

**Newborn Screening Advisory Committee**  
**June 7, 2010**  
**Texas Department of State Health Services**  
**1100 West 49<sup>th</sup> Street, Austin, Texas**  
**Moreton Building, Room M653**  
**Minutes**

**Members Present**

Sandra Billings  
Charletta Guillory, MD  
William Morris, LVN  
Javier Ramirez, LCSW  
John Saito, MD  
V. Reid Sutton, MD

**Guests**

Denise Rose, Texas Hospital Association  
Elizabeth Sjoberg, Texas Hospital Association  
Morgan Sanders, March of Dimes

**Staff**

Amanda Broden, Department of State Health Services (DSHS), Governmental Affairs  
Debra Freedenberg, MD, DSHS, Newborn Screening Unit  
Eldgridge Hutcheson, DSHS, Laboratory Operations Unit  
Marcie Kirtz, DSHS, Newborn Screening Unit  
David R. Martinez, DSHS, Newborn Screening Unit  
Jann Melton-Kissel, RN, MBA, DSHS, Specialized Health Services Section  
Susan Tanksley, PhD, DSHS, Biochemistry and Genetics  
Maria Vega, DSHS, Specialized Health Services Section  
Mike Young, DSHS, Office of General Counsel

**Welcome, Committee, Staff and Guest Introductions; and Review of Packet Materials**

Jann Melton-Kissel, Director of the Specialized Health Services Section, welcomed the committee members and thanked the members for serving on the committee. She spoke of her vision of collaboration, informative sharing, and positive communications for the meetings and committee. Mrs. Melton-Kissel spoke of the advisory role of the committee. She informed committee members that the focus of the initial meeting of the advisory committee was on business matters such as elections, bylaws, etc.

Committee members, staff, and guests introduced themselves.

Maria Vega reviewed the meeting packet for committee members and pointed out key items including copies of the statute that formed the committee, a list of members, travel reimbursement information, required training information, and draft webpage text.

Members are to:

- provide comment on the webpage text to Maria Vega by July 3, 2010;

- return any travel reimbursement requests related to the meeting to Komal Rathod by July 3, 2010; and
- complete the required open record and public information trainings (available at [http://www.oag.state.tx.us/open/og\\_training.shtml](http://www.oag.state.tx.us/open/og_training.shtml).) and send copies of the completion certificates to Maria Vega by September 1, 2010.

### **Member Orientation**

Michael Young, an attorney with the Office of General Counsel, presented a member orientation for all members. Mr. Young reviewed the statute that created the committee, the composition of the committee, and the advisory nature of the committee. Topics covered in the orientation, included but were not limited to honorariums, bribery, and the acceptance of gifts. Mr. Young discussed the completion and posting of meeting minutes, agendas, majority voting, quorums, and information related to the Open Information Act. Committee members discussed, along with Mr. Young, that committee business should not be discussed or actions taken when a quorum of this group is meeting elsewhere for other purposes.

Mr. Young provided the committee with an additional resource by referring them to the Texas Ethics Commission and by providing each member with a copy of the Texas Ethics Commission's "A Guide to Ethics Laws for State Officials and Employees." (Editorial note: The Texas Ethics Commission's website is available at <http://www.ethics.state.tx.us/>.)

Members viewed the mandated Open Meetings Act training and were asked to provide certificates of completion for both the Open Meetings Act training and the Public Information Act training to Maria Vega. (Editorial note: Both trainings and printing of applicable certificates can be accessed at [http://www.oag.state.tx.us/open/og\\_training.shtml](http://www.oag.state.tx.us/open/og_training.shtml).)

### **Overview of Newborn Screening in Texas: Questions and Answers:**

Dr. Susan Tanksley and David R. Martinez presented an "Overview of Newborn Screening in Texas." The overview focused on current screening for disorders, laboratory processes that support newborn screening, and how short and long term follow-up (clinical care coordination) with both clinicians and parents occurs in order to achieve the best possible outcome.

### **Appointment of Temporary Presiding Officer (Chairperson)**

Dr. Saito made a motion to appoint William (Bill) Morris as the temporary chairperson. Dr. Guillory seconded the motion. The motion passed unanimously.

### **Call to Order**

Mr. Morris called the first meeting of the Newborn Screening Advisory Committee Meeting to order at 2:00 p.m. on Monday, June 7, 2010.

### **Bylaws Discussion and Adoption**

The committee made several edits to the draft bylaws including:

- use of the term chairperson and vice chairperson versus presiding and assistant presiding officer;
- establishing future terms of membership as three (3) years;
- modifying verbiage relating to the posting of an agenda for each meeting; and the
- addition of sexual orientation to the list of how committee members shall make the decision in the discharge of its duties

Additional substantive discussion on the bylaws included discussion of the circumstances for modifying bylaws and recusing oneself due to financial interests in matters brought before the committee.

Dr. Sutton made a motion to adopt the bylaws as edited. Dr. Guillory seconded the motion. The motion passed unanimously.

### **Discussion and Election of Presiding (Chairperson) Officer and Assistant Presiding Officer (Vice Chairperson)**

Members discussed that they would like to have the whole committee make the decisions about who would be chairperson and vice chairperson. The committee decided that a meeting of the committee be called for June 29, 2010, with the sole purpose of holding elections for chairperson and vice chairperson.

Dr. Saito made a motion to table election of committee members until June 29, 2010. Mr. Ramirez seconded the motion. The motion passed unanimously.

### **Future meeting/agenda items**

A special meeting will be held on June 29, 2010, to hold elections for chairperson and vice chairperson.

Dr. Saito made a motion for the next regular meeting of the Newborn Screening Advisory Committee to be October 18, 2010, from 8:30 am to 12:30 pm. Dr. Guillory seconded the motion. The motion passed unanimously.

Committee members discussed several topics they would like to see on future meeting agendas. These are:

- Adding Severe Combined Deficiency (SCID) to the newborn screening panel
- Discussion of secondary targets
  - Ranking secondary targets
- Raising public awareness of the need for and purpose of newborn screening
  - Status of what DSHS is presently doing to keep public aware and to encourage newborn screening
  - Plan to improve public education
- Status of loss to follow-up

- Is there a geographical representation of cases lost to follow-up?
- Is there a problem with loss to follow-up?
  
- Discussion on increase in parents refusing newborn screening
  - Knowledge of need for newborn screening
  - Reporting and tracking refusals
  - Potential causes of increase in refusals
  - Addressing the issue of refusals
  
- Update on newborn hearing screening
  - Who is using different methodology when doing newborn hearing screening?

**Public Comment**

There were no public comments.

**Adjournment**

The meeting adjourned at 3:28 p.m.