



DESSH Local Fundraising – How, What, Where and When?
By Melissa Sidebottom

As a parent or caregiver of a DESSH warrior, you are the cornerstone to the DESSH Foundation's success and continued operations. It is through your advocacy, drive and determination that help us raise funds to support research, clinics and awareness for this rare and unique disorder. One of the many ways you can help support the Foundation is by hosting local fundraising events. I know it sounds scary, but there are so many simple and easy ways to launch a fundraiser that is so very beneficial to supporting the path to finding interventions to help our DESSH community. Below are some easy fundraising ideas that you can do to help raise funds and support our warriors. Take a look and fundraise on!

School-Based Fundraising

School-based fundraising is one of the easiest ways to raise funds which your school can donate directly to the DESSH Foundation. Schools are always willing to support charities, especially those that affect one of their own students. The first step to school-based fundraising is to create a one page "proposal" about your fundraiser that you will present to the school's administration. The proposal does not need to be lengthy or overly scientific. It should contain the basics about DESSH, how it affects your child, the way the fundraiser will support your child and the DESSH Foundation, and the specifics of the fundraiser. Next, set a meeting with the administration and present your proposal asking for their support. Lastly, once they approve, we fundraise away, and they donate to DESSH. Easy and simple. Here are some ideas for fundraisers. There is also a sample proposal you can use for your school and flyer; you can tailor to your situation.

- **Coin Drive** – This one is really simple and doesn't require a lot of time, materials or explanation. It simply entails putting jars/containers in each classroom with a little blurb about DESSH. The teacher takes 5 minutes to tell their students about it and over the next month, students bring in loose change from their homes and add it to the jars/containers. If a school does a monthly or weekly newsletter, they can inform their families of the fundraiser. Sometimes the local parent school support group (PTA) will join up with the fundraiser and offer a prize to the classroom that raises the most money. Once the fundraiser ends, the school counts the money and sends a check to the DESSH Foundation. Usually, the school sends it on behalf of your child.
- **Tickets for Special Privileges** – This fundraiser can be done a variety of ways with lots of privileges or incentives to "buy". This can be tailored to the type of school your child attends or requirements/allowances. For example, if your child wears a uniform, for a certain amount of money (\$3), they would be able to purchase a day to wear their regular clothes. Another example is children being able to purchase a day to wear a hat, or pajamas, or costume, or any other item that they may not normally be able to wear or bring. Teachers can purchase a day to wear jeans (dress down) or pajamas. You would work with the school to determine what can be

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purchased, for how much and when/what day they all get to cash in on their purchase. This can be done several times a year.

- School Sponsored Fundraising – Asking your local PTA/School parent organization, if they are willing to donate a percentage of profits they make from any school-based fundraiser. This is an easy way to piggyback off of their fundraiser, and often times, family and friends are willing to buy more if they know it also supports a local child in their school.
- Can Pull Tabs (Pop Tabs) – Before you do this one, you want to check with your local scrap metal recycle center to see if they will take the tabs. Similar to the coin drive, you would work with your local school to collect the tab tops of cans. I recommend putting gallon jugs in the school at the beginning of the year, and have students bring them in throughout the school year. At the end of the year, collect the jugs and turn them in for money. Many people also donate these to the Ronald McDonald House (RMH), which can be a donation made in the name of the Desanto Shinawi Foundation. Many patients with DESSH use the RMH for ease of expense during treatment.

Local Area Fundraising

Don't worry if your DESSH warrior isn't in school or they are unable to support a fundraiser, there are other opportunities to fundraise in your community. Similar to school-based fundraising, the first step is preparing a proposal to submit to the business, fraternity or other organization to ask for their support. Some of these can be a bit more involved, so feel free to reach out for help or with questions. There is a sample proposal letter you can give to your local business.

- Proceeds Donation – This entails asking local businesses, usually restaurants, bars or local food establishments, but other locally owned businesses are willing to support as well (maybe a local athletic store, paint place, nail salon, etc.), to donate a portion of their proceeds for the day, night, or event to our Foundation. This is an excellent way to bring patronage to a business while supporting our Foundation; it truly is a WIN/WIN! In addition to the patronage, it also provides the local business with a tax-deductible donation. Once you submit your proposal to your business asking for them to support DESSH through proceeds donation, you will pick a mutual date to hold the fundraiser and advertise to your friends, family and community to come out and support DESSH. You can advertise on Facebook or other Social Media Platforms, via email, on our DESSH site, at local schools, and through other local sites. On the day of the event, have your DESSH Warrior there, maybe even have some info on DESSH (make up a little half page write-up on your warrior and DESSH, with our website), and have a great time. Once the event is over, the business donates the percentage/portion agreed upon to DESSH.
- Donation Match – Similar to the Proceeds Donation, you can ask local businesses to match the donations you are able to get from your friends and family. If you yourself work for a company,

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you can ask your company to match what you can get your co-workers to donate. This can be done similar to school-based fundraising, where you present local businesses with a proposal to match. If they agree, you begin collecting donations, or having people donate to DESSH directly (we can keep track by having a certain sentence your donators write when donating), and at the cutoff date, you present your donations to the business and they match. Again, this is a WIN/WIN for any company, because in the end, they get to donate to a great cause, while being able to take the tax-deductible donation.

- **Hosting a Meal** – Many local churches, organizations and local restaurants/food trucks are willing to help you host a meal, like a spaghetti dinner, pit beef, etc. The first step is finding a venue willing to host your meal without cost to you; think Church or Fire Halls, Moose Lodges, Elks Clubs, VFW's, etc. You can then ask either a local restaurant/food truck to donate the food, or for things like spaghetti dinners, you purchase all of the food, make it in your venue, and charge a price. Often times, you can get local businesses to support the costs, or you can ask your local grocery store if they have an In-Kind donation they can give to cover the costs. Everything above and beyond the cost is your donation.
- **Food Truck Night** – This entails contacting a local organization that has a large parking lot, like a Church, school, park to first see if they would allow the use of their space for food trucks to come for a donation night. You will explain what you are trying to accomplish. Then you would contact local food truck vendors to see if they would be willing to come to your event and give a proceed donation to the Foundation. This is very similar to the restaurant proceeds night. This is a win-win. As the advocate, you advertise through family, friends and social media to come out to the food truck on a given day, and usually timeframe, to support DESSH. The local food truck receives business advertisements, increased sales, and they get to make a tax deductible donation.
- **Purse (Other Item) Bingo/Seafood Feast** – These types of fundraisers are larger scale events that are more involved. However, they are an excellent way to get a large donation for the Foundation. If you have any interest in what this entails or how to go about setting one up, please contact Melissa Sidebottom at 410-336-8976 or via email at melissa@dessh.org or jmside2@yahoo.com.

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[SAMPLE EMAIL]

Dear (Principal),

As you may know, our child, (NAME), a student at your school, was diagnosed with DeSanto-Shinawi Syndrome (DESSH), a rare neurodevelopmental genetic disorder with only about 220 known cases worldwide. Children and adults living with DESSH may experience developmental delays, intellectual disabilities, hypotonia, epilepsy, behavioral challenges, autism, and other medical complications.

Because this condition was only identified in 2015, it has not yet received the level of attention or funding from the medical community, researchers, and pharmaceutical companies that is so urgently needed. The DESSH Foundation—a non-profit created by parents—works to raise awareness, support families, and fund critical research and clinics with the hope of finding treatments.

We are asking (School Name) to join us in this important mission by hosting a fundraiser—such as a Coin Drive during February in honor of Rare Disease Day, a can tab collection, or a special privileges fundraiser (e.g., pajama or dress-down day). These activities are simple to run, but they have a powerful impact. At the close of the fundraiser, the school would collect the contributions and make a charitable donation to the DESSH Foundation. (More information about DESSH and how to give can be found at www.DESSH.org.)

This type of fundraiser not only helps children like (NAME) but also teaches students valuable lessons about inclusion, empathy, and philanthropy. Every contribution—no matter how small—moves us closer to treatments.

We are deeply grateful for your consideration and support.

With appreciation,
(Name)

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[SAMPLE FLYER]

COIN DRIVE

Loose change all over your house? Coins weighing down your purse?

Collecting coins in bowls, jars or other places?

Did you know these coins can help your school in supporting the
DESSH Foundation

Students and staff are encouraged to bring in loose change to add to jars in student's classrooms and around the school. Proceeds will be donated to the DESSH Foundation in honor of Rare Disease Day. Your donations will help fund research and development of treatments and therapies for children and adults who have this rare genetic disorder.

REMEMBER.....EVERY LITTLE BIT HELPS!

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[SAMPLE EMAIL]

Dear Community Partner,

(You may keep this salutation or personalize it with the recipient's name.)

I am reaching out as a parent/legal guardian/family member/friend of my (son/daughter/friend), (NAME), who was diagnosed with DeSanto-Shinawi Syndrome (DESSH). This ultra-rare neurodevelopmental genetic disorder has only about 220 known cases worldwide. Children living with DESSH may experience developmental delays, intellectual disabilities, hypotonia, epilepsy, autism, behavioral challenges, and other medical complications.

Because DESSH was only identified in 2015, it has not yet received the recognition or support from the medical community, researchers, and pharmaceutical companies that it deserves. The DESSH Foundation—a nonprofit founded and led by parents—works to raise awareness, provide support to families, and fund critical research and clinics in pursuit of treatments and, one day, a cure.

We are writing to ask for your support in hosting a **Proceeds Donation Night** at your restaurant. This would involve designating one evening—such as 5:00 p.m. to 10:00 p.m.—during which a percentage of sales would be donated to the DESSH Foundation as a tax-deductible contribution. In return, we would actively promote the event through social media, flyers, email, and community outreach, encouraging families, friends, and neighbors to dine at your restaurant in support of both this important cause and your business. (More information about DESSH and the Foundation can be found at www.DESSH.org.)

This type of event is simple to organize but makes an enormous impact for DESSH warriors and their families. It is truly a win-win: the Foundation benefits from much-needed support, while your restaurant gains visibility and patronage from a grateful community.

Thank you for considering this opportunity to partner with us. Every contribution brings us closer to effective treatments and, we hope, a cure.

With gratitude,

(Name)

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