

What is Wiedemann-Steiner Syndrome?

Wiedemann-Steiner Syndrome is a rare genetic disorder resulting from mutations in the MLL (aka KMT2A) gene on the long arm of chromosome 11. The syndrome, originally described in 1989 through recognition of similar features, was not officially verified until 2012 through whole exome sequencing. There are currently about 750 people that have been diagnosed with WSS worldwide. WSS is often related to global developmental delays, sleeping difficulties, feeding and digestion complexities, atypical facial features, short/petite stature, hypotonia, dental issues, hairy elbows, long eyelashes, etc. Those affected by WSS endure hours of physical, speech, behavioral, occupational, and music therapies and academic supports every week. In their first few years of life, WSS children experience far more medical procedures and surgeries than most of the population will experience in a lifetime.

What is the Wiedemann-Steiner Syndrome Foundation?

The Wiedemann-Steiner Syndrome (WSS) Foundation was founded in 2016 and serves as the cornerstone of knowledge for individuals affected by the syndrome, their families, physicians, and researchers. Together we advocate for comprehensive research with meaningful discoveries and connect the WSS community through thoughtful engagement.

What will the money raised be applied towards?

In 2016, the Wiedemann-Steiner Syndrome Foundation set out to raise \$250,000 to initiate crucial research for Wiedemann-Steiner Syndrome. With the help, commitment and generosity of the friends and family of those affected by WSS, we reached that initial goal in November of 2018. While our first monetary benchmark has been reached, it is not a finish line, rather a launching point. The Foundation's work has only just begun. In 2019, the WSS Foundation will be able to fund multiple mouse projects to gather comprehensive baseline data on WSS. As baseline data is collected, the Foundation will initiate research on particular symptoms affecting the WSS population. Disease specific research will help doctors, educators, and parents better understand WSS and will hopefully lead to pharmaceutical companies taking an interest in developing treatments for WSS patients; ultimately allowing our WSS Warriors to reach their greatest potential. The Foundation also supports multiple regional gatherings around the world, including its annual international conference. These gatherings allow families an opportunity to be around those that "get it," an experience unparalleled by any other.

Sponsorship Opportunities

We would be honored if you or your business would consider a sponsorship opportunity for this event. Sponsorships are available from the \$100 level to the \$5,000 level. Those sponsoring a minimum of \$250 will have their logo printed on the back of the t-shirts and will be able to hang a banner (if you don't have a banner, one will be made up for you). Those sponsoring less than \$250 will have their name listed on the back of the t-shirt. Sponsorship commitments are requested by Thursday, May 23. See sponsorship form for more information.

Volunteer on the Day of the Triathlon

This event would not be possible without volunteers. We utilize about 75 volunteers on the day of the event. If you would like to help, there is a volunteer interest section on the registration form.



CONTACT

Libby Woolford
1-916-502-2120

libby.woolford@gmail.com

or

John Rodrigues
1-916-296-3769

jrodptc@gmail.com

with any
questions!

Other Ways to Stay In Touch

Be sure to follow or like us on all social media platforms to stay up-to-date on all information pertaining to the WSS Foundation!



Tax ID Number:
81-1260031

WSS Foundation | 1601 42nd Street | Sacramento, CA
916-502-2120 | www.wssfoundation.org

SWIM • BIKE • RUN

Sutter Lawn Tennis Club at 3951 N Street | Sacramento, California

Sunday, June 9

7:30 a.m. to 8:00 a.m.

Same Day Registration

7:30 a.m. to 8:30 a.m.

Check-In Table and Transition Area Open for Setup

8:40 a.m.

Welcome Ceremony and Start of Race

*All participants and spectators are asked to gather poolside.

*The first heat will be 13-18 year old participants with younger divisions to follow.

Who can participate?

Any child five to 18 years old is invited to participate. Children should be able to ride a bike and complete the swim distance for their age division (below). Every child, regardless of finish place or time, will be treated as a winner!

Age Division	Swim*	Bike	Run
13-18	200 YARDS	FOUR (4) MILES	ONE (1) MILE
11-12	150 YARDS	THREE (3) MILES	3/4 of a MILE
9-10	100 YARDS	TWO (2) MILES	1/2 of a MILE
7-8	50 YARDS	ONE (1) MILE	1/2 of a MILE
5-6	25 YARDS	ONE (1) MILE	1/4 of a MILE

*Accommodations can be made for the swim portion. Kickboards will be available. Life jackets and any other flotation devices, if needed, must be furnished by the participant.

What to Bring

Swimsuit

Goggles

Swim Cap

Towel

Athletic Shoes and Socks

Shirt and Shorts

Bike

Bike Helmet **NO EXCEPTIONS**

Sunscreen



CONTACT

Libby Woolford

1-916-502-2120

libby.woolford@gmail.com

or

John Rodrigues

1-916-296-3769

jrodptc@gmail.com

with any
questions!

