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Message from the Executive Director:

As I write this, I have learned that former Board Member, Advisory Board Member, Friend and long time MS supporter, Ron Ross has passed away. Ron was instrumental in the inception of MS Resources and helped us get it off and running. Over the past 21 years his generosity, support and commitment to our agency was truly commendable. He was the first recipient of the Crusader for a Cure Award presented at the MS Dinner of Hope. Ron was active in the Annual Jackson Golf Tournament, The MS Dinner of Hope, the Annual Mission Steps Walk, the Mike Goss Memorial Comedy Show and most recently our Annual MS Clambake. He was always the first person to purchase any type of raffle tickets, help sell them and always donating gift certificates for prizes. Many of you, I am sure, knew Ron Ross, he was the owner and operator of Twin Trees Too! on Milton Ave. Ron will be deeply missed and never forgotten! Rest In Peace – My Friend!

We have recently acquired an intern from OCC working in our office for a few months. Jay assisted us with our booth display at the Fair and has been working with Annette on the Poker Walk and client services. Annette has asked her to create a Satisfaction Survey as we inch closer and closer to starting year 22 of MS Resources. This survey will be put on the website and you can answer it there

or feel free to contact the Office at (315) 438-4790 and request a paper copy. We can also email it to you. We would love your candid remarks and honest comments as we move into a new year of the agency. Thank you in advance for your participation.

Wishing you all a happy fall and before you know it the Holiday Season will be upon us. To all those who take little goblins and witches door to door to trick or treat, stay safe.



Look inside for:

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Paleo Diet May Reduce Fatigue by Improving Cholesterol

By Ana Sandoiu – Medical News Today

Fact checked by Jasmin Collier – Aug. 2019

New research investigates the effect of following a Wahl's paleo diet on fatigue in MS.

According to some estimates, at least two-thirds of people with MS experience debilitating fatigue as part of their condition. There are many possible explanations for fatigue in MS.

For example, exhaustion can result from the pathobiological processes associated with this condition, such as inflammation of the nervous system or demyelination. It may also result from psychological conditions that often accompany MS, such as depression and stress.

Alternatively, it could be due to the poor diet and insufficient sleep that people with MS often report. Regardless of its precise causes, treatment options for fatigue in MS are scarce, and anti-fatigue drugs such as modafinil and amantadine often have side effects. Some research has suggested that making dietary changes could improve fatigue in MS. For instance, a previous study has shown that a very low fat, plant based diet can improve exhaustion in people with RRMS.

New research aimed to investigate whether such positive effects were down to a change in lipid profile and cholesterol.

Murali Ramanathan, Ph.D, a professor in the University of Buffalo School of Pharmacy and Pharmaceutical Sciences in Western NY, is the lead author of the new research,

the results of which now appear in the journal PLOS One.

Professor Ramanathan and colleagues clinically followed 18 people with progressive MS over the course of 12 months. During this time, the participants followed a strict Wahls diet, that is, a "Paleo" diet that Dr. Wahls developed in 2008.

The Wahls diet excludes grains, dairy, eggs and legumes and encourages the consumption of fruits, vegetables, meat and fish.

In addition to making these dietary changes, the participants enrolled in an exercise program that included stretches, strength training exercises and neuromuscular electrical stimulation as well as meditation and stress reducing self massages.

During the follow-up period, the researchers tracked changes in the participants body mass index (BMI), calorie intake, overall cholesterol levels, triglycerides, high density lipoprotein (HDL) cholesterol levels, and low density lipoprotein (LDL) cholesterol levels. Participants also reported their fatigue levels using the Fatigue Severity Scale.

The study found that higher levels of HDL or "good" cholesterol, correlated with improvements in fatigue. Reductions in total cholesterol also correlated with a reduction in exhaustion.

"Highest levels of HDL had the greatest impact on fatigue," Prof. Ramanathan reported.

He speculates on the potential mechanism behind the findings, saying that the positive role of good cholesterol may be "because it

plays a critical role in muscle, stimulating glucose uptake and increasing respiration in cells to improve physical performance and muscle strength.”

