

## Pathfinding to awareness of CDKL5 research

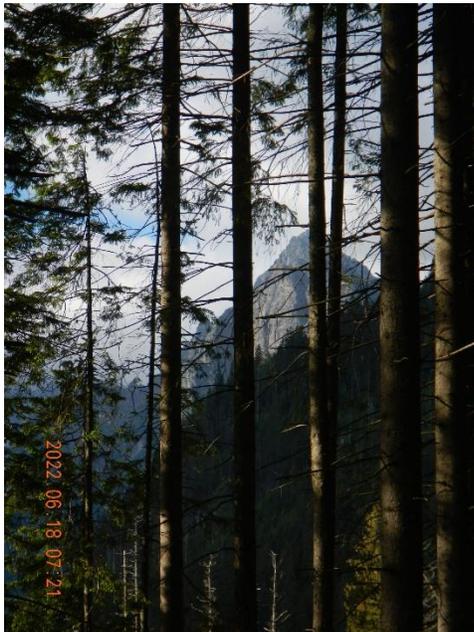
Stanislaw D. Glazek

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.

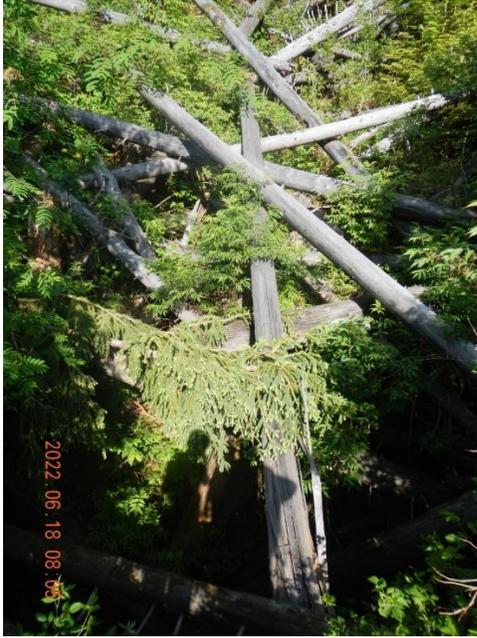
Mimi cannot describe the difficulties and obstacles she has along her path. The overwhelming majority of the approximately 2,500 known cases of CDKL5 are non-verbal, including Mimi. June is CDKL5 Awareness Month, and Mimi's battle reminded me of an old steep mountain forest path that I heard about many 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>