### AMERICAN PARKINSON DISEASE ASSOCIATION

# INSIGHTS

# THE RISE OF BIOMARKER TECHNOLOGY IN PARKINSON'S DISEASE

A biomarker is a clue inside the body that indicates that disease is present. A biomarker can be an imaging test, a biopsy, or a test on a body fluid such as blood or cerebral spinal fluid. Recently, there has been an abundance of news about biomarkers and possible new ways of testing for Parkinson's disease (PD). This is an exciting time for the PD community as these biomarkers are already changing how PD clinical trials are conducted — and in the near future, could revolutionize how PD is diagnosed, treated, and monitored over time.

### A biomarker is a clue inside the body that indicates that disease is present.

For a long time, there were no reliable biomarkers for PD. This was challenging for researchers as they were not sure whether everyone in a clinical trial truly had PD or whether their disease changed with therapy.

Dr. David Standaert — a professor and Chair of the UAB Department of Neurology, senior member of the faculty of the Division of Movement Disorders, and chairman of APDA's Scientific Advisory Board — spoke with us in a recent webinar about PD biomarkers. He discussed an imaging biomarker called a DaTscan which detects the loss of dopamine nerve projections that occurs in PD. It is used when the diagnosis of PD is uncertain (such as when there are very mild symptoms), there is an uncertain response to levodopa, or there are other unusual clinical features.

"Not only are we looking for a treatment for Parkinson's, but we're also starting to talk about prevention."

### – Dr. Standaert

Alpha-synuclein is a protein that is normally found in cells in the brain and throughout the body. In PD, for reasons that are not yet known, alpha-synuclein aggregates into abnormal forms. Dr. Standaert discussed two recently developed biomarker tests that detect this abnormal alpha-synuclein. One is a skin biopsy that is stained to see whether the abnormal alpha-synuclein is present in nerve cells within the skin biopsy. The other test, on *cerebral spinal fluid*, takes advantage of the "seeding properties" of abnormal alpha-synuclein. If normally shaped alpha-synuclein molecules are mixed with abnormally shaped molecules, the normal molecules will take on the abnormal shape. This grows the amount of abnormally shaped alphasynuclein which can then be detected in a lab test. Research is underway to use the seeding assay to detect abnormal alpha-synuclein in blood, a more easily accessible body fluid for testing.

Of particular interest is the fact that abnormal alpha-synuclein can be detected in people with non-motor symptoms of PD such as loss of smell



and REM behavior sleep disorder, who do not yet show motor signs of PD such as slowness, stiffness, or tremor. This means that biomarkers could potentially change when a diagnosis of PD is made. By moving up the diagnosis to when there is less disease present, researchers hope that interventions will have a better chance of preventing progression of PD.

To watch the full webinar and learn more about the importance of biomarkers in PD, visit **apdaparkinson.org/PDTesting.** 

> **BREAKING NEWS INSIDE:** Read more about the National Plan to End Parkinson's Act!



For more information, or to learn about the many ways you can support APDA, visit our website at apdaparkinson.org/Renewal or call (800) 223-2732.

AMERICAN PARKINSON DISEASE ASSOCIATION

# A MESSAGE FROM OUR PRESIDENT & CEO

#### Dear Friend,

For more than sixty years, we have worked tirelessly to help everyone facing Parkinson's disease



(PD) thrive. Thanks to partnerships like yours, we can continue to make headway in the fight against this chronic disease.

There are so many exciting things happening here at the American Parkinson Disease Association (APDA). In this latest issue of *Insights*, you'll learn more about the role of biomarkers in the diagnostic progress for PD, discover the pivotal impact of the National Plan to End Parkinson's Act that recently passed, and much more.

You have the power to help maintain our momentum as we move closer to finding a cure for this disease. In the meantime, we will continue to provide the very best support for those affected by PD and their loved ones so they can live each day to the fullest. Thank you for your generosity.

Warm regards,

Lexus Q. Clamsert

Leslie A. Chambers President & CEO American Parkinson Disease Association



# **LEGOS FOR PARKINSON'S**

As part of the FIRST\* LEGO<sup>®</sup> League program, a group of students (11–13-year-olds) from South Carolina calling themselves the "Argent Agents" developed three tools out of Legos that make it easier for people with Parkinson's disease and essential tremors to use a paint brush, pencil, or marker so they can create art.

After winning the SC State Championship, these ingenious inventors advanced to the FIRST LEGO League Challenge World Championships in Houston, Texas, where they captured the Best Robot Design award! The competition included the top 110 teams — out of about 30,000 from around the world. The FIRST LEGO League program teaches young people how to think like engineers and solve problems as a team. As they were fine-tuning their inventions, they reached out to APDA for expert feedback, and Dr. Rebecca Gilbert spent some time learning about their project and sharing her thoughts.

Importantly, they added a fundraising component and are raising money for APDA (\$804 raised so far!) We are so impressed with these intelligent and compassionate young students and so thankful for their efforts to support APDA!



The Argent Agents include six Greenville students: Lily Arzt, Nicky Arzt, Benjamin Frick, Jackson Champion-Wescott, Jackson Haughton, and Henry Quackenbush. What a team!

If you are interested in raising funds for APDA through a local project or event, please contact jcolasuonno@apdaparkinson.org.

\*FIRST: For Inspiration and Recognition of Science and Technology

# VICTORY FOR THE PARKINSON'S DISEASE COMMUNITY:

# THE NATIONAL PLAN TO END PARKINSON'S ACT IS NOW LAW

It's official: The President has signed The National Plan to End Parkinson's Act into law! This is a momentous event for the PD community — and APDA is proud to have been a part of the efforts that made this happen.

