



## CHAPTER PRESIDENTS

July 13, 2012	CC: All
<b>Save the Date: 2012 Family Support and Engagement Implementation Plan Information Sessions</b>	

The Family Support and Engagement Implementation Team invites you to participate in an information session to learn more about the progress made to date in reaching the various milestones described in the plan. The plan defines the needs, outlines the scope of the Society's work and describes those key areas and touch points of focus moving forward. The plan is posted on SharePoint in the Goal Steering Teams section; to review the full plan please click [here](#).

Much progress has been made since the plan was approved in May, and the team hopes you can join in and learn more about not only the accomplishments, but the work planned for the remainder of the fiscal year and what this all means as you develop your FY2013 operational plans and budgets.

A total of six sessions will be offered, each facilitated by the region liaison. The sessions will begin with a high-level overview of the plan and recommendations, followed by a discussion on the accomplishments and plans for future work, possible implications for your operational plans and budgets, and a question and answer period.

Because family engagement and support ultimately lies with all of us, the sessions are open to all interested staff members –Chapter Presidents, Programs and Services, Advocacy, Fundraising, Marketing, Volunteer Engagement, etc.

### Regional Information Sessions Schedule

The calls are scheduled as follows:

#### South Central

- Hosted by: Erica Sutton (Region Liaison)
- Tuesday, July 24<sup>th</sup> from 3-4 pm ET (2 pm CT/1 pm MT/12 pm PT)

#### Southeast

- Hosted by: Jim O'Brien (Region Liaison)
- Thursday, July 26<sup>th</sup> from 10-11 am ET (9 am CT/8 am MT/7 am PT)

### **East**

- Hosted by: Julie Vallelunga (Region Liaison)
- Thursday, July 26<sup>th</sup> from 2-3 pm ET (1pm CT/12 pm MT/11 am PT)

### **West**

- Hosted by: Jaclyn Smoczynski (Region Liaison)
- Friday, July 27<sup>th</sup> from 2-3 pm ET (1 pm CT/12 pm MT/11 am PT)

### **Midwest**

- Hosted by: Jeremy Otte (Region Liaison)
- Wednesday, August 1<sup>st</sup> from 11 am-12 pm ET (10 am CT, 9 am MT, 8 am PT)

### **Northeast**

- Hosted by Anastatia Fabris (Region Liaison)
- Friday, August 3<sup>rd</sup> from 2-3 pm ET (1pm CT/12 pm MT/11 am PT)

The call in number is the same for each call: 15100 or 1-888-279-3775, 5158#.

If you are unable to join the call scheduled for your region, please attend the call that best works for your schedule. **Pre-registration is not required.**

Questions? For additional information please contact Kim Koch at [kimberly.koch@nmss.org](mailto:kimberly.koch@nmss.org) or (303) 698-6100, ext. 15158.



**PROGRAMS & SERVICES**

<b>July 13, 2012</b>	<b>CC: Chapter Presidents</b>
<b>Everyday Matters - FY 2013 SHG Meeting-in-a-box Tool Kits and In-person Program Pilot Project</b>	

As you are developing your FY 2013 operational plans, the Everyday Matters project team would like to announce that as part of phase two of the project we will be developing two new products– a self-help group meeting-in-a-box tool kit and a multi-week in-person program curriculum for people with MS and their support partners and family members.

The meeting-in-a-box tool kit for self-help groups will be similar in format to other tool kits (Free From Falls, North American Education Program (NAEP) and Live Fully, Live Well), with a facilitator’s guide, DVD, participant handouts, and an evaluation tool.

The curriculum for the in-person program is under development. The design and delivery model will be similar to the Free From Falls program - a multi-week in-person program where participants will have the opportunity to learn and discuss the various tenets of positive psychology and how to incorporate them into their lives. The program materials will include a facilitator’s guide, DVD, participant handouts, and pre- and post-assessments.

