



August 23, 2021

Francis Collins MD, PhD
Director, National Institutes of Health (NIH)
9000 Rockville Pike
Bethesda, Maryland 20892

Dear Dr. Collins:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We appreciate the opportunity to provide input to the NIH on the future of the Advanced Research Projects Agency for Health (ARPA-H). As policy discussions progress around the development of ARPA-H, we write to encourage you to prioritize childhood cancer research.

The President's Fiscal Year 2022 Budget would create ARPA-H to drive transformational innovation in biomedical research. We welcome the Administration's commitment to spurring research to combat complex, hard-to-solve medical challenges. Childhood cancer research faces numerous challenges and would benefit from the measures proposed in ARPA-H.

Each year in the U.S., an estimated 15,780 children are diagnosed with cancer. Approximately 1 in 264 children in the U.S. will develop cancer before their 20th birthday. Annually, there are more than 300,000 children diagnosed with cancer worldwide. Unfortunately, cancer remains the leading disease-related cause of death in the U.S. for children and adolescents ages 1-19.

We have made significant advances to develop better treatments for the most common forms of childhood cancer. However, for many other types, progress is limited, and for too many children there is no available cure. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have had a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

Research plays a pivotal role in advancing childhood cancer care and treatment, but many childhood cancers have not seen new therapies in decades. Research for many diseases is principally funded by non-government sources, including philanthropies, academia, and industry. Childhood cancer research, however, uniquely depends on the federal government as its primary source of funding. About 60% of all funding for drug development in adult cancers comes from



pharmaceutical companies, but for kids, almost none. Innovative programs like ARPA-H have the potential to fill this funding gap.

Thank you for your consideration. The Alliance for Childhood Cancer welcomes the opportunity to discuss the unique challenges of childhood cancer research and how ARPA-H can further spur innovation for kids with cancer and childhood cancer survivors. Please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at smilberg@allianceforchildhoodcancer.org, or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mink@stanford.edu, for any additional information.

Sincerely,

The Alliance for Childhood Cancer

American Academy of Pediatrics
American Association for Cancer Research
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Society of Pediatric Hematology/Oncology
The Andrew McDonough B+ Foundation
Association for Clinical Oncology
Association of Pediatric Hematology/Oncology Nurses
Association of Pediatric Oncology Social Workers
Children's Brain Tumor Foundation
Children's Cancer Cause
Children's Cancer Research Fund
Children's Oncology Group
Leukemia & Lymphoma Society
Mattie Miracle Cancer Foundation
National Brain Tumor Society
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
Sarcoma Foundation of America
St. Baldrick's Foundation
St. Jude Children's Research Hospital



July 16, 2021

The Honorable Diana DeGette
United States House of Representatives
2111 Rayburn House Office Building
Washington, DC 20515

The Honorable Fred Upton
United States House of Representatives
2183 Rayburn House Office Building
Washington, DC 20515

Dear Representative DeGette and Representative Upton:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. We appreciate the opportunity to provide input on the future of the Advanced Research Projects Agency for Health (ARPA-H). As policy discussions progress around the development of ARPA-H, we write to encourage you to prioritize childhood cancer research.

The President's Fiscal Year 2022 Budget would create ARPA-H to drive transformational innovation in biomedical research. We welcome the Administration's commitment to spurring research to combat complex, hard-to-solve medical challenges. Childhood cancer research faces numerous challenges and would benefit from the measures proposed in ARPA-H.

Each year in the U.S., an estimated 15,780 children are diagnosed with cancer. Approximately 1 in 264 children in the U.S. will develop cancer before their 20th birthday. Annually, there are more than 300,000 children diagnosed with cancer worldwide. Unfortunately, cancer remains the leading disease-related cause of death in the U.S. for children and adolescents ages 1-19.

