

The Canadian Pediatric Surgery Network



Le Réseau Canadien de Chirurgie Pédiatrique



2008 Network Report

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ACKNOWLEDGEMENTS

In the past year, use of the CAPSNet database has expanded greatly and we acknowledge all those that have contributed and utilized the database to answer important questions pertaining to the treatment and outcomes of Gastroschisis and Congenital Diaphragmatic Hernia patients. In particular we would like to acknowledge each of our Data Abstractors, whose attention to detail and high quality work serves as the foundation for the database. 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). We acknowledge the ongoing financial contributions of both the Canadian Institutes of Health Research (CIHR) and the Canadian Association of Pediatric Surgeons (CAPS). And finally, we acknowledge the Canadian Neonatal Network (CNN) as a partner in our endeavors.

Many thanks also to the work of Ms. Daisy Robson and Ms. Jennifer Claydon in compiling this report.

Participating CAPSNet Sites for the 2008 Report:

Victoria General Hospital, Victoria, BC

Children's and Women's Health Centre of British Columbia, Vancouver, BC

Alberta Children's Hospital, Calgary, AB

Stollery Children's 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: Mt. 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, NF

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Dr. P. von Dadelszen, University of British Columbia, Vancouver

Dr. N. Yanchar, IWK Health Centre, Halifax

INTRODUCTION & OBJECTIVES OF THE NETWORK

The **CA**nadian **P**ediatric **S**urgery **N**etwork (CAPSNet) is a multi-disciplinary group of Canadian health researchers working together on research issues concerning pediatric surgical care. To date there are 26 network members of which the majority are clinically active pediatric surgeons. Network membership spans the perinatal disciplines including: neonatology, perinatology, and medical genetics. Financial support of CAPSNet's initial project: "Establishing best perinatal practices for Gastroschisis and Congenital Diaphragmatic Hernia" has been provided by a grant from the Canadian Institutes of Health Research (CIHR).

The main objectives of the network are to:

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

Population Definition

The CAPSNet database captures:

- A) 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

- B) 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.

Data presented in this report includes data on all eligible patients either referred antenatally or born on or after May 1st, 2005 and discharged from hospital prior to May 1st, 2008. Data presented in the following pages of this report include primarily aggregate level data.



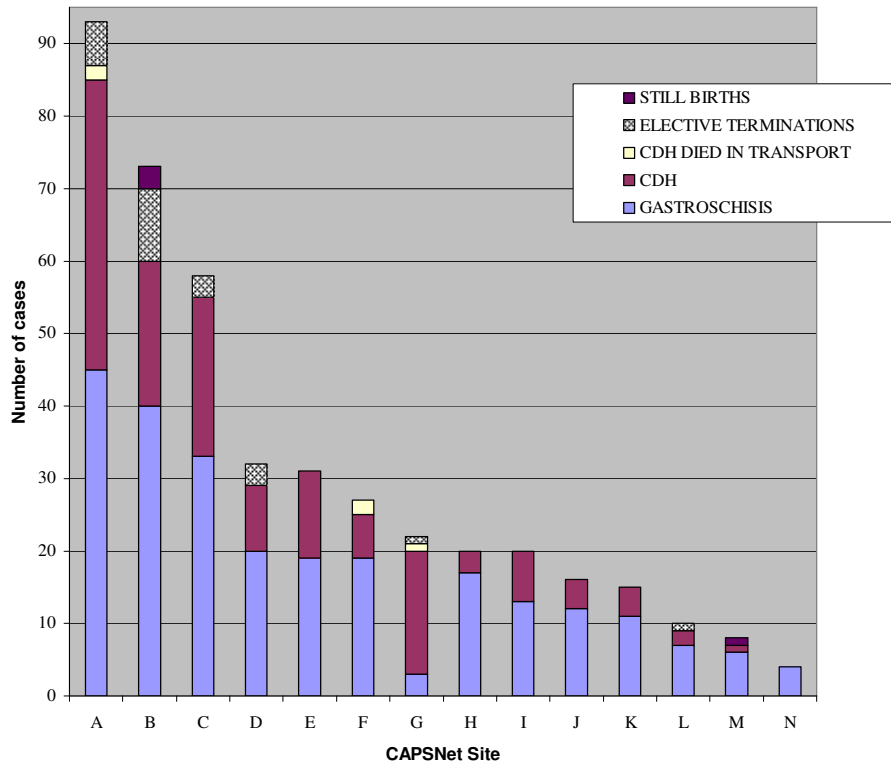
SUMMARY OF DATA BY DIAGNOSIS AND BIRTH OUTCOME

Gastroschisis (GS)		Congenital Diaphragmatic Hernia (CDH)	
Complete live births (N)	249	Complete live births (N)	147
Incomplete live births†	35	Incomplete live births†	13
Died in Transport*	0	Died in Transport*	6
Elective Terminations	5 (1.7%)	Elective Terminations	20 (10.4%)
Still-Births	2	Still-Births	2
Unknown Outcome	8	Unknown Outcome	4
Total Case Incidence	299	Total Case Incidence	192

† Represents cases for which there are known live-births, but the infant was still in hospital as of May 31st, 2008. Only completed cases where patients have been fully discharged from hospital have been included in this report (N).

* Represents postnatally diagnosed live-births, where the infant was born at a community hospital and did not survive postnatal transfer to the CAPSNet tertiary pediatric centre.

Figure A: Distribution of Cases by Centre





SECTION I: GASTROSCHISIS - Descriptive Analyses -

Table 1: Patient Population

Gastroschisis N= 249	
Overall Survival rate (%)	96 %
Inborn rate (%)	69.5 %
Mean Birth Weight (g)	2556 g
Proportion of Males (%)	54.6 %
Proportion of Males with Undescended Testis/Testes (%)	15.4 %
Isolated Defect (%)	70 %
<i>Mean SNAP Scores</i>	
Survivors	8.6
Non-Survivors	23.0

Figure 1.1: Gestational age at birth (in complete weeks)

