# CHERUBS

**The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support**

# CHERUBS' 2000
# Congenital Diaphragmatic Hernia
# Research Survey Results ©

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The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support

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CHERUBS
P.O. Box 1150
Creedmoor, NC 27522
USA

The following information was taken from our parent worksheets (also known as membership forms) sent in by February 25, 2001. This document is written in an easy-to-understand format for parents. We have tried to keep the medical terminology to a minimum and have separated the results into 2 categories: Membership Survey Results (taken from Parent Membership Forms) and Congenital Diaphragmatic Hernia Research Survey Results (taken from t he 10-page surveys sent out to parents of non-survivors and survivors over 1 year old). The reliability of this data is dependent upon the reliability of the knowledge of our members. Every effort has been made to educate our members on the membership form and survey questions in order to enable them to answer as correctly as possible.

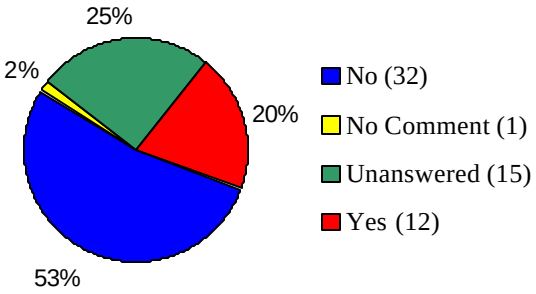
# Membership Survey Results

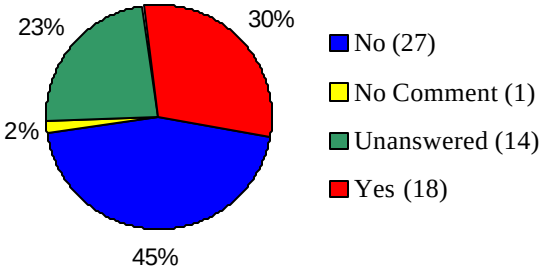
Based on 727 Parent Membership Forms completed by February 25, 2001, by parents of Survivors, Non-Survivors, and Expectant parents. Parents who joined while still expecting and whose forms have not been updated since their child's birth are still classified as Expectant.

## Medical Professional Opinion On The Parent-Hospital Experience

(from the membership forms of our 60 medical professional members)

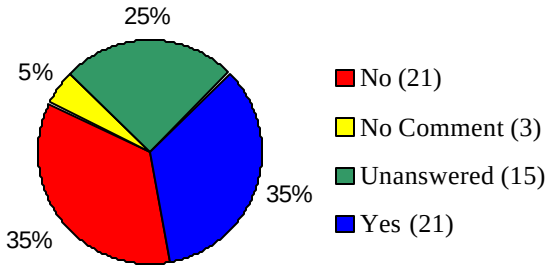
Do you find it difficult to explain medical diagnoses and procedures to the parents of these children in terms that they can comprehend?




Do you feel that most of these parents have difficulty comprehending the information that you give them?

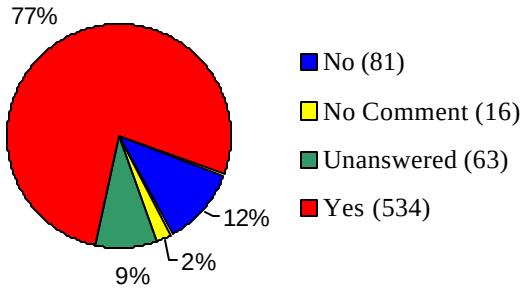
Does your hospital or organization provide parent support group information regarding congenital diaphragmatic hernia?

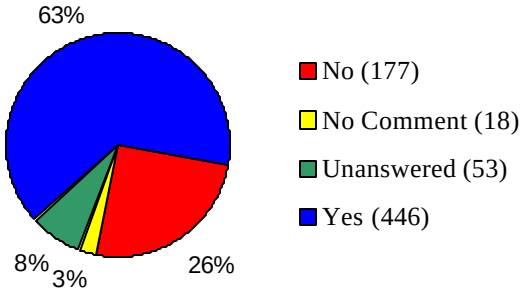


# Parental Opinion On The Hospital Experience

(not including expectant parents- 694)

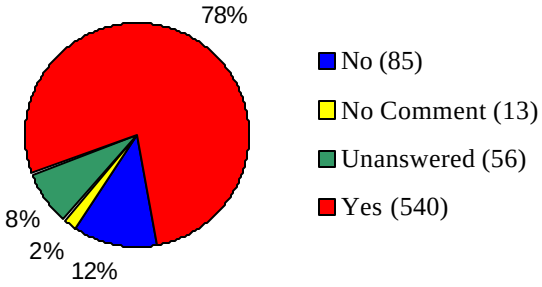
Do you feel that the hospital staff that cared for your child informed and involved you in decisions regarding your child's health care?



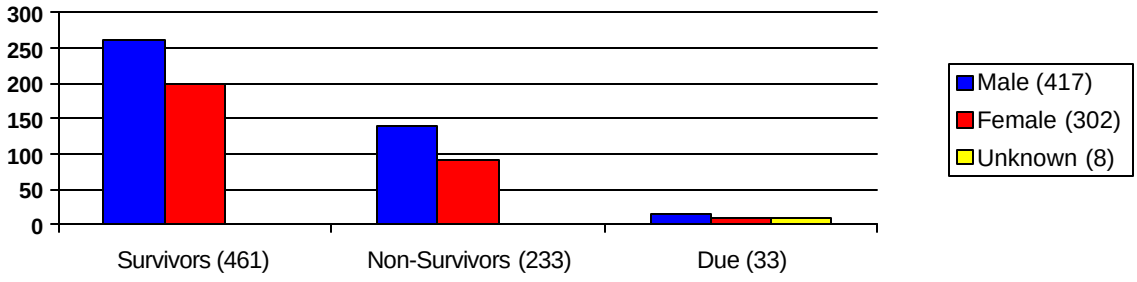




Do you feel that you were given enough information about your child's diagnosis?

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




## Basic Statistics

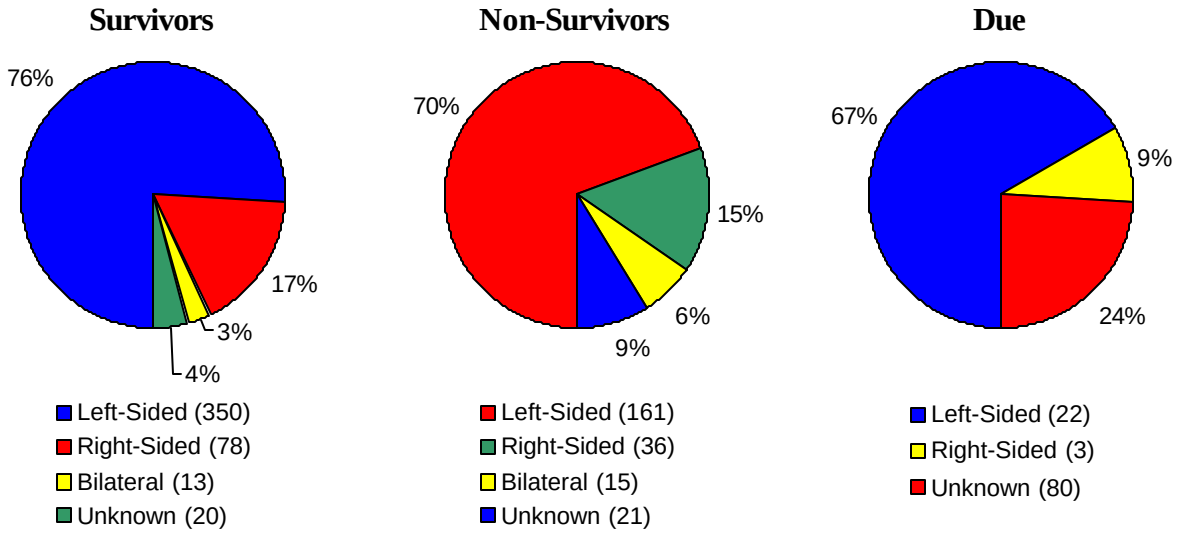



From our membership numbers, you can see that CDH seems to occur more often in males (58% male, 42% female) with a 65.43% survival rate (68.15% female, 65.17% male). Of course this is highly influenced by which parents (of survivors or non-survivors) join CHERUBS. We have a higher rate of parents of survivors (63.4%) joining than parents of non-survivors (32.05%). Most CDH medical research articles are still giving an overall 50% survival rate for CDH.

| | Due | Survivors | Non-Survivors | Totals |
|---|---|---|---|---|
| **Male** | 15 (45.45%) | 262 (56.83%) | 140 (60.09%) | 417 (57.36%) |
| **Female** | 10 (30.30%) | 199 (43.17%) | 93 (39.91%) | 302 (41.54%) |
| **Unknown** | 8 (24.24%) | 0 | 0 | 8 (1.10%) |
| **Totals** | 33 (4.54%) | 461 (63.41%) | 233 (32.05%) | 727 |

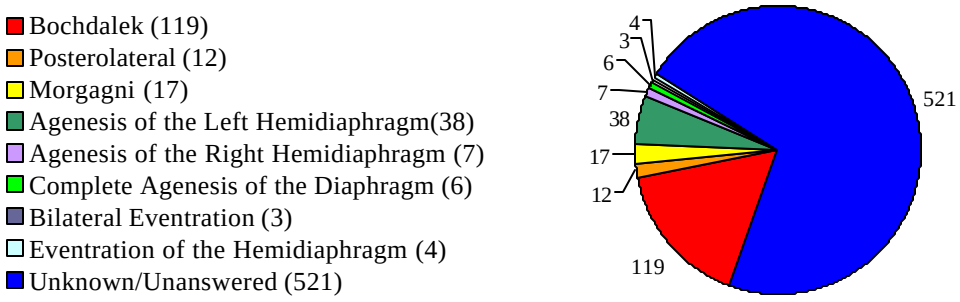
## Side(s) of Congenital Diaphragmatic Hernia

| | Survivors (461) | | Non-Survivors (233) | | | |
|---|---|---|---|---|---|---|
| | Male | Female | Male | Female | Due (33) | Totals |
| **Left-Sided** | 192 (73.28%) | 158 (79.40%) | 103 (73.57%) | 58 (62.37%) | 22 (66.66%) | 533 (73.31%) |
| **Right-Sided** | 49 (18.70%) | 29 (14.57%) | 22 (5.71%) | 14 (15.05%) | 3 (9.09%) | 117 (16.09%) |
| **Bilateral** | 8 (3.05%) | 5 (2.51%) | 7 (5.00%) | 8 (8.60%) | 0 | 28 (3.85%) |
| **Unknown** | 13 (4.96%) | 7 (3.52%) | 8 (5.71%) | 13 (13.98%) | 8 (8.60%) | 49 (6.74%) |
| **Totals** | 262 | 199 | 140 | 93 | 33 | 727 |




As you can see, Left-Sided CDH is drastically more common than Right-Sided or Bilateral CDH, with a higher rate of Right-Sided CDH in Non-Survivors than in Survivors. There is also a much higher rate of Right-Sided CDH in males (62.28%) than females (37.72%). It is disturbing that many of our parents do not know which side(s) their child's hernia is located on.

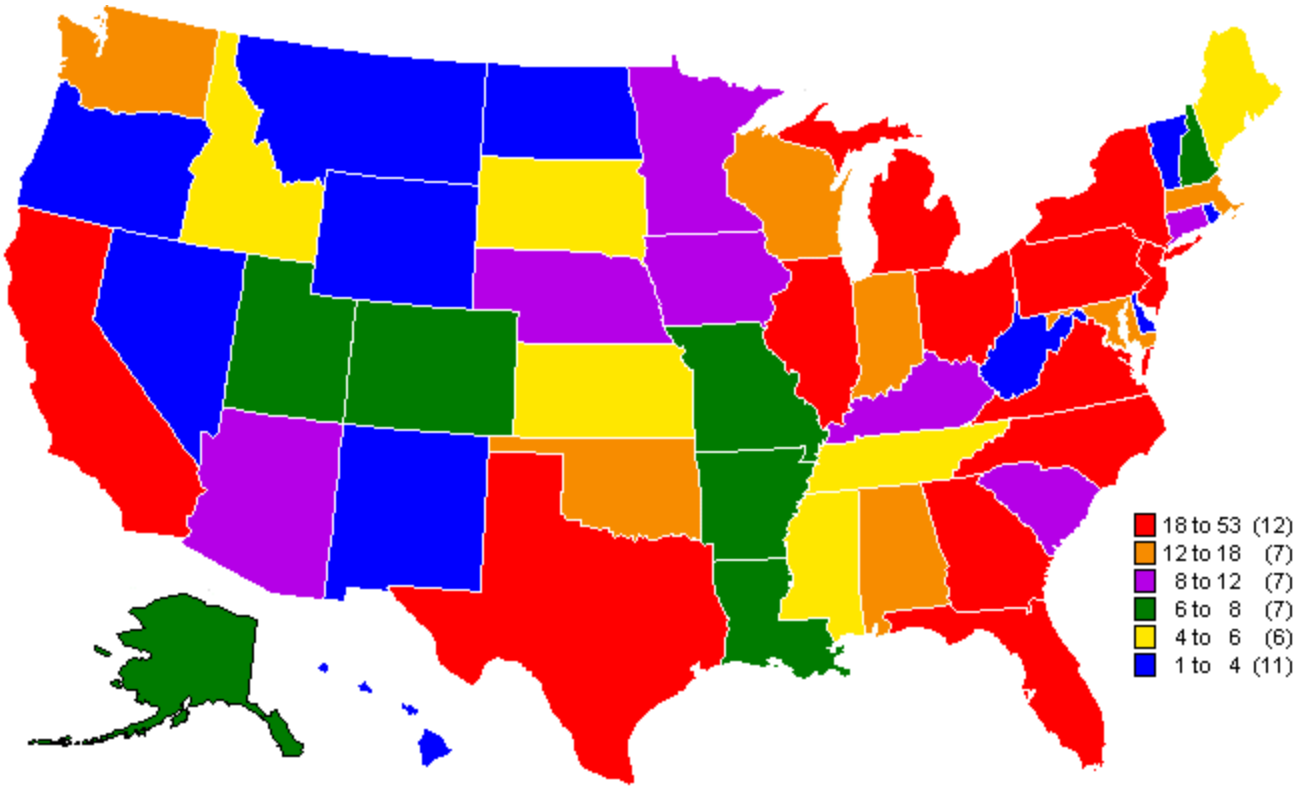
## Type of Congenital Diaphragmatic Hernia



| | Survivors (461) | | Non-Survivors (233) | | | |
|---|---|---|---|---|---|---|
| | Male | Female | Male | Female | Due (33) | Totals |
| **Bochdalek** | 54 | 36 | 16 | 10 | 3 | 119 |
| **Posterolateral** | 5 | 4 | 0 | 3 | 0 | 12 |
| **Morgagni** | 4 | 8 | 3 | 2 | 0 | 17 |
| **Agen of Left Hemidiaphragm** | 15 | 8 | 13 | 2 | 0 | 38 |
| **Agen of Right Hemidiaphragm** | 4 | 1 | 1 | 1 | 0 | 7 |
| **Complete Agenesis** | 2 | 1 | 2 | 1 | 0 | 6 |
| **Bilateral Eventration** | 0 | 0 | 2 | 1 | 0 | 3 |
| **Hemi Eventration** | 1 | 2 | 1 | 0 | 0 | 4 |
| **Unknown / Unanswered** | 177 | 139 | 102 | 73 | 30 | 521 |
| **Totals** | 262 | 199 | 140 | 93 | 33 | 727 |

Again this year we can note that most of our members do not know what type of CDH their child had. We think the largest factor is that when parents ask their child's doctor, he/she does not know what to answer and a few were surprised to learn that there are different types of CDH. It is helpful to know what type of CDH your child has because it helps you to know more about the position of the defect, the organs involved, and the "average" chance of survival. We also question the accuracy of this portion of survey, due to the high numbers Agenesis of the Hemidiaphragm and Complete Agenesis of the Diaphragm in survivors. The survival rate for these types of CDH is rather low and we think it is more likely that parents guessed the type of CDH their child had based on hearing their surgeons say "Your child had no diaphragm" or "almost no diaphragm"- which is most likely an exaggeration on the surgeons' part to try to explain the procedure and defect to the parents.

## Member Locations



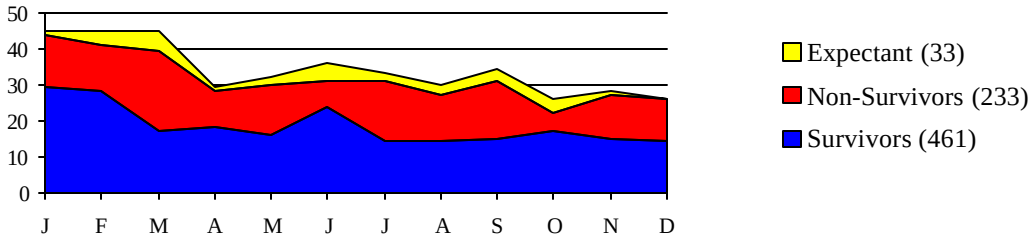
| Location | Due | Non-Survivor Male | Non-Survivor Female | Survivor Male | Survivor Female | Parent Member Total | Grand-parent Members | Non-Member Families | Medical Professional Members |
|---|---|---|---|---|---|---|---|---|---|
| Australia | 1 | 8 | 5 | 9 | 9 | 32 | 0 | 1 | 0 |
| Belgium | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 0 |
| Canada | 2 | 4 | 5 | 17 | 11 | 39 | 0 | 5 | 2 |
| Chile | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| England | 3 | 3 | 0 | 10 | 7 | 23 | 0 | 4 | 0 |
| France | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Germany | 0 | 2 | 0 | 1 | 0 | 3 | 0 | 0 | 0 |
| Greece | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Hong Kong | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 |
| India | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 1 |
| Israel | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 1 |
| Ireland | 0 | 2 | 0 | 2 | 2 | 6 | 0 | 0 | 1 |
| Italy | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| Mexico | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 1 |
| New Guinea | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 |
| New Zealand | 0 | 1 | 3 | 3 | 1 | 8 | 0 | 1 | 0 |
| Northern Ireland | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| Norway | 0 | 0 | 0 | 2 | 0 | 2 | 0 | 0 | 0 |
| Oman | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Pakistan | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Romania | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Saudi Arabia | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Scotland | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 1 | 0 |
| South Africa | 0 | 0 | 0 | 0 | 1 | 1 | 0 | 0 | 0 |
| Spain | 0 | 0 | 0 | 1 | 0 | 1 | 0 | 0 | 1 |
| Switzerland | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| The Netherlands | 0 | 0 | 3 | 0 | 1 | 4 | 0 | 0 | 0 |
| Turkey | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| United Arab Emirates | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| United States | 27 | 120 | 75 | 215 | 162 | 599 | 15 | 160 | 46 |
| Totals | 33 | 140 | 94 | 262 | 199 | 727 | 15 | 177 | 61 |

Most of our members are in the United States, with a large concentration on the East Coast and Texas and California, due to the general population of the those states. Thanks to the internet, our membership is growing worldwide with approximately 150 new members each year for the past 2 years.

## Seasonal Fluctuations

**8 weeks**

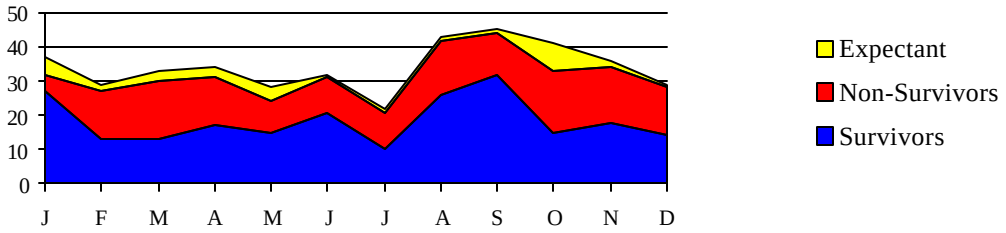
(approximate time of Diaphragm formation in utero, based on due dates)



| | J | F | M | A | M | J | J | A | S | O | N | D | Unanswered | Totals |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Survivors** | 29 | 28 | 17 | 18 | 16 | 24 | 14 | 14 | 15 | 17 | 15 | 14 | 240 | 461 |
| **Non-Survivors** | 15 | 13 | 22 | 10 | 14 | 7 | 17 | 13 | 16 | 5 | 12 | 12 | 77 | 233 |
| **Expectant** | 1 | 4 | 6 | 1 | 2 | 5 | 2 | 3 | 3 | 4 | 1 | 0 | 1 | 33 |
| **Totals** | 45 | 45 | 45 | 29 | 32 | 36 | 33 | 30 | 34 | 26 | 28 | 26 | 318 | 727 |

**8-Week Mark**- There is a drastic jump in the number of diaphragmatic hernias formed in the first 4 months of year. The only correlation that we can find with environmental factors during those months is the stress of tax season, but there is a decrease during months with major holidays, with the exception of February. There is also a slight jump during the summer months, which may be attributed to heat or an increase in pesticides (through crop spraying, insect repellents, etc).