Other Ways to Stay In Touch

Be sure to follow or like us on all social media platforms to stay up-to-date on all information pertaining to the WSS Foundation!



Tax ID Number: 81-1260031

How the Triathlon will Work

The WSS Foundation Triathlon will be held in the traditional triathlon format of swim, bike and run. Participants will complete each sport in that order. Age-based waves or heats will determine the starting time for your child. They will swim in Sutter Lawn's pool then head immediately to the transition area located in the alley area.

Upon arrival at the race start, participants need to check in. When checking in, your child will be "body-checked" (a triathlon tradition of writing each participant's race number on their arms and legs) with their race number, division and heat. After checking in, your child should arrange their equipment in their assigned area within the transition area.

The transition area should be treated as "home base." Here is where your child will select a bike spot in the morning for their bike (areas labeled by age division) and put their helmet, shoes, towel, etc. next to their bike. After completing the swim, your child should go to the transition area and retrieve their bike, helmet and shoes, then start the bike course on M Street. Plenty of volunteers will be available in the transition area to assist your child.

After your child finishes the bike portion, they will walk their bike back to the transition area, find their bike spot and park their bike. Then, they will take off on the run course. The race finishes when your child crosses the finish line.

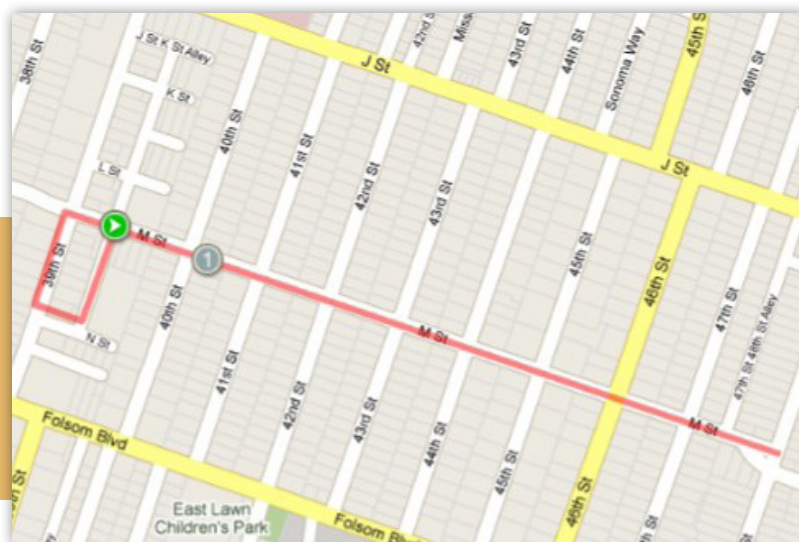
Parents and siblings are not allowed in the transition area at any time including before, during or after the race.

Parking and Directions

Sutter Lawn Tennis Club is located at 3951 N Street in Sacramento, California. The club is situated between N and M Streets and 39th and 40th streets. N Street will be used as the transition area and the alley will be used as part of the biking and running course; thus, parking will not be available for participants and spectators. M street between 39th and 48th Streets will be used for the race course; parking will not be available on M Street either. Street parking will be available on streets running perpendicular to M Street (ie. 38th, 39th, 40th and 41st Streets). Participants and spectators are encouraged to walk to the triathlon if possible.

Course Map

- SWIM** Sutter Lawn Pool
25 yard pool: one lap (ages 5-6), two laps (ages 7-8), four laps (ages 9-10), six laps (ages 11-12) and eight laps (ages 13-18)
- BIKE** Sutter Lawn Alley at N Street to 48th and M Streets and back to Sutter Lawn Alley
Counterclockwise: one loop (ages 5-8), two loops (ages 9-10), three loops (ages 11-12) and four loops (ages 13-18)
- RUN** Sutter Lawn Alley at N Street to 39th and M Streets to 39th and N Streets back to Sutter Lawn Alley
1/4 Mile Loop: one loop (ages 5-6), two loops (ages 7-10), three loops (ages 11-12) and four loops (ages 13-18)



Other Ways to Stay In Touch

Be sure to follow or like us on all social media platforms to stay up-to-date on all information pertaining to the WSS Foundation!



Tax ID Number: 81-1260031

WSS Foundation | 1601 42nd Street | Sacramento, CA | 916-502-2120 | www.wssfoundation.org



2019 Entry Form

Sunday, June 9 | Sutter Lawn Tennis Club and Surrounding Neighborhood

Participant Information

Child's First and Last Name _____ Child's Age (as of June 9, 2019) _____

Child's Shirt Size (circle one): **Youth** XS S M L **Adult** XS S M L XL

Child's First and Last Name _____ Child's Age (as of June 9, 2019) _____

Child's Shirt Size (circle one): **Youth** XS S M L **Adult** XS S M L XL

Child's First and Last Name _____ Child's Age (as of June 9, 2019) _____

Child's Shirt Size (circle one): **Youth** XS S M L **Adult** XS S M L XL

Child's First and Last Name _____ Child's Age (as of June 9, 2019) _____

Child's Shirt Size (circle one): **Youth** XS S M L **Adult** XS S M L XL

Parent or Guardian Name(s): _____

Daytime Phone Number: _____ Email Address: _____

Address: _____

☐ As a parent of a race participant, I am available and willing to volunteer during the day of the event.

