



# NATIONAL TWIN LOSS SUPPORT NEWSLETTER

May 2014 Edition

Editor: Lynne Harford

*“Celebrated 21 Years in 2013!”*



Copyright © 2014 NTLS



## Editorial

Hello everyone. Well Mother’s Day has just passed and I am sure that for many of you, it feels like a double-edged sword as you struggle to enjoy the attention showered upon you from your loved ones, whilst needing to grieve for the children that we no longer have, or in some cases, were unable to have.

It can be a challenge to communicate these feelings to those family and friends around us who naturally assume that we should be happy to have an ‘official day’ to ourselves, where we are supposed to be spoilt and pampered. It is a blessing when we are surrounded by family who understand the complexities of grief, and who don’t view wishes to visit the cemetery as being negative.

My message is simple—do what feels right for you. If you want to be surrounded by lots of people, then enjoy the time. However, if you want to have some peace and quiet, then put your feet up, have a cuppa and enjoy that DVD you’ve been putting off watching!

Changing the subject now—“The Diary” is almost ready for its test run. Once we’ve had a look through a real, hands-on copy, we will allow it onto the market. Our plan is for hard copy, as well as e-book format. We are just combating the final hurdle of tax issues in the US. Our new US publisher Lulu, wants to deduct 30% tax from all sales in the US. Our frustrations lie in the fact that our former publisher, Winepress, had sorted out our charitable tax status back in 2011. Since we are unable to contact Winepress, we are in the midst of sorting things out between Lulu and the US tax office. Stay tuned!

Hope you enjoyed “Fluffy Slippers Day” on 1st March. We have a picture of a couple of our doggy NTLS family members on page 6 who turned the ‘day’ into a ‘week’!!

And we are publishing our final instalment of our investigation series. This investigation has now been included in our book “The Survivor”, which is the sequel to “The Diary”, and should be available once again, later this year.

Until next time,

Yours in bereavement care,  
Lynne Harford  
Founder  
NTLS



## What’s in this edition?

- **Editorial—pg1**
- **NTLS History—pgs 2 &3**
- **2008-2010:NTLS Research Project—pg 4**
- **A Twin Loss Inspiration—pg 5**
- **Have times really changed? - pg 5**
- **Stop Press—pg 6**
- **Fluffy Slippers Day 2014—pg 6**

**“Everyone has a story to tell if someone will but listen!”**

( Gordon Caskey )



## **NTLS History—The Background of the Apex Australia Twin Loss Awareness Kit Project (2002-2006)**

**By Lynne Harford**

(Taken From the manuscript, The Survivor 2nd Edition. Used with permission.)



The stories of Australian families disappointed in how their situations were handled; continue. In 2002, with no money and a lot of determination, I approached a small group of Australian and Canadian colleagues and proceeded to put together a collection of information that would hopefully go some way towards filling this void. I had no

(2006: Lynne with Apex National President)

idea that I would be giving up most of my life for the next four years in order to try and make a difference.

This ‘collection’ which became known as the “APEX Australia Twin Loss Awareness Kit” went on to win the 2003 South Australian Premier’s Community Service Encouragement Award, and the 2004 Apex National Donald McKay Citizenship Initiative Award. It was also accepted as the 2005/2006 Apex National Service Project.

Whilst waiting for APEX to decide about taking the project onto the next level, that is, nationally, the concept was almost stolen right from under us by another multiple birth support group to whom we had generously donated several of the South Australian kits. This particular group, who were caught out by our Canadian colleagues, thought they could gain from all our hard work by making their own copy-cat version of the kit, and donating it to the same hospitals that we were planning to distribute to. However, after much heated discussion, we successfully argued our case against their idea and eventually coerced them into changing their minds before they had had the chance to ‘gazump’ us.

Interestingly enough, when I have mentioned these kits to health care professionals who work in some of the hospitals where donations were made, they have not known anything about them. It is my personal opinion that the problem in donating resource materials to places such as hospitals, is that after a while they either disappear out the door with someone who doesn’t bother to return them, or they lay dormant in some back cupboard until they are thrown away.

However, back in December 2002, both Jane Warland and I were invited to attend a meeting in Adelaide held by the

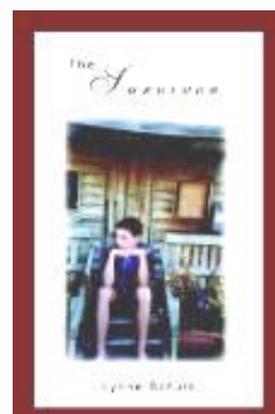
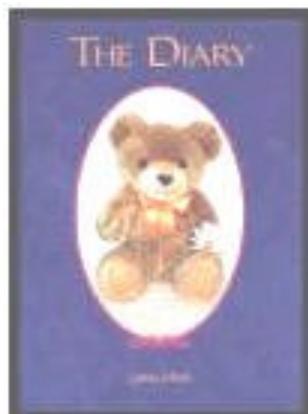


South Australian/Northern Territory State Board of the APEX club, to present our case for the proposed funding of this unique project. The speech I gave, highlighted the reasons behind the creation of the kit, what each kit would contain, and to whom they were aimed. I truly believed that these kits would help to build that positive future I have already spoken of, for both the surviving twins and their immediate families.

