

1998 CDH Research Survey Results



The following information was taken from our parent worksheets (also known as membership forms) sent in by July 25, 1998. This year instead of writing a long explanation of the data, I thought charts would be easier to read and understand. However, I highlighted a few things. One thing that really jumped out at me, though it is not of significant medical research importance, is that most parents do not know what type of CDH their child has. Knowing what type of hernia your child has helps you to know more about the position of the defect, the organs involved, and the "average" chance of survival. Also, the rate of undetected CDH in utero is still drastically high considering modern ultrasound technology. A few things that we did not include in the charts: we have 4 members who are fraternal twins (their twins are healthy), we did not include detailed family medical histories like we did last year because of the lack of information on the worksheets, and most of our cherubs are "only children" or the eldest child in their families - I'm still trying to figure out if this has any significance.



Parental Satisfaction With Medical Care



Do you feel that the hospital staff that cared for your child informed and involved you in decisions regarding your child's health care?

Yes- 60 (58.25%) Survivors, 19 (45.24%) Non-Survivors

No- 16 Survivors, 4 Non-Survivors

Unanswered- 59 Survivors, 19 Non-Survivors




Do you feel that you were given enough information about your child's diagnosis?

Yes- 47 (45.63%) Survivors, 16 (38.1%) Non-Survivors

No- 26 Survivors, 11 Non-Survivors

Unanswered- 30 Survivors, 15 Non-Survivors

 Did your child's doctor explain this information to you in terms that you could understand?

Yes- 70 (67.96%) Survivors, 22 (52.38%) Non-Survivors

No- 10 Survivors, 4 Non-Survivors

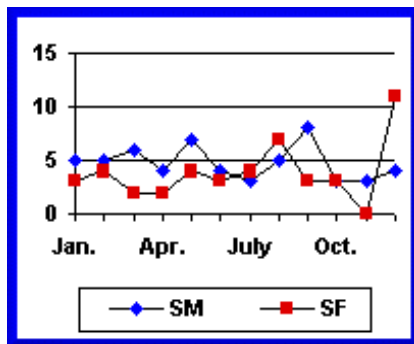
Unanswered- 23 Survivors, 16 Non-Survivors



Seasonal Charts

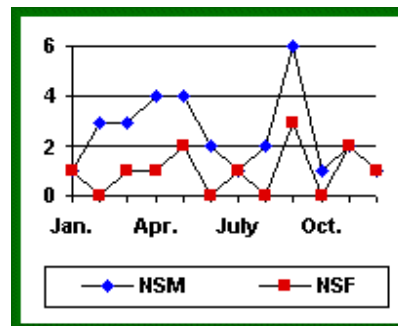
The following information was taken from Parent Worksheets. It is based on birth month and gestational age at the time of birth. Of our members yet to be born- 1 female each is due in the following months; July and November- 1 male each is due in; February, March, July, September, and October. We are looking for common months, that would show us temperature increases, holiday stresses, and seasonal viruses that would show us common factors.

Survivors Birth Months

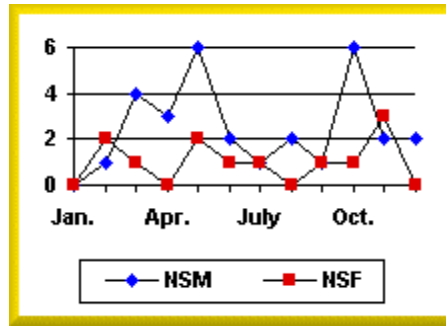
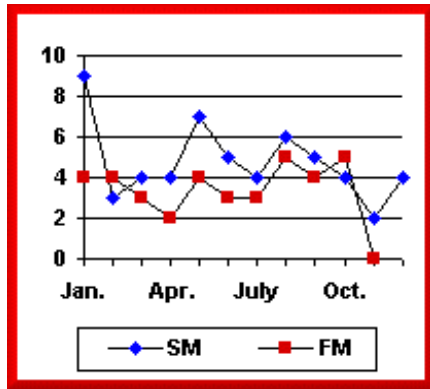


Due Dates of Survivors

Non-Survivors Birth Months



Due Date of Non-Survivors



(KEY: SM-Surviving Males, SF-Surviving Females, NSM- Non-Surviving Males, NSF- Non-Surviving Females, MD-Males Due, FD-Females Due)



Worksheet Data

Number (percentage of total in that category)

TOTALS

| SURVIVORS | | | NONSURVIVORS | | | DUE | TOTALS | | |
|---------------|---------------|-------------|---------------|---------------|---------------|----------|---------------|---------------|-----------|
| Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
| 67 (55.34) | 46 (44.66) | 103 (67.76) | 30 (71.43) | 12 (28.57) | 42 (27.63) | 7 (4.61) | 92 (60.53) | 60 (39.47) | 152 (100) |

Side of Diaphragmatic Hernia

| | SURVIVORS | NONSURVIVORS | DUE | TOTALS |
|--|-----------|--------------|-----|--------|
| | | | | |

| | Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
|-------------|---------------|---------------|---------------|----------|--------------|---------------|--------------|---------------|---------------|----------------|
| Left-Sided | 45 (78.95) | 33 (71.74) | 78 (75.73) | 21 (70) | 8 (66.67) | 29 (69.05) | 5 (71.43) | 69 (75) | 43 (71.67) | 112 (73.68) |
| Right-Sided | 11 (19.3) | 8 (17.39) | 19 (18.45) | 6 (20) | 4 (33.33) | 10 (23.81) | 0 | 17 (18.48) | 12 (20) | 29 (19.08) |
| Bilateral | 1 (1.75) | 4 (8.7) | 5 (4.85) | 2 (6.67) | 0 | 2 (4.76) | 0 | 3 (3.26) | 4 (6.67) | 7 (4.61) |
| Unanswered | 0 | 1 (2.17) | 1 (0.97) | 1 (3.33) | 0 | 1 (2.38) | 2 (28.57) | 3 (3.26) | 1 (1.67) | 4 (2.63) |

Type of Diaphragmatic Hernia

| | SURVIVORS | | | NONSURVIVORS | | | DUE | TOTALS | | |
|---|---------------|---------------|---------------|---------------|---------------|---------------|--------------|---------------|-------------|----------------|
| | Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
| Bochdalek/ Posterolateral | 14 (24.56) | 8 (17.39) | 22 (21.36) | 5 (16.67) | 0 | 5 (11.9) | 2 (28.57) | 20 (21.74) | 9 (15) | 29 (19.08) |
| Morgagni | 1 (1.75) | 3 (6.52) | 4 (3.88) | 0 | 0 | 0 | 0 | 1 (1.09) | 3 (5) | 4 (2.63) |
| Agenesis of the Hemi- Diaphragm | 4 (7.02) | 0 | 4 (3.88) | 2 (6.67) | 2 (16.67) | 4 (9.52) | 0 | 6 (6.52) | 2 (3.33) | 8 (5.26) |
| Complete Agenesis of the Diaphragm | 1 (1.75) | 1 (2.17) | 2 (1.94) | 0 | 0 | 0 | 0 | 1 (1.09) | 1 (1.67) | 2 (1.32) |
| Unanswered | 37 (64.91) | 34 (73.91) | 71 (68.93) | 23 (76.67) | 10 (83.33) | 33 (78.57) | 5 (71.43) | 64 (69.57) | 45 (75) | 109 (71.71) |

