



## CHAPTER PRESIDENTS

Date: 9/04/09

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### **Tami Caesar -- New Chapter President for the Greater Delaware Valley Chapter**

I am very pleased to announce that Tami Caesar has accepted an offer to be the Chapter President of the Greater Delaware Valley Chapter effective October 2, 2009.

Tami's commitment to our mission spans 18 years with the National Multiple Sclerosis Society. She began her career as Operations Director of the Greater Washington Chapter providing oversight and management for finance, information technology, strategic and operational planning. In 1999, she assumed the role of Chapter President at the Mid Florida Chapter. During her time there, the chapter has seen strong development growth in both special events and individual and corporate giving. New clinic affiliations were established along with a growth in outreach through self help groups and the increase in delivery of services and programs.

Tami has been involved in numerous task forces: IT database solutions, Organization of Choice/Talent Management, Safeguarding Society Assets and Reputation, National Marketing and Branding Review Committees. She was elected by her peers to serve on the Executive Management Team Council; and Tami was a founding member and Co-Chair of the Southeast Collaborative, a voluntary partnership established by 11 NMSS chapters to create a regional collaborative approach to achieving the NMSS Strategic Response. Most recently, she was a member of the Society's Charting Our Future Task Force.

Tami is excited to join the Greater Delaware Valley Chapter and continue its deep tradition of support for people living with MS. Please join me in congratulating Tami Caesar on her accomplishments and wishing her the very best in this new chapter of her career.

John H Scott  
Regional Executive Vice President  
[John.scott@nmss.org](mailto:John.scott@nmss.org)



## MARKETING

9/2/09	CC: ALL
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<b><u>Design Training for 2010 Event Core Materials</u></b>	
<b>See Dates Below</b>	

Creative Services will be offering 3 design training sessions in September/October 2009 on customizing 2010 event materials. These sessions will be conducted via Webex and will cover the following topics:

- Customizing event logos in Adobe Illustrator
- Customizing event brochures and other materials in Adobe InDesign
- Exporting event logos in different formats
- Creating PDFs of brochures for review
- Packaging files for print

Below are dates, times, and Webex info for the 3 sessions.  
No need to sign up, just show up for the offerings!

**Wednesday, September 30. 11:00am – 12:30pm MST**

Go to <https://nmss.webex.com/nmss/j.php?ED=126672212=1017013927>

**Tuesday, October 6. 11:00am – 12:30pm MST**

Go to <https://nmss.webex.com/nmss/j.php?ED=126673212=1017015002>

**Tuesday, October 13. 11:00am – 12:30pm MST**

Go to <https://nmss.webex.com/nmss/j.php?ED=126673347=1017015167>

If you have trouble with the above links, just go to <http://nmss.webex.com> and look for the 2010 Core Event Materials Design Training and click JOIN.

Any questions, please contact Mark Serratonni at [mark.serratonni@nmss.org](mailto:mark.serratonni@nmss.org)

**MARKETING/PR**

9/4/09	CC: All
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<b><u>Society Social Media Update and Opportunity</u></b>	



**Updated Society Social Media Guidelines are Now Available:**

**Intranet > Topics > Marketing > Documents > Social Media Guidelines Society August 2009**

Updates include suggestions and tips from chapters, the national online marketing team, and industry consultants like Carrie Kerpen from theKbuzz. Remember the Guidelines are a starting point — a “living” document that is updated regularly. Sharing Society-wide knowledge of social media is very important. Successes, challenges, lessons learned and best practices will continue to be communicated across the Society in a variety of ways.

**Virtual Summit Acknowledgments**

We have received excellent feedback about the August Virtual Summit’s social media keynote and breakout sessions and again thank Carrie Kerpen, co-founder of theKbuzz, a social networking and strategy agency for her fantastic presentation. In addition, we acknowledge and appreciate the work of the many chapter staff who participated in the social media breakout sessions.