The estimated completion date for the tool kit and the in-person curriculum is mid- to late March 2013, in time for your and your group leaders’ Spring programming.

**Funding Available for Pilot Programs**

As part of Genzyme’s support of this project, a limited amount of funds are available to pilot the program in selected locations across the country. The maximum amount of funding available for each program is \$4,500, which would be used to cover expenses such as professional fees for facilitators, marketing, space rental, printing, etc.

The requirements for being selected as a pilot are as follows:

- The curriculum is used as is, with no modifications
- The program is facilitated or co-facilitated by a licensed clinical social worker, counseling professional, or certified coach (Society staff or contracted professional)

- The pre- and post-assessments are completed as described and the data submitted for analysis; participants are also contacted several months after the program and asked to complete a brief program survey
- A detailed accounting of expenses is provided

Details for pilot chapter application will be communicated through news sheets and other appropriate channels by December 2012. Even if you are not selected for the pilot program, we hope you will consider offering this program in 2013. The program did not appear in the budget package. We anticipate the associated costs to be \$4,000-\$5,000 for the multi-week program.

### **What is Everyday Matters?**

Everyone has their own idea of their best life. For people living with MS, the idea of that “best life” can change due to the challenges of having a chronic, unpredictable and lifelong disease.

The Society and Genzyme have teamed up to launch Everyday Matters, an interactive national project to uncover the stories of real people who are facing the everyday challenges that MS can bring on the path to one’s best life. In addition to providing a platform to share the stories of five chosen participants who are living with MS, the project will provide participants and the greater MS community with connections, access to experts and tools, which they can put to use in their own lives. Please see the May 4, 2012 [news sheet](#) for additional details.

For more information on the meeting-in-a-box tool kit or the in-person pilot program please contact Kim Koch at [kimberly.koch@nmss.org](mailto:kimberly.koch@nmss.org) or 303-698-6100, ext. 15158. For more information on the Everyday Matters project please contact Beth Clark at [beth.clark@nmss.org](mailto:beth.clark@nmss.org) or 303-698-6100, ext. 15126.



## PROGRAMS & SERVICES

July 13, 2012	CC: Chapters Presidents
<b>Kids Get MS Too Family Camp Now Accepting Applications</b>	
<b>Action Requested/Deadline: August 1, 2012</b>	

The Greater New England Chapter is opening up registration to the *Kids Get MS Too Family Camp* to all chapters interested in making this available to their pediatric MS clients and their families. This is the third year for the family retreat program.

### ***Kids Get MS Too Family Camp***

Children and teens with MS (ages 8-18 years old) and their families are invited to a 3-day, 2-night weekend to meet others with MS, share strengths and strategies, and make friends and memories that will last forever.

- Where: Camp Yavneh, Nottingham, New Hampshire
- When: August 17-19, 2012 (Friday, Saturday & Sunday)
- Cost: FREE to families
- Registration deadline: August 1, 2012

Please note: For families that live at a distance, the Greater New England Chapter will be working with the family's chapter to assist with travel costs.

Camp Yavneh is situated on 65 acres of woodlands and waterfront in southern New Hampshire, a short 90-minute drive from Boston. Camp Yavneh is kosher and the kitchen staff is very considerate of all kinds of food related requests.

Camp activities include boating, swimming and fishing at the lakefront, sports and outdoor games, and arts & crafts. This year includes a field trip to the University of New Hampshire Browne Center Challenge Ropes Course! At night there is time to dance, dine, sing, roast s'mores and tell stories, or just hang out. Pediatric MS specialists and National MS Society staff will lead seminars and discussion groups on topics of interest for kids/teens with MS, their parents and siblings.

