



FUNDRAISING GUIDE

Foundation for USP7-Related Diseases

Email: admin@usp7.org

Website: www.usp7.org

11 Innkeepers Lane

Falmouth, ME 04105



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FIX THE DIMMER SWITCH

Ever see one of those circular knobs on the wall?

Those dimmer switches let you adjust your lighting until it's just right.

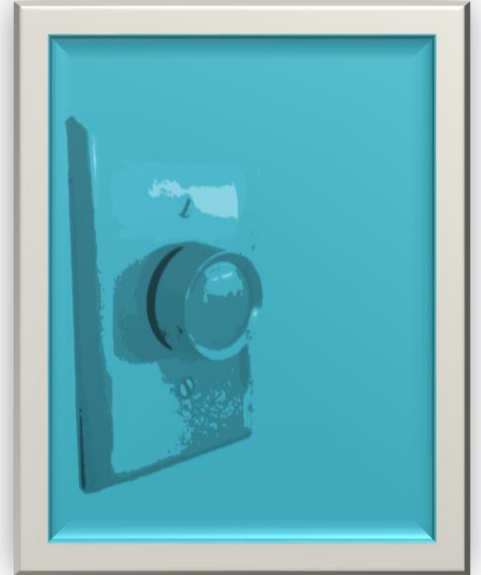
Well, the USP7 gene is just like one of those switches. It fine-tunes everything in your cells to exactly the correct levels.

When those levels are right on, then your cells recycle proteins properly. But if the levels are off, that recycling doesn't work.

And we're pretty sure that the faulty recycling is what causes this disease in our kids.

We have a plan to fix the dimmer switch that is USP7.

#FixTheDimmerSwitch



GETTING STARTED

Why?

Our foundation stands ready to fund our first major research initiative: a phenotyping study. This study, slated for 2018 at Baylor College of Medicine in Houston, Texas, will further define our disease, and pave the way for major breakthroughs that will help our kids. The study will cost about \$11,000-\$12,000 per patient. We need to raise that money.

What should I say?

As you ask friends and family for money, here's some general info you may want to share with them:

- 100% of their donation will be used to fund research into our disease. They won't be paying for overhead or employee salaries, since every single person who works for the foundation is a USP7 parent and volunteer.
- Our foundation has been designated by the IRS as exempt from federal income tax under Internal Revenue Code (IRC) Section 501(c)(3), so donors can deduct contributions to our foundation under IRC Section 170.
- So far, we've raised about \$70,000, or about half of what we'll need for the phenotyping study.

Questions?

Email Bo at bo.bigelow@usp7.org

“As one person I cannot change the world, but I can change the world of one person” - Paul Shane Spear

FUNDRAISING PARTY OR GALA

What do I need to do?

Hosting a fundraising gala is a premier “Bombdiggity” event. We know this is a big undertaking, and want to support you with as much information as we can.

Key benefits to hosting a large party or gala:

- Raise a larger amount of funds for the foundation, thus creating a bigger impact on the lives of those with USP7-related disease
- Share our stories with family and friends and spread awareness
- Socialize with friends and family over a good cause

Because this is a large undertaking we’ve created a thorough guide for hosting a party/gala.

You can download this file to help you plan: [Fundraising Party/Gala](#)



PARTNER WITH A RESTAURANT

What do I need to do?

Contact a local restaurant about holding a USP7 fundraiser. It's wise to pick a date and time when business would otherwise be slow, like a Monday night, so there's an incentive for the restaurant to partner with you.

Ask the restaurant to agree to donate a portion of the proceeds to our foundation. This amount will probably seem small, like 2% or 3%, but it adds up!

Promote the event to your local friends and family, using email and social media.

After the event, send the proceeds to the Foundation via PayPal at admin@usp7.org or mail a check to:

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HOST A TICKETED FILM SCREENING

What do I need to do?

You can host a screening of our award-winning short documentary, Tess Is Not Alone: A USP7 Story. Here's the website for the film: <http://www.portlandrootsmedia.com/usp7-film>

ONE: Pick a date, invite your friends and family.

TWO: Charge admission. Don't be shy about asking for more than people would pay to go to a movie theater. This is a fundraiser, after all. [Click here](#) to complete a short form about your event and we will create a unique link for you to sell your tickets. Be sure to let your guests know that 100% of their ticket price will support research into our disease.

THREE: Depending on the size of your group and your venue, you may need to rent a projector and movie screen from a local event planning or tent rental company.

How You Can Access the Film: You can stream the film directly on YouTube (http://youtu.be/8w_Lejbi6sE) or get Bo to send you the full file of the film. Email him at bo.bigelow@gmail.com. It's a good idea to practice showing the film well before your guests arrive, to be sure that everything works properly with the video and audio.



BIRTHDAY OR CELEBRATION

What do I need to do?

On your birthday, tell your friends and family you don't want gifts. Instead, they should spend that money on a donation to the Foundation for USP7-Related Diseases. They can do this in any of three ways:

ONE: Send a check made out to the "Foundation for USP7-Related Diseases" and mail it to this address:

Foundation for USP7-Related Diseases
11 Innkeepers Lane
Falmouth ME 04105

TWO: Donate directly to our Foundation through our website: www.usp7.org/donate

THREE: Donate through your Facebook fundraiser. [Click here for instructions.](#)



HOST AN ONLINE FUNDRAISER

What do I need to do?

You can choose from a variety of sources to hold an online fundraising event and donate what you collect to the Foundation for USP7-Related Diseases.

Here are some of the different sites you can use to launch a fundraiser for the Foundation for USP7-Related Diseases:

www.fundly.com

www.youcaring.com

www.generosity.com

www.facebook.com/fundraisers/about

Once your fundraiser is complete send the donations to the Foundation by PayPal at admin@usp7.org or mail a check to:

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SPORTING EVENT/RACE/GAME

What do I need to do?

If you participate in sporting events or races it is very easy to raise money for the foundation just doing what you love to do!

Visit pledgeit.org where you can create a fundraising event based on your sport!

Once your fundraiser is complete send the donations to the Foundation by PayPal at admin@usp7.org or mail a check to:

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WORKPLACE DONATIONS

What do I need to do?

Even if your workplace has already picked a charity to support, like the United Way, sometimes they'll still let you select your own charity. Since our foundation is a 501(c)(3) nonprofit organization, you can make a donor-designated donation. Contact the human resources department at work, and ask to do this. Here's the info about our foundation that you'll need:

Foundation for USP7 Related Diseases

501(c)(3) nonprofit organization

Employer Identification Number (EIN): 82-1697564

11 Innkeepers Ln

Falmouth, ME 04105



PROMOTIONAL TIPS

Press Release

If you are hosting a public event, having a press release is a great way to spread the word. Contact your local press (newspapers, radio, TV) about your event. You'll want to make sure to grab their attention with a great opening sentence/headline and make sure you provide specific details about who, what, when, where, and why.

Getting the Word Out

Here are some ways you can get the word out about your event or fundraiser:

- Advertise your event everywhere you can think of: work, school, church, in a newsletter, bulletin, posters and email
- If you are on Facebook, create an Event and invite all your family and friends. Ask them to invite all their family and friends.
- Tell your friends and relatives about your event -through word of mouth and emails. Ask them to tell their friends, family and colleagues about your event or fundraiser.
- Tweet about your event, with a link to information about your event, an event picture or your online fundraising page
- "Like" and post about your event on our Facebook page

Reminder: Don't forget to thank everybody who donated, supported or featured your event after it's finished! A nice touch is to include a photo and the amount of money you raised.



Including a personal story, if you can, will help your supporters feel a connection and want to help.

USP7 INFORMATION

We want to assist you in your fundraising efforts by providing relevant information that you can share with your supporters. Below you will find facts about USP7 and some of our demographics.

Relevant Facts:

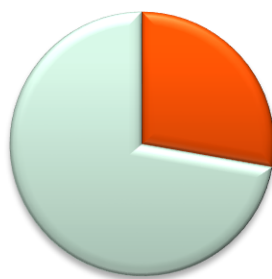
These are some of the most common symptoms of USP7-related disease:

- 100% Speech Impairment. 25% are non-verbal.
- 94% Developmental Delay/Intellectual Disability
- 90% Abnormal Brain MRI
- 63% Hypotonia
- 61% Eye Abnormalities (strabismus, myopia, nystagmus, or other)
- 58% Autism Spectrum Disorder
- 58% Significant Feeding Problems
- 58% Hypogonadism
- 55% Reflux/GERD
- 44% Seizures
- 43% Neonatal Hypotonia
- 40% Abnormal Gait

USP7 Patients Breakdown

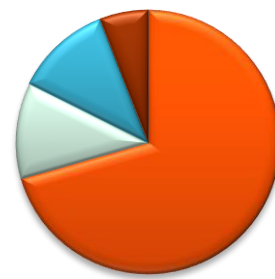
Currently there are 32 people in the world that have received this diagnosis. While many of them are still unknown to us, we wanted to provide you with some statistics on those who are known to us.

Gender



■ Male ■ Female

Location



■ U.S. ■ France ■ Netherlands ■ Canada

PERSONAL STORIES

In your fundraising efforts, we know how important it is to be able to share about USP7, but we also realize the impact of personal stories about those who have this diagnosis.

On the following pages you'll find some of their stories. Each person featured is done with permission from them/their family, so you can share these stories with your friends, family and colleagues to give them a better understanding of why you are fundraising for the foundation and exactly who their donation will benefit. Feel free to print these for your events as well, letting supporters get to know these beautiful people who are impacted by a USP7-related disease.

ELLA'S STORY



A typical picture of Ella being her silly self.

History

Ella was born in 2011. From early on there were signs of developmental delay. It was until seeking a second opinion after her family moved that they began their journey to discovering her USP7 mutation.

Daily Life

Life for Ella is typical of most kids in America. She goes to school and is currently in Kindergarten. Some of Ella's challenges are speech, learning difficulties, fine motor and gross motor skills. She attends private speech therapy, occupational therapy and physical therapy.

She is a happy little girl who loves her friends. She enjoys spending time with her siblings and pets at home. She loves all things Disney!

Sadly, she also knows what it means to get "pokes" from the doctor and has been through many tests in her short 6 years - more than some people have in a life time!

What your help means to Ella

Your donation will go to fund research that will help Ella have a future of possibilities. Our hope is with research we can provide better treatment options for symptoms and find a cure!



TESS' STORY



Sweet Tess showing her beautiful smile.

History

Tess was born in 2009. Right away, her parents saw how different she was from her older brother. She couldn't walk or talk, and didn't respond to sounds. Round after round of genetic testing revealed no cause. Finally, when she was four, whole exome sequencing revealed a mutation in her USP7 gene. Her parents used social media in order to find more USP7 patients. You can hear about Tess's journey in the award-winning short film *TESS IS NOT ALONE: A USP7 STORY* (https://youtu.be/8w_Lejbi6sE)

Daily Life

Tess is in second grade at her local public school. She loves going to school every day. She is nonverbal but is able to use a device to communicate. It has buttons that she uses in order to tell people what she wants.

Her favorite things are sitting with her friends, wrestling with her brother, listening and dancing to music, and being outside. She also enjoys swimming, horseback riding, and downhill skiing.

What your help means to Tess

Your donation will go to fund research that will help Tess have a future of possibilities. Our hope is with research we can provide better treatment options for symptoms and find a cure!

