

May 16, 2022

To the Hon. Ms. Phillips, NYS Public Services:

I have epilepsy and migralepsy. I cannot neurologically tolerate any LED exposure, and I am thrown instantly into violent seizures from the briefest strike of LED light. From the first moment that LEDs replaced the previous HPS streetlamps, that is what happens every time I'm anywhere in reach of a lit LED, as my family and other witnesses will attest. I am perfectly fine one minute, dashed thrashing to the ground the next, after being struck by the light. The original street lamps caused no such problems, effectively lighting public village streets as safely for me as for anyone else. Cambridge's switch to seizure-triggering LEDs has devastated my life and made my house and community dangerously unlivable for me. For two and a half years now, LED-light-reactive seizures have bruised and bloodied me, causing repeated bodily injury, severe pain, incapacitating sickness, chronic after-effects, fear, emotional trauma and crushing stress. I have been cut off from my job and other necessities, been forced to give up all evening activities, have lost my entire income, been trapped inside our house or stranded outside village limits, and been separated from my family. Avoiding the village altogether every evening, dark day and winter afternoon is the only way I have to be basically safe.

Mayor Carman Bogle and the Village Trustees were alerted more than a year in advance that voting to change public lighting to LEDs would radically alter the village environment and put me specifically at risk of physical attack on my brain and body as I tried to get to or from village settings. They knew that our village home and my workplaces would also be affected when the LEDs were on. Between May 2018 and late December 2019, the Trustees didn't reply to my urgent letters, calls, messages and requests for an official response and an opportunity to discuss the issue. (The meeting hall has long been inaccessible due to migraine inducing fluorescent lights, or I'd have gone to them in person.) Over that time, I had several chance encounters with Mayor Bogle. She variously told me everything would be fine; that other residents did not want LED streetlights; that I'd gotten the Trustees' attention with the technical and medical research materials I'd sent; and that they talked about putting the HPS lamps on motion detectors as an alternative cost-saving method. (That approach would've been safe for me as well.) Each conversation was brief, and ended when Mayor Bogle excused herself and hurried away. Dissatisfied and uneasy with such offhand, non-specific assurances, I called National Grid several times. Each time I told NG about the problem and asked to speak to whoever was working with Cambridge, the representative answered that NG wouldn't talk to me, only to the Mayor, so I should go right back to the Village with my concerns.

Despite the Mayor's reassurances, the LEDs started appearing on Main Street in late December, 2019, and then in our own neighborhood. I was thrust overnight into the very crisis I'd feared. We scrambled to get shades, and tried every method we could think of to protect me. Nothing really worked. I was having LED-reactive seizures in our home if a bit of light got by the shades, also on our porch, and on the sidewalks and in the car as I tried to get to work or anywhere else in the village. Each day was scarier than the last. Light-reactive epilepsy often intensifies with repeat episodes, getting progressively worse, so each successive seizure needed less provocation than the one just past. Soon there were many days when I was so disabled by the seizures being triggered and re-triggered that I couldn't walk or stand, and needed to crawl from room to room. I wasn't recovering between incidents anymore. Continuously incapacitated and very, very ill, I couldn't function and my life just - stopped. I was terrified, traumatized and overwhelmed, my family was aghast and angry. We had immediately started contacting Mayor Bogle, reporting the severe, frequent, daily attacks the new LEDs were causing, but it quickly became obvious that the Mayor and Trustees had never taken my concerns seriously and had probably purposely misled me to believe that they had. It was also soon clear that they'd neglected to pass on any critical information about my LED-light-reactive medical disability to National Grid, as I'd requested once I realized NG wouldn't communicate directly with me.

The Trustees barely communicated with us either. I had exactly one phone call with Mayor Bogle in early January, 2020. She seemed incapable of grasping the enormity of the problem, or was perhaps deliberately refusing to do so. She said the good news for me was that National Grid was going to bring a “shield” for that streetlight that was “bothering” me. As if I hadn't told her over and over that the problem would be village-wide, or said that if a shield is just a lampshade, it won't do anything except direct the same seizure-triggering LED light onto the sidewalk where I expect to walk. I said that shield sounded useless; I need to utilize public streets to get to work and other places. Mayor Bogle, sounding irritated, said she'd have to check with National Grid to see if it was “feasible” to get me a route to my workplace. As if, since the LEDs went in, it's now up to the Mayor and National Grid whether I can reach my job and earn money for my family! I remember being confused and affronted by that phone call. At the end of it, that January day, Mayor Bogle said impatiently that “soon” it would be summer, and then I could be outdoors longer. She couldn't have made it clearer that the Trustees and National Grid would be letting those LED lights dictate my every step in Cambridge from now on.

