

## Rights of Preterm and NICU Babies to Standardized Follow-Up Care



Anne Synnes MDCM, MHSc, FRCPC  
Neonatologist, BC Women's Hospital & Director, Neonatal Follow-Up Program  
Clinical Associate Professor, UBC

## Goals- Consider the Following

- What neurodevelopmental services should high risk newborns have access to?
- Should there be a quality assurance for newborn health care?
- Do newborns have a right to evidence based care?
- What other Neonatal Follow-Up care services do babies & families benefit from?

## Plan for Today

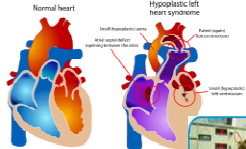


- Background
- Neonatal Follow-Up Programs in Canada
- CNFUN
- Current issues to be addressed
- Your opinion counts

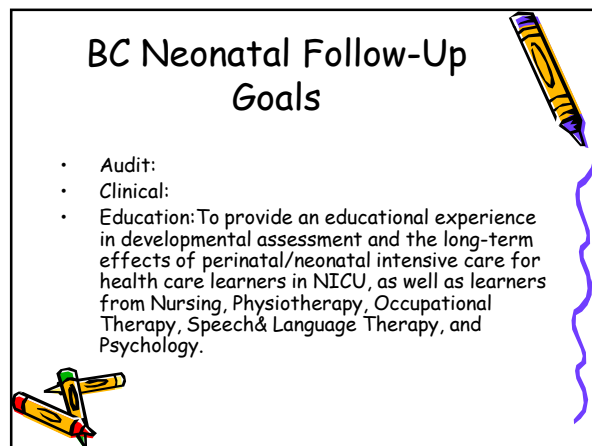
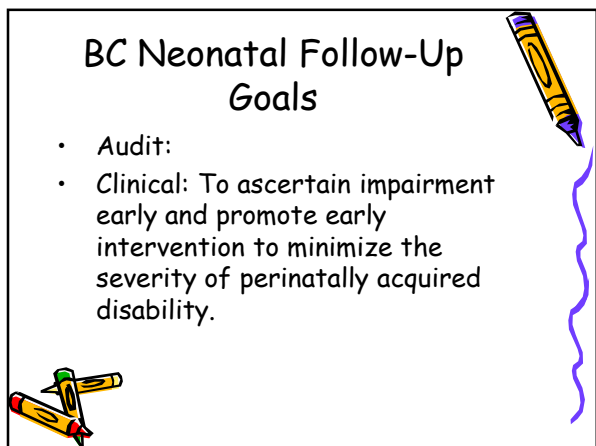
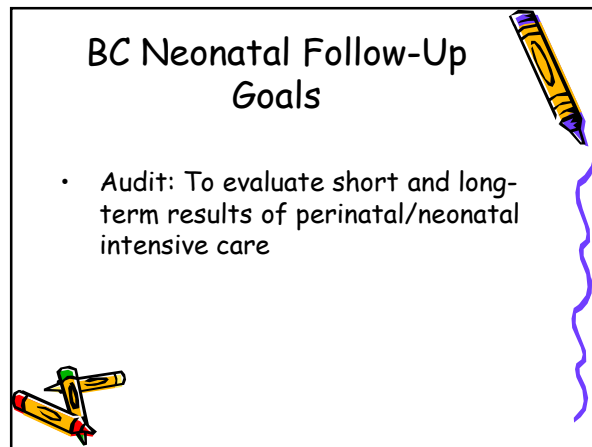
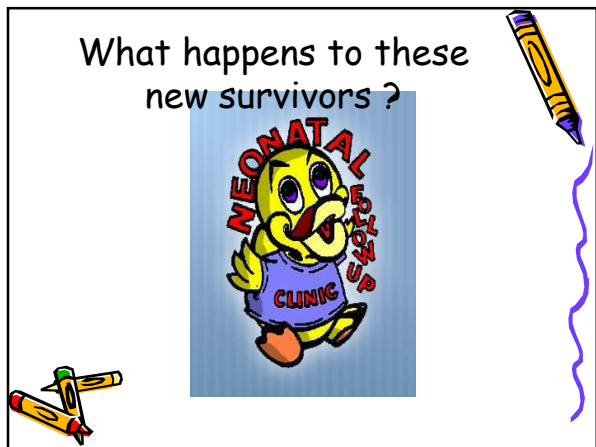
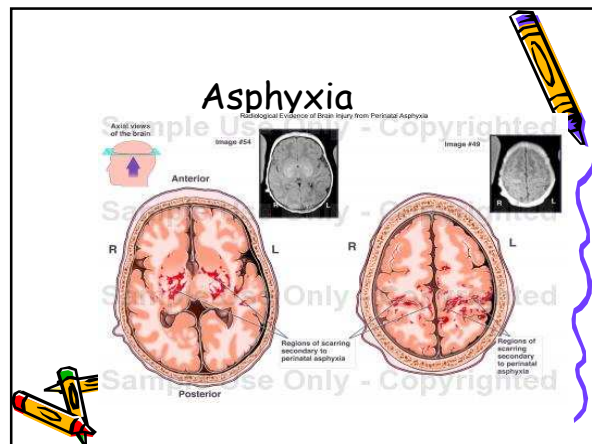
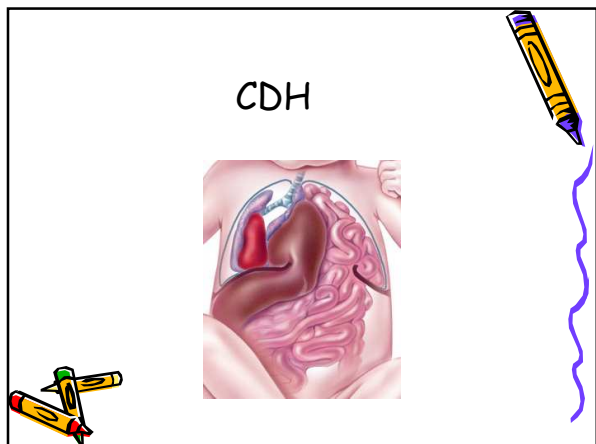



