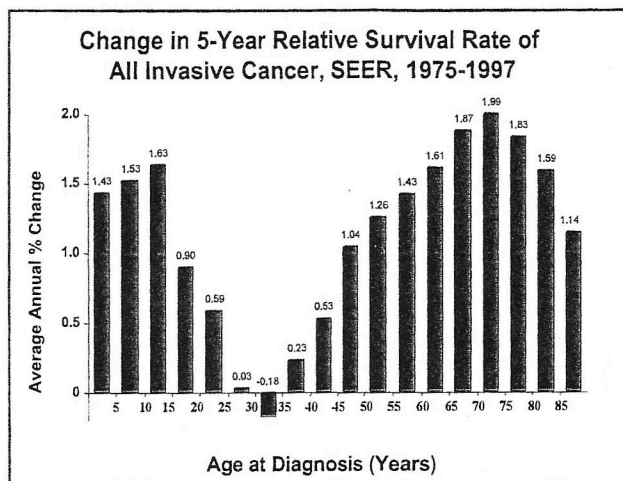


THE ADOLESCENT AND YOUNG ADULT (AYA) ONCOLOGY PROBLEM

Adolescents and young adults (AYAs) with cancer are unique patient population:

- In the US each year, approximately 24,000 16-29 year olds are diagnosed with cancer.

- Although children and older adults had a 1-2% per year increase in survival rates over the interval 1975-1997, AYAs had stagnant survival rates.



- The most common cancers that occur in this age interval are a mix of tumors traditionally treated by pediatric or medical oncologists
 - Lymphoma
 - Testicular cancer
 - Thyroid cancer
 - Melanoma
 - Leukemia
 - Brain tumors
 - Sarcoma
- Significant medical issues for AYAs with cancer include:
 - Delays in diagnosis
 - Fertility preservation
 - Genetic predisposition
 - Choice of treatment site or specialist (AYAs with ALL have a 25% better survival when treated according to pediatric protocols than adult protocols)
 - Undetermined differences in tumor biology and host pharmacodynamics
 - Lowest rates of clinical trial enrollment
 - Adherence
- Significant psychosocial issues for AYAs with cancer include:
 - Sense of isolation/need for peer support
 - Maintaining “normalcy” and developmentally appropriate goals (school, career, appearance, intimate relationships)
 - Shared decision-making/dependency on parents
 - Substance abuse/risk-taking behavior
 - Insurance and financial issues

- Young AYAs can be seen at either pediatric or adult facilities, dividing their care and expertise. At most pediatric hospitals, patients over age 15 account for less than 15%; at adult hospitals, only less than 5% of patients are under age 30.

There are 2.5x as many 16-29 year olds diagnosed with cancer each year as children, but there are no dedicated facilities or resources, research agendas and support services focused on this population. In 2006, the National Cancer Institute performed a Progress Review Group that recommended that improvements in AYA care and survival would necessitate a focused, programmatic approach, team and environment.

GUIDELINES ON ADDRESSING THE AYA NEED

Each institution or community must determine how it can best meet the needs of AYAs. There have been recent guidelines to help do so:

- In 2010, the Live**STRONG** Young Adult Alliance Standards of Care Task Force published a consensus-based position statement that named access to health care professionals with knowledge specific to the biomedical and psychosocial needs of AYAs and efficient processes for diagnosis, initiation of treatment, and promotion of adherence as critical elements of care.
- In 2012, the National Comprehensive Cancer Network (NCCN) published the first set of clinical practice guidelines for supportive care for AYA oncology.
- An independent US non-profit, Change it Back, has developed 8 criteria for becoming an AYA Center of Excellence based on professional consensus.
- The British have developed the National Institute for Health and Clinical Excellence “Improving Outcomes in Children and Young People with Cancer” as well as the “Teenage Cancer Trust’s “Blueprint of Care for Teenagers and Young Adults with Cancer”
- The Australians have “The National Service Delivery Framework for Adolescents and Young Adults with Cancer”
- New Zealand has “Coordination of the Adolescent/Young Adult Cancer Service Specification”
- The Canadians stakeholder workshop developed a “Framework of care”

THE FORMATION OF THE FORT WORTH AYA ONCOLOGY COALITION

In March 2011, representatives from 11 oncology care centers and organizations and interested individuals in Fort Worth were invited to discuss the care of AYAs with cancer in our community; they decided to organize into an Adolescent and Young Adult Oncology Task Force. All participation has been voluntary and without external funding support. The group agreed to become a formal Coalition, developed Mission and Vision statements, performed a SWOT analysis, created a logo, and prioritized goals. At the end of 2012, we became a legal non-profit foundation under the auspices of a community health

501C3, Healthy Tarrant County Collaboration, and established bylaws, membership structure and dues.

