

Crew - Neurofibromatosis Type 1

by Hilary, Mother

6 Months



13 Months



2 Years



3 Years



3.5 Years

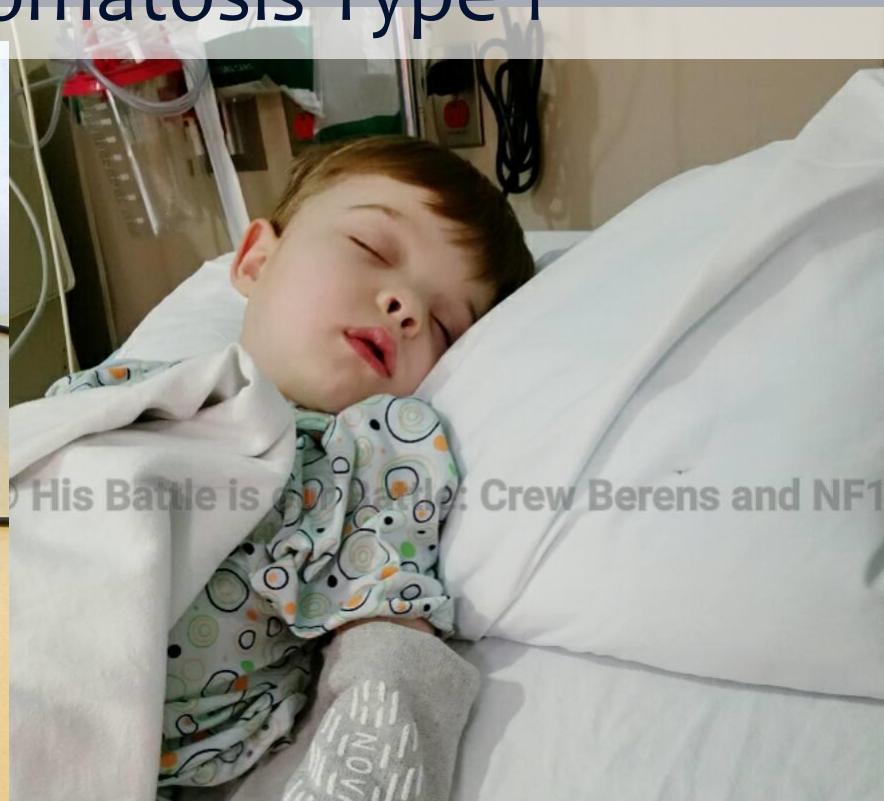


7 Years





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PROFESSION:

Just successfully graduated Kindergarten and will be starting 1st Grade in the Fall

13 Months

14 Months

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14 Months



18 Months

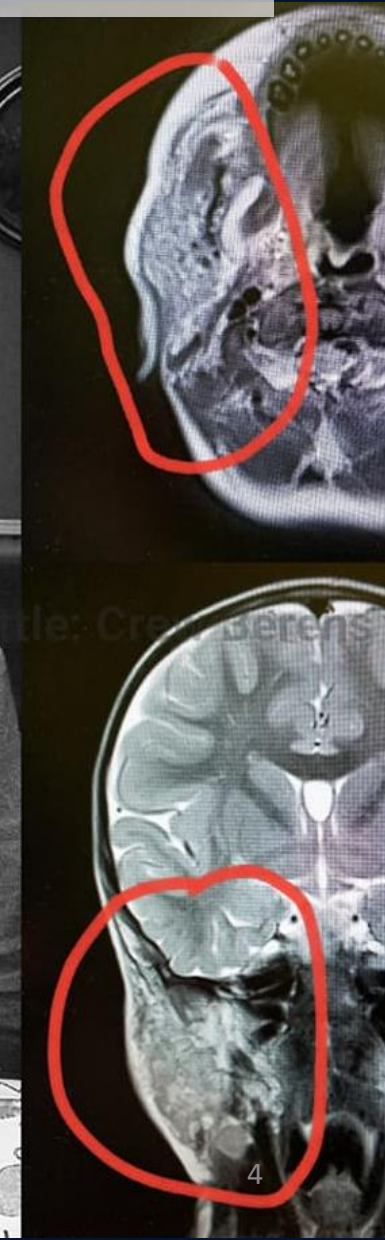
HOBBIES:

- Going to the beach or on the pontoon with family
- playing with Legos or transformers



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18 Months



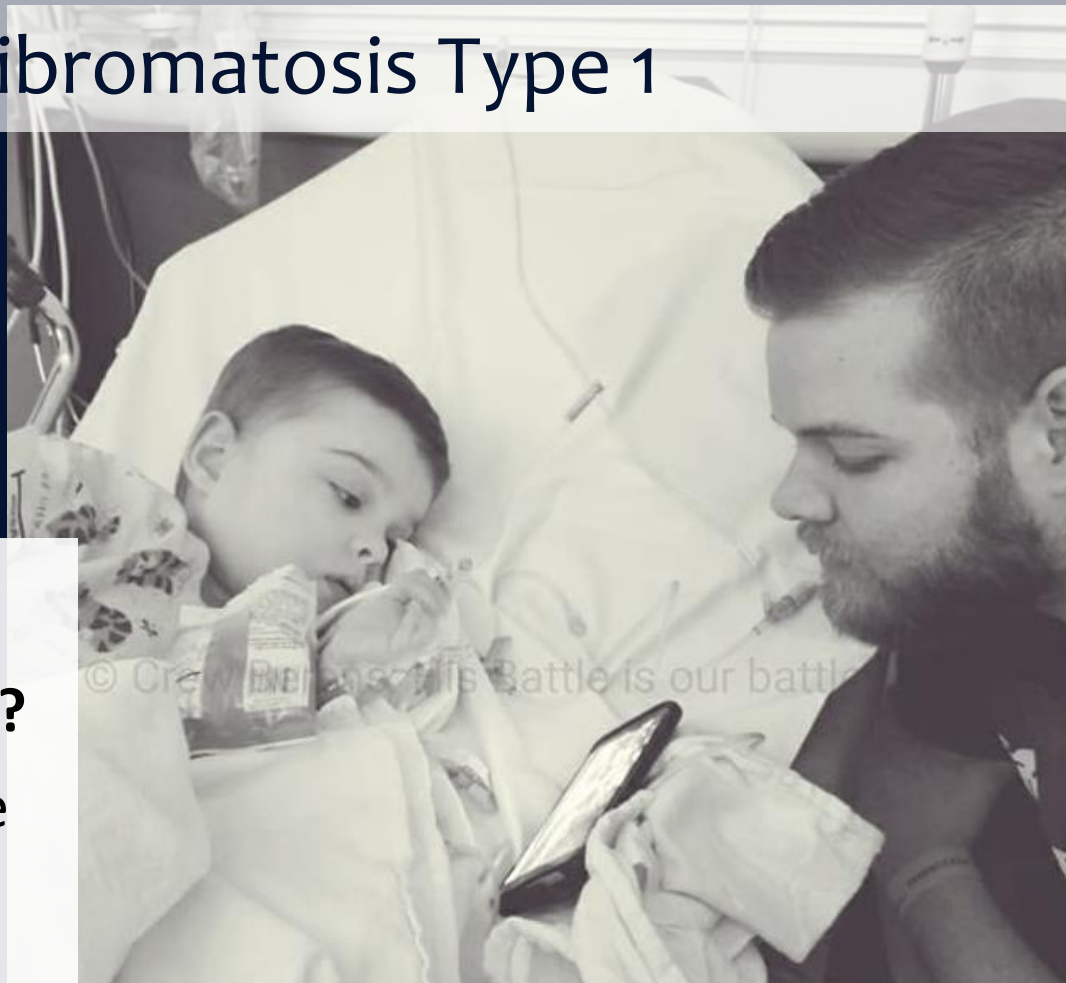
DESCRIBE YOURSELF IN 5 WORDS:

- Strong
- Smart
- Goofy
- Loving
- Inquisitive

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HOW CAN OTHERS INCLUDE YOU BETTER?

