



# CHANNELING IN

The Newsletter of the IDEA League

International Dravet syndrome Epilepsy Action League • P.O. Box 797 Deale, Maryland 20751 USA • 443-607-8267 • www.IDEA-League.org

## Report from the American Epilepsy Society Conference

By Karen Glenn

The American Epilepsy Society (AES) 2010 meeting was held Dec 3-7 at the Gonzales Convention Center in San Antonio, Texas, USA. The annual symposium is an international forum for the exchange of current findings in epilepsy research and is attended by hundreds of physicians, medical practitioners and scientists from around the world,

The IDEA League exhibited at the conference for the fifth consecutive year. Representing the League were Angela Black, MD, Chair of the Medical Advisory Board; Chuck and Lauren Sparks; and Leslie Moccia. IDEA League Founder Joan Skluzacek also participated, attending the AES-sponsored Vision 2020 meeting. See related article on page 4.

The conference boasted several poster presentations on subjects relevant to Dravet syndrome, including results from the "Face & Hands of Dravet" study by Drs Peter and Carol Camfield, Dr. Kathleen Nolan, and Dr. Kay, from Nova Scotia, Canada. A number of IDEA League families participated in the study, which did not find identifiable features in children diagnosed with Dravet syndrome. You can view this



*Leslie Moccia, Dr. Angela Black, and Lauren and Chuck Sparks.*

study and other research of interest at [www.idea-league.org/research-pub](http://www.idea-league.org/research-pub).

Other posters of interest included two from the lab of Dr. Bill Catterall: 1.032, discussing sleep impairment in SCN1A mice; and 3.026, looking at the effectiveness of dual-drug therapy with tiagabine and clonazepam in Dravet mice. Poster 3.019 from Japan looked at seizure-related deaths in SCN1A mice. 2.001 from Dr. Alicia Goldman discussed "High Resolution Copy Number Variation of Ion Channel Genes in Epilepsy"; and 2.169 from Birmingham, UK reviewed that center's experience with stiripentol.

While at the conference, Dr. Black met with members of the IDEA League's Collaborative Clinic Research and Comprehensive Care Network (CCR-CCN) regarding plans for an upcoming study involving the use of pulse-oximeters for patients with Dravet syndrome.

Said Dr Black, "The conference was an excellent opportunity to learn the latest in research, connect with medical professionals and others with whom we can collaborate, and get the word out regarding our 2011 research grant."

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Happy New Year!

As 2011 begins, my heartfelt best wishes go out to all of the thousands of patients, parents and family members affected by Dravet syndrome and related conditions who are facing this coming New Year with hopes and fears.

Parents whose children have Dravet

syndrome always have a different set of resolutions than those families who don't have kids with special needs. Our parents resolve to celebrate the tiniest of victories, such as a couple of hours of uninterrupted sleep, a single day without seizures, or a hug from our child. Most continue our resolution of ignoring the imperfections of the day and instead look for smiles amidst all the mess! And of course, the one New Year's resolution that we never break—to continue to fight for our child's care. This is the resolution that the IDEA League was founded on...helping parents to help their child.

Last year, I promised you that the IDEA League planned to offer more services to help parents care for their child. And because of your generous support during 2010, we now have the funds to start creating these programs. Thank you! We have already begun working on many new resources and support which are slated to be launched in late spring.

Watch for them!

And finally, to end on a personal note, I am grateful to serve another year as President of the IDEA League. This role has expanded my devotion to my daughter, Michaela, into a devotion to all children struggling with Dravet syndrome and related disorders. My objectives have always been to do what is best for the foundation, what furthers our cause, and what can help our families. I urge you to add a similar dedication to your list of resolutions this year.

Together we can make a difference. Together we can find a cure.

## 2010 Research Award Renewed

By Karen Glenn

In April 2010, the IDEA League awarded the first half of a \$30,000 research award to Dr. Jing-Qiong (Katty) Kang of Vanderbilt University Medical Center in Nashville, Tennessee, USA, in support of her efforts to further the understanding of GABRG2 mutations associated with epilepsy and Dravet syndrome.