The researchers acknowledge, however, that their study is only a pilot one, and that more research is necessary. “Our results require confirmation given the limitations of the current pilot study design, which include the small sample size, lack of control group, and randomization,” they write. “However, if confirmed in larger studies, lipid monitoring may become useful for guiding fatigue treatment decisions,” explains Prof. Ramanathan and colleagues.

“Fatigue in people with MS has been viewed as a complex and difficult clinical problem with contributions from disability, depression, and inflammation. Our study implicates lipids and fat metabolism in fatigue.”

- Professor Murali Ramanathan

Drug Costs Rise

Over the course of a decade, out-of-pocket costs for multiple sclerosis drugs rose more than sevenfold for Medicare Part D beneficiaries, according to a *JAMA Neurology* study published by researchers at the University of Pittsburgh.

Using Medicare claims data from 2006-2016, the researchers looked at trends in multiple sclerosis drug prices over time. Not only did they find steep increases in list prices -- the starting point before rebates, coupons or insurance kicks in -- but also in the ultimate costs to both Medicare and its recipients.

"We wanted to see how increases in list prices translated to increases in out-of-

pocket spending, and we discovered that actual price increases do get passed down to patients, and that can negatively affect access," said study senior author Inmaculada Hernandez, Pharm.D., Ph.D., assistant professor of pharmacy at Pitt.

Several drugs on the market reduce the frequency and severity of multiple sclerosis flare-ups, which can involve a variety of disabling neurological symptoms, such as vision loss, pain, fatigue and muscle weakness.

From 2006-2016, the annual list prices of these drugs more than quadrupled, ballooning from about \$18,000 to nearly \$76,000 per patient per year.

Some of the most popular drugs for treating multiple sclerosis are Copaxone, Tecfidera and Avonex, and, despite increased market competition over time, prices have been rising steadily for nearly all of them.

"One of the most significant findings was that the prices of these drugs have increased in parallel," said lead author Alvaro San-Juan-Rodriguez, Pharm.D., a pharmacy fellow at Pitt. "Only a couple exceptions deviate from that general trend."



Although this trend among list prices is alarming on its own, critics have argued that since some of the cost is canceled out by manufacturer rebates and other kinds of discounts, rising list prices may not be translating into increased spending.

But since Medicare claims provide a detailed cost breakdown, the researchers were able to measure changes in what Medicare Part D beneficiaries actually paid out of

Drugs Cont'd

pocket for multiple sclerosis drugs, as well as what Medicare itself paid. What they found was that from 2006-2016, Medicare spending increased by more than tenfold, and the patients themselves saw more than a sevenfold increase in their share of the bill.

"We're not talking about patients without health insurance here," Hernandez said. "We're talking about insured patients, under Medicare. Still, they are paying much more for multiple sclerosis drugs than they were 10 years ago."

Additional authors on the study include Chester Good, M.D., M.P.H., Natasha Parekh, M.D., M.S., and William Shrank, M.D., M.S.H.S., from the UPMC Health Plan; and Rock Heyman, M.D., from Pitt and UPMC. Funding was provided by the Myers Family Foundation and the National Heart, Lung, and Blood Institute (grant number K01HL142847). Hernandez disclosed fees paid to her personally by Pfizer, for services unrelated to the scope of this work.

Story Source: Materials provided by **University of Pittsburgh**. *Note: Content may be edited for style and length.*

ScienceDaily. ScienceDaily, 26 August 2019. www.sciencedaily.com/releases/2019/08/190826110402.htm.

MS Resources Support Group Information

Interested in sharing experiences about MS, come with family/friends to a meeting.

