



International Council of Multiple Birth Organizations

ICOMBO MEDIA RELEASE

PROFESSIONALS AND FAMILIES UNITE TO PROMOTE THE RIGHTS AND NEEDS OF TWINS AND HIGHER ORDER MULTIPLES

FOR IMMEDIATE RELEASE - The International Council of Multiple Birth Organizations (ICOMBO) is advocating for worldwide endorsement and promotion of an important document during its first International Multiple Births Awareness Week, November 1-7, 2010.

The document is the newly updated **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** featuring over 40 statements relating to the human, civil and constitutional rights and fundamental needs of twins and higher order multiples. These statements identify such issues as culturally sanctioned banishment and/or infanticide of twins, lack of proper prenatal care for mothers and their fetuses, a need for breastfeeding support, the importance of placing multiples together in adoptive environments, addressing the multiple bond when making classroom placement decisions, the balancing of individuality within the co-multiple relationship, and ongoing myths and practices that endanger the lives of twins and higher order multiples. "A pledge card was distributed to members of ICOMBO and the International Society on Twin Studies (ISTS), along with other national organizations supporting multiple births this week asking them to endorse and promote the Declaration so we can collectively identify the gaps and shortfalls and address the need for improvements in some countries and/or regions," said Kimberley Weatherall, Chair of ICOMBO.

At the 1992, ISTS Congress in Japan, multiple-birth organizations worked together to begin compiling a —**Declaration of Rights and Statement of Needs for Twins and Higher Order Multiples**. This declaration was formally adopted by ICOMBO (formerly COMBO) members at the 1995 ISTS Congress, held in Richmond, VA. The Declaration was more recently updated in 2007 and again in June 2010. Endorsed at the 2010 ISTS Congress in Seoul, South Korea; it includes current research citations to support the rights and needs expressed in the document. The Declaration can be found online at the following link:

<http://www.multiplebirthscanada.org/english/declarerightsmb.php>

ICOMBO is a global collaboration of over a dozen national multiple-birth organizations with the objective of promoting the principles detailed in the **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples**. ICOMBO provides a structure to enable individuals and multiple-birth organizations to share and develop resources, promoting and conducting projects and research regarding multiple birth development, care, and education, disseminating information and results of ICOMBO research projects and recruiting multiple-birth organizations worldwide. ISTS is an international, nonprofit multidisciplinary organization furthering research and public education in fields related to multiple birth development and care including health, psychology and education.

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Kimberley Weatherall, ICOMBO Chair at kimberley.weatherall@multiplebirthscanada.org



International Council of Multiple Birth Organizations

ICOMBO PLEDGE FORM FOR:

International Multiple Births Awareness Week – November 1-7, 2010

I pledge to complete the following (please circle your intentions for each):

- Coordinate translations of the newly updated **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** to the national language(s) of our country. YES NO
 - If yes, please note which language(s):

- Post the attached **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** on our website. YES NO
 - If yes, please note URL address:

- Distribute and promote the **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** to other agencies and organizations working in our country. YES NO

- Encourage other agencies and organizations in our country to post the **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** on their websites. YES NO

Name of respondent: _____

Name of organization representing: _____

Country assessed: _____

Email address: _____

SIGNED: _____

DATED: _____

Completed pledge forms and report cards should be sent to:

Kimberley Weatherall, ICOMBO Chair at kimberley.weatherall@multiplebirthscanada.org

International Council of Multiple Birth Organizations **ICOMBO BACKGROUNDER**

While the newly updated **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** seems fundamental to those involved with the world's multiple-birth community – the importance of promoting and supporting this document was recently highlighted by author Alessandra Piontelli in her book **Twins in the World**. In her travels throughout Africa, Asia, South America, and the Pacific rim, Piontelli observed how some cultures deify twins while other cultures attribute evil spirits to them and others outright destroy all multiple siblings. When asked to endorse the newly updated **Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples** Ms. Piontelli offered these words and the following pictorial documentary as evidence of the importance of the focus of International Multiple Births Awareness Week.

“I hereby declare to be fully in agreement with the Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples approved on June 5, 2010 and Adopted by the International Council of Multiple Birth Organizations (ICOMBO) and the International Society of Twin Studies (ISTS), May 1995 (updated 2007 and 2010).

I also find the initiative to celebrate an International Multiple Births Awareness Week - on behalf of the International Council of Multiple Birth Organizations (ICOMBO) - very laudable and necessary for spreading knowledge about the unique needs of twins, thus improving their condition.