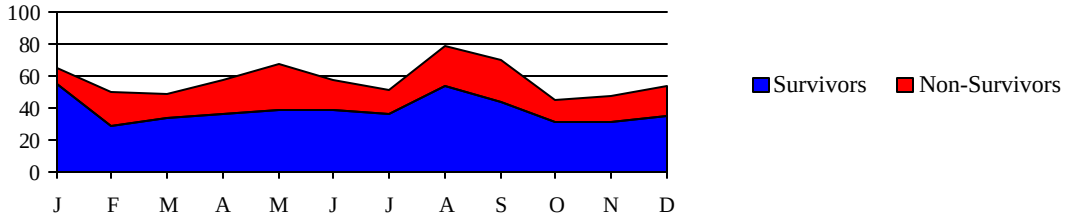
**Due Dates**




| | J | F | M | A | M | J | J | A | S | O | N | D | Unanswered | Totals |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Survivors** | 27 | 13 | 13 | 17 | 15 | 21 | 10 | 26 | 32 | 15 | 18 | 14 | 240 | 461 |
| **Non-Survivors** | 5 | 14 | 17 | 14 | 9 | 10 | 11 | 16 | 12 | 18 | 16 | 14 | 77 | 233 |
| **Expectant** | 5 | 2 | 3 | 3 | 4 | 1 | 1 | 1 | 1 | 8 | 2 | 1 | 1 | 33 |
| **Totals** | 37 | 29 | 33 | 34 | 28 | 32 | 22 | 43 | 45 | 41 | 36 | 29 | 318 | 727 |

**Due Dates**- Our trend seems to follow the normal population for the births, given that a large number of babies are conceived during the cold winter months.

**Birth Dates**

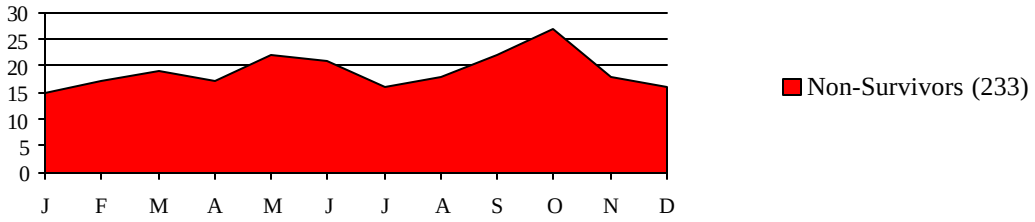



| | J | F | M | A | M | J | J | A | S | O | N | D | Unanswered | Totals |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Survivors** | 54 | 28 | 33 | 36 | 38 | 39 | 36 | 53 | 43 | 31 | 31 | 35 | 4 | 461 |
| **Non-Survivors** | 11 | 22 | 15 | 21 | 29 | 18 | 15 | 25 | 27 | 14 | 16 | 18 | 2 | 233 |
| **Totals** | 65 | 50 | 48 | 57 | 67 | 57 | 51 | 78 | 70 | 45 | 47 | 53 | 6 | 694 |

**Birth Dates**- Our trend seems to follow the normal population for the births, given that a large number of babies are conceived during the cold winter months.

## Dates of Death

(5 parents did not answer- all were families who joined while still expecting and who haven't updated their forms)



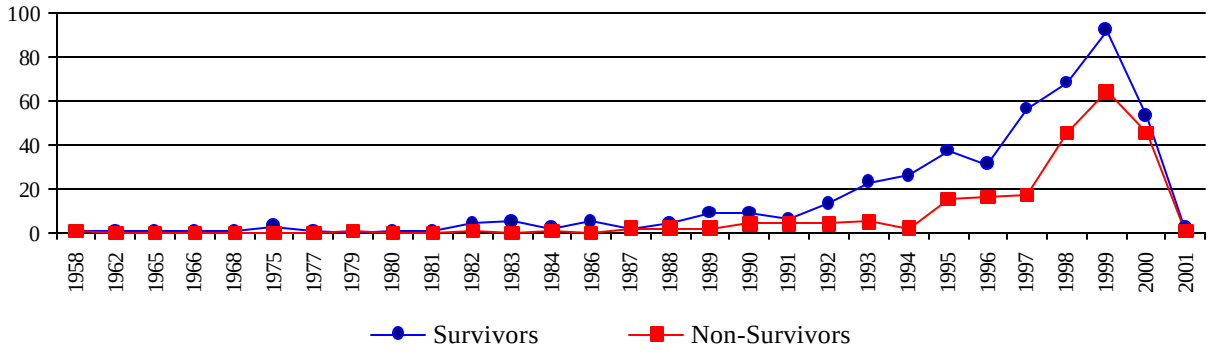

| | J | F | M | A | M | J | J | A | S | O | N | D | Unanswered | Totals |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Non-Survivors** | 15 | 17 | 19 | 17 | 22 | 21 | 16 | 18 | 22 | 27 | 18 | 16 | 5 | 233 |

**Death Dates**- The increase in September and October is disturbing and correlates with the beginning of flu, cold, and virus seasons. With so many "bugs" caught during hospitalizations and the low immunity of critically ill, and often premature, newborns with low lung capacity, it is highly likely that viruses are the cause of most pneumonias and some deaths. This can be avoided with careful hand washing and screening of all parents, hospital workers, and patient visitors. The increase in May also correlates with the beginning of allergy season.

## Parental Ages

| | Survivors Male | Survivors Female | Non-Survivors Male | Non-Survivors Female | All |
|---|---|---|---|---|---|
| **Average Mother's Age** | 29.1 | 28.5 | 28.8 | 28.3 | 28.8 |
| **Average Father's Age** | 31.4 | 31.0 | 30.7 | 30.4 | 31.0 |

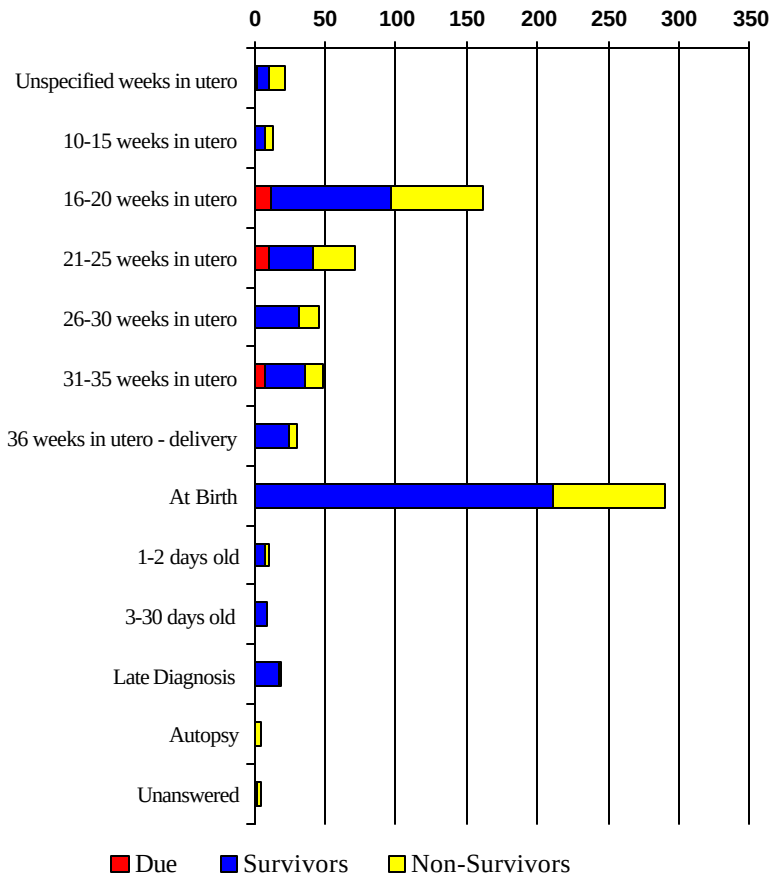
## Years of Birth




This chart shows the years that our members were born, with our oldest member born in 1958 and our youngest born in 2001. The increase from 1994 to today is most likely due to the internet, giving parents access to CHERUBS and more information and support. We do not believe that the increase is due to a higher incidence rate. 4 parents did not answer the "date of birth" question on their forms (3 parents of survivors and 1 grieving parent).

# Ages of Diagnosis

| | Due | Survivors | Non-Survivors | Total |
|---|---|---|---|---|
| **Unspecified wks in utero** | 2 (6.06%) | 8 (1.74%) | 11 (4.72%) | 21 (2.89%) |
| **10-15 wks in utero** | 1 (3.03%) | 7 (1.52%) | 5 (2.15%) | 13 (1.79%) |
| **16-20 wks I n utero** | 12 (36.36%) | 84 (18.22%) | 65 (27.90%) | 161 (22.15%) |
| **21-25 wks in utero** | 10 (30.30%) | 32 (6.94%) | 29 (12.45%) | 71 (9.77%) |
| **26-30 wks in utero** | 1 (3.03%) | 30 (6.51%) | 14 (6.01%) | 45 (6.19%) |
| **31-35 wks in utero** | 7 (21.21%) | 28 (6.07%) | 13 (5.58%) | 48 (6.60%) |
| **36 wks in utero - delivery** | 0 | 24 (5.21%) | 6 (2.58%) | 30 (4.13%) |
| **At Birth** | 0 | 211 (45.77%) | 79 (33.91%) | 290 (39.89%) |
| **1-2 days old** | 0 | 8 (1.74%) | 2 (0.86%) | 10 (1.38%) |
| **3-30 days old** | 0 | 9 (1.95%) | 0 | 9 (1.24%) |
| **Late Diagnosis** | 0 | 18 (3.90%) | 1 (0.43%) | 19 (2.61%) |
| **Autopsy** | 0 | 0 | 5 (2.15%) | 5 (0.69%) |
| **Unanswered** | 0 | 2 (0.43%) | 3 (1.29%) | 5 (0.69%) |
| **Totals** | 33 | 461 | 233 | 727 |




The number of patients undiagnosed in utero is still drastically high, given the high resolution ultrasounds now available. Unfortunately, this can be attributed to the United States' lack of a law for certification of all ultrasound technicians and the insurance companies who limit patients to 1 ultrasound. Often, ultrasounds are taken so early that the hernia is hard to see, though we do have many members who were diagnosed before the 20th week of gestation. Many insurance companies will not pay for more than one ultrasound so late gestation ultrasounds are not as common. There seems to be a higher incidence of mortality in those diagnosed early in gestation.

# Pregnancy Complications

(in 694 pregnancies)

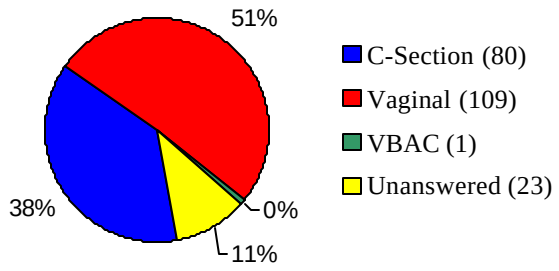
| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| **Premature Labor** | 94 (35.88%) | 58 (29.15%) | 63 (45.00%) | 43 (45.24%) | 258 (97.73%) |
| **Polyhydramnios** | 55 (20.99%) | 27 (13.57%) | 44 (31.43%) | 24 (25.81%) | 150 (56.82%) |
| **Multiple Birth** | 10 (3.82%) | 13 (6.53%) | 6 (4.29%) | 3 (3.23%) | 32 (12.12%) |
| **Gestational Diabetes** | 13 (4.96%) | 6 (3.02%) | 4 (2.86%) | 0 | 23 (8.71%) |
| **Maternal Hemorrhaging** | 0 | 0 | 1 (0.71%) | 2 (2.15%) | 3 (1.14%) |
| **High Blood Pressure** | 6 (2.29%) | 4 (2.01%) | 4 (2.86%) | 1 (1.08%) | 15 (5.68%) |
| **Vaginal Bleeding** | 11 (4.20%) | 9 (4.52%) | 2 (1.43%) | 3 (3.23%) | 25 (9.47%) |
| **PROM** | 5 (1.91%) | 1 (0.50%) | 8 (5.71%) | 0 | 14 (5.30%) |
| **IUGR** | 2 (0.76%) | 0 | 0 | 0 | 2 (0.76%) |
| **Hyperemesis** | 3 (1.15%) | 4 (2.01%) | 1 (0.71%) | 2 (2.15%) | 10 (3.79%) |
| **Fetal Distress** | 5 (1.91%) | 6 (3.02%) | 2 (1.43%) | 3 (3.23%) | 16 ( 6.06%) |
| **Fetal Death** | 0 | 0 | 2 (1.43%) | 1 (1.08%) | 3 (1.14%) |
| **Placenta Acreta** | 0 | 0 | 2 (1.43%) | 0 | 2 (0.76%) |
| **Placental Abruption** | 2 (0.76%) | 1 (0.50%) | 2 (1.43%) | 1 (1.08%) | 6 (2.27%) |
| **Placenta Previa** | 5 (1.91%) | 4 (2.01%) | 2 (1.43%) | 0 | 11 (4.17%) |
| **Pre Eclampsia** | 4 (1.53%) | 1 (0.50%) | 0 | 0 | 5 (1.89%) |
| **Elective Termination** | 0 | 0 | 3 (2.14%) | 1 (1.08%) | 4 (1.52%) |
| **Hydrops** | 0 | 2 (1.01%) | 2 (1.43%) | 1 (1.08%) | 5 (1.89%) |
| **Oligohydramnios** | 3 (1.15%) | 0 | 0 | 0 | 3 (1.14%) |
| **None** | 30 (11.45%) | 30 (15.08%) | 11 (7.86%) | 15 (16.13%) | 86 (32.58%) |
| **Other** | 22 (8.40%) | 23 (11.56%) | 16 (11.43%) | 7 (7.53%) | 68 (25.76%) |
| **No Answer** | 110 (41.98%) | 91 (45.73%) | 56 (40.00%) | 41 (44.09%) | 298 (112.88%) |

According to our survey results, the survival rate is lower for CDH patients who are also premature, with 45.49% of non-survivors and 32.97% of survivors who were premature. Because both medical problems greatly affect lung growth, these numbers are to be expected. With in utero steroid treatments that were once given only to babies who had a high chance of prematurity now given to CDH patients in utero also, the survival rate for both of these illnesses is slowly increasing though many prenatally diagnosed patients are still not receiving in utero steroid treatment.

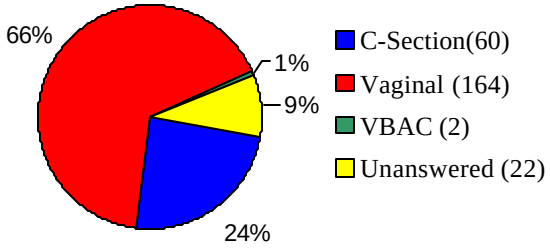
# Birth History

| | Survivors | Non-Survivor | Totals |
|---|---|---|---|
| **Vaginal** | 273 (59.22%) | 128 (59.94%) | 401 (57.78%) |
| **C-Section** | 140 (30.37%) | 68 (29.18%) | 208 (29.97%) |
| **VBAC** | 3 (0.65%) | 2 (0.86%) | 5 (0.72%) |
| **Unanswered** | 45 (9.76%) | 35 (15.02%) | 80 (11.53%) |
| **Average Birth Weight** | 6lbs 0.37oz | 6lbs 13.76oz | 6lbs 9.6oz |
| **Average Gestational Age** | 19.94 | 19.08 | 19.67 |

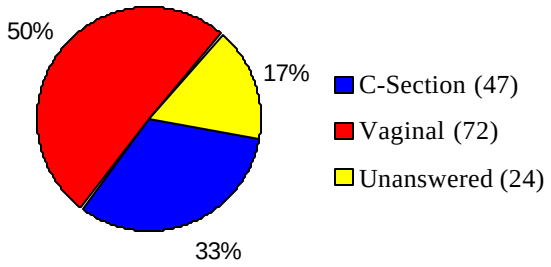
**Survivors Diagnosed In Utero**



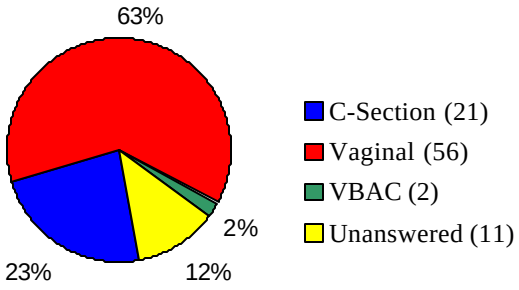

**Survivors Diagnosed After Birth**




**Non-Survivors Diagnosed In Utero**




**Non-Survivors Diagnosed After Birth**




There is a 33% increase in C-Sections performed on patients who are diagnosed in utero, with only a 5% increase in survival rate. The increase survival rate is more likely attributed to the readiness of the delivery team to take care of an ill newborn rather than the actual C-Section delivery. There is currently no proof by other researchers that C-Section delivery vs. Vaginal delivery helps the survival rate of babies born with CDH. However, there has been research that states vaginal delivery helps produce surfactant in newborn lungs.