Parental Ages (in years)

| | SURVIVORS | | | NONSURVIVORS | | | DUE | TOTALS | | |
|----------------------|-----------|--------|-------|--------------|--------|-------|-------|--------|--------|-------|
| | Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
| Average Mother's Age | 29.43 | 29.37 | 29.4 | 25.5 | 27.42 | 26.11 | 27.5 | 28.1 | 28.9 | 28.4 |
| Average Father's Age | 31.5 | 31.87 | 31.65 | 30.81 | 32 | 31.18 | 28.83 | 31.13 | 31.87 | 31.4 |

Pregnancy Complications

| | SURVIVORS | | | NONSURVIVORS | | | DUE | TOTALS | | |
|----------------|---------------|--------------------|---------------|---------------|--------------|---------------|-------|---------------|--------------|---------------|
| | Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
| Polyhydramnios | 14 (24.56) | 3 (6.52) (16.5) | 17 (16.5) | 10 (33.33) | 5 (41.67) | 15 (35.71) | 0 | 24 (26.09) | 8 (13.33) | 32 (21.05) |
| Other | 5 (8.77) | 6 (13.04) | 11 (10.68) | 4 (13.33) | 3 (25) | 7 (16.67) | 0 | 9 (9.78) | 9 (15) | 18 (11.84) |

Diagnosis

| | SURVIVORS | | | NONSURVIVORS | | | DUE | TOTALS | | |
|--------------------|---------------|---------------|---------------|---------------|--------------|---------------|------------|---------------|---------------|----------------|
| | Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
| Ultrasound Done | 51 (89.47) | 42 (91.3) | 93 (90.29) | 27 (90) | 12 (100) | 39 (92.88) | 7 (100) | 83 (90.22) | 56 (93.33) | 139 (91.45) |
| Diagnosed In Utero | 23 (40.35) | 13 (28.26) | 36 (34.95) | 11 (36.67) | 6 (50) | 17 (40.48) | 7 (100) | 39 (42.39) | 21 (35) | 60 (39.47) |
| Diagnosed in 24hrs | 31 (54.39) | 30 (65.22) | 61 (59.22) | 16 (53.33) | 5 (41.67) | 21 (50) | 0 | 47 (51.08) | 35 (58.33) | 82 (53.95) |

| | | | | | | | | | | |
|----------------|----------|----------|----------|--------|----------|----------|---|----------|----------|----------|
| Late Diagnosis | 0 | 2 (4.35) | 2 (1.94) | 0 | 0 | 0 | 0 | 0 | 2 (3.33) | 2 (1.32) |
| Unanswered | 3 (5.26) | 1 (2.17) | 4 (3.88) | 3 (10) | 1 (8.33) | 4 (9.52) | 0 | 6 (6.52) | 2 (3.33) | 8 (5.26) |

Birth History

| . | SURVIVORS | | | NONSURVIVORS | | | TOTALS | | |
|----------------------------------|---------------|---------------|---------------|---------------|--------------|---------------|---------------|---------------|---------------|
| | Male | Female | Total | Male | Female | Total | Male | Female | Total |
| Vaginal | 31 (54.39) | 27 (58.7) | 58 (56.31) | 13 (43.33) | 8 (66.67) | 21 (50) | 44 (50.57) | 35 (60.34) | 79 (54.48) |
| Cesarean Section | 19 (33.33) | 13 (28.26) | 32 (31.07) | 9 (30) | 3 (25) | 12 (28.57) | 28 (32.18) | 16 (27.59) | 44 (30.34) |
| Unanswered | 7 (12.28) | 6 (13.04) | 13 (12.62) | 8 (2.67) | 1 (8.33) | 9 (21.43) | 15 (17.24) | 7 (12.07) | 22 (15.17) |
| Average Birth Weight | 7lbs 2oz | 6lbs 12oz | 6lbs 15oz | 6lbs 7.5oz | 6lbs 9oz | 6lbs 8oz | 7lbs | 6lbs 11oz | 6lbs 13oz |
| Premature | 16 (28.07) | 10 (12.74) | 26 (25.24) | 9 (30) | 5 (41.67) | 14 (33.33) | 25 (27.17) | 15 (25) | 40 (26.32) |
| Average Gestational Age at Birth | 38.13w | 38.54w | 38.32w | 38w | 37.23w | 37.78w | 38.09w | 38.29w | 38.17w |

Medical Procedures

| . | SURVIVORS | | | NONSURVIVORS | | | TOTALS | | |
|------|---------------|--------------|---------------|---------------|--------------|---------------|---------------|---------------|---------------|
| | Male | Female | Total | Male | Female | Total | Male | Female | Total |
| ECMO | 28 (49.12) | 19 (41.3) | 47 (45.63) | 10 (33.33) | 5 (41.67) | 15 (35.71) | 38 (43.68) | 24 (41.38) | 62 (42.76) |

| | | | | | | | | | |
|-------------------------|--------------|----------|----------|----------|----------|----------|---------|---------|--------------|
| Nitric Oxide | 6 (10.53) | 3 (6.52) | 9 (8.74) | 2 (6.67) | 1 (8.33) | 3 (7.14) | 8 (9.2) | 4 (6.9) | 12 (8.28) |
| Average Ventilator Time | 27.7d | 24.9d | 26.2 | --- | --- | --- | 27.7d | 24.9d | 26.2d |
| Average Oxygen Time | 36.7d | 31.1d | 32.1 | --- | --- | --- | 36.7d | 31.1d | 32.1d |

Type of CDH Repair

| | SURVIVORS | | | NONSURVIVORS | | | TOTALS | | |
|------------------|---------------|---------------|---------------|---------------|--------------|---------------|---------------|---------------|---------------|
| | Male | Female | Total | Male | Female | Total | Male | Female | Total |
| Total Repairs | 66 | 47 | 113 | 11 | 7 | 18 | 77 | 54 | 131 |
| Synthetic Patch | 21 (31.82) | 18 (38.3) | 39 (34.51) | 4 (36.36) | 2 (28.57) | 6 (33.33) | 25 (32.47) | 20 (37.04) | 45 (37.04) |
| Tissue/Muscle | 3 (4.55) | 1 (2.13) | 4 (3.54) | 0 | 0 | 0 | 3 (3.9) | 1 (1.85) | 4 (1.85) |
| Sutures | 2 (3.03) | 3 (6.38) | 5 (4.42) | 0 | 0 | 0 | 2 (2.6) | 3 (5.56) | 5 (5.56) |
| Unknown Material | 40 (60.61) | 25 (53.19) | 65 (57.52) | 7 (63.67) | 5 (71.43) | 12 (66.67) | 47 (61.04) | 30 (55.56) | 77 (55.56) |
| Multiple Repairs | 9 (15.79) | 8 (17.39) | 17 (16.5) | 1 (3.33) | 0 | 1 (2.38) | 10 (11.49) | 8 (13.79) | 18 (12.41) |
| No Repair | 0 | 0 | 0 | 6 (20) | 3 (25) | 9 (21.43) | 6 (6.9) | 3 (5.17) | 9 (6.21) |
| 1 Repair | 41 (71.93) | 31 (67.39) | 72 (69.9) | 9 (30) | 7 (58.33) | 16 (38.1) | 50 (57.47) | 38 (65.52) | 88 (60.69) |
| Unanswered | 7 (12.28) | 7 (15.22) | 14 (46.67) | 14 (46.67) | 2 (16.67) | 16 (38.1) | 21 (24.14) | 9 (15.52) | 30 (20.69) |

