

## PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

### MESSAGE

PRESIDENT'S

**P**RO is really percolating with new Projects, Referrals, Opportunities along with information, inspiration, hope, and encouragement.

The Partnership with **MACY'S SHOP FOR A CAUSE** has a new twist that offers huge support for PRO. Read the details here: As we continuously work to support the PRO mission ensuring "No one is isolated because of Parkinson's", we can't forget to HAVE FUN along the way...

Our **PINOT'S PALETTE FOR PRO** event is almost sold out! Just a few spaces available, so see page 7 for details.

The **BELMONT CAR SHOW** in Long Beach, California *is always fun!* September 10 marks our 9th year having a booth and sharing the good work of PRO with new friends. Mark your calendars for a wonderful experience and come visit us.

The **BIG** news is our **ON THE ROAD TO THE CURE symposium October 28th**. We are in the planning stages of an exciting, informative full day of presenters, an impressive roster of **Wellness Village** booths and representatives, a VIP reception on the 27th, and a wonderful evening of fine food and entertainment on the 28th. Meet and talk with the experts, ask questions and leave the symposium informed and inspired. Registration details will be coming soon. Check our website under Special Events, and also on Facebook, Linked-In and Twitter. All the details will be in our Newsletter as well.

Our **NEW WEBSITE** is scheduled to launch September 1st! Every part of our information-filled site is being redesigned with YOU, the viewer, in mind and we can hardly wait to share it. Finding the information you need, connecting with professionals in the **WELLNESS VILLAGE** that understand the Parkinson's journey and being motivated and inspired will be **easy** and enjoyable.

To keep everything moving forward, providing exceptional communication and personnel to answer the needs of our community is indeed costly. Without YOU we could not do what we do. Thank You for your tax-deductible donations which gives us the opportunity to help: MORE people, MORE often, MORE timely, with MORE information in a MORE compassionate way. We know we are providing valuable information and support in the Parkinson's community. Please keep giving, as we continue to appreciate your monthly or general donations through our safe PayPal donation page at [ParkinsonsResource.org/contribute-2/](http://ParkinsonsResource.org/contribute-2/) or by mail to our office in Palm Desert, California.

Check out **Alpha-Synuclein and Multiple System Atrophy**, in this month's Update on **ROAD TO THE CURE** on this page.

We know you will find other articles of interest and effective use such as; **DEWM FILES PAPERWORK TO SECURE INTELLECTUAL PROPERTY RELATED TO CANNABINOIDS AND PARKINSON'S DISEASE** on page 2; **HOSPICE AND PALLIATIVE CARE: DID I WAIT TOO LONG FOR THEIR SERVICES?** by Dr. Howard Cohen of Family Hospice Care, a New & Renewed Wellness Villager, on page 3; Is it Parkinson's

cont. on page 7

### UPDATE ON PARKINSON'S "ROAD TO THE CURE" PROJECT

*The results are ground-breaking Alpha-Synuclein and Multiple System Atrophy*

The often misdiagnosed as Parkinson's, Multiple System Atrophy (MSA) is a rapidly progressive, fatal neurodegenerative disorder. The disease typically affects individuals between the age of 50 and 75 years of age and is characterized by a combination of autonomic dysfunction and motor abnormalities. The disease causes rapid deterioration of the central nervous system with a median survival of 6-10 years. The incidence rate is 3 per 100,000 individuals annually.

In 2007, MSA disease was divided into two categories: MSA-P and MSA-C. MSA-P denotes patients predominantly exhibiting Parkinson's-like symptoms, including postural rigidity and instability, bradykinesia, and tremor. MSA-C encompasses patients with more prominent cerebellar symptoms, including gait and limb ataxia (*the loss of full control of bodily movements*) with cerebellar dysarthria (*difficult or unclear articulation of speech that is otherwise linguistically normal*) associated with oculomotor dysfunction (*a fairly common eye problem in which people are unable to follow a moving object accurately or unable to quickly shift their eyes from one point of fixation to another (saccadic fixation is necessary for tracking skills while reading or copying)*). In addition to the parkinsonian and cerebellar manifestations, patients with MSA may also exhibit other neurological abnormalities, such as pyramidal signs and stupor. Autonomic manifestations may include a wide range of symptoms, such as cardiovascular, genitourinary (*relating to the genital and urinary organs*), and thermoregulatory (*a process that allows your body to maintain its core internal temperature*), but the defining autonomic features are orthostatic hypotension or autonomic urinary abnormalities.

Like Parkinson's disease (PD), the neurodegenerative MSA disease rises from the misfolding and accumulation of the protein alpha-synuclein in glial cells that surround and provide support to neurons. Alpha-synuclein aggregates isolated from MSA patient samples were shown to infect cultured mammalian cells and to transmit the neurological disease to transgenic mice. These findings argue that alpha-synuclein becomes a prion (*prions are infectious agents composed entirely of a protein material that can fold in multiple, structurally abstract ways, at least one of which is transmissible to other prion proteins, leading to disease in a manner that is epidemiologically comparable to the spread of viral infection*). A 2015 study concluded that multiple system atrophy (MSA), a rare human neurodegenerative disease, is caused by a misfolded version of a protein called alpha-synuclein, and is therefore also

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# OUR WELLNESS VILLAGERS:

## ACUPUNCTURE

- Dr. David Shirazi

## ADAPTIVE CLOTHING

- Health Aides Made Easy



## AROMA THERAPY

- Renee Gauthier

## ASSISTIVE TECHNOLOGY

- California Phones

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- Brain Optimizers

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- Gentiva Hospice (regional)
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## LSVT BIG PROGRAM

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- Rosi Physiotherapy



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- In & Out Mobility

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## DEWM FILES PAPERWORK TO SECURE INTELLECTUAL PROPERTY RELATED TO CANNABINOIDS AND PARKINSON'S DISEASE

NEW ORLEANS, LA – (Marketwired - Jul 24, 2017) – Dewmar International BMC, Inc. (OTC PINK: DEWM) today announced that it has filed documents with the United States Patent and Trademark Office for the treatment of Parkinson's disease with cannabinoids.

Medical Marijuana has over 100 molecules or cannabinoids within the plant that in the right combinations or using the right delivery methods, can be used to treat anything from cancer to Parkinson's disease. It is Dewmar's goal to utilize the experience and the education of its CEO, Marco Moran DPh, MBA to commercialize its intellectual property assets related to marijuana and most importantly, the precise delivery of medical marijuana and its constituents and/or byproducts to bring a new era in targeted therapeutics to improve patient care and outcomes.

Marco Moran, CEO of Dewmar International, commented, "Research suggests two problems persist with medicines used to treat Parkinson's disease today; 1) low metabolic absorption of the medicine by the human body and 2) severe side effects. Cannabinoids may prove to be more effective in some instances with fewer side effects when compared to common medicines used to treat Parkinson's disease. So, our goal is to utilize our patent pending technology to deliver effective cannabinoids to Parkinson's patients with a rapid onset of action and high bioavailability. This is the essence of the intellectual property that we are seeking to protect."

