



ICOMBO

INTERNATIONAL COUNCIL OF
Multiple Birth Organisations

NEWSLETTER – JANUARY 2012

FROM THE BOARD

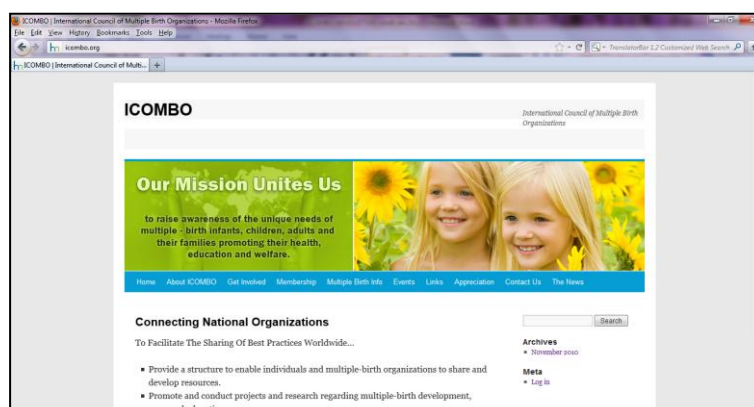
Hello everyone! We hope that you enjoyed receiving the last ICOMBO Newsletter sent in the fall of 2011 to you and have learned a little more about ICOMBO as well as other multiple-birth organizations worldwide. It is our sincere wish that we will be able to continue to offer you these regular updates and look forward to all of you contributing the latest news, events and resources from your organizations with us to share with others. The Board is busy getting ready for the Congress in Italy, planning for our ICOMBO Business Meeting, looking forward to attending and learning from the sessions, but most importantly we are getting excited about spending time with all of you who will also be attending.

In this newsletter you will have the opportunity to learn a little more about the Congress in Italy in April, the loss organization Center for Loss in Multiple Birth, Inc. (CLIMB) (USA), Jumeaux et Plus (France), PPH Survey, ICOMBO Survey, new resources developed by Multiple Births Canada (Canada) and the Divorce and Multiple Birth Family Survey from Mothers of Super Twins (MOST) (USA).

Please forward future submissions to Kim at chair@icombo.org or Monica at membership@icombo.org.

ICOMBO WEBSITE – www.icombo.org

The ICOMBO Board is thrilled to announce that our website is now LIVE!!! Admittedly it is still a work in progress. Without funding, the work of the website is all done by volunteers and therefore will take a bit of time and patience to get it where we would love it to be. However we are pleased to have a presence on the web and hope with your help we can create a site that will be full of information that will be important to all of you and your organizations. Take the time to have a browse. If you have any suggestions for additions, events you would like us to publicize, links, articles or other suggestions, please contact Kim at chair@icombo.org or Monica at membership@icombo.org



CONGRESS 2012



The momentum is building for the ISTS Congress being held in Florence from 1st – 4th April 2012.

There are some sessions for ICOMBO organizations – for presentations from our members and from the ICOMBO Board; and also time to hold the ICOMBO Business Meeting. It is at this meeting that the Chairperson and Directors will be elected, to work on the business of ICOMBO for the next two years.

The Board is hoping that as many organizations as possible will be represented at Congress. We would like to use the opportunity of meeting together to plan some future directions of ICOMBO and lots of input would be appreciated.

To date the following organizations have notified us that they will be attending:

Australia – Australian Multiple Birth Assoc. (2 representatives)
Canada – Multiple Births Canada
Czech Republic – Czech & Moravian Assoc of Twins and Multiplebirth Clubs
Denmark – Nordic Twinnet & Tvillinger
Finland – Finnish Multiple Births Association
Finland – Finnish Triplet Organisation
France – Jumeaux-et-Plus
Germany – ABC Club
Japan – Japanese Multiple Births Association
Norway – Tvillingforeldreforeningen (2 representatives)
South Africa – South African Multiple Birth Association
USA – National Organisation of Mothers of Twins Clubs (3 representatives)

We need a full list of all ICOMBO members and friends who will be attending, to assist with planning. If you, or someone in your organization will be attending, please notify Kim at chair@icombo.org or Monica at membership@icombo.org.

If you are planning on delivering a presentation at Congress and have already sent your details to the Congress Planners, please also send a copy to Kim at chair@icombo.org.

Please feel free to bring information to share with the other ICOMBO delegates in attendance. It is a wonderful way to share your resources and learn from one another.

We are hoping to arrange a Meet and Greet at a restaurant at the Sheraton on the night before the Congress is to begin as well as other meetings and times not seen as part of the official Congress Schedule. Please forward your availability to Monica or Kim. Thank you – we are so looking forward to meeting many new faces but also seeing friends we have made from previous Congresses.

