



January 2014

News From Around The World

Chairperson Report



Monica Rankin

Greetings to all members!!

As we start a new year, it is a good time to reflect on all that has occurred during 2013. At ICOMBO, I have seen more relationships develop between organisations — communication, shared resources and participation in research.

An exciting project within ICOMBO at present is the Postpartum Mood Disorder (or Post Natal Depression) Survey. We are very excited that it will be available in a number of languages — English, French, German, Czech and Spanish at present. We are finalising all the details and hope to have it available for multiple birth parents to complete soon. I know it has taken some time for us to complete this project, but there is a lot of work involved by a number of people to prepare the survey, and then to have it translated. I believe that this is the first time ICOMBO has attempted such research and we will be looking forward to seeing the results, particularly in relation to comparisons between countries.

As usual, there are some interesting articles about some of our member organisations to read in this issue, please enjoy!

Wishing everyone a successful and happy 2014,

Regards,

Monica Rankin

MEMBERSHIP NEWS

The membership renewal notices for 2014 were emailed to all members in November 2013. If you have not received a notice, please contact Monica - membership@icombo.org As in 2013, Level One membership is \$140AUD and Level Two membership is \$60AUD.

DID YOU KNOW?

Being a member of ICOMBO will save you money when attending the 2014 Congress in Budapest Hungary. Registration fees are lowered for ICOMBO members. Check out the Congress news on page 2 and learn more.

ICOMBO/ISTS CONGRESS 2014



2014 Congress - Budapest, Hungary Moved to November 2014

By now you should be aware that ISTS has postponed the 2014 Congress. It was to be held in Budapest, Hungary in April 2014. There were some issues with the venue. One positive outcome from the delay is that the ICOMBO Board has more time to plan more exciting things for our time together.

The congress will now be held from 16 - 19 November 2014, in Budapest. The new venue is the Danubius Hotel Flamenco. There is an early bird registration which closes on 15 July.

The congress website is now active at: http://www.etouches.com/ehome/77754

Please visit the site to gain more information on the venue and the congress.

Check out the registration cost below and you can see that if you are planning to attend Congress, it is well worth paying for a Level One membership of ICOMBO for 2014.

Join us in Budapest to share and learn from member organisations from around the world. See you there!

Registration Costs

	REGISTER BY 15 JULY	REGISTER AFTER 15 JULY
ICOMBO Level One Member	€100	€150
ICOMBO Level Two Member	€180	€230
Non-members of ICOMBO	€ 350	4 00



Congratulations to Tamba on organising some vital clinical research. At present they are appealing for funds to do the research, you can find more information on their website—www.tamba.org.uk The research will compare foetal charts from many twins at a major London hospital and produce some foetal charts specifically for twins. These charts can then be used by clinicians around the world when dealing with a multiple birth pregnancy. This research has the potential to improve the outcome of multiple births worldwide, assist in avoiding in utero issues, prevent preterm labour and prevent neonatal deaths. Well done, Tamba!



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ICOMBO is pleased to highlight the Czech Association of Twins and Multiple Birth Clubs in this edition. A special thanks to Klara Vitkova Rulikova, chairwoman of CAKDAV for submitting this article. For more information you can reach her at the following email: dvojcata@atlas.cz





The Czech Association of Twins and Multiple Birth Clubs Českomoravská asociace Klubů dvojčat a vícerčat (CAKDAV)

The first Twins and Multiple birth Club in the Czech Rebublic was formed in the 1995. The Twins Clubs operate through a system of self-help groups and solidarity among the parents of twins and multiples. There are now about 55 Twins and Multiple Birth Clubs all over the Czech Republic and new branches join every year. Representatives of the regional branches set up the **The Czech and Moravian Association of Twins and Multiple Birth Clubs** in 2003 in order to better coordinate and further twins' interests and needs among specialists and the general public. The head of office is located in Prague, the capital of Czech Republic.

