



INTERNATIONAL MULTIPLE SCLEROSIS  
Management Practice

Fall 2016  
Volume 3, Issue 33



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# Healing MS

THE IMSMP NEWSLETTER TO ADDRESS THE NEEDS OF OUR PATIENTS  
AND KEEP YOU INFORMED OF THE LATEST RESEARCH TREATMENTS  
AND WAYS TO HEAL

## **BUILD-OUT COMMENCES ON LARGEST STEM CELL RESEARCH LAB DEDICATED TO MS**

### ***Tisch MS Research Center of New York Invests \$4 Million to Jump Start Phase II of the Stem Cell Clinical Trial for MS***

#### **A Letter from Dr. Saud A. Sadiq:**

December 14<sup>th</sup>, 2016

Dear Patients, Friends & Supporters,

It gives me great pride and joy to announce that the Tisch MS Research Center of New York has received a financial boost enabling construction to commence on the largest stem cell research facility dedicated to multiple sclerosis. The build-out of our state-of-the-art laboratory will enable Phase II of Tisch MSRCNY's stem cell clinical trial for MS to proceed in 2017.

The new laboratory and treatment center will be the only one of its kind dedicated to researching the use of stem cells to regenerate new myelin in MS patients. It will support the growth of more than 20 billion adult stem cells and allow 50 patients to participate in our double-blind, three year trial. Phase II could establish efficacy of stem cells as a reparative therapy.

The Tisch MS Research Center is unique in many ways, especially when it comes to the generosity of our donors. Their unwavering support over the years is truly responsible for the construction of our new stem cell lab and ultimately will leave a legacy in the form of regenerative medicine, offering hope that a *Future Without MS* is possible. It is with deepest gratitude that I thank Gaye and James Pigott, Town Fair Tire Foundation, and Nancy and Alan Schwartz for their exceptional support of this endeavor. Together, these three donors have enabled Tisch MS to set aside \$4 million for the sole purpose of accomplishing this build-out and initiating our trial.

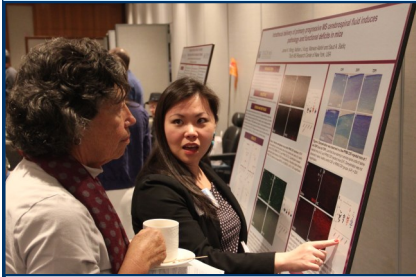
As we embark on this project, Dr. Violaine K. Harris, myself, and the entire stem cell research team remain dedicated to investigating the use of regenerative medicine to repair the damage caused by MS. As 2016 comes to a close, we are excited to submit the results of our successful Phase I trial for publication. We have no doubt that with your continued support for Phase II and the inspiration provided by our incredible patients, we will continue to succeed. Our goal is to establish a treatment that will reverse disability. Today, together, we take one step closer to reaching that goal.

Warmest regards,

Saud A. Sadiq, MD, FAAN

## TISCH MS LABORATORY RESEARCH

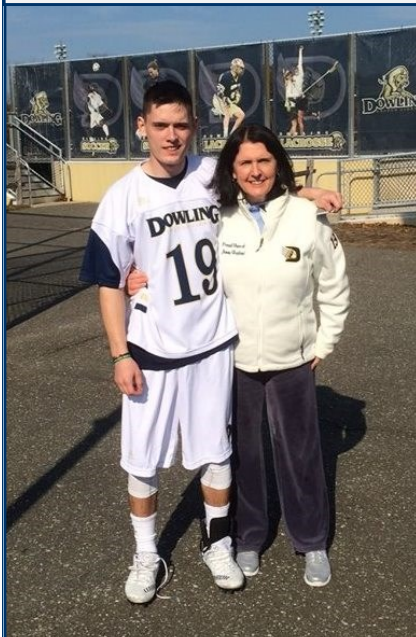
### Research Review from the 2016 Society for Neuroscience



**Dr. Jamie Wong presents her research to a guest at the 2016 Tisch MSRCNY Symposium**



**Dr. Saud A. Sadiq with Kathleen Ragland at the 2016 Symposium**



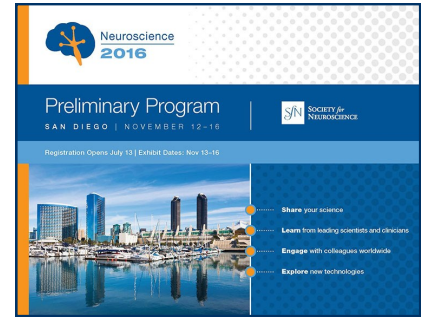
**Kathleen Ragland with son, Jimmy**

Tisch MSRCNY presented three research abstracts at the 2016 SFN Conference held in San Diego, California.

