

March 2022

Parkinson's Perspective

Newsletter of the Colorado Springs Parkinson's Support Group
Colorado Parkinson Foundation, Inc.

www.co-parkinson.org 719-884-0103

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The Colorado Springs
Parkinson's Support Group meets
the second Saturday of each
month at 10AM (with exceptions
to be noted in this newsletter)

March Meeting: Saturday, March 12th – 10:00 am – 1:30 pm

We will not be Zooming and recording this meeting

*Location: First United Methodist Church, 420 N. Nevada Ave. downtown
just south of St. Vrain*

9:30 am – Come early for a group sing-along with music therapist, Heather Johnson. See more about Heather's business under '**Other Opportunities:**' later in this newsletter

9:45 am – Everyone else come in a few minutes early to check in, greet other members and ask questions.

First time visitors: Be sure to sign in, get a name tag and proceed to the visitors' table for some special attention and information.

Knowledge is power and enables us all to live well, so plan to attend the meetings at First United Methodist Church

March program: Break-Out Sessions

Moderators: Parkinsonians: Steve Locke; Caregivers: Jill Reid & Julie Pfarrer

March PL main dish: For St. Patrick's Day—Anything Green!

If you would like to sign up to be one of the providers of a main dish or a side dish/dessert for the March meeting, you can sign up through our website or you can contact Bill Hicks at [REDACTED] or potluck@co-parkinson.org, no later than Wednesday, March 9th, and tell him what you would like to bring.

If you'd like to go through the website, go to the "Events" page of the website and find the meeting you're volunteering for and select "Event Details." That will take you to the main sign-up page. In addition to the meeting information, you will see how many chefs and the number of servings per batch are needed. Click on "Sign Up" in the box and then select "Submit and Sign Up" which will take you to a page where you will select how many of the number of chefs you are signing up for. For example, if the # of servings requested is 10 but you're making 20 servings, then the quantity you would select should be 2...the equivalent of 2 chefs. There is also a place for any comments you may have there. You must then provide your name and email address. When finished, select "Sign Up Now;" you will receive a confirmation email, and your information will be sent to our potluck coordinator, Bill. This capability should help make Bill's job considerably easier. To return to the website, close the sign-up tab at the top of the screen.

Remember that bringing food for the potluck is voluntary.

We look forward to seeing you there!

The President's Corner

Jill Reid – Acting President, CPF and CSPSG

We have some exciting news this month: the article on the results of the 12-week study on the effects of the ketogenic diet on Parkinson's symptoms has been published and is available globally. We have put it up on the Colorado Parkinson Foundation website (co-parkinson.org) under the Study tab. Congratulations to all the participants in this study—without you, none of this important research would have happened. According to Dr. Tidman, our lead researcher, the article concerning the results of the expanded 24-week study will be published mid- to late-2022, again globally and available for all to read.

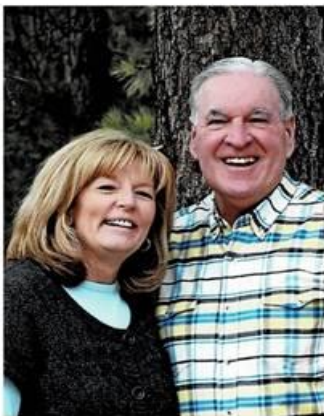
As we prepare for our first break-out session of the year (the March meeting will be dedicated to this vital activity), I would like to share with you the reasons we do break-out sessions several times each year. While speakers bring us a lot of knowledge about their areas of expertise, break-out sessions, during which the people with Parkinson's meet in one area and their caregivers in another, enable all of us to ask questions and get answers and ideas that are very relevant to where each of us is in our Parkinson's journey. We do this in a very safe and confidential environment, and nothing that is said leaves the room. In my experience, these are our **most important meetings** because we share our knowledge with each other and learn practical solutions to difficult problems from one another. Everyone has the chance to bring up issues that are occurring NOW and find out how others have dealt with them—and there's always someone who has already found good solutions to every issue.

Julie and I have been around people with Parkinson's (PWP's) since Mom was diagnosed in 1993. Yet, we're always learning more about the disease and its management every time we have break-out sessions. Here's a really great example: A few years back, Julie had found herself in the unwanted role of chauffeur for Ric because he was having difficulty staying in his lane and not running up on the car in front of him. Julie just assumed that she would forever have to take Ric wherever he needed to go, and Ric was understandably feeling the squeeze of dependency—both were unhappy about the situation but neither of them knew there was a solution—until a break-out session, when another caregiver asked if anyone else's PWP was having exactly the same issues as Ric. And, sure enough, someone was and had already found the solution—an affordable car with “lane assist” that kept her husband from drifting into the next lane and from driving too close to the car in front of him. Julie and I had never heard of that technology!! If it hadn't been for that break-out session, we might never have heard about it. Julie and Ric bought a used car with lane assist, and both of them got their independence back.

