Transitions:
From Cancer Kid to Adulting

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Transitions

- Definition
- Why is it important?
- What can we do to help?
- What are the transitions in our patients?

Transitions: A definition

- a change from one state or condition to another
  - Merriam-Webster Dictionary

Why are transitions important?

- *“There is nothing permanent except change. “*
  - **Heraclitus,** Ancient Greek Philosopher (540 BC - 480 BC)

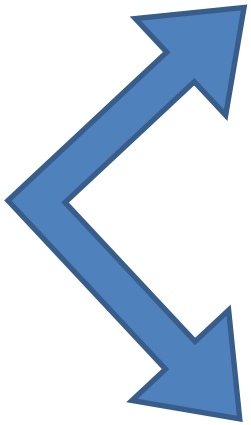
- *"If you always do what you've always done*
  You'll always be where you are right now."
  - **Unknown**

Why are transitions important?

- In other words,

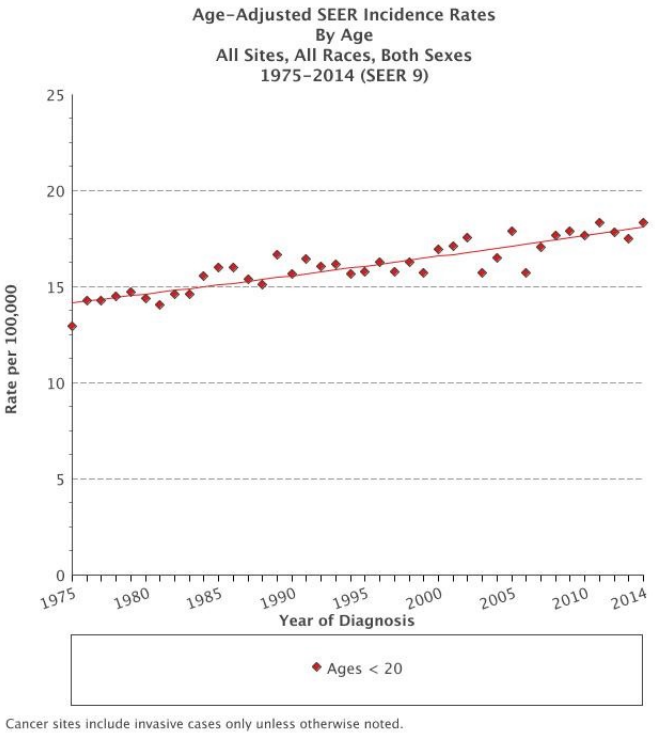
- No matter what you do or how hard you try, **your kids are going to grow up**.

Transitions



- *“When I grow up I want to be a little boy.”*
  – Joseph Heller

Pediatric Cancer Background



- The incidence of pediatric cancer is approximately 18 cases/100,000
- It is a relatively rare disorder