The mission of the <u>Association of Twins and Multiple Birth Clubs</u> is to promote the interests of families with multiples and to raise awareness about their specific needs.

MAIN OBJECTIVES:

Support for families with twins and multiples, raising awareness about the special needs of families with multiple children and the development of the network of Twins and Multiple Birth Clubs in the Czech Republic

Creating all the conditions and aspects necessary for improving the quality and quantity of the information provided to families with twins and multiples and promoting their interests with regards to the state authorities

Presenting proposals and recommendations concerning all laws, regulations and activities that may affect the needs of families with multiple children in the Czech Republic.

AREAS OF ACTIVITY:

- Conferences, seminars and lectures attended by leading experts
- The coordinated running of Twins and Multiple Birth Clubs all over the country
- Publications concerning issues that affect families with twins and multiples, including translations from foreign sources

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Czech Republic.....continued

Consultation services for both people working with twins and multiples (medical staff, teachers, psychologists and parents of twins and multiples, adolescent and adult twins.

We offer systematic support in setting up and running Twins and Multiple Birth Clubs, expert advice (pedagogical, psychological, social and lactation), lectures and seminars with topics focusing on twins and multiples (ranging from birth to adulthood).

THE RESOURCES AND FINANCING OF CAKDAV:

The staff work as volunteers (board members, advisors, leaders of some Twins clubs, organizers of workshops, seminars, conferences). The other costs (booklet printing, rent space for conferences, seminars and workshops, travel costs) are paid by the subsidy from the Ministry of Labor and Social Affairs (MoLSA), membership fees and donations. Local twins and multiple birth clubs are run by volunteers, donations or their own grants by MoLSA or other.

SOCIAL POLICY IN CZECH REPUBLIC:

State social support

The term state social support indicates the benefits provided to families in socially acknowledged situations, where the state partially assumes the co-responsibility for the social situation by paying out said benefits. The following benefits are provided within the framework of the state social support system: the child allowance, the parental allowance, the social allowance, the housing allowance, the birth grant, the funeral grant and the foster care benefits.

The only benefit for multiplebirth families is the prolonged maternity leave.

Maternity leave

• A female employee (mother) is entitled, in relation to childbirth and care of the newborn baby, to the maternity leave for the period of 28 weeks; if the mother gave concurrent birth to two or multiple children, she shall be entitled to the maternity leave for the period of 37 weeks.

A female employee would as a rule commence her maternity leave from the beginning of the sixth week prior to the expected birth date, however no earlier than from the beginning of the eighth week before that date.

Parental leave

• The entitlement to parental allowance is for the parent that personally and properly cares fulltime for a child who is the youngest in the family, until the exhaustion of the total amount of CZK 220 000 (about 8 800 Euro) and up to 4 years of age.

There is no benefit for twins or multiples.

If you have triplets or quadruplets, you have the right to a care person paid by the state for children under the age of 4 years.

GENERAL INFORMATION ABOUT CZECH REPUBLIC:

Czech Republic has:

- about 10 milions inhabitans
- about 1.4 children per one woman

GENERAL INFORMATION ABOUT MULTIPLE RESEARCH IN CZECH REPUBLIC:

There is no global research about twins in Czech. The only research has been the longitudinal study about the

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Continued......

Czech Republic.....continued

twins inheritance of intelligence. There is some individual research within theses about life as twin or as parent of twins. These are presented at our seminars or conferences. Our statistical office collects the number of twins and multiples born each year.

STATISTICS ABOUT MULTIPLES:

The multiples that are born in Czech Republics are almost always twins. The triplets are rare and are mainly connected with IVF reproduction. The number of births of twins in relation to singleton births is 1:48. The following tables present the development of multiple birth in numbers and percentage.

