

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

MESSAGE

PRESIDENT'S

The month of May has the energy to help us reach our goals and hearts desires. Through the breezes and tides, May carries with it a second chance. MAY you always be the happiest person you can be.

On March 1st, we installed our Director of Development, Dan Ball, and on April 12th we had our "Ball Goes PRO" event, which, in a few words, was an EPIC success and a monumental undertaking. In just just 42 DAYS, we hosted over 400 people, raised awareness about Parkinson's to a brand new audience and experienced the generosity and support of many new sponsors. The monies raised will propel us forward as we continue our mission of helping those with Parkinson's, their families and caregivers.

The audience was awestruck and deeply moved by the personal testimony of Cheryl Epstein and her daughter and caregiver Sophie, age 17. Cheryl is only 58 years old and has suffered Parkinson's Disease for more than 14 years. The microphone and lights went to them rather than them walking on stage as Cheryl, experiencing an unwelcome dyskinesia rampant, shared her personal message of gratitude and overwhelming love for Jo Rosen and the help provided by PRO. You could have heard a pin drop during their determined and uplifting message. Their words and their bravery brought the audience to tears. The blessing in this story is that an entirely new audience witnessed the wrath of Parkinson's disease. It needs to be shared that Cheryl and her children, Sophie, 17, and Luke, 15, manage their daily lives with grace and poise; going to school and managing daily chores, all while being solely in charge of her care. Be sure to visit Facebook for event photos and details of her speech.

The drive continues as we commit to the **#YearOfTheCure**. This month check out why Stem Cell may NOT be the answer as we provide you with "real time" science covered in our Update on **ROAD TO THE CURE** on this page. The scientists are making tremendous strides in bringing the Road to the Cure to fruition.

We proudly bring you an article from our newest Wellness Villagers; Informative news such as: **POSITIVE THINKING FOR HEALTHY LIVING** by Madeline R. Vann, MPH on page 3; **WHAT IS NEUROFEEDBACK & NEUROPTIMAL® BRAIN-TRAINING?** on page 4; plus we've added **10 THINGS PEOPLE WITH DEMENTIA MIGHT SAY AND HOW TO RESPOND** by Esther Heerema, MSW on page 5; **FATIGUE** on page 7; and our **Inspirational Corner, COLONEL SANDERS | KENTUCKY**

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

Why Stem Cell therapy may NOT be the answer

And stem-cell therapies have been associated with other adverse effects as well... such adverse effects are probably more common than is appreciated, because there is no reporting requirement...

USFDA CLARIFIES STEM-CELL THERAPY'S BENEFITS AND RISKS

[*The New England Journal of Medicine*, 376 (11), 1007 (2017)]

The US Food and Drug Administration (USFDA) share the current excitement over the potential of stem-cell therapy to improve patient outcomes or even cure diseases. The USFDA states that increasingly hematopoietic stem cells (stem cells that give rise to all other blood cells) and stem cells derived from sources such as adipose (*especially of body tissue*) used for the storage of fat tissues are being used to treat multiple orthopedic, neurological, and other diseases. Often these stem cells are being used in practice on the basis of minimal clinical evidence of safety or efficacy, sometimes with the claim that they constitute revolutionary treatment for various conditions.

USFDA'S VIEW ON THE EFFECTIVENESS OF STEM-CELL THERAPY

"Despite the absence of compelling evidence from adequate, well-controlled clinical trials, some practitioners assert that stem cells have a unique capacity to restore health because they can sense their environment and differentiate in a manner that repairs any defect. A separate argument is that conducting controlled trials and meeting regulatory standards for such promising therapies is too complex for all, except large industrial sponsors and that therefore broad use in clinical practice should be allowed and encouraged while evidence regarding efficacy is gathered. Proponents of both arguments generally assert that stem-cell therapies are quite safe, particularly when the cells are derived from an autologous (*of cells or tissues*) obtained from the same individual source. Outside the setting of hematopoietic reconstitution and a few other well-established indications, the assertion that stem cells are intrinsically able to sense the environment into which they are introduced and address whatever functions require replacement or repair — whether injured knee cartilage or a neurologic deficit — is not based on scientific evidence.

Published data derived primarily from small, uncontrolled trials plus a few well-controlled randomized trials have not reliably demonstrated the effectiveness of stem-cell treatments even in some

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OUR WELLNESS VILLAGERS:

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Colonel Sanders | Kentucky Fried Chicken

Once there was an older man, who was broke, living in a tiny house and owned a beat up car.

He was living off \$99 Social Security checks. At 65 years of age, he decided things had to change. So he thought about what he had to offer. His friends raved about his chicken recipe. He decided that this was his best shot at making a change.

He left Kentucky and traveled to different states to try to sell his recipe. He told restaurant owners that he had a mouthwatering chicken recipe. He offered the recipe to them for free, just asking for a small percentage on the items sold. Sounds like a good deal, right?

Unfortunately, not to most of the restaurants. He heard "No" over 1000 times. Even after all of those rejections, he didn't give up. He believed his chicken recipe was something special. He got rejected 1009 times before he heard his first "Yes."

With that one success Colonel Hartland Sanders changed the way Americans eat chicken. Kentucky Fried Chicken, popularly known as KFC, was born.

Remember, never give up and always believe in yourself in spite of rejection.

POSITIVE THINKING FOR HEALTHY LIVING

Madeline R. Vann, MPH

Reviewed by Niya Jones, MD, MPH for Everyday Health

Having a positive attitude can improve your health and relationships. Find out how to shift from negative thoughts to a healthier way of thinking for healthy living.

Taking an optimistic view of life can strengthen your relationships, improve your coping ability, and protect your health. Tackling negative thoughts can be challenging, but you can make the switch with simple strategies that show you how to spot and replace harmful thought patterns with positive thinking for healthy living.

The Benefits of Being Positive: People who have a more positive, optimistic outlook also have lower levels of inflammation and heart disease risk, according to research in Psychosomatic Medicine.

In addition to protecting your heart health, having a positive outlook can help improve relationships and self-esteem and lead to better decision-making and less stress throughout your day, says David Burns, MD, a psychologist and an adjunct clinical professor emeritus of psychiatry and behavioral sciences at the Stanford University School of Medicine and the author of *The Feeling Good Handbook*.

About Negative Thinking: Cognitive behavioral therapy (CBT) seeks to identify negative thoughts and find alternative approaches. Dr. Burns, a CBT pioneer, outlined 10 thought distortions that can lead to negative thinking and even depression:

1. Black and white thinking or thinking in terms of absolutes such as “always or never” or “all or nothing”;
2. Overgeneralizing one mistake or bad outcome into a lifelong pattern, also called “catastrophizing”;
3. Focusing on bad aspects instead of good aspects of events;
4. Ignoring the positives and giving negatives too much weight;
5. Making assumptions, both about people and the future;
6. Minimizing or magnifying issues;
7. Reasoning by emotion, such as saying, “I don’t feel good about that person, so she must be awful”;
8. “Should” statements, such as: “By now I should be rich”;
9. Negative self-labeling or name-calling, such as, “I’m an idiot”;
10. Blaming or personalizing and overlooking shared responsibility for situations or events.

“These distortions cluster into two patterns: One would be the thought pattern of ‘I’m no good.’ That includes all-or-nothing thinking, overgeneralization, and ‘should’ statements, where you’re beating up on yourself,” Dr. Burns says. “The second is the ‘you’re no good’ pattern, where you’re projecting the distortions onto someone else.”

How to Be Positive: Be aware that switching from a negative to a positive outlook takes effort. Burns says that there are times when people don’t want to give up negative thoughts because that feels like giving in. Other people might find their negative thoughts rewarding in some way.

“It’s easier for some people if they see these distortions and write down their thoughts,” he says. The hard part is taking the next step and choosing to become more positive or, at least, more realistic. “It’s not easy for people to change these patterns within themselves.”

Research published in the March 2013 issue of the journal *Psychology of Aging* shows that older adults actually have a slightly greater chance of staying positive overall, in part because they have a longer life context in

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WHAT IS NEUROFEEDBACK & NEUROOPTIMAL® BRAIN-TRAINING?

