

THE Synapse



SHEPHERD
CENTER

Andrew C. Carlos
Multiple Sclerosis
Institute

Connecting the **Multiple Sclerosis Community**

From the Medical Director, Andrew C. Carlos MS Institute

What Type of MS Do I Have? Ben Thrower, M.D.



Ben Thrower, M.D.

Medical Director,
Andrew C. Carlos
Multiple Sclerosis Institute

One of the most common questions for the person with MS is, "What type of MS do I have?" It really doesn't matter whether we're talking about someone with a new diagnosis or a person with MS for 20 years. Humans are by nature categorizers; we need to know which 'box' we fit in. In general, we divide MS into four categories: relapsing-remitting, primary progressive, secondary progressive and progressive relapsing.

Most people, 85% in fact, start with relapsing-remitting MS (RRMS). There's another term we should mention, clinically isolated syndrome (CIS).

A CIS is the first attack or relapse. This could be visual loss from optic neuritis, changes in strength/sensation from transverse myelitis, or any number of other symptoms. The person with a CIS who has abnormalities on brain MRI consistent with demyelination is felt to be at high risk for future attacks, meaning they have relapsing-remitting MS. A CIS patient with abnormal antibody production in the spinal fluid, called oligoclonal bands is also at risk for developing MS.

The person with RRMS has relapsed with periods of stability in between. Relapses are also called attacks or exacerbations. A relapse is defined as a new or worsened neurological symptom lasting at least 24 hours. Remission does not mean symptom-free. Even during remission, most people with MS have some symptoms, things like fatigue, bladder issues or maybe spasticity.

That brings us to secondary progressive MS (SPMS). If a person with RRMS is not treated, they tend to move towards SPMS. After 10 years, about 50% of untreated people with RRMS will have progressed towards SPMS. As we said earlier, RRMS is characterized by relapses and periods of stability or remission. Relapses in SPMS become less frequent or stop all together. They are replaced by slow progression of disability. The brain MRI goes from showing evidence of active inflammation or enhancing lesions, to showing little inflammation. The brain MRI in SPMS is more likely to show tissue damage, like atrophy or 'black holes'. One of the mysteries of MS is why this transition occurs. So, RRMS and SPMS are not so much different 'boxes' as much as they are a spectrum

or time line for MS. One of the goals of early MS therapy is to slow or prevent the move from RRMS to SPMS. Progressive relapsing MS (PRMS) is a term not used frequently. This refers to a person who starts with slow progression of symptoms, like SPMS, then starts having relapses later. Many MS healthcare providers think PRMS is just a variation of RRMS. Without treatment, PRMS will evolve into SPMS for most people.

That brings us to primary progressive MS (PPMS). This form of MS may really deserve to be thought of as a separate box. In contrast to RRMS, which is more common in women, PPMS is more common in men. PPMS also begins a little later in life than RRMS. The typical person with PPMS would be a guy in his 40's, who notices a gradual decrease in his strength and endurance in the legs. MRIs in PPMS tend to show more damage in the spinal cord than the brain.

Categorizing your MS can be both a blessing and a curse. Determining where a person is at on the spectrum from RRMS to SPMS is not an exact science. To complicate matters further, many people with MS are on a therapy that alters the natural history of their MS. This means we may stop relapses but not all progression of symptoms. It would be tempting to label that person incorrectly as having SPMS, when in fact, they have partially-controlled RRMS. These labels can have implications for medication insurance coverage or for participation in clinical research. Again, applying these categories may be an important, but an exact science.

Hopefully, this helps sort out some of the confusion regarding the different types of MS. If not, ask Tracy Walker or Colby Doepel, our nurse practitioners, when you see them. They'll explain everything! ■

MS School Update

The Andrew C. Carlos MS Institute has been busy with MS 101 and MS 102. MS School 101 is designed for patients, and caregivers, diagnosed within the past year. The most recent MS School 101 was held in January. Several speakers provided education inflation for patients. Dr. Ben Thrower presented on the diagnosis and treatment of MS. Tracy Walker, NP, presented on symptom management and

answered the question: What IS an exacerbation. Emily Cade, case manager, provided information on vocation issues related to MS. Quinnett Ezzard, LPN, discussed ways to get the most out of your MS center. Melinda Hodgson, OT, educated attendees on the importance of rehab for MS patients, and Julie Shepherd, case manager for the National MS Society, provided an update on community resources.

MS 102 provides education for patients, families, and community members with an interest in MS. This fall, we were excited to host a Marriage and Family seminar. This seminar was lead by Len and Cheryl Chatman, authors of the book *The Art of Living with MS*.

More classes are on the horizon. Check with your provider at your next appointment to get an update! ■



Staff and friends
of the MS Institute
had a blast at their annual
Halloween open house.

