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# C.O.M.B.O. NEWS

Council of Multiple Birth Organisations

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## A Message From The Chair

Welcome to another issue of COMBO News. There is much news to share since our last newsletter.

- Many of us had a busy summer preparing for the 2005 Mid-Congress Conference, held in Los Angeles, CA. Representatives from AMBA, MOST, Twinsight and NOMOTC presented at the conference.
- Our COMBO Editor, J. Susan Griffith, wrote an article concerning the research results from studies some of our groups have completed in the area of postpartum depression. She has been working to get the article published in a professional journal.
- Some of our COMBO workgroups have also been busy with e-mail discussions concerning their work. Look for further information on some of these items inside this newsletter.

I am always on the lookout for good material for the next newsletter so if your organization has some ideas, information, or questions you would like to share, please e-mail me at:  
[mjadcock@cox.net](mailto:mjadcock@cox.net).

Until next time. Regards,  
Mary Adcock  
COMBO Chair

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## Website Review...

*A quick check of the internet gives an overview of some of the most recent happenings and work of Multiple Birth Organizations around the world.*

### “Multiples en Masse” (AMBA)

AMBA is planning to set a Guinness World Record attempt for “Multiples en Masse” - ie. Gatherings of twins, triplets, quads and quintuplets - as a Twins Plus Festival highlight on Saturday March 11, 2006 at the festival venue (subject to sponsorship).

### Tooth Emergence Study (AMBA)

AMBA is looking for participants for an Australia-wide research project that will be the first of its type in the world. It is funded by the National Health and Medical Research Council of Australia. The study focuses on tooth emergence and oral health. The plan is to include around 500 families in the study. The study will look specifically at when the baby teeth of twins, both identical and non-identical, first appear in the mouth and also when the bacteria that are associated with dental decay first begin to grow.

### Twinline (TAMBA)

Twinline is a national, confidential, support, listening and information service for all parents of twins, triplets and more, and the professionals involved in their care. The Twinline service operates from 10 am to 1 pm and from 7 pm to 10 pm, every day, all year round.

### Support Groups (TAMBA)

TAMBA sponsors an infertility support group — For families who are contemplating or receiving infertility treatment, and those who enjoyed a multiple birth following treatment.

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# Mid-Congress Conference Builds ‘Research Connections’

The International Society for Twin Studies (ISTS) held a Mid-Congress Conference last June on the campus of USC in Los Angeles, CA. Titled “Research Connections,” the one-day conference brought together over 75 researchers from around the world to network and to present information on the latest findings from twin-based research. Several COMBO members attended at the conference.

Conference attendees learned about the work of the European-based **GenomeUtwin** project, and heard a keynote speech by Professor Leena Peltonen, one of the leading molecular geneticists



worldwide and a pioneer in the use of genetically isolated populations in the genetics-based identification of disease genes. Presentation and poster sessions were also held,

featuring information on a variety of topics such as risk factors associated with asthma in twins, processes of working memory in middle-aged twins, and risk factors affecting smoking initiation and persistence in California twins.

COMBO representatives were also among the presenters. Presentations from COMBO members included the following areas:

- Changing Challenges — Life isn’t always fair (AMBA)

- Having a co-twin with ADHD (Dr. David Hay)
- Hospital protocol after a multiple birth child has died (AMBA)
- Learning needs of multiple birth children and the response of the educational system (NOMOTC)
- Post-Partum depression in higher order multiples (MOST)
- Post-Partum depression in mothers of multiples (NOMOTC)
- Reading Proficiency and Multiples (NOMOTC)

## Website Review...

### PreemieCare (MOST)

The mission of PreemieCare is to educate, support and offer additional resources for families of babies born preterm. Issues such as breastfeeding preemies, RSV awareness, parenting in the NICU, early intervention and much more are also addressed by PreemieCare. PreemieCare also acts as a mentoring and networking organization for hospital and community-based parent-of-premie support group. You can learn more about Preemie Care at the website: <http://www.preemiecare.org>

### Multiple Births Canada (MBC)

MBC announces the new release of the Low Birth Weight & Preterm Multiple Births: A Canadian Profile resource. This resource is provided in partnership with The Best Start Resource Centre and MBC. It can be downloaded from the MBC website at: <http://www.multiplebirthscanada.org>

## MARK YOUR CALENDAR

*as noted on the ISTS website, the*

**12th ISTS Congress**

will be held

**June 7-10, 2007**

in Ghent, Belgium

### **Travel Tip:**

*Ghent (in Dutch : Gent)* is the fourth largest city of Belgium with about 250,000 inhabitants. It is not as big as Antwerp but bigger than Bruges. For some people Ghent is the real diamond of Flanders and Belgium. In a unique way, Ghent has managed to preserve its medieval power while keeping up with the times.

