



CHANNELING IN

The Newsletter of the IDEA League

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

Conference Brings Together Families to Share, Connect, Learn

By Angie Mimms

The title of the IDEA League's 2010 Family Conference—Sharing Research, Sharing Hope—beautifully sums up the four days that families from around the world spent together learning about the epilepsy that profoundly affects their lives.

About 200 participants, some from as far away as Australia and Israel, attended the Aug. 26-29 conference at the Hyatt Regency in Greenwich, Connecticut USA. Sixteen speakers presented information pertaining to Dravet syndrome and related epilepsies. Topics ranged from sodium ion channel mutations to developing hopes and dreams for disabled children to restorative yoga for caregivers.

"I was incredibly inspired," said Marilyn Baker, IDEA League Executive Director, commenting on the strength and determination of the families attending. "These parents are all amazing heroes to me."

The families hailed from 14 countries. They shared meals, experiences, tears and laughter and were joined by top medical experts, including Dr. Charlotte Dravet. The experts provided valuable

information, League President Laura Cossolotto said, and further impressed her with their "true and genuine interest in helping and caring for our families."



Dr Charlotte Dravet presents at the IDEA League family conference.

Laura, who is also the mother of a child with Dravet syndrome, said the conference provided families a supportive atmosphere where there was no need for explanations or apologies—a welcome change for many. When a child seized, doctors responded and other parents helped. The bonding among parents was uplifting and one of the top reasons to attend the conference, she said. "(Parents) do want to learn but

that's only a part of it."

Held every two years, the international conference was the IDEA League's third. Additions to this year's agenda included group discussions based on the Dravet child's age and on family locale. Laura said those sessions got good feedback as did the change from one-on-one doctor consultations to group consultations.

League member Jennifer McMahan said the group consultations promoted a broader perspective. "I learned not only from the doctor but from the other family," she said.

Another new and memorable event occurred after dinner one evening when a parade of families stepped to the microphone to introduce their children with Dravet syndrome. About 40 Dravet children attended the conference along with at least 20 siblings.

The IDEA League thanks all the volunteers who made the conference possible. We especially wish to thank all of the speakers for sharing their time, expertise and generous hearts with our families.

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This past summer's conference was amazing in so many ways; not only was the sharing of information and support a life-changing experience, but the scientific exchange between researchers was extraordinarily hopeful.

On the first night of the conference, I attended dinner with Drs Charlotte Dravet and Phillip Pearl and listened to the comparison of diagnostic techniques 30 years ago versus those employed

today. I was inspired as Dr. Dravet, who has since retired, passionately explained her original findings to Dr. Pearl, who confirmed that her discoveries were still relevant today. And Dr. Pearl proved to be a man of many surprises when later that evening at the cocktail party, we were all charmed by his jazz piano performance extraordinaire!

It was wonderful to see Miami Children's Hospital represented by most of their Dravet syndrome medical team—nurses, social workers, and Dr. Parul Jayakar, who helped us to understand the complex genetic causes of this disease.

While all the presentations were valuable, two standouts came from IDEA League members Karen Mull and Nicole Villas. As both a mother of a child with Dravet syndrome and a physician's assistant, Karen has an excellent perspective from both sides of the fence. Meanwhile, Nicole's parent-friendly explanation of genetic mutations was

nothing short of brilliant. Watch for both of these presentations to be posted on our website shortly.

A critically important aspect of our meeting was the personal exchange that took place between the doctors and the parents. Dr's. Linda Laux, Christina Bergqvist, Eric Kossof, and Beverly Wical all took the time to talk to dozens of parents, giving answers to their many questions, and gathering first hand information that they took back with them to their clinics.

It is through this exchange of information and partnership that we advance medical management of this condition, improve lives, and eventually find a cure for individuals with Dravet syndrome and their families.

Second Annual Research Award Announced!

