

# CHERUBS' 1999



## Congenital Diaphragmatic Hernia Research Survey Results

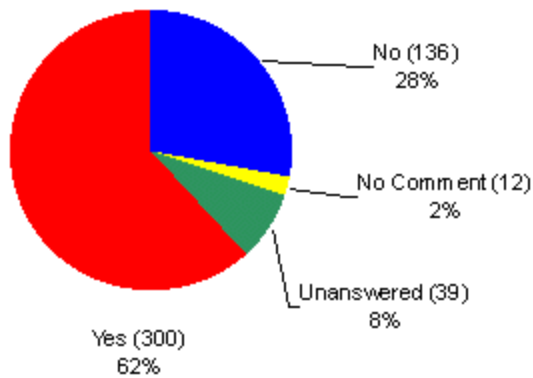
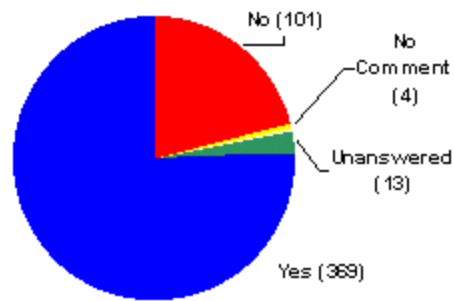
The following information was taken from our parent worksheets (also known as membership forms) sent in by February 15, 2000. Again this year, we thought it would be easier to read and understand charts rather than long explanations of data. We have separated the results into 2 categories; Membership Survey Results (taken from Parent Membership Forms) and Congenital Diaphragmatic Hernia Research Survey Results (taken from the 10-page surveys sent out to parents of non-survivors and survivors over 1 year old).

## Membership Survey Results

Based on 501 Parent Membership Forms completed by February 15, 2000, by parents of Survivors, Non-Survivors, and expectant parents.

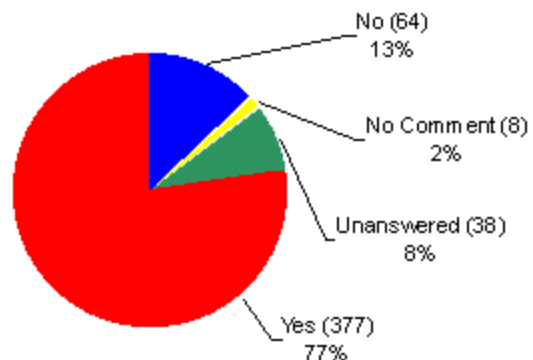
### Parental Opinion On The Hospital Experience

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

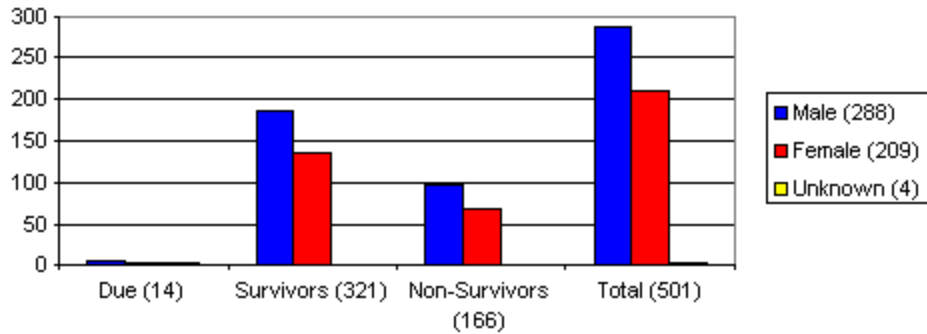


Do you feel that you were given enough information about your child's diagnosis?

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

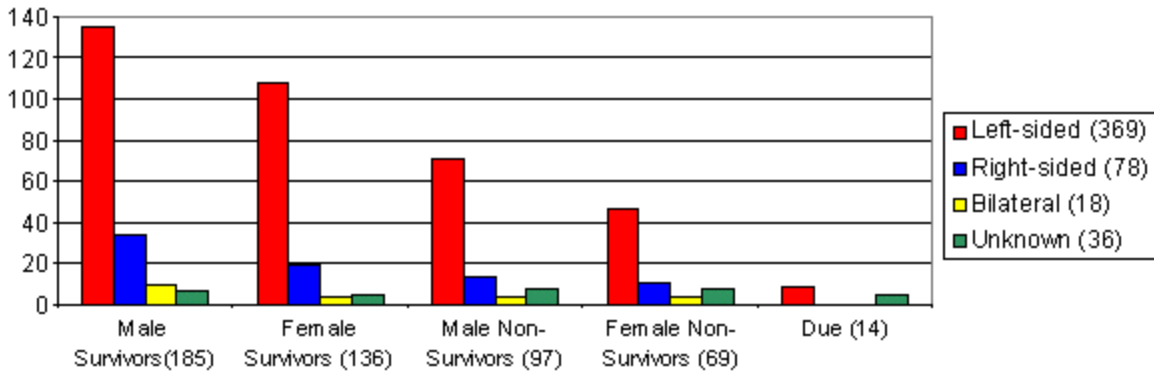


## Basic Statistics



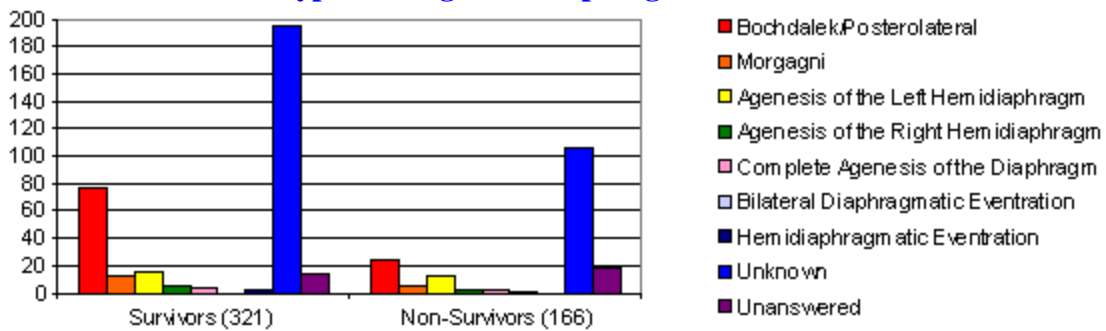
From our membership numbers, you can see that CDH seems to occur more often in males (58% male, 42% female) with a 65.5% survival rate (66% female, 65% male). Of course this is highly influenced by which parents (of survivors or non-survivors) join CHERUBS. We have a higher rate of parents of survivors (66%) joining than parents of non-survivors (34%). Most CDH medical research articles are still giving an overall 50% survival rate for CDH.

## Side(s) of Congenital Diaphragmatic Hernia



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.

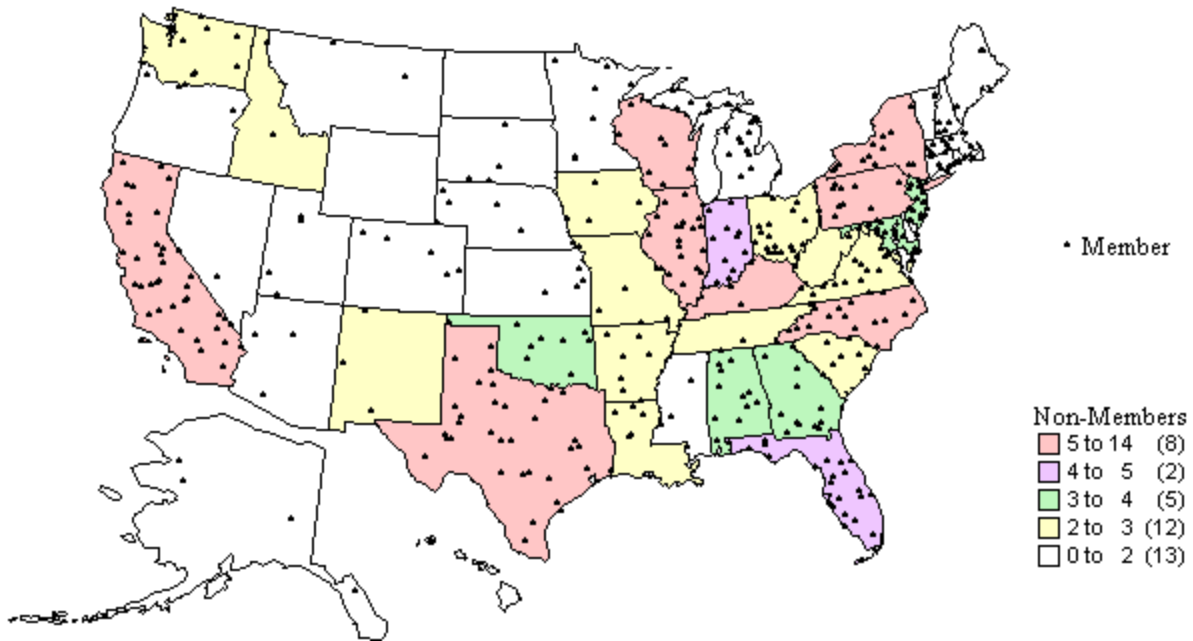
## Type of Congenital Diaphragmatic Hernia



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 Agnesis of the Hemidiaphragm and Complete Agnesis 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.