Learn about NF and be
understanding



18 Months



CREW 
HIS BATTLE IS OUR BATTLE

2 Years

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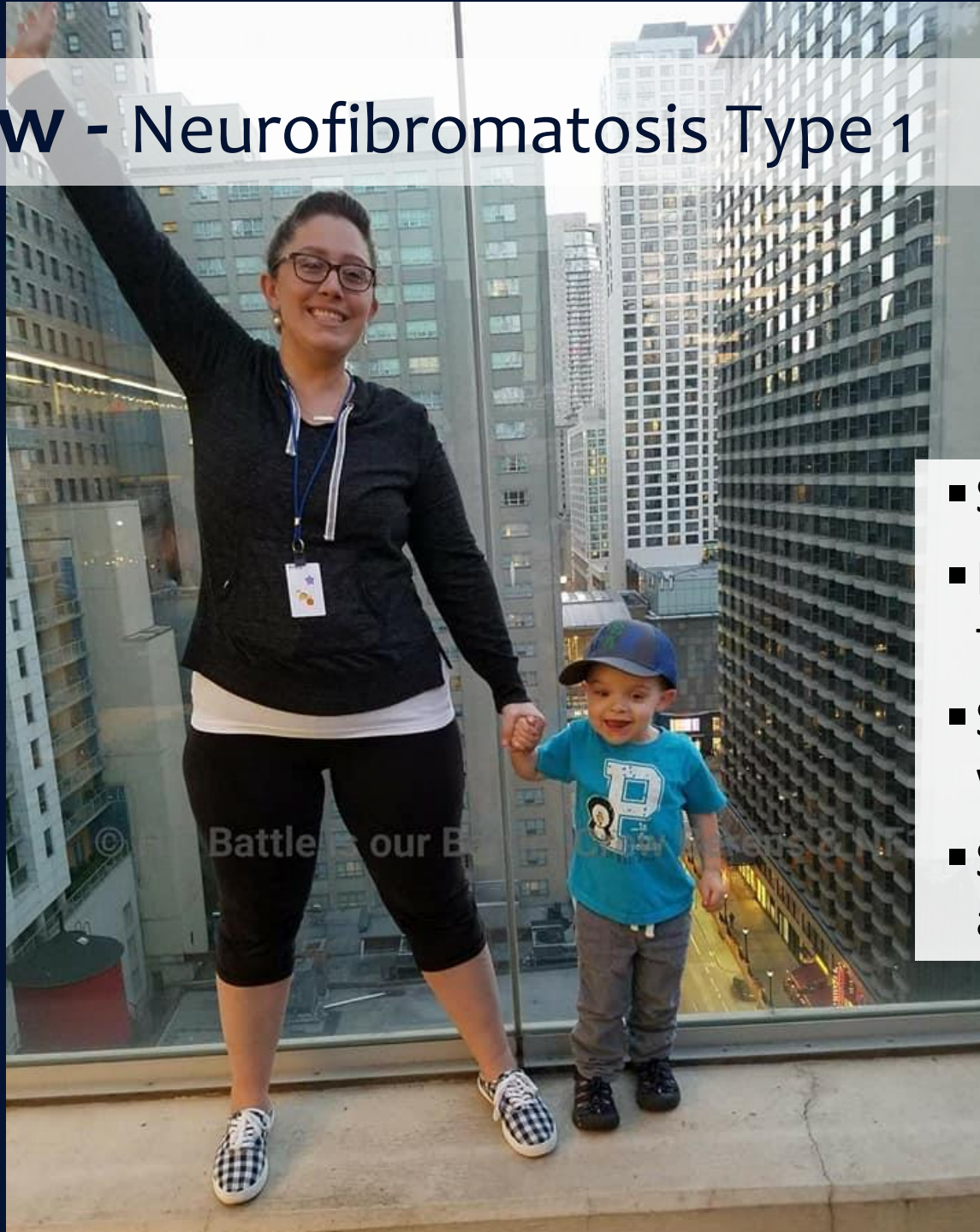
MOST CHALLENGING NEUROCOGNITIVE ISSUE:

- Only behaviors during MEK inhibitor side effects
- 4-5 Years old at the time, hard for him to know how to express how bad or tired he felt



2 Years

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- Support from school
- Patient and understanding teacher
- Speech therapist also helped with problem-solving
- School counselor helped him ask for a break/calm corner

2.5 Years

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MOST CHALLENGING CARDIO ISSUE:

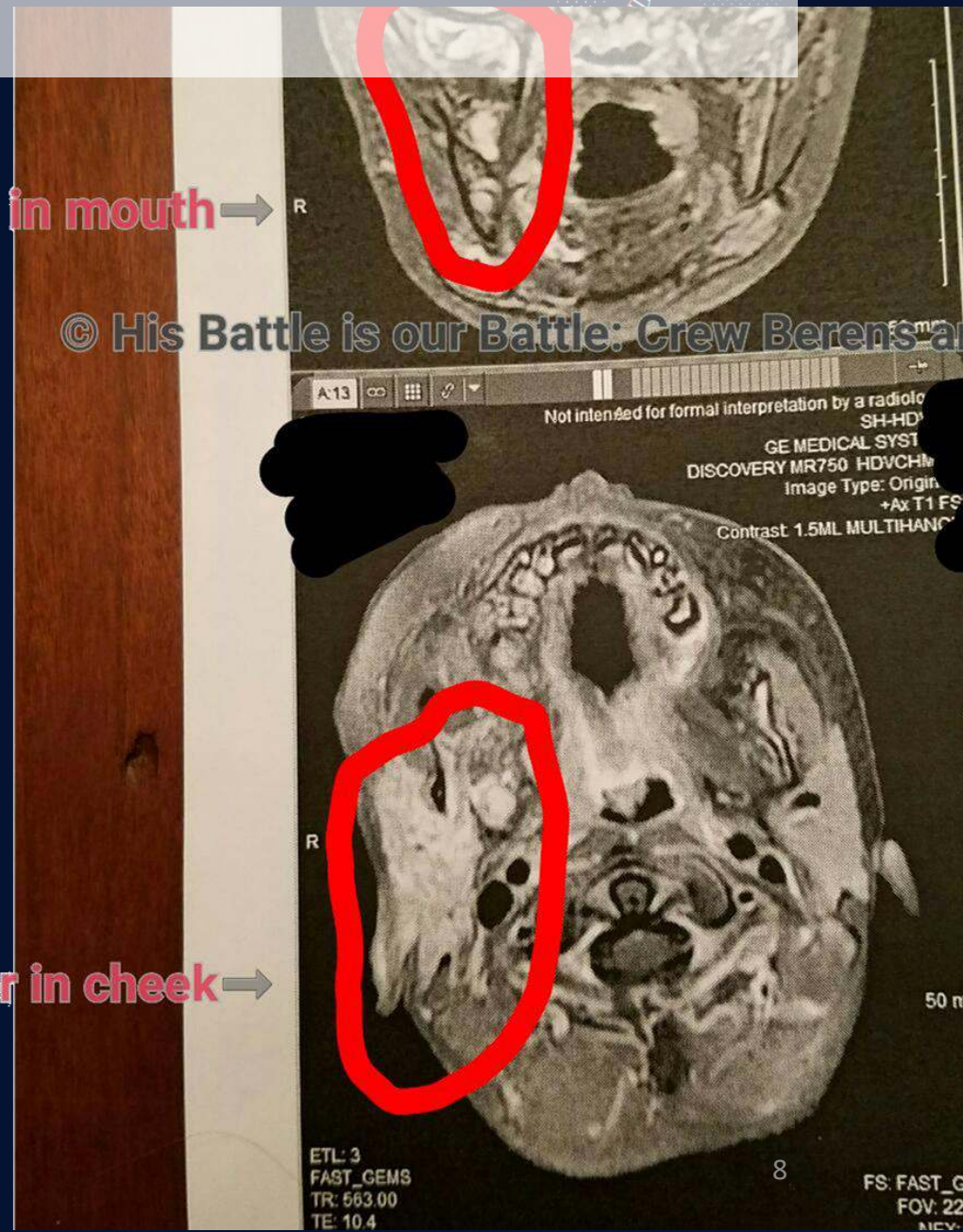
- None before/during/after MEK inhibitor
- Multiple echocardiograms while on drug trial

