

# Katie - Noonan Syndrome/BRAF

by Katie



1 Day

28 Years





# Katie - Noonan Syndrome/BRAF



Newborn

**PROFESSION:**  
Childcare/Education



8 Months - cried like this daily from infancy



Toddler, age 2-3. Feeding self. Food textures were an issue and never ate baby food or hot cereal. This is probably Cheerios – a staple for years



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4 Years. For the first time, jumped off of furniture, a big deal, given apparent impaired depth perception

## HOBBIES:

- Cooking
- Baking
- Swimming
- Movies
- Travel



8 Years, with sister Molly , two years older

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## HOW CAN OTHERS INCLUDE YOU BETTER?

By taking the time to know me. I'm very honest and upfront about things so it doesn't take to long.

Just talk to me.

14 Years  
with Dr. Noonan



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## DESCRIBE YOURSELF IN 5 WORDS:

- Funny
- Animated
- Awkward
- Loud
- Caring



16 Years, with another person with NS

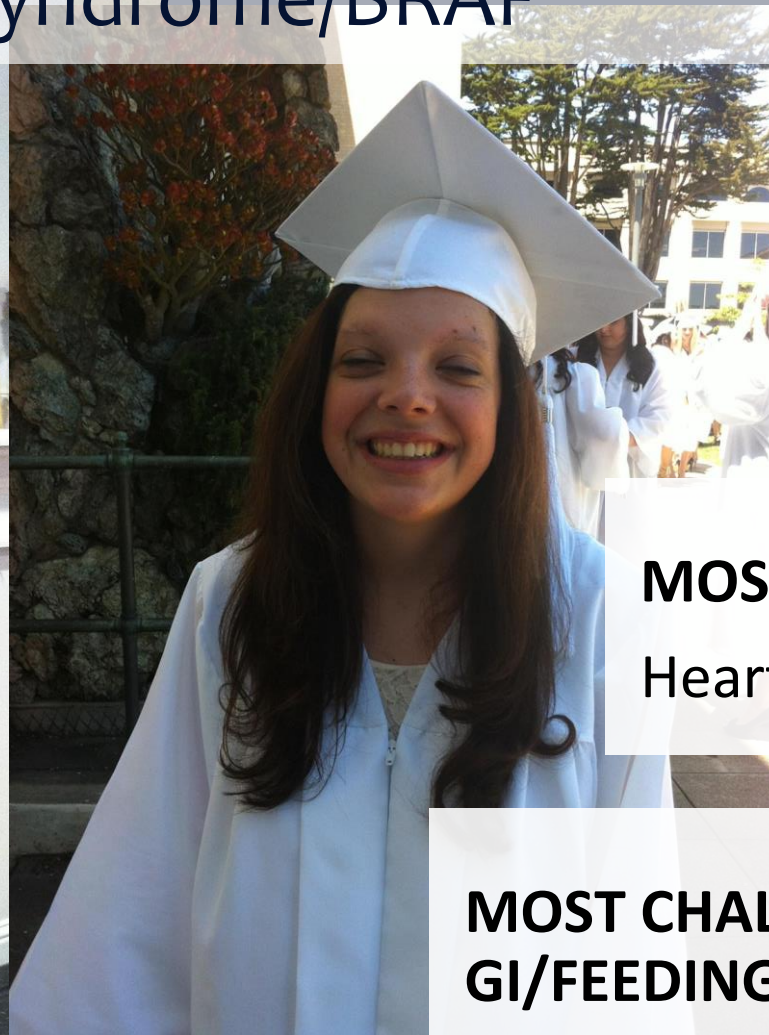


24 Years, with same person





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**MOST CHALLENGING  
NEUROCOGNITIVE ISSUE:**  
Studying/memory

**MOST CHALLENGING CARDIO ISSUE:**  
Heart murmur

**MOST CHALLENGING  
GI/FEEDING/SWALLOWING/SPEECH ISSUE:**  
Acid reflux/GERD

Age 19,  
Prom and  
Graduation



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**MOST CHALLENGING GROSS MOTOR/  
REHAB ISSUE:**

Balancing

**MOST CHALLENGING SLEEP ISSUE:**

Ability to fall asleep



23 Years





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## **MOST UNIQUE CHALLENGE:**

