



ADVOCACY

Date: November 20, 2009	CC:
	Chapter Presidents
Correction: Total Numbers of MS Activists	
Action Requested/Deadline: NA	

*****Note:** Our percentage formula was off. The numbers are correct, but the percent increase has been updated below.***

Total Numbers of MS Activists by Chapter and by State

November 1 totals of MS activists by chapter and by state are now available **on the Intranet under Advocacy > Convio for Advocacy**. We'll continue to track and report these numbers through December 31, 2009.

Top Chapters	Increase since March	Total to Date
▪ Southern California	262%	6,057
▪ New York City	97%	2,621
▪ Ohio Valley	61%	1,151
▪ Greater Illinois	57%	3,513

Top States	Increase since March	Total to Date
▪ California	105%	10,286
▪ Illinois	51%	3,821
▪ Alaska	46%	158
▪ Ohio	41%	4,968
▪ District of Columbia	41%	524
▪ Maryland	40%	3,258

For more information, contact Tara Raeber in the Public Policy Office at 202-408-1500 or tara.raeber@nmss.org



ADVOCACY

Date: 11/20/09	CC: All
Public Policy Conference 2010	
Action Requested/Deadline:	

Please save the date for the **2010 Public Policy Conference – March 1-3, 2010 at the Washington Hilton & Towers in Washington, D.C.**

The annual MS Public Policy Conference is our national gathering of MS activist leaders. The Society has had a successful legislative year that included the introduction of several pieces of legislation, support to increase funding for MS research and influencing major health care reform legislation! Join nearly 400 MS activists as we head to Capitol Hill to meet with federal legislators to advance policies that directly impact the lives of people living with MS and their families.

When identifying those activists who will join you at the Conference, keep in mind that we are looking for individuals who:

- Are active volunteers with a passion for advocacy or are already serving your Government Relations Committee
- Will be leaders in MS activism, assisting with MS issues throughout the year and recruiting other MS activists
- Are veterans living with MS
- Have a keen interest in the legislative process and the ability to cultivate activism on the Hill and at home.

Schedule:

- The Conference will begin with an Opening Reception on Monday evening, March 1st. We recommend arriving in Washington, D.C., before 5 p.m. EST.
- The Conference will conclude with a day of Congressional meetings on Capitol Hill on Wednesday, March 3rd. Like last year's conference we will not have a closing reception on Capitol Hill.
- You can make travel plans to return after your last Congressional meeting.

Additional information on registration and our 2010 priority policy issues will be provided later this year. If you have questions in the meantime, please contact the Public Policy Office at 202-408-1500.

Shawn O'Neil
Vice President
Federal Government Relations



ADVOCACY

November 20, 2009	CC:
	Programs and Services
<u>Call for 2010 PPC Visit Coordinators</u>	
Action Requested/Deadline: Dec 18, 2009	

The 2010 Public Policy Conference begins on March 1 and will culminate on Wednesday, March 3 as volunteers and National MS Society meet with members of Congress to advocate for the interests of those affected by MS.

In order to facilitate and arrange these appointments with members of Congress, please identify a state coordinator, from among all chapters within your state territory, to track all scheduled appointments and provide this person's name to Renee Vandlik at Renee.Vandlik@nmss.org by Friday, December 18.

An overview of the state coordinator's roles and responsibilities will be provided on:

Wednesday January 6, 2009 at 3:00 pm ET/2:00 pm CT/1:00 pm MT/12:00 pm PT
<https://nmss.webex.com/nmss/j.php?ED=129675857&UID=0>

Telephone Number: 1-866-417-3327
Conference Code: 2513408376



CHAPTER PRESIDENTS

November 20, 2009	CC: Development
	Marketing
Marketing and Development Team Realigns to Support Regional Advancement	

As our organization continues to evolve to best serve people affected by MS through the advancement of a regional structure, the national marketing and development team has made changes in its team structure to more effectively engage and interact with our colleagues across regions, individual chapters, and other home office departments.

