Pediatric Heart Network: Single Ventricle Reconstruction Extension Study

Form R19A Ages and Stages Questionnaire (36 months)

Section A: KEY IDENTIFYING INFORMATION

A1.	Stud	y Identification Number	····					
A2.	Acro	stic Identifier						
A3.	Stuc	ly visit	Study Visit 6 (age 3 years)6					
			Study Visit 7 (age 4 years)7					
			Study Visit 8 (age 5 years)8					
A4.	Subj	ect date of birth	$-\underline{M} - \underline{M} - \frac{M}{D} - \underline{D} - \frac{M}{D} - \frac{M}{V} - \frac{M}{V}$					
A5.	Subj	ect gender	MALE					
A6.	assis	the form completed without stance from the study coordinator her health care provider?	YES2 (A6b)					
	a.	Who completed the form? (without assistance)	Mother1 (A7)					
			Father2 (A7)					
			Other primary caregiver3					
		1. If other primary caregiver, spe	ecify: (A7)					
	b.	Who completed the form? (with assistance)	Mother1 (A6c)					
			Father2 (A6c)					
			Other primary caregiver3					
		1. If other primary caregiver, spe	ecify:					
	C.	Method of form completion? (with assistance)	Phone Interview1					
			In-person2					
A7.		e of instrument completion by nt or caregiver	$-\underline{M} = \frac{1}{M} \frac{1}{M} \frac{1}{D} \frac{1}{D} \frac{1}{D} \frac{1}{Y} \frac{1}$					
A8.	Date	e of form completion	$-\underline{M} \underline{M} / \underbrace{D} \underline{D} / \underbrace{Y} \underline{Y} \underline{Y} \underline{Y} \underline{Y}$					
A9.	Nam	e of person completing form	PRINT FULL NAME INITIALS					

Form R19A Ages and Stages Questionnaire (36 months)

INSTRUCTIONS TO STUDY COORDINATORS:

- 1. Do not send **Section A** (pages 1-2) to the family with questionnaire. This section must be completed by study coordinator after receiving completed questionnaire from participant's family.
- 2. Instruct the family to complete the information on the front page of the ASQ. This information may be transcribed on to Section A by the study coordinator when the instrument is returned to the study center.
- 3. Affix patient ID study label on the front page after receiving completed questionnaire from participant's family. **Blacken all confidential information** such as child's name, telephone number, mailing address on this page. Photocopy entire packet and maintain in the study subject's research file.
- 4. Re-attach **Section A** (page 1- 2) to the completed questionnaire and send original instrument packet to DCC.

INSTRUCTIONS TO FAMILIES*

- 1. Try each activity with your child before checking a box.
- 2. Try to make completing the questionnaire a game that is fun for you and your child.
- 3. Make sure your child is rested, fed, and ready to play.
- 4. If you have questions or concerns about your child or about the questionnaire, feel free to ask your study coordinator for assistance.
- 5. All information is strictly confidential, and your name will not be used in any reports. This questionnaire is completely voluntary and will not affect your medical care. Please answer each question as accurately as you can.

* Instructions for families to be delivered by study coordinators.



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On the following pages are questions about activities children do. Your child may have already done some of the activities described here, and there may be some your child has not begun doing yet. For each item, please check the box that tells whether your child is doing the activity regularly, sometimes, or not yet.

Important Points to Remember:

- Be sure to try each activity with your child before checking a box.
- Try to make completing this questionnaire a game that is fun for you and your child.
- Make sure your child is rested, fed, and ready to play.
- Please return this questionnaire by _____
- If you have any questions or concerns about your child or about this questionnaire, please call:
- Look forward to filling out another questionnaire in _____ months.



<u>36</u>	Month • 3 Questionna	ne ne konstant i na kaj kaj kaj kaj kaj kaj kaj kaj kaj ka
	Please provide the following informat	
nild's name:		
nild's date of birth:		
oday's date:		
erson filling out this question	naire:	
hat is your relationship to th	e child?	
our telephone:		
our mailing address:	·	
ity:		
ate:		ZIP code:
	onnaire completion:	
	vider:	

