



## PRIVACY STATEMENT

Rare Disorders NZ takes your privacy seriously and keep information you submit to this website secure. We do not share your personal information with other organisations, unless required to by law or specified in this privacy statement.

We collect personal information from you, including information about your:

- name and contact information;
- ethnicity;
- region;
- computer or network;
- interactions with us;
- reason for contacting us;
- the name of your rare disorder.

We collect your personal information only to:

- send you our bimonthly newsletters (which you can unsubscribe from);
- enable connections with others who have the same condition (we will always check with you first to see if you are interested in being connected);
- fundraise;
- inform you about our surveys or important advocacy updates;
- keep in contact with you, for example sharing relevant information;
- collect anonymised data for reporting and funding purposes.

We do not share any other information without your prior consent.

We keep your information safe by storing it in encrypted files, secure locations and only allowing authorised staff to access the information.

You have the right to ask for a copy of any personal information we hold about you, and to ask for it to be corrected if you think it is wrong. If you would like to ask for a copy of your information, or to have it corrected, please contact us at [enquiries@raredisorders.org.nz](mailto:enquiries@raredisorders.org.nz), 027-250-0619, or PO Box 7081 Newtown, Wellington 6242.

Note: we reserve the right to alter this privacy policy at any time without notice.