

TEAM CAPTAIN GUIDE

for the Walk & Roll to Cure FSHD



STRONGER THAN FSHD

Ending FSHD will take all of us. That's why the **Walk & Roll to Cure FSHD** is so important and why you matter so much to the effort. The Walk & Roll helps us team up with friends, loved ones, and co-workers to change the world for everyone affected by FSHD.

STRONGER TOGETHER

Participating in a Walk & Roll has been a life-changing event for so many in the FSHD community. It has forged powerful connections, strengthening our families and our community. Together, through donations large and small, ***we have raised nearly \$2 million for research and patient support.***



TOGETHER WE'LL GO FURTHER

Together we will catalyze a global movement to shorten the drug development timeline. Together we can ensure no one on this journey travels alone. Together we bring help and hope to patients worldwide as we build a global patient community that is informed, empowered, and engaged.



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STEPS TO SUCCESS

This guide will allow you to easily personalize your Walk & Roll to Cure FSHD experience, engage your entire team, and put you on a path to success. We encourage you to share this information with your teammates, too.

- **Register** for the Walk & Roll to Cure FSHD—done!
- **Set a personal and team fundraising goal**—establishing a goal is an easy way to maintain motivation as well as give you and your team a benchmark for success. Use our Goal Setting Worksheet to help!
- **Kick-start your fundraising**—show your commitment by making a self-donation.
- **Customize your Personal Page**—everyone who registers for the Walk & Roll automatically receives a Personal Fundraising Page. Customize yours with a personal photo and story, upload or link to a video, manage donations, thank donors, send emails and more!
- **Know Your Networks**—understanding and connecting with your network can be key to your team success! Take a few minutes to identify people you will ask to join your team and donate. You can also log in to your Participant Center for pre-made sample emails.
- **Fundraise with Facebook**—use Facebook to make your fundraising easier. Through your participant center you can connect to your Facebook page ensuring all funds raised through Facebook properly credit to your campaign. We even have a super-short, super-easy video showing you how, in our Walk & Roll playlist on YouTube: [youtube.com/c/FSHDSociety/playlists](https://www.youtube.com/c/FSHDSociety/playlists)
- **Go mobile**—You can get text alerts, send thank you texts, and more when you connect your participant center to your cell number. It makes fundraising on the go super-simple!

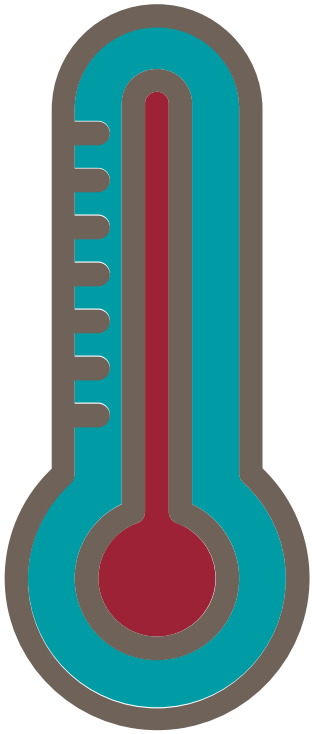


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SETTING YOUR GOALS

Goals should be realistic, but significant — if it requires hard work to attain, it will be a source of pride for your team.



- **100%** — make it a goal to have every team member an active fundraiser by encouraging them to donate and to ask others to donate to their fundraising effort.
- **Kick off your fundraising by making a donation** — participants who make a personal donation fundraise six times as much as those who don't.
- **Set a goal for team size as well as collective fundraising** — recruiting more team members can mean a substantial increase in fundraising.
- **Keep stretching!** – If you hit your goal, log in and increase it! Give donors the opportunity to help you attain your goal.
- **Share your goal** — use email, social media, and your team page to make your goal known to your network. Encourage your team members to do the same! Send thank you emails/letters/texts to friends, family, and other supporters.
- **Double your impact with matching gifts** — Many companies offer matching gifts for employees as well as loyal customers. Ask your donors to check if their company has a matching gift program that they can utilize.