Dr. Fozia Mir presented the abstract, **“Thromboxane A2 levels are increased in the cerebrospinal fluid of active multiple sclerosis patients.”** This study looked at the involvement of the pro-inflammatory molecule, thromboxane A2, in multiple sclerosis. Results show that thromboxane A2 levels are higher in the cerebrospinal fluid (CSF) of multiple sclerosis patients compared to controls.

Dr. Jamie Wong presented the abstract, **“Intrathecal delivery of primary progressive MS cerebrospinal fluid induces behavioral deficits and spinal cord pathology in mice.”**

Dr. Wong created an animal model of primary progressive MS (PPMS) using intrathecal injections of CSF derived from PPMS patients.



John Tuddenham, Research Assistant to Dr. Violaine Harris, presented the abstract, **“Correlating Biomarker Levels with Disease Subtypes in Multiple Sclerosis.”** This study looked at potential biomarkers of clinical response to intrathecal mesenchymal stem cell-neural progenitor treatment in multiple sclerosis patients.

For more information regarding the research published by Tisch MSRCNY, please visit our website at:

[www.tischms.org](http://www.tischms.org)

### *Kathleen Ragland’s Story — A 2016 Symposium Patient Profile*

I was diagnosed with MS in February, 2008. I had trouble moving my left leg, but was walking without assistance. I met Dr. Sadiq in September of that year and had a bad relapse in October and another in November. By Thanksgiving, I could not feed myself, I had no "trunk" control (needed the use of a wheelchair and slid out of it, onto the ground... I was a rag doll). I couldn't even hold my head up. Dr. Sadiq used several different medications and I regained a lot of what I had lost. I had plateaued. I used a wheelchair or a walker (for very short distances). I often felt exhausted, not tired... but exhausted. Then, I participated in Dr. Sadiq's phase I stem cell clinical trial.

My son started to play lacrosse when he was 8 years old. I had always gone to every game, but when he was in high school, I would Google the field, call the school about accessibility, even drive by the field. Often I couldn't go unless my husband was there to help me. For home games, they would let me park on the grass near the field, but I still needed assistance to get to the bleachers. My son is 18 years old now and plays in college. Since receiving stem cell treatments, I can go watch him play by myself. I take the walker and just go. It's often a really long walk but I don't even hesitate. I know I can do it! It's so huge to be so independent! I now have more energy, I don't feel so exhausted all the time. I have walked 410' without any assistance... it's not pretty, but it is amazing!

## CELEBRATING A DEDICATION TO MS RESEARCH, TREATMENT & CARE

**During the Month of September, the IMSMP & Tisch MSRCNY Acknowledged Some Very Special Anniversaries at the Center.**



**L to R: Jerry Lin, Dr. Andrew Sylvester, Margaret Calarco & Dr. Saud A. Sadiq**

In this day and age, it is considered rare to find employees who work at an organization longer than 15 years and remain truly committed to their role and the mission of their company during that time. Not at the IMSMP and Tisch MS Research Center! This past fall, we recognized three professionals who have done just that.

**Jerry Lin**, is a Senior Staff Associate at Tisch MSRCNY. He is leading investigations into the cause of multiple sclerosis alongside Dr. Sadiq. Jerry Lin has collaborated with Dr. Sadiq since 1996, where he worked as a research assistant at Columbia University Presbyterian Hospital under Dr. Sadiq and Dr. Norman Latov. As a research associate, he helped establish Dr. Sadiq's research program at the MS Research & Treatment Center at Roosevelt Hospital from 1998-2006, and subsequently as a senior staff associate at the MSRCNY (now the Tisch MSRCNY) from 2006 to present. His motivation for continual research

lies in his strong work ethic and understanding that Dr. Sadiq cultivates a unique and collaborative environment at the Center. Jerry Lin is a graduate of Johns Hopkins University with a BA in Chemistry. He reached his **20** year milestone with the Center this year!

