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CPLD
CRITICAL PATH FOR
LYSOSOMAL DISEASES
CRITICAL PATH INSTITUTE

You're Invited!

Lysosomal Storage Disease Data Sharing Workshop, Webinar Series

Hello Data Sharing Enthusiasts, Lysosomal Storage Disease Scientific Colleagues, and Patient Advocates,

The [Orphan Disease Center \(ODC\)](#) in collaboration with the [Critical Path for Lysosomal Diseases \(CPLD\)](#) are putting on a Lysosomal Storage Disease Data Sharing Workshop, webinar series over the next 4 months.

Date and time – All workshops will be held virtually from **11am – 1pm EST** on the following dates: **Monday, February 24th, Monday, March 24th, Monday, April 28th, Monday, June 2nd.**

Vision and Outcomes – to obtain a thorough understanding of the current approaches to data sharing within the lysosomal storage disease community through the workshop and related activities. Outcomes will include the creation of written materials which will provide sponsors, participants, and patient advocacy organizations involved in **non-interventional** programs (from any sector – academic, nonprofit, government, and industry) including **registries and natural history studies**, with a **case-study toolkit for sharing data and to empower the formation of data sharing collaboratives**.

Overview - series of **2-hour workshops held once monthly for 4 months**. Case Studies on each topic presented, with extensive opportunity for discussion through Q&A and written feedback. Topics included, but are not limited to the following:

- **Session #1: Setting the Scene. Monday, February 24th**. Overview of data sharing elements, considerations, data sharing policy, grantees responsibilities, repositories infrastructure, capacity building, the ethics of data sharing, and more. Presenters from academic and regulatory agencies.
- **Session #2: Case Studies #1 - Proactive Data Sharing, Monday, March 24th**. How sponsors approach future data sharing before a study begins.

- Session #3: Case Studies #2 - Retroactive Data Sharing, Monday, April 28th.
How sponsors approach data sharing once a study has already begun or has closed.
- Session #4: Case Studies #3 - Data Sharing Collaboratives, Monday, June 2nd.
How collaboratives set up a framework for collaboration and encourage data sharing within their communities.

Additional information, calendar invites, background materials, slides, feedback opportunities, and workshop recordings will be available for participants and will be sent to registrants over the next couple weeks. Please note, you do not need to be on the webinar in real-time to participate.

[Register Here!](#)



<https://www.orphandiseasecenter.med.upenn.edu/events/lysosomal-storage-disease-data-sharing-workshop-webinar-series>

Thank you for your time and efforts on this important project. We look forward to your participation.

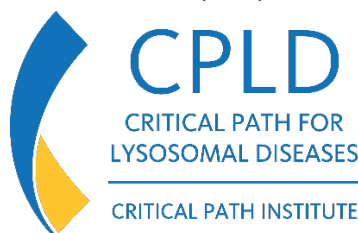
Sincerely,

CPLD & ODC

Questions? Please email your organizers:

ODC: Cara M. Weismann, PhD weismann@upenn.edu

CPLD: Krista Casazza PhD, RD, CSSD casazza@c-path.org



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