The below organizational chart outlines each team and their respective roles. As you'll see, we have organized into four key areas -- some of which are already existing teams and some of which are new. Further, we have dedicated teammates to support the Advancing the Regions team in each core focus area:

- Campaign and Corporate Development
- Marketing
- Individual Giving
- Corporate and Community Relations

We believe this structure will allow us to work more effectively and efficiently across the organization, as well as allow us to maximize our team's diverse talents to support the Society during this exciting time of growth and new opportunities.

Please don't hesitate to contact me with questions.

Graham McReynolds
Executive Vice President, Marketing and Development
Graham.McReynolds@nmss.org

NATIONAL MULTIPLE SCLEROSIS SOCIETY Organization Chart – Campaign Development October - 2009

Graham McReynolds
Executive Vice President
Development and Marketing

Betty Ross
Associate VP
Campaign Development

Michelle Larsen
Development and Marketing
Specialist

Amy Boulas
Director, Walk MS

Fred Flanders
Sr. Director, Corporate Teams
and Relations

Rachael Nuwash
Director, Bike MS

Christy Fath
Sr. Director, Campaign and
Corporate Development,
Advancing the Regions

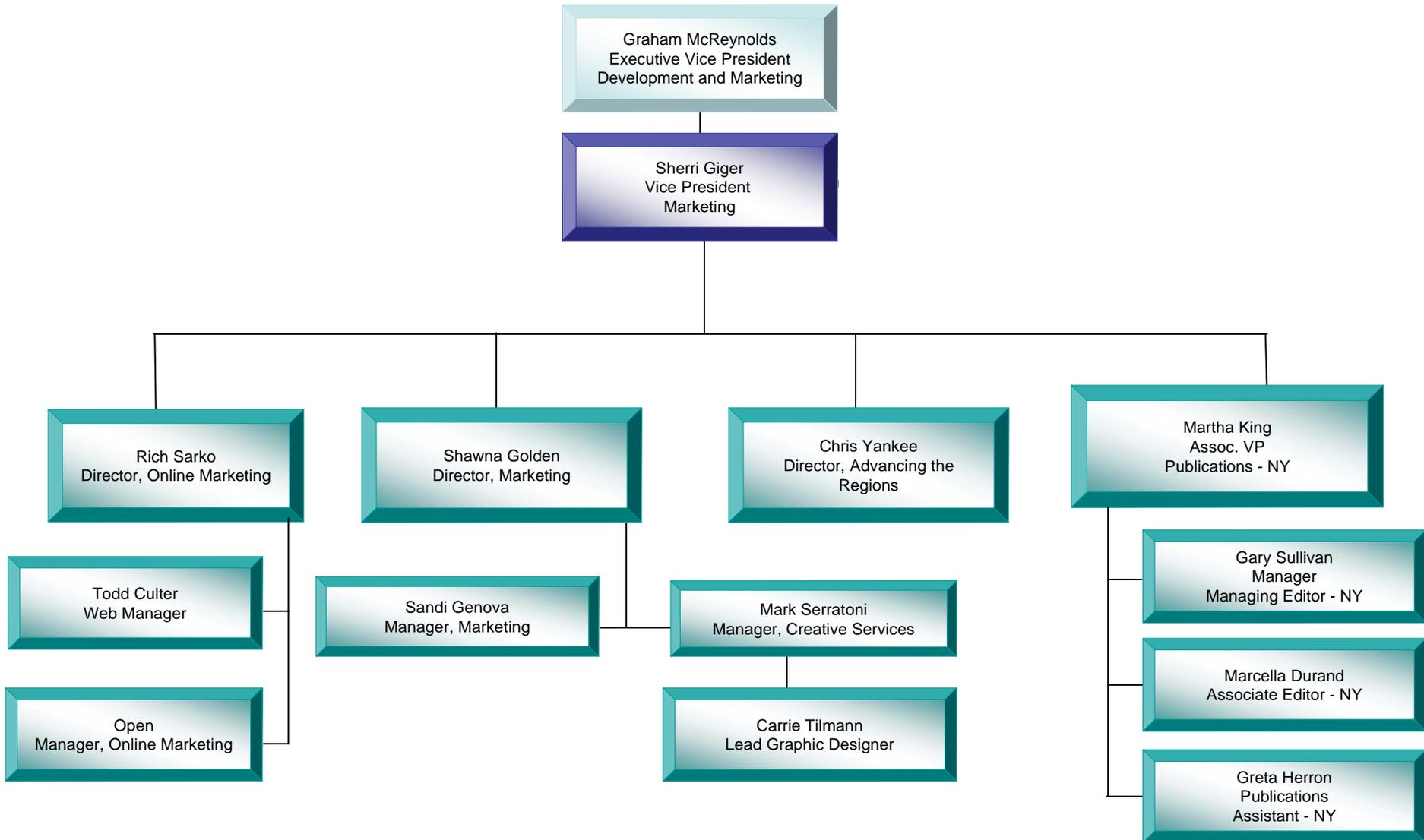
Ellen Penrod
Sr. Manager, Walk MS

Sarah Klein
Sr. Manager, Bike MS

NATIONAL MULTIPLE SCLEROSIS SOCIETY

Organizational Chart –Marketing

October - 2009



Graham McReynolds
Executive Vice President
Development and Marketing

Sherri Giger
Vice President
Marketing

Rich Sarko
