

# Canadian Neonatal Follow-Up Network Réseau Canadien de Suivi Néonatal



## CNFUN Annual Report 2018

## **Introduction**

The Canadian Neonatal Follow-Up Network (CNFUN) is a collaboration between Neonatal and Perinatal Follow-Up Programs in Canada and their multidisciplinary team members. It was developed in liaison with the Canadian Neonatal Network (CNN) to facilitate collaboration in research, integrated data collection, knowledge translation and to improve the quality of care and long term outcomes of children seen in their programs.

## **CNFUN's Mission**

CNFUN's mission is to be a network of health care professionals dedicated to improving the care of newborns and children at high risk of adverse outcome as a result of conditions requiring intensive medical care.

## **CNFUN's goals include:**

- Establish a network of Canadian health care professionals involved in neonatal / perinatal follow-up programs
- Develop a common standardised set of assessments to be done at standardised ages and common definitions to create the CNFUN data set.
- Develop a national electronic database of the CNFUN dataset and link it to neonatal and perinatal datasets including the Canadian Neonatal Network
- Use the CNFUN database to improve health care and it's provision by providing accurate up to date information for decision making, identifying best practices and facilitating the acquisition of long term outcomes data in neonatal, perinatal and early intervention research.
- Be advocates for our population of children by ensuring that the best evidence is translated into practice.

## **Administrative Structure**

A Steering Committee oversees CNFUN activities and makes policy decisions. Site representatives from participating institutions provide representation, input and liaison for participating institutions.

The Steering Committee was appointed for the first 5 years and has been elected every 2 years since. It is to be composed of 9 members:

- The director of the network
- 5 members representing different geographic regions of Canada. In the upcoming 2019 elections, one of these members will be elected as a co-director.
- 3 members representing allied health professionals in the fields of nursing, psychology, occupational or physiotherapy or speech and language. One of these professionals must be trained in the Bayley-III.

The Network Coordinating Centre will provide administrative support to CNFUN, its committees and institutional and individual members.

## Membership

Membership is open to all health care professionals with an interest in neonatal/perinatal follow-up. There are two types of membership – institutional and individual.

Institutional Membership is open to all institutions which have a neonatal or perinatal follow-up program.

- **Application:** to be submitted to the Chair of the Steering Committee
- **Membership fee:** none
- **Obligations:** membership requires commitment by the institution to collect and contribute the data to the CNFUN data set. Institutional members agree that their data may be used at the discretion of the network, within guidelines agreed upon between network members.
- **Benefits:** The database will be maintained and error checked by CNFUN and MiCare (Maternal Infant care Network). An institution's own data will be available for its own use. Research projects and resultant manuscripts using network data need to be approved by the Steering Committee.
- **Representation:** The institution will appoint a liaison representative who will represent the institution for policy decisions of the Network. The number of members who can vote for members of the Steering Committee

shall be proportional to the number of participant data submitted to the CNFUN database.

- **Renewal and Termination:** Institutional membership is on-going until terminated by the institution, by written notice to the Chair of the Steering Committee. Membership may also be terminated by the Steering Committee if an institution fails to maintain data contribution to the CNFUN database.

Individual membership: is open to all health care professionals with an interest in neonatal / perinatal follow-up.

- **Application:** should be submitted to the chair of the Steering Committee and should be endorsed by an existing member.
- **Membership fee:** none
- **Obligations:** members agree to abide by the rules governing research conduct and use of the data.
- **Benefits:** Members may use network infrastructure for research collaboration. Research projects using network data must be approved by the Steering Committee.
- **Renewal and termination:** Individual membership will need to be renewed every three years.

## **CNFUN Funding**

CNFUN was initiated with support from the Canadian Institutes of Health Research through a grant to the CIHR Team in Maternal-Infant Care (CTP 87518). The study coordinating centre, the Maternal-Infant Care Research Centre, is supported by program funding from the Ontario Ministry of Health and Long-Term Care.

Current funding is from the CIHR SPOR grant “CHILD-BRIGHT” (Child Health Initiatives Limiting Disability- Brain Research Improving Growth and Health Trajectories) for the “Parent-EPIQ” project and the CIHR Pan-Canadian Network to Improve Outcomes of Preterm Birth.

Participating sites contribute additional funding for patient outcome assessments.

### **CNFUN steering committee**

Dr. Anne Synnes – Neonatologist / neonatal follow-up- founding director (British Columbia)

Dr. Thuy Mai Luu –Neonatal follow-up (Québec)

Dr. Diane Moddemann –Neonatal follow-up (Manitoba)

Dr. Dianne Creighton (retired Aug 2018)- psychologist (Alberta)

Dr. Jill Zwicker- Occupational therapist / researcher (British Columbia)

Dr. Marilyn Ballantyne – Nurse / researcher (Ontario)

Dr. Paige Church –Neonatologist / neonatal follow-up (Ontario)

Dr. Kevin Coughlin-Neonatologist / neonatal follow-up (Ontario)

Dr. Jehier Afifi-Neonatologist / neonatal follow-up (Nova Scotia)

### **Annual report review committee**

Dr. Anne Synnes – Neonatologist, neonatal follow-up- founding director (British Columbia)

Dr. Thuy Mai Luu –Neonatal follow-up (Québec)

Dr. Jehier Afifi-Neonatologist, neonatal follow-up (Nova Scotia)

Dr. Matt Hicks-Neonatologist, neonatal follow-up, epidemiologist (Alberta)

Carolina Segura- CNFUN National Coordinator (British Columbia)

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I. Summary of Publications

## A. Executive summary

As the first CNFUN annual report this marks a new milestone. One of the CNFUN goals is to provide accurate up to date information and to improve health care and long term outcomes. The latter is not possible without measuring outcomes over time. With new funding as part of the parent-EPIQ study this is now possible. We thank the MiCare Coordinating Site for their work in developing and maintaining our database and data analysis. Thank you to the CNFUN annual report working group and our CNFUN coordinator, Carolina Segura.

Standardized neonatal follow-up, especially in a country as geographically large as Canada is very difficult. This report is the result of a long journey made possible by the personal commitment by the site investigators and teams at all of the Canadian Neonatal/Perinatal Follow-Up Programs (NFUPs) across Canada. The results you find in this report required much more than collecting existing data. NFUPs had to change or adapt their infrastructure to accommodate the agreed upon 18 - 21 month corrected age assessment, including identifying one or more trained assessors for the standardized neurodevelopmental evaluation using the Bayley Scales of Infant and Toddler Development 3<sup>rd</sup> edition (Bayley-III). A strategy to identify and recruit all children born preterm at 28 completed weeks' gestation or less has to be in place. The CNFUN database group worked tirelessly to develop the standardized history, physical exam and the data base elements and their definitions which created the CNFUN database and manuals. Thank you to Sonny Yeh at the MiCare Coordinating site for developing and supporting the database. Sites have entered and uploaded all the data, using limited resources, to the web based CNFUN database maintained at the MiCare Coordinating Site. Linkage to the Canadian Neonatal Network required that the NFUPs track down the unique identifier before entering the data. The CIHR Team in MiCare grant provided partial funding to sites to participate for the "MiCare" cohort born April 1, 2009 to September 30, 2011. NFUP sites received no funding for providing CNFUN data for births October 1, 2011 until approximately April 1, 2016. The cost of data abstraction, but not collection, is now covered by the Parent-EPIQ study.

Most importantly the willingness of the families of children born preterm to attend the NFUP visits made this possible. Families travel on average 100 kilometers to the NFUP



and some travel over 1000 kms! Many of these families come, not just to get excellent clinical care but also to give back to their NICU and to contribute to improving neonatal care. This report recognizes their contribution.

As shown in our results, the journey to improve neurodevelopmental outcomes in our preterm graduates has just started. Evidence based Practice to Improve Quality (EPIQ) has successfully improved short term outcomes in the NICU. The 11 “Parent-EPIQ” intervention sites are committed to demonstrating whether they can do the same for long term outcomes.

In the process of creating this report we have identified some issues with the database which we are working on. As this is our first annual report we welcome feedback and comments.

Anne Synnes MDCM, MHSc, FRCPC

Director, CNFUN

## B. Participating sites

### Presentation No 1

#### i. CNFUN site description

Abbreviation	NFUP Program Name / City	Hospital Site	Site Investigator	Number of CNFUN members
BCWH	Neonatal Follow-Up Program Vancouver	BC Women's Hospital & Health Centre	Anne Synnes	7
VGH/GVS	Neonatal Follow-Up Team Victoria	Victoria General Hospital	Thevanisha Pillay	3
ACH/FMC	Perinatal Follow-up Clinic Calgary	Foothills Hospital University of Calgary	Leonora Hendson	3
EDM	Neonatal and Infant Follow-Up Clinic Edmonton	Glenrose Rehabilitation Hospital	Amber Reichert	3
RQHR	Developmental Assessment Clinic Regina	Regina General Hospital	Zarin Kalapesi, J.P. Bodani	4
RUH	Saskatoon	Royal University Hospital	Sibasis Daspal	2
SBGH	High Risk Newborn Follow-Up Program Winnipeg	St. Boniface General Hospital	Diane Moddemann, Cecilia de Cabo	4
HSCC	High Risk Newborn Follow-Up Program Winnipeg	University of Manitoba Health Sciences Centre / Children's Hospital	Diane Moddemann, Cecilia de Cabo	6
HHSC	Neonatal Follow-Up Clinic Hamilton	McMaster Children's Hospital Hamilton Health Sciences Centre	Saroj Saigal, S el-Helou	1
KGH	Special Infant Clinic Kingston	Kingston General Hospital	Sarah McKnight (new), Kim Dow (retiring)	2

<b>Abbreviation</b>	<b>NFUP Program Name / City</b>	<b>Hospital Site</b>	<b>Site Investigator</b>	<b>Number of CNFUN members</b>
SJHC (LHSC)	Developmental Follow-Up Clinic London	St. Joseph's Health Care London	Kevin Coughlin	1
CHEO/OTTA	Neonatal Follow-Up Clinic Ottawa	Children's Hospital of Eastern Ontario	Thierry Daboval	1
SUNY	Neonatal Follow-Up Program Toronto	Sunnybrook Health Sciences Center	Paige Church	3
HSC	Neonatal Follow-Up Program Toronto	Hospital for Sick Children	Linh Ly	1
MSH	Neonatal Follow-Up Program Toronto	Mount Sinai Hospital	Edmond Kelly	2
WRH	Neonatal Neurodevelopment Follow-Up Program Windsor	Windsor Regional Hospital	Chukwuma Nwaesei	2
CHUS	Clinique de suivi neonatal Sherbrooke	Centre Hopitalier Universitaire de Sherbrooke	Alyssa Morin	2
CHUQ	Centre Hospitalier Universitaire de Quebec (Laval Site)	Centre Mere Enfant Centre Hospitalier de L'Université Laval	Sylvie Bélanger	2
HSJ	Clinique de suivi neonatal Montréal	Universite de Montreal, Hôpital Sainte-Justine	Thuy Mai Luu, V. Dorval	3
JGH	Neonatal Follow-Up Clinic Montréal	Jewish General Hospital	Ermelinda Pelausa, Kim-Anh Nguyen	3
MUHC	Neonatal Follow-Up Program Clinic de Suivi Neonatal Montréal	McGill University Health Centre/ Montreal Children's Hospital/ L'Hôpital de Montréal pour enfants	Marc Beltempo, May Khairy	2

<b>Abbreviation</b>	<b>NFUP Program Name / City</b>	<b>Hospital Site</b>	<b>Site Investigator</b>	<b>Number of CNFUN members</b>
ECH	Fredericton	Dr. Everett Chalmers Hospital	Ramaiyer Krishnaswamy	1
SEHC	Neonatal Follow-Up Clinic Moncton	Moncton Hospital	Roderick Canning	3
SEHC	Neonatal Follow-Up Program Saint John	Saint John Regional Hospital	Luis Monterrosa	2
IWK	Perinatal Follow-Up Program Halifax	IWK Health Centre and Cape Breton Regional Hospital	Jehier Afifi	4
JCHC	High-Risk Follow-Up Clinic St. John's	Janeway Children's Health & Rehabilitation Centre	Phil Murphy	2
HMR	Montréal	Hôpital Maisonneuve-Rosemont	Marie St-Hilaire	1

