



Childhood Cancer

Strategic Plan 2008-2010

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Thanks to American Cancer Society, Make-A-Wish Foundation®, Mountain States Tumor Institute, Trevor's Trek and the families they work with for providing many of the photos in this plan. Thank you to the Cancer Data Registry of Idaho and the Bureau of Vital Records and Health Statistics for providing the data.

Dedication

This plan is dedicated to the memory of all those children who are battling the many forms of childhood cancer, to the survivors, and to those who did not survive. We will hold them in our thoughts and hearts as we proceed in making this plan a reality.

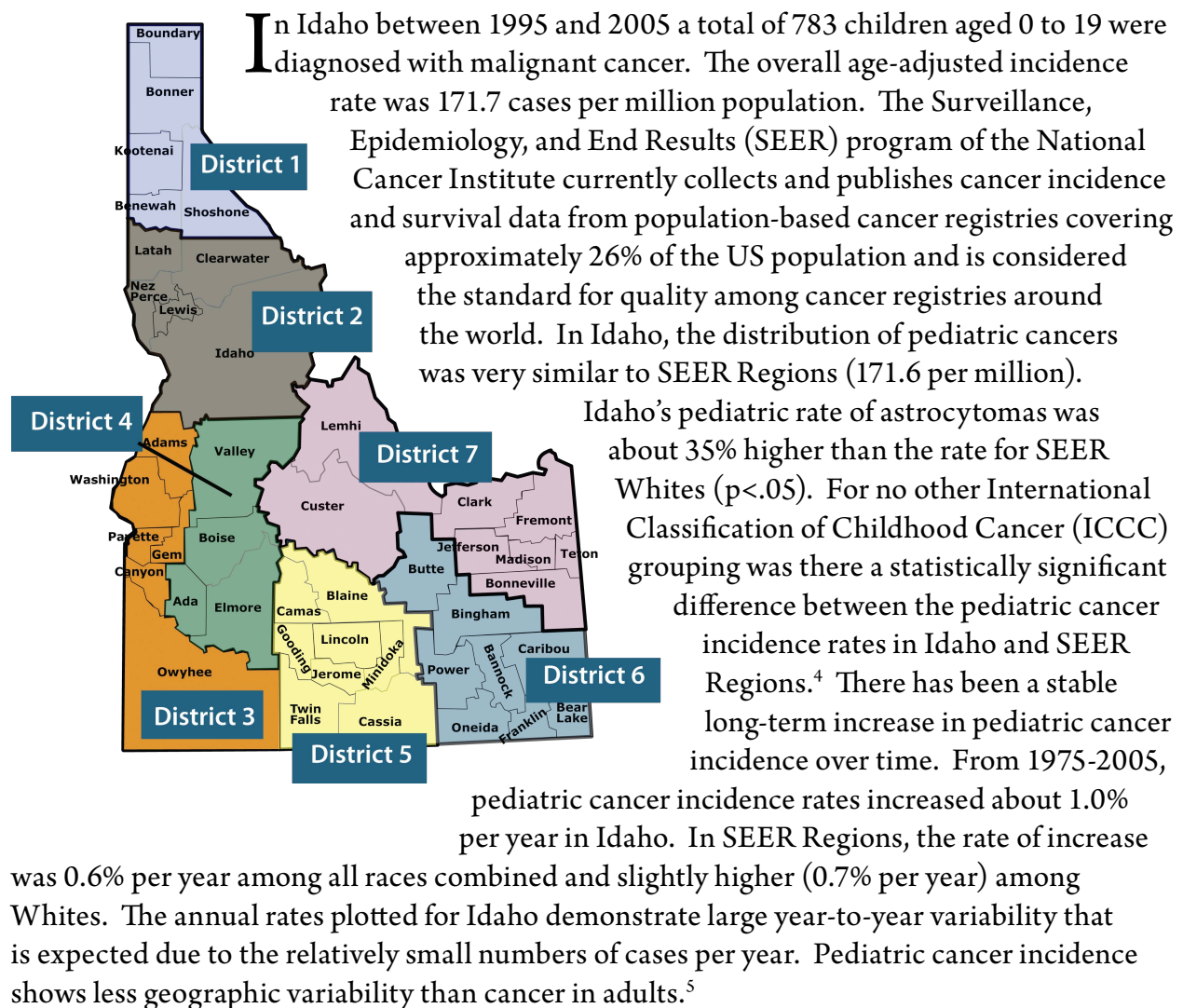
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INTRODUCTION AND BASIC STATISTICS/DATA

