



Preliminary 2015 CDH Research Survey Results

CHERUBS - The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support
www.cdhrefsearch.org

Congenital Diaphragmatic Hernia

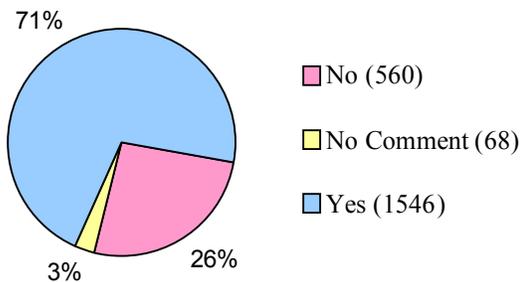
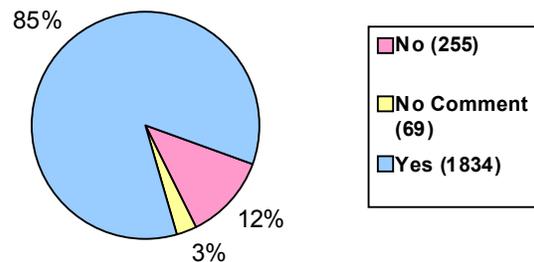
Congenital Diaphragmatic Hernia (CDH) is a birth defect that occurs when the diaphragm fails to fully form, thus allowing abdominal organs into the chest cavity. CDH occurs in approximately 1 in every 2500 live births¹. There are estimated 78 million babies born worldwide each year²; 31,200 born with CDH (based on 1:2500 odds). Every 15 minutes, a CDH baby is born. 3,952,841 babies were born in the United States in 2014³; approximately 1581 with CDH. Of these babies, approximately only 50% survive⁴.

CHERUBS' 2015 Congenital Diaphragmatic Hernia Research Survey Results ©

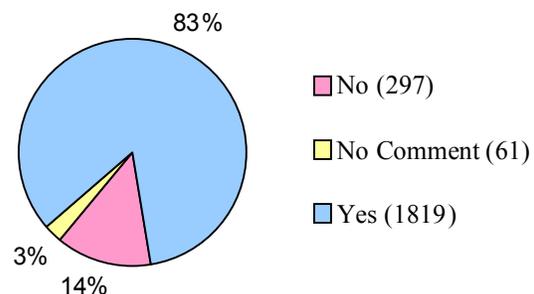
The following information was taken from our parent worksheets (also known as membership forms) and surveys sent in by December 1, 2014. This document is written in an easy-to-understand format for parents. We have separated the results into 2 categories: Membership Survey Results (taken from Parent Membership Forms) and Congenital Diaphragmatic Hernia Research Survey Results (taken from 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.

Parental Opinion On The Hospital Experience (not including expectant parents- 3854)

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

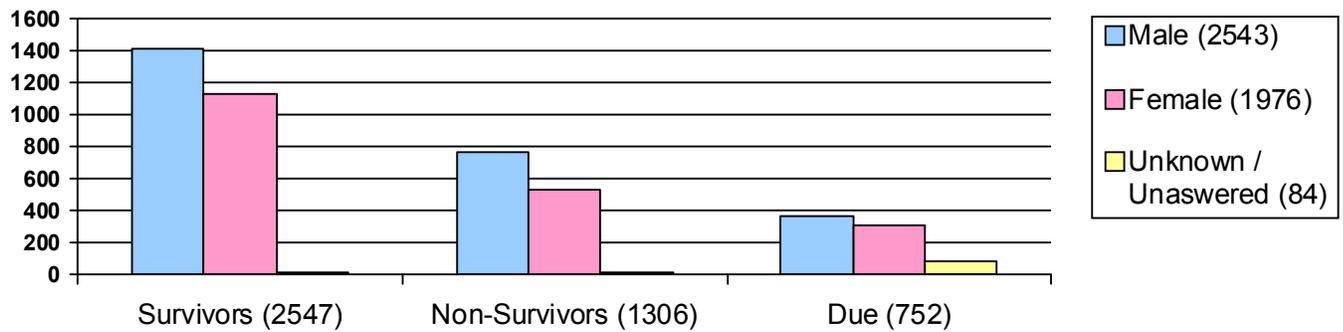


Do you feel that you were given enough information about your child's diagnosis?



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

Basic Statistics



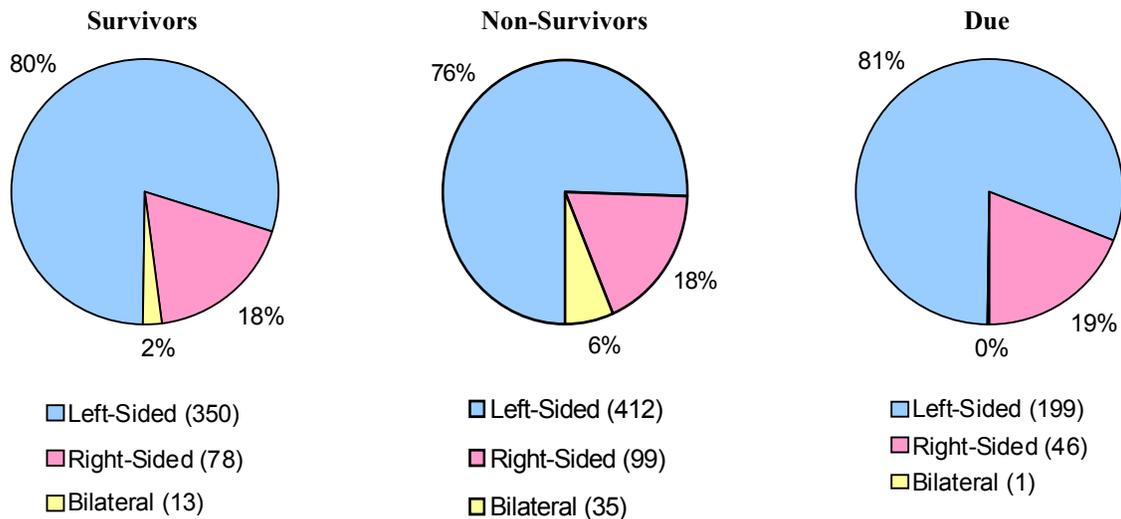
From our numbers, you can see that CDH seems to occur more often in males (1.29:1). This is higher than the previously reported (1.25:1)⁵. Of course this is highly influenced by which parents (of survivors or non-survivors) join CHERUBS. We have a higher rate of parents of survivors (55.30%) joining than parents of non-survivors (28.35%).

