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Wasserman Schultz, Klobuchar, Cardin, Fitzpatrick, and DeSaulnier Lead Cancer Survivorship Bill

Washington, DC – Today, U.S. Rep. **Debbie Wasserman Schultz** (FL-23), Sen. **Amy Klobuchar** (D-MN), Sen. **Ben Cardin** (D-MD), Rep. **Brian Fitzpatrick** (PA-1), and Rep. **Mark DeSaulnier** (CA-11) introduced *The Comprehensive Cancer Survivorship Act (CCSA)*, legislation that will address gaps in survivorship care and develop desperately needed standards to improve the overall patient-centered quality of care and navigation needs of cancer survivors and their families.

For every cancer survivor, this deadly disease imposes vastly different and highly personal experiences. With more than 18 million cancer survivors in the United States, and 26 million expected by 2040, there is an urgent need to empower them with the best possible resources and care to overcome this terrible disease. The CCSA will set new standards of care to ensure the best and most seamless experience for survivors, their families, and caregivers, throughout their survivorship journey, from diagnosis to end of life.

“As a fifteen-year cancer survivor, confronting it head-on, with an all-hands-on-deck approach, is my personal and professional mission. With the *Comprehensive Cancer Survivorship Act*, I am proud to introduce far-reaching legislation that better enables cancer survivors to choose their own path, provides them agency and autonomy over their personal health experiences and decisions, and addresses the entire survivorship continuum of care,” said **Wasserman Schultz**. “From the point of diagnosis, through active treatment and transitions to primary care, until the end of life, this legislation sets the standards of care that all survivors need and deserve. The CCSA confronts care planning, transition, navigation, workforce, education, and awareness, and empowers survivors with the best possible resources and care to overcome this terrible disease.”

“As a result of advances in early detection and access to effective treatments, more people are recovering after their cancer diagnoses. That’s why we must do everything we can to improve care services and quality of life for cancer survivors,” said **Klobuchar**. “This bipartisan legislation will do just that, ensuring that more survivors receive comprehensive, coordinated post-diagnosis and post recovery care that addresses their unique treatment needs throughout the course of their life.”

“Living with or surviving cancer is personal for so many families across our nation, and, thanks to increased access to preventive care, which leads to early detection, the rate of cancer survivorship continues to grow,” said **Cardin**. “Our legislation recognizes the importance of investing in improving quality of life and long-term care of cancer survivors who have bravely fought and won their battles against cancer.”

“Each year, our nation makes new advancements in cancer treatment, increasing the number of cancer survivors across the country,” said **Fitzpatrick, Co-Chair of the Congressional Cancer Caucus**. “It is time that we set standards of care for those who are cancer survivors, and we address the emotional, financial, and physical challenges that these millions of Americans are faced with. Like so many in America, the fight against cancer is personal to me, and I am proud to join my colleagues in both chambers on both sides of the aisle in introducing the Comprehensive Cancer Survivorship Act.”

“As an 8-year survivor of a non-curable treatable blood cancer, I know firsthand how important a seamless continuum of care is,” said **DeSaulnier**. “I am proud to join Congresswoman Wasserman Schultz and my colleagues in leading this effort to ensure every cancer survivor in America has access to the support and resources they need to be healthy and happy in all facets of life. I am also pleased that this legislation includes my Cancer Care Planning and Communications Act to help Medicare patients be better informed about their cancer diagnoses.”

The CCSA’s key pillars:

- **Care Planning and Transition**: Provides coverage to address the transition to primary care to help survivors develop personalized treatment care plans, standardizes processes, and consolidates treatments to guide survivorship monitoring and follow-up care;
- **Alternative Payment Model**: Studies existing reimbursement landscape to develop an alternative payment model to ensure a coordinated approach to survivorship care across an episode of care;
- **Navigation**: Develops effective and comprehensive navigation services that emphasize the continuum of care, such as follow-up and health disparities and determinants, like food insecurity, housing, transportation, labor, broadband, telehealth access, and childcare;
- **Quality of Care**: Establishes grants to promote utilization of navigation, employment of risk-stratification, transition to primary care, utilization of care plans, potential use of at-home care, and better use of information technology for patient experience data;
- **Workforce**: Establishes workforce assistance grants to help survivors, their families, and caregivers when faced with a range of workforce challenges; and
- **Education, Awareness**: Creates resources for survivors and health professionals to promote early detection, preventive care and help providers provide high-quality services.

The CCSA also addresses innovation and technology use, fertility preservation, long-term studies, survivorship resources, and provisions concerning childhood and adolescent cancer.

