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Tuesday 7 February 2023

Caroline De Luca

By email caroline.deluca@pharmac.govt.nz

Kia Ora Caroline and Covid 19 Treatments Advisory Group

Re Request for review to widen access of Covid 19 Anti Viral Criteria for those living with a rare disorder

Further to our discussion at our quarterly meeting between Rare Disorders NZ and Pharmac on 11/01/23 we raised a concern about the narrow access criteria for Covid 19 anti virals. We stated that the rare disorders community are struggling to access Covid 19 anti virals despite in some circumstances a significant increase in risk on their health and outcomes from Covid 19.

In recent months we have had an increase in concern raised by those living with a rare disorder not being able to access Covid 19 anti virals as they don't meet the current criteria. Many of the rare disorders community still live with many restrictions to limit their exposure or potential exposure to Covid 19. As you will be aware many of those with rare disorders experience significant health challenges and suffer daily in their lives managing their conditions, often with multiple chronic health conditions. This concern adds to their burden and the inequity of healthcare access here in New Zealand. We are hearing from our community that they believe from their experiences the driver for anti viral access is still mainly about reducing hospitalisations and not in any way focused on the factors that might lead to long term health detriment for those with a rare disorder, which would impact on health needs and burden on healthcare services.

We agree with the rare disorders community and believe that the current access criteria for Covid 19 anti virals is inequitable for those living with a rare disorder. There are currently some people with rare disorders able to access through the current criteria but there are many that are not, and with similar health risk, this appears to be inequitable.

We understand from your correspondence following our meeting that you are undertaking a literature review looking for any evidence relevant to people with rare disorders and risk of severe impacts of COVID-19 prior to the next meeting of the COVID-19 Treatments Advisory Group scheduled for 14 February. We are pleased to hear this. We do not believe it is the role of the Not For Profit/Charitable sector to undertake this work and that it is absolutely the role of Pharmac and the health system to ensure the right experts and clinicians are canvassed for their research and clinical findings both here in New Zealand and globally.



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We have however also undertaken to seek out information from both our community and their clinicians and we have the following information to share with you.

- We have contacted the Rare Care Centre in Perth WA. Their clinical lead Dr Gareth Baynam has recently been involved in peer review of clinical papers in England on Covid 19 and outcomes for those with rare disorders. From our discussions it appears England have data and now concerns about the impact of Covid 19 on those people living with a rare disorder, and a need to review access to care and treatment. We can connect you with Dr Gareth Baynam.
- We are also aware Scotland have made people living with rare disorders a high risk population and they are included along with other high risk population in their criteria for higher level access to Covid 19 care and treatments.
- Please find attached a letter from Dr Gemma Poke Clinical Geneticist Genetic Health Service NZ in regard to request for widening access to Covid 19 Anti Virals.
- We also know that CF NZ (CF being a rare disorder) has requested on more than one occasion for a review and widening access for those with CF and have provided evidence for this request from clinicians.

Rare Disorders NZ therefore requests that Pharmac provides for an equitable situation and widens the access criteria to enable all people living with a rare disorder to have access to COVID-19 antivirals if their treating clinician considers it appropriate. This would not only reduce the need to access hospital services if they were to catch COVID-19 and for the treatment of post-viral exacerbations of their rare disorder, it would also help to prevent further clinical health decline.

We look forward to hearing directly from you following the consideration of the Covid 19 Treatments Advisory Group on the outcomes of the meeting in respect to people living with rare disorders.

In the meantime if we can be of help or assistance to you and the advisory group please do get in touch.

Nga mihi
Michelle

Michelle Arrowsmith
Chief Executive Officer
Rare Disorders NZ

On behalf of Rare Disorders NZ