

Additionally, FAST includes explicit language for FDA to think about the challenges of rare diseases when developing their guidance and gives the rare disease community an opportunity to publically comment on FDA's draft guidance. FAST ensures that the voices of the 30 million Americans with a rare disease will be heard by FDA. There are about 7,000 rare diseases and only about 250 have any treatment. FAST will save lives, and give a voice to the voiceless; and I am glad it is in the bill.

Lastly, the committee included the Expanding and Promoting Expertise in Review of Rare Treatments, EXPERRT Act, H.R. 4156, a bill my fellow Co-Chairs of the Cystic Fibrosis Caucus and I introduced. EXPERRT will have the FDA consult with experts in rare diseases. This will ensure that FDA has access to the knowledge needed when dealing with drug approvals for diseases where FDA may lack subject matter expertise. As one of the Co-Founders of the Cystic Fibrosis Caucus, I am glad that we are giving this tool to the FDA.

I'd like to submit this letter of support for FAST signed by over 150 rare disease groups into the RECORD.

H.R. 5651 is a good bill that will help new drugs and new medicines get into the market and be available to patients. I support passage of the FDA Reform Act.

MARCH 23, 2012.

Hon. CLIFF STEARNS,  
*House of Representatives, Rayburn House Office Building, Washington, DC.*

Hon. EDOLPHUS TOWNS,  
*House of Representatives, Rayburn House Office Building, Washington, DC.*

DEAR CONGRESSMEN STEARNS & TOWNS: On behalf of patients, physicians, and other members of the health advocacy community we are writing to express our support for H.R. 4132, the Faster Access to Specialized Treatments (FAST) Act. This legislation will modernize and expand the FDA's Accelerated Approval pathway to encompass a broader range of diseases and leverage 21st century drug development tools and strategies. This reform will speed the approval of much-needed therapies and cures to patients who are facing serious and life-threatening conditions, including Alzheimer's disease, autoimmune diseases, multiple sclerosis, Parkinson's disease, neuromuscular disease and hundreds of rare diseases that remain untreated.

We commend you for championing legislation that maintains the FDA's high standard for approval while at the same time ensuring the Agency can help facilitate the development of new and novel therapies to patients in a more timely manner. In many cases our patients have no available treatment for their diseases, or they are using a therapy that is older and may not work as effectively and safely. This is not acceptable. We believe that this legislation will ensure patients receive the best, modern treatment as soon as possible and we applaud your efforts on their behalf.

Thank you for your leadership on this important bill and we look forward to working with you as it moves forward.

Sincerely,

Abigail Alliance for Better Access to Developmental Drugs; Advocacy for Patients with Chronic Illness, Inc.; Affiliated American CSA Foundation; Alliance for Aging Research; Alliance for Patient Access; American Autoimmune Related Diseases Association; American Brain Tumor Association; American Childhood Cancer Organization; American College of Medical Genetics;

American Institute for Medical and Biological Engineering; American Society of Clinical Psychopharmacology; Batten Disease Support and Research Association; Break Through Cancer Coalition; Californians for Cures.

Celiac Disease Center at Columbia University; Celiac Sprue Association; Charcot-Marie-Tooth Association (CMTA); Children's Cardiomyopathy Foundation, Inc.; Chinese American Association of Greater Chicago; Coalition Duchenne; Coalition for Pulmonary Fibrosis; Colon Cancer Alliance; Cooleys Anemia Foundation; Crohn's and Colitis Foundation of America; Cryoglobulinemia Vasculitis Organization; CureDuchenne; CurePSP; Digestive Disease National Coalition; Erik Metzler Foundation.

EveryLife Foundation for Rare Diseases; Fabry Support & Information Group; Georgia PKU Connect; GIST Support International; Hadley Hope Fund; Hannah's Hope Fund; Hayden's Batten Disease Foundation Inc.; HealthHIV; Hope4Bridget Foundation; ICE Epilepsy Alliance; I Have IHH; In Need of Diagnosis, Inc. (INOD); Inspire; International Cancer Advocacy Network (ICAN); Jacob's Cure, Inc.

