

News From Around The Globe

President's Welcome

Greetings everyone, from Down Under!! As you are probably aware by now, I took on the role of ICOMBO Chairperson at our recent Business Meeting in Florence.



Monica Rankin

Welcome to the first edition of the newsletter from our new team. I hope you find it interesting reading. There is quite a bit of information about our Business Meeting, and about the ISTS Congress. There is also a report on the survey we sent out in late 2011 – some interesting findings there! You will also be able to read about one of our member organisations.

I would like to take this opportunity to thank Kimberley Weatherall, the ICOMBO Past-Chair for all the work she did over the last 5 years in her role of ICOMBO Chairperson – I have big shoes to fill. I would like to thank Mary-Jane Adcock for her work while on the ICOMBO Board, as she stepped down at our meeting in April. Thanks also to Terri Gillis, Kimberley Weatherall, Mari Kaihovaari and Christine Disselkamp who volunteered to continue working on the ICOMBO Board. I would also like to welcome Pat Preedy, Tiffany Wimberley, Donald Keith and Keith Reed onto the Board. I am looking forward to working with all of you. You can read more about each of the Directors later in the newsletter.



Florence, Italy

The ISTS Congress and the ICOMBO Sessions were fabulous. I really enjoyed meeting with so many people from so many different countries. I learnt so much, including how so many of us, who claim to speak English, do it with very different accents!!! If you ever get the opportunity to attend a congress, consider it seriously as you will gain so much. It was great to hear about the new developments in medical science – from fertility treatments to childhood and beyond; as well as meeting the people who work with multiple birth families; and to also meet with members of our ICOMBO family. It is reassuring to learn that the difficulties we experience here in Australia are much the same as those experienced in every other country. We can learn so much from each other. I am sure that all ICOMBO members went home with some new knowledge, and equally certain that they were able to pass on valuable information to other members.

Enjoy the newsletter. If you have any comments or questions please do not hesitate to contact me at chair@icombo.org

Regards

Monica

REPORT ON ICOMBO BUSINESS MEETING

FLORENCE, ITALY APRIL 2012

It was exciting to have 17 organisations represented at the recent Business Meeting (one organisation was present via Skype). A copy of the full minutes has been sent to all organisations but if you did not receive a copy, please contact Monica at chair@icombo.org.

Board Members for 2012 – 2014

Monica Rankin – Chair and Membership Director

Terri Gillis – Vice Chair and Editorial Director

Kimberley Weatherall – Treasurer and Past Chair

Susan Griffith – Research Director

Mari Kaihovaari

Christine Disselkamp

Donald Keith

Pat Preedy

Keith Reed

Tiffany Wimberly was appointed after the meeting.



ICOMBO members enjoy a working session during the ICOMBO Business Meeting

Donald Keith spoke briefly about the initial findings of the Post Partum Hemorrhage Survey. He thanked the ICOMBO members for their support in getting mothers of multiples to complete the survey. Special mention must go to Emmanuelle from France who translated the survey into French!

Terri Gillis presented an overview of the organizational survey we conducted over December/January. It showed where our organisations are similar and how they differ. It will also give some information to the ICOMBO Board on how we can best help our members.

The new ICOMBO membership structure was accepted and will be in place for 2013. Membership renewal will be a much easier process. The ICOMBO Board will organize ISTS membership for our organisations.

Some of the work going into the next term for the ICOMBO Board will include:

- Continued improvement of the ICOMBO website
- International Multiple Birth Awareness Week – to be held in November 2012
- Improve communications between Board and members; and between members
- Raising revenue in order to improve services
- Support member organisations



Dr. Griffith

ISTS Congress/World Congress on Twin Pregnancy

FLORENCE, ITALY APRIL 2012

This year, the ISTS Congress was combined with the World Congress on Twin Pregnancy, so there were four days of presentations, hearing lots about multiples – from pregnancy and birth through to adult life.

