

CHOC

Business Development Virtual Pediatric Lecture Series

A Whirlwind Tour of the Current State of Adolescent and Young Adult Cancer

April 14, 2021 from 12:30 – 1:30 PM (PST)



WELCOME

John Behzad, FACHE
Vice President, Strategy & Partnerships

DISCLOSURES RELEVANT TO POTENTIAL COMMERCIAL BIAS

CHOC fully complies with the CMA Accreditation Guidelines and the updated ACCME Standards for Commercial Support[SM]: Standards to Ensure Independence in CME Activities. The following disclosures meet SCS 6.0: Disclosures Relevant to Potential Commercial Bias (6.1-6.5).

Pediatric Virtual Lecture Series:
A Whirlwind Tour of the Current State of Adolescent and Young Adult Cancer

Planning Committee Disclosures – *The following Planning Committee members have had no relevant financial relationships in the last 12 months with any entity producing, marketing, re-selling, or distributing health care goods or services consumed by, or used on, patients:*

- Leslie Castelo
- Mary Hickcox
- James D. Korb, MD

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- Jamie Frediani, MD

CME Planning Committee Disclosure -

This live activity was approved outside of the CME Committee. The following CME Committee members have had no relevant financial relationships in the last 12 months with any entity producing, marketing, re-selling, or distributing health care goods or services consumed by, or used on, patients:

- Mary E. Hickcox
- James D. Korb, MD

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HYUNDAI Cancer Institute

CHOC Children's

A Whirlwind Tour of the Current State of Adolescent and Young Adult Cancer

Jamie Frediani, MD

Pediatric Oncology

Medical Director of AYA Program

CHOC Hospital

Disclosures

- I have no financial conflict of interest to disclose

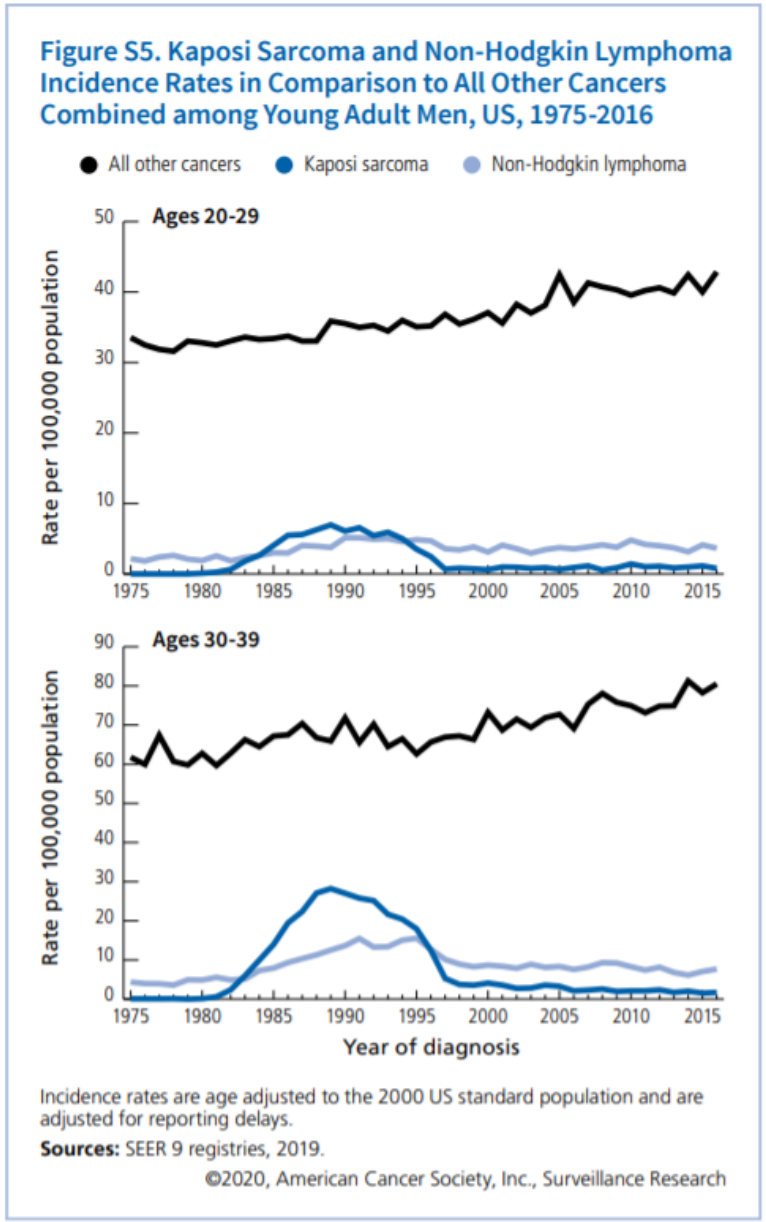
Educational Objectives

- Review unique challenges to adolescent and young adult (AYA) cancer patients, including accessing optimal treatment
- Recognize the primary care provider's role in helping AYA patients navigate the health care system.
- Identify key tenets of multidisciplinary care required to provide support to this population during treatment
- Describe the survival gap in AYA oncology patients

CHOC Children's

Who is an AYA???

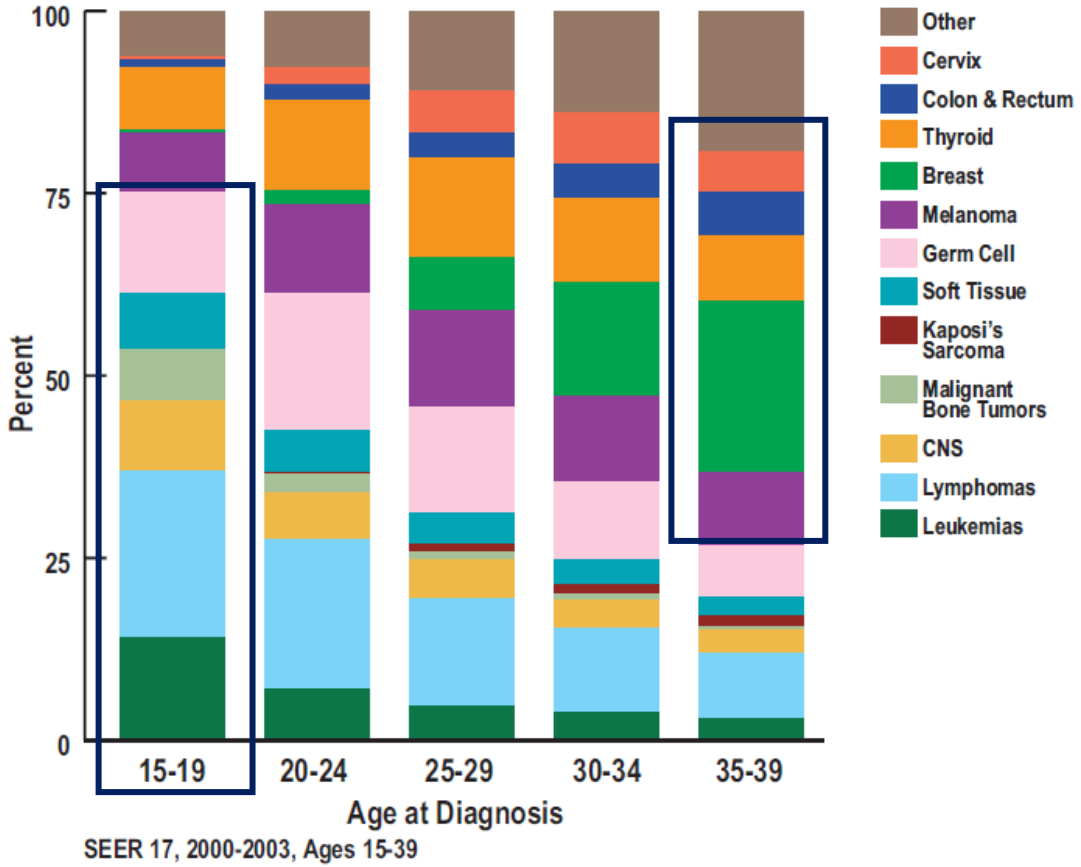
- NCI Definition: Age 15-39 years old
- ~89,000 patients/year in the US
- Increase incidence ~1% yearly
- Cancer is the leading cause of disease related death (behind suicide, homicide, unintentional injury)
  - ~9000 deaths/year
- ~25% AYAs treated at Community Centers



Albritton, K. et al. *Report of the AYA PRG,* 2006.
www.cancer.gov/research/progress/snapshots/adolescent-young-adult

What types of Cancer do these patients have?

- Variable across the spectrum
- In the 15-24 year age range, leukemia/lymphoma are the most prevalent.
  - Sarcomas, germ cell tumors and brain tumors also common
  - Leukemia is the leading cause of death
- In the 30-39 year age range, carcinomas become the prevalent tumor type (breast cancer dominant)
  - Breast cancer and brain tumors are the leading cause of death



Albritton, K. et al. *Report of the AYA PRG,* 2006.
www.cancer.gov/research/progress/snapshots/adolescent-young-adult.
Special Section: Cancer in Adolescents and Young Adults. Cancer Facts and Figures 2020.

