



Channeling In

The Newsletter of the IDEA League

IDEA League UK Gains Charity Status

By Karen Glenn

On February 26, 2008, the IDEA League UK became an officially registered charity in England and Wales. The IDEA League UK is the first regional chapter of the IDEA League and its purpose is to more fully serve the particular needs of families within England, Scotland, Ireland and Wales. Registered members of the IDEA League who reside within the United Kingdom are automatically considered to be members of the IDEA League UK, which currently boasts 59 members.

Trustees for the IDEA League UK include Marie Baker, Frances Baker, Dawn Paterson and Amy Thompson. These dedicated ladies have worked hard to establish this charity and are looking forward to making a difference in the lives of all children and families in the UK with Dravet syndrome. Marie Baker also serves on the Board of Directors of the IDEA League as Chair of the Executive Committee. The IDEA League UK is very pleased to have as its Professional Advisors respected physicians Professor Helen Cross of Great Ormond Street Children's Hospital and Dr. Elaine Hughes of Kings College Hospital, London.

There were several requirements which needed to be met before obtaining charity status, including defining the specific objectives of the charity and raising an initial £5,000. This last requirement is meant to demonstrate the organization's ability to fundraise.

Objectives of the IDEA League

UK are: 1) to fund medical research into Dravet syndrome and other related genetic sodium channel epilepsies to benefit sufferers of Dravet syndrome and their families; 2) to advance the education of the medical community in the subject of Dravet syndrome, therefore prompting accurate and early diagnosis and benefiting sufferers of Dravet syndrome and their families, and; 3) to promote the physical and mental health of sufferers of

and fundraisers on the horizon. For more information on happenings within the chapter, or to volunteer time or resources, you may contact Marie Baker at marie.b@idea-league.org

The establishment of regional and country chapters of the IDEA League allows for services to be provided that are more direct and targeted to meet the needs of individuals. Having registered charity status within countries



IDEA League UK Trustees from left to right: Frances Baker, Dawn Paterson, Marie Baker and Amy Thompson

Dravet syndrome and their families through the provision of financial assistance, support, education and practical advice.

To date, the IDEA League UK has already purchased and provided to families on a loan basis four pulse-oximeters, which help in monitoring for seizures by alerting to changes in heart rhythms and blood oxygen saturation levels. They have also produced a flyer which will shortly be sent to the 350 members of the British Paediatric Neurology Association introducing them to the organization. The IDEA League UK has several events

outside of the US also allows for better networking with other organizations and encourages individuals and companies to give directly to the organization providing services within their community. While the need and requirements for obtaining charity status vary around the world, it is the hope of the IDEA League to establish regional and country chapters wherever they are deemed helpful and appropriate. If you are interested in volunteering toward a chapter in your country or region, please contact Marie Baker.

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Our IDEAL is a Cure



We don't have to live long to leave a legacy – it is enough to have lived, loved and been loved.

Encouraging Words From Our Founder

By Joan Skluzacek

Twice now, I have thought to myself: “how does one ask newly bereaved parents for a gift from their beloved child who has just passed away?” With distance between us, I couldn't even ask them face-to-face. Yet given the need for that gift, how could I fail to ask?

Twice now, I have been amazed by courageous parents who have responded to my question graciously and generously. Last June, Scott L. and Jeanne Crossland lost their 8-year-old son, Scott C., to SUDEP (Sudden Unexpected Death in Epilepsy). When I mentioned this in a communication to Dr. Alica Goldman, neurologist and researcher at Baylor College of Medicine, she inquired whether the family might consider donating tissue for their SUDEP research project. I did not know. I had to ask. On April 11, 5-year-old Rose, daughter of Steve and Devora Chavez passed away during the night. With an ache in my

heart, I needed to ask again.

One of the things that make the death of a child such a difficult loss is the sense of lost opportunity – that is, the opportunity for that child to grow up, live well, and leave the world a better place. We want our lives to make a difference, to leave a personal legacy that goes beyond material things – and we want this for our children too. We tend to think of a legacy as something it takes a long lifetime to create – as something left by elders. But while adults are concerned about who their children will become in the future, our children are already busy being someone in the present. We don't have to live long to leave a legacy – it is enough to have lived, loved and been loved.

Scott and Rose's parents loved them deeply, and that love extended to their “Dravet brothers and sisters.” In the midst of their anguish, each of

these families said “yes” to donating tissues for research, and along with Dr. Goldman, they have offered their support toward the development of a tissue bank for research of Dravet syndrome and SUDEP. They have left legacies of hope with the potential to benefit many children now and far into the future.

