We are excited to announce the launch of our international retrospective natural history study of metachromatic leukodystrophy (MLD). This study is in collaboration with the Global Leukodystrophy Initiative Clinical Trials Network (GLIA-CTN), the Lysosomal Disease Network, and the Children's Hospital of Philadelphia. Contributors will be included as part of a working group or as co-authors (depending on level of participation) on any future publications arising from this study. Individual physicians may contribute to the success of this LDN-sponsored research by enrolling one or more metachromatic leukodystrophy participants. Collaborators will also be remunerated on a per-patient basis for data contributed to the study.

With the pressing need of emerging therapies for MLD, we are eager to begin this project as soon as possible. Please let us know how we can best help foster our collaboration. With questions or to refer patients, please contact Laura Adang MD PhD at adangl@email.chop.edu or our study coordinator, Omar Sherbini at sherbinio@email.chop.edu or 1(215)590-3068.

Sincerely,

Laura Adang MD PhD
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Adeline Vanderver, MD
Program Director of the Leukodystrophy Center of Excellence and Jacob A. Kamens Endowed Chair in Neurological Disorders and Translational NeuroTherapeutics at the Children's Hospital of Philadelphia; Associate Professor of Neurology at the University of Pennsylvania, Perelman School of Medicine