© 2006 Encyclopædia Britannica, Inc.




## Cardiac and ECLS




## BC Neonatal Follow-Up Goals

- Audit:
- Clinical:
- Education:
- Research: To promote and carry out research to further knowledge of the long-term effects of selected aspects of perinatal and neonatal management.



## BC Neonatal Follow-Up Goals


- Audit:
- Clinical:
- Education:
- Research:
- Collaborative: To co-operate with perinatal follow-up programs across Canada and the U.S. in assessing patients belonging to those programs who move to British Columbia.



## Variations in Neonatal Follow-Up

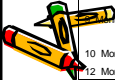
Birth weight and gestational age	Number of FUPs
≤ 1500 grams	9
Small for gestation (< - 3 SD)	6
<1250 grams bwt	5
< 31 or < 32 or < 33 wks GA	5
< 28 wks GA	3
≤ 800 or < 1000 grams bwt	2
< 25 weeks GA	1

Synnes AR, Lefebvre F, Caké HA. Current status of neonatal follow-up in Canada. *Pediatr Child Health* 2006;11:271-4.



**Table 2. Age for Scheduled Visits in 19 Canadian Neonatal Follow-up Programs**


First Year		Second Year		After 2 Years	
Age	NFUPs (No.)	Age	NFUP (No.)	Age	NFUP (No.)
Term	6	15 Months	1	3 years	14
2 Months	1	18 Months	16	4 Years	6
3 Months	2	20 Months	1	4.5 Years	2
4 Months	15	21 Months	1	5 Years	5
6 Months	5	24 months	12	6 Years	3
8 Months	14			8 Years	1
10 Months	1			13 Years	1
12 Months	2			No Visits	3
	14				




