

TTTS Times

Official Newsletter of the



Australian Twin To Twin Transfusion Syndrome Support Group

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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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Website: www.twin-twin.org

Email: info@twin-twin.org

Australian Twin To Twin Transfusion Syndrome Support Group aims to:

- Disseminate information about TTTS as a disease 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:

- Monthly meeting, held in members' homes
- Coffee Mornings/Afternoons in members' homes or suitable venues

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 Group. 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 Group.

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The President's Say...

Hello and welcome to *TTTS Times* and the Australian TTTS Support Group! Linda and I have enjoyed getting everything up and running and we look forward to helping as many people as possible.

I am mum to 5 sons: Matt (13), Ben (10), Daniel (7) and my TTTS twins, Mitchell (2 1/2) and Antony ^^i^. When I was diagnosed with TTTS at my 19 week scan, I searched high and low for local printed information. The only information, readily available, was on the Internet and all of it was from overseas.

After Mitchell was released from hospital, after 10 weeks, I decided to do something to help Australian TTTS parents. I wrote my story for the local multiple birth association's newsletter and from that, I met Linda. Over the past 2 and a bit years, we have met so many wonderful people. Some have provided us with assistance in getting the group started, others have been a rock to lean on when times were tough. To all of you - Thank you! Without your help this would have remained a dream.

Some of our goals for the future are as follows:

- To provide support to those who have been diagnosed with TTTS;
- To educate the community as a whole about TTTS;
- To raise funds to be distributed to research in TTTS.

I hope that we can all find the support that we may need from being in contact with other parents who have experienced a TTTS pregnancy. Some of us will be fortunate to have both our twins, others, sadly, will have lost one or both. We have all suffered a pregnancy tainted by TTTS and that is a common bond we all have.

Take care,
Victoria Sciacca

Phone Contacts

QLD Victoria - Phone (07) 3849 8198
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

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 and welcome to our very first issue of *TTTS Times*! Let me introduce myself, I'm Linda, and I'm mother to (nearly) 3-year-old TTTS survivors, Joshua & Caleb. These two, needless to say, keep me very busy and really are a pair of high-energy munchkins! They were my first pregnancy (boy was that a shock!) and we are very lucky to have them.

Well, down to business, we've got some good reads in this, our inaugural issue - a big thank you goes to Susan for her wonderful article on raising a surviving twin. We wish Susan and her family all the best with raising little Brianna. And please have a read of the special Christmas article - with Christmas approaching it is the time to spare a thought for those who may have suffered a bereavement. I've also included an story about my experience with having separate hospital discharge of twins.

Finally, I'd like to welcome new members to our club. If you have any suggestions, or if you would like to become involved in the club in any way, please don't hesitate to contact either Victoria or myself on the numbers/ addresses below. We are endeavoring to make the newsletter cater to the various situations that can result from TTTS (ie 2 survivors, 1 survivor, 0 survivors) so please keep in mind that we may include both bereavement and surviving twin issues in this newsletter, to cover all aspects of the condition.

Catch you all next month!

Linda

To Contribute to TTTS Times...

Stories
Birth Notices
Memorials
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

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



New Book available from bookstores...

"TWINS"

By Louise Ryan and Katrina Bowman

'A practical and emotional guide to parenting twins'

The number of multiple births is rapidly increasing due to IVF and the older age range of new mothers. More people are having twins than ever before.

Twins offers sound practical advice that is backed up by medical practitioners and health professionals. Detailed information with user-friendly explanations of medical jargon is peppered with amusing and moving stories of catastrophe, chaos and coping. There are at-a-glance hints and tips at the end of each chapter and easy-reference tables of information throughout.

Louise Ryan has worked in the book trade for over fourteen years. She is the mother of 3-year-old non-identical twins, Camille and Celeste, conceived through the IVF program. As well as working full-time she has been a Committee Member, Ante-Natal Coordinator and Librarian for the South Eastern Multiple Birth Association (SEMBA), hosting regular ante-natal information nights.