Hopefully, this project did have a positive, flow-on effect somewhere out in the wider community that changed someone's life for the better. I would like to think so. The phone call I received many years ago during breakfast, from an Adelaide Grandmother thanking me for creating the kit project, and for writing "The Diary", left me with that little glimmer of hope that I may have actually succeeded in helping at least one person to better understand the trials of twin loss.

As a result of our speech, Apex members voted in favour of the idea at their next annual state convention. The kit project was then accepted and trialed on a state level, with the Apex State Board funding the purchase of the kit componentry, and the Apex members providing the labour. Working in conjunction with The Apex Club of Murray Bridge, I became the project's coordinator, and oversaw all facets including promotion, the ordering of componentry, the collation of kits, the filling of orders and their eventual distribution. Twin Loss Kits were donated to sixty-six maternity hospitals around South Australia and the Northern Territory during 2003. The award we won later that year provided enough money to fund an extra seventy kits, donated to emergency service groups, church groups, schools, as well as other bereavement care charities throughout the wider community.

I hope that this book, "The Survivor" will follow on from "The Diary", in helping to fill the void that many twin loss families have experienced over the years in obtaining useful and accurate information. I would like to think it could also provide a positive starting point or become an 'ice-breaker', by showing both medical professionals and parents the benefits of working together.





## **2008-2010: NTLs Research Project: Investigation into the quality and type of care provided by Health care professionals to Multiple Birth Loss Families after the Hospital Stay.**

By Lynne Harford

This will be the final in our series regarding our project where 15 participants from countries such as Australia, New Zealand, Canada and the United States, kindly provided their thoughts and experiences regarding their own multiple birth losses. All information has been used with permission.

Material from this study has been used in the manuscript for our book, "The Survivor 2nd Edition", due out later this year. My sincerest thanks to all participants for their open and honest responses.

### **Responses to the question: "Do you think that there are enough twin loss or higher order multiple pregnancy loss resources available?"**

**Joanne—Canada:** "No."

**Elizabeth—Canada:** "NO!"

**Jane—New Zealand:** "Yes, from a NZ perspective. We were given SANDS brochures but felt that multiple loss needs to be dealt with in that domain."

**Kim—Sydney, NSW:** "No, not at all. I think we are all put in the same box as a singleton loss, and it is very different as we deal with two complex emotions at the same time."

**Jenny—Port Pirie, SA:** "Well certainly compared to what was available to me. I would think that there is certainly quite a bit around."

**Angela—Sydney, NSW:** "I feel I have enough support from the group I am in, so have not even looked further."

**Bindi—Bendigo, VIC:** "No. About all the Mercy [Hospital] did was put us in a private room, and sent in a Psychiatrist, and Pastoral Care lady."

**Anon—Adelaide, SA (lost both twins):** "No, due to the fact that I found it very hard to find such resources."

**Annette—Sydney, NSW:** "No. There was no literature available aside from the OzMOST info. Even the books designed for twin pregnancies only covered a small chapter of the bereavement process."

**Linda—Brisbane, QLD:** "Yes."

**Narelle—Bunbury, WA** "As I live outside Perth, I feel that there is never going to be a lot of resources available specifically for twin loss as we don't have the population. It is disappointing that though SIDS and Kids operate in Bunbury, they don't have regular meetings or support groups (though the times I have dealt with them they have been very supportive and understanding). I also think that the booklets put out by OzMOST would be very beneficial for all professionals to have but I don't know how practical that would be. However, I have handed out a few myself."

**Emily—USA:** "No."

**Sylvia—Adelaide, SA:** "Most of the people I have met already know of these resources. I think there should be a support group specifically for families who have experienced twin-twin syndrome in SA, with informal face to face get-togethers. Although we would like to see this group open to those families that did not lose a baby, as well as those that have."

**Sally—Bright, VIC:** "I think so, it is just a matter of making sure people know about them and have access."

**Rachell—New Zealand:** "Absolutely not, and unless you are active you wouldn't know. Even my GP's practice didn't know where to go."



