

INDIANA STATE CHAPTER

# MS CONNECTION

MOVING TOWARD A WORLD FREE OF MS | FALL 2010

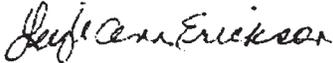


With the 2010 Indiana State Fair closing its gates on yet another successful year, I found myself reminiscing. Reminiscing about riding amusement park rides in my younger years. I grew up with the scrambler being my absolute favorite ride. Remember that one? You spin and spin while rotating around the axis of the ride. The thrill of the wind frantically blowing your hair and the tickling sensation in your tummy! Then there was the ferris wheel. What a kick to have the bird's eye view of the flurry of activity below you!

Then I think about how people use the word "ride" to describe a particular experience in their life like, "It was a wonderful ride". They often use that phrase when referencing a period of time as a journey. An individual can experience a journey alone or as part of a group of individuals who share a common denominator, and that is precisely what I want for all of us, as a collective group.

Our common denominator is MS. Won't you join me in the journey to end multiple sclerosis forever and, in the meantime, support those with MS until that cure is found? There are plenty of opportunities to hop on a ride with me on our journey to end MS. You can experience the bird's eye view by providing a monetary gift to support the worldwide research efforts to help find a cure or to help fund a potentially new break-through treatment for those with primary progressive MS. Or you can experience the thrill of the ride by setting a personal challenge of riding 50 miles in our Bike MS event or roll up your sleeves to volunteer at your nearest community Walk MS event. And there are many other ride opportunities throughout the year that are available to enhance our journey together.

For more information on joining the journey to end MS forever, contact Heather Donegan at 317-870-2501 or [heather.donegan@nmss.org](mailto:heather.donegan@nmss.org). Thank you!

  
Leigh Ann Erickson  
Chapter President

**1-800-344-4867**

PUBLICATION OF THE NATIONAL  
MULTIPLE SCLEROSIS SOCIETY

Indiana State Chapter  
7301 Georgetown Road, Suite 112  
Indianapolis, IN 46268

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## CALL FOR BOARD NOMINATIONS

The Board of Trustees of the National MS Society, Indiana Chapter is elected at the Chapter's Annual Meeting each year. If you are interested or know of someone who is interested in serving on the Board of Trustees, please send a letter expressing that interest and a resume to the **Board of Trustees Governance Committee, c/o the Indiana Chapter, 7301 Georgetown Road, Suite 112, Indianapolis, IN 46268** prior to October 29, 2010.

If you have any questions, please call Chapter President, Leigh Ann Erickson, at 317-870-2501 or email her at [leighann.erickson@nmss.org](mailto:leighann.erickson@nmss.org).

## GO GREEN (and help the chapter cut down on expense too!)

Would you like to receive this publication via email? You can! Simply email us and let us know. The issue will be emailed to you in a link to a page on our chapter website, which you can click on to view the document as a .pdf file.

We promise to be vigilant and considerate in our use of this information, and won't share this information with anyone outside of the chapter. By providing your email address, we will be able to communicate with you on a more frequent basis while offsetting the growing cost of print materials and postage. Not only that, you can help us in our continued efforts to preserve the environment.

Please email the chapter at [indiana@nmss.org](mailto:indiana@nmss.org) to receive the MS Connection electronically.

# Save the Date!

Saturday, November 13

2010 Indiana State Chapter

Let's Tackle MS! Celebration & Annual Meeting

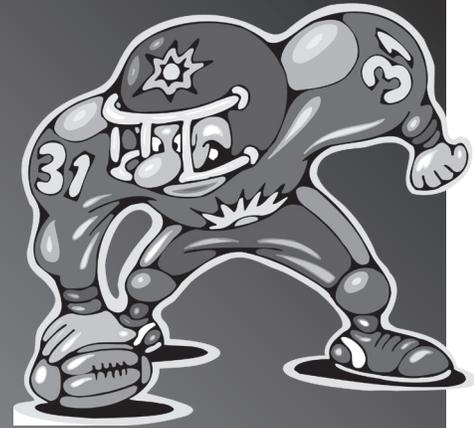
Conference Center at the Pyramids, Pyramid III, basement level

3500 DePauw Boulevard Indianapolis

11:00-1:30 – Annual Board Meeting with Elections

11:00-1:30 – Self-Help Group & MS Ambassador Training

2:00-4:00 – Let's Tackle MS! Celebration & Program



Thank you for being the voices of MS. Our volunteers, clients and constituents play an integral part as advocates, mentors, and fundraisers for the National MS Society, Indiana State Chapter. You help us in moving our mission forward, to end the devastating effects of multiple sclerosis.

