

OPEN LETTER TO SIMON HARRIS

30/01/2018

Dear Minister Harris,

My son Michael is 17 months old, and is today, 14 days seizure free on CBD. This letter is written in support of the unending efforts of Vera Twomey to open the eyes of this country and its leaders to the life changing effects of this substance, both for those who are fighting to have a quality of life, and for some, to have a life at all. In an attempt, firstly, to appeal to your humanity, let me give you an idea of the year we have had since my son's diagnosis, though there are no words in this world that could do it justice.

On the 19th of December 2016, my seemingly perfect, happy, healthy baby boy at three and a half months old had a seizure. This would be the first of thousands to come in the year to follow. We left my family home in Kilgarvan, Co. Kerry that day by ambulance, and spent two nights in Kerry General Hospital, before being transferred to Cork where we would spend another three months in hospital. During this time, I would be told I needed to take extended leave from my career as a teacher and that returning home to Kerry would not be prudent given the need now for proximity to the hospital. I will never forget the day the neurologist walked into our room and said, 'so the MRI shows'. I am no stranger to life changing events. I lost both my parents before their time, but this feeling was in a league of its own. Her words made me feel like vomiting. I could literally feel my heartbeat in my throat and pins and needles raking over me. Have you, Minister Harris, ever had reason to experience this feeling? For me, this would become a regular feeling over the next year also.

In the following few months, all the milestones Michael had reached before his seizures began had vanished, including his smiles, which was soul destroying. At his worst, Michael was having up to 20 seizures in one day. Can you imagine what it's like to watch a baby convulsing, Minister? During those times, a typical day in the hospital would be me waking up to get sick before I did anything else. The thought of what lay ahead and what would become of my baby literally turned my stomach daily. Some days, I had already been up all night as he was having nocturnal seizures intermittently. The rest of the day would be spent watching as he entered seizure after seizure after seizure, despite being on the maximum doses of several different anticonvulsant drugs. The days were interjected by blood tests, urine tests, EEGs, MRIs, physical examinations, IV lines, multiple medications and emergency seizure medication at times. What his little body went through was nothing short of torture! We left the care of the hospital on the 13th March 2017 with a diagnosis of Bilateral Frontal Polymicrogyria and Global Developmental Delay. I was told there was little chance, if any, of ever gaining seizure control, and we couldn't stay in hospital forever. Home we went, or rather to the house I had to rent near CUH, absolutely petrified that I was now solely responsible for Michael with no nurses or doctors outside my door if something went wrong.

It's strange how you can get used to things however. Michael's seizures became 'normal' in our lives and we lived with them and in-spite of them. Michael was on three different anticonvulsant drugs at the time; Epilim, Trileptal and Frisium. The Epilim was deemed to be of little effect after a while and was phased out, but the Trileptal it seemed was having a

slow and steady decreasing effect on seizures. I thought this was his answer. What I didn't realise was what else it would take from Michael. Having always fed like a little piglet, Michael suddenly began getting very crackly breathing on taking bottles and meds. Then a chest infection, followed by another, and another, followed by an aspiration pneumonia. This prompted a video fluoroscopy exam in early September to examine his swallow. A week we spent in hospital again, and we came home with a tube in his nose which he would now be fed through. Again, Minister, there are no words that can describe what this was like. I had to leave the room when they put the tube in as I knew I would not stay on my feet. Michael would also become unable to swallow his saliva, and so drooled to the point of soaking through towels. At this point, these failings were attributed to Michael's condition. I was told at this point, that while the tube would protect him from aspirating his milk, they could not protect him from aspirating his saliva, and over time this would destroy his lungs beyond repair, and ultimately end his life. I would from then on spend 6 hours of each day on feeding, with four feeds daily, each taking one and a half hours.

I began taking Michael to Craniosacral Therapy and Feldenkrais Therapy five days a week. He made leaps and bounds developmentally over the following six weeks, despite the fact that his seizures were on the rise again and he had developed ferocious reflux (a side effect of anticonvulsants). It was often the case where I would have to turn back from therapy or pull in at the side of the road and suction him to stop him choking on his own spit or vomit. I remember one day in particular when he vomited so bad he extubated himself. I was standing in front of a farmer's gate on the side of the road with Michael in one arm and trying to suction the vomit out with the other before he inhaled it. The number of times my focus was taken off the road as I would see him change colour in the mirror or a stream of milk pulping out his nose. The amount of dinners I burned from racing between the kitchen and his feeding chair if I heard him make a strange sound or got side tracked cleaning up vomits. My life became a series of hospital appointments, pharmacy trips, therapy trips, trips for his feeding equipment, not to mention the frantic dashes to A&E, of which there were so many. Microwave dinners and hand held food running out the door became the norm. I couldn't remember the last time I had a proper dinner on a plate. I was living in a constant state of 'fight or flight'. Constantly on edge, analysing, watching, listening, adrenaline rushing, every single day. I stopped watching TV as I was terrified I would be distracted and miss something.