## Birth Complications

| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | **Male** | **Female** | **Male** | **Female** | **Totals** |
| **Breech** | 11 (4.20%) | 8 (4.02%) | 4 (2.86%) | 0 | 23 (8.71%) |
| **Umbilical Cord Injuries** | 7 (2.67%) | 2 (1.01%) | 1 (0.71%) | 1 (1.08%) | 11 (4.17%) |
| **Premature** | 89 (33.97%) | 50 (25.13%) | 58 (41.43%) | 41 (44.09%) | 238 (90.15%) |
| **Stillborn** | 0 | 0 | 2 (1.43%) | 2 (2.15%) | 4 (1.52%) |
| **Other Complications** | 14 (5.34%) | 17 (8.54%) | 13 (9.29%) | 2 (2.15%) | 46 (17.42%) |
| **None** | 52 (19.85%) | 54 (27.14%) | 27 (19.29%) | 13 (13.98%) | 146 (55.30%) |
| **Unanswered/Unknown** | 100 (38.17%) | 75 (37.69%) | 45 (32.14%) | 35 (37.63%) | 255 (96.59%) |

# Multiple Birth Defects

(in 694 Survivors and Non-Survivors)

## Cardiac Defects (116)

| | Total |
|---|---|
| Unspecified Heart Defect | 30 |
| Atrial Septal Defect | 12 |
| Ventral Septal Defect | 12 |
| Patent Ductus Arteriosis | 12 |
| Supraventricular Tachycardia | 7 |
| Coarctation Of The Aorta | 3 |
| Hypoplastic Ventricle | 3 |
| Tetralogy Of Fallot | 3 |
| Arteriovenous Malformation | 2 |
| Cardiac Aneurysm | 2 |
| Hypoplastic Left Heart Syndrome | 2 |
| Hypoplastic Pericardium | 2 |
| Small Aortic Arch | 2 |
| Transposition Of The Great Arteries | 2 |
| "Blood Flowing In Wrong Direction" | 1 |
| Anatomical Coarctation | 1 |
| Benign Chest Wall Syndrome | 1 |
| Cardiac Displacement | 1 |
| Double Outlet Ventricle | 1 |
| Enlarged Atrium | 1 |
| Enlarged Vena Cava | 1 |
| Enlarged Ventricles | 1 |
| Fluid Around Heart | 1 |
| Hypoplastic Aortic Arch | 1 |
| Hypoplastic Superior Vena Cava | 1 |
| Interrupted Aortic Arch | 1 |
| Mildly Malformed Mitrovalve | 1 |
| Minor Tri-Cuspid Regurgitation | 1 |
| Mitral Valve Prolapse | 1 |
| Pericarditis | 1 |
| Peridical Cyst Attached To The Heart | 1 |
| Persistent Left Vena Cava | 1 |
| Small Aortic Valve | 1 |
| Subaortic Valve Growth | 1 |
| Ventriculomegaly | 1 |

## Organ Defects (53)

| | Total |
|---|---|
| Microgastria | 3 |
| Omphalocele | 3 |
| Congenital Intestinal Malrotation | 2 |
| Hirschsprung's Disease | 2 |
| Polysplenia | 2 |
| Ventral Hernia | 2 |
| Abnormal Nerve Ganglia In Colon | 1 |
| Atopic Appendix | 1 |
| Atopic Spleen | 1 |

## Pulmonary Defects (107)

| | Total |
|---|---|
| Pulmonary Hypoplasia | 85 |
| Pulmonary Sequestration | 8 |
| Bronchopulmonary Dysplasia | 4 |
| Punctured Lung | 2 |
| Bronchomalacia | 1 |
| Extra Lung | 1 |
| PPH | 1 |
| PPHN | 1 |
| Pulmonary Atresia | 1 |
| Pulmonary Stenosis | 1 |
| Total Anomalous Pulmonary Venous Return | 1 |
| Tracheomalacia | 1 |

## Uritogenitary Defects (94)

| | Total |
|---|---|
| Undescended Testicle | 33 |
| Inguinal Hernia | 20 |
| Renomegaly | 6 |
| Hypospadius | 5 |
| Polycystic Kidney | 4 |
| "Abnormal Kidney" | 2 |
| Dual Collection Kidney | 2 |
| Hypoplastic Kidney | 2 |
| Kidney Reflux | 2 |
| Malrotated Kidney | 2 |
| Unspecified Genital Defect | 2 |
| "One Kidney Higher Than The Other" | 1 |
| Horseshoe Kidney | 1 |
| Hydrocele | 1 |
| Hydronephrosis | 1 |
| Hyperspadius | 1 |
| Kidney "Changed Cells" | 1 |
| Kidney- Extra Renal Pelvis | 1 |
| Kidney Stones, Congenital | 1 |
| Male And Female Genitals | 1 |
| Malformed Uterus-Tubula | 1 |
| Neurogenic Bladder | 1 |
| Ovarian Cysts | 1 |
| Renal Pyelectasis | 1 |
| Testicle Hydrocele | 1 |

## Other Defects (51)

| | Total |
|---|---|
| Skin Tag | 4 |
| 2 Vessel Cord | 3 |
| Analatresie | 2 |

| Organ Defects | Total |
|---|---|
| Autolytic Changes To Kidneys | 1 |
| Autolytic Changes To Liver | 1 |
| Autolytic Changes To Pancreas | 1 |
| Autolytic Changes To Spleen | 1 |
| Autolytic Changes To Thymus | 1 |
| Cleaved Liver | 1 |
| Congested Liver | 1 |
| Displaced Anus | 1 |
| Enlarged Liver | 1 |
| Extraphepatic Biliary Obstruction | 1 |
| Gastroscisis | 1 |
| Horseshoe Shaped Spleen | 1 |
| Hydronephrosis | 1 |
| Hypoplastic Thymus | 1 |
| Intestinal Malabsorbtion | 1 |
| Liver Fused To Lung | 1 |
| Liver Sequestration | 1 |
| Lung And Liver Fused Together | 1 |
| Malrotated Stomach | 1 |
| Meckels Diverticulum (Intestines) | 1 |
| Multilobed Spleen | 1 |
| Organoaxial Twist | 1 |
| Pancreatic Insuffiency | 1 |
| Pyloric Stenosis | 1 |
| Sigmoid Colon | 1 |
| Two Lobed Liver | 1 |
| Umbilical Hernia | 1 |

## Limb Defects (46)

| | Total |
|---|---|
| Polydactylia | 5 |
| Simian Crease | 4 |
| Hypoplastic Nails | 3 |
| Biforcated Toes | 2 |
| Clenched Fists | 2 |
| Clubbed Feet | 2 |
| Hypoplastic Foot | 2 |
| Rocker Bottom Feet | 2 |
| "Abnormal Arm" | 1 |
| "Abnormal Thumb" | 1 |
| "Limb Abnormalities" | 1 |
| Adducted Thumbs | 1 |
| Cleft Right Hand | 1 |
| Congenital Dislocated Elbow | 1 |
| Femur Fracture | 1 |
| Fused Finger Joint | 1 |
| Hypoplastic Finger | 1 |
| Hypoplastic Hands | 1 |
| ITT Right Lower Leg | 1 |
| Large Thumbs | 1 |
| Leg Shorter And Smaller | 1 |
| One Leg Growing Slower | 1 |
| Short Limbs | 1 |
| Syndactyl Toes | 1 |
| Thumb Abnormalities | 1 |
| Toe Curling | 1 |

| Other Birth Defects | Total |
|---|---|
| Central Hyperalime | 2 |
| Hypoplastic Jugular Vein | 2 |
| Short Esophagus | 2 |
| 1 Vessel Umbilical Cord | 1 |
| Absent Septum Pellucidum | 1 |
| Anus Patent With A Small Sacral Dimple | 1 |
| Broad Nose | 1 |
| Bronchomalasia | 1 |
| Cleft Nose | 1 |
| Combined Tracheoesphageal System | 1 |
| Dandy Walker Malformation | 1 |
| Delayed Puberty | 1 |
| DORV | 1 |
| Downward Turned Mouth | 1 |
| Dysphagia | 1 |
| Esophageal Atresea | 1 |
| Fatty Acid Oxidation Defect | 1 |
| Fetal Alcohol Syndrome | 1 |
| Floppy Esophagus | 1 |
| Hypotonic Malroglopsia | 1 |
| Infantile Estropia | 1 |
| Interhemispheric Cyst | 1 |
| Malformed Esophagus | 1 |
| Port Wine Stain | 1 |
| Premature Qualities | 1 |
| Redundant Neck Skin | 1 |
| SBS | 1 |
| Sensory Startal Reflex | 1 |
| Short Neck | 1 |
| Skin Edema | 1 |
| Subglottic Stenosis | 1 |
| Tracheoesaphageal Fistula | 1 |
| Tracheoesophageal Cleft | 1 |
| Tracheomalasia | 1 |
| Type Iv Choledocal Cyst | 1 |
| Upward Turned Nose | 1 |
| Webbing Of The Neck | 1 |
| Wide Nasal Bridge | 1 |

## Skeletal Defects (45)

| | Total |
|---|---|
| Hypoplastic Rib | 6 |
| Hemi Vertebrae | 4 |
| Chest Pectus | 3 |
| Congenital Scoliosis | 3 |
| Abnormal Rib | 2 |
| Abnormal Vertebrae | 2 |
| Dislocated Hips | 2 |
| Micrognanthia | 2 |
| 13 Bilateral Thoracic Defect | 1 |
| Abnormal Shoulder | 1 |
| Abnormal Spine | 1 |
| Chest Recession | 1 |
| C-Spine Abnormality | 1 |
| Dermoid Cyst On Nose | 1 |
| Facial Hirsutism | 1 |

| Limb Defects | Total |
|---|---|
| Underdeveloped Hand | 1 |
| Webbed Fingers | 1 |
| Webbed Hand | 1 |
| Webbed Toes | 1 |
| Webbing Behind Knees | 1 |
| Webbing Under Arms | 1 |

## Genetic Syndromes & Chromosomal Anomalies (38)

| | Total |
|---|---|
| Fryn's Syndrome | 12 |
| Pallister-Killians Syndrome | 3 |
| "Cross Over On The 9th Chromosome" | 1 |
| 13:14 Translocation | 1 |
| Brown Syndrome | 1 |
| Partial Deletion Of 1 X Chromosome | 1 |
| Possible Thoracoabdominal Syndrome | 1 |
| Translocation ? | 1 |
| Translocation Of 8th Chromosome | 1 |
| Trisomy | 1 |
| Trisomy 11/22 | 1 |
| Trisomy 18 | 1 |
| Trisomy 9 | 1 |
| Asperger Syndrome | 1 |
| Balanced Translocation Of Chromosomes | 1 |
| Cystic Fibrosis Carrier | 1 |
| Digeorge Syndrome | 1 |
| Ehlers Danlos Syndrome | 1 |
| Klippel-Feil Syndrome | 1 |
| Multiple Pterygium Syndrome | 1 |
| Partial Trisomy 22 | 1 |
| Speech Apraxia? | 1 |
| Triple 8, Missing Part Of 7 | 1 |
| Trisomy 14- Partial | 1 |
| Unnamed Monosomal Chromosomal Disorder | 1 |

## Eye and Ear Defects (23)

| | |
|---|---|
| "Deformed Ear" | 2 |
| Coloboma | 2 |
| Hypoplastic Eye | 2 |
| Posterior Ear | 2 |
| Underdeveloped Ear | 2 |
| Congenital Hearing Impairment | 1 |
| Ear Pits | 1 |
| Ear Tags | 1 |
| Folded Ears | 1 |
| Halo | 1 |
| Hypoplastic Optic Nerve | 1 |
| Lazy Eye | 1 |
| Low Set Ears | 1 |
| Membrane Over Eye | 1 |
| Slighty Mongloided Eyes | 1 |
| Strabysmus | 1 |
| Underdeveloped Eye | 1 |
| Wide Set Eyes | 1 |

| Skeletal Defects | Total |
|---|---|
| Hip Dysplasia | 1 |
| Hypoplastic Sternum | 1 |
| Left Cervical Rib | 1 |
| Metabolic Bone Disease | 1 |
| Nasal Abnormality | 1 |
| Short Neck | 1 |
| Spina Bifida Occulta | 1 |
| Spinal Fusion | 1 |
| Sunken Sternum | 1 |
| Tethered Spinal Cord | 1 |
| Thin Ribs | 1 |
| Torticollis | 1 |
| Tracheal Tug | 1 |
| Vertebrae Fusion- Partial Congenital | 1 |

## Neurocranial Defects (39)

| | Total |
|---|---|
| Hydrocephalus | 9 |
| Tethered Spinal Cord | 4 |
| Agenesis Of The Corpus Collusum | 3 |
| Microcephaly | 3 |
| Anacephaly | 2 |
| Craniosynatosis | 2 |
| Spina Bifida | 2 |
| Autolytic Changes To Brain | 1 |
| Bilateral IUH | 1 |
| Brain Atrophy | 1 |
| Cerebral Infarction | 1 |
| CNS Infarct | 1 |
| Enlarged Ventricles Of Brain | 1 |
| Epilepsy | 1 |
| Grade 3 Hemorrhage | 1 |
| Hypoplastic Supraorbital Ridges | 1 |
| Macrocephaly | 1 |
| Severe Bilateral Cephalahematomas | 1 |
| Subarachnoid Brain Hemorrhage | 1 |
| Open Neural Tube Defect (not spina bifida) | 1 |
| Seizure Disorder | 1 |

## Oral Clefts (24)

| | Total |
|---|---|
| Cleft Palate | 14 |
| Cleft Lip | 5 |
| High Palate | 3 |
| Hair Lip | 1 |
| Tongue Tied | 1 |

**"Multiple Birth Defects"** 1

**None** 414

**Unanswered/Unknown** 70

# Family History of CDH

| | Survivors | Non-Survivors | Due | Totals |
|---|---|---|---|---|
| **Sibling** | 3 (0.65%) | 11 (4.72%) | 0 | 14 (1.93%) |
| **Parent** | 1 (0.22%) | 0 | 0 | 1 (0.14%) |
| **Child** | 1 (0.22%) | 0 | 0 | 1 (0.14%) |
| **Aunt/Uncle** | 3 (0.65%) | 1 (0.43%) | 1 (3.03%) | 5 (0.69%) |
| **Cousin** | 5 (1.08%) | 3 (1.29%) | 0 | 8 (1.10%) |
| **Niece/Nephew** | 0 | 2 (0.86%) | 0 | 2 (0.28%) |
| **Distant Relative** | 6 (1.30%) | 4 (1.72%) | 0 | 10 (1.28%) |
| **Unspecified Relative** | 1 (0.22%) | 1 (0.43%) | 1 (3.03%) | 3 (0.41%) |
| **Total** | 20 (4.39%) | 22 (9.44%) | 2 (6.06%) | 44 (6.05%) |
| **No CDH History/Unknown** | 443 (96.10%) | 214 (91.85%) | 31 (93.94%) | 688 (94.64%) |

Our research agrees with most research articles on the 2% chance of having another child with CDH. 2 of our siblings with CDH had Fryn's Syndrome, which is familial and often involves CDH. We have several families who have more than 1 child with CDH but who have not filled out membership forms for all of their children. We also have 2 families that had a parent and child with CDH, but only have membership forms for 1 family member. Only one of our families with more than one CDH child knows the cause of their familial CDH; this is the family who had 2 children with Fryn's Syndrome. Several of our families have non-immediate family members who were born with CDH, bringing the total odds of having 2 extended family members with CDH to 6.05%.

# Sibling History

| | Survivors (461) | | Non-Survivors (233) | | Due (33) | | | |
|---|---|---|---|---|---|---|---|---|
| | Male | Female | Male | Female | Male | Female | Unknown | Totals |
| **No Siblings** | 74 | 52 | 31 | 26 | 10 | 3 | 4 | 200 |
| **Twin** | 9 | 10 | 5 | 2 | 1 | 0 | 1 | 28 |
| **Triplet** | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 2 |
| **Sextuplet** | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 1 |
| **Total Healthy Siblings and Half-Siblings** | 326 | 244 | 187 | 123 | 9 | 7 | 3 | 899 |
| **Total Siblings With Medical Problems** | 8 | 7 | 8 | 7 | 0 | 1 | 1 | 32 |
| **No Answer** | 6 | 5 | 6 | 1 | 0 | 0 | 1 | 19 |
| **Total Miscarriages** | 76 | 55 | 61 | 42 | 2 | 13 | 3 | 252 |
| **No Miscarriages** | 111 | 92 | 57 | 36 | 10 | 3 | 5 | 314 |
| **Miscarriages-Unanswered** | 103 | 69 | 55 | 33 | 3 | 2 | 1 | 266 |
| **Infertility** | 7 | 3 | 3 | 6 | 0 | 0 | 0 | 19 |

We have 28 twins in our membership- 24 are fraternal twins (22 twins are healthy, 2 had other medical problems) and 4 were identical twins (1 set with both having CDH, 2 sets with healthy twins). We also have 2 sets of fraternal triplets (healthy siblings) and 1 fraternal sextuplet (2 surviving siblings, 1 of which had heart defects).

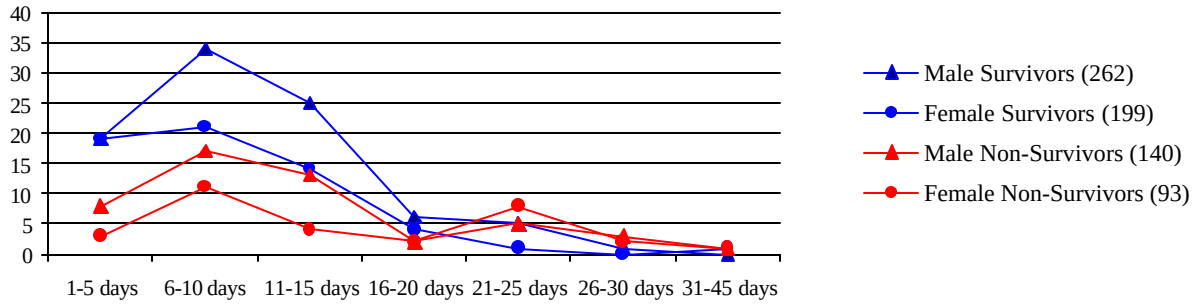
## Sibling Birth Defects
(in 32 siblings)

| Birth Defect | # |
|---|---|
| Congenital Diaphragmatic Hernia | 14 |
| Heart Defects | 4 |
| Cleft Palate | 2 |
| Fryn's Syndrome | 2 |
| Pyloric Stenosis | 2 |
| Autism | 1 |
| Cleft Lip | 1 |
| Complete Situs Inversus | 1 |
| Cornelia de Lange Syndrome | 1 |
| Down's Syndrome | 1 |
| Hydrocephalus | 1 |
| Hypoplastic Thyroid | 1 |
| Low Imperforated Anus | 1 |
| Malrotated Intestines | 1 |
| Obstructed Kidney | 1 |
| Potter's Syndrome | 1 |
| Pulmonary Stenosis | 1 |
| Spina Bifida | 1 |
| Tethered Spinal Cord | 1 |

# Interventional Procedures

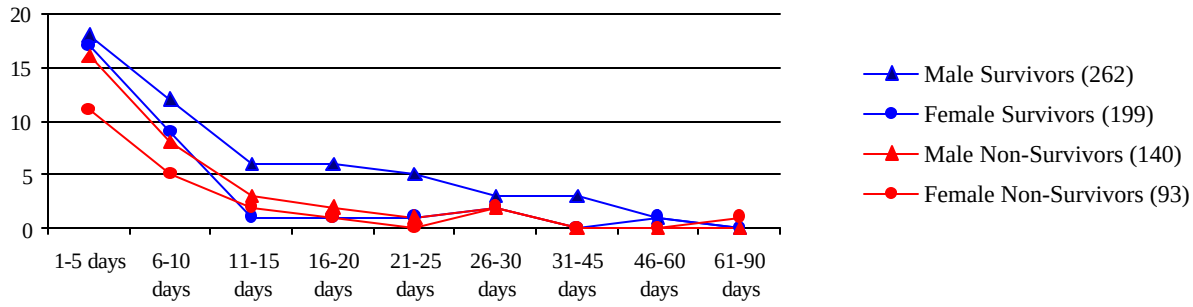
| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| **In Utero CDH Repair** | 2 (0.76%) | 1 (0.50%) | 1 (0.71%) | 1 (1.08%) | 5 (0.72%) |
| **In Utero Tracheal Ligation/Occlusion** | 6 (2.29%) | 3 (1.51%) | 5 (3.57%) | 2 (2.15%) | 16 (2.31%) |
| **In Utero Steroid Treatments** | 18 (6.87%) | 16 (8.04%) | 13 (9.29%) | 9 (9.68%) | 56 (8.0%) |
| **ECMO** | 90 | 60 | 49 | 31 | 230 |
| **Average Time on ECMO** (days) | 10.21 | 9.23 | 12.57 | 14.87 | 11.08 |
| **Nitric Oxide** | 54 | 32 | 32 | 22 | 140 |
| **Average Time on Nitric Oxide** (days) | 12.11 | 8.53 | 8.03 | 11.64 | 10.35 |
| **Oscillating Ventilator** | 79 | 64 | 42 | 31 | 216 |
| **Average Time on Oscillator** (days) | 14.25 | 10.27 | 7.37 | 7.68 | 10.80 |
| **Ventilator** | 223 | 163 | 89 | 53 | 528 |
| **Unknown/Unanswered** | 33 | 27 | 12 | 8 | 80 |
| **Average Time on Ventilator** (days) | 68.20 | 25.69 | 45.29 | 22.17 | 46.59 |
| **Ventilator Dependent** | 11 | 4 | 4 | 1 | 20 |
| **Oxygen** | 192 | 150 | 95 | 61 | 498 |
| **Unknown/Unanswered** | 68 | 46 | 12 | 9 | 135 |
| **Average Time on Oxygen** (days) | 122.48 | 113.65 | 81.46 | 27.03 | 100.31 |
| **Oxygen Dependent** | 58 | 31 | 7 | 2 | 98 |