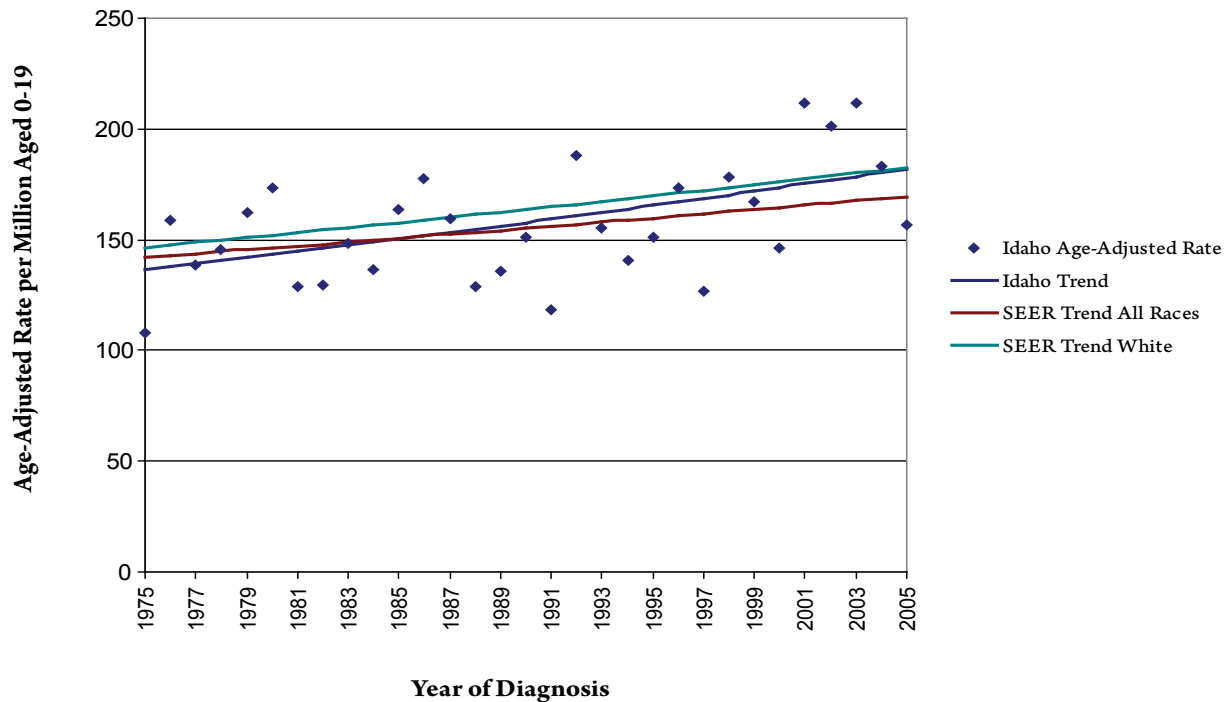
Childhood cancer is the second leading cause of death after accidents and is the leading cause of death by disease among children ages 0-15.¹ The American Cancer Society estimates that in the U.S. in 2008 there will be 10,730 new cases of cancer among children aged 0-14. About 1,490 children aged 0-14 are expected to die from cancer in 2008, about one-third of these from leukemia.² The three most often diagnosed pediatric cancers are leukemia (30% of all childhood cancers), cancers of the central nervous system including the brain, and lymphomas.³

IDAHO INCIDENCE



A full Idaho childhood cancer incidence report can be viewed on the Cancer Data Registry of Idaho (CDRI) web site at: <http://www.idcancer.org/specialreports.html>.

Trends in Pediatric Cancer Incidence Idaho and SEER, 1975-2005



Source: Cancer Data Registry of Idaho (July 2008).

