



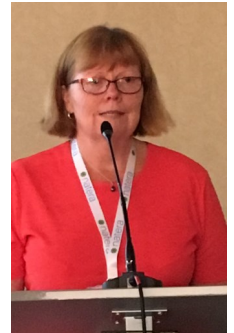
ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations



News From Around The World

December 2019

Chairperson Report



Monica Rankin

Welcome to the final ICOMBO newsletter for 2019. What a year it has been! We were preparing for our congress, to be held in Hong Kong in late November. Unfortunately due to the unrest in Hong Kong, it was considered unsafe for us to travel there. After much discussion, the meeting has been postponed and will be held in Beijing from 3 – 5 July 2020. In addition, ISTS are in discussion regarding a possible meeting in Europe in 2021.

I have been involved in a workshop that was recently held in Melbourne, Australia, looking at the needs of multiple birth families in Australia. You can read a full report later in the newsletter. I am excited to be working on this project, improving the lives of multiple birth families in Australia.

I was thrilled to receive an award from Australian Multiple Birth Association (AMBA) for my work on the Multiple Perspectives paper, that the workshop came from

We continue to gain traction with a couple of papers I have co-authored including one on zygosity determination for multiples, and why it should be a right of all multiple birth families.

I have been invited to write a chapter of a book that covers “all things twins”, from research to medical. I will be writing about parenting twins. This is very exciting as it is significant recognition from the research community for the work of ICOMBO, and who we represent.

On a personal note, I am looking forward to spending some time with my family, who are all “grown up” and mostly living away from home, on a family weekend just before Christmas. We will then be travelling to spend Christmas with my mother and siblings. Our family is very much looking forward to spending some time together. I hope that you get to spend some time with your loved ones over Christmas and New Year.

Wishing everyone a safe holiday, and a happy and healthy 2020!

Warm wishes,

Monica



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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

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 publicly. 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



We want to hear from you! Send us your organisation news, photos, and aims for 2020 so we can share your news with ICOMBO members around the globe.

Send information to: newsletter@icombo.org

Congress News:



CONGRESS 2020

As mentioned earlier, the congress will be held in Beijing from 3 – 5 July 2020. The program will be similar to what was planned for Hong Kong 2019. We will forward information to you as we receive it.

There is a Facebook page :

https://www.facebook.com/twinscongress/?_tn_=%2Cd%2CP-R&eid=ARAXLqhSfK9qpJDBBWyN3YaM1ApT6CPct7Emjv7CGasPEDKohoo09zTe9_YPklgph1ekO2v86jxeXMKf

The website is :

<https://www.mcascientificevents.eu/twins/>

South Florida Mothers of Multiples, Florida, USA (Multiples of America) gather during this holiday season and send best wishes to parents of multiples around the *Globe*. Have you shared the holiday spirit with your members?



ICOMBO MEMBERSHIP

You should have received your ICOMBO renewal notice for 2020 by now. If you haven't seen the email or have any questions, please contact Monica at chair@icombo.org

Membership fees are due and payable now.

WORKSHOP – BETTER OUTCOMES FOR FAMILIES OF MULTIPLES

I recently attended a national agenda-setting workshop on this topic, for the Australian multiple birth community.

Some background to the workshop:

Two years ago, Twins Research Australia (TRA) hosted a forum of people with an interest in multiples – researchers, clinicians, parents and multiples themselves. Here we discussed various issues regarding multiple birth families in Australia. Many of the themes are relevant to families in our wider ICOMBO community too. I was involved in this forum, and speakers included Ashlee Tenberge from AMBA and Keith Reed from Twins Trust (formerly Tamba).

From this forum a number of priorities for multiple birth families were identified, and we collaborated to write a discussion paper – *Multiple Perspectives: What support do multiple birth families need to live happy and healthy lives?* This paper provided recommendations for research, education, policy and practice.

A number of research gaps and priorities emerged. The next step has been to facilitate a workshop on setting a national agenda to commence the work required in providing happy and healthy lives for multiples.

