



MINUTES - NM Cancer Council, Executive Committee
 Date: April 17, 2012; 2:30 – 4:30 pm, NM Cancer Center, 4901 Lang Avenue, NE

NEXT MEETING:

ATTENDEES	<p><u>EXECUTIVE COMMITTEE MEMBERS:</u> Sandra Adondakis (American Cancer Society, Cancer Action Network) Susan Baum (NM Department of Health) Remona Benally* (Breast Cancer Resource Center) Nathan Bush (American Cancer Society, Cancer Action Network) Barbara Damron (Damron Oncology Consulting) Jahaan Martin* (Breast Cancer Resource Center) Barbara McAneny (NM Cancer Center) Maria Otero (UNM Cancer Center) Beth Pinkerton (NM DOH Comprehensive Cancer Program) Susan Simons (Susan G. Komen for the Cure, Central NM) – Acting as Chair Terri Stewart* (NM Cancer Care Alliance) Patricia Torn (Cancer Support Now) Robyn Viera (Individual Member) Hugo Vilchis* (NMSU Border Epidemiology Center)</p> <p><u>OTHER PARTICIPANTS:</u> Christine Brown (NM DOH Comprehensive Cancer Program) Paul Sanchez (NM Oncology Hematology Consultant)</p> <p>*Participation via conference call.</p>
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AGENDA ITEMS

AGENDA ITEM: I. WELCOME AND INTRODUCTIONS

ROBYN VIERA

DISCUSSION	<p>Robyn Viera welcomed everyone; brief introductions were made by everyone present.</p>
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AGENDA ITEM: II. EXECUTIVE COMMITTEE ACTIVITIES

ROBYN VIERA

DISCUSSION	<p>Robyn Viera confirmed that everyone had received and reviewed the minutes from the February meeting. Susan Baum recommended the minutes be modified slightly to more accurately reflect the Council's logistical inability to accept an invitation to host a meeting in Carlsbad, per the request of Jeffrey Diamond. With these changes, Susan Baum motioned to approve and Barbara McAneny seconded. The minutes were approved with no additional changes.</p> <p>Robyn reviewed the following action items.</p> <ul style="list-style-type: none"> • Forward links for more information about cancer drug shortages to Beth: This was done. • Post links for more information about cancer drug shortages on web site and address in next meeting: This was not completed. <p>Dr. McAneny provided some information about the current drug shortage and the FDA User Fee Act (which funds the FDA). The AMA has taken the drug shortage issue on in an attempt to get the FDA to address it. It is a significant financial issue for drug companies who want to be paid for</p>
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	<p>what they do. There is no profit in producing cheap drugs. CMS has been made aware of this; however, it is unclear what they'll do with the information. The Cancer Council may be limited in what it can do to address the drug shortage problem. No action to be taken by the Council at this time.</p> <ul style="list-style-type: none"> • Draft prepared statement around drug shortages: Not completed at this time, but PR Workgroup will address it when the time is appropriate. • Contact Mr. Diamond to decline invitation: Robyn followed up with Dr. Diamond about this. • Discuss palliative care at next EC meeting: To be discussed later in the meeting. 	
DISCUSSION	<p>New Member Application: Geri Schmotzer applied in an individual capacity; Barbara McAneny motioned to approve Geri as a new member of the NMCC and Susan Baum seconded. An application from Ana Portillo from the Leukemia and Lymphoma Society was reviewed and approved. This new member application does not technically need to be voted on since she is part of an organization that is already a member.</p>	
ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
February meeting minutes to be modified slightly re: Council invitation to Carlsbad	Beth	May 31