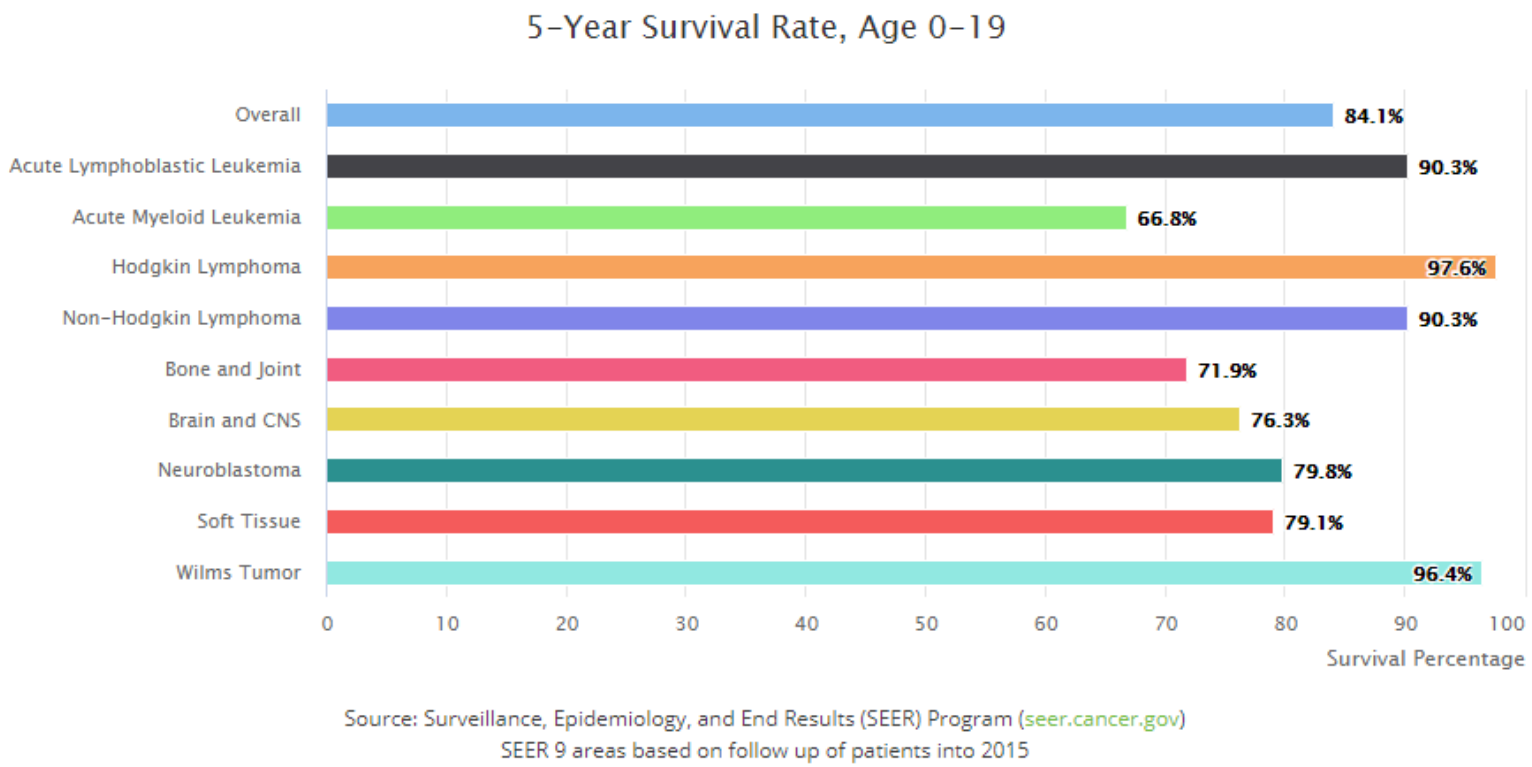
Pediatric Cancer Background

Table 6. Ten Leading Causes of Death by Age and Sex, United States, 2014

	ALL AGES		AGES 1 to 19		AGES 20 to 39	
	MALE All Causes 1,328,241	FEMALE All Causes 1,298,177	MALE All Causes 12,128	FEMALE All Causes 6,538	MALE All Causes 65,486	FEMALE All Causes 30,221
1	Heart diseases 325,077	Heart diseases 289,271	Accidents (unintentional injuries) 4,409	Accidents (unintentional injuries) 2,023	Accidents (unintentional injuries) 24,467	Accidents (unintentional injuries) 8,850
2	Cancer 311,296	Cancer 280,403	Intentional self-harm (suicide) 1,681	Cancer 757	Intentional self-harm (suicide) 10,353	Cancer 4,440
3	Accidents (unintentional injuries) 85,448	Chronic lowe respiratory diseases 77,645	Assault (homicide) 1,563	Intentional self-harm (suicide) 581	Assault (homicide) 7,040	Intentional self-harm (suicide) 2,649
4	Chronic lower respiratory diseases 69,456	Cerebro-vascular disease 77,632	Cancer 1,028	Assault (homicide) 477	Heart diseases 5,077	Heart diseases 2,459
5	Cerebro-vascular disease 55,471	Alzheimer disease 65,179	Congenital anomalies 498	Congenital anomalies 428	Cancer 4,020	Assault (homicide) 1,287
6	Diabetes mellitus 41,111	Accidents (unintentiona injuries) 50,605	Heart diseases 373	Heart diseases 266	Chronic liver disease & cirrhosis 971	Pregnancy, childbirth & puerperium 748
7	Intentional self-harm (suicide) 33,113	Diabetes mellitus 35,377	Chronic lower respiratory diseases 158	Influenza & pneumonia 126	Diabetes mellitus 970	Chronic liver disease & cirrhosis 628