Associated Anomalies

| | SURVIVORS | | | NONSURVIVORS | | | TOTALS | | |
|---------------------------|---------------|---------------|---------------|---------------|--------------|---------------|---------------|---------------|---------------|
| | Male | Female | Total | Male | Female | Total | Male | Female | Total |
| Multiple | 23 (40.35) | 16 (34.78) | 39 (37.86) | 7 (23.33) | 4 (33.33) | 11 (26.19) | 30 (34.48) | 20 (34.48) | 50 (34.48) |
| Non-Chromosomal Syndromes | 1 (1.75) | 0 | 1 (0.97) | 1 (3.33) | 2 (16.67) | 3 (7.14) | 2 (2.3) | 2 (3.45) | 4 (2.76) |
| Chromosomal Anomalies | 1 (1.75) | 0 | 1 (0.97) | 0 | 0 | 0 | 1 (1.15) | 0 | 1 (0.69) |
| Trisomies | 1 (1.75) | 1 (2.17) | 2 (1.94) | 0 | 0 | 0 | 1 (1.15) | 1 (1.72) | 2 (1.38) |
| Unanswered/ None | 34 (60.65) | 30 (65.22) | 64 (62.14) | 23 (76.67) | 8 (66.67) | 31 (73.81) | 57 (65.52) | 38 (65.52) | 95 (65.52) |

Family History of CDH

| SURVIVORS | | | NONSURVIVORS | | | DUE | TOTALS | | |
|-------------|-------------|-------------|--------------|-------------|-------------|-------|------------|---------|-------------|
| Male | Female | Total | Male | Female | Total | Total | Male | Female | Total |
| 2 (3.51) | 3 (6.52) | 5 (4.85) | 2 (6.67) | 1 (8.33) | 3 (7.14) | N/A | 4 (4.6) | 4 (6.9) | 8 (5.52) |

Average Hospital Stay

| SURVIVORS | | |
|-----------|--------|-------|
| Male | Female | Total |
| 98.94d | 64.39d | 83.1d |

KEY: Avg.- Average, N/A- Non-Applicable. Number (Percentage of Total in that category)



| | | |
|--|---|---|
| <p><u>Complications</u> (In 43 of 145 cases)</p> <p>Feeding Problems -65 Developmental Delay-40 Oxygen Dependency-32 Pneumonia-10 Vent dependency-9 Reflux-7 Pulmonary Hypertension-6 Blood Infections-4 Cerebral Palsy-4 "Infections"-4 Nephritis -4 RSV-4 Staph infection-4 Scoliosis -4 Bowel Adhesions-3 Hearing Impairment-3 Kidney Failure-3 Seizures-3 Bed sores-2 Brochopulmonary Dysplasia-2 Hydrocephalus-2 Respiratory Infection-2 Severe Asthma-2 Sight impairment-2 Slow Weight Gain-2 Tracheomalacia-2 ADHD-1</p> | <p>The accuracy of these results depends on the accuracy of the information filled out by parents on the Parent Worksheet. We did not include Hypoplastic Lungs in the Birth Defect list, as the numbers were drastically off, considering it is very rare for CDH patients to have 100% lung capacity. You may notice that some problems are listed in both lists- this is because some of these problems occurred before birth (birth defect), and some after birth (complication). A birth defect is classified as something that is present at the time of birth. A complication is classified as a medical problem bought on by long hospitalizations, medical malpractice, viruses and infections caught during the initial hospitalization, or subsequent problems bought on by effects of hernia repairs, etc. Ventilator and Oxygen Dependency was classified as being on the ventilator or oxygen longer than 6 months.</p> <p>We think the following classifications are vastly inaccurate, as many parents have stated in their stories, letters, e-mails, and phone calls that there children have/had</p> | <p><u>Associated Birth Defects</u> (in 50 of 145 cases)</p> <p>Cleft Palate- 5 Atrial Septal Defect- 4 Undescendend Testicles-4 Bowel Malformation-3 Fryn's Syndrome- 3 Hemi Vertebrae-3 Hypospadias-3 Unspecified Heart Murmur-3 Brain Hemorrhage-2 Bronchomalasia-2 Chest Pectis -2 Hydrocephalus-2 Tracheoesophageal Cleft-2 Abnormal Vertebrae-1 Absence of Anal Canal-1 Agenesis of The Corpus Collusum-1 Atopic Appendix-1 Atopic Spleen-1 Bilateral Phrenic Nerve Agenesis -1 Brain Atrophy-1 Cervical Rib-1 "Chest Raised"-1 Cleft Lip-1 Dextrocardia-1 Dual Collective Kidney-1</p> |
|--|---|---|

| | | |
|--|--|--|
| <ul style="list-style-type: none"> Brain Swelling-1 "Clot in Heart"-1 CryptosporidiumGastritis -1 Esophageal Dialation-1 Gastric Disorder-1 Hemoperitoneum-1 Hiatal Hernia-1 Ileus-1 Internal Hemorrhage-1 Laryngomalacia-1 Lymph Nodes Cut During Repair-1 Mastitis -1 Microcephaly-1 Mild Spastic Diaplegia-1 Occiput Hematoma-1 Pneumothorax-1 Pulmonary Edema-2 Recurrent Otitis Media-1 Retinopathy of Prematurity-1 Severe Allergis -1 "Severe Respiratory Dsorder"-1 Splenic Torsion-1 Stroke-1 Subglottic Edema-1 Traumatic ulcer-1 | <p>these complications and birth defects- but they were not listed on their Parent Worksheets. This is the main reason we have asked our members to redo their Worksheets. Hopefully, by doing so, next year's results will be more accurate. Please refer to your Parent Reference Guides for definitions, and if you have any questions, feel free to contact me. The categories are:</p> <p style="text-align: center;"><u>Complications</u></p> <ul style="list-style-type: none"> Allergies Asthma Blood Infections Developmental Delay Feeding Problems Hydrocephalus Kidney Infections Oxygen Dependency Pneumonia Pulmonary Hypertension Urinary Tract Infections Viruses <p style="text-align: center;"><u>Birth Defects</u></p> <ul style="list-style-type: none"> Chest Pectis Genetic Syndromes Heart Murmurs Hydrocephalus Pulmonary Hypoplasia Scoliosis | <ul style="list-style-type: none"> Easily Dislocated Elbow-1 Femur Fracture-1 High Palate- 1 Hirschsprung's Disease- 1 Horseshoe shaped spleen-1 Inguinal Hernia-1 Malformed Uterus-1 Meta Bone Disease-1 Microcephaly-1 Omphalocele-1 Open Palate-1 Organoaxial Twist-1 Partial Trisomy 22-1 Pericardial Effusion-1 Polysplenia-1 Pulmonary Sequestration-1 Pyloric Stenosis -1 Renal Pelvis-1 Short Bowel Syndrome-1 Small Heart-1 Small Stomach-1 Spina Bifida-1 Spinal Deformity-1 Strabysmus-1 Sunken Sternum-1 Tethered Spinal Cord-1 Tetrology of Fallot-1 Trisomy 14-1 |
|--|--|--|



