

## STUDY: LOW CARB LIFESTYLE FOR PARKINSON'S DISEASE \*

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### Intriguing findings

As I worked to put together our report [ExerciseKetoDisease.pdf](#) I found information that—if I am right—can be significant to a great many Parkinson's patients and care givers.

### Resource readings

As shown in our [Holiday Report](#), our (Christine's and mine) understanding flows from these and other works:

- (A) [The Art and Science of Low Carbohydrate Living](#)     The science.
- (B) [The New Atkins for a New You](#)                     How to get started.

### Resource websites

Both the [Parkinson's Foundation](#) and [Michael J. Fox Foundation](#) sponsor scientific research. [The Davis Phinney Foundation](#) provides plenty of online resources, print and video.

Low carb, high fat, adequate protein resource sites are [www.artandscienceoflowcarb.com/](http://www.artandscienceoflowcarb.com/), <https://charlifoundation.org/>, and [www.matthewsfriends.org/](http://www.matthewsfriends.org/)

### Understanding MDS-UPDRS

The studies (2) and (6) both refer to the [Unified Parkinson's Disease Rating Scale](#) to evaluate patient progress. The [International Parkinson and Movement Disorder Society](#) originated this rating scale in 2003, expanded and refined it in 2008 with the latest update in 2019. This explains the slightly different UPDRS reporting in studies (2) and (6).

The MDS-UPDRS is designed for use by an administrator, with a care giver and patient. With a close friend (read daughter) as administrator, we will now take stock at least once a year, so we will have a record of Christine's progress.

### Reading scientific papers

The two studies, as well as all 14 review articles and the book, are promising indeed. They suggest that a low carb, high fat, adequate protein lifestyle can significantly mitigate Parkinson's disease by providing the brain's preferred fuel, which supports neuron regeneration and diminishes inflammation.

The five patients in the 2005 study (2) reduced their UPDRS scores in just four weeks by 21, 46, 46, 23, and 81%, respectively. 24 patients in the 2018, 8 week study (6) reduced Part 1 non-motor scores by 41%, Part 2 motor scores by 25%, Part 3 motor examination by 17%, and Part 4 motor complications, by 32%.

All scientific paper authors call for further study.

\* This report focuses on Parkinson's Disease. With just a little imagination, the ideas presented here apply just as well to Alzheimer's and other neurodegenerative diseases.

This PDF: <http://www.forssell.com/StudyKetoParkinsons.pdf>

## **Benefits from adopting a low carb, high fat, adequate protein lifestyle**

Parkinson's disease comes in many flavors. Each patient and care giver will have to develop their own understanding from reading the Resource readings, watching the 2019 scientific conference *Emerging Science of Carbohydrate Restriction and Nutritional Ketosis*, and reading the scientific research studies and reviews to form their own opinion regarding the benefits they may derive from adopting a keto lifestyle. This will be true whether they undertake their personal journey of discovery, adopting a ketogenic lifestyle on their own, or participate in a research study such as I advocate below, which would support their education, support, monitoring, and documentation of progress.

## **Obstacles to adopting a low carb, high fat, adequate protein lifestyle**

Changing from our dominant western carbohydrate-based diet to a low carb, high fat, adequate protein diet means changing ingrained habits, some of which seem to define who you are. You have to rethink your shopping and eating habits, develop a taste for alternate foods and more. Given your current understandings of what is healthy eating, a ketogenic diet may seem strange indeed. We live in a carbohydrate culture, where carbohydrate foods are promoted everywhere you look in media, stores, and restaurants. You may have doubts yourself, and get blowback from family and friends. To overcome any and all obstacles to a ketogenic diet that mitigates Parkinson's, in-depth study and understanding will be absolutely necessary. It won't do to make the change to keto because someone else tells you to. That won't last.

## **Suggesting an educational, scientific study**

The Parkinson's Foundation estimates that "at least one million people in the United States suffer from Parkinson's disease, and roughly six million worldwide".

The foundation's website features a page on the [Neuroprotective benefits of exercise](#). Exercise is promoted throughout the Parkinson's community.

The scientific literature shows that a ketogenic diet also provides neuroprotective benefits, but this is nowhere promoted in the Parkinson's community. We are left to wonder why not. Do they suffer from the common misperception that this is a 'fad diet' for losing weight? It appears to me that the benefits of adopting a proper ketogenic diet will be fully equal to the benefits of vigorous exercise, perhaps even more so.