NeuroOptimal®'s EEG biofeedback or Neuro-feedback system is a powerful technology that can greatly enhance your well-being and generally help you get the most out of life.

Brain training can unlock untapped cognitive potential and help you achieve long-held goals and dreams.

Biofeedback has been around for almost 40 years, but its practical use was inhibited by the scarcity of a practical delivery system. In the past, a neurofeedback interface would have required a room full of computers and technicians.

Today, Zengar Institute, Inc. has created a simple, interactive software that harnesses this powerful technology in an easy to use program called NeuroOptimal® that loads onto a laptop computer.

Because neurofeedback has been time-tested, it is also very safe. Respected institutions such as the USFDA and the American Academy of Pediatrics have endorsed neurofeedback.

Neurooptimal® Brain-Training Tech-Nology Utilizing Zengar's Exclusive Dynamical Neurofeedback®

When it comes to improving your quality of life, NeuroOptimal® neurofeedback is a game changer.

Most everyone understands how a good diet and exercise regimen can increase longevity and improve strength and stamina. But what about your mental fitness? The fact is, your brain – just like your body – can be trained for greater performance (or "strength") and focus (or "stamina"). A resilient and flexible brain improves our state of mind.

And nothing impacts the quality of our lives more directly than our state of mind.

Your brain already possesses everything you need for an exceptional quality of life. NeuroOptimal® helps draw out this untapped potential to make "the good life" a reality.

NeuroOptimal®'s Dynamical Neurofeedback® is essentially a brain fitness program which facilitates a more efficient use of neural resources. What does more efficient brain function "feel" like? The first thing most will notice is a substantial improvement in the quality of their sleep. Many report that they dream more vividly and sleep more soundly.

After a few NeuroOptimal® neurofeedback sessions, users report feeling more focused, calm and centered. They work faster, more efficiently and experience a significant reduction in physical complaints. They're less bothered by doubts and insecurities and are more apt to experience confidence and satisfaction. Nagging, upsetting thoughts simply drop away with no effort on the user's part. Free from distraction, the brain can focus on the present and naturally discover the best way to tackle the task at hand.

NeuroOptimal® Neurofeedback is a 100% non-invasive, safe method for restoring serenity, confidence and wellness back into your life.

NeuroOptimal® is safe. It is utilized every day by thousands of trainers and home neurofeedback users worldwide. Collectively, our neurofeedback systems have logged in an excess of THREE MILLION training hours.

NeuroOptimal® is effective. But don't take our word for it. Read our clients' life-changing experiences in their own words. Watch inspiring video stories from people just like you who have used NeuroOptimal® neurofeedback to overcome incredible life challenges.

At a recent conference in Palm Springs, California, neurofeedback trainers documented positive outcomes when NeuroOptimal® neurofeedback training was utilized to address a plethora of difficult issues arising from ADD, ADHD, PTSD disorder, Alzheimer's & Parkinson's disease, autism, sleep disorders, insomnia and cognitive dysfunction from chemo-therapy.

But the only way to truly appreciate the benefits of NeuroOptimal® is to

cont. on next page bottom

10 THINGS PEOPLE WITH DEMENTIA MIGHT SAY AND HOW TO RESPOND

Esther Heerema, MSW – VeryWell.com

1. *"You're cheating on me! I can't believe you went off with that tramp!"*

Sometimes, it's hard to know how to respond to someone with disease or another kind of dementia, especially when they make comments that -to you don't make sense or are hurtful. Here are some practical suggestions to try, and while none of them will work all of the time for everyone, perhaps you'll find one or two that are helpful in your situation.

Response: "Oh Fran, you know that no one else would be able to put up with me! I love you. Let's go for a walk. Remember when Freddy was born, what a little miracle he was? He's coming over at 3:00 o'clock today."

Using humor and distraction when coping with challenges can help both the caregiver and the person with dementia.

2. *"Where's my mom? Mom, come here!"*

Response: "Are you looking for your mother? I bet you miss her. Can you tell me about her? What did you like about her? Was she a good cook? What was your favorite food that she made?" (This is an example of using validation therapy to support the reality of the person with dementia.)

