

These forms are  
for:

## CHILDREN WITH

## IMMUNE DEFICIENCY

In this packet are two sets of forms: one form is for a parent to fill out and the other is for a child with an immune deficiency between the ages of 5-18 years. If your child is younger than 5 years, please fill out the parental form only.

It is important that the child answer the questions on their form for themselves. Children have different ideas than adults and we want to understand their views. The form will take about 30 minutes to fill out. Some of the questions may not apply to you. Please answer all the questions anyway. When you are done, please hand the form back to the USIDNET staff before the end of the meeting or mail it in. This will help us identify the major issues facing patients today and how well the treatments work.

## Parental Form Section 1

Name of Patient \_\_\_\_\_ Gender   M   F  
 Patient Initials   /  /   Date or Year of Birth   

Name of Parent \_\_\_\_\_  
 Today's date \_\_\_\_\_

### *Your Child's Global Health*

**1.1 In general, would you say your child's health is:**

Excellent	Very Good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Your Child's Physical Activities*

**2.1 During the past 4 weeks, has your child been limited in any of the following activities due to health problems?**

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited at all
Doing things that take some energy, such as playing soccer or running?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing things that take some energy, such as riding a bike or skating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ability (physically) to get around the neighborhood, playground, or school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking one block or climbing one flight of stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bending, lifting, or stooping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking care of him/herself, that is, eating, dressing, bathing, or going to the toilet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 1

### *Your Child's Everyday Activities*

**3.1 During the past 4 weeks, has your child's school work or activities with friends been limited in any of the following ways due to **EMOTIONAL** difficulties or problems with his/her **BEHAVIOR**?**

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited at all
Limited in the <b>KIND</b> of schoolwork or activities with friends he/she could do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited in the <b>AMOUNT</b> of time he/she could spend on schoolwork or activities with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited in <b>PERFORMING</b> schoolwork or activities with friends (it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3.2 During the past 4 weeks, has your child's schoolwork or activities with friends been limited in any of the following ways due to problems with his/her **PHYSICAL** health?**

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited at all
Limited in the <b>KIND</b> of schoolwork or activities with friends he/she could do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited in the <b>AMOUNT</b> of time he/she could spend on schoolwork or activities with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Pain*

**4.1 During the past 4 weeks, how much bodily pain or discomfort has your child had?**

None	Very Mild	Mild	Moderate	Severe	Very Severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4.2 During the past 4 weeks, how often has your child had bodily pain or discomfort?**

None	Very Mild	Mild	Moderate	Severe	Very Severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 1

### *Behavior*

**5.1 How often during the past 4 weeks did each of the following statements describe your child?**

	Very Often	Fairly Often	Sometimes	Almost Never	Never
Argued a lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had difficulty concentrating or paying attention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lied or cheated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stole things inside or outside the home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had tantrums or a hot temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**5.2 Compared to other children your child's age, in general would you say his/her behavior is:**

Excellent	Very Good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Well-Being*

**6.1 During the past 4 weeks, how much of the time do you think your child:**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Felt like crying?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acted nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acted bothered or upset?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acted cheerful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 1

### *Self-Esteem*

**7.1 During the past 4 weeks, how satisfied do you think your child has felt about:**

	Very satisfied	Somewhat satisfied	Neither satisfied nor dissatisfied	Somewhat dissatisfied	Very dissatisfied
His/her school ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
His/her athletic ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
His/her friendships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
His/her looks/appearance?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
His/her family relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
His/her life overall?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Your Child's Health*

**8.1 How true or false is each of these statements for your child?**

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
My child seems to be less healthy than other children I know.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My child has never been seriously ill.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When there is something going around my child usually catches it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I expect my child will have a very healthy life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry more about my child's health than other people worry about their children's health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 1

### 8.2 Compared to one year ago, how would you rate your child's health now:

Much better now that 1 year ago	Somewhat better now than 1 year ago	About the same as 1 year ago	Somewhat worse now than 1 year ago	Much worse now than 1 year ago
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *You and Your Family*

#### 9.1 During the past 4 weeks, how MUCH emotional worry or concern did each of the following cause YOU?

	Not at all	A little bit	Some	Quite a bit	A lot
Your child's physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your child's emotional well-being or behavior?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your child's attention or learning abilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### 9.2 During the past 4 weeks, were you LIMITED in the amount of time YOU had for your own needs because of:

	Yes, limited a lot	Yes, limited some	Yes, limited a little	No, not limited at all
Your child's physical health?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your child's emotional well-being or behavior?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your child's attention or learning abilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 1

### 9.3 During the past 4 weeks, how often has your child's health or behavior:

	Very Often	Fairly Often	Sometimes	Almost Never	Never
Limited the types of activities you could do as a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interrupted various everyday family activities (eating meals, watching tv)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited your ability as a family to "pick up and go" on a moment's notice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused tension or conflict in your home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Been a source of disagreements or arguments in your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused you to cancel or change plans (personal or work) at the last minute?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### 9.4 Sometimes families may have difficulty getting along with one another. They do not always agree and they may get angry. In general, how would you rate your family's ability to get along with one another?

Excellent	Very Good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Facts About Your Child*

#### 10.1 Is your child:

Male	Female
<input type="checkbox"/>	<input type="checkbox"/>

#### 10.2 Was this your first child (natural or adopted)?

Yes	No
<input type="checkbox"/>	<input type="checkbox"/>

Parental Form Section 1

10.3 What is the highest grade of school your child has completed? (Mark  one only)

Preschool  
Kindergarten  
1<sup>st</sup> Grade  
2<sup>nd</sup> Grade  
3<sup>rd</sup> Grade  
4<sup>th</sup> Grade  
5<sup>th</sup> Grade  
Ungraded

6<sup>th</sup> Grade  
7<sup>th</sup> Grade  
8<sup>th</sup> Grade  
9<sup>th</sup> Grade  
10<sup>th</sup> Grade  
11<sup>th</sup> Grade  
12<sup>th</sup> Grade

If ungraded how many years attended?  
\_\_\_\_\_

## Parental Form Section 1

**10.4 Have you ever been told by a teacher, school official, doctor, nurse, or other health professional that your child has any of the following conditions?**

	Yes	No
Anxiety problems	<input type="checkbox"/>	<input type="checkbox"/>
Asthma	<input type="checkbox"/>	<input type="checkbox"/>
Attentional problems	<input type="checkbox"/>	<input type="checkbox"/>
Behavioral problems	<input type="checkbox"/>	<input type="checkbox"/>
Chronic allergies or sinus trouble	<input type="checkbox"/>	<input type="checkbox"/>
Chronic orthopaedic, bone or joint problems	<input type="checkbox"/>	<input type="checkbox"/>
Chronic respiratory, lung or breathing trouble (NOT ASTHMA)	<input type="checkbox"/>	<input type="checkbox"/>
Chronic rheumatic disease	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>
Developmental delay or mental retardation	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes	<input type="checkbox"/>	<input type="checkbox"/>
Epilepsy (seizure disorder)	<input type="checkbox"/>	<input type="checkbox"/>
Hearing impairment or deafness	<input type="checkbox"/>	<input type="checkbox"/>
Learning problems	<input type="checkbox"/>	<input type="checkbox"/>
Sleep disturbance	<input type="checkbox"/>	<input type="checkbox"/>
Speech problems	<input type="checkbox"/>	<input type="checkbox"/>
Vision problems	<input type="checkbox"/>	<input type="checkbox"/>
Does your child have any other chronic medical condition that is affecting what they do or how they feel? (Please describe below)	<input type="checkbox"/>	<input type="checkbox"/>

# Parental Form Section 1

## Fact About You

11.1 Are you:

Male

Female

11.2 What is your date of birth?

Month	Day	Year
<input type="text"/>	<input type="text"/>	<input type="text"/>

11.3 Which of the following best describes your current work status? (Mark  all that apply)

- |  |   |   |   |   |
|--|---|---|---|---|
| Not working due to my child's health<br><input type="checkbox"/> | Not working for "other" reasons<br><input type="checkbox"/> | Looking for work outside the home<br><input type="checkbox"/> | Working full or part time (either outside the home or at a home based business)<br><input type="checkbox"/> | Full time homemaker<br><input type="checkbox"/> |
|--|---|---|---|---|

11.4 Which of the following best describes your relationship to your child?

- |   |   |   |   |                                      |  |
|---|---|---|---|--------------------------------------|--|
| Biological Parent<br><input type="checkbox"/> | Step Parent<br><input type="checkbox"/> | Foster Parent<br><input type="checkbox"/> | Adoptive Parent<br><input type="checkbox"/> | Guardian<br><input type="checkbox"/> | Other (please explain on the line below)<br><input type="checkbox"/> |
|---|---|---|---|--------------------------------------|--|

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11.5 What is the highest grade of school you have completed?

