

**P-04-603 Helping Babies Born Under 22 Weeks to Survive –
Correspondence from the Petitioner to the Committee, 25.02.2015**

Petition Committee

Following the meeting on 24/2/15 the committee asked for an update on my meeting with Dr. Heather Payne on the 18/2/15. The meeting went well I expressed my own personal situation to Dr. Payne as well as other mothers who have had the same circumstances, which I am in contact with. I showed Mrs. Payne my evidence I have gathered and why I believe the guideline should be changed, she explained that she did not ask for me to meet her regarding changing the guideline as she is unable to do that herself but that is why there is need for the petition. What she wanted to meet me for was to set changes now, while I am fighting the guideline, she wanted to know what we could set in place for situations like my own for other mothers who will have premature babies and a percentage of them will have a baby born breathing before 23 weeks. I expressed my concerns to her about the poor care being received, that the guideline is not being used correctly and only being seen as a set guideline. I showed Mrs. Payne my solicitor files and the investigation report from the health board at heath hospital, she also received a copy of this for her own reading. It was to my understanding agreed that she would go back to meet her colleagues and express my personal case, for them to make arrangements and support for the future situations like my own. Mrs. Payne agreed to keep me informed on what they come with and what they can do, she will then ask my opinion and for me to meet her again to set something in place. I am waiting on contact from her in the meantime I have met chief executive Mr. Adam Caines at his office in headquarters, along with 4 hospital members such as a lead midwife, a doctor from neonatal, premature unit nurse and head of care and social. After a 90 minute meeting we discussed what to do, what can be changed for the care of premature babies born early and breathing. Again, Mr. Caines expressed he could not change the guideline right there and then but that the petition will focus on what I want to change with gestation but with him I could change something's anyway, to start off I was given an official apology on behalf on the health board for the care myself and riley received. This was appreciated and I am pleased to see they understand what happened was wrong. In owning up to this they want to set procedures in place for woman in my position from now on, they want me to help them with this as they said with me being through this I can help midwives understand and see the feels from a mum who has been through a premature loss. To make the midwives

prepared for this situation and how they'd deal with it, rather than just go by the guideline as its set but with procedures being made so they contact a head medical professional to see the baby and mother, to go through the possible outcomes with the parents. Over all they asked if I was happy to help the health board with procedures to be set in place and to give my opinion and ideas on these new procedure ideas. This was all recorded on tape and I will be sent my own copy next week.

I feel some success have come from these meeting for the time being and for the care of a baby and mother but I am still not receiving any offer of change in guidelines gestation, I need a procedure for babies born breathing to be given the chance of survival, for medical assistance to be given if after reviewed and agreed with parents for the baby to be given a chance, the options have to be given firstly and after checking the babies condition and what the possible outcomes can there be medical assistance to try and save that baby and to prepare the parents for the journey ahead once resuscitation is given. (Resuscitation meaning help to continue breathing)

I would like further information on the next steps for the petition and what we will do for the gestation age to be reduced to 22 weeks or an underlined guideline to be placed for when babies are breathing on 23 weeks and what actions should be taken when this occurs. I am happy to meet with Dr Heather. Payne as well as Mr. Adam Caines to take up their offers for procedures to be put in place, but I still need the guidelines to be changed or information to be added for babies after 22 weeks. I still stand by what I asked from the beginning and that is for each baby to born with signs of life to be given appropriate care and to be seen as an human being needing to be saved.

Emma Jones