**Table 3. Standardized Assessments in 19 Canadian Neonatal Follow-up Programs**

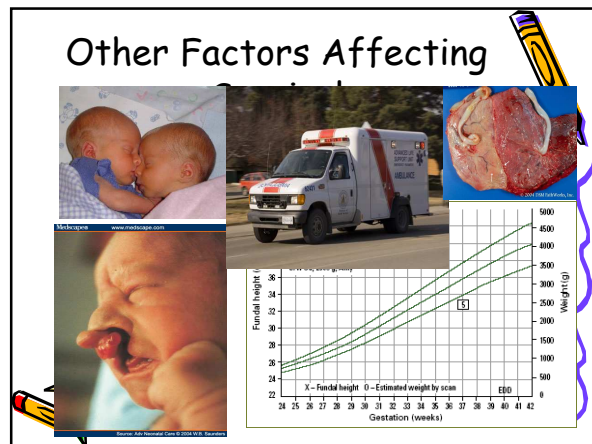
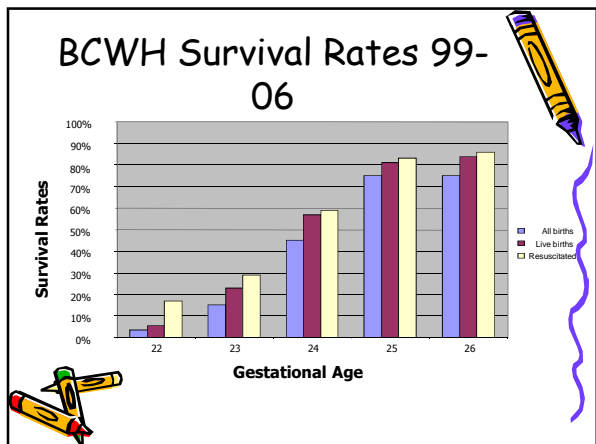
Assessments	Age	Number of NFUPs
<b>Motor</b>		
Alberta Infant Motor Scales	4-60 months	8
Test of Gross Motor & Reflex Development	4 months	1
Movement Assessment of Infants	4-8 months	2
Peabody Developmental Motor Scales	4-72 months	8
Beery Visual Motor Integration	36 months	3
Kaufman-Assessment Battery for Children (or subsets)	36-60 months	4
Bruninks Oseretsky Motor Proficiency Agility	54 months	2

Synnes AR, Lefebvre F, Caké HA. Current status of neonatal follow-up in Canada. *Pediatr Child Health* 2006;11:271-4.



## What have we learned?





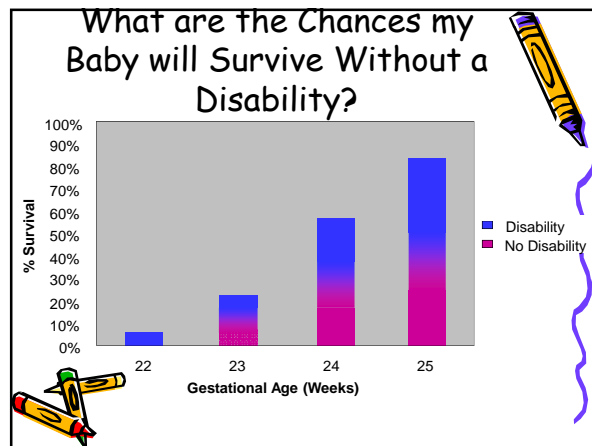
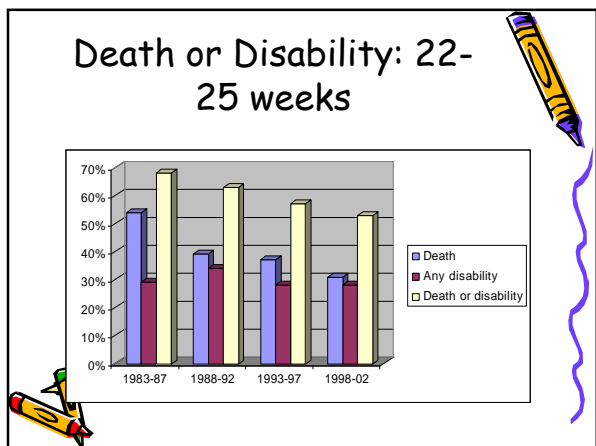
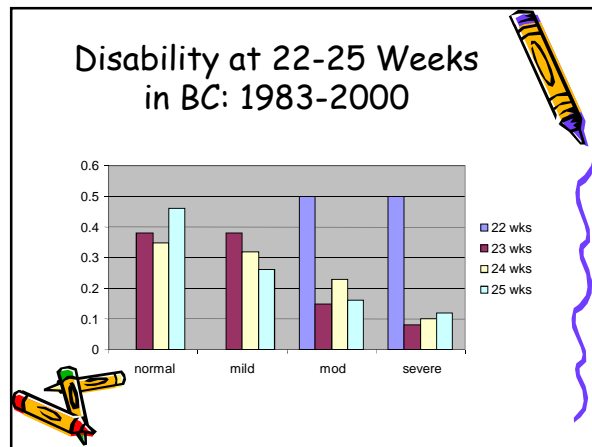
### The Extremely Premature Baby

