



January 2013

News From Around The World

Chairperson Report

Greetings to everyone!

It has been a busy time at ICOMBO since our last newsletter. We have celebrated International Multiple Birth Awareness Week (IMBAW), created a new Facebook page, made updates to our website and begun discussions on some research activities.



Monica Rankin

A new page for IMBAW 2012 was created on the website and all documents that we circulated have been uploaded onto the site. These documents will be edited into a generic format that does not have reference to IMBAW 2012, so that they can continue to be used in the future. Also on this page are some documents that have been translated into languages other than English, and some links to useful websites. In the coming weeks, a new page will be created to cover Multiples in Education, and all documents will be located here. If you would be able to assist in translating any documents into your preferred language, please contact me at chair@icombo.org I would love to hear from you.

Regards,

Monica

HAPPY NEW YEAR HAPPY NEW YEAR

Membership Renewal 2013

By the time you receive this newsletter, you should have received your membership renewal notice for 2013. This year's notice includes information on our new dues structure which allows you to join ICOMBO directly, with or without an ISTS membership. We encourage organisations to join now and take advantage of networking with other multiple organisations from around the world.

Return the form to ICOMBO, at membership@icombo.org and we will forward your details to ISTS on your behalf if you chose the ICOMBO/ISTS membership level.

If you haven't received a membership renewal request, please contact membership@icombo.org.

If you have any questions, or, if your organisation already paid ISTS directly and you want to be an ICOMBO member, contact Monica directly for further instructions. chair@icombo.org.

International Multiple Birth Awareness Week 2012

To address specific issues, ICOMBO utilizes International Multiple Birth Awareness Week to draw attention to benchmarks from the **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** to stimulate international discussion and action on a specific theme. In 2012 we celebrated the following topic: "School placement of multiples, and issues regarding whether separation or not is best".

What a great week for our multiple birth community! I would like to thank everyone involved in promoting IMBAW this past November in many different countries around the world.

Prior to November, the new public ICOMBO Facebook was launched, and an event was created for IMBAW. We had a lot of interest shown in both the event and in the Facebook page, with a reach of nearly 2,000 people during the week.

Some of our member organisations used the opportunity to gain some publicity for their own organisation. It is often easier to get the media interested if you can provide a topic for them. This is a list of some of the activities I heard about -

- Stories written in online magazines. I believe at least one has been translated from English to Portuguese, and is on a Brazilian website about multiples
- Interview with multiple birth parent and school principal on television news
- Production of leaflets specific to the issues of multiples in school
- Contact with parent organisations and education facilities to distribute information on multiples in school
- National conference held to coincide with IMBAW
- ICOMBO documents translated into languages other than English
- Magazine articles
- Newspaper articles
- Celebration get-togethers picnic, play-date, shared meal, story time

I am sure this list does not cover everything that occurred. If your organisation had an activity you would like everyone to hear about, please post it to our Facebook page.

I hope that the information circulated by ICOMBO has been beneficial to your families. It will continue to be available on the ICOMBO website, in a more generic format, without reference to IMBAW so that it can continue to be used in the future. I would like to thank Gail Moore from Multiple Births Canada and all those from organizations around the world that contributed articles and assisted with for her work in preparing much of the documentation.



International Multiple Birth Awareness Week (IMBAW) is held every two years to coincide with the ISTS Congress year.

The Next Congress and IMBAW are scheduled for 2014.

We invite all members to submit suggestions for 2014 IMBAW themes.

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ICOMBO Facebook Page



Our new Facebook page has been building steadily in "likes" since its launch. 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 Chairwoman, 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!

Other Facebook News.....



Our brand new Facebook public page is open! Please feel free to like it even if you don't know French; or, to share with French language families!

https://www.facebook.com/#!/FDJumeauxetplus

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Organisation News





MBC is now a Registered Charity!

It's a very exciting time for Multiple Births Canada (MBC). For a long time we've known that our national organization could do so much more if we became a Canadian registered charity (allowing MBC to receive donations that could now be receipted and apply for grants), however we were limited by financial and human resources. Working with the Canada Revenue Agency (CRA) to put together a successful application seemed impossible as a result.

