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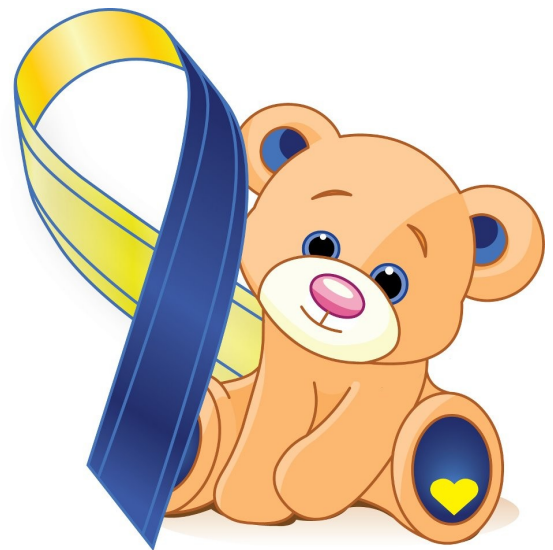
FIFTH ANNUAL OMS TEDDY BEAR DRIVE A SUCCESS

The annual fundraiser for The OMSLife Foundation was held again this past fall. As in previous years, the objective of the fundraiser was to raise money for OMS research while also raising awareness of OMS. It was also an opportunity to give back to many hospitals across the country for their tremendous assistance to OMS warriors.

In 2013, over 6,000 new toys and teddy bears were donated to children in more than 40 hospitals across the US.

Our 2013 campaign also raised over \$40,000 for OMS research and awareness. In just two short years, over \$83,000 has been raised for OMS research and awareness.

The foundation would like to thank the many teddy bear drive coordinators who spent countless hours coordinating their local drive. Also, thank you to the many donors who supported the drive this year.



Meet One of our Corporate Sponsors

For the past two years, we have had the privilege of having CK Technologies as a corporate sponsor. CK Technologies first came onboard as a corporate sponsor when their Mt Airy, NC division hosted an OMS teddy bear drive for the Brenner Children’s Hospital in Winston Salem, NC. Local coordinator Jennifer Ault has a cousin afflicted by the disease and decided to do a local drive.

In 2013, they expanded their OMS teddy bear drive to include the corporate office in Montpelier Ohio and hosted events for Bryan and Montpelier, Ohio hospitals as well as the Brenner’s Children’s Hospital. Through the efforts of CK Technologies, they have raised several thousands of dollars for OMS research and collected hundreds of new toys and teddy bears for children in hospitals.



CK technologies

a cascade engineering company

Bruce Arps, Vice President stated that their corporate values drive their efforts and the alignment with The OMSLife Foundation was a natural fit. For more information on CK Technologies, visit www.cktech.biz.

Inside this issue:

Foundation Recipients	2
OMS Graphs	2
Our OMS Warriors	3
• Chloe’s story	
• Alexia’s story	
Lucy’s Story	4

THE OMSLIFE FOUNDATION 2013 RESEARCH GRANTS

The board of directors of The OMSLife Foundation is pleased to announce their 2013 research grant recipients. Proceeds collected from the Fifth Annual OMS Teddy Bear Drive provided grants to the following recipients:

Dr. Michael Pranzatelli, The National Pediatric Myoclonus Center, Springfield, Illinois.

Dr. Pranzatelli is a pioneer in the OMS research field. He has been instrumental in accelerating research in OMS for over 20 years. Through his research, he has helped

hundreds of OMS children around the world enjoy a higher quality of life.

Dr. Pranzatelli received a grant of \$18,000 to help fund three new research projects.

Dr. Wendy Mitchell, Children's Hospital Los Angeles.

Dr. Mitchell, Director of Pediatric Neurology has been actively engaged in the OMS battle over her career. Dr. Mitchell received a \$10,000 grant to fund training for a new member of her team, Dr. Megan Langille.

A special thank you to our volunteers:

- Our 2013 OMS Teddy Bear Drive coordinators
- Our web administrators— Cathleen Garner, Hank Holley, and Marc Benson

And thank you to our 2013 sponsors. For the complete list of sponsors, visit

www.omslifefoundation.org

Please help us provide grants for OMS research. You can send checks to:

**The OMSLife Foundation
P.O. BOX 2899
Cypress, TX 77410**

Or give an online donation at

www.omslifefoundation.org

The OMSLife Foundation is a 501(c)3 non-profit organization and donations are tax deductible.

ANNOUNCING 2014 OMSLIFE FAMILY CONFERENCES

The OMSLife Foundation is pleased to announce we are hosting three regional OMS family conferences in 2014. Beginning in Los Angeles in May, we will co-host a family conference with Children's Hospital Los Angeles.

We are also partnering with Boston Children's Hospital and Texas Children's Hospital to provide regional conferences in Boston and Houston later this fall.

The regional conferences provide an opportunity for caregivers to network and get updates from OMS experts. The conferences are open to all OMS caregivers. For more information, please contact Mike@OMSLife.org

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HELP US BEAT OMS!!!! I want to help raise awareness of OMS and help in research funding! Enclosed is my donation.

NAME: _____

ADDRESS: _____

CITY: _____ STATE _____ ZIP _____

\$50

\$100

\$200

OTHER

Check the box if you like to receive our e-newsletter?