	Due	Survivors	Non-Survivors	Totals
Male	363 (48.27%)	1407 (55.24%)	769 (58.88%)	2540 (55.15%)
Female	311 (41.36%)	1131 (44.41%)	526 (40.28%)	1968 (42.73%)
Unknown / Unanswered	78 (10.37%)	9 (0.35%)	11 (0.84%)	98 (2.13%)
Totals	752 (16.33%)	2547 (55.30%)	1306 (28.35%)	4606

Side(s) of Congenital Diaphragmatic Hernia

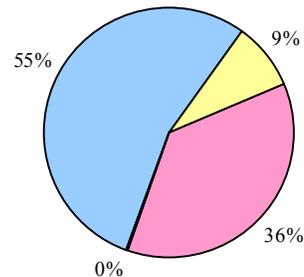
	Survivors (2538)			Non-Survivors (1295)			Due (752)			Unknown	Totals
	Male	Female	Unknown/Unspecified	Male	Female	Unknown/Unspecified	Male	Female	Unknown/Unspecified		
Left-Sided	608	465	0	328	82	2	109	73	17	0	0
Right-Sided	149	93	2	72	27	0	23	18	5	0	389
Bilateral	16	14	0	28	7	0	0	1	0	0	66
Unknown / Unanswered	634	559	7	341	410	9	231	219	56	1	2467
Totals	1407	1131	9	769	526	11	363	311	78	1	4606

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. 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

- Bochdalek / Posterolateral (327)
- Morgagni / Retrosternal (55)
- Agenesis of the Diaphragm (218)
- Diaphragmatic Eventration (2)



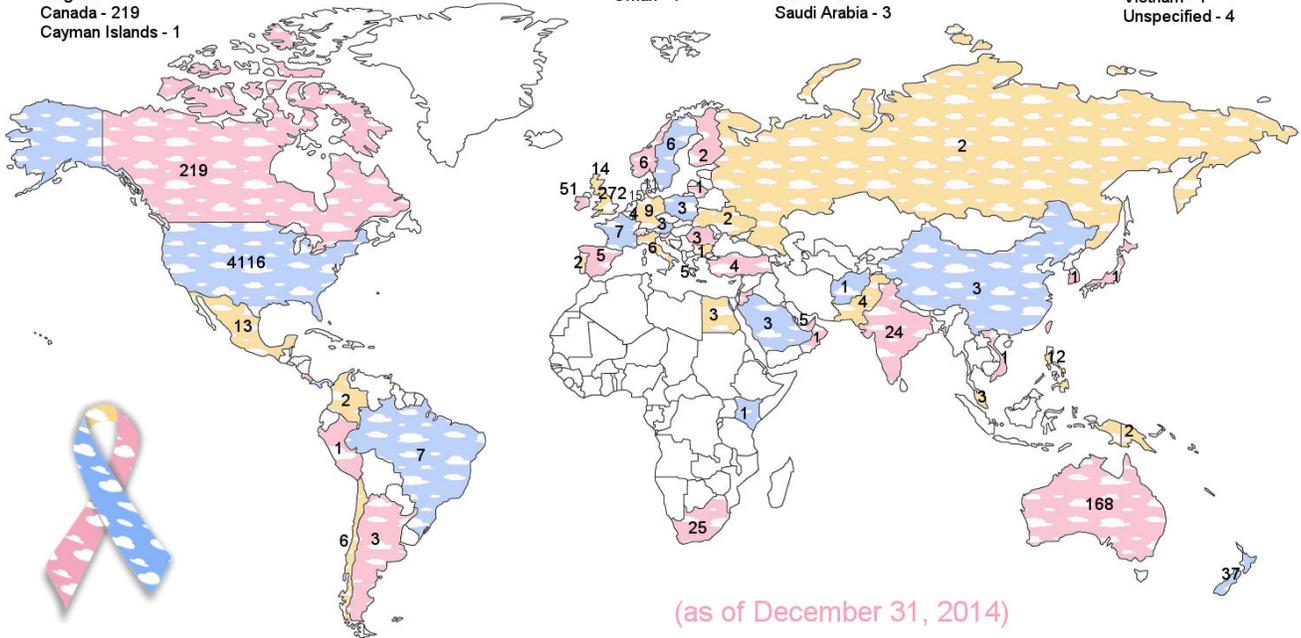
	Survivors (2538)		Non-Survivors (233)		Due (33)	Totals
	Male	Female	Male	Female		
Bochdalek / Posterolateral	115	103	47	14	47	326
Morgagni / Retrosternal	20	18	7	4	6	55
Agenesis of the Diaphragm	84	48	67	13	6	218
Diaphragmatic Eventration	1	1	0	0	0	2
Unknown / Unanswered	1187	961	648	495	693	3984
Totals	1407	1131	769	526	752	4585

86.89% of our members included in this survey did not know the type of CDH that their child has. Most answered "?" in the parent worksheet blank for "type of hernia", meaning that most of our members did not know there were different types of CDH. In most studies, 80% of posterolateral CDH have been reported to happen on the left side⁶. Bilateral (both sides) posterolateral CDH is extremely rare, with only 11 reported cases⁷. Morgagni (retrosternal) CDH accounts for only 2% of all diaphragmatic defects⁸. Morgagni hernias are more common on the right side but are bilateral in 15% to 30% of cases⁹.

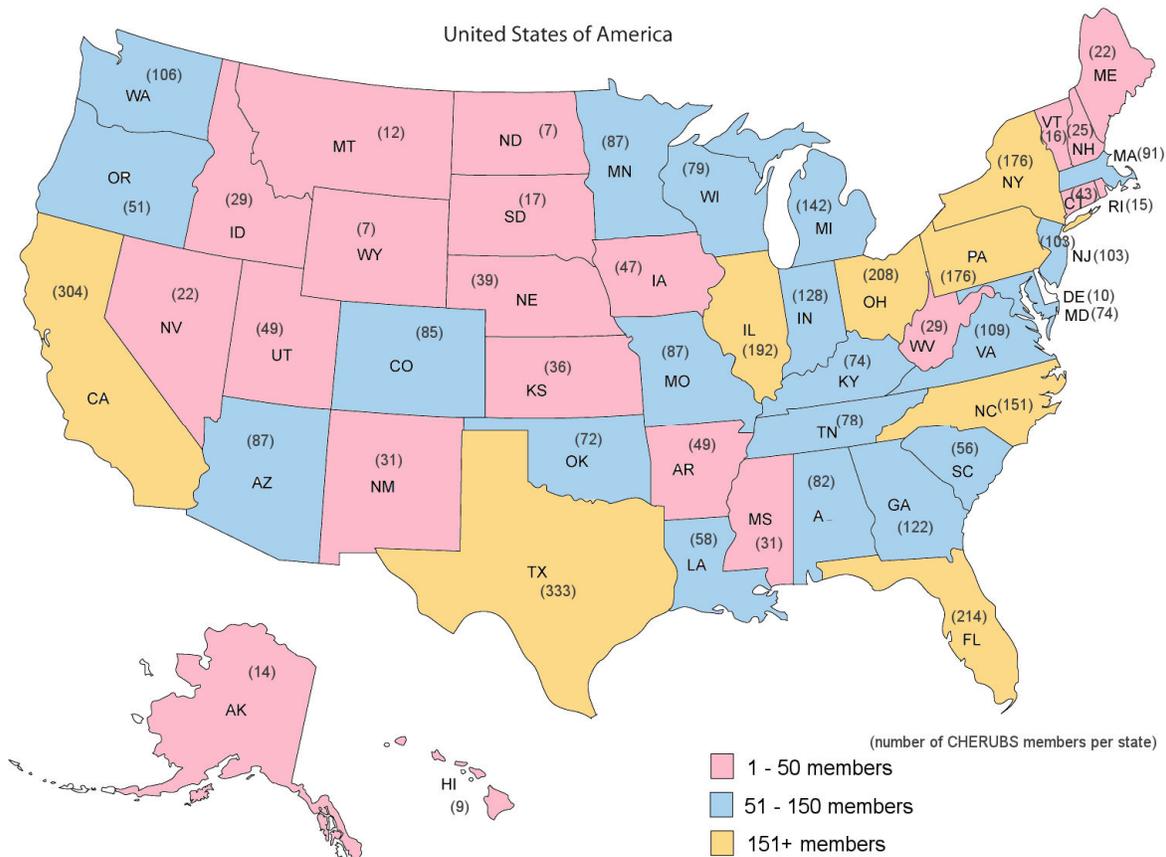
We also question the accuracy of this portion of survey, due to the high numbers Agenesis of the Hemidiaphragm and Complete Agenesis of the Diaphragm in survivors. The survival rate for these types of CDH is rather low and we think it is more likely that parents guessed the type of CDH their child had 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

