

Polycystic Kidney Disease Foundation Industry Relations Policy

Strategic Objectives: To further its mission of advancing the development of treatments for people with Autosomal Dominant Polycystic Kidney Disease and Autosomal Recessive Polycystic Kidney Disease, collectively referred to as “PKD”),” the Polycystic Kidney Disease Foundation (PKDF) may engage in appropriate collaborations with pharmaceutical, biotechnology, pharmacy and medical, and other industry partners with an interest in Polycystic Kidney Disease (collectively referred to as “Industry”). “Industry” includes companies, entities, groups and associations involved with researching, developing, manufacturing, marketing or distributing pharmaceutical products, medical devices or health care services.

The goal of the PKDF’s engagement with Industry is to:

- Build greater awareness throughout Industry about PKD and potential therapeutic targets or treatments.
- To be the recognized source for Industry to gain a better understanding of the needs of PKD patients, their families, and care providers.
- To establish effective communication channels and working relationships between Industry, the PKDF, PKD patients and PKD families.

Purpose Statement: The PKDF intends to operate under clear and transparent policies and guidelines in its interactions with Industry. Therefore, the PKDF has established this policy and underlying guidelines and procedures to ensure that any financial support received from Industry does not impact the PKDF’s independence or detract from the PKDF’s mission and obligations to the PKD community.

General Principles: The best interest of PKD patients and families is paramount in all decision-making involving Industry-related activities. The PKDF will maintain an independent position on issues affecting the welfare of patients with PKD.

The PKDF is determined to avoid any conflict of interest, or even its appearance, in any agreement with Industry. To assure that conflicts of interest do not occur, the acceptance of funds from Industry and the PKDF’s relationships with Industry organizations will be governed by the following principles:

1. The PKDF will not enter into any agreement that could threaten its not-for-profit status.
2. The PKDF will not be influenced in organizational decisions by Industry support. All relationships with Industry must be consistent with the PKDF’s Mission and Vision statements, principles, public positions, policies, guidelines and standards.
3. The PKDF will maintain guidelines that clearly define appropriate and acceptable interactions with Industry for PKDF staff, the Board of Trustees, medical and scientific advisors, chapter leaders and other volunteers.
4. All collaborations must be consistent with the PKDF’s guidelines and *must be* with strategic partners who have important interests in assisting the PKD community.
5. The PKDF may make product or treatment information available through Foundation

- communication vehicles but **will not** endorse any commercial products or services.
6. The PKDF will accept support for projects or programs only with the assurance that the privacy of patients with PKD and their families will be protected.
 7. Financial relationships with Industry will comply with all applicable federal, state and local laws and regulations.
 8. The PKDF shall not accept support in cash or in kind from Industry that is or appears to be in exchange for the recommendation of a product or products.
 9. The PKDF will ensure that all financial relationships with Industry are TRANSPARENT and CLEARLY communicated in all external materials. PKDF will disclose amounts received from Industry as required by law and to provide transparency.
 10. The PKDF will evaluate on an annual basis the total amount of Industry support received as a percentage of total revenue.
 11. The PKDF will disclose the name of Industry companies it receives financial support from on its website.

Approved by PKDF Board of Trustees on 04/27/2019