Go to FSHDSociety.org/walk-roll-teams for printable fundraising tools and resources to answer your questions about online fundraising and your Participant Center.

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SHARING YOUR STORY

It's easier than ever to raise money with our online fundraising tools! Start by logging in and setting up your Personal Page. Use your Participant Center to:

- Share your story, upload photos/videos and display your fundraising progress
- Create a custom URL to take people directly to your Personal Page
- Import contacts into your Participant Center address book
- Send emails to recruit team members and ask for donations
- Send thank you emails/texts to your supporters

Participants who customize their Personal Page fundraise five times more than those who don't.

While your story and why you personally decided to Walk & Roll for FSHD is most important, these sample 'elevator speeches' may help you get started...

"I am raising funds to change the world for people living with facioscapulohumeral muscular dystrophy, or FSHD. I will be participating in the Walk & Roll to Cure FSHD with a goal of raising [insert goal amount]. With your help, we can catalyze a global movement to shorten the drug development timeline. Together we can bring help and hope to patients worldwide so that no one need ever face FSHD alone."



"Your donation ensures that each person affected by FSHD is able to connect with others on the same journey, helps advance FSHD research, and provides access to resources that connect FSHD families to the information and people they need to live their best lives. Ending FSHD will take more than the people with FSHD. With every step we take, every dollar we raise, we're that much closer."

TEAM CAPTAIN GUIDE

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FUNDRAISING INCENTIVES

Walk & Roll participants who go the extra mile with their fundraising qualify for special rewards!

All participants who raise \$100 or more will receive a commemorative Walk & Roll event t-shirt. Shirts will be available for pick-up on event day.

Additional prizes are available to those raising \$250 or more. Prizes are based on a person's individual fundraising total by the prize deadline. Donations can be received up to 2 weeks after the event to meet the fundraising prize deadline.



Sending regular updates to your team members can help keep their fundraising on track. Share your own fundraising ideas and personal fundraising progress to help inspire them. Highlight a fundraising success story within your own team. You can also send emails from your Participant Center to easily communicate with all your team members.





Team Fundraising

Beyond the camaraderie and fun that comes from participating as a team, another benefit is that you are working together to have the greatest impact possible for those living with FSHD. Here are a few fundraising activities you can do as a team:

- Bake sale
- Balloon or candy grams at work
- Bowl-a-thon
- Chili cook-off
- Garage or yard sale
- Pancake breakfast
- Penny wars or loose change drive
- Plant or flower sale
- Silent auction

These are just a few fun suggestions. Take some time to brainstorm with your team!

Prizes shown below can be earned in addition to a Walk & Roll t-shirt. You may select any prize at or below your achieved fundraising level.

\$250 Ear buds OR Tote bag		\$500 Ceramic lidded travel mug	
	\$1,000 Wireless speaker		\$2,500 North Face Fleece Vest

We are so grateful for your help in advancing the research that will bring treatments and cures to our families!

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TAKING IT TO THE NEXT LEVEL!

Motivate your entire team to fundraise by creating some friendly competition. The prize for the winner doesn't have to be anything elaborate. Usually bragging rights are enough! Prizes can be awarded to someone who:

- Personalizes their online fundraising page first
- Posts the best Walk & Roll picture on their page
- Raises the most money in a week
- Receives the largest donation to date
- Sends out the most fundraising emails
- Makes a personal donation
- Has the highest goal
- Meets their goal

Get Creative

Show your team spirit by ordering your own custom team shirts to commemorate your Walk & Roll. There are many online vendors that can accommodate, like 4imprint.com, customink.com, or vistaprint.com, to name a few.

