INSIDE THIS ISSUE

9 CONGRATS TO MS INTERN ON RURAL HEALTH OUTREACH
10 FAMILY WEEKEND RETREAT
11 NINE CITIES IN FIVE DAYS
14 HAVE A VOICE IN MS RESEARCH

BIKE MS 2015: BLUEGRASS, BIKES, BOURBON & BBQ
Dear Friends,

Recently I had the pleasure of meeting with the new University of Louisville MS/Neuroimmunology specialist Dr. David Robertson. He reminded me how important partnerships with healthcare professionals are to the National MS Society’s success.

A commitment such as Dr. Robertson’s and other healthcare professionals will help further the MS mission. As quoted by Brian Boyle; Healthcare Advocate “The power that healthcare providers have is extraordinary. On a daily basis they are not only caring for the health of their patients, but they are also creating reasons to smile, making living conditions suitable and pleasant, and forming connections.” I find this more powerful than ever.

The National MS Society takes great pride in our Partners in MS Care program. We work first hand with healthcare providers who recognize and support quality MS Care. The program involves Comprehensive MS Care, Neurologic Care, Rehabilitation, and Mental Health. We are honored to recognize our current partners in MS Care:

**KentuckyOne Multiple Sclerosis Care**
Partners in MS Care - Centers for Comprehensive
www.kentuckyonehealth.org/multiplesclerosisicare
Gregory Anderson, Neurologist, Warren Chumley, Neurologist
Nicole Everman, Neurologist, Cary Twyman, Neurologist
1021 Majestic Dr, Ste 200, Lexington, KY 40513-1867
(859) 296-1922

**Baptist Health Rehab**
Partners in MS Care - Rehabilitation
www.baptisthealthkentucky.com
Dana Lykins, Physical Therapist
1775 Alysheba Way, Ste 10, Lexington, KY 40509-2479
(859) 260-4540

The National MS Society is united in our collective power to do something about MS now and end this disease forever. Becoming
a Partner in Care and working one on one with healthcare providers will help reach our goal.

We strive to allow everyone living with MS have enjoyable and meaningful lives, with more connections to information, resources, and others with shared experiences.

Advancements made throughout the years would not have been possible without the remarkable healthcare providers on our team striving for success.

The National MS Society Kentucky-Southeast Indiana Chapter gives gratitude to all healthcare providers working hard for an end result, for that I am grateful.

With Kindest Regards,

Stacy Funk,
President, Kentucky-Southeast Indiana Chapter

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**WELCOME**

We would like to introduce our new Development Coordinator at the National MS Society, Kentucky-Southeast Indiana Chapter; Maci Baurle.

“I am grateful to have been given the opportunity to work for the National MS Society. As the new Development Coordinator, my main motivation is to be a leader in the vision to make a world free of MS. I look forward to meeting everyone with this same goal in mind at upcoming events in the Kentucky area.”

Maci Baurle

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and expert opinion. Information provided in response to questions does not constitute therapeutic recommendations or prescriptions. The National Multiple Sclerosis Society recommends that all questions and information be discussed with a personal physician.

The Society does not endorse products, services or manufacturers. Such names appear here solely because they are considered valuable information. The Society assumes no liability for the use or contents of any product or service mentioned.
BOARD OF TRUSTEES OFFICERS FY 2015

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NATIONAL MS SOCIETY, KENTUCKY-SOUTHEAST INDIANA STAFF

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Chapter President

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Mary Carabella
Director of Development

Trinity Campisano
Senior Development Manager

Maci Baurle
Development Coordinator

Jinny Cornett
Programs & Services Manager

Cathy Kemple
Office Manager

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Brett Corbin - Raymond James and Associates
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Tami Hatfield-Kennedy - Ford Motor Company
Kenny Jewell - Heritage Electric
Dr. Stephen Kirzinger - Quintiles Clinical Research Organization
Karen Krinock - Brown-Forman
Debbie Nelson - Baptist Health Louisville

Walter “Dub” Newell - FirstLight HomeCare
Nick Papachristou - Hilliard Lyons
Dan Rattner - Rattner Bloodstock
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Dr. Cary Twyman - KentuckyOne Health
Mary Van de Kamp - Rehab Care/Kindred
Jason Waters - ARGI Financial Group*
Julie Garrison - Baptist Health*

*New Trustee Members
At Bike MS: Bluegrass, Bikes, Bourbon & BBQ, cyclists wound through the rolling hills of Kentucky and Southern Indiana, experiencing historic landmarks, the banks of the Ohio River and the beauty of our Olmstead Park System. With our new staggered start this year, many cyclists finished around the same time – even if you did the Century or the 25 mile route, making Saturday evening a celebration everyone enjoyed.

