



Dravet Syndrome
Foundation

2026



FAMILY & PROFESSIONAL
CONFERENCE
ORLANDO

Event Overview

www.dsfconference.org

Welcome Letter

On behalf of Dravet Syndrome Foundation (DSF), we are pleased to invite you to join us at this year's DSF Family & Professional Conference. We hope you will consider being part of this meaningful biennial gathering.

This conference brings together families, caregivers, clinicians, researchers, and industry partners who share a common commitment to improving the lives of individuals living with Dravet syndrome. Throughout the event, you will have the opportunity to learn from leading experts, explore the latest research and therapeutic developments, and connect with others who truly understand the complexities of this journey.

Whether you are attending your first DSF conference or returning once again, our goal is for you to leave feeling informed, supported, and empowered. Beyond the educational sessions, we encourage you to take full advantage of the time dedicated to connection—these shared conversations and relationships are at the heart of our community.

DSF was founded by parents, for parents, and everything we do is guided by the lived experiences of families like yours. Your participation strengthens our mission and fuels our collective progress toward better treatments, improved care, and ultimately, a cure.

This guidebook is designed to help you prepare for the conference and gives you an overview of what to expect, so you can make the most of your experience. Please reach out to myself or another team member with any questions you have.

With warm regards,

Mary Anne Meskis

Mary Anne Meskis, CEO
Dravet Syndrome Foundation
maryanne@dravetfoundation.org
Mom to Elliot, age 26, living with Dravet syndrome



Who Should Attend?

The Dravet Syndrome Foundation (DSF) Family & Professional Conference is a unique and invaluable event dedicated to supporting families affected by Dravet syndrome. This conference brings together the entire Dravet syndrome community - including patient families, healthcare professionals, researchers, and industry partners - to connect, collaborate, and learn from one another.

You'll have the opportunity to learn from leading experts in the field, gain insights into the latest research, treatments, and care strategies, and engage in practical workshops that cater to the challenges of everyday life with Dravet syndrome.

Whether it's your first time attending or your sixth, you will leave the conference with not only enhanced knowledge but also meaningful relationships that will last a lifetime. Through shared stories, support, and a sense of community, you'll find hope, inspiration, and a renewed sense of strength on your family's medical journey.

Registration Fees

Thanks to the generous support of our conference sponsors, DSF is able to offer subsidized registration rates to help make the conference more affordable for families.

Adult (non-medical professional)	\$250
Sibling (4-17 years old)	\$75
Sibling (3 and under)	Free
Patient with Dravet syndrome	Free
Healthcare Professional	\$350
Industry Partner	\$350
Virtual Registration	\$75



Conference Registration Includes:

- Admission to all educational sessions, workshops, and activities throughout the conference
- Breakfast and lunch on Friday and Saturday
- Dinner and activities on Thursday, Friday, and Saturday
- VIP Sibling Camp
- Patient Activity Room Access

Registration Cancellation Policy

Cancellation requests must be submitted in writing to info@dravetfoundation.org. Requests received on or before June 4th are eligible for a refund, minus a \$50 administrative fee.

Cancellation requests made after June 4th are nonrefundable, except in cases of family emergencies. Cancellation requests must be submitted via email to info@dravetfoundation.org. If you cancel and are eligible for a refund, you can expect to receive it within 30 days. All refunds will be processed to the original payment method. Please note that no-shows will not be eligible for a refund.

Venue

The Renaissance Orlando at SeaWorld is our flagship hotel for this year's event and all conference sessions and activities will take place onsite at the hotel. More details on the hotel can be found on the next page.

Name Badges

Registered attendees will receive their name badge upon check-in at the registration desk. All attendees are required to wear their official conference badge at all times during conference activities. A badge is necessary for entry into all sessions, workshops, and events.

Suggested Attire

All activities are casual so dress for comfort. Keep in mind that indoor spaces in Orlando can be quite cool due to air conditioning, so it's a good idea to bring a sweater, sweatshirt, or light jacket that you can easily layer to stay comfortable throughout the event.



