

## Duchenne Muscular Dystrophy Community Unites to Help Families During COVID-19

**DETROIT, May 20, 2020 --** Having a child with a severe medical condition like Duchenne muscular dystrophy brings a whole new set of challenges, especially during COVID-19. That is why <u>Team Joseph</u> and ten other Duchenne nonprofits are working together to ease the additional challenges Duchenne families are currently facing. **The Coronavirus Relief Fund** is a part of the <u>Duchenne Family Assistance Program</u>, which offers financial assistance related to care and help for families who need access to recommended treatments and equipment, clinical care, and social services.

About 12,000 children and young adults are living with Duchenne, a progressive form of muscular dystrophy, in the United States. To date, there have been more than 350 requests from Duchenne families in 43 states for support with critical needs, such as groceries and utilities. In addition to Team Joseph, other organizations aiding with this effort are 4 Jake's Sake, Hope for Gus, JB's Keys to DMD, Joaquin's Warriors, Cure Duchenne, Kindness Over Muscular Dystrophy, Little Hercules Foundation, Michael's Cause, Peitro's Fight and Walking Strong.

"The situation we are facing with COVID-19 is unprecedented, but so is the collaboration we are seeing among Duchenne organizations," said Marissa Penrod, Team Joseph Founder/CEO. "We have been inundated with requests from families who are severely impacted by this crisis. As requests were coming in and we realized how great the needs are, I reached out to my colleagues at other Duchenne nonprofits and asked them to be a part of this. Within 48 hours, they had all pledged funding to ensure that, collectively, we could quickly help the Duchenne community that we all serve."

Duchenne families are already challenged with caring for a child who is battling a rare disease. Often, this means their child is confined to a wheelchair and may suffer from breathing issues and cardiac problems. The stark reality is that every Duchenne child has underlying conditions.

Rob Capolongo, a sergeant in the New York City Police Department's Intelligence Bureau, said the collaboration between Team Joseph and these organizations is more important than ever before, especially with the financial and health impacts of COVID-19 that will linger even after states begin to reopen. Capolongo also serves as president/co-founder of Michael's Cause, a Duchenne nonprofit named in honor of his son.



"I have a son with Duchenne, and I know the struggle of taking care of a child with a severe medical condition," said Capolongo. "Living and working in New York City, we have seen first hand the devastation of COVID-19. We are happy to be a part of this team effort with other fine charities to help Duchenne families who are in need during these very trying times."

To date, the program has provided more than \$130,000 in funds for Duchenne families who are uniquely impacted by the pandemic. The funds can be used for essential needs such as living expenses, groceries and utilities.

There is a fundraising goal of \$250,000 due to the expectation that the need for assistance will continue into the summer and fall. Over \$150,000 has been committed so far, but additional donations are still needed. Any donation - no matter the amount - matters and will help the Duchenne Family Assistance Program meet its goal of not having to turn any family away.

JB Brown-Crowley, a small business owner who's lost 75% of her income due to Covid-19, has 2 children, including a son, Charlie, with Duchenne. The support their family has received through the Coronavirus Relief Fund is helping them to buy groceries and pay utilities.

"This program is wonderful," Brown said. "We are heading into uncertain months ahead, and this help is such a blessing for our family. Not having our regular paychecks has compounded our already tight financial situation, and is really hitting our family hard. The Relief Fund is helping us get by."

In addition to emergency funding, families can also apply for a mini-grant for each child in their household to go towards educational materials, entertainment, a new hobby or outdoor fun while social distancing is in place.

Donations to support the Coronavirus Relief Fund can be accepted at <u>teamjoseph.org</u>. Families who are in need can visit <u>duchennefap.org</u> to apply for assistance.

## **About Team Joseph**

Team Joseph is a non-profit organization whose mission is to aggressively fund cutting-edge research to find a treatment or cure for Duchenne muscular dystrophy. Team Joseph also provides direct financial assistance to families struggling with Duchenne, funding everything from medical equipment to home modifications and travel to specialized clinics.



## **About the Duchenne Family Assistance Program.**

The Duchenne Family Assistance Program is a collaboration between Team Joseph and Little Hercules Foundation. The two non-profits have a strong history of working together to fund promising Duchenne research. In addition to believing in the promise of future treatments, they also see the need to help families with immediate needs. The Program has two priorities—to offer families financial assistance with expenses related to the care of a child or young adult with Duchenne, and to provide help and expertise to families who need access to recommended treatments and equipment, clinical care, and social services.

Team Joseph manages direct assistance to families that includes assisting with equipment (scooters, manual wheelchairs, shower chairs, etc.), accessible ramps, transportation to clinic visits, vehicle and home modifications. Little Hercules Foundation provides case management services to patients and caregivers who have been denied access to treatments, clinical care, equipment, and social services.

With the addition of the Coronavirus Relief Fund, families can now request additional support to help with utilities, groceries and other emergency needs.

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