The following organizations support The Comprehensive Cancer Survivorship Act (CCSA): Alliance for Fertility Preservation (AFP), American Association for Cancer Research (AACR), American Cancer Society Cancer Action Network (ACS-CAN), American Lung Association, American Society for Reproductive Medicine (ASRM), Asian American Pacific Islander Nurses Association (AAPINA), Association for Clinical Oncology, Breast Care for Washington, Brem Foundation, Cancer Support Community (CSC), CancerCare, Child Cancer Cause (CCC), FORCE: Facing Our Risk of Cancer Empowered, LUNgevity Foundation, Lymphoma Research Foundation (LRF), Malecare and the National LGBT Cancer Project, Moffitt Cancer Center, National Coalition for Cancer Survivorship (NCCS), National Comprehensive Cancer Network (NCCN), Nueva Vida, Oncology Nursing Society (ONS), Prevent Cancer Foundation, Sisters Network Inc., Susan G. Komen, Tigerlily Foundation, Sylvester Comprehensive Cancer Center at the University of Miami, YMCA of the USA, Young Survival Coalition

“Cancer survivors face many unmet care needs that are complex and include physical and emotional symptoms, concerns about finances and social roles, and limited care coordination. The Comprehensive Cancer Survivorship Act legislation sponsored by Congresswoman Wasserman Schultz, Congressman Fitzpatrick, and Congressman DeSaulnier, and Senators Klobuchar and Cardin proposes to implement much needed fundamental standards of care including care coverage and coordination that will address the unique needs of the more than 18 million cancer survivors in the US. Having these standards of survivorship care in place will benefit cancer survivors and their families and caregivers. Sylvester Comprehensive Cancer Center is proud to support this Bill which will enhance our capacity to provide essential comprehensive cancer survivorship care for the South Florida community and surrounding region,” said **Stephen D. Nimer, M.D., Director of Sylvester Comprehensive Cancer Center.**

“Barriers to equitable access and appropriate care coordination stand in the way of achieving equity in cancer care and delivering high-quality care to all patients with cancer. The Comprehensive Cancer Survivorship Act addresses cancer disparities throughout the cancer care continuum and is responsive to the benefits of patient navigation. Nueva Vida applauds this Bill and its intent to support patient navigation managing the late and long-term effects of cancer and cancer treatment,” said **Laura A. Logie, Ph.D., Director of Research, Nueva Vida.**

“Young Survival Coalition (YSC) understands the unique issues young adults with breast cancer face, particularly the long-term impacts of a young breast cancer diagnosis. Young adults are more susceptible to long-term consequences of their cancer treatment, and cancer survivors of racial and ethnic diversity have a disproportionately lower health-related quality of life and those living in rural areas have less access to services and have poorer outcomes. We know best practices and standardized care for cancer survivorship would improve treatment, quality of life, and long-term health outcomes. YSC enthusiastically supports the Comprehensive Cancer Survivorship Act,” said **Jennifer Merschorf, Young Survival Coalition CEO.**

“YMCA of the USA (Y-USA) is grateful to Representatives Wasserman Schultz, Fitzpatrick and DeSaulnier and Senators Klobuchar and Cardin for introducing the bipartisan Comprehensive Cancer Survivorship Act (CCSA). As the largest provider of in-person health and well-being programs for cancer survivors, the Y has seen unprecedented growth in demand for services for individuals living with, through and beyond cancer. Since 2008, the Y has supported more than 80,000 individuals and their families to help them heal and be well, but there are so many more who need our help. CCSA would provide resources to expand and sustain this work,” said **Suzanne McCormick, President and CEO YMCA of the USA.**

“Over the last 20 years, we've seen tremendous strides made in the treatment of lymphoma and in understanding of the unique needs of all cancer survivors. The Lymphoma Research Foundation commends Reps. Wasserman Schultz, Fitzpatrick, and DeSaulnier, and Senators Klobuchar and Cardin for their co-sponsorship of the Comprehensive Cancer Survivorship Act and for recognizing that surviving cancer brings with it a set of physical, psychological, and financial needs that require ongoing attention and support. The Lymphoma Research Foundation is committed to the continued support of cancer survivors and their caregivers through survivorship education programs and in funding related research to ensure that more people survive a cancer diagnosis and go on to live full lives,” said **Meghan Gutierrez, Chief Executive Officer, Lymphoma Research Foundation.**

“Our systems need to adapt to meet the needs for a growing population of long-term cancer survivors, as treatments become more and more effective. The ‘Comprehensive Cancer Survivorship Act’ would address critical gaps, for both adults and children, by providing coverage for vital services to ease the transition from oncology to primary care. These services include cancer care planning and coordination plus new models for workplace support. We applaud Congresswoman Wasserman Schultz, Congressmen DeSaulnier and Fitzpatrick, and Senators Cardin and Klobuchar for their bipartisan efforts to transform our health and social systems to better serve cancer survivors,” said **Robert W. Carlson, MD, Chief Executive Officer, National Comprehensive Cancer Network (NCCN).**

“From detection and diagnosis to treatment and long-term support, people living with cancer face numerous challenges in receiving the best possible care,” said **Andrea Ferris, President and CEO of LUNgevity Foundation.** “We applaud Reps. Wasserman Schultz, Fitzpatrick and DeSaulnier, as well as Sens. Klobuchar and Cardin, for leading this comprehensive legislation that would take meaningful steps toward improving the way that cancer care is coordinated, delivered, and covered. We look forward to working with these congressional champions and our partners in the cancer advocacy community to ensure that these important measures are enacted.”

