



Channeling In

The Newsletter of the IDEA League

IDEA League Announces Research Grant

By Karen Glenn

The IDEA League is pleased to announce the initiation of our Research Award program. Our first research grant of \$30,000 will be awarded on April 1, 2010. This program was launched at the American Epilepsy Society conference in Boston, Massachusetts, USA, in early December 2009. Applications for our 2010 grant are currently being accepted and are due on February 15. Several researchers are applying.

The IDEA League is committed to following only the best practices in awarding research grants. Applications will be evaluated by the IDEA League's Scientific Research Review Committee, a distinguished group of research scientists, utilizing the peer-review model of the National Institutes of Health. Criteria for the judging will include: relevance, quality of the research lab, scientific merit, and potential for new therapeutic approach.

Research looking into the epidemiology, etiology, natural course, treatment and cure of Dravet syndrome and related forms of epilepsy will be considered.

Research awards will be paid out over a two-year period, with second-year funding



pending progress during the first year. Watch for the announcement of this year's winning grant in our April newsletter.

"Funding research that will

lead to the improved understanding and treatment of Dravet syndrome is an important component of the IDEA League's mission." said Angela Black, MD, Chair of the IDEA League's Medical Advisory Board, who played an integral part in writing the protocols for this new initiative. "I am excited for the initiation of this new program and the opportunity to have an even greater impact on this condition."

The IDEA League plans to expand this program to award many more grants in the coming years. Please see the related article below for how you can help.

For more information regarding this program, or to request an application, please contact Marilyn Baker, Executive Director, at Baker@IDEA-League.org.

Now You Can Personally Fund Research!

By Angie Mimms

Honor your child. Fund research. Provide hope.

All this is possible through a new IDEA League program called Funds of Hope, which allows individuals, families and corporations to raise research dollars to be named for their child, family, loved one or business. *One hundred percent of funds you raise through this program go directly to research—not one penny is used for administrative expenses.*

The first step is to register

your fund with the IDEA League. Next, start a mail campaign, social networking blitz and/or plan a fundraising event. The IDEA League will collect, manage and reserve the donations you receive in your fund's name. There is no time limit in which you must raise the money. Once any fund reaches \$30,000, it will be eligible to be awarded. The IDEA League will advertise annually for research award applications and our Scientific Research Review Committee, comprised of leading scientists and medical

researchers from around the world, will evaluate and score those applications, selecting only the best to receive the funds.

Kimberly Skriba, a League Board Member, has established a fund named for her son, Ryan Smith, age 11. "I wanted to do something positive to honor Ryan for all the struggles he has been through," Kimberly said. Haley Smith, 9, also has a fund named for her. "I'm so excited about it," said mom

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IDEA League
International Dravet Syndrome Epilepsy Action
The voice for Dravet syndrome.

Our IDEAL is a Cure



When raising our fragile children, it is easy to forget the importance of making our marriage a priority.



Encouraging Words From Our Founder

By Joan Skluzacek

“The most important thing a father can do for his children is to love their mother.”

–Theodore M. Hesburgh, Former President, University of Notre Dame

As Valentine’s Day approaches, the shops have been filling up with hearts, candy and flowers in red and pink, chocolates, and boxes of valentine cards with amusing little sayings from Scooby Doo and Winnie the Pooh. Parents will soon receive notes from their children’s teachers with instructions for classroom valentines and lists of classmates that should receive them, as well as requests for donations and volunteers for the class parties. An event once focused on courtship and romantic love has become a widespread celebration of love of all kinds, and we may feel pressure to remember our family members and friends on this day, as well as to help our children do the same. I don’t really object to this expansion of the holiday. When celebrating love, I feel inclusiveness is a good thing. I just want to make sure that my romance doesn’t get lost in the shuffle.

I can’t imagine that Dr. Hesburgh would object to my extrapolation that the most important thing a mother can do for her children is to love their father. For a healthy relationship it has to go both ways. Most parents of children with special needs are conscious of reports that divorce rates are higher than

average among our families. No one is surprised by this. The daily pressures of family life are compounded by the added physical, social, emotional, time and financial pressures of caring for a loved one with special needs. Some marriages that might have worked under more typical circumstances will not be able to survive this added pressure. In those circumstances, I imagine Dr. Hesburgh might counsel us to find a different way to love our children’s other parent – at least enough to meet the children’s needs and be good parents together.

