



Complaints Policy

Cystinosis Ireland is committed to ensuring that all our communications and dealings with our families, the general public, our supporters and all who engage with us are of the highest possible standard. We listen and respond to outside views so we can work to the best possible standards. Cystinosis Ireland welcomes both positive and negative feedback. We aim to ensure that:

- it is as easy as possible to make a complaint, where the need arises;
- we treat as a complaint any clear expression of dissatisfaction with our operations which calls for a response;
- we treat every complaint seriously, whether made by telephone, letter, email or in person;
- we deal with any complaint quickly and politely;
- we respond accordingly – for example, with an explanation or apology where we have got things wrong, and with information on any action taken, etc;
- we learn from complaints, use them to improve, and monitor them at Board level.

What to do if you have a Complaint?

If you do have a complaint about any aspect of our work, you can contact Cystinosis Ireland in writing or by telephone. In the first instance, your complaint will be dealt with by our Operations Manager.

Denise Dunne
Cystinosis Ireland
Denise.dunne@cystinosis.ie / 01 687 5758.

When submitting your complaint, please include your contact details so we can respond to you directly.

If you complain in person or over the phone, we will try to resolve the issue there and then. If your complaint is by email, we will acknowledge it within 7 days, and do everything we can to resolve it with 21 days. If this is not possible, we will explain why and give a new deadline.

All complaints will be logged in our 'complaints register' and tracked until they are resolved. The complaints register is reviewed by the board of directors annually.

Research - Awareness - Support

Cystinosis is a rare, degenerative, incurable disease that primarily affects children. It slowly destroys all the body's organs and muscles. Cystinosis Ireland is a volunteer-led, non-profit organisation dedicated to funding cystinosis research and providing support to those living with the condition.



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What happens if the complaint is not resolved?

If you are not happy with our response, you may get in touch again by writing to Cystinosis Ireland's Chairperson who will if necessary ensure that your complaint is considered by our Board of Directors. The Chairperson will respond within two weeks of this consideration by Board members.

Acting on findings

Where we identify an issue with our practice or processes Cystinosis Ireland will do everything we can to put things right and will review our procedures where necessary to stop problems happening again.

Cystinosis Ireland also welcomes constructive and positive reflections on our work and may from time to time include these in our reporting, both internally and publicly. We will seek your permission to use this feedback where we do.

Staff complaint procedures

This process for lodging complaints does not apply to Cystinosis Ireland's staff or volunteers, who have a separate policy for lodging any complaints as outlined in the staff handbook. A similar process is outlined in the Board handbook for those members of our team.

Approved by the Board of Directors, March 2022

Review date: March 2025

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Directors: J. Ennis (NI), A. Maguire, S. Maguire, K. McCullagh, T. McDonald, L. McFadden, AM. O'Dowd, R. Reilly, M. Swift.

Patron: Stephen Rea

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