# ECLI:NL:RBLIM:2025:6034

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| **Agency** | Limburg District Court |
| **Date of pronouncement** | 25-06-2025 |
| **Date of publication** | 25-06-2025 |
| **Case number** | C/03/342246 / KG ZA 25-201 |
| **Areas of law** | Civil law |
| **Special features** | Summary proceedings |
| **Content indication** | Claim by parents of a three-year-old girl, who suffers from a very rare and serious disease, to prohibit the decision of the Maastricht University Hospital to discontinue medical treatment or artificial respiration. The interim relief judge dismisses the claim. The decision to discontinue treatment is in principle up to the doctors. They can reasonably take that decision, taking into account all interests (marginal review). The decision was taken carefully, after, among other things, two second opinions were obtained from two other hospitals. The girl's parents' appeal to three treaty rights (right to life, right to "family life" and right to freedom of religion) is dismissed. |
| **Locations** | Rechtspraak.nl |

Enriched pronunciation

## Pronunciation

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verdict

**COURT OF LIMBURG**

Civil law

Seat Maastricht

case number: C/03/342246 / KG ZA 25-201

**Summary judgment of June 25, 2025**

in the matter of

**1 [claimant sub 1] ,**

and

2. **[plaintiff sub 2] , acting pro se and in their capacity as legal representatives of their minor daughter [minor] ,**
both residing in [place of residence] ,
claimants,
attorney Mr. AFG Pennino;

in return for:

the public law legal entity
**ACADEMIC HOSPITAL MAASTRICHT** ,
seated in Maastricht,
defendant,
lawyer mr. K. Mous.

The parties will hereinafter be referred to as the parents of [minor] and the AZM.

## 1 The course of the procedure

1.1. The course of the procedure is apparent from:

- the summons;
- the conclusion of the answer, with productions 1 to 35;
- production 36 sent subsequently by the AZM;
- the oral hearing;
- the statement of defense of the parents of [minor];
- the AZM's plea.

1.2. Finally, the interim relief judge stated that he would render judgment no later than 25 June 2025, in deviation from what the parties were informed of in the letter from the court dated 3 June 2025.

## 2 The facts

2.1. Mr and Mrs [plaintiffs] have a daughter, named [minor] (hereinafter also referred to as: [minor]). [minor] was admitted to the AZM on 19 February 2025 due to worsening complaints of muscle weakness in her arms and legs; she had previously been admitted to the AZM (on 19 August 2023) due to loss of strength and swallowing difficulties and had previously been admitted to Adelante Zorggroep (hereinafter referred to as: Adelante), after the first admission to the AZM, for rehabilitation therapy.

2.2. On admission on February 19, 2025, [minor] was diagnosed with progressive hypotonic paresis, with progressive deterioration of bulbar (the part of the brain responsible for coordinating swallowing, speaking, and chewing), respiratory (breathing), and autonomic (regulation of heart rate, blood pressure, digestion, and body temperature) functions. As a result, [minor] was transferred to the Pediatric Intensive Care Unit (hereinafter: PICU). On February 26, 2025, [minor] had to be intubated for ventilation.

2.3. [Minor]'s parents have an older daughter who has been admitted to hospital in Egypt since she was two years old. She has been on artificial respiration there for four years due to "acute flaccid paralysis." Doctors in Egypt refer to her condition as Guillain-Barré syndrome. According to the treating physicians, [minor]'s sister probably suffers from the same or a similar condition as [minor].

2.4. On March 5, 2025, a consultation took place between the AZM and the Erasmus Medical Center in Rotterdam (hereinafter: EMC) about a special gene – namely the RCC1 gene – that could explain the clinical picture of [minor].

2.5. After consultation with the EMC, urgent genetic diagnostics were initiated on March 6, 2025, focused on the RCC1 gene, due to the suspicion of an underlying genetic cause for the clinical picture. On March 7, 2025, the laboratory reported that a homozygous change in the RCC1 gene (Regulator of chromosome condensation 1) had been found.

2.6. The EMC shared an article (a pre-publication) with the AZM about abnormalities in the RCC1 gene, in which patients with homozygous mutations were described with no, or hardly any recovery, and serious relapses upon recovery. Because the clinical picture of [minor] completely matched the case history described in the article, the AZM interpreted the picture as clinically consistent with a homozygous RCC1 mutation.

2.7. [name 2] et al. (the interim relief judge assumes that they are the authors of the article referred to in 2.6.) made a study available as a preprint in October 2024

in which 24 patients from 12 families with an acute axonal polyneuropathy after a previous infection have a biallelic variant in the RCC1 gene. The clinical presentation varies from a rapidly progressive fatal axonal polyneuropathy with an encephalopathy to a mild motor neuropathy resulting in a worsened gait function. In almost all patients, the neurological complaints arose after an infection. IVIG and plasmapheresis (gold standard in treatment for Guillain-Barré syndrome) had no effect in the described patients. The majority of the patients required long-term ventilation with a severe persistent muscle weakness as residual damage. More than half of the patients had multiple episodes (preceded by an infection) which further worsened the already existing symptoms. Ultimately, 15 (of the 24) patients died between the ages of 11 months and 23 years. The authors emphasize in the article that nerve damage in this condition is permanent in most cases, and that the condition of patients worsens with subsequent infections. Unlike, for example, Guillain-Barré syndrome, recovery here is exceptional and the damage caused is therefore permanent (p. 18):

*"Whilst the natural history of GBS tends towards recovery, almost all of the patients described in this cohort had limited clinical improvement, indicating permanent neuronal damage".*

The condition has a recurrent course in many patients, with new episodes often leading to further deterioration of the health condition. In 15 cases this eventually led to death, at ages between 11 months and 23 years (p. 8):

*"Recurrent episodes precipitated by periods of infection were observed in the majority of patients (15/24). These subsequent episodes often led to a severe deterioration in symptoms, and 15 individuals died as a result of their condition between the ages of 11 months and 23 years of age."*

2.8. On March 12, 2025, a multidisciplinary consultation took place at the AZM. Pediatric neurologists, pediatric intensivists, AIOS and a nurse participated in that consultation. The following is included in the report **1 that was drawn up:**

*"1) Both the group of pediatric neurologists and pediatric intensivists agree with a do not resuscitate policy. There is a poor prognosis based on deterioration in the clinic (increased hypertension, bradycardia), insufficient improvement in combination with the found RCC1 mutation.*

*(…)*

*There are no other treatments for [minor]. With regard to possible long-term ventilation (tracheal cannula), the pediatric neurologists and pediatric intensivists agree that this is not desirable in the case of a poor quality of life. (…)."*

2.9. On March 14, 2025, it was discussed with the parents of [minor] that treating [minor] would be medically pointless if her state of health did not improve. Continued treatment would only lead to a prolongation of [minor]'s suffering. The following is included in the report **2 made of this:**

*"(…) Then we discussed that if [minor] does not improve, we consider it medically pointless to keep [minor] alive, who cannot express himself, is anxious, cannot indicate/move anything and is continuously ventilated by the machine. There are also no other centers in the Netherlands that can offer this. Parents are initially angry, they think this is a choice that is up to God and not the doctors. Moreover, they still hope for a treatment for the disease.*

*Discussed that if there is a treatment, it will take a very long time to make it. Moreover, it is very important for treatments for other conditions that you start early with the treatment before the damage has occurred. In [minor], the nerves are unfortunately already damaged by the disease. [addition: and this is irreparable]*

*Discussed that we are still doing everything at this moment, that we are going to see if [minor] shows improvement. Discussed that there will be another meeting with many doctors next week, in which we have to see what is best for [minor]. Also discussed that if parents cannot support this at all, we have to see if there are possibilities to transfer [minor] to another country, but that this is not what we would want for [minor].*

*Parents indicate that they see that we do our best for [minor]. There are no questions at the moment."*

2.10. On March 24, 2025, the situation of [minor] was discussed in the Medical Ethics Committee (hereinafter referred to as: CMEA) of the AZM. [minor]'s situation was compared to the situation of patients with a very high spinal cord injury and by some care providers with the lock-in syndrome.