**Special Social Media Opportunity for the Society – from Carrie Kerpen and theKbuzz**

Carrie’s presentation was informative, practical, passionate and inspiring – among many other things! We are very pleased to announce that Carrie and her team at theKbuzz have offered the Society a special social media opportunity:

**Society Facebook “thePageStarter” Program**

Summary: This two-month program will kick your social media strategy into high gear by helping you build robust and dynamic Facebook pages – includes three hours of consultation from theKbuzz experts, a custom growth plan and more. [Please review theKbuzz flyer for more information.](#)

Society Cost: \$500 (Regular Cost: \$1,888)

Deadline: This opportunity is available to the Society for a limited time. If interested, please contact Mandy Murphy at theKbuzz ([mandy@theKbuzz.com](mailto:mandy@theKbuzz.com) – or – 718-416-2899) **by September 30, 2009.**

**Social Media or General Online Marketing Questions? Please Contact:**

Rich Sarko, Director of Online Marketing, at [rich.sarko@nmss.org](mailto:rich.sarko@nmss.org) or 303-698-6100 x15171

Todd Culter, Web Manager, at [todd.culter@nmss.org](mailto:todd.culter@nmss.org) or 303-698-6100 x15202



## PROGRAMS & SERVICES

<b>September 4, 2009</b>	<b>CC: Chapter Presidents</b>
<input type="checkbox"/> <u><i>Do Not Post on NMSS.org</i></u>	Development
	Marketing
<b><u>2010 Scholarship Program</u></b>	

The start of the 2010 scholarship program is just around the corner. Foremost in the news for our 2010 program is that we have contracted with a new vendor, ACT, for the administration of the program.

Some changes to the processes include:

1. Applications will be available in online format only. A link will be posted on our scholarship web page (<http://www.nationalmssociety.org/get-involved/programs-and-services/scholarship/criteria-and-information/index.aspx>). Applicants will create a user account and password. Applicants do not have to complete the application in one session. They can log in and out at their convenience.
2. Chapter, home office and reviewer procedures should remain relatively unchanged. Chapters will request the number of applications they want to receive and they will be made available in PDF format.
3. The only information being collected by mail are the confirmation of diagnosis and the transcripts. Academic/transcript information will be entered by the applicant in the online application. You (and your reviewers) will be able to see GPA, class rank, SAT/ACT test scores, etc. The hard copy transcripts will be sent to each chapter, and it will be the chapter's prerogative to cross check the transcript with the application, as you and your selection committee deem appropriate. The language of the online application and the requirement to send documentation should discourage any falsification of information. If you should discover significant discrepancies please notify Wenda Carlson.
4. Applicants will send an email request to one required appraiser and can request up to two additional letters of recommendation. The appraisal and the recommendation letters (if any) will be included in the PDF file.

Fees to chapters are described in the budget package the same as last year: \$150 per new application and \$75 for renewals. We are expecting some savings with our new management company and will determine final fees for 2010 when we have a better scope of incidental charges...and before we do chapter billing. If there are savings as we hope, we will pass these on to you in terms of reduced fees.

## Gearing up for the 2010 program

Remember to include a link on your website to the scholarship web page starting October 1<sup>st</sup> and blurb in MS Connection. A box for the Society scholarships is scheduled for the October core pages. If you need some blurb text before the MS Connection core pages are available, please contact Wenda Carlson for recommendations.

For more in-depth details, the Scholarship Program Manual is posted on SharePoint under Topics>Programs and Services>Scholarship Information. Please take time to read and/or re-familiarize yourself with the administrative process. The manual includes:

- Home office and chapter procedures
- Annual timeline
- Frequently Asked Questions
- Review process and materials (award guidelines, scoring sheets)
- Ideas for “Developing a Local Presence”
- How to “Approach and Engage” donors
- How to “Keep your Students Involved”

Be on the lookout for scholarship brochures coming your way. Our local printer will be sending a small supply to each chapter (at no cost), which should arrive in the next week or two. Additional brochures can be ordered from Chapter Supplies. Use these brochures for:

- Students/potential scholars – to communicate the basics of how to apply, when to apply, who is eligible, etc.
- Potential funders/financial supporters – to communicate the basics of the program (what they would be supporting), showing faces and some hint of the impact it has, and give them info on how to learn more about supporting scholarship in their area.
- General audience – to show this great direct assistance program as just one of the many compelling programs we offer. Not just for people with MS but for their families too.

Susan Goldsmith in the Development Department is available for consultation around donor funding of the scholarship program. Please contact her at [susan.goldsmith@nmss.org](mailto:susan.goldsmith@nmss.org) or 303-698-6100, ext. 15102.

Thank you all for your growing support of this program!

