

# EXTENSIONS OF REMARKS

## A TRIBUTE TO AMELIA BOYNTON ROBINSON, CONGRESSMAN LOUIS STOKES, AND JULIAN BOND

SPEECH OF

**HON. BARBARA LEE**

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Monday, September 28, 2015*

Ms. LEE. Mr. Speaker, I rise today to pay tribute to three heroes of the Civil Rights Movement: Julian Bond, Amelia Boynton Robinson and Former Congressman Louis Stokes.

My thoughts and prayers are with their families during this very difficult time.

First let me thank Rep. DONALD PAYNE, JR., and Rep. ROBIN KELLY for organizing this Special Order and for their leadership in the Congressional Black Caucus. I have known Julian since the 1970s and most recently stood with him to remember the 50th anniversary of the Vietnam Peace Movement at the Martin Luther King, Jr. memorial in Washington, DC. As a cofounder of the Student Nonviolent Coordinating Committee (SNCC), Julian galvanized young people to fight against segregation, march in the Civil Rights movement, and better the lives of all Americans.

Julian dedicated his career to public service. After his work with SNCC, he served in the Georgia Legislature and as president of the National Association for the Advancement of Colored People (NAACP). I know his legacy of tireless advocacy for equality and social justice will live on. It inspires me every day as we work to address inequality and reform our broken criminal justice system.

I also rise to remember Amelia Boynton Robinson, a true hero of the Civil Rights Movement. Ms. Boynton Robinson was a trailblazer who championed civil rights and worked tirelessly for justice and equality. As one of the brave protestors at Selma, Amelia Boynton Robinson was brutally beaten in what would become known all around the world as "Bloody Sunday." Ms. Boynton Robinson, along with her fellow protestors, drew nationwide attention to the plight of African Americans and led us to the Voting Rights Act.

Last but not least, I want to commemorate the life of Former Congressman Louis Stokes. Congressman Stokes was a wonderful mentor to me as a member of Congressman Ron Dellums' staff and later as a Member of Congress. Congressman Stokes grew up in Cleveland public housing and his childhood informed the policies he championed.

He was the first African American Congressman to represent Ohio, one of the Founders of the Congressional Black Caucus and also the first African American to win a seat on the Appropriations committee, a committee on which I now sit. Congressman Stokes spent his congressional career fighting for the poor and the voiceless; he is a true American Hero.

Mr. Speaker, it is because of the tireless advocacy of these leaders that we saw an end to legal segregation, the enactment of the voting rights act, and the election of so many African Americans to Congress.

It was a great honor to count myself among the lives they touched. May the work they started continue until all forms of inequality are addressed.

And may their spirits soar as their memories live on in our hearts.

## RECOGNIZING FLORIDA'S 16TH CONGRESSIONAL DISTRICT FIRE AND RESCUE AND EMS PERSONNEL

**HON. VERN BUCHANAN**

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, September 30, 2015*

Mr. BUCHANAN. Mr. Speaker, I rise today to recognize fire and rescue and EMS personnel who have provided distinguished service to the people of Florida's 16th Congressional District.

As first responders, fire departments and emergency medical service teams are summoned on short notice to serve their respective communities. Oftentimes, they arrive at scenes of great adversity and trauma, to which they reliably bring strength and composure. These brave men and women spend hundreds of hours in training so that they are prepared when they get "the call."

In 2012 I established the 16th District Congressional Fire and Rescue and EMS Awards to honor officers, departments, and units for outstanding achievement.

On behalf of the people of Florida's 16th District, it is my privilege to congratulate the following winners, who were selected this year by an independent committee comprised of a cross section of current and retired fire and rescue personnel living in the district:

Firefighter/EMT Michael Dunn of the Cedar Hammock Fire Rescue was chosen to receive the Preservation of Life Award

Lt. Don Rossow of the Englewood Area Fire Control District was chosen to receive the Dedication and Professionalism Award

District Chief/Paramedic Robin Thayer of the Manatee County Emergency Medical Services was chosen to receive the Career Service Award

Lt. Jason Wilkins, Lt. Jamie Mann, Firefighter/EMT Nicholas Jones, Firefighter/Paramedic Sean Sponable and Firefighter/EMT Clayton Huber were chosen to receive the Unit Citation Award

Deputy Chief Brett Pollok of the West Manatee Fire and Rescue was chosen to receive the Career Service Award

Fire Investigator/Inspector Larry Betts of the Southern Manatee Fire and Rescue District was chosen to receive the Dedication and Professionalism Award.

