

# Austrian study shows transparency of pharmaceutical sponsorship for patient initiatives increased significantly

May 22 2023, by Ozren Sehic

---



Credit: Pixabay/CC0 Public Domain

A current monitoring of the Austrian Institute for Health Technology Assessment (AIHTA) shows that the member companies of PHARMIG

have disclosed their financial contributions to patient initiatives significantly more often in 2021 than in 2019. "However, there is still a lack of transparency on the part of the patient organizations and thus a lack of awareness of the problem," says Claudia Wild, managing director of AIHTA.

Patient initiatives include self-help groups or organizations such as PH Austria—Initiative Pulmonary Hypertension, the Austrian Hemophilia Society (ÖHG), Diabetes, AIDS or Hepatitis Help. They serve as a contact point for those affected and should, for example, represent the concerns and interests of patients towards health insurance companies or in the formulation of guidelines for the treatment of diseases. In addition, counseling, help in coping with the disease or support for those affected and their relatives are among the core tasks.

The increasing professionalization of patient initiatives also increases their need for [financial resources](#), which is often covered by sponsoring from [pharmaceutical companies](#). In order to make these financial flows more transparent, the [pharmaceutical industry](#) has responded with a voluntary commitment to disclosure. Since 2014, the AIHTA has been monitoring these money flows and can thus make any conflicts of interest visible. The fifth report of the monitoring has now been published, which examined the financial contributions of the pharmaceutical industry to various patient organizations.

According to the AIHTA report, 90 of the 115 PHARMIG member companies reported [financial contributions](#) to 117 patient initiatives in 2021. This also includes 45 so-called "zero declarations," in which it was stated that no monetary benefits were provided to various organizations and self-help groups. Compared to 2019, the disclosure rate rose from 34 percent to 78 percent. For the authors of the study, this development is proof that regular monitoring has a positive effect on the pharmaceutical industry's willingness to be transparent.

## Lack of problem awareness among patient initiatives

The amount of money declared also increased significantly from just under 2.3 to about 2.7 million euros (+19 percent). For the AIHTA analysis, the websites of all 115 PHARMIG member companies were examined for information on financial sponsorship to patient initiatives. In 2021, PHA Europe (European pulmonary hypertension association) received the highest donations with almost 252,000 euros, the Austrian Hemophilia Society (ÖHG) was second with about 195,000 euros.

The seven disease areas "lung diseases, haemato-oncology, [rare diseases](#), neurology, hemophilia, intestinal diseases and AIDS/HIV" accounted for money flows of more than 100,000 euros, together they received almost 90 percent of the individually disclosed donations.

"It is striking that especially those patient initiatives receive high sponsorship amounts in which there are very expensive therapies. For example, the relatively generous donations in the field of hemophilia are probably related not least to the development of new, cost-intensive gene therapies. The price per treatment is up to 2 million euros," says Claudia Wild.

While the transparency of the pharmaceutical industry has clearly increased in this area, the individual patient initiatives hardly disclosed their sponsorship amounts received. "It cannot be assumed that the organizations and self-help groups are deliberately non-transparent, but rather that there is a lack of awareness of the problem," explains Claudia Wild.

According to the study authors, however, it is important that patients and their relatives are informed about possible conflicts of interest of the initiatives, as they represent a risk for the development of bias. "To support [public trust](#) and professional integrity, they should therefore be

disclosed," the AIHTA report concludes.

**More information:** Gregor-Patera, N., Sponsoring of patient initiatives in Austria. 5th Update of the Systematic Analyses 2014 to 2019. *AIHTA Policy Brief* 007/ 5. Update. (2023). [eprints.aihta.at/1443/](https://eprints.aihta.at/1443/)

Provided by Austrian Institute for Health Technology Assessment GmbH

Citation: Austrian study shows transparency of pharmaceutical sponsorship for patient initiatives increased significantly (2023, May 22) retrieved 15 May 2024 from <https://medicalxpress.com/news/2023-05-austrian-transparency-pharmaceutical-sponsorship-patient.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------