



NEWS FLASH:
ISTS CONGRESS—2014
Budapest, Hungary
April 6 - 9th, 2014

News From Around The World

July 2013

Chairperson Report



Monica Rankin

Greetings !

It has been a great start to the year for ICOMBO, with our first year of financial independence and our own membership list. I'm excited about meeting the needs and expectations of our members. If you have any ideas, concerns or comments please do not hesitate to contact me or post a comment on our Facebook page – www.facebook.com/InternationalCouncilofMultiupleBirthOrganisations

Our Facebook community is growing slowly. If you haven't visited yet, please pop in and take a look and "like" us. I would love to see more posts – there must be things of interest from your organisation or your part of the world that you could share from time to time.

Earlier in the year, I was asked to supply information from our International Multiple Birth Awareness Week 2012 (Multiples in Education) for a local multiple birth group in Australia. They have produced a folder of information (Resource Pack) for kindergartens and schools in their area. It contains loads of information to assist the educators when working with multiples. It was pleasing that ICOMBO was invited to participate in this work and have our documents included.

Lastly, I am beginning to work on the ISTS/ICOMBO Congress for 2014 – read more about this later in the newsletter. In the near future, I plan to work on our website – updating our information and perhaps adding some more information/articles. If you have any suggestions, please contact me at chair@icombo.org.

Regards,

Monica

PARENTAL LEAVE FOR MULTIPLE BIRTH FAMILIES

In this newsletter you will find survey results completed in the UK that addressed parental leave. (See pages 7 and 8) We also know Canada has recently dealt with the same topic. (See pages 10 and 11) As we think this is a concern to many of our members, we would like to know if your country is dealing with similar situations. You will soon be receiving an email asking you to complete a short survey on the current practice in your country. We would ask that you take the time to complete it so that we can get a picture of what is happening at present around the world. You never know, the results may be of assistance to your organisation as well as other ICOMBO members.

ICOMBO/ISTS CONGRESS 2014



I am excited to announce that the 2014 Congress will be held in Budapest, Hungary from Sunday 6th April to Wednesday 9th April.

The venue has not been decided yet but I hope to have news on this very soon. I have begun preliminary work on the program and will be looking at ways for ICOMBO members to have more time together during the congress. I know that in Florence, this was an issue for many of us – there just wasn't enough time for us to meet and discuss ideas. If you have any agenda suggestions for ICOMBO members at congress, please contact me at chair@icombo.org

I have been informed that ICOMBO members will receive a discounted rate for registration and I will be working to ensure that this is in place from the time registration opens so that we do not have the problems that some people encountered last year.

I am looking forward to the trip and exploring parts of Eastern Europe. Fortunately my husband will also be able to travel with me, so we will be combining a holiday with the congress. If you start planning now, there is time for you to start saving funds to find your way to Budapest in 2014 so you can join us. It would be wonderful to see all (or most) of our members represented at Congress 2014. *Submitted by, Monica Rankin, ICOMBO Chair*

MEMBERSHIP NEWS

We currently have 18 financial members, 16 at Level One and 2 at Level Two. Although this probably seems like a small number of groups, we have been increasing in the number of member organisations over the past couple of years.

As members, you all have access to the closed Facebook group and receive this newsletter. All Level One members should have already received a copy of the ISTS journal - Twin Research and Human Genetics (if you joined prior to the end of February), and a registration number that enables you to access the journals online. If you have any questions about this, please contact Monica at chair@icombo.org

Also, if you are a Level One member when it comes time to register for the 2014 Congress, you will receive a reduced registration fee.

As a result of creating our own membership, we hope it has been simpler for groups to join ICOMBO and ISTS this year. One exciting aspect of this new process is that ICOMBO now has a small amount of funds. We currently have \$684 AUD that has been collected through our membership fees. This money will be used in the future to further the work of ICOMBO. We will keep our members informed as we continue to look at opportunities to further the mission of our organisation.



LIKE US ON FACEBOOK

ICOMBO Facebook Page



Have you “liked us” online? If not, check us out and visit often to hear and share news about multiples and multiple birth organisations from around the globe.

