

# TTTS Times

*Official Newsletter of*



## **Twin to Twin Transfusion Syndrome Australia Inc**

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 TTTS Australia Inc., 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 club. 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

The President's Say	Page 3	Zoe & Taylor Wall - TTTS Survivors	Pages 6-7
Phone Contacts	Page 3		
From the Editor's Desk	Page 4		
How to Contribute to TTTS Times	Page 4	Membership Application Form	Page 9



**Twin To Twin Transfusion Syndrome Australia Inc**

Founded 2002

Phone: (07) 3849 8198 or (07) 3823 4612

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)

**Twin To Twin Transfusion Syndrome Australia Inc 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 association
- 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 association 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

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

**DISCLAIMER**

TTTS Times is Copyright. AMBA members may reprint provided source is acknowledged. Statements, opinions and viewpoints expressed in this newsletter are those of the writers and do not necessarily represent those of the association. Information contained herein is not a substitute for personal, medical, psychiatric or psychological advice and readers are urged to consult their healthcare advisors about specific questions or problems. Mention of goods or services in this newsletter does not represent a recommendation or endorsement by the association.

## The President's Say...

Hi Everyone,

Well, the last two months have gone by so quickly. Matt brought home a stack of literature this week on university and picking his subjects for Year 11. It is so hard to believe that he is already at that stage of his life. It just reinforces to me how quickly children grow up. I am determined to try and enjoy all my time with Mitchell (even when he is pushing the limits).

I hope you all approve of our new logo. I was sitting at my PC one Sunday morning playing around with some ideas. When this one appeared it seemed perfect for the group. It signifies TTTS in that there are similar babies together but of differing sizes.

Well, until next time, stay healthy and safe,  
Vicki

### Phone Contacts

QLD	Victoria	Phone: (07) 3849 8198 Email: <a href="mailto:vicki@twin-twin.org">vicki@twin-twin.org</a> 1 survivor (recipient twin) born at 29wks gestation. Donor twin stillborn, due to Acute TTTS Recipient twin 1339g, donor 1191g. Surviving twin home on O2
	Linda	Phone: (07) 3823 4612 Email: <a href="mailto:linda@twin-twin.org">linda@twin-twin.org</a> 2 survivors born at 30wks gestation. Recipient twin 1560g, Donor 808g. Steroid injections before birth, Hospital bed rest, Separate hospital discharge (one twin home before the other).
VIC	Rachel	Phone: (03) 9459 7374 One survivor (Recipient twin), born at 28wks gestation. Donor twin survived 6 days. Serial Amnioreduction, Steroid injections.
NT	Nicole & Darren	Phone: (08) 8947 0725 Mob: 0418 199 173 2 survivors, born at 37wks gestation. Stage 1V TTTS, Hydrops in recipient twin, Fetal Laser Surgery performed at 23 weeks. Hospital bed rest. Donor twin 2.3kg, Recipient twin 2.2kg

## From the Editor's Desk...

Hi everyone, welcome to yet another edition of TTTS Times. As you have probably noticed, our front cover has a brand new LOGO - yes, we are now an incorporated association!!! The official new name of the club is "Twin to Twin Transfusion Syndrome Australia Inc". Thanks to Victoria for designing the new logo, which really gives a good picture of TTTS at a glance, and it also ties in well with the logo of the Australian Multiple Birth Association, of which we are a member-club. As well as the incorporation of our club, we also celebrated our 2nd anniversary in July - the club is officially 2 years old!!!

Many thanks to Lee King for her wonderful story about her survivors. We wish Lee, Jamie and Jake all the best when they bring their precious bundles home from hospital! On the home front, it has been a busy couple of months. Caleb recently spent 3 nights in hospital after coming down with quite a severe case of pneumonia. Thankfully he is fine now, although they tell me that once you've had a case of pneumonia you always need to be careful of getting colds afterwards as they can go straight to your chest. This is a bit unfortunate, as Caleb managed to come through the whole prematurity rollercoaster with no lung problems at all! Oh well, I guess that's life.....

Don't forget about the AMBA Convention, which this year is being hosted by the Brisbane Multiple Birth Association (Southside) Inc from 15th -18th October - both Victoria and I are involved in the organization of this event, and it would be lovely to see some of our members come along. Representatives from most of the multiple birth clubs from around Australia attend this event, which is designed as an informative and also relaxing event for parents of multiples. If you are interested, please contact me and I can send you a registration form.