There were 4 main priority areas identified from the paper, and these were the foci for the recent workshop:

- To develop educational resources for allied health professionals specific for the needs of multiple birth families.
- Support further research on the financial disadvantage experienced by multiple birth families, to lobby government support.
- Advocate for further research to more precisely understand the unique mental health concerns of multiple birth families.
- Advocate for further research to reduce pregnancy and birth complications.

Clearly, these themes are also very relevant to every organisational member of ICOMBO. We hope to share our experiences with all ICOMBO members, and also to learn from you, where you have already achieved success.

Speakers, what they told us about issues/lack of information/lack of support for multiple birth families:

- There are very few resources available in Australia for professionals working with multiple birth families.
- The Elizabeth Bryan Centre for Multiple Births Centre in UK, offers online courses for professionals. This appears to be a good model for other countries to adopt.
- In Australia, 3.6% of IVF treatments result in multiple births. Australia and New Zealand have some of the lowest rates in the world.
- The average length of a twin pregnancy in Australia is 36 weeks for twins, and 33 weeks for triplets. The international recommendation for twins is that the optimal delivery should be by 37 weeks at the latest, early if there are other complications.
- Multiples are 2.7% of the total Australian population, and 1.4% of all pregnancies in Australia, but have the following outcomes:
 - There is 4 times the number of perinatal deaths for twins, and 11 times the number for HOM's.
 - This data shows that multiples are much more at risk for pregnancy and birth complications.

Workshop - Families of Multiples...continued

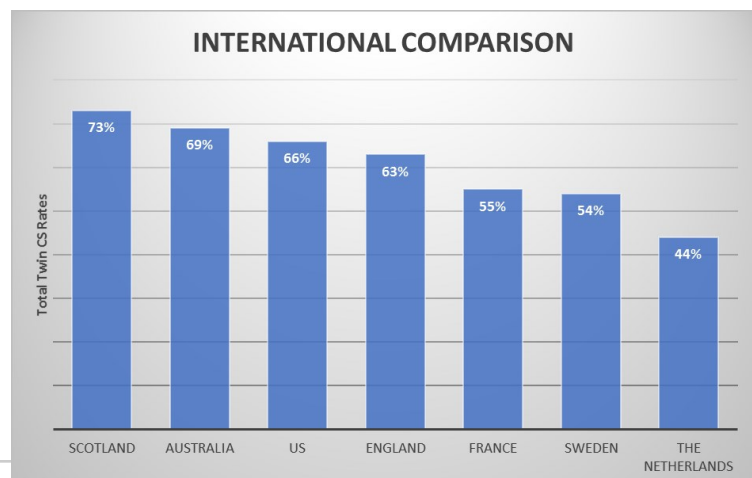
| | SINGLETON | TWIN | HOM |
|------------------|-----------|------|-------|
| PRETERM BIRTH | 7% | 64% | 98.7% |
| LOW BIRTH WEIGHT | 5% | 56% | 95% |
| CESAREAN BIRTH | 33% | 70% | 94% |

- A health economist has recently completed some studies on comparative health costs for multiples vs singletons (in Australia). The table below shows the mean costs for services that are included in our medical rebates scheme. Services such as physiotherapy and other allied and alternative health services are not included:

| | SINGLETON FAMILY | TWIN FAMILY |
|--|------------------|-------------|
| DURING PREGNANCY | \$1300 | \$1315 |
| HEALTH SERVICES COSTS, FOR CHILDREN UP TO 1 YR OLD | \$188 | \$1024 |

- Positive mental health outcomes are much more challenging for parents of multiples than parents of singletons. The rate of Postnatal depression (PND, PPMD) is approx. 10% generally for mothers. There has been very little quantitative research completed for parents of multiples, particularly in the Australian context. ICOMBO conducted an international study in 2014, which appears to be the main study that has a significant cohort of Australian multiple birth parents. The rate of PND in the international group was approx. 33%, with the Australian rate being approx. 35%. This means that more than 1 in 3 of the parents who responded to the study had been given a diagnosis of PND, from a total of 5200 respondents.
- There are many stressors for PND, and until these are adequately addressed, the multiple birth community will continue to struggle with this serious mental health issue.
- Chorionicity can be determined from 9 – 14 weeks gestation. It is important to get accurate chorionicity at this stage, as monochorionic twins have increased risks compared to dichorionic twins. (e.g.TTTS).
- There is an increased risk of a congenital abnormality in monozygotic twins, compared to dizygotic (fraternal) twins.
- Parents have shown that continuity of care is very important in a healthy mental outcome for the family; having the same clinicians, or at least the same small group of clinicians. The familiarity is very important to the parents as they build trust with their clinicians.
- In Victoria, Australia, recent studies have documented the increase in caesarean deliveries vs vaginal deliveries for all babies, not just multiples. There has been a 10fold increase in the caesarean rate for twin deliveries from 1983 – 2015. In up to 20% of deliveries, the sole reason for choosing a planned caesarean was “they are twins”.

