RESEARCH REPORT #106

National Organization of Mothers Of Twins Clubs, Inc.

SUBJECT: **Incidence of Congenital Defects in Multiple Births and Use of Fertility Drugs**

RESEARCHER: National Organization of Mothers of Twins Clubs, Inc.

DATE: September 2010 – June 2011

PURPOSE: To gather information on prevalence of birth defects and types in multiple births.

METHOD: A survey consisting of 16 questions was made available online via Survey Monkey. The survey was to be completed by a parent of multiple birth children.

BACKGROUND INFORMATION / RESULTS

There were 378 responses to the survey.

1. Zygosity of multiples:
   a. Monozygotic (identical) 17% (66)
   b. Dizygotic (fraternal) 77% (292)
   c. Unknown 3% (10)
   d. Higher order 3% (10) – all triplets

2. Were the multiples born prematurely?
   a. Yes 65.5% (246)
   b. No 34% (130)
   c. Unknown .005% (2)

3. Gestational age of multiples:
   a. 37 weeks and above 31% (119)
   b. 36-37 weeks 19% (73)
   c. 35-36 12% (45)
   d. 34-35 13% (48)
   e. 33-34 5% (19)
   f. 32-33 6% (21)
   g. 31-32 3% (10)
   h. 30-31 2% (8)
   i. 28-30 4% (17)
   j. 27 weeks or less 3% (10)
   k. Outliers: one at 20 weeks, one at 41 weeks
   l. Blanks – 5

4. Interval between births: majority in minutes; two 3 days; one a week.

5. Age of mother at birth of multiples:
    a. Under 20 years 0
    b. 20-30 9% (33)
    c. 31-35 41% (153)
    d. 36-40 19% (70)
    e. over 40 6% (21)

6. Were fertility treatments used in the multiple pregnancy?
    a. Yes 63% (239)
    b. No 37% (138)

7. Types of fertility treatments used:
    a. Drugs used to stimulate ovulation 32% (121)
    b. Artificial insemination 12% (45)
    c. IVF (In Vitro Fertilization) 37% (141)
    d. GIFT (Gamete Intra-Fallopian Transfer) 0.3% (1)
    e. PROST (PRO-nuclear Stage Tubal Transfer) 0
    f. TET (Tubal Embryo Transfer) 0
    g. ZIFT (Zygote Intra-Fallopian Transfer) 0
    h. ICSI (Intra-Cytoplasmic Sperm Injection) 17% (65)
    i. IUI (intrauterine insemination) 1% (5)
    j. Other fertility treatments: donor eggs: (8), Frozen embryo transfer: (8)

8. Were one or more of the multiples diagnosed with a congenital defect?
    a. Yes 15% (56)
    b. No 85% (320)

9. Congenital defect for :
    a. only one of the multiples 76% (41)
    b. two multiples 24% (13)
    c. triplet (2 out of 3 of the multiples) for one triplet pregnancy

10. When defect discovered:
    a. In utero 22% (14)
    b. At birth 34% (22)
    c. Within first 6 weeks 23% (15)
    d. 2 months 2%(1)
    e. 3 months 2% (1)
    f. 4 months 2% (1)
    g. 5 months 2% (1)
    h. 7 months 2% (1)
    i. 9 months 2% (1)
    j. 10 months 2% (1)
    k. 2 yrs 6% (4)
    l. 3 yrs 2% (1)
    m. 5 yrs 2% (1)

11. What was the defect? 56 responses.

a. Heart defects - 113
    i. Non specified heart defect (1)
    ii. Anomalous L superior vena cava (1)
    iii. Aortic stenosis (3)
    iv. Atrial septal defect (9)
    v. Atrial tachycardia (1)
    vi. Bicuspid aortic valve (1)
    vii. Coarctation of the aorta (1)
    viii. Hypoplastic L heart syndrome (1)
    ix. Left ventricular non compaction cardiomyopathy (1)
    x. PDA – patent ductus arteriosis (8)
    xi. Patent foramen ovale (3)
    xii. Pulmonary atresia (1)
    xiii. Pulmonary stenosis (4)
    xiv. Tetralogy of Fallot (1)
    xv. Transposition of great arteries (3)
    xvi. Tricuspid atresia (2)
    xvii. Truncus arteriosus (1)
    xviii. Ventricular Septal Defect (10)
    xix. Wolff Parkinson White Syndrome (1)

