BABY HUG FOLLOW-UP STUDY II

QUESTIONNAIRE

PART I: IDENTIFYING INFORMATION

1. Patient's ID Number: ___ ___ ___ ___ SUBJECT_ID
2. Current Clinic: ___ ___ SITE_ID
3. Patient's Letter Code: ___ ___ ___ LETTER_CD
4. Visit: ___ ___ ___ VISIT_NBR
5. Form Date: ___ ___ ___ - ___ ___ - ___ ___ ___ ___ VISIT_DT
   Month Day Year

This is a composite questionnaire to be done annually on patients. Please ask the questions as they are written and record the responses on this form (this is your source document). Please read ALL of the possible responses before accepting a patient's answer. Ensure that there is privacy during the conversation.

PART II: SLEEP

Please answer these questions regarding the behavior of your child during sleep and wakefulness. The questions apply to how your child acts in general during the past month, not necessarily during the past few days since these may not have been typical if your child has not been well. A "Y" means "yes," "N" means "no," and "DK" means "don't know."

	Yes	No	Don't Know (DK)	
1. While sleeping, does your child:				
A. snore more than half the time?	(1)	(2)	(3)	SNR_HLFT2
B. always snore?	(1)	(2)	(3)	SNORE2
C. snore loudly?	(1)	(2)	(3)	SNR_LOUD2
D. have heavy or loud breathing?	(1)	(2)	(3)	BRTHLOUD2
E. have trouble breathing, or struggle to breathe?	(1)	(2)	(3)	BRTHTRBL2
2. Have you ever seen your child stop breathing during the night?	(1)	(2)	(3)	BRTHSTP2
3. Does your child:				
A. tend to breathe through the mouth during the day?	(1)	(2)	(3)	BRTHMTH2
B. have a dry mouth on waking up in the morning?	(1)	(2)	(3)	DRYMTH2
C. occasionally wet the bed?	(1)	(2)	(3)	WETBED2
D. wake up feeling unrefreshed in the morning?	(1)	(2)	(3)	WKPRFRSH2
E. have a problem with sleepiness during the day?	(1)	(2)	(3)	SLP_PROB2
4. Has a teacher, supervisor or other adult commented that your child appears sleepy during the day?	(1)	(2)	(3)	SLPY_DAY2

		Yes	No	DON'T KNOW (DK)	
5.	Is it hard to wake your child up in the morning?	(1)	(2)	(3)	WKP_HARD2
6.	Does your child wake up with headaches in the morning?	(1)	(2)	(3)	WKP_HDCH2
7.	Did your child stop growing at a normal rate at any time since birth?	(1)	(2)	(3)	GROW_STP2
8.	Is your child overweight?	(1)	(2)	(3)	OVERWGHT2
9.	This child **often**				
	A. Does not seem to listen when spoken to directly	(1)	(2)	(3)	IGNRPPL2
	B. Has difficulty organizing tasks and activities	(1)	(2)	(3)	DIFF_ORG2
	C. Is easily distracted by extraneous stimuli	(1)	(2)	(3)	DISTRACT2
	D. Fidgets with hands or feet or squirms in seat	(1)	(2)	(3)	FIDGET2
	E. Is "on the go" or act as if "driven by a motor"	(1)	(2)	(3)	OVERACT2
	F. Interrupts or intrudes on others (e.g., butt into conversations or games)	(1)	(2)	(3)	INTRDOTH2

PART III: ENURESIS

Now we would like to ask you some questions about bedwetting or 'enuresis'. Please listen to all of the answers offered and then tell me the response that best describes how your child has dealt with this common problem for children with sickle cell disease.

			YES	NO
1.	Has your child wet the bed at night during the last 3 months?	WET_3MON	(1)	(2)

If No, skip to 4.