2.11. The members of the CMEA concluded the following: **3**

*"Given the limitations in functioning and existence that treatment outside the hospital will entail, this treatment will also not lead to a minimum quality of life. This quality of life will also continue to decrease with each new incident (e.g. an innocent infection that children often suffer from). This does not allow for any scenario in which one can speak of medically meaningful action."*

2.12. Now that the parents of [minor] do not support the policy of the AZM, the AZM has requested a second opinion from the Erasmus MC (hereinafter referred to as: EMC), asking whether the EMC saw other realistic treatment options. [name neurologist 1] (neurologist at the EMC) and [name neurologist 2] ((child) neurologist at the EMC) conclude the following: **4**

*"3-year-old girl with worsening of her severe axonal polyneuropathy with tetraparalysis, autonomic dysfunction and respiratory failure requiring ventilation most likely based on a genetic variation in the RCC1 gene.*

*With this diagnosis, there is only a very limited possibility of improving the nerve function and thus the strength of [minor]. In addition, there is a high chance of the disease worsening with a subsequent infection.*

*The condition of [minor] (and possibly also her sister) was first described very recently and unfortunately there are no treatment options aimed at the underlying cause.*

*Considering that we expect that [minor] will no longer be able to breathe independently, swallow food or saliva, speak, move independently or have active hand function, we see no indication for chronic home ventilation. For a child of her age, it is essential to be able to feel, move and communicate in order to learn and participate. We expect that [minor] will no longer be able to achieve this. In addition, she will experience more infections that could trigger further deterioration. Based on the above arguments, we believe that continuing the current respiratory support for a long period of time is not in the interest of [minor].*

*We realize that only a small group of patients has been described and there is variation in that group, but in all the patients described there is little to no recovery after a period of deterioration, which is understandable from the underlying cause. There are undoubtedly mildly affected patients, but they will not have the picture that [minor] shows at this age.*

*We expect that there is a significant risk that [minor] will end up in a resuscitation setting if he deteriorates further due to autonomic dysfunction. We do not consider this to be reversible and therefore it is not in the interest of [minor] to perform cardiac resuscitation."*

2.13. On April 2, 2025, [name of pediatric intensivist 1] (pediatric intensivist at the

Radboudumc and [name pediatric intensivist 2] (pediatric intensivist at the EMC-Sophia Children's Hospital) spoke with both parents and the medical and nursing team of the AZM, in order to assess the intention of the AZM to discontinue the treatment of [minor] as best as possible. Their conclusion of April 8, 2025 **5** is as follows:

" ***Conclusion:***

*3-year-old girl with worsening of her severe axonal polyneuropathy, most likely due to RCC1 mutation, and only minimal recovery during more than 1 month of invasive mechanical ventilation. There are no treatment options and the chance of recovery is very small. Long-term and invasive support of the ventilation by means of invasive ventilation, accompanied by discomfort with no recovery of the underlying picture is disproportionate. In this we support the decision of the MUMC+ medical team to discontinue long-term invasive mechanical ventilation."*

2.14. Given the limited awareness of [minor]'s clinical picture, the AZM - based on the advice of [name pediatric intensivist 1] and [name pediatric intensivist 2] - contacted the authors of the article *'Genetic risk of axonal neuropathy following Infection'* . The AZM asked the authors for their insights into the expected course of [minor]. The authors stated that the prognosis is often very poor in general. According to the AZM, the consultation with the authors did not provide any new insights.

2.15. **On 15 April 2025, a new multidisciplinary consultation took place. The report 6** made thereon contains the following:

" *(…) It is difficult to assess the comfort of [minor] given her neurological picture, which can be assumed to be overestimated. She can grimace, sometimes the nurses see that she is anxious, sometimes she can shake her head no (subtle but clear). Last week she was uncomfortable several times a day with activities such as suctioning. In a stable situation like now, she is very short of breath 2-3 times a week with a sputum plug. At those moments you can see the fear in her eyes. (…).*

*Considerations:*

*Based on the current ventilation conditions in combination with the knowledge gained about the underlying disease, after consultation with the authors of the article, it is unlikely that [minor] can be weaned off ventilation. There is complete consensus on this among all present. Patients with an RCC 1 mutation show that it is a progressive disease, triggered by repeated new infections. Recovery between infections is limited, with (complete) recovery to the pre-existing situation being virtually impossible. It is likely that a new episode of illness will again lead to further neurological deterioration. This knowledge, combined with the very limited progress that [minor] has shown in the past 6 weeks and the high degree of dependence on intensive medical necessary support prior to the current episode of illness, ensures that all present do not consider it realistic*

*that there is a possibility of recovery. Given that the burden of minor but necessary medical procedures, such as suctioning and care, has a major impact on [minor]'s comfort, all present estimate that [minor] is currently suffering and will not improve with time.*

*Taking all of the above into consideration, namely the expected impossibility of weaning from ventilation, the lack of recovery from the current neurological limitations and the impact of the current therapy on the quality of life of [minor], supported by the various second opinions and CMEA, lead to the unanimous decision by all those present that the current treatment is medically pointless and that it is therefore not justified to continue the treatment."*

2.16. In view of the outcome of both second opinions, the AZM has made a definitive decision to discontinue the ICU treatment, effective 23 April 2025. In a conversation with the parents of [minor], the AZM stated that the treatment team did not consider it responsible to continue the treatment for much longer.

2.17. [name of pediatric neurologist] (pediatric neurologist at AZM) stated the following on May 23, 2025: **7**

*"(…). [Minor] is not expected to make any significant recovery and further deterioration is to be expected in the event of a new, even mild infection. This results in a hopeless and uncomfortable situation. [Minor] is suffering greatly from the current supportive treatment that is keeping her alive artificially. Even before her current admission, [Minor] was anxious when she came to my outpatient clinic. In addition, she now undergoes several necessary procedures such as suctioning, but also the normal care moments during which she is uncomfortable and anxious. Even at times when nothing needs to be done, we often see her crying/being anxious. In addition, there are times when she is awake and suddenly has problems with mucus that she cannot swallow or cough up. She literally chokes and has acute fear of death. We cannot adequately treat these moments of anxiety with medication. If such intensive IC treatment serves to create a bridge to the recovery of functions, it is proportionate, but this recovery is not expected in [Minor]. In the Netherlands, children with progressive muscle weakness non-invasive continuous ventilation. At the time of the decision to intubate, there was no diagnosis. Therefore, the decision to intubate and start ventilation was the only option. The diagnosis came shortly thereafter, which is why the decision to intubate turned out to be undesirable in retrospect. However, this decision at that time cannot be reversed. The decision of the past few weeks to continue ventilation for the time being in a situation in which intubation in the Netherlands is not medically useful and therefore considered unacceptable. As a department of child neurology, we believe that continuing the current policy with ventilation is medically pointless and not in the interest of [minor]. (…)."*

2.18. [name of pediatric intensivist 3] (pediatrician/intensivist at the AZM) states the following in a report dated May 23, 2025 **8 :**

*"(…). At this moment, [minor] is still on a ventilator because she is still too weak to take proper breaths. As a result of this muscle weakness, she cannot cough or sigh and mucus must therefore be sucked out by the nurses, which means she has an increased risk of pneumonia and collapse of parts of the lung. This has already happened twice since the end of February, whereby we were able to improve the picture by intensifying the ventilation and antibiotics. In addition, the mucus also causes moments of airway obstruction, whereby the nurses are sometimes unable to easily suck out the mucus. For [minor], this gives a feeling of suffocation and leads to a decrease in oxygen levels and, if this is severe, also to loss of consciousness due to the lack of oxygen. Since it is expected that there will be no significant recovery, [minor] will remain completely dependent on ventilation, the risk of pneumonia and collapse of parts of the lung will remain and she will continue to feel suffocated at times.(…)."*

2.19. Nurse [name of nurse 1] made the following statement about [minor]'s state of mind: **9**

*"(…). During actions such as sucking, washing, turning, changing diapers and taking blood, you noticed that she became sad and anxious. The signs of anxiety and sadness in [minor] are generally, high heart rate, sweating, crying, dull look in her eyes, angry look and shaking her head no.*

