

Event Coordinator Handbook

**DRAVET
SYNDROME
FOUNDATION'S**



STEPS

TOWARD A CURE

www.dravetfoundation.org

WELCOME

On behalf of the Dravet Syndrome Foundation (DSF), I would like to thank you for volunteering to be an event coordinator for a DSF Steps Toward a Cure event.

As an event coordinator, you play a very important role in the success of DSF by raising both funds and awareness for Dravet syndrome (DS) and related intractable childhood epilepsies. Coordinating an event is a fun and easy way to bring families and friends together to support a great cause. You will be amazed at the generosity and support from your community.

Myself, as well as other members of our DSF staff are available to help you every step of the way. It is our job to make your experience planning this event easy, fun and rewarding!

Sincerely,
Misty Ried
Campaign Director
misty@dravetfoundation.org



TABLE OF CONTENTS

Section 1: Planning Your Event.....Page 3-5

Section 2: Committee & Volunteers.....Page 6

Section 3: Fundraising.....Page 7

Section 4: Raffle/Silent Auction Donations.....Page 8

Section 5: In-kind Donation & Sponsorship FAQs.....Page 9

Section 6: Handling Money at the Event.....Page 10

Section 7: Logistics for the Day of the Event.....Page 11-12

Section 8: Event Wrap-up.....Page 13

Section 9: Coordinator Toolkit and Forms.....Page 14



ABOUT DRAVET SYNDROME FOUNDATION

The mission of Dravet Syndrome Foundation (DSF) is to aggressively raise funds for Dravet syndrome and related epilepsies; to support and fund research; increase awareness; and to provide support to affected individuals and families. In accordance with our mission, DSF focuses its work and funding in several key areas: Research Grant Awards; Annual Research Roundtable; Patient Registry; Patient Advocacy; Patient Assistance Grants; Biennial Family & Professional Conference; and Professional Education. Through our programs, we are able to fortify our efforts to increase research, provide support and advocacy, and increase education and awareness.

DSF is a 501c3 nonprofit organization founded in 2009 by a group of parents who wanted to expedite research to find a cure and better treatments for their own afflicted children. Since its inception, DSF has awarded over \$5.6M in Dravet-specific research grants and over \$196K in patient assistance grants.

To learn more about Dravet syndrome, or DSF and its programs, visit www.dravetfoundation.org.

SECTION 1: Planning Your Event

Event Expenses

Event Coordinators are not expected to take responsibility for any of the expenses associated with their event. We ask you to try to keep venue fees below \$400. Venue contracts and raffle contracts should be forwarded to DSF Staff to be completed and/or reviewed prior to being signed and submitted. You should notify DSF staff immediately if venue fees will be more than our approved limit. Coordinators must keep receipts for event costs and submit them along with a completed expense reimbursement form for reimbursement.

Any expenses in addition to venue and raffle permit fees must be pre-approved by DSF in order to guarantee full reimbursement. If you choose not to be reimbursed for any or only for some expenses, you should still submit your receipts along with a completed expense reimbursement form in order to receive an in-kind tax donation receipt.

Key Tips To Remember:

- There is nothing wrong with keeping your event simple—especially if this is your first event.
- Securing event sponsors is one of the best ways to underwrite the event costs and ensure that event proceeds go directly to DSF's programs.
- Forming an event committee allows you to distribute the work load, while getting others involved and excited about the event.
- For insurance purposes, DSF typically prohibits alcohol, bounce houses and dunk tanks at events.
- Being an event coordinator should be fun and rewarding and the DSF staff are here to help every step of the way!

What should your event include?

Start considering what optional extra activities you would like to include at your event.

- Food and beverages
- Raffle and/or silent auction
- Kids' activities—face painting, balloons, games, costumed characters, etc.

Make a “wish list” that includes potential resources for in-kind donations. Remember to approach businesses for in-kind donations a minimum of 60-90 days before your event, as many require you fill out an application that must be reviewed and approved by the store manager.