When raising our medically fragile children, it is easy to forget the importance of making our marriage a priority. Our children’s needs are so intense that we push our own needs and those of our spouse completely aside. We may become more like co-workers than lovers. We tell ourselves that being ‘grown up’ and responsible means that we must delay our own gratification. And that is true – to a degree. The problem is that failing to care for ourselves and our partners can result in failing our children. They need us to keep ourselves and our marriage healthy and whole in order to best meet their needs. This assertion is supported not only by common sense, but by research as well.

So as Valentine’s Day approaches, I will try to make my romance a priority. I will try

to keep in mind the following “Twelve ‘T’s for Healthy Relationships”:

- Truth** – fidelity of heart, mind and body;
- Trust** – confidence and faith in one another;
- Talk** – communication that is open, respectful and frequent;
- Teamwork** – support of one another in daily tasks and in interactions with others;
- Thoughtfulness** – consideration of one another’s feelings and needs;
- Tolerance** – empathy and understanding of one another’s human failings;
- Tenacity** – determination to succeed;
- Thanks** – expressing appreciation of each other’s gifts and efforts.

And for February 14, I will challenge myself to plan something special involving one or more of the following (and to make this plan before I buy valentines for my children to exchange at school):

- Tryst** – setting aside some special time to share with each other;
- Touch** – cuddling, a gentle caress;
- Tenderness** – loving words and actions;
- Token** – handmade or purchased on the fly, it is the thought that counts.

I wish you all a healthy and happy Valentine’s Day!

Further reading: [Married with Special Needs Children](#) by Laura Marshak and Fran Prezant and [Special Needs Child: Maintaining Your Relationship](#) by Antonia Chitty and Victoria Dawson.

Special Promotion

Emfit Corp. is currently offering their Movement Monitor at a reduced price of \$450. The monitor, which can detect many types of nocturnal seizures, regularly sells for \$600. This promotion lasts only through January 31, 2010. Mention the IDEA League when you purchase and 10% will be donated to our cause. Call toll-free at (877) 32EMFIT or visit www.emfit.com.

Executive Minute

By Marilyn Baker, Executive Director

It is truly an honor to be working with each of you and alongside such an amazingly dedicated Board to further this important cause. I am impressed with the amount that this organization has accomplished over the past several years and at the number of parents who, despite the exhausting challenges of caring for their own child with Dravet syndrome, are reaching out around the world to help other families who are similarly struggling. The international partnership which you have created has become the major force that is improving the outcome and working to find a cure for this challenging condition.

This coming year will be a great time of growth, excitement and hope as we make new strides in furthering the treatment of Dravet syndrome and related forms of epilepsy. If you are not

already actively involved in the work that this organization is doing, please join with us!

Our vision for the coming year is to accomplish our mission by:

- 1) Ensuring professional business practices. We are conducting our operations according to the highest standards of ethical and legal practices, including an annual financial audit and peer-reviewed research awards.
- 2) Increasing our research fund. We are awarding one \$30,000 study in 2010 and have commitments to raise \$90,000 for 2011.
- 3) Creating valuable services. We will deliver more support, additional education, and further help to families around the world.
- 4) Expanding our partnerships. We will develop

more working relationships with international health care professionals, scientists, hospitals, families, and others who can help us to improve treatment and find a cure.

This vision will take hard work, perseverance, and financial support. With your help, we can do it! Please contact me to discuss how you can contribute to this amazing league of parents and professionals dedicated to helping families with Dravet syndrome and related conditions.



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Join Our Team for the National Walk

By Karen Glenn

Team Dravet is gearing up to storm Washington once again! For the third year in a row, IDEA League families will gather in Washington, DC, USA, for the National Walk for Epilepsy. This year's event will take place on Saturday, March 27. Thanks to the efforts of volunteers Lisa Smith and Kimberly Skriba, along with all the families who attended, last year Team Dravet was the second largest group at the event. "This year, we are shooting for first!" stated Kim.

The Team is working to raise awareness and funds for

Dravet syndrome and related conditions. They have set up a Facebook page for Team Dravet where you can find information about the walk and make a donation. So far, at least 10 families are planning to attend the walk. The National Walk for Epilepsy is put on annually by the Epilepsy Foundation.

