



Channeling In

The Newsletter of the IDEA League

Welkom! Dravet Groep Nederland

By Angie Mimms

The IDEA League welcomes its newest affiliate: Dravet Groep Nederland. Established in June, the Dutch organization joins affiliates in the UK and France to help the League better serve its international population.

“Because every country is so very different, with different policies, procedures and practices in place, the best way to ensure optimum care and understanding for our children is for each country to have an affiliate or chapter,” said Marie Baker, IDEA League VP and International Development Team Leader.

Myra de Groot-Schokker worked to organize the new affiliate and is excited about its potential to reach Dravet families in her country.

“This syndrome is so rare that we have to work together internationally and share our knowledge and experiences,” said Myra, who is the Dutch group’s official contact. “We’ve just started this group, and we are already full of ideas and plans. But we have to be realistic and take things step-by-step.”

Dravet Groep Nederland is also part of EpilepsiePlus, a support group within the Dutch Epilepsy Association, dedicated to children with drug-resistant epilepsy. Myra began discussing with Maaïke Ballieux from the staff the challenges she faces caring for her 8-year-old son, Harm, who has Dravet syndrome. That’s how they came to the idea of creating a special group. Harm’s neurologist, Dr. Boudewijn Gunning, suggested working with the IDEA League, and from that collaboration Dravet Groep Nederland was born.

The group’s first priority is to provide information and emotional support to the country’s Dravet families. It also aims to educate health care professionals about Dravet syndrome and its impact. A brochure to help accomplish these goals was almost finished at press time, and an Oct. 9 family gathering is in the works.

In addition, the Dravet Groep Nederland will target extended family, friends, neighbors, teachers and others with efforts to create greater

awareness and understanding. “Their support and help is so valuable,” Myra said.

According to Myra, there are about 100 known cases of Dravet syndrome in the country. Many of these families have joined EpilepsiePlus. The new IDEA League group will reach out to these families and find others by distributing its brochure to the country’s epilepsy centers and academic hospitals. It will refer families to the websites and forums of the IDEA League and EpilepsiePlus for practical information and support. And it will continue to develop accurate, up-to-date written information with the help of medical professionals.

For more information about the Dravet Groep Nederland, please send an e-mail to EpilepsiePlus@Epilepsievereniging.nl. If you would like to know more about establishing an international affiliate, please contact Marie Baker at marie.b@IDEA-League.org. To read more about Myra and her family, see the related article on page 4.

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IDEA League Wins 20K Grant from Chase!

By Karen Glenn

The IDEA League recently won a \$20,000 grant in a hotly contested online competition held on Facebook, a popular social networking site. Sponsored by JPMorgan Chase & Co, the 2010 Chase Community Giving Challenge was a huge corporate philanthropic crowdsourcing campaign, bringing together more than 2.5 million

participants to cast votes for their favorite small and local charities.

Launched on June 9, the Giving Challenge was the second annual for Chase, giving away \$5 million to 200 worthy causes. More than 500,000 small and local charities entered the competition, with those

receiving the most votes winning grants of \$20,000 to \$250,000. The IDEA League is thrilled and honored to have placed among the top 200 organizations entered.

To be eligible for the program, charities were required to be a registered 501(c)3 public non-profit (continued on page 6) with an annual



Our IDEAL is a Cure



*Become an advocate.
In doing so, you will
help your child and
many others around
the globe.*

President's Message

By Laura Cossolotto

Occasionally, a simple action such as clicking "like" on a social networking site can truly make a difference. Thanks to many of you, on June 13th Chase Bank announced that out of over 500,000 eligible organizations, the IDEA League will be awarded \$20,000 in the Chase Community Giving program. The winners were chosen by Facebook, LinkedIn, and Twitter users, with the 200 charities receiving the most votes winning.

Opportunities like the Chase Community Giving Challenge are few and far between. In most cases, support through social networking sites is not true advocacy, but just the first step. It is raising your hand to say you support a cause, but not yet taking the

action necessary to further the cause. True advocacy requires tangible action.

Advocacy comes in many different forms and includes many different activities, each representing a way in which change is brought into society. Advocacy is an action aimed at a beneficial outcome for your cause. It is a letter written to your legislator. It is volunteering with an organization, educating a physician, participating in research or offering support to a family who has just received a diagnosis. Advocacy is about what you do to help your child, what you do to help a larger community, and what you do to make decision-makers pay attention to our shared cause.

