INTERNATIONAL COUNCIL OF
MULTIPLE BIRTH ORGANISATIONS

DECLARATION OF RIGHTS AND STATEMENT OF NEEDS OF TWINS AND HIGHER ORDER MULTIPLES

May 2022

Championing the rights of multiples

ICOMBO
INTERNATIONAL COUNCIL OF
Multiple Birth Organisations

Declaration of Rights of Twins and Higher Order Multiples

I. Myths and superstitions about the origins of multiples have resulted in the banishment and/or infanticide of multiples in some regions.

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

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II. The conception and care of multiples increases the health and psychosocial risks of their families. Genetic factors, fertility drugs and in vitro fertilisation techniques are known to increase the chance of a multifetal pregnancy.

Therefore, fertility treatment should be conducted in a manner which minimises risks and provides information with regards to the reality of having multiples.

i. Individuals or couples planning their families and/or seeking infertility treatment have a right to be fully informed about:
   - the factors which influence the conception of multiples;
   - the associated pregnancy risks and treatments;
   - facts regarding parenting multiples and support to consider the practical, financial and emotional/ psychological impact on the family; and
   - the multifetal pregnancy reduction procedure, its associated risks and longer-term emotional consequences.

ii. Infertility treatment should aim for one healthy baby as an outcome of treatment. Every fertility service should have a strategy and protocol to minimise the risk of a multiple pregnancy, especially triplets and higher order multiples.

iii. Fertility services should collect and disclose data about the number of and outcome of multiple birth pregnancies. This should include the number of embryos replaced in IVF cycles.

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III. The zygosity of same-sex multiples cannot be reliably determined by their appearances. The availability of the placenta, blood cord and optimal conditions for determining zygosity are present at birth. Knowledge of zygosity is important for:

- family planning because dizygotic (two egg) twinning can be a familial trait and increases the chance of future multiples;
- health (e.g. monozygotic multiples are perfect blood, organ and umbilical blood stem cell donors for each other); and
- understanding development of the co-multiples.

Therefore:

i. parents have a right to expect accurate recording of placentation, determination of chorionicity and amnionicity via ultrasound, and the diagnosis of zygosity of same-sex multiples at birth;

ii. older, same-sex multiples of undetermined zygosity have a right to testing to ascertain their zygosity; and

iii. zygosity should be respected as any other human trait and deserves the same privacy rules.

IV During World War II, twins were incarcerated in Nazi concentration camps and submitted by force to experiments which caused emotional harm, physical distress, disease and/or death.

Therefore, any research involving multiples must be conducted in an ethical and considered manner.

i. Research involving multiples must:
   - include the informed consent of the multiples and/or their parents;
   - comply with international codes of ethics governing human experimentation and other types of research;
   - consider the perspectives of the multiples and their families in the design of the research; and
   - consider the research priorities set by multiples and their families in the 2019 International Priority Setting Partnership and discussion paper.

ii. Involvement in registries of multiple birth individuals should be voluntary on the part of the multiples.

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V. Inexperience, misconceptions and inadequate documentation regarding multiples and multiple births increase the risk of misdiagnosis and/or inappropriate treatment of multiples.

Therefore, pregnant women, parents and their multiples have a right to:

i. appropriate management of their multiple birth pregnancy, no matter what the outcome;
ii. care by professionals who are knowledgeable regarding the management of multiple birth pregnancies, particularly when there are potential complications;
iii. accurate recording of multiple births, perinatal and infant deaths, and singleton births that started as a multiple gestation; and
iv. their surviving multiple/s being recognised as part of a multiple birth set by health professionals.

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VI. The bond between co-multiples is a vital aspect of their normal development.

Therefore, the bond between co-multiples must be considered in a range of settings. Co-multiples have the right to be placed:

i. together in foster care, adoptive families and custody arrangements; and
ii. together or apart in educational settings, depending on the wishes of the parents and the multiples themselves.

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VII. Multiple birth individuals are sometimes treated as a unit by parents, professionals and the general public.

Therefore, multiples, as with any other human being, have the right to be respected and treated as individuals with their own needs, preferences and dislikes.

Statement of Needs of Twins and Higher Order Multiples

Summary
Twins, triplets and higher order multiples have unique conception, gestation, and birth processes; health risks; impacts on the family dynamics; developmental environments; and individuation processes. Therefore, to ensure 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.

A. The needs of multiple birth individuals and families during pregnancy, after the birth and beyond are complex and diverse.