Staff Spotlight

Dr. Sherrill Loring

Dr. Sherrill Loring, a neurologist in the Andrew C. Carlos MS Institute, knew that she wanted to be a doctor at age six after her father suffered a series of strokes. Her father died when she was 13, but his spirit stayed with Dr. Loring as she continued through school, graduating from Columbia College with a bachelor of arts in chemistry degree and later with a medical doctorate from the Medical University of South Carolina. Her interest shifted from stroke patients to multiple sclerosis as she encountered more people with the disease.

Dr. Loring joined Shepherd Center in July 2008 after meeting MS Medical Director Dr. Ben Thrower several times at various conferences. Prior to her move to Atlanta, she was an associate professor of neurology at the University of Florida. She also worked as the chief of neurology at University Hospital in Augusta, Ga., and later directed the MS Clinic at Georgetown University Hospital in Washington, D.C.

“The MS patients typically I work with are younger,” she said. “They have their whole lives ahead of them, getting married, raising kids, fulfilling their dreams. It’s my role to help them understand their disease and find ways to treat it which allows them to do what they want in life.”

Aside from her daily duties of treating patients, Dr. Loring is a blinded evaluator for Shepherd Center’s trials and performs

the EDSS at certain visits. The EDSS is a neurological exam that is used to assess the status of a patient’s MS. The EDSS is graded on a 0-10 scale; with 0 being no neurological problems and the higher the score the more the disability caused by MS. As a blinded evaluator, Dr. Loring cannot know the status of the patient’s health in regards to what treatment they are receiving, or any problems or improvements that they may be having while they are enrolled in the research study. But the patients are being followed by Dr. Thrower and evaluated at study visits for any problems, relapses, or improvements.

“In five or ten years, I hope to still be treating patients here and delving more into research through a primary investigator role,” she says. “The brain is a captivating object and understanding how it works and how treatments affected it is fascinating.” The primary investigator is ultimately responsible for the conduct of the study, patient safety, and working with the research team to recruit and retain patients enrolled in the study.”

When she isn’t busy conducting research or treating patients, Dr. Loring has a flair for cooking (especially Asian cuisine,) baking bread, and gardening. ■



Dr. Sherrill Loring,

Disability 101

by Emily Cade, M.S., CRC, CCM, CLCP

Navigating the world of disability can be overwhelming. Acronyms like SSDI, STD, LTD, and FMLA circle in your brain. And language like ‘own occ’ or ‘any occ’ can be intimidating when trying to understand the information. But never fear! The following is a kind of ‘dictionary’ of terms you need to know when navigating the world of disability:

FMLA: Under the Family and Medical Leave Act of 1993 (FMLA), many workers are entitled to a total of up to 12 workweeks of unpaid leave during any 12-month period for the following purposes:

- the birth of a son or daughter of the employee and the care of such son or daughter;
- the placement of a son or daughter with the employee for adoption or foster care;
- the care of spouse, son, daughter, or parent of the employee who has a serious health condition; or
- A serious health condition of the employee that makes the employee unable to perform the essential functions of his or her positions.

Under certain conditions, an employee may use the 12 weeks of FMLA leave intermittently. This is especially important to note for patients diagnosed with a chronic condition like MS.

Upon return from FMLA leave, an employee must be returned to the same position or to an “equivalent position with equivalent benefits, pay, status, and other terms and conditions of employment.”

An employee who takes FMLA leave is entitled to maintain health benefits coverage. An employee on unpaid FMLA leave may pay the employee share of the premiums on a current basis or pay upon return to work.

It is important to note that not everyone is entitled to FMLA. FMLA applies to all public agencies, all public and private elementary and secondary schools, and companies with 50 or more employees. Employees are eligible for leave if they have worked for their employer at least 12 months, at least 1,250 hours over the past 12 months, and work at a location where the company employs 50 or more employees within 75 miles. Whether an employee has worked the minimum 1,250 hours of service is determined according to FLSA principles for determining compensable hours or work.

SSDI: Social Security Disability Insurance pays benefits to you and certain members of your family if you are “insured,” meaning that you worked long enough and paid Social Security taxes. “Disability” under Social Security is based on your inability to work. You are considered disabled under Social Security rules if:

- You cannot do work that you did before;
- SSA decides that you cannot adjust to other work because of your medical condition(s);
- Your disability has lasted or is expected to last for at least one year or to result in death

The five-month waiting period ensures that during the early months of disability benefits are not paid to persons who do not have long-term disabilities. Social Security disability benefits can be paid only after you have been disabled continuously throughout a period of five full calendar months. Therefore, Social Security disability benefits will be paid beginning with the sixth full month after the date your disability began. You are not entitled to benefits for any month in the waiting period. You can apply for SSDI and receive additional information by calling Social Security Administration at 1-800-772-1213 or online at www.ssa.gov

STD: Short Term Disability: Many employers offer some kind of disability insurance. The first benefit you may encounter if going out on disability would be STD. Many STD policies have a waiting period of 0 to 14 days with a maximum benefit period of no longer than two years. Policies vary from company to company, plan to plan. Many cover up to 60% of your pre-disability wage.