Venue / Flagship Hotel

Renaissance Orlando at SeaWorld

Address: 6677 Sea Harbor Dr, Orlando, FL 32821

\$209 per night, plus taxes and fees and a reduced resort rate of \$30 plus tax per day

Resort Fee includes (subject to change):

- Enhanced Wireless In-room Wi-Fi
- Daily Basic Wi-Fi In Convention & Meeting Space
- Transportation to Magic Kingdom, Hollywood Studios, Epcot, Animal Kingdom, Disney Springs and Universal Studios. **Reservations are required and must be made at the Concierge Desk at least 2 hours prior to departure**
- Two Drink Vouchers per room, per stay - Choose from a selection of spirits, wine, beer or soft drinks (**Premium Spirits & Signature Beverages Excluded**)

The Renaissance Orlando at SeaWorld is perfectly located just minutes from Orlando's most popular theme parks and attractions, and offers convenient daily shuttle service to Walt Disney World, Universal Orlando Resort, Universal EPIC Universe, SeaWorld, and the Vineland Premium Outlets. It offers a pool, water park, and fitness center.

Hotel Check-in: 4:00 PM Hotel Check-out: 11:00 AM

Daily Parking Rate: Self-park \$40; Valet \$54

The nearest airport is Orlando International Airport (MCO), approximately 13 miles from the hotel.

This hotel does not provide shuttle service. Alternate Airport Transportation: Mears Shuttle Service; fee: \$20 per person (one way); reservation required

Pets are welcome. Max of 2 pets per room, Dogs or Cats only, under 40 lbs. \$150 non-refundable pet fee per stay.

Please contact the hotel directly in advance with any special requests* (e.g., early check-in, accessible rooms, cribs, rollaway beds, etc.)

Hotel Cancellation Policy: **You must cancel 72 hours prior to arrival date.** If not, you will forfeit one (1) night's room and tax.



Conference Scholarships

DSF will provide a limited number of scholarships to individuals or families who might otherwise not be able to attend our 2026 Family & Professional Conference.

There are four types of scholarships available:

- Virtual registration: fees covered for one individual
- In-person registration only: in-person registration fees covered for one individual
- Individual Scholarship: registration for 1 adult and up to 3 nights hotel accommodations
- Family Scholarship: registration for up to 2 adults, 2 children, and up to 3 nights hotel accommodations. *Note: Hotel fire regulations only allow up to 4 people per double bed room and up to 3 people for king rooms. There are no exceptions.

You can find the link to complete a scholarship application on our event page at www.DSFConference.org. Applications must be submitted by February 13, 2026. Scholarship awardees will be notified by February 27, 2026. For questions, please contact karen@dravetfoundation.org.

Budget Planning

The budget worksheet available on our event page at www.DSFConference.org can help set a plan and savings budget for conference attendance. Download the worksheet and use it to estimate the cost of travel, accommodations, meals, and registration to help you set a budget to save.

Logo Use for Personal Fundraising

Many families seek financial support for conference expenses through local grants, funding opportunities, or by organizing private fundraisers. If you're planning a personal fundraiser, please do not use the official Dravet Syndrome Foundation (DSF) logo on your materials due to legal restrictions. However, you are welcome to include any publicly available information from the DSF website in your applications or fundraising efforts. If you have any questions, feel free to reach out to us at info@dravetfoundation.org.



Other Financial Assistance

Financial support may be available through local community networks and agencies. Many organizations provide assistance to families of children with disabilities, recognizing the value of conferences like this in promoting inclusion and building strong support systems.

To find potential funding, start by searching online, connecting with friends, neighbors, or local advocacy groups, and simply asking. Many families are surprised by the generosity and support available in their communities. To help you begin your search, we've compiled a list of U.S.-based resources that may offer funding opportunities that is available on the event webpage at www.DSFConference.org.

Keep in mind that your own community may offer additional options not included in this list. Don't hesitate to reach out - asking can open doors you didn't expect. If you come across a helpful funding source, please share it with us at info@dravetfoundation.org so that we can so they can pass it along to other families.

June is Dravet Syndrome Awareness Month

June is recognized as Dravet Syndrome Awareness Month, a time to raise awareness and support for those affected by this rare and challenging condition. Although our conference takes place this year after International Dravet Syndrome Awareness Day on June 23rd, we still encourage all attendees to show their support by wearing DSF gear during the event. You can wear your existing gear or purchase new items at the conference to help spread awareness. Your participation plays a crucial role in amplifying the voice of the Dravet syndrome community.

