

# TTTS Times

*Official Newsletter of the*



## **Australian Twin To Twin Transfusion Syndrome Support Group**

This edition of TTTS Times is developed for electronic use only. Certain images from the paper copy may have been deleted to enable as fast a download as possible.

By becoming a member of the Australian TTTS Support Group, you will assist us in our aim to become a charity. We hope to be able to raise funds in the future, which will be tax deductible to the donor. Our aim is to then use a portion of these funds to produce a brochure with information for parents who are diagnosed with the condition. These brochures will eventually be available at hospitals, obstetricians and other pregnancy related centres. The information to be provided on these brochures has been approved by AMBA and TTTS specialists. We plan to use the rest of our donated funds in our support of parents as well as donating some to TTTS research.

Our membership form is included in this newsletter. If you enjoy our newsletter and would like to help us help other TTTS parents, please feel free to join our support group. Every little bit helps in our quest to promote TTTS and make sure that all parents get as much information as possible.

Thank you,  
Vicki and Linda

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## Australian Twin To Twin Transfusion Syndrome Support Group

Founded 2002

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P.O. Box 1343  
Carindale QLD 4152

Website: [www.twin-twin.org](http://www.twin-twin.org)

Email: [info@twin-twin.org](mailto:info@twin-twin.org)

### **Australian Twin To Twin Transfusion Syndrome Support Group aims to:**

- Disseminate information about TTTS as a complication affecting multiple pregnancy
- Increase public awareness of TTTS
- Provide information regarding TTTS treatments currently available in Australia
- Provide a general forum for members of the Group
- Co-operate with and participate actively in research projects at local, national and international levels, into all aspects of Twin to Twin Transfusion Syndrome

**In pursuit of its objectives, the Group shall be conducted as a non-profit organisation, and shall refrain from sectarian and political activity of any kind.**

### **Services:**

- Advice and support for families who are experiencing/have experienced a TTTS pregnancy
- Advice and support for families with intact twins, as well as bereaved, and special needs families
- 6 editions per year of 'TTTS Times', received by all members
- Phone contact on request

### **Meetings:**

- Quarterly meetings, held in members' homes
- Coffee Mornings/Afternoons in members' homes or suitable venues

**Subscriptions: \$20 per annum (\$15 for AMBA members)**

### **DISCLAIMER**

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## The President's Say...

Hi and Welcome to the March/April edition of TTTS Times.

The last couple of months, like always, have been very busy for my family. With winter approaching and a late Easter, soccer has started. This has meant that the summer and winter sports are all on together for a few weeks. Futsal, thankfully, is into the final series so at least that will be finished by the end of March although the State Titles are held during the Easter weekend so Vince, Matt and Ben are in full training for those. The swimming championships are held during the weekend before Easter so we still have a few weeks of that and the soccer preseason matches start next week. I am really looking forward to the week following Easter, I can tell you.

On top of all that, Ben scared us a couple of weeks ago by contracting a pain in his lower right abdomen. With a slight fever and loss of appetite, my first instinct was appendicitis. Vince and I took him up to the hospital as it was a Sunday evening and they kept him overnight for observation. He was taken off all oral intakes and had an IV inserted for fluid and other nutrients. They were planning on operating on him the following morning if the pain was still there but it disappeared during the night. After keeping an eye on him throughout the day, he was discharged late Monday afternoon. After sleeping in a bed next to him, I think it took me the whole week to recover from the scare!

I attended the Multiple Pregnancy Conference in Melbourne mid-February and found it to be a very interesting weekend. I met many doctors and support workers who were interested in learning more about TTTS. Linda and I have developed a flyer that I gave out to everyone I spoke to. This has been very beneficial in the awareness of the group. I am currently working on a report of what I learnt and it will be printed in following newsletters.

I hope everyone is well,  
Vicki

## Phone Contacts

QLD Victoria - Phone (07) 3849 8198  
[vicki@twin-twin.org](mailto:vicki@twin-twin.org)

1 survivor (recipient twin) born at  
29wks gestation. Donor twin stillborn,  
due to Acute Twin to Twin Transfusion.  
Recipient twin 1339g, donor 1191g.  
Surviving twin home on oxygen.

Linda - Phone (07) 3823 4612  
[linda@twin-twin.org](mailto:linda@twin-twin.org)

2 survivors born at 30wks gestation  
Recipient twin 1560g, Donor 808g  
Steroid injections before birth,  
Hospital bed rest,  
Separate hospital discharge.