Improvements in AYA Survival Lag

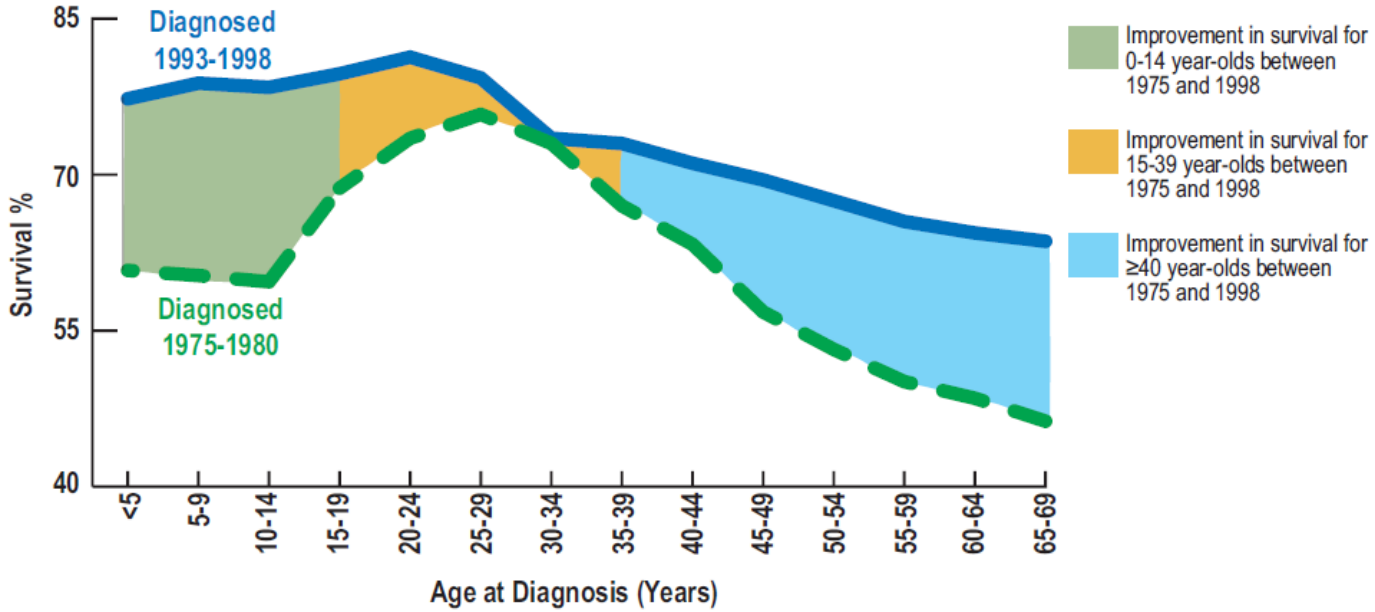
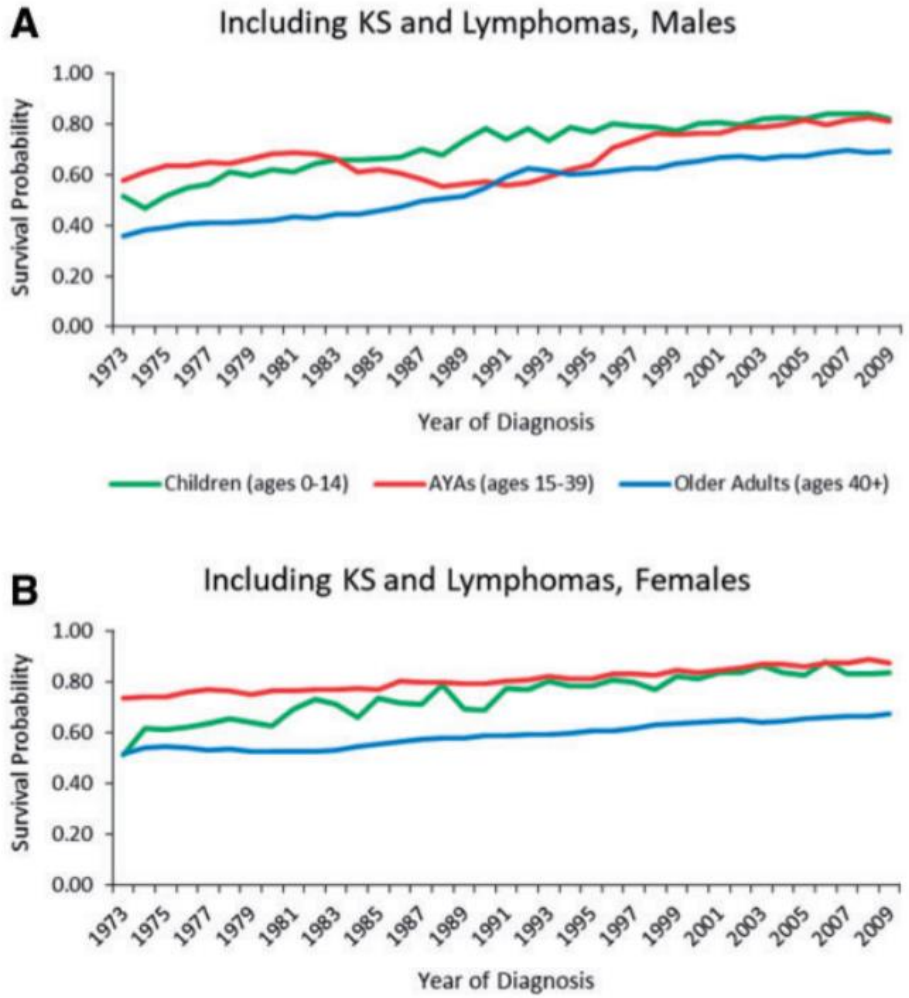
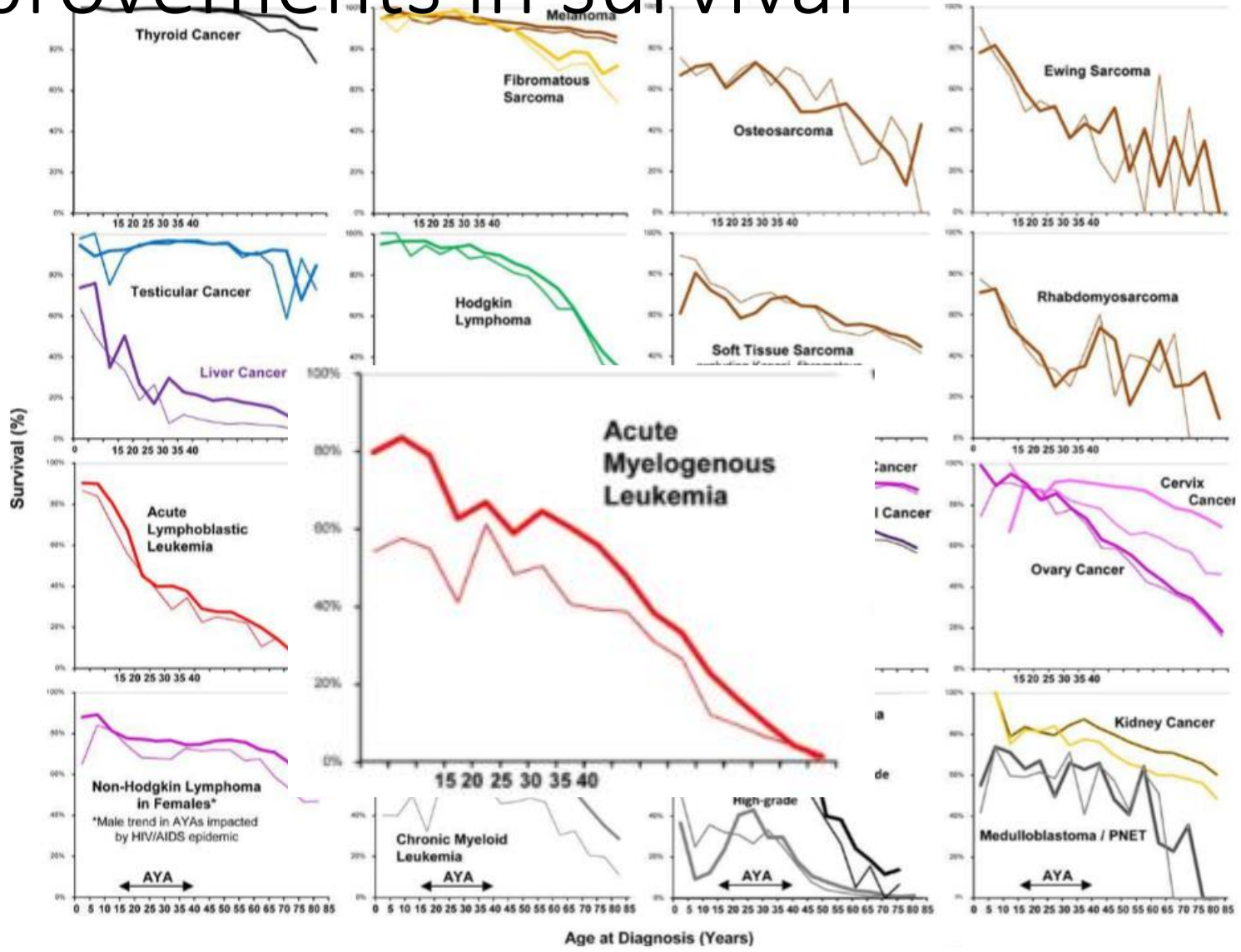


Figure 3. 5-Year Survival of Patients with Cancer by Era, SEER, 1975-1998



Albritton, K. et al. *Report of the AYA PRG,* 2006.
Liu, L. et al. *JNCI,* 2019.

Cancer Subtypes have differential improvements in survival

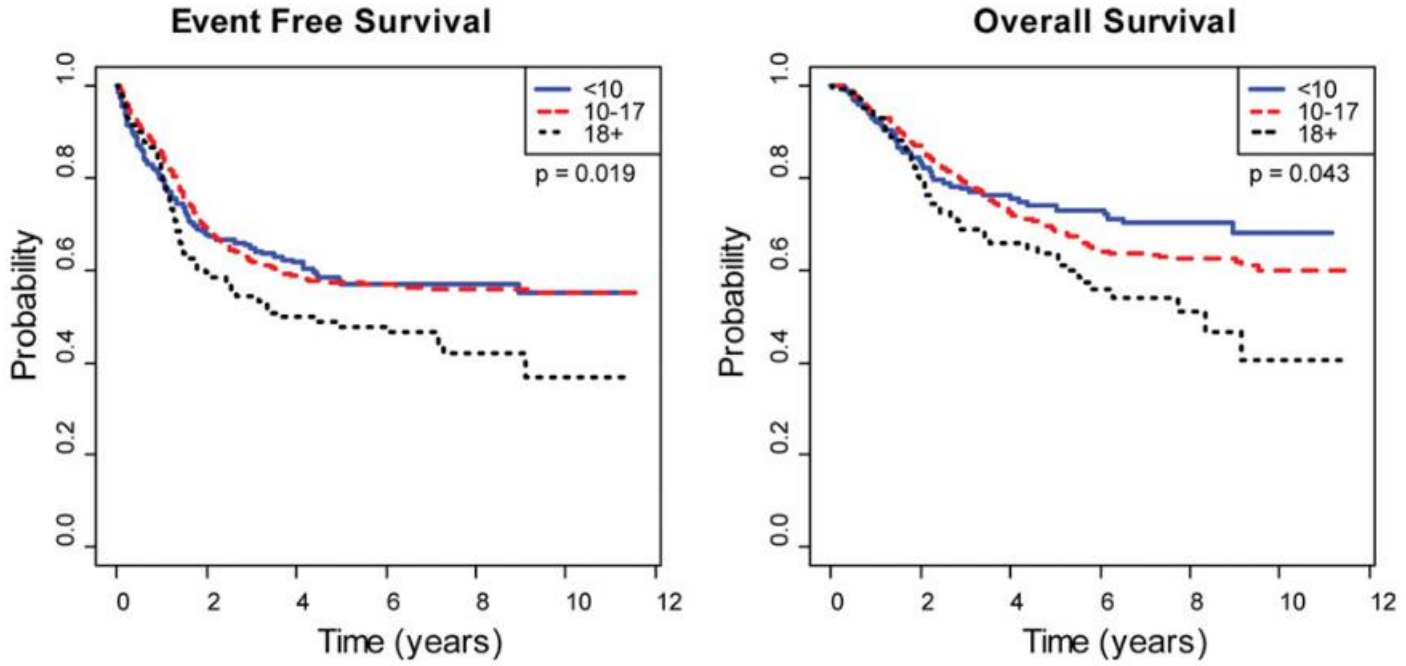


- 5 year survival rate of cancers
  - Thin line: 1992-1996
  - Thick line: 2002-2006
- 14 AYA cancers showed significant improvement in 5-year survival since 1992. 59% did not.
- However, many of those improved less than the gains seen in either children or older adults
- For example: Pediatric AML showed significant improvement in survival. The gap between the two lines narrows considerably in the AYA range

Keegan, THM et al. *Cancer,* 2016.

Survival Disparities in Osteosarcoma

- Secondary analysis of INT-0133, CCG-7943/POG-9754, AOST0121
- All using MAP-based backbone
- 10 year overall survival stratified:
  - < 10 years – 68%
  - 10-17 years – 60%
  - > 18 years – 41%



Janeway, K. et al. *Cancer,* 2012.