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

If you have any events you would like publicised, please contact Monica Rankin, ICOMBO Chair, and she will create an event for you. If you have anything of interest from your country, or organisation, please create a post for it. We are hoping that this page will be a way for our members to reach each other and the multiple birth community throughout the world.

We are reaching individuals in countries where we do not have ICOMBO memberships, extending our reach further across the globe. So, join us, we hope to see you online!

Have Organisation or event news to share?

We want to hear what is happening in your organisation! Articles are welcome for the Oct/Nov edition of the ICOMBO newsletter. Deadline: September 15th, 2013

Send to: vicechair@icombo.org.

Would you like to be an ICOMBO volunteer?

Contact us at chair@icombo.org to learn more about becoming an ICOMBO volunteer.



Introducing the New Zealand Multiple Birth Association (NZMBA)

The Mission Statement of the NZMBA is “to address the special and unique needs of families experiencing a multiple birth, by providing information and support to multiple birth clubs and members.” The NZMBA is a valuable, free national resource for all parents expecting a multiple birth, or new (and vulnerable) parents of multiples.

NZMBA is a parent organisation for the 22 multiple birth clubs throughout New Zealand. Members pay a small fee to the local club. There are currently approximately 1500 member families in the country.

The association was established in 1980, at a time when there was very little information or support available for parents expecting multiples. One of their first achievements was lobbying to make 240 hours of Home Help available to parents of twins (with a pre-schooler) and triplets—this replaced 6 weeks of community nursing, that commenced when the babies were born (even if they were in hospital!). Further lobbying over the next few years saw the 240 hours become more flexible, and an increase to 750 hours of home help for triplets and higher-order multiples; this was further increased to 1560 hours several years later. The New Zealand Multiple Birth Register was also established in 1980, and as in other countries, is an invaluable tool for research.



Most clubs throughout the country will offer much of the following:

- Contact people for prospective and new parents
- A Buddy System, or contact people so that members have someone to turn to for help, advice, advocacy, support or just a friendly chat
- Weekly/fortnightly Playgroups or coffee mornings
- Regular social activities
- Websites and/or a Facebook page, and a local club newsletter
- New Parent Packs
- Distribution of the free box of Huggies nappies that all new parents of twins and triplets are entitled to
- A range of hire equipment for multiples
- A club library



Continued

Larger urban clubs, such as those in Auckland, Christchurch and Wellington, can offer services that may include:

- Multiple-specific antenatal education
- Parent education
- A hospital visiting team
- Social events for mums, dads and families
- Bereavement support
- Meals for new families, and in some clubs, a grocery hamper
- Free, or very cheap, second-hand baby/children's clothing.

Our website features an extensive article archive (250 articles!) from our quarterly, national Newsletters, all written by New Zealand parents of multiples, and covering a huge range of topics. The website also seeks to ensure that all parents expecting multiples have access to crucial information regarding chorionicity diagnosis and maternity care—all with the help of our Medical Advisor, Fetal Maternal Medicine specialist, Dr Emma Parry. In a similar vein, in the past few years the Executive and other supportive club members have rewritten our key multiple birth resources, and gained sponsorship to provide these for free to new parents of multiples.

Although we have more to do, we are very proud of our achievements—particularly that it has been accomplished with volunteer labour! Also, in recent years, the Executive has worked very hard to be involved as a stakeholder in health policy decisions by the Government and District Health Boards, and has developed a very a good working relationship with The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) and the New Zealand College of Midwives (NZCOM).



FINNISH TRIPLET ASSOCIATION

In Finland, approximately 1000 sets of twins and 10 sets of triplets are born each year. There are currently no sets of quads, quins (quints) or other higher order multiples. The Triplet Association was founded by ICOMBO Director, Mari Kaihovaara 19 years ago. There are 100 member families at present.

There is no funding for the association, all the funds are raised from membership fees. There is a “Winter” meeting on 3rd March each year, on the Finnish Triplets Day – a day that is marked on the Finnish Calendar. There are also one or two summer meetings each year. Meetings are held in various places – spas, parks, camping indoors.