*Given that [minor] is largely paralyzed, these signals are subtle but certainly readable. Especially considering that we as a nursing team have been providing care for a long time. What also became a sign was her closing off for us as nurses when she knew that we were going to care for her, for example. She would then close her eyes, no longer respond to anything, not even when you tried to entice her to open her eyes, for example by*

*doing something she likes. Like dancing and acting a bit crazy. She only opens her eyes again when she knows that you have finished the unpleasant procedure. (…).”*

2.20. Nurse [name of nurse 2] stated the following: **10**

*“I did not know [minor] before intubation, after intubation I saw a girl quite comfortable due to sedation, with an occasional smile. After a few weeks I saw her smile less and less and she could clearly indicate that she did not want care and nursing actions, she did this by shaking her head and crying.*

*During reading and music of the cliniclown I saw no emotions, but when it was over she started to cry. She often closes her eyes and it is difficult to get in touch with her.*

*She regularly had difficult periods due to desaturations. You could see the panic in her eyes.*

*She likes it when her mother is present, you can see that she enjoys her mother's attention. Mother is not always available for [minor]. If her mother does not give her attention, she seems desperate.”*

2.21. Nurse [name of nurse 3] states the following: **11**

*“(…). I myself have experienced few acute incidents with [minor]. I can report little about this. But I mainly remember the continuous consideration, to assess whether [minor] was suffering from discomfort. I could read few facial expressions from her face. Think for example of grimacing, frowning, making movements with arms and legs… I was not able to determine these movements/facial expressions. She could only grab objects with her hand/fingers. The parents could not always answer when I asked whether they could assess whether [minor] was satisfied/dissatisfied. I often got the answer from dad (who only has a limited command of Dutch) to the question whether [minor] was comfortable 'Maybe yes, maybe not…'.*

*I often asked [minor] to try to communicate with me, by keeping her eyes open for a 'yes' answer, or closing them for a 'no' answer. I did not get a clear response to this. I could therefore not derive a clear answer from it. Her young age also makes it difficult to communicate with her in this way. I am convinced that [minor] has full awareness. She often followed me with her eyes when I walked through the room, did things, and kept a close eye on everyone who came in, without her attention seeming to wane.*

*[minor] suffered a lot from salivation. Which later seemed to decrease somewhat. As a result, her mouth often had to be suctioned/cared for. She really didn't seem to like this. I felt increased muscle tension in her mouth, her eyes were often wide open and sometimes tears flowed from her eyes. I also noticed the same non-verbal signals more often, when she had to be suctioned endotracheally. I also saw this more often when she was in a toggle position, and tube stimulation occurred. I remember a moment when she had to be suctioned acutely, and [minor] started crying really hard during the intervention. Big tears rolled down her cheeks and she looked me straight in the eye... Mom also saw this and had to cry. (…).”*

2.22. Nurse [name of nurse 4] states the following: **12**

*“[minor] has different types of behavior, she can be very cheerful and likes games, acting crazy, enjoys songs, really likes personal care like painting nails, she likes coloring.*

*However, she can also be very sad and then cries with big tears, by asking short closed questions you usually find out what she means, you see frustration if we don't find out what's wrong, she then has an angry look or closes her eyes (ignore)*

*She cries when she says goodbye to mommy and daddy, you can reassure her by explaining that they will come back after her nap.*

*[Minor] usually finds the suctioning very unpleasant and pulls a worried face.*

*Caring for the cannula and brushing her teeth is also an unpleasant task for her, she also shows this by crying.*

*Over time you get to know [minor] better and you can gauge how she reacts to*
*actions or activities, by asking parents you can anticipate more on what they like or don't like.”*

2.23. Nurse [name of nurse 5] states the following: **13**

*"I have been caring for [minor] regularly over the past few months (especially for the cannula placement)*

*I see a girl who is completely dependent, who cannot perform any movement independently except for her fingers, which she can move minimally, and her head, which she can move from one side to the other (shaking no). [Minor] does not like being washed and having her teeth brushed. She then closes her eyes and lets it happen "resignedly". When the care is finished, you can make her laugh with some nonsense. She likes to watch daddy Pig on the iPad. She enjoys it when the clinic clowns come and [name 1] plays the guitar for her. When they leave again, she cries (tears run from her eyes). She likes it when her mother is busy with her, but does not like it when the attention goes to the baby.*

*"During the recording I found her to be more depressed, but only with distraction did I manage to bring a small smile to her face."*

2.24. Nurse [name of nurse 6] states the following: **14**

*"I have been caring for [minor] and her parents on a regular basis recently.*

*She was given a cannula and after that it was not possible to mobilize her properly for a while. She needs continuous ventilation and the mucus in her lungs often has to be sucked out, which [minor] finds unpleasant, but really has to be done. [minor] is given a toggle position, but is also put upright and occasionally sits on the lap of one of the parents. Her body is very limp, and she occasionally moves a hand. She slumps to one side if you do not support her and has no trunk balance.*

*You can tell from her facial expressions whether she likes something or not. She shakes her head no, and blinks her eyes to say yes. Over the weeks I think you can see more and more often that she doesn't want something. She smiles less and closes her eyes more and more often when she doesn't want contact with you. When you are caring for her it is really clear that she doesn't like this, she cries or has a sad facial expression. But even if you don't do anything with her she closes herself off, cries and has bad days. [minor] cannot indicate what she wants and how she wants something. (…)."*

2.25. Nurse [name of nurse 7] states the following: **15**

*"(…). How is the course over time….*

*A few weeks ago she received immunotherapy, it seemed that she made small movements with her hands and feet but this was only for a short time. Despite the fact that we do a lot with her in terms of exercises together with physiotherapy, the situation remains unchanged and I have not seen any progress in her movements lately.*
*Age-related she understands more and she increasingly clearly indicates what she wants and does not want by nodding or with her eyes (this only makes the situation more difficult) (…)."*

## 3 The dispute

3.1. The parents of [minor] state that they do not want [minor]'s ventilation to be stopped, as it would be unacceptable to them if that were to happen. According to them, there is still enough life and vitality in [minor] to continue to hold on to life. It is not yet sufficiently clear to the parents of [minor] whether and when medical (curative) treatment can be initiated. They do not want to anticipate this. According to them, [minor] is also not suffering.

3.2. The parents of [minor] do not want to decide for their daughter whether the treatment should be continued; they want to give their daughter the time and space to make her own decision.

3.3. The parents of [minor] further point out that according to their (Islamic) religious beliefs, stopping the medical treatment is not accepted as long as [minor]'s heart is still beating. For them, it is an impossible decision to actively cooperate or to agree to the termination of their child's life. They dispute that the treatment is

medically futile. They believe that [minor] still has enough joy in life that her life should not be ended. The parents accept that this may be a long-term process, but according to them that is no reason to stop the medical treatment.

3.4. The parents of [minor] claim on the basis of the above that the interim relief judge, by judgment, to the extent possible enforceable provisionally and to the minute, insofar as the law permits:

1. prohibits the AZM from stopping the medical treatment – in particular the artificial respiration – of [minor], and therefore orders the AZM to continue this medical treatment in accordance with the medical treatment agreement in force between the parties or to transfer [minor] to a nursing clinic so that she can continue to be treated there, with an order that the AZM make its full efforts and cooperate in this regard;

Subsidiarily:

2.
prohibits the AZM from stopping the medical treatment – in particular the artificial respiration – of [minor] for a period of six months, starting from the date of the present judgment, or at least a period of time to be determined by the interim relief judge in good justice, so that [minor] is given the opportunity to investigate (or have investigated) whether there are real possibilities of being transferred to a (children's) nursing home in the Netherlands, or to make a transfer of [minor] to the hospital in Egypt, where her sister is staying, possible.

More subsidiary:

3. makes a proper provision which the interim relief judge deems appropriate;

4. orders the AZM to pay the costs of these proceedings.