		YES	SOMETIMES N	IOT YET	
co	MMUNICATION Be sure to try each activity with your child.				
1.	When you ask her to point to her nose, eyes, hair, feet, ears, and so forth, does your child correctly point to at least <i>seven</i> body parts? (She can point to parts of herself, you, or a doll.)				
2.	Does your child make sentences that are three or four words long?				
	Please give an example:				
3.	Without giving him help by pointing or using gestures, ask your child to "Put the shoe <i>on</i> the table" and "Put the book <i>under</i> the chair." Does your child carry out both of these directions correctly?				
4.	When looking at a picture book, does your child tell you what is hap- pening or what action is taking place in the picture? (For example, "Barking," "Running," "Eating," and "Crying") You may ask, "What is the dog (or boy) doing?"				
5.	Show your child how a zipper on a coat moves up and down, and say "See, this goes up and down." Put the zipper to the middle and ask your child to move the zipper <i>down</i> . Return the zipper to the middle and ask your child to move the zipper <i>up</i> . Do this several times, placin the zipper in the middle before asking your child to move it up or dow Does your child consistently move the zipper up when you say "up" and down when you say "down"?	ng			
6.	When you ask, "What is your name?" does your child say both her first and last names?				www.sineworvinie
			COMMUNICAT	ION TOTA	·
GI	ROSS MOTOR Be sure to try each activity with your child.				
1.	Without holding onto anything for support, does your child kick a ball by swinging his leg forward?				
2.	Does your child jump with both feet leaving the floor at the same time?				
3.	Does your child walk up stairs, using only one foot on each stair? (The left foot is on one step, and the right foot is on the next.) She may hold onto the railing or wall. (You can look for this at a store, on a playground, or at home.)				



		YES	SOMETIMES N	OT YET	
GF	COSS MOTOR (continued)				
4.	Does your child stand on one foot for about 1 second without holding onto anything?				
5.	While standing, does your child throw a ball <i>overhand</i> by raising his arm to shoulder height and throwing the ball or throwing the ball underhand does not count.)				
6.	Does your child jump forward at least 6 inches with both feet leaving the ground at the same time?		GROSS MOTO	DR TOTAL	
FI	YE MOTOR Be sure to try each activity with your child.				
1.	After she watches you draw a line from the top of the paper to the bottom with a pencil, crayon, or pen, ask your child to make a line like yours. Do not let your child trace your line. Does your child copy you by drawing a single line in a vertical direction?	- -			
2.	Does your child thread a shoelace through either a bead or an eyelet of a shoe?	O			
3.	After he watches you draw a single circle, ask your child to make a circle like yours. Do not let him trace your circle. Does your child copy you by drawing a circle?				
4.	After she watches you draw a line from one side of the paper to the other side, ask your child to make a line like yours. Do not let your child trace your line. Does your child copy you by drawing a single line in a horizontal direction?) □			

1

		YES	SOMETIMES N	IOT YET	
FI	NE MOTOR (continued)				
5.	Does your child try to cut paper with child-safe scissors? He does not need to cut the paper but must get the blades to open and close while holding the paper with the other hand. (You may show your child how to use scissors. Carefully watch				
	your child's use of scissors for safety reasons.)	L			
6.	When drawing, does your child hold a pencil, crayon, or pen between her fingers and thumb like an adult does?				
			FINE MOT	OR TOTA	L
PR	COBLEM SOLVING Be sure to try each activity with your child.				
1.	While your child watches, line up four objects like blocks or cars in a row. Does your child copy or imitate you and line up <i>four</i> objects in a row? (You can also use spools of thread,				
_	small boxes, or other toys.)	است	(und		
2.	If your child wants something he cannot reach, does he find a chair or box to stand on to reach it?	D,			
3.	When you point to the figure and ask your child, "What is this?" does your child say a word that means a person? Responses like "snowman," "boy," "man," "girl," and "Daddy" are correct. Please write your child's response here:				
4.	When you say, "Say seven three," does your child repeat <i>just</i> the two numbers in the correct order? <i>Do not repeat the numbers</i> . If necessa try another pair of numbers and say, "Say eight two." Your child must repeat just one series of two numbers for you to answer "yes" to this question.	ry,			
5.	Show your child how to make a bridge with blocks, boxes, or cans, like the example. Does your child copy you by making one like it?	D			
6.	When you say, "Say five eight three," does your child repeat <i>just</i> the three numbers in the correct order? <i>Do not repeat these numbers.</i> If necessary, try another series of numbers and say, "Say six nine two." Your child must repeat just one series of three numbers for you to answer "yes" to this question.				
			PROBLEM SOLV		۱ L

