Dear PAC2,

Childhood cancer statistics can be confusing. Any statistics can hide or distort the truth, and even the statistics we trust may only tell part of the story.

This article delves into some familiar childhood cancer statistics and attempts to determine the projected lifelong outcomes for a child diagnosed with childhood cancer in the United States today. By lifelong outcomes, we mean what may happen over that child's entire life--not just today or in five years, but 10, 20 or 30 years from now (which is as far as the data will let us project).

Why do this?

Children have their whole lives ahead of them, so life-long outcomes carry more weight and meaning than the commonly tracked and quoted "80%" that only represents the subgroup of children who live for 5-years after diagnosis. Children who die as a result of their cancer beyond the 5-year milestone or who experience the impact of chronic health conditions caused by their cancer treatments are counted.

But we all want to plan for our child's future. College. Marriage. Having kids of their own. We need to ensure our children live to 70, 90, 110! We can't just be satisfied that a child diagnosed at age 2 lives to age 7! Our goal can **ONLY** be that any child diagnosed with cancer **lives a normal lifespan** not struck short by premature death from being "cured" or hampered by chronic health conditions.

The article will estimate the likelihood of these four life-long outcomes for a child diagnosed with cancer:

Outcome #1	A child lives at least 30 years after diagnosis without chronic health conditions
Outcome #2	A child lives at least 30 years but faces mild to moderate chronic health conditions
Outcome #3	A child lives at least 30 years but faces life-threatening or disabling chronic health conditions
Outcome #4	A child dies

Data Set for Childhood Cancer - Current Outcomes

This section will identify the key statistics used in the analysis and the source of the statistics. The first data set is provided by the Children's Oncology Group. Both sets of remaining data come from the Childhood Cancer Survivor Study (CCSS). The CCSS is the largest, nationwide project to track and evaluate the outcomes for childhood cancer survivors. About the CCSS: "The CCSS is a component of the Long Term Follow Up Study, began in 1994 and is a collaborative, multi-institutional study funded by a grant from the National Cancer Institute of the National Institutes of Health and funds from ALSAC, St. Jude fundraising organization. The CCSS is composed of individuals who survived five or more years after diagnosis for cancer, leukemia, tumor, or similar illness diagnosed during childhood or adolescence. The CCSS, which includes all participants in the Long Term Follow Up Study with a confirmed diagnosis of cancer, is a retrospectively ascertained cohort of 20,346 childhood cancer survivors diagnosed between 1970 and 1986. It also includes approximately 4,000 siblings of survivors who serve as the comparison group for the study."

Data Set #1 – Number of diagnosis and the average 5-year childhood cancer survival rate

The first set of data is provided by the Children's Oncology Group (COG). The data includes the number of children under age 20 diagnosed annually in the US (13, 500) and the percentage of those children that will survive at least 5 years (80%). Note that 80% is not representative of any specific type of childhood cancer; but instead represents the average result for 100% of the children diagnosed every year in the US. The data can be viewed here: Childhood Cancer Facts and Statistics.

Data Set #2 – Number of children that suffer chronic health condition

The second data set is from *Chronic Health Conditions in Adult Survivors of Childhood Cancer: The Childhood Cancer Survivor Study* (N Engl J Med 2006; 355:1572-1582 October 12, 2006).

The study reviewed the health status of 10,397 adults who received a childhood cancer diagnosis between 1970 and 1986. The survivors range in age from 18 to 48, with an average age of 27 years old. The time from the initial diagnosis to participation in the study ranged from 6 to 31 years and averaged 18 years. The study compared the health status of the survivors to that of siblings.

The primary cancer diagnosis for the study participants included; leukemia (30%), Hodgkin's disease (18%),central nervous system tumor (13%), bone tumors (11%), sarcoma (10%), non-Hodgkin's lymphoma (9%), Wilm's tumor (7%), and neuroblastoma (4%). Treatments included chemotherapy (67%), radiation (62%), unknown treatment (15%) and no treatment (6%).

Survivors reported chronic health conditions including; vision, hearing and/or speech problems, infertility, psycho-social issues, cardiovascular, pulmonary, gastrointestinal, renal, musculoskeletal, neurological, and/or endocrine conditions, and/or secondary cancers.

Conditions were assigned a Grade, or severity level, relating to specific conditions, as shown below:

Grade One	Mild (night blindness, hearing loss, hypertension, shortness of breath, kidney stones, diabetes)
Grade Two	Moderate (cataracts, cardiomyopathy, hepatitis, seizure disorders)
Grade Three	Severe (blind, deaf, emphysema, major joint replacement/amputation, infertility)
Grade Four	Life-threatening or disabling (heart transplant, cardiac arrest, paralysis, respiratory arrest, kidney transplant, cognitive deficit)
Grade Five	Death

It should be noted that for deceased survivors, the maximum Grade condition reported before death was used.

Key conclusions from the report include:

1. Survivors of childhood cancer have a high rate of illness owing to chronic health conditions.
2. Among survivors, the cumulative incidence of a chronic health condition reached 73.4% 30 years after the cancer diagnosis.
3. Among survivors, the cumulative incidence for severe, disabling, or life-threatening conditions or death due to a chronic condition is 42.4% 30 years after cancer diagnosis.
4. Thus, by subtraction, the cumulative incidence of mild to moderate conditions 30 years after diagnosis is 31% (73.4%-42.4%).

To read more on chronic health conditions of childhood cancer survivors visit the PAC2 Library.

Data Set #3 – Number of Children that die after surviving five years

The third data set is also from the CCSS: *Cause-Specific Late Mortality Among 5-Year Survivors of Childhood Cancer: The Childhood Cancer Survivor Study* (JNCI J Natl Cancer Inst (2008) 100 (19): 1368-1379. doi: 10.1093/jnci/djn310).

The term "Late," or "Excess Mortality" refers to a child dying as the result of recurrence of the original cancer, secondary cancer, or other health effect resulting from the toxicity of treatment, such as chemo or radiation.

This study included 20,483 five-year survivors of childhood cancer that were diagnosed between 1970 and 1986. The study group was searched in the National Death Index for deaths occurring between 1979 and 2002.

The study concludes that for a 5-years survivor the estimated probability of survival 30 years from diagnosis is 82% (probabilities were 94% at 10 years and 88% at 20 years). Put another way, the projected probability of a 5-year survivor dying within 30 years of diagnosis due to a cancer related cause is 18%. Highest excess mortality was observed in non-ALL, non-AML, medulloblastoma or PNET, other CNS malignancy and Ewing sarcoma. Excess mortality resulted from recurrent disease (58%), secondary cancers (19%), circulatory disease (7%) and respiratory disease (3%).

Data Set #2 states that the cumulative incidence is 42.4% 30 years after diagnosis for severe, disabling, or life-threatening conditions or death due to a chronic condition. The 18% of 5-year survivors that die from years 6 to 30 should be included in that 42.4%. Thus, the likelihood that a 5-year survivor of will suffer severe, disabling or life-threatening condition, but not death is 42.4% - 18.0% = 24.4%.

Calculation of Childhood Cancer – Current Outcomes

This data is then used to calculate the potential, long-term outcomes. The calculations are shown in the table below.