Dr. Kang's research to date was recently up for review by the IDEA League's Scientific Review Committee, which determined that she and her team had made excellent progress in their work. We are pleased to announce that the review committee has approved the continuation of funding for this important project. It is hoped that Dr. Kang's work will lead to novel approaches in the treatment of Dravet syndrome.

Dr. Kang offered these thoughts on her work: "I am extremely grateful to the IDEA League for supporting my research. The IDEA League's funding has provided me with the resources to carry out my current proposal. This proposal seeks to

understand the molecular underpinnings of the epilepsy and Dravet syndromes associated with mutations in a critical GABA receptor and of the phenotypic differences among these patients. It is my hope that completion of this project will bring a cure for Dravet syndrome a step closer. Funding medical research in Dravet syndrome is crucial if we are to find a cure in our lifetime. We are very encouraged by the progress we have made thus far and hope to help provide vital knowledge for designing new therapies for Dravet syndrome in the near future. The integration of concerned parents and scientists fostered by the IDEA League has helped researchers such as myself to better understand the disease and those families who are affected by it, and has further helped to keep concerned parents in touch with researchers like myself who are working together toward a cure."

The IDEA League thanks Dr. Kang and her team for their significant efforts with this cause, which is critical to so many



*Dr. Katty Kang*

children and families, and wishes them continued success in the coming year.

The IDEA League has accepted applications for a second two-year research grant to be awarded shortly. For further details, please see the announcement on page 8 of this publication.



*"I have had dreams and I have had nightmares, but I have conquered my nightmares because of my dreams."*

—Jonas Salk, developer of the polio vaccine

Sometimes it feels as if we are living a nightmare. Watching our loved ones struggle to function despite jerking and twitching muscles and convulsions; riding with them in an ambulance with the lights blazing and the siren blaring; seeing the effects of seizures and strong medicines on their ability to think, speak, move, eat and sleep; struggling to process the words of the doctors, nurses and therapist and make difficult

decisions—it can seem that surreal.

Over time, it becomes clear to parents that life with their child is not likely to be as they imagined in the beginning. School activities, sports, friendships, graduation, work life and family life will all be different than we first envisioned. But the future still holds many possibilities and the choices we make will influence the direction of our lives and our children's lives.

Like Dr. Salk, we must not let the nightmare discourage us from dreaming. Instead, together with our loved one, we must dream to conquer the nightmare. Though few thought that the son of working class Jewish immigrants from Russia was a likely candidate to eradicate polio, Jonas Salk found moral and financial support for his research from his mentor, Dr. Thomas Francis, and from Basil O'Connor, Co-founder of what is now known as the March of Dimes. In 1955, when Dr. Salk's polio vaccine was declared a success, he was hailed as a miracle worker. Dr. Salk made no bones about the fact that the key word in that phrase was "worker."

With encouragement and support from

others and lots of hard work, some of our dreams for Nick, our family, and for others with Dravet syndrome are coming true. Nick is receiving a high-quality education that fits his needs and will walk in commencement this June. He will continue to go to school until he is 21 years old, focusing on basic vocational skills that may permit him to have a job in a sheltered workshop some day. With the help of professional staff, he will live family-style with housemates. Nick and his "family" will go out into the community to do service projects and for recreation. Our family, once isolated in terms of the experience of Dravet syndrome, is now connected with others who share our experience and has opportunities to contribute toward achieving the ultimate dream, a cure for Dravet syndrome.

And just last November a very important dream came true—our Nick began to say words again for the first time in 11 years.

DREAM ON!

## Benvenuti, Dravet Italia Onlus

By Angie Mimms

Families in Italy facing the challenges of Dravet syndrome now have a new resource: Dravet Italia Onlus.

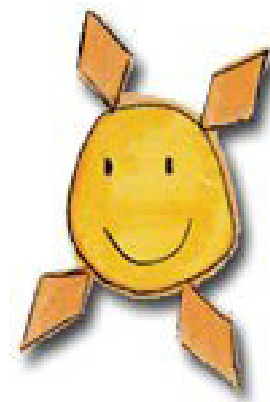
With the introduction of this new group, the IDEA League has grown to include four international affiliates to address the different policies, procedures and practices in the countries of Italy, the Netherlands, France and the UK. Each affiliate is an independent organization working to serve the needs of local families within the framework of their own country and culture.

