# **CAPSNet 2013 Annual Report**

The Canadian Pediatric Surgery Network – Le Réseau Canadien de Chirurgie Pédiatrique

Version 1 March 2014



# TABLE OF CONTENTS

TABLE OF CONTENTS	1
INTRODUCTION TO THE NETWORK	1
RECENT NETWORK ACTIVITY	1
New Network Co-Director and CAPSNet Coordinator	1
CAPSNET FUNDING	
CAPSNET DATA ABSTRACTION COSTS	
DATABASE HARMONIZATION PROJECTS	
THE CANADIAN BILIARY ATRESIA REGISTRY (CBAR)	2
OTHER PROJECTS	3
EPIQ	3
Secondary Analysis Project	
ACKNOWLEDGEMENTS	
2013 DATA ANALYSIS (DATA UNTIL MARCH 31, 2013)	5
CONTRIBUTING CENTRES FOR THE 2013 ANNUAL REPORT	
SUMMARY OF DATA BY DIAGNOSIS AND BIRTH OUTCOMES	
Antenatal Misdiagnoses	
Graph A: Distribution of GS cases by centre	
Graph B: Distribution of CDH cases by centre GASTROSCHISIS DESCRIPTIVE ANALYSES	
GASTROSCHISTS DESCRIPTIVE ANALYSES         Table 1.0: Patient population	
Table 1.0: Fallent population         Table 1.1: Survival by centre volume	
Gastroschisis Prognostic Score (GPS)	
Figure 1.2: Maximum bowel dilation reported on antenatal ultrasound	
Figure 1.2: Maximum bower analion reported on antendial utrasound Figure 1.3: Early vs. late antenatal referral	
Graph 1.4: Gestational age at birth	
Table 1.5: Antenatal Delivery Plan as of 32 Weeks Gestational Age	
Graph 1.6: Proportion of Caesarean Section Grouped By Site - 2005 to 2013	
Table 1.7: Timing of gastroschisis closure	
Graph 1.8: Surgeon's treatment intent by centre	13
Figure 1.9: Method of Surgical Closure	14
Figure 1.9a: Method of surgical closure – 2005 to 2008	
Figure 1.9b: Method of surgical closure – 2009 to 2000	14
Table 1.10: Operative success	
Figure 1.11a: Proportional gastroschisis prognostic score (GPS) scoring	
Table 1.11b: Selected neonatal outcomes stratified by GPS Risk	
Graph 1.12: Selected neonatal complications	
CONGENITAL DIAPHRAGMATIC HERNIA DESCRIPTIVE ANALYSES	
Table 2.0: Patient population	
Table 2.1: Survival by centre volume	
Figure 2.2: Maximum lung-head ratio (LHR)	
Figure 2.3: Early vs. late initial Visit	
Graph 2.4: Gestational age at birth	
Graph 2.5: Proportion of caesarean delivery grouped by site - 2005 to 2013	20
Graph 2.6: Mean age at surgical repair by centre	
Figure 2.7: Method of surgical closure	21
Graph 2.8: Size of CDH defect	22
Graph 2.9: Selected neonatal complication	22
Graph 2.10a: Selected neonatal outcomes at discharge	
Table 2.10b: Selected neonatal outcomes	23
APPENDIX I: DEFINITIONS	24
APPENDIX II: LIST OF PUBLICATIONS, PRESENTATIONS AND ONGOING PROJECTS	25

# **INTRODUCTION TO THE NETWORK**

**The Canadian Pediatric Surgery Network** (CAPSNet) is a multi-disciplinary group of Canadian health researchers working together on research issues concerning pediatric surgical care. To date there are 30 network members, including 21 pediatric surgeons, 5 perinatologists/maternal fetal medicine specialists and 4 neonatologists.

The main objectives of the network are to:

- ✓ Maintain a national pediatric surgical database, providing an infrastructure to facilitate and encourage collaborative national research.
- ✓ Identify variations in clinical practices across Canadian centres and identify those practices which are associated with favourable and unfavourable outcomes.
- ✓ Disseminate new knowledge through effective knowledge translation, and study impact of practice change.
- ✓ Study the economic impact of clinical practice decisions to enable identification of treatment strategies that are efficacious and cost-effective.

Currently, CAPSNet is in its 9<sup>th</sup> year of data collection and we are pleased to report that the Network has 28 manuscripts published and 1 in press. To date, there have been 50 conference proceedings (podium or poster presentations) at national and international conferences. For a complete list of all past and current CAPSNet projects, please see <u>Appendix II</u>.

# **RECENT NETWORK ACTIVITY**

# NEW NETWORK CO-DIRECTOR AND CAPSNET COORDINATOR

Dr. Pramod Puligandla has been appointed as the network co-director. Alison Butler has joined the team as the new network coordinator. She has worked hard to get up to speed and was able to attend the CAPS meeting in Charlottetown, PEI, last September.

# **CAPSNET FUNDING**

CAPSNet remains in a reasonably solid financial position with remaining CIHR grant funds and the financial support provided by CAPS. Funding for the CAPSNet Coordinator position has been awarded by Dr. Shoo Lee for 3 years, which means sites will continue to have ongoing support. The ultimate sustainability of data collection requires a continued transition of the costs of data collection to the participating hospitals. We need to continue to work towards this goal.

# **CAPSNET DATA ABSTRACTION COSTS**

Our centres across Canada continue to seek out alternate funding sources to ensure the longevity of the project, which is a testament to the progress CAPSNet has made over the last couple of years. The network is a valuable source of data for researchers across Canada and is also an excellent resource for national benchmarking, which can lead to improved health services for CDH and gastroschisis babies. Kudos to all the centres that have made this successful transition and thanks to those centres that continue to seek out funding for the project. As of December 2013, centres now paying for their own data abstraction are:



Site		PROVINCE
BC Children's Hospital	BCCH	British Columbia
Children's Hospital of Eastern Ontario	CHEO	Ontario
Hamilton McMaster Children's	HHSC	Ontario
London Health Sciences Centre	LHSC	Ontario
Montreal Children's Hospital	МСН	Quebec
Royal University Hospital	RUH	Saskatchewan
Toronto Sick Kids	HSC	Ontario
Victoria General Hospital	GVS	British Columbia

# **DATABASE HARMONIZATION PROJECTS**

Three projects which will combine CAPSNet data with comparable datasets are under way. Dr. Sherif Emil is the PI of a collaborative group at McGill who have partnered with colleagues at UCLA to try to harmonize gastroschisis data from CAPSNet with the OSHPD database (A California Hospital administrative database). Using common data definitions established a priori, data will be analyzed independently and combined afterwards, similar to what might be done in a meta-analysis. Another collaboration is underway between CAPSNet and BAPS-CASS, the birth defects database of the British Association of Pediatric Surgeons. In this proposal, a pediatric surgeon from the UK has proposed bringing BAPS-CASS data into Canada, and combining the datasets here. A third project spearheaded by Dr. Rob Baird at McGill with colleagues in the US is exploring the use of a technique of dataset harmonization called "Fenestrated Analysis". Working with a McGill epidemiologist, Dr. Isabel Fortier from the Maelstrom Research Centre, the groups plan to use database harmonization methods and software to conduct combined studies of cohorts of GS and CDH patients between CAPSNet and the Children's Hospitals Neonatal Consortium (CHNC). This method is especially appealing since it offers robust dataset integration for outcomes analysis, without exporting data out of either country. Stay tuned for exciting developments in this area!

# THE CANADIAN BILIARY ATRESIA REGISTRY (CBAR)

Developed by Dr. Rick Schreiber, a pediatric gastroenterologist at BC Children's Hospital, CBAR is modeled after the structure and governance of CAPSNet, and shares much of its data collection infrastructure. CBAR will create a national network and database for biliary atresia to enable outcome studies and identification of best practices for BA. The CBAR steering committee will be co-chaired by Dr. Schreiber and Dr. Jean-Martin Laberge. Other members include Dr. Najma Ahmed (Montreal, gastroenterologist), Mr. George Anthopoulos (Montreal, BA parent), Dr. Brian Cameron (Hamilton, surgeon), Dr. Sherif Emil (Montreal, surgeon), Dr. Carolina Jimenez (Ottawa, gastroenterologist), Dr. Steven Martin (Calgary, gastroenterologist), and Dr. Natalie Yanchar (Halifax, surgeon). In addition to her 0.5 FTE role as coordinator for CAPSNet, Alison Butler has been hired as the CBAR coordinator, which brings additional synergy to the two networks.

- Page 2 of 33



# **OTHER PROJECTS**

# **EPIQ**

The Canadian Neonatal Network (CNN) has developed a national, collaborative practice improvement program called EPIQ (Evidence Based Practice for Improving Quality). This program uses Best Practice Evidence as determined by comprehensive literature reviews ("EPIQ Evidence Reviews") combined with quality improvement methods and infrastructure to drive care improvement in NICUs across Canada.

As a collaborative initiative between CNN and CAPSNet, a congenital diaphragmatic hernia (CDH) EPIQ program, led by Pramod Puligandla, is being organized to develop a parallel approach to improve care and outcomes for CDH across Canada. Two years ago, a group of CAPSNet surgeons attended a Canadian EPIQ conference and workshop to receive methodology training and to meet with a number of interested neonatologists to create a preliminary list of potential "best practice" topics that would be the basis for CDH evidence reviews.

