

TEXAS BLEEDING DISORDERS ADVISORY COUNCIL MEETING
NOVEMBER 29, 2007 10:00 A.M.
TEXAS DEPARTMENT OF STATE HEALTH SERVICES
1100 W. 49TH STREET, AUSTIN, TEXAS
7TH FLOOR (M-739) – MORETON BUILDING

MINUTES

MEMBERS PRESENT

Patricia Amerson, R.N., Nurse
Elizabeth Bailey, CPC, CMC, Person or caregiver of a person with a clotting disorder
Katrina Daniel, Texas Department of Insurance, Commissioner's designee
Debbie de la Riva, M.Ed., Person experienced in diagnosis, treatment, care and support of persons with hemophilia or other bleeding or clotting disorders
Michael B. Farnell, Jr., Representative of a volunteer or non-profit organization
Charles P. Garcia, Person or caregiver of a person with hemophilia or other bleeding or clotting disorder
Brendan Hayes, Person or caregiver of a person with hemophilia or other bleeding or clotting disorder
Aliya Esmail Hussaini, M.D., Texas Department of State Health Services, Commissioner's designee
Katherine Lipsky, LCSW, ACSW, Social Worker
Mark J. Netoskie, M.D., MBA, FAAP, Representative of a health insurer or other benefit plan
Mary Evelyn Schuwerk, Person or caregiver of a person with hemophilia or other bleeding or clotting disorder
Maria E. Yu, Person or caregiver of a person with hemophilia
Susan Zappa, RN, CPN, CPON, Person experienced in diagnosis, treatment, care and support of persons with hemophilia or other bleeding or clotting disorders
Michael Rash, Person or caregiver of a person with a bleeding disorder other than hemophilia
Cynthia J. Rutherford, M.D., Representative of a hemophilia treatment center

GUESTS

Carol Cates, Texas Department of Insurance
Ricardo Garcia, Health and Human Services Commission, Government Relations
Kate Cross, Hillco Partners
Don Valdes, Health and Human Services Commission

STAFF

Carol Labaj, Texas Department of State Health Services, Purchased Health Services Unit
Jann Melton-Kissel, Texas Department of State Health Services, Specialized Health Services Section
Dina Ortiz, Texas Department of State Health Services, Specialized Health Services Section

Brian Castrucci, Texas Department of State Health Services, Office of Title V and Family Health

Mike Young, Texas Department of State Health Services, Office of General Council

Melonee Carter, Texas Department of State Health Services, Purchased Health Services Unit

Cattina Horn, Texas Department of State Health Services, Purchased Health Services Unit

Welcome and Introductions

Ms. Carol Labaj, Manager, Purchased Health Services Unit , welcomed council members and introduced herself. Council members and Texas Department of State Health Services (DSHS) staff members introduced themselves. Members of the public introduced themselves.

Opening Remarks

The first meeting of the Texas Bleeding Disorders Advisory Council was opened by Ms. Labaj at 10:06 a.m.

Review of Agenda and Packet Materials

Ms. Labaj reviewed the agenda and packet materials with the council members. Council members decided to have a working lunch due to time constraints and for the convenience of those members who needed to travel.

Open Meetings Training

A video on open meetings from the Texas Attorney General's Office was presented, outlining the basics of the Open Meetings Act and its requirements. Ms. Labaj informed the council members of their responsibility, as mandated by Senate Bill 286 (79th Legislature, Regular Session), to complete open meetings and open records training within 90 days of their appointment. Copies of the Certificates of Completion of the open meetings training were given to each council member for their personal files. Ms. Dina Ortiz presented the option to council members, as recommended by the Office of General Counsel (OGC), to complete the mandated open records training by completion of the delegation form included in the council packets. The delegation form designates authority to Patricia Reedy, Public Information Coordinator for DSHS, to take the training on the requirements of the Public Information Act on their behalf, as allowed by Senate Bill 286. Delegation forms will be maintained by DSHS. Certificates of Completion on the open meetings training will also be maintained by DSHS. Council members signed and returned their delegation forms to DSHS.

Ms. Labaj asked the council if they had any questions for Mr. Mike Young regarding the open meetings training or anything that relates to the legal aspect of the advisory council. Mr. Young addressed the council's questions regarding the history and different aspects of the Open Meetings Act.

