

From: [Joel and Luci Janzen](#)
To: [DOH.WSBOH](#)
Cc:
Subject: ALD screening
Date: Saturday, September 27, 2014 11:22:48 AM

Dear Sirs and Madames,

We are writing this letter in support of newborn screening for ALD. We would like to request that it be added to the Washington State Newborn Screening Program. We have an eleven year-old grandson (Matthew Reimer) in Lawrence, KS who was diagnosed back in 2010 before he exhibited any breakdown of the myelin sheath around his brain. Fortunately he was eligible for participation in a study through Kennedy Krieger Institute in Baltimore which prescribed an MRI of his brain every six months and consultation with Dr. Raymond every year plus a supply of Lorenzo's Oil which he takes every day. His only manifestation of the disease to date has been the development of Addison's disease for which he takes hydrocortisone daily. If lesions had already started to develop around his brain there would have been no hope. Needless to say his condition and its treatment has resulted in a lot of stress for him, his parents, and us every 6 months as we await the results of the 6 month MRI.

We are urging you to support the addition of ALD to the Washington State Newborn Screening Program so that early detection can instigate early treatment before the boys become symptomatic for the disease as was the case of our grandson. Studies have shown that boys who do not yet exhibit symptoms stand a 90% chance of living long term, healthy lives if stem cell transplants are performed when they are young before symptoms become apparant. We understand the anxiety generated when parents and others dear to the affected one hear the news that their son is afflicted by ALD. We feel that early detection is the only way to provide hope for a cure or at least a way to manage the condition.

Sincerely,

Joel and Lucille Janzen
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