Isabella Brambilla Kerschhackl, whose 6-year-old son, Stefano, has Dravet syndrome, started the affiliate with doctors Bernardo Dalla Bernardina and

Renzo Guerrini, both members of the IDEA League Medical Advisory Board. The doctors also organized an international Dravet syndrome workshop in Verona, Italy, in 2009 with Dr. Charlotte Dravet.

"We all together have felt the necessity to lead all the families concerned by the same problem to join together in order to help each other face this illness and share feelings and doubts," said Isabella, affiliate president.

The group's purpose is to collect funds to support Dravet syndrome research through activities such as golf tournaments, music events and charity dinners. Because the group is still young, it does not yet have a meeting schedule.



Logo for Dravet Italia Onlus

But the group is getting the word out with a Facebook page named Dravet Italia Onlus and a website, [www.dravet-italia.org](http://www.dravet-italia.org). The group can also be reached by e-mail address at [info@dravet-italia.org](mailto:info@dravet-italia.org).

# IDEA League Helps Sponsor Landmark Study

By Joan Skluzacek

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The IDEA League is the voice for Dravet syndrome in a groundbreaking project aiming a spotlight on the broad spectrum of the epilepsies. Since December 2009, the IDEA League has participated in a coalition of scientific and advocacy organizations focused on epilepsy known as 'Vision 2020.' Vision 2020 has recently partnered with the U.S. Department of Health and Human Services (HHS) and the National Institutes of Health (NIH) to commission a landmark study by the U.S. National Institute of Medicine (IOM) on the public health dimensions of the epilepsies. In a recent press release, Dr. Howard Koh, U.S. Assistant Secretary for Health, stated that this study "will recommend national priorities and strategies for improving the lives of those with epilepsy with respect to dimensions of health care, human services, health literacy, public awareness and public health."

Vision 2020 is a consortium of organizations concerned with finding cures for the epilepsies and improving the lives of people with epilepsy and their families. Activities of interest to the Vision 2020 group include: 1) coordinating efforts to support the efficient and effective use of resources for research; 2) developing a common message and supporting data that can be used in a collaborative way to market the cause of the epilepsies, thus raising awareness, educating the public, and increasing resources for this purpose; 3) evaluating the impact of health care reform on epilepsy care; and 4) developing epilepsy rare disease networks. One completed initiative has been the creation of a Resources in Epilepsy Research website. The group is also interested in exploring ways to encourage participation in clinical research. Toward these ends, Vision 2020 joined forces with the HHS and the NIH and raised a collective contribution of \$248,000 in NGO (non-government organization) support for the IOM report. Sponsoring members of Vision 2020 include American Epilepsy Society (AES), International League Against Epilepsy (ILAE), Citizens

United for Research in Epilepsy (CURE), Columbia University Epidemiologists, Epilepsy.com, Epilepsy Foundation (EF), Epilepsy Therapy Project (EPT), Finding a Cure Against Epilepsy and Seizures (faces), Hemispherectomy Foundation, Milken Family Foundation, National Association of Epilepsy Centers (NAEC), Parents Against Childhood Epilepsy (PACE), Rasmussen's Encephalitis (RE) Children's Project, Tuberous Sclerosis Alliance, and the IDEA League.

Vision 2020's government partners, HHS and NIH, are each represented by a number of sponsoring agencies concerned with the epilepsies.