Parent Information Sheet #2

Like other children, babies born early have their own strengths and weaknesses. The following information is provided to help you better understand the effects of being born early. We have defined different kinds of disability as follows:

Disability	Movement	Intelligence	Hearing/Speech	Eyesight
Mild	Clumsy or difficulties with paper and pencil work	Learning difficulties in schoolwork	Mild hearing loss	Needs glasses
Moderate	Cerebral palsy but can walk by themselves	Slower than average, but learns with support	Permanent hearing problem corrected with hearing aids	Poor eyesight, even with glasses
Severe	Unable to walk without help	Very low; will need care lifelong	Deaf: cannot hear even with hearing aids	Blind

More than half of children born extremely preterm need special assistance in school.



## Factors Associated with Worse Neurodevelopmental Outcome

- Boys<sup>1</sup>
- Multiples (twins, triplets, etc)<sup>1</sup>
- Sick at birth<sup>1</sup>
- Abnormal brain images, lung problems (BPD), or eye problems (ROP)<sup>2</sup>
- Prenatal care, higher birth weight, and being female were associated with a better outcome<sup>1</sup>

## Are we meeting our goals?

- Audit: Annual report BUT
- Clinical: For some BUT
- Education: nonstandardized
- Research: variable
- Collaborative: usually
- Advocacy: ???

## Canadian Neonatal Follow-Up Network (CNFUN)



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.

www.cnfun.ca

- CNFUN is a voluntary collaboration between Neonatal and Perinatal Follow-Up Programs in Canada
- Developed in liaison with the Canadian Neonatal Network
- Facilitates
  - Collaboration in research
  - Integrated data collection
  - Knowledge translation
  - Improvement of the quality of care and long-term outcomes of children seen in their programs.
- CNFUN Director: Dr. Anne Synnes

- 25 participating sites across Canada
- Will follow all babies born at  $\leq 28$  weeks gestation ( $n = 2400$ )
- Linked to Level-III NICUs (CNN)
- Two cohorts:
  - Pilot: born April 1-Sept 30, 2009
  - MiCare: born Oct 1 2009-Sept 30, 2011
- Sites will complete two neurodevelopmental assessments:
  - 18 months (corrected)
  - 36 months (chronological)



### Details of CNFUN Assessments

- At 18 months corrected age:
  - Clinic visit
  - Sociodemographic information and post-NICU discharge health utilization
  - Growth and physical examination
  - Gross Motor Function Classification System
  - Bayley Scales of Infant and Toddler Development (3<sup>rd</sup> edition)
- At 36 months corrected age:
  - Questionnaire mail out
  - Identify parental concerns
  - Health Status Classification Pre-School (HSCS-PS)
  - Ages and Stages Questionnaire
  - Behaviour Rating Inventory of Executive Function-Preschool (BRIEF-P)

## Optimal Follow-Up Project Workshop

There are three over-arching rationales for conducting a meeting:

- 1) Key FUP stakeholders have never met to identify needs, gaps and opportunities of FUPs.
- 2) The benefit and effectiveness of FUPs have never been reviewed.
- 3) National standardized long term outcome data collection (eg CNFUN) provides additional benefits to FUP knowledge users.

A meeting June 2012 will determine stakeholders priorities.