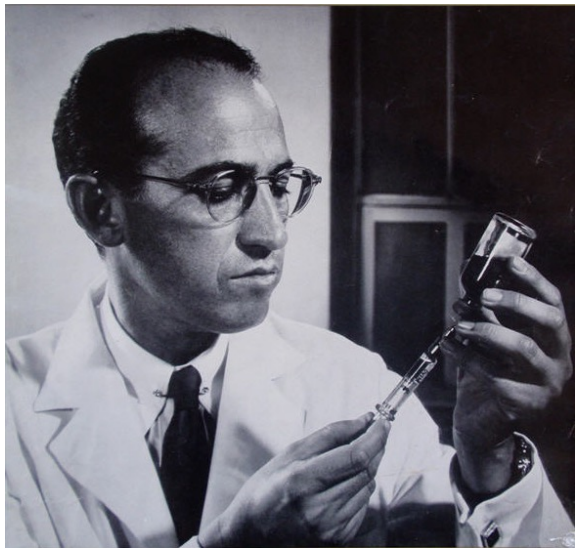
- Cancer is the 2nd- Leading cause of death in children, only behind accidents and injuries

Pediatric Cancer Background



- Survival for all pediatric cancers has been steadily improving.
- In 2017, 85% of children diagnosed with cancer are expected to survive

THE MEDICAL TRANSITION



- *"Good parents give their children Roots and Wings. Roots to know where home is, wings to fly away and exercise what's been taught them."*
  - Dr. Jonas Salk, Discoverer of the Polio Vaccine

2018 AAP Report on Transitions

Youth with medical complexity represent approximately 1% of all US children.

..programs have been established to provide outpatient and inpatient coordination and management for youth and young adults with medical complexity, recognizing their needs for more individualized planning and collaborative care partnerships between pediatric and adult clinicians or practices.

…Special populations may not represent the majority of youth transitioning to adulthood, but in the aggregate, they include those most vulnerable to poor outcomes and higher health care costs.

-**Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home.** *Pediatrics* (2018) 142 (5): e20182587.

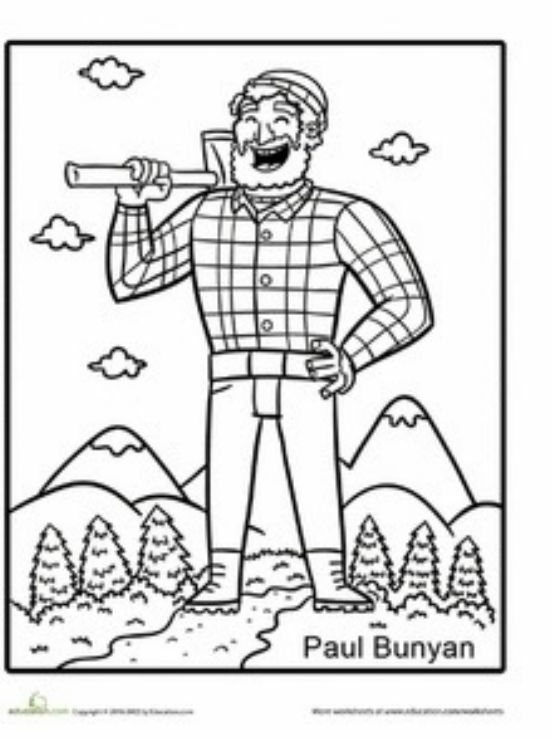
Survivorship

- Late Effects
  - Surgery: Local effects (Neurologic development, orthopedic function, scarring, cosmetic appearances)
  - Radiation: Local effects (Neurologic development, growth, secondary malignancy, organ and endocrine dysfunction)
  - Chemotherapy: Systemic effects (cardiomyopathy, pulmonary fibrosis, growth, neurologic development, xerostomia, secondary leukemia)

