



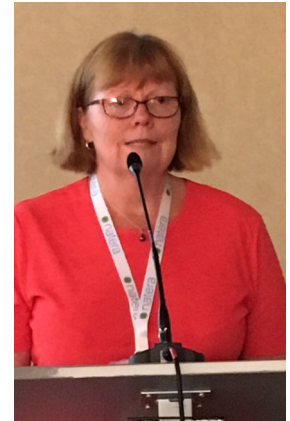
ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations

Start planning now:
Multiple Birth Awareness Week
November 4–11, 2018

News From Around The World

April 2018

Chairperson Report



Monica Rankin

It has been some time since our last newsletter and a lot has been happening at ICOMBO. As you know, we had the ISTS Congress last November. It was a great event spanning 3 days. ICOMBO members gained knowledge of other multiple birth organisations and heard the latest findings of research into twin and multiple related issues – both scientific and medical. We enjoyed the company of a new member Lucila and her family who live in Madrid. It was great to be taken out into the city by locals. The ICOMBO members (and a few partners) enjoyed each other’s company with informal dinners and outings during our free time. We were reluctant to part at the end of the congress; and, we are looking forward to meeting again in Hong Kong in 2019. We would love to have more ICOMBO members there with us so please start to think about how you might be able to make it to Hong Kong in 2019.

It is very pleasing that at each congress I have attended (Seoul, Florence, Budapest, Madrid), I sense that the scientists and medical professionals are showing a greater understanding of ICOMBO and appreciation for the work we are doing and what we can offer their communities. I believe we are now a valued part of the congress and the ongoing projects that continue between meetings.

Since Congress, the ICOMBO Board has been busy commencing the projects that were discussed in our meetings.

- The Sole Parenting survey was presented along with materials to be shared with members and the public. These factsheets have been circulated to all members and are also available in the google folder.
- Work has commenced on 2 new surveys/research projects. Carolyn has taken the lead on Multiples in Research and Susan has taken the lead on research into school aged multiples.
- It was decided to move the ICOMBO documents into a Google drive to allow easy access for all. Information on how to access these documents has been circulated to all ICOMBO members.

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From The Chairperson...continued



We said goodbye to board members Pat Preedy and Tiffany Wimberley. We are thankful for the work they have completed and the valuable contributions they made to ICOMBO while on the board.

We also welcomed new board members Carolyn Lister (New Zealand), Lucila Menendez Bueno (Spain), Abelone Glahn (Denmark) and Marion Gevers (Australia). I am excited that we have a great team who are keen to move our organisation forward in the next few years. I have particularly appreciated the work of Carolyn in making regular posts to our Facebook page. As a result, we have many more followers and our profile is spreading further.

As the ICOMBO Chair I am currently involved in the following activities:

- I have just finished reading a book soon to be published by Dr Joan Friedman – *Twins in Session: Case Histories in Treating Twinship Issues*. I was asked to read the book and write a short comment for use in publicity materials. The aim of the book is to assist therapists who are working with twins, to inform them of the unique psychology of twins and same-age siblings. The book is due to be released in June 2018 and I would highly recommend it to any therapists who works with multiples.
- I have been invited to co-author a paper aimed at identifying research gaps related to health, socio-economic and educational aspects in pregnancy, post-natal period (0 to 1 year of age), and early childhood (1 to 5 years of age)
- I have been invited to participate in a project on TTTS. The project team is The International Collaboration to Harmonise Outcomes for Twin-Twin Transfusion Syndrome (CHOOSE). Research studies testing new treatments for TTTS often measure different outcomes, (e.g. one may measure visual loss in childhood and another study may measure hearing loss in childhood). These are different outcomes and the studies cannot easily be compared or combined. The current project involves developing a core set of outcomes for the treatment of TTTS. This will allow different studies to be compared and combined easily. The ICOMBO Vice Chair, Keith Reed is also a part of the project team.
- We have created new email addresses for all ICOMBO Board members and these are listed in the newsletter for your reference. Please note that you can contact the board at any time, using board@icombo.org and, you can reach all ICOMBO members at members@icombo.org Feel free to make contact with these groups if you have any comments, suggestions or questions. Meanwhile, enjoy the pictures from Madrid included in this newsletter.....and thanks again to all our ICOMBO members that were able to attend.

Regards,

Monica

About ICOMBO

Our Mission:

The mission of the International Council of Multiple Birth Organisations (ICOMBO) is to raise awareness of the unique needs of multiple - birth infants, children, adults and their families promoting their health, education and welfare.

Did you know?



CONGRESS 2019 –Hong Kong

The location for Congress 2019 was tentatively announced during Congress 2017.