- | | | | | | | | |
|--------------------|------------------|---------------|--------------|------------------|----------------------|-------------------|--------------------------|
| Afghanistan - 1 | Chile - 6 | Finland - 2 | India - 24 | Lebanon - 1 | Pakistan - 4 | Scotland - 14 | The Netherlands - 15 |
| Argentina - 3 | China - 3 | France - 7 | Ireland - 51 | Lithuania - 1 | Papua New Guinea - 2 | Singapore - 4 | Trinidad and Tobago - 1 |
| Australia - 168 | Columbia - 2 | Germany - 9 | Israel - 3 | Malaysia - 3 | Peru - 1 | Slovenia - 1 | Turkey - 4 |
| Bahamas - 1 | Costa Rica - 1 | Greece - 5 | Italy - 6 | Malta - 1 | Philippines - 12 | South Africa - 25 | Ukraine - 2 |
| Belgium - 4 | Denmark - 11 | Guam - 3 | Kenya - 1 | Mexico - 13 | Poland - 3 | Spain - 5 | United Arab Emirates - 5 |
| Bermuda - 2 | Egypt - 3 | Hong Kong - 7 | Korea - 1 | New Zealand - 37 | Portugal - 2 | Sweden - 6 | United Kingdom - 272 |
| Brazil - 7 | Faroe Island - 1 | | | Norway - 6 | Romania - 3 | Taiwan ROC - 1 | United States - 4116 |
| Bulgaria - 4 | | | | Oman - 1 | Russia - 2 | | Vietnam - 1 |
| Canada - 219 | | | | | Saudi Arabia - 3 | | Unspecified - 4 |
| Cayman Islands - 1 | | | | | | | |



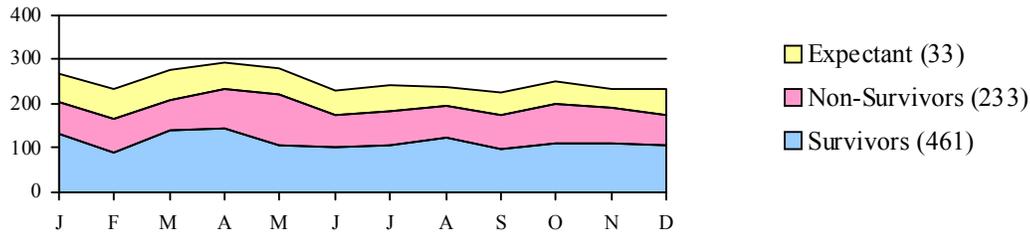
Most of our members are in the United States, with a large concentration on the East Coast and Texas and California, due to the general population of those states. Thanks to the internet, our membership is growing worldwide with approximately 150 new members each year for the past few years.



Seasonal Fluctuations

8 weeks

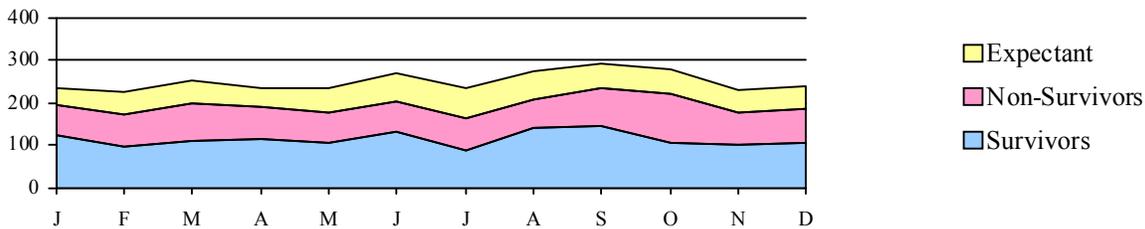
(approximate time of Diaphragm formation in utero, based on due dates)



	J	F	M	A	M	J	J	A	S	O	N	D	Unanswered	Totals
Survivors	133	89	140	144	107	103	105	123	98	111	112	107	1175	2547
Non-Survivors	70	75	68	88	114	72	78	70	75	89	79	68	360	1306
Expectant	66	68	65	61	59	53	57	43	51	52	41	60	76	752
Totals	269	232	273	293	280	228	240	236	224	252	232	235	1611	4605

8-Week Mark- There is a drastic jump in the number of diaphragmatic hernias formed in the spring. 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

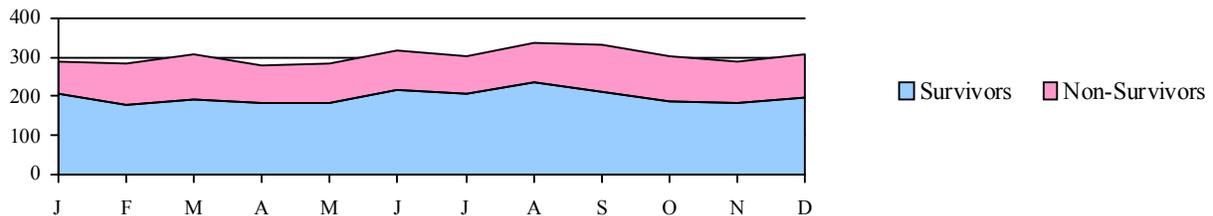
Due Dates



	J	F	M	A	M	J	J	A	S	O	N	D	Unanswered	Totals
Survivors	123	98	111	112	107	133	89	140	144	107	103	105	1175	2547
Non-Survivors	70	75	89	79	68	70	75	68	88	114	72	78	360	1306
Expectant	43	51	52	41	60	66	68	65	61	59	53	57	76	752
Totals	236	224	252	232	235	269	232	273	293	280	228	240	1611	4605

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.