Congenital Diaphragmatic Hernia Research Survey Results

The following information is taken from our 10-page, detailed, Congenital Diaphragmatic Hernia Research Surveys. These surveys were filled out by members whose children were deceased or over 1 year of age. Not as many surveys were returned as we would like to have had. We could not find any links that affected all of the families surveyed, but we found quite a few of "higher than normal" rates in many categories, including genetic and environmental factors.



Parental Ethnicity

| | | | | | | | | | |
|-------------------|----|-----------------|---|--------------|---|-----------------|---|-----------------|---|
| "American" | 21 | American Indian | 6 | Anglo Saxon | 2 | Puerto Rican | 2 | French Canadian | 1 |
| German | 14 | English | 5 | Asian Indian | 2 | Slavic | 2 | Greek | 1 |
| "White/Caucasian" | 14 | Hungarian | 3 | Canadian | 2 | Czechoslovakian | 1 | Penn. Dutch | 1 |
| Italian | 9 | Polish | 3 | Croatian | 2 | "European" | 1 | Scottish | 1 |
| Irish | 7 | Unanswered | 3 | Danish | 2 | French | 1 | . | . |

Ethnic and Religious categories were included because there are known medical problems associated with certain populations (Jewish- Tay Sachs, African American- Sickle Cell Anemia, etc.) and we want to know if there is an "ethnic link" to CDH. Unfortunately, many of our members simply listed themselves as "American", "White", "Christian", etc- which really does not put them into specific categories. We were also looking for the ethnicity and religion of their ancestors and not necessarily themselves, so that if a parent listed themselves as "white, Jewish" when their ancestors were French Catholics and they themselves converted to Judaism, then this alters the accuracy of our results. Parents of various ethnic groups were categorized in all groups that they listed.



Parental Religious Affiliations

| | | | | | | | |
|-----------------------|----|-------------------|---|--------------|---|-----------------------|---|
| Baptist | 13 | Church of England | 2 | Methodist | 7 | Seventh Day Adventist | 4 |
| Catholic | 23 | Episcopalian | 1 | Mormon | 1 | Southern Baptist | 2 |
| Charismatic Christian | 1 | Hindu | 2 | Presbyterian | 2 | Unanswered | 8 |
| "Christian" | 4 | Lutheran | 3 | Protestant | 6 | . | . |



Parental and Grandparent Occupations

| | | | | | | | | | |
|----------------|----|------------------|----|----------------------|---|----------------|---|-------------|---|
| Homemakers | 45 | Education | 12 | Custodial Work | 5 | Clergy | 3 | Postal Work | 1 |
| Clerical Work | 39 | Factory Work | 11 | Electrician | 4 | Chemistry | 2 | Fireman | 1 |
| Transportation | 19 | Military | 9 | Food Service | 4 | Metal Work | 2 | . | . |
| Construction | 16 | Unanswered | 9 | Security Enforcement | 4 | Cosmetics | 1 | . | . |
| Medical | 16 | Telephone Repair | 6 | Botanical Work | 4 | Airplane Pilot | 1 | . | . |
| Sales | 15 | Management | 5 | Computer Work | 4 | Logging | 1 | . | . |

We studied the occupations of parents and grandparents to learn about levels of stress and environmental exposures on the job. The category of clerical work includes book-keepers, secretaries, bank tellers, office assistants, accountants, office managers, etc.. "Military" includes all branches and all fields of the military. "Metal work" includes welders, tool grinders, etc.. "Transportation" includes car mechanics, body shop workers, train conductors, bus drivers, truckers, etc.. "Construction" includes architects, surveyors, boat builders, woodworkers, engineers, construction workers, (anyone exposed to building materials), etc.. "Medical" includes doctors, nurses, and therapist. "Computer" includes computer operators, computer repair, etc.. "Security Enforcement" includes civilian police, detectives, security guards, lawyers, etc.. "Education" includes school teachers and day care teachers. "Chemistry" includes, chemists, chemical sales, etc.. "Botanical Work" includes plant nursery workers, farmers, etc..



Family Medical Histories

| | | | |
|----------------------------|---------------------|-----------------------------|---------------------|
| Anemia | 3m | Epstein's | 1c |
| Anorexia | 1m, 1u | Fryn's Syndrome | 2s |
| Asthma | 3c, 4gp, 3u, 4a, 6m | Heart Defects | 4gp, 3m, 3u, 3c, 1s |
| Autism | 1s, 1u, 1c | High Blood Pressure | 27gp, 1a, 1u |
| Beta Thalassemia Minor | 1u | Hirschsprung's Disease | 1s |
| Bulimia | 2a | Hypoplastic Nails | 2s |
| Cancer | 22gp, 4a, 3m, 1u | Infertility | 3m |
| Cleft Lip/Palate | 2s, 1a | Lyme's Disease | 2f, 1m |
| CFIDS | 1u | "Multiple Birth Defects" | 2c |
| CDH | 2s, 1a, 2c | Neuropsychiatric Disorders | 1m, 1gp |
| Cornelia de Lange Syndrome | 1c | Osteogenesis Imperfecta | 1u, 1c |
| Diabetes | 1u, 1gp, 1m | Rubella- Menieres Disease | 1m |
| Displaced Anus | 1s | Polynephrosis | 1m |
| Down's Syndrome | 3c | Septated Uterus | 1m |
| Ears, Abnormal | 1s, 1f | Strokes | 12gp, 2m |
| Ectodermal Dysplasia | 1c | Tilted Uterus | 2m |
| Epilepsy | 2a, 1c | Unnamed Chromosomal Anomaly | 1c, 1a |

(KEY: m-mother, f-father, gp-grandparent, s-sibling, a-aunt, u-uncle, c-cousin) We studied the family medical histories to see if there is higher incidence of other birth defects and medical problems in family members. Our members were not included in this chart. As you can see, the incidence of heart defects, asthma, cancer, strokes, high blood pressure, eating disorders, and birth defects in siblings is slightly high in comparison to the general population. Not included in this chart- there are 3 sets of great-grandparents who are first-cousins.



