

Dear *[insert name of school principal, dean, or deputy]*

My name is *[insert name]* and my *[child/grandchild/sibling/niece/nephew*] is *[insert child’s name and classroom number].*

I am writing to you to ask that [insert school] gets behind Rare Disease Day this year to show support for families in our school community affected by rare disorders.

Rare Disease Day - a global day of solidarity for people living with a rare disorder, is observed every year on the last day of February. What makes this day extra special in 2024 is that it is a leap year, which means it will be observed on the very rarest of days – 29th February. A day as unique as this is the perfect opportunity to celebrate uniqueness in our community!

It’s not rare to have a rare disorder. In Aotearoa, more than 300,000 people live with one of over 7,000 rare disorders - and more than half of these people affected are children. That’s the equivalent of 1-2 students in every classroom.

[If applicable, Insert detail about a child affected by a rare disorder. Detail the everyday struggles they face, difficulties they’ve faced receiving a diagnosis and/or treatment, and what it would mean to them if the school got behind Rare Disorders Month. State that they are just one of many children in the school affected by a rare disorder].

Rare Disease Day is also the day that Rare Disorders NZ, the collective voice for rare disorders in NZ, kicks off it’s Rare Disorders Month campaign with the theme Glow Up Show Up for Rare. So, if the 29th February isn’t suitable for your school calendar, any day in March is a good day to celebrate rarity!

**How can [insert school name] help?**

There are many ways your school could get involved and #GlowUpShowUp for the rare disorder community:

* Gold coin day and encourage dressing up in bright colours
* Morning tea
* Colour run
* Speech competition
* or a disco.

Rare Disorders NZ have put together resources to make it easy for schools to organise relevant and fun events, which you can view [here.](https://www.raredisorders.org.nz/get-involved/for-schools/)

Please let me know if you would like to receive a pack with everything you or your teaching staff need to organise an event for Rare Disorder Month. Temporary tattoos, event plans and printable posters are available for schools getting involved.

I would greatly appreciate *[insert school name]’s* involvement, and it would mean a lot to *[insert child’s name]* and the rest of the rare disorder community within the school. Please let me know if you have any questions, or contact RDNZadmin@raredisorders.org.nz.

Please help us to #GlowUpShowUp for rare disorders.

Kind regards,

*[Insert name]*

Visit raredisorders.org.nz and follow @RareDisordersNZ to get involved and #GlowUpShowUp