Idaho Resident Cancer Incidence Aged 0-19 Years 1995-2005

Site Category (ICCC grouping)	Cases	Percent
All Sites Combined	780	100.0%
I Leukemias, myeloproliferative and myelodysplastic diseases	190	24.4%
II Lymphomas and reticuloendothelial neoplasms	115	14.7%
III CNS and misc. intracranial and intraspinal neoplasms	162	20.8%
IV Neuroblastoma and other peripheral nervous cell tumors	25	3.2%
V Retinoblastoma	13	1.7%
VI Renal tumors	26	3.3%
VII Hepatic Tumors	7	0.9%
VIII Malignant bone tumors	48	6.2%
IX Soft tissue and other extrasosseous sarcomas	53	6.8%
X Germ cell and trophoblastic tumors and neoplasms of gonads	52	6.7%
XI Other malignant epithelial neoplasms and melanomas	85	10.9%
XII Other and unspecified malignant neoplasms	4	0.5%

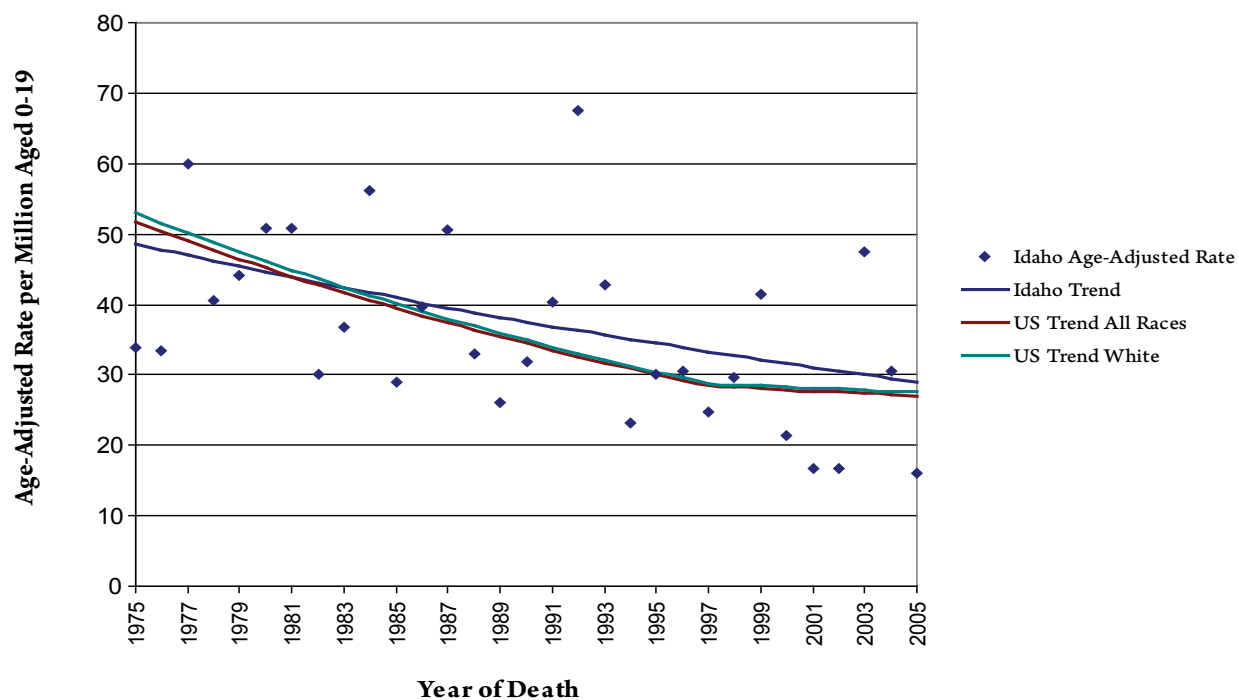
It was not possible to assign a group code of the International Classification of Childhood Cancer system to 3 cases.