Syracuse Area-

2nd Tuesday of the month

Lincoln Middle School

1613 James St. Syracuse NY 13203

6:30PM-8:00PM School Cafeteria

Contact: Angela McBride- (315) 876-2614

Madison County Area-

1st Monday of the month

Onondaga Center, Russell Street,

Chittenango – Conference Room

2:00PM-4:00PM Contact: Donna Denison

for more info at (315) 655-3517

Auburn/Cayuga County Area-

4th Tuesday of the month

Finger Lakes Mall, Rts. 5 & 20

Auburn, Community Room

Enter at Mall Entrance by Penney's. 7PM

Contact: Susan Rusinko (315) 255-0982 or

Bernie Caruana at (315) 252-1183

Liverpool Group –

3rd Tuesday of the month

United Church of Christ (UCC) in

Bayberry, 215 Blackberry Rd. 6PM – 8 PM

in Fellowship Hall, follow the signs to the

meeting room. Contact: Carolyn Vickery –

(315) 409-9692

Broome County Group –

4th Thursday of the month

Dunkin Donuts on Reynolds Rd. Johnson

City in the Community Room 6:30PM –

8:00PM Contact: Steve Yeager – (607) 785-

7703 or Rick Fiori – (607) 321-1489

MS Breakfast Buddies –

Meeting in the Binghamton area:

Contact Sue Maston: (570) 623-2302 for

times and locations.

Fairmount/Camillus Area -

1st Tuesday of the month

Fairmount Community Library

Chapel Dr. Fairmount NY 13219

1:30PM – 3:00PM Community Room

Contact: Ericka Braundel- (315) 391-6912

Amazon.com Offers Incentives to Charity

For all of you who purchase items through Amazon.com, we have news for you.

*******News Flash*******

For a direct link to MS

Resources use:

smile.amazon.com/ch/16-1558498

We will receive .5% of your overall sales when you select us. Log onto the computer and remember MS Resources as you make your purchases, but it must be entered through Smile.Amazon.com. Questions, call Jessa at (315) 438-4790.

Annette's Corner

The Great NY State Fair ended in September with record breaking attendance. This was a remarkable feat under the new State Fair Director. I attended on Wednesday, August 28 (my birthday) for the women's day health fair which the agency had a table display set up in Chevy Court under the pavilion. I still think of that spot as Miller Court or Cole Muffler Court from yesteryear. The sights, smells and sounds were exactly the same as they were from as far back as I can remember. My parents would take my brother and I during the run of the fair three or four times. I recall packing picnic lunches and snacks and climbing in to the station wagon for a day of excitement. We would go through the buildings with the highlights being the butter sculpture, getting chocolate MILK, doing a hand writing analysis and of course playing games on the midway and possibly catching a horse show at the coliseum. (my cousin Tracy was a rider and we would try to see her competition) My dad and I would ride the overhead monorail across the midway

which was a really cool thing. I could identify for him all the games I wanted to play and he would check the finances to be sure we had enough cash for this. We would meet up with my mom and brother who had secured our pizza fritte from the Villa, a regular tradition for most people and especially Italians who love pizza fritte (friend dough). This was a staple in my house much the same way mile and eggs were. One bag would house 4 pieces for Grandma and Grandpa and the other would have 6 pieces for us to enjoy at home.

As the years passed, my parents were more inclined to provide us with a Fair Allowance and Centro bus fare. I guess I was about 13 or 14 when I traveled to the Fair without parental guidance. My best friend, Sharon and I would go downtown and catch the bus to the Fairgrounds, often with her younger sister and a friend in tow. We would guard our cash like priceless gems because that was all we had to spend the entire day. We would make the "mad dash" through the buildings checking out the butter sculpture and getting our 10cent milk. We would often sit in on the fire safety presentation (knowing our parents would be so proud of us) We would plot out our route down the midway and strategize our combined talents to win one of the coveted largest, bulkiest, most colorful Fair stuffed prizes. We would pass the barkers yelling about guessing your age, weight, etc. I'd like to have them try to guess what street I lived on, now that would be amazing for just \$1. We found our sweet spot at the basketball shoot. This was our game of choice, the one we had the best odds to win. Back then you could get 3 balls for \$2. Sharon and I were both on the girls basketball team at our elementary school, so we thought with our NBA talent we surely would leave the Fair with multiple

