



David Rees
Chair of the Health and Social Care
Committee
National Assembly for Wales
Tŷ Hywel
Cardiff Bay
CF99 1NA

Bae Caerdydd / Cardiff Bay
Caerdydd / Cardiff
CF99 1NA

Our ref: P-04-603

23 April 2015

Dear

Petition: P-04 -603 Helping Babies Born at 22 Weeks to Survive

The Committee has been considering the following petition from Emma Jones, which has collected 2,579 signatures.

We call upon the National Assembly for Wales to urge the Welsh Government to:

- *change the guidelines so that babies born after 22 weeks and who show signs of life are given appropriate medical care; and*
- *In changing these guidelines ensure that they include a guarantee that a Paediatrician will review and weigh every baby born after 22 weeks who shows signs of life immediately after their birth so that parents and clinicians can make informed decisions based on the individual baby's chance of survival.*

I attach copies of correspondence that the Committee has received on this matter from the petitioner and from the Minister for Health and Social Services. As you will see the issue revolves around current guidelines, which suggest that babies born before 23 weeks should only receive medical care in exceptional circumstances. In the petitioner's case, her child was born breathing and alive and lived for over an hour and a half. The petitioner claims that despite the fact – and this does not seem to be in dispute – that her son Riley was alive, repeated

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Croesewir gohebiaeth yn y Gymraeg a'r Saesneg/We welcome correspondence in both English and Welsh



requests for assistance and medical intervention were refused on the basis of the current guidelines.

You will note from the correspondence that the petitioner has now had the chance to meet senior Welsh Government medical advisers and with the Chief Executive and other staff from Cardiff and the Vale UHB. We understand that Ms Roberts has received an apology from the Health Board for the care she and her son Riley received. We have agreed to ask the Minister for Health and Social Services and the Local Health Board to provide an update on any work in hand to ensure that lessons are learned from this case for the future.

However, this case does appear to raise questions about the current guidance within which clinicians work and how that guidance is applied. As the Minister says in his most recent letter, whether medical assistance should be given to babies born alive and breathing before 23 weeks is both difficult and nuanced. He believes that these decisions are best made by clinicians in discussion with parents. We do not disagree with this as a general point. However, that is not to say that the current guidelines strike the right balance or that they should not be subject to public scrutiny to ensure that they remain appropriate.

The Petitions Committee would therefore like to ask your Committee to consider whether it should undertake a scrutiny inquiry into the guidelines on resuscitation and medical intervention for babies born prematurely before 23 weeks. While there is nothing to prevent the Petitions Committee from undertaking this work, the sensitivities involved and the expertise needed to look at this area are ones that seem more appropriate to the lead Scrutiny Committee for health matters. Given the far more limited time that we have available, it would also be unlikely that the Petitions Committee could devote the time necessary to do this sensitive matter the justice it deserves.

Please forward your response to the Clerking Team at:
SeneddPetitions@Assembly.Wales

Yours sincerely

William Powell AC / AM
Cadeirydd / Chair

ENCs:

- Minister for Health and Social Services to Committee Chair - 3 November 2014
- Petitioner to Committee - 18 November 2014
- Minister for Health and Social Services to Committee Chair - 31 January November 2015
- Petitioner to Committee Chair - 11 February 2015
- Petitioner to Committee Chair - 25 February 2015

Mark Drakeford AC / AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: MD/05424/14

William Powell AM
Assembly Member for Mid & West Wales
Chair Petitions Committee

Petitions@Wales.gov.uk

31 October 2014

Dear William,

Thank you for your letter of 15 October informing me of Emma Jones's petition in relation to the care of babies born after 22 weeks gestation.

As I am sure you are aware, the care of extremely preterm babies is extremely challenging and reviewed regularly as medical advances are made.