Key Issues in AYA Population

- Access to health care (lack of insurance, work restrictions)
- Delay in diagnosis and treatment
- Treatment location
- Clinical trial enrollment and treatment standardization

- Unique Tumor Biology
- Increased toxicity
- Fertility preservation
- Psychosocial and developmental needs
- Survivorship and Transition of Care

Delay in Diagnosis increased by age

- Identified as #1 priority by TYA Priority Setting Partnership
- Metanalysis showed significantly longer TTD with older age at diagnosis
- More likely advanced stage; Uncertain effect on survival

TABLE I. Multivariate Linear Regression of Significant Relationships Between Study Factors and the Natural Logarithm of Delay Time

Study factor	Median total delay (weeks)	Coefficient	SE of coefficient	95% CI	*P*-value
Constant		4.244	0.102	4.04–4.44	<0.001
Tumor site					
Abdomen (vs. thorax, head and neck, limbs, genitalia)	3.1	−0.772	0.153	−1.07 to −0.47	<0.001
Pelvis (vs. thorax, head and neck, limbs, genitalia)	3.3	−0.635	0.302	−1.23 to −0.04	0.036
Age at diagnosis					
0–1 year old (vs. 2–14 years old)	2.3	−0.560	0.201	−0.96 to −0.16	0.006
15–18 years old (vs. 2–14 years old)	13.7	0.512	0.194	0.13–0.89	0.009
Point of first detection of symptoms					
Healthcare worker (vs. non-healthcare worker)	1.1	−0.957	0.300	−1.55 to −0.37	0.002
First healthcare unit contacted					
Pediatric ER physician (vs. non-pediatric ER physician)	4.3	−0.346	0.163	−0.67 to −0.03	0.034
Point of first suspicion of malignancy					
Pediatric ER physician (vs. non-pediatric ER physician)	4.4	−0.554	0.234	−1.01 to −0.09	0.018

Lethaby, CD et al. *Arch Dis Child,* 2013.
Loh, AHP et al. *Pediatr Blood Cancer,* 2012.

Public insurance delays access to care

Table 3. Lagtime according to type of cancer and health insurance status

	Insurance status[a]					
	Private		Public		Difference[c]	
	Lagtime, days		Lagtime, days			
	n	Mean (SD)	*n*	Mean (SD)	Days	*p*-Value
Leukemia	17	14 (5)	6	52 (8)	38	.0009
Acute lymphoblastic	12	14 (4)	4	38 (5)	24	.008
Acute myeloid	5	12 (7)	2	98 (1)	86	.018
Non-Hodgkin's lymphoma	7	22 (7)	5	66 (12)	44	.025
Diffuse large cell lymphoma	3	22 (4)	5	66 (12)	44	.026
Hodgkin's lymphoma	29	68 (17)	9	70 (20)	2	NS
Sarcomas	41	124 (34)	19	209 (40)	85	.050
Bone sarcomas	18	78 (24)	9	232 (39)	154	.011
Osteosarcoma	12	87 (26)	7	235 (45)	148	.043
Soft-tissue sarcomas	23	178 (42)	10	191 (42)	13	NS
Brain tumors	36	90 (29)	6	143 (25)	53	NS
Gliomas	27	94 (30)	5	174 (28)	80	NS
Thyroid cancer	21	159 (47)	5	216 (34)	57	NS
Follicular thyroid cancer[b]	20	154 (47)	5	216 (34)	62	NS

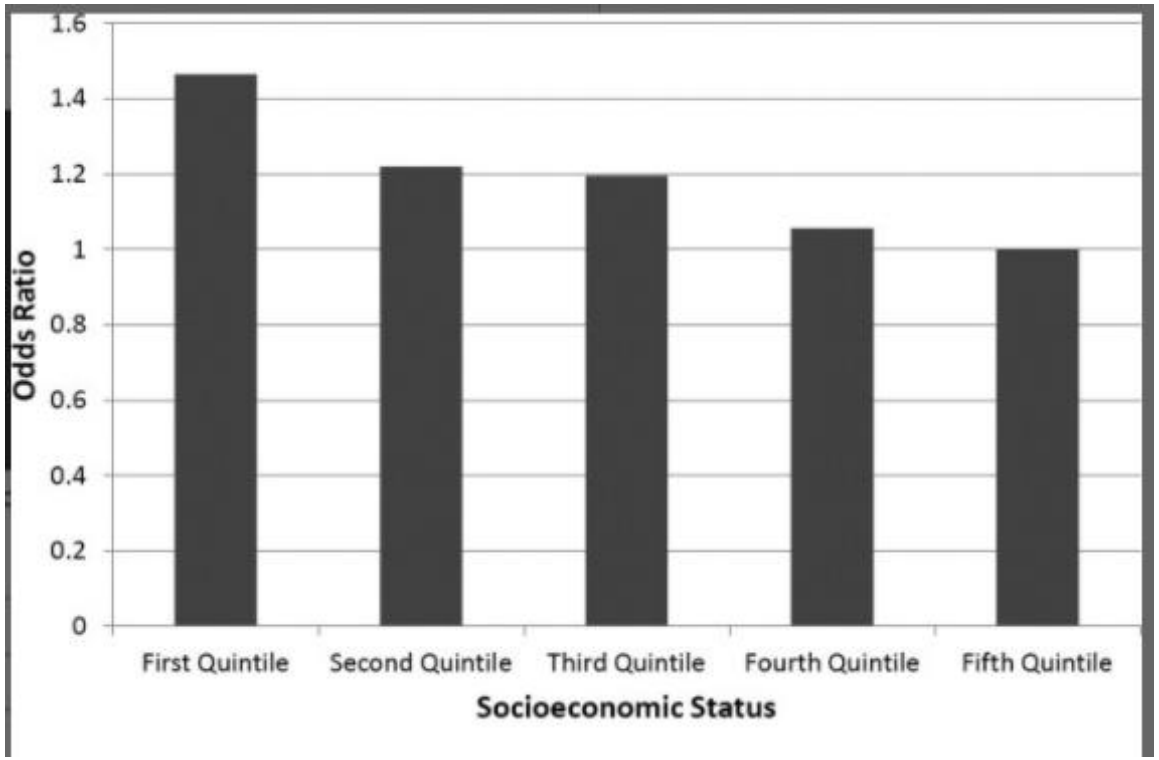
[a]Excludes self-pay patients.
[b]Includes mixed papillary-follicular.
[c]Public minus private.
Abbreviations: NS, not significant; SD, standard deviation.

Median Lagtime:
Public Insurance: 124 days
Private Insurance: 76 days

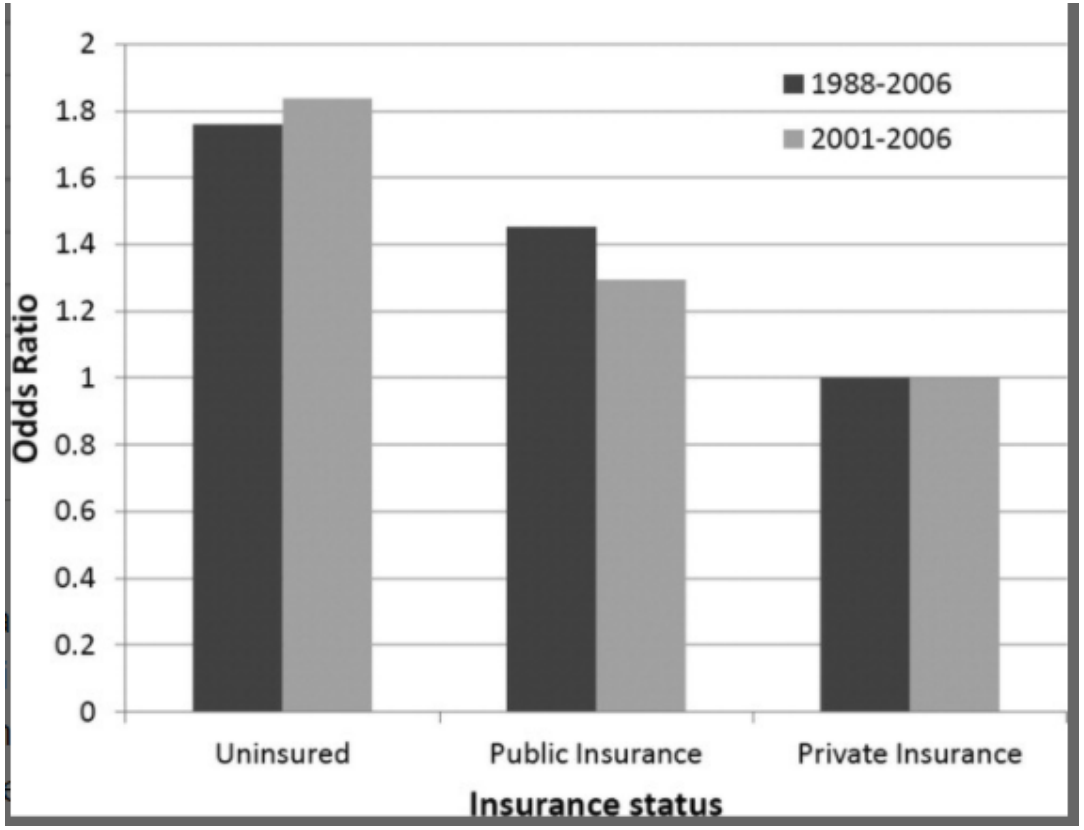
13.1 weeks longer!!

Martin, S. et al. *The Oncologist,* 2007.

Public insurance increased Late Stage Disease

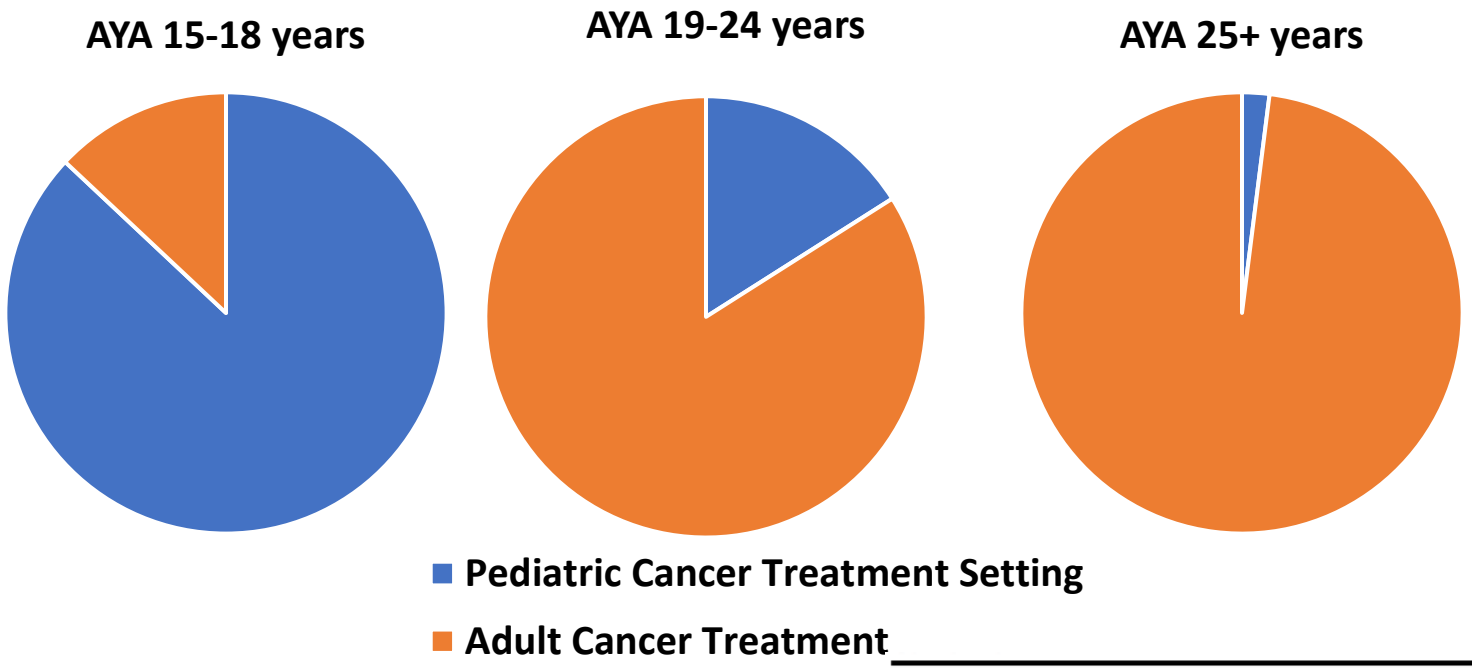


Risk of Presenting with Advanced Stage Hodgkins Lymphoma
Retrospective case analysis
7243 CA patients 15-40 years old



Smith, EC. Et al. *Cancer,* 2012.