For more information visit the website (English language):

<http://www.kolmosperheet.fi/yleinen/Englanti%20paasivu.html>

Twins and Multiple Births Association (Tamba), UK

New Project – Hands on Help in the Home

We have teamed up with the Norland Nanny College to offer families in crisis free help from a qualified nanny. Our first involvement with the College was last year when a new father of triplets lost his wife eight days after she gave birth. Keen to help him cope, we gathered donations towards the costs of bringing up his three new babies during the first year. After contacting the College, they drew up a rota of willing volunteers who went into the home, without charge, to support him caring for his babies for the first eight months of their lives. Tamba paid for their out of pocket travel expenses and accommodations. Since this first case, we have been supporting one to two families each month in this way. The project will be publicly promoted later in the year. We are producing formal criteria to prioritise cases as we expect to have a higher demand than supply.

Availability of Formula Milk in the UK

Retailers in the UK are rationing sales of formula milk because of the increased demand in China, which has resulted in bulk buying of stocks for export. Most supermarkets have introduced a restriction of two tins per customer per day.

The restriction placed on consumers did not take into consideration the unique requirements of multiple birth families. In response Tamba contacted all the major retailers to ask them to ensure that multiple birth families are able to buy sufficient amount of formula milk for each child. The supermarkets agreed to allow multiple birth families to show their membership cards to store managers in order to bypass the maximum limits imposed.

Tamba responds to new NICE fertility guidelines

The National Institute of Clinical Excellence (NICE) recently issued guidelines on Fertility. These guidelines are a partial update to the Fertility NICE guidelines that were published in 2004.

The key changes include:

- Raising the IVF upper age limit from 39 to 42 years old
- In most cases decreasing the number of embryos transferred during treatment
- For women aged under 37 years: In the first full IVF cycle use single embryo transfer; in the second full IVF cycle use single embryo transfer if 1 or more top-quality embryos are available. Consider using 2 embryos if no top-quality embryos are available; in the third full IVF cycle transfer no more than 2 embryos.
- For women aged 37–39 years: In the first and second full IVF cycles use single embryo transfer if there are 1 or more top-quality embryos. Consider double embryo transfer if there are no top-quality embryos; in the third full IVF cycle transfer no more than 2 embryos.
- For women aged 40–42 years consider double embryo transfer
- Making fertility treatment available to new groups of the population that require special consideration in their treatment or care

“The guidelines are flawed as they overlook that it can be a positive experience to have twins. Although there are associated risks with multiple pregnancies, with the right care and support the vast majority of families raising twins can have a unique, happy experience.

“It’s a concern that the unintended consequence of these guidelines could be more families decide to seek treatment overseas where they still have a choice about their treatment options and the costs are likely to be much lower than here in the UK.”

Link to the full NICE Fertility guidelines is here <http://publications.nice.org.uk/fertility-cg156>

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Tamba recently published a report outlining our families' experiences.

<http://www.tamba.org.uk/document.doc?id=516>

Maternity & Paternity Leave Proposals and the financial costs

This report found that multiple birth families face crisis due to lack of maternity and paternity leave provision in the UK. Despite the additional costs and time required to care for multiples, families will still receive the same provision of maternity and paternity leave in the new Children and Families Bill 2013 as parents with only one baby. The Twins and Multiple Birth Association are calling for the following amendments to be made to the bill that is currently going through parliament. Double the duration of paid paternity (4 weeks of paid paternity leave) and maternity leave (78 weeks of paid maternity leave, with an additional 26 weeks of unpaid leave) for these families.

The survey of over 1000 multiple birth families showed that over half of the babies were born prematurely. Of those that were born prematurely, over two-thirds of families (67.7%) spent more than a week in neonatal care with 1 in 5 families with premature babies spending more than a month in neonatal care.

In the absence of enough paid paternity leave, 3 out of 4 of the partners in our survey had to take additional leave during pregnancy to help support the family following the birth of the babies or to look after the mother during ill health in pregnancy.

Furthermore, almost half of the respondents said they experienced ill health during their multiple birth pregnancy. Of those who experienced ill-health during pregnancy just over half were hospitalised and almost a third began their maternity leave often weeks before they gave birth.

The current lack of additional maternity and paternity provision for families with multiples in the UK means unnecessary financial hardship for families putting increased strain on the family. Almost 3 out of 4 families used their savings to get by with 51.3% building up debt.

