



RARE DISEASE

PARTNERSHIP PROGRAMME

Code of Conduct: Rare Disease Partnership Programme

When becoming a member of the **Rare Diseases Partnership Programme (RDPP)**, the company accepts and adheres to the following terms of association:

- The purpose of the RDPP is to **discuss issues of common interest** related to orphan product development with the ultimate goal of developing safe, effective diagnostics and treatments for patients.
- RDPP members understand and respect that RDSA is the voice of the 4 million South African's with rare diseases and, as such, will always be guided by its determination of what is in the best interests of the patient community.
- RDPP members understand and respect RDSA's need to remain neutral with respect to specific products or services. RDSA maintains independence in its advocacy positions and initiatives.
- RDSA maintains independence in the content of its educational materials and decisions within its policy priorities.
- RDPP members seek to work in an active partnership among patients, health professionals, and industry.
- Meetings of the RDPP including regular meetings, may be attended **ONLY** by staff of RDPP members. Contract consultants or external advisors may not attend on behalf of member organizations.
- Understand that the RDPP is not a platform to advocate or to attempt to influence specific decisions or positions of RDSA.
- Understand that participation in the RDPP will have absolutely no influence on the decisions made by RDSA representatives in their role as patient advocacy.
- Fully respect the independence and integrity of RDSA, its representatives and members.
- Recognise the role of RDSA and its member organisations in representing people affected by rare diseases, who, as such, are entitled to express critical views on any relevant matter.
- Recognise the role of patient groups in clinical trials and seek to encourage active partnership between patients, health professionals and industry.
- Support the equitable access of treatments and services in a sustainable manner.
- Read and conform to the RDSA Policy on Financial Support by Commercial Companies.

I, _____ have read and accepted the above code of conduct and accept its contents as a member of the Rare Diseases Partnership Programme, on behalf of _____.

Name (and/or stamp) of company:

Signature of company representative: _____

Date: _____

Full name of signatory: _____