

Summary position statement on receiving funding from the pharmaceutical industry

Rare Disorders New Zealand (RDNZ) relies on grants, donations and Government funding to carry out its work to support people living with a rare disorder in New Zealand with information and advice, and to advocate for a health system that can support the needs of rare disorder patients.

RDNZ works with a variety of sectors with an interest in rare disorders, including patient groups, government agencies, researchers, health professionals and the pharmaceutical and medical device industry.

This position statement outlines RDNZ's position on receiving funding from the pharmaceutical industry.

Background

In 2019, Rare Disorders New Zealand (RDNZ) established the Round Table of Companies (RTC) to bring together pharmaceutical companies with an interest in rare disorders and orphan drug development. The RTC provides an important forum to foster transparent working relationships with industry and encourage open communication between industry and the rare disorder patient community. Maintaining independence and integrity is of the utmost priority to RDNZ.

The RTC currently consists of eight members: Alexion, Biogen, Vertex, BiOMARIN, MAXHealth, Amicus Therapeutics, Pfizer and Takeda. RDNZ welcomes other pharmaceutical companies to join if they have an interest in rare disorders and orphan drug development.

The RTC meets twice a year to discuss topics relevant to the development of orphan drugs and treatments for rare disorders in New Zealand.

RTC members pay an annual membership fee of \$8,500. This funding supports RDNZ's sustainability to continue to support people living with a rare disorder in New Zealand. It provides RDNZ with a source of pooled, unrestricted financial support for activities of common interest and benefit such as:

- Improving access to information, treatment, care, services and support for people living with a rare disorder across New Zealand;
- Raising public awareness on orphan drugs, rare disorders and on the need for more research;
- Improving identification and increasing knowledge of rare disorder patient groups in New Zealand and facilitating networking and reaching out to them.

Occasionally RDNZ receives one-off financial support from RTC members to support RDNZ's activities in the areas of public awareness, patient support, capacity building, and social, health and educational services.

RDNZ's principles regarding engagement with the pharmaceutical industry

RDNZ's engagement with the pharmaceutical industry occurs in a transparent manner, and does not imply RDNZ's endorsement of any pharmaceutical industry activities or products. RDNZ is committed to full transparency and disclosure in all dealings with commercial companies.

RDNZ will not endorse any specific drug or treatment.

From time to time at the request of patient groups, RDNZ may support patient-led campaigns for access to specific treatments that are backed by evidence and for which there is a clear need. RDNZ will always focus its advocacy efforts on issues around systemic barriers to accessing approved treatments rather than the treatment itself.

RDNZ will not accept or distribute promotional products provided by pharmaceutical companies.

RDNZ has clear ethical principles for receiving financial support resulting from partnerships with industry:

- must be for the benefit of the patients RDNZ represents;
- must not entail product advertisement;
- cannot influence in any way RDNZ's policy, positions or decisions, whether explicitly or implicitly;
- industry funding for specific events or activities driven by RDNZ will be publicly acknowledged by RDNZ throughout printed materials, documents, website, and electronic communication to ensure transparency and recognition;
- industry support has no influence on the design and conduct of the project, event or activity.

RDNZ's full policy on working with the pharmaceutical industry can be accessed [here](#).