

Robert Rauner

United Leukodystrophy Foundation



Robert's sons Paul and Kevin have both been affected by Adrenoleukodystrophy (ALD), and the adult form of the disease, Adrenomyeloneuropathy (AMN).

His youngest son Kevin was diagnosed in November of 1993 with Adrenoleukodystrophy(ALD). After his diagnosis his older brother Paul was diagnosed with Adrenomyeloneuropathy (AMN). Since the initial diagnosis Robert's family found that his wife's older brother had and passed away from AMN. As far as they can tell there is no continuation of the disease through their family. Robert and his family became aware of the United Leukodystrophy Foundation (ULF) at the time of his son's diagnosis and have continued their involvement with the ULF having become board members to ensure that there will always be a place for the newly diagnosed to come and be educated and directed to the best research that is available.

Robert wants to be involved in the LCN because he feels that this will be an opportunity to help lead newly diagnosed families to a place that will give them the best chance to help them cope with the new challenges in their life and make sure they have access to all the care they need in one place near them.

His hope is that there can be a cure for all leukodystrophies. Before that happens, he wants the families to have all the necessary information and resources they need in the way of therapy, treatment options and expert care as the research continues.

Robert lives in Lincoln, Nebraska.