



***An Overview of the Programs and Services of the
National MS Society and Our Partners***

A Telelearning for Connection Program Volunteers of the
National Multiple Sclerosis Society

October, 2011

Thank you for registering for *An Overview of the Programs and Services of the National MS Society and Our Partners*. We know that finding answers and making decisions relies on having the right information at the right time. During this telelearning you will learn more about the variety of programs, services and resources available to people with MS and their families at all levels of the organization, as well as how to access these resources – valuable information to share with your group members and peers. During the call we will discuss not only those programs and services offered by the Society, but also those of our partners.

Our presenters are Cathy Castor and Kim Koch. Ms. Castor is the Information Resource Center's Training Director. She began her career with National MS Society almost 10 years ago when she was hired as one of the first Information and Referral Specialists. She has a Master's degree in Audiology and clinical experience in providing diagnostic testing for MS. Ms. Koch began her career with the Society in 2003 and is currently Vice President, Programs and Services. She oversees nationwide initiatives in the areas of client education, family support and connection programs.

Call Information & Schedule

- Two calls are scheduled; it is the same agenda offered at two different times. You only need to attend one call.
- Please call in at least 5 minutes prior to the start of the call, and have the conference id number available. The call operator may ask you for this information.
- To assist in the tracking and recording of telelearning please provide your first and last name, city and state when asked by the call operator.
- The call will be recorded for those who miss it or would like to listen again. You can request the playback information by contacting your chapter liaison. The recording and associated handout will also be available for download on the self-help group leaders' resource page on the Society's website (<http://www.nationalmssociety.org/selfhelpgroupleaders>).

CALL OPTION ONE	
Tuesday, October 25, 2011	
1-2:00 pm ET	12 pm CT 11 am MT 10 am PT
Participant Dial-In Number:	(877) 715-5282
Conference ID:	20770502

CALL OPTION TWO	
Tuesday, October 25, 2011	
8-9:00 pm ET	7 pm CT 6 pm MT 5 pm PT
Participant Dial-In Number:	(877) 715-5282
Conference ID:	20777211

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For more information on any of the programs and resources referenced in this document please contact an MS Navigator at 1-800-344-4867 (1-800 FIGHT MS) or visit www.nationalMSSociety.org.

A special thank you to CaringBridge for making this learning opportunity possible.

Programs for Children and Families

Timmy's Journey to Understanding MS

Timmy's Journey to Understanding MS is a 15 minute cartoon featuring a young boy named Timmy and his trusted guide, Captain Kip S'myelin. When Timmy becomes frustrated by his dad's MS, he is visited by his new friend, Captain S'myelin, who takes Timmy on an exciting trip through the human body to learn about MS. Through his journey, Timmy gains a better understanding of MS and becomes more accepting of the unpredictability MS can bring. The cartoon is available in both English and Spanish on the same DVD.

Keep S'myelin®: A Newsletter about MS for Children

This FREE newsletter is for children ages 5-12. Each issue addresses a different topic related to MS and is distributed 3-4 times/year. Interactive versions are also available at www.nationalmssociety.org.

Also available is the *Keep S'myelin Activity Book*. The 24-page activity book is a colorful, engaging, informative, and reassuring publication to help parents and their children talk and learn about MS together. The book features information on a variety of MS-related topics, such as: what is MS, who treats people with MS, feelings, and communication strategies, along with games and activities. The activity book is available in English and Spanish.

Children and Teens with MS: A Network for Families

A support and education network for children and teens with MS and their families.

Scholarship Program

MS shouldn't stand in the way of an education. This is why the National MS Society's scholarship program exists - to help highly qualified students who have been diagnosed with MS or who have a parent with MS achieve their dreams of going to college.

The scholarship program is open to:

- High school seniors who have a parent with MS who will be attending an accredited post-secondary school for the first time.
- High school seniors who have MS and will be attending an accredited post-secondary school for the first time.
- High school (or GED) graduates of any age who have MS and who will be attending an accredited post-secondary school for the first time.
- High school (or GED) graduates of any age who have a parent with MS and who will be attending an accredited post-secondary school for the first time.
- Applicants must be United States citizens or legal residents living in the U.S., Puerto Rico, U.S. Virgin Islands, Guam or any other U.S. territory and plan to enroll in an undergraduate course of study at an accredited two-or four-year college, university, or vocational-technical school located in the U.S., PR, VI, Guam or any other U.S. territory. Applicants must be enrolled in at least six credit hours per semester in course work leading to a degree, license, or certificate.

For more information contact an MS Navigator at 1-800-344-4867 (1-800 FIGHT MS) or visit www.nationalmssociety.org/scholarship.

Health and Wellness

Knowledge is Power

The *Knowledge Is Power* (KIP) program is designed as an at-home educational series for people newly diagnosed with MS and their families, but could be adapted for use in the group setting. Knowledge Is Power provides information about dealing with one of the greatest challenges presented by MS - the unpredictability and uncertainty of the future.

