Medical Marijuana Program

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E-mail: dcp.mmp@ct.gov • **Website:** www.ct.gov/dcp/mmp

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DRUG CONTROL DIVISION
STATE OF CONNECTICUT

Petition to Add a Medical Condition, Medical Treatment or Disease to the List of Debilitating Conditions

INSTRUCTIONS: Please complete each section of this Petition and attach all supportive documents. All attachments must include a title referencing the Section letter to which it responds. Any Petition that is not fully or properly completed will not be submitted to the Board of Physicians.

Please Note: Any individually identifiable health information contained in a Petition shall be confidential and shall not be subject to disclosure under the Freedom of Information Act, as defined in section 1-200, Connecticut General Statutes.

Section A: Petitioner's Information

Name (First, Middle, Last): [redacted]		
Home Address (including Apartment or Suite #): [redacted]		
City: [redacted]	State: CT	Zip Code: [redacted]
Telephone Number: [redacted]	E-mail Address: [redacted]	

Section B: Medical Condition, Medical Treatment or Disease

Please specify the medical condition, medical treatment or disease that you are seeking to add to the list of debilitating medical conditions under the Act. Be as precise as possible in identifying the condition, treatment or disease. Hydrocephalus, Chiari I Malformation, Chronic intractable Headache

Section C: Background

Provide information evidencing the extent to which the condition, treatment or disease is generally accepted by the medical community and other experts as a valid, existing medical condition, medical treatment or disease.

- Attach a comprehensive definition from a recognized medical source.
- Attach additional pages as needed.

See attached

Section D: Negative Effects of Current Treatment

If you claim a treatment, that has been prescribed for your condition causes you to suffer (i.e. severe or chronic pain, spasticity, etc.), provide information regarding the extent to which such treatment is generally accepted by the medical community and other experts as a valid treatment for your debilitating condition.

- Attach additional pages as necessary.
- If not applicable, please indicate N/A.

medication side effects - unable to speak, memory loss, Nausea or just do not help

Section E: Negative Effects of Condition or Treatment

Provide information regarding the extent to which the condition or the treatments thereof cause severe or chronic pain, severe nausea, spasticity or otherwise substantially limits one or more major life activities.

- Attach additional pages as necessary.

See attached

Section F: Conventional Therapies

Provide information regarding the availability of conventional medical therapies, other than those that cause suffering, to alleviate suffering caused by the condition or the treatment thereof.

- Attach additional pages as necessary.

See attached

Section G: General Evidence of Support for Medical Marijuana Treatment

Provide evidence, generally accepted among the medical community and other experts, that supports a finding that the use of marijuana alleviates suffering caused by the condition or the treatment thereof.

- Attach additional pages as necessary.

See attached

Section H: Scientific Evidence of Support for Medical Marijuana Treatment

Provide any information or studies regarding any beneficial or adverse effects from the use of marijuana in patients with the condition, treatment or disease that is the subject of the petition.

- Supporting evidence needs to be from professionally recognized sources such as peer reviewed articles or professional journals.
- Attach complete copies of any article or reference, not abstracts.

See attached

Section I: Professional Recommendations for Medical Marijuana Treatment

Attach letters in support of your petition from physicians or other licensed health care professionals knowledgeable about the condition, treatment or disease at issue.

See attached

Section J: Submission of Petition
In the event you are unable to answer or provide the required documentation to any of the Sections above (excluding Section D); provide a detailed explanation indicating what you believe is "good cause" for not doing so. • Attach additional pages as necessary.

I hereby certify that the above information is correct and complete.	
My signature below attests that the information provided in this petition is true and that the attached documents are authentic. I formally request that the commissioner present my petition and all supporting evidence to the Board of Physicians for consideration.	
Signature: [redacted]	Date Signed: 10/24/16

Section C - Background

Hydrocephalus Association

Headaches and Hydrocephalus

It is not uncommon for people with hydrocephalus to experience headaches. This Information Sheet will discuss headaches and hydrocephalus in an attempt to give a better understanding of the issues.

Individuals with hydrocephalus, shunted or not, are frequently troubled by headaches. A diagnosis of the cause of headaches can be difficult and complicated, and, as with the management of any chronic pain, it requires tremendous patience on the part of the patient and the physician.

Possible Causes of Headaches
Dr. Harold L. Rekate, Chief of Pediatric Neurosurgery at the Barrow Neurological Institute in Phoenix, Arizona, suggests five different reasons for headaches in a person with hydrocephalus:

- Intermittent proximal shunt obstruction. This is often referred to as the classic 'slit ventricle syndrome.' Frequently the headaches last from 10-90 minutes and resolves on its own. Often occurring in the late afternoon, they can happen at any time. The headache can be severe, and may be associated with vomiting, photophobia (aversion to light), and it can resemble, to some extent, a migraine.

- Small ventricles when the shunt fails and the ventricles can't grow to accommodate cerebro spinal fluid (CSF). This is more severe in patients in who headaches come and stay; are present mostly in the morning, and can be associated with double vision. There headaches are usually progressively more severe.

- Intermittent failure of the shunt can produce a variety of headaches. The length of time that failure occurs is indeterminate and not predictable.

- Extremely low shunt pressure can cause headaches that are similar to spinal headaches. In these cases, headache complaints are minimal when the patient is lying down but become more severe when the patient sits up or stands.

- Migraine, a common affliction, can also occur in a person with hydrocephalus. Often there is a positive family history. Varying degrees of neurological dysfunction, headaches, vomiting, difficulty with vision and impairment of consciousness (including stupor) have been documented. Migraine attacks in shunted children and adolescents can create a disconcerting clinical situation for the patient, the family and the physician.

Dr. Gordon McComb, Head of Neurosurgery at Children's Hospital in Los Angeles, identifies similar reasons for headaches, but he narrowed them down to just three causes: migraine, shunt failure and low pressure.

fix the shunt. So, if the headaches occur at such and such a frequency and continue getting more frequent, the criteria have been put into place to change the shunt." Both physicians suggest that it is very important to put all of the various pieces together to get a perspective, as well as to individualize the care of each and every patient.

Drs. Fred Epstein and Rick Abbott, of Beth Israel Hospital in New York City, and Jeffrey H. Wisoff, of New York University Medical Center, suggest that difficulties in the diagnosis and treatment of headaches arise when there have been no changes in ventricular size and headache symptoms are of a more chronic, non-progressive nature. This can be caused by intracranial hypotention (low) or intracranial hypertension (high). They and their colleagues recommend Intracranial Pressure Monitoring (ICP) for severe, persistent cases where CT or MRI demonstrates no enlargement of the ventricular system. ICP monitoring involves hospitalizing the patient for a day or two, inserting the monitoring device and continually measuring the pressure inside the brain. The patient is alert and active so that pressures can be recorded in relation to body position and activity. If the pressure changes can be correlated with the patient's symptomatology, the shunt can then be revised with either a higher or lower pressure valve. Dr. McComb suggests that another way to test shunt function is to inject a tracer into the shunt and do a flow study.

The cause of many headaches can be related to the altered pressures and functions inside the head once a shunt has been placed. "Unfortunately," say Dr. Rekate, "The perfect valve is one you don't have to put in." Today, most of the valves are pressure differential valves which react to the pressure above versus the pressure below. The valve can't tell the difference between 300 and 100 because the pressure differential is the same. Research continues on flow regulated valves as well as shunts that are programmable.

Dr. Jack Walker, past President of the American Society of Pediatric Neurosurgeons, suggest that in some cases when intracranial compliance is extremely low, treating patients with migraine therapy will often produce an improvement because of the stability provided to the intracranial vasculture by such medication. "Dilation of cerebral vessels and increased blood flow may not occur as often due to the vasoactive drugs and stabilization of the patient's intracranial blood flow. Relief of the symptoms may occur even though the symptoms were not caused by a true migraine mechanism."

The criteria for establishing the diagnosis of migraine includes "Recurrent headaches with symptom-free intervals, as well as nausea, vomiting, abdominal pain, hemicrania, throbbing pulsating pain, complete relief after rest, aura and a family history of migraine," states Drs. Hector James and Thomas Nowak of Children's Hospital of San Diego. When a protocol of shunt testing, scans, and ICP monitoring, and perhaps shunt revision with a valve change have failed to alleviate the condition, management with medications for migraine may be indicated. Propranolol, Periaction and Inderal are just a few of the medications prescribed for migraine control.