On January 10, 2010, the IOM convened a panel of 17 experts in epilepsy, epidemiology, public health, health education, professional medical education and more, who will serve as the study committee and produce a report on the results in about 18 months. The panel was presented with the committee charge, heard testimony from the study sponsors regarding priorities for their investigation, and heard presentations from a number of experts that provided an overview of background and context for the study. The statement of task developed by the study sponsors together with the IOM study directors acknowledges the following: 1) there are more than 40 types of epilepsy—referred to collectively as the epilepsies - that cause recurrent seizures and can be responsible for brain damage; neurological, cognitive, or psychiatric impairment; and death; 2) advances in research are improving our understanding of the scope of epilepsy and its public health impact; and 3) current approaches do not fully take into account either the broad range of epilepsy disorders and their comorbidities, or their consequences for health and quality of life. This study will consider the public health dimensions of the epilepsies—including health care and human services and patient, public, and professional education. The IOM panel will recommend policy priorities that will improve our understanding

of the public health impact of the epilepsies and how to meet the needs of people with epilepsy and their caregivers. Specifically, the IOM will focus on the following questions: 1) How can the public health burden of epilepsy for patients and families be more accurately assessed? 2) What priorities for future population health studies could inform treatment and prevention? 3) How can the access to health and human services and the quality of care for people with epilepsy be improved? 4) How can the education and training of professionals who work with people with epilepsy be improved? And 5) How can the understanding of epilepsy in patients and the general public be improved to create supportive communities? The Vision 2020 sponsors created five working groups that collaborated to develop testimony which was presented to the study panel. The IDEA League participated in four of the five working groups, which addressed needs and priorities for the study in the following areas: co-morbidities, the pediatric population, patient advocacy and therapies. Joan Skluzacek represented the IDEA League at the January 10 meeting.

Details of the study—including the members of the IOM committee, the full statement of task, written versions of the testimony presented to the panel, and the expert presentations given to the panel are available for public review online at [www.IOM.edu/epilepsy](http://www.IOM.edu/epilepsy). Future meetings that will include the study sponsors are planned for March and July. The meeting in March will focus on the assessment of the prevalence, incidence and etiology of the epilepsies and examine approaches for collection and integration of data that will provide a better understanding of the public health burden of the epilepsies, which may lead to the development of interventions or preventive strategies. The Vision 2020 sponsor working groups are hard at work preparing relevant testimony.

# Families Find Reprieve at Kentucky Camp

By Jennifer May

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*The beautiful lake at the Camp for Courageous Kids.*

What better way to spend Halloween weekend than hanging out and having fun with other 'Dravet families'? Nineteen families who have children with Dravet syndrome joined nine families with children with epilepsy at the Center for Courageous Kids, a medical camping facility that provides free and memorable camping experiences for children with life-threatening diseases and disabilities.

The Center is located in the rolling hills of Scottsville, Kentucky and, being founded only recently in 2004, is still very shiny and new. Each family is provided private heated/air-conditioned living quarters with a large private bathroom. There are also laundry facilities readily available and living room areas for families to relax and visit. Campers are served plentiful food at family-style meals. It

has been described as more like staying at a Holiday Inn than camping.

At the Center for Courageous Kids, a large group of experienced counselors is always eager to entertain and ensure the safety of all campers, whether they are children with special needs or their siblings. Activities are endless and meet every interest; they include indoor swimming, horseback riding, canoeing, paddle boats, fishing, archery, hayrides, basketball, bowling, rock wall climbing, woodworking, arts and crafts, face painting, and cooking classes. A couple of favorites are the hands-on music room full of instruments and the beauty shop where counselors are the camper's "victims". Families can bond through organized games, camp songs and bon fires. Kids can be found singing and dancing with counselors, giggling all the while.

What makes the Center unique is the level of unconditional love and acceptance felt by the families who so desperately need a place to go for recreation where seizures and difficult behavior become "normal". One mom said that "As Dravet moms, we seldom get to see all of our kids having fun at the same time and in the same place." Families can spend time together, siblings can bond with other siblings,

and respite care is cheerfully provided so parents can take a break to get to know and enjoy one another. On-site medical facilities and staff, as well as heliport



*Horseback riding and trick-or-treating were just two of the activities available during the weekend of camp.*

access to Nashville Children's Hospital, ease families' concerns for the health and safety of their medically fragile children. What an amazing opportunity!

Family camping will be available again this year. Although there is no fee for families to attend, priority is given to families who raise funds for donation. The IDEA League will be working to raise funds this year to support the center and all it offers. To learn how you can help, see the note below.

You can learn more about The Center for Courageous Kids by visiting [www.courageouskids.org](http://www.courageouskids.org) or contacting Dina Nelson at [hopeforsydney@hotmail.com](mailto:hopeforsydney@hotmail.com).