The week will be celebrated for the first time ever this fall November 1-7, 2010 and I wish the organizers a great success.”

Alessandra Piontelli, M.D. University of Milano
Email: alessandra.piontelli@fastwebnet.it



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Brought up by the Elderly (Laos)

In this region twins are thought to affect negatively the fertility of the soil, and consequently of the crops. Further north they are killed. Here only all those past reproductive age are allowed to bring them up. These twins will never see their parents.



Copyright Alessandra Piontelli

Orphanage (Central-Southern Madagascar)

So-called ‘orphanages’ filled with twins abound in the region. Twins are almost invariably killed at birth for superstitious reasons. Some religious groups try to rescue them. Knowing the mothers go and deliver in special places considered to be free from evil spirits, they snatch the twins and put them in shelters. This is no guarantee of survival. As seen in the picture, the shelters are frequently filthy, unhealthy, and look like prisons. Besides often-severe physical problems, none of the twins in this orphanage could walk or talk.

Fate (The Philippines)

In this remote, mountainous region twins were usually disposed of. However even living few kilometres apart made all the difference. This village offered slightly better living conditions. These twins were spared.



Copyright Alessandra Piontelli



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Abuse and Neglect (Northern Paraguay)

The mother of these twins abandoned them at birth. Their grandmother rescued them unwillingly. Being married to the chief of the a community of Indios, she was blackmailed, and tormented by the corrupt police. Though the twins were not killed, their condition was one of extreme neglect. Abuse was also present: both twins had several burns on their skinny bodies as well as numerous bone fractures.



Copyright Alessandra Piontelli

Marginalized (Guinea Bissau)

Twins are almost inevitably killed by the two main ethnic groups living near the capital. Superstitious reasons lay at the basis of this conduct. This woman rebelled. However she was heavily marginalized. Nobody spoke to her, she was obliged to go around bare breasted, had to scrape for a living, and was given no shelter. Some children can be seen laughing at her in the background.



Copyright Alessandra Piontelli

The Good and the Bad Use of Ultrasounds (Assam, India)

These two proud female twin doctors were the living proof that sex discrimination is punishable under the law and not practiced in hospitals. However portable ultrasounds were used to by-pass the law as indicated by the massive number of females missing 'to the call' (Amartya Sen, 1990). Twin females were almost inevitably doomed.



Copyright Alessandra Piontelli

Poverty (Northern Uganda)

A devastating war has been raging in the region for more than 24 years. These parents had to walk for 4 days and nights in order to carry their 5 months old twins suffering from malaria to the only 'hospital' in the region. The parents are wearing their 'best clothes', and the mother is transporting all their possessions in a bag on her head.



Copyright Alessandra Piontelli

Being Venerated Can Be a Burden (Northern Togo)

Twins are generally venerated in all west African countries where Voodoo is practiced. However being venerated can carry disadvantages. These twins will be obliged to move about at all times holding the same oblong object symbolizing their perennial, sacred union. Only when the twins will reach the age of 7, the object will be broken and the twins be allowed to move separately.



Copyright Alessandra Piontelli

An Unjust Reputation (Middle Sepik Region, Papua)

In several books the inhabitants of both sides of Papua are described with an aura of ferociousness. Twin infanticide is declared to live on only amongst the Papua. As this photo shows twins are very much loved by most. Possibly aided by a largely matrilineal structure of the society, besides their mothers, most fathers take tender care of them.



International Council of Multiple Birth Organizations (ICOMBO)

International Society of Twin Studies (ISTS)

Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples

Introduction: The mission of the Council of Multiple Birth Organizations (COMBO) of the International Society for Twin Studies is to promote awareness of the unique needs of multiple-birth infants, children, and adults. The multi-national membership of COMBO has developed this Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples as benchmarks by which to evaluate and stimulate the development of resources to meet their unique needs.

Declaration of Rights

WHEREAS myths and superstitions about the origins of multiples have resulted in the culturally sanctioned banishment and/or infanticide of multiples in some countries:

I. Multiples and their families, as any other individuals, have a right to full protection, under the law, and freedom from discrimination of any kind.

WHEREAS the conception and care of multiples increase the health and psychosocial risks of their families, and whereas genetic factors, fertility drugs, and in vitro fertilization techniques are known to promote multifetal pregnancies:

II.

