# Long Term Survivorship after Cancer Treatment

Waseem Alhushki,MD Long Term Follow-Up Lead Physician Cure4thekids StoryBook Homes



# Goals

- To review the history and the current standard guidelines for cancer survivorship.
- To discuss Adolescent and Young Adults (AYAs) cancer survivor's unique needs and concerns.
- To present Cure4thekids foundation survivorship experience "StoryBook Homes".



# History of chemotherapy





# The New England Journal of Medicine

JUNE 3, 1948

Volume 238

TEMPORARY REMISSIONS IN ACUTE LEUKEMIA IN CHILDREN PRODUCED BY FOLIC ACID ANTAGONIST, 4-AMINOPTEROYL-GLUTAMIC ACID (AMINOPTERIN)\* SIDNEY FARBER, M.D.,† LOUIS K. DIAMOND, M.D.,‡ ROBERT D. MERCER, M.D.,§ ROBERT F. SYLVESTER, JR., M.D.,¶ AND JAMES A. WOLFF, M.D.|| BOSTON

Number 23

Sufficient encouragement was obtained from these observations to justify further studies on the effect of more powerful antagonists to folic acid on the course of acute leukemia in children. Since November, 1947, when a sufficiently pure substance became available, to the time of this writing (April 15, 1948) we have made studies on 16 children with acute leukemia to whom the most powerful folic antagonist we have yet encountered, 4-aminopteroylglutamic acid (aminopterin††) was administered by intramuscular injection. Many of these children were moribund at the onset of therapy. Of 16 infants and children with acute leukemia treated with aminopterin 10 showed clinical, hematologic and pathological evidences of improvement of important



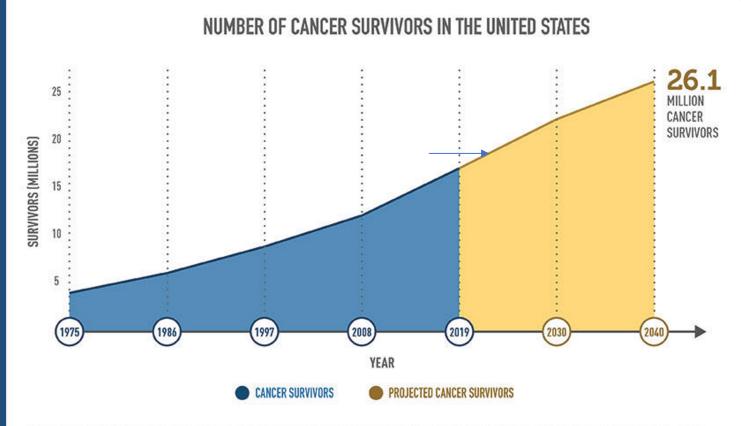


# <section-header>

If prayers are based in Hawan, this prayer and addiverse the work . America can do this There is not a doubt in "Dear Goly, bases Not cancer." America can do this There is not a doubt in the minist of our type cancer measurements that here is a start and the second se are today-almost noneristant. Hyorasii ug, Mr. Freeident, this will happen: Ore in mir Americans none alive, 34,000,000 people, will die of cancer unless new cures are found. South arithmet noneristicht former. School and Sch To the public, cancer patients, their friends Write or agive the President, urging him to "Description, possion Not canteer." Still, more than 138,000 Anwinicases died of accouncileux your. This your, Mr. Preddant, you have it in your Common that the second second Common that the second second Altrendy, 4 out of about 200 types of cancer can be cured with drugs. And 30 other drugs will cance the second this cancer can be cured with drugs. And 30 other drugs will cance the second this cancer can be cured with drugs. And 30 other drugs will cancer to be first and this cancer. pat more funds behind cancer research. Or, POQUED SUIT SELL PROFESSION. This year, Mr. Preddent, year have is in year power to kept is real this case. As you agained were the Budget, we beg you to generative the again of those 305,000 Amer-icans. And their families. We gray you be encomber sho that we space more each sky on military matters than each year on cancer research. And, hast year, more than it times as much an space research se on concerneeanch. people, will have cancer in the future. We simply concest afford this. Our nation has the money on one hand and the skills on the other. We must, under your Dear Mr. Nizoez Cancer research needs more fizzde. Pierce pro cancer. Dr. Sidney Farber, Part President of the American Cancer Society, believes: "We are so close to a cure for cancer. We lack only the will eadership, put our hands together and get this uses us access or cannot reast and and use you as you account, proceer manits bigitists and get this and the kind demonstrand comparison of the state of the state of the state of the state and get the try lo genues are near by prot of 2005 of the paper, but is a wear in which America's 2008 birthday? What a halding that sould be Change read. fail this coupen to: The President The White House Washington, D.C. We sek a boller perspective, a batter way to allocate our money to rave hundreds of thou-CITIZENS COMMITTEE FOR THE CONQUEST OF CANCER

