



**ICOMBO**  
INTERNATIONAL COUNCIL OF  
Multiple Birth Organisations

*Check out the 2014 Congress news on pages 2 & 3 and be sure to review the attachments sent with this newsletter.*

## News From Around The World

May 2015

### Chairperson Report



*Monica Rankin*

Hello, I cannot believe how time has flown since our meeting in Budapest - where does the time go? I believe our meetings at the 2014 Congress in Budapest were very informative and helped the ICOMBO Board plan our direction for the new term. A few of the items discussed have already been acted on and you can read about this later in the newsletter. You will see more results as we move through the year.

I was very pleased with the general interactions I had with scientists and researchers at the Congress. A few people were keen to meet with an ICOMBO member and hear about what we are doing. At a few meetings, it was good to hear ISTS Board members, and others, mention ICOMBO in a positive way. Our Declaration of Rights and Statement of Needs of Multiple Birth Children was mentioned several times to emphasise various points, including the need for multiples to be aware of their zygosity.

There were some new faces on the ICOMBO Board and I am confident that we will have a very positive relationship with the ISTS over the next few years. I have worked with Jeff Craig, from Melbourne, a few times already. He is a great supporter of AMBA and ICOMBO. Another new board member, Asma Khalil has worked with, and is a supporter of, Tamba.

At this stage, it seems the next Congress will be held in Madrid, Spain in 2017. I am planning to attend and already look forward to seeing my ICOMBO friends there too. Please plan on joining us!

*Regards, Monica*

#### *In this edition:*

<i>Chairperson report.....</i>	<i>page 1</i>
<i>Meet up in Budapest.....</i>	<i>page 2—3</i>
<i>Bulletin Board .....</i>	<i>page 4</i>
<i>Book Review—Sam and Finn .....</i>	<i>page 5</i>
<i>ICOMBO Boardmembers.....</i>	<i>page 6</i>

## Meeting-up in Budapest - A Social Event by Ainslee Jacobson

---



The NEW Zealand Multiple Birth Association (NZMBA) worked hard to get a representative to the Twin Congress in November. Travelling 17,000 odd kilometres was no mean feat, but in the end it was well worth the trip.

Fortunately for me, the social aspects of the trip started early when I happened upon Keith Reed from TAMBA in the shuttle from the airport. I'm not too sure if he would class an in-depth grilling about antenatal programmes, constitutional issues and governance as 'social', but it certainly gave me a great start to the week.

Thankfully our esteemed Chair Monica has had her face splashed over the internet so I knew who I was looking for when I made it to breakfast in the morning. I quickly met the many other representatives from other multiple birth organisations shortly after.

That first day helped to ease me into the week ahead. Starting the ICOMBO workshops with presentations from each of the organisations represented at the Congress was a great way to put a face to a name. It made it a lot easier to connect with people over the remainder of the Congress. Luckily the group was easy going and we were all able to converse with relative ease, language differences aside. Facebook has certainly made it easier to keep track of everyone, even if I have had to click the 'translate now' button a fair bit.

Sunday evening was the first social event of the week and for me it was quite a treat to be able to enjoy a glass of wine without having to worry about when the kids were going to be waking up in the morning. There was a lot of lively banter and it was nice to meet some of the partners who had taken the opportunity to visit Budapest. Of course, having only been in the Northern Hemisphere for two days, sleep wasn't much of an option for me.

In an attempt to combat the jet lag, I made an effort to get up early and walk around the local streets. Thankfully, New Zealand was just coming out of winter so the 10 degree weather was almost tropical. Autumn is a beautiful time of the year and that was certainly the case in Budapest.

I wasn't prepared for how intense the Congress was going to be. With limited medical knowledge I sat through the majority of the obstetrician workshops with my eyes wide open and my brain working overtime. It was quite confronting to hear the various presenters talk about preventing preterm birth through the reduction of multiples and then there were the constant references (and sometimes photos) of placentas, cervix, ultrasounds and blood vessels.

I found the ICOMBO workshops much easier to digest. I was pleased to bump into Dr Joan Friedman again, having met her back in New Zealand at the NZ Multiple Birth Association National Conference. I had been looking forward to hearing about the ICOMBO PPMD research and the TAMBA Maternity Care survey results, both of which New Zealand families had been able to participate in. The ICOMBO AGM was an eye-opener, especially the finances. There is little funding available for ICOMBO and as such the organisation is reliant on the support of multiple birth organisations. It made me a lot more appreciative of Monica's commitment to the organisation.

