



# Channeling In

The Newsletter of the IDEA League

## Welcome, IDEA League France!

By Sue Goodliffe

We are pleased to announce that IDEA League France (ILF) was formed in May 2009 and received registered status from the French regulatory authorities in June 2009. ILF is an "association", which is the equivalent of a non-profit organisation in the US or a charitable trust in the UK. The official announcement was made at the first ever French family gathering on May 30th (see related article on page 7.)

The executive committee is comprised of Meryl Asselino as President, David Lacour as Vice President, Olivier Parsy as Secretary, Rachel Lacour as Treasurer, and Sue Goodliffe.

Meryl and Olivier are parents to 3-year-old Paloma. Meryl is a social worker and Olivier is an IT project manager. David and Rachel parents to 3-year-old Nathan and two other sons. David is a pastor and works with children with special needs and Rachel is a full-time mother. Sue is mum to Theo, age 6, and 3 other children. She works as a tax accountant.

After a short break from all the effort of getting charitable status and organising the French gathering in May, the committee is now working hard to establish a plan of action and the priorities. Their main general goals are to get quick wins to help Dravet families in the most efficient way, while starting with limited resources in both time and money. They want to involve and work with all other ILF members who can offer expertise, time and enthusiasm. They are also very committed to working

with other established organisations in France, as well as our doctors, striving for positive and effective measures to make a real difference to families. The committee will be having a 2-day working party session at the home of the Lacours in August. They will also be giving representation at Dr Dravet's workshop in Verona this coming October, Dravet Syndrome: 30 Years Later.

Members of ILF are very grateful for the major role of the IDEA League in bringing forward information about Dravet syndrome and for establishing a community of international families. They are especially grateful that the IDEA League has allowed the bringing together of French families affected by Dravet syndrome, who may otherwise never have met one another.

The goals of IDEA League France are, of course, very close to those of the IDEA League, as regards supporting families and striving for a cure. Yet there are also some major differences. The medical knowledge about Dravet syndrome in France is the best in the world. In addition, the French have a very different charity ethos.

The committee of ILF looks forward to continuing the wonderful work of the IDEA League and a continued collaboration in our fight together to improve the lives of children and families affected by Dravet syndrome.



The Executive committee of IDEA League France, from the top down: Meryl Asselino (President), David Lacour (Vice President), Olivier Parsy (Secretary), Rachel Lacour (Treasurer) and Sue Goodliffe.

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*“Patience is not passive; on the contrary... it is active; it is concentrated strength.”*  
—Edward Bulwer-Lytton

## Encouraging Words From Our Founder

By Joan Skluzacek

As parents of children with Dravet syndrome, we grieve for, or with, our children over experiences they miss the opportunity to enjoy. But sometimes we just have to wait for a better time. And who understands waiting better than we do? We wait for words, we wait for steps, we wait for sleep to come (theirs and ours). We wait for our children to outgrow difficult and unsafe behaviors. We wait for doctors, for insurance approvals and for test results. We wait for seizures to stop. Good things really can come to those who wait.

Our family has attended fireworks displays for all 16 years of Nicholas’ life, but he has never really been able to enjoy them. All the flashing light, and booming noise has

resulted in responses ranging from irritation, to absolute overstimulation, to (when he was little) seizures. We have kept him home while his brothers went to the show and we have taken him along, protecting his eyes and ears as best we could.

Things have changed. This year was different. We took Nick with us to see the fireworks. We had a great location from which to view them. I was prepared protect his eyes and ears and watched him closely as the show began. It was set to music – including a couple of favorite pop songs that they play at school often. This caught his attention. As he sat enjoying the music, he began cautiously to raise his face to the sky. He liked what he saw.

Soon, eyes shining and grinning from ear to ear, he was clapping and nodding his approval. He did not flinch at the loud bangs and pops, and when I tried to cover his ears for the raucous grand finale, he pushed my hands away. In his seventeenth year, he was finally having a great time at the fireworks.

British poet Edward Bulwer-Lytton said, “Patience is not passive; on the contrary, it is active; it is concentrated strength.” It is having the wisdom to wait and hope, while doing your best to reach for your goal. The rewards can be awesome. I had the best time watching the fireworks with Nick!



