Ending Childhood Cancer As We Know It
Research Progress and Opportunities

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182nd Meeting of the National Advisory Child Health And Human Development Council
For the lives we can save and for the lives we have lost, let this be a truly American moment that **rallies the country and the world together** and proves that we can still do big things.

**Let’s end cancer as we know it and cure some cancers once and for all.**

*President Biden  
February 7, 2023*
A plan for the National Cancer Program to align broad societal engagement and focus on critical needs to end cancer as we know it.

**EIGHT GOALS**
- Prevent Cancer
- Detect Cancers Early
- Develop Effective Treatments
- Eliminate Inequities
- Deliver Optimal Care
- Engage Every Person
- Maximize Data Utility
- Optimize the Workforce

**EVERYONE HAS A ROLE!**
- The White House
- Congress
- National Cancer Institute
- NIH Institutes and Centers
- U.S. Department of Health and Human Services
- Cancer Cabinet
- Professional Societies
- Advocacy Organizations
- Academia
- Industry
- Foundations
- Health Care Providers
- People with Cancer and Other Individuals

**CANCER MOONSHOT**
Providing the vision and charge for a whole-of-government approach to stimulate collaboration and accelerate progress across the National Cancer Program.
Describes goals, strategies, and actions needed to end cancer as we know it

- Long-term vision for ending cancer as we know it
- A framework for collaboration
- All-of-government approach
- All-of-society approach
- Inclusive of everyone (organizations and individuals)

- Not a medium-term strategic/action plan
- Not confined to research –includes care, advocacy, policy, individual behaviors
## GOALS  What success looks like

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<thead>
<tr>
<th>Prevent Cancer</th>
<th>Deliver Optimal Care</th>
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<tbody>
<tr>
<td>All people and society adopt proven strategies that reduce the risk of cancer</td>
<td>The health care system delivers to all people evidence-based, patient-centered care that prioritizes prevention, reduces cancer morbidity and mortality, and improves the lives of cancer survivors, including people living with cancer</td>
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<th>Detect Cancers Early</th>
<th>Engage Every Person</th>
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<td>Cancers are detected and treated at early stages, enabling more effective treatment and reducing morbidity and mortality</td>
<td>Every person with cancer or at risk for cancer has an opportunity to participate in research or otherwise contribute to the collective knowledge base, and barriers to their participation are eliminated.</td>
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<th>Develop Effective Treatments</th>
<th>Maximize Data Utility</th>
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<td>Effective treatment, with minimal side effects, is accessible to all people with all cancers, including those with rare cancers, metastatic cancers, and treatment-resistant disease</td>
<td>Secure sharing of privacy-protected health data is standard practice throughout research, and researchers share and use available data to achieve rapid progress against cancer</td>
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<th>Eliminate Inequities</th>
<th>Optimize The Workforce</th>
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<td>Disparities in cancer risk factors, incidence, treatment side effects, and mortality are eliminated through equitable access to prevention, screening, treatment, and survivorship care</td>
<td>The cancer care and research workforce is diverse, reflects the communities served, and meets the needs of all people with cancer and those at risk for cancer, ensuring they live longer and healthier lives</td>
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Research is essential to achieving the National Cancer Plan’s goals.
Opportunities for Achieving the Cancer Moonshot Goal of a 50% Reduction in Cancer Mortality by 2047

Meredith S. Shiels, Stanley Lipkowitz, Nicole G. Campos, Mark Schiffman, John T. Schiller, Neal D. Freedman, Amy Berrington de González

We need to:
- Accelerate progress for all cancers
- Increase use of what is already known to prevent, detect, and treat common cancers
- Develop/implement new methods of preventing, diagnosing, treating, and surviving cancer
- Address health disparities/inequities
Childhood Cancer Research Leadership at NCI

Gregory Reaman, M.D.
Childhood Cancer Data Initiative (CCDI)
Scientific Director
CC-DIRECT Director

Brigitte C. Widemann, M.D.
Chief, Pediatric Oncology Branch, Center for Cancer Research, NCI
Special Advisor to the NCI Director for Childhood Cancer
Childhood Cancer Data Initiative (CCDI)

Building a community centered around childhood cancer care and research data.
Childhood Cancer Data Initiative (CCDI)

Three foundational goals:

| Gathering data from every child, adolescent, and young adult diagnosed with a childhood cancer, regardless of where they receive their care | Creating a national strategy of appropriate clinical and molecular characterization to speed diagnosis and inform treatment for all types of childhood cancers | Developing a platform and tools to bring together clinical care and research data that will improve preventive measures, treatment, quality of life, and survivorship for childhood cancers |
# Childhood Cancer Data Initiative (CCDI)

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<tr>
<th>CCDI Molecular Characterization Initiative (MCI)</th>
<th>National Childhood Cancer Registry (NCCR)</th>
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| • Open to children and adolescents and young adults with newly diagnosed central nervous system tumors and soft tissue sarcomas receiving care at Children’s Oncology Group-affiliated hospitals  
   • Provides more precise diagnoses to patients and doctors to inform treatment and care  
   • Data are made available to researchers  
   • Program eligibility will continue to expand | • Integrates data from registries, hospitals, research centers, and insurers  
   • Enhances access to and use of childhood cancer / survivorship data  
   • Will generate accurate count of cancer cases  
   • Database to expand with genomic and tumor characteristics, treatment info, recurrence indicators, etc. |
National Rare Childhood Cancer Initiative can enable:

- State-of-the-art clinical and research molecular profiling
- Building a rare cancer registry with structured and real-world data to inform study design
- Facilitation of patient navigation and treatment recommendations
- Identification of therapeutic targets and inform interventional trials
- Potential data source for external controls for interventional clinical trials
- Meaningful comparisons across multiple rare cancer types
**CCDI Coordinated National Study of Pediatric/AYA Rare Cancers**

Key elements of the proposed national rare cancer study will be synergistic with CCDI and other rare tumor efforts:

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<th>Other efforts:</th>
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<td>• Conduct of longitudinal epidemiological cohort studies</td>
<td>• Support data collection and connection</td>
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<tr>
<td>▪ Genetic tumor predisposition</td>
<td>• Patient navigation</td>
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<td>• Collect core clinical information on the Molecular Characterization Initiative (MCI)</td>
<td>• Portable patient owned medical record</td>
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<td>• Ability to follow patients longitudinally and facilitate data for survivorship studies</td>
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CC-DIRECT Childhood Cancer Data Integration for Research, Education, Care and Clinical Trials program

Major components
• Standardized electronic health record
• Patient navigation services

Status
• Currently in planning stages
• As the project evolves, there will be opportunities for provider and advocacy communities to be involved

Stay informed: nciadvocacy@nih.gov

Collaborators:
• National Cancer Institute
• Centers for Medicare and Medicaid Services
• Office of the National Coordinator for Health Information Technology
• Alliance for Clinical Trials in Oncology
• American Cancer Society
• American Society of Clinical Oncology
• Children’s Oncology Group
• MITRE Corporation
Childhood Cancer Efforts from Initial Cancer Moonshot

My Pediatric and Adult Rare Tumor Network (MyPART)

Fusion Oncoproteins in Childhood Cancers (FusOnC2) Consortium

Pediatric Immunotherapy Discovery and Development Network (PI-DDN)

Learn more: cancer.gov/moonshot
What You Can Do

• **Read the National Cancer Plan:** nationalcancerplan.cancer.gov

• **Follow @theNCI & @NCIDirector** on social media and use #Every1HasARole and #NationalCancerPlan

• **Subscribe for email updates** to learn about ways to engage with the plan
Thank you!