Jain Foundation Inc.; Jonah's Just Begun—Foundation to Cure Sanfilippo Inc. LAM Treatment Alliance; LGS Foundation; Liddy Shriver Sarcoma Initiative; Little Miss Hannah Foundation; Lung Cancer Alliance; Lupus Foundation of America; Lymphangiomatosis & Gorham's Disease Alliance (LGDA); Lymphatic Malformation Institute (LMI); Macular Degeneration Support, Inc. Madisons Foundation; Midwest Asian Health Association (MAHA); MLD Foundation; Mpdsupport.org—Myeloproliferative Disease Support; Muscular Dystrophy Association.

National Family Caregivers Association; National MPS Society; National MS Society; National Niemann-Pick Disease Foundation, Inc.; National PKU Alliance; National Tay-Sachs & Allied Diseases Association; National Venture Capital Association; NBIA Disorders Association; New Jersey Association for Biomedical Research; NKH International Family Network; Noah's Hope—Batten Disease Fund; Oxalosis and Hyperoxaluria Foundation; Pachyonychia Congenita Project.

Parkinson's Action Network; Parry-Romberg Syndrome Resource, Inc.; Partnership for Cures; Polycystic Kidney Disease Foundation; RARE Project; Russell-Silver Syndrome Support; Scleroderma Research Foundation; Sickle Cell Disease Association of America, Inc.; Society for Women's Health Research; Solving Kids' Cancer; Student Society for Stem Cell Research; Sudden Arrhythmia Death Syndromes (SADS) Foundation; Taylor's Tale.

The Association for Frontotemporal Degeneration (AFTD); The Children's Medical Research Foundation, Inc.; The Erythromelalgia Association; The Focus Foundation; The Manton Center for Orphan Disease Research, Children's Hospital Boston; The Reflex Sympathetic Dystrophy Syndrome Association (RSDSA); The Stop ALD Foundation; Tuberous Sclerosis Alliance; Veterans Health Council; VHL Family Alliance; Vietnam Veterans of America; ZERO—The Project to End Prostate Cancer.

IN RECOGNITION OF "HAND IN HAND"

HON. FRANK PALLONE, JR.

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

Tuesday, June 5, 2012

Mr. PALLONE. Mr. Speaker, I rise today to congratulate the efforts of the Hand in Hand organization, as its members gather to honor its outstanding teen volunteers. Hand in Hand continues to cultivate friendships and build life long relationships between local teen volunteers and special needs children. Hand in Hand teen volunteers will be recognized for their outstanding service to the community at an awards dinner on June 5, 2012. Aimee and Gerald Ostrov and Nona and Dennis Drazin will serve as Guests of Honor. Their faithful service and dedication to the community is worthy of this body's recognition.

Hand in Hand is a local volunteer based organization founded in 2006 under the direction of Chabad of the Shore. The organization is dedicated to building friendships between children with special needs and teen volunteers. Students involved in the Hand in Hand organization remain fully exposed to a wide variety of Jewish activities and social experiences. Teen volunteers learn to become effective friends and mentors while children learn to interact and build social skills. The interaction has helped build eye opening experiences and strong, life long relationships. The unending generosity demonstrated by the Hand in Hand teen volunteers has undoubtedly touched many lives and has helped countless people throughout central New Jersey.

Hand in Hand volunteers and children have also benefited from the steadfast leadership and mentoring of Rabbi Laibel Schapiro and the Chabad of the Shore staff. Rabbi Schapiro received his rabbinical ordination from the Central Chabad Yeshiva in Brooklyn, New York. He has directed the Chabad of the Shore of Monmouth County since 2002 and is a powerful presence in the Monmouth County Jewish community. Rabbi Schapiro's steadfast leadership and contributions to Chabad of the Shore, the Hand in Hand organization and Jewish community are an inspiration to future generations throughout Monmouth County, New Jersey.

