

New Findings in Parkinson's May be More Than a Gut Feeling

By April Ingram

Despite how careful we are to wash our hands and steer clear of germs, we are essentially walking petri dishes, covered in bacterial colonies from our skin to the deepest, darkest corners of our gut. Microbiologists estimate that we have roughly 40 trillion bacterial cells (2-5 pounds worth) in our bodies compared with only 30 trillion human cells. Before you start to feel too creepy about being more bacteria than human, it is actually a very good thing.

While some bacteria are associated with disease, most are extremely important for your immune system, heart, weight and many other aspects of health. The trillions of bacteria, viruses and fungi (microorganisms) are collectively known as the microbiome and it is crucial for good health. In fact, the more diverse your microbiome, meaning the more different types of microbial species you have, the better.

The gut microbiome controls how your immune system responds to infection, and recent research has suggested that it may also influence the central nervous system (CNS), controlling brain function. Data from several studies indicate that the gut communicates with the CNS possibly through neural, endocrine and immune pathways that may influence brain function and behaviour. Studies conducted in germ-free animals were compared to animals exposed to pathogenic bacterial infections, probiotic bacteria or antibiotic drugs and the results suggested a role for the gut microbiome in the regulation of anxiety, mood, cognition and pain. These findings provided the framework for a microbiome-gut-brain axis and hypothesized that changing or regulating microbiome may be a plausible strategy for developing novel therapeutics for complex CNS disorders.

Typically, studies in Parkinson's disease are focused on nerve cells and the deepest parts of the brain. However, researchers from the University of Alabama at Birmingham, lead by Dr. Haydeh Payami, Ph.D., professor in the Department of Neurology, believe that the symptoms of Parkinson's disease could be a consequence of the type of bacteria living (and not living) in our gut. This may not be entirely new thinking; according to Hippocrates, "All disease begins in the gut."



The researchers wanted to compare the microbiome from people with Parkinson's to those without. They collected and analysed samples of gut microbes from 197 patients with Parkinson's disease and 130 individuals without. Individuals were from Seattle, New York, and Atlanta to also see if there were any regional differences.

The researchers found that the gut bacteria of someone with Parkinson's disease was different from someone who does not have the disease, in terms of the prevalence of different species. This raised the question of whether having Parkinson's caused changes in the gut microbiome, or whether changes could be a predictor or early warning sign of Parkinson's.

The important role of the microbiome may also explain why some initial signs of Parkinson's often manifest as gastrointestinal symptoms, such as inflammation or constipation. Additionally, the research team detected unexpected differences in gut imbalance as a function of geography, which may reflect the environmental, lifestyle and diet differences between the three regions across the country.

(Continued on Page 2)

The Parkinson's and Movement Disorder Foundation

14772 Moran Street
Westminster, CA 92683
(714) 369-7426
www.pmdf.org

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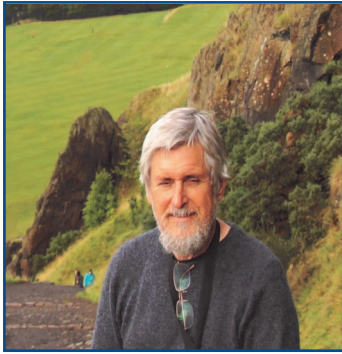
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President's Letter



Dear friends of PMDF

It's time once again to do what PMDF was established to do: provide funds to support important research on movement disorders. This year we received 26 applications, the second-highest number ever. The proposals are being evaluated now, and at the next board meeting we will choose the two we will fund in 2018. This is an exciting time, as we see all the new ideas that are being pursued in understanding, assessing, treating, and ultimately curing these diseases. It's a disappointing time, too, though, because there are always worthy projects we can't support.

A quick calculation will show that we are only funding a small fraction of the proposed projects. It's not too late for you to help expand our impact with a donation. PMDF has a very low overhead, with only one part-time paid employee, so most of the money we receive is spent on research. Your donations make a difference!

Sincerely,

A handwritten signature in cursive script that reads "Mark Wadsworth".

Mark Wadsworth
PMDF President

New Findings in Parkinson's May be More Than a Gut Feeling (Cont.)

Not only did the results show marked differences in the numbers and types of bacteria between the two groups, they also noticed a difference in the metabolism of various medications. Either the different drugs taken by people with Parkinson's disease were having a unique impact on the bacteria, or their microbiome was affecting how their bodies responded to the drugs. This was a bit of a chicken and egg result, and left the researchers to wonder if the differences in people's microbiome were caused by, or an effect of Parkinson's disease.

Microorganisms in the gut also play an important role in breaking down and ridding the body of environmental toxins. An interesting finding of the study was that the composition of bacteria responsible for removing these toxins was different in individuals with Parkinson's, suggesting that exposure to environmental toxins may alter gut bacteria in people with Parkinson's. This result may be applica-

ble to previous research related to pesticide and herbicide exposure in agricultural settings and the relationship to Parkinson's risk.

