

Role: Pediatric pulmonologist (consultant)

You are a pediatric pulmonologist. One of your long-term patients is a 5-year-old boy who was diagnosed with a rare, progressive, genetic disease at birth. Consequently, he is severely developmentally delayed, tracheostomy and ventilator dependent, and fed via a gastrostomy tube. You are not really an expert in his genetic disease, but you were brought on to manage his ventilator settings, and since there aren't any pediatric geneticist in your medical system, you've ended up managing most of his other syndromic issues as well. As far as you can tell, the patient's parent has dedicated the past 5 years towards caring for their child as best as they could. They quit their job and refused at home nursing care, preferring to do everything themselves. Recently, the patient's parent emailed you about an experimental therapy they think can be used to treat their son. As far as you can tell, the therapy has only been tested on rats and hasn't even passed phase 1 trials yet. And you don't think your patient has more than a year or two left to live.

Last night, your patient was admitted to the PICU. The attending physician has asked you to join them in a care conference and explain to the parent that their son likely won't survive this admission.

For this exercise, you are part of a care conference with the patient's parent, his bedside nurse, a consultant expert in his genetic disease, and the social worker. The attending will lead the care conference and you will provide your "expert" opinion, when asked. For the past year, you have been hoping to refer your patient to a palliative care specialist, but whenever you bring it up the parent has gotten upset. Maybe this time they will finally realize how sick their lungs are getting and start to move towards comfort and hospice measures