



## **MEETING MINUTES**

Monday, October 20, 2014 --- 5:30 P.M.

UNT Health Science Center MET Building Rooms 109 - 111

### **ATTENDEES**

FWAYAOC Officers and Staff

- Karen Albritton (Chair), Paula Fultz (Vice-Chair), and Shana Berenzweig (Staff)

FWAYAOC Members

- Lisa Bashore, Paul Bowman, Brittany Doering, Britton Douglas, Prasanthi Ganesa, Stacey Guillen, Keith Hamilton, Laurie Hamilton, Becky Hardie, Amanda Hodges, Bill Jordan, Chris Jordan, Sally King, Suzy Lockwood, Rachel Masters, Sophia Mata, John Nugent, Stuart Pickell, Lisa Queralt, Laura Rutledge, Sue Shields, Glenna Stone, Amber Stroupe, Lesley Sweeney Weems, Liberty Taylor, Carly Witulski

### **WELCOME**

FWAYAOC Chair, Karen Albritton, called the meeting to order at 5:30 pm and reviewed the Coalition's mission and vision, as well as the agenda for the evening.

### **AYA INPATIENT UNIT UPDATE**

MOU --- Dr. Albritton provided an update on the status of the Memorandum of Understanding (MOU) with Baylor All Saints by beginning with review of what will be covered in the MOU and what will be included in a more detailed and comprehensive Unit Agreement, such as financial arrangements. The MOU is almost ready to be signed, just finaling the unit's title and awaiting approval from Baylor corporate. Also mentioned was the unit marketing efforts and how Coalition members will have access to PR materials.

IMPLEMENTATION TEAMS --- Dr. Albritton also discussed the governance and Implementation Teams for the development of the unit.

- *AYA Unit Leadership Committee* meets every two weeks and is composed of the three FWAYAOC officers and one staff member, Shana Berenzweig, and Dr. David Klein, Beckie Hardie, and Stacey Guillen from Baylor.
- *AYA Unit Steering Committee* is composed of the Implementation Co-Chairs and the Leadership Committee, and meets monthly for team progress reports.
- *Operations Team* will address issues of unit staffing, operational plans, policies and procedures, taking into account the requirements of hospital regulations and guidelines for AYA centers of excellence
  - Co-Chairs: Teresa Clark (Cook Children's), Ellen Pitcher (Baylor All Saints), and Sue

Shields (THR Harris)

- *Facilities Team* will address the design and build out of physical unit
  - Co-Chairs: Stan Davis (Cook Children's) and Janice Walker (Baylor All Saints)
- *Fundraising Team* will develop and implement fundraising opportunities to support the capital and operational needs of the Unit.
  - Co-Chairs: Kristie Gibson (Baylor All Saints) and some TBD from Cook Children's.
- *Marketing Team* will promote Unit in the communities served by Hospital and Coalition
  - Co-Chairs: Debbie Dolan (FWAYAOC community) and someone TBD from THR Harris.
- *General Team* will maintain an overall view of the unit project and mobilize Coalition membership and community to tasks as needed.
  - Co-Chairs: Amy Hailey (THR Harris) and Lori Drew (Moncrief Cancer Institute)
- A contact list for the AYA Unit Steering Committee was handed out and is additionally posted on the 'Members' section of the FWAYAOC website.
  - ***ACTION ITEM: If you have input on the AYA Unit, the preferred and best way will be to please get in touch with the appropriate Implementation Team Co-Chairs. A contact list will be email to you as well as posted on the 'Members' section of the website.***

FUNDRAISING --- Dr. Albritton also discussed that there will be some overlap between fundraising for the AYA Unit and the Coalition. However, she also stressed the need for more fundraising efforts on behalf of FWAYAOC. A budget for the Coalition and its programs are in the works. She also mentioned that, while the details have yet to be worked out, there will most likely be designated, separate bank account for the AYA Unit. And finally, Dr. Albritton told the group about a Young Texans Against Cancer (YTAC) grant she applied for on behalf of FWAYAOC to create a 'New Patient Notebook' and a Peer-to-Peer Mentoring program.

## **FWAYAOC**

COALITION PRIORITIES --- Dr. Albritton remarked that besides the AYA Unit, there is a lot more to do programmatically with FWAYAOC, and she then reviewed the priorities and what has been accomplished thus far.

### *1. Awareness and Marketing*

- a. Branding, Speaker's Bureau, and Philanthropy.
- b. Accomplished so far --- AYA Awareness Week; TCU 15-40 Club; Website; and New Logo, Stationery, etc.

### *2. Decrease Time to Oncologic Care*

- a. Educate primary care providers of incidence of cancer in AYAs, most common cancers and their presenting symptoms, and appropriate oncologic resources in community if concerned about cancer diagnosis.
  - i. Mailing? Primary care conferences? Tarrant County Medical Society?
- b. Education of young adults (at TCU, other area colleges).
- c. Research with UNT primary care program into incidence and reasons for delay.