Conclusion

Hydrocephalus is not a disease, it is the brain reacting to a blockage. Placement of a shunting device is currently the most common way to control this blockage. However, as noted above, shunting creates an unnatural condition. While a number of people shunted for hydrocephalus have few or no problems with their shunts, the limited statistics that are available suggest that more than 50% will need some kind of revision. Because headaches can be an indication of malfunction or obstruction, establishing a mutually respecting relationship with your neurosurgeon and your medical team, is the best way to insure continued, comprehensive care.

The occurrence of headaches in children and adults with hydrocephalus, especially if recurring, can be a complicated problem that requires tremendous patience thorough medical attention and an agreed up plan of action.

Hydrocephalus

Hydrocephalus comes from the Greek words **hydro** meaning water and **cephalus** meaning head.

Hydrocephalus is an abnormal accumulation of cerebrospinal fluid (CSF) within cavities in the brain called ventricles. Cerebrospinal fluid is produced in the ventricles and in the choroid plexus. It circulates through the ventricular system in the brain and is absorbed into the bloodstream. This fluid is in constant circulation and has many functions, including to surround the brain and spinal cord and act as a protective cushion against injury. It contains nutrients and proteins necessary for the nourishment and normal function of the brain, and carries waste products away from surrounding tissues.

Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed. As the CSF builds up, it causes the ventricles to enlarge and the pressure inside the head to increase.

Click here to learn more about brain physiology relevant to hydrocephalus.

Who develops hydrocephalus?

Hydrocephalus affects a wide range of people, from infants and older children to young, middle-aged and older adults.

- Over 1,000,000 people in the United States currently live with hydrocephalus.
- For every 1,000 babies born in this country, one to two will have hydrocephalus.
- Hydrocephalus is the most common reason for brain surgery in children.
- It is estimated that more than 700,000 Americans have NPH, but less than 20% receive an appropriate diagnosis.

There are no comments published yet.

Leave a Comment

Comment

HydroAssist

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Treatment

There is currently no known way to prevent or cure hydrocephalus and the only treatment option today requires brain surgery. With early detection and appropriate intervention of hydrocephalus, the future for many is promising. Recent research is advancing knowledge and moving us closer to a cure. Advances in technology as well as diagnostic and treatment protocols are helping more and more people with hydrocephalus to lead full and active lives.

There are three forms of surgical treatment currently used to manage hydrocephalus.

Shunt System

The most common treatment for hydrocephalus—and the most common procedure performed by pediatric neurosurgeons in the United States—is the surgical implantation of a device called a shunt.

A shunt is a flexible tube placed into the ventricular system of the brain which diverts the flow of CSF into another region of the body, most often the abdominal cavity, where it can be absorbed. A valve within the shunt maintains CSF at normal pressure within the ventricles.

Click here to download our fact sheet on shunt systems.

Endoscopic Third Ventriculostomy (ETV) and Endoscopic Third Ventriculostomy with Choroid Plexus Cauterization (ETV/CPC)

A second treatment option for hydrocephalus is a surgical procedure called endoscopic third ventriculostomy (ETV). This same ETV procedure with the addition of choroid plexus cauterization is available for infants. In the ETV procedure, an endoscope is used to puncture a membrane in the floor of the third ventricle creating a pathway for CSF flow within the cavities in the brain. This approach is an important alternative to shunting for obstructive hydrocephalus and may be useful in other cases as well.

whether there is scarring in the fluid space below the floor of the third ventricle. For some patients, the chance for success of the ETV may be up to 90%; however, for others, ETV – with the addition of CPC for infants – may not be recommended because the chances for success are sufficiently low. Your neurosurgeon should be able to provide you with a reliable estimate of the likelihood for success in your particular situation prior to the operation. It's critical that parents and patients understand that ETV is not always a permanent cure for hydrocephalus. Candid communication with your physician regarding the definition of success is important when considering ETV.

Click here to download our fact sheet on ETV.

Hydrocephalus

What is hydrocephalus?

Classifications and Causes

Symptoms and Diagnosis

Treatment Options

Shunt Systems

Complications of Shunt Systems

Complications of ETV and ETV/CPC

Signs and Symptoms of Complication

Management of Hydrocephalus

Brain Physiology Relevant to Hydrocephalus

HydroAssist

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I am a...

Parent

Teen and Young Adult

MAKE A DONATION

Doctor

Community Network

WALK

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SUBMIT

Section E: Negative Effects of Condition or Treatment

E) I live in chronic debilitating pain 24/7, headaches that have defied traditional medical and homeopathic treatments. I can't enjoy daily activities that a healthy person is able to. At the age of 18, I am a prisoner to my excruciating pain, having to organize my life around my pain because medical professionals are unable to control it. I am unable to work and support myself due to the debilitating pain that plagues me every minute of every day. Fun activities that an 18 year old should be doing are impossible for me because of the debilitating pain. My pain is so bad that it is uncontrolled by all my past medical treatments and interventions. I am currently trying to attend college, but I am fighting against my own body due to uncontrollable pain, therefore it is near impossible. The pain consumes me, making it hard to focus and comprehend in classes. In college it is hard to keep up with the workload being that it takes me much longer to comprehend what I am learning because I am constantly fighting pain every minute of every day. Right now I am not living my life, I am trying to survive. I am 18 years old and I want to do more than just survive with my life.

Section F: Conventional Therapies

F) I have tried so many treatments and therapies and still continue to live with debilitating headaches

-Brain surgery for Hydrocephalus, ETV, VP Shunt, EVD and ICP monitoring

-Biofeedback, Guided Imagery, yoga

-Cranial Sacral therapy

-Chiropractic

-Acupuncture

-Massage therapy

-Pain management

Numerous medications, Occipital nerve blocks, Sphenopalatine Ganglion block, Botox

-IV treatment

-Facet injections

-Homeopathic treatments

-Special diets

Section I . Professional Recommendations

[redacted] is also seeing Pain Management who believes Medical Marijuana is the next course of treatment for her, but because her condition is not on the approved State of CT list we must Petition the State to add the medical condition.

She is currently under the care of:

Dr. [redacted], MD

[redacted]

Section I - Professional Recommendations

Connecticut Children's Specialty Group Department of Neurosurgery
282 Washington Street
Hartford, CT 06106-3322
TEL: 860-545-8373
FAX: 860-545-8233

June 1, 2016

[redacted] MD
[redacted]

AHH 6/3/16

Patient: [redacted]
MR Number:
Date of Birth:
Date of Visit:

Dear Dr. [redacted]:

[redacted] is an 18-year-old high school senior bound for Bay Path College next fall. As you know, she has shunted hydrocephalus with long-term control for raised pressure previously causing transient visual obscurations and memory dysfunction. [redacted] has a very complex headache management challenge. She has undergone numerous treatments including medications which have included Keppra, Botox, etc. We recently repeat monitored intracranial pressure with parenchymal transducer and separately with a ventricular catheter. In both cases despite any patient position her pressures were never over 3 to 4 mmHg at many times, it was negative. Spine MRI scan showed no evidence of Tarlov cysts or pseudomeningoceles. Her brain scan shows a Chiari malformation without anatomic progression. [redacted] best headache management recently has been supplementing Dilaudid with hydrocodone. She is eager to be headache free and looks forward to that freedom for her college career.

On examination, [redacted] is alert and cooperative. Her speech is clear and articulate. Her cognitive function is normal. Her left frontal scalp incision is well healed and sutures removed without difficulty. She has normal motor tone, power, strength, gait and sensation. Heel toe and tandem walking is normal. [redacted] is very frustrated by her chronic headache, I consulted with Dr. [redacted] from the Chiari Institute and he speculated that [redacted] could be one of rare patients who have well drained intracranial subarachnoid space and normal pressure, but without pressure relief from her spinal axis. That may be true especially in light of her Chiari malformation. I have recommended on 06/06/2015 a spinal tap in the operating room under optimum conditions. If the pressures are elevated as they have been in the past, this would suggest she is noncommunicating and would benefit from a separate shunt drainage to the lumbar peritoneal system. [redacted] is agreeable to proceed with that diagnostic test. We also discussed the potential use of medical marijuana for chronic headache control and actually consultation with Dr. [redacted] at the Chiari Institute. I am very honored to be part of [redacted] team.