Source: Cancer Data Registry of Idaho

MORTALITY

In Idaho from 1995 to 2005, 126 children aged 0-19 died from some form of cancer (73 males and 53 females). The leading cause of cancer deaths was leukemia (31.0%) followed by brain and other parts of the central nervous system (24.4%).⁶ While pediatric cancer incidence has increased over time, mortality has decreased. From 1975-2005, pediatric cancer mortality rates decreased about 1.7% per year in Idaho. In the U.S. overall, the rate decreased about 2.7% per year from 1975-1997, and at a lower rate of 0.6% per year from 1997-2005. The rates of decrease were about the same for Whites and all races combined. The annual rates plotted for Idaho demonstrate large year-to-year variability that is expected due to the relatively small numbers of deaths per year.⁵

**Trends in Pediatric Cancer Mortality
Idaho and US, 1975-2005**



Source: Idaho Department of Health and Welfare, Bureau of Health Policy and Vital Statistics (July 2008).

IDAHO RESIDENT CANCER DEATHS
AGED 0-19 YEARS
1995-2005

Malignant Neoplasms	Number	Percent
Total, all malignant neoplasms	126	100.0%
Leukemia	39	31.0%
Brain and other parts of central nervous system	31	24.4%
Bone and articular cartilage	14	11.1%
Connective and soft tissue	8	6.3%
Non-Hodgkin's Lymphoma	7	5.5%
All other malignant neoplasms	27	21.4%

Statistic for 1995-1998 have been revised using the Modified ICD-9 codes and comparability ratios.

Source: Idaho Department of Health and Welfare, Bureau of Health Policy and Vital Statistics (August 2007).

Prior to 1970 most children diagnosed with cancer had very little chance for survival. Since then, five-year survival rates have increased to about 80%.⁷ The Childhood Cancer Survivor Study (CCSS), established in 1993, is conducted by a consortium of 25 pediatric oncology treatment centers that have pooled data on their survivors treated between 1970 and 1986.⁸ They have found that there are a wide range of potential concerns for survivors including the need for long-term follow-up care. The late effects of long-term survivorship include physical, emotional, and impacts on the family.



PHYSICAL IMPACTS

Physical impacts include medical problems that develop years after treatment ends. Development of long-term physical effects depends on several factors including type of cancer, age at diagnosis, gender, treatment received, genetic pre-disposition, and complications during treatment. The risk for developing a recurrence or secondary cancer anywhere in the body, as a potential outcome of cancer treatment, is also dependent on the factors listed above. Follow-up medical care, complete records of the child's cancer treatment, and counseling on health behaviors and risk reduction are critical steps needed to maintain the health of the childhood cancer survivor.⁹

EMOTIONAL IMPACTS

Cancer affects many aspects of a child's life and the emotional side effects can be devastating to a once active and vibrant child. They can feel a range of emotions that include fear, depression, anxiety, and symptoms similar to post-traumatic stress disorder (PTSD). They may also feel lost or isolated because they no longer have stability or a sense of control over their lives. Lack of interest and poor self-esteem can last long after their final treatment is over. Children may also experience confusion and embarrassment as they try to return to a normal life and are dealing with the physical side effects related to their diagnosis and treatment. Teens sometimes experience a sense of invincibility and may make unhealthy behavior choices. However, they may also be motivated to undertake challenging work or hobbies because of that same feeling of invincibility. Remembering that all of this can have lasting effects on children for years after their diagnosis reminds those around them to provide the best physical and emotional care possible.



FAMILY IMPACTS

Childhood cancer touches all members of the family and impacts are felt socially, emotionally, and financially. It is not uncommon for one parent to give up his or her job and spend extended time away from the family caring for the child with cancer while in treatment. Other children in the family are often left in the care of other caregivers. Siblings may experience concern, fear, jealousy, guilt, resentment, and feelings of abandonment which can last long term.¹⁰ Relationships between family members can become tense and cause stress on the marriage.¹¹

“Having cancer at such a young age made me often wonder, ‘Why me?’ While receiving my treatment of radiation and chemotherapy (for 14 months) I witnessed so many children also battling this horrific disease. I began to wonder, ‘Why them?’”

Trevor Smith, Boise



EDUCATION AND SCHOOL RE-ENTRY

Treatment for cancer during childhood or adolescence may affect educational progress because of lost school time and therapies which impact memory, cognitive function, and learning abilities.¹² School personnel may not be aware of the potential for long-term and late effects of treatment so parents, counselors, teachers, and medical professionals need to work together to ensure that the child is receiving the services and accommodations needed to succeed when returning to school.⁹



Pictured above:
Hayley Welch, St. Luke's Hospital Teacher,
and student Garrett.