Date and Location

The majority of DSF Steps Toward a Cure events are held in the Fall, when weather conditions are cooler and it is less likely that children with Dravet syndrome will overheat. However, events can be held at anytime that works best for the coordinator. When selecting your date, make sure to check your Community Calendar for any conflicting events. When considering locations, be sure to enquire if a Certificate of Insurance (COI) is required. If a COI is required, forward the required limits to DSF staff so we can secure it for you.

Tips for choosing your venue:

- If your event will be outdoors, make sure it is handicap accessible and has a paved path.
- If doing an event with a route, avoid sites that will require participants to cross streets. For these events, often police or other staff are required to keep participants safe when crossing.
- Is the venue large enough to accommodate your expected number of participants and is there adequate, free parking?
- For outdoor activities, are there adequate facilities including restrooms, shaded space, seating, electrical power and shelter (in case of inclement weather)?

What type of Event should you host?

The type of event that you decide to host will factor into your site selection. Most first-time event coordinators find holding a family walk is the easiest. Others have organized 5Ks, Camp Days and Burn Bootcamps, to name a few. The Steps Toward a Cure program is flexible and we are here to help you design your event as you envision it.

Registration and Fundraising Pages

Each event is web-based, meaning it has an individual event portal that will allow participants to register, fundraise and promote the event through social media. Once your date and location is finalized, we will build your event portal and help you start promoting your event.

Recruiting Participants

Friends, family, co-workers, neighbors, vendors, and local businesses are all great people to approach to ask to participate in, or to sponsor your event. It helps to personally recruit participants, in addition to sending out emails and posting flyers around your community. Encourage participants to pre-register and consistently encourage participants to set a fundraising goal to help you meet your event goal. Consider asking a local business to donate a gift certificate that you will award to your top fundraiser as an incentive.

Registration Fees

We suggest the following registration fees for most Steps Toward a Cure events. Registration fees typically include an event t-shirt (which can be personalized for your event) and a DSF drawstring backpack or other promotional item.

\$25 for adults

\$15 for children

Participants must register a minimum of four weeks prior to the event to guarantee their event shirt.



CHECKLIST FOR GETTING STARTED

- Contact our Campaign Director to let them know you are interested in becoming an Event Coordinator
- Participate in a phone call with our Campaign Director to discuss your event
- Research event sites and select a date for your event
- Read through the coordinator handbook and complete an event application and forward it to DSF - this application gives us the information we need to set up your event portal
- After approval from DSF, secure your event site. DSF can complete any associated paperwork and pay for the site (make sure to get fees pre-approved if they exceed \$400)
- Request a Certificate of Insurance (COI) from DSF, if it is required by the owner of the event site
- Start to assemble your Event Committee

Support for your event

While the DSF Coordinator Handbook will provide you with a solid overview of the event planning process, we know that there will be questions and concerns throughout the planning process that may not be covered or addressed in great length in the handbook. For specific questions, as well as support, please do not hesitate to reach out to a member of the DSF staff. We all have hands-on experience in the planning and execution of various fundraising events.

We are all here to help you in making your event a great success and we are excited to work with you!

DSF is responsible for:

- The cost of your approved site, raffle permit (if needed), any associated paperwork and additional event fees
- Supplying Certificate of Insurance, if needed
- Establishing your event portal
- Helping you secure in-kind donations
- Helping with promotion of event
- Answering questions & troubleshooting event issues
- Sending registration reports for event check in
- Sending coordinator all items needed for the day of your event—shirts, banners, signage, registration materials, etc.

