



The Legacy of Angels FOUNDATION

For Immediate Release

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The Legacy of Angels Foundation Announces the 2022 Award Recipient The Sue Rosenau Legacy Award

It is with great pleasure to announce the recipient of the **2022 Sue Rosenau Legacy Award**. The Legacy of Angels Foundation (TLOAF) created this award in 2019 to honor the late Co-Founder and Chief Operating Officer, Sue Rosenau. Sue, a remarkable and driven wife, mother, and rare disease advocate lost her 3-year battle with ovarian and serous endometrial cancer in July of 2018. To keep Sue's legacy alive within the foundation and community at large, TLOAF honors an individual each year for his/her achievements in Sue's name.

This year, our foundation is pleased to congratulate, ***Dr. Dietrich Matern, MD, PhD., Clinical Biochemical and Co-Director of Mayo Clinic's Biochemical Genetics and Genomics Laboratory at the Mayo Clinic in Rochester, Minnesota.*** Dr. Matern is a recognized leader in the development and improvement of laboratory assays for the biochemical diagnosis and follow-up of patients with inborn errors of metabolism. Dr. Matern's research has been funded by the NICHD, ACMG's Newborn Screening Translational Research Network (NBSTRN), industry, and The Legacy of Angels Foundation (TLOAF). His focus, in recent years, has been on newborn screening for lysosomal storage disorders, including Krabbe disease.

Krabbe disease is one of the primary focus areas for TLOAF, a rare, inherited degenerative disorder of the central and peripheral nervous systems. Co-founders, Paul and the-late Sue Rosenau were impacted by Krabbe disease as their first granddaughter was diagnosed in July of 2001. Makayla lost her battle with Krabbe disease in May of 2003.

Dr. Matern has devoted more than 2-decades of research efforts to improving newborn screening for multiple diseases including lysosomal disorders to help reduce unnecessary health care costs. The work of Dr. Matern and his colleagues in the Biochemical Genetics Laboratory has also significantly reduced the number of families that have to go through unnecessary worries and tests because the result of their baby's screening test was a false positive. In addition to this benefit to families, these improvements also helped reduce overall health care expenditures by avoidance of unnecessary follow-up evaluations. For example, Infantile Krabbe disease is one of the lysosomal disorders for which Mayo Clinic Laboratories provides first and second-tier newborn screening. Care is taken to ensure rapid turnaround in less than 48 hours. In fact, if a blood sample for 2nd tier testing was to arrive in the morning, Mayo Clinic Laboratories can usually have results within a day. Paul Rosenau, president of TLOAF states, "every minute counts in the first few days of life for a baby identified at high risk for Infantile Krabbe disease (IKD). The sooner a baby is identified with IKD,

the sooner medical intervention can occur. Early treatment is very important in IKD in preserving optimal health in affected patients.”

TLOAF selected Dr. Matern because his work and commitments align with the Sue Rosenau Legacy Award conditions. The purpose of this award is to recognize an inspirational leader who collectively creates lasting change and measurable differences in one or more areas of our mission. Dr. Matern has delivered extraordinary contributions, worked to propel progress in those living with Krabbe disease, and continuously supports other Krabbe disease work whenever possible; a replica of the late Co-Founder, Sue Rosenau. For more information about The Legacy of Angels Foundation, we invite you to visit tloaf.org.

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