Sincerely,

[redacted], MD

CC: [redacted], MD
[redacted]

Section I - Professional Recommendations

[redacted] (MR # [redacted])

Progress Notes by [redacted], MD at 05/02/16 1603

Author: [redacted], MD | Service: (none) | Author Type: Physician
Filed: 05/11/16 0739 | Note Time: 05/02/16 1603 | Status: Signed
Editor: [redacted], MD (Physician)

[redacted] is an 18-year-old high school senior currently accepted to Bay Path College for next year. She looks forward to physician assistant studies. As you know, she has a chronic headache syndrome, which has been defiant of medical management. Her headache has been treated recently with high dose indomethacin, escalating Keppra dose to 1500 mg per day and Botox. [redacted] describes all of her symptoms as progressive with global headache, bitemporal and bifrontal. She reports some mild retroorbital pain, but no visual obscurations. Her memory remains excellent and improved compared to a time before her shunt was inserted. Her transient visual changes have been resolved since her original endoscopy. She reports only rare and random suboccipital pain. Most of her headache is static with cough, strain in Valsalva and only occasionally is it intensified by these maneuvers. She admits to running out of patience and energy to get through her school day and is fatigued with her years of chronic pain. She has no new drug, latex or food allergies. She is not vomiting and is not sleeping more than normal.

On examination, for the first time, I see some indistinctness to the superior disk margin. Visual fields are preserved to confrontation. Pupils are briskly reactive and ocular motility is normal. Facial features are symmetric. Speech is clear and articulate. [redacted] has normal motor tone, power, strength, gait and sensation with no dysmetria or dysdiadochokinesia. Dynamic neck movements do not intensify her pain. Her MRI today is compared to numerous prior studies going back to before her ETV and shunt was inserted. Overall, the ventricles remain dilated, left greater than right. There is a small remnant of flow void within the third ventricle. There is a Chiari 1 malformation with triangular tonsillar displacement below the dorsal rim of the foramen magnum, but not underneath the dorsal ring of C1. There is no transependymal flow.

[redacted] headache has been refractory to all spectrum of medical management. I had previously inserted a left ventriculostomy catheter for ICP monitoring and recorded low pressures that never were elevated during sleep or activity. The only intervention I recommend at this point is to repeat that study both with an invasive catheter to allow drainage and the Codman parenchymal monitor to record pressures during all activities when [redacted] can be up and walking about. If her pressures remain consistently low despite her shunt turned to 2.5, it is possible that taking the shunt out to externalize it and a trial of essentially no drainage would be helpful for her.

I also discussed a trio of patients all teenage women in my practice over 30 years who ended up needing both VP and lumbar peritoneal shunts. This was necessary as their subarachnoid spaces were under pressure not drained by the VP shunt above it was demonstrated after simultaneous lumbar puncture and lumbar drainage catheter. I doubt very much that the untreated Chiari malformation is the etiology of headache of this severity. [redacted] and her mother are agreeable to proceed to repeat ICP monitoring and we plan this for next Monday. She has been a very challenging headache management, but I remain confident in the end we will be successful energizing her lifestyle.

Warmest regards,

Section G - General Evidence of support for medical Marijuana Treatment
Section H - Scientific evidence of Support for medical marijuana Treatment

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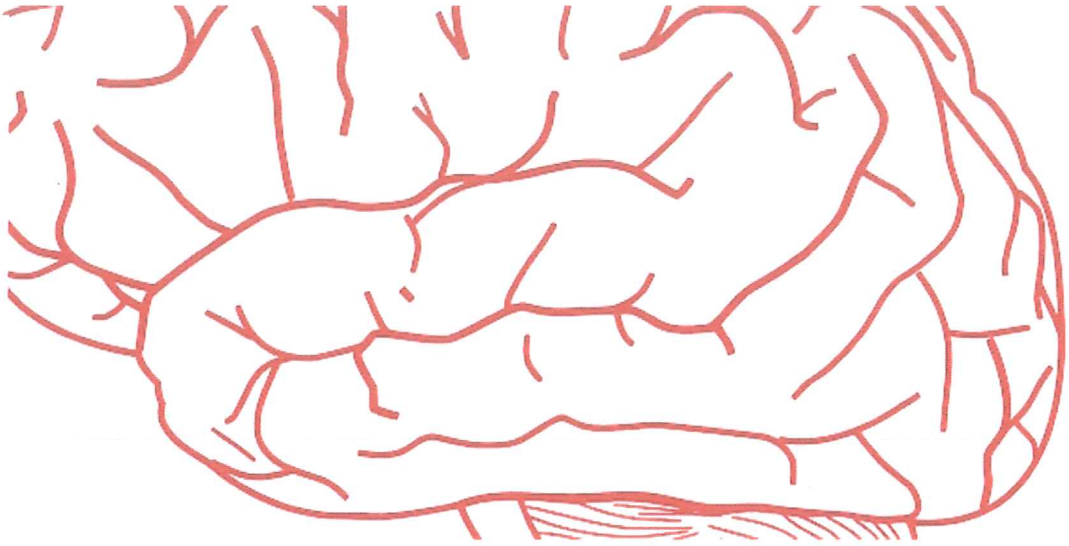

Hydrocephalus – Medical Marijuana Research Overview

28 September, 2015

The following information is presented for educational purposes only. Medical Marijuana Inc. provides this information to provide an understanding of the potential applications of cannabidiol. Links to third party websites do not constitute an endorsement of these organizations by Medical Marijuana Inc. and none should be inferred.

Hydrocephalus is spinal fluid building up in the brain and is a condition that is most common among infants and older adults. Studies have shown that marijuana helps improve the secondary symptoms associated with hydrocephalus.

Overview of Hydrocephalus

Hydrocephalus is the condition where fluid accumulates in the ventricles, or cavities, of the brain. The fluid that builds up is cerebrospinal fluid (CSF), which surrounds both the brain and spinal cord to keep the brain buoyant, provide cushioning, moderate pressure and remove waste products. An imbalance in how much CSF is produced and how much is absorbed in the bloodstream is what causes hydrocephalus and the buildup of CSF can put pressure on the brain and cause impairments in function.

Why hydrocephalus develops is still unknown, but according to the National Institute of Neurological Disorders and Stroke, it may result from inherited genetic abnormalities or developmental disorders.

Common symptoms of hydrocephalus include an unusually large head or a bulging or tense soft spot on the top of the head, nausea and vomiting, irritability, seizures, sleepiness, poor feeding, poor balance, headaches, decline in memory and concentration. The condition, especially in infants, poses risks to cognitive and physical development.

Surgery, where a shunt is inserted to divert the CNS elsewhere so that it can be absorbed, is capable of restoring the CSF back to normal levels, but it commonly requires a variety of methods to comprehensively manage the symptoms associated with the condition.

Findings: Effects of Cannabis on Hydrocephalus

Medical cannabis can help treat the symptoms associated with hydrocephalus. Cannabis has shown to be effective at managing seizures, nausea, sleep problems and pain.

Top Resources

Medical Marijuana CBD Oil

Popular

What is CBD (cannabidiol) Hemp

Industrial Hemp Now Growing ir York

CBD-Based Cannabis Products A to All Florida Customers, Despite

Inflammation – Medical Marijuar Research Overview

Cirrhosis – Medical Marijuana Re Overview

Latest News

Recreational Marijuana Initiative Pass in Massachusetts, Poll Indic

UK's All Party Parliamentary Grc Recognizes Cannabis's Medicina Calls for Legalization

Cannabis has been proven to decrease or prevent nausea and vomiting (Sharkey, Darmani & Parker, 2014) (Parker, et al., 2015). Two major cannabinoids found in cannabis, tetrahydrocannabinol (THC) and cannabidiol (CBD) regulate nausea and vomiting because they activate cannabinoid receptor 1 (CB1) of the endocannabinoid system and activating the CB1 receptor has been shown to suppress vomiting (Parker, et al., 2003).

