

March 2016

Vice President Joe Biden  
Old Executive Office Building  
1650 Pennsylvania Avenue NW  
Washington, DC 20502

Dear Vice President Biden:

First and foremost, you are in our continued thoughts and prayers. There are no words to describe what it means to lose a child, especially one at the prime of his life. Many of us know too well the grief and pain that cancer can inflict on a family. But like you, we have not allowed our suffering to incapacitate us. As Maya Angelou once wrote: "I've learned that you shouldn't go through life with a catcher's mitt on both hands. You need to be able to throw something back."

Critical Mass is an established, multi-faceted coalition of organizations that speak on behalf of the 70,000 adolescents and young adults (AYAs) diagnosed with cancer each year. Our mission is to transform the care and treatment of 15 to 39 years olds diagnosed with cancer to ensure they have no barriers to survive their treatment and thrive long after their cancer care is completed. As a result of these efforts, Critical Mass has helped develop standards of care, supported research specific to the needs of AYAs, and opened a dialogue to break down the silos across pediatric and adult communities in both clinical care and research.

However, AYA cancer patients continually find themselves alone in the world of cancer. People between 15 and 39 fall into a grey area between childhood and established adulthood—a critical time of *becoming*, where cancer has an outsize impact on every aspect of their lives, for the rest of their lives. Their cancers, their issues, and even their biology can differ from those of patients over 40 and under 15. Responses to treatment often diverge from older or younger patients. Most shocking, in contrast to younger and older cancer patients, survival rates for patients in this age group have not improved since the 1970s.

A young adult cancer patient is the odd one out in both the pediatric or adult setting. One hospital or practice might only see one or two young adult patients a year, and those two may never cross paths. However, at Critical Mass, we know well that those two people are actually part of a sizeable population that is fragmented across our cancer care system. When you step back and take a national look, nearly 2 million people in the United States are living with or have survived being diagnosed with cancer as an adolescent or young adult. That's a large enough group to deserve closer investigation into just how unique they are, from their fertility status to their developmental stage to their molecular makeup to their long-term needs as survivors.



We hope that you and other members of President Barack Obama's Cancer Moonshot Task Force will listen to the millions of adolescents and young adults who need a champion. Critical Mass applauds your efforts to fully fund cancer research and we hope that you will specifically explore the needs of AYA cancer care. Our coalition of medical professionals and advocates have been on the frontlines of AYA oncology for more than a decade. Should you need any additional information, we have a nexus of research and connections that we would be privileged to share.

Thank you for your consideration but, more importantly, thank you for your dedication to this country. The leadership and commitment you have shown in the midst of such tragedy gives us strength to push forward.

Sincerely,

Members of Critical Mass

Michelle Landwehr, COO at The Samfund

Brynn Fowler, Program Manager at Huntsman Cancer Institute

Brian Sladek

Brad Love

Gwendolyn Quinn, Professor and Senior member at Moffitt Cancer Center

Brandon Hayes-Lattin, MD

Robin Raskob, Marketing & Communications Manager at HopeLab Foundation

R. Lor Randall, Director at Huntsman-Intermountain AYA in Utah

Karen Albritton, President at Fort Worth Adolescent & Young Adult Coalition

Anne Kirchhoff, Assistant Professor at Huntsman Cancer Institute

Olivia Fridgen, AYA Program Coordinator at Moffitt Cancer Center

Craig Nichols, Director at Testicular Cancer Commons

Jeanne Erickson, Assistant Professor at Univ of Wisconsin-Milwaukee College of Nursing

Vanessa Barone

Christabel Cheung, Doctoral Student at University of California, Los Angeles

Pam Simon, Nurse Practitioner/Program Manager at Stanford Adolescent & Young Adult Cancer Program

Mallory Casperson, CEO at Lacuna Loft

Simon Davies, Executive Director at Teen Cancer America

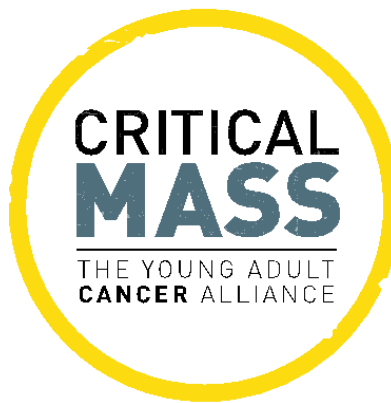
Scott Borinstein, Director, AYA Cancer Program, Vanderbilt at Vanderbilt University

