St. Baldrick's FOUNDATION
Conquer Childhood Cancers

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www.StBaldricks.org

Childhood Cancer Realities

How Big is the Problem?

1) Childhood cancer is the # 1 disease killer of children in the U.S.
Multiple sources; here's one: http://seer.cancer.gov/publications/childhood/

2) In the U.S., cancer is still the second leading cause of death (following accidents) in children ages 5-14.
Source: Cancer Facts & Figures 2012, American Cancer Society:
http://www.acco.org/LinkClick.aspx?fileticket=EcECXIUZyeA%3d&tabid=670

3) 80% of children diagnosed with cancer are in developing countries.
Source: (SIOP: International Society of Pediatric Oncology)

4) Worldwide, 300,000 children a year are diagnosed with cancer.
Source: Union for International Cancer Control

5) Worldwide, every 2 minutes a child is diagnosed with cancer.
Source: World Health Organization (WHO), GLOBOCAN 200 (listed on PAC2)

6) One in five children diagnosed with cancer in the U.S. will die.
Multiple sources; "Pediatric Cancers" pdf provided by Peter Adamson, Chair of the Children's Oncology Group; Surveillance, Epidemiology, and End Results (SEER) Program and the National Center for Health Statistics.

7) Approximately 1 in 285 children in the US will be diagnosed with the disease before the age of 20.
Source: http://www.cancer.org/acs/groups/content/@research/documents/webcontent/acspc-041787.pdf

Progress

NOTE: Stats about the tremendous progress made over the last few decades are to show there is hope and progress – good motivation to keep going. But while offering that light at the end of the tunnel, we must emphasize that for some types of childhood cancer, there has still been little progress, and for some, in fact, there is still no hope for a cure.

8) Fifty years ago, fewer than 10% of children diagnosed with cancer survived long term. Today, that number is almost 80% overall.
Source: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page4

9) The progress in survival rates is largely attributable to improvements in treatment and the high proportion of patients participating in clinical trials.
Sources: SEER, NCI: http://www.acco.org/LinkClick.aspx?fileticket=M5NeDHMG-u4%3d&tabid=670 and Cancer Facts & Figures 2012, American Cancer Society (ACS): http://www.acco.org/LinkClick.aspx?fileticket=EcECXIUZyeA%3d&tabid=670

10) While great progress has been made in curing some childhood cancers, for many others progress has been limited, and for some kids there is still little hope for a cure.
Multiple sources: SEER, NCI, COG, Cancer Facts & Figures 2012, ACS: http://www.acco.org/LinkClick.aspx?fileticket=EcECXIUZyeA%3d&tabid=670

Ages

11) The average age of diagnosis for childhood cancer is 6. The average number of years lost: 67. (Note: These figures differ by a year or two depending on the source.)
Sources: Children's Oncology Group (http://www.curesearch.org/ArticleView2.aspx?id=8811) and PAC2 website

12) Cancer is diagnosed in all ages, from newborn infants, to children, teens and young adults.
Multiple sources: (ex: Surveillance, Epidemiology and End Results (SEER) data http://seer.cancer.gov/)

13) Cancer survival rates for patients who are those diagnosed with cancer at ages 15 through 39 have seen little or no improvement for decades.
Source: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page10

Sub-stat: "… factors that contribute to the problem: high numbers of uninsured AYAs [adolescents & young adults] and a tendency for kids and young adults with cancer to fall into a "no man's land" between pediatric and adult oncology practices…"
Source: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page10

14) Without making a single new discovery, 30% more teens with cancer could be cured with one simple change: they need to be treated by pediatric oncologists.
Source: (http://www.stbaldricks.org/where-the-money-goes/research-priorities/ (Dr. Mary Lou Schmidt and other participants of the 2010 Research Priorities Summit of the SBF.) Also: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page10

Sub-stat: Because families, patients and often doctors do not realize the profound difference this makes in survival rates, too many are treated by medical oncologists without access to pediatric cancer protocols. (Same sources as above)

30% more teens and young adults can be cured today if treated on a pediatric, rather than adult, protocol [Different words, same sources as above]

15) The most common cancers among children and adolescents vary by age.