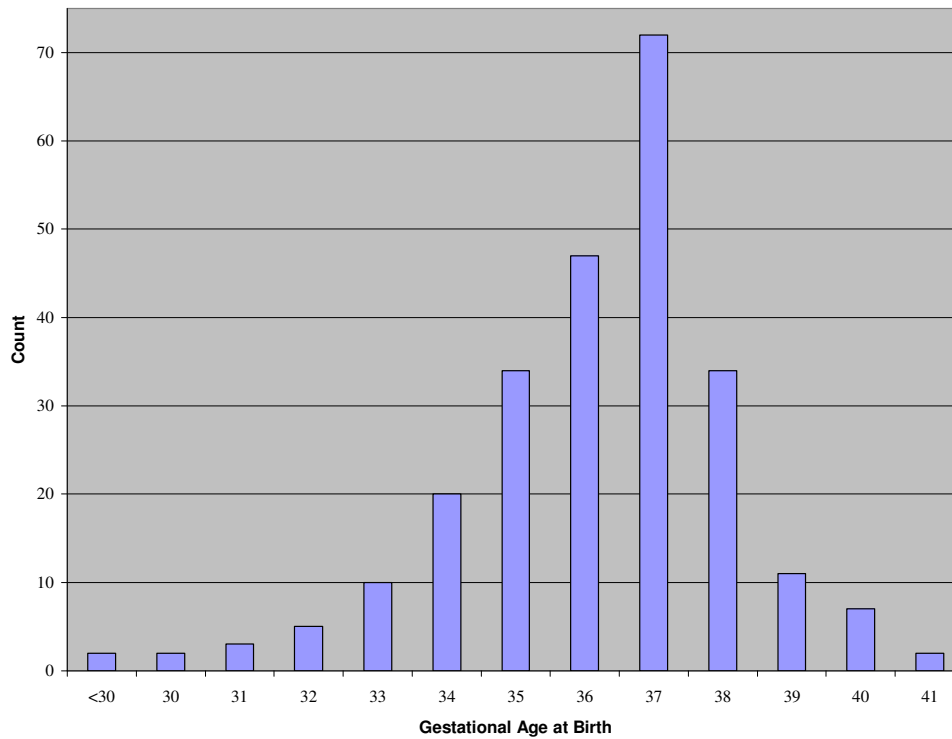
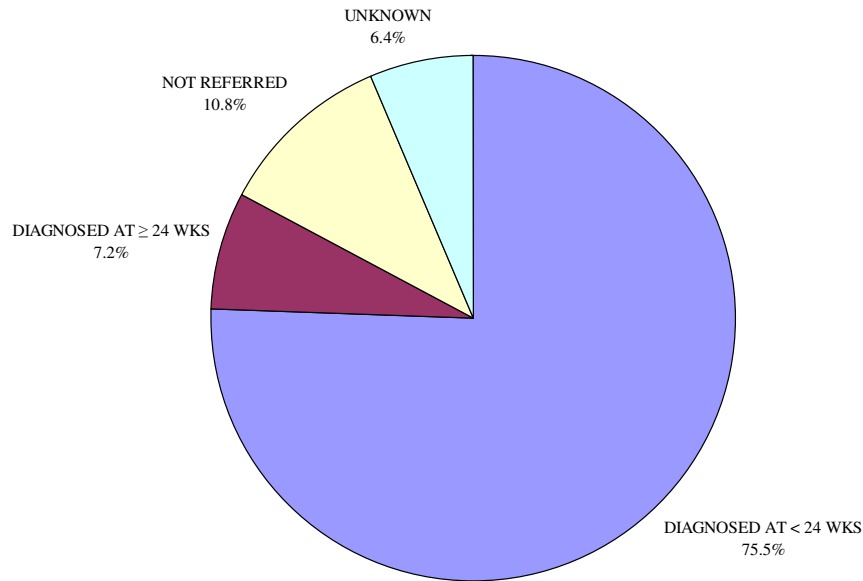


Figure 1.2: Early vs. late antenatal diagnosis

Graph shows percentage of cases that were diagnosed: antenatally before 24 weeks (75.5%); antenatally at 24 weeks or greater (7.2%); and cases not referred to a tertiary CAPSNet centre that were first diagnosed postnatally (10.8%).



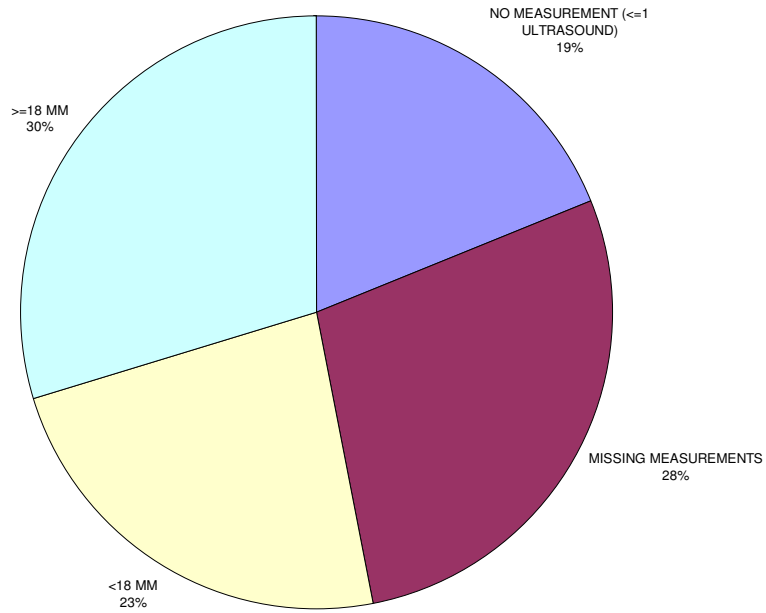
ULTRASOUND MEASUREMENTS (Figures 1.3 & 1.4)

Bowel dilation and bowel wall thickness measurements were recorded on up to four ultrasounds taken at varying time points:

- (i) first ultrasound taken at the tertiary CAPSNet centre
- (ii) last ultrasound taken between 23+0 and 31+6 weeks;
- (iii) last ultrasound taken between 32+0 and 34+6 weeks, and
- (iv) last ultrasound before delivery.

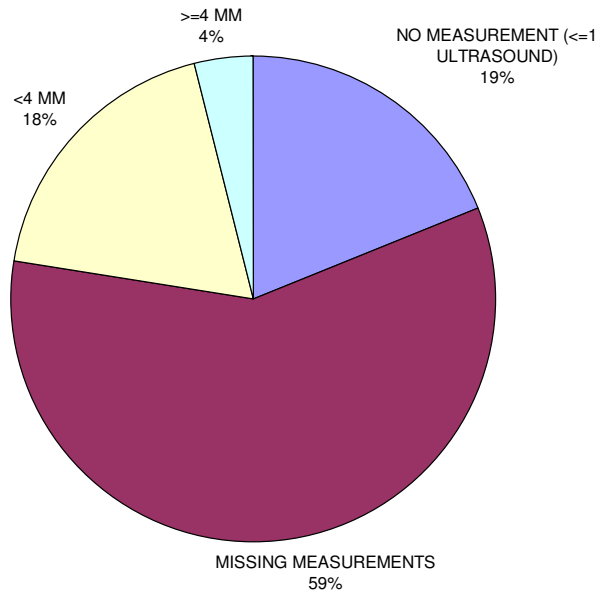
The data presented here reflects the worst (i.e. greatest) measurement reported on any one of the above measured ultrasounds. Where there was no measurement due to the infrequency of antenatal ultrasounds (i.e. one or fewer) this has been reported separately.

