



no guess work. She had months and months of lab work. Then her blood was sent to Cincinnati Childrens Hospital and studied. Pretty much the best way they explained it was starting at the top of a pyramid and working its way down. That's when they found that the EBV virus decided it would make its home in the CD20 protein in her B Cell. The treatment would only work if it was in her B Cell and not T Cell. Pretty much they studied until they found where her body "had a short" and kept the EBV virus from going dormant like it should have been. It was literally eating her muscles away where she couldn't even make it up our stairs. Her senior year last home football game she cheered at was the absolute toughest trying to see her cheer and her body wouldn't do the motions. Absolutely no guess work just one determined Dr who also worked with her Oncologist since her symptoms, labs and Pet Scans all mocked B Cell Lymphoma. It wasn't until the bill came back EBV and that's when they started studying her blood. Her primary care doctor could not even interpret these lab results. We had one amazing team of about 5 different Doctors who were so determined and never gave up. I will say it took many times early in her high school where some Doctors made her feel it was just in her head. Her Immunologist is now over her care and we are so blessed to only have to go now every 3 months but this is just one binder I have with her team of Doctors and medical records. It was so overwhelming but my daughter wasn't giving up and neither were they. She is now able to go to college 5 hours away and her senior year we were mentally preparing ourselves for the worst. Lots and lots of lab work though over about 9 months.



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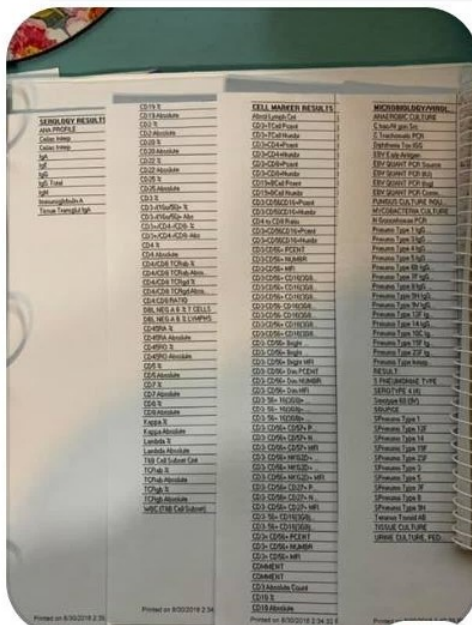
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I cannot remember in which order these test were done but these are the studies right off that I can recall. The results seemed to take forever to get in too but the wait was so worth it.

- B Cell Subtype Screening
- NK Cell Study
- Humoral Immunity Panel
- STAT 1 and 4 Signaling Mechanism (plays big role in killing virus)
- T Helper 17/ IL17
- Autoimmune Lymphoproliferative Panel (ALP5)
- Perforin/Granzyme Test
- Antibody Dependent NK Cell Cytotoxicity
- EDTA Plasma
- Whole Exome Sequencing Genetic Testing (with appeal my insurance finally agreed to cover)
- Cell Markers (A TON - attaching picture I took from my daughters just left out her name and results.
- **NK Cell and B Cell Sorting** (this is one where they narrowed down the break down in her bone marrow, B Cell and specifically in the CD20+protein

I hope this helps a little bit and I pray you get answers too!!! It's so tough and so much harder when Drs make people feel it's in their heads. I hate that and I'm sorry you are having such a hard time. Good luck and keep searching for answers!!!



SEROLOGY RESULTS**ANA PROFILE**

Cellac Interp

Cellac Interp

IgA

IgE

IgG

IgG Total

IgM

Immunoglobulin A

Tissue Transglut IgA

CD19 %

CD19 Absolute

CD2 %

CD2 Absolute

CD20 %

CD20 Absolute

CD22 %

CD22 Absolute

CD25 %

CD25 Absolute

CD3 %

CD3+/16or56+ %

CD3+/16or56+ Abs

CD3+/CD4-/CD8- %

CD3+/CD4-/CD8- Abs

CD4 %

CD4 Absolute

CD4/CD8 TCRab %

CD4/CD8 TCRab Abso...

CD4/CD8 TCRgd %

CD4/CD8 TCRgd Abso...

CD4 CD8 RATIO

DBL NEG A B % T CELLS

DBL NEG A B % LYMPHS

CD45RA %

CD45RA Absolute

CD45RO %

CD45RO Absolute

CD5 %

CD5 Absolute

CD7 %

CD7 Absolute

CD8 %

CD8 Absolute

Kappa %

Kappa Absolute

Lambda %

Lambda Absolute

T&B Cell Subset Cnt

TCRab %

TCRab Absolute

TCRgd %

TCRgd Absolute

WBC (T&B Cell Subset)