	Survivors (321)		Non-Survivors (166)		Due (14)		U/K	Totals
	Male	Female	Male	Female	Male	Female		
Bochdalek	46	25	11	7	1	0	1	91
Posterolateral	3	4	0	3	0	0	0	10
Morgagni	4	8	2	3	0	0	0	16
Agen of Left Hemidiaphragm	11	4	11	1	0	0	0	27
Agen of Right Hemidiaphragm	3	1	1	1	0	0	0	6
Complete Agenesis	2	1	2	0	0	0	0	5
Bilateral Eventration	0	0	1	0	0	0	0	1
Hemi Eventration	1	1	0	0	0	0	0	2
Unknown	105	89	60	45	5	4	3	311
Unanswered	10	3	9	9	0	0	0	31
<b>Totals</b>	<b>185</b>	<b>136</b>	<b>97</b>	<b>69</b>	<b>6</b>	<b>4</b>	<b>4</b>	<b>501</b>

### Locations



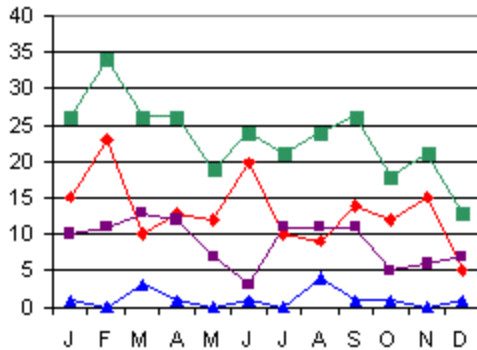
Location	Due	Non-Survivor Male	Non-Survivor Female	Survivor Male	Survivor Female	Parent Member Total	Professional Members	Grand-parent Members	Non-Member Families
Australia	-	7	3	3	5	18	-	-	1
Canada	1	2	4	14	9	30	1	-	3
Chile					1	1	-	-	
England		2		3	5	10		-	5
Germany		2		1		3		-	
Hong Kong			1			1		-	
India					1	1		-	1
Israel								-	1
Ireland					1	1	1	-	
New Guinea			1			1		-	
New Zealand		1	1	3	1	6		-	1
Northern Ireland				1		1	1	-	
Norway				1		1		-	
Scotland					1	1		-	1
Spain				1		1		-	
The Netherlands			3		1	4		-	
United States	13	83	56	158	111	421	22	11	121
<b>Totals</b>	<b>14</b>	<b>97</b>	<b>69</b>	<b>185</b>	<b>135</b>	<b>501</b>	<b>24</b>	<b>11</b>	<b>135</b>

## Seasonal Fluctuations

◆ Survivors   
 ■ Non-Survivors   
 ▲ Expectant   
 ■ Total

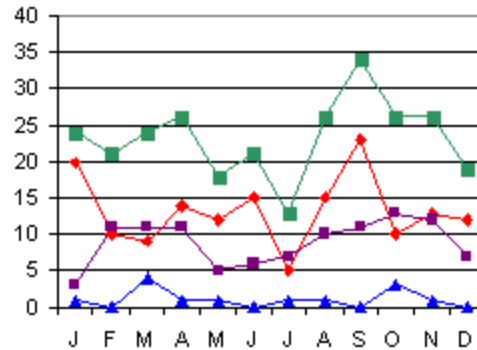
### 8 weeks

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



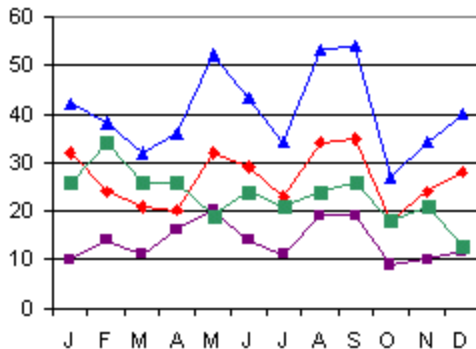
### Due Dates

(223 parents did not answer- 163 survivors, 59 non-survivors, and 1 expectant)



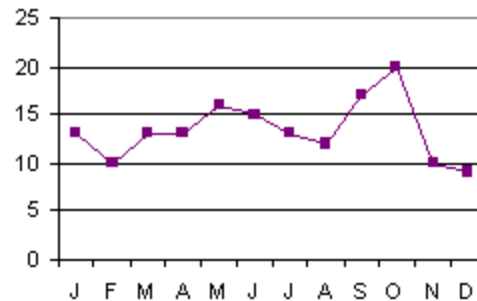
### Birth Dates

(2 parents did not answer- 1 survivors, and 1 non-survivor)



### Dates of Death

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



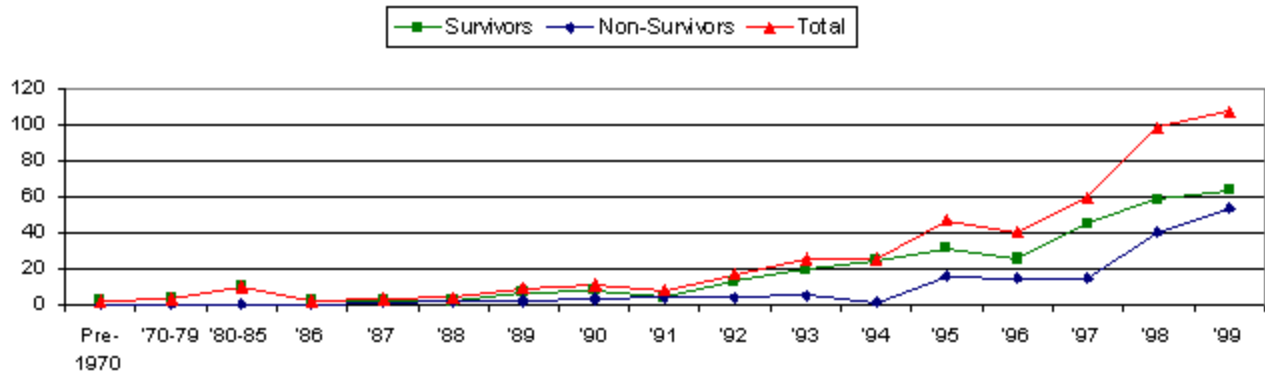
**8-Week Mark-** There is a drastic jump in the number of diaphragmatic hernias formed in the first 4 months of year. The only correlation that we can find with environmental factors during those months is the stress of tax season, but there is a decrease during months with major holidays, with the exception 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-** 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.

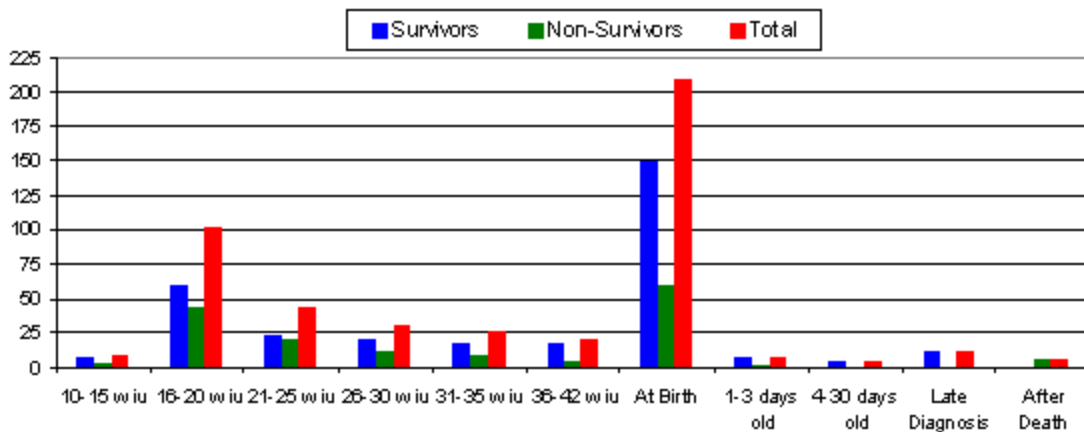
**Birth Dates-** Our trend seems to follow the normal population for the births, given that a large number of babies are conceived during the cold winter months.