Making friends

## **MEDICAL SUCCESS STORY:**

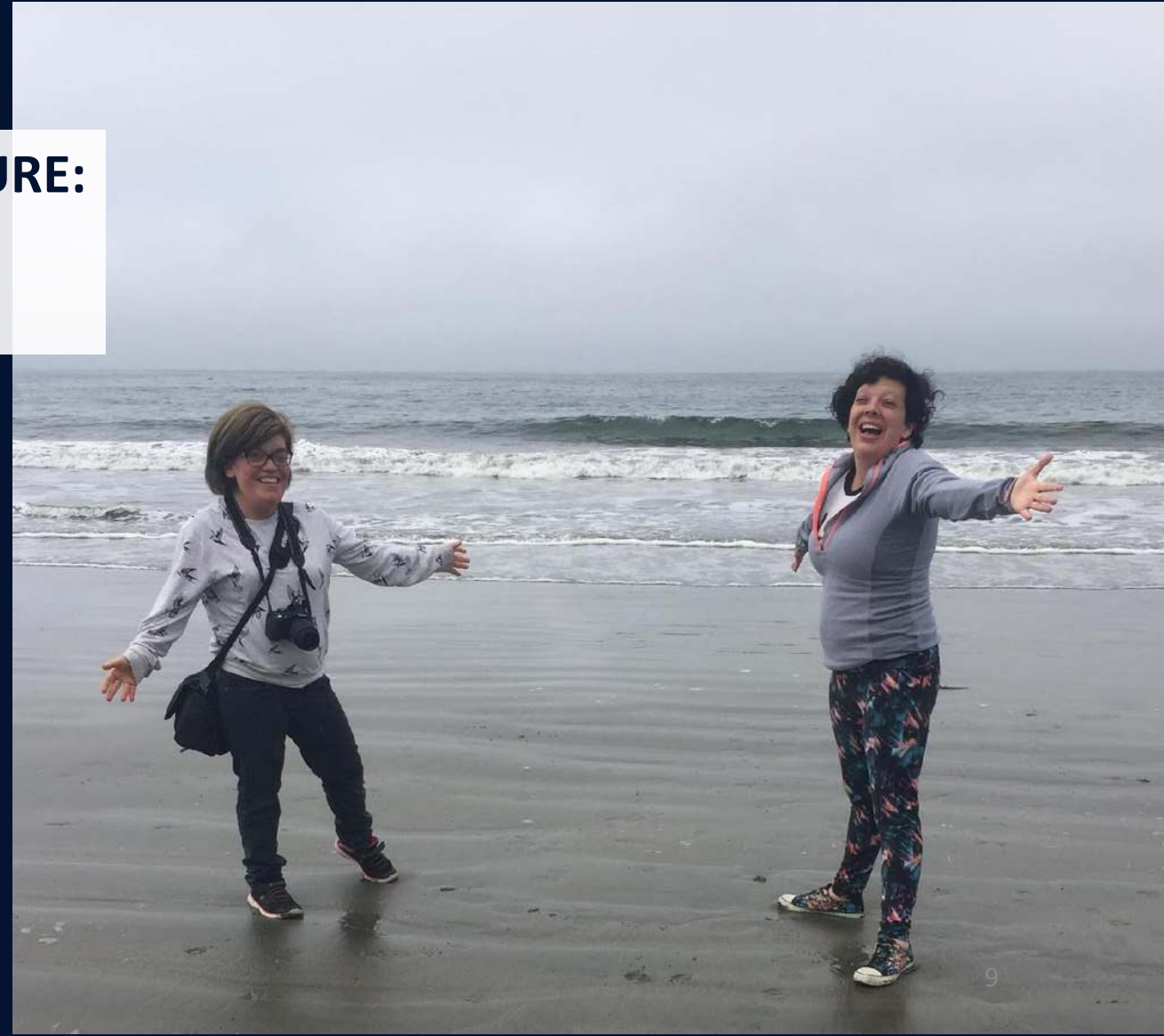
Recently I was in the hospital for internal bleeding, twice within a month. It was extremely unpleasant - from the condition I was in, to the way the hospitals are being run during a pandemic.



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**STRENGTHS GAINED BY PREVIOUS FAILURE:**  
To never give up



25 Years



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**I WOULD LIKE RESEARCHERS TO FURTHER STUDY:**

Vision issues.

I would like to see a treatment available for vision because I think it's a struggle we all deal with in one way or another, some incidents like mine might be more severe and could benefit from earlier intervention.

26 Years

After tripping on an uneven pavement and falling on face, worse for wear due to Von Willebrands, which was found in 2018 by anesthesiologist for endoscopy pre-op.



