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AAN NEWS & NOTES

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Two AAN members among UAB researchers to find new gene mutation as cause of crippling condition

al.com
by Mike Cason

Researchers at the University of Alabama at Birmingham have found a new genetic mutation as the likely cause of a condition that left a woman in her 20s unable to walk.

UAB's Undiagnosed Diseases Program made the discovery, which is reported in the Sept. 9 issue of *Neurology*, the journal of the American Academy of Neurology. UAB announced the findings in a press release.

The woman began having problems at age 5 and by adulthood could not walk, had hand tremor, leg spasms, intermittent slurred speech and occasional tingling in her fingers and toes. She was evaluated in the Department of Genetics at UAB's Undiagnosed Diseases Program.

Researchers conducted an exhaustive review of symptoms and family history and tests to rule out possibilities.

The patient underwent whole genome sequencing and variant analysis at HudsonAlpha Institute for Biotechnology. That revealed a previously unknown mutation in the ADCY5 gene.

Other variants of the same gene have been linked to childhood movement disorders. The woman's parents did not have the mutation, indicating it was a spontaneous mutation in the woman.

Marissa Dean, MD, assistant professor in the Department of Neurology and the first author of the case study, said the woman's diagnosis was dystonia with spastic paraparesis, likely caused by the variant in the ADCY5 gene, a finding that follows the guidelines of American College of Medical Genetics and Genomics.

Dean said there is no treatment to reverse the condition but having a diagnosis often gives patients and families closure and relief. Dean is overseeing supportive therapy for the patient, including physical and occupational therapy and medications for muscle spasms and stiffness.

Bruce Korf, MD, PhD, UAB's chief genomics officer and director of the Undiagnosed Diseases Program, said finding the cause of a rare condition can lead to more breakthroughs.

"The discovery of a new variant of a gene is extremely important," Korf said. "Every piece of information that we can decipher sheds a bit more light on our understanding of genetic disease."

Co-authors on the case study from UAB are Korf, Ludwine Messiaen, PhD, Dept. of Genetics; Salman Rashid, MD, Dept. of Pediatrics; and **David Standaert, MD, PhD**, Dept. of Neurology. Co-authors from HudsonAlpha Institute for Biotechnology are Gregory M. Cooper, PhD, and Michelle D. Amaral, PhD.

The Alabama Academy of Neurology is seeking nominations of neurologists to fill positions on the AAN Board, including a Scientific Chair to help plan our annual conference.

Contact Meghan Martin at *mmartin@alamedical.org* if you are interested in serving or nominating a colleague.

All Things 401(K): Participants education, plan structure and assessments

alabamamedicine.org

Article contributed by Jack Adams, Asset Management Member & Retirement Plan Consultant, Warren Averett

The ultimate goal of any retirement plan is for participants to prepare for retirement, but physicians must also maintain the appropriate structure of the plan. How can you be sure everything is handled correctly? Below, one of our 401(k) plan experts, Jack Adams, answers a few frequently asked questions about 401(k) plan education, structure and design.

How do we prepare our participants for retirement?

With participants, one of the most important things you want to do is talk to them about the reason they need to save for retirement. Other advisors seem to focus on the investments, but if a participant isn't properly saving for retirement, they will never reach their ultimate goal. What we do in our retirement meetings, from an education standpoint, is focus on how much a participant needs to be saving to accomplish their goals. Typically, we tell them they need to save eight to ten times their salary, because they will live off about 80% of their pre-retirement income when they retire. This money has to last them 20 to 25 years. So again, getting them to start saving and then try to increase the amount saved each year is going to be important in reaching those retirement goals.

You also want to talk to participants about Social Security. Many people believe Social Security is going to be a large portion of their income at retirement. During our retirement meetings, we show them an estimate of the percentage of their income that will come from Social Security and what percentage has to be made from their private sources.

I think it is important to educate participants along the way to ensure that they are not surprised when they are 65 years old and ask "am I going to have enough to retire?" The last thing we try to incorporate in every one of our meetings is a retirement estimate. That is something we put on the fourth quarter statement for our clients. We calculate a projected retirement income based on their personal contributions, along with their employer contributions. When you look at this calculation each year, if the number has gone up, you're doing the right things. That number is what you can expect to live on, along with social security, during retirement.

Tell us about the different kind of structures that could be in place for a physician practice

Typically, the ultimate goal is to try to get as much of a contribution into the physician's account as possible while attempting to minimize the required contribution to the rest of the staff. There are different ways you can structure a plan depending on which safe harbor contributions you choose to make. The two options we see most often include a 3% non-elective contribution, which means that every participant would receive a fully-vested 3% contribution based on their compensation or a basic safe harbor match of 100% on the first 3% they defer and 50% on the next 2% deferred. Which scenario a practice chooses depends on the ultimate goal of the practice. If the practice is going to make a profit-sharing contribution in addition to the safe harbor contribution, then choosing the 3% safe harbor, non-elective contribution is often the better approach. This is because this 3% contribution counts towards satisfying the practice's minimum required non-elective contribution that each eligible participant is required receive in a cross-tested profit-sharing plan. The two most common types of physician practice profit sharing plan designs are the aforementioned cross-tested design or the integrated design. Depending on the age of the physicians and their ultimate goal, we can look at each plan design to ensure the maximum benefit at the lowest cost.

What can Physicians do to ensure they have the right plan?

