

TEXAS COMPREHENSIVE CANCER CONTROL COALITION

MINUTES

Tuesday, August 24, 2004

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| Mary Lou Adams, Ph.D., U.T. School of Nursing Joel Dunnington, M.D., M. D. Anderson Cancer Center Lewis Foxhall, M.D., M. D. Anderson Cancer Center Phil Huang, M.D., TDH Pam Jackson, M.S., Intercultural Cancer Council Judy Jonas, Ph.D., American Cancer Society Andy Miller, MHSE, CHES, Lance Armstrong Foundation Rosamaria Murillo, TDH Jane Osmond, Texas Cancer Council Juanita Salinas, M.S.W., Texas Department of Health Sandra San Miguel Majors, M.S., Baylor College of Medicine Tanya Skaarup, POEP Thom Sloan, MBA, Children's Cancer Research Institute Karen Torges, American Cancer Society Paula Traffas, TDH Jo Ann Ward, M.P.H., M. D. Anderson Cancer Center Armin Weinberg, Ph.D., ICC Anne Williamson, Texas Department of Health Sherry Woodard, NOEP Heather Becker, Ph.D., U. T. School of Nursing Susan Nenny, MPH, Project Coordinator John Hopkins, Texas Cancer Registry | Maria Fernandez, Ph.D., U.T. Health Science Center Jeannie Frieden, Cancer Therapy and Research Center Ramona Magid, MBA, Komen Foundation-Austin Margaret Mendez, TDH Lynne Nguyen, CIS Billy U. Philips, Ph.D., UTMB Amelia Ramirez, Dr.P.H., B.C.M. K. Vendrell Rankin, D.D.S., TAMHSC Carol Rice, Texas Cooperative Extension V.O. Speights, M.D., Scott & White Elizabeth Sjoberg, Texas Hospital Association Nancy Weiss, Ph.D., Texas Cancer Registry |
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Dr. Foxhall welcomed the members. The minutes were distributed as amended.

Coalition Membership

Dr. Foxhall reported that the Executive Committee met to discuss membership. In anticipation of the November Strategic Planning meeting, seven individuals were invited to join the Coalition.

- Thom Sloan, Administrator, Children's Cancer Research Institute
- David Euhus, M.D., UT Southwestern, Dallas
- Barry Feig, M.D., M. D. Anderson Cancer Center
- David Boldt, M.D., Interim Director of SACI, CCRC, Chief, Division of Hematology
UT Health Science Center, San Antonio

- Angelina Esparza, RN, Program Director, Community Relations Center for Research in Minority Health, M. D. Anderson Cancer Center and Board member, Hispanic Health Coalition
- Davor Vugrin, M.D., Clinical Professor, Internal Medicine, Texas Tech University Health Sciences Center
- Karen Jackson, Sisters Network

MEMBER UPDATES

Sandra Balderrama, Executive Director, Texas Cancer Council. The TCC staff is in the midst of the legislative process. Ajay Castro has resigned from the TCC Board and the Coalition. Sandra welcomed input from Coalition members.

Jane Osmond, Texas Cancer Council. A TCC priority activity is the update of the *Texas Cancer Plan*. She thanked the Coalition for participation in the update process. The board has just approved 2005 program funding for continuing programs and an additional five new programs, including tobacco and children's outreach through public television.

Thom Sloan, Administrator, Children's Cancer Research Institute. CCRI was established in 1999 with funds from the tobacco settlement's \$200 million endowment. Capital construction and staffing have been priorities. Move-in occurred in January 2004. Three labs are operational, and three Principle Investigators have been hired with a goal of 15-20 PIs. The Institute's major research component is cancer prevention and control research studies. The Pediatric Cancer Colloquium July 16-17 brought pediatric oncologists together to discuss common research agendas. It was attended by 40 people, from most major pediatric programs statewide. These programs working together create an opportunity to look at pediatric oncology statistics and work is beginning in that area. Preliminary pilots at Children's Memorial in Dallas are putting together registry-type information for children's cancer, going above and beyond state registry level.

