



## Department of Government Services

Consumer Affairs Victoria

Regulatory Transaction Services  
GPO Box 4567  
Melbourne Victoria 3001  
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[consumer.vic.gov.au](http://consumer.vic.gov.au)

10 December 2024

Kieran Klep  
RARE NEUROLOGICAL DISEASE RESEARCH LTD  
[kieran.klep@msaresearch.org.au](mailto:kieran.klep@msaresearch.org.au)

Dear Kieran Klep

### **NOTIFICATION OF INTENTION TO CONDUCT A FUNDRAISING APPEAL UNDER THE *FUNDRAISING ACT 1998* (the Act)**

I refer to your notification as a registered charity of the intention to conduct a fundraising appeal in Victoria and confirm that the fundraiser is now deemed to be registered under the Act. Please find below the registration details for your records:

**Fundraiser name:** RARE NEUROLOGICAL DISEASE RESEARCH LTD  
**Registration number:** FR0017501  
**Effective date:** 10/12/2024

The deemed fundraiser registration will continue without the requirement for renewal or annual reporting unless:

- the charity's registration is revoked by the Australian Charities and Not-for-profits Commission (ACNC), or
- the fundraiser is deregistered by the Director, Consumer Affairs Victoria (the Director), or
- the fundraiser ceases its fundraising activities in Victoria.

The nominated Fundraiser Responsible Person is responsible for ensuring that the fundraiser complies with all relevant legislation. The responsible person must notify Consumer Affairs Victoria via myCAV if the fundraiser:

- retains a commercial fundraiser to administer all or part of a fundraising appeal, or
- becomes insolvent or externally administered, or
- is found guilty of a disqualifying offence.

## **The fundraiser must keep accurate financial records**

Although the fundraiser is not required to renew its registration or report annually to CAV, both the National Fundraising Principles and the *Fundraising Act 1998* require the fundraiser to keep accurate financial accounts. Our inspectors can request access to these records at any time. In addition, the Director can direct a fundraiser to submit an auditor's report on the accounts and records kept in relation to an appeal.

The financial records must include full details of:

- all funds and assets received as a result of the appeal
- what happened to all those funds and assets
- the amount applied to the purposes or objects of the appeal and how it was distributed
- any expenditure on assets
- any expenditure on wages, salaries, commissions and other remuneration in relation to the appeal
- any other administrative expenses related to the appeal
- any other expenditure related to the appeal.

## **THE FUNDRAISER MUST CONDUCT APPEALS THAT COMPLY WITH THE VICTORIAN *FUNDRAISING ACT 1998* AND FUNDRAISING REGULATIONS 2019**

The *Fundraising Act 1998* contains a detailed description of how to conduct a compliant fundraising appeal. This includes how people should represent the appeal and identify themselves. The penalties for failing to comply with these requirements are listed in **[consumer.vic.gov.au/fundraisers](http://consumer.vic.gov.au/fundraisers)**.

The Fundraising Regulations 2019 includes the National Fundraising Principles, which provide charities and donors a clear understanding of appropriate conduct and harmonise requirements on charitable fundraiser conduct across Australian jurisdictions. The Fundraising Regulations also include certain exemptions from requirements of the Act for fundraisers that comply with the National Fundraising Principles.

## **The fundraiser must conduct appeals that comply with the National Fundraising Principles**

As a registered charity fundraising in Victoria, the fundraiser is required to comply with the National Fundraising Principles, which are listed at **[consumer.vic.gov.au/about-us/in-focus/national-fundraising-principles](https://consumer.vic.gov.au/about-us/in-focus/national-fundraising-principles)**.

When conducting fundraising activities, the fundraiser must always ensure that their employees, volunteers, contractors, and anyone else they engage or arrange to raise funds on their behalf follow these Principles.

## **Public Register**

The fundraiser will appear on our public register of fundraisers. You can search the register at **[registers.consumer.vic.gov.au/frsearch](https://registers.consumer.vic.gov.au/frsearch)**.

## **Privacy**

View our privacy policy at **[consumer.vic.gov.au/privacy-statement](https://consumer.vic.gov.au/privacy-statement)**.

Yours sincerely,

## **Operations Manager**

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