Here are some tips to make your team's experience truly memorable:

- Prior to event day, designate a time and area to meet your team. If you're not familiar with the site, bring a brightly colored flag or make a large team sign so members can easily find you.
- Wear your team t-shirt or come up with a creative theme that your team can rally around – everyone wears a “Cat in the Hat” hat, feather boas, Mardi Gras beads...
- Create inspiring signs to carry during the walk.
- Take pictures and post them on social media, using your local event's hashtag and [#internationalwalkroll](https://www.facebook.com/hashtag/internationalwalkroll). Tag your teammates. Let everyone know what you're doing and be sure to include the link to your Personal or Team Fundraising Page—event day is a great opportunity to ask for more support!
- Gather your team after the event for a picnic or after-party. This is a great way to celebrate and build an even stronger FSHD community!



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FSHD FACTS & TALKING POINTS

Since it began with a few dedicated volunteers in 2018, the Walk & Roll to Cure FSHD has already raised nearly \$2 million for research and patient support.

FSHD Society Promise - As long as we are here, no patient need ever face this disease alone. With generous support - gifts of time, talent, and treasure - from patients, families, friends, major donors, and sponsors, the FSHD Society will keep working to accelerate research leading to treatments by 2025 and eventually a cure.

FSHD Society Vision - A world free of the suffering caused by FSH Muscular Dystrophy (FSHD)

FSHD Society Mission - Find treatments and a cure for FSHD while empowering our families

What is FSHD?

Facioscapulohumeral muscular dystrophy, or FSHD, is a genetic disorder that leads to the weakening of skeletal muscles. Typically beginning in early teenage years with the loss of muscles in the face (facio), shoulders (scapula), upper arms (humeral), legs or core, FSHD can spread to any muscle. Around 20 percent will need a wheelchair by age 50. Over 70 percent experience debilitating pain and fatigue. There is no effective treatment or cure—but there is hope.



Who is affected?

An estimated 1 in 8,000 individuals, or 1 million people worldwide. FSHD strikes men, women, and children of all races and ethnicities. Ten percent develop symptoms before age 10. The condition is inherited and can affect many family members across generations. Some 30 percent of cases arise in families with no prior history. No individual or family is immune.

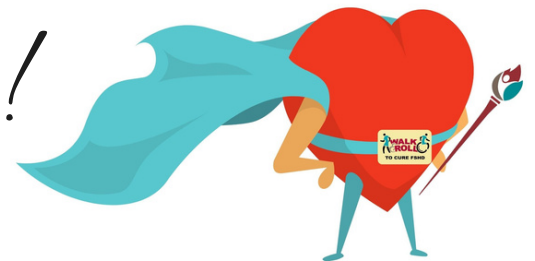
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WE'RE HERE TO HELP!

We are grateful for your efforts to raise awareness and funds for people affected by FSHD. We want to do all we can to ensure your experience is fantastic. If you have questions, need assistance or just have a comment to share, please contact your local Walk Leader or our home office. We'd love to hear from you.

Thank You!



FAQs

How do I turn in donations?

Raising money online is the fastest and easiest way, but if you have checks to turn in you can either deliver them on Walk & Roll day or mail them to FSHD Society, Department 960, P O Box 4106, Woburn, MA 01888

Who should checks be made payable to?

Make checks payable to “FSHD Society”. Please be sure to write the participant’s name and event location on the memo line of each check (e.g., “John Smith, Colorado Walk & Roll”).

If you receive a check payable to your team, simply write “FSHD Society” above the team name entry. If the check is made out to you, please endorse the check “payable to the FSHD Society”.

What is a matching gift?

A matching gift is a gift from a donor’s employer that matches the donor’s original gift. Many employers match dollar-for-dollar. Ask your human resources staff or visit your company’s intranet for more information.

How long are Walk & Roll routes?

Walk & Roll routes are fully accessible, offering a one-mile route; some also offer a longer route near 3 miles. Please contact your local Walk & Roll Leader for specifics on your event location.

Are the routes accessible?

Walk & Roll routes are accessible for scooters and wheelchairs, by walker, or with a cane. There will also be accessible restrooms at each site.