CBD has been shown to be a well-tolerated and promising therapeutic treatment for reducing or even eliminate seizures (Blair, Deshpande & DeLorenzo, 2015). CBD's activation of the CB1 receptor dampens the release of a neurotransmitter and causes an overall reduction in neuronal excitability (Wallace, Wiley, Martin & DeLorenzo, 2001) (Hoffman & Frazier,

205
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ıd CBD have demonstrated they are both effective at lowering pain levels caused by a variety of affections, including ancer, neuropathy, spasticity, headache, migraines, and other acute pain and chronic pain conditions (Jensen, Chen, ı & Wallace, 2015) (Baron, 2015).

es That Have Approved Medical Marijuana for Hydrocephalus

tly, only the state of Illinois has approved medical marijuana specifically for the treatment of hydrocephalus.

er, other states have approved medical marijuana to treat nausea, seizures and pain. The states that have approved is for nausea include: Alaska, Arizona, California, Colorado, Delaware, Hawaii, Maine, Maryland, Michigan, ıa, Nevada, New Hampshire, New Mexico, Oregon, Rhode Island, Vermont, and Washington. The states that have ed cannabis for the treatment of seizures include: Alaska, Arizona, California, Colorado, Delaware, Florida, Hawaii, Maryland, Michigan, Minnesota, Montana, Nevada, New Hampshire, Oregon, Rhode Island, Tennessee (intractable seizures), Vermont and Washington. Several states that have approved cannabis to treat "chronic pain," including Alaska, Arizona, California, Colorado, Delaware, Hawaii, Maine, Maryland, Michigan, Montana, New Mexico, Ohio, Oregon, Pennsylvania, Rhode Island and Vermont. The states of Nevada, New Hampshire, Ohio and Vermont allow medical marijuana to treat "severe pain." The states of Minnesota, Ohio, Pennsylvania and Washington have approved cannabis for the treatment of "intractable pain."

A number of other states will consider allowing medical marijuana to be used for the treatment of hydrocephalus with recommendation by a physician. These states include: California (any debilitating illness where the medical use of marijuana has been recommended by a physician), Connecticut (other medical conditions may be approved by the Department of Consumer Protection), Massachusetts (other conditions as determined in writing by a qualifying patient's physician), Nevada (other conditions subject to approval), Oregon (other conditions subject to approval), Rhode Island (other conditions subject to approval), and Washington (any "terminal or debilitating condition").

In Washington D.C., any condition can be approved for medical marijuana as long as a DC-licensed physician recommends the treatment.

Recent Studies on Cannabis' Effect on Hydrocephalus

Cannabis significantly improves neuropathic pain that had proven refractory to other treatments.
The effectiveness of cannabinoids in the management of chronic nonmalignant neuropathic pain: a systematic review.
(http://www.ncbi.nlm.nih.gov/pubmed/25635955)

Studies have demonstrated that cannabinoids' impact on the endocannabinoid system helps to regulate nausea.
Regulation of nausea and vomiting by cannabinoids. (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3883513/)

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Sharkey, K.A., Darmani, N.A., and Parker, L.A. (2014). Regulation of nausea and vomiting by cannabinoids and the endocannabinoid system. European Journal of Pharmacology, 722, 134-46.

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Your Email Address

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These statements have not been evaluated by the FDA and are not intended to diagnose, treat or cure any disease. Always check with your physician before starting a new dietary supplement program.

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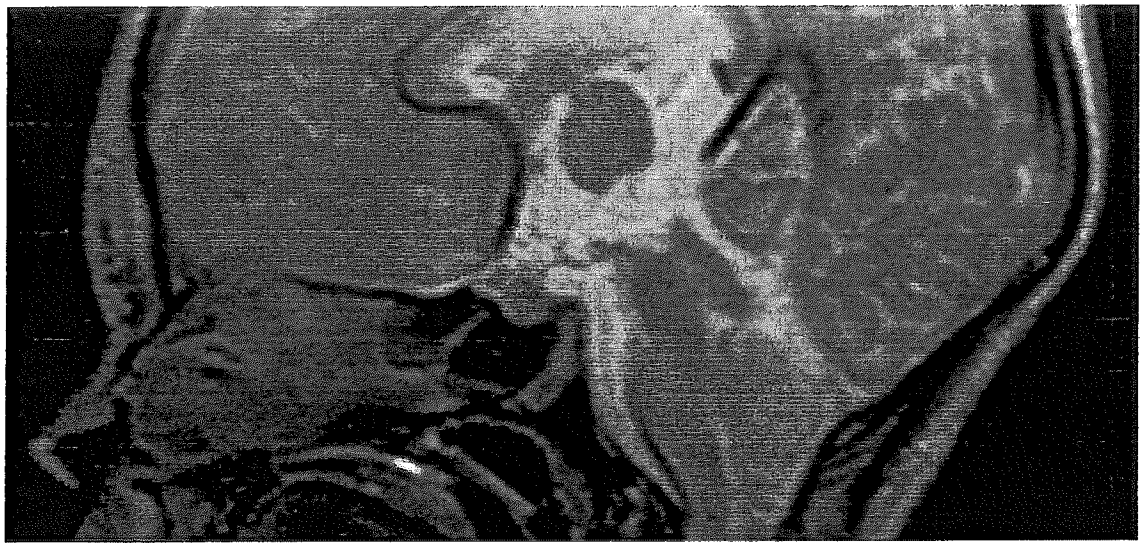
* Cannabidiol (CBD) is a naturally-occurring constituent of the industrial hemp plant.

Medical Marijuana Inc. does not sell or distribute any products that are in violation of the United States Controlled Substances Act (US.CSA). The company does grow, sell and distribute hemp based products.

Section G & - General Evidence of Support for Medical Marijuana Treatment
Section H - Scientific Evidence of Support for Medical Marijuana Treatment



Arnold-Chiari Malformation and Syringomyelia – Medical Marijuana Research Overview

24 September, 2015

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A Chiari malformation is a structural defect that causes the cerebellum to be positioned incorrectly within the skull that can cause a syringomyelia, or cyst filled with cerebrospinal fluid, to form. Studies have shown marijuana can help curtail the pain, sleeping problems and spasms often associated with the condition.

Overview of Arnold-Chiari Malformation and Syringomyelia

Chiari malformations are structural defects in the cerebellum. Normally, the cerebellum and parts of the brain stem rest at the lower rear of the skull, just above the foramen magnum. In a Chiari malformation, less commonly known as Arnold-Chiari malformation, the cerebellum is positioned below the foramen magnum. Chiari malformation is the leading cause of syringomyelia, which is a syrinx or cyst that accumulates cerebrospinal fluid within the spinal cord and causes the cord to expand.

According to the National Institute of Neurological Disorders and Stroke, primary or congenital Chiari malformations occur during fetal development and may be caused by genetic mutations or a lack of adequate vitamins or nutrients in the maternal diet. The malformations can also be caused later in life, in what's referred to as a secondary Chiari malformation, if an injury, infection or exposure to harmful substances requires that spinal fluid be drained excessively from the lumbar or thoracic areas of the spine.

Chiari malformations commonly cause headaches, swallowing problems, sleep disturbances, vocal quality changes and balance problems or dizziness. If developed, syringomyelia's can cause a sensory loss or an exaggerated response to pain, limb weakness and atrophy, muscle spasms, and pain.

Surgery to correct the functional disturbances and prevent the progression of damage to the central nervous system is the only treatment option for a Chiari malformation and syringomyelia.

Findings: Effects of Cannabis on Arnold-Chiari Malformation and Syringomyelia

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Tripp, D.A., Nickel, J.C., Katz, L., Krsmanovic, A., Ware, M.A., Santor, D. (2014, November). A survey of cannabis (marijuana) use and self-reported benefit in men with chronic prostatitis/chronic pelvic pain syndrome. Canadian Urological Association Journal, 8(11-12). Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4277530/.

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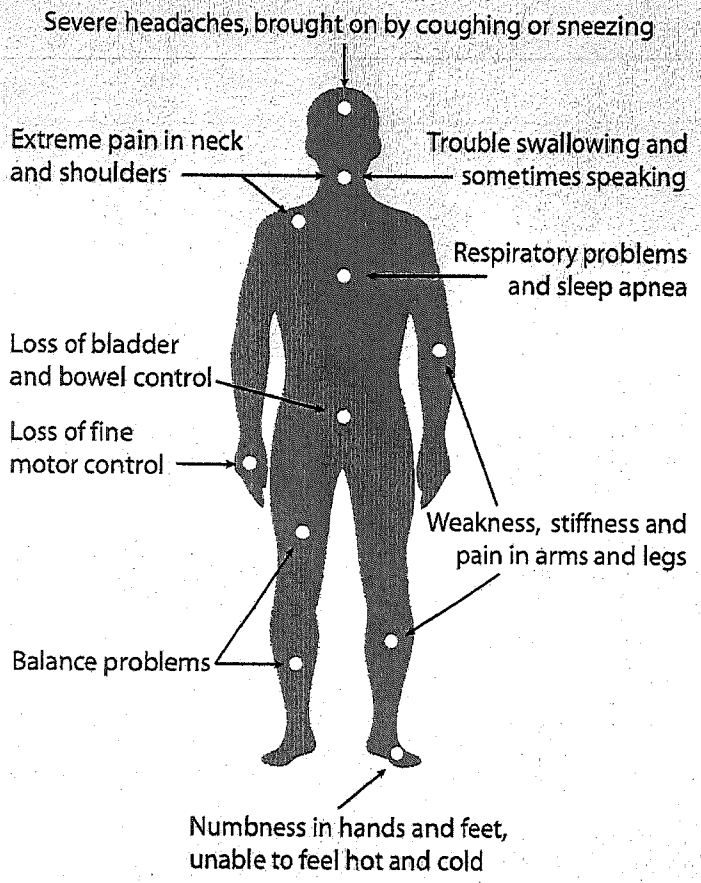
Symptoms



