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20 years demographics and preliminary survey results from 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 difficult to measure the true medical knowledge that CDH parents grasp and remember.

Biography

Dawn M. (Torrence) Ireland is the founder of CHERUBS – The Association of Congenital Diaphragmatic Hernia Research, Awareness and Support. Created in 1995, after the birth of Ms. Ireland's son, who was born with Congenital Diaphragmatic Hernia (CDH), she wished to create a supportive, collaborative community of families of researchers. It was built upon a foundation of research, awareness and support – providing as many services and as much information as the budget and volunteer system could withstand. With the encouragement of several prominent pediatric surgeons, CHERUBS began to have a presence at medical conferences in 1996. By 2000, the CDH Research Survey Database was created. In 2017, the charity was restructured. Ms. Ireland stepped away as President of CHERUBS and into the role of President of CDH International to further the research projects that the organization is involved in. CHERUBS still exists as the family support division of CDH International. Currently, Ms. Ireland oversees CDH International which now runs the world's largest natural history database of CDH, has 3 boards, employees, many volunteers, assists over 6300 patient families in 70 countries, presents research abstracts, and works with both the NIH and the EU. Ms. Ireland also is a founding member of the Rare Advocacy Movement and senior level patient advocate, mentors several other non-profit organizations, is a founding member of the Alliance of Congenital Diaphragmatic Hernia Organizations, has written/edited 4 books and spends her time between the United States and Europe to continue the organization's growth and outreach.

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