Figure 1.3: Maximum bowel dilation reported on antenatal ultrasound



47% of cases had no bowel dilation measurement done.

Figure 1.4: Bowel wall thickening reported on antenatal ultrasound



78% of cases had no bowel wall thickness measurement done.

Figure 1.5: Mode of Delivery

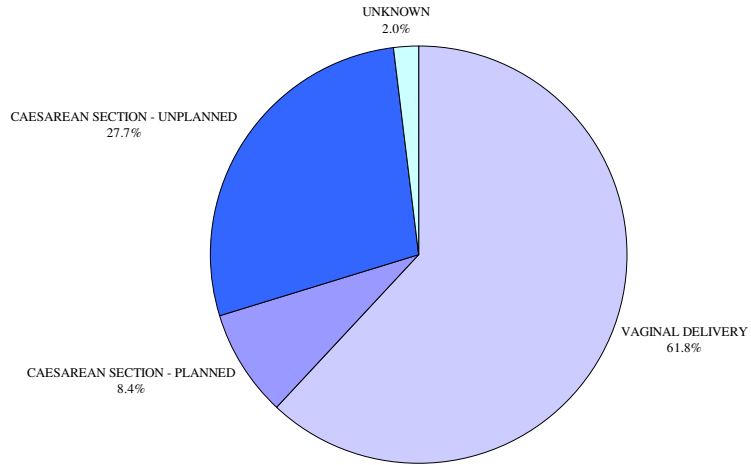


Figure 1.6: Antenatal plan for delivery

Delivery plan as of 32 weeks	N	%
No pre-determined plan	59	23.7 %
Spontaneous Vaginal Delivery	71	28.5 %
Elective Caesarean Section	25	10.0 %
Induction	77	30.9 %
Other	1	0.4 %
Unknown	16	6.4 %

Figure 1.7A: Types of pre-operative bowel protection

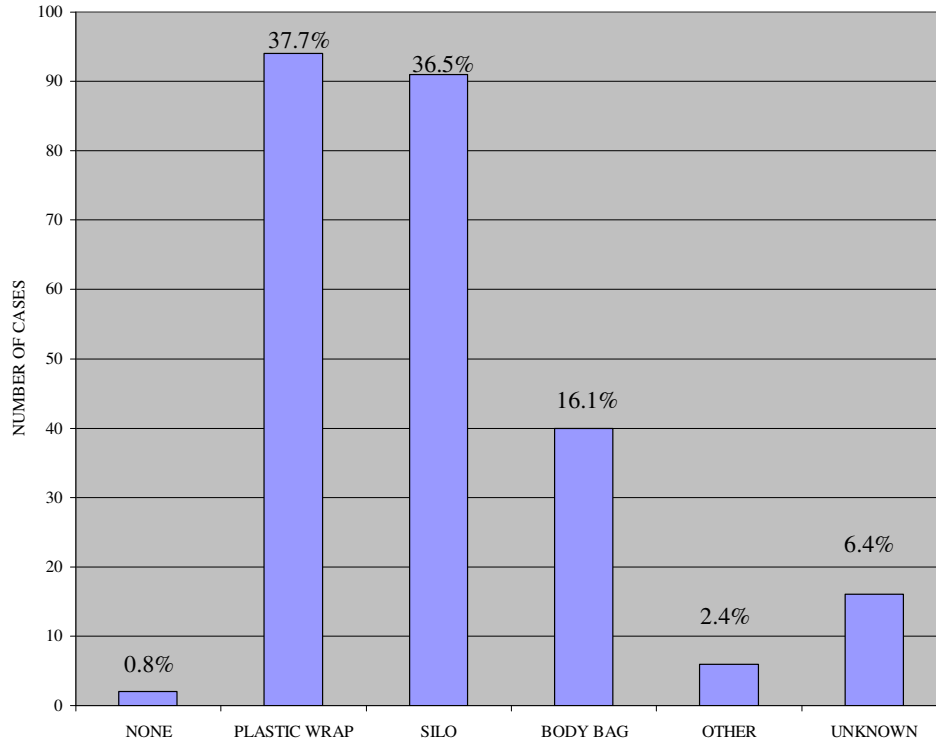


Figure 1.7B: Timing of pre-operative bowel protection

Reports the time since birth to initial placement of bowel protection

Timing of pre-operative bowel protection	N	%
<= 1 hr	160	64.3 %
1-4 hrs	44	17.7 %
> 4 hrs	25	10.0 %
Unknown	18	7.2 %
No bowel protection	2	0.8 %

Figure 1.8A: Timing of Gastroschisis closure

Timing of closure refers to the time since birth to the first attempted surgical closure of the defect.