My literature search yields only the two studies (2) and (6) done in the last 15 years, both showing favorable effects of a ketogenic diet; both calling for further study. Yet it appears that no studies of the keto diet and PD are on the horizon. None are listed in the web pages (linked above) that show studies funded by the Parkinson's Foundation or Michael J. Fox Foundation.

## Designing an educational, scientific study

A scientific study question might be:

*Will a proper ketogenic, user-friendly lifestyle such as defined by Volek and Phinney, slow down or even reverse the progression of Parkinson's Disease?*

There are many ways to design studies. Small or large. Tightly controlled by medical staff or open to participation and control by self-selected individuals.

Given that studies have already shown that this lifestyle is beneficial, it seems desirable to give Parkinson's patients every opportunity to enjoy the benefits without further delay. I would advocate for a large, web-based, information intensive, open study that takes full advantage of today's technologies.

The foundations mentioned above have large mailing lists. Mailings, press releases, and articles in media can invite patients and care givers to join, whenever they are ready, to a long-term, unlimited and open-ended, study program that will take them by the hand, educate them about a low carb, high fat, adequate protein lifestyle, help them get started while paying attention to initial metabolic changes and requirements such as the need to increase salt intake, and document results.

Given the ready availability of programs designed for customer interaction, whether PCs or smart phones, it cannot be difficult to design an application that provides the necessary progressive education by text and video, starting the moment a patient signs on.

The program can document the study participant's initial condition with a web-based version of the MDS-UPDRS, and request participants to update this assessment from time to time.

The program can suggest cook books and meal plans and record actuals. Naturally, the program should also ask for and record patient data about exercise and any other relevant conditions, such as medication. This will not be a weight loss program, but existing weight loss programs (and the only one I am personally somewhat acquainted with is Cronometer) may be a place to start. These programs are designed to keep track of your physical condition and food habits. Incorporating a progressive education should not be that difficult.

Even if a rather small percentage of possible participants start the program, and many drop out for any number of reasons, a substantial number are likely to catch on and stay with the study program for years for the simple reason that they feel and function better. Data collected by this web-based study application over several years from those who continue will document the rate of disease progression, a trend that can be compared with equivalent data about PD progression during the last several decades.

## **Implementing and funding an educational, scientific study**

Suppose an existing commercial program comes close to providing all the educational and record-keeping features I have suggested above, what would be required to make it scientific? A commercial program may come with an annual fee, such as \$50.- to pay for development, customer support, and some profit.

To my mind, our educational, scientific study may come with technical support just the same, but no fee. Or a fee that makes the program self-funded, but now the worry will be that long-term participation suffer. Better yet, a single, up-front fee for lifetime support, such as \$100. That might be sufficient for the study to be self-funding and an incentive for participants to follow-through. No incentive to drop out.

The big difference will be that an organization such as the Parkinson's Foundation, Michael J. Fox Foundation, Charlie Foundation, Ohio State University, or Stanford, supervise development and operation of this program.

And all data will be archived for analysis with full permission by study participants.

For supervision of the educational part of the program, I would nominate Jeff S. Volek and Stephen D. Phinney. [www.artandscienceoflowcarb.com](http://www.artandscienceoflowcarb.com)

Well, I am way out of my element here. I don't know how foundations, existing health maintenance web-based programs, professors and their grad students, startups, or whoever, might grab this tiger by the tail. I just think that there is an opportunity here to do a lot of good for lots of people. Both near- and long term.

And Parkinson's is not the only neurodegenerative disease that can benefit from an educational, scientific study along these lines.

## **Crystallizing my thoughts**

Reflecting on my rambling thoughts above, it occurs to me all elements for the educational study program I envision are already represented on the web, ready to be adapted.

- Website with sign-up and tabs / links to ...
- Resources, text and video
- Health and Keto monitoring app with download for PC, Mac, Smartphone
- A pre-programmed sequence of follow-up emails, pointing to text and video
- Tech support center — email and telephone
- Keto / Parkinson support center — email and telephone
- User forum, moderated of course
- FAQ

Best to all,

*Dag Forssell*