



CureDuchenne Expands Global Initiatives and Spreads Awareness for World Duchenne Day 2024

Newport Beach, CA - August 15, 2024 — CureDuchenne, a global leader in research, patient care and innovation for improving and extending the lives of those with Duchenne muscular dystrophy, proudly recognizes World Duchenne Day, celebrated on September 7, by launching new global initiatives and amplifying awareness of the disease. Duchenne muscular dystrophy is a severe and progressive muscle-wasting disease that affects an estimated 300,000 individuals worldwide. Although there is currently no cure for Duchenne, comprehensive multidisciplinary care is critically important and has improved life expectancy in recent decades. This year's efforts build on CureDuchenne's commitment to expanding international outreach and support, providing clinicians and healthcare providers with the knowledge and expertise to deliver the best multidisciplinary care and treatments possible to their patients.

CureDuchenne's International Outreach Program delivers awareness, training and knowledge to healthcare providers, filling an unmet need for information, resources, and best practices for diagnosing and treating Duchenne and helping improve the overall quality of life of individuals living with Duchenne. After identifying underserved areas and assessing access to education, healthcare and resources, research progress and the availability of medical equipment, CureDuchenne hosts events around the world with high-level educational programs and resources for clinics and allied healthcare professionals. CureDuchenne's first-of-its-kind Physical and Occupational Therapy Professional Development program trains these professionals in optimal care and support for patients in an effort to maximize mobility, flexibility, and quality of life at all stages and ages for individuals living with this devastating disease. CureDuchenne has made a global impact by training healthcare professionals in India, Nepal, Canada, Italy, Russia, England, South Africa, Hungary, Australia and Ukraine.

This year, CureDuchenne is extending its reach to several key regions around the globe:

- **Uganda:** CureDuchenne and AYINZA Duchenne Support Center (ADSC) will co-host the first ever Duchenne Muscular Dystrophy Insight Conference in Kampala on August 22, 2024, building on previous virtual trainings and resource outreach. This landmark event, aimed at healthcare professionals and policymakers, will focus on improving care standards, raising awareness, and influencing public policy in Uganda. Duchenne is believed to be significantly underdiagnosed in Uganda. While it is estimated that there are approximately 5,000 males living with Duchenne based on population statistics, there are very few confirmed cases documented in the country.
- **China:** On September 21-22, CureDuchenne will participate in the "Global Reconnections: 2024 International Conference" on Duchenne, hosted by ZhiAi DMD Care and Support Center and China DMD Care and Support Association (CASA) in Beijing. This conference aims to bridge the gap between families affected by Duchenne and medical professionals. CureDuchenne will present on the critical role of physical therapy at various stages of Duchenne and collaborating with a multidisciplinary team and lead hands-on sessions to assess and provide personalized recommendations for patients.
- **Nepal:** CureDuchenne is collaborating with the multidisciplinary Medharma CliniX Hospital in Kathmandu on an awareness campaign, leveraging social media to spread vital information about Duchenne in local languages. With a modern neuromuscular clinic already established, the Medharma group is equipped to increase the standard of care for those living with Duchenne in Nepal, however they face a pervasive lack of awareness about Duchenne within the general

population. This campaign aims to increase the number of people diagnosed with Duchenne and properly treated.

On World Duchenne Day, CureDuchenne is also actively spreading awareness through social media campaigns and community engagement activities. The organization encourages global participation by providing resources, graphics, and customizable social media templates to its supporters to help spread awareness about the disease. These efforts are part of a broader campaign to amplify the voices of those affected by Duchenne, ensuring the disease receives the attention it deserves. Resources can be downloaded at www.cureduchenne.org/general/world-duchenne-day-2024/.

These initiatives support CureDuchenne's ongoing commitment to improving care and expanding its global impact, fostering international collaboration and driving forward the mission of finding a cure for Duchenne muscular dystrophy.

About CureDuchenne

Over twenty years ago, CureDuchenne was created with one goal: to find and fund a cure for Duchenne muscular dystrophy, one of the most common and severe forms of muscular dystrophy. Today, CureDuchenne is recognized as a global leader in research, patient care and innovation for improving and extending the lives of those with Duchenne. CureDuchenne's innovative venture philanthropy model has advanced transformative treatments for Duchenne muscular dystrophy, including 18 projects that advanced to human clinical trials and multiple projects to overcome the limitations of exon-skipping and gene therapy. In addition, CureDuchenne contributed early funding to the first FDA-approved Duchenne drug, pioneered the first and only Duchenne physical and occupational therapist certification program and created an innovative biobank and data registry, accelerating research toward a cure. For more information on how to help raise awareness and funds needed for research, please visit cureduchenne.org.

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