Event Coordinator is responsible for:

- Finding & securing the event site
- Forming a committee for the event
- Publicizing and promoting the event
- Securing volunteers
- Securing in-kind donations
- Entertainment or special activities
- Recruiting participants
- Securing sponsorships
- Securing auction or raffle items, if applicable
- Site layout
- Completing post event paperwork



DSF STAFF

- Misty Ried, Campaign Director—misty@dravetfoundation.org
- Mary Anne Meskis, Executive Director - maryanne@dravetfoundation.org
- Jamie Cohen, Accountant - jamie@dravetfoundation.org
- Jenny Gallo, Special Events Director - jenny@dravetfoundation.org
- Erin Reoyo, Family Network Support Group Liaison - erin@dravetfoundation.org



SECTION 2: Committee & Volunteers

You may decide to champion the planning and logistics for your event alone, while other coordinators will choose to recruit individuals and build an Event Committee. Your committee members and volunteers can be built from local DSF families, as well as your own family and friends. Once you recruit committee members, be certain to have meaningful work or projects for them to take on, based on their interest, expertise and amount of time they can commit. Hand out assignments and get everyone motivated for the day. Make sure volunteers understand their roles and your expectations.

When creating your committee:

- Create a committee roster, phone & email list
- Schedule regular meetings in-person or by phone
- Take notes at all meetings and distribute them to your committee within a day or two
- Allow enough lead-time to make sure you accomplish all of your objectives
- DSF will put together a Google Doc folder where committee members can add information on what they are working on for the event, in real-time



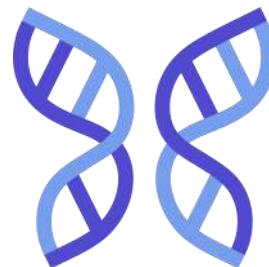
Pre-event tasks for committee members include:

- Assisting with event planning
- Attendance at planning meetings
- Soliciting sponsors
- Soliciting in-kind donations
- Community promotion & outreach
- Participant recruitment
- Event activity planning
- Soliciting donations for silent auction or raffle



Day-of tasks for committee members & volunteers include:

- Set-up and tear down of event
- Placing directional signage for event
- Registration & check in
- Greeting participants and assisting with questions
- Overseeing refreshment station
- Selling raffle tickets
- Overseeing silent auction
- Assisting with onsite activities



Resources for volunteers:

- Churches & synagogues
- Scout troops
- Cheerleading/Dance teams
- Community sports teams
- High School service clubs
- Local epilepsy foundations or support groups
- Company volunteer programs (such as Kohl's Cares)

SECTION 3: Fundraising

Personal Fundraising Pages

Your online event portal will make it easy for event participants to fundraise for your event. Participants will be able to create a personalized fundraising page, with easy step-by-step instructions. From their fundraising page headquarters, participants can send out email appeals to their contacts or share their fundraising page via social media.

Encourage all participants to set a minimum fundraising goal of \$100 or more. Ask team leaders to set up friendly fundraising competitions with one another. You may want to secure donations of desirable items and use them as prizes to award to the top fundraiser(s) at your event.

Additional Fundraising Ideas

FUNdraisers

You and your committee may want to hold a “kick-off” event before your event to raise additional awareness and donations for your event.

Ideas include:

- Cocktail party at a local bar, restaurant, or in your home. Ask for a cover charge or donation to DSF
- At-home party (such as Pampered Chef), with a portion of sales going to DSF rather than the hostess earning rewards
- Yard/Garage sale
- Dress down day at work or school
- Golf Outing
- BBQ/Chili cook-off
- Bake sale
- Movie night
- Car wash
- Karaoke contest

Company Matching Gifts

Ask your employer if they will match donations made to your fundraising campaign.

Encourage your donors to apply for matching gifts from their employer. It is an easy way to double, sometimes triple, a donation.

Be sure to include the information below on Matching Gift Donation applications:

Mailing Address:

Dravet Syndrome Foundation
PO Box 3026
Cherry Hill, NJ 08034

IRS EIN#: 27-0924627

Contact Information:

203.392.1950
Jamie Cohen, Accountant
jamie@dravetfoundation.org

SECTION 4: Raffle/Auction Donations & Sponsorships

Securing Raffle or Auction Items

Raffles and auctions are one of the most cost-effective and popular ways to raise money during a fundraising event. To make a raffle or auction successful, you must first secure desirable items. The best place to start is to survey your committee members, family and friends. Every supporter could possibly know of a business or individual that would have something of value to contribute to the prize pool.

When reaching out to local businesses, begin canvassing your community early on. Come prepared with a request letter, flyer, donation contract and 501c3 paperwork. Every business is a viable option and it never hurts to ask. Remember, you are more likely to have success at businesses where you are a frequent customer. And don't let NO discourage you—another opportunity will always arise.

Examples of raffles:

- 50/50 Raffle - Half of the money collected goes to a single winner with the balance going to DSF.
- Single-Prize Raffle - Sell raffle tickets and offer one or more items as prizes in your drawing.
- Teacup Raffle - Items are displayed on a table with a small paper bag in front of each item. Participants drop purchased tickets in the bag of the item they would like to win.



Suggested items for raffle or silent auction:

- Gift certificates from local businesses
- Items or gift baskets from local stores (such as a bakery, sweet shop, jewelry, clothing, etc.)
- Tickets to the movies, sporting event or local theater
- Signed sports memorabilia
- Services, such as child or pet care
- Tickets for a tour, such as a winery tour
- Many grocery stores will only support charities incorporated in their State, but may still make a small donation called a neighbor to neighbor donation

Food & Beverage Donation Suggestions:

- **Costco & Sam's Club** often donate a gift card that can be used for water, fruit or other items needed for your event. Applications typically must be submitted 60-90 days in advance of your event. Check with the manager of your local store for more details.
- **Whole Foods or local grocery stores** will often donate granola bars or fruit. In most cases, applications should be submitted at least 90 days before the event. Applications for Whole Foods can be completed online.
- **Starbucks** will often donate brewed coffee for your event. Contact the manager of your local store for more details. You will need to arrange pick-up of the coffee the morning of the event, as well as return the carafes after the event.
- **Einstein's Bagels or other bagel or donut store** often will donate end-of-day bagels. Bagels will need to be picked up at closing time the evening before your event.
- **Panera** will sometimes donate fresh bagels for fundraising events. You can stop in at your local store, or ask us to fill out an online donation request.

SECTION 5: In-kind Donations & Sponsorship FAQs

What is an in-kind donation?

In-kind donations are donations of goods or services, rather than cash. Examples would be food, water, raffle & auction items, entertainment, etc.

What is a sponsorship?

A sponsorship is a financial payment by a business or individual to support a special event.

Why should I solicit in-kind donations and sponsorships?

In-kind donations and sponsorships help to subsidize the costs associated with your event, allowing event donations to go directly to the programs of DSF.

Who should I ask for in-kind donations and sponsorships?

Typically a business owner or manager is the person to approach. However, sometimes individuals or families may also be interested in supplying needed items for your event or purchasing a sponsorship in their name or in honor of a loved one.

How do I go about requesting for in-kind donations & sponsorships?

Make sure to have a sponsorship packet (sponsor levels, donation contract, request letter, etc.) when you approach someone. You may be asked to fill out an application and supply the DSF EIN# (27-0924627) and/or a copy of our 501c3 letter.

What does the donor need to do?

They should fill out the donation contract in full, then return it to an event coordinator. They may also return it to DSF by fax or email. You should make arrangements to have the item picked-up or delivered, based on the donor's preference.

What does the event coordinator need to do?

Make sure to keep a copy of the donation contract to be returned with the event paperwork. This will assure that the donor receives a tax receipt. Ask for a hi-res logo if the donor contributes at a level that includes signage or inclusion on the event shirt. If an item needs to be picked up, make the arrangements to do so.

Will in-kind donors or sponsors receive a tax-donation receipt?

All in-kind donors and sponsors will receive a tax-donation receipt, based on the information on their donation contract. Donations are tax deductible to the full extent of the law. If you have questions regarding the issuance of tax receipts, email Jamie at jamie.c@dravetfoundation.org.

When reaching out to sponsors & donors, come prepared with a request letter, flyer, copy of DSF 501c3 letter, sponsorship packet and donation contract.

SECTION 6: Handling Money at the Event

Tracking Revenue at your Event

In your event coordinator box that you will receive about a week before the event, you will find onsite registration tracking sheets. It is important that volunteers use these sheets to track onsite registrations and donations, as well as the method of payment. It is important that you track the money raised at your event by category, so our accountant can properly reconcile your event.