The online survey was conducted between 17th January and 19th February 2013 and collected the views of 1,118 parents of multiples. (97% were parents of twins and 3% were parents of triplets)

Further statistics from the report:

- Due to the increased likelihood of complications during pregnancy, 29% took more than a month off sick and nearly 25% of mothers were hospitalised.
- Ill health necessitated many mothers to take early maternity leave 29% of twin mothers took leave at 28-31 gestation (the average gestation for single birth is 40 weeks and for twins 37 weeks), 50% of triplet mothers started their leave at this time.
- Over 10% of partners took holiday or unpaid leave to look after their other children, whilst their mother was poorly.
- Several respondents said they needed weekly or fortnightly scans. Over half (58.8%) of partners took additional time off during pregnancy to attend antenatal appointments or scans. Of these, a third of partners (31.3%) took more than five days of unpaid leave.

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Maternity & Paternity Leave Proposals and the financial costs

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- Over half (53.2%) of respondents' babies were born prematurely and needed to spend some time in neonatal care. Of those who were born prematurely, over two-thirds of families (67.7%) spent more than a week in neonatal care. Over 1 in 5 families (20.6%) with premature babies spent more than a month.
- Looking after twins or more can be very intensive in the early months. Over 64% of mothers spent more than 6 hours a day feeding their babies in the first month. Fewer than 1 in 10 (8.3%) new mothers get 6 or more hours sleep a night.
- Our families are also more likely to experience financial hardship. 61.4% did not have enough maternity and paternity pay to cover the cost of their (and their partner's) leave.
- Many found themselves in serious financial difficulties with 32.3% of families putting money on their credit card that they could not pay off in full at the end of the month, 27.9% borrowing money from family/friends, 21% (usually partners) worked longer hours or took on an additional source of income, and 7.7% took out a loan from a bank or financial institution.

MULTIPLE BIRTH AWARENESS WEEK - AUSTRALIA

In March, the Australian Multiple Birth Association (AMBA) celebrated Multiple Birth Awareness Week (MBAW) (10-17 March). MBAW is a national event, held annually, to celebrate the joy of parenting multiples and also to educate communities and professionals about the joys and challenges of parenting twins, triplets and more. The theme was 'getting social', recognising the many events that clubs hold and the growth of the online connections and support that AMBA's social media presence is providing.

AMBA clubs around Australia had events to celebrate the week including visits to Sydney and Melbourne Zoo. The media covered a number of the events which helped to raise awareness and to get the conversation started about the joy of raising multiples. AMBA's Facebook page and Twitter presence (@AMBAConvention and @MultipleBirths) also helped to spread the word along with a number of blogs. Lovely MBAW messages were sent in by ICOMBO, Multiple Births Canada, New Zealand Multiple Birth Association and Tamba. These were shared via AMBA's social media presence and appreciated by members.



AMBA
March 2013



ORGANISATION NEWS

Submitted by : Anne von Bestenbostel + Burkhard



The ABC-Club is Germany's group for multiple birth parents of triplets. My (very nice) husband Burkhard is president or chairman of the ABC-Club. In April we went to our Annual General Meeting of the club which is always very fun and very tiring at once.

Our triplets Jette, Hannah, and Theo were born in 2010. We found out about this club for triplet parents through "the blue book" which I read when I was pregnant. (Other books about "normal pregnancies" with one child were immediately of no more interest, I just loved advice like "buy a dryer!") Anyway, we became members of the ABC-Club before we knew how great it would be to meet other triplet parents.

The annual general meeting (AGM) is held every year in Duderstadt, a small and pretty town in the middle of Germany. Last year was our first try – and our first family trip ever. The children learned to walk on steps there, they hardly ate anything because watching the other families was so interesting, and we loved to meet other families and have time to visit and talk after everybody under three feet went to sleep.

The AGM is combined with a big family weekend. This year, 26 families with triplets and their siblings showed up. Also, three monozygotic women age 30, also three young men from Burkina Faso going to college in Germany. The founder of ABC-Club, Helga Gruetzner (84), came, a great old lady with lots of energy and good humor. When we talked about the homework we need to do in order to keep the ABC-Club alive, she said "that's a lot of work – and I am so old by now – and I want to do so many other things!" No, I think, the ABC-club is in really good hands with the new board elected in 2012, although it definitely is a lot of work.

