



# Overcoming the Fear of Fundraising!



Fear is a human emotion, triggered by a real or perceived threat, that can have health consequences – physical and emotional.

Even though we logically know we need to raise money to fulfill the mission of getting treatments and a cure to all patients, to support FSHD families, to run the organization that makes it all possible, fundraising can be intimidating.

**Fear of fundraising is a real threat to our collective success.**

# We Need an Active FSHD Community!

Chapters... Gathering Place... Walk & Roll events... World Alliance...  
FSHD U... BetterLife ...Website ...Social Channels

The one thing that sets patient organizations apart is their access to patient communities: informed patient communities that can participate as peers and opinion leaders with academics, with the industry, with regulators, and policymakers are powerful agents in shaping policy, the funding and direction of research, and decisions on access to and funding of new therapies. This role is only going to become more important.

Patient organizations are the ultimate source of knowledge about their patient communities...

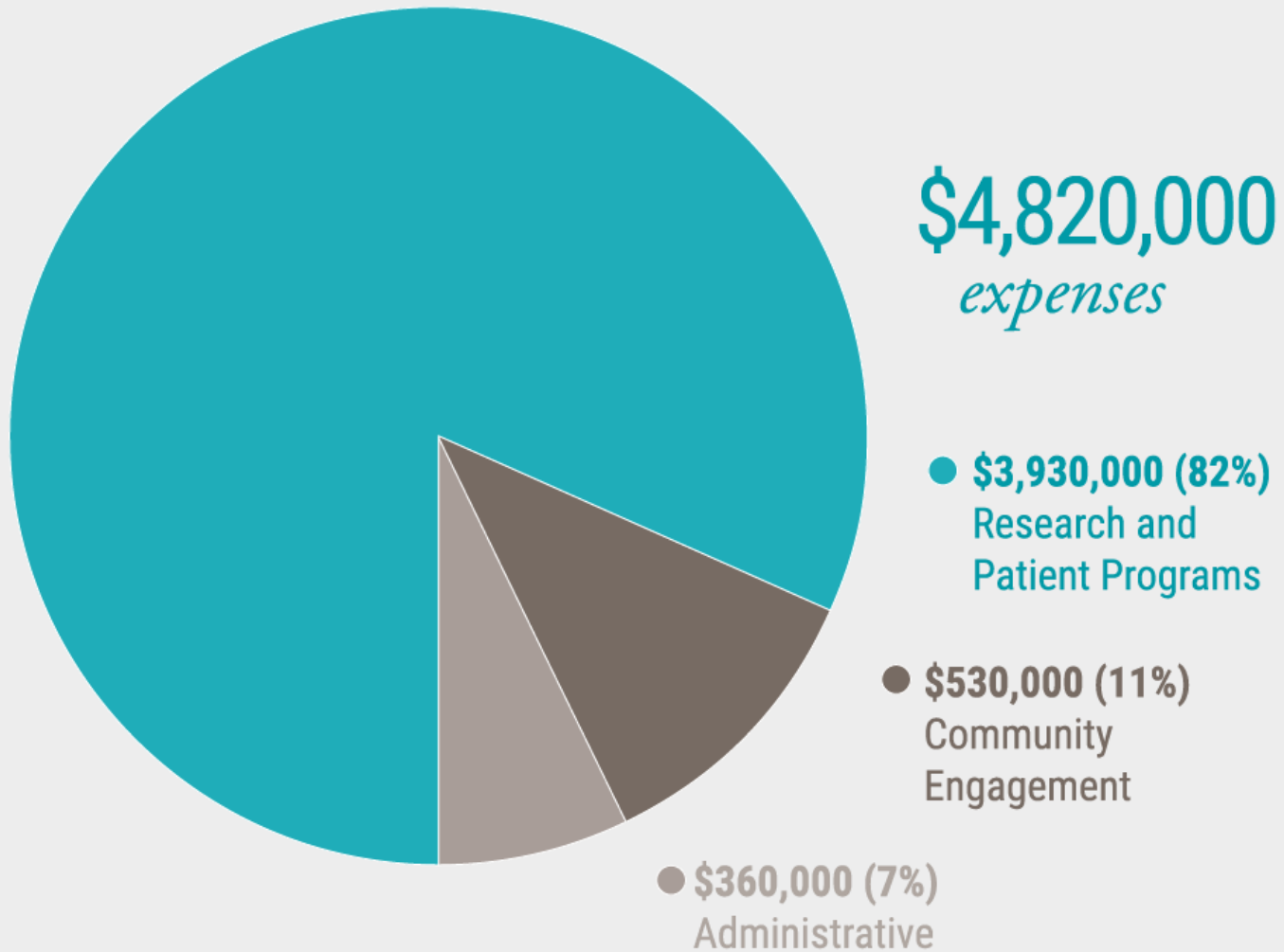
White Paper

Making Best Bets: Prioritizing Expenditure for Maximizing Impact on Patient Communities