What can we do to help

www.gottransition.org

SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

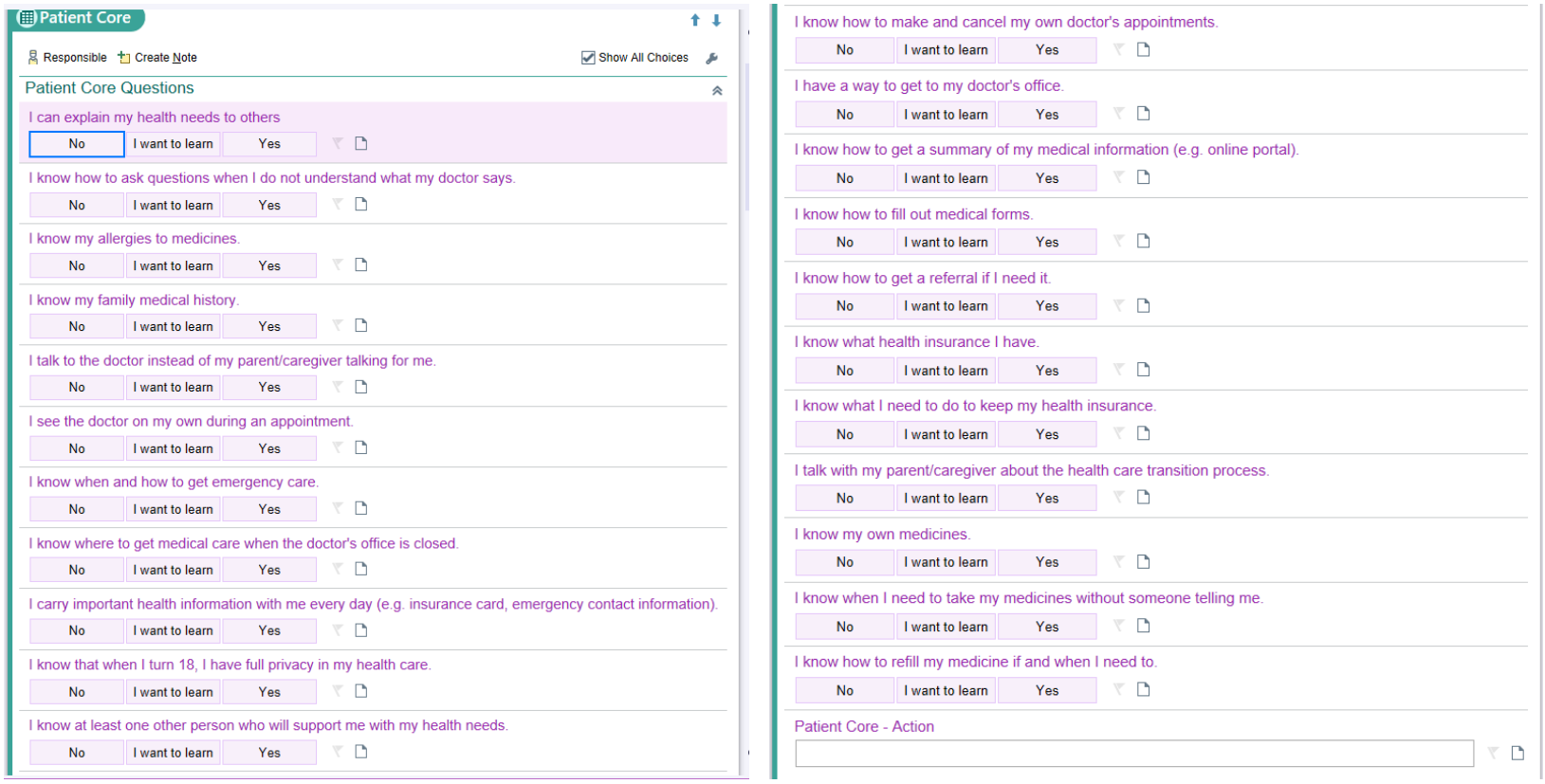


- *“You have to do your own growing no matter how tall your grandfather was.”*
  - Abraham Lincoln