An international comparison:



Workshop - Families of Multiples...continued

Outcomes from the workshop –

After listening to speakers about the 4 priority areas, the participants worked in groups based on these priorities and discussed some more specific details about what to do and how to do it – eg, conduct research in a particular area, produce literature for a professional group etc.

I am hopeful that many of these outcomes will be applicable to our international ICOMBO membership.

CHORIONICITY AND TWINS

If you want some reading on the importance of chorionicity, this is an interesting and relatively easy article to read - <https://s3.amazonaws.com/cdn.smfm.org/publications/169/download-65e68f6425b86afc4ae632928eda39f5.pdf>



Survey Says....

The ICOMBO School Placement of Multiples is in the final stages of being tabulated. I hope to have the full report done sometime in January. Since the November Congress was cancelled, and the next Congress will not be until July, the ICOMBO Board has decided to go ahead and release the results of the study before the July Congress. Thanks for your patience.

J. Susan Griffith MD
Research Chair, ICOMBO

We Want Your Input

It is time to put thinking caps on and gather ideas for the theme of International Multiple Birth Awareness Week which will happen from 9th to 15th November 2020 (so mark this in your diary now!). Themes in recent years have been as follows:

- ◆ 2018: Research with Multiples Benefits Everyone
- ◆ 2016: Adolescence in multiples: the transition from a child to an adult in a multiple birth relationship
- ◆ 2014: Helping Our Multiples Shine as Individuals
- ◆ 2012: School Placement of Multiples - to Separate or Not?
- ◆ 2010: Promotion of the newly updated Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples

To date I have started putting together the following ideas (note I haven't developed into taglines yet, just the general idea):

- WHO has marked 2020 as 'Year of the Nurse and Midwife'. So we could possibly do something around that – the importance of nurses and midwives in the care of our families and supporting training to better support our needs.
Links to Declaration of Rights Item V - A. *Pregnant women, parents and their multiples have a right to professionals who are knowledgeable regarding the management of multiple gestation and/or the lifelong unique needs of multiples.*
Also Statement of Needs Item I - B. *Individuals and families require care from health and other professionals who are informed about multiple birth issues and possess the necessary skills; and C. Coordination and continuity of care among disciplines and services are essential for care effectiveness.*
- Supporting families through death & disability
I know potentially a more 'negative' subject but could focus on some positive stories of families who have faced challenges, support services, early interventions, ways to help families facing loss, etc.
Links to Statement of Needs Item V - *Families experiencing the disability and/or death of co-multiples need: A. Care and counselling by professionals who are sensitive to the dynamics of grief associated with disability and/or death in co-multiples, and emotional attachment to surviving comultiples; B. Access to therapies, counselling and resources when one or more multiples is affected by a disability or disorder in order to help them manage the discordance of needs and abilities among co-multiples. C. Policies which facilitate appropriate mourning of a deceased multiple or multiples.*
- The importance of understanding zygosity
Links to Declaration of Rights item III A. *Parents have a right to expect accurate recording of placentation, determination of chorionicity and amnionicity via ultrasound, and the diagnosis of zygosity of same sex multiples at birth. B. Older, same sex multiples of undetermined zygosity have a right to testing to ascertain their zygosity. Furthermore, involvement in registries of multiple-birth individuals should be absolutely voluntary on the part of the multiples. C. Zygosity should be respected as any other human trait and deserves the same privacy rules.*
- A Global Community
Sharing our common issues and support networks, the importance of an international community for the cases where things aren't very common so connections are critical (e.g. first set of quad born in NZ last year for 20 years so needed advice from others overseas). Relevance of Declaration of Rights no matter where you are.