Sometimes, when you use validation, the person may be comforted just by talking about her mother or father that she misses. Those memories may be enough to calm and reassure the person. At other times, validation can even help a person come to the point in the conversation where they say, "You know, I really miss my mom. She died several years ago."

3. *"It's time for me to go to work. I don't want to be late!"*

Response: "Before you go, stop a moment to eat some breakfast or you'll be too hungry during the day. Hey, would you mind taking a look at the sink for me? It's not draining correctly. Oh, and I just heard that your brother Harry and his wife are stopping by soon today."

Remember how much routine and identity may be connected to leaving for work each day in the past.

4. *"Look at that fat lady. Wide load coming through!"*

Response: (If heard by person, you can quietly say to her): "I'm so very sorry. She's has dementia and doesn't understand that she's being rude. I'm so sorry."

If this is a frequent problem, you can also consider handing out a pre-printed very brief explanation of how Alzheimer's disease affects people. You may also need to limit outings if this is a significant issue.

This type of behavior can also be quite hurtful when directed to family members and friends.

5. *"Help me. Help me. Help me!"*

Response: "Hi, Frank. I'm right here. Are you in pain? Can I get you a glass of water? Let's go for a walk together and stretch our muscles."

6. *"You're just a *&@#!" (Foul language)*

Response: "Mom, please don't speak like that. It scares the children. You sound frustrated. Can I help you? Would you like to read your daily newspaper?"

7. *"Don't you dare touch me or I'll clock you one."*

Response: "Good morning, Sally. If you don't need anything right now, I'll come back and check on you in 15 minutes."

cont. on page 7

experience neurofeedback training yourself. Be the Best You. It's time.

Pamela S. Hartman, M.S. and Angela Martinucci are the owners of Brain Optimizers in Palm Desert, Los Angeles, El Cerrito, San Francisco and Bay areas and are new members of the Wellness Village. To get more information about them and their practice visit the **Brain Optimizer** under Brain Optimization

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ROAD TO THE CURE – cont. from page 1

of the most systematically studied conditions, such as heart failure and graft-versus-host heart failure and graft-versus-host [References: JAMA, Cardiol., 2016; 1: 831; Expert Rev Clin. Immunol., 2016; 29 : 1-14].

This lack of evidence is “worrisome”. The literature is replete with examples of therapeutic interventions pursued on the basis of expert opinion and patient acceptance that ultimately proved ineffective or harmful when studied in well-controlled trials comparing them with the standard of care. One of the most unfortunate therapeutic misadventures in contemporary times was the widespread use of autologous stem-cell transplantation for treating metastatic breast cancer, a practice ultimately shown to be ineffective, costly and risky.

USFDA’s VIEW ON THE SAFETY OF STEM-CELL THERAPY

The safety of stem-cell therapies for indications other than hematopoietic reconstitution also cannot be taken for granted. In one recent case, a patient was treated with multiple injections of allogeneic stem cells from different sources that were intended to reduce neurologic deficits stemming from a middle cerebral artery stroke [(Reference: N Engl J Med 2016; 375 : 196)]. The injections were associated with the development of a glioproliferative lesion, which led to paraplegia and ultimately required radiotherapy.

Although autologous stem cells may typically raise fewer safety concerns than allogeneic stem cells, their use may be associated with significant adverse events. Autologous hematopoietic stem cells injected into the kidneys of a patient with renal failure resulting from systemic lupus erythematosus were associated with the development of tumors (angiomyeloproliferative lesions) that eventually led to nephrectomy [Reference: J. Am. Soc. Nephrol., 2010; 21 : 1218]. In another instance, autologous stem cells derived from adipose tissue and injected intravitreally into the eyes of people with macular degeneration were associated with worsening vision in three people, two of whom became legally blind [Reference: Presented at the American Academy of Ophthalmology Annual Meeting, Las Vegas, November 13–14, 2015].

Stem-cell therapies have been associated with other adverse effects as well. Such adverse effects are probably more common than is appreciated, because there is no reporting requirement when these therapies are administered outside clinical investigations. The occurrence of adverse events highlights the need to conduct controlled clinical studies to determine whether these and allogeneic cellular therapies are safe and effective for their intended uses. Without such studies, the USFDA will not be able to ascertain whether the clinical benefits of such therapies outweigh any potential harms.

