SJLIFE

Behavior Survey

11-17 Years of Age Parent Report

St. Jude Children's Research Hospital
ALSAC • Danny Thomas, Founder
Finding cures. Saving children.

The questions in this booklet relate to:

Person completing this questionnaire is:

Your relationship:

☐ Parent ☐ Other: ______________________

Today's date: __ __ / __ __ / __ __ __ __
m m d d y y y y

Our mailing address is:
St. Jude Children's Research Hospital
Department of Epidemiology
Mail Stop 735
262 Danny Thomas Place
Memphis, TN 38105-3678

Toll-free phone number:
1-800-775-2167

e-mail:
SJLIFE@stjude.org

Finding cures. Saving children.

INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

1. Use a black ballpoint pen or a number 2 black pencil. Do not use a felt-tip or roller-ball pen. These may cause smudging. If you must erase answers, erase them completely.
2. When marking boxes, make an x inside the box (see examples below).
3. Make no stray marks of any kind. Please keep the form as clean as possible.
4. Written responses must stay within the boxes provided:

CORRECT: Grape

INCORRECT: Grape

MARKING EXAMPLES

Below are some examples of how to fill out this questionnaire. Please look these over before you begin.

Example 1

1. During the past month, did your child participate in any physical activities or exercises such as running, aerobics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?

☐ No ☒ Yes

Example 2

2. Has your child ever taken. . .

	No	Yes	Not sure	If yes, age at first use
a. PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)	X	☐	☐	
If yes, specify the name of the drug(s) or indicate you do not know the specific name				
b. MEDICATIONS FOR ATTENTION OR MEMORY PROBLEMS such as Ritalin, Adderall, Concerta, Strattera, Aricept (donepezil), or Provigil (modafinil)		☒	☐	1 0
If yes, specify the name of the drug(s) or indicate you do not know the specific name: ritalin				

Example 3

3. When was this condition diagnosed?

0 4 — Month (mm)

2 0 0 0 — Year (yyyy)

Please! Do not mark below this line

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SCHOOL HISTORY

A1. What is the highest grade or level of schooling your child has now completed?

- ☐ 1 - 8 years (grade school)
- ☐ 9 - 12 years (high school) but did not graduate
- ☐ Completed high school/GED
- ☐ Training after high school, other than college
- ☐ Some college
- ☐ College graduate
- ☐ Post graduate level
- ☐ Other

If Other, please describe.

A2. What is the highest grade or level of schooling that your child's <u>mother</u> has completed?

- ☐ 1 - 8 years (grade school)
- ☐ 9 - 12 years (high school), but did not graduate
- ☐ Completed high school/GED
- ☐ Training after high school, other than college
- ☐ Some college
- ☐ College graduate
- ☐ Post-graduate level
- ☐ Not Applicable
- ☐ Unknown
- ☐ Other ***Specify.***

A3. What is the highest grade or level of schooling that your child's <u>father</u> has completed?

- ☐ 1 - 8 years (grade school)
- ☐ 9 - 12 years (high school), but did not graduate
- ☐ Completed high school/GED
- ☐ Training after high school, other than college
- ☐ Some college
- ☐ College graduate
- ☐ Post-graduate level
- ☐ Not Applicable
- ☐ Unknown
- ☐ Other ***Specify.***

Continue on next page.

A4. In school was your child <u>ever</u> in any of the following programs? ***(Mark all that apply)***

	No	Yes	Not sure
Advanced placement or talented program?	☐	☐	☐
Homebound education (instruction at home by a school teacher) for at least one school year?	☐	☐	☐
Learning disabled or special education program?	☐	☐	☐

If no, skip to A6.

If yes, was he/she in the program because of. . .