**Death Dates-** The increase in September, October, and January is disturbing and correlates with the 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.

## Years of Birth



## Ages of Diagnosis



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 20<sup>th</sup> week of gestation. There seems to be a higher incidence of mortality in those diagnosed early in gestation.

## Timing of Diagnosis

	Survivors (321)		Non-Survivor (166)		Totals
	Male	Female	Male	Female	
<b>Ultrasound Performed</b>	160	117	87	62	427 (87.68%)
<b>AFP Performed</b>	72	40	38	24	174 (35.73%)
<b>Amniocentesis Performed</b>	65	48	44	33	190 (39.01%)
<b>Diagnosed In Utero</b>	89	59	55	43	246 (50.51%)
<b>Diagnosed within 24 hours</b>	85	64	37	22	208 (42.71%)
<b>Diagnosed within 30 days</b>	6	4	0	1	11 (2.26%)
<b>Late Diagnosis</b>	4	9	0	0	13 (2.67%)
<b>Diagnosed After Death</b>	0	0	3	2	5 (1.03%)
<b>No Answer</b>	1	0	2	1	4 (0.82%)

## Parental Ages

	Survivors Male	Survivors Female	Non-Survivors Male	Non-Survivors Female	All
Average Mother's Age	29.17	28.37	28.75	28.73	28.81
Average Father's Age	31.33	31.14	30.52	30.71	31.03

## Pregnancy Complications (in 487 pregnancies)

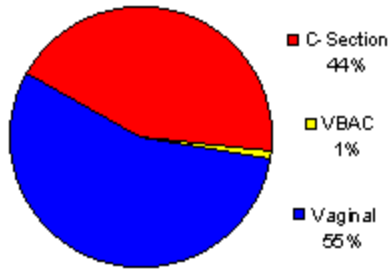
	Survivors (321)		Non-Survivor (166)		Totals
	Male	Female	Male	Female	
Premature Labor	54	26	41	28	134 (27.52%)
Polyhydramnios	40	15	30	18	103 (21.15%)
Multiple Birth	8	8	5	2	23 (4.72)
Gestational Diabetes	11	2	6	0	19 (3.9%)
Maternal Hemorrhaging	8	4	2	3	17 (3.49%)
High Blood Pressure	6	4	3	1	14 (2.87%)
PROM	2	0	4	0	5 (1.03%)
Hyperemesis	1	1	1	2	5 (1.03%)
Placenta Previa	3	2	0	0	5 (1.03%)
Pre Eclampsia	4	1	0	0	5 (1.03%)
Elective Termination	0	0	3	1	4 (.82%)
Hydrops	0	0	1	1	2 (.41%)
Abrupted Placenta	0	1	0	1	2 (.41%)
IUGR	1	1	0	1	2 (.41%)
Oligohydramnios	2	0	0	0	2 (.41%)
None	41	38	17	16	112 (23%)
Other	4	9	6	2	21 (4.31%)
No Answer	102	68	55	41	266 (54.62%)

According to our survey results, the survival rate is lower for CDH patients who are also premature, with 41.57% of non-survivors and 21.81% 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.

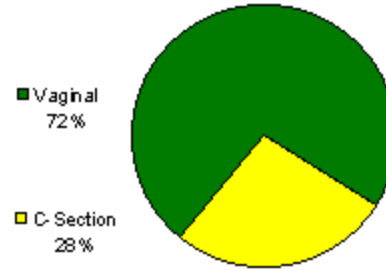
## Birth History

	Survivors (321)	Non-Survivor (166)	Totals
Vaginal	182	90	272 (55.85%)
C-Section	99	45	144 (29.57%)
VBAC	1	1	2 (.41%)
Unanswered	39	30	69 (14.17%)
Average Birth Weight	6 lbs 13.55 oz	6 lbs 2 oz	6 lbs 7.8 oz
Average Gestational Age	37.98 weeks	36.23 weeks	37.1 weeks

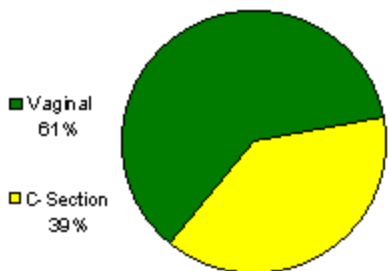
**Survivors  
Diagnosed In Utero**



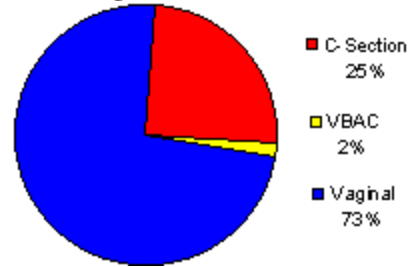
**Survivors  
Diagnosed After Birth**



**Non-Survivors  
Diagnosed In Utero**



**Non-Survivors  
Diagnosed After Birth**



**Birth Complications**

	Survivors (321)		Non-Survivor (166)		Totals
	Male	Female	Male	Female	
<b>Breech</b>	7	2	3	0	12
<b>Umbilical Cord Injuries</b>	7	1	1	1	10
<b>Premature</b>	49	20	36	28	133
<b>Stillborn</b>	0	0	2	2	4
<b>Other Complications</b>	2	7	4	0	13
<b>None</b>	49	49	24	13	135
<b>Unanswered/Unknown</b>	75	55	31	26	187

**Multiple Birth Defects**

**Genetic Syndromes and Chromosomal Anomalies (24)**

Fryn's Syndrome	8	"Cross Over On The 9th Chromosome"	1	Trisomy 11/22	1
Pallister-Killian Syndrome	3	DiGeorge Syndrome	1	Trisomy 14- Partial	1
Asperger Syndrome	1	Ehlers Danlos Syndrome	1	Trisomy 18	1
Balanced Translocation Of Chromosomes	1	Partial Deletion Of 1 X Chromosome	1	Unnamed Monosomal Chromosomal Disorder	1
Brown Syndrome	1	Partial Trisomy 22	1	Unspecified Translocation	1

**Organs (17)**

Accessory Spleen	1	Autolytic Changes To Spleen	1	Hypoplastic Thymus	1
Atopic Appendix	1	Autolytic Changes To Thymus	1	Liver Fused To Right Lung	1
Atopic Spleen	1	Cleaved Liver	1	Multilobed Spleen	1
Autolytic Changes To Liver	1	Congested Liver	1	Organoaxial Twist	1
Autolytic Changes To Pancreas	1	Diverticulosis	1	Polysplenia	1
		Horseshoe Shaped Spleen	1	Two Lobes (Liver)	1



### Cardiac Defects (58)

Atrial Septal Defect	11
Unspecified Heart Murmur	7
Ventral Septal Defect	7
Paten Ductus Arteriosus	6
Unspecified Heart Defect	3
Coartion Of Aorta	2
Hypoplastic Left Ventricle	2
Anatomical Coarctation	1
A-V Canal Defect	1
Arteriovenous Malformation	1

Benign Chest Wall Syndrome	1
Coartation Of The Aortic Arch	1
Congenital Heart Disease	1
Fluid Around Heart	1
Hypoplastic Left Heart	1
Hypoplastic Pericardium	1
Hypoplastic Right Superior Vena Cava	1
Irregular Heart Beat	1

Large Ventricles	1
Mildly Malformed Mitrovalve	1
Minor Tri-Cuspid Regurgitation	1
Pericarditis	1
Peridical Cyst	1
Persistent Left Vena Cava	1
Small Aortic Valve	1
Supraventricular Tachycardia	1
Tetrology Of Fallot	1

### Gastrointestinal

Malrotated Intestines	6
Hiatal Hernia	6
Inguinal Hernia	4
Hirschsprung's Disease	2

Omphalocele	2
Malrotated Stomach	1
Partial Organoaxial Volvulus	1
Pyloric Stenosis	1

Small Stomach	1
Short Bowel Syndrome	1
Subglottic Stenosis	1

### Uritogenitary

Undescended Testes	17
Hypospadias	4
Renomegaly	3
Hydronephrosis	2
Hypoplastic Kidney	2
Inguinal Hernia	2
Malrotated Kidney	2

Polycystic Kidney	2
Autolytic Changes To Kidneys	1
Bilateral Orthopexy	1
Coronal Hypospadias	1
Dual Collection In Left Kidney	1
Extra Renal Pelvis	1
Horseshoe Kidney	1

Hyperspadias	1
Malformed Uterus	1
"One Kidney Higher"	1
Kidney Reflux	1
Renal Pyelectasis	1
Hydrocele	1