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## PROGRAMS & SERVICES

September 4, 2009	CC: Advocacy
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<b><u>National Disability Employment Awareness Month</u></b>	

Did you know that October is National Disability Employment Awareness Month (NDEAM)? The U.S. Department of Labor’s Office of Disability Employment Policy (ODEP) plans a variety of activities and offers materials in recognition and celebration of this congressionally designated month. This year’s theme is **Expectation + Opportunity = Full Participation**. There are ways that you can get involved:

- Order NDEAM posters and display them proudly in support of our many clients in the workforce. Information about the posters can be found at [National Disability Employment Awareness Month](#). Posters are free and available in English and Spanish.
- Promote Disability Mentoring Day (DMD) with the clients and employers you work with. This year, DMD will be commemorated on Wednesday, October 21, 2009. This national event, hosted by the American Association of People with Disabilities (AAPD), promotes “career development for students and job seekers with disabilities through hands-on career exploration, on-site job shadowing, and ongoing mentoring leading to internship and employment opportunities.” The event is a community-based program and there are local coordinators across the country. You can contact your Local Coordinator to get information about the activities and events that will be available in your area as part of Disability Mentoring Day. For a list of coordinators by state, check out [Disability Mentoring Day Local Coordinators](#). For additional information about DMD, check out [Disability Mentoring Day](#). Though officially commemorated on October 21<sup>st</sup>, DMD activities may occur on many different days.
- Check your employment resources to make sure they are up-to-date. For example, the Career One-Stop website has streamlined their re-employment resources into one navigation page: [CareerOneStop ReEmployment Portal](#). Disabilityinfo.gov has become Disability.gov, with a new look and easy-to-use set of employment resources: [Employment: Disability.gov](#). The Job Accommodation Network now has live chat available for accommodation questions (hover over their “Contact Us button to pull up the live chat link: [The Job Accommodation Network](#)). On that note: stay tuned as we will

have a list of employment resources posted on the intranet in the near future under Programs and Services – Employment and Insurance Resources to help with those updates.

- And finally, we are excited to announce a new collaborative partnership with a company called Hire Disability Solutions, whose mission is to help people with disabilities to obtain employment. We will provide a link on the employment pages on our website to them at [www.Hireds.com](http://www.Hireds.com) and will also post special opportunities and invite you also to do so when they become available. Here is the first:

*Hire Disability Solutions is seeking individuals with MS and their caregivers to fill certain work-at-home positions. If you are interested, please go to [www.Hireds.com](http://www.Hireds.com) and click on the Teletech icon to work at home today. For a listing of all employment opportunities that are currently available for job candidates with disabilities, browse and click on the Featured Employers icons. Any questions may be directed to Hire Disability Solutions at 1-800-238-5373 or e-mailed to the CEO of Hire Disability Solutions, Jeffrey Klare, at [JKlare@hireds.com](mailto:JKlare@hireds.com).*

This is an exciting time in the history of employment for people with disabilities, so what better than to recognize and celebrate the important role people with disabilities play in the workforce through these great opportunities in October!

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## RESEARCH/CLINICAL UPDATE

<b>Keyword:</b>	BIIB017 (PEGylated interferon beta-1a)
<b>Section:</b>	TREATMENTS, INVESTIGATIONAL
<input type="checkbox"/> <a href="#">Do Not Post on NMSS.org</a>	Chapter Presidents, Programs

September 4, 2009

### **MS Trial Alert:**

### **Investigators Recruiting 1260 People with MS for Study of PEGylated Interferon Beta-1a**

**Summary:** Investigators worldwide are recruiting 1260 people with relapsing MS for a Phase III clinical trial comparing the effectiveness of BIIB017 (PEGylated interferon beta-1a, delivered under the skin) and inactive placebo. The study is sponsored by Biogen Idec.

**Rationale:** Avonex® (interferon beta-1a, Biogen Idec) is approved by the U.S. Food and Drug Administration for the treatment of people with relapsing forms of MS to slow the accumulation of physical disability and decrease the frequency of clinical exacerbations. BIIB017 is a “pegylated” form of the interferon beta-1a molecule. Pegylated molecules are attached to a molecule of polyethylene glycol, which enables them to maintain effects in the body for longer periods of time.

This formulation has been tested in healthy individuals in two phase I clinical trials, but has not yet been tested in people with MS. If proven to be safe and effective in treating MS, this drug may help to reduce the frequency of administration of interferon beta and the flu-like side effects that can occur with each treatment.

