



# NATIONAL TWIN LOSS SUPPORT NEWSLETTER

Spring Edition  
Editor: Lynne Harford

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## Editorial

The search for a reliable and steady income source continues, and as a result of my experience over the years, I have shared my personal opinion about the subject of Government funding for bereavement care organisations in Australia, on pages 2 and 3.



Our Project '08 Research is turning out to be more of a long-term ongoing commitment, but I remain convinced that it will provide useful feedback, and eventually new resource material for multiple birth loss families and the health care professionals who support them.

Fundraising is continuing for the reprinting of *The Diary's*, 2nd edition with Pleasant Word in the US. Pleasant Word is the publisher who handles "The Survivor". Having both books under the one publishing house will mean both will be available through major markets such as Amazon Books.

And for those members who have been with us for a while, you may notice I have had a name change. For personal reasons I am now using my maiden name.

Please enjoy our newsletter and don't forget to send in any contributions or comments you may wish to share.

Yours in bereavement care  
Lynne Harford

## SAMBS has arrived!

SAMBS is the acronym for: Surviving Adolescent Multiple Birth Support and is an offshoot of NTLs which will specifically cater for the needs of surviving multiple birth teens AND their siblings.

There are already a number of groups available that cater for the needs of bereaved multiple birth parents, (NTLS is of course one), and there are a small number of groups that cater for the needs of adult survivors. However, not much seems to be available for our teenagers.

Now they will have access to an internet group that will be specifically geared towards their unique emotional needs.

Siblings are often forgotten as parents may unwittingly focus upon the needs of the survivors. This can lead to feelings of jealousy or feelings that singleton children are not as important. Hopefully by discussing their feelings with other sambs members, survivors and their singleton siblings will be able to work through this period in their lives.

Our new Facebook group 'sambs' is available NOW. Our next plan is to make a 'blog' page or something similar, available through our NTLs website. Teens enjoy computer contact so this will work better for them than perhaps face-to-face meetings, such as coffee mornings, which tend to appeal to adults.



## What's in this edition?

- *Editorial*
- *SAMBS has arrived!*
- *Grab a Bucket!*
- *Thanks Jules!*
- *Dividing the pie*
- *OzMOST has a new website address!*
- *Survivors may appear like 'loners' at times*





## Grab a bucket!

We have a few donation buckets available for members to put on their front counters at work. All members need to do is to make sure they keep an eye on what money is being placed into the bucket and regularly bank the funds into the NTLS account. When the member decides they have had the bucket long enough, just post it back to NTLS.

There is no pressure for anyone to take a bucket and we are happy to post them out at no cost.



So if you want to help raise our profile as well as a few dollars here and there, just grab a NTLS donation bucket and make it happen!

## Thanks Jules!

A special 'thank you' to our Support Worker Julie Bryant who has made our support worker website page look bright and snazzy with her creative talents! Well done and thank you so much for taking the time and effort to do that for NTLS.

Don't forget to show support for our wonderful Support Workers, Julie and Karen. They are there to listen to your concerns, share your problems and to just make you feel a lot more positive about life.

Thanks ladies!!!



*Julie Bryant*  
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Julie is the founder of OzMOST (Aussie Mothers of Surviving Twins) and has many years experience in working with bereaved parents. Julie and her team at OzMOST created the two-booklet series, "Multiple Birth Bereavement Care", which are available through OzMOST. Based in Wollongong NSW, Australia, Julie is currently finishing her counselling degree.



*Karen Jefferson*  
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Karen works with the Christchurch Multiple Birth Club in New Zealand and has many years experience in grief counselling. She has certificates in Applied Grief Studies Training, Grief Support, and Basic Integrative Counselling Skills and Personal Growth. Karen is currently completing a CPIT Diploma in Counselling. She is also a Committee member of NALAG's Canterbury Branch.

