

PARKINSON'S RESOURCE ORGANIZATION

Working so no one is isolated because of Parkinson's

MESSAGE

PRESIDENT'S

Having lost my youngest brother in an ATV accident on the 4th of July prompts me to say, "One doesn't have to have Parkinson's to think about having your life in order." Is your Will up to date? Do you have your Insurances in order, will your family be left in a shambles or in good place? Amazingly, Patrick's life was in order and every project he had started was completed. What a legacy to leave for his family. I'm glad I got to dance with him two weeks before he left. Keep making memories.

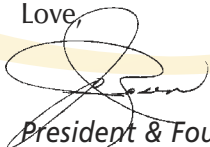
Here is another jam-packed newsletter covering **DETOURS AND HAPPY ACCIDENTS LEAD TO WELLNESS** by Risto Hurme, DDS on this page along with Teri J's **MY TMJ Journey** on page 3. **THE MYTHS AND TRUTHS BEHIND THE ALKALINE DIET** By **Dariella Gaete, MS, RD** appears on page 5 and tastefully her **RECIPE OF THE MONTH Chicken and Strawberry Salad: An Acid/Alkaline Balanced Meal:** is on page 4. Then there are the **FIVE STAGES OF GRIEF: Living through Transitions in Parkinson's** on page 2.

Check out our beautiful website **ParkinsonsResource.org** for the articles we didn't have room for in this newsletter.

Please remember **we need your donations.** Summer is the slowest time for revenue generation. Please continue using the **mailing address: 74-478 Highway 111, No. 102, Palm Desert, CA 92260** when making snail mail donations or make donations online through our secure Website **ParkinsonsResource.org/contribute.**

Until next month **HAPPY EVERYTHING, CELEBRATE YOU and PRAY FOR OUR TROOPS!**

Love,



President & Founder

DETOURS AND HAPPY ACCIDENTS LEAD TO WELLNESS

By Risto Hurme, DDS

The San Antonio Center for Headache Pain And TMJ Disorders

In December 2003, Richard G. shuffled haltingly into my office carrying his printed list of twenty symptoms, which included headaches, tremors and muscle spasms, and asked if I could help him. He had been suffering with these symptoms for seven years, and eventually was forced to retire at age 46 from his job as an airplane mechanic because of them. He had happened to read a letter I'd written to the **San Antonio Express-News** saying that TMD (Temporomandibular Jaw Disorder) should be considered when diagnosing chronic headaches that presented with seemingly unrelated symptoms. It was lucky for him that he did not show up in 1999, because that was before I had stumbled onto my awareness of TMD.

Like most dentists, I was not taught much about the TMD/health connection in dental school, or how to treat it. Like Richard G., I had been heading down a path of progressively worse symptoms of chronic pain, migraines, eye, ear and sinus pain, dizziness, vertigo, poor sleep, chronic fatigue, and anxiety – however, unlike Richard, I was still able to work and function, if only in survival mode! In 2000, on the first day of an orthodontic conference in Minneapolis, I was lucky to be sitting next to Harold Gelb, DDS, a pioneer in the study and treatment of TMD. He listened to my story and then performed a short exam. At age 50, after twenty years as a General Dentist, I was diagnosed with TMD during a 10:00 AM coffee break! My whole life changed in that moment. That night I stayed up all night reading Dr. Gelb's book, **Killing Pain Without Prescription**, published in 1982. I remembered his remark, "The jaw joint is the most important joint in the whole body". It suddenly dawned on me that a dislocated jaw was the cause of my symptoms. We are the only species that suffer from malocclusion (*crooked teeth*), a condition which is becoming more prevalent all the time, due to our modern soft diet of highly refined foods. Malocclusion is more than a cosmetic problem, but a condition detrimental to your head/neck/jaw relationship that can have grave consequences! Malocclusion = Bad Health, Good Occlusion = Good Health. I started my TMD journey that day and now I am pain free and full of LIFE! I have been learning all I can about TMD ever since.