Health boards follow guidance from both the Royal College of Paediatrics and the British Association of Perinatal Medicine. Whilst the care of the mother and her baby will always need to be individualised, current guidance suggests that it would be considered in the best interests of the baby, and standard practice, for resuscitation not to be carried out. If the parents wish, they should have the opportunity to discuss outcomes with a second senior member of the perinatal team.

Best wishes,
Mark

Mark Drakeford AC / AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

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Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



Llywodraeth Cymru
Welsh Government

Ein cyf/Our ref: MD/05424/14

William Powell AC
Aelod Cynulliad Canolbarth a Gorllewin Cymru
Cadeirydd y Pwyllgor Deisebau

Petitions@Wales.gov.uk

31 Hydref 2014

Annwyl William

Diolch am eich llythyr dyddiedig 15 Hydref yn fy hysbysu am ddeiseb Emma Jones mewn perthynas â gofal babanod sy'n cael eu geni ar ôl cyfnod beichiogrwydd o 22 wythnos.

Fel y gwyddoch mae'n siŵr, mae gofal babanod cynnar iawn yn fater heriol iawn sy'n cael ei adolygu'n rheolaidd wrth i feddygaeth symud ymlaen.

Mae byrddau iechyd yn dilyn cyfarwyddyd gan Coleg Brenhinol Pediatreg a Chymdeithas Meddygaeth Amenedigol Prydain. Er bod angen rhoi gofal unigol i'r fam a'i babi bob amser, mae'r cyfarwyddyd presennol yn awgrymu y byddai er budd gorau'r babi, ac yn arfer safonol, i beidio â dadebru. Os yw'r rhieni'n dymuno hynny, dylai fod cyfle iddynt drafod canlyniadau gydag ail uwch-aelod o'r tîm amenedigol.

*In gywir,
Mark*

Mark Drakeford AC / AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

P-04-603 Helping Babies Born Under 22 Weeks to Survive – Correspondence from the Petitioner to the Committee, 18.11.14

Hello,

I sent you an email which is my response. I would like its seen as important and taken into the committee meeting. I also write a response to the health ministers letter which is underlined. Please take this as important also as i need resuscitation to be clearly understood, as the health minister havent looked into my petition properly as he has an opinion on something im not even asking for it the petition.

Thanks Emma jones

Emma Jones's statement for her petition being considered on Tuesday 25th November.

I will start by noting all the evidence and proof i have gained since starting my petition.

- babies born early should be given a chance to live, i am fighting for change so that babies born with any signs of life are given appropriate care and medical assistance if needed. I am not asking for resuscitation to be carried out, i am asking for assistance to a breathing living baby.
- Resuscitation is not what i am asking, a baby born with signs of life are alive not dead meaning resuscitation is not needing to be carried out.
- A baby is entitled to rights, there right to live. Any baby born and breathing must have help, not be left to die because he/she has been born early.
- There is enough medical help and treatment available to babies born so premature, every baby has the right to be given the chance.
- I know babies been premature can die, but i also know babies can survive. I have proof and success stories from parents who have been able to take their baby home after being born so early.
- It is LAW that each human has rights, when born and living in this world that individual has rights. A baby should never be left to die down to a guideline.
- Babies born before 24 weeks have been seen to do very well in the last 5 years, research and numbers have shown babies can survive and live normal lives when born so early.

- Some babies before 23 weeks have survived with no disabilities at all, other have survived but with minor/ severe difficulties. Unless the baby is given the chance no one will know that babies fate.

Personal experience

After suffering the loss of my first child at 22 weeks gestation, i learnt to cope and deal with my loss. My first son was still born and passed away during labour. Not once and would i ever had asked for resuscitation after my son had died. He was at rest and i would never had know what harm it would have done bringing him back. But, back in December 2012 i gave birth to my second son at the heath hospital wales. Not only was my son born breathing and alive, no one helped! he was said to be incompatible with life. As he was born just before 23 weeks. My son was alive and no assistance was offered even after begging and hoping for help. He was left to die because he was early, he live for 93 minutes with no help, breathed all on his own.

