

### David Egan NIH DS Consortium July 2023

During the NDSC Conference in Orlando this past July, I was not able to give my report to the NIH DS Consortium because I was in the hospital with pneumonia. My mom sent my prepared remarks to Melissa A. Parisi, M.D., Ph.D., the Chief of the Intellectual & Developmental Disabilities Branch, the DS-Connect, Registry Coordinator at the NICHD. Dr. Parisi read them to the group and I am sharing them with you. You can learn more about the DS. Consortium at <https://downsyndrome.nih.gov/about#members>. Various organizations beyond DS belong to the Consortium and each presents their update with the group at this bi-annual meeting. Michael Levitz and I represent individuals with Down Syndrome.

“Hello Everyone. This is David Egan and I am joining to represent my peers with Down Syndrome. I wish I could have been with you all in person like we did in New Orleans at the last NDSC conference. I want to thank all of you for caring about the issues that affect the lives of individuals with Down syndrome and working together.

Since last June 2022 and after having Covid, I have not yet fully recovered. It is called Long COVID. I lost about 90lbs since last year and a lot of it in the summer of 2022. I am getting better but not back fully myself with the energy and strength in my muscles.

So today my update is to urge all of us as a Consortium to look more closely at health issues of individuals with Down syndrome. I am especially concerned about physical and mental wellness. I joined the NIH RECOVER group discussion and another support group of individuals who are hurting from Long COVID with Brain Fog and other physical and emotional pains.

I also have some good news for which I am very thankful. This July, Nick Leto from NDSS and I visited with new Congressional Members and shared my book with them. I will be going again in September and it is always a good experience to advocate for our cause. Also, I am very thankful for the Global Down Syndrome Foundation who presented me with the prestigious Quincy Jones Award and I participated in the June Acceptability Gala in DC.

I continue to be busy with talks to different groups. One of them, is the Waisman Center 50<sup>th</sup> celebration in Madison Wisconsin. They asked me to be the Gala Keynote Speaker on Oct. 12<sup>th</sup>.

While the Waisman Center was created in 1973, and I was not yet born, I played a key role in 1979, when at age 2, I was the first child with an intellectual disability together with another toddler who had autism to start the Waisman Center Early Childhood Program. What started with 12 kids (and two of them with a disability), is now a big program with over 6 classrooms and about 150 preschoolers with and without disabilities. All fully included and with both Special Education and Typical Education teachers. It made a big difference in my life, especially my social and verbal skills. So I was shocked when I found out that many states, including many counties here in Virginia where I live do not offer inclusive preschool programs to their citizens.

**So today, I have 2 requests: One about researching the impact of early childhood inclusive experiences. The second one is related to health issues, as in the past year, more than often, the health professionals that had to take care of me, knew nothing or very little about Down syndrome. It is not acceptable and we need more Down Syndrome Clinics in every state at a minimum including Virginia.**

I want you to know that I am available to all of you that belong to this consortium. I want to promote participation in research, clinical trials and more inclusive services at your events and in your programs. Feel free to call on me as I am ready to help promote and advocate the needs of individuals with Down syndrome. And as we all know, none of us can do this alone. Collaboration makes us stronger. I welcome feedback and contributions from all of you. Thanks for giving me the opportunity to share my update”.



- You can learn more about my work in advocacy in my book: “More Alike Than Different: My Life With Down Syndrome.” [www.davideganadvocacy.com](http://www.davideganadvocacy.com)