A survey was sent out to Neonatologists and Pediatric Surgeons across Canada in late summer of 2012 to identify key topics of interest. Seven key topics were identified, which resulted in the creation of 7 CDH EPIQ review groups whose members are a mixture of pediatric surgeons, neonatologists, pediatric intensivists and pediatric anesthesiologists. A list of the seven groups along with their selected review topic is listed below:

Ventilation Strategies in CDH				
Dr. Guilherme Sant'Anna	Dr. Pramod Puligandla			
Dr. Doug McMillan	Dr. Peter Cox			
Dr. Avash Singh				
Management of Pulmonary Hypertension in CDH				
Dr. Therese Perreault	Dr. Alfonso Solimano			
Dr. Nicola Rouvinezbouali				
Perinatal Management of CDH				
Dr. Keith Barrington	Dr. Georg Schmoelzer			
Dr. Karel O'Brien				
Type, Timing and Indications for	Surgical Repair in CDH			
Dr. Erik Skarsgard	Dr. Mary Brindle			
Dr. Ahmed Nasr	Dr. Jamie Blackwood			
Dr. Jeremy Luntley				
Use of Surfactant in CDH	_			
Dr. Bruno Piedboeuf	Dr. Amuchou Soraisham			
Dr. Andreana Butter				
Surveillance Protocols for Disabi	lity in CDH			
Dr. Anne Synnes	Dr. Michelle Bailey			
Dr. Patricia Riley	Dr. Priscilla Chiu			
Palliation in CDH				
Dr. Natalie Yanchar	Dr. Robert Baird			
Dr. Aideen Moore				



Groups are currently in the process of developing literature search strategies in collaboration with health sciences librarians. The working groups are due to complete their literature searches and consort diagrams by Spring, 2014. Evidence will be summarized and graded and will be used by expert panels for the development of practice guidelines and care bundles.

# SECONDARY ANALYSIS PROJECT

This CIHR-funded project combines CAPSNet data with Vital Statistics data and explores the epidemiology of gastroschisis based on geospatial incidence variation in Canada. Working with Geographic Information System epidemiologists in Toronto, the research team (Skarsgard, PI, Brindle, co-PI) is using a case control methodology to study maternal exposures at the level of household dissemination areas (determined by maternal postal code of residence). The other component of the study looks at aboriginal health outcomes for gastroschisis and CDH, and is being done in collaboration with an Aboriginal Health outcomes researcher, Dr Margo Greenwood of UNBC.

# ACKNOWLEDGEMENTS

Dr. Sarah Bouchard	Hôpital Ste-Justine, Montréal
Dr. Ioana Bratu	University of Alberta, Edmonton
Dr. Mary Brindle	University of Calgary, Calgary
Dr. Priscilla Chiu	Hospital for Sick Children, Toronto
Dr. Helen Flageole	McMaster University Medical Centre, Hamilton
Dr. Sharifa Himidan	Hospital for Sick Children, Toronto
Dr. Richard Keijzer	Children's Hospital, Winnipeg
Dr. Jean-Martin Laberge	Montréal Children's Hospital, Montréal
Dr. Aideen Moore	Mount Sinai Hospital, Toronto – Neonatology
Dr. Pramod Puligandla	Montréal Children's Hospital, Montréal
Dr. Greg Ryan	Mount Sinai Hospital, Toronto-Perinatology
Dr. Prakeshkumar S Shah	Mount Sinai Hospital, Neonatology
Dr. Erik Skarsgard	BC Children's Hospital, Vancouver
Dr. Doug Wilson	University of Calgary, Calgary-Perinatology
Dr. Natalie Yanchar	IWK Health Centre, Halifax

We would like to acknowledge the CAPSNet Steering Committee members for their leadership and commitment to the Network:

We send our sincere appreciation to Mr. Sonny Yeh, the MiCare System Administrator at Mount Sinai Hospital, for his work in compiling the national dataset, updating the CAPSNet software, and maintaining the database.

We acknowledge each of our Data Abstractors, whose attention to detail and high quality work serves as the foundation for the database. Many thanks to: Afsaneh Afshar, Debbie Arsenault, Sheryl Atkinson, Charlene Cars, Lola Cartier, Megan Clark, Natalie Condron, Valerie Cook, Victoria Delio, Alda DiBattista, Nathalie Fredette, Aimee Goss, Faye Hickey, Ullas Kapoor, Erin Kehoe, Robin Knighton, Lizy Kodiattu, Tanya McKee, Richa Metha, Nima Mirakhur, Loreanne D'Orazio, Kruti Patel, Daniel Pierrard, Rashmi Raghavan, MaryJo Ricci, Margaret Ruddy, Andrea Secord, Wendy Seidlitz, Ellen Townson, François Tshibemba, Jocelyne Vallée, and Susan Wadsworth.



We also acknowledge the many trainees, their site sponsors and the CAPSNet Steering Committee members who have and are currently utilizing the data for analyses (for a full list of ancillary projects to date see Appendix II).

CAPSNet is grateful for the financial support received from the Canadian Institutes of Health Research (CIHR), the Executive Council of the Canadian Association of Pediatric Surgeons (CAPS), the CIHR team in Maternal-Infant Care (MiCare) as well as in-kind contributions from CNN.

# 2013 DATA ANALYSIS (DATA UNTIL MARCH 31, 2013)

This CAPSNet Annual Report combines data from two versions of the CAPSNet database (2005 and 2012) and includes babies born until March 31, 2013. Changes in data definitions and variable formatting meant that some variables previously reported may be reported or analyzed in different ways. Every effort was made to analyze the data in a manner that unifies all variables and that considers any changes in definitions. Babies born until December 31, 2011 were entered into the old database version. For all data requests, it is important to note that new variables added into the database redesign will only be available for babies born January 1st, 2012 or later.

Cases included in this report were contributed by the CAPSNet centres listed below. All cases meet the CAPSNet eligibility criteria of a diagnosis of Gastroschisis (GS) or Congenital Diaphragmatic Hernia (CDH) made prenatally or within 7 days of life. Data from the CAPSNet database has been cleaned by the CAPSNet coordinating centre and checked with abstractors in the event of a possible discrepancy. Data from the CNN database has been cleaned by the CNN coordinating centre.

Individual cases are attributed to the centre in which the surgery took place (i.e., if a baby was admitted at CAPSNet centre **A** but transferred to CAPSNet centre **B** for surgery, the baby is included as a case for CAPSNet centre **B**). Finally, information from transfers within CAPSNet or CNN have been linked where possible in order to provide as complete of a picture as possible for the baby's complete course of hospital care.



### **CONTRIBUTING CENTRES FOR THE 2013 ANNUAL REPORT**

Site	City	Province
Victoria General Hospital	Victoria	BC
British Columbia Children's Hospital	Vancouver	BC
Alberta Children's Hospital	Calgary	AB
University of Alberta Hospital	Edmonton	AB
Royal University Hospital	Saskatoon	SK
Winnipeg Health Sciences Centre	Winnipeg	MB
in cooperation with St. Boniface General Hospital	Winnipeg	MB
Hospital for Sick Children	Toronto	ON
in cooperation with Mount Sinai Hospital	Toronto	ON
McMaster Children's Hospital	Hamilton	ON
London Health Sciences Centre	London	ON
Kingston General Hospital	Kingston	ON
Children's Hospital of Eastern Ontario	Ottawa	ON
in cooperation with The Ottawa Hospital	Ottawa	ON
Montréal Children's Hospital	Montréal	QC
in cooperation with McGill University Health Centre	Montréal	QC
Hôpital Ste-Justine	Montréal	QC
Centre Hospitalier de L'Université Laval	Ste-Foy	QC
IWK Health Centre	Halifax	NS
Janeway Children's Health and Rehabilitation Centre	St. John's	NL



# SUMMARY OF DATA BY DIAGNOSIS AND BIRTH OUTCOMES

\*Cases included in this analysis are grouped as aggregate data for babies born from 2005 to March 31<sup>st</sup>, 2013. There were a total of (11), birth cases that have not been included in any of the tables or analyses due to unlinked CNN data.