**Eligibility and Details:** Investigators are seeking participants aged 18 to 55 who have experienced at least two relapses that have been medically documented within the last three years, with one occurring in the last 12 months.

Participants will be randomly assigned to one of three groups, for a study period of approximately two years and three months:

- Placebo
- BIIB017 125 mg delivered subcutaneously (under the skin) every two weeks
- BIIB017 125 mg delivered subcutaneously every four weeks

The primary objective of the study is to determine the effects of the drug versus placebo on the annualized relapse rate. Secondary objectives include the effects on tissue damage as observed on MRI scans, quality of life, and disease progression as measured by the EDSS scale.

**Contact:** To learn more about the enrollment criteria for this study, and to find out if you are eligible to participate, please email [ADVANCEStudy@biogenidec.com](mailto:ADVANCEStudy@biogenidec.com). As of now, sites are located in the following cities in the United States:

Lexington, KY  
Dallas, TX  
Akron, OH  
Raleigh, NC  
Franklin, TN  
St Petersburg, FL  
Atlanta, GA  
Round Rock, TX

[Download a brochure that discusses issues to think about when considering enrolling in an MS clinical trial \(PDF\).](#)

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## RESEARCH/CLINICAL UPDATE

[Do Not Post on NMSS.org](#) | CC: Chapter Presidents, Programs

September 4, 2009

### **New Studies Associate Smoking with Tissue Damage and Disease Development in People with MS**

In a further confirmation of the negative impacts of cigarette smoking by people who have multiple sclerosis, one study recently reported finding links between smoking and brain tissue damage observed on MRI (magnetic resonance imaging) scans of 368 people with MS. Robert Zivadinov, MD, PhD, and Murali Ramanathan, PhD (State University of New York, Buffalo) and colleagues report their findings in *Neurology* ([2009;73:504-510](#)). A second study also reports negative effects of tobacco smoking, but cites no association between the use of Swedish snuff and risk for MS. Anna K. Hedström, MD, and colleagues (Karolinska Institute, Stockholm) report on a study of 902 people with MS in *Neurology* (2009;73:696–701).

**Background:** MS is not contagious or directly inherited, but scientists have identified factors that help determine whether a person will develop MS. These factors include genes, gender, age, geography, and ethnic background. Previous studies have suggested that cigarette smoking increases a person's risk for developing MS. Some studies have also hinted that smoking could contribute to disease progression (worsening), and a [recent study](#) found that MS disability progressed more quickly in smokers, and suggested that quitting may delay MS progression.

**The Buffalo Study:** The team administered a questionnaire on smoking history and current smoking habits to 368 consecutive people with MS during the course of routine clinical follow-up visits, which showed that 240 had never smoked, and 128 were current or former smokers. The investigators compared participants' MRI scans that measured disease activity and brain tissue atrophy (shrinkage), and the results were correlated with smoking history/habits and clinical characteristics of their disease. Smoking (active smokers or ever-smokers) was associated with increased physical disability as measured by the EDSS (Expanded Disability Status Scale) over that observed for never-smokers, supporting previous studies. Smokers also had greater amounts of tissue damage (lesions) observed on gadolinium-enhanced MRI (which highlights areas of breakdown in the blood-brain barrier that indicate inflammation); a greater volume of brain lesions; and more brain atrophy.

The Stockholm Study: The team looked at the incidence of MS tobacco smokers and the users of Swedish snuff in a sample of 902 people with MS and 1,855 people without the disease. Smokers had an increased risk of developing MS, and the risk increased with the cumulative amount of smoking. There was an apparent association between using snuff and decreased risk of MS. The authors suggest that this implies that nicotine – which is an ingredient of both – may not be the culprit for the clear increase in risk among cigarette smokers; more research is necessary to determine the molecular mechanisms for this risk increase. It is important to note that Swedish snuff, and all oral tobacco, can cause cancer of the mouth, pancreas, and esophagus, as well as gum disease, destruction of the bone sockets around the teeth, and tooth loss.

Comment: These studies adds new information to the case against cigarette smoking for people with MS, providing details on how smoking may affect underlying tissue damage. The National Institutes of Health provides resources to help quit smoking: visit [smokefree.gov](http://smokefree.gov) or call 1-800-QUITNOW (1-800-784-8669). [Read more](#) about healthy living with MS.