**Dr. Andrew Sylvester** has been a neurologist on Dr. Sadiq's team for **15** years. He began his career by subspecializing in MS and completing a two-year clinical neuroimmunology fellowship through Columbia University at the MS Research and Treatment Center at St. Luke's Roosevelt Hospital Center. He joined the MS Research and Treatment Center as an attending neurologist in 2001, where he practiced until moving with Dr. Sadiq to the IMSMP in 2006. Recently, Dr. Sylvester earned an additional subspecialty certification as a diplomat for Neural Repair and Rehabilitation.

**Margaret Calarco** started in February 2001 as a front office secretary. Shortly after, she was promoted to office supervisor. When Dr. Sadiq was appointed Chair of Neurology at St. Luke's Roosevelt Hospital Center, Margaret became his executive assistant. Within two years Margaret was promoted to office manager for the Center while holding the Executive Assistant to the Chairman position. In 2006, Margaret was instrumental in the move to 521 West 57th Street and the opening of the IMSMP. It was at that time she was promoted to Practice Director. She celebrates **15** years at the Center this year!

**Congratulations to All!**

### ***Find Tisch MSRCNY On Social Media***

**Tisch\_MS**



**@tischms**

Simply Search Tisch MS Research Center of New York





**Dr. Violaine Harris  
at the 2016 Symposium**

## THANK YOU FOR ATTENDING THE 2016 SYMPOSIUM

Tisch MSRCNY & the IMSMP would like to thank everyone who attended the Tisch MS Research Center of New York's 19th Annual Patient Symposium. This year, more than 800 attendees filled the grand ballroom of the New York Hilton Midtown.

Every year we are overwhelmed by the growing number of guests dedicated to learning more about multiple sclerosis research, ways to handle symptom management and improvements to their quality of life.

We are also grateful to all of those who took a moment to complete our survey and offered feedback on ways to improve upon next year's event! Plans are already in the works. We hope to see you there!

**SAVE THE DATE: 10.22.17 - Our 20th annual symposium!**

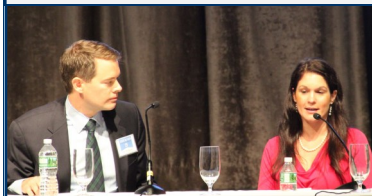
### *Tailor Made Treatment Plans Make a Difference*



**Dr. Andrew Sylvester with  
Christine Tiedemann**

#### **The Thought Process of Management**

At this year's patient education symposium, MS Specialists from the IMSMP presented four very different profiles of a person with multiple sclerosis. These scenarios included a person newly diagnosed with relapsing remitting multiple sclerosis (RRMS), a RRMS patient who has experienced exacerbations, a person with secondary progressive multiple sclerosis (SPMS) and a patient with the progressive form of the disease.



**Dr. Armistead Williams with  
Melinda Saffioti**

In all instances, the importance of communication with your neurologist, the use of complimentary services such as physical therapy, social work, a naturopathic consult and a positive attitude were all stressed.



**Dr. James Stark with  
Tony Hughes**

Dr. Sylvester spoke with Christine Tiedemann and discussed the goals of a management program for a newly diagnosed patient with RRMS. Dr. Williams presented Melinda Saffioti who has battled relapses with her MS. He explained how to detect if you're on the proper treatment and the importance of lifestyle in addition to finding the right medication. We then met Tony Hughes, a patient of Dr. Stark's. Tony stressed the importance of staying positive while dealing with secondary progressive MS. Dr. Stark reviewed some of the drugs commonly associated with this form of the disease and confirmed that not everyone with RRMS will develop SPMS.



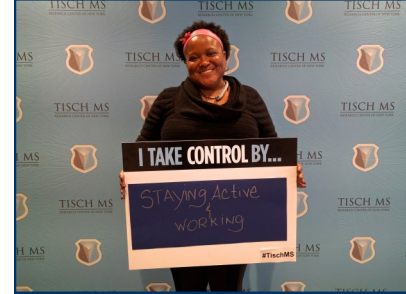
**Dr. Saud A. Sadiq with  
Nancy Crooks**

Dr. Sadiq introduced us to Nancy Crooks, who has a progressive form of multiple sclerosis. Dr. Sadiq explained treatments used at the IMSMP for patients with progressive MS and a neurologist thought process when selecting these drugs. In Nancy's case intermittent plasma exchange was found to be the most effective stabilizing treatment. Instead of the usual Q&A session following these presentations, audience members were encouraged to take notes on the questions they will ask their neurologist on THEIR thought process when managing their MS.