Table 1: Number of births in 2003-2009

Year	2003	2004	2005	2006	2007	2008	2009
Total number of births	92 335	96 078	100 546	103 985	112 605	117 429	116 261
From that: twins	1 591	1 813	1 926	2 115	2 298	2 381	2 378
triplets	14	19	13	15	22	16	14
quads	1	0	0	0	0	0	0

Table 2: Birth rate in%

The first set of quintuplets to be born in Czech Republic were born in 2013.

year	singletons	twins	triplets
2003	98,26%	1,72%	0,02%
2004	98,09%	1,89%	0,02%
2005	98,07%	1,92%	0,01%
2006	97,95%	2,03%	0,01%
2007	97,94%	2,04%	0,02%
2008	97,96%	2,03%	0,01%
2009	97,94%	2,05%	0,01%



The National Organization of Mothers of Twins Clubs, Inc. adopted a new trade name in 2013

Check out the annual report that was shared with the 2013 Convention attendees in Phoenix Arizona: 2013 Annual Report

Multiples of America invites you to their 2014 Convention in Austin, Texas in July 2014. For more information check out their convention webpage in April as details are shared online: 2014 Convention

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Scandinavian Soul Sisters Share their Twinterest

What do you do if you are a twin mother and a journalist and you want to write a book on twins, because there is none written recently in your language? You start by researching relevant material from other countries in bookstores, in libraries and when you travel abroad. This is what I did 13 years ago, when my MZ twin boys turned 10, and I wanted to share my experiences of the first lively years with other Danish twin parents. The internet wasn't as common as it is now, but I searched and found interesting news mostly in English-speaking countries. But the best was that I found useful material in my neighboring countries of Sweden and Norway. Though interesting enough, the English material didn't reflect the Scandinavian way of life, and the way we look upon issues such as fertility treatment, child upbringing and social help to twin families. I was delighted to find The Norwegian Twin parents organization, "Norsk tvillingforeldreforening", founded 1984, and the Swedish group, "Svenska Tvillingklubben", founded 1993. Two very different organizations but managed by two twin mothers, who both are the founders or/and the backbone in their organizations.

I simply found my soul sisters!

We almost share language

It helps to better understand our countries. Some people are confused by our Scandinavian countries, but to make a long story short, our three Scandinavian countries - Denmark, Norway and Sweden have a lot in common; and, we share the roots of our languages. Though we each have our own pronunciations and use of letters like æ, ø and å (ae oe and aa or ä and ö) we easily understand one another, and to some extend we also speak one another's language. Somehow, when a Norwegian, a Dane and Swede are in the same room, we quickly begin to talk, especially if we show a little effort in clear and distinct pronunciation. Coming to read one another's language, is even easier. "Twins" are "tvillinger", the same word in Danish and Norwegian, and "tvillingar" in Swedish.

Bearing this in mind, it is no surprise, that we three Scandinavian twin mothers are closely connected. Norway's Ingun Ulve Lie is running the daily business at the well established office in Oslo, Norsk Tvillingforeldreforening (www.tvilling.no). Margareta Ölwe is running Svenska Tvillingklubben (www.tvillingklubben.se) which was established by her, she also runs courses and a web shop, as do the Norwegians. I run a large webpage, a web shop and some mailing lists, but not a club, in Denmark. (www.tvillinger.com) I have no membership or courses. Freya from the Danish twin parent organization used to operate in a similar fashion before closing down some years ago. The other two run their clubs with great success and different funding models. We have twins within ten years of range, we are entrepreneurial and creative women, and we have become close friends.

Nordic inspiration

In Finnish twins is "kaksoset" and multiple birth is "monikkoperheet". The language is quite different, but nevertheless we have met in some years with the Finnish multiple organization, Suomen Monikkoperheet too. The organisation is run in a totally different way and yet very inspiring too to learn from. But the language difference can be a huge barrier when we meet. We have to speak English in order to get everything right. On a day to day basis this is challenging, but it is still very important to learn from and laugh with the Finnish multiple enthusiasts, Ulla Kumpula and Mari Kaihovaara. Both of these wonderful ladies were blessed with multiples and in Mari's case, she is blessed with two sets of multiples; a set of twins and triplets.

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Scandinavian continued....