## Extracorporeal Membrane Oxygenation (ECMO)



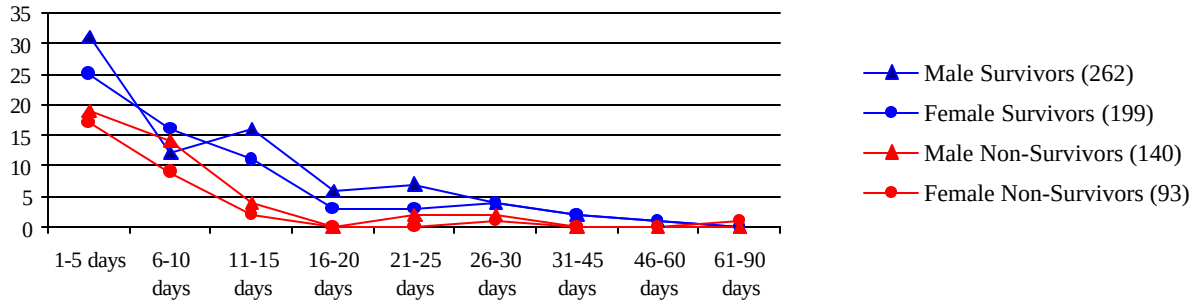

| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| ECMO Support | 90 (34.35%) | 60 (30.15%) | 49 (35.00%) | 31 (33.33%) | 230 (33.14%) |
| No ECMO Support | 156 (59.54%) | 126 (63.32%) | 83 (59.29%) | 53 (56.99%) | 418 (60.23%) |
| Unknown/Unanswered | 16 (6.11%) | 13 (6.53%) | 8 (5.71%) | 9 (9.68%) | 46 (6.63%) |

## Nitric Oxide



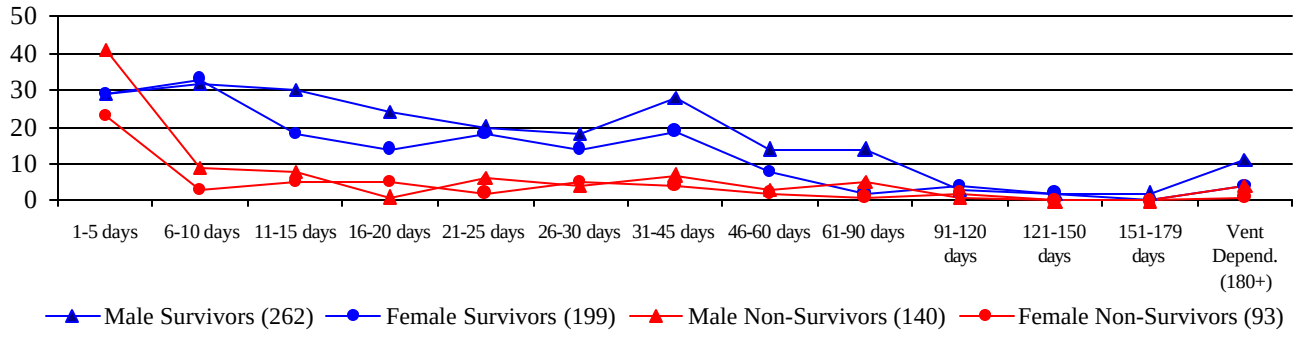

| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| Nitric Oxide Support | 54 (20.61%) | 32 (16.08%) | 32 (22.86%) | 22 (23.66%) | 140 (20.17%) |
| No Nitric Oxide Support | 180 (68.70%) | 144 (72.36%) | 95 (67.86%) | 56 (60.22%) | 475 (68.44%) |
| Unknown/Unanswered | 28 (10.69%) | 23 (11.56%) | 13 (9.29%) | 15 (16.13%) | 79 (11.38%) |

## Oscillatory Ventilation



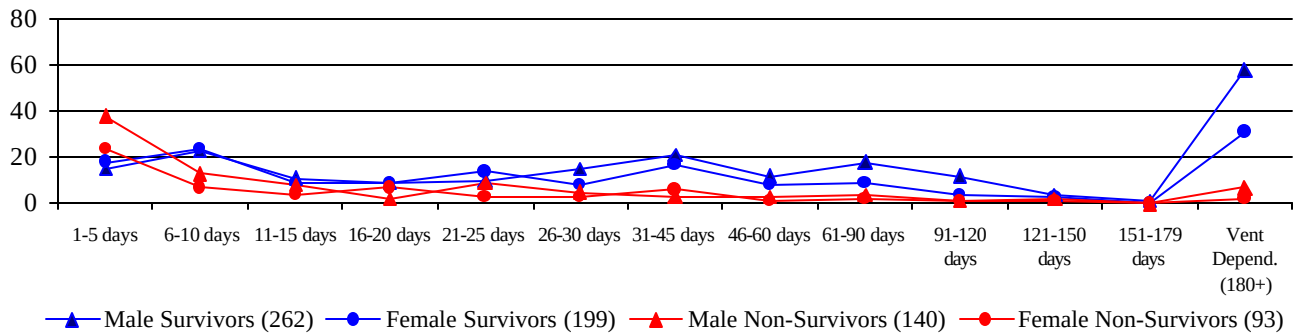
| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| Oscillator Support | 79 (30.15%) | 64 (32.16%) | 41 (29.29%) | 30 (32.26%) | 214 (30.84%) |
| No Oscillator Support | 152 (50.02%) | 110 (55.28%) | 83 (59.29%) | 48 (51.61%) | 393 (56.63%) |
| Unknown/Unanswered | 31 (11.83%) | 25 (12.56%) | 16 (11.43%) | 15 (16.13%) | 87 (12.54%) |

## Standard Ventilation




| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| No Ventilator Support | 6 (2.29%) | 9 (4.52%) | 39 (27.86%) | 32 (34.41%) | 86 (12.39%) |
| 1-5 days | 29 (11.07%) | 29 (14.57%) | 41 (29.29%) | 23 (24.73%) | 122 (17.58%) |
| 6-10 days | 32 (12.21%) | 33 (16.58%) | 9 (6.43%) | 3 (3.23%) | 77 (11.10%) |
| 11-15 days | 30 (11.45%) | 18 (9.05%) | 8 (5.71%) | 5 (5.38%) | 61 (8.79%) |
| 16-20 days | 24 (9.16%) | 14 (7.04%) | 1 (0.71%) | 5 (5.38%) | 44 6.34%) |
| 21-25 days | 20 (7.63%) | 18 (9.05%) | 6 (4.29%) | 2 (2.15%) | 46 (6.63%) |
| 26-30 days | 18 (6.87%) | 14 (7.04%) | 4 (2.86%) | 5 (5.38%) | 41 (5.91%) |
| 31-45 days | 28 (10.69%) | 19 (9.55%) | 7 (5.00%) | 4 (4.30%) | 58 (8.36%) |
| 46-60 days | 14 (5.34%) | 8 (4.02%) | 3 (2.14%) | 2 (2.15%) | 27 (3.89%) |
| 61-90 days | 14 (5.34%) | 2 (1.01%) | 5 (3.57%) | 1 (1.08%) | 22 (3.17%) |
| 91-120 days | 3 (1.15%) | 4 (2.01%) | 1 (0.71%) | 2 (2.15%) | 10 (1.44%) |
| 121-150 days | 2 (0.76%) | 2 (1.01%) | 0 | 0 | 4 (0.58%) |
| 151-179 days | 2 (0.76%) | 0 | 0 | 0 | 2 (0.29%) |
| Ventilator Dependency (180+ days) | 11 (4.20%) | 4 (2.01%) | 4 (2.86%) | 1 (1.08%) | 20 (2.88%) |
| Unknown/Unanswered | 29 (11.07%) | 25 (12.56%) | 12 (8.57%) | 8 (8.60%) | 74 (10.66%) |
| Totals | 262 | 199 | 140 | 93 | 694 |

## Oxygen Support

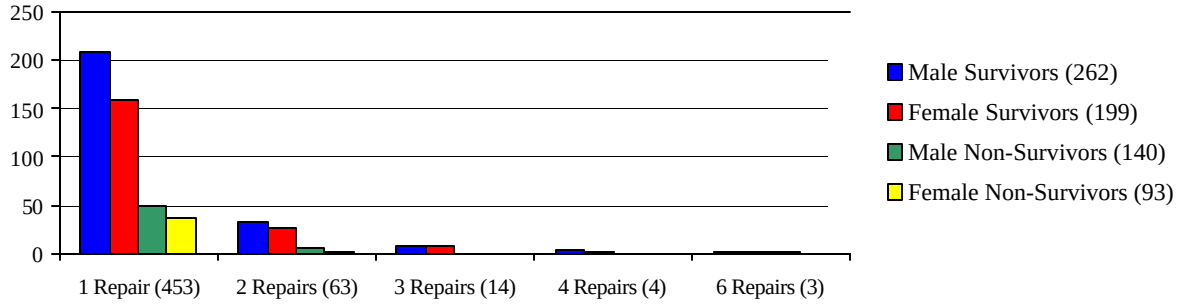


| | Survivors | | Non-Survivor | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| No Oxygen Support | 2 (0.76%) | 3 (1.51%) | 33 (23.57%) | 23 (24.73%) | 61 (8.79%) |
| 1-5 days | 15 (5.73%) | 18 (9.05%) | 38 (27.14%) | 24 (25.81%) | 95 (13.69%) |
| 6-10 days | 23 (8.78%) | 24 (12.06%) | 13 (9.29%) | 7 (7.53%) | 67 (9.65%) |
| 11-15 days | 11 (4.20%) | 9 (4.52%) | 8 (5.71%) | 4 (4.30%) | 32 (4.61%) |
| 16-20 days | 9 (3.44%) | 9 (4.52%) | 2 (1.43%) | 7 (7.53%) | 27 (3.89%) |
| 21-25 days | 10 (3.82%) | 14 (7.04%) | 9 (6.43%) | 3 (3.23%) | 36 (5.19%) |
| 26-30 days | 15 (5.73%) | 8 (4.02%) | 5 (3.57%) | 3 (3.23%) | 31 (4.47%) |
| 31-45 days | 21 (8.02%) | 17 (8.54%) | 3 (2.14%) | 6 (6.45%) | 47 (6.77%) |
| 46-60 days | 12 (4.58%) | 8 (4.02%) | 3 (2.14%) | 1 (1.08%) | 24 (3.46%) |
| 61-90 days | 18 (6.87%) | 9 (4.52%) | 4 (2.86%) | 2 (2.15%) | 33 (4.76%) |
| 91-120 days | 12 (4.58%) | 4 (2.01%) | 1 (0.71%) | 1 (1.08%) | 18 (2.59%) |
| 121-150 days | 4 (1.53%) | 3 (1.51%) | 2 (1.43%) | 1 (1.08%) | 10 (1.44%) |
| 151-179 days | 1 (0.38%) | 0 | 0 | 0 | 1 (0.14%) |
| Oxygen Dependency (180+ days) | 58 (22.14%) | 31 (15.58%) | 7 (5.00%) | 2 (2.15%) | 98 (14.12%) |
| Unknown/Unanswered | 51 (19.47%) | 42 (21.11%) | 12 (8.57%) | 9 (9.68%) | 114 (16.43%) |
| Totals | 262 | 199 | 140 | 93 | 694 |

According to our survey results, boys seem to require long-term ventilator and oxygen support more than girls and are more prone to dependency. This could be attributed to the higher incidence in CDH in males. We did not include the "Gentle Ventilation" technique because most parents do not know what it is, and neither did many medical professionals (including pediatric surgeons).

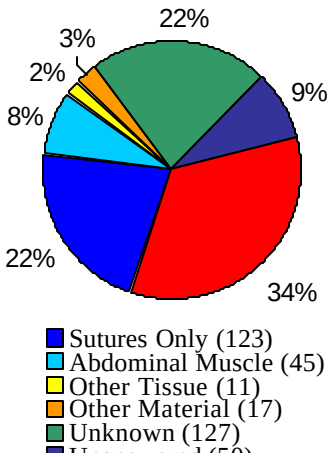
## CDH Repairs

| | Survivors (461) | | Non-Survivors (233) | | |
|---|---|---|---|---|---|
| | Male | Female | Male | Female | Totals |
| **Total Repairs** | 251 | 192 | 57 | 37 | 537 |
| **1 Repair** | 209 (79.77%) | 158 (79.40%) | 50 (35.71%) | 36 (38.71%) | 453 (65.27%) |
| **2 Repairs** | 31 (11.83%) | 25 (12.56%) | 6 (4.29%) | 1 (1.08%) | 63 (9.08%) |
| **3 Repairs** | 7 (2.67%) | 7 (3.52%) | 0 | 0 | 14 (2.02%) |
| **4 Repairs** | 3 (1.15%) | 1 (0.50%) | 0 | 0 | 4 (0.58%) |
| **5 Repairs** | 0 | 0 | 0 | 0 | 0 |
| **6 Repairs** | 1 (0.38%) | 1 (0.50%) | 1 (0.71%) | 0 | 3 (0.43%) |
| **Multiple Repairs** | 42 (16.03) | 34 (17.09%) | 7 (5.00%) | 1 (1.08%) | 84 (12.10%) |
| **No Repairs** | 2 (0.75%) | 1 (0.50%) | 78 (55.71%) | 49 (52.69%) | 130 (18.73%) |
| **Unanswered** | 9 (3.44%) | 6 (3.02%) | 5 (3.57%) | 7 (7.53%) | 27 (3.89%) |

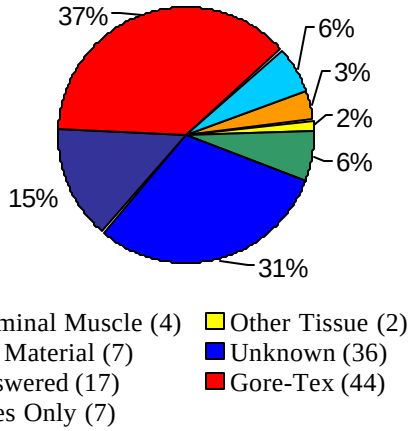


# Types of Repairs

## Repairs in Survivors




## Repairs in Non-Survivors

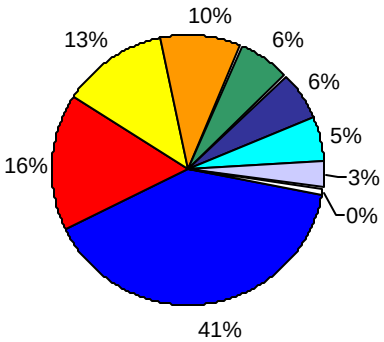



| | Number of Repairs Survivors | | | | | | | Number of Repairs Non-Survivors | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **1** | **2** | **3** | **4** | **5** | **6** | **Total** | **1** | **2** | **3** | **4** | **5** | **6** | **Total** |
| **Gore-Tex** | 146 | 38 | 11 | 2 | 1 | 1 | 199 | 39 | 3 | 1 | 0 | 0 | 1 | 44 |
| **Sutures Only** | 115 | 8 | 0 | 0 | 0 | 0 | 123 | 5 | 1 | 0 | 0 | 1 | 0 | 7 |
| **Abdominal Muscle** | 33 | 11 | 1 | 0 | 0 | 0 | 45 | 3 | 0 | 0 | 1 | 0 | 0 | 4 |
| **Other Tissue** | 8 | 3 | 0 | 0 | 0 | 0 | 11 | 2 | 0 | 0 | 0 | 0 | 0 | 2 |
| **Other Material** | 16 | 1 | 0 | 0 | 0 | 0 | 17 | 5 | 2 | 0 | 0 | 0 | 0 | 7 |
| **Unknown** | 103 | 15 | 5 | 2 | 1 | 1 | 127 | 34 | 2 | 0 | 0 | 0 | 0 | 36 |
| **Unanswered** | 39 | 8 | 2 | 1 | 0 | 0 | 50 | 17 | 0 | 0 | 0 | 0 | 0 | 17 |

# Medical Complications

## Feeding Problems

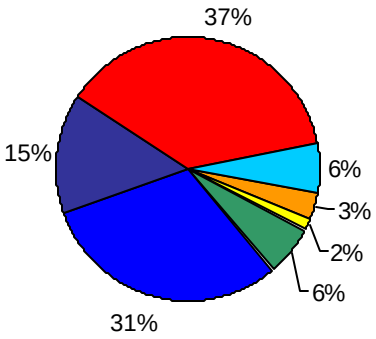
(survivors only)




None (185)
Slight Difficulty (75)
Moderate Difficulty (58)
Currently Using A G-Tube (45)
No Answer/Unknown (28)
Severe Difficulty (28)
Currently Using A Mic-Key (24)
Currently Using An NG-Tube (16)
Currently Using An GJ-Tube (2)

## Developmental Problems

(survivors only)




Abdominal Muscle (4)
Other Tissue (2)
Other Material (7)
Unknown (36)
Unanswered (17)
Gore-Tex (44)
Sutures Only (7)

## Pulmonary Complications (416)

| | Total |
|---|---|
| Pneumonia | 107 |
| RSV | 45 |
| Asthma | 43 |
| Pulmonary Hypertension | 37 |
| Unspecified Respiratory Virus | 21 |
| Tracheostomy | 20 |
| Chronic Lung Disease | 19 |
| Unspecified Respiratory Infections | 15 |
| Bronchopulmonary Dysplasia | 11 |
| Tachyphenia | 11 |
| Pneumothorax | 10 |
| Collaped Lungs | 9 |
| Reactive Airway Disease | 7 |
| Brochialitis | 4 |
| Pseudomonis Pneumonia | 4 |
| Pulmonary Hemmorrhaging | 4 |
| Aspiration | 3 |
| Recurrent Respiratory Infections | 3 |
| Bi-Pap Dependency | 2 |
| Chronic Bronchitis | 2 |
| Parainfluenza | 2 |
| PPHN | 2 |
| Pulmonary Edema | 2 |
| Respiratory Distress | 2 |
| Trach Infection | 2 |
| Tracheomalasia | 2 |
| Adenovirus | 1 |
| Apnea | 1 |
| Atelectasis | 1 |
| Bacterial Infection From ET-Tube | 1 |
| Bilaternal Phrenic Nerve Agenesis | 1 |
| Brochitis | 1 |
| Brochospasms | 1 |
| Bronchomalacia | 1 |
| C-Diff | 1 |
| Colonized Trach | 1 |
| Cpap | 1 |
| Emphysema | 1 |
| Homophelous Influenza Type B | 1 |
| Hyperinflated Left Lung | 1 |
| Influenza | 1 |
| Laryngomalacia | 1 |
| Lobectomy | 1 |
| Phrenic Nerve Palsy | 1 |
| Pleural Effusion | 1 |
| Pneumoectomy | 1 |
| Pneumotosis | 1 |
| Pnuemoperitenium | 1 |
| Pulmonary Artery Stenosis | 1 |
| Pulmonary Effusion | 1 |
| Pulmonary Hypotension | 1 |
| Pulmonary Stenosis | 1 |
| Unspecified Respiratory Disorder | 1 |

## Gastrointestinal Complications (295)

| | Total |
|---|---|
| Reflux | 95 |
| Nissen/Thal Fundoplication | 51 |
| Intestinal Obstruction | 32 |
| Intestinal Adhesions | 20 |
| Intestinal Malrotation | 15 |
| Failure To Thrive | 12 |
| Hiatal Hernia | 12 |
| Intestinal Resection | 4 |
| Pyloric Stenosis | 4 |
| Roto-Virus | 4 |
| Malrotated Stomach | 3 |
| Stomach Viruses | 3 |
| Colostomy | 2 |
| Esophageal Reflux | 2 |
| Ileostomy | 2 |
| Intestinal Rupture | 2 |
| Paraesophageal Hernia | 2 |
| Short Bowel Syndrome | 2 |
| Sub-Glottic Stenosis | 2 |
| TPN Dependency | 2 |
| Volvulus | 2 |
| Abdominal Adhesions | 1 |
| Abdominal Hernia | 1 |
| Cryptosporidium Gastritis | 1 |
| Dumping Syndrome | 1 |
| Gangrene Intestines | 1 |
| Gastric Disorders | 1 |
| Gastric Emptying | 1 |
| Gastrointestinal Herniated Esophagus Ulcers | 1 |
| Gastroparesis | 1 |
| Grade III Vesicoureteral Reflux | 1 |
| Intacecption Of Bowel | 1 |
| Intestinal Injury (Unspecified) | 1 |
| Intestinal Perforation | 1 |
| Meckles Diverticulum | 1 |
| Motility Problems | 1 |
| NEC | 1 |
| Nutrient Absorption Problem | 1 |
| Perforated Intestines | 1 |
| Proctosigmoidectomy | 1 |
| Pylorotomy | 1 |
| Severe Traumatic Ulcer | 1 |
| Stomach Still Above The Diaphragm | 1 |

## Blood Complications (195)

| | Total |
|---|---|
| Unspecified Blood Infection | 107 |
| Staph Blood Infection | 38 |
| Blood Clot | 10 |
| Candida Blood Infection | 8 |
| Infected Incision | 4 |
| Patch Infection | 4 |
| Anemia | 3 |

## Other Complications (216)

| | Total |
|---|---|
| Allergies | 52 |
| Hearing Impairment | 23 |
| Chylo Thorax | 9 |
| Sight Impairment | 9 |
| "Complications" | 8 |
| Dehydration | 6 |
| Deafness | 5 |
| Ear Infections (Frequent) | 5 |
| Hypotonia | 4 |
| Bedsore | 3 |
| G-Tube Complication | 3 |
| Hyaline Membrane Disease | 3 |
| Liver Failure | 3 |
| Seizure Disorder | 3 |
| Speech Impairment | 3 |
| Unspecified Fistula | 3 |
| Unspecified Hemorrhaging | 3 |
| ADHD | 2 |
| Appendectomy | 2 |
| Chest Tubes Put In Incorrectly | 2 |
| Ear Surgery | 2 |
| Internal Hemorrhaging | 2 |
| Low Muscle Tone | 2 |
| Lymph Nodes Cut During CDH Repair | 2 |
| Peritonitis | 2 |
| Retinopathy of Prematurity | 2 |
| Textile Aversion | 2 |
| Throat Infection | 2 |
| ABO | 1 |
| Aggressive Skin Infection | 1 |
| Apraxia | 1 |
| Blindness | 1 |
| Bronchialitis | 1 |
| Carotid Artery Ligated | 1 |
| Chicken Pox | 1 |
| Cholestatic Jaundice | 1 |
| DIC | 1 |
| Erbs Palsy | 1 |
| Excema | 1 |
| Excessive Snoring | 1 |
| Extraphepatic Biliary Obstruction | 1 |
| Eye Surgery | 1 |
| Gastropleural Fistula | 1 |
| Hepatomegaly | 1 |
| Incisional Hernia | 1 |
| Interic Cyst Duplication | 1 |
| ISO Immunization | 1 |
| Jaundice | 1 |
| Kylas Assities | 1 |
| Laceks | 1 |
| Lasix Dependent | 1 |
| Liver Adhesion | 1 |
| Liver Is Still Above Diaphragm | 1 |
| Mastitis | 1 |
| Mega Esophagus | 1 |
| Meningitis | 1 |

| Blood Complications | Total |
|---|---|
| Hepatitis | 3 |
| Central Line Infection | 2 |
| E-Coli Blood Infection | 2 |
| Fetal Circulation | 1 |
| Fungal Blood Infection | 1 |
| Hyperglycemia | 1 |
| Hypernaturmia | 1 |
| Hypocomplementemia | 1 |
| Hypoglycemia | 1 |
| Hyponatraemia | 1 |
| Periventricular Leukomalacia | 1 |
| Persistant Fetal Circulation | 1 |
| PIC Line Sepsis | 1 |
| Pseudomonis Blood Infection | 1 |
| Thrombocytopenia | 1 |
| Unspecified Bacterial Infection | 1 |
| Veq'd Transfusion | 1 |

## Cerebral and Cranial Complications (83)

| | Total |
|---|---|
| Cerebral Palsy | 24 |
| Cerebral Hemorrhaging | 11 |
| Hydocephalus | 9 |
| Seizures | 9 |
| "Brain Damage" | 7 |
| Stroke | 7 |
| Occiput Hematoma | 3 |
| Microcephaly | 2 |
| "Mental Retardation" | 1 |
| Brain Hemorrhage | 1 |
| Brain Infarction | 1 |
| Cerebral Cyst | 1 |
| Cerebral Scar Tissue | 1 |
| Empty Sella Syndrome | 1 |
| Grade 1 Rt Parietal Bleed | 1 |
| Hydroencephalus | 1 |
| Intracranial Bleed | 1 |
| Migraines | 1 |
| Right Occipital Bleed | 1 |

## Uritogenitary Complications (46)

| | Total |
|---|---|
| Kidney Failure | 18 |
| Urinary Tract Infections | 12 |
| Kidney Infection | 10 |
| "Yes" | 1 |
| Chronic Urinary Tract Infections | 1 |
| Kidney Reflux | 1 |
| Kidney Stones | 1 |
| Nephritis | 1 |
| Protein Urial And Hematuria | 1 |

| Other Complications | Total |
|---|---|
| Mild Spatic Diaplegia | 1 |
| Morphine Withdrawl | 1 |
| Narrow Stryder | 1 |
| Oral Aversion | 1 |
| Perirectal Abscess | 1 |
| POD | 1 |
| Poor Motor Skills | 1 |
| Progressive Metabolic Acidosis | 1 |
| Prosthetic Replacement | 1 |
| PVL | 1 |
| Recurrent Fevers | 1 |
| Sensory/Vestibular/Tactile Dysfunction | 1 |
| Septic Shock | 1 |
| Severe Laryngomalacia | 1 |
| Severe Oral Facial Aversion | 1 |
| Splenic Torsion | 1 |
| Stridor | 1 |
| Tracheomalacia | 1 |
| Ventral Hernia | 1 |
| VP Shunt | 1 |
| Wound Dehiscience | 1 |

## Unknown/Unanswered

| | |
|---|---|
| Survivors | 35 |
| Non-Survivors | 82 |

## **No Complications** (survivors only)

| | |
|---|---|
| Survivors | 142 |

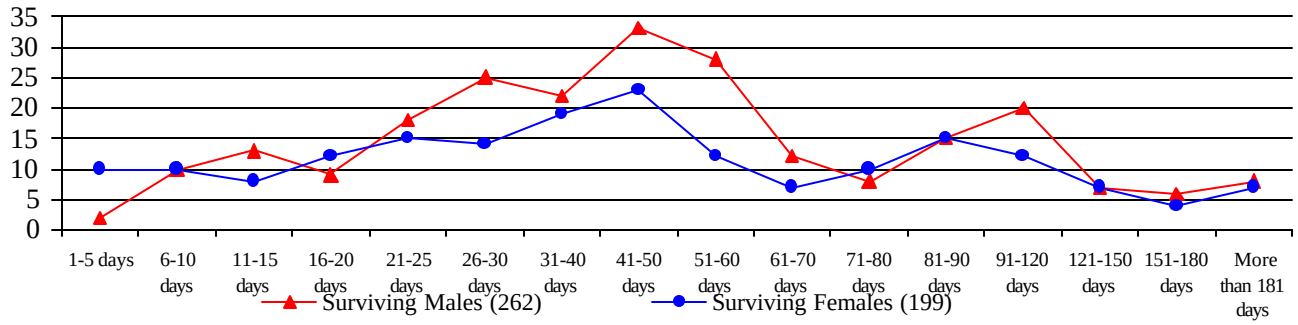
## Skeletal Complications (56)

| | Total |
|---|---|
| Scoliosis | 31 |
| Chest Pectus | 23 |
| Curved Rib | 1 |
| Vertebrae Fusion- Partial Congenital | 1 |

## Cardiac Complications (26)

| | Total |
|---|---|
| Mitrocardial Infarction | 4 |
| Cardiac Arrest | 3 |
| Congestive Heart Failure | 3 |
| Bradycardia | 2 |
| Enlarged Ventricle | 2 |
| Blocked Superior Vena Cava | 1 |
| Cardiac Blood Clot | 1 |
| Cardiac Stent | 1 |
| Cardiac Stun | 1 |
| Chest Tube Punctured Heart | 1 |
| CMV | 1 |
| Coarctation Of Aorta | 1 |
| Grade II Intraventicular Hemorrhage | 1 |
| Right Myocardial Embolism | 1 |
| SVC Syndrome | 1 |
| Unspecified Clotting | 1 |
| Unspecified Heart Problem | 1 |

# Average Hospital Stay




| Survivors (461) | Male | Female |
|---|---|---|
| **Shortest Time** | 5 days | 2 days |
| **Longest Time** | 730 days | 365 days |
| **Average** | 62.36 days | 58.7 days |

# Congenital Diaphragmatic Hernia Research Survey Results

Taken from 144 10-page, detailed surveys filled out by grieving parents and parents of CDH children over 1 year of age. We do not include younger survivors because we believe that waiting for the first year allows most of child's health problems to be diagnosed that could not be diagnosed in the neonatal period (developmental delay, feeding problems, etc.).

## Parental Ethnicity

| Parents | # |
|---|---|
| "American" | 83 |
| German | 35 |
| Irish | 34 |
| British | 26 |
| "White/Caucasian" | 24 |
| Italian | 20 |
| Scottish | 11 |
| Canadian | 10 |
| American Indian | 9 |
| French | 9 |
| "European" | 7 |
| Australian | 7 |
| Danish | 5 |
| French Canadian | 5 |
| Hungarian | 5 |
| Polish | 5 |
| Asian Indian | 4 |
| Dutch | 4 |
| Swedish | 4 |
| Hispanic | 3 |
| New Zealand | 3 |
| Russian | 3 |
| Belgian | 2 |
| Croatian | 2 |
| Greek | 2 |
| Norweigen | 2 |
| Puerto Rican | 2 |
| Slovinian | 2 |
| Spanish | 2 |
| Czechoslovakian | 1 |
| Friesian | 1 |
| Icelandic | 1 |
| Maltese | 1 |
| Menonite | 1 |
| Penn. Dutch | 1 |
| Slavic | 1 |
| Ukranian | 1 |
| Unanswered/Unknown | 4 |

## Parental Religious Affiliations

| Parents | # |
|---|---|
| Catholic/Roman Catholic | 75 |
| "Christian" | 26 |
| Baptist | 23 |
| Methodist | 21 |
| None | 19 |
| Protestant | 19 |
| Jewish | 7 |
| Lutheran | 7 |
| Church of Christ | 5 |
| Church of England | 5 |
| Presbyterian | 5 |
| Seventh Day Adventist | 4 |
| Southern Baptist | 3 |
| Anglican | 2 |
| Hindu | 2 |
| Mormon | 2 |
| Penecostal | 2 |
| Charismatic Christian | 1 |
| Episcopalian | 1 |
| Unanswered/Unknown | 15 |

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 and Grandparent Occupations

| Parents | # |
|---|---|
| Homemaking | 36 |
| Medical | 25 |
| Computer | 22 |
| Education | 14 |
| Accounting | 13 |
| Management | 12 |
| Sales | 10 |
| Military | 9 |
| Secretarial | 9 |
| Automotive | 7 |
| Construction | 7 |
| Factory Work | 7 |
| Law | 7 |
| Engineering | 6 |
| Landscaping | 4 |
| Maintenance | 4 |
| Retail | 4 |
| Telephone | 4 |
| Banking | 3 |
| Food Service | 3 |
| Security | 3 |
| Airplane | 2 |
| Boating | 2 |
| Business Owner | 2 |
| Extermination | 2 |
| Firefighting | 2 |
| Goldsmith | 2 |
| Heating and Air Conditioning | 2 |
| Lodging | 2 |
| Printing | 2 |
| Architecture | 1 |
| Athletics | 1 |
| Carpentry | 1 |
| Chemicals/Science | 1 |
| Child Care | 1 |
| Cosmetics | 1 |
| Media | 1 |
| Postal | 1 |
| Social Work | 1 |
| Welding | 1 |
| Unanswered/Unknown | 5 |

We studied the occupations of parents and grandparents to learn about levels of stress and environmental exposures on the job. We have a high rate of medical professionals in both the parents and grandparents, this could be attributed to stress or chemical exposure, as many of the occupations can. Even homemakers are subjected to a high amount of stress and cleaning chemicals. We were looking for correlations of occupations that either showed a majority of parents/grandparents in highly stressful jobs or high chemical exposures - we found both.

| Grandparents | # |
|---|---|
| Homemaking | 84 |
| Secretarial | 36 |
| Education | 26 |
| Medical | 22 |
| Sales | 19 |
| Construction | 17 |
| Automotive | 14 |
| Farming | 13 |
| Management | 13 |
| Engineering | 11 |
| Electrical | 10 |
| Telephone | 10 |
| Trucking | 9 |
| Accounting | 8 |
| Realty | 8 |
| Business Executive | 7 |
| Clerical | 7 |
| Custodial | 7 |
| Business Owner | 6 |
| Carpentry | 6 |
| Civil Service | 5 |
| Food Service | 5 |
| Military | 5 |
| Transportation | 5 |
| Banking | 4 |
| Child Care | 4 |
| Computer | 4 |
| Insurance | 4 |
| Specialized Trade | 4 |
| Bookkeeping | 3 |
| Clergy | 3 |
| Law | 3 |
| Maintenance | 3 |
| Postal | 3 |
| Printing | 3 |
| Security | 3 |
| Railroad | 3 |
| Boating | 2 |
| Chemicals/Science | 2 |
| Factory Work | 2 |
| Firefighting | 2 |
| Goldsmith | 2 |
| Landlord | 2 |
| Logging | 2 |
| Media | 2 |
| Music | 2 |
| Retail | 2 |
| Sewing | 2 |
| Welding | 2 |
| Advertising | 1 |
| Airline Work | 1 |
| Architecture | 1 |
| Cosmetics | 1 |
| Landscaping | 1 |
| Politics | 1 |
| Social Work | 1 |
| Statistician | 1 |
| Unanswered/Unknown | 55 |

# Environmental Exposures

| | Yes | No | Unanswered |
|---|---|---|---|
| Resided Near Airport | 22 | 99 | 0 |
| Agriculture Region | 19 | 102 | 0 |
| Chemical Exposure During Pregnancy | 13 | 108 | 0 |
| High Voltage Power Lines/Electromagnetic Fields | 11 | 109 | 1 |
| Resided Near Factory During Preconception | 11 | 110 | 0 |
| Electric Blanket During Pregnancy | 7 | 114 | 0 |
| Struck By Lightening/Electrocuted | 7 | 114 | 0 |
| Resided Near Factory During Pregnancy | 6 | 115 | 0 |
| Hazardous Waste Site- Pregnancy | 5 | 116 | 0 |
| Hazardous Waste Site- Mother (pre-conception) | 4 | 117 | 0 |
| Hazardous Waste Site- Father (pre-conception) | 2 | 119 | 0 |

# Family Medical Histories

| | Parent | Sibling | Grandparent | Aunt/Uncle | Cousin | Distant Relative | Total |
|---|---|---|---|---|---|---|---|
| High Blood Pressure | 9 | 1 | 78 | 10 | 0 | 11 | 109 |
| Cancer | 3 | 0 | 57 | 9 | 1 | 27 | 97 |
| Asthma | 17 | 7 | 13 | 18 | 9 | 2 | 66 |
| Heart Defects | 6 | 5 | 16 | 11 | 13 | 3 | 54 |
| Diabetes | 2 | 0 | 11 | 7 | 4 | 14 | 38 |
| Strokes | 0 | 0 | 20 | 2 | 1 | 11 | 34 |
| Anemia | 19 | 0 | 4 | 5 | 0 | 4 | 32 |
| Reflux | 7 | 3 | 10 | 2 | 7 | 2 | 31 |
| Heart Attack/Disease | 0 | 0 | 19 | 1 | 0 | 8 | 28 |
| Neuropsychiatric Disorders | 4 | 1 | 6 | 6 | 0 | 2 | 19 |
| Rh Factor Complications | 5 | 0 | 6 | 2 | 3 | 0 | 16 |
| Epilepsy | 1 | 1 | 1 | 4 | 4 | 2 | 13 |
| STDs (at time of conception/ pregnancy) | 11 | 0 | 1 | 0 | 0 | 0 | 12 |
| Eating Disorders | 2 | 0 | 1 | 4 | 1 | 3 | 11 |
| Genetic Abnormalities (non-Down's) | 0 | 0 | 0 | 1 | 6 | 2 | 9 |
| CDH | 0 | 5 | 0 | 0 | 0 | 3 | 8 |
| Diabetes, Gestational | 4 | 0 | 0 | 4 | 0 | 0 | 8 |
| Hypo/Hyperthyroidism | 3 | 1 | 3 | 1 | 0 | 0 | 8 |
| Seizure Disorder (Non-Epilepsy) | 1 | 1 | 2 | 2 | 2 | 0 | 8 |
| Down's Syndrome | 0 | 1 | 0 | 2 | 3 | 1 | 7 |
| Blood Disorders | 0 | 0 | 2 | 1 | 1 | 1 | 5 |
| Unspecified Birth Defect | 0 | 0 | 0 | 1 | 3 | 1 | 5 |
| "Multiple Birth Defects" | 0 | 0 | 0 | 1 | 2 | 1 | 4 |
| Limbs and Extremities, Abnormal | 0 | 2 | 0 | 0 | 1 | 1 | 4 |
| Lyme's Disease | 3 | 0 | 0 | 0 | 0 | 0 | 3 |
| Non-Chromosomal Syndromes | 0 | 1 | 0 | 0 | 2 | 0 | 3 |
| Osteogenesis Imperfecta | 0 | 0 | 0 | 2 | 1 | 0 | 3 |
| Tilted Uterus | 3 | - | - | - | - | - | 3 |
| Autism | 0 | 1 | 0 | 0 | 1 | 0 | 2 |
| Cleft Lip/Palate | 0 | 0 | 0 | 1 | 0 | 1 | 2 |
| Fryn's Syndrome | 0 | 2 | 0 | 0 | 0 | 0 | 2 |
| Hirchsprung's Disease | 0 | 2 | 0 | 0 | 0 | 0 | 2 |
| Septated Uterus | 2 | - | - | - | - | - | 2 |
| Spina Bifida | 0 | 1 | 0 | 1 | 0 | 0 | 2 |

# Family Pregnancy Histories

| | Mother | Maternal Grandmother | Paternal Grandmother | Total |
|---|---|---|---|---|
| **Miscarriages** | 98 | 42 | 36 | 176 |
| **Stillbirths** | 3 | 10 | 4 | 17 |
| **Siblings** | 144 | - | - | 144 |

# Parental Exposures Up To The Time of Conception

| Exposure | Yes | No | Don't Know | Mother | Father | Before Conc. | At Conc. |
|---|---|---|---|---|---|---|---|
| Computers | 84 | 34 | 3 | 71 | 66 | 84 | 25 |
| Natural Gas | 70 | 46 | 5 | 68 | 53 | 66 | 15 |
| Stress | 69 | 49 | 3 | 66 | 38 | 46 | 7 |
| Aerosol Spray | 67 | 44 | 10 | 67 | 49 | 67 | 15 |
| Paint Fumes | 55 | 61 | 5 | 46 | 45 | 42 | 4 |
| Chicken Pox | 51 | 67 | 3 | 50 | 45 | 49 | 0 |
| X-rays | 43 | 75 | 3 | 43 | 32 | 41 | 2 |
| Solvents | 36 | 71 | 14 | 22 | 14 | 34 | 3 |
| Insect Repellant | 28 | 84 | 9 | 23 | 25 | 26 | 1 |
| Glues | 23 | 90 | 8 | 18 | 20 | 23 | 0 |
| Marijuana | 22 | 99 | 0 | 19 | 18 | 21 | 1 |
| Professional Spraying | 20 | 87 | 14 | 17 | 15 | 17 | 1 |
| Diesel Fuel | 19 | 95 | 7 | 5 | 17 | 19 | 0 |
| DEET | 17 | 86 | 18 | 12 | 15 | 17 | 0 |
| Photography Chemicals | 17 | 97 | 7 | 13 | 5 | 17 | 0 |
| Steroids | 17 | 102 | 2 | 13 | 4 | 7 | 3 |
| High Temperatures | 16 | 98 | 7 | 14 | 10 | 10 | 0 |
| Asbestos | 15 | 88 | 18 | 6 | 13 | 14 | 2 |
| Formaldehyde | 15 | 91 | 15 | 11 | 13 | 15 | 1 |
| Industrial Chemicals | 15 | 93 | 13 | 4 | 12 | 15 | 3 |
| Printing Inks | 15 | 97 | 9 | 9 | 9 | 15 | 2 |
| Agriculture Spraying | 14 | 92 | 15 | 11 | 10 | 12 | 2 |
| Nasal Spray | 14 | 103 | 4 | 8 | 7 | 14 | 4 |
| Fiberglass | 12 | 101 | 8 | 5 | 11 | 12 | 2 |
| Mercury | 11 | 97 | 13 | 5 | 9 | 12 | 3 |
| Rubella | 11 | 101 | 9 | 9 | 8 | 11 | 0 |
| Lead | 9 | 94 | 18 | 7 | 6 | 12 | 5 |
| Coal | 8 | 101 | 12 | 4 | 7 | 8 | 0 |
| Diazanon | 8 | 91 | 22 | 6 | 7 | 7 | 0 |
| Tar | 7 | 104 | 10 | 3 | 7 | 6 | 0 |
| Organic Solvents | 6 | 95 | 20 | 4 | 3 | 6 | 1 |
| Trichlorethylene | 6 | 99 | 16 | 1 | 6 | 6 | 0 |
| Cocaine | 5 | 115 | 1 | 2 | 3 | 5 | 0 |
| Dursban | 5 | 91 | 25 | 1 | 5 | 5 | 0 |
| Other Insect Repellants | 5 | 100 | 16 | 4 | 5 | 5 | 1 |
| Other Pesticides | 5 | 103 | 13 | 3 | 4 | 4 | 0 |
| PCBs | 5 | 97 | 19 | 1 | 4 | 5 | 0 |
| Benzocaine Sulfur | 4 | 99 | 18 | 3 | 3 | 2 | 0 |
| Lindane | 4 | 94 | 23 | 2 | 2 | 4 | 1 |
| Permethrin | 4 | 98 | 19 | 3 | 3 | 4 | 0 |
| Sodium Chlorate | 4 | 99 | 18 | 2 | 3 | 2 | 0 |
| Xylene | 4 | 103 | 14 | 0 | 4 | 4 | 0 |
| Chlordane | 3 | 94 | 24 | 2 | 1 | 3 | 0 |
| Hashish | 3 | 115 | 3 | 3 | 0 | 3 | 0 |
| LSD | 3 | 116 | 2 | 3 | 1 | 3 | 0 |
| Uranium | 3 | 107 | 11 | 1 | 2 | 2 | 0 |
| Chemical Warfare | 2 | 119 | 0 | 0 | 2 | 2 | 0 |
| Damaged Microwaves | 2 | 112 | 7 | 2 | 2 | 2 | 2 |
| Nitrofen | 2 | 93 | 26 | 2 | 2 | 2 | 0 |
| Quinine | 2 | 102 | 17 | 1 | 1 | 2 | 0 |

# Maternal Exposures During Pregnancy

(in 141pregnancies)

We included only chemical exposures that affected more than 1 member. While we believe that most of this category is accurate, we have to question the "stress" column. We meant to include only exposures to high levels of stress, such as grief, loss of jobs, natural disasters, divorce, etc, but many parents wrote in "highly stressful life", "always", or other such vague responses.

| Exposure | Yes | No | Don't Know | 1st Tri. | 2nd Tri. | 3rd Tri. | Unspec. |
|---|---|---|---|---|---|---|---|
| Pre-Natal Vitamins | 54 (44.63%) | 66 (54.55%) | 1 (0.83%) | 5 | 1 | 2 | 49 |
| Caffeine | 51 (42.15%) | 68 (56.20%) | 2 (1.65%) | 4 | 1 | 0 | 47 |
| Computers | 48 (39.67%) | 70 (57.85%) | 3 (2.48%) | 1 | 1 | 0 | 47 |
| Stress | 41 (33.88%) | 77 (63.64%) | 3 (2.48%) | 6 | 4 | 3 | 32 |
| Antacids | 38 (31.40%) | 81 (66.94%) | 2 (1.65%) | 5 | 7 | 8 | 24 |
| Natural Gas | 36 (29.75%) | 80 (66.12%) | 5 (4.13%) | 5 | 2 | 0 | 29 |
| Aerosol Spray | 31 (25.62%) | 80 (66.12%) | 10 (8.26%) | 2 | 0 | 0 | 29 |
| Folic Acid | 28 (23.14%) | 91 (75.21%) | 2 (1.65%) | 4 | 0 | 0 | 24 |
| Antibiotics | 21 (17.36%) | 97 (80.17%) | 3 (2.48%) | 6 | 2 | 6 | 9 |
| Alcohol | 19 (15.70%) | 102 (84.30%) | 0 | 7 | 0 | 2 | 9 |
| Painkillers | 18 (14.88%) | 101 (83.47%) | 2 (1.65%) | 3 | 2 | 1 | 13 |
| Allergy/Cough/Cold Medications | 17 (14.05%) | 97 (80.17%) | 7 (5.79%) | 5 | 3 | 3 | 7 |
| Paint Fumes | 16 (13.22%) | 100 (82.64%) | 5 (4.13%) | 6 | 4 | 3 | 6 |
| Nicotine | 12 (9.92%) | 107 (88.43%) | 2 (1.65%) | 1 | 0 | 0 | 11 |
| Anti-Nausea Medications | 11 (9.09%) | 107 (88.43%) | 3 (2.48%) | 7 | 0 | 0 | 4 |
| Steroids | 11 (9.09%) | 108 (89.26%) | 2 (1.65%) | 2 | 3 | 6 | 2 |
| Vaginal Medications | 11 (9.09%) | 108 (89.26%) | 2 (1.65%) | 5 | 0 | 2 | 5 |
| Insect Repellant | 7 (5.79%) | 105 (86.78%) | 9 (7.44%) | 1 | 2 | 1 | 4 |
| Vitamin A | 7 (5.79%) | 91 (75.21%) | 4 (3.31%) | 1 | 0 | 0 | 6 |
| Anesthetics | 6 (4.96%) | 113 (93.39%) | 2 (1.65%) | 1 | 2 | 1 | 2 |
| Chicken Pox | 6 (4.96%) | 112 (92.56%) | 3 (2.48%) | 3 | 1 | 2 | 0 |
| Professional Spraying | 6 (4.96%) | 101 (83.47%) | 18 (14.88%) | 2 | 2 | 1 | 3 |
| Solvents | 6 (4.96%) | 101 (83.47%) | 18 (14.88%) | 1 | 1 | 0 | 5 |
| Agriculture Spraying | 5 (4.13%) | 101 (83.47%) | 15 (12.40%) | 1 | 2 | 0 | 3 |
| Aspirin | 5 (4.13%) | 115 (95.04%) | 1 (0.83%) | 1 | 0 | 1 | 3 |
| High Temperatures | 5 (4.13%) | 109 (90.08%) | 8 (6.61%) | 1 | 1 | 1 | 2 |
| Laxatives | 5 (4.13%) | 114 (94.21%) | 2 (1.65%) | 1 | 0 | 1 | 3 |
| Lead | 5 (4.13%) | 98 (80.99%) | 18 (14.88%) | 1 | 0 | 0 | 4 |
| Mercury | 5 (4.13%) | 103 (85.12%) | 13 (10.74%) | 1 | 0 | 0 | 4 |
| Thyroid Medication | 5 (4.13%) | 114 (94.21%) | 2 (1.65%) | 0 | 0 | 0 | 5 |
| DEET | 4 (3.31%) | 99 (81.82%) | 18 (14.88%) | 0 | 0 | 0 | 4 |
| Diabetes Medication | 4 (3.31%) | 115 (95.04%) | 2 (1.65%) | 0 | 1 | 3 | 1 |
| Glues | 4 (3.31%) | 109 (90.08%) | 8 (6.61%) | 0 | 0 | 1 | 3 |
| Sedatives | 4 (3.31%) | 115 (95.04%) | 2 (1.65%) | 1 | 1 | 0 | 2 |
| Blood Pressure Medication | 3 (2.48%) | 116 (95.87%) | 2 (1.65%) | 0 | 0 | 0 | 1 |
| Muscle Relaxers | 3 (2.48%) | 115 (95.04%) | 3 (2.48%) | 0 | 1 | 2 | 0 |
| Printing Inks | 3 (2.48%) | 109 (90.08%) | 9 (7.44%) | 0 | 0 | 0 | 3 |
| Artificial Hormones | 2 (1.65%) | 118 (97.52%) | 1 (0.83%) | 1 | 0 | 0 | 1 |
| Asthma Medication | 2 (1.65%) | 117 (96.69%) | 2 (1.65%) | 1 | 0 | 0 | 1 |
| Bendectin | 2 (1.65%) | 116 (95.87%) | 3 (2.48%) | 2 | 0 | 0 | 0 |
| Benzocaine Sulfur | 2 (1.65%) | 101 (83.47%) | 18 (14.88%) | 1 | 0 | 0 | 1 |
| Blood Thinners | 2 (1.65%) | 117 (96.69%) | 2 (1.65%) | 0 | 0 | 1 | 1 |
| Damaged Microwaves | 2 (1.65%) | 112 (92.56%) | 7 (5.79%) | 1 | 1 | 1 | 1 |
| Photography Chemicals | 2 (1.65%) | 112 (92.56%) | 7 (5.79%) | 2 | 2 | 2 | 0 |
| X-rays | 2 (1.65%) | 116 (95.87%) | 3 (2.48%) | 1 | 1 | 0 | 0 |

# Pregnancy Histories

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

| | VO | O | Y | N | U | % Yes |
|---|---|---|---|---|---|---|
| Fetal Movement | 47 | 44 | 28 | 1 | 1 | 98.35 |
| Fatigue | 15 | 29 | 56 | 21 | 0 | 82.64 |
| Heart Burn | 25 | 18 | 43 | 32 | 3 | 71.07 |
| Morning Sickness | 28 | 8 | 48 | 37 | 0 | 69.42 |
| Mood Swings | 6 | 12 | 63 | 33 | 7 | 66.94 |
| Fetal Hiccups | 18 | 23 | 38 | 30 | 12 | 65.29 |
| Sleeping Problems | 13 | 11 | 55 | 41 | 1 | 65.29 |
| Headaches | 6 | 11 | 60 | 40 | 4 | 63.64 |
| Food Cravings | 6 | 22 | 40 | 48 | 5 | 56.20 |
| Reduced Sex Drive | 9 | 9 | 49 | 47 | 7 | 55.37 |
| Constipation | 9 | 11 | 44 | 52 | 5 | 52.89 |
| Colds | 0 | 1 | 62 | 52 | 6 | 52.07 |
| Breathing Problems | 2 | 3 | 37 | 76 | 3 | 34.71 |
| Bleeding Gums | 0 | 5 | 34 | 79 | 3 | 32.23 |
| Dental Work | 0 | 0 | 39 | 78 | 4 | 32.23 |
| Polyhydramnios | 8 | 1 | 23 | 75 | 14 | 26.45 |
| Hot/Cold Sensitivity | 3 | 5 | 22 | 81 | 10 | 24.79 |
| Joint Pain | 1 | 6 | 20 | 89 | 5 | 22.31 |
| Hair Dye | 3 | 3 | 20 | 94 | 1 | 21.49 |
| Anemia | 5 | 2 | 18 | 95 | 1 | 20.66 |
| Depression | 2 | 2 | 20 | 96 | 1 | 19.83 |
| Flu | 0 | 0 | 24 | 89 | 8 | 19.83 |
| Emotional Problems | 2 | 3 | 18 | 95 | 3 | 19.01 |
| Allergies | 1 | 2 | 18 | 99 | 1 | 17.36 |
| Dehydration | 2 | 0 | 16 | 100 | 3 | 14.88 |
| Night Sweats | 2 | 0 | 15 | 101 | 3 | 14.05 |
| Hot Tub | 0 | 2 | 12 | 105 | 2 | 11.57 |
| Low Blood Pressure | 2 | 1 | 11 | 104 | 3 | 11.57 |
| Unexplained Itching | 2 | 5 | 7 | 106 | 1 | 11.57 |
| High Blood Pressure | 2 | 1 | 10 | 106 | 2 | 10.74 |
| Hair Loss | 0 | 3 | 9 | 104 | 5 | 9.92 |
| In Utero Steroid Treatments | - | - | 12 | 109 | 0 | 9.92 |
| Hair Permanent | 0 | 0 | 11 | 105 | 5 | 9.09 |
| Unexplained Rashes | 0 | 4 | 7 | 109 | 1 | 9.09 |
| Hyperemesis | 2 | 2 | 4 | 94 | 19 | 6.61 |
| Genital Herpes | 0 | 0 | 6 | 115 | 0 | 4.96 |
| Other Hair Treatments | 0 | 0 | 6 | 114 | 2 | 4.96 |
| Strep B | 0 | 0 | 6 | 114 | 1 | 4.96 |
| Artificial Nails | 0 | 0 | 5 | 116 | 0 | 4.13 |
| Gestational Diabetes | - | - | 5 | 116 | 0 | 4.13 |
| Vaccinations | 0 | 0 | 5 | 116 | 0 | 4.13 |
| Multiple Pregnancy | - | - | 4 | 117 | - | 3.31 |
| PROM | 0 | 0 | 4 | 117 | 0 | 3.31 |
| Toxemia | 2 | 0 | 2 | 116 | 1 | 3.31 |
| Unexplained Fevers | 1 | 0 | 2 | 118 | 0 | 2.48 |
| Whirl Pool | 0 | 0 | 3 | 116 | 2 | 2.48 |
| Non-Food Cravings | 0 | 0 | 2 | 115 | 4 | 1.65 |

# Pregnancy Testing

| | Survivors Diagnosed In Utero (47) | Survivors Diagnosed After Birth (38) | Non-Survivors Diagnosed In Utero (21) | Non-Survivors Diagnosed After Birth (15) | Totals |
|---|---|---|---|---|---|
| **Ultrasound** | | | | | |
| No Ultrasound | n/a | 7 | n/a | 1 | 8 |
| 1 Ultrasound | 1 | 6 | 2 | 5 | 14 |
| 2 Ultrasounds | 4 | 13 | 0 | 5 | 22 |
| 3 Ultrasounds | 6 | 4 | 3 | 1 | 14 |
| 4 Ultrasounds | 3 | 1 | 1 | 0 | 5 |
| 5 or More Ultrasounds | 30 | 7 | 15 | 2 | 54 |
| Unanswered/Unknown | 3 | 0 | 0 | 0 | 3 |
| Total Number | 348 | 111 | 185 | 35 | 679 |
| 4 - 15 weeks | 21 | 29 | 8 | 3 | 61 |
| 16 - 25 weeks | 62 | 17 | 37 | 7 | 123 |
| 26 weeks - birth | 99 | 25 | 52 | 8 | 184 |
| Unspecified | 166 | 40 | 88 | 7 | 301 |
| Abnormal Findings | 46 | 6 | 21 | 3 | 76 |
| **Amniocentesis** | | | | | |
| Total Number | 47 | 8 | 19 | 3 | 77 |
| No Amniocentesis | 14 | 33 | 4 | 13 | 64 |
| Unanswered | 0 | 0 | 1 | 0 | 1 |
| Abnormal Findings | 2 | 0 | 1 | 1 | 4 |
| **AFP** | | | | | |
| Total Number | 20 | 11 | 11 | 7 | 49 |
| No AFP | 26 | 28 | 12 | 8 | 74 |
| Unanswered | 0 | 0 | 1 | 0 | 1 |
| Abnormal Findings | 1 | 0 | 0 | 1 | 2 |
| **In Utero Procedures** | | | | | |
| In Utero CDH Repair | 2 | n/a | 1 | n/a | 3 |
| Tracheal Ligation | 2 | n/a | 2 | n/a | 4 |
| In Utero Steroid Treatments | 8 | 1 | 3 | 0 | 12 |

Despite the large number of ultrasounds in the 2nd and 3rd trimesters, many CDH babies are still undiagnosed. Several babies had "abnormal" ultrasound findings, but were still not diagnosed with CDH. 3 mothers listed that their child's CDH was found by amniocentesis; currently amniocentesis can tell many things, such as abnormal chromosomes and lung growth, but, in itself, it cannot diagnose CDH. Also, only 2 mothers had abnormal AFP results, leading us to believe that AFP is not a good indicator for CDH or lung growth.

# Labor and Delivery History

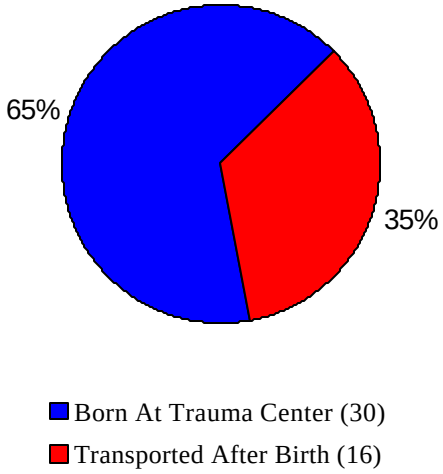
| | Survivors Diagnosed In Utero (46) | Survivors Diagnosed After Birth (39) | Non-Survivors Diagnosed In Utero (21) | Non-Survivors Diagnosed After Birth (15) | Totals |
|---|---|---|---|---|---|
| **C-Section** | 20 (43.48%) | 7 (17.95%) | 10 (47.62%) | 4 (26.67%) | 41 (33.88%) |
| **Vaginal** | 26 (56.52%) | 31 (79.49%) | 10 (47.62%) | 10 (66.67%) | 77 (63.64%) |
| **VBAC** | 1 (2.17%) | 0 | 0 | 1 (6.67%) | 2 (1.65%) |
| **Forceps** | 6 (13.04%) | 4 (10.26%) | 4 (19.05%) | 2 (13.33%) | 16 (13.22%) |
| **Epideral** | 32 (69.57%) | 24 (61.54%) | 13 (61.94%) | 10 (66.67%) | 79 (65.29%) |
| **Demoral** | 5 (10.87%) | 6 (15.38%) | 1 (4.76%) | 3 (20.00%) | 15 (12.40%) |
| **Natural Delivery (no drugs)** | 3 (6.52%) | 5 (12.82%) | 0 | 1 (6.67%) | 9 (7.44%) |

# Labor and Delivery Complications

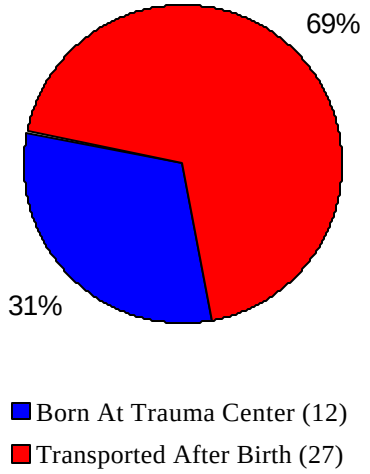
| | Survivors | Non-Survivors | Total |
|---|---|---|---|
| **Fetal Distress** | 9 | 4 | 13 |
| **Premature Delivery** | 19 | 11 | 30 |
| **Breech Delivery** | 3 | 3 | 6 |
| **Stillbirth** | n/a | 3 | 3 |
| **Chorioamniotisis** | 0 | 1 | 1 |
| **Funditis** | 0 | 1 | 1 |
| **Umbilical Cord Injuries** | 2 | 2 | 4 |
| **Fetal Stroke** | 1 | 0 | 1 |
| **Multiple Birth** | 4 | 0 | 4 |
| **Emergency C-Section** | 1 | 0 | 1 |