Katrina Bowman is the mother of Charlotte and Ella, identical 2-year-old twins. She has over ten years experience in the Public Relations industry where she is currently working part-time. Katrina is also a Committee Member and Social Secretary for SEMBA, where she organises a full program of social events to help parents of multiples to develop networks and share information.

Published by ALLEN & UNWIN \$29.95 tpb

Available from all good booksellers.

WARNING SIGNS OF PRE-TERM LABOUR:

Treatment of pre-term labour is most effective when it is begun before the labour becomes too advanced. It is important to recognise it before cervical changes occur (before the neck of the womb opens too far). Drugs can be given to prevent going into full labour if pre-term symptoms can be treated early. If you have any of the following signs go straight to your doctor or labour ward.

- * **uterine contractions**
- * **pelvic pressure**
- * **leakage of fluid from the vagina**
- * **increase/change in vaginal discharge**
- * **abdominal cramping with or without diarrhoea**
- * **menstrual-like cramps**

Reprinted from 'Double Treble News', Aug/Sept 2002
Via 'Multiplicity', October 2002



Christmas Love

By Joyce McKeough

Reprinted from Australian Multiples Magazine, Issue #90

Christmas...a time of joy and happiness....of presents and smiling faces.... lots of cuddles.... lots of food. Isn't it great?

Well, that is what you would predict for all those families who celebrate the festive season....right? We learn of a very special birth on that morning. Of many nations throughout the world remembering and experiencing the joy of the difference the birth of a child brings into the world. I know that I used to look at the faces of my children and revel in their respective births and this would add to the joy of my Christmas. Well, unfortunately that is not the case for many families. Christmas can be one of the saddest and most "gut-wrenching" times for many families.

I do not want to take away your joy, I would just like you to spare a thought for those many families who have experienced the death of one (or more) of their children. Can you spare a thought for your fellow parents? You may find a mum just a little grumpy or that friend who seems not wanting to be happy when everyone else seems to be. They have good cause. Their child may have been just a few moments old or never been able to take that most glorious of first breaths. They may have been a toddler or a teenager. It does not matter at what stage of their development they died. With their death went our dreams....our hopes and our joys for what might have been.

We as bereaved parents find that at these special times of the year we cannot fully give ourselves over to the joy of the moment. The joy is always "tinged". Tainted by the thoughts of what could have been. Torn between the joy of those surviving children you have and the sadness that they are not able to share this joyful time with their siblings. It is just so difficult to buy gifts for some of your children and not others.

I can give you a small glimpse of Christmas morning for me -

I sit in the garden on the seat near Liam's pond. I "talk" to him about my year and what milestones of his I have missed. This year I will talk about not being able to plan a 21st for him in the next few short months. I will tell him of my plans for his sister's 18th. And of the troubles I am experiencing with his younger brother....wishing he were here to help guide me through this most difficult stage of parenting. I will tell him how much I miss his smile and his most precious sense of humour. I will tell him how my life has changed recently and the direction I hope it will take. I can't say how long I will sit and "talk" with him but when it feels right I will dry my tears and put a smile back on my face and go and enjoy Christmas day with other precious children....grateful I at least have them. I will also think about those parents who have no children to share Christmas with and wish I could give each and every one of them a cuddle and tell them I care about their pain and their loneliness.

So if you know someone who has walked this dreaded path of grief, take a moment to call them. Tell them you care. Ask them if it is a difficult time of year for them. If they answer yes, ask if they want to talk about their children. If they do, use their child's name. Do not worry if you shed a tear....most of us will take it as a compliment you remember as so many don't. Don't be surprised at the depth of feeling. There is no rule as to how you should feel. For some the pain is as fresh as if the death were yesterday, when it could have been many years. For others the pain may not appear to be very deep at all when the loss was only recently. Just offer your ear....your shoulder....your time.

And please more than anything give all of your children a very special hug just for being "your kids" and tell them how much you love them.