A. Individuals or couples planning their families and/or seeking infertility treatment have a right to be fully informed about:

- 1. factors which influence the conception of multiples;**
- 2. the associated pregnancy risks and treatments;**
- 3. the associated risks to one, more or all of the fetuses/infants;**
- 4. facts regarding parenting multiples; and**
- 5. the option of multifetal pregnancy reduction along with its associated risks and profound emotional consequences.**

B. Infertility treatment should intend to prevent multiple pregnancies, in particular high order multiples.

C. Fertility services should disclose their number of multiple pregnancies, both intentional and unintentional.

WHEREAS the zygosity of same sex multiples cannot be reliably determined by their appearances; and whereas 1) the heritability of dizygotic (two-egg) twinning increases the rate of conception of multiples; 2) the similar biology and inheritance of monozygotic (one-egg) multiples profoundly affect similarities in their development; 3) monozygotic multiples are blood, organ and umbilical blood stem cells donors of choice for their co-multiples; and 4) the availability of the placenta and optimal conditions for determining zygosity are present at birth:

III.

- A. Parents have a right to expect accurate recording of placentation, determination of chorionicity and amnionity via ultrasound, and the diagnosis of zygoty of same sex multiples at birth.**
- B. Older, same sex multiples of undetermined zygoty have a right to testing to ascertain their zygoty. Furthermore, involvement in registries of multiple-birth individuals should be absolutely voluntary on the part of the multiples.**
- C. Zygoty should be respected as any other human trait and deserves the same privacy rules.**

WHEREAS during World War II twins were incarcerated in Nazi concentration camps and submitted by force to experiments which caused disease and/or death:

IV. Any research incorporating multiples must be subordinated to the informed consent of the multiples and/or their parents and must comply with international codes of ethics governing human experimentation and other types of research.

WHEREAS ignorance, misconceptions and inadequate documentation regarding multiples and multiple births increase the risk of misdiagnosis and/or inappropriate treatment of multiples:

- V.**
- A. Pregnant women, parents and their multiples have a right to care by professionals who are knowledgeable regarding the management of multiple gestation and/or the lifelong unique needs of multiples; and**
 - B. Multiple births, perinatal and infant deaths, and singleton births that started out as a multiple gestation, must be accurately recorded.**

WHEREAS the bond between co-multiples is a vital aspect of their normal development:

VI. Co-multiples have the right to be placed together in foster care, adoptive families, custody agreements, and educational settings.

WHEREAS multiple-birth individuals are sometimes treated as a unit by parents, professionals, and the general public:
VII. Multiples, as any other human being, have the right to be respected and treated as individuals with their own needs, preferences and dislikes.

Statement of Needs

Summary: Twins, and higher order multiples have unique conception, gestation and birth processes; health risks; impacts on the family system; developmental environments; and individuation processes. Therefore, in order to insure their optimal development, multiples and their families need access to health care, social services, and education which respect and address their differences from single born children.

WHEREAS the needs of multiple birth individuals and families during pregnancy, after the births and beyond are complex and diverse:

I.

- A. Individuals and families require information about, and need access to, a wide variety of disciplines and services such as health professionals, social services, employment services, education, and the multiple birth community;**
- B. Individuals and families require care from health and other professionals who are informed about multiple birth issues and possess the necessary skills; and**
- C. Coordination and continuity of care among disciplines and services are essential for care effectiveness.**
- D. Training and professional development to support the learning needs of health, social services and education professionals are necessary to ensure they can provide the multiple-birth community with the best possible health care and educational experience.**

(See References, Section I).

WHEREAS mothers are at high risk of maternal stress and pre and postnatal complications, and twins and higher order multiple births are at high risk of low birth weight (<2500 grams), and very low birth weight (< 1500 grams), disability, and infant death:

II. Parents who are expecting multiples have a need for:

- A. Education about evidence-based self-care strategies that foster maternal health and optimal fetal development;**
- B. Education regarding the prevention and recognition of pre-term labor; and**
- C. Prenatal resources and care designed to avert the pre-term birth of multiples, and foster maternal health and optimal fetal development including:**
 - 1. diagnosis of a multiple pregnancy, ideally by the fourth month, which is communicated tactfully, with respect for the privacy of the parents;**
 - 2. chorionicity and amnionicity established by ultrasound as accurately and early as possible as this information is critical for antenatal care.**
 - 3. nutrition counselling and dietary resources to support a weight gain of 18-27 kilos (40-60 pounds)**
 - 4. prenatal care which follows protocols of best practice for multiple birth; and when the health of the mother or family circumstances warrant:**
 - a. extended work leave;**
 - b. bed rest support; and**
 - c. child care for siblings.**

- 5. heightened diligence toward diagnosis and treatment (when needed) for the conditions to which multiples are uniquely at risk, including but not limited to twin-to-twin transfusion syndrome (TTTS).**
- 6. attention to the timing and mode of delivery of multiples.**

(See References, Section II).