Families can request an application packet by:

- Visiting [www.MSnewengland.org](http://www.MSnewengland.org) and following the link for *Kids Get MS Too Family Camp*
- Contacting Amber Stalker at 781-693-5127 or [Amber.Stalker@nmss.org](mailto:Amber.Stalker@nmss.org)

*Kids Get MS Too* brings families together to learn more about childhood MS in an environment geared to make both parents and kids feel comfortable. Participants are able to ask questions, talk with other kids and families who understand, and have fun while making new friends!

This program is made possible through the generous support of Robert and Jennifer Scumaci.

For more information, or to request a copy of the camp brochure, please contact Amber Stalker (contact information above).



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

July 13, 2012

### Study Identifies Possible Target of Immune Attacks in Some People with MS

Researchers have identified a protein that may be a target of the immune attack in some people with MS, according to a new study published in *The New England Journal of Medicine*. An immune response to this protein – a protein called “KIR4.1,” which is found on several types of brain cells – was observed in the serum of 47% of people with MS who were tested. Further research is needed to confirm these findings, and to understand what the role of this protein may play in MS and its potential for developing new treatments. Rajneesh Srivastava, MSc and Bernhard Hemmer, MD (Technische Universität, Munich) led the international team, who are supported by grants from the German Ministry for Education and Research and the National MS Society, among others (2012;367:115-23, <http://www.nejm.org/doi/full/10.1056/NEJMoa1110740>).

**Background:** Multiple sclerosis involves immune system attacks that damage the brain and spinal cord, particularly myelin (the substance that surrounds and supports nerve fibers). Myelin-making cells and nerve fibers are also damaged during the course of the disease. The spinal fluid of most people with MS contains increased amounts of a type of antibody called IgG. Antibodies are immune proteins directed against an immune target, or “antigen.” IgG antibodies are present almost exclusively in infectious and inflammatory disorders and are usually directed against the disease-causing agent. However, previous attempts to identify antigens to which antibodies are targeted in MS have failed. The current study focused on the serum portion of blood samples from people with MS and from others, rather than on spinal fluid.

**The study:** In a series of experiments, the authors screened serum samples from people with MS and observed that IgG antibodies were attaching themselves to specific myelin-making cells. Using “proteomics” – advanced technology that scans hundreds of thousands of proteins simultaneously – they screened numerous proteins on the cells. They identified the protein

KIR4.1 as the target of the IgG reaction. KIR4.1 is an ion channel; these are proteins that are active on the surfaces of several types of brain cells and are critical for cell function.

The team then developed a method of testing people for the presence of antibodies against KIR4.1 in serum samples, and found antibodies to KIR4.1 in a substantial proportion of people with MS in comparison with others tested. In fact, the antibodies were found in serum of 186 of 397 (46.9%) people with MS, versus only 3 out of 329 people with other neurologic disorders, and in none out of 59 people without disease.

Further studies revealed that when anti-KIR4.1 antibodies that were obtained from people with MS were injected into mice, abnormalities in the nervous system occurred. In previous studies, KIR4.1 has been shown to be important in myelin formation, so the authors conclude that this protein is a plausible candidate to be a target of the immune attack in at least some people who have MS. The investigators did not observe any clinical or other differences in people with MS who had the antibodies versus those who did not. How this protein may be involved in MS, and whether this finding will lead to new approaches to treating MS, awaits further research.

**Comment:** In an accompanying editorial, Anne H. Cross, M.D (Washington University School of Medicine, St. Louis) and Emmanuelle Waubant, M.D., Ph.D. (University of California, San Francisco) discuss the strengths of this study. “First, the authors used an unbiased approach to search for serum antibodies specific to patients with multiple sclerosis and, once they found them, methodically sought the target,” they write.

The specific role of the protein awaits definition, especially since half of the people with MS did not have the antibodies to KIR4.1. They note that even if these antibodies arise sometime after the nervous system has already sustained damage in MS, “it is conceivable that they may perpetuate destruction of the central nervous system.”



Read more (<http://www.nationalmssociety.org/research/stop/index.aspx>) about efforts to stop MS in its tracks.