- Cancers that are most common in children ages 0-14 are acute lymphocytic leukemia (26%), brain and CNS (21%), neuroblastoma (7%), and non-Hodgkin lymphoma (6%).
- The most common cancers among adolescents ages 15-19 are Hodgkin lymphoma (15%), thyroid carcinoma (11%), brain and CNS (10%), and testicular germ cell tumors (8%).

Source: ACS: http://www.cancer.org/acs/groups/content/@research/documents/webcontent/acspc-041787.pdf

Childhood Cancers vs. Adult Cancers

16) The types of cancers that develop in children are very different from the types that develop in adults. Childhood cancers are often the result of DNA changes in cells that take place very early in life, sometimes even before birth. Children must be treated by pediatric oncologists, who have the specific expertise needed.
Source: ACS: http://www.cancer.org/Cancer/CancerinChildren/DetailedGuide/cancer-in-children-differences-adults-children

17) Unlike many cancers in adults, childhood cancers are not strongly linked to lifestyle or environmental risk factors.
Source: ACS: http://www.cancer.org/Cancer/CancerinChildren/DetailedGuide/cancer-in-children-differences-adults-children

18) Many adult cancers can be diagnosed early. In 80% of kids, cancer has already spread to other areas of the body by the time it is diagnosed.
Sources: National Cancer Institute (NCI), Children's Oncology Group (COG)

19) Much of what we know about treating adult cancers has been learned from childhood cancer research. ("Some fundamental aspects of cancer treatment today, such as combination chemotherapy and knowledge of tumor suppressor genes, can be traced to research first completed on pediatric cancer patients.")
Source: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page2

20) Most kids are treated on clinical trials; most adults are not.
("The majority of children for whom there are clinical trials, and who are eligible for those trials, are actually enrolled on clinical trials, in stark contrast to adults, where only a few percent of eligible patients participate in clinical research.")
Source: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page4

Survivorship & Late Effects

Note: When a child survives cancer, he or she faces a lifetime that is forever changed. Because survival statistics use the 5-year mark, those who die of childhood cancer related late effects add significantly to the "mortality" rate. The late effects of treatment – which are often life-threatening – mean that "childhood cancer is forever."

21) Survivors stats:

- There are about 300,000 survivors of childhood cancer in the U.S.
- 1 in 640 young adults age (20 to 39) is a childhood cancer survivor
- Soon 1 in 450 adults will be a childhood cancer survivor
- Multiple sources: COG, NCI, individual researchers

22) For kids who survive, the battle is not over. Because of the treatments they had as kids, by the time they're in their 30's or 40's, more than 73% of survivors will have a chronic health problem and 42% will have severe or life-threatening conditions.
Source: http://www.mskcc.org/magazine/may-2009/late-effects-childhood-treatment
Similar: Almost 2/3 of survivors have at least one chronic health problem, ¼ have a severe condition, and almost ¼ have three or more chronic health problems. These late effects of treatment can include heart damage, second cancers, lung damage, infertility, cognitive impairment, growth deficits, hearing loss, and more.
Sources: http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page12 and http://www.acco.org/Information/AboutChildhoodCancer/ChildhoodCancerStatistics.aspx

23) For kids who survive, the battle is not over. Because of the treatments they had as kids, by the time they're 45, more than 95% of survivors will have a chronic health problem and 80% will have severe or life-threatening conditions.
Sources: St. Jude - http://www.stjude.org/hudson-survivors and Wall Street Journal - http://online.wsj.com/article/SB10001424127887324904004578539611296432752.html and Time - http://healthland.time.com/2013/06/12/childhood-cancer-survivors-have-significant-chronic-disease/

24) Cancer treatments such as chemo and radiation therapy can cause long-term side effects, so children who survive cancer need careful attention for the rest of their lives. Most childhood cancer survivors are not aware of the life-threatening effects of their treatment and are not getting the specialized follow-up care they need.
Sources: ACS: http://www.cancer.org/cancer/cancerinchildren/detailedguide/cancer-in-children-differences-adults-children - and Hewitt, M; Weiner, SL; Simone, JV. Childhood Cancer Survivorship: Improving Care and the Quality of Life. Institute of Medicine publication. 2003.

