



# Interagency Council for Genetic Services

Texas Department of State Health Services \* Genetic Services Contractors  
Texas Department of Aging and Disability Services \* Texas Department of Insurance  
University of Texas Health Science Centers \* Consumer and Public Representatives

## Meeting Minutes December 2, 2005

### **Members Present:**

Margaret Drummond-Borg, M.D., DSHS, Chair  
Patricia Brewer, TDI  
Bob Cleveland, Consumer Representative  
Mary Kukulich, M.D., Provider Representative  
Lillian Lockhart, MD, UTMB

### **Absent:**

Alicia Essary, DADS  
Janet Shephard, L.M.S.W., Consumer Rep.

### **Staff:**