

Section A: KEY IDENTIFYING INFORMATION

A1. Study Identification Number _____ - _____ - _____ - _____

A2. Acrostic Identifier _____

A3. Study visit
 Study Visit 6 (age 3 year).....6
 Study Visit 7 (age 4 year).....7
 Study Visit 8 (age 5 year).....8
 Study Visit 9 (age 6 years).....9

A4. Patient date of birth
 ____ / ____ / ____ - ____ - ____ - ____
M M D D Y Y Y Y

A5. Patient gender
 MALE.....1 FEMALE.....2

A6. Was the form completed without assistance from the study coordinator or other health care provider?
 YES.....1 NO.....2 **(A6b)**

a. Who completed the form? (without assistance)
 Mother1 **(A7)**
 Father2 **(A7)**
 Other primary caregiver.....3

1. If other primary caregiver, specify: _____ **(A7)**

b. Who completed the form? (with assistance)
 Mother1 **(A7)**
 Father2 **(A7)**
 Other primary caregiver.....3

1. If other primary caregiver, specify: _____

A7. Does patient attend school or daycare? YES.....1 NO.....2

A8. Is patient currently taking heart medicine? YES.....1 NO.....2

A9. Date of instrument completion by parent or caregiver
 ____ / ____ / ____ - ____ - ____ - ____
M M D D Y Y Y Y

A10. Date of form completion
 ____ / ____ / ____ - ____ - ____ - ____
M M D D Y Y Y Y

A11. Name of person completing form

 PRINT FULL NAME INITIALS

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. Affix study label to **FRONT PAGE** of the Instrument prior to sending to participant's family. When instrument is returned, photocopy entire packet and maintain in the study subject's research file.
Blacken all confidential information, if needed.
3. Complete and re-attach **Section A** to the completed questionnaire and send original instrument packet to DCC.

INSTRUCTIONS TO FAMILY:

1. On the following pages are lists of things that might be a problem for your child.
2. Please tell us how much of a problem each one has been for your child during the past **ONE month** by circling:
 0 if it is **never** a problem
 1 if it is **almost never** a problem
 2 if it is **sometimes** a problem
 3 if it is **often** a problem
 4 if it is **almost always** a problem
3. There are no right or wrong answers. If you do not understand a question, please ask for help.
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.

ID# _____

Date: _____

PedsQL™

Cardiac Module

Version 3.0

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

Children with heart conditions sometimes have special problems. On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has your child had with ...*

HEART PROBLEMS AND TREATMENT <i>(problems with...)</i>	Never	Almost Never	Some-times	Often	Almost Always
1. Getting out of breath while doing active play or exercise	0	1	2	3	4
2. Chest pain or tightness while doing active play or exercise	0	1	2	3	4
3. Catching colds easily	0	1	2	3	4
4. Fast heartbeat	0	1	2	3	4
5. His/her lips turning blue when running	0	1	2	3	4
6. Waking up at night with trouble breathing	0	1	2	3	4
7. Having to rest more than his/her friends	0	1	2	3	4

**If your child is currently taking heart medicine, please answer the following...
Otherwise, please skip to "Perceived Physical Appearance".**

TREATMENT II <i>(problems with...)</i>	Never	Almost Never	Some-times	Often	Almost Always
1. Refusing to take heart medicine	0	1	2	3	4
2. Difficulty taking heart medicine	0	1	2	3	4
3. Heart medicine making him/her feel sick	0	1	2	3	4

PERCEIVED PHYSICAL APPEARANCE <i>(problems with...)</i>	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling that he/she is not good looking	0	1	2	3	4
2. Not liking other people to see his/her scars	0	1	2	3	4
3. Being embarrassed about others seeing his/her body	0	1	2	3	4

TREATMENT ANXIETY <i>(problems with...)</i>	Never	Almost Never	Some-times	Often	Almost Always
1. Getting anxious when waiting to see the doctor	0	1	2	3	4
2. Getting anxious about going to the doctor	0	1	2	3	4
3. Getting anxious about going to the hospital	0	1	2	3	4
4. Getting anxious when he/she has to have medical treatments	0	1	2	3	4

*In the past **ONE month**, how much of a **problem** has your child had with ...*

COGNITIVE PROBLEMS (<i>problems with...</i>)	Never	Almost Never	Some-times	Often	Almost Always
1. Figuring out what to do when something bothers him/her	0	1	2	3	4
2. Difficulty paying attention to things	0	1	2	3	4
3. Remembering what is read to him/her	0	1	2	3	4

COMMUNICATION (<i>problems with...</i>)	Never	Almost Never	Some-times	Often	Almost Always
1. Telling the doctors and nurses how he/she feels	0	1	2	3	4
2. Asking the doctors or nurses questions	0	1	2	3	4
3. Explaining his/her heart problem to other people	0	1	2	3	4

ID# _____

Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in active play or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Bathing	0	1	2	3	4
6. Helping to pick up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Playing with other children	0	1	2	3	4
2. Other kids not wanting to play with him or her	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

***Please complete this section if your child attends school or daycare**

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Doing the same school activities as peers	0	1	2	3	4
2. Missing school/daycare because of not feeling well	0	1	2	3	4
3. Missing school/daycare to go to the doctor or hospital	0	1	2	3	4