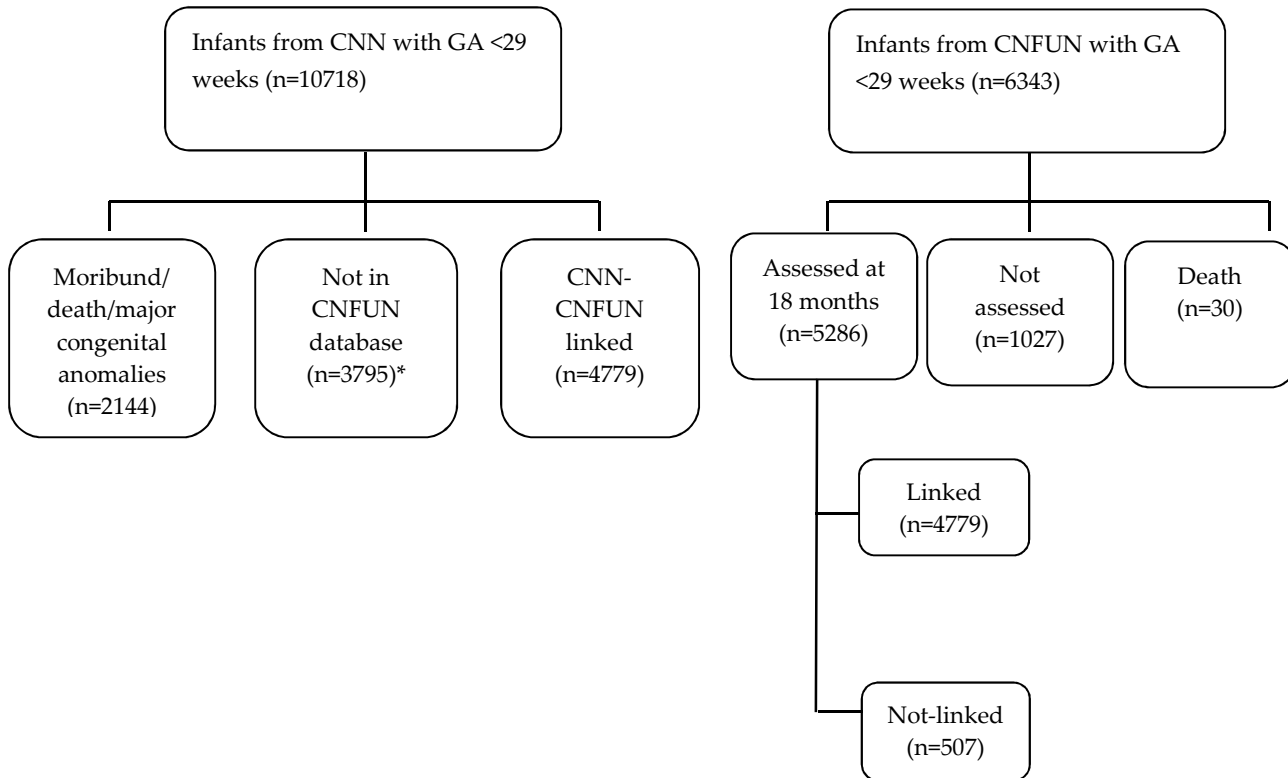
Presentation No 2

ii. CNFUN site participation and follow-up rates

CNFUN Site	MiCare data	MiCare Follow-Up Rate n (%)	Post-MiCare Follow-Up rate- n (%) preliminary	Parent-EPIQ Intervention site Yes/No
	Yes / No			
7	Yes	30/53 (56.6)	14/83 (16.9)	No
1	Yes	170/222 (76.6)	235/343 (68.5)	Yes
6	Yes	213/249 (85.5)	276/487 (56.7)	Yes
5	Yes	205/256 (80.1)	7/484 (1.4)	Yes
18	Yes	43/47 (91.5)	9/74 (12.2)	No
19	Yes	17/66 (25.8)	5/106 (4.7)	No
10	Yes	56/69 (81.2)	70/121 (57.9)	Yes
21	Yes	55/59 (93.2)	81/110 (73.6)	Yes
26	Yes	18/22 (81.8)	24/36 (66.7)	No
17	Yes	64/163 (39.3)	3/250 (1.2)	No
15	Yes	31/51 (60.8)	7/62 (11.3)	No
23	Yes	132/166 (79.5)	60/222 (27)	Yes
9	Yes	53/110 (48.2)	4/117 (3.4)	No
16	Yes	250/301 (83.1)	262/561 (46.7)	Yes
25	Yes	241/308 (78.2)	511/665 (76.8)	No
14	Yes	103/135 (76.3)	161/246 (65.4)	Yes
20	Yes	79/101 (78.2)	115/166 (69.3)	Yes
11	Yes	178/223 (79.8)	229/321 (71.3)	Yes
3	Yes	11/13 (84.6)	9/92 (9.8)	No
2	Yes	115/131 (87.8)	177/233 (76)	No
22	Yes	13/20 (65)	6/44 (13.6)	No
24	Yes	7/13 (53.8)	0/20 (0)	Yes
4	Yes	13/17 (76.5)	7/23 (30.4)	No
12	Yes	84/102 (82.4)	158/194 (81.4)	Yes
13	Yes	21/37 (56.8)	0/68 (0)	No
8	Yes	145/203 (71.4)	2/339 (0.6)	No
27	No	-	-	No

Presentation No 3

iii. CNN and CNFUN flow diagram for births April 1, 2009- Dec 31, 2015



\*Includes infants at CNFUN sites that were not actively recruiting 2012-2015

## C. Outcomes Definitions

Impairments	Significant neurodevelopmental disability = sNDI (Any one or more of the following)*	Neurodevelopmental impairment =NDI (Any one or more of the following)**
<b>Motor</b>	CP with GMFCS 3,4 or 5	CP with GMFCS 1 or higher
	Bayley III Motor Composite <70	Bayley III Motor Composite <85
<b>Cognitive</b>	Bayley III Cognitive Composite <70	Bayley III Cognitive Composite <85
<b>Language</b>	Bayley III Language Composite <70	Bayley III Language Composite <85
<b>Hearing</b>	Hearing aid or cochlear implant	Sensorineural/mixed hearing loss
<b>Vision</b>	Bilateral visual impairment	Uni- or bilateral visual impairment

CP-cerebral palsy defined as per Rosenbaum et al. Dev Med Child Neurol suppl 2007;109:8-14 : “group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.”

Bayley-III- Bayley Scales of Infant and Toddler Development-3rd edition

Hearing impairment- determined from audiology reports

Visual impairment- from ophthalmology report. If no report available, impairment defined as a small scarred eye, sustained sensory nystagmus or lack of response to a 1cm object (cheerio) on a white background at 30 cms.

\*Children who could not be tested using the Bayley-III with a Bayley-III Adaptive Behavior score < 70 or if no Bayley-III score assessed to have a significant developmental delay

\*\*Children with a sNDI or those who could not be tested using the Bayley-III with a Bayley-III Adaptive Behavior score < 85

## D. Descriptive Analyses

### Presentation No 4 Survival and participant assessments

Year of birth	NICU admission (n)	NICU death n (%)	NICU survivors n (%)	Death After NICU (%)	CNFUN data** (n)	Linked CNN-CNFUN data for NICU survivors n (%)**	Known outcome*** for NICU admissions n (%)
2009*	1201	212 (17.7)	881 (73.4)	(0.4)	774	659 (75%)	876 (73%)
2010	1613	244 (15.1)	1335 (82.8)	(0.9)	1123	1014 (76 %)	1272 (79%)
2011	1527	258 (16.9)	1218 (79.8)	(0.3)	935	852 (70 %)	1115 (73%)
2012	1590	251 (15.8)	1288 (81.0)	0 (0)	722	676 (52%)	927 (58%)
2013	1622	256 (15.8)	1307 (80.6)	(0.2)	664	615 (47%)	874 (54%)
2014	1621	232 (14.3)	1319 (81.4)	(0.1)	637	597 (45%)	830 (51%)
2015	1544	201 (13.0)	1256 (81.4)	(0.1)	431	366 (29%)	569 (37%)
'09-'15	10718	1654 (15.4)	8604 (80.3)	30 (0.3)	5286	4779 (56%)	6463 (64%)

n= number

\* April 1 to December 31

\*\* CNFUN number of participants (includes those not linked to CNN)

\*\*\* Death or CNFUN outcomes

#### Comments:

Partial funding by the CIHR team in MiCare for data collection and abstraction was provided for the April 1, 2009 – September 30, 2011 birth cohort. Data collection and participation dropped significantly with no funding. About 10% (507) of patients in the CNFUN database are not able to be linked to CNN.



Presentation No 5  
Follow-up rates

Year of birth	NICU admission n	NICU survivors n (%)	Lost to Follow up n (%)**	Linked CNN-CNFUN data for NICU survivors n (%)	Known outcome*** for NICU admissions n (%)	NICU survivors at participating sites# n	Follow-up rate for participating CNFUN sites n (%)
2009*	1201	881 (73.4)	222	659 (75%)	876 (73%)	881	659 (75%)
2010	1613	1335 (82.8)	321	1014 (76 %)	1272 (79%)	1335	1014 (76%)
2011	1527	1218 (79.8)	366	852 (70 %)	1115 (73%)	1218	852 (70%)
2012	1590	1288 (81.0)	612	676 (52%)	927 (58%)	884	645 (73%)
2013	1622	1307 (80.6)	692	615 (47%)	874 (54%)	933	611 (65%)
2014	1621	1319 (81.4)	722	597 (45%)	830 (51%)	902	589 (65%)
2015	1544	1256 (81.4)	890	366 (29%)	569 (37%)	869	361 (42%)
'09-'15	10718	8604 (80.3)	3825	4779 (56%)	6463 (64%)	7022	4731 (67%)

n= number

\* April 1 to December 31

\*\* Either not known to a CNFUN site or not seen by a CNFUN site

\*\*\* Death or CNFUN outcomes

# After 2012, CHUS, ECH, EDM, GVS, HHSC, HSC, JCHC, KGH, OTTA, RQHR, SEHC, SJRH did not provide data and are excluded

**COMMENTS:**

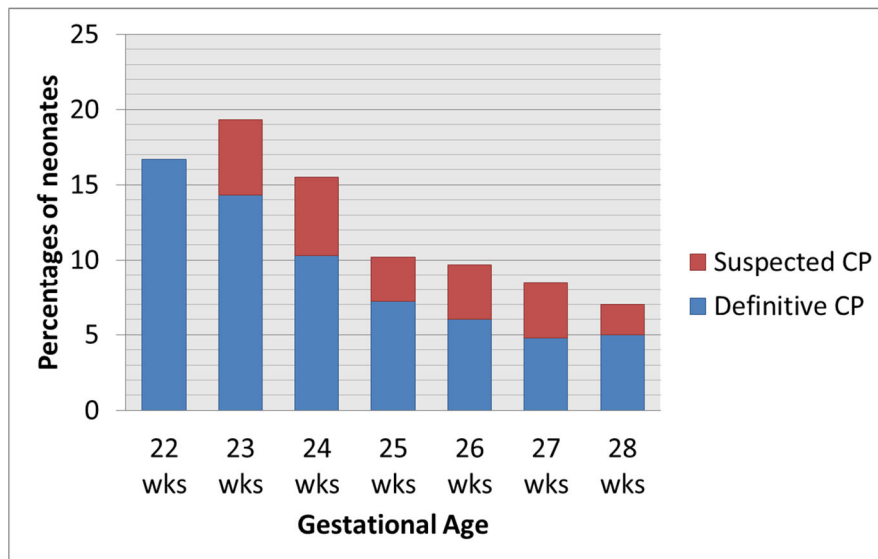
Results from 2015 will be reviewed due to variations in number of participant uploads at local sites and the MiCare coordinating site. Analyses using the MiCare cohort are more reliable than the post-MiCare cohort due to larger attrition bias in the later period.

## E. Gestational Age based Outcomes from CNFUN participating sites

Presentation No 6

Cerebral palsy rates by gestational age (GA)

GA	CNN- CNFUN linked cases or deaths n	Death or definitive CP n (%)	CNN- CNFUN linked cases with CP data for n	Definitive CP n (%)	Missing CP GMFCS	GMFCS ≤2 N (%)	GMFCS 3-5 N (%)	Suspected CP n (%)
22 wks	44	39 (89%)	6	(16.7)	0	(100)	0 (0)	0 (0)
23 wks	396	290 (73%)	119	17 (14.3)	2	9 (60.0)	6 (40.0)	6 (5.0)
24 wks	871	470 (54%)	439	45 (10.3)	4	28 (68.3)	13 (31.7)	23 (5.2)
25 wks	1156	422 (37%)	776	56 (7.2)	4	30 (57.7)	22 (42.3)	23 (3.0)
26 wks	1236	325 (26%)	945	57 (6.0)	6	31 (60.8)	20 (39.2)	35 (3.7)
27 wks	1339	236 (18%)	1134	54 (4.8)	6	30 (62.5)	18 (37.5)	42 (3.7)
28 wks	1421	195 (14%)	1271	63 (5.0)	6	33 (57.9)	24 (42.1)	25 (2.0)
Total	6463	1977 (31%)	4690	293 (6.3)	28	162 (61.3)	103 (38.9)	154 (3.3)



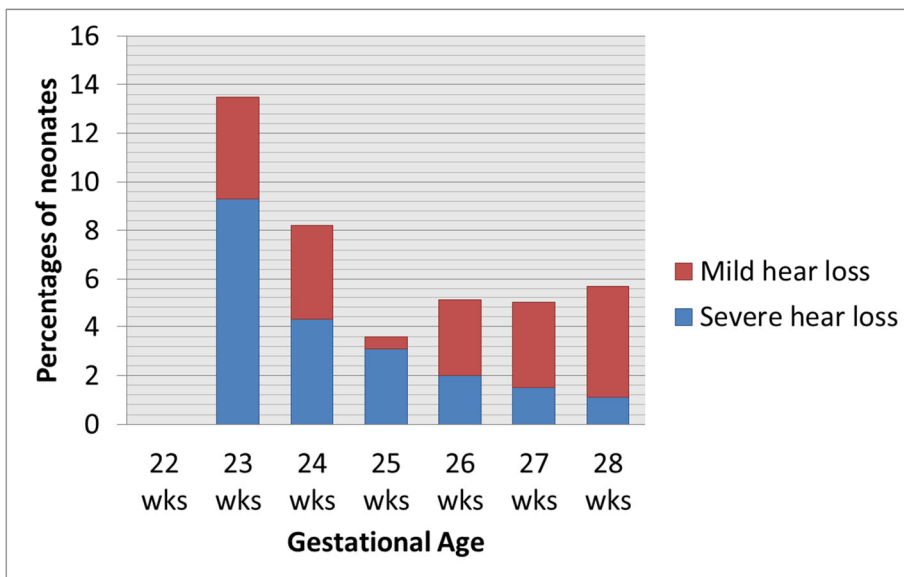
### COMMENTS:

Cerebral palsy rates decrease with increasing gestational age.

