

Funding Statement 2023

This statement outlines how EHA works with partners who provide funding to support the implementation of our annual workplan and arising activities.

EHA funding arises from a small number of sources, including the pharmaceutical industry and the Huntington Study Group.

It is important to remember that EHA is an extremely broad-based organization, which attempts to improve the quality of life for people in Europe living with Huntington's Disease.

In order to make funding partnerships work in practice, to ensure the integrity of both the funder and EHA is maintained, and to demonstrate to other stakeholders that our relationships are absolutely scrupulous, we commit to the below principles in relation to our funding:

MULTI-SOURCE

EHA commits to ensuring that our projects are supported by a consortium of funding partners, and that no individual company/organization provides more than 25 percent of our annual income in one year.

TRANSPARENT

A written agreement between the funder and EHA outlining the nature and amount of the funding and the period covered – is required before EHA will accept funding from any source. The funding sources will be acknowledged with thanks on relevant publications linked to an event/initiative. The amount of funding received and the sources are included in the EHA Annual Report and published separately on the HNA website within one month of the Annual Accounts being approved by the Annual General Assembly of the following year.

INDEPENDENT

Relationships between non-governmental organizations (NGOs) and pharmaceutical and biotech companies can and should be based on equal partnership. Both sides must be prepared to move beyond the NGOs being passive recipients of money to a scenario where the two work together on policy development and practical initiatives, in the interests of the patients and their carers whom the NGO represents. While preserving its independence, NGOs should recognise that pharmaceutical and biotech companies have to be profitable, and have their own particular marketing agenda, to which no NGO should ever feel obliged to conform. Funding should be rejected if the alternative is compromising the NGOs independence in any way.

<https://eurohuntington.org/about-eha/collaborative-pharmaceutical-guidelines/>

ETHICAL

EHA will apply the EFPIA Code of Good Practice on working with patients' organizations in relation to any funding received from the pharmaceutical industry whilst also building on the above principles adopted, and other relevant European codes.

ACKNOWLEDGEMENT OF FINANCIAL SUPPORT

EHA would like to acknowledge the below support in 2023:

INDUSTRY FUNDING	AMOUNT €	% INCOME
Hoffmann - La Roche Ltd	58,000.00	23.76%
Novartis	21,000.00	8.60%
Prilenia Neurotherapeutics Ltd	42,500.00	17.41%
PTC Therapeutics	27,948.50	11.45%
Uniqure	17,637.48	7.23%
Wave Life Sciences	30,500.00	12.50%
	197,585.98	80,95%

NON-INDUSTRY FUNDING	AMOUNT €	% INCOME
Revenue from 2022	7,055.79	2.89%
Huntington Study Group Clinical Research, Inc	26,797.68	10.98%
Huntington Liga	12,634.30	5.18%
	46,488.77	19,05%
TOTAL:	244,074.75	

Note: Percentages rounded up/down to one decimal place

Total percentage of industry funding:	80.95%
Total percentage of non industry funding:	19.05%