



News From Around The World **October 2020**

FROM THE CHAIR

Hello to everyone around the world!

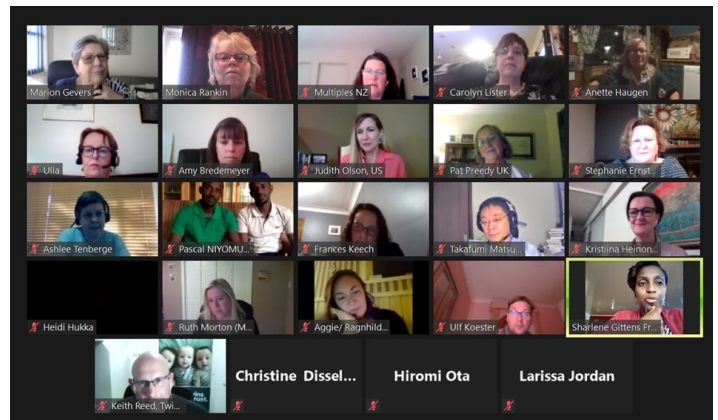
Last weekend, ICOMBO hosted our first-ever virtual meeting. We are living in a very different time at the moment and this is the only way we can meet. I was not sure how successful it would be, but I believe it was a big success!!



Monica Rankin

There were 30 attendees at the meeting from 12 countries, representing 14 different organisations. It was not easy to organise a meeting at a time that suits everyone. There were people who were enjoying a Friday afternoon, for some it was midnight and for our Japanese friends it was a 5am start for the meeting. I want to thank everyone again for making the time to come together, it was fabulous to see you all!

At the meeting I announced that Abalone Glahn has resigned from the ICOMBO Board and that there are two new members of the board – Pat Preedy, from UK and Joan Friedman, from USA. Both ladies bring varied experiences and skills to the board. I am looking forward to working with them. I am sure they will enhance the great work already occurring at board level.



Carolyn Lister has been working very hard to create some graphics, twibbon and facebook posts for use before and during International Multiple Birth Awareness Week (IMBAW). We also have a press release that can be used to promote yourselves in your local community. You will receive this information by separate email. If you have any questions, please contact carolyn@icombo.org

A copy of the minutes has been distributed to members, along with a link to the video presentation that celebrated the 11 chairpeople over the past 40 years.

I am looking forward to seeing your activities for IMBAW, please remember to send us information on what you do, and any images that we can share would be great.

Regards,

Monica

This year from the 9th-15th November 2020 we will celebrate International Multiple Birth Awareness Week (IMBAW). The theme for this year is 'Building a Global Community: Championing the rights of multiples'.

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. A key objective is to promote the principles detailed in our Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples.



welcomes you to join us for:

INTERNATIONAL MULTIPLE BIRTH
AWARENESS WEEK
9TH-15TH NOVEMBER 2020

our theme is:

**BUILDING A GLOBAL COMMUNITY:
CHAMPIONING THE RIGHTS OF
MULTIPLES**



For more Information on International Multiple Birth Awareness Week visit our Facebook page and watch for the distribution of the **Informational Pack for Organisations/Clubs**

<https://www.facebook.com/InternationalCouncilofMultipleBirthOrganisations/>

Update on Congress

The next congress is planned for 4 – 6 June 2021 in Beijing, China. This will be a minor ISTS conference. At this stage MCA Events, the conference organising company, are confident that it will go ahead. They are not currently considering an online alternative, but it will be discussed again later in the year. There are a few concerns about traveling to China:

- ◆ Human rights issues/concerns
- ◆ Personal safety as an Australian citizen, maybe an issue for citizens of some other countries too?
- ◆ Health concerns regarding Covid-19.

ISTS is planning the next major conference to be in Budapest 30 October – 1 November 2021. Adam and David Tarnocki, identical twins and twin researchers who live in Budapest, are the leads on this conference. They are putting together plans for an online component.



Updated Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples

The updated Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples was formally accepted by members at the recent meeting.

The updated Declaration has been published on the ICOMBO website:

<http://icombo.org/wp-content/uploads/2020/09/Declaration-of-Rights-2020.pdf>

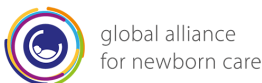
Welcome to our new partners!

- ◆ EFCNI - European Foundation for the Care of Newborn Infants - <https://www.efcni.org/>



- *The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.*

- ◆ GLANCE - Global Alliance for Newborn Care - <https://www.glance-network.org/>



GLANCE has the vision that every baby born receives the best start in life. Worldwide. GLANCE aims to create, empower and support a global patient voice in each region of the world while taking into account the respective cultural, historical and socio-economic backgrounds and needs of families.