## Dividing the pie

By NTLS Founder, Lynne Harford

How often do we hear the term 'dividing the pie'? It may make you think of eating, but it is often used when referring to financial situations. In other words, how does the Government divide up its huge economic pie? No doubt it's a difficult job and in reality, there's always going to be someone who misses out, and of course, many who will in turn complain about either how big or small their portion is, or about being the person sitting there still waiting.

National Twin Loss Support is a very small bereavement care organisation that has managed to hold its head up high amongst its larger relations. We have been in existence for almost 17 years and during that time have rarely asked for Government funding. Due to useful contacts many years ago, we managed to receive a small grant which allowed us to cover administrative expenses, donate books to schools, information centres and other bereavement care organisations, as well as run a small half day seminar in the South Australian country town of Tailem Bend.

I am used to fighting battles alone, with very little support and eventually winning. The fight to try and be recognised greatly enough to be given just a few crumbs of the Australian Government's financial pie would really make me feel like a winner! It would also assist me in sharing my personal observations and experiences about the Australian bereavement care community. Being outspoken is often lonely. However I remain steadfast in my determination to speak out against social injustices, standing up for the rights of those who are unable to speak for themselves; our deceased multiple birth children, as well as our survivors who may not know how to speak out.

When I started NTLS in 1992 under the name of 'Murraylands Lutheran Stillborn Infant Support Service', my aim was to work with my fellow bereavement care organisations. I was a referral service, treating all groups with equal respect. Regardless, I remained a thorn in their sides. I did not show allegiance to any one particular group, and that made them all feel uncomfortable. I referred people to them, but the gesture was rarely reciprocated. Feeling unwanted I labeled myself a 'rebellious maverick', determined to make my mark for the sakes of multiple birth loss families and survivors everywhere.





Operating on a shoe-string budget, I self-funded my work. I donated office equipment, time and energy. Discovering 'freebies' such as advertising became a talent developed through trial and error. I learned who my friends were and valued their support. Proudly, I still survive on a shoe-string budget to this very day.

Eventually with the assistance of several close bereavement care colleagues such as Dr Jane Warland and Julie Bryant, I found success. My first book "The Diary" which I funded from my estranged husband's accident payout, helped many people around Australia and overseas. The alliance I forged with Apex Australia gave birth to the first major Australian-specific twin loss awareness kit. My second book "The Survivor" was published by a Christian publishing house in the United States, through the help of a few generous donations.

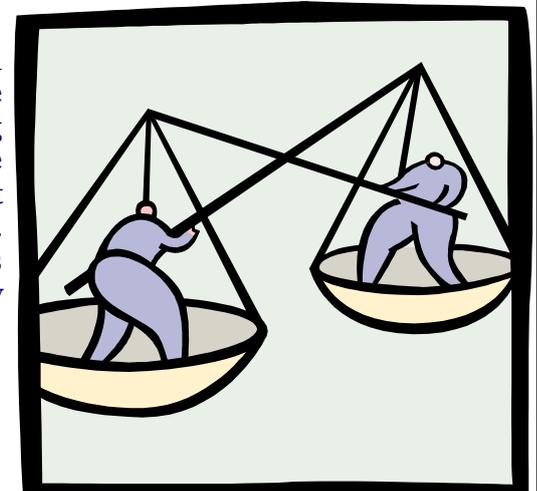
People still overlook multiple birth loss issues. Often they are swept under the mat and considered insignificant, lacking enough importance to warrant their own funding. Years of personal ridicule from skeptics who have viewed my opinions as 'crazy' have toughened my resolve to not give up.

However many times I have been knocked down, I have tenaciously picked myself up. My battle is for those who have approached me for support over the many years I have been established, rather than for my own selfish reasons. Therefore, a politician promising to give a massive financial donation to just one bereavement care organisation becomes the trigger that makes my blood boil in frustrated anger! Staying silent is not an option and although I am in a minority of vocal opponents, I am not ashamed to stand up and publicly say exactly what I think. So, what do I think? It's downright shameful and unjust!