John Hopkins, Texas Cancer Registry. TCR's main goal is improvement in quality and completeness of data to achieve Gold Certification from the North American Association of Central Cancer Registries, NAACCR. M.D. Anderson Cancer Center is providing two certified tumor registrars to address a work backlog. The University of Texas Medical Branch at Galveston has hired a person to perform case finding and abstracting for small facilities with caseloads of less than 100 in 16 Southeast Texas counties. Texas A&M School of Rural Public Health is working to help establish a border registry in McAllen. Baylor College of Medicine and M.D. Anderson Cancer Center provided two interns to survey exemplary state registries. After meeting with the Governor's Office, Commissioner Sanchez asked the TCR to establish a small ad hoc work group to consider funding options for the TCR in advance of the upcoming legislative session. The Governor's office has opened the door to consider all options for the Registry and its improvement efforts. The nucleus of the work group will come from the Cancer Data Work Group.

The Registry has conducted training sessions for cancer reporters in three locations this summer, with two sessions remaining before the end of August. The training is provided under contract by the Emory University's School of Public Health. Updated cancer reporting software and manuals are being distributed via CD, revision pages to the cancer reporting handbook are being distributed, and staff members are concluding an independent pathology lab pilot project to collect data from path labs. A second phase is physician follow-back testing, which just began. The Registry will receive

\$282,900 in one-time Preventative Health and Health Services Block Grant funds for a project beginning in October to hire contract Certified Tumor Registrars to collect data at approximately 200 small cancer caseload facilities statewide. This is being coordinated with the UTMB-Galveston circuit rider abstractor to avoid duplication.

The 2000 cancer incidence report and the 2001 cancer mortality report are available and posted on the web. (<http://www.dshs.state.tx.us/tcr>) The NAACCR Call for Data is due December 3, 2004 for certifying 2002 data.

Heather Becker, UT School of Nursing. Dr. Becker is under contract to TDH to provide evaluation of the Cancer Control program. Her yearly evaluation report was submitted July 2004 and included activities of the Coalition as well as those of TDH CCC Program. She will provide a summary of her findings before the retreat. Heather thanked everyone who responded to the survey (28 members or 80% of the membership).

Two focus groups were conducted in June in Del Rio and Wichita Falls. Findings were consistent with the SUMA/Orchard forums conducted in other communities. Participation was great and included librarians and ACS personnel as well as many others. Participants described many challenges, for instance, Del Rio's one clinic serving a 150 mile area, and the treatment difficulties when breast cancer is diagnosed outside of the BCCCP program. Both groups emphasized that traditional written materials (even those in Spanish) are not as effective as information delivered to people verbally. Both communities have an advantage being in small media markets. They want to know what works in other areas. The Coalition could use this opportunity to share members' expertise which these communities want. Participants felt a regional health conference had some promise. Local coalitions were viewed as a good idea, but most people are fully engaged, and leadership is a challenge. Juanita Salinas (TDH) will follow-up on coalition issues. Participants had not been aware of each others' activities in some cases. Virtually no one knew about *Texas Cancer Plan*. Participants would like technical assistance and want to be sure their activities fit their communities.

Judy Jonas, American Cancer Society. The update of the Texas Facts and Figures document has been a major focus. It is in final review and will go to press next week. Community assessment e-tool Version 3 will be out in its third and final CD version before it goes web-based. It will also link to Cancer Planet. The National Cancer Data Registry provided data to augment local data. Texas is one of 25 states that won't be on Cancer Planet because of the state's data limitations.

CCLI series continues with the third to be held at the end of September in California with 14 states participating. Judy will be attending.

Sherry Woodard, Nurse Oncology Education Program. NOEP is gearing up for its fall schedule. The full schedule September to May will offer 40 conferences. A grant proposal on childhood survivorship is due to the LAF in September. Red Book CCNT chemotherapy material will be out end of September. Sherry asked the group for suggestions and contacts in communicating with Schering about a lingering 2002 grant commitment, which was renewed 2004.

Armin Weinberg, Baylor College of Medicine & Intercultural Cancer Council

ICC will be releasing in September a health professionals' pocket guide on cultural competency (probably in Tennessee) funded by HRHSA. Funding was insufficient for the large printing needed, and the agency is looking for inexpensive distribution opportunities. ICC fact sheets (<http://iccnetwork.org/cancerfacts/>) are available on a range of topics, including two new ones. Another upcoming sheet is on fatigue. ICC will be the recipient of International Spirit of Life Foundation Award in Washington DC on October 14, 2004.