					Y	ΈS	SOMETIME	S NOT YET	
PI	ERSONAL-SO	CIAL	Be sure to try e	each activity with you	ur child.				
1.	Does your child	d use a	spoon to feed her	self with little spilling	1?		D		
2.				art, stroller, or wagon ners if he cannot turr		D			
3.			a mirror and you her "Me" or her ov	ask, "Who is in the i vn name?	mirror?"				
4.	Can your child	put on a	a coat, jacket, or s	hirt by himself?					
5.	Using these ex Does your child			"Are you a girl or a	boy?"				
6.	Does your child a turn?	d take tu	irns by waiting wh	ile another child or a	adult takes				
							PERSONAL-S	SOCIAL TOTA	·L
0	VERALL		s and províders m nal comments.	ay use the space be	elow or the	back d	of this sheet for		
1.	Do you think y	our child	d hears well?					YES 🗋	NO 🔲
	If no, explain: .								
2.			d talks like other c	-				YES 🗋	NO 🗋
	If no, explain: .		,			******			
3.	•		nost of what your	child says?				YES 🗋	NO 🛄
4.				l climbs like other ch		-		YES 🔲	NO 🔲
5.	Does either pa	rent ha	ve a family history	of childhood deafne	ess or hear	ing im	pairment?	YES 🗋	NO 🗋
6.	Do you have a	ny conc	erns about your c	hild's vision?				YES 🛄	NO 🗋
7.	Has your child	had an	y medical problem	ns in the last several	months?		, ,	YES 🔲	NO 🔲
8.	Does anything	about y	our child worry yo	pu?				YES 🗋	NO 🔲



36 Month/3 Year ASQ Information Summary

Child's name:	Date of birth:
Person filling out the ASQ:	Relationship to child:
Mailing address:	City: State: zıp:
Telephone:	Assisting in ASQ completion:
Today's date:	

OVERALL: Please transfer the answers in the Overall section of the questionnaire by circling "yes" or "no" and reporting any comments.

1.	Hears well? Comments:	YES	NO	5.	Family history of hearing impairment? Comments:	YES	NO
2.	Talks like other children? Comments:	YES	NO	6.	Vision concerns? Comments:	YES	NO
3.	Understand child? Comments:	YES	NO	7.	Recent medical problems? Comments:	YES	NO
4.	Walks, runs, and climbs like others? Comments:	YES	NO	8.	Other concerns? Comments:	YES	NO

SCORING THE QUESTIONNAIRE

- Be sure each item has been answered. If an item cannot be answered, refer to the ratio scoring procedure in The ASQ User's Guide. 1.
- Score each item on the questionnaire by writing the appropriate number on the line by each item answer. 2.
 - YES = 10SOMETIMES = 5NOT YET = 0
- З. Add up the item scores for each area, and record these totals in the space provided for area totals.
- Indicate the child's total score for each area by filling in the appropriate circle on the chart below. For example, if the total score for 4. the Communication area was 50, fill in the circle below 50 in the first row.

Total	0	5	10	15	20	25	30	35	40	45	50	55	60
Communication	O	Ο	0	0	0	O	0	0	\bigcirc	0	0	0	0
Gross motor	Ô	O	Ō	O	0	O	O	Q	0	0	0	0	0
Fine motor	Ō	0	0	0	O ·	0.	Q	0	0	0	0	0	0
Problem solving	O.	0	0	O	0	Ō	0	0	0	0	0	0	0
Personal-social	0	O	- O	O	O	\circ	\circ	0	0	0	0	0	0
Total	0	5	10	15	20	25	30	35	40	45	50	55	60

Examine the blackened circles for each area in the chart above.

5. If the child's total score falls within the area, the child appears to be doing well in this area at this time.

If the child's total score falls within the me area, talk with a professional. The child may need further evaluation. 6.

OPTIONAL: The specific answers to each item on the questionnaire can be recorded below on the summary chart.

		Score Cutoff	Communication	Gross motor	Fine motor	Problem solving	Personal-social
		[]	1000				1000
6	Communication	38.7		2 0 0 0	2 000		
years	Gross motor	35.7	3000	3000	3000	3 000	3000
months/3	Fine motor	30.7	4 000	4000	4 000	4 000	4000
	Problem solving	38.6	5 0 0 0	5 0 0 0	5 000	5 000	5000
36	Personal-social	38.7					

Administering program or provider:

