

18<sup>th</sup> International Conference on **Pediatrics Health**

&amp;

2<sup>nd</sup> Edition of International Conference on **Adolescent Health & Medicine**

August 06-07, 2018 Madrid, Spain

***Dawn M Ireland****CDH International, USA***Parent opinion in medical care for congenital diaphragmatic hernia**

**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.

**Methods:** We reviewed the results of our survey for 161 patients between the years 1995 and 2017. This study included 53 female survivors, 64 male survivors, 27 female non-survivors, and 17 male non-survivors. 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.

**Results:** 90.6% of survivors' and 77.3% of non-survivors' parents said they felt the hospital staff did well in taking care of the patient and involved the parents in the decision making process. 3.4% survivors' and 15.9% of non-survivors' parents responded negatively. A total of 6.2% either didn't respond or had no comment. When asked if the parent was given enough information about their child's diagnosis, 76.9% of parents of survivors and 68.2% of parents of non-survivors answered affirmatively. 19.7% of survivors' and 27.3% of non-survivors' parents responded in the negative. 3.8% either had no comment or did not respond. The participants were then asked if the patient's doctor explained the diagnosis in terms they could easily understand. Of the non-survivor's families, 77.3% said "yes" and 15.9% said "no." Of the survivor's families, 88% responded "yes" and 6.8% "no." The remaining 6.2% of both survivors and non-survivors either did not know or had no comment.

**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.

**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.

dawn.ireland@cdhi.org