

Take charge of your health today. Be informed. Be involved.



ESTHER BUSH

Down Syndrome

This month, the "Take Charge of Your Health Today" page focuses on Alzheimer's disease, as it relates to those living with Down syndrome. Jennifer Jones, MPH, community engagement senior coordinator, and Esther L. Bush, president and CEO, Urban League of Greater Pittsburgh, chatted about this topic.

JJ: Good afternoon, Ms. Bush. It's been awhile since you and I have discussed one of our monthly health topics. Last month, you and Erricka talked about Alzheimer's disease (AD). To refresh our memories, Dr. Annie Cohen stated that over 5 million people are living with this disease in the United States, and approximately 400,000 of those persons live here in Pennsylvania. There is a lot of great research being done to understand the genetic components of that disease. Technology advancements have changed how AD is diagnosed, and there is a lot more to learn. This month, we are going to build on that knowledge base and get a little more specific. Our health focus is how Alzheimer's disease affects those persons living with Down syndrome.

EB: Thank you for that reminder Jennifer. Last month one of the most fascinating parts of learning more about Alzheimer's research was understanding how the disease is detected, based on proteins that build up in the brain. I believe they are called amyloids. Dr. Handen once again talks about amyloids in those who have Down syndrome. They may be producing more amyloid due to the extra chromosome copy. Research has shown that the levels of amyloids in the brain are higher, especially those over 40 years old.

JJ: That is correct. Even though I work in research, I am constantly amazed at all the research studies happening here in Pittsburgh. Studies, like the one outlined on this page and talked about by Drs. Handen and Bulova, will help the medical and research community continue to learn more about diseases. Knowing that 75 percent of people over 60 who have Down syndrome also have Alzheimer's is a high percentage. My hope is that we continue to learn more so in the future we know better how to both prevent and treat Alzheimer's, in everyone. I also learned about organizations like The Down Syndrome Center of Western PA and The Down Syndrome Association of Pittsburgh, who have great resources for families. And if anyone knows an adult 25 or older living with Down syndrome who may be interested in a research study, they can call Masha the study recruiter at 412-235-5486.

EB: I agree, I truly hope that these pages are helpful to readers, and that they share it with friends and family. What are we talking about next month?

JJ: Me too! For April we will be talking about hypertension, or high blood pressure, and what we can do to lower our blood pressure especially as we age. If anyone has any questions or concerns, they can email our research and community engagement team at partners@hs.pitt.edu

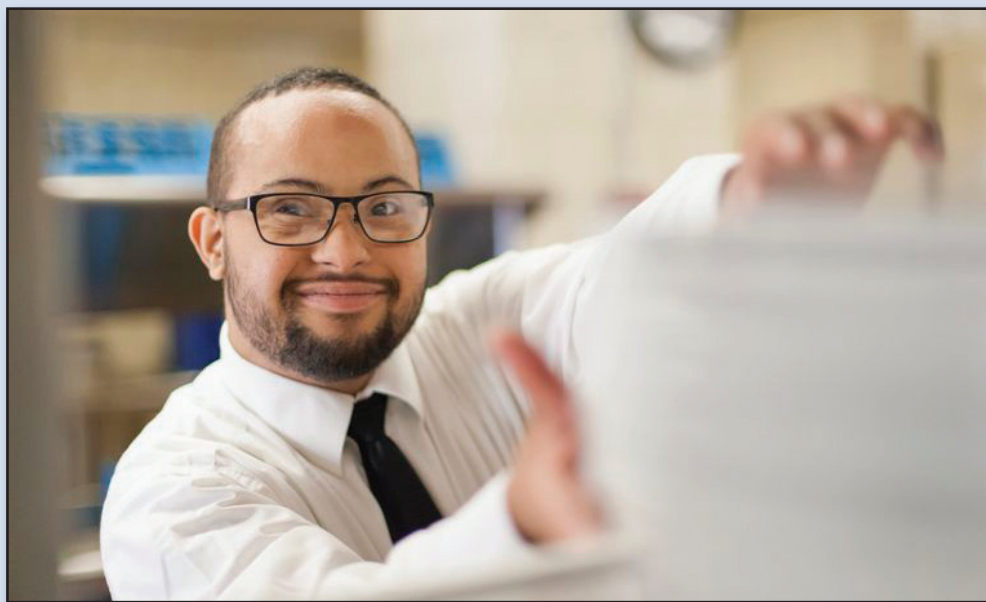
The link between Down syndrome and Alzheimer's disease

Last month, the "Take Charge of Your Health Today" page discussed Alzheimer's disease. This month, we are going to dig a little deeper and talk about how common the disease is in a certain population—people with Down syndrome.

As presented last month, Alzheimer's disease is the most common form of dementia. Dementia describes symptoms of memory loss and the loss of other cognitive and functioning abilities that are serious enough to affect everyday life. Though researchers do not know exactly what causes Alzheimer's disease, it is characterized by abnormal deposits of proteins in the brain called amyloid plaque and tau tangles. It is a disease that gets worse over time, leading to breakdowns in a person's ability to think and move and, eventually, to death. There is no cure for Alzheimer's.