3.5. The AZM is defending itself.

3.6. The parties' positions will be discussed in more detail below, insofar as relevant.

**4 The assessment**

*Introduction*

4.1. By way of introduction, the following. Behind these summary proceedings lies a human drama in which [minor], a girl who is only three years old and suffers from a rare and incurable disease, is central. The suffering and sorrow of her parents about this and the concerns they have about the future of their daughter are therefore very understandable. The AZM wants to stop the medical treatment and artificial respiration of [minor]. It is now up to the interim relief judge to assess this decision, contested by the parents of [minor], on its legal merits.

4.2. For this, under '2. The facts', extensive quotations have been made from letters, reports and statements. For the sake of readability, these quotations have been partly or abbreviatedly repeated in the following assessment, so that they recur in various places in this judgment.

4.3. There is also repetition in the discussion of the arguments of the parents of [minor], as these arguments intertwine and overlap at some points.

*Urgency*

4.4. The parties agree on the urgency of this procedure. Also ex officio, the urgency of the present case arises from the nature of the case.

*The primary request for a ban on stopping ventilation*

4.5. The interim relief judge will first consider the primary claim made by the parents of [minor], namely a ban on the discontinuation of [minor]'s medical treatment, in particular artificial respiration, and an order that the AZM continue this medical treatment.

4.6. The AZM opposed this and, in short, took the position that continuing ventilation of [minor] is medically pointless and should therefore be discontinued. This position, according to the AZM, is a medical judgment, and the decision to discontinue ventilation of [minor] is in principle reserved for the treating physicians, with the judge having only a limited margin to review that judgment.

1. *Marginal or full assessment?*

4.7. The interim relief judge will first address the question of whether the judge should only marginally review the medical decision that there is medically futile action on the basis of which the ventilation of [minor] must be stopped, as stated by the AZM.

4.8. The parents of [minor] take the position that the intention of the treating physicians to stop treating [minor] should not be subject to a marginal review, but that a full review should take place. Given the exceptional circumstances of this case, such a review is justified, according to them, because it concerns a very young child who is also fully conscious; moreover, as the interim relief judge understands the position of the parents of [minor], it concerns a very rare condition about which relatively little is known. According to the parents of [minor], this cannot be compared with the cases in the cited case law **16** , in which the question is also always whether the physicians are allowed to stop treatment, but in those cases, according to the parents of [minor], it often concerns "greenhouse plants", patients who are in a vegetative state. In other words, the parents ask the interim relief judge to make an "independent" **17** judgment. This also fits, according to the parents of [minor], in a democratic constitutional state in which it is ultimately up to the judge to rule on (in this case) disputes between private parties.

4.9. However, the interim relief judge cannot take that step. After all, the implication of this would be that the judge would be taking the doctor's place and would have to make a substantive medical decision in this case himself. The judge would then be required to have a certain expertise that he does not have. The interim relief judge is therefore of the opinion that in this case too, the decision of the treating doctors at the AZM to stop the treatment of [minor] must be tested marginally, despite the exceptional circumstances in this case. Only if the treating doctors acted in such a way that, when weighing up all the interests involved, they could not reasonably have reached the contested decision - this must then concern obvious cases - is there room for the judge to intervene within the democratic constitutional state (mentioned in this context by the parents of [minor]) and can the judge exercise his safety net function in cases such as this within that constitutional state.

4.10. The treating physician therefore has his own responsibility, which is determined by law, in particular article 7:453 BW and article 7:465 paragraph l and paragraph 4 BW, and various guidelines and rules of conduct that the physician must adhere to. The interim relief judge reiterates that the fact that in this case it concerns a very young child who has a very rare condition and is fully conscious, is insufficient reason to deviate from the principle that the actions of the treating physicians must be marginally reviewed. However, this must be a reason, which is also fully acknowledged by the AZM, to very well substantiate the medical judgment that there is a medically futile action on the basis of which the ventilation of [minor] must be stopped.

4.11. In light of the foregoing, the interim relief judge will marginally review the AZM's decision. In doing so, the interim relief judge will address the question of whether the AZM could reasonably have reached the contested decision when weighing all the relevant interests. In doing so, the interim relief judge will discuss the various arguments that the parents of [minor] have put forward to ensure that the AZM continues to ventilate [minor].

2. *Medically futile action or not?*

4.12. An important argument of the parents of [minor] to contest the decision to stop the ventilation of [minor] is that according to them there is no medically futile action. They base this on the criteria included in the most recent edition of the Handbook for Health Law **18** to answer the question when medically futile action occurs. According to the parents of [minor], the AZM has not met these criteria. These criteria are as follows:

a. the action does not contribute to the solution of the medical problem or the maintenance or improvement of the patient's medical condition, or cannot reasonably result from it. Maintenance of the medical condition generally takes place with a view to future improvement or to allow the patient to continue living in the same medical condition;

b. the means to be used are not in reasonable proportion to the objective. Instrumental proportionality is not present if a disproportionately heavy medical procedure must be used to achieve a relatively advantage. The pain to be caused must also be taken into account in the considerations of instrumental proportionality;

c. a certain minimum level can no longer be achieved. Due to the nature of the disease or defect, the patient is very seriously affected or violated and medical action can do little or nothing to improve this, or there is a tragic situation due to the accumulation of conditions and defects, which with a disproportionate effort may each be treatable, but together as a whole not or hardly at all.

4.13. The parents of [minor] state that the treatment of [minor] has a positive effect. [minor] can move her hands and wrists again (to some extent). Given the limited available knowledge, the parents of [minor] believe that it cannot be judged that the treating physicians could reasonably have reached their controversial decision. After all, it is impossible to state with certainty that the medical condition of [minor] will or will not improve. It could just as well be that her condition does improve. Furthermore, the proportionality of the actions (i.e. artificial respiration) cannot be assessed. The 'severity' of the treatment is in reasonable proportion to the goal intended by the parents. Finally, the parents of [minor] state that [minor] is fully conscious and that she triggers the ventilation herself and breathes herself. [name pediatrician-intensivist 1] and [name pediatrician-intensivist 2] from the Radboudumc and the EMC respectively report during the physical examination of the vital functions of [minor] that she makes good contact, can follow simple instructions and can answer yes/no questions by closing her eyes when she wants to say 'yes'. According to the parents of [minor], this is a great improvement compared to the previous months.

4.14. The interim relief judge considers that the criteria on which the parents of [minor] rely are generally accepted and that they are also used by the AZM to substantiate their decision that there is medically futile action. The interim relief judge will therefore also apply those criteria.

4.15. The interim relief judge considers that it follows from (also already mentioned) case law and literature that medical treatment must always be justifiable. **19** This justification must lie in a certain interest of the patient. If a treatment is no longer in the interest of the patient, this is a case of medically futile action. Medically futile action is not permitted according to the guidelines by which the physician must act. A physician cannot therefore be obliged to (continue) medical treatments that no longer serve a medically meaningful purpose. **20** The interim relief judge is of the opinion that it follows from the statements of the treating physicians, the content of the *second opinions* , the advice of the CMEA and the content of the scientific article that it is highly likely that no improvement in the state of health of [minor] can be expected. The treating physicians do not doubt that the state of health of [minor] will deteriorate further. They rightly state that a decision to treat [minor] must be able to be based on valid arguments and not on hope, however understandable and distressing it is that [minor]'s parents want to hold on to that spark of hope. Although the condition from which [minor] suffers has apparently not yet been extensively documented in the medical world, it is plausible that the treating physicians can make a reasoned prediction about the expected course of [minor]'s condition on the basis of comparable, well-documented conditions.

4.16. The foregoing is supported, among other things, by the following letters, reports and statements (see also above under '2. The facts').