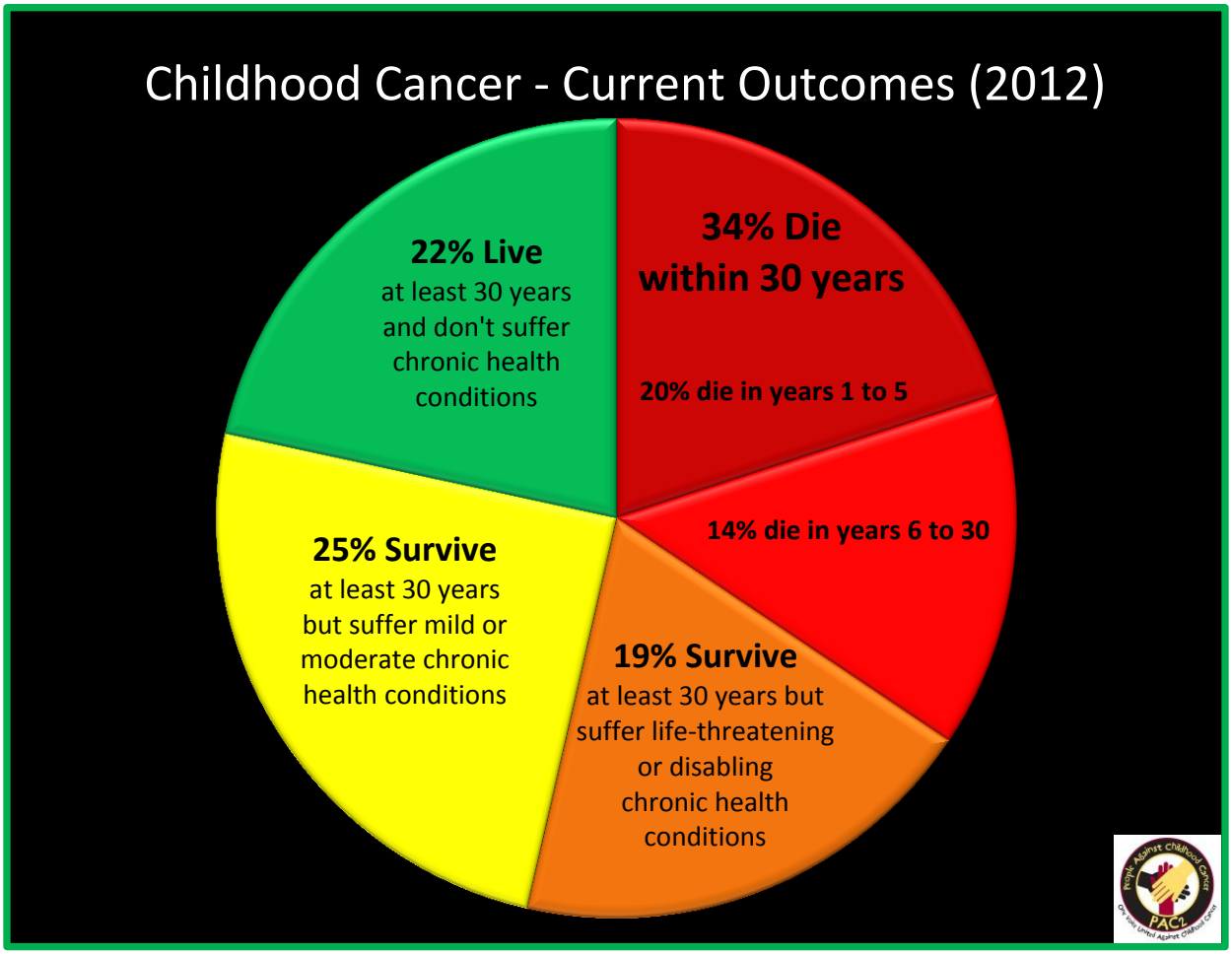
Calculations: Childhood Cancer – Projected Outcomes	
Data	**Calculation**
Estimated number of children under 20 diagnosed annually in the US	13,500
Estimated number of children that will die within 5 years	13,500 x 20% = 2,700
Estimated number of children that will survive 5 years	13,500 x 80% = 10,800
What are the projected outcomes for the 10,800 5-year survivors?	
Estimate of the number of 5 year survivors that don't suffer chronic health conditions?	10,800 x 27% = 2,916
Estimate of the number of 5 year survivors that suffer chronic health conditions, health effects, including death?	10,800 x 73% = 7,884
What are the projected outcomes for the 73% of 5-year survivors that experience chronic health conditions, including death?	
Estimate of the number of 5 year survivors that die from chronic health conditions from year 6 to year 30	10,800 x 18% = 1,944
Estimate of the number of 5 year survivors that suffer life-threatening or disabling chronic health conditions from year 6 to year 30	10,800 x 24% = 2,592
Estimate of the number of 5 year survivors that suffer mild to moderate health conditions but live at least 30 years	10,800 x 31% = 3,348

Integrating the analysis produces the following summary table of projected outcomes.

Childhood Cancer - Projected Outcomes	#	%
Child dies within 5 years of diagnosis	2,700	20%
Child dies within 30 years of diagnosis	1,944	14%
Child lives 30 years but experiences severe, life threatening or disabling heath conditions	2,592	19%
Child lives 30 years but experiences mild or moderate health conditions	3,348	25%
Child lives 30 years and experiences no chronic health conditions	2,916	22%
Total	**13,500**	**100%**

Childhood Cancer – Current Outcomes (2012)

The chart below summarizes the projected outcomes for children diagnosed with cancer.



Here are the projected results for the four outcomes:

Outcome #1 About 1 in 5 lives at least 30 years after diagnosis without chronic health conditions

Outcome #2 About 1 in 4 lives at least 30 years but face mild to moderate chronic health conditions

Outcome #3 About 1 in 5 lives at least 30 years but face life-threatening or disabling chronic health conditions

Outcome #4 About 1 in 3 die

Only #1 is acceptable!

Visit the PAC2 September 2012 Childhood Cancer Event Calendar to make #1 the outcome for all kids through raising awareness and funding childhood cancer research in your area during September, National Childhood Cancer Awareness Month.

PAC2

Note: Thanks to all contributors and reviewers. Projections are based on PAC2's evaluation of the data sets. Please excuse all rounding errors. While we present raw, cold, hard data, the article was created by raw emotion. If you identify an issue please contact us at info@peopleagainstchildhoodcancer.org.