Kristin Smith, Patient Navigator for Fertility Preservation at Oncofertility Consortium of Northwestern University

Paula Sanborn, BSN,RN,CPHON,CPN, Sarcoma nurse Navigator at Nationwide Children's Hospital AYA Program

Kerry Beliveau

Laurel Finster



Justin Ozuna, Director of Communications & Community Engagement at Fort Worth AYA Oncology Coalition

Nicholas Iannarino, Assistant Professor of Health Communication at University of Michigan-Dearborn

Angie Giallourakis, President at The Steven G AYA Cancer Research Fund

Kristin Stegenga, Nurse Researcher

Archie Bleyer, Founder at Pediatric & Young Adult Oncology

Maria Marek, RN Navigator for young adult cancer survivors

Emily Drake, Health Promotion Consultant

Tully Saunders, Program Coordinator at Tufts Medical Center AYA Cancer Program

Stephanie Samolovitch, Director of Support Services at Cancer Caring Center

Damon Reed, MD, Director, Moffitt Cancer Center's AYA Program at Moffitt Cancer Center's AYA Program

Jodi Mayfield, Physician

Dawn Kenneavy, President and Co-founder at Dan's House of Hope

Katherine Breitenbach, Assistant Professor/Oncology Nurse Practitioner

Robert Kahn, Senior Safety Science Leader, Pediatric Oncology

Stefanie Thomas

Kirsten Norslien, Program Director at Gilda's Club Madison

Colin Ferro

Geraldine Lee, Volunteer at Teen Cancer America

Kathi Croce, AYA(Adolescent & Young Adult)Psychologist at Yale Pediatric Hematology Oncology Department

Monica Bryant, Chief Operating Officer at Triage Cancer

Corey Heath, Ph.D., Licensed Psychologist

Melanie Goldfarb, Director, Endocrine Tumor Program at John Wayne Cancer Institute at PSJHC

Nancy Burton, RN, BS, MS, RN, Masters, Exercise Physiologist, Health Educator

Jackie Ogg, Mother of Brendan - an AYA with brain cancer at The Brendan Ogg Memorial Fund

Anna Franklin, at MD Anderson Cancer Center

Pat Taylor, Founder at Chasing Rainbows Young Adult Cancer Advocacy

Stacy Sanford, Ph.D., Director of Adolescent and Young Adult Oncology at Robert H. Lurie Cancer Center of Northwestern Uni.

Nancy Ferro, Founder, Mother of a Cancer Thriver and CEO at Epic Experience

Brad Zebrack, Professor

Barbara Strong, Chief Communications Officer at Allyson Whitney Foundation

Peggy Burkhard, Executive Director at National Bone Marrow Transplant Link

John Salsman, Director of Clinical Research in AYA Oncology at Wake Forest School of Medicine

Ashley Priskey, Board of Director at The Cassie Hines Shoes Cancer Foundation

Jennifer Reichel, Attending Physician Pediatric Oncology at Lurie Children's Hospital of Chicago

Brooke Cherven, Nursing Researcher/EBP Coordinator at Children's Healthcare of Atlanta

Anthony Audino, Pediatric Oncologist, MD at Nationwide Children's Hospital AYA Program

Deborah Morgan, AYA Nurse Navigator at AYA@USC (University of Southern California)

Samantha Watson, CEO and Founder at The Samfund



Ryan O'Donoghue, Executive Director at First Descents

Christine Baze, Survivor, Founder, Executive Director at The Yellow Umbrella Organization

Karen Hines, Awareness Director at Cassie Hines Shoes Cancer Foundation

Dan Dean, Founder at M Powerment

Carmina Valle, Research Assistant Professor, Health Behavior

Kristin Bingen, Oncology Psychologist/Associate Professor at Medical College of Wisconsin/Children's Hospital

Lynda Beaupin, AYA Director - Adolescent and Young Adult Program at Roswell Park Cancer Institute

Kristi Hutchins, Ky Chapter Board President at 3 Little Birds 4 Life

Meredith Cooper, Executive Director at Wonders & Worries

Peter Shaw, Clinical Director of Oncology at Children's Hospital of Pittsburgh of UPMC

Douglas Bank, President at The Testicular Cancer Resource Center

Stuart Siegel, Chair of Board of Directors at CureSearch

Michael Craycraft, President at Testicular Cancer Society

Lara Davis, MD, Assistant Professor, OHSU

Beth Jones, Camp Director at Camp Mak-A-Dream