In 2022, the U.S. House of Representatives introduced the National Plan to End Parkinson's Act — the first-ever legislation in Congress focused on curing and preventing PD and ensuring quality care for those living with the disease. Since then, with the help of many advocates in the PD community, it has worked its way through both houses of Congress and was signed into law.

This legislation will create an advisory council composed of representatives from federal agencies already working to end PD, as well as people living with PD, caregivers, health care providers, and representatives from non-profit organizations with experience in PD research and care. The advisory council will meet quarterly to create a strategic plan to end PD and will be responsible for reporting to Congress every two years on its progress and impact.

We are thrilled that there will be more focus on PD from the government to help make an impact on the PD community. This is an extraordinary victory for those living with this challenging disease — but there is still so much work to be done. APDA eagerly supports this new law, and we plan to keep you updated about the next steps in this process as the advisory council is formed and begins its critical work.

In the meantime, the need for APDA's programs and services remains as vital as ever and our commitment to improving the lives of those affected by PD is unwavering.

To learn more about The National Plan to End Parkinson's Act, visit apdaparkinson.org/EndPDAct.

# Want to help even more people facing the challenges of PD?

Scan here to make a difference today.





# Join us for an Optimism Walk!

We've got a robust fall schedule of APDA Optimism Walks and would love for you to come walk with us! Every Optimism Walk is an incredible day of community, inspiration, and family-friendly fun - so grab your friends, family members, and neighbors and start a team; or register on your own and meet lots of great people when you get there! Everyone can win great prizes for fundraising, and the funds raised help fuel local APDA educational programs and resources, exercise classes, support group development, and much more. Visit apdaparkinson.org/ Optimism-Walks to see if there is a Walk near you.

## Are you following us?

If you're not following us on YouTube, you are missing out! Simply search **APDAparkinson** on YouTube and then <u>be sure to hit that SUBSCRIBE button</u> so you never miss a new APDA virtual program. Once subscribed, you'll get notified whenever a new program is coming your way. We've always got great programming in the works for you — including new episodes of *Dr. Gilbert Hosts, Let's Keep Moving With APDA, Café con la doctora,* and more!



# **ASK THE DOCTOR**

### **Q.** I always seem to be nauseous. Are there treatments for this?

A. Nausea can be a side effect of carbidopa/levodopa, the most common and effective medication for PD. If this is the case, then try taking the medication with food. Some people find that dietary protein such as beef, chicken, or fish interferes with absorption of levodopa. So, it is best to take the levodopa with a food that doesn't contain protein, such as crackers, vegetables, pasta, etc. Since ginger can be effective against nausea, you can also try taking the medication with ginger ale or ginger tea. If these strategies are not enough to quell the nausea, your doctor may try a prescription medication to help. It is important to choose the right one since some medications for nausea can make the symptoms of PD worse and should not be taken by people with PD.

Nausea can also be a symptom of gastroparesis, or delayed gastric emptying, a non-motor symptom of PD in which the transit time through the stomach is slowed. If nausea is persistent and does not seem to be a side effect of carbidopa/levodopa (does not occur after ingesting a dose of medication), ask your neurologist for a referral to a gastroenterologist who can evaluate you for gastroparesis. Lifestyle modifications such as eating small frequent meals, avoiding fatty



foods, and walking/moving after eating can go a long way to help with this condition.

#### Q. My mom is experiencing very troubling delusions that someone is coming to hurt her. She is constantly calling me because she is worried that she is not safe. I assure her that she is. What can help the situation?

A. Very often, PD medications are the cause of psychosis - which can be broken down into delusions (thoughts that are not consistent with reality) or hallucinations (sensory phenomenon - visual, auditory, or tactile - that are not based in reality). When the delusions or hallucinations are related to medication, then the first thing to do is to lower the dose of medication. However, sometimes the dose of medication can't be lowered enough to stop the delusions or hallucinations either because that decreases mobility too much or because the hallucinations or delusions are not related to medications and are a non-motor symptom of the disease itself.

When this is the case, the person with PD may need to start a medication to treat hallucinations or delusions. There are specific medications that are used in people with PD with psychosis, since some medications used in the general population to treat psychosis can worsen



the motor symptoms of PD and need to be avoided in people with PD. Be sure to talk to your mother's doctor about her delusions and the possible solutions that can help her.

### Q. My husband's voice is very low, and this makes it difficult for him to communicate. What can be done?

**A.** A low voice volume is unfortunately very common in PD. There are speech therapy techniques directed at raising voice volume. These include Lee Silverman Voice Technique and the Speak Out program from Parkinson's Voice Project. You can find a clinician trained in these techniques on each of their websites. In addition, there is a device called Speech Vive, which some people find helpful as well. This device produces extraneous sound only when you speak, which induces you to speak louder. When you are silent, the device is silent, so that you can hear what is going on around you. In addition, participating in singing programs like APDA's Sing Loud for PD can help exercise your voice. It is important to try to improve this symptom as people with PD can get frustrated and ultimately withdraw from social interactions if they feel like people can never hear them.

Dr. Rebecca Gilbert is the Chief Mission Officer at APDA. She oversees APDA's research portfolio in conjunction with APDA's Scientific Advisory Board. She also provides medical and clinical expertise to support APDA programming as well as print and web content.

American Parkinson Disease Association is exempt from federal income taxes under Section 501(c)(3) of the Internal Revenue Code. apda@apdaparkinson.org | apdaparkinson.org

Published quarterly by the American Parkinson Disease Association, P.O. Box 750, Merrifield, VA 22116 (800) 223-2732 Chairman of the Board of Directors: Bernard F. Battista; Chairman of the Scientific Advisory Board: David G. Standaert, MD, PhD; President & CEO: Leslie A. Chambers