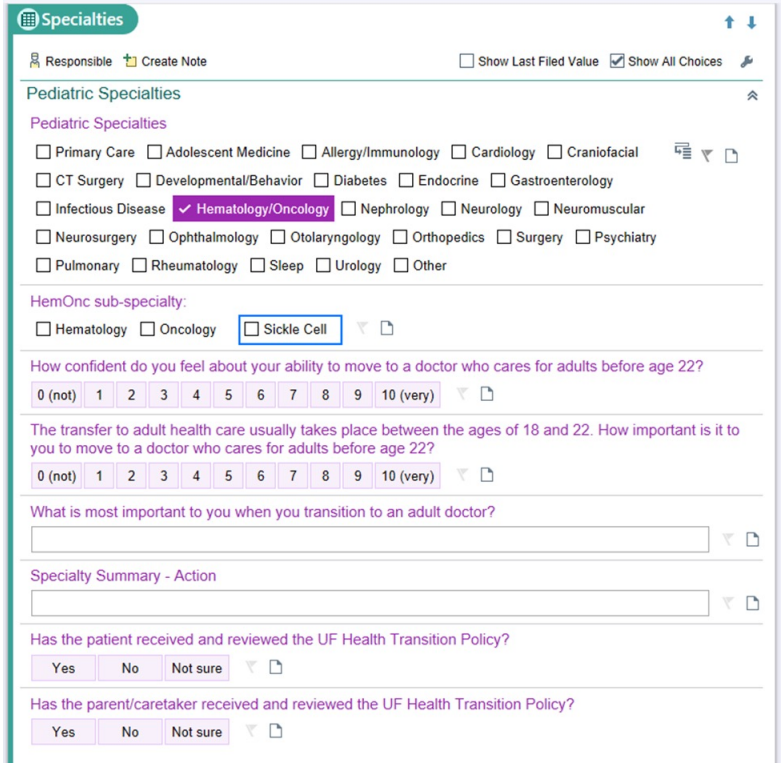
Transition Readiness Assessments

- University of Florida's Electronic Pediatric Transition Assessment Tool
- Transition Readiness Assessments are completed in all General Pediatric and certain Pediatric Subspecialty Clinics including Hematology and Oncology
- EMR allows for patient access and communication

Transition Readiness Assessments



Transition Readiness Assessments



Transition Education

- Education and Documentation Tool

ransition Education provided:

	Topic	Date	Educator Initials
Age 12-14			
☐	Transition Policy Provided		
☑	Diagnosis	1/3/23	DMR
☐	Medications and their purpose		
☐	Keeping track of your medications		
☑	Disease Treatment Plan	1/3/23	DMR
Age 15-16			
☐	Clinic visit preparation		
☐	Communicating with your care provider		
☑	Following up with tests and labs	1/3/23	DMR
☐	Contacting your care provider		
☐	Keeping track of your appointments		
Age 17-Adults			
☐	Managing your money and budgeting		
☐	Eating right and managing meals		
☐	Refilling Medications		
☐	Insurance		

SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

Planning the Transfer

- Set a time of the transfer
- Identify barriers
- **Identify an Adult Physician**
- Outline the process
- Complete Medical Summary
- What happens after the transfer?

Planning the Transfer - Barriers

- Developmental Disability
- Financial Dependency
- Continuing Education – College or Trade School
- Relocation
- Intimate Relationships
- Transportation
- Successful Adult Role Models

Planning the Transfer - Adult Physician

- Relates to overcoming the barriers
  - Relocation
  - Insurance

- Dedicated Survivorship Clinic
- Another Adult Oncologist
- An Adult Oncologist “practicing” Pediatrics
- Academic Center or Private Practice
- Primary Care Physician

- Offer to contact the new physician

Why are transitions important?

- *"Parents can only give good advice or put them on the right paths, but the final forming of a person's character lies in their own hands."*
  - Anne Frank
- If change is inevitable, it is important that we give our patients the right tools to take care of themselves and lead successful lives

Cancer Treatment Summary

- Basic Demographics
- Diagnosis information
- Treatments Used
  - Chemotherapy
  - Surgery,
  - Radiation
- Complications experienced