By Karen Glenn

The IDEA League is pleased to announce the establishment of the 2011 Derek Rudawsky Research Award! This \$30,000 grant, which will fund research specific to the understanding and treatment of Dravet syndrome and related conditions, is the second of its kind to be awarded by the IDEA League and has been made possible thanks to the loving efforts of the Rudawsky family and friends. The Rudawsky's teenaged son, Derek, is diagnosed with Dravet syndrome. *See the related article on page 5 of this issue.*

Established and new investigators are invited to apply for this award. Applications are due February 1, 2011. The winner will be announced on March 1, with the two-year grant beginning April 1. Applications will be judged according to relevance, quality of research lab, scientific merit, and potential for new therapeutic approach as determined by the IDEA League's Scientific Research

Review Committee, a distinguished group of research scientists.

The Rudawsky family took up the challenge to raise the funds for this grant less than one year ago. They are the first to reach the necessary total of \$30,000. We thank them for their tremendous work and generosity, which will assist us in finding answers to this challenging condition.

Shares Staci Rudawsky, "Derek's struggles with Dravet syndrome began when he was 6 months old. Like other families with children suffering from this diagnosis, we have tried so many drug, diet, naturopathic and homeopathic treatments and, unfortunately, have not found a cure or a treatment that adequately controls Derek's seizures. Despite his daily struggles, Derek is still the sweetest child you could ever meet. Believe it or not, he has never had a temper tantrum in his 15 1/2

years of life. We would love to be able to improve Derek's condition, the condition of others suffering like Derek, and all of our families."

She continues, "We feel fortunate to have found the IDEA League, which provides us with support and advice, and we were thrilled when this organization offered the opportunity to fund research to hopefully find better treatments and maybe some day a cure for this disorder. We are grateful for our many friends and family who helped us reach our goal to fund a research project. And we won't stop now; we hope to fund a second research grant some day."

For a grant application, guidelines, and inquiries; or to learn more about establishing a named research grant, contact Marilyn Baker, Executive Director, at Baker@IDEA-League.org or 443.607.8267.



In the summer of 1999, we wheeled Nick into an exam room to meet Dr. Beverly Wical. With his 7th birthday approaching, our family was afraid he might not survive to see that day. He was having many types of seizures, and more of them each day than we could count. There was almost never any real recovery between seizures. He had stopped using the few words he'd had left upon starting kindergarten. He was withdrawn, in part due to frequent migraine headaches. He struggled with such severe tremors that he couldn't walk safely or feed himself. He had little interest in eating

and was losing weight. He couldn't focus on much of anything or even get a good night's sleep. The doctors that had been seeing him were confused and could not explain what was happening to this child who had once seemed the picture of health. None of the treatments they tried worked.

Dr. Wical correctly diagnosed Nick with Severe Myoclonic Epilepsy of Infancy (SMEI), now called Dravet syndrome, and started him on a course of treatment consistent with that diagnosis. Things quickly began to change for the better.

This October, Nick celebrated his 18th birthday and entered his adult life in the company of family and friends. Like any 18-year-old might, he smiled and blushed while we sang the birthday song to him. He blew out the candles with the help of his siblings and a friend who shares the experience of having Dravet syndrome, and he forked down his cake and ice cream with gusto. Nick has been enjoying good seizure control. He's been growing and is nearly as tall as his parents. He meets most of his own mobility needs by walking, he skis

and he rides a bike. Next June he will walk in commencement ceremonies with his graduating classmates. He was just measured for his cap and gown. We are planning for a future we were afraid he might not have.

This is the difference that an accurate diagnosis, appropriate treatment, coordinated comprehensive care and an atmosphere of collaboration and support have made in the life of one person with Dravet syndrome. Nicholas' improved condition upon diagnosis and corresponding treatment has been inspiring. Now the IDEA League is helping others to receive the same opportunity, often at much younger ages and many from the very beginning of their journey. It is exciting to think about what their 18th birthdays and school graduations might be like!