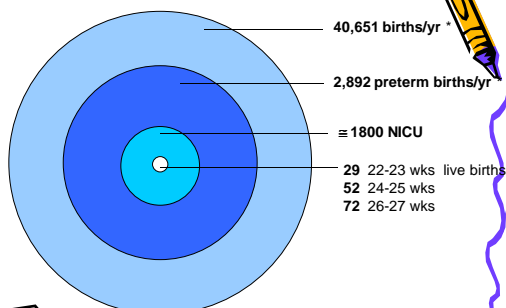
## Who are You

- Provide clinical care to children?
  - Are some survivors of new technologies?
  - Provide (N)ICU care using new technologies?
- Parent / relative of child treated in (N)ICU?
- Researcher?
  - Interest in NFUP populations?
- Administrator?
- Educator?
- Child Advocate?

## Roles of Follow-Up Programs

- Provide clinical care (includes screening and preventive health care).
- Audit
- Facilitate and support research.
- Advocate for individuals
- Advocate for populations of children and their families
- Provide teaching (MD, RN, OT/PT etc)

## British Columbia Births



Canadian Perinatal Health Report, 2003

## Which children should be seen?

- High risk of disability
- Those most likely to benefit from FUP
- Those most likely to fall through the cracks
- Those with the most complex health and social situations
- Other

## Who decides?

Who should determine the recruitment criteria for a FUP ?

- The FUP
- NICU administrators
- A provincial body
- A national collaborative body
- Other

## Accessing FUP Services

- All should meet specified recruitment criteria
- Referral from community
- Recruitment criteria or community referral
- Families should self refer
- Other

## Types of children

- Very preterm.
- NICUs- multiple criteria
- Serious health conditions requiring invasive treatments in the newborn period (eg ECMO, surgery for complex congenital heart disease).
- Infants or young children with health conditions where the outcome is unknown.
- Children of any age with health conditions where the outcome is unknown.

## What should we assess in a FUP?

- Growth?
- Feeding problems?
- Motor problems ?
- Developmental delay?
- Intelligence?
- Learning disabilities?
- Behavioural problems?
- Hearing?
- Vision and Ophthalmology assessments?
- Respirologist assessment?
- Cardiologist assessment?
- Neurologist assessment?

## Audit in the FUP

- Parental input /satisfaction about the(N)ICU
- Capture individual patient adverse outcomes
- Provide institutional based outcome data
- Provide institutional based outcome data which is nationally benchmarked and adjusted for risk factors.

## Expertise in the FUP

- Motor assessments in young children (< 3 yrs)
- Motor assessments in children 4 to 8 years of age
- Standardized neurological exam eg Amiel-Tison
- Diagnose and classify cerebral palsy
- Developmental assessments up to 3 years of age
- IQ 3-5 years of age
- IQ 6-10 years of age
- Learning disabilities
- Behaviour including autism and ADHD
- Speech assessments
- Hearing
- Visual acuity and ocular diseases
- Manage chronic lung disease / children discharged on home oxygen
- Dietary management
- Feeding problems
- Other

## Teaching- How important is it?

0 1.0

Not important Essential

## Who should advocate for an individual child / family?

- Community therapist
- Family physician
- Paediatrician
- Developmental paediatrician
- FUP physician
- Other

## Who should advocate for at risk children?

- Community therapists
- Family physicians
- Paediatricians
- Developmental paediatricians
- FUP staff
- Parent groups
- Research groups
- Social workers
- Other



## Canadian standards?

- Minimal criteria for the patient populations to be offered clinical services through a FUP
- Core clinical services / assessments to be available in a FUP
- The age at which children should be discharged from a FUP
- A national standardized assessment protocol to be used for audit
- FUP infrastructure
- FUP funding
- Curriculum for neonatal perinatal medicine trainees



## A National Body (CNFUN /CPS)?

Should a national body:

- Develop standards for FUPs
- Maintain a database
- Benchmarking and write an annual report
- Facilitate research
- Develop an educational curriculum?



## How should FUPs be funded?

- Clinical and research should be kept separate and each funded separately
- Provincial health care dollars
- Charity and fundraising
- Other



## FUP Location

- Close to the NICU ?
- Close to developmental pediatric services?
- Close to audiology / ophthalmology and services deemed most important ?
- Outreach programs?



## Questions