## From the Editor's Desk...

Hi everyone and welcome to edition #3 of *TTTS Times*. This is our biggest issue yet, I've had to add an extra couple of pages to fit everything in! Firstly, a big Thank-You goes to Rachel for sending in her story about her twin boys Max and Oliver (pages 6-9). What a brave family you are, and we wish Max all the best. Thanks also to Austprem, who have been kind enough to allow us to print their "NICU Checklist" in this issue. Prematurity and TTTS so often go hand in hand, and this list is full of great ideas. I've also included a "Survivor Update" on my twins - we'd love to hear about how any survivors out there are going, so feel free to send me an update to include in a future newsletter!

We've got our AGM coming up on the 20th May, so if you have any ideas or suggestions that you would like put forward at the meeting, feel free to let either Victoria or myself know. At the moment we're busily preparing for the AMBA QLD State Seminar, at which we are going to be presenting a workshop on TTTS, and hopefully increase some awareness of the condition. All the best,

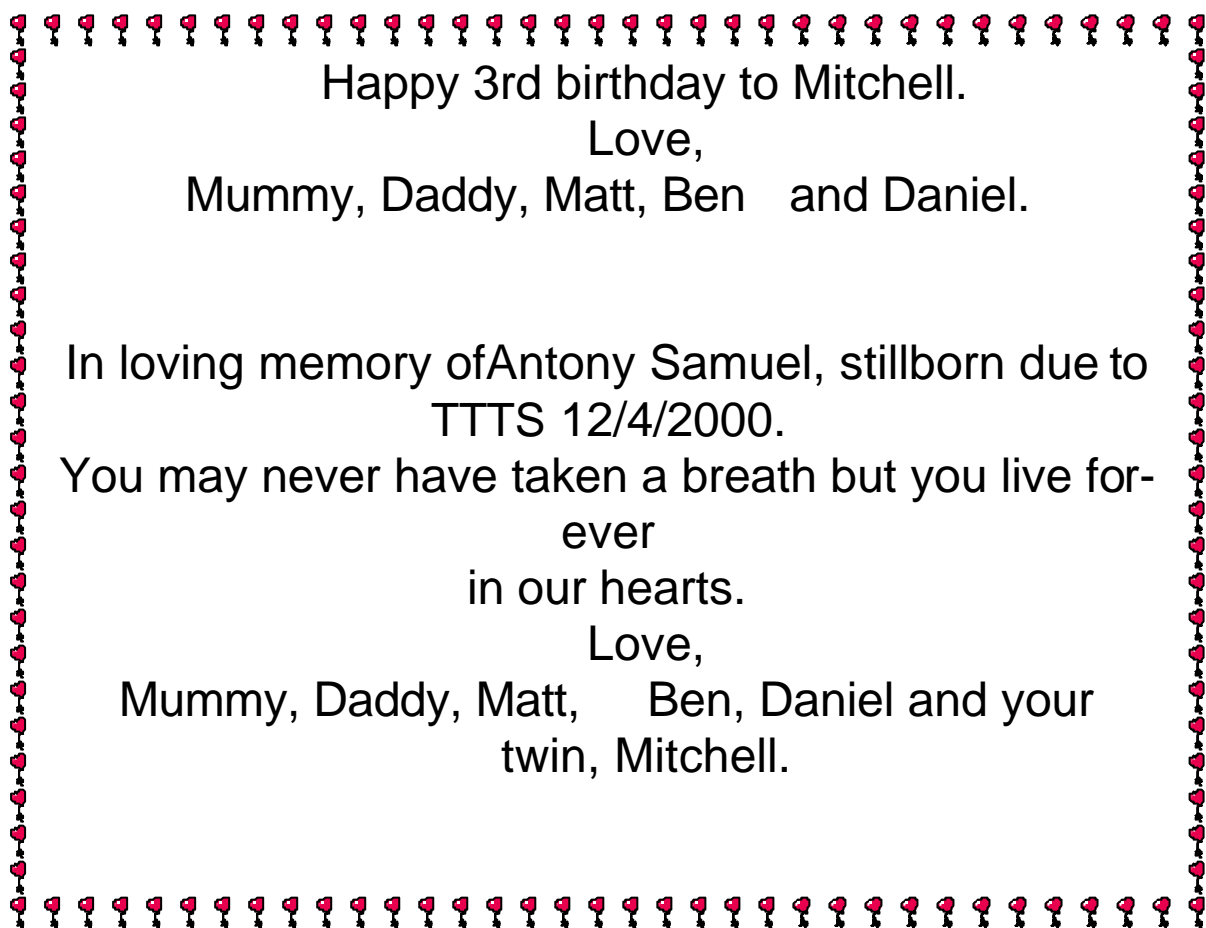
**Linda**

## **To Contribute to TTTS Times...**

Stories  
Birth Notices  
Memorials  
Survivor Updates  
Poems etc  
...are all welcome

