



Volume 4 - October 2015

SEVENTH ANNUAL OMSLIFE TEDDY BEAR DRIVE KICKS OFF

The 2015 OMSLife Foundation Teddy Bear Drive is in full swing! Since 2009, we have been bringing smiles to thousands of children in hospitals across the US by delivering new toys and teddy bears.

While we love handing out the teddy bears to the kids, this fundraiser is also our big event to raise money for OMS research. Since 2012, The OMSLife Foundation has provided grants to researchers across the US including Dr. Michael Pranzatelli at SIU School of Medicine, Dr. Mark Gorman at Boston Children’s Hospital, Dr. Wendy Mitchell and Dr. Megan Langille at Los Angeles Children’s Hospital, Dr. Pedro DeAlarcon at University of Illinois at Peoria, and most recently, the Pablove Foundation.

We have also hosted four OMS caregiver conferences in Los Angeles, Houston, Cincinnati, and Boston. The caregiver conferences bring together OMS experts with the parents and friends who support the daily



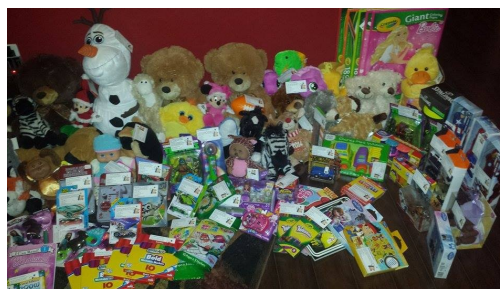
needs for our OMS warriors. The conferences have been well attended and while providing much needed resource information, they have also



given the caregivers and the OMS warriors the opportunity to meet each other. In some cases, these OMS warriors had never met another with their affliction!

Our plans for 2015 call for distributing 5,000 new toys and teddy bears to children in hospitals across the country, and to raise \$50,000 for OMS research. Please join us in this effort to spread awareness, and to help raise funds for a cure!

www.omslifefoundation.org



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MEET A FEW OF OUR OMS WARRIORS

Keira: In October 2010, our 18 month old daughter Keira was diagnosed with neuroblastoma, cancer of the nervous system. This cancer triggered the extremely rare autoimmune disorder called Opsoclonus Myoclonus Syndrome (OMS). It was debilitating in almost every way, stripping Keira of her ability to walk, stand, speak and sleep. Just days before we were happily living in San Francisco with a freespirted toddler, and suddenly we were being admitted to the pediatric oncology department. We were now cancer parents.

Having our daughter diagnosed with cancer was probably one of the most dreadful moments in our lives. However, as we learned more about OMS, we were even more devastated to realize what was happening to Keira's body. Even if Keira beat the cancer, we were told that Keira might never develop as a normal child, need assistance walking, and be cognitively impaired due to the ongoing effects of OMS. To make matters worse there was no research being done to unlock the mysteries of this rare disease; no cure or protocol that would put the OMS into remission. The odds were stacked against Keira and the outlook was grim.

The interesting thing about kids is that they don't understand statistics. For the last four years, Keira has endured countless treatments, infusions, a daily drug regimen, sedations, and scans. She has done so with strength, courage, and even smiles and laughs. Keira battled back from not even being able to sit without assistance, to crawling, then standing, then walking, then running, then jumping, then climbing. She can ride a 2-wheel bike, plays soccer, and loves her rock climbing class. Keira is thoughtful, caring and generous to her little sister Akemi, and her friends. This year she is attending kindergarten... learning to read, write and do math, something we were not sure would be in her future when we were first diagnosed.

Keira has shown us that she is a fiercely independent and stubborn little girl who doesn't know how to quit. **She's an inspiration to our family and anyone who knows her.**

Why has she done so well? We have no idea, and that's the problem. We don't know why she responded to treatment where others have not. But we also don't know why she can't be weaned off treatment, where others have. We don't know if she will relapse at any moment or later in life. This is life living with OMS. We're thankful for how far she has come, but always worried if it will all be stripped away. This is why we strongly believe in funding research that could help answer some of these questions so that we can better diagnose and treat this disease.



Ella: In May 2014, in less than 48 hours, our 2-year-old daughter suddenly lost the ability to walk. Three months, four hospitals, and several misdiagnoses later, she was finally correctly diagnosed with a rare disease called Opsoclonus Myoclonus Syndrome (OMS). Ella experienced ataxia, chaotic eye movement, and fits of rage. She couldn't feed herself anymore and could barely talk by the time she was diagnosed. In July 2014, surgeons had to remove her left adrenal gland which was intertwined with a neuroblastoma. After the surgery, Ella began her OMS treatment: immune suppressing chemo, IVIg infusions and steroids.

It's been over a year since Ella was diagnosed with OMS, and she is slowly improving. She's still shaky, and has her ups and downs, but if we think back to where she was a year ago, she's come a very long way.



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Ella: Currently she's back on injections of ACTH (high dose steroid) every other day, and she still gets monthly treatments of IVig at Children's Hospital Los Angeles. The first try to wean her off these meds caused a relapse of symptoms, so we're hoping that the second try of weaning her works out better. As parents, we are trying to figure out how to best support her recovery. The OMS Life Foundation has been an incredible resource and knowledge base. Ella is amazingly bright and yes, a little mischievous, and she will persevere.



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OMSLifeTeddyBearDrive

Alexa's OMS battle began in October 2009 when she began to develop odd symptoms. The toddler woke up one morning and was unable to sit up. Later in the morning, she became irritable and her balance continued to degrade. Her parents rushed her to the doctor and later the hospital, but she was sent home with the diagnosis of a virus.

During the month, Alexa's condition continued to worsen until she remained in an infantile state and just cried day and night. The doctors in her home town offered no solutions.