Our Invisible Twins

By Susan Morgan

I am the mother of identical twin girls. They were born on the 9th of February 2001 at 29 weeks gestation due to chronic twin to twin transfusion syndrome which went undiagnosed until 24 hours prior to their birth. Like all mothers of twins, I knew while I was pregnant with them which was which – they had such different personalities! Brianna Hope was my 'big' twin, and my firstborn daughter, weighing 1055 grams. Devon Grace was my 'little' twin, my second born girl, weighing just 470 grams. I knew when I was carrying them during an absolutely dreadful 2nd trimester that there was a big size difference. But even though I felt so certain of this, my instinct was disregarded by my care providers. I was not referred for a scan between 19 weeks and 29 weeks, until after I had begged to be allowed to return for specialist follow-up.

Only one of my daughters survived the first night – Devon Grace passed away in my arms at 8.20pm, 3 hours after her birth. She was beautiful; absolutely perfect in every way, and I am blessed that I had even that very short amount of time with her. My surviving twin Brianna Hope was critical at birth – her heart would not have held out much longer and she was still at risk for the first 2 weeks of her life; such is the nature of this cruel syndrome. The babies are developmentally perfect; it is a malformation of the placenta that takes so many of these babies, long before their due dates. However, after a very tenuous beginning to life outside the womb, Brianna lived and thrived and is now very much caught up with her 'corrected age' peers. I am fortunate here as well. Many – no, the majority of twins who suffer from twin to twin transfusion syndrome will die without treatment, and many that survive it will suffer mild to severe neurological problems and developmental problems both from the effects of the syndrome combined with prematurity. Many mothers lose both of their babies. That my girls were liveborn after suffering a severe form of TTTS undiagnosed and untreated to 29 weeks, was in itself a miracle. Still, to find yourself in the position of trying to embrace new life whilst in the early stages of child-loss is a confusing and heart-breaking situation.

Since my loss I now understand the term 'high risk' as it pertains to a twin pregnancy. I think I understand this better than a great many medical care providers. I assumed, when I was diagnosed with twins, that 'high risk' (only mentioned to me once in passing) meant that my babies may be born early, that I may be more prone to high blood pressure or pre-eclampsia. Nobody explained to me the abundant risks that arise in a twin pregnancy, far too many to mention. Sadly, I now know a lot of women who have lost one or both of their twins in a staggering multitude of circumstances.

There is still so much unknown about twins and even more so unknown about surviving twins – which is why people like to research them! From a research point of view there is an added attraction in studying twins separated at birth or early infancy, and it is astonishing at the parallel lives, traits, lifestyles, likes and dislikes that these twins share. But more amazing is the response from an adult who was never told about their twin – they often say that they 'always knew' that there was something missing and that their lives may have been made that much more fulfilling if they had been able to know and have contact with their womb-mate. This is how I look at my daughter. I think a part of her will always know, but there is obviously no chance for reconciliation with her twin during her lifetime. The research I have uncovered also indicates that a surviving twin is more likely to suffer depression during their lives; from my point of view I have to wonder if a lot of this depression is the lack of recognition that they

will receive from society towards their twin-ness. They know they are different from the many. I have heard stories of twins 'recognising' each other, even without their twin siblings present. And I have read that my solo twin will, on some level, be able to sense this about other people, as intact twins will recognise this about her. The consensus is, from a bereavement perspective, that it is important that our survivors know about their twin from the start; and this should also be supported by family, friends, teachers and peers, as rejection of this unique part of our solo child twins can lead to a very real emotional struggle within themselves as they grow older - they 'feel' different, but without that recognition of their difference, they cannot explore this part of their psyche and deal with issues that may arise, such as a strong sense of loss, detachment from their peers and even, sadly 'survivor's guilt'.

Often, there are also parallels between our survivors and intact twins. Our solo twins will often show similar developmental delays; many of our survivors babble incessantly in their own language, well past the point when they should be forming words, which also occurs with intact twins. Our twins can show a certain aloofness in social situations, happily playing alone as if they were enjoying the company of their twin. And as they grow, our survivors will often become very attached to a select few people - this very strong attachment is a way in which they try to recreate the bond they are missing with their own twin.