If you have a "must-include" contribution that will be late, please contact the Editor so that ample space will be left available. Some contributions may be edited. Word-processed contributions should be forwarded on diskette or by email. Pictures and photos are welcome as bitmaps or .jpg or hard copies, and photos will be returned. Handwritten submissions are also welcome. Please inform me of the source if it is not your own as permission to reprint is required. Any questions, just call me on (07) 3823 4612 or email [linda@twin-twin.org](mailto:linda@twin-twin.org)

Any postal submissions to:  
Attn: Linda  
Australian TTTS Support Group  
P.O. Box 1343  
Carindale QLD 4152



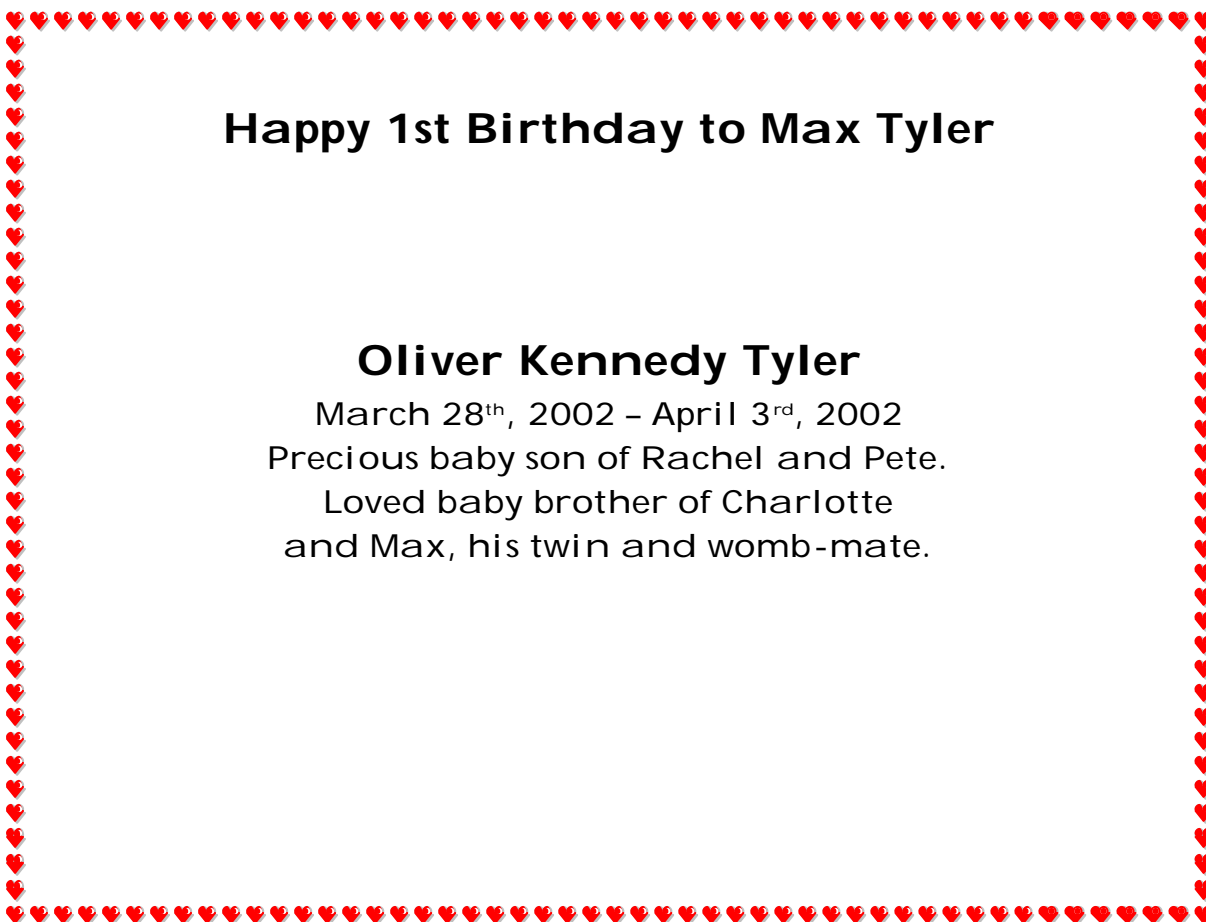
Happy 3rd birthday to Mitchell.

