## We are proud to announce the recipients of the second annual Sanofi Genzyme TORCH Awards!



The TORCH Awards recognize four recipients who have made a significant contribution to the LSD community by educating, empowering, advancing or connecting patients with information, resources or each other. Individuals were nominated for the TORCH Awards by both Sanofi Genzyme employees, as well as the external LSD community. Nominees of all ages were welcome, and Scholarship America reviewed all nominations.

We look forward to having this year's TORCH Award recipients join us at Genzyme Center for Rare Disease Day on February 28<sup>th</sup> to receive their awards. Sanofi Genzyme will also donate \$5,000 to the nonprofit organization of each of the four recipients' choosing, subject to certain conditions.

## Please find the recipients below:



Ryan Bragg serves on the board of the Cure GM-1 Foundation and along with his wife Jenny, is actively involved in spreading awareness and education about GM-1 Gangliosidosis. Their daughter Cara was recently diagnosed with GM-1 and the Braggs have hosted large scale fundraisers in their hometown to support ongoing research for gene therapy with the goal of supporting a human clinical trial.



Shannon and Steven Laffoon created the Wylder Nation Foundation to continue the fight after losing their 3 year old son, Wylder, to Niemann-Pick Disease type A. Their goal is to further research and provide hope in the form of treatment options for Lysosomal Storage Disorders.



Eileen Linzer and her husband Brett established the Quinn Madeline foundation in honor of their daughter Quinn, who passed away at 15 months from Niemann-Pick Disease type A. They developed "Quinn's List" to help facilitate memorable experiences for children under the age of 3 diagnosed with a terminal or life-threatening illness. The foundation also offers free carrier screening for Niemann-Pick types A and B to any family member of an affected child.



Lanier Craft was influential in helping to add Pompe disease to the newborn screening panel for the state of Mississippi. Her son Townes is diagnosed with infantile Pompe Disease. Lanier volunteers with hospitals, serving as a mentor and support to other families receiving a new diagnosis. She is instrumental in helping them navigate their journeys.

Join us in congratulating Jenny & Ryan, Shannon & Steven, Eileen, and Lanier as we celebrate their contributions to the Rare Disease community!