The Annual Meeting is an opportunity to elect our upcoming Board of Trustees, and to serve as the annual training for Self Help Group Leaders and MS Ambassadors. The afternoon ceremony "Let's Tackle MS!" will consist of a celebration of this year's accomplishments, unveiling goals for the upcoming year, and thanking our volunteers for their service and dedication. All individuals with MS, their families, friends, volunteers and other members of the chapter are invited to be our guest. The program is FREE and refreshments will be provided. Please call 1-800-344-8467 or go on-line at [www.nationalmssociety.org/ini](http://www.nationalmssociety.org/ini) to register today!

In the spirit of football season and in order to carry out the "Let's Tackle MS!" theme, we strongly encourage everyone to don the gear of their favorite sports team! Be creative! Have fun with it!!! There will be prizes!! Casual dress is allowed.

In addition, we'd like to honor those folks that you nominate as being MS Superstars (Most Valuable Players in football lingo)! Please notify the chapter with your nominations for excellence in the following categories:

- Neurologist/Doctor
- Nurse
- Clinic/Medical Practice
- Employer
- Service Provider/Community Agency

You can fax your nominations to (317) 870-2520 or e-mail [marci.corbin@nmss.org](mailto:marci.corbin@nmss.org). Nominations will be accepted through October.



## MEMORIUM

### Dear Indiana State Chapter Multiple Sclerosis Society Supporter:

It is with a heavy heart that I regret to inform you that the MS Society has lost a dear friend and champion. Tiffany Bogard, the former President of the Indiana Chapter, lost her battle with cancer on May 9, 2010, surrounded by her family. As many of you know, Tiffany battled breast cancer, which recently metastasized. She retired from the MS Society last fall to spend time with her family and friends.



Tiffany has been a long time supporter of the MS Society, and particularly the Indiana Chapter. She joined the Society in 2001 as the Director of Programs. Shortly thereafter, she was promoted to the President of the Chapter. Tiffany spent 8 years working to raise funds and awareness of MS and coordinating programs in support of the nearly 10,000 Hoosiers with MS. She traveled the State to meet with MS supporters and clients. Despite her retirement in 2009, Tiffany remained active with the Chapter, attending the Dinner of Champions and keeping up on Chapter events. The Chapter will sorely miss her dedication and support.

Tiffany is survived by her husband, Micha, and her two boys Henry and Cooper. She is also survived by her father, Don, her mother, Jane, and her sister, Dierdre. Tiffany certainly brought her work home, as her entire family supported the MS Society and could often be seen on event committees and supporting the Chapter's endeavors. As you may know, the Dinner of Champions annual event was one that Tiffany handled personally and which meant a great deal to her, so if you would like to offer your assistance with that event or in another volunteer capacity with the Indiana Chapter, please contact Heather Donegan at [heather.donegan@nmss.org](mailto:heather.donegan@nmss.org) or call 317-870-2501.

If you wish to support Tiffany's family or the legacy Tiffany has left behind, there is a Trust set up for her children and the MS Society's Indiana Board of Directors is creating a scholarship in Tiffany's name to be awarded through the MS Society. For more information on the MS Society scholarship, please contact Leigh Ann Erickson, Indiana Chapter President, at [leighann.erickson@nmss.org](mailto:leighann.erickson@nmss.org) or call 317-870-2501.

Best Regards,

Monica Brownwell Smith  
*Vice Chair, Board of Trustees*  
*Indiana State Chapter of the*  
*National Multiple Sclerosis Society*

## WALKING TO BEAT MS

Walking to get exercise is good for your body, but walking for a cause is great for your soul. More than 6,000 walk participants and event volunteers learned that this past year as they rallied at one of eight statewide walks hosted by the Indiana State Chapter.

Think about an average day in your life. How is the majority of this day spent? Working? Taking care of kids? Taking care of yourself? Now think about what happens when you're sick one day, and can't manage your normal responsibilities. What would happen if you couldn't get back to your normal schedule for a week, a month, or even a year? You cannot function normally because you're exhausted every time you get up, and you can't predict what your muscles will do next, or if they will even move? What if you lost your ability to walk or you opened your eyes to find you were temporarily blind?