# HOW DO YOU TAKE CONTROL?

During the 2016 Tisch MS Research Center Symposium, We Asked People With MS, How Do You Take Control?

Here's What They Told Us . . .



Our sincere appreciation to all who participated and provided such inspirational images!  
To view the full photo album, please visit our Facebook page at:  
<https://www.facebook.com/Tisch-MS-Research-Center-of-New-York-237020273060207/>

**KEEP IN TOUCH!**  
update your information

## FROM THE FRONT DESK

Making any changes? As soon as your insurance plan, home address or telephone numbers change, please do not hesitate to contact the office and give them the new information.

This will allow us to keep our files up to date and we can better serve our patients when we have all the correct information to work with.

Thank you!



# 10.22.17

20th Annual  
Tisch MSRCNY  
Patient Symposium

## A NOTE FROM THE NURSES



### Do You Have a Primary Care Physician?

Please keep in mind the importance of seeing a primary care physician (PCP) yearly. Many patients have either not had a physical in a few years or have no primary care physician at all. Having a good relationship with a PCP will assist us in giving you the most comprehensive care possible. Many medical conditions such as hypertension, high cholesterol, diabetes, and thyroid disorders, just to name a few, require specific blood work at precise intervals. This blood work should be ordered and tracked by your PCP, especially since it can affect various medications you may be taking for some of these other conditions. Medications for conditions that are not MS or related

to MS symptoms should be directed to your PCP.

Another benefit of having a good relationship with a PCP is that they can keep you up to date on guidelines for preventative health screenings such as mammograms, colonoscopies, and prostate exams. In addition, if unrelated to MS, you contract an illness or have any injury, already having a PCP will be very helpful to be seen quickly and avoid emergency rooms.

Any new medical conditions or medication should be brought to our attention at your next office visit or you can always call us with a medical update.

## SOCIAL WORK NEWS



### Medicare Reminder

Medicare's open enrollment period runs from January 1<sup>st</sup>-February 14<sup>th</sup>.

Please note that if you are currently enrolled in a Medicare Advantage Plan, you can leave your current plan and switch to Original Medicare. Your Original Medicare coverage will begin the first day of the following month. If you switch to Original Medicare during this period you will have until February 14<sup>th</sup> to

also join a Medicare Prescription Drug Plan (Part D) to add drug coverage. Your prescription drug coverage will begin the first day of the month after the plan receives your enrollment form.

Please inform the front staff if your insurance has changed, and please remember that an IMSMP social worker is available to discuss insurance questions or changes.

## PHYSICAL THERAPY & REHABILITATION

A Two Part Article from Dr. Stephen Kanter, Supervisor of Rehabilitation Services.

### Part 2: It's Never a Bad Time to Reflect . . .

As we move toward the last couple of months of 2016, it is a good time for patients with multiple sclerosis to reflect on what has (or has not) been done as part of a DAILY physical wellness routine. Whereas, this can be true of all people, those with multiple sclerosis can change the course of their disease related impairments more than others. There are many instances seen at the IMSMP where patients who have the same "type" of MS have marked differences in the ability to walk and perform functional activities independently.

When planning for 2017, changing behaviors related to exercise compliance, following up with your physical therapist, and addressing activity withdrawal are some things that can be considered. However, to complement being on a disease modifying treatment prescribed by your neurologist, it is important to start thinking about how you want and can do more for yourself in the

upcoming year. This is done by setting up realistic goals, using necessary equipment, and being honest with yourself and your caregivers about how to, "thread exercise into your life."

In the summer issue of Healing MS, your physical therapy team at the IMSMP wanted you to ask yourself:

***"Have I stretched every day?"***

***"Did I see a Physical Therapist at least once in the past 6 months?"***

***"Is there anything I cannot do this year that I was able to do much better last year?"***

Take a moment to review your responses to these questions. The expectation of performing exercises everyday can be daunting for people who feel overwhelmed by their schedule and other obstacles. In short, the answer can be "Do the best you can." As the physical therapists at the IMSMP tell their



patients, performing ZERO exercises on a given day is not an option. Any number of repetitions, even if fewer than prescribed, must be done every day with very few exceptions (Dr. Kanter allows patients to take a day off for their birthday. Dr. Woods allows patients to take a day off if their team is playing in the World Series).