If you are interested in accepting credit cards at your event, we can offer you a Square device, which can be plugged into a smart phone or tablet to process credit cards. In order to use the Square, an internet connection must be available at your event location. Please verify a connection is available before requesting a Square for your event.

On Site Registrations

Anyone who registers the day of the event needs to complete an onsite registration form and sign the accompanying waiver, as well as pay their registration fees. They may select an event shirt from left-over stock. Even if you run out of shirts, all participants must pay a registration fee to participate.

Donations/Pledges

If participants turn in donation money the day of the event, make sure it is marked down on the onsite tracking sheet. If they bring an accompanying offline pledge sheet, make sure to include it in the paperwork that is sent to us at closeout so we can get tax donation receipts sent out to the appropriate donors.

Raffle and/or Auction Items

Volunteers selling raffle tickets should turn over all of the cash collected to the Event Coordinator or other assigned committee member. The total money collected for the raffle should be entered on the onsite tracking sheet. If someone uses a check to purchase raffle tickets, mark “raffle” on the check to assist with closing out the event. Individual receipts are not issued for raffle tickets, as they are not tax deductible donations.

Cash or checks from silent auction items should be treated in the same way. On the silent auction forms, write in the winning bidder’s name and method of payment to help us to close out event. Mark “silent auction” on the check. Silent auction items are only tax deductible for the amount above the value of the item.

Sharing the Total Raised at your Event

Before the event begins, you may want to share the total money raised to that point with participants so they can see how their efforts paid off. About a week after the event, DSF will send out a thank you email to all participants that tells them the total money raised for the event. Make sure to capture emails of onsite registrants on their registration form so they can receive this email. We want all participants, donors, sponsors and volunteers to know how much their efforts are appreciated by DSF and the Dravet community.



SECTION 7: Logistics for the Day of the Event

Having a detailed plan in place for the day of your event will assure that it runs smoothly. Set up a timeline, from set-up through tear-down, including where volunteers are needed. Make copies to distribute to your committee members or key volunteers so that everyone has knowledge of the event plans and can answer questions if you are otherwise engaged.

Plan your Event Layout

Make sure to visit the site the week prior to your event to assess the area. At this point you should make definitive decisions on your final layout for the event. It helps to make a map for your volunteers to use for set up. On the Event Coordinator Portal, you can find a suggested timeline for the day of the event.

Meet with Volunteers

Take the time to meet with your volunteers and make sure they understand their assigned tasks for the day. If you have volunteers picking up items the morning of, call them the evening before and remind them of the item, pick up time and location.

Walk the Route

If your event is a walk or 5K, make sure to arrive early enough to walk or ride the route and make sure there are no unexpected obstacles such as branches or sitting water. Post volunteers or signs near any obstacles to keep everyone safe.

Set-up & Clean-up

Make sure that the volunteers you recruit for set-up and clean-up understand that this is an active role that requires some manual labor—lifting tables, stacking bottles of water or carting boxes of shirts and supplies. When it comes time for clean-up, make sure to remove all litter and return the site to its original state.



Supplies

You might want to pack an emergency kit for the day of your event. Make sure to consider any additional activities you have added and what they might require.

Items may include:

- Additional pens
- Money boxes & petty cash
- Scissors, tape & a stapler
- Clipboards (DSF supply on request)
- Cord or string
- Garbage bags
- Emergency medical kit

Event Day Registration

Registration will be one of the busiest times of the day for your event. Make sure you have enough volunteers and that the volunteers you choose are friendly, quick to respond, comfortable handling money, and do well under pressure. Offer one table for pre-registered participants and a second table for those registering the day of the event.

Each coordinator will receive a package of supplies before the event that are necessary for registration and the event. It will include event banners, directional signage, onsite registration, etc. You will receive event shirts and promotional items separately, at least a week before the event.

