



PARENT PROJECT MUSCULAR DYSTROPHY AND THE MOTHER OF PEARLS PROJECT

Parent Project Muscular Dystrophy and Positive Exposure began the Mother of PEARLS project to help medical professionals gain insight into the daily lives of those living with Duchenne Muscular Dystrophy. Take another look at one of Positive Exposure's partners and learn more about the Mother of PEARLS project.

Parent Project Muscular Dystrophy (PPMD) is a nonprofit organization leading the fight against Duchenne muscular dystrophy, a fatal genetic condition that appears in childhood. The organization provides the public with invaluable information about caring for individuals with muscular dystrophy and about opportunities to advocate and fundraise on behalf of these individuals. PPMD also works to connect and support community members and helps fund research endeavors, as well as broaden treatment options for Duchenne.

Since 2000, PPMD has raised \$450 million for muscular dystrophy research and has been instrumental in bringing together scientists from all over the world to address muscular dystrophy. PPMD also played an essential role in passing the MD-CARE Act in 2001, which has significantly increased the amount of NIH research into muscular dystrophy. The bill was reauthorized in 2008 and, in the same year, the Center for Disease Control established Standards of Care for the treatment of muscular dystrophy for the first time in history. The efforts of organizations like PPMD have changed influential policies and increased funding for treatment research, which, in the past decade, has added ten years to the life expectancy of patients of individuals with Duchenne.

Taken by Positive Exposure's vision to change perceptions of beauty and inspire self-advocacy, PPMD and Positive Exposure have established a meaningful partnership. The two organizations recently embarked on an exciting new project called the Mother of PEARLS project. According to Pat Furlong, President and Founder of PPMD, and Kathi Kinnett, Vice President, Clinical Care at PPMD, "a lot of therapists do not have a ton of experience with Duchenne, let alone other chronic conditions." This inexperience can lead to a distorted view of the condition and unrealistic treatment expectations. In response to the need for a well-rounded view of Duchenne, PPMD and Positive Exposure created the Mother of PEARLS project, in which the mothers of children with muscular dystrophy provide medical professionals with insights into the daily lives of those living with Duchenne.

Working off of the pre-existing PEARLS project model, these mothers blogged for an audience, including physical, occupational, and speech therapists. Rick photographed the mothers and their sons both separately and together and these photographs were featured on the Mother of PEARLS blogs, along with the mothers' written posts. "The hope was that the Mother of PEARLS project to demonstrate to these therapists just how hard it is to meet strict treatment demands," says Furlong.

Additionally, the blogs served as an outlet for the mothers and caregivers of individuals with Duchenne. "People can forget about the caregivers and the fact that they have committed their lives to caring for their sons. And moms are carriers, which means that they might perceive themselves negatively," says Kinnett. In this way, the blogs serve as a venue for both empowerment and education.

A survey conducted at the end of the trial period revealed that the Mother of PEARLS blogs changed not only the medical professionals' perception of what is like to live with Duchenne, but also their practice and their expectations of individuals with Duchenne and their caregivers. Furthermore, many of the mothers enjoyed the experience and almost all of them have agreed to continue blogging.

Both Positive Exposure and PPMD intend to continue the Mother of PEARLS project in the future. Hopefully, the Mother of PEARLS will expand to include bloggers who are mothers of individuals with other genetic conditions and audiences from other areas of medicine. At the end of February, Rick will travel to Rome, Italy to attend to the PPMD Italy International Conference on Duchenne Muscular Dystrophy as well as plan a global Mother of PEARLS project and traveling exhibition.



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