Save the date for next year’s event - Saturday and Sunday June 25 and 26, 2016 at the Louisville Water Tower Park! Online registration will be open October 2. For up to date information please visit our site at www.bikemsky.org.

This event could not happen without the extraordinary vision and help from some of our very special friends. We want to pay a special thank you to Dub Newell (Bike MS Chair), John McCafferty (Graphic Designer), Upper Crust Catering, SmokeHawgs BBQ, Clarksville Schwinn, Glenn Todd (SAG Support Lead), Drew Foster (HAM Operator Lead) and the illustrious Andy Murphy with the Louisville Bicycle Club. These leaders made Bike MS safe, fun, and successful.

We want to extend a very big thank you to our Lead Volunteers who worked unbelievably long and hot hours all weekend; Andrew Bankston PhD, Clay Mathis, Josh and Alesia LaRoche, Michael Griffin and Eric Kemple. And to all the volunteers who worked rest stops, drove SAG vehicles, ran errands, and so much more, we thank you.

And thank you, of course, to everyone who fundraised and cycled!
SPONSORS:
- Clarksville Schwinn
- Middletown Fitness & Cycling
- WFPK Louisville Public Media
- West 6th Brewing
- Heine Bros.
- Castle Brands (Jefferson Reserve)
- Alltech (Town Branch)
- Alltech (Kentucky Ale)
- Four Roses
- Papa John’s
- Evan Williams (Trolley Hop)
- Falls City Community Bike Works
- Buckhead Mountain Grill / Rocky’s Sub Pub
- Bicycling for Louisville
- SmokeHawg’s BBQ
- L&D Mail Masters
- ValuMarket
- YUM! Brands
- Commonwealth Bank & Trust
- LBM Construction Company, Inc.
- Norton Healthcare
- Kentucky One Health
- Novartis
- Biogen

BIG SHOTS:
1. Phillip Patterson - $10,010
2. Jeff Hamilton - $10,010
3. Andrew Miller - $9,950
4. Dean Brooks - $7,762
5. Maurice John, Md - $5,296

TOP FUNDRAISING TEAMS:
(Does not include unconfirmed or outstanding matching gifts)
1. Team DOT Louisville - $20,383
2. JudeMar Juggernaut - $19,625
3. YUM! Brands - $9,482
4. Slow and Steady - $9,288
5. Chino Hills - $8,706
FUNDRAISING

THE BEST OF LOUISVILLE

The Best of Louisville is a unique partnership with Louisville Magazine, the National MS Society and more recently VIA Studio. Because of all the creative minds at work, this event is the place to be every July. Jason Clark, VIA Studio President, who also claims to hold the titles “El Conquistador” and “the boss who never grew up”, said, “Best of Louisville has been an incredible opportunity for our agency to work with a non-profit and a publisher on an event with such impact. For the last two years, through teamwork and hard work, we’ve been able to re-envision Best of Louisville into a celebration that is well regarded in the community. MS Society in particular has turned into an amazing ally and partner.”

THE BEST OF LOUISVILLE SPONSORS:

- Louisville Magazine
- PLAY Louisville
- Hilliard Lyons
- VIA Studio
- The Kentucky Gent
- VIVID Impact
- MAC Construction
- Baptist Health Louisville
- boice.net
- Acorda
- ARGI Financial Group
- Kindred Healthcare
- Genzyme
- Brown Forman
- Stoll, Keenon, & Ogden
- YELP Louisville

Stacy Funk (Chapter President), Luke Hancock (former U of L basketball player) and Diana Quesada (Chair).
LEXINGTON HERALD READERS’ CHOICE 2015

The first ever Lexington Herald Readers’ Choice Awards Event was held at the Grand Reserve in Lexington, Kentucky, benefiting the National MS Society. Stacy Funk, Chapter President, said, “The event was the result of a beautiful partnership with the Lexington Herald. We had so many things to offer guests including a silent auction, raffles, drinks, food and music. I’m grateful we were able to partner with the Lexington Herald as they are so committed and have such a strong presence in the community.”