If you have any comments on these ideas or have something else to suggest please email me (carolyn@icombo.org). The ICOMBO board can then discuss early next year and select the theme. As with our last event in 2018 I will put together an information package a couple of months ahead of Awareness Week providing information that will hopefully be useful for organisations in getting ready for the event. I look forward to your feedback.



World TTTS Awareness Day was held on the 7th December and is an international mobilization effort created by The Twin to Twin Transfusion Syndrome Foundation to increase awareness of the #1 problem facing multiples. It is crucial for women to get an ultrasound in the first trimester to identify multiples and then to determine whether there is one placenta or two. Women must learn the warning signs of TTTS, the 15 questions to ask at each ultrasound, and the available treatment options.

There are some key things if you or someone you know are carrying identical twins that share a placenta:

- Get Educated
- Get Ultrasounds
- Ask Questions
- Get Treatment
- Get Involved!

Below is some more detailed information that may be helpful to share with parents newly expectant parents who may be facing TTTS.

What is TTTS?

Twin to Twin Transfusion Syndrome (TTTS) is a rare but life-threatening condition that affects around 15% of identical twins that share a placenta (monochorionic twins). TTTS can also occur in triplet or higher order pregnancies. Abnormal blood vessel connections form in the placenta and allow blood to flow unevenly between the babies. The common placenta may also be shared unequally by the twins. One twin, the 'donor' twin donates its blood to the other twin, the 'recipient' through the placenta. Because the donor twin has less blood flow, this baby grows slower and is smaller. The baby acts dehydrated and cannot make much urine. Thus, the bladder is small or invisible and the amniotic fluid begins to decline. The recipient twin, however, has too much blood flow. It grows faster and is larger than the other twin. The recipient baby tries to urinate the excess fluid from having more blood, so it has an enlarged bladder and too much amniotic fluid. The lives of both twins are endangered by this condition.

Twin anemia polycythemia sequence (TAPS) is another form of twin-to-twin transfusion. In TAPS, there is an imbalance of the red blood cells between the babies. The recipient twin has more red blood cells, producing thick blood (polycythemia), whereas the donor twin has a low blood count (anemia). TAPS also differs from classical TTTS in that amniotic fluid levels remain normal during the pregnancy.

It is important to note that the events in pregnancy that lead to TTTS are all random. TTTS is not hereditary or genetic, nor caused by anything the parents did or did not do. TTTS can happen to anyone carrying monochorionic twins.

TTTS can have serious consequences to the babies so it is important that anyone with monochorionic twins is monitored very closely by experienced medical professionals. Early identification and intervention (e.g. treatments such as laser surgery) can improve outcomes in many cases.

Expecting twins? The importance of asking questions

The TTTS Foundation have developed a list of 15 questions to see where your babies are in the diagnosis of TTTS so you can determine, along with your doctors, the why and when for treatment and when delivery is indicated. Further information on these questions can be found here:

https://www.tttsfoundation.org/questions_explained.php

World TTTS Awareness Day...continued

Confirm the following questions at initial ultrasounds preferably by 10-16 weeks (these determine if you are carrying monochorionic twins and therefore at risk of TTTS)

1. Is the placenta monochorionic?
2. Are the babies the same gender?
3. Can you see the dividing membrane?
4. Is the placenta implanted on the anterior or posterior surface of the womb?
5. Do the twins' umbilical cords each have the normal 3 blood vessels, or does one of them have 2 vessels?
6. Are the umbilical cords fully attached to the placenta?

Once monochorionic are indicated then these are questions to ask at weekly ultrasounds (which should be done from 16 weeks to delivery)

7. What is the largest vertical pocket of amniotic fluid in each baby's sac?
8. What is the largest vertical pocket of amniotic fluid in each baby's sac?
9. What are the weights of the babies in grams? (every 2-3 weeks)
10. Are the Doppler ultrasound studies normal for both babies?
11. Is the heart of the recipient baby thickened or enlarged?
12. Does the recipient baby have any signs of hydrops?
13. How long is my cervix by ultrasound, and it is showing any signs of funnelling or thinning?
14. Is the smaller baby growing at the same rate?
15. What is the fundal height measurement?

