understatement. Arriving early in September, which to a novice seemed like a lifetime away, I set out to figure out the route, get a radio sponsor, print and distribute brochures, and plan the other complicated logistics that make one of the Society’s most successful events.

We had a small committee of focused dedicated hard-core cyclists and one board member. I had never ridden a bike more than five miles then. Let’s just say that it was a difficult weekend. Early September in Missouri can be very hot and humid, and it was especially so that year. This was before the days of air conditioning as we thrust through the miles I wouldn’t really notice that the route was closer to 170 than 110 miles. We were wrong about that. My committee had assumed that the 90-degree heat would make it possible for a four-hour ride from and to dinner at the end of the first day. We were wrong about that. And the 90-degree heat resulted in my assisting a parade of cyclists who were complaining about heat exhaustion and dehydration.

The next day things continued downhill. The cyclists were up and ready to roll well before we had had our breakfast. The bunches for the day had been inadvertently left at the overnight stop. Therefore, the first cyclist to arrive at the dinner buffet consumed 300 people’s food in about an hour. And just to top things off, a 12-foot high rental truck discovered that it couldn’t pass under an 11-foot-6-inch high viaduct.

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pleted, a community of people eager to move as close to a world free of multiple sclerosis as we can give them the chance.

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“T’ve been head of the Kansas City bike club for three years. For all of our sake, I will help you the next year.”

“Motorcycle, MS, and I may try to stay a Gold Wing motorcycle. Have you thought about recruiting motorcycle to serve as Ms. scarf? Here’s his name and his contact information.

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I can’t remember a time when multiple sclerosis was not a part of my life. My mother, Amy Zilkes has lived with the challenges of MS for 25 years. She struggles with her mobility, dexterity, energy, and to keep up her spirits every day. Through the years, if I learned of a product, therapy or strategy that might help MS, I read, or tried to use it. It is because of my mother’s struggle to maintain her independence and her dedication to try every strategy that I have developed and championed in the Society.

Amy and all registered marks are the property of their respective owners.

What Is MS? Why Do We Need to Know Every Hour?

Stumbling, sudden blindness, unexpected fatigue, numbness, pain...Every hour, every day, symptoms such as these lead doctors across the country to make a diagnosis of multiple sclerosis.

Multiple sclerosis (MS) is a disease of the central nervous system, under the cause is unknown, it’s believed to be an autoimmune disease, which means that in MS the immune sys-

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To make a tax deductible donation to multiple sclerosis research, please visit www.msrcny.org or call 646-557-3864.

The National Multiple Sclerosis Society
President and CEO

Jon Silverman
Best Regards,

Dr. Bernard Silverman
President

The International Multiple Sclerosis Management Practice

The International Multiple Sclerosis Management Practice offers unparalleled care, treatment, and expertise.

The mission of the Multiple Sclerosis Research Center of New York is to apply innovative and unprecedented research to find the cause and cure for MS.

The National Multiple Sclerosis Society

President and CEO, I continue this tradition by building collaborations and united researchers and institutions worldwide so that year. This was before the days of the Society’s most successful events.

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Good news is plentiful in the world of MS treatment, and each year brings more hope and promise. Although there is still no cure, effective therapies are available to modify the disease course, treat exacerbations (also called attacks, relapses or flare-ups) and manage disease symptoms—all of which serve to enhance the quality of life for people living with MS.

Though not a cure, clinical trials and evidence over the last decade and a half provide convincing evidence that the six FDA-approved disease-modifying medications reduce disease activity and disease progression for a significant percentage of people with MS. The therapies appear to be especially beneficial if started early in the course of the disease. MS studies have confirmed that most people have many “silent” attacks early on, and that lesions and brain atrophy can develop even before people experience any symptoms or attacks. These drugs, which are all administered by injection or infusion, have been approved by the FDA for use in reducing the activity of the disease.

Avonex (interferon beta-1a)
Betaseron (interferon beta-1b) (now also available as Extavia)
Copaxone (glatiramer acetate)
Novantrone (mitoxantrone)
Tysaba (interferon beta-1a)
Tylenol (ibuprofen/acetaminophen)

People, however, need to work closely with their physicians to monitor any potential side effects or adverse reactions to these drugs.

Not everyone responds the same to these medications, so having options to choose among is important. One option expected in the near future is a subcutaneous disease-modifying medication, which may be off the shelves alongside or as a replacement for the current medications that are administered by injection or infusion. While a small percentage of patients do well with no therapy, no one can predict for whom this will be true.

Research in Progress
And Intriguing Leads on the Horizon

In a fascinating and hopeful time in MS research, with scientists looking far and wide to slow the disease’s progression, every bit and piece of recent research is providing new insights into how we manage MS from a cellular level.

Treatments such as Rebif, Copaxone and Avonex are proving invaluable in monitoring disease activity, making it possible to visualize and follow the development of MS lesions in the brain and spinal cord. This helps tremendously in assessing new medications and can speed the process of evaluating new treatments.

