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)
Mother ……..……1 **(A7)**
Father ……..…….. ……..2 **(A7)**
Other primary caregiver.…..……...…3

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

b. Who completed the form? (with assistance)
Mother ……..……1 **(A7)**
Father ……..……..2 **(A7)**
Other primary caregiver.…..……...…3

1. If other primary caregiver, specify:_____

A7. Is patient currently taking heart medicine? YES……..……1 NO……...2

A8. Date of instrument completion by parent or caregiver ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

A9. Date of form completion ___ ___ / ___ ___ / ___ ___ ___ ___
M M D D Y Y Y Y

A10. 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 (**page 1 - 2) 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 **YOUNG CHILDREN** (ages **5-7**)

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 *(problems with…)*	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Getting out of breath while doing sports activity or exercise	0	1	2	3	4
2. Chest pain or tightness while doing sports activity 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 *(problems with…)*	**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 *(problems with…)*	**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. Getting teased when other kids see his/her scars	0	1	2	3	4

TREATMENT ANXIETY *(problems with…)*	**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 ***(problems with…)***	**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. Trouble with numbers or math worksheets	0	1	2	3	4
3. Trouble writing letters or words	0	1	2	3	4
4. Difficulty paying attention to the teacher	0	1	2	3	4
5. Remembering what is read to him/her	0	1	2	3	4

COMMUNICATION ***(problems with…)***	**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 **YOUNG CHILDREN** (ages **5-7**)

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 more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, like picking 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 about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	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

SCHOOL FUNCTIONING ***(problems with…)***	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school activities	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

