NEWS, VIEWS AND COMMENTS

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

adopted by the Council of Multiple Birth Organizations of the International Society for Twin Studies May 1995

Introduction: The mission of the Council of Multiple Birth Organizations (COMBO) of the International Society for Twin Studies is to promote awareness of the special 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 special 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 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. Couples planning their families and/or seeking infertility treatment have a right to information and education about factors which influence the conception of multiples, the associated pregnancy risks and treatments, and facts regarding parenting multiples.

WHEREAS the zygosity of same sex multiples cannot be reliably determined by their appearance; 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 and organ donors of choice for their co-multiples; and 4) the availability of the placenta and optimal conditions for determining zygosity are present at birth:

Ш.

- A) Parents have a right to expect accurate recording of placentation and the diagnosis of the zygosity of same sex multiples at birth.
- B) Older, same sex multiples of undetermined zygosity have a right to testing to ascertain their zygosity.

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

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

V.

- A) Multiple births and deaths must be accurately recorded.
- B) Parents and multiples have a right to care by professions who are knowledgeable regarding the management of multiple gestation and/or the lifelong special needs of multiples.

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 and custody agreements.

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 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.

WHEREAS twins and higher order births are at high risk of low birth weight (< 2500 grams), and very low birth weight (< 1500 grams), disability, and infant death:

- I. Women who are expecting multiples have a need for:
 - A) education regarding the prevention and symptoms of pre-term labor,
 - B) prenatal resources and care designed to avert the pre-term birth of multiples, including:
 - diagnosis of multiple pregnancy, ideally by the fifth month, which is communicated tactfully, with respect for the privacy of the parents;
 - nutrition counseling and dietary resources to support a weight gain of 18-27 kilos (40-60 pounds);
 - obstetrical care which follows protocols of best practice for multiple birth;

and when the health of the mother or family circumstances warrant:

- 4. extended work leave;
- 5. bed rest support; and



6. child care for siblings.

(See References, Section I).

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

- II. Families expecting and rearing multiples need the following:
 - A) education regarding the nutritional, 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 bottle 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 II).

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

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

(See References, Section III).

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

IV. 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 comultiples; and
- B) policies which facilitate appropriate mourning of a deceased multiple or multiples.

(See References, Section IV).

WHEREAS the unassisted care of newborn, infant, and toddler multiples elevates their families' risk of illness, substance abuse, child abuse, spouse abuse, divorce, and potential for child abuse:

V. 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 the care of siblings;
- E) facilitate child safety;
- F) facilitate transportation; and
- G) facilitate pediatric care.

(See References, Section V).

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:

VI. 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 comultiples with developmental delays and/or behavior problems.

(See References, Section VI).

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

VII: 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 VII).

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

VIII. 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:
- the treatment of medically fragile co-multiples in the same hospital:
- the neonatal placement together of co-multiples in isolettes and cribs to extend the benefits of their fetal position together;
- medical, developmental, and educational assessment and treatment which is respectful of the relationship between comultiples;
- 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 each set of co-multiples;
- the simultaneous participation of co-multiples on sports teams and other group activities;
- specialized grief counseling for multiples at the death of a comultiple;
- counseling services addressing the special 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:

IX: 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.

Adopted by the Council of Multiple Birth Organizations (COMBO) (comprised of representatives of 16 organizations from ten countries: Australia, Belgium, Canada, Germany, Indonesia, Japan, Sweden, Taipei, United Kingdom, United States) 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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STATEMENT OF NEEDS

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Section IV: Loss

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Translations in Dutch, French, German and Italian are available on request from the underneath

Submit text for the section NEWS, VIEWS AND COMMENTS directly to: Jacob F. Orlebeke, Vrije Universiteit, Dept. of Physiological Psychology, De Boelelaan 1111, 1081 HV Amsterdam, The Netherlands. Email: JF.Orlebeke@psy.vu.nl.

The editor invites organizations of multiples and parents of multiples to submit a brief summary (max about 300 words, to be sent directly to Jacob F. Orlebeke) containing information about goals, activities, size, telephone, fax, e-mail, and if possible web location and address, as well as names of persons to whom correspondence should be addressed. A summary of these organizations will be published in forthcoming issues of the



Book review

Guidelines for Professionals

E. Bryan, J. Denton, F. Hallet, 1 Facts about multiple births (22 pp); 2 Multiple pregnancy (58 pp); 3 Bereavement (42 pp): Multiple Births Foundation: London. ISBN Nos. 1. 1902068025 £7.99; 2. 1902068033 £2.99. 3; 1902068017 £5.99 to be published: Spring 1998.