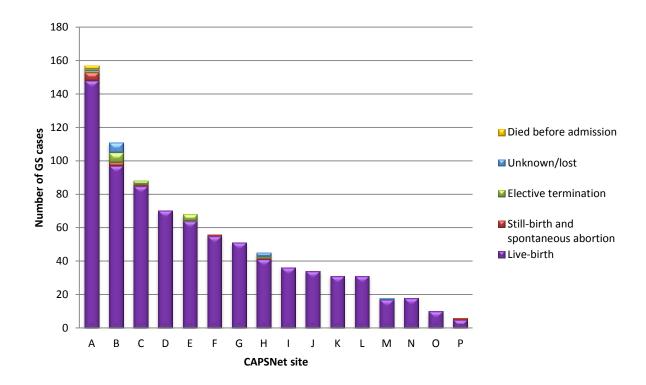
	Congenital Diaphragmatic Hernia (CDH)	Gastroschisis (GS)	Other/Unknown	CAPSNet total
Complete live births	442	793		1235
Still-births and spontaneous abortions	5	11		16
Elective terminations	56	14		70
Died prior to CAPSNet admission Represents live births where the infant did not survive to admission at a CAPSNet tertiary pediatric centre (e.g., live births in a community setting where the baby did not survive transfer, or live births at a non- CAPSNet with a planned palliative approach).	17	2		19
Unknown/Lost	6	10		16
Subtotal	526	830		1356
Incomplete cases/ Other Diagnosis Represents 2005-2013 cases for which there is only partial data entry and/or the baby is still in hospital, as of Oct 30 <sup>th</sup> , 2013.	17	50	42	109
Total Case Incidence				1465

#### ANTENATAL MISDIAGNOSES

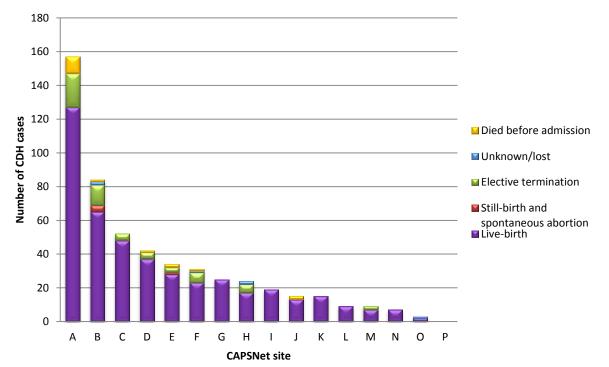
- ✓ 2 cases of suspected CDH were confirmed at birth as "other" (n=1) and "congenital hiatal hernia" (n=1).
- $\checkmark$  7 cases of suspected GS were confirmed at birth as "omphalocele" (*n*=5), and "other" (*n*=2).



#### **GRAPH A: DISTRIBUTION OF GS CASES BY CENTRE**



#### **GRAPH B: DISTRIBUTION OF CDH CASES BY CENTRE**





# **GASTROSCHISIS DESCRIPTIVE ANALYSES**

#### TABLE 1.0: PATIENT POPULATION

GS complete live births n = 793		
Overall survival rate*		97.1%
Inborn rate		77.9%
Mean birth weight		2450.0 g
Mean GA		36 weeks
Proportion of males		52.1%
Proportion of males with undescended testis/testes		14.0%
Isolated defect**		73.4%
SNAP-II scores (n = 737)***		
Mean - survivors (n=714) Mean-non-survivors (n=23)	9.7 17.8	
<b>Median - survivors</b> (n=714) <b>Median-non-survivors</b> (n=23)	6 14	

\* Cases with a reported discharge destination as "home" or "hospital" were grouped under survivors.

\*\* An isolated defect determined based on the absence of other congenital anomalies as entered in the CNN database. \*\*\*SNAP-II: Score for Neonatal Acute Physiology, version II. See Appendix I for definitions.

#### TABLE 1.1: SURVIVAL BY CENTRE VOLUME

The following table shows the survival rate grouped by centre volume. Low volume centres are those that see an average of <3 GS cases per year, high volume centres see an average  $\geq$  9 GS cases per year; and *mid volume* centres includes all those in between.

# **GASTROSCHISIS PROGNOSTIC SCORE (GPS)**

The Gastroschisis Prognostic Score (GPS) was developed by Cowan et al<sup>1</sup> using CAPSNet data collected at the time of the surgeon's first visual assessment of the bowel. The bowel injury variables (matting, atresia, necrosis, perforation) were weighted based on a regression analysis, thus creating the GPS, which was validated using the CAPSNet database (patients born May 2005–May 2009). The GPS risk group is assigned based on the composite GPS score. For scores of <2, the patient is considered low risk. Patients are considered as high risk for morbidity if their score is  $\ge 2$  while infants with scores  $\ge 4$  have a high risk for both morbidity and mortality.



<sup>&</sup>lt;sup>1</sup> Cowan KN, Puligandla PS, Laberge JM, Skarsgard ED, Bouchard S, Yanchar N, Kim P, Lee SK, McMillan D, von Dadelszen P, and the Canadian

			SNA	P-II	Gastroschisis P	rognostic Score
Centre volume	Count ( <i>n</i> )	Survival (%)	Median	Range	Mean	Range
High (4 centres)	400	97.5%	5	0-51	1.4	0-12
Mid (8 centres)	343	97.1%	7	0-68	1.1	0-10
Low (4 centres)	50	94.0%	7	0-50	1.5	0-9

\* Non-survivors are defined as those babies whose discharge destination was reported as "died". All other cases reported as discharged to "home", "hospital" or another destination were grouped under survivors.

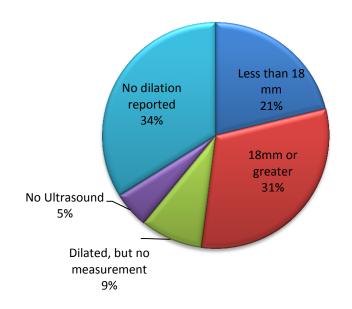
# **GS Ultrasound Measurements**

Bowel dilation thickness measurements taken during ultrasound examinations at 4 different time points were recorded as follows:

- 1. First ultrasound taken at the tertiary CAPSNet centre;
- 2. Last ultrasound taken between 23+0 and 31+6 weeks;
- 3. Last ultrasound taken between 32+0 and 34+6 weeks; and
- 4. Last ultrasound before delivery

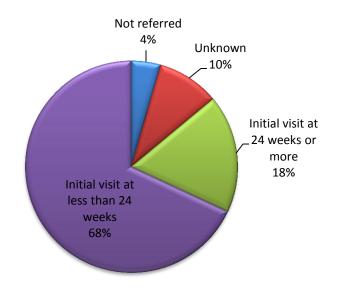
The data presented reflects the worst (i.e. greatest) measurement reported on any of the above ultrasounds. *No dilation reported* indicates that at least one ultrasound examination was recorded but the variable was either not measured or reported as not dilated; *dilated, but no measurement* indicates that bowel dilation was reported, but no measurement was provided; *no ultrasound* indicates that no ultrasound examination was recorded.

#### FIGURE 1.2: MAXIMUM BOWEL DILATION REPORTED ON ANTENATAL ULTRASOUND



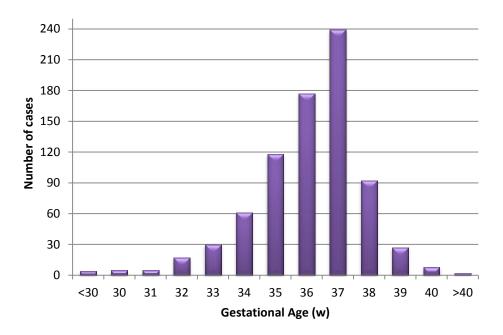
#### FIGURE 1.3: EARLY VS. LATE ANTENATAL REFERRAL

*Not referred* means that the mother was not referred to a tertiary centre prior to delivery.



#### GRAPH 1.4: GESTATIONAL AGE AT BIRTH

Gestational age is in complete weeks and calculated according to an algorithm in CNN, which considers both pediatric and obstetric estimates.





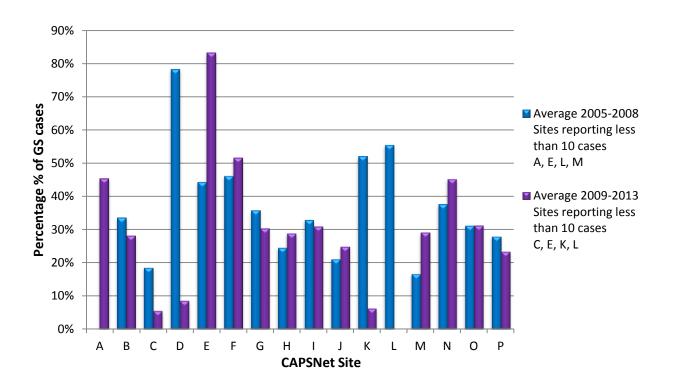
#### TABLE 1.5: ANTENATAL DELIVERY PLAN AS OF 32 WEEKS GESTATIONAL AGE

	N	%
No pre-determined plan	148	18%
Spontaneous vaginal delivery	235	28%
Elective Caesarean Section - Maternal Factors	30	4%
Elective Caesarean - Fetal Factors	27	3%
Induction	309	37%
Other	10	1%
Unknown	71	9%

\*This table includes all pregnancy outcomes (n =830)

#### GRAPH 1.6: PROPORTION OF CAESAREAN SECTION GROUPED BY SITE - 2005 TO 2013

CAPSNet data reports delivery type in 3 categories: vaginal delivery, caesarean, and unknown. The percentage of caesarean section deliveries is presented below by site. The denominator for each year is the total number of GS cases where delivery type was reported. Note that years in which a site had zero reported cases were not included in the average calculation.





#### TABLE 1.7: TIMING OF GASTROSCHISIS CLOSURE

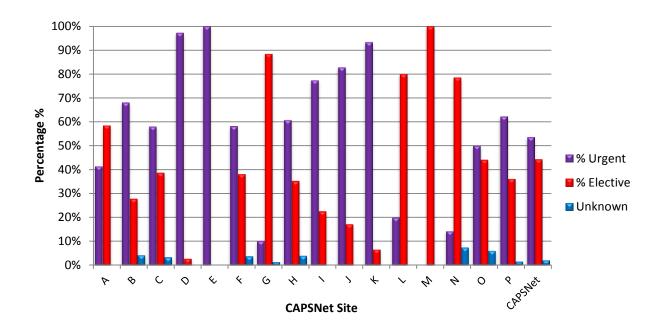
The denominator in this figure is the number of cases in which surgery was performed (*n*=785).

