



## TO CURE FSHD TEAM CAPTAIN GUIDE

### 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

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.

Together we will lead a global movement to shorten the drug development timeline.

TEAMING UP TO END FSHD!

**THANK YOU** for serving as a team captain for the Walk & Roll to Cure FSHD. Participating in the Walk & Roll has been life-changing for many who are impacted by FSHD; forging powerful connections, strengthening families, and building community. Together, through donations large and small, ***we have raised more than \$3.3 million for research and patient support. With one of the lowest expense ratios in the industry, more than \$0.91 of every dollar raised supports patient programs and funds FSHD progress.***

This guide will help you to easily personalize your Walk & Roll to Cure FSHD experience, engage your entire team, and put you on a path to success. The FSHD Society is here to help you every step of the way!

## LET'S GET STARTED

- ☐ **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 and give you and your team a benchmark for success. Use our Goal Setting Worksheet to help! You can also review page 4 for more information on how to set up your goal.
- ☐ **Kick-start your fundraising**—Show your commitment by making a self-donation.
- ☐ **Customize your Team Page and Personal Page**— As the captain, you have a Team Page you can customize, plus 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!
- ☐ **Share on social** - Use social media to let your friends and family know that you are walking (and rolling!) to cure FSHD. You can even connect your fundraising directly to Facebook through the platform. It's a really powerful way to raise funds! Share why you are walking and your personal connection to FSHD to make the most impact.
- ☐ **Recruit** - Invite at least 5 team members to help you meet your fundraising goal.

Keep a look out for Team Captain pro tips to maximize your team captain efforts



# FUNDRAISING AS EASY AS 1-2-3

Fundraising doesn't have to be hard. Follow these three steps to success as a team captain to support your team and meet your fundraising goal!



## 1 Be the Role Model

Encourage your team to follow your example by making your own donations to your team, sharing your story and team page online, and reaching out to your network. People will be more willing to donate if they already see a gift on your page. Don't forget to take advantage of social media, calling, or texting a friend to donate.

## 2 Coach Your Team

Being a team captain is all about coaching your team to do their best and have fun! Make sure you educate them on the tools available to them, encourage them to donate, brainstorm on DIY fundraisers together, and ask about matching gift programs.

## 3 Celebrate

The Walk & Roll is a time for the community to **come together** to raise awareness of FSHD and change the world for everyone affected by FSHD. This is why it is important you cheer your team EVERY step of the way, send thank you notes, offer prizes to your top fundraisers, and have FUN!

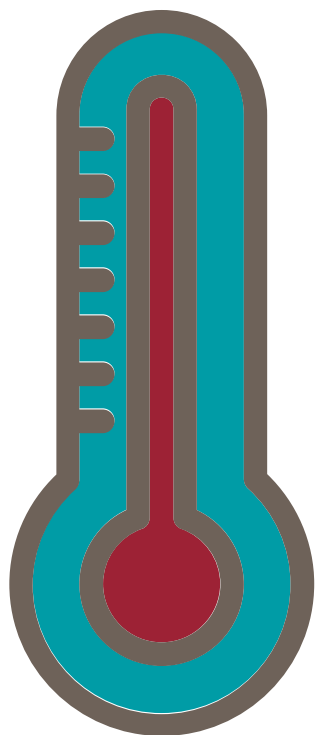
### Team Captain Pro-Tips

- **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.
- **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!



# SETTING YOUR GOALS

When setting your goal, think about the number of people you can get to join your team, how much you think you can raise together, and the impact you want to make by participating in Walk & Roll. Goals should be realistic, but don't be afraid to push the limit – if it requires hard work to attain, it will be a source of pride for your team.



- **Know your networks** - Understanding and connecting with your network can be key to your team's success! Take a minute to identify people you will ask to join your team and donate.
- **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/texts/DMs 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](https://FSHDSociety.org/walk-roll-teams) for printable fundraising tools and resources to answer your questions about online fundraising and your Participant Center.



## Team Captain Pro-Tip

Access your Participant Center and take advantage of helpful tools, such as template emails, links for social media, and more.

# SHARING YOUR STORY

Sharing your FSHD story and why participating in the Walk & Roll is important to you is a great way for people to understand the impact of the Walk & Roll as well as how they can be join you in making a difference. While your story 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."



# 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](http://4imprint.com), [customink.com](http://customink.com), or [vistaprint.com](http://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 #FSHDWalkRoll and #CureFSHD. Tag the FSHD Society and 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!

### Team Captain Pro-Tip



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 show your 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 raise 5x's more than those who don't.***

# 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, 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. All earned prizes will be sent out after the event, with prize notifications going out in October.



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

~ 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:  
Flashlight



\$500:  
Umbrella



\$1,000:  
Camping  
Chair



\$2,500:  
North Face  
Vest



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

These are just a few fun suggestions. Take some time to brainstorm with your team or feel free to call your chapter's director!

# FSHD FACTS & TALKING POINTS

Since it began with a few dedicated volunteers in 2018, the Walk & Roll to Cure FSHD has raised more than \$3.3 million for research and patient support. With one of the lowest expense ratios in the industry, more than \$0.91 of every dollar raised supports patient programs and funds FSHD progress.

**FSHD Society Promise** - As long as we are here, no patient need ever face this disease alone. The FSHD Society is deeply committed to working with ingenuity and integrity to accelerate research leading to the first-ever approved treatments by 2025 and ultimately a cure. It is the generous support - gifts of time, talent, and treasure - from patients, families, friends, major donors, and sponsors, that make this imperative work possible.

**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. Your work on the Walk & Roll is a key factor of fueling that hope and progress!



## 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.



Did you know if you donated just \$10 dollars a week for 10 weeks, you would raise **\$100**. And if you asked 10 friends to do the same, you would raise **\$1,000**! Let your network know how they can help you reach your goal and don't be afraid to share how easy it is to support.

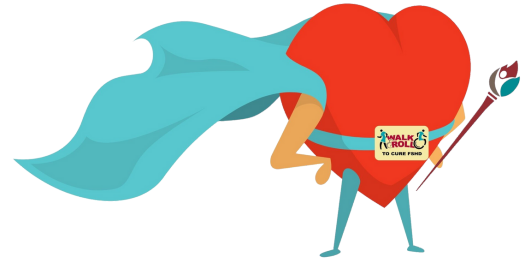
# TEAM CAPTAIN GUIDE

*for the Walk & Roll to Cure FSHD*

## 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, PO Box 411617 Boston, MA 02241-1617

### 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 anywhere from a one-mile route to longer routes up to 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.