Making 2017 a better year for one's physical wellbeing is possible for everyone. Sometimes, it is the person with MS and sometimes it is the caregiver(s) for someone with MS. Improved physical wellbeing requires a level of reflection and planning. If this is done with the guidance of a trusted physical therapist or wellness professional, MS does not have to cause disability. MS can be the fire under your bottom to take control of something you have control of.

## NEWS ON NATUROPATHY— A 2016 SYMPOSIUM PRESENTATION REVIEW



At our 2016 Patient Symposium, Dr. Bates discussed Nutritional Strategies for Myelin Repair, including nutrients which help to trigger new myelin growth, nutrients that provide building blocks for healthy myelin, and nutrients that help to protect existing myelin. Some of the most important nutrients for triggering new myelin growth include polyphenols

(molecules from certain plant foods particularly colorful fruits and vegetables, spices, coffee, tea, and red wine), essential fatty acids (especially from clean oily fish) and vitamin D. Myelin is primarily composed of fats, and nutrients that help provide building blocks for healthy myelin include dietary fats and essential fatty acids (best from clean oily fish, nuts and seeds, and grass-fed animal products) and the supplements biotin and carnitine. Nutrients that help to protect myelin include iron (which can be good or bad for people with MS, depending on the individual), vitamin K, creatine, and vitamin B12. For more information, or to view all of the slides from this informative presentation, visit: [www.imsmp.org](http://www.imsmp.org). Interested in creating a personalized plan that is right for you? Schedule your appointment with Dr. Deneb Bates by calling (212) 265-8070.

# TISCH MSRCNY DEVELOPMENT DEPARTMENT NEWS

## 2016 *FUTURE WITHOUT MS* GALA The Stars Came Out to Help End Multiple Sclerosis

Over 400 people packed the ballroom at The Plaza Hotel in New York, on Thursday, October 27<sup>th</sup>, 2016 for what turned out to be our most successful, *Future Without MS* Gala ever. Legendary musician, **Paul Shaffer**, and star comedian, **Amy Schumer**, both entertained and shared with guests, their personal relationships to the Center. The evening included, cocktails, dinner, musical performances, a live auction, and a very special video featuring the Tisch MS extended family, raised over \$2.5 million for MS research at the Center.

The dinner began with a welcome from Chairman of the Board, David Greenstein. Before introducing Paul Shaffer and his Longtime Special Friends Band, Greenstein reminded guests of the evening's fundraising for research purpose, and how research happening today at the Center gives people living with MS and their families something priceless, hope.

After a rousing performance, Paul Shaffer spoke of his relationship with the Center and then brought Dr. Sadiq to the stage. Dr. Sadiq shared his thanks for the generous support of our community of donors, his excitement that we're finally ready to begin the FDA approved Phase II stem cell trial – and our challenge to fund that initiative, as well as the other patient-driven research projects at the Center.

Next, the crowd watched a moving video featuring the children of patients who shared their experience living with MS. It ended with one unified request – for a *Future Without MS*. Finally, Amy Schumer came to the podium to tell with both humor and emotion, her story of growing up with a parent with MS. Amy had the crowd howling with laughter as she spoke about her dad. She also had them crying with her heart felt tribute to Dr. Sadiq and the entire staff at the Center.

Before dinner, Paul Shaffer and the band came back to the stage for another set and spectacular grand finale.

It's the incredible generosity and commitment of our contributors that inspires our research team to continue their work and lead us down the path to a *Future Without MS*.