Now back to that day in 2003 and Richard G's original list of 20 symptoms:

1. A constant headache 24/7. Some days the pain is debilitating.
2. Head rush feeling, the feeling one has when one gets up too quickly. Also 24/7, then when I do get up from a crouch position I often feel I could pass out.
3. Headache behind the eyes, very painful and can stay for weeks. Began in my early 30s.
4. Severe tinnitus (*persistent noise in ears*). I thought it came from years of working with jet aircraft.
5. Very small mouth, cannot open wide and easily gagged.
6. Ataxic gait with my right knee giving way on occasion.
7. Poor balance and I bump into walls often. The earth is stable and I am the one off balance. I cannot walk heel to toe or on my toes or heels.
8. Grind teeth daily with the hardest in the evenings.

FIVE STAGES OF GRIEF: *LIVING THROUGH TRANSITIONS IN PARKINSON'S*

As the need for change becomes clearer, a sense of grief and loss can be felt by all members of the family. Just as in death, the five stages of grief (DABDA) can apply to this difficult transition in life.

- 1) *Denial about the reality of the health and safety conditions at home.*
- 2) *Anger at the changes that have occurred, at the loss of security of one's personal space and at the family members who may be responsible for this change.*
- 3) *Bargaining to remain in the home longer, promises to fix the problems and making deals to avoid a move.*
- 4) *Depression that may be present or develop as the result of moving and having to let go of one's current lifestyle.*
- 5) *Acceptance of the change; a chance to refocus, gain energy and set new goals in a different environment.*

Some suggestions to help caregivers and family members grieve and assist in the transition from the family home to assisted living or another care setting:

- Plan a family meeting where all concerned can come together and thoroughly discuss needs and moving options. Be truthful and realistic about the need for the loved one to move. Initially, keep emotions to the side and focus on the facts at hand, especially if the loved one is unable to comprehend the situation and see the bigger picture.
- Talk with others who may have already traveled this journey to learn from their experiences. Seek out others who can 'walk' beside you during this transition such as a physician, clergy, friend, social worker, caregiver consultant or the care provider of the residence in which your loved one will reside.
- Best possible, prepare for good days and bad days as change and loss are realized by everyone who is involved. Be aware that decisions and emotions may waiver during this transition process. Remain focused on the risks and facts surrounding the need for change and continue to move forward. Offer reassurance when resistance surfaces and keep a positive attitude about the move and the opportunities that may be available at the new residence.
- If possible, involve the family member or loved one in the planning and preparation to move by touring several housing options. Allow choices for items to take along such as old or familiar items, furniture, photos, a radio or music player, things that generate fond memories.
- Married couples forced to separate due to differing care needs, should allow time to grieve the change in the relationship, address fears, and seek opportunities for each to spend mealtime, bedtime or other quality times with the other on a daily basis. Encourage the spouse remaining at home to seek out new activities, volunteer, return to past hobbies or renew old friendships to help fill the empty hours of the day.
- Because full-time caregiving from the well-spouse is no longer needed, time can be spent on rekindling the relationship with the loved one that may have become strained during the caregiving years. Reminiscing, reviewing photo albums or sharing memories and family stories can be fulfilling activities for everyone.
- For the well spouse, joining a caregiver support group to share your feelings and receive support from others who have had similar experiences is very helpful. Write down feelings or ideas in a journal, check out the library for helpful reading material, find information through the Internet or seek support from counselors, professionals or local organizations such as the Parkinson's Resource Organization or other Parkinson's organizations, for people with dementia, the Alzheimer's Association can be helpful, or most "caregiving" support forums.

 **WEAR A SILVER RIBBON!** 



- *To show you care about someone with Parkinson's disease or any other brain disease or disability.*
- *To help break the barriers to treatment and support.*
- *To help eliminate the stigma against those who suffer.*
- *To show you believe there's hope through education & research.*



**If you would like to make a donation, please make checks payable to
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MY TMJ Journey

I hope to share with others who have Parkinson's the value I received from a TMJ appliance. I have been wearing only a lower appliance 24 hours a day since Feb.15, 2011; 5 months.

Background

When I was young I had 7 permanent teeth removed for braces. Over time my jaw receded because the "place holders" had been removed. My lower jaw receded and my back teeth no longer touched.

I was diagnosed with Parkinson's September 2009, age 62 with the following presenting symptoms: tripping over right foot; tiny handwriting; painful stiffness/rigidity; pain on right side; no tremor.