WHEREAS breastfeeding provides optimal nutrition, nurture and brain development for pre-term and full-term multiples; and whereas the process of breastfeeding and/or bottle feeding of multiples is complex and demanding:

III. Families expecting and rearing multiples need the following:

- A. Education regarding the nutritional, immunological, psychological, and financial benefits of breastfeeding for pre-term and full-term infants;**
- B. Encouragement and coaching in breastfeeding techniques;**
- C. Education and coached practice in simultaneous feeding of co-multiples; and,**
- D. Adequate resources, support systems, and family work leave to facilitate the breastfeeding and/or bottle feeding process.**

(See References, Section III).

WHEREAS 60% of multiples are born before 37 weeks gestation and/or at low birth weight and experience a high rate of hospitalization both which endangers the attachment process and breastfeeding; and whereas newborn multiples are comforted by their fetal position together:

IV. Families with multiples need specialized education and assistance to promote and encourage bonding and breastfeeding. Hospital placement of multiples and hospital protocols should facilitate family access, including co-multiples' access to each other.

(See References, Section IV).

WHEREAS multiple birth infants suffer elevated rates of birth defects and infant death:

V. Families experiencing the disability and/or death of co-multiples need:

- A. Care and counseling by professionals who are sensitive to the dynamics of grief associated with disability and/or death in co-multiples, and emotional attachment to surviving co-multiples;**
- B. Access to therapies, counseling and resources when one or more multiples is affected by a disability or disorder in order to help them manage the discordance of needs and abilities among co-multiples.**
- C. Policies which facilitate appropriate mourning of a deceased multiple or multiples**

(See References, Section V).

WHEREAS the unassisted care of newborn, infant, toddler and preschool multiples elevates their families' potential for illness, postpartum depression/anxiety, substance abuse, child abuse, spouse abuse, and relationship discord:

VI. Families caring for multiples need timely access to adequate services and resources in order to:

- A. Insure access to necessary quantities of infant and child clothing and equipment;**
- B. Enable adequate parental rest and sleep;**
- C. Facilitate healthy nutrition;**
- D. Facilitate the care of siblings;**
- E. Facilitate child safety;**

- F. Facilitate transportation;**
- G. Facilitate pediatric care; and**
- H. Protect parental mental health.**

(See References, Section VI).

WHEREAS families with multiples have the unique challenge of promoting the healthy individuation process of each co-multiple and of encouraging and supporting a healthy relationship between the co-multiples; and, whereas the circumstance of multiple birth affects developmental patterns:

VII. Families expecting and rearing multiples need:

- A. Access to information and guidance in optimal parenting practices regarding the unique developmental aspects of multiple birth children, including the processes of: socialization, individuation, and language acquisition; and**
- B. Access to appropriate testing, evaluation, and schooling for co-multiples with developmental delays and/or behavior problems.**

(See References, Section VII).

WHEREAS twins and higher order multiples are the subjects of myths and legends and media exploitation which depict multiples as depersonalized stereotypes:

VIII. Public education, with emphasis upon the training of professional health and family service providers, and educators, is needed to dispel mythology and disseminate the facts of multiple birth and the developmental processes in twins and higher order multiples.

(See References, Section VIII).

WHEREAS twins and higher order multiples suffer discrimination from public ignorance about their biological makeup and inflexible policies which fail to accommodate their unique needs:

IX. Twins and higher order multiples need:

- A. Information and education about the biology of twinning; and**
- B. Health care, education, counseling, and flexible public policies which address their unique developmental norms, individuation processes, and relationship. For example by permitting and/or fostering:
 - 1. the treatment of medically fragile co-multiples in the same hospital;**
 - 2. the neonatal placement together of co-multiples in isolettes and cribs to extend the benefits of their fetal position together;**
 - 3. medical, developmental, and educational assessment and treatment which is respectful of the relationship between co-multiples;**
 - 4. avoidance of staggered hospital discharge of the co-multiples whenever possible**
 - 5. the annual review of the classroom placement of co-multiples, and facilitation of their co-placement or separate placement according to the particular needs of multiple birth children and their families;**
 - 6. to pursue their own and unique interests including simultaneously participating on sports teams and in other group activities and/or to pursue individual sports, group or hobby interests.**
 - 7. specialized grief counseling for multiples at the death of a co-multiple;**
 - 8. counseling services addressing the unique needs of adult multiples.****