Therefore, it is important that:

a. individuals and families be provided with information about, and have access to, a wide variety of disciplines and services such as health professionals, social services, relationship counsellors, employment services, education, and the multiple birth community;
b. individuals and families receive care from health and other professionals who are informed about multiple birth issues and possess the necessary skills to care for a multiple birth family;
c. there is coordination and continuity of care across disciplines and services that are essential for care effectiveness; and
d. training and professional development is available to educate health, social services and education professionals to ensure they can provide the multiple birth community with the best possible health care and educational experiences.

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B. Mothers and fathers are at high risk of maternal stress and pre/postnatal complications, and twins and higher order multiple births are at high risk of low birthweight (< 2500 grams), and very low birthweight (< 1500 grams), disability and infant death.

Therefore, parents who are expecting multiples have a need for:

a. education about evidence-based self-care strategies that foster parental health and optimal fetal development;
b. education regarding the recognition and management of preterm labour; and
c. prenatal resources and care designed to avert the preterm birth of multiples, and foster maternal health and optimal fetal development including:
    - diagnosis of a multiple birth pregnancy, ideally within the first trimester, which is communicated tactfully, with respect for the privacy of the parents;
    - determination of chorionicity and amnionicity, established by ultrasound as accurately and as early as possible, as this information is critical for antenatal care;
    - nutrition counselling and dietary resources to support healthy weight management during pregnancy where the guidelines have been derived from twin and higher order pregnancies rather than singleton pregnancies;
    - prenatal care which follows best practice protocols for multiple births; and
    - when the health of the mother or the family circumstances warrant:
        - extended work leave and/or modification of duties;
        - support to provide expectant mother with adequate rest; and

- childcare for siblings;
- heightened diligence towards 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); and
- attention to the timing and mode of delivery of multiples taking into account chorionicity, amnionicity and potential complications.

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C. Breastfeeding provides optimal nutrition, nurture and brain development for pre-term and full-term multiples. The process of breastfeeding and/or formula feeding of multiples is complex and demanding.

Therefore, families expecting and rearing multiples need the following:

a. education regarding the nutritional, immunological, psychological and financial benefits of breastfeeding for preterm and full-term infants;
b. information and support with breastfeeding to suit their individual needs and wishes;
c. education and practical support in feeding of co-multiples;
d. support from all professionals for families who formula-feed their multiples; and
e. adequate resources, support systems and family work leave to facilitate the breastfeeding and/or formula-feeding process.

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D. Up to 60 per cent of multiples are born before 37 weeks gestation and/or are low birthweight and therefore experience a high rate of hospitalisation. This endangers the attachment process. Newborn multiples are comforted by having their co-multiple/s close by.

Therefore, families with multiples need specialised education and assistance to promote and encourage bonding. Hospital placement of multiples and hospital protocols should facilitate family access, including co-multiples' access to each other.

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E. Co-multiples are at higher risk of congenital abnormalities and perinatal or infant death.

Therefore, families experiencing the disability or death of co-multiples need:

a. care and counselling by professionals who are sensitive to the dynamics of grief associated with genetic disorders, disability and/or death in co-multiples and emotional attachment to surviving co-multiples;
b. access to therapies, counselling 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; and
c. policies which facilitate appropriate mourning and recognition of a deceased multiple or multiples.

F. 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.

Therefore, families caring for multiples need timely access to adequate services and resources in order to:

a. ensure access to necessary quantities of infant and child clothing and equipment;
b. enable adequate parental rest and sleep;
c. facilitate healthy nutrition;
d. facilitate child safety;
e. facilitate the care of siblings;
f. facilitate transportation;
g. facilitate medical care; and
h. protect parental mental health.

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G. Families with multiples have the unique challenge of promoting individuality while encouraging and supporting a healthy relationship between the co-multiples. The circumstances of a multiple birth may affect developmental patterns.

Therefore, families expecting and rearing multiples need:

a. access to information and guidance in optimal practices regarding the unique developmental aspects of multiple birth children, including the processes of socialisation, fostering individuality and language acquisition;
b. access to appropriate testing, evaluation for co-multiples with developmental delays and/or behaviour problems; and
c. access to additional support to enable appropriate schooling for multiples with developmental delays and/or behaviour problems.

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H. Twins and higher order multiples are the subjects of misconceptions and media exploitation which depict multiples as stereotypes.

Therefore, public education, with emphasis on the training of professional health and family service providers, and educators, is needed to dispel mythology and disseminate the facts of multiple births and the developmental processes in twins and higher order multiples.

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I. Twins and higher order multiples suffer discrimination due to public ignorance about their biological makeup and inflexible policies which fail to accommodate their unique needs.

