



## 2023 TORCH Awards Application Guidelines

**This program has been established to recognize individuals who have made a meaningful contribution to a lysosomal storage disorder community, or to a disease area within Sanofi's rare disease research and development program. Individuals receiving TORCH awards have found a way, in their own capacity, to bring awareness to rare diseases and to educate, empower, advance, or connect patients.**

This program is through Sanofi US. All applications are de-identified prior to review, and will be evaluated using a scoring rubric by a panel of Sanofi employees who are familiar with the rare disease community but do not currently work in the space.

**Timeline: Completed applications must be received on, or before, May 12, 2023 to be considered for the 2023 cycle.**

You can read more about this program online at <https://www.sanofi.us/en/Our-Responsibility/corporate-giving-and-support/torch-awards>.

### **How it works**

Help us recognize individuals who have taken action in contributing to the LSD community or rare disease community! The nomination period for the TORCH Awards is listed on the current year's application, which is available for download at a link below. If you cannot download the application and need a copy sent to you directly, please reach out to [TorchAwards@Sanofi.com](mailto:TorchAwards@Sanofi.com). Applications received with email timestamp or postmark by the close of the nomination period will be considered. There will be no applications accepted after the period closing. Applications not accepted due to incomplete content should be resubmitted for the following program year.

You have the opportunity to nominate multiple individuals for a TORCH Award. You can nominate yourself, a family member/loved one, or an individual you know.

Sanofi will review the nominations and choose up to five (5) recipients for a TORCH Award. Recipients will be honored as part of the TORCH Awards ceremony, which is held in the second half of each year, and recognized publicly in external communications as well as social media activities hosted by Sanofi. Recipients have no obligation to Sanofi.

In addition to publicly recognizing each recipient and sharing their story, Sanofi will donate \$5,000 to one non-profit organization connected to the community of each recipient's choosing, subject to certain limitations required by company policy. Sanofi will send a check directly to the selected organizations following review by our internal charitable contributions team.

## Eligibility

Requirements for nominees and award recipients of the Sanofi TORCH Awards program are listed below.

- Nominee must have made a significant contribution to an LSD community, or to a Sanofi rare disease research and development area of focus to educate, empower, advance, or connect patients.
- Nominee must accept the opportunity to be recognized through the TORCH Awards program.
- The application must have been submitted prior to the program closing deadline, as stated on the current year's application. You may submit an application by email or mail.
- There is no limit to the number of nominations you can submit. Each nominee must be submitted on their own application, unless it is an effort where multiple individuals are involved, in which case one application should be submitted for those relevant nominees. Examples of appropriate group nominations include a family that plans a community awareness event, a pair/team that work together at an organization to raise awareness for health equity, or a married couple who hosts a fundraiser.
- Nominated individuals must be residents of the United States or its territories.
- Nominees of all ages are welcome, including children.
- Nominators are required to identify themselves on the application.
- Employees, former employees, or relatives of Sanofi employees may nominate individuals for a TORCH Award, but cannot receive a TORCH Award.
- Recipients of a TORCH Award are ineligible for future TORCH Awards.
- Physicians treating patients with a condition listed in the chart below are not eligible to receive a TORCH Award.

If an organization received a gift as part of the 2022TORCH Awards, they cannot receive a gift as part of the 2023TORCH Awards. Individuals from that community are still eligible to receive a TORCH Award.

*Organizations selected for a contribution during the TORCH 2022 cycle were: Courageous Parents Network, Cure Sanfilippo Foundation, National Tay-Sachs & Allied Disorders, Rare Village Foundation, Razom, UNC Children's Research Institute, and Uplifting Athletes.*

The list of currently eligible rare diseases is listed below. This list may not be comprehensive. Many of these disorders have alternative names that are not all listed. Some diseases may be more commonly classified in other ways but still be within the LSD or rare disease category. **If you do not see a diagnosis on this list that you believe should be included in this application cycle, we encourage you to contact us to clarify eligibility.**

|   |                               |
|---|-------------------------------|
| Acid Sphingomyelinase Deficiency (ASMD) | MPS I Disease                 |
| Alport Syndrome                         | MPS II – Hunter Syndrome      |
| Aspartylglycosaminuria                  | MPS III - Sanfilippo Syndrome |
| Cystinosis                              | MPS IV -Morquio Syndrome      |