**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  
TTTS Australia Inc  
P.O. Box 1343  
Carindale QLD 4152

**Deakin University Advertisement**  
**A Study of Couples’**  
**Experiences**  
**of Complicated Births**

The School of Psychology at Deakin University is currently conducting a study of the experiences of couples who have had children born under medically difficult or complicated circumstances, such as prematurity or multiple births. We seek to investigate the specific kinds of stress couples experienced, the way they typically dealt with their situations, and the type and value of support they received (or would like to have received) from hospital staff, family, friends, and each other. We are particularly interested in the way mothers’ and fathers’ experiences and responses to these difficult circumstances might differ from each other, and, as such, whether they may have different needs in these situations. At this time, we are seeking couples whose child is currently 12 months or older. It is hoped that the study will contribute to improving the way that couples are prepared for and assisted through the process of dealing with problems that occur during or around childbirth.

We are seeking couples who are prepared to be interviewed by the researcher, Sarah. Sarah is currently completing her Doctorate of Health Psychology under the supervision of Dr Greg Tooley. Interviews will be conducted separately with each partner, and each interview will take around an hour. If you and your partner might be interested in participating in the research, please contact Sarah Phillips at Deakin University for more information.

If interested, please call for full information on 0421 060 757, or (03) 9898 2051. Sarah Phillips, Doctorate of Psychology, Deakin University.

**CONGRATULATIONS!!!**

To Rachel, Pete, Charlotte, Max and Oliver

Our Angel Ollie guided his baby brother into our family’s loving embrace on July 24th 2004.

James Anthony Robert Tyler, 3.3kg - a healthy full term babe

# TAYLOR & ZOE WALL

## A TTTS Survival Story

My husband Jamie and I (Lee) found out that I was pregnant with twin girls at my 12 week scan on Friday the 13th February 2004.

We also have a 19 month old boy (Jake) and live in Hong Kong so we decided to have the twins at a public hospital in Hong Kong.

At 13 weeks I had a large bleed which sent us into a panic but an ultrasound showed the girls were fine. My 16 week and 18 week ultrasounds were normal and our excitement began to mount in anticipation of the girls' arrival.

Between 18 and 20 weeks my girth expanded to the size of a full term mother and back pain, breathlessness and general lethargy began. I thought this pregnancy was different from my first because I was carrying twins, so I ignored the signs and my concerns.

At our 20 week ultrasound the doctors explained that we had TTTS and that I required laser surgery within the week.

Jamie and I were very shocked, upset and nervous about the girls' outcomes. We wanted a second opinion, so we flew to Adelaide and went to see a specialist at the Womens & Childrens Hospital who confirmed our worst nightmare. The doctor did an amnio reduction removing two litres of fluid, to help my pain (which came from a contracting uterus). He then gave us options:

1. Terminate the pregnancy
2. Amnio reductions on a regular basis
3. Laser surgery in Brisbane

After many days of research, tears and another amnio reduction Jamie and I chose surgery in Brisbane.

At 21 weeks I was the first woman in Australia to undergo laser ablation surgery under local anaesthetic. Jamie was present throughout the procedure to offer me support. The operation was a success in stopping all connections between the girls but I was still quite large and in pain due to the excess fluid.

We returned to Adelaide where I was monitored weekly. At 25 weeks my fluid levels were slowly reducing and my donor baby (Zoe) finally had some fluid around her after weeks of being stuck to my uterus wall wrapped in her membrane. Taylor (recipient) on the other hand was still swimming in a pool of fluid.

At 26 weeks and 6 days I felt something was wrong and went to the hospital. After blood tests and an examination I was told that I needed a steroid injection and was admitted to the labour ward. My blood tests showed an elevated white blood cell count and CRP which both indicate an infection. The doctor was unable to find any infection in me and we feared the babies may have had an infection. I was told another amniocentesis was required to rule out an infection in the babies. Tuesday afternoon I had an amniocentesis which came back negative, but 3 hours later my uterus started contracting. My contractions were irregular and the babies' heart rates were normal so I was just observed. The contractions continued throughout Wednesday as well after a sleepless night.

Wednesday night the contractions increased in their intensity and regularity and no analgesic seemed to relieve me. I knew this was it, the girls were coming tonight!

At 3am I called the nurse and told her I thought the girls were coming. At this point I was 6cm dilated and the doctor decided to do an emergency caesarean.

Taylor and Zoe were born at the Womens and Childrens at 27 weeks and 3 days, weighing 1110g & 1030g.

Neither required ventilation and had some oxygen support via CPAP. After the first 14 days in NICU they were transferred to SCBU1. Both are now 5 weeks old weighing 1725g & 1480g and doing well. They are being fed my breast milk via nasogastric tube and both remain in humidicribs with a small amount of oxygen.

It has been a long, rocky road and we still have a long way to go but I'm confident that my pain and suffering during pregnancy was all worth it!