Helen Keller said: “Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.” Thank you, Scott, Jeanne and young Scott. Thank you, Steve, Devora, Anna and Rose. What a bittersweet thing it is to accept your precious gifts.



ASCENT attendees Karen Mull, Lisa and Haley Smith, and Laura Cossolotto in front of the IDEA League booth.

IDEA League Represented at ASENT Conference

By Karen Glenn

On March 5-7, 2009, representatives of the IDEA League attended the ASENT 11th Annual Meeting in Arlington, Virginia, USA. ASENT is the American Society for Experimental NeuroTherapeutics.

IDEA League representatives included Laura Cossolotto, President; Joan Skluzacek, Founder; Karen Mull, P.A. and parent of Christopher; and Lisa Smith along her daughter, Haley, who has Dravet syndrome. Between the group, they attended a variety of sessions on topics

related to neurotherapeutics, an information exchange and poster presentation, a networking reception, and a dinner symposium— Resource Allocation in Translational Neuroscience: Perspectives on Influencing the Pipeline. The moderator of this symposium was Russell Katz, MD, Director of Neurology Products for the FDA.

Along with learning more about neurological advances and networking with interested parties, the IDEA League also exhibited at the event to raise awareness for

Dravet syndrome and the organization.

Said Laura Cossolotto of the experience, “The ASENT 11th Annual Meeting was a wonderful opportunity to network with many professionals from all over the world to encourage both the development and advancement of improved therapies for individuals with Dravet syndrome and related sodium ion channel epilepsies.”

IDEA League Leads in Credit Card Program

By Karen Glenn

This past January, Capital One launched the Affinity Credit Card Program. This program allows non-profit organizations to create custom-designed credit cards. When used, these credit cards serve the dual purpose of raising both awareness and funds for their causes.

Thanks to the enthusiastic participation of members, the IDEA League currently has the highest rate of participation in this program of any

organization. Just in the first quarter of this year, donations from the Affinity Card program were \$228.20. We hope to continue to lead out in this endeavor, and raise even more funds as the year progresses.

If you haven't already, please consider applying for a Capital One Affinity Credit Card. It is a simple, painless way to give to an organization whose purposes you share. Then, each time you use the card

you will know that you are helping to improve services to children and families struggling with Dravet syndrome and related epilepsies.

To learn more about the Capital One Charity Affinity Program or to apply for a card with one of the three custom IDEA League designs, please visit online at www.capitalonecharityprogram.com/idealeague.



...the IDEA League currently has the highest rate of participation in this program of any organization.

Team Dravet Takes Washington!

By Krista Lazott

"Facing challenges arm in arm." That was the slogan carried around the National Mall as Team Dravet marched on Washington, DC during the 3rd Annual Walk for Epilepsy put on by the Epilepsy Foundation.

The walk, which took place on March 28, 2009, was a great opportunity for individuals and families touched by epilepsy to make a statement and raise awareness. Team Dravet, a group representing the IDEA League and ion channel epilepsies and enthusiastically put together by team captains Lisa Smith and Kim Skriba, was the second largest team walking in this national event. Eight families affected by Dravet syndrome were represented, and along with friends and supporters the group totaled 37-40 people. IDEA League members attending along with team captains included Kim Amend, Brenda Ferrell, Karen Mull, Kim Waters, Lori O'Driscoll, and Tricia Taylor. Not only did the team make their presence known, they were also able to raise over

\$4000, part of which will be going to directly to the IDEA League. This is the second year that Team Dravet has participated in this event.

The team captains worked together to find ways for the group to stand out from among the crowd of more than 8,000 people present at the event. Two large banners shared messages about Dravet syndrome and the IDEA League. Group members were also easily recognizable wearing bright orange caps and Team Dravet t-shirts. Many thanks to Karen Mull and her friend, Mark, for the hats and to Ruth Mayo, friend of Lisa, for the t-shirts, which were generously donated to all of the Team Dravet members free of charge.

As they walked around the National Mall, the group took the opportunity to meet and talk with other people who are also affected by epilepsy. They shared stories and educated as many as possible about Dravet syndrome. At one point, the whole team gathered to participate in the

"Tell Our Stories" project, where several team members were videotaped speaking about the struggles of Dravet syndrome and the fight to find a cure. Brenda and Tricia held up the Dravet Celebration Quilt, a work in progress designed to share the story of Dravet children from all over the world. This video can be viewed on the Epilepsy Foundation website at <http://epilepsyfoundation.ning.com/Video/personal-story-5>.