## HONORING THE LIFE OF PAUL HLYNSKY

**HON. TIM RYAN**

OF OHIO

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, September 30, 2015*

Mr. RYAN of Ohio. Mr. Speaker, I rise today to remember and honor the life of Paul Hlynsky, an Akron, Ohio community leader who passed away on September 23, 2015 at the age of 61 after a long and hard fought battle with cancer. As a man of great conviction and dedication to those he served, Paul will be remembered as a strident defender of his friends, family, and colleagues.

Through his 18 years of service as President of the Akron Lodge 7 Fraternal Order of Police, Paul led countless fights for the rights of his coworkers as the longest serving President of the Order. After 16 years in the Army where he rose to the rank of Major, Paul became a police officer in 1992, serving his country and community for decades. Paul was a unifier, bringing together Akron union leaders to work collectively on fighting for their workers' rights and interests.

As the child of Ukrainian immigrants who had been in a German labor camp during World War II, Paul faced difficult life challenges from the start, learning the value of staying dedicated to those you know and love.

Paul was preceded in death by his parents and older sister. Paul is survived by his sister, Irene (Dan) Harland; nieces, Stephanie (Scott) Jowers and Jeannette Harland; fiancée, Olya Tymciurak. He is also survived by many of his police brethren for whom he worked tirelessly.

I am deeply saddened by the loss of Paul Hlynsky, a man who was such a vital servant of the Akron, Ohio community. I hope you all will join me in offering my thoughts and prayers to him and his family.

## IMPROVING RESEARCH AND TREATMENT FOR DYSTONIA

**HON. CHRISTOPHER H. SMITH**

OF NEW JERSEY

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, September 30, 2015*

Mr. SMITH of New Jersey. Mr. Speaker, Janice and Len Nachbar of Freehold, New Jersey, who lead the Central New Jersey Dystonia Support and Action Group, eloquently addressed a congressional briefing yesterday on dystonia—a neurological movement disorder characterized by muscle contractions causing abnormal and often painful body movements and postures. Dystonia can cause a range of impairments, in some cases leaving a person legally blind or unable to walk or communicate.

Janice and Len are the loving parents of Joanna, a remarkably brave and smart woman who is afflicted with dystonia. Janice and Len explained their daughter's multi-year battle with this condition, saying in part:

• This "bullet" symbol identifies statements or insertions which are not spoken by a Member of the Senate on the floor.

Matter set in this typeface indicates words inserted or appended, rather than spoken, by a Member of the House on the floor.

"Eventually, her dystonia became so advanced and painful; she was approved for Deep Brain stimulation surgery, or commonly known as, DBS. She underwent seven hours of brain surgery while wide awake to implant electrodes in her brain with a second surgery to follow."

Ultimately, says Janice, "[Dystonia's] largest tolls are emotional. How hard it is to see a bright child with the world open to her disintegrate daily."

Today, though Joanna faces significant mobility and communication challenges, she serves as an online mentor for dystonia patients around the globe.

Mr. Speaker, I would like to submit the Nachbars' compelling testimony from the briefing, along with testimony from Janet Hieshetter, executive director of the Dystonia Medical Research Foundation. I urge my colleagues to read their statements and seek to join us in expanding improved research and treatments for this little-understood condition.

TESTIMONY OF JANET HIESHETTER, EXECUTIVE DIRECTOR OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

Thank you all for being here today and joining us for Dystonia Awareness Month. If you don't know a great deal about dystonia, you are in the right place. We have a great line up of speakers that can talk extensively about these conditions.

My name is Janet Hieshetter, and I am Executive Director of the non-profit Dystonia Medical Research Foundation. The DMRF works to advance medical research and support individuals and families impacted by dystonia. We also work collaboratively with four other patient-driven dystonia organizations, the Benign Essential Blepharospasm Research Foundation, DySTonia, Inc., the National Spasmodic Dysphonia Association and the National Spasmodic Torticollis Association to improve patient care through a nationwide grassroots effort known as the Dystonia Advocacy Network.

Briefly, dystonia is a neurological movement disorder that is characterized by persistent or intermittent muscle contractions causing abnormal, often repetitive, movements, postures, or both. The movements are usually patterned and twisting, and may resemble a tremor.

There are multiple forms of dystonia, and dozens of diseases and conditions may include dystonia as a symptom. Dystonia can affect a single body area like the eyelids leaving the person legally blind or be generalized throughout multiple muscle groups in the body—often placing people in wheelchairs.