Love,  
Mummy, Daddy, Matt, Ben and Daniel.

In loving memory of Antony Samuel, stillborn due to  
TTTS 12/4/2000.

You may never have taken a breath but you live for-  
ever  
in our hearts.

Love,  
Mummy, Daddy, Matt, Ben, Daniel and your  
twin, Mitchell.



**Happy 1st Birthday to Max Tyler**

**Oliver Kennedy Tyler**

March 28<sup>th</sup>, 2002 – April 3<sup>rd</sup>, 2002  
Precious baby son of Rachel and Pete.  
Loved baby brother of Charlotte  
and Max, his twin and womb-mate.

## **Twin to twin transfusion syndrome** **– a patient's perspective**

*Rachel Kennedy, together with her husband Pete Tyler, are the proud parents of Charlotte, Max and Oliver.*

*At nineteen weeks gestation, Max and Oliver were diagnosed with severe twin to twin transfusion syndrome. They were born at 28 weeks gestation. Max, our recipient twin thrived. Oliver gave his all and died in our arms at six days of age cuddled up next to his brother.*

*This presentation was given at the Multiple Birth Conference held in Melbourne on February 15<sup>th</sup> and 16<sup>th</sup>, 2003.*

Nature can be cruel. Severe twin to twin transfusion syndrome is nature at its cruellest. First there is one, then two, and then in our case only one again.

My name is Rachel Kennedy. I am married to Pete and we are the proud parents of three beautiful children. Charlotte is three, Max will be one at the end of March and Oliver is our angel child in heaven. The following is our own personal experience.

January 23<sup>rd</sup> 2002 was the day my family's life was turned upside down forever.

At 19 weeks gestation I was very big. Twin jibes had started early. At my sixteen week check up with my independent midwife I was slightly bigger for dates, but there was no second heartbeat. We talked about twins and Annie had a good feel of my stomach – it appeared to be one. Over the next three weeks I ballooned out so that by the time I was checking in for my ultrasound at 19 weeks I was getting many questioning looks. I was in fact the size of a full term pregnant woman – and although I felt very uncomfortable and was trying to work out where the next 20 weeks of growth was going to go, I didn't realize I was THAT big !

The signs were there that this was a twin pregnancy – extreme morning sickness, early movement at 14 weeks, big for dates.....

When the ultrasonographer pointed out two babies within a few seconds of commencing the ultrasound my heart jumped but it only confirmed what I already knew. Overwhelming tears followed – how was I going to cope with a toddler and two babies? But something was not right and I sensed it almost immediately. Twin 1 was swimming in a huge pool of fluid. Twin 2 was smaller.

I had heard of TTTS – I had worked with the severely disabled survivors in two different cases in my profession as a paediatric physiotherapist. I offered this information to the sonographer – she didn't say much only that all the babies' structures were present and normal. A second opinion was sought immediately from the head of the practice and then we were asked to sit in a private room. Having worked in the health field I know that this is not a good sign. Bad news was pending. In an honest and frank way we were given the news. Severe twin-to-twin transfusion syndrome. The prognosis was presented – our twin boys were in significant danger of premature birth, death or disability.

Our plans and preparations for a homebirth with our independent midwife were thrown into disarray. As a proponent of minimal intervention in normal pregnancy and birth, I was distrusting of the obstetric profession. Suddenly this pregnancy was no longer normal and I needed an obstetrician. Someone who knew about TTTS, and importantly respected my opinions and wishes. We were given a name and after phone calls to Annie and my GP we fronted up to his private rooms unannounced, without a referral and in fairly desperate need of some quick attention. Within three hours we were sitting in his office and spent over an hour on that first day with him. It was important that we make some rather difficult decisions quickly as premature labour was predicted to be imminent.

