

Pathfinding to awareness of CDKL5 research

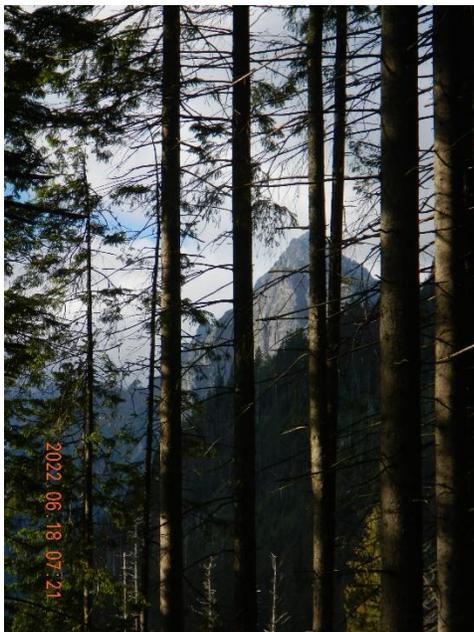
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My granddaughter Mimi has CDKL5, an extremely rare genetic disorder, also called CDD. The CDKL5 gene is responsible for the formation of a very important protein in the brain. When the gene is affected, so is the brain. Mimi has many severe cognitive and physical delays and life-long disabilities. But she is a beautiful, loving, and extremely intelligent little girl, albeit with extreme difficulties that she constantly battles. The path ahead is uncertain and a cure is still a long way off.

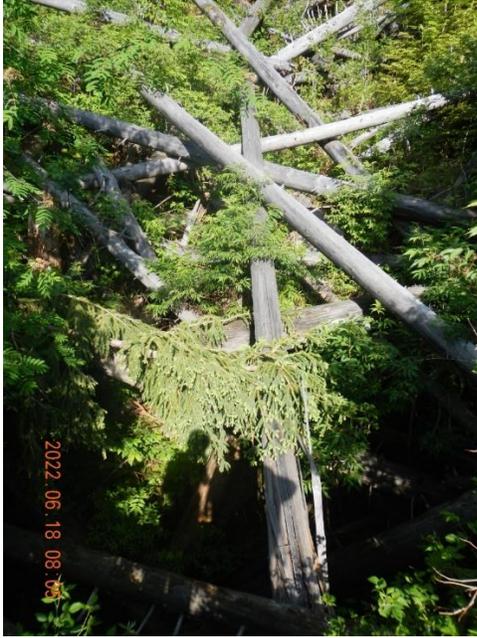
Mimi cannot describe the difficulties and obstacles she has along her path. The overwhelming majority of the approximately 2,500 known cases of CDKL5 are non-verbal, including Mimi. June is CDKL5 Awareness Month, and Mimi's battle reminded me of an old steep mountain forest path that I heard about many times. I thought, "if I climb a difficult path, and share my experience, it could raise awareness about hard-to-overcome challenges and what is possible." I set a challenge for myself to find the old path through that forest and up the slopes, all the way up the high ridge to the summit with a view that is wide and unobstructed.

That path in the mountains is marked on my more-than-half-a-century old map. I got up from my desk, drove about 300 miles, went some miles on the road in the valley and finally entered a steep mountain forest.

I found that the trailhead glade is no longer there. It is grown over by tall trees. There is no path. I was walking through a wild forest, feeling my way forward.



I had to be careful. Giant stems of trees felled by the winds blocked the way up. There were deep, dark spaces among them.



But eventually I got through and above the trees and I went into a gully covered by mountain pines. They hung above the gully's rocky bottom.



Following the gully, I came to the spot where a giant stone avalanche from above has stopped. That could make one nervous. I went further up and discovered that a recent, large rock and mud slide covered the upper parts of the gully. I struggled through the mud and overhanging vegetation and eventually reached the grass fields above. The view was slowly widening as I proceeded.



Finally, a ridge of rock led me further up and I stood on the summit.



There was a long way down. I came back to my car in the evening light.



I was tired.

We all go on pathless terrain. Research is forging the path to a cure for CDKL5, in large part made possible by the International Foundation for CDKL5 Research (IFCR) funding research at universities across the United States to develop therapies and a cure (<https://www.cdkl5.com/cdkl5-centers-excellence/>). If you wish to contribute to this effort, you can donate at <https://www.cdkl5.com/donate/>. Any amount will help. If you donate, please add a note that it is in honor of Mimi Glazek.

Instagram: #cdkl5forward #mimispitcrew @cdkl5_usa

<https://www.facebook.com/CDKL5foundation>