## HOSPICE AND PALLIATIVE CARE: DID I WAIT TOO LONG FOR THEIR SERVICES?

Dr. Howard Cohen, Medical Director for Family Hospice Care

The very first hospice patient I ever cared for (about 15 years ago) was a 64-year-old male with advanced cancer. He and his wife lived in Orange County, CA and lived in an upscale neighborhood in a beautiful home on a golf course. He had battled cancer for about two years and had undergone surgery, chemotherapy, and radiation. His cancer had spread throughout his body and was now in his final days of life. His oncologist had exhausted all traditional treatment but his cancer had come back with a vengeance. So he was referred to a clinical trial which was not effective and had caused several intolerable side effects and was therefore discharged from the trial. His wife said that he had suffered from many of the traditional treatments as well but, initially, he wanted to fight the cancer and "beat it". His oncologist continued to offer other treatments and he reluctantly accepted them despite suffering ill side effects from previous chemotherapeutic medication and radiation. By the time he was referred to hospice, he was extremely weak, bed-bound, and eating very little. He was dehydrated and having abdominal pain along with severe nausea. The hospice team immediately supplied an electric hospital bed and other equipment to assist with his comfort at home. He and his wife chose to put the bed (and all of the comfort equipment) in the main living room so he could be a part of all activity and not feel cloistered to a bedroom and isolated. Aggressive comfort medications were instituted as agreed upon by the patient (and his wife) which included pain medication, anti-nausea medication, and medication for anxiety. He also continued some of his usual medications including medications for his diabetes of which the hospice team assisted in monitoring his blood sugars as he was at great risk for low blood sugar (hypoglycemia) which could cause very serious side effects. We even offered and he accepted an antidepressant since he mentioned he felt "down". During the first 72 hours of his admission to hospice, the entire hospice team had contacted him, including me, to offer him, his wife, his family, and caregivers our support and service. After 24 hours, his symptoms were well controlled and he was comfortable. He passed away five days after being admitted to hospice services. I had visited him a couple of times and during my second visit, his wife asked me "why wasn't he referred to hospice sooner?" She had remarked that the hospice team was able to make him comfortable as well as offer support to her. She said she could have had him home and enjoy their life together spending time going places and visiting friends and family as opposed to running around to different medical appointments during his last few months.

I didn't realize how important her question was. Now, after being a hospice physician for almost 15 years, that question is still asked by many patients and their families. I think that one of the most common reasons that there is a delay in referral to hospice or palliative care is a poor understanding of what hospice and palliative care actually can do for end stage disease (cancer and non-cancer diseases). Many people, including some physicians, think that hospice is for people who are close to death. But that is not actually true. Hospice in the USA is a service to assist patients, where they live, who have a disease or condition who most likely will not live more than six months. They can be highly functional and go on trips, go to the movies, go out to dinner and enjoy their lives. It is the time for these individuals, and probably for all of us, to truly "live in the moment". In hospice, we encourage patients to do what makes them happy, today... not tomorrow... but today. In fact, I often say, as it is often said in our field, hospice is about living, not dying.

Some statistics state that the median length of stay in hospice is only three weeks and the average length of stay hasn't changed much since the mid-1990s. Although more patients are being referred to hospice, many receive the hospice benefit for very short periods of time, such as

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## FUNCTIONAL NEUROLOGIC DISORDERS / CONVERSION DISORDER

### Overview

#### Mayo Clinic Staff

Functional neurologic disorders — a newer and broader term that includes what some people call conversion disorder — feature nervous system (neurological) symptoms that can't be explained by a neurological disease or other medical condition. However, the symptoms are real and cause significant distress or problems functioning.

Signs and symptoms vary, depending on the type of functional neurologic disorder, and may include specific patterns. Typically these disorders affect your movement or your senses, such as the ability to walk, swallow, see or hear. Symptoms can vary in severity and may come and go or be persistent. However, you can't intentionally produce or control your symptoms.

The cause of functional neurologic disorders is unknown. The condition may be triggered by a neurological disorder or by a reaction to stress or psychological or physical trauma, but that's not always the case. Functional neurologic disorders are related to how the brain functions, rather than damage to the brain's structure (such as from a stroke, multiple sclerosis, infection or injury).

Early diagnosis and treatment, especially education about the condition, can help with recovery.

**Symptoms:** Symptoms of functional neurologic disorders may vary, depending on the type of functional neurologic disorder, and they're significant enough to cause impairment and warrant medical evaluation. Symptoms can affect body movement and function and the senses.

Signs and symptoms that affect body movement and function may include:

- *Weakness or paralysis*
- *Abnormal movement, such as tremors or difficulty walking*
- *Loss of balance*
- *Difficulty swallowing or feeling "a lump in the throat"*
- *Seizures or episodes of shaking and apparent loss of consciousness (nonepileptic seizures)*
- *Episodes of unresponsiveness*
- *Signs and symptoms that affect the senses may include:*
- *Numbness or loss of the touch sensation*
- *Speech problems, such as inability to speak or slurred speech*
- *Vision problems, such as double vision or blindness*
- *Hearing problems or deafness*

**When to see a doctor:** Seek medical attention for signs and symptoms listed above. If the underlying cause is a neurological disease or another medical condition, quick diagnosis and treatment may be important. If the diagnosis is a functional neurologic disorder, treatment may improve the symptoms and help prevent future problems.

