

## **Development of a Child and Young Adult Neurofibromatosis Type 1 Health Related Quality of Life Measure**

We want to better understand and be able to measure how having neurofibromatosis type1 (NF1) affects people's health and well-being.

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### **Development of a Child and Young Adult Neurofibromatosis Type 1 Health Related Quality of Life Measure**

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## **Do you or your child have Neurofibromatosis Type 1?**



Riley Hospital for Children

## **Are you (or your child) willing to take a survey about Neurofibromatosis Type1 and how it affects your health and well being?**



## Who?

Young Adults with NF1 (18-25)  
Children with NF1 (5-17y)  
Parents of children with NF1 (5-25y)

## What will I be asked to do?

We are asking for about 360 people to participate in field testing. To take part in field testing, you are required to answer surveys about NF1, how it affects your health and your general well-being. You can do the surveys at the clinic or can mail them back.

## How do I find out more?

Fill out the form on the next page and give it to your doctor. A person from the study will contact you and explain how to take part in the field testing.

I want to know more about the health related quality of life and neurofibromatosis type 1 study.

Please contact me:

Name: \_\_\_\_\_  
(printed)

Phone: \_\_\_\_\_

Alternate phone: \_\_\_\_\_

Signature: \_\_\_\_\_

Please send this information to:

**Kavitha Nutakki**  
**Development of a Child and Young**  
**Adult Neurofibromatosis Type 1**  
**Quality of Life Measure**  
**knutakki@iupui.edu**  
**Phone: (317) 278-0534**