I must say that the little Safe T Sleep™ Headwedge that we used has worked a treat and Ty's head shape is getting better and better. I used it for every sleep for a couple of months and really worked, so please thank Miriam for that!

Kindest regards Amanda Beets

Dear Miriam

Happy New Year. I am so sorry I haven't spoken to you for so long, the time seems to have flown by.

Well, I have finally got around to sending back your questionnaire which I filled out 2 months ago. I also have the measurements of my shrunk Safe T Sleep (after putting it in the dryer) to compare with the new one's size.

Madison is now 10 months old and her head shape is so improved no one can believe the speed with which it improved. Tristan de Chalain at Middlemore Hospital Plagiocephaly Clinic has now discharged her since she is symmetrical again. I will still keep her on her side all the time when I can but she can now roll over and likes her tummy during the day sleeps. Also she is 95% close to opening up the Safe T Sleep but it is holding firm so far.

The whole situation was so stressful for me and I really got very down about it thinking she would never come right. Thank you so much for all your help and support and thank you for Safe T Sleep without which Madison would look like a book-end forever.

I will be promoting it wherever and whenever I can and am more than happy to help wherever I can especially if other Mothers need someone to talk to like I did. Feel free to give anyone my phone number. If you need any help please feel free to ask me and wherever possible I will be glad to support you and Safe T Sleep.

With a wilful child like Madison my success cam by using the STS with 4 rolled up towels to hold her on her side. I never liked the safety pin as you know, but I didn't need it if I used the towels. I still use this method now and will for a while longer. I think the leg-piece is a great option but needs to be trialed on a much younger baby as Madison forces her way through and ends up in a tight predicament. However for children not required to lie on their sides (eg: children who naturally turn their heads) it would be brilliant!

Well again thank you so much for everything. I don't know if I would have had nearly as much success without your support. I hope we can meet again as I sincerely would like to be involved with helping people with the 'flat-head' problem, and Safe T Sleep is the 'key' to curing it.

Kindest regards,

26 November 2002

TO WHOM IT MAY CONCERN:

As a senior consultant in the Craniofacial Clinic at a tertiary referral hospital in New Zealand, I see a large number of babies who present with a condition call Plagiocephaly – a form of flattening or deformity of the skull. Where this is caused by positioning a newborn infant in the same sleeping position day after day, or due to associated torticollis (wry neck). I often advise parents of my patients to position the infant for sleeping so that they are not lying on the flat spot on the skull. This may be difficult to achieve with an active infant, where there is a strong tendency to roll back onto the flat spot. In such cases, I have found that the Safe-T-Sleep sleepwrap device is a safe and very useful adjunct to keeping the infant in a selected sleeping position. During 2002, I ran a trial of this device using it on over 30 babies and infants, who were then observed for more than 300 hours. We found that in more than 90% of cases, the device maintained the selected sleeping position, and in no instance was there any risk to a baby from the device. In my estimation, this is a useful and effective device whose use could safely be encouraged by all health care professionals who take care of babies and neonates.

TRISTAN de CHALAIN FRACS, MBCHB, MSC, FSSA, FRCSC, FRACS CONSULTANT PLASTIC SURGEON

To whom it may concern,

Our story starts when our son Ben was only six weeks old. We noticed that he had a dent on the right side of the back of his head. Since birth we had back slept our son, as instructed at the antenatal classes we had attended and attempted to turn his head from side to side with different sleeps. We informed our obstetrician of this irregularity at Ben's six week check up. We were told not to concern ourselves with this, indeed not to even worry about rotating his head from side to side as it would come right over time. We took this advice on board, but deep down we were not happy, the dent was getting worse right in front of our eyes.

We carried on until we went to the Plunket nurse for Bens three moth check, again we mentioned the dent and the Plunket nurse said that it was of concern, she advised us to visit our G.P. so off we went. He also agreed that Bens head was quite misshapen and that he favoured his right side when he was on his back, and yes something needed to be done, but unfortunately he did not know where to send us for help.

We were now finally in the position of two health professionals agreeing that something needed

to be done about Ben's head shape, but nobody knew where to send us to get help. By this stage we had become obsessed with our sons head shape, so after many phone calls we managed to find; (a) a Neuro developmental therapist (Ros Saffer from Child Development Services) and (b) a G.P. (Dr M Stone) that actually knew all about this condition and referred us to a specialist in the field.

After a months wait to get into the specialist (Dr T. de Chalain) we were finally given a name for our sons dent – Positional Plagiocephaly. It can be caused or exacerbated by the baby always returning their head to the same side when placed to sleep on their back. This puts pressure on the same spot repeatedly and therefore causes the head to become dented, the ears to become misaligned and the forehead to bulge, all at varying degrees depending on when it was picked up. Also associated with this can be torticollis (tightening of neck muscles due to only turning/stretching the head predominantly in one direction).

With this diagnosis in firstly came the reassurance that it was not affecting Bens brain function and secondly we were also instructed to keep him off the dented part of his head continuously. This in theory sounds easy, but by this stage Ben was almost 5 months old and retraining him to sleep on his side was not going to be easy. We struggled for weeks and Ben struggled against us, until we finally called Miriam Rutherford, creator of Safe T Sleep.

We were able to visit with Miriam in her home and when we met her we found that she had a wealth of knowledge of Plagiocephaly and had helped many families deal with repositioning their babies. She showed us numerous ways to use the Safe T Sleep effectively and gave us much needed encouragement and support to persist with our endeavours. From that night on, after our visit with Miriam and with a lot of love and encouragement Ben slept blissfully on his side.