Director, Online Marketing

Shawna Golden
Director, Marketing

Chris Yankee
Director, Advancing the
Regions

Martha King
Assoc. VP
Publications - NY

Todd Culter
Web Manager

Sandi Genova
Manager, Marketing

Mark Serratoni
Manager, Creative Services

Gary Sullivan
Manager
Managing Editor - NY

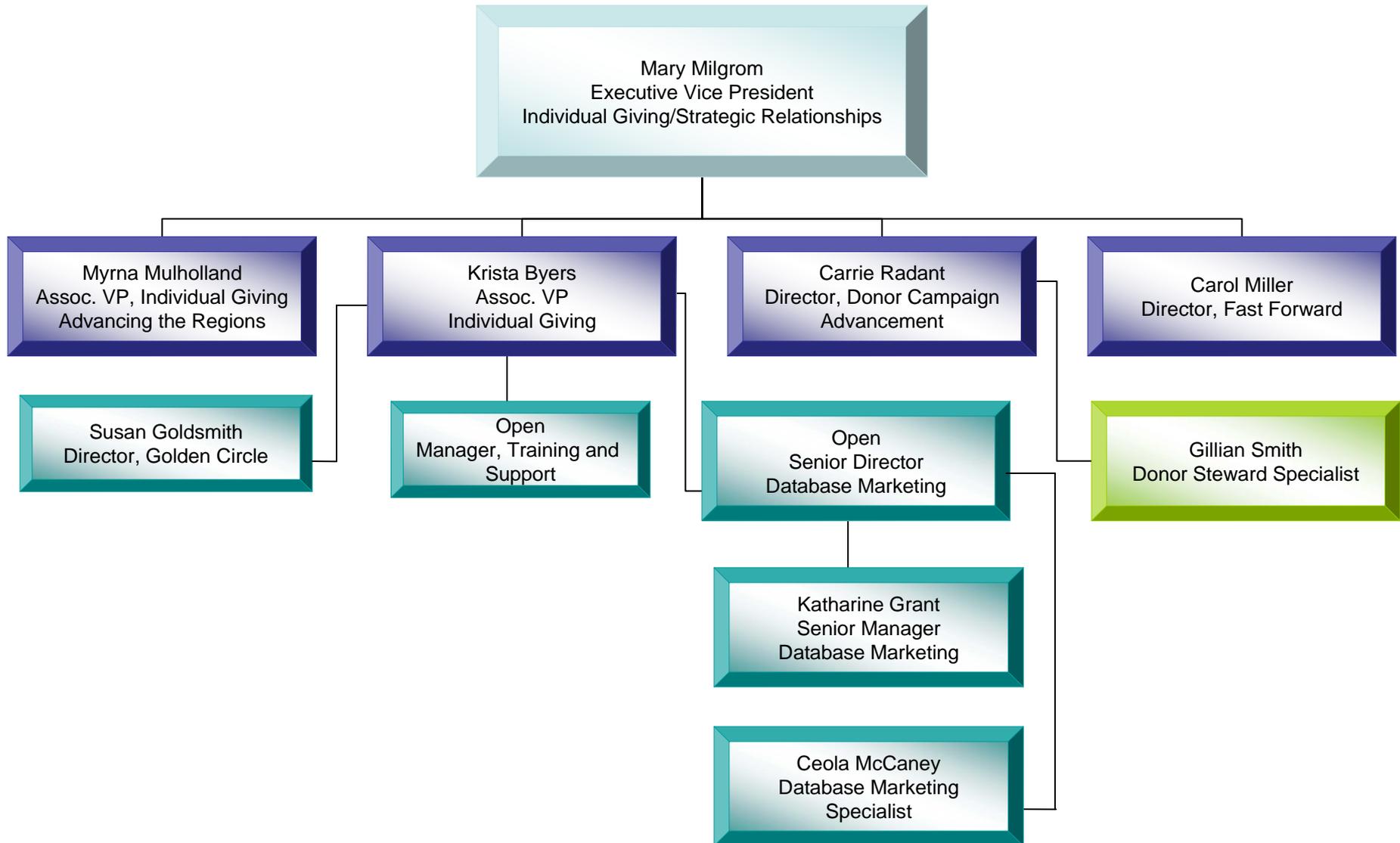
Open
Manager, Online Marketing

Carrie Tilmann
Lead Graphic Designer

Marcella Durand
Associate Editor - NY

Greta Herron
Publications
Assistant - NY

NATIONAL MULTIPLE SCLEROSIS SOCIETY
Organization Chart – Individual Giving/Strategic Relationships
October - 2009



NATIONAL MULTIPLE SCLEROSIS SOCIETY
Organization Chart – Corporate and Community Relations
October - 2009

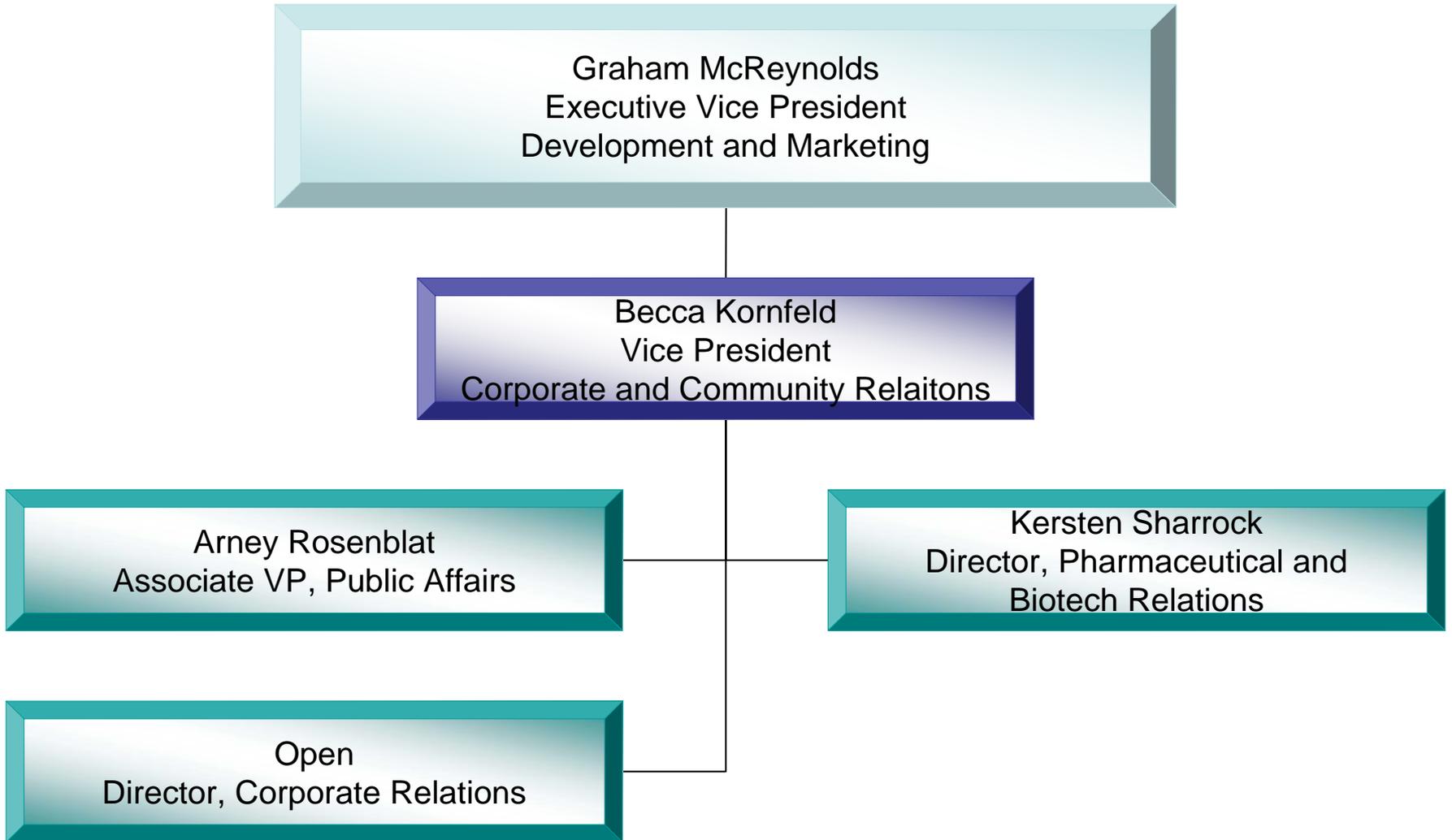
Graham McReynolds
Executive Vice President
Development and Marketing

