

No two cases of Spina Bifida are ever the same and so this birth defect is commonly referred to as the “snowflake condition.” Children born with Spina Bifida typically undergo dozens of surgeries before they reach the age of 18. And during their lifetime, someone with Spina Bifida will face at least \$1 million in medical expenses, including multiple surgeries, and most can expect to spend much of their lives in a wheelchair or walking with braces.

Despite these challenges—and thanks to advances in research and medicine, along with policies supportive of children with disabilities—nearly two-thirds of Americans currently living with Spina Bifida have made it to adulthood. And while these strides are certainly worth celebrating, people with Spina Bifida—particularly adults—continue to face a crisis of care that could be largely prevented with the right resources and policies.

For instance, while we have a coordinated system of care designed to treat children with Spina Bifida in the U.S., there is no equivalent for adults. The result is that adults face a “care cliff” and enter a very fractured medical system where they are unable to find physicians willing or even knowledgeable enough to provide treatment, as Spina Bifida is still largely taught in medical schools as a pediatric condition and education has failed to keep pace with the rapid rise in the adult Spina Bifida population.

Thousands of adults are left with few options other than to seek care in the emergency room or continue to see their pediatric care team until insurance will no longer cover their care because of their age. And to make matters worse, many of these adults rely on Medicaid as their insurance provider, so even if they have the means to travel to an adult specialist, if they are located in another state—as is often the case—their coverage is denied. Across the country, there are more than 100 pediatric clinics devoted to caring for children with Spina Bifida. There are only 20 whose focus is on adults.

Constituents in my district are fortunate to be in proximity to Children’s Hospital of Philadelphia, home to the Spina Bifida Program, which offers comprehensive and expert care from diagnosis through adulthood. We offer great thanks to the medical professionals and researchers who endeavor to improve the quality of life for individuals living with Spina Bifida and their families.

At the federal level, we can and should make dramatic improvements in the ability of adults with Spina Bifida to access quality care by increasing the funding of the CDC’s National Spina Bifida Program—the only federal program tasked with improving the care and outcomes for people living with Spina Bifida.

In 2008, the Federal Spina Bifida Program created a National Spina Bifida Patient Registry to collect the scientific data needed to evaluate existing medical services for Spina Bifida patients, and to provide clinicians, researchers, patients, and families a window into what care models are effective and what treatments are not making a measurable difference.

Building on this in 2014, the Spina Bifida Program funded the development of a Spina Bifida Collaborative Care Network to identify and to disseminate best practices for the care of people with Spina Bifida at all ages.

However, with only \$7.5 million in annual funding—and this amount has been stag-

nant—there are only 11,000 patients in the national registry, limiting the ability of medical professionals to glean knowledge that would advance research in areas critical to improving quality of life. Even modest increases to this funding would make an enormous difference.

Additionally, we should urge NIH to work collaboratively across their many divisions to better understand Spina Bifida. As Spina Bifida can affect every organ and every system in the human body, a collaborative effort undertaken by NIH could result in research that would lead to better care for both this generation and future generations of Spina Bifida patients.

We are so fortunate today that our country is benefiting from the talent and contributions of the first generation of adults living with Spina Bifida. Today, I honor and celebrate all of them, along with their care partners, and also remember those we have lost to this condition. And I urge my colleagues to not only increase funding for the National Spina Bifida Program, but to work together so that these Americans receive the care and treatment all of us want for our families and loved ones.

I invite my colleagues to join me in this mission and join me in the Spina Bifida Caucus to broaden our efforts and advance the goal of a better future for people living with Spina Bifida.

#### RECOGNIZING PA-1’S HOMETOWN HERO: JIM McDEVITT

**HON. BRIAN K. FITZPATRICK**

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 29, 2024*

Mr. FITZPATRICK. Mr. Speaker, I rise today to recognize an extraordinary individual from Pennsylvania’s First Congressional District someone who has gone above and beyond the call of duty in service to both our community and our country. It is with great respect and admiration that I recognize Jim McDevitt, one of our district’s distinguished Hometown Heroes.

Hometown Heroes are not defined by titles or accolades but by the quiet power of their actions. They are distinguished by their unwavering integrity, the strength of their character, and their steadfast commitments to the people and places they serve. They are the foundation upon which our communities stand—the ones who lift others up, inspire hope, and in doing so, call us all to higher standards of service, and compassion. Jim McDevitt has embodied this spirit in ways that words can scarcely capture.

Jim’s lifetime of service began in 1959 when he joined the U.S. Coast Guard at just nineteen years old. For seven years he diligently served our Nation as a patrol boat operator, safeguarding our shores and ensuring the safety of countless lives. Following his honorable service in the Coast Guard, Jim answered the call to serve once more and embarked upon a career as a Philadelphia Police Officer. Upon retirement, his devotion to service continues in a profoundly meaningful role honoring his fellow veterans. Jim, a member of Sons of The American Legion Post 798 in Warminster, has sounded taps at more than 5,000 burials, honoring veterans at their final resting place. This act of reverence, performed

with Jim’s signature unwavering precision and heartfelt respect, is his way of offering a final goodbye to those who served our Nation with honor. When asked why he continues to serve in this role, he replied, “I’m going to continue to do it until I can’t.” Jim’s lifetime of service to our community and country and unwavering commitment to his fellow servicemen and women exemplify the true essence of selfless service, sacrifice, and love of country and neighbor.