Here are some snippets from the presentations made during the ICOMBO sessions:



Opening Reception

Donald and Louis Keith, of CSMB requested mothers of twins to complete an online survey on Post-Partum Hemorrhage (PPH) late last year. The results of this survey showed a very significant risk of PPH for mothers delivering a multiple birth. More research will now take place to quantify the risk and hopefully prevent deaths in the future.

Twinship is a great resource when twins are commencing school. Studies have shown that the effect of school placement is very important in the development of the twins. It is known that when starting school, problems are less likely if the twins are placed together. However little research has been done to see what placement is most effective as they get older. The common belief is that each set of twins should be treated individually rather than have a rigid set of rules for all twins (unfortunately this does happen in some countries).

A study in USA found that most teachers had no idea that there has been any research done on multiples in school; and nearly 50% of teachers interviewed had no knowledge of the school's policy on placement of twins in the classes. This study also found that the best placement policy is a flexible one – and that teachers need to be made aware of this.

Alessandra Piontelli gave a thought-provoking presentation about the life of multiples in some of the less westernized countries. She has written a book- *Twins of the World: The Legends They Inspire and the Lives They Lead*.

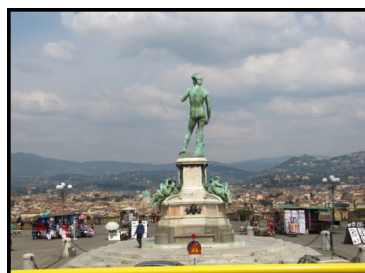
The representative from Multiple Births Canada talked of the work they have done with a reproductive technology organisation in Canada to produce leaflets about life with multiples. These leaflets would be intended for people who may be expecting multiples, or are making decisions about fertility treatments, so they can be a little prepared for what to expect if they have a multiple birth.

NOMOTC (USA) presented an overview of how their Research Department is structured, their process for identifying research topics, and how they work jointly with outside researchers.

ICOMBO members also attended many sessions presented by researchers and doctors attending the joint Congress.



ICOMBO Members



Florence, Italy

Organisation Profile



WHAT IS SAMBA?

SAMBA is a support group for parents with multiple-birth children. It is a non-profit organization, founded in 1975, and headed by a National Committee. Activities are controlled on a local group basis, in various areas throughout Southern Africa. All administration is controlled from Gauteng by the National Committee.

Current membership: 700– 1000 members

WHO CAN BELONG TO SAMBA?

Parents or caretakers of twins or higher order multiples, parents-to-be of multiples, adult twins and super twins may join the association. This includes foster parents, guardians and single parents. SAMBA draws its members from the RSA and our Southern African neighbouring states and countries.

WHAT DOES SAMBA OFFER?

The primary purpose of SAMBA is to offer emotional and moral support to parents and to increase understanding and awareness of child development and rearing, which relates especially to multiple birth families.

SAMBA allows its members access to reading and research material, especially concerning the rearing of multiple birth children. The “Multiple Magic” which is a bi-monthly publication is compiled by the National Committee sourcing its information locally and abroad and also serves as the mouthpiece of the organization. In this respect SAMBA also seeks to acquire and contribute to the latest research data to maximize the benefits to its members.

SAMBA forms a network of contacts between parents of multiples, their doctors, educators, and others having an interest in caring for families and children. It focuses attention on solutions to problems specifically related to multiple-birth children and their families.

SAMBA creates awareness amongst the public of what it means to be a parent or sibling of multiples. It promotes the individuality of the child.

SAMBA recognizes that the material needs of a member family is often put under strain and therefore runs a second-hand facility we like to call “Samaritan” and negotiates discounts on products such as milk formula and baby equipment.

WHERE IS SAMBA?