Becca Kornfeld
Vice President
Corporate and Community Relations

Arney Rosenblat
Associate VP, Public Affairs

Kersten Sharrock
Director, Pharmaceutical and
Biotech Relations

Open
Director, Corporate Relations





CHAPTER PRESIDENTS

November 20, 2009	CC: All
<u>Summit Dates Announced</u>	

We are pleased to announce the Society's 2010 Summit – bringing staff leaders together from Marketing and Development, Programs and Services, Clinical Programs, Advocacy, and Volunteer initiatives.

When: August 10 – 13, 2010
Where: Sheraton Chicago Hotel & Towers

The Summit will begin with a reception on Tuesday evening the 10th, and conclude at approximately 12 Noon on Friday the 13th. Attendees will enjoy time together in general sessions, as well as workshops over the course of the week. The Executive Management Team meeting and Regional Management Team meetings will be held on Tuesday the 10th. Please hold the dates now, and we'll look forward to seeing you in Chicago!

Additional information will be coming in early February.



MARKETING

Date: 11/20/09

CC: All

Home Office Holiday Card Artwork Available on ftp site

In the spirit of the upcoming Holidays, the Home Office created a 2009 National MS Society Holiday Card. The artwork is currently available on the ftp site and can be used and adapted for chapter purposes. A special thank you to the Greater Delaware Valley chapter, who provided the cover photo/art for this year's card.

Chapters have access to the two versions of the card:

Artwork for the standard printed Holiday Card w/ envelope

- Card design is full color, 4.25x6 inches folded/8.5 inches flat)
- Location: <ftp://ftp.nmss.org/> in the following folder 2010 Holiday Card > 2009-NMSS-HolidayCard_Final-ForChapters Folder

Free musical e-card design:

- Go to: http://main.nationalmssociety.org/site/Ecard?ecard_id=1222
- Fill in the form. You can email to up to 10 people at a time.
- Preview the card by clicking the Preview button at the bottom of the page.
- Edit the card, if needed, then click Send.