Women who were treated with radiation to the chest for childhood cancer have an increased risk for breast cancer... comparable to women with BRCA *mutations.*
Chaya Moskowitz, PhD, who presented the study at the 2012 ASCO Scientific Meeting - http://www.mskcc.org/pressroom/press/childhood-treatment-found-pose-similar-risk-breast-brca-mutations

Causes

25) Unlike many cancers in adults, childhood cancers are not strongly linked to lifestyle or environmental risk factors.
Source: American Cancer Society

26) Children with Down syndrome have an increased risk of developing leukemia.
Source: http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood

Funding of Childhood Cancer Research

27) Only about 4% of the NCI's funding goes to all childhood cancers combined.
Source: PAC2 (and others)

28) The St. Baldrick's Foundation is the largest private funder (non-government) of childhood cancer research grants. (NOTE: It's important to use the word grants here, as a few other – like St. Jude – raise more money for research, but for their own institutions, not to make grants.)

A Few Disease-Specific Stats

Acute Lymphoblastic Leukemia (ALL) is a "liquid" tumor, a cancer of the blood and bone marrow. It is the single greatest killer of children with cancer, accounting for about 35% of all childhood cancer diagnoses. – NCI and the Children's Oncology Group (COG):
http://www.curesearch.org/Articleview2.aspx?id=9403&l=8669&b=8462

Cancers of the brain and brain stem are the most common "solid" tumors of childhood and they have the highest mortality rate of the childhood cancers. COG:
http://www.curesearch.org/Articleview2.aspx?id=9282&l=8669&b=8462

Neuroblastoma is the most common type of cancer in infants, and is often present at birth. The average age of diagnosis is 2, and it is rare in children over 10. - Ped-Onc: http://www.ped-onc.org/diseases/SOCC.html

The average age of diagnosis for osteosarcoma, a type of bone cancer, is 15. Big dogs often get this cancer too, so research to find cures helps both people and St. Bernards!

(Osteosarcoma is almost identical in companion animals and in people, so research in basic cancer biology and treatment is readily translational across the species. - http://dels-old.nas.edu/ilar_n/ilarjournal/51_3/pdfs/v5103Withrow.pdf - **also** http://health.usnews.com/health-news/family-health/cancer/articles/2011/12/02/dogs-with-cancer-helping-to-find-a-cure

And http://www.akcchf.org/canine-health/your-dogs-health/bone-cancer-in-dogs.html

Osteosarcoma is the most common bone tumor in dogs and typically afflicts middle-age large and giant breed dogs such as Irish Wolfhounds, Greyhounds, German Shepherds, Rottweilers, mountain breeds (great Pyrenees, St. Bernard, Leonberger, Newfoundland), Doberman Pinschers and Great Danes. It has a ten times greater incidence in dogs than humans.[10 - http://en.wikipedia.org/wiki/Osteosarcoma

While there are many types of childhood cancer, the "rare" types – when added together – account for about 30% of cancers diagnosed in children and adolescents. Because so few children are diagnosed with each type, however, it is very difficult to do research on these cancers. (NCI, COG)

Good Overall Sources

ACS Cancer facts and figures 2014: *Special Section:* Cancer in Children & Adolescents
http://www.cancer.org/acs/groups/content/@research/documents/webcontent/acspc-041787.pdf

http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood

NCI Cancer Bulletin, March 18, 2008, Milestones in Pediatric Oncology:
http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page9
http://www.cancer.gov/aboutnci/ncicancerbulletin/archive/2008/031808/page13

Incidence and Survival among Children and Adolescents: 1975-1995
http://seer.cancer.gov/publications/childhood/

The main portal for information from NCI is at
http://www.cancer.gov/cancertopics/types/childhoodcancers
Epidemiology in Older Adolescents and Young Adults 14 to 29 Years of Age
http://seer.cancer.gov/publications/aya/

SEER Cancer Statistics Review, 1975-2004
http://www.seer.cancer.gov/csr/1975_2004/

New Malignancies among Cancer Survivors: 1973-2000
http://www.seer.cancer.gov/publications/mpmono/

The Following Info on Childhood Cancer Types is Provided in Case it is Helpful

Acute Lymphoblastic Leukemia (ALL) is the most common type of childhood cancer. It is a cancer of the blood and bone marrow. Normally the bone marrow makes stem cells that mature into blood cells over time. In ALL, too many stem cells turn into immature white blood cells (lymphoblasts) that don't mature

into the normal blood cells (lymphocytes) that fight infection by attacking germs and other harmful bacteria.

