

### A NEW YEAR

What does that mean? New perspectives? New resolutions? New wishes? We all celebrated and cheered!



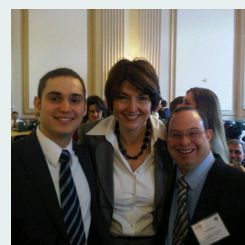
As I ponder about it, I am grateful for all of the gifts, the ones we can use and the intangible ones that we neglect to acknowledge at times. Those are the gifts that keep giving. So today as we start the new year, I have been thinking about the [Bipartisan Congressional Down Syndrome Caucus](#), a valuable gift for our Down Syndrome Community. It was founded in 2008 by Representative Cathy McMorris Rodgers (R-WA) along with co-chairs former Representative Pete Sessions (R-TX), former Representative Patrick Kennedy (D-RI), and Delegate Eleanor Holmes Norton (D-DC) to educate members of Congress and their staff about Down Syndrome.

<https://mcmorris.house.gov/posts/the-congressional-task-force-on-down-syndrome>

I met Representative Cathy McMorris Rodgers when she had her first child Cole, born with Down syndrome. Phil Pedlikin, the first president of the DSANV took his son, Casey and Brendan Hammeke and I to meet with her. She became my family and especially my friend. We have met often on various occasions on Capitol Hill and in my home for my 40th birthday. It was a joy to have her join the Senate at the invitation of Senator Tom Harkin, the chairman of the HELP Committee when I testified about employment in 2011 <https://www.help.senate.gov/hearings/improving-employment-opportunities-for-people-with-intellectual-disabilities>

She was instrumental for my success when I was the first person with an intellectual disability to serve on Capitol Hill as a Joseph P. Kennedy Jr. Public Policy Fellow in 2015 working for the Ways and Means Social Security Subcommittee. That was a unique experience networking with Congressional members and seeing policy in action.

<https://jpkf.org/kennedy-fellows/>



You can learn more about me in my book: "More Alike Than Different: My Life With Down Syndrome."

[www.davideganadvocacy.com](http://www.davideganadvocacy.com)





January 2024

Today, the Task Force includes both the Senate and the House. The current co-chairs are:

Senator Robert Casey (D-PA)  
Senator Jerry Moran (R-KS)

Representative Cheri Bustos D-IL)  
Delegate Eleanor Holmes Norton (D-DC)  
Representative Cathy McMorris Rodgers (R-WA)

In Virginia, Gerald Connolly (D-VA) is on the Caucus. However, we also need to have our Senators from Virginia to join.

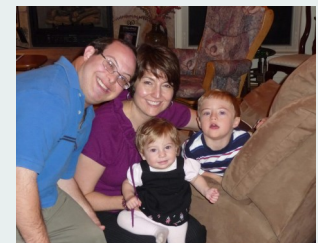
The goal of the task force is to serve as an informal group of members dedicated to educating their colleagues and their staff about Down syndrome, while working towards the common goal of promoting legislative activities, developing public policies priorities, positions and legislation that will be incorporated into an annual Caucus legislative agenda. The purpose is to enhance the quality of life for those with Down syndrome.

So what are our needs? What do we want them to do for us? Where do we have gaps and issues that need to be addressed?

As I look at the years since the 70's when I was born, we have made good progress. We are living longer but as I always say, it is not enough to live longer, we need to prosper. The quality of our lives matter and that means community inclusion throughout our life span and at all levels of our society in education, employment, health care and social opportunities to thrive. All of those needs are critical for our well-being. In each of these issues, each one of us has had unique good and bad experiences, stories to share and aspirations that need to be voiced.

Join me on Capitol Hill on World Down Syndrome Day March 21st when all of the Down Syndrome Organizations gather together to meet with our legislators and advocate for our priorities. It is a good time to share our stories and ask them to promote policies that will improve the quality of our lives and that of our community.

<https://ndss.org/down-syndrome-advocacy->



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