Though we all work very differently, we are keen to give the correct and fulfilling information to twins and multiple parents. By meeting almost every second year, corresponding regularly and also paying visits as private friends, we have learned a lot about running an organization as a business, exchanging materials, books, breastfeeding cushions, body stockings and so on. We have learned from Ingun how to run a weekend at a tourist resort for 100 twin mothers without kids and how to arrange courses for healthcare personnel in remote areas of Norway; from Margareta we have learned how to run a large twin shop in the center of Stockholm with trolleys (strollers) and huge piles of twin equipment, and how to expand it to include kids clothing.

I only run my tvillinger.com as a web project with no courses or information pamphlets. I write books that are sold in Denmark and Norway and have shown the others ways to expand the use of social media and the web in order to crowd-create a book on twin tips. Plus two of my Danish twin experts are actually consulting in Norway. We have exchanged articles on our websites or in our magazines published in Sweden and Norway, and we regularly share important information on the conditions of maternity leave in each of our countries to help politicians understand that conditions can be improved by comparing policies in the other Scandinavian countries.

Securing the next generation?

The best part of working together is that we found that each of us were in the same, very rare situation: establishing and running an organization by mere enthusiasm and personal interest at the crossroads of being a volunteer and running a business. Executed in three very different ways, and yet so alike.

The question we are concerned most with today is: *How can we secure the continuation of our work?* When we met in Florence in 2011 at the ISTS-Congress, I noticed again, that I met almost the same women at the ICOMBO conference as I met at my first ISTS Congress ten years ago in London. Twin mothers, whose twins are long grown up. We all still want to run our volunteer work/business and to see our efforts have a long lasting effect. *But how do we secure the next generation of twin parents to take over when we retire?* This is our question to you, and we would like to discuss it at the next ICOMBO meeting, now in November 2014. *How does your organisation plan your generation change?* Please join us in Budapest for this important topic.



In Ghent the Scandinavian representatives met in front of this much appropriate window.

From left: Abelone Glahn, tvillinger.com the author of several books on twins and Danish journalist, Margareta Ölwe, founder and CEO of Svenska tvillingklubben, Mette Svangren Guttesen, Freja multiple organization (ceased to exist), Joan Grønning, author of twinbooks, Ingun ulven Lie (in the back) leader of Norsk tvillingforeldreforening, the Norwegian twin parent organization, Annette Haugen, journalist at Norsk TvillingeForeldreForening and Kidi Oller-Westerberg, journalist at Svenska Tvillingklubben. All of us are mothers of twins.

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VOU ARE NOT ALONE! Chanada's multiple stills community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you. Service of the community is here to support you.

Multiple Births Canada

Multiple Births Canada (MBC) has developed a new publicity poster in English and French, to display in medical clinics, hospitals, community centres and other public locations to promote MBC (and our local Chapters) and bring people to our website.

Look for news soon on another publicity tool currently under development with the same look and information to be used as a take away item for those interested in learning more about MBC.

To view this poster in English <u>click here</u> and to view in French <u>click here</u>.

Multiple Births Canada (MBC) produces a report annually to summarize the work completed over the previous year. The <u>Annual Report</u> for 2012-2013 is now posted on the MBC website. The report was presented at the Annual General Meeting on September 28th, 2013. Check out our Top 10 Achievements, including becoming a Registered Charity, and detailed information on many of MBC's activities in support of multiple-birth families in Canada. You will find at the same link the past Annual Reports for MBC. This report was printed with the help of a donation from one of our Chapters -Temiskaming Multiple Births. The extra reports printed will be used to accompany funding requests from potential donors.



Multiple Births Canada New / Updated Fact Sheets

MBC is delighted to announce that 7 new/updated Fact Sheet publications are now available on the MBC website at the following URL: http://multiplebirthscanada.org/index.php/education/publications/fact sheets. These resources are free to members, but are sold for a small fee to non-members.