# Delivery Location

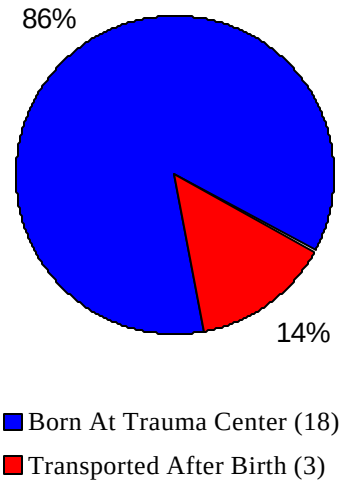
**Survivors Diagnosed In Utero (46)**



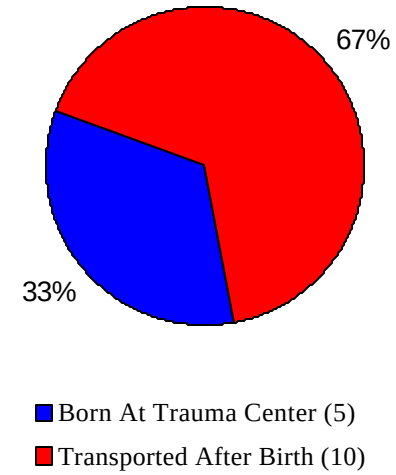

**Survivors Diagnosed After Birth (39)**




**Non-Survivors Diagnosed In Utero**



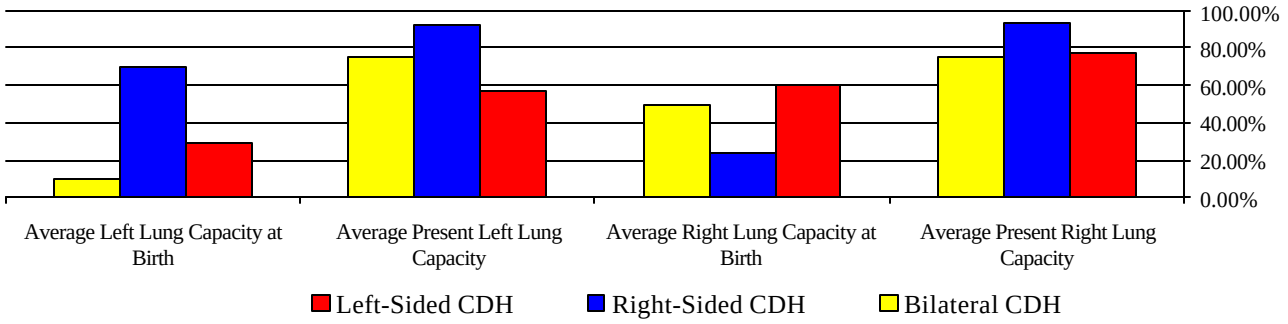

**Non-Survivors Diagnosed After Birth**



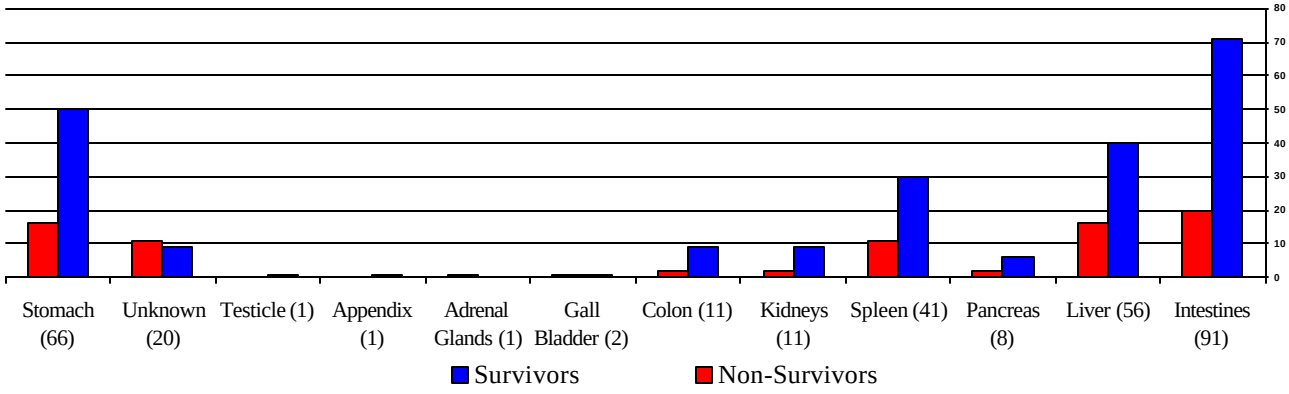
# Lung Capacity

| | Survivors | | | Non-Survivors | | |
|---|---|---|---|---|---|---|
| | L-Sided CDH | R-Sided CDH | Bilateral CDH | L-Sided CDH | R-Sided CDH | Bilateral CDH |
| **Number** | 69 | 15 | 1 | 31 | 4 | 1 |
| **Average Left Lung Capacity at Birth** | 28.68% | 69.50% | 10.00% | 26.33% | 51.67% | u/a |
| **Average Present Left Lung Capacity** | 57.18% | 92.22% | 75.00% | - | - | - |
| **Average Right Lung Capacity at Birth** | 60.37% | 23.75% | 50.00% | 36.56% | 16.67% | u/a |
| **Average Present Right Lung Capacity** | 77.00% | 93.25% | 75.00% | - | - | - |
| **Unknown/No Answer** | 29 | 5 | 0 | 15 | 1 | 1 |

## Lung Growth In Survivors




## Organs In The Chest Cavity




# Therapies

(survivors only)

| | Male (46) | Female (39) | Total (85) |
|---|---|---|---|
| Physical Therapy | 26 (56.52%) | 13 (33.33%) | 39 (45.88%) |
| Occupational Therapy | 15 (32.61%) | 12 (30.77%) | 27 (31.76%) |
| Speech Therapy | 13 (28.26%) | 8 (20.51%) | 21 (24.71%) |
| Feeding Therapy | 1 (2.17%) | 1 (2.56%) | 2 (2.35%) |
| Physiotherapy | 1 (2.17%) | 1 (2.56%) | 2 (2.35%) |
| Developmental Therapy | 1 (2.17%) | 0 | 1 (1.18%) |
| Massage Therapy | 0 | 1 (2.56%) | 1 (1.18%) |

# Detailed Medical Histories

*Listing of Individual Complications and Birth Defects have been omitted to insure member privacy. A complete listing of all members' complications and birth defects can be found in the "Membership Form Survey Results" section.

| Case# | Gender | Side of CDH | Type of CDH | Year of Birth | Gestational Age At Birth | Birth Type | Birth Weight (oz) | Ultrasounds Number- Findings | Age Child Was Diagnosed | Hospital Stay (days) |
|---|---|---|---|---|---|---|---|---|---|---|
| D0001 | Male | left | Agen. of L Hemi. | 1995 | 32 | C-Section | 68 | 3- CDH | 18 wiu | 129 |
| D0002 | Female | left | Agen. of L Hemi. | 1993 | 38 | Vaginal | 111 | 30- CDH, enlarged kidneys, cleft palate | 32 wiu | 180 |
| D0003 | Male | left | u/k | 1995 | 34 | Vaginal | 109 | CDH | 16 wiu | 1 |
| D0004 | Male | left | u/k | 1995 | 37 | C-Section | 95 | 2- borderline polyhydramnios | birth | 12 |
| D0005 | Female | right | Agen. of R Hemi. | 1995 | 32 | Vaginal | 102 | 5- CDH | 32 wiu | 30 |
| D0006 | Male | left | u/k | 1989 | 40 | Vaginal | 107 | 9 | birth | 1 |
| D0007 | Male | left | Agen. of L Hemi. | 1996 | 38 | Vaginal | 119 | 0 | birth | 30 |
| D0008 | Female | left | u/k | 1996 | 34 | C-Section | 77 | 20- CDH | 16 wiu | 27 |
| D0009 | Male | left | Bochdalek | 1996 | 38 | C-Section | 98 | 2 | birth | 90 |
| D0010 | Male | bilateral | Complete Agenesis | 1997 | 38 | C-Section | 99 | 5- CDH | 36 wiu | 1 |
| D0011 | Male | right | Bochdalek | 1997 | 40 | Vaginal | 79 | 2 | autopsy | 1 |
| D0012 | Female | left | u/k | 1997 | 32 | Vaginal | 52 | 1 | birth | 10 |
| D0013 | Male | left | Complete Agenesis | 1989 | 40 | Vaginal | 128 | 7- stomach dysplasia | 34 wiu | 1 |
| D0014 | Male | left | Bochdalek | 1993 | 38 | Vaginal | 105 | 2 | birth | 450 |
| D0015 | Male | left | Agen. of L Hemi. | 1998 | 24 | Vaginal | 20 | 4- heart dysplasia, CDH, fetal demise | 19 wiu | 0 |
| D0016 | Female | left | u/k | 1998 | 37 | C-Section | 88 | 5- CDH | 21 wiu | 20 |
| D0017 | Male | left | u/k | 1991 | 30 | Vaginal | 85 | 2 | birth | 2 |
| D0018 | Female | left | Bochdalek | 1992 | 42 | Vaginal | 152 | 1 | birth | 1 |
| D0019 | Male | left | Bochdalek | 1998 | 33 | C-Section | 79 | 10- hydrocephalus, CDH, clenched fists | 27 wiu | 0 |
| D0020 | Male | left | Agen. of L Hemi. | 1997 | 35 | Vaginal | 80 | 1 | birth | 1 |
| D0021 | Male | left | Agen. of L Hemi. | 1997 | 32 | Vaginal | 26 | 3- fetal demise | birth | 0 |
| D0022 | Female | left | u/k | 1998 | 24 | Vaginal | 85 | 5- CDH, fetal demise | 16 wiu | 0 |
| D0023 | Male | left | Agen. of L Hemi. | 1998 | 38 | Vaginal | 119 | 1 | birth | 24 |
| D0024 | Male | left | Bochdalek | 1999 | 37 | C-Section | 80 | 30- CDH | 21 wiu | 6 |
| D0025 | Male | left | Bochdalek | 1996 | 28 | C-Section | 35 | u/a | u/a | 0 |
| D0026 | Male | left | Agen. of L Hemi. | 1998 | 40 | C-Section | 105 | 1 | birth | 43 |
| D0027 | Male | left | Agen. of L Hemi. | 1995 | 31 | C-Section | 46 | 3- Septated Uterus | birth | 1 |
| D0028 | Female | left | u/k | 1999 | 38 | Vaginal | 90 | 18- CDH, and Hypoplastic Aortic Arch | 20 wiu | 2 |
| D0029 | Female | left | Agen. of L Hemi | 2000 | 38 | C-Section | 93 | 6- CDH | 22 wiu | 38 |
| D0030 | Male | right | Agen. of R Hemi | 1999 | 39 | Vaginal | 153 | 6- CDH | 26 wiu | 49 |
| D0031 | Male | left | u/k | 1994 | 33 | C-Section | 73 | 5- "abnormal findings" | 28 wui | 4 |
| D0032 | Male | left | Bochdalek | 2000 | 37 | Exit Procedure | 90 | 3- CDH | 22 wui | 1 |
| D0033 | Male | left | u/k | 2000 | 38 | Vaginal | 127 | 3- CDH | 32 wui | 24 |
| D0034 | Male | right | u/k | 1998 | 30 | Vaginal | 58 | 5 | Birth | 2 |
| D0035 | Male | left | u/k | 2000 | 38 | Vaginal | 110 | 8 | 19 wui | 22 |
| D0036 | Female | left | u/a | 2000 | 37 | C-Section | 62 | 10- CDH | 18 wiu | 1 |
| S0001 | Male | left | Agen. of L Hemi. | 1983 | 30 | C-Section | 141 | 0 | birth | 90 |
| S0002 | Female | left | u/k | 1992 | 42 | Vaginal | 112 | 1 | birth | 180 |
| S0003 | Female | left | Agen. of L Hemi. | 1992 | 37 | Vaginal | 80 | 3 | birth | 90 |
| S0004 | Male | right | Agen. of R Hemi. | 1975 | u/a | Vaginal | 90 | 0 | birth | 675 |
| S0005 | Male | right | Agen. of R Hemi. | 1993 | u/a | Vaginal | 153 | 20- CDH | 28 wiu | 35 |
| S0006 | Female | right | Bochdalek | 1993 | 37 | C-Section | 113 | 2 | birth | 122 |
| S0007 | Male | left | u/k | 1992 | 37 | C-Section | 73 | 5- Single Umbilical Artery, CDH | 26 wiu | 24 |
| S0008 | Male | left | u/k | 1995 | 42 | Vaginal | 150 | 0 | birth | 60 |
| S0009 | Male | left | Agen. of L Hemi. | 1993 | 34 | Vaginal | 75 | 2 | birth | 25 |
| S0010 | Female | left | u/k | 1995 | 40 | Vaginal | 143 | 2 | birth | 14 |
| S0011 | Female | left | u/k | 1992 | 39 | C-Section | 97 | 8- CDH | 30 wiu | 90 |
| S0012 | Male | left | u/k | 1995 | 39 | Vaginal | 120 | 3- CDH | 28 wiu | 28 |
| S0013 | Female | left | Posterolateral | 1995 | 38 | C-Section | 107 | 3- CDH, breech | 36 wiu | 210 |
| S0014 | Male | left | Bochdalek | 1995 | 42 | Vaginal | 128 | 2 | birth | 47 |
| S0015 | Male | left | Bochdalek | 1992 | 39 | Vaginal | 141 | 6- CDH | 16 wiu | 120 |
| S0016 | Male | left | u/k | 1982 | 36 | Vaginal | 75 | 0 | birth | 33 |
| S0017 | Male | left | Bochdalek | 1995 | 42 | Vaginal | 117 | 3 | birth | 40 |
| S0018 | Female | left | Agen. of L Hemi. | 1993 | 39 | C-Section | 133 | 8-CDH | 18 wiu | 48 |
| S0019 | Female | left | u/k | 1994 | u/a | Vaginal | 80 | 2 | birth | 60 |
| S0020 | Female | left | Bochdalek | 1994 | 38 | Vaginal | 103 | 2- CDH | 22 wiu | 42 |

| Case# | Gender | Side of CDH | Type of CDH | Year of Birth | Gestational Age At Birth | Birth Type | Birth Weight (oz) | Ultrasounds Number- Findings | Age Child Was Diagnosed | Hospital Stay (days) |
|---|---|---|---|---|---|---|---|---|---|---|
| S0021 | Female | left | u/k | 1977 | u/a | Vaginal | 125 | 0 | birth | 10 |
| S0022 | Male | left | Posterolateral | 1995 | 42 | C-Section | 110 | 8 | birth | 45 |
| S0023 | Male | right | u/k | 1995 | 36 | VBAC | 104 | 2- CDH | 34 wiu | 70 |
| S0024 | Female | left | Posterolateral | 1994 | 36 | Vaginal | 97 | 4- CDH | 19 wiu | 34 |
| S0025 | Female | left | Bochdalek | 1991 | 38 | Vaginal | 118 | 2 | birth | 56 |
| S0026 | Male | left | u/k | 1995 | 39 | C-Section | 127 | 8- CDH | 27 wiu | 90 |
| S0027 | Male | left | u/k | 1996 | 39 | Vaginal | 145 | 3- CDH | 36 wiu | 21 |
| S0028 | Male | left | Agen. of L Hemi. | 1997 | 35 | Vaginal | 76 | 2- Cord around neck | birth | 70 |
| S0029 | Male | left | Agen. of L Hemi. | 1997 | 38 | C-Section | 120 | 9- Polyhydramnios, CDH | 33 wiu | 59 |
| S0030 | Male | left | u/k | 1997 | 41 | Vaginal | 147 | 2 | birth | 12 |
| S0031 | Female | bilateral | Complete Agenesis | 1984 | 40 | Vaginal | 104 | 1 | birth | 90 |
| S0032 | Male | left | Agen. of L Hemi. | 1992 | 27 | C-Section | 38 | 1- CDH | 21 wiu | 350 |
| S0033 | Female | right | u/k | 1996 | 39 | Vaginal | 119 | 2 | birth | 82 |
| S0034 | Male | left | Bochdalek | 1996 | 37 | C-Section | 117 | 3 | birth | 42 |
| S0035 | Male | left | Bochdalek | 1996 | 39 | C-Section | 100 | 3 | birth | 14 |
| S0036 | Female | right | u/k | 1995 | 38 | Vaginal | 115 | 10 | 18 wiu | 151 |
| S0037 | Female | left | Bochdalek | 1997 | 40 | Vaginal | 135 | 10- CDH | 26 wiu | 45 |
| S0038 | Female | left | u/k | 1997 | 39 | C-Section | 98 | 5- CDH | 22 wiu | 16 |
| S0039 | Male | right | Posterolateral | 1997 | 37 | C-Section | 102 | 1 | birth | 91 |
| S0040 | Male | left | Bochdalek | 1996 | 39 | Vaginal | 117 | 15- CDH | 21 wiu | 42 |
| S0041 | Male | left | u/k | 1997 | 37 | Vaginal | 85 | 6 | birth | 28 |
| S0042 | Female | right | Posterolateral | 1997 | 41 | Vaginal | 102 | 3 | birth | 45 |
| S0043 | Female | left | Bochdalek | 1997 | 33 | Vaginal | 46 | 4- SGA, IUGR, diastolic umbilical flow | birth | 50 |
| S0044 | Female | left | Bochdalek | 1997 | 37 | Vaginal | 118 | 3-CDH | 16 wiu | 78 |
| S0045 | Male | left | u/a | 1989 | 32 | Vaginal | 63 | 2 | birth | 34 |
| S0046 | Female | right | Agen. of R Hemi. | 1997 | 38 | Vaginal | 112 | 7 | birth | 70 |
| S0047 | Male | left | Bochdalek | 1999 | 38 | C-Section | 106 | 12- CDH | 17 wiu | 25 |
| S0048 | Male | left | u/k | 1997 | 40 | Vaginal | 143 | 3- placenta previa | birth | 13 |
| S0049 | Male | right | u/k | 1998 | 39 | Vaginal | 88 | 3- CDH, kidney abnormality | 39 wiu | 90 |
| S0050 | Female | left | Bochdalek | 1998 | 40 | Vaginal | 124 | 10- CDH | 36 wiu | 14 |
| S0051 | Male | left | Agen. of L Hemi. | 1998 | 40 | Vaginal | 126 | 1 | birth | 65 |
| S0052 | Female | left | u/k | 1998 | 40 | Vaginal | 100 | 5- CDH | 17 wiu | 28 |
| S0053 | Female | left | u/k | 1997 | 31 | C-Section | 51 | CDH | 18 wiu | 84 |
| S0054 | Female | left | u/k | 1998 | 36 | Vaginal | 79 | twins, CDH | 17 wiu | 150 |
| S0055 | Male | left | Bochdalek | 1998 | 38 | Vaginal | 115 | 10-CDH, polyhydramnios | 23 wiu | 89 |
| S0056 | Male | left | Bochdalek | 1998 | 41 | C-Section | 105 | 10- dextrocardia | birth | 97 |
| S0057 | Female | left | u/k | 1999 | 38 | Vaginal | 130 | 4- CDH | 24 wiu | 111 |
| S0058 | Male | right | Morgagni | 1998 | 40 | C-Section | 150 | 5- CDH, polyhydramnios | 30 wiu | 75 |
| S0060 | Male | right | u/k | 1998 | 37 | C-Section | 127 | 5- CDH, polyhydramnios | 31 wiu | 49 |
| S0061 | Female | left | Bochdalek | 1998 | 38 | C-Section | 110 | 6- CDH, large cerebral ventricles | 20 wiu | 120 |
| S0062 | Male | left | u/k | 1999 | 37 | Vaginal | 106 | 12- CDH | 36 wiu | 20 |
| S0063 | Female | left | Agen. of L Hemi. | 1999 | 32 | C-Section | 50 | 10- CDH, Twin to Twin Transfusion | 20 wiu | 57 |
| S0064 | Male | left | Agen. of L Hemi. | 1999 | 39 | Vaginal | 107 | 30- CDH | 12 wiu | 67 |
| S0065 | Male | left | u/k | 1999 | 42 | C-Section | 112 | 2 | Birth | 29 |
| S0066 | Female | left | Bochdalek | 1999 | 38 | C-Section | 145 | 8- CDH | 16 wiu | 28 |
| S0067 | Male | left | u/k | 1999 | 40 | Vaginal | 82 | 2 | Birth | 335 |
| S0068 | Female | left | Agen. of L Hemi. | 1962 | 40 | Vaginal | 113 | 0 | 21 days | 10 |
| S0069 | Male | left | Agen. of L Hemi. | 1999 | 38 | C-Section | 99 | 10- CDH | 26 wiu | 90 |
| S0070 | Male | left | Posterolaterl | 1989 | 40 | Vaginal | 130 | 8- CDH | 32 wiu | 33 |
| S0071 | Female | left | Agen. of L Hemi. | 1999 | 36 | Vaginal | 93 | 10- CDH | 31 wiu | 180 |
| S0072 | Female | right | u/k | 1991 | 38 | C-Section | 98 | 15- CDH | 28 wiu | 180 |
| S0073 | Female | right | u/k | 1995 | 40 | Vaginal | 100 | 8 | Birth | 15 |
| S0074 | Male | left | u/a | 1999 | 38 | Vaginal | 109 | 15 | Birth | 24 |
| S0075 | Male | left | u/k | 1995 | 38 | Vaginal | 142 | 20- CDH | 23 wiu | 180 |
| S0076 | Female | left | Bochdalek | 1982 | 42 | Vaginal | 134 | 1 | Birth | 20 |
| S0077 | Male | left | u/k | 1999 | 37 | C-Section | 120 | 8 | Birth | 21 |
| S0078 | Female | right | u/k | 1999 | 39 | Vaginal | 106 | CDH | 16 wiu | 32 |
| S0079 | Female | left | Bochdalek | 1999 | 38 | Vaginal | 96 | 4- CDH | 19 wiu | 32 |
| S0080 | Female | left | u/k | 2000 | 37 | Vaginal | 102 | 2 | Birth | 10 |
| S0081 | Male | left | Bochdalek | 1999 | 33 | C-Section | 70 | 10- CDH2 | 19 wiu | 63 |
| S0082 | Male | left | u/k | 1999 | 38 | Vaginal | 109 | 2- CDH | 20 wiu | 35 |
| S0083 | Male | left | u/k | 1999 | 38 | Vaginal | 105 | 1 | 2 days | 10 |
| S0084 | Female | left | u/k | 1999 | 38 | Vaginal | 136 | 8- CDH, polyhydramnios | 18 wiu | 41 |