**Let's Go to Camp!** Every child should be able to experience the joys of summer camp.

Center for Courageous Kids (CCK) is a unique medical camping facility in Scottsville, Kentucky, USA, specifically designed to meet the special needs of children battling serious illness. For the past three years, the camp has provided a fun-filled weekend at their beautiful camp FREE of charge to our families with Dravet syndrome.

It's time to give back to this wonderful organization! Please help us raise \$5000 to SEND OUR KIDS AND THEIR FAMILIES TO CAMP, where they can build magical memories that will last a lifetime! If you would like to help with the cause, sponsor a camper, or make a tax-deductible (US) donation, please contact Marilyn Baker, Executive Director, at [Baker@IDEA-League.org](mailto:Baker@IDEA-League.org)

Camp Dates for this year are Oct. 28-30. Applications are now being accepted



## In the Spotlight

By Paula Lyles

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*Charlotte Kuhnle, age 13*

Greetings from Karlsruhe, Germany and the Kuhnle Family: mother Elisabeth, wonderful big brother Samuel, and 13-year-old Charlotte!

Charlotte's first seizure occurred at the age of six months during her sleep. A few days later, she had a similar event in the hospital. She was diagnosed with Intractable Grand Mal Epilepsy of Early Infancy. Elisabeth found her tiny daughter now subjected to so much "mainstream medicine" and found herself having to make choices to use what she terms "harsh drugs" to save Charlotte's life.

The first six years of Charlotte's life were accompanied by constant weaning her on and off different anti-epileptic drugs (AEDs). Even a trial of the ketogenic diet was a short-lived success, as were most of the medications.

Because Charlotte's epilepsy was diagnosed as "therapy-refractory" at an early age and after many drug failures,

Elisabeth felt it was quite logical to wean Charlotte off all her daily AEDs. During the more than four-year period without medications, Charlotte's seizures were no better but no worse than those with AEDs. Elisabeth has also pursued some alternative healing methods with various levels of success with Charlotte.

At age 10 and the beginning of puberty, Charlotte's seizure frequency increased, and AEDs were restarted. Through internet research, Elisabeth discovered Dravet syndrome, and Charlotte's genetic testing revealed a missense mutation of the SCN1A gene.

Elisabeth found the IDEA League next, and learned more on the family forum and a specialized German forum than she had in all previous years. Elisabeth writes, "The practical knowledge of the parents and that being standard outside the German speech area were just overwhelming."

Charlotte is currently on a low dose of stiripentol and preemptive use of benzodiazepines in low doses to treat her mostly nocturnal seizures.

As a single, stay-at-home mother of two, Elisabeth describes their family as an "avant garde, unschooling family." Home schooling is not legal in Germany.

The beauty of unschooling allows Charlotte to take part in normal daily life. Charlotte loves to shop and cook with her mom. She also enjoys short trips to visit her friends and grandparents.

Charlotte is a verbal, conversational girl, and is still making progress with her speech. She is mostly a happy child, mobile and strong minded, but also quiet and reasonable.

Through her journey, Elisabeth says she has learned to be "more grateful and, perhaps, more aware. I wouldn't choose this life by choice, but I am living it as a matter of course."

Elisabeth is excited to be presenting Charlotte's case at the first Dravet Syndrome Family Conference in Germany this coming June! Dr. Dravet will attend and speak as well. "It is my pleasure", says Elisabeth, "to represent German families among the big family of the IDEA League!"

## Purple Day Is Coming!

Get ready to don your purple and spread awareness for epilepsy on March 26.

Nine-year-old Cassidy Megan of Nova Scotia, Canada, created Purple Day in 2008, motivated by her own struggles with epilepsy. Cassidy's goal is to get people talking about epilepsy in an effort to dispel myths and inform those with seizures that they are not alone. The Epilepsy Association of Nova Scotia came on board in 2008 to help develop Cassidy's idea. Purple Day is now celebrated around the world.

Congratulations to Ryan Smith, son of Kimberly Skriba, on being chosen as one of the 'faces of purple day' for 2011! Ryan's is pictured on the Purple Day website and in other materials promoting the event.

