

Should PANDAS / PANS be renamed Basal Ganglia Encephalitis?

Hey everyone! Today I'm filming a video answering the question, "Should PANDAS / PANS be renamed basal ganglia encephalitis?"

Now of course this is just my own opinion because I believe everyone will have a different perspective on this, so I can't fully answer the question, but I can share what I am aware of about it. Now a lot of people in the PANDAS / PANS community want PANDAS / PANS to be renamed basal ganglia encephalitis, doctors included - some of the doctors do want it renamed. This is because it's a more accurate name. The basal ganglia is the part of the brain affected by PANDAS / PANS and encephalitis means brain inflammation, so it's a bit more descriptive, whereas with PANDAS and PANS, the first letter of the acronym stands for paediatric, but we know that that's not true because people can develop PANS in adulthood, people can have symptoms that last into adulthood, and people can have flares in adulthood. So the names PANDAS and PANS aren't actually that accurate. As well as that, some people do have a negative attitude towards PANDAS and PANS; when you say PANDAS / PANS some people may just roll their eyes and go "ugh, that". Thankfully, most people here (obviously) aren't like that, but there are a few people who kind of have that sort of negative assumption about it, so changing the name could potentially gain more understanding and people won't view it like that anymore, because I think calling it basal ganglia encephalitis will allow it to be put with the other forms of autoimmune encephalitis like anti-NMDA receptor encephalitis, therefore it will be taken more seriously and people should be able to get more effective treatments rather than just being given psychiatric medication and therapies which don't usually work that well for people with PANDAS / PANS, because you wouldn't give someone with other forms of autoimmune encephalitis purely psychiatric treatment when the brain is being attacked by the immune system.

Now of course, there may be some issues with renaming it basal ganglia encephalitis because with PANS it may not always be linked to inflammation, because PANS can sometimes be triggered

by non-infectious triggers like metabolic disturbances and psychosocial stress so it may not always come under the category of autoimmune encephalitis, and another thing is that inflammation in the brain is associated with OCD and Tourette's as well as PANDAS / PANS; therefore, that could lead to some confusion. However, that does not mean that they are the same thing, so it would take a specialist to get the correct diagnosis and not have that sort of confusion, because schizophrenia for example is associated highly with inflammation of the brain, but so is anti-NMDA receptor encephalitis, which causes psychosis; they are different conditions - both associated with inflammation of the brain, but have different symptoms. So maybe there could be some confusion, but PANDAS / PANS is different from Tourette's and OCD, so hopefully there wouldn't be that confusion there if people were aware of how it presents differently, such as with different symptoms.

Putting it as a form of autoimmune encephalitis, as in the name, may make some autoimmune encephalitis specialists research it more, which means more awareness, better treatments, and a better quality of life for those living with the condition. Calling it a form of autoimmune encephalitis as in the name, may also make more doctors aware of it because it comes under other forms of AE and the doctors may feel more comfortable treating it because some doctors do actually shy away from treating PANDAS / PANS because of the current views towards it, so if the name changed - you can't leave encephalitis untreated, so they'd have to treat it as it's that change of perception, and I think that renaming it basal ganglia encephalitis - it just sounds different, it has different connotations. When people say PANDAS / PANS, they may not take it seriously; but when people say encephalitis, you know what encephalitis is, it's taken a lot more seriously, so it could help people in the community be listened to a lot more as well.

I've been adding to my videos (in the title) basal ganglia encephalitis, which is a bit of a mouthful, so I may just say BGE instead, but that's just so you know what's going on and why I've added that in the titles because a lot of people in the PANDAS /

PANS community have said they want it renamed so we've started using the term more I think.

As well as this, I used to know what PANDAS / PANS was before I knew I had it, but I didn't know it was a form of autoimmune encephalitis, so having it in the name would make more people aware of what it really is.