University of Houston students have formed a student ICC organization and hope to replicate the existing ICC. Members are highly motivated, already chartered, and have a faculty advisory Whitney Boling PhD. (see contact information above)

The TMA POEP is conducting two physician Talk Back surveys through POEP, one on obesity and one on pain management.

The CATCHUM executive committee recently met. Its NCI funding was renewed, and the program will be developing additional resources – 16 or so modules for students. Texas is the only state we know of in which all medical schools collaborate through this mechanism led by Dr Billy Phillips at UTMB.

Dr. Weinberg reported on the C-Change: Collaborating to Conquer Cancer organization (former National Dialog on Cancer) meeting highlights: 1) Prevention Task Force, 2) a CEO Roundtable which would develop gold standard for employee benefits. Former President Bush asked Bog Ingram to organize top level CEOs to discuss cancer benefits for employees, i.e. screening, early detection and coverage when appropriate for clinical trials. They developed a Gold Standard Benefits Program. These CEOs could effect 20 million lives. Dr Weinberg suggested that the Coalition organize Texas CEOs to replicate this process. 3) Dr. Mark Clanton presented the Trans DHHS PRG Cancer Health Disparities Progress Report "Making Cancer Disparities History" which should be reviewed in detail by the Coalition to determine how we can anticipate changes that we can participate in as well.

Baylor College of Medicine: The transition with a new teaching hospital continues and is beginning to come together. Staff positions are changing but will continue to seek designation as an NCI comprehensive cancer center. The new teaching partner, St. Luke's Episcopal Hospital and their charity foundation, bring a significant new partner to the process, including their web-based Community Health Information System (CHIS) and neighborhood health system.

President's Cancer Panel will conduct another panel in Texas on translational research on November 1st at M. D. Anderson.

Sandra San Miguel Majors, BCM. Staff members have submitted the Redes in Accion grant and are awaiting the outcome, as well as writing smaller grants for community and national projects. They are completing edits of a book entitled Noestros Historios ? featuring 25 stories from breast cancer survivors of all ages, primarily Mexican American women in the San Antonio area. Many organizations have participated in this project which targets Hispanic breast cancer survivors and will be published in English and Spanish. Themes include family, faith, and inspiration for other women to cope with cancer. The staff is developing a distribution process for this free publication. Initial funding was a seed grant from the Susan G. Komen Foundation.

Tanya Skaarup, POEP. Content for two NCI modules (head and neck cancer and cervical cancer) are due for review in September. POEP will next focus on the *Cancer Plan* and initiating related programs, followed by projects of the TMA Summit and Cancer Registry issues. Talk Back surveys will feed into programming and planning activities. The pain management survey is working towards a Pain Management event. For 2005, POEP will be networking with county medical societies, taking exhibits and programs to their annual meetings to improve contact and usage.

Joel Dunnington, TMA/ M. D. Anderson Radiology. Cancer Symposium group meets in October to plan next year's conference, collaborating with POEP. Staff are working to make Houston smoke-free. A grant from the Robert Wood Johnson Foundation will fund the Houston symposium. They will be collaborating with other Houston organizations and City Council members.

Phil Huang, TDH. TDH will officially become the Department of State Health Services HSH next week with many changes to follow. Staff members are reapplying for their positions.

Activities continue regarding cancer.

1. Nicotine patches still available through the Quitline in Jefferson County. Fax referral forms also work in Harris County.
2. In a special initiative, MCH staff are making rounds to physicians to encourage improved interaction with pregnant women to reduce maternal smoking. (Jefferson County.) The partnership for this project includes WIC and others.
3. State of the art smoking ordinance data base working with U of H is complete and will be online in September, listing and ranking various anti-smoking ordinances.
4. Media campaigns are under way in pilot areas. The Paso Del Norte Foundation may fund continued airing of messages. Other entities are also looking at using them.
5. The Austin Fire Department contacted TDH because all fire deaths in Austin are smoking-related.

TDH is also working with C-Change on recommendations to 1) elevate priority of tobacco among C-Change, and 2) partner with AHRQ to work on early detection and prevention, bringing in CEO partners to gather support for evidence-based programs and to move organizations from dialog to action.

Karen Torges, ACS. The ACS nationwide prioritization continues through a sophisticated process. Now each individual division will address action planning within national plan. Texas ACS observed that process and strategized about collaboration with others and outreach to existing entities, such as schools and hospitals to enhance impact. Last year ACS focused on work place, schools, health systems (starting with hospitals), faith and community-based settings.

ACS Texas is considering merger with Oklahoma, Missouri, Nebraska and Kansas, a regional consolidation trend which has been seen nationwide.

Andy Miller, Lance Armstrong Foundation. In his new position as Director of Public Health, for LAF, Andy oversees activities on a national level, which have implications for local activities. Overview: Nationally LAF has joined a number of national organizations to become a partner of the Comprehensive Cancer Leadership Institute and is working to bring survivorship to forefront in CCLI gatherings. The National Action Plan for Cancer Survivorship (distributed to Coalition) is in a

dissemination phase. An LAF strategy is to work within existing structures to implement priorities. CCCCPS are target audience nationwide to assist them in integrating survivorship priorities into their Plans. Another activity to strengthen state cancer coalitions is to provide grants to community coalitions. This year LAF funded about 40 community organizations in 26 states. For the first time, the agency is trying to draw connection between state coalitions and community organizations. The goal is sharing and partnerships with larger coalitions to increase awareness. In Texas, the President's Cancer Panel will be held in early November in Houston. Topics for next year's series of President's Cancer Panel include comprehensive cancer control projects. LAF will try to get Texas as a site for one of the meetings. The Ride for the Roses in October 17, with a goal of 5,000 riders, is the culmination of fundraising. Another ride is the Tour of Hope, a program created by Bristol Meyers Squibb and others which focus on creating awareness of clinical trials and increasing enrollment, culminates in Washington, D.C. Twenty riders with unique connections to survivorship will ride with Lance. A radiation oncologist from Pasadena TX and UTMB has been selected for this group. The call to action is to get as many people as possible to sign the cancer Promise supporting clinical trials.

LAF hosted its first conference of about 75 LAF-funded organizations for a weekend of capacity building activities, i.e. fundraising, building boards, etc. Prior needs assessment guided the agenda. Goals were to increase capacity and competency and to facilitate building community of organizations addressing survivorship.

The success of the Yellow bracelet project was completely underestimated.

Jo Ann Ward, M. D. Anderson Cancer Center Jo Ann will notify members about the November 9 President's Cancer Panel topics and opportunities for individual participation. The event will be held at M. D. Anderson, with Dr. Margaret Kripke hosting.

The Texas Cancer Plan Survivorship work group is making good progress, using the LAF/CDC Plan, the NCI President's Cancer Panel 2004 reports. The concept of caregiver as survivor is inconsistently conveyed among these three. The TCP will adopt the LAF/CDC definition that includes caregivers as survivors.

The September 9-11 Annual Anderson Network Cancer Survivor Conference will be held at the Sheraton Houston Omni Hotel and will draw about 600 – 800 survivors nationwide. Registration is still open and can be done on-line.

On behalf of Lynne Nguyen, Jo Ann reported that the Cancer Information Service contract renewal covering 17 central states is in its third iteration, with award notification expected in December.

Latin pop singer and breast cancer survivor, Soraya, will visit M. D. Anderson in conjunction with the Race for the Cure. She has a national contract with Komen Foundation and might be an access point for Hispanic breast cancer education funding contacts.

The Public Education Office has launched a puppet program for grades K – 3 in Houston area schools and community centers to teach kids about the dangers of tobacco. The program has reached about 1,000 kids in four months.

Paula Traffas, TDH. A fact sheet on tobacco use in day care centers was distributed noting that tobacco is not to be used in day care homes and centers.

Mary Lou Adams, UT School of Nursing. The Breast Cancer Awareness program focuses on minority women's breast cancer screening. Staff members are working with TDH to expand community programming. Mary Lou has recently devoted some time to the establishment of the Travis County Health Care District.