	No	Yes	Not sure
a. Missed school.	☐	☐	☐
b. Low scores on tests.	☐	☐	☐
c. Problems learning or concentrating.	☐	☐	☐
i. In Reading?	☐	☐	☐
ii. In Math?	☐	☐	☐
iii. In Writing?	☐	☐	☐
d. Emotional or behavioral problems	☐	☐	☐

A5. If your child was in a learning disabled or special education program, what grades was he/she in at that time? ***(Mark all that apply)***

- ☐ Pre-K
- ☐ K
- ☐ 1st
- ☐ 2nd
- ☐ 3rd
- ☐ 4th
- ☐ 5th
- ☐ 6th
- ☐ 7th
- ☐ 8th
- ☐ 9th
- ☐ 10th
- ☐ 11th
- ☐ 12th

A6. Has your child <u>ever</u> . . .

	No	Yes	Not sure
a. Attended summer school?	☐	☐	☐
b. Repeated a grade?	☐	☐	☐
c. Skipped a grade?	☐	☐	☐
d. Taken adaptive physical education?	☐	☐	☐
e. Been suspended from school?	☐	☐	☐
f. Been expelled from school?	☐	☐	☐
g. Been physically bullied?	☐	☐	☐
h. Been emotionally bullied?	☐	☐	☐
i. Bullied others?	☐	☐	☐
j. Been socially isolated by classmates?	☐	☐	☐
k. Engaged in self harm?	☐	☐	☐
l. Engaged in dangerous or risky internet behavior?	☐	☐	☐

Continue on next page.

A7. **Is your child currently receiving . . .**

	No	Yes	Not sure
a. Physical therapy?	☐	☐	☐
b. Occupational therapy?	☐	☐	☐
c. Speech therapy?	☐	☐	☐
d. Counseling?	☐	☐	☐
e. Services via 504 plan?	☐	☐	☐
f. Services via IEP?	☐	☐	☐
g. Services for sensory impairment (vision/hearing)?	☐	☐	☐

A8. Has your child ever received neuropsychological/ psychoeducational assessment (also known as "testing")?

☐ No → *Go to Question B1.*

☐ Not sure

☐ Yes

A8a. Where did he/she get tested?

A8b. How many years has it been since your child's last testing took place? ☐☐ years

EMPLOYMENT

B1. Has your child ever had a job?

☐ No → *Go to Question C1, next page.*

☐ Yes

B2. What is his/her current employment status? Include unpaid work in the family business or farm. ***(Mark all that apply)***

☐ Not currently working → *Go to Question C1.*

☐ Working full-time (30 or more hours per week)

☐ Working part-time (less than 30 hours per week)

☐ Caring for home or family (not seeking paid work)

☐ Unemployed and looking for work

☐ Unable to work due to illness or disability

☐ Student

☐ Other

If Other, please describe.

B3. The following questions are about your child's present occupation. Please write his/her job title and brief details of what he/she does. If he/she has more than one job, please give the title of your child's main job.

B3a. Main job title:

B3b. Please briefly describe the primary tasks in your child's job:

Please! Do not mark below this line

INSURANCE

Health Insurance

C1. Have you ever had difficulty obtaining health insurance for your child because of his/her health history?

☐ No

☐ Yes

C2. Does your child currently have health insurance coverage?

☐ Non U. S. resident → *Go to D1, next page.*

☐ No → *Go to D1, next page.*

☐ Yes

C3. How is this insurance provided? *(Mark all that apply)*

☐ Through parent's place of employment

☐ Through parent's policy

☐ Through a policy you have purchased for your child

☐ Affordable Care Act (Obama Care)

☐ Medicaid or other public assistance program

☐ Medicare

☐ Military dependent/Veteran's benefits (CHAMPUS)

☐ Other ***If other, please specify.***

C3a. Does this health insurance plan have any exclusions or restrictions because of your child's health history?

☐ Don't know

☐ No

☐ Yes ***If yes, please specify.***

C3b. Is there an extra premium charge on your health insurance policy because of your child's health history?

☐ Don't know

☐ No

☐ Yes

Continue on next page.

Please! Do not mark below this line

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LIVING ARRANGEMENT

D1. What is your child's <u>current</u> living arrangement? *(Mark all that apply)*

☐ Lives with parent(s)

☐ Lives with spouse/partner

☐ Lives with roommate(s)

☐ Lives with brother(s) and/or sister(s)

☐ Lives with other relative(s) (not including minor children)

☐ Lives alone

☐ Other

Specify.