Presentation No 7

Hearing impairments rates by gestational Age (GA)

GA	CNN- CNFUN linked cases or deaths n	Death or any hearing impairment n (%)	CNN- CNFUN linked cases with data for hearing	Normal hearing n (%)	Mild hearing impairment n (%)	Severe hearing impairment n (%)
22 wks	44	38 (86%)	6	6 (100)	0 (0)	0 (0)
23 wks	396	289 (73%)	118	102 (86%)	5 (4%)	11 (9%)
24 wks	871	461 (53%)	438	402 (92%)	17 (4%)	19 (4%)
25 wks	1156	432 (37%)	767	701 (91 %)	42 (6%)	24 (3%)
26 wks	1236	316 (26%)	939	891 (95 %)	29 (3%)	19 (2%)
27 wks	1339	238 (18%)	1128	1072 (95 %)	39 (4%)	17 (2%)
28 wks	1421	204 (14%)	1261	1189 (94 %)	58 (5%)	14 (1%)
Total	6463	1978 (31%)	4657	4363 (94 %)	190 (4 %)	104 (2%)



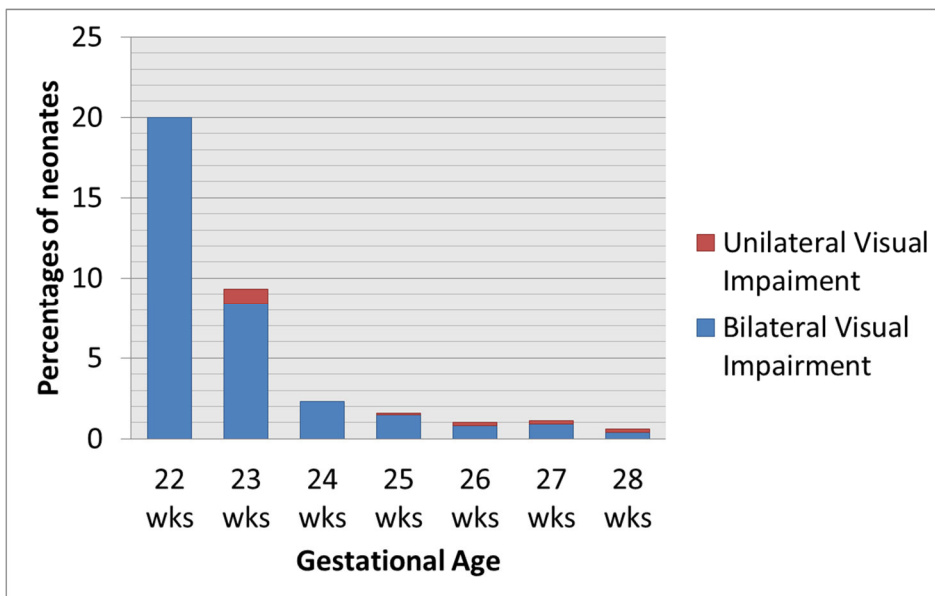
**COMMENTS:**

Hearing impairment was determined at CNFUN sites based on audiology reports. Hearing impairment is infrequent but approximately 10 times as frequent in the very preterm infant than in the normal population. Severe hearing impairment incidence decreases with gestational age.

Presentation No 8

Visual impairment rates by gestational Age (GA)

GA	CNN- CNFU N linked cases or deaths n	Death or any visual impairment n (%)	CNN- CNFUN linked cases with data for vision n	Normal Vision n (%)	Unilateral visual impairment n (%)	Bilateral visual impairment n (%)
22 wks	44	39 (89%)	5	4 (80%)	0 (0)	(20%)
23 wks	396	283 (71%)	107	97 (91%)	(0.9%)	9 (8.4%)
24 wks	871	434 (50%)	399	390 (98%)	0 (0)	9 (2.3%)
25 wks	1156	378 (33%)	724	712 (98%)	(0.1%)	11 (1.5%)
26 wks	1236	277 (22%)	887	878 (99%)	(0.2%)	7 (0.8%)
27 wks	1339	194 (14%)	1065	1053 (99%)	(0.2%)	10 (0.9%)
28 wks	1421	139 (10%)	1190	1183 (99%)	(0.2%)	5 (0.4%)
Total	6463	1744 (27%)	4377	4317 (99%)	8 (0.2%)	52 (1.2%)

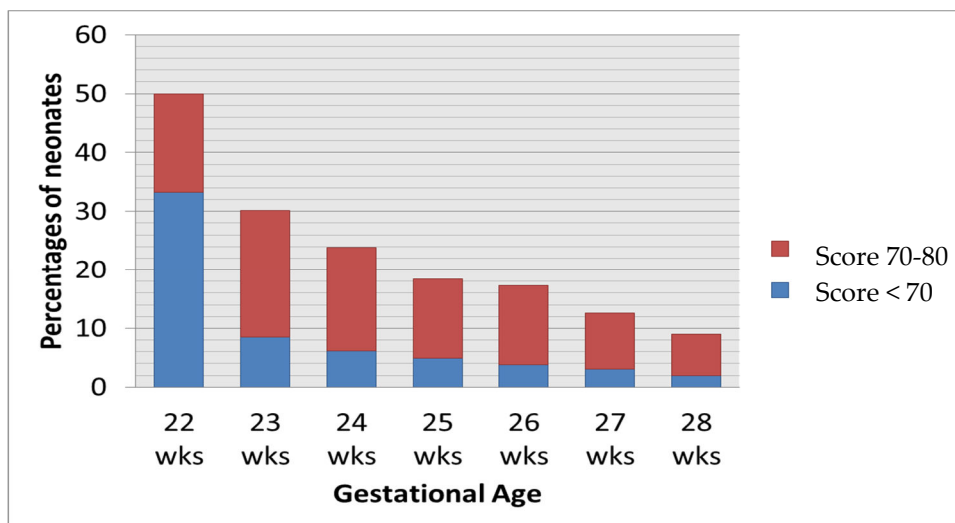


**COMMENTS:**

Visual impairment was determined from ophthalmology reports. If no report was available, impairment was defined as a small scarred eye, sustained sensory nystagmus or lack of response to a 1cm object (cheerio) on a white background at 30 cms. Visual impairment is an infrequent outcome.

Presentation No 9  
Bayley- III cognitive composite scores rates by gestational Age (GA)

GA	CNN- CNFUN linked cases or deaths n	Death or cognitive score < 85 n (%)	CNN- CNFUN linked cases with cognitive data n	Median score (IQR)	Bayley-III ≥ 85 n (%)	Score 70- 84 n (%)	Score < 70 n (%)
22 wks	44	41 (93%)	6	83 (65, 90)	(50%)	(17%)	(33%)
23 wks	396	305 (77%)	106	90 (80, 100)	74 (70%)	23 (22%)	9 (9%)
24 wks	871	523 (60%)	410	90 (85, 100)	312 (76%)	73 (18%)	25 (6%)
25 wks	1156	502 (43%)	741	95 (85, 105)	605 (82%)	100 (14%)	36 (5%)
26 wks	1236	423 (34%)	894	95 (85, 105)	739 (83%)	121 (14%)	34 (4%)
27 wks	1339	317 (24%)	1071	95 (90, 105)	936 (87%)	102 (10%)	33 (3%)
28 wks	1421	239 (17%)	1192	100 (90, 105)	1085 (91%)	85 (7%)	22 (2%)
Total	6463	2350 (36%)	4420	95 (90, 105)	3754 (85%)	505 (11%)	161 (4%)



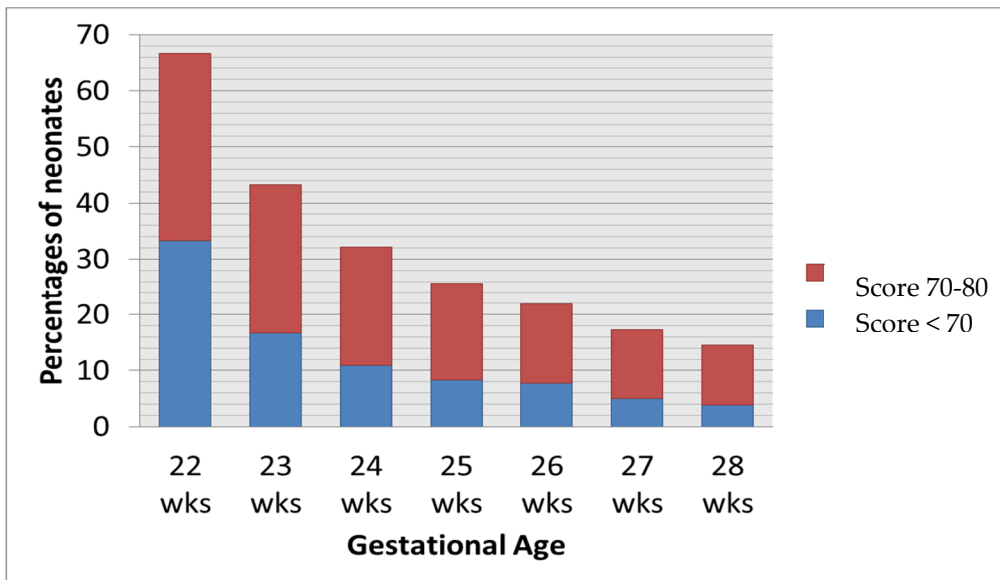
**COMMENTS:**

Cognitive scores on the Bayley Scales of Infant and Toddler Development- 3<sup>rd</sup> edition (Bayley-III) improve with increasing gestational age. The Bayley-III has a mean score of 100 and standard deviation of 15 (Less than 70 is therefore < - 2 standard deviations). Bayley-III scores tend to underestimate developmental delay and have limited predictive ability.

Presentation No 10

Bayley- III motor composite scores rates by gestational age (GA)

GA	CNN-CNFUN linked cases or deaths n	Death or motor score < 85 n (%)	CNN-CNFUN linked cases with motor data n	Median score	Bayley-III ≥ 85 n (%)	Score 70-84 n (%)	Score < 70 n (%)
22 wks	44	42 (95%)	6	76 (67, 94)	(33%)	(33%)	(33%)
23 wks	396	317 (80%)	102	88 (73, 97)	58 (57%)	27 (27%)	17 (17%)
24 wks	871	552 (63%)	394	90 (79, 97)	267 (68%)	84 (21%)	43 (11%)
25 wks	1156	548 (47%)	713	94 (82, 100)	531 (75%)	123 (17%)	59 (8%)
26 wks	1236	456 (37%)	856	94 (85, 100)	668 (78%)	121 (14%)	67 (8%)
27 wks	1339	357 (27%)	1011	94 (88, 100)	836 (83%)	124 (12%)	51 (5%)
28 wks	1421	299 (21%)	1151	97 (88, 103)	984 (86%)	122 (11%)	45 (4%)
Total	6463	2571 (40%)	4233	94 (85, 100)	3346 (79%)	603 (14%)	284 (7%)



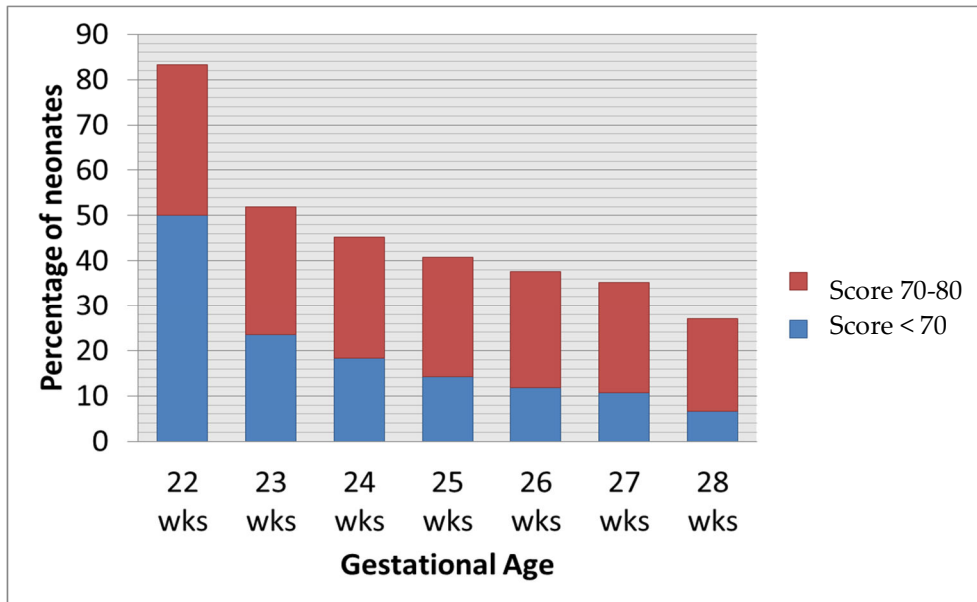
**COMMENTS:**

Motor scores on the Bayley Scales of Infant and Toddler Development- 3<sup>rd</sup> edition (Bayley-III) improve with increasing gestational age. The Bayley-III has a mean score of 100 and standard deviation of 15 (Less than 70 is therefore < - 2 standard deviations). Bayley-III scores tend to underestimate developmental delay and have limited predictive ability.

Presentation No 11

Bayley- III language composite scores rates by gestational Age (GA)

GA	CNN- CNFUN linked cases or deaths n	Death or language score < 85 n (%)	CNN- CNFUN linked cases with language data n	Median score (IQR)	Bayley-III ≥ 85 n (%)	Score 70-84 n (%)	Score < 70 n (%)
22 wks	44	43 (98%)	6	71 (62, 79)	(17%)	(33%)	(50%)
23 wks	396	326(82%)	102	83 (71, 94)	49 (48%)	29 (28%)	24 (24%)
24 wks	871	605(69%)	398	86 (74, 97)	218 (55%)	107 (27%)	73 (18%)
25 wks	1156	658(57%)	716	89 (77, 100)	424 (59%)	190 (27%)	102 (14%)
26 wks	1236	594(48%)	865	89 (77, 100)	539 (62%)	223 (26%)	103 (12%)
27 wks	1339	543(41%)	1024	91 (79, 100)	663 (65%)	250 (24%)	111 (11%)
28 wks	1421	440(31%)	1137	94 (83, 103)	829 (73%)	233 (21%)	75 (7%)
Total	663	3209(50%)	4248	91 (79, 100)	2723 (64%)	1034 (24%)	491 (12%)



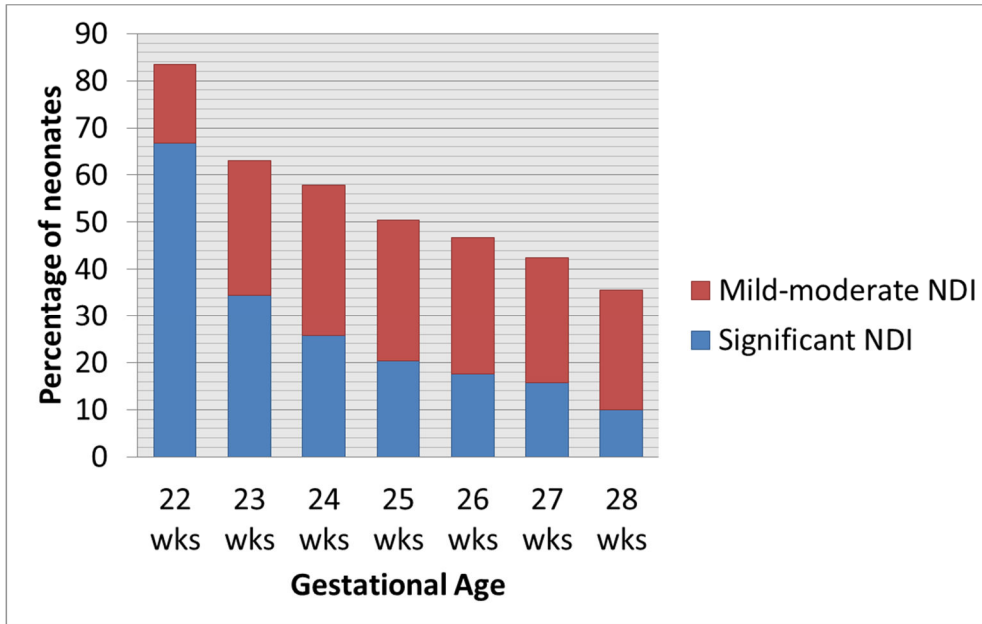
**COMMENTS:**

Language scores on the Bayley Scales of Infant and Toddler Development- 3<sup>rd</sup> edition (Bayley-III) improve with increasing gestational age. The Bayley-III has a mean score of 100 and standard deviation of 15 (Less than 70 is therefore < - 2 standard deviations). Bayley-III scores tend to underestimate language delay and have limited predictive ability.

