Newsletter for June 2019

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News from around our organizations and our members:

Save the date for our annual meeting October 11-12, 2019 at the Radisson in Madison.

Save the date for the DQA’s annual FOCUS conference November 20-21 at the Kalahari in Wisconsin Dells. This year’s special session will be “Let’s Talk About It: Topics Too Important to Ignore” including sexual expression, abuse and resident rights—Teepa Snow will deliver the keynote address “Dementia 360”.

Save the date for AMDA’s annual meeting April 2-5, 2020 at the Hyatt Regency in Chicago.

Other News from around our state and our partners. There is a link in this to get the AMDA guidelines free on-line; you need the AMDA guidelines free on-line.

The Nursing Home team wants to ensure you are aware of important new resources, updates and webinars.
Upcoming Webinars

**Success Stories Webinar Series | Achieving Community Goals by Partnering with Aging and Disability Resource Centers**
Tuesday, June 25, Noon - 1:00 p.m. CT
Aging and Disability Resource Centers (ADRCs) are key partners in many communities. Their collaborations with other community organizations have been proven to be successful in bringing about effective community change.

Past Recorded Events

**Pressure Inj**
A wonderful presentation by Dr. Joyce Black, a leading expert in pressure injuries. This covers intervention and sustainment strategies.

**Trauma Informed Care (TIC) in Long Term Care (LTC)**
Presented by Scott Webb, the TIC Coordinator in Wisconsin, this presentation is a great overview of TIC including key concepts and terminology to prepare you and your staff for the new regulations in November.

**Achieving Psychotropic Medication Reduction in Long Term Care**
From our partners in Michigan, a well-done series of five short videos entitled "Reducing Psychotropic Medication Use". Great for just-in-time training! Learn more about our national partnership to improve dementia care.

Resources

**Dementia/Antipsychotics**
- [Dementia Capable Wisconsin](#)
- [Person Directed Care Assessment Tool](#)
- [The DICE Approach™](#)
- [IA ADAPT Improving Antipsychotic Appropriateness in Dementia Patients](#)
  (Registration is free)

**Clinical Resource Center (CRC) AMDA Updates**
The CRC is a great site for evidence-based tools/resources including pain, medication management, diabetes, chronic obstructive pulmonary disease (COPD) and pain. Create and account to access all the materials.

Please let us know if there are additional resources you may need, or if we can be of assistance in some other way.

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From the Trenches: questions about the meaning of PA/LTC life:

“I attended the AMDA State Chapter Open Mic Conference Call on May 29. Here are the highlights for you to know and use:

- The AMDA IOU (Improving Outcomes in UTI) tool kit is available for downloading on the internet. You are encouraged to use this!
- AMDA webinars are free for members, $99 per session for non-members. Previous webinars are archived. CME, CMD, and ABIM MOC credits are available. The schedule is on the AMDA website, paltc.org (Post-Acute and Long-Term Care). The next webinar is on June 26, the topic is "Integration of Medical Marijuana in Long Term Care: Positives and Pitfalls".
- AMDA has on-the-go podcasts (short reports on various PALTC issues) and on-the-hill podcasts (legislative issues) on their website. These are very informative. Please check them out.
- DO NOT adjust or alter a diagnosis of dementia to schizophrenia in order to justify use of an antipsychotic. Several physicians across the country are getting cited for misdiagnosis.
- Several state legislatures are now pushing through legislation requiring informed consent for nursing home patients for prescription of antipsychotic/anxiolytics/antidepressants. Several high ranking AMDA members are vehemently opposed to the legislation of physicians’ prescribing patterns. I reported that this has been the lay of the land in the Badger State for many years.
- The next upcoming controversy for which you should prepare: remote video recording of residents in their rooms. Multiple legal/ethical/privacy issues involved.
- Enjoy your summer! Don’t text and drive! Join us for our annual conference in Madison, October 11-12. We have a great list of speakers.”

Ron Schreiber, MD, CMD
President, WAMD

Other Reviews: publications from around the world of geriatrics and PA/LTC

Can CBD Really Do All That? How one molecule from the cannabis plant came to be seen as a therapeutic cure-all.


When Catherine Jacobson first heard about the promise of cannabis, she was at wits' end. Her 3-year-old son, Ben, had suffered from epileptic seizures since he was 3 months old, a result of a brain malformation called polymicrogyria. Over the years, Jacobson and her husband, Aaron, have tried giving him at least 16 different drugs, but none provided lasting relief. They lived with the grim prognosis that their son — whose cognitive abilities never
advanced beyond those of a 1-year-old — would likely continue to endure seizures until the cumulative brain injuries led to his death.