Rosamaria Murillo, TDH BCCP. The BCCCP competitive grant process brought in additional contractors, including Planned Parenthood El Paso, Llano County Hospital, Texas Tech, Community Health Dallas, and Planned Parenthood Lubbock. Contractors' orientation was completed. Staff are committed to educating providers about breast cancer plan. A CDC site visit in November will include interaction with BCCCP contractors. CDC visitors will be validating data submitted by BCCCP. Awareness activities for breast cancer will take place the first Tuesday in October. BCCP is collaborating with other agencies to provide clinical and didactic training.

LUNCH

Program "Texas Cancer Registry: Recent Training Outcomes and Observations"

John Hopkins, TCR, reported on the Cancer Reporter Training conducted this summer by Emory University School of Public Health. The training was designed to provide technical assistance to state cancer reporters on both basic and intermediate levels. Three trainings in Houston, Austin, McAllen are complete. Training in Irving and Tyler will be completed shortly. About 126 individuals will participate in the five events. Stipends improved rural participation. The courses qualified for 12 continuing ed hours from the National Cancer Registrars Association.

Evaluation included pre- and post testing as well as participant subjective comments. The greatest improvement in knowledge was among those with minimal experience in cancer reporting. The training was rated excellent (87.5%) or good (12.5%) by 72 responding attendees in the three sessions completed to date.

TCR has 25% vacancy rate at this time. Certification by NAACR is a priority focus, and trained reporters are critical to the quality and completeness of data. Future plans include recruitment/retention of certified tumor registrars, a web-based training module, and partnerships with allied health schools to provide training.

TDH/TCC Tool Kit Update

Juanita Salinas reported that the Tool Kit subcommittee of the *Texas Cancer Plan* Steering Committee will meet Friday and is working with a contractor (Interlex) to advance the project. Content has been narrowed. The tool kit's purpose is to provide information resources to communities about how to implement cancer control, and it is due to be completed by December.

TDH Community Projects

Juanita reported that working on breast and cervical cancer is of great interest in Tyler and Lubbock, the communities in which she has been working. Tyler wants to continue to meet and become more organized as a coalition. Lubbock has met once and will meet again in September. TDH is working

with the Health Lubbock Initiative which already promotes health living. Jefferson Texas (Marion County) will be the other location and has fewer resources.

Juanita attended the CDC Program Conference in June. The main focus was to share what national partners were doing. For comprehensive cancer control, the info provided is general. There are 52 funded programs, with about half in planning and a few in implementation. The emphasis was on evaluation.

CDC Site Visit

The CDC's site visit is scheduled for Nov 15 – 19. The program officer may want to meet with Coalition partners. Susan True may be attending also.

CDC Implementation Visit

Juanita Salinas reported that the CDC will visit in the spring. Also a genomics project will interview TDH about the *Texas Cancer Plan*.

Texas Cancer Plan Update Update

Dr. Foxhall thanked all who have been helping with the update of the *Texas Cancer Plan*. The agenda has been moved forward by the update process. Information continues to be collected to add to Coalition data. Health Disparities and Survivorship work groups are working hard. The Steering Committee has met several times and will meet Friday to review information developed in larger input meetings. The format will be refreshed and text completed this fall.

November 3-4 Strategic Planning

Susan Nenney briefly discussed the November 3-4 planning retreat. The goals will encompass recommendations in Heather Becker's evaluation report, including infrastructure basics (by-laws, membership), strategies, partners and activities for the next two years, and implementation of the *Plan*. SUMA/Orchard will donate a coffee break to the event.

Coalition Projects Update and Information

Susan reported that the 2005 linkage letter is drafted and will be distributed by e-mail for agency use. Draft copy for the educational brochure has been distributed to the Executive Committee and will be shortly distributed to all members for feedback. It is scheduled to be published by the November retreat. A new travel reimbursement form was distributed for use in the current Coalition year.

Other Business

It was agreed that a Certificate of Appreciation would be developed for Coalition acknowledgement of individual support.

Future agenda items were suggested including

1. GAP Global Access Project
2. Linkage with US Conference of Mayors which has taken on cancer issues.

The meeting was adjourned.