SPONSORS:
Acorda,
Sleep Outfitters
& Massage Envy
Programs

Congratulations to Angela Graham, MS Society Intern

Last year, Angela interned with the Kentucky-Southeast Indiana Chapter focusing on Rural Health Outreach and partnering with the Kentucky Appalachian Rural Rehabilitation Network (KARRN). Since then, she has received her Master’s in Public Health from the University of Louisville and currently works for the Louisville Metro Health Department as a Wellness Quality Improvement Coordinator. Recently, Angela submitted and was selected to present a poster of her project at the KARRN Conference illustrating available services in Kentucky’s rural areas. Angela competed against hundreds of other state health specialists to win this esteemed honor.

Congrats Angela!

To View the Full Poster Please Go to Our Website at www.nationalmssociety.org/kyw

Rural Outreach with the National Multiple Sclerosis Society
Angela Graham
University of Louisville, Louisville, KY

Introduction

The Kentucky-Southeast Indiana Chapter of the National MS Society sought to develop a rural outreach program to target healthcare providers in rural areas. The Chapter had a set of guidelines to follow from the National office, and needed to develop something appropriate for the Kentucky population. A three-part project was developed to meet these goals, and included (1) discussion and planning with other chapters who had already developed rural outreach (2) networking with other Kentucky organizations serving rural populations and (3) developing a survey to identify HCPs treating MS patients and understand barriers to care.

Chapter Recommendations

Several other chapters had already developed successful rural outreach campaigns and provided feedback to the Kentucky – Southeast Indiana Chapter to inform our decisions. We held meetings with chapters serving Texas, Arizona, New Mexico, the Southeast, and the Midwest. The National office had a conference call with our Chapter to provide background and information resources to be utilized in our outreach. Learnings were shared and the most successful outreach steps are detailed in Table 1.

Survey Methods & Results

A link to an online survey was sent to 9,002 members of the chapter. 153 caregivers and patients responded. County of residence of respondents is shown in Figure 1. The survey took approximately 5 minutes to complete and consisted of 10 open-ended, multiple-response, and Likert scale questions.

METHOD

A link to an online survey was sent to 9,002 members of the chapter. The survey was sent via email to chapter members. The survey was developed using Qualtrics and disseminated via email to chapter members. The survey was sent out 3 times over a period of 10 days. Participants were encouraged to complete the survey and participate in the survey. The survey consisted of 10 questions and took approximately 5 minutes to complete. The survey included demographic questions, questions about healthcare providers, and questions about barriers to care.

SATISFACTION WITH HEALTHCARE PROVIDERS

Respondents were asked to rate their likelihood of recommendation of each HCP they identified. Average likelihood (on a 5 point Likert scale) is shown in Figure 3. Research conducted by Buchanan et al. (1) show that having a neurologist primarily responsible for managing MS is linked to higher quality of life. Trust, success to neurologists is crucial.

BARRIERS TO CARE

Respondents were asked to rate the degree to which they faced barriers to getting care they want and need for their MS. They were asked to rate the degree to which they faced barriers to care on a 5 point Likert scale. Figure 4 depicts the results of the question. Notably, younger adults were more likely to report barriers than their older counterparts. Figure 5 shows the results by age group. This may be due to higher expectations on the part of younger patients, or structural barriers such as lack of insurance coverage, especially among young and low income individuals.

Recommendations

The Chapter should act on the information gathered and continue to find ways to collaborate with the organizations identified. In addition, the Chapter should foster relationships with Louisville-based neurologists who are interested in finding creative ways to reach rural patients who visit those providers, along with support groups in rural areas. The Chapter should also continue to develop closer outreach with rural primary care providers, and continue to incorporate rural communities into activities and fundraising events, such as Walk MS.

References


Society Chapters

Networking With KY Organizations

In order to find partners for potential collaboration, as well as build a network to help share information with a wider audience of professionals, organizations were researched and contacted. We had meetings with representatives from a variety of organizations to discuss potential collaborations and information sharing. We introduced ourselves to the Appalachian Rural Rehabilitation Network (KARRN) and developed one-pagers and joined articles to newsletters for the Kentucky Primary Care Association, KARRN, Northeast Area Health Center, Kentucky Office of Rural Health, and others.

To View the Full Poster Please Go to Our Website at www.nationalmssociety.org/kyw

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References

FAMILY WEEKEND RETREAT

Families are invited to a fun filled and educational weekend retreat, targeted to individuals living with MS, their partners, and children ages 5-18. This program is exclusive to families where a parent, grandparent, or child is living with MS.