b. Lung defects - 1
    i. Pulmonary agenesis (1)

c. GI disorders - 5
    i. Diaphragmatic hernia
    ii. Esophageal Atresia/Trachio Esophageal Fistula
    iii. Eventration of the L diaphragm
    iv. Microgastria
    v. Pyloric stenosis

d. Skeletal/skin - 19
    i. Arthrogryposis (2)
    ii. Beckwith-Wiedemann Syndrome (3)
    iii. Cleft palate (3)
    iv. Club foot (3)
    v. Craniosynostosis
    vi. Dermoid cyst
    vii. Hemangioma
    viii. Polydactyly – extra digit on hand
    ix. Preauricular ear tag
    x. Symbrachidactyly (small or missing fingers)
    xi. Syndactyly (webbed digits) (2)

e. GU - 5
    i. Duplicated ureter, ureterocele

ii. Hypospadius (3)
iii. Vesicoureteral reflux

f. EYE - 3
   i. Abnormal optic nerve
   ii. Congenital cataract
   iii. Duane's Syndrome eye movement disorder

g. OTHER - 8
   i. Autism (3)
   ii. Charcot Marie Tooth nerve disorder
   iii. Trisomy 21 - Down syndrome
   iv. Goldenhar syndrome (oculo-auricular-vertebral syndrome)
   v. Hypothyroidism
   vi. Trisomy 16

12. How the congenital defect was discovered.

a. Ultrasound	26% (14)
b. While hospitalized	30% (16)
c. Physician discovered a sign or symptom	21% (11)
d. Medical screening	6% (3)
e. Regular check-up (well-child visit)	9% (5)
f. Parent noticed	6% (3)
g. Early intervention	2% (1)
h. No answer	6% (3)

13. Are you currently a member of NOMOTC?

a. Yes	75% (279)
b. No	25% (91)
c. No answer	8

CONCLUSIONS:

1. There were a total of 378 responses. Most of respondents had fraternal (dizygotic) twins. There were ten sets of triplets. The majority were premature, although 31% were 37 weeks or above, considered full term.
2. Most of the mothers were between the ages of 31-40. There were none < 20 years.
3. A majority used some type of fertility treatment (63%). The most common was IVF (37%) and the second most common was drugs to stimulate ovulation (32%). Next was some type of artificial insemination (12%) including ICSI (intra-cytoplasmic sperm injection) (17%) and IUI (intra-uterine injection) (1%).
4. 85% of respondents had a multiple with one or more birth defects. 24% of them had both multiples affected.
5. Most of the time the defect was discovered at birth (34%), while nearly equal amounts were found in utero (22%) or in the first 6 weeks (23%). Very few were discovered after age 1, with one having the defect discovered at age 5.

6. 56 responded with the type of defect for each of their multiples (112 incidences), but interestingly named 166 different birth defects, indicating that many had more than one defect.
7. The most common birth defect was a heart defect (113 incidences), which numbered 68% of all defects. The most common heart defect mentioned was some type of hole in the heart (VSD, ASD, PFO) at 22.
8. The next most common body system affected was the skeletal/skin system, followed by GI/GU system, eye and lung. There were 8 in the "other" category, including Trisomy 18 and 21, Autism, Charcot Marie Tooth disorder, Goldenhar syndrome, and Hypothyroidism.
9. When asked how the defect was discovered, most indicated it happened while hospitalized (30%), while 26% were noted at birth. 21% indicated that a physician discovered a symptom or issue. Fewer (9%) were found at a well-child visit, and in 6% it was the mother who noticed something was wrong. One was found during early intervention.
10. 75% of the respondents belonged to a club that was a member of NOMOTC.