PHN-02

Form S113: Functional Status II (R)

		Section A: KEY IDEN	TIFYING INFORMATION			
A1.	Study Ident	tification Number				
Repla	aced by blin	ided ID				
blind_	id	Blinded ID				
				_		
A2.	Acrostic Ide	entifier				
Remo	oved to prot	tect privacy				
A3.	Study visit		Study Visit 6 (age 14 mo)	6		
VISIT		A3. Visit: 1=Day 4, 2=Week 2 10mo, 6=Age 14mo	, 3=pre-Glenn, 4=Restart, 5=Age			
A4.	Patient date	e of birth	$\frac{1}{M} \frac{1}{M} \frac{1}{D} \frac{1}{D} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y}$	<u> </u>		
Remo	oved to prot	tect privacy				
A5.	Patient gen	der	MALE 1 FEMALE	Ē2		
GEN	DERS113	A5. Patient gender (1=M 2=F)				
A6.	Date of form	m completion		- - -		
Repla	aced by age	at form completion		· ¬		
comp	_age	A6. <created var="">Age at form</created>	completion, days			
A7.	Name of pe	erson completing form				
Remo	PRINT FULL NAME INITIALS emoved to protect privacy					

Form S113: Functional Status II (R)

INSTRUCTIONS:

- 1. Please read each question carefully and select the response that you feel most accurately represents your answer.
- 2. In some cases, the answer you choose may allow you to skip the next question, or the next several questions. In these situations, you will be given a directive either in bold type in parenthesis or with an arrow. If you do not see a directive next to your answer choice, simply continue to the very next question.
- 3. It is important for accurate study results that *when asked for only one answer, you give only one answer.* We understand that sometimes it is hard to choose just one, but try to decide which is closer. If you mark more than one answer, we will not be able to use either one.
- 4. 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.

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Section B: BEHAVIOR

Here are some statements that mothers have made to describe their children. Please think about your child during the <u>last 2 weeks</u>, and choose the response that most accurately describes him or her.

B1. Over the last two weeks, did your child...

a.	Eat well?	Never or rarely	□₁┐		Fully	
		Some of the time		i. Was this due to illness?	Partly	1
		Almost always	□ ₃ (Go to B1b)		Not at all	2

EATWEL	B1a. Eat well
EATWEL_I	B1ai. Was this due to illness

b Sleep well?	Never or rarely		: Mas this due to	Fully	
	Some of the time		i. Was this due to illness?	Partly	\square_2
	Almost always	□ ₃ (Go to B1c)		Not at all	\square_3

SLEEP	B1b. Sleep well
SLEEP_I	B1bi. Was this due to illness

(Seem	Never or rarely			Fully	\square_1
	contented and cheerful?	Some of the time		i. Was this due to illness?	Partly	\square_2
		Almost always	□ ₃ (Go to B1d)		Not at all	\square_3

CONTNT	B1c. Seem contented and cheerful
CONTNT_I	B1ci. Was this due to illness

d Act moody?	Never or rarely	□ ₁ (Go to B1e)		Fully	
	Some of the time		i. Was this due to	Partly	\square_2
	Almost always		illness?	Not at all	\square_3

MOODY	B1d. Act moody
MOODY_I	B1di. Was this due to illness

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	Pediatric Heart Network: Infant Single Ventricle Trial		
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	Form S113: Functional Status II (R)	— . II	
e Communica . what (he/she	, ¬ ¬	Fully	
wanted?	Some of the time \square_2 illness?	Partly	\square_2
	Almost always □ ₃ (Go to B1f)	Not at all	\square_3
COMMUN	B1e. Communicate what he/she wanted		
COMMUN_I	B1ei. Was this due to illness		
f. Seem to	· · · · · · · · · · · · · · · · · · ·	Fully	
sick and t	tired? (Go to B1g) Some of the time □₂_	Partly	1
	Almost always \square_3 i. Was this due to illness?	Not at all	2
, ,			3
FLSICK	B1f. Seem to feel sick and tired		
FLSICK_I	B1fi. Was this due to illness		
g Occupy	Never or rarely □ ₁	Fully	□ ₁
. (him/herself))? Some of the time \square_2 i. Was this due to illness?	Partly	\square_2
	Almost always □ ₃ (Go to B1h)	Not at all	\square_3
OCCUPY	B1g. Occupy him/herself		
OCCUPY_I	B1gi. Was this due to illness		
h Seem lively . energetic?	and Never or rarely □₁ i. Was this due to	Fully	□ ₁
. Chergelle:	Some of the time \square_2 illness?	Partly	\square_2
	Almost always □ ₃ (Go to B1i)	Not at all	\square_3
LIVELY	B1h. Seem lively and energetic		
LIVELY_I	B1hi. Was this due to illness		
L			

