

1 ZENIA K. GILG, SBN 171922
HEATHER L. BURKE, SBN 270379
2 809 Montgomery Street, 2nd Floor
San Francisco CA 94133
3 Telephone: 415/394-3800
Facsimile: 415/394-3806

4 Attorneys for Defendant
5 BRIAN PICKARD

6
7 UNITED STATES DISTRICT COURT
8 EASTERN DISTRICT OF CALIFORNIA
9

10 UNITED STATES OF AMERICA,

11 Plaintiff,

12 v.

13 BRIAN PICKARD,

14 Defendant.

Case No. 2:11-CR-00449-KJM-16

DIRECT EXAMINATION OF
JENNIE STORMES

15
16 I, JENNIE STORMES, declare as follows:

17 1. I am a registered nurse living in the state of New Jersey. I graduated from Fresno
18 State University in 1991, with a BS in Business Accounting. In 2009, however, I returned to
19 school to earn an Associates Degree in Nursing from Warren County Community College. I am
20 presently within months of earning a BS in Nursing, and am working towards an MSN in
21 Nursing Education. Since graduating I have worked as a pediatric nurse and supervisor, as well
22 as a geriatric case manager. Further details regarding my training and experience are described in
23 my resume, attached as Exhibit A.

24 2. I am also a mother of two children. My daughter Sidnee is 18 years old, and
25 fortunately in good health. My 14 year old son, Jackson, however, suffers from Dravet
26 Syndrome.

27 3. In 2009, Jackson was diagnosed with Dravet Syndrome after having genetic testing
28 done for the SCN1A mutation. Prior to the genetic testing, he had a diagnosis of "medically

1 refractory, idiopathic, cryptogenic epilepsy." This is a fancy way for the doctors to say that they
2 "do not know what is causing his seizures, nor do they know how to treat his seizures because
3 they are not responding to the medications or to other medical interventions." Jackson had his
4 first seizure on October 21, 1999, when he was only four and a half months old. His second
5 attack was on November 3, 1999, after which he was started on narcotic medications in an
6 attempt to control his seizures.

7 4. Dravet Syndrom is a form of epilepsy which is rare and catastrophic. His symptoms
8 include:

- 9 • Neurological Dysfunction with frequent seizures
- 10 • Cognitive Delays
- 11 • Expressive Language Speech Delays
- 12 • Dysautonomia: difficulties regulating his body temperature & breathing
13 irregularities while sleeping
- 14 • Autistic-like characteristics and behaviors
- 15 • ADD/ADHD Combined Form
- 16 • Sensory Integration Disorder
- 17 • Ataxia
- 18 • Orthopedic issues with awkward gait and flat feet
- 19 • Possible Cardiac issues from the repeated seizures and work load on the heart
- 20 • Brain injury related to the ongoing seizures
- 21 • Inability to recognize danger or to care for himself
- 22 • Side effects of medications including lethargy, drowsiness, and aggressive
behaviors.

23 5. There is no cure for this disease, and Jackson will not outgrow the symptoms.

24 6. Jackson has been treated by experienced physicians specializing in this disorder. Since
25 2009, Jackson has met with Dr. Charlotte Dravet from France and Dr. Ian Miller from Miami
26 Children's Hospital and the Brain Institute in Miami, Florida. Jackson is presently being seen by
27 Eric Segal M.D. at the Northeast Regional Epilepsy Group in Hackensack, New Jersey, Jeffrey
28 Politsky, M.D. at Overlook Hospital in Summit, New Jersey, and in Jean Talleyrand, M.D. in San

1 Francisco, California.

2 7. Over the course of the past fourteen years Jackson has been prescribed a cocktail of
3 medications and treatments including: Phenobarbital, Klonopin, Tranxene, Onfi, Versed,
4 Diastat, Valium, Lorazepam, Tegretol, Depakote, L-Carnitine, Topomax, Keppra, Keto Diet
5 with many nutritional supplements, Zonegram, Zaratin, Felbatol, Ritalin, Lamictal, Diamox,
6 Vitamin B6, Prednisone, Clonidine, Gabapentin, Banzel, Stiripentol, Prozac. As is reflected in
7 the attached Exhibit B, he was prescribed these 20 drugs in 50 different combinations resulting in
8 debilitating side effects, and addictions.

9 8. In addition to the pharmaceutical treatments, Jackson has had surgical interventions:
10 VNS, Right Frontal Lobectomy, 2/3 anterior corpus Callosotomy.

11 9. In November 2012, Jackson's cocktail began to include a trial of Cannabidiol (CBD)
12 rich butter. Before using medicinal cannabis, he tried 50+ different combinations of FDA
13 approved pharmaceuticals which are not approved for children under the age of 12 and have
14 dangerous and scary side-effects; he underwent two brain surgeries, was on a medically restricted
15 diet which was nutritionally incomplete, and was given non FDA approved orphan drugs.
16 Nothing worked. The seizures were getting worse.