Bringing an end to a long day of fun and sharing, Lisa Smith's parents, Harlan and Dorothy Oelmann, kindly opened their home in Dumfries, VA, to all of the Team Dravet members for a lasagna dinner. The day was a wonderful experience of coming together and increasing understanding. Huge thanks go out to Kim and Lisa for putting team Dravet together and to everyone who participated in the walk. You are all Tiger Parents!



Team Dravet at the national Walk for Epilepsy in Washington, DC, USA.

Team Dravet... was the second largest team walking in the national event.



A portion of Mr. Johnson's book sales will benefit the IDEA League.

Book Sales to Benefit IDEA League

By Krista Lazott

I'd like to introduce you to an insightful new book titled 'Without Warning'. It's an intriguing way of looking at silent problems in the workplace and how to tackle those cumbersome obstacles one tends to push aside. We are all too aware how problems seem to be ignored and ultimately fester, and then "without warning" present themselves with enormous magnitude. A quote from the author says it best—"With great optimism, now anyone in your organization can have the ability to see these silent problems for what

they are and take simple steps to solve them ... without risk, penalty, or politics".

The author, Rodney Johnson, is an experienced and dedicated professional who has a keen sense about the ways of the business world. He has previously served as an advisor to the IDEA League. In this book, he has given the reader much vital information to use and put to work. His philosophy shares crucial building tools, opportunities to learn how to succeed and how to help organizations persevere in

these tough times.

To view more about Mr. Johnson and his book, check out the website at www.withoutwarningcoach.com. The book is available through Amazon.com and Barnes & Noble, however, thanks to the generosity of Mr. Johnson, it will shortly be available through the IDEA League online store at reduced cost, with a portion of the proceeds benefitting the League.



The Sun-Chau family

In the Spotlight

By Paula Lyles

Adorable, five-year-old Kirsten Chau lives in Hong Kong with her parents, Sally Sun and Dominic Chau. Dominic works as a chartered building surveyor, and Sally as a human resource director. Although Chinese is the family's native language, Kirsten speaks English in complete sentences rather than Chinese.

At the age of three, Kirsten was the first patient formally diagnosed with Dravet syndrome in Hong Kong. Like many of our children, Kirsten's seizure history is pretty much a textbook case of Dravet syndrome. Amazingly, despite her diagnosis, her full-scale IQ in the normal range. Using Kirsten's case for medical education, doctors have now diagnosed ten other children in Hong Kong. It is Sally's hope that awareness of Dravet syndrome will progress even further in their city.

Currently, Kirsten takes Epilim and Clobazam for seizures

and Vitamins C and B6, Omega 3 and Chinese herbs to help support her immune system. Although her seizure control seems to be improving with age, Kirsten's parents are always mindful that things may worsen at any time and that regression may occur as well. "Since we can't guarantee the future, we just continue to do the best that we can today," Sally says. "Our strength comes from our Christian faith."

Kirsten attends a regular kindergarten with a shadow teacher. Her favorite things may surprise you. She is more a fan of Gordon and Sir Topham Hat than Thomas the Train, and prefers Goofy to Minnie Mouse and Prince Phillip over Snow White! She is fond of puzzles and books and enjoys watching Baby Einstein videos and Disney Playhouse, too. And like her father, she enjoys golf. She strongly dislikes the sound of coughing and hearing news broadcasts. Nothing wrong with that, I

don't like hearing the news myself!

Life is very busy for Kirsten thanks to early intervention, extensive therapy, exercise, and a careful diet.

Traveling, the family's favorite pastime, had until recently been avoided due to Kirsten's seizures. However, after successfully traveling to Singapore and to Chicago for the Dravet Syndrome Conference during 2008, Sally, Dominic, and Kirsten are looking forward to a trip "back home" to Sydney next month. Although they are Australian citizens, Sally and Dominic feel it is best to stay put in Hong Kong, where their positions allow them to provide the private therapies which have benefitted Kirsten greatly.

"I feel so lucky to see Kirsten growing older," says Sally, "We trust God and follow him every day. Prayers are our strength now and forever!"

"Since we can't guarantee the future, we just continue to do the best that we can today," Sally says. "Our strength comes from our Christian faith."

Ryan's Lions Roar into Houston!

