

S.H.I.P. PASSPORT

Spina Bifida & Hydrocephalus Interdisciplinary Program



Girl

Client name:

Emergency contact and phone n°:

.....

WHAT IS SPINA BIFIDA AND HYDROCEPHALUS

Spina Bifida is a neural tube birth defect which occurs within the first four weeks of pregnancy. The spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system, leading to some degree of paralysis. Most children and adults have problems with bowel and bladder control. Spina Bifida is often visible as a sac on the outside of the back.

Hydrocephalus (“water on the brain”) is a condition that occurs when the normal drainage pathways of cerebrospinal fluid are blocked. Fluid accumulates in the ventricles inside the brain, causing them to swell - resulting in compression of surrounding brain tissue. In babies and infants, the head will enlarge. Hydrocephalus can either be congenital or acquired, mostly as a result of infection (e.g. meningitis).

Both conditions are not the fault of the child nor its parents.

HOW TO USE THIS PASSPORT

This SHIP Passport is designed to collect the most important data in the medical and lifelong care of children with Spina Bifida and Hydrocephalus.

It provides a quick overview of the child’s condition to all specialists involved in its treatment and follow-up, and improves the coordinated multidisciplinary approach for an individualized care program for each child.

The Passport stays with the child at all times, and should be brought to each appointment, either at the hospital, CBR centre or during home visits.

PERSONAL DATA

Full names of client:

Birth Date:

Mother: Alive / Dec. Occupation:

Father: Alive / Dec. Occupation:

With whom does the child live? Relation:

Contact phone no:

.....

Languages:

Parish: County.....

Sub county: District:

Local Leader/Chief:

Contact Phone No:

.....

.....

MAIN CONTACT PERSONS

S.H.I.P. Coordinator:

Phone No:

Email:

Parent support group:

Phone No:

Email:

CBR Centre:

Hospital:

Continence Nurse (name & location):

Social worker (name & location):

Other:

MEDICAL FILES

Hospital: File n°:

Hospital: File n°:

CBR center: File n°:

CBR center: File n°:

MEDICAL HISTORY – SPINA BIFIDA

Date 1st assessment.....

Date of birth:

Location:

Diagnosis: **Spina Bifida** with / without **Hydrocephalus**

Cele level:

Cele wound **at birth**: open / closed / infected / lipomeningocele

MEDICAL HISTORY - HYDROCEPHALUS

Date 1st assessment.....

Date of birth:

Location:

When and how did the problem start:

.....

.....

.....

Head circumference (cm): *Fill in head circumference chart – page 17-18*

Mental development: normal / delayed

CONTINENCE MANAGEMENT

Bladder continence - CIC

CIC regime: yes / no

Start date CIC:

Medication:

Bowel continence – Wash-out

Wash-out: yes / no

Start date:

Supplies

Date	Size of catheters	Number of catheters, cones

FOLLOW-UP NOTES (1)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (2)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (3)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (4)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (5)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (6)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (7)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

FOLLOW-UP NOTES (8)

Date	Location, home visit	Procedures done, treatment, medications, investigations, skin care, folic acid	General results, complications, advices, training