| Case# | Gender | Side of CDH | Type of CDH | Year of Birth | Gestational Age At Birth | Birth Type | Birth Weight (oz) | Ultrasounds Number- Findings | Age Child Was Diagnosed | Hospital Stay (days) |
|---|---|---|---|---|---|---|---|---|---|---|
| S0085 | Female | left | Bochdalek | 1999 | 40 | Vaginal | 160 | 0 | Birth | 8 |
| S0086 | male | left | u/k | 1998 | 40 | Vaginal | 130 | 6- CDH | 19 wiu | 62 |

| Case# | Number of Repairs | ECMO (days) | Nitric Oxide (days) | High Frequency Oscillator (days) | Ventilator (days) | Oxygen (days) | Multiple Birth Defects | Compli-cations | Feeding Problems | Developmental Stage | Estimated Total Cost of Child's Medical Care | Age At Time of Death (days) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| D0001 | 2 | 8 | 0 | 7 | 90 | 129 | No | Yes | n/a | n/a | $1,500,000.00 | 143 |
| D0002 | 1 | 0 | 0 | 0 | 60 | 90 | Yes | Yes | n/a | n/a | $2,500,000.00 | 360 |
| D0003 | 0 | 0 | 0 | 0 | 1 | 1 | No | Yes | n/a | n/a | u/a | 1 |
| D0004 | 0 | 12 | 0 | 0 | 1 | 12 | No | Yes | n/a | n/a | $145,000.00 | 12 |
| D0005 | 1 | 25 | 2 | 21 | 29 | 29 | No | Yes | n/a | n/a | u/a | 29 |
| D0006 | 0 | 0 | 0 | 0 | 0 | 0 | Yes | Yes | n/a | n/a | u/a | 1 |
| D0007 | 1 | 10 | 0 | 0 | 8 | 10 | No | Yes | n/a | n/a | $125,000.00 | 7 |
| D0008 | 1 | 21 | 0 | 0 | 21 | 21 | Yes | Yes | n/a | n/a | u/a | 27 |
| D0009 | 2 | 0 | 0 | 0 | 75 | 80 | No | Yes | n/a | n/a | $400,000.00 | 136 |
| D0010 | 0 | 0 | 0 | 0 | 0 | 0 | No | Yes | n/a | n/a | $3,000.00 | 1 |
| D0011 | 0 | 0 | 0 | 0 | 1 | 1 | Yes | Yes | n/a | n/a | u/a | 1 |
| D0012 | 0 | 0 | 0 | 8 | 2 | 10 | Yes | No | n/a | n/a | $90,000.00 | 10 |
| D0013 | 1 | 0 | 0 | 0 | 1 | 1 | No | Yes | n/a | n/a | u/a | 1 |
| D0014 | 6 | 0 | 0 | 21 | 910 | 1095 | Yes | Yes | n/a | n/a | $4,000,000.00 | 2419 |
| D0015 | 0 | 0 | 0 | 0 | 0 | 0 | Yes | Yes | n/a | n/a | $5,000.00 | 0 |
| D0016 | 1 | 10 | 3 | 0 | 20 | 20 | Yes | Yes | n/a | n/a | $35,000.00 | 21 |
| D0017 | 0 | 2 | 0 | 2 | 2 | 2 | Yes | Yes | n/a | n/a | $10,000.00 | 2 |
| D0018 | 0 | 0 | 0 | 1 | 1 | 1 | Yes | Yes | n/a | n/a | u/a | 1 |
| D0019 | 0 | 0 | 0 | 0 | 0 | 0 | No | Yes | n/a | n/a | u/a | 1 |
| D0020 | 1 | 13 | 24 | 24 | 24 | 24 | Yes | Yes | n/a | n/a | $750,000.00 | 23 |
| D0021 | 0 | 0 | 0 | 0 | 0 | 0 | No | Yes | n/a | n/a | u/a | 0 |
| D0022 | 0 | 0 | 0 | 0 | 0 | 0 | No | No | n/a | n/a | u/a | 0 |
| D0023 | 1 | 19 | 0 | 2 | 5 | 24 | No | Yes | n/a | n/a | $450,000.00 | 24 |
| D0024 | 0 | 6 | 0 | 1 | 1 | 1 | Yes | Yes | n/a | n/a | u/a | 7 |
| D0025 | 0 | 0 | 0 | 0 | 0 | 0 | No | Yes | n/a | n/a | u/a | 1 |
| D0026 | 1 | 5 | 14 | 1 | 43 | 43 | Yes | Yes | n/a | n/a | u/a | 43 |
| D0027 | 0 | 0 | 0 | 0 | 1 | 1 | No | Yes | n/a | n/a | u/a | 2 |
| D0028 | **1** | **0** | **2** | **2** | **2** | **2** | Yes | Yes | n/a | n/a | u/a | 3 |
| D0029 | 1 | 32 | 14 | 14 | 24 | 38 | No | Yes | n/a | n/a | $1,000,000.00 | 39 |
| D0030 | 1 | 22 | 20 | 9 | 27 | 27 | Yes | Yes | n/a | n/a | $600,000.00 | 49 |
| D0031 | 0 | 3 | 0 | 0 | 1 | 4 | Yes | Yes | n/a | n/a | u/a | 5 |
| D0032 | 0 | 0 | 1 | 1 | 2 | 2 | Yes | Yes | n/a | n/a | $40,000.00 | 3 |
| D0033 | 1 | 14 | 2 | 8 | 0 | 0 | No | Yes | n/a | n/a | $400,000.00 | 25 |
| D0034 | 0 | 0 | 0 | 1 | 1 | 1 | Yes | Yes | n/a | n/a | $11,000.00 | 2 |
| D0035 | 1 | 21 | 0 | 2 | 22 | 22 | No | u/a | n/a | n/a | $215,087.05 | 22 |
| D0036 | 0 | 0 | 0 | 0 | 2 | 2 | No | Yes | n/a | n/a | $20,000.00 | 2 |
| S0001 | 2 | 0 | 0 | 30 | 30 | 150 | No | Yes | None | Normal | $500,000.00 | n/a |
| S0002 | 1 | 20 | 0 | 0 | 150 | 545 | Yes | Yes | Severe | Above Average | $500,000.00 | n/a |
| S0003 | 1 | 0 | 3 | 6 | 22 | 910 | Yes | Yes | No Answer | No Answer | $500,000.00 | n/a |
| S0004 | 1 | 0 | 0 | 0 | u/a | u/a | No | Yes | G-Tube | No Answer | $1,500,000.00 | n/a |
| S0005 | 1 | 10 | 0 | 1 | 42 | 270 | No | Yes | Slight | Normal | $300,000.00 | n/a |
| S0006 | 1 | 0 | 0 | 0 | 29 | 31 | Yes | Yes | Slight | Normal | u/a | n/a |
| S0007 | 1 | 0 | 0 | 0 | 14 | 14 | No | Yes | None | Normal | $52,000.00 | n/a |
| S0008 | 1 | 21 | 0 | 0 | 32 | 150 | Yes | Yes | Moderate | Slight | $500,000.00 | n/a |
| S0009 | 1 | 2 | 0 | 0 | 14 | 14 | Yes | Yes | G-Tube | Normal | $500,000.00 | n/a |
| S0010 | 3 | 0 | 0 | 0 | 1 | 1 | Yes | Yes | Slight | Slight | $200,000.00 | n/a |
| S0011 | 1 | 9 | 0 | 0 | 30 | 90 | No | No | None | Normal | u/a | n/a |
| S0012 | 1 | 0 | 3 | 4 | 18 | 18 | Yes | No | G-Tube | Moderate | $500,000.00 | n/a |
| S0013 | 1 | 17 | 1 | 1 | 14 | 1500 | No | No | NG-Tube | Normal | $800,000.00 | n/a |
| S0014 | 1 | 6 | 1 | 5 | 21 | 30 | Yes | Yes | Slight | Slight | $300,000.00 | n/a |
| S0015 | 3 | 10 | 0 | 0 | 1460 | 1460 | No | No | Slight | Slight | $1,500,000.00 | n/a |
| S0016 | 1 | 0 | 0 | 0 | 0 | 30 | Yes | Yes | TPN | Normal | $35,000.00 | n/a |
| S0017 | 1 | 3 | 0 | 1 | 11 | 28 | Yes | Yes | Moderate | Moderate | $275,000.00 | n/a |
| S0018 | 1 | 6 | 0 | 0 | 28 | 30 | Yes | No | G-Tube | Slight | u/a | n/a |
| S0019 | 1 | 10 | 1 | 0 | 25 | 1825 | Yes | Yes | Moderate | Normal | u/a | n/a |
| S0020 | 1 | 0 | 0 | 0 | 21 | 7 | No | Yes | G-Tube | Slight | u/a | n/a |

| Case# | Number of Repairs | ECMO (days) | Nitric Oxide (days) | High Frequency Oscillator (days) | Ventilator (days) | Oxygen (days) | Multiple Birth Defects | Compli-cations | Feeding Problems | Developmental Stage | Estimated Total Cost of Child's Medical Care | Age At Time of Death (days) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| S0021 | 1 | 0 | 0 | 0 | 0 | 4 | No | Yes | None | Normal | u/a | n/a |
| S0022 | 1 | 14 | 0 | 21 | 75 | 425 | Yes | Yes | G-Tube | Slight | $675,000.00 | n/a |
| S0023 | 1 | 2 | 0 | 0 | 6 | 180 | No | Yes | None | Normal | $600,000.00 | n/a |
| S0024 | 1 | 0 | 9 | 0 | 19 | 425 | Yes | Yes | NG-Tube | Severe | $180,000.00 | n/a |
| S0025 | 1 | 0 | 0 | 15 | 21 | 21 | No | Yes | No Answer | No Answer | $200,000.00 | n/a |
| S0026 | 1 | 12 | 3 | 4 | 60 | 60 | No | Yes | Severe | Normal | $500,000.00 | n/a |
| S0027 | 1 | 0 | 0 | 0 | 4 | 7 | Yes | Yes | Slight | Normal | $40,000.00 | n/a |
| S0028 | 2 | 0 | 0 | 28 | 7 | u/a | Yes | Yes | G-Tube | Slight | $150,000.00 | n/a |
| S0029 | 1 | 0 | 0 | 14 | 7 | 200 | Yes | No | G-Tube | Normal | $400,000.00 | n/a |
| S0030 | 1 | 0 | 0 | 0 | 10 | 10 | Yes | Yes | Moderate | Normal | $60,000.00 | n/a |
| S0031 | 4 | 0 | 0 | 45 | 60 | 90 | No | No | Slight | Normal | $250,000.00 | n/a |
| S0032 | 1 | 3 | 30 | 21 | 40 | 500 | Yes | No | None | Normal | $4,000,000.00 | n/a |
| S0033 | 1 | 13 | 0 | 14 | 14 | 75 | Yes | Yes | NG-Tube | Above Average | $1,000,000.00 | n/a |
| S0034 | 6 | 7 | 1 | 4 | 26 | 35 | Yes | Yes | Slight | Normal | $500,000.00 | n/a |
| S0035 | 1 | 0 | 0 | 0 | 9 | 11 | No | Yes | None | Normal | $100,000.00 | n/a |
| S0036 | 3 | 0 | 0 | 0 | 60 | 180 | Yes | No | None | Normal | u/a | n/a |
| S0037 | 1 | 2 | 0 | 0 | 10 | 21 | Yes | Yes | Severe | Normal | $500,000.00 | n/a |
| S0038 | 1 | 0 | 0 | 2 | 10 | 11 | No | Yes | None | Slight | $50,000.00 | n/a |
| S0039 | 3 | 0 | 0 | 28 | 3 | 28 | Yes | Yes | Slight | Normal | u/a | n/a |
| S0040 | 1 | 8 | 1 | 20 | 36 | 54 | No | No | Slight | Normal | $650,000.00 | n/a |
| S0041 | 1 | 0 | 0 | 0 | 8 | 28 | Yes | Yes | Severe | Slight | u/a | n/a |
| S0042 | 1 | 6 | 1 | 1 | 7 | 245 | Yes | Yes | Mic-Key | Slight | $350,000.00 | n/a |
| S0043 | 1 | 0 | 0 | 15 | 22 | 20 | No | No | Severe | Normal | $500,000.00 | n/a |
| S0044 | 1 | 6 | 0 | 0 | 16 | 42 | Yes | Yes | G-Tube | Moderate | u/a | n/a |
| S0045 | 1 | u/a | u/a | u/a | u/a | u/a | No | Yes | None | Normal | u/a | n/a |
| S0046 | 1 | 0 | 0 | 5 | 16 | 455 | No | No | None | Normal | $1,000,000.00 | n/a |
| S0047 | u/a | 10 | 6 | 0 | 0 | 9 | Yes | No | None | Normal | u/a | n/a |
| S0048 | 1 | 0 | 0 | 0 | 10 | 12 | Yes | Yes | Slight | Normal | $175,000.00 | n/a |
| S0049 | 1 | 0 | 21 | 0 | 56 | 63 | No | No | Moderate | Normal | u/a | n/a |
| S0050 | 1 | 0 | 0 | 7 | 0 | 9 | Yes | Yes | Slight | Normal | u/a | n/a |
| S0051 | 1 | 14 | 0 | 1 | 28 | 330 | No | Yes | None | Normal | $600,000.00 | n/a |
| S0052 | 1 | 0 | 0 | 10 | 0 | 21 | No | Yes | Mic-Key | Moderate | $85,000.00 | n/a |
| S0053 | 2 | 0 | 0 | 0 | 77 | 77 | No | No | None | Normal | $2,000,000.00 | n/a |
| S0054 | 3 | 7 | 0 | 1 | 140 | 510 | No | Yes | None | Moderate | $2,000,000.00 | n/a |
| S0055 | 1 | 12 | 0 | 1 | 50 | 86 | No | Yes | G-Tube | Normal | $450,000.00 | n/a |
| S0056 | 1 | 0 | 16 | 7 | 64 | 73 | Yes | No | None | Normal | u/a | n/a |
| S0057 | 1 | u/a | u/a | u/a | u/a | u/a | Yes | Yes | Mic-Key | u/a | $1,000,000.00 | n/a |
| S0058 | 1 | 21 | 27 | 28 | 53 | 98 | No | No | None | Normal | $450,000.00 | n/a |
| S0060 | 1 | 16 | 1 | 0 | 30 | 365 | Yes | No | Moderate | Normal | $300,000.00 | n/a |
| S0061 | 1 | 0 | 0 | 0 | 5 | 6 | No | No | None | Normal | $700,000.00 | n/a |
| S0062 | 1 | 0 | 0 | 0 | 5 | 6 | No | Yes | None | Normal | $250,000.00 | n/a |
| S0063 | 1 | 0 | 0 | 0 | 6 | 21 | No | Yes | Moderate | Normal | $250,000.00 | n/a |
| S0064 | 3 | 15 | 31 | 16 | 33 | 125 | No | Yes | Slight | u/a | $800,000.00 | n/a |
| S0065 | 1 | 0 | 0 | 0 | 9 | 21 | No | No | Slight | Normal | u/a | n/a |
| S0066 | 1 | 0 | 0 | 0 | 8 | 18 | No | No | None | Normal | $80,000.00 | n/a |
| S0067 | 2 | 10 | 14 | 0 | 60 | 450 | Yes | Yes | G-Tube | Slight | $10,000,000.00 | n/a |
| S0068 | 1 | 0 | 1 | 10 | 17 | 17 | Yes | Yes | None | Normal | $1,800.00 | n/a |
| S0069 | 1 | 0 | 6 | 6 | 30 | 80 | Yes | Yes | None | Normal | u/a | n/a |
| S0070 | 4 | 0 | 0 | 0 | 0 | 0 | No | No | None | Moderate | u/a | n/a |
| S0071 | 1 | 0 | 0 | 0 | 360 | 360 | Yes | Yes | Mick-Key | Moderate | $1,000,000.00 | n/a |
| S0072 | 2 | 0 | 0 | 0 | 14 | 60 | Yes | No | Severe | Slight | $1,000,000.00 | n/a |
| S0073 | 1 | 0 | 0 | 0 | 2 | 2 | Yes | No | None | Slight | $200,000.00 | n/a |
| S0074 | 2 | 0 | 0 | 0 | 10 | 120 | No | Yes | Severe | Normal | $280,000.00 | n/a |
| S0075 | 1 | 0 | 0 | 7 | 1825 | 1825 | Yes | Yes | G-Tube | Severe | $1,000,000.00 | n/a |
| S0076 | 3 | 0 | 0 | 0 | 5 | 10 | No | Yes | None | Normal | u/a | n/a |
| S0077 | 1 | 0 | 0 | 0 | 14 | 0 | No | Yes | None | Normal | u/a | n/a |
| S0078 | 2 | 5 | 4 | 3 | 14 | 40 | Yes | No | None | u/a | $280,000.00 | n/a |
| S0079 | 1 | 0 | 0 | 6 | 3 | 0 | No | Yes | None | Normal | $200,000.00 | n/a |
| S0080 | 1 | 0 | 7 | 0 | 7 | 7 | No | No | None | Normal | u/a | n/a |
| S0081 | 1 | 0 | 0 | 0 | 45 | 120 | No | Yes | None | Slight | $600,000.00 | n/a |
| S0082 | 1 | 0 | 8 | 3 | 23 | 10 | No | No | None | Normal | u/a | n/a |
| S0083 | 1 | 0 | 0 | 0 | 2 | 7 | Yes | No | None | Normal | $80,000.00 | n/a |
| S0084 | 1 | 5 | 1 | 1 | 28 | 33 | Yes | No | None | Normal | $400,000.00 | n/a |

| Case# | Number of Repairs | ECMO (days) | Nitric Oxide (days) | High Frequency Oscillator (days) | Ventilator (days) | Oxygen (days) | Multiple Birth Defects | Compli-cations | Feeding Problems | Developmental Stage | Estimated Total Cost of Child's Medical Care | Age At Time of Death (days) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| S0085 | 1 | 0 | 0 | 0 | 1 | 2 | No | No | None | Normal | $75,000.00 | n/a |
| S0086 | 1 | 0 | 36 | 0 | 43 | 400 | No | No | NG-Tube | Slight | $80,000.00 | n/a |

Compiled by:

# CHERUBS

The Association of Congenital Diaphragmatic Hernia Research, Advocacy, and Support

P.O. Box 1150
Creedmoor, NC 27522
USA
919-693-8158
707-924-1114 (fax)
research@cherubs-cdh.org
www.cherubs-cdh.org

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