The overall process took approximately 30 months and thousands of hours of volunteer time to review documents and develop objectives that would be approved by the CRA. It took a number of Board meetings and two Special Members meetings to make important changes to our existing articles of incorporation and bylaws – creating new objectives for MBC. We knew it would be worth all the work, because without it, it was getting very difficult to move MBC forward. In 1978, when MBC was first formed as Parents of Multiple Births Organization (POMBA), information was shared differently, family structures were such that many parents were able to volunteer, and the cost to provide resources was a lot less. Much has changed in over three decades – as a volunteer-driven organization MBC was facing two challenges: an increase in multiple pregnancies resulting in greater need for MBC's educational resources, and the transition toward two-income families, leaving less available time for volunteering. Further, in today's digital age MBC needed a way to provide multiple-birth families with information quickly and efficiently. The volunteer model that has driven MBC forward since 1978 needed to change, now requiring paid staff and access to on-going funds – and the only way to achieve that was to go through the process of applying again (after 3 previous attempts failed). With the assistance of the law firm Wideboer Dellelce LLP we have finally been successful!

Getting the news from the CRA that we were approved as a Registered Charity was both a surprising and sobering experience. Now the real work is about to begin. As all parents know, the real hard work physically is in the first two years after the birth of your babies. We expect the same to be true with the birth of a new national charity, but are eager to see what the future holds and how our organization will grow!



Have Organisation or event news to share?

We want to hear what is happening in your organisation! Articles are welcome for the April edition of the ICOMBO newsletter. **Deadline: March 31, 2013**

Send to: vicechair@icombo.org.

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Organisation Event News



National Organization Mothers of Twins Clubs, Inc. 2012 Annual Meeting

The Charlotte Mothers of Multiples (CMOMS) hosted the $52^{\rm nd}$ annual National Organization of Mothers of Twins Clubs, Inc. (NOMOTC) convention, *Life in the Fast Lane*, in Charlotte, North Carolina.

Pre-convention tours were held the beginning of the week, all of which provided attendees venues to learn more about NASCAR racing and its heritage; and, the city of Charlotte.

Highlights of Convention:

- Wednesday night's "Start Your Engines" opening ceremony was the kickoff to convention and was officially opened for business by Pam Krell, NOMOTC's President.
- **The Resource Area**, also known as "Victory Lane" provided members with a glimpse of the volunteer work done by each department of NOMOTC, as well as the opportunity to meet NOMOTC's commercial vendors/sponsors.
- Thursday through Saturday mornings, members attended the **general business sessions** where they elected NOMOTC's 2012-13 Executive Committee, approved the budget, adopted bylaw changes, and received reports on a variety of topics including Advisor Terri Gillis presenting the 2011—2012 Annual Report.
- Terri Gillis and President Pam Krell reported on their trip to Italy representing NOMOTC at the **ISTS conference** and shared news about the restructuring of dues to go through ICOMBO.
- Workshops included Simplicity in the Fast Lane by Anne Steppe; Twinsight, not Hindsight by Dr. Joan Friedman; Running a Home-Based Business; Scrapbooking in the Digital Age; Educating Multiples with Dr. John Mascazine; Multiples Cost Money; Reset your Buttons with Mary Elizabeth Murphy; My Self, Your Self with Dr. Joan Friedman; Book Club with Dr. Susan Griffith; Advocating for Special Needs, and Zumba fitness. Also offered were various share shops club networking, state networking, and one for National Reps, all moderated by NOMOTC's Membership Department.
- Local clubs, outside vendors, and individual members came together on Friday night to offer attendees a shopping opportunity with the largest selection of multiple-related goods under one roof. The annual **Showcase** was also open to the public. Later that evening, convention attendees kicked back a bit and had a "Girls' Night Out" at the **Friday Night Party**. They were pampered and danced the night away all in pajamas!
- Saturday night's banquet, "Welcome to the Winner's Circle" was the finale to a grand week. This Included the installation of the newly elected Executive Board, and the appointment of the 2012 2013 national workers. Attendees were treated to the President's Reception, where we finished the convention with a night on the dance floor once again.

2012-2013 NOMOTC Board of Directors

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Organisation Event / Other News

NOMOTC Convention 2013



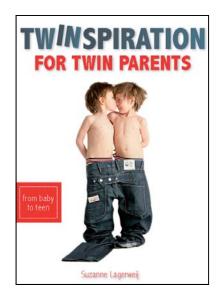
JOIN US!

We would like to invite all our international friends to join us for a wonderful, relaxing experience next summer in Phoenix, Arizona, at our 53rd annual NOMOTC Convention.

Everyone is welcome and we promise a fun, informative week at the luxurious Arizona Biltmore Resort and Spa in Phoenix, AZ July 21- 27, 2013 to *Relax, Refresh Renew!*

Visit our website and learn more. Registration to open this Spring!