About

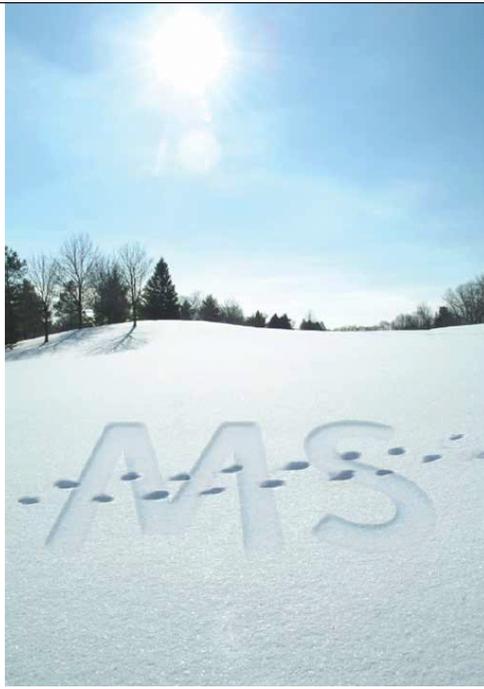
THE NATIONAL MS SOCIETY

MS stops people from moving. The National MS Society exists to make sure it doesn't. Because of your support in 2009:

The Society invested more than \$35 million to support 345 research projects around the world; We offered an extensive variety of programs, services and resources for people living with MS, including family members, caregivers and other members of their support systems; MS activists advocated for federal and local policies and government programs; More than 250,000 Bike MS and Walk MS participants raised over \$155 million; and, Thousands of volunteers across the nation served as community leaders, ambassadors and champions to support and serve people living with MS.

Join the Movement® at nationalMSSociety.org. Early and ongoing treatment with an FDA-approved therapy can make a difference for people with multiple sclerosis. Learn about your options by talking to your health care professional and contacting the National MS Society at nationalMSSociety.org or 1-800-FIGHT-MS (344-4867).

We would like to thank the Greater Delaware Valley Chapter for providing the photo on the cover of this holiday card.



Back & Front



With warmest appreciation
for helping to move us all
closer to a world free of MS.

Happy Holidays

THE NATIONAL MS SOCIETY

Inside

Questions? Please contact: Shawna Golden, Shawna.golden@nmss.org or Carrie Tilmann, carrie.tilmann@nmss.org



MARKETING

Date: 11/20/09

CC:

Chapter Marketing Plans on SharePoint

As requested, the 2010 Chapter Marketing Plans have been posted and are available to view on SharePoint, located under the [Marketing section <Marketing Plans](#). Take some time to review and learn about what other chapters are focusing on in 2010 and identify opportunities for collaboration and idea sharing.

Questions? Contact:

Sandra Genova, Sandra.genova@nmss.org
Shawna Golden, Shawna.golden@nmss.org
Becca Kornfeld, Becca.kornfeld@nmss.org
Chris Yankee, christopher.yankee@nmss.org



PROGRAMS & SERVICES

Date: November 20, 2009

CC:

New Teleclass Programs from *Relationship Matters: A Program for Couples Living with MS*

The *Programs and Services Department* announces two new teleclass series for couples living with MS, **“8 Hours to a Lifetime of Relationship Satisfaction”** and **“Jumpstart Your Relationship: Reclaim Your Well-Being”**. Both teleclasses are being offered in FY 2010 as part of the federally-funded program, *Relationship Matters: A Program for Couples Living with MS*.

“8 Hours to a Lifetime of Relationship Satisfaction” is adapted from the in-person workshop curriculum of the same name. While there is some discussion about MS, the focus of this series is on the development of foundational communication skills. Feedback received from couples participating in the pilot program include the preference for a more general communications class because they are already overwhelmed with too many issues related to MS, and the series is a way to do something together that does not center on MS or just the person who has it.

“Jumpstart Your Relationship: Reclaim Your Well-Being” is a new program, and was developed in collaboration with Can Do Multiple Sclerosis (formerly The Heuga Center for Multiple Sclerosis). Different from the *8 Hours* teleclass series, this curriculum, while teaching basic communications skills, does so within the context of living with MS. Each weekly call focuses specifically on MS symptoms, while discussing healthy ways to talk about symptoms and the emotional reactions they create. As part of the learning experience, couples will also learn practical communication strategies to deal with particular symptoms. This could be a good program recommendation for people who traditionally avoid "relationship skills"-type classes and perhaps feel more comfortable talking about something more shared and familiar, like issues with fatigue and the impact on the relationship.