Treatment Setting Matters

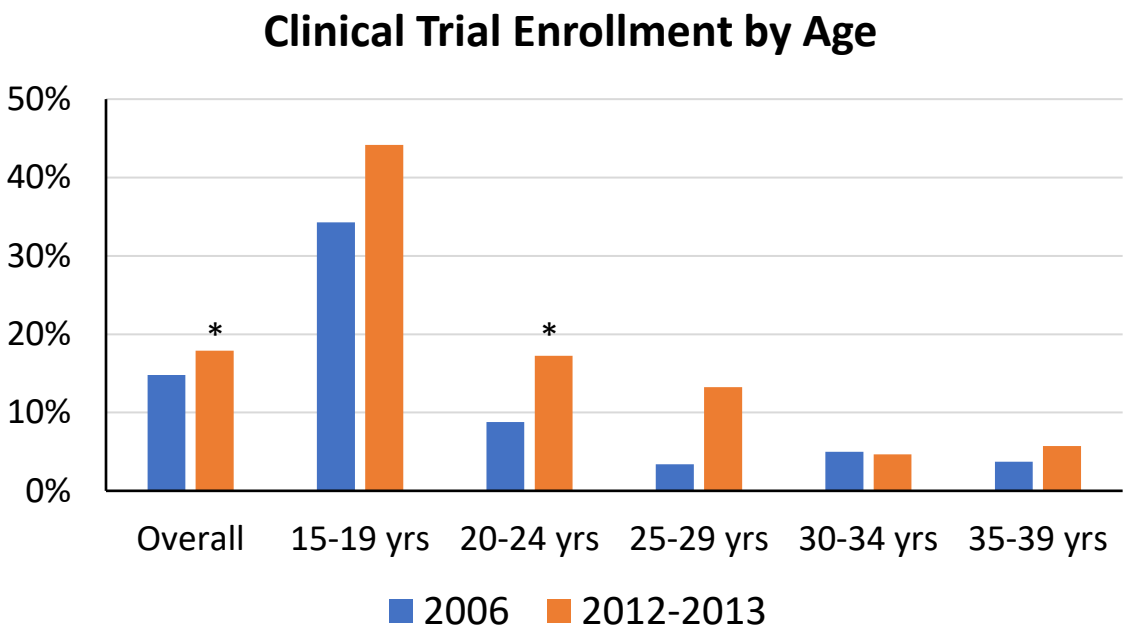


- 67.7% treated in an adult setting
- 40.7% were treated at an NCI-designated center
- Of those treated in adult setting, only 24.8% received a pediatric regimen

	OS		LSS	
	HR (95% CI)	*P*	HR (95% CI)	*P*
Treatment setting		.001		<.001
Pediatric	0.53 (0.37-0.76)		0.51 (0.35-0.74)	
Adult	Ref.		Ref.	
Induction facility is COG center or NCI CC		.019		.026
Yes	0.80 (0.66-0.96)		0.80 (0.65-0.97)	
No	Ref.		Ref.	

Muffly, L et al. *Blood,* 2018.
Wolfson, J et al. *AACR,* 2017.

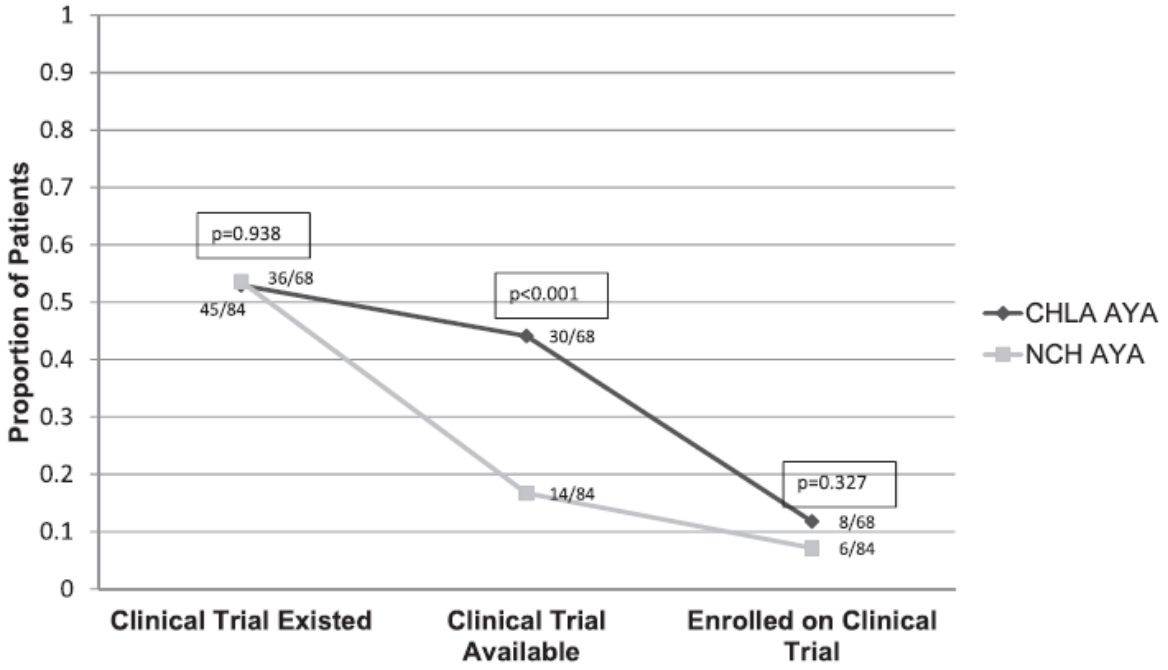
Clinical Trial Enrollment



- Provider –
  - Knowledge about available trials
  - Attitude towards clinical trials
  - Administrative burden (time, resources)
- Patient –
  - Patient Knowledge
  - Discomfort with experimentation
  - Too sick to enroll
  - Attitudes toward medical system
  - Personal, professional, and family obligations conflicting
  - Geographic inconvenience
- System –
  - Age restrictions on trials and at institutions
  - Limited trial availability
  - Extensive regulatory barriers

Keegan, THM and HM Parsons. *ASH*, 2018.
Parsons et al. *Pediat Blood Cancer,* 2019.

Clinical Trial Availability differs



- 152 AYAs treated at a children (15-20 yo) and adult (18-39 yo) hospital
- Existence of eligible trial similar nationally
- Conclusion:
  - Patient/provider barriers crucial in pediatric setting
  - Trial availability crucial in adult setting

Thomas, S et al. *Cancer,* 2018.

Pediatric setting higher clinical trial enrollment

Table 1: Baseline characteristics

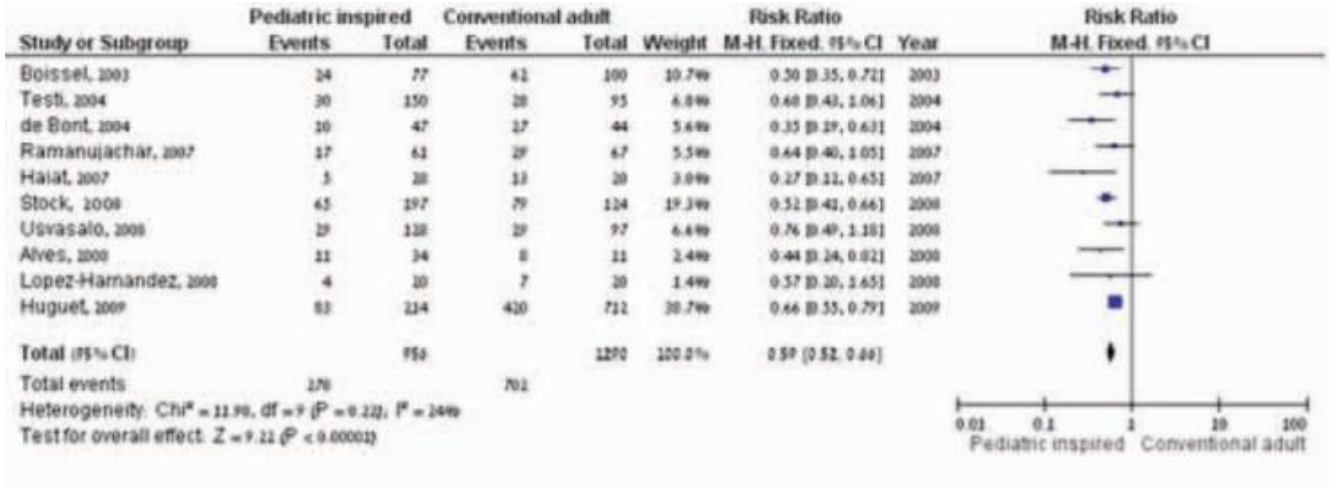
	LEUKEMIA (n=84)			LYMPHOMA (n=112)		
	Pediatric n (%)	**Adult n (%)**	***p* value**	**Pediatric n (%)**	**Adult n (%)**	***p* value**
Total patients	25 (30)	59 (70)		26 (23)	86 (77)	
Age (years)						
Range	15-25	19-40		15-23	18-39	
Mean	17	30		17	30	
Gender			*0.60*			*0.22*
Female	7 (28)	20 (34)		8 (31)	38 (44)	
Male	18 (72)	39 (66)		18 (69)	48 (56)	
Disease			*0.0073*			*0.54*
ALL	19 (76)	26 (44)				
AML	6 (24)	33 (56)				
HL				16 (62)	47 (55)	
NHL				10 (38)	39 (45)	
Disease status:			*0.0081*			*0.0060*
New diagnosis	25 (100)	46 (78)		26 (100)	67 (78)	
Relapse/progressive disease	0 (0)	13 (22)		0 (0)	19 (22)	
Enrolled on clinical trial	21 (84)	13 (22)	*<0.0001*	1 (4)	7 (8)	*0.68*
Tumor banking	19 (83)	45 (82)	*>0.99*	17 (65)	64 (77)	*0.23*
Deaths	3 (12)	2 (3)	*0.16*	0 (0)	2 (2)	*>0.99*

- Retrospective cohort
- 196 patients treated between adult and peds facilities
- More likely to enroll on clinical trial at pediatric facility
- Of note, also more referrals for psychology, SW, case management, palliative care in peds facility.

Moskop, Amy et al. *Blood,* 2019.