SAMBA is within easy access of city dwellers at local groups, and country groups are run for those in the outlying areas. Regular get-togethers are arranged by key members of SAMBA in each area, often addressed by guest speakers, to provide an informative atmosphere of awareness, togetherness and friendship. SAMBA National arranges Expectant Parents Seminars. SAMBA is a telephone call away:

Maxicall telephone number: 072 190 8615

SAMBA can be found on Facebook, or check out their website:

www.samultiplebirth.co.za

Organisation News

French Multiple Birth Organization



- **New Board**

Our General Meeting took place on 13th of May in Tours. Although the prior year was challenging, it was also a successful year. During the general meeting, the incoming board was elected as prior board members were at the end of their term.

The new board has a new Chairlady: Isabelle Sudre (mother of 4 children including 7 years old twins). Our chairman is now one of the three vice chairs. A new vice treasurer, a new secretary and vice secretary are completing the board executive and a new board member joined us.

- **New communication plan**

One of our actual plans is to modernize our communication material. So we just put 3D in our logo and worked on a very new poster with a professional designer that I really enjoy. www.mademoisellecaroline.com

We are now working on our publications: presentation leaflet, prematurity information leaflet, pregnancy booklet, breastfeeding booklet.

- **Coming soon**

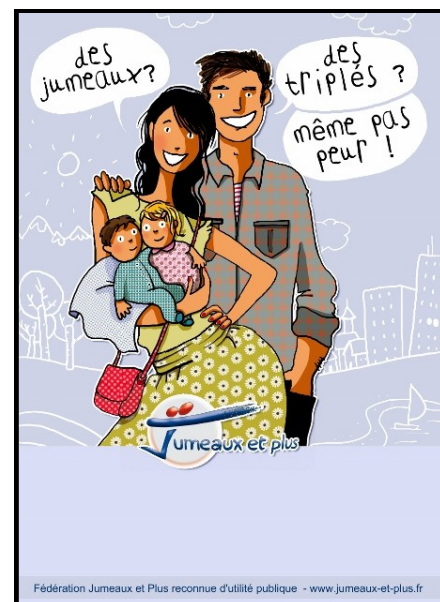
We're preparing our Scientific Convention which will take place the 3rd weekend of November. The subject is: Language and schooling. I would be proud to inform you further if you're interested.



Board of Directors



NOMOTC (USA) members are heading for Charlotte, North Carolina for the 52nd Annual Convention July 22– 28th.



Meet your ICOMBO Board Members

Monica Rankin (Australia) – ICOMBO Chair



Monica lives in Melbourne, Australia. At present, she is sitting on the committee of her local multiple birth club and has been a volunteer with multiple birth associations in Australia for the past 22 years, at local, state and national levels. Monica worked in many roles including Treasurer, local and state President, representative to Australian Twin Registry and Secretary. She has held a number of roles on the national Australian Multiple Birth Association Board. In early 2012, she was part of a very successful team of volunteers who hosted the third Australian Twins Plus Festival.

Monica has attended two ISTS/ICOMBO Congresses. She represented AMBA at the ISTS/ICOMBO Congress in Seoul in 2010 where she was appointed to the ICOMBO Board. At the recent congress in Florence in 2012, Monica was appointed ICOMBO Chairperson.

Monica has been a teacher of Mathematics for a number of years. She recently resigned from her position, taking a “change in job status”. She will no longer be working in a permanent role but will be working in a casual role a few days a week.

She and her husband, John, are the proud parents of 22 yr old identical twin sons, Chris and Anthony, an old son yr old son, Luke and a 16 yr old daughter, Alison.

Mari Kaihovaara (Finland)



Mari Kaihovaara lives in Nummi-Pusula, which is a nice countryside town outside Finland’s capital Helsinki. She does a lot of both voluntary and paid work in the Finnish Multiple Birth Association. She is the founder and Chair of the Finnish Triplet Association, which is more of peer-support organization for families with triplets in their unique situation. These two organizations work together for the benefit of multiple birth families. Mari has been involved with the Multiple Birth Associations for almost 20 years.