Timing of Closure	n	%
< 6 hours	376	48%
6-12 hours	73	9%
12-24 hours	29	4%
> 24 hours	295	38%
Unknown	12	2%

#### **GRAPH 1.8: SURGEON'S TREATMENT INTENT BY CENTRE**

The denominator in this figure is the number of cases in which surgery was performed (n=785). Across all centres, the surgeon's treatment intent was to perform an urgent primary closure in 54% (n=421) of cases and elective primary closure (enabled by a silo) in 44% (n= 348). In the remaining 2% (n=16) of cases, the surgeon's treatment intent is unknown.

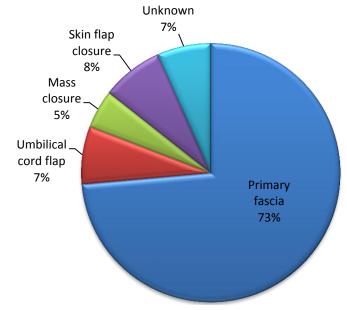
The CAPSNet definition of *urgent primary closure* is repair of the defect within 6 hours of NICU admission. *Elective primary closure* is delayed repair (>24 h) of the defect facilitated by silo placement.





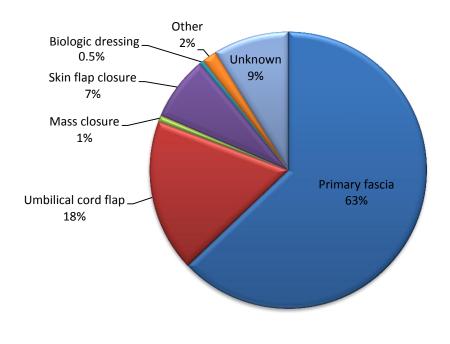
### FIGURE 1.9: METHOD OF SURGICAL CLOSURE

CAPSNet data reports method of surgical closure in 7 categories: primary fascia, mass closure, umbilical cord flap closure, skin flap closure, biologic dressing\*, and unknown. The percent of each closure type reported is presented below. The denominator for each time period is the total number of surgical closure types. Where DOB is unknown (n= 7), cases were grouped in the time period of 2005-2008. \**Category added in 2012* 



# FIGURE 1.9A: METHOD OF SURGICAL CLOSURE - 2005 TO 2008

FIGURE 1.9B: METHOD OF SURGICAL CLOSURE - 2009 TO 2013





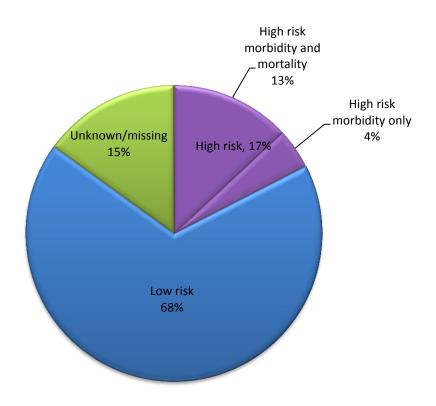
### TABLE 1.10: OPERATIVE SUCCESS

Of 785 primary operations, 83% were recorded as successful. The 17% reported as failed initial closures were for the following reasons:

	N	%
Bowel not reducible	90	67%
Bowel would reduce, but IPP or PIP too high to close	12	9%
Bowel would reduce, but seemed too tight to close	23	17%
Unknown or missing	10	7%

### FIGURE 1.11A: PROPORTIONAL GASTROSCHISIS PROGNOSTIC SCORE (GPS) SCORING

The GPS risk group is assigned based on the composite GPS score. For scores of <2, the patient is considered low risk (67.5%; n=535). Patients are considered as high risk for morbidity if their score is  $\geq$  2 while infants with scores  $\geq$  4 have a high risk for both morbidity and mortality. Of the patients at high risk (17.5%; n = 139), 75% are at a high risk for mortality (n = 104).

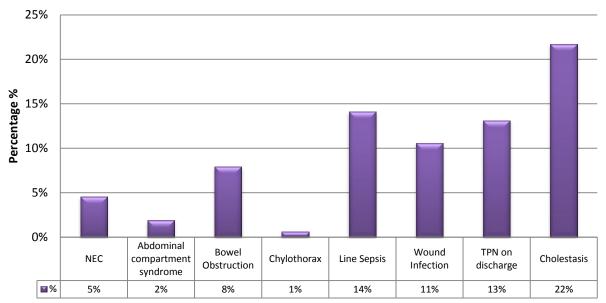




#### TABLE 1.11B: SELECTED NEONATAL OUTCOMES STRATIFIED BY GPS RISK

	Leng	th of Stay	TPN Days	Days to Enteral Feeds
	or unverified dat	a were omitted from f	inal calculations for each stratified <u>c</u>	group
<b>ALL CASES</b> (n = 793)				
Mean		57.4	45.3	18.0
Median		36.5	28	14
Range	1	- 627	2-604	1-216
Low Risк (GPS < 2; *0.9% (n=5) of low risk				
Mean		46.5	36.8	16.1
Median		34	27	13
Range	1	- 595	3 – 573	3 - 216
HIGH RISK: MORBIDIT *11% (n=13) of high risk	•	= 139)		
Moon		26.2	75.4	25.2
Mean		96.3	75.1	26.3
Mean Median		96.3 68	75.1 51	26.3 19
			-	
Median	1 Нідн Risk: М	68 627	51	19 2 - 166
Median	1 Нідн Risk: М	68 627 Mortality <b>(GPS</b> ≥ 4	51 4 - 604	19 2 - 166
Median	1 HIGH RISK: N *12.5% (n=13	68 – 627 MORTALITY (GPS ≥ 4 ) of subgroup died	51 4 - 604 ; subgroup of high risk group	19 2 - 166 above: n = 104)

# GRAPH 1.12: SELECTED NEONATAL COMPLICATIONS



\*For outcome definitions, please see appendix I



#### **CONGENITAL DIAPHRAGMATIC HERNIA DESCRIPTIVE ANALYSES**

#### TABLE 2.0: PATIENT POPULATION

CDH complete live births n = 442				
Overall survival rate*	79.2%			
Died without surgery	14.3%			
Inborn rate	60.6%			
Mean GA	37 weeks			
No prenatal diagnosis	35.7%			
Mean birth weight	3054.3 grams			
Mean age at repair	6 days			
Proportion of males	59.0%			
Isolated defect**	59.0%			
Proportion requiring ECMO	7.0%			
Proportion with left-sided defect	71.0%			
SNAP-II scores***				
Mean – survivors ( <i>n</i> = 323)	14.6			
Mean – non-survivors ( <i>n</i> = 87)	33.9			
Median – survivors ( <i>n</i> =323)	12.0			
Median – non-survivors ( <i>n</i> =87)	32.0			

\* Cases with a reported discharge destination as "home" or "hospital" were grouped under survivors.

\*\*An isolated defect determined based on the absence of another congenital anomalies as entered in the CNN database. \*\*\*SNAP-II: Score for Neonatal Acute Physiology, version II. See <u>Appendix</u> I for definitions.



#### TABLE 2.1: SURVIVAL BY CENTRE VOLUME

This table shows the survival rate grouped by centre volume. Low volume centres are those that see on average  $\leq 2$  CDH cases per year, high volume centres see an average  $\geq 5$  CDH cases per year; and mid volume centres include all those in between.

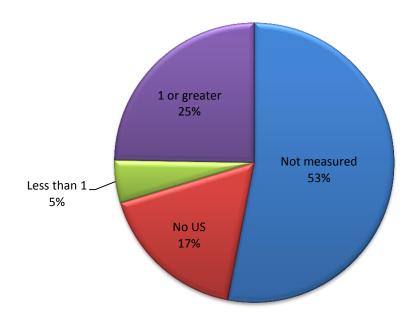
	Count ( <i>n</i> )	Survival (%)	SNAP-II Median	SNAP-II Range	
High volume (4 centres)	268	79.1%	12	0-77	
Mid volume (7 centres)	143	79.0%	16	.6 0-68	
Low volume (5 centres)	31	87.1%	16	0-53	

#### FIGURE 2.2: MAXIMUM LUNG-HEAD RATIO (LHR)

LHR is measured during ultrasound interrogations for infants with a prenatal diagnosis of CDH. The data presented here reflects the best (i.e. greatest) measurement reported on any one ultrasound examination for the periods listed below:

- 1. First ultrasound taken at the tertiary CAPSNet centre;
- 2. Last ultrasound taken between 23+0 and 27+6 weeks;
- 3. Last ultrasound taken between 28+0 and 32+6 weeks; and
- 4. Last ultrasound before delivery

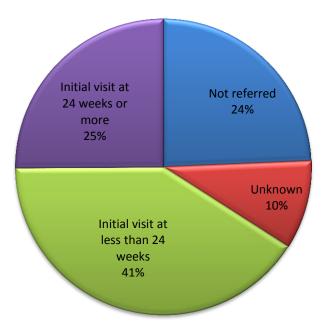
*Not measured* indicates that at least one ultrasound was recorded, but the lung-head ratio was not measured.





