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Maternity Services Consumer Council

WELCOME, TENA KOUTOU KATOA, KIA ORANA, TALOFA LAVA, MALO LELEI, FAKAALOFA ATU.

This is the first issue of the MSCC's Newsletter for 2013. Since we sent out the December 2012 newsletter we have had a great summer holiday and returned to work feeling very relaxed and rested, revised and reprinted the *Epidurals during Labour* pamphlet in our "The Facts" series, started work on a revision of the *Caesarean Section* one, written lots of grant applications, and mailed out thousands of our pamphlets.

Nicola & Poppy

Nicola's baby daughter, Poppy, was born on 28 September weighing 1.5kg. She is now six months old and weighs 5.5kg. The story of her birth appears below.

Funding application results

Thanks to Emma the MSCC has received a grant of $3,000 from The Trust Community Foundation and $5,000 from the Lion Foundation for reprints of our leaflets, and some administrative and organisational costs. The MSCC is very appreciative of the funding we have received so far this year, and we are working hard on avoiding the financial low we have experienced over the past two years.

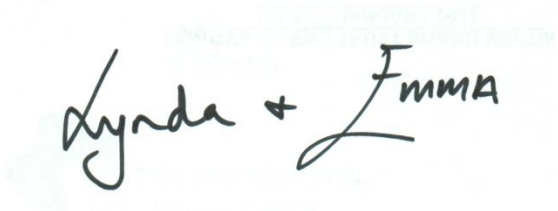
20th Anniversary of becoming an Incorporated Society

On 4 March 1993 the MSCC became an incorporated society, two to three years after its formation, thanks to the sterling efforts of Judi Strid who is now the Director of Advocacy at the Office of the Health & Disability Commissioner. Lynda was asked to take on the role of co-ordinator in 1992 after the work became too much for a part-time volunteer working from home.

What's in this issue of the newsletter

The March issue of the newsletter contains Nicola's account of her eventful pregnancy and the birth of Poppy, a brief item on pain management post caesarean at National Women's at Auckland City Hospital, an article on the rising rates of perinatal hysterectomies in New Zealand, and information on several workshops and events.

Don't forget to check the dates for the MSCC's Steering Group meetings for the next few months.



Poppy's Birth Story

This is the birth story of my daughter Poppy. It is weird being on this end of maternity care when I have been so involved in other aspects. I wanted one more baby. Easy, right? Get pregnant, have a worry-free pregnancy, a beautiful birth. Done.

Well life had other plans. It took 4½ years and some heart breaking miscarriages to conceive. When we found out in March 2012 that Valentine's Day had proven rather productive we were cautiously happy. However bleeding at seven weeks had me convinced that unfortunately this pregnancy, like others, was going to end in tragedy. I couldn't relax even though a scan showed a baby with a good heartbeat. Another big bleed at nine weeks and another anxious wait for a scan which I was positive would show my pregnancy wasn't viable.

That nine week scan showed a beautiful baby, lovely heartbeat and it also gave us a reason for the bleeding. I had a sub chronic hematoma. No one really knows how scary scans can be for a woman who has experienced miscarriage. I don't think we offer enough support for women either. Just a phone call before or after to let her know someone understands would be so valuable.

It was a really anxious time waiting to get to 12 weeks. Every time I went to the toilet I was positive I would find more blood. Every day I thought that I was going to lose my baby. To be honest that fear never really left until she was born.

At 19 weeks I fell and broke my ankle. It was my own stupid fault, running down stairs in the wet, but this accident was the changing point in my pregnancy. The hospital wanted to do a scan to check on the baby after the fall so I went off anxiously. While the baby was fine the scan did show that it wasn't growing as well as it should be. The baby measured about two weeks behind and even though they were fairly sure this was because of the sub chronic hematoma, they wanted to watch it closely.

Suddenly my dreams of a normal pregnancy were up in smoke. Two weeks later I was diagnosed with gestational diabetes as well. Nothing seemed to be going right. At this point my care was transferred to a team at Auckland Hospital and I had to say goodbye to my midwife I liked and trusted.

From then on my pregnancy became more about tests and scans, than this amazing baby growing inside of me. Fortnightly scans showed baby was not growing well, blood flow from placenta wasn't great and blood flow to uterus was impaired. Also just to add a new dimension, they noticed the baby had an odd head shape and they weren't sure why.