# Work Group Focuses On Update Of COMBO Declaration of Rights

## The Foundation

*Patricia Malmstrom, former COMBO Chair, recently shared her reflections about the Declaration of Rights and how it was originally written.*

By Patricia Malmstrom

In my many years as a COMBO member, I was frustrated by the repetitive nature of COMBO presentations which seldom inspired interaction or collaboration between organizations and the ISTS researchers. A representative of each member organization would give a report listing all its activities in the preceding years and then sit down. But during coffee breaks, members would hold animated discussions about their various experiences, challenges, and successes in developing and providing a wide variety of programs to address multiples' needs.

When I became Chair in 1992, I proposed we write a bill of rights of multiples to help organize the amazing energy of COMBO members to document the special issues related to multiple birth which our organizations attempt to address. I hoped it would help us link what we were all doing to a set of common goals. Once we got going on a draft we realized that we needed to also spell out the special needs which multiples and their families. So the document took shape as two parts:

- one spelling out rights of multiples and
- the other spelling out needs which support those rights.

I always hoped it would become a living document which we updated regularly on the ISTS website to incorporate:

- references and/or links to relevant new research findings published by ISTS members and/or other folks in relevant research.
- reports on successful programs for multiple birth families offered by parent clubs and/or other organizations
- reports on advocacy efforts related to the health and welfare of multiples, including work with public health and social service systems and educators at the local and

national level.

## Looking Toward The Future

At the 2004 ISTS Congress in Odense, Denmark, COMBO members decided to review and update (if needed) the Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples, which was originally adopted in 1995. Since that time, a work group has been discussing the best way to complete this review. In true research fashion, the work group decided the best way to begin their work was to issue a survey. That survey is printed on page 4 of this newsletter. It can also be accessed online at: <http://www.surveymonkey.com/s.asp?u=646291746605>

There are three options for responding:

- Surveys can be printed, completed in hard copy form and mailed to:  
Mary Adcock  
804 Newport  
Hutchinson, KS 67502 USA
- Answers can be emailed to Mary Adcock at: [mjadcock@cox.net](mailto:mjadcock@cox.net)
- The survey can be completed online using the link noted above.

Choose whichever method you prefer. Just please share your thoughts on this revision by answering the survey questions.

NOTE: A copy of the Declaration of Rights is also attached with the e-mail sending this newsletter. The Declaration can also be viewed online at: <http://www.ists.qimr.edu.au/Rights.html>

### A few other COMBO Work Groups...

Group Focus	Group Leader
Finances	Helen Forbes, TAMBA
Welfare	Helen Forbes, TAMBA
Bereavement	Joyce Keating, AMBA
Education	Jenny Noonan, AMBA
Quality of Maternity Services	Judi Linney, TAMBA
Website	Mary Adcock, NOMOTC
Parenting	Helen Forbes, TAMBA
COMBO Directory	Margareta Olwe, Sweden

*Please contact the group leader if you are interested in assisting COMBO in a specific area.*

## **Declaration of Rights Survey**

*At the 2004 ISTS Congress in Odense, Denmark, COMBO members decided to review and update (if needed) the Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples, which was originally adopted in 1995. Please share your thoughts on this revision by answering the following questions.*

1. Give examples of how your organization has used the current declaration for advocacy.
2. Give examples of how your organization has used the current declaration for the development and/or stimulation of special services and support.
3. Did you or your organization promote the current declaration in any way? If “yes”, please explain.
4. Did your organization receive any outside support/use for the document (i.e. from other related organizations, governments, professionals)?
5. Is the present form of the declaration appropriate for your country (i.e. Declaration of Rights/ Statement of Needs)? If answer is "no", is there another title you would suggest?
6. Are any issues significant to multiples and their families that are not mentioned in the current declaration? If “yes”, please explain.
7. Are there any issues important to multiples and their families that are not mentioned in the current declaration? If "yes", please list.
8. Are there any suggested changes in wording? If “yes”, please explain.
9. Are there any suggested changes in content? If “yes”, please explain.
10. Would it be helpful to explore translation of the document into other languages (Spanish, French, German, Japanese, other languages)? If "yes", please note specific languages desired.

***Please use a separate sheet for answers if needed.***

*Thank you for responding to this survey. We value your opinions.*

If you would be interested in being a part of the COMBO Bill of Rights group, contact COMBO Chair, Mary Adcock, via email at: [mjadcock@cox.net](mailto:mjadcock@cox.net)

*Send responses via postal mail to: Mary Adcock, 804 Newport, Hutchinson, KS 67502 USA*

*Send responses via email to: [mjadcock@cox.net](mailto:mjadcock@cox.net)*