Pediatric Protocols have improved survival

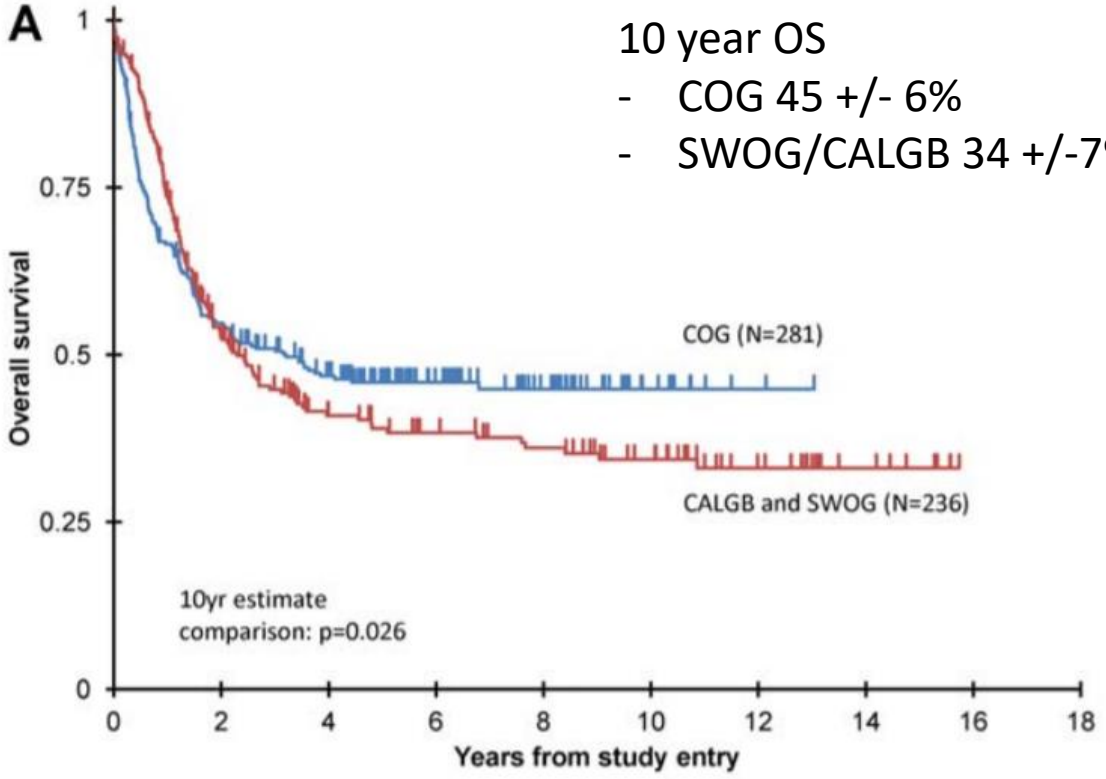
Acute Lymphoblastic Leukemia



3 year All Cause Mortality

- Absolute Risk Reduction 0.2 on pediatric inspired regimen
- NNT = 5

Acute Myeloid Leukemia

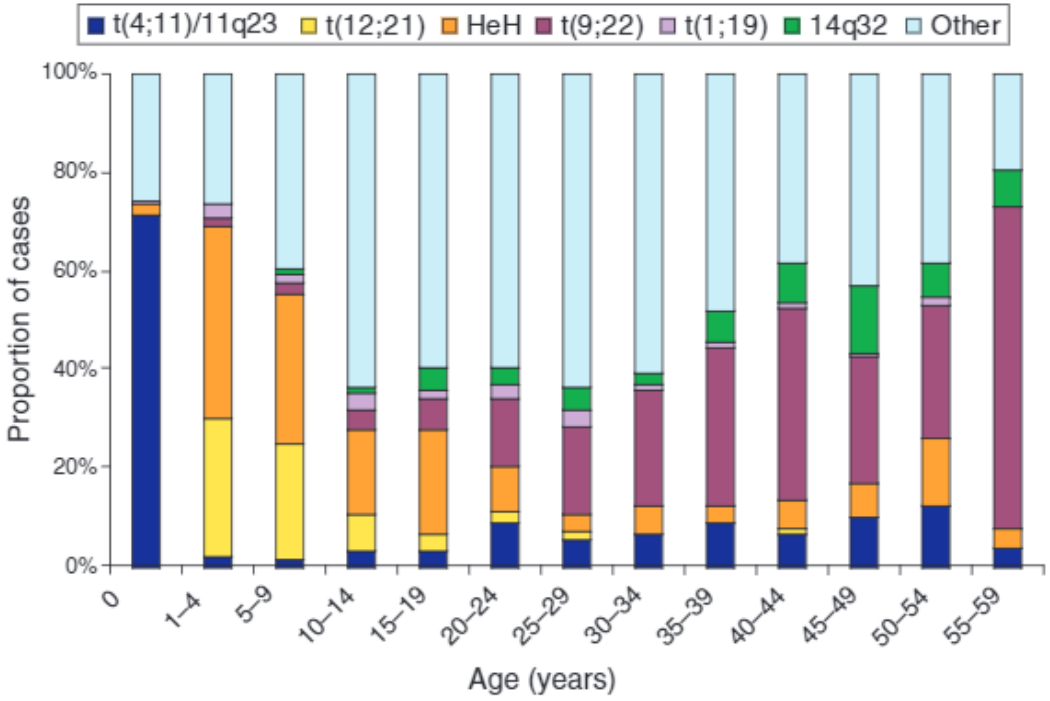


10 year OS

- COG 45 +/- 6%
- SWOG/CALGB 34 +/-7%

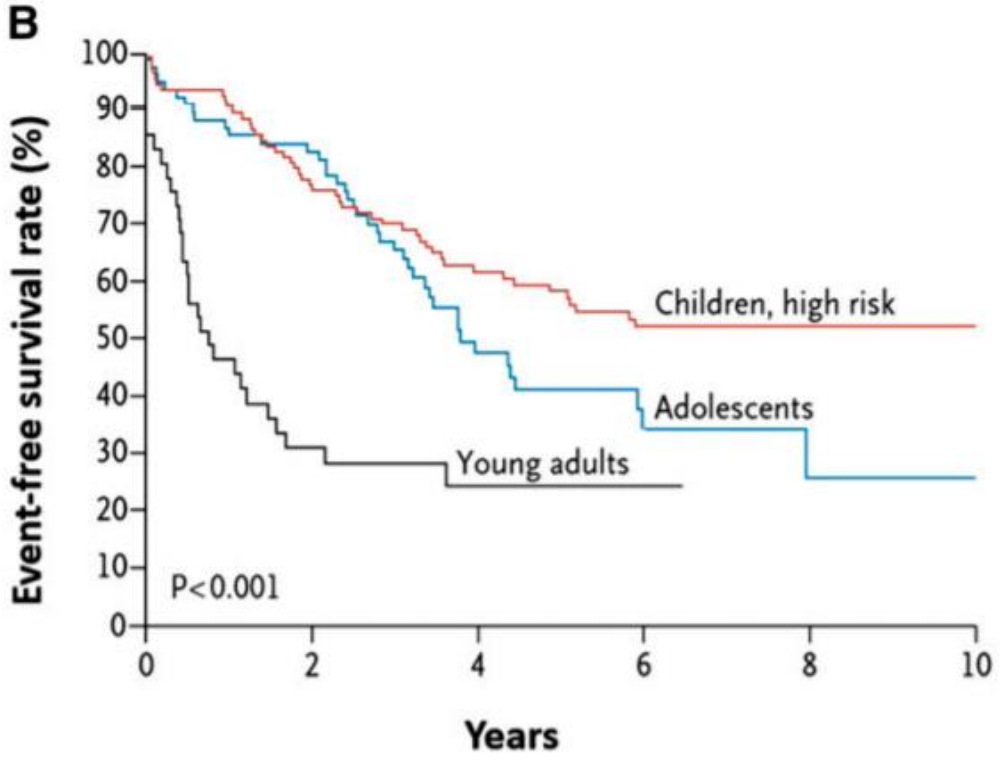
Ram, R et al. *Am Jour Hematol,* 2012.
Woods, WG et al. *Cancer,* 2013.

Tumor Biology in AYA Cancers



Ph-like ALL

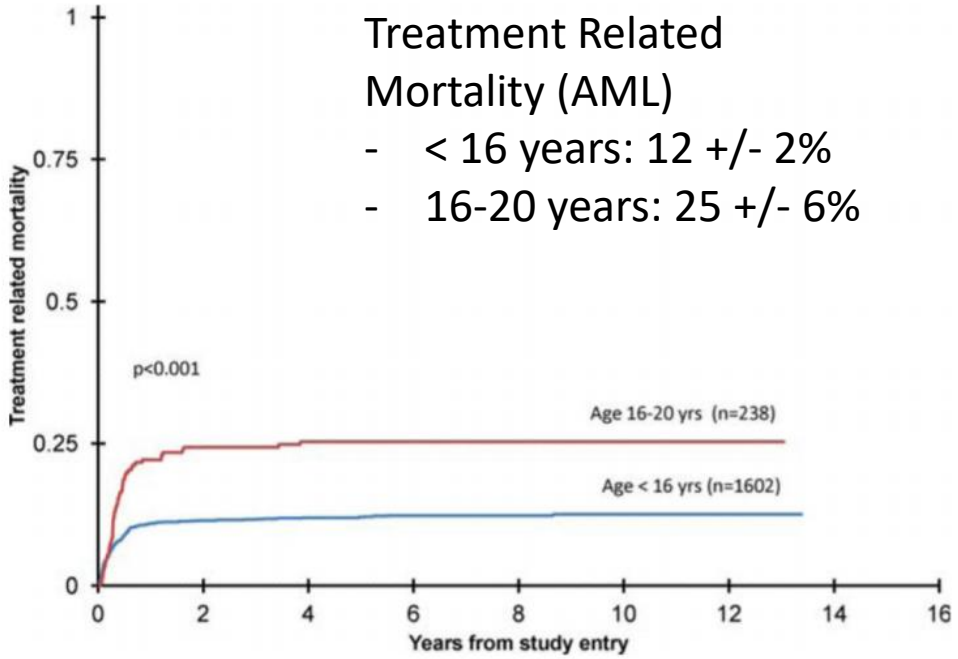
- 10% NCI SR
- 15% NCI HR (10-15 yrs)
- 21% NCI HR (adolescents 16-20 yrs)
- 27% NCI HR (young adults 21-39 yrs)



Harrison CJ et al. *Br J Haematol,* 2009.
Tran TH and Loh ML. *ASH Education*, 2016.

Increased Toxicity in AYAs

Acute Myeloid Leukemia



Treatment Related Mortality (AML)

- < 16 years: 12 +/- 2%
- 16-20 years: 25 +/- 6%

Acute Lymphoid Leukemia

		< 16 years	16-30 years	p value
Induction	Febrile Neutropenia	**13.4**	7	<0.0001
	Hyperglycemia	15.4	**22**	0.0002
	Hyperbilirubinemia	3.7	**6.7**	0.0022
	Mortality	1.7	2.2	NS
Post-Induction	Mucositis	11.3	**18.5**	0.0002
	Peripheral Motor Neuropathy	7.4	**11.5**	0.0015
	Febrile Neutropenia	**48.6**	35.6	<0.0001
	Remission Mortality	2.1	**5.5**	<0.0001

Canner, J et al. *Cancer,* 2013.
Gupta, AA. Et al. *Pediat Blood Can,* 2016.
Larsen, E.C. et al. *Blood, 2011.*

Psychosocial Challenges to AYA Patients

Age range of crucial developmental stages and transition:

- Physical and sexual maturity
- Acquisition of skills needed to carry out adult roles
- Gaining increased autonomy from parents
- Realigning social ties – importance of friends
- Interruption in school and work trajectory
- Establishing a new family structure with own children

Health-Related Quality of Life – AYA HOPE

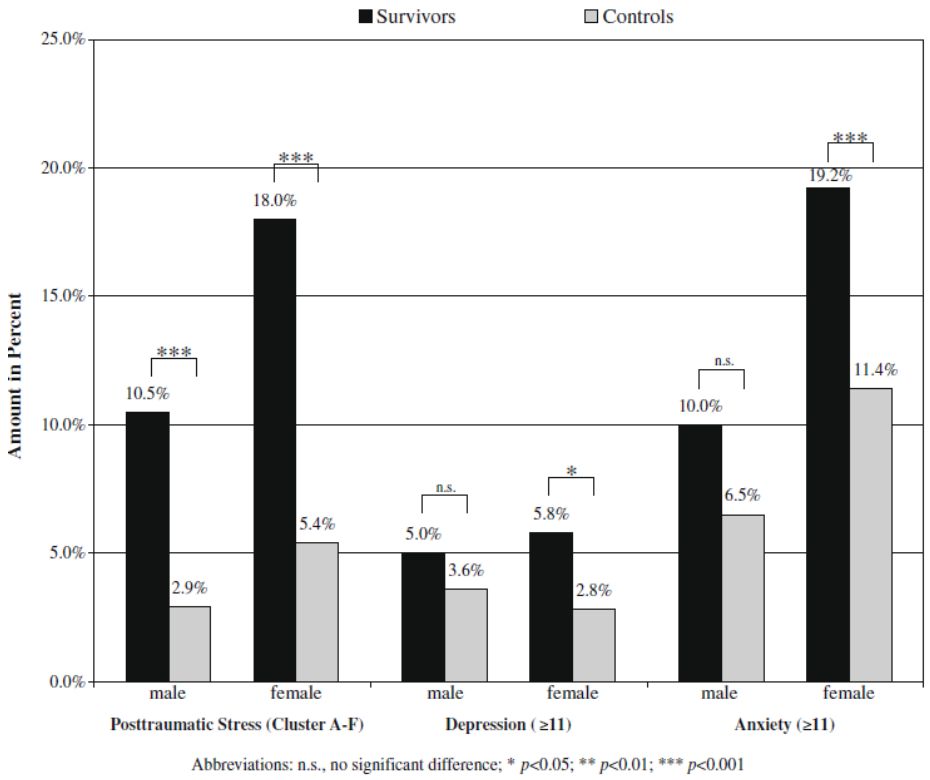
- Population- based cohort
- 523 AYAs, aged 15-39 years
- Conclusions:
  - Significantly worse HRQOL across physical and mental health domains
  - Significantly worse levels of fatigue
  - Most vulnerable populations are Hispanic patients, less educated, and uninsured

