

## C-Path Awarded \$1.5 Million Grant from Ara Parseghian Medical Research Fund at Notre Dame to Enhance Collaboration in Niemann-Pick Disease Research and Drug Development

**TUCSON**, Ariz., August 22, 2024 — Critical Path Institute (C-Path) is thrilled to announce its Critical Path for Lysosomal Diseases (CPLD) Consortium has been awarded a grant from the Ara Parseghian Medical Research Fund (APMRF) at the University of Notre Dame. This generous grant will bolster C-Path's collaborative efforts in the research and development of treatments for Niemann-Pick Disease Type C (NPC). This rare and devastating genetic disorder affects children, causing severe brain and liver damage and often leading to early death.

The APMRF was established by Cindy and Mike Parseghian, whose three youngest children (grandchildren to Legendary Notre Dame Coach, Ara Parseghian) were diagnosed with NPC. The foundation supports NPC research and is dedicated to finding a cure. "We are deeply honored to receive this grant from the Ara Parseghian Medical Research Fund," said C-Path CEO Klaus Romero, M.D., M.S., FCP. "This support will significantly enhance our efforts to bring together the brightest minds from relevant fields to collaborate and accelerate the development of life-changing therapies for the NPC community."

The collaboration between C-Path and the APMRF marks a pivotal step forward in the fight against NPC. By leveraging collective expertise and resources, this partnership aims to make meaningful progress toward effective treatments, and ultimately, a cure for NPC.

"We are delighted to support C-Path's groundbreaking work in NPC research," said Sean Kassen, Ph.D., director of the APMRF. "This grant represents our shared commitment to advancing scientific discoveries and developing therapies that can change the lives of those affected by NPC. By partnering with C-Path, we are confident that we will accelerate progress towards a cure for this devastating disease."

Krista Casazza, Ph.D., CPLD Scientific Director, added, "This grant from the Ara Parseghian Medical Research Fund is a testament to the critical importance of collaborative efforts in the fight against NPC. The memories of Cindy and Mike's children, Michael, Marcia, and Christa, who succumbed to this disease, inspire every step we take forward."

Cindy K. Parseghian, founder of the APMRF, emphasized, "This program will be a big leap forward and by combining our expertise and resources, we are well-positioned to make significant advancements in understanding the disease mechanisms and developing innovative therapies. Our ultimate goal is to provide hope and improved outcomes for patients and their families."

For more information about the CPLD consortium, please visit https://c-path.org/cpld.



## **About Critical Path Institute**

Critical Path Institute (C-Path) is an independent, nonprofit established in 2005 as a public-private partnership, in response to the? FDA's Critical Path Initiative.? C-Path's mission is to lead collaborations that advance better treatments for people worldwide. Globally recognized as a pioneer in accelerating drug development, C-Path has established numerous international consortia, programs and initiatives that currently include more than 1,600 scientists and representatives from government and regulatory agencies, academia, patient organizations, disease foundations and pharmaceutical and biotech companies. With dedicated team members located throughout the world, C-Path's global headquarters is in Tucson, Arizona and C-Path's Europe subsidiary is headquartered in Amsterdam, Netherlands. For more information, visit? c-path.org.

Critical Path Institute is supported by the Food and Drug Administration (FDA) of the Department of Health and Human Services (HHS) and is 54% funded by the FDA/HHS, totaling \$19,436,549, and 46% funded by non-government source(s), totaling \$16,373,368. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, FDA/HHS or the U.S. Government.



## **About Ara Parseghian Medical Research Fund at Notre Dame**

The Ara Parseghian Medical Research Fund at the University of Notre Dame is dedicated to finding a treatment or cure for Niemann-Pick Type C disease—a rare and deadly neurodegenerative disorder that primarily strikes children, with death occurring before or during adolescence. The APMRF was formed in 1994 as an external foundation when Cindy and Mike Parseghian's three youngest children—Michael, Marcia, and Christa—were diagnosed with NPC disease. In 2016 the Foundation merged with the Fund at Notre Dame.

## **Contacts:**

Roxan Triolo Olivas C-Path 520.954.1634 rolivas@c-path.org

Kissy Black C-Path 615.310.1894 kblack@c-path.org