Plains States Families Gather

By Joan Skluzacek

On October 2, 2010, members of the IDEA League came together for a U.S. Plains States-based family gathering in the Upper Midwest location of Afton, Minnesota. The families of 15 children and youth with Dravet syndrome from Minnesota, Iowa, South Dakota and Kansas took advantage of the rare opportunity to socialize in person, discuss their experiences raising children with Dravet syndrome, and increase their understanding of the disorder. The approximately 60 participants included moms and dads, brothers and sisters, grandparents, aunts, uncles, cousins, caregivers and close family friends. The event was organized and hosted by the Paul and Joan Skluzacek family at their home.

Dr. Beverly Wical of Gillette Children's

Specialty Healthcare in St. Paul and Dr. Katherine Nickels of the Mayo Clinic/ Eugenio Litta Children's Hospital in Rochester joined in the event, bringing members of their own families to share in the experience. Following a potluck feast, the children had a great time painting pumpkins and enjoying the outdoors while the parents had the opportunity for some adult discussion, as well as questions and answers with the doctors.

Special thanks are extended to Drs. Wical and Nickels, and also to IDEA League President, Laura Cossolotto, for generously sharing their time with the group.

Said Carmen Herea, mother of Emma, "It was wonderful to gather together so



Children paint pumpkins during the Plains States family gathering.

many families with kids that have Dravet syndrome. It was a great opportunity to have the doctors speak in a more familial environment and it was nice that they came. I think the kids had a wonderful time and the food was awesome."

Get to Know Our New Board Members

By Karen Glenn



Tina Catterall



Jerry Glenn



Lisa Smith



Ryan Day

The IDEA League is pleased to welcome four new members to its Board of Directors. Their varied backgrounds and talents will bring increased depth and experience to the organization's leadership as we further our efforts to meet the needs of families dealing with Dravet syndrome and related conditions.

Tina Catterall is a co-founder and managing partner of Global Interactions LLC. Her background includes over 20 years in academic and industry research in the fields of immunology, autoimmune diseases and tumor biology.

Tina says she became interested in working with the IDEA League after learning about Dravet syndrome and then reading our website. Her background is in developing programs that communicate scientific and clinical information to healthcare providers, so her hope is to extend the great work that has been done by the IDEA League to communicate important information to families and care providers. Says Tina, "I am honored to be on the Board of Directors and look forward to working with my colleagues to make life better for patients and their families."

In her spare time, Tina enjoys studying French (she and her husband, Bill, are living in France for 3 months), gardening, traveling and keeping up with their busy family.

Jerry Glenn has a Bachelor's Degree in Business Management with an Accounting emphasis as well as over 20 years' experience working for a business

that provides full supply-chain services focusing on clients with computer software and hardware products. He also has extensive years of volunteer service in both the Boy Scouts of America and in a variety of church leadership positions. He plans to put his business background to work in helping the IDEA League with both short- and long-term planning.

Says Jerry, "I've watched as my wife has spent many, many hours learning about epilepsy and Dravet syndrome and volunteering for the IDEA League. When her term on the Board of Directors was ending, I felt strongly that I needed to step up. I am excited for the future of the IDEA League and for the opportunity to be a part of building on the tremendous foundation of services the organization provides to families struggling with Dravet syndrome and related conditions."

Jerry and his wife, Karen, have six children, including Amelia, their 16-year-old daughter with Dravet syndrome. They reside in Orem, Utah USA.

Lisa Smith has a Bachelor's Degree in Business Administration with a concentration in Sports Management and has worked in the fitness industry for over 20 years, including owning her own personal training business. Since the birth of her twins, Peyton and Parker, she has become a full-time, stay-at-home Mom. She is actively involved with her church as well as her children's Montessori school, which she and her husband, Bobby, helped to bring to their community.

In addition to twin boys, Lisa and Bobby

are also the parents of 10-year-old daughter Haley. Shares Lisa, "It took six-and-a-half long years to get Haley's diagnosis of Dravet syndrome. Since receiving a name for her condition, I have been drawn to volunteering for the IDEA League and helping other families struggling with this difficult disorder." Lisa has spear-headed 'Team Dravet', a group of families and friends that have walked in the Epilepsy Foundation's National Walk for Epilepsy, among many other endeavors for the League. Team Dravet has been the largest individual team at the walk for the past two years.