CELL MARKER RESULTS

Absol Lymph Cnt

CD3+TCell Pcent

CD3+TCell Numbr

CD3+CD4+Pcent

CD3+CD4+Numbr

CD3+CD8+Pcent

CD3+CD8+Numbr

CD19+8Cell Pcent

CD19+8Cell Numbr

CD3-CD56CD16+Pcent

CD3-CD56CD16+Numbr

CD4 to CD8 Ratio

CD3+CD56CD16+Pcent

CD3+CD56CD16+Numbr

CD3-CD56+ PCENT

CD3-CD56+ NUMBR

CD3-CD56+ MFI

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ CD16(3G8)

CD3-CD56+ Bright

CD3-CD56+ Bright

CD3-CD56+ Bright MFI

CD3-CD56+ Dim PCENT

CD3-CD56+ Dim NUMBR

CD3-CD56+ Dim MFI

CD3- 56+ 16(3G8)+

CD3- 56+ 16(3G8)+

CD3- 56+ 16(3G8)+

CD3-CD56+ CD57+ P...

CD3-CD56+ CD57+ N...

CD3-CD56+ CD57+ MFI

CD3-CD56+ NKG2D+ ...

CD3-CD56+ NKG2D+ ...

CD3-CD56+ NKG2D+ MFI

CD3-CD56+ CD27+ P...

CD3-CD56+ CD27+ N...

CD3-CD56+ CD27+ MFI

CD3- 56+ CD16(3G8)

CD3- 56+ CD16(3G8)

CD3-CD56+ PCENT

CD3-CD56+ NUMBR

CD3-CD56+ MFI

COMMENT

COMMENT

CD3 Absolute Count

CD10 %

CD10 Absolute

MICROBIOLOGY/VIRO

ANAEROBIC CULTURE

C trac/N gon Sic

C Trachomatis PCR

Diphtheria Tox IgG

EBV Early Antigen

EBV QUANT PCR Source

EBV QUANT PCR (IU)

EBV QUANT PCR (log)

EBV QUANT PCR Comm...

FUNGUS CULTURE ROU

MYCOBACTERIA CULTURE

N Gonorrhoea PCR

Pneumo Type 1 IgG ...

Pneumo Type 3 IgG ...

Pneumo Type 4 IgG ...

Pneumo Type 5 IgG ...

Pneumo Type 6B IgG ...

Pneumo Type 7F IgG ...

Pneumo Type 8 IgG ...

Pneumo Type 9N IgG ...

Pneumo Type 9V IgG ...

Pneumo Type 12F Ig...

Pneumo Type 14 IgG ...

Pneumo Type 16C Ig...

Pneumo Type 15F Ig...

Pneumo Type 23F Ig...

Pneumo Type Interp...

RESULT:

S PNEUMONIAE TYPE ...

SERO TYPE 4 (4)

Serotype 6B (9V)

SOURCE

SPneumo Type 1

SPneumo Type 12F

SPneumo Type 14

SPneumo Type 19F

SPneumo Type 23F

SPneumo Type 3

SPneumo Type 5

SPneumo Type 7F

SPneumo Type 8

SPneumo Type 9N

Tetanus Toxoid AB

TISSUE CULTURE

URINE CULTURE, FED...



██████████ my daughter the first couple years of high school struggled so bad. I hated dropping her off at school knowing how bad she felt but she didn't want to miss. I would always ask her "do you want me to find another Dr" and she would say "why so they can just keep telling me it's in my head" Seriously I felt so helpless and would just cry. Of course not in front of her because man she was strong. Then at the end of her Jr year we were seen 3 times in a week and then finally ended up in the Urgent Care where the Dr told me "something is seriously wrong with your daughter.....I don't know what but please take her straight to the ER". I raised the question what if they just tell us the same and I will never forget her words she said "you keep pushing and pushing until you get answers but it's not in her head". That gave me all the push to keep on fighting until we had answers but in that time it was amazing to see such lack of knowledge. I told her Doctor so many people struggle with this and there is definitely a shortage of Doctors with proper knowledge and research. The Doctors seriously thought they were going to have to tell us she had B cell lymphoma. When they did the biopsy in her neck they came out and said "whelp it definitely was all in her head because she had 100's of swollen clusters of lymphnoids in her neck. When pathology came back her EBV count was 28,800 craziness. It took us from March her Junior year to February her senior year to get answers. I believe even though she's at the children's hospital she sees adults too but it's finding an immunologist who will do a cell study on your blood and finding where your body has the short and fixing that. Her oncologist actually did extensive research in EBV and him and her Immunologist worked together and they had a research team have meetings every 3-4 weeks when her lab results would come back. So now that we have been down the road with her and she is feeling much better I am trying to see her too because I got mono in college and have never felt the same. I've been told for years I had narcolepsy but it's made me search and find answers for me too. I have been seeing a functional medicine Doctor who has helped tremendously in vitamin deficiencies but there is still a reason that our body doesn't work properly. It's finding a Dr that will find the source of the problem and not just treating the symptoms. Good luck and keep fighting!!!! It's a tough battle to fight ❤️❤️