- d. Accomplished so far --- AYA Awareness Week; TCU 15-40 Club; Website; and New Logo, Stationery, etc.
- 3. *Develop AYA Unit*: in process.
- 4. *Age-Appropriate Patient Education and Resources*
  - a. Website; Smart phone app; Book ("Everything Changes" by Kairol Rosenthal); Resource list of local and national AYA resources.
  - b. Accomplished so far --- Website; Rutledge Foundation New Patient Backpacks; New Patient Notebook at Cooks; and Peer-to-Peer Mentoring at Cooks.
- 5. *Psychosocial Support*
  - a. Assess psychosocial status and needs near diagnosis.
    - i. Developmental maturity; Psychiatric co-morbidities; Risk-taking behaviors; Support systems; Social responsibilities (school, work, finances, transportation); Etc.
  - b. Reassess at certain time points in treatment and survivorship.
- 6. *Fertility*
  - a. Educate all new AYA patients of risk of infertility.
    - i. Use systematic "alert" as providers see new patient under 45; Have brochure of information for patient.
  - b. Provide new patient referral to preservation options when appropriate.
  - c. Discuss fertility issues with survivors.
  - d. Provide survivor referral to infertility options when appropriate.

After reviewing the priorities, Dr. Albritton opened the floor to a discussion of what the Coalition should focus on next.

- *Fertility* was suggested by Laura Rutledge and the group discussed the challenges of pursuing this goal and how a multi-prong approach is needed in order to be successful.
- *Decrease time to diagnosis* was suggested by Lisa Bashore and suggested a program at TCU related to this.
  - ***ACTION ITEM:** The group agreed to move forward with the following priorities: 1) 'Awareness and Marketing' perhaps via a Speaker's Bureau; 2) 'Decreasing Time To Oncologic Care' via the 15-40 Club and PCPs; 3) 'Patient Resources' via the YTAC grant; and 4) Fertility.*
- Young Adult Cancer Awareness Week - an ongoing programmatic Coalition activity.
  - ***ACTION ITEM:** Form committee to brainstorm on ways to raise awareness during first week of April 2015.*

COALITION FINANCES --- Dr. Albritton reviewed the current financial situation for the Coalition and the need for the Coalition to diversify the funds in beyond just Membership Dues.

- FUNDS (IN) Develop strategic plan - current revenue mix is Membership Dues, Grants, and Philanthropy
- BUDGET (OUT) - current budget mix of AYA Inpatient Unit, Programs, and

## Infrastructure

BYLAWS --- As was announced at the Coalition's Summer Meeting on 7.21.14, the bylaws are outdated and need to be reviewed and updated.

- *ACTION ITEM: Bylaws will be voted on at the next meeting in Spring 2015.*

501C3 NONPROFIT STATUS --- Dr. Albritton remarked that FWAYAOC is in good standing with Healthy Tarrant County Collaboration (HTCC), but as the Coalition continues to grow and mature, we need to eliminate any potential confusion between the two organizations. We need more a formal structure as the Coalition moves forward, thus we are in the process of preparing our 501c3 application in order to be our own independent nonprofit.

OFFICERS --- As was discussed at the Coalition's previous meeting on 7.21.14, the current bylaws require re-election of officers (Secretary/Treasurer in 2014, Vice-Chair in 2015). Dr. Albritton offered two options: 1) to proceed with nominating new officers or 2) suspend the bylaws and allow the current officers to continue to serve.

- *ACTION ITEM: A motion was made by Sue Shields to suspend the bylaws and allow the current officers to continue. Dr. Ganesa seconded the motion and there were no objections.*

## OTHER BUSINESS

Additional updates were given on AYA activities by the Coalition and in the community.

- The Coalition co-sponsored speaker Dan Shapiro with Rutledge Foundation. Dr. Albritton suggested that perhaps this type of event could be a future opportunity for AYA speakers.
- Dr. Albritton and FWAYAOC Director Shana Berenzweig are both attending the Critical Mass Meeting in Denver on Nov 12-14, 2014.
- The Rutledge Foundation is coordinating 100 tickets to the FW Rodeo. This is another opportunity for the Coalition to partner/join on the event.
- In the spring will be the DFW Young Adult Cancer Survivor Conference (March 7, 2015) at UTA.
- The WHO is coming to Dallas on May 2, 2015 at the AA Center (\$1 of every ticket will go to Teen Cancer America). This is potential opportunity for FWAYAOC to auction off a suite and/or take some kids. More information to come.
  - *ACTION ITEM: Coalition Members are asked to please let the Coalition leadership know if they know anyone with a suite.*

## ADJOURNMENT

Meeting was adjourned by Dr. Albritton at 7:15 pm.