4.16.1. The following is included in report **21** of the multidisciplinary consultation in the AZM, drawn up on 12 March 2025 (see also paragraph 2.8):

*"1) Both the group of pediatric neurologists and pediatric intensivists agree with a do not resuscitate policy. There is a poor prognosis based on deterioration in the clinic (increased hypertension, bradycardia), insufficient improvement in combination with the found RCC1 mutation.*

*(...)*

*There are no other treatments for [minor]. With regard to possible long-term ventilation (tracheal cannula), the pediatric neurologists and pediatric intensivists agree that this is not desirable in the case*

*of a poor quality of life. (…).”*

4.16.2. On 24 March 2025, the situation of [minor] was discussed in the CMEA (see also paragraphs 2.10 and 2.11 above). The situation of [minor] was compared with the situation of patients with a very high spinal cord injury and with the lock-in syndrome by some care providers. The members of the CMEA concluded the following: **22**

*“Given the limitations in functioning and existence that treatment outside the hospital will entail, this treatment will also not lead to a minimum quality of life. This quality of life will also continue to decrease with each new incident (e.g. an innocent infection that children often suffer from). This does not allow for any scenario in which one can speak of medically meaningful action.”*

4.16.3. [name neurologist 1] and [name neurologist 2] from the EMC concluded in the context of the *second opinion* obtained by the AZM (see also paragraph 2.12 above): **23**

*“(…) With this diagnosis, there is only a very limited possibility of improving the nerve function and thus the strength of [minor]. In addition, there is a high chance of the disease worsening with a subsequent infection. The condition of [minor] (and possibly also her sister) was described for the first time very recently and unfortunately there are no treatment options aimed at the underlying cause.*

*Considering that we expect that [minor] will no longer be able to breathe independently, swallow food or saliva, speak, move independently or have active hand function, we see no indication for chronic home ventilation. For a child of her age, it is essential to be able to feel, move and communicate in order to learn and participate. We expect that [minor] will no longer be able to achieve this. In addition, she will experience more infections that could trigger further deterioration. Based on the above arguments, we believe that continuing the current respiratory support for a long period of time is not in the interest of [minor]. (…).*

*We expect that there is a significant risk that [minor] will end up in a resuscitation setting if he deteriorates further due to autonomic dysfunction. We do not consider this to be reversible and therefore it is not in the interest of [minor] to perform cardiac resuscitation.”*

4.16.4. On April 8, 2025, [name of pediatric intensivist 1] and [name of pediatric intensivist 2] concluded (see also paragraph 2.13 above): **24**

*(…). 3-year-old girl with worsening of her severe axonal polyneuropathy, most likely due to RCC1 mutation, and only minimal recovery during more than 1 month of invasive mechanical ventilation. There are no treatment options and the chance of recovery is very small. Long-term and invasive support of the ventilation by means of invasive ventilation, accompanied by discomfort with no recovery of the underlying picture is disproportionate. In this we support the decision of the MUMC+ medical team to discontinue long-term invasive mechanical ventilation.”*

4.16.5. The report of the multidisciplinary consultation of 15 April 2025 (see also paragraph 2.15 above) contains the following: **25**

*“(…). Based on the current ventilation conditions in combination with the knowledge gained about the underlying disease, after consultation with the authors of the article, it is unlikely that [minor] can be weaned off ventilation. There is complete consensus on this among all those present. Patients with an RCC 1 mutation show that it is a progressive disease, triggered by repeated new infections. Recovery between infections is limited, with (complete) recovery to the pre-existing situation being virtually impossible. It is likely that a new period of illness will again lead to further neurological deterioration. This knowledge, combined with the very limited progress that [minor] has shown in the past 6 weeks and the high degree of dependence on intensive medical necessary support prior to the current period of illness, ensures that all those present do not consider it realistic that there is a possibility of recovery. Given that the burden of small but necessary medical procedures, such as suctioning and care, has a major impact on the comfort of [minor], all those present estimate that [minor] is currently suffering and this is not will improve with time.*

*Taking all of the above into consideration, namely the expected impossibility of weaning from ventilation, the lack of recovery from the current neurological limitations and the impact of the current therapy on the quality of life of [minor], supported by the various second opinions and CMEA, lead to the unanimous decision by all those present that the current treatment is medically pointless and that it is therefore not justified to continue the treatment."*

4.16.6. [name of child neurologist] stated the following on 23 May 2025 (see also paragraph 2.17 above): **26**

*"(…). In [minor] there is no expectation of significant recovery and further deterioration is to be expected in the event of a new, even mild infection. This results in a hopeless and uncomfortable situation. (…) If such intensive IC treatment serves to bridge the gap to recovery of functions, it is proportionate, but this recovery is not expected in [minor]. In the Netherlands, children with progressive muscle weakness are not invasively ventilated continuously. At the time of the decision to intubate, there was no diagnosis. Therefore, the decision to intubate and start ventilation was the only option. The diagnosis came shortly thereafter, which is why the decision to intubate turned out to be undesirable in retrospect. (…) As a pediatric neurology department, we believe that continuing the current policy with ventilation is medically pointless and not in the interest of [minor]. (…)."*

4.16.7. [name of pediatric intensivist 3] stated the following in a report dated May 23, 2025 **27** (see also paragraph 2.18 above):

*"(…). At this moment, [minor] is still on a ventilator because she is still too weak to take proper breaths. As a result of this muscle weakness, she cannot cough or sigh and mucus must therefore be sucked out by the nurses, which means she has an increased risk of pneumonia and collapse of parts of the lung. This has already happened twice since the end of February, whereby we were able to improve the picture by intensifying the ventilation and antibiotics. In addition, the mucus also causes moments of airway obstruction, whereby the nurses are sometimes unable to easily suck out the mucus. For [minor], this gives a feeling of suffocation and leads to a decrease in oxygen levels and, if this is severe, also to loss of consciousness due to the lack of oxygen. Since it is expected that there will be no significant recovery, [minor] will remain completely dependent on ventilation, the risk of pneumonia and collapse of parts of the lung will remain and she will continue to feel suffocated at times.(…)."*

4.17. In view of all of the foregoing, the AZM has met the three criteria mentioned and the interim relief judge is of the opinion that, on this point, the AZM could reasonably have reached the decision contested by the parents of [minor] that there was medically futile action, after weighing up all the interests involved.

3. *Is [minor] being deprived of the opportunity to benefit from future developments in medical science?*

4.18. Furthermore, the parents of [minor] have argued that stopping [minor]'s treatment implies that she is being deprived of the opportunity to benefit from a gene therapy that may be developed. In this regard, the following.

4.19. Medical science does not stand still, and fortunately, important progress is also being made in the field of gene therapy. It is possible that a therapy will be developed for [minor]'s condition in the near future and that it will subsequently appear that progress has been made more quickly than initially expected. However, it is impossible to predict whether and when such a therapy will become available. Nor has it been demonstrated that such a therapy can be expected in the foreseeable future. In this regard, it is important to note that the request for information, made by [name 2], (co-)author of the aforementioned scientific article, was not intended to develop a specific therapy together with the AZM, but only to gather information for the purpose of scientific research. It should be taken into account that the development of such a therapy is not expected to be able to repair the damage to [minor]'s health that has already occurred, namely serious damage to important nerves. The interim relief judge understands very well that [minor]'s parents feel that [minor] is being deprived of the opportunity to benefit from possible gene therapy and that they derive hope from this. However, the decision of the treating physicians of [minor] was motivated by the desire to spare her further and increasing serious suffering, while there is no prospect of improvement. Further treatment would mean that the AZM would be acting in breach of its legal obligation to act as a good healthcare provider.

4.20. The fact that the AZM, as the parents of [minor] state, has looked for a good chair for [minor] in which she can sit safely and comfortably, and that the AZM has asked Adelante to provide advice regarding

communication with and by [minor] does not mean that the AZM takes into account an improvement in the state of health of [minor]. This only concerns attempts to alleviate [minor]'s suffering as much as possible, where possible. Increasing the sedation cannot provide a solution either, contrary to what the parents of [minor] suggest (as a suggestion). Because [minor] has become accustomed to this and its effect has therefore decreased, the AZM has already changed the composition of the sedatives and has now reduced it. Moreover, increasing the sedation also has disadvantages.

4. *Is [minor] experiencing (hopeless) suffering?*

4.21. A further argument of the parents of [minor] is that according to them there is no question of the degree of suffering by [minor] as described by the AZM. They say that the suffering noted by the AZM are only observations of doctors and nurses, but have not been (objectively) established. They themselves do regularly see that [minor] feels comfortable. The following in this regard.