Founding Partner Institutions:

- Cook Children Medical Center
- Texas Oncology, PA
- University of North Texas Health Science Center
- Texas Christian University Harris School of Nursing
- Baylor All Saints
- Moncrief Cancer Institute
- Carley Rutledge Foundation

Founding Individual Partners:

- Lisa Bashore
- Joe Busch
- Britton Douglas
- Keith Hamilton
- Laurie Hamilton
- Paula Fultz
- Sally King
- Sana Massad

Member Institutions:

- Cancer Care Services
- Center for Cancer and Blood Disorders
- Harris Methodist Hospital
- John Peter Smith Hospital

Projects have included:

- Collection and sharing of de-identified patient data to define the local AYA problem
- Initiation of an AYA activity-based peer support group
- In spring, 2013, a 1½ day regional AYA Oncology educational conference for providers
- A toll-free phone line for AYA questions from any provider or patient
- Development of a webpage www.fortworthaya.org,
- Facilitation of the startup of a student club at TCU for YA cancer awareness

Future goals include more quality improvement projects in the areas of delays in diagnosis, clinical trial participation, psychosocial and palliative care and delivery of support and resource materials to patients.

In the Spring 2013, the Coalition voted that the next step for improving care of AYAs in our community was the development of an AYAO inpatient unit and infusion center.

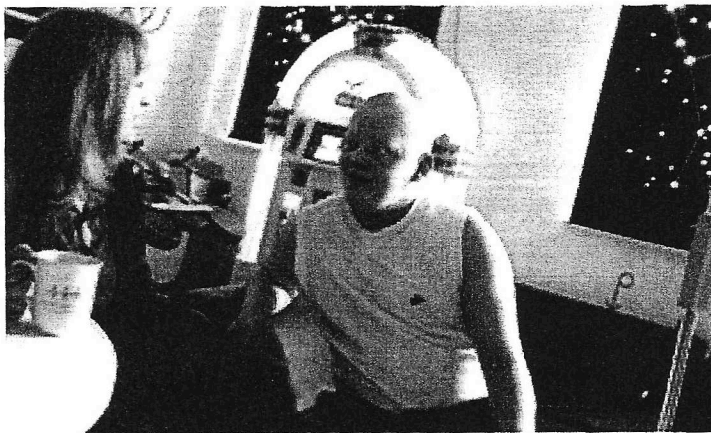
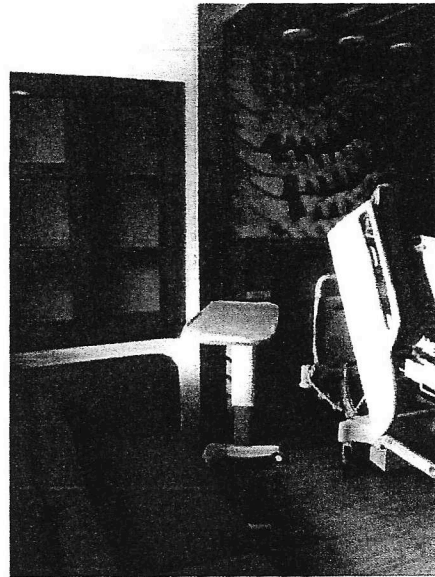
WHY AN INPATIENT UNIT FOR YOUNG ADULTS WITH CANCER?

A common unit provides efficient management of many of the “burdens” of AYA care. They often require unique services and can be labor-intensive for staff. For the social worker, there is an added burden to stay abreast of all the insurance options, employment laws and college scholarship, etc. For the child life specialist, the usual distractions and games for children are not appropriate. For the nurse, additional expertise in adherence and communication is required. Focusing on an inpatient unit rather than an outpatient care setting allows medical providers to continue to have patient “ownership.” Of note, the local outpatient environment in Fort Worth is a competitive one, led by Texas Oncology and The Center for Cancer and Blood Disorders. John Peter Smith serves as the county-supported facility and both University of North Texas Health Science Center and University of Texas Southwestern’s Moncrief Cancer Institute have expressed interest in developing outpatient clinics. However, the hospitals are independent; the private practices are not aligned with

specific facilities. Development of an inpatient hospital-based unit will allow access to all AYAs from those competitive outpatient clinics. We feel this model allows the most continued partnership of all oncology care institutions.