Lisa has arranged for hotel rooms for families at L'Enfant Plaza Hotel at a special price of \$109 per night, but space is limited. Service dogs will be allowed at no additional charge. The group will also

have access to a meeting room so families can comfortably gather and visit with one another, regardless of what the weather brings. A lunch is planned immediately following the walk. If you are interested in attending, please contact Lisa soon by emailing her at haleyandtwins@aol.com.

If you are unable to attend but wish to show your support, please consider making a donation to Team Dravet to support their efforts.



"This year, we are shooting for first!" stated Kim.



The IDEA League is pleased to have this opportunity to collaborate on a project that will raise awareness of the seriousness of epilepsy within the general public.

IDEA League Contributes to AES Initiative

By Joan Skluzacek

The American Epilepsy Society conference brought with it some interesting new prospects for the IDEA League. Among these is the opportunity to participate in Vision 2020, an initiative being led by the AES in an effort to bring together epilepsy organizations and develop a common strategy for educating the public that will enhance each organization's mission and increase awareness and funding for epilepsy research.

IDEA League Director Kimberly Skriba and Founder Joan Skluzacek represented the IDEA League at a Vision 2020

meeting held during the AES conference. Ten leading epilepsy organizations and agencies were represented in this meeting. The agenda was to assess existing statistics on epilepsy and determine what additional data is needed to develop a common message about epilepsy. Each group is asked to contribute its thoughts on what should be reflected in the message. The AES will lead an effort to bring this message to the public, a plan that is expected to include televised public service announcements.

The IDEA League is pleased to have this opportunity to

collaborate on a project that will raise awareness of the seriousness of epilepsy within the general public.

On a separate note, plans were initiated at AES for a new collaborative research study in which IDEA League families can participate. For further information about this exciting new project, please see the article on page 5 of this issue.



The McNulty family at Give Kids the World Village for Kyle's Make-A-Wish trip.

I am glad my parents have the IDEA League to be able to talk with other parents who know what they are going through.

In the Spotlight

By Paula Lyles and Tina McNulty

Hello! My name is Kyle McNulty; I was born on July 16, 2001. My older sister is Mikayla and my two older brothers are Ryan and Sean.

When I was three months old, my arm started shaking on its own for some reason, so my Mum and Dad took me to the hospital. By the time we got there, it had stopped. When I was six months old, I had my first grand mal seizure which lasted 40 minutes. This time I went to the hospital by ambulance and stayed two days. It happened again; the doctors said my seizures were coming from fevers.

In 2002, I had 6 seizures. In 2003, I had 10 seizures; some of these were without fevers. I was taking medication, but it was not stopping the seizures. In 2004, I had more without fevers, but the doctors still weren't worried. Even though I had only had 2 seizures in 2005, my doctors put me on

Topomax, which made it difficult for me to speak. My EEG results were normal in 2006, but my doctors decided to adjust my medications, as I would be entering school in the fall. The more the doctors tried to find the correct combination, the worse I got. I ended up back in the hospital in November of 2006 with what the doctors determined was status epilepticus. I had to stay in the hospital for three weeks this time. I even tried the ketogenic diet; but I didn't like it, and it didn't work. The seizures continued, and I was having trouble remembering things.

After a battery of tests done by a new doctor, I found out that I have Dravet syndrome. It's nice to have a name for what is happening to me. We learned that the Lamictal and Trileptal I was on were causing more seizures for me. I still have seizures, but sometimes I can go 2-3 days

without one. My entire family must watch me constantly because I can have a seizure almost anytime, but they usually happen at night. I go to a special school because of the difficulties I have remembering things—it causes me to have trouble getting my words out, and it clouds my thinking. I am 8 years old now and I like Dora, Max & Ruby and the Backyardigans. I enjoy playing games on the computer, but it's hard for me to concentrate there, too. When I see old videos of myself and the way I used to speak, I wish I could be that way again.

I am glad my parents have the IDEA League to be able to talk with other parents who know what they are going through. The IDEA League has helped my parents know they are not alone, and it's such a great support network!