Of the seven produced there are two brand new to add to our collection of MBC resources:

Bottle Feeding Multiples – to help families who may choose to use bottles to feed with expressed breast milk and/or formula, in addition to or in place of breastfeeding. This Fact Sheet covers the benefits of breastfeeding, the importance of closeness and bonding during feeding time, how to prepare bottles, and the best techniques for feeding the babies.

Speech and Language Development in Multiple-Birth Children - this Fact Sheet was written by two Speech-Language pathologists, Michelle Phoenix and BJ Cunningham. It includes a chart of developmental milestones for children from 6 months to 5 years old, and tips for parents to help their children's language development, and when and where to find help if you want to get an SLP assessment.

And five updated MBC resources:

Three updated Fact Sheets on Breastfeeding: 11 Tips for Breastfeeding your Multiples, How do I know if my babies are getting enough, and Storing Breast Milk. These titles include newly revised content from author Lynda Haddon, Chair of our Breastfeeding Support Network, with updated resources and references.

Two updated Fact Sheets on Loss: *Grieving Grandparents,* and *Getting through the Holidays and other Celebrations* – including revised content from author Lynda Haddon who chairs the Loss Support Network, with updated resources and links.

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Nordic News:

The Norwegian Twin association (TvillingforeIdreforeningen) (TFF) will be celebrating our 30 year anniversary in 2014. During the past 30 years we have been working on many issues for our members.

tvilling

This is some of what we have achieved:

- Extended parental leave for parents of twins. Today the parents get five extra weeks per extra child with a 100% coverage of their salary.
- Maternity payment per child, not per birth.
- We have developed literature for expectant twin parents, parents of twins in kindergarten, parents of twins in school and for parents of twins that have reached puberty.
- We arrange theme days/evenings for parents and training days for professionals working with our children in kindergartens, schools and in health services.

For many years, we have organised twin family festivals, and in recent years we have organised relaxing, social weekends for mothers of twins and their friends. We also organised get-together events for triplets and their parents.



Our national twin day, on 22nd August, is celebrated in different parts of the country. The attached picture is from the event in Tromsø this year. Tromsø is Norway's most northern University City, also famous for its fabulous Northern Lights. The celebration took place in a huge indoor playground, where both parents and children had a great time. This was a joint celebration between TFF and the local twin club.

At present, TFF has approximately 2400 family members. Approximately 1000 pair of twins are born in Norway each year. TFF has a board of seven volunteers and some good partners, like the editor of our magazine, Twin News (Tvillingnytt). There are four editions of the magazine every year. We also

cooperate with approximately 14 different "trainers" in four of the big cities in Norway, where we arrange "twin preparation courses". We also have good cooperation with quite a few different presenters that share their professional skills to assist us. A few years ago we also made a commercial for TV.

http://www.tvilling.no/index.php?page_id=15&article_id=349

In addition to our website, we are on Facebook and Instagram and we also send out a newsletter to our members as well as professionals. TFF gets a small amount of state support, but we have to reapply every year to maintain this support. This money helps us to run the organisation. The daily manager is an employee of the organisation and TFF also has a paid webmaster.

COMING SOON! ICOMBO's Post Partum Mood Disorder (Depression) Survey

Look for this in the next few months.

Please distribute to your members and to your OB/GYN's and put it on your website -- we need non-members to take the survey also!

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The NZMBA Conference, 2013



I recently attended my fifth New Zealand Multiple Birth Association (NZMBA) national conference, this time in Hamilton. Once again I was reminded why our conferences are so important. As the parent organisation for the 21 Multiple Birth Clubs throughout New Zealand (about 1500 families), the NZMBA represents the interests of large and small, geographically spread clubs from Whangarei in the North, to Invercargill, at the bottom of the South Island.

Our Executive Committee, whose members are similarly geographically spread, correspond mostly by email and sometimes by phone, and 'meet' formally via a Skype conference call each month and annually, we get together in person, as early as we

can all get to Conference. So for us, conference is a chance to *actually* get together: to share information and ideas, to problem solve, to identify areas of need in our community, to recharge for another year of meeting by phone or email—and, if I am being really honest, to have a weekend away from our kids, to have some good wine, great dinners and a whole heap of fun!