### PUBLIC LAW 92-216-DEC, 22, 1971 778 [85 STAT. Public Law 92-216 JOINT RESOLUTION December 22,1971 [S. J. Res. 184] Extending the dates for transmission of the Economic Report and the report of the Joint Economic Committee. Resolved by the Senate and House of Representatives of the United States of America in Congress assembled, That (a) notwithstanding the provisions of section 3 of the Act of February 20, 1946, as amended President's Economic Report. 60 Stat. 24; 70 Stat. 289. (15 U.S.C. 1022), the President shall transmit to the Congress not later (10 G.S., Avza), the Fresident small transmit to the Congress Not later than February 15, 1972, the Economic Report; and (b) notwithstand-ing the provisions of clause (3) of section 5(b) of the Act of Feb-ruary 20, 1946 (13 U.S.C. 1034 (b)), the Joint Economic Committee shall file its report on the President's Economic Report with the House of Representatives and the Senate not later than March 10, 1972. 62 Stat. 16. Approved December 22, 1971. Public Law 92-217 JOINT RESOLUTION December 22,1971 [5. J. Res. 186] To provide for the beginning of the second session of the Ninety-second Congress. State Congress. Second session session of the Ninety-second Congress assembled, That the second regular session of the Ninety-second Congress hall begin at non on Tuesday, January 18, 1972. Approved December 22, 1971. Public Law 92-218 AN ACT December 23,1971 [5:1923] To amend the Public Health Service Act so as to strengthen the National Cancer Institute and the National Institutes of Health in order more effectively to carry out the national effort against cancer. Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, The National Cancer Act of 1971. SHORT TITLE SECTION 1. This Act may be cited as "The National Cancer Act of 1971". FINDINGS AND DECLARATION OF PURPOSE SEC. 2. (a) The Congress finds and declares-(1) that the incidence of cancer is increasing and cancer is the disease which is the major health concern of Americans today; (2) that new scientific leads, if comprehensively and energetiof 1971 into la





The number of cancer survivors in the United States is projected to grow to 26.1 million by 2040. NCI considers a person to be a cancer survivor from the time of diagnosis until the end of life.

Source: Institute of Medicine and National Research Council. 2006. From Cancer Patient to Cancer Survivor: Lost in Transition. The National Academies Press. doi: 10.17226/11468. de Moor JS, et al. Cancer Epidemiol Biomarkers Prev. 2013 Mar. doi: 10.1158/1055-9965.EPI-12-1356. Cancer.gov



Male		
Prostate	3,523,230	7
Melanoma of the skin	760,640	
Colon & rectum	726,450	
Urinary bladder	597,880	
Non-Hodgkin lymphoma	451,370	
Kidney & renal pelvis	376,280	
Oral cavity & pharynx	311,200	
Testis	303,040	
Leukemia	300,250	
Lung & bronchus	287,050	
All sites	8,321,200	

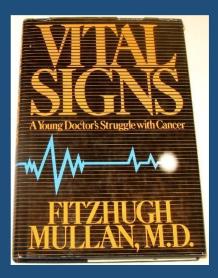
Female	
Breast	4,055,770
Uterine corpus	891,560
Thyroid	823,800
Melanoma of the skin	713,790
Colon & rectum	710,670
Non-Hodgkin lymphoma	394,180
Lung & bronchus	367,570
Uterine cervix	300,240
Ovary	246,940
Kidney & renal pelvis	230,960
All sites	9,738,900