At 24 weeks they started to prepare me for the possibility that my baby was not going to make it to 40 weeks and I had my first hospital stay. I was admitted for

two nights for monitoring. At this point the baby weighed only around 400 grams and I have to admit I didn't hold a lot of hope that if she was born then, I would ever take her home. We decided to take the offered steroids to help develop the baby's lungs in preparation for a premature birth.

I got to go home again which was great but I was back in twice a week for scans and monitoring. Over the next nine weeks I would spend more nights in hospital then at home. The shortest stint I had was two days. The longest was two whole weeks before the birth.

At 30 weeks we opted for another course of steroids to develop the lungs as they just weren't sure how much longer my placenta would hold out. We chose not have an amniocentesis to see if there was any reason for her head shape, as we would not have done anything regardless of the results and there was a high risk of it putting me into labour.

One of the hardest things about my pregnancy was conflicting advice and comments from various people. In hospital I would see people from the "team" looking after me and they would be following one plan and have one view, and then I would see other people in the weekend or after hours who had other ideas and other views. Even with a good knowledge base I felt confused and unsure.

I felt adrift in the system. I didn't feel like I had a central person who was my "go to" person when I had questions or concerns. No one was looking after my emotional state and no one was there to give me the support or shoulder to cry on that I desperately craved. Yes, I have wonderful family and friends who supported me, but I wanted someone who knew all the ins and outs and wanted me to understand too.

It is really hard when you are up against this medical wall of tests, scans and everything is evaluated in risk, but all you really want is to know you will get to hold your baby. I had lost control and I felt like there was this wave just carrying me along by myself. While sometimes I managed to come up for air and be in a good place, the next day something would change or I would be unsure again and this wave would sweep over me.

I wish I could have just had some key person who was there for me and not just focused on my body and my baby. Not only did we know that the baby would be premature but she was also small. She was consistently measuring 3 – 4 weeks behind in growth so I couldn't even begin to imagine how tiny she might look. I grieved over those nine weeks in hospital. Not just because I was worried for my baby, but also because I had lost control. My pregnancy seemed to be measured in terms of tests, scans, discussions on viability, and I had lost the chance to have the birth I wanted to. Given the baby's small size, concern over the head shape and the potential for bleeding, we had chosen to have a caesarean

section. This grief wasn't ever really acknowledged by any of the staff and it led me to feeling a bit detached from my pregnancy and my baby.

I found missing my other two children especially hard. The hospital staff tried their best to keep me upbeat and to be lovely but hospital isn't home. My family visited me when they could, but we did have to balance that with trying to keep the boys in their normal routine mostly. It was great when I got to have home visits but being away from my family for so long left me feeling a little isolated. I often ended up sharing a room and this often made things harder. You can't spend the night crying when someone else is in there with their own fears too.

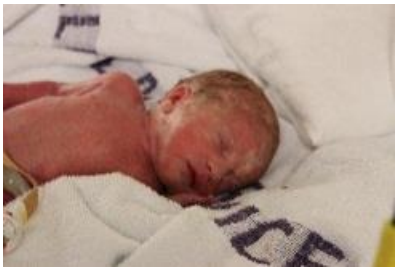
At 33 weeks I had a scan and was told to prepare that if that scan didn't look good, the baby would need to be born. I didn't really believe it was going to happen. I thought it would be much of the same, stay in hospital have tests. I thought I probably had more time. I didn't. The baby had not grown much in two weeks and today was going to be her birthday.

It was a really scary wait for a theatre to be free. Can you see the fear hidden behind my smile? Once we made it into the operating theatre it was pretty quick for Poppy to be born. I got a quick view as the obstetrician lifted her up, and then she was whisked off to the next room. Daniel went with her as we'd planned, but I found this really hard, being alone in theatre not knowing how she was doing.

Poppy was born 28th September at 12:26pm, weighed 1500grams and was 41cms long. It was so bizarre lying there and being so uninvolved with my baby after her birth. No one gave me her details. They were all busy and so I just lay there, silently crying wondering what I had had, and how my baby was doing.

The anaesthetist realised I was struggling and so chatted to me and also went and found out about Poppy for me. I was encouraged to hear that she was trying to breathe on her own. It is very surreal to be lying there and not having your baby lying skin to skin.

Also everyone was so busy doing their roles that no one talked much to me and I felt so scared. It would have been so great for someone to sit with me, hold my hand and just distract me. I know this is usually a support person but in this situation one support person isn't enough as you want someone to be with the baby too.