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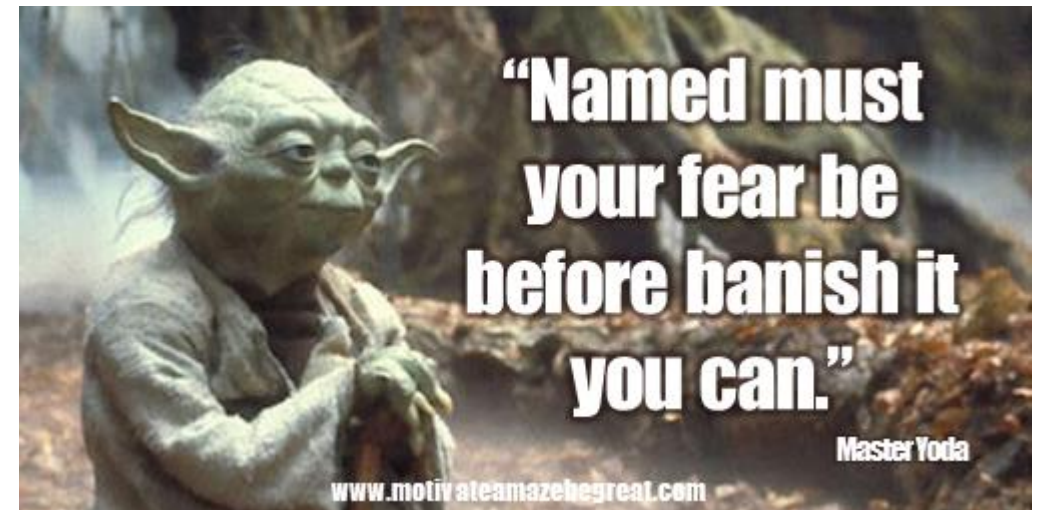
[FSHDSociety.org/2022-annual-report](https://FSHDSociety.org/2022-annual-report)

Fear of fundraising is a real threat to our collective success.

**Yet we simply can not help patients and families live a better life or advance research into treatments and a cure without funding.**

## 5 Main Fundraising Fears that Hold Us Back

- Fear of asking for money
- Fear of donor fatigue
- Fear of the unknown
- Fear of failure
- Fear of speaking with donors



# Fear of asking for money



- Money seems to be a taboo topic – nearly half of Americans struggle with financial conversations
- But fundraising is not about money. It is about impact.
- *We are not begging for money, we are inviting people into an opportunity to impact change for 1 million+ people worldwide.*

# Fear of asking for money



- Embrace it as a way to build relationships
- *Donors give because:*
  - *They believe in your mission*
  - *They want to be a part of something bigger than themselves*
  - *They trust the FSHD Society to make an impact*
  - *They have a personal connection to FSHD*



# Fear of donor fatigue

- We often believe donors are ‘tired of giving’
- But fundraising is more about creating powerful, lasting, impactful relationships.
- Donor fatigue is a myth.
- Even in 2020, there was an uptick in giving that continued in 2021.



# \$484.85 billion

In 2021, Americans gave \$484.85 billion to charity, a 4.0% increase over 2020. Adjusted for inflation, total giving remained relatively flat, with -0.7% growth.

## Where did the generosity come from?

**Contributions by source**

By percentage of the total

**67%** \$326.87 billion

**Giving by Individuals**

⬆ increased 4.9% over 2020

**19%** \$90.88 billion

**Giving by Foundations**

⬆ increased 3.4% over 2020

**9%** \$46.01 billion

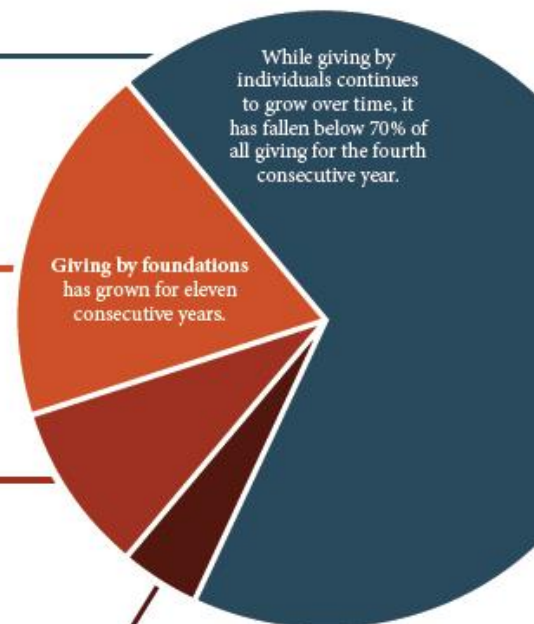
**Giving by Bequest**

⬆ decreased 7.3% over 2020

**4%** \$21.08 billion

**Giving by Corporations**

⬆ increased 23.8% over 2020



\*All figures on this infographic are reported in current dollars unless otherwise noted.

