

# KKI Lay Policy on Interactions with Patients, Care Partners, Patient Advocates and Patient Advocacy Groups

## Introduction

At Kyowa Kirin International (KKI), patients are the reason we are driven in our work, and our commitment to patient-centered care drives us to engage closely with patient advocacy groups, individual patients, care partners, and other members of the patient community. The evolving healthcare environment, with patients playing an increasingly active role in their decisions, cements the importance of patient-centricity in the development and lifecycle management of our products. By listening to and learning from patients, and partnering with advocacy groups, we gain valuable insights that help us incorporate the patient perspective at every stage—from research and development to market access and beyond. This policy outlines our approach to ensuring that our interactions are ethical, transparent, and focused on improving patient outcomes and lived experiences.

## Our Commitment to Patients and Patient Advocacy Groups

KKI is committed to building strong, sustainable partnerships with patient advocacy groups. These collaborations help us understand the needs and experiences of patients, allowing us to create innovative solutions that truly address unmet medical and patient needs. Our commitment to patients is demonstrated through our dedication to ethical practices, transparency, and respect for the independence of the groups we work with.

## Principles Guiding Our Interactions

We adhere to the following principles to ensure that our interactions with patient advocacy groups and patients are conducted in an ethical, compliant, and transparent manner:

1. **Integrity and Independence:** We respect the independence of patient advocacy groups and do not seek to influence their activities or decision-making processes. Our interactions are based on mutual respect and shared goals, with a focus on improving patient outcomes and lived experiences.
2. **Transparency:** We are committed to being open about our interactions with patient advocacy groups. We disclose all financial and non-financial support provided to these groups, as well as any significant contracted services, on our website.
3. **Ethical Collaboration:** Our collaborations with patient advocacy groups are guided by high ethical standards, ensuring that all interactions are conducted with integrity, respect, and equity.
4. **Patient-Centered Focus:** We engage with patient advocacy groups to better understand the patient journey and incorporate their perspectives into our work. This helps us develop medicines and treatment solutions that meet the real needs of patients.

5. **No Promotion of Medicines:** We do not ask patient advocacy groups to promote our medicines or endorse our products. Any discussions about disease management or treatments are led by our Corporate Affairs, Medical and R&D teams, independent of commercial influence.

### Criteria for Partnering with Patient Advocacy Groups

When selecting patient advocacy groups to partner with, we consider several factors to ensure that the collaboration is appropriate and aligned with our mutual goals:

- **Patient-Centered Mission:** The group must have a mission focused on the interests of patients.
- **Credibility and Independence:** The group should be a credible, independent, and a legally recognised organisation.
- **Transparency:** The group must be transparent about its funding sources and governance practices.
- **Non-Profit Status:** The group should operate on a non-profit basis.

### Written Agreements and Compensation

- **Agreement Before Action:** A written agreement signed by both KKI, and the patient/patient advocacy group representative must be in place before starting any activities. Transparency is important so patients can understand the reasons and full context of the interaction.

### Fair Compensation:

Patients, care partners and patient advocacy groups may be paid for their advice or support, in line with a fair market value rate. We do not fund individuals in their capacity as patient advocacy group representatives unless they are providing speaker services. Payments go to the patient advocacy group if the participant is an employee or representative of the group, not to the individual directly.

### Types of Support Provided

KKI supports patient advocacy groups in various ways, including:

- **Project-Specific Funding:** Support for specific activities or events that align with our shared goals.
- **In-Kind Support:** Non-financial assistance, such as media outreach or educational resources.

We ensure that our support is proportionate and that no group becomes overly reliant on KKI for funding. We strongly advocate for multi-source funding to maintain the independence of the groups we support. To make sure we maintain independence, we will only fund less than 50% of a patient advocacy group's total income during any given calendar year and will never request that KKI be the sole funder of a patient advocacy group.

### Disclosures

We disclose all support given to patient advocacy groups on our website and request similarly on their website, programmes.

**Governance and Oversight**

KKI has established rigorous governance structures to oversee our interactions with patient advocacy groups. Grants are reviewed and approved internally through regional or country specific committees to ensure appropriate oversight. Our Patient Advocacy Directors and local Patient Primary Points of Coordination (PPOCs) help effective relationship building and streamlined communication with patient and patient advocacy groups.

**Conclusion**

At KKI, we believe that collaborating with patient advocacy groups and patients is essential to delivering innovative medicines that truly meet patient needs. By adhering to high ethical standards and maintaining transparency in our interactions, we strive to build sustainable partnerships that benefit patients, healthcare systems, and society.