

July 2022 News & Events

#### Hello!

The countdown is on! For the entire month of September, you can support research of Smith-Magenis Syndrome by participating anywhere, anytime in our annual global Steps Move Science 2022 Virtual Walk.

With your help, we can move **One Step** closer to finding a treatment for Smith-Magenis Syndrome. All proceeds will benefit the **SMS Research Foundation** (SMSRF) to help fund current and future **research** projects.

Walk, donate, share and invite - fundraising for our favorite cause has never been easier!



Start spreading the word and gathering your teammates now.
Walk Registration site goes live
August 1!

#### How does the Virtual Walk work?

You have several ways to participate:

#### Register (starting Aug 1):

- 1) Sign up as an individual participant,
- 2) Create a team invite friends and family to join your team and use your social network to raise funds.
- 4) Join an existing team, or
- 3) Create a fundraising page without joining or creating a team.

#### **Donate (available Aug 1):**

Make a donation to support the SMS Research Foundation and help us create a brighter future for SMS individuals and their families.

#### Match your donation!

Many employers offer donation matching! When you register, there's a special place in the registration process where you'll be asked to check to see if your employer matches donations. We hope you'll enter your work email and let our system check for you. This is a wonderful opportunity to double your impact on SMS research!

After August 1, you will also be able to donate by text to **50155** with the keyword SMS and the amount you want to donate (e.g., SMS 50). You will immediately be sent a link to a simple donation page populated with your donation amount.

### **Event Details**

To recognize the deletion in the 17th chromosome which causes SMS, we are

encouraging (but not requiring) participants to walk, run, stretch or meditate for 17 minutes, 17 blocks, 1.7 or 17 miles at any time that's convenient. You choose your activity, you chose your time, and you choose your distance. Use the entire month of September to meet your goal!

Date - Anytime in September

Location - Anywhere of your choosing

Registration - \$25 for adults/\$15 for kids



# Registration for the Virtual Walk begins August 1

Keep us updated on your progress by posting photos, tagging us, and using the hashtags #stepsmovescience and #smswalk. Thank you for your support!



#### **RETURNING FOR 2022!**

We hope you'll join our virtual post-race afterparty on Wednesday, September 28, 2022 from 8:30 - 9:30pm EST as we celebrate all the walkers, teams, families, donors and sponsors who participated in our **Steps Move Science** 2022 Virtual Walk for SMS!

Anyone who joins, creates a team or makes a donation receives a free entry into our virtual **Finish Line** event. This promises to be an amazing night where we are able to gather people together from all over the world who are passionate about supporting research of **Smith-Magenis Syndrome**.

The **Finish Line** event will be an evening of inspiration and information where we get to honor YOU for your efforts in advancing SMS research! The presentation will include live research updates from our scientists and personal messages from walk participants. You don't want to miss it!! We hope you will join us as we celebrate all we have accomplished together and all we continue to work towards with the SMS Research Foundation!

### **T-Shirts**

Celebrate our Steps Move Science 2022 Virtual Walk with a new t-shirt. Names included on the t-shirt represent loved ones with SMS (from our 2021 shirt campaign). New colors and styles are available for this year. Get your shirt in time to participate in our 2022 Virtual Walk or order some for friends and family for the holidays. These shirts make gift giving easy! Proceeds from the sales of these items support research into finding treatment options for individuals with Smith-Magenis Syndrome.

We are so thankful for all of your support!

We are so thankful for all of your support! Visit our t-shirt sales site **HERE**.





### **Virtual Walk Sponsorship Opportunities!**

Want to help us reach our financial 'Finish Line? View our sponsorship opportunities <u>Here</u> or contact us to create a sponsorship package designed just for you!

Please email walk@smsresearchfoundation.org for further details.

# **Looking for Volunteers!**

#### We are growing!

We are looking for passionate and enthusiastic people with fresh, creative ideas and a commitment to advancing research of Smith-Magenis Syndrome to join our team. We need volunteers to help with doing the work of the organization, planning events, community outreach, marketing, communications, fundraising and serving on our Board of Directors.



You do not have to be directly connected to someone with SMS, just have an interest in using your talents and skills to advance the SMSRF mission. Not ready to hold a leadership position? Just share your time and energy with us for a few hours each month. Send an email to <a href="mailto:info@smsresearchfoundation.org">info@smsresearchfoundation.org</a> for more information or to volunteer. We'd love to have you join us and help us advance our mission of supporting research to find innovative treatment options for individuals with SMS!

## 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 three research projects, but more research 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.

The SMS Research Foundation is a 501(c)(3) nonprofit organization founded in June 2010. Tel: (203) 450-9022 Copyright © 2022. All Rights Reserved.

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