Presentation No 12

Neurodevelopmental impairment (NDI) rates by gestational age (GA)

GA	CNN-CNFUN linked cases or deaths n	Death or any NDI n (%)	CNN-CNFUN linked cases with complete data n	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI n (%)
22 wks	44	43 (98%)	6	(17%)	(17%)	(67%)
23 wks	396	350 (88%)	122	45 (37%)	35 (29%)	42 (34%)
24 wks	871	683 (78%)	446	188 (42%)	143 (32%)	115 (26%)
25 wks	1156	762 (66%)	784	388 (50%)	236 (30%)	160 (20%)
26 wks	1236	719 (58%)	966	515 (53%)	282 (29%)	169 (18%)
27 wks	1339	669 (50%)	1149	662 (58%)	307 (27%)	180 (16%)
28 wks	1421	589 (41%)	1286	829 (65%)	329 (26%)	128 (10%)
Total	6463	3815 (59%)	4759	2628 (55%)	1333 (28%)	798 (17%)



**COMMENTS:**

Neurodevelopmental impairment rates decrease with increasing gestational age.

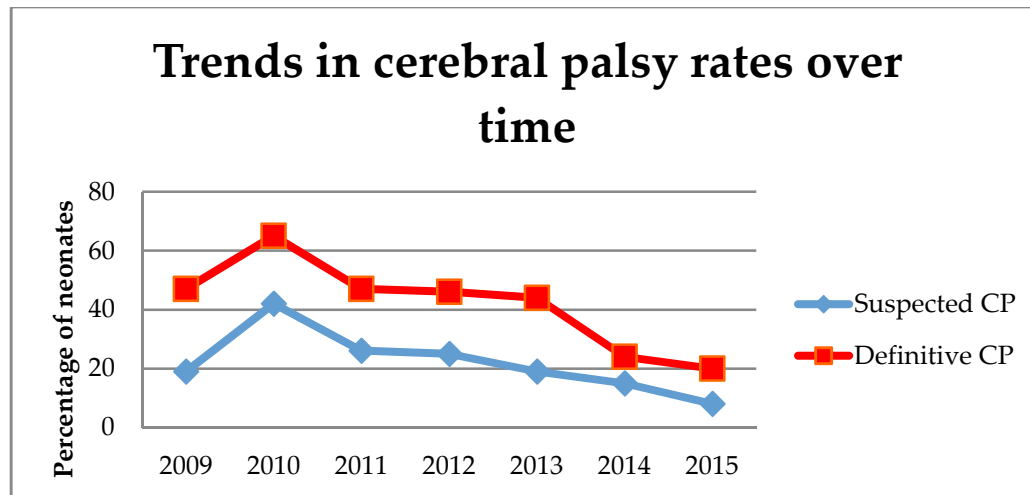


## F. Outcomes Over Time

### Presentation 13

#### Trends in cerebral palsy rates over time

Yr of birth	CNFUN with complete CP data (n)	Missing CP data (n)	No CP n (%)	Suspected CP n (%)	Definitive CP n (%)	Missing CP GMFCS n	CP GMFCS ≤ 2 n (%)	CP GMFCS 3-5 n (%)
2009	647	12	581 (90%)	19 (2.9%)	47 (7.3%)	7	26 (65%)	14 (35%)
2010	998	16	891 (89%)	42 (4.2%)	65 (6.5%)	11	33 (61%)	21 (39%)
2011	827	25	754 (91%)	26 (3.1%)	47 (5.7%)	4	22 (51%)	21 (49%)
2012	669	7	598 (89%)	25 (3.7%)	46 (6.9%)	3	25 (58%)	18 (42%)
2013	607	8	544 (90%)	19 (3.1%)	44 (7.2%)	2	28 (67%)	14 (33%)
2014	589	8	550 (93%)	15 (2.5%)	24 (4.1%)	1	15 (65%)	8 (35%)
2015	353	13	325 (92%)	8 (2.3%)	20 (5.7%)	0	13 (65%)	7 (35%)
'09-'15	4690	89	4243 (90%)	154 (3.3%)	293 (6.2%)	28	162 (61%)	103 (39%)



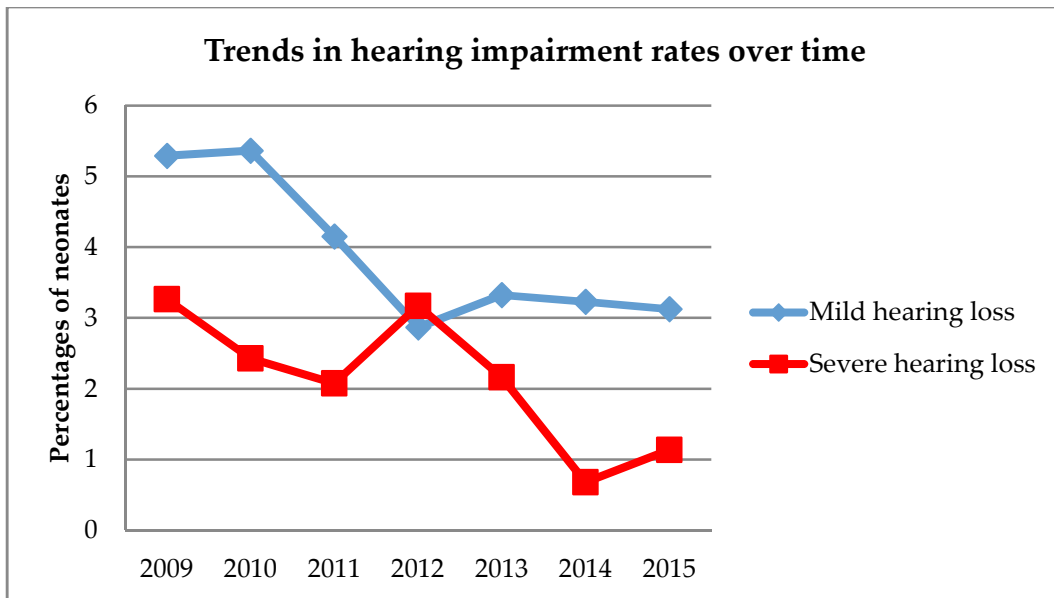
#### COMMENTS:

Higher attrition rates in the later years may impact the results. There has not been a clinically significant change in cerebral palsy rates with a possible downward trend in definitive cerebral palsy. The majority of cerebral palsy cases are mild.

Presentation No 14

Trends in hearing impairment rates over time

Yr of birth	CNFUN complete data (n)	Missing hearing data (n)	Normal hearing n (%)	Mild hearing impairment n (%)	Severe hearing impairment* n (%)
2009	643	16	588 (91%)	34 (5.3%)	21 (3.3%)
2010	989	25	912 (92%)	53 (5.4%)	24 (2.4%)
2011	819	33	768 (94%)	34 (4.2%)	17 (2.1%)
2012	663	13	623 (94%)	19 (2.9%)	21 (3.2%)
2013	602	13	569 (95%)	20 (3.3%)	13 (2.2%)
2014	589	8	566 (96%)	19 (3.2%)	4 (0.7%)
2015	352	14	337 (96%)	11 (3.1%)	4 (1.1%)
'09-'15	4657	122	4363 (94%)	190 (4.1%)	104 (2.2%)



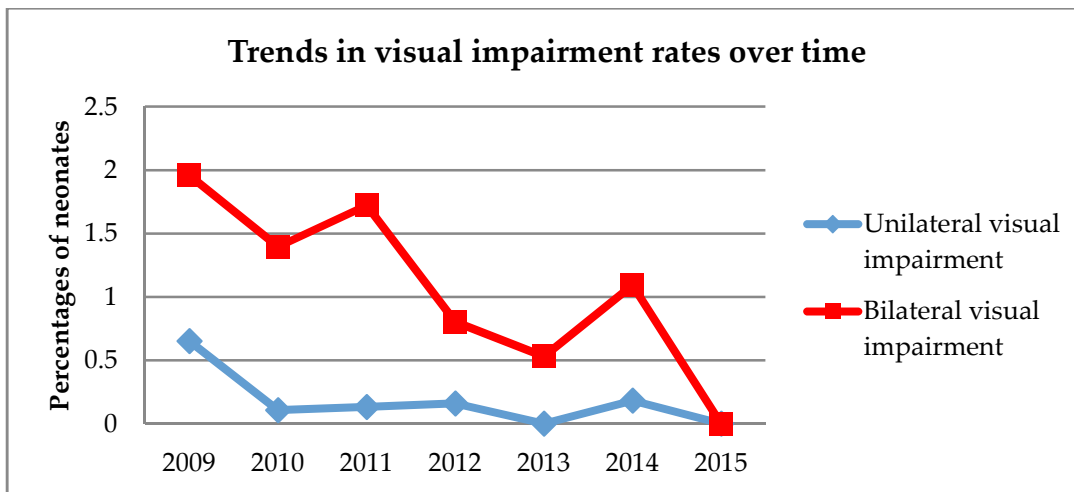
**COMMENTS:**

Severe hearing impairment was defined as prescribed hearing aid(s) or cochlear implant(s). A mild hearing impairment is any hearing impairment identified by an audiologist not prescribed hearing aid(s) or cochlear implant(s). Hearing impairment rates have shown a downward trend over time though numbers are small. Higher attrition rates in the later years may impact the results.

Presentation No 15

Trends in visual impairment rates over time

Yr of birth	CNFUN complete data (n)	Missing vision data (n)	Normal Vision n (%)	Unilateral visual impairment n (%)	Bilateral visual impairment n (%)
2009	613	46	597 (97%)	(0.7%)	12 (2.0%)
2010	932	82	918 (98%)	(0.1%)	13 (1.4%)
2011	755	97	741 (98%)	(0.1%)	13 (1.7%)
2012	622	54	616 (99%)	(0.2%)	5 (0.8%)
2013	565	50	562 (99%)	0 (0)	(0.5%)
2014	549	48	542 (99%)	(0.1%)	6 (1.0%)
2015	341	25	341 (100%)	0 (0)	0 (0)
'09-'15	4377	402	4317 (99%)	8 (0.1%)	52 (1.1%)



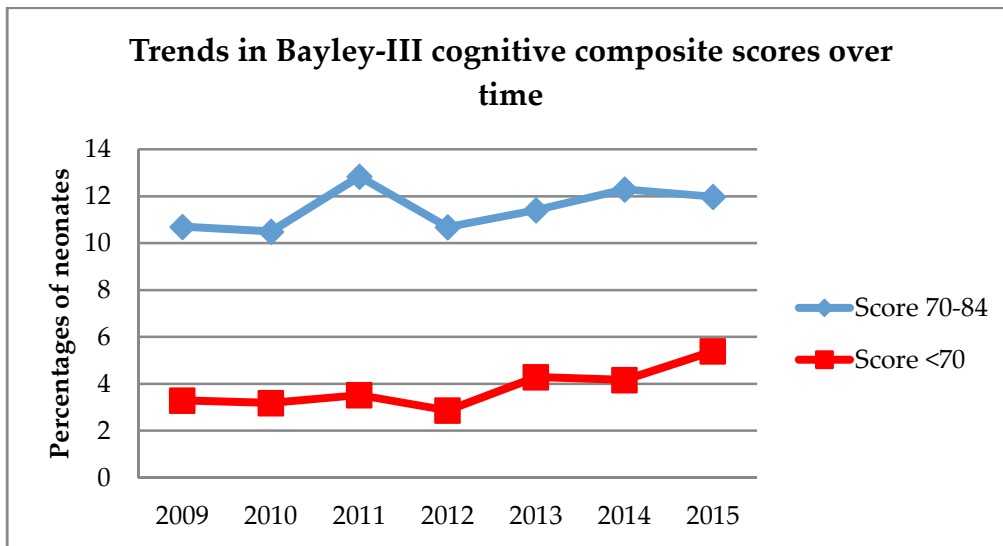
**COMMENTS:**

Visual impairment at 18 months corrected age is now a rare complication of prematurity.