With the Congress starting so early and finishing well after dark there wasn't a great deal of time to get out and sightsee. I was fortunate enough to enjoy a meal out with a couple of the members of the group. And on the last night in Budapest, we were able to sample the traditional street food of paprika sausage and sweet chimney cakes. A river cruise, while cold, was pretty incredible and the Hungarians really know how to light their buildings. On my final morning in Budapest I had just enough time to power up to Citadel. From the top of the hill I was able to see evidence of the many wars waged over Buda and Pest, and to get a panoramic view of the city.

.....continued on page 3

## Meeting-up In Budapest - Congress 2014

I learned a lot, and not necessarily about how multiple birth organisations in other countries work. Finding out about funding structures in other countries, how the healthcare systems work, even how other countries list multiple births on birth certificates helped to put New Zealand systems into perspective. In the past few months there has been a lot of discussion in New Zealand regarding the Government's Paid Parental Leave programme. Comparisons have been made with other countries such as Finland, but I knew, having spoken with Ulla, that Finland residents are also required to pay large taxes for the pleasure of their extensive parental leave programme. Something I'm not sure many Kiwi's would be keen on.

Seven days away from my little boys was enough for me and I was more than happy to get on the plane to return home. Since my return, I have been very slow to complete my Congress to-do list. That said, many of the discussions I had while in Budapest have shaped my approach to funding applications and other projects. The biggest benefit of this trip was the connections made, and while I am not likely to be at the next event, those connections are sure to carry on.



**ICOMBO Members gather  
in Budapest**



**ISTS  
Congress 2014**



### ICOMBO Research Report

Before the next Congress in 2017, we will be working on a project about Single Parenting of Multiples. A survey will be written this year and then open for responses during 2016. In 2017, the survey will be tabulated and then we hope to produce a pamphlet/publication about Single Parenting of Multiples in several languages to be first distributed during the Congress. Work is beginning now on this project. Anyone interested in participating in the survey construction please let me know.

*J. Susan Griffith MD, Research Chair, COMBO*

# Events Bulletin Board and other ICOMBO News

---

## May

Congratulations to MBC who celebrated their annual Multiple Birth Awareness Day in May by including a National fundraiser—*Strolling to Save Lives*. This year's focus was on TTTS. Planning an event of your own? Check out MBC's webpage that includes resource materials for planning and TTTS resource info.

<http://multiplebirthscanada.org/index.php/about-us/national-multiple-births-awareness-day-may-28th-2015>

## July/August

26th–1st The 55th Annual Multiples of America Convention, Cincinnati, Ohio

[http://www.nomotc.org/index.php?option=com\\_content&task=view&id=566&Itemid=374](http://www.nomotc.org/index.php?option=com_content&task=view&id=566&Itemid=374)

## October

2 - 4th New Zealand Multiple Birth Association Annual Conference, Wellington

<http://www.multiples.org.nz/index.php/news-events/conference>

23 - 25 Australian Multiple Birth Association Annual Conference, Adelaide, South Australia

<https://www.facebook.com/AMBA.Convention>

---

## ADOLESCENT MULTIPLES



You may have seen a post about the new publication from Finnish Multiple Birth Association on Adolescent Twins. We are fortunate that FMBA has organised translators to translate the complete booklet into English to be shared with all ICOMBO members. Thank you Ulla, and Finnish Multiple Birth Association Board, it is much appreciated.

As you can imagine, it is a large task. The work won't be completed for several months. We are working with FMBA on the best way to share the material once it has been translated into English.

---

## SHARING RESOURCES ELECTRONICALLY

At Congress, there was some discussion about members being able to share publications and information on various topics. Tamba have generously provided some electronic space on their server for use by ICOMBO members, and have uploaded several documents to share. Information on where to find this information, how to access it, and what topics are currently covered was circulated to all members in January. Thank you to Tamba for offering this valuable service.

If you cannot locate the document please contact Monica at [chair@icombo.org](mailto:chair@icombo.org) for more information. If your group has any documents they would like to share, please contact Monica regarding this.

---

## MEMBERSHIP RENEWALS

Most members have renewed their membership for 2015 - thank you. If you have not renewed your membership, then this will be the last newsletter for you unfortunately. Please contact Monica at [membership@icombo.org](mailto:membership@icombo.org) if you have any questions or concerns about your membership status.

---



# Book Review - Sam and Finn - A Story of Hope



**Author:** Kate Polley, United Kingdom

'Sam and Finn' is the story of my twin sons, one of whom died unexpectedly 12 hours after birth.

Originally written for my surviving twin son, Finn, it is a children's book designed for all children and families who have experienced the devastating death of a twin, sibling or child. The book explains in simple and gentle terms, the many ways that a loved one still lives within us, even though they have passed away.