Therefore, twins and higher order multiples need:

a. information and education about the biology of twinning; and
b. health care, education, counselling and flexible public policies which address their unique developmental norms, individuation processes and relationships. For example, by permitting and/or fostering:

- the treatment of medically fragile co-multiples in the same hospital;
- the neonatal placement together (co-bedding where permissible), to extend the benefits of their fetal position together;
- medical, developmental and educational assessment and treatment which is respectful of the relationship between co-multiples;
- avoidance of staggered hospital discharge of co-multiples whenever possible;
- the annual review of the classroom placement of co-multiples, and facilitation of their co-placement or separate placement according to the particular needs and considerations of the multiple birth children and their family;
- the ability to pursue their own and unique interests including simultaneously participating on sports teams and in other group activities and/or to pursue individual sports, groups or hobby interests;
- specialised grief counselling for multiples at the time of the death of a co-multiple, and at future times in their lives; and
- counselling services addressing the unique needs of adult multiples.

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J. The participation of multiple birth infants, children and adults in research projects has made significant contributions to the scientific understanding of the heritability of diseases, personality variables and the relative influences of nature and nurture on human development. However, there is still much to learn about the unique developmental patterns of multiples.

Therefore, scientists and medical professionals must be encouraged to investigate:

a. norms for developmental processes which are affected by multiple birth such as individuation, socialisation and language acquisition;
b. benchmarks of healthy psychological development, and relevant therapeutic interventions for multiples of all ages and in the event of the death of a co-multiple;
c. strategies and interventions that are effective in promoting the health of multiple birth families during the parenting period such as breastfeeding, employment policies, and prevention of postpartum mood disorders;
d. management of ethical issues by health professionals and multiple birth families such as assisted reproduction, and multifetal and selective pregnancy reduction; and
e. medical, developmental and educational assessment/treatment that is respectful of the relationships between co-multiples.

Multiple Birth Resources

See the supplementary document

History of adoption

Update adopted by the International Council of Multiple Birth Organisations (ICOMBO) at the 2020 business meeting, held online, 10 October 2020

Monica Rankin, Chair, International Council of Multiple Birth Organisations (ICOMBO)

Endorsed by the board of the International Society for Twin Studies, November 2020 (Jeff Craig, President)

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Canada
Multiple Births Canada (MBC) – Ruth Morton, Frances Keech
Toronto Parents of Multiple Births Association (TPOMBA) – Kassandra Kaminskas

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Japanese Multiple Birth Association (JAMBA) – Takafumi Matsuba, Oti Hiromi

Netherlands
TAPS Foundation – Stephanie Ernst-Milner

New Zealand
Multiples NZ – Heather Ben, Kirsty Saxon

Norway
Tvillingforeldreforeningen – Ragnhild Hartviksen, Anette Haugen

Rwanda
Rwandan Twins Family – Pascal Niyomuremyi

Trinidad & Tobago
Trinidad & Tobago Multiple Birth Association – Sharlene Gittens

United Kingdom
Elizabeth Bryan Multiple Birth Centre (EBMBC) – Jane Denton
Multiple Births Foundation (MBF) – Jane Denton
Twins Trust (formerly Tamba) – Keith Reed

USA
Multiples of America (MOA, formerly NOMOTC) – Amy Bredermeyer, Terri Gillis,
Twinless Twins Support Group International (TTSGI) – Judith Olson

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

Kimberley Weatherall, Chair, International Council of Multiple Birth Organisations (ICOMBO)

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

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Denmark
Nordic Twinnet – Abelone Glahn

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Finnish Triplet Organisation – Marie Kaihovaara

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Japanese Multiple Birth Association (JAMBA) – Teniko Tanka
Japanese Association of Twin Mothers (JATM) – Yoko Sugiuna

SwItzerland
Association Jumeaux – Sabine Herbener

USA
The Center for the Study of Multiple Births – Donald Keith, Louis Keith

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

Mary Adcock, Chair, Council of Multiple Birth Organisations (COMBO)

Endorsed by the board of International Society for Twin Studies, June 2007 (Jaakko Kaprio, President)

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Sweden
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Association Jumeaux – Sabine Herbener

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

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Mothers of Super Twins (MOST)
National Organisation of Mothers of Twins Clubs (NOMOTC) – Mary Adcock, Dr Susan Griffith, Tiffany Wimberley, Misty Fry
The Center for Loss and Grief in Multiple Births (CLIMB) – Joan Kollantai

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Adopted by the Council of Multiple Birth Organisations (COMBO) at the 8th International Congress on Twin Studies, Richmond, Virginia – 31 May 1995

Patricia Malmstrom, Chair, Council of Multiple Birth Organisations (COMBO)

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

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The Center for Loss and Grief in Multiple Births (CLIMB) – Joan Kollantai
The Center for Study in Multiple Birth (CSMB) – Donald Keith
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