

Sent: Monday, 25 May 2020 2:39 PM

To: Nicole Millis <nicole.millis@rarevoices.com.au>

Subject: RE: COVID-19 pandemic: critical care guidelines for Australians living with a rare disease

Dear Ms Mills

Thank you for your email to the Chief Health Officer and for providing a copy of the statement issued by Rare Voices Australia about the development and use of critical care guidelines for people living with a rare disease to inform Australian hospitals and clinicians during the COVID-19 pandemic. Your enquiry was forwarded to the Public Health Emergency Operations Centre.

NSW Health acknowledges the challenge of people living with rare diseases. NSW Health is engaging with clinical communities, including those caring for people with rare diseases, through Communities of Practice. Communities of Practice provide a depth and breadth of clinical response across the disease spectrum.

NSW Health has encouraged people to continue to seek routine clinical care and to ensure that they consult with their health care team regarding any additional precautions they may need to take regarding COVID-19.

Many NSW Health clinics are now being conducted online or via telephone – this facilitates regular contact between the health care team and patients and their carers, especially during a time when some patients are reluctant to enter health care facilities.

NSW Health notes that rates of non-attendance for routine clinical issues have increased. We would ask that Rare Voices Australia works with its consumers to reassure them that seeking medical care is safe and that patients should continue to attend routine clinical appointments.

Thank you again for writing.

Yours sincerely

COVID-19 Ministerial Team