4.22. It is established that [minor] is unable, due to her age and serious limitations, to indicate whether she is suffering and, if so, to indicate the degree of her suffering, for example by rating it on a scale of 1 to 10 (where 10 indicates the highest degree of suffering). That suffering must therefore be determined on the basis of various observations by doctors and nursing staff. To that end, the following.

4.23. The AZM does not dispute that [minor] also has good days, but states that the general picture is bad and has deteriorated further since 19 August 2023, when [minor] was first admitted, and then in 2025. In this context, [name of pediatric intensivist 3] explained at the hearing that the bright spots noted by [minor]'s parents do not alter the fact that the extent to which [minor] experiences pain, suffering and stress can be determined on the basis of objective parameters, such as heart rate, blood pressure, saturation value, etc. In addition to these objective parameters, the doctors and nurses also observe with their own eyes that [minor] is suffering. These observations, unlike the objective parameters, are not measurable and in that sense not completely objective - after all, they are 'only' observations - but they are based on (often years of) experience and expertise in the field of pediatrics. In this context, it is illustrative that [name of pediatric intensivist 3] states that [minor] feels like she is choking, which sometimes causes her to lose consciousness:

*"(…). In addition, the mucus also causes moments of airway obstruction, in which the nurses sometimes cannot easily suction the mucus. For [the minor], this gives a feeling of suffocation and leads to a decrease in oxygen levels and, if this is severe, also to loss of consciousness due to the lack of oxygen. Since it is expected that no significant recovery will occur, [the minor] will remain completely dependent on ventilation, the risk of pneumonia and collapse of parts of the lung will remain and she will sometimes continue to feel like she is suffocating.(…).*

*Without reducing the sedation, she has become increasingly more awake and is now awake almost all day. Changing drugs and combining three drugs have not improved this picture. Because [minor] now has an almost clear consciousness, she is aware of all her limitations and actions that must be performed for good care. This causes stress, which manifests itself in crying, increased breathing and increased heart rate. We also see that [minor] is anxious during the actions and sad when her parents are not with her. Due to the muscle weakness and ventilation, she cannot talk, which means she cannot express herself verbally. And due to the muscle weakness of her arms and legs, she cannot physically respond to everything that happens, which is why we as the PICU team (doctors, nurses, physiotherapists, paramedics) believe that [minor] is suffering. (…)."* **28**

4.24. [name of child neurologist] speaks in this context of:

*"(…) She literally suffocates and has acute fear of death. (…)."* **29**

4.25. Several nurses have also stated about the suffering of [minor] as stated by the AZM (see paragraphs 2.19 to 2.25). For example, [name of nurse 5] stated: **30**

*"(…). I see a girl who is completely dependent, who cannot perform any movement independently except for her fingers, which she can move minimally, and her head, which she can move from one side to the other (shaking her head no). [Minor] does not like being washed and having her teeth brushed. She then closes her eyes and lets it happen "resignedly". When the care is finished, you can make her laugh with some nonsense. She likes to watch daddy Pig on the iPad. She enjoys it when the clinic clowns come and [name 1] plays the*

*guitar for her. When they leave again, she cries (tears run from her eyes). She likes it when her mother is busy with her, but does not like it when the attention goes to the baby.*

*"During the recording I found her to be more depressed, but only with distraction did I manage to bring a small smile to her face."*

4.26. In view of this, and in particular the combination of the objective measurement data and the observations of the treating physicians and nurses based on experience and expertise, it is plausible that [minor] is suffering hopelessly.

5. *There is only one scientific article available*

4.27. The parents of [minor] further accuse the AZM of the fact that the decision to discontinue [minor]'s treatment was based only on one scientific article about [minor]'s clinical picture, the aforementioned *'Genetic risk of axonal neuropathy following Infection'* by [name 2] et al. **31** , in which the development of 24 patients suffering from the same condition as [minor] was followed. Of those patients, fifteen patients died between the ages of 11 months and 23. Nine of them are still alive, of whom one person is said to have recovered. It is not clear that [minor] will suffer the same fate as the fifteen deceased patients in any case. According to the parents of [minor], that article shows that there is no clear course in the patients examined. According to them, it is therefore impossible to predict how [minor]'s condition will develop in the (near) future. According to the parents of [minor], the article also does not justify the assumption that [minor] will deteriorate further. Given the uncertainty and the limited available knowledge about the genetic defect of [minor]'s condition, further research is appropriate.

4.28. The interim relief judge considers the following. It is incorrect that the decision of the AZM is based on a single scientific article. It is primarily based on the medical opinion of the treating physicians and subsequently substantively (fully) reviewed by physicians from the EMC and the Radboudumc who endorsed the decision of the AZM; in addition, the CMEA was involved in the decision, which concluded that no scenario can be imagined in which medically meaningful action can be said to have been taken. The authors of the scientific article in question also stated, after being asked by the AZM about their insights into the expected course of [minor], that the prospects are often very poor in general. They emphasize that nerve damage in this condition is permanent in most cases, and that the condition of patients deteriorates with subsequent infections. Recovery is exceptional:

*"Whilst the natural history of GBS* [Guillain-Barré Syndrome, addition of the preliminary relief judge] *tends towards recovery, almost all of the patients described in this cohort had limited clinical improvement, indicating permanent neuronal damage".*

Consultation between the AZM and the authors did not provide any new insights. To that extent, the article is one of the elements that ultimately and together with all other elements formed the decision of the AZM. Once again, the interim relief judge emphasizes that the function of the article must be kept in mind. It is not aimed at medical treatment, but at scientific research. The communication between [name 2], (co-)author, and the AZM must be viewed in that light. The comment by [name 2] that:

*"We would be happy to learn more about you family if they are agreeable and include them in a follow up paper – we have a lot of new interesting data"* **32** *,*

from which the parents of [minor] infer that extensive research is still being conducted with opportunities for [minor], is therefore insufficient to substantiate the claim that the decision of the AZM to discontinue ventilation of [minor] is unsound, more specifically that the AZM could not reasonably have reached its decision when weighing all the relevant interests. In this context, attention must be paid to the findings of the (several mentioned) treating physicians [name of pediatric neurologist] and [name of pediatric intensivist 3] (see above under '2. The facts') who have been involved in the treatment of [minor] for a long time and know her well from a medical perspective. The interim relief judge quotes (again) from the statement of [name of pediatric neurologist], who conducted the consultation with the authors:

*""(…). In [minor] there is no expectation of significant recovery and further deterioration is to be expected in the event of a new, even mild infection. This results in a hopeless and uncomfortable situation. (…) If such intensive IC treatment serves to create a bridge to recovery of functions, it is proportionate, but this recovery*

*is not expected in [minor]. In the Netherlands, children with progressive muscle weakness are not invasively continuously ventilated. At the time of the decision to intubate, there was no diagnosis. Therefore, the decision to intubate and start ventilation was the only option. The diagnosis came shortly thereafter, which is why the decision to intubate turned out to be undesirable in retrospect. (…) As a department of child neurology, we believe that continuing the current policy with ventilation is medically pointless and not in the interest of [minor]. (…).”* **33**

And [name of pediatric intensivist 3]:

*"(…) Since there is no treatment for the disease (…) and recovery is therefore not expected, there is no question of us bridging the gap with the ICU treatment. (…) That is why we as the PICU team still stand by our decision that this is a medically futile act and that we must discontinue the treatment.”* **34**

4.29. It is, moreover, very understandable and sympathetic that the parents of [minor] draw hope from the fact that the study by [name 2] et al. of a group of 24 patients with the same condition as [minor] shows that one patient has recovered. However, the hope that [minor] will also recover is, as is also apparent from the previous statements of the aforementioned doctors, not justified, because that patient had much milder symptoms than [minor], as [name pediatric intensivist 3] explained during the oral hearing. Given the serious clinical picture of [minor] that manifested itself at a very young age, and bearing in mind that the nerve damage suffered by [minor] is of such a nature that she will most likely no longer be able to speak, chew, swallow and cough, it cannot be expected that further treatment of [minor], including her artificial respiration, will yield any further benefit. Unfortunately, it is expected that, as can also be deduced from the statements given above, [minor]'s state of health will deteriorate further, partly as a result of unavoidable infections, resulting in increasing suffering for [minor]. In this context, the 'Stephen Hawking' argument of [minor]'s parents should also be considered. In this world-famous physicist, cosmologist and mathematician, who reached the age of 76, the disease (ALS) first manifested itself when he was an adult. As an adult, he was also able to make independent decisions. In his case, the disease also had a different course than in other ALS patients. In light of this, a comparison between him and [minor]'s situation is therefore difficult or impossible to make.

