



# Participant 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

**No one should face FSHD alone.** With your help--friends, family, and colleagues--we're creating a global community that is informed, empowered, and connected. We're building a movement of hope and action for everyone impacted by FSHD.

**Together, we'll fast-track** progress and bring treatments to patients faster.

**WALKING & ROLLING TO END FSHD!**

# WELCOME!

You're not just participating in an event, **you're part of a movement.** Walk & Roll is bringing families together, creating life-changing connections, and strengthening the FSHD community nationwide.

Thanks to dedicated supporters like you, we've raised over \$3.3 million to fund critical research and support programs for those living with FSHD. With over 91 cents of every dollar going directly to these efforts, your impact is powerful and far-reaching.

This Participant Guide is your go-to resource; filled with tips and tools to help you personalize your Walk & Roll experience, reach your fundraising goals, and make a real difference. The FSHD Society is here to support you every step of the way. Together, we're rolling closer to a world without FSHD!

## WHY WE WALK & ROLL

**The FSHD Society Promise:** No one should face FSHD alone. We are committed to accelerating research with ingenuity and integrity; driven by the generous support of our community of patients, families, donors, and sponsors.

**Our Vision:** A world free from the suffering caused by FSHD.

**Our Mission:** To find treatments and a cure for FSHD while empowering families.

### What is FSHD?

Facioscapulohumeral muscular dystrophy (FSHD) is a genetic disease that weakens muscles, often starting in the face, shoulders, and upper arms, and progressing to other areas. Many experience severe pain, fatigue, and 1 in 5 may need a wheelchair by age 50.

**There's no cure yet—but there is hope.** Your participation in Walk & Roll brings us one step closer. With over 91 cents of every dollar directly funding programs and research, your efforts make a real impact.





# GETTING STARTED

- ☒ **Register** for the Walk & Roll to Cure FSHD—done!
- ☐ **Set a Personal Fundraising Goal**—Establishing a goal is an easy way to maintain motivation and give you a benchmark for success.
- ☐ **Kick-Start Your Fundraising**—Show your commitment by making a self-donation.
- ☐ **Share Your Why**—Customize your personal page with a personal photo and story.
- ☐ **Share on Social** - Launch a Facebook Fundraiser through the participant center, and share your fundraising link on channels like Instagram, X (formerly Twitter), LinkedIn, Snapchat and TikTok
- ☐ **Send Emails** - Prewritten templates make it easy to ask your contacts for support right from your participant center.
- ☐ **Thank Your Donors:** A simple “thank you” goes a long way. Gratitude not only makes donors feel appreciated but also increases the changes they’ll support future fundraisers.



# FUNDRAISING TOOLS & RESOURCES

## MAXIMIZE YOUR FUNDRAISING

### **Get Social:**

Post your fundraising link on Instagram, TikTok, LinkedIn, X, and Snapchat. Add it to your email signature too, easy visibility!

### **Challenge Your Crew:**

Set fun goals like “\$100 by tonight!” or “Help me hit \$250 in 5 days!”; short-term challenges spark quick support.

### **Use Video:**

Share a quick, heartfelt video about why you’re walking. Real stories connect, and inspire people to give!

### **Post Regularly:**

Keep your network engaged by sharing updates on your fundraising journey—not just donation asks. Mix in inspiring content, photos, or milestones. Aim to post when your audience is most active (usually Friday–Sunday), and don’t forget to use LinkedIn; it’s a great place to reach colleagues and professional contacts who want to support your cause!

## CONSIDER YOUR SPHERE OF INFLUENCE

Who do you interact with regularly? Ask them to join your mission to advance breakthroughs. Using the guide below, write down the names of people you know from each category for a quick list of people you can ask to donate!

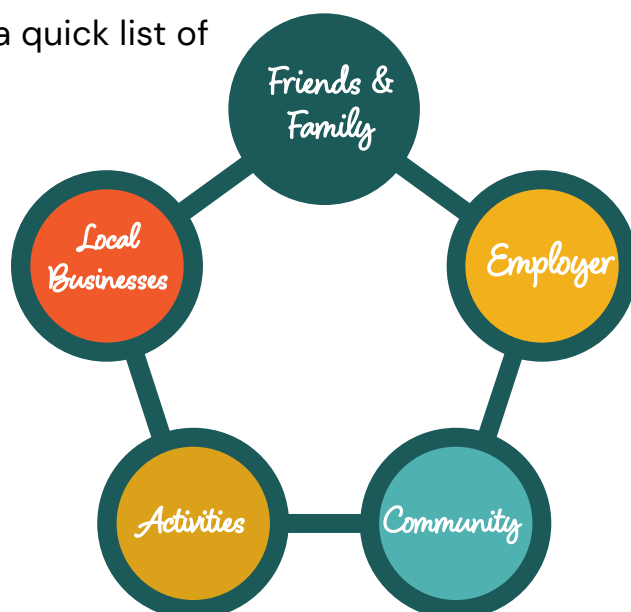
**Friends & Family:** parents, siblings, in-laws, cousins, grandparents, friends

**Employer:** co-workers, clients, vendors,

**Community:** neighbors, HOA, civic clubs, networking groups,

**Activities:** gyms, book clubs, sports, places of worship

**Businesses You Frequent:** salons, doctors, mechanics, restaurants, maintenance, cleaning





# FUNDRAISING TOOLS & RESOURCES

## SHARE YOUR STORY



Sharing your FSHD story and why Walk & Roll matters to you helps others understand its impact and how they can join you in making a difference. Your personal story is powerful—these sample elevator speeches can 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."*

# FUNDRAISING INCENTIVES

Every dollar you raise helps drive the extraordinary work of the FSHD Society—funding groundbreaking research, accelerating clinical trials, and advancing treatments for families impacted by FSHD. Together, we're breaking down barriers to a cure and bringing hope within reach.

Walk & Roll participants who go above and beyond with fundraising earn special rewards! Raise **\$100** to get a commemorative event t-shirt (pick up on Walk day).

## STAY TUNED

## COMING SOON!

Prizes are based on individual totals by the deadline—donations count up to 3 weeks post-event. Prizes ship after the event, with notifications in November.

# FREQUENTLY ASKED QUESTIONS:

## 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 For All You Do!*

## 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.

**Contact us at [FSHCommunity@FSHDSociety.org](mailto:FSHCommunity@FSHDSociety.org)**