A system, originally designed by Microsoft for business networking, called “round table” allows Garrett to actually attend class at Sawtooth Middle School in Meridian even though he's at St. Luke's Children's Hospital in Boise.

CAUSES OF CHILDHOOD CANCERS

The causes of childhood cancers are not yet well understood. Two factors may determine a child's susceptibility to developing cancer: genetic predisposition to the disease and environmental cues that may initiate the disease or cause it to progress. A child may inherit mutations in a gene that cause cancer to occur, or a child may suffer sporadic mutations in a gene that cause cancer to occur. For a few adult cancers, scientists have identified inherited mutations of certain genes that predispose a person to a specific cancer and they can test for these mutations. However, most childhood cancers are due to sporadic instead of inherited mutations. Scientists are working to determine what environmental cues pose the greatest risk to children. It is known, for example, that exposure to benzene in the environment increases leukemia risk. There are numerous other cues that may also increase risk.

There are a few conditions, such as Down syndrome, other specific chromosomal and genetic abnormalities, and ionizing radiation exposures, that are known risk factors for childhood cancers and that explain a very small percentage of cases.



High-level radiation and high doses of certain chemicals are known risk factors for developing certain childhood cancers, but the influence of low-level contaminants is harder to define. At sufficient doses over time, chemicals and other agents in the environment may contribute to initiation or promotion of certain cancers. Scientists continue to research chemical agents that are known to cause cancer in animals to determine if they might also cause cancer at fairly low doses in children. Despite advances in this research, it remains difficult to identify past exposures, particularly if they occurred many years in the past. Preventing in utero and early childhood exposures to known and potential carcinogens is imperative for reducing potential risks to children.¹³

CLINICAL TRIALS

Childhood cancer patients have a much higher rate of participation in clinical trials, at about 60%, than adults, which is one reason that cure rates for childhood cancers have improved so remarkably over the past few decades. In contrast, only about 5% of adult cancer patients enroll in clinical trials. One reason so many children take part in clinical trials is that most young cancer patients are treated at academic medical centers. These centers have always had the two-fold mission of caring for patients and doing research to improve treatment methods and survival rates.



Children must be included in clinical research because they have different cancers than adults. Any new treatment for children must be tested in children. In addition, children respond differently to drugs than adults do, and can often tolerate higher doses (relative to their size) of chemotherapy drugs.¹⁴ It is important that research continues and children have access to clinical trials.

POPULATION GROWTH IN IDAHO

The population of Idaho is growing rapidly. In December 2007 Idaho was ranked as the fourth fastest growing state in the nation for the third year in a row behind Arizona, Utah, and Nevada.¹⁵ Because of the increasing population, the number of cases of childhood cancer will increase in the coming years. The additional cases will lead to an increased need for treatment, other support services, and resources for childhood cancer patients and their families.

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ACCESS TO CARE AND RESOURCES GOAL

Ensure access to quality comprehensive and coordinated care from the time of a suspected diagnosis of cancer and throughout the cancer continuum.

Objective 1

By 2010, at least ten agencies, health care facilities, and/or non-profit organizations will partner to hold at least six community events to raise awareness about childhood and adolescent cancer.

Strategies

1. Identify national health observances or local events that can be utilized to raise awareness about childhood cancer and hold events or conduct media outreach to obtain coverage.
2. Identify and engage non-profit and for profit organizations, agencies, health care facilities, and individuals with an interest in childhood cancer and partner to hold events and education to raise awareness about childhood cancer issues around the state.

Objective 2

By 2010, work with Idaho third party payers to improve and streamline the approval process for evidence-based treatment protocols for child cancer patients.

Strategies

1. Determine methods to open dialogue with Idaho third party payers responsible for approving treatment for child cancer patients and implement those methods.

“It was difficult being diagnosed as a young adult...there needs to be more support available to those that don't fit in the pediatric or adult cancer care; this was one area where there wasn't much available.”

Heather Feely, Boise

PATIENT AND FAMILY QUALITY OF LIFE GOAL

Focus on issues related to the quality of life of childhood cancer survivors and their families including social and emotional needs, family economic concerns, school re-entry issues, and access to psychosocial support programs.