It is these types of difficulties and uncertainties that drive people with multiple sclerosis to encourage their friends, family, and co-workers to rally and bring life to the vision of a world free of MS.

Despite a turbulent and difficult economy, walkers from all areas of the state joined forces to raise more than \$700,000 to support the programs, services and research of the National MS Society.



## WALKING TO BEAT MS - TEAMS

*A very special thanks to the walk participants, team captains, and event & committee volunteers who made it all possible!*

### **East Central**

221 Participants – \$24,236

#### **Top Teams**

1. BSU Exercise Science Club
2. Muncie Self Help Group
3. Team Applegate

### **Indianapolis Walk**

2,371 Participants – \$343,620

#### **Top Teams**

1. Broyles-Dallas: BDing MS
2. YAMS (Youth Against MS)
3. MS Cure Seekers

### **Michiana Walk**

806 Participants – \$70,360

#### **Top Teams**

1. Kate's Hope
2. Star Walkers
3. Team Rafalski

### **Northeast Walk**

390 Participants – \$69,980

#### **Top Teams**

1. Team Gillispie
2. Mary's Crew
3. Ellen's Legs

### **Northwest Walk**

1050 Participants – \$120,000 (projected)

#### **Top Teams**

- To Be Determined (information not available at this printing)

### **South Central Walk**

129 Participants – \$24,058

#### **Top Teams**

1. The Naturals
2. SmoFamily
3. team grider

### **River Valley Walk**

237 Participants – \$15,524

#### **Top Teams**

1. Derrick's Faith Walkers
2. Deaconess Health System
3. Vectren

### **Wabash Valley Walk**

330 Participants - \$45,000 (projected)

#### **Top Teams**

- To Be Determined (information not available at this printing)

## WALKING TO BEAT MS - STATE SPONSORS

*A Very Special Thanks as well to our Sponsors  
throughout the State*

3 Rivers Credit Union	Healy Group
95.9 The Valley	Heart to Heart Gifts
Albert's Diamond Jewelers	Helping Hands Companion Care LLC
Alicks Home Medical	Hoosier Storage
Anderson's Medical Products	Horseshoe Casino
Associated Imaging	James Medical
Barnes & Thornburg	Marsh Supermarkets
Bemis	Martins Supermarkets
Budweiser Zink Distributing	Methodist Hospital
Central Indiana Orthopedics and Sports Medicine	O'Daniel West
Consumers Life Insurance Company	Pure Protein
Deco-Art	Railcats Baseball
Dekalb Memorial Hospital	Sanofi Aventis
Elkhart Neurology	South Bend Neurological
Ellison Bakery	St. Johns Health System
EMD Serono	St. Vincents Hospital
Firestone Building Product	Starbucks Coffee
First Federal Bank	Strongbow Inn Restaurant
Ft. Wayne Nuerological	Teachers Credit Union
Garrett State Bank	The Imaging Center
Gartland Foundry	Union Hospital
Gatorade	Wells Fargo
Glenbrook Rehabilitation & Skilled Nursing Center	WFXW - Fox 38
Grossnickle Eye Center	WLBC 104.1 FM
Grabill Bank	WZVN Z107
Great Dane Trailers, PDC	
Hammond Clinic	
Harris Bank	

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## NEW MS DRUG IN PIPELINE

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On August 8, 2010, a U.S. Food and Drug Administration advisory committee recommended that the agency approve marketing of fingolimod capsules (formerly called Gilenia, Novartis International AG) for the treatment of relapsing multiple sclerosis. If approved, fingolimod would be the first oral disease-modifying therapy for the treatment of MS. While the FDA is not required to follow the recommendations of its advisory committees, it usually does. According to Novartis, the agency is expected to make a final decision about whether to approve the drug in late 2010.

Fingolimod is different than current MS therapies on the market and represents a new class of therapy, for one because it is taken orally rather than by injection or infusion, and secondly because of its mode of action. Fingolimod binds to a docking site (sphingosine-1-phosphate receptor, or S1P receptor) on immune cells, including T cells and B cells that have been implicated in causing nervous system damage in MS. The drug appears to force immune cells to remain in lymph nodes where they can do little harm, and prevents them from migrating into the brain and spinal cord. Fingolimod is considered a disease-modifying agent, and if it is approved, it would not be taken along with other disease-modifying therapies. Fingolimod comes in capsules. If approved for marketing, it will likely be taken by mouth once a day, which is how it was taken during the clinical trials.