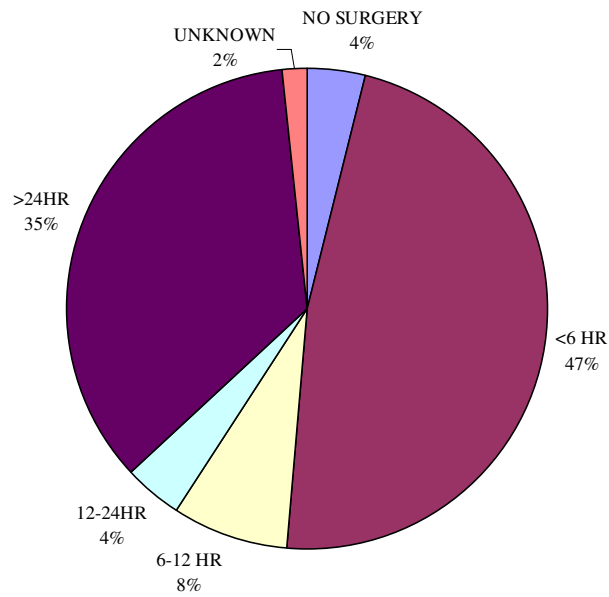


Figure 1.8B: Surgeon's Treatment Intent

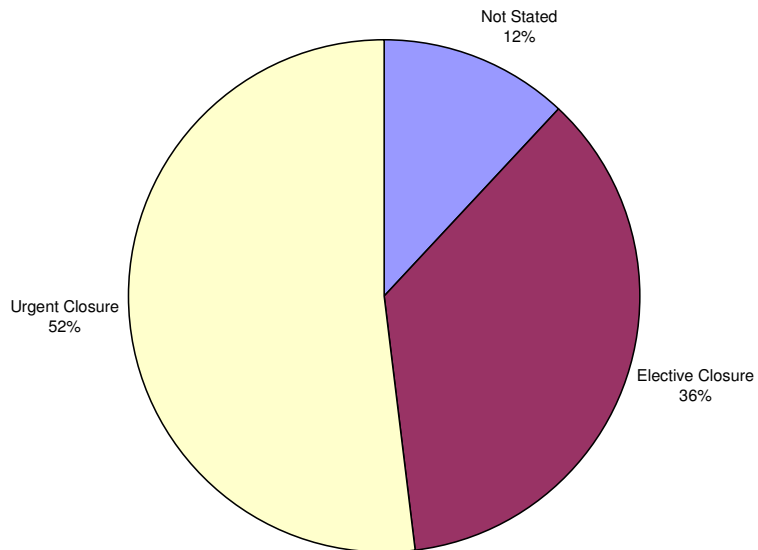


Figure 1.9A: Method of surgical closure

The denominator in the following two figures includes only those cases in which surgery was performed (ie. N=239).

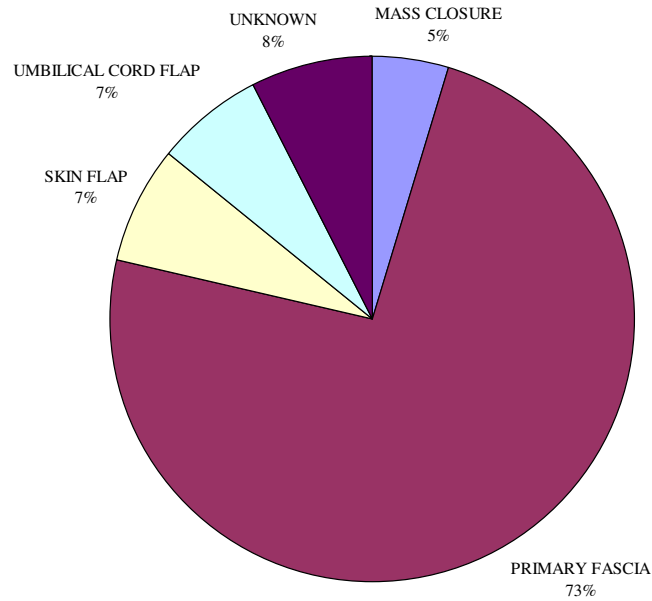


Figure 1.9B: Operative Success

Of 239 primary operations, 85% were recorded as successful. 15% were reported as failed initial closures for the following reasons:

Reasons for Failed Surgery	N	%
Bowel not reducible	26	70.3%
Bowel would reduce, but IPP or PIP too high to close abdomen (or seemed to tight to close – if IPP not measured)	11	29.7%