Social Media

During the conference, we encourage you to share your experience on social media. Whether it's a moment from a session, a conversation with others in the community, or simply a reflection of your experience, your story can make a powerful impact. Use the hashtag [#2026DSFConference](https://twitter.com/2026DSFConference).



Program at a Glance

Thursday: The conference kicks off with important industry updates, followed by a comprehensive overview of Dravet syndrome at noon. A special session will be held for first-time attendees to help them navigate the event and make the most of their experience. A dinner for all attendees will be held that evening.

Friday: Friday features a full day of programming centered on clinical care and research advancements. Topics will include the latest in diagnosis, treatment options, and ongoing clinical trials. Presentations will be led by leading clinicians and researchers in the field. Alongside the sessions, our VIP Sibling Camp and Patient Activity Room will be open.

The day concludes with a dinner reception and brief program, offering time to relax, connect, and reflect on the day's insights. Our Moms' Night Out will take place after dinner in the Atrium Bar.

Saturday: Saturday's sessions focus on the daily realities of living with Dravet syndrome, offering guidance, resources, and shared experiences. The day begins with our 4th Wings of Hope butterfly release - a moving ceremony to honor those we've lost and celebrate the hope we carry forward. In the afternoon, an interactive workshop will provide attendees with the opportunity to explore genetic therapies and important considerations surrounding them. Led by leading experts in the field and featuring insights from families with lived experience, this session will offer a well-rounded perspective on the promise, challenges, and real-world implications of emerging genetic treatments for Dravet syndrome. Alongside the sessions, our VIP Sibling Camp and Patient Activity Room will be open.

We will close the day with another dinner reception and short program, where we will proudly present the Ciara's Spirit of Hope Award, recognizing strength, resilience, and advocacy within our community. Our Dads' Night Out will take place after dinner in the Atrium Bar.

During our dinner on Saturday, we are excited to offer Camp Small Steps, sponsored by UCB. Camp Small Steps is a supervised, inclusive program that provides a safe, engaging, and accessible environment with camp-style and sensory-friendly activities designed for shared family participation.



Schedule at a Glance

THURS, JUNE 25th	
12:00pm-1:00pm	Registration
1:00pm-1:10pm	Welcome
12:00pm-1:00pm	Lunch
1:10pm-4:00pm	Industry Updates
4:00pm-5:00pm	Tips for Attendees & Dravet Syndrome Overview
6:00pm-8:00pm	Dinner
FRI, JUNE 26th	
8:00am-9:00am	Registration & Breakfast
9:00am-12:00pm	Sessions (<i>Sib Camp & Patient Activity Room run concurrently</i>)
12:00pm-1:00pm	Lunch
1:00pm-5:00pm	Sessions (<i>Sib Camp & Patient Activity Room run concurrently</i>)
6:00pm-9:00pm	Dinner & Socializing
8:30pm-10:30pm	Moms' Night Out
SAT, JUNE 27th	
8:00am-9:00am	Wings of Hope & Breakfast
9:00am-12:00pm	Sessions (<i>Sib Camp & Patient Activity Room run concurrently</i>)
12:00pm-1:00pm	Lunch
1:00pm-5:00pm	Workshop (<i>Sib Camp & Patient Activity Room run concurrently</i>)
6:00pm-9:00pm	Dinner & Socializing
8:30pm-10:30pm	Dads' Night Out



Caregiving Choices

If you're bringing a caregiver or sharing caregiving duties with a partner, you can take advantage of our patient activity room which will offer a variety of engaging activities on both Friday and Saturday, specifically tailored to the unique needs of our patients. Please note that patients must be accompanied by a parent or designated caregiver to participate, ensuring that everyone receives the attention and care they need while enjoying the activities.

We recognize that some families may need flexible ways to participate in sessions while caring for their loved ones. We have two options to help you stay engaged:

- **Attend Sessions Together:** If your child or adult is able to remain quiet, they are welcome to accompany you into sessions. We kindly ask that you help maintain a quiet environment so all attendees can fully engage with the presentation.
- **View from Your Hotel Room:** Sessions will be livestreamed, allowing you to participate from the comfort of your hotel room while attending to caregiving needs.