*Spread the word...let everyone know about the walk and encourage participation.*

## A Day for Dravet

By Angie Mimms

Put on your walking shoes and start warming up! It will shortly be time to raise awareness and funds for Dravet syndrome.

On Oct. 10, walkers in cities across the U.S. and Sydney, Australia, will step up for the first annual A Day for Dravet walk. The League was looking for an annual campaign event, said Lori O’Driscoll, IDEA League Development Director. A walk seemed like something Dravet families and friends would enjoy.

“It’s a great way to have a family day with kids,” she said.

At press time, confirmed walk sites were: West Des Moines, IA; Auburn, GA; Chicago, IL; Simsbury, CT; Taylor Mill, KY; Austin, TX; Lehi, UT; San

Francisco, CA; Sydney, Australia; and Michigan. People interested in coordinating a walk in their area should contact Lori at 203-220-8274. Coordinators will be responsible for scouting a site that would be suitable for a 3K walk, which is about two miles. They would recruit volunteers for the day and seek business donations of food, water and other items or services The League will pay any fees or permits required and will offer support for all aspects of the walk.

A website will be available soon for those who would like to register for the walk. Cost will be \$25 for walkers 13 and older, \$15 for walkers 3 to 12, and free for younger children. Walks will begin at 9 a.m. local time unless otherwise noted.

Those who would like to participate but cannot walk are encouraged to create a virtual team. Watch for an upcoming e-mail with the website address and more information on how you can participate.

If there’s a walk scheduled in your area, Lori asks you to spread the word to people in your neighborhoods, faith communities, work places and schools. Let everyone know about the walk and encourage participation. Funds raised from the walk will be used to continue the League’s programs and services and help with the organization’s needs as it continues to grow.

Let’s all do our part to help make A Day for Dravet a step in the right direction!



## Conference Announcements

The IDEA League is pleased to announce our 2010 Bi-Annual Conference. This event will take place August 25-29 at the Hyatt Regency in Old Greenwich, Connecticut, USA. Please join us if you are able. More details to follow.

The IDEA League UK will also be holding a one-day family conference, date to be determined.

All members of the IDEA League, as well as interested parties, are welcome to attend any of our conferences. It is our hope to sponsor similar workshops for families and/or professionals across the globe as support and funding allow.

## In the Spotlight

By Paula Lyles



Gregory Walmacq

Handsome Gregory Walmacq and his family hail from Ile de France, a State in the Paris region near renowned Versailles. Gregory was born in 1982, which means his parents Gerard and Nathalie have a great deal of experience with a child, now adult, diagnosed with Dravet Syndrome. Gerard works as a business/system analyst. Nathalie, like many of us moms, has sacrificed her career to stay home and care for Gregory. The Walmacq's have an older son, Frederic, a top level rower, who is currently working in advertising.

In his 26-year Dravet journey, Gregory has been on medications that are no longer prescribed and also participated in the 1996 trials of stiripentol, which he still takes today along with Depakote and Clobazam. Gerard admits that the stiripentol trial was difficult for Gregory while he adapted to the new medication. His current seizure pattern is roughly two to three sleep seizures per month. Gregory is also presently a subject of a Rima Nabbut research project at Necker Hospital in Paris.

Gregory's life resulted in fewer seizures, a new found joy in living, and a serene family.

Gregory currently lives at home and goes to an adult center facility during the day, where he participates in his favorite activities and goes on community outings with his peers. Labeled a hyperactive child, Gregory has grown into a very laid back adult. Gregory is attracted to photographic things like video and computer but is not interested in console games. He loves theater, concerts, music, and everything to do with nature, just like his family.

Gregory is SCN1A negative but was diagnosed at age one with SMEI by a team of specialists under the guidance of Professor Olivier Dulac at St. Vincent de Paul in Paris and Dr. Catherine Chiron. Nearly 26 years later, Dr. Chiron is still Gregory's primary neurologist. The Walmacqs are extremely fond of Dr. Chiron and are grateful for her expert medical knowledge, help, and support with the educational and social integration pieces of the Dravet Syndrome puzzle.

