



SMS RESEARCH FOUNDATION

Fall/Winter 2019 Research, News, & Events



Greetings!

As the holiday season is upon us, we find ourselves reflecting on the past year and those who have helped shape our organization.

We would like to express our sincerest appreciation for the trust and faith you have placed in us. With your support and partnership, we are diligently working toward a better future for those with Smith-Magenis Syndrome. Please take a few minutes to review our new sletter as it is filled with progress, dedication, and hope.

We know you'll hear from many deserving charities during the upcoming season of giving, and we hope you will consider the SMS Research Foundation during this time. We wish everyone a peaceful and enjoyable season ahead.

With gratitude,

Jennifer Iannuzzi
President, SMS Research Foundation

New Research Project Yale University School of Medicine

Kavli Institute for Neuroscience at Yale University School of Medicine \$75,000 Grant - October 1, 2019

Researchers at the Kavli Institute for Neuroscience will study how the disruption of the RAI1 gene alters the development and function of the brain in mice with SMS. They have developed novel strategies using light microscopy to monitor or "image" the activity of millions of neurons in the brain.

Researchers will focus on the neocortex, as this brain region is critical to most cognitive and emotional functions. By imaging neocortical signals in mouse models with disrupted RAI1, they hope to identify previously unknown functional signatures of brain activity associated with SMS. They expect their findings will provide fundamental insight into the function of RAI1 in the neocortex and generate a novel experimental platform from which to evaluate potential therapies aimed at modifying brain activity and improving functional outcomes for SMS patients.

Please visit our [website for more information](#) about this exciting new research project.



Research Symposium Recap

SMS Research Symposium September 28-29, 2019

The SMSRF partnered with PRISMS to co-host the 10th annual SMS Research Symposium. This event represented the first major collaborative effort for the two organizations and was a huge success.

The conference was a full-day event with over 40 participating scientists and researchers interested in SMS

from around the world. The event was kicked off by a member of our Scientific Advisory Panel, Gianluca Pirozzi, MD, PhD, with a moving and inspiring keynote address on hope and research from the unique perspective of a scientist and SMS father.

There were 20 presentations that covered a range of important topics including: sleep, clinical care coordination, caregiver and sibling implications, and basic and clinical research. There were networking opportunities for researchers and robust discussions regarding the current status of medical progress and the steps needed to work towards therapeutic strategies that will improve the lives of those with SMS.



SMS Research Foundation
and PRISMS

Upcoming Event

Los Angeles 5K Walk for SMS Santa Monica, CA - November 17

Susan and Paul Diamond will be celebrating SMS Awareness Day by hosting their 8th Annual 5K Walk for SMS on Sunday, **November 17th** in honor of their 14-year-old son, Jeremy. This is a fun event for the whole family with a silent auction, music, lunch, and more!

Come out to support a great cause while getting your workout for the day! To register and/or donate, go to the [Los Angeles 5K Walk for SMS event page](#).



Recent Event

Wyatt's Walk & Run 5K Mt. Juliet, TN - September 11

Thank you to **Jessica and Eric Rogers** for hosting their 4th Annual Wyatt's Walk and Run 5K in honor of their 5-year-old son, Wyatt. With over 100 participants, they raised more than **\$17,000** for SMS research! Thank you to all the organizers, sponsors, and participants who helped make the event such a success!



SMS Awareness Day - Nov. 17

The SMSRF and PRISMS are coming together to promote SMS Awareness Day! Throughout the month of November, we are encouraging our SMS community to share stories of how we are **#strongertogether**. How did you find our community? Who was your first contact? What was your first SMS event?

- Please share pictures, videos, and text to tell us about your **#strongertogether** moments with the SMS community.
- Make sure to use our hashtags **#strongertogether** and **#SMSAwarenessDay**, and tag SMSRF and PRISMS so we can see your posts!

We will be highlighting member stories all month. We all gather strength from each other – let's celebrate that strength. We want to hear your story.



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and PRISMS

#GivingTuesday - December 3rd

#GivingTuesday is an international day of charitable giving on the Tuesday after Thanksgiving. Facebook will again be matching donations dollar-for-dollar this year. In addition, we have an anonymous donor who will also be matching your donation. That means your donation will have triple the impact on December 3rd!

YOU + FACEBOOK + MATCHING DONOR = 3X THE IMPACT!



Research Symposium Video

This video was a joint effort between PRISMS and the SMS Research Foundation as an opener for the 2019 Research Symposium in Houston, TX. Please watch and see why collaboration and research for Smith-Magenis Syndrome is so important to SMS families. Thank you to the SMS researchers, donors, and members of the SMS community who give their time and energy to support this effort. [#StrongerTogether](#)



10-Year Anniversary

Next year will mark the 10-year anniversary of the SMS Research Foundation! In honor of this milestone, we will be sharing our accomplishments from the past ten years, as well as our goals and vision for the future. We will be also rolling out a national 5K walk to commemorate our anniversary, so stay tuned for more information!



Holiday Pop-Up Store

The SMSRF will launch its first-ever pop-up store just in the time for the holidays! The store will open on SMS Awareness Day, November 17, and last through December 2, 2019.

We'll be selling apparel, ornaments, mugs, and more! All items will be shipped in time for Christmas delivery. Be on the lookout for the direct link coming soon!



[DONATE TO SMS RESEARCH](#)

The mission of the SMS Research Foundation is to advance scientific research leading to innovative treatment options for people living with Smith-Magenis Syndrome (SMS).

The SMS Research Foundation is a 501(c)(3) nonprofit organization founded in June 2010.
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