**Lee, Jamie and Jake Wall**

**Update:** As of 12/7/04 the girls were upgraded to SCBU2, on 3 hourly feeds & being weaned off O2. By the time this issue goes to print, Lee, Jamie & Jake should have their girls home with them. Well done!

# Twin Toddler Safety

*By AnnMarie Killam*

*Reprinted from [www.bellaonline.com](http://www.bellaonline.com)*

Around 4 months of age your twins will start to grab for items they find interesting. It is at this time that you should consider baby-proofing your home. In order to do so, it is my recommendation that you think like your babies do. This may take getting down on all fours and examining the world around you from a baby's point of view. You will be surprised at how many things you may not have thought of that could be a potential safety hazard for your little ones. It is important that you do not wait until your twins are crawling to baby-proof your home. That could be too late.

Even before you brought your little ones home from the hospital, there were safety items you had to take care of.

- Make sure there is a list of all emergency phone numbers close to all phones. If these numbers are programmed into speed dial, make sure they are labelled clearly.
- Secure all cords away from cribs, changing tables, bassinets, play pens and any other play areas. All cords, especially from mini blinds pose a potential hanging danger to small infants.
- Always secure infants in car seats when travelling. Make sure there are proper attachments to your vehicles seat fasteners. Some manufacturers include child safety devices to be attached to the belts for maximum and efficient use of restraints. If your vehicle does not have them, check with the manufacturer. They should give them out free.

Now that your twins have started the searching phase, it will not be long before they will be examining everything they can get their hands on, and with two of them, that is double the amount of trouble they can find in half the time. So here is a partial list of safety precautions you should take in your own home.

- Make sure all chemicals and toxic items are out of reach of the twins. This might mean installing locks on cabinet doors or putting the chemicals high. Just remember, soon they will learn how to climb.
- In case of accidental swallowing of a poisonous substance, syrup of ipecac should be kept in the medicine cabinet. With twins, you should have two bottles, one for each twin. Remember do not administer syrup of ipecac without the advice of your paediatrician.
- Now is a good time to install special locks on all your cabinet doors. These are available at your local discount/hardware store. While pots and pans may seem harmless, they could fall and insure one or both of your twins. They may also be used a potential "weapons", one twin against the other. It is best to keep them locked up.
- Plug all outlets. These are tempting places for little fingers and at the perfect level.
- If you have older children at home, it is a good time to discuss with them the dangers of leaving little toys laying around. Your twins should be able to grasp small objects now and will undoubtedly put them into their mouths. Small items such as buttons, crayons, legos, money, small foods, and other small toys should be picked up. Older children need to get into the habit now of always checking the floor for these items.
- Get rid of any bookcases that are not secured to the wall. As your twins grow, they will learn to pull themselves up on anything within reach. Unsecured bookcases pose an obvious danger. Put these items into another room until the twins are older.
- Never leave your twins unattended and never leave them laying on a bed or sofa by themselves. It is too easy for them to roll over and fall off. Do not use a pillow to keep them secure. This is an unreliable means of protection. It is better to just lay them on the floor or put them in their cribs.
- While you may love displaying your favourite crystal, these shiny glass ornaments are appealing to your twins. Besides getting broken, the tiny shatterings could cause cuts on your twins. It is best to put these away until your twins go to college.

While this is just a partial list, it is best to evaluate your own house. Check for stairways, doors, glass, sharp edges, and any other surface that could hold a possible danger to your twins. Remember, if you have to, get down on your hands and knee and scout around just like your twins will.

Good luck and have a safe home.



**Twin to Twin Transfusion Syndrome Australia Inc**

**APPLICATION FOR MEMBERSHIP**

Membership Fee: \$20.00 per annum  
\$15.00 for members of an AMBA club

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: (\_\_\_\_) \_\_\_\_\_ Email: \_\_\_\_\_

Are you a member of an AMBA club? \_\_\_\_\_

If so, which club? \_\_\_\_\_

Could you please give us a brief description of your pregnancy and birth of your twins/triplets: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Names & birth date of your multiples:

Multiple 1: \_\_\_\_\_ Did this baby survive? \_\_\_\_\_

Multiple 2: \_\_\_\_\_ Did this baby survive? \_\_\_\_\_

Multiple 3: \_\_\_\_\_ Did this baby survive? \_\_\_\_\_

Names and birth dates of other children (optional):

Child: \_\_\_\_\_

Child: \_\_\_\_\_

Child: \_\_\_\_\_

Child: \_\_\_\_\_

Please send a cheque/money order made payable to "T.T.T.S. Australia Inc" to:

T.T.T.S. Australia Inc  
P.O. Box 1343  
Carindale QLD 4152

**Education, Compassion, Support**