This research was supported by funding from the National Institute of Neurological Disorders and Stroke and published in the journal, *Movement Disorders*, (2017 May;32(5):739-749). Although the authors suggest that the present findings lend support to the notion that the composition of the gut microbiome may hold new information for assessing efficacy and toxicity of Parkinson's medications, they note that additional studies are needed, with larger numbers of treated and untreated patients, as well as individuals who do not have Parkinson's.

PMDF Social Media Platform

By Tien Nguyen

Recently, it has become an interest of the Parkinson's and Movement Disorder Foundation to develop a greater impact on social media. In order to gain further awareness on the mission of our organization, we have reinitiated our Facebook page. Along with having information about our organization, we post news and content relative to various movement disorders, including Parkinson's disease.

Building a greater following online, we will be able to build more interest in our community, while further promoting events such as our end of the year fundraiser & annual Zent-a-thon. In turn, this can engage our friends of the PMDF to generate further awareness and interest, as well as generating potential funds to supplement research towards movement disorders in 2018. Please join us in spreading the word and liking us on Facebook (www.facebook.com/thePMDF).

Parenting Children with Dystonia

By April Ingram

Receiving the diagnosis that your child has dystonia can be overwhelming, filling you with questions and uncertainty. Quite often, even getting to the diagnosis itself can feel like you have already been through battle.

Heather Connor, a mother of two children with dystonia, knows the challenges and the victories first-hand and has chronicled them in her blog, *Raising Dystonia*. Connor describes when her first son was born seven years ago. Unlike other infants that spit up after a meal, he did so more frequently and appeared to be in excruciating pain. She took him to the pediatrician and received a diagnosis of GERD (gastroesophageal reflux disease) and was given omeprazole, a proton pump inhibitor to calm the symptoms. At 6 months, Connor noticed her son would arch backwards, he looked awkward, twisted . . . different from other babies. Her physician told her not to worry and assured her that he would grow out it, but she requested a referral to a neurologist. They received a diagnosis of Sandifer syndrome, a disorder characterised by gastrointestinal symptoms and associated neurological features. When Connor's son was age 3, she

felt that sometimes he walked a bit funny (although he never did so while in the doctor's office) and he had not outgrown the reflux and chronic pain, now compounded with respiratory issues from inhaling stomach acid. She knew that there was definitely something wrong.

Fast forward through referrals and consultations with nine specialists, until finally at age 4 1/2 Connor's son received the diagnosis of dystonia. After another 6 months, the family learned that the specific diagnosis was myoclonic dystonia. By this time, the Connor family had welcomed their second child, who also demonstrated the same symptomatic arching and was eventually diagnosed with myoclonic dystonia.

Heather Connor shares that one of the biggest challenges of parenting a child with dystonia is separating the behavior from the disorder, meaning discerning whether the tantrum is because her child is cramping or spasming or just a typical angry, frustrated 3-year-old.

Although dystonia affects each child differently and the impact of the dystonia on their daily lives and the lives of family members varies, as a mother of two children with dystonia, Heather Connor offers some real-world insight and candid advice based on her experiences.

Be persistent, educate yourself and ask more of your physicians – when you feel that something is wrong and perhaps you aren't feeling heard by your physician, or having your questions brushed off, you aren't crazy, educate yourself, be persistent. "Don't quit. Be vigilant, you can't ask too many questions. Dystonia is a long journey and there is no quick fix, you are in it for the long haul, so get your gloves on and get ready to fight."

Find support – parents can feel isolated, because they are dealing with a disorder that is ever-present in their lives but invisible to others, and there is a lack of resources in most communities. Often, physicians don't know where to direct parents for support. Connor suggests that online support (groups or forums) is the most helpful, easily accessible and convenient.

Educate others – Connor shares that people cannot support what they do not know and suggests that parents tell others about dystonia, and help them understand. She explains that other children in her sons' school and peer group seem to be better than most adults. Children are curious, but most react with empathy, concern and compassion. Adults often take more convincing, especially if they have not heard of dystonia or haven't witnessed an episode. Since learning about dystonia, the school has been understanding and incredibly accommodating.

Be the paparazzi – Take lots of photos and video of your child. Document episodes of dystonia as well as the times

when things appear to be normal, or even when they are asleep. This will help to explain movements, postures, sounds or other issues to your physician and illustrate apparent changes as the children grow, or when on or off different treatments.

Be flexible – despite living in a highly structured world, with a disorder like dystonia that can be episodic, being flexible and having the ability to surrender the day's plan will make things less stressful. "Accept that things are not likely to go as planned...and when they do, it's a bonus."

The Connor family describes parenting children with dystonia as an incredible journey and, despite the challenges, they are grateful. The children are now seeing a Pediatric Movement Disorder Specialist at The Hospital for Sick Children in Toronto and have participated in dystonia research and gene trials at Toronto Western University.

5K Walk/Run Fundraiser

The Parkinson's and Movement Disorder Foundation and The National Spasmodic Torticollis Association are hosting the 8th 5K Walk/Run Fundraiser to raise funds and help spread awareness of Parkinson's and other movement disorders. The fundraising event will take place at Mile Square Park in Fountain Valley, California, on Saturday, May 19, 2018.

