

I translated our Japanese questionnaire about congenital heart disease into English.

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25 January, 2013

Dear All,

I am writing to you regarding the questionnaire about congenital heart disease in your child (if he or she has any). If you are agreeable to the contents, please return the completed questionnaire in the enclosed envelope.

Congenital heart diseases are the most frequent complications in Down syndrome. The increased life expectancy may be attributed to improvement of heart surgery. However, we have little data about congenital heart diseases after adolescence. For that reason, we would like to conduct some inquiries about congenital heart diseases, the therapy and the prognosis.

Though we would like to have your child's name in the questionnaire in order to avoid mistakes or overlapping of the data, we anonymize the data and use only numerical values for statistical work. Thus, there is no possibility of private information being exposed to the public.

It is greatly appreciated if you would return the questionnaire by the end of February. I apologize for taking up your valuable time. If you have any questions, please do not hesitate to contact me.

Thank you very much for your attention.

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Questionnaire about Congenital Heart Disease

Please fill in the blanks, or choose and circle the mark (*) of the most accurate answer from the list. If you don't know the answer, please choose "unknown" instead of leaving it unanswered. Please write the details as far as you know in the brackets [].

Your child's Name _____ Sex (*Male, *Female)

Your child's Birthday _____(year) _____(month)

(1) Chromosome type of Down syndrome: *trisomy 21 *translocation *mosaic

(2) Does your child have congenital heart disease (including cured state)? (Yes, No)

→ If No, please go to (4).

(3)-1 Please circle the lesion of congenital heart disease. (Circle all, if multiple.)

- * patent ductus arteriosus * fossa ovalis * atrial septal defect * ventricular septal defect
- * tetralogy of Fallot * atrioventricular septal defect * tricuspid atresia *coarctation of aorta
- * pulmonary artery stenosis *other [_____] *unknown

(3)-2 Has your child been diagnosed with "pulmonary hypertension"? (Yes, No)

(3)-3 Did your child undergo cardiac surgery (including catheter-based therapy)? (Yes, No)

(3)-4 Please write the date or age of the cardiac surgery.

First operation: Date _____(year) _____(month) or Age _____(year) _____(month)old

Second operation: Date _____(year) _____(month) or Age _____(year) _____(month)old

Third operation: Date _____(year) _____(month) or Age _____(year) _____(month)old

(3)-5 Regarding the status of cardiac diseases in your child at present. Please circle the most accurate choice (*).

1) Does your child see a doctor regularly?

- *Yes *Not now

2) The status of cardiac diseases of your child at present:

- * fully healed, no abnormality *minor abnormality, but no limitation of daily activities
- * limitation of daily activities

3) Does your child have symptoms?

- *nothing * dyspnea on exercise *dyspnea at rest *cyanosis *edema
- * other [_____]

4) Is your child taking any treatment?

- *No *taking medicine [drug name: _____]
- *pacemaker or implantable cardiac defibrillator
- * waiting for a surgery date [in detail _____]

(4) If your child has other complications except cardiac disease, circle all appropriate choices and write in detail.

*No

*disease of the gastrointestinal tract [disease name: _____ *during therapy, *operated, *cured]

*leukemia [disease name: _____ *during therapy, *operated, *cured]

*other [disease name: _____ *during therapy, *operated, *cured]

(5) Please use this space if you have any questions about your child's medical problems.

I am grateful for your cooperation.