Now and in the coming decades, researchers will be working on improving control of inflammation and the immune response, repairing myelin and developing “neuroprotection” — agents that can protect myelin from damage.

The National MS Society has responded to scientists’ expanding knowledge of MS by creating ever-wider networks of cooperation. The most dynamic example is the Multiple Sclerosis Repair & Protection Initiative, a five-year grant funded by the Society’s Promise: 2010 campaign. The project is so big that it has no one but four principal investigators and encompassing institutions, researchers and collaborators based at universities in 11 time zones in North America and Europe.

The Society also supports hundreds of other projects. Here are just a few recent findings and possibilities:

• The first of the new therapies, this one designed to improve nerve conduction, is presently before the FDA for review. Two more oral therapies, both disease-modifying drugs, are expected to go to the FDA soon.

• Investigators successfully used human nervous system progenitor cells to repair brain and spinal cord nerve tissue in mice.

• Thirteen new genes that predispose humans to MS were identified in large-scale genetic screening, and a new genetics project was launched to catalog and understand the genes that affect MS susceptibility. Finding these genes should help scientists understand what causes MS and may lead to new therapies.

• The Society supported investigations on the potential roles played by sunlight, vitamin D and Epstein-Barr virus in triggering MS.

• Sex hormones, which can regulate the immune system in people with MS, are another area of study, with a large trial under way to test whether the hormone estrogen can decrease disease activity.

• Neuropsychologists at the University of Alabama at Birmingham are studying whether a type of physical therapy that has benefited people with strokes, traumatic brain injury and cerebral palsy could help those with MS too.

MS research is ongoing on literally dozens of fronts. The Society’s Promise: 2010 campaign, which includes four major components, has united the MS community behind some very big but achievable goals. The Nervous System Repair & Protection Initiative reached a milestone two years ahead of schedule by launching a small clinical trial of new medications. Six Pediatric Centers of Excellence are providing services and care to people with MS under 18 and their families. The Sonya Slifka Longitudinal MS Study is re-creating myths with facts about the social and financial consequences of MS. And the international team involved in the MS Lemon Project is exploring a collection of tissue samples from people at all stages of MS, making it possible to see the disease as never before.

A growing number of therapies are now available that effectively alter the underlying course of MS or treat MS symptoms. In addition, there are a number of treatments under investigation, some of them too recent than injected or infused, that may curtail attacks or improve function of demyelinated nerve fibers. Over a dozen clinical studies testing potential therapies are in late stage trials moving through the MS pipeline, and additional new treatments, including therapies aimed at repairing MS damage, are being devised and tested in animal models.

At present there is no cure for multiple sclerosis, but to the countless scientists, physicians and researchers who are bringing us closer to understanding MS, it is not “incurable.”

One mission: MS remission

Our mission to stop a disease like multiple sclerosis requires not just a single-minded focus—but one that’s as relentless as the disease itself. That’s why at Biogen Idec and Elan, we view fighting MS as not only our job at work, but as our mission in life.
Moving Forward After An MS Diagnosis

One woman possesses an MS diagnosis, managing the disease becomes an ongoing process, beginning with the very first symptoms and continuing throughout the disease course. Knowing what to look for, where to find it, and how to work effectively with doctors and other health professionals is essential to maintaining a healthy, happy quality of life.

The National Multiple Sclerosis Society offers comprehensive information and programs, typically provided through its 50-state network of chapters, that are designed to help everyone with MS, from the newly diagnosed, full of questions on every aspect of their new reality, to the more seasoned person with MS who might be checking out a new therapy or new tools to manage a troubling symptom. Wherever someone fits on the life with MS spectrum, there are specially targeted Society programs.

The following are just some of the resources available:

- Online classes on medical decision-making, financial planning, employment strategies and intimacy.
- MS Navigator™ who helps people find pharmaceutical company patient assistance programs or other financial assistance programs, including the Society’s own program, that help manage the costs of MS drugs and other daily living expenses.
- Guides and manuals to improve the success of private disability insurance claims, they’re customized for people with MS, health care professionals and disability insurance professionals.
- Abundant information from chapters and the Society’s Web site about preventive health care and the role of exercise, diet, stress management and other complementary and alternative strategies in optimizing general health.
- The Society’s network of chapters, chapters offer a broad scope of services and programs to people with MS, their families, and their health care providers, ranging from the most current and comprehensive information on MS, to networking with community resources, to self-help and peer support programs, to educational teleconferences, exercise and wellness programs, to social activities for the whole family. They also include employment counseling, insuring services, durable equipment loans and advocacy. To learn more about local programs or to call 1-800-344-4867 or visit the Society’s Web site at www.nationalmssociety.org.