Both teleclass series are scheduled to begin in January, 2010 and continue throughout the fiscal year. Each teleclass series classes takes place over a period of six weeks, with each call in the series lasting an hour and 30 minutes per week.

Pre-registration is required. This allows for the development and nurturing of the small group experience. The closed group format ensures that participants receive a good foundation for their learning and that new skills build upon others learned previously.

Couples interested in registering for a teleclass may either call 1-800 FIGHT MS (1-800-344-4867) or email couplesprogram@nmss.org with their teleclass choice. If you have a couple interested and your chapter does not use IRC services, you can tickle Jessica Roeder through Altair or email the couple's information to couplesprogram@nmss.org and we will follow up with the client.

A benefit to chapters of the teleclass programs is that they can be promoted within the chapter program plan as educational opportunities, with no program delivery costs incurred by the chapter. Class schedules and chapter-based marketing materials are available on SharePoint at: Programs and Services>Family and Youth Resources>Relationship Matters ([http://intranet.nmss.org/Topics/programs_services/Documents/Forms/Family Relationships.aspx](http://intranet.nmss.org/Topics/programs_services/Documents/Forms/Family_Relationships.aspx)). The calendars and information are constantly updated and can be used as links on your website (housed on your server), inserted in email blasts, MS Connections or any chapter programs brochure.

A current course calendar and marketing materials have been provided to chapter staff on the *Relationship Matters* contact list. Please direct all questions and requests to be added to the contact list to Lara Rezzarday at lara.rezzarday@nmss.org.

Submitted by:

Lara Rezzarday, MPA

Director, *Relationship Matters* Program

303-698-6100, ex. 15205

Lara.rezzarday@nmss.org



PROGRAMS & SERVICES

Date: November 20, 2009	CC:
<u>Upcoming Teletraining for New Self-help Group Leaders</u>	
Action Requested/Deadline: December 31, 2009	

The first teletraining for **NEW** self-help group leaders to be offered in FY 2010 is scheduled for January, 2010. The training allows new leaders to participate in discussions on a variety of important topics necessary to facilitate a self-help group. A National MS Society staff member, or consultant, and a veteran self-help group leader will facilitate the training calls. (Please note: This training is for **new** self-help group leaders only. Additional teletrainings for **all** self-help group leaders are offered throughout the year.)

The registration form, as well as additional information on training dates, times and agenda, leader pre-work requirements, and cancellation information are available on SharePoint at Programs and Services>Social Connections and Support Resources>Self-help Group Materials.

There is no charge for the training. This teletraining is made possible through an unrestricted educational grant from Teva Neuroscience.

Please direct any questions about the teletraining to Julie Gibson. Julie is a project consultant for the Programs and Services Department. She can be reached at (253) 921-2027 or Julie.Gibson@nmss.org

FROM: Kimberly Koch, MPA
Associate Vice President, Family and Support Programs
Programs and Services Department
(303) 698-6100, ext. 15158
kimberly.koch@nmss.org



PROGRAMS & SERVICES

November 20, 2009

CC: Chapter Presidents

Book and DVD for People with Primary-Progressive MS

Thanks to a generous, unrestricted educational grant from Genentech, the Society now has two new resources, a book and DVD, for people with primary-progressive MS (PPMS), their caregivers and families. People with PPMS account for an estimated 10 percent of the total multiple sclerosis population. With most of the attention focused towards the relapsing-remitting form of MS, people with PPMS often describe themselves as “orphans” of the MS world.

Primary Progressive Multiple Sclerosis - What You Need to Know, is a comprehensive book that discusses the diagnosis of PPMS, treatment and research, rehabilitation, wellness, family and social issues, and life planning. The book was written by Drs. Jack Burks, Nancy Holland and Diana Schneider and published by DiaMedica Publishing.

Bound within the book is a companion DVD, *Primary-Progressive Multiple Sclerosis - Perspectives on Moving Forward*. The DVD profiles four people living with the significant challenges of PPMS who share their strategies for maintaining health quality of life and planning for life with primary-progressive MS.

Both of these resources are a direct result of a joint National MS Society and MS Association of America conference in 2008. The goal of the meeting was to develop a better understanding of the needs of people PPMS. One outcome was a recommendation to improve the programs and services of this population, including the development of this book and DVD.

