



21345 Miles Drive
West Linn, OR 97068-2878

1+503-656-4808
www.MLDfoundation.org
deansuhr@MLDfoundation.org

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CONTACT: Dean Suhr
503-656-4808
deansuhr@MLDfoundation.org

Local MLD Foundation Holds Annual Family Conference

(West Linn, OR—October 28, 2007) Dean and Teryn Suhr of the locally based MLD Foundation announced a successful 2007 annual MLD Family Conference in Boston, MA. The Conference enabled those affected by MLD to meet other families, often this is the first time that they are able to meet another MLD affected family. Family members were able to learn from the leading researchers during their presentations and then sit down and informally ask questions over lunch or dinner. Many families brought their affected children and/or spouse.

The West Linn based foundation reaches families for compassion and support, and scientists to influence research around the world focusing its efforts on MLD, metachromatic leukodystrophy, a rare genetic defect carried by 1 in 200 people and affecting 1 in 40,000 births, including three families in the Lake Oswego – West Linn community.

“Families from across the US and Canada came to learn and interact with research scientists and doctors from as far away as Denmark and Italy” said Dean Suhr, President of the international organization. “For as rare as MLD is, to have 24 families in the same room is phenomenal. This was our largest and most successful Family Conference.”

Over 65 people attended, including 14 scientists and doctors, and two invited guest speakers including the FDA’s office of Orphan Products.

“Thank you so much for the wonderful conference you put together for us. This was the first time I have been able to attend and it far exceeded my expectations (and my expectations were high!) I was so impressed with the Doctors. They were so friendly and approachable. I was really nervous about it. I pictured being "lectured" at. It was very professional and yet lay back and comfortable. I came away with some new information but more importantly to me, I came away feeling more confident in my care of [my daughter] Rachel.” -- Judy P. - Maine.

“Most important, I got to meet in person, all of the family members I have been talking with over the computer for a while. I also got to meet new family members“ -- Kim B. – New Jersey

The MLD Foundation is the world’s only organization focused exclusively on MLD that provides a full support system for families and is driving researchers toward a cure.

“Several other foundations raise money for MLD and leukodystrophies as a whole, but only the MLD Foundation has the depth to incorporate a full family support community”, said Suhr. “We have built credibility so that we are recognized and welcomed into university and industry research labs across the world, as well as the FDA’s Orphan Products Division, and the Office

of Rare Diseases at the NIH.”

Prior to the Conference, the MLD Foundation hosted a meeting of the International MLD Registry Consortium, a formal group of nearly 20 international research scientists, foundations, and industry, all working on standardizing the collection of data describing the progression of MLD. Mr. Suhr is a member of the 3-person steering committee leading the MLD Registry project, which is required to establish the baseline for the progression of the disease that drug companies will use to compare the effectiveness of their therapies when they go to the FDA and EMEA for approval.

“So many of the international experts for MLD were in Boston for our family conference that it made sense to meet to discuss our biggest joint project, the International MLD Registry and Natural History Database”, said Suhr. “With one drug in clinical trials, and potentially two more trials scheduled for 2008, it is critical that we pave the way for approval of viable therapies.”

Teryn Suhr, Executive Director and co-founder said “We are very pleased with our progress these past eight years. We have grown from being simply a voice on the phone and an email address, to being the world’s primary source of family compassion and MLD information, as well as becoming a key player in increasing awareness, influencing research, and promoting education for MLD.”

Additional information can be found at the Foundation’s web site: www.MLDfoundation.org

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The MLD Foundation is a 501(c)(3) non-profit public charity based in West Linn Oregon. MLD (metachromatic leukodystrophy) is a rare genetic condition passed on from the parents to children that is terminal. There is no cure today, however, several therapies are being used with moderate success to try to reduce the progression of the disease. The disease is diagnosed about 60% of the time in infants at age 18-24 months, and often leads to death by age 4 or 5. It can also appear in the early to mid teen years or in the adult form can show up as late as the 40’s. In infants loss of physical skills show first, whereas in teens and adults it is mental skills that decline first.

One of the primary impacts if the disease is white mater in the brain and the loss of the myelin sheath, the insulator around the nerves. The disease is carried by 1 in 200 individuals and affects approximately 1 in 40,000 births. The disease is often mis-diagnosed. There are 6 families known in northern Oregon, including 3 in the West Linn – Lake Oswego communities.

Dean and Teryn Suhr founded the MLD Foundation after two of their three daughters were diagnosed with MLD. Their youngest, Darcee, passed away in 1995 during a treatment to try to stop the disease, and their oldest, Lindy, is terminally ill with the disease. The Suhr’s did not know any other MLD affected families during the early days of their MLD odyssey and vowed to not let that be the experience of other families. The Foundation focused its early years on educating and connecting the affected families, but has since grown to have a strong impact on the research into therapies and eventually a cure for the disease.

The MLD Foundation relies completely on donations and has no paid staff. The Foundation is not a fund-raising “machine”; instead it focuses its efforts on making a direct impact on families and researchers.

The MLD Foundation’s motto is “we C.A.R.E.”, representing facilitating Compassion, increasing Awareness, influencing Research, and promoting Education for MLD.

More information can be found at the Foundation’s web site: www.MLDfoundation.org