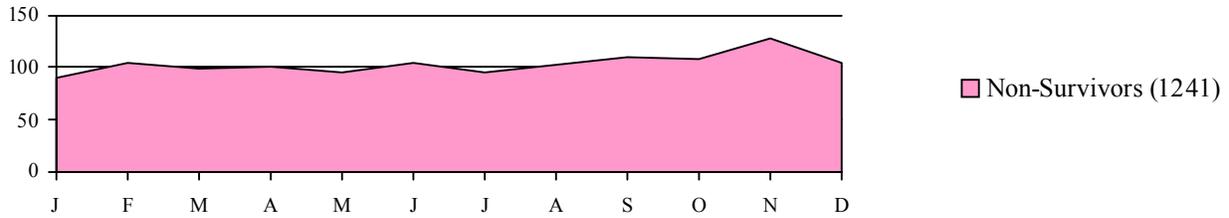
Birth Dates



	J	F	M	A	M	J	J	A	S	O	N	D	Unanswered	Totals
Survivors	206	178	194	184	181	218	206	237	213	188	183	197	162	2547
Non-Survivors	81	105	113	94	103	97	97	97	116	117	105	111	70	1306
Totals	287	283	307	278	284	315	303	334	329	305	288	308	232	3853

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



	J	F	M	A	M	J	J	A	S	O	N	D	Unanswered	Totals
Non-Survivors	91	104	99	101	96	104	95	103	109	108	127	104	3365	4606

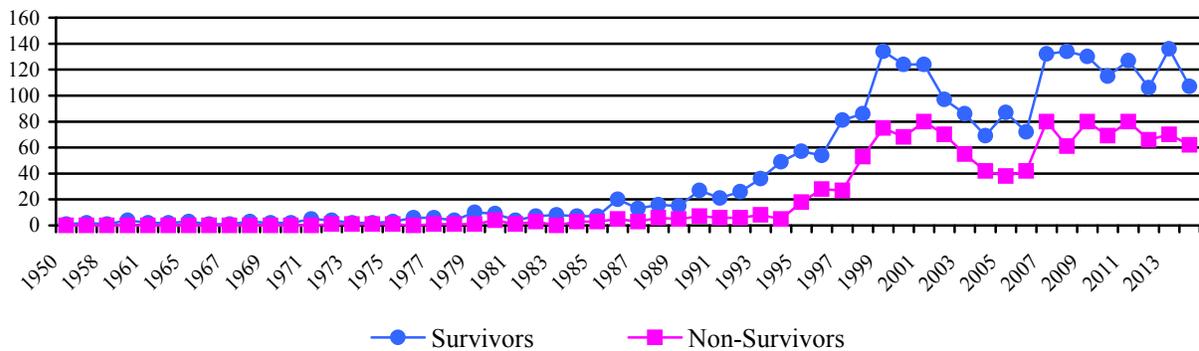
Death Dates- The increase in November is disturbing and correlates with the beginning of flu, cold, and virus seasons. With so many viruses and infections caught during hospitalizations and the low immunity of critically ill, and often premature, newborns with low lung capacity, it is highly likely that 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.

Parental Ages

	Survivors Male	Survivors Female	Non-Survivors Male	Non-Survivors Female	All
Average Mother's Age	28.8	28.4	27.6	28.8	28.4
Average Father's Age	31.1	30.9	29.9	30.6	30.6

Mother's ages range from 15 to 61, while father's ages range from 16 to 67. Unlike many birth defects and genetic problems, such as Down's Syndrome, that have a higher incidence among older mothers, we believe that CDH does not discriminate among age groups.

Years of Birth

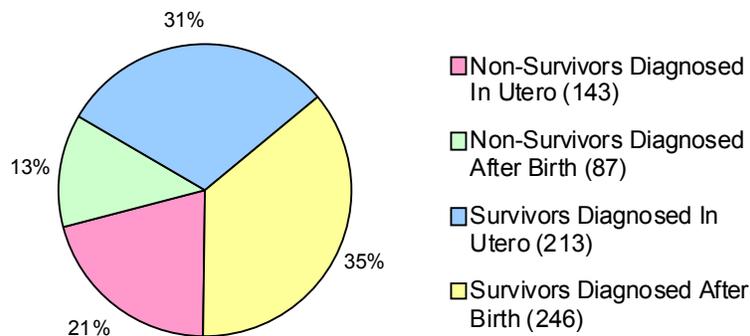
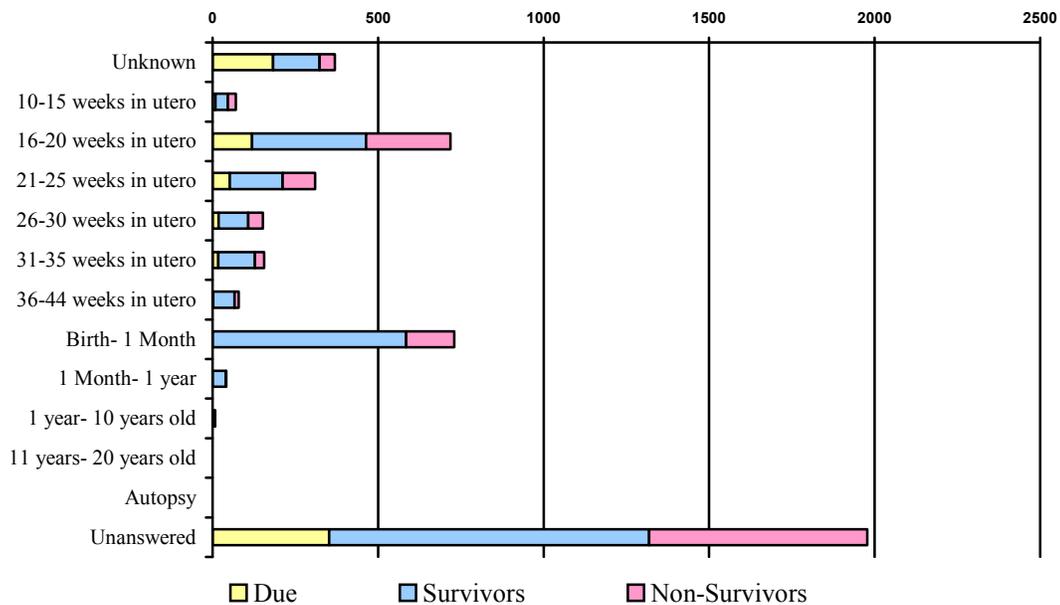


This chart shows the years that our members were born, with our oldest member born in 1958 and our youngest born in 2014 (the year this data was last updated). The increase from 1994 to today is most likely due to the internet, giving parents access to CHERUBS and more information and support. We do not believe that the increase is due to a higher incidence rate.

