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Project Alive's Inaugural Hunter Syndrome Family Fair & Casino Night Raises $68,000 for Research and Support Programs

The McKay family attended this successful event.

REDONDO BEACH, CALIFORNIA, UNITED STATES, November 9, 2023 /EINPresswire.com/ -- Project Alive, a non-profit organization dedicated to advancing research and supporting families affected by Hunter syndrome, hosted its first-ever Hunter Syndrome Family Fair and Casino Night at the Hilton in Costa Mesa on Saturday, October 28, 2023.

The Hunter Syndrome Family Fair drew over 100 individuals from across the country impacted by this rare, life-limiting, and progressive genetic disorder. Families gathered to connect with pharmaceutical companies conducting clinical trials and offering treatments for the condition. Notable organizations such as Denali Therapeutics, JCR Pharmaceuticals, UC San Francisco, Takeda, and Regenxbio were present, providing valuable information about their drugs and engaging attendees with carnival games for children, as well as participating in afternoon trick-or-treat festivities.

Distinguished speakers from Children’s Hospital of Orange County (CHOC), Beyond Blindness, and other specialists in occupational and speech therapy, IEP advocacy, and special education shared crucial information vital to the daily lives of families affected by Hunter syndrome. Dr. Kimberly Stephens, President of Project Alive was a featured speaker. She frequently speaks as a rare disease advocate at conferences and events and serves as a mentor and resource for newly-diagnosed families.

In the evening, Project Alive hosted the Hunter Syndrome Casino Night, attracting support and participants from the local Orange and Los Angeles counties. The event featured dinner, a heartfelt tribute to children with Hunter syndrome, and charity casino games and bingo. To facilitate parents' participation, Beyond Blindness, an Orange County nonprofit agency, offered free childcare, marking a rare opportunity for families to enjoy an evening out.

The event received generous support from organizations such as the Angels Baseball team, Modern Woodman Financial, Arcs Builders, E&S Grounding Solutions, and Briddlewood Facility Services.

The combined efforts of the day resulted in an impressive $68,000 raised for Project Alive. These funds will contribute to Hunter syndrome research through Project Alive’s research grants program and community resources program. Currently, Project Alive provides free IEP advocacy services, quarterly webinars, and workshops from leading experts, and is building a comprehensive database of educational resources to support the community.

Kristin McKay, Project Alive Executive Director, expressed gratitude for the overwhelming support and stated, “For many years, Project Alive, built by parents desperately fighting the ticking clock to find a cure, did not have the luxury to focus on anything other than saving our kid’s lives. There was no interest by researchers or pharmaceutical companies. But through our tireless efforts, Hunter syndrome is now studied, and we have multiple clinical trials currently enrolling patients. With that, we now have the opportunity to look for the other gaps. Our families struggle with the day-to-day, and we want to address that. In 2024, we hope to begin providing more assistance to families struggling during their relocation for clinical trials, along with providing more access to information for our Spanish-speaking families. As pharmaceutical companies explore treatments, we will seek equity among our community. We are grateful for the money raised during our first year of this event and look forward to the impact we can make next year!”

Project Alive remains committed to its mission, working towards a future where Hunter syndrome families receive the comprehensive support they need. For more information about Project Alive and its initiatives, visit www.projectalive.org.

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