



SMS RESEARCH FOUNDATION

March 2021 - Research Update, News & Events

Greetings!

After a year full of upheaval and hardship, it finally feels as though there is light and hope ahead. We are deeply grateful to everyone who supported us throughout 2020. Your generous donations helped us earn matching gifts through our virtual walk fundraiser, Giving Tuesday, and our year-end campaign. Your contributions have helped continue SMS research projects at McGill University, Baylor College of Medicine, and Yale School of Medicine in 2021.

In our next 3 newsletters, we will highlight each research lab to help you gain a better understanding of how these labs function, who is involved in SMS research, and how they help the SMSRF accomplish its mission and vision. This month we are highlighting Professor Wei-Hsiang Huang, PhD, at McGill University.

We look forward to continued growth and appreciate your support. Thank you for bringing us one step closer to improving the lives of those with Smith-Magenis Syndrome!

Sincerely,
SMS Research Foundation Board of Directors

Research Update

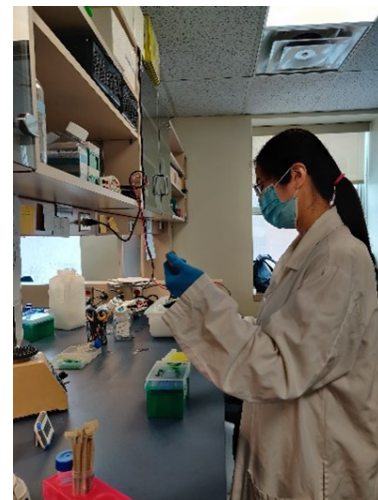
McGill University

\$81,000 Grant (Jan. 1 - Dec. 31, 2021)

The SMSRF awarded a second-year grant to Dr. Wei-Hsiang Huang's lab at McGill University in Montreal. The lab uses modern human cell lines and animal models, as well as cutting-edge molecular and neuroscience technologies to develop therapies for SMS.

Preliminary data from last year's grant showed that in different human cell lines, Rai1 protein has a very short half-life (approximately 2 hours). This means that Rai1 is actively being degraded by unknown pathways.

The current project will: (1) identify druggable targets to modify Rai1 levels, and (2) reverse SMS-like phenotypes in mice by targeting an important Rai1 downstream pathway. Please visit our [website for more information](#).



Rare Disease Day - Recap

Thank you to everyone who sent in photos of their kids, which we shared on social media, to help raise awareness for SMS and **Rare Disease Day** on Feb. 28th! SMS is one of 7,000+ rare diseases that are chronic, progressive, degenerative, and/or disabling.

We also asked our community to help recognize Rare Disease Day by making a one time (or monthly recurring) \$17 donation (in recognition of the deletion

on the 17th chromosome, which is responsible for SMS). As a result, we raised over \$4K in one day. Thank you to everyone who contributed!

To keep the momentum generated by rare disease day going, [please consider making a one time \(or recurring\) \\$17 donation.](#)



Hugo Garcznski, age four

Leadership News

The SMSRF recently welcomed two new board members who bring extensive experience and skills to the organization. We are excited to have them on our team!

Jonathan Miller is the Managing Partner at Nye, Stirling, Hale & Miller, LLP, where he specializes in handling complex civil litigation. Jonathan has represented Fortune 500 companies, public entities, universities, and individuals in cases involving higher education law, civil rights, wrongful termination, consumer class actions, unfair business practices, catastrophic personal injury, and copyright, trademark and patent infringement.

Jonathan lives in Santa Barbara with his wife and two children. His son, Griffin, is nine years old and was diagnosed with SMS at two months of age.



Manny Garcznski has over twenty years of experience in non-profit management and medical research fundraising. Most recently, Manny worked at Versiti's Blood Research Institute, raising funds to support thirty leading-edge researchers.

Manny lives in Milwaukee with his wife and two children. His son, Hugo, is four years old and was diagnosed with SMS when he was twenty months old.



Partnerships

We are incredibly grateful for the recent financial support from two non-profit organizations that are committed to funding necessary research for SMS.

Smith Magenis Italia, based in Rome, donated \$12,000 and is a new international partner for the SMSRF. **Grinning with Gavin** was started by SMS parents, Bethany and Greg Bonetti. They are longtime supporters of the SMSRF and donated \$3,000. Thank you to both organizations for believing in our mission.



Fundraising

Steps Move Science Virtual Walk June 2021

Due to continuing covid restrictions in some states, we anticipate our in-person events will be cancelled in 2021. As a result, we will be hosting our second Steps Move Science virtual 5K walk, which will take place in June 2021. Stay tuned for more information!



Recycle for Research Wilton, CT, Ongoing

Cole Iannuzzi continues his Recycle for Research fundraiser in Wilton, CT. If you live in the area, please [email Cole](#) to coordinate a time to drop off empty water bottles. He will recycle them to raise money for SMS research. If you would like to start your own Recycle for Research fundraiser, please [email Jen Iannuzzi](#).

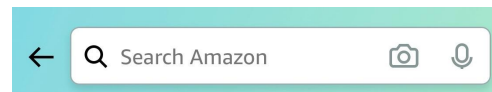


Amazon Smile App

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.

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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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