By Karen Glenn

Meet Ryan's Lions! Ryan's Lions is the team of supporters put together by Nina and Jeff Otchis in honor of their son, Ryan, who has an SCN1A mutation. The Otchis family and friends participated in the Houston Stroll for Epilepsy on Saturday, March 28, 2009. The event was held at the Houston Zoo—a perfect location for the Lion's to prow! And although it was unseasonably cold for Houston, with a wind chill in the 30's, 81 people showed up to support the cause. Walk-related donations were slightly over \$9,000, making Ryan's Lions the #1 Family Fundraising Team for the Houston/Dallas/Fort Worth area in their inaugural year!

The Otchis family followed up the walk with a fundraiser on April 14th at a local pizza restaurant, who generously agreed to donate 15% of that night's purchases to the team. Along with dinner, the evening also included a question and answer session about epilepsy by a representative of the local Epilepsy Foundation and a

raffle, which raised over \$1,000. The total raised for the two events combined has exceeded \$10,250 with half of the money going to the Houston Epilepsy Foundation and half to the IDEA League.

Says Nina, "The whole experience has been amazing and we highly encourage others out there to participate in their local events. Ever since Ryan's seizures started last year we've had lots of people ask what they can do and how they can help and we finally had an answer! It was also great to finally be *doing* something about these seizures instead of waiting around stressing and wondering when the next one is coming, will the emergency meds work, are we going into status or not – you know, the "everyday" concerns we all share."

"Getting the Houston EF to donate 50% of team proceeds to the IL was really as simple as asking." Nina added. "If it wasn't for reading something on the (IDEA League) site about Team CHAR BAR in

Colorado having a similar arrangement I never would have thought to ask. We also received donations big and small from very unexpected places, such as from several people we have no connection to but who were touched by our story. One of the craziest and most heartwarming came from our neighbor's sister who posted Ryan's website on her corporate intranet (where people post cars for sale, etc). That posting alone generated almost \$750 in donations. As I told my husband that very day—you never know where kindness grows. At first, we were very, very hesitant to put Ryan and our family out there, but slowly and surely did. We hope to duplicate our success in 2010!"

To read more about Ryan's Lions and check out the other ways that the Otchis family is raising money for epilepsy and the IDEA League, visit their website at Ryanslions.com.



Ryan's Lions pose together before the walk at the Houston Zoo.

"It was... great to finally be doing something about these seizures instead of waiting around stressing and wondering when the next one is coming..."

—Nina Otchis

Tiger Wish List

Tiger Wish List is a new addition to the newsletter. Here you can read about some of the goods, services, talents or other needs of the IDEA League that would help us in furthering our mission. Check back regularly—you never know when you might have just what we are looking for!

The IDEA League is currently in need of volunteers with a medical background to review applications for research grants. Work on this project is expected to begin in late

summer or early fall.

We are also looking for volunteers with a background in education willing to assist families with the IEP process.

The Policy Development committee is hoping for one more volunteer member from outside the US to help on their Tiger Team.

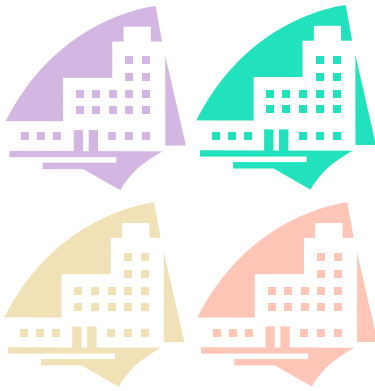
It's time to update the table banners we use at our booths when exhibiting at medical conferences and other venues. If you have

connections that help us get these printed at reduced cost, we would love to hear from you.

The Print Materials committee is looking for a volunteer fluent in both English and Spanish to assist in the translation our brochures.

To help in any of these areas, or if you have questions or other services you could offer, please contact Janice Stanley at Janice.s@idea-league.org.





...this association of clinics will work together to develop a unified standard of care to best meet the needs of children with Dravet syndrome.

CCR-CCN Initiative Underway

By Karen Glenn

One of the key objectives of the IDEA League for 2009 is the establishment of a network of epilepsy centers dedicated to providing optimal care to patients with Dravet syndrome and related ion channel epilepsies. As we reported in our last issue of *Channeling In*, Angela Black, MD, Chair the League's Professional Advisory Board introduced this initiative this past December at a dinner associated with the AES meeting in Seattle, WA, USA. Thanks to the hard work of Dr. Black and others, and to the keen interest of a number of clinicians, that goal is well underway.