### **Twin to twin transfusion syndrome – a patient's perspective (Cont'd)**

We were given all the facts, with medical literature and websites to review. We were told that we had a 33% chance of bringing both boys home, and a 60% chance of getting one of the boys home. Firstly though I needed to have an amnioreduction. This allowed us a little more time to make the hard decision about ongoing management of the pregnancy. In our minds we had to give both of our boys every chance. Therefore, amnioreduction and laser surgery were the only two options that we were prepared to consider.

At the time no laser surgery had yet been performed in Australia. To us it was extremely risky, especially as it presented a maternal risk. Added to this complex and in our minds, experimental surgery was the fact that I had an anterior lying placenta. It was explained to us that this made the surgical procedure more technically difficult. I would also have to fly to Brisbane to be assessed for surgery. It was a very difficult decision for us to choose the more routine management of serial amnioreductions. By not trying to stop the placental blood flow problem we felt that we were sacrificing one or both our boys. We sat down with all the facts as they had been presented to us and drew up a list – pros and cons for the two options we were considering. In the end we felt we made an informed decision. A decision that we felt was right for ourselves, our two year old daughter and our unborn babies at that very moment in our lives.

The next nine weeks we lived from ultrasound to ultrasound, reduction to reduction. It was a roller coaster ride. I immediately quit work and tried to rest as best I could with a two year old. She had seven day a week care from family for the entire time until we brought her brother home from hospital 17 weeks after that first U/S. I found that the most crucial time that I needed to rest was after a reduction. I tended to have uterine contractions for several hours after each reduction and I found a combination of rest, listening to relaxation tapes and meditation assisted me in recovering from each reduction.

By the eighth reduction I was a pro, but I wasn't sure I would make it past the first reduction when as the needle was passed into my swollen uterus, amniotic fluid spurted forth like a geyser. I soon was able to predict when I would need a reduction – generally discomfort in my back, a hard stomach and difficulty taking a deep breath were good indicators, but I also became quite in tune with the boys movements. Once Max slowed down and I could not palpate his limbs, a reduction was pending.

I also became a bit of a pro at how my boys looked on U/S – I was probably the radiologists worst nightmare as I was asking questions one step ahead of the picture on the screen. Each time the image flicked up on the screen I would immediately look for two heartbeats. Then we would go through the checklist – brains, hearts (Max our recipient, had a VSD and cardiomyopathy), tummies – no excess fluid around any of the organs, Oliver's (our donor) kidneys and bladder. Umbilical blood flow. Estimation of excess amniotic fluid around Max. Need for a reduction or not. It was so reassuring to see each of the boys moving – they always had their little heads orientated the same way – Oliver squashed down on the left and Max swimming around on the right. The first six weeks I needed a lot of fluid removed – I became a pin cushion - this was always stressful, but at 25 weeks after 2 litres came off in one reduction the process seemed to stop and I didn't require another reduction. Those last three weeks were a little more reassuring as we felt we were being blessed with extra time.

During those nine weeks I did a lot of research and planning. As a type A personality this helped to ease some of my stress. I went on a high protein diet –with daily banana and egg smoothies and red meat or fish or both every day. I wrote and emailed regular updates to my family who are scattered across the globe so that all our family had the latest news. I kept a diary. We met with the neonatologist that would look after the boys in the NICU to discuss likely outcomes when the boys were born. We made heart-wrenching decisions about when we would ask for life support to be given and when we would ask for it to be withheld. I drew up birth plans for pre 25 weeks gestation and then once we

**Twin to twin transfusion syndrome – a patient's perspective (Cont'd)**

made it past 25 weeks I drew up a new birth plan and plans for how we wished our boys to be cared for in the NICU. It was important to us that if we were not with our boys that the staff looking after them knew how we felt about certain aspects of their care. I researched the effect of prematurity on family and siblings so that we could best prepare ourselves for the road ahead.

It was very important to me that my midwife continue to be part of my birth team, as I needed her emotional and psychological support for the rest of the pregnancy and at the birth. We spoke on the phone regularly and I visited her office a couple of times for a cuppa and a reassuring chat. It was important that once the boys were born, Pete would go with them to the NICU, but I did not want to be left alone in theatre and recovery with strangers. My babies were fighting for their lives and I needed a friend with me. My midwife was "with woman" not in her traditional sense but still with me nonetheless and her role in my birth team was vital.

All of my wishes in respect to my birth team, birth plans and the boys care plans were respected by the health professionals we came into contact with. This respect was so very important to my sense of being in some semblance of control in a situation that was totally out of my control. I felt that Pete and I were part of the team that was caring for this high-risk pregnancy and the very fragile little individuals that were to be born.