- |  |   |   |  |   |
|--|---|---|--|---|
| Some high school or less<br><input type="checkbox"/> | High school diploma/GED<br><input type="checkbox"/> | Vocational school or some college<br><input type="checkbox"/> | College degree<br><input type="checkbox"/> | Professional or graduate degree<br><input type="checkbox"/> |
|--|---|---|--|---|

## Parental Form Section 1

11.6 Which of the following best describes your current marital status?

Married	Widowed	Divorced	Separated	Remarried	Never Married
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11.7 Which of the following best describes your racial background?

Caucasian	Afro-American	Hispanic	Asian/Oriental or Pacific Islander	Other (please explain on the line below)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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## Parental Form Section 2

**These questions are about how your child's illness has affected your life**

1. In the last month, how often have you been upset because of something that happened unexpectedly?

Never	Almost Never	Sometimes	Fairly Often	Very Often
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. In the last month, how often have you felt that you were unable to control the important things in your life?

Never	Almost Never	Sometimes	Fairly Often	Very Often
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. In the last month, how often have you felt nervous and "stressed"?

Never	Almost Never	Sometimes	Fairly Often	Very Often
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 2

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

Never  Almost Never  Sometimes  Fairly Often  Very Often

5. In the last month, how often have you felt that things were going your way?

Never  Almost Never  Sometimes  Fairly Often  Very Often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

Never  Almost Never  Sometimes  Fairly Often  Very Often

7. In the last month, how often have you been able to control irritations in your life?

Never  Almost Never  Sometimes  Fairly Often  Very Often

8. In the last month, how often have you felt that you were on top of things?

Never  Almost Never  Sometimes  Fairly Often  Very Often

9. In the last month, how often have you been angered because of things that were outside of your control?

Never  Almost Never  Sometimes  Fairly Often  Very Often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Never  Almost Never  Sometimes  Fairly Often  Very Often

## Parental Form Section 3

This section asks questions about how stressful your child's illness has been. These questions ask you to answer for yourself.

By marking  one box per line, please indicate how true each statement has been for you during the past 7 days.

### Social/Family Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel distant from my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get emotional support from my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get support from my friends and neighbors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has accepted my child's illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family communication about my child's illness is poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel close to my partner (or the person who is my main support)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been sexually active during the past year? No _____ Yes _____ If yes: I am satisfied with my sex life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above seven questions, how much would you say your Social/Family Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 3

### Relationship with doctor

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have confidence in my child's doctor(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor is available to answer my questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above two questions, how much would you say your Relationship with the Doctor affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Emotional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am proud of how I'm coping with my child's illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am losing hope in the fight against my child's illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel nervous about my child's health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry about my child dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry that my child's condition will get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above six questions, how much would you say your Emotional Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Parental Form Section 3

#### Functional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to work (include work in home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My work (include work in home) is fulfilling	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am able to enjoy life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have accepted my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am sleeping well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am enjoying the things I usually do for fun	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am content with the quality of my life right now	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above seven questions, how much would you say your Functional Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Parental Form Section 3

Additional concerns

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I worry that the transplant/treatment will not work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The effects of treatment are worse than I had imagined	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I regret having the transplant/treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What is your child's immune deficiency? \_\_\_\_\_

Has your child had a bone marrow transplant/stem cell transplant \_\_\_\_\_

If so, how many years ago? \_\_\_\_\_

How many courses of antibiotics has your child required in the past year? \_\_\_\_\_

How many times has your child been hospitalized in the past year? \_\_\_\_\_

Have you lost your insurance as a result of your child's illness? \_\_\_\_\_

Has your work been affected by your child's illness? \_\_\_\_\_

Have you had trouble getting medications for your child's illness? \_\_\_\_\_

Have you had trouble finding a physician with knowledge of your child's condition? \_\_\_\_\_