PERSPECTIVE

According to the article published by the USFDA, even after more than three decades of research and billions

spent in R&D expenses, the stem-cell research is still in its infancy. The USFDA is “worrisome” about the lack of evidence for the efficacy and safety of the stem cells. The reason for this is that mammalian cells comprise tens of thousands of different proteins, lipids, carbohydrates, and other molecules, all interacting in an extraordinarily complex manner. This complexity makes it challenging, if not impossible, to predict cellular behavior a priori when stem cells are introduced into a new environment, and empirical data are therefore necessary to document safety. There is no scientific reason to believe that demonstration of efficacy and safety for stem-cell products should be any different from that for other biologic products. Therefore, stem-cell therapy is far from being ready for use in humans. Patients and their loved ones should not expect access to stem-cell therapies sometime soon in the future.

We at PRO and the scientists at ICB International, Inc., (“ICBI”), highly recommend all patients afflicted with neurodegenerative and other diseases and their families to carefully review the research article published in the above referenced “The New England Journal of Medicine” by the US Food and Drug Administration (USFDA). The copies of this article are available from Jo Rosen, President of Parkinson’s Resource Organization (PRO). The patients must make their own decisions objectively and rationally with the help of their physicians without any bias regarding the current status of stem-cell therapy. Conflict of interest on the part of medical professionals and practitioners can do more harm than good. The information published in the foregoing article is for educational purpose only.

If you meet certain qualifications, you too may be able to take part in “history-making” science. You can still get in at ground floor if that appeals to you. Or you can continue waiting until SOMEONE ELSE handles this pandemic. Please get in touch with Jo Rosen at Parkinson’s Resource Organization with whom we are in constant communication, updating her on our progress, while learning from her why it is so important to continue working to eradicate this horrific disease.

IMAGINE a world without Parkinson’s or Alzheimer’s disease. Just Imagine.

Ever notice how diseases that were considered rare a hundred years ago are almost considered normal (and even expected) today?

PRESIDENT'S MESSAGE – cont. from page 1

FRIED CHICKEN on page 2 (this one could be meant for me).

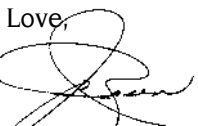
Thank you for your tax-deductible donations, giving us the opportunity to help MORE: to help MORE people, MORE often, MORE timely, with MORE information in a MORE compassionate way. We know we are providing valuable information and support in the Parkinson's community, we continue to appreciate your monthly or general donations through our safe PayPal donation page at ParkinsonsResource.org/contribute-2/ or by mail to our office in Palm Desert, California.

Until next month, REMEMBER; May Day on the 1st, Cinco De Mayo on the 5th, Kentucky Derby on the 6th, Mother's Day on the 14th, Armed Forces Day on the 20th, National Brother's Day on the 24th, and Memorial Day will be celebrated on the 29th.

The flowers are Lily of the Valley & Hawthorn and the Birthstone is the Emerald.

You might also take note that May is National Physical Fitness and Sports. Keep up your workouts.

ALWAYS remember to CELEBRATE YOU and PRAY FOR OUR TROOPS!

Love,

 President & Founder

FATIGUE

A lot of things can make you very tired, and most of them aren't serious. But fatigue is one early sign of some cancers, like leukemia. Some colon and stomach cancers can cause blood loss that you can't see, which can make you feel very tired. If you're wiped out all the time and rest doesn't help, talk to your doctor.

POSITIVE THINKING – cont. from page 3

which to place negative events, while younger people see setbacks as more dramatic failures.

Want a more positive outlook? Try these healthy-thinking strategies: **Create alternative thoughts.** Write down a bothersome thought and assign it to one of the 10 distortions. For example, after a bad decision, you might think, "I've messed up my entire life." Put this in the "magnification" category. Now write down a more positive thought, such as, "I haven't made a mess of my whole life. I made one bad decision, but I can fix it. And I've made many other good decisions."

Practice gratitude. In addition to tackling specific thoughts, try focusing on what you're grateful for each day. Write down two or three things that you're thankful for in your life, no matter how big or small they may be.

