

Key Findings and Recommendations from Novo Nordisk Haemophilia Foundation’s 2024 Grantee Perception Report

Prepared by the Center for Effective Philanthropy

In April and May of 2024, the Center for Effective Philanthropy conducted a survey of the Novo Nordisk Haemophilia Foundation’s (“NNHF’s” or “the Foundation’s”) grantees, achieving an 87% response rate. The memo below outlines CEP’s summary of key strengths, opportunities, and recommendations from NNHF’s Grantee Perception Report (“GPR”). The Foundation’s grantee perceptions should be interpreted in light of its goals, strategy, and context.

This memo accompanies the comprehensive survey results found in NNHF’s interactive online report at <https://cep.surveyresults.org> and in the downloadable online materials. The full report also contains more information about survey analysis and methodology.¹

Overview

The Center for Effective Philanthropy is pleased to share the results of NNHF’s second Grantee Perception Report.

- ▶ CEP most recently surveyed NNHF’s grantees in 2022. As in 2022, grantees continue to hold positive perceptions of NNHF and their work together, and NNHF is rated in line with or above the typical funder in CEP’s overall comparative dataset across most survey measures.
- ▶ In particular, grantees’ feedback highlights the Foundation’s role in advancing access to care for and increasing the visibility of haemophilia, its strengthening of grantees’ organisations and their projects through funding and assistance beyond the grant, and strong funder-grantee relationships.
- ▶ Grantees’ ratings and written comments also indicate an opportunity for NNHF to more deeply engage with grantees to understand the contexts in which they operate and to maintain its focus on and commitment to diversity, equity, and inclusion.

Notable Impact on Haemophilia Care and Visibility

Grantees view NNHF as playing a leading role in expanding access to care for haemophilia and other bleeding disorders, writing that “the Foundation [provides] grants worldwide to improve care for patients with bleeding disorders” and in doing so, gives “visibility to the needs of groups who require fair care and support.”

- ▶ Reflecting these comments, NNHF is now the **second-highest rated** funder in CEP’s comparative dataset for the extent to which it advances knowledge in grantees’ fields, representing a significant improvement since 2022. Ratings are also significantly higher compared to 2022, and now place NNHF in the top 10 percent of CEP’s dataset, for its effect on public policy in grantees’ fields.

¹ Throughout this summary, NNHF’s ratings are defined as higher than typical when average ratings are above the 65th percentile in CEP’s overall dataset, lower than typical when average ratings are below the 35th percentile, and typical when ratings fall between those thresholds. Ratings described as “significantly” higher or lower reflect statistically significant differences at a P-value less than or equal to .1.

- ▶ More broadly, grantees continue to provide higher than typical ratings – near the top 5 percent of CEP’s dataset – for its impact on and understanding of their fields.
- ▶ NNHF’s impact on the haemophilia field extends to grantees’ communities, as well. NNHF is rated above the typical funder in CEP’s dataset for its impact on grantees’ local communities, and they note in comments that NNHF “[lobbies] for identifying new patients in different countries” and “urges [grantees] to focus more on decentralizing services toward peripheral regions” to expand access to care.
- ▶ Overall, in custom questions asked specifically of NNHF grantees, over 85 percent of grantees strongly agree (rating a 6 or 7 on a 7-point scale) that the Foundation’s support has helped to create lasting impact for people living with bleeding disorders in their countries and that their work with NNHF has contributed to greater voice on or visibility of haemophilia and bleeding disorders.



“NNHF is a significant influencer in the realm of bleeding disorders, making a profound impact on a global scale... This partnership... represents a united effort toward a common objective, enhancing our collective capacity to tackle challenges in our field. Their contributions extend well beyond financial aid, encompassing valuable expertise, resources, and a shared commitment to improving outcomes for those affected by bleeding disorders.”

Continued Positive Perceptions of Impact on Grantees’ Organisations

Grantees now provide higher than typical ratings for their perceptions of NNHF’s impact on their organisations, and ratings remain typical for the Foundation’s understanding of their strategies and goals.

