



# SMS RESEARCH FOUNDATION

April 2022 - News & Events

## News

The Smith-Magenis Syndrome Research Foundation (SMSRF) is pleased to announce that Keith Gee has been hired as the organization's first full-time Executive Director. This is a dramatic and significant step forward for the SMSRF as well as those living with Smith-Magenis Syndrome (SMS), a complex neuro-developmental disorder that affects multiple organ systems of the body. Keith brings a wealth of leadership and fundraising experience to the SMSRF through a 30-year career in nonprofit management. He has an MBA from Columbia Southern University. Keith is passionate about raising money and making a difference in the world.



"I am so excited to join the SMS Research Foundation and look forward to making an important impact on the research surrounding SMS and expanding research opportunities through increased funding" Gee stated.

"Our organization has experienced significant growth and our capacity to fund basic science research has improved as evidenced by our recent portfolio consisting of 4 different labs. We believe Keith will provide the necessary full-time resources to incite change and support our organization as it continues to expand – we are truly excited to welcome him aboard," SMSRF Board President Jennifer Iannuzzi reported.

Founded in 2010, the SMSRF has raised more than \$1M for research related to SMS. Their mission is to advance scientific research leading to innovative treatment options for people living with SMS. Over the past 11 years, the SMSRF has been responsible for some of the most comprehensive and promising basic science research exploring the fundamental genetic and biologic changes that occur in these individuals.

The nationwide Board of Directors of the SMSRF is very optimistic about the future of the SMS Research Foundation as it prepares for the years ahead.

## Events

### Kendra Scott Shopping Event

SMS Community member Jen Sauer has coordinated a fundraising event with the Kendra Scott Gives Back community-giving program.

Anyone in the Sugar Land, TX area is invited to the Kendra Scott Sugar Land store on April 23 from 3-5pm for special Mother's Day sweets and treats. While shopping, show the event coupon and 20% of your purchase will be donated to the SMS Research Foundation.



Not in the area for the event? You can also shop online April 23-24th using the code shown on the coupon! Have a special Mom, Grandmother or Aunt you'd like to honor? Kendra Scott has beautiful jewelry specifically for Mom! You can see the Mother's Day Gift ideas [HERE](#). Have a special lady who's not a mom yet? You can give her something special, too! See the full Kendra Scott collection [HERE](#). Just remember to enter the discount code so your purchase benefits the SMS Research Foundation.

We thank you so much!

shop for good online or in-store!

April 23rd-24th

Enter code

GIVEBACK-BUDAJ

in your cart or at checkout on [kendrascott.com](http://kendrascott.com), or mention it at checkout in-store, and 20% of your purchase will benefit



SMS RESEARCH  
FOUNDATION

Not combinable with other offers.

*Kendra Scott*

## Western Round-Up

SMS Co-Founder and Board member Missy Longman, is coordinating a fun in-person event in south Florida. The Round-Up will be a joint fundraiser for 2 organizations Missy dearly loves, the SMSRF and the David Posnack JCC's Giborium United program.

For more information about the Round-Up, to buy tickets or see sponsorship opportunities, visit here... [www.dpjcc.org/roundup](http://www.dpjcc.org/roundup).



With great fundraising events taking place in the next few months, we've decided to postpone our SMS Virtual Walk until a little later in the year. We'll keep you posted as new decisions are made and a new date selected.



## Sharing our Stories

### From the SMSRF Executive Director...

It is indeed, an interesting world we live in. After working for the SMSRF for just a few days the following story happened.

*My neighbors are an older couple. They live halftime in Philadelphia and half the year in Florida. They have a daughter with special needs. She is now 45 years old. The wife has basically dedicated the last 45 years to be a full time caregiver for their daughter.*

*Since I have been learning more about SMS and the characteristics of people living with SMS, I wondered if their daughter had SMS.*

*Over the weekend the husband was out in the yard working, so I struck up a conversation with him and asked him about his daughter. He responded that they have never received a diagnosis other than she suffered from oxygen deprivation when she was born. She had a heart issue when she was 32 and is now on medication for that.*

*I told the husband about SMS and about my new job. He had never heard of SMS, but found it very interesting. After the conversation, I thought to myself, "he is never going to remember the name Smith-Magenis Syndrome or anything about it.*

*A few days later my wife and I were in the kitchen working on dinner. The doorbell rang and it was the wife from next door. She came over to thank me for speaking to her husband. They did some research on SMS and agreed that their daughter has a lot of the characteristics of SMS. They have a doctor's appointment in July and will be asking their doctor about this.*

*The wife commented that getting a diagnosis at this point would not really change anything, but would give them a sense of relief by understanding more about their daughter.*

Raising awareness is critical to what we are doing at the SMSRF. You never know who you are going to impact when you talk about SMS. Please continue to support the SMSRF and share and like our social media posts. You just never know...

## Make a Difference Today!

Please consider making a tax-exempt contribution to SMS Research Foundation. Your gift of support will allow us to fund more necessary research into Smith-Magenis Syndrome and improve the lives of those living with SMS. Currently we are funding four research projects, but more is needed. Please use the link below and make your generous gift. Any amount you give will make a difference! Thank you.

[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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