MODELS FOR AN AYA UNIT

The gold standard for the development of an AYA unit is the Teenage Cancer Trust (TCT) model in England. Teenage Cancer Trust is a London-based philanthropy, founded by a small number of concerned individuals (especially families of teens) twenty years ago. It has grown into a 12 million pound per year organization (<http://www.teenagecancertrust.org/what-we-do/specialist-services/units/>), with impressive support of celebrities.



They have funded the building of 27 Teen-Young Adult (TYA) units in England that include patient rooms, recreational rooms, study rooms, parent rooms, kitchens, and fitness areas with a large focus on age-appropriate design consultation from the AYAs themselves.

One of the largest celebrity supporters of TCT has been Roger Daltry of the rock band The Who. His vision of bringing the TCT model to the United States was shared with the administration of UCLA Medical Center, who is now building a unit. In the last year, a new foundation called Teenage Cancer America (TCA) has been established to continue to encourage centers to create AYA units.

Separately from TCA, Seattle Children's Hospital opened an AYA oncology unit in the fall of 2013 with 16 private rooms and gym for patients up to age 30. Although other children's hospitals have developed dedicated spaces for their oldest patients, and several cancer centers have AYA programs in varying levels of development, **there is no AYA unit in a community-based adult hospital in the U.S.**

CHOICE OF AGE RANGE AND ONCOLOGY FOCUS

The National Cancer Institute defines the AYA Oncology population as those patients diagnosed with cancer between the age of 15 and 39. A unit that includes this entire age range would certainly have a larger census (approximately 300%), as the incidence of cancer continues to climb with age. However, the types of cancer seen in the 30-39 year olds are more similar to those in older adults (mainly carcinomas and predominantly breast cancer) and the developmental issues and psychosocial needs are quite different. On the lower end of age range, we acknowledge that most of the types of cancer in 15-18 year olds are familiar to pediatric oncologists and most of these patients would be comfortable in a pediatric hospital (at least one that has an AYA program). However, some of these adolescents have "adult-type" cancers, and some are developmentally mature (perhaps married or with children). Therefore, our proposal is for an AYA unit that is open to 16-29 year olds, but acknowledges that most 16 and 17 year olds will still be preferentially cared for at the pediatric facility.

Pediatric oncology is not the only specialty that has seen marked improvements in survival over the last decades. Children with cystic fibrosis, sickle cell disease, congenital heart disease, renal disease, and other chronic pediatric illnesses now can expect to live well into their adult years. The issue of transitioning these AYAs into adult medical care and creating medical homes for them is a hot topic in medicine today. The development of an AYA unit for cancer patients could certainly be the first step in creating such a medical home for AYA patients with a variety of diseases; such a goal would truly be revolutionary and forward-thinking for an adult hospital.

DATA THAT INFORMS OUR VISION OF AN AYA UNIT

We have attempted to collect data to characterize the AYA population in Fort Worth and the referral basin. (See appendix for more detailed data).

- There are approximately 235 15-29 year olds diagnosed in the 20 county region surrounding Fort Worth each year; 2.3x as many cases as occur in 0-14 year olds. This accounts for 1.8% of all cancer diagnoses (1.9% of all adult cancer diagnoses).
- The most common diagnoses are: Thyroid (15%), Lymphomas (15%), Germ cell tumors (12%), Melanomas (11%), Leukemia (8%), Sarcoma (8%), other carcinomas (8%), and CNS tumors (7%).
- Between Cook Children's, THR Harris Fort Worth and Baylor All Saint's, there were 486 admissions of 16-29 year olds in 2011 and 2012 (243 per year). The average length of stay was 5.1 days. Available data approximates charges at \$50,000 per admission, with about half being pharmacy charges. If the data is limited to 18-29 year olds, there were 274 admissions (137 per year) with an average LOS of 4.7 days.
- Based on available data from Cook Children's, Center for Cancer and Blood Disorders and Baylor All Saint's (and a projection of data for Texas Oncology), there are approximately 2000 infusion room encounters per year for 16-29 year olds (Approximately 1300 for 18-29 year olds).
- Approximately 58% of AYA patients have commercial/managed care insurance coverage; 38% have government program insurance coverage and less than 5% are self-pay.

WHAT WE ENVISION OUR AYA UNIT LOOK LIKE:

We seek to craft a space of dedicated inpatient rooms, common space and infusion center within an adult hospital that already provides outstanding cancer care. The unit will be open to any AYA age 16-29 with cancer; primary oncologists will be required to present all new admissions at biweekly multi-disciplinary AYA tumor boards, where medical and AYA-specific issues will be discussed.

Specific physical space needs include:

- 4-5 single inpatient rooms that include generous-sized and well-planned ensuite bathrooms and sleeping accommodation for family/friend
- Common multi-functional space that can accommodate many group activities including music, movies, support groups
- Separate space for family
- Kitchen area with refrigerator and stove that encourages healthy nutrition education and group cooking activities
- Space and equipment for fitness and exercise
- State of the art patient-centric technology including wifi connectivity
- Infusion room with 4-6 chairs and 2 private rooms that flex into inpatient rooms

Specific staff and care needs include:

- Fulltime coverage by dedicated AYA oncology hospitalist/NP
- Dedicated oncology certified nurses who have chosen to work with this age group and receive ongoing training in AYA oncology
- Social worker with FTE adequate to cover needs
- Activity coordinator (child life) with FTE adequate to cover needs
- Psychologist with FTE adequate to cover needs
- Access to dietician
- Access to PT/OT/wellness trainer
- Access to fertility preservation
- Age-appropriate unit rules and visitation guidelines

CONCLUSION:

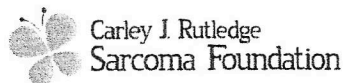
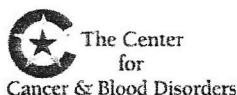
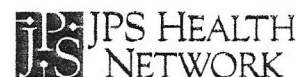
AYAs with cancer are a population that would benefit greatly from a focused effort in a dedicated inpatient unit. Fort Worth is in a unique position to answer this need: we have a remarkably willing, collaborative team of partners that include every cancer group in town. Fort Worth is a generous community. We would be the first community-based program to build an AYA oncology unit. Even as more academic settings build such AYA units, the limited data we have suggests that the minority of AYA patients are seen in academic settings or comprehensive cancer centers. Therefore, developing a model on how to care for AYAs in a community setting is a large need.

We invite your organization to consider responding to this invitation to partner in the creation of an AYA unit in Fort Worth. We ask for responses to the attached questionnaire by May 1. After committee consideration and site visits, the FWAYAOC will seek to make

recommendations on next steps by June 1, 2014, with the hope to open a FW AYA unit no later than March 2016.

Respectfully submitted March 20, 2014 by the Fort Worth Adolescent and Young Adult Oncology Coalition,

Karen Albritton, MD President
Paula Fultz, Vice-President
Joseph Busch, Secretary



The **Fort Worth AYA Oncology Coalition** is a 501C3 non-profit organization composed of health care organizations, oncology providers, foundations and concerned individuals who want the best in AYA care for our community.

A member of



DATA

Texas Registry Data:

Source: Texas Cancer Registry (www.dshs.state.tx.us/tcr) SEER*Stat Database, 2010-2011 Limited-Use Incidence, Texas statewide, Texas Department of State Health Services, created March 2014, based on NPCR-CSS Submission, cut-off 11/30/13.

20-county region around Fort Worth defined as: Tarrant, Johnson, Parker, Hood, Somerville, Bosque, Erath, Stephens, Young, Shackelford, Denton, Wise, Jack, Palo Pinto, Hill, Eastland, Comanche, Brown, Callahan, Throckmorton counties.

5-county region around Fort Worth defined as: Tarrant, Johnson, Parker, Hood, Wise counties.

Average Yearly incidence by Age and Region

	0-14	15-29	30-39	40+	Total
20 county region	102	235		12161	12992
5 county region	71	162		8682	9273

Cancer Diagnoses in 15-29 year olds in 20-county region

	YEARLY INCIDENCE	PERCENT OF TOTAL
Thyroid carcinoma	36	0.15
Lymphomas	36	0.15
Germ Cell and Trophoblastic Neoplasms	28.5	0.12
Melanoma and Skin Carcinomas	25	0.11
Leukemias	18.5	0.08
Sarcoma	18	0.08
CNS (all behavior)	16.5	0.07
Miscellaneous neoplasms	12	0.05
Other carcinoma	18	0.08
Carcinoma of gastrointestinal tract	10	0.04
Carcinoma of breast	8	0.03
Carcinoma of cervix and uterus	8	0.03
TOTAL	234.5	0.99

FORT WORTH ADOLESCENT AND YOUNG ADULT ONCOLOGY IN-HOUSE UNIT PROSPECTUS RESPONSE

TELL US ABOUT YOUR HOSPITAL

1. What is your total number of beds?
2. What is your number of ICU beds?
3. What is your number of Operating Rooms?
4. What accreditations does your hospital have?
5. Tell us about your electronic medical record system; does it include CPOE? What is its ability to interact with outside systems?
6. Tell us about your quality improvement programs and any special designations and awards for quality (Magnet, Leapfrog...)
7. Describe your Patient Safety Improvement and Safe Culture efforts (bedside medication verification, etc)
8. Tell us about your Nursing:
 - a. Staffing ratio
 - b. Shared governance structure
 - c. Turnover rate
 - d. Evidenced Based practice
 - e. Percentage of BSN prepared nurses at the bedside
9. What is available in the areas of Rehabilitation, Vocational Rehabilitation, Physical and Occupational Therapy? Exercise and Physical activity programs?
10. Describe your Social Media presence
 - a. How do you interact digitally with patients (texting, e-mail, other digital options)
 - b. Is there a Facebook page for your hospital and how active is it? Are there any restrictions to the postings? Who is the moderator?
11. Give information about your radiology services: Do you have one or more PET scanners? Do you have interventional radiologists (do they place port-a-caths? do they do CT guided biopsies?)
12. Do you have Palliative Care Services: do you have inpatient beds? What dedicated staffing do you have? What accreditation do you have? What number of patients are followed? What percent of the caseload is oncology?
13. Tell us about your Pain Management Team: Who and how many staff the team; how are they utilized, and how accessible are they?
14. Do you have a Child Life Specialist or Activities Coordinator or other staff that attends to patient activity needs?
15. Do you have any psychosocial staff that is specifically trained and focused on the needs of young adults?
16. Do you have a Complementary/Alternative Medicine Program? What is available to patients?
17. Describe your Pastoral care program? What services and programs are developed for patients?

CANCER PROGRAM

1. What is your total number of new cancer cases per year?
2. How many designated oncology inpatient beds do you have?
3. Do you have an infusion center? How is it staffed? How many oncology encounters per year are seen?
4. Describe your Cancer Registry: How many staff work; what is your 6-month date case completion rate and your follow-up rate?
5. Do you have stem cell transplant accreditation?
6. Describe your Cancer Committee: How often do you meet? What are their functions or activities?
7. Tell us about your Tumor Board(s): What is your average attendance? How many cases do you discuss each year?
8. How many Cancer Navigators do you have? Are they specialized? How are they trained or accredited? How do they function?
9. Tell us about your clinical research activities: What Staffing is dedicated to research; what IRB do you utilize? Do you have any institutional cancer specific research studies? Do you have affiliation with a clinical trial or cooperative oncology group? How many clinical trials do you have open? What number (and %) of your cancer cases were on intervention trials in the last two years ?
10. What have been your programs of focus in oncology in the last 3 years? What have you achieved?
11. Are you accredited by ACOS? What were your deficiencies and commendations on the last review?
12. What are your Community Outreach services in cancer? How would you envision outreach services for AYA cancer?
13. Do oncology patients have access to an oncology dietician/nutritionist? What percent of cancer patients are seen by nutritionist? Are there outpatient educational or consultative options?
14. How many oncology trained and oncology certified nurses do you have?
15. List all cancer specific QI projects completed in last 3 years.
16. How many Social worker FTEs are working with cancer patients? Are any social workers oncology certified?
17. Describe any post treatment follow-up and long-term survivorship programs you have.
18. What access do cancer patients have to a psychologist with expertise in psycho-oncology including individual and family services?
19. Who educates your patients about fertility preservation? Do you have on staff and/or refer to fertility specialists prior to treatment?

ABILITY TO MEET DESIRED SPECIFICS OF AYA INPATIENT UNIT:

For each of the elements listed, reply with specifics on how you will accomplish

Elements	Comments
1. Fulltime coverage of unit by dedicated hospitalist or NP	
2. Dedicated oncology certified nurses who have chosen to work with this age group and receive ongoing training specifically in AYA oncology	
3. Activity coordinator/ "child life" specialist	
4. AYA psychologist and social worker	
5. Kitchen	
6. Multi-functional common space	
7. Family room	
8. (4) inpatient beds	
9. "High tech" services, including wifi access	
10. Infusion room with (6) chairs and (2) beds	
11. Space and equipment for fitness and access to fitness consultant	
12. Ensuite bathrooms that are large, accessible	
13. AYA specific visitation guidelines	
14. Family/guest accommodations	