Down syndrome is caused by an extra copy of chromosome 21, one of the 23 human chromosomes. Instead of the usual two copies, one from each parent, a person with Down syndrome has three copies of chromosome 21. Chromosomes carry genes that tell the body how to build proteins. Proteins determine what a body looks like and how it functions. Though researchers do not know how, the extra genetic material causes people with Down syndrome to have developmental and certain health problems.

The gene that codes for the production of amyloid is on chromosome 21. Because people with Down syndrome have an extra copy of that chromosome, researchers believe they are



Mixed race server with Down syndrome (Getty Images/File)



BENJAMIN L. HANDEN, PhD

producing much more amyloid than people who do not have Down syndrome. This is one of the reasons that people with Down syndrome have a much higher risk of developing Alzheimer's disease.

"All brains make amyloid," says Benjamin L. Handen, PhD, professor of psychiatry, University of Pittsburgh School of Medicine. "The



PETER D. BULOVA, MD

body is typically able to eliminate it. But if the body is making a lot more amyloid, the amyloid will eventually overwhelm the system. On brain scans of people with Down syndrome who are age 40 and older, we see that most of them have measureable amyloid—levels that are more like people in their 70s and 80s in the general population."

syndrome and the general population," says Dr. Bulova. "This is a disease that, by the time people are diagnosed, it's very progressed. Yet, some of the causes of the disease, such as amyloid deposits, began 15 years before we see any symptoms. So, we hope this study will help us to identify people at a much earlier age. If we could intervene much earlier in the disease process, we'd have a better chance of preventing it."

Drs. Bulova and Handen are looking for volunteers with Down syndrome who are 25 and older. They are also looking for volunteers who are not showing any signs of having Alzheimer's disease. And, because researchers know that African Americans have a greater risk of developing Alzheimer's disease, the doctors would like to have a diverse pool of participants.

"Much of the information we have about Alzheimer's disease is generalized from research participants who are white. We'd love to change that," says Dr. Handen.

Dr. Bulova points out that this study is part of a multi-site study and is probably one of the largest studies of Down syndrome that has been funded by the government. The results of the study may help not only people with Down syndrome but all populations.

"People with Down syndrome offer so much to the world," he says, "and participating is a valuable way to contribute to helping everyone's overall health. We want people with Down syndrome to have a voice in research, and this is a great opportunity."

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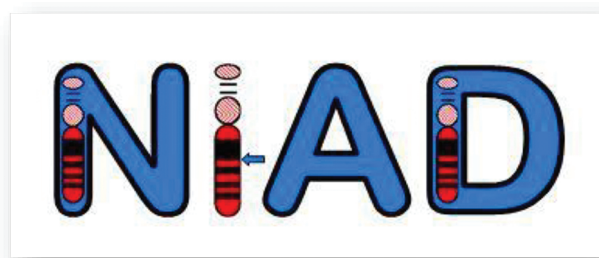
Down Syndrome Center of Western PA
@downsyndromecenterofwpa

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The University of Pittsburgh is seeking adults with Down Syndrome to participate in a research study.



Is this study right for you?

This study is for:

- Adults with Down syndrome
- 25 years of age or older
- Must be accompanied by a caregiver

What does this study involve?

- Four two-day visits over a four-year time period
- Caregivers will complete questionnaires at each visit
- Adults with Down syndrome will complete a physical exam and cognitive testing at each visit. The study will also involve a blood draw, MRI and PET scans of the brain.

Participants will be compensated for their time and expenses. Funds are available for participants and caregivers who reside a distance from the Pittsburgh area to stay overnight.

For additional information please contact:

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Study Recruiter
412-235-5486
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Visit our website:

www.niad-project.org

The Down Syndrome Center of Western PA

The Down Syndrome Center of Western PA offers many services. Services include medical advice and connections to local medical experts.

The center also supports two programs. Children are seen at Children's Hospital of Pittsburgh of UPMC by Dr. Kishore Vellody. Adults are seen at UPMC Montefiore by Dr. Peter Bulova.

The center is supported by private charities, community programs and other donations.

Contact The Down Syndrome Center of Western PA at downsyndromecenter@gmail.com or call (412) 692-7963.

Check out their Facebook page, and ride, run or walk on May 20 for their 2018 Tri-21 4 DS fundraiser event!

The Down Syndrome Association of Pittsburgh

The Down Syndrome Association of Pittsburgh (DSAP) is a group of parents and professionals. They work together to improve the lives of people with Down syndrome.

The mission of DSAP is simple. The group is here to support families by providing resources.

Resources include giving new parent packets to families starting their journeys.

DSAP makes donations to the Down Syndrome Center, to community resources and also makes donations to national efforts that try to improve the lives of people with Down syndrome.

Contact The Down Syndrome Association of Pittsburgh at (412) 218-2940.

Join DSAP on Saturday May 19 for Down Syndrome Awareness Night at the Pittsburgh Pirates game!

