



Harmony Biosciences Announces Funding for Unique Community Initiatives Through its Patients and Progress at the Heart Awards Programs

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Awards accelerate nonprofit organizations' commitments to addressing unmet needs within the sleep and rare neurological disease communities

PLYMOUTH MEETING, Pa., July 25, 2023 /PRNewswire/ -- Harmony Biosciences selected the latest round of nonprofit organizations for its Patients at the Heart and Progress at the Heart awards, which provide funding toward interdisciplinary community initiatives that address complex challenges facing people living with sleep disorders and rare neurological diseases.



Harmony Biosciences Holdings, Inc. ("Harmony") (Nasdaq: HRMY), is a pharmaceutical company dedicated to developing and commercializing innovative therapies for patients with rare neurological diseases.

Over the last four years, Patients at the Heart has provided funding for 22 initiatives working to address the holistic needs of people and their families affected by sleep disorders and rare neurological diseases.

"Women living with narcolepsy encounter distinct challenges that persist throughout their lives, leading to additional health burdens during pregnancy, lactation, and caregiving," said Kathryn Schubert, President and CEO of the Society for Women's Health Research, a Patients at the Heart award recipient. "With the support of this funding, we can advance our educational program 'The Impact of Narcolepsy on Women's Health Across the Lifespan.' This new work will focus on caregiving aspects, aimed at helping combat stigma, promote timely diagnosis in children, and empower mothers to advocate for their children within school systems by providing educational narcolepsy resources and related support."

Progress at the Heart provides funding support for novel initiatives addressing disparities, injustices, and inequities in the rare neurological disease and sleep disorder communities. Since its inception two years ago, it has provided funding for 13 initiatives.

"Receiving a Progress at the Heart award enables us to further address social determinants of health predominantly affecting Latino and Hispanic families at the US-Mexico border," expressed Michael Grandner, PhD, Director of the Behavioral Sleep Medicine Clinic at the University of Arizona. "Through strategic local partnerships, health literacy education, and culturally competent care sessions with sleep medicine psychologists, our family-based initiatives are vitalizing equitable sleep health and overall well-being within this incredibly resilient yet underserved community. This progress is particularly crucial as we enhance quality care amid extraordinary humanitarian and public health challenges in the region."

The Patients at the Heart awardees include the following organizations:

- **Project Sleep – Social Support Survey Publication & Dissemination**

In April 2021, Project Sleep conducted a global survey on the social experiences of individuals with narcolepsy and idiopathic hypersomnia (IH). With over 1,200 responses, this project will enable them to analyze and publish academic findings about psycho-social issues. Survey results have the potential to shape future social support programs and improve health outcomes for those with narcolepsy and IH.

- **Sleep Consortium – Empowering Next Generation Advocates: Virtual Conference and Intro to EL-PFDD Initiative**
This initiative entails preparing a letter of intent for FDA submission to host an Externally-Led Patient-Focused Drug Development (EL-PFDD) meeting for IH. They will organize a webinar for people with central disorders of hypersomnolence and their families, featuring expert sessions on diagnosis, management, advocating amid a changing research landscape, supporting future research, and concluding with progress made on the EL-PFDD.
- **Society for Women's Health Research (SWHR) – The Impact of Narcolepsy on Women's Health Across the Lifespan: Women as Caregivers**
This program aims to combat stigma and delayed diagnosis of narcolepsy in children. SWHR will provide educational resources empowering mothers advocating for their children within K-12 school systems by addressing stigma and securing necessary support.

The Progress at the Heart awardees include the following organizations:

- **American Academy of Neurology (AAN) – Health Care Equity Program**
The annual Health Care Equity Program enhances 10 neurologists' knowledge of disparities and promotes more impactful neurology and healthcare policies. Programs include meetings, educational workshop sessions, and individual projects to help close health disparity gaps.
- **The University of Arizona**
 - **Platicamos Sueno: Engaging Community Health Workers in Sleep Health at the US-Mexico Border**
This program expands upon existing initiatives at the US-Mexico border through collaboration with the Mariposa Community Health Center and their "Platicamos Salud" program to train community health workers ("promotoras de salud") to improve access to quality care through panels, in-language educational resources and training sessions.
 - **QuE PASE? ("What Happens?"): Querying Everyday Perceptions About Sleep Experiences**
This project empowers Hispanic and Latino families at the US-Mexico border to address sleep disorder and awareness gaps through a family-based approach. The 20 families already enrolled will have access to new programming focused on recognizing symptoms and two sessions with a psychologist focused on sleep medicine to promote overall health well-being.
- **The University of Utah – Nuestro Sueno: Focus Groups for the Development of a Culturally-Tailored Sleep Health and CPAP Adherence Intervention for Latino Couples**
This project aims to fill the gap of culturally adapted positive airway pressure (PAP) adherence interventions for Latinos through rigorous qualitative research and feedback from patients and community stakeholders. The insights will inform the intervention's cultural appropriateness and acceptability in the pursuit of future research.

Harmony will announce recipients for the next round of Patients and Progress at the Heart awards in October 2023, continuing its commitment to the rare neurological and sleep disorder communities.

"With empathy and innovation as our guiding principles, our Patients and Progress at the Heart programs are an extension of our commitment to collaborating with nonprofit community organizations as they address the complex challenges of sleep and rare neurological disorders beyond clinical care settings," said Cate McCanless, Chief Corporate Affairs Officer at Harmony Biosciences. "We acknowledge that a collective effort is necessary to make meaningful change, and we believe these initiatives have the potential to create a lasting, positive impact on individuals and communities impacted by rare neurological disorders."

To learn more about Patients at the Heart, please visit: <https://www.harmonybiosciences.com/funding-programs/patients-at-the-heart/>.

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About Harmony Biosciences

At Harmony Biosciences, we specialize in developing and delivering treatments for rare neurological diseases that others often overlook. We believe that where empathy and innovation meet, a better life can begin for people living with neurological diseases. Established by Paragon Biosciences, LLC, in 2017 and headquartered in Plymouth Meeting, PA, our team of experts from a wide variety of disciplines and experiences is driven by our shared conviction that innovative science translates into therapeutic possibilities for our patients, who are at the heart of everything we do. For more information, please visit www.harmonybiosciences.com.

Harmony Biosciences Media Contact:


Cate McCanless
202-641-6086

cmccanless@harmonybiosciences.com

Harmony Biosciences Investor Contact:

Luis Sanay, CFA
445-235-8386

lsanay@harmonybiosciences.com

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