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LEUKODYSTROPHY
FOUNDATION

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The United Leukodystrophy Foundation Board of Directors' statement regarding the changes to healthcare and research because of reduced NIH funding.

February 24, 2025

"The United Leukodystrophy Foundation (ULF) is deeply concerned about proposed changes in healthcare and research. These changes may limit patient access to life-saving treatments; may impact the ability of physicians and other providers to effectively perform their jobs; and may threaten support for the world's leading research institutes, the National Institutes of Health (NIH).

"*The mission of the ULF* is *to provide support to the leukodystrophy community* and enable *platforms to accelerate improving patient quality of life and finding cures.*

"Leukodystrophies are a group of more than 50 rare, genetic neurodegenerative diseases that impact thousands of children and adults across the U.S. and throughout the world. The symptoms include developmental delays, loss of motor skills, cognitive decline, seizures, vision issues, and premature death.

"Reductions in funding could impede progress on clinical trials, slow or stop the research needed to discover treatments and cures; and create delays in treating the most vulnerable populations, such as those individuals who are affected by leukodystrophies and other diseases. Limits to medical care or treatments for patients, or restrictions on physicians and their services, can cause real and lasting harm.

"The ULF stands together with its community of patients, families, and professionals. We urge a considered approach to changes that should occur only in the framework of putting patients and their healthcare teams as the guiding focus."

The United Leukodystrophy Foundation (ULF) is a voluntary health organization dedicated to providing patients and their families, whether newly diagnosed or living with leukodystrophy, with the support they need to navigate their illness and enable platforms to accelerate improving patient quality of life and finding cures. Ulf.org