Nine weeks later, eight reductions, more than 13 litres of amniotic fluid removed, over 12 ultrasounds, weekly reviews with the obstetrician and meetings with a neonatologist and other hospital staff... nine weeks later, Oliver's heart started to fail – it was time for the boys to be born. Max, twin 1, the recipient twin and Oliver, twin 2, the donor twin, were born at 28 weeks and one day gestation. Our initial goal had been to get them to between 28 and 32 weeks – we scraped in. I had a second dose of steroids the night before the boys were born, having had a dose at 25 weeks when we thought their birth was imminent earlier.

Max breathed at birth and went on to thrive. He did so very well in those early days. Oliver struggled for life from the moment he was born. After six days, his little lungs and heart were finding the struggle too hard. We agreed to turn off life support and he died in my arms cuddled up to his big brother and with his daddy kissing him. It was the hardest decision we have ever had to make.

In the last 12 months we have ridden the biggest roller coaster ride of our lives. We have faced the devastating blow that a diagnosis such as TTTS brings, we have had the uncertain stress of imminent premature labour, experienced uncomfortable procedures, we have witnessed the premature birth of our babies and watched helplessly as they have fought for life, our hearts have broken as we watched our son die in our arms and our hearts have rejoiced as his brother has gone from strength to strength. We continue to live with the uncertainty of the possible long term effects on Max of the TTTS and his premature birth. We continue to mourn the loss of Oliver, our son, Charlotte's brother and Max's twin. There are so many "what ifs". Despite knowing in my head that where we are today is where we are meant to be, my heart agonises over the events and decisions that we made.

We would not have made it through the last year without the love and support of our family, friends and community and without the professional knowledge and expertise of the health professionals we entrusted our care in. We have been humbled by the overwhelming response from those around us that has come from such devastation.

First there was one, then there were two and now we have one here with us on earth and one above us in heaven.

## NICU Checklist

*This is a list of some things you might like to think about and do if your baby or babies are in the NICU. Some of these things you may already have been told, or know about, which is great, but some you may not have thought about and might be helpful to you during your NICU stay.*

### Photos/Video

- Take lots.
- Remember photos that include all the equipment that surrounds your baby - they may be interested in it when they are older, it can be easy to just take photos of your baby's beautiful face when the NG tube is out for example, but get a couple with it in too.
- Try to take photos that have something in them, such as a doll or teddy bear, for a size comparison. You can keep including the item at regular intervals, and it helps you to see how small your baby was, and how much they have grown.
- If your baby is small enough you could put your wedding ring, or other ring, over their arm like a bracelet.
- Consider a camera with date/time stamps on the photos so you know when they were taken - it can be difficult to keep track.
- You might want to see if you can leave a disposable camera with your baby for the nurses to take pictures with (however keep in mind that the quality may not be great, and it may go missing).
- Ask if the NICU has a video camera available, some hospitals have a video camera available and you just have to bring in your own film and can then video your baby (easier than bringing in your own video camera).
- If you have twins with similar toys but a different colour (or just different toys) try to include the toy in each picture so that later you will know which twin the photo is of.

### Diary/Journal

- Keep a diary or journal.
- It is great to try to include some personal things like how you are feeling and thinking, and what is going on with you.
- A start is just to include some of the more medical information such as how much oxygen your baby is on and their current weight.
- When you are feeling like your baby isn't progressing, being able to look back to where they were a month ago can show you how far they have come.
- Another idea is to leave some pages for the nurses to write on that you can stick in the book, just a couple of sentences is enough (they probably won't have time for much else).

### Parking/Meals/Accommodation

- If you haven't been told anything about subsidised parking, ask. Most hospitals offer some sort of parking discount for the families of long term patients.
- Check if meals can be provided for you, or if you can get meal vouchers for the cafeteria.

### **NICU Checklist (Cont'd)**

- Find out if there is accommodation available within the hospital or nearby for when your baby is struggling and you don't want to leave.
- If you live a long way from the hospital, the hospital should be able to help you find accommodation nearby eg a Ronald McDonald House or similar.

