

**Transition Readiness in Adolescents and Young Adults with Neurofibromatosis Type 1
(NF1)**

Section 1: Demographic Questions

1. What is your age?

2. What is your gender?

☐ Male

☐ Female

3. Please check the box that best describes you:

☐ Caucasian/White

☐ African American or Black

☐ Hispanic or Latino

☐ American Indian or Alaska Native

☐ Hawaiian or Pacific Islander

☐ Other (Please Specify)

4. What is your relationship status?

☐ Single

☐ In a relationship

☐ Married

☐ Divorced/Separated

5. Please check the box that best describes the area you live in:

☐ Within or near a major city

☐ Within 60 miles of a major city

☐ More than 60 miles from a major city

6. Who do you currently live with (all that apply)?

☐ My parents/siblings

☐ My spouse

☐ My boyfriend/girlfriend

☐ My friend(s)

☐ My roommate

☐ Alone

☐ Other (Please specify)

7. What is your guardianship status?

- ☐ I am my own guardian
☐ My parent or another family member has guardianship
☐ I do not know
☐ Other

8. Are you currently a student?

- ☐ Yes
☐ No

9. What is the highest level of education you have completed?

- ☐ Some middle school
☐ Some high school
☐ High school graduate
☐ Some college
☐ College graduate
☐ Trade or technical school
☐ Some graduate school
☐ Graduate degree
☐ Other (Please specify)

10. Please check the box that best describes your employment status (all that apply):

- ☐ Employed full-time (More than 30 hours per week)
☐ Employed part-time (Up to 30 hours per week)
☐ Receive disability
☐ Student
☐ Not employed
☐ Other (Please specify)

11. Please check the box that best describes your health insurance status:

- ☐ Insurance coverage through employer

- ☐ Insurance coverage through parents/spouse policy
- ☐ Insurance coverage through college or educational institution
- ☐ Qualify and receive health insurance benefits from Medicaid/Medicare
- ☐ Other please specify:

12. Does anyone else in your family have NF1?

- ☐ Yes
- ☐ No
- ☐ I don't know

Section 2: Transition Readiness - Part 1

Please check the box that best describes **your** skill level in the following areas that are important for transition to adult health care. There is no right or wrong answer and your answers will remain confidential and private.

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
<i>Managing Medications</i>					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take your medications correctly and on your own?					
4. Do you reorder medications before they run out?					
<i>Appointment Keeping</i>					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups, or labs?					
7. Do you arrange for your ride to medical appointments?					

8. Do you call the doctor about unusual changes in your health? (For example: Allergic reactions?)					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell your doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Section 3: Transition Readiness - Part 2

Please check the box that best describes **your** skill level in the following areas that are important for transition to adult health care for people with Neurofibromatosis type 1 (NF1). There is no right or wrong answer and your answers will remain confidential and private.

	I plan to work on this or learn this	I can do this with some help or somewhat know this	I can do this well or know this well	This does not apply to me
Knowledge of Condition				
I know the main symptoms of NF1.				
I know why I need to see an NF1 doctor on a regular basis.				

I know what to do if I am having an NF1 related emergency.				
I know how to explain NF1 to other healthcare providers.				
I know how to explain NF1 to friends and family.				
<i>NF1 Information</i>				
I know how to contact my NF1 care team.				
I keep a folder or electronic document with important medical information, such as a list of my doctors and medications.				
<i>Genetics and Inheritance of NF</i>				
I know how NF1 is inherited or passed through families.				
I know my chance of having a child with NF1.				
I know about different options of birth control.				
I know how to protect myself and/or my partner from pregnancy and sexually transmitted infections.				

Section 4: Factors of Young Adult Life

Please indicate the impact that having NF1 has had on the following:

	<i>Significant impact</i>	<i>Some impact</i>	<i>No impact</i>	<i>Not Applicable</i>
<i>Education or School Plans</i>				
<i>Career/Job Choices</i>				
<i>Relationships</i>				
<i>Family Planning/ Having Children</i>				

Education

- How has NF1 affected your education plans after high school? (Check all that apply)

- ☐ Having NF1 has not affected my education plans
- ☐ I had/have to choose a school close to my family, friends, or doctors because of

NF1

- ☐ I had/have to live at home while going to college because of NF1
- ☐ I had/have to choose a certain major in college because of NF1
- ☐ I had/have to stop or take a break from my education (college or graduate school) because of NF1
- ☐ I cannot attend college or graduate school because of NF1
- ☐ Other (Please specify)

Employment

2. How has NF1 affected your career or job choices? (Check all that apply)

- ☐ Having NF1 has not affected my career or job choices
- ☐ I was/am limited in my career or job choices because I have NF1
- ☐ I had/have to find a job close to my family, friends, or doctor because of NF1
- ☐ I am not able to work because I have NF1
- ☐ Other (Please specify)

Relationships

4. Do you think NF1 has impacted your dating or marital relationships?

- ☐ No, having NF1 has not affected my dating or marital relationships
- ☐ Yes
- ☐ I don't know
- ☐ Prefer not to answer

5. If you answered "Yes," "I don't know," or "Prefer not to answer," please share why you feel this way by selecting all that apply. If you answered "No" in Question 4, please skip this question.

- ☐ I feel different because I have NF1
- ☐ I have trouble meeting people because I have NF1
- ☐ I feel less attractive because I have NF1
- ☐ I feel unable to do the same things as my significant other
- ☐ I was/am afraid of telling my significant other that I have NF1
- ☐ It is not easy for someone to understand my issues with NF1

- ☐ I am worried about how my NF1 will impact my relationship/marriage in the future
- ☐ I am worried about being able to support a family in the future
- ☐ Other (Please specify)

Family Planning

6. Do you have children (check all that apply)?

- ☐ No
- ☐ Yes, I have biological children
- ☐ Yes, I have adopted or foster children
- ☐ I am or my partner is currently pregnant

7. If no, do you want children in the future?

- ☐ No
- ☐ Yes, I want biological children
- ☐ Yes, I want adopted or foster children
- ☐ Not sure

8. How has NF1 influenced your thoughts about having children? (Check all that apply)

- ☐ Having NF1 has not influenced my thoughts about having children
- ☐ I do not want to have biological children because I am worried they may also have

NF1

- ☐ I do want to have biological children, but I am worried they may also have NF1
- ☐ I am not worried that my biological children may also have NF1
- ☐ I want to use/would consider using assisted reproductive technologies to have biological children who do not have NF1
- ☐ I would rather adopt or foster children so that I do not have to worry about them

also having NF1

- ☐ I am worried that I will not be able to have children because I have NF1
- ☐ I am worried that I will not be able to support my children because I have NF1
- ☐ Other (Please specify)

9. Is there any other information you would like to share with us about the topics of this survey?

Thank you for completing this survey. We hope our results will provide information to NF1 care providers leading to improved care for individuals with NF1.

If you would like to participate in the raffle to win one of fifteen \$30 Amazon gift cards, please follow the link below. Your contact information for the raffle will not be linked to your survey responses.