- ◆ TAPS Support Foundation - twin anemia polycythemia - <https://www.stichtingtapssupport.com/>



We are a not-for-profit foundation based in the Netherlands. We passionately support research into Twin Anemia Polycythemia Sequence (TAPS) and related conditions, as well as supporting patients who are diagnosed with this disease.



A HISTORY OF ICOMBO 1980 – 2020

The ISTS is an international, not for profit multidisciplinary organisation furthering research and public education in fields related to multiple birth development and care including health, psychology and education. The Society was formed in 1974 and at the time, Collective Membership was introduced to provide an opportunity for multiple birth organisations (parents and others) to support research and share resources complementing and enriching the work of professionals who have an interest in multiple birth research across a range of disciplines. Any person who joined ISTS was automatically also a member of the Collective.

At the first Congress, held in Rome in 1974, there were only two Collective Members – USA and Australia. Joyce Maxey represented the USA organisation – National Organisation for Mothers of Twins Clubs, Inc. (NOMOTC). By 1977, parents of twins organisations had been established in five countries, and the Twins Association had commenced in UK. At the second Congress, held in Washington in 1977, three groups represented. Parents of Twins associations – the USA (NOMOTC), Australia (AMBA) and Canada (POMBA). During the 1977 congress, it was agreed that Collective Members provision be made in future congress programs for presentation of papers of a psychosocial nature, to encourage the sharing of information between the scientific and lay groups. The three Parents of Twins associations agreed to exchange newsletters and resource materials to compare and complement their individual support for multiple birth families. They also agreed to participate in a research project on zygosity determination, using handprint/footprints, which was initiated by the late Prof. Kloepfer in USA and managed by Joyce Maxey, USA.

In 1978, Sheryl McInnes, Canada, launched the second international project, which reviewed the situation of families with quadruplets in each country and resulted in a leaflet offering guidelines on the care and management of the babies and home. During the same year, Donald and Louis Keith extended the resource services of the Centre for Study of Multiple Birth, Chicago, to international groups.

At the 3rd Congress, in Jerusalem in 1980, papers were presented by representatives from Australia, USA, Canada South Africa, UK and Germany at the first “Twins, Parents of Twins and HOM’s” Research Session.

During this meeting in 1980, COMBO was formed. Sheryl McInnes (Canada) and Pat Stewart (Australia) had prepared a proposal for the formation of COMBO (Council of Multiple Birth Organisations) and drafted a research policy which would govern research projects proposed by COMBO members. COMBO was formed as a Working Group of ISTS. The documents prepared by Sheryl and Pat included voting rights, policy for the proposal and adoption of projects, principles concerning communication, election of COMBO chairperson, actions of the group as well as a Research Policy, designed to protect participating members. The Working Group proposal and policies were adopted by the ISTS Board, and were evident in projects conducted by COMBO members for a number of years.

Between 1980 and 1986 international liaison between COMBO members developed including exchange of newsletters, resources and research.

In 1993, at the 4th Congress in Helsinki, a proposal was put to the ISTS Board, and accepted, that the current Working Group should be divided so that COMBO represented the Parents of Twins and Twin Associations, while the other Working Group would be service groups. The underlying reason was the different research interests of the two groups. The first cooperative project between COMBO and the Scientific Members was initiated in 1983, that each country standardise their Twin Register database to promote cooperative international research.

In the months leading up to the 1992 Congress, there was a review of the ISTS structure, including changes to the constitution and to the Collective Membership. Two significant events occurred during 1992 to 1995 – Dr Elizabeth Bryan opened the Multiple Birth Foundation in London and the Declaration of Rights and Statement of Needs for Multiple Birth Children was created. At the 1992 Congress in Japan, multiple birth organisations were asked to submit five items for a Charter of Rights. These were collected from around the



world and compiled into the document. Pat Malmstrom, USA, initiated and coordinated this ambitious project through to its adoption in 1998. The Declaration was formally adopted by COMBO and ratified by a vote of the general membership of ISTS at the 1995 Congress in Virginia.

During the 1998 Congress in Helsinki, a new management structure for COMBO was proposed and accepted by COMBO members and ratified by the ISTS Board. The COMBO Board now consisted of:

- ◆ Chairperson
- ◆ Vice Chairperson
- ◆ Organisational and Development Officer
- ◆ Editorial Director
- ◆ Membership Director
- ◆ Past Chairperson

Subsequent to Congress, a COMBO Development Plan was drawn up detailing the aims, objectives and activities of COMBO. The Development Plan was updated for each congress.

At the 2010 Congress in Seoul, the name of COMBO was changed to ICOMBO (International Council of Multiple Birth Organisations) and it was agreed that ICOMBO would become an independent body, rather than remain as a Working Group of ISTS. Also at this Congress, the proposal for an International Multiple Birth Awareness Week was accepted by ICOMBO members. The week was to be held every two years, with a theme that reflected on an issue in the Declaration.