We were brought in to have his swallow reassessed in late October, and to my utter dismay, I was told it had in fact gotten worse. This prompted me to look into his main drug, Trileptal. Having looked into various reports from the United States, I discovered a barrage of personal accounts of loss of swallow not to mention scores of law suits citing the same. I began to nudge down Michael's dose and sure enough within a week his mouth started to make shapes, he was audibly swallowing, and the drooling began to recede. I notified Michael's medical team and they supported my decision to take him off the drug. But this was drug number 9 he had failed after Clonazepam, Diazepam, Lacosamide, Phenobarbital, Keppra, Phenytoin, Epilim, and Frisium. The plan was then to transfer him to Tegretol.

It was around this time also, aware that we were out of options if the Tegretol failed, that I discovered Charlotte's Web CBD Oil and the story of Charlotte Figi in the United States. I sourced the oil and familiarised myself with dosage guidelines and calculations. I began giving Michael a miniscule dose to introduce it to his system. Michael was switched from Trileptal to Tegretol on January 4th, 2018. The following ten days his seizures worsened, despite blood tests showing a 'therapeutic' level of the drug in his body he was having up to

14 seizures a day. He entered a prolonged seizure on Thursday January 11th and required Buccalmidazolam to bring him back. He was also biting his tongue badly at this stage and bleeding profusely from the mouth. The following day I started Michael on the specified CBD dosage for his body weight.

Michael's seizures halved the following day, and halved again the day after. On the third day, I waited for seizures to come, very much expected them to come, and they did not, and have not since! It is now day 14, and to say life is different would be an immense understatement.

Yesterday I cooked dinner, uninterrupted, and I was able to sit down and actually eat it. We went for a walk, and I didn't have to bring the suction machine or cut it short to race back to the house. We watched two Disney movies, to the actual end! I was able to do the Hoovering, and not stop at two minute intervals to check him. Michael's smiles came back last Friday and he hasn't stopped since. Until or unless you have a baby of your own Minister Harris, there is no point in me even trying to explain what this was like. When my nurse is here now, I can leave and feel I likely won't get a call to say something has gone wrong. My stomach no longer lurches when the phone rings and I am out. I can make plans again for us to do the normal things mothers do with their babies. My own extended family also feel the effect, and they too no longer assume immediately something is wrong when they see my number calling. People often use the expression 'I feel like I have won the lotto', but even that does not exemplify the elation I feel.

Michael's swallow continues to improve and I hope to have him back feeding orally by his second birthday on August 31st, or even sooner. My expectations for him are the highest of the high. I have always said to the hospital staff, one member in particular, that Michael would surprise everybody yet. Despite his diagnosis and his prognosis, I believe Michael will defy all odds and not only live a normal life, but the best life.

Minister Harris, you are a normal person like the rest of us. You go to bed at night with your thoughts and get up and go to work every day. You have a social life and a family life and hobbies and interests and friends and whatnot. You are, however, also in a position of immense authority when it comes to the passing of legislation surrounding medicinal cannabis in Ireland. I am not writing this letter to attack you, but to beseech you to listen, to really listen, to people who are not fortunate enough to be able to live a normal life like you. Leaders leave legacies, good and bad. Imagine if yours was the sparing of thousands of people all over this country from pain, grief, panic, fear, loss of quality of life, loss of life itself!

I am typing this letter on my laptop, with my baby smiling and kicking away here beside me. It is inexpressible what it's like to see him this minute. I feel we both have a future now. I can see myself going back to work in the future, paying tax, no longer needing to take your money! I can see him going to creche, to school, to adulthood!

LISTEN to Vera Twomey, Minister. HEAR what she and others have to say. You should be immensely admirable of her like the rest of the country, and not dismissive of the lay person. She has demonstrated more leadership and valour than most people in official positions of power in this country. Her daughter Ava is living proof of her assertions. Gino Kenny's bill is currently being obstructed on this 'money matter'. Minister, think of your legacy, pay no heed to the habits of your predecessors, please get behind it and not in front of it. Consultants' eyes are opening now but their hands are tied. It is a time of powerful

change in many arenas Minister. This country has broadened its mind hugely in recent times. NOW is the time, more than any, to effect change in the access to medicinal cannabis, in keeping with the progressive path this country is now on.