Dystonia affects men, women, and children of all ages and backgrounds. Estimates suggest that no fewer than 300,000 people are affected in North America. Dystonia causes varying degrees of disability and pain, from mild to severe.

Thanks in large part to our federal investment in medical research, significant advancements have been made in our understanding of these conditions. While there remains no cure, clinical research has led to meaningful treatment options including botulinum toxin injections and deep brain stimulation.

TESTIMONY OF JANICE NACHBAR

Joanna was a very bright, articulate child. She walked at ten months. She had a high and big voice.

Her hands always had tremors, but so did those of my mother and grandmother, so we shrugged it off. She also never vomited. A good thing, right.

She was in the gifted class in first grade. She attended dancing school and gymnastics and was good at both.

Strange symptoms started appearing between the ages of six and ten. Her handwriting became cramped and her reading was not advancing properly. In the third grade, she was moved out of the gifted class.

By the sixth grade, she was on the verge of repeating the grade. Although she moved up to the seventh grade, her work was still below grade level.

We took her to a multitude of specialists, including an eye therapist, reading labs and psychologists, thinking she had a learning disability. Nothing was helping. She became frustrated and felt she was a failure.

While in High School, Joanna had braces on her teeth. Coincidentally, her speech started to become cluttered and hard to understand. We attributed it to the braces.

She was classified as a learning disabled student and was placed in a special academic program in school. She was given individual help with her work. We also hired tutors, but her work was still unsatisfactory.

We knew something was radically wrong when her braces came off and we still could not understand her.

Physically, she was still functional. She drove her car. After graduation, she became licensed as a home and nursing home aide and briefly was able to work.

By age 21, her speech was almost gone and she was having pain and spasms. Her back was pulled to the side and her hips were uneven. Her balance was off and she fell repeatedly.

The first neurologist she saw told us she had Fazio-Land disease. This was a form of muscular dystrophy and we were told she would slowly strangle to death.

We next took her to a well-known neurologist in a large teaching hospital in NYC. He admitted her to their testing center and spent three days having various medical staff poke, prod and test. He came up with nothing, other than to watch her.

As parents, we were panicking as we watched her diminish and were fortunate enough to obtain an appointment with Dr. Mark Hallett, Senior Investigator of the Human Motor Control Section of the NINDS.

Joanna and I traveled to Bethesda and spent an afternoon with Dr. Hallett.

Thanks to him, and after 15 years of searching, we finally had a diagnosis.

He referred us to a movement disorder specialist who, coincidentally, was in the same building and one floor below the neurologist she had been seeing for two years, but who had never mentioned the movement disorder clinic in his own department.

This kind of disconnect by physicians is a huge issue for those seeking a diagnosis and treatment. If a physician does not recognize a movement disorder or avoids a referral to a movement disorder specialist, the patient is helpless.

After seeing the new movement disorder neurologist, Joanna began taking medications for Dystonia. At this point, the mystery of her school failure was revealed. Her hairdresser commented that her head no longer had minute tremors. Tremors? I never saw them. When the tremors stopped, she could read.

She didn't have a learning disability; she just couldn't see the page. Imagine how different her school experience would have been with an early diagnosis and treatment? Now she was able to go to a local college and obtain an associate's degree, something none of us could have imagined.

Eventually, her dystonia became so advanced and painful; she was approved for Deep Brain stimulation surgery, or commonly known as DBS. She underwent seven hours of brain surgery while wide awake to implant electrodes in her brain with a second surgery to follow.

Some people have miraculous results. Joanna had minimal results, but the DBS did lessen her pain.

Remember she never vomited? It seems she has no gag reflex. She also cannot cough. As a result, Joanna has had numerous pneumonias, with the last one requiring 11 days in CCU, five days of which on a ventilator. It was a devastating experience for all of us. I spent the entire 11 days next to her, only leaving her side to eat or shower in the hospital or to take a short break when another family member sat with her. All patients need advocates, but a non-verbal one is even more vulnerable.

Because her dystonia affects her mouth so intensely, she cannot take in enough nourishment to sustain health.

At 5'3 inches in height, she weighed about 88 pounds. She now has a permanent feeding tube and takes all nutrition and hydration through it.

She can eat very little, since just about everything is a choking risk and she can't cough to move the food out. Her g tube became infected and she spent 7 weeks in a rehab center. Of course, her dad and I spent 7 weeks there, as well.

Despite all of these treatments, Joanna's dystonia worsened. She lost all speech, most of the use of her hands and the ability to walk safely.

My husband and I are aging and were fearful for Joanna's future security. As a family, we made the most difficult decision of a lifetime. In March of 2014, Joanna moved to a long-term care facility in Philadelphia.