Parental Exposures Up To The Time of Conception

| | M | D | | M | D | | M | D | | M | D |
|--------------------|----|----|-----------------------|---|---|--------------------|---|---|----------------------------------|---|---|
| Aerosol Spray | 25 | 24 | Glues | 3 | 9 | Damaged Microwaves | 2 | 2 | Electrocuted | 1 | 1 |
| Stress | 22 | 19 | Diazanon | 6 | 4 | Printing Inks | 3 | 1 | Thalidomide | 2 | 0 |
| Natural Gas | 20 | 19 | High Temperatures | 4 | 6 | Organic Solvents | 2 | 2 | Heptachlor | 2 | 0 |
| X-rays | 17 | 14 | Diesel Fuel | 1 | 8 | Steroids | 0 | 4 | Muscle Relaxers | 0 | 2 |
| Computers | 12 | 15 | Industrial Chemicals | 2 | 7 | Xylene | 0 | 4 | Lived Near Hazardous Waste Sites | 1 | 1 |
| Agriculture Fields | 10 | 10 | Fiberglass | 3 | 6 | DDT | 3 | 0 | Sodium Chloride | 0 | 2 |
| Paint Fumes | 8 | 10 | Formaldehyde | 3 | 4 | Benzocaine Sulfur | 1 | 2 | Tar | 1 | 1 |
| Solvents | 7 | 11 | Rubella | 3 | 4 | Trichlorethylene | 0 | 3 | Phenmetrazine | 0 | 2 |
| DEET | 5 | 9 | Photography Chemicals | 5 | 1 | Chemical Warfare | 0 | 3 | Within 3 miles of Airports | 1 | 1 |
| Marijuana | 7 | 7 | Professional Spraying | 2 | 3 | Lead | 3 | 0 | Aluminum | 0 | 1 |
| Insect Repellant | 5 | 8 | Lindane | 2 | 3 | Coal | 2 | 1 | Mercury | 1 | 0 |
| Asbestos | 5 | 8 | PCBs | 2 | 3 | Uranium | 1 | 1 | Hashish | 0 | 1 |
| Agriculture | 7 | 5 | Chlordane | 4 | 0 | Heptachlor | 2 | 0 | Cocaine | 1 | 0 |

| | | | | | | | | | | |
|----------|--|--|--|--|--|-------|--|--|--|--|
| Spraying | | | | | | Epoxy | | | | |
|----------|--|--|--|--|--|-------|--|--|--|--|

In the above chart, we included exposures up to the time of conception of their CDH children. This includes exposures from the time of the parents' births. Not included- 1 mom was exposed to DES in utero. In the chart below, we included exposures from the time of conception. (KEY: M-Moms, D-Dads)



Maternal Exposures During Pregnancy

| | | | | | | | | | |
|--------------------------|----|-------------------------|---|-----------------------|---|--------------------------|---|---------------------|---|
| Pre-Natal Vitamins | 30 | Agriculture Fields | 8 | Steroids | 3 | DDT | 1 | Organic Solvents | 1 |
| Caffeine | 25 | Airports | 8 | Artificial Hormones | 3 | Chlordane | 1 | Chicken Pox | 1 |
| Aerosol Spray | 21 | Painkillers | 7 | DEET | 3 | Hazardous Waste Site | 2 | Sedatives | 1 |
| Natural Gas | 21 | Alcohol | 6 | X-rays | 3 | Hot Tub | 2 | Diabetes Medication | 1 |
| Stress | 20 | Anti-Nausea Medications | 6 | Professional Spraying | 2 | High Voltage Power Lines | 2 | Cold Medicine | 1 |
| Tylenol/OTC Pain Killers | 18 | Hair Dye | 6 | Printing Inks | 2 | Trichlorethylene | 2 | Nasal Spray | 1 |
| Prescription Drugs | 14 | Glues | 5 | Anesthesia | 2 | Lead | 2 | Sodium Chlorate | 1 |
| Computers | 14 | Hair Permanents | 5 | Thyroid Medication | 2 | Insect Repellant | 2 | Marijuana | 1 |
| Allergy Medications | 14 | Electric Blanket | 5 | Contraceptives | 2 | Sodium Chloride | 1 | Asbestos | 1 |
| Antacids | 14 | Vaginal Medications | 5 | Damaged Microwaves | 2 | Mercury | 1 | Xylene | 1 |
| Solvents | 12 | Laxatives | 4 | Agriculture Spraying | 2 | PCBs | 1 | Benzocaine Sulfur | 1 |
| Paint Fumes | 9 | High Temperatures | 3 | Nicotine | 2 | Flu Shot | 1 | | |

| | | | | | | | | | |
|-------------|---|-----------------|---|-------------------|---|-----------------------|---|--|--|
| Antibiotics | 9 | Muscle Relaxers | 3 | Asthma Medication | 2 | Photography Chemicals | 1 | | |
|-------------|---|-----------------|---|-------------------|---|-----------------------|---|--|--|



Pregnancy Histories

| | vo | o | y | n | u | | vo | o | y | n | u |
|----------------|----|---|----|----|---|--------------------------------|----|---|----|----|---|
| Food Cravings | 2 | 6 | 14 | 16 | 2 | Gestational Diabetes | 0 | 0 | 2 | 38 | 0 |
| Night Sweats | 1 | | 5 | 34 | 0 | Polyhydramnios | 0 | 0 | 11 | 29 | 0 |
| Sleep Problems | 6 | 3 | 19 | 12 | 0 | Premature Rupture of Membranes | 0 | 0 | 2 | 37 | 1 |
| Bleeding Gums | | 1 | 7 | 31 | 1 | High Blood Pressure | 0 | 0 | 2 | 38 | 0 |
| Heart Burn | 7 | 4 | 12 | 14 | 3 | Reduced Sex Drive | 3 | 2 | 14 | 19 | 2 |
| Fetal Hiccups | 3 | 8 | 11 | 14 | 4 | Breathing Problems | 1 | 2 | 9 | 25 | 3 |
| Constipation | 2 | 3 | 17 | 15 | 3 | Low Blood Pressure | 1 | 1 | 4 | 33 | 1 |
| Hyperemesis | 2 | 1 | 1 | 31 | 5 | Threatened Miscarriage | 0 | 0 | 1 | 39 | 0 |
| Joint Pain | 1 | 1 | 0 | 38 | 0 | Hot/Cold Sensitivity | 1 | 0 | 6 | 33 | 0 |
| Prenatal Care | 0 | 0 | 40 | 0 | 0 | Unexplained Itching | 1 | 2 | 2 | 34 | 1 |
| Mood Swings | 2 | 4 | 20 | 13 | 1 | Unexplained Rashes | 0 | 1 | 2 | 37 | 0 |
| Dehydration | 0 | 0 | 7 | 33 | 0 | Morning Sickness | 9 | 5 | 12 | 14 | 0 |
| Depression | 0 | 0 | 7 | 33 | 0 | Allergies | 0 | 1 | 2 | 36 | 1 |
| Dizzy Spells | 0 | 0 | 2 | 38 | 0 | Anemia | 4 | 2 | 5 | 28 | 1 |
| Fatigue | 5 | 6 | 23 | 6 | 0 | Hair Loss | 0 | 2 | 3 | 33 | 2 |
| Toxemia | 1 | 0 | 1 | 37 | 1 | Strep B | 0 | 0 | 1 | 39 | 0 |

| | | | | | | | | | | | |
|-----------|---|---|----|----|---|-------|---|---|----|----|---|
| Flu | 0 | 0 | 8 | 26 | 0 | Colds | 0 | 0 | 23 | 16 | 1 |
| Headaches | 2 | 4 | 18 | 14 | 2 | | | | | | |