The application to the FDA requested approval to market fingolimod for the treatment of relapsing forms of MS. In other words, people who experience periodic MS attacks, such as those who have relapsing-remitting MS or secondary-progressive MS with relapses. However, this agent is also being tested in people with primary-progressive MS who experience steady worsening without acute attacks. If the FDA approves fingolimod for relapsing MS, and if it shows significant benefit in primary-progressive trials, it is likely that the sponsor will apply to expand its labeling to include progressive forms of MS.

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### Want to learn more?

**Live research webcast:** *The June 2010 webcast program "What's New in MS Research and Treatment," is available for viewing online at [www.nationalmssociety.org/news](http://www.nationalmssociety.org/news).*

**Research Now:** *The Fall 2010 edition of Research Now - an 8-page insert on research in the Society's national magazine, Momentum - is available on the Web site. Research Now is a PDF that can be photocopied or printed. If you do not have access to a computer, you can call the chapter and request a hard copy to be sent to you.*

**MS-Learn Online - Research:** *Explore our video library of MS Learn Online segments on MS research on the Web site. These videos are categorized into three types of segments - Daily Minutes, Q&A, and Feature Presentations.*

## CLINICAL STUDY IN PATIENTS WITH RELAPSING REMITTING MULTIPLE SCLEROSIS (RRMS)

The neurology department of the Indiana University Hospital is taking part in a research program for the development of a new oral drug for multiple sclerosis. We are currently looking for patients suffering from Relapsing-Remitting Multiple Sclerosis for a clinical study. If you are a man or woman, 18 to 55 years of age, with a diagnosis of Relapsing-Remitting Multiple Sclerosis, you may be a potential candidate for this study.

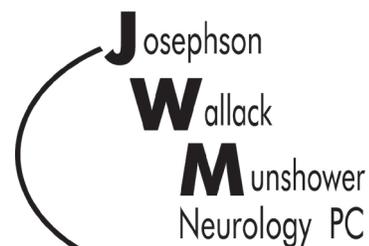
There will be a 4-week period to evaluate your eligibility followed by a 24-week study period. During this time you will visit the neurology department 11 times and will have an MRI (Magnetic Resonance Imaging/Image) 7 or 8 times. You will also be asked to come back to the neurology department 1 week and 4 weeks after the end of the study. You will have an additional MRI at the visit 4 weeks after the end of the study. Following the 24 week study period, participants will be offered to continue with an extension study. Lee Hayward can provide you with more information about the study.

Participation in the study (including study medication and all clinical examinations and laboratory tests) will be free of charge. Study participants will be reimbursed a reasonable amount for their transportation costs.

**Are you interested in taking part in this clinical study?** Please contact Lee Hayward, RN, MSCN at (317)278-7293 for more information.



Fort Wayne Neurology is currently enrolling patients in a relapsing-remitting multiple sclerosis clinical research trial. For more information about the trial and how to qualify for participation, go to <http://www.DreaMSClinicalTrial.com> or call 260-460-3214.



Comprehensive Neurological Expertise  
Compassionate Patient Care

The JWM Neurology Center for Multiple Sclerosis is currently recruiting for several Multiple Sclerosis Clinical Trials. If you would like more information, please contact our Research Department at 317-537-6060 or 317-537-6061.  
[www.jwmneuro.com](http://www.jwmneuro.com)

# HELP & SUPPORT

## SELF-HELP GROUPS

The Indiana State Chapter of the National MS Society has Self-Help Groups throughout the state of Indiana. Our Self-Help Groups are located in the following cities:

Anderson	Ellettsville	Martinsville
Angola	Evansville (one MS group, one group for caregivers)	Merrillville (two groups)
Auburn	Fort Wayne	Mooreland
Avon	Gary	Muncie
Bloomington	Greenfield	Noblesville
Calumet City, Illinois	Huntington	South Bend
Carmel	Indianapolis (three groups)	Terre Haute
Centerville	Lafayette	Tipton
Columbus	LaPorte	Valparaiso (also for caregivers)
Columbia City	Lebanon	Whiteland
Crawfordsville	Marion	Winamac

***New groups forming in: Muncie (for caregivers) Terre Haute Madison***

***Please contact Heather Donegan at 800-344-4867 x2, 317-870-2500 x2, or via email at [heather.donegan@nmss.org](mailto:heather.donegan@nmss.org) for more information about Self-Help Groups including their meeting dates, times and locations.***

## HELP OUR CHAPTER - VOLUNTEER!

Contact Heather Donegan at 800-344-4867 (option 2), 317-870-2500 (option 2), or via email at [heather.donegan@nmss.org](mailto:heather.donegan@nmss.org) to learn about volunteer opportunities.