- ▶ In a custom question, the majority of grantees indicate that as a result of their NNHF-funded projects, they have experienced new ideas for subsequent projects (90 percent) and the strengthening of their organisations (80 percent).

Grantmaking Characteristics

- ▶ NNHF provides grants that are similar in size compared to 2022 and to those of the typical funder in CEP’s dataset (111K CHF at the median) to much smaller than typical organisations, with a median annual budget of 52K CHF.
- ▶ Additionally, nearly all NNHF grants (93 percent) are made for two years or longer, placing the Foundation near the top of CEP’s dataset for its provision of multi-year funding.
- ▶ As in 2022, grantees often mention aspects of the Foundation’s funding guidelines and criteria in their written suggestions for improvement. One-quarter of all suggestions relates to this theme, where grantees most often ask for NNHF to expand allowed funding guidelines to include expenses such as “salary items for at least two employees,” “drugs for patients,” or “basic medical supplies.”



“Be more flexible to use the funds provided, to purchase basic medical supplies that will impact patient lives. Example is lack of reagents to diagnose a suspected hemophilia patient in low resource settings.”

Assistance Beyond the Grant

- ▶ Beyond its financial support, 80 percent of grantees (a larger than typical proportion) report receiving at least one form of assistance beyond the grant from NNHF. Over half of grantees receive programme-related assistance or training and workshops provided by NNHF.
- ▶ Ratings place NNHF in the top five percent of CEP’s dataset for the extent to which this support met an important need for grantees’ organisations and/or programmes, and ratings are also higher than typical

for the extent to which NNHF’s assistance beyond the grant was a worthwhile use of the time required of grantees.



“NNHF has been instrumental in promoting institutional strengthening for our organisation and has also introduced us and supported us to interact with new potential partners.”

Opportunity to More Deeply Engage with Grantees’ Contexts

Grantees’ ratings and written comments indicate an opportunity for the Foundation to engage more deeply with grantees in certain regions to better understand and adapt its approach to fit their local contexts.

- ▶ As in 2022, grantees provide lower than typical ratings for NNHF’s understanding of the social, cultural, or socioeconomic factors that affect their work.
- ▶ Of note, ratings for this measure show differences according to grantees’ regions. While ratings from grantees in Asia and the Americas are higher than typical, grantees located in Africa provide ratings near the bottom of CEP’s dataset for this measure.
- ▶ This theme also comes through in grantees’ written suggestions for improvement, where they ask for NNHF to “take local realities more into account” and have an “adaptive approach for each country.” Some grantees also request that NNHF have a “project overseer across sub-regions they support.”
- ▶ Relatedly, ratings have significantly declined since 2022, and now place NNHF in the bottom 20 percent of CEP’s dataset, for the extent to which the Foundation exhibits compassion for those affected by grantees’ work.
- ▶ While grantees strongly agree that NNHF helps their organisations address inequity in bleeding and blood disorders care, ratings have also significantly declined since 2022 for measures related to NNHF’s own approach to diversity, equity, and inclusion (DEI) – including grantees’ agreement that NNHF has clearly communicated what DEI means for its work and demonstrates an explicit commitment to DEI in its work.



“[NNHF could further support our organisation] by conducting physical assessments and actually visiting the country to study the setting, identify challenges, and observe all our activities, at least once every other year, or alternatively having a contact person across all sub-regions they support.”

Strong Funder-Grantee Relationships

Grantees hold the NNHF team in high regard, describing them as “friendly,” “proactive,” “helpful,” and offering “flexibility, responsiveness, and crucial support” to grantees.

- ▶ Grantees provide higher than typical ratings on most measures related to their interactions with NNHF, including the team’s responsiveness, their comfort approaching NNHF if a problem arises, and NNHF’s openness to grantees’ ideas about its strategy.
- ▶ NNHF continues to engage with grantees often and more frequently than is typical in CEP’s dataset. Eighty-five percent of grantees report having contact with their programme manager monthly or more often, and 80 percent of grantees report having received a virtual or in-person site visit from the NNHF team.
- ▶ Still, grantees indicate a desire for even more frequent touchpoints with the NNHF team in their written suggestions for improvement, including visiting “[project] sites every year” and “more open discussions with NNHF and grantees.” This theme represents one-quarter of all grantee suggestions.