Hang out with kindred spirits. Certain people can lift you up and help you stay positive while others may tend to do the opposite. Reach out to and surround yourself with the uplifting ones or make an effort to find like-minded new friends. Limit your time with or avoid people who make life feel more negative and heavy to you.

If you try these tips but negative thoughts continue to plague you, consider working with a therapist to help you identify and change the thought patterns that are holding you back.

10 THINGS AND HOW TO RESPOND – cont. from page 5

8. "Why are you letting her steal my money? I had it right here and she took it!"

Response: "When was the last time you saw the money? Let's look together for it. How much was it? Let's look through your purse. You know, I misplaced \$20 the other day and finally found it on the kitchen counter under a book. I'll help you look."

9. "Don't leave me! Where are you? Come here!"

Response: "Dad, I love you so much. I'm right here. I need to go out to cut the grass but you can watch me if you'd like." Or- "I just need to use the bathroom for a few minutes but I'm not going anywhere. Can I turn your favorite show on for you?" (Sometimes, if you're visiting a loved one at a facility, you may need staff to distract your loved one at mealtime for you to slip away without causing her to be upset.)

If you're able, you can also just choose to spend a little more time with your loved one before you leave.

10. "I want to go home now. Please take me home!"

Response: "We can't go out right now, Fred. The weather's not very good. While we wait, can I get you a cup of hot chocolate? Also, I'm wondering if you can help me sort through these family pictures." Or- "While I get ready for our walk, I wondered if you could you tell me about your brother and sister when you all were little. Did you share a room with Uncle Fred? I bet you and he had a lot of fun together. Did Aunt Sarah pester you, or was she a fun little sister? Can you tell me again about the time you played that joke on your mom and dad? I love to hear about your family! You must have had such fun growing up together."

PRO CALENDAR FOR MAY 2017

The current support group meeting locations are listed below.
For any information regarding any of these meetings, please contact the PRO Office at 877-775-4111.

	1 PALM DESERT For Everyone 10:00 am PRO Office 74-090 El Paseo Suite 104	2	3	4	5	6
7	8 PALM DESERT Round Table for Everyone 6:30 pm Atria Hacienda 44-600 Monterey Ave	9	10 GLENDDORA For Everyone 6:30 pm Kindred Rehab at Foothill 401 W Ada Ave	11 NEWPORT BEACH Caregivers Only 6:30 pm Oasis Senior Center 801 Narcissus Corona Del Mar	12	13
14	15 PALM DESERT Caregivers Only 10:00 am PRO Office 74-090 El Paseo Suite 104	16	17 ENCINO Emotional & Educational Speaker Meeting for Everyone 7:00 pm Providence Tarzana Outpatient Therapy Cntr 5359 Balboa Blvd	18 WEST LA Emotional & Educational Speaker for Everyone 6:30 pm OPICA Adult Day Care Center 11759 Missouri Ave	19	20
21	22 PALM DESERT Emotional & Educational Speaker for Everyone 6:30 pm Atria Hacienda 44-600 Monterey Ave	23 MANHATTAN BEACH Emotional & Educational Speaker for Everyone 6:30 pm Parish House 659 15th Street	24	25	26	27
28	29	30	31			

CAREGIVER MEETING: (For caregivers only) Come share the ups and downs of living with someone with Parkinson's. Together there are ways of finding solutions that, when alone, might never be considered. No need to continue with your frustrations because you are not alone. Give yourself a break.

EDUCATIONAL MEETING: We invite the community, especially the Person with Parkinson's and their family or friends, to attend. Educational meetings usually feature guest speakers who are professionals servicing the Parkinson's Community. Educational meetings are packed with a wealth of amazing information so bring your pencil and notepad!

"ROSEN ROUND TABLE" MEETING: Join a loving circle of like-minded individuals including local professionals. Learn what works for others, share what works for you. Find out what doesn't work for certain individuals. Share emotional trials and tribulations. Realize that you are not alone and that others can relate to and learn from your story.

*"The mediocre teacher tells.
The good teacher explains.
The superior teacher demonstrates.
The great teacher inspires."*

— William Arthur Ward

NEWSWORTHY NOTES

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PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

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