

CHILDHOOD CANCER

A SILENT CRISIS IN OUR SOCIETY

GROUP E



What is Childhood Cancer?



Definition

Childhood cancer refers to cancers affecting children from birth to age 14 and adolescents ages 15 to 19 (National Cancer Institute [NCI], 2024).

Common types and prevalence

Estimated 14,910 children and adolescents (0-19 years) diagnosed in 2024 (American Cancer Society [ACS], 2025).

Most common types: leukemias, brain tumors, lymphomas (ACS, 2025).

Age-specific characteristics

Average age at diagnosis: 10 years overall, 6 years for children (0-14), 17 years for adolescents (15-19) (Children's Cancer Cause, 2024).



Why is This a Social Issue?

Childhood cancer is not just a medical issue—it's a significant social issue with far-reaching effects on families, healthcare systems, and society as a whole.

Key Statistics:

- Leading cause of disease-related death in children (ACS, 2025).
- Every day, 47 children in the U.S. are diagnosed with cancer. (CAC2)
- Research is significantly underfunded compared to adult cancers (Children's Cancer Cause, 2024).
- NJ ranks 3rd in the country for pediatric cancer incidence rates (U.S. Environmental Protection Agency [EPA], 2024).
- 1 in 3 children with cancer are on Medicaid (WITH Grace Initiative, 2025, Alliance for Childhood Cancer Action Days).
- Challenges in access to care, especially for those away from large pediatric hospitals (WITH Grace Initiative, 2025, Alliance for Childhood Cancer Action Days).



Why is This a Social Issue?

Childhood and adult cancers differ significantly in types, causes, aggressiveness, and treatment outcomes, with childhood cancers generally being more aggressive and rarer but also having higher survival rates than adult cancers.

Long-Term Societal and Economic Costs:

- More than 95% of childhood cancer survivors develop significant health issues due to treatment. (St. Jude)
- Survivors are twice as likely to be unemployed as adults. (American Cancer Society)
- The financial burden on families is enormous, with an average cost of \$833,000 per child (including medical expenses and lost income). (National Children's Cancer Society)
- Parents of children with cancer often reduce work hours or quit their jobs, leading to financial instability.



Why is This a Social Issue?

Childhood cancer affects entire communities—schools, workplaces, and healthcare systems must adjust to the needs of young patients and survivors.

Health Disparities & Access Inequality:

- 1 in 4 families loses more than 40% of their household income due to treatment-related costs. (American Cancer Society)
- Children from low-income or rural areas face higher mortality rates due to limited access to cutting-edge treatment.
- Black and Hispanic children have lower survival rates than white children, pointing to healthcare inequities. (NCI)

Psychological and Emotional

- Parents of childhood cancer patients have higher rates of PTSD, anxiety, and depression. (Source: National Institutes of Health)
- Siblings often experience emotional distress, academic struggles, and feelings of neglect.
- Social reintegration after treatment is challenging, with many survivors experiencing bullying, cognitive impairments, and isolation.



Key Challenges Today



Limited access to care:

- Geographic accessibility is a significant barrier to providing long-term follow-up care for childhood cancer survivors (Xu et al., 2024).
- Fear of treatment effects and perceived poor health of the child are frequently cited barriers to accessing childhood cancer care in Sub-Saharan Africa (Ascopubs, 2025).

Insurance coverage difficulties:

- Interruptions in Medicaid coverage are associated with higher risks of late-stage diagnoses in pediatric and young adult lymphoma patients (Hematology Advisor, 2025).
- Only 47.6% of pediatric cancer patients with Medicaid had continuous coverage during the period surrounding their diagnosis (Winship Cancer Institute, 2024).

Delayed diagnosis:

- Patients who gain Medicaid coverage only at or after diagnosis face a significantly higher risk of five-year all-cause death (adjusted hazard ratio = 1.41) compared to those with continuous coverage (Winship Cancer Institute, 2024).

Past & Ongoing Efforts

Federal Government

- **STAR Act (2023)** (Childhood Cancer Survivorship, Treatment, Access, and Research Act) – Expands research on childhood cancer and survivorship, improving the quality of life for survivors.
- **RACE Act (2017)** (Research to Accelerate Cures and Equity for Children Act) – Requires pharmaceutical companies to conduct pediatric trials for adult cancer drugs if relevant molecular targets exist.
- **CCDI** (Childhood Cancer Data Initiative) – Enhances data collection, analysis, and sharing in childhood cancer research.
- **Financial Support** – \$500M increase in pediatric cancer research funding over 10 years (NCI), initiating the Childhood Cancer Data Initiative (CCDI)

NJ State Government

- **S1431 (2021)** – Established the New Jersey Pediatric Cancer Research Fund, allowing taxpayers to contribute a portion of tax refunds.
- **S3724 (2021)** – Allocated \$5M to childhood cancer research (prevention, causes, and treatments).
- **New Jersey PHORCE Center** – Provides \$10M annually for pediatric cancer research at Rutgers Cancer Institute.
- **Pediatric Cancer Research Advisory Committee** – Established within the NJ Commission on Cancer Research to guide pediatric cancer research initiatives.



