

OCTOBER 2011

NWRSF

www.nwrettysndrome.org

We Must Be: Informed, Empowered, & United Conference Highlights

The 2011 conference was held in Olympia, WA in August, with meetings on Friday and group outings on Saturday. Dr. Patrick MacLeod began with a report from the IRSF meeting held in Boston, including research on MeCP2 replacement therapies, using stem cells from baby teeth, how enriched environments effect behavior, and more. He stressed the need for a NWRSF registry—an up-to-date list of all Rett families in the Northwest—to provide a way for researchers to contact families when they have found successful treatments. The board intends to follow-up with this in the near future, so please be prepared to help us with this important task. Vicki McKinney from PAVE (wapave.org) presented information on how to be a better advocate for your child's education. She stressed the need for specific IEP goals and gave steps to follow before, during, & after the IEP meeting. Dr. Mario Petersen led a discussion panel where parents asked questions about anything and everything. It was wonderful to “pick the brains” of our medical advisors & speakers. Dr. Petersen also talked about how to practice defensive medicine as parents. He mentioned the importance of keeping a concise documentation of your child's medical history, including one sheet with emergency information & signs of alarm. He said that it was important for parents to have questions ready when meeting with doctors and to ask other Rett parents for advice. Dr. John Bissonnette reported on his NWRSF-funded research project on the effect of sarizotan on respiration and locomotion. He found sarizotan is very effective in correcting respiratory problems, but also decreases locomotion. Dr. Nino Ramirez gave a fascinating keynote address on the neurological basis of breathing disturbances in Rett Syndrome. Families went out in the community on Saturday, spending time socializing and having fun together. A special thank you for everyone who helped to make this conference a success!



October is Rett Syndrome Awareness Month!!

Many states across the USA have declared October to be Rett Syndrome Awareness Month. This is a great opportunity to share our daughter's stories with our friends, our neighbors, and even the cashier at the grocery store or row-mate on the bus. Wherever you are and whomever you are talking with, take a moment to share information about Rett Syndrome. The foundation has printed business cards with basic information and a link to the website. If you would like some cards to hand out, please email the foundation at nwrettysndrome@gmail.com and we will get them in the mail to you today! You can also download a copy of the official Governor's proclamations for Washington, Oregon, & Idaho on the website. Print it out and hang it up at schools, at gyms, at the library—anywhere and everywhere! And be sure to wear purple as much as possible and tell people why!

SAVE THE DATES!

Run for Rett
Olympia, WA
June 2, 2012

Annual Conference
Seaside, OR
July 26-29



OCTOBER 2011

It's great to be a member!

Thank you for your support of the Northwest Rett Syndrome Foundation! Inside this newsletter you will find information about Rett Syndrome Awareness Month and a summary of the 2011 conference in Olympia, WA. Please visit our website regularly for updated information from the foundation and please contact us with any questions you may have.



If you are not a current NWRSF member,
please renew your membership today!



4545 Trenton Loop SE
Olympia, WA 98501