Every parent of a child with Dravet syndrome knows that

one of the hardest things to deal with is the realization that we cannot immediately remedy this terrible situation for our children. This leaves many of us feeling helpless. One of the ways you can turn feelings of helplessness to empowerment is by volunteering and supporting the IDEA League, the globally recognized Dravet syndrome patient advocacy organization. In doing so, you make a difference.

This fall we will be introducing new programs and projects aimed at further improving the outcomes for patients with Dravet syndrome. Please join us. Become an advocate. In doing so, you will help your child and many others around the globe.



CCR-CCN Update

By Karen Glenn and Cathy Holt

The IDEA League is pleased to announce the addition of Dr. James Wheless and LeBonheur Children's Hospital in Memphis, Tennessee, USA, to the list of doctors and clinics participating in the our Collaborative Clinical Research and Comprehensive Care Network, or CCR-CCN.

Dr. Wheless and his team join 12 other prestigious clinics in

the Network. For a complete list, visit <http://www.idea-league.org//ccr-ccn>.

Miami Children's Hospital, another CCR-CCN clinic, recently hosted a Dravet Syndrome Symposium that included guest speaker Dr. Charlotte Dravet. For more information on this meeting, see the related article on page 5 of this issue.

A dinner meeting for participating members of the CCR-CCN will be held in conjunction with the upcoming IDEA League Family Conference. Parent Liaisons for each clinic are also invited to attend. If you would be interested in serving as a Parent Liaison, please contact Angela Black at Dr.Black@IDEA-League.org.



Announcement

The IDEA League will hold a Membership Meeting via teleconference on Saturday, August 21, 2010 at 10:00 am CST. Voting members have already been notified. Other interested IDEA League supporters are also welcome to attend. For more information, please send an email to info@IDEA-League.org.

Encouraging Words From Our Founder

By Joan Skluzacek

I've always been a list maker. Shopping lists, "to do" lists, "honey do" lists (sorry Paul)—it helps me cope. The original title of the list below was *Ten Things I Love about Nick*, but I found ten wasn't enough. In fact, I could still go on.

Tulips, Windmills and Rembrandts—Fourteen Things I Love About Nick (in no particular order):

1. He asks for kisses when he needs comfort... or he thinks I need comfort.... or he's just feeling affectionate. He tilts his forehead my direction so I can plant one there. Even though he is seventeen, he does not care who sees him getting a kiss from his mother.
2. He laughs at his own jokes... and at my jokes... and at anything that strikes his funny bone. He has a great, infectious belly laugh.
3. He seems to like my cooking... or at least he eats it without complaining and often with enthusiasm.
4. He has big blue eyes that sparkle with mischief when he thinks he has a secret... or that he's gotten away with something... or he's trying to be charming.
5. He turns off the TV and pays attention when Oma and Opa come to visit... he plays with his 2-year-old cousin... he knows people are important and he loves his family.
6. He is very forgiving.
7. He gets an obvious kick out of going for rides: car rides, boat rides, bike rides, horseback rides, carnival rides, and airplane rides... you name it!
8. He's always happy to go to school... even in the summer.
9. He doesn't mind if I sing while I'm working around the house... or driving the car... he even still lets me sing to him at bedtime.
10. He inspires me with his determination... his ability to overcome adversity.
11. He has a sunny smile.
12. He appreciates the "little things."
13. He is never less than genuine and true.
14. He makes me a better mom... and maybe a better person.

This list helps me put things in perspective on the tough days. What is on your list? If you are happy to share, send it to me at Joan.S@IDEA-League.org.



This list helps put things in perspective on the tough days. What's on your list?

New Dravet Jewelry Now Available!

By Karen Glenn

A new line of Dravet beads and finished jewelry from famed artist May Tagher is now available for purchase.

Tagher and her company, May Creations, create beautiful custom beads based on an ancient technique known as millefiori—or 'thousand flowers'. The technique involves the production of polymer clay canes in which intricate designs are visible only from the cut ends. Slices from these canes are then taken and manipulated into various types of beads. Thus, the designs are not painted on, but actually a part of the

finished bead. Each bead is an original, unique, handmade work of art.

Tagher began creating beads for the IDEA League more than two years ago, and many a 'Dravet Mom' has enjoyed wearing her beautiful work while raising funds and awareness for our cause.

The new line of beads includes the words Hope, Hero, Dream, Believe, Dravet, and of course ,Tiger! The polymer clay beads are then combined with sterling silver, crystals, and a variety of other elements to create stunning

masterpieces.

