

International Alliance of Patients' Organizations A global voice for patients A global voice for patients

Pharma industry and patient groups collaborate on a NEW guidance note on best practices for interaction

Geneva, March 17, 2020 - The International Association of Pharmaceutical Manufacturers and Associations (IFPMA) and the International Association for Patients' Associations (IAPO) announce the launch of an advisory Note for Guidance for IFPMA member companies and associations worldwide on best practice for interaction with patients, caregivers, and patient organizations. The guidance also advises on the design and implementation of patient support programs that are supported by IFPMA members.

The Note for Guidance aims to complement the 2019 IFPMA Code of Practice which covers the promotion of pharmaceutical products and interactions with Healthcare Professionals (HCPs), medical institutions and patient organizations. The new advisory note sets out principles of interaction on how to protect the independence, privacy and integrity of patients, caregivers and patient organizations when they receive financial and non-financial support from companies and associations. It provides best practice on what should be included in agreements and puts great emphasis on advising pharmaceutical companies and associations to carefully consider how and when to engage with patients and caregivers as individuals, as advisors, or as guest speakers at events and congresses.

Speaking on the occasion, Kawaldip Sehmi, Chief Executive Officer of IAPO said: "the Guidance Note provides practical and actionable best practice to our patient organizations. Patients and patient groups play a crucial role in advocacy, education, and research, and it is essential to ensure they remain independent and interactions are transparent." Sehmi highlighted that although industry funding of patient groups is common and necessary, it is essential to ensure that whatever the interaction and wherever it takes place in the world, the needs of patients are put first. "I support collaboration between patients' organizations, and the pharmaceutical industry, as long as it is ethical and is in support of high-quality patient care," said Sehmi.

Thomas Cueni, IFPMA Director General stressed that "trust and behaving with integrity when dealing with patient organizations is already included in the IFPMA Code. It is in the interests of all parties to use the new global guidelines." Cueni added: "When money or resources are involved in interactions, we must at all cost avoid the impression that patient organizations depend on one single company. A wide base of support increases the independence and credibility of all parties."

The Note for Guidance was developed in consultation with a number of patient associations and stakeholders who provided their valuable input in making sure the guidance was practical and would serve as a useful tool for patient groups to work with. IFPMA and IAPO remain committed to ensuring that patients' interests are protected.

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Endorsements from our partners:

"As many patient organizations work with pharma industry on various different levels - from knowledge sharing to financial support - it is key to shape those relationships in a transparent way. The IFPMA Note for Guidance on Patient Interactions will provide a common basis across countries for companies as well as patient organizations", said Andreas Herdt, Vice Chair of Adipositaschirurgie Selbsthilfe Deutschland e.V.

"As Patient Co-Chair of the APEC Biopharmaceutical Working Group on Ethics, I appreciate the outreach of the IFPMA regarding the Guidance for Interactions with Patient and Patient Organizations and I believe it will be helpful to all," Russell Williams, Senior Vice President, Mission Diabetes Canada.

The IFPMA Note for Guidance can be accessed <u>here</u>. IFPMA and IAPO encourage a wide dissemination of the document.

About IFPMA

IFPMA represents innovative biopharmaceutical companies and associations across the globe. The biopharmaceutical industry's two million employees discover, develop, and deliver medicines and vaccines that improve the lives of patients worldwide. Based in Geneva, IFPMA has official relations with the UN and contributes industry expertise to help the global health community find solutions that improve health for populations around the world.

For more information, visit IFPMA at www.ifpma.org

About IAPO

The International Alliance of Patients' Organizations (IAPO) is a unique global alliance representing patients of all nations across all disease areas. IAPO works to promote patient-centred healthcare around the world. It has 276 member organizations from 71 countries representing 50 disease areas. Our vision is to see patients placed at the centre of healthcare.

For more information, visit IAPO at www.iapo.org.uk

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