***What would the ideal situation be for you and your daughter to obtain cannabidiol, both in the short and long term?***

My daughter Mallory is currently taking a CBD oil that is delivered through the mail. This is not common practice for most providers, however this grower believes that their oil falls under the category of “hemp” and so they are willing to ship it. In today’s undependable grower/provider environment, they have demonstrated to be one of the more “reputable” companies we have dealt with and they claim to regularly test their product and willingly share their results. Although this situation is not perfect, based on our past experience with less reputable growers we are currently content with this company and the manner in which we receive their medication.

Ultimately, we’d like to get Mallory’s oil from a local pharmacy and have it covered by insurance just like any other medication. Pharmacies like Walgreens, CVS or Wal-Mart don’t dispense medications that aren’t regulated or approved in some manner.

While our family has been fortunate to be able to afford the cost of our daughter’s medications, it would seem appropriate that CBD oil be covered under most health insurance plans so that all Americans can afford their medicine and have a shot at a quality life.

Finally, the manufacturer and distributor of these oils, just like any other pharmaceutical company, should be held accountable if their product is contaminated, if they misrepresent the content of the oil, if they have variances in dosage levels, if they make mistakes or if they mislead their customers.

***How would you like to see cannabidiol produced and dispensed, and how do you believe it should be regulated?***

The FDA should be able to set up safeguards and processes to approve and oversee these oils. Perhaps there could also be a process for growers to apply for certification and their facilities, processes and labs be tested and approved just like any other pharmaceutical manufacturer. Ideally I would like to see cannabidiol mass-produced and dispensed just like any other medication. As a physician and a dad, I would like to see regulated testing procedures and standardized labeling so that I know how much CBD, CBC, THC, etc. is in my daughter’s mediation. I’d like to be able to trust the dosing and purity of the medication just like the potentially deadly opiates that I prescribe for my patients. And I’d like to see this medication FDA approved and recognized as a legitimate medicine instead of some home remedy or antiquated folklore treatment.

In my opinion, moving this from Schedule I classification to Schedule II would also help remove barriers to research. Let me explain how the stigma of Schedule I blocked a potentially decent study.

About a year ago my daughter was one of 1000 people on a waiting list for a quality CBD oil called Charlotte's Web. At that time, I tried to embark on a research project to find out 1) who these patients were 2) what was their situation 3) then track them for a year and see what happened to them from both a quality of life and seizure frequency standpoint.

It was only going to be an observational study. We were not going to suggest or handle any medications. This was simply an “ask and report” study.

After spending many hours getting participants on board and successfully recruiting a well-publicized epilepsy expert to help, I went to my hospital's Institutional Review Board (IRB). At this meeting I explained my daughter's situation and how I'd like to simply "observe" how people are currently doing and see how they trend over 12 months.

They wouldn't have anything to do with it.

One administrator said she was afraid that we "might get in trouble, as we get funding from the federal government.” Another said that, "if the study is positive, we would be promoting marijuana."

I went to the IRB three times to plead that this was simply observing people using something (that had no street value). Eventually they agreed to the study (reluctantly), but only after many lawyers and county supervisors were consulted.

They requested though, that I obtain a “Certificate of Confidentiality” from the NIH. I eventually obtained the certificate and went to back to our administration for a signature. After talking with several administrators, no one would sign as the “institutional official.” One administrator suggested I try another hospital to obtain this signature.

Because of the delay, the waiting list vanished and so did the opportunity to study CBD oil.

This schedule I drug, which has changed my daughter’s life, scared my hospital’s administration and prevented a study to come to fruition. Surely this stigma haunts administrators of other institutions and drug companies who are not willing to hurt their reputation or threaten their government funding resources by breaking the law or going against federal regulations.

Dr Thomas F Minahan