

**2014 OMSLife and CHLA Caregiver Conference
May 17, 2014 at Children's Hospital Los Angeles**

**Dr. Wendy Mitchell – Dept Head Children's Neurology at CHLA –
"What I have learned about OMS in 33 years"**

- OMS is very individualized. "Statistics don't really help if your child is the anomaly".
- She began in early 1980's with a couple of OMS kids. Sandy Greenberg was a college student and parent of an OMS child. She started the first web site for OMS.
- She has found over the years that almost no one gets better by themselves.
- She also found that the damage is not always reversed by treating immediately, but it can impact the long term outcome.
- Study at CHLA concluded three drugs are better than two (high dose steroids, iVIG, and Rituximab).
 - o Dr. Pranzatelli was an early proponent of Rituximab use. It is now the treatment of choice.
 - o The issue is that it turns off the immune response to the entire body instead of just targeted areas.
- OMS is much worse than originally thought. It is easy to get under control with aggressive treatment but a challenge long term.
- The 7th OMS meeting in England brought together roughly 30 researchers and clinicians. The group is working together on a protocol

Dr. Susan Terkel CHLA – "Behavioral and Psychiatric Problems in children with OMS"

- The challenge with OMS and other diseases like this is that how do we know if the behavior that we are seeing is due to OMS or other reasons?
- The reason does matter because the child still has to grow up to be a good citizen
- What parts of the brain guide what we feel?
 - o The cerebellum regulates balance and behavior / mood
 - o When the cerebellum calculator interference messes up calculations, it is trying to balance them. This is where Pt and OT help greatly.
 - o The brain learns that what you have now is not what you have in 20 years
 - o When your child has a problem, you work around it and move forward
- Consistent rules such as bed times are key. The more you keep expectations high, the more you allow them to rise to the occasion.
 - o It is easy to create a behavior you don't like but difficult to get rid of it
 - o Set limits, be consistent, have the same rules for everyone
 - o Anyone can say yes to a child. You have to really love them to say no.

- Focus on positive reinforcement. Even with rage fits, wait for the opportunity to reinforce the positive.

Questions to Dr Mitchell and Dr Terkel:

Q: What is the age of the oldest OMS patient?

A: Male age 25 had OMS and NB as a baby. No treatment until age 4. Age 11 needed a walker – put back on steroids and was able to walk. Sent patient to Dr P for lumbar puncture and still had B cells present. Now in an OT program where he has a supervised job.

A: Young Asian girl misdiagnosed with Acute Cerebellar Ataxia. Put on steroids and ivig for 3 years. Improved to walking and speaking. Went back home.

Q: For adults who had childhood OMS, what does it feel like when a relapse is coming on?

A: Dr M - Feel “foggy”. Eyes feel funny.

Q: Does residual behavior and symptoms indicate active OMS?

A: Dr M – fever and cold and minor OMS symptoms is NOT a relapse. A relapse is when every day, the symptoms get a little worse. A doctor does not know on day 1 if it is a relapse. ALL immune diseases have symptoms flare on occasion. She considers a patient stable if off of all meds for one year. The key is to get an annual baseline assessment with your specialist.

Q: What is the correlation on OMS and Neuroblastoma?

A: Dr M – Roughly 60% of OMS children have a neuroblastoma. Many specialists suspect all OMS children had a NB at one point in time and in the other cases, the immune system got rid of it.

Q: Residual OMS – can it be mood also? How do you know if it is active disease?

A: Mood swings and behavior are started with OMS onset, but often become learned behavior as the child gets better. Once the patient stabilizes, the expectations should be set with the child regarding behavior, mood, and being a good citizen.

Q: What are your thoughts on utilizing behavior medicines?

A: Dr M – Some OMS kids may need to be on a drug for ADHD, but otherwise it is not advisable.
Dr T – She advocates Physical Therapy, Occupational Therapy, setting high expectations, and tough love and staying away from behavior meds.

Q: What about sleep issues?

A: Sleep issues will certainly be bad at onset and can be treated with drugs such as trazadone and clonidine when necessary. As they stabilize, restless sleepers need positive reinforcement to stay in their own bed, even when they awake in the night. Kids are developmental and learn bad behavior. The key is to train and re-train once they are past the worst of the onset or relapse.

Q: Are better drugs for OMS on the horizon?

A: Our drugs are borrowed from other diseases such as Multiple Sclerosis. They have millions of dollars for research and pharmaceutical companies have a market to do R&D. OMS is too small for Pharmaceutical companies. So we rely on parallels to diseases such as MS.

Q: Are there different forms of OMS like there are different forms of MS?

A: The definitions are blurry mainly because the numbers of patients are too small.

Megan LanGille – Neuroimmunology Fellow at CHLA

- Did clinical fellowship with MS at CHLA
- Began working with Dr Mitchell this spring
- Received a training grant from The OMSLife Foundation - Spent a month in Boston working with Dr Mark Gorman's team and studying their approach
- Next year will work full time in Pediatric Neurology at CHLA
- Goal is to build an immunology clinic and continue working with Dr Mitchell

Mike Michaelis – The OMSLife Foundation

- www.omslifefoundation.org
- Mission is to raise awareness of Opsoclonus Myoclonus Syndrome (OMS), to maintain support networks for families, and contribute in research for a cure.
- Have FaceBook presence in OMSLife, OMSLife Teens, and OMSLife en Espanol.
- Have raised \$85,000 in 2012 and 2013 for OMS research and awareness
- Resources such as Wikipedia, web conferences, surveys, list of doctors
- Want to encourage sharing knowledge and provide the support network for OMS care givers
- Want to encourage developing baseline assessments of your OMS warrior on a regular basis – at least quarterly. See the self assessment form.
- Our road map for 2014 and 2015
 - o Care giver conferences in Los Angeles, Boston, Houston (2014)
 - o Surveys formalized (2014)
 - o Work with Dr Tim Lotze and Dr Pedro DeAlarcon to define a Latin American protocol
 - o Increased social media presence on YouTube, Flickr, Pintrest, Twitter, etc... (2015)
 - o Updated and enhanced Wiki/OMS Manual (2015)
 - o Alignment with school specialists to provide school resources and advocacy (2015)

Naveen Viswnatha

- www.pablove.org/oms
- Organizing funding for OMS research via the Pablove Foundation
- Pablove works via a scientific peer review to determine how funds are administered
- Currently the OMS designated fund has \$140,000 awaiting funding for OMS research
- The peer review is currently reviewing five proposals for 2014
- For more information, contact Naveen or Crystal Viswanatha

Limor and Daniel Gallo

- www.edensjourney.org
- Created Eden's Journey to help families with rare diseases
- Raise funds for CHLA research

Brainstorming ideas for future events

- Have events once or twice annually
- Rotate event to north and south California
- Annual family camp for a weekend – Maybe at Painted Turtle Camp
- Include other OMS specialists and other specialists related to OMS
- Invite kids to family event
- Have OMS kids and/or parents and/or siblings share their experiences
- Presentation topic ideas – school transition
- Had good balance of Q&A and presentations