AGENDA ITEM: III. UDAY DESAI, PHD, GUEST: CANCER COLLABORATION NETWORK STUDY

DISCUSSION	<p>A presentation was provided by Uday Desai and his colleague who are staff from the UNM MPA program on how collaborative partnerships enhance cancer service delivery. Prior to their presentation, Terri noted that these researchers found the Council by contacting the NMCCA which was found through the online ACC Directory. Terri thought the researchers want the Council leadership (or a leader in the oncology community) to send a letter of support from the Council for their survey when it's sent out to the target audience, but expressed uncertainty about what benefit the survey would ultimately have for the Council (and organizations responding to the survey). Barbara Damron also expressed some concerns with the survey, including methodology.</p> <p>The presenters indicated that the survey should allow them to assess the extent to which cancer organizations are working together, how they are linked, how new knowledge is translated into practice and how organizations adapt to new information and knowledge. The intent would be to use this information to improve organizational performance.</p> <p>EC members expressed various concerns about the survey: the questions as they are currently worded won't provide the kind of information the researchers want; physicians won't respond because it's too cumbersome and there's no incentive; the questions didn't seem relevant to certain organizations; there is uncertainty about how the survey was developed and whether pilot-testing had taken place; there is uncertainty about who the information would ultimately be shared with and that clarification is still needed on the target audience.</p> <p>It was suggested that they partner with an expert to assist them in revising and improving the survey using a structured methodological approach.</p>
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	The decision was made to let the researchers edit the survey and request Council assistance again in the future if it's needed.
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IV. OTHER BUSINESS

**AGENDA ITEM: A. CANCER COUNCIL MEETING FEB. 23 FOLLOWUP ROBYN VIERA/ALL
B. SUSTAINABILITY TRAINING (IDENTIFY DAY 2 PARTICIPANTS)**

DISCUSSION	<p>Robyn applauded the success of the February meeting and the good attendance. Robyn commended Sandy on her thorough overview of the 2012 Legislative Session and Susan Baum and Laura Tomedi on their cancer survivorship presentation.</p> <p>June 13th and 14th will be the date for the Sustainability and Collaboration training. Shelli Bischoff and Deborah Openden will be the facilitators. The EC needs to determine who will attend day two. This will be a leadership group, capped at 20 participants. Everyone who attends day two needs to have participated in day one. Are there other non-EC people we know that should be at this training?</p> <p>Robyn proposed inviting new EC members (as well as existing members) to the June 14th training, but it must be made clear that folks must be willing to attend two days. Beth will send out an email to entire EC requesting they let her know if they're interested in attending the two days. This will allow us to see how many remaining slots (if any) we have left in which to fill with "new" members.</p>
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AGENDA ITEM: V. UPDATE ON 2011 COUNCIL PRIORITIES

DISCUSSION	<p>A. Cancer plan revision: Beth Pinkerton The Native American workgroup is developing an implementation guide for the Cancer Plan and will host a day-long meeting to discuss writing a section on how to use the Plan in Native Communities. They will be using approved goals to guide these efforts.</p> <p>A few issues came up regarding objectives in the current Plan draft and their lack of data sources. The first objective is: <i>"Improve healthcare providers' ability to educate patients about hereditary cancer risk assessment including genetic testing and counseling, by 2016 by conducting XX numbers of training sessions for primary care providers."</i></p> <p>Beth spoke with a genetics counselor at UNM who said these types of trainings were feasible because she and the VA are doing this type of training. Dr. McAneny also stated her practice is doing this. She also said that conducting genetic testing in Native communities is difficult due to cultural beliefs that may translate into barriers. The NMCC received a grant to conduct cultural sensitivity trainings around talking about cancer in Native communities.</p> <p>The second objective in question is <i>"Raise awareness about hereditary risk assessment, genetic testing, and genetic counseling among the New Mexico population, by 2016."</i> Dr. McAneny stated they also do outreach and education of</p>
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the public about this, but the group agreed that this objective as written (as well as the first) is difficult to measure, so perhaps it will remain “un-measurable”.

One suggested change to these objectives is to use the term “family history” instead of “hereditary risk assessment” which may be more meaningful to people.

Susan Baum will work with Beth on revising the second objective.

B. Survivorship Care Plan/Treatment Summaries: Patricia Torn

Beth Brown, chair of the Survivorship Workgroup, has resigned and so the group is looking for a new chair. The group continues to work with Patient Navigators and other professionals in similar roles to supply them with information helpful to their patients.

C. Sustainability of cancer control operations and services: Robyn and Susan Baum

Once we have the Council trainings on June 13th and 14th, we’ll have a clearer picture of how to address Council sustainability.