Ages of Diagnosis

		Survivor	Non-Survivor	Due	Total
Before 12 weeks in utero	Count % of Total	7 0.15%	5 0.11%	1 0.02%	13 0.28%
12 weeks in utero	Count % of Total	12 0.26%	6 0.13%	0 0%	18 0.39%
13 weeks in utero	Count % of Total	3 0.07%	5 0.11%	2 0.04%	10 0.22%
14 weeks in utero	Count % of Total	10 0.22%	4 0.09%	2 0.04%	16 0.35%
15 weeks in utero	Count % of Total	5 0.11%	4 0.09%	4 0.09%	13 0.28%
16 weeks in utero	Count % of Total	25 0.54%	25 0.54%	9 0.20%	59 1.28%
17 weeks in utero	Count % of Total	24 0.52%	11 0.24%	7 0.15%	42 0.91%
18 weeks in utero	Count % of Total	85 1.85%	47 1.02%	18 0.39%	150 3.26%
19 weeks in utero	Count % of Total	60 1.30%	47 1.02%	25 0.54%	132 2.87%
20 weeks in utero	Count % of Total	151 3.28%	125 2.71%	60 1.30%	336 7.29%
21 weeks in utero	Count % of Total	46 1.00%	33 0.72%	23 0.50%	102 2.21%
22 weeks in utero	Count % of Total	49 1.06%	26 0.56%	13 0.28%	88 1.91%
23 weeks in utero	Count % of Total	16 0.35%	8 0.17%	6 0.13%	30 0.65%
24 weeks in utero	Count % of Total	36 0.78%	23 0.50%	4 0.09%	63 1.37%
25 weeks in utero	Count % of Total	13 0.28%	8 0.17%	6 0.13%	27 0.59%
26 weeks in utero	Count % of Total	22 0.48%	10 0.22%	3 0.07%	35 0.76%
27 weeks in utero	Count % of Total	9 0.20%	5 0.11%	2 0.04%	16 0.35%
28 weeks in utero	Count % of Total	30 0.65%	11 0.24%	5 0.11%	46 1.00%
29 weeks in utero	Count % of Total	13 0.28%	8 0.17%	5 0.11%	26 0.56%
30 weeks in utero	Count % of Total	16 0.35%	2 0.04%	3 0.07%	21 0.46%
31 weeks in utero	Count % of Total	17 0.37%	4 0.09%	3 0.07%	24 0.52%
32 weeks in utero	Count % of Total	39 0.85%	15 0.33%	5 0.11%	59 1.28%
33 weeks in utero	Count % of Total	20 0.43%	3 0.07%	3 0.07%	26 0.56%
34 weeks in utero	Count % of Total	13 0.28%	5 0.11%	4 0.09%	22 0.48%
35 weeks in utero	Count % of Total	22 0.48%	1 0.02%	2 0.04%	25 0.54%
36 weeks in utero	Count % of Total	29 0.63%	3 0.07%	2 0.04%	34 0.74%
37 weeks in utero	Count % of Total	11 0.24%	5 0.11%	0 0%	16 0.35%
38 weeks in utero	Count % of Total	10 0.22%	0 0%	0 0%	10 0.22%
39 weeks in utero	Count % of Total	7 0.15%	1 0.02%	0 0%	8 0.17%
40 weeks in utero	Count % of Total	4 0.09%	2 0.04%	0 0%	6 0.13%
41 weeks in utero	Count % of Total	3 0.07%	2 0.04%	0 0%	5 0.11%
42 weeks in utero	Count % of Total	0 0%	0 0%	0 0%	0 0%
43 weeks in utero	Count % of Total	0 0%	0 0%	0 0%	0 0%

		Survivor	Non-Survivor	Due	Total
44 weeks in utero	Count % of Total	0 0%	0 0%	0 0%	0 0%
Birth - 1 month old	Count % of Total	585 12.70%	145 3.15%	0 0%	730 15.85%
1 month - 1 year old	Count % of Total	40 0.87%	1 0.02%	0 0%	41 0.89%
1 year - 10 years old	Count % of Total	7 0.15%	1 0.02%	0 0%	8 0.17%
11 years - 20 years old	Count % of Total	1 0.02%	0 0%	0 0%	1 0.02%
21 years or older	Count % of Total	0 0%	0 0%	0 0%	0 0%
Unknown	Count % of Total	140 3.04%	46 1.00%	183 3.97%	369 8.01%
Unanswered	Count % of Total	967 20.99%	659 14.31%	352 7.64%	1979 42.97%
Total	Count % of Total	2547 55.30%	1306 28.35%	752 16.33%	4606 100.00%

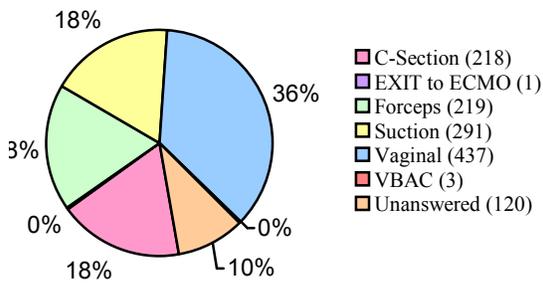


The number of patients undiagnosed in utero is still drastically high, given the high-resolution ultrasounds now available. Often, ultrasounds are taken so early that the hernia is hard to see, though we do have many members who were diagnosed before the 20th week of gestation.

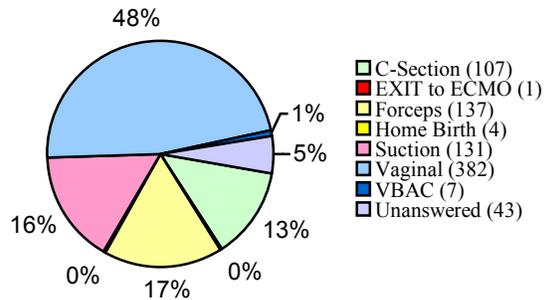
Birth History

	Survivor	Non-Survivor	Due	Unanswered	Total
Vaginal	913 19.82%	384 8.34%	0 0%	0 0%	1297 28.16%
Cesarean Section	340 7.38%	134 2.91%	0 0%	0 0%	474 10.29%
VBAC	13 0.28%	7 0.15%	0 0%	0 0%	20 0.43%
Exit to ECMO	2 0.04%	0 0%	0 0%	0 0%	2 0.04%
Forceps	421 9.14%	192 4.17%	0 0%	0 0%	613 13.31%
Suction	414 8.99%	190 4.13%	0 0%	0 0%	604 13.11%
Home Birth	5 0.11%	1 0.02%	0 0%	0 0%	6 0.13%
Unknown	197 4.28%	74 1.61%	0 0%	0 0%	271 5.88%
Unanswered	1078 23.40%	706 15.33%	752 16.33%	1 0.02%	2537 55.08%
Total	2547 55.30%	1306 28.35%	752 16.33%	1 0.02%	4606 100.00%

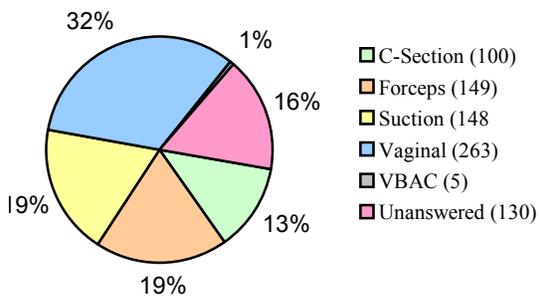
Survivors Diagnosed In Utero



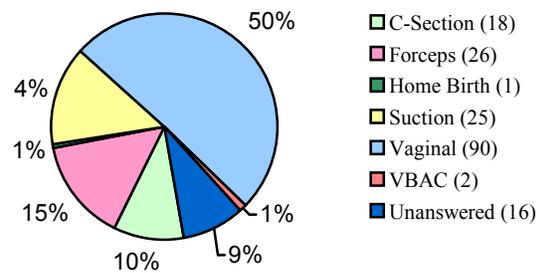
Survivors Diagnosed After Birth



Non-Survivors Diagnosed In Utero



Non-Survivors Diagnosed After Birth



Multiple Birth Defects

(in 4605 Survivors and Non-Survivors)