Once Poppy was put into her incubator she was wheeled off to NICU and Daniel gave me a quick update and a kiss before going with her.

When surgery was completed I was transferred to recovery. The nurse left me to go find medication etc so I was alone in recovery waiting and waiting. This was incredibly hard as I wasn't sure what was happening with Poppy and I had no one to talk to, or to cry with. All around me I could hear parents with their babies and I had no baby and no support. Again I wish someone had told me about this or someone took the time to see I was struggling. If I had known maybe we could have got someone else to sit with me. I guess it is hard to prepare for the unknown but some guidance would have been good.

Finally the nurse had me all organised and I was wheeled into NICU. Nothing prepared me for that moment. There was this tiny wee girl hooked up to machines and all I could do was touch her hand. I wasn't able to hold her. It broke my heart and I wanted so badly just to hold her.

As I had been alone in recovery and was struggling from the birth and not knowing what was going on, I had a wee meltdown in SCBU and yelled at the staff (I am so sorry if you are reading this). I just felt like everyone else was getting to touch my baby and know everything while I was in the dark. My poor husband copped it too. I wish I had been prepared more for what would happen after the birth and what I could expect. No one took the time to tell me that there would be people around her, what they would be doing, or what Poppy's set up would be in NICU. They assumed I would know.

I stayed for as long as I could in NICU but had just had surgery so I needed to rest. Once I was settled on the ward we went about ringing family and friends.

Originally I was told that I wouldn't get a private room and would be sharing. I got a bit upset and annoyed at this. I was already coping with so much and couldn't handle the thought that I would be sharing while I cried over my baby. Thank you so much to the midwife who managed to get me a private room. It was a positive thing when it all looked so bleak.

Overall Poppy spent five days in NICU at Auckland. I spent those five days expressing as much milk as I could for her, having cuddles as often as I could and recovering from the birth. One of the hardest things in those five days was that she didn't feel like mine. I often asked permission to touch her, felt like I couldn't disturb her if they had put a cover over her incubator and was scared to ask to hold her as often as I would have liked.

I found it quite hard to combat the pain team after the birth. Even though I was not really using the pain pump, and found it hard to carry around to NICU, etc

they kept pushing me to keep it just for another day. I felt more encouraged to stay on it, than helped and supported to get off the pump as soon as possible. I wish I had felt more empowered to be more forceful and insist it be removed, but with all that was going on it became a battle I didn't fight. In hindsight, I should have as I developed a slight infection in the site and had a sore back.

On Day 6 Poppy was transferred to Waitakere Hospital as we were from the Waitemata District Health Board (WDHB) area and she was stable. This was a hard day for me as nothing can prepare you for going home but leaving your baby in someone else's care.

Something that would have been helpful was if I could have had just one night at Waitakere Hospital with her to get used to the new surroundings. Having Poppy transferred and me being discharged all in one day was too much.

I was looked after by a community midwife following the transfer as my ADHB Gestational Diabetes midwife didn't do my postnatal out of area, and while they were lovely this meant every time I met with someone they wanted me to go through my story again. I am sure they had notes but they wanted to hear my side. The problem was that my side of the story was painful to tell. Consistency of care would have been so much better, seeing the same midwife may have eased my transition.

We were lucky and finally after 20 days in care Poppy passed all her tests and we took her home. I finally felt like I had actually had a baby!

Poppy is doing really well and six months on is a happy smiley baby who is well and truly spoilt. I am so thankful every day that she is here and that despite her rocky start, her progress has been really positive. Currently she is 5.5kgs and 57cms long and still fits newborn clothes. At least she is getting the wear out of them!

I want to say thank you so much to my wonderful independent midwife, you know who you are, because even though you had to hand over care up until then you exceeded my high expectations!

Thank you, too, to the staff at Auckland Hospital on Ward 96/98, the gestational diabetes team, my ADHB Gestational Diabetes midwife and my team at the clinic who looked after Poppy and I. You do amazing work, even in difficult situations.

Arohanui

Nicola

PUSHING PAIN RELIEF AFTER A CAESAREAN

As Nicola noted in her account of the caesarean birth of her daughter Poppy, the issue of how National Women's/Auckland City Hospital deals with providing pain relief for women following a caesarean section has become a significant problem for some of the reasons Nicola mentioned in her story – the risk of infection and not permitting women to come off the pain pump when they feel ready.