We recommend that you review your plan or have a professional assist, periodically, to better understand your fees structure, plan design and investments. When it comes to fees, it can be difficult to understand where they're coming from, what they're for and how the they are paid. In particular, understanding the different ways that fees are structured can reveal some areas for cost savings.

We suggest you find out how your plan advisors are compensated. They're often compensated through a 12b-1 agreement or some type of commission-based arrangement within the fund options. Also, it's a good idea to find out if there is an amount contributed towards record keeping. We offer plan assessments where we look at your plan's design, fees, investment diversification, investment performance and your investment policy statement. We want to make sure your plan is appropriately designed to get the maximum benefit. During our assessments, we typically find that people determine what they like and don't like about the plan, and from there, we give them recommendations. The goal is just to understand your plan better.

Health, dental insurance available from the Medical Association of the State of Alabama

The Physicians Insurance Plan of Alabama (PIPA), administered through Blue Cross Blue Shield, is a benefit available to members of the Medical Association of the State of Alabama. PIPA provides the physician, their family and staff with strong benefits at affordable premiums.

Open enrollment is Oct. 1 - Oct. 31 for a Jan. 1, 2020, effective date. Current PIPA participants do not have to reapply. However, any changes to current plans must be made no later than Oct. 31.

Visit ***www.alamedical.org/insurance*** for full details of the plan and for links to applications and materials. Contact Brenda Green at ***bgreen@alamedical.org*** with questions specific to the insurance application procedure.

For information on joining the Medical Association of the State of Alabama, contact Meghan Martin, Director of Membership and Specialty Society Management, at ***mmartin@alamedical.org***.

Congress is Back in Washington: *American Academy of Neurology Report*

aan.com

Congress is back in session after a lengthy summer recess with the hopes of tackling several high-profile health care issues before the end of the year, including:

Drug Pricing

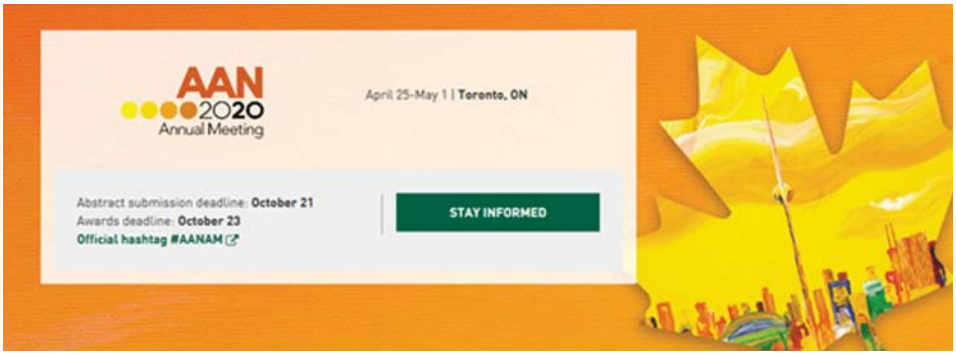
- In the House, both the Energy & Commerce and Ways & Means committees are expected to consider the yet-to-be released comprehensive drug pricing proposal from Speaker Nancy Pelosi (D-CA).
- Both the House and Senate may move forward with components of the Senate Finance proposal, the Prescription Drug Pricing Reduction Act of 2019. The ***AAN submitted extensive comments*** on this proposal, which were recently highlighted in *Politico*, supporting direct price negotiation, price transparency, and the proposed cap of $3,100 for out-of-pocket drug costs for Medicare patients, while sharing concerns about proposed reductions to Medicare Part B add-on payments for physician-administered drugs.
- The White House may take executive action on drug pricing, including releasing a draft of their proposal to establish an international pricing index (IPI) that would base drug prices on an international benchmark. The ***AAN has stated opposition*** to the model and urged CMS to scale back and reconsider the proposal to make it more in line with the size and scope of previous pilot programs. The AAN is also concerned that IPI implicitly places the blame for high drug prices on physicians rather than on the pharmaceutical companies who are responsible for setting high prices.

Surprise Billing

- Legislation to protect patients from charges when they unknowingly receive care from an out-of-network provider has become a contentious debate on Capitol Hill. All stakeholders agree that patients should be held harmless from surprise bills, but a debate is raging in Washington over the best way to resolve payment disputes.
- Committees in the House and Senate have passed bills to address surprise billing, but further changes will likely be considered in the coming months. The AAN joins the American Medical Association in urging Congress to include an independent resolution process to resolve payment disputes.

Federal Funding

- Although the House passed their fiscal year 2020 Labor, Health and Human Services, Education, and Related Agencies bill, the Senate hasn't introduced any of its 12 appropriations bills.
- Congress has 13 working days to pass all the funding bills for 2020 or extend current funding levels in order to avoid a government shutdown on October 1.
- The AAN supports a $2.5 billion increase for NIH, including $500 million for the BRAIN Initiative.
- The AAN urged Congress to ensure that funding for the CDC's National Neurological Conditions Surveillance System remain focused on neurology conditions.



American Academy of Neurology 2020 Annual Meeting • April 25 - May 1

Make plans to join your colleagues at the American Academy of Neurology 2020 Annual Meeting in Toronto!

Dates to know:

Abstract submission deadline: October 21, 2019
Awards deadline: October 23, 2019
Additional information will be available in August 2019.

More information

Sign up to receive updates about the AAN 2020 Annual Meeting

www.aan.com

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