Table 3. PedsQL Outcomes Among AYA HOPE Participants by Age at Survey Compared With Healthy Young Adults

Participant Group	No. of Patients	Mean	SD	Groups Compared	*t* Test*	*P*	Effect Size (Cohen's *d*)
Total score							
1. Reference, AYA HOPE, ages 18-25 years	135	71.17	20.42				
2. Healthy young adults, ages 18-25 years†	1,171	78.18	9.20	1 *v* 2	**3.94**	**.001**	**0.6**
3. AYA HOPE, ages 15-17 years	23	64.54	18.89	1 *v* 3	1.54	.14	0.3
4. AYA HOPE, ages ≥ 26 years	363	67.61	21.03	1 *v* 4	1.71	.09	0.2
Psychosocial summary							
1. Reference, AYA HOPE, ages 18-25 years	134	71.70	20.96				
2. Healthy young adults, ages 18-25 years†	1,171	73.87	10.53	1 *v* 2	1.18	.24	0.2
3. AYA HOPE, ages 15-17 years	23	66.26	18.02	1 *v* 3	1.30	.21	0.3
4. AYA HOPE, ages ≥ 26 years	363	69.48	20.07	1 *v* 4	1.06	.29	0.1
Physical functioning							
1. Reference, AYA HOPE, ages 18-25 years	136	75.60	23.24				
2. Healthy young adults, ages 18-25 years†	1,171	86.25	10.63	1 *v* 2	**5.28**	**< .001**	**0.9**
3. AYA HOPE, ages 15-17 years	23	64.69	26.06	1 *v* 3	**1.88**	.07	**0.5**
4. AYA HOPE, ages ≥ 26 years	364	70.00	25.76	1 *v* 4	**2.32**	**.02**	0.2
Emotional functioning							
1. Reference, AYA HOPE, ages 18-25 years	135	66.21	25.24				
2. Healthy young adults, ages 18-25 years†	1,171	66.68	15.00	1 *v* 2	0.21	.83	0.0
3. AYA HOPE, ages 15-17 years	23	68.04	21.99	1 *v* 3	−0.36	.72	0.1
4. AYA HOPE, ages ≥ 26 years	363	63.61	22.59	1 *v* 4	1.05	.29	0.1
Social functioning							
1. Reference, AYA HOPE, ages 18-25 years	133	80.70	23.47				
2. Healthy young adults, ages 18-25 years†	1,171	85.48	11.90	1 *v* 2	**2.31**	**.02**	0.4
3. AYA HOPE, ages 15-17 years	23	75.36	22.54	1 *v* 3	1.04	.31	0.2
4. AYA HOPE, ages ≥ 26 years	362	78.78	22.07	1 *v* 4	0.82	.41	0.1
Work/school functioning							
1. Reference, AYA HOPE, ages 18-25 years	129	72.96	23.76				
2. Healthy young adults, ages 18-25 years†	1,171	69.47	13.94	1 *v* 2	−1.64	.10	0.2
3. AYA HOPE, ages 15-17 years	22	58.86	19.70	1 *v* 3	**3.00**	**.01**	**0.6**
4. AYA HOPE, ages ≥ 26 years	347	70.72	23.54	1 *v* 4	0.91	.36	0.1
Fatigue‡							
1. Reference, AYA HOPE, ages 18-25 years	136	61.31	26.90				
2. Healthy young adults, ages 18-25 years‡	391	70.92	16.94	1 *v* 2	3.91	**.001**	**0.6**
3. AYA HOPE, ages 15-17 years	23	59.78	23.75	1 *v* 3	0.28	.78	0.1
4. AYA HOPE, ages ≥ 26 years	363	57.01	25.27	1 *v* 4	1.61	.11	0.2

Wilder Smith A. et al. *Journ Clin Oncol,* 2013.

Psychosocial Outcomes



Abbreviations: n.s., no significant difference; * $p<0.05$; ** $p<0.01$; *** $p<0.001$

Fig. 3 – Proportion of subjects with psychological symptoms according to the questionnaires.

AYA survivors are 1.5 times more likely than age-matched peers to report clinically relevant levels of anxiety and/or depression

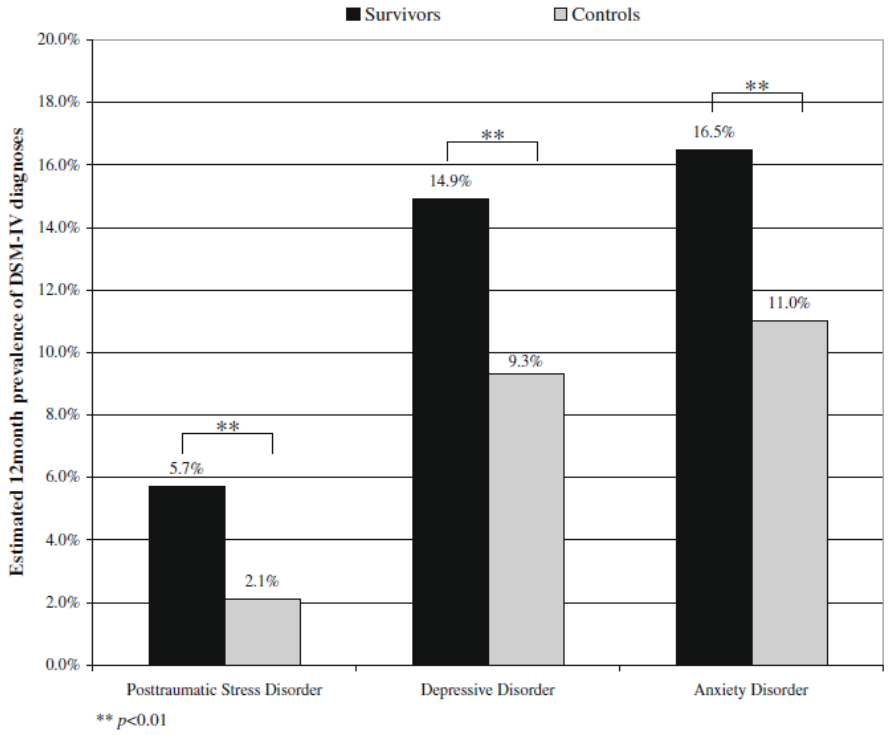


Fig. 5 – Prevalence of DSM-IV diagnoses based on the structured clinical interview.

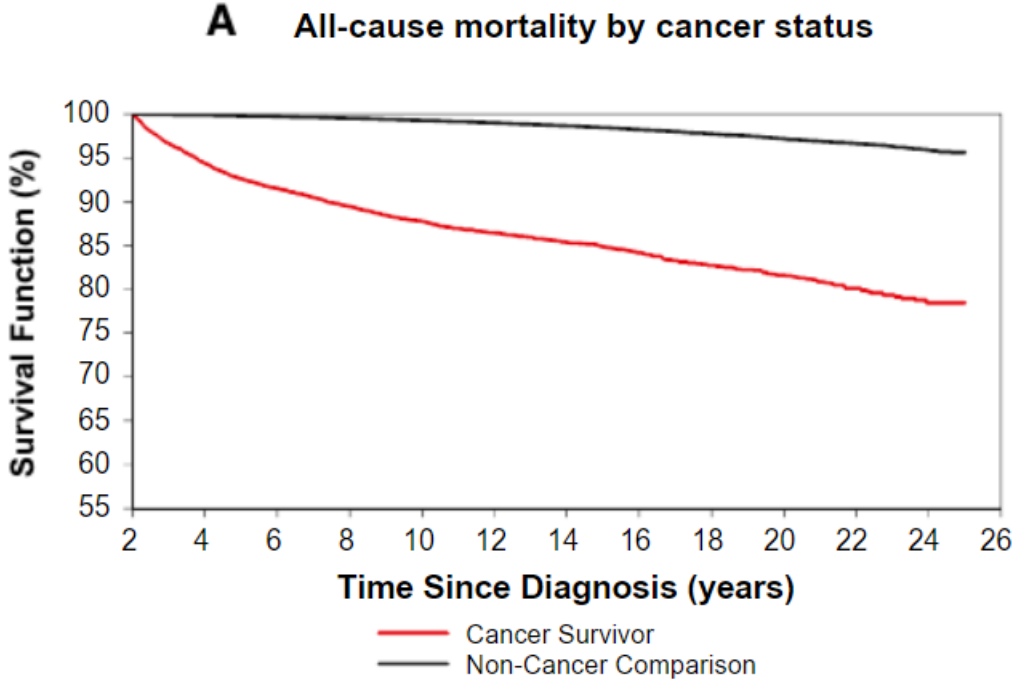
Further studies have confirmed higher levels of psychological distress, higher rates of antidepressant use, and significant impact on relationships and vocational functioning

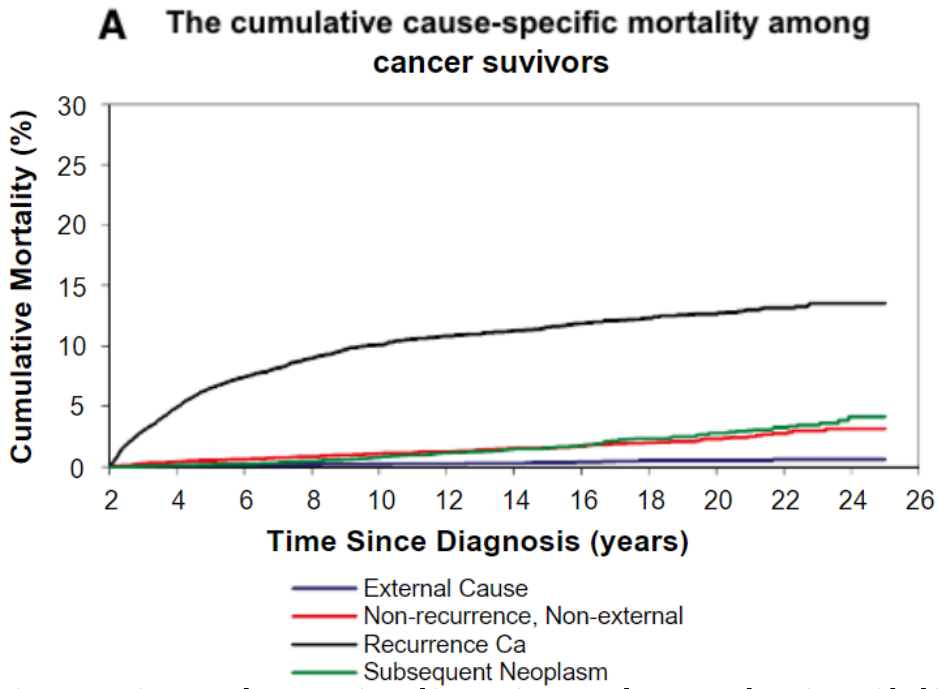
Bellizzi KM, et al. *Cancer,* 2012.
Deyell, RJ et al. *Pediatr Blood Cancer,* 2013.
Dyson, GJ et al. *Support Care Cancer,* 2012.
Seitz, DCM et al. *Euro Journ Cancer,* 2010.