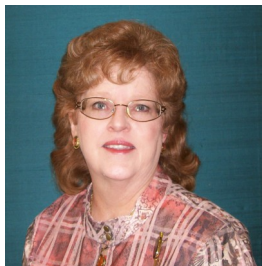
Mari attended the ISTS congress for the first time in Helsinki. She also attended in Seoul in 2010 and Florence this year, where she was appointed to the ICOMBO Board.

She is a proud mother of 21 yr old triplets, Hanna, Jaakko and Emilia and 15 yr old twin boys Lauri and Matias. Now that the triplets have moved out, Mari is wondering if she will have more time for herself. At the moment work with the Multiple Birth Association seems to take all of her spare time, but she is enjoying all of it and would not change any part of her life.

In her other life, Mari is a planning officer for First Aid Training in the Finland Red Cross.

Meet your ICOMBO Board Members

Terri Gillis (United States) – Vice-Chair



Terri Gillis is the immediate Past President and current Advisor of the National Organization of Mothers of Twins Clubs, Inc. (NOMOTC), where she has been a volunteer for 20 years. She has served in the Finance, Education, Convention, and Publicity Departments as well as several special committees. In her current role as Advisor, she oversees two committees; The EDGE (Endowment) Committee and the Nominating Committee.

In addition to her National work, Terri continues to serve as a member of the Board of Directors for the Florida State Organization of Mothers of Twins Clubs. She is a Past President of this organization as well as her local club, Greater Orlando Mothers of Twins and Triplets Club, where she has been a member for 38 years. In addition to her local club, Terri is also a founding member of the Flamingo Mothers of Multiples.

Outside of her volunteer efforts, Terri is wife to Charles, mom to Tricia and Tara, and loves being a new Grandmother to Landry. In her “spare time” she continues to lead a Sales Administration team at SunTrust Banks, Inc. where she has been employed for 42 years and holds the position of Senior Vice President. She manages a diverse group of teammates that support bankers across 14 states in the United States. Terri resides in Orlando, Florida.

J. Susan Griffith, MD (United States)



J. Susan Griffith MD -- mother of 27 y.o. fraternal sons, Brandon and Chad Moore. I've been a physician for 30 years, and for the past 20 years I've been a physician for the students and employees of the University of Kentucky. I carried my twins during my third year of residency -- and I was the Chief Resident during that time. I got used to seeing startled expressions on the faces of the patients when I lumbered into their hospital room!

We moved from Lexington KY to Cincinnati OH when my twins were 6 weeks old -- my first friends there were my Eastern Hills Mothers of Twins Club friends and my La Leche League for Twins friends. Their support and friendship meant so much to me that I have been a volunteer at the local, state, national and international level ever since then.

I'm completing my 20th year as a volunteer for NOMOTC, with 6 years being spent on the Board. I have divided my time in NOMOTC between the Research and Education departments, but my first love is really Research so I am thrilled to be working with ICOMBO's research interests.

I started attending the ISTS Congress in 1995 when it was held in Richmond VA, and I have attended every Congress but two since that time.

In my free time, I am an avid tennis player, reader and gardener. I also spend a lot of time with my elderly parents who we are caring for in their home 24/7.

My sons are both working full-time -- Brandon with an engineering company and Chad with the YMCA (and he also works for us 20 hours a week in my parents' home). I am really proud of the young men that they have become!

Meet your ICOMBO Board Members

Donald Keith



Mr. Keith is the co-founder of The Center For Study of Multiple Birth, located in Chicago. The Center's purpose is to stimulate and foster medical and social research in the area of multiple births and to provide assistance to mothers with the special problems that they and their offspring will encounter.

