

20 years demographics and preliminary survey results from CDH International - Dawn M - CDH International

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Purpose: Our objective was to assess the amount of medical information retained by parents of children born with Congenital Diaphragmatic Hernia. Our goal is to review the difference in our study with the population studies of other CDH research groups such as the CDH Study Group and DHREAMS in the amount of information given and correctly retained by CDH parents. **Methods:** We reviewed the answers provided to a questionnaire between 1995 and 2014. Members included 2547 survivors, 1294 non-survivors and 740 expectant or who did not follow up. Parents were asked basic medical questions as well as a detailed medical and familial history. **Results:** Our questionnaire was answered by 4548 families. A higher percentage of families of non-surviving infants than surviving infants did not know if their child's CDH occurred on the left versus right side (46.8% vs 57.8%). When families were asked to further characterize the type of defect their child had, the percentage of those who did not know jumped to approximately 87%, showing that even fewer parents remembered the finer details of their child's diagnosis. Familial CDH is reported in the literature to be known in approximately 2% of all cases. Our membership reports 1.6%, which is similar to what has been reported. **Conclusion:** Until this study is compared to the studies of DHREAMS and the CDH Study Group and exact patient matching occurs, it will be difficult to measure the true medical knowledge that CDH parents grasp and remember.