ICOMBO SURVEY

The ICOMBO Board would like to thank all organizations who have taken the time to complete this survey. We are hoping it will provide valuable information that will assist us in planning the future directions of ICOMBO. It should also enable the Board to coordinate sharing and exchange of information, resources and support between our organizations.

CLIMB - Fast Facts

- Founded in 1990 by Jean Kollantai with assistance from other parents.
- 100's of members from USA, Canada and other countries who have experienced the death of one or more of their multiples.
- Membership also includes grandparents, other relatives, professionals, multiple birth groups.
- Members receive a newsletter, monthly e-bulletin, access to members-only site on website and facebook group.
- No membership fee – funded by donations.
- Members can choose to be available on a parent contact list for one-to-one contacts between members.

- Contact – climb@pobox.alaska.net
- Website – www.climb-support.org

FOCUS ON CLIMB

The Center for Loss in Multiple Birth, Inc. (CLIMB), is often referred to by its members as “the club no one wants to join—but we’re so glad it’s here.” It is made of up hundreds of families throughout the United States, and also in Canada and other countries, who have experienced the death of one or more, both or all of their twins or higher order multiples at some time from conception up to the age of about ten years old. Over the years since its inception in 1987, thousands of families have been involved. It is rare for a day to pass without a contact from a newly bereaved parent of twins or multiples who is getting in touch for the first time, a parent who has had a loss in recent months or years and is in the process of support, or a parent who has been a member of CLIMB for 10, 20, or more years—or all of these. Because the number of twin births is continuing to increase more than the medical risks for twins can decrease, the need for the organization is not expected to diminish, and probably increase, even though the number of higher order multiple pregnancies and births has declined in recent years.

CLIMB was founded in 1990 as a 501(c)(3) non-profit organization as a result of the efforts of Jean Kollantai to locate “a few” others like herself who had experienced the death of one of their twins at birth, beginning in 1986. Unbeknownst to her yet, fertility technology was producing more twin and multiple pregnancies, and her contacts soon became a flood, from parents everywhere with every kind of multiple birth loss experience and feeling like “the only one”. Lisa Fleischer, a local mother who lost one of her fullterm twins after birth, Patti Dubler, a leader of the Anchorage Parents of Twins and Multiples Club, and several mothers who had lost both of their twins, worked together to form a bereavement support group in the APOTMC and do outreach in Alaska about loss; then they incorporated CLIMB formally in 1990 as a national and international organization, in response to the overwhelming need. Jean Kollantai has been the staff person since then. CLIMB is supported by voluntary donations from bereaved parents and relatives, as well as caring others, and fundraising efforts by members.

CLIMB has published *Our Newsletter* regularly since December, 1987, sharing people’s personal stories and other information. Being a “member” of CLIMB consists of contacting CLIMB for a sample copy of the most recent newsletter, and then sending in the form to join the ongoing mailing list (with an optional donation). The mailing list is also open to grandparents, other relatives, professionals, and multiples groups. Bereaved parents and grandparents who are on it also receive the monthly e-bulletin, and may join the members-only section of the website as well as CLIMB’s Facebook group for current and previous members. They may also choose to join the parent contact list, available in print only, which expedites one-to-one contacts between members with similar experiences. Since CLIMB established its extensive website in 2001, most people hear about it through the site, which offers a lot to those not yet ready to get in touch, as well as to professionals and multiples groups. The heart of the organization is that anyone may be in touch with a recent, or not-yet-supported, loss in multiple pregnancy or birth, and even if their situation seems very unusual, have (usually within several hours) contact with someone with a similar experience who is

glad to talk with them, as well as having information appropriate to their loss and on any potential other resources. Many of the “older” members and previous members, whose loss is more than 15 or 20 years ago, have taken it on themselves to give back to others who have joined on the Facebook group and in individual contacts, as well as many others. Some members have started local networks of others with loss in multiple birth, and there is a great demand for more of these.

Jean has published a number of articles related to multiple birth loss, and written or co-written with Lisa Fleischer numerous articles available on the website. She has made presentations in a number of venues, beginning with the 9th International Workshop on Multiple Pregnant in Tel Aviv in 1994, and including the 10th International Congress on Twin Studies in London in 2001; she and CLIMB member Elizabeth Pector, MD, co-presented the keynote at the National Association of Perinatal Social Workers in 2006, and at The 12th International Congress on Twin Studies in Ghent, 2007.

PPH SURVEY

Dear Mothers of Twins,

The time period of our Post Partum Hemorrhage survey is rapidly drawing to a close. We have looked at the 842 responses so far and are very pleased with the results. We hope to add hundreds more mothers who participate by the end of the month. We are surprised, to be very frank. The numbers of mothers of multiples who report that they had PPH astounded us. What is so very important about this study is that it will be the first of its kind in the medical literature. The data we are collecting has been suspected to be the case, but no one has ever asked the mothers themselves.