Figure 1.10: Proportion and Severity of Bowel Injury

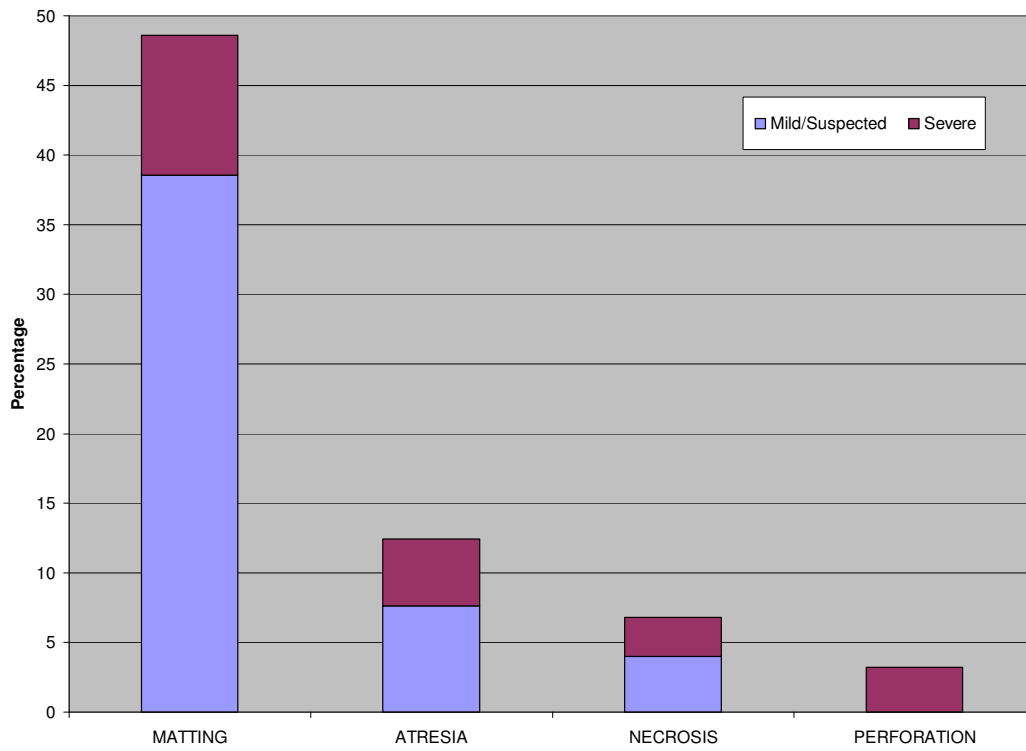


Figure 1.11: Selected Neonatal Complications

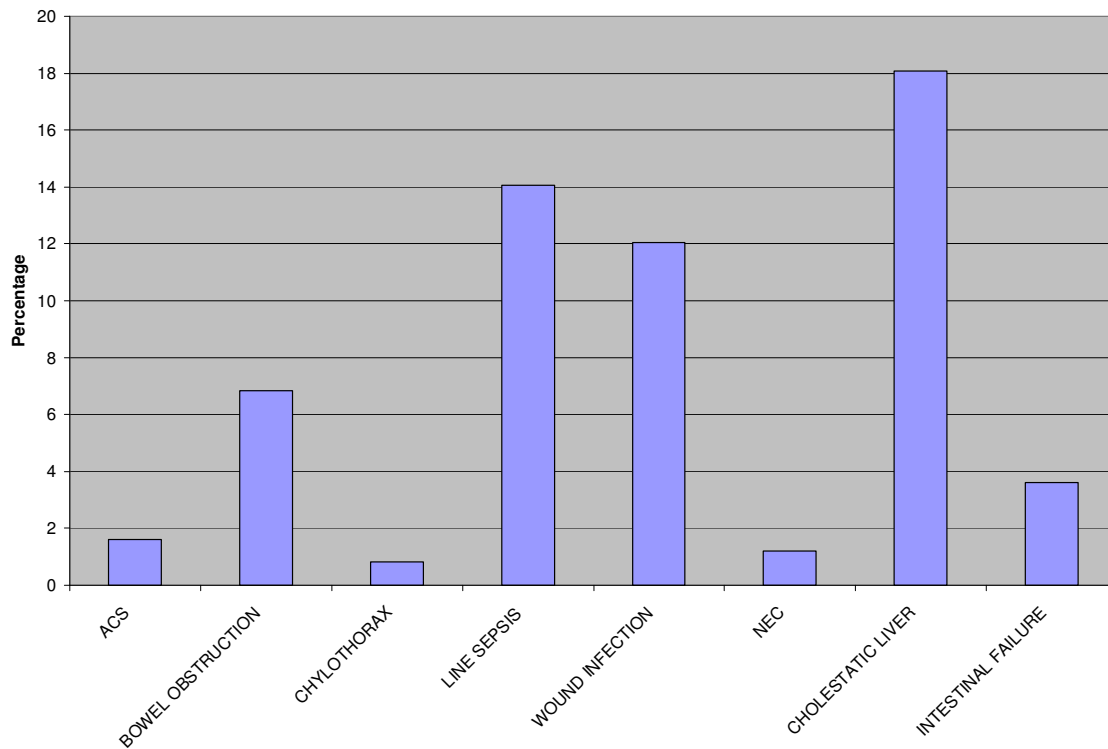
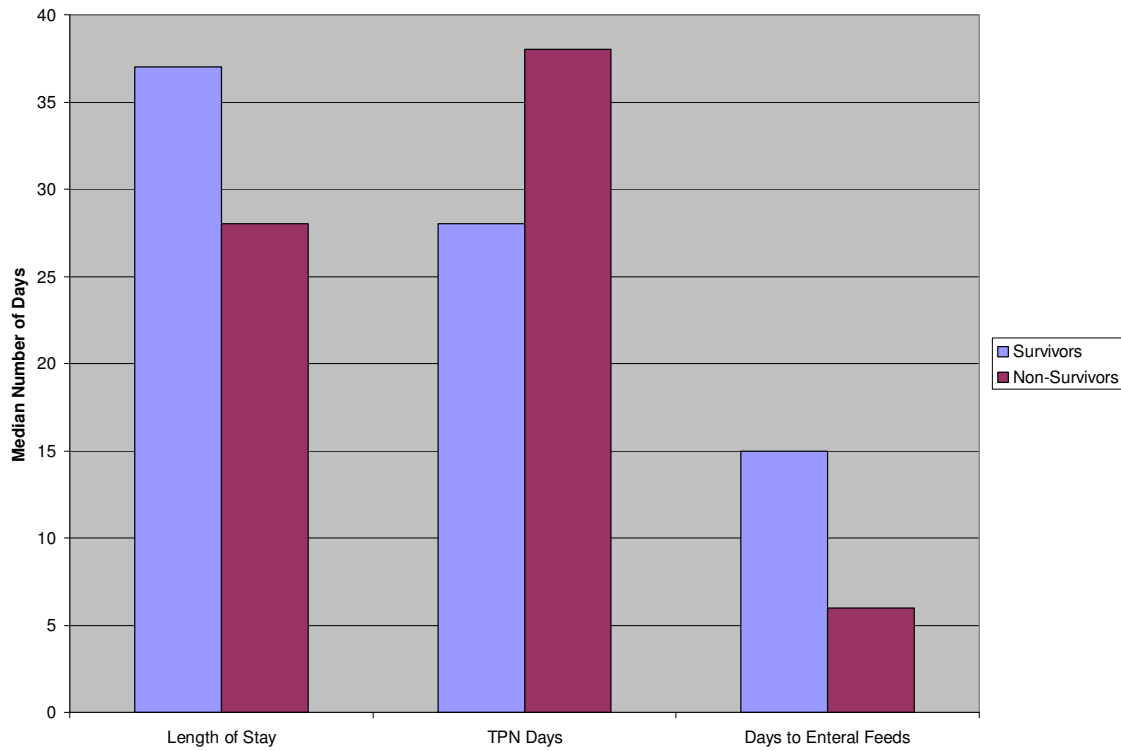


Figure 1.12: Neonatal outcomes: Median length of stay, Total TPN days and Days to initiation of enteral feeds



	Survivors (N=239)			Non-Survivors (N=10)		
	Median	Mean	Range	Median	Mean	Range
Length of Stay (days)	37	49.1	1-349	28	64.0	2-272
TPN Days	28	36.9	5-221	38	50.6	8-172
Days to Enteral Feeds	15	17.4	3-78	6	8.3	2-17



SECTION II: CONGENITAL DIAPHRAGMATIC HERNIA - Descriptive Analyses –

Table 2: Patient Population

Congenital Diaphragmatic Hernia N= 147	
Overall Survival rate (%)	81.6 %
Inborn rate (%)	41.5 %
Mean Birth Weight	3053 g
Proportion of Males (%)	57.8 %
Isolated Defect (%)	51.7 %
Proportion requiring ECMO (%)	7.5 %
Proportion with Left sided Defect (%)	69.4 %
<i>Mean SNAP Scores</i>	
Survivors	13.4
Non-Survivors	29.3

Figure 2.1: Gestational age at birth (in complete weeks)