Nominations and Vote for Chair and Co-chair

As mandated by Senate Bill 1566, council members shall elect from among the voting council members a presiding officer. Ms. Labaj asked the council to discuss whether or not they would like to have two officers, a presiding officer and a co-presiding officer. She stated that the only restriction in the legislation is that the presiding officer must be a voting member. The legislation does not state that a co-presiding officer must be a voting member. Mr. Young suggested that if there is going to be a co-presiding officer, that the member be a voting member so that, in the event the co-presiding officer needs to assume the presiding officer's duties, the legislation's requirement will be met. Council members voted to have two officers, Chair and Co-chair. Mr. Rash asked for information on what is expected of the elected officials. Ms. Ortiz read aloud the principle duties of a presiding officer from Robert's Rules of Order, Newly Revised, 10th Edition. Ms. Labaj added that a Chair and Co-Chair will assist staff in developing the agenda and that DSHS staff will have the Chair and Co-chair review most of the communications that are sent to council members. The Chair will be asked to review the meeting minutes before they are distributed as draft minutes to the rest of the membership.

Mr. Michael Rash nominated himself for Chair. Mr. Rash's nomination was seconded by Mike Farnell. Mr. Rash was elected by consensus vote for the position of Chair of the Texas Bleeding Disorders Advisory Council. Upon his election as Chair, Mr. Rash shared his background with the members. He stated that his interest is to insure that, not only the hemophilia issues are addressed, but also other bleeding disorders and clotting disorders. He also stated that he would like to raise awareness of the issues among people who may not know that they are affected by the disorders.

Mr. Rash asked for nominations for the position of Co-chair. Ms. Liz Bailey nominated herself for Co-chair. Ms. Bailey provided the council with her background. Mr. Charles Garcia nominated Mr. Mike Farnell for the position of Co-chair. Mr. Farnell provided the council with his background information. Dr. Mark Netoskie nominated Dr. Cynthia Rutherford for position of Co-chair. Dr. Rutherford provided the council with her background information. Seconds were obtained on all nominations.

Mr. Rash asked for a ballot vote for nominees. Dr. Cynthia Rutherford was elected as Co-chair based on popular vote.

Overview of Senate Bill 1566: Council Duties, Goals, Objectives, and Deliverable

Ms. Labaj presented an overview of Senate 1566 and its requirements of the Texas Bleeding Disorders Advisory Council. She discussed the composition and formation of the council. Ms. Labaj outlined the tasks of the council and discussed with them the end-product required by the legislation, a report on findings and recommendations. Ms. Labaj provided the council members with a timeline on the process and production of the report. She discussed with the council members the 5 points that are the mandated focus of the report:

1. Legislative or administrative change to policies and programs, including access to appropriate health insurance or similar health coverage.
2. Legislative or administrative change to policies and programs that affect product-specific reimbursement to providers, including new payment for anti-hemophilic factors in Medicaid program that provide access to appropriate treatment
3. Best practices in standards of care and treatment for persons with hemophilia and other bleeding or clotting disorders.
4. Establishment of community-based initiatives to disseminate information on services and related activities to the medical and health care community, the academic community, primary caregivers, advocacy associations, and the public.
5. Coordination of public & private support networking systems.

Ms. Labaj discussed with the council resources that are available to them, including State agency staff. Ms. Labaj then introduced Brian Castrucci, MA, Director of Family Health Research and Program Development, Office of Title V and Family Health.

Ms. Debbie de la Riva stated that Texas Bleeding Disorders Advisory Council is one of only three advisory councils for bleeding disorders in the country.

Mr. Rash asked Mr. Castrucci to provide the council with his background. Mr. Castrucci discussed the role of his office. Mr. Castrucci informed the council that his role would be to provide them with data sources and advise them of data they may want to include in their report. Discussion ensued regarding the collection of data and how the council's questions, ideas and suggestions would be filtered to Mr. Castrucci. Mr. Castrucci stated that he would work with Ms. Labaj in responding to their questions.

Discussion ensued on the type of data available to the council and the different types of data sources Mr. Castrucci would use to assist the council. The council also discussed the level of data and whether or not data sources could be on a national level. Mr. Castrucci informed the council that they can use any data available but that it will be important to site local data specific to Texas.

Ms. Mary Schuwerk recommended using literature on bleeding disorders studies conducted through the Centers for Disease Control and Prevention (CDC). Dr. Rutherford added that the CDC has a large depository of data specific to bleeding disorders. Mr. Castrucci stated that the challenge would be pulling Texas specific data out of that depository. Mr. Castrucci assured the council that he will support them in whatever they want to get from data sources.

