



# OMSLIFE FOUNDATION PRESENTS THE FIFTH ANNUAL TEDDY BEAR DRIVE

Volume 1 September 2013

Alexa Jennings, OMS warrior and inspiration for the OMS Teddy Bear Drive, cuddles a furry friend.

The OMSLife Foundation is pleased to present their fifth annual Teddy Bear Drive. The purpose of the drive is threefold— to create awareness for an extremely rare disease: Opsoclonus Myoclonus Syndrome, to raise money for research of this disease, and to give a teddy bear or stuffed animal to children who are in the hospital in order to brighten their day.

The Teddy Bear Drive began in 2009 at Texas Children’s Hospital. The following year it expanded to in-

cluded two hospital in Lubbock, Texas. Twenty hospitals were included in 2011. By 2012, the Teddy Bear Drive reached 32 hospitals in eight states, and raised \$43,000 dollars that went directly to three research recipients. (see story page 2)

The goal for 2013 is to reach 100 hospitals throughout the country, to raise \$100, 000 for research, and to distribute 10,000 stuffed animals to children in hospitals all over the United States.



## What Is OMS?

Opsoclonus Myoclonus Syndrome (OMS) is a rare childhood disease striking roughly 1 in 10 million people annually, mainly children. It is caused by the immune system attacking the brain, and is often associated with a neuroblastoma cancer. The child afflicted with OMS quickly loses his or her ability to walk or talk. The child shows signs of opsoclonus— eyes darting or moving erratically, and myoclonus— limbs shaking uncontrollably. The average age of these OMS warriors is about 18 months. Many of these children will ultimately find cancer in its early stages.

Unfortunately, OMS is often a misdiagnosed disease. This causes children to remain impaired, sustaining continuous brain damage, until the correct diagnosis is made.

While there is no cure for OMS today, there are treatment protocols that are encouraging. For more information, visit our websites at:

[www.omslifefoundation.org](http://www.omslifefoundation.org)

[www.omslife.org](http://www.omslife.org)

<http://wiki.omslife.org>

or find us on FaceBook at OMSLife.



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# THE 2012 OMS RESEARCH GRANT RECIPIENTS

The board of directors of The OMSLife Foundation has elected to direct the monetary proceeds collected from the Fourth Annual OMS Teddy Bear Drive 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. Mark Gorman, Boston Children’s Hospital, Boston, Massachusetts.**

Dr. Gorman, through collaboration with OMS researchers and doctors worldwide, has embraced the approach of holistic treatment of OMS. He has aligned a team of experts of varying disciplines to assist

families in addressing issues with oncology, neurology, physical, speech, and occupational therapies, nutrition, and school placement and programs.

**Pediatric OMS Research Fund, Chicago Illinois.**

In collaboration with The Dancing Eyes Syndrome Trust in London, England, Pediatric OMS Research Fund has been a leader in bringing the OMS medical community together. This group has hosted multiple medical conferences with leading OMS experts from around the world, enabling collaboration at a greater level than would normally occur for a rare disease.



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.omslife.org/content/2013-omslife-teddy-bear-drive](http://www.omslife.org/content/2013-omslife-teddy-bear-drive)

Donations are tax deductible.

**A special thank you to our volunteers:**

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

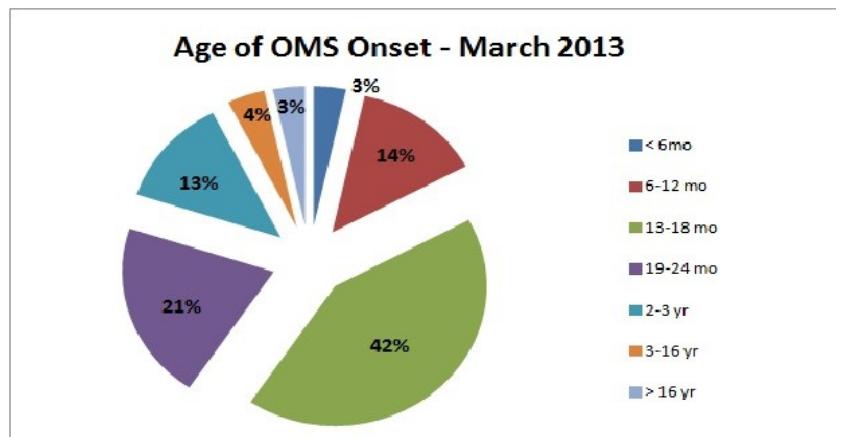
And thank you to our 2012 and 2013 sponsors. For the complete list of sponsors, visit [www.omslifefoundation.org/](http://www.omslifefoundation.org/)

**A special thank you to the dedicated researchers who care for many of our OMS warriors:**

- **Dr. Michael Pranzatelli**
- **Dr. Mark Gorman**
- **Dr. Wendy Mitchell**

## OMS Attacking Our Toddlers

Recently, we gave an informal survey to OMS caregivers regarding the age of onset of OMS. We received 175 responses from the US, South and Central America, Asia, and Europe. A full 80% of the responses indicated onset began under the age of 24 months. Imagine being the parent of an infant or toddler and trying to determine why they have the mysterious symptoms. The child is too young to explain what they are experiencing, leaving the parents at a loss to know how to help their rapidly deteriorating child. This is OMS, and one of the reasons why it is so difficult to diagnose.