Soon family, friends, co-workers, neighbors, medical professionals and Epilepsy Foundation representatives were contacting them too, trying to impress upon the Mayor and Trustees how serious and real the threat to me is. Many of them had witnessed my LED-triggered seizures, and many were watching the sudden, unprecedented erosion of my former good health in horrified alarm. We sent yet more technical and medical research, and we sent Epilepsy Foundation and CDC materials about Sudden Death in Epilepsy (SUDEP) and status epilepticus, confirming for them that any single LED-reactive seizure could stop my heart and kill me. We sent it all to National Grid Representative Joseph Pallone also, when we were finally given his contact email several months in. We explained to both National Grid and Village Trustees why my individual medical history puts me at high risk of dying in a seizure that way. They all also received numerous accounts of what was happening to me, but we might as well have been talking to a wall. In January, 2021, there was a terrible incident where I couldn't get emergency medical care after a bad accident because I can't be near LEDs without having injurious, complicating epileptic seizures. We reported the event to the Trustees, National Grid and Police Chief Bobby Danko. None of them responded; none of them expressed any concern or interest.

Just as the Trustees ignored me through 2018 - 2019, after LED conversion they disregarded everything anyone said or sent. Residents and supporters who attended public meetings and asked questions were stonewalled. Mayor Bogle in particular consistently misrepresented the situation and spread misinformation about my medical condition, my circumstances, the sequence of events and about epilepsy and the ADA in general. Many of her public remarks were minimizing and insinuating, obvious attempts to discredit me and cast doubt about the frequent, life-threatening reactions I was having to the now inescapable light from LEDs. The trustees conceded that they knew lining village streets with LED lighting would hurt me, but decided that a cash incentive and lower lighting bills for the village mattered more. At the same time Mayor Bogle was publicly claiming to be hard at work seeking a solution, she'd already gone to NYCOM's lawyer asking for a law to cite that showed they didn't have to do anything for me. As months went by with no corrective action taken, Mayor Bogle deflected other officials making inquiries at our behest, telling them she was taking care of it. Mid-summer 2020, Mayor Bogle also actively deterred Chief Public Safety Officer/Police Chief Sargent Danko's attempts to get me minimally safe emergency routes in and out of the village and to medical care, telling him it was a civil matter and nothing to do with him. Sometimes Mayor Bogle selectively quoted from my letters, attributed statements to me which I did not make, and seemed bent on taking my own words out of context and using them against me. At one public meeting she called me a liar without saying why or what she meant. Repeated requests that the Trustees and National Grid speak to me personally went unanswered.

Fifteen months into this nightmare, they finally brought five HPS lights back to the corner by our house. They did not consult with me before or since, didn't get my agreement, and never checked whether 5 lights made any material difference whatsoever. They do not, as light from the very next ring

of LEDs still hits our house. The 5 light switch is more insult than accommodation, and it's not even permanent: When the HPS lights burn out, NG will replace them with the offending LEDs. I have no say and no control over that eventuality, any more than I had over the LED conversion project itself. Both parties know full well that I've been subjected to pain, illness and injury, and that I'm at risk of brain damage and sudden death from random encounters with the remaining LED streetlamps. Telling me their grudging and belated allotment of a 5-light area is TEMPORARY sounds like a threat. It certainly lays bare their utter contempt for me. Deliberately exposing a person with epilepsy to a known seizure trigger is a form of assault, leaving me to wonder: are the Village Trustees and National Grid exempt from laws that prohibit making threats and assaulting people?

Not once has anyone on the Board of Trustees or at National Grid inquired about my well-being or the extent of my injuries and losses. The Mayor claims that they care deeply about the welfare of village residents, and she says they are not heartless. National Grid also says they care about their customers, and claims to address all known human health and safety impacts from LED lighting. Apparently neither statement is true for someone suffering LED-reactive epileptic seizures. No-one has ever told me what I'm supposed to do if I want to move to a different house in the village, either. Am I expected to get their permission first? Do I get to bring any still-working HPS bulbs with me?

In December of 2020 we had our only face-to-face meeting with Mayor Bogle and Trustee Hallock. My husband and daughter were there too. Lori Kidd of the NENY Epilepsy Foundation and the good friend who's given me a safe place to sleep on her farm were also present. Mayor Bogle made it plain they'd only come to demand yet again that I produce more of my personal medical records, and leave them to judge if I'd proved that the LED lights were hurting me. I'd hand over my records, then they'd discuss whether or not I was entitled to any kind of disability accommodation. They claimed to need a single, set standard to apply to all constituent complaints. At that meeting, Mayor Bogle shrugged off the hundreds of LED-reactive seizures that have injured, sickened and displaced me from the village, saying with a wave of her hand, "You've had seizures before." When I said in frustration that they had never taken into account the life-threatening nature of my seizures, Trustee Hallock dismissed my risk of dying as merely "anecdotal" and "part of my story." (I've been forced to prove a hundred times over that the LED streetlights give me seizures. How exactly would they have me prove one of those seizures could kill me?) That meeting ended with Mayor Bogle calling my husband a liar without explanation. She and Trustee Hallock then walked off down our front porch steps, saying to one another, "Well, we tried!" There's a recording of that meeting. Trustee Hallock made one and sent our daughter a copy at her request.

