



SMS RESEARCH FOUNDATION

Spring 2019 Research, News, & Events



Greetings!

Happy Spring! At the SMS Research Foundation, we have two major milestones we expect to reach by the end of this year – to complete the proof-of-concept phase of our gene therapy project and to pass the \$1 million mark in total fundraising!

We recently completed a formal strategic planning session and set priorities and key initiatives for the next five years. To that end, we have expanded our Board, strengthened our Scientific Advisory Panel, and formalized our annual grant process to continue funding new and innovative SMS research projects.

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!

With gratitude,

Jennifer Iannuzzi
President, SMS Research Foundation

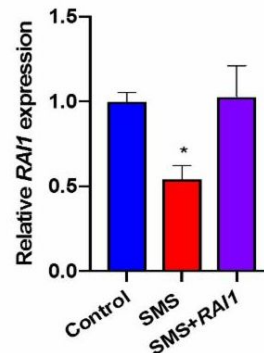
Research Update

The Elsea lab at Baylor College of Medicine is working on **two approaches** to identify a treatment for SMS. The first is done by replacing a gene (via gene therapy) and the second is by enhancing gene expression from the remaining functional copy of RAI1 (via drug therapy). Normalizing the expression of RAI1, while not a cure, should have a positive impact toward correcting the abnormalities observed in SMS, ultimately leading to an improved quality of life.

Researchers at the Elsea Lab have made progress with both of these approaches. With the gene therapy approach, functional viral vectors containing RAI1 were designed and validated. The figure shows that SMS cells treated with the RAI1 lentiviral vector successfully restored levels of RAI1 to normal levels in SMS cells.

These RAI1 viral vectors are **ready for injection in SMS mouse models** to determine the distribution and physiological impact on growth and development of the SMS mice.

Please visit our [website](#) for the [full research update](#).



Upcoming Events

Avengers Movie Fundraiser Wilton, CT - April 25

Christopher Grass, of Grass Realty Group and a longtime friend of the Iannuzzi family, is hosting a special premiere screening of *Avengers: Endgame* in Wilton, CT on Thursday, April 25 at 7:30 pm.

Tickets may be purchased at the door or by emailing cgrass@kw.com. Thank you to the Grass family for their incredibly generous and thoughtful support!

CAN THE AVENGERS DEFEAT THANOS AND "SNAP" THE UNIVERSE BACK INTO PLACE?

Grass Realty Group, powered by Keller Williams Prestige Properties, presents a special premiere screening of:

AVENGERS: ENDGAME

Wilton Bow-Tie Cinemas
Thursday April 25th, 7:30 pm
Tickets are \$10 and include
a seat, popcorn and drink.

All proceeds from the event go
to the SMS Research Foundation
founded by Wilton resident
Jennifer Iannuzzi.

To buy tickets: call, text, or email Christopher Grass at 203.803.9326 or cgrass@kw.com

A portion of the funds will cover event costs with our partner organization, so we welcome additional donations.



The Smith-Magenis Research Foundation funds only the best, most comprehensive SMS research projects shared with the best and brightest scientists focused on this issue. Through this science, SMS Research Foundation is committed to improving the lives of children around the world.

West Broward Food, Wine & Music Event Plantation, FL - June 13

Missy and Dan Longman will be co-hosting the inaugural West Broward Food, Wine & Music event with the Davie-Cooper City Chamber of Commerce on Thursday, June 13.

Enjoy food tasting, wine sampling and live music while raising money for the SMS Research Foundation. You may [purchase tickets or sponsorships here](#).



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Recent Event

Crossfit Open Games Sunrise, FL

Thank you to **Crossfit RGTC** for using the Crossfit Open Games as an opportunity to fundraise for the SMS Research Foundation and bring awareness to Smith-Magenis Syndrome! The team participants raised over \$1,000 during the 5 week competition, February 21 - March 25. We appreciate your generosity!



Advocacy & Awareness

Webinar: Self-Care Strategies for Families of Children with Disabilities

On January 9, 2019, **Missy Longman** hosted a webinar that encouraged parents of children with disabilities to reframe self-care in the context of our challenging lives. She explored obstacles that often sabotage our own self-care and ways we can overcome them. This was presented in coordination with the Center for Appropriate Dispute Resolution in Special Education (CADRE)



Click on the image to view the webinar.

State of Connecticut Hearing

On February 19, 2019, **Jennifer Iannuzzi**, co-founder and president of the SMSRF, testified in front of the Human Services Committee in the state of Connecticut to introduce an act concerning services for individuals with SMS. With the help of her state representative, Gail Lavielle, Jen advocated for additional state level services to help those with SMS and their families. Click [here](#) to watch the video.



With Jen's initiative, we are bringing SMS to the attention of lawmakers and the rare disease community. State Bill 834 is expected to be voted on in April 2019. If passed, a study will be conducted to determine whether children with SMS are receiving adequate services, including, but not limited to, early intervention, special education, and other supportive services.



Photo: Jennifer Iannuzzi & Rep. Gail Lavielle

DECA Competition Award

On March 9, 2019, **Hannah Hatley** and **Jack Vaughn** won

2nd place in the state of Tennessee for their DECA project and presentation on Smith Magenis Syndrome and SMS research. Hannah has a 5 year-old cousin, Wyatt, with SMS. We are so proud of them and so honored that they are spreading awareness for SMS.

We are wishing them all the best at the national DECA competition in April!



Personal Story

The Serio Family's Journey

Milton, MA

Our SMS journey started eleven years ago when our son, Rocco, was diagnosed at the age of seven months. My husband and I knew that Rocco was missing some milestones as evidenced by his twin brother, but nothing seemed alarmingly off. We believed that although they were twins, they ran at different speeds and each child would hit milestones in his own time. It was really at the insistence of his pediatrician that Rocco took a genetic test. I think that's why his diagnosis came as such a shock to us. We had him tested at the insistence of others, not because we had an overwhelming sense that something was wrong.



Read Amanda Serio's [full story on our website](#).

[DONATE TO SMS RESEARCH](#)

The mission of the SMS Research Foundation is to support research to improve the knowledge and understanding of SMS so that viable therapeutic options can be developed in order to improve the quality of life of those living with Smith-Magenis Syndrome.

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

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