Pediatric Heart Network: Infant Single Ventricle Trial Form S113: Functional Status II (R) I Seem unusually Never or rarely							
Seem unusually Never or rarely Co to B1j) I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to Not at all Co to B1j I. Was this due to II. Was this due to III. Was this d	Pediatric Heart Network: Infant Single Ventricle Trial					PH	N-02
irritable or cross? Some of the time			Form S113:	Functional Status	s II (R)		11 02
irritable or cross? Almost always	i Seem unusu	ually Ne	ever or rarely			Fully	
Almost always		Sc	ome of the time	•	i Was this due to	Partly	\square_2
IRRIT_I B1ii. Was this due to illness j Sleep through	01033 :	Alı	most always			Not at all	\square_3
J Sleep through the night? Some of the time □₂ i. Was this due to illness? SLEEPN B1j. Sleep through the night SLEEPN_I B1ji. Was this due to illness K Respond to your attention? Some of the time □₂ ii. Was this due to illness? K Respond to Hot ime □₂ ii. Was this due to illness? Some of the time □₂ ii. Was this due to illness? RESPND B1k. Respond to your attention RESPND_I B1ki. Was this due to illness Some of the time □₂ ii. Was this due to illness? Fully □₁ ii. Was this due to illness Some of the time □₂ ii. Was this due to illness? DIFFIC B1l. Seem unusually difficult	IRRIT	B1i. See	em unusually irrita	able or cross			
the night? Some of the time □₂ i. Was this due to illness? Partly □₂ Almost always □₃ (Go to B1k) i. Was this due to illness? Partly □₂ SLEEPN B1j. Sleep through the night SLEEPN_I B1ji. Was this due to illness K Respond to Never or rarely □₁ i. Was this due to illness? Partly □₂ Almost always □₃ (Go to B1l) i. Was this due to illness? Partly □₂ Not at all □₃ RESPND B1k. Respond to your attention RESPND_I B1ki. Was this due to illness I Seem unusually Never or rarely □₁ (Go to B1m) Fully □₁ I Seem unusually Never or rarely □₁ (Go to B1m) Fully □₁ Almost always □₃ i. Was this due to illness? Not at all □₃ DIFFIC B1l. Seem unusually difficult	IRRIT_I	B1ii. Wa	as this due to illne	ess			
Some of the time		gh Ne	ever or rarely		i Was this due to	Fully	□1
SLEEPN B1j. Sleep through the night SLEEPN_I B1ji. Was this due to illness k Respond to	. the riight:	Sc	ome of the time			Partly	\square_2
SLEEPN_I B1ji. Was this due to illness k Respond to		Alı	most always			Not at all	\square_3
RESPND B1k. Respond to your attention RESPND_I B1ki. Was this due to illness Fully D1	SLEEPN	B1j. Sle	ep through the ni	ght			
. your attention? Some of the time □₂ ii. Was this due to illness? RESPND B1k. Respond to your attention RESPND_I B1ki. Was this due to illness I Seem unusually Never or rarely □₁ (Go to B1m) difficult? Some of the time □₂ ii. Was this due to illness? DIFFIC B1I. Seem unusually difficult	SLEEPN_I	B1ji. Wa	as this due to illne	ess			
Some of the time	•		ever or rarely		: \Mag this due to	Fully	
RESPND B1k. Respond to your attention RESPND_I B1ki. Was this due to illness I Seem unusually Never or rarely Go to B1m) difficult? Some of the time Gallows I. Was this due to illness? Almost always Gallows II. Seem unusually difficult DIFFIC B1I. Seem unusually difficult	. your attentio		ome of the time			Partly	\square_2
RESPND_I B1ki. Was this due to illness I Seem unusually Never or rarely		Alı	most always			Not at all	\square_3
RESPND_I B1ki. Was this due to illness I Seem unusually Never or rarely	RESDNID	B1k Be	sepond to your att	ention			
I Seem unusually Never or rarely \square_1 (Go to B1m) difficult? Some of the time \square_2 i. Was this due to illness? Partly \square_2 DIFFIC B1I. Seem unusually difficult			· · · · · · · · · · · · · · · · · · ·				
difficult? Some of the time \square_2 i. Was this due to illness? Not at all \square_3 DIFFIC B1I. Seem unusually difficult							
difficult? Some of the time \square_2 i. Was this due to illness? Not at all \square_3 DIFFIC B1I. Seem unusually difficult	I Seem unusu	ually Ne	ever or rarely			Fully	
Almost always □₃ illness? Not at all □₃ DIFFIC B1I. Seem unusually difficult	difficult?	Sc	ome of the time		i Was this due to	Partly	\square_2
·		Alı	most always			Not at all	Пз
DIFFIC_I B1li. Was this due to illness	DIFFIC	B1I. See	em unusually diffi	cult			
	DIFFIC_I	B1li. Wa	as this due to illne	ess			

