



Dear NF2 families,

We at NF2 Biosolutions are working hard, daily, to fund a cure for NF2. Very real possibilities lie in genetic therapy and we are determined to bring NF2 into gene research. Our greatest challenge is funding but the road ahead will be shorter with your help.

We are asking as many families as are willing, to take part in an inspirational video. We hope that NF2 patients and families can share their experiences with NF2 and encourage viewers to support our cause. We have a professional videographer that will edit our personal videos into a short movie that we can all share with family, friends, on social media, with clubs and organizations, and more.

There are detailed instructions on how to film from home with just a smart phone. Guidelines include how to set a phone to a higher filming resolution, what type of light to use, how to orient the camera.

We have also put together a list of suggested questions. Our goal is to have the children share about their everyday lives, the youth to explain NF2, and older patients and families to share experiences, fears and challenges, etc. These questions are flexible and are just a guide to inspire topics. Children can talk about NF2 or anything else they feel comfortable with, or filmed with no talking at all. We hope families will film each other answering questions and talking about NF2 in a comfortable setting, at home. If anyone is visiting a doctor, we would love any footage taken there as well. Children can also be filmed just being a kid. We want viewers to see the faces of this disorder and truly understand its challenges.

Please let us know if you have any questions and we are so grateful for your help and participation. If you would like to know more about NF2 Biosolutions, what we are working on, and how you can fundraise on your own, please reach out!

Thank you,

Nicole, Jill, and Gil  
Parents fighting for their NF2-affected children

questions about filming: [jill@nf2biosolutions.org](mailto:jill@nf2biosolutions.org)  
questions about NF2 Biosolutions: [nicole@nf2biolsolutions.org](mailto:nicole@nf2biolsolutions.org)  
interest in getting involved: [gilles@nf2biosolutions.org](mailto:gilles@nf2biosolutions.org)

Videos should be recorded in single question segments to avoid creating large files.

Suggested questions & topics:

Please feel free to expand and explore these topics as you feel comfortable.

\*Everyone should share where they are from (names do not have to be shared)

For all children/youth:

\*film their activities, their hobbies, etc.

\*if your younger child feels comfortable talking about a surgery and NF2, please ask

What's your favorite thing to do with your family?

What's your favorite place you've visited?

What do you love to do or play with?

What do you want to be when you grow up?

What's your favorite part of school?

Can you tell me about a time when you were brave?

For anyone that has had a surgery, experienced drug trials, and/or avastin, etc:

\*film in an interview style, share photos or video of the experience if you have it

How was your surgery?

How was the hospital?

How did you feel after surgery?

Tell us about the trial or treatment? Explain emotions and physical affects if comfortable.

For older kids/young adults:

\*film in an interview style

What is NF2?

Tell me about your life with NF2

What are some of your struggles due to NF2?

What does it mean to you that you have NF2?

How was your year?

How often do you see the doctor and what do they do?

How do you feel about the future?

Has NF2 changed your view of your future?

questions to ask parents:

\*film in an interview style

Describe your journey with NF2

How has NF2 affected your family?

What was it like to find out your child has NF2?

What fears do you have for your child?