BUT we can't have productive break-out sessions unless people attend the meeting in person. Since it's impractical to use Zoom for break-out sessions, I encourage you to join us live for the March meeting. Both rooms where we will meet are quite large and allow people to spread out if they are concerned about COVID-19. Another important reason to attend all of our meetings in person is the socialization that naturally occurs after the guest speaker or break-out session. Many of you have been missing out on this most significant benefit of a support group such as ours. And we've missed being with you!

Getting To Know You: Sherry and Alan Whitaker

Sherry and Alan are recent additions to our support group; Sherry was diagnosed as having PD with Lewy Body Dementia in the spring of 2020. Sherry likens her early experience with PD symptoms to “contact and abduction by Aliens”! She continues, “Basically, I knew something unusual and weird was afoot, but inside, I didn't feel hugely different and I was confused as to how to react and respond”.



The Whitakers view our Support Group as one of several resources they intend to employ to minimize PD's effect on their active life of hiking, dog walking, dancing, fishing, and playing/watching a variety of sports. To illustrate our Groups' value as a resource, Sherry notes that advice from “Groupies” Jill and Julie led her to seek out Dr. Grabert as a Movement Disorder Specialist. Thus, through CSPSG, Dr. Grabert became a new resource for two, already, very resourceful people.

Sherry was born and raised in Colorado Springs. Alan and his parents moved here from Indiana in 1962 when he was eleven. Interestingly, although they both are products of area schools, both studied at CSU Fort Collins, and both worked in the City, they never met until 33 years later. An August night in 1995 found them, with friends, line dancing to country music at a local watering hole. Making up for their many years of unacquaintance, they married less than two years later.

Their interesting backgrounds and skills (masonry, hair styling, construction management, dancing, crafting, flag football, participating in church activities and others) simply invite you to meet them, make an introduction and swing into conversation. **So – have at it and enjoy getting to know them better.**

Caregiver Pampering Day!
Take 5: Soothe All of Your Senses
 Sponsored by PPACG Area Agency on Aging

When: Sat. April 30, 2022, 8:30 AM to 1:00 PM
Where: Colorado Springs Senior Center, 1514 N. Hancock Ave
Admission: Free with registration

The event is for family members who are caring for another family member who is 60+ years of age.

The day includes a catered continental breakfast, pampering time, drop-in activities, classes, and catered lunch.

Scheduled classes will include:

The Healing Power of Music:
Being Present Through Your Senses:
Sit and Fit:
Be A Creative Cookie:

Emergency Preparedness:
Aromatherapy:
Caring Conversation:

Registration begins on March 21, 2022 and closes on April 15, 2022.

Registration can be done

Online: [ppacg.org/pampering day](http://ppacg.org/pampering-day)

Email: kmathews@ppacg.org

Phone: 719-886-7526

For more information or to have questions answered, please call Kent Mathews MSW at 719-471-2096 or email Kent at kmathews@ppacg.org

Ketogenic Recipe(s) of the Month

Lois Lang's Luscious Bread

¼ - 1/3 C melted butter, coconut oil, or olive oil

1 C dry curd cottage cheese (Whole Foods & Sprouts carry this under the name Farmer's Cheese)
 (press down as you measure)

1 t baking soda

3 eggs

½ t salt

2 ½ C blanched, ground almonds (almond flour)

Preheat oven to 350 degrees

Place melted butter, Farmer's Cheese, baking soda, salt, and eggs in food processor using metal blade. Process until the mixture is thick and resembles butter in texture.

Add almond flour and process until mixed thoroughly. If the stiffness of the mixture stops the processor, remove the dough with wet hands and knead by hand until almond flour is thoroughly mixed into other ingredients.

Grease a loaf pan (about 4" by 8") generously with butter and coat bottom with ground almond flour OR do what I do and line the loaf pan with parchment paper (this way, I don't have to wash the loaf pan every time!).

Bake at 350 degrees for about 1 hour (50 minutes works at my house at 7200-foot elevation). Removed bread from loaf pan and let it cool before cutting.

Freezable.