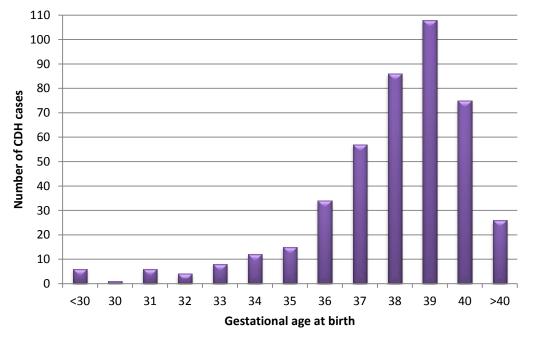
#### FIGURE 2.3: EARLY VS. LATE INITIAL VISIT

*Not referred* means that the mother was not referred to a tertiary centre prior to delivery. Of the patients who were not referred prenatally (24%, n=128), 87.5% were not prenatally diagnosed (n=112).



#### **GRAPH 2.4: GESTATIONAL AGE AT BIRTH**

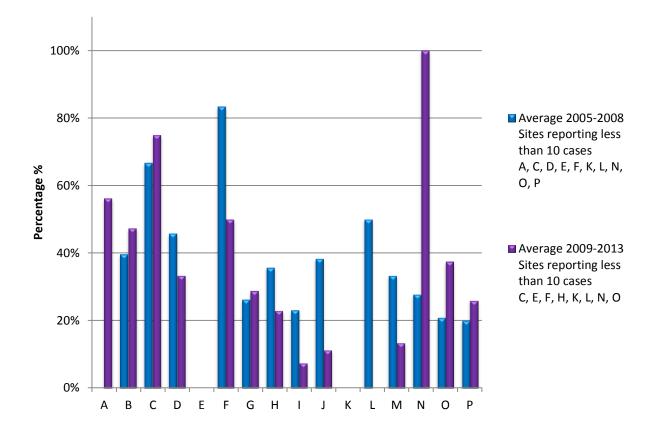
Gestational age is in complete weeks and calculated according to the CNN algorithm, which considers both pediatric and obstetric estimates.





#### GRAPH 2.5: PROPORTION OF CAESAREAN DELIVERY GROUPED BY SITE - 2005 TO 2013

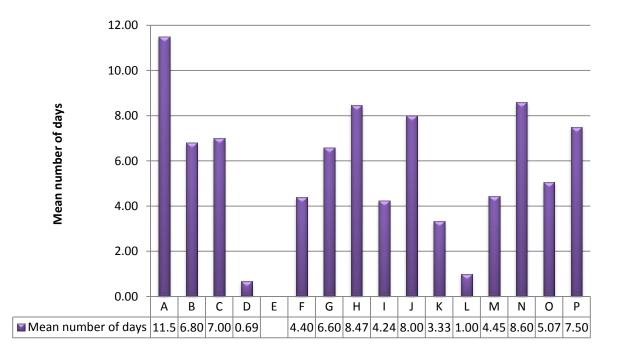
CAPSNet data reports delivery type in 3 categories: vaginal delivery, caesarean and unknown. The percentage of caesarean section deliveries is presented below by site. The denominator for each year is the total number of CDH cases where delivery type was reported. Note that years in which a site had zero reported cases were not included in the average calculation.





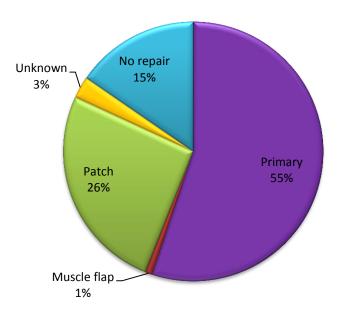
#### GRAPH 2.6: MEAN AGE AT SURGICAL REPAIR BY CENTRE

The denominator in this figure indicates only those cases in which surgery was performed and the date of surgery was recorded (i.e., n = 370).



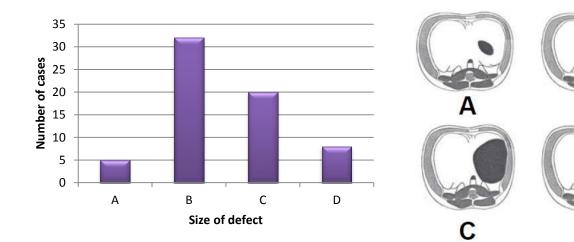
# FIGURE 2.7: METHOD OF SURGICAL CLOSURE

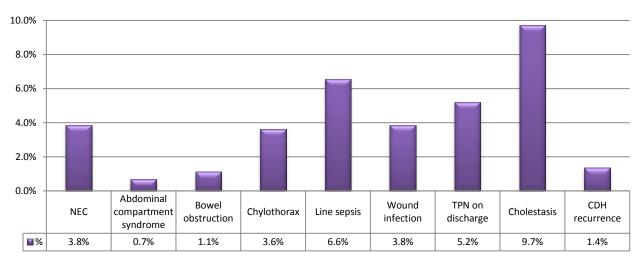
Of those patients reported as having no repair (n=67), all died.



#### GRAPH 2.8: SIZE OF CDH DEFECT

Starting in January 2010, CAPSNet added a variable to its data collection asking for the relative size of the CDH defect. The variable was not routinely reported for babies born prior to Jan 1, 2012; however, it is routinely reported in the new database for babies born from Jan 1, 2012 onwards. To date, 65 cases had a size of defect indicated.



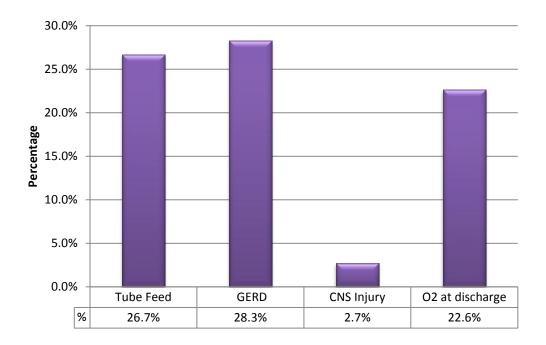


#### **GRAPH 2.9: SELECTED NEONATAL COMPLICATION**

\*\*For outcome definitions, please see appendix I



#### GRAPH 2.10A: SELECTED NEONATAL OUTCOMES AT DISCHARGE



Tube Feeds: defined as any tube feed (G, J feeds) at discharge

**GER (Gastroesophageal Reflux):** defined as a need for any anti-reflux medications at discharge **CNS Injury:** defined as a need for anticonvulsant medications at discharge **Oxygen Support:** defined as a need for supplemental oxygen at discharge

TABLE 2.10B: SELECTED NEONATAL OUTCOMES

	Survivors (n = 295)			
	Mean	Median	Range	
Length of stay (days)	41.1	29	1-340	
TPN days	22.9	17	4-185	
Days to enteral feeds	11.8	9.5	1-64	
Ventilation days (if required)	13.2	9	1-289	
ECMO days (if required)	12.8	10.5	3-32	
Supplemental O <sub>2</sub> days (if required)	13.6	5	1-260	

# **APPENDIX I: DEFINITIONS**

**ABDOMINAL COMPARTMENT SYNDROME:** Defined as an increase in intra-abdominal pressure requiring surgery to relieve pressure.

**CAPSNET POPULATION DEFINITION:** The CAPSNet database captures:

- ✓ All cases of confirmed or suspect Congenital Diaphragmatic Hernia (CDH) and Gastroschisis (GS) diagnosed antenatally and referred to one of the participating tertiary perinatal centres for ongoing prenatal care of the fetus, regardless of the final outcome of pregnancy; and
- ✓ All cases of CDH and GS diagnosed postnatally up to 7 days of life who were either born at or transferred after birth to one of the participating centres.

**CHOLESTASIS/LIVER DISEASE:** Defined as two or more consecutive measurements of 50 umol/l or greater of conjugated bilirubin, over a period of at least 14 days, with no documented bacteremia over that time period.

**CHYLOTHORAX:** defined as: a pleural effusion with fluid triglyceride level >1mmol/l and /or white cell differential >90% lymphocytes appearing after CDH repair requiring treatment (usually chest tube placement).

**GASTROSCHISIS BOWEL DILATION:** Refers to the maximum internal (i.e. endoluminal) diameter measured from inner wall to inner wall along the short axis of the bowel loop at the most dilated segment of the extruded bowel in millimeters (mm).

**GASTROSCHISIS BOWEL WALL THICKENING:** Refers to the maximum bowel wall thickness measured from the inner wall to the outer wall of the thickest portion of the small bowel in millimeters (mm).

**LINE SEPSIS:** Defined as documented bacteremia in the presence of an indwelling central line (PICC, percutaneous or surgically tunnelled) requiring antibiotics or line removal.

**LUNG (AREA) TO HEAD (CIRCUMFERENCE) RATIO (LHR)**: Refers to the measurement that reflects the severity of fetal pulmonary hypoplasia, and, if it has been measured, it will be reported as "lung to head ratio" or "LHR" within the ultrasound report. It is typically measured by a standardized technique, and reported (without units of measurement) *for the lung on the side opposite of the diaphragmatic hernia* (ie Right LHR will be reported for a left CDH).