A new website was launched for ICOMBO in 2012, with a new modern logo. It is a useful tool for promoting the work of ICOMBO with the public, particularly information on research projects and IMBAW every two years. In addition, a public Facebook page and a closed Facebook group for ICOMBO members was launched in 2012. These are important tools in reaching the wider community and for members to interact with each other.

A new ICOMBO membership structure was accepted by members and ratified by the ISTS Board at the 2012 Congress in Florence. There were to be three membership categories – one would be for individuals and organisations and include membership to ISTS, the second would be for the same groups but not include ISTS membership; and the third category was for professionals. This category did not include membership to ISTS.

A whole day dedicated to workshops for ICOMBO members was introduced at the 2015 Congress in Budapest. This has enabled valuable networking and sharing of information, resources and concerns between the members.

ICOMBO has had a large banner produced that was displayed at the 2017 Congress in Madrid, promoting the organisation. At this Congress, ICOMBO was involved in a discussion with researchers for a presentation. This resulted in discussions about how multiple birth families and researchers need to work together to produce the best research outcomes. Further from this, there was significant interaction between ICOMBO Chair and some researchers, with papers co-authored on zygosity and a group who worked on setting priorities for research topics. From 2017 to 2020, there was significant interaction between ICOMBO and researchers, for the benefit of all. The website is updated as required with new information on research projects. It has become an excellent tool for promoting research studies, with links to the online studies available for the public. The Facebook page continues to grow in popularity, with daily posts of relevance to the multiple birth community. It is also a great way to showcase the work of our member organisations.

The next Congress was scheduled for November 2019 in Hong Kong. Unfortunately there was a lot of political unrest in Hong Kong at the time and it was decided to defer the Congress and hold it in Beijing in July 2020. Unfortunately the world was challenged with the Covid-19 pandemic. Most international travel was cancelled and it was exceedingly difficult and unwise to travel to Beijing at this time. The Congress is now scheduled to be held in Beijing in June 2021, assuming that the pandemic is no longer a threat to public health.



ICOMBO PAST OFFICERS AND PROJECTS

CONGRESS DATE	CONGRESS	ELECTED CHAIR	RESEARCH PROJECTS
1974	Rome, Italy	Joyce Maxey, USA	Hand/footprint research
29 August - 1 September 1977	Washington DC, USA	Joyce Maxey, USA	
16 - 20 June 1980	Jerusalem, Israel	Sheryl McInnes, Canada	Oral contraceptive study
28 June - 1 July 1983	London, England	Pat Stewart, Australia	Survey of triplet families Multiple birth bereavement study (stage 1) International oral contraceptive study
15 - 29 September 1986	Amsterdam, Holland	Judi Linney, UK	Multiple birth bereavement study (stage 2)
28 - 31 August 1989	Rome, Italy	Christine Gleeson, Australia	
22 - 25 June 1992	Tokyo, Japan	Patricia Malmstrom, USA	Declaration of Rights and Statement of Needs for Twins and Higher Order Multiples
28 May - 1 June 1995	Richmond, Virginia, USA	Patricia Malmstrom, USA	Declaration of Rights and Statement of Needs for Twins and Higher Order Multiples
4 - 6 June 1998	Helsinki, Finland	Pat Preedy, UK	Assisted with organization of 2001 ISTS Congress Liaised with David Hay on creation of education website Worked on compilation of policies on parental leave after birth of multiples, adoption and foster care, zygosity determination
4 - 7 July 2001	London, England	Jennifer Harland, Australia	Work continued on the education website
2 - 4 July 2004	Odense, Denmark	Mary Adcock, USA	Hosted mid-congress meeting in USA Created an online "wiki" resource sharing tool on the education of multiples Website development
4 - 7 June 2007	Ghent, Belgium	Kimberley Weatherall, Canada	
4 - 7 June 2010	Seoul, South Korea	Kimberley Weatherall, Canada	Development and launch of new website Creation of Facebook group and page Post Partum Hemorrhage Study ICOMBO Membership Survey First IMBAW event
1 - 4 April 2012	Florence, Italy	Monica Rankin, Australia	Promotion of Maternity Services study from Tamba Post Natal depression study
16 - 19 November 2014	Budapest, Hungary	Monica Rankin, Australia	Sole Parenting Study ICOMBO Member Survey
16 - 18 November 2017	Madrid, Spain	Monica Rankin, Australia	Classroom placement of multiples study Study on what encourages mb families to participate in research Global Twins and Multiples Priority Setting Partnership – with St George's University, London & Twins Trust Collaboration with Twins Trust, AMBA, researchers and clinicians to produce an overview of the challenges for multiple birth families and health professionals during pregnancy, birth and early life Major update for Declaration of Rights and Statement of Needs for Twins and Higher Order Multiples