Now, should the above fail to appeal to your humanity, I now appeal to your pocket. I am assuming, that the issue being purported in the Dáil is the cost to the HSE if medicinal cannabis is legalised. Let me begin by informing you, that in the last 13 months alone, my son's illness has cost the HSE almost twenty-six thousand euro, and the principal reason for this, has been the management of side-effects incurred from a barrage of failed anticonvulsants. You paid for Michael's anticonvulsants, nine failed to control his seizures, but caused hyper salivation, so you paid for secretion control medication and suctioning equipment. They also compromised his swallow, causing repeated chest infections and inability to feed orally, so you paid for antibiotics and nasogastric feeding equipment and supplies. They also caused reflux, so you paid for his reflux medication, which caused constipation, so you paid for constipation medication. Because of all this, his care needs escalated, and so you paid for 30 hours a week home nursing care. His home nursing care, alone, is costing you €2,210.00 a month, excluding agency fees. His hospital stays, have cost you €10,080.00.

While I am so admirable of, and grateful for, the Long-Term Illness Scheme and the GMS Scheme, and the home care and hospital care, I do not want to waste tax payers' money *unnecessarily*. My son is seizure free since starting CBD a fortnight ago. For you, consider the money that could have been spared if this had happened a year ago! I likely would have been able to return to work and would be paying *you* money by now. For me, I just imagine the dreadful side-effects that my son could have been spared!

I reiterate my plea to you to support the bill and see it through to legislation. Please do not insult the collective intelligence of the country by stating that cost is the obstacle, especially considering the indisputability of what I have outlined above and illustrated below.

I have included, as further evidence of the potential of medicinal cannabis, a picture of my son before and after beginning treatment with CBD. I think you will agree, Minister, no amount of facts or figures could illustrate my argument more perfectly.

I thank you for your attention.

Yours sincerely,

N O'Neill

HSE FUNDED MEDICAL EXPENSES TO DATE

ITEM	PURPOSE	COST TO HSE TO DATE
CLONAZEPAM	ANTICONVULSANT (FAILED)	141.69
DIAZEPAM	ANTICONVULSANT (FAILED)	160.00
LACOSAMIDE	ANTICONVULSANT (FAILED)	33.81
PHENOBARBITOL	ANTICONVULSANT (FAILED)	107.40
PHENYTOIN	ANTICONVULSANT (FAILED)	15.56
KEPPRA	ANTICONVULSANT (FAILED)	52.73
EPILIM	ANTICONVULSANT (FAILED)	175.00
TRILEPTAL	ANTICONVULSANT (FAILED)	356.40
TEGRETOL	ANTICONVULSANT (FAILED)	20.14
FRISIUM	ANTICONVULSANT	92.01
CLOBAZAM	ANTICONVULSANT	169.13
BUCCAL MIDAZOLAM 2.5MG	EMERGENCY ANTICONVULSANT	192.06
BUCCAL MIDAZOLAM 5MG	EMERGENCY ANTICONVULSANT	98.03
LANZOPRAZOLE	ANTI REFLUX	78.24
OMEPRAZOLE	ANTI REFLUX	90.40
RANITIDINE	ANTI REFLUX	21.00
INFANT GAVISCON	ANTI REFLUX	42.40
LACTULOSE	CONSTIPATION	5.99
GLYCEROL SUPPOSITORIES	CONSTIPATION	36.60
MOVICOL PAEDIATRIC	CONSTIPATION	25.42
SCOPODERM PATCHES	HYPERSALIVATION	500.00
GLYCOPYRROLATE	HYPERSALIVATION	142.38
AUGMENTIN	ANTIBIOTIC	31.16
FLOCARE FEEDING PUMP		900.00
TRAVEL BAG AND STAND		125.00
Z-FORM STAND		114.89
FLOCARE GIVING SETS		580.35
500ML RESERVOIRS		2,686.50
TUBE FEEDING FORMULA		2,300.00
ENFIT 1.0 ML SYRINGES		93.00
ENFIT 2.5 ML SYRINGES		109.00
ENFIT 5 ML SYRINGES	NASOGASTRIC TUBE FEEDING	100.50
ENFIT 10 ML SYRINGES		124.70
NASOGASTRIC TUBES		214.00
DUODERM DRESSING		245.95
TEGRADERM DRESSING		673.30
REMOVE SACHETS		47.95
Ph INDICATOR STRIPS		467.00
SUCTION MACHINES X 2		1,057.67
HYDROPHOBIC FILTERS		220.17
SUCTION CATHETERS		246.00
SUCTION YANKERS	SUCTIONING EXCESS SALIVA/VOMIT/REFLUX	244.00
SILICONE TUBING		133.00
DISPOSABLE LINERS		92.25
18 WEEKS HOSPITAL CARE	SEIZURE AND SIDE EFFECTS MANAGEMENT	10,080.00
30 HSE NURSING HOURS	WEEKLY HOME NURSING CARE	3,315.00
	TOTAL COST TO HSE TO DATE	25,700.11

BABY MICHAEL