Have your other children been affected by your child's illness? \_\_\_\_\_

# CHILD FORM Section 1

Please help your child fill out this form but it is important that they answer for themselves

NAME \_\_\_\_\_ Birthdate \_\_\_\_\_

## *Your Global Health*

1.2 In general, would you say your health is:

Excellent

Very Good

Good

Fair

Poor

## *Your Physical Activities*

2.1 During the past 4 weeks, has it been difficult you to do the following activities due to health problems?

	Yes, very difficult	Yes, somewhat difficult	Yes, a little difficult	No, not difficult at all
Do things that take some energy, such as playing soccer, running or hiking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do things that take some energy, such as riding a bike or skating?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get around your neighborhood, playground, or school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking one block or climbing one flight of stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bend, lift, or stoop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eat, dress, bath, or go to the toilet by yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do tasks around the house?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walk several blocks or climb several flights of stairs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

### *Your Everyday Activities*

**3.1 During the past 4 weeks, has it been difficult to do your school work or usual activities with friends because of problems like **FEELING SAD OR WORRIED**?**

Has is been difficult to:	Yes, very difficult	Yes, somewhat difficult	Yes, a little difficult	No, not difficult at all
Do certain KINDS of schoolwork or activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spend the usual AMOUNT of time on schoolwork or activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get schoolwork DONE at all or do any activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3.2 During the past 4 weeks, has it been difficult to do your schoolwork or usual activities with friends because of problems with your **BEHAVIOR**?**

Has it been difficult to:	Yes, very difficult	Yes, somewhat difficult	Yes, a little difficult	No, not difficult at all
Do certain KINDS of schoolwork or activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spend the usual AMOUNT of time on schoolwork or activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get schoolwork DONE at all or do any activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

**3.3 During the past 4 weeks, has it been difficult to do your schoolwork or usual activities with friends because of problems with your **PHYSICAL** health?**

	Yes, very difficult	Yes, somewhat difficult	Yes, a little difficult	No, not difficult at all
Has it been difficult to:				
Do certain KINDS of schoolwork or activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Spend the usual AMOUNT of time on schoolwork or activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Get schoolwork DONE at all or do any activities with friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

***Pain***

**4.1 During the past 4 weeks, how much bodily pain or discomfort have you had?**

None	Very Mild	Mild	Moderate	Severe	Very Severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4.2 During the past 4 weeks, how often have you had bodily pain or discomfort?**

None of the time	Once or twice	A few times	Fairly often	Very often	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

### *Getting Along*

5.1 During the past 4 weeks how often did each of the following statements describe you?

	Very Often	Fairly Often	Sometimes	Almost Never	Never
Acted too young for your age?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Argued?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had a hard time paying attention?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did not do what your teacher or parent asked you to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wanted to be alone?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lied or cheated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had a hard time getting others to like you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt clumsy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ran away from home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had speech problems (e.g. stuttering)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stole things at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Stole things outside home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Acted mean or moody if you did not get what you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Got really mad when you did not get what you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Found it hard to be with others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had a hard time getting along with others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**CHILD FORM Section 1**

5.2 Compared to other children your age, in general would you your behavior is:

Excellent	Very Good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**General Well-Being**

6.1 During the past 4 weeks, how much of the time did you:

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Feel sad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel like crying?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel afraid or scared?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worry about things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel unhappy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel bothered or upset?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel happy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel cheerful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Enjoy the things you do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have fun?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feel jittery or restless?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have trouble sleeping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have headaches?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Like yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

### *Self-Esteem*

7.1 During the past 4 weeks, how good or bad have you felt about:

	Very good	Somewhat good	Neither good nor bad	Somewhat badly	Very badly
Yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your school work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your ability to play sports?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your friendships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The things you CAN do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way you get along with others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your body and your looks?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way you seem to feel most of the time?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way you get along with your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way life seems to be for you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your ability to be a friend to others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The way others seem to feel about you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your ability to talk to with others?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your health in general?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

### *Your Health*

#### 8.1 How true or false is the statement for you?

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
My health is excellent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was so sick once I thought I might die.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I do not seem to get very sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I seem to be less healthy than other kids I know.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have never been very, very sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I <u>always</u> seem to get sick.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think I will be less healthy when I get older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think I will be healthy when I get older.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I never worry about my health.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think I am healthy now.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I think I worry about my health more than other kids my age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