With the aid of ICOMBO, The Center for Study of Multiple Birth has done this. We will present the data at the 2nd World Congress on Twin Pregnancy in Florence Italy the first 4 days in April. ICOMBO will be a listed author.

Join us and ICOMBO at the Congress!! There will be a retrospective expedition of twin photographs by David Teplica, MD, MFA, arguably the most distinguished photographer of twins in the world. There will be 4 days of scientific presentations on twin pregnancy. And. there will be Florence, Italy, the Statue of David, and lots of Gelato, coffee, fine food, and a drop of the grapes.

Donald & Louis Keith

Centre of Study for Multiple Births <http://www.multiplebirth.com/>

DIVORCE AND THE MULTIPLE BIRTH FAMILY

MOST (Mothers of Supertwins, USA) conducted a survey of parents with multiples (twins, triplets, quadruplets, etc.) from June 25, 2009 to July 27, 2009. The survey was designed to develop baseline statistics about the prevalence of divorce among multiple birth parents and contained 10 multi-part questions on family background, socioeconomic status, parent and children's age, as well as questions about marital status and divorce.



The research team consisted of:

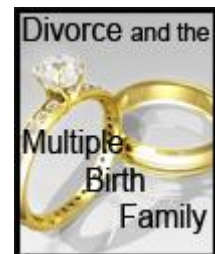
- Laurie LaMonde, Ph.D., MOST Research Director
- Marcia W. DiStaso, Ph.D., Assistant Professor at Penn State University
- Maureen A. Doolan Boyle, MOST Executive Director
- Laretta Shokler, MOST Technology Director
- Kelly Ross, MD, MOST Medical Director, Assistant Professor of Pediatrics, Division of Newborn Medicine Washington University School of Medicine & Pediatric Hospitalist at Missouri Baptist Hospital

All the data is still being analyzed for detailed statistics, but below are some initial findings.

Initial Findings

The survey had a large sample size. A total of 2,849 parents or guardians of multiples completed the MOST Divorce and the Multiple Birth Family survey questionnaire. The majority of survey participants were:

- Mothers (97.5%)
- Residents of the United States (93.4%)
- Predominately Caucasian (92.4%).
- An average age of 32 when their multiples were conceived.
- Households with an average of 3 children, mostly families of twins (61%) or triplets (30%).
- Married for the first time (86%).



Researchers commonly report that the lifetime divorce rate is about 40 to 50% for first marriages in the United States, and although it certainly makes sense that parents of multiples would face additional emotional, financial, and medical-related stressors, this study is the first known research examining the divorce rate among this growing population of parents. The survey found:

- That 4.3% of respondents divorced during the pregnancy or following the birth of multiples (indicating that the divorce rate among this group may not be as high as many have speculated.)
- Over 95% of the marriages were intact.
- About 82% of the respondents reported an overall positive level of marital satisfaction.

According to MOST researcher, Dr. Laurie LaMonde, a clinical psychologist and mother of triplets, *"Identifying a more accurate divorce rate is important to ease the concerns of multiple birth families as well as to determine if additional services may be beneficial for families that may be at greater risk of marital discord."*

Specifically, the divorce rate was:

- 3.6% for parents with twins
- 5% for parents with triplets
- 9.2% for parents with quadruplets
- 4.2% for parents with quintuplets/sextuplets or multiple sets of multiples

Among those who divorced, the majority of their multiples were between the ages of 1 and 5 at the time of divorce.

In addition, 4.8% of respondents reported that their marriage involved a history of physical or substance abuse. Of those reporting abuse, marital dissatisfaction ratings were higher and the likelihood of divorce was greater.

UPCOMING EVENTS

We would like to highlight upcoming events that are being hosted by our ICOMBO members, in future newsletters. In order to do this, could you please send to Monica membership@icombo.org any details of events that are being planned for your organization in 2012?

March 18, 2012 Twins Plus Festival, Melbourne, Australia. Co-hosted by Australian Multiple Birth Association and Australian Twin Registry. www.twinsfestival.com.au

April 1 – 4, 2012 ISTS Congress, Florence, Italy

July 25 – 28, 2012 NOMOTC Annual Conference, Hilton, NC, USA

FOCUS ON FRANCE –

Federation Jumeaux et Plus (Twins and More Federation)



Jumeaux et Plus - Fast Facts

- Founded in 1979 as National Mutual Aid of Multiple Births Parents Organisation.
- In 1998 the name was changed to Twins and More Association.
- In 2002 the name was changed to Twins and More Federation.
- 1500 families in 80 local clubs.
- 800 volunteers who are all multiple birth parents.
- Has a board with 24 members, elected by local clubs
- One paid Secretary
- In 2003, a Scientific Committee was created. This is a group of eminent experts who act as an interface between the parents and the medical profession.
- Has a newsletter to all members two times a year.