- Signature symptom is a severe headache in the back of the head brought on by straining, coughing, etc.
- It is not known why, but symptoms can develop at any age
- Trauma may play a role in sparking symptoms
- Symptoms are due to compression of brain and spinal tissue, disruption of the natural flow cerebrospinal fluid, and increased pressure in the brain
- Some people with malformations are asymptomatic, meaning they have no symptoms
- The cognitive effects of Chiari are being researched, but are not well understood

Chiari symptoms can range from mild, to severe, to completely debilitating

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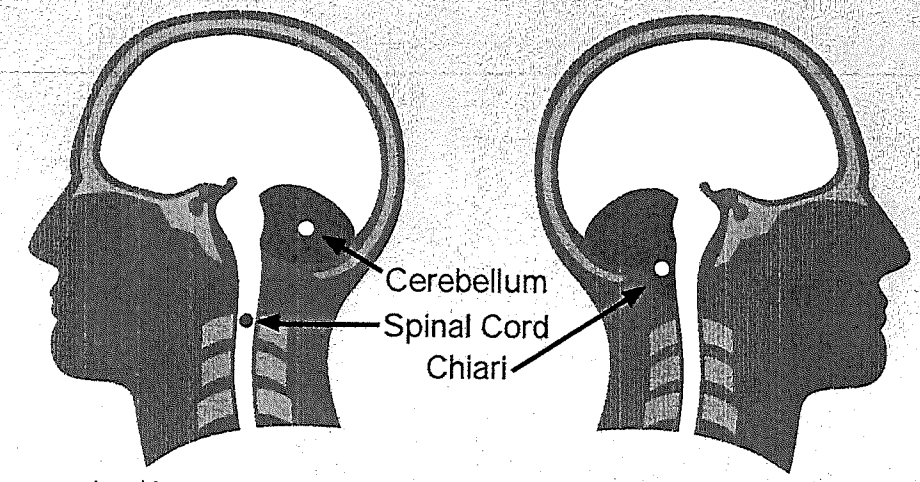
What Is Chiari Malformation?



Chiari Malformation (Arnold-Chiari) - is a serious neurological disorder where the bottom part of the brain, the cerebellum, descends out of the skull and crowds the spinal cord, putting pressure on both the brain and spine causing many symptoms.

- First identified by Hans Chiari in the 1890's
- Several types, Type I is shown above; Type II is associated with Spina Bifida
- Also known as: Chiari Malformation (CM), Arnold-Chiari Malformation (ACM), tonsillar herniation, tonsillar ectopia, hindbrain herniation

Chiari affects everyone differently!!

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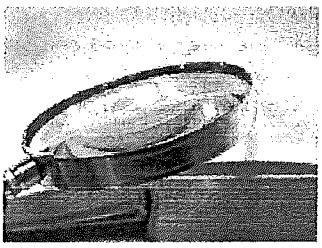
Questions About Chiari



The Importance of Education

Patient education is a powerful weapon in our battle against Chiari and syringomyelia.

An informed patient is able to intelligently select a doctor, understand the issues and choices that must be made, be proactive, and most importantly, take charge of their healthcare.

Chiari FAQ's

These FAQ's are for informational purposes only and in no way represent an attempt to provide medical advice. This information may or may not apply to your case and anyone with a question or concern about their health is strongly encouraged to consult with a medical professional.

Syringomyelia FAQ's →

1. What is a Chiari Malformation?

Chiari Malformation Type I (CM) is a neurological disorder where part of the brain, the cerebellum (or more specifically the cerebellar tonsils), descends out of the skull into the spinal area. This results in compression of parts of the brain and spinal cord, and disrupts the normal flow of cerebrospinal fluid (a clear fluid which bathes the brain and spinal cord).

2. Is Arnold-Chiari different from Chiari?

Not everyone uses the same terminology when describing Chiari. Some people use Arnold-Chiari (ACM) interchangeably with Chiari. Others only use Arnold-Chiari to refer to Chiari Type II which involves more of the brain descending out of the skull, is predominantly diagnosed in children, and is commonly associated with Spina Bifida. Other terms for Chiari include tonsillar ectopia and hindbrain herniation, meaning the cerebellar tonsils are out of position.

3. What are the symptoms?

Because Chiari involves the nervous system, symptoms can be numerous and varied. In fact, one large study showed that the vast majority of Chiari patients reported 5 or more symptoms, and 49 distinct symptoms were reported by 2 or more patients. Despite this variety, the most common Chiari symptom, and the hallmark of the disease, is a headache. Usually, the Chiari headache is described as an intense pressure in the back of the head and is brought on, or aggravated, by exercise, straining, coughing, sneezing, laughing, bending over, or similar activities. Other common symptoms include balance problems and fullness in the ears. In very young children, trouble swallowing is one of the most frequent symptoms. When thinking about symptoms, it is also important to keep in mind that once a person's health is compromised in one way (with Chiari for example), secondary problems are more likely to develop, especially if a person is in chronic pain. Research has shown that people with chronic pain are much more likely to develop other chronic conditions, so not every symptom may be a direct result of a Chiari Malformation.

4. Does the size of the malformation matter?

Traditionally, Chiari Malformation has been defined as the cerebellar tonsils descending more than 3-5mm out of the skull. However, research has shown there is no real correlation between the amount of descent (or herniation) and clinical symptoms. Some people with herniations of less than 3mm are extremely symptomatic and some people with quite large herniations are symptom free. Because of this, doctors are now focusing on whether the cerebellar tonsils block the normal flow of cerebrospinal fluid (CSF). The current theory is that disruption of CSF flow is a more important measure than the size of the herniation.

risks and potential outcomes of surgery. Many of the complications of decompression surgery have to do with opening the dura and research has shown that opening the dura does increase the complication rate. There is a risk of infection and sometimes the patch that is sewn in leaks or becomes scarred. A more serious complication - not necessarily related to opening the dura - occurs when the brain slumps further into the spinal area after the surgery.

17. What will happen to me if I don't have surgery?

The natural progression of Chiari - as doctors call it - varies from person to person and is not well understood. For example, why do some people develop symptoms in their 30's while others have symptoms their whole life? For many people with no or mild symptoms, the symptoms will not get worse and surgery will not be necessary. However, there are also anecdotal reports of symptoms becoming rapidly worse, sometimes after a sneeze or a fall. If a patient does not have surgery, many doctors will recommend monitoring the situation with routine MRI's and neurological exams.

18. How long will it take to recover from surgery?

As to be expected, recovery will vary from person to person and will depend in part on a person's overall health and fitness before the surgery. Barring any complications, some people recover from a successful surgery in a few weeks, others take a few months, and others may take more than a year. Your doctor may suggest a physical rehabilitation program to regain strength and flexibility in your neck and may refer you to a physiatrist - a doctor of physical medicine and rehabilitation. One factor that people sometimes overlook during recovery is that if they were inactive due to severe symptoms for a long period of time prior to surgery, they will need time to regain a general level of strength and conditioning.

19. How can I find a doctor with a lot of Chiari experience?

The American Association of Neurological Surgeons (AANS) does not recognize Chiari as a sub-specialty. This, combined with liability issues and the difficulty in establishing expert-level criteria (what does it take to qualify as an expert?) make it difficult to put together a list of Chiari experts. Each person must find a doctor they are comfortable with. Some people like to see university based researchers, some would prefer a regular neurosurgeon; some are willing to travel for surgery, others aren't; some want a surgeon they can relate to, others think surgical skill is more important. When trying to find a doctor, some things to consider are how many Chiari surgeries they do a year, how many total surgeries they do a year, are they up to speed on the latest thinking on Chiari, how they relate to patients, and what type of reputation they have among patients and the medical community (this is by no means comprehensive). There is no right answer to these questions; they are just intended as a way for a patient to feel comfortable with their doctor. One way to find a doctor is to ask around. Ask people in your community, ask any medical professionals you know, or go on the internet to find what you are looking for.