Latterly, in FOI documents, we saw where Mayor Bogle and NG's Joseph Pallone discussed another attempt by Sargent Danko to help us, in October 2021. He tried to reach National Grid on our behalf. Mayor Bogle makes it clear to Mr. Pallone that he does not need to talk to Sgt. Danko because she's made sure Sgt. Danko already knows where the Village stands on the topic. (It is a specific ADA violation to interfere with anyone trying to assist a disabled person seeking restoration of their equal rights.) Sgt. Danko has never answered what we should do if I suffer any kind of emergency anywhere in the village beyond that 5 HPS stretch of sidewalk. He tells us to ask the mayor, as if she's my only public safety provider now. (One catch: Since late 2020, Mayor Bogle has said she's done with us.) Other FOI documents show Mayor Bogle and Mr. Pallone discussing their mutual awareness that the LED street lights were impeding my ability to work; speculating about my doctor visits and medical care; dismissing my neurologist letter as nothing of substance; coordinating on what limits they intended to impose on disability accommodations; one where Mr. Pallone assures Mayor Bogle that no-one else at National Grid will act on our complaints; updating one another on who heard what, how and how recently; and swapping notes about every effort we made to get me relief from the village LED installation causing us this much hardship and harm. In one appalling exchange, Mayor Bogle enthuses about the money the village saved by using LEDs, saying it made dealing with this issue worth it.

We did not see any emails where Mr. Pallone and Mayor Bogle discuss a June 3, 2021 phone

call I managed to have with a National Grid representative. The representative – who gave his name only as Joshua – told me he found where our complaints since 2020 had been misfiled in a more minor category of complaint. He also saw an order from mid-2020 to change Cambridge LED lights back to HPS that had been “banked” which I assume means shelved. I got the impression that order didn't limit it to 5 temporary lights. Joshua said my complaints belonged instead in a category he called “escalation” because they dealt with health and immediate safety. He said he was writing up a veritable essay for his supervisor, and spoke briefly to someone else while I was on hold. When he returned, he apologized for his company, affirmed with me that HPS bulbs do not cause me to have seizures, then outlined how National Grid would address the problem. Starting in 7 – 10 days, crews would start replacing LED street lights with HPS where the LEDs impact our property, then go on to replace LEDs along routes in and out of the village, to necessities like essential shops and medical care, and along the routes I take to and from work. I was relieved to the point of tears. Once off the phone, I excitedly told my family, put together the suggested list of relevant pole numbers, and looked out for the NG work crews Joshua had said would come to our house. That was nearly a full year ago. National Grid seems to have reneged on their offer.

I believe the Cambridge Village Trustees and National Grid have dealt with this family in consistent bad faith and dishonesty. They cannot continue to be permitted to control or impede my or any person's free movement in society, through any means, and they can't be allowed to use their official voting power to victimize me or any resident for any reason. Local government and utility companies must never be permitted to impose limits on citizens' lives, health, safety and equal public access rights based on whose circumstances inconvenience their plans and whose don't. Any civic leaders caught behaving this way should be disqualified from office. The Trustees' and National Grid's willingness to single out a disabled resident for protracted, determined, deliberate abuse is why minority protection laws came into existence in the first place. That this vivid, egregious perversion of every principle of human decency, good governance and ethical business practice has gone unchecked for two and a half years is, however, only a reflection on the people tasked with upholding the law – not on the law itself. Someone in New York State must take responsibility for allowing this all-encompassing harm to LED-light-disabled New Yorkers. It's as if we cease to exist as citizens, after our first bad reaction to LEDs.

Ms. Phillips, please help put a stop to this assault on my well-being, and to this outrageous interference in a private citizen's life and livelihood. The trustees had ample opportunity to pick a different way to save money and energy on municipal lighting besides seizure-causing LEDs. They could've avoided creating the problem, or corrected it the instant they realized their mistake. Instead, they chose to fight their own constituents' vital interests. Are the Trustees and National Grid actually arguing that my life, health, safety, income and career, and the health, safety, eyesight, quality of life, ease of travel, and enjoyment of private property for other affected families is worth *less* than what it'd take for multi-billion dollar National Grid and the Cambridge Trustees to put back the HPS lights? They need to be told to get their priorities straight, to behave like responsible, fair minded public servants and public utility providers, whatever their own opinions or personal priorities.

I will be sending a sampling of letters and emails from me and family members to the Mayor, Trustees, National Grid and other official entities like NYCOM, NYSERDA, and RPI's Lighting Research Center. I hope I have given you a full picture of how serious the situation is, how strenuously we tried to communicate the urgency of the matter, and how determined the Trustees and National Grid are to keep the LEDs in place even if it ultimately costs me my life. I will gladly supply any additional materials you may find helpful, and to answer any questions you may have for me. Thank you for investigating the catastrophic effects of LED street lighting on my family and on others harmed by public installation of these damaging lights.

Sincerely,

MarieAnn Cherry, Cambridge, New York