Ryan Day has worked in Government Affairs/Relations for the past five years. He is currently the Associate Director of Government and Public Affairs for a professional association in Washington, DC USA. His experience has included grassroots campaigns, legislative language review, and direct lobbying. He has particular expertise in IT solutions for advocacy.

Ryan is married to Marissa and they have two young boys, Haiden, age 2 and Brooks, age 5 months. Haiden was diagnosed with Dravet syndrome at the age of 15 months. Says Ryan "I knew when Haiden was diagnosed that I had to do more than just get through each day. I couldn't fix his DNA, but as a member of the IDEA League at least I can do SOMETHING and hopefully together we can help find a cure."

Jerry and Lisa are serving as Directors. Tina has taken the Secretary position and Ryan is serving as Vice President.

Siblings Raise Funds In Honor of Cousin

By Karen Glenn

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Above: Ethan Widoff (left) and Molly Widoff (right).

Derek's Dash 2010 was a soaring success, garnering over \$35,000—more than enough to establish a two-year research grant as part of the IDEA League's Funds of Hope program. The grant will be named in honor of the event's namesake, Derek Rudawsky.

This is the second annual Derek's Dash, a 5K walk/run to raise funds and awareness for Dravet syndrome. The event was founded by young Ethan Widoff in honor of his cousin, who valiantly braves the frequent seizures and developmental challenges that accompany this diagnosis.

This year's event took place on a sunny August 29 at Village Greens Park in Greenwood Village, Colorado, USA. It was co-hosted by 14-year-old Ethan and his 10-year-old sister, Molly. Many of their school-aged friends also volunteered to take leadership roles. Over 200 supporters attended the race,

which included a silent auction as well. More than 40 friends and neighbors volunteered at the event, including high school classmates of Derek.

Said Ethan of the day, "It was an amazing experience because of all the lives that we hope we will be able to touch. From the beginning we have said that we won't give up till we cause a change by finding a cure, and we look forward to next year. To all the families who have children who suffer from Dravet syndrome, be strong because things are going to get better!"

Molly added, "It is amazing what kids can do. It really depends on how big of a heart you have. I hope that the money that we raised will someday find a cure for Dravet syndrome for Derek and other kids like him."

"We are always so amazed at how much work our nephew and niece put into this

event." shared Staci Rudawski, Derek's mother. "We are very grateful for all of their hard work and the opportunity to support Dravet syndrome research."

Edie, mother to Ethan and Molly shared, "One of the benefits I see of doing this event, beyond raising the money for the IDEA League and hopefully helping to find a cure for Dravet syndrome, is that our community has become more aware of seizure disorders and the challenges that face those who have to deal with it every day."

The Widoff team garnered support from an impressive variety of sponsors,



Derek Rudawsky

including the Colorado Rockies baseball team and financial giant Merrill Lynch. An anonymous donor also agreed to match any funds raised, up to \$2000.

Tremendous thanks to Ethan, Molly, the Widoff and Rudawsky families, and everyone who volunteered and supported this fantastic event. And congratulations to all of you for reaching your goal!

Newsletter Redesign

You may have noticed that *Channeling In: the Newsletter of the IDEA League* is sporting a new look! The updated layout is timed to honor our 4th anniversary edition. The newsletter has been published quarterly since the fall of 2006, and shares happenings within the organization and topics of importance relating to Dravet syndrome.

In the Spotlight

By Paula Lyles



*Fritz and Todd Peterson (top),
and son, Noah (below)*

Meet the Peterson family: Todd, Frances—who goes by Fritz—and Noah. The Petersons attended their first IDEA League Conference in August of 2008. It was in those four days that they learned

more about Noah's Dravet syndrome than they had in the previous ten years of his life.

The Petersons live in Cheyenne, Wyoming USA where the social services they receive are good, but they have to travel to the children's hospital in Denver, Colorado for Noah's medical care.

