The United Leukodystrophy Foundation was founded in 1982 with a mission dedicated to helping children and adults who have leukodystrophy and assisting the family members, professionals, and support services that serve them. The ULF is committed to the identification, treatment and cure of all leukodystrophies through programs of education, advocacy, research and service.

The ULF represents over 12,000 families and individuals affected with leukodystrophy in every state in the United States and 73 foreign countries.

We are honored to have been able to support the Newborn Screening Project for Adrenoleukodystrophy during its inception. It was reviewed and approved by our Scientific and Medical Advisory Board. Our Board of Directors enthusiastically gave their endorsement.

We presented this research opportunity to our membership in July 2005. To our surprise, we were overwhelmed by the response as it was not just from the current active members, but from many families like my own that had lost sons and other family members many years ago. Their calls and letters mirrored my personal thoughts and experiences that I wish to share with you today.

My family's saga with this genetic disorder began in 1977. For many months we searched for answers to explain the subtle, mysterious, and unexplainable changes in our bright eight year old son Howard. I remember clearly the day we were told our son had a disease we had never heard of and could not even spell. Following more tests, we learned our one year old son Timothy also had ALD and our four year old daughter was a carrier. Only a year and a half after our oldest son died, our youngest son became symptomatic. We cared for him until he was lost to ALD. During these thirteen years of caring for our sons, I also lost a brother at the age of twenty three and my uncle was diagnosed with Adrenomyeloneuropathy (AMN). He previously was diagnosed with MS for twenty years before we learned of a genetic disorder in our family. He died two years ago. Other relatives were screened and found to be carriers of ALD. Our story is not unique. Yet it demonstrates the impact of the diagnosis of one young boy.

Years ago, even to know the cause would not give hope. My family, as many others, did not have the benefit of years of research. Today we have the opportunity to make a difference. Unlike research and clinical trials that have an uncertain outcome, newborn screening for ALD offers the first ray of hope in identifying and giving the chance for life to boys with the ALD gene.

In one laboratory in the United States, each year approximately 300 boys are diagnosed with ALD. Unfortunately, only twenty percent or nearly sixty boys will have a chance for life. The other 240 boys will die as it is too late when the diagnosis of ALD is made for any potential therapy.

2304 Highland Drive, Sycamore, IL 60178; Telephone (815) 895-3211; Fax (815) 895-2432; Toll Free (800) 728-5483
E-Mail: office@ulf.org ULF Website: www.ulf.org

If a child could be diagnosed at birth, we can now prevent the development of Addison's disease, begin a dietary therapy with Lorenzo's oil and monitor for changes to the brain with an annual MRI. If there is any change in the MRI, a boy would be a candidate for a Bone Marrow Transplant during the window of opportunity for a successful outcome.

Comments from families in every state reflect an eagerness to take action. They have all asked "What do we need to do?" "How do we get this test in our state?" "How quickly can we get this done?" The most empowering theme thru all our communications can be summarized in one sentence. "We can finally reach out and do something to prevent the grief and tragedy for others that we have suffered, while research continues to search for a cure."

Most important, I believe the ULF is supporting and sharing true hope for the future and not unrealistic expectations. Newborn Screening for Adrenoleukodystrophy will save many lives.