## MEET A FEW OF OUR OMS WARRIORS

**Audrey** is an OMS warrior under the care of Dr. Mark Gorman at Boston Children's Hospital. Audrey's OMS battle began in early 2010 after a strep throat infection compromised her immune system. Initially diagnosed with Sydenham's Chorea, it took a year and a half before she was correctly diagnosed. The family's search for the correct diagnosis eventually led them to Dr. Gorman, who made that diagnosis in the summer of 2011. During the next year, Audrey went through a variety of intensive treatments, including chemotherapy.

Since that time, the family has become a big advocate for OMS research. Brian and Kristen participated in the 2012 OMS Teddy Bear Drive and were able to bring smiles to many children at Boston Children's Hospital.

In August 2013, their campaign to help OMS research grew bigger as Brian participated in a seven day, 550 mile bike ride from Niagara Falls, NY to Hampton, NH to raise money for OMS research. Through Brian's efforts, he raised over \$5,000 for OMS research. The picture below shows OMS warrior Audrey cheering her father on as he crosses the finish line.



**Camilla** is an OMS warrior from El Salvador. She was diagnosed in July 2012 and contacted our foundation after finding information about OMS while searching the web. Working with Texas Children's Hospital in Houston, The OMSLife Foundation was able to bring Camilla and her parents to Houston for free treatment. During their seven week stay, many volunteers came forward to provide housing, meals, and transportation for the family. Camilla is responding well to her treatments; though the medicines are difficult to find at times in El Salvador.

A special thank you to Dr. Timothy Lotze and the International Charity Board at Texas Children's Hospital for taking on Camilla's case.



**Valen's** OMS battle began in February 2012. Within two days, Valen went from a happy, toddler who loved to walk, talk, and jump to an OMS warrior who was immobile and could not stop shaking.

Initially diagnosed with Post Infectious Ataxia, Valen initially made progress, but then regressed again. Finally diagnosed with OMS, Valen began treatments by Dr. Wendy Mitchell at Children's Hospital L.A. Like a number of OMS children, for months, doctors could not find cancer in Valen. But eventually, a tumor was found a few months later. After surgery, Valen continued to make progress in his OMS battle. Like many OMS warriors, Valen had a port put in to make infusions easier for him.

Valen's treatment protocol of chemotherapy, ACTH ( a high dose steroid), and IvIG have stabilized his OMS and helped him to slowly make progress. Despite steady progress after surgery in 2012, Valen experienced a second tumor in the summer of 2013. Like all OMS warriors, getting regular MRI, MIBG, and CT scans are part of the routine. It was during one of those routine scans that a tumor was found once again in the same place as the previous year. Once again, surgery removed Valen's tumor. Valen's OMS battle is an example of the constant ups and downs that is experienced. Infections, tumors, scans, surgeries, frequent hospital visits, and expensive drugs with inconsistent results are all part of the OMS battle for these toddlers. His battle continues as he is tapering medications and continuing scans for more tumors.





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



## MEET OMS WARRIOR JOVANI....

**Jovani's** OMS battle began shortly after age two. Like many toddlers, he was diagnosed with Acute Cerebellar Ataxia and sent home.

His condition continued to deteriorate and doctors ran scans and tests, but eventually admitted to not knowing. For over two years, Jovani's parents sought answers as they visited neurologists and oncologists. Finally, Dr. Michael Pranzatelli diagnosed Jovani with atypical OMS. Jovani was prescribed with an OMS treatment protocol of Dexamethasone, IVIG, and Rituximab chemotherapy in March 2011.

Like many OMS warriors, speech therapy, physical therapy, and occupational therapy have played an important part

of Jovani's gradual recovery. While he has good days and bad, he continues to make gradual progress in his battle.



Jovani is on lockdown since his white blood counts are repopulating slowly. Keeping Jovani isolated enables him to avoid viruses and germs that could be detrimental to his treatment. So, he relies on homebound schooling provided by the local school district to help him maintain pace with his peers in school.

## HOW YOU CAN HELP

**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.

Donations to our foundation help to provide grants to OMS researchers. Please consider a donation to help find a cure for these OMS warriors.

You can make a check to The OMSLife Foundation and place it into the envelope provided or give an online donation at

**[www.omslife.org/content/2013-omslife-teddy-bear-drive](http://www.omslife.org/content/2013-omslife-teddy-bear-drive)**