

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

**Introduction:** The mission of the International Council of Multiple Birth Organizations (ICOMBO) 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 ICOMBO 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 amnionicity 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**

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**Statement I: Professional Services, Support & Development**

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### **Statement III: Infant Feeding**

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## **Statement IV: Attachment and Relationships**

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## **Statement VIII: Public Education and Professional Development**

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Update adopted by the International Council of Multiple Birth Organizations (ICOMBO) at the 13<sup>th</sup> International Congress on Twin Studies, Seoul, South Korea – June 5, 2010

Update coordinated by: Donna Launslager, Multiple Births Canada

As requested by: Kimberley Weatherall, Chair, International Council of Multiple Birth Organization (ICOMBO) and Gail Moore, Vice Chair, International Council of Multiple Birth Organization (ICOMBO)

Endorsed by: the Board of the International Society for Twin Studies, June 5, 2010 (Matt McGue, President)

**Endorsing organizations and representatives, June 2010 (Country/Organization/Name):**

**Australia**

Australian Multiple Births Association (AMBA) – Monica Rankin

**Canada**

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

**Finland**

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

Finnish Triplet Organization –Mari Kaihovaara

**Germany**

ABC Club – Dr. 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 / Louis Keith

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

Amendment coordinated by: Mary Adcock Chair, Council of Multiple Birth Organization (COMBO)

Endorsed by: the Board of the International Society for Twin Studies, June 2007 (Jakko Kaprio, President)

**Endorsing organizations and representatives (Country/ Organization /Name):**

**Australia**

Australian Multiple Birth Association (AMBA) – Joyce Keating

**Canada**

Multiple Births Canada (MBC) – Kimberley Weatherall / Gail Moore

**Denmark**

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Finnish Multiple Birth Association (FMBA) – Katri Algren / Ulla Kumpula

**Germany**

ABC Club- Dr. Christine Disselkamp

**Norway**

Tvillingforeldreforeningen – Ingun Ulven Lie / Anette Haugen

**Sweden**

Swedish Twin Association – Margareta Olwe

**Switzerland**

Association Jumeaux - Sabine Herbener

**United Kingdom**

Twins and Multiple Births Association (Tamba) – Judi Linney / Janet Rimmer / Carol Robins / Gillian Smith /Helen Forbes

**United States of America**

The Center for Loss in Multiple Births (CLIMB) – Jean Kollantai

National Organization of Mothers of Twins Clubs (NOMOTC) – Mary Adcock / Susan Griffith / Tiffany Wimberley / Misty Fry

Mothers of Super Twins (MOST)

Adopted by the Council of Multiple Birth Organizations (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 (COMBO)

Endorsed by the Board of the International Society for Twin Studies, May 31, 1995 (Lindon Eaves, President)

**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