INCOME

D2. Over the <u>last year</u>, what was the total income of the primary <u>household</u> your child lived in?

☐ Less than $20,000

☐ $20,000 - $39,999

☐ $40,000 - $59,999

☐ $60,000 - $79,999

☐ $80,000 - $99,999

☐ Over $100,000

☐ Don't know

D3. During the <u>past year</u>, how many people in this primary household were supported on this income?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

☐ 6

☐ 7

☐ 8

☐ 9 or more

Continue on next page.

Please! Do not mark below this line

PHYSICAL FUNCTIONING

E1. Would you rate your child as being:

- ☐ Completely disabled
- ☐ Severely disabled
- ☐ Moderately disabled
- ☐ Mildly disabled
- ☐ Not at all disabled

E2. In general, would you say your child's health is:

- ☐ Excellent
- ☐ Very good
- ☐ Good
- ☐ Fair
- ☐ Poor

E3. <u>Compared to one year ago</u>, how would you rate your child's health in general <u>now</u>?

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse now than one year ago

E4. Please respond to each item by marking one box per row.

In the <u>past 7 days</u>. . . .	**With no trouble**	**With a little trouble**	**With some trouble**	**With a lot of trouble**	**Not able to do**
a. My child could do sports and exercise that other kids his/her age could do	☐	☐	☐	☐	☐
b. My child could get up from the floor	☐	☐	☐	☐	☐
c. My child could keep up when he/she played with other kids	☐	☐	☐	☐	☐
d. My child could move his/her legs	☐	☐	☐	☐	☐
e. My child could stand up without help	☐	☐	☐	☐	☐
f. My child could stand up on his/her tiptoes	☐	☐	☐	☐	☐
g. My child could walk up stairs without holding on to anything	☐	☐	☐	☐	☐
h. My child has been physically able to do the activities he/she enjoys most	☐	☐	☐	☐	☐

Continue on next page.

Please! Do not mark below this line

SOCIAL FUNCTIONING

F1. About how many close friends does your child have?

- ☐ 0 → *Go to Question F3.*
- ☐ 1
- ☐ 2 or 3
- ☐ 4 or more

F2. About how many times a week does your child do things with close friends?

- ☐ Less than 1
- ☐ 1 or 2
- ☐ 3 or more

F3. Compared to other children of his/her age, how well does your child . . .

	Worse	About Same	Better
a. Get along with his/her brothers and sisters?	☐	☐	☐
b. Get along with other children?	☐	☐	☐
c. Behave with his/her parents?	☐	☐	☐
d. Play and work by himself/herself?	☐	☐	☐

F4. How well do the following statements describe your child's behavior?

	Often True	Sometimes True	Not True
a. Has sudden changes in mood or feelings	☐	☐	☐
b. Feels or complains that no one loves him/her	☐	☐	☐
c. Is rather high strung, tense, or nervous	☐	☐	☐
d. Cheats or tells lies	☐	☐	☐
e. Is too fearful or anxious	☐	☐	☐
f. Argues too much	☐	☐	☐
g. Has difficulty concentrating, cannot pay attention for long	☐	☐	☐
h. Is easily confused, seems to be in a fog	☐	☐	☐
i. Bullies, or is cruel or mean to others	☐	☐	☐
j. Is disobedient at home	☐	☐	☐
k. Is disobedient at school	☐	☐	☐
l. Does not seem to feel sorry after he/she misbehaves	☐	☐	☐

F4. (Cont.) How well do the following statements describe your child's behavior?

	Often True	Sometimes True	Not True
m. Has trouble getting along with other children	☐	☐	☐
n. Has trouble getting along with teachers	☐	☐	☐
o. Is impulsive, or acts without thinking.	☐	☐	☐
p. Feels worthless or inferior	☐	☐	☐
q. Is not liked by other children	☐	☐	☐
r. Has a lot of difficulty getting his/her mind off certain thoughts, has obsessions	☐	☐	☐
s. Is restless or overly active, cannot sit still	☐	☐	☐
t. Is stubborn, sullen, or irritable	☐	☐	☐
u. Has a very strong temper and loses it easily	☐	☐	☐
v. Is unhappy, sad or depressed	☐	☐	☐
w. Is withdrawn, does not get involved with others	☐	☐	☐

