

Joele Ruppert and Joseph Colton are a much-loved daughter and son, both diagnosed with ASMD, whose parents, Jeff and Kara Ruppert and James and Alexandra Colton, demonstrated compassion, courage, selflessness, and perseverance from the beginning to the end of their children's journeys. The words and deeds of these two families proved inspirational to another family of a child diagnosed with ASMD, and indeed, to all who knew Joele and Joseph. This scholarship is in honor of the lives of these two cherished children and their parents who embodied the highest values of the human spirit.

The Joele Ruppert and Joseph Colton ASMD Scholarship fund began in August 2020 when Evren Ayik, at that time a graduating high school senior, was awarded the Sanofi Genzyme TORCH Award for his work in advocacy for individuals and families affected by ASMD. The NNPfD, in gracious acknowledgement of Evren's wishes to endow a scholarship for other students with ASMD, supported his proposal for the financial contribution that is offered to the TORCH Award recipient's chosen non-profit organization serving the rare disease community. In naming the scholarship, Evren recognized that many years earlier, he and his own family were also encouraged and inspired by the Ruppert and Colton families, and he wished to honor both of the children who lived with ASMD, Joele and Joseph, and their respective parents, all of whom are exceptional people.

The Joele Ruppert and Joseph Colton ASMD Scholarship provides scholarship funding one-time funding of \$500.00 to individuals diagnosed with ASMD for studies in post-secondary (high school) degrees, including two-year colleges, four-year colleges, vocational schools, and other post-secondary institutions.

Criteria for Eligibility:

- Applicant must be diagnosed with ASMD. If applicant is not currently a member of the NNPfD, applicant must submit proof of diagnosis from a physician.
- Scholarship recipients must be US residents pursuing studies in the U.S.
- Applicants are eligible for one-time participation in the scholarship program.
- Applicants must submit proof of enrollment in a degree program or vocational school program within 90 days of receiving the scholarship.
- If chosen, recipients must be willing to allow the NNPfD to publish their name and photograph on the NNPfD's website and in the family newsletter.

APPLICATION DEADLINE IS JULY 15, 2021

Send applications to Itturner@nnpdf.org

Joele Ruppert & Joseph Colton ASMD Scholarship Application

NAME:	
EMAIL:	PHONE:
I am currently:	<input type="checkbox"/> a graduating high school senior <input type="checkbox"/> attending a post-secondary educational program
What post-secondary school/institution do you plan to attend?	
<input type="checkbox"/> 4-year degree <input type="checkbox"/> 2-year degree <input type="checkbox"/> Vocational/Trade School <input type="checkbox"/> Other _____	
Briefly state your ultimate career goals and aspirations. What do you seek to accomplish by attending the school you have chosen?	
If awarded, how will the scholarship money be used to support your continued education? (For example, tuition, books, personal expenses, travel.)	
List any involvement with NNPfD such as family events, conferences, or fundraisers:	
List any involvement in volunteer activities and any special recognitions or awards you have received:	
Briefly explain how you have demonstrated one or more of the following values: compassion, courage, selflessness, or perseverance.	

Essay Question:	
Choose one (1) of the following three questions and submit <u>either</u> of the following:	
<input type="checkbox"/> A 150-300 word written response (attach as a separate document) or <input type="checkbox"/> A two-to-three-minute audio or video recording of your response	
<ol style="list-style-type: none"> 1. What would you share with a younger child diagnosed with ASMD? 2. What would you share with a sibling or parent of a newly diagnosed individual (for siblings/children) 3. What have you learned about yourself and others in the face of living with ASMD? 	
Please include both items below:	
<input type="checkbox"/> A high-resolution photo which may be used in future publications if you are awarded a scholarship. <input type="checkbox"/> A brief biography (attach as a separate document) which may be used in future publications if you are awarded a scholarship*	
I certify that the information submitted in this application is accurate and true, and the funds awarded will be used by the recipient for the purpose of supporting a post-secondary educational or vocational program:	
APPLICANT SIGNATURE:	DATE:

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