**Generous people are generous.**  
They will donate to your cause, support your mission, and bring you a casserole when you move into the neighborhood.

**Donors should be thanked, engaged, and educated about the impact of their previous donation.** Inspire donors and demonstrate how their support has had a real-life impact.

# Fear of the unknown



- It is common to fear something you have little experience in:
  - Lack of predictability – not enough info to know what's next
  - Lack of control – losing a sense of agency

# Fear of the unknown



- Address your fear - *Is there evidence to support this fear? When have I successfully coped with uncertainty?*
- Make a plan and set realistic goals.
- Worst thing that can happen – someone says no.
- Don't go it alone. Connect with your peers, problem-solve together.

# Fear of failure



- Fear of failure happens when we allow it to stop us from doing the things that move us forward.
- The best way to overcome the fear of failure is to redefine what success looks like.
- ***Goal = to make an impact. No effort that advances that goal is wasted.***

# Fear of speaking with donors



- More people are afraid of public speaking than they are of dying! You can't avoid speaking with others while fundraising.
- Good communication is an important part of fundraising – it's about meaningful conversations. Being a good listener. Sharing authentically.

# Fear of speaking with donors



- Organize your thoughts
- Visualize good things happening
- Remind yourself you are helping someone connect to a cause and make a difference
- Be authentic. Be yourself. People connect with and invest in people.



# REMEMBER the power of our signature fundraising event, the WALK & ROLL!



A servant to all...

- Capitalizes on group effort and greater 'lift'
- Engages people in our programs
- Builds a broad community
- Empowers patients, families, friends
- Tells an important story
- Limitless fundraising potential



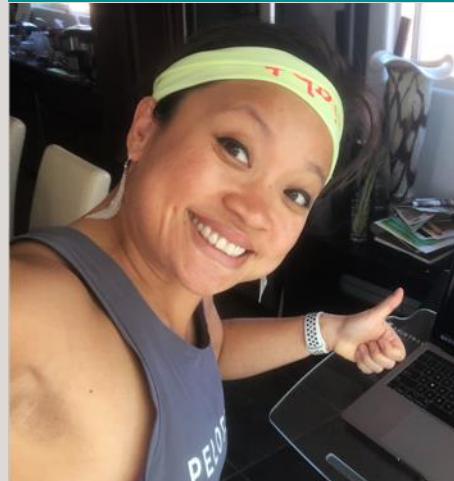
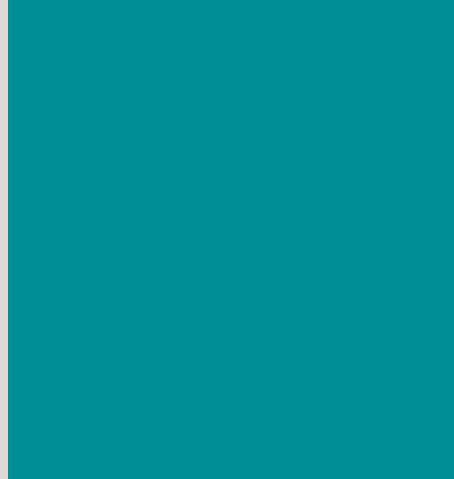
# Stay **Connected**, Informed, *In The Know!*

- Volunteer Resources Page:  
[www.FSHDSociety.org/Volunteer-Resources](http://www.FSHDSociety.org/Volunteer-Resources)
- Volunteer Leaders Facebook Page:  
<https://www.facebook.com/groups/2184658054918993>
- Volunteer Leaders on Microsoft Teams:  
[https://teams.microsoft.com/l/team/19%3aXAw7D7hiR2ml6P\\_rs3V4rF56lsfWGt4qTh3zFiH4CA1%40thread.tacv2/conversations?groupId=053bc1bc-5035-4f19-b284-2ac17ffd0622&tenantId=3fcab860-edd0-4e50-8f41-9f4ce87abcab](https://teams.microsoft.com/l/team/19%3aXAw7D7hiR2ml6P_rs3V4rF56lsfWGt4qTh3zFiH4CA1%40thread.tacv2/conversations?groupId=053bc1bc-5035-4f19-b284-2ac17ffd0622&tenantId=3fcab860-edd0-4e50-8f41-9f4ce87abcab)



## Stay **Connected**, Informed, *In The Know!*

- USE YOUR OFFICIAL EMAIL @fshdsociety.org
- Read the monthly Hot Sheets
- Read and refer to the quarterly *In The Know* doc
- Join Jack for a volunteer-only discussion each month on Zoom, first Monday, pick either time that works for you
- Check in often with your regional director



**THANK YOU!**