2. If your child wet the bed during the last 3 months, how often have they wet the bed: WET_FRQ

Rarely	(1)
Several times a month (but less than once a week)	(2)
1-2 times per week	(3)
3-5 times per week	(4)
Every night or almost every night	(5)

3. Which of the following have you tried with your child to treat the bedwetting? Has the therapy been successful in stopping bed wetting?

		Yes	No	
A.	Fluid restriction before bedtime			
	1. Tried	(1)*	(2)	FLURES_T
	*a. Successful	(1)	(2)	FLURES_S
B.	Using pull-ups or diapers when sleeping			
	1. Tried	(1)*	(2)	PROT_T
	*a. Successful	(1)	(2)	PROT_S
C.	Waking them up at night			
	1. Tried	(1)*	(2)	WKP_T
	*a. Successful	(1)	(2)	WKP_S

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		Yes	No	
D.	Bell alarm			
	1. Tried	(1)*	(2)	ALARM_T
	*a. Successful	(1)	(2)	ALARM_S
E.	Medication DDAVP (desmopressin)			
	1. Tried	(1)*	(2)	DDAVP_T
	*a. Successful	(1)	(2)	DDAVP_S
F.	Medication Tofranil (imipramine)			
	1. Tried	(1)*	(2)	TOFR_T
	*a. Successful	(1)	(2)	TOFR_S
G.	Therapy or counseling?			
	1. Tried	(1)*	(2)	THRPY_T
	*a. Successful	(1)	(2)	THRPY_S

4. After going to bed, has your child ever woken up at night to urinate in the bathroom during the last 3 months? (1) (2) NT_URI

If No, skip to 6.

5. If your child urinates in the bathroom during the night, how often? NTURIFRQ

Rarely	(1)
Several times month (but less than once a week)	(2)
1-2 times per week	(3)
3-5 times per week	(4)
Every night or almost every night	(5)

		Yes	No	
6.	Does your child urinate in his or her clothes during the day?	(1)	(2)	WET_DAY
7. A.	Does your child have an immediate family member (parent, sibling) with history of bedwetting when a child?	(1)	(2)	WTBD_FM

If No, skip to 8.

		Yes	No	
B.	Does the family member with bed wetting have sickle cell disease?	(1)	(2)	FM_SCD
8.	Does your child drink any caffeinated beverages (coffee, tea, energy drinks, soda with caffeine) after 4:00 p.m.?	(1)	(2)	DRK_CAFF
9.	Is your child a deep sleeper?	(1)	(2)	DP_SLPER
10.	Does your child have constipation?	(1)	(2)	CONST

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		Yes	No	
11.	Does your child soil their underwear with stool (more than a smear)?	(1)	(2)	SOILY_UW
12.	Does your child have a diagnosis of attention deficit disorder?	(1)	(2)	ATTNDD
13.	Does your child have a diagnosis of developmental delay?	(1)	(2)	DEVDELAY

PART IV: ADHERENCE – To be asked of the parent or guardian of patients currently taking Hydroxyurea only

		Yes	No	
1.	Child is taking HU	(1)	(2)	HU

If No, skip to Part V.

Your child is taking hydroxyurea for their sickle cell anemia. Parents and children have identified several issues about their medication-taking behavior and we are interested in your experiences. There is no right or wrong answer. Please answer each question based on your personal experience with your sickle cell medication – hydroxyurea.

A.	Do you sometimes forget to give your child their hydroxyurea?	(1)	(2)	FRGT_HU
B.	People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when your child did not take their hydroxyurea?	(1)	(2)	MISS_HU
C.	Have you ever cut back or stopped giving your child hydroxyurea without telling your doctor, because your child felt worse when they took it?	(1)	(2)	STPHU_1
D.	When you travel or leave home, do you sometimes forget to bring along your child's hydroxyurea?	(1)	(2)	HU_TRVL
E.	Did your child take their hydroxyurea yesterday?	(1)	(2)	HUYSTRDY
F.	When you feel like your child's sickle cell anemia is under control, do you sometimes stop giving your child their hydroxyurea?	(1)	(2)	STPHU_2
G.	Taking hydroxyurea every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your child's sickle cell treatment with hydroxyurea?	(1)	(2)	DIFF_HU

H. How often do you have difficulty remembering to give your child all of their hydroxyurea? (**Please circle the correct number**) DIFF_FRQ

Never/Rarely	(1)
Once in a while	(2)
Sometimes	(3)
Usually	(4)
All the time	(5)

PART V: PRIAPISM – ask of parents/guardians of MALE patients only (regardless of age)

		Yes	No	
1.	Is the child male?	(1)	(2)	MALE

If No, skip to Part VI.

A. Have you ever heard the word priapism before? (1) (2) PRIAPWRD

If No, skip to "Read to Patient and Parent."

B. Where have you heard the word priapism before? (Check all that apply)

1.	Doctor or nurse	(1)	SRC_DR
2.	Friend or relative	(1)	SRC_FR
3.	Written information	(1)	SRC_INFO
4.	Other	(1)*	SRC_OTH
	*a. Specify: _____		SRCOTHSP

READ TO PATIENT AND PARENT: *Priapism is a painful erection of the penis. It may last minutes to hours. It is more common in boys and men with sickle cell disease.*

		Yes	No	
C.	Has your son ever had a painful unwanted erection of the penis that lasted 30 minutes or more?	(1)	(2)	PRIAP30M

If No, skip to Part VI.

D. Has your son ever had a painful unwanted erection of the penis that lasted 4 hours or more? (1) (2) PRIAP4HR

For the next two questions, read all of the answers, then ask for one best answer.

E. How many episodes of priapism has your son had in the last year? PRIAPEP1

None	(1)
One	(2)
2 to 5	(3)
6 to 20	(4)
More than 20	(5)
Do not know	(6)

F. How many episodes of priapism did your son have before the last year? PRIAPEP2

None	(1)
One	(2)
2 to 5	(3)
6 to 20	(4)
More than 20	(5)
Do not know	(6)

G. How old was your son when the first episode happened? _____ years old PRIAPAGE

PART VI: PICA

		Yes	No	
1.	Does your child (currently, or in the last 3 months) chew on, but not swallow things that are not food (e.g., pencils, eraser, rim of cup)?	(1)	(2)	PICA_1
2.	Does your child (currently, or in the last 3 months) chew on and swallow things that are not food (e.g., dirt, foam, hair)?	(1)	(2)	PICA_2
3.	Have other people (currently, or in the last 3 months) observed your child chewing on or eating non-food items?	(1)	(2)	PICA_OBS

PART VII: EDUCATION – SCHOOL QUESTIONNAIRE

1. What is your child's current grade? _____ GRADE

2. What is your child's current age? AGE_YR _____ years _____ Months AGE_MON

		Yes	No	
3.	Has your child ever been held back or repeated a grade?	(1)	(2)	RPGRADE

If No, skip to 4.

A. How many grades? (1) (2) (3 or more) RPTIMES

B. Which grade(s)? (List up to 3 most recent grades) RPGRADE1 _____ RPGRADE2 _____ RPGRADE3 _____

4. Does your child have any accommodations because of learning differences? Check all that apply:

A.	Special Education Services	(1)	ACCM_SES
B.	504 plan	(1)	ACCM_504
C.	IEP-individualized education plan	(1)	ACCM_IEP
D.	Special tutoring or classes not available to regular students	(1)	ACCM_SPE
E.	Other	(1)*	ACCM_OTH
	1. *Describe: _____		ACCM_OSP
F.	My child does not receive any accommodation for learning differences	(1)	ACCMNONE

PART VIII: COORDINATION

1. Checked for completeness and accuracy:

A. Certification number: ___ ___ - ___ ___ CERT_NO

B. Signature: _____ CERT_SIG

C. General Comments: _____ GEN_CMNT

_____

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