It's a wonderful place and she has many friends, but it's still not the life any of us envisioned for our bright and lively child.

Dystonia has affected Joanna and us in many ways. Economically, we made huge changes in our work so as to be able to care for her. Her medical bills, hospitalizations and trips to see doctors added up.

Socially, our family became hermits, avoiding social activities either because Joanna couldn't keep up or we had nobody who could stay with her. We missed birthdays, weddings, family vacations and other important events due to Dystonia.

The largest tolls are emotional. How hard it is to see a bright child with the world open to her disintegrate daily. How hard is it for Joanna?

That's our family story and Joanna's journey. Thank you.

TESTIMONY OF LEN NACHBAR

My wife, Janice, spoke to you about how dystonia has affected our daughter, Joanna, and our family. I'm going to tell you about how dystonia changed the lives of members of our New Jersey and Philadelphia support groups and of friends of ours around the country.

Last week, a bright, beautiful and talented friend in her twenties wrote: "Feeling so completely broken. Why was I even born? I live in such pain and agony. There is no end in sight." She's a graduate student who should have a promising career and life, but the constant pain caused by her dystonia hasn't allowed it.

Sometimes the pain, the inability to work and the resulting poverty becomes too much to bear. A few years ago, a member of our New Jersey support group attempted to commit suicide. She is also a bright woman and was a graduate student at Rutgers University when dystonia struck.

Another member of our support group was the Facilities Administrator at a major Philadelphia hospital before he developed dystonia. His neck is involuntarily pulled to the side. He's unable to straighten it. He tried to continue working, but the constant pain made him retire.

A member of our New Jersey support group has been a teacher for many years. She loves the career and wants to continue teaching, but says that her school district is trying to force her to resign. A second grade teacher who's a member of our Philadelphia group is still working, but sometimes needs assistance. So far, her colleagues have been able to help her hide the problems.

A New Jersey Special Ed teacher is an "expert" on the accommodations that people with disabilities need. She's angry because her school makes accommodations for her students, but has refused to do so for her. She asked for a chair and a program that would enable her to dictate because she has difficulty writing.

Dystonia has impacted or ended the careers of many other friends and support group members. The bass member of a singing group can no longer sing. A travel agent can no longer drive and has difficulty speaking to clients. An attorney has similar problems. A guitarist friend, who was a Grammy winner, lost the ability to finger the strings. A French Horn player's lips stopped working properly.

A half year ago, a story about a Midwest woman in her thirties received a lot of Internet and media attention. Her story was featured on national news programs and she was interviewed on the Today show. The woman had been diagnosed with CP, was treated unsuccessfully for that disease for over thirty years and led a very disabled life. After living as a CP patient for over three decades, she finally received the correct diagnosis: dystonia. Her story is even more frustrating. The woman is one of a minute percentage of dystonia patients who have dopa responsive dystonia. The symptoms that those people have can be controlled by medication. After thirty years, the woman is now leading an almost "normal" life.

Misdiagnosis is common. Many patients are told that their symptoms are psychosomatic.

A third of the hundreds of thousands of dystonia patients in this country are children. An eight and a half year old girl from New Jersey and a fifteen year old young woman from Connecticut were both diagnosed with CP. Both had unnecessary and very painful surgeries that cut their leg tendons in an attempt to straighten their feet. Both actually have dystonia. A foot turning in is often a first symptom. It wasn't recognized by their pediatricians or by their orthopedists.

When we started our New Jersey support group, it took our daughter and many of the original members over ten years to be diagnosed correctly. Research conducted by the NIH has shortened that time for many patients. It has also improved the types and number of treatments that are available. However, as our presentations have illustrated, there's much more to learn and it's important to continue funding the research.

Please help us.

Thank you.

#### RECOGNIZING THE 100TH BIRTHDAY OF GERTRUDE HENDRICK

**HON. DANIEL M. DONOVAN, JR.**

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, September 30, 2015*

Mr. DONOVAN. Mr. Speaker, I rise today to recognize the 100th Birthday of Staten Island's Gertrude Hendrick.

Ms. Hendrick currently resides on Staten Island at the New Lane Shores assisted living

facility. She is a mother of three sons: Michael; John; and Raymond, and a grandmother of eleven, and a great-grandmother of two.

Ms. Hendrick is originally from Brooklyn, NY, where she attended Bay Ridge High School. She retired 35 years ago in 1980 from Bankers Trust, where she worked in the accounting department for 23 years. After her retirement, she moved from Brooklyn to Staten Island. Two years later, on August 24, 1984, she moved into the New Lane Assisted Living Facility where she is now the longest, and oldest, resident in New Lane.