- Can anyone say if my son was helped he would not have survived for sure?
NO
- Can any medical professional tell me that my sons death was uncontrollable?
NO
- Could my son have lived? YES
- Will we ever know if he would be here today? NO

Many babies have died down to these guidelines being 24 weeks, at 22 weeks gestation a baby can near enough weigh the same or even more than a baby at 24 weeks. At 22 weeks a baby is strong enough to breath on its own for an amount of time, at 22 weeks babies have survived when been given the chance to live.

I am in contact with many parents who elsewhere have been lucky. There babies were chosen to be given the chance, their babies were lucky to have the medical staff that couldn't turn away this helpless little baby.

Lately, a number of stories have been coming out to the public on premature babies. Many families who have suffered a loss down to the guidelines have been speaking out, stories on a baby being helped before 23 weeks has been printed and shared. The numbers of babies surviving at such a low age have been rising and Wales are behind in the success of this.

Because they are not given the chance, i have documents and stories all available to share with you.

Documentaries have also been aired on premature babies, such as "miracle babies" a program behind small babies and how they get on. The number of babies in this series alone has struck the news and social media. In this one series alone 5 babies in total have survived and gone home to family. This is one of the best examples i can give you. This is proof smaller babies are surviving.

I am fighting for guidelines to change from 24 weeks gestation to 22 weeks gestation. I am fighting to change this knowing babies can survive at this age, but must be given the chance.

In response to the Health minister's letter

I am not sure you have looked into my petition properly, as stated on it title i am asking for help and assistance to be given to a baby born at or after 22 weeks if born with any signs of life. If a baby is born breathing it should not be left to die, as you stated resuscitation should not be carried out in the best interests of the baby. I fully agree with you that a baby who is dead should not be resuscitated. What i am asking is nothing to do with resuscitation and its guideline. I am asking for a living human being to have appropriate care and as much fight as possible to be kept alive.

This is as clear as i can be.

Please consider what i am asking in respect of parents and the babies being born into this world before their time.

We can be saving so many more, babies are dying for no reason.

Please look at what the people want, the parents and families who have to deal with losses that would have been prevented.

Thank you

Emma I jones

Mark Drakeford AC / AM
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services



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Welsh Government

Eich cyf/Your ref P-04-603
Ein cyf/Our ref MD/00088/15

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31 January 2015

Dear William,

Thank you for your letter of 9 January regarding Emma Jones's petition in relation to the care of babies born after 22 weeks gestation.

This is of course a very sensitive issue, and I am not aware of all the details of Emma Jones's case, beyond those she has provided in her letters. I would like to clarify my earlier comments to explain that clinically speaking resuscitation describes the need to support breathing where a baby is unable to continue breathing unaided. The details provided suggest that her child was unable to continue breathing independently and would therefore have required resuscitation, and that is why I referred to resuscitation in my previous letter.

To expand on my letter of the 31 October, whilst the care of the mother and her baby will always need to be individualised, clinicians are guided in their judgements by current guidance, in this case that would be the British Association of Perinatal Medicine and the Nuffield Council Guidelines. These guidelines are based on extensive evidence and set out current best practice, and they are reviewed and updated to take account of improvements in clinical care. Both guidelines consider that resuscitation of babies below 23 weeks should only be carried out in exceptional circumstances.

An appointment has been offered for Emma to discuss these issues with the Welsh Government Professional Adviser for Maternal and Child Health, Dr Heather Payne, but no response to this offer has so far been received. This offer of course still stands and I would encourage Emma to take up this offer. Of course, the clinicians involved in the delivery of

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Wedi'i argraffu ar bapur wedi'i ailgylchu (100%)

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Emma's baby would be best placed to discuss the precise issues relating to that birth, and the decisions made subsequently.

In response to your enquiry on behalf of the committee, as to whether "medical assistance should be given to babies born alive and breathing", my view is that for babies born before 23 weeks of gestation the position is both difficult and nuanced. I consider that decisions need to be made by the clinicians involved, in discussion with the parents whilst taking account of the current best guidance practice.

