

Report from the Congenital Diaphragmatic Hernia Study Group

Report on Patients Born 1/1/2007 - 9/5/2019

The CDH Registry

Number submitted	6948	
Inborn	3883	56%
Male	4049	58%
Race		
Asian	804	12%
Black	508	7%
Hispanic	944	14%
White	3808	55%
Other/Not Stated	884	13%
Birth Wt (kgs, avg)	2.92	
EGA (weeks, avg)	37.4	
5 minute Apgar (avg)	6.58	
Prenatal Diagnosis	4981	72%
Side of Hernia		
Left	5795	83%
Right	1096	16%
Bilateral	44	1%
Mean Age at Repair (Days, avg)	6.5	(120)
Morbidity in infants who survived		
Survivors	5015	
Pulmonary		
Vent Days (avg)	17.3	(68)
On O2 at 30 days of Life	2123	43%
On O2 at DC or TX	1198	24%
GI		
Enteral Feeds (days, avg)	25.3	(143)
Tube feeds at DC or TX	1700	35%
GERD at DC or TX	2509	53%
Neurological		
Abnl MRI/CT/Ultrasound	794	16%
Length of Stay (days, avg)		
Discharged Home	49.2	(152)
Transferred Out	31.2	(80)

The CDH Registry

	N	N Surv	% Surv	% Distrib
All CDH	6948	5015	72%	100%
Repaired	5854	4995	85%	84%
Not Repaired	1088	19	2%	16%
Isolated CDH	6015	4578	76%	87%
ECMO	1921	998	52%	28%
Primary Repair	2693	2593	96%	39%
Patch Repair	3141	2387	76%	45%
Defect A	769	761	99%	11%
Defect B	2233	2122	95%	32%
Defect C	1889	1504	80%	27%
Defect D	795	457	57%	11%
Defect not described	168	151	90%	2%
High Risk (C+D+Non-Repair)	3772	1961	52%	54%

% Distrib means % of total patients represented by each defect/repair status

Isolated CDH: CDH with no chromosomal or cardiac anomalies (except isolated ASD or VSD).

Outlier values for mean Age at Repair, Vent Days, Enteral Feeds, and Length of Stay are:

Age at Repair > 30 days

Ventilator Days > 90 days

Enteral Feeds > 90 days

Length of Stay > 180 days for discharge and > 90 days for transfer

Number of outliers is given in () and usually represents about 2-3 % of values.