Depending on your event, we will close online registration 3-7 days before your event. Once the event is closed, your final pre-registered participants report will be emailed to you. It will include the participant's name, team name, and event shirt size. You will use this report to sort and prep your event shirts and promotional items, as well as to check-in participants who have pre-registered for the event. Make sure to print 2-4 copies of the online registration report for use at registration.

Registration Procedures

Pre-Registered Participants

- Greet the participant
- Find participant name on registration report and place a check mark by their name
- If participant hands in a pledge form and donations, make sure to mark down the donations on the onsite registration and donation form. Hold on to pledge form to be returned with other walk paperwork.
- Give participant their event shirt and backpack as listed on the registration report. If they want to switch sizes and it is available in the pile of onsite registrations shirts, they may exchange it.
- Thank participant for their support

On site Registrants

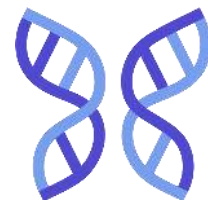
- Greet the participant
- Have participant complete the onsite registration form and waiver
- Collect registration form, payment, and any pledge forms or donations they have brought with them.
- Make sure to add participant info to onsite registration and donation form
- Ask participant what size shirt they need. Be sure to only take shirts from the onsite registration pile. It is \$3 additional for shirts 2XL or larger
- Thank participant for their support

SUPPORTING FAMILIES
FUNDING RESEARCH
ADVANCING TOWARDS A CURE

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SECTION 8: Event Wrap-up



- Congratulate yourself and your committee on a great event!
- Send back event paperwork in the prepaid priority mailing envelope. Make sure to include:
 - * The onsite registration & donation tracking forms
 - * All onsite registration forms & waivers
 - * Checks that were collected prior to and on the day of the event
 - * A check or money order for the total cash collected prior to and on the day of the event
 - * Reimbursement/in-kind donation request form (if applicable)
 - * A list of anyone who donated cash and requested a tax-donation receipt
- Box up leftover supplies that will be shipped back to Jenny Gallo
 - * Contact Jenny (jenny@dravetfoundation.org) with the dimensions & weight of each box
 - * You will receive prepaid shipping labels to print out and attach to the boxes
 - * If you do not have a UPS drop off center near you, we can request an at-home pick up
- Thank your volunteers. They are the foundation and the key to hosting a smooth and successful event. Recognizing them is critical and will keep them motivated and interested in supporting DSF and your future fundraising efforts for many years to come!
- Thank your participants and donors. It is their energy and enthusiasm for our cause that allows DSF to *Raise Hope Through Research*. DSF will send out an email to all participants and donors, letting them know how much was raised at the event, as well as to thank them for their generosity and dedication to DSF.



SECTION 9: Coordinator Toolkit & Forms

DSF's online event coordinator toolkit allows coordinators and their committees to access forms they will need for their event. You can access the toolkit at this link: www.dravetfoundation.org/dsf-fundraising-resources/

There is flexibility in establishing sponsorship levels and benefits for your event. You should discuss your ideas with a DSF staff member, who can also help you customize the sponsorship and auction/raffle donation contracts for your event.

Many of the forms online are in pdf writeable format, allowing you to type your information directly into the document. Once you have completed a writeable document, make sure to save it as a file before emailing it.

All forms may be emailed to misty@dravetfoundation.org. If you prefer mail your forms, complete them and return by mail to: DSF, PO Box 3026, Cherry Hill, NJ 08034

DSF COORDINATOR TOOLKIT FORMS

Planning & Site Documents

- Coordinator Handbook
- Coordinator Event Application
- Event Timeline



Sponsorship & Item Donation Contracts

- DSF 501c3 letter
- Local Event Sponsorship Levels & Contract
- National Event Sponsorship Levels & Contract
- Printable letterhead
- Sample of sponsorship/item donation request letter
- Auction/raffle item donation contract
- Request for reimbursement or in-kind donation receipt form



Fundraiser Information

- DSF Fundraising Guide
- Offline pledge form

Day of Event Documents

- Onsite registration & donation tracking form
- Day of event timeline