For more flavor, try these variations:

1. Add 2 T rubbed sage with the butter, cheese, baking soda, salt, and eggs
2. Add 3 grains of saccharin or experiment with your sugar substitute (think of substituting for 12 t of sugar), 2/3 C chopped pecans, 1 T cinnamon, and 1 t nutmeg to the butter, cheese, baking soda, salt, and eggs.

Other Local Support Groups:

Other Opportunities

<p>Ladies w/Parkinson's Support Group</p> <p>If you are a fun-idea person, please consider volunteering to lead this valuable group. If you're interested please notify Julie Pfarrer at db_mgr@co-parkinson.org or [REDACTED].</p>	<p>Tri-Lakes Parkinson's Support Group</p> <p>Meets the 3rd Saturday of every month at 10 am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. For more information contact Barry Hanenburg at [REDACTED].</p>	<p>Adult Speech Therapy at Home</p> <p>Outpatient speech therapy services conducted in the comfort of the patient's home. Personalized speech therapy for restoration of function due to illness or injury.</p> <p>Treating: Parkinson's Voice & Swallowing</p> <p>For more info, contact Jana Hothan, MA, CCC-SLP at sip@janahothan.com or by phone at (719) 338-8165.</p>
<p>Parkinson's Caregivers Support Group</p> <p>All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings. We meet the 3rd Thursday of each month from 10:00 to 12:00 at 6310 Gemstone Way on the east side of Powers and Dublin. Contact Brenda Hicks at [REDACTED].</p>	<p>Essential Tremor Support Group</p> <p>Meeting Location: ENT Conference Room Pikes Peak Library District. Colorado Springs Library 21c, 1175 Chapel Hills Drive.</p> <p>For meeting dates/times or for questions, contact Jim Sanchez at 719-660-7275.</p>	<p>Parkinson's Sing-a-Long Group</p> <p>No music experience necessary! Join board certified music therapist, Heather Johnson, every Monday at 1 pm as we participate in group singing focused on improving breath control, strengthening of the throat muscles, and improving voice control, volume, and quality!</p> <p>Location: Square Music Co, 2332 Vickers Drive in Colorado Springs.</p> <p>For more information or to sign up please email heather@squaremusic.co or call/text 719-345-2887.</p>

<p>Happy March Birthdays!</p> <table> <tr> <td>John Baker</td> <td>Marti Purdy</td> </tr> <tr> <td>Karen Baker</td> <td>Ken Rowe</td> </tr> <tr> <td>Marci Braithwaite</td> <td>Shelley Runkle</td> </tr> <tr> <td>Donna Deis (Rickett)</td> <td>David Smith</td> </tr> <tr> <td>John Farley</td> <td>Patrick Smith</td> </tr> <tr> <td>Stephanie Graczyk</td> <td>Karl Stengel</td> </tr> <tr> <td>Judy Horton</td> <td>Daniel Theis</td> </tr> <tr> <td>Mary Lekarczyk</td> <td>Marny Weckwerth</td> </tr> <tr> <td>Donna Lee McDonnell</td> <td>Keith Woestehoff</td> </tr> <tr> <td>Keith Mitchell</td> <td></td> </tr> </table> <hr/> <p>Thank You!</p> <p>Thanks to ALL who brought food and to those that helped set up & clean up at the last meeting!!</p>	John Baker	Marti Purdy	Karen Baker	Ken Rowe	Marci Braithwaite	Shelley Runkle	Donna Deis (Rickett)	David Smith	John Farley	Patrick Smith	Stephanie Graczyk	Karl Stengel	Judy Horton	Daniel Theis	Mary Lekarczyk	Marny Weckwerth	Donna Lee McDonnell	Keith Woestehoff	Keith Mitchell		<p>Help us spread some sunshine to our members!</p> <p>If you know of a Parkinsonian or PD caregiver that is having a tough time (illness, surgery) or has passed away, please let our Sunshine Chairman, Sharon Carlson, know at [REDACTED].</p> <hr/> <p>March Executive Committee Meeting</p> <p>March 15th at 11:00 at a place to be determined. You will be notified by email. Contact Jill at president@co-parkinson.org if you haven't been to an Executive Meeting so we will know that you're coming. Leave your email address so Jill can contact you if anything changes.</p>
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February 12, 2022, Program Review

Results of the 24-week CPF Study on the effects of a low-carb/healthy fat diet/ketogenic diet (LCHF/KD) on PD

Speakers: Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP & Dr. Dawn White, PHD, RT (R)

Dr. Tidman announced that this study received Ethics approval and a Phase II approval from the A.T. Sill University Institutional Review Board, Mesa, Arizona and that we were granted an International Registry with Bio Medical Central ISRCTN in compliance with World Health Organization guidelines. After giving a brief overview of the topics she was going to present, she recognized the support group's participants in the study.