Objective 3

By 2010, implement at least two methods that will reduce the financial and/or emotional impacts on the families of children with cancer.

Strategies

1. Improve access to services by addressing concerns regarding transportation, lodging, and distance care costs.
2. Develop communication methods to increase awareness of existing quality of life and survivorship resources available to assist childhood cancer patients, survivors, and their families.
3. Increase the number of activities for siblings of child cancer patients.
4. Enhance existing school re-entry programs and expand to rural areas.
5. Identify ways to educate school personnel about childhood cancer issues.
6. Raise awareness of cancer prevention behaviors among child and adolescent survivors (e.g. diet, physical activity, sun protection, no tobacco, and cancer screenings).



LONG TERM CARE AND SURVIVORSHIP GOAL

Improve long-term care and the assessment and management of the late effects of childhood cancer.

Objective 4

By 2010, develop at least two strategies to coordinate oncology and community care. Address the unique needs of childhood cancer survivors and the need for continuity of care between primary care, the pediatric oncologists, and subsequent healthcare providers.

Strategies

1. Educate the patients and families on the importance of continuity of care.
2. Identify an existing or develop a program to assist the transfer from pediatric to adult medical care, including treatment records and education for the patients and families.
3. Identify channels (e.g. newsletters, professional meetings, etc.) and educate healthcare professionals (pediatrics, family, and general practice) about the unique needs of childhood cancer survivors including physical effects, psychosocial impacts, and risk for long-term effects and secondary cancers.



“It wasn’t until I lost all delusions of control that I was truly able to experience life. I had a plan and my life took a turn for what at the time seemed like the worst but now I realize that it was a blessing in disguise. I come to this conclusion in retrospect. Life comes at you fast when you’re diagnosed with a life threatening disease and support is essential to survival.”

Charmayne (Charly) Alegria, Boise



ADVOCACY GOAL

Address advocacy concerns to strengthen work in the area of childhood cancer. This includes advocacy on behalf of patients and families for legislation and public policy.

Objective 5

By January 2010, establish a child and adolescent cancer advocacy network to link Idahoans to national childhood cancer efforts.

Strategies

1. Develop communication channels to keep people apprised of national or local advocacy efforts (email listserves, newsletter, or appropriate materials).
2. Network with and link organizations with interest in childhood cancer to address policy and legislative issues and strengthen the impact of efforts (e.g. American Cancer Society, Leukemia and Lymphoma Society, Make-A-Wish, etc.).
3. Keep apprised of national efforts to maintain or increase research and research funding and prevent reductions in research funding.
4. Support continued federal funding for research into the genetic determinants of childhood cancer and support continued funding for new drug therapies.
5. Identify national health observances that can be utilized to raise awareness about childhood cancer and hold events or support media coverage to raise awareness of childhood cancer.
6. Support advocacy efforts for high quality insurance coverage for all children in Idaho.
7. Ensure that every child in Idaho diagnosed with cancer has the opportunity to enroll in clinical trials they are eligible for.
8. Support advocacy efforts to create policy to reimburse family members as caregivers for child cancer patients (Oregon model).

ENVIRONMENTAL GOAL

Reduce exposure of Idahoans to known carcinogens.

Objective 6

By 2010, conduct at least two campaigns to increase awareness about ways to reduce pediatric and adult exposure to known carcinogens.



Strategies

1. Identify compounds that are “Carcinogenic to Humans” or “Likely to be Carcinogenic to Humans” as defined by the U.S. Environmental Protection Agency (EPA). (*Appendix A.*)
2. Identify opportunities to provide information to the general public and health professionals about reducing exposure to carcinogens and provide information on alternatives (e.g. solvents, lawn and garden chemicals).
3. Support efforts of existing programs to disseminate messages about reducing hazardous environmental exposures.

Appendix A.

Carcinogenic to Humans

This descriptor is appropriate when there is convincing epidemiologic evidence demonstrating causality between human exposure and cancer.