I am the mother of twins. I know I am. But in my situation, there are few in my life that will recognise this. Not only have I lost this recognition, so has my surviving twin Brianna; and because of this my other daughter Devon Grace does not get acknowledged either. Because I have a living child from my pregnancy, the expectation is that I will not grieve for too long. So many people, trying to be kind, have diminished my loss with thoughtless platitudes - "At least you still have one", "It was God's will", "She wouldn't have had quality of life", or "It was meant to be". These words did not, do not, and will never comfort me. I lost a daughter. My amazing, strong and beautiful Brianna has lost her twin. But from the perspective of my peer group, Brianna is the product of my 3rd pregnancy, and they cannot see where I have lost. Who can better understand the extent and depth of our loss than the mothers who have both of their twins?

I will probably never become an active member of my local MBA - instead I am a member of MBABS, OzMOST (Australian Mothers of Surviving Twins) and the Australian Twinless Twins group. I will never be able to celebrate Multiple Birth Week, so instead I support SIDS / SANDS, and the Australian TTTS Information and Support group. It is unlikely that I will ever socialize with mothers who have both their twins, because I will never get to talk about the wonderful and amazing things that my twins do. Instead I befriend and support other mothers who have lost their own twins. I need this contact for a huge variety of reasons. It is likely that only 'these' mothers will allow me to talk (for the rest of my life) about my angel twin, and not feel uncomfortable when I refer to my Brianna as a twin. Who else will remember both my girls on their Birth-Day, and cry for me when the sadness overwhelms me, as it will throughout my life. Who else would understand me when I instinctively reach out to embrace my living daughter, because I can sense an aura of 'aleness' around her. And who better to comprehend the bittersweet sensation that envelops me when I see my twin leaning against a mirror - her reflection shows me two little identical girls who are joined at the point where Brianna's body touches the glass. Our solo twins will often also be uniquely different from our singleton children, and it reassures me to know that the many surprises and challenges ahead of me can be shared with other mothers who will understand.

I would have given almost anything to have had the chance to bring both my daughters home with me. To have stumbled through that first hard year of raising twins, constantly sleep deprived, nerves taut with stress, wondering when the 'hard part' would end, just for the joy of seeing my daughters sleeping side by side.

I don't know for sure, but maybe more mothers like myself should become involved in our local MBA – maybe our survivors would benefit from inclusion and interaction with intact twins. But from a mother's perspective, a decision like this would take a lot of courage. Many of us find it hard to overcome the yearning we feel when we look at a set of twins, particularly a set that mirrors our own (in my case, identical girl twins of a certain age!); and because of this very deeply felt yearning, a part of me feels that I need to protect Brianna from the same sort of longing she may experience as she sees other twins with their partner, where she has none. My wish is that she does not yearn – I hope I can bring her up to find her own way of coming to terms with her unique situation, and to provide her with the love and support she needs to deal with it as she grows.

My daughter is still so young, and there are so many unknowns ahead of me. She shares a unique bond with her sister, but will never have the opportunity to physically express this bond. It is a daunting journey for me, and for so many mothers like me. We don't know what to expect with our survivors, but we love them fiercely, protect them in every way that we can, and almost without exception, will bring them up with the knowledge of their twin. Devon is a part of our family, and I will not hide that from anyone, especially her sister. I wish I didn't have to spend the rest of my life looking at my living twin and wondering "does she miss her?", "is she lonely?", but that isn't the way things turned out for me. I am still grieving while the rest of the world has already forgotten, and not only do I grieve for Devon, but for Brianna as well. Already she has survived so much, and soon she will be old enough to realise that she is destined to live without her irreplaceable twin sister. In my heart, I am the mother of twins. In reality, my daughter Brianna will always be a twin.