The volumes offered as part of the KIP program are:

- Taking the First Steps
- Disease-modifying Treatments for MS
- Maximizing Your Employment Options & Financial Security

- Treating Yourself Well
- Maintaining Healthy Relationships
- Working with Your Doctor
- Building and Maintaining Intimate Relationships
- Parenting with MS

MS Next Step®

The *MS Next Step* product is designed to be given to a person by his doctor at the time of diagnosis. The materials serve as an early introduction to multiple sclerosis, and the programs and services of the National MS Society. This product contains a DVD and information for a person just diagnosed.

Free From Falls: A Comprehensive Fall Prevention Program for People with MS

This 8-week program consists of a detailed curriculum, participant materials and a facilitator's guide and is designed to: increase awareness of fall risk, teach strategies to minimize risk and increase confidence in minimizing and managing falls. The target audience is people with MS who are ambulatory (alone or with a cane, walking stick or crutch). A DVD, also entitled: *Free From Falls*, is a stand-alone education and awareness tool and also can serve as an introduction and overview of fall risk and prevention in persons with MS. Finally, a client education brochure, entitled: "*Minimizing Your Risk of Falling: A Guide for People with MS*" will be available in November.

Living Well with MS

Living Well with MS is a series of workbooks that contain exercises and reflection pieces that challenge individuals to problem solve and think creatively about living with MS. Topics include:

- Coping with Change
- MS and Wellness
- Considering Adaptive Devices

Gateway to Wellness

The Gateway to Wellness program is a six week health and education program designed to enhance the quality of life of individuals with multiple sclerosis. Every session includes education and skills training, exercise, and a goal-setting discussion. A trained facilitator should lead this program.

Fatigue: Take Control

This program focuses on the fatigue and mobility issues associated with MS. Participants can learn about various ways to cope with dealing with fatigue during daily routines and how to mitigate the effects of fatigue on everyday life.

Materials available (all free of charge):

- Participant and leader workbooks
- DVD

Web-based Education

MS Learn Online

MS Learn Online is the National MS Society's online educational webcast series. New webcasts are debuted bi-monthly, but past webcasts can be viewed at any time from the Society's website (www.nationalMSSociety.org and go to Multimedia Library/MS Learn Online – Educational Video Series).

Sample MS Learn Online Series

MS: The Basic Facts:

- Understanding Exacerbations
- MS 101

Treatments:

- Gilenya: What is it and How Does it Work?
- Amprya: A New Medication to Improve Walking
- Disease Modifying Therapies
- Tysabri: What You Need to Know
- Complementary and Alternative Medicine

Symptom Management:

- Speech Disorders in MS
- MS and Your Emotions
- Invisible Symptoms in MS
- Gait and MS

To find MS Learn Online, visit www.nationalmssociety.org/MSLearnOnline.

Anyone interested in receiving the email notification of new programs can register for the mailing list by emailing mslearnonline@nmss.org.

My Life, My MS, My Decisions

My Life, My MS, My Decisions is a program to help people with MS make medical decisions about all aspects of their health. The program includes a DVD and four online classes:

1. Teaming Up with Your Healthcare Providers
2. Navigating the Medication Maze
3. Considering Clinical Trials
4. Achieving Optimal Wellness (in development)

The DVD follows three different people through the medical decision-making process:

- Annie is a woman in her twenties, who has been recently diagnosed. Her doctor would like her to begin taking a disease modifying medication, but she is feeling a bit reluctant. She researches the medications, talks with her doctor, and decides to start. During her decision-making process, she explores clinical trials, addresses her depression and overall good health.
- James is in his thirties and has had MS for 10 years. It is affecting his walking and his physical relationship with his partner. James talks with his doctor and his partner, researches possible medications, talks with his pharmacist about side-effects of medications, and decides to try an

ED medication. James explores clinical trials, works on his relationship with his partner, and finds new ways to stay healthy.

- Joann is in her forties and uses a wheelchair to get around. She feels that her MS is getting worse and her current doctor isn't willing to try some of the newer therapies. She decides to change doctors. Her new doctor encourages her to explore a clinical trial and she decides to participate.

The online courses provide more in-depth information and decision making tools.

Additional Online Classes

Adapting: Financial Planning for a Life with MS Together

MS can be an expensive disease. Participants can learn how to plan for their financial future as a couple through classes in budgeting, debt management, and building savings.

Intimacy: Enriching Your Relationship

Participants in this class can learn how to talk about the tough issues that can get in the way of true intimacy. The class presents creative ways to address and overcome those issues in a relationship.

Career Decisions: Relationship Matters

Employment concerns can add strain to any relationship and MS can make these issues even more challenging. Through participation in this class couples can learn strategies to manage employment choices together.

To register for the online classes please go to

<http://www.nationalmssociety.org/living-with-multiple-sclerosis/society-programs-and-services/online-classes/index.aspx>.