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

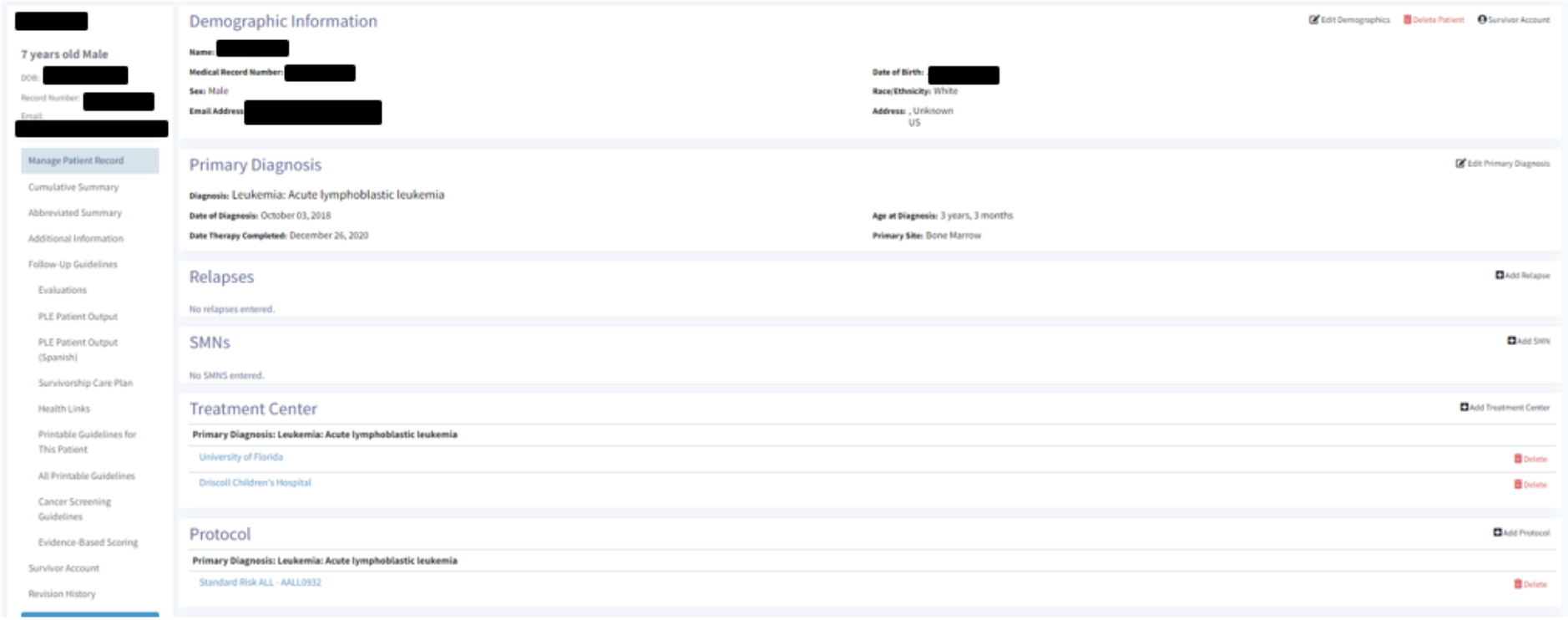
Survivorship Care Plan

- Known or expected effects resulting from the treatments
- Degree of risks to health of these effects
- A monitoring and treatment plan for health maintenance