New Study Seeks Further Causes of Dravet Syndrome

By Karen Glenn

Mutations in the sodium channel gene SCN1A are understood to contribute to between 50 percent and 80 percent of cases of Dravet syndrome. This leaves another 20 percent to 50 percent of patients and families—and their physicians—baffled and without an explanation for their severe seizures. A new study hopes to uncover the answers these families and doctors desperately need and further the understanding of this devastating condition.

The study, being conducted by Gleeson Neurogenetics Laboratory, is one of the first to employ a new technology that allows scientists to sequence every coding gene in the human genome at one time. Researchers at the lab will apply this knowledge toward discovering and identifying additional genes that cause Dravet syndrome and, in turn, these discoveries will lay the foundation for

future disease-specific therapies and possibly a cure.

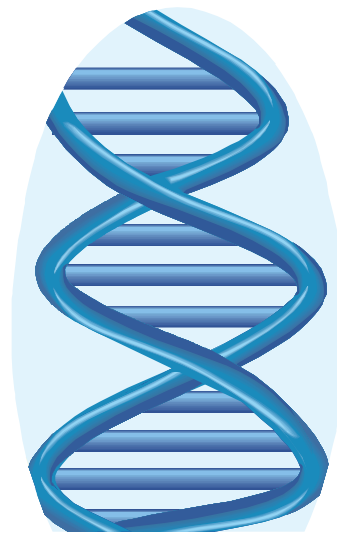
IDEA League families are being recruited to participate in this important study and assist in broadening the understanding of the causes of Dravet syndrome. Qualifications include having at least two family members with a history of epilepsy, one of them having Dravet syndrome and a negative SCN1A test. The epilepsy cannot be due to trauma, tumors, infection of the central nervous system, stroke, pregnancy or birth complications, or other environmental factors. If your family meets these criteria and you are willing to participate, please contact Karen Glenn at Karen.G@IDEA-League.org for more information.

While participation in any study should always be at the families' discretion, the IDEA

League feels strongly that together we carry the information needed to find the answers to this challenging condition, and we encourage our members to seriously consider taking part in appropriate research whenever it is feasible.

The goal of Gleeson Neurogenetics Laboratory's research at the University of California, San Diego, and Howard Hughes Medical Institute, is to identify new genes that cause pediatric brain disorders and to further understand how genetic mutations affect brain development.

The IDEA League extends thanks to Tracy Dixon-Salazar, PhD, and Dr. Joseph Gleeson for their willingness to delve further into the causes of Dravet syndrome and help us to find the critical answers we need.



IDEA League families are being recruited to participate in this important study and assist in broadening the understanding of the causes of Dravet syndrome.

New Website Launched!

By Karen Glenn

On December 1, 2009, the IDEA League launched a new and more comprehensive website. The new site has an updated look and boasts a whopping 31 pages of helpful information for families and professionals looking to learn about Dravet syndrome and related forms of epilepsy.

"We are so excited to finally have the new site up and running," said Kimberly Skriba, who headed the team working on the project. "This endeavor sort of took on a life of its own and grew into something bigger and better

than any of us first envisioned. It took a little longer than planned, but we think it was worth it!"

The improved site has many new features, which we hope visitors will find helpful. One of the most exciting features is the ability to include information in multiple languages. The site already has information available in Spanish and will soon have pages in French as well. Ensuring the accuracy of medical data shared on the site is critical, so translation

can be labor-intensive and will take time to expand.

The skills of Paul Skluzacek, who has served as the IDEA League's webmaster since our inception, have been invaluable for troubleshooting challenges and ensuring that the site runs properly and that the transition was seamless.

Many thanks go out to Kim Skriba, Paul Skluzacek, and Karen Glenn for the many hours of work they put into this endeavor.



The improved site has many new features, which we hope visitors will find helpful.



Jay McConnell, Vice President of South County Properties, hands over the keys to the new IDEA League headquarters to Marilyn Baker.

IDEA League Establishes Headquarters

By Karen Glenn

For the first time in our four-year history, the IDEA League has a brick-and-mortar office!

The office space, located in Deale, Maryland, USA, has generously been leased to the IDEA League free of charge for the coming year by South County Properties. The office furniture was kindly donated by our own Marilyn Baker, Executive Director.

The mailing address for the IDEA League will remain at: P.O. Box 797, Deale, Maryland, USA 20751.