All the members met on Friday afternoon. We met old friends, got to know new ones, moved into our apartments (Duderstadt had great accommodations for big families, and it is in the center of Germany, so it is ideal for our needs) and were happy to go to dinner that first night.

On Saturday we had the chance to go on a guided tour through the quaint town of Duderstadt, enjoy the huge and fantastic playground downtown, or just stay by ourselves.

In the afternoon after extensive soccer matches for big kids or naptime for small kids, it was time to feed the horses and goats on the grounds, enjoy another playground, or relax in the café. Board-games and billiard, walks in the woods, cake and coffee – time flies when you are not at home. That night we had a little birthday party; the ABC-Club turns 30 this year. I think everybody was a little proud when we remembered what the club had achieved for the members, and how good it feels to be part of this big and wonderful community. ABC-Club has about 1100 members in Germany and a handful in other countries.

Sunday morning after breakfast the actual AGM was held. (Every German Verein, or Club, has to hold a AGM once a year by the law, and we are famous for our Vereinsrecht, Club Bylaws!) Babysitters were organized for attendees. Discussions about our goals and chores, the problems of the club, the opportunities, the hopeless old homepage, and the needs of the members. In Germany, there are about 250 triplet births every year, and we gain about 50 new members each year. Unfortunately, lots of parents drop out after about ten years because they feel they don't benefit any longer. We are not sure yet what to do about that, but it is very sad. The fewer parents of older kids and teenagers we have, the less knowledge we have about their needs. Not to mention the triplets themselves, once they are old enough to be real members and not "the children of".

Officially the AGM is over after lunch. In reality, after packing and saying good-byes, and one last coffee, and one more trip to the bathroom, and one last ice-cream, and one last "I forgot my stuffed animal" it is almost impossible to actually roll off the parking-lot. But when you do, you might hear a big sigh from the back seat "why don't we do that more often?"

PARENTAL LEAVE—MULTIPLE BIRTHS CANADA

Written by Gail Moore – Past Chair Multiple Births Canada, Past Co-Vice Chair ICOMBO



The last six months have brought immense national attention to an issue that will greatly impact how Parental Benefits are allocated to future multiple-birth families after the birth of their twins, triplets or more.

On one hand, we have father of twin girls, who has made it his personal mission to focus on the wording of Canada's Employment Insurance (EI) Act. In his words, Christian Martin says:

“ I had assumed that my wife Paula and I would be able to get 35 weeks of parental benefits for each child that we would have under the current EI rules, presuming that we would continue to work sufficient hours before each child. We were thrown for a loop when we found out we were having twins. Any parent can get 35 weeks of benefits to care for their child except in multiple children cases where the second parent and the additional children don't count. I believe inequality for the parents of multiple birth children, not special treatment.”

“It should be common sense that caring for two, three or four children at once brings additional challenges to simply caring for one. We decided that the best thing to do was for me to stay home with her and share the duties for those first few months of our twins' lives, given that our financial situation could bear it if we exhausted our savings. It seemed like the right thing to do.”

To make a long story shorter, after the birth of his daughters in 2009 while his wife was on Parental Leave for one daughter, Christian applied for Parental Leave to care for their other daughter. He was denied. He appealed to a Board of Referees. He won that appeal. The Government of Canada was not happy with that decision and brought the case to an Umpire. In 2011 the Umpire ruled in favour of the Government of Canada, which Christian and his lawyer Stephen Moreau, another father of twins, quickly appealed to the Federal Court of Appeal. Regrettably in January 2013, the three judge panel at the Federal Court of Appeal upheld the Umpire's decision. Recently, just before his twins turn four years old, Christian requested his case be heard by the Supreme Court of Canada, but unfortunately the decision to hear the case was also rejected. This was the final step in what has become a test of stamina for multiple-birth parents who want to see change for future families. Documents covering all these steps are posted on the Multiple Births Canada website on this page - <http://multiplebirthscanada.org/index.php/about-us/media-inquiries/>