KEY: vo-very often, o-often, y-yes/sometimes, n-no/never, u-unanswered/don't remember



Complications

(in 35 of 40 CDH Patients)

| | | | | | |
|----------------------|----|--------------------------|---|----------------------------|---|
| Blood Infections | 40 | Brain Damage/C.P. | 5 | Low Muscle Tone | 2 |
| Feeding Problems | 22 | Ventilator Dependency | 5 | Clotted Superior Vena Cava | 1 |
| Pneumonia | 17 | Viruses | 5 | Congestive Heart Failure | 1 |
| Developmental Delay | 14 | Urinary Tract Infections | 4 | Liver Enlargement | 1 |
| Oxygen Dependency | 13 | Kidney Failure | 4 | Seizures | 1 |
| Repeated CDH Repairs | 10 | Sight Impairment | 4 | Mastitis | 1 |
| Scoliosis | 7 | Hydrocephalus | 4 | Bronchitis | 1 |
| Chronic Lung Disease | 7 | Kidney Infections | 3 | Perirectal Abscess | 1 |
| Chronic Asthma | 7 | Pulmonary Hemorrhage | 2 | . | . |
| Hearing Impairment | 6 | Bed Sores | 2 | . | . |

In our Additional Birth Defects chart, we included only medical problems present at the time of birth. Any problems that occurred after birth are listed in the Complications chart. In both charts we included the number of occurrences, not the number of patients affected.



Additional Birth Defects

(in 20 of 40 CDH Patients)

| Cardiovascular | 12 | Gastrointestinal | 9 | Genitourinary | 12 |
|------------------------------|-----------|-------------------------------|----------|----------------------|-----------|
| Atrial Septal Defect | 3 | Hirschprung's Disease | 1 | Undescended Testes | 5 |
| Unspecified Heart Murmur | 2 | Meckel's Diverticulum | 1 | Hypospadias | 1 |
| Pulmonary Sequestration | 2 | Partial Organoaxial Volvulus | 1 | Chordee | 1 |
| Bronchopulmonary Dysplasia | 2 | Short Esophagus | 1 | Hydronephrosis | 1 |
| Supraventricular Tachycardia | 1 | Pyloric Stenosis | 1 | Inguinal Hernia | 2 |
| Mildly Malformed Mitrovalve | 1 | Displaced Anus | 1 | "One Kidney Higher" | 1 |
| Malformed Subaortic Valve | 1 | Abnormal Rectal Nerve Ganglia | 1 | Bilortopexys | 1 |
| | | Organoaxial Twist | 1 | | |
| | | Small Stomach | 1 | | |



Non-Chromosomal Syndromes-

2

Limbs-3

Liver-3

Spleen-1

Accessory Spleen-1

Fryn's Syndrome-2

Hypoplastic Nails-2

"Possible Defect"-1

Biforcated Toes-1

Extra Lobe-1

Sequestered Liver-1



Craniofacial-11

Oral Clefts-5

Chromosomal Anomalies-5

Skeletal and Chest-5

Hydrocephalus-2

Cleft Palate-1

Monosomal (Un-named)-2

Hemivertebra-3

Abnormal Ears-2

Soft and Hard Cleft Palate-1

Partial Trisomy 22 -1

Chest Pectis -1

Craniosynatosis -2

High Palate-1

Partial Trisomy 14 -1

Hypoplastic Nipples-1

Short Neck-1

Soft Palate Into Esophagus-1

Possible TAS Syndrome-1

Micrognathia-1

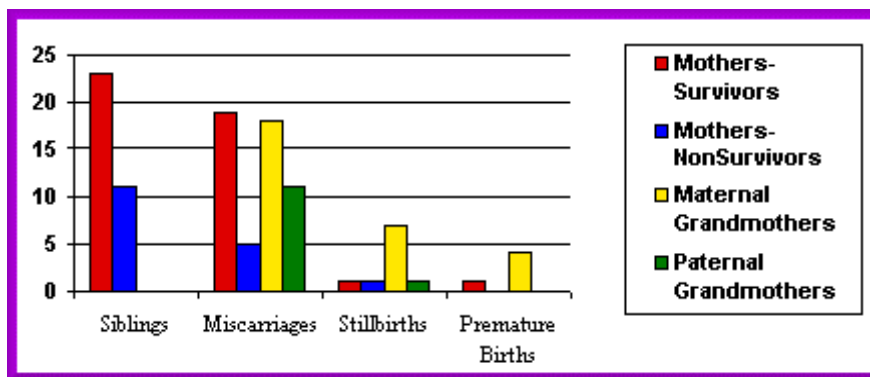
Tracheoesophageal Cleft-1

Microcephaly-1

Brood Nose-1

Brain Atrophy-1





| Case no. | Sex | Side of CDH | Type of CDH | Year of birth | Pregnancy complications | Vitamins Taken | Length of Preg. | Type of Delivery | Birth Weight | Ultrasounds Done (No./ Findings) | Age at time of diagnosis | No. of re-pairs |
|----------|-----|-------------|-------------|---------------|---------------------------------------|----------------|-----------------|------------------|--------------|----------------------------------|--------------------------|-----------------|
| S1 | M | L | Boch | 1993 | anemia, poly., dehy, threatened misc, | N | 38w | V-forceps | 6lbs9oz | 2-none | birth | 5 |
| S2 | F | L | Agen | 1992 | anemia | N | 42w | V | 7lbs | 1-none | birth | 1 |
| S3 | F | L | Agen | 1992 | --- | Y | 37w | V-forceps | 5lbs | 3-none | birth | 1 |
| S4 | M | R | BPNA | 1975 | --- | Y | u/a | V | 5lbs10oz | u/a | birth | 1 |
| S5 | M | R | u/a | 1993 | gestational diabetes | Y | n/a | V | 9lbs9oz | 20-CDH | 28w iu | 1 |
| S6 | F | R | CAgen | 1993 | anemia | Y | 36w | C | 7lbs1oz | 2-none | birth | 1 |
| S7 | M | L | u/k | 1992 | --- | Y | 37w | C | 5lbs13oz | 5-CDH | 26w iu | 1 |
| S8 | M | L | u/k | 1995 | --- | N | 42w | V | 9lbs6oz | 0 | birth | 1 |