Something for the Entire Family

The DSF Family and Professional Conference offers two and a half days of educational sessions, workshops, and family-friendly social activities for attendees of all ages. On Friday and Saturday, participants can attend a wide range of sessions focused on cutting-edge scientific research, medical care guidelines, and caregiving updates. Families may choose to arrive a day or two early, or stay after the conference, to enjoy all that Orlando has to offer.

VIP Sibling Camp: Our Sibling Camp is packed with exciting activities both on and off-site, designed to create meaningful connections and provide support for siblings of individuals with Dravet syndrome. Through interactive sessions and adventures, siblings will have the opportunity to bond, share experiences, and develop a deeper understanding of their unique roles within the family. Whether it's making new friends, engaging in fun activities, or simply enjoying time together, the camp provides a space where siblings can feel supported, understood, and celebrated.



Patient Activity Room: Our Patient Activity Room, hosted by *Ciara's Light Foundation*, will offer a variety of engaging activities on both Friday and Saturday, specifically tailored to the unique needs of our patients. These sessions are designed to provide a supportive and fun environment for individuals affected by Dravet syndrome. Please note that patients must be accompanied by a parent or designated caregiver to participate, ensuring that everyone receives the attention and care they need while enjoying the activities.

Moms' and Dads' Nights Out: After the scheduled dinner and evening events, we invite you to unwind at our informal Night Out gatherings - Friday night for moms and Saturday night for dads. These meetups will take place in the Atrium Bar area of the hotel and offer a relaxed space to connect with other parents and caregivers. It's a great opportunity to continue conversations from the day's sessions, share personal experiences, and build meaningful connections with others who truly understand the journey. Please note that each attendee is responsible for their own drinks and any additional purchases.

Wings of Hope: At every conference, we hold our Wings of Hope butterfly release to honor the memory of those we've lost and celebrate the strength of those living with Dravet syndrome. This heartfelt ceremony serves as a symbol of resilience, love, and the enduring spirit of our community. Each butterfly released represents not only a life remembered but also the ongoing journey of those continuing to fight each day. It's a poignant moment of reflection, hope, and unity that brings us all closer together in our shared mission.

Family Network Ambassadors (FNAs): First-time conference attendees (or anyone who feels that they need additional support) can ask to be matched with one of our FNAs for mentoring and support. FNAs are able to provide support and friendship, answer questions, and help new families feel at home. Families interested in signing up for this program should email austin@dravetfoundation.org

DSF Store: Stock up on your swag! A dedicated on-site store will be open during the event, offering a variety of DSF merchandise, including t-shirts, accessories, and other exclusive items. Whether you're looking to show your DSF pride or bring home a keepsake, be sure to stop by and check out the full selection. Quantities may be limited, so shop early for the best picks!



Nearest Medical Facilities

Nemours Children's Hospital
6535 Nemours Parkway, Orlando, FL 32827
15.6 miles from flagship hotel

Orlando Health Arnold Palmer Hospital for Children
92 W Miller St, Orlando, FL 32806
12.7 miles from flagship hotel

Nearest Pharmacy

Walgreens
12650 International Drive S, Orlando, FL 32821
3.4 miles from flagship hotel

Nearest Grocery Store

Walmart Supercenter, 8990 Turkey Lake Rd
Orlando, FL 32819
3.1 miles from flagship hotel

Illness Guidance

Although we will not be in peak cold and flu season, respiratory viruses continue to circulate. We ask all attendees to help protect the most vulnerable members of our patient community.

If you have a fever or symptoms of a respiratory illness (such as congestion, cough, or sore throat), please refrain from attending conference events. If you are recovering from a recent illness and still experiencing mild symptoms, we kindly request that you wear a mask during sessions. We also encourage everyone to practice good hand hygiene and ensure vaccinations are up to date.

If you have any questions or concerns, please don't hesitate to contact the conference team. Thank you for helping us create a safe and healthy environment for our community.



Contacts

The DSF staff is here to help ensure you have a positive experience. If you have any questions or need support, please reach out to us at any time.

For Event Sponsorship Questions

Mary Anne Meskis, CEO

maryanne@dravetfoundation.org

For Exhibitor Questions

Cheyenne Wolf, Development Coordinator

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For Registration and General Questions

Sarah Pasternak

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For Conference Scholarship Questions

Karen Masters-Foster, Family & Community Engagement Director

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For VIP Sibling Camp Questions

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For Patient Activity Room Questions

Austin Watson, Family Network Coordinator

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