17 10. While at a professional conference in Minneapolis, I learned of how high CBD
18 cannabis was being successfully used to treat children with severe seizure disorders, and
19 thereafter, began to take the steps necessary to use medical cannabis to treat Jackson. Almost
20 immediately he came out of a fog. He was more open and alert. As his cannabis dosing increased
21 he began to show signs of cognitive improvements, lessened seizure intensity and quicker
22 recovery from seizure events. His VEEG background is now showing normal without slowing or
23 spike waves.

24 11. For the last nineteen months we have embarked on weaning him off those ineffective
25 pharmaceuticals. He has completely weaned from phenobarbital (highly addictive barbiturate)
26 Klonopin (highly addictive benzodiazepine) and Onfi (highly addictive benzodiazepine),
27 Stiripentol, banzel, and decreased the depakote by 75%. Jackson is also no longer on the
28 ketogenic diet with 5 additional nutritional supplements.

1 12. Jackson has always been a resilient child, waking up every morning with a smile and
2 a warm greeting: "Good Morning Mom!". Even when he suffered 10+ seizures between 2 and 6
3 a.m., he still wakes with a smile and willingness to tackle the day. Since Jackson has begun to
4 use cannabis as medicine, however, he is less hyperactive, and exhibits fewer self destructive
5 tendencies. Previously he would intentionally put his head through walls, windows and has
6 aimed many times at the TV. He was in pain and could not verbalize to anyone what he was
7 feeling, a known side effect of the pharmaceuticals he was prescribed. This behavior is now
8 gone. He is the inspiration and sunshine which empowers me to continue each day to fight for
9 his needs, inspires me to request access to appropriate medical care and hope for a future for him
10 to live the happiest and best life possible. (See, photographs of Jackson and his prescribed
11 medications taken before and after embarking on cannabis treatment, Exhibit C.)

12 13. The challenge in New Jersey is that children who are allowed to use medicinal
13 cannabis must have the approval of three physicians, and even with such approval no medication
14 is available for purchase in a non-smoked form: who wants their child smoking a medication?
15 However, I can and do make Jackson's medication into an edible form with the cannabis
16 obtained lawfully in the state of New Jersey, and when visiting family in California am able to
17 obtain it lawfully in any form necessary to treat my son.

18 14. In May of 2014, Jackson was hospitalized for the second time since being on
19 cannabis. The hospital threatened to kick him out for using his state-permitted cannabis in an
20 edible form because of the federal government's Schedule I classification. At one point the
21 hospital staff indicated that they could place a security guard at my son's door to ensure no
22 medical cannabis was administered. This was a devastating experience for it left me with two
23 options both of which risked my child's life. I could either stop the cannabis medication or take
24 him home. Having to choose between lifesaving medication and medical care at a level 4
25 epilepsy center is not a decision any parent should have to make. To say that the position taken
26 at the hospital was life threatening is not the words of an over anxious mother. As indicated in
27 the Abstract presented as Exhibit D, studies have shown that patients responding to cannabis
28 therapy will experience increased seizure activity when admitted to a hospital which refuses to

1 allow the administration of a Schedule I controlled substance.

2 Fortunately, no action was taken. Jackson's crisis resolved after being aggressively
3 weaned from the pharmaceutical which caused his increase in seizures, decrease in abilities such
4 as chewing, swallowing, walking, talking, using the bathroom, and bending; all side effects of the
5 medication listed from the drug company for Banzel. Within days, and I was able to bring him
6 home without further jeopardizing his health.

7 15. Jackson needs safe access to state approved medical marijuana to control his seizures
8 regardless of the state in which he resides. Unfortunately, I feel I may have to move to Colorado,
9 where the federal government has eased restrictions on marijuana prohibition since that state
10 legalized it for recreational use.

11 16. I must emphasize that before learning about the therapeutic uses of cannabis I was
12 not an advocate for the legalization of marijuana. Further, I did not decide to try this treatment
13 on my son without first thoroughly investigating the risks and benefits involved, and the reasons
14 for prohibition in 1937. In this regard, I have discovered that the properties which make cannabis
15 an effective medicine can be scientifically explained by the endocannabinoid system which was
16 not discovered in the human body until 1992. Based on my training and experience I can attest to
17 the fact that various strains of marijuana are particularly effective in treating many disorders by
18 working with the endocannabinoid receptors naturally existing within our body in all systems
19 known to scientist. I have further determined that the cannabis plant is non-toxic and its
20 ingestion results in addiction far less than the pharmaceuticals which my son has been prescribed
21 since he was five months old. It is physically impossible to overdose on cannabis or to die from
22 cannabis, unlike opioids, benzodiazapines, barbitutates, and other street drugs often used. The
23 reason for the low harm potential can be explained by the fact that there are no CB1/CB2
24 endocannabinoid receptors in the brain stem where the breathing and other autonomic body
25 functions are regulated, unlike the other drugs listed. For this reason alone, cannabis is the least
26 harmful of all the medications my son has ever been prescribed. In effect, I can state as both a
27 mother and a medical practitioner that cannabis is a safe and effective medicine.

28 I declare under penalty of perjury that the foregoing is true and correct, except for those

1 matters stated on information and belief, and as to those matters I believe them to be true. This
2 declaration signed on the 18th day of June, 2014, in Hope, New Jersey.

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4 /s/ Jennie Stormes
JENNIE STORMES

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