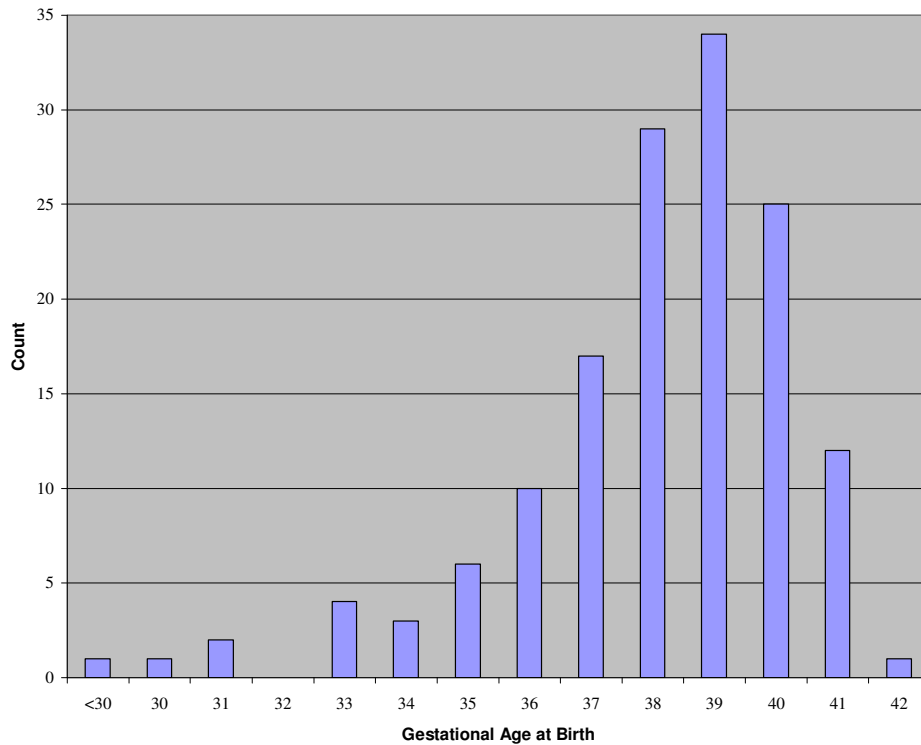
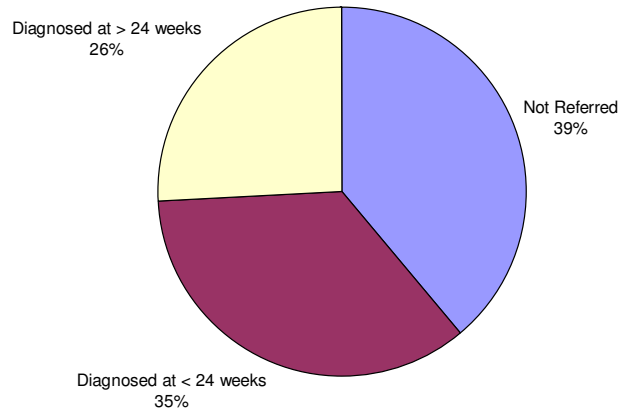


Figure 2.2: Early vs. late antenatal diagnosis

Graph showing percentage of cases that were diagnosed: antenatally before 24 weeks (35%); antenatally at 24 weeks or greater (26%); and those not referred to a tertiary CAPSNet centre and first diagnosed postnatally (39%).



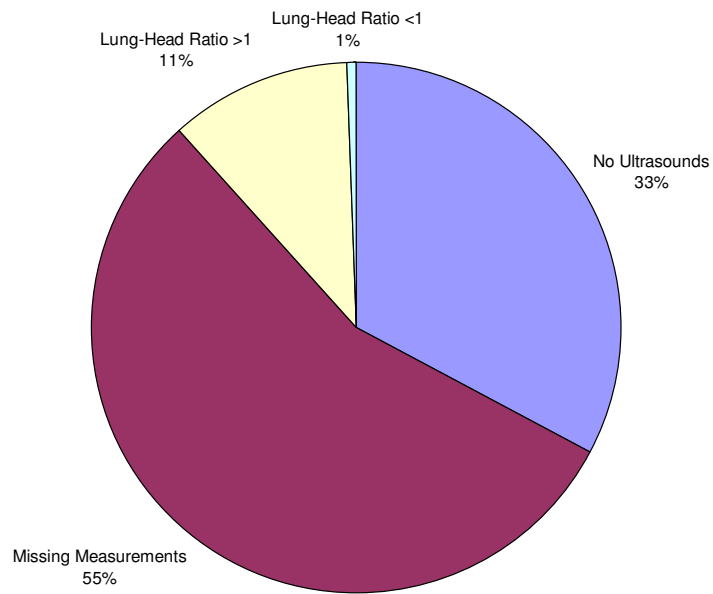
ULTRASOUND MEASUREMENTS (Figure 2.3)

Measurements are recorded on up to four ultrasounds taken at varying time points:

- (i) first ultrasound taken at the tertiary CAPSNet centre
- (ii) first ultrasound taken between 23+0 and 27+6 weeks;
- (iii) first ultrasound taken between 28+0 and 32+6 weeks, and
- (iv) last ultrasound before delivery.

The data presented here reflects the worst (i.e. greatest) lung to head ratio reported on any one of the above measured ultrasounds. Where there was no measurement due to a lack of antenatal ultrasounds this has been reported separately.

Figure 2.3: Maximum lung-head ratio reported on antenatal ultrasound



88% of cases had no lung to head ratio measured.