**Causes:** The exact cause of functional neurologic disorders is unknown. Theories regarding what happens in the brain to result in symptoms are complex and involve multiple mechanisms that may differ, depending on the type of functional neurologic disorder.

Basically, parts of the brain that control the functioning of your muscles and senses may be involved, even though no disease or abnormality exists.

Symptoms of functional neurologic disorders may appear suddenly after a stressful event, or with emotional or physical trauma. Other triggers may include changes or disruptions in how the brain functions at the structural, cellular or metabolic level. But the trigger for symptoms can't always be identified.

**Risk factors:** Factors that may increase your risk of functional neurologic disorders include:

cont. on next page

***BITS AND PIECES:*****APHASIA: WHAT IT IS AND HOW TO COMMUNICATE WITH PEOPLE AFFECTED BY IT*****Aphasia is:***

- *Damage that specifically affects the portions of the brain that support language;*
- *Generally associated with damage to the left hemisphere of the brain;*
- *It usually occurs in adults;*
- *It is an acquired language impairment; and*
- *People with aphasia indicate that they know what they want to say, but they just can't say it.*

Aphasia is an impairment of language, that affects the production or comprehension of speech and the ability to read or write. Particularly in older people, Aphasia is due to an injury to the brain - most often from a stroke; however, it can also be from brain injuries arising from head trauma, brain tumors, or brain infections.

Aphasia can be so severe that it makes communication almost impossible, OR it can be mild. It may affect a single aspect of language use, such as the ability to retrieve the names of objects, the ability to put words together into sentences, or the ability to read. More commonly, however, multiple aspects of communication are impaired.

The National Aphasia Association, in conjunction with the American Stroke Association, has communication tips for those experiencing aphasia and those speaking with someone with aphasia. Here are a few key tips to get you started:

1. *Keep it simple. Speak in short, simple sentences.*
2. *Be Patient. Allow plenty of time for a response.*
3. *Remove distractions. Turn off radios and TVs.*
4. *Be Creative. Try writing, gesturing, pictures and communication tools like an iPad.*
5. *Confirm. Repeat back what you think he/she is saying.*

The different types of aphasia are Global, Broca's, Wernicke's, Primary Progressive, Anomic, and Mixed Non-fluent aphasia.

More information will be on our new website when it launches, hopefully by September first.

**FUNCTIONAL NEUROLOGIC** – cont. from previous page

- Having a neurological disease or disorder, such as epilepsy, migraines or a movement disorder
- Recent significant stress or emotional or physical trauma
- Having a mental health condition, such as a mood or anxiety disorder, dissociative disorder or certain personality disorders
- Having a family member with a functional neurologic disorder
- Possibly, having a history of physical or sexual abuse or neglect in childhood

Women may be more likely than men to develop functional neurologic disorders.

Complications: Some symptoms of functional neurologic disorders, particularly if not treated, can result in substantial disability and poor quality of life, similar to that caused by medical conditions or disease.

July 11, 2017 / [MayoClinic.org/diseases-conditions/conversion-disorder/](http://MayoClinic.org/diseases-conditions/conversion-disorder/)

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PRODUCT OR SERVICE.  
WE INTEND IT TO SERVE AS  
AN INFORMATION GUIDE.

**ROAD TO THE CURE** – cont. from page 1

*classifiable as a prion disease*) in MSA patients, similar to its role in Parkinson's patients. It is for this reason that both MSA and PD are classified as prion-like diseases. Thus, there is an overwhelming evidence that alpha-synuclein is the common pathological target for MSA and PD. Neuronal loss in the substantia nigra of MSA patients is similar as in PD patients.

