Annual Meeting: Wednesday, November 4, 2015  
The American Association for the Advancement of Science (AAAS)  
1200 New York Avenue, NW Washington, DC

General Session

9:30 am  Welcome Remarks: Dr. Emil Kakkis, President, EveryLife Foundation
9:40 am  Keynote Address: The Honorable Cliff Stearns
9:55 am  Keynote Address: David Fajgenbaum, MD, MBA, MSc
10:10 am Keynote Address: The Honorable Bart Gordon
10:25 am Keynote Q&A
10:35 am Foundation Milestones: Julia Jenkins, Executive Director, EveryLife Foundation
10:45 am Community Congress Overview: Max Bronstein, Senior Director, Advocacy & Science Policy, EveryLife Foundation
10:55 am Working Group Updates  
Public Policy: Matt Might, Ph.D., President, NGLY1.org  
Regulatory Science: Steve Smith, Chief Patient Advocate, Medidata Solutions  
Newborn Screening: Dean Suhr, Consultant, EveryLife Foundation
11:45 am Networking Lunch

For Community Congress Members Only

12:30 pm Working Group Breakout Sessions  
- Public Policy (Revelle Room)  
- Regulatory (Ableson Room)  
- Newborn Screening (Haskins Room)

2:30 pm Meeting Concludes
Keynote Speaker Bios

The Honorable Cliff Stearns
The Honorable Cliff Stearns is a former U.S. Representative from Florida; born in Washington, D.C. and elected to Congress from 1989-2012. Currently he is an executive director at APCO Worldwide’s DC office and serves as a member of their International Advisory Council. Former Representative Stearns exhibited leadership on rare disease issues in 2012 by introducing the Unlocking Lifesaving Treatments for Rare Disease Act (ULTRA; HR 3737) and the Faster Access to Specialized Treatments (FAST Act; HR 4132). These bills helped reform, codify and apply the FDA’s Accelerated Approval pathway for rare diseases. FAST rewrote and modernized the Accelerated Approval pathway and included instructions for FDA to issue guidance applying this pathway to rare diseases.

David Fajgenbaum, MD, MBA, MSc
Dr. David Fajgenbaum, MD, MBA, MSc, is the co-founder and Executive Director of the Castleman Disease Collaborative Network (CDCN) and a Research Assistant Professor of Medicine in the Division of Hematology/Oncology at the University of Pennsylvania. Dr. Fajgenbaum was recently named a member of Forbes Magazine’s 2015 30 Under 30 list for Healthcare and awarded the 2015 RARE Champion of Hope: Science by Global Genes. Dr. Fajgenbaum co-founded the CDCN in 2012 to accelerate research and treatment discovery for Castleman disease. His recent publication in the journal, *Blood*, initiated a paradigm shift in the iMCD disease model and classification system. He is applying business-inspired solutions to drive forward iMCD research and working to turn this innovative model into a blueprint for accelerating rare disease research.

The Honorable Bart Gordon
Mr. Gordon joined K&L Gates as partner in the Washington, D.C. office after 26 years representing the state of Tennessee in the United States House of Representatives. Mr. Gordon served as Chairman of the House Committee on Science and Technology from 2007 to 2010. During his chairmanship the committee passed 151 bills and resolutions and all were bipartisan. In 2007, he championed the America COMPETES Act, signed into law by President Bush, which promotes federal investments in innovation in order to make the US more competitive. Mr. Gordon was also a senior member of the House Committee on Energy and Commerce, and served on the House Committee on Financial Services and the House Committee on Rules. During his distinguished congressional career, Mr. Gordon developed a reputation as the undisputed bipartisan leader in innovation policy in the U.S. Congress. Gordon was also a leading proponent of America’s space program, and of improving the nation’s performance in science, technology, engineering, and math (STEM) education.

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