### Take Heart, Take Part in Cookies for a Cure!

This Valentine's Day, families will be rolling up their sleeves, rolling out cookie dough, and 'taking a bite out of Dravet syndrome' as part of the IDEA League's first annual Cookies for a Cure bake sale fundraiser. All proceeds from this event will go to support the mission of the League, providing support to patients and families while funding research that will lead to better treatments and a cure. The event is the brainchild of IDEA League member and supporter Paula Lyles.



*Taking a bite out of Dravet syndrome!*

Many thanks to the families participating in this year's bake sale. Watch for your chance to join the fun in 2012!

### Team Dravet and the National Walk for Epilepsy

Once again Team Dravet will be gathering in Washington, DC for the Epilepsy Foundation's National Walk for Epilepsy. The dates for the event are March 26-27. Come join the team that has been the largest single group at the walk and raise awareness and funds for Dravet syndrome. A block of rooms has been set aside at the lovely L'Enfant Plaza Hotel, located near the Mall (close to the walk and most DC attractions) for the great rate of \$119 per night.

Participants are invited to a special PURPLE DAY meet and greet reception hosted by the IDEA League and LGS Foundation at the L'Enfant Plaza Hotel. There will be a food buffet starting at 6 pm. Dr. Philip Pearl of Children's National Medical Center and Dr. Jack Pellock of VCU Medical Center will speak. Don't forget to wear your purple!

For more information, please contact Lisa Smith at [Lisa.s@IDEA-League.org](mailto:Lisa.s@IDEA-League.org)

### Australian and German Family Conferences

A Dravet Family Conference is scheduled for Saturday and Sunday March 19-20 in Melbourne, Australia. Presentations will run Saturday from 10 am until 4 pm in the Ella Latham Theatre at York Children's Hospital. Sunday will be an informal day for families, with venue and activities still to be determined. For further information, you may contact Jean Ewing at [jewing@epilepsy.asn.au](mailto:jewing@epilepsy.asn.au).

German Families will hold their first ever Family Conference June 24-26 in Tübingen in Southern Germany, not far from Stuttgart. Dr. Dravet will be in attendance. For information, visit the German-speaking forum on the IDEA League website, [www.IDEA-League.org](http://www.IDEA-League.org).

### 2011 Dravet Mom's Retreat

Mother's of Children with Dravet syndrome can always use a little break, and here's your chance to get one! The 6th Annual Dravet Mom's Weekend will be held May 12-15 at the Omni Severin Hotel in Indianapolis, Indiana. Join other 'Dravet Moms' for food, fun and frolic—as little or as much as you like! For more information and details on registering, email Dina Nelson at [HopeForSydney@hotmail.com](mailto:HopeForSydney@hotmail.com). Thanks to Dina for once again arranging this event!

## In Loving Memory

By Karen Glenn

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*Katie Elizabeth Hunter  
May 20, 1991–Oct 18, 2010*

### **Katie Hunter**

Katie Elizabeth Hunter was born May 20, 1991. In her nineteen years of life, Katie grew to enjoy many activities including: singing, dancing, participating in karaoke, horseback riding, playing cards (especially rummy!), playing paintball, baking brownies and cookies, and watching movies.

Katie graduated in 2010 from Emmaus High School, where she was a member of the school chorus and participated in Special Olympics. Her favorite foods were pancakes, macaroni and cheese, and popcorn. She loved to go anywhere with her family, but her favorite spot to visit was her uncle Jimmy's beach house in Virginia.

Katie's father shares that she had "beautiful brown eyes, a smile that melted hearts and an infectious laughter. She was so incredibly brave and kind to everyone. Katie was both innocent and

wise. While she had difficulty learning, she was a great teacher. We all learned so much more from her than she ever learned from us."

Katie was being evaluated to determine if she was a candidate for a corpus callosotomy—a type of surgery that separates the two hemispheres of the brain—the week prior to her death. It was hoped that this procedure would improve her quality of life.