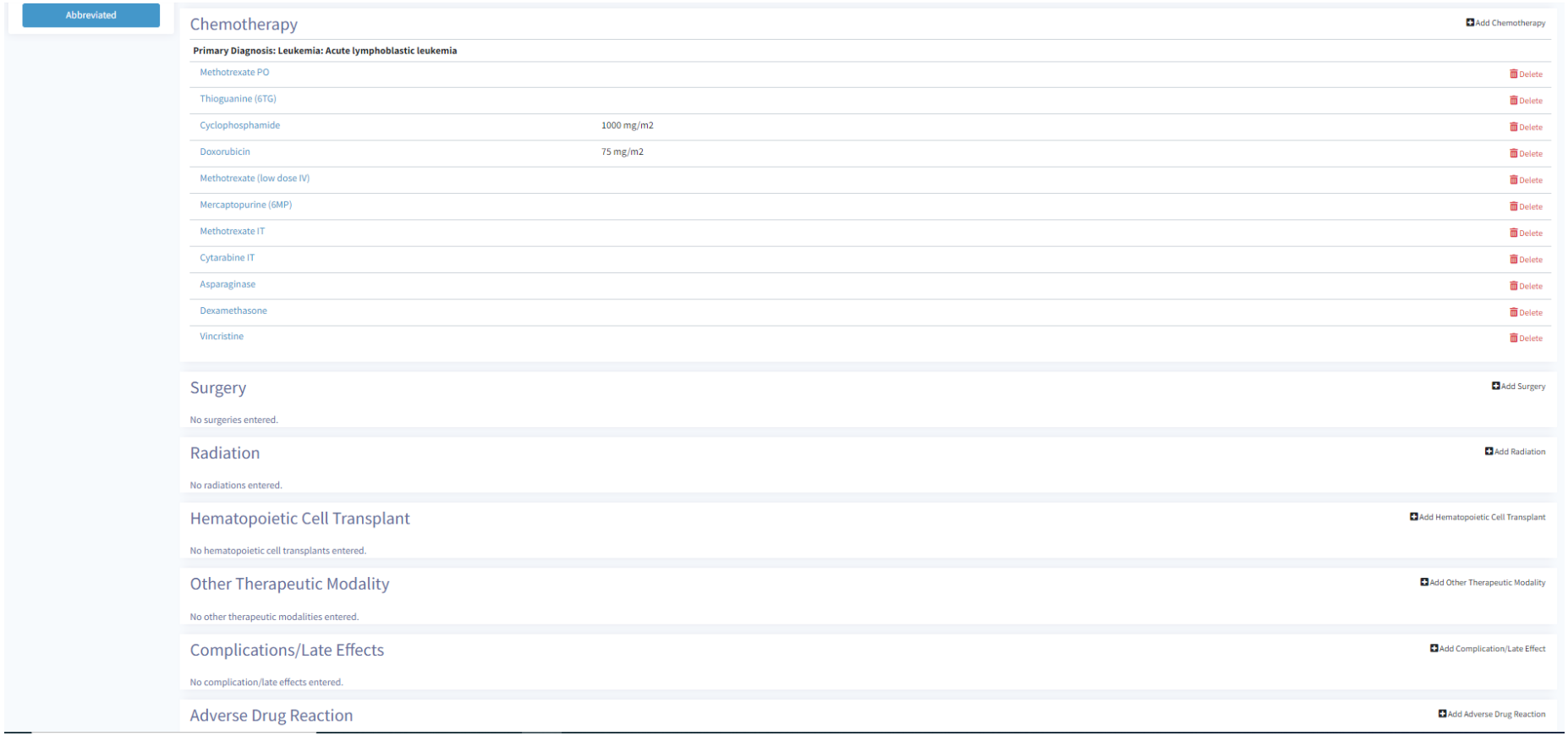
Passport for Care

Passport for Care® with the CHILDREN'S ONCOLOGY GROUP

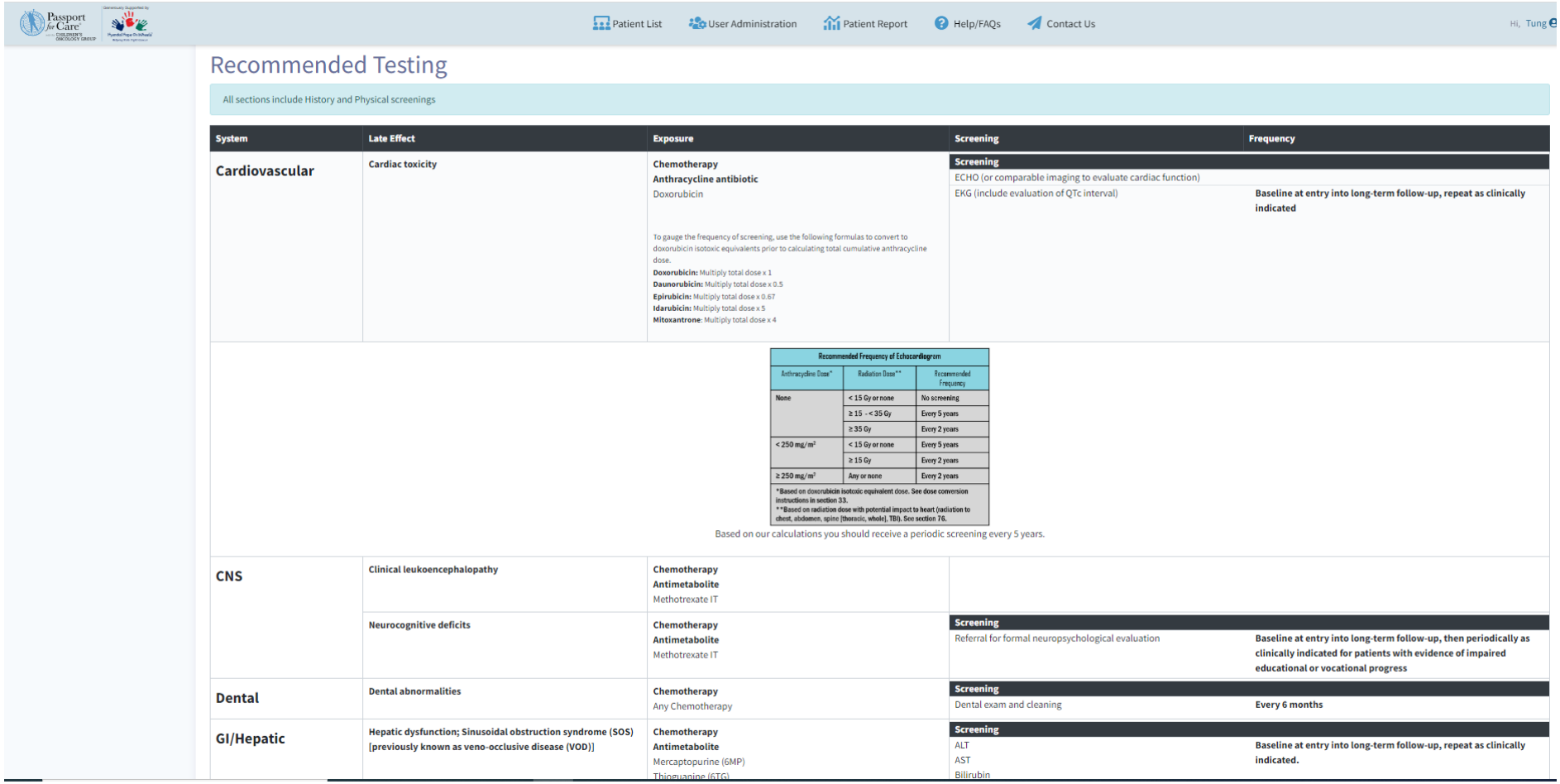
Generously Supported by Hyundai Hope On Wheels® Helping Kids Fight Cancer