Pediatric Heart Network: Infant Single Ventricle Trial PHN-02 Form S113: Functional Status II (R) Never or rarely **Fully** Seem \Box_{\perp} \square_1 interested in i. Was this due to what was going Some of the time $\square_2^$ illness? Partly \square_2 on around (him/her)? Almost always Not at all \square_3 \square_3 (Go to B1n) **INTRST** B1m. Seem interested in what was going on around him/her INTRST I B1mi. Was this due to illness n React to little Never or rarely □₁ Fully \square_1 (Go to B1o) things by crying? Some of the time Partly \square_2 \square_2 i. Was this due to illness? Almost always \square_3^- Not at all \square_3 **CRYING** B1n. React to little things by crying CRYING I B1ni. Was this due to illness Does your child Fully \Box_1 depend on any special medical \square_2 i. Was this due to Yes Partly equipment or illness? appliance in No \square_2 Not at all \square_3 (Go to C1a) daily living? **EQUIP** B1o. Does your child depend on special medical equipment

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B1oi. Was this due to illness

EQUIP_I

Section C: STIMULI

C1. Over the last 2 weeks, did your child...

a Smile and coo?	Never or rarely		: \\\- = (-:	Fully	\square_1
	Some of the time		i. Was this due to illness?	Partly	\square_2
	Almost always	□ ₃ (Go to C1b)		Not at all	\square_3

SMILE	C1a. Smile and coo
SMILE_I	C1ai. Was this due to illness

b Babble or use	Never or rarely		i Waa thia dua ta	Fully	\square_1
. other sounds?	Some of the time		i. Was this due to illness?	Partly	\square_2
	Almost always	□ ₃ (Go to C1c)		Not at all	\square_3

BABBLE	C1b. Babble or use other sounds
BABBLE_I	C1bi. Was this due to illness

Try to get	Never or rarely			Fully	\square_1
objects that were near but beyond	Some of the time		i. Was this due to illness?	Partly	\square_2
•	Almost always	\square_3 (Go to C1d)		Not at all	\square_3

GETOBJ	C1c. Try to get objects that were near but beyond his/her reach
GETOBJ_I	C1ci. Was this due to illness

d.	Hear and turn	Never or rarely		i Waa thia dua ta	Fully	\square_1
	to sound?	Some of the time		i. Was this due to illness?	Partly	\square_2
		Almost always	□ ₃ (Go to C1e)		Not at all	\square_3

HEAR	C1d. Hear and turn to sound
HEAR_I	C1di. Was this due to illness
LOOK	C1e. Seem to look at things
LOOK_I	C1ei. Was this due to illness

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e.	Seem to look at things?	Never or rarely		i. Was this due to	Fully	\square_1
	umigs:	Some of the time		illness?	Partly	\square_2
		Almost always	□ ₃ (Go to D1a)		Not at all	\square_3

LOOK	C1e. Seem to look at things
LOOK_I	C1ei. Was this due to illness

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Section D: TRIGGERS

D1. Over the last two weeks, did your child...

a Act afraid of . new situations?	Never or rarely	□ ₁ (Go to D1b)		Fully	
	Some of the time		Was this due to	Partly	\square_2
	Almost always		illness?	Not at all	\square_3

AFRAID	[Added Version B] D1a. Act afraid of new situations
AFRAID_I	[Added Version B] D1a.i Was this due to illness

b Get around the	Never or rarely		i Waa thia dua ta	Fully	
. house without assistance?	Some of the time		i. Was this due to illness?	Partly	\square_2
	Almost always	□ ₃ (Go to D1c)		Not at all	\square_3

	[Added Version B] D1b. Get around the house without assistance
GETAROUND_I	[Added Version B] D1b.i Was this due to illness

c Have frequent . temper	Never or rarely	□ ₁ (Go to D1d)		Fully	
tantrums?	Some of the time		i. Was this due to	Partly	\square_2
	Almost always		illness?	Not at all	\square_3