In early 2012, when Jacobson learned about cannabis at a conference organized by the Epilepsy Therapy Project, she felt a flicker of hope. The meeting, in downtown San Francisco, was unlike others she had attended, which were usually geared toward lab scientists and not directly focused on helping patients. This gathering aimed to get new treatments into patients’ hands as quickly as possible. Attendees weren’t just scientists and people from the pharmaceutical industry. They also included, on one day of the event, families of patients with epilepsy.

The tip came from a father named Jason David, with whom Jacobson began talking by chance outside a presentation hall. He wasn’t a presenter or even very interested in the goings-on at the conference. He had mostly lost faith in conventional medicine during his own family’s ordeal. But he claimed to have successfully treated his son’s seizures with a cannabis extract, and now he was trying to spread the word to anyone who would listen.

The idea to try cannabis extract came to David after he found out that the federal government held a patent on cannabidiol, a molecule derived from the cannabis plant that is commonly referred to as CBD. Unlike the better-known marijuana molecule delta-9-tetrahydrocannabinol, or THC, CBD isn’t psychoactive; it doesn’t get users high. But in the late 1990s, scientists at the National Institutes of Health discovered that it could produce remarkable medicinal effects. In test tubes, the molecule shielded neurons from oxidative stress, a damaging process common in many neurological disorders, including epilepsy.

Jacobson had a Ph.D. in neuroscience. She had started her postdoctoral research at the University of California, San Francisco, by studying how cancer cells metastasize and spread, but after Ben was born, she moved to Stanford and switched her focus to epilepsy — a shift that compounded her anguish. She often wept in the parking lot before heading into the lab, overwhelmed by dread at the prospect of deliberately causing epilepsy in rodents. “I couldn’t watch animals seize all day and then watch Ben seize all night,” she told me. “It was just too much.”

After meeting David and reading through the small body of published work on CBD, Jacobson changed postdoctoral directions once again, from primary research to the study of this community of parents who were treating their epileptic children with cannabis extracts. In reality, she was preparing to join it herself. One small, double-blind study particularly caught her attention. In 1980, scientists in Brazil treated eight epileptic patients with CBD and eight patients with sugar pills as a placebo. For half the group that received CBD, the seizures almost completely disappeared; another three experienced a reduction in the intensity of their seizures. Only one person in the placebo group got better.
The epilepsy drugs that had been approved to date, none of which had helped Ben much, typically targeted the same few ion channels and receptors on the surface of neurons. But CBD worked on different and still somewhat mysterious pathways. If she could find a suitable CBD extract, Jacobson thought, she might have a truly new class of drug for Ben. The other experimental drugs and devices she had heard about at epilepsy conferences were under development, unapproved by the F.D.A. and thus largely unavailable. But medical marijuana had been legal in California since 1996, so CBD was theoretically accessible right away.

Seven years later, cannabidiol is everywhere. We are bombarded by a dizzying variety of CBD-infused products: beers, gummies, chocolates and marshmallows; lotions to rub on aching joints; oils to swallow; vaginal suppositories for “soothing,” in one company’s words, “the area that needs it most.” CVS and Walgreens each recently announced plans to sell CBD products in certain states. Jason David now sells a cannabis extract called Jayden’s Juice, named for his son — one of several extracts on the market, including Haleigh’s Hope and Charlotte’s Web, that are named after children who are said to have benefited from being treated with CBD.

Many of these products are vague about what exactly CBD can do. (The F.D.A. prohibits unproven health claims.) Yet promises abound on the internet, where numerous articles and testimonials suggest that CBD can effectively treat not just epilepsy but also anxiety, pain, sleeplessness, Crohn’s disease, arthritis and even anger. A confluence of factors has led to this strange moment. Plenty of legitimate, if still inconclusive, research is being done on CBD. Many scientists are truly excited about it. The laws governing cannabis and its chemical components have loosened up. And the anecdotes that have emerged from what Elizabeth Thiele, an epileptologist at Harvard, calls the “vernacular” cannabis movement have lent emotional force to the claims made for CBD.

Amid the current deluge of products, it now seems almost quaint that, back in 2012, after deciding to try treating Ben with CBD, Jacobson couldn’t actually locate the stuff. Other parents of epileptic children were using D.I.Y. techniques to treat their children: tinctures; cannabis-infused butter in baked goods; crushed cannabis buds in capsule form; even cannabis suppositories. Some reported positive results. Over the years, Jacobson has had many of these products tested at labs; almost invariably they contained very little or no CBD and too much THC. It has psychoactive effects, and there wasn’t much science suggesting THC could treat seizures.

[Redacted for citation; you can find the full text on line, or contact me]

CBD is not always an unqualified success, even in the best-known case studies. For Sam Vogelstein, the inspiration behind Epidiolex, it helped control his seizures for years, limiting them to around six per day. But in the fall of 2015, Sam began suffering from a new type of seizure. These were more severe, causing him to fall to the floor writhing, which hadn’t occurred in the past. “You instantly understand why people used to say that people who have
epilepsy are possessed by the devil,” Fred, Sam’s father, told me, “like some external force has taken control of this person.”