Cancer Treatment Summary



Survivorship Care Plan



Passport for Care

Patient List | User Administration | Patient Report | Help/FAQs | Contact Us

Hi, Tung

Recommended Testing

All sections include History and Physical screenings

System	Late Effect	Exposure	Screening	Frequency
Cardiovascular	**Cardiac toxicity**	**Chemotherapy** **Anthracycline antibiotic** Doxorubicin To gauge the frequency of screening, use the following formulas to convert to doxorubicin isotoxic equivalents prior to calculating total cumulative anthracycline dose. **Doxorubicin:** Multiply total dose x 1 **Daunorubicin:** Multiply total dose x 0.5 **Epirubicin:** Multiply total dose x 0.67 **Idarubicin:** Multiply total dose x 5 **Mitoxantrone**: Multiply total dose x 4	**Screening**	
			ECHO (or comparable imaging to evaluate cardiac function)	
			EKG (include evaluation of QTc interval)	**Baseline at entry into long-term follow-up, repeat as clinically indicated**

Recommended Frequency of Echocardiogram

Anthracycline Dose*	Radiation Dose**	Recommended Frequency
None	< 15 Gy or none	No screening
	≥ 15 - < 35 Gy	Every 5 years
	≥ 35 Gy	Every 2 years
< 250 mg/m²	< 15 Gy or none	Every 5 years
	≥ 15 Gy	Every 2 years
≥ 250 mg/m²	Any or none	Every 2 years

*Based on doxorubicin isotoxic equivalent dose. See dose conversion instructions in section 33.
**Based on radiation dose with potential impact to heart (radiation to chest, abdomen, spine [thoracic, whole], TBI). See section 76.

Based on our calculations you should receive a periodic screening every 5 years.

CNS	**Clinical leukoencephalopathy**	**Chemotherapy** **Antimetabolite** Methotrexate IT		
	Neurocognitive deficits	**Chemotherapy** **Antimetabolite** Methotrexate IT	**Screening**	
			Referral for formal neuropsychological evaluation	**Baseline at entry into long-term follow-up, then periodically as clinically indicated for patients with evidence of impaired educational or vocational progress**
Dental	**Dental abnormalities**	**Chemotherapy** Any Chemotherapy	**Screening**	
			Dental exam and cleaning	**Every 6 months**
GI/Hepatic	**Hepatic dysfunction; Sinusoidal obstruction syndrome (SOS) [previously known as veno-occlusive disease (VOD)]**	**Chemotherapy** **Antimetabolite** Mercaptopurine (6MP) Thioguanine (6TG)	**Screening**	
			ALT AST Bilirubin	**Baseline at entry into long-term follow-up, repeat as clinically indicated.**

Why use Passport for Care

- Quick and Easy to Use
- Linked to the Children's Oncology Group's Long-Term Survivorship Guidelines
  - Recommendations are up to date
- Accessible electronically from any computer

SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

The Transfer

- Stick to the Plan
- Support the new team
  - Provide them with information
  - +/- Peds team at first clinic visit
  - Emphasize the adult team's leadership
- Support the patient and the family
  - Reassurance

SIX CORE ELEMENTS™ APPROACH AND TIMELINE FOR YOUTH TRANSITIONING FROM PEDIATRIC TO ADULT HEALTH CARE

Transition Completion

- Be available for questions
- Opportunity to get feedback on the process
- Quality Measures of the Transition Process
  - # visits/year to adult hematologist
  - # visits/year to Emergency Room
  - # prescription refills for hydroxyurea
- It is not closing the door
  - It is a child leaving his family to go to college
  - The pediatric team is still there to support them
  - Still like to know how patients are doing and where they are in life

Not just the medical transition

THE LIFE TRANSITIONS

What does adulting mean?

- Where in the world am I
- Your on your own
- College and Trade school
- Independence
- It’s my decision
- My significant other
- Do I make enough money
- What is my health insurance plan

- *“Too many people grow up. That's the real trouble with the world-- too many people grow up. They forget. They don't remember what it's like to be 12 years old.”*
  - Walt Disney

Introduction of the Panel

- In their own words….