TANTRUM	[Added Version B] D1c. Have frequent temper tantrums
TANTRUM_I	[Added Version B] D1c.i Was this due to illness

	[Added Version B] D1g. Act timid or shy [Added Version B] D1g.i Was this due to illness
וואווט_ו	[Added Version b] big.i Was this due to liness

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NERVOUS	[Added Version B] D1k. Act nervous or tense
NERVOUS_I	[Added Version B] D1k.i Was this due to illnes

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Г	 Cut down on	Nover or resolv			Fully	

I.	Cut down on things (he/she)	Never or rarely	□ ₁ (Go to D1m)		Fully	
	usually does?	Some of the time			Partly	\square_2
		Almost always		i. Was this due to illness?	Not at all	\square_3

CUTDOWN	[Added Version B] D1I. Cut down on things (he/she) usually does
CUTDOWN_I	[Added Version B] D1I.i Was this due to illness

m.	Get involved in games and	Never or rarely		▶i. Was this due to	Fully	
	other play?	Some of the time		illness?	Partly	\square_2
		Almost always	□ ₃ (Go to E1)		Not at all	\square_3

INVOLVED	[Added Version B] D1m. Get involved in games and other play
INVOLVED_I	[Added Version B] D1m.i Was this due to illness

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Section E: HOSPITALIZATION				
These questions	ask about your child's hospitalization in the <u>last 6 months</u> .			
E1. Has your o	hild been hospitalized in the <u>last 6 months</u> ?			
	YES1 NO2 (E1			
HOSPITAL	E1. Has your child been hospitalized in the last 6 months			
E2. How many	times was he/she hospitalized? Number of Times			
HOSPTIME	E2. How many times was he/she hospitalized			
E3. For how m	any days was he/she hospitalized?			
	Total number of days			
HOSPDAYS	E3. For how many days was he/she hospitalized			
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	Section F: GENERAL INFORMATION			
-	Section F: GENERAL INFORMATION ions asks some general information about you and your child. Please formation is confidential.			
remember, all inf	ions asks some general information about you and your child. Please			
remember, all inf	ions asks some general information about you and your child. Please formation is confidential. ur child's date of birth? M M D D Y Y Y Y			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. ur child's date of birth? M M D D Y Y Y Y			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. ur child's date of birth? M M D D Y Y Y Otect privacy			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. ur child's date of birth? \[\frac{M}{M} \frac{M}{D} \frac{D}{D} \frac{M}{Y}			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. ur child's date of birth? \[\frac{\pi}{M} \frac{\pi}{M} \frac{\pi}{D} \frac{\pi}{D} \frac{\pi}{Y} \frac{\pi}{Y} \frac{\pi}{Y} \frac{\pi}{Y} \frac{\pi}{Y} \] etect privacy ne following best describes your relationship to your child? BIOLOGICAL PARENT			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. Formation is confi			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. Formation about you and your child. Please formation is confidential. Formation is confidential. Formation about you and your child. Please formation is confidential. Formation is confidential. Formation about you and your child. Please formation is confidential. F			
remember, all interest for the F1. What is your Removed to pro	ions asks some general information about you and your child. Please formation is confidential. Formation about you and your child. Please formation is confidential. For			

RELATN	F2. Which best describes your relationship to your child
RELAT_SP	F2a. If other, please explain

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F3. What is the	e highest grade of school that you have completed?	
	SOME HIGH SCHOOL OR LESS	1
	HIGH SCHOOL GRADUATE/G.E.D	2
	SOME COLLEGE OR 2-YEAR DEG	3REE3
	4-YEAR COLLEGE GRADUATE	4
	GRADUATE DEGREE	5
GRADE	F3. What is the highest grade of school you have completed	
	he following categories best represents the combined income for al in your household added together for the past 12 months?	I family
	< \$20,000	1
	\$20,000 - \$39,999	2
	\$40, 000 - \$59,999	3
	\$60,000 - \$79,999	4
	\$80,000 - \$99,999	5
	≥\$100,000	6
	Do not wish to provide	7
INCOME	F4. Which best describes the combined income for your household	
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THANK YOU FOR YOUR PARTICIPATION

END OF FORM

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Calculated FS II(R) scores:

totalall	<pre><created var="">Total score for all ages</created></pre>
total	<pre><created var="">Total score for 1 year old child (12-23 months)</created></pre>
genhealth	<pre><created var="">General health score for 1 year old child (12-23 months)</created></pre>
response	<pre><created var="">Responsiveness score for 1 year old child (12-23 months)</created></pre>