In regards to the educational opportunities afforded to Gregory, Gerard admits his displeasure that special needs teaching and accommodations were virtually non-existent during Gregory's early schooling years. It wasn't until the ages of 15-20 years that Gregory was a part of a phenomenal specialized schooling program, called an IME. IMEs in France are created by family members and are funded by the country. What Gerard describes sounds like an exciting undertaking and a labor of love. "Those five years were the best period of life for Gregory. The Catholic nature of his schooling was a most important aspect too." Gerard credits stiripentol for additional success during that time as well. These changes in

In closing, the Walmacqs wish to encourage fellow parents with a child diagnosed with Dravet syndrome to take heart. With early diagnosis, good treatment protocols, and special social and educational instruction, Nathalie and Gerard believe children with Dravet syndrome can have a positive outcome. "Leave no stone unturned and provide your children with lots of love and stimulation! We wholeheartedly wish you all simply the best life possible and grace in dealing with differences. It is our pleasure to represent the French families among the big family of the IDEA League."

*"Leave no stone unturned and provide your children with lots of love and stimulation!*

*We wholeheartedly wish you all simply the best life possible and grace in dealing with differences."*

*—Gerard and Nathalie Walmacq*

## Ciara's Butterfly Bash Soars

By Karen Glenn

Saturday, April 28, 2009 launched the first annual Ciara's Butterfly Bash—A Benefit for Children with Dravet Syndrome. A semi-formal event held at the Hyatt Regency in Greenwich, Connecticut, Ciara's Butterfly Bash brought together nearly 200 people to raise much-needed funds for children and families struggling with this challenging form of epilepsy.

Ciara's Butterfly Bash is the brainstorm of Lori and Liam O'Driscoll and was named in honor of their young daughter, Ciara (Keera), who was diagnosed with Dravet syndrome at the age of 11 months. In addition to raising funds, the event also honored Dr. Paule Couture, Ciara's pediatrician, for her caring and dedication. Dr. Couture has gone above and beyond expectation, learning about Dravet syndrome and the ketogenic diet in order to provide the best possible care for Ciara.

The evening began with cocktails and an opportunity

to peruse the many wonderful items donated for the silent auction, all while listening to a performance of traditional Irish music. Cocktails were followed by a lovely dinner. As the meal ended, attendees heard a few words from IDEA League Executive Director Mary Anne Meskis and Board Member Michelle Townsend. Lori O'Driscoll then presented Dr. Couture with her honors. The presentations concluded with a moving film sharing Ciara's story, which enlightened the audience on the challenges and joys of having a child with Dravet syndrome. The evening ended with a live auction of several exciting items, including box seats to a Yankees game and a Nantucket getaway.

Additional IDEA League members attending the event included Karen Glenn, Kerim May, Sabrina Montford and Kyle Delaney, Carin and Larry Shapiro, Gemma Cuomo, Gemma May, and Lisa Defaranos-Peterson and Joann Peterson. IDEA League members enjoyed a special

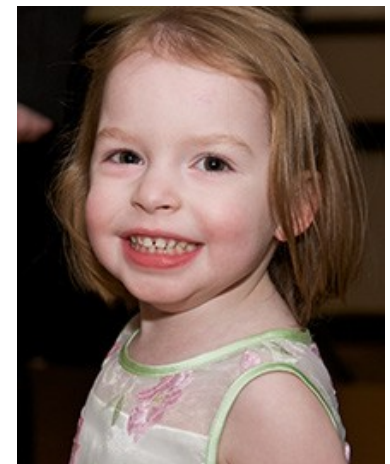
reception together before the event.

Huge thanks to the O'Driscoll family, event co-chair Lauren Winter, as well as the entire Butterfly Bash committee, for their efforts in putting together this fantastic event. Ciara's Butterfly Bash was a tremendous success, netting \$40,000, with all proceeds going to the IDEA League's research and medication assistance funds.

The O'Driscolls are committed to holding this event on an annual basis. Says Lori "We are so thrilled with the outcome of this year's event and we expect it will only grow next year. It is our intent that Ciara's Butterfly Bash serve as the premier gala for the IDEA League." The next Butterfly Bash is already scheduled for March 27, 2010, when the honoree will be Dr. Linda Laux from Children's Memorial Hospital in Chicago.