20. I had surgery, but I'm still in a lot of pain. What can I do?

One possibility is to see a pain specialist. A certified pain doctor will perform a thorough examination to determine the exact cause of your pain and may recommend therapies such as acupuncture, trigger point injections, over the counter medications, or prescription medications. Unfortunately, neuropathic pain - pain caused by damage to a nerve - can be very difficult to treat. Anti-seizure drugs, like Neurontin, work for some people but can have strong side effects. Many Chiari patients have found that they must try different things and see what works best for them.

21. Am I eligible for disability?

Many people with Chiari have qualified for government disability. Some people have been able to get disability easily, while others have had to fight for it.

22. How many people have Chiari?

There is no exact answer to this, because a rigorous study to determine this has not been performed. Once thought to be rare, the increased use of MRI's has shown that Chiari is much more common than originally believed. Confusing the issue is the question of how you define Chiari. Many people may have cerebellar tonsils that descend out of the skull, but they have no symptoms and probably never will. Studies have shown the incidence of this tonsillar ectopia may be as high as .5%-.7% of the general population. However, this does not mean that all these people have Chiari. Estimates for the number of people with true Chiari range as high as 500,000 in the United States. A more conservative estimate of 300,000 would mean that 1 in 1,000 people have Chiari, or 0.1% of the population.

23. I'd like to talk with other people who have this. Is there a support group?

You can visit our Support Group page and look for a group in your area or let others know you are interested in forming a local support group.

Facebook is a great place to meet others with Chiari, check out Conquer Chiari's Facebook page to converse with other chiari patients, and for the latest information in the Chiari Community.

Additionally, the Pediatric Chiari Facebook page is a great place for parents to connect with other parents and talk about whats going on with their child.

Syringomyelia FAQ's →

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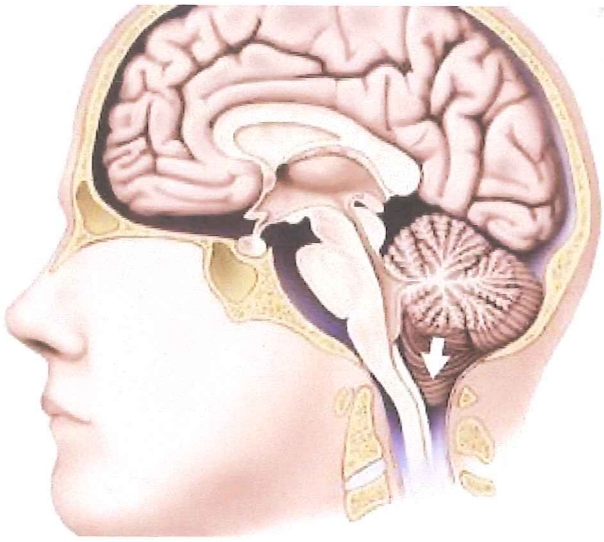

admin 18 May 2015 Arnold Chiari Malformation 0

Treating Arnold Chiari Malformation with Cannabis

Medical Cannabis use of Arnold-Chiari Malformation and Syringomyelia Sufferers

The Arnold-Chiari Malformation and Syringomyelia are conditions in which the spinal cord is affected. In cases of the Arnold-Chiari Malformation, part of the brain reaches to the spinal cord

CATEGORIES

- ALS
- Alzheimer's Disease
- Anorexia Nervosa
- Arnold Chiari Malformation
- Cachexia and Wasting Disorder
- Cancer
- Cannabis and Federal Government
- Cannabis Research
- Chronic Inflammatory Demyelinating Polyneuropathy
- Chronic Post Operative Pain

because of structural and developmental problems primarily caused at birth which resulted in a abnormally small skull. In Syringomyelia, recesses form in the spinal chord. Both of these conditions have negative side effects, but the most important one in arguing the benefits of cannabis use in patients would be the pain experienced.

Cannabis has a positive effect on patients suffering both from the Arnold-Chiari Malformation and Syringomyelia because it is a sleep aid,and has been shown to reduce suffering in those with chronic pain, which patients with these two conditions certainly do suffer from. Many of these patients also have trouble falling asleep or staying asleep due to chronic pain. Research also shows that as many as 70% of medical cannabis users report that when used as a sleep aid, cannabis promotes longer sleep, and that they fell asleep sooner if they had trouble falling asleep before. But what is the best way to use medical cannabis?

There are several different ways to administer the drug. The most popular of course is inhalation, but this can expose the body to harmful byproducts of the drug. It is suggested if this is the chosen method of administration that at least a filter be used to cut down on these byproducts. Another method, although not the best is the use of a vaporizer, which releases less toxins than smoking. Probably the best choice for patients suffering from Syringomyelia and the Arnold-Chiari Malformation would be to consume the cannabis. Consuming the drug is said to relieve chronic body pain more than vaporizing or smoking. This method is also the most effective for relieving spastic movement and for use as a sleep aid. That being said, it is very important that it is not recommended to consume just the raw cannabis plant. Cannabis by itself would be much less effective than the edibles sold in dispensaries made from the oils and byproducts of the cannabis.

Other methods of cannabis that would likely be of use to sufferers of the conditions would be medical cannabis teas and sodas. These teas and sodas are available at many medical marijuana dispensaries and offer much the same sort of pain relief, sleep aid, and anti-spasticity as consuming edible cannabis does. There are a few different ways that patients who are suffering from Syrinomyelia and the Arnold-Chiari Malformation

- Crohn's Disease
- CRPS Type 2
- Cultivation Corner
- Dystonia
- Ehler-Danlos Syndrome
- Epilepsy
- Fibrous Dysplasia
- Glaucoma
- Hepatitis C
- HIV
- Hydrocephalus
- Hydromyelia
- Illinois Cannabis Cultivation Center
- Illinois Cannabis Dispensary
- Illinois Cannabis Patient Application
- Illinois Cannabis Patients
- Illinois Cannabis Qualifying Condition
- Illinois Department of Financial and Professional Regulation

can begin to find relief from the chronic pain and every day suffering that they face.

Medical cannabis use in these patients is a natural and normal solution to the pain that Arnold-Chiari Malformation and Syrinomyelia patients suffer from every single day. It is important to seek healthy treatment to ensure healthy and happy life!

For more information visit the American Syringomyelia & Chiari Alliance Project.

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- Polycystic Kidney Disease
- PTSD
- Reflex Sympathetic Dystrophy Syndrome
- Residual Limb Pain
- Rheumatoid Arthritis
- RSD
- Severe Fibromyalgia
- Sjogren's Syndrome
- Spinal Cord Injury
- Spinocerebellar Ataxia
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- Syringomyelia
- Tarlov Cysts
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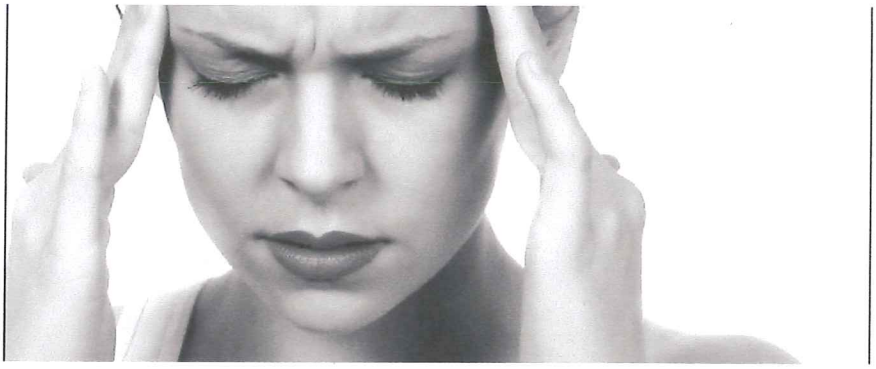

admin 18 May 2015 Migraine 0

Treating Migraines with Cannabis

Migraine

Migraines are a specific type of painful, chronic headache that typically manifest along with nausea and vomiting, visual and auditory disturbances, and sensitivity to light and sound. According to the National Headache Foundation, approximately 28 million Americans suffer from chronic migraines, with a quarter of those experiencing four or more headaches per month that can last up to three days.In addition to pounding or throbbing pain that may be increased with physical activity, migraines are

CATEGORIES

- ALS
- Alzheimer's Disease
- Anorexia Nervosa
- Arnold Chiari Malformation
- Cachexia and Wasting Disorder
- Cancer
- Cannabis and Federal Government
- Cannabis Research
- Chronic Inflammatory Demyelinating Polyneuropathy
- Chronic Post Operative Pain

characterized by light sensitivity, nausea and vomiting, dizziness, fatigue, and blurred vision. Most people experience an "aura" up to a few hours before the onset of a headache, which can include hearing strange sounds or having vision disturbance.Migraine headaches have a variety of causes, with treatment often centering around identifying and avoiding headache "triggers." These can include emotional stress; certain foods such as caffeine, alcohol, preservatives, and other ingredients; hormonal changes, especially related to menstruation; changes in barometric pressure, and fatigue. Experts believe that migraines are related to an abnormality in a specific area of the brain; approximately 80 percent of people who have migraines have another family member who also experiences these headaches.