### Pulmonary

Pulmonary Sequestration	6
Brochopulmonary Dysplasia	3
PPHN	2

Bilateral Phrenic Nerve Agenesis	1
Cylothorax	1
Pulmonary Atresia	1

Total Anomalous Pulmonary Venous Return	1
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### Neurocranial

Hydrocephalus	6
Tethered Spinal Cord	3
Microcephaly	2
Autolytic Changes To Brain	1
Agenesis Of The Corpus Collosum	1
Brain Atrophy	1
Central Hyperalime	1

Cerebral Infarction	1
Central Nervous System Infarction	1
Complete Agenesis Of The Corpus Collosum	1
Craniosenatosis	1
Dandy Walker Malformation	1

Grade 3 Hemorrhage	1
Macrocephaly	1
Severe Bilateral Cephalahematomas	1
Seizure Disorder	1
Subarachnoid Brain Hemorrhage	1

### Oral Clefts

Cleft Palate	9
Cleft Lip	3

Hair Lip	1
High Palate	1

Soft Cleft Palate	1
Robin Sequence	1

### Skeletal

Pectus Excavatum	6
Hemi Vertebrae	4
Hypoplastic Rib	4
Scoliosis	2
Short Neck	2
Abnormal Vertebrae	1
Broad Nose	1

Craniosynotosis	1
Easily Dislocated Elbow	1
Hip Dysplasia	1
Left Femur Fracture	1
Metabolic Bone Disease	1
Spinal Fusion	1

Sunken Sternum	1
Thin Ribs	1
Torticollis	1
"Several Bone Abnormalities"	1
Spina Bifida	1
Sacral Dimple	1

### Limb

Polydactylism	3
Simian Creases	3
Biforcated Toes	2
Hypoplastic Nails	2
Abnormal Thumb	1

Clenched Fists	1
Distal Digits	1
Extra Finger	1
ITT right lower leg	1
Large Thumbs	1

Rocker Bottom Feet	1
Syndactyl Toes	1
Thumb Abnormalities	1
Toe Curling	1

<b>Other</b>					
Abnormal Ears	4	Congenital Hearing Impairment	1	Nasal Abnormality	1
Skin Tag	4	Esophageal Atresia	1	Port Wine Stain	1
Abnormal Nerve Ganglia	2	Facial Hirsutism	1	Sigmoid Colon	1
Hypoplastic Jugular Vein	2	Floppy Esophagus	1	Tied Tongue	1
Single Umbilical Artery	2	Halo (eye)	1	Tracheoesophageal Cleft	1
Ventral Hernia	2	Hypoplastic Anus	1	Tracheoesophageal Fistula	1
2 Vessel Umbilical Cord	1	Hypoplastic Eyes	1	Type IV Choledocal Cyst	1
Anal Atresia	1	Hypoplastic Left Optic Nerve	1	Umbilical Hernia	1
Coloboma (eye)	1	Hypoplastic Supraorbital Ridges	1	Strabismus	1
Combined Tracheoesophageal System	1	Interhemispheric Cyst	1	Webbing Of The Neck	1
		Membrane Over Right Eye	1		
<b>"Multiple Birth Defects"</b>	<b>1</b>	<b>None</b>	<b>295</b>	<b>Unanswered/Unknown</b>	<b>2</b>

## Medical Complications

<b>Uritogenitary</b>					
Kidney Failure	15	Urinary Tract Infection	11	Kidney Reflux	2
Kidney Infection	10	Inguinal Hernia	3	Peritoneal Dialysis	1
		<b>Gastrointestinal</b>			
Reflux	67	Subglottic Stenosis	2	Motility Problems	1
Fundoplication	39	Abdominal Adhesions	1	NEC	1
Bowel Obstructions	18	Abdominal Blockage	1	Nephritis	1
Failure To Thrive	11	Abdominal Closure	1	Nutrient Absorption Problem	1
Bowel Adhesions	8	Abdominal Malrotation	1	Peritonitis	1
Intestinal Malrotation	5	Cryptosporidium Gastritis	1	Pylorotomy	1
Hiatal Hernia	5	Dumping Syndrome	1	Severe Traumatic Ulcer	1
Bowel Resection	4	Gastric Emptying	1	Stomach Turned Twice	1
Pyloric Stenosis	3	Gastrointestinal Herniated	1	Subglottic Edema	1
Colostomy	2	Esophagus Ulcers	1	Ventral Hernia	1
Roto-Virus	2	Ileostomy	1	Volvulus	1
Ruptured Intestines	2	Intaception Of Bowel	1	Wound Infection	1
Short Bowel Syndrome	2	Meckles Diverticulum	1	"Gastric Disorders"	1
		<b>Skeletal</b>			
Scoliosis	22	Scoliosis	4	Easily Dislocated Hips	1
Pectus Excavatum	11	Curved Rib	1		
		<b>Cardiac</b>			
Mitrocardial Infarction	4	Enlarged Ventricle	2	Coarctation Of Aorta	1
Supraventricular Tachycardia	4	Unspecified Heart Problems	2	Grade II Intraventricular Hemorrhage	1
Bradycardia	2	Cardiac Blood Clot	1	Right Myocardial Embolism	1
Clotted Superior Vena Cava	2	Cardiac Stent	1	Superior Vena Cava Syndrome	1
Congestive Heart Failure	2	Cardiac Stun	1		
		<b>Pulmonary</b>			
Pneumonia	84	Chronic Lung Disease	2	Influenza	1
Pulmonary Hypertension	36	Chylothorax	3	Left Phrenic Nerve Palsy	1
RSV	28	Mucas Plug	2	Left Pulmonary Artery Stenosis	1
Asthma	24	Pulmonary Edema	2	Lobectomy	1
Respiratory Virus	12	Pnemothorax	2	Parainfluenza	1
Tracheostomy	11	Bipap Dependency	1	Pariflu	1
Collapsed Lung	8	Brochial Infections	1	Pneumoectomy	1
Pneumothorax	8	Bacterial Infection From ET-Tube	1	Pneumoperitenum	1
Respiratory Infection	7	Bronchomalacia	1	Pseudomonas	1
Brochopulmonary Dysplasia	5	Brochospasms	1	Pulmonary Bleeding	1
Reactive Airway Disease	4	Emphysema	1	Pulmonary Stenosis	1
Aspiration	3	Homophelous Influenza Type B	1	Respiratory Distress	1
Bronchiolitis	3	Hyaline Membrane Disease	1	Trach Infections	1

## Neurocranial

Cerebral Palsy	26	Migraines	2	Microcephaly	1
Cerebral Hemorrhage	11	Cerebral Scar Tissue	1	Mild Spatic Diaplegia	1
Hydrocephalus	9	Enlarged Ventricles	1	Occiput Hematoma	1
Seizure Disorder	6	Hydroencephalus	1	Right Occipital Bleed	1
Stroke	3	Meningitis	1	Right-Sided Brain Enfarct	1
Intracranial Hemorrhage	2				

## Blood Infections and Complications

Unspecified Blood Infection	84	Cytomegalovirus	1	Hyponatraemia	1
Staph	37	E-Coli Infection	1	Low Immunity.	1
Candida Infection	8	Hematuria	1	Low White Blood Cell Count	1
Blood Clot	4	Hyperglycemia	1	Pseudomonis	1
Hepatitis	2	Hypernatremia	1	Thrombocytopenia	1
Periventricular Leukomalacia	2	Hypocomplementemia	1		
Anemia	1	Hypoglycemia	1		

## Sight and Hearing

Hearing Impairment	16	Otitis Media	6	Blindness	2
Deafness	5	Sight Impairment	5	Retinopathy of Prematurity	2

## Other

Hypotonia	4	Chest Tube Put In Incorrectly	2	Mega Esophagus	1
Bedsore	3	Cholestatic Jaundice	1	Nicked Lymph Node	1
Edema	3	DIC	1	Perirectal Abcess	1
Internal Hemorrhaging	3	Excessive Snoring	1	POD	1
Tracheomalacia	3	Extraphepatic Biliary Obstruction	1	Prosthetic Replacement	1
Unspecified Fistula	3	Gastropleural Fistula	1	Protein Urial	1
Appendectomy	2	Grade Iii Vesicoureteral Reflux	1	Recurrent Fevers	1
G-Tube Infection	2	Hydrops	1	Right Carotid Artery Ligated	1
Hepatomegaly	2	Jaundice	1	Speech Apraxia	1
Laryngomalacia	2	Kylas Assities	1	Speech Problems	1
Lymph Nodes Cut	2	Laceks	1	Splenic Torsion	1
Paraesophageal Hernia	2	Lasix Dependent	1	Stridor	1
Peritonitis	2	Liver Failure	1	Tracheoesophageal Fistula	1
TPN Dependency	2	Lymph Drainage Around Left Lung	1	Unspecified Apraxia	1
Adeno Virus	1	Mastitis	1	URI	1
ADHD	1			Wound Dehiscience	1