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**MEDICATIONS:**  
Prevacid



26 Years, with Mom's side of the family





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## MEDICAL CONSULTANTS:

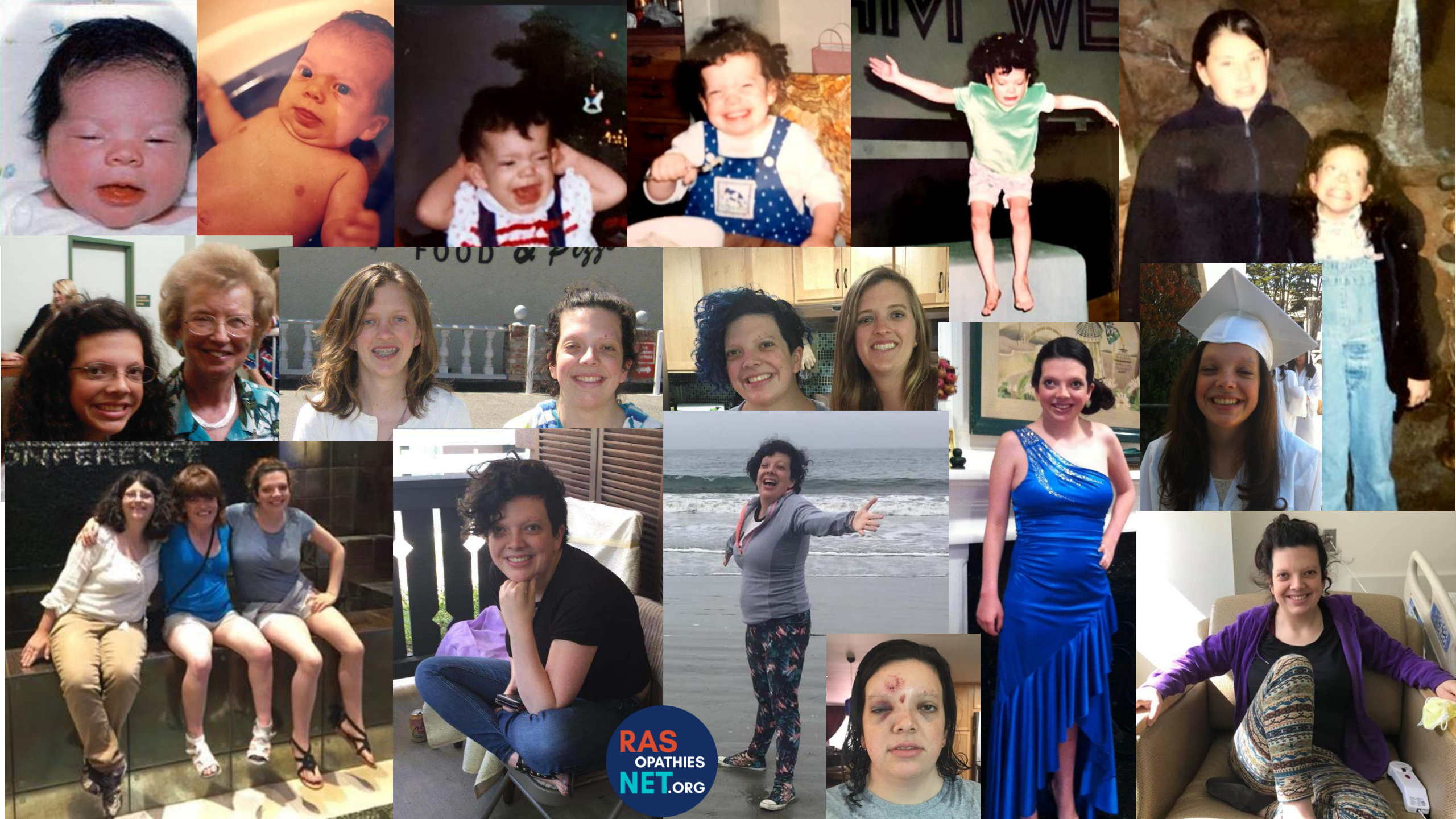
- Eye doctor
- GI
- Hematology
- Cardiology
- Regular physician

28 Years

Survivor! after hemorrhagic ovarian cyst (found ~ 2018) ruptured and caused internal bleeding. Blood trapped in upper abdomen was not accessed due to adhesions from a malrotated intestine surgery at 11 years old.

This is a picture from 2<sup>nd</sup> hospitalization in one month; GI bleed due to ulcers. More blood loss – survived again and “back in business”





**RAS**  
OPATHIES  
**NET.ORG**