If child is 12 years of age or older → *Go to Question F6.*

Please! Do not mark below this line

F5. FOR CHILDREN UNDER 12 YEARS OF AGE

	Often True	Sometimes True	Not True
a. Breaks things on purpose, deliberately destroys his/her own things	☐	☐	☐
b. Clings to adults	☐	☐	☐
c. Cries too much	☐	☐	☐
d. Demands a lot of attention	☐	☐	☐
e. Is too dependent on others	☐	☐	☐

If child is under 12 years of age → *Go to Question F7.*

F6. FOR CHILDREN 12 YEARS OF AGE OR OLDER

	Often True	Sometimes True	Not True
a. Feels others are out to get him/her	☐	☐	☐
b. Hangs around with kids who get into trouble.	☐	☐	☐
c. Is secretive, keeps things to himself/herself	☐	☐	☐
d. Worries too much	☐	☐	☐

F7. Please respond to each item by marking one box per row.

In the past 7 days. . . .

	Never	Almost Never	Sometimes	Often	Almost Always
a. My child felt accepted by other kids his/her age	☐	☐	☐	☐	☐
b. My child was able to count on his/her friends	☐	☐	☐	☐	☐
c. My child was good at making friends.	☐	☐	☐	☐	☐
d. My child and his/her friends helped each other out	☐	☐	☐	☐	☐
e. Other kids wanted to be my child's friend	☐	☐	☐	☐	☐
f. Other kids wanted to be with my child	☐	☐	☐	☐	☐
g. Other kids wanted to talk to my child.	☐	☐	☐	☐	☐

Continue on next page.

SLEEP

G1 to G8 relate to the past 7 days.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
G1. His/her sleep was restless	☐	☐	☐	☐	☐
G2. He/she was satisfied with his/her sleep	☐	☐	☐	☐	☐
G3. His/her sleep was refreshing.	☐	☐	☐	☐	☐
G4. He/she had difficulty falling asleep.	☐	☐	☐	☐	☐

	Never	Rarely	Sometimes	Often	Always
G5. He/she had trouble staying asleep	☐	☐	☐	☐	☐
G6. He/she had trouble sleeping	☐	☐	☐	☐	☐
G7. He/she got enough sleep.	☐	☐	☐	☐	☐

	Very poor	Poor	Fair	Good	Very good
G8. His/her sleep quality was	☐	☐	☐	☐	☐

Continue on next page.

PAIN

H1. Does your child currently have pain as a result of his/her cancer or similar illness, or its treatment?

- ☐ No pain
- ☐ Small amount of pain
- ☐ Medium amount of pain
- ☐ A lot of pain
- ☐ Very bad, excruciating pain

H2. For pain that your child has had during the past 4 weeks, where has this pain been located?
(Mark all that apply)

- ☐ My child did not have pain in the past 4 weeks.
- ☐ Head
- ☐ Neck
- ☐ Chest
- ☐ Hands/Arms
- ☐ Abdomen
- ☐ Back
- ☐ Pelvis
- ☐ Legs/Feet
- ☐ Other

If other, please specify.

H3. How much bodily pain has your child had during the past 4 weeks?

- ☐ None
- ☐ Very mild
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very severe

H4. Please respond to each item by marking one box per row.

In the past 7 days. . . .	**Never**	**Almost Never**	**Sometimes**	**Often**	**Almost Always**
a. My child had trouble sleeping when he/she had pain	☐	☐	☐	☐	☐
b. My child felt angry when he/she had pain	☐	☐	☐	☐	☐
c. My child had trouble doing schoolwork when he/she had pain . .	☐	☐	☐	☐	☐
d. It was hard for my child to pay attention when he/she had pain	☐	☐	☐	☐	☐
e. It was hard for my child to run when he/she had pain	☐	☐	☐	☐	☐
f. It was hard for my child to walk one block when he/she had pain	☐	☐	☐	☐	☐
g. It was hard for my child to have fun when he/she had pain	☐	☐	☐	☐	☐
h. It was hard for my child to stay standing when he/she had pain	☐	☐	☐	☐	☐

Continue on next page.