A table with the jewelry will be set up at the upcoming family conference. If you are there, be sure to stop by and see the new line. If you have any questions, want to pre-order for the conference, or to place an order, please email Jennifer McMahan at mcmahanj@mac.com.

Proceeds from the sales of this beautiful jewelry help to further the mission of the IDEA League.





Attendees of the Mom's Get-a-way weekend, from left to right: Audra Miller, Dina Nelson, Danielle Horner, Trish Montgomery, Sally Gaer and Becky Hodson.

A Mother's Day Tradition Continues

By Karen Glenn

Midwest Moms of children with Dravet syndrome gathered in Indiana, USA on May 6-9 for a weekend of fun, and camaraderie. The fifth annual retreat, headed up by past IDEA League Board Member Dina Nelson, has become a Mother's Day tradition for many.

The get-a-way was held at the beautiful Omni Hotel in Indianapolis. Activities for the weekend focused on relaxation and pampering, and

included beauty treatments and make-overs.

The five "Dravet Mom's" attending this year's event were Trish Montgomery, Becky Hodson, Dina Nelson, Danielle Horner, and Sally Gaer. Also attending and adding to the fun was Audra, a rep from Cyberonics, the company that makes the vagus nerve stimulator (VNS), a treatment for epilepsy.

Caring for a child with Dravet

syndrome can often be exhausting. The Mom's Get-away weekend gives mothers a chance to take a break from the day-to-day demands illness can bring and allows them to relax and refresh with others that have shared experiences. Said Sally, "We enjoyed shopping and eating, chatting and laughing. We really had some laughs and bonding, which is so good for the soul."

In the Spotlight

By Jennifer May



Harm and Myra

Myra de Groot-Schokker has been hard at work furthering the cause of the IDEA League in Europe. She and her husband, Tom, have one child, eight-year-old Harm, who has Dravet syndrome. The three of them live in The Netherlands in a little village called Ammerzoden.

Myra works part-time as an advisor in patient communication at a local hospital. She loves her work, but balancing a job with her role as mother to Harm is sometimes tough. Fortunately, Tom works from home where he makes beautiful furniture and kitchen cabinets and is able to care for Harm when Myra is away.

Harm had his first seizure shortly after his third DTP vaccination. Although Harm suffered through countless seizures of varying types through the next few years, his development was normal and his first SCN1A test came back negative. Myra and Tom were hopeful that Harm would outgrow his seizures, but when he was five years old a

more in-depth genetic test known as MLPA, or multiplex ligation-dependent probe amplification, showed that Harm had a duplication in the SCN1A gene. Harm continues to battle a variety of types of seizures every day. His latest struggle is with "frightening" night seizures, which have required yet another adjustment in life. Myra is committed to succeed because, "Harm means everything to us and we are very proud to be his parents!"

Spending time together at home or in the garden is what Harm and his parents love to do most. Outings are limited because Harm's seizures are triggered by excitement, physical activity and heat. They sometimes go out to a little restaurant in the village, which is a treat for Harm after three years on the ketogenic diet! Harm loves to play in the garden with his dog, Abi, and enjoys Lego and Playmobil activities.

He is a snuggly boy who cuddles a lot with his parents and his grandmothers.

When asked to share her thoughts about life with Dravet syndrome, Myra says, "Although the syndrome can't be cured (yet!), there are people around us who really make all the difference: our loving family, close friends, caring neurologist and of course all those supportive parents from the IDEA League forum and other forums. To realize we are not alone in this is a great help. Living with Dravet syndrome implies living with lots of restrictions, stress and grief. But it has also enriched and deepened my life. I will do anything I can to help Harm. I can't cure his seizures so I focus on being a loving, cheerful mother."

Myra has recently spear-headed the formation of the newest IDEA League chapter, Dravet Groep Nederland (see [related article on page 1](#)). Says she, "I hope that the Dutch affiliate will bring Dutch-speaking parents support, knowledge, hope and much more!"

"Living with Dravet syndrome implies living with lots of restrictions, stress and grief. But it has also enriched and deepened my life."

—Myra de Groot-Schokker

Dravet Symposium Held in Miami

By Karen Glenn

A one-day seminar focused on Dravet syndrome was held in Miami, Florida, USA on July 7, 2010, as part of the XXXI Annual Child Neurology, Neurosurgery, and Psychiatry Postgraduate Course at Miami Children's Hospital (MCH). The Dravet Syndrome Symposium brought together more than 100 physicians and parents to learn about the latest updates on this difficult-to-treat condition.