# Survivorship



# Pioneers of the Survivorship Movement



### OCCASIONAL NOTES

Seasons of Survival: Reflections of a Physician with Cancer

WHEN I was given a diagnosis of cancer, my first thought was not, Will I die? but rather, How can I beat this? Like a youngster who flunks a big test, I immediately began to worry about what to do to pass the course. I was 32 years old at the time, a physician, a husband, a parent, and a son. I had been healthy, athletic, and free of pain, but with the diagnosis, I became formally sick. My mind and my hopes riveted

The New England Journal of Medicine







# National Coalition for Cancer Survivorship (NCCS)

Co-founder of NCCS / First Executive Director

Catherine Logan Carillo



### **Cancer Survivor**

An individual is considered a cancer survivor from the time of diagnosis through the balance of life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

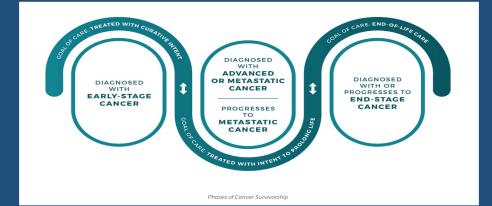
Adapted from the National Coalition for Cancer Survivorship

The National Coalition for Cancer Survivorship (NCCS) defined survivorship as a distinct phase along the cancer control continuum.

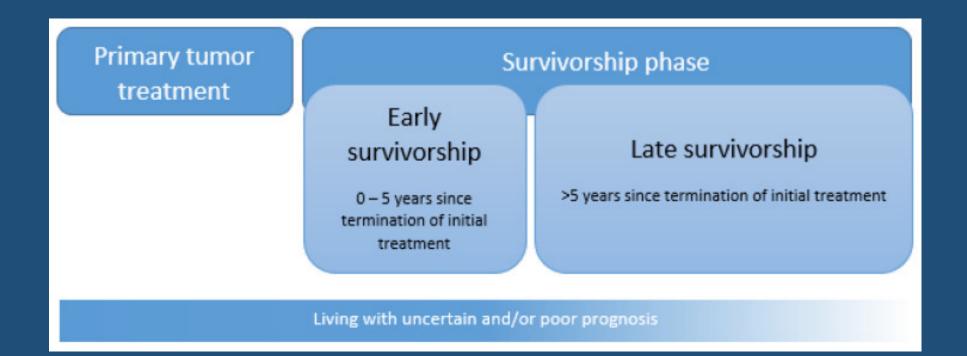
Institute of Medicine's (IOM) definition of cancer survivorship focuses on the phases of cancer care following completion of primary treatment and lasting until cancer recurrence or end of life.

### NCCN's Definition of Survivorship-

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted.







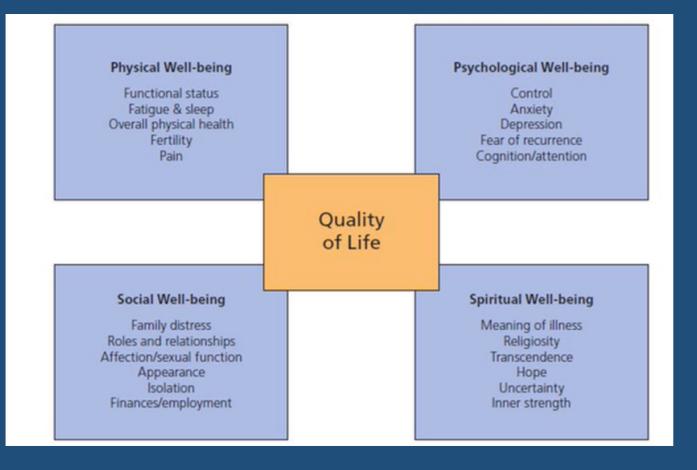




# Late Effects of Cancer Treatment

- Physical/Medical (e.g., second cancers, cardiac dysfunction, pain, lymphedema, sexual impairment)
- Psychological (e.g., depression, anxiety, uncertainty, isolation, altered body image)
- <u>Social</u> (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job loss, return to school, financial burden)
- Existential and Spiritual Issues (e.g., sense of purpose or meaning, appreciation of life)







# Long Term Follow-Up Guidelines

- To raise awareness of the risk of late treatment-related sequelae
- To facilitate early identification and intervention for these complications
- To standardize follow-up care and improve quality of life of young cancer survivors
- Provide guidance to health care professionals including pediatricians who supervise survivors