**" Experience is the child of Thought,  
and Thought is the child of Action."  
( Benjamin Disraeli )**



## A Twin Loss Inspiration



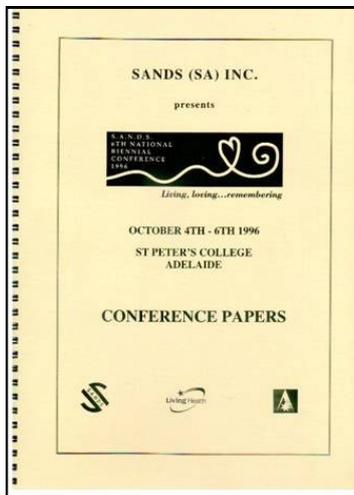
The NTLS team was sad to read recently that UK twin loss advocate, and sole proprietor of Wren Publications, Althea Hayton, retired from public life last year due to an ongoing battle with Motor Neurone Disease. We had the privilege of being asked to contribute to one of Althea's many books back in 2007.

Althea's book, "Untwinned: perspectives on the death of a twin before book", is a compilation of works from numerous twin loss authors who specialise in twin loss issues, and contains a chapter from Lynne Schulz, author of "The Diary" and "The Survivor".



Although she is no longer able to respond to individual emails, NTLS has contacted Althea via her website to wish her all the best, and to thank her for her work over the years. She will continue to write for as long as she is able. In the meantime, her books are still available for sale through Wren Publications, as well as Amazon books.

## Have times really changed? By Lynne Schulz



In October 1996 I was invited to present a paper about my personal experience as a twin loss mother. This work was subsequently published in the book of Conference Papers later that same year.

This was the material that was used in my first book, "The Diary", which was literally based upon the diary that I kept during the 7 week hospital stay in an Adelaide Maternity Hospital during early 1990. The Hospital has since been sold and refurbished by a different organisation.

The hospital was a teaching hospital and during my stay I was bombarded with eager medical students who were looking for an unusual subject upon which to base their assignment work. I became a bit of a guinea pig for the medical staff who worked with me. They had not experienced a situation like mine before and were unsure of what to do and what to say. Some of them pretended that I didn't exist. Some of them tried to pretend that nothing had gone wrong with my pregnancy at all.

None of them took the time to sit down and ask me what my needs were, how I felt or what I wanted.

Things have changed since the early 1990's. Unfortunately changes to care of twin loss families appear all too slowly, and when compared to the advances made in singleton loss care, we sadly appear to remain in a bubble-wrapped time warp.

I am determined to continue the fight for change, no matter how long it takes. Please share my story...

**NB/ please read Stop Press on page 6!!!**



### STOP PRESS

We got all excited when we were recently invited to speak at a SANDS (Stillborn And Neo-natal Death) SA Seminar. In 1996 we presented a paper based on our then un-published manuscript "The Diary". Was wonderful to think that in 2014 we could perhaps re-launch "The Diary" 2nd Edition at the Seminar. Then suddenly we received an email from SANDS SA saying that "on this occasion they have found someone else". Short, sharp and shiny! What a kick in the guts! Read more about this in our Facebook page where members have voiced their opinions.

### Fluffy Slippers Day 2014

Fluffy Slippers Day started as a joke about types of fundraising activities that occur on an annual basis.

We decided to make it our own NTLS annual promotion day. We do not ask people for money—we purposely prompt people to ask why are we wearing fluffy slippers. This gives us an opportunity to say it is to raise awareness about twin loss and higher order multiple birth loss issues, and about the work done by NTLS.

Costs nothing apart from a bit of time, and can be a good chance to inject some humour into your day.

Below: Adelaide 'kids' Tilly and Abby Castle turned Fluffy Slippers Day into a marathon event!! Thanks to their Mum, Linda who shared this on our Facebook page. ... hope you doggies are good to your Mum on Mum's Day!!!!



### Contributions

If you would like to make a contribution to our newsletter, please send your photos, information, announcements to:

[enquiries@nationaltwinloss.org.au](mailto:enquiries@nationaltwinloss.org.au) and put the words "Newsletter Contribution" in the Subject field of the email.

We will be happy to publish your items relating to multiple birth loss issues.

Please ensure that permission has been obtained from the author if not your own work, and advise if it has been previously published in another bereavement care organisation's newsletter so an acknowledgement can be printed.



**"Our lives improve only when we take chances - and the first and most difficult risk we can take is to be honest with ourselves"**

(Walter Anderson)

### National Twin Loss Support

ABN: 69 695 149 922  
PO Box 3157  
Salisbury East SA 5109  
Australia  
**Phone:** 0419 039 194  
**Email:** [enquiries@nationaltwinloss.org.au](mailto:enquiries@nationaltwinloss.org.au)  
**Website:** [www.nationaltwinloss.org.au](http://www.nationaltwinloss.org.au)  
**FaceBook Page—NTLS:**  
<https://www.facebook.com/#!/groups/49624969102/>  
**FaceBook Page—SAMBS:**  
<https://www.facebook.com/#!/groups/150126301514/>