6. *The parents of [minor] do not want to decide about stopping ventilation*

4.30. As previously discussed, the parents of [minor] state that she is being deprived of the opportunity for possible future curative treatments and is being denied the right to life. As parents, they do not want to make the decision to stop the treatment. They believe that [minor] should be able to decide for herself whether her treatment should be stopped, so that moment should be awaited. Since she is not yet able to do so, it is up to her parents to decide.

4.31. With regard to the question of who decides on the discontinuation of medical treatment and ventilation, the interim relief judge considers the following. Contrary to what the parents of [minor] (seem to) state, the decision whether the medical treatment should be continued or discontinued is in principle, as also considered above, a medical decision. In other words, that decision is up to the treating physician and not to the parents – even though they have parental authority over their child – and in principle not to the judge either. This is evident not only from the provisions of Article 7:465 paragraph 1 and paragraph 4 of the Dutch Civil Code, but also from the (also already mentioned) case law and literature. Physicians cannot be forced to act in conflict with the statutory obligations and guidelines that apply to them. The physician must properly inform the patient or the patient's representative during the treatment and about major decisions such as discontinuing the treatment.

7. *The ECHR: right to life, right to 'family life' and right to freedom of thought, conscience and religion*

4.32. Furthermore, the parents of [minor] have invoked the treaty protection of Articles 2 (right to life), 8 (right to respect for private and family life, in short *'family life'* ) and 9 (freedom of thought, conscience and religion) of the European Convention for the Protection of Human Rights and Fundamental Freedoms (hereinafter: ECHR). To that end, the following.

4.33. The AZM has argued in response that the ECHR has no direct horizontal effect in the Netherlands and that the aforementioned rights, such as the right to *family life* , cannot generally be invoked in private-law

relationships such as the relationship between the parents of [minor] and the AZM. Furthermore, the contracting states, such as the Netherlands, have broad policy discretion with regard to allowing the discontinuation of medical treatment and the manner in which contracting states wish to balance the right to life with the right of patients to privacy and self-determination.

4.34. Although the AZM must concede that the ECHR has no direct horizontal effect in the legal relationship between citizens, which means that citizens cannot directly rely on provisions in the ECHR – in principle, the ECHR only applies in the relationship between government and citizens (vertical effect) – this does not alter the fact that such provisions can influence the legal relationships between citizens and thus have indirect horizontal effect. This indirect horizontal effect implies that although the ECHR is not directly applicable, it does influence the interpretation of national laws and regulations, whereby the spirit and intention of the ECHR can be taken into account.

*(Article 2 ECHR)*

4.35. In short, the parents of [minor] argue that withholding necessary medical care from a person in need of care or serious shortcomings in providing that care can, in appropriate cases, be regarded as a violation of Article 2 ECHR, as, as the interim relief judge understands, also in the case of [minor].

4.36. Although this statement raises the question whether this does not constitute a direct complaint about a violation of Article 2 ECHR – that line may not be drawn very clearly – the interim relief judge considers the following.

4.37. The interim relief judge states on this point that the treating doctors and nurses did everything in their power to preserve [minor]'s life. If they had not given [minor] the medical care they did, more specifically [minor] connected to the ventilator, [minor] would already have died a natural death.

4.38. The AZM has stated that it acts and has acted on the basis of Article 7:453 of the Dutch Civil Code. **35** This stipulates that a care provider must exercise the care of a good care provider in their work and must act in accordance with the responsibility incumbent on them, arising from the professional standard and quality standards applicable to care providers as referred to in Article 1, first paragraph, of the Healthcare Quality, Complaints and Disputes Act (Wkkgz). In the Wkkgz, the professional standard referred to in this article is understood to mean the entirety of private standards and rules, medical scientific insights and experiences that give substance to the professional conduct of care providers or care providers. Further elaboration of the responsibility referred to in the article is given, among other things, in the KNMG's position statement 'End-of-life decisions' from 2021. **36** This sets out three criteria that are very similar to the criteria mentioned above in recital 4.12 from the aforementioned Handbook of Health Law. According to the KNMG position, medically futile action occurs if (1) the expected effect of the treatment is insufficient (effectiveness), (2) there is no longer a reasonable relationship between the intended goal and the resources to be deployed (proportionality) or (3) it is no longer possible to achieve an intended minimum level of functioning. Furthermore:

*"There is often a grey area, in which a discussion with the patient or his/her relatives can arise about whether there is medically futile action. The judgment about medically futile action is ultimately a medical-professional judgment and it is the duty of the physician to refrain from medically futile action. A patient and/or his/her relatives cannot demand that the physician perform actions that are medically futile. (…).*

*Not starting or stopping treatment that is judged to be medically futile is normal medical practice. If a patient subsequently dies as a result of the underlying condition, it is considered a natural death.*

4.39. In the balancing of interests to be made by the national court, the interim relief judge considers the following. The interest of the AZM that its actions must always be justified, in this case in the interest of [minor] – her interest is central, it must be emphasized – and that in the absence of such justification the medical action must be stopped, must, in the opinion of the interim relief judge, outweigh the – undiminished – interest of [minor] to live, even if that is a life below the required minimum level. In this context, the interim relief judge considers it important that continuing with medical action would only result in prolongation of suffering or prolongation of the dying process. In terms of its purpose, the medical action would then be the opposite. It can even make dying undignified or more undignified than necessary. Pointless prolongation of death is an infringement of someone else's right to die. **37**

4.40. In light of the foregoing, it must therefore be concluded that Article 2 ECHR, insofar as it concerns the decision of the AZM to discontinue ventilation of [minor], does not shed any other light on the legislation and regulations applicable in the Netherlands, i.e. Article 7:453 BW ca and Article 7:465 paragraphs 1 and 4 BW, and therefore does not require an interpretation thereof such that the interim relief judge must prohibit the AZM from discontinuing ventilation of [minor]. **38**

*(Article 8 ECHR)*

4.41. The parents of [minor] further state that, if the AZM unilaterally decides to discontinue treatment, their fundamental right to *family life* (Article 8 ECHR) will be violated. They state that interference is only permitted by law or is necessary in a democratic society in the interest of the grounds mentioned in paragraph 2 of that article. None of these grounds play a role in this case, according to the parents of [minor], and therefore a violation of this right cannot be justified in this case. Moreover, according to the parents of [minor], there is no medically futile action and therefore the right to *family life* prevails over the assessments of the medical team of the AZM.

4.42. Leaving aside the fact that here too a direct appeal seems to be made to a provision of the ECHR, this position cannot be endorsed either. The interim relief judge has already considered in detail that there is medically futile action. In light of this, the interest of the AZM to provide good care – it is generally accepted that normal medical action also includes ending medically futile action – prevails over the right to *family life* asserted by the parents of [minor] . **39**

4.43. Also with reference to what the interim relief judge has considered above with regard to the right to life, it follows from the foregoing that Article 8 ECHR does not require an interpretation of Article 7:453 BW and 7:465 paragraphs 1 and 4 BW in such a way that AZM should be prohibited from stopping ventilation of [minor].

