



## PROGRAMS AND SERVICES

April 15, 2011	CC: Chapter Presidents
<b><i>Keep S'myelin</i>® Issue #13</b>	

Issue #13 of *Keep S'myelin*® will be arriving at your chapter and in subscribers' mailboxes over the next several weeks. This issue is entitled *Fun Activities* and it contains games for children and families, reader-submitted materials and important information for parents. *Keep S'myelin* is a newsletter for children (ages 5-12) who have a parent or loved one with MS.

Distribution to chapters and subscribers is managed centrally by the Programs and Services team. Registration requests are managed through the IRC, with interested persons registered in Altair. For more information on the Altair registration process please contact Heather Webb Jones at [heather.webb@nmss.org](mailto:heather.webb@nmss.org).

The materials in *Keep S'myelin* are not dated, so they have a long "shelf-life." Please distribute this valuable resource as widely as possible to families in your area:

- Distribute *Keep S'myelin* at chapter programs and events, including your fundraising events. *Keep S'myelin* makes a great stuffer for the MS Walk goodie bags.
- Make sure branch offices have an adequate supply to distribute locally. Branch offices can request additional copies from their chapter office.
- Conduct targeted mailings and distribution to MS clinics, physicians and other health provider offices, libraries, schools, self-help groups, etc. *Keep S'myelin* also is a great addition to newly diagnosed packets.
- Advertise *Keep S'myelin* in your chapter's newsletter and website.

All 24 issues of the newsletter are available on the National MS Society website in both downloadable PDF and interactive versions.

We welcome your suggestions and comments about *Keep S'myelin* and hope it is viewed as a valuable resource. Questions and comments may be directed to Kim Koch at 303-698-6100, ext. 15158 or [Kimberly.koch@nmss.org](mailto:Kimberly.koch@nmss.org).



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April 15, 2011

CC: Chapter Presidents

### 2011 Scholarship Program Awards and other news

Thanks to all chapters for your participation in the 2011 scholarship program.

Applicants have been reviewed and finalists selected. Notification letters will be mailed to all recipients and non-recipients on April 15<sup>th</sup>. Please do not contact students or publicize scholarship recipients until end of April when notifications have been received.

**Stats:** Nationwide we received 811 eligible applications and awarded 439 new scholarships – over 100 more recipients than last year. In addition, 200 renewals were granted.

New awards total \$741,450 and renewals total \$452,900 for a grand total of \$1,194,350. This is our most successful year in terms of number of recipients and dollar amounts awarded. We appreciate all your efforts in promoting and growing this program!

**Thanks:** We would like to acknowledge the outstanding support of chapters, Diversified Developers Realty, Teva Neuroscience, CentiMark, the O'Donnell Family Foundation and the Modestus Bauer Foundation—and all of the many donors and event participants nationwide who make this program possible and who change so many lives with their contributions.

**Publicity:** All recipients will be listed by state/chapter/recipient name on our national web site by end of May. The top scholars will also include brief bios and photos. All recipients are asked to email a digital photo to the home office by May 16<sup>th</sup> and photos will be forwarded to chapters. Chapters can publicize their recipients via their local website, chapter newsletters and press releases. Please use your chapter website to recognize and honor your scholarship recipients. We have found that families are very proud to see their child recognized in this way, and this can be a good way to drive traffic to your site. You may also want to use your site as a reference for donors as you develop relationships for future funding. For chapters who find a 'Swiss cheese' template helpful, a press release template is posted on SharePoint under Programs and Services/Scholarship Information. (**Note:** A list of students who did not agree to terms of the media release was forwarded to chapters.)

**Altair:** The home office will upload all applicants to Altair. Please wait for further instructions on how to enter the awards once the upload is complete.

**Top Scholars:** The home office will recognize 17 top scholars and offer them the opportunity to apply to renew their awards. The Kathryn Dailey Scholarship is a one-time award.