WORRY/CONCERNS

I1. Does your child currently have anxieties/fears as a result of his/her cancer or similar illness, or its treatment?

- ☐ No anxiety/fears
- ☐ Small amount of anxiety/fears
- ☐ Medium amount of anxiety/fears
- ☐ A lot of anxiety/fears
- ☐ Very many, extreme anxiety/fears

MOOD

I2. Please respond to each item by marking one box per row.

In the past 7 days. . . .

	Never	Almost Never	Sometimes	Often	Almost Always
a. My child could not stop feeling sad	☐	☐	☐	☐	☐
b. My child felt everything in his/her life went wrong	☐	☐	☐	☐	☐
c. My child felt like he/she couldn't do anything right	☐	☐	☐	☐	☐
d. My child felt lonely	☐	☐	☐	☐	☐
e. My child felt sad	☐	☐	☐	☐	☐
f. My child thought that his/her life was bad	☐	☐	☐	☐	☐

I3. In the past 12 months, has your child ever made statements about wanting to hurt or kill him or herself?

- ☐ No
- ☐ Yes

I4. In the past 12 months, has your child ever done anything to try to hurt or kill him or herself?

- ☐ No
- ☐ Yes

Please respond to each item by marking one box per row.

In the past 7 days. . . .

	Never	Almost Never	Sometimes	Often	Almost Always
I5. My child felt nervous	☐	☐	☐	☐	☐
I6. My child felt scared	☐	☐	☐	☐	☐
I7. My child felt worried	☐	☐	☐	☐	☐
I8. My child felt like something awful might happen	☐	☐	☐	☐	☐
I9. My child thought about scary things	☐	☐	☐	☐	☐
I10. My child was afraid that he/she would make mistakes	☐	☐	☐	☐	☐
I11. My child worried about what could happen to him/her	☐	☐	☐	☐	☐
I12. My child worried when he/she went to bed at night	☐	☐	☐	☐	☐

ATTENTION/CONCENTRATION

Please read each item carefully and tell us how true it is about your child in the past month.

	Never or seldom	Occasionally	Often	Very often
J1. It is hard for my child to pay attention to details	☐	☐	☐	☐
J2. My child can't pay attention for long	☐	☐	☐	☐
J3. My child loses track of what he/she is supposed to do	☐	☐	☐	☐
J4. My child gets distracted by things that are going on around him/her	☐	☐	☐	☐
J5. My child has trouble finishing things	☐	☐	☐	☐
J6. My child has trouble concentrating	☐	☐	☐	☐

Please! Do not mark below this line

IMPACT ON FAMILY

These questions ask about the impact cancer or a similar illness has had on your family. For each item, please indicate whether or not the statement describes your family.

	Strongly Agree	Agree	Disagree	Strongly Disagree	Don't Know	Prefer Not To Answer
K1. Because of the illness, we are not able to travel out of the city	☐	☐	☐	☐	☐	☐
K2. People in the neighborhood treat us special because of my child's illness	☐	☐	☐	☐	☐	☐
K3. We have little desire to go out because of my child's illness	☐	☐	☐	☐	☐	☐
K4. It is hard to find a reliable person to take care of my child	☐	☐	☐	☐	☐	☐
K5. Sometimes, we have to change plans about going out at the last minute because of my child's condition	☐	☐	☐	☐	☐	☐
K6. We see family and friends less because of the illness.	☐	☐	☐	☐	☐	☐
K7. Sometimes I wonder whether my child should be treated "special" or the same as a normal child	☐	☐	☐	☐	☐	☐
K8. I think about not having more children because of the illness.	☐	☐	☐	☐	☐	☐
K9. I don't have much time left over for other family members after caring for my child	☐	☐	☐	☐	☐	☐
K10. Our family gives up things because of my child's illness.	☐	☐	☐	☐	☐	☐
K11. Fatigue is a problem for me because of my child's illness.	☐	☐	☐	☐	☐	☐
K12. I live from day to day and don't plan for the future	☐	☐	☐	☐	☐	☐
K13. Nobody understands the burden I carry	☐	☐	☐	☐	☐	☐
K14. Traveling to the hospital is a strain on me	☐	☐	☐	☐	☐	☐
K15. Sometimes I feel like we live on a rollercoaster: in crisis when my child is acutely ill, OK when things are stable	☐	☐	☐	☐	☐	☐