**Allergies** 40  
**None** 118

**“Yes” to “Complications?”** 5  
**Unanswered/Unknown** 2

**Death** 166

## Interventional Procedures

	Survivors (321)		Non-Survivor (166)		Totals
	Male	Female	Male	Female	
<b>In Utero CDH Repair</b>	3 (1.62%)	1 (.74%)	2 (2.06%)	2 (2.9%)	8 (1.64%)
<b>In Utero Tracheal Ligation</b>	6 (3.24%)	3 (2.21%)	3 (3.09%)	1 (1.45%)	12 (2.46%)
<b>In Utero Steroid Treatments</b>	10 (5.41%)	7 (5.15%)	5 (5.15%)	5 (7.25%)	27 (5.54%)
<b>ECMO</b>	66 (35.68%)	45 (33.09%)	33 (34.02%)	28 (40.58%)	172 (35.32%)
<b>Average Time on ECMO</b>	10.22 days	9.16 days	11.79 days	15.54 days	---
<b>Nitric Oxide</b>	37 (20%)	21 (15.44%)	18 (18.56%)	21 (30.43%)	97 (19.92%)
<b>Average Time on Nitric Oxide</b>	12.54 days	8.86 days	6.39 days	11.62 days	---
<b>Oscillating Ventilator</b>	63 (34.05%)	47 (34.56%)	22 (22.68%)	27 (39.13%)	159 (32.65%)
<b>Average Time on Oscillator</b>	15.16 days	10.57 days	8.05 days	8.78 days	---
<b>Ventilator</b>	161 (87.03%)	113 (83.09%)	62 (63.92%)	40 (57.97%)	376 (77.21%)
<b>Unknown/Unanswered</b>	24 (4.93%)	23 (16.91%)	35 (36.08%)	29 (42.03%)	111 (22.79%)

	Survivors (321)		Non-Survivors (166)		Totals
	Male	Female	Male	Female	
<b>Average Time on Ventilator</b>	28.87 days	19.99 days	18.41 days	21.18 days	---
<b>Ventilator Dependent</b>	7 (1.44%)	2 (1.47%)	4 (4.12%)	0	13 (2.67%)
<b>Oxygen</b>	102 (55.14%)	81 (59.59%)	58 (59.79%)	49 (71.01%)	290 (59.55%)
<b>Unknown/Unanswered</b>	83 (44.86%)	55 (40.44%)	39 (40.21%)	20 (28.99%)	197 (40.45%)
<b>Average Time on Oxygen</b>	43.61 days	30.57 days	20.26 days	22.24 days	---
<b>Oxygen Dependent</b>	45 (24.32%)	28 (20.59%)	6 (6.19%)	0	79 (16.22%)

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.

### CDH Repairs

	Survivors (321)		Non-Survivors (166)		Totals
	Male	Female	Male	Female	
<b>Total Repairs</b>	225	173	50	33	481
<b>1 Repair</b>	144 (77.84%)	111 (81.62%)	34 (35.05%)	29 (42.03%)	318 (65.3%)
<b>2 Repairs</b>	26 (14.05%)	17 (12.5%)	5 (5.15%)	2 (2.9%)	50 (10.27%)
<b>3 Repairs</b>	5 (2.7%)	6 (4.41%)	0	0	11 (2.26%)
<b>4 Repairs</b>	2 (1.08%)	1 (.74%)	0	0	3 (.62%)
<b>5 Repairs</b>	0	0	0	0	0
<b>6 Repairs</b>	1 (.54%)	1 (.74%)	1 (1.03%)	0	3 (.62%)
<b>Multiple Repairs</b>	34 (18.38%)	25 (18.39%)	6 (6.19%)	2 (2.9%)	67 (13.78%)
<b>No Repairs</b>	0	0	52 (53.61%)	35 (50.72%)	87 (17.86%)
<b>Unanswered</b>	7 (3.78%)	0	5 (5.15%)	3 (4.35%)	15 (3.08%)

### Types of Repairs

	Number of Repairs Survivors						Number of Repairs Non-Survivors					
	1	2	3	4	5	6	1	2	3	4	5	6
<b>Gore-Tex</b>	95	28	9	1	1	1	30	3	1	-	-	1
<b>Sutures Only</b>	78	3	-	-	-	-	4	1	-	-	1	-
<b>Abdominal Muscle</b>	24	9	-	-	-	-	1	-	-	1	-	-
<b>Other Tissue</b>	5	1	-	-	-	-	2	-	-	-	-	-
<b>Other Synthetic Material</b>	12	3	-	-	-	-	4	2	-	-	-	-
<b>Unknown</b>	81	11	4	2	1	1	25	2	-	-	-	-
<b>Unanswered</b>	26	8	3	1	-	-	13	-	-	-	-	-
<b>Totals</b>	321	63	16	4	2	2	79	8	1	1	1	1

Gore-Tex is still the most commonly used material to repair CDH, and is the most likely to cause reherniation. Those patients whose hernias are small enough to require only sutures appear to have the highest success rate in avoiding reherniation. The rather new technique of using the Lattismus Dorsi (abdominal wall muscle) was successful in preventing reherniation in the majority of patients.

Hopefully someday soon, with the use of “growing” diaphragms in the lab with genetic engineering, and thereby using the patients own “diaphragm” for use in repairs, the incidence of reherniation will decrease. This is currently still in the testing stage.

### Family History of CDH

	Survivors	Non-Survivors	Due
<b>Sibling</b>	2	10	0
<b>Parent</b>	1	0	0
<b>Aunt/Uncle</b>	1	0	1
<b>Cousin</b>	4	1	0
<b>Distant Relative</b>	5	3	0
<b>Total</b>	13	14	1
<b>No CDH History/ Unknown</b>	306	153	13

The high occurrence rate in familial CDH in Non-Survivors is due to genetic and non-chromosomal syndromes, such as Fryn’s Syndrome, in some cases. Other cases are not explained and could be due to genetic problems that our medical community has not yet mapped out or due to environmental factors. The occurrence rate of having more than one child with CDH is 2% in families with no known genetic problems, but we suggest genetic counseling for all members.

### Sibling History

	Survivors (321)		Non-Survivors (166)		Due (15)			Totals
	Male	Female	Male	Female	Male	Female	Unknown	
<b>No Siblings</b>	51	40	18	24	5	0	1	139
<b>Twin</b>	8	8	5	1	0	0	0	22
<b>Sextuplet</b>	0	0	0	1	0	0	0	1
<b>Healthy Siblings and Half-Siblings</b>	220	151	128	84	3	4	2	592
<b>Siblings With Medical Problems</b>	6	5	6	6	0	0	0	23
<b>No Answer</b>	6	4	8	2	0	0	1	21
<b>Miscarriages</b>	41	35	38	17	0	0	-	131
<b>No Miscarriages</b>	53	49	24	25	2	2	-	155
<b>Miscarriages-Unanswered</b>	102	66	55	32	4	2	4	265
<b>Infertility</b>	7	4	3	7	0	0	0	21

We have 23 twins in our membership- 21 are fraternal twins (their twins are healthy) and 2 were identical twins (both had CDH). This leads us to think that CDH was mostly likely caused by a genetic problem in these pregnancies, due to the fact that all babies (including their healthy twins) were exposed to the same environmental factors in utero. We also have 1 set of sextuplets, including 1 child with CDH, 1 child with a heart defect, 2 lost in utero, and 2 healthy children. CDH is more common in multiple births, with an incidence of 1:1250 per child as compared to single births with an incidence of 1:2500. The cause is not known.