LTD: Long Term Disability: A type of disability income insurance that provides income benefits after short-term disability income benefits terminate and continues until the earlier of the date when the insured person returns to work, dies, or becomes eligible for pension benefits. Typical group long-term disability benefits replace about 60 percent of the worker’s usual salary. These benefits usually start when short-term benefits are exhausted. Again, as with STD, policies vary from company to company, plan to plan.

Own Occ and Any Occ: An important component related to LTD is the definition of disability. Some policies pay benefits if you are unable to perform the customary duties of your own occupation. Others pay only if you are unable to perform any job suitable for your education and experience. Many policies define disability in terms of your own occupation for an initial period of two or three years and then continue to pay benefits only if you are unable to perform any occupation.

When dealing with SSDI, STD and LTD, it is important to remember that just because your doctor says you are disabled, this does not mean that the insurance company will deem you disabled. You must make sure your providers document objective information (abnormal neuro exams, abnormal MRI results, neuropsych results, and therapy notes) showing why you are disabled. ■

Sources - Insurance Information Institute, SSA, US Dept. of Labor

Wireless Technology — Results from Survey of User Needs

The Shepherd Center is home to the Rehabilitation Engineering Research Center for Wireless Technologies

(Wireless RERC), which is funded by the U.S. Department of Education. Together with our partners at the Georgia Institute of Technology, we conduct research to make wireless communications and related technology more usable and useful for people across the range of age and abilities.

One of the RERC’s research projects is the Survey of User Needs (SUN), which asks respondents about how they use wireless technology (like cell phones, mobile internet, etc.) and what they would like to have in their wireless devices and services.

In terms of what makes their wireless devices important, the most frequent response was “makes me feel more secure” and “can get emergency help”, both identified by 67% of our MS respondents.

We have been collecting data for the current survey since April 2007 and have more than 1500 respondents to date. Of those, 57 have indicated that they have multiple sclerosis. Because MS impacts people in various ways and to various degrees, it can be difficult to make generalizations. Still, the data give us a general idea of the uses and usability challenges that people with MS experience when using wireless communications technology.

First of all, the vast majority of MS respondents (88%) reported owning or having access to a wireless communications device. And a majority (60%) said that their wireless device was very important to them; another 34% said it was somewhat important to them.

In terms of what makes their wireless devices important, the most frequent response was “makes me feel more secure” and “can get emergency help”, both identified by 67% of our MS respondents. Notably, relatively few MS respondents valued their mobile devices for getting directions (26%) or for appointment reminders (16%).

Why is your wireless device important to you?

- Makes me feel more secure 67%
- Can get emergency help 67%
- Can reach anyone, anytime..... 52%
- Can get directions wherever I am..... 26%
- Reminds me of appointments 16%

Almost three-fourths of our MS respondents use their wireless devices every day, and a similar percentage finds their devices either easy or very easy to use. Generally, those that used their devices more often also tended to report greater ease of use.

How often do you use it?

- Every day..... 47%
- 3-6 times per week 26%
- 1-2 times per week 22%
- Never 4%

How easy is it to use?

- Very easy 24%
- Easy 49%
- Hard 24%
- Can’t use it without help 2%

The Wireless RERC continues to collect data on wireless use and usability needs of people with disabilities so that we can educate wireless manufacturers and services providers on how to serve their customers better. We invite you to take our Survey of User Needs either via telephone (800-582-6360) or online at: www.wirelessrerc.org/for-consumers/survey-of-user-needs.html. For a Spanish language version, please go to: www.cansurvey.wirelessrerc.org/survey2_sp/.

In addition to the ongoing Survey of User Needs, the Wireless RERC conducts focus group research and user testing of wireless products and services. If you would like to participate in these research projects, please contact John Morris at 404-367-1348. ■

MEET Wanda Bagley



Wanda Bagley

Wanda Bagley is no stranger to challenge. After growing tired of the wear and tear of living in New York, Wanda decided to move to Atlanta to start a new adventure with her young son. She had already heard of Shepherd Center from a patient of hers at Rusk Institute of Rehabilitation Medicine, where she had been a registered nurse for 10 years. The patient shared a story about a place of hope and rebuilding lives, prompting Wanda to think to herself, “That’s the kind of place I want to be.”

In 2002, she joined Shepherd Center as a RN in the urology and wound clinic. Just as her former patient had described, Shepherd Center was a place of hope and rebuilding lives. And Wanda was proud to be a part of it.