Presentation No 16

Table 4: Trends in Bayley- III cognitive composite scores over time

Yr of birth	CNFUN with complete data (n)	Missing Bayley cognitive (n)	Median score (IQR)	Bayley-III $\geq$ 85 n (%)	Score 70-84 n (%)	Score < 70 n (%)
2009	608	51	95 (90, 105)	523 (86%)	65 (11%)	20 (3.3%)
2010	943	71	95 (90, 105)	814 (86%)	99 (10%)	30 (3.2%)
2011	794	58	95 (90, 105)	664 (84%)	102 (13%)	28 (3.5%)
2012	627	49	95 (90, 105)	542 (86%)	67 (11%)	18 (2.9%)
2013	561	54	95 (90, 105)	473 (84%)	64 (11%)	24 (4.3%)
2014	553	44	95 (85, 105)	462 (84%)	68 (12%)	23 (4.2%)
2015	334	32	95 (90, 105)	276 (83%)	40 (12%)	18 (5.4%)
'09-'15	4420	359	95 (90, 105)	3754 (85%)	505 (11%)	161 (3.6%)



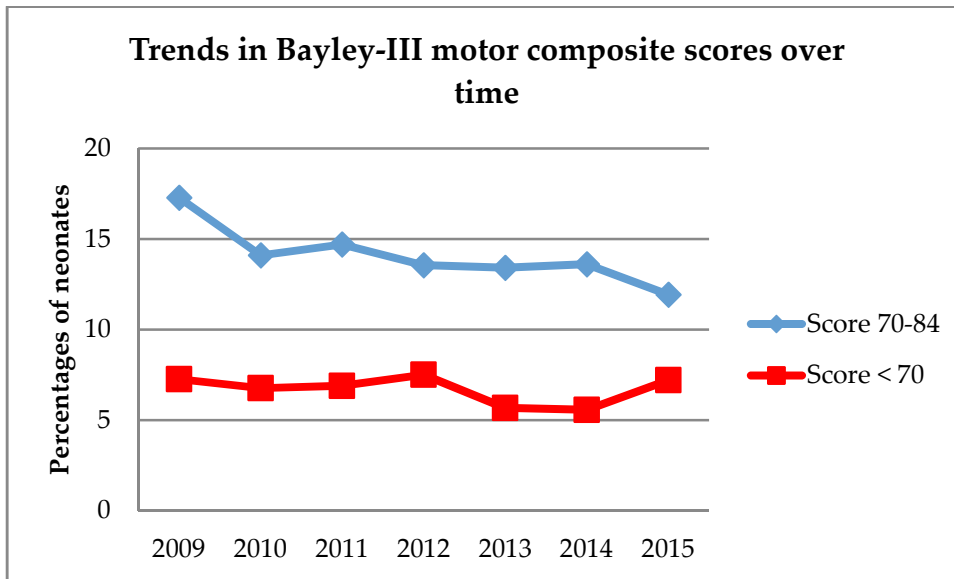
**COMMENTS:**

Higher attrition rates in the later years may impact the results. There has not been a clinically significant change and no evidence of reduction in cognitive developmental delay incidence as measured by the Bayley-III at 18 months corrected age. The Bayley-III has a poor predictive value.

Presentation No 17

Trends in Bayley- III motor composite scores over time

Yr of birth	CNFUN complete data (n)	Missing Bayley motor scores (n)	Median score (IQR)	Bayley-III $\geq$ 85 n (%)	Score 70-84 n (%)	Score < 70 n (%)
2009	579	80	94 (85, 100)	437 (75%)	100 (17%)	42 (7.3%)
2010	901	113	94 (85, 100)	713 (79%)	127 (14%)	61 (6.8%)
2011	769	83	94 (85, 100)	603 (78%)	113 (15%)	53 (6.9%)
2012	613	63	94 (85, 100)	484 (79%)	83 (14%)	46 (7.5%)
2013	530	85	94 (85, 100)	429 (81%)	71 (13%)	30 (5.7%)
2014	522	75	94 (88, 103)	422 (81%)	71 (14%)	29 (5.6%)
2015	319	47	94 (88, 103)	258 (81%)	38 (12%)	23 (7.2%)
'09-'15	4233	546	94 (85, 100)	3346 (79%)	603 (14%)	284 (6.7%)



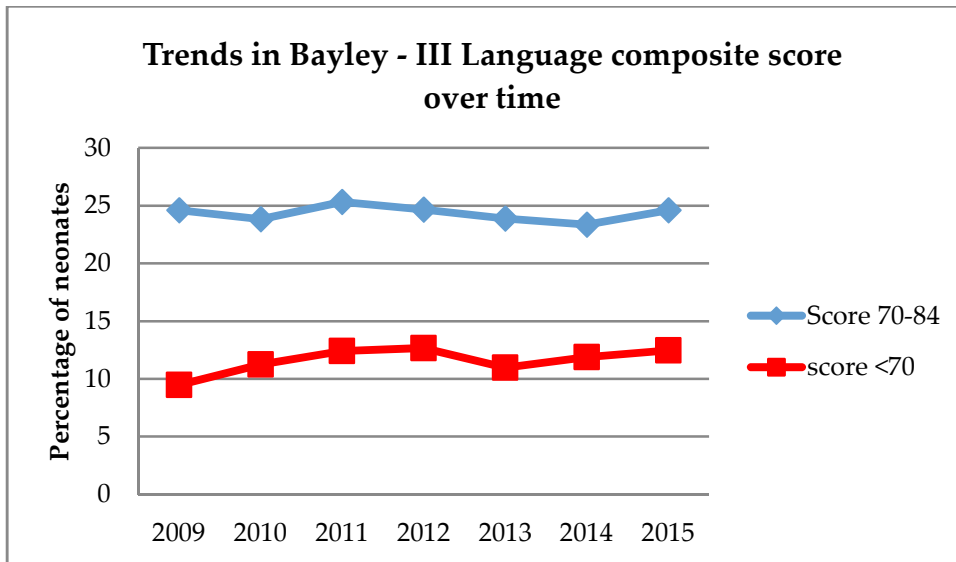
**COMMENTS:**

Higher attrition rates in the later years may impact the results. There has not been a clinically significant change in motor developmental delay incidence as measured by the Bayley-III at 18 months corrected age. The Bayley-III has a poor predictive value. Not all children with low Bayley-III motor composite scores have cerebral palsy and vice versa (data not shown).

Presentation No 18

Trends in Bayley- III language composite scores over time

Yr of birth	CNFUN with complete data (n)	Missing Bayley language scores n (%)	Median score (IQR)	Bayley-III $\geq$ 85 n (%)	Score 70-84 n (%)	Score < 70 n (%)
2009	581	78	91 (79, 100)	383 (66%)	143 (25%)	55 (9%)
2010	915	99	89 (79, 100)	594 (65%)	218 (24%)	103 (11%)
2011	774	78	91 (77, 100)	482 (62%)	196 (25%)	96 (12%)
2012	616	60	90 (79, 100)	386 (63%)	152 (25%)	78 (13%)
2013	519	96	91 (79, 100)	338 (65%)	124 (24%)	57 (11%)
2014	522	75	90 (77, 100)	338 (65%)	122 (23%)	62 (12%)
2015	321	45	89 (79, 100)	202 (63%)	79 (25%)	40 (12%)
'09-'15	4248	531	91 (79, 100)	2723 (64%)	1034 (24%)	491 (12%)

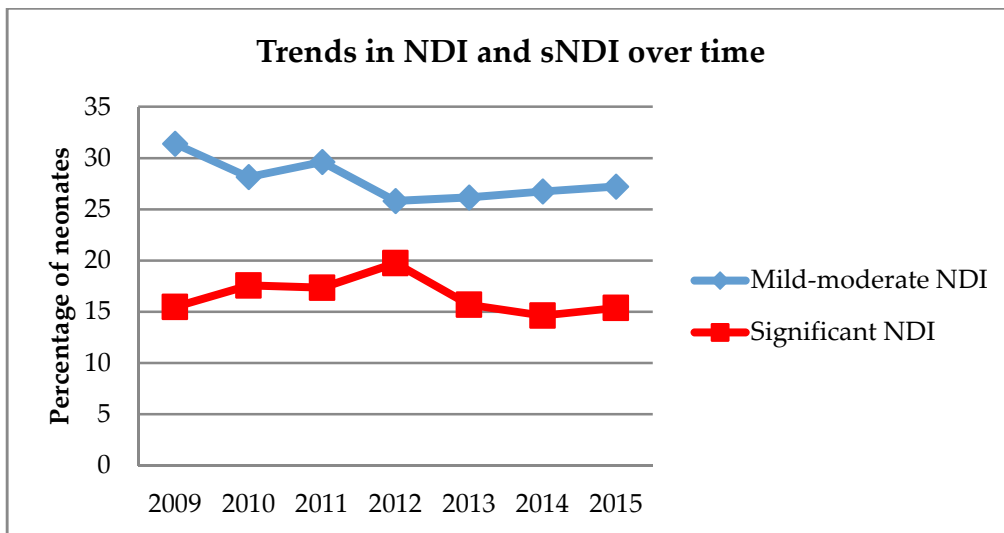


**COMMENTS:**

Higher attrition rates in the later years may impact the results. There has not been a clinically significant change and no evidence of decrease in the incidence of language developmental delay as measured by the Bayley-III at 18 months corrected age. Low language scores on the Bayley-III is the most frequent domain of neurodevelopmental impairment in this report. The Bayley-III has a poor predictive value.

Presentation No 19  
Trends in NDI and sNDI over time

Yr of birth	CNFUN with complete data (n)	Missing data n (%)	No NDI n (%)	Mild-moderate NDI n (%)	Significant NDI n (%)
2009	659	6	347 (53%)	205 (31%)	101 (15%)
2010	1014	1	550 (54%)	285 (28%)	178 (18%)
2011	852	4	450 (53%)	251 (30%)	147 (17%)
2012	676	2	367 (54%)	174 (26%)	133 (20%)
2013	615	3	356 (58%)	160 (26%)	96 (16%)
2014	597	2	349 (59%)	159 (27%)	87 (15%)
2015	366	2	209 (57%)	99 (27%)	56 (15%)
'09-'15	4779	20	2628 (55%)	1333 (28%)	798 (17%)



**COMMENTS:**

Higher attrition rates in the later years may impact the results. There has not been a clinically significant change in neurodevelopmental impairment rates.

## G. Site Comparisons-Crude

Presentation No 20

Neurodevelopmental outcomes for MiCare cohort (Births April 1, 2009-Sept 30, 2011)\*

Site	CNFUN (n)	No NDI n (%)	Any NDI n (%)	CP with GMFCS 1-5 n (%)	Any hearing Impairment n(%)	Any visual Impairment n(%)	Bayley score <85m Motor n(%)	Bayley score <85 Language n(%)	Bayley score <85 Cognitive n(%)
1	168	110 (65.5)	58 (34.5)	< 5%	9 (5.4)	0 (0)	23 (13.7)	40 (23.8)	8 (4.8)
2	115	70 (60.9)	45 (39.1)	< 5%	12 (10.4)	0 (0)	17 (14.8)	29 (25.2)	10 (8.7)
5	205	118 (57.6)	87 (42.4)	7 (3.4)	29 (14.1)	< 5%	24 (11.7)	57 (27.8)	21 (10.2)
6	212	95 (44.8)	117 (55.2)	11 (5.2)	25 (11.8)	11 (5.2)	58 (27.4)	76 (35.8)	30 (14.2)
7	27	19 (70.4)	8 (29.6)	< 5%	0 (0)	< 5%	5 (18.5)	7 (25.9)	< 10%
8	145	67 (46.2)	78 (53.8)	14 (9.7)	< 5%	< 5%	41 (28.3)	53 (36.6)	31 (21.4)
9	53	30 (56.6)	23 (43.4)	5 (9.4)	< 5%	0 (0)	< 10%	10 (18.9)	9 (17)
10	56	15 (26.8)	41 (73.2)	< 10%	9 (16.1)	< 5%	19 (33.9)	34 (60.7)	18 (32.1)
11	178	92 (51.7)	86 (48.3)	9 (5.1)	13 (7.3)	< 5%	45 (25.3)	55 (30.9)	20 (11.2)
12	84	43 (51.2)	41 (48.8)	12 (14.3)	< 5%	< 5%	25 (29.8)	26 (31)	14 (16.7)
13	21	16 (76.2)	5 (23.8)	< 15%	< 15%	0 (0)	0 (0)	< 5%	0 (0)
14	103	56 (54.4)	47 (45.6)	6 (5.8)	< 5%	0 (0)	17 (16.5)	42 (40.8)	12 (11.7)
15	30	17 (56.7)	13 (43.3)	< 5%	6 (20)	0 (0)	< 15%	9 (30)	5 (16.7)
16	250	128 (51.2)	122 (48.8)	18 (7.2)	16 (6.4)	< 5%	48 (19.2)	75 (30)	44 (17.6)
17	64	33 (51.6)	31 (48.4)	0 (0)	< 5%	< 5%	18 (28.1)	22 (34.4)	12 (18.8)
18	43	23 (53.5)	20 (46.5)	< 10%	< 5%	< 5%	9 (20.9)	14 (32.6)	9 (20.9)
20	79	40 (51.3)	39 (48.7)	5 (6.3)	< 5%	< 5%	14 (17.7)	34 (43)	9 (11.4)
21	55	19 (34.5)	36 (65.5)	5 (9.1)	10 (18.2)	< 5%	19 (34.5)	29 (52.7)	15 (27.3)
23	132	85 (64.4)	47 (35.6)	10 (7.6)	11 (8.4)	< 5%	17 (12.9)	27 (20.5)	10 (7.6)
25	238	125 (52.5)	113 (47.5)	0 (0)	13 (5.5)	< 5%	40 (16.8)	95 (39.9)	33 (13.9)
Total	2258	1198(53.1)	1055(46.8)	123 (5.4)	174 (7.7)	38 (1.7)	446 (19.8)	735 (32.6)	312 (13.8)

\*Cells with less than 5 show only % , rounded up to a multiple of 5%



Presentation No 21

Significant neurodevelopmental outcomes for MiCare cohort (Births April 1, 2009-Sept 30, 2011)\*