The phone number for the office is also unchanged at 443.607.8267.

Many thanks to South County Properties for donating this space for our cause. It is only from generous contributions

such as this that we are able to direct so much of our donations to research, support and education.



IDEA League attendees of the 63rd annual AES conference included (left to right): Karen Glenn, Director; Angela Black, MAB Chair; Marilyn Baker, Executive Director; Kim Skriba, Director; and Joan Skluzacek,

American Epilepsy Society Meeting

By Joan Skluzacek

The 63rd annual conference of the American Epilepsy Society (AES), the US chapter of the International League Against Epilepsy (ILAE), took place December 4-8, 2009, in Boston, Massachusetts, USA. The IDEA League was pleased to participate for the fourth time in as many years. Representatives of the IDEA League in attendance were Marilyn Baker, Executive Director; Angela Black, Medical Advisory Board Chair; Joan Skluzacek, Founder; and Karen Glenn and Kimberly Skriba, Directors.

At our booth, the IDEA League exhibited the abstract posters presented by our organization at the international workshop in Verona last October (available for viewing at <http://www.idea-league.org/research-pub>). Epilepsy specialists visiting our booth showed significant interest in the data on both SUDEP/mortality and comorbidities. In addition to our educational brochures and awareness materials, the IDEA League also distributed information regarding our CCR-CCN and applications for the research grant we will award this

spring. (See related article on p. 1)

Many IDEA League professional friends and Medical Advisory Board members were in attendance and a number of them, including Drs. Alica Goldman, Katherine Nickels, Ingrid Scheffer, Peter De Jonge, Sameer Zuberi, Marcio Sotero, Helen Cross, and Carol Camfield, were presenting lectures or research abstracts.

Of particular interest to our members, 54 of whom participated through the IDEA League Family Forum, may be the abstract presented by lead author Dr. Beverly Wical: *Signs of Dysautonomia in Children with Dravet Syndrome*. Dysautonomia is a term that refers to dysfunction within the autonomic nervous system. The autonomic nervous system controls 'unconscious' bodily functions such as heart rate, body temperature, digestion and breathing. Dr. Wical is a pediatric neurologist practicing at Gillette Children's Specialty Healthcare in St. Paul, Minnesota, USA. Her study revealed that signs of

dysautonomia are common in children with Dravet syndrome. They are more than twice as likely as the children in the control group to have nine of the ten signs of dysautonomia evaluated in this study. She highlighted the need for further studies of the clinical significance and additional approaches to management of autonomic dysfunction.

This year's conference highlighted research addressing some very difficult challenges associated with epilepsy, including mortality and SUDEP. Marilyn Baker observed, "While researchers have found effective treatments for many of the more common forms of epilepsy, it is encouraging to see investigations focusing on the rarer pediatric disorders, which are devastating thousands of families each year. Research is needed for all forms of epilepsy because increasing our knowledge base leads to the discovery of effective treatments and cures for all."

Of particular interest to our members... may be the abstract presented by lead author Dr. Beverly Wical: Signs of Dysautonomia in Children with Dravet Syndrome.

In Loving Memory

By Sloane Stricker and Cathy Holt

Reed Thomas Stricker was born April 21, 2008. He was born healthy at 8 lbs, and for his first six months was a perfectly normal and developing baby boy.

At six months old, Reed had a generalized seizure following a routine vaccination. The initial ER diagnosis was a simple “febrile” seizure that, while not uncommon, was the result of an elevated temperature. In the subsequent five months Reed had many more seizures, some up to 30 minutes and longer. All common tests such as spinal tap, CAT scan, and blood tests were negative. We were abruptly introduced to epilepsy and our lives were changed.

Reed went on several anti-epileptic drugs (AEDs) but continued to have complex seizures and status epilepticus. In late March of 2009, he was hospitalized at Denver Children’s Hospital after a long seizure for several days of EEGs, monitoring, and tests. Eventually, he was diagnosed with Severe

Myoclonic Epilepsy of Infancy (SMEI) or “Dravet syndrome”. Although Reed still carried on like a normal toddler, played happily, grew quickly, and met all pediatric milestones, he had a total of 20 major seizures, 16 ambulance rides, and thousands of brief absence seizures. But for 20 months he had many adventures in camping, swimming, running, climbing, sledding, cuddling, traveling, helping, and playing—all while not the slightest bit aware of his condition or seizures when they occurred.