**NECROTIZING ENTEROCOLITIS (NEC):** Defined as the occurrence of impaired blood supply to portions of the bowel. This leads to small perforations with air dissecting in the bowel wall (pneumatosis) or even entering the peritoneal cavity (pneumoperitoneum).

**SNAP-II (SCORE FOR NEONATAL ACUTE PHYSIOLOGY):** An illness severity scoring system which stratifies patients according to cumulative severity of physiologic derangement in several organ systems within the first 12 hrs of admission to the intensive care unit. This scoring system has been shown to be highly predictive of neonatal mortality and to be correlated with other indicators of illness severity including therapeutic intensity, physician estimates of mortality risk, length of stay, and nursing workload. SNAP provides a numeric score that reflects how sick each infant is. The scoring system is modeled after similar adult and pediatric scores, which are already widely in use. For more information, see: D K. Richardson et al . SNAP-II and SNAPPE-II: Simplified newborn illness severity and mortality risk scores. J Pediatr 2001; 138: 92-100

If more than 65% of the SNAP score data elements were missing, SNAP-II scores cannot be computed and were thus excluded from any analyses.

# **APPENDIX II: LIST OF PUBLICATIONS, PRESENTATIONS AND ONGOING PROJECTS**

# **PUBLICATIONS**

# 2014 (In Press)

Stanger J, Mohajerani N, Skarsgard ED, Canadian Pediatric Surgery Network: Practice Variation in gastroschisis: Factors Influencing Closure Technique. J Pediatr Surg (in press).

#### 2014

Gover A, Albersheim S, Sherlock R, Claydon J, Butterworth S, Kuzeljevic B, Canadian Pediatric Surgery Network. Outcome of patients with gastroschisis managed with and without multidisciplinary teams in Canada. Paediatr Child Health 2014 Mar; 19(3): 128-32

#### **2013**

- Alshehri A, Emil S, Laberge JM, Skarsgard E, Canadian Pediatric Surgery Network. Outcomes of early versus late intestinal operations in patients with gastroschisis and intestinal atresia: results from a prospective national database. J Pediatr Surg 2013 Oct;48(10):2022-6.
- Aljahdali A, Mohajerani N, Skarsgard ED, Canadian Pediatric Surgery Network. Effect of timing of enteral feeding on outcome in gastroschisis. J Pediatr Surg 2013 May;48(5):971-6.
- Beres A, Puligandla PS, Brindle ME, Canadian Pediatric Surgery Network. Stability prior to surgery in Congenital Diaphragmatic Hernia: is it necessary? J Pediatr Surg 2013 May;48(5):919-23.
- Goodwin Wilson M, Beres A, Baird R, Laberge J-M, Skarsgard ED, Puligandla PS, Canadian Pediatric Surgery Network. Congenital diaphragmatic hernia (CDH) mortality without surgical repair? A plea to clarify surgical ineligibility. J Pediatr Surg 2013 May;48(5):924-9.
- Maxwell D, Baird R, Puligandla P, the Canadian Pediatric Surgery Network. Abdominal closure in neonates after congenital diaphragmatic hernia. J Pediatr Surg 2013 May;48(5):930-4.
- Nasr A, Ryan G, Bass J, Langer J, Canadian Pediatric Surgery Network. Effect of delivery philosophy on outcome in fetuses with gastroschisis. J Pediatr Surg 2013 Nov;48(11):2251-5.

#### **2012**

- Akhtar J, Skarsgard ED; Canadian Pediatric Surgery Network. Associated Malformations and the "Hidden Mortality" of Gastroschisis. J Pediatr Surg 2012 May;47(5):911-6.
- Nasr A, Langer JC; Canadian Pediatric Surgery Network. Influence of location of delivery on outcome in neonates with gastroschisis. J Pediatr Surg 2012 Nov;47(11):2022-5.
- Baird R, Puligandla P, Skarsgard ED, Laberge JM; Canadian Pediatric Surgery Network. Infectious complications in Gastroschisis: A CAPSNet Study. Pediatr Surg Int 2012 Apr;28(4):399-404.

- Page 25 of 33

- Brindle ME, Flageole H, Wales PW. Influence Of Maternal Factors And Aboriginal Status On Health Outcomes In Gastroschisis: A Canadian Population-based Study. Neonatology 2012;102(1):45-52.
- Cowan KN, Puligandla PS, Laberge JM, Skarsgard ED, Bouchard S, Yanchar N, Kim P, Lee SK, McMillan D, von Dadelszen P, and the Canadian Pediatric Surgery Network. The Gastroschisis Prognostic Score: Outcome prediction in Gastroschisis. J Pediatr Surg 2012 Jun;47(6):1111-7.
- Jansen LA, Safavi A, Lin Y, MacNab YC, Skarsgard ED; and the Canadian Pediatric Surgery Network. Pre-closure Fluid Resuscitation Influences Outcome in Gastroschisis. Am J Perinatol 2012 Apr;29(4):307-12.
- Mills J, Safavi A, Skarsgard ED; Canadian Pediatric Surgery Network. Chylothorax Following Congenital Diaphragmatic Hernia Repair: A Population-based Study. J Pediatr Surg 2012 May;47(5):842-6.
- Safavi A, Skarsgard ED, Butterworth SA; Canadian Pediatric Surgery Network. Bowel Defect Disproportion in Gastroschisis: Does the need to extend the fascial defect predict outcome? Pediatr Surg Int 2012 May;28(5):495-500.
- Safavi A, Synnes AR, O'Brien KK, Chiang M, Skarsgard ED, Chiu P; Canadian Pediatric Surgery Network. Multi-institutional follow up of congenital diaphragmatic hernia (CDH) patients reveals severe disability and variations in practice. J Pediatr Surg 2012 May;47(5):836-41
- Van Manene M, Bratu I, Narvey M, Rosychuk RJ; Canadian Pediatric Surgery Network. Use of paralysis in silo-assisted closure of gastroschisis. J Pediatr 2012 Jul;161(1):125-8.

# **2011**

- Baird R, Eeson G, Safavi A, Puligandla P, Laberge JM, Skarsgard ED; Canadian Pediatric Surgery Network. Institutional practice and outcome variation in the management of congenital diaphragmatic hernia and gastroschisis in Canada: a report from the Canadian Pediatric Surgery Network. J Pediatr Surg 2011 May;46(5):801-7.
- Brindle ME, Brar M, Skarsgard ED; and the Canadian Pediatric Surgery Network (CAPSNet).
   Patch repair is an independent predictor of morbidity and mortality in congenital diaphragmatic hernia. Pediatr Surg Int 2011 Sep;27(9):969-74. Epub 2011 May 18.
- Nasr A, Langer JC; Canadian Pediatric Surgery Network. Influence of location of delivery on outcome in neonates with congenital diaphragmatic hernia. J Pediatr Surg 2011 May;46(5):814-6.

#### **2010**

Brindle ME, Ma IWY, Skarsgard ED. Impact of target blood gases on outcome in congenital diaphragmatic hernia (CDH). Eur J Pediatr Surg 2010 Sep;20(5):290-3.

2013 CAPSNet Annual Report (V1)



- Mills JA, Lin Y, MacNab YC, Skarsgard ED and the Canadian Pediatric Surgery Network. Does overnight birth influence treatment or outcome in Congenital Diaphragmatic Hernia? Am J of Perinatol 2010; 27 (1): 91-95.
- Mills J, Lin Y, MacNab Y, Skarsgard ED JM and the Canadian Pediatric Surgery Network. Perinatal predictors of outcome in gastroschisis. J Perinatol 2010 Dec;30(12):809-13.
- Safavi A, Lin Y, Skarsgard ED; Canadian Pediatric Surgery Network. Perinatal management of congenital diaphragmatic hernia: when and how should babies be delivered? Results from the Canadian Pediatric Surgery Network. J Pediatr Surg 2010 Dec;45(12):2334-9.

#### 2009

- Boutros J, Regier M, Skarsgard ED and the Canadian Pediatric Surgery Network. Is timing everything? The influence of gestational age and intended and actual route of delivery on treatment and outcome in Gastroschisis. J Pediatr Surg 2009; 44:912-7.
- Grushka JR, Laberge JM, Puligandla P, Skarsgard ED and the Canadian Pediatric Surgery Network. The effect of hospital case volume on outcome in Congenital Diaphragmatic Hernia. J Pediatr Surg 2009; 44:873-6.

#### 2008

- Skarsgard ED, Claydon J, Bouchard S, Kim P, Lee SK, Laberge JM, McMillan D, von Dadelszen P, Yanchar N and the Canadian Pediatric Surgery Network. Canadian Pediatric Surgical Network: a populationbased pediatric surgery network and database for analyzing surgical birth defects: The first 100 cases of gastroschisis. J Pediatr Surg 2008; 43(1):30-4.
- Baird R, MacNab YC, Skarsgard ED, and the Canadian Pediatric Surgery Network. Mortality prediction in congenital diaphragmatic hernia. J Pediatr Surg 2008;43(5):783-7.
- Weinsheimer RL, Yanchar NL, Bouchard S, Kim P, Laberge JM, Skarsgard ED, Lee SK, McMillan D, von Dadelszen P, and the Canadian Pediatric Surgery Network. Gastroschisis closure – does method really matter? J Pediatr Surg 2008;43(5):874-8.
- Weinsheimer RL, Yanchar NL and the Canadian Pediatric Surgical Network. Impact of maternal substance abuse and smoking on children with Gastroschisis. J Pediatr Surg 2008; 43(5):879-83.