WHEREAS the participation by multiple birth infants, children, and adults as research subjects has made important contributions to scientific understanding of the heritability of disease, personality variables, and the relative influence of nature and nurture on human development; and, WHEREAS relatively little is known about optimal management of plural pregnancy and the unique developmental patterns of multiples:

X. Scientists must be encouraged to investigate:

- A. The optimal management of plural pregnancies;**
- B. Norms for developmental processes which are affected by multiple birth such as: individuation, socialization, and language acquisition;**
- C. Benchmarks of healthy psychological development, and relevant therapeutic interventions for multiples of all ages and at the death of a co-multiple;**
- D. Strategies and interventions that are effective in promoting the health of multiple birth families during the parenting period such as: breastfeeding, employment policies, prevention of postpartum mood disorders;**
- E. Management of ethical issues by health professionals and multiple birth families such as: assisted reproduction, multifetal and selective pregnancy reduction; and**
- F. Medical, developmental and educational assessment/treatment respectful of the relationships between co-multiples.**

STATEMENT OF NEEDS – REFERENCES

Statement I: Professional Services, Support & Development

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Update coordinated by: Donna Launslager

As requested by: COMBO Chair Kimberley Weatherall and Vice Chair Gail Moore

Endorsed by: the Board of the International Society for Twin Studies, June 5, 2010

Matt McGue, President - International Society for Twin Studies

Endorsing organizations and representatives, June 2010:

Country/Organization/Name

Australia

Australian Multiple Births Association (AMBA) – Monica Rankin

Canada

Multiple Births Canada (MBC) – Kim Weatherall and Gail Moore

Finland

Finnish Multiple Birth Association (FMBA) – Ulla Kumpula and Mari Kaihovaara

Finnish Triplet Organization –Mari Kaihovaara

Germany

ABC Club – Christine Disselkamp

Japan

Japan Multiple Births Association (JAMBA) –Teniko Tanka

Japanese Association of Twins’ Mothers (JATM) –Yoko Sugiuna

Switzerland

Association Jumeaux –Sabine Herbener

U.S.A.

The Center for the Study of Multiple Birth - Donald Keith and Louis Keith

Amendment adopted by the Council of Multiple Birth Organizations (COMBO) at the 12th International Congress on Twin Studies, Ghent, Belgium – June 2007

Amendment coordinated by: Mary Adcock

Endorsed by Most (Mother of Supertwins) – Maureen A. Doolan Boyle

Adopted by the Council of Multiple Birth Organizations (COMBO) (comprised of representatives of 16 organizations from ten countries: Australia, Belgium, Canada, China, Germany, Indonesia, Japan, Sweden, United Kingdom, United States) (COMBO) of the International Society for Twin Studies at the Eighth International Twin Congress, Richmond, Virginia - May 31, 1995.

Patricia Malmstrom, Chair

Council of Multiple Birth Organization

Endorsed by the Board of the International Society for Twin Studies, May 31, 1995

Lindon Eaves, President

International Society for Twin Studies

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Adopted at the Eighth International Twin Congress, Richmond, Virginia - May 31, 1995 by the Council of Multiple Birth Organizations (COMBO), International Society for Twin Studies.

Endorsing organizations and representatives, May 1995:

Country/Organization/Name

Australia

LaTrobe Twin Study - David Hay

Australian Multiple Births Association - Maureen Copeland

Belgium

Association for Research in Multiple Births - Robert Derom

Canada

Parents of Multiple Births Association of Canada - Kim Johnson
(known today as Multiple Births Canada)

China

Taipei Twins Association - Cheh Chang

Germany

ABC Club - Ute Grutzner

Indonesia

Twins Foundation - Seto Mulyadi

Japan

The Japanese Association of Twins' Mothers - Yukiko Amau

Sweden

The Swedish Twin Society - Margareta Olwe

United Kingdom

Twins and Multiple Births Association - Rachel Hudson and Audrey Sandbank

Multiple Births Foundation - Elizabeth Bryan

U.S.A.

The Center for Loss in Multiple Birth - Jean Kollantai

The Center for the Study of Multiple Birth - Donald Keith

Illinois Mothers of Twins Clubs - Jean Herr

National Organization of Mothers of Twins Clubs - Rebecca Moskwinski and Marion Meyer

The Twins Foundation - Kay Cassill

The Twin to Twin Transfusion Syndrome Foundation - Mary Slaman-Forsythe

Twin Services, Inc. - Patricia Maxwell Malmstrom