Volunteer's Shirt Size (circle one): **Men's** XS S M L XL XXL

Women's XS S M L XL XXL

Participant Fee

Before Sunday, May 19: \$30 for one child **Sibling Discount:** \$30 for first child and \$25 per sibling

After Sunday, May 19: \$35 for one child **Sibling Discount:** \$35 for first child and \$30 per sibling

Registration Payment

☐ Cash
☐ Check _____ (Name on the check) _____ (Check number) (Make checks payable to WSS Foundation)

☐ Credit Card: visit www.wssfoundation.org - click **DONATE**. Enter the full registration fee plus \$2.50 per registrant.

Register Online

To register online visit <https://conta.cc/2AXKtKf>.

Drop off or mail forms to: WSS Foundation | 1601 42nd Street | Sacramento, CA 95819

Registration Deadline: You may register up until 8:00 a.m. the day of the race.

T-Shirts are only guaranteed to those who register prior to Thursday, May 24.

No refunds, credits or transfers. Entry fees are non-transferable. Event will occur rain or shine.



Liability Release

As consideration for being allowed to participate in this race, I acknowledge that this waiver and release of liability form will be used by the event holders, sponsors and organizers including Sutter Lawn Tennis Club, the City of Sacramento, and the City of Sacramento Police Department, in which I may participate and that it will govern my actions and responsibilities in this event. I certify that I am physically fit, have sufficiently trained for participation in this event, and have not been otherwise advised by a qualified medical physician. I hereby act for myself, my executors, administrators, heirs, next of kin, and successors. I hereby waive, release, and discharge from any claims, losses, injuries, liabilities for death, disability, personal injury, property damage, theft, or damage of any kind resulting from my participation in this event. I also grant permission to use my picture in any broadcast, telecast, or photograph taken at this event. I grant permission to post my race results at the event with the Sutter Lawn Tennis Club. I hereby certify that I have read this document and completely understand all its contents.

Parent or Guardian's Signature _____ Date _____

Name of Child(ren) _____

Photo Release

I consent to the recording, use and reuse by the WSS Foundation of my voice, image, actions, likeness, name, and appearance, whether I provide to the WSS Foundation or someone provides on behalf of the WSS Foundation, in any WSS Foundation publication and/or for the WSS Foundation's fundraising purposes in newsletters, letterhead, internet postings, website design, pamphlets, flyers, or other publications. I am voluntarily allowing myself and/or my child(ren) to participate in these activities with knowledge of this potential publication and/or fundraising use. I am aware that neither I nor my child(ren), nor any person other than the WSS Foundation, will receive any benefit, monetary or otherwise, from any of my and/or my child(ren)'s photographs or other activities offered by the WSS Foundation. I hereby agree to accept that this publication and/or fundraising may occur under these terms.

Initials _____

I hereby agree that I, my assignees, heirs, distributees, guardians, and legal representatives will not make a claim against, sue, or attach the property of the WSS Foundation or any of its affiliated organizations, board members, or officers for any injury, damage, or loss resulting from the publication of any drawings, photographs, writings, interviews, or other activities.

Initials _____

I have carefully read this agreement and fully understand its contents. I am aware that this is a release of any potential liability and a contract between myself and the WSS Foundation and/or its affiliated organizations and sign it of my own free will.

Parent or Guardian's Signature _____ Date _____

Name of Child(ren) _____



It is our goal that each triathlon participant acquires a minimum of \$25 in pledges from family, friends, and/or area businesses. Pledge forms and monies are to be turned in at the check-in desk on race day. Please make checks payable to WSS Foundation. Credit card donations may be made via the "Donate" tab at www.wssfoundation.org. Tax ID Number 81-1260031. Please have any sponsors type WSS Triathlon and your child's name in the PayPal memo box.

Participant's Name _____

Sponsor's Name _____

Email Address _____

Amount _____ Form of Payment (circle one) Check Cash Online Donation

Sponsor's Name _____

Email Address _____

Amount _____ Form of Payment (circle one) Check Cash Online Donation

Sponsor's Name _____

Email Address _____

Amount _____ Form of Payment (circle one) Check Cash Online Donation

Sponsor's Name _____

Email Address _____

Amount _____ Form of Payment (circle one) Check Cash Online Donation

Sponsor's Name _____

Email Address _____

Amount _____ Form of Payment (circle one) Check Cash Online Donation

Sponsor's Name _____

Email Address _____

Amount _____ Form of Payment (circle one) Check Cash Online Donation