Todd and Fritz have been tireless advocates for Noah through multiple hospitalizations, a go at the ketogenic diet, a boatload of medications tried and failed, a VNS implant, a successful corpus callosotomy to stop drop seizures, a g-tube placement, and much more. After a long and very rocky road, things are much better than they were. Noah's seizures are down from hundreds or thousands to 2-6 per month.

"Never give up; never give in," Todd

says, quoting a motto he and Fritz have clearly taken to heart. "As long as there was a new option to try, we did. You keep looking and keep fighting." Noah turns 13 in January, and at this point the Petersons feel they have lots to be thankful for. "If Noah never gets better than he is now, we're in a good place," Todd told me.

Todd describes their Barney-lover, Noah, as a happy, friendly, outgoing boy who touches the lives of those he meets. He doesn't use words to do so, as Noah utilizes a communication device to make his wants and needs known.

"Noah has taught me patience and not to take the little things in life for granted," Fritz says. "We keep fighting because he is so worth it!"

Fantastic Fundraising Across the USA

By Angie Mimms

IDEA League families across the United States are rocking, walking, running, swimming and biking to support the IDEA League in its mission to serve children and families with Dravet syndrome and further the search for a cure for this challenging condition.

In Cheyenne, Wyoming, Fritz and Todd Peterson organized "Rock the Plaza." Classic rock and blues band Another Kind of Magick put on a great show in downtown Cheyenne Aug. 14 before 300 to 400 people. The event also featured pizza, beer and wine, and raffle prizes including a \$300 gift card from Southwest Airlines and a .22 rifle. The almost \$7,000 raised was split between the IDEA League and the Wyoming Epilepsy Association. Fritz and Todd, whose son Noah has Dravet syndrome, presented a check to the IDEA League at the 2010 conference.

Teresa and Wayne Stephens helped organize Anna's Walk at Miami Whitewater Forest on Oct. 2 in Harrison, Ohio, near Cincinnati. Wayne's employer, Siemen's Industry Inc., sponsored the event, which raised more than \$5,800 in honor of the couple's 7-year-old daughter. Anna's two older brothers were among the 110 people who attended the one-mile walk. Walkers enjoyed donated refreshments and entered drawings for tickets to the Cincinnati Bengals-Cleveland Browns Dec. 19 football game and passes to the Cincinnati Zoo.

Just a bit south, Erica Crump held a walk at a park in Walton, Kentucky, in honor of her daughter Grace, who has Dravet syndrome. About 50 people turned out on the mild Oct. 23 morning. Joining Grace for the walk were two other area children with Dravet syndrome, Melorah

McMahan and Anna Mimms. Area businesses donated pizza and desserts and two local television stations covered the event. At press time it had raised more than \$500 and donations were still coming in.

On Oct. 31, Ashley Wood raced for a cure for Dravet syndrome. The triathlete and mother of 2-year-old Piper, who has Dravet syndrome, defended her title as first amateur woman finisher at the Marin Triathlon in the North San Francisco Bay Area in California. She finished with a time of 2:18:09.7 and had raised more than \$30,000 at press time for the IDEA League. Ashley and husband Tim have three children. The family raised about \$25,000 in 2009, and they are grateful for a generous donation from First Republic Bank that contributed to their fundraising momentum this year.

Thanks to all the IDEA League members who reach inside themselves and out to their communities to raise money to find answers for Dravet syndrome. You rock! And walk! And bike and run and...



Samedi 23 octobre 2010 9h - 17h
Assemblée générale - Rencontre IDEA League France

The poster for the ILF Annual Meeting

IDEA League France

French families affected by Dravet syndrome gathered on October 23 for the annual meeting of IDEA League France. Said Carolin Wenzel, "It was a very nice and productive gathering. We had about 60 people in attendance and more than 10 children."

In the morning, Meryl Asselino, President, gave the annual report of the activities of the association, which was approved by vote of the general assembly. Some changes in the governing Board took place and the Officers now consists of: Meryl Asselino, President; Carolin Wenzel, Vice President; Stéphanie Legras, Secretary; and Claire Quintard, Treasurer.

