**Team Fundraising Toolkit**

Social fundraising is one of the most effective forms of grassroots advocacy. Starting a campaign and inviting your social network to support your cause can multiply your impact sevenfold.

If you (or someone you know) are planning to run a distance race, compete in an Iron Man, celebrate a birthday, become a Bar Mitzvah, etc., turn the occasion into a team fundraising event! It’s easy:

1. Register for your event. Or if it’s a do-it-yourself feat, set a date and goal.
2. Figure out how you will collect the funds. Ask donors to write checks or pay online to the FSH Society “in honor of” your event (http://fshsociety.org/pages/conHonor.html). Or set up an online donation page on Razoo.com, with the FSH Society as the designated recipient. This way, your supporters have the assurance of knowing their gifts are going directly to charity.
3. Invite your friends to contribute. You can use the attached sample letter to create yours. Include the FAQ page to educate them about FSHD.
4. Send weekly progress reports and reminders. Offer incentives (“next five people to donate will receive X”; call the FSH Society office for ideas).
5. Provide all your donors with a final thank you letter or email about your event and how much you've raised, with their help, for FSHD - include a photo or two from your big day.

Here are some helpful tips from Anne Caterino, who has raised thousands of dollars for the FSH Society by running in marathons:

* Ask anyone and everyone that you know to contribute, even if it's a very small amount.
* Don't be afraid to ask. It's not about you; it's about the research and greater cause for/of FSHD. Put any fear aside and think of the people this will impact.
* Focus on participation - many donations from many people add up, even if the individual amounts are not large. Use your phone contacts.... your holiday card list, etc.
* Start your fundraising early and work consistently at it - just like training for an event.
* Don't forget that some people may have matching charitable donations through their work and companies. This can really help your efforts.

**Sample Invitation Letter**

DATE

NAME

ADDRESS

CITY, STATE, ZIP

Re: FSH Society Picnic Fundraiser

Dear NAME,

On DATE, my family and I will be hosting a [DESCRIBE EVENT] to support the research and treatment for a little-known disease, FSHD, otherwise known as facioscapulohumeral muscular dystrophy. [YOUR PERSONAL CONNECTION TO FSHD, HOW IT HAS AFFECTED YOU OR A FRIEND OR FAMILY MEMBER.]

FSHD is a degenerative muscular dystrophy disease that affects approximately 870,000 people worldwide, causing a progressive loss, wasting and atrophy in all skeletal muscles. The severity of the disease can vary greatly as some patients are asymptomatic or have minimal symptoms while others become wheelchair bound. Triggered by an unusual genetic mechanism, FSHD affects both sexes equally and has no particular racial, geographic or ethnic distribution. Currently, there is no cure.

Many people and physicians are completely unaware of this disease, which is what the FSH Society aims to change. The Society is a world leader in combating FSHD and has helped raise millions of dollars to support scientific research and treatments for FSHD patients. The FSH Society has earned Charity Navigator’s prestigious four-star rating and designation as one of America’s “Ten Charities Worth Watching,” achieving near perfect scores in fundraising efficiency, accountability, transparency and more.

We want to do our part to help find a treatment and raise awareness. Please join us if you can:

DATE:

LOCATION:

TIME:

CONTACT INFORMATION:

Whether or not you can attend, donations of at least $25 will gratefully accepted, all of which will go directly towards the FSH Society’s mission. Refreshments will be served. Please RSVP with your donation amount and number of attendees in your party using the enclosed pre-paid envelope or contact me at EMAIL; PHONE.

Sincerely,

**Facioscapulohumeral Muscular Dystrophy (FSHD) Fact Sheet**

**What is FSHD?**

* FSHD is one of the most prevalent of the nine primary types of muscular dystrophy affecting adults and children.
	+ It affects approximately 1 in 8,333 people around the world, or over 870,000 worldwide. The actual frequency may be three times higher due to undiagnosed cases.

**What are the symptoms?**

* + - FSHD causes a progressive loss of all skeletal muscle. Weakness is usually noticeable starting with facial, scapular/back and upper arm muscles.
* Weakness in facial muscles is a hallmark of FSHD – early symptoms can include difficulty whistling or smiling and eyes not fully closing during sleep.
* Loss of muscular strength limits both personal and occupational activities. 95% of patients develop noticeable muscle weakness by the age of 20. Approximately 20% of patients become unable to walk.
* Respiratory insufficiency, which can be life-threatening, is also a symptom.

**Who is affected?**

* + - * FSHD occurs with equal frequency in both males and females and can affect children and adults of all ages and all racial groups.
	+ An affected parent has a 50% chance of passing the genetic defect to each child. The majority of cases of FSHD are caused by a genetic deletion on chromosome 4.
		- * The age of onset is variable, as is the eventual extent and degree of muscle loss.
			* Every person has the DUX4 gene that leads to FSHD. Usually, the gene is “bottled up” so it can’t cause harm, but when the bottle “breaks”, FSHD results.
* 30% of new FSHD patients have no prior family history and are a result of a spontaneous genetic change. In this sense, every person has a risk of having a child with FSHD.

**What are the Treatments?**

* Currently, there is no treatment to slow down or cure FSHD.
* Low-intensity aerobic exercise appears to be safe and potentially beneficial. This should be done under the supervision of a physical therapist.
* [Genetic diagnostic](http://www.athenadiagnostics.com/content/test-catalog/find-test/service-detail/q/id/57) and prenatal diagnostic tests are available for FSHD.
* Researchers hope to develop new drugs for FSHD over the next 3-5 years. There is hope!

**Team Fundraiser Pledge & Gift Form Template
[Customize, print out and use for in-person solicitations]**

On DATE, my family and I will be hosting a [DESCRIBE EVENT] to support the FSH Society, a national top-rated charity that funds research on a devastating disease, facioscapulohumeral muscular dystrophy (FSHD). We appreciate your donation to support our team’s efforts! Gifts are tax-deductible.

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| --- | --- | --- | --- | --- |
| **Donor Name(s)** | **Address, phone, email** | **Gift amount** | **Payment method** | **Done** |
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