“The needs of people who have cancer are many and they don’t end for those whose treatment ends. The Comprehensive Cancer Survivorship Act will provide the tools and resources needed to address current barriers in delivering survivorship care. Given that cancer survivors represent 5% of the US population it is an important step in improving their lives,” said **Deborah K. Mayer, PhD, RN, AOCN, FAAN, Oncology Nursing Society (ONS).**

“The Comprehensive Cancer Survivorship Act is a huge step forward for millions of people living with, through, and beyond cancer in the United States. With an array of measures to improve the

entire continuum of care - from diagnosis through active treatment and post-treatment - this legislation will strengthen our ability to meet the unique needs of cancer survivors,” said **Smitha Pabbathi, MD, Medical Director, Survivorship Clinic, Moffitt Cancer Center.**

“The American Lung Association is pleased to support the Comprehensive Cancer Survivorship Act,” said **Harold Wimmer, President and CEO of the American Lung Association.** “This bill gives individuals and their families facing a devastating diagnosis the resources to live their lives. It also gives providers the tools they need to improve treatment and quality of life for cancer survivors. The Lung Association sincerely appreciates the work of Representatives Wasserman Schultz, Fitzpatrick and DeSaulnier, and Senators Klobuchar and Cardin to improve the lives of people living with cancer.”

"Malecare and The National LGBT Cancer Project encourage bipartisan passage of this legislation. Sexual and Gender Minority cancer patients have unique and life-threatening needs that the Comprehensive Cancer Survivorship Act (CCSA) fearlessly and effectively addresses. Our LGBTQ+ cancer survivor community has been invisible to healthcare providers for far too long. The CCSA will shine a light on interventions that will help thousands of cancer patients live longer and happier lives," says **Darryl Mitteldorf, LCSW, Director of Malecare and the leading pioneer of LGBTQ psycho-oncology.**

“The AACR commends Representatives Wasserman Schultz, Fitzpatrick, and DeSaulnier and Senators Klobuchar and Cardin for their extraordinary leadership of the Comprehensive Cancer Survivorship Act. Breakthroughs in cancer treatment have resulted in more than 18 million Americans living today as cancer survivors, and this Act will provide vital resources for many of them, including supporting personalized survivorship care plans for follow-up care, navigation services, and evidence-based survivorship resources,” said **Lisa M. Coussens, PhD, FAACR, President of the American Association for Cancer Research (AACR).**

“We are deeply grateful for Representative Wasserman Schultz’s inclusion of fertility preservation coverage in the *Comprehensive Cancer Survivorship Act*. Young cancer patients should not have to sacrifice a basic and vital life experience – parenthood – because they suffered the misfortune of a cancer diagnosis. This act will finally establish equitable protection for these vulnerable patients’ reproductive futures,” said **Joyce Reinecke, Executive Director of the Alliance for Fertility Preservation.**

“Cancer has a lasting impact—physical, social, emotional, and financial—on the affected individual and their family. Improved screening, early detection, and therapies allow us to save more lives than ever before so understanding the needs of cancer survivors and helping them successfully navigate life after cancer is crucial. We applaud Representative Wasserman Schultz and the other bill co-leaders. This legislation will pave the way for survivors to have better quality of life, providing guidance to address short- and long-term treatment effects, and an evidence-based plan that includes screening for recurrence, new cancers, and other complications,” **Lisa Schlager, Vice President, Public Policy, FORCE.**

“Susan G. Komen applauds long-time cancer community champions, Representatives Debbie Wasserman-Schultz, Mark DeSaulnier and Brian Fitzpatrick and Senators Amy Klobuchar and

Ben Cardin, in their efforts to support the growing number of people living with and surviving cancer in our country. With the increasing availability of screening, earlier detection and improvements in breast cancer treatments, the overall breast cancer mortality rate among women in the U.S. has declined by 41 percent over the last 30 years. However, statistics do not illustrate the challenges breast cancer patients, those living with metastatic disease and survivors face every day to maintain their health and quality of life. The Comprehensive Cancer Survivorship Act would increase access to the tools those impacted by breast cancer may need to navigate their care, wherever they are on their cancer journey,” said **Molly Guthrie, Vice President of Policy and Advocacy at Susan G. Komen**