Permission to Re-print is given by the author, although I would be appreciative of a copy of each magazine or newsletter that it appears in. (Contact TTTS Times Editor for details)

Separate Hospital Discharge

By Linda Back

My TTTS survivors were born at 30 weeks gestation, by planned C-section, after many weeks of bed rest and what seemed like hundreds of ultrasounds. With one baby almost twice the size of the other (Joshua, my recipient, was 1560g (3lb7oz), and my donor, Caleb, was 808g (1lb12oz)) they were off to an unusual start, it's quite common for twins, even identicals, to be different in size, but usually not to this degree! Initially in Intensive Care, they both needed quite a bit of help with the usual preemie stuff - Joshua was ventilated, Caleb had C-PAP (continuous positive airways pressure) and also a blood transfusion due to anemia, and both needed the IV lines in their tummies, and phototherapy (sunbaking under the blue lights!). We were lucky that they really didn't have any major setbacks while they were in ICN, which is the time when you worry most, I think, as that is obviously where they go when they are sick and small. The boys progressed relatively quickly from ICN to Special Care Nursery 2 (the next level nursery), which I was grateful for, and Joshua led the way, being the bigger, stronger baby. Caleb joined him a few days after, and for a short while we were able to have both humidicribs side-by-side which was wonderful. Shortly after that, Joshua graduated to Special Care Nursery 1 (aka the 'Fat Farm' or 'Chub Club!'), where he stayed for the next few weeks, leaving Caleb in Special Care 2, right next door. This was difficult as we had to keep going from nursery to nursery, trying to attend to two babies in two different nurseries. I think most people didn't realize that we had twins, as they would only see us attending to one baby in each nursery. Day by day both boys would put on a little weight, although Caleb generally gained a little less than Joshua did. It didn't take more than a few weeks before Joshua was out of the humidicrib, once he hit 1750g, and we were able to put him in a 'normal' newborn cot. More cuddles, more baths, more feeds - hooray! Towards the end of his hospital stay I was even able to take him next door to be near Caleb, although Caleb was still having tube-feeds at this stage, so I was never able to twin-feed the boys at the same time (something I regret not doing). After 7 weeks of hospital accomodation, our pediatrician announced that Joshua was ready to be taken home - he weighed in at 2122g. I opted to room-in with him (staying in hospital with him, just like when you have a term baby!), which went well. I was appreciative of the fact that I had had the time to recover from the birth and wasn't in any pain - it meant that I could focus completely on my baby. Knowing that Caleb was just downstairs in the nursery was good too, I could visit him whenever I wanted, and I took Joshua down to see him before we left the hospital to go home. Leaving Caleb while I took Joshua home for the first time was very difficult, a nurse had pointed out to me that "the one left in hospital is usually the sicker one - the one that needs you the most" which is exactly how I felt - I worried more about him than Joshua. The only thing I could do was remind myself that he just had to be there, he was still too small to come home (he was still in a humidicrib) and that the doctors and nurses were helping him to come home as fast as possible. I also tried to look on the bright side - I had a few weeks to be able to get used to having one baby, before I had to deal with two! Of course, the down side to this was that I was having to get up to Joshua in the night, then trot up to the hospital to attend to Caleb each day, as well as express breastmilk for Caleb and take the milk up, which took a bit of organizing! Luckily my mother was able to come to the hospital each day (my husband had to return to work), which helped a lot, she was able to feed Joshua a bottle, or change or burp him while I was looking after Caleb. Shortly after Joshua came home, Caleb finally hit the 1750g mark and was moved out of the humidicrib and into an open cot, which made life a lot easier, I could get him out when I wanted, and my husband often had a "twin cuddle" with both the boys asleep in his arms. Three weeks after Joshua came home, our pediatrician said that Caleb was ready, he was still on the small side (1922g) but he was a 'term' baby (ie had reached his due date) so he would be able to cope fine. So, finally, 2 days after the twins' due date, we got both of our babies home! I had the option of re-admitting Joshua and myself to the hospital so I could room-in with Caleb and have both babies with me, but I opted not to, I just wanted to get my little boy home with me, I'd had enough of the hospital by then!

All in all, it was an eye-opening experience (although not one I'd care to repeat again!). To me, after being faced with the reality of TTTS, the outcome we had was the best we could have hoped for and I think focusing on that fact helped me get through.