Best wishes,

Mark

Mark Drakeford AC / AM

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

**P-04-603 Helping Babies Born Under 22 Weeks to Survive –
Correspondence from the Petitioner to the Chair, 11.02.15.**

Chair of the Petitions Committee, William Powell

This is my response to the health minister Mark Drakeford's recent letter dated 31/01/15. I will start with saying I agree that this is a sensitive issue and this is the whole reason why I am asking for change. The guideline as it is set is not in the interest of the baby when the baby is born breathing, it is uncertain to say whether or not any baby born before 23 weeks will or will not survive but when it is born independently breathing it should be given the chance and not immediately left to die because of sadistic or seen as a percentage. There is no fact that that baby wouldn't survive, that baby could be the low percentage but no one will know until each baby is given that chance. If each baby born independently breathing at or after 22 weeks they should be seen as a full term baby, just because that baby has sadly been born early at no fault of its own does not mean it has any less right to be medically helped or have its rights taken away from them.

As the health minister has explained resuscitation is set on the guideline as to been seen by medical professionals as when a baby needs support to continue breathing, meaning the baby will need resuscitation to stay alive. If this is true then how long does a baby need to be independently breathing before given help? As the committee know the reason I began this petition was because of my personal loss, my son was born breathing at 22+3 days and breathing, he breathed independently for 83 minutes with no help. We were told he couldn't have any help because of his gestation, the fact that he was breathing was of no interest to them. No higher medical staffs were called apart from the midwives on that ward, no one came and discussed any options or the outcome with me. The midwives just referred to the guideline as it was set in stone.

What are exceptional circumstances? When is a baby seen as valuable enough to be helped? How long before help is given after a baby is born and struggling to stay alive. My son lasted 83 minutes but he was not seen as an exceptional circumstance for even the paediatricians to come down before he finally gave up!

As the minister states in his letter each mother and baby needs to be individualised. This is not the action taken in these hospitals, I was not individualised and neither was my son.

He says the situation will always need to be individualised by clinicians; they should be guided by current guidance. They are not seeing this guideline as guiding them but as a set guideline, they are not using it to make a decision for a baby but as that's how it is and that's its attitude. I know this from not only my own experience in the hospital but from parents contacting me with their stories on how their baby was treated and left to die. Since starting this petition I have been contacted various ways by families who have lost their baby from not being helped after being born before 23 weeks but breathing independently. I have all these saved and have the support of families for this petition. What is going on? How can all these babies before 23 weeks be left to die because of its age. If the baby is fighting for a chance the baby should be given help each time, it is that baby's decision whether or not it'll live not the midwives at that time of labour.

It is frustrating to hear the health minister say the guideline does include 'exceptional circumstances' what do these babies born breathing have to do to be an exceptional circumstance. What qualifies the baby chosen to be helped, to be given the chance that each baby should have. It is as if the guideline is a lucky baby guideline, one lucky baby gets chosen to be given help. My son was not even looked at, so how do we know he wasn't that baby who'd survive out of your percentage! Babies no matter how small should never be seen as a percentage.

For us parents who have suffered the loss of a premature baby in the hands of medical staff are taking a stand and I will not let other parents go through this in the future, our son like many others should not be seen as a possible death but as hope and hope that that baby survives. Until each baby is given that chance is born with signs of life we will not know which baby will pull through or which baby will sadly die but each needs the help to have that chance to be the baby that survives. Leaving a baby breathing to die is not in the best interest of the baby or the mother, the baby fights till the end and is given no hope and the mother will always wish the medical staff there that day helped her baby and why their baby wasn't chosen to be saved. I will be fighting for each baby to be that one baby given the chance of hope and medical assistance he/she needs. Leaving a baby to die is murder and there is no other word than letting a baby die other than that.

Emma Jones

Emma Jones
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25/02/15
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