Medicinally, while Levodopa provides transient symptomatic relief to Parkinson's patients, it provides a very poor response with MSA patients. Like other neurodegenerative diseases, a definite diagnosis of MSA can only be made upon autopsy by the presence of misfolded alpha-synuclein in glial cells, the pathological landmark of the disease, along with neurodegenerative changes in the striatonigral structures in an individual's brain. The diagnosis of possible MSA is based on the presence of either parkinsonian or cerebellar symptoms in patients, with at least one feature of autonomic and/or urogenital dysfunction, plus one other clinical feature (such as a Babinski sign with hyperreflexia) in patients over the age of 30 presenting with progressive disease. Probable MSA patients, also over the age of 30, exhibit rapidly deteriorating autonomic activity with urinary dysfunction and either poor levodopa-responsive parkinsonism or cerebellar dysfunction.

Unfortunately, currently, there are no therapies available that can slow down and/or halt the MSA disease

progression. Current treatments are focused on symptom alleviation, but these treatments typically offer only partial and transient relief for patients.

The good news is that ICB, International, Inc., ("ICBII"), has developed a drug for Parkinson's disease which has been shown, in animals, to inhibit the production of pathological alpha-synuclein which is the hallmark of Parkinson's and MSA diseases. The scientists of ICBII are now in search of MSA animal models to test its drug. There is a high probability that after cloning and humanization, ICBII's alpha-synuclein-SM will be effective in halting Parkinson's and MSA diseases. The Company is now looking for investors to raise funds to achieve its goal of translating its drug for human use.

**HOW CAN YOU HELP?** The joy of being a part of this historical event can be had by helping ICBI find the funds to bring these trials to fruition through your personal, including your IRA, investment, and/or by finding others with the financial ability and humanitarian mindset to accomplish the - until now - impossible. Please contact Jo Rosen at Parkinson's Resource Organization 760-773-5628 or jorosen@Parkinsonsresource.org or by contacting ICBI directly through their website <http://icbii.com/> or by phone 858-455-9880.

IMAGINE the world without Parkinson's, MSA or Alzheimer's disease. JUST IMAGINE.

Mark your calendars and join us at the Parkinson's Resource Organization "On the Road to the Cure" symposium October 28th in Palm Desert, California.



We're thrilled to, once again, be participating in the Macy's Shop for a Cause Charity Challenge and wanted to fill you in on all the details about the most exciting aspect of the campaign: Macy's Shop for a Cause Savings Passes.

**Here we go!**

If you have participated in Macy's Shop for a Cause event in the past, you know the drill. Like always, every donor that donates \$5 or more to Parkinson's Resource Organization will receive an exclusive Shop for a Cause Savings Pass before the event.

In the past, you've received a hard copy of the pass. This year, Macy's is moving everything online and savings passes will be emailed to each donor and a reminder email will be sent by August 10th, the day before Shop for a Cause.

If you contribute to PRO on 7/26 or after, your Savings Pass will be sent on 8/9. So, so amazing!

Macy's 12th annual Shop For a Cause will take place Thursday, August 10 – Sunday, August 13 both in-store and online.

**Macy's Shop for a Cause Savings Pass Promotions**

- EXTRA 25% OFF select regular-priced, sale clothing, accessories & jewelry, exclusions, and restrictions apply.
- EXTRA 20% OFF select regular-priced items & select sale home items, exclusions and restrictions apply.
- EXTRA 10% OFF select regular-priced & sale electrics/electronics (in-store only), exclusions and restrictions apply.

Thanks to the generosity of its customers and associates, Macy's raised more than \$3.6 million for local charities across the country in 2016. PRO and Macy's looks forward to another successful year.

Thanks so much for responding to our "Shop For A Cause" Campaign either on line at [Crowdrise.com/parkinsons-resource-organization/fundraiser/parkinsonsresource](http://Crowdrise.com/parkinsons-resource-organization/fundraiser/parkinsonsresource) or by sending a donation to us at our address on the outside of this Newsletter.