On the other hand, we have a mother of a singleton child, who as a Member of Parliament (MP) chose to draw attention to the unfairness in the payment of Parental Benefits to multiple-birth parents by presenting a Private Member's Bill in Ottawa. Bill C-464: Parental Leave for Multiple Births or Multiple Adoptions was introduced in November 2012 in the House of Commons of Canada by MP Sana Hassainia. The enactment would have amended the Canada Labour Code and the Employment Insurance Act to increase the maximum number of weeks during which parental benefits can be paid from 35 weeks to 70 weeks in the case of multiple births or multiple adoptions for qualified EI recipients. *.....continued on page 11*

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PARENTAL LEAVE—MULTIPLE BIRTH CANANDA continued from page 10

As MBC's Awareness and Advocacy Coordinator I was heavily involved in the communication and outreach work we directed toward this effort. Currently, the Government of Canada is ruled by a majority led by the Conservative Party of Canada. We directed our education campaign towards those members, and from what we were told the issue received some heated debate within their caucus by several members who understood the need for fairness for multiple-birth families within the Parental Benefits Program (PBP). Sadly, on March 27th the Bill was defeated by a vote that was 11 short of passing.

In a statement we released the following morning MBC said:

"The PBP was designed to support six key pillars: promote child development; balance demands of work and very young children; make short-term investment for long-term economic gain; use EI as an effective instrument; promote gender equality; and allow businesses to retain valuable, experienced employees. Unfortunately, the PBP is currently failing multiple-birth families on three pillars – promoting child development, balancing work/family demands, and providing employment security."

It is our hope the MPs who voted against Bill C-464 did so because they may have had issues with the wording of the Bill and not the intent to create fairness for multiple-birth families. We will continue to draw attention to the need for change and stated:

"We know the Conservative Party of Canada believes in family values. We are confident they will take a closer look at the intent of Bill C-464 and find a way to amend the Parental Benefits Program to better address the needs of Canada's multiple-birth families. We are sure that today's "no" vote was simply an issue of the Conservatives not having a full understanding of the issues surrounding Bill C-464. We know we can count on them to review this matter and recommend extended parental leave benefits to ensure fairness for multiple-birth families."

We are aware there are parents in other countries who admire Canada's Parental Benefits – rightfully so, we have a well-meaning family-centered system in Canada. However, we also know that today's realities of two-income families has extended implications – many families do not live close to their relatives, most people are left with little time to volunteer to assist parents of twins, triplets and more during that hectic first year, daycare rules make it difficult to find places for more than one baby at a time before they turn 18 months old. Conversely, we know there are many other countries that recognize the additional demands of having more than one baby at a time by providing additional support during those formative months. This is why we will continue to focus on this issue in Canada. We will make a difference for future multiple-birth families.

Again, we have posted the supporting documents for this work on our website -

<http://multiplebirthscanada.org/index.php/about-us/media-inquiries/>

A big thank you to Tamba and MBC for their efforts in championing
Parental Leave for Multiple Birth Families.

**The
NATIONAL ORGANIZATION OF MOTHERS OF TWINS CLUBS
is proud to present**



..... our new trade name & logo

National Organization of Mothers of Twins Clubs (NOMOTC) members are on their way to Phoenix Arizona this month for their annual business meeting and convention. Highlights of the week include fun tours, a national worker appreciation luncheon, opening ceremonies and a new name for their annual buy and sell eventMOMs Mall. The week will include a Keynote address, a preview luncheon for the 2014 Convention which will be held in Austin, Texas; a fun-filled Friday night party where members and guests will put on their best western wear and come prepared to dance the night away. Concluding the week will be a special banquet where the newly elected officers will be installed.

The organization has been busy this past year, working with a marketing firm to rebrand the organization's look and feel. "We are proud of the work that went into rebranding our organization", stated Terri Gillis, Advisor and ICOMBO Vice-Chair. "It started with several member surveys and ended with a member survey once the new look was introduced via webinars that were offered to all clubs."

The new logo provides a fresh new look to a wonderful and historical organization; an organization that will always have the same mission, to support multiple birth families and help create awareness about the wonderful world of multiples.

**That's the news from around the world from many of our
member organisations.**

**Watch for more news regarding the 2014 ISTS Congress
and start planning now to attend!**