Please! Do not mark below this line

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DAILY STRESS

These questions ask about your child's feelings and thoughts during the last month. For each item, please indicate with a mark how often your child felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
L1. How often did your child appear frustrated by being unable to control or do something?	☐	☐	☐	☐	☐
L2. How often did your child appear confident about his or her ability to handle personal problems?	☐	☐	☐	☐	☐
L3. How often did your child seem to feel things were going well?	☐	☐	☐	☐	☐
L4. How often did difficulties pile up so high that your child did not seem able to overcome them?	☐	☐	☐	☐	☐

OTHER ISSUES

Please rate how concerned you are about the following:

	Very concerned	Somewhat concerned	Concerned	Not very concerned	Not at all concerned
M1. Your child's future health	☐	☐	☐	☐	☐
M2. Your child's ability to have children	☐	☐	☐	☐	☐
M3. Your child developing another cancer	☐	☐	☐	☐	☐
M4. Your ability to get health insurance for your child	☐	☐	☐	☐	☐
M5. Your ability to get life insurance for your child	☐	☐	☐	☐	☐
M6. Your ability to cover expenses for health care for your child	☐	☐	☐	☐	☐
M7. Your ability to cover expenses for prescribed medicine for your child	☐	☐	☐	☐	☐
M8. Any other issues	☐	☐	☐	☐	☐

Please specify.

Please! Do not mark below this line

Has your child been diagnosed with any of the following medical problems?

N1. Depression ☐ Yes ☐ No

If yes, did your child ever receive treatment?

☐ Yes, in the past ☐ Yes, currently ☐ No

If yes, what type of treatment? ***(Mark all that apply)***

☐ Behavior/talk therapy/counseling

☐ Hospitalization

☐ Medication

List medications:

N2. Anxiety ☐ Yes ☐ No

If yes, did your child ever receive treatment?

☐ Yes, in the past ☐ Yes, currently ☐ No

If yes, what type of treatment? ***(Mark all that apply)***

☐ Behavior/talk therapy/counseling

☐ Hospitalization

☐ Medication

List medications:

N3. Attention Deficit Disorder (with or without hyperactivity) ☐ Yes ☐ No

If yes, did your child ever receive treatment?

☐ Yes, in the past ☐ Yes, currently ☐ No

If yes, what type of treatment? ***(Mark all that apply)***

☐ Behavior/talk therapy/counseling

☐ Hospitalization

☐ Medication

List medications:

N4. Bipolar Disorder ☐ Yes ☐ No

If yes, did your child ever receive treatment?

☐ Yes, in the past ☐ Yes, currently ☐ No

If yes, what type of treatment? ***(Mark all that apply)***

☐ Behavior/talk therapy/counseling

☐ Hospitalization

☐ Medication

List medications:

N5. Oppositional Defiant/Conduct Disorder ☐ Yes ☐ No

If yes, did your child ever receive treatment?

☐ Yes, in the past ☐ Yes, currently ☐ No

If yes, what type of treatment? ***(Mark all that apply)***

☐ Behavior/talk therapy/counseling

☐ Hospitalization

☐ Medication

List medications:

N6. Other psychiatric disorder (e.g. obsessive-compulsive disorder) ☐ Yes ☐ No

If yes, please specify the disorder:

If yes, did you ever receive treatment?

☐ Yes, in the past ☐ Yes, currently ☐ No

If yes, what type of treatment? ***(Mark all that apply)***

☐ Behavior/talk therapy/counseling

☐ Hospitalization

☐ Medication

List medications:

Do any of these medical conditions prevent your child from attending work, school or engaging in extracurricular activities on a regular basis (more days than not)?

☐ Yes ☐ No

If yes, which condition(s):

Please! Do not mark below this line