Lori O'Driscoll and gala honoree Dr. Paule Couture



Ciara O'Driscoll

## Derek's Dash

By Karen Glenn

Derek's Dash, a 5K walk/run, will take place on August 30, 2009 in Greenwood Village, Colorado. Derek's Dash is being organized by 12-year-old Ethan Widoff in honor of his cousin, Derek Rudawsky, who has Dravet syndrome. The slogan for the event is: Working to fight childhood epilepsy one step and one syndrome at a time.

Says Ethan, "I wanted to make a difference for Derek, his family, and everyone else worldwide who suffers or

knows someone who suffers from Dravet Syndrome. We have all been working hard to make this event fun, fabulous, and successful! We hope you enjoy it, and we hope to raise an amazing amount of support for the IDEA League."

The IDEA League applauds Ethan and his event team for their efforts on behalf of Derek and all children with Dravet syndrome. To learn more about Derek's Dash or to register to attend the event, please visit the website,

[www.dereksdash.com](http://www.dereksdash.com).

All proceeds from this event will benefit the IDEA League and will help to promote research, support and education for Dravet syndrome and related forms of epilepsy. If you live in the area, or have friends and family who do, please consider supporting or encouraging support for Ethan in this fantastic endeavor.

Thank you for putting this event together, Ethan!



Derek's Dash is being organized by 12-year-old Ethan Widoff in honor of his cousin, Derek Rudawsky, who has Dravet syndrome.

Living with Dravet Syndrome

## A Story of Two Sisters

By Cathleen Hackett

My daughters, Elise and Lauren, love each other very much. Elise is 11 and afflicted with Dravet Syndrome. Lauren is 8 and does not have Dravet syndrome.

Elise is home schooled and deals with cognitive and physical delays due to her illness. She reads well, but has to take her time to get the words right. She can play outside, but she can't run like the other kids do. Elise knows all the words to every Disney musical. She loves to listen to the Broadway soundtracks. She can't sing very well, but that doesn't stop her. She is always kind and loving. She will never say anything impolite and negative to anyone under any circumstances. She is the epitome of grace.

Lauren attends a charter school with high academic standards. According to school testing, she is considered "gifted". She is cognitively and

physically advanced. At age 8, she reads at a tenth grade level. She can play tennis and swim well enough to give adults a run for their money. She can sing and play the piano very well. She is critical of herself, and sometimes others. She strives for perfection in everything she does...even though we tell her to slow down and enjoy life. She is loving, yet requires a large amount of personal space. She is very cautious when she first meets people. She needs to trust a person before she develops a friendship with him or her.

My daughters are the opposite of each other in many ways, but the one thing they have in common is a deep love for one another.

I asked them how they felt about Dravet syndrome and how it has affected our family. Here are their words...

Elise: "I don't like having "eye flutters" because they frustrate me. I feel happy about my family. I love my sister Lauren and feel good that she is here with me. I love it when we play together."

Lauren: "I want her to like the shows that I am watching now, like The Suite Life of Zack and Cody. She prefers Dora the Explorer, Go Diego Go, and the Backyardigans. They are not the shows I like to watch. I love Elise so much that I pray secretly behind my locker or desk at school that she won't have Dravet syndrome anymore. I hope that God will take Elise's seizures away. One of my favorite memories with my sister Elise is to go outside and play in the fort on a really beautiful day. I understand her condition and love her anyway."



*Elisa and Lauren Hackett*

*My daughters are the opposite of each other in many ways, but the one thing they have in common is a deep love for one another.*

## Brave Boy Pitches for the Braves Game

By Karen Glenn

Ryan Smith practiced for a month to get ready for his big day. On July 20, 2009 he had his moment to shine, throwing the starting pitch for a Gwinnet Braves baseball game. "Ryan threw it straight in there. Not hard and not for distance, but with lots of spirit," shared his mother, Kimberly Skriba.

The Gwinnet Braves are a minor league baseball team new to the Skriba's community Georgia. Kim, an IDEA League Board Member, arranged with the team to allow Ryan to throw the first pitch and, in exchange, the

Skriba's agreed to sell 500 tickets to the game, with a portion of the proceeds going to help children who, like Ryan, have Dravet syndrome

"I was so overwhelmed by the support we received that last week before the game," said Kim. "We had sold all but 24 tickets by the time the game started." Hundreds of friends and family gathered to watch Ryan pitch. IDEA League members who attended the game included Ross and Polly Nichols, Paige and Luis Ontiveros and their children, and Joan Skluzacek. Several family members of Brenda

Ferrell also came to the game.

Many thanks to all those who showed up to support the Skribas and the IDEA League by attending this event. Special thanks to the Skriba family for their continued dedication to helping the IDEA League and children with Dravet syndrome and related conditions. This was definitely a win for all of us!

It was a great day. "I could not have been more proud than to see Ryan standing on the baseball mound with 100's of fans cheering him on," said Kim.



*Ryan Smith and his mother, Kim Skriba, on the pitcher's mound.*



*The investigators are seeking photographs of the faces and hands of children with Dravet syndrome...*

## Study to Look at Features of Ds Children

By Angela Black, MD and Karen Glenn

The IDEA League is pleased to announce a new study of Dravet syndrome being conducted by Drs. Kathleen Nolan, Carol Camfield and Peter Camfield of IWK Health Centre in Halifax, Nova Scotia, Canada. The purpose of the study is to determine if there are physical characteristics common to children with a diagnosis of Dravet syndrome.

The investigators are seeking photographs of the faces and hands of children with Dravet syndrome, as well as unaffected siblings, where possible. There are two parts to the study, and families may participate in one, the other,

or both. In the first part, measurements will be taken from the photos of children with Dravet syndrome and compared with the measurements of children without Ds. In the second study, the photos will be compiled in a booklet and shown to a group of pediatric neurologists, who will be asked if they can identify the children with a specific syndrome. In this way, the investigators hope to determine if there are particular facial features specific to Dravet syndrome.

IDEA League families are encouraged to participate in

this study as they feel appropriate. Full information regarding the study, as well necessary forms, are available on the IDEA League website or by emailing Angela Black, MD, chair of the League's Medical Advisory Board at [dr.black@idea-league.org](mailto:dr.black@idea-league.org).

The IDEA League would like to thank Dr. Nolan and Drs. Peter and Carol Camfield for their efforts to increase understanding of Dravet syndrome. This is the second study relating to Ds to be conducted by these physicians, and the Camfields serve on the Medical Advisory Board for the League.



*Attendees of the French gathering during the afternoon presentations*

## First Ever French Gathering Held

By Sue Goodliffe and Karen Glenn

Twenty-six families, about 60 people in all, gathered in Versailles, France on May 30 of this year. Though they had conversed previously via computer, most had never met in person. Nevertheless, there were many tears and hugs upon arrival. These were the families of children with Dravet syndrome and they shared a common bond.

The first ever French gathering of Dravet syndrome-affected families was well-planned. Members of the IDEA League French forum put loads of energy and enthusiasm into the event, making use of the internet as well as conference calls, in order to get every detail worked out, from the childcare to the food.

The venue was a beautiful villa with lovely gardens owned by the town council and often used for weddings. It was kindly donated by the mayor, with assistance from the manager who is an aunt to

Audrey, one of the French members. The morning was filled with informal exchanges within the group. Lunch was a wonderful spread of food, all home-cooked. Families brought local specialties from their regions, to enhance the spirit of sharing.

After lunch came the more formal session. Meryl Asselino gave an introduction and welcome, Sue Goodliffe gave a history about the IDEA League and a welcome on behalf of the leadership, and David Lacour announced the formal creation of IDEA League France. Following this was a Question and Answer session with the doctors. French physicians Charlotte Dravet, Catherine Chiron and Rima Nabbout were true to form in their passion and commitment to informing and helping the families, answering a series of prearranged questions. As a thank you, a gift of books with photos of the children and words from the parents,

prepared by Olivier and Meryl, was presented to the doctors.