Annette's Corner Cont'd

prizes. I will admit, we did pretty well, sinking basket after basket and peeling off dollar bills until our wads of cash had diminished in size. One year, Sharon's younger sister Lori brought her friend Kathy with her to the Fair and I was desperate for the Giant Pooh (my favorite) I saw. We searched for the game where we could win this and it was the HIGH Basketball game. I dug out \$3 and Kathy professed quite emphatically that she could do it, and on the very first try, she sunk the basket and Pooh was handed to me. Our attitudes changed as we walked around the Fairgrounds as if we just cashed in a winning jackpot lottery ticket. We smiled, or maybe smirked as we walked past these muscular dudes holding their girlfriends hands with their teeny 3inch stuffed animal. We were the best, the coolest the most proficient basketball shooters that the fair ever had! The days would wind down and before we boarded the bus, we would run to the Villa to bring home the cherished pizza fritte. We boarded the bus, Pooh in his own seat and we dreamt of getting basketball scholarships—well that never happened. Our talents were strictly for the hot tar of the midway.

This year, I had the best little companion to enjoy the fair with, Jessa's little 5year old granddaughter, Mikala. We had a blast as we navigated the buildings and dodged the torrential rain, though Mikala did find several puddles to wade through. She held my hand and we picked out a mermaid she needed and we saw the sand sculpture, enjoyed lunch and met up with Kimberly, Jessa's daughter to check out the other exhibits. We colored a picture by the State Legislative booth and then made our way to the games. I was instantly transformed to that 13 year old kid trying my best to win

Mikala a prize. Swish after swish at the basketball game, and 2 giant balls later, I knew I still had it! My little buddy directed me to where the Villa stand was and I made my purchase. Nothing really has changed in 40 or more years, the sights, sounds and smells are still the same. Until next year, I await the fun the fair holds for me and another opportunity show off my skill at the basketball shoot.

Save The Date

We have scheduled the Annual Client Holiday Party at the DoubleTree on Carrier Circle for December 8, 2019.
(note date change)



It will be from 11:30am – 2:30pm. Limit 2 people and there will be a \$10 per person cost.

Mark your calendar.



Harmar Scooter Lift and Swing Away Bracket – asking \$900

Harmar Micro Scooter Lift - \$1,195

Rollator – White , Petite - \$235

Contact: Jessica.bartle1@gmail.com

More Items For Sale

Upper & Lower Body Passive Assist
Trainer- Used only a few times

Drop Arm Roll in Shower Commode Chair
with soft seat & footrest, Never Used – all
assembled

Go-Go Elite Traveller Plus – 3 wheel
scooter - (has brand new battery)

Medline Excel Transfer Chair -
**Contact MS Resources if interested in any
of this equipment.**



Special thanks to Andy Sayles for thinking
of MS Resources for his fund raiser. Andy
had 18 friends play Super Smash Brothers
for hours and he had them donate \$15 per
player. His grandfather matched what was
raised and they presented the check to the
agency. Thank you again for your
thoughtfulness and generosity.

Newsletter is written and edited by:
Annette Simiele

Call (315) 438-4790/1-800-975-2404

Fax (315) 438-4704

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Website - www.msresources.org

Call us if you need us.....

MSing Link

About 2.3 million people live with MS
worldwide. Once diagnosed, people with
MS undergo a series of tests with
neurologists and are unlikely to see a PT

unless recommended by their doctor. The
MSing Link was created as a way for those
living with MS to have the opportunity to
interact with an MS certified PT. Dr.
Gretchen Hawley, founder of The MSing
Link says that this interactive site is
“flexible with options to sign up for
monthly, semi-annual and annual
subscriptions.”

To read more about Dr. Hawley visit:
MSingLink.com or email her at
Gretchen@DoctorGretchenHawley.com. If
you would like a subscription, mention
MSPT and receive \$10 off your semi-annual
or annual subscriptions.

For the one page flyer that was sent to MS
Resources, please call the Office and request
the MSing Link page.

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HAPPY FALL.....

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