Past & Ongoing Efforts

Nonprofit Organizations – WITH Grace Initiative (2020)

- successfully raised awareness and funding, including \$30,000+ in six weeks and nearly \$300,000 through Grace's House, a fundraising event.
- provides direct support to families, offering care packages, financial assistance, and support group connections.
- It's advocacy efforts contributed to securing federal and state-level pediatric cancer research funding, including the establishment of the NJ Pediatric Cancer Research Fund and sustained funding for NJ PHORCE Center.

Corporate Initiatives – Hyundai Hope On Wheels (1998)

- Funded through Hyundai dealers nationwide, with a portion of every Hyundai vehicle sale contributing to pediatric cancer research.
- \$260M+ donated to fund 1,300+ pediatric cancer research projects with partnership over 175 hospitals across the U.S.

Successes & Limitations

- Surpassing 500,000 Childhood Cancer Survivors, 5-year survival rate increase (1990s 77.8% → 2000s: 82.7% → 2010-2016: 85.4%)
 - Yet, still the leading cause of disease-related death in children. More than 95% of childhood cancer survivors experience significant health-related issues by age 45
- Legislation & Budget Increases
 - Yet, childhood cancer research remains underfunded, leading to a disproportionate focus on funding for adult cancers. (Share of NCI budget: 2007 3.61% → 2023: 2.75%)
 - Long-term budget allocations lack short-term breakthroughs (e.g., CCDI: over 10 years)
 - Policy consistency concerns due to shifts in administration
- Raising Awareness Through Advocacy Groups, including Campaigns by organizations like WITH Grace Initiative
 - Yet, nonprofit and corporate efforts are subject to economic fluctuations



What Can Be Done?

Policy Recommendations

- Advocate for dedicated pediatric cancer research funding at the state and federal level.
- Strengthen Drug Development & Access – ensuring new treatments include pediatric applications.
- Expand Insurance Coverage – Require coverage for long-term effects, including mental health and survivorship care.
- Standardize and enhance pediatric cancer registries for better research and outcomes.

Community-Based Support Programs

- Provide financial aid, lodging, and transportation for families in treatment.
- Partnerships with nonprofits & hospitals
- Offer mental health support, peer mentorship, and community outreach for patients and survivors.
- Survivorship – Establish long-term care programs to address late effects of treatment.
- Empower communities to push for policy change and resources at the state level.

Awareness & Education Efforts

- Promote Childhood Cancer Awareness Month and other campaigns.
- Require pediatric oncology education for healthcare professionals.
- Educate educators and employers on supporting childhood cancer patients and survivors.
- Use storytelling, social media, and influencer partnerships to drive awareness and action.



Key Takeaways

Childhood cancer is a major yet under-recognized social issue

- Leading cause of disease-related death in children, yet receives a fraction of research funding.
- Unique challenges compared to adult cancers, including long-term health impacts on survivors.

Funding, treatment access, and family support are crucial

- Increased research funding is essential for developing safer, more effective treatments.
- Equitable access to cutting-edge therapies and clinical trials must be prioritized.
- Families need comprehensive support—financial, emotional, and medical—to navigate the journey.

Collective action and public awareness are necessary

- Policymakers, researchers, healthcare providers, and advocates must collaborate for systemic change.
- Public engagement through awareness campaigns drives action and funding.
- Everyone has a role—whether through advocacy, donations, or spreading awareness.





TAKE THE INITIATIVE. MAKE AN IMPACT.
WITHGRACEINITIATIVE.ORG

A Nonprofit Making a Difference

WITH Grace Initiative has made significant contributions to childhood cancer support:

- They provide Grace's Care Bags to children undergoing cancer treatment, offering comfort during hospital stays
- The organization offers family support and aid, including assistance with funeral costs and connecting support groups
- WITH Grace Initiative funds critical research for better treatments and cures
- They engage in advocacy and awareness efforts, including legislative initiatives for better healthcare and research funding



Ways to help | Discussion Question



What are the most effective ways society—through policy, philanthropy, and community action—can better support children with cancer and their families?

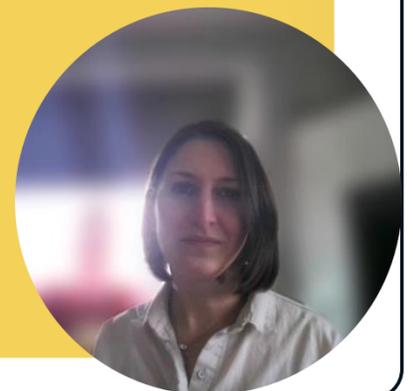
THANK YOU!

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