Mr. Speaker, it is through the work of people like Jim McDevitt that our communities thrive, and our Nation grows stronger. His actions and service remind us that progress is not forged in grand gestures, but in the cumulative power of selfless acts. He embodies the timeless American values of resilience, generosity, and compassion, showing us that the future is built by those who care deeply, act decisively, and give without hesitation.

On behalf of Pennsylvania’s First Congressional District, I extend my deepest gratitude to Jim McDevitt for his extraordinary service. I ask my colleagues to join me in honoring this exceptional individual, whose leadership and spirit of service will inspire generations to come. May his example remind us of the boundless potential within each of us to make our communities, country, and world a better place.

#### SPINA BIFIDA AWARENESS MONTH

**HON. KEVIN HERN**

OF OKLAHOMA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 29, 2024*

Mr. HERN. Mr. Speaker, I rise today in honor of National Spina Bifida Awareness Month to pay tribute to the numerous individuals and their families across our country living with this condition.

Spina Bifida is a condition I am very familiar with. My sister and my niece both suffer from spina bifida. I know how it can impact a family.

Spina Bifida is the nation’s most common permanently disabling birth defect-compatible with life. Spina Bifida stems from a hole in the spinal cord, a condition known as a neural tube defect, as the spinal column fails to close properly during development in the womb, and it impacts virtually every major organ system. Children born with Spina Bifida typically undergo dozens of surgeries before they become adults. Adults living with Spina Bifida face myriad physical health, mental health, and other challenges, such as unemployment and limited access to quality primary and specialty care.

There are currently an estimated 166,000 individuals in the United States living with Spina Bifida, approximately 65 percent of whom are adults. This disease is now witnessing its first generation of adults, an incredible milestone, considering that the original designation of Spina Bifida as a childhood condition meant that the vast majority did not experience life beyond youth.

We have taken tremendous steps forward in recent years due to dedicated medical research, but there is so much we still don’t know.

Unfortunately, funding for Spina Bifida is limited. The only place in the Federal Government that is specifically studying this complex

condition for children and adults is the Spina Bifida Program at the National Center on Birth Defects and Developmental Disabilities at the CDC through the National Spina Bifida Patient Registry and the Spina Bifida Collaborative Care Network.

People with Spina Bifida deserve no less than the rest of us as we age. We must ensure that adults with Spina Bifida can receive high-quality medical care and that researchers have the funds necessary to continue the development of treatments for spina bifida.

#### HONORING THE CONSECRATION OF DR. PAUL L. BINION II TO THE OFFICE OF BISHOP

#### HON. JIM COSTA

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 29, 2024*

Mr. COSTA. Mr. Speaker, I rise today with great honor and excitement on behalf of the Westside Church of God Consecration Planning Teams' announcement of Dr. Paul L. Binion II. Today, we will witness the Episcopal Consecration of Dr. Paul L. Binion to the esteemed office of Bishop.

Elevating an individual to the position of Bishop is a recognition of their exceptional leadership, unwavering service, and unblemished integrity. Dr. Paul L. Binion, fondly known as Pastor Binion, has dedicated over four decades of his life to serving both his local community and the state of California. He is not only a spiritual leader but a mentor, confidant, and guiding light to countless individuals.

Pastor Binion's remarkable journey began in Fairfield, Alabama, where he was born to Paul Lawrence Binion, Sr. and Sara Ellafair House Binion. As the eldest of five siblings, he embarked on a path that would lead him to Los Angeles, California, and eventually to Fresno, where he assumed the role of Senior Pastor at the Westside Church of God in 1977. His educational achievements include a Bachelor's Degree in History from California State University, Los Angeles, and a Master's Degree of Divinity from Fuller Theological Seminary in Pasadena, California. His profound commitment to faith and education was acknowledged when the Southern California School of Ministry conferred upon him the honorary title of "Doctor of Divinity."

Pastor Binion's impact extends far beyond the walls of his church. He has been an active leader in various organizations and initiatives, demonstrating his dedication to the betterment of the community. Some of his notable roles include serving as a Presbyter of Berean Fellowship of Churches, participating in the African American Clergy Task Force, contributing to the Southwest Fresno Development Corporation, and advising the President of Fresno Pacific University on Clergy and Church Development. He has also been an advocate for social justice through his involvement with Central California Evangelicals for Social Action in addition to his contributions to the City of Fresno Mayoral Advisory Board and the Police Advisory Council. Pastor Binion's deep commitment to mental health and well-being is exemplified through the establishment of the Westside Community Counseling Center, which has served as a vital resource for the community.