TERM	CHAIR
1974 - 1980	Joyce Maxey, USA (deceased)
1980 - 1983	Sheryl McInnes, Canada (deceased)
1983 - 1986	Pat Stewart, Australia (deceased)
1986 - 1989	Judi Linney, UK
1989 - 1992	Christine Gleeson, Australia
1992 - 1998	Patricia Malmstrom, USA
1998 - 2001	Pat Preedy, UK
2001 - 2004	Jenny Harland, Australia
2004 - 2007	Mary Adcock, USA
2007 - 2012	Kimberley Weatherall, Canada
2012 - present	Monica Rankin, Australia





Pat Stewart
1983-86



Judi Linney
1986-89



Pat Breedey
1998-2001



Jenny Harland
2001-04



Mary Adcock
2004-07



Kimberly Weatherall
2010-12



Monica Rankin
2012-current

Judi-Ajibha Linney, MBE
President - Twins Trust UK
ICOMBO Chair— 1986-89

Twins Trust (formerly Tamba)



Early links with COMBO and ISTS

I recall how the **Twins Clubs Association (TCA)** got involved with ISTS as UK clubs. I was in discussion with Dr Elizabeth Bryan who was also a co founder of Twins Clubs Association, about ISTS. I attended my first Congress in 1980 for TCA (I was funded through a grant and donations from UK Twins clubs). I was pleased to be present when the Council of Multiple Birth Organisations (**COMBO**) was formed at the 1980 ISTS Congress, held in Jerusalem.

I was **Vice-President/Chair of COMBO and on the Board from 1986-89**. I went to nearly all the Conferences every 3 yrs for over 25 yrs and chaired and presented numerous papers and posters. Since 1980 international liaison developed with COMBO members including exchange of newsletters, resources and research.

Several **Tamba UK** Committee members and Honorable Consultants from a variety of professions were also volunteers & very active and supported development of services globally. Papers from Tamba UK candidates were presented on education, health, psychology, research and also on running our organisations and developing partnerships to increase funding. As Tamba members we chaired, presented papers, displayed posters, ran workshops, shared resources and enjoyed meeting up with other organisations and making friends.

As parent organisations and other professionals got interested in ISTS and its work towards clinical and medical research through twin studies, we were pleased ISTS developed and grew to include social and educational and psychological research.

Highlights included – Sharing, supporting and enjoying meeting people from different countries to improve services to meet the needs of families with multiples. Exciting to see the various countries developing resources and services to support their specific population needs; and, also share in their frustration when policy makers and national services inadequate. COMBO members were committed to promote the parent organisations in order to support families with multiples and learn from each other and to keep professionals aware of their needs and objectives.

I enjoyed my volunteer role and being a part of ISTS and COMBO as President of Tamba –now **Twins Trust**. I would like to thank all colleagues for their commitment and dedication to benefit families of twins and higher order births globally and wish ICOMBO all the best in the future.

Kimberley Weatherall, Multiple Births Canada
ICOMBO Chair - 2007-2012



Congratulations ICOMBO **on your 40th Anniversary**

I joined the Board of ICOMBO in 2007 and took on the role of Chair from 2007 to 2012, and I remain on the Board currently as Past Chair. I am very proud of the work that we were able to accomplish during that time, but also of the great strides that were made prior to and since that time to make a difference for multiple-birth children and their families.

One of the greatest challenges that ICOMBO faced at the time I joined the Board was to find ways we could bring organizations that supported multiple-birth families together from all over the world to build one global community. Our goal was to learn more from one another, to share resources and create ways we could more easily communicate as organizations and parents caring for multiple-birth children.

We worked hard to create a new organizational structure and identity that would be recognized world-wide. We started with changing the name from the Council of Multiple Births Organizations (COMBO) to become the International Council of Multiple Births Organizations (ICOMBO). We also created its very first logo, which I am proud to say was paid for by my daughters as a gift to me for Mother's Day.

We worked to make communication between countries, organizations, and families easier by launching the very first ICOMBO website, and Facebook Groups for ICOMBO Members and for those interested in multiple birth issues.

One of ICOMBO's greatest accomplishments was to launch International Multiple Births Awareness Week, first celebrated in 2010 worldwide. It has and continues to help create awareness throughout the world of the unique needs and challenges that families with multiples face. It has also helped to gain greater respect for ICOMBO from the medical and research communities.

In addition to the wonderful feeling of accomplishment for the work achieved during that time, there are really no words that can describe just how fortunate and grateful I am for my time serving on the ICOMBO Board. I am so very thankful for the experiences I have had and the lifelong international friendships that have been made.

Congratulations to ICOMBO and its volunteers on its 40th Anniversary and many wishes for continued success in the years to come! None of it could happen without the passion and hard work of so many dedicated volunteers.

Thank you for all that you do!