Other symptoms: fuzzy thinking, tired—needed to nap every day. A wave of exhaustion crashed over my head and I had to lie down/body felt limp and soon I would be asleep, only to be awake at night until 3 AM, no energy, no appetite, balance issues, felt no joy in life, hardly laughed, dropped out of socializing, lost interest in activities/people around me, needed to use the restroom every 20–30 minutes, difficulty with gait and right leg dragging sometimes, holding my right arm at my waist and not swinging it, no sense of smell.

Medication: 1 mg Azilect once a day

September 2009–June 2010

My initial neurologist was traditional and did not promote alternative remedies. If something like massage or acupuncture brought me relief, that was fine but she didn't offer any alternative recommendations. For the pain in my hip, I was told it was due to Parkinson's and the only relief would be surgery. She wanted me to participate in the BIG and LOUD speech, occupational and physical therapy program to monitor my decline. After one visit, I stopped going to therapy. I wanted to take a more positive approach to look for ways to improve.

I changed my diet to mostly raw and vegan, eliminated inflammatory foods, had acupuncture treatments regularly. This helped with the pain and rigidity.

June 2010

I consulted another neurologist because I liked the fact that his office used email. He gave me several tests, one being the Motor Exam. I scored 13.

September 2010–July 2011

Feeling that I wanted to be more involved with the direction my health was headed, I remembered a Tai Chi class I had taken at the community college years ago. While registering for Tai Chi I found Gyrokinesis. It incorporates principles from yoga, dance, swimming, massage, and Tai Chi. Entire body is worked using three-dimensional movements. It focuses on spinal movements and breath patterns intended to improve overall health of body, mind, and spirit. This class has been like a miracle for me loosening up my rigidity, learning about the scapula so now on most days my arm swings naturally when I walk. All of the gentle movements are done mostly sitting on a stool. I see myself taking this class working with the bodies' energy for many years.

January 2011

As I continued my search for natural, positive ways to improve my life, I heard and attended an "Ultimate Quality of Life" seminar put on by Parkinson's Resource Organization in Palm Springs presenting TMJ as an effective way for Parkinson's people to regain their quality of life.

Visit www.parkinsonsresource.org to watch video testimonials and/or buy the DVD of the weekend event and lectures. After the symposium I went to see a TMJ dental specialist.

At the symposium I was most impressed with a man with Parkinson's who kayaked in the ocean and was always falling over, couldn't keep his balance. After being fitted with a TMJ appliance he is now able to continue ocean kayaking. I love rowing, so decided to go for a consultation.

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TMJ JOURNEY – cont. from page 3

February 15, 2011

I was fitted with an appliance and noticed immediate results. I could step over the tub and into the shower without holding onto the walls. I could shower and spin under the showerhead to wash the shampoo out of my hair without holding onto the walls. My balance was significantly improved. The next day I had a client meeting in LA. We talked for 3 hours and I made sense! And I didn't have to leave every 20 minutes to use the bathroom! I could understand what she was saying, got my thoughts together and verbalized them, sounding professional again! My executive thinking had returned! I was my old self again. I also noticed I slept more soundly getting up maybe once in the night.

February 26, 2011

A close friend said, "You didn't have to tell me you had the appliance. I could see in your eyes the YOU WERE BACK." This meant so much to me as I truly felt like my old self again and was glad others could see it, too.

March 5, 2011

Two weeks later I took an hour drive, hiked for 2 hours, drove back, changed clothes, attended a wedding wearing 3-inch heels. I was perfectly comfortable with good balance for 6 hours, even danced for an hour! I could never have worn high heels, had that much energy or felt that social without the TMJ appliance. I laughed; my face had expression; I made interesting conversation; I was involved. What a difference!!!

March 11–21

I worked in NY City for 9 days setting up a large trade show booth. On my day off I walked 44 blocks with a bad cold. But not tired after all that walking. Upon return I had several meetings with my attorney; I could process all the information. I could never have handled all

cont. on page 7

RECIPE OF THE MONTH: Chicken and Strawberry Salad An Acid/Alkaline Balanced Meal

INGREDIENTS

DRESSING:

- 1 tablespoon sugar
- 2 tablespoons red wine vinegar
- 1 tablespoon water
- 1/8 teaspoon salt
- 1/8 teaspoon freshly ground black pepper
- 2 tablespoons extra-virgin olive oil

SALAD:

- 4 cups torn romaine lettuce
- 4 cups arugula
- 2 cups quartered strawberries
- 1/3 cup vertically sliced red onion
- 12 ounces skinless, boneless rotisserie chicken breast, sliced
- 2 tablespoons unsalted cashews, halved
- 1/2 cup (2 ounces) crumbled blue cheese

PREPARATION:

1. To prepare dressing, combine first 5 ingredients in a small bowl. Gradually drizzle in oil, stirring constantly with a whisk.
2. To prepare salad, combine romaine and next 4 ingredients (through chicken) in a bowl; toss gently. Place about 2 cups chicken mixture on each of 4 plates. Top each serving with 1 1/2 teaspoons cashews and 2 tablespoons cheese. Drizzle about 4 teaspoons dressing over each serving.



