



September 2021 - Research Update, News & Events

Greetings!

The community response to our annual signature Steps Move Science Virtual Walk this past June was a huge success. We exceeded our goal and continue to raise awareness regarding the importance of supporting critical research projects that will lead to therapy for individuals with SMS. If you haven't had the opportunity to view our Finish Line Event from June I would encourage you to do so as it highlighted our donors, participants, and research partners. In particular, we heard from the Lead investigator from all 3 labs that we support: Baylor, McGill and Yale. They were able to provide a synopsis of their project, an update in terms of progress and future plans and how each project was consistent with the mission of the SMSRF. We have received very positive feedback from the event and it motivates us to work even harder to try and support more projects. We are also in the middle of our annual grant cycle and our Scientific Advisory Panel (SAP) is currently reviewing submitted projects to determine which lab and/or labs will get support for 2022. In order to continue this kind of financial commitment we need your support. We have numerous events and activities throughout the year and we hope you can get involved in one or all of them so we can change and improve the lives of those with SMS.

Sincerely,
SMS Research Foundation Board of Directors

Steps Move Science 2021 Virtual Walk

WE DID IT!!!

With your support, our 2021 Virtual Walk surpassed our goal and raised over \$72,000 for research for Smith-Magenis Syndrome.

It wouldn't have been possible without our 19 teams, 119 participants and 262 donors sharing our message, encouraging your friends to support a cause you care deeply about, and joining us with your 17 minutes or miles of walks, runs, yoga stretches, or meditations! You all are rock stars!!

Of course we must thank our sponsors for helping us across the Finish Line. So, to the great folks at [Dewey Insurance Agency](#), [The Fairweather Family](#), [Priority Lending](#), [Nye, Stirling, Hale & Miller, LLP](#), [Living Special Needs](#), [Title Guaranty](#), [Fratarcangeli Wealth Management](#), and [Gift Baskets R Us](#), **thank you!**

We hope you found new energy, renewed strength, or maybe a sense of calm during our Steps Move Science 2021 Virtual Walk and that this energy carries you through the rest of the year.

Mark your calendars for June 2022 and join us again next year!!



THANK YOU to our generous 2021 Steps Move Science Virtual Walk for SMS sponsors!

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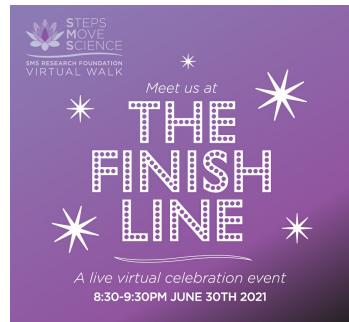
SMS T-shirts

Our commemorative shirts from our 2021 Steps Moves Science Virtual Walk, with your SMS loved ones' names on the back, are now ready for orders. Available in a wide variety of colors and styles. Orders close on 9/30/21 and will ship approximately 2 weeks after that. A portion of the proceeds will benefit the SMS Research Foundation. Thank you for your support! [Order Here](#)



Research Update

We closed out the end of our 2021 Virtual Walk at the **Finish Line**, an event that celebrated our amazing participants, donors, sponsors and SMS community. We also heard from our Scientific Advisory Panel as well as from each of our researchers who gave us personal updates on their exciting projects. If you are looking for some serious inspiration as to why you should support research of SMS then you definitely don't want to miss these presentations! You can watch the full video recording of the [Finish Line](#) [HERE](#).



If there is a specific body of work that you are particularly interested in, we've broken down the presentations for you. You can watch their individual videos by clicking the links below.

SCIENTIFIC ADVISORY SPOTLIGHT

Gianluca Pirozzi, M.D, PhD.

Senior Vice President, Clinical Development Head, Hematology, Nephrology and Translational Sciences, at Alexion Pharmaceuticals



Scientific Advisory Panel update from Dr. Gianluca Pirozzi

RESEARCH SPOTLIGHT

Dr. Wei-Hsiang Huang

Lab for Neuro-developmental Disorders, Centre for Research in Neuroscience

McGill University, Montreal



Update from Dr. Wei-Hsiang Huang from McGill University.

