

Support for The Charlotte & Gweneth Gray Foundation CLN6 Gene Therapy Program



Shivanya, Age 5 and half, Hyderabad, India.

Dear CIRM Review Team,

Thank you for your time and for considering The Charlotte and Gwyneth Gray Foundation's application to advance the CLN6 gene therapy program. We are Vamsi and Pratyusha from Hyderabad, India, parents of Shivanya who is now 5 and half years old and is living with CLN6 Batters disease. We are deeply grateful to The Charlotte and Gwyneth Gray Foundation for the relentless effort shown by them to make clinical trials for gene therapy for this deadly disease, a reality for parents like us around the globe waiting with immense hope for a miracle to happen in their child's life that could give them the opportunity to experience and live life like every child deserves. Our daughter has immense potential and has the ability to lit up any space with her charm and

positivity. We as parents are immensely proud of her resilience and strength that she shows every day through every therapy and every medical procedure she has been put through in this process. For us every small milestone is an achievement and we really hope she finds that scientific opportunity to lead her life on better terms in any way possible given her prognosis. With immense hope and respect for the team members we hereby sincerely request to support this important program and request the CIRM to partner with The Charlotte and Gwyneth Gray foundation by providing the necessary support and give hope and help bring new possibilities to families like ours.

With sincere gratitude and hope,

Vamsi and Pratyusha,

Parents of Shivanya.

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