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überregional**Low transparency on pharmaceutical sponsorship for patient initiatives****A recent study by the Austrian Institute for Health Technology Assessment (AIHTA) shows that only about one third of Austrian pharmaceutical companies disclose their sponsorship of patient initiatives.**

Patient initiatives, for example self-help groups or organisations such as for Diabetes, AIDS or Hepatitis, provide an important voice for the interests of people with the acute or chronic disease and their relatives. They do valuable work in counselling, coping with the diseases and problems, and offer mutual support for those affected. "Ideally, they also point at relevant endpoints of treatments and thus provide information on when a therapy brings about an improvement," says Claudia Wild, head of the Austrian Institute for Health Technology Assessment (AIHTA)

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. Although this makes possible conflicts of interest visible, the willingness to be transparent is still relatively low, as the analyses of the AIHTA - conducted since 2014 - show .

In 2019, according to the AIHTA report, only 39 of a total of 115 PHARMIG member companies disclosed financial contributions to patient initiatives. Compared to 2018, the disclosure rate dropped from 43 to 34 per cent, while at the same time there was a significant increase in the amount of money declared by 37 per cent to around 2.3 million euros. The supported tasks range from funding for associations' activities and events to financial assistance for information, training seminars and conferences as well as printing subsidies.

Disclose conflicts of interest

For the analysis, the websites of all 115 Austrian PHARMIG member companies were searched for information on financial sponsorship to patient initiatives. In 2019, haemato-oncology (354,325 euros or around 16 per cent of the total) and haemophilia (287,552 euros or around 13 per cent of the total) received the largest shares, followed by lung diseases, diabetes and metabolic diseases. "The significant increase in grants in the field of haemophilia is probably related to the development of new, very expensive gene therapies. Overall, it is striking that mainly those patient initiatives are supported for which expensive therapies are available," says Claudia Wild.

The study leader emphasises that possible conflicts of interest do not necessarily influence the judgement of decision-makers of the patient initiatives, but they are a risk for distorted perceptions: "The sponsored patient initiatives may lose their critical views and attitudes and their awareness of which therapy options are still available apart from the drugs offered by the supporting pharmaceutical companies".

The conclusion of the AIHTA report: In order to support public trust and professional integrity, financial contributions must be disclosed. However, current practice shows that "awareness of the problem is still very selective. Therefore, it

is necessary to continue critical monitoring to support the transparency process”, Claudia Wild sums up.

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