Diagnosed with TTTS? - what can you do?

If you are diagnosed with TTTS or find out you are at risk of developing it, first of all, try to stay calm. Please remember that lots of families have happy outcomes. A key thing is to watch for warning signs which include sudden weight gain; feeling breathless at rest and having palpitations; uncomfortable or tight tummy; thirst; spotting; feeling early contractions; and back/leg pain.

Below is some advice from parents who have been in your situation (taken from Twin-To-Twin Transfusion Syndrome: A Guide for Parents By Dr Erika Mcaslan Fraser):

- Only worry about tangible things and try to stay positive
- Talk to your medical professionals if you're worried
- Be cautious of internet coverage of TTTS
- Be aware of the warning signs
- Ask to attend antenatal classes earlier in your pregnancy
- Do the tours of neonatal wards (NICU/SCBU/HDU)
- Speak to your doctor if you are experiencing pain or discomfort
- Talk about your own needs and emotions with your midwife
- Ask as many questions as you want
- Remind your health professionals to keep you in the loop
- Don't presume there will be 'joined up thinking' between health professionals
- Talk to your partner and offer each other support when you need it
- Speak to medical experts or families who have experienced TTTS
- Continue to voice your concerns when you get your babies home, if there are things you are worried about

World TTTS Awareness Day...continued

What are the treatment options?

If your TTTS is mild, you may require no treatment and it is possible that the condition will remain stable or improve. Your pregnancy will be closely monitored and if TTTS becomes more severe, your doctors may recommend intervention, such as laser surgery or amnioreduction (draining excess amniotic fluid from around the larger recipient twin). Laser ablation therapy involves finding every blood vessel connecting the babies and closing them to prevent the flow of blood from one baby to another and the possible risk of transfusion.

Useful resources/websites/Facebook groups:

Twin-To-Twin Transfusion Syndrome: A Guide for Parents By Dr Erika Mcaslan Fraser <http://online.fliphtml5.com/ozzs/utdp/>

<http://www.worldtttsawarenessday.org/>

<http://www.fetalhealthfoundation.org/fetal-syndromes/twin-to-twin-transfusion-syndrome/>

MoDi Twins: <https://www.facebook.com/groups/MoDiTwins/>

TTTS Hope and Connections: <https://www.facebook.com/groups/203496653079054/>

The Twin to Twin Transfusion Syndrome Foundation TTTS <https://www.facebook.com/tttsfoundation/>



Happy Holidays :

- in **French**: Joyeuses Fêtes!
- in **Spanish**: Felices Fiestas!
- in **Vietnamese**: Hạnh phúc ngày lễ
- in **Chinese**: 節日快樂
- in **Filipino**: Masaya pista opisyal
- in **Irish**: Laethanta saoire sona
- in **Swedish**: Trevlig Helg!
- in **Portuguese**: Boas Festas!
- in **Turkish**: Mutlu Bayramlar!
- in **Romanian**: Sarbatori Fericitel!
- in **Korean**: 행복 휴일
- in **Slovenian**: Vesele Praznike
- in **Indonesian**: Selamat Hari Raya!
- in **Croatian**: Sretni praznici!
- in **Hungarian**: Boldog Ünnepek

Happy Holidays:

- in **Greek**: Καλές δικάκοπές! (kales diakopes)
- in **Danish**: Glade feriedage
- in **Albanian**: Gëzuar Festat
- in **Mandarin**: Jie Ri Yu Kuai
- in **Catalan**: Bones Festes!
- in **Latin**: Felix feriarum
- in **Swahili**: Furaha likizo
- in **Japanese**: 幸せな休日
- in **Hebrew**: חג שמח
- in **Italian**: Buone Feste!
- in **South African (Xhose)**: Ii holidwe eximnandi
- in **German**: Frohe Feiertage
- in **Dutch**: Prettige feestdagen
- in **Hawaiian**: Hau'oli Lanui
- in **Gaelic**: Beannachtaí na Féile



Your **ICOMBO** Board wishes the
Multiple Birth Community
around the globe a
Happy Holiday Season.