The 2012 Annual Hand in Hand Dinner will also recognize four outstanding individuals who will serve as the Guests of Honor. Aimee and Gerald Ostrov are residents of Long Branch, New Jersey and Herzliya Pituch, Israel. Aimee served the Hadassah organization for 30 years and has served in numerous prominent positions including President of the East Brunswick Chapter, President of the Southern New Jersey Region and National Board and Executive Committee. She is an alumna of Cornell University and completed a dietetic internship at Massachusetts General Hospital. Aimee worked as a dietitian in hospitals and nursing homes before dedicating her time exclusively to family and philanthropy. Jerry is an alumnus of Cornell University and earned his Masters in Business Administration from Harvard Business School. He has spent most of his career at Johnson & Johnson where he was later promoted to Company Group Chairman. After a short retirement, he returned to work as Chairman and CEO of Bausch & Lomb. He currently serves on several Boards and provides guidance for start-up

companies, particularly in Israel. The Ostrovs are dedicated to sharing their Jewish faith with the community through various charitable and volunteer activities. Their recent volunteer work has provided professional and strategic leadership to educate the community about Israel.

Nona and Dennis Drazin continue to serve with various organizations throughout Monmouth County, New Jersey. Dennis Drazin currently serves as President at Drazin and Warshaw, an esteemed position that oversees 12 attorneys and 40 support staff members. Dennis earned his Juris Doctorate from Dickinson School of Law and is a current member of multiple organizations including the Monmouth County, New Jersey and American Bar Associations. He often lectures for the American Bar Association and Monmouth Bar Association, among others. Dennis Drazin is also chairman of Elite Equine Consultants, providing advice and consultation for the Thoroughbred Horseman's Association. Nona Drazin is an alumna of the University of Pennsylvania and earned her Juris Doctorate in 1994 from American University. She has practiced law in Washington, DC and New Jersey. Nona was also employed by the New Jersey Thoroughbred Horseman's Association as their General Counsel and serves as President on their Board of Trustees. Until recently, she served two terms as an elected Trustee at Congregation B'nai Israel in Rumson, New Jersey. Nona was recently elected to the Monmouth Parks Charity Foundation's Board of Directors. The Ostrovs and Drazins continue to provide valuable and dedicated time to the Hand in Hand organization and the Monmouth County community.

Mr. Speaker, once again, please join me in thanking the Hand in Hand teen volunteers and congratulating the guests of honor for their service and dedication. Their efforts continue to enhance the lives of individuals throughout Monmouth County and New Jersey.

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PEYTON MOORE

**HON. ED PERLMUTTER**

OF COLORADO

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, June 5, 2012*

Mr. PERLMUTTER. Mr. Speaker, I rise today to recognize and applaud Peyton Moore for receiving the Arvada Wheat Ridge Service Ambassadors for Youth award. Peyton Moore is a 12th grader at Warren Tech North and received this award because her determination and hard work have allowed her to overcome adversities.

The dedication demonstrated by Peyton Moore is exemplary of the type of achievement that can be attained with hard work and perseverance. It is essential students at all levels strive to make the most of their education and develop a work ethic which will guide them for the rest of their lives.

I extend my deepest congratulations to Peyton Moore for winning the Arvada Wheat Ridge Service Ambassadors for Youth award. I have no doubt she will exhibit the same dedication and character in all her future accomplishments.

ENERGY AND WATER DEVELOPMENT AND RELATED AGENCIES APPROPRIATIONS ACT, 2013

SPEECH OF

**HON. ROBERT E. ANDREWS**

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

*Thursday, May 31, 2012*

The House in Committee of the Whole House on the state of the Union had under consideration the bill (H.R. 5325) making appropriations for energy and water development and related agencies for the fiscal year ending September 30, 2013, and for other purposes:

Mr. ANDREWS. Mr. Chair, I stand today in opposition to this legislation because it provides funding for the fundamentally flawed and wasteful Delaware Deepening project. Prior to the Army Corps' recent decision to partially fund this \$300 million project, it had previously only been funded through Congressional earmarks for the previous 6 years.