The retreat will focus on healthy approaches to aspects of MS, the latest MS research, the challenges of living with MS, and improving quality of life for persons with MS and their families. Children’s programs include music, arts and crafts, healthy lifestyle, and fun activities.

Family Weekend Retreat will be October 16-18 at the Capital Plaza Hotel in Frankfort, KY.

To register, call 1-800-344-4867, ext. 1 or visit NationalMSsociety.org/kyw. There is an all-inclusive $40.00 family registration fee and financial assistance available upon request. The registration DEADLINE is October 1, space is limited.

Special thanks to Kosair Charities, Etscorn Foundation, Genzyme, and Healthline.com for making this retreat possible.
COMMUNITY

NINE CITIES IN FIVE DAYS
WE'RE COMING TO A TOWN NEAR YOU!

Senior Staff of the Kentucky-Southeast Indiana Chapter are traveling throughout the state in November to connect with you. Help us get the word out. We want to connect with elected officials, healthcare practitioners and outreach in each community. We want you to understand our strategic and focused plan that will take us through 2018.

Monday, November 9, 2015
Richmond & Hazard

Tuesday, November 10, 2015
Middlesboro & Somerset

Wednesday, November 11, 2015
Columbia & Bowling Green

Thursday, November 12, 2015
Paducah

Friday, November 13, 2015
Madisonville & Elizabethtown

Please contact Jinny Cornett at 502-526-5061 or at jinny.cornett@nmss.org to help us get the word out in your town.

Please check email and website for times!

WATCH FOR US
#WHEREARETHEYNOW OR #MSROADWARRIORS
MEMBER SPOTLIGHT
TINA MCELLENNAN

Tina was diagnosed in 1990 at age 22 while attending the University of Louisville. During her first year of nursing school at Spalding University, Tina had to withdraw due to progressive MS complications.

Six short years after being diagnosed with multiple sclerosis, Tina gave birth to her son, David. During David’s first years, she relied heavily on her mother for help and eventually he left to live with his father full time.

Today, at age 47, Tina lives in a nursing facility with a progressive form of MS. We are dedicated to finding solutions for Tina and to help her live her best life with more connections to information and resources.

Despite having MS, Tina is a very happy woman who smiles often. She enjoys being with family, listening to Bon Jovi, going to movies, and the spring and fall seasons.
SAVE THE DATES

Craig Family car-show at TK’s Pub - Saturday, October 24
- 5442 Delmaria Way, Louisville, KY
- 10 a.m. - 3 p.m.
- For more information call Wade Craig at 502-797-8292

Annual Meeting at St. Matthew’s Community Center - Thursday, October 29
- 5 - 7 p.m.
- For more information or to RSVP go to nationalmssociety.org/kyw and look at our calendar of events

4th running BG 26.2 & half marathon - Sunday, November 1
(Any cyclist who participates will receive free Bike MS 2016 registration)
- PACKET PICKUP - Saturday, Oct. 31
  5 - 8p.m. @ National Corvette Museum
- Race Day 6-6:45am @ BG Ball Park
- Go to bg262.com for more information

2016 Leadership Conference in Dallas/Fort Worth, TX - November 4-7
- Stay tuned for more details if you would like to attend

MADISON COUNTY/RICHMOND
Estill County Public Library
"Myelin Matters" First Monday at 6 p.m.
Contact Lisa at 606-560-9240 or ls_combs@yahoo.com

MADISONVILLE
Trover Clinic (8th floor)
Every fourth Monday 6 p.m.
Contact Dan & Carolyn at 270-635-1178 or dinosaur@bellsouth.net

LEXINGTON
Different locations
First Wednesday of every month at 11:30 a.m.
Contact Leslie at 859-269-4036

MUHLENBERG COUNTY
Muhlenberg Community Hospital
(Basement Conference Room)
Every third Thursday 6 - 7 p.m.
Contact Kim at 270-315-3248 or kmorgan123@aol.com

CAMPBELLSVILLE
Taylor County Extension Office
Every first Tuesday at 6 p.m. Contact Melissa at mldooley@windsteam.net or 502-507-3724

BOWLING GREEN
Sky Rehab
Second Tuesday of the month 6 p.m.
Contact Shannon at sgoolesby@skyrehab.com

MIDDLESBORO
Middlesboro ARH Hospital
3600 W Cumberland Ave, Middlesboro, KY
Contact Nina at 606-499-1987 or nshoemaker@ymail.com

SELF HELP GROUP MEETINGS:

PADUCAH
West End Baptist Church
Every fourth Thursday 12 - 2 p.m.
Call or email Alicia at 270-564-9010 or aliciaray@hotmail.com
RESEARCH

HAVE A VOICE IN MS RESEARCH

Today, there are more options than ever before for people with multiple sclerosis to help drive MS research. They can choose to participate in clinical trials, donate DNA through blood samples, or complete health surveys. No matter where they live, what their background is, or what stage of the disease they are in, people with MS are at the heart of MS research. Here are some of the ways you can make your voice count.