Patient-controlled analgesia (PCA) that allows patients to control postoperative pain by self-administration of intravenous opioids using pain pump devices designed for this purpose is a relatively new development in the treatment of post caesarean pain. A recent Cochrane Collaboration Review of randomised controlled trials (RCTs) comparing PCA with conventional analgesia such as a nurse administering an analgesic upon a patient's request, found that PCA provided slightly better pain control and increased patient satisfaction when compared with conventional methods. Patients tended to use higher doses of medication with PCA and suffered a higher occurrence of itching, but otherwise adverse effects were similar between groups. (1)

National Women's Health's patient information pamphlet "*What to expect following a caesarean birth*" states:
"Like any operation it is quite common to experience some pain afterwards. Immediately after the birth, you will be offered pain relief that you can control yourself. This drug is usually Morphine and can sometimes make you feel itchy, drowsy and nauseous. You will also be offered Paracetomol, and anti-inflammatory drugs if they are suitable for you, such as Diclofenac or Ibuprofen. We encourage you to take these tablets regularly, which should cut down the amount of Morphine-like painkillers that you might need. All these medications are safe in breastfeeding." (2)

For some years concerns have been raised at the way mothers at National Women's are encouraged or coerced into staying on the pain pump. The MSCC has heard from a number of mothers about how they are encouraged to stay hooked up to a pain pump even when they no longer need it. Sometimes this has resulted in the development of an infection. While the Australian and NZ College of Anaesthetists' website refers to the need for a doctor to determine when it is appropriate to come off a pain pump, at NWH PCA is under the control of a nurse who brooks no interference with her decisions about PCA use. It is long past time for changes to be introduced into pain management post caesarean at NWH.

References:

1. http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD003348.pub2/pdf
2. http://nationalwomenshealth.adhb.govt.nz/Portals/0/A%20to%20Z/A%20to%20F/C/C%20Caesarean%20Birth%20-%20What%20to%20expect%20following%20a%20C-Section.pdf
3. http://www.anzca.edu.au/patients/different-procedures/different-procedures.html#patient-controlled-analgesia

PERINATAL HYSTERECTOMY

Few midwives and even fewer women are aware of the alarming increase in the numbers of emergency hysterectomies, known as perinatal or postpartum hysterectomy, performed during or soon after the birth of the baby in order to save the life of the mother. Such surgery is undertaken when other interventions fail to stop severe haemorrhaging which sometimes accompanies a caesarean section.

The rising numbers of perinatal hysterectomies are a direct result of the rising rate of caesarean sections.

In response to the MSCC's Official Information Act request for the numbers of hysterectomies performed on women in New Zealand over the past 12 years, it was revealed that several dozen women enter hospital each year to give birth to a baby and leave hospital having had their uterus removed. The numbers of such hysterectomies ranged from 18 in 2001 to 46 in 2008. Over the past seven years the figures have remained between 36 and 46 with one exception – in 2010 there were 24 women who had a hysterectomy during or soon after birth.

Perinatal hysterectomy is often the consequence of a previously performed caesarean section, which in a subsequent birth gives rise to complications such as uterine rupture in the scar from the previous caesarean, and bleeding from the villi of the placenta located on the front wall of the uterus, which have grown into the scar.

Placenta accreta

Placenta accreta, a condition where the placenta implants too deeply into the muscle in the walls of the uterus, is now the most common cause of uncontrolled bleeding during the birth process that leads to the necessity of removing the uterus. Once a rare event that affected 1 in 30,000 pregnant women in the 1950s and 1960s, placenta accreta now affects 1 in 2,500 pregnancies, according to a 2007 report in the *Journal of Obstetrics and Gynecology*. In some hospitals in the USA the number is as high as 1 in 522. (1)

A retrospective study undertaken of data from three obstetric hospitals in Dublin from 1966 – 2005 of 358 women who had had perinatal hysterectomy (out of a total of 872,379 births), revealed that the percentage of perinatal hysterect-omies that occurs after a previous caesarean birth increased from 27% to 57%. During these four decades uterine rupture as an indication for perinatal hysterectomy decreased from 40.5% to 9.3%, while placenta accreta increased from 5.4% to 46.5%. The overall caesarean section rate increased from 6% during the first decade of the study to 19% during the fourth decade. (2)

Previous caesarean sections

In 2007 a total of 36 women in New Zealand had a hysterectomy during or following giving birth. Of these, 16 women had had a previous caesarean section – 11 women had had one previous caesarean section, four women had had two previous caesarean sections, and one woman had had three previous caesarean sections. In 2008, 46 women had a baby which was followed by a hysterectomy. Of these, 22 women had had a previous caesarean section – 10 women had had one previous caesarean, two women had had two previous caesareans, five women had had three previous caesareans, two women had had four previous caesareans, two had had five previous caesareans and one had had eight previous caesareans.