CARDIAC DEFECTS	Total
Pulmonary Hypertension of Unspecified Lung	157
Persistent Pulmonary Hypertension of the Newborn	90
Pulmonary Hypertension of Left Lung	65
Ventral Septal Defect	64
Atrial Septal Defect	63
Patent Ductus Arteriosus	44
Unspecified Pulmonary Defect	42
Dextrocardia	36
Coarction of the Aorta	24
Hypoplastic Left Heart Syndrome	14
Pulmonary Sequestration	12
Tetralogy of Fallot	10
Patent Foramen Ovale	6
Supraventricular Tachycardia	6
Tracheomalacia	6
Pulmonary Hypertension Bilateral	5
Bronchopulmonary Dysplasia	4
Pulmonary Stenosis	4
Transposition of the Great Arteries	4
Congenital Cystic Adenomatoid Malformation	3
Hypoplastic Ventricle	3
Pericardium	3
Stynotic Heart Murmur	3
Bicuspid Aortic Valve	2
Congestive Heart Failure	2
Double Arch	2
Double Outlet Right Ventricle	2
Emphysema	2
Hypoplastic Right Heart Syndrome	2
Mitral Valve Prolapse	2
Pulmonary Arterial Stenosis	2
Pulmonary Cysts	2
Subaortic Stenosis	2
Tracheoesophageal Fistula	2
Two Vessel Umbilical Cord	2
Ventriculomegaly	2
Anatomical Coarctation	1
Aneurysm	1
Aortic Valve Stenosis	1
Arrhythmia	1
Atrioventricular Canal Defect	1
Atrioventricular Septal Defect	1
Azygos Defect	1
Benign Chest Wall Syndrome	1
Branchial Cyst	1
Cardiomegaly	1
Cronotrunchal Defect	1
Hypoplastic Aorta	1
Hypoplastic Pericardium	1

Hypoplastic Right Pulmonary Artery	1
Hypoplastic Right Ventricle	1
Hypoplastic Superior Vena Cava	1
Interrupted Aortic Arch	1
Lung Rupture	1
Mildly Malformed Mitrovalve	1
Mitral Valve Regurgitation	1
Narrowing of Aorta	1
No Right Lung	1
Pentalogy of Cantrell	1
Pericardial Sac Herniation	1
Pericardial Effusion	1
Peridical Cyst	1
Persistent Left Vena Cava	1
Pleural Effusion	1
Pulmonary Atresia	1
Pulmonary Consolidation	1
Pulmonary Dysplasia	1
Pulmonary Hypertension	1
Pulmonary Hypoplasia	1
Respiratory Distress Syndrome	1
Secondum Atrial Septal Defect	1
Small Aortic Valve	1
Small Left Pulmonary Artery	1
Superior Vena Cava Syndrome	1
Total Anomalous Pulmonary Venous Return	1
Tracheal Fistula	1
Trachebronchomalacia	1
Tracheomegaly	1
Transposition of the Great Vessels	1
Tri-Cuspid Regurgitation	1
Truncus Arteriosus	1
Two Superior Vena Cava	1
Unspecified Heart Defect	1
Unspecified Heart Murmur	1
Unspecified Vascular Anomaly	1

EYE AND EAR DEFECTS	Total
Coloboma	4
Unspecified Congenital Hearing Impairment	3
Congenital Blindness	2
Dacryocele	2
Low Ears	2
Strabismus	2
Congenital Absence of Eyes	1
Congenital Deafness	1
Congenital Hearing Impairment	1
Cross Eyes	1
Folded Ears	1
Hypertelorism	1
Hypoplastic Optic Nerve	1

Infantile Esotropia	1
Lazy Eye	1
Microphthalmia	1
Preauricular Pits	1
Preauricular Sinuses	1
Ptosis	1
Undersized Ear Canals	1
Unspecified Eye Muscle Hypoplasia	1

FACIAL DEFECTS	Total
Cleft Palate	29
Cleft Lip	9
Tongue Tied	9
Unspecified	5
Dermoid Cyst	1
Downward Turned Nose	1
Enlarged Tongue	1
Facial Dysmorphia	1
Facial Hirsutism	1
Incompetent Palate	1
Lip Malformation	1
Nasal Abnormality	1
Shortened Fenectulum	1
Trachoesophageal Cleft	1
Upward Turned Nose	1
Wide Nasal Bridge	1

GENETIC DEFECTS	Total
Unspecified Genetic Defect	18
Fryns Syndrome	16
Trisomy 21 Downs Syndrome	8
Cornelia deLange Syndrome	3
Cystic Fibrosis Carrier	2
DiGeorge Syndrome	2
Klinefelter Syndrome	2
Klippelfiel Syndrome	2
Trisomy 18	2
Trisomy 22	2
Trisomy 8	2
Trisomy 9 Mosaic	2
Walker Warburg	2
Apert	1
Aspergers	1
Balanced Translocation of Chromosomes	1
Beckwied	1
Brown Syndrome	1
Cystic Fibrosis	1
Deletion of 13th Chromosome	1
Deletion of 15th Chromosome	1
Deletion of 2th Chromosome	1
Deletion of 8p Chromosome	1
Ehlers Danlos	1
Heterotaxy	1
Jarcholevin	1
Marfan Syndrome	1

McAdd Syndrome	1
Multiple Pterygium Syndrome	1
Pallister Killians	1
Partial 1x	1
Partial 7	1
Partial Trisomy 22	1
Short Bowel Syndrome	1
Translocaiton of 14th Chromosome	1
Translocation of 3rd Chromosome	1
Trisomy 11	1
Trisomy 19	1
Trisomy 9	1
Unnamed Monosomal Chromosomal Disorder	1
VonHippel	1
Wolf Hirschhorn	1

LIMB DEFECTS	Total
Polydactyly	10
Club Foot	9
Webbed Hand	8
Hypoplastic Finger	3
Hypoplastic Nails	3
Simian Crease	3
Syndactyly	3
Camptodactyly	2
Hypoplastic Forearm	2
Webbed Fingers	2
Unspecified Hypoplastic Limb	2
Abnormal Thumb	1
Abnormally Short Limb	1
Adducted Thumbs	1
Biforcated Toes	1
Webbed Neck	1
Cleft Hand	1
Clinodactyly	1
Deformed Fingers	1
Digitized Thumb	1
Distal Digits	1
Finger Contractures	1
Hip Dysplasia	1
Hypoplastic Foot	1
Hypoplastic Hand	1
Hypoplastic Middle Phalanx	1
ITT Right Lower Leg	1
Large Thumbs	1
Left Femur Fracture	1
Long Digits	1
Proximal Placement of Thumb	1
Rocker Bottom Feet	1
Severe Metatarsal Abductus	1
Short Fmurs	1
Short Leg	1
Short Limbs	1
Toe Curling	1