MOBILITY/ASSISTIVE DEVICES, APPLIANCES

Date of order	Date of delivery	Item	Workshop/Centre

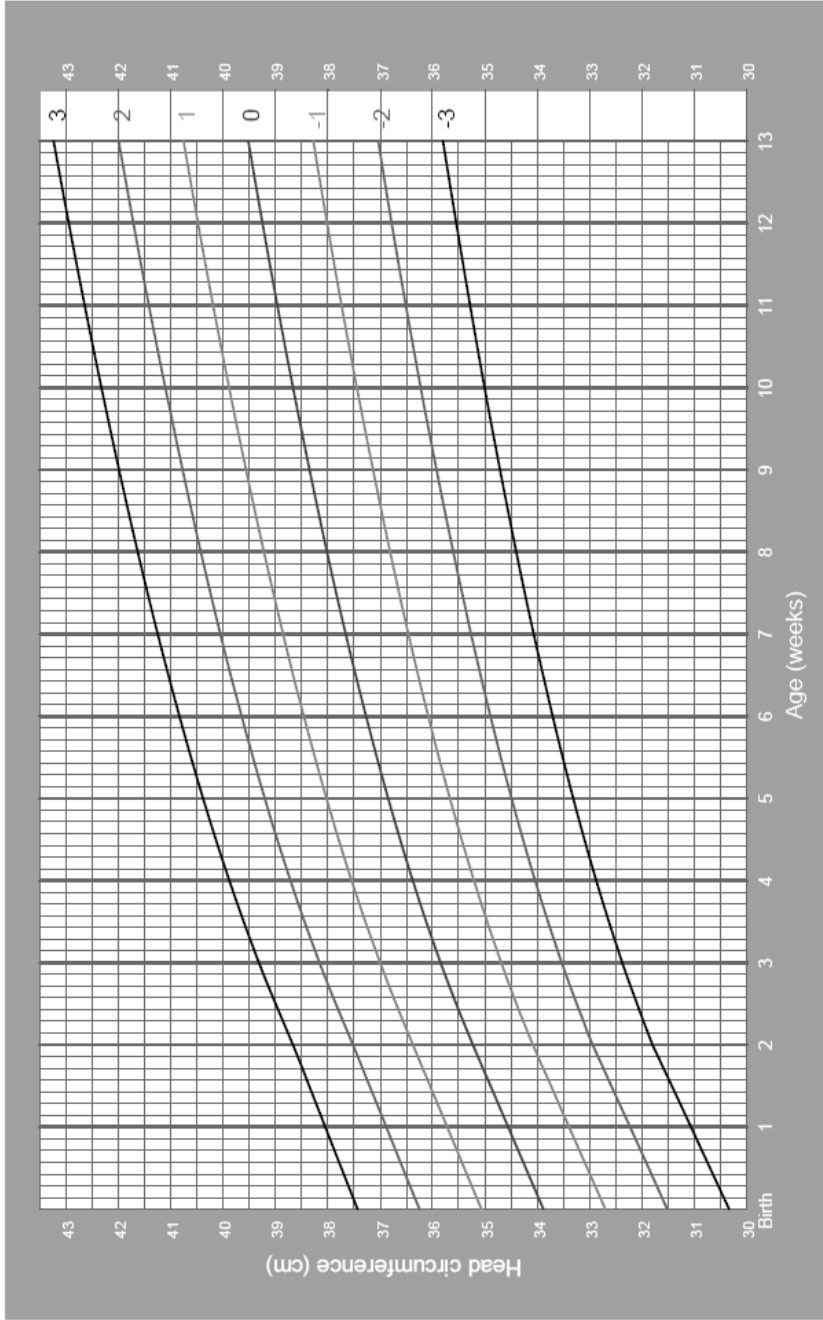
INFORMATION TO BE PROVIDED TO PARENTS

This list is intended to provide an overview of topics of which parents should be informed about. This list is not exhaustive.

Topic	Date(s)
Condition (degree & risks) and next steps in treatment	
Cost implications & available resources	
Measuring head circumference	
Signs of High pressure (Hydrocephalus)	
Care of cele	
Continance management (bladder & bowel)	
Sensitization & Skin care	
Mobility & physiotherapy	
Development & physio-/occupational therapy	
Deformities	
Appliances	
Folic acid	
Vaccination / immunization	
Life skills	
Schooling / education	
Parent support group	
Other:	

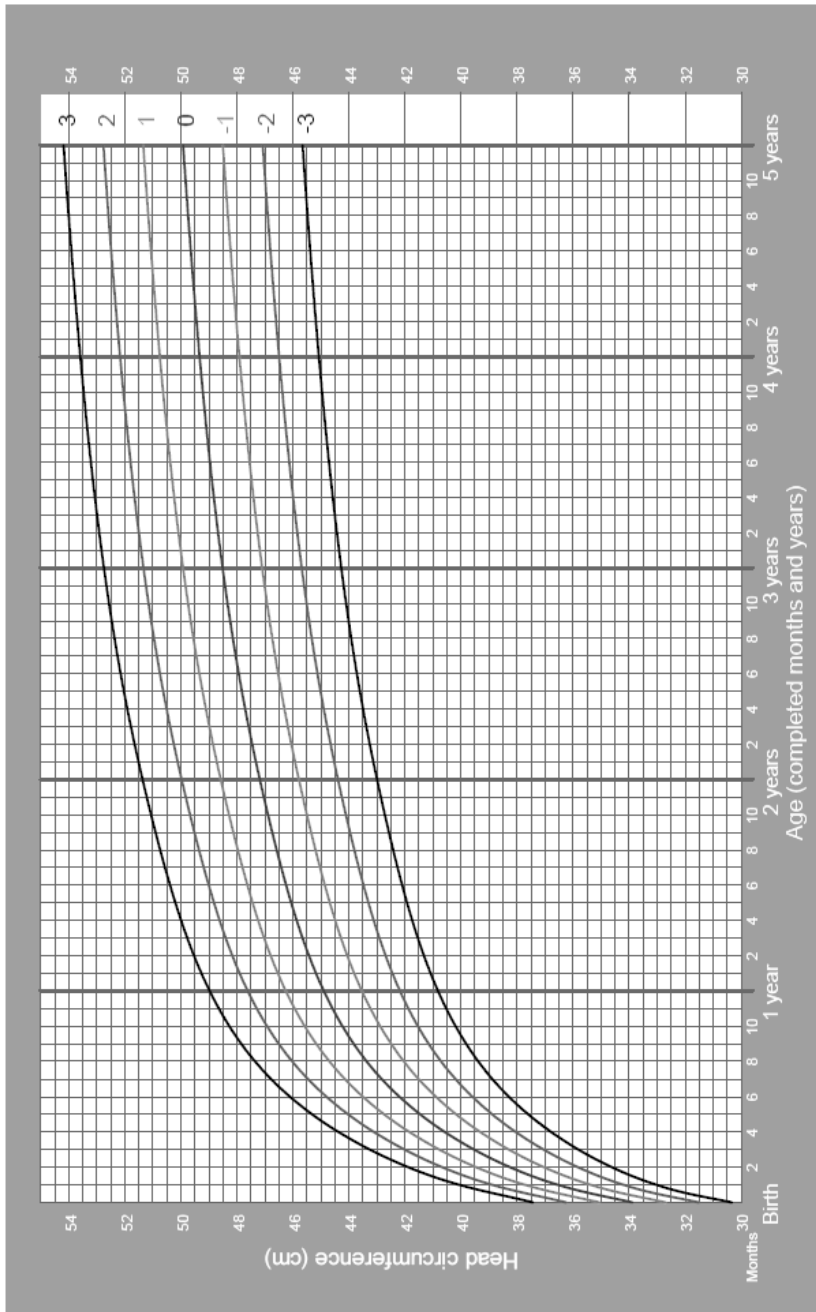
Head circumference-for-age GIRLS

Birth to 13 weeks (z-scores)



Head circumference-for-age GIRLS

Birth to 5 years (z-scores)





© International Federation for Spina Bifida and Hydrocephalus, 2013