In his foreword to the classic The Placenta in Twin Pregnancy, by SJ Strong & G Corney, J Chassar Moir wrote 'It is a curious fact that a happening so remarkable as the occurrence of a twin pregnancy should, hitherto, have attracted but little serious attention from obstetricians'. Regretfully, this statement remains valid today and may be extended to other professionals as well. The three booklets, published by the MBF and supported by the European Commission, aim at filling the gap in the special care of multiples with quickly produced and easily accessible information.

Facts about Multiple Births provides basic knowledge about the types of twins, the cause of twinning, the placentation, the reasons for and methods of determining zygosity, the prevalence rates and some obstetrical and perinatal statistics. As in the other booklets, key references allow the reader to study the different topics in depth. The booklets end with a glossary of terms.

The cover of Multiple Pregnancy mentions 'Recommendations covering specific medical problems as well as the emotional, social and practical issues associated with a multiple pregnancy (including labour and delivery) and the postnatal care of the mother and babies. The guide does not include the clinical management of a multiple pregnancy as this information is more appropriately covered bv other sources'. The different aspects of carediagnosis, monitoring the pregnancy (ultrasound, prenatal screening, congenital anomalies, selective foetocide, foetofoetal transfusion syndrome, single intrauterine death), antenatal care, preparation for parenting, feeding, labour and delivery, postnatal care-are summarised in an easily accessible way: issues on one page and response recommendations on the opposite

People's attitudes towards parents having lost a twin, triplet or more, are

often inappropriate if not, frankly, out of place. Insensitive remarks such as 'How would you have coped with two?' or 'You've still got one lovely baby' are extremely offensive and hurtful. The senior author of the booklet 'Bereavement' has many years of experience in the counselling of parents who are struggling to cope with the loss of one or more multiple. In Bereavement, issues and recommendations are handled on facing pages as in the booklet on multiple pregnancy. The recommendations testify to the experience and sensitivity of the paediatrician who has developed an intimate understanding of bereaved parents of multiples.

The three booklets are fine basic references for people interested in, or in charge of, multiple pregnancies. The booklets should be readily available in antenatal clinics, maternity hospitals, children's daycare centres, social institutions, and are highly recommended to every women carrying multiples. It is hoped that the booklets, currently published in English, will be rapidly translated into most world languages.

Robert Derom

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Interesting new publications

Multiple Births Organisations Worldwide. Multiple Birth Foundation, 1997.

Wright L. Twins: Genes, Environment and the Mystery of Identity. London: Weidenfeld & Nicolson, 1997.

Cooper C. Twins and Multiple Births. The essential parenting guide, from pregnancy to adulthood. London:Vermilion, 1997.

Forthcoming:

Landau E. Multiple Births (First Book). New York: Franklin Watts, 1998 (a book for children aged 9–12 years).

Announcements

- First International Workshop on Genetic Epidemiology of Complex Traits using Twins and Sib-Pairs. Cambridge, 26–27 March 1998. Information available on Internet-location: http://www.umds.ac.uk/twin-unit/ workshop.htm.
- Conference of the International Society for Twin Studies (ISTS).

Helsinki, 4–6 June 1998. Deadline for submitting abstracts (posters and oral presentations) is 31 March 1998. Details about abstract requirements and address for submission can be obtained from web-site http://kate.pc.helsinki.fi/twin/ists.html.

Main topics areas: Design and analysis of twin studies, management of twin pregnancies, foetal programming, cardiovascular disease and twins, biology and genetics of twinning, psychopathology, sleep disorders, neurological diseases, asthma and allergy, (abnormal) child development, substance abuse, health related behaviour (smoking, drinking etc), parents of twins, twin and higher multiple (parents) clubs.

NB! The ISTS conference takes place immediately preceding the

• 1998 Annual Meeting of the Behavior Genetics Association (BGA). Stockholm, 8–10 June 1998. Deadline for submitting abstracts and suggestions for symposia is 9 February 1998. Abstracts should be sent to Dr Norm Henderson, by e-mail to bgaabs98@bga.bga.org. NB! The BGA conference takes place immediately after the ISTS conference in Helsinki.

BGA conference in Stockholm.

 Statistics and methods for twin and family studies: Tenth International Workshop on Methodology of Twin and Family Studies. Boulder, Colorado, first week of March 1998. Mx-site: http:/ /views.vcu.edu/mx.

This course is intended to be introductory. Advanced courses are planned for 1999, 2001 and 2003 in Boulder and in September 1998 in Leuven, Belgium. For the latter workshop, information can be obtained from hmaes @ruby.vcu.edu or ruth.loos@med.kuleuven.ac.be

Application forms for the March 1998 course in Boulder can be printed from: http://ibgwww.colorado.edu/twin98/

registration.html. A provisional schedule is available at http://ibgwww.colorado.edu/twins98/schedule.html.