NEUROCRANIAL DEFECTS	Total
Hydrocephaly	28
Cerebral Hemorrhage	6
Craniosynatosis	6
Tethered Spinal Cord	6
Unspecified	6
Agenesis of the Corpus Callosum	5
Microcephaly	5
Congenital Stroke	4
Enlarged Ventricles of Brain	4
Skull Malformation	4
Ventriculomegaly	4
Cerebral Cyst	3
Cerebral Infarction	3
Choroid Plexus Cyst	3
Spina Bifida	3
Cranial bleed	2
Dandy-Walker Syndrome Malformation	2
Intracranial Hemorrhage	2
Intraventricular Hemorrhage	2
Macrocephaly	2
Bilateral Cephalahematomas	1
Brain Atrophy	1
Brain Autolysis	1
Brain Injured Prenatally	1
Cephalohematoma	1
Cerebrovascular Accident	1
Chiari Malformation	1
Congenital Cerebral Palsy	1
Grade 3 Hemorrhage	1
Grade 4 Hemorrhage	1
Hereditary Spastic Paraplegia	1
Hydrocephalus	1
Hypertension	1
Hypoplasia of Corpus Callosum	1
Hypoplastic Supraorbital Ridges	1
Hypoxia	1
Malformed Brainstem	1
Malformed Cerebellum	1
Sacral Dimple	1
Schizencephaly	1
Thymus Autolysis	1
Unspecified Brain Cell Damage	1
Unspecified Seizure Disorder	1

ORGAN DEFECTS	Total
Intestinal Malrotation	17
Omphalocele	6
Pyloric Stenosis	6
Malrotated Stomach	5
Unspecified	5
Intestinal Obstruction	4
Microgastria	4
Meckels Diverticulum	3
Polysplenia Syndrome	3

Wsplen	3
Unspecified Liver Defect	3
Accessory Spleen	2
Enlarged Organs	2
Hiatal Hernia	2
Hypoplastic Thymus	2
Jaundice	2
Lung and Liver Fused Together	2
Pancreatic Insufficiency	2
Polysplenia	2
Short Esophagus	2
Splenectomy	2
Vovulus	2
Abdominal Closure	1
Abnormal Nerve Ganglia in Colon	1
Adhesions	1
Appendices on Wrong Side	1
Appendix Upper Left Quad	1
Ascites	1
Atopic Appendix	1
Atopic Spleen	1
Cholestatic Jaundice	1
Congenital Abdominal Rectus Muscle Hypoplasia	1
Congenital Bands around Intestines	1
Congested Liver	1
Cryptosporidium Gastritis	1
Displaced Spleen	1
Enlarged Liver	1
Fused Lung and Liver	1
Gastroschisis	1
GERD	1
Hepatomegaly	1
Hirschsprungs Disease	1
Horseshoe Spleen	1
Hypoplastic Appendix	1
Hypoplastic Pancreas	1
Intrathoracic Spleen	1
Intrathoracic Stomach	1
Inverted Intestines	1
Irritable Bowel Syndrome	1
Lesion on Liver	1
Liver Autolysis	1
Liver Hemangioma	1
Nephrotic Syndrome	1
Organoaxial Twist	1
Pancreas Autolysis	1
Paraesophageal Hernia	1
Short Bowel Syndrome	1
Sigmoid Colon	1
Spleen Autolysis	1
Swollen Liver	1
Tubularized Stomach	1
Two Lobes on Liver	1
Umbilical Hernia	1
Ventral Hernia	1

Unspecified Stomach Defect	1
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SKELETAL DEFECTS	Total
Scoliosis	51
Pectus Excavatum	31
Hypoplastic Rib	10
Hemivertebrae	9
Hip Dysplasia	6
Unspecified	5
Extra Rib	3
Unspecified Vertebrae Abnormality	3
13 Bilateral Thoracic Ribs	2
Curvature of Back not scoliosis	2
Fused Ribs	2
Hypoplastic Sternum	2
Hypoplastic Vertebrae	2
Kyphosis	2
Shortened Ribs	2
Spinal Fusion	2
Tortiollis	2
Butterfly Vertebrae	1
C Spine Abnormality	1
Cerebellar Hematoma	1
Cervical Rib	1
Congenital Dislocated Elbow	1
Dislocated Hip	1
Excess Rib Cartilage	1
Hypoplastic Clavicle	1
Hypoplastic Jaw	1
Intrauterine Growth Restriction	1
Inverted Sternum	1
Low Set Ears	1
Malformed Pelvis	1
Malformed Rib Cage	1
Metabolic Bone Disease	1
Metatarsal Abductus	1
Osteopenia	1
Sacral Dimple	1
Short Femur	1
Skeletal Dysplasia	1
Spina Bifida	1
Split Sternum	1
Thin Ribs	1
Underdeveloped Pelvis	1
Unspecified Arm Bone Abnormality	1
Unspecified Calcifications	1
Unspecified Rib Abnormality	1
Unspecified Shoulder Bone Abnormality	1
Unspecified Spine Defect	1

URITOGENITARY DEFECTS	Total
Undescended Testes	60
Bilateral Undescended Testes	41
Imperforated Anus	40
Hypospadias	30

Unspecified Kidney Abnormality	17
Horseshoe Kidney	7
Enlarged Kidney	6
Hypoplastic Kidney	6
Kidney Reflux	6
Polycystic Kidney	6
Unspecified Genital Defects	6
Urinary Reflux	5
Hydronephrosis	4
Pelvic Kidney	4
Displaced Kidney	3
Ambiguous Genitalia	2
Chordee	2
Cystic Hygroma	2
Cystic Kidney	2
Dual Collection Kidney	2
Dysplastic Kidney	2
Genital Deformity	2
Hypoplastic Anus	2
Micro Testes	2
Testicle Hydrocele	2
Bicornutate Uterus	1
Blockage of Urethra	1
Congenital Kidney Stones	1
Cystic Dysplastic Kidney	1
Detrusor Instability	1
Duplex Kidney	1
Ectopic Kidney	1
Extrarenal Pelvis	1
Hydrocele	1
Hyperbilirubinemia	1
Hyperspadias	1
Hypoplastic Renal Artery	1
Kidney Autolysis	1
Kidney Higher Than Other	1
Malrotated Kidney	1
Megacystis Inutero	1
Megameatus	1
Micro Bladder	1
Micropenis	1
Nephroblastomatosis	1
Nephrotic Syndrome	1
Neurogenic Bladder	1
Nonfunctioning Kidney	1
Ovarian Cysts	1
Phimosis	1
Polycystic Kidney Disease	1
Renal Pyelectasis	1
Rotated Kidneys	1
Total Kidney Blockage	1
Ureteral Reimplantation	1
Yeast Infection	1

OTHER DEFECTS	Total
Skin Tags	7

Umbilical Hernia	6
Hiatal Hernia	3
Umbilical Cord around Legs and Feet	3
Esophageal Fistula	2
Omphalocele	2
Paraesophageal Hernia	2
Short Esophagus	2
Ventral Hernia	2
Accessory Auricle	1
Anemia	1
Anophthalmia	1
Arteriovenous Malformation	1
Atresia	1
Benign Bilateral Retroareolar Cysts	1
Benign Growth Nasal Passage	1
Branchial Cleft Cyst	1
Chest Recession	1
Chylothorax	1
Damaged Placenta	1
Dilated Esophagus	1
Dumping Syndrome	1
Duodenal Atresia	1
Dysgraphia	1
Dyspraxia	1
Epicanthic Fold	1
Esophageal Atresia	1
Esophageal Flap Hypoplasia	1
Fatty Acid Oxidation Defect	1
Febrile Seizures	1
Fetal Alcohol Syndrome	1
Floppy Esophagus	1
Gastrointestinal Herniated Esophagus Ulcers	1
Intrajugular Vein Hypoplasia	1
Low Hairline	1
Malformed Esophagus	1
Megaesophagus	1
Muscular Dystrophy	1
Narrow Airway	1
Pectus Murmur	1
Persistent Umbilical Vein	1
Port Wine Stain	1
Pyloric Stenosis	1
Recurrent Esophageal Stricture	1
Redundant Neck Skin Folds	1
Scarring	1
Speech Apraxia	1
Subglottic Stenosis	1
Supernumerary Nipple	1
Supraumbilical Muscular Deficiency of Anterior Abdominal Wall	1
Tethered Cord	1
Tracheal Tug	1
Tracheoesophageal Fistula	1
Type 1 Diabetes	1
Type 4 Choledocal Cyst	1