Figure 2.4: Mean days to surgical repair by site

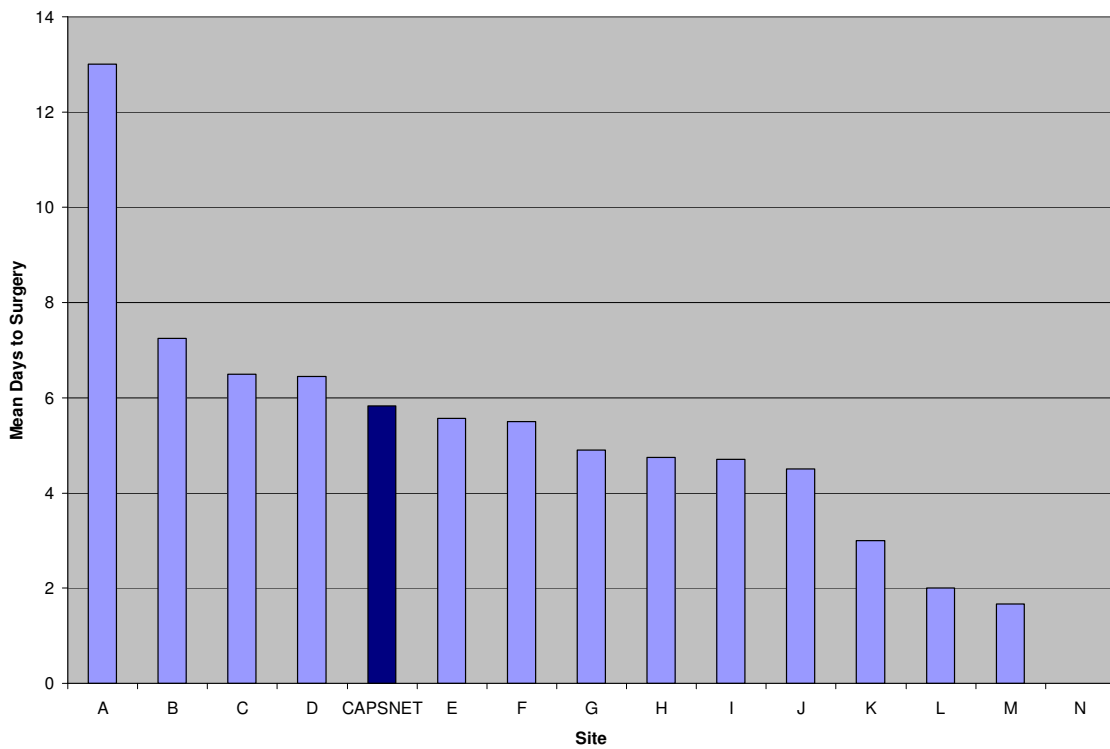


Figure 2.5: Method of surgical closure

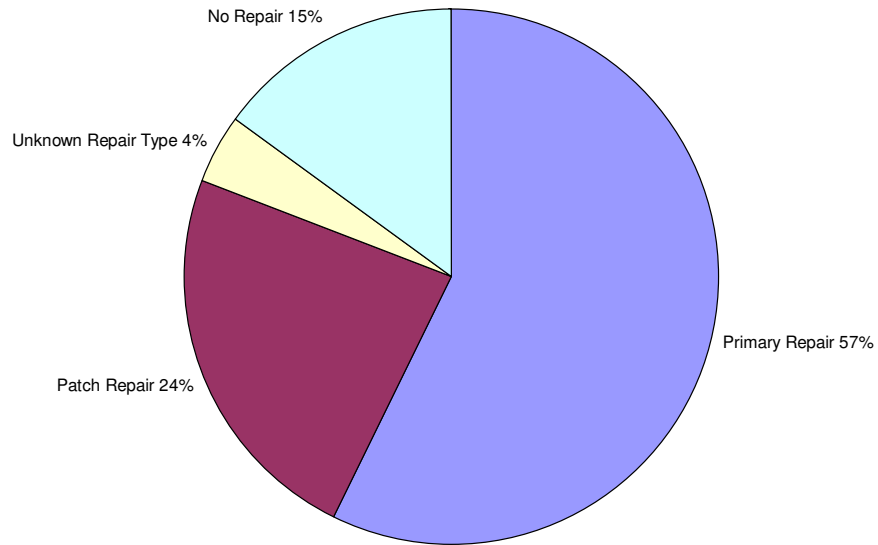


Figure 2.6: Timing and type of chest tube

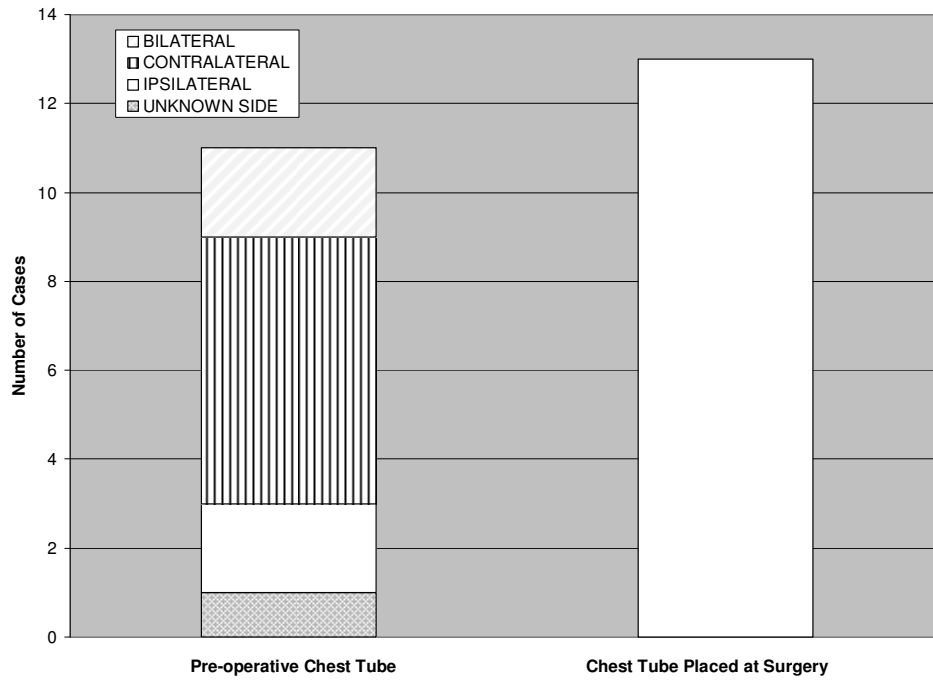


Figure 2.7: Selected Neonatal Complications

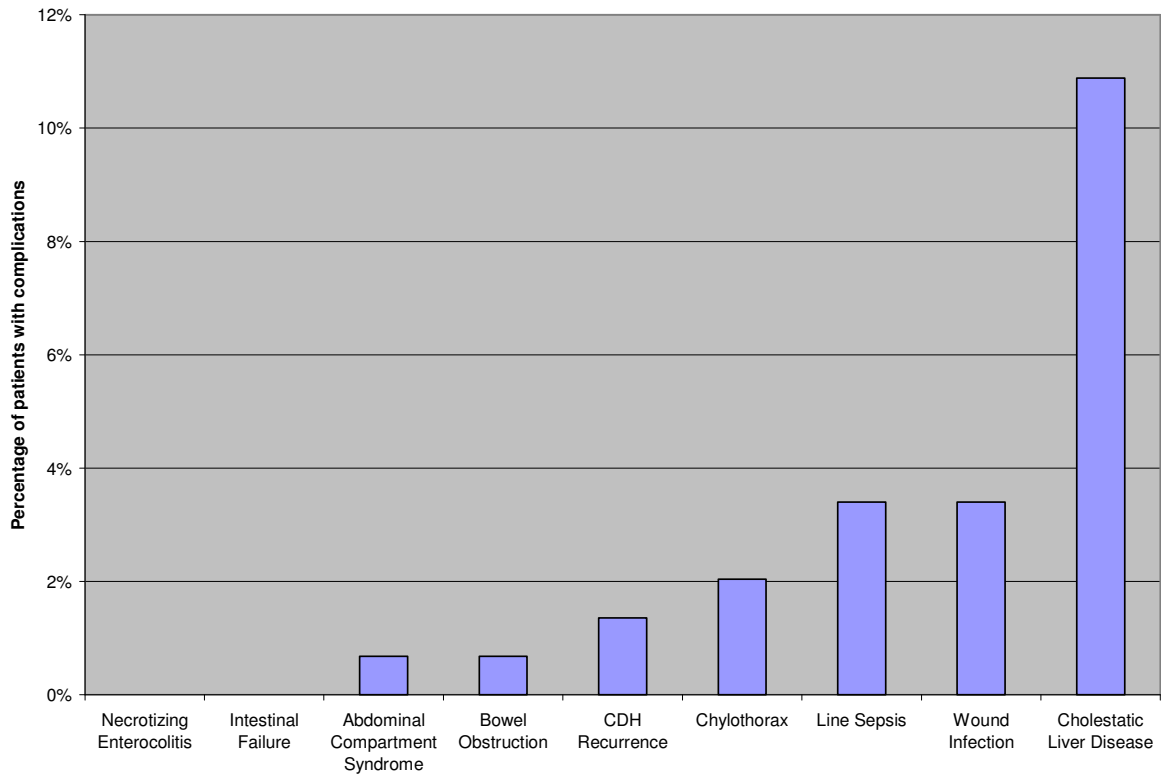


Figure 2.8: Neonatal Outcomes

	Survivors (N=120)			Non-Survivors (N=27)		
	Median	Mean	Range	Median	Mean	Range
Length of Stay (days)	27	36	2 - 148	11	22	1 - 125
ECMO days (if required)	11	10.2	2 - 23	15	16.5	4 - 29
Ventilation days	8.5	11.8	0 - 83	9	19.2	1 - 86
Supplemental O2 days	2	6	0 - 115	0	0.9	0 - 18
TPN Days	15	19	5 - 68	14	20	2 - 46
Days to Enteral Feeds	8	10	2 - 30	20	21	12 - 30
Tube feeds @ discharge (number/%)	38 patients (31.66 %)			n/a		
GER @ discharge (number/%)	36 patients (30.0 %)			n/a		
CNS injury @ discharge (number/%)	0 patients (0.0 %)			n/a		

APPENDIX I: DEFINITIONS

SNAP (Score for Neonatal Acute Physiology): is 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.

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).

CDH Lung-Head Ratio: refers to the maximum recorded lung to head ratio measured from a transverse axial image through the chest demonstrating the four-chamber view of the heart with associated shift to the contralateral side. The contralateral lung is observed and the longest diameter measured (in millimeters). A line perpendicular to the first is then drawn and measured again in millimeters (mm).

**APPENDIX II: CONFERENCE PRESENTATIONS AND ANCILLARY PROJECTS
(Updated August 1, 2008)**

Primary Author	Short Title of Project	Date Request Granted	Proposed Time-line	Publications/Presentations
Erik Skarsgard Steering Committee	A population based pediatric surgical network and database		2007 APSA Meeting	-Presented at APSA (May '07) -Published J. Pediatr Surg (2008) 43, 30-34.
Rob Baird Erik Skarsgard	Outcome Predictors in CDH	Jan 30, 2007	2007 CAPS Meeting abstract deadline: Mar 24, 2007	-Presented at CAPS (Aug '07) -Published J. Pediatr Surg (May 2008)
Rob Weinsheimer Natalie Yanchar	Closing Gastroschisis – Does method really matter?	Feb 27, 2007	2007 CAPS Meeting abstract deadline: Mar 24, 2007	-Presented at CAPS (Aug '07) -Published J. Pediatr Surg (May 2008) -Submitted to PAPS (June '08)