THE MYTHS AND TRUTHS BEHIND THE ALKALINE DIET

By Dariella Gaete, MS, RD and Natalie Maurtua, Dietetic Student

Alkaline diets are becoming more popular in recent nutrition discussions. What is all the buzz about? Well, alkaline diets are supposed to, assumedly, balance your body's pH levels to a more alkaline state to reduce the amount of yeast and fungi within the body. The claims state that this can be achieved by consuming alkaline foods such as vegetables, coconut juice, chestnuts, limes, avocados, millet, quinoa as an alternative to wheat, and fish or lamb instead of chicken or beef and the list goes on. This diet is supposed to increase your immunity by reducing exposure of acidic foods into the body. This diet has been recommended to people who have autoimmune and immune-compromised diseases such as cancer patients, along with other illnesses.

The truth is that foods you eat can affect the acidity or alkalinity of the urine, not your blood. The acid is formed by calcium, phosphorus, and sulfur compounds in our foods. Alkalinity is caused by intake of sodium, potassium, calcium, and magnesium. Therefore, fruits and vegetables contribute alkaline "ash" to the urine. Prunes, plums, and cranberries are the exceptions, and are considered "acid-ash" foods. High-protein foods, such as meat, fish, poultry, eggs, and cheese, are classified as acid-ash foods. Grains, such as breads and cereals, also are acid-ash foods. Milk contributes both acidity and alkalinity.

For years, companies have made claims to sell food products or supplements, stating that what you eat can have an effect on the alkalinity/acidity of your blood or stomach contents. This is nonsense. Even drinking large amounts of vinegar would not change the pH of your stomach, because it is so acidic. Likewise, ascorbic acid or folic acid will not change the pH of your stomach or blood.

All food, regardless of the food's individual pH, is acidic in the stomach and alkaline in the intestine. Some people claim that cancer cells cannot survive in an alkaline environment, so people with cancer should eat a diet that is high in alkaline. In fact, none of your body cells can survive in an alkaline environment, so thank goodness that we cannot change the pH of our body with food!

The human body is amazing at adapting to maintain the exact level of pH needed to live. For example, if you eat more protein than you needed, your body converts the amino acids to organic acids, which would acidify the blood briefly. Your body then releases calcium (alkaline) to counteract the acid buildup. This explains why eating a diet too high in protein will lead to osteoporosis (from leaching calcium from the bone to maintain pH balance because of the consumption of excessive amounts of protein).

Even though the pH in our system cannot be drastically altered, the alkaline diet does provide great insight to consuming more vegetables, green foods, and whole grains. By consuming more vegetables and whole grains, you are consuming more fibers, which not only helps with digestion it helps lower cholesterol as well. So, consume more alkaline foods to help with digestion and lower your cholesterol, but know that the body will always maintain a balanced pH.

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**As the WELLNESS VILLAGE is populated,
check it often for resources in your area.**

ParkinsonsResource.org/wellness-village



DETOURS – cont. from page 1

9. Ears sensitive to touch.
10. Blurred vision.
11. Eyelid muscle spasms very severe. I also have difficulty in opening my eyes once closed.
12. What I call my “stretchy thing” all the muscles in my body feel tight. I stretch but without any relief.
13. Seizure-like tremors in left and right hands.
14. Poor concentration due to pain.
15. Difficulty in finding words, with everyday jargon, and technical terms while working in aircraft maintenance.
16. Eye pain, tired eyes most of the day.
17. Whole body jumps or shakes for no apparent reason.
18. Very light and wind sensitive eyes. I currently wear frames with a ptosis crutch to keep my eyelids open.
19. My wife says my body jumps in my sleep, and my feet bend in strange positions, they tend to point up to my head.
20. I have always been right handed. I can no longer write with my right hand. One doctor told me to learn to write left-handed. I can print with my left hand but no cursive except for my signature.