Sadly, on New Year’s Day, Reed died quietly in a normal afternoon nap after playing in the park with his brother, father, and grandpa. The official cause of death was Sudden Unexpected Death in Epilepsy (SUDEP).

We could not have asked for a more loving and expressive child, who just recently learned to hug on his own free will and initiative. As I carried him into his final afternoon nap, he deliberately turned to me and put both arms around

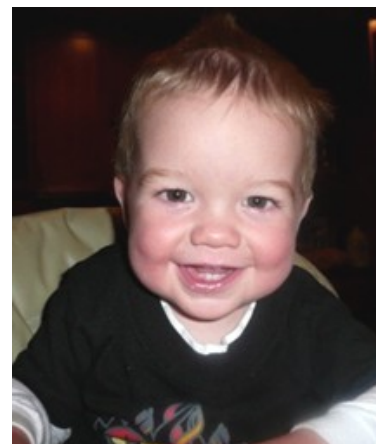
me and squeezed. I’ll cherish that and the memory of Reed for the rest of my life. We will miss him dearly.

—Sloane Stricker, father

It is not often that children are born with Dravet syndrome. When those babies come to a family, they change our lives. They make us better people than we were before. The amazing thing about each of these children and their families is the positive impact they have on everyone around them. This beautiful little boy and his family’s example will continue to touch all who knew him.

Thank you, Tami & Sloane, from all of us in the IDEA League, for sharing Reed with everyone around him. Thank you for helping our children by positively impacting, influencing and educating your community about the reality, the struggles and the blessings of knowing a child with Dravet syndrome.

—Cathy Holt



Reed Stricker

April 21, 2008 – January 1, 2010

“As I carried him into his final afternoon nap, he deliberately turned to me and put both arms around me and squeezed. I’ll cherish that and the memory of Reed for the rest of my life.” —Sloane Stricker

Funding Hope, *continued*

Lisa, a League member. “We love that we can tell benefactors that 100 percent of the funds will go directly to research, and having Haley’s name on the fund helps them feel connected and know they are truly having an impact.”

Kimberly plans to form a committee of friends and family to work on fundraising activities, such as softball and bowling tournaments and a dance or concert in a park. Lisa said a local church and school have pledged

donations from fundraising events to benefit Haley. In fact, the Smith family has already had an article written about their fundraising in their local newspaper.

Funding for desperately needed research is something the IDEA League has wanted to do for a long time, Executive Director Marilyn Baker said. “It’s part of our mission,” she added, “and we’re growing so we’re now able to go to our next step.” Funds can be named to honor

a child, a wedding anniversary—any important person, company or special occasion.

Anyone interested in the Funds of Hope program can go to www.IDEA-League.org and click on “research” and then “Funds of Hope” for more information. You also may contact Marilyn at Baker@IDEA-League.org or 443.607.8267.



“We love that we can tell benefactors that 100 percent of the funds will directly to research...”

—Lisa Smith



The nearly complete Dravet Quilt of Celebration. Families are now invited to contribute blocks to a new project—the Dravet Quilt of Hope.

Second Dravet Quilt Under Way

By Brenda Ferrell and Karen Glenn

The first quilt created to honor our beautiful children with Dravet syndrome—the Dravet Quilt of Celebration—is nearly complete! Many families contributed blocks for this quilt, which was lovingly assembled by Brenda Ferrell.

If you missed the opportunity to participate in the Dravet Quilt of Celebration, we have good news for you! Brenda is now starting a second quilt—the Dravet Quilt of Hope—and any family of a child with Dravet syndrome is invited to contribute.

To be a part of this wonderful project, all you need to do is contact IDEA League Board

Member Kim Skriba. She will send you an 8.5-inch white quilt square and give you any needed guidelines. You will design and decorate the block as you see fit and return it to Kim. Families that would like to create a photo quilt square of their child, but do not have the means to do this can get help from the quilt team.

The quilt team requests that you send a letter describing how your quilt square represents hope for you. A \$10 contribution is also requested to help offset the expenses involved with the construction of the quilt.

A Dravet Quilt web site has

been set up by Sharon Wills at <http://quilt.shazzas.info>. There you can learn more about both quilts and also make your contribution via Paypal.