## 2011 TOP SCHOLAR RECOGNITION

### Presidential Scholar

Rebecca Merlenbach – Gateway Area Chapter

### Mike Dugan Scholar

Breanna Burkes –Alabama-Mississippi Chapter

William Rosser – Central Virginia  
Jessica Plaggenberg – Gateway Area  
Jared Applebaum – Gateway Area  
Andrew Smith – Greater Delaware Valley  
Lauren DiLorenzo – Greater Illinois  
Caitlin Lowell – Greater New England  
Jessica Curry – Inland Northwest

Ryan Vesey – Minnesota  
Brianna Johnson – Minnesota  
Jane Brach – NY City-Southern NY  
Jessica Axelrod – NY City-Southern NY  
Shelby Kramer – North Central States  
Brittany Wyre – Southern California-Nevada  
Christopher Jacobus – Upstate NY  
Rebecca LeBeau – Wisconsin

Jessica Walls – Northwestern Ohio – Recipient of Kathryn Dailey Scholarship

**Top scholar awards:** The home office will supplement whatever the chapter has already awarded the student so that their award is the maximum \$3,000. We will also provide each top scholar an equal opportunity to renew their scholarship for up to four years. We ask chapters who already offer renewals to continue their support of top scholars, and the home office will continue to supplement the award if necessary. Chapters are not obligated to provide any funding for renewals, though we know several of you have this in your plans. Top scholar renewals will be competitive—dependent on the student’s academic performance and renewal essay—and on our ability to obtain funding.

**Scholar Engagement:** It is important to keep your scholarship recipients involved in the National MS Society. These young scholars have an important connection to the Society and may someday become valued volunteers and donors. They can also inspire and motivate more people to give to your chapter’s scholarship program by simply being willing to share their story. Please read the section on “Keeping Your Students Involved” in the [Scholarship Manual](#), which is posted on SharePoint under Programs & Services > Scholarship Program.

Please contact Wenda Carlson with any concerns or questions.

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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs, Development

**April 15, 2011**

### **Positive Results Announced from Phase 3 Study of Oral BG-12**

Biogen Idec announced that the experimental oral therapy BG-12 significantly reduced the proportion of people with MS who experienced relapses in a two-year study of more than 1200 people with relapsing-remitting MS. Although its exact mode of action is not known, BG-12 is thought to inhibit immune cells and molecules involved in MS attacks on the brain and spinal cord. The results were announced in an April 11 press release. Data analysis is ongoing and the company expects to provide a full report at an upcoming medical meeting. Another trial of BG-12 is currently underway.

Background: Multiple sclerosis involves immune system attacks against brain and spinal cord tissues. Although its exact mechanism of action is not known, BG-12, an oral drug, is thought to inhibit immune cells and molecules and may be protective against damage to the brain and spinal cord. In an earlier phase 2 study, compared to inactive placebo, the highest tested BG-12 dose led to a 69% reduction in active inflammation on MRI scans from weeks 12 to 24. Side effects (formally known as adverse events) included abdominal pain, flushing, headache, fatigue, and feeling hot. (*The Lancet* 2008;372:1463-1472, [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(08\)61619-0/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(08)61619-0/abstract)).

This Study: The primary goal of the DEFINE study was to determine whether BG-12 could decrease the proportion of participants experiencing relapses and whether the agent was safe and well tolerated. Secondary objectives included assessing BG-12's effects on the frequency of relapses, disability progression, and disease activity detected by MRI.

Participants were randomly assigned to one of two treatment groups receiving different doses, or a group receiving placebo. According to the press release, in both groups taking BG-12, the primary endpoint was met, meaning a significant reduction in the proportion of people experiencing relapses at 2 years. All secondary endpoints were met as well in these groups, with

significant reductions in relapse rate, disease activity on MRI scans, and in disability progression as detected by the EDSS, a standard scale that measures disability. According to the press release, adverse events were similar to those experienced during the Phase 2 study (those included abdominal pain, flushing, headache, fatigue, and feeling hot):

Comment: These positive results are the first reported from this large, Phase 3 study of BG-12. Full details and evaluation of this study, and from another Phase 3 study now underway, should help define the safety and promise of BG-12 as a potential therapy for relapsing MS.



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## RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

April 15, 2010

### Noted Mayo Clinic Neurologist and Researcher Dr. Brian Weinschenker Wins 2011 John Dystel Prize for MS Research

Professor Brian G. Weinschenker, MD, has been chosen by a committee of his peers to receive the National MS Society/American Academy of Neurology's 2011 John Dystel Prize for Multiple Sclerosis Research. Dr. Weinschenker (Mayo Clinic, Rochester, MN) is being honored for groundbreaking findings relating to the diagnosis and treatment of MS. The \$15,000 prize is being presented at the annual meeting of the American Academy of Neurology in Honolulu.

