

HB0027 Maryland Technology Development Corporation – Long COVID Innovation Grant and Loan Program

I, Alexander W. Barth, a U.S. citizen and a Maryland resident since 2001, am submitting written testimony as an ME/CFS patient advocate to support above bill.

My nephew, Lukas Barth (age 30), has been severely ill with ME/CFS for over a year. The illness is still progressing.

Over 23 hours of his day are spent lying in bed in a dark room. He is extremely sensitive to light and noise. He must wear a mask over his eyes to block out light and earplugs to quiet noise. He cannot listen to music or podcasts, watch television, or listen to a conversation that lasts longer than a few minutes. Reading an online newspaper, long text messages, or even multiple short text messages in a day is likewise impossible. He cannot speak for more than 10 to 15 minutes a day at most.

And if the extreme physical restrictions were not enough, his inability to socialize or connect with friends, family, and the outside world has been devastating. I have watched him slowly disappear from his life, week after week. Sometimes he manages to use his minimal energy to make a joke and bring smiles to our faces; other times, he is barely able to acknowledge my presence because he lacks the strength to even wave.

The most striking characteristics of his illness—post-exertional malaise (PEM) and postural tachycardia syndrome (POTS)—mean that even basic activities such as taking a shower can cause a severe crash. These crashes can last for many days and often result in a worsening of symptoms and disease progression. They lead to silent, dark meals where he cannot share even a single word with his family. They lead to extreme physical pain and the crushing realization that his own body is broken and fighting against him.

Before becoming ill, Lukas was a very athletic young man who worked as a consultant for McKinsey & Company. He graduated from Fordham University in New York with a BBA, *magna cum laude*, and later earned an MBA from the University of California, Berkeley.

His mother and her ex-husband, my brother, now take turns serving as his caregivers. ME/CFS has therefore had a profoundly life-changing effect on my brother's family. I would also add that my niece Theresa Barth's (age 25) health has been negatively affected by ME/CFS, although not as severe as her brother's. Her rapidly declining health forced her to quit her internship last September. This illness has prevented her from continuing her education or obtaining employment after graduating *magna cum laude* from Middlebury College.