We also now have the Neuro development therapist visit us every two weeks or so to keep an eye on Ben's developmental progress, which can be delayed due to not being on his back as much as other babies, and also to teach us exercises to loosen any tight neck muscles which can become a problem with this condition. Ben is now 6.5 months and slowly we are starting to see changes in his head shape. It seems that we had to go to extraordinary lengths to get this far, all because we slept our baby on his back. If only from the beginning we could have known how important to change sleep positions (i.e. Rt side sleep/back sleep/Lft side sleep) and/or if only the first contact health professionals we were in touch with had had better knowledge of what appears to be a very common problem, we would not have had to go through this ordeal.

In writing this we hope that we will at least be able to inform one parent/nurse/doctor about this problem to avoid the absolute agony and frustration we had to endure, after all we only want what's best for our babies. Right?

Yours faithfully,

Julie and Alun Rees-Williams (Parents to Ben)

To: ATTN: Miriam (Safe T Sleep)

Dear Miriam.

Our Story,

We have a beautiful daughter who is nearly nine months old and developing really well. However there is something that has been concerning me since she was 11 weeks old, and that is the shape of her head. I was told that I had to sleep her on her back, but in my mind I thought she was to sleep on her sides, now I wish I had followed my instinct and done that which is against the current thinking of sleeping babies on their backs.

Out story has become a saga, but I will try and condense this. Once I discovered that our daughter's head was becoming a funny shape, we saw Plunket who said it was ok and nothing to worry about unless the sutures had prematurely fused. A couple of weeks later I mentioned to Plunket again, who then said to go and see our doctor to have it checked if I was concerned. We took her to the doctor, who looked at her head and said that it seemed ok, but to try and sleep her on her back with her head on the other side. One thing that was not told to me about sleeping a baby on their back (either at antenatal, hospital, plunket, etc) was to check that they are not putting their head to the same side all the time, which I would have done had I have known!. After another month we returned to the doctor (as suggested) because there has been no change. She promptly wrote a letter to Starship to have an appointment made with a paediatrician. After a number of weeks waiting for Starship to contact us, I rang to make sure the appointment would not be while we were overseas on holidays. They proceeded to tell me that there would still be some months to wait for an appointment. Getting really frustrated at this point I rang ahead to have an appointment set up overseas. This was arranged and we saw a paediatrician who had x-rays done and commented that it looked like there was a premature fusion of the sutures. Armed with this information we took it along to our appointment at Starship after months of waiting for the appointment. I really believe that it is because we had done this, that from that moment on things started to happen here in NZ. The Paediatrician at Starship agreed with the Paediatrician from overseas and had us booked in for a CT (cat) scan at Auckland Hospital, which took a four more weeks to wait for. The Starship Paediatrician also booked us in to see the cranio-facial department at Middlemore. So we first went to Auckland for the scan and we have now been to Middlemore.

The conclusion is that our daughter is to be fitted with a moulded helmet, so that her head will grow out in the right places by putting pressure on the areas that have grown properly. She will have to wear this for almost 24 hours a day and for a fairly lengthy time period. All this has caused my husband and I a lot of stress and anxiety that I feel has been unnecessary. What is interesting is that there was another mother with a child that was a month older than mine, and that child has a head shape exactly the same as my daughters.

The other day in 'The Herald' newspaper, there was an article about flat heads, which commented that this is what is happening to babies but that it is all right and anyway if something does need to be done to correct it, it can! This really missed the point in my view.

Our health system is struggling at the moment, so why put babies on their backs and spend a fortune having to fix the problem??? In my opinion this is ludicrous. Why put people, especially first time parents through all this. This has no only affected us but our whole family who have been very concerned. Another interesting point is that many others are noticing the shape of babies heads. For example, I was talking on the phone to a lady from The Baby Factory, who had noticed that a lot of the babies who were coming into the store had funny shaped heads now, whereas this had not happening in the past!

I do want to set the record straight. Plunket are doing a wonderful job and I don't know where I would have been without them, especially in the early days of suddenly being a mother. However I do not believe that it is in the best interests to put babies on their backs to sleep. If I am able to have another child it will certainly be sleeping on the side to side and definitely not on its back. Another interesting thing is that when our daughter was about 5 months, I sat and watched a video at Plunket regarding sleep patterns for babies. This video was made in Australia and it mentioned that your would put your baby either their back or side and showed a baby peacefully sleeping on its side in a bassinet. Before ay of us asked about sleeping a baby on its side, the Plunket nurses said something like "we do not sleep our babies on their sides here in NZ"! it seems to me that this is a fad. Generations upon generations have slept babies on their sides, and from what I have been finding out these babies did not end up with odd shape heads!

What has really upset me is that I was not given a choice, and I was not told of the consequences of a flat head by sleeping a baby on its back by any of the health professionals. If I had known that there was a possibility of our daughter having a flat head (let alone what has actually happened!) then I would have at least thought about other options and made an informed decision, or at least been forewarned!

I will never advocate to sleep a baby on its back, which is why I am now letting expectant friends know what had happened to our daughter, which I firmly believe is a result of lying her on her back. At least it gives them food for thought and they can research for themselves.

Yours sincerely,

R. Hanscamp

Dear Miriam

Safe-T-Sleep

I am writing to share my experiences with using your safety-sleep. My son was developing a flat spot on his head. No matter which way we placed him in his cot he would turn his head to the one favoured side.

At last resort we tried the Safe-T-Sleep. I say last resort because he was a good sleeper and I was afraid he would fight the restriction and wake up during the night. Much to my delight our son continued to sleep through the night and within a few months the flat spot was corrected, he now has a normal shaped head and is happy to lie on either side.

My nephew developed a severe flat spot and in the end he wore a helmet to correct, I was relieved to be able to reshape our son's head without having to resort to such drastic measures.

I hope you are encouraged by our story, we as parents considered the safe-t-sleep a lifesaver.

Thank you.

Brenda Scully