Very Clear, Effective Communications

On the other side of funder-grantee relationships – NNHF’s communications – grantees continue to hold positive perceptions.

- ▶ Ratings have significantly improved since 2022, and now place NNHF in the top two percent of funders in CEP’s dataset, for the clarity of its communications about its goals and strategy and for the consistency of its communications resources. Ratings remain near the top of CEP’s dataset for the Foundation’s transparency with grantees.
- ▶ In a custom question about the Foundation’s communications, grantees indicate that the most helpful NNHF communications in spreading awareness about the impact of funded projects are personal stories, short films about NNHF-funded projects, and social media posts on Facebook, Instagram, and LinkedIn.



“We have built a good relationship with NNHF and together we are impacting care on many lives of people... It’s [a] mutual type of relationship bearing in mind that we have the same cause [and] interests. This makes interaction and communication very easy when working together.”



“Communications are always clear and informative. They’re always available during the processes and remind you of objectives and timeframes so you can make the plan truly effective and successful.”

Increasingly Time-Intensive, Yet Helpful Processes

Grantees spend more time on NNHF-required processes than in 2022. At the median, grantees now report spending 111 hours over their grant’s lifetime on NNHF-required processes, compared to 70 hours in 2022. This time demand for processes is greater than that of most other funders in CEP’s comparative dataset.

Combined with the size of NNHF grants, grantees receive a much lower than typical monetary return for the time they spend on NNHF processes. It’s important to interpret these findings in light of NNHF’s context, goals, and approach to working with grantees.

- ▶ Overall, grantees continue to hold positive perceptions of the Foundation’s processes. Ratings place NNHF in the top five percent of CEP’s dataset for the extent to which the selection process was an appropriate level of effort given the amount of funding received and a helpful opportunity to strengthen their funded efforts.
- ▶ When it comes to the reporting and evaluation processes, ratings now place NNHF in line with the typical funder for the straightforwardness and adaptability of the reporting process. Ratings remain higher than typical for the extent to which the reporting process was relevant and helpful and that the evaluation process incorporated grantees’ input in its design and resulted in change.



“NNHF really holds your hands and provides excellent guidance through all the stages of the grant, from application, to interval reporting, to clarifying issues during the process of the grant. They also provide resource material to modify once relevant to the grant application.”



“The variables included in the guidelines of NNHF projects are very important because they lead to the achievement of the results and social impact sought by the requesting community, thus improving the network of health services, community empowerment... etc.”

CEP Recommendations

Based on this grantee feedback, CEP recommends that Novo Nordisk Haemophilia Foundation consider the following in order to build on its strengths and address potential opportunities for improvement:

- ▶ Celebrate continued strong perceptions of NNHF’s impact on the field of haemophilia visibility and care, and improved perceptions of NNHF’s role in advancing knowledge and affecting policy related to this field.
- ▶ Consider grantees’ desire for a broader scope of allowed funding expenses. Explore opportunities for NNHF to offer more flexibility in its grant funding to address what grantees note as being some of their greatest needs.
- ▶ As CEP recommended in 2022, utilize frequent touchpoints with grantees to deepen and better demonstrate NNHF’s understanding of grantees’ local contexts and their unique circumstances. Reflect upon the variation in grantees’ ratings for this measure across regions and ensure that the Foundation seeks to understand the diverse contexts that exist within its portfolio.
- ▶ Consider declines in ratings related to the Foundation’s approach to diversity, equity, and inclusion and ensure that these principles are embedded and visible in NNHF’s strategy and goals.
- ▶ Reflect on the increase in time that grantees report spending on NNHF processes since 2022 and whether this additional time is adding value to the Foundation and grantees. Where possible, review and refine processes to streamline time spent.

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