Dr. Tidman's background

- Intellectual Bias: I believe in (and personally practice) the LCHF/KD approach for health
- Professional Bias: As a Metabolic Health Practitioner, I work with patients with chronic diseases implementing the LCHF/KD lifestyle to improve health and reduce chronic illness (specifically neurological disorders, metabolic conditions and diabetes)

This 24-week epidemiological study was an extension of a 12-week study, the results of which have just been published in the Journal of Neurodegenerative Disease Management. You can read the article on the CPF website under the tab 'Study'.

Seven of the original 17 that participated in the 12-week study chose to continue on to participate in the 24-week study.

The goal over the 24-week extension of this study was to explore:

- any changes in symptoms of PD, depression or anxiety
- the results of LCHF/KD on Health biomarkers, which included Triglycerides, HDL, Fasting Insulin, C-Reactive Protein, and HgA1C as well as weight, BMI and waist measurements
- the effects of this diet on cardiovascular risk
- and highlight any trends or need for future research on the effects of LCHF/KD on symptoms of Parkinson's disease, depression and anxiety

Approach that was used:

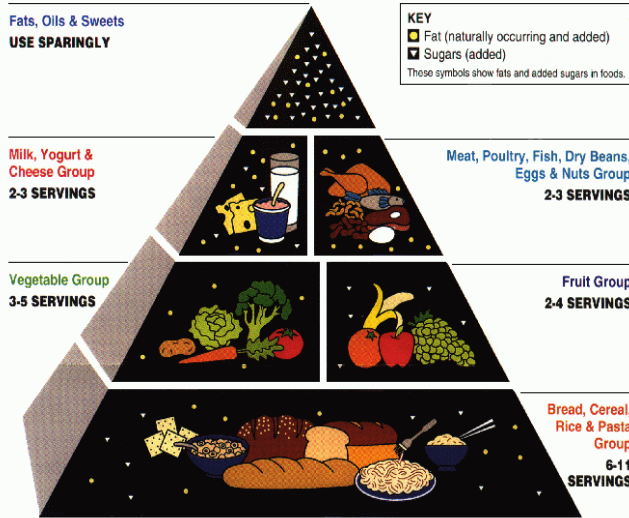
- direct comparison of the same study participants at baseline, 12 weeks, and after the 24-week dietary intervention (pretest/posttest design)
- pre/post scores were compared on the UPDRS Scale (Parts 1 to 4), a widely used PD symptom scale after 24 weeks
- pre/post study scores were compared on the CESD-R020 depression scale and the Parkinson's Anxiety Scale (PAS)
- biomarkers were compared between the baseline, 12 weeks and after 24 weeks of dietary intervention

Dietary Compliance/Adherence:

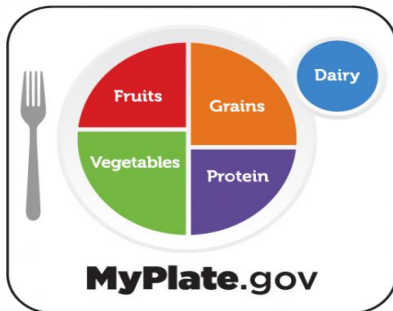
- dietary tracking application: Myfitnesspal or written food logs were submitted weekly to record dietary compliance
- using the KetoMojo Blood Glucose/Ketone meter, weekly Glucose/Ketone results were submitted by participants testing in the comfort of their own homes, and then analyzed by researchers to verify dietary compliance.

Brief review of the low carb-healthy fats/ketogenic diet:

- what we've been eating since 1977:

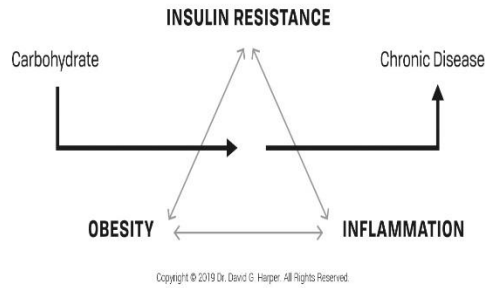


- current governmental guideline:

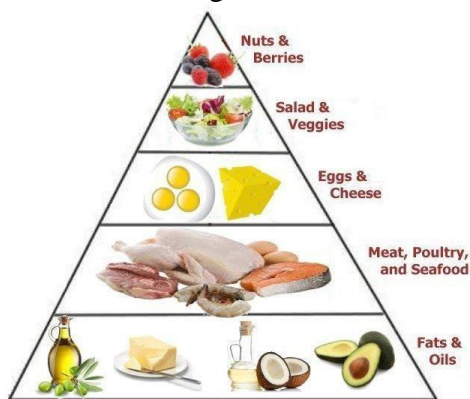


- metabolic syndrome (MetSyn): a new diagnosis
 - high triglycerides (>150mg/dl)
 - low HDL – good cholesterol – (men<40mg/dl; women<50mg/dl)
 - large waist circumference (women > 35; men>40)
 - high blood pressure (>130/85)
 - high blood sugar (hgA1C>5.6)
- Chronic conditions linked to diet and insulin resistance

• High blood pressure	Irritable bowel syndrome
• PCOS/infertility	Acne/skin disorders
• NAFLD/NASH	Obesity/overweight
• T2Diabetes	Autism/ADD/ADHD
• Crohn’s disease	Alzheimer’s disease
• Parkinson’s disease	Some cancers
• Fibromyalgia	GERD/Reflux
• Some eating disorders	Some psychiatric disorders
• Hormonal imbalance	Brain fog/cognitive issues
- The axis of illness:



- The LCHF/Ketogenic Diet:



Use this Food Pyramid as HIGH FAT basis of your LCHF lifestyle

KETO ZONE

[facebook.com/ketozone](https://www.facebook.com/ketozone)

- The LCHF/Ketogenic Diet

- Meat, fish, poultry, eggs
- Very little (or no) dairy (inflammation and dairy connection)
- Fats: 70%-80%
- Protein: 15%-20%
- Carbs: less than 5%-10%
- Mostly green veggies or low glycemic veggies
- Coconut oil, avocado oil, olive oil, grass-fed butter, beef tallow and lard
- Drink water...drink water...drink water

- What does the LCHF/Ketogenic Diet do?

- Raises HDL
- Lowers triglycerides
- Decreases blood pressure
- Decreases abdominal fat
- Decreases blood sugar

- Organizations endorsing LCHF/KD:

- The American Diabetes Association
- NASA
- The Veterans Administration
- The American College of Cardiologists
- The American College of Physicians
- The Society of Metabolic Health Practitioners
- The Epilepsy Society

The Results: statistical or nearly statistical significant improvements in:

- BMI and weight from baseline

- Depression scores (not significant in 12 weeks but improvement appeared to take 24 weeks).
- HgA1C (the Type 2 Diabetes marker)
- Fasting insulin
- Hoehn and -Yahr Stages of PD
- Reduction in inflammatory markers (CRP)
- Anxiety scores
- Triglycerides
- Cardiac risk (triglyceride to HDL ratio)
- Behavior, cognition and mood
- Waist circumference (marker of health)

Study limitations:

- Possible limitations in study results from influence of COVID-19 pandemic and social isolation
- Small sample size limits the ability to generalize the results to larger populations and influence level of statistical significance
- Dietary compliance issues can limit the power of the LCHF/KD diet approach for some participants and dampen the study results
- One participant dropped out due to issues of sustainability (original n=8)
- Some nutritional studies are difficult to measure as far as dietary compliance and longevity especially in observational population health study designs. We controlled for this variable with home testing.

The research team wishes to thank the Board of Directors of the Colorado Parkinson Foundation for funding and sponsoring this study. Their commitment to research endeavors in the study of Parkinson's disease is a tremendous contribution to the body of research concerning this condition.

Study publication for the 24-week study is anticipated mid-late 2022.

The Ketogenic Diet and Quality of Life: Results of a Qualitative Interview

Having Parkinson's disease affects your entire body and soul. Understanding who you are and what is happening begins early, and finding a way to ease these feelings is paramount. Finding a study to become part of offers a glimmer of hope that the intervention will increase your mental, physical, and social quality of life. This study started as a 12-week intervention and was extended to a 24-week longitudinal study. The following is a glimpse into the words and experiences from their person journey.

