

Statement of Congressman Pete Sessions (TX-32)
As Submitted for the Record
House Committee on Appropriations Subcommittee on Labor, Health and Human
Serves, Education, and Related Agencies (LHHS) Hearing, Down Syndrome:
Updated on the State of the Science and Potential Discoveries Across Other Major
Diseases
October 25, 2017

Thank you Chairman Cole for providing me with the opportunity to submit this statement for the record. I appreciate the opportunity to participate in a hearing on an issue that is near and dear to my heart, especially during the month of October which is Down Syndrome Awareness Month. As you may know, I am the proud father of Alexander Gregory Sessions, a 23-year old man with Down syndrome. Alex is an Eagle Scout, an avid competitor in the Special Olympics, and in my opinion, a really cool guy.

While Alex has been a driving force with my involvement with the Down syndrome community, another reason behind my efforts started with a call from Gene Stallings the infamous head football coach for the University of Alabama. Gene was a fearless leader who always had his biggest fan at this side, his Down syndrome son, Johnny. 19 years ago, Coach Stallings, Johnny and I teamed together to form the Rise School of Dallas. Now called the Ashford Rise School of Dallas, it provides the highest quality of early childhood education services to children with Down syndrome, other developmental disabilities as well as children without disabilities. Since its founding, this non-profit has continued to grow throughout the country and has shown that there is nothing greater that families can provide their children than love and commitment.

Fast forward to 8 years later when I had the privilege to lead the effort to pass the Family Opportunity Act. This important law gives states the option to create a Medicaid “buy in” for families of children with disabilities whose family income or resources are up to 300% of federal poverty level. It was actually through a conversation my son, Alexander Gregory Sessions had with President George W. Bush that led to the final push of passing this legislation through Congress.

I tell you the background of my journey today because a common thread of the success of it all is due to the progress Down syndrome research has made over the past few decades. One important discovery in recent years that I have seen is the prevalence of Alzheimer’s disease in people with Down syndrome. The Alzheimer’s Association states that studies suggest that more than 75 percent of people with Down syndrome aged 65 and older have Alzheimer’s disease, which is nearly six times the percentage of people in this age group who do not have Down syndrome. That is why at the request of Congress in the Labor-HHS-Education Appropriations legislation for Fiscal Year 2007 the National Institutes of Health (NIH) developed a working group to specifically focus efforts on the connection between late-life dementia and Down syndrome, with the goal of using current NIH-supported research on Down syndrome. This then led to the creation of the Down Syndrome Consortium by NIH in 2011 that today consists of leading

research groups, such as the Global Down Syndrome Foundation led by Michelle Sie Whitten, who you will have the pleasure of hearing from today.

Today, the NIH continues to conduct critical research that has the potential to improve the lives of those impacted by medical conditions such as Alzheimer's disease and Down syndrome. Under the leadership of my dear friend Dr. Francis Collins, the NIH plays a key role in ensuring that our country is at the leading-edge of medical discoveries and life-changing therapies. I frequently host breakfasts attended by the NIH and my fellow members of Congress so that the impact and importance of the NIH remain top-of-mind as we develop federal policy. We live in an exciting time of break-through discoveries, and it is important that we continue to support the NIH in its mission to uncover new knowledge that will lead to better health for everyone, including those impacted by the connection between Down syndrome and Alzheimer's.

For example, groundbreaking research at institutions such as the NIH found that almost all adults with Down syndrome will develop Alzheimer's disease pathology by the age of 40 due to significant levels of plaques and tangles, as I am sure you will hear about many times today. Because of this finding, researchers such as Dr. William Mobley, Executive Director of Down Syndrome Center for Research and Treatment and Florence Riford Chair of Alzheimer's disease Research, who is also here with us today to testify, was able to build off that success. That discovery along with numerous other medical advances that helped to extend the life expectancy of those with Down syndrome over the years allowed Dr. Mobley to create a research study that used a mouse model of Down syndrome that ultimately led to the findings of an extra copy of an important gene that is also a key protein in Alzheimer's disease.

While much progress has been made, I believe there are many more research discoveries yet to come and look forward to hearing testimony from the folks like Michelle Sie Whitten, Dr. William Mobley and Dr. Joaquin Espinosa, Executive Director of the Linda Crnic Institute for Down syndrome, on what additional research opportunities they believe are possible. Their work and discoveries along with other researchers at the National Institutes of Health and private sector entities have come a long way and I look forward to collaborating with them in the years to come.

Every appropriations dollar counts and I look forward to working with my fellow Members of Congress such as Congressman McMorris Rodgers and Congresswoman Bustos to ensure that research dollars are used to their true potential. These research projects are more than dollars and cents to individuals like my son Alex. This research creates opportunities for him to break through the glass ceiling and achieve his dreams.