Site	CNFUN (n)	No NDI n (%)	Significant NDI n (%)	CP GMFCS 3-5 n (%)	Severe hearing Impairment n (%)	Bilateral visual Impairment n (%)	Bayley score <70 Motor n (%)	Bayley score <70 Language n (%)	Bayley score <70 Cognitive n (%)
1	168	110 (65.5)	10 (6)	<5%	0 (0)	0 (0)	6 (3.6)	7 (4.2)	<5%
2	115	70 (60.9)	10 (8.7)	0 (0)	<5%	0 (0)	<5 %	<5 %	< 5%
5	205	118 (57.6)	18 (8.8)	< 5%	< 5%	<5 %	5 (2.4)	9 (4.4)	< 5%
6	212	95 (44.8)	45 (21.2)	< 5%	< 5%	9 (4.2)	15 (7.1)	32 (15.1)	5 (2.4)
7	27	19 (70.4)	< 15%	< 5%	0 (0)	< 5%	< 15%	< 15%	< 5%
8	145	67 (46.2)	29 (20)	6 (4.1)	< 5%	< 5%	13 (9)	14 (9.7)	7 (4.8)
9	53	30 (56.6)	8 (15.1)	0 (0)	< 5%	0 (0)	< 5%	< 10%	< 5%
10	56	15 (26.8)	23 (41.1)	0 (0)	0 (0)	< 5%	8 (14.3)	22 (39.3)	< 10%
11	178	92 (51.7)	27 (15.2)	5 (2.8)	5 (2.8)	< 5%	13 (7.3)	16 (9)	7 (3.9)
12	84	43 (51.2)	16 (19)	< 5%	< 5%	< 5%	9 (10.7)	6 (7.1)	< 5%
13	21	16 (76.2)	5 (23.8)	< 15%	< 15%	0 (0)	0 (0)	< 5%	0 (0)
14	103	56 (54.4)	13 (12.6)	< 5%	< 5%	0 (0)	6 (5.8)	8 (7.8)	0 (0)
15	30	17 (56.7)	8 (26.7)	< 5%	< 15%	0 (0)	< 10%	< 15%	0 (0)
16	250	128 (51.2)	47 (18.8)	8 (3.2)	10 (4)	< 5%	10 (4)	24 (9.6)	9 (3.6)
17	64	33 (51.6)	14 (21.9)	0 (0)	0 (0)	0 (0)	6 (9.4)	10 (15.6)	< 5%
18	43	23 (53.5)	12 (27.9)	< 10%	0 (0)	< 5%	6 (14)	7 (16.3)	< 10%
20	79	39 (48.7)	17 (21.5)	< 5%	< 5%	< 5%	< 10%	12 (15.2)	< 5%
21	55	19 (34.5)	18 (32.7)	< 5%	< 5%	< 5%	9 (16.4)	15 (27.3)	6 (10.9)
23	132	85 (64.4)	19 (14.4)	5 (3.8)	9 (6.8)	< 5%	5 (3.8)	5 (3.8)	< 5%
25	238	125 (52.5)	39 (16.4)	0 (0)	10 (4.2)	< 5%	9 (3.8)	26 (10.9)	< 5%
Total	2258	1198 (53.1)	380 (16.8)	49 (2.2)	58 (2.6)	34 (1.5)	133 (5.9)	228 (10.1)	67 (3)

\*Cells with less than 5 only show %, rounded up to a multiple of 5%

Presentation No 22

Neurodevelopmental outcomes for post MiCare cohort (Births Oct 1, 2011- Mar 31, 2015)\*

Site	CNFUN (n)	No NDI n (%)	Any NDI n (%)	GMFCS 1-5 n (%)	Any hearing Impairment n(%)	Any visual Impairment n(%)	Bayley score <85m motor n(%)	Bayley score <85 Language n(%)	Bayley score <85 Cognitive n(%)
1	221	129 (58.4)	92 (41.6)	11 (5)	10 (4.5)	< 5%	44 (19.9)	63 (28.5)	22 (10)
2	140	86 (61.4)	54 (38.6)	8 (5.7)	9 (6.4)	0 (0)	18 (12.9)	40 (28.6)	12 (8.6)
6	276	163 (59.1)	113 (40.9)	11 (4)	14 (5.1)	5 (1.8)	54 (19.6)	77 (27.9)	44 (15.9)
10	62	21 (33.9)	41 (66.1)	< 10%	6 (9.7)	< 5%	18 (29)	37 (59.7)	9 (14.5)
11	229	123 (53.7)	106 (46.3)	18 (7.9)	14 (6.1)	< 5%	56 (24.5)	71 (31)	39 (17)
12	139	74 (53.2)	65 (46.8)	15 (10.8)	< 5%	< 5%	35 (25.2)	46 (33.1)	24 (17.2)
14	154	87 (56.5)	67 (43.5)	8 (5.2)	9 (5.8)	< 5%	26 (16.9)	50 (32.5)	15 (9.7)
16	219	122 (55.7)	97 (44.3)	12 (5.5)	8 (3.7)	0 (0)	30 (13.7)	78 (35.6)	35 (16)
20	89	54 (60.7)	35 (39.3)	5 (5.6)	5 (5.6)	< 5%	15 (16.9)	24 (27)	13 (14.6)
21	63	31 (49.2)	32 (50.8)	< 10%	< 5%	0 (0)	14 (22.2)	26 (41.3)	13 (20.6)
23	56	39 (69.6)	17 (30.4)	< 10%	< 10%	< 5%	7 (12.5)	10 (17.9)	< 10%
25	457	261 (57.1)	196 (42.9)	21 (4.6)	17 (3.7)	< 5%	64 (14)	154 (33.7)	66 (14.4)
26	20	14 (70)	6 (30)	< 10%	< 20%	0 (0)	< 20%	< 20%	< 10%
Total	2125	1205 (56.7)	920 (43.3)	122 (5.7)	104 (4.9)	19 (0.9)	384 (18.1)	679 (31.9)	296 (13.9)

\*Cells with less than 5 only show % , rounded up to a multiple of 5%

Presentation No 23

Significant neurodevelopment for post MiCare cohort (Births Oct 1, 2011- Mar 31, 2015)\*

Site	CNFUN (n)	No NDI n (%)	Significant NDI n (%)	CP 3-5 n (%)	Severe hearing Impairment n(%)	Bilateral visual Impairment n(%)	Bayley score <85m Motor n(%)	Bayley score <85 Language n(%)	Bayley score <85 Cognitive n(%)
1	221	129 (58.4)	44 (19.9)	5 (2.3)	8 (3.6)	< 5%	18 (8.1)	20 (9)	5 (2.3)
2	140	86 (61.4)	18 (12.9)	< 5%	< 5%	0 (0)	< 5%	11 (7.9)	5 (3.6)
6	276	163 (59.1)	36 (13)	< 5%	< 5%	< 5%	15 (5.4)	27 (9.8)	14 (5.1)
10	62	21 (33.9)	14 (22.6)	< 5%	< 5%	< 5%	< 10%	13 (21)	< 5%
11	229	123 (53.7)	31 (13.5)	< 5%	0 (0)	< 5%	21 (9.2)	19 (8.3)	< 5%
12	139	74 (53.2)	23 (16.5)	< 5%	< 5%	< 5%	11 (7.7)	18 (12.9)	7 (5.0)
14	154	87 (56.5)	23 (14.9)	5 (3.2)	< 5%	< 5%	8 (5.2)	11 (7.1)	< 5%
16	219	122 (55.7)	31 (14.2)	< 5%	6 (2.7)	0 (0)	9 (4.1)	21 (9.6)	9 (4.1)
20	89	54 (60.7)	20 (23)	< 5%	< 5%	< 5%	7 (7.9)	12 (13.5)	5 (5.6)
21	63	31 (49.2)	17 (27)	< 5%	< 5%	0 (0)	5 (7.9)	14 (22.2)	< 10%
23	56	39 (69.6)	9 (16.1)	< 10%	< 10%	< 5%	< 10 %	< 5%	< 5 %
25	457	261 (57.1)	85 (18.6)	11 (2.4)	12 (2.6)	< 5%	16 (3.5)	55 (12)	13 (2.8)
26	20	14 (70)	< 20%	0 (0)	< 15%	0 (0)	0 (0)	< 10%	0 (0)
Total	2125	1205 (56.7)	354 (16.7)	44 (2.1)	43 (2)	17 (0.8)	122 (5.7)	224 (10.5)	72 (3.4)

\*Cells with less than 5 only show %, rounded up to a multiple of 5%

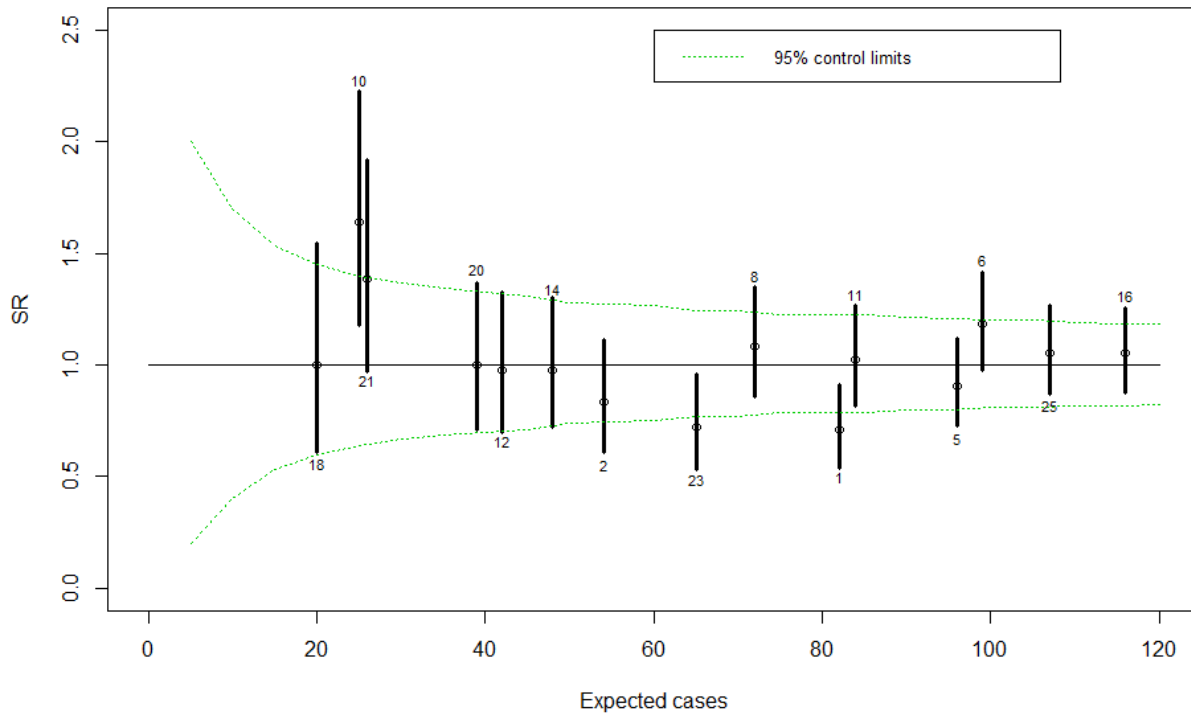
## H.Site Comparisons- Adjusted Standardized Ratios

Presentation No 24

Adjusted Standardized ratios by site – Neurodevelopmental Impairment (NDI)- MiCare cohort

Site	No. of children	Follow-up Rate (%)	Included Yes/ No	NDI n	Adjusted Expected NDI	Adjusted standardized ratio (95%CI)
1	168	76.6	Y	58	82	0.71 (0.54, 0.91)
2	115	87.8	Y	45	54	0.83 (0.61, 1.12)
3	10	84.6	N	7		
4	13	76.5	N	3		
5	205	80.1	Y	87	96	0.91 (0.73, 1.12)
6	212	85.5	Y	117	99	1.18 (0.98, 1.42)
7	27	56.6	N	8		
8	145	71.4	Y	78	72	1.08 (0.86, 1.35)
9	53	48.2	N	23		
10	56	81.2	Y	41	25	1.64 (1.18, 2.22)
11	178	79.8	Y	86	84	1.02 (0.82, 1.26)
12	84	82.4	Y	41	42	0.98 (0.70, 1.32)
13	21	56.8	N	5		
14	103	76.3	Y	47	48	0.98 (0.72, 1.30)
15	30	60.8	N	13		
16	250	83.1	Y	122	116	1.05 (0.87, 1.26)
17	64	39.3	N	31		
18	43	91.5	Y	20	20	1.00 (0.61, 1.54)
19	17	25.8	N	5		
20	79	78.2	Y	39	39	1.00 (0.71, 1.37)
21	55	93.2	Y	36	26	1.38 (0.97, 1.92)
22	13	65	N	2		
23	132	79.5	Y	47	65	0.72 (0.53, 0.96)
24	7	53.8	N	4		
25	238	78.2	Y	113	107	1.06 (0.87, 1.27)
26	18	81.8	N	9		

1. Sites with < 20 participants for the 2.5year MiCare cohort period and / or < 70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, outborn, severity of illness (SNAP> 20), bronchopulmonary dysplasia, necrotizing enterocolitis and brain injury



**COMMENTS:**

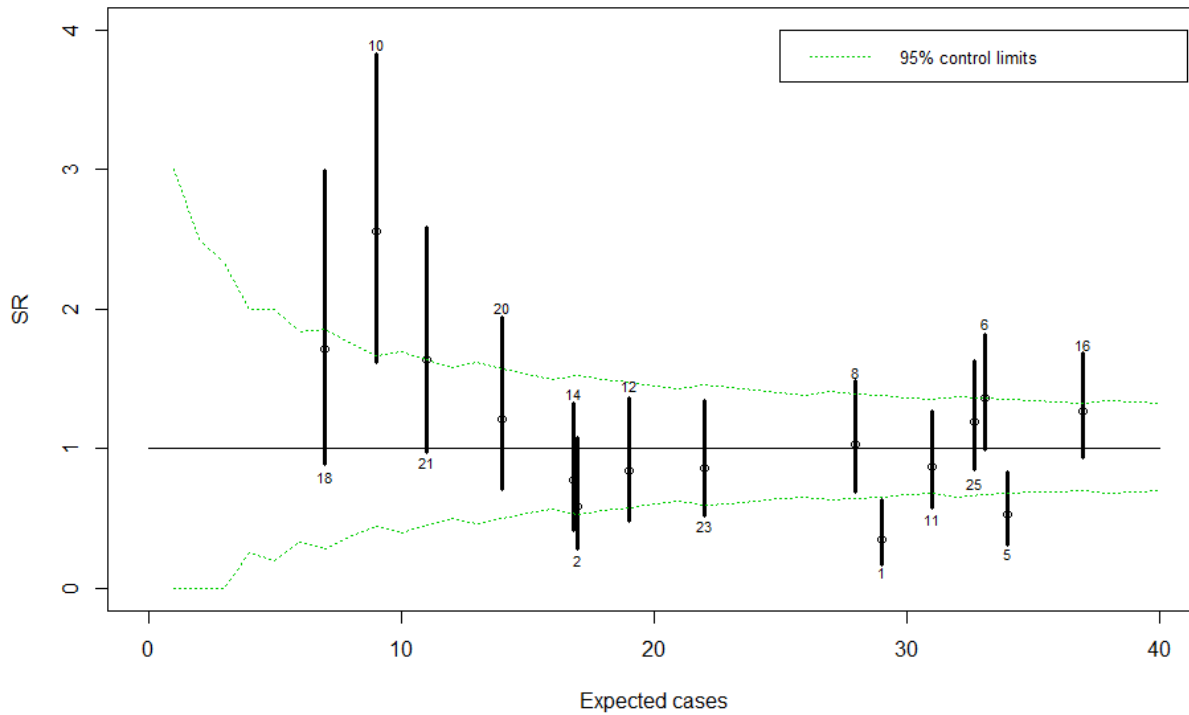
Sites with points outside the green “funnel” represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 3 sites have statistically higher or lower NDI rates.