“Racial/ethnic minority cancer survivors, especially Asian American cancer survivors, have reported high needs for help and subsequent low quality of life. To address the high needs for help among Asian American cancer survivors, there is a clear necessity for an innovative way of identifying their needs and delivering information and support to this specific population. This new legislature will definitely help meet their high needs through various ways that were not possible in previous years,” said **Eun-Ok Im, PhD, MPH, RN, CNS, FAAN, Senior Associate Dean for Research and Innovation, Professor & Edith Folsom Honeycutt Endowed Chair, Emory University, Nell Hodgson Woodruff School of Nursing.**

“CancerCare applauds the introduction of The Comprehensive Cancer Survivorship Act (CCSA) which recognizes the ongoing needs, concerns, and challenges confronting cancer survivors and their loved ones. With approximately 18.1 million cancer survivors currently in the United States, a number expected to grow to 22.5 million in ten years, this timely legislation will be instrumental in ensuring that survivors and their family members receive the continuing care and services they require and rely on to lead their best lives. Congresswoman Wasserman Schultz and the bill’s cosponsors have paved a much needed path to help navigate survivorship, replacing a previously unmarked map that left millions adrift without appropriate care and support,” said **Patricia Goldsmith, CEO of CancerCare.**

“With advances in cancer treatments, more people are living long lives after cancer. Yet, cancer survivors are often lost in transition from the support they received during treatment to life after cancer. They deal with physical, emotional, and financial issues, often for the rest of their lives. We need to provide better support to cancer survivors so that they can live as well as they can for as long as they can, during and after their treatment. We are grateful to Congresswoman Debbie Wasserman Schultz, Senator Amy Klobuchar, Senator Cardin, Congressman Brian Fitzpatrick, and Congressman Mark DeSaulnier for their leadership and dedication to improving the lives of cancer survivors, and we look forward to working with them to enact the Comprehensive Cancer Survivorship Act,” said **Shelley Fuld Nasso, National Coalition for Cancer Survivorship (NCCS).**

“After finishing active treatment, cancer patients must manage a frequently difficult to navigate and disjointed transition to survivorship care. Notably, there are over 19 million current cancer survivors in the US alone. These individuals often continue to pay higher costs of care for the remainder of their lives. The Comprehensive Cancer Survivor Act offers numerous ways to address these financial challenges and ensure that those who survived their initial diagnosis and treatment maintain the greatest opportunity to remain cancer free, and to effectively address long-

term effects from cancer. We offer enthusiastic support for this bill and urge momentum in Congress,” said **Karen E. Knudsen, MBA, PhD, CEO of the American Cancer Society Cancer Action Network (ACS CAN)**.

“Today’s introduction of the Comprehensive Cancer Survivorship Act is a testament to Congresswoman Wasserman-Schultz’s bravery and relentless advocacy for those whose lives have been impacted by cancer. On behalf of the Cancer Support Community, the largest, professionally-led nonprofit network of cancer support worldwide, and those who continue to access community-based navigation emotional support from our network partners, I would like to thank Representative Wasserman Schultz, along with Senators Klobuchar and Cardin and Representatives. DeSaulnier and Fitzpatrick for their leadership in introducing this landmark legislation,” said **Debbie Weir, CEO, Cancer Support Community**.

“Many pediatric cancer survivors face a multitude of lifelong health challenges caused by the toxicity of their treatment. Many lack a survivorship care and transition plan when they leave treatment and go into primary care and are unprepared for the significant health issues they may face, including hearing loss, infertility and cardiac late effects. Innovations in the Comprehensive Cancer Survivorship Act help to address the specialized needs of this population through the development of best practices to ease transitions of care. The bill would also encourage the creation of a Center for Medicare and Medicaid Innovation pediatric survivorship care demonstration model that could help to establish a standard of post-treatment transition care,” said **Steve Wosahla, Chief Executive Officer, Children’s Cancer Cause (CCC)**.

“ We must have a Comprehensive Cancer Survivorship care plan in place for all cancer patients. What we used to know to be normal is different now. We cannot rely on Google university for information around cancer,” said **Sharon Rivera-Sanchez, founder of Trials of Color & Saving Pennies 4 A Cure**.

Tigerlily Foundation is proud to support this important legislation championed by Representative Wasserman Schultz. Being diagnosed with breast cancer changed my life, and one of most challenging times was “after” treatment ends and the lack of survivorship care. With the number of cancer survivors growing – this means that patients will live longer – but with comorbidities and a variety of psychosocial, financial, quality of care and other needs. In addition, with the socioeconomic challenges and inequities that face BIPOC populations, we must ensure that patients have legislation that support and protect all, especially vulnerable populations. We are honored to have worked with Congresswoman Wasserman Schultz for so many years and look forward to seeing this survivorship legislation impact the lives of patients,” said **Maimah Karmo, President and CEO, Tigerlily Foundation**.

The original bill text can be found [here](#), the section by section [here](#), and one-pager [here](#).

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