Also, Susan Baum provided some clarification on some information shared during the Council presentation on cancer survivorship. Some confusion exists about an accurate, up-to-date number of cancer survivors in New Mexico. There is no gold standard and will differ depending on what measure is used. Chuck Wiggins with the NM Tumor Registry suggested using BRFSS estimates rather than Registry data. The main reason for this is that Registry data only captures people whose cancer was diagnosed in NM and may miss a significant number of survivors who were diagnosed outside of NM but moved to the state afterwards. BRFSS tends to overestimate cancers. A range can be used to cite survivor numbers: A lower range (using Registry data) or an upper range (using BRFSS data), recognizing that the reality is somewhere in between.

Susan will be on the EC agenda for the next meeting to discuss this issue in more detail.

D. Council Operations

Robyn went over the list of EC members whose terms are expiring on June 30th, 2012. Currently we have eleven members whose terms will be up. If they choose to continue, their names will go on the ballot. The group discussed how to address the issues of inconsistent participation by EC members. Questions included how will attendance be enforced? Are member expectations clear and is there recourse if people don’t meet commitment criteria? The bylaws are absent of specific language that allows the EC to relieve members of their position due to inactivity and low participation in meetings. Susan Simons suggested developing a form or commitment letter that could be used to formalize EC members’ agreement to their EC responsibilities. Barbara McAneny expressed concerns that this new requirement may interfere with other critical job obligations and isn’t always feasible. Sending a proxy is an acceptable alternative for those unable to participate.

Susan Baum proposed developing a policy to acknowledge the gap in bylaws, but emphasize EC member obligations and responsibilities which newly elected EC members will receive. Susan Simons and Terri will work together on



	<p>developing this policy.</p> <p>Workgroup charters are on hold until the Plan is complete; however, a form was discussed to provide to the workgroups in lieu of actually presenting to the EC. Robyn will communicate with workgroups about how they'd prefer to report to the EC about their ongoing activities.</p> <p>Robyn also mentioned the Council's letters of support for the DOH's application to CDC for the Comprehensive Cancer Program and the BCC Program.</p>
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ACTION ITEMS	PERSON RESPONSIBLE	DEADLINE
Reword objective related to " <i>Raise awareness about hereditary risk assessment, genetic testing, and genetic counseling among the New Mexico population, by 2016.</i> "	Beth/Susan Baum	May 31
Ask workgroups about their preferred method of reporting to the EC about their activities.	Robyn	
Develop policy statement on EC member attendance	Susan Simons/Terri	

**AGENDA ITEM: V. WORKGROUP UPDATES
A. ACC**

BLAIRE LARSON

DISCUSSION	No report
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AGENDA ITEM: B. COLORECTAL CANCER

TRESA VANWINKLE

DISCUSSION	The workgroup discussed coordinating a scaled-down version of the "Undie 5000" race. Several concerns around this idea. Who would sponsor? (Costs can be very high.) The workgroup itself is very small, and Fred Pintz is stepping down from the position as Chair – probably not feasible. The main concern is that there are turf/competition issues related to raising money for any particular organization; this could harm the Council.
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AGENDA ITEM: C. NATIVE AMERICAN

REMONA YAZZIE

DISCUSSION	There is a meeting coming up this Friday, but no other update. Remona tried to give a phone update, but could not be heard through the line. She will send an email with meeting updates to the EC.
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AGENDA ITEM: D. POLICY & ADVOCACY

PAUL SANCHEZ

DISCUSSION	Paul Sanchez and Susan Simons will schedule a meeting.
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AGENDA ITEM: E. PUBLIC RELATIONS

MARIA OTERO

DISCUSSION	Working on first issue of cancer council newsletter. Should expect committee to review within next few weeks and to NMCC shortly thereafter.
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AGENDA ITEM: F. RURAL HEALTH ISSUES

BETH PINKERTON

	Hugo will send an email to the group.
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AGENDA ITEM: VI. COMMUNICATIONS FROM THIS MEETING

SUSAN SIMONS

DISCUSSION	No time to discuss this item.
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AGENDA ITEM: VII. MEMBER ANNOUNCEMENTS AND UPDATES

DISCUSSION	
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ADJOURNMENT	There being no time to further discuss, Robyn adjourned the meeting at approximately 4:30 pm.
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