*(Article 9 ECHR)*

4.44. The parents of [minor] would also like to point out that in their religious beliefs, stopping medical treatment is not accepted as long as [minor]'s heart is beating. This right, according to the parents of [minor], is absolute. The right to freedom of religion and thus, among other things, to observe commandments and regulations – including the obligation to continue [minor]'s medical treatment as long as her heart is beating – can only be restricted by law or to protect the rights and freedoms of others. Since there are no grounds whatsoever to restrict the right to freedom of religion in this case – after all, it concerns the continuation of [minor]'s medical treatment – her ventilation cannot and may not be stopped.

4.45. Here too, the interim relief judge notes that the decision of the AZM to stop the treatment of [minor] is a medical decision that is reserved for the treating physicians. This is therefore not a decision that requires the consent of the parents of [minor], not even as her legal representatives (see also Article 7:453 BW and 7:465 paragraph 1 and paragraph 4 BW). In light of this, it cannot be accepted that the parents of [minor] do not have the freedom to adhere to and express their religious beliefs. The fact that they are confronted with a decision to stop the treatment of [minor] that is contrary to their religious beliefs does not mean that their freedom of religion is thereby infringed.

4.46. The foregoing means that the arguments of the parents of [minor] must also be disregarded on this point.

4.47. The primary claim will therefore be rejected, also with regard to the requested ban for a period of six months, given that the AZM had initially decided to stop the ventilation on 23 April 2025.

*The subsidiary request for a ban on stopping ventilation for a period of six months in order to investigate the possibilities of transfer to a (children's) nursing home in the Netherlands or a hospital in Egypt*

4.48. In the alternative, the parents of [minor] have requested that the AZM be prohibited from discontinuing ventilation for a period of six months, so that this time can be used to investigate the possibilities of transferring [minor] to a (children's) nursing home, more specifically Adelante, or to a hospital in Egypt, where the one-year-older sister with the same condition as [minor] is also staying. To this end, the following.

4.49. The email that Adelante sent to the AZM on 6 June 2025 **40** shows that Adelante sets ten conditions for admitting and taking over the care of [minor]. One of those conditions is that in the event of an incident or deterioration of [minor], she must be immediately taken back over by the AZM. In addition, one of the conditions is that the care management remains with the AZM and that the policy regarding medical care is determined from the AZM. The AZM, the interim relief judge considers, therefore remains ultimately responsible, even if the question is whether the treatment or ventilation of [minor] should be stopped. Moving [minor] to Adelante then in fact only means that the medical care of [minor] is provided elsewhere, but is still devoid of any medical justification. The interim relief judge also takes into account that [name pediatric intensivist 3] stated at the hearing that there is no ICU doctor and nurse present at Adelante. In view of this, this does not provide a solution to the dispute between the parties that underlies these summary proceedings.

4.50. Transferring the care of [minor] to a hospital in Egypt is also not an option. The AZM has argued, which has not been disputed by the parents of [minor], that it has not been demonstrated that this is possible, since the AZM has not succeeded in contacting that hospital despite several attempts to do so. The parents of [minor] also provide little information about this – concrete data from this hospital are lacking – which means that the interim relief judge has no starting points for this option. In addition, the parents of [minor] stated during the oral hearing that they wanted to focus on a takeover by Adelante, in response to the question from the interim relief judge about the possibilities of a takeover by an Egyptian hospital.

4.51. The subsidiary and further subsidiary claims will therefore also be rejected.

*Conclusion*

4.52. It follows from all of the above that the AZM, when weighing all the relevant interests, could reasonably have arrived at its decision to terminate the medical treatment of [minor] and to stop her ventilation. The AZM acted carefully and the treating physicians made and had to make this difficult decision in good faith, in which they had to acknowledge that the limit of what is medically possible and permissible has been reached. Given the legal frameworks given to the interim relief judge in this case, he endorses the decision of the AZM, however heartbreaking it may be. After all, the consequence of stopping the ventilation is that [minor] will die a natural death.

4.53. All claims will be dismissed. [plaintiffs] will be ordered to pay the legal costs as the unsuccessful parties. The costs on the side of the AZM are estimated at:

- court fee € 714.00;
- lawyer's salary € 1,107.00;

Total €1,821.00.

**5 The decision**

The interim relief judge:

5.1. dismisses the claims;

5.2. orders [plaintiffs] to pay the legal costs, on the side of the AZM to date estimated at € 1,821.00;

5.3. declares this judgment provisionally enforceable with regard to the award of costs.

This judgment was rendered by Mr. TAJM Provaas, interim relief judge, and pronounced in public. **41**

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1 Production 10 in conclusion of answer, p. 47-48

2 Production 10 in conclusion of answer, p. 63-64

3 Production 15 in conclusion of answer, p. 3

4 Production 17 in conclusion of answer, p. 4

5 Production 18 in conclusion of answer

6 Production 14 in conclusion of answer, p. 13-14

7 Production 27 in conclusion of answer

8 Production 28 in conclusion of answer

9 Production 29 in conclusion of answer

10 Production 30 in conclusion of answer

11 Production 31 in conclusion of answer

12 Production 32 in conclusion of answer

13 Production 33 in conclusion of answer

14 Production 34 in conclusion of answer

15 Production 35 in conclusion of answer

16 See District Court of Central Netherlands, 13 July 2018, ECLI:NL:RBMNE:2018:3428, District Court of Gelderland, 17 December 2018, ECLI:NL:RBGEL:2018:5765 and District Court of 's-Hertogenbosch, 29 March 2011, ECLI:NL:RBSHE:2011:BP9894

17 Oral hearing of 11 June 2025

18 Handbook of Health Law, 9th edition (2024), page 396.

19 See, among others, Almelo District Court, 1 July 1987, TvGR 1987/50, Arnhem Court of Appeal, 31 October 1989, TvGR 1990/18 and Supreme Court, 28 April 1989, TvGR 1989/51.

20 See HR 28 April 1989, TvGr 1989 no. 51 and Utrecht District Court, 12 October 1999, ECLI:NL:RBUTR:1999:AA3827.

21 Production 10 in conclusion of answer, p. 47-48

22 Production 15 in conclusion of answer, p. 3

23 Production 17 in conclusion of answer, p. 4

24 Production 18 in conclusion of answer

25 Production 14 in conclusion of answer, p. 13-14

26 Production 27 in conclusion of answer

27 Production 28 in conclusion of answer

28 Production 28 in conclusion of answer

29 Production 27 in conclusion of answer

30 Production 33 in conclusion of answer

31 The article in question has not been submitted by the parties as production. To the extent that the provisional relief judge quotes from it, the quotes come from the procedural documents of the parties themselves.

32 See previous footnote

33 Production 27 in conclusion of answer

34 Production 28 in conclusion of answer

35 In this regard, see also Article 7:465 paragraph 1 and paragraph 4 of the Dutch Civil Code (and the 'unless' provision)

36 https://knmg-standpunt (https://knmg-standpunt).maglr.com/knmg-standpunt-levenseinde/standpunt-levenseinde

37 See Handbook of Health Law, 9th edition (2024), pages 395-396

38 In a direct review by the ECtHR, the choice for *therapeutic abstention* would be tested against three principles: (1) the presence of a relevant legal framework; (2) the wishes of the patient and family, and the opinions of medical experts; and (3) the possibility of judicial intervention in case of doubt about what is in the best interests of the patient. It should be borne in mind that Member States have a wide margin of appreciation. These criteria

have been met for the Netherlands: (1) there is a legal framework, namely Article 7:453 BW ca and Article 7:465 paragraphs 1 and 4 BW, (2) the wishes of the parents of [minor] and the opinions of the medical staff have been extensively taken into account in the decision-making process and (3) the possibility of judicial intervention is provided for in Dutch law and in the present proceedings.

39 According to the ECtHR, interference is permitted on the basis of Article 8 paragraph 2 ECHR, insofar as provided for by law (Article 7:453 BW ca and Article 7:465 paragraphs 1 and 4 BW) and is necessary in a democratic society in (among other things) the interest of protecting health. In the Netherlands, a care provider can ignore the decision or opinion of a legal representative if this is incompatible with the care of a good care provider. This must be done with reasons, which was the case given the procedure followed by the AZM.

40 See production 36 sent by the AZM

41 type: MT