Rob Weinsheimer Natalie Yanchar	Maternal Smoking and Complicate Gastroschisis	Feb 27, 2007	2007 CAPS Meeting abstract deadline: Mar 24, 2007	-Presented at CAPS (Aug '07) -Published J. Pediatr Surg (May 2008)
Tracy Pressey Peter von Dadelszen Erik Skarsgard	Ultrasound predictors of outcome in antenatally diagnosed Gastroschisis	Mar 7, 2007 Jan 30, 2008 (updated #s)	2007 IFMSS Meeting abstract deadline: Mar 16, 2007 2008 ISPD Meeting abstract deadline: Feb 11, 2008	-Presented at IFMSS (Apr '07) -Updated presentation ISPD meeting, Vancouver (June '08) Manuscript in press Prenatal Diagnosis
Pramod Puligandla Jean-Martin Laberge	Can the Gastroschisis bowel score prognosticate outcomes?	Jul 3, 2007 Feb 7, 2008 (updated #s)	2008 AAP–not accepted Plan to resubmit to SUS or APSA 09	
Jessica Mills Erik Skarsgard	Does overnight birth affect outcomes in Gastroschisis?	Aug 1, 2007	2008 PCS Meeting abstract deadline Sept 4, 2007	-Presented PCS (Feb '08)- manuscript rejected (Arch Surg) Revised numbers manuscript under preparation
Jessica Mills Erik Skarsgard	Does overnight birth affect outcomes in CDH?	Aug 1, 2007 Jan 15, 2008 (updated #s- CDH)	2008 CAPS	-rejected by CAPS 08 -updated numbers -manuscript in preparation
Mary Brindle Natalie Yanchar	Does overnight birth affect outcomes in Gastroschisis?	Aug 1, 2007	2008 PAS/SPR (updated numbers)	-Accepted PAS/SPR (poster). –presented by Brindle (Honolulu-May/08)
John Boutros Erik Skarsgard	Impact of mode and timing of delivery on outcome in gastroschisis	Jan 2008	2008 CAPS	-accepted by CAPS (podium)
Jeremy Grushka Jean-Martin Laberge	Impact of centre volume on CDH mortality	Jan 2008	2008 CAPS	-accepted by CAPS (podium)
Jean-Martin Laberge	CAPSNet CDH outcomes	May 2008	2008 IFMSS	-accepted by IFMSS (podium)
Mary Brindle	Effect of blood gas target values on survival in CDH	Jan 29, 2008	2009 APSA Meeting (May) – abstract deadline: Oct 2008	**update numbers again in August??
Rebecca Sherlock Phillipe Chessex Erik Skarsgard	Effect of TPN photoprotection on cholestasis in gastroschisis	Mar 2008	2009 PAS/SPR meeting	

Jeremy Grushka Jean-Martin Laberge	The influence of prenatal diagnosis of CDH on outcome	Denied (Oct 3, 2007)	2008 APSA Meeting (May) – abstract deadline: Oct 15, 2007	n/a
Saleh Alabbad Jean-Martin Laberge	Does CDH patch repair correlate with outcomes	Denied (Oct 3, 2007)	2008 APSA Meeting (May) – abstract deadline: Oct 15, 2007	n/a
Erik Skarsgard	Inter-observer variation in GBS	May 2008		