

## Transparency of pharmaceutical sponsorship for patient initiatives increased significantly

**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 organisations and thus a lack of awareness of the problem," criticises Claudia Wild, managing director of AIHTA.**

Vienna, May 22 2023 – Patient initiatives include self-help groups or organisations such as PH Austria - Initiative Pulmonary Hypertension, the Austrian Haemophilia 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, counselling, help in coping with the disease or support for those affected and their relatives are among the core tasks.

The increasing professionalisation 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 organisations.

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 organisations and self-help groups. Compared to 2019, the disclosure rate rose from 34 per cent to 78 per cent. 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 Haemophilia Society (ÖHG) was second with about 195,000 euros.

The seven disease areas "lung diseases, haemato-oncology, rare diseases, neurology, haemophilia, 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 haemophilia are probably related not least to the development of new, cost-intensive gene therapies. The price per treatment is up to two 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 organisations 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.

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**Link to the study:** <https://eprints.aihta.at/1443/>

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