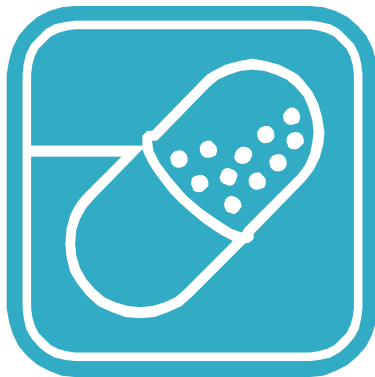
Dubbed the 'Collaborative Clinical Research and Comprehensive Care Network', or CCR-CCN, this association of clinics will work together to develop a unified standard of care to best meet

the needs of children with Dravet syndrome. Because Dravet syndrome is a multi-system disorder that has a broad impact on children physically and developmentally, the League is working with a number of respected epilepsy centers to provide evidence-based, family-centered medical care focused on maximizing seizure control, identifying and treating co-morbid conditions, and helping families find community support resources.

Roles of the IDEA League within the CCR-CCN will be to coordinate communication between the clinics, facilitate multi-center research, assist with physician training by sponsoring Grand Rounds, and to provide a wealth of clinical data for research via our patient registry, which is currently under development. A number of respected

epilepsy centers as well as experts from several prestigious academic institutions are now partnering with the IDEA League on this effort. These include Boston Children's Hospital, Duke University Medical Center, Children's National Medical Center, Miami Children's Hospital, Mayo Clinic, Gillette Children's Specialty Healthcare, Seattle Children's Hospital and Chicago Children's Memorial Hospital. It is hoped that other clinics will shortly join in this important partnership.

The CCR-CCN program will make appropriate treatment for children with Dravet syndrome and related epilepsies more widely accessible, improve early diagnosis, and ultimately contribute to a better understanding of ion channel epilepsies.



Laura has created a "road map" for families in order to answer questions and to make the approval process as easy as possible...

Help Getting Coverage for Medications

By Paula Lyles

It has been and continues to be a long, hard fight—a real TIGER fight—to get insurance companies in the US and Canada to cover two of the most successful medications used for treating Dravet syndrome: stiripentol (Diacomit) and clobazam (Frisium). Thanks to the diligent work of many IDEA League members and especially IDEA League President, Laura Cossolotto, there is good reason to celebrate as a number of families in our group have won the battle and are now receiving prescription coverage for these necessary medications.

Ed Safdie, pharmacist from Caligor Pharmacy in New York

and Mike Sharp, Pharmaceutical Director of Indiana Medicaid, have both been instrumental in helping with this process. Mike is thrilled to have the opportunity to really make a difference in the lives of our children by seeing that stiripentol and clobazam are approved in his home state of Indiana. He is now spreading the word about these medications and educating individuals in other states as well.

Both Ed and Laura encourage families to contact their congressional offices for assistance in the process. Ed states that "congressional offices really do like to work with our issues because our issues are issues of the heart.

It exposes some of the real work that they do on behalf of their constituency."

Laura has created a "road map" for families in order to answer questions and to make the approval process as easy as possible, but she warns that it can be a long and daunting process. "It's easy to get discouraged and give up," she says, "But for many that have persisted, it has paid off." For a list of insurers currently providing coverage, if you are interested in applying for coverage, or if you are currently appealing a denial and would like assistance, you can contact IDEA League President, Laura Cossolotto, at laura.c@idea-league.org.

Living with Dravet Syndrome

Courage

By Julie DeLara

I am in the family room with my sons Daniel and Michael at about 4 pm on a Monday night. Daniel is seven years old at this time and Michael is 9 months old. I am cooking, Daniel is watching television and Michael is toddling around. It appears to be a typical early evening with a family gathered together, relaxing, preparing dinner, and awaiting the arrival of their father and husband.

In our case, however, the tension is mounting. I turn periodically to watch Michael. Each time I turn around, I catch Daniel watching him as well. My heart is beginning to race and every time I hear a bump or a thud I whip around to see what it is. I can tell that Daniel is getting worried as well by the way his eyes dart back and forth from the T.V. to his brother. I say to Daniel, "Don't worry. He seems fine." I take a deep breath and exhale slowly. I stir my pasta. Then I hear a crash and Daniel saying urgently "Mom, Michael is having a seizure!"

Daniel and I leap into action. I run to Michael and crouch over him, rolling him to his side and away from the furniture. I grab the anti-seizure medication and give it to him. My seven-year-old calls 911 and says, "My baby brother is having a seizure. We live at 2712 Prairie Avenue. Please come quickly." Then he grabs a flashlight and runs outside into the darkness that ordinarily frightens him, to waive the ambulance to our home. I never asked Daniel for this assistance. He assumed these responsibilities out of love and a desire to help. I am awed by Daniel's composure and his courage.