“Dr. Weinschenker’s discoveries have had enormous impact on contemporary MS clinical practice,” said Dean Wingerchuk, MD (Mayo Clinic, Scottsdale, AZ), who nominated Dr. Weinschenker to receive the Dystel Prize.

Dr. Weinschenker’s contributions: Dr. Weinschenker made some of his earliest contributions to the field as the first author of a series of landmark papers describing the natural history of MS. Together with colleagues at the University of Western Ontario led by George Ebers, MD, he analyzed a group of 1,099 people with MS who had been evaluated between 1972 and 1984 in the London, Ontario MS Clinic. The team analyzed the impact of factors determined early in the disease course on long term MS disability, and their findings still inform the design of MS studies. (*Brain* 1989;112:133-46 (<http://brain.oxfordjournals.org/content/112/1/133.abstract>); *Brain* 1989;112:1419-28 (<http://brain.oxfordjournals.org/content/112/6/1419.abstract>); *Brain* 1991;114:1045-56 (<http://brain.oxfordjournals.org/content/114/2/1045.abstract>); *Brain* 1991;114:1057-67 (<http://brain.oxfordjournals.org/content/114/2/1057.abstract>))

Dr. Weinschenker revolutionized the treatment of severe attacks of MS with a study of plasmapheresis. Plasmapheresis, or plasma exchange, is a process in which whole blood is withdrawn from an individual; the liquid portion or plasma is removed from the blood and replaced; and the blood, with all its red and white blood cells, is transfused back into the

person with a plasma substitute. This process is a successful method for treating some autoimmune diseases because it removes the circulating antibodies that are thought to be active in these diseases. Because MS may involve an autoimmune process and because damaging factors have been found in plasma from people with MS, plasmapheresis has been tried as a treatment for MS. Dr. Weinshenker carefully designed a novel study, including a control group that received a sham procedure. More than 40% of those in the plasmapheresis group had marked improvement in symptoms, compared with 5% in the control group. (*Annals of Neurology* 1999;46:878-86, <http://preview.ncbi.nlm.nih.gov/pubmed/10589540>) Because of these findings, plasmapheresis guidelines distributed by the American Academy of Neurology were revised to include its use as a back-up therapy for exacerbations of MS and other inflammatory demyelinating syndromes that are unresponsive to corticosteroids.

Dr. Weinshenker, with Dr. Wingerchuk, defined diagnostic criteria that distinguish an uncommon MS-like disorder, neuromyelitis optica (NMO, also known as Devic's syndrome), from typical MS. NMO was until recently regarded as a severe form of MS. With colleague Vanda Lennon, MD, PhD, and others, he broke new ground with the discovery of a specific antibody in the blood of individuals with NMO that is unique to this disorder. (*The Lancet* 2004;364:2106-12, [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(04\)17551-X/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(04)17551-X/abstract)) The antibody attaches to a protein, called aquaporin-4, that regulates the flow of water in brain cells known as astrocytes and leads to a cascade of destructive inflammation. Now, a positive result on a simple blood test can help a neurologist to identify people at risk for NMO early in the course of the disease, allowing appropriate treatment to be initiated early and hopefully reduce the damage caused by this disease.

Dr. Weinshenker also has contributed to our understanding of genes that make people susceptible to MS, as well as gender differences – in some cases, simultaneously. With Orhun Kantarci, MD, and other members of his team, he found that men less commonly have genetic variants that are associated with high levels of interferon gamma (a powerful immune messenger chemical linked to immune attacks in MS) production than women. This observation may partially explain why fewer men have MS than women. (*Genes and Immunity* 2005;6:153-61, <http://preview.ncbi.nlm.nih.gov/pubmed/15674394>, *Archives of Neurology* 2008;65:349-357, <http://archneur.ama-assn.org/cgi/content/abstract/65/3/349>)

Read the complete news sheet on SharePoint, at:

[http://intranet.nmss.org/Topics/cr/Pages/Weinshenker\\_Wins\\_2011\\_Dystel\\_Prize.pdf](http://intranet.nmss.org/Topics/cr/Pages/Weinshenker_Wins_2011_Dystel_Prize.pdf)