Our history

Created in 1979, as “ANEPNM” (which means National mutual aid of multiple births parents organization), it existed first as a national organization. Each year it became more efficient at answering the needs of our families.

ANEPNM grew up, and it became necessary to create local clubs in each French department.

In 1998, its name changed to “Twins and More Association” and then in 2002 to “Twins and More Federation”.

In February 2003 the Federation created its own Scientific Committee.

The Federation has relationships with authorities to show the needs of special requirements of multiple birth families.

Our Actions

Federal Actions:

- Information for medical professionals, parents-to-be and others who work at helping families – information about our member families' life experiences.
- Recognition of the specific needs of multiple births.
- Moral and material protection from our family members to suppliers or institutions.
- Prematurity prevention.
- Federal publication for member families is issued twice a year, it is called Multipl'infos.
- Website: www.jumeaux-et-plus.fr has information files and a very active discussion forum.
- Scientific Committee: made up of eminent experts on multiples, its main action is to be an interface between families in need and medicals professions. Once a year, it holds a scientific information day about everything to do with multiples, which is open to everyone who is interested.

Local Actions:

- Telephone support: to help and support pregnant and multiple birth parents
- Psychological help
- Multiples children care material lending
- Low prices in a purchasing group
- Discussion groups about breastfeeding, schooling, childcare...
- Parents and family meetings
- Second hand material or clothing sales
- Information meetings in maternity hospitals
- Local publication: member guide, local diary...

Our Goals

Federation and local clubs are looking to get recognition from institutions about:

- The costs of educating multiple-birth children simultaneously, from birth to the end of their studies.
- Specific needs of multiple-births families during different times of their lives.
- The tiredness at the end of this particular family situation.
- Be a reference for everything about multiples.

Our successes:

- Paternal leave: 18 days for multiple births (against 11 for single birth).
- Multiple births consideration in child benefit calculation.
- Clinical Guide Lines about pregnancy care.
- This year, for the first time we are getting a subsidy from the national child benefits office for volunteers training.

Our next projects:

- Large sharing of clinical guidelines.
- Volunteers training improvement.
- Explain the needs of families whose children are at university.

The following new or updated resources have now been posted on the Multiple Births Canada (MBC) website as part of their publications. They were created with financial assistance from Assisted Human Reproduction Canada (AHRC) as part of a joint project. AHRC will use the information from the fact sheets to create a multiple-births portal on their website. The goal of this joint project is to make available information about the risks associated with carrying multiples before the decision has been made about using assisted reproduction techniques (ART) (i.e. deciding on the number of embryos to transfer) so that individuals / families can make an informed decision. The goal is to encourage a healthy singleton pregnancy. MBC decided to make these very important resources free to the public to allow AHRC to provide links to the MBC website, and so that those who are considering ART are made aware of the resources and information available to them through MBC. In addition, new and expectant parents of multiples will have access to the information early in their pregnancy.

Challenges of Parenting Multiples:

Part 1: Risks for the Mother

http://www.multiplebirthscanada.org/english/documents/FS-RisksforMothers-Part1_FINAL.pdf

Part 2: Risks to the Children

http://www.multiplebirthscanada.org/english/documents/FS-RisksforChildren-Part2_FINAL.pdf

Part 3: Reducing the Risks

http://www.multiplebirthscanada.org/english/documents/FS-Risks-ReducingtheRisks-Part3_FINAL.pdf

Monochorionic Multiple Pregnancy and Twin to Twin Transfusion Syndrome:

<http://www.multiplebirthscanada.org/english/documents/FS-TTTS-FINAL.pdf>

Biology of Multiples

http://www.multiplebirthscanada.org/english/documents/FS-BiologyofMultiples_FINAL.pdf

Challenges of Parenting Multiples

Part1: Couple Relationships

http://www.multiplebirthscanada.org/english/documents/FS-ChallengesofParenting-Relationship-Part1_FINAL.pdf

Part 2: Twins & Higher Order Multiples

http://www.multiplebirthscanada.org/english/documents/FS-ChallengesofParenting-Twins-HOMs-Part2_FINAL.pdf

A list of all of the MBC Fact Sheets can be found at the following link:

<http://www.multiplebirthscanada.org/english/booklets.php#factsheets>

These Fact Sheets are available for any organization to use, with acknowledgement to MBC.

For more information please feel free to contact Kimberley Weatherall, Acting Executive Director for Multiple Births Canada at kimberely.weatherall@multiplebirthscanada.org.