### **Looking after your baby/babies**

- Once your baby is relatively stable, you should be able to start doing some of the care yourself.
- If you haven't been shown how to change a nappy or wipe the eyes or mouth, ask, things like that can easily be done by parents rather than the nursing staff. Bed baths, "proper" baths, and gently rubbing oil into dry skin are other cares that parents can do.
- Bring in prem sized clothes to dress your baby in (great for taking photos to show size too, as you can keep the garment). Make sure the clothes have been washed and are named. Provide a few spare sets in case your baby needs to be changed, and make sure there is somewhere (eg a bag) for the dirty ones to be put for you to take home and wash (if they end up in the hospital wash, you may never see them again).
- If the baby has relatives who can sew (eg grandparents) they may be able to make something appropriate for the baby to wear, and it will help them to feel involved with the baby.
- Check with the hospital as to what clothing is appropriate. It will need to be easy to get on and off if your baby is still on oxygen or has other medical needs. Some hospitals won't allow clothing until your baby has reached a certain stage. Some hospitals sell clothing, you may also be able to find some on our [Products page](#).
- Ask for cuddles as often as you like. Always remember that if the nurse says no because your baby is not well enough just then, that is okay, check again later or the next day. Learn about Kangaroo Care.
- Get the nurses to go through and explain not only the equipment and their settings but also the medical charts and how to read them ... you'll know exactly what your baby did and what tests were done without having to ask the nurses. Remember to ask for clarification about anything you don't understand or aren't sure about. If the nurse doesn't explain enough, or you don't understand the first time, ask again. It can be hard to take everything in all at once. Speak to the doctor concerned if you need more information.
- Ask as many questions as you want ... it is your baby, and you have every right to know what is happening to him/her.
- Some hospitals have a training session available where they officially teach you how to do tube feeds (what to watch for etc) and you can then help do the feeds even if you aren't breastfeeding (a nurse just has to be on-call should you run into trouble).
- Ask for foot and hand prints if possible. They grow so quickly you won't remember how small they were.

### NICU Checklist (Cont'd)

- If things don't go so well, take all the time you need. Do the things you have always desired to do - one mother 'breastfeed' her baby - one drop of milk on her lips as she slipped away.

### The Family

- Find out how many visitors your baby may have at once, and if there are restrictions on who. If you have other children, check when they may visit and if there are any restrictions there too.
- Take Tissues - nurseries have them but not always enough.
- Get dad involved as much as possible - but don't push him - some dad's can't cope with full term babies, let alone prems. By the same token some dad's might feel left out or pushed away. If there are any problems, find out if there is a male nurse or doctor that can talk to the father and support him.
- Ask to see a lactation consultant or a social worker etc if you feel the need ... these services are usually available even though they may not be directly offered to you. Dad's can make use of the social work service too.
- Find out if there are any talks for parents (or grandparents). Read noticeboards regularly. Check in the Parent's Room (or whatever it is called in your hospital) to see if information is posted there.
- It is important to realise that you and your baby have rights. If you are not sure about something, ask for a second opinion. Make sure you understand the risks and side effects of any treatments offered to your child. Just as you can say "yes", you also have the right to say "no" to participating in research trials if you don't want to do it. Whether you are a public or private patient, you have the right to ask for the options to be presented to you, and to ask for a different doctor to take a look at your baby and to give his/her suggestions about treatment.
- Find out if the hospital offers a support group, or at least try to get to know some of the other parents who also have their baby in the NICU. Get contact details from them, you might see them everyday while your babies are in hospital, but once you go home you will need a phone number or email address to keep in contact.
- Access the Austprem [Discussion Forum](http://www.austprem.org.au) to find a heap of parents who have been through the NICU experience and understand what you are going through. Ask questions, get support.

### Most Importantly

- **DON'T FORGET THAT IT IS YOUR BABY ... NOT THE NICU'S**

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*We hope it is helpful to you and wish you well during your NICU stay.*

# **SURVIVOR UPDATES**

Well, as my TTTS surviving twins have their original due date in April, I thought I might do a "stocktake" of the past 3 years and give everyone an update on how they are going.