| | | | | | | | | | | | | |
|-----|---|---|------|------|---------------------------------|---|-----|-----------|-----------|------------|--------|---|
| S9 | M | L | u/k | 1993 | --- | Y | 34w | V | 4lbs11oz | 2-none | birth | 1 |
| S10 | F | L | Boch | 1995 | --- | Y | 40w | V-breech | 8lbs15oz | 2-none | birth | 3 |
| S11 | M | L | u/a | 1992 | poly, toxemia | Y | 39w | C | 6lbs1oz | 8-CDH | 30w iu | 1 |
| S12 | M | L | u/a | 1995 | --- | Y | 39w | V | 7lbs8.5oz | 3-CDH | 28w iu | 1 |
| S13 | F | L | Boch | 1995 | --- | Y | 38w | C | 6lbs11oz | 3-CDH | 36w iu | 1 |
| S14 | M | R | Boch | 1995 | --- | Y | 42w | V-forceps | 8lbs | 2-none | birth | 1 |
| S15 | M | L | u/a | 1992 | --- | Y | 39w | V-forceps | 8lbs13oz | 6-CDH | 16w iu | 3 |
| S16 | M | L | u/a | 1982 | --- | N | 36w | V | 4lbs11oz | 0 | birth | 1 |
| S17 | M | L | Boch | 1995 | --- | Y | 42w | V-forceps | 8lbs5oz | 3-none | birth | 1 |
| S18 | F | L | Agen | 1993 | anemia | Y | 39w | C | 8lbs5oz | 12-CDH | 16w iu | 1 |
| S19 | F | L | u/a | 1994 | anemia | Y | u/a | C | 5lbs | 2-none | birth | 1 |
| S20 | F | L | Boch | 1994 | --- | Y | 38w | V | 6lbs7oz | 2-CDH | 22w iu | 1 |
| S21 | F | L | Agen | 1997 | --- | Y | u/a | V | 7lbs13oz | 0 | Birth | 1 |
| S22 | M | L | Agen | 1995 | Long labor, fetal decelerations | Y | 42w | C | 6lbs14oz | 8-none | Birth | 1 |
| S23 | M | R | u/a | 1995 | PROM, poly | Y | 36w | V | 5lbs15oz | 1-CDH, PRM | 34w iu | 1 |
| S24 | F | L | Boch | 1994 | --- | Y | 36w | V | 6lbs1oz | 4-CDH | 19w iu | 1 |
| S25 | F | L | Boch | 1991 | --- | Y | 38w | V | 7lbs7oz | 2-none | Birth | 1 |
| S26 | M | L | u/a | 1995 | Emergency C-section | N | 39w | C | 7lbs15oz | 8-CDH | 32w iu | 1 |
| S27 | M | L | u/a | 1996 | --- | Y | 39 | V | 9lbs1oz | 3-CDH | 36iu | 1 |
| D1 | M | L | u/a | 1995 | anemia | Y | 32w | C | 4lbs4oz | 3-CDH | 18w iu | 2 |
| D2 | F | L | Agen | 1994 | poly | N | 38w | V-forceps | 6lbs15oz | 30-CDH | 32w iu | 1 |

| | | | | | | | | | | | | |
|-----|---|---|-------|------|---|-----|-------|------------------|------------|-----------------|---------|---|
| D3 | M | L | Agen | 1995 | poly | Y | 34w | V | 6lbs13oz | 6-CDH | 16w iu | 0 |
| D4 | M | L | Boch | 1995 | poly, anemia, PRM | Y | 37w | C-at. forceps | 5lbs15oz | 2-bl poly | birth | 0 |
| D5 | F | R | Agen | 1995 | poly, anemia | N | 32w | V- suction | 6lbs6oz | 5-CDH | 32w iu | 1 |
| D6 | M | L | u/a | 1989 | --- | D/K | 40w | V | 6lbs11oz | 7-none | birth | 0 |
| D7 | M | L | Agen | 1996 | --- | Y | 38w | V- suction | 7lbs7oz | 0 | birth | 1 |
| D8 | F | L | u/a | 1996 | --- | Y | 34.5w | C | 4lbs13oz | 20-CDH | 16w iu | 1 |
| D9 | M | L | Boch | 1996 | --- | Y | 38w | C | 6lbs2oz | 2-none | Birth | 2 |
| D10 | M | B | CAgen | 1997 | Breech, poly | Y | 39w | C | 6lbs3oz | 5-CDH | 36 w iu | 0 |
| D11 | M | R | Boch | 1997 | Placenta previa | Y | 40w | V | 4lbs15.7oz | 2-none | Birth | 0 |
| D12 | F | L | u/a | 1997 | FGR, placental abruption, Erythemic Nudosem | Y | 32.5w | V | 3lbs4oz | 1-none | Birth | 0 |
| D13 | M | L | CAgen | 1989 | Poly | Y | 40w | V | 8lbs | 6-no stomach | birth | 1 |

KEY

S5-survivor case #5, D5- deceased case #5, F-female, M-male, L-left, R-right, Y=yes, N=no, D/K-don't know, w-weeks, lbs-pounds, oz-ounces, Agen- Agensis of the Hemi-Diaphragm, Boch- Bochdalek, CAgen- Complete Agensis of the Diaphragm, u/a=unanswered poly-polyhydramnios, PRM-premature rupture of membranes, home-delivered at home, FGR- Fetal Growth Restriction, iu- in utero, at.-attempted



PERCENTAGES

67.5% Survivors, 32.5% Non-Survivors

| | Survivors | Non-Survivors |
|---------------------------------|---------------------|------------------------------|
| Gender | M- 59.26% F 40.74% | M- 69.23% F- 30.77% |
| Side of CDH | L- 81.48% R- 18.52% | L- 76.92% R- 15.38% B- 7.69% |
| Pregnancy Complications | 37.04% | 69.23% |
| Pre-Natal Vitamins Taken | 81.48% | 76.92% |
| Premature | 11.11% | 38.46% |
| Pre-Natal Diagnosis | 44.44% | 46.15% |



| Case no. | Type(s) of CDH repairs | Time on ECMO | Time on vent | Time on oxygen | Time spent in hospital | Feeding problem | Developmental delay | Multiple birth defects | Complications | Cost of medical care | Age at time of death |
|-----------|-----------------------------------|--------------|--------------|----------------|------------------------|-----------------|---------------------|------------------------|---------------|----------------------|----------------------|
| S1 | lungtis - 1x, mus- 1x, Gortex- 3x | 0 | 2.5 y | 2.5 y | 10m | yes | yes | yes | yes | \$4,000,000 | --- |
| S2 | spleen mus | 2 w | 2.5 w | 2.5 y | 6 m | yes | yes | no | yes | \$500,000 | --- |
| S3 | mesh | 20 d | 5 m | 1.5 y | 3 m | yes | no | yes | yes | \$350,000 | --- |
| S4 | u/k | 0 | 22 y | 22 y | 2 y | yes | no | no | yes | \$1,500,000 | --- |
| S5 | sutures | 10 d | 6 w | 6 m | 5 w | yes | yes | yes | yes | \$300,000 | --- |