Beyond identifying triggers, migraines are typically treated with over the counter pain medications. If these are ineffective, doctors may prescribe stronger prescription pain relievers. There are also drugs on the market that can be taken daily to prevent migraines from developing.

According to research published by The Journal of Neuroscience, cannabis not only offers relief from the chronic pain associated with migraine headaches, but may actually prevent these headaches from occurring. Other doctors agree that ingestion of marijuana can alleviate the pain of migraine headaches without the side effects associated with stronger prescription pain medication. One possible reason is that the substances called cannabinoids in marijuana have anti-inflammatory properties, so they relax blood vessels that are constricted during a headache. Marijuana is also effective in treating nausea, a common side effect of migraines.

In Illinois, medical marijuana is approved for use to treat migraine headaches; in all but one other state with medical cannabis, it is approved to treat chronic pain. While smoking marijuana is known to cause lung damage, the safest way to ingest medical cannabis is either through vaporization or edibles.

- Crohn's Disease
- CRPS Type 2
- Cultivation Corner
- Dystonia
- Ehler-Danlos Syndrome
- Epilepsy
- Fibrous Dysplasia
- Glaucoma
- Hepatitis C
- HIV
- Hydrocephalus
- Hydromyelia
- Illinois Cannabis Cultivation Center
- Illinois Cannabis Dispensary
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- Illinois Cannabis Patients
- Illinois Cannabis Qualifying Condition
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If you experience more than one headache a month, talk with your doctor. He or she can determine whether you're experiencing migraines and recommend a course of treatment.

For more information visit the American Migraine Foundation.

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Legalizing Weed: Tweets About Medical Marijuana Legalization in Illinois

By Connie Jankowski | Saturday, 04 Apr 2015 03:55 PM

Illinois House Bill 1 was passed in 2013, legalizing medical use of marijuana in that state. Today, 23 states allow the sale and use of medical marijuana, and each has specified conditions for use and purchase of the substance, also known as "weed."

Medical therapy to treat disease and/or symptoms using cannabis or any of its products, is commonly referred to as using medical marijuana. The practice has been legalized in 23 states, including Illinois, with a few stipulations in place. Users and caregivers (who can pick up the marijuana for very ill patients) in Illinois must register with the state, as stipulated on the Illinois government website.

Urgent: Should Marijuana Be Legalized in All States?

Conditions that qualify a person for medical marijuana use in Illinois are Alzheimer's disease, amyotrophic lateral sclerosis (ALS), Amold Chiari malformation, cachexia, cancer, causalgia, chronic inflammatory demyelinating polyneuropathy, Crohn's disease, dystonia, fibromyalgia, glaucoma, hepatitis C, HIV/AIDS, hydrocephalus, hydromyelia, interstitial cystitis, lupus, multiple sclerosis, myasthenia gravis, myoclonus, nail patella syndrome, neurofibromatosis, Parkinson's disease, reflex sympathetic Dystrophy (RSD), rheumatoid arthritis, Sjogren's syndrome, spinal cord disease, spinocerebellar ataxia (SCA), Tarlov cysts, Tourette's syndrome, and traumatic brain injury and post-concussion syndrome. Users are limited to purchasing two-and-a-half ounces of medical marijuana within 14 days, reports the **National Organization for Marijuana Legalization (NORML)**.

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Medical Marijuana and Hydrocephalus

What Is Hydrocephalus?

Hydrocephalus (also known as "water on the brain"), is a medical condition in which there is an abnormal accumulation of cerebrospinal fluid in the ventricles, or cavities, of the brain. This may cause increased intracranial pressure inside the skull and progressive enlargement of the head, convulsion, tunnel vision, and mental disability. Hydrocephalus can also cause death in extreme cases, but not all cases tend to be extremely severe. Although this condition does occur in older adults, it is more common in infants and younger children.

Cerebrospinal fluid normally flows through the ventricles and bathes the brain and spinal column. Too much cerebrospinal fluid associated with hydrocephalus can damage brain tissues and cause a large spectrum of impairments in brain function. These are impairments that tend to last throughout the course of the patient's condition/diagnosis.

Medical Marijuana and Hydrocephalus

The symptoms of normal pressure hydrocephalus usually get worse over time if the condition is not treated, although some people may experience temporary improvements. While the success of treatment with shunts varies from person to person, some people recover almost completely after treatment and have a good quality of life. One of the most beneficial forms of therapy for this condition would be medical marijuana.

Medical Marijuana for symptom relief of hydrocephalus may be helpful in relieving symptoms associated with this condition such as sleep apnea, chronic seizures, manic attacks (or bi-polar outbursts), chronic or debilitating pain, pain within the head or common headaches and severe or debilitating nausea.

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Cannabis has demonstrated that it can be helpful for managing some of the symptoms associated with Arnold-Chiari malformation and syringomyelia. Cannabis use is prevalent among patients with a chronic illness, and the most frequently reported reasons for use include improvements in pain, sleep and mood (Ware, et al., 2003).

The cannabinoids found in cannabis, tetrahydrocannabinol (THC) and cannabidiol (CBD), are effective at lowering pain levels associated with a wide variety of conditions, including spasticity, headache, migraines, and other acute pain and chronic pain conditions (Jensen, Chen, Furnish & Wallace, 2015) (Baron, 2015).

Cannabis has been long known to help with sleep. One survey study analyzing cannabis' effect on patients of chronic illnesses found that 75% to 84.2% of respondents reported that cannabis "slightly/much better" improved their sleep. Users are able to fall asleep faster and sleep longer (Tripp, et al., 2014).

There's also strong evidence that suggests that cannabinoids contained in cannabis reduce muscle tremors and spasticity because of their activation of the cannabinoid receptors, CB1 and CB2, of the endocannabinoid system (Pertwee, 2002). The CB1 and CB2 receptors regulate the excitatory and inhibitory neurotransmitters necessary to curtail spasms (Syed, McKeage & Scott, 2014) (Smith, 2002).

States That Have Approved Medical Marijuana for Arnold-Chiari Malformation and Syringomyelia

Currently, the only state to have approved medical marijuana for the treatment of Arnold-Chiari malformation and syringomyelia is Illinois. However, other states allow medical marijuana to treat some of the symptoms commonly associated with the Arnold-Chiari malformation and syringomyelia.

Several states have approved medical marijuana specifically to treat "chronic pain." These states include: Alaska, Arizona, California, Colorado, Delaware, Hawaii, Maine, Maryland, Michigan, Montana, New Mexico, Ohio, Oregon, Pennsylvania, Rhode Island and Vermont. The states of Nevada, New Hampshire, Ohio and Vermont allow medical marijuana to treat "severe pain." The states of Minnesota, Ohio, Pennsylvania and Washington has approved cannabis for the treatment of "intractable pain."

Fifteen states have approved medical marijuana for the treatment of spasms. These states include: Arizona, California, Colorado, Delaware, Florida, Hawaii, Maryland, Michigan, Minnesota, Montana, Nevada, New Hampshire, Oregon, Rhode Island and Washington.

A number of other states will consider allowing medical marijuana to be used for the treatment of Arnold-Chiari malformation and syringomyelia with recommendation by a physician. These states include: California (any debilitating illness where the medical use of marijuana has been recommended by a physician), Connecticut (other medical conditions may be approved by the Department of Consumer Protection), Massachusetts (other conditions as determined in writing by a qualifying patient's physician), Nevada (other conditions subject to approval), Oregon (other conditions subject to approval), Rhode Island (other conditions subject to approval), and Washington (any "terminal or debilitating condition").

In Washington DC, any condition can be approved for medical marijuana as long as a DC-licensed physician recommends the treatment.