Does size alone of an organisation dictate the financial division of the Government's pie? Do the high profile players get their generous shares at the expense of the quieter achievers? Do the Government decision-makers feel my contribution is relatively insignificant simply because my requests are smaller? Can they not understand that size does not necessarily matter and that each and every organisation has an important role to play? We are like pieces of a huge jigsaw puzzle. Some pieces are large and colourful, easy to see and usually chosen first. But the smaller, less attractive pieces are just as important. A tiny border piece may be the cornerstone of the whole setting, whilst another serves to make sense of a complex area. I'm not saying the big guys shouldn't get their share. On the contrary, they deserve to receive support and recognition. What I am saying is that the financial pie needs to be cut into more slices, and all bereavement care groups treated as equal. By the Australian Government choosing a selected few to financially support, they compromise the futures of hundreds of other community organisations right around this country. It sends the message out that the big guys matter, the big guys will always win, so don't even bother knocking on the door if you are one of the little guys, because nobody will answer.

However, little guys should not give up. We need to cooperate, view each other as useful and respected colleagues, instead of as irritating thorns in each others' sides. I remain convinced that through our combined efforts we will one day, finally gain the attention of the Australian Government who will hopefully realise before it is too late, that we **all** have a role to play in bereavement care, and in mental health issues.

I'm sure many of you have heard the term 'pester power', a phrase coined by modern advertising companies to describe one of the most effective selling methods today. It might be annoying when your children 'pester' you for that toy, or those lollies in the supermarket aisle, but I'm definitely going to be a pest when it comes to standing up for the rights of multiple birth loss families. I'm going to make sure that I continue to speak out. After all, it's simply the right thing to do. I just hope that I won't be alone in my endeavours.





## **OzMOST has a new website address!**

Our support worker Julie Bryant has worked hard over the years to provide a practical and easily accessible method of communication for bereaved mothers through her OzMOST online chat group. Her work hasn't stopped there! She not only created those inspirational booklets for parents and health care professionals which are available through the OzMOST website, but has been busily working on a DVD as well! I am proud to be a bereavement care colleague with Julie, and wish to announce that OzMOST has a brand new website address:

**[www.ozmost.com.au](http://www.ozmost.com.au)**

**Well done Jules and well done to the team at OzMOST!!**

## **Survivors May Appear Like “Loners” at Times.**

It is interesting to observe my surviving twin as he matures into a fine young man. 18 months ago he left home to join the Australian Army, and for the first time in many years he was thrust into a new and challenging environment.

My son Rhys is a very likeable person, and gets along with just about everyone he meets. Highly intelligent, there is a tendency for him to keep to himself. He worries that he may become a 'nuisance' to people if he bothers them too often.

I acknowledge that some people have personalities which place them into the category of being a 'loner', but I know from having watched my son grow up, that this isn't completely accurate.

Research has shown that surviving multiple birth children may struggle to establish new, long-term relationships. I remain convinced that the natural feelings that a young person experiences upon leaving home and moving far away, such as homesickness and loneliness, are exacerbated by their own early loss of their multiple birth sibling. As a result they require a little more understanding and support in order to settle in.

My son is preparing to transfer to another training base very soon and has spent the past few months assisting the administrative staff with daily tasks.

Whilst for most people this would drive them crazy, Rhys seems to enjoy interacting with older people, and has the patience to undertake each task asked of him, and still return for more with a smile upon his face.

I am sure that this brief period has provided an opportunity for him to settle in a bit better, and become accustomed to being away from his immediate family.

Although many of you would still have your survivors at home, perhaps still babies in your arms, one day you will also be contemplating their 'leaving the nest', and you too may be observing how they cope.

My conclusion is that our survivors will cope very well as they move out into the big wide world. They may require a little more support than a singleton person, but with people who understand their unique needs, your survivors should cope just as well as Rhys.

Remain supportive, don't hesitate to show your love, and your survivors will be hopeful of a wonderful and fulfilling life, I am sure.

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