Dravet Syndrome Foundation
Dimes for Dravet Handbook

Dimes For Dravet
Collect Coins for a Cure
Thank you for coordinating a *Dimes for Dravet: Collect Coins for a Cure* campaign on behalf of the Dravet Syndrome Foundation (DSF). As a coordinator, you play a very important role in the success of DSF by raising both funds and awareness for Dravet syndrome and related childhood epilepsies.

I am here to support your efforts every step of the way. Please feel free to contact me for help at any point during the planning and execution of your fundraiser. It is my job to make this fundraiser easy, fun, and rewarding for you.

Sincerely,

Mary Anne Meskis  
Program Director  
maryanne.m@dravetfoundation.org

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**About Dravet Syndrome Foundation**

The mission of Dravet Syndrome Foundation (DSF) is to aggressively raise research funds for Dravet syndrome and related epilepsies, while providing support to affected individuals and their families. In accordance with our mission, DSF focuses its work and funding in four areas: Research Grant Awards; Annual Research Roundtable; Patient Registry; and Patient Assistance Grants.

DSF is a nonprofit organization founded in Connecticut in 2009 by a group of parents with the purpose of expediting research to find a cure and better treatments for their afflicted children. Since its inception, the DSF has awarded over $1M in Dravet-specific research grants.

To learn more about Dravet syndrome or our foundation and its programs, visit our website: [www.dravetfoundation.org](http://www.dravetfoundation.org)
What is Dimes for Dravet?

*Dimes for Dravet* is a great fundraiser that allows you to raise awareness of Dravet syndrome and related intractable childhood epilepsies, while teaching children the importance of giving back to their community. Coordinate this event with the leadership at the event venue (principal, teacher, Scout leader, youth group leader, etc.) and then ask participants to collect coins to donate to the campaign.

Once all the coins are collected on the due date, money will be tallied and a winner will be announced. The DSF will supply silicone awareness wristbands to all participants and we will treat the winning class/team to donuts.

All you need is a few coin collection containers and some willing participants. Simply approach your school or other leadership and ask for their approval to hold a Dimes for Dravet campaign for the Dravet Syndrome Foundation. Then set out the containers and let the fun begin! When the campaign is completed, collect the containers, count the coins, and rest assured you have made a difference in the lives of many special children.

How Dimes for Dravet Works:

**Get Approval**
Speak with school/venue staff for approval to hold event.

**Promote**
Hold a school-wide assembly to kick off the campaign and/or distribute materials to each classroom. Promote the campaign throughout the week(s) through PA announcements, posters, bulletin boards, etc. Make sure to notify parents of the campaign. Work with local businesses to see if they would like to join the campaign and offer an incentive for participants (i.e. free ice cream cone or toy)

**Teamwork**
Develop a friendly competition between the grades/classes. For instance, have each grade level/classroom draw a thermometer and post it in the hallway near their classroom. Have them fill in the thermometer each day as students turn in the money they have collected.

**Achievement**
All children who participate in *Dimes for Dravet* will receive a DSF Awareness Bracelet. The DSF will also treat the winning class to a Donut Day. Everyone involved will feel a sense of accomplishment.

**School Recognition**
All participating schools will receive recognition in an upcoming DSF newsletter. We also suggest you contact local media to let them know about the event and how students are learning to give back.

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**Your DSF Dimes for Dravet kit includes:**

- Dimes for Dravet container templates
- Silicone Awareness Wristbands
- Informational Brochures
- Sample correspondence for your campaign
- Gift certificate for Donut Day for winning class/team
Explaining Seizures and Epilepsy to Children

Witnessing a seizure can be a frightening experience for a child. Children who will be exposed to a child with epilepsy need to be prepared for what they may see if the child has a seizure in their presence. Adults need to be very careful about how they explain the situation to children. It is important to provide age-appropriate information and facts and to reassure each child. With proper education, you can help children learn to be sympathetic and helpful instead of fearful of seizures and epilepsy.

Educate yourself first. Before relaying any information about seizures to children, it is important to know the basics yourself. Either do research in the library or online, or speak to your doctor.

Explain to children that when a person has a seizure, part of their brain does not communicate quite right. This causes unusual movements, actions or other problems. Seizures are brief and as soon as the brain is working well again, these strange symptoms will stop. Keep the conversation simple and non-technical and phrase and use descriptions that are age-appropriate.

Tell children that the person has seizures because of a medical condition, in this case, Dravet syndrome. The child who had the seizure is not in danger, nor are the other children around that child in danger. Seizures are not contagious.

Have a plan for what the other children should do when a child has a seizure. By teaching children a helpful response to employ during or after someone has a seizure, you can help them manage their anxiety and fear about the situation. Young children should be taught the importance of "being a good friend" to a person who has had a seizure by being kind, reassuring him or her, and continuing to include him or her socially.

Make sure to arrange a time for children who witness a seizure to talk and discuss what happened. Encourage children to ask questions and let them know that no question is too strange. This helps children process their feelings and shows them that this is a subject that can be discussed openly and without stigma.

Recommended reading:
- Taking Seizure Disorders to School: A Story About Epilepsy—Kim Gosselin
- Becky the Brave: A Story about Epilepsy—Laurie Lears
- Lee: The Rabbit with Epilepsy (Special Needs Collection) - Deborah Moss
Sample Letter to Parents

Dear Parents,

Our school will hold a charity drive, *Dimes for Dravet: Coins for a Cure*, on {insert dates} for the Dravet Syndrome Foundation. Your child will have the opportunity to participate in the *Dimes for Dravet* campaign if he/she wishes and upon your consent.

As you may know there is a child in our school with Dravet syndrome *{OR there is a sibling in our school of a child with Dravet syndrome}*. We would like to take this opportunity to help raise awareness and educate the children about Dravet syndrome and other childhood epilepsies, while raising money for a great cause.

Each day from {insert start date} to {insert end date}, children are encouraged to bring in coins to donate to this cause. All children in the school will receive silicone awareness bracelets just for participating. In addition, the classroom that raises the most money will celebrate with a Donut Day.

*This campaign gives your child the opportunity to learn more about epilepsy and feel good about helping others!*

Please do not allow your child to raise money without your supervision. The decision to collect money is optional, but all children will participate in an epilepsy awareness activity in class.

*All coins must be turned in by {insert date}*

*Remember that every coin gets us closer to a CURE!*

Sincerely,

The Dravet Syndrome Foundation thanks you for your support!

www.dravetfoundation.org