



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

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!

Thank you for stepping up as a Team Captain for the Walk & Roll to Cure FSHD! You're not just leading a team—you're leading a movement. The Walk & Roll has become a powerful force for change, creating life-changing connections, uniting families, and strengthening the FSHD community.

Thanks to passionate supporters like you, we've raised more than \$3.3 million to fund groundbreaking research and vital patient programs. And with more than 91 cents of every dollar directly supporting these efforts, your impact goes further, faster.

This Team Captain Guide is your roadmap to success—packed with ideas and tools to personalize your Walk & Roll experience, rally your team, and hit your goals. The FSHD Society is with you every step of the way. Together, we are 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.



TEAM CAPTAIN CHECKLIST



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.



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 – Launch a Facebook Fundraiser through the participant center, and share your fundraising link on channels like Instagram, X (formerly Twitter), LinkedIn, Snapchat and TikTok



Recruit – Invite at least 5 team members to help you meet your fundraising goal.



BUILD & ENGAGE YOUR TEAM

1. **Make a List:** Keep a running list of people to invite—you'll think of more throughout your day.
2. **Create Your Team Page:** Add photos and your story in the participant center.
3. **Set a Goal:** Aim for 10 teammates, each raising \$100. Use our goal setting tips on the next page
4. **Recruit:** Use emails, texts, and social media. Invite people nationwide!
5. **Follow Up:** It often takes a few asks. Make sure everyone registers online for updates and incentives.
6. **Encourage Outreach:** Ask teammates to invite their own network. Offer tips if needed.
7. **Motivate:** Help members set personal goals. Suggest group fundraisers and share what's working.

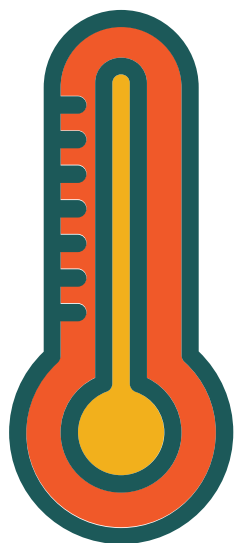
Keep the Momentum

1. **Kickoff Event:** Build excitement, share tips, and connect. A great chance to educate others about FSHD.
2. **Friendly Competition:** Recognize achievements—most funds raised, top recruiter, best spirit, etc.
3. **Share Updates:** Keep your team informed and celebrate milestones. Use updates to re-engage unregistered members.



FUNDRAISING TOOLS & RESOURCES

GOAL SETTING TIPS



Set Meaningful Goals

Aim high, but keep it achievable. Work together with your team to set goals everyone can get behind—it builds momentum and shared purpose.

Think about setting goals in two key areas:

- Team & Personal Fundraising
- Team Member Recruitment

Strive for 100% Participation

Encourage every team member to become an active fundraiser by making a self-donation or reaching out to others for support. When everyone's involved, your impact grows!

Celebrate and Share Your Progress

Keep your goals visible and share your team's success along the way. As you hit milestones, don't be afraid to raise the bar!

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



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."

EASY AS 1... 2... 3...

1

Be the Role Model: Lead by example—make a personal donation, share your story and team page, and reach out to your network. People are more likely to give when they see others have. Use social media, calls, and texts to boost support.

2

Coach Your Team: Support and motivate your team! Share tools, encourage donations, plan fundraisers together, and remind them to check for matching gifts.

3

Celebrate: Walk & Roll is a time to unite, raise FSHD awareness, and have fun! Cheer on your team, send thank yous, recognize top fundraisers, and celebrate every step.

TAKING IT TO THE NEXT LEVEL

GET CREATIVE & MOTIVATE YOUR TEAM

Spark friendly competition to boost fundraising—bragging rights are often enough! Offer simple prizes for things like:

- First to personalize their page
- Best Walk & Roll photo
- Most raised in a week
- Largest single donation
- Most fundraising emails sent
- Highest goal or first to meet it
- Personal donation made



MAKE IT MEMORABLE

Make Walk & Roll more than just a walk—make it an experience your team won't forget. Celebrate your shared purpose, have fun with it, and create lasting memories that keep your team coming back year after year.

- Design custom team shirts (try 4imprint, Custom Ink, or Vistaprint) and pick a fun theme—like matching hats or boas.
- Before Walk day, set a team meeting spot (bring a flag or sign if needed).
- Bring signs, wear your shirts, take tons of photos, and share them using #FSHDWalkRoll and #CureFSHD.
- Tag the FSHD Society and include your fundraising link—event day is perfect for last-minute gifts!
- Wrap it up with a team picnic or after-party to celebrate your impact and community.

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!

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