#### 2006

Skarsgard E. Networks in Canadian pediatric surgery: Time to get connected. Paediatr Child Health 2006; 11(1):15-18.



# **CONFERENCE PROCEEDINGS**

# **2013**

Stanger J, Mohajerani N, Skarsgard ED, Canadian Pediatric Surgery Network: Practice Variation in gastroschisis: Factors Influencing Closure Technique. Presented at the 45<sup>th</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Charlottetown, PEI. Sept 26-28, 2013.

# **2012**

- Yanchar N, Canadian Pediatric Surgery Network. CAPSNet The Past, Present, and Future. Presented at the 13<sup>th</sup> EUPSA Congress and 59<sup>th</sup> BAPS Congress, Rome, Italy. June 13-16, 2012.
- Aljahdali A, Mohajerani N, Skarsgard ED, Canadian Pediatric Surgery Network. Effect of timing of enteral feeding on outcome in gastroschisis. Presented at the 44<sup>th</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Victoria, Canada. Sept 20-22, 2012.
- Beres A, Puligandla PS, Brindle ME, Canadian Pediatric Surgery Network. Conformity to stability criteria for the surgical correction of congenital diaphragmatic hernia: Is it necessary? Presented at the 44<sup>th</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Victoria, Canada. Sept 20-22, 2012.
- Goodwin WM, Beres A, Baird R, Laberge J-M, Skarsgard ED, Puligandla PS, Canadian Pediatric Surgery Network. Congenital diaphragmatic hernia (CDH) mortality without surgical repair? A plea to clarify surgical ineligibility. Presented at the 44<sup>th</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Victoria, Canada. Sept 20-22, 2012.
- Hazell A, Bassil K, Arbour L, Brindle M, Skarsgard E, Canadian Pediatric Surgery Network. Geographic variation and clustering of gastroschisis in Canada. Presented at the 39th ICBDSR and 10th CCASN Joint Annual Scientific Meeting, 2012, Ottawa, Canada. Oct 30th Nov 2<sup>nd</sup>, 2012.
- Laberge J-M. Primero Curso Internacional de Actualizacion en Ginecologia y Perinatalogia (First update course in gynecology and perinatalogy) Hospital Alcivar, Guayaquil, Ecuador, July 12-14 2012.
- Laberge, J-M. Hernia diafragmática congénita. Resultados Canadienses y la implicación de la oclusión traqueal fetal (CDH: Canadian results and the role of fetal tracheal occlusion).
- Laberge, J-M . El resultado de la Red Canadiense de Cirugía pediátrica en el manejo de Gastroquisis. (Results from the Canadian Paediatric Surgery Network in the management of gastroschisis).
- Maxwell D, Puligandla P, Baird R, the Canadian Pediatric Surgery Network. Abdominal closure in neonates with congenital diaphragmatic hernia. Presented at the 44<sup>th</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Victoria, Canada. Sept 20-22, 2012.
- Nasr A, Ryan G, Bass J, Langer J, Canadian Pediatric Surgery Network. Effect of delivery approach on outcome in fetuses with gastroschisis. Presented at the 44<sup>th</sup> Annual

2013 CAPSNet Annual Report (V1)

- Page **28** of **33** 

Meeting of the Canadian Association of Pediatric Surgeons, Victoria, Canada. Sept 20-22, 2012.

Skarsgard E. Collaborative Outcome Improvement in Canadian Pediatric Surgery. Presented at the 2012 Canadian Association of Pediatric Health Centres (CAPHC) Annual Meeting. Vancouver, Canada. October 28, 2012.

- Nasr A, Langer JC; Canadian Pediatric Surgery Network. Influence of Location of Delivery on Outcome of Neonates with Gastroschisis. Presented at the 42<sup>nd</sup> Annual Meeting of the American Pediatric Surgical Association, Palm Springs, CA. May 22-25, 2011.
- Akhtar J, Skarsgard ED; Canadian Pediatric Surgery Network. Associated Malformations and the "Hidden Mortality" of Gastroschisis. Presented at the 43<sup>rd</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Ottawa, Canada. Sept 22-25, 2011.
- Safavi A, Skarsgard ED; Canadian Pediatric Surgery Network. Antenatal Ultrasound Predictors of Bowel Injury in Gastroschisis. Presented at the 43<sup>rd</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Ottawa, Canada. Sept 22-25, 2011.
- Mills J, Safavi A, Skarsgard ED; Canadian Pediatric Surgery Network. Chylothorax Following Congenital Diaphragmatic Hernia Repair: A Population-based Study. Presented at the 43<sup>rd</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Ottawa, Canada. Sept 22-25, 2011.
- Brindle ME, Flageole H, Wales PW. Influence Of Maternal Factors And Aboriginal Status On Health Outcomes In Gastroschisis: A Canadian Population-based Study. A Population-based Study. Presented at the 43<sup>rd</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Ottawa, Canada. Sept 22-25, 2011.
- Moore AM, Madhoo P, Himidan S, Ryan G, Skarsgard ED; Canadian Pediatric Surgery Network. Examining the Hidden Mortality of Congenital Diaphragmatic Hernia. Presented at the 52<sup>nd</sup> Annual Meeting of the European Society for Pediatric Research, Newcastle, UK. October 14-17, 2011.
- Moore AM, Madhoo P, Himidan S, Ryan G, Skarsgard ED; Canadian Pediatric Surgery Network. Health Care Utilisation for Pregnancies Complicated by Fetal Gastroschisis. Presented at the 88<sup>th</sup> Annual Meeting of the Canadian Pediatric Society, June 15-18, 2011. Quebec City, CA.
- Safavi A, Synnes AR, O'Brien KK, Chiang M, Skarsgard ED, Chiu P; Canadian Pediatric Surgery Network. Multi-institutional follow up of congenital diaphragmatic hernia (CDH) patients reveals severe disability and variations in practice. Presented at the 43<sup>rd</sup> Annual Meeting of the Canadian Association of Pediatric Surgeons, Ottawa, Canada. Sept 22-25, 2011.
- Cowan KN, Puligandla PS, Laberge JM, Skarsgard ED, Butter A, Bouchard S, Yanchar N, Kim P, Lee SK, McMillan D, von Dadelszen P and the Canadian Pediatric Surgery Network. The gastroschisis bowel score predicts outcome in gastroschisis (updated numbers). Presented at the Surgical Section of the American Academy of Pediatrics, NCE, Boston MA. October 15-18, 2011.





- Laberge JM and the Canadian Pediatric Surgery Network. Congenital Diaphragmatic Hernia: Results and factors affecting outcomes in the Canadian Pediatric Surgery Network. Presented at the 3<sup>rd</sup> World Congress of Pediatric Surgery; New Delhi, India. October 21-24, 2010.
- Eeson G, Safavi A, Skarsgard E, and the Canadian Pediatric Surgery Network. Practice and outcome variation in CDH in Canada. Presented at the 42<sup>nd</sup> annual meeting of the Canadian Association of Pediatric Surgeons; Saskatoon, Saskatchewan. September 23-28, 2010.
- Nasr A, Langer JC and the Canadian Pediatric Surgery Network. Influence of location of delivery on outcome in neonates with congenital diaphragmatic hernia. Presented at the 42<sup>nd</sup> annual meeting of the Canadian Association of Pediatric Surgeons; Saskatoon, Saskatchewan. September 23-28, 2010.
- Baird R, Puligandla, Laberge JM and the Canadian Pediatric Surgery Network. Practice and outcome variation in Gastroschisis in Canada. Presented at the 42<sup>nd</sup> annual meeting of the Canadian Association of Pediatric Surgeons; Saskatoon, Saskatchewan. September 23-28, 2010.
- Safavi A, Lin Y, Skarsgard ED and the Canadian Pediatric Surgery Network. Perinatal management of congenital diaphragmatic hernia: When and how should babies be delivered? Presented at the 43<sup>rd</sup> Annual Meeting of the Pacific Association of Pediatric Surgeons; Kobe, Japan. May 23-27, 2010.
- Wilson D and the Canadian Pediatric Surgery Network. The Canadian Pediatric Surgery Network (CAPSNet): Targeting national outcome improvement for structural birth defects through collaborative knowledge synthesis and evidence-based practice change. Presented at the 18<sup>th</sup> Annual Western Perinatal Research Meeting; Banff, Alberta. February 11-14, 2010.
- Jansen L, Lin Y, MacNab Y, Skarsgard ED, Puligandla PS and the Canadian Pediatric Surgery Network. Pre-closure fluid resuscitation influences outcome in gastroschisis. Presented at the 41<sup>st</sup> Annual Meeting of the American Pediatric Surgical Association; Orlando, Florida. May 16-19, 2010.
- Cowan KN, Puligandla PS, Laberge JM, Skarsgard ED, Butter A, Bouchard S, Yanchar N, Kim P, Lee SK, McMillan D, von Dadelszen P and the Canadian Pediatric Surgery Network. The gastroschisis bowel score predicts outcome in gastroschisis. Poster presented at the 2010 Annual Meeting of the Pediatric Academic Societies; Vancouver BC. May 1-4, 2010.
- Gover A, Albersheim S, Sherlock R, Claydon J, Butterworth S, Kuzeljevic B and the Canadian Pediatric Surgery Network. Does a multidisciplinary team improve outcome of gastroschisis patients? Poster presented at the 2010 Annual Meeting of the Pediatric Academic Societies; Vancouver BC. May 1-4, 2010.
- Gover A, Albersheim S, Sherlock R, Claydon J, Butterworth S, Kuzeljevic B and the Canadian Pediatric Surgery Network. Early stratification of gastroschisis patients: Are we there yet? Poster



presented at the 2010 Annual Meeting of the Pediatric Academic Societies; Vancouver BC. May 1-4, 2010.