## My Story:

At 32 weeks, after a perfect twin pregnancy with no complications, our lives took an unexpected and devastating turn. On the evening of my baby shower, my boys were delivered by emergency C-section. Finn, "my little survivor", was born premature weighing 1.5kg's, but otherwise completely healthy.

Sam, "my boy with wings" was resuscitated for 9 minutes at birth. After a long and harrowing night, Sam died the next morning in his dad's arms. He had suffered severe blood loss caused by an undetected cord defect. We were heartbroken, to say the least. After a month in NICU, Finn finally came home - it was a bittersweet moment.

I wrote 'Sam and Finn' 15 months after the twins were born. I remember sitting down to record on paper, the words which had been bouncing around in my head for months and they literally tumbled onto the page. Without realising it, I had been rehearsing what I wanted to say for so long, that before I knew it, I had my twins' story, and mostly importantly, Sam's message to Finn, right in front of me. Documenting Sam's short, yet precious life was a huge relief. It made his existence 'real' and helped ease my very broken heart. Most importantly it gave me hope.

A stroke of good fortune and the help of published children's book writer and illustrator, Alex Latimer, saw my book illustrated and printed in record time. I chose to print only a few copies of the book, for each of my children and family. A few months later, I posted an electronic version of the book on a private online twin loss forum. I did so in the hope of providing comfort to other grieving families, who had provided me with so much love and understanding. The response was overwhelming.

When Sam died, I remember feeling so utterly alone. Like I was the only person in the world that this could possibly have happened to. My connection with twin and baby loss parents from all over the world, quickly made me realise, that this wasn't true - that there were families in every corner of the globe trying to wade through the same murky waters of grief. I reprinted a small quantity of my book and posted it to a few families with whom I have made a special connection. Each time I parted with a copy, my heart felt a tiny bit more at peace. By sharing my twin's story and providing some comfort to bereaved families, Sam was making his imprint on the world. His life was both real and purposeful.

From there, the demand for the book spread. Initially, I resisted printing further copies as my intention when writing the book was never anything more than personal. With some encouragement I decided to print and distribute the book on a wider scale in the hope of helping other bereaved families.

The book is now published and distributed by OodleBooks, a UK based publishing house. The book can be ordered online from [www.oodlebooks.com/sam-and-finn-kate-polley/](http://www.oodlebooks.com/sam-and-finn-kate-polley/) and posted anywhere in the world. A portion of the sales proceeds are donated to Bliss and also the Twin and Multiple Birth Association in the UK.

You can also view the book online [http://issuu.com/katepolley/docs/sam\\_and\\_finn](http://issuu.com/katepolley/docs/sam_and_finn) or through the Sam and Finn Facebook page [www.facebook.com/samandfinn](http://www.facebook.com/samandfinn)



*Picture: Author Kate Polley with Finn and his younger brother, Jude*

# Join us on FaceBook

---

## ICOMBO ON FACEBOOK

ICOMBO public Facebook page:

<https://www.facebook.com/InternationalCouncilofMultipleBirthOrganisations?ref=hl>



We are gaining more interest from individuals around the world. Have you taken a look and “liked” the page?

Do you have any information you would like to see posted on this page? If so, please contact Monica at [chair@icombo.org](mailto:chair@icombo.org)

ICOMBO also has a members-only closed group on Facebook. The concept behind this group is so that members can discuss issues about their organisations with some privacy, rather than post comments and questions publically. There are up to 4 or 5 individuals from each of our member groups who are members of this ICOMBO Facebook group. For more information, please contact Monica at [chair@icombo.org](mailto:chair@icombo.org)

---

## ICOMBO Board Members

- ◆ Monica Rankin, Australian Multiple Birth Association, Chair
- ◆ Susan J. Griffith, Multiples of America
- ◆ Tiffany Wimberly, Multiples of America
- ◆ Terri Gillis, Multiples of America
- ◆ Kimberley Weatherall, Multiple Births Canada
- ◆ Donald Keith, The Center for Study of Multiple Birth
- ◆ Keith Reed, Twins and Multiple Births Association, UK
- ◆ Christine Disselkamp, ABC Club, Germany
- ◆ Pat Preedy, Twins and Multiple Births Association, UK



***Do you have organisation or event news to share?***

*We want to hear what is happening in your organisation! Articles are welcome for the next edition of the ICOMBO newsletter. **Deadline: August 1st 2015***

*Send to: [vicechair@icombo.org](mailto:vicechair@icombo.org)*