At that visit, I examined Richard G. and told him I thought I could help him to some degree. I took diagnostic impressions and two days later he returned for custom-fitted temporary occlusal guards made of soft, thick rubber. I called him three days later and his seven-year 24/7 severe headache was gone! He had also slept well from 10:00 PM to 8:30 AM, whereas he usually slept no more than an hour or two at a time, with his pain worse in the evenings and at its worst at 3:00 AM.

Richard had an over-closed,

retrognathic mouth, and every time he put his teeth together his jaw would slide to the right 3 mm. His jaw was dislocated. He could open his mouth only 30 mm (50 – 60 mm is normal) with pain. Right jaw deflection (sideways movement) was 5 mm, left jaw 6 mm (12 mm is normal). All the muscles of his head and neck were in severe spasm and very painful. He described it as “It feels like someone is pushing my head down from the top.” He was a severe clencher and grinder and shortly chewed through the occlusal guards. I decided to start his treatment with a Bionator oral appliance to correct the jaw position. Richard was a very compliant patient; he wore it 24/7 for nine months, and it is a mouthful of an appliance! I adjusted it every four weeks and he steadily improved.

The next step in his treatment was expanding his narrow upper and lower arches. This was accomplished with upper and lower 3-way Sagittal expanders which he wore for two and a half years (he moved away to Chicago during his treatment). In January, 2007 he lost his lower expander! He sent me new models taken by his general dentist in Chicago and I fabricated a Gelb MORA lower orthotic which I gave him at his next visit to San Antonio three months later. The purpose of the MORA is to maintain the jaw in its proper Gelb 4/7 position (nature’s position!) 24/7. At that visit, we took impressions for an Elastodontic aligner to finish his orthodontic tooth movement. He returned nine months later for this aligner, which is worn only at night. At his next visit, eleven months later, I saw that he had chewed through the Elastodontics! I adjusted his MORA, and took impressions to fabricate for him an Upper Farrar nighttime appliance (to prevent grinding while asleep) and an Upper MAPA daytime appliance. I fitted him with these appliances at his next visit, which was ten months later.

He didn’t return to San Antonio until June, 2011, almost two years later! He was still doing quite

well, but his bite was slightly off. We took new x-rays, models and measurements. There had been some relapse in his bite but fortunately his nervous system had recovered sufficiently so that a total catastrophic relapse did not take place. I adjusted his bite and made him a new MORA orthotic, also a new Farrar nighttime appliance in a little more forward and higher setup to prevent snoring.

He probably will need to be monitored for the rest of his life, but fortunately he’s now planning to spend his winters here for some Texas sun therapy! Richard spent seven years going from doctor to doctor (including two neurologists) searching for a cure before he found me. Although no diagnosis was ever reached, he did display many symptoms of Parkinson’s disease, and his case should offer hope to Parkinson’s patients.

This case illustrates the downward spiral that engulfs many TMD and Parkinson’s patients. They get stuck in the ‘survival mode’ of existence, with the body using all of its available energy just to maintain life at this level, so there’s very little energy left for the repair function, and eventually doom and despair set in. Richard G. had been in this mode for seven years and had bought his casket and plot, unable to imagine another future. Fortunately, he had enough energy reserves left in him to be able to switch to ‘normal mode’, in which the body can repair and rebuild itself, and normal life can resume. There are four requirements for this to happen:

1. *Correct jaw position 24/7*
2. *Open airway 24/7*
3. *Eliminate excessive dental distress from occurring 24/7*
4. *Treat the affected muscles, tendons and ligaments*

Unfortunately, the medical and dental establishment’s understanding of TMD has not changed much in the thirty years since Dr. Gelb’s book was published. Fortunately for me, I was diagnosed by him, and I was able to diagnose and treat Richard

DETOURS – cont. from previous page

G., who now is traveling the world, feeling good, and enjoying life!

You can hear more of Richard G.'s story on Youtube, including his symptom #21 which he remembered in Interview 3 – which will be of interest to anyone suffering from PD:

DR. HURME TMJ PATIENT INTERVIEW 3

YouTube.com/watch?v=r__Oj5sKxXg&feature=mfu_in_order&list=UL

TMJ JOURNEY – cont. from page 4

these details and managed all these people prior to the appliance.