### CHILDREN'S ONCOLOGY GROUP

The world's childhood cancer experts

# Long-Term Follow-Up Guidelines

for Survivors of Childhood, Adolescent, and Young Adult Cancers

### Version 5.0 - October 2018





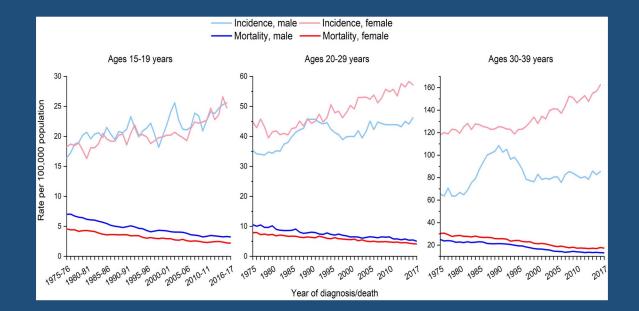
Website: www.survivorshipguidelines.org Copyright 2018 © Children's Oncology Group All rights reserved worldwide



# The adolescent and young adult (AYA) cancer survivorship population



- Patients aged 15 to 39 years old at their initial diagnosis constitute the adolescent and young adult (AYA) cancer survivorship population
- 2% of all invasive cancers diagnosed &<10% of all cancer survivors
- AYA cancer survivors are at risk of several late and long-term effects that can influence cognitive, psychosocial, and physical functioning as well as financial prospects.

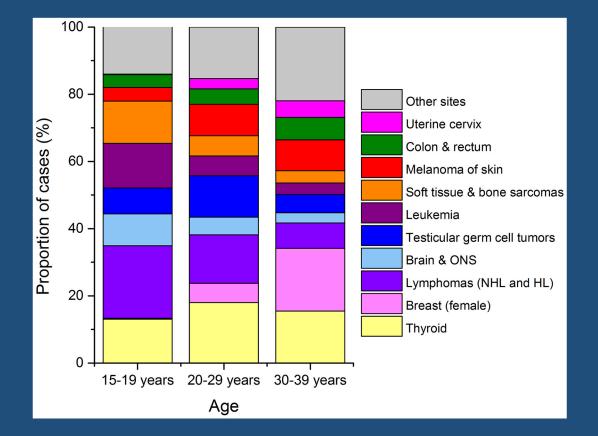


LIVESTRONG Young Adult Alliance http://www.livestrong.org/What-We-Do/Our-Actions/Programs-Partnerships/LIVESTRONG-Young-Adult-Alliance (Accessed on June 30, 2014).

Bleyer A, Viny A, Barr R.. Introduction. In: Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975-2000. National Cancer Institute, NIH Pub. No. 06-5767., Bleyer A, O'Leary M, Barr R, Ries LAG (Eds), National Institutes of Health, Bethesday 2006. p.1.



# Cancer statistics for adolescents and young adults, 2020

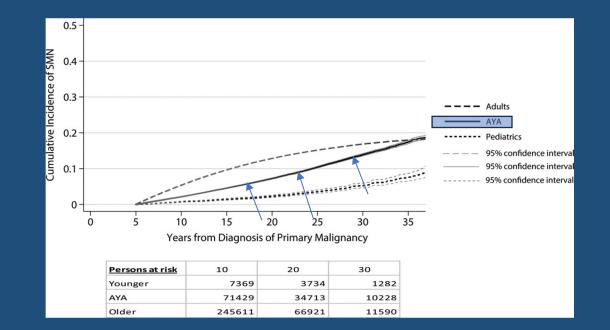


CA A Cancer J Clinicians, Volume: 70, Issue: 6, Pages: 443-459, First published: 17 September 2020, DOI: (10.3322/caac.21637)



# What unique about AYA ?

- 1.5-fold higher risk of dying from recurrence or progression of their primary cancer
- 14% of AYA cancer survivors developed a subsequent cancer 30 years postdiagnosis
- Worse overall psychosocial functioning due to difficultly in coping with cancer during early life transitions.
- Substantial disruptions in school, career, functioning and appearance, leading to further challenges in resuming daily-life activities.
- Special difficulties with fertility, sexual dysfunction, and body image, particularly among AYA women
- Tend to present at a more advanced stage
- AYAs have been underrepresented in clinical trials, particularly when compared with pediatric populations





# "AYA gap"

### Report of the Adolescent and Young Adult Oncology Progress Review Group

Recommendation 1: Identify the characteristics that distinguish the unique cancer burden in the AYAO patient.

Recommendation 2: Provide education, training, and communication to improve awareness, prevention, access, and quality cancer care for AYAs.

Recommendation 3: Create the tools to study the AYA cancer problem.

Recommendation 4: Ensure excellence in service delivery across the cancer control continuum (i.e., prevention, screening, diagnosis, treatment, survivorship, and end of life).

Recommendation 5: Strengthen and promote advocacy and support of the AYA cancer patient.









U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES National Institutes of Health National Cancer Institute LIVESTRONG<sup>TM</sup> Young Adult Alliance



Closing the Gap:

**Research** and

Care Imperatives for Adolescents and

Young Adults with Cancer

Adolescent and Young Adult Oncology

Report of the

**Progress Review Group** 



# Fertility

- In our US population-based study, >70% of AYA cancer patients reported being told that treatment may affect their fertility
- Male patients were more than twice as likely as female patients to report that fertility preservation options were discussed
- Almost one-third of males reported making arrangements for fertility preservation, 4 to 5 times higher than females
- 18% of males and 38% of females had not made such fertility-preservation because they were not aware

	Male (n=283)					Fem ale (n=176)**				
	W	as Told	Di	scu ssed		fade ngem ent	w	as Told	Di	scussed
Characteristic	N	(%) <sup>*</sup>	N	(%)	N	(%)	N	(%)	N	(%)
und er age 18										
No	152	(84.9)	139	(77.7)	74	(41.3)	73	(73.7)	44	44.4
Yes	73	(70.9)	61	(59.2)	13	(12.6)	57	(74.0)	16	20.8
Health insurance at diagnosis										
Private/HMO/IPA	163	(79.1)	154	(74.8)	72	(35.0)	101	(76.5)	51	38.6
Government	34	(79.1)	23	(53.5)	6	(14.0)	19	(61.3)	2	6.5
None	11	(84.6)	6	(46.2)	2	(15.4)	4	(80.0)	2	40.0
# comorbid conditions										
None	169	(80.9)	157	(75.1)	70	(33.5)	93	(73.8)	44	(34.9)
One	39	(83.0)	29	(61.7)	14	(29.8)	20	(76.9)	9	(34.6)
Two+	17	(63.0)	15	(55.6)	3	(11.1)	17	(70.8)	7	(29.2)
At least one provider a medical oncologist										
No	57	(75.0)	56	(73.7)	17	(23.4)	9	(60.0)	6	(40.0)
Yes	149	(81.0)	124	(67.4)	62	(33.7)	117	(75.5)	51	(32.9)
Treatment fertility risk level										
None/Low	45	(73.8)	29	(47.5)	11	(18.0)	78	(82.1)	37	(39.0)
Interm ediate/High	130	(82.8)	121	(77.1)	49	(31.2)	22	(75.9)	9	(31.0)
Unknown/Missing	50	(76.9)	51	(78.4)	27	(41.5)	30	(57.7)	14	(26.9)





Unmet adolescent and young adult cancer survivors information and service needs: A population-based cancer registry study

### Table 2

Total<sup>a</sup> and unmet<sup>b</sup> services needed before, during or after cancer treatment for adolescents and young adults recently diagnosed with cancer, frequency (percent), overall and by cancer site.

Type of service	Total need <sup>a</sup>	Unmet need <sup>b</sup>	Missing <sup>C</sup>
Participate in a support group	96 (19.2)	72 (75.0)	22
See a pain management expert	68 (13.5)	43 (63.2)	20
Get professional advice to help figure out payment for healthcare	131 (26.1)	80 (62.0)	21
See a physical or occupational therapist for rehabilitation	80 (16.0)	46 (58.2)	23
See a psychiatrist, psychologist, social worker or mental health worker	139 (27.5)	76 (55.5)	18
Talk with a spiritual or religious counselor about your cancer	92 (18.3)	33 (35.9)	19
Have a nurse come to your home	38 (7.5)	11 (29.0)	16
Any service need	d	179(34.9)	

<sup>a</sup>Total need is the number of participants who reported needing the service. Participants who reported receiving the service but did not answer the need question were assumed to have needed the service. The denominator for the total need percentage is the number of participants who answered the service questions.



NIH Public Access

J Cancer Surviv. Author manuscript; available in PMC 2013 September 0

Published in final edited form as: *J Cancer Surviv.* 2012 September ; 6(3): 239–250. doi:10.1007/s11764-012-0219-9.



Young and Uninsured: Insurance Patterns of Recently Diagnosed Adolescent and Young Adult Cancer Survivors in the AYA HOPE Study

### Parsons et al.

### Table 1

Characteristics of AYA HOPE Participants (N=465)

	All Survivors		Continuous Insurance* (N=347)	At least some time uninsured (N=118)	
	N	%	%	%	p-value
Demographic Characteristics †					
Age at Diagnosis					
15-19	62	13.3	80.7	19.4	0.45
20-24	81	17.4	71.6	28.4	
25-39	322	69.3	74.2	25.8	
Sex					
Male	287	61.7	71.8	28.2	0.07
Female	178	38.3	79.2	20.8	
Race					
white	375	80.7	74.7	25.3	0.97
Non-white	90	19.4	74.4	25.6	
Education					
≤High School	130	28.0	64.6	35.4	< 0.01
Some College/Vocational School	123	26.5	72.4	27.6	
≥College Graduate	212	45.6	82.1	17.9	
Marital Status					
Married/Living as married	198	42.6	78.3	21.7	0.12
Not married	267	57.4	71.9	28.1	
Change in Work/School after Diagnosis					
Yes*	115	24.7	80.9	19.1	0.08
No	350	75.3	72.6	27.4	
Ongoing Treatment **					
Yes	92	19.8	65.2	34.8	0.02
	373	80.2	76.9	23.1	

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NIH-PA Author Manuscript

Demographic, Treatment and Health Characteristics Associated with Insuran Since Diagnosis(N=465)

Table 2

	Adjusted Odds	95%CI
	Ratio	95%0C1
Demographic Characteristics †		
Age at Diagnosis		
15-19(Reference)	1.00	
20-24	2.99	1.26-7.09
25-39	3.35	1.49-7.55
Sex		
Male(Reference)	1.00	
Female	0.71	0.43-1.16
Race		
white(Reference)	1.00	
Non-white	0.91	0.52-1.60
Education		
≤High School	2.80	1.55-5.06
Some College/Vocational School	1.76	1.00-3.08
≥College Graduate <sup>*</sup> (Reference)	1.00	
Marital Status		
Married/Living as married	0.69	0.42-1.13
Not married *(Reference)	1.00	
Change in Work/School after Diagnosis		
Yes <sup>*</sup> (Reference)	1.00	
No	0.70	0.40-1.23
Ongoing Treatment**		
Yes	1.53	0.87-2.67
No/Don't know <sup>*</sup> (Reference)	1.00	



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# **Disparities of care**

### Table 5

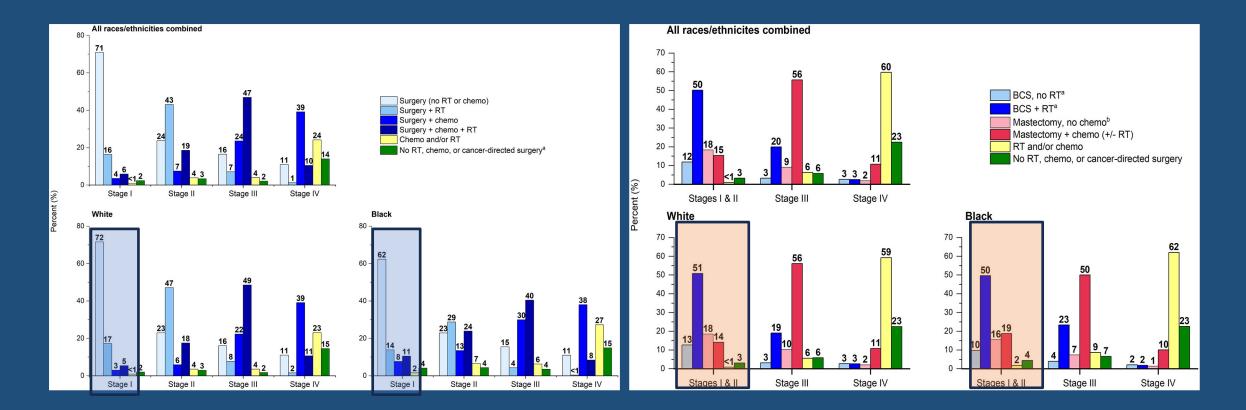
Multivariate adjusted<sup>d</sup> odds ratios (OR) and 95% confidence intervals (95% CI) for high unmet information needs or any service need among adolescents and young adult cancer survivors by sociodemographic and health-related characteristics.

Characteristics	Six or More Unmet information needs OR (95% CI)	Any unmet service needs OR (95% CI)		
Age group (years)				
15-19 years	0.49 (0.22 - 1.09)	0.71 (0.30 - 1.67)		
20-29 years	0.90 (0.56 - 1.43)	1.08 (0.67 - 1.72)		
30-39 years	reference	reference		
Gender				
Female	reference	reference		
▶ Male	1.66 (1.04 - 2.64)	1.35 (0.84 - 2.16)		
Race/ethnicity				
Non-Hispanic White	reference	reference		
Asian /Pacific Islander	1.31 (0.65 - 2.62)	0.97 (0.47 - 2.00)		
Black and AI/AN	2.58 (1.24 - 5.36)	1.43 (0.72 - 2.86)		
Hispanic	1.81 (1.07 - 3.06)	1.17 (0.68 - 2.01)		
Education				
College graduate or postgraduate	reference	reference		
High school or less	1.37 (0.75 - 2.50)	0.63 (0.34 - 1.18)		
Some college or associate degree	1.34 (0.83 - 2.18)	1.30 (0.79 - 2.14)		
Currently in Treatment				
No or unknown	reference	reference		
Yes	1.09 (0.61 - 1.96)	0.56 (0.31 - 1.00)		
Marital Status <sup>b</sup>				
Married	reference	reference		
Not married	1.14 (0.69 - 1.89)	0.94 (0.57 - 1.55)		
Raising children				
No	reference	reference		
Yes	1.27 (0.76 - 2.12)	1.03 (0.62 - 1.73)		

### More likely to report unmet needs related to recurrence, treatment, and financial support for medical care



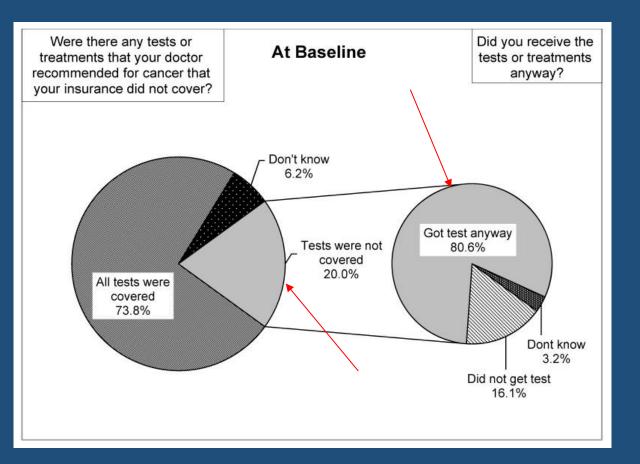
NIH Public Access Author Manuscript Concer Surve Author manuscript, available in PMC 2013 September 01 Published in final edited form as: J Cancer Surviv; 2023 September; 6(3): 239–250. doi:10.1007/s11764-012-0219-9





# Financial Burden

- 25% of cancer survivors indicated there were doctor-recommended tests/treatments not covered by their insurance
- 80.6% of the individuals with non-covered tests/treatments stated that they chose to receive the tests/treatments regardless
- Compared with older survivors, young survivors have higher rates of bankruptcy and more frequently forgo needed medical care because of cost







### In 2022,

36 OPEN Children's Oncology Group Studies



ACTIVE Clinical Research Studies



At C4K, we understand our role as the primary patient advocate. We aim to provide the children we treat and their families with an actionable example of hope. In 2020, we opened the Andre Agassi Foundation for Education Learning Center and though their ongoing generous support, we were able to incorporate, in its' entirety, a robust technology upgrade in 2022.

In 2022, we also focused our efforts on

some normalcy to our patients' lives.

Our core philosophy is understanding

that by supporting a child's cognitive

development, we provide hope for a

The mission of the Learning Center is to

provide quality academic services to all

patients in need of educational support

while being committed to the overall

physical, psychological, social, and

better tomorrow.

spiritual well-being

of the student patient.

individualized education plans to ensure

Our Learning Center has allowed us to provide critical educational services to our patients. With these unique additional advancements in our onsite capabilities, we are able to provide easy access to educational support. Beginning in 2022, patients can now seamlessly connect to the Learning Center from the infusion suite. We understand the massive impact uniterrupted education has on our fragile patient population. The goal of the Learning Center is to ensure our patients are receiving unique support and guidance for their individual education needs.

As our program grows, we are thrilled to report that the services and depth of the program continues to evolve and transform. Throughout the last school year, we were able to establish 6 components of the Learning Center, all of which are providing comprehensive educational support services to our patient population. These components consist of Janie's Classroom, CCSD Collaboration, Young Childhood Development, Arts in Medicine, College & Career Guidance, Disease-specific Education & Resources.









RANKED #1 Among Best Nonprofits to Work For







# Staying Healthy After Treatment

The most important thing you can do as a childhood cancer survivor is to stay healthy. That's why we created the StoryBook Homes Long-Term Follow-Up Clinic For Childhood Cancer Survivors. Thanks to a generous gift from the principals of StoryBook Homes, Wayne and Catherine Laska, the Long-Term Follow-Up Clinic is intended to help survivors – no matter where they received their treatment – navigate through the after effects of their treatment throughout their entire life.





- A comprehensive visit and is seen by one of our Board-Certified Pediatric Hematology-Oncology providers, a Pediatric Neuropsychologist, a Social Worker, and an Education Specialist.
- After utilizing the clinic, each patient receives a binder containing all the details and specific cancer treatments each patient received, as well as the possible future health risks those treatments may cause.

### cancer experts GROUP Long-Term Follow-Up Guidelines

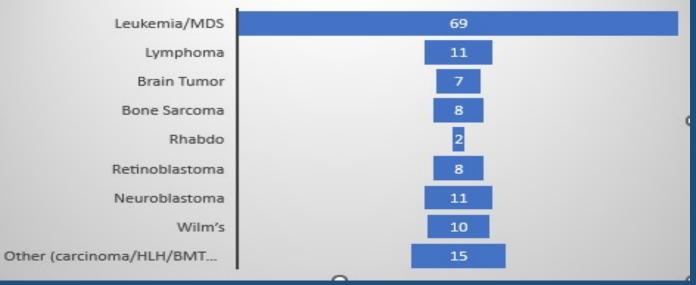
CHILDREN'S

ONCOLOGY

for Survivors of Childhood, Adolescent, and Young Adult Cancers

# The world's childhood

## 2022 LTFU diagnosis





Children's Oncology Group Adolescent and Young Adult (AYA) Oncology Discipline Committee

**ANNUAL REPORT 2022** 

Optimizing AYA Health & Survival Through Collaborative Cancer Clinical Trials

> CHILDREN'S ONCOLOGY GROUP

To improve survival and other health related outcomes for all adolescent and young adult patients (15 to 39 years of age) diagnosed with cancer





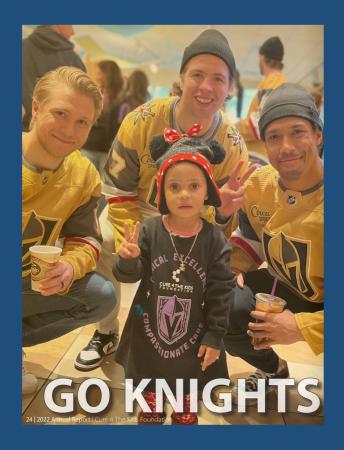
"It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can."

> Dr. Fitzhugh Mullan-Seasons of Survival: Reflections of a "Physician with Cancer



1942-2019





# Thank you