Start planning now for a fantastic Congress and **let's make this the most well attended ICOMBO Session in our history!!**

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 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



Congress 2017



Twins 2017 was the 4th joint congress of ISTS (International Society of Twin Studies) and Twin Pregnancy global perspective. It was also the 16th ISTS congress. ICOMBO had the opportunity to have a full day pre-congress workshop and a business meeting during the main congress. In addition, we had a session where we chose the theme and presentations. For the first time, there was a joint session of ICOMBO and ISTS – Monica Rankin (ICOMBO Chair), Jennifer Harris (ISTS President) and Jeff Craig (ISTS Board member) worked together to deliver a presentation on twins and research – expectations, rights and obligations were discussed from the perspective of the multiple birth family and the perspective of the researcher. It was very exciting to be involved in this panel and to present our perspective to the research community.

A full report on ICOMBO sessions and minutes of the business meeting have been forwarded to all ICOMBO members. If you have not received a copy, please contact Monica – chair@icombo.org

Enjoy the pictures of our ICOMBO attendees below and check out the 2017-19 ICOMBO board on page 7.



Gathering in front of Tamba Display



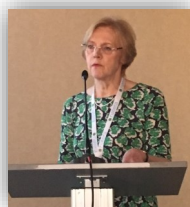
ICOMBO Attendees



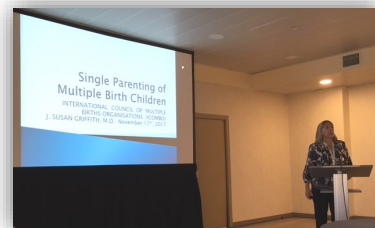
Social Time

The ISTS Board for 2017 – 2019 is:

- President - Jeffrey Craig
- Secretary General - Asma Khalil
- Treasurer - Nick Martin
- Past President - Jennifer Harris
- ICOMBO Representative - Monica Rankin
- Board members -
 - Bart Baselmans
 - Lucia Colondro Conde
 - Nancy Segal
 - Karri Silventoinen
 - Petra Zwijnenburg
 - Mark Kilby



Jane Denton



Susan Griffith



Ashlee Tenberge

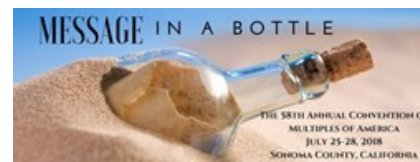


Keith Reid

Join us this July in Sonoma County, California for our 58th annual convention.



Contact us at info@multiplesofamerica.org



Multiple Birth Awareness

International Multiple Birth Awareness Week

Our awareness week will be celebrated from Sunday 4 – Sunday 11 November 2018. Please make a note and share with all your member groups/clubs/chapters so that everyone can begin to plan activities.



The theme for 2018 is about the importance and value of twins in research. More information will be supplied as we get closer to November.

If you would like to be involved in planning any activities, or writing materials for distribution to our members, the media or the wider community, please contact Monica at chair@icombo.org

Survey News



Survey on Multiples in Research

One of the international collaborations we are progressing is a survey about multiples in research. This involves parents of multiples and the multiples themselves to understand if they are willing to participate, their reasons for doing so, exactly what types of research they may be happy to volunteer for and their expectations in doing so. The result will be a set of criteria that clearly explains what families and multiples want from the experience. It should hopefully help to move us on from families and multiples being subjects of research to being supported by the research itself. The survey has been written and is currently being translated into a number of languages. We are very grateful to a number of our members who have volunteered to help with that. At the moment we have translations, or promises of translation for Arabic, Dutch, French, German and Spanish. If you may be able to assist in translation or checking of the translation once I load it into Survey Money please feel free to contact me (carolyn@icombo.org). We are also planning to use multiples in research as the theme of an International Multiple Birth Awareness Week in November this year, so please take part in the survey and support the campaign in the coming months and years. We'll let you know how you can fill out the survey when it becomes available (hopefully in the next couple of months).

School Placement Survey

At the ISTS Congress in Madrid in November 2017, it was decided that the most pressing issue that needed to be researched worldwide was school attendance for multiples. mainly whether they were told which classrooms they had to attend or if the parents got to decide if they were together or separate. This study is now on its second round through our committee and hopefully will be ready to be distributed this summer. The results will be presented at the next ISTS Congress in Hong Kong in 2019.

In the United States, parents of multiples were instrumental in lobbying legislatures in many states to pass a "Twins Law" that encourages parents and educators to work together to determine the best outcome for each set of multiples versus a universal rule. This was a grassroots effort that required local parents of multiples to take the issue to their state legislature.

We invite all member organizations to share what is being done in the area of School Placement in your country by sending a brief overview to research@icombo.org.

We also encourage parents of multiples from across our organisations to participate in this survey once released.