This is a great opportunity to get outdoors with family and friends, support the two organizations, get some health benefits, and raise awareness. This will be a fun and friendly family event that everyone can enjoy. Kids under 12 do not need to pay the registration fee.

Prizes will be awarded to the 1st, 2nd and 3rd persons to cross the finish line. Prizes listed on next page.

All participants who paid the registration fee will automatically be entered in a raffle and have the opportunity to win gift card prizes ranging from \$79.99 to \$5. There are over twenty-five prizes being raffled off! In addition to winning prizes, registered participants will also receive lunch catered by Katella Deli Restaurant and Bakery located in Los Alamitos, a T-shirt, and beverages.

This year we are adding activities for kids, including a coloring and drawing area, and "beach volleyball" for kids. If there is an activity you would like us to add please contact us and we will see if it is feasible. This is a family event so we welcome any suggestions to make it more fun and entertaining for everyone.

We would like to give special thanks to the following companies for their generous sponsorships: Katella Deli Bakery and Restaurant, AbbVie, ACADIA Pharmaceuticals, Lundbeck Worldwide, Merz Inc., and US WorldMeds. We would also like to thank our new Treasurer, Gianni Truong in helping us to secure funding to continue this fun family event.

If you are in Orange County, LA County, or San Diego County, bring your family and friends and participate in the Zent-A-Thon! You can walk the 5K, run the 5K, or both. Street parking is available around Mile Square Park, meter-free. If you park your car on the grounds, parking is \$5 per vehicle. You can register online by visiting <http://www.pmdf.org/events.php> or by mail using the form on the last page in the newsletter. If you are bringing a child (or children) under 13, please let us know so we can make sure food arrangements can accommodate everyone attending. Due to park regulations, registration cannot be processed at the park. Please register by June 5.

If you are unable to attend the event please consider helping us to promote the event and raise more awareness by promoting it on Facebook by liking the page and/or sharing the page with your friends. The link can be found on our Facebook page at www.pmdf.org/thePMDF.

Zent-A-Thon 5K Walk/Run Fundraiser

Mile Square Park
Fountain Valley

Saturday, May 19, 2018

8:30 am: Sign-In

10:00 am: Race Start Time

11:00 am: Lunch Available

First Place Prize –TBA
Second Place Prize –TBA
Third Place Prize - TBA

Chance to win a prize in raffle drawing. Raffle prizes include: Complimentary Six Flags Magic Mountain Ticket, Katella Deli Gift Card, Amazon Gift Card, Starbucks Gift Card, iTunes Gift Card, Target Gift Card & More

\$20 – per person to register

\$5 – parking inside the park

Free – street parking

Lunch, T-shirt and beverages are provided for participants

Register online at: <http://www.pmdf.org/events.php>

Sponsors



**5K Run/Walk
Saturday
May 19, 2018
8:30 a.m.**

Movement Disorders

**Mail-in registrations
must be postmarked
by May 3, 2018**

Registration Form

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

EMAIL: _____ PHONE: _____

5K T-SHIRT SIZE (Circle One) Adult: M L XL Minimum age of entry 13

How many child/children you will be bringing under 13: _____ (free)

IN CASE OF RAIN: The race will proceed as planned. We reserve the right to change the date under extreme circumstances.

ADDITIONAL DONATIONS

Donations are tax-deductible and an acknowledgement letter will be sent to the donor for tax purposes

Contributor Information			
First Name	Last Name	Mailing Address	Amount

ENTRY FEE(S) OR DONATION

Entry Fee: \$ _____ (\$20)

Donation: \$ _____

Total: \$ _____

My Employer has a Matching Gift Program: \$ _____

Please make check payable to NSTA

Visa () MasterCard ()

Credit Card No.

Expiration Date

CVV Code (last 3 digit on the back of your card)

Mail Entry Form & Payment to:

PMDF
14772 Moran St.
Westminster, CA 92683
For more information call: 714-369-7426

RELEASE FORM (all registrations must be signed)

I hereby waive any and all claims against NSTA, PMDF, event sponsors, personnel, and all other persons, firms, corporations and/or entities or anyone associated with this event, their respective or successors, for any injury or claims for damages that I may suffer from participation in this event. I grant full permission for organizers to use photographs, videotapes, recordings or any other record for this event.

Signature

Date

Signature of parent or guardian (if under 18 years old)

Date



THE PARKINSON'S AND MOVEMENT DISORDER FOUNDATION

14772 Moran Street
Westminster, CA 92683

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OUR MISSION

To support basic and clinical research into the causes, treatments and cures for Parkinson's disease and other movement disorders such as dystonia, myoclonus, spasticity, and tremor.

The Parkinson's and Movement Disorder Foundation is committed to working with other organizations that have similar philosophies in an effort to bring together expertise from both basic and clinical science perspectives.

We are dedicated to enhancing the quality of life for those who suffer from movement disorders and their families, through research, education, and community outreach.