A fragment of an interview with Ania, the mother of Monika, a four-year-old suffering from cystic fibrosis**. Reporter:** *Can you tell us when you found out about your daughter's illness?* **Ania:** *It was a few days after my daughter was born, so I was lucky that we were diagnosed quickly. Although after giving birth and long stay in the hospital, I was depressed. The physician who informed me about my daughter's illness was not well prepared for sharing such news with patients. He spoke in a monotone voice, as if he didn't care at all. He even told me that I should carefully consider whether I wanted to have another child with my husband, given that both of us are carriers of the abnormal gene that causes the disease. That was painful, I cried for a long time. Fortunately, one of the nurses brought me a piece of paper with the phone number of the Polish Society for Fighting Cystic Fibrosis on it and advised me to contact them. I got a lot of support from them. They still help me, even though it's been a few years. Thanks to them, I have met many people who either suffer from cystic fibrosis themselves or, like me, are family members of affected people*. **Reporter*:*** *And you don't mind that the Society is supported by pharmaceutical companies?* **Ania:** *That's very noble on the part of companies. Reporter: On the one hand, yes, but accepting these funds can place the organization in a conflict of interest situation, where it may start to care more about the welfare of the pharmaceutical company than the patients it represents. They may encourage patients to use the medications of a specific manufacturer. Such organizations might promote the use of drugs where, for instance, lifestyle changes would be more desirable. Some patient organizations (POs) are even created at the initiative of drug manufacturers to lobby for the reimbursement of a particular drug, with patients unwittingly used to stage protests outside the Ministry of Health. There is no transparency regarding how much money companies give and for what purposes.* **Ania:** *What you're saying to me is strange. It seems to me that if this is true, then it is in certain isolated cases. I am convinced that the Polish Society for Fighting Cystic Fibrosis makes good use of payments from industry, I am an example of that. With this support, the Society can help more people, and that's the most important thing, isn't it?*[1]

Stories like Ania's are common in Poland. Patients often feel alone after receiving a traumatic and often life changing diagnosis, and if they get the support they need it comes from outside the public health system. POs, struggling with financial problems, eagerly accept the support of drug business. There is no denying that this cooperation brings benefits to both sides: to the POs and to the industry. It gives organizations the opportunity to raise funds, to access information on the latest forms of treatment and knowledge about clinical trials. It allows companies to obtain information about medicines from people directly using them, to better understand the needs of patients, and to build their image as a socially responsible company. However, it also raises the kind of controversies mentioned in the interview above. These controversies can damage the public trust in POs and pharmaceutical companies. Some companies have already begun to realize this and publish transparency reports, in which they declare what resources they have donated to which organization and for what purposes, in order to counteract suspicions. In Poland, INFARMA Code of Good Practice signatories publish such data. These reports provide valuable information that can be analyzed. Studies of such transparency reports have already been performed in other countries (e.g. in GB, Sweden), supplying valuable knowledge about how funds from drug manufacturers are distributed and what organizations they support. Fabbri et al.'s (2020) systematic review concluded that there is a lack of research in countries other than wealthier Western countries. The project proposed for implementation aims to fill this gap. Poland is particularly interesting in this respect because it is an Eastern European, post-communist country with a distinctive history of the development of non-governmental organizations. Most POs in Poland are young, with only about 2% predating the socio-economic transformation of the 1990s. The project will describe the cooperation between pharmaceutical companies and POs in Poland and will determine how transparent it is. The project will identify existing obstacles to transparency. Moreover, the project will be innovative in relation to other projects conducted so far in its use of research triangulation – employing a combination of interviews, focus groups, survey and analysis of existing data. The project will examine the stakeholders of this cooperation, i.e., POs, drug business, Polish citizens, and patients under the care of POs. The project will show why it is important to monitor cooperation between pharmaceutical companies and POs, so that they really do serve citizens as much as possible. Transparency of cooperation is one such monitoring method, but perhaps the project may bring forward some other recommendations regarding how this should be done, in order to raise as few controversies as possible.

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[1] This is a fictional interview, designed to introduce the topic.