Speakers at the symposium included Charlotte Dravet, MD, the physician who first described Dravet syndrome and a member of the IDEA League's Medical Advisory Board; MCH experts Parul Jayaker, MD and Ian Miller, MD; Seattle neurologist John C. Oakley, MD; and Katherine Hsaio, parent of a child with Dravet syndrome and member of the IDEA League. Key topics

included an overview of Dravet syndrome, the genetics of the condition, current and future research, and a parent's perspective.

"The purpose of this conference was a 'common' theme, to promote knowledge for early diagnosis of Dravet syndrome and available treatments that are both indicated & contraindicated. There was also ample time to meet with Dr. Dravet and all the physicians in an informal forum," said Michelle Perez, nurse coordinator for the Miami Children's Ion Channel Epilepsy Program who helped facilitate the conference.

Said Kimberly Deribeaux, long-time advocate and parent of a child with Dravet syndrome, "Miami Children's Hospital continues to impress me with their dedication to caring for

Dravet children. They have gone above and beyond what I dreamed was possible. They are dedicated to the excellent care of children as well as educating other neurologist and hospital staff. The education from this conference will help many children receive a proper diagnosis and appropriate care."

MCH's Ion Channel Epilepsy Program is a participating center in the IDEA League's Collaborative Clinical Research and Comprehensive Care Network.

Drs Dravet and Jayakar, as well as Michelle Perez, will be presenting at the upcoming IDEA League Family Conference August 26-29 in Greenwich, Connecticut, USA.



"The education from this conference will help many children receive a proper diagnosis and appropriate care"

—Kimberly Deribeaux

Derek's Dash to Raise Research Funds

By Karen Glenn

The Second Annual Derek's Dash 5K walk/run and accompanying silent auction will take place on August 29, 2010 at 10:00 am at Village Greens Park in Greenwood Village, Colorado.

The event is being co-chaired by siblings 13-year-old Ethan and 9-year-old Molly Widoff. The Widoff's cousin, Derek, for whom the event is named, has Dravet syndrome.

"I decided for my 13th birthday, which is so important in the Jewish religion, I really wanted to make a bigger difference. I have always been a strong believer that change doesn't just 'happen'—it takes

hours of work from so many people... and I have been so thrilled by the way that my friends and the community have responded to our event," shared Ethan.

The Widoff's hope to raise \$30,000 dollars at this year's event—enough for the Derek Rudawsky Research Fund, a named grant started as part of the IDEA League's Funds of Hope program. Through Funds of Hope, families and businesses that raise at least \$30,000 can name a research grant for their loved one.

Last year's Derek's Dash boasted about 220 participants and raised

\$20,000. The 50 or so volunteers were mostly middle school and elementary school peers of the Widoff siblings.

To learn more about Derek's Dash and the Widoff's, or to read Derek Rudawsky's story, visit the event website at derekdash.org. To register for the event or to make a donation, visit the IDEA League's website at www.IDEA-League.org and click on the link for Derek's Dash. On our site, you can also learn more about establishing a named research fund.



Ethan, Derek and Molly

"I have always been a strong believer that change doesn't just 'happen'..."

—Ethan Widoff



Alana Theodora Schruben
November 18, 2008 - Sept. 17, 2009



Alana and Darcy



Cecelia 'CeCe' Louise Cunningham
January 11, 2007 - March 17, 2010



CeCe and Reese

In Loving Memory

By Karen Glenn with Ann Schruben and Sarah Cunningham

Alana Theodora Schruben

Alana and her twin sister Darcy were born nearly full-term. Both seemed perfectly healthy, but Alana suddenly began having intractable seizures at only 11 weeks of age. Over the coming months, it was clear that she had a terrible seizure disorder that would prove to be highly resistant to treatment. While it was determined that she had an SCN1A gene defect, due to the unusual presentation of her illness, it remains unclear whether the most appropriate diagnosis was Dravet syndrome or the even more rare Partial Migrating Seizures in Infancy. Alana entered the hospital for the fourth time on May 3, 2009 at 4 1/2 months old and did not leave until she passed away, just one day short of ten months of age.

Alana was an exceptionally sweet little baby. Though her personality was just beginning to emerge, she seemed to respond delightfully to music and loved to have stories read to her. She was also very affectionate and even when

she was swaddled in her blankets, she would somehow wiggle free and reach out to hold her twin sister's hand in the crib that they shared.