We spent a cumulative 22 weeks in hospital - 5 weeks for myself pre-birth being monitored due to the TTTS, Joshua, our recipient twin spent 7 weeks in the intensive & special care nurseries, and Caleb, our donor twin spent 10 weeks (the twins were born at 30wks). After finally coming home we had an absolute whirlwind of never-ending bottles, nappies and crying babies. We had a huge size difference between the boys to begin with - Caleb only weighed 1922g when he came home from hospital, and Joshua was about 3kg by this stage, so the difference was very noticeable, made all the more so by the fact that Joshua was your typical chubby baby, whereas Caleb really looked like he had been through a recent famine! Quite a few people came up to me when we were out in public and would comment on the size difference - I'm sure some of them thought I only fed one baby! They both fed well though, and Caleb began to plump out before too long. We joined our local multiple birth group, and began attending their playgroup when the boys were about 8 months old. Throughout the first year, we had many checkups at our hospital's Growth and Development clinic, where the boys were checked for things like length, weight, hearing, and developmental milestones according to their corrected age. Caleb also needed a few checkups for his eyes, as he was under 1000g at birth. We got the all-clear in all departments. Caleb also had a bout of bronchiolitis at about 10 months of age, and needed to be hospitalised overnight, but recovered quickly. Joshua also got the virus a few days after his brother, but to a lesser degree.

On to the second year - Joshua walked at about 13 months (corrected) and Caleb at about 14 months (corrected). Our house was turned into a barricaded fortress from then on with two toddlers on the move! They got into anything and everything, and taking them out anywhere was a major exercise as they tended to run off in different directions, which was especially trying when I was by myself! They both had some recurring ear infections, Caleb in particular - due to his small size his tubes blocked easily. They also battled a bit of asthma from time to time (mainly when a few colds & flus were around). The size gap had reduced considerably by this stage, although by the time the boys were 2, there was still 2kg weight difference, and Caleb was still noticeably shorter than Joshua when they stood side-by-side.

The 3rd year has seen the last G&D clinic checkup for Joshua, as he has been developing normally and has had no problems, and Caleb doesn't need another checkup until he is 4. The size difference has closed quite a bit - Caleb is still about 6cm shorter than Joshua, and they have about 2kg between them, and 1 clothing size (which has been very economical!). They are starting to look more alike, too, which has been interesting, as the size difference has made their faces look quite different at times. They are also starting to talk, although they are both a bit behind in this department due to their prematurity - at 3 years of age, Joshua is about the level of a 2.5 year old, and Caleb is at the level of a 2 year old. They both recently went for a checkup with a speech pathologist, who is happy to just let Joshua develop on his own for another 3 months, and then do a checkup, and Caleb is about to commence 6 sessions of speech therapy. Their asthma has lessened to almost non-existent, and they haven't had any illnesses for a while, which is a relief!

Overall, a very busy but successful 3 years!

Linda Back

**AUSTRALIAN**  
**TWIN TO TWIN TRANSFUSION SYNDROME**  
**SUPPORT GROUP**

**MINUTES OF MEETING 11<sup>th</sup> FEBRUARY 2003**

Held: at the home of Linda Back.

Opening: 9:43am

Present: L. Back, V. Sciacca

Previous Minutes: Minutes were accepted as true and correct.

Business Arising from those Minutes: AMBA QLD clubs not to receive a newsletter at this stage – info brochures to be sent instead.

Correspondence In: AMBA – Year Planner, Convention Information, Special General Meeting. Special Needs Register – change of address. Toowoomba MBA – State Seminar. Cathy Vellacott – Multiple Pregnancy Conference in Melbourne, February.

Business Arising from Correspondence: Victoria to attend Multiple Pregnancy Conference in Melbourne.

Toowoomba State Seminar in May – Victoria and Linda to be providing a workshop on TTTS at the Seminar.

Correspondence Out: AMBA Literary Review – Flyer sent to Susanne Thompson to be approved.

**REPORTS:**

Treasurer's Report:

Membership Report: 2 member families.

**GENERAL BUSINESS:**

Flyer has been approved by Literary Review. 100 copies to be printed, Victoria is to take some to the Multiple Pregnancy Conference in Melbourne. Information Brochure, Membership Application Form and Website to be sent to Literary Review, as well as a final copy of the Flyer.

Movement to adopt AMBA Constitution: moved by V. Sciacca, seconded by L. Back

Movement to adopt AMBA Code of Ethics: moved by V. Sciacca, seconded by L. Back

Disclaimer to be put on bottom of outgoing emails – 1 x medical and 1x error.

New enquiries and members contact letters to be addressed individually, according to need & situation.

Treasurer: Accounting system has been set up.

Newsletter: Minutes to be included in the newsletter.

Next Meeting: To be advised.

Close: 10:58am

Australian TTTS Support Group

**ANNUAL GENERAL MEETING**

Tuesday 20<sup>th</sup> May 2003

At Linda Back's Home

Ph: (07) 3823 4612

Followed by Committee Meeting