It was decided to change the name of the organization, as IDEA League is difficult to pronounce and understand

Chapter Corner

By Karen Glenn

for the French. The new name of the organization is **Alliance Syndrome de Dravet**.

Three presentations followed after a group lunch, They included a sociological overview of the Dravet syndrome childhood population by Stephanie Legras, a discussion of the accessibility of Diastat within the French public school system, and a summary of international ongoing research by Sue Goodliffe. Dr. Rima Nabbut gave some concluding remarks.

IDEA League UK

The IDEA League UK has been very busy organizing a range of fundraising events including the Bupa 10K run for next May bank holiday. At the beginning of October, they were delighted to attend the Global Symposium on Dietary Treatments for Epilepsy in Edinburgh, Scotland. Their conference is taking place November 6, and with over 125 delegates registered, it should be an informative day for families and professionals alike. More details to follow in the next issue of *Channeling In*.

Dravet Groep Nederland

On Saturday October 9, Dravet Groep Nederland had its first meeting. About 50 parents gathered to listen to a very interesting presentation from neurologist Dr. Boudewijn Gunning, and to share experiences and advice. Many valuable

topics were discussed, including: gene mutation and inheritance, the prospects of children with Dravet syndrome, behaviour problems, and treatment of life threatening seizures. Dr. Gunning listened to the concerns of parents and answered many of their questions. At the end of the meeting, the new Dutch brochure about Dravet syndrome was officially presented.



Maaïke Ballieux of the Dutch Epilepsy Association, neurologist Boudewijn Gunning, and Myra de Groot of Dravet Groep Nederland receive the first

The next meeting is expected to focus on Basic Life Support and the use of emergency medications. Date and place will be forthcoming.

Calling All Australian IDEA League Families!

A Dravet Family Conference is scheduled for Saturday and Sunday March 19-20, 2011 in Melbourne, Australia. Saturday's agenda will consist of presentations on a variety of topics, including: an overview of Dravet syndrome, eating problems, behavioral issues, educational options, and services for families. Presentations will run from 10:00 am until 4:00 pm in the Ella Latham Theatre at York Children's Hospital.

Sunday will be an informal day for families, with venue and activities still to be determined.

All Australian families are encouraged to mark the dates of this event in their calendars and plan to attend, if possible. For further information, you may contact Jean Ewing at jewing@epilepsy.asn.au.



*Jemima Rose Simmons
October 9, 2008–October 8, 2010*

Jemima Rose Simmons was born to parents Olivia and James Simmons, and two-year-old sister Charlotte, of Sydney Australia on October 9, 2008.

At 6 months of age, Jemima had her first seizure; it was a 12-minute focal seizure. The following four months brought more unprovoked seizures, both focal and generalized tonic-clonic, at the rate of one or two per week. At 10 months old, Jemima tested positive for a mutation in the SCN1A gene. While the confirmation was shattering, Jemima's family could

In Loving Memory

By Jennifer May and Olivia Simmons

stop looking for answers.

Jemima was taken off of Tegretol and placed on Topomax. From that time forward, she only had convulsive seizures with fever. Shortly after her first birthday, she began to have absence seizures and more recently, she became photo sensitive, which began to cause some partial seizures.

On October 8th, 2010, one day before her second birthday, Jemima passed away in her sleep. Her mother, Olivia, explains, "I have thought often of Jemima's last day. It has taken on an absurd importance to piece together everything I can about that Thursday, hour by hour, but I can't because it was a truly unremarkable day. I can remember her running round laughing with Charlotte before bed, wearing a knitted pink hat she had found. I also remember that I could not find a clean pajama top, so I randomly plucked a different top; it was pink and had the word Angel emblazoned across it. It was this she was wearing when I put her to bed that night." Olivia checked on

Jemima before she went to bed at 10.30 pm, and she was fine. She had an EMFIT seizure monitor in her cot, which Olivia knew was working; however, Jemima died sometime in the night. Although tests are being conducted to rule out any other conditions, SUDEP is most likely the cause of her passing.