Ms. Brendan Hayes suggested narrowing down the data sources to lessen the task. Mr. Rash stated that council will have to determine what type of data they are trying to capture and then try to figure out a format for that data. Ms. Jann Melton-Kissel suggested that the council keep in mind that the report should be brief, maintaining its focus on the five points. Ms. Katherine Lipsky asked for a report that can be used as an example to guide the council. Ms. Melton-Kissel stated that she could ask for reports from the different advisory councils of DSHS.

Ms. Schuwerk asked how the council would go about measuring access to resources such as treatment facilities and knowledgeable physicians. Mr. Castrucci stated that if the council members gave him addresses of facilities, he could map them and make projections of how far a client would have to travel to access a facility.

Bylaws and Subcommittees

Mr. Rash asked council members if subcommittees should be formed for each of the five topics.

Mr. Rash stated that the council will need to decide how the committees will form and meet. Ms. Labaj informed the council that DSHS can provide them with teleconferencing capabilities.

Mr. Rash asked if subcommittee meetings needed to be recorded. Mr. Young stated that if it is likely that recommendations of subcommittees will be “rubber stamped” by the main council, the subcommittee meetings should be viewed as public meetings and subject to the requirements of the Open Meetings Act. Discussion ensued on how the Open Meetings Act affects the council and whether or not subcommittees would have to comply with the Open Meetings Act. Mr. Young clarified that subcommittee meetings held via teleconference need to be treated as public meetings so the public can have access. Mr. Farnell asked that compliance with the Open Meeting Act be considered so as not to put a burden on staff and council members. Mr. Rash asked that the subcommittees be considered fact-finding committees and not subcommittees subject to the requirements of public meetings. Mr. Young said he would have to check department policy on whether or not that would be a problem since the public would not be able to participate.

Mr. Farnell made several suggestions regarding the bylaws of the council:

- The subcommittees will consist of voting and non- voting members;
- A quorum of the council will consist of voting and non-voting members;
- A simple majority of the voting members will be required when the council votes on issues;
- Sub-committees shall have no more than 7 members;
- Sub-committees will not be subject to the Open Meetings Act and will serve only in an advisory capacity.
- Non-committee members will not be able to participate on calls of the sub-committees.

Mr. Farnell offered to undertake the task of drafting a set of bylaws. The council agreed to Mr. Farnell’s suggestions. Ms. Labaj offered to provide the council with draft bylaws compiled by DSHS staff for their consideration. Mr. Farnell asked the draft bylaws be sent to him.

Mr. Rash asked council members to volunteer to sit on subcommittees for each of the five focus points.

Three subcommittees were formed as follows:

Subcommittee	Focus Points	Subcommittee Members
A	1 and 2	Mark Netoskie (Chair), Susan Zappa, Michael Farnell, George Buchanan, Debbie de la Riva, Brendan Hayes, Katherine Lipsky, and Katrina Daniel
B	3	Cynthia Rutherford (Chair), Trish Amerson, Michael Farnell, Debbie de la Riva, Aliya Hussaini, Mary Schuwerk
C	4 and 5	Elizabeth Bailey (Chair), Shannon Carpenter, Charles Garcia, Brendan Hayes, Michael Rash, Mary Schuwerk, Maria Yu

Council members agreed that each subcommittee will draft a report consisting of: 1) the importance of the issue; 2) the priorities; 3) research needs. The drafts are to be sent to Ms. Labaj and Ms. Ortiz by February 1, 2008.

Ms. Schuwerk suggested that the legislative report include an Executive Summary.

DSHS Hemophilia Assistance Program

Due to a small fire in the building, the council had to break. The council meeting resumed in a different meeting location due to inaccessibility of the Moreton elevators. The council members agreed to have Dr. Aliya Hussaini's presentation of the DSHS Hemophilia Assistance Program put on the agenda for the next meeting. Dr. Hussaini agreed to email the Power Point presentation to the council members.

Ms. Dina Ortiz will email council members regarding possible dates for the next council meeting.

Public Comment

No one was available for public comment.

Agenda Items for Next Meeting

1. Review/Approval of Meeting Minutes and Bylaws
2. Review subcommittee reports for the three subcommittees
3. Presentation on DSHS Hemophilia Assistance Program
4. Subcommittee breakout sessions

Adjourn

There being no further business, the meeting was adjourned at 3:53 p.m.