His dedication to education and career development has shone through the Education and Career Initiative, a program designed to empower students in the pursuit of their educational and professional aspirations. Throughout his journey, Pastor Binion has been a source of guidance and wisdom, not only for his congregation but also for fellow pastors and community leaders. He has shared his knowledge and faith as a conference speaker, preacher, and teacher of the Bible, leaving a lasting impact on both local and national levels. In addition to his remarkable professional achievements, Pastor Binion is a devoted husband to Valerie Jean Metoyer Binion, and a loving father and grandfather. He and Valerie have been married since 1978 and have three daughters, Tiffany, Crisandra, and Kimberley, along with several grandchildren.

As we come together to witness the Episcopal Consecration of Dr. Paul L. Binion, we recognize not only a spiritual leader but a dedicated servant of the community. His journey is a testament to the enduring impact that one individual can have when guided by faith, compassion, and a commitment to the betterment of others.

Mr. Speaker, I invite my esteemed colleagues to join me in commemorating this significant moment in the life of Dr. Paul L. Binion, a man whose contributions have touched the hearts and souls of many.

#### CELEBRATING THE 100TH BIRTHDAY OF VICTOR MONACELLI

#### HON. VINCE FONG

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 29, 2024*

Mr. FONG. Mr. Speaker, I rise to wish a happy 100th birthday to Mr. Victor Monacelli of Ridgecrest, California, a veteran of the Second World War and a soon-to-be great-great-grandfather.

Born in Humphrey, Washington, to Tom Monacelli and Myrtle Winsor Monacelli on November 16, 1924, Victor was raised with his brothers Cecil, Leroy, and Thomas Monacelli. At age seventeen, Victor was one of the many brave young men who, along with his brother, Thomas, volunteered for service in World War II just after his graduation from Ellensburg High School. With his enlistment in the U.S. Navy on October 27, 1942, Victor would soon find himself stationed in the South Pacific's New Hebrides Islands where he supported the Guadalcanal Campaign for 19 months. During his time stationed in what he recalls as a "tropical paradise," enemy aircraft launched waves of attacks against Victor's position. Auguring well for his posterity, he was never once injured in these airstrikes. After roughly two years serving our country through some of its greatest naval operations, Victor would finally return to the United States. On his birthday in 1944, he managed to cross the International Date Line while being transported stateside to San Francisco, granting Victor and his friends one additional day to celebrate his twentieth birthday.

Following a brief posting in Jacksonville, Florida, in 1947, Victor was transferred to the Naval facility in Lakehurst, New Jersey, where he attended flight school and completed his first parachute jump on August 2, 1947.

Through this training, he became certified as a Parachute Rigger, safely packing and repacking parachutes for airborne personnel. It was near the facility there in Lakehurst, New Jersey that Victor met his first wife Jeanne. In 1949, he was transferred to Naval Auxiliary Air Station Charlestown in South Carolina, where for six months, he was stationed on the nation's longest-serving aircraft carrier in American history—the U.S.S. *Midway*.

Returning to the Pacific once again with the U.S. Navy, Victor served in Hawaii from 1950 to 1958, serving in the Korean War through the training and instruction of airborne personnel in the use of aviation survival equipment. Witnesses described him as instrumental in establishing the survival school at Naval Air Station Barber's Point where he continued to safely pack and inspect parachutes and survival equipment as well as airborne personnel. His final assignment in the U.S. Navy saw him move to New Iberia, Louisiana, where he met his second wife Mary, and retired from active duty by joining the Fleet Reserve in 1961. Victor retired from the Navy on November 1, 1971, achieving the rank of E7 Petty Officer after nearly 30 years of service to the United States.

Victor moved to La Verne, California in 1974, where he owned a gas station and later worked as a travel agent. He soon fell in love with California's beauty, next moving to Bakersfield, Lake Isabella, and finally to Ridgecrest. These days, Victor enjoys spending quiet time at home with his wife Juliette and spending time with his two sons, David and Victor Jay, daughter Lorri, six grandchildren, nine great-grandchildren, and soon his first great-great-grandchild. In 2022, Victor was one of two living World War II veterans in Ridgecrest who were both honored and presented with certificates of appreciation for their service to the country.

Mr. Speaker, from our nation's Capitol, and on behalf of a most grateful Nation, I ask my colleagues to join me in celebrating 100 years of Victor Monacelli's incredible life. His patriotism and pursuit of the American dream should inspire future generations and this dedication to defending our warrior is another symbol of this legacy.

#### RECOGNIZING PA-1'S HOMETOWN HERO: JOSEPH A. FLUEHR III

#### HON. BRIAN K. FITZPATRICK

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 29, 2024*

Mr. FITZPATRICK. Mr. Speaker, I rise today to recognize an extraordinary individual from Pennsylvania's First Congressional District—someone who has gone above and beyond the call of duty in service to both our community and our country. It is with great respect and admiration that I recognize Joseph A. Fluehr III, one of our district's distinguished Hometown Heroes.

Hometown Heroes are not defined by titles or accolades, but by the quiet power of their actions. They are distinguished by their unwavering integrity, the strength of their character, and their steadfast commitment to the people and places they serve. They are the foundation upon our communities stand—the ones who lift others up, inspire hope, and, in