After three years at Shepherd Center, an opportunity opened in the MS Institute and Wanda jumped on it. Once again, she was ready for a new challenge. “Here I can continue to learn and increase my knowledge of MS and its associated neurological problems on a daily basis,” said Wanda. “My brain loves the challenge.”

In fact, she loves it so much Wanda is currently studying to take her MS certification test in August. In the meantime, she

continues caring for her patients, providing education on MS and available resources, administering multiple infusions, and assisting Dr. Ben Thrower and Dr. Sherrill Loring with their medical examinations.

During the last several years, Wanda began running road races. Already a vegetarian, the more she learned as a nurse, the more important it became for her to stay fit and healthy. When she started, Wanda wasn’t much of a runner, but her sister encouraged her to run in a local 5k race. The challenge inspired her to do it again. Since her first race, Wanda has participated in more than 15 races, including a biathlon.

Whether it’s training for a 10k race, helping a patient with medical concerns, or parenting an independent 13-year-old who she says won’t clean his room, Wanda Bagley enjoys the challenges life brings her – and loves even more when she overcomes them. ■

Multiple Sclerosis Foundation supports Shepherd Center Patients

Since 1996, the Multiple Sclerosis Foundation (MSF) has awarded grants and endowments to universities and other organizations to actively promote quality of life and create a brighter tomorrow for those living with multiple sclerosis (MS). Over the past three years, Shepherd Center has received three “Quality of Life” grants from the MSF totaling \$85,000 for various programs that include:

- \$15,000 in operating support for the MS Call Center Nurse which serves patients with concerns and questions about their diagnosis and treatment while providing resources and patient education.
- \$30,000 to purchase a manual treadmill and provide scholarships for patients to participate in Shepherd Center’s wellness programs: Promotion and Beyond Therapy.

- \$40,000 to survey patients to identify the most common patient concerns and develop education materials to address those concerns. This grant helped establish our Synapse newsletter, a bi-annual publication for newly diagnosed patients that communicates the latest research about new approaches in the treatment and cure of MS.

Shepherd Center would like to recognize the MSF’s generous support over the years. Their support is making a direct impact on our patients every day and strengthens our ability to provide excellent patient care and education. Thank you, to the MSF for their continued support and leadership! To learn more about the mission of the MSF visit www.msfocus.org. ■

All Aboard! MS Foundation Cruise for a Cause 2009

It’s All About MEE (Motivation, Education and Empowering)

The 2009 Multiple Sclerosis Foundation Cruise for a Cause holds a special honor for the MS Institute at Shepherd Center. The conference, designed for patients with MS and caregivers, has honored Shepherd Center by requesting Shepherd MS Institute providers create and present the educational programs for the attendees! Candy Tefertiller, PT; Melinda Hodson, OT;

Bonnie Schaudé, ST; Robert Godsall, Ph.D; Emily Cade, MS, CCM; Tracy Walker, NP; and Ben Thrower, M.D. are up to the challenge of creating and presenting innovative and exciting information that the patients/caregivers will be able to take home and use for their benefit. Congratulations, Shepherd, for this wonderful honor! ■

Wellness Program Update

The MS Outpatient Rehab Department is excited to begin work on a wellness program study. The study, funded by Teva, is to observe the effects of a combination of cardio exercise, strengthening/weight training exercise and education about general wellness on MS patients' physical

functioning and self-reported quality of life. Before and after the study, we will measure subjects' walking speed, grip strength, and several other factors relating to ADL function, and will give them a questionnaire about how they perceive their quality of life. The study runs 12 weeks and subjects will

come in for 1 1/2 - 2 hours, two days a week (Mondays and Wednesdays) to work out with a therapist and get a short, interactive lecture on one of several wellness topics. Our goal is to begin our first class in March 2009. For additional information, contact Melinda at 404-367-1251. ■

Congratulations to Emily Cade, case

manager of the MS Institute at Shepherd Center. Emily was chosen as the 2008 Medical Provider Volunteer of the Year by the National MS Society, GA Chapter. This award honors volunteers for their years of dedication and success in helping to raise awareness for MS, raise funds for MS, and provide direct services and resources to clients living with MS. ■



MS Resources

MS Association of America – www.msaa.com
856-488-4500

National MS Society – www.mssociety.org
800-FIGHT-MS

MS Foundation – www.msfocus.org
888-MS-FOCUS

Consortium of MS Centers – www.ms-care.org
201-837-0727

MS Research Web Sites
Shepherd Center –
www.shepherd.org/clinicaltrials

Multiple Sclerosis International Federation
www.msif.org

Clinical Trials Listing Service
www.centerwatch.com

Q: How do I contact folks in the center when I need assistance with issues?

A: Call (404) 352-2020 and ask the operator to connect you to the appropriate department. Medication refill/prior-authorization? Ask for MS Medication Nurse. Medical Issue? Ask for MS Nurse. Scheduling appointment? Ask for scheduling line (established patients only). ■



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