My husband arrives home at the same time as the paramedics, filling my tiny kitchen with their big bodies,

their big boots and their equipment. I say to my husband, "Honey, don't take off your coat. We're going to the emergency room again." My thoughtful and steadfast neighbors, Jane, Pam, and Lynne, magically appear and turn off the stove, put food away and take Daniel to feed him dinner and wait with him until we return with Michael many hours later.

This was our routine at least once a week for about a year. Michael's seizures occurred often on a Monday, but not always. Often between 4:00 pm and 7:00 pm, but not always. Things have calmed down a bit since then, although we still call the paramedics from time to time to our home, to the beach, to Michael's preschool, to my mother's house and even once to the doctor's office. We carry the emergency seizure medication with us at all times, even when we go for a walk around the block.

We now have a diagnosis for Michael: Dravet syndrome, a severe and intractable form of epilepsy that has a spectrum of psychomotor delays from learning disabilities to severe mental retardation. It is one of the three most "catastrophic" epilepsies. Dr. Charlotte Dravet is a French neurologist living in Marseilles, France, and the condition was named for her. When we received Michael's diagnosis, we sent her an email in French. We wrote, "Our son has just been diagnosed with Dravet syndrome. We don't know what to do and we are in despair." She sent us an email within 24 hours. She wrote, "Courage. I will help your child."

We met with Dr. Dravet shortly thereafter. She examined

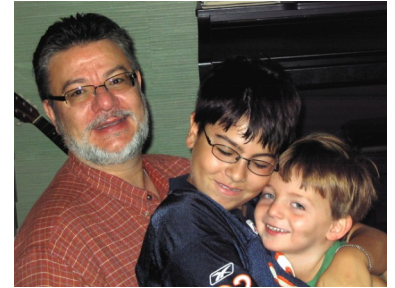
Michael and spoke to us at length. She told us his long-term prognosis was impossible to predict. He seemed to be doing well but that could change. Science knows very little about epilepsy. However, Dr. Dravet did give us an invaluable piece of advice--

"Have courage. Don't give up hope. Michael depends on you to believe in him and tell him that he will be okay."

There is an expression: "Desperation is the enemy of a parent with a sick child". It is so true. The grief can be overwhelming, paralyzing. It can leave you breathless. It is so hard sometimes to push it away, but of course you must pull yourself together to take care of your children. There is no one else.

Michael is 4 ½ years old now and doing better. He is a warm and engaging little boy with a sense of humor and full of mischief. Although he is behind his peers, his development continues to progress, defying the odds. We are lucky and we work hard with him to maximize his potential. Others that we know are not so lucky. Daniel is better as well. He is less traumatized, less worried about leaving Michael to go to school, or a friend's house or to visit his grandmother. As for my husband and I, our dreams for Baby Boy De Lara burned to ashes, but new dreams are rising and taking flight and we see their reflection every day in Michael's sparkling blue eyes.

Have courage. Don't give up hope. Your child depends on you to believe in him and tell him that he will be okay.



*Francois, Daniel and
Michael DeLara*

*Have
courage.
Don't give up
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him that he
will be okay.*



Rose Chavez

June 19, 2003-April 11, 2009

She captured the hearts of those around her with her beautiful, curious eyes and her fierce determination.

In Loving Memory

By Joan Skluzacek

Rose Louisa Eisenberg Chavez was born June 19, 2003 to Steve and Devora of Seattle, Washington. Though it was soon apparent that the challenges of Dravet syndrome would be a part of her life, Rose still shined through sweet and clear. She captured the hearts of those around her with her beautiful, curious eyes and her fierce determination.

Rose was fortunate to have incredible teachers and learning experiences throughout her life. She had a wonderful birth-to-three experience at the Boyer Children's Clinic and then two happy years at Green Lake Elementary. She was enjoying kindergarten class at Thornton Creek School, where her father has been a teacher the last 17 years. Many of the other students in the school befriended Rose and helped her with many of her activities

throughout the day. One of the teachers who worked with Rose called her an "ambassador," building a bridge between students with special needs and other students in the school.

Rose loved her weekly swimming lessons, watching Elmo videos, running wild in malls, and taking long baths with her sister, Anna. Two of her recent accomplishments were learning to use the potty and controlling her DVD player. Rose never tired of singing her favorite songs (Hello song, Slippery Fish, Itsy Bitsy Spider) with her parents and grandparents. She loved playing Peek-a-Boo and delighted in saying "mei mei" (excuse me) when she heard people sneeze or cough. Lately, she would even fake a sneeze just to be able to say "mei mei." (In her memory, her family has adopted this tradition).