In 2011, 38 women had a baby which was followed by a caesarean section. Of these, 25 women had had a previous caesarean – seven women had had one previous caesarean, seven women had had two previous caesareans, nine women had had three previous caesareans, one woman had had four previous caesareans, and one had had seven previous caesareans.

The physical and emotional trauma of having gone through a life or death experience while giving birth is immense. When this happens to a mother having her first baby she is also faced with adjusting to the fact that she cannot have any more children. The MSCC knows of one young woman who is currently struggling to come to terms with the caesarean birth of her first baby which was quickly followed by a hysterectomy.

The horror and trauma that lies behind the above statistics is just one of the unspoken risks associated with the increasing numbers of caesarean sections.

References

1. http://abcnews.go.com/Health/caesarian-rates-placenta-accreta-contributing-rise-maternal-death/story?id=13399308
2. Karen M Flood et al. “Changing trends in peripartum hysterectomy over the last 4 decades.” *American Journal of Obstetrics & Gynecology*. June 2009.

PRIVACY COMMISSIONER ANNOUNCES IMPROVEMENTS TO LEGAL PROTECTIONS AROUND GUTHRIE CARDS

A media release on 21 March 2013 announced amendments Privacy Commissioner Marie Shroff has made to the privacy health code to protect newborn blood samples collected as part of the national newborn metabolic screening programme, known as the Guthrie Test. The samples or Guthrie Cards are held permanently unless parents request their return. The amendment will restrict how information derived from the samples may be used and disclosed.

"DNA testing is getting cheaper and faster all the time and that makes national bloodspot collections more valuable. Because of this it is possible someone in the future will want to use the collection as a national DNA database. If this were to happen, trust in the programme would be severely damaged. To protect this important programme, which saves dozens of lives each year, we want to give parents confidence their babies' blood samples aren't going to be misused," Ms Shroff said.

The changes in Amendment 7 which will lock in administrative protections developed by the National Screening Unit after consultation with various stakeholders will come into force on 30 April 2013.

A copy of the amendment, with an explanatory information paper, is available on the Privacy Commissioner's website:

http://privacy.org.nz/news-and-publications/statements-media-releases/health-information-privacy-code-1994-amendment-no-7/

MSCC Meeting Dates for 2013

Our MSCC Steering Group is growing and this can only mean great things for the women of New Zealand. Make sure your voice is heard - please make a note of the following dates for the coming year in your diary and come along to our monthly meetings. You can be assured of a warm welcome. The MSCC meets at 10am on Tuesday mornings – and the days have been fitted around school holidays.

The Steering Group meetings are currently being held at Birthcare in Parnell. The meeting dates for 2013 are**:**

9 April, 7 May, 11 June and 9 July.

So if you have an issue of concern or would like to share information about women's experiences of maternity care then do come along. Babies and toddlers welcome.

CONFERENCES/WORKSHOPS 2013

Birthspirit

The Wise-Woman Midwife and the Birth Machine Workshop

These workshops by Maggie Banks aim to strengthen the midwifery foundation of supporting, protecting and promoting physiological birth in primary care settings to ensure healthy outcomes for well women and their babies throughout continuum of pregnancy, birthing and early mothering.

They will be held at the Birthspirit Cottage at Tamahere, as well as in Christchurch, Palmerston North, Whangarei, Auckland and Tauranga between March and July 2013.

www.birthspirit.co.nz/Education/Seminars/TheWiseWomanMidwife&TheBirthMachine.php

'Working Towards Safer Beginnings'

The Perinatal and Maternal Mortality Review Committee will hold its annual workshop at Te Papa in Wellington on 12 June 2013.

Key note speaker: Professor Marian Knight from the University of Oxford, UK.

For further information see: http://www.hqsc.govt.nz/news-and-events/event/804/

The 6th Joan Donley Midwifery Research Forum

The NZ College of Midwives is holding its 6th Biennial Joan Donley Midwifery Research Forum in Queenstown on **19 – 20 September 2013**.

Further information is available at:
http://www.midwife.org.nz/index.cfm/1,140,0,0,html/The-JDMRC-Research-Forum