In June of 2002 the General Accounting Office (report # GA0-02-604) found that the Army Corps grossly misrepresented the costs and benefits of the project. The GAO determined that the economic analysis provided for the project contained a number of "material errors," "miscalculations, invalid assumptions, and the use of significantly outdated information." Based on the GAO's findings, the benefit to cost ratio of the project is closer to 0.49 to 1 as opposed to the 1.4 to 1 originally asserted by the Army Corps. A re-analysis completed by the GAO in 2010 (report # GA0-10-420) came to the same conclusion that the Delaware River Main Channel Deepening would not provide a good return on investment for the taxpayers. The latest re-analysis completed by the Army Corps last year fails to re-examine the costs. It also makes highly questionable projections about future benefits based on limited historical data.

The OMB, at President Obama's direction, has said the federal government should only provide funding for projects that are a demonstrated benefit for the nation; i.e. projects that have a benefit cost ratio of at least 2.5 to 1. As noted by the Corps of Engineers, the Delaware River Deepening is the only navigation project nationwide that had a benefit cost ratio less than the 2.5 minimum criteria. Previous Presidents, both Democrat and Republican, have not supported this project because it makes no economic sense.

Mr. Chair, there also continues to be an overwhelming number of serious environmental concerns raised by state and federal environmental protection agencies and experts about the project's impact on drinking water, commercial and recreational fish, shellfish, wetlands, wildlife, water quality—not to mention the hundreds of millions of dollars of economic revenue and jobs these natural resources support. This project is an economic loser and Congress should not be in the business of funding old earmarks.

REYNA CANTOR-GUTIERREZ

**HON. ED PERLMUTTER**

OF COLORADO

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, June 5, 2012*

Mr. PERLMUTTER. Mr. Speaker, I rise today to recognize and applaud Reyna Cantor-Gutierrez for receiving the Arvada Wheat Ridge Service Ambassadors for Youth award. Reyna Cantor-Gutierrez is a 7th grader at Wheat Ridge 5-8 and received this award because her determination and hard work have allowed her to overcome adversities.

The dedication demonstrated by Reyna Cantor-Gutierrez is exemplary of the type of achievement that can be attained with hard work and perseverance. It is essential students at all levels strive to make the most of their education and develop a work ethic which will guide them for the rest of their lives.

I extend my deepest congratulations to Reyna Cantor-Gutierrez for winning the Arvada Wheat Ridge Service Ambassadors for Youth award. I have no doubt she will exhibit the same dedication and character in all her future accomplishments.

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OUR UNCONSCIONABLE NATIONAL DEBT

**HON. MIKE COFFMAN**

OF COLORADO

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, June 5, 2012*

Mr. COFFMAN of Colorado. Mr. Speaker, on January 20, 2009, the day President Obama took office, the national debt was \$10,626,877,048,913.08.

Today, it is \$15,728,112,402,859.92. We've added \$5,101,235,353,946.84 to our debt in just over 3 years. This is debt our Nation, our economy, and our children could have avoided with a balanced budget amendment.

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PAYCHECK FAIRNESS ACT

**HON. EDDIE BERNICE JOHNSON**

OF TEXAS

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, June 5, 2012*

Ms. EDDIE BERNICE JOHNSON of Texas. Mr. Speaker, with the Senate expected to consider the Paycheck Fairness Act today, it is imperative that the House get serious about addressing pay inequality for working women across the United States. The House version of the Paycheck Fairness Act, H.R. 1519, seeks to achieve this pay equality and fairness by holding employers accountable for sex-based pay discrimination.

On average, women earn only seventy-seven cents for every dollar earned by their male counterparts, and that disparity can fluctuate even further across professions. For African American and Latina women, they are paid only 62 and 54 cents respectively for every dollar paid to their male counterparts. For countless families and single mothers trying to make ends meet, this wage disparity threatens their financial stability, and negatively impacts the livelihood of these women and their dependents.