Technologies

Assistive Devices and Adaptive Technology

An assistive device is a tool or implement that makes a particular function easier or possible to perform. It may be as simple as an electric toothbrush, or as elaborate as an environmental control system that can be operated with a mouth switch. Bowsers, canes or walkers, and those who have trouble walking. Wheelchairs and electric scooters can provide mobility for those who need additional assistance. Transfer boards and lifts can be used to help people with MS, those who are too tired or out of a bed, tub, automobile or wheelchair.

About half of people living with MS develop cognitive challenges, affecting areas of processing speed, working memory and complex attention. These challenges can involve difficulty in learning and remembering information, focusing, maintaining and shifting attention, and organizing plans and solving problems. To address this, the MS Technology Collaboration, an alliance of Remee Healthcare Pharmaceuticals, Microsoft and the National Multiple Sclerosis Society, recently launched a way for people living with MS to exercise that brain power with MyBiologyGames, the first online games designed specifically for people with MS. MyBiologyGames is available free at MyMSBI

Getting Involved

There are many ways to both personally and professionally benefit from being involved in a world free of multiple sclerosis. These include:

- Serving on a team and participating in Walk MS, Bike MS or the Challenge Walk which connects people throughout the country and funds the research programs. Every year hundreds of companies bring teams to Society events because employees say that a company’s charitable activities are important to them and the company finds team-building an important skill among business leaders. To learn more about team building through participation in Society special events, visit BikeMS.org and WalkMS.org.
- Volunteering special talents or skills to help the Society advance its goal to end MS.
- Donating funds, furnishing instruments or services to support Society-led research and treatment initiatives.
- Sponsoring Society programs, services and events.
- Becoming an MS advocate to help shape the public policies and programs that affect people living with multiple sclerosis.

www.NationalMSSociety.org

EMD Serono, Inc. is proud to work with Fast Forward, LLC to close the gap between laboratory discoveries and life changing therapies.

Fast Forward Speeding Treatments To People With MS

For more information about Fast Forward and funded research projects visit: Fastforward.org
Financial Planning For Those Living with MS

If you or someone you love has been diagnosed with a chronic disease such as multiple sclerosis, this news will provide a new lens through which you will view the world and which will affect all future plans, including financial planning to protect you and your family. The first step in financial planning is to assess your current health status and the likely course of your disease with your healthcare provider. Then define your goals, present your adviser with the facts, create a plan then implement and monitor that plan. See Estate Planning for People with a Chronic Condition on Disability on www.demoshealth.com.

The following is a brief roadmap that can assist in your financial planning for more details, click on the “Chronic Disease” tab on www.baways.com.

Define your goals—What do you wish to accomplish? Every person has a unique list of goals identified and written down.

Determine resources—Once you have determined your goals, you need to assess the resources you’ll have to meet those goals. Prepare a balance sheet: List the sources of cash flow that provide the projected changes in earnings.

Estimate your needs—The foundation of every financial estate plan is a budget. For those living with chronic illness, additional costs typically have to be estimated. For instance, what do your hospice and other medical needs cost and how much of that is covered by insurance or government programs?

Protect yourself—While most people living with MS don’t experience significant cognitive issues, do the risk of this should be planned for. Simplify and consolidate your investment accounts if automatic bill paying is frequently as possible, have duplicate monthly statements sent to a trusted family member or friend.

Disseminate emergency information—Make a detailed listing with account numbers, locations and contact information of all key personal, financial and related information, and give it to several trusted friends and family members.

Plan your investments—Your investment plan must be tailored to your specific age and situation. For example, if you are in your 50s, you may need a more aggressive investment plan in order to reach your financial goals, as you may not be sure how long you will be able to continue working.

Create an and sign a durable power of attorney—Every adult needs to sign a power of attorney, which authorizes a named person (agent) to handle financial matters for them. If you have MS, you need to tweak the standard powers to fit your situation. For instance, in dealing with the possibility of an uncontrolled attack, consider a power that is effective immediately.

Sign and implement a revocable living trust—The best mechanism to protect you during the advance of your MS is a funded irrevocable living trust. You’ll need to hire an estate planner to execute this.

Give back to charities that help you and others with MS—Charitable gift annuities are commonly used to obtain higher cash payments than could be obtained from a Certificate of Deposit or money market account. If you or a loved one is living with MS, the added bonus is that they will help the organizations helping you. Consider speaking to your investment manager and estate planner about using charitable remainder trusts.

Conclusion—Financial and related planning is important for everyone, but if you or a loved one is living with MS, it is even more vital that you take steps to plan and protect yourself and all those who depend upon you.
Mobility impairment is a major concern for patients with MS.1-3

The 2008 Multiple Sclerosis Association of America (MSAA) poll, which included more than 2,400 persons with MS, revealed that4†:

77% of people with MS said they experienced some limitation to their mobility

In a study of 166 patients with MS of either <5 or >15 years duration, 162 responded to a questionnaire designed to force rank 13 bodily functions based on severity and relevance to their experience. Of the 162 useable responses, 82 had MS for <5 years and 80 had MS for >15 years. The graph below shows the percentage first rank for each of the bodily functions.5


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