Here are some examples of the feedback from the interviews conducted by Dr. White:

Physical changes:

- "Some of the issues I had was pain in the feet and pain in the knees and pain in the fingers and just overall body pain. And a lot of that has gone away. I'd say about 50% of it has gone away. Maybe more"
- "I'm definitely stronger and more stamina. I rode my mountain bike Saturday, Sunday. I don't remember. Just from what I had been doing on my Peloton, I was night and day different, from where I would usually conk out during the ride or during some portion. This routine I had; I could tell a huge difference.
- I don't really have any serious sugar cravings anymore. They probably became unnoticeable around week six or seven. So, it's been a long time since I've craved sugar."

Mental clarity:

- "I'm liking the coconut oil. I think my vocabulary and my thought process has really come around a lot." His spouse suggested "his cognition has definitely improved, especially when he's consistent on his coconut oils. When he does both the regimen of the coconut oil and the diet. The difference is huge."

- "I think I have less fogginess. I did have a lot of fogginess in my mind, before the diet, and now I have less fogginess. So, it's been a very good thing for that."

Rolling with the punches:

- "I think I have been noticeably more relaxed about day-to-day frustrations and unexpected events that come up and have been taking them in stride for the most part."
- "I'm more outgoing, more alive, basically, is the best way I can describe it."

Family is everything:

- "My son, who's 18 and way overweight, actually joined me and my fiancée, in eating the keto. I never pushed him because he's a teenager; you push them, they go the other way. But through our example, through my example, he decided it would be something good for him. And he's really come around. He's not as rigid as me, but it's pretty rigid for a teenager. And one day he was like, "Boy, this sugar really makes me feel like crap if I eat it, and then the next day I'm just sick. So, this stuff is really toxic, isn't it?" so from his mouth, I appreciated someone of his age being able to go to that attitude as well."

Looking into the future:

- "My attitude and my emotional outlook have improved significantly."
- "He has made lifestyle changes in his thought processes. It's just being able to stay focused on the goal long-term to see how it can optimally affect him."
- "It's made me more optimistic that I'll probably have more of a life to live. Before, I thought that I was getting worse in my Parkinson's disease and then I'd pass away soon, but now I don't have that feeling. So I think I'll be here now for 20 years."

Continuing the Ketogenic way of life:

Every single participant explained how they plan to stay on the Ketogenesis diet for their health and to meet their personal goals. Here are a few of the comments.

- "I was highly skeptical, when I went into this study, that it would do anything or that it was a healthy way to eat. But all of the arguments that Dr. Tidman (and the team) presented, when I really thought about them, trying to think about them objectively and not carrying with me all my previous biases, they actually made sense. Now for me personally, the proof is in the results. And I am now gone from a highly skeptic to...I'm like an ambassador for this way of life now, because I'll tell anyone who will listen."
- "I'll continue to do it because I'm still not to my goal. My goal is to be a 40 waist and I'm 40 and a half inches. So I got to stay there. I think it'll just be a lifetime of commitment in changing my eating habits."
- "I plan on continuing with the diet."
- "I still am doing that and my daughter is jumping back on board with me."
- "Oh, yeah. For permanent, absolutely. Definitely permanent."
- "Yeah, I'm planning on staying on it."
- "I just want to say thank you very much for creating the study. And I'm really happy that I participated in it. I'll continue participating in it as long as I can."

Future Studies

Healthy fats consumption and LCHF/Ketogenic diet effects on cognition (memory, attention span, etc.) in PD

- MCT oil
 - Coconut oil
 - Avocado oil
-

Colorado Parkinson Foundation, Inc.

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Suite #111

Colorado Springs, CO 80920

Parkinson's Perspective

March 2022

Coming Events

See inside for More Information

(Current location for all meetings listed below is the First United Methodist Church with the exception of the August picnic)

March 12th: Reg Mtg – 10 am; **Program:** Breakout Sessions; **Moderators:** Steve Locke-Parkinsonians; Jill Reid & Julie Pfarrer-Caregivers

April 9th: Reg Mtg – 10 am; **Program:** Wealth Preservation & Planning for Long Term Care; **Speaker:** Kim Searles, Beneficent – LTC Consulting Group

May 14th: Reg Mtg – 10 am; **Program:** Results of the CPF Phenomenological Study of Wives Caring for their Husbands with Parkinson's Disease; **Speaker:** Dawn White, PhD, RT (R)

June 11th: Reg Mtg – 10 am; **Program:** Breakout Sessions; **Moderators:** Steve Locke-Parkinsonians; Jill Reid & Julie Pfarrer-Caregivers

July 9th: Reg Mtg – 10 am; **Program:** TBD

August 13th: 11 am; Picnic at John Venezia Park!!!!
