



ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations



News From Around The World

June 2020

Chairperson Report

FROM THE CHAIR:

Wow. What a year 2020 has become! Even now, I often have trouble believing what has happened, and wonder if I will wake one day and discover this has all been a bad dream. Sadly, though, we all know that the reality of COVID-19 is true. We have all been touched, in different ways – many of us know family or friends who have contracted the virus (including me). I suspect that some of you have gone through the difficult task of mourning the passing of a loved friend or family member too. My condolences go out to all who have suffered in this way.

We have all found new ways to communicate with family and friends, I have regular virtual dinner with my children who do not live with me; we also have virtual dinner with friends regularly. It is important that we stay in touch with our loved ones even when we cannot physically visit them.

We have found new ways to work too. As a teacher I have been teaching my students remotely for 8 weeks, and we are currently transitioning back to school. I am sure many of you also have experiences of your work from home, and remote learning for your children. Somehow we have managed, and I believe that the world will be a better place.

If you have any interesting stories of how you are remaining connected to your multiple birth community, I would love to hear from you. Contact me at chair@icombo.org

Our international multiple birth community is often in my thoughts, I hope and pray that we have seen the worst and we will be able to celebrate together at some point.

Regards,
Monica



Monica Rankin



POSTPONEMENT OF CONGRESS

As previously announced, the ISTS/ICOMBO Congress was meant to be held in November 2019 in Hong Kong. Due to the unrest in Hong Kong late last year, the congress was postponed and rescheduled in Beijing in July 2020. And now we have had to postpone again due to the COVID-19 pandemic.

The current plan is to meet in Beijing in 2021, 4-6 June. Click [here](#) for further information.

There is still much discussion at the ISTS board level about the Congress. There may be another meeting in Europe in late 2021 or early 2022. I will inform everyone as soon as I have more details.



Graphic Design Skills

Do you or anyone in your club have graphic design skills and have some time to help us out?

We are looking for someone, or even a number of people, that can help with creating materials for ICOMBO. This will include infographics to communicate the results of our school and research surveys (These will be needed over the next couple of

months). It would also be great to have some new banners for our Facebook page – we have a selection of photos that we have permission to use. In an ideal world we would love to have someone create some memes or some other interesting graphics to use during Awareness Week in November. If you think you can help us out with any of these please contact carolyn@icombo.org



Have you checked out and liked the ICOMBO public page on Facebook?
(<https://www.facebook.com/InternationalCouncilofMultipleBirthOrganisations/>)

We are getting close to 2,500 followers so please help us get there. To entertain everyone as well as educate people during lockdown I have been creating a series of trivia questions, all relating to multiples. It has created some increased traffic for our page, in particular the amount of commenting. Feel free to share any or all of these on your club Facebook pages too. If you have any ideas for multiples related trivia questions please email me (carolyn@icombo.org). We are always looking for other content to share too so if you have any notable stories or happenings in your club please let us know so we can share.



Newsletter Content/Pictures

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

Multiple Birth Awareness Week

Multiple Birth Awareness Week 2020

International Multiple Birth Awareness Week (IMBAW) 2020 will take place from 9th-15th November. The theme for this year is 'Building a Global Community: Championing the rights of multiples'. This theme fits nicely with talking about evolution of ICOMBO and the development and promotion of the declaration of rights. Even though we had no idea when we chose the theme of building a global community, it fits well with the Covid-19 situation. There are many ways that our member organisations have built communities this year in slightly different ways than normal. It will be great to share these stories.

At the 1992 ISTS Congress in Japan, multiple-birth organisations worked together to begin compiling a Declaration of Rights and Statement of Needs for Twins and Higher Order Multiples. This declaration was formally adopted at the 1995 ISTS Congress, held in Richmond, VA. We have recently updated the declaration to modernise it and bring it in line with recent research and thinking. The changes are being reviewed by Jeff Craig (lecturer at Deakin University and President of the International Society for Twin Studies), Mark Umstad (a highly experienced Obstetrician with a strong interest in high-risk obstetrics, particularly multiple pregnancies) and Jane Denton (Director at The Multiple Births Foundation). The next step is to update the references. This updated declaration will be promoted during International Multiple Birth Awareness Week (IMBAW) to raise awareness of the issues it covers.

There are seven rights so each day during IMBAW we will focus on one of these:

- ◆ Freedom from discrimination of any kind
- ◆ Full information around fertility treatment and chances of multiples
- ◆ Zygosity
- ◆ Research with multiples
- ◆ Appropriate care
- ◆ Importance of the twin bond
- ◆ Recognition of individuality

Watch as we share more information over the next few months, and we will be asking for your stories that we can share during the year. If you have any ideas feel free to email me: Carolyn@icombo.org

Let's Celebrate 40 Years of ICOMBO!



Did you know this year we celebrate 40 years of The International Council of Multiple Birth Organisations (ICOMBO)?

ICOMBO (formerly COMBO) was formed at the 1980 ISTS Congress, held in Jerusalem. Between 1980 to 1986 international liaison between COMBO members developed including exchange of newsletters, resources, and research. A new management structure for COMBO was approved at the 1998 Congress in Helsinki, and COMBO was ratified as a working group of International Society for Twin Studies (ISTS). During the 2010 Congress in Seoul Korea, COMBO formally changed their name to the International Council of Multiple Birth Organisations (ICOMBO) to better reflect their global reach.