Central Nervous System (CNS) tumors are cancers of the brain and brain stem. They are the most common solid tumors of childhood and they have the highest mortality rate of the childhood cancers. Types include medulloblastoma, PNET, germ cell tumors, high-grade and low-grade gliomas, ependymoma, astrocytoma and more.

Clear Cell Sarcoma of the Kidney (CCSK) is a very rare type of kidney tumor. It is not recognizable as different from Wilms tumor before removal of the tumor, but requires a different treatment

Ewing Sarcoma is a less common form of bone tumor, affecting mostly children ages five and older. These tumors form in the cavity of the bone.

Hodgkin disease is a type of lymphoma, a cancer of the lymph nodes. It affects teens most commonly, but also younger children. The lymph system is present throughout the body and helps fight infections. Hodgkin disease can start almost anywhere and then spread to almost any organ or tissue, including the liver, bone marrow and spleen.

Myeloid leukemias are more rare and difficult to cure than the more common Acute Lymphoblastic Leukemia. In leukemia, the bone marrow produces large numbers of abnormal blood cells, which flood the bloodstream and lymph system and may invade vital organs. The most common cancer of the myeloid cells is Acute Myeloid Leukemia (AML). Others include Juvenile Myelomonocytic Leukemia (JMML), Chronic Myelogenous Leukemia (CML), Acute Promyelocytic Leukemia (APL), and Myelodysplastic Syndromes (MDS).

Neuroblastoma is a cancer of the sympathetic nervous system, a message network between the brain and other parts of the body. Neuroblastoma tumors can grow in the abdomen, neck or pelvis. It is the most common type of cancer in infants, and can form before birth. The average age of diagnosis is 2, and it is rare in children over 10.

Non-Hodgkins Lymphomas (NHL) are cancers of the cells of the immune system (T and B lymphocytes, natural killer cells). Cells of the immune system are produced in the bone marrow and then travel to all the lymph glands, the thymus gland, areas of the intestinal tract, tonsils, and spleen, so a lymphoma can develop in any of those sites. The four major subtypes of NHL in children are Lymphoblastic, Burkitts, Large B cell, and Anaplastic large cell.

Osteogenic sarcoma (or Osteosarcoma) is the most frequently diagnosed type of bone tumor, usually found in adolescents and young adults. Tumors are most often in the large bones of the upper arm (humerus) and the leg (femur and tibia).

Retinoblastoma is a cancer of the retinoblasts, or "baby" cells in the retina, responsible for vision. Retinoblastoma occurs most often in children from birth to age 3. About 40% of these children have the genetic form of the disease; with every cell in the retina susceptible to tumor formation, usually both

eyes are affected. The other 60% have the non-genetic type, affecting only one eye. Since removal of the eye can cure most children research is now focused on preserving vision.

Rhabdoid Tumor of the Kidney is a very rare type of kidney tumor, and rhabdoid tumors can occur in other places of the body, as well. Researchers have found a specific gene mutation that leads to rhabdoid tumors.

Rhabdomyosarcoma is the most common of the **soft tissue sarcomas** which can be found anywhere in the body. Rhabdomyosarcoma is a tumor that arises in the muscle cells, and is the most common type in children under age ten. The other soft tissue tumors are more rare and tend to be found in adolescents. They include fibrosarcomas, synovial sarcomas, malignant peripheral nerve tumors, leiomyosarcoma, liposarcoma, and others even more rare. Some soft tissue tumors are similar to those found in adults, while others are very unique to children.

Wilms Tumor accounts for about 90% of kidney tumors in children. About 95% of children with this tumor have a "favorable histology" (better cure rate with less treatment) as determined by the pattern the pathologist sees in the tumor cells. The other 5% have anaplastic Wilms tumor, which is much more resistant to treatment.

Other Rare Childhood Cancers are actually not so rare, when added together, as they account for about 30% of cancers diagnosed in children and adolescents. Because so few children are diagnosed with each type, however, it is very difficult to do research on these cancers. They include germ cell tumors, liver tumors (hepatoblastoma and hepatocellular carcinoma), adrenocortoco carcinoma, colon cancer, melanoma, nasalpharangyal cancer, thyroid tumors and others.

If at any time you need assistance, please contact the St. Baldrick's Foundation media staff at media@stbaldricks.org.

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