Symptom Management and Research

North American Education Program

The North American Education Program (NAEP) is an educational program that focuses on topics related to symptom management and research. The 2011 NAEP focuses on research on progressive forms of MS. Previous programs may still be available in DVD or online at www.nationalmssociety.org/MSLearnOnline.

Titles include:

- Who? Why? How? – Searching for the Cause of MS
- Clinical Trials: Solving One Piece of the MS Puzzle
- Hold That Thought! Cognition and MS
- To Repair and Protect: The Future of MS Treatments
- The Clues of Epidemiology
- Getting There: Staying Mobile with Multiple Sclerosis
- The Genetic Connection

Career and Employment Decisions

Career Crossroads

This program focuses on the legal employment rights of employees with MS, and also examines the various ways they can mitigate the physical effects of MS from affecting their work performance. It also introduces information on assisting a person with MS of ways to disclose their MS to their employer, and informs them of the rights they have.

This program is available in two versions – the original group program and a new, coached version designed for trained employment advisors to work with people with MS on an individual basis.

MS and the Workplace - Employer Education DVD

Using interviews and footage from the Career Crossroads programs, we have developed a DVD to help employers work with their employees with MS (and other disabilities). This DVD provides basic information to employers about the impact of MS in the work setting.

Connection Programs

National MS Society connection programs bring together people who share a common life experience for support, education and mutual aid.

Benefits of participating in a connection program include:

- Learning new information and strategies for managing your MS
- Finding support from others
- The opportunity to help others
- New power and confidence in facing the challenges of living with MS

Connection programs are available in a variety of formats including:

- In-person
- On the phone
- Online
- Group settings
- One-on-one opportunities

Connection programs are based on the belief that positive personal change happens through individual efforts with the support of others.

Additional Resources

Financial Assistance Program

This nationwide program is comprised of a range of initiatives that support independence, safety, health and quality of life for people living with MS, as well as their families. These initiatives address areas of special importance to the MS community and leverage knowledge and resources that can have a significant, lasting impact. In the past, the program has provided support for needed modifications to homes and automobiles, helped with the purchase of wheelchairs and walkers, and provided immediate resources to overcome urgent financial crises. The Financial Assistance Program was developed to bring meaningful financial assistance to as many people living with MS as possible, with emphasis on helping people maintain their independence, safety, health and quality of life.

We may be able to help with the following types of requests:

- Respite services such as short term home care
- Durable medical equipment and air conditioners
- Accessibility modifications to homes or automobiles such as ramps and hand controls
- Transportation to medical appointments
- Critical short term needs such as emergency help with utilities or rent
- Health and wellness support

Since resources vary by community, eligible items and services available in a given area may differ.

Client Publications

Over 60 Booklets and brochures are available to people with MS and their families. Information is available in the following categories: General Information, Newly Diagnosed, Employment Issues, Staying Well, Managing Specific Problems, Managing Major Changes, and For Children & Teenagers. Select publications are available in Spanish.

Publications can be found at www.nationalmssociety.org/brochures or by contacting an MS Navigator at 1-800-344-4867 (1-800 FIGHT MS).

Partner Organizations (please note: this is not an exhaustive list)

Can Do Multiple Sclerosis

Can Do MS (formerly The Heuga Center for Multiple Sclerosis) is an innovative provider of lifestyle empowerment programs that empower people with MS and their support partners to transform and improve their quality of life. For more information, visit www.mscando.org or call 970-926-1270.

CaringBridge

[CaringBridge](http://www.caringbridge.org) is a free one-stop shop that connects and updates communities of supporters on a person's ongoing health status, treatment, surgeries, progress in therapies and recovery. A personalized CaringBridge website helps keep loved ones informed during difficult times. In return, family and friends give support through guestbook messages.

A personalized CaringBridge website allows families to:

- Journal about their treatment and recovery
- Ask for help with meals and transportation
- Receive love and support from family and friends

Every personalized CaringBridge website includes:

- Patient care journal
- Guestbook for messages
- Photo gallery
- Free online support for using the service

Please visit <http://www.caringbridge.org/partner/nationalmssociety/> to learn more about setting up your own CaringBridge website.

MSWorld®, Inc.

MSWorld provides a global virtual community of support to people living with multiple sclerosis. The site's sole mission is to create a safe, informative, useful, and fun place for people to meet, share ideas and gain useful resources to help manage and cope. MSWorld, Inc. maintains a well-trained staff of volunteers that moderate live chats, message boards and other resources to provide a safe and useful online community. MSWorld has message boards and chat rooms tailored to a variety of specific populations and needs:

- People newly diagnosed
- People with Primary/Secondary Progressive MS
- Partners, family and friends
- Teens
- Young adults
- Employment
- Medications and MS
- Social Security benefits

The National MS Society and MSWorld have been collaborative partners since 2001. For more information please visit www.msworld.org.