### 2009

- Cowan KN, Puligandla PS, Bütter A, Skarsgard ED, Laberge JM and the Canadian Pediatric Surgery Network. The Gastroschisis Bowel Score Predicts Outcome in Gastroschisis. Presented at the 4<sup>th</sup> Annual Academic Surgical Congress; Fort Myers, Florida. Feb 2009.
- Baird R, Skarsgard ED, Laberge J-M, Puligandla PS, and the Canadian Pediatric Surgical Network. The Use of Antibiotics in the Management of Gastroschisis-Canadian Practice Patterns. Presented at the 40<sup>th</sup> Annual Meeting of the American Pediatric Surgical Association; Fajardo, Puerto Rico. May 28-30, 2009.
- Brindle M, Ma IW, Skarsgard ED and The Canadian Pediatric Surgery Network. Impact of Target Blood Gases on Outcome in Congenital Diaphragmatic Hernia (CDH). Presented at the 40<sup>th</sup> Annual Meeting of the American Pediatric Surgical Association; Fajardo, Puerto Rico. May 28-30, 2009.
- Brindle M, Oddone E, Skarsgard ED and The Canadian Pediatric Surgery Network. Need for Patch Repair Influences Outcome in Congenital Diaphragmatic Hernia (CDH). Presented at the 40<sup>th</sup> Annual Meeting of the American Pediatric Surgical Association; Fajardo, Puerto Rico. May 28-30, 2009.
- Mills J, Lin Y, MacNab Y, Skarsgard ED JM and the Canadian Pediatric Surgery Network. Perinatal Predictors of Outcome in Gastroschisis. Presented at the 40<sup>th</sup> Annual Meeting of the American Pediatric Surgical Association; Fajardo, Puerto Rico. May 28-30, 2009.
- Grushka JR, Laberge JM, Puligandla P, Skarsgard ED and the Canadian Pediatric Surgery Network. The Effect of Prenatal Diagnosis on the Contemporary Outcome of CDH. Presented at the 40<sup>th</sup> Annual Meeting of the American Pediatric Surgical Association; Fajardo, Puerto Rico. May 28-30, 2009.
- Butterworth SA, Brant R, Skarsgard ED and the Canadian Pediatric Surgery Network. Is the need for fascial defect extension a predictor of adverse outcome in gastroschisis? Presented at the 41<sup>st</sup> Annual meeting of the Canadian Pediatric Surgery Association; Halifax, Nova Scotia. October 1-4, 2009.

- Mills J, MacNab Y, Skarsgard ED and the Canadian Pediatric Surgery Network. Does Overnight Birth Time Influence Surgical Management of Outcome in Neonates with Gastroschisis? Presented at the 79<sup>th</sup> Annual Meeting of the Pacific Coast Surgical Association; San Diego, California. Feb 16, 2008.
- Brindle M, Mills J,Lin Y, MacNab Y, Skarsgard ED and the Canadian Pediatric Surgery Network.
   Influence of Birth Time on Surgical Management and Outcomes of Neonates with Gastroschisis.
   Presented at the 2008 Joint Meeting of the Pediatric Academic Societies and the Society for
   Pediatric Research. Honolulu, HI, May 2008.



- Pressey TP, Skarsgard ED, Claydon J, von Dadelszen P, and the Canadian Pediatric Surgery Network. Antenatal Ultrasound Detection of Abnormal Amniotic Fluid Volume Predicts Adverse Perinatal Outcomes. Presented at the 14<sup>th</sup> International Conference on Prenatal Diagnosis and Therapy. Vancouver, Canada, June 2008.
- Laberge JM, Skarsgard ED and the Canadian Pediatric Surgical Network. CAPSNET: The Canadian Pediatric Surgical Network. Presented at the Pan-African Pediatric Surgical Association Meeting; Ghana, Africa: August 14-22, 2008.
- Laberge JM and the Canadian Pediatric Surgery Network. Contemporary outcome of CDH: Results from the Canadian Pediatric Surgery Network (CAPSNet). Presented at the International Fetal Medical and Surgical Society (IFMSS), Athens, Greece, September 11-14, 2008.
- Boutros J, Regier M, Skarsgard ED and the Canadian Pediatric Surgery Network. Is timing everything? The influence of gestational age and intended and actual route of delivery on treatment & outcome in Gastroschisis. Presented at the 2008 Annual Meeting of the Canadian Association of Pediatric Surgeons. Toronto, Canada, September 2008.
- Grushka JR, Laberge JM, Puligandla P, Skarsgard ED and the Canadian Pediatric Surgery
   Network. The effect of hospital case volume on outcome in Congenital Diaphragmatic Hernia.
   Presented at the 2008 Annual Meeting of the Canadian Association of Pediatric Surgeons.
   Toronto, Canada, September 2008.

- Baird R, MacNab YC, Skarsgard ED, and the Canadian Pediatric Surgery Network. Mortality prediction in congenital diaphragmatic hernia. Presented at the 2007 Annual Canadian Association of Pediatric Surgeons Meeting; St. John's, Newfoundland. Aug 25, 2007.
- Skarsgard ED, Claydon J, Bouchard S, Kim P, Lee SK, Laberge JM, McMillan D, von Dadelszen P,
   Yanchar N and the Canadian Pediatric Surgery Network. Canadian Pediatric Surgical Network: a population-based pediatric surgery network and database for analyzing surgical birth defects:
   The first 100 cases of gastroschisis. Presented at the 38<sup>th</sup> Annual Meeting of the American Pediatric Surgical Association. May 2007. Also presented at the 26<sup>th</sup> Annual Meeting of the International Fetal Medicine and Surgery Society. Apr 30, 2007, Aruba.
- Pressey TP, Skarsgard ED, Claydon J, von Dadelszen P and the Canadian Pediatric Surgery Network. Ultrasound Predictors of Outcome in Antenatally Diagnosed Gastroschisis. Presented at the 26<sup>th</sup> Annual Meeting of the International Fetal Medicine and Surgery Society. Apr 30, 2007, Aruba.
- Weinsheimer RL, Yanchar NL, Bouchard S, Kim P, Laberge JM, Skarsgard ED, Lee SK, McMillan D, von Dadelszen P, and the Canadian Pediatric Surgery Network. Gastroschisis Closure – Does Method Really Matter? Presented at the 2007 Annual Canadian Association of Pediatric Surgeons Meeting; St. John's, Newfoundland. Aug 25, 2007.



Weinsheimer RL, Yanchar NL and the Canadian Pediatric Surgical Network. Impact of Maternal Substance Abuse and Smoking on Children with Gastroschisis. Presented at the 2007 Annual Canadian Association of Pediatric Surgeons Meeting; St. John's, Newfoundland. Aug 25, 2007.

# **ADDITIONAL ONGOING PROJECTS**

Dr. Ravi Bhargava, Dr Radha Chari, and Dr. Gordon Lees: Predication of outcome of fetal CDH by lung to liver signal intensity ratios by fetal MRI.

Dr. Melanie Morris, Dr. Yasser AlFraih, and Dr. Richard Keijzer: Where do Chest Tubes fit into the Management of Congenital Diaphragmatic Hernias?

Dr. Claudia Emami, Dr. Faoud Youssef, Dr. Pramod Puligandla, and Dr. Robert Baird: A comparison of the "sutureless" and traditional fascial closure techniques on the in-hospital outcomes of infants with gastroschisis.

Dr. Sherif Emil, Dr. Claudia Emami, and Dr. Fouad Youssef: Do practice patterns affect gastroschisis outcomes? An international comparison.

Dr. Priscilla Chiu, Dr. Taylor Petropoulos, Dr. Mary Brindle, and Dr. Sharifa Himidan: Gastroesophageal reflux management among CDH infants in Canada - a CAPSNet analysis of surgical vs medical therapies.

Dr. Alya Al-Kaff, Dr. Nancy Kent, Dr. Jason Burrows, Dr. Jennifer Hutcheon, and Dr. Erik Skarsgard. The Impact of Delivery Planning on Neonatal Outcome for Fetuses with Gastroschisis.

Dr. Erik Skarsgard and Dr. Catherine Beaumier: Clinical characteristics and outcomes of patients with right congenital diaphragmatic hernia: A Population-based Study.

Dr. Robert Baird, Dr. Jean Martin Laberge, Dr. Fouad Youssef: The Correlation Between the Time Spent in Utero and the Severity of Bowel Matting in Newborns with Gastroschisis.