Challenges in Survivorship

- 2 out of 3 (66%) survivors will experience at least one late effect
- 4 out of 10 (40%) survivors will develop multiple late effects
- 1 out of 4 (25%) survivors will develop a severe or life-threatening late effect

Cumulative mortality remains higher





- Survivors of AYA Cancer have higher burden of inpatient hospitalization than their siblings
- Survivors of leukemia (HR 4.76), CNS tumors (HR 3.45) have the most elevated risk
- Mortality risk of suicide is doubled
- 2 fold increase risk of dying from other health-related causes

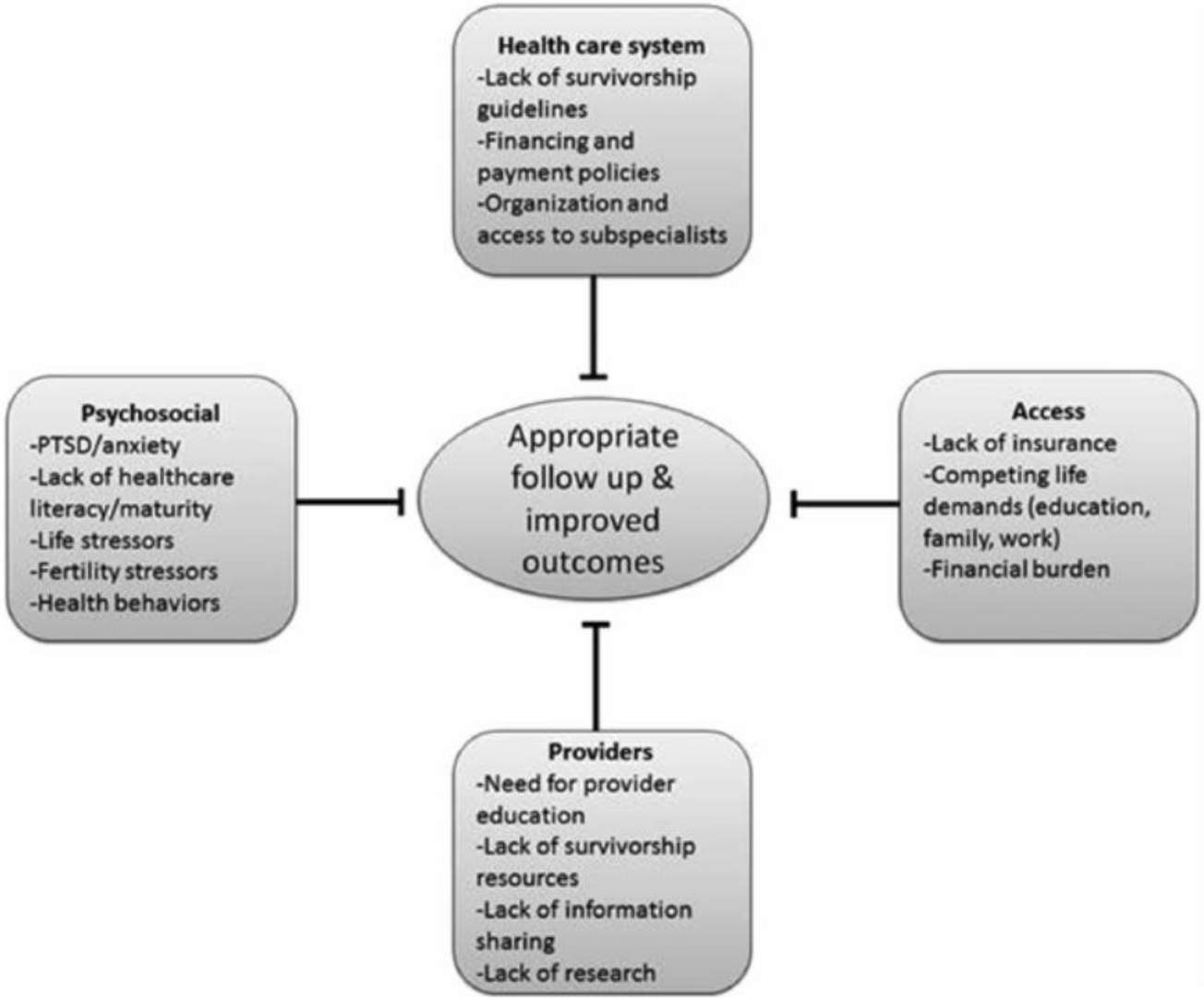
Anderson, C et al. *CEBP,* 2020.
Armenian, SH et al. *Cancer,* 2020.

Challenges in Survivorship

- Younger AYA survivors who are followed in a pediatric survivorship program are more likely to have closer surveillance than older AYA survivors (>25 years)
  - Most AYA care is delivered in the community, requiring communication
- Risk-based survivorship care is key
- Psychosocial health is a critical component
- Many long-term complications from therapy – may occur years or decades later
  - Infertility
  - Cardiomyopathy
  - Pulmonary compromise
  - Hormone dysregulation
  - Metabolic Syndrome

Burkhart M, et al. *Pediat Blood & Cancer, 2019*.

Barriers to survivorship care



Burkhart M, et al. *Pediat Blood & Cancer, 2019*.

Complex follow up required

Screening/ test	When screening or test is recommended
Annual history and physical exam	- Annual blood pressure, aggressive management of cardiovascular risk factors (blood pressure, cholesterol, smoking, obesity) - Pneumococcal, meningococcal, and H-Flu revaccination after 5–7 years, if the patient treated with splenic radiation or previous splenectomy - Annual influenza vaccine
Labs	- Annual (or more often posttreatment) CBC, differential, platelets, comprehensive chemistry panel - Biannual lipids (cholesterol) or as clinically directed - Annual fasting glucose - TSH at least annually if the patient received radiation to chest, neck, or cranial (>40 Gy) to the hypothalamic pituitary axis - Assess for history of blood in urine or signs of a urinary tract infection, change in stream. If positive or a history of abnormal urinalysis obtain a urinalysis - Annual urinalysis if treated with ifosfamide, carboplatin, cisplatin, renal radiation
Cardiovascular/ Echocardiogram	- The NCCN (v 3.2017) Anthracycline-Induced Cardiac Toxicity Guidelines recommend considering an **echocardiogram within one year** after the completion of therapy for anthracycline doses > 250 mg/m^2, age > 65, hx chest radiation therapy, hx smoking, obesity, hypertension, DM, hx of other cardiovascular comorbidities (i.e., afib, known CAD, baseline evidence of structural heart disease), low-normal EF (50%–54%) at baseline - Echocardiogram screening per COG Long-Term Follow-Up Guidelines recommend a baseline echocardiogram at entry into long-term follow-up. Repeat per the following schedule based on history of chest radiation and total anthracycline dose or as clinically indicated: - Total anthracycline dose > 250 mg/m^2 and/or >15 Gy chest radiation **every 2 years** - Total anthracycline dose < 250 mg/m^2 and/or <15 Gy chest radiation **every 5 years** - Consider color Doppler ultrasound of carotid vessels as clinically indicated or 10 years after completion of radiation to the neck as a baseline and refer to cardiologist if abnormal (<40 Gy to cranial, nasopharyngeal, cervical, neck, spine, STLI, chest, extended mantle, mantle, mediastinal, mini mantle, whole lung, total lymphoid irradiation (TLI))
Respiratory	- Pulmonary function tests (including DLCO and spirometry) at baseline into long-term follow-up and then as clinically indicated if treated with bleomycin, busulfan, carmustine (BCNU), lomustine (CCNU), and/or chest irradiation
Breast Cancer (females only)	- >20 Gy to the chest: Yearly mammogram beginning 8 years after radiation or age 25, whichever comes last - Breast MRI (if radiated under age 30): Yearly as an adjunct to mammography (alternating every 6 months) beginning 8 years after radiation or age 25, whichever comes last - 10–19 Gy to the chest or TBI: Clinician should discuss risk/harm of screening with patient. If screening, follow recommendations above - Screening mammogram at age 40 for women without chest radiation
Colon cancer screening	- Colonoscopy: Every 10 years for patients age > 45, if high risk begin at age 35 and repeat at 5-year intervals (high risk e.g., >30 Gy abdominal, inverted Y, para-aortic, renal, right flank/hemi abdomen, RUQ, spleen, whole abdomen, extended mantle, TLI), or for high-risk family history
Other cancer screening	- Routine surveillance tests for cervical, endometrial, lung, and prostate cancers as per the ACS Screening Guidelines
Functional asplenia (> 40 Gy to spleen area) or asplenia	- Physical examination and blood cultures at the time of febrile illness (T > 101 degrees F) to evaluate degree of illness and potential source of infection - Annual flu vaccination - Immunizations per CDC recommendations for functional asplenia
Cataracts, sicca syndrome, microvascular retinopathy	- Yearly ophthalmologic exam (visual acuity, funduscopic exam for lens opacity) if treated with busulfan, corticosteroids and/or > 10 Gy cranial/orbital radiation, GVHD
Bone health	- Treatment with corticosteroids such as dexamethasone and prednisone or the chemotherapy methotrexate can lead to reduced bone mineral density (osteopenia/osteoporosis) - Recommend baseline DEXA at entry into long-term follow-up and repeat as clinically indicated - Counseling about physical activity, vitamin D, and calcium supplementation to prevent loss of bone density
Cognitive effects	- Neurocognitive testing if experiencing difficulty with high-level functioning or memory
Counseling topics	- Reproduction, sexual health, health habits, psychosocial, cardiovascular, breast self-exam, skin cancer risk, dental hygiene, end of treatment discussion

- Children's Oncology Group Survivorship guidelines
  - www.survivorshipguidelines.org
  - Can be applied for pediatric treatment backbones, not for more adult based carcinomas
- NCCN AYA Guidelines:
  - Nccn.org/professionals/physician_gls/pdf/aya.pdf

Burkhart M, et al. *Pediat Blood & Cancer, 2019*.