Alana is survived, in addition to Darcy, by her parents, Anna and Thomas Schruben, and older sisters, Kate, Emma and Lillian. She was predeceased by her brother Tucker, who died of the also extremely rare Sudden Unexplained Death in Infancy at the age of 4.

Cecelia Louise Cunningham

Cecelia, known as CeCe, along with twin sister Reese, was born January 11, 2007, to parents Sarah and Peter Cunningham of Chicago, Illinois, USA.

CeCe loved people and was an incredibly affectionate child. She knew she was funny and would regularly do things to get people to laugh. She had a beautiful smile and eyes that lit up a room, both of which made a big impression on all she met.

CeCe loved music and would play her Ipod and request songs so she could dance and sing. Her favorites, at the tender age of three were: Jackson Brown's "Somebody's Baby," Psychedelic Fur's "Pretty In Pink" (her favorite color), REM's "Shiny Happy People," and "Sugar Sugar" by The Archie's. Her love of popular music said a lot about her personality.

CeCe also loved anything Dora, Yo Gabba Gabba the TV show, decorating herself with Dora and Hello Kitty band-aids, cupcakes, swimming, reading books like "Twinkle Twinkle Little Star" and playing chase with her twin sister and her boxer, Jack.

Sadly, Cece passed away of Sudden Unexplained Death in Epilepsy (SUDEP) on March 9, 2010.

Chase Community Giving, *cont.*

operating budget of \$1 million or less, among other requirements. Other winners in the challenge include organizations that support literacy, autism, suicide prevention, clean drinking water, and much more. For a list of the top 200 charities, visit <http://apps.facebook.com/chasecommunitygiving>.

Board Member Kim Skriba championed the cause on behalf of the IDEA League. Says Kim, "I was blown away by the support the IDEA

League received during this challenge and very proud to have been part of it all."

Thanks go out to all of our members and supporters who made the effort to vote for the IDEA League and spread the word about our cause. The money raised through the Chase Community Giving Challenge will go a long way toward furthering the understanding and treatment of Dravet syndrome and related forms of epilepsy and to supporting affected individuals and families as

they battle this challenging condition.

Thanks also to Chase for their generous support of small but critical causes like ours. JPMorgan Chase & Co. donates more than \$100 million annually to charitable giving.

Watch for your chance to help the IDEA League in next year's challenge!

Chapter Corner

By Karen Glenn

IDEA League UK

Fifteen UK families of children with Dravet syndrome, as well as a few extended family members, joined together from June 18-22 at Center Parcs resort in Sherwood Forest, Nottingham, UK (Robin Hood country!) for a weekend away. The event included a mum's evening and a dad's evening. The first night included a family meal, which was funded by the Dean Henshall Memorial Fund. The children participated in activities such as swimming and cycling and spent time enjoying the numerous parks. The parents/carers enjoyed getting to know new friends and catching up with the old. All of the families had a terrific time at the gathering and plans are already in the works

for next year's event.

IDEA League UK is now taking bookings for their Professional & Family Conference to be held on the 6th of November. The conference is a one-day event. Cost is £10 for a Dravet family member and £20 per professional. A full itinerary and booking form can be found on the organization's website at www.idea-league.org.uk.

The IDEA League UK website has recently been updated. Massive thanks to Conrad Wace and Henry Dale for their advice and support with the original site.

Dawn Paterson and Amy Thompson attended the National Centre for Young

People with Epilepsy's one day conference in Manchester on Saturday July 3, representing the IDEA League UK and further raising awareness for Dravet syndrome.

IDEA League France

Check this spot next issue for an update on the activities of IDEA League France.

Dravet Groep Nederland

The Dravet Groep Nederland was just formed in June of this year. They have a family gathering scheduled for November 9th. For further information, see the article on page 1 or feel free to send a query via email to EpilepsiePlus@Epilepsievereniging.nl.



Families of children with Dravet syndrome gathered at the Center Parcs Resort in Sherwood Forest, Nottingham, UK

IDEA League UK is now taking bookings for their Professional & Family Conference to be held on the 6th of November.

The 2010 Conference Is Almost Here!

By Karen Glenn

The IDEA League 2010 Family Conference is coming up on August 26-29. The biennial event will be held at the beautiful Hyatt Regency in Greenwich, Connecticut, USA.

This conference is bringing together leading experts to share information relative to recent advances in laboratory and therapeutic approaches for Dravet syndrome and related epilepsies.