Watch for the opening of this survey soon.

The Elizabeth Bryan Multiple Births Centre



Elizabeth Bryan was a consultant paediatrician and former President of the International Society for Twin Studies who dedicated her career to helping families with twins, triplets or more. Dr Bryan's research into Twin to Twin Transfusion Syndrome brought her into contact with many families with twins and triplets. She was shocked to see the extensive practical and psychological difficulties for parents caring for more than one baby and the almost complete lack of awareness of health care professionals of their problems and how to help them. After helping set up local twins clubs (which evolved into Tamba) which gave excellent peer support, Dr Bryan realised that there was still a need for a focus on

health care and allied professionals. As a result, Dr Bryan established the Multiple Births Foundation (MBF) in 1988 and over the past 30 years the paediatricians, midwives, neonatal nurses and health visitors and psychologists working with the MBF have gained extensive experience and knowledge of how to support multiple birth families. The MBF has also published papers and guidance for professional colleagues. However, the challenge now is share the expertise of MBF staff more widely and offer education programs for all health and social care professionals about how to meet the special needs of multiple birth families. We also need to conduct more research on which to base best practice.

After working increasingly closely with Birmingham City University (BCU) it seemed a natural progression to join forces in order to bring together the academic prowess and range of disciplines within BCU, with the direct experience of the MBF. A formal collaboration was agreed and the Elizabeth Bryan Multiple Births Centre (EBMBC) was launched in September 2017.

The EBMBC vision is "to deliver excellence in education, practice and research".

Ours core aims are:

- To develop evidence-based education and professional development programs for health care and allied professionals involved in the care of multiple birth families.
- To establish standards for education and professional development for health care and allied professionals.
- To establish a dedicated research program which will provide an evidence base for practice.
- To support the provision of best possible care for babies, children and their families.
- To collaborate with families to inform education, practice and research.



Elizabeth Bryan

The EBMBC already has two work streams underway. The first is developing education and continuing professional development programs and resources for health care and allied professionals who work with families, including an online training module. The second is the development of a research program. PhD students at BCU already have studies in progress which include families' experiences of antenatal care, preterm birth and parenting multiples in the first five years. A study is also underway exploring health visitors' experiences of supporting multiple birth families.

A fundamental principle of the EBMBC is that families with twins, triplets and more are at the heart of all our work, and this includes the children and wider family as well as parents.

We are planning to establish a Family Faculty to support our work and will be circulating more information about this shortly.

With the focus on families we already have close links with Tamba, but as our work is international as well as national, we look forward to collaborating with ICOMBO in the future.

The EBMBC is co-led by Jane Denton, Director of the MBF and Dr Merryl Harvey, Professor of Nursing and Family Health at BCU. If you have any queries we would love to hear from you. The following page includes our contact information.

The Elizabeth Bryan Multiple Births Centre ...continued

Jane Denton
Jane.Denton@bcu.ac.uk

Dr Merryl Harvey
Merryl.Harvey@bcu.ac.uk

Elizabeth Bryan Multiple Births Centre
Multiple.Births@bcu.ac.uk
0121 331 5185
www.bcu.ac.uk/ebmbc
Twitter: @EBMBC



Launch of the centre

FRONT: Jane Denton and Professor Merryl Harvey, Co-leads, EBMBBC

BACK: Faith Hallett, MBF Chair of Trustees; Professor Julian Beer, Deputy Vice-Chancellor (Research, Innovation and Enterprise); Professor Louise Toner, Associate Dean (Academic Portfolio and Market Development).

For more information about the EBMBBC and to read our latest newsletter please visit our website:

www.bcu.ac.uk/ebmbc.

Meet Your ICOMBO Board:

- ◆ Monica Rankin (Australia) – Chairperson chair@icombo.org
- ◆ Kimberley Weatherall (Canada) – Past Chair pastchair@icombo.org
- ◆ Keith Reed (UK) – Vice Chair vicechair@icombo.org
- ◆ Terri Browning Gillis (USA) – Newsletter Editor newsletter@icombo.org
- ◆ Susan Griffith (USA) – Research research@icombo.org
- ◆ Marion Gevers (Australia) – Treasurer treasurer@icombo.org

- ◆ **General board members:**
- ◆ Christine Disselkemp (Germany)
- ◆ Abelone Glahn (Denmark)
- ◆ Lucila Menendez Bueno (Spain)
- ◆ Carolyn Lister (New Zealand)



Do you have organisation or event news to share?

Would you like us to highlight your organisation?

Contact us newsletter@icombo.org

We want to hear what is happening in your organisation!

Articles are welcome for the next edition of the ICOMBO newsletter.

Deadline: May 31, 2018