Higher doses of Epidiolex didn’t help, so Sam’s doctor, the neurologist Roberta Cilio, recommended an anti-seizure drug called Depakote. He had taken it before, without benefit, but this time, in combination with Epidiolex, it worked wonders: Sam has been completely seizure free for more than three and a half years. He’s a tall, lanky 17-year-old who likes to fence, run and engages in “normal aggravating boy teenager stuff,” his father says — and “cause for celebration,” both parents say.

Ben Jacobson’s condition is more ambiguous. In an effort to stop the seizures, doctors surgically removed half of Ben’s parietal lobe in 2015, but the procedure didn’t mitigate the epilepsy. His doctor, Cilio, didn’t think the Epidiolex was aiding him, either, and recommended he stop taking it. Jacobson, who like many mothers of epileptic children keeps a detailed diary about seizure activity, disagreed. By her count, the number of Ben’s seizures had declined by 40 percent while on Epidiolex, particularly the severe grand mal seizures that caused him to stop breathing.

This disagreement between doctor and mother prompted Jacobson to find a new neurologist who, she told me, took one look at Ben and told her to do whatever she felt might help. Except for a few breaks, Ben, who’s now 10 and can’t walk unaided, has remained on Epidiolex, but his prognosis isn’t great. “He’s still going downhill,” Jacobson told me. “His life expectancy is short enough that we don’t like to think about it.”

Charlotte Figi, now 12, continues to be almost entirely seizure-free. She’s developmentally delayed, Paige Figi told me. And she suffers from osteoporosis caused, Figi thinks, by the high doses of steroids she took to control seizures at a young age. But she is otherwise a happy, playful girl, Figi says. And what Figi discovered about CBD on Charlotte’s behalf came in handy for Charlotte’s fraternal twin sister, Chase.

Two years ago, Chase, who until then had exhibited no problems, began to have seizures out of the blue. Figi didn’t even bother with allopathic drugs this time. She turned straight to the Charlotte’s Web CBD extract, and the seizures stopped. “If I hadn’t done this,” Figi says — that is, experiment with CBD extracts on Charlotte — “Charlotte would be dead. And Chase would now be starting all those drugs.”

Meanwhile, as the science inches forward, CBD has become a pop-culture phenomenon. Kim Kardashian recently hosted a CBD-themed baby shower. In April, Carl’s Jr. tested a CBD-infused burger in Colorado. Some scientists are concerned by how far the CBD craze has moved beyond the science. But Staci Gruber, associate professor of psychiatry at Harvard Medical School, does not think the two are necessarily in conflict. This might seem odd, given her work. She has found that recreational users, particularly those who begin using cannabis earlier in life, exhibit some cognitive difficulties and altered brain structure and function.
In 2014, Gruber started the Marijuana Investigations for Neuroscientific Discovery, or MIND, program to examine the effects of medical cannabis, and so far, she has found exactly the opposite in people who use cannabis as medicine. Their cognitive function appears to improve over time and preliminary evidence suggests that, after initiation of medical-cannabis treatment, their brain activity begins to normalize. Although Gruber is not certain what accounts for the contrasting effects, she has several theories. Seeking a euphoric high, recreational users often gravitate toward products higher in THC. Medical patients, meanwhile, want to control symptoms and may thus seek whole-plant products that not only contain more CBD than what recreational users typically encounter but also other potentially healthful cannabinoids. Medical users tend to be older, too, and some evidence suggests that THC is less toxic to older brains than younger and may in some cases benefit older brains.

Gruber has likewise observed that medical cannabis patients tend to reduce their use of conventional medications over time, which might itself be beneficial to brain structure and function. Whatever the explanation, Gruber believes greater scientific engagement with the CBD phenomenon is as important as more careful regulation. “People have been using cannabis forever,” she told me. “The question now is, how do we as scientists catch up?”

**Reflections**
Sandra Draus (center), one of ten honorees of the Wisconsin State Journal’s “Celebrate Nurse’s Week” shown with her collaborating physician T R Flygt, MD and manager Deirdre Suchomel.

The Wis-PALTCM Mission Statement

It will be the purpose of this organization:

• To promote quality and compassionate medical care for patients of all ages in post-acute and long-term care.
• To establish better communication among physicians serving as medical directors and other providers.
• To promote better communication between medical directors and (a) other post-acute and long-term care professionals, (b) various long-term care associations, and (c) officials of various government agencies.
• To represent medical directors in defining their roles and equitable compensation.
• To serve as a conduit between AMDA and the WAMD membership.
• To conduct continuing education programs, emphasizing the area of geriatrics and post-acute and long-term care.
• To promote a better understanding by the public of issues concerning the post-acute and long-term care facilities and residents.
• To support evidence-based treatments and best practice policies to manage post-acute and long-term care facilities.

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