March 31 2011

I met my Movement Disorder Specialist, for the second time. He retested me with the motor exam. This time I scored 11; a 15% improvement. He was amazed and asked what I was doing because Parkinson's patients always deteriorate and never improve. I showed him my TMJ appliance. Since my improvement was so great, he now questioned whether I had Parkinson's or not. The University had just received approval to perform DAT scans and the machine was to be installed in April. He wanted me to be tested to see my level of dopamine. Initially, I agreed but changed my mind after hearing the \$2,000 cost.

April 2011

On occasion I started to smell things again. Walking past a neighbor's yard I smell the flowers, going into a restaurant I smell the food, walking down the sidewalk I smell the soap being used in a doggy spa.

Mother's Day; May 2011

Wore 3-inch heels for about 6 hours; walked around a large mall, attended a classical music concert in the afternoon and no trouble staying awake. Started a big project of filling in my swimming pool, adding 9 raised vegetable beds, a citrus orchard, and a tetherball (good exercise for my arm/shoulder) court. A very stressful couple of weeks and I did lose a lot of the qualities I had gained. But an adjustment of the appliance gave them back to me instantly...as soon as the corrected appliance was put into my mouth I felt differently.

June 2011

I found a new TMJ doctor closer to home. We've discussed Phase 2, stabilizing my bite with braces. My former TMJ doctor wanted to do crowns and maybe implants where my wisdom teeth had been. My teeth are in good shape and I prefer braces. My new TMJ Dentists is treating about 20 people with Parkinson's. On one of my visits I met a doctor with Parkinson's undergoing TMJ Treatment. He's 77 years old, has returned to playing golf twice a week, practicing medicine one day a week and has an active social life.

Overview

In the past 5 months, my balance has been good, I have lots of energy and enthusiasm for life, and occasionally I even have my sense of smell! My executive thinking is back. I have days where I'm non-stop energy. My gait is improved, some days are better than others for handwriting; the pain on my right side is gone as long as I am faithful with my Gyrokinesis and acupuncture. At the end of July I'm getting a top appliance to wear at night which, I'm told, will give me my REM sleep again which is necessary for the body to heal itself. I'm told I'll have even more energy. If you met me, you probably wouldn't know I had Parkinson's.

What does the appliance look like?

My first appliance is on the left and my current one is on the right. Both worked great.

**What I've Learned**

- Stress is still a saboteur. Sometime when I've hit a wall and regressed, it's usually due to stress and/or my appliance needing to be adjusted. I think as the bite changes, the appliance needs to be adjusted. I also think it is the body just trying to catch up with all the changes and it just takes a timeout.
- I need to do all I can to stay healthy, like exercising, eating right, listening to my body and getting the sleep I need. I take 3 exercise classes plus I try to walk everyday (walking a neighbor's dog makes it more fun and gets me off the couch). My diet now is mostly raw, vegan, no wheat for keeping down inflammation. Building up my core muscles and maintaining flexibility is essential for me. I take a Gyrokinesis class, gentle movements sitting on a stool.
- Dental hygiene is critically important to keep cavities away, such as brushing the teeth and the appliance after each meal.
- Not just any TMJ doctor can help a Parkinson's person. Questions to ask: Have they worked on Movement Disorder patients, where and how were they trained, where and how do they keep up their continuing education, how much of their practice is TMJ, how do they build the appliance, what is their philosophy of treatment; who does the work—The doctor or staff; how they will stabilize your bite, what do they do for maintenance, how often, how do they track improvements?

I have a good part of my old self back and I am once again participating in life...looking to contribute wherever I am needed. TJM has given me back to me.

Ms Teri J
July 2011



The Parkinson's Resource Organization has its own US Postage Stamp, the very first charitable organization to do so. You can now show your support for PRO by using this stamp on all your mail! PRO has partnered with PhotoStamps.com to create the PRO Stamp, and now you can order personalized postage stamps with your own favorite photos via the new PRO website! Either way, by using PRO's Partnership with Photostamps.com you'll be helping us and yourself. Just start by using the form below.

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"Without gratitude, happiness is rare. With gratitude, the odds for happiness go up dramatically"

NEWSWORTHY NOTES

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Working so no one is isolated because of Parkinson's

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