Rose passed away unexpectedly in her sleep of SUDEP in the very early hours of April 11, 2009. She was 5 years old. On Friday, April 17, more than 400 people participated in celebrating Rose's life, and many warm and funny stories were shared. In tribute to Rose, everyone sang "Elmos's/Rose's song." In her honor, her school has plans to build a special playground area that is designed for children with special sensory needs.

In the hopes that good can come from their loss, her parents have established a fund through the IDEA League toward the development of a "Clinic of Excellence" for Dravet syndrome in Seattle that will be part of the Collaborative Clinical Research and Comprehensive Care Network (CCR-CCN) for this disorder.



French Family Gathering

On May 30, 2009, families who have previously only met through the internet will have the opportunity to gather face-to-face. Members of the IDEA League's French Forum will assemble near Versailles, a suburb of Paris, to become better acquainted and to learn more about the condition their children share. Approximately fifteen families are planning to attend the get together. The group has a full day of activities planned, including meeting with physicians who are leading experts in Dravet syndrome and related conditions. Members of the IDEA League's Professional Advisory Board Drs. Charlotte Dravet, Rima Nababout and possibly Catherine Chiron have graciously agreed to join the families, where they will hold an informal question and answer session. In addition, the group will also hold discussions regarding the formalization of a French chapter of the IDEA League. Many thanks to the families who have planned this event!



Medication Assistance Fund Re-opens

Applications will once again be accepted for the IDEA League's Medication Assistance Program beginning on Monday, May 4, 2009. Applications will be reviewed and approved on a first-come, first-served basis and as funding allows. The Medication Assistance Fund is a fund of last resort and all other resources should be exhausted before applying. Families who wish to receive assistance will also need to provide a prescription from their child's physician, a letter of medical necessity and income verification. Qualifying families can expect to receive 10 to 50% of the cost of their stiripentol covered for one year.

Application forms are available on the IDEA League's website at www.idea-league.org. For more information, please contact Angela Black at dr.black@idea-league.org.

Mother and Son Team Up as Advocates

By Karen Glenn and Brenda Ferrell

Meet 14-year-old Brian Ferrell. Brian was one of 50 children between the ages of six and fifteen chosen from applicants across the US to participate in the Epilepsy Foundation's Kids Speak Up! Program. At the same time, his mother, Brenda Ferrell, participated in the Public Policy Institute Report. These two programs invite kids and parents to share their stories of living with epilepsy and how the condition affects their lives with leaders of Congress. Brian has Dravet syndrome and Brenda discovered and joined the IDEA League just this past year.

Brian and Brenda traveled together to Washington, DC as representatives of the Epilepsy Foundation of East Tennessee. While the KSU and PPI took place March 28-31, mother and son chose to arrive a few days early in order to join Team Dravet for the National Epilepsy Walk. Said Brenda of that experience, "This was one of the many highlights of our trip for me—finally meeting seven other families with a Dravet child. All of the sudden, I knew that I had another family—the Dravet family. Brian was so excited to be able to make some new friends. These included the kids, but also the parents, and the seizure dogs! He loves people, but I'm afraid that he loves dogs even more."

After the fun of participating in the walk, it was time to get to work. Brian and Brenda spent two days in training and workshops to learn how to be effective advocates on Capitol Hill. Brian joined many other children with epilepsy as they toured the city, learned about how the government works and how to 'speak up and speak out' about their

epilepsy. Finally, they were given time to draft their own personal stories, which they would share with congressional leaders on March 31st.

While the kids had their KSU program, the parents, along with epilepsy affiliate representatives, were in separate workshops for the Public Policy Institute. They met with Epilepsy Foundation leaders and representatives from a number of government committees where they heard updates on many issues relating to health and epilepsy currently facing Congress and learned how they could make their voices heard.

The culmination of the programs was on Tuesday, March 31, when all the KSU and PPI participants descended on Capitol Hill to visit the Senators and Representatives from their respective states in order to share their messages. Brenda gave a portion of her message then introduced Brian so he could share his own comments.

Said Brenda, "I was amazed and so proud of Brian when I heard the story that he had prepared all by himself, without me there to coach him. The KSU assistants had written his story down for him, so when it came time to share it with the senator, Brian said, 'Mom, I need my notes.' I frantically dug in my bag to find them and then he proceeded to 'read' the notes (he did read some of the words, but recited most of his message). He named each drug that he takes by name! 'I take Depakote, Topamax, folic acid, clobazam, stiripentol . . . One day I had a seizure on the bus. The bus driver stopped so the nurse could give me the Diastat. Then the ambulance

came, and the police cars, the fire truck, the ladder truck, the pumper truck, and the police motorcycle.' In reality, not all of these came, but these are the vehicles that he loves the best, so he embellished his story a little bit." When Brian had finished, Brenda shared more of her concerns with the Tennessee Senator.

Previously, while with the other Team Dravet families, Brenda had asked them to tell her what they would like her to say to the Epilepsy Foundation and to the congressional leaders. "I made notes and then as the opportunities arose, I voiced these Dravet family concerns to the groups who have the power to make a difference. I felt that I was not only representing the families of East Tennessee," stated Brenda, "but also our Dravet families. I took this responsibility seriously, jumping up to be the first person to ask a question during question and answer sessions, putting our IDEA League family and physician brochures in the hands of all the doctors present, as well as the representatives from the state affiliates, administrative personnel from the national Epilepsy Foundation, and all the congressional aides who were present over the course of this workshop. If these people had not heard of us before, they will certainly remember our name now!"

Many thanks to both Brenda and Brian for having the courage and tenacity to **Speak Up!** about epilepsy and Dravet syndrome.



Brenda and Brian Ferrell

"If these people had not heard of us before, they will certainly remember our name now!"



Brian addresses Tennessee Senator Lamar Alexander



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Updated Pamphlets Now Available!

By Karen Glenn

The IDEA League's educational pamphlets have recently been updated. *Understanding Dravet Syndrome—A Guide for Parents* is an introduction to Dravet syndrome perfectly suited for the families of newly diagnosed patients, and for sharing with educators, caregivers and other interested parties. It discusses what Dravet syndrome is and the general course of the disease, and also includes information about the IDEA League.

Dravet Syndrome: Improve

the Outcome—A Guide for Physicians gives a more technical medical explanation of Dravet syndrome and related ion channel epilepsies. Topics include epidemiology, genetics, differential diagnosis, treatment options, and comorbid conditions. This pamphlet is appropriate for medical professionals and others looking for a more in-depth understanding of the condition.

Both pamphlets have been reviewed and approved by the Professional Advisory Board of

the IDEA League. If you are interested in obtaining copies of these pamphlets, please contact Janice Stanley at janice.s@idea-league.org.

Both of these pamphlets are currently being translated into both French and Spanish. Many thanks to the members of League assisting in this important endeavor. This is expected to be a somewhat extensive process, in order ensure medical accuracy. We will be certain to inform the membership as soon as these translations are available.

Dates to Remember

APRIL 2009

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| 25 | Ciara's Butterfly Bash, A Benefit for Children with Dravet Syndrome—Sponsored by the O'Driscoll family | Greenwich, CT, USA |
| 25-2 | American Academy of Neurology Conference | Seattle, Washington, USA |

MAY 2009

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| 8-10 | Midwest Mom's Retreat | Indianapolis, IN, USA |
| 13-19 | Epilepsy Awareness Week | Australia |
| 18-24 | National Epilepsy Week | United Kingdom |
| 29 | Elvis Tribute Night Fundraiser to benefit the IDEA League UK | Chester, UK |
| 30 | French Family Gathering | Paris, France |

JUNE 2009

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|-------|--|-------------------|
| 12-15 | UK Family Get-Away at Butlins Resort | Skegness, England |
| 20 | Walk for Epilepsy with Team Dravet Sponsored by Suzie Englehardt | Washington, USA |

AUGUST 2009

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| 30 | 2nd Annual Chester Challenge Cycling Race/Fundraiser To benefit the IDEA League UK | Chester, UK |
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SEPTEMBER 2009

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| 7-13 | Epilepsy Awareness Week(2) | New Zealand |
| 19 | North East Family Gathering | Monroe, CT, USA |

OCTOBER 2009

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| 2-4 | Camp Courageous Dravet Weekend | Kentucky, USA |
| 3-6 | Dravet Syndrome: 30 Years Later | Verona, Italy |
| 14-17 | Child Neurology Conference | Louisville, KY, USA |
| 17-20 | Society for Neurosciences Conference | Chicago, IL, USA |

DECEMBER 2009

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| 4-8 | American Epilepsy Society Conference | Boston, MA, USA |
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