Email address: _____

The OMSLife Foundation is a 501(c)(3) nonprofit organization founded in 2012 dedicated to educate people around the world about Opsoclonus Myoclonus Syndrome and raise funds for the research and cure of this disease.

MEET A FEW OF OUR OMS WARRIORS

Chloe was diagnosed with OMS in late 1993 at the age of about 18 months in southern California. There was very little information about OMS or the treatment protocols back then. So, when diagnosis was confirmed between her pediatric neurologist in Long Beach, CA (Dr. Jeffrey Levin) and Dr. Michael Pranzantelli, a treatment that included large daily doses of prednisone was prescribed to inhibit Chloe's immune system. The treatments helped, but in order to wean Chloe off of the prednisone (which took about 4 years once starting the process to actually get her off it without the OMS symptoms returning), IVIG was used as a monthly supplement. After about 7 years of treatments that included prednisone and IVIG's, Chloe has been completely medicine free.

Chloe began speech therapy at age 3, and has benefitted from ballet classes, karate classes, horseback riding, occupational therapy and physical therapy to get her muscle tone and senses back to what one might consider "normal." School has always been a struggle because Chloe retained residual cognitive issues, which include being able to sequence directions and math. It took her years to learn to read, but for all you parents out there that are worried that your OMS child's literacy will forever be stunted, you might take comfort in knowing that Chloe is now a voracious reader and enjoys a lengthy novel in a shortened time-span that would impress most adults.

The Bruland Family relocated from southern California to southwestern Wisconsin in 2003 when Chloe was 11. They now own a small organic farm where Chloe and her family grow asparagus (1/2 mile of rows) along with apples (selling them fresh as well as and making cider and applesauce). They grow red raspberries (about 1 acre), raise their own turkeys and chickens for both eggs and meat, and tend about 10 colonies of honeybees. Chloe often helps her dad in the bee yard (and loves honey!).

Chloe and her dad have also taken painting classes and she is an accomplished "one-stroke" method painter (loves to paint the outsides of the bee boxes). They enjoy camping, golf and fishing as a family.

21 years old now, Chloe has mastered driving and got her license on her first try at the DMV at age 16. She is extremely creative and loves music and singing. Watching Chloe interact with young children at the day care where she has worked demonstrates that her empathy for children, and especially children with disabilities, is her life gift. Attending college now at University of Wisconsin – Richland, Chloe still struggles with the amount of homework and the testing processes that the schools use. She receives accommodations if she requests them, but is bound and determined to work towards completing a child psychology degree. Chloe loves to connect with parents and children that live with OMS – she uses phone calls, e-mail, webcasts and texts. It is apparent that this young lady will overcome whatever she sets her mind on... in her own time and in her own way.



Alexia is an OMS warrior from Romania. Her mother, Simona, noticed symptoms in summer 2012 and she was diagnosed with OMS at Szeged Hungary six months later. However, the local doctor was unsure how to treat Alexia's OMS. Simona reached out to The OMSLife Foundation in search of an OMS specialist who could care for her daughter. An email to Dr. Eugene Boltshausen in Switzerland directed the family to Dr. Craiu in Bucharest, as well as other clinicians in Europe and US.

The website and Facebook forum have also provided an avenue for Simona to engage with other OMS caregivers to understand best practices to utilize.

The OMSLife Foundation
P.O. BOX 2899
Cypress, TX 77410



MEET OMS WARRIOR LUCY....

Lucy's battle with OMS began in October 2011 when we noticed our normal 18 month old developing unusual symptoms which included fluttering eyes, unsteady walking and rage attacks that lasted for long periods of time. By the time we saw a neurologist later that month Lucy had begun having Parkinson like tremors that caused her legs and arms to shake even while she was sleeping. We were sent directly to Medical City Dallas Children's for testing. The initial diagnosis by the neurologist was Cerebellar Ataxia, but the pediatric oncologist who was consulted felt that OMS was the correct diagnosis.

We were referred to Dr. Pranzatelli, an OMS specialist located in Springfield, IL. By the time Dr. Pranzatelli saw Lucy on Halloween she could no longer walk and had lost the ability to talk. She was diagnosed with a severe case of OMS, and we were sent back to Dallas to begin a treatment protocol including Rituximab infusions, IVIG infusions, and ACTH injections. She was also given Zantac, Bactrim, Trazedone, Potassium and Calcium supplements.

During the following weeks Lucy underwent more tests in search of a tumor but none was found. After enduring daily steroid shots and monthly infusions she began

showing signs of improvement. However, it was not until the following February that she began to speak again, and a few weeks after that before she could stand up on her own. Lucy was continuing to improve with regular speech and physical therapy while continuing medication. In July 2012 we were dealt another blow when a tumor was discovered on a follow up MRI. She underwent surgery that week to remove the tumor, and then began chemotherapy treatment for cancer.

Today, after three surgeries and more shots than I can count Lucy still receives treatment with steroids and IVIG infusions after suffering a relapse this past fall. However, she is a vibrant four year old who is full of life. We are blessed to have a wonderful inspiration for a

daughter, and to have had the opportunity to meet so many wonderful families who are also fighting this disease. The OMSLife Foundation has helped to facilitate a community of OMS fighters while raising awareness about OMS in the medical community. We are grateful that funds raised by the foundation have helped to further OMS research and treatments.