Presentation No 26

Adjusted standardized ratios by site – Significant NDI- MiCare cohort

Site	Children (n)	Follow-up Rate (%)	Included Yes/ No	sNDI (n)	Adjusted Expected sNDI n	Adjusted standardized ratio (95%CI)
1	168	76.6	Y	10	29	0.34 (0.17, 0.63)
2	115	87.8	Y	10	17	0.59 (0.28, 1.08)
3	10	84.6	N	3		
4	13	76.5	N	0		
5	205	80.1	Y	18	34	0.53 (0.31, 0.84)
6	212	85.5	Y	45	33	1.36 (0.99, 1.82)
7	27	56.6	N	4		
8	145	71.4	Y	29	28	1.04 (0.69, 1.49)
9	53	48.2	N	8		
10	56	81.2	Y	23	9	2.56 (1.62, 3.83)
11	178	79.8	Y	27	31	0.87 (0.57, 1.27)
12	84	82.4	Y	16	19	0.84 (0.48, 1.37)
13	21	56.8	N	5		
14	103	76.3	Y	13	17	0.76 (0.41, 1.31)
15	30	60.8	N	8		
16	250	83.1	Y	47	37	1.27 (0.93, 1.69)
17	64	39.3	N	14		
18	43	91.5	Y	12	7	1.71 (0.88, 2.99)
19	17	25.8	N	0		
20	79	78.2	Y	17	14	1.21 (0.71, 1.94)
21	55	93.2	Y	18	11	1.64 (0.97, 2.59)
22	13	65	N	1		
23	132	79.5	Y	19	22	0.86 (0.52, 1.35)
24	7	53.8	N	1		
25	238	78.2	Y	39	33	1.18 (0.84, 1.62)
26	18	81.8	N	4		

1. Sites with < 20 participants for the 2.5 year MiCare cohort period and / or < 70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, severity of illness (SNAP > 20), retinopathy of prematurity, nosocomial infection and brain injury



**COMMENTS:**

Sites with points outside the green “funnel” represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 3 sites have statistically higher or lower sNDI rates.

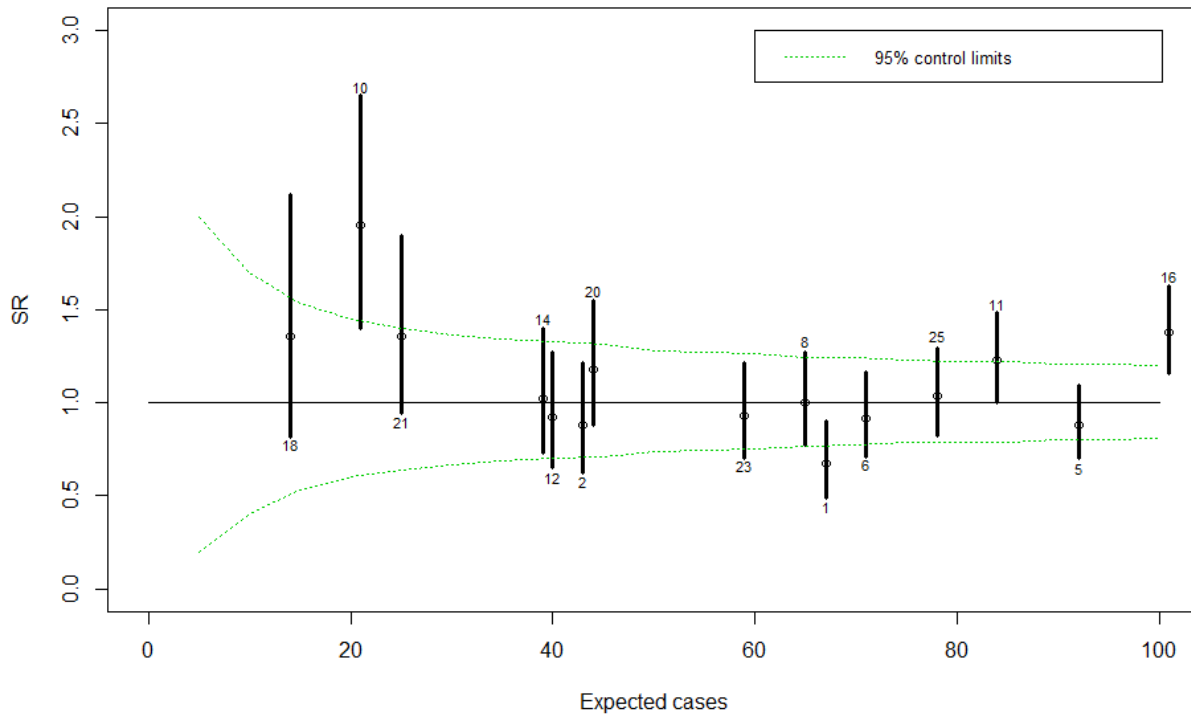
Presentation No 26

Adjusted standardized ratios by site – significant NDI or death- MiCare cohort

Site	Children (n)	Follow-up Rate (%)	Included Yes/ No	sNDI or death (n)	Adjusted Expected outcome (n)	Adjusted standardized ratio (95%CI)
1	205	76.6	Y	45	67	0.67 (0.49, 0.90)
2	143	87.8	Y	38	43	0.88 (0.63, 1.21)
3	11	84.6	N	3		
4	16	76.5	N	3		
5	268	80.1	Y	81	92	0.88 (0.70, 1.09)
6	233	85.5	Y	65	71	0.92 (0.71, 1.17)
7	33	56.6	N	7		
8	181	71.4	Y	65	65	1.00 (0.77, 1.27)
9	80	48.2	N	35		
10	74	81.2	Y	41	21	1.95 (1.40, 2.65)
11	254	79.8	Y	103	84	1.23 (1.00, 1.49)
12	105	82.4	Y	37	40	0.93 (0.65, 1.27)
13	30	56.8	N	14		
14	130	76.3	Y	40	39	1.03 (0.73, 1.40)
15	44	60.8	N	21		
16	342	83.1	Y	139	101	1.37 (1.16, 1.62)
17	115	39.3	N	65		
18	50	91.5	Y	19	14	1.36 (0.82, 2.12)
19	28	25.8	N	11		
20	114	78.2	Y	52	44	1.18 (0.88, 1.55)
21	71	93.2	Y	34	25	1.36 (0.94, 1.90)
22	15	65	N	3		
23	168	79.5	Y	55	59	0.93 (0.70, 1.21)
24	13	53.8	N	7		
25	283	78.2	Y	81	78	1.04 (0.82, 1.29)
26	19	81.8	N	5		

1. Sites with < 20 participants for the 2.5 year MiCare cohort period and / or < 70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, Apgar < 7, multiples, outborn, severity of illness (SNAP > 20), necrotizing enterocolitis and brain injury





**COMMENTS:**

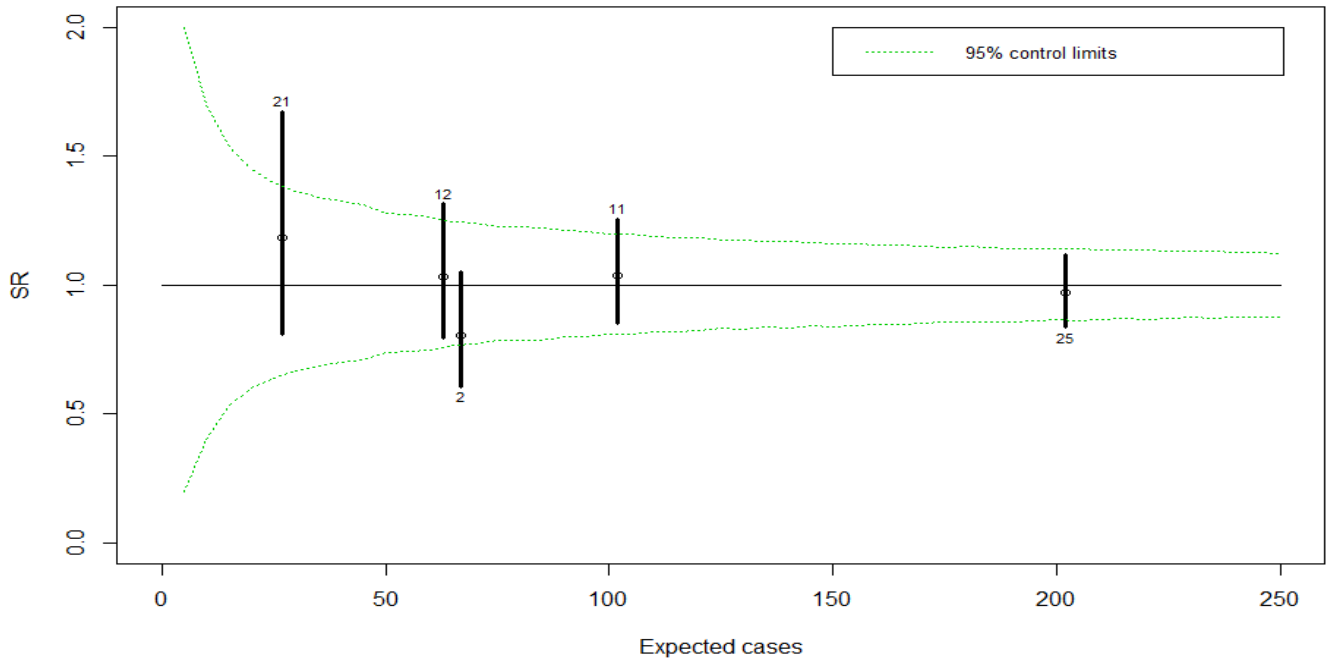
Sites with points outside the green “funnel” represent higher or lower adjusted significant NDI or death rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 3 sites have statistically higher or lower significant NDI or death rates.

Presentation No 27

Adjusted Standardized ratios by site – Neurodevelopmental Impairment (NDI)- Post- MiCare cohort (Oct 1 2011- Dec 31, 2015 births)

Site	Children (n)	Follow-up Rate %	Included Yes/ No	NDI (n)	Adjusted Expected NDI (n)	Adjusted standardized ratio (95%CI)
1	221	68.5	N	92		
2	140	76	Y	54	67	0.81 (0.61, 1.05)
3	9	9.8	N	3		
4	7	30.4	N	1		
5	6	1.4	N	5		
6	276	56.7	N	113		
7	11	16.9	N	2		
8	1	0.6	N	0		
9	4	3.4	N	2		
10	62	57.9	N	41		
11	229	71.3	Y	106	102	1.04 (0.85, 1.26)
12	139	81.4	Y	65	63	1.03 (0.80, 1.32)
14	154	65.4	N	67		
15	7	11.3	N	1		
16	219	46.7	N	97		
17	1	1.2	N	0		
18	9	12.2	N	5		
19	5	4.7	N	2		
20	89	69.3	N	35		
21	63	73.6	Y	32	27	1.19 (0.81, 1.67)
22	6	13.6	N	4		
23	56	27	N	17		
25	457	76.8	Y	196	202	0.97 (0.84, 1.12)
26	20	66.7	N	6		

1. Sites with < 20 participants for the 4 year post MiCare cohort period and / or < 70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, outborn, severity of illness (SNAP> 20), bronchopulmonary dysplasia, necrotizing enterocolitis and brain injury



**COMMENTS:**

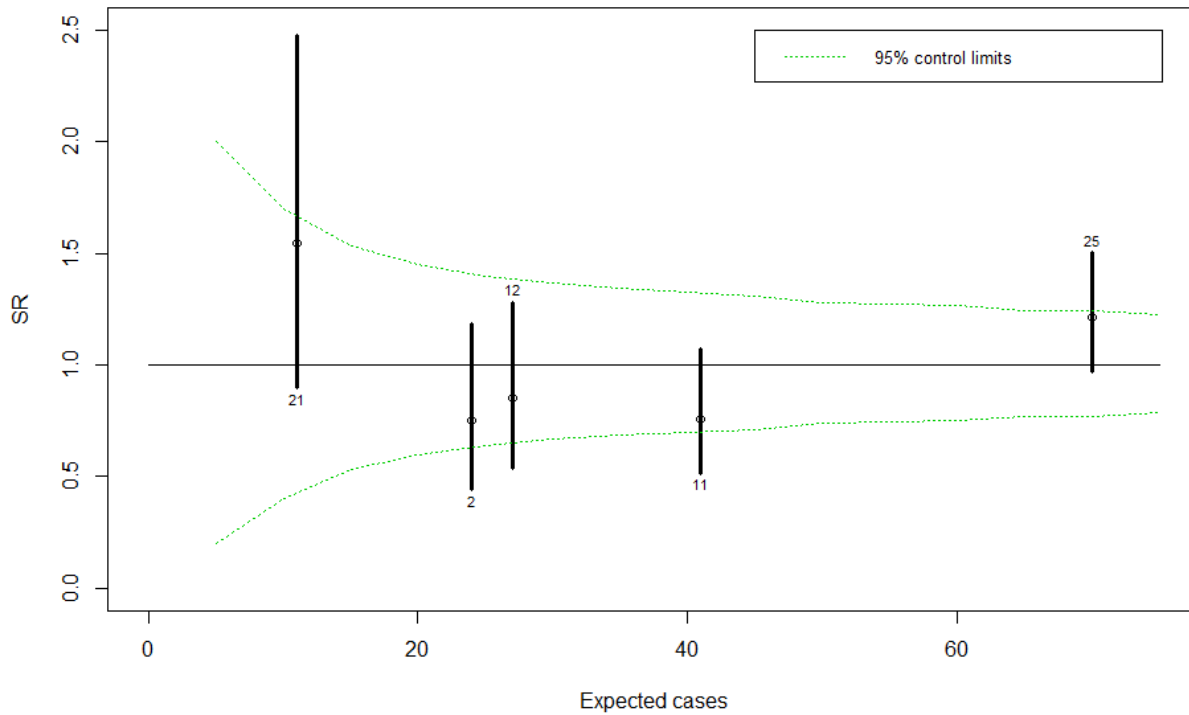
Sites with points outside the green “funnel” represent higher or lower adjusted NDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore no sites have statistically higher or lower NDI rates.