## Average Hospital Stay

	Survivors (321)	
	Male	Female
<b>Shortest Time</b>	5 days	2 days
<b>Longest Time</b>	730 days	365 days
<b>Average</b>	66.07 days	62.69 days

## Congenital Diaphragmatic Hernia Research Survey Results

### Parental Ethnicity

Parents	#
"American"	64
"White/Caucasian"	20
English	15
German	14
Italian	14
Irish	10
American Indian	8
"European"	6
Australian	6
Canadian	5
Danish	5
Polish	5
Scottish	5
French	4
Hungarian	4
French Canadian	3
New Zealand	3
Croatian	2
Puerto Rican	2
Spanish	2
Unanswered	3
Asian Indian	2
Czechoslovakian	1
Dutch	1
Greek	1
Menonite	1
Norweigen	1
Penn. Dutch	1
Russian	1
Slavic	1
Slovinian	1
Swedish	1
Ukranian	1

### Parental Religious Affiliations

Parents	#
Catholic	55
Protestant	19
Baptist	17
"Christian"	17
None	14
Methodist	13
Church of England	5
Jewish	5
Presbyterian	5
Lutheran	4
Seventh Day Adventist	4
Hindu	2
Penecostal	2
Southern Baptist	2
Episcopalian	1
Charismatic Christian	1
Mormon	1
Unanswered	10

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

<b>Parents</b>	<b>#</b>
Homemakers	25
Medical	15
Computer Work	14
Education	11
Automobiles	9
Industrial	9
Management	9
Construction	7
Law	7
Military	6
Sales	6
Accounting	5
Banking/Stockbroking	5
Secretarial	5
Bookkeeping	4
Engineering	4
Retail	4
Security	4
Business Owner	3
Chemistry	3
Metal Work	3
Telephone	3
Airplane Pilot/Attendant	2
Food Service	2
Lodging	2
Sports	2
Architecture	1
Boating	1
Botanical Work	1
Carpentry	1
Cosmetics	1
Firefighting	1
Postal Work	1
Social Work	1
Unanswered	1

<b>Grandparents</b>	<b>#</b>
Homemakers	60
Secretarial/Clerical	28
Sales	21
Automobiles	20
Medical	20
Education	19
Agriculture/Farming	10
Construction/Home Repair	10
Engineering	9
Electrician	8
Banking/Stockbroking	7
Telephone	7
“Business”	6
Custodial Work	6
Industrial	6
Business Owner	5
Carpentry	4
Computer Work	4
Management	4
Metal Work	4
Bookkeeping	3
Child Care	3
Clergy	3
Food Service	3
Insurance	3
Law	3
Military	3
Postal Work	3
Retail	3
Specialized Trade	3
Accounting	2
Chemistry	2
Firefighting	2
Lodging/Landlord	2
Logging	2
Media	2
Railroad Transportation	2
Security	2
Airplane	1
Architecture	1
Boating	1
Civil Service	1
Cosmetics	1
Music	1
Social Work	1
Unanswered	42

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.

## Environmental Exposures

	Yes	No	Unanswered
Resided Near Airport	17	68	3
Agriculture Region	13	72	3
Chemical Exposure During Pregnancy	11	74	3
High Voltage Power Lines/Electromagnetic Fields	8	77	3
Electric Blanket During Pregnancy	6	79	3
Resided Near Factory During Preconception	6	79	3
Hazardous Waste Site- Pregnancy	5	80	3
Resided Near Factory During Pregnancy	4	81	3
Struck By Lightening/Electrocuted	4	81	3
Consignous Ancestors	3	82	3
Hazardous Waste Site- Mother	2	83	3
Consignous Parents	2	83	3
Hazardous Waste Site- Father	1	84	3

## Family Medical Histories

	Parent	Sibling	Grandparent	Aunt/Uncle	Cousin	Distant Relative
"Multiple Birth Defects"	0	0	0	1	2	1
Anemia	14	0	4	2	0	3
Asthma	13	4	7	14	6	0
Autism	0	1	0	1	1	0
Blood Disorders	0	0	0	1	0	0
Cancer	2	0	36	7	1	18
CDH	0	11	0	0	0	3
Cleft Lip/Palate	0	2	0	1	1	0
Diabetes	1	0	8	7	4	5
Diabetes, Gestational	0	2	2	4	0	0
Displaced Anus	1	0	0	0	0	0
Displaced Hips	0	0	0	1	0	0
Ears, Abnormal	0	0	0	0	1	0
Eating Disorders	1	0	1	5	1	0
Epilepsy	1	1	1	3	2	1
Genetic Abnormalities	0	1	0	1	6	2
Heart Defects	5	4	13	6	10	2
Hiatal Hernia	3	3	0	0	0	0
High Blood Pressure	6	0	57	7	0	6
Hirschsprung's Disease	0	2	0	0	0	0
Hypothyroidism	2	1	2	1	0	0
Limbs and Extremities, Abnormal	0	2	0	0	1	1
Lyme's Disease	3	0	0	0	0	0
Neuropsychiatric Disorders	2	1	3	6	0	0
Non-Chromosomal Syndromes	0	4	0	0	2	1
Obstructed Kidney	0	1	0	0	0	0
Pyloric Stenosis	0	1	0	0	0	0
Polynephrosis	1	0	0	0	0	0
Reflux	0	2	3	1	1	0
Rh Factor Complications	2	0	5	1	2	0
Rubella- Menieres Disease	1	0	0	0	0	0
Seizure Disorder	0	0	1	1	1	0



	Parent	Sibling	Grandparent	Aunt/Uncle	Cousin	Distant Relative
Septated Uterus	2	-	-	-	-	-
STDs (at time of conception/during pregnancy)	7	-	-	-	-	-
Spina Bifida	0	0	0	1	0	0
Strokes	0	0	17	4	1	9
Tilted Uterus	2	-	-	-	-	-
Tracheoesophageal Fistula	0	0	0	0	1	0

**Parental Exposures Up To The Time of Conception** (in 176 parents)

Exposure	Yes	No	Don't Know	Mother	Father	Before Conc.	At Conc.
X-rays	107	68	1	57	50	56	0
Natural Gas	89	83	4	40	49	85	79
Computers	87	87	2	48	39	93	87
Aerosol Spray	84	85	7	49	35	49	46
Stress	82	92	2	48	34	54	48
Paint Fumes	67	105	4	34	33	51	5
Chicken Pox	64	110	2	34	30	61	0
Insect Repellant	39	130	7	17	22	37	15
Solvents	34	132	10	18	16	35	26
Glues	32	126	8	15	17	33	4
Marijuana	29	147	0	14	15	29	0
DEET	22	141	13	9	13	22	6
Professional Spraying	21	144	11	10	11	10	9
Formaldehyde	18	147	11	8	10	18	2
High Temperatures	18	153	5	10	8	12	11
Rubella	16	153	7	8	8	16	0
Asbestos	14	148	14	4	10	14	0
Diesel Fuel	13	158	5	1	12	13	10
Industrial Chemicals	13	152	11	2	11	13	12
Photography Chemicals	13	159	4	9	4	13	3
Mercury	12	156	8	5	7	11	0
Printing Inks	12	158	6	7	5	12	2
Diazanone	11	149	16	5	6	10	1
Agriculture Spraying	10	152	14	5	5	9	6
Fiberglass	9	162	5	3	6	9	2
Nasal Spray	8	165	1	4	4	8	2
Tar	8	162	6	6	2	6	3
Coal	7	163	6	4	6	7	1
Trichlorethylene	7	155	14	1	6	7	4
Organic Solvents	6	155	15	2	4	6	4
Benzocaine Sulfur	5	158	13	3	2	2	2
Lead	5	157	14	5	3	7	3
Cocaine	4	171	1	2	2	4	0
Damaged Microwaves	4	172	0	2	2	4	4
Nitrofen	4	152	20	2	2	4	2
PCBs	4	158	14	0	4	4	1
Permethrin	4	159	13	2	2	4	0
Steroids	4	171	1	2	2	4	0
Xylene	4	161	11	0	4	2	2
Chemical Warfare	3	173	0	0	3	3	0
Chlordane	3	156	17	2	1	3	1
Hashish	3	172	1	3	0	3	0
Lindane	3	156	17	2	1	3	0
LSD	3	172	1	2	1	3	0

Exposure	Yes	No	Don't Know	Mother	Father	Before Conc.	At Conc.
Sodium Chlorate	3	160	13	2	1	2	1
Uranium	3	167	6	1	2	3	0
Carbon Monoxide Poisoning	2	174	0	1	1	0	0
DDT	2	158	16	1	1	2	0
Dursban	2	156	18	0	2	2	0
Quinine	2	161	13	1	1	2	0

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.

