

## **Lysosomal Storage Disease Data Sharing Webinar Series – Session #3: Retroactive Data Sharing**

The recent webinar from C-Path's Critical Path for Lysosomal Diseases (CPLD) team focused on the critical issue of retroactive data sharing related to lysosomal storage diseases, encompassing contributions from organizations like the Orphan Disease Center and the Critical Path Institute. This session marks the third in a series that previously addressed proactive data sharing techniques and the necessity of clear consent language for data utilization arising from natural history studies and registries.

The primary intention of the workshop was to develop resources that enhance data sharing capabilities amongst sponsors, patient advocates, and various organizations engaged in research. Discussions centered on the complexities of retroactive data sharing, highlighting challenges such as legal agreements, the need for modified consent language, and the vital role of institutional backing.

As conversations progressed, topics like data ownership, community engagement, and the value of personal patient narratives in research were brought to light, reinforcing the workshop's aim to enhance collaboration within the rare disease research community. The collaborative efforts discussed incorporated frameworks from C-Path and RDCA-DAP regarding data sharing protocols, emphasizing how multi-stakeholder engagement can drive drug development and trial design.