Jemima was a very happy little girl. She walked through life with a toothy grin and was full of mischief. Her capacity for love was enormous. One of her most recent words was cuddle (pronounced "duddle") and one of her mother's happiest images is of her running across the room to greet her father, throwing herself at his knees, shouting 'duddle' as she did.

Of being Jemima's mum, Olivia shares, "It has been frightening and painful; it has also been joyous, exhilarating and full of laughter. Most of all, it has been a privilege. Jemima has put life into perspective for us. All that really matters is that the people you love are happy and healthy and that you give them a Jemima-sized hug every single day."

Cyclists Ride for IDEA League UK

By Jennifer May

The Discover Adventure website gives the event a rating of "tough," but six fearless men in the UK "did it for Dravet!"

The Paris to Geneva Cycle Challenge is an event coordinated by Discover Adventure, a UK organization who specializes in fundraising through trekking and cycling challenges around the world. On Sunday, September 5, a group of 30 cyclists supporting various charitable organizations met under the Eiffel Tower in Paris to begin their adventure. On each of the next four days, they would complete a course of approximately 80 miles, finishing at Lake Geneva in Switzerland with a total of 324 miles logged. Whew! Discover Adventure describes the route as beautiful with "rolling chalk hills, quiet woodland and



The cyclist pose before the challenge.

rural plateaux..." Toward the end of the challenge, the cyclists tackled the toughest section of the course, the hair-pin bends of *Col de la Faucille*, a climb frequently used in the *Tour de France*.

The cycling team included Martin Baker, father to Aimee and his brother-in-law, Keith Talbot; Adam Rigler, father to Harley and his friend, Willi Moore; Alex Watts, brother to Laura; and Kyle Spears, father to Libbie. When all was said and done, this small group of ambitious men had raised around £6000 for the IDEA League UK, the equivalent of \$9600 US dollars! To this we say, "Well done, gentlemen, and may your back ends soon recover!"



Conference Moments Captured

sharing
research,
sharing
hope in
2010

1. Lisa Smith, Rob Moss of Seizure Tracker, and Christina SanInocencio of the Lennox-Gastaut Syndrome Foundation 2. The Meyers family 3. Mitch, Paula and Jordan Lyles 4. Zachariah Moccia 5. _Teresa, Roger and Molly Moberly 6. Dr. Philip Pearl at the piano 7. Ross and Polly Nicholas 8. Kim Skriba, Marilyn Baker, Kathy Fisher, and Patti Thistle 9. Children with Dravet syndrome gather on the stage with Dr. Dravet 10. Laura Cossolotto, Lisa Smith, Dr. Charlotte Dravet, Karen Glenn, Karen Mull and April Sintz 11. Amanda and Carin Shapiro

NOVEMBER	National Epilepsy Month-USA	
6	IDEA League UK Conference	East Sussex, UK
DECEMBERS		
3-7	American Epilepsy Society Meeting,	San Antonio, TX, USA
FEBRUARY		
1	Derek Rudawsky Research Award Applications due	
18	Grand Rounds at Children’s Hospital of Michigan	Detroit, MI, USA
MARCH		
1	Derek Rudawsky Research Award Recipient Announced	
19-20	Australian Dravet Conference	Melbourne, Australia
26	International Purple Day, Team Dravet celebration	Worldwide/Washington, DC USA
27	National Walk for Epilepsy, Team Dravet participating	Washington, DC USA
APRIL		
1	Derek Rudawsky Research Award Granted	

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

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

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

Join the League. Improve the Outcome.

3 EASY WAYS YOU CAN MAKE A DIFFERENCE!

- 1 REGISTER** to become a member. Broaden our pool of medical data and connect with other families.
- 2 VOLUNTEER** your time, and talents to increase awareness, advocate for change or encourage others.
- 3 DONATE** funds or gifts in kind to help us further our mission and find a cure for children and families.

