

## **Introductions**

Members present made introductions of themselves to the group. Dr. Allbritton introduced herself and spoke to our purpose of meeting today. The group then watched a video from Simon Davis, Executive Director of Teen Cancer America (ages 13-25)

## **History**

The group then discussed the history of AYA Oncology. AYA focuses on cancer patients ages 15-40 .. 72K cases per year – 6% of cancer incidence. Our age range goal for FWAYA is 16-29. There is a mix of cancers for this age group: lymphoma, testicular, thyroid, melanoma, leukemia, brain tumors, sarcoma. Issues that AYA patients face include: delays in diagnosis, fertility preservation, genetic predisposition, choice of treatment site or specialist (pedi vs adult), do not know tumor biology and host pharmacodynamics, low rates of clinical trial enrollment, and adherence. Psychosocial issues is a big problem with this group.

Our vision/mission statement is that every AYA cancer patient in our community receives quality care. In 2012, FYAYA became a 501(c)3 non-profit organization. The next step was to decide whether or not we had enough volume to build a unit. There are 235 (15-29YO) diagnosed each year. Around 2.5 x more than pediatrics. Other goals for AYA: prevent delays in diagnosis, encourage clinical trial participation, provide psychosocial care, provide palliative care, fertility preservation, delivery of support and resource materials to patients.

## **Specialized treatment unit**

Unit must be located in a functional facility. Design must be efficient and an effective use space.

Core: Provide the best medical treatment ... then practicality ... then control, comfort, stimulation – things they enjoy, personalization, connectivity – friends, school.

Guidelines/standards: Optimal diagnosis, improving outcomes, reducing morbidity, enhancing supportive multidisciplinary care, increasing research and supporting patients and families.

Components 1: multidisciplinary team drawing from pediatric and medical oncology, Defined pathways and referral procedures, Supportive clinical care, Psychosocial support, Survivorship support, Long term follow-up and management of late effects.

Components 2: transitional care, specialist PC, fertility preservation, research, insurance advice & support.

The group decided to call the project the “Fort Worth Experience”

**How we arrived today:**

March 2013: Unit was identified as one of the top three priorities to address for the coming year.

February/March 2014: Prospectus written, evaluation team selection

June/July 2014: Evaluation team analyzed data and leadership team visited sites.

July 2014: 10 out of 13 members voted for Baylor. MOU process started.

Memorandum of agreement will have to be a definitive agreement. Agreement needs to be done before anything irrevocable being done. Fundraising asks, remodeling/building, etc. Dr. Klein indicated he is very close to finalizing the MOU.

**Committee structure:**

Operations, Fund Raising, Marketing, General, Facilities.

Leadership team meets every 2 weeks

Steering Committee (co-chairman of various committees) will meet monthly to review. Baylor + coalition members on the teams.

**Tour of AYA Unit**

Comments from the tours included:

1. Space was one concern, that the program may outgrow the existing space
2. Good potential to take the last room and open into a commons
3. Positive feel with the window area
4. Rooms large enough to add Murphy bed? Becky indicated it should be.
5. Need retreat space for families ... Dr. Klein suggested using the family room on the other end of the unit.

*The group divided into their teams, the chairs and members met and brainstormed. Outcomes are listed below:*

**Operations:**

Committee needs to set competencies: how to interview and continue. There needs to be plans for Patient Pathways: how to get them connected and take them through journey –how to help manage their disease and empower their friends with information on their condition. Certain procedures need to be put in place: how to handle on unit, what are the rules? Need to gather information for quality, tracking metrics, national benchmarks. Next would be to create a plan for integrating the EMR to share data with all providers involved. Begin looking into clinical research and learn how to get patients enrolled into trials. Create a list of interdisciplinary team members by scanning through all aspects of the health system: nurse managers, psychology, social work, trainers, child life, nutrition, educators, etc. Alternative medicine was also recommended.

## **General**

Unit needs to have an Advisory Board, which would consist of key leaders within the community, ambassadors, and possible philanthropists. This group would aid with outreach into the community. Next step would be to create partnerships with all non-profits, young leadership groups, universities, payors, chambers, physician relations and outreach, TMA, etc. Would like to see AYA on the road, doing outreach and education to other teens & young adults. Unit would need to have a concierge approach .. navigation, guest relations, family relations, community resources.

## **Facilities**

Members on the facilities team would like to reach out to units who are up and running ... look for innovation. Also need to communicate with TDH on regulatory standards ... especially if we are doing bone marrow or not? Dr. Klein said to keep separate for now, but we need to have the facility ready for those type rooms. Facility will have a need for additional procedure space. Technology upgrades is important; making sure we're able to meet their needs. Facility needs to be AYA friendly, and we have a good understanding of what that means. Not only does there need to be control for the patients, but also the families, to make them feel like they're in control as well. Need to recruit an innovative expert with IT and/or an advisory group for connectivity of young adults. Another thing to consider is, some of these patients may have small children. Need to be conscious of that as well.

## **Advertising**

Branding is the first and foremost priority. What we are, how we're doing it, etc. Everyone's getting together to make it happen. Planning for press releases, printed materials, etc. That will start mission patient ambassadors - local Fort Worth survivors, that would get out in the community. We also need to look for possible celebrity spokespeople – local and outside DFW to promote. The most important priority is getting the young people on board. Need to focus that this is a conjunctive efforts from 3 hospitals for the community – not just Baylor.

## **Fundraising**

Reach out to top donor prospects. Research prospects from all facilities; include naming opportunities. Need to approach key foundations: this would be attractive since this is a collaborative effort from all local health systems. Later down the road we can start planning fundraising events in the community. We need some general idea of how much to ask. It was mentioned that capital and operations should be 2 different asks. It was suggested having a component included that focused on research.

Karen encouraged chairs to meet within the next couple weeks. The planning committee will get with you in the coming month. Continue with our task list.