RESEARCH SPOTLIGHT



Michael J. Higley,
MD, PhD and
Jessica A. Cardin,
PhD

Kavli Institute for
Neuroscience,
Yale Department of
Neuroscience



Yale SCHOOL OF MEDICINE

Update from Dr. Michael Higley from Yale University

RESEARCH SPOTLIGHT

Dr. Sarah Elsea

Professor, Molecular and
Human Genetics & Sr. Director,
Biochemical Genetics

Baylor College of Medicine
Houston, Texas

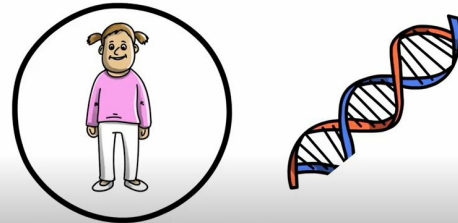


Update from Dr. Sarah Elsea from Baylor College of Medicine

WATCH: SMS Animation Video

Understanding Smith-Magenis Syndrome

The fastest, most comprehensive yet simplest to understand explanation of Smith-Magenis Syndrome and why we're furthering research with the goal of improving the quality of life for those living with the disorder. Click on the video to learn more (right).



Smith Magenis Syndrome (SMS)

What's Ahead...



SMS Awareness Day is November 17, 2021! Smith-Magenis Syndrome families across the world participate in raising awareness of SMS on this day, 11/17, in honor of the microdeletion 17p11.2 which is responsible for the disorder.

How you can join the celebration:

- Follow the Smith-Magenis Research Foundation Facebook and Instagram pages and share our posts to help educate your friends and family about SMS.
- Create a social media fundraiser and suggest a \$17 donation.
- Tag us in your posts about your loved one with SMS.
- Make sure to use our hashtag #SMSAwarenessDay and tag SMSRF so we can see your posts!

We can't wait for you to join our global community in spreading the word about SMS throughout the day on 11.17.21!!

#GivingTuesday is an international day of charitable giving on the Tuesday after Thanksgiving. Facebook will again be matching donations dollar-for-dollar this year. That means your donation will have double the impact on November 30! Visit our [Facebook page](#) on 11/30 and make a donation to further research for Smith-Magenis Syndrome or create your own fundraising event on your Facebook page.



Fundraising

Recycle for Research Wilton, CT, Ongoing

Six years ago, Ben Iannuzzi started the Recycle for Research fundraiser in honor of his sister Sydney who has SMS. Brother Cole, took over when Ben moved away to college. Now that both young men are in college, we'd love to open the fundraiser up to others. Do you have a pre/teen looking for a service project or volunteer hours? Consider starting a Recycle for Research in your town. Email SMS Board President Jennifer Iannuzzi at jmiannuzzi@gmail.com to learn how. It's easy, fun and helps to fund our research projects. Now that her brothers are out of the house, Sydney Iannuzzi is stepping in to take over the project in Wilton, CT. If you live in the area, please [email Jennifer](#) to coordinate a time to drop off empty water bottles.

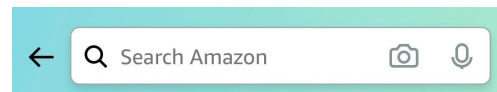


Amazon Smile App

You can now support the SMSRF through AmazonSmile on the Amazon Shopping app!

- 1) **Join AmazonSmile** - if you are not already an AmazonSmile member, sign up at smile.amazon.com. Simply select SMS Research Foundation to start generating donations, at no cost to you.
- 2) **Get the App** - download or update the latest version of the Amazon Shopping app on your phone.
- 3) **Open the app and find 'Settings' in the main menu (☰)**. Tap on 'AmazonSmile' and follow the on-screen instructions to turn on AmazonSmile on your phone.

If you don't want to shop on the app, you can always shop at smile.amazon.com on your desktop or mobile browser.



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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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