The Importance of Research for People with Down syndrome

Frank Stephens, Global Down Syndrome Foundation Ambassador
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.
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 syndromeE) Project Research Plan