This descriptor is also appropriate when there is an absence of conclusive epidemiologic evidence to clearly establish a cause and effect relationship between human exposure and cancer, but there is compelling evidence of carcinogenicity in animals and mechanistic information in animals and humans demonstrating similar mode(s) of carcinogenic action. It is used when all of the following conditions are met:

there is evidence in a human population(s) of association of exposure to the agent with cancer, but not enough to show a causal association, and;

there is extensive evidence of carcinogenicity, and;

the mode(s) of carcinogenic action and associated key events have been identified in animals, and;

the key events that precede the cancer response in animals have been observed in the human population(s) that also shows evidence of an association of exposure to the agent with cancer.

Likely to be Carcinogenic to Humans

This descriptor is appropriate when the weight of the evidence is adequate to demonstrate carcinogenic potential to humans but does not reach the weight of evidence for the descriptor “Carcinogenic to Humans.” Adequate evidence consistent with this descriptor covers a broad spectrum. As stated previously, the use of the term “likely” as a weight of evidence descriptor does not correspond to a quantifiable probability. The examples below are meant to represent the broad range of data combinations that are covered by this descriptor; they are illustrative and provide neither a checklist nor a limitation for the data that might support use of this descriptor. Moreover, additional information, e.g., on mode of action, might change the choice of descriptor for the illustrated examples. Supporting data for this descriptor may include:

an agent demonstrating a plausible (but not definitively causal) association between human exposure and cancer, in most cases with some supporting biological, experimental evidence, though not necessarily carcinogenicity data from animal experiments;

an agent that has tested positive in animal experiments in more than one species, sex, strain, site, or exposure route, with or without evidence of carcinogenicity in humans;

a positive tumor study that raises additional biological concerns beyond that of a statistically significant result, for example, a high degree of malignancy, or an early age at onset;

a rare animal tumor response in a single experiment that is assumed to be relevant to humans, or;

a positive tumor study that is strengthened by other lines of evidence, for example, either plausible (but not definitively causal) association between human exposure and cancer or evidence that the agent or an important metabolite causes events generally known to be associated with tumor formation (such as DNA reactivity or effects on cell growth control) likely to be related to the tumor response in this case.

Source: US EPA. 1999. *Proposed Guidelines for Carcinogen Risk Assessment*. NCEA-F-0644, available on-line at <http://www.epa.gov/pesticides/health/cancerfs.htm>.

Appendix B.

LOCAL RESOURCES & SUPPORT GROUPS

American Cancer Society
2676 S. Vista Ave. Boise, ID 83705
(208) 343-4609
(800) 632-5934
<http://www.cancer.org/docroot/home/index.asp>

Leukemia and Lymphoma Society
921 S. Orchard Street Suite I Boise, ID 83705
(208) 658-6662
(866) 357-9051
http://www.leukemia-lymphoma.org/all_page.adp?item_id=377295

Make-A-Wish Foundation® of Idaho
4355 Emerald Street Suite 280 Boise, ID 83706
(208) 345-9474
(877) 405-9474
<http://idahowish.org/>

St. Luke's Children's Hospital
190 E. Bannock St. Boise, Idaho 83712
(208) 381-1200
http://www.stlukesonline.org/boise/specialties_and_services/childrens_hospital/

ONLINE RESOURCES

Alliance for Childhood Cancer
<http://www.childhoodcanceralliance.org/acc/Resources/>

Beyond the Cure
<http://www.beyondthecure.org/resources/>

Childhood Cancer Guides
<http://childhoodcancerguides.org/>

National Childhood Cancer Foundation
<http://www.nccf.org/>

Outlook: Life Beyond Childhood Cancer
<http://www.outlook-life.org/index.pl>

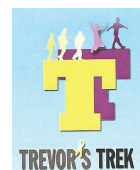
Ped Oncology Resource Center
<http://www.acor.org/ped-onc/resources/supportorg.html>

The Children's Cause
http://www.childrenscause.org/key_resources.php

ONLINE SUPPORT GROUPS

DMOZ Open Directory Project: Health:
Child Health: Conditions and Diseases:
Cancer: Support Groups
http://dmoz.org/Health/Child_Health/Conditions_and_Diseases/Cancer/Support_Groups/

On Top of Cancer
http://www.ontopofcancer.org/childhood_cancer_support_group.php



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