Mr. Keith is a Logistician and Systems Engineering Manager, for Science Applications International Corporation ([SAIC](#)), a Washington-based consulting company. Prior to joining them, he spent over twenty four years in the U.S. Army and retired as a Lieutenant Colonel. A native of Chicago, Illinois, Keith was commissioned in the U.S. Army Signal Corps in 1956 from the University of Wisconsin with a Bachelor's Degree in Business Administration.

Keith earned a Master's Degree in Business Administration from Monmouth University in 1973 and graduated from the U.S. Army Command and Staff College in 1974. He is also a graduate of the Signal Officers Advanced Course and numerous other Army courses.

He attained Fellow status in the Society of Logistics Engineers, the Society of Advanced Medical Systems, and the International Society for Twin Studies. He is designated a Professional Logistics Manager, Advanced, by the Air Force Institute of Technology and the Society of Logistics Engineers. He is dually certified as a Professional Logistician and a Professional Resource Manager by the National Security Agency.

His military decorations include the Meritorious Service Medal, Bronze Star Medal with "V" device for heroism in combat with one Oak Leaf Cluster (OLC), the joint Service Commendation Medal, the Army Commendation Medal with two OLC, the Air Force Commendation Medal, the Vietnamese Cross of Gallantry with Gold Star, the Vietnamese Armed Forces Medal of Honour, 1st Class (Heroism) and the Vietnamese Civic Action Medal, 1st Class.

He has over 200 publications, oral presentations, scientific exhibits, research reports, and copyrighted surveys on logistics, multiple birth, and health issues to his credit.



Christine Disselkamp (Germany)

Dr. Christine Disselkamp is a Psycholinguist from Germany who represented the German ABC-Club at the last four ISTS/ICOMBO Congresses in Denmark, Belgium, Seoul/ South Korea and Florence/Italy. As a Board member of the ABC-Club Christine is responsible for research and international contacts.

Some years ago she did a study about triplets, because she wanted to know what it really means to be a triplet. Her research investigates various areas of the development and contains questions about the social and emotional development, about the speech, the identity development, the physical likeness and about the advantages and disadvantages of being taught together or separately in school. Two hundred and seventy six families with triplets from Germany, Austria and Switzerland have taken part in her study. Christine chose her topic for her dissertation based on her personal experience as a proud mother of 16-year-old triplet boys.

Watch for more Board member profiles in our next edition of the ICOMBO Newsletter this Fall.

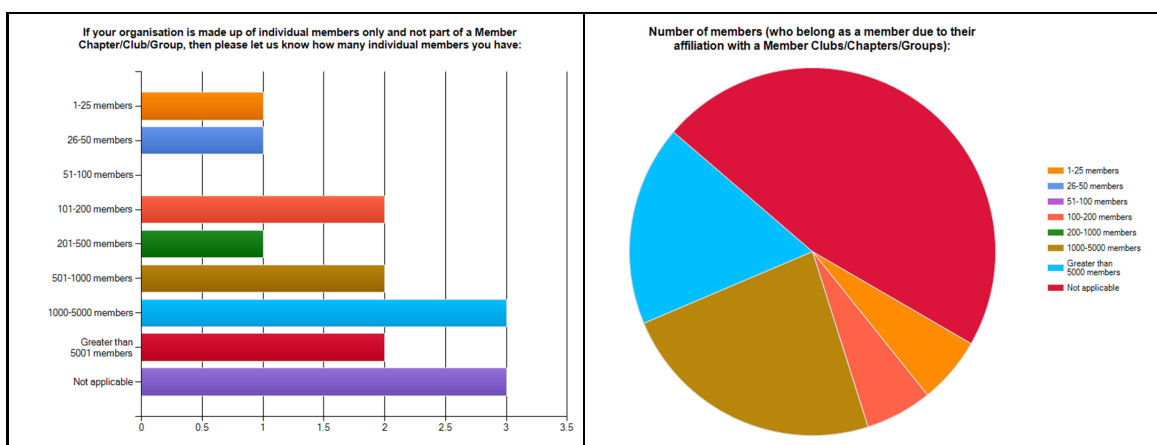
ICOMBO Survey

During the past year, ICOMBO (the International Council of Multiple Birth Organizations) surveyed Multiple Birth Organizations (MBOs) from all over the world. This was done jointly by NOMOTC and ICOMBO, via Survey Monkey, online. For the next few ICOMBO newsletters, I will be summarizing the results of this survey.