tumor in mouth →

© His Battle is our Battle: Crew Berens and

tumor in cheek →

2.5 Years



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MOST CHALLENGING GI/FEEDING/SWALLOWING/SPEECH ISSUE:

- Started baby-led weaning at 6 months, with twin sister
- His right cheek, sometimes right ear/scalp, flushed red every time he ate food
- Didn't happen when nursing, drinking from bottle or pacifier



2.75 Years



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- Ruled out allergic reaction
- At 13 months, identified cause of flushing when salivating/chewing: tumor near brainstem on 5th cranial nerve
- Parotid and salivary glands continue to be affected by tumor growth

2.75 Years

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- At 3 Years, first swallow study showed aspiration
- Liquids had to be thickened, for 2 years



3 Years

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- Tumors affecting tongue and swallowing due to tumor growth
- Local NF doctor had never seen them

3 Years

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- Found, and flew to see Dr. Bruce Korf at the University of Alabama, Birmingham
- Genetic testing done
- Dr. Korf remains on Crew's medical team

3 Years





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- Tumors under right side of tongue raised the tongue, enlarged cheek, and affected salivary glands
- Affected speech as well

3 Years



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- Speech services via Early On Services, Headstart preschool and then through Public School Special Education Services

4 Years

4 Years



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MOST CHALLENGING GROSS MOTOR/ REHAB ISSUE:

- Developmentally on track and age appropriate
- Working on balance/riding a bike without training wheels
 - Could be completely age-appropriate or a balance/ ear issue due to tumor growth in right ear

5 Years





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MOST CHALLENGING SLEEP ISSUE:

A sleep study showed mild sleep apnea but not enough to warrant medical intervention

5 Years

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5 Years

MOST UNIQUE CHALLENGE:

Tumors affecting:

- tongue
- swallowing
- mouth
- speech
- closing up right ear
- hearing
- right eye vision





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MEDICAL SUCCESS STORIES:

1. Taking the MEK inhibitor and having 36% overall reduction!
2. Crew weaning off of thickening liquids and doing extremely well with general diet and thin liquids.

5 Years

5 Years



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STRENGTHS GAINED BY PREVIOUS FAILURE:

For Crew: Heartbreaking Skills

- Overcoming fear/anxiety
 - seeing a hospital gown
 - from “pokes”
- Comfortable knowledge of his medical appointments - knowing what to do and when



5 Years

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6 Years

STRENGTHS GAINED BY PREVIOUS FAILURE:

For Crew: Heartbreaking Skills

- Telling nurses or doctors what they would do next during exams/ vitals

...Yet easier knowing how strong he is.