Also on the agenda are topics

designed to assist families in coping with the challenges of caring for their family member with Dravet syndrome. These include issues such as managing behavior, education advocacy, transitioning to adulthood, sibling care, and more. Discussion groups by age and geographic location will also be held. You can view the full conference agenda on our website at <http://www.idea-league.org/agenda>.

You won't want to miss this

opportunity to learn the latest on Dravet syndrome and to share the invaluable experience of gathering with parents and families members who understand life with this unique and challenging condition.

Registration is currently available on our website at www.IDEA-League.org. But act quickly! Walk-in registration will not be available at the conference.



You won't want to miss this opportunity to learn the latest on Dravet syndrome and share the invaluable experience of gathering with parents and families members who understand life with this unique and challenging condition.

Did You Know?

In addition to parent/caregiver forums in several languages, the IDEA League Family Network also has a Sibling Forum—a place where brothers and sisters of patients diagnosed with Dravet syndrome can 'gather' and share experiences and feelings. In order to join, siblings must be under the age of 18 and have a parent's permission. For more information, contact Kim Skriba at Kim.S@IDEA-League.org.



Marvelous hosts, the Lyles family.



Auction items lined the room.



Christmas Comes Early to Ohio!

By Paula Lyles

Take one steamy, humid night in Cleveland, Ohio; add nearly 200 guests, a fireplace hung with stockings, festive hors d'oeuvres, and auction items as far as the eye can see; then add pine trees surrounded with new fallen snow, and what does one get? Christmas Eve in July, of course!

The fundraising event began with a silent auction. Men had the chance to bid on items such as Santa's "Clauaset", autographed sports items from Nascar and legendary golfer Jack Nicklaus, and a 3-foot Christmas tree decorated with a pool hall theme. Ladies bid on lovely winter attire, jewelry, and a wonderfully laden Brutus the Buckeye picnic basket. Giddy children tugged on their parent's arms for a chance to win items ranging from Jonas Brothers concert tickets to Build-A-Bear packages.

Family and group photos were taken in the frosty winter wonderland by Terry Schordock, of Studio South Photography. Then guests

were invited by local Cleveland weatherman and emcee/auctioneer for the evening, Jon Loufman, to be seated for the holiday feast. Hearts were touched as Mitch and Paula Lyles, the host and hostess for the evening, shared a short film about life with a child who has Dravet syndrome. As the dinner was concluding, a surprise guest magically appeared! Each child squealed with delight as his or her name was called by Santa to come forward and receive an especially chosen gift. Santa had tears in his eyes as he wished the children a Merry Christmas.

Just as Santa had to head back to the North Pole, Christian recording artists Praise-Apella took the stage and dazzled the crowd with their renditions of Christmas favorites, including a special Feliz Navidad dedicated to the daughter of the hosts, Jordan Lyles. As guests enjoyed the show while feasting on the magnificent Christmas dessert buffet, sheer bliss permeated every inch of the room. It was

a sight to behold as children with Dravet syndrome, along with several with other disabilities, danced with every bit of heart and soul they could muster. This was the most magical moment of the evening!

As Praise-Apella said their goodbyes, John Loufman donned his Santa hat and went to work to raise money for the IDEA League. Live auction items included a fabulous outdoor playhouse custom built by the architects of Mitch Lyles' firm, Westlake Reed Leskosky; a gorgeous \$1500 hand carved magnolia wood guitar; trips to Florida; autographed items by OSU Buckeye greats of the past and present; and two show stopping Christmas trees. The success of the event was measured not only by the money raised for an important cause, but by the joy of the evening, the goodwill spread, the information shared, and the friendships renewed and formed—all of which made the evening priceless.

Dates to Remember

AUGUST

- 21 Biennial Membership Meeting of the IDEA League via teleconference
- 26-29 IDEA League Family Conference Greenwich, Conn, USA
- 29 Derek's Dash: A Benefit for the IDEA League Greenwood Village, Co, USA
- 29 Annual Chester Challenge Cycle Ride Chester, Cheshire, UK
- A Benefit for the IDEA League UK

SEPTEMBER

- 17 Grand Rounds at Cleveland Clinic Cleveland, OH, USA

OCTOBER

- 5-9 Matthew's Friends Global Symposium Edinburgh, Scotland
- IDEA League UK exhibiting

NOVEMBER

- 6 IDEA League-UK Conference East Sussex, UK

DECEMBER

- 3-7 American Epilepsy Society Meeting San Antonio, TX, USA

FEBRUARY

- 18 Grand Rounds at Children's Hospital of Michigan Detroit, MI, USA



The voice for Dravet syndrome.

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