We have made significant advances to develop better treatments for the most common forms of childhood cancer. However, for many other types, progress is limited, and for too many children there is no available cure. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have had a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

Research plays a pivotal role in advancing childhood cancer care and treatment, but many childhood cancers have not seen new therapies in decades. Research for many diseases is principally funded by non-government sources, including philanthropies, academia, and industry. Childhood cancer research, however, uniquely depends on the federal government as its primary source of funding. About 60% of all funding for drug development in adult cancers comes from



pharmaceutical companies, but for kids, almost none. Innovative programs like ARPA-H have the potential to fill this funding gap.

Thank you for your consideration. The Alliance for Childhood Cancer welcomes the opportunity to discuss the unique challenges of childhood cancer research and how ARPA-H can further spur innovation for kids with cancer and childhood cancer survivors. Please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at smilberg@allianceforchildhoodcancer.org for any additional information.

Sincerely,

The Alliance for Childhood Cancer

American Academy of Pediatrics
American Association for Cancer Research
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Society of Pediatric Hematology/Oncology
The Andrew McDonough B+ Foundation
Association for Clinical Oncology
Association of Pediatric Hematology/Oncology Nurses
Association of Pediatric Oncology Social Workers
Children's Brain Tumor Foundation
Children's Cancer Cause
Children's Cancer Research Fund
Children's Oncology Group
Leukemia & Lymphoma Society
Mattie Miracle Cancer Foundation
National Brain Tumor Society
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
Sarcoma Foundation of America
St. Baldrick's Foundation
St. Jude Children's Research Hospital



July 7, 2021

Dr. Eric S. Lander
Director
Office of Science and Technology Policy
Executive Office of the President
Eisenhower Executive Office Building
1650 Pennsylvania Avenue NW
Washington, DC 20504

Dear Dr. Lander,

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals and scientific organizations, representing millions of Americans who care deeply about childhood cancer. As policy discussions progress around the development of the Advanced Research Projects Agency for Health (ARPA-H), we write to encourage the Office of Science and Technology Policy (OSTP) to prioritize childhood cancer research and to request a meeting to further discuss the importance of this initiative for childhood cancer research.

The President's Fiscal Year 2022 Budget would create ARPA-H to drive transformational innovation in biomedical research. We welcome the Administration's commitment to spurring research to combat complex, hard-to-solve medical challenges. Childhood cancer research faces numerous challenges and would benefit from the measures proposed in ARPA-H.

Each year in the U.S., an estimated 15,780 children are diagnosed with cancer. Approximately 1 in 264 children in the U.S. will develop cancer before their 20th birthday. Annually, there are more than 300,000 children diagnosed with cancer worldwide. Unfortunately, cancer remains the leading disease-related cause of death in the U.S. for children and adolescents ages 1-19.

We have made significant advances to develop better treatments for the most common forms of childhood cancer. However, for many other types, progress is limited, and for too many children there is no available cure. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have had a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.

Research plays a pivotal role in advancing childhood cancer care and treatment, but many childhood cancers have not seen new therapies in decades. Research for many diseases is



principally funded by non-government sources, including philanthropies, academia, and industry. Childhood cancer research, however, uniquely depends on the federal government as its primary source of funding. About 60% of all funding for drug development in adult cancers comes from pharmaceutical companies, but for kids, almost none. Innovative programs like ARPA-H have the potential to fill this funding gap.

Thank you for your consideration. The Alliance for Childhood Cancer welcomes the opportunity to discuss the unique challenges of childhood cancer research and how ARPA-H can further spur innovation for kids with cancer and childhood cancer survivors. Please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at smilberg@allianceforchildhoodcancer.org for any additional information.

Sincerely,

The Alliance for Childhood Cancer

American Academy of Pediatrics
American Association for Cancer Research
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Society of Pediatric Hematology/Oncology
The Andrew McDonough B+ Foundation
Association of Pediatric Hematology/Oncology Nurses
Association of Pediatric Oncology Social Workers
Children's Brain Tumor Foundation
Children's Cancer Cause
Children's Cancer Research Fund
Children's Oncology Group
Leukemia & Lymphoma Society
Mattie Miracle Cancer Foundation
National Brain Tumor Society
Rally Foundation for Childhood Cancer Research
Sarcoma Foundation of America
St. Baldrick's Foundation
St. Jude Children's Research Hospital