| | | | | | | | | | | | |
|------------|-----------|---------|-------|-------|-------|-----|-----|-----|-----|-------------|-------|
| S6 | Gortex | 0 | 29 d | 31 d | 4 m | yes | yes | yes | yes | d/k | --- |
| S7 | sutures | 0 | u/a | u/a | 24 d | no | no | no | yes | \$52,000 | --- |
| S8 | u/k | 21 d | 32 d | 5 m | 8 w | yes | no | no | yes | \$500,000 | --- |
| S9 | u/k | 2 d | 2 w | 2 w | 3.5 w | yes | yes | no | yes | \$500,000 | --- |
| S10 | Gortex | u/k | u/a | u/a | 14 d | no | yes | yes | yes | \$200,000 | --- |
| S11 | Gortex | 8 d | 1 m | 2 m | 3 m | yes | yes | yes | yes | d/k | --- |
| S12 | sutures | 0 | 2.5 w | 1 d | 4 w | no | yes | no | no | \$500,000 | --- |
| S13 | Gortex | 17 d | 2 w | 1.5 y | 7 m | yes | yes | yes | yes | \$800,000 | --- |
| S14 | sutures | 6 d | 3 w | 4 w | 7 w | no | no | yes | yes | \$300,000 | --- |
| S15 | Gortex | 10 d | 4 y | 4 y | 3 m | yes | yes | yes | yes | \$1,500,000 | --- |
| S16 | u/k | u/k | u/a | 1 m | 1 m | no | no | no | no | \$3,500,000 | --- |
| S17 | Gortex | 3 d | 1.5 w | 4 w | 5.5 w | yes | no | no | yes | \$275,000 | --- |
| S18 | sutures | 6 d | 28 d | 30 d | 48 d | yes | no | no | no | d/k | --- |
| S19 | u/k | 10 d | 3.5 w | 2 y | 2 m | yes | no | no | yes | d/k | --- |
| S20 | Gortex | 0 | u/a | u/a | 5 w | yes | yes | yes | yes | d/k | --- |
| S21 | groin mus | 0 | 0 | none | 10 d | yes | no | yes | no | d/k | --- |
| S22 | Dacron | 2 weeks | 0 | 4.5 m | 14 m | Yes | Yes | Yes | Yes | \$675,000 | --- |
| S23 | Gortex | 0 | 0 | 6 d | 6 m | No | No | Yes | Yes | \$600,000 | --- |
| S24 | Gortex | 0 | 9 d | 19 d | 14 m | Yes | No | No | Yes | \$180,000 | --- |
| S25 | u/k | 0 | 0 | 18 d | 2 w | No | No | No | Yes | \$200,000 | --- |
| S26 | Gortex | 12 d | 12 d | 2 m | 2 w | Yes | Yes | No | Yes | \$500,000 | --- |
| S27 | u/k | 0 | 0 | 4 d | 1 w | no | no | no | no | \$35,000 | --- |
| D1 | Gortex | 8 d | 3 m | 4.5 m | 4.3 m | yes | u/k | no | yes | \$1,500,000 | 143 d |
| D2 | Gortex | 0 | 2.5 m | 2 m | 7 m | yes | yes | yes | yes | \$2,500,000 | 360 d |

| | | | | | | | | | | | |
|------------|---------|-------|-------|--------|--------|-----|-----|-----|-----|-----------|-------|
| D3 | 0 | u/k | 1.5 h | 1.5 h | 1.5 h | u/k | u/k | yes | yes | \$8,000 | 1 d |
| D4 | 0 | 12 h | u/a | u/k | 12 d | u/k | u/k | no | yes | \$145,000 | 12 d |
| D5 | u/k | 3.5 w | 3.5 w | 3.5 w | 29 d | u/k | u/k | no | yes | d/k | 29 d |
| D6 | 0 | u/a | u/a | u/k | 1 d | u/k | u/k | no | yes | d/k | 1 d |
| D7 | u/k | 1 w | 7 d | u/a | 1 w | u/k | u/k | yes | yes | \$125,000 | 7 d |
| D8 | Gortex | 21 d | 27 d | 27 d | 27 d | u/k | u/k | no | yes | d/k | 27 d |
| D9 | Sutures | 0 | "yes" | 2 m | u/a | Yes | u/k | Yes | Yes | \$400,000 | 136 d |
| D10 | 0 | 0 | 0 | 0 | u/a | u/k | u/k | Yes | No | \$3000 | 1 h |
| D11 | 0 | 0 | U/a | 15 min | 1 hour | u/k | u/k | Yes | No | U/k | 1 h |
| D12 | 0 | 0 | 0 | 10 d | u/a | u/k | u/k | no | No | \$90,000 | 10 d |
| D13 | Dura | 0 | 1d | u/k | u/a | u/k | u/k | Yes | no | U/k | 1 d |

KEY

suction-suction used to remove baby, C-Cesarean Section, V-Vaginal, blpoly-borderline poluhydramnios, w iu weeks in utero, birth-within 24 hours of birth, tis -tissue, mus-muscle, abdwol-abdominal wall, u/k-unknown, mesh (Gortex, Marlex, etc.: synthetic patches)



Regional Inquiries

The following data is based on the number of inquiries we received from families of children with CDH as of July 25, 1998. Physician inquiries and membership are not included on this chart. There are approximately 1400 babies born with CDH in any given year. The amount of inquiries that we have had proves that we have a lot of parents out there still looking for support and information. Given the state population differences, this chart is fairly accurate. North Carolina's number is pretty high- most likely due to the fact that we are based there and are more "well known" and accessible. The high numbers in Illinois and Indiana are most likely due to a physician who refers his/her patients to us, though we do not have professional members in either state. Though there could be a incidence rate in both of these states, we have no way of knowing.

| | | | | | | | | | |
|---------------|---|-------------|---|----------------|----|---------------|----|----------------|----|
| Alabama | 4 | Alaska | 1 | Arizona | 6 | Arkansas | 0 | California | 22 |
| Colorado | 1 | Connecticut | 3 | Delaware | 1 | Florida | 13 | Georgia | 8 |
| Hawaii | 0 | Idaho | 1 | Illinois | 10 | Indiana | 10 | Iowa | 2 |
| Kansas | 1 | Kentucky | 6 | Louisiana | 4 | Maine | 1 | Maryland | 5 |
| Massachusetts | 6 | Michigan | 7 | Minnesota | 3 | Mississippi | 0 | Missouri | 5 |
| Montana | 2 | Nebraska | 1 | Nevada | 5 | New Hampshire | 1 | New Jersey | 5 |
| New Mexico | 4 | New York | 8 | North Carolina | 15 | North Dakota | 0 | Ohio | 8 |
| Oklahoma | 6 | Oregon | 1 | Pennsylvania | 11 | Rhode Island | 1 | South Carolina | 4 |
| South Dakota | 1 | Tennessee | 2 | Texas | 15 | Utah | 2 | Vermont | 0 |
| Virginia | 6 | Washington | 3 | West Virginia | 3 | Wisconsin | 9 | Wyoming | 1 |
| Australia | 2 | Canada | 6 | Egypt | 1 | Great Britain | 8 | Hong Kong | 1 |
| India | 1 | Ireland | 1 | Israel | 1 | New Zealand | 2 | Scotland | 1 |

1999 CDH Survey Results

1997 CDH Survey Results