### Maternal Exposures During Pregnancy (in 88 pregnancies)

Exposure	Yes	No	Don't Know	1 <sup>st</sup> Tri.	2 <sup>nd</sup> Tri.	3 <sup>rd</sup> Tri.
Pre-Natal Vitamins	80	6	2	80	80	79
Computers	50	36	2	50	50	50
Caffeine	49	39	0	49	44	44
Aerosol Spray	46	35	7	46	45	45
Natural Gas	41	43	4	41	41	40
Stress	41	45	2	41	40	39
Antacids	34	53	1	32	29	32
Solvents	22	56	10	22	22	22
Allergy/Cough/Cold Medications	21	63	4	16	11	10
Antibiotics	16	71	1	8	7	8
Alcohol	15	72	1	15	8	9
Paint Fumes	12	72	4	4	6	2
Painkillers	10	75	3	9	6	3
Anti-Nausea Medications	8	78	2	8	0	0
Nicotine	8	79	1	8	7	7
Artificial Hormones	7	81	0	7	2	2
Vaginal Medications	7	80	1	6	4	0
X-rays	7	80	1	3	2	2
Glues	6	74	8	6	6	6
Insect Repellant	6	75	7	6	6	6
Steroids	6	81	1	0	2	6
Laxatives	5	82	1	5	4	4
Asthma Medication	4	83	1	4	3	3
Professional Spraying	4	73	11	4	4	4
Chicken Pox	3	83	2	0	2	1
Contraceptives	3	84	1	3	0	0
Lead	3	71	14	3	3	3
Mercury	3	77	8	3	0	0
Sedatives	3	84	1	3	0	0
Benzocaine Sulfur	2	73	13	2	1	1
Damaged Microwaves	2	86	0	2	2	2
Diesel Fuel	2	86	5	2	2	2
Flu Shot	2	85	1	2	0	0
High Temperatures	2	81	5	1	2	0
Nasal Spray	2	85	1	2	2	2
Photography Chemicals	2	82	4	2	2	2
Printing Inks	2	80	6	2	2	2

## Pregnancy Histories

	VO	O	Y	N	U	%
Prenatal Care	-	-	88	0	-	100
Fetal Movement	31	35	20	1	1	97.73
Fatigue	11	22	40	15	0	82.95
Heart Burn	16	12	33	24	3	70.01
Mood Swings	4	12	42	25	5	68.18
Morning Sickness	17	6	37	28	0	68.18
Sleeping Problems	11	9	39	28	1	67.04
Headaches	6	6	45	29	2	64.77
Fetal Hiccups	11	16	26	27	8	60.23
Food Cravings	3	18	30	33	4	57.95
Constipation	7	8	34	34	5	55.68
Reduced Sex Drive	7	6	36	32	7	55.68
Colds	0	1	47	34	6	54.55
Dental Work	-	-	30	55	3	34.09
Breathing Problems	1	2	26	58	3	32.95
Bleeding Gums	0	4	24	58	2	31.82
Anemia	5	2	16	64	1	26.14
Hot/Cold Sensitivity	2	4	15	59	8	23.86
Polyhydramnios	-	-	20	58	10	22.73
Joint Pain	1	5	13	64	5	21.59
Flu	-	-	18	64	6	20.45
Depression	1	2	14	70	1	19.32
Hair Dye	1	2	13	71	1	18.18
Unexplained Rashes	0	2	6	79	1	9.09
Allergies	1	2	12	72	1	15.91
Emotional Problems	1	2	12	70	3	15.91
Night Sweats	2	0	12	72	2	15.91
Low Blood Pressure	2	1	9	74	2	13.64
Dehydration	2	0	9	76	1	12.5
Unexplained Itching	2	4	5	76	1	12.5
Hair Loss	0	2	8	74	4	11.36
Hair Permanent	0	0	10	73	5	11.36
Hot Tub	0	1	8	77	2	10.23
Hyperemesis	2	2	3	69	12	7.95
Electric Blanket	-	-	6	3	-	6.82
High Blood Pressure	2	1	4	80	1	6.82
Other Hair Treatments	0	0	4	84	0	4.54
Fetal Death	-	-	3	85	-	3.41
Gestational Diabetes	-	-	3	85	0	3.41
PROM	-	-	3	85	-	3.41
Toxemia	-	-	3	84	1	3.41
Unexplained Fevers	1	0	2	85	0	3.41
Artificial Nails	0	0	2	86	0	2.27
Strep B	-	-	2	85	1	2.27
Vaccinations	0	0	2	86	0	2.27

KEY: vo-very often, o-often, y-yes/sometimes, n-no/never, u-unanswered/dont remember

## Organs In The Chest Cavity

	Survivors	Non-Survivors
Stomach	36	17
Small Intestines	53	19
Large Intestines	6	2
Liver	29	12
Pancreas	0	2
Spleen	19	9
Kidneys	3	1
Colon	5	2
Gall Bladder	1	1
Adrenal Glands	0	1
Unknown/Unanswered	5	7

### Associated Anomalies

We did not include this category this year because we have more updated information in the Membership Form Survey Results in the first part of this report.

### Complications

We did not include this category this year because we have more updated information in the Membership Form Survey Results in the first part of this report.

### Current Health and Residence (survivors only)

	Male	Female	Total
<b>Initial Hospitalization</b> (average days)	80.24	77.41	78.97
<b>Currently On Medications</b>	18	12	30
<b>Receiving Therapy*</b>	23	20	43
<b>Chronic Care Facility</b>	2	0	2
<b>Home With Nursing Care</b>	8	8	16

\*Physical, Speech, Occupation, Feeding, Sight, or Play Therapy

## Lung Capacity

	Survivors			Non-Survivors		
	L-Sided CDH	R-Sided CDH	Bilateral CDH	L-Sided CDH	R-Sided CDH	Bilateral CDH
<b>Number</b>	47	12	1	25	2	1
<b>Left Lung Capacity at Birth</b>	50.06%	85%	10%	36.5%	80%	---
<b>Right Lung Capacity at Birth</b>	87.11%	23%	50%	53.89%	25%	---
<b>Present Left Lung Capacity</b>	78.18%	92.5%	75%	---	---	---
<b>Present Right Lung Capacity</b>	97.36%	82.6%	75%	---	---	---
<b>Unknown/No Answer</b>	22	5	0	15	1	1

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
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

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)
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
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

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)
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

Case#	Number of Repairs	Material Used	ECMO (days)	Nitric Oxide (days)	High Frequency Oscillator (days)	Ventilator (days)	Oxygen (days)	Multiple Birth Defects	Complications	Feeding Problems	Developmental Stage	Estimated Total Cost of Child's Medical Care	Age At Time of Death (days)
D0001	2	Gore-Tex, u/k	8	0	7	90	129	no	yes	n/a	n/a	\$1,500,000.00	143
D0002	1	Gore-Tex	0	0	0	60	90	yes	yes	n/a	n/a	\$2,500,000.00	360
D0003	0	n/a	0	0	0	1	1	no	yes	n/a	n/a	u/a	1
D0004	0	n/a	12	0	0	1	12	no	yes	n/a	n/a	\$145,000.00	12
D0005	1	Gore-Tex	25	2	21	29	29	no	yes	n/a	n/a	u/a	29
D0006	0	n/a	0	0	0	0	0	yes	yes	n/a	n/a	u/a	1
D0007	1	Gore-Tex	10	0	0	8	10	no	yes	n/a	n/a	\$125,000.00	7
D0008	1	Gore-Tex	21	0	0	21	21	yes	yes	n/a	n/a	u/a	27
D0009	2	Sutures, Sutures	0	0	0	75	80	no	yes	n/a	n/a	\$400,000.00	136
D0010	0	n/a	0	0	0	0	0	no	yes	n/a	n/a	\$3,000.00	1
D0011	0	n/a	0	0	0	1	1	yes	yes	n/a	n/a	u/a	1