In desperation, they drove 500 miles to Houston to get help from the doctors at Texas Children's Hospital, arriving late in the evening. By 10AM the next morning, they had their answer- Opso-clonus Myoclonus Syndrome. After searching for 30 days, her Alexa's parents now knew the disease; but the battle was just beginning.

Over the course of the next five months, Alexa had numerous tests performed and was put on a treatment of high dose steroids and iVig. While it helped her make some progress, she was still far from stabilizing. Finally, after six months, she was sent to see Dr. Michael Pranzatelli in Springfield Illinois. Dr. Pranzatelli put her on a series of treatments including ACTH, cytoxin, and rituximab. During 2010, Alexa made tremendous progress in her recovery. She had regressed so much that it was necessary for her to receive physical and speech therapies. She continued the speech therapy for a number of years as she battled the disease.

While the medications had helped Alexa's recovery, the parents now found that the battle was in attempting to wean her from the drugs that had saved her. Over the next four years, Alexa slowly got weaned off of the drugs. Today, she now celebrates two years of remission and no drugs!

In honor of Alexa, her family began a teddy bear drive in 2009 for patients at the Texas Children's Hospital in Houston. Since that time, this has turned into The OMSLife Foundation which dedicates its efforts to raise awareness of OMS, provide resources for caregivers, and raise funding for research.

For more information on Alexa's story, go to YouTube and search for "The Toddler who Stopped Walking".

Alexa's family would like to thank the many OMS specialists in her life; especially Dr. Michael Pranzatelli, Dr. Tim Lotze, Nurse Cinnamon, Nurse Lisa, and Dr. Amanda Guderslogh.



NEXT STOPS FOR CAREGIVER CONFERENCES - CINCINNATI AND BOSTON

After successful 2014 caregiver conferences in Los Angeles and Houston, OMSLife travelled to Boston and Cincinnati. In April, Dr. Don Gilbert and team met with our families at Cincinnati Children's Hospital. The team of presenters included:

- Dr. Don Gilbert, Pediatric Neurology,
- Dr. Allen DeSena, Pediatric Neuro-Immunology
- Dr. Brian Weiss, Oncology,
- Dr. Wendi Lopez, Psychology



OMSLife Foundation president Mike Michaelis and Dr. Don Gilbert, Cincinnati Children's Hospital.



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Next up was our Boston conference in May with Dr. Mark Gorman and his team.

- Dr. Mark Gorman, Neuro-Immunology
- Dr. Ferne Pinard, Pediatric Neuropsychology
- Catherine Petty, Special Education Consultant
- Michelle Souris, Pediatric Nurse
- Lisa Duffy, Pediatric Nurse

Both caregiver conferences were followed with a family social time where the entire family could enjoy dinner and an opportunity to network. In some cases, it was the first time an OMS warrior had met another afflicted with the disease.

Presentations for these and all of our caregiver conferences can be found on our web site at <http://www.omslifefoundation.org/?q=en/content/oms-conferences>.



MEET ONE OF OUR SPONSORS - DEBEUKELEAR COOKIE COMPANY



OMSLife Foundation president Mike Michaelis and De Beukelaer Cookie Company Plant Manager Herwig De Beukelaer

DBC Corp DBA De Beukelaer Cookie Company is known for its irresistible Crème de Pirouline rolled wafers that have been baked in America over the last thirty years. They are set apart from their competitors by the trademark swirl that is wrapped around each of their delectable wafers. They annually produce two delicious flavors of cream filled wafers, chocolate hazelnut and dark chocolate in the USA. All of their main competitors import their products from overseas. The Crème de Pirouline brand is continuing to grow and can be found on the shelves of large retailers such as Wal-Mart, Target, Fresh Market, Publix, and Dollar Tree. In addition, De Beukelaer Cookie Company strives to be environmentally friendly with all

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

aspects of the manufacturing process of their packaging. All cardboard used in their packaging is 100% post-consumer recyclable and the steel cans are produced from recycled steel as well.

Not only is De Beukelaer Cookie Company proud of their wafers, they are proud to be making a difference in the lives of others, especially OMS patients. They joined together last year with the OMSLife Foundation to help raise money and awareness of this life changing disease. The impact of OMS hit close to home when discovering a member of the DBC family was diagnosed in early 2014. "Being able to give back to the community, as well as our own DBC family, is something we are always working towards. Joining together with OMS Life Foundation is a great way for us to show the world that we are not



only here to share our love of wafers, but to change the lives of others in need." states Herwig De Beukelaer, plant manager at De Beukelaer Cookie Company.

De Beukelaer Cookie Company is having their second annual online sale during the month of October. Fifty percent of all proceeds from online sales will go directly to the OMS Life Foundation. You can visit www.Pirouline.com to shop all Pirouline products and help make a difference in the lives of these precious patients. What better way is there to support a great cause than by enjoying rolled wafers from the one and only De Beukelaer Cookie Company!

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



OMSLIFE FOUNDATION—REVIEW OF RECENT ACTIVITIES

- **Caregiver Conferences** Hosted events in Los Angeles, Houston, Cincinnati, and Boston that connected OMS caregivers
- **2014 Fundraiser** Raised \$36,500 for OMS research and awareness
- **Teddy Bear Drive** Collected and distributed almost 6,000 new toys and teddy bears to kids in children's hospitals
- **Web Site and Facebook Page** Connecting new OMS warriors with OMS specialists, and raising awareness of OMS
- **New members** Have added over 200 new cases since January 2014
- **Surveys** Beginning pilot program to collect OMS data for researchers and clinicians

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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: _____ \$50

ADDRESS: _____ \$100

CITY: _____ STATE _____ ZIP _____ \$200

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

Email address: _____

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