NOMOTC Convention 2014



Suzanne Lagerweij announces her new book:

TWINSPIRATION

Twinspiration is a handbook for twin parents full of information and personal experiences of twin parents. This book differs from other handbooks, because it doesn't tell you 'how your twins should be raised', for each twin, each parent and each situation is different. This book does give loads of information based on twin studies, as well as many tips and suggestions that could be usefull for other twin parents. This book is meant to inspire parents during the big adventure of raising twins.

Watch for more information about the release of this book by visiting: www.twinsvideoblog.com.

More information about raising twins in the Netherlands can be found at: www.twinspiratie.nl,

Have a book or product you want to promote?

Financial members of ICOMBO can submit ads for placement in this newsletter. The frequency and size of the ad to be determined by the editor based on space availability.

Contact vicechair@icombo.org.

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Organisation News



Twin Health and the Australian Twin Registry

We thank ICOMBO for this opportunity to provide a profile of the Australian Twin Registry (ATR).

As part of this profile, we would like to acknowledge our great appreciation to the Australian Multiple Birth Association for its wonderful support since the

Registry began some 30 years ago. By working together, our two organizations have contributed to improving health not only for multiple birth families in Australia but for all in our community.

The ATR is also a member of the International Network of Twin Registries and we look forward to working closely with ICOMBO to develop global networks to support multiple birth services.

What is the Australian Twin Registry?

The ATR brings twins and researchers together to undertake studies that aim to improve the health of twins as well as all in the community.

Because of the genetic and environmental makeup of twin pairs are able to help researchers better understand factors that influence health and disease.

Over 450 twin studies have been conducted by researchers using the ATR over our 30-year history. This research has contributed to breakthroughs in a wide range of medical conditions including epilepsy, asthma, diabetes, cancer and heart disease.

These studies have also helped multiple birth families in particular by researching issues of importance to them, such as twin social development, and learning and education.

Today nearly 40,000 volunteer twin pairs are on the ATR, making it one of the largest twin volunteer registries in the world.

The ATR comprises twin members of all ages from newborn babies through to people in their 90's. It is open to identical and non-identical twins and higher order multiples (HOM), males and females, and in any state of health.

The ATR and Multiple Birth Community in Australia

The ATR has valued the support of the Australian Multiple Birth Association since it began in 1981. AMBA encouraged its members to join some of the very first twin research studies facilitated by our registry. Many of our registry twins are AMBA members who were registered as babies by their parents and have gone on to have a long association with the ATR.

Today, our close association is reflected in a number of joint projects. A national Twins Festival, for example, is organised every two to three years by the AMBA and ATR to provide support to multiple birth families and to raise awareness of the importance of twins to research.

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Organisation News

Austrialian Twin Registry, continued:

The ATR also has an initiative to support AMBA clubs in their local communities. Clubs can apply to the ATR for a small grant to help meet the cost of special projects such as new playgroups, first aid training, website development, and an antenatal video.



This initiative enables us to acknowledge the enormous difference that AMBA clubs make in the lives of multiple birth families, many of whom are members of the ATR.

International Connections

In addition to its work in Australia, the ATR is at the forefront of the drive to develop a global network of twin registries. Why is this initiative so important?

This international collaboration will help in with research in many way. One example is very rare conditions such as multiple sclerosis. If we can involve twins in research with these rare conditions where only one twin has the disease, it will provide great insights to benefit future treatments. The challenge is to find sufficient numbers of twins, one with the disease and one without, to enable relevant analysis. No one country can do this alone but by combining forces as an international network, there is the potential to make major medical discoveries.

At the ATR, we look forward to working with local and global multiple birth organisations to deliver the best possible services and support to individuals and families in need.

Congratulations

To the Australian Twin Registry and Danish Twin Registry on the appointment of **Princess Mary of Denmark** as patron of both organisations.

WE WANT TO HEAR FROM YOU!

- Have pictures from your organisation you would like to share? This space is waiting for pictures of your organisations events or to announce your new board of directors or officers. vicechair@icombo.org
- Would you like to become an **ICOMBO volunteer**? All members are encouraged and welcomed to become an ICOMBO volunteer. chair@icombo.org



We hope you enjoyed this edition of ICOMBO's news from around the world.

Watch for our next edition in late April 2013.

Terri Gillis, ViceChair/Newsletter Editor

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