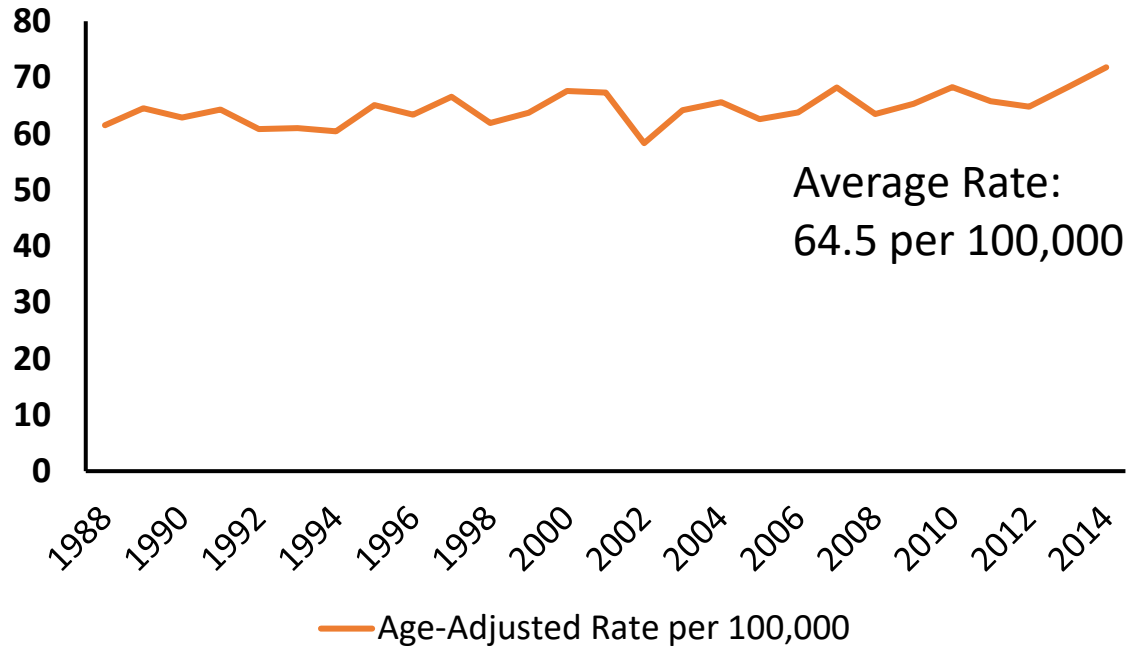
Financial Toxicity

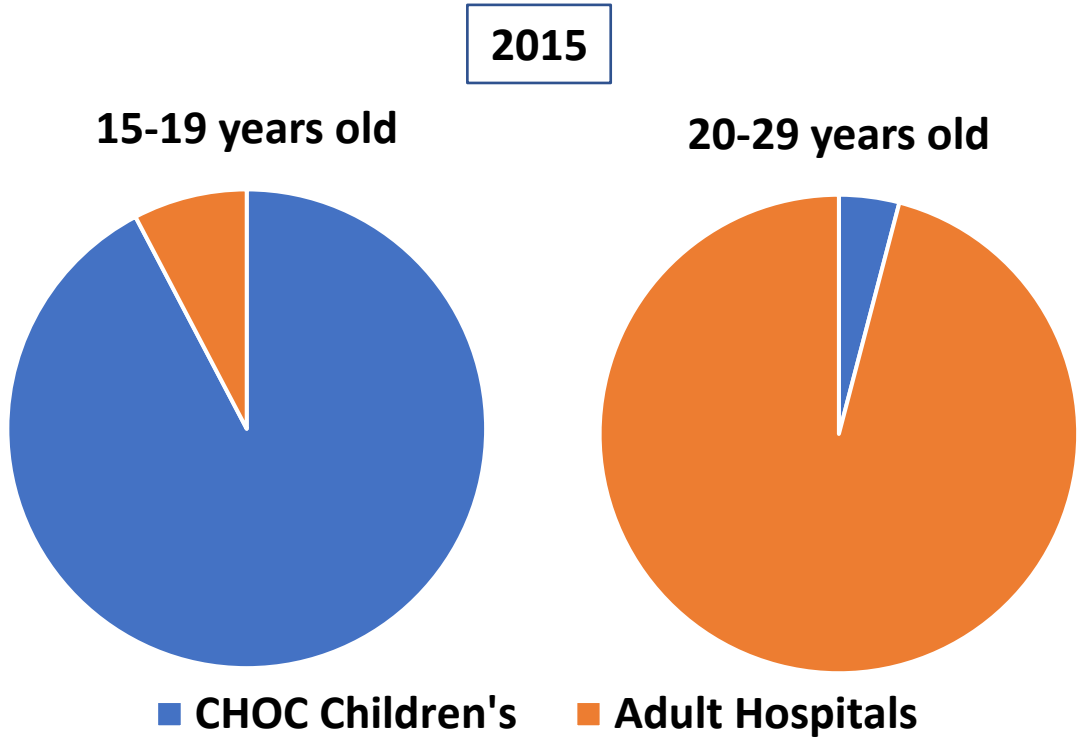
- AYAs are particularly vulnerable to financial toxicity due to disruptions related to education, employment, physical limitations, identity, and relationships
- AYA survivors:
  - Are more likely to not be working compared to controls
  - Have higher direct annual medical costs
  - Have lower family incomes then age-matched controls
- Across diagnosis, 14.4% of AYA survivors reported their families borrowed > $10,000
  - Exposure to chemotherapy increases the risk
- 1.5% reported they or their family had reported bankruptcy because of their treatment

	Chemotherapy[a]		
	No. Yes/No (% Yes)	OR	95% CI
Variable			
Interfered with physical tasks required by job			
No	96/119 (44.7)	1.00	Ref
Yes	187/115 (61.9)	1.97	1.22-3.11[d]
Interfered with mental tasks required by job			
No	144/189 (43.2)	1.00	Ref
Yes	269/130 (67.4)	3.22	2.15-4.79[d]
Extended paid time off from work, unpaid time off, or a change in hours, duties, or employment status			
No	64/108 (37.2)	1.00	Ref
Yes	352/212 (62.4)	3.56	2.31-5.47[d]
Extended paid time off from work			
No	115/63 (64.6)	1.00	Ref
Yes	228/138 (62.3)	1.02	0.62-1.67
Unpaid time off from work			
No	159/96 (62.4)	1.00	Ref
Yes	183/103 (64.0)	1.39	0.79-2.36

Ketteri, TG et al. *Cancer,* 2019.

In Orange County …





AYA Program at CHOC

- Patient Leadership Team who guide program direction
- Multidisciplinary staff involvement

- Psychosocial:
  - Robust mentorship program
  - Peer support both inpatient and outpatient
  - Weekly gatherings with larger monthly events
    - Range from coffee hour to paint night to annual Prom
  - Service events (for families, for siblings, etc)

- Leadership:
  - Annual Retreat focused on leadership training
  - Mentorship training

AYA Program at CHOC

- Education:
  - Nursing education curriculum
  - AYA nurse champions
  - 6-8 annual educational nights for the AYAs (topics chosen by leadership team)

- Research:
  - Fertility Preservation
  - Clinical Trial Enrollment when available
  - Hospital and local initiatives to look at AYA HR-QoL outcome measures
  - Forming partnerships with local community oncologists and adult centers

After the Cancer Treatment Survivorship (ACTS) Program

- Multidisciplinary Treatment Team
- Yearly visits start 4-5 years after completion of chemotherapy
- Provide comprehensive treatment summary
- Education, education, education!

After the Cancer Treatment Survivorship (ACTS) Program

Prevention
- Diet/Exercise
- Sun Exposure
- Alcohol
- Tobacco Control
- Chemo-prevention

Early Detection
- Cancer screening
  - ✓Pap test
  - ✓Mammogram
  - ✓Fecal occult blood test
  - ✓Colonoscopy
  - ✓Prostate-specific antigen/Digital rectal exam
- Awareness of cancer risk, signs, symptoms
- Informed decision making

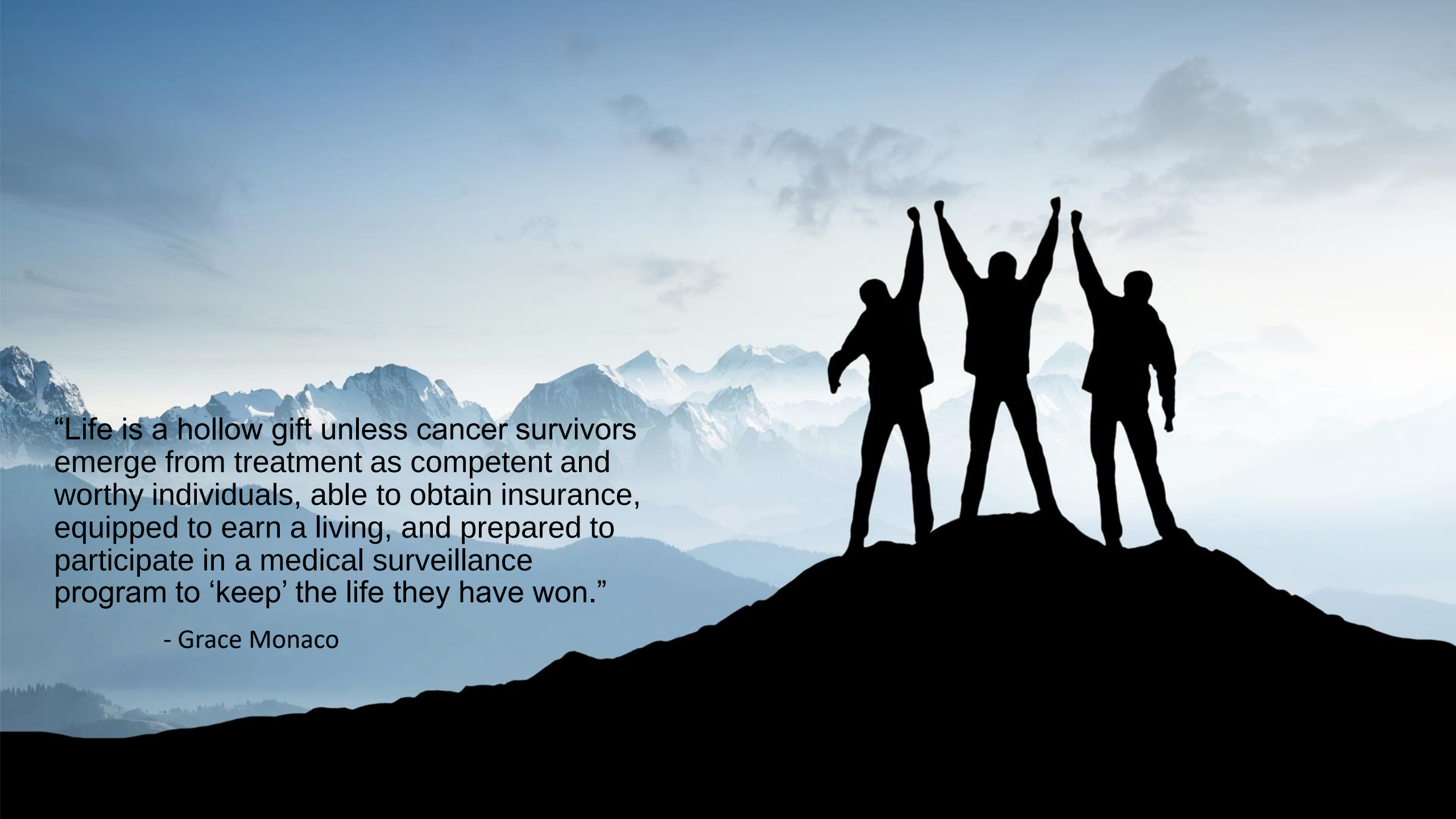
Diagnosis
- Oncology/ surgery consultation
- Tumor staging
- Patient counseling & decision making
- Clinical trials

Treatment
- Chemotherapy
- Surgery
- Radiation
- Symptom management
- Psychosocial care

Survivorship
- Long-term follow-up/ surveillance
- Manage late-effects
- Rehabilitation
- Coping
- Health promotion
- Prevention

Conclusions

- AYAs have inferior survival outcomes and with poor gains in OS when compared to pediatric and adult patients
- This is multifactorial including access to care, delay in diagnosis, treatment protocol and treating facility
- AYAs are at a critical time point in development, leading to significantly worse HR-QOL and psychosocial distress
- A comprehensive, multifaceted approach is critical to improving AYA's overall survival


“Life is a hollow gift unless cancer survivors emerge from treatment as competent and worthy individuals, able to obtain insurance, equipped to earn a living, and prepared to participate in a medical surveillance program to ‘keep’ the life they have won.”
- Grace Monaco

PRACTICE INFORMATION

CHOC SPECIALISTS – ONCOLOGY DIVISION

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Orange, CA 92868

Scheduling Line: 714-509-8636

Please feel free to reach out:

Jamie Frediani, M.D.

Email: jfrediani@choc.org

Cell: 909-229-1949

Physicians available via telehealth and accessible on pingmd

CHOC

THANK YOU

CHOC