Seventeen MBOs responded to this survey request. Sixteen countries were represented: Argentina, Australia, Canada, Chile, Czech Republic, Denmark, Finland, France, Germany, Ireland, Japan, New Zealand, Norway, South Africa, United Kingdom and the United States of America.

In this first article about the survey, I'll go over the results in general. After that, the following articles will be about the individual organizations.

The majority allowed Professional Members (Douglas, physicians, researchers, etc.) to join their organization. The number of Professional Members ranged from five clubs with 1-25 to one club with 100-500.



The number of members in the individual MBOs varied from one organization with 25 members to two organizations with > 5001 members. More than half of the MBOs were comprised of member clubs/chapters/groups.

Eleven of the MBOs belong to the International Society of Twin Studies (ISTS) – and, therefore, are also members of ICOMBO.

In more than half of the MBOs, annual dues were paid by the individual members. Other MBOs had dues paid by the individual clubs/chapters/groups or by their Professional Members.

The two main benefits of membership were a newsletter/magazine and social events. Other benefits included website access (via a members-only section), group-specific services and non-profit/charitable status (as a result of belonging to the MBO). The vast majority of the MBOs did have non-profit status in their country.

The majority of the MBOs were governed by an Executive Board/Board of Directors. Others were governed by either an Executive/Head Office or by their Officers/Chairmen/National Volunteers. Most met twice a year, while other MBOs governing bodies met either once a year or quarterly. Day-to-day running of the organization is done mainly by e-mail, but many MBOs use video chat/Skype or conference telephone calls to communicate with each other.

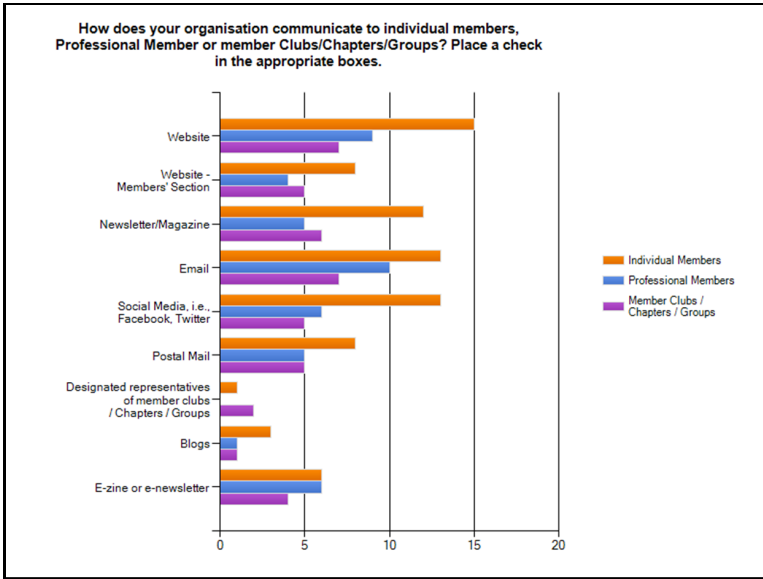
Only two-thirds of the MBOs had bylaws/governing documents or an annual budget. About half produced an Annual Report.

Most MBOs had <25 volunteers and no paid staff. Four organizations had >25 volunteers, and two had >100 volunteers. One-third of the MBOs had <10 paid staff and one had 11-25 paid staff.

Thirteen organizations create literature addressing topics pertinent to Multiple Birth Families. Some of these booklets/information packets are free but many must be purchased from the MBO.