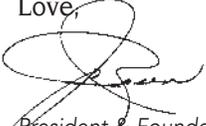
Parkinson's Resource Organization (PRO), through its WELLNESS VILLAGE ([ParkinsonsResource.org/wellness-village](http://ParkinsonsResource.org/wellness-village)) has begun its campaign to populate all categories of professionals that provide services or products to people with Parkinson's or their caregivers. If you refer a professional into the WELLNESS VILLAGE that has helped you or your family gain "quality of life," alleviate symptoms, helped you through the Parkinson's Journey in some fashion and therefore wants to and can help others, and if that professional becomes a subscriber, we will thank you with 100 Parkinson's Resource Organization 49¢ postage stamps.

**PRESIDENT'S MESSAGE** – cont. from page 1

or is it **FUNCTIONAL NEUROLOGIC DISORDERS / CONVERSION DISORDER: An Overview** on page 4; and, **APHASIA: WHAT IT IS AND HOW TO COMMUNICATE WITH PEOPLE AFFECTED BY IT** on page 5.

Did you know you can communicate with us through Facebook at [facebook.com/Parkinsonsresourceorganization/](https://www.facebook.com/Parkinsonsresourceorganization/) or on Twitter at [@ParkinsonsPRO](https://twitter.com/ParkinsonsPRO), on Linked-In at [Linkedin.com/in/jorosenpro/](https://www.linkedin.com/in/jorosenpro/) and now on Instagram at [Instagram.com/parkinsonsresourceorg/](https://www.instagram.com/parkinsonsresourceorg/) There's no reason not to stay in touch with us now. We would love to receive your social media handles so we can be more easily in touch with you as well.

Until next month, REMEMBER some fun holidays such as National Girlfriend Day on the 1st, International Beer Day on the 4th, National Sister Day on the 6th, International Left-Handers Day on the 13th, World Humanitarian Day on the 19th, and National Dog Day on the 26th. The flowers are the Poppy & Gladiolus, and the Birthstone is the Peridot which symbolizes strength. ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,  
  
 President & Founder

**HOSPICE AND PALLIATIVE** – cont. from page 3

the patient mentioned above in this article.

Earlier this year, I attended the American Academy of Hospice and Palliative Medicine conference in Phoenix, AZ. One session I attended was presented by the oncology group from Massachusetts General Hospital. They conducted a study and found that their patients with advanced cancer who received an early palliative care consult (not admission to hospice, just a consult) found that anxiety and depression of the patient and their family were reduced significantly. Other symptoms were suspected to have improved including pain and blood pressure. These patients also accepted an earlier referral to hospice as they had been educated to the true benefits of hospice. In addition, they had already met some of the hospice team members. The oncologist who spoke had mentioned that, historically, oncologists are reluctant to refer to palliative care for consultation believing that their patients will be stolen from them too soon. More importantly, many oncologists reported that they feel as though they have let their patients down and feel guilty that they cannot offer them a cure when the cancer becomes advanced and is no longer responding to treatment.

As I noted above, patient's can be referred to hospice for non-cancer diseases such as Parkinson's which is a progressive incurable disease. Putting someone through treatment after treatment for Parkinson's hoping they can "beat it" can often result in significant pain and trauma, not unlike the ill effects seen with patients being treated for advanced cancer with chemotherapy.

No matter what the reason is for a delay to a hospice referral, better education of what hospice and palliative care can provide is paramount. Education not just to patients but also to the entire medical community. Only then will many of our loved ones be able to enjoy their latter days in comfort at home with their friends and family foregoing exhausting tests and treatments that may not promote a good quality of life if they so choose but they need to be informed.

As Auntie Mame said to Agnes Gooch in the classic movie, "Life is a banquet and most poor suckers are starving to death...live!..live!"

**NEW & RENEWED:** Family Hospice Care has been a member of the Wellness Village since July 2015 and has renewed their membership through 2018. To get more information about them, visit Family Hospice Care in The Wellness Village at [ParkinsonsResource.org/caregiver/family-hospice-care/](https://www.ParkinsonsResource.org/caregiver/family-hospice-care/)



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(See Page 7 for details.)

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