

TEAM CAPTAIN SUCCESS PACKET

THANK YOU for serving as a Team Captain for the Steps Move Science Virtual Walk for Smith-Magenis Syndrome! With each step you take with us, we are funding research and ultimately getting closer to improving the lives of people with Smith-Magenis Syndrome.



WELCOME!

BOB ROBINSON

Executive Director

Our Annual **Steps Move Science Virtual Walk** is a fun and effective way to raise awareness and research funding for Smith-Magenis Syndrome (SMS).

Even though we won't be running on the same course – we will be on the same track: our efforts will raise awareness and much-needed funding to fuel our quest to reach the day when we have innovative treatment options for people living with Smith-Magenis Syndrome.



Why Step Up and Lead

Be the driving force that inspires others, raises awareness, and fuels the quest for innovative treatment options in Smith-Magenis Syndrome.

If you have any questions or need additional information, please contact us at info@smsresearchfoundation.org.

Take Steps-Ignite Hope!

EVENT DETAILS

WHO

Anyone can join! Register to create your own team, support an existing team, or just walk on your own. You'll have the chance to set up your own fundraising page, with your story and pictures, and all of the support to make your efforts to fund SMS Research successful.

WHAT

You will walk to raise awareness and research funding for SmithMagenis Syndrome. To recognize the deletion in the 17th chromosome which causes SMS, we are encouraging (but not requiring) participants to walk for 17 minutes, 17 blocks, or 1.7 miles.

WHEN

Join us (virtually) any time before the end of September for the Annual Steps Move Science Walk to support the SMS Research Foundation! Identify a time that works best for you, your family and friends and cover your chosen distance.

WHERE

Any location that is convenient for you!

WHY

Currently there are no treatment options available. That's why we walk. Smith-Magenis Syndrome is a complex developmental disorder that affects multiple organ systems of the body. The disorder is characterized by a pattern of abnormalities that are present at birth (congenital) as well as behavioral and cognitive problems.

The SMS Research Foundation is a non-profit organization dedicated to supporting research to improve the knowledge and understanding of Smith-Magenis Syndrome so that viable therapeutic options can be developed in order to improve the quality of life of those with SMS.

The Steps Move Science Virtual Walk for Smith-Magenis Syndrome supports the mission of the SMS Research Foundation as we raise public awareness and funds for life-changing research.

HOW

By taking Steps to Move Science! A great way to spread awareness is posting photos and/or videos of your walk on social media. Be sure to tag the SMS Research Foundation, using the hashtags #stepsmovescience and #smswalk. Thank you for your participation!

If you have any questions or need additional information, please contact us at info@smsresearchfoundation.org



CAPTAIN CHECKLIST

Set Fundraising Goal ✓

Set expectations for your team by setting your team's fundraising goal. Think about the number of people you can get to walk with you! Your network is larger than you think.

Get the Word Out ✓

Share the link to your personal team page through your e-mail contacts and social media followers to let people know you've created a team. Our best supporters are those who are close to us. Ask your friends and family members to join you on your walk team. We find that the most successful fundraisers are those who share why this fundraiser is so important to them – they will want to help you because this cause matters to you!

Get Personal ✓

Sharing why you walk is one of the main reasons people decide to give. Customize your fundraising page with a personal message and photos. Share the link with friends, family, and on social media. Tell your personal story about Smith-Magenis Syndrome and why supporting SMSRF's work means so much to you!

Seek Out Sponsors ✓

Seek out Sponsors: It's easier than you think! We've developed a Sponsorship Packet to assist you.



Gear Up! ✓

Gear Up: Order shirts for walk day and encourage your team to as well at <https://www.bonfire.com/store/sms-research-foundation/> - all proceeds fund the SMSRF's mission of funding life-changing research. Want to create a personalized Team Shirt for walk day with proceeds that will benefit the SMSRF? Design your own Team fundraiser shirt on Bonfire. Be sure to Gear up early so all t-shirts are shipped for your Walk.

Make Being a Part of Your Team Fun! ✓

Use a poll on social media to choose your Team name. Offer prizes and incentives. Host an in-person walk event in your community! See tips for hosting a Steps Move Science walkathon, bikeathon, or runathon fundraiser.