During her time at New Lane Shores, she volunteered and orchestrated trips for residents, which included collecting money for transportation that allows the residents to go shopping, demonstrating her commitment to helping others.

At the age of 100, Ms. Hendrick is very energetic and loved by all. She enjoys playing poker and dancing with her walker. She loves to attend parties and is a source of positive energy in every room.

Mr. Speaker, Gertrude Hendrick's positive personality and commitment to helping others embodies the perfect example of a model American citizen. I commend her outstanding life and I am proud to honor this citizen from New York's 11th District on her 100th birthday.

#### IN RECOGNITION OF NATIONAL RECOVERY MONTH

**HON. WILLIAM R. KEATING**

OF MASSACHUSETTS

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, September 30, 2015*

Mr. KEATING. Mr. Speaker, I rise today in recognition of September as National Recovery Month.

Established 26 years ago, National Recovery Month strives to educate Americans about opportunities for addiction treatment and mental health services, and the urgent need to take advantage of them. This year, National Recovery Month is highlighting the value of peer-to-peer support in educating, mentoring, and helping others in their recovery.

Addressing the prescription drug abuse epidemic is a uniquely American problem. It is not limited by geography or demographics. Prescription drug abuse has spread across the country like wildfire—with the U.S. accounting for less than five percent of the world's population yet consuming over 80 percent of the world's opioids and 99 percent of its hydrocodone. Tragically, 46 people die each day from an overdose of prescription drugs, and, each year, a staggering 185,000 people over the age of twelve in Massachusetts are at risk of an overdose. This number rises to a chilling 424,000 when taking into account those suffering from alcohol abuse. These statistics neither fully convey the dangers of drug and alcohol abuse nor the toll of this epidemic—both on families nationwide and on the limited resources available to law enforcement and social service agencies.

The first step toward stemming the rising rates of addiction is investing directly in our communities. This includes promoting and encouraging prevention, treatment and recovery measures in every state, as well as ensuring robust funding for the Substance Abuse and

Mental Health Services Administration (SAMHSA). I am proud of the programs in my district that serve as a positive and successful example for others to follow—including, but not limited to, High Point Treatment Center, South Shore Mental Health, Gosnold Treatment Center, and Stanley Street Treatment and Resources (SSTAR) Addiction Treatment. They have proven the extent to which we can fight substance abuse through the integration of mental health services and treatment, thereby providing opportunity for individuals in recovery.

Mr. Speaker, I urge my colleagues to join me in highlighting this important issue. There is no single solution to fighting this epidemic, but together we can make a difference.

#### HONORING BEN RICHMOND OF THE LOUISVILLE URBAN LEAGUE ON HIS RETIREMENT

**HON. JOHN A. YARMUTH**

OF KENTUCKY

IN THE HOUSE OF REPRESENTATIVES

*Wednesday, September 30, 2015*

Mr. YARMUTH. Mr. Speaker, I rise today in honor of Benjamin K. Richmond, the President and C.E.O. of the Louisville Urban League, who retires today after serving our proud city and community for nearly three decades.

Since 1987, Ben and his staff have helped countless individuals and families across the city of Louisville achieve economic stability. Under Ben's leadership, the League has broken down barriers to ensure that all Louisvillians have the opportunity to pursue a better education, a better career, and a better life for their families. The organization has been a national model for success, regularly exceeding expectations and finding new ways to tackle the challenges facing our community.

Ben was instrumental in creating REBOUND Inc., the Urban League's charitable arm dedicated to housing development and rehabilitation. This program not only transforms vacant and abandoned properties into new houses for low and moderate income families, it helps transform the lives of those families and the neighborhoods they will call home.

At every level, Ben's passion and dedication has increased the Urban League's presence and stature throughout Louisville, forging new partnerships with local organizations, businesses, and members of the community.

Ben has spent his entire life making sure that all individuals have the opportunity to not only be successful, but to achieve that success while helping others. Quite simply, he is the very embodiment of the mission of the Urban League: to empower communities and change lives.

Louisville would not be what it is today without the contributions and commitment of Ben Richmond. I am proud to have worked closely with him through the years, but I'm even prouder to be able to call him a friend.

On behalf of the people of Kentucky's Third Congressional District and the city of Louisville, thank you, Ben, for your service and for being such a powerful source of inspiration for so many of us. I wish you all the best in your retirement. It certainly is well deserved.