

NEWS RELEASE



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NS Pharma Unveils *Duchenne Heroes*, a Program to Inspire and Amplify the Voices of People Living with Duchenne Muscular Dystrophy

- *Duchenne Heroes will share their insights on [WeSpeakDuchenne.com](https://www.wespeakduchenne.com), a new educational platform for families living with Duchenne*

Paramus, NJ: November 21, 2023 – NS Pharma, Inc. (“NS Pharma”) today announced the launch of [Duchenne Heroes](https://www.wespeakduchenne.com) a program created to raise awareness and champion the voices of people affected by Duchenne muscular dystrophy (Duchenne). *Duchenne Heroes* are individuals, caregivers and family members who hope to inspire others by sharing their personal experiences in navigating diagnosis and daily life with Duchenne.

Duchenne Heroes share their authentic insights on a new educational website, [WeSpeakDuchenne.com](https://www.wespeakduchenne.com), which provides straightforward information to help families navigate the complexities of the Duchenne journey, and a platform to hear from others who have been down the same path.

“Our goal is to make a positive impact in the lives of people living with Duchenne by providing helpful information and uplifting voices from the community,” said Gilberto Gil, Director of Patient and Caregiver Marketing at NS Pharma. “The *Duchenne Heroes*’ insights and authentic experiences can inspire families who may be navigating a Duchenne diagnosis. It is my hope

that these unique perspectives combined with easy-to-understand information about Duchenne Muscular Dystrophy, will make [WeSpeakDuchenne.com](https://www.wespeakduchenne.com) a valuable online resource for the community.”

WeSpeakDuchenne.com includes educational resources such as a “[Duchenne-opedia](#),” a glossary of useful terms to know, as well as a primer on the importance of increasing dystrophin for people with Duchenne, and a section where caregivers share their responses to commonly asked questions around diagnosis and treatment. The [Duchenne Heroes Stories](#) page shines a light on different families’ path to diagnosis and the learnings that helped as they navigate life with Duchenne.

“It means a lot to our family to participate in the *Duchenne Heroes* program as we know how life-changing a Duchenne diagnosis can be,” said Elizabeth Cojeen, member of the *Duchenne Heroes* program. “Our son, Emmett, inspires us every day with his bright smile and big personality to stay positive, and we hope sharing our story helps other families do the same.”

Additional Duchenne Heroes stories will be included over time to showcase diverse perspectives around topics relevant to the broader community.

“The biggest lesson I’ve learned since my son Brantley’s Duchenne diagnosis is that there is no clear-cut path or single solution for a lot of life’s transitions,” said Dianna Marlow, member of the *Duchenne Heroes* program. “Our family’s journey, like everyone else’s, is unique when it comes to things like schooling, independence and accessibility. As *Duchenne Heroes*, we’re proud to share our experiences if it helps to bring ideas or encouragement to other families.”

In addition to being featured on the website, *Duchenne Heroes* will share their stories across NS Pharma’s social media platforms (Facebook: @NS Pharma, Inc.; X: @NSPharmaInc.) and make appearances at advocacy events in the coming year.

To learn more about the *Duchenne Heroes* program and explore educational resources, please visit [WeSpeakDuchenne.com](https://www.wespeakduchenne.com).

About Duchenne Muscular Dystrophy (Duchenne)

Duchenne is a progressive form of muscular dystrophy that occurs primarily in males. Duchenne

causes progressive weakness and loss of skeletal, cardiac and pulmonary muscles. Early signs of Duchenne may include delayed ability to sit, stand or walk. There is a progressive loss of mobility, and by adolescence patients with Duchenne may require use of a wheelchair. Cardiac and respiratory muscle problems begin in the teenage years and can lead to serious, life-threatening complications.

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