Copies of the book/DVD packets are scheduled to be shipped to chapters in December, 2009. There is no charge to chapters for the initial mailing. The number of books provided as part of this mailing was determined by client census. Chapters may wish to distribute the materials at programs that target people with progressive MS, certain self-help groups, and most certainly to individuals known to you to have a diagnosis of PPMS.

In addition to distribution methods managed by chapters, the Information Resource Center will also have copies available for distribution to clients who say they have primary-progressive MS.

Chapter requests for additional copies of the book/DVD packet should be directed Heather Webb at heather.webb@nmss.org. Chapters will be charged for shipping only. It is important to note that there are a limited number of copies of the book/DVD packets available. Once the supply is gone, the books can be ordered through Amazon.com. The book advises readers to call the Society's 1-800# for a free copy of the DVD (the IRC will distribute). Chapters can request extra copies of the DVD by contacting Heather Webb.

Special thanks go to the Minnesota, New York City - Southern New York, and Wisconsin chapters for their help on this project.

From: John Aden
Senior Manager, Program Development
Programs and Services Department
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Nationalmssociety.org

RESEARCH/CLINICAL UPDATE

cc: Chapter President, Programs

November 20, 2009

Pregnancy Study Shows Increase in C-Sections and Slightly Lower Fetal Size among Women with MS

A new study of pregnancy hospitalizations in a large national sample of women with MS shows that the disease is associated with a significant increase in cesarean deliveries and in intrauterine growth restriction (fetal weight below the 10th percentile). However, blood pressure disorders and premature rupture of membranes were not increased. Victoria Kelly, MD, Eliza F. Chakravarty, MD, and colleagues (Stanford University School of Medicine) report what they term “generally reassuring” findings in *Neurology* (Early online publication, November 18, 2009).

Background: When young women receive a diagnosis of MS, they frequently have questions about the possible effects of the disease on pregnancy and delivery, and on how pregnancy may impact their disease. Studies undertaken over the past several decades allow health professionals to provide answers to only some of these questions.

The Study: The investigators used a large database (the Nationwide Inpatient Sample of The Healthcare Cost and Utilization Project, a database that contains information from inpatient hospitalizations in 1,054 hospitals in 38 states of the United States) to analyze information on pregnancy and deliveries in women with MS, epilepsy, diabetes mellitus, and the general population during a four-year period. Specifically, they looked at the following pregnancy-related outcomes: length of hospital stay, high blood pressure problems such as preeclampsia, premature rupture of membranes, intrauterine growth restriction (small fetal size), and cesarean (surgical) delivery.

Of an estimated 15.2 million deliveries occurring overall from 2003 to 2006, 7,697 occurred in women with MS, 2,745 with epilepsy, and 112,650 with diabetes. The women with MS were more likely than women without chronic medical conditions to be older (31.6 vs. 27.5), have significantly smaller fetal size (2.7 percent of deliveries vs. 1.9 percent), and were more likely to

have a cesarean delivery (42 percent vs. 33 percent). However, they were not more likely to have blood pressure disorders (such as preeclampsia) or premature rupture of membranes. Similar increases were reported for women with epilepsy, and diabetes mellitus was associated with an increased risk of all adverse outcomes.

The authors note that the database is limited because it does not capture information about early pregnancy losses, about the severity of the women's underlying disease, their use of medications, tobacco or alcohol nor other factors that might impact pregnancy outcomes, and it cannot link deliveries to the health of the infants.

Comment: In an accompanying editorial, Gary M. Franklin, MD, MPH (University of Washington, Seattle) and Helen Tremlett, PhD (University of British Columbia, Vancouver) comment that the effects of MS on pregnancy reported here are significant, but are relatively minor in terms of effect on health of the child. They cite a critical need for more information on how MS affects pregnancy outcomes. "While we are still some way off from being able to produce evidence-based practice guidelines in MS, the Stanford group and others, in conducting population-based studies using existing computerized databases, are beginning to supply the critical information needed for this essential task."

[Read more](#) about MS and pregnancy.

-- Research and Clinical Programs Department