Unilateral Choanal Atresia	1
Webbed Neck	1
Unspecified Marking on Ear	1
Unspecified Premature Qualities	1
Unspecified Sphincteral Muscle Hypoplasia	1

Family History of CDH

	Survivor	Non-Survivor	Due	Total
None	787	336	227	1350 29.31%
Unknown	753	303	170	1226 26.62%
Twin	1	1	0	2 0.04%
1 Sibling / Half-Sibling	6	11	1	18 0.39%
2 Siblings / Half-Siblings	0	5	0	5 0.11%
3 Siblings / Half-Siblings	0	0	0	0 0%
Aunt or Uncle	6	2	1	9 0.20%
Parent	3	0	0	3 0.07%
Child of Patient	1	1	0	2 0.04%
Grandparent	0	0	0	0 0%
First Cousin	8	4	0	12 0.26%
Other Family Member	19	6	1	26 0.56%
Unanswered	964	638	352	1955 42.44%
Total	2547	1306	752	4606 100.00%

Our research agrees with most research articles on the 2% chance of having another child with 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 encourage every member to seek genetic counseling and participate in all CDH genetic studies to find out their own specific odds of recurrence of CDH in their families.

Sibling History

Identical Twin:

	Male	Female	Other	Unknown	Total
Survivor	0	1	0	0	1
Non-Survivor	0	1	0	0	1
Due	0	0	0	0	0
Total	0	2	0	0	2

Fraternal Twin:

	Male	Female	Other	Unknown	Total
Survivor	27	28	0	0	55
Non-Survivor	17	5	0	0	22
Due	3	7	0	1	11
Total	47	40	0	1	88

Triplet:

	Male	Female	Other	Unknown	Total
Survivor	1	1	0	0	2
Non-Survivor	0	1	0	0	1
Due	0	1	0	0	1
Total	1	3	0	0	4

Sextuplet:

	Male	Female	Other	Unknown	Total
Survivor	0	0	0	0	0
Non-Survivor	0	1	0	0	1
Due	0	0	0	0	0
Total	0	1	0	0	1

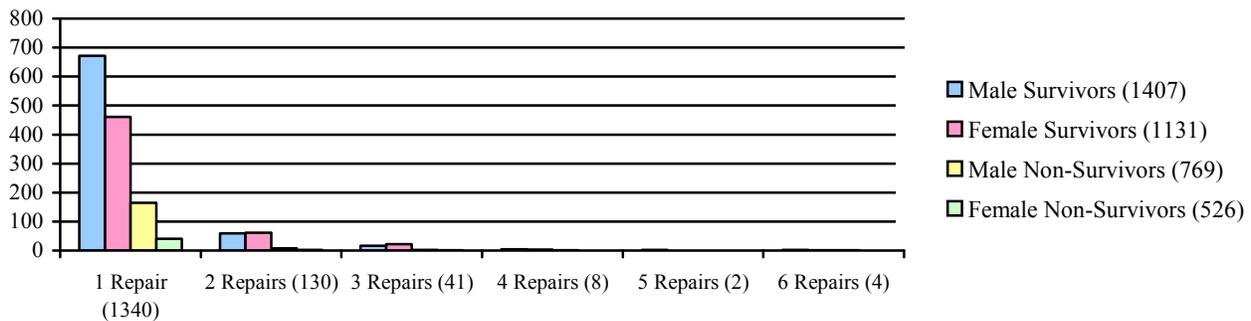
CDH Repairs

Survivors:

Number of Repairs	Male	Female	Unknown	Total
0	139 5.46%	99 3.89%	2 0.08%	240 9.42%
1	672 26.38%	461 18.10%	1 0.04%	1134 44.52%
2	59 2.32%	61 2.39%	0 0%	120 4.71%
3	16 0.63%	22 0.86%	0 0%	38 1.49%
4	4 0.16%	3 0.12%	0 0%	7 0.27%
5	2 0.08%	0 0%	0 0%	2 0.08%
6	2 0.08%	1 0.04%	0 0%	3 0.12%
Unanswered	513 20.14%	484 19.00%	6 0.24%	1003 39.38%
Total	1407 55.24%	1131 44.41%	9 0.35%	2547 100.00%

Non-Survivors:

Number of Repairs	Male	Female	Unknown	Total
0	325 24.89%	93 7.12%	1 0.08%	419 32.08%
1	165 12.63%	41 3.14%	0 0%	206 15.77%
2	8 0.61%	2 0.15%	0 0%	10 0.77%
3	2 0.15%	1 0.08%	0 0%	3 0.23%
4	1 0.08%	0 0%	0 0%	1 0.08%
6	1 0.08%	0 0%	0 0%	1 0.08%
Unanswered	267 20.44%	389 29.79%	10 0.77%	666 51.00%
Total	769 58.88%	526 40.28%	11 0.84%	1306 100.00%



We are aware of 4 other children who have had 6 CDH repairs but whose membership forms have not been updated. As we move on with the on-line research survey site, we will work harder to have parents and survivors update their information as their medical histories change. This type of information is extremely valuable to not only other CDH families, but to researchers as well.

¹ Harrison, M.R., N.S. Adzick, J.M. Estes, and L.J. Howell (1994) A Prospective Study of the Outcome for Fetuses With Diaphragmatic Hernia. *Journal of the American Medical Association*, 271:382-384.
² World Overpopulation Awareness Organization, FAQ, <http://www.overpopulation.org/faq.html>
³ Centers For Disease Control and Prevention (2012) <http://www.cdc.gov/nchs/births.htm>
⁴ Bax, N.M.A and D.L. Collins (1984) The Advantage of Reconstruction of the Dome of the Diaphragm in Congenital Posterolateral Diaphragmatic Defects. *Journal of Pediatric Surgery*, 19:484-486.
⁵ Torfs, C.P., C.J.R. Curry, T.F. Bateson, and L.H. Honore' (1992) A Population-Based Study of Congenital Diaphragmatic Hernia. *Teratology*, 46:555-565.
⁶ Puri P. Congenital Diaphragmatic Hernia. *Curr Prob Surg* 1994;31:785-856.
⁷ Furuta Y, Nakamura Y, Miyamoto K. Bilateral Congenital Posterolateral Diaphragmatic hernia. *Journal of Pediatric Surgery* 1987;22:182-3.
⁸ David TJ, Illingworth CA. Diaphragmatic Hernia In The South-West Of England. *J Med Genet* 1976;13:253-62.
⁹ Irving IM, Booker PD. Congenital diaphragmatic hernia. In: Lister J, Irving IM, eds. *Neonatal Surgery*. 3rd ed. London: Butterworths, 1990:199-220.