Katie passed away due to SUDEP (sudden unexplained death in epilepsy) on October, 18, 2010. She is survived by her parents, Robert and Angela Hunter of Emmaus, PA; mother, Lisa Hunter of Lehigh, PA; brothers Scott, Jesse and Jordan; grandmother, Maryanne Balogach; and many loving aunts, uncles and cousins. Katie's family loves her very much and misses her terribly.

### **Erica Crump**

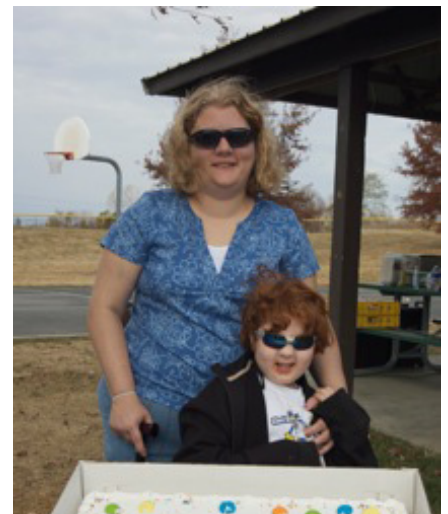
Erica Crump of Walton, Kentucky, was born Sep 26, 1979 to Dale and Linda Crump. Despite the severity of her epilepsy, she accomplished a great deal, attending Northern Kentucky University and later transferring to Gateway Community College, where she earned a degree as a pharmacy technician. She loved music and played the piano. She was a member of the women's Republican Party and was active in Banklick Baptist Church.

Erica was blessed with a daughter, who, like herself, began having seizures in

infancy. It was not until DNA testing for both Grace, and then herself, that Erica received an accurate diagnosis for the condition that had so impacted her life.

Erica's passion then became educating the community about Dravet syndrome. She organized two 'Walking for a Cure' events in her area, which included media coverage. She met with legislators and anyone who would listen.

Erica passed away following a seizure on Dec 28, 2010. She is survived by her parents; brother, Dr. Brian Crump; and six-year-old daughter, Grace. Erica will always be remembered as a compassionate and loving mother. Her smile and kind heart will be greatly missed.



*Erica Crump  
Sep 26, 1979–Dec 28, 2010*

## Derek Rudawsky Research Award

The application period for the Derek Rudawsky Research Award has recently closed. The IDEA League's Scientific Review Committee will now review the applications and the award-winner will be announced on March 1. This two-year, \$30,000 grant will fund research specific to the understanding and treatment of Dravet syndrome and related conditions. It is the second of its kind to be awarded by the IDEA League and has been made possible thanks to the loving efforts of the Rudawsky and Widoff families and their supporters.

For information on establishing a named research grant, contact Marilyn Baker at [Baker@IDEA-League.org](mailto:Baker@IDEA-League.org)

## FEBRUARY

1 Derek Rudawsky Research Award Applications due  
18 Grand Rounds at Children's Hospital of Michigan Detroit, MI, USA

## MARCH

1 Derek Rudawsky Research Award Recipient Announced  
19-20 Dravet Family Conference Melbourne, Australia  
26 International Purple Day/Team Dravet celebration Worldwide/Washington, DC USA  
27 National Walk for Epilepsy, Team Dravet participating Washington, DC USA

## APRIL

1 Derek Rudawsky Research Award Granted

May

12-15 6th Annual Dravet Mom's Weekend Retreat Indianapolis, IN USA

October

28-30 Dravet Family Camping Weekend at CCK Scottsville, KY USA

The International Dravet syndrome Epilepsy Action (IDEA) League is the world's leading patient advocate support organization for Dravet syndrome and related conditions.

We are working hard to reduce the impact of this disease on patients and their families by providing—

- Advocacy & Awareness
- Education & Up-to-date Information
- Patient & Family Support
- Critical Data & Funding for Medical Research

Join the League. Improve the Outcome.

3 EASY WAYS YOU CAN  
MAKE A DIFFERENCE!

1

**REGISTER** to become a member. Broaden our pool of medical data and connect with other families.

2

**VOLUNTEER** your time and talents to increase awareness, advocate for change or encourage others.

3

**DONATE** funds or gifts in kind to help us further our mission and find a cure for children and families.