**Chairman of the Board,  
David Greenstein**



**Amy Schumer gives an  
emotional speech about  
having a parent with MS**



**Dr. Saud A. Sadiq &  
Paul Shaffer at the 2016  
*Future Without MS* Gala**



**Guests Support MS Research**



**Paul Shaffer & His Longtime  
Special Friends**



## DEVELOPMENT DEPARTMENT NEWS CONT'D



### ***FUTURE WITHOUT MS GALA DONORS\****

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#### **\$75,000+**

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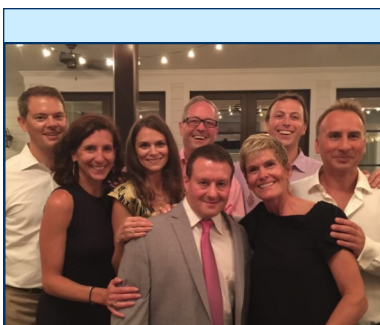
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Val Urry  
Patricia Wolff

\*Due to space limitations this list includes donors of \$1,000 or more, received as of October 31, 2016. We sincerely appreciate contributions at all levels as they made our research possible.

## DEVELOPMENT DEPARTMENT NEWS CONT'D

### Inspiring Events by Patients & Friends

#### The Putman Family - #StandUpForStemCells



**Susan & James Putman with Dr. Andrew Sylvester and IMSMP/Tisch MSRCNY staff**

On September 10<sup>th</sup>, 2016 Susan Putman and family held their first #StandUpForStemCells fundraiser at their home in Bernardsville, New Jersey. All aspects of the event were donated including food, drinks and the amazing live band. The goal was to raise **\$100,000** for stem cell research at the Tisch MSRCNY and the night was a huge success. The Putman's achieved their goal and spread awareness to friends and family.

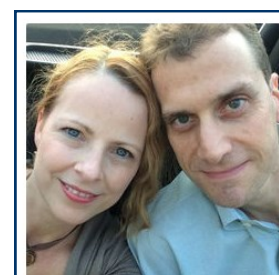
#### Timmer's Way

The annual Timmer's Way Music Festival Benefit for Tisch MSRCNY on September 17<sup>th</sup>, 2016 was a fun time for all and huge fundraising success donating **\$30,000** to MS research. The event, named to honor Timmer Wood, included a raffle, silent auction, cornhole tourney and an evening of great music. Thanks to the Wood family and all their guests for helping us reach our goal for a *Future Without MS*.



#### Barry's 15<sup>th</sup> Annual MS Benefit & Concert

For the last 14 years, Tammy and Neil Barry have opened their Raleigh, NC home for a night of music, fun and fundraising for MS. Hopeful and inspired by the groundbreaking stem cell research and successful Phase I clinical trial, this year the Barry's chose to donate all money raised to Tisch MSRCNY. Congratulations to all who attended on October 15<sup>th</sup>, 2016 and together raised a record **\$16,000** for stem cell research.



**Tammy & Neil Barry**

### Congratulations to Team Tisch MS Over \$103,000 Raised for A Future Without MS

Team Tisch MS (TTMS) ran strong among the thousands in the TCS NYC Marathon on November 6<sup>th</sup>, 2016. Volunteers, sponsors and staff came together to make this a huge success from the opening gun to our post-race celebration at Park Avenue Tavern. The Team has collectively raised over **\$103,000** and, for the second year in a row, has more than doubled their fundraising goal. Shout out to Dr. Stephen Kanter for kick-starting TTMS into the fundraising powerhouse it has become.

#### Join TTMS!

Whatever you do – a walk, a triathlon, a 5k or bike ride – do it as part of Team Tisch MS. We'll help you setup your Team Tisch MS fundraising page for your event. Sounds too hard? It's super easy and we'll support you all the way. Plus, we'll give you our stylin' TTMS t-shirt for your event day!

For more info, call Meaghan Browne at 646-557-3863 .

#### 2016 Team Tisch MS NYC Marathon Times

Behrad Derakhshan 3:47:43, Caroline Epner 4:41:47 Gregg Hayim 6:07:31, Whitney Mallis 4:35:40, Mireya Montalvan-Panzer 5:15:23, Elizabeth Woods 4:06:13, Allan Zapanta 4:54



Racing to Repair Multiple Sclerosis



#### THANK YOU TO THE 2016 TTMS SPONSORS



## DEVELOPMENT DEPARTMENT NEWS CONT'D

### WITH SINCERE APPRECIATION, WE HONOR & RECOGNIZE OUR DONORS\*

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#### \$250,000+

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#### \$100,000+

Noel & Edward Foley

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Bonnie & Clifford Eisler

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#### \$10,000+

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#### \$5,000+

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#### \$2,500+

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