Presentation No 28

Adjusted standardized ratios by site – significant NDI- post MiCare cohort

Site	No. of children	Follow-up Rate (%)	Included Yes/ No	No. with sNDI	Adjusted/Expected sNDI (n)	Adjusted standardized ratio( 95%CI)
1	221	68.5		44		
2	140	76	Y	18	24	0.75 (0.44, 1.19)
3	9	9.8		2		
4	7	30.4		0		
5	6	1.4		3		
6	276	56.7		36		
7	11	16.9		2		
8	1	0.6		0		
9	4	3.4		2		
10	62	57.9		14		
11	229	71.3	Y	31	41	0.76 (0.51, 1.07)
12	139	81.4	Y	23	27	0.85 (0.54, 1.28)
14	154	65.4		23		
15	7	11.3		1		
16	219	46.7		31		
17	1	1.2		0		
18	9	12.2		2		
19	5	4.7		1		
20	89	69.3		20		
21	63	73.6	Y	17	11	1.55 (0.90, 2.47)
22	6	13.6		3		
23	56	27		9		
25	457	76.8	Y	85	70	1.21 (0.97, 1.50)
26	20	66.7		3		

1. Sites with < 20 participants for the 4 year post MiCare cohort period and / or < 70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, severity of illness (SNAP > 20), retinopathy of prematurity, nosocomial infection and brain injury



**COMMENTS:**

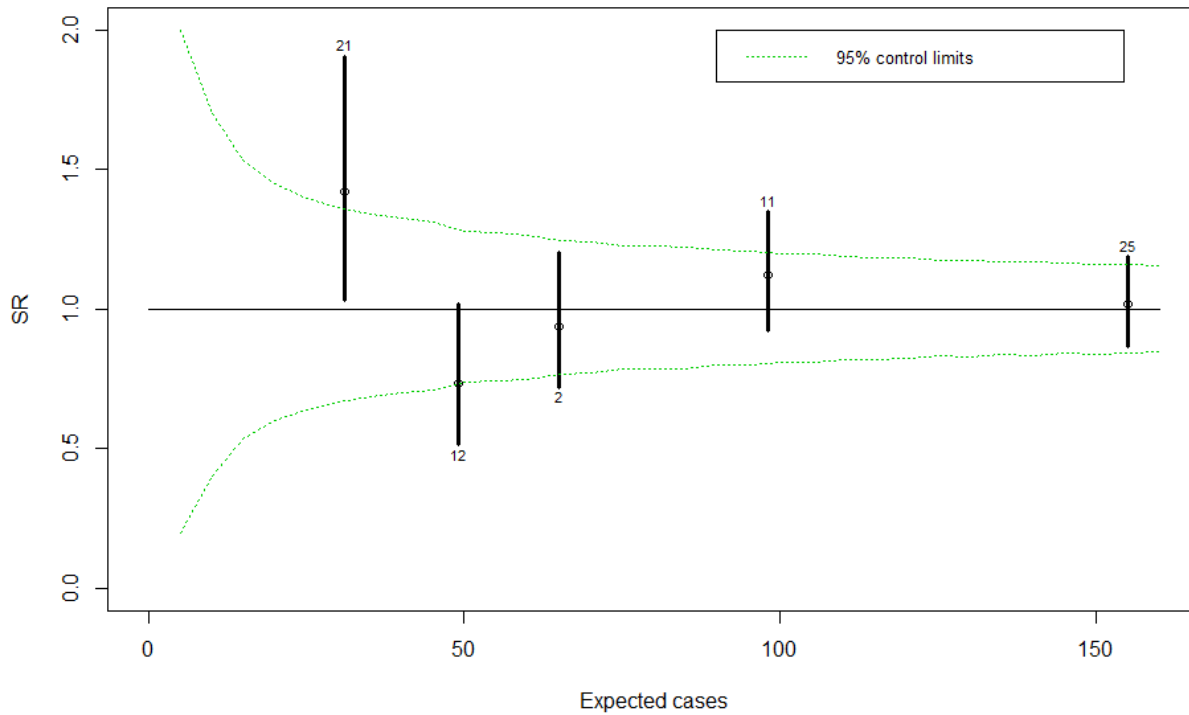
Sites with points outside the green “funnel” represent higher or lower adjusted sNDI rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore no sites have statistically higher or lower sNDI rates.

Presentation No 29

Adjusted Standardized ratios by site – significant NDI or Death post- MiCare cohort

Site	No. of children	Follow-up Rate (%)	Included Yes/ No	No. with outcome	Adjusted/Expected outcome (n)	Adjusted standardized ratio (95%CI)
1	263	68.5				
2	184	76	Y	61	65	0.94 (0.72, 1.21)
3	30	9.8				
4	16	30.4				
5	76	1.4				
6	326	56.7				
7	20	16.9				
8	54	0.6				
9	20	3.4				
10	81	57.9				
11	308	71.3	Y	110	98	1.12 (0.92, 1.35)
12	153	81.4	Y	36	49	0.73 (0.51, 1.02)
14	185	65.4				
15	26	11.3				
16	310	46.7				
17	42	1.2				
18	24	12.2				
19	16	4.7				
20	122	69.3				
21	92	73.6	Y	44	31	1.42 (1.03, 1.91)
22	15	13.6				
23	109	27				
25	530	76.8	Y	158	155	1.02 (0.87, 1.19)
26	22	66.7				

1. Sites with < 20 participants for the 4 year post MiCare cohort period and / or < 70% follow-up rates are excluded.
2. Model is adjusted for gestational age, sex, antenatal steroids, Apgar < 7, multiples, outborn, severity of illness (SNAP> 20), necrotizing enterocolitis and brain injury



**COMMENTS:**

Sites with points outside the green “funnel” represent higher or lower adjusted sNDI or death rates than expected. When the 95% confidence interval doesn’t cross 1, the results are statistically significant. Therefore 1 site has a statistically higher sNDI or death rates.

## I. Summary of Publications

### Manuscripts 2016:

1. Morin J, Luu TM, Superstein R, Ospina LH, Lefebvre F, Simard MN, Shah V, Shah PS, Kelly EN; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network Investigators. Neurodevelopmental Outcomes Following Bevacizumab Injections for Retinopathy of Prematurity. *Pediatrics* 2016 Apr;137(4) pii: e20153218. doi: 10.1542/peds.2015-3218.

### Manuscripts 2017:

1. Isayama T, Lee SK, Yang J, Lee D, Daspal S, Dunn M, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow - Up Network Investigators. Revisiting the Definition of Bronchopulmonary Dysplasia: Effect of Changing Panoply of Respiratory Support for Preterm Neonates. *JAMA Pediatr.* 2017 Mar 1;171(3):271-279
2. Asztalos E, Church PT, Riley P, Fajardo C, Shah PS, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network investigators. Neonatal factors associated with a good neurodevelopmental outcome in the very preterm infant. *Am J Perinatol.* 2017 Mar;34(4):388-396.
3. Asztalos E, Church PT, Riley P, Fajardo C, Shah PS, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network investigators. Association between Primary Caregiver Education and Cognitive and Language Development of Preterm Neonates. *Am J Perinatol.* 2017 Mar;34(4):364-371
4. Synnes A, Luu TM, Moddemann D, Church P, Lee D, Vincer M, Ballantyne M, Majnemer A, Creighton D, Yang J, Sauve R, Saigal S, Shah P, Lee S, CNN, CNFUN. Determinants of developmental outcomes in a very preterm Canadian cohort. *Arch Dis Child Fetal Neonatal Ed.* 2017 May;102(3):F235-F234.
5. Raghuram K, Yang J, Church PT, Cieslak Z, Synnes A, Mukerji A, Shah PS, CNN and CNFUN. Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Head growth trajectory and neurodevelopmental outcomes in preterm neonates. *Pediatrics.* 2017 Jul;140(1) pii: e20170216. doi: 10.1542/peds.2017-0216
6. Soraisham AS, Rabi Y, Lodha AK, Shah PS, Synnes A, Yang J, Singhal N, CNN, CNFUN. Neurodevelopmental outcomes of preterm infants resuscitated with different oxygen concentration at birth. *J Perinatol.* 2017 Oct;37(10):1141-1147.



## Manuscripts 2018:

1. Shah P, McDonald S, Barrett J, Synnes A, Robson K, Foster J, Pasquier JC, Joseph KS, Piedboeuf B, Lacaze-Masmonteil T, O'Brien K, Shivananda S, Chaillet N, Pechlivanoglou P, for the Canadian Preterm Birth Network Investigators. The Canadian Preterm Birth Network: a study protocol for improving outcomes for preterm infants and their families. doi: 10.9778/cmajo.20170128 CMAJO January 18, 2018 vol. 6 no. 1 E44-E49
2. Amer R, Moddemann D, Seshia M, Alvaro R, Synnes A, Lee KS, Lee SK, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-up Network Investigators. Neurodevelopmental Outcomes of Infants Born at <29 Weeks of Gestation Admitted to Canadian Neonatal Intensive Care Units Based on Location of Birth. *J Pediatr.* 2018 May;196:31-37.e1
3. Haslam MD, Lisonkova S, Creighton D, Church P, Yang J, Shah PS, Joseph KS, and Synnes A; Canadian Neonatal Network and the Canadian Neonatal Follow-Up Network. Severe Neurodevelopmental Impairment in Neonates Born Preterm: Impact of Varying Definitions in a Canadian Cohort. *J Pediatr.* 2018 Jun;197:75-81
4. Ting JY, Synnes AR, Lee SK, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network. Association of admission temperature and death or adverse neurodevelopmental outcomes in extremely low-gestational age neonates. *J Perinatol.* 2018 Jul;38(7):844-849.
5. Ting JY, Synnes A, Roberts A, Deshpandey AC, Dow K, Yang J, Lee KS, Lee SK, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network. Association of Antibiotic Utilization and Neurodevelopmental Outcomes among Extremely Low Gestational Age Neonates without Proven Sepsis or Necrotizing Enterocolitis. *Am J Perinatol.* 2018 Aug;35(10):972-978
6. Kelly EN, Shah VS, Levenbach J, Vincer M, DaSilva O, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Inhaled and systemic steroid exposure and neurodevelopmental outcome of preterm neonates. *J Matern Fetal Neonatal Med.* 2018 Oct;31(20):2665-2672
7. Lodha A, Entz R, Synnes A, Creighton D, Yusuf K, Lapointe A, Yang J, Shah PS; investigators of the Canadian Neonatal Network (CNN) and the Canadian Neonatal Follow-up Network (CNFUN). Early Caffeine Administration and Neurodevelopmental Outcomes in Preterm Infants. *Pediatrics.* 2018 Dec 5. pii: e20181348. doi: 10.1542/peds.2018-1348.
8. Stockley EL, Ting JY, Kingdom JC, McDonald SD, Barrett JF, Synnes AR, Monterrosa L, Shah PS; Canadian Neonatal Network; Canadian Neonatal Follow-up Network; Canadian Preterm Birth Network Investigators. Intrapartum magnesium sulfate is associated with neuroprotection in growth-restricted fetuses. *Am J Obstet Gynecol.* 2018 Dec;219(6):606.e1-606.e8.

9. Iwami H, Isayama T, Lodha A, Canning R, Abou Mehrem A, Lee SK, Synnes A, Shah PS; Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Outcomes after Neonatal Seizures in Infants Less Than 29 Weeks' Gestation: A Population-Based Cohort Study. *Am J Perinatol*. 2018 Jul 17. doi: 10.1055/s-0038-1667107. [Epub ahead of print]
10. Shafey A, Bashir RA, Shah PS, Synnes A, Kelly E, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network Investigators. Outcomes and resource usage of infants born at  $\leq 25$  weeks gestation in Canada. Accepted to *Paediatrics & Child Health*.

### **Theses:**

1. Silva M. Trend in incidence rates of inguinal hernia in a population-based study of preterm infants. (MHSc, University of BC, 2016)
2. Haslam M. The Effect of Neurodevelopmental Impairment Definition on Incidence Rates among Very Preterm Infants (MSc, Population and Public Health, University of BC, 2016)
3. Panczuk, J. Socio-demographic and health characteristics among Aboriginal mothers of preterm infants born less than 29 weeks gestation and infant short- and long-term outcomes in Canada. (MSc, 2016)

### **Manuscripts Submitted:**

4. Fischer N, Soraisham A, Synnes A, Shah PS, Singhal N, Ting J, Creighton D, Dewey D, Metcalfe A, Ballantyne M, Lodha A, CNN and CNFUN. Long-term neurodevelopmental outcomes following extensive cardiopulmonary resuscitation in the delivery room for preterm infants born  $<29$  weeks GA in Canada. Under revision by *Resuscitation*
1. Ediger K, Hasan S, Synnes A, Shah J, Creighton D, Isayama T, Shah PS, Lodha A, Canadian Neonatal Network and Canadian Neonatal Follow-Up Network. Maternal Smoking and Neurodevelopmental Outcomes in Infants  $<29$  Weeks' Gestation: A Multicenter Cohort Study. Submitted to *J Perinatol*.

### **Manuscript drafts**

1. Synnes A, Gillone J, Majnemer A, Lodha A, Creighton D, Moddemann D, Shah P, CNN and CNFUN. Preterm children with suspected cerebral palsy at 18 months corrected age in the Canadian Neonatal Follow-Up Network. Ready for submission to *Acta Paediatr*.
2. Albaghli F, Church P, Ballantyne M, Girardi A, Synnes A, CNFUN and the Provincial Council for Maternal and Child Health, Ontario. Neonatal Follow-up in Canada: Results from a National Survey. In final draft form for submission to *Paediatrics & Child Health*.

3. Synnes A, Zhang S, Butt A, Colby L; Canadian Neonatal Follow-Up Network Investigators. Effect of social risk and home environment on preterm children. Semifinal draft.
4. Girardi A, Church P, Luu TM, Lee D, Ballantyne M, Moddemann D, Creighton D, Sauve R, Vincer M, Majnemer A, Saigal S, Shah P, Lee SK, Synnes A, CNFUN. Health and developmental outcomes of children born preterm: Three-year follow-up of the Canadian Neonatal Follow-up Network (CNFUN) cohort. Semi final draft.