Continued.....

ICOMBO Survey ...continued



Almost all of the MBOs communicated with their members via their website, and most also used e-mail, social media (Facebook, Twitter, etc) and their own newsletter/magazine. Other forms of communication included postal mail, blogs, e-zine and club/chapter representatives.

Eleven MBOs produce a national newsletter/magazine. Most are done in print but some are done electronically. One-third sell subscriptions of their newsletter/magazine to non-members.

The majority of MBOs advertise via their website or social media, but some still advertise in newspapers or magazines.

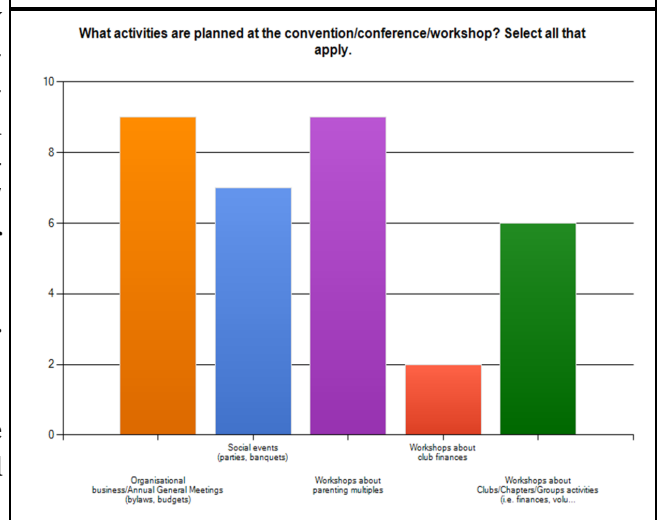
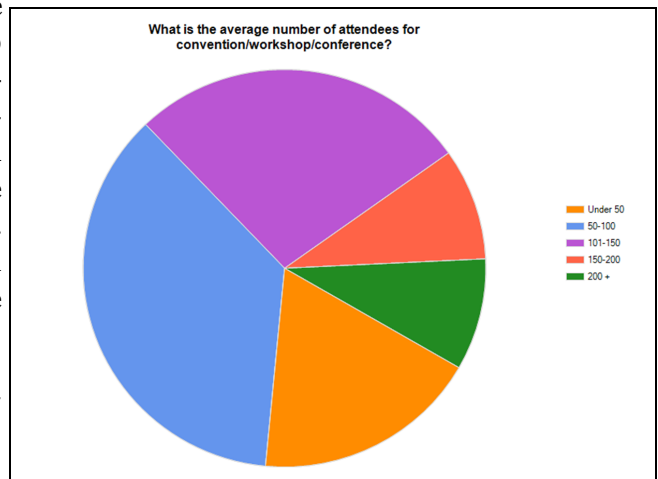
Eleven MBOs host a National convention/workshop/conference yearly. Most have about 50-100 attendees while a few have >200 attendees. Most allow non-members to attend. The main activities at these annual events are General Business meetings, workshops, and social events (parties, banquets). The most common type of workshop was about parenting multiples, but there were also workshops about club/chapter/group activities and finances. Most MBOs advertise their annual meeting via their website, with social media and newsletter/magazine communication a close second.

Half of the MBOs hold a yearly event to promote their organization and to raise awareness about multiple birth children.

Ten organizations conduct research with their members. They also provide their membership with information concerning research studies done by outside sources. Research is mainly conducted using survey tools, like Survey Monkey, but e-mail and Website communication were also done. To a lesser degree, contact was made by postal mail or through their newsletter/magazine. Seven MBOs worked with researchers outside of their organization.

When asked if there was a twin or multiple birth registry in their country, 1/3 said Yes, 1/3 said No, and 1/3 were not sure.

Thirteen MBOs responded that they were aware of the "Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples" written by ICOMBO.



Look for information about the individual MBOs in the next issues of this ICOMBO newsletter.