|                                       |                                  |
|---------------------------------------|----------------------------------|
| Danon Disease                         | MPS VI - Maroteaux-Lamy Syndrome |
| Fabry Disease                         | MPS VII – Sly Syndrome           |
| Farber Disease                        | Mucopolipidosis                  |
| Fucosidosis                           | Neuronal Ceroid Lipofuscinosis   |
| Galactosialidosis                     | Pompe Disease                    |
| Gaucher disease (Type 1, 2 and 3)     | Pycnodysostosis                  |
| Glycogen storage diseases             | Salla Disease                    |
| GM1 gangliosidosis                    | Sandhoff Disease                 |
| Infantile sialic acid storage disease | Sialidosis                       |
| Krabbe Disease                        | Tay-Sachs (GM2 Disease)          |
| Mannosidosis                          | Wolman Disease                   |
| Metachromatic leukodystrophy          |                                  |

### **Selection criteria**

The program will select winners based on the evaluation of the deidentified nomination letter and application and the extent to which the nominee embodies the qualities of the TORCH Awards program. Based on the applications received, every effort will be made to identify at least one recipient who is making an impact on health equity, diversity, and inclusion and to select at least one recipient who is under the age of 18.

### **Nomination Information**

Nominators must submit a completed application, which is available as a separate download on <https://www.sanofi.us/en/corporate-responsibility/corporate-giving-and-support/torch-awards> or by emailing [TorchAwards@sanofi.com](mailto:TorchAwards@sanofi.com). **The email sent stamp deadline for applications to be considered during the 2023 cycle is May 12, 2023.**

With the application, nominators should also include a free-form letter or essay describing why they believe the nominated individual(s) should receive a TORCH Award. Prompts to consider as part of this nomination letter are:

- How has the nominee raised awareness for this rare disease?
- What impact has come from the efforts of the nominee?
- What do you think motivates the nominee to advocate for this rare disease?
- Why do you think the nominee deserves to be recognized with a TORCH award?

### **Past Recipients**

To date, the TORCH Awards program has recognized the following individuals, and made gifts to the following organizations:

| <b>Year</b> | <b>Recipient</b>                             | <b>Organization</b>  |
|-------------|--|--|
| 2017        | Shaylee Boger                                | NIH Grant  |
| 2017        | Glenn O'Neill                                | Cure Sanfilippo Foundation   |
| 2017        | Sabrina Low-DuMond                           | Every Life Foundation  |
| 2017        | Christine Waggoner                           | Cure GM1 Foundation  |
| 2018        | Eileen Linzer                                | Quinn Madeline Foundation  |
| 2018        | Ryan & Jenny Bragg                           | Cure GM1 Foundation  |
| 2018        | Lanier Craft<br>Steve & Shannon              | Pompe Mom  |
| 2018        | Laffoon                                      | Wylder Nation Foundation   |
| 2019        | Kavi Gandhi                                  | Yash Gandhi Foundation   |
| 2019        | Marilee Leishman                             | Cure GM1 Foundation  |
| 2019        | Scott Lewia                                  | Cure Sanfilippo Foundation   |
| 2019        | Brian & Sherri Manning                       | Dylan James Manning Foundation   |
| 2020        | Evren Ayik                                   | National Nieman Pick Disease Foundation  |
| 2020        | Mark Dant                                    | Every Life Foundation  |
| 2020        | Sharon Lagas                                 | Alport Syndrome Foundation   |
| 2020        | Melanie McKay                                | Ryker's Foundation for Pompe Disease   |
| 2020        | Rylee Noble                                  | National MPS Society   |
| 2021        | Justin Hopkin                                | National Nieman Pick Disease Foundation  |
| 2021        | Kaley Herman                                 | PKD Foundation   |
| 2021        | Shannon von Felden &<br>Adrian Palau-Trejeda | Every Life Foundation<br>Every Life Foundation   |
| 2021        | Tia & Brian Jones                            | Fabry Support & Information Group  |
| 2021        | Kyle & Kylie Harrison                        | Cure GM1 Foundation  |
| 2022        | Nathaniel Kleytman                           | Razom  |
| 2022        | Rob Long                                     | Uplifting Athletes<br>National Tay-Sachs & Allied Disorders, Courageous Parents<br>Network (CPN) |
| 2022        | Blyth Lord                                   | Courageous Parents Network (CPN), Cure Sanfilippo<br>Foundation                                  |
| 2022        | Jennifer Seidman                             | UNC Children's Research Institute  |
| 2022        | Dr. Kimberly Stephens                        | UNC Children's Research Institute  |
| 2022        | Cristina Vargas                              | Rare Village Foundation  |