

There's a strange kind of feeling that comes when your body turns on you, and your brain forgets how to be yours. Before the stroke, before anyone even used words "transient ischemic attack", I was happy. I halfway through grade 12, senior year. I had momentum. I was a volleyball player, chasing my goals, counting down the days to graduation, thinking about life after high school. I had committed to go play USports volleyball, something no one from our small community had ever done; I was the talk of the town. Everything felt like it was finally coming together. I had my routines, my team, my identity. I knew who I was. Sure, I had a rare bleeding disorder that no one had ever heard of, but that didn't matter. I did my own research, had 2 surgeries for my lungs, and bounced back without complications. Often, I forget that I've even been diagnosed, besides the nosebleeds that come without warning. But every part of me was whole, a well-oiled machine.

And then suddenly, it wasn't.

It started as a strange feeling, a moment that didn't feel quite. My fingers felt numb, then my arm, and my words began to slur. Uncontrollable laughter – what I learned later to be a main symptom – caused my brother, who was with me, to think I was just playing around. Then came the panic in my parent's voices. Something was wrong, but no one knew what. And I don't blame them; when I think of a stroke, I think of it happening to a more elderly person, or someone with health complications. And so, we rushed to the nearest hospital, 20 minutes away. 20 minutes of anxious thoughts and worries. After the symptoms stopped and the numbness went away, I was expecting to be told that it was just a weird muscle problem, or a pinched nerve, or any simple explanation to what had just happened. What I wasn't expecting, however, was to be told I had just suffered a mini stroke. And just like that, everything changed. When my brain shut down—even just briefly—it came back differently. And so did I.

Physically, I look the same. That's almost the cruelest part. People look at me and don't see my condition or my changes. And the people that do know about my stroke or disorder don't see what I see, don't feel the way I do. "At least it wasn't worse," they say. "You're young, you'll be able to bounce back." But mentally? I feel like I've been rewired wrong. My emotions are heavier. My thoughts often don't feel like mine. And I just can't shake the fear that my body might betray me again at any moment.

I thought volleyball would be my escape, but even that feels off. I feel as if my hands move sluggishly, my brain isn't there, and my reaction time is a fraction slower than it was. I often feel like a shadow of the player I used to be, constantly comparing myself to who I was just a few months ago. The sport I love has been turning into something uncertain, something fragile.

But the worst aftermath that came from the stroke was the mental health spiral: the sadness that lingers for days, the anxiety that keeps me up at night, the pressure to pretend I'm okay when I'm really not. I feel robbed of a part of my senior year, and no one seems to understand how much I'm struggling on the inside. I just have an image to uphold: perfect grades, amazing time management, incredible skill on the volleyball court. And I hate blaming

the stroke. I keep thinking, why can't I keep my grades up? Why can't I focus, why do I feel so anxious, why do I feel so sad, why, why, why?

However, slowly, painfully, I've been starting to rebuild. I'm learning that healing isn't just about getting back on the court or hitting the same grades. It's about learning to trust myself again. To ask for help when I need it. To be okay with not being okay. Some days, I still wish I was the girl I was before the stroke, but I'm starting to make space for who I'm becoming after it.

I didn't choose this, and I still wish it never happened. But it did. I can't undo it, and I can't rid myself of my diagnosis. And if I can find strength in that—if I can keep going, even when it's hard—then maybe I'm stronger than I ever thought I was.



Referral Result

Patient Name: SPENCER, AMIYAH LAETIN
PHN: 230 699 766

Date of Birth: 28 Nov 2006
Sex: Female

DR. NITA CHAUHAN
PEDIATRIC RHEUMATOLOGY CLINIC
JIM PATTISON CHILDREN'S HOSPITAL
103 HOSPITAL DRIVE
SASKATOON, SK S7N 0W8

Accession #: N0901R017658
Requisition #: 49414391
Collection date: 30 Aug 2022 15:42
Received date: 01 Sep 2022 07:45
Reported date: 21 Nov 2022 9:20

Ordering Physician: DR. NITA CHAUHAN
Date of Onset:
In / Out patient: Out Patient
Specimen Type: Blood (EDTA)/Extraction
Diagnosis:
Medication:
Hospital ID:

Results

| | |
|---------------------|----------|
| Testing Requested | |
| Testing Requested | HHT |
| Testing Requested | |
| Interpretation | Complete |
| Genetic Referral | |
| Testing Requested | HHT |
| Genetic Referral*** | |

- - - All attached reports are indicated with*** - - -

Report Comments

The test result has been reported to the ordering provider and will be made available online one month after the test completion date to allow time for appropriate results disclosure and/or genetic counselling.

Associated Samples

| Area | Accession # | Status | Date Reported |
|----------------------------------|--------------|------------|-------------------|
| Molecular Diagnostics Banking | N0901D110445 | Authorized | 08 Sep 2022 14:32 |

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FINAL REPORT

Date Printed: 21 Nov 2022 9:20 am

SPENCER, AMIYAH LAETIN - N0901R017658

| | | | | | |
|-------------------------------|----------------|--------------------------------|-------------|-----------------------|--------------|
| Patient name: | SPENCER AMIYAH | Sample type: | gDNA | Report date: | 16-NOV-2022 |
| DOB: | 28-NOV-2020 | Sample collection date: | 30-AUG-2022 | Invitae #: | RQ4295176 |
| Sex assigned at birth: | Female | Sample accession date: | 04-NOV-2022 | Clinical team: | Nita Chauhan |
| Gender: | | | | | |
| Patient ID (MRN): | 230699766 | | | | |

Reason for testing

Diagnostic test for a personal and family history of disease

Test performed

Sequence analysis and deletion/duplication testing of the 6 genes listed in the Genes Analyzed section.

- Invitae Hereditary Hemorrhagic Telangiectasia and Vascular Malformations Panel


RESULT: POSITIVE

One Likely Pathogenic variant identified in ENG. ENG is associated with autosomal dominant hereditary hemorrhagic telangiectasia.

| GENE | VARIANT | ZYGOSITY | VARIANT CLASSIFICATION |
|------|-----------------------|--------------|------------------------|
| ENG | c.155G>T (p.Gly52Val) | heterozygous | Likely Pathogenic |

About this test

This diagnostic test evaluates 6 gene(s) for variants (genetic changes) that are associated with genetic disorders. Diagnostic genetic testing, when combined with family history and other medical results, may provide information to clarify individual risk, support a clinical diagnosis, and assist with the development of a personalized treatment and management strategy.

Clinical comments

- When a single Variant of Uncertain Significance is found in a requisitioned gene that is only associated with autosomal recessive condition(s), it may not be included in the report.