### CHANGE HAPPENS THROUGH MS ACTIVISM

*Until a cure is found, people living with MS and their families face many challenges. We must pursue legislative progress and improved government programs to better meet those needs.*

The Society continues to advocate for two of its 2010 priority issues-robust funding for the Lifespan Respite program and increased funding for MS research in the Congressionally Directed Medical Research (CDMRP) program. Due to continued work of MS activists, the Senate has provided a substantial increase for the Lifespan Respite program and early indications are positive in terms of funding for MS research in the CDMRP. Please stay tuned for updates as the federal appropriations process continues. MS activists must remain engaged so that these vital programs receive the funding they need.



2-1-1 is an easy to remember telephone number that connects callers to information about critical health and human services available in their community. It is free, confidential, and available 24 hours a day, 7 days a week.

## MAKE A BUDDY CONNECTION

by Lorena Montgomery

Thank you to all of you who have participated in Buddy Connection!

The Buddy Connection program is a way for people within our Chapter area affected by multiple sclerosis to connect with each other. Whether you have MS or know someone with MS, the program is a great way to share your story or lend an ear to someone in need. Also, feel free to discuss non-MS related topics such as your favorite recipes or sports – we want this to be the start of a wonderful friendship!

Those interested in the program can send in an application and be matched with a “buddy” based on their similar hobbies and interests. On the application you can indicate how to connect with your buddy (phone, email, letters, etc.) and also what information you would like to be shared.

Due to this being a new program, it was just as much a learning experience for us as it was for you. We have had great success thus far and many “buddy connections” have been made. We hope that you will all continue to be involved with Buddy Connection as we continue to make improvements for the future! The feedback we have received through surveys about the program has been a big help, and if you have any further recommendations about the program, please do not hesitate to contact us.

If the Buddy Connection program sounds like something you are interested in, or if you have any questions regarding this program, please contact Heather Donegan at 800-344-4867 x2, 317-870-2500 x2, or via email at [heather.donegan@nmss.org](mailto:heather.donegan@nmss.org).

## THE INDIANA STATE CHAPTER AWARDS TWO SCHOLARSHIPS

The National MS Society established its scholarship program in 2003 and it continues to grow immensely. In each of the past two years, over \$1 million has been awarded to over 300 students. One hundred percent of contributions are distributed to students for scholarship assistance. The Indiana State Chapter received a record number of applications this year and was faced with a difficult decision. The Chapter is pleased to award two local scholarships to **Jarrold Buchanon of South Bend, IN, and Cassandra Lynn Hopper of Plymouth, IN.**



**Jarrold Buchanon**

Plans to attend:  
University of Notre Dame  
Major:  
Pre-Medicine



**Cassandra Lynn Hopper**

Plans to attend:  
Indiana University-Purdue  
University, Indianapolis  
Major:  
Social Work, Psychology

### Eligibility for 2011

High school seniors or graduates that have MS or a parent with MS and who will be attending an accredited post secondary school for the first time in Fall 2011 are eligible. Applications will accepted until January 14, 2011, and can be found at [nationalmssociety.org/scholarship](http://nationalmssociety.org/scholarship).



**National  
Multiple Sclerosis  
Society  
Indiana State Chapter**

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Suite 112  
Indianapolis, IN 46268

NON-PROFIT  
ORGANIZATION  
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Indianapolis, IN  
Permit # 1854

## CALENDAR

10/11/2010	Midwest Teleconference Call - Vitamins & Supplements	Statewide
11/8/2010	Midwest Teleconference Call - Pain & MS	Statewide
11/13/2010	Let's Tackle MS! Celebration & Annual Meeting	Indianapolis
3/14-20/2011	MS Awareness Week	
4/25/2011	World MS Day	
Ongoing	MS Aquatics Class- Spiece Fitness	Fort Wayne
Ongoing	MS Aquatics Class- IUPUI Natatorium	Indianapolis
Ongoing	Yoga - Community Center	Fort Wayne