



ESTHER BUSH

Down Syndrome

These monthly pages focus on health disparities in the Pittsburgh region. They educate readers about key health issues and inform them about research opportunities and community resources. All articles can be accessed online at the New Pittsburgh Courier website (newpittsburgh-courier.com). The monthly series is a partnership of the New Pittsburgh Courier, Community PARTners (a core service of the University of Pittsburgh's Clinical and Translational Science Institute—CTSI), the Urban League of Greater Pittsburgh and the UPMC Center for Engagement and Inclusion.

This month, the "Take Charge of Your Health Today" page focuses on dispelling the many myths about Down syndrome. We will also share the range of resources available here in Allegheny County. Erricka Hager and Bee Schindler, community engagement coordinators, CTSI, and Esther L. Bush, president and CEO of the Urban League of Greater Pittsburgh, spoke about this topic.

BS: Good afternoon, Ms. Bush. It's been a while since we last discussed Down syndrome. This month we connected with Annie Cohen, PhD, associate professor of psychiatry and associate director of the Alzheimer's Disease Research Center's Neuroimaging Core. Dr. Cohen shared that her team is assembling focus groups in the Down syndrome community.

EH: Yes, Bee. It was great to connect with Dr. Cohen again to talk about Down syndrome. These focus groups will allow individuals with Down syndrome, their family members and caregivers and other community stakeholders the opportunity to voice their opinions about and share their experiences with research.

EB: Wow—it sounds like Dr. Cohen is continuing to do great work in the Pittsburgh community. This is the perfect time for us to raise awareness about Down syndrome. World Down Syndrome Day happens each year on March 21. I'm glad we're helping our readers learn more about Down syndrome and how it can affect their loved ones. What are some ways we can encourage our readers to talk about Down syndrome?

BS: I would suggest that our readers review the Down syndrome myths that were shared in the overview. Dr. Cohen did a great job of dispelling a few of the misconceptions that are related to Down syndrome. It's important that we boost community outreach and awareness to highlight Down syndrome community assets and real-life barriers.

EB: I second that, Bee! Our readers would benefit from reviewing the resources that are listed on this page. I would also encourage them to review the studies that are listed on the Pitt+Me website (pittplumse.org). Their voices are valuable. Researchers need to hear their thoughts and opinions. Participating in Dr. Cohen's focus group is a great way to provide feedback about ways to improve the research experience.

EH: Dr. Cohen also does a great job of making research a two-way street. She understands that in order for people to open up to her, she has to open up to them. Thank you for having this conversation with us, Ms. Bush. April's page will explore how financial issues can affect our parenting skills. I look forward to hearing your thoughts about this topic.

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

Myths and Research about Down Syndrome

According to the Centers for Disease Control and Prevention (CDC), about 1 in every 700 babies born has Down syndrome, a chromosomal disorder. Chromosomes are structures in cells that carry long pieces of DNA. DNA segments make up genes, which help determine many things about the body, including what we look like and for which diseases we are at risk. Down syndrome is caused by an extra copy of chromosome 21, one of the 23 human chromosomes. The extra genetic material can cause people with Down syndrome to have developmental and certain health problems, though the severity varies from person to person.

Over the years, people have learned more about Down syndrome, but they still have outdated information or myths about the syndrome. Annie Cohen, PhD, associate professor of psychiatry and associate director of the Alzheimer's Disease Research Center's Neuroimaging Core, works to address some of these myths and bring awareness to the experiences of people with Down syndrome.

Myth: Down syndrome causes a lower quality of life.

People with Down syndrome can experience developmental delays, behavioral problems and an increased risk of developing



Server with Down syndrome working in a restaurant. "Many people with Down syndrome have jobs, are very productive members of their communities and live life—just as people who are typically developing are," says Dr. Cohen. (Getty Images/File)

certain health conditions. These health conditions include congenital heart disease, thyroid disease, leukemia and Alzheimer's disease. However, Dr. Cohen says that many people with Down syndrome live long and healthy lives and that having the condition does not mean a person is chronically ill.

"Also, many people with Down syndrome have jobs, are very productive members of their communities and live life—just as people who are typically developing are," says Dr. Cohen.

Myth: People with Down syndrome cannot speak for themselves.

People with Down syndrome have a broad range of capabilities. There is no one way to characterize everyone's experiences with the condition. In fact, "individuals with Down syndrome are some of the most involved and critical advocates for their community," says Dr. Cohen. Their opinions about their health care and research involvement are crucial.

Myth: Scientists know everything about Down syndrome.

Researchers know that advanced parental age is a risk factor for having a child with Down syndrome, though pregnant parents of

any age can have a child with the condition. Despite what researchers know about Down syndrome, they have trouble understanding exactly why it happens.

Dr. Cohen is especially interested in making sure that the various experiences of people with Down syndrome are represented in research so that research addresses everyone's needs.

For example, according to the CDC, African American infants with Down syndrome in the United States have a lower chance of surviving beyond their first year of life compared with white infants with the condition. Researchers do not yet know why. However, Dr. Cohen thinks that racial disparities like this can be addressed by researchers making sure they have appropriate representation in their studies.

Dr. Cohen is looking to engage diverse groups of peo-



ANNIE COHEN, PHD

ple in the Down syndrome community—people with the syndrome, family members, caregivers and leaders—to better understand barriers to participating in research. To improve the research experience for everyone, she will be looking for people to discuss what keeps them from participating in research.

"The more input we get from a diverse community, the better our research studies can be of service to the entire Down syndrome community," says Dr. Cohen.



Join DS-Connect®: The Down Syndrome Registry today.
DSconnect.nih.gov

Down Syndrome Resources:

DS-Connect

DS-Connect is a powerful resource where people with Down syndrome and their families can:

- connect with researchers and health care providers;
- express interest in participating in certain clinical studies on Down syndrome, including studies of new medications and other treatments; and
- take confidential health-related surveys. These surveys are aimed

at better understanding the health of people with Down syndrome across their lifespans.

For more information about DS-Connect visit: <https://dsconnect.nih.gov/en.html>.

Down Syndrome Association of Pittsburgh

The Mission of the Down Syndrome Association of Pittsburgh is to enrich the lives of individuals with Down syndrome, their families and

the communities in which they live. The association accomplishes this through communication, education, advocacy, fellowship and support for community members' well-being through their longstanding alliance with the pediatric and adult Down Syndrome Centers of Western PA. Visit <https://dsapgh.org> for more information.

Down Syndrome Diagnosis Network

The Down Syndrome Diagnosis Network's mission is to connect, support and provide accurate information for families that include a person with a Down syndrome diagnosis. The network's vision is to ensure that families have nonbiased and factually accurate diagnosis experiences, every time, during which families quickly know that they are not alone.

For more information, visit <https://www.dsdiagnosisnetwork.org>.