Recent Studies on Cannabis' Effect on Arnold-Chiari Malformation and Syringomyelia

One survey study found that for most, using cannabis improves mood, pain, muscle spasms, and sleep.
A survey of cannabis (marijuana) use and self-reported benefit in men with chronic prostatitis/chronic pelvic pain syndrome. (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4277530/)

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Mechanics

Brain volume, blood volume and CSF volume determine intracranial pressure (ICP). If one of these goes up, pressure in the brain will rise unless one of the others compensates by decreasing. In hydrocephalus, this balance is distorted and an unnatural condition takes place. Under normal conditions, a person should have one ounce of spinal fluid in the ventricles and about four ounces of spinal fluid around the outside of the brain. When all the components of the brain are functioning normally, without a shunt, the brain has the ability to be elastic. That is, an increase in volume means an increase in pressure (and vice versa), the brain is compliant, or able to adapt. When a shunt is in place, the brain's normal ability to compensate for things that we normally do like cough, or strain at stool, disappears.

Additionally, when we enter REM sleep, about 80-90 minutes after we fall asleep, plateau waves and high intracranial pressure (CIP) develop. In patients with shunts who undergo ICP monitoring overnight, those changes are dramatic. The normal things that cause pressure to go up create huge changes in the ICP of people who have been shunted. Under REM sleep, the normal rise of the ICP pressure is absent and is accentuated by the fact that there is no compliance. That is, there is no extra spinal fluid in the brain to be able to be displaced.

The placing of a shunt creates an unnatural situation. The brain fills the intracranial space while the shunt drains essentially all of the available CSF from the ventricles. The result is a large brain in a fixed (NOT elastic) solid skull, with very little room for changes in intracranial pressure. If changes in cerebral blood flow occur, resulting in increased blood volume in the intracranial space, then increased intracranial pressure will result, possible causing a headache.

Headaches can be related to the altered pressures inside the skull once the shunt is place. They can occur when the intracranial pressure is too high, and also when the intracranial pressure is too low. And what's too high for one person can be too low for another.

Treatment

Children and adults with hydrocephalus have headaches, just like everyone else. It is the frequency and severity, suggests Dr. McComb, that determines the possible relationship between hydrocephalus and headaches. "If the headaches are getting progressively worse, many time it's (due to) an intermittent malfunction of the shunt. We change the proximal end of the shunt and that's it. (The upper end of the shunt is the proximal end, and the bottom end is the distal.) "Just because a CT scan does not show enlarged ventricles does not mean that the shunt is not working. In a given percentage of cases, the ventricles are going to remain the exact same size whether the pressure is normal or elevated," adds Dr. Rekate.

With slit ventricle syndrome, argues Dr. McComb, small ventricle size is not the problem. The problem occurs if the shunt clogs and the ventricles don't dilate (get larger). If this happens repeatedly, and headaches accelerate, it often means that there is a blockage of the shunt that builds up and then releases, and builds up and releases. Again, replacing the proximal ventricular catheter, the part of the shunt that is plugged, often takes care of the problem, and relieves the headache.

One of the things that both Drs. Rekate and McComb recommend is sketching out a plan of action. This involves a patient-doctor conference where a time line and course of action are established. "We'll set up parameters and if these parameters are exceeded, then we'll go ahead and

12. How is Chiarl treated?

If the symptoms aren't severe, doctors may recommend just monitoring the situation with regular MRI's and treating the symptoms individually. However, if symptoms are interfering with quality of life, are getting worse, or if the nervous system is being impaired, doctors may recommend surgery. The most common surgical treatment, performed by a neurosurgeon, is known as decompression surgery (see details in Question 14). An alternative surgery involves placing a shunt (a tube like device) to channel the flow of CSF and relieve pressure

13. How do I know whether to have surgery?

The decision whether to have surgery is up to each individual and their doctor. Some of the factors that are considered are the severity of symptoms, whether the symptoms are getting worse, whether the nervous system is being compromised, whether there are any complicating issues, and the surgeon's own experience and judgment. Unfortunately, there is no single, objective measure to say whether someone should have surgery and many patients will find that different doctors may have different opinions. Some doctors are more aggressive in their treatment approach and some are more conservative. A recent survey about when to recommend surgery showed that there was general agreement among surgeons in the extreme cases - no or mild symptoms, don't operate; severe, progressive symptoms or syringomyelia, operate - but there was little agreement in the middle. In one of the survey's hypothetical cases, the surgeons were split almost evenly down the middle on whether to operate or not.

14. What is the surgery like?

Decompression surgery is a general term used to refer to any of a number of variations on the same basic procedure. The goal of the surgery is to create more space around the cerebellar tonsils and restore the normal flow of CSF. The procedure involves removing a piece of the skull in the back of the head near the bottom (craniectomy). Often part of the top one or two vertebra are also removed (laminectomy). At this point, depending on the individual case and doctor, some doctors will also open the covering of the brain, the dura, and sew a patch in to make it larger (duraplasty). There are many variations in how the surgery is performed, including (but not limited to) how much bone to remove, whether to open the dura, what type of material to use for a dural patch, whether to shrink or remove the cerebellar tonsils, and whether to replace the missing piece of skull with anything. Unfortunately, there is no consensus, and no strong evidence, on which technique(s) is the best. Because of this, it is important for patients to understand specifically what their surgeon will be doing and why. The procedure itself lasts several hours and most people will spend a night in the ICU and an additional couple of days in the hospital.

15. Is the surgery always successful?

As with any surgery, the chance of success depends on the individual case, so each person should ask their doctor what their chance of having a successful surgery is. It should be noted that success can mean different things to different people, so it is best to ask specific questions such as what are the odds I will be symptom free; what are the odds I will be mostly better; and what are the odds I will get worse.

Unfortunately, there is not a lot of strong surgical outcome research, but there are enough reports to get a general idea of the overall success rates. For patients with just Chiari (no syringomyelia), up to 50% become symptom free after surgery, with another 10%-30% improving significantly. On the flip side, for 10%-20%, the surgery will be a failure and they will likely require additional surgeries. Keep in mind these are not scientific numbers and each patient should discuss their own chance of success with their doctor.

16. What are the possible complications of surgery?

This is another question that is important for every patient to ask their doctor so that they fully understand the

5. How is a Chiari Malformation diagnosed?

An MRI (Magnetic Resonance Imaging - a non-invasive test which uses a large magnet to create a picture of internal organs) can clearly show if the cerebellar tonsils are out of position. However, since the definition of Chiari is changing, most doctors will use a combination of reported symptoms, a neurological exam, MRI results, and their experience and judgment to determine if a person has Chiari. Unfortunately, there is no single, objective test which can clearly say that someone has a Chiari malformation which is causing problems.

6. What is a cine MRI?

Cine MRI is a type of MRI where the machine is programmed to measure the flow of cerebrospinal fluid (CSF). Doctors use this to see if the cerebellar tonsils are blocking the normal flow of CSF from the brain to the spinal area and back. While many doctors now consider cine MRI to be a routine test in diagnosing Chiari, some experts question it's usefulness and are reserving judgment.

7. What is a borderline Chiari?

Since Chiari was traditionally defined based on the size of tonsillar herniation, a borderline Chiari can refer to when the cerebellar tonsils are descended only a couple of millimeters out of the skull. Alternatively, borderline Chiari can refer to someone with mild symptoms which may not be directly attributable to Chiari.

8. How did I get this condition?

Chiari was originally thought to be a congenital condition - meaning you are born with it. While this may be true for many people, published case studies have also demonstrated that Chiari can be acquired and even reverse itself if the source of the problem is removed. It is not known how many cases are congenital and how many are acquired. Complicating the situation is that for reasons that aren't clear, some people develop symptoms as children, and some people develop symptoms as adults. What triggers symptoms is not fully understood.

9. I don't have any symptoms, but an MRI shows a malformation. What does this mean?

This is sometimes referred to as an incidental finding. Someone has an MRI for an unrelated reason, but it shows a Chiari malformation - meaning the cerebellar tonsils are descended - yet the person has no Chiari type symptoms. As MRI's become more common, this is happening more frequently and is one reason that diagnosing Chiari can be difficult and can not be based on an MRI alone.

10. Does Chiari run in families?

An ongoing study at Duke University has identified more than 100 families where two or more members are affected by Chiari. This implies that for some cases there is a genetic basis for Chiari. It is not known, however, what percent of cases may have a genetic component. In other words, this does not mean that the family of everyone with Chiari is carrying a Chiari gene.

11. Will my children get it? Is there a genetic test to see if someone has Chiari?

A Chiari gene has not yet been identified, so there is currently no genetic test.