Kim has already received five squares for our Dravet Quilt of hope. Don't be left out this time. Design and send in your quilt square, your story, and your contribution today! Contact Kimberly Skriba at Kim.S@IDEA-League.org.

Many thanks to Kim, Shazza, Brenda, and the other volunteers who are working to make these beautiful pieces of art a reality!



A Tiger Mom Tradition Continues

By Karen Glenn

Mothers of children with Dravet syndrome are invited to gather for the 5th annual Dravet Mom's Weekend.

Traditionally held over Mother's Day weekend, this year's gathering will take place on May 6-10 in Indianapolis, Indiana, USA, at the 5-star Omni Hotel. 'Tiger Moms' will be able to receive a special room rate of just \$99/night and reservations can be cancelled at no charge, if needed, so you can

book with confidence.

The Omni hotel is located in thriving and very safe downtown Indianapolis, close to a variety of restaurants, bars, museums, specialty food stores, beauty shops and much more. The weekend will include a guest speaker and a Mother's Day brunch with the best moms around!

This event is being graciously organized by IDEA League volunteer and former Board

Member, Dina Nelson. Says Dina, "Most moms never get a break away or think they could never leave their Dravet child. I thought the same thing for two years before I attended. You *can* leave, and you will be a better mom and wife for having done so." For more information, to hook up with a roommate, or to see if you may qualify to fly on Angel Flights, you may contact Dina at HopeForSydney@live.com.



Mark your calendars and plan to attend—you won't want to miss it!

2010 Family Conference

The IDEA League will be holding our 3rd Bi-Annual Family Conference on August 26-29 at the Hyatt Regency in Greenwich, Connecticut, USA. This event will bring together leading experts from around the world to share information relative to recent advances in laboratory and therapeutic approaches for Dravet syndrome and related epilepsies. Families will have the opportunity to interact with others, learn more about progress being made in research, receive education on lifestyle and coping issues, and take advantage of a personal consultation with doctors. Registration will be available on our website, www.IDEA-League.org, beginning February 1.

’Twas the Night Before Christmas (In July!)

By Paula Lyles and Karen Glenn

Are you ready for the magic?

It may seem like an ordinary summer evening, but for those who step through the doors of the Fountain Bleu in Avon, Ohio, on July 23, 2010, it WILL BE Christmas Eve. Be prepared to blink your eyes a time or two! At this marvelous benefit for the IDEA League, you will feel as if you have stepped right into all the festivities and grand decorations that are such a very special part of Christmas! There will be phenomenal and festive auction items sure to delight every bidder, a Christmas play land and craft area just for

the kiddos, and scrumptious holiday hors d’oeuvres and beverages to get the evening started.

Glide next door, and you will experience a winter wonderland! Indulge yourself in the decadent food, seasonal drinks, and sounds of Christmas like you’ve never heard before! Sit back and listen to Praise-Apella, a totally awesome vocal group that will have you on your feet in amazement, as they share the true meaning of Christmas. Soon your heart will believe that it IS Christmas Eve!

Kids, bring your Christmas pajamas to change into later in the evening, because you just never know who may stop by! Remember that this is all happening in northeast Ohio, and it is quite possible that it may even snow!

This magical event is brought to you courtesy of the Lyles family. The proceeds of Twas the Night Before Christmas will help the IDEA League further our mission of education, support and research. For more information, please contact Paula Lyles at pal601@aol.com.



Soon your heart
will believe that it
IS Christmas Eve!

Dates to Remember

MARCH	EPILEPSY AWARENESS MONTH-CANADA	
26	Purple Day	Worldwide
27	Team Dravet at the National Walk for Epilepsy	Washington, DC, USA
May		
6-9	5th Annual Dravet Mom’s Weekend	Indianapolis, Ind, USA
JUNE		
18-21	UK Family Holiday	Sherwood Forest , Centerparc, UK
July		
23	’Twas the Night Before Christmas: A Fundraiser to Benefit the IDEA League	Avon, Ohio, USA
AUGUST		
26-29	IDEA League Bi-Annual Conference	Greenwich, Conn, USA
NOVEMBER		
6	IDEA League-UK Conference	East Sussex, UK



IDEA League
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