The Congenital Diaphragmatic Hernia (CDH) Guidelines

“The Canadian Congenital Diaphragmatic Hernia Collaborative Evidence and Consensus-Based National Clinical Management Guideline” by the Canadian CDH Collaborative will be appearing in the Canadian Medical Association Journal in the fall of 2017. The goal of the guidelines is to provide guidance on care for CDH patients from prenatal diagnosis to childhood. Recommendations on prenatal diagnosis, risk stratification, optimal delivery, ventilation, hemodynamic support, echocardiography, use of prostaglandin E1 and pulmonary vasodilators, extracorporeal life support, surgical criteria and repair, follow-up, and fetal interventions are addressed in the guidelines.

We would like to acknowledge the effort of all the members of the Canadian CDH collaborative in helping establish and finalize the guidelines. These guidelines are another step towards improving care for children with CDH in Canada.

Standardization of Necrotizing Enterocolitis (NEC) Diagnosis and Treatment

The etiology of the NEC is currently unknown. Drs. Prakesh Shah and Richard Keijzer are leading a collaboration between the Canadian Neonatal Network (CNN) and Canadian Association of Pediatric Surgeons (CAPS) to begin the process of standardizing the diagnosis and treatment of NEC across Canada. The process in standardizing the NEC guidelines will be similar to the steps taken for the CDH guidelines— an evidence review, consideration of pre-existing guidelines, and a consensus meeting to establish working guidelines; and the addition of pre-existing data fields specific to NEC to the CAPSNET database.

The Canadian National Perinatal Research meeting will be held in Banff in February, 2018, and the plan is to hold a one day stakeholder’s meeting to conduct some of this work towards multidisciplinary NEC guidelines after the meeting. Dates and further details to follow.
Annual Report

We are currently working on cleaning the data for the upcoming annual report. This report will include two years of data, 2015 and 2016. Further updates and information will be provided closer to the release of the report.

New CAPSNet Coordinator

We would like to welcome Crystal Ng as the new CAPSNET coordinator. She will be responsible for interacting with CAPSNET site investigators and abstractors, and will work closely with the Steering Committee, in advancing the strategic priorities of the Network. If you have any questions or concerns about case entry, REB, or other issues, please do not hesitate to contact her at 604-875-2345 x 4313 or crystal.ng@cw.bc.ca

Recent Publications

(1) Congenital diaphragmatic hernia: The role of multi-institutional collaboration and patient registries in supporting best practice.
This review article describes the role of disease-specific registries in creating and disseminating knowledge and improving care for rare diseases such as CDH. Exemplar registries (CAPSNet and the CDHSG) are featured.

(2) Determinants of outcomes in patients with simple gastroschisis
The goal of the paper is to analyze the determinants of outcomes in simple GS from 700 patients enrolled in the CAPSNET registry from 2005 to 2013. The paper concludes that prenatal bowel dilation is associated with increased morbidity in simple GS, CLABSI is the strongest predictor of outcomes, and bowel matting is not an independent risk factor.

(3) Outcome Prediction in Gastroschisis- The Gastroschisis Prognostic Score (GPS) Revisited
The goal of the study is to revalidate the GS prognostic score characterization of a group with high morbidity and quantify relationships between GPS and outcomes. Using CAPSNet data from 2005-2015, GPS was revalidated and length of stay, 1st enteral feeding days, TPN days, and aggregate complications were compared between low and high morbidity groups. The results show that the GPS is effectively in discriminating low from high morbidity risk groups.

The article outlines the value of clinical research networks and the process CAPSNet will undertake to produce national consensus guidelines for CDH care. The goal is to use the successful Evidence-based Practice for Improving Quality (EPIQ) method and national, multidisciplinary efforts to standardize best practices for CDH from prenatal diagnosis to hospital discharge, based on the best available evidence.
Recent Publications

(5) Spatial Variability of gastroschisis in Canada, A 2006-2011: An exploratory analysis

The objective of the paper is to describe the geographic variation in incidence of GS and characterize the spatial pattern of all GS cases in Canada between 2006 and 2011. Analysis shows that there is significant spatial heterogeneity of the rate of GS across Canada at both the provincial/territorial and census-division level. The Yukon, Northwest Territories and Prince Edward Island have higher overall rates of GS relative to other provinces/territories.

(6) Flap Versus Fascial Closure for Gastroschisis: A systematic review and meta-analysis

This paper compares the outcomes of the flap and fascial closure techniques for GS using a systematic review and meta-analysis. A total of 1124 patients were evaluated from twelve studies and 350 underwent the flap closure. The meta-analysis shows that there is no significant differences in mortality, LOS, or feeding parameters between groups. On the other hand, flap patients had less wound infections and an increased risk of umbilical hernia. The authors conclude that the flap closure may be the more superior and preferred strategy for GS as it is a bedside closure and does not require as much sedation.


The article outlines the value of clinical research networks and the process CAPSNet will undertake to produce national consensus guidelines for CDH care. CAPSNet has been collecting population-based data regarding CDH across its 17 perinatal sites since 2005. With >500 infants registered to date, CAPSNet has addressed many critical knowledge gaps pertaining to CDH care. Most importantly, it has identified variability in both CDH practice and outcome across Canada.

(8) Gastroschisis outcomes in North America: a comparison of Canada and United States

The goal of the article is to complete an outcomes comparison between the care of infants with GS which is centralized in Canada and non-centralized in the United States. Inpatient mortality and hospital stay of GS patients were the two main outcomes compared throughout the study. The article concludes that the mortality for simple GS is higher in the US compared to Canada, while no outcome differences exist between the two countries for complex GS.


This article outlines the goals of CAPSNet and its role as a registry that has allowed 16-center network to make contributions to the knowledge base informing best practices for GS and CDH care. In addition, the article focuses on how CAPSNet has expanded its focus to include quality assurance and improvement at each of its sites, by issuing a benchmarked outcomes “report card” with its annual report. It further outlines a major objective of CAPSNet, which has been to establish and adopt standardized, evidence-based practice guidelines for GS and CDH across all Canadian perinatal centers.