Send Thank You Messages ✓

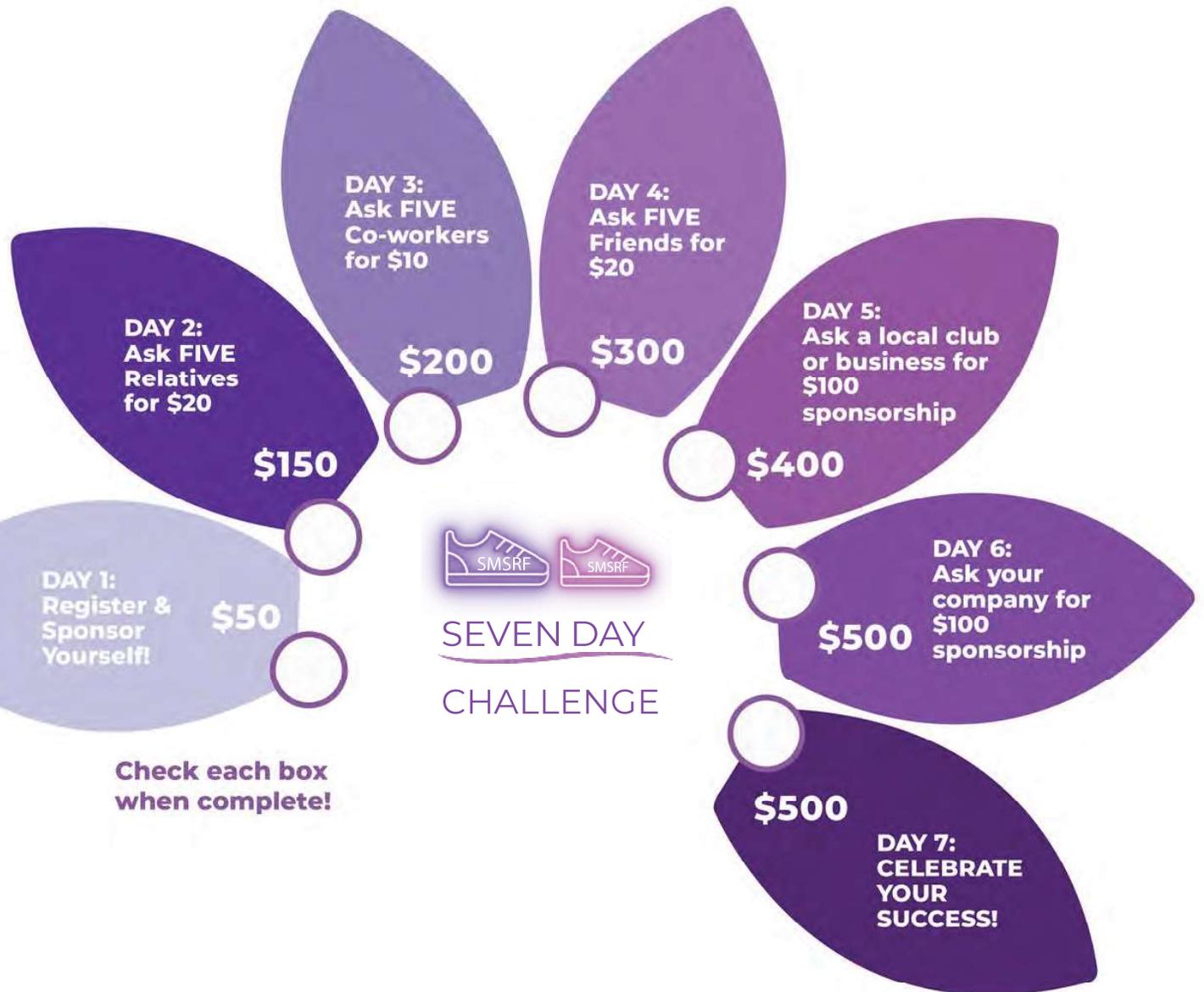
A simple thank you goes a long way, so consider different ways to recognize your| team members and your donors. Send thank you letters, text, or e-mails to everyone who participates and donates. Showing gratitude will keep your team and donors excited and will encourage everyone to continue supporting the team!

Take Photos ✓

Take photos of your Walk! Share your photos on social media with the hashtag #stepsmovescience #smswalk and let people know WHY you are walking! This is the easiest way to spread awareness through your network.