Case#	Number of Repairs	Material Used	ECMO (days)	Nitric Oxide (days)	High Frequency Oscillator (days)	Ventilator (days)	Oxygen (days)	Multiple Birth Defects	Complications	Feeding Problems	Developmental Stage	Estimated Total Cost of Child's Medical Care	Age At Time of Death (days)
D0012	0	n/a	0	0	8	2	10	yes	no	n/a	n/a	\$90,000.00	10
D0013	1	Dura	0	0	0	1	1	no	yes	n/a	n/a	u/a	1
D0014	6	Tissue, Gore-Tex, Gore-Tex, Abdominal Wall Muscle, Sutures, Gore-Tex	0	0	21	910	1095	yes	yes	n/a	n/a	\$4,000,000.00	2419
D0015	0	n/a	0	0	0	0	0	yes	yes	n/a	n/a	\$5,000.00	0
D0016	1	Gore-Tex	10	3	0	20	20	yes	yes	n/a	n/a	\$35,000.00	21
D0017	0	n/a	2	0	2	2	2	yes	yes	n/a	n/a	\$10,000.00	2
D0018	0	n/a	0	0	1	1	1	yes	yes	n/a	n/a	u/a	1
D0019	0	n/a	0	0	0	0	0	no	yes	n/a	n/a	u/a	1
D0020	1	Other	13	24	24	24	24	yes	yes	n/a	n/a	\$750,000.00	23
D0021	0	n/a	0	0	0	0	0	no	yes	n/a	n/a	u/a	0
D0022	0	n/a	0	0	0	0	0	no	no	n/a	n/a	u/a	0
D0023	1	Gore-Tex	19	0	2	5	24	no	yes	n/a	n/a	\$450,000.00	24
D0024	0	n/a	6	0	1	1	1	yes	yes	n/a	n/a	u/a	7
D0025	0	n/a	0	0	0	0	0	no	yes	n/a	n/a	u/a	1
D0026	1	Gore-Tex	5	14	1	43	43	yes	yes	n/a	n/a	u/a	43
D0027	0	n/a	0	0	0	1	1	no	yes	n/a	n/a	u/a	2
D0028	1	Other Synthetics	0	2	2	2	2	yes	yes	n/a	n/a	\$0.00	3
S0001	2	Gore-Tex, Abdominal Wall Muscle	0	0	30	30	150	no	yes	None	Normal	\$500,000.00	n/a
S0002	1	Gore-Tex	20	0	0	150	545	yes	yes	Severe	Above Average	\$500,000.00	n/a
S0003	1	Abdominal Wall Muscle	0	3	6	22	910	yes	yes	No Answer	No Answer	\$500,000.00	n/a
S0004	1	u/a	0	0	0			no	yes	G-Tube	No Answer	\$1,500,000.00	n/a
S0005	1	Tissue	10	0	1	42	270	no	yes	Slight	Normal	\$300,000.00	n/a
S0006	1	Gore-Tex	0	0	0	29	31	yes	yes	Slight	Normal	u/a	n/a
S0007	1	Sutures	0			14	14	no	yes	None	Normal	\$52,000.00	n/a
S0008	1	Gore-Tex	21	0	0	32	150	yes	yes	Moderate	Slight	\$500,000.00	n/a
S0009	1	u/k	2	0	0	14	14	yes	yes	G-Tube	Normal	\$500,000.00	n/a
S0010	3	Sutures, Gore-Tex, Gore-Tex	0	0	0	1	1	yes	yes	Slight	Slight	\$200,000.00	n/a
S0011	1	Gore-Tex	9	0	0	30	90	no	no	None	Normal	u/a	n/a
S0012	1	Tissue	0	3	4	18	18	yes	no	G-Tube	Moderate	\$500,000.00	n/a
S0013	1	Marlex	17	1	1	14	1500	no	no	NG-Tube	Normal	\$800,000.00	n/a
S0014	1	Sutures	6	1	5	21	30	yes	yes	Slight	Slight	\$300,000.00	n/a
S0015	3	Gore-Tex, Gore-Tex, Gore-Tex	10	0	0	1460	1460	no	no	Slight	Slight	\$1,500,000.00	n/a

Case#	Number of Repairs	Material Used	ECMO (days)	Nitric Oxide (days)	High Frequency Oscillator (days)	Ventilator (days)	Oxygen (days)	Multiple Birth Defects	Complications	Feeding Problems	Developmental Stage	Estimated Total Cost of Child's Medical Care	Age At Time of Death (days)
S0016	1	u/k	0	0	0	0	30	yes	yes	TPN	Normal	\$35,000.00	n/a
S0017	1	Gore-Tex	3	0	1	11	28	yes	yes	Moderate	Moderate	\$275,000.00	n/a
S0018	1	Sutures	6	0	0	28	30	yes	no	G-Tube	Slight	u/a	n/a
S0019	1	u/a	10	1	0	25	1825	yes	yes	Moderate	Normal	u/a	n/a
S0020	1	Gore-Tex	0	0	0	21	7	no	yes	G-Tube	Slight	u/a	n/a
S0021	1	Other	0	0	0	0	4	no	yes	None	Normal	u/a	n/a
S0022	1	Gore-Tex	14	0	21	75	425	yes	yes	G-Tube	Slight	\$675,000.00	n/a
S0023	1	Gore-Tex	2	0	0	6	180	no	yes	None	Normal	\$600,000.00	n/a
S0024	1	Gore-Tex	0	9	0	19	425	yes	yes	NG-Tube	Severe	\$180,000.00	n/a
S0025	1	u/a	0	0	15	21	21	no	yes	No Answer	No Answer	\$200,000.00	n/a
S0026	1	Gore-Tex	12	3	4	60	60	no	yes	Severe	Normal	\$500,000.00	n/a
S0027	1	u/a	0	0	0	4	7	yes	yes	Slight	Normal	\$40,000.00	n/a
S0028	2	Gore-Tex, Gore-Tex	0	0	28	7		yes	yes	G-Tube	Slight	\$150,000.00	n/a
S0029	1	Gore-Tex, Mylex	0	0	14	7	200	yes	no	G-Tube	Normal	\$400,000.00	n/a
S0030	1	Sutures	0	0	0	10	10	yes	yes	Moderate	Normal	\$60,000.00	n/a
S0031	4	Abdominal Wall Muscle, u/a , u/a , u/k	0	0	45	60	90	no	no	Slight	Normal	\$250,000.00	n/a
S0032	1	u/k	3	30	21	40	500	yes	no	None	Normal	\$4,000,000.00	n/a
S0033	1	Gore-Tex	13	0	14	14	75	yes	yes	NG-Tube	Above Average	\$1,000,000.00	n/a
S0034	6	Gore-Tex, Abdominal Wall Muscle, Gore-Tex, Gore-Tex, Gore-Tex, Abdominal Wall Muscle	7	1	4	26	35	yes	yes	Slight	Normal	\$500,000.00	n/a
S0035	1	Sutures	0	0	0	9	11	no	yes	None	Normal	\$100,000.00	n/a
S0036	3	Other Synthetic, Other Synthetic, Gore-Tex	0	0	0	60	180	yes	no	None	Normal	u/a	n/a
S0037	1	u/a	2	0	0	10	21	yes	yes	Severe	Normal	\$500,000.00	n/a
S0038	1	Sutures	0	0	2	10	11	no	yes	None	Slight	\$50,000.00	n/a
S0039	3	Gore-Tex, Gore-Tex, Gore-Tex	0	0	28	3	28	yes	yes	Slight	Normal		n/a
S0040	1	Sutures	8	1	20	36	54	no	no	Slight	Normal	\$650,000.00	n/a
S0041	1	Other Synthetic	0	0	0	8	28	yes	yes	Severe	Slight	u/a	n/a
S0042	1	Gore-Tex	6	1	1	7	245	yes	yes	Mic-Key	Slight	\$350,000.00	n/a
S0043	1	Sutures, Abdominal Wall Muscle	0	0	15	22	20	no	no	Severe	Normal	\$500,000.00	n/a
S0044	1	Gore-Tex	6	0	0	16	42	yes	yes	G-Tube	Moderate	u/a	n/a
S0045	1	u/a						no	yes	None	Normal	u/a	n/a



Case#	Number of Repairs	Material Used	ECMO (days)	Nitric Oxide (days)	High Frequency Oscillator (days)	Ventilator (days)	Oxygen (days)	Multiple Birth Defects	Complications	Feeding Problems	Developmental Stage	Estimated Total Cost of Child's Medical Care	Age At Time of Death (days)
S0046	1	Gore-Tex	0	0	5	16	455	no	no	None	Normal	\$1,000,000.00	n/a
S0047		Sutures	10	6	0	0	9	yes	no	None	Normal	u/a	n/a
S0048	1	Sutures	0	0	0	10	12	yes	yes	Slight	Normal	\$175,000.00	n/a
S0049	1	Sutures	0	21	0	56	63	no	no	Moderate	Normal	u/a	n/a
S0050	1	u/k	0	0	7	0	9	yes	yes	Slight	Normal	u/a	n/a
S0051	1	Gore-Tex	14	0	1	28	330	no	yes	None	Normal	\$600,000.00	n/a
S0052	1	Sutures	0	0	10	0	21	no	yes	Mic-Key	Moderate	\$85,000.00	n/a
S0053	2	Gore-Tex, Gore-Tex	0	0	0	77	77	no	no	None	Normal	\$2,000,000.00	n/a
S0054	3	Gore-Tex, Gore-Tex, Gore-Tex	7	0	1	140	510	no	yes	None	Moderate	\$2,000,000.00	n/a
S0055	1	Gore-Tex	12	0	1	50	86	no	yes	G-Tube	Normal	\$450,000.00	n/a
S0056	1	Abdominal Wall Muscle	0	16	7	64	73	yes	no	None	Normal	u/a	n/a
S0057	1	Sutures						yes	yes	Mic-Key		\$1,000,000.00	n/a
S0058	1	Gore-Tex	21	27	28	53	98	no	no	None	Normal	\$450,000.00	n/a
S0060	1	Gore-Tex	16	1	0	30	365	yes	no	Moderate	Normal	\$300,000.00	n/a
S0061	1	u/k	8	1	15	32	395	no	no	None	Normal	\$700,000.00	n/a

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