-- Research and Clinical Programs Department



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## RESEARCH/CLINICAL UPDATE

[Do Not Post on NMSS.org](#) | CC: Chapter Presidents, Programs

September 4, 2009

### **International Team Refutes Finding of Evidence of Epstein-Barr Virus in Brains of People with MS**

Harvard investigators funded in part by the National MS Society, in collaboration with an international team, reported finding no evidence of Epstein-Barr virus infection in the brains of people with MS, refuting earlier studies claiming physical evidence of the virus in brain specimens. This study does not address other previous findings showing that people with high antibody levels against the virus or who have experienced infectious mononucleosis as a result of the virus are more susceptible to MS than the general population, and does not close the door on EBV as a possible risk factor for MS. Researchers Kevin C. O'Connor, PhD (a Society Career Transition Fellowship recipient), Simon N. Willis, PhD, and others report their findings in the journal *Brain*, published early online July 28, 2009.

(<http://brain.oxfordjournals.org/cgi/content/abstract/awp200>)

Background on EBV and MS: Epstein-Barr virus is a herpesvirus known to cause infectious mononucleosis and other disorders. Most people in the general population have been exposed to the virus. After an initial infection EBV becomes latent or dormant, and can be reactivated at a later date. EBV infects B cells, the cells of the immune system that make antibodies. There is currently no vaccine that can protect against an initial infection by EBV, and no anti-viral medication that can fight the active infection or kill latent virus harbored in the body. This virus does not infect other species, so research on EBV can only be carried out in humans.

The cause of MS, an unpredictable immune-mediated disease that attacks the central nervous system, is unknown, but the disease is thought to occur when susceptible individuals encounter a triggering factor or factors in their environment. Several previous studies have suggested a possible link between EBV and MS, but other infectious agents have also been linked to MS, leading some researchers to suggest that the way the immune system responds to infections, rather than the infectious agent itself, may lead to the onset of MS. Previous examinations of MS brain tissue for signs of EBV have been mixed, some negative and some positive.

In 2006, National MS Society-supported investigators at Harvard and Kaiser Permanente showed evidence that individuals who had elevated antibody titers against EBV were twice as likely to develop multiple sclerosis up to 20 years later ([Archives of Neurology](#)). In 2007, investigators from Italy (Istituto Superiore di Sanita, Rome) and the United Kingdom reported finding traces of Epstein-Barr virus in postmortem brains examined from people with different forms of MS, finding evidence of EBV infection in immune cells (B cells and plasma cells) that had infiltrated the brain in 21 out of 22 brains ([Journal of Experimental Medicine](#)). And earlier this year, University of Buffalo researchers also [reported](#) on a link between EBV antibody levels and the loss of nerve tissue, and on a study exploring interactions between a person's genes and EBV.

This study: The investigators conducted this study to try to shed better light on whether an EBV infection in the brain actually triggers or participates in MS activity, or whether the link with MS is less direct. They focused on trying to replicate previous findings of traces of EBV in brains of people with MS and EBV infection in immune cells that had infiltrated MS brain specimens, examining in some cases specimens from the same brains that had been used by the Italian investigators for their 2007 study. In total they examined multiple specimens from 24 MS brains.

The team used several different techniques to detect the presence of EBV, including PCR (polymerase chain reaction) to amplify very low signals and *in situ* hybridization, and also looked for the virus with a tissue staining technique (immunohistochemistry). Signs of EBV were absent from MS lesions, even those that contained B cells, the type of immune cell that harbors the virus. The team also looked at B cell follicles in or near the meninges, the membrane that encloses the brain, where the Italian investigators had reported striking evidence of the virus. They found low levels of EBV in only two of the 12 specimens of meninges examined.

The investigators conclude that EBV infection in the brain is rare in MS and unlikely to be directly involved in MS pathology in most cases.

Comment: This study raises doubts about the possibility that persistent Epstein-Barr virus infection in the brain plays a role in multiple sclerosis. It also draws attention to the fact that there remain some unresolved technical issues related to detecting the virus. This study does not negate other findings showing that people with high antibody titers to Epstein-Barr virus, or who have experienced infectious mononucleosis as a consequence of EBV, are more susceptible to MS than the general population, and does not close the door on EBV as a possible risk factor for MS.

-- Research and Clinical Programs Department