HOW TO RAISE \$500 IN SEVEN DAYS!



HOST A STEPS MOVE SCIENCE WALK IN YOUR COMMUNITY!

Organizing an in-person Steps Move Science Walk in your community is an exciting and rewarding method of fundraising for the SMSRF!

Hosting a successful walkathon requires careful planning and organization. If you're looking for advice on how to get started, you've come to the right place!

Assemble a Leadership Team for Your Walk

Before you start doing anything else, look for people who are willing to help you.

However large your Steps Move Science Walk may be, it's important to have a solid base of volunteers who are willing to put in that extra effort for your cause.

Select a Date, Time, and Location

Now that you have your leadership team lined up, it's crucial to solidify the major details of your walk. We suggest having your walk any time before the end of September. The fundraising platform will be available for your use from August 1 - September 30, 2025.

However, if you cannot host your walk during this time period please contact us at info@smsresearchfoundation.org and we will work with you to help you make it happen.

Secure Sponsorships

As soon as you've finalized a date, time, and place, you should begin to look for sponsorships. Check out SMSRF Sponsorship Packet.

File Necessary Event Paperwork

In order to keep everyone safe and happy at your walkathon you will need to distribute waivers to every participant and file any requisite forms with local authorities.

Design T-Shirts for Your Event Participants on Bonfire

Create a personalized shirt for walk with all proceeds benefitting the SMSRF. Design your fundraiser shirt on Bonfire at <https://www.bonfire.com/org/sms-researchfoundation-272906662/>. Be sure to create your shirt early so all t-shirts are shipped in time for your Walk.



Spread the Word About Your Walk

With planning completed, it's time to start promoting your event! Take out an ad in the local paper, send out an email blast to your contacts, put flyers up around your community, share on social media, call up local media to make a press release, ask your friends and family to help spread the word. Marketing your Walk is crucial for its ultimate success.

Have Volunteers Show Up Early

On the day of the event, you want to have a plan in place for your volunteers. That way, everyone knows where they need to be, what they need to be doing, and when they need to be there. It's best to have your volunteers show up a couple of hours before the kick-off time, ensuring you're fully prepared for anything.

Walk and have a Great Time!

You've worked long and hard to get to this point. It's 100% okay to celebrate and enjoy the event!

Thank Your Participants

The #1 rule when thanking event participants is to send your sincere gratitude within the first 48 hours following the Steps Move Science Walk. The earlier you send out thank you notes, the more appreciated your participants will feel!



FAQ

People want to know what they are giving to!

Here are some of the more common questions (and answers to them!) that you might encounter.

What is Smith-Magenis Syndrome?

Smith-Magenis Syndrome is a complex developmental disorder that affects multiple organ systems of the body. The disorder is characterized by a pattern of abnormalities that are present at birth (congenital) as well as behavioral and cognitive problems. 1 in 25,000 live births in the US are affected by SMS. Identified only in 1982, the SMS Research Foundation is working tirelessly to fund research to improve the treatment options and lives of those living with Smith-Magenis Syndrome.

What is the mission of the SMS Research Foundation?

**T
To advance scientific research leading to innovative treatment options for people living with Smith-Magenis Syndrome (SMS).**

How does my donation make a difference?

The SMS Research Foundation puts your donations into action immediately by aggressively funding cutting-edge research. Your donation ignites more opportunities to find life-changing therapeutic options and truly help individuals with SMS and their families.

Are donations tax-deductible?

Yes! The SMS Research Foundation is a 501(c)(3) nonprofit organization. 100% of your donation is tax deductible. (Tax ID: 27-2906662)

Should I share my fundraising page on social media?

Yes! We encourage you to use social media to help you succeed in your fundraising efforts.

What key points should I use on social media?

Always include a link to your own personal fundraising page. Don't be afraid to post often! Messages are forgotten quickly so make them regular and frequent.

Publicly thank your donors:

Thanks Jane Smith for your donation, your support is so appreciat-

What other ways can I share my fundraising page?

Include a link to your fundraising page in your email signature: SMS I'm participating in this year's SMS Steps Move Science Walk. Visit my page to learn more and support my efforts [your fundraising link here]



CONTACT

We are here to help!
Contact us with your questions.



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SMS RESEARCH
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smsresearchfoundation.org/walk
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