Many thanks to all those who attended and to everyone who put so much work and preparation into making the event a success. Special thanks to Meryl Asselino for her excellent organization. And, of course, to doctors Dravet, Chiron and Nabbout for so generously giving of their time and expertise. Said H el ene Banos, on the forum, "thanks also to the doctors ... we have learnt more about the condition in two and a half of hours of exchanges with them than after ten years of hospital appointments."

Those in attendance voiced that the event was helpful in building friendships and enforced the sense of belonging. It was felt that meeting in person was a vital step in helping the French families move forward and accomplish great things together.

*...meeting in person was a vital step in helping the French families move forward and accomplish great things together.*



Angela Black, Suzie Englehardt, Amanda Stansfield and Joan Skluzacek at the AAN Conference.

*In just a few years, the IDEA League has really increased the awareness the medical community has of this disorder. “*

*—Angela Black, MD*

## IDEA League at AAN Conference

By Holly Harrison

Thousands of neurologists from all over the world travelled to Seattle, Washington April 25-May 2, 2009, to attend the 61<sup>st</sup> annual meeting of the American Academy of Neurology (AAN).

Participating in this key event were two active members of the IDEA League –Joan Skluzacek, Founder, and Angela Black, MD, Chair the Medical Advisory Board. The two agreed on three purposes for attending the conference: to raise awareness of Dravet syndrome, connect with other groups attending, and make time to spend with League families in the Seattle area. Angela was very pleased with the IDEA League’s progress towards the goal of raising awareness about Dravet syndrome. “I was impressed

with how many physicians recognized our name, *IDEA League*, and had at least some understanding of Dravet syndrome. In just a few years, the *IDEA League* has really increased the awareness the medical community has of this disorder. We were approached by physicians from as far away as the Middle East who were interested in working with the League to improve the care of their Dravet patients.”

Connections with both the American Epilepsy Society and Transgenomics, were strengthened at the conference. (Transgenomics is the lab that does much of the SCN1A testing for families in the League.) Additionally, connections were made with the representatives from the *Essential Tremor Foundation*, whose booth was adjoining

the League’s.

IDEA League members Dale Cunningham, Amanda Stansfield, Suzie Englehardt, and Davora and Steve Chavez were very supportive in helping to staff the League’s booth. It was particularly poignant to have the Chavez’ there, as they had only very recently lost their daughter, Rose, to SUDEP (sudden unexplained death in epilepsy). Many thanks to all these members for their assistance at the event.

The AAN has an international membership of 21,000 neurologists and neuroscience professionals. It’s 2010 annual meeting will be held April 10-17 in Toronto, Ontario, Canada.



**IDEA League**

The voice for Dravet syndrome.

IDEA League  
P.O. Box 803338 #18880  
Chicago, IL, USA 60680-3338  
Phone/fax: 312-821-9020  
Toll-free phone: 888-402-IDEA  
www.idea-league.org  
email: info@idea-league.org

## Dates to Remember

### AUGUST 2009

- 30 2nd Annual Chester Challenge Cycling Race/Fundraiser  
To benefit the IDEA League UK Chester, UK
- 30 Derek’s Dash to benefit the IDEA League Greenwood Village, CO, USA

### SEPTEMBER 2009

- 7-13 Epilepsy Awareness Week(2) New Zealand
- 11-13 East Coast Mom’s Weekend
- 19 North East Family Gathering Monroe, CT, USA

### OCTOBER 2009

- 2-4 Camp Courageous Dravet Weekend Kentucky, USA
- 3-6 Dravet Syndrome: 30 Years Later Verona, Italy
- 10 A Day for Dravet walks global
- 14-17 Child Neurology Conference Louisville, KY, USA

### NOVEMBER

EPILEPSY AWARENESS MONTH-USA

### DECEMBER 2009

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

### MARCH 2010

EPILEPSY AWARENESS MONTH-CANADA

- 27 IDEA League’s 2nd Annual Ciara’s Butterfly Bash:  
A Benefit for Children with Dravet Syndrome Greenwich, CT, USA
- 27 National Walk for Epilepsy Washington, DC, USA

### AUGUST 25-29

IDEA League Bi-Annual Conference Greenwich, CT, USA