



GLOBAL
DOWN SYNDROME FOUNDATION®

The Importance of Research for People with Down syndrome

Frank Stephens, Global Down Syndrome Foundation Ambassador

*Global Down Syndrome Foundation Research & Medical Care Roundtable
NDSC 2020 - VIRTUALLY- June 25, 2020*

A Message to Researchers

- **We are people, not just test subjects.**
- **Include our role prominently in the published results**
 - It's accurate
 - Reminds society that we have value
 - Acknowledges our role in your funding
- **Stand with us when we need you**
 - Promote an up-to-date view of life with Down syndrome
 - No discrimination in medical care



A Message To The Down Syndrome Community

- **Stand up and make a difference**
 - Register and participate
 - Redouble our advocacy for funding and equal treatment under the law
- **Commit to at least one thing you believe in and make it happen**



Make A Personal Commitment

- ❖ "Global Therapeutic Leverage"- people with Down syndrome can be the key to solid tumor cancers and Alzheimer's disease
- ❖ Grateful for any small part I play in ending the scourge of Alzheimer's.
- ❖ Thank you to the NDSC, Global Down Syndrome Foundation, our Congressional Champions, and the NIH for making us a priority.



We Can Make A Difference

- ❖ October 25, 2017 - I testified at the **first-ever** Congressional Appropriations Committee hearing on DS research on behalf of GLOBAL.
 - I received a standing ovation and my testimony on C-SPAN went viral and has now reached nearly 200 million views!
- ❖ Call to action for increased Down syndrome research funding from the NIH.
- ❖ Resulted in the INCLUDE (Investigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) Project Research Plan



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