

25 Year Retrospective on Congenital Diaphragmatic Hernia

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Purpose:

To assess the opinions of parents of children born with Congenital Diaphragmatic Hernia on how well the medical professionals cared for and communicated with the patients and their families.

Congenital Diaphragmatic Hernia (CDH) is a structural birth defect of the diaphragm that occurs at 8 weeks gestation when the muscle fails to fully form. This allows abdominal organs to migrate into the chest cavity and prevents lung growth. Patients born with CDH spent weeks or months in the hospital undergoing surgery and recovery.

Methods:

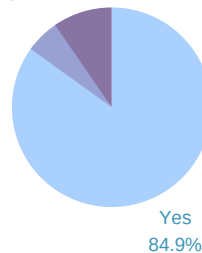
CDH International runs the world's only Natural History Registry of Congenital Diaphragmatic Hernia patients and data was used from the registry for this report.

We reviewed the results of our survey for 221 patients between the years 1995 and 2020. Parents were asked basic subjective questions on how well they felt they were treated and how well they were informed of their child's diagnosis.

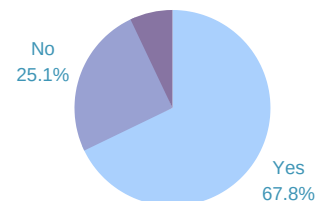


The participants were then asked if the patient's doctor explained the diagnosis in terms they could easily understand. 83.41% (186) said "yes" and 9.42% (21) said "no." The remaining 7.17% (16) either did not know or had no comment.

No Comment 5.5%
No 9.6%



No Comment 7%
No 25.1%



When asked if the parent was given enough information about their child's diagnosis, 69.06% (154) of parents answered affirmatively. 25.56% (57) parents responded in the negative. 5.38% (12) either had no comment or did not respond.

Conclusion:

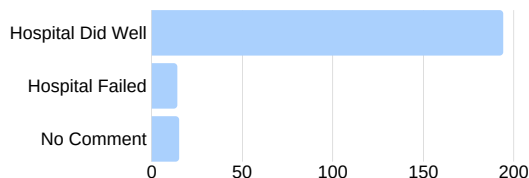
The vast majority of respondents agreed that their hospital experience was sufficient, there is still room to improve within the field of medical professionals. Our collected data can offer important insight into which hospitals need development and which institutions can be models for such development.

With over 6500 patients worldwide in the CDH Registry and only 221 responses, we need to improve more respondents to these types of questions, and investigate why so many hesitate to share their experiences with hospital staff.



Results:

87.3% (194) parents said they felt the hospital staff did well in taking care of the patient and involved the parents in the decision making process. 6.28% (14) parents responded negatively. A total of 6.71% (15) either didn't respond or had no comment.



CDH International is the world's oldest and largest Congenital Diaphragmatic Hernia charity, working in 70 countries.

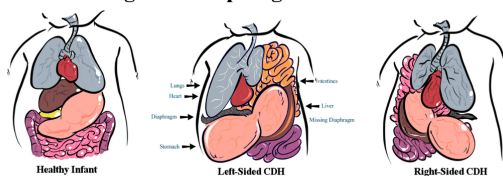
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Congenital Diaphragmatic Hernia



Congenital Diaphragmatic Hernia (CDH) is a birth defect that occurs when a baby's diaphragm (a thin sheet of muscle that separates the abdomen from the chest) fails to fully form, allowing abdominal organs to enter the chest cavity and prevent lung growth.

CDH occurs in approximately 1 in 2500 births, with over 1600 babies diagnosed each year in the United States alone. There is currently no known cause, but studies have suggested that it is likely due to a number of genetic and environmental factors.

www.cdhi.org