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6 Years

STRENGTHS GAINED BY PREVIOUS FAILURE:

For Me:

Succeeding in struggle with
the unknown:

- “Wait and See”
- Anxiety
- Depression

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STRENGTHS GAINED BY PREVIOUS FAILURE

For Me, cont'd:

Growth:

- Handling the unknown and the waiting
- “Medical mom”
- Advocating for my child medically
- Balancing all the new realities of life
- Taking care of myself, my family, my child with medical needs

6 Years



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STRENGTHS GAINED BY PREVIOUS FAILURE:

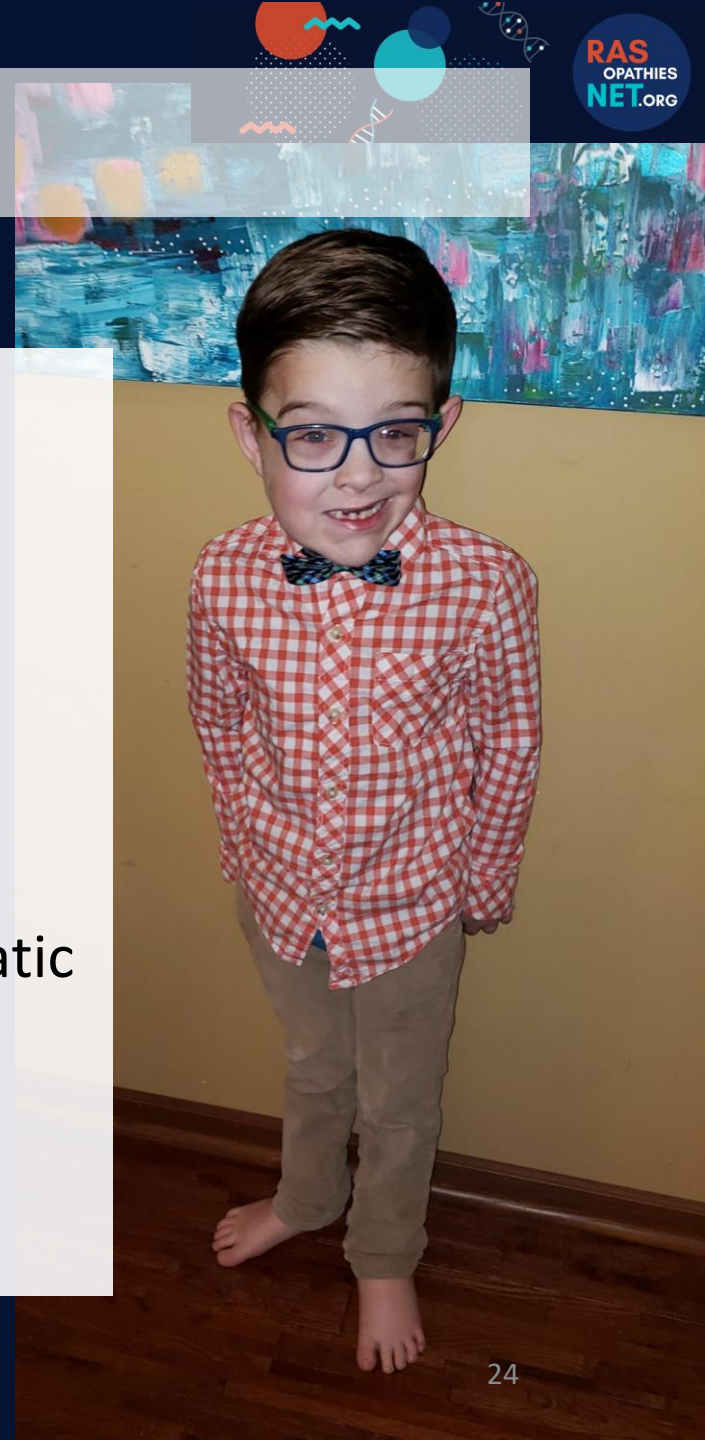
For Me, cont'd:

Resiliency Factors - Professional Experience:

- A Bachelors in Social Work
- Working with adults with Traumatic Brain Injuries
- Team care approach
- Case Manager

6.5 Years

6.5 Years



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I WOULD LIKE RESEARCHERS TO FURTHER STUDY:

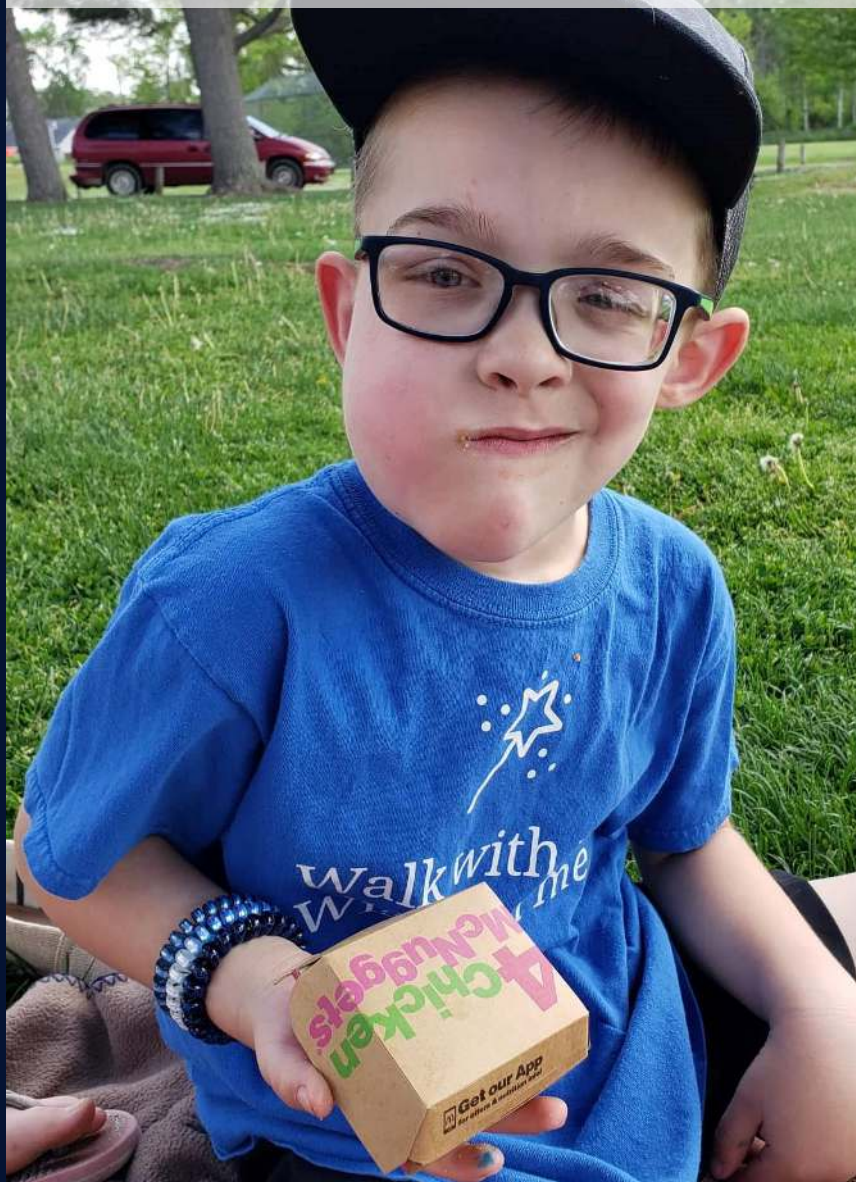
More drugs that can slow down tumor growth, more research into proactive surgical options

I would like to see a treatment available for **NF patients' tumors earlier on, when growth starts** because **tumor growth could be deterred/slowed down before major problems start**





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MEDICATIONS:

Currently:

- OTC children's multivitamin & allergy meds

Previously:

- MEK inhibitor binimetinib
- Ointments, creams, eyedrops for side effects to skin, nails, eyes, as needed
- Imatinib, stopped for not halting tumor growth

7 Years

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MEDICAL CONSULTANTS:

- Pediatric Neurooncologist
- NF Specialist
- Pediatrician
- Pediatric Ophthalmologist
- ENT
- PT
- OT
- Speech/Language Pathologist (no longer)
- NF Doctor (at UAB)

7 Years