We are considering how we will mark this milestone. This could be a virtual event or some sort of activity during International Multiple Birth Awareness Week (IMBAW).

If you have any ideas please email Carolyn@icombo.org.

School Placement Survey/Study - July Release

SCHOOL PLACEMENT STUDY



Our Director of Research, Dr Susan Griffith, has completed the write-up of the report on our school placement study. The report will be released in a **special edition** of the newsletter; therefore, keep your eyes peeled for a very informative July Newsletter. We are very excited to share the results of this survey which had participation from around the Globe.

As schools begin to reopen for the next term, parents will have timely information as they makes decisions on school placement. This is going to be a great resource to pass on to your local chapters as school placement is a hot topic that continues to be high on the minds of our multiple birth community.

Here is a little snippet from the report:

The report is the result of a survey that was conducted in 2018/19. It was available in English, French and Spanish. Parents whose multiples were 3 years of age or older were invited to participate. A total of 2,842 parents of multiples completed the survey. The respondents were from over 18 countries. More than half of the surveyed parents asked for their multiples to be placed together in the classroom at some point in their school years. Many parents recognised a need to separate their multiples and over 40% asked for their multiples to be separated in the classroom at some point in their school years. No decision should be binding, as the need to separate or not may change over time.



Be sure to read Dr. Griffith's article in this month's newsletter detailing how ICOMBO selects a survey topic and the series of events/steps that occur to bring the survey and final study results to life.

*A **big thank you** goes out to all our participants and volunteers who helped with this study.*

RESOURCES ON SCHOOL PLACEMENT OF MULTIPLES

REQUEST FOR ASSISTANCE

When making decisions about school placement, parents often look for resources to assist their decision making. Over half of the parents who responded to the survey were not aware that there are books and other publications available that may be valuable to them. And in one country, there are Twin Laws in various parts of the country that support parents in having an active role in the placement decision that survey participants were not aware of.

ICOMBO wants to gather resource materials and make them readily available. We are preparing a document that lists the various resources (books, publications, websites etc) that can assist parents when making decisions on classroom placements.

Does your organisation have any resources that we can share within the ICOMBO community or to the general public? If so, can you please contact Monica at chair@icombo.org?

We would love to hear from you before June 30th.

ICOMBO Surveys...The Process

As we get ready to release the School Placement Survey next month, we thought it would be interesting to share the process and work tasks which we follow in producing an ICOMBO survey:

♦ **First, we need to come up with a timely topic.**

The last three big ICOMBO surveys, our current one on School Placement, Single Parents of Multiples and Post-Partum Mood Disorder (PPMD) in Mothers of Multiples, came from ICOMBO members brainstorming for pertinent topics at ICOMBO sessions during ISTS Congresses. The last survey prior to the School Placement survey was the Multiples in Research, which was also decided upon at Congress.

♦ **To start a survey, we need to gather survey questions.**

Usually one person is assigned the lead role to kick things off, then several ICOMBO members write pertinent questions, and the ideas are bounced around in the group. Once the first draft is made, more input is asked for and after several drafts, the hopefully final version goes before the entire ICOMBO Board.

♦ **Once we are nearing the final survey, often the survey is sent not only to the ICOMBO Board for review/suggestions, but also to experts in the field.**

For example, Carolyn Lister sent draft questions for the Multiples in Research survey to several people in the twin research field, e.g. Jeff Craig and others.

♦ **We then look to ICOMBO members for volunteers to translate the survey into other languages. Marion Gevers and Lucila Menendez, along with others are quick to assist in this effort.**

The most recent survey was translated from English to French and Spanish. The PPMD survey was translated from English to Czech and French. And the Single Parent study was translated from English to Czech, Danish, French, German, Japanese and Spanish. Carolyn Lister has also used Marion and some local club members to translate a survey from English to Arabic, French, German, Japanese and Spanish. It all hinges on who volunteers.

♦ **For the last ten years, we have primarily used Multiple of America's Survey Monkey site to distribute the surveys.**

This is supplemented with a lot of advertising on Facebook, within our organisations, and at annual organisation meetings.

♦ **We generally set up a 6 month deadline to complete a survey.**

However, sometimes we extend the time if we feel we don't have enough subjects who have completed the survey. The Research VP for ICOMBO, a position I have held for the past several Congresses, generally does the interpretations. Also, as a Multiples of America national worker, I was given access to their Survey Monkey site for our surveys. When the review is near completion, it is sent to the other ICOMBO Board members for their approval. Carolyn Lister has also used the Multiples New Zealand survey account for the recent Multiples in Research survey and also for a smaller research survey previously completed.

♦ **Once the final paper is complete, we have generally presented it at the next Congress.**

This has worked well in the past because the Congresses are generally every 2-3 years therefore, it gives us enough time to write up the survey questions, distribute the surveys and analyze the results. However, with the November 2019 and July 2020 Congresses in Beijing being cancelled because of the COVID-19 pandemic, we feel we should go ahead and release the survey results of the **School Placement of Multiples survey** to our members and to the public. This will be done in July 2020. We will then look to ICOMBO member Carolyn Lister to write-up the Multiples in Research survey as a scientific paper and hopefully present it at the next Congress in 2021.

I look forward to releasing the results of the ICOMBO School Placement of Multiples next month.

J. Susan Griffith MD

Research Director, ICOMBO

National Worker, Multiples of America