#### 8.2 Compared to one year ago, how would you rate your health now:

Much better now that 1 year ago	Somewhat better now than 1 year ago	About the same as 1 year ago	Somewhat worse now than 1 year ago	Much worse now than 1 year ago
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

### *You and Your Family*

9.1 During the past 4 weeks, how often has your health or behavior:

	Very often	Fairly often	Sometimes	Almost never	Never
Limited the types of activities you could do as a family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interrupted various everyday family activities (eating meals, watching tv)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Limited your ability as a family to "pick up and go" on a moment's notice?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused tension or conflict in your home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Been a source of disagreements or arguments in your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caused your family to cancel or change plans at the last minute?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9.2 Sometimes families may have difficulty getting along with one another. They do not always agree and they may get angry. In general, how would you rate your family's ability to get along with one another?

Excellent	Very Good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### *Facts About You*

10.1 Are you:

Male	Female
<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 1

10.3 What is the highest grade of school you have completed? (Mark  one only)

Preschool	<input type="checkbox"/>	6 <sup>th</sup> Grade	<input type="checkbox"/>
Kindergarten	<input type="checkbox"/>	7 <sup>th</sup> Grade	<input type="checkbox"/>
1 <sup>st</sup> Grade	<input type="checkbox"/>	8 <sup>th</sup> Grade	<input type="checkbox"/>
2 <sup>nd</sup> Grade	<input type="checkbox"/>	9 <sup>th</sup> Grade	<input type="checkbox"/>
3 <sup>rd</sup> Grade	<input type="checkbox"/>	10 <sup>th</sup> Grade	<input type="checkbox"/>
4 <sup>th</sup> Grade	<input type="checkbox"/>	11 <sup>th</sup> Grade	<input type="checkbox"/>
5 <sup>th</sup> Grade	<input type="checkbox"/>	12 <sup>th</sup> Grade	<input type="checkbox"/>
Ungraded	<input type="checkbox"/>	If ungraded how many years attended?	<input type="checkbox"/>

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10.4 Have you ever seen someone at school, clinic or doctor's office for any of the following: (Please check Yes or No for each)

	Yes	No
Injuries due to accident?	<input type="checkbox"/>	<input type="checkbox"/>
Bed wetting?	<input type="checkbox"/>	<input type="checkbox"/>
Chest pain?	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhea or constipation?	<input type="checkbox"/>	<input type="checkbox"/>
Not having a lot of energy to do things for a long time?	<input type="checkbox"/>	<input type="checkbox"/>
Headaches?	<input type="checkbox"/>	<input type="checkbox"/>
Not feeling like eating very much for a long time?	<input type="checkbox"/>	<input type="checkbox"/>
Bad dreams, trouble falling asleep or staying asleep?	<input type="checkbox"/>	<input type="checkbox"/>
Stomach aches?	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 2

By marking  one box per line, please indicate how true each statement has been for you during the past 7 days.

### Physical Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have lack of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have nausea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Because of my illness, I have trouble meeting doing things with my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am bothered by side-effects of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel sick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am forced to spend time in bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above 7 questions, how much would you say your Physical Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Social/Family Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel distant from my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get emotional support from my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I get support from my friends and neighbors	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family has accepted my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family communication about my illness is poor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above questions, how much would you say your Social/Family Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 2

### Relationship with doctor

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I have confidence in my doctor(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My doctor is available to answer my questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above two questions, how much would you say your Relationship with the Doctor affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Emotional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel sad	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am proud of how I'm coping with my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am losing hope in the fight against my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry about dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry that my condition will get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above six questions, how much would you say your Emotional Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## CHILD FORM Section 2

### Functional Well-Being

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I am able to enjoy life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have accepted my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am sleeping well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am enjoying the things I usually do for fun	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am content with the quality of my life right now	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above questions, how much would you say your Functional Well-Being affects your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Additional concerns

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I feel distant from other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I worry that the transplant/treatment will not work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The effects of treatment are worse than I had imagined	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I like the appearance of my body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have concerns about my ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have confidence in my nurse(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I regret having the transplant/treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Looking at the above questions, how much would you say these Additional Concerns affect your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>