



BEFORE THE IOWA MEDICAL CANNABIDIOL BOARD

Rebecca Lucas

Petition by *(Your Name)*

for the **(addition or removal)** of

Any rare condition or disease that affects less than 200,000 individuals in the U.S., as defined in federal law, refractory to conventional treatment



PETITION FOR
ADDITION or REMOVAL
(Circle one)

(medical condition, medical treatment or debilitating disease) to the list of debilitating medical conditions for which the medical use of cannabidiol would be medically beneficial.

Petitioner's Information			
Name (First, Middle, Last or Name of Organization):			
Rebecca Lucas			
Home Address (including Apartment or Suite #):			
1953 F Market Street			
City:	Des Moines	State:	Zip Code:
		IA	50317
Telephone Number:	Des Moines	Business:	
Is this the person/ organization to whom information about the petition should be directed?	Yes	No	
	<input checked="" type="radio"/>	<input type="checkbox"/>	

Representative's Information <i>(If applicable)</i>			
Name (First, Middle, Last):			
Mailing Address (including Apartment or Suite #):			
City:		State:	Zip Code:
Is this the person/ organization to whom information about the petition should be directed?	Yes	No	
	<input type="checkbox"/>	<input type="checkbox"/>	



Telephone Number: <input type="text" value="515-509-4556"/>	Email Address: <input type="text" value="Rebecca.Lucas@Medpharmiowa.com"/>
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1. Please provide the name of the specific medical condition, medical treatment, or debilitating disease you are seeking to add to or remove from the list of debilitating medical conditions for which patients would be eligible to receive a medical cannabidiol registration card. *Please limit to ONE condition, treatment, or debilitating disease per petition.*

Recommended Action	Condition or Disease
<input checked="" type="radio"/> Add <input type="checkbox"/> Remove	<input type="text" value="Any rare condition or disease that affects less than 200,000 individuals in the U.S., as defined in federal law, refractory to conventional treatment"/>

2. Please provide a brief summary statement that supports the action urged in the petition. *Attach additional pages as needed.*

<input type="text" value="See attached"/>

3. Please provide a brief summary of any data or scientific evidence supporting the action urged in this petition. *Attach additional pages as needed*

See attached

4. Please provide a list of any reference material that supports your petition.

See attached



7. Please indicate whether you have attached a brief in support of the action urged in the petition.	Yes <input checked="" type="radio"/>	No <input type="checkbox"/>
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8. Please indicate whether you are asking to make an oral presentation of the contents of the petition at a board meeting following submission of the petition.	Yes <input checked="" type="radio"/>	No <input type="checkbox"/>
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9. Acknowledgement and Signature

By signing this document I certify that the information provided in this petition is true and accurate to the best of my knowledge.

Rebecca Lucas – Signed electronically – 04/01/2020

Signature

Date (mm/dd/yyyy)

Rare Condition Petition

This is a petition covering any rare condition that affects fewer than 200,000 persons in the US as defined by section 526 of the Federal Food, Drug, and Cosmetic act AND is not adequately managed despite treatment attempts. This category of conditions should qualify for medical cannabis use within the state of Iowa.

Background: In the state of Utah, the following is an approved condition. This was added legislatively and reads: “any rare condition or disease that affects less than 200,000 individuals in the U.S., as defined in federal law and is not adequately managed despite treatment attempts using conventional medications (other than opioids or opiates) or physical interventions.”

This allows for patients and providers to potentially treat conditions that may not have specific research in cannabinoids due to their orphan status.

During a previous Iowa Board of Medicine meeting, a petition was discussed with limited direct scientific literature. This petition, Intellectual Disability with Self-Injurious Behavior, was passed by this board due to the small potential patient size. It is with similar logic that rare conditions that are not adequately managed should also be certified due to their small potential patient size.

Orphan or Rare Diseases

In the United States, a rare disease is defined as a condition that affects fewer than 200,000 people. This definition was created by Congress in the Orphan Drug Act of 1983. Rare diseases became known as orphan diseases because drug companies were not interested in taking up the disease as a viable R&D project to develop treatments.

The NIH’s National Center for Advancing Translational Services keeps a list A-Z of rare diseases. Noting that prevalence of a rare disease usually is an estimate and may change over time, this site could be a good indicator of whether or not a disease may be considered a “rare” condition. Practitioners could also use the lists available at the National Organization for rare disorders (NORD):

<https://rarediseases.org/for-patients-and-families/information-resources/rare-disease-information/>

Some examples of rare conditions that may be benefited by access to medical cannabis based on symptom cluster similarity to approved conditions include the following:

- Polymyositis
 - Symptoms include muscle stiffness, pain, anorexia
- Dermum’s Disease
 - Characterized by multiple painful fatty growths on the trunk
 - Can also then have inflammatory and nerve pain
- Polymyalgia Rheumatica
 - Inflammatory diseases characterized by muscle stiffness
- Polyarteritis Nodosa
 - Multi-system disorder characterized by widespread inflammation to heart, muscles, nervous system
- Behcet’s Syndrome
 - Characterized by extreme inflammation of the joints, digestive tract

- Perry Syndrome
 - Neurodegenerative disorder characterized by early-onset neuro conditions, weight loss, insomnia, depression.

With over 250 new conditions being described in medical literature every year (European Medicines Agency 2016) , it is important that we be able to address conditions for which there is very little literature out there,. Approving this category of diseases allows providers and patients with underserved diseases to determine whether medical cannabis may be appropriate to treat symptoms of these rare diseases.