Our clubs also interact with each other, and use Conference to strengthen and renew these links. Conference has ensured that we continue to have a strong, shared sense of community. A memorable example of this community spirit, was how multiple birth clubs throughout the country quickly rallied to assist the Christchurch club following the 2010/11 earthquakes. And as club members relocate around the country,

there are regular stories about how quickly they slot into their new clubs.

Conferences are also memorable for their keynote speakers. This time we were treated to Dr Joan Friedman. The world renowned psychologist and twin expert gave a riveting opening speech, and hosted several informative and well-received workshops. I was lucky enough to sit next to Joan and her husband at dinner on Friday night. In real life, she was a gentle, well-informed mother of five, with lots of inspiring and funny stories to share about her family. Opposite me at dinner, was New Zealand's own parenting guru, the fabulous Diane Levy—our second guest speaker. She also gave a memorable speech, and a couple of great workshops. In between, it was her turn to ask us questions, as she is soon to join the sacred world of multiple-birth families, when she becomes a grandmother to twins early this year.



NZMBA Execs in their fancy dress

Terri-Lynn Mitchell

NZMBA Magazine Editor

Visit our website at: multiples.org.nz



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A Meeting with Royals

Her Royal Highness Crown Princess Mary of Denmark is Patron of the Australian Twin Registry. (ATR) During their visit to Australia in October 2013, HRH Princess Mary and HRH Crown Prince Frederik visited the Twin Registry facilities at the Sydney Children's Hospital. A few families from Australian Multiple Birth Association (AMBA) were fortunate enough to meet the Royals. This is the story of the Harding family's meeting, as told by the mother, Catherine.

It was mid October when I received a phone call asking if I was free on October 26 for a very important, top secret function. All I was told at that time was that AMBA had been asked to present at a function hosted by the ATR at Sydney Children's Hospital Randwick and there was the potential that our girls could be involved. Over the next few days I was told I would be presenting to Princess Mary, the ATR International Patron, about the important role that AMBA plays in the community in providing social and emotional support for families with multiples.

On the morning of the event, the activity started early in our house to ensure we were ready and on the road as we didn't want to be late. It takes a lot to get three girls ready to meet a princess! I curled the girls' hair and made sure they looked perfect before leaving home as theirs was a very important role on this day.

Charlotte recalls feeling very excited as she got ready and Lily remembers feeling scared but very excited to be meeting a princess. When we arrived at the hospital the girls quickly showed everyone that they were naturals and that no nerves would get in the way of their very big role!

Princess Mary and Prince Frederik were both very warm and relaxing to be around. This can be seen in many of the intimate photos captured by parents in the playground. Prince Frederik was just like any other proud father, whipping out his phone to show off photos of his children at every given opportunity. One of Charlotte's memories of the day was seeing the Prince put his pass code into his phone!

My favourite photo of the day is one of Princess Mary leaning against play equipment talking to the children. I'm told she was enquiring about what sports they play.

Lily's shared her favourite memory of the day was talking to Princess Mary. "She looked me in the eyes and talked to me."

Charlotte's favourite memory was giving Princess Mary her flowers and talking to Princess Mary about sports.

It was such a fantastic experience to be part of such a special day. This is something that will be a highlight in our household for a long time to come.

More information and photos can be found at the ATR website :

http://www.twins.org.au/about-us/patron/269-royal-introduction

We hope you enjoyed this edition.

Do you have organisation or event news to share?

We want to hear what is happening in your organisation! Articles are welcome for the next edition of the ICOMBO newsletter. <u>Deadline: March 30, 2014</u>

Send to: vicechair@icombo.org (Terri Gillis, Editor)

Would you like to become an **ICOMBO volunteer?** All members are encouraged and welcomed to become an **ICOMBO** volunteer. chair@icombo.org

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