PARTICIPATE IN CLINICAL TRIALS

From testing a potential new therapy for MS to trying an exercise program to help manage symptoms of fatigue or spasticity, people with MS who participate in clinical trials make it possible to bring new medications and symptom-management strategies from the lab to their doctor’s office.

WHO KNOWS MORE ABOUT MS AND ITS DIVERSE IMPACTS ON LIFE THAN PEOPLE WHO LIVE WITH THIS DISEASE EVERY DAY?

“The willingness of people with MS to participate in research studies and clinical trials is vital to understanding the complexities of the disease and to developing better treatments,” says Timothy Coetzee, PhD, Chief Advocacy, Services and Research Officer at the National MS Society. “They are the experts — who else knows more about MS and its diverse impacts on life than people who live with this disease every day?”

In fact, researchers are increasingly looking at “patient-reported outcomes,” gathering information directly from individuals participating in studies to better capture how a treatment makes people feel.

For more information on how to participate in current clinical trials, visit www.nationalMSSociety.org/clinicaltrials or search www.clinicaltrials.gov for ongoing MS research.
**NARCOMS: DATA THAT COUNTS**

Participating in the North American Research Committee on Multiple Sclerosis, or NARCOMS, is another way people with MS can express their willingness to participate in MS research. Since its founding in 1993, more than 37,500 people with MS across the globe have joined its registry and more than 80 papers with research results utilizing data provided by participants have been published. Anyone with a diagnosis of MS can participate in NARCOMS. Visit [www.narcoms.org](http://www.narcoms.org) to learn more.

**iConquerMS™: ASK THOSE WITH MS**

“If you want to know what it is like to live with MS, or how different lifestyle choices impact a person’s quality of life, or what questions people with MS are most interested in exploring, you ask those living with the disease,” says Lisa Emrich, a Washington, DC-based writer and blogger who was diagnosed with MS in 2005.

Emrich is one of the first to sign up to participate in a new initiative, iConquerMS™, a unique patient-centered data collection system that allows people with MS to safely and securely share their health information and ideas for MS research with MS researchers nationwide.

**IF YOU WANT TO KNOW WHAT IT IS LIKE TO LIVE WITH MS, YOU ASK THOSE LIVING WITH THE DISEASE.**

Through its online portal at [www.iConquerMS.org](http://www.iConquerMS.org), people with MS can share their health information and ideas about research. MS researchers can then use this shared data to find patterns in the disease that may not be visible otherwise, opening the potential to identify causes of MS, determine who will respond best to what therapy, and find new improved treatments for the disease.

iConquerMS™ is focused on research topics driven by people with MS, and governed by people with MS at every step of the process. As part of a larger nationwide research network called PCORnet, iConquerMS™ contributes health data to many research efforts, while also providing MS researchers access to data from millions of people across the country.

To learn more about the many ways you can help drive MS research forward, visit [www.nationalMSsociety.org/Research/Participate-in-Research-Studies](http://www.nationalMSsociety.org/Research/Participate-in-Research-Studies) or call us at 1-800-344-4867.
Please make check payable to the National MS Society, Attention: Stacy Funk
Mail to: 1201 Story Avenue, Suite 200, Louisville, Kentucky 40206

Your dollar may be the dollar that finds the cure! We continue to pave the way for MS treatments, none of which existed 20 years ago!

Name: ____________________________________________
Address: __________________________________________
_________________________________________________
Phone: _____________________________________________
Email: _____________________________________________

I commit to $: ________________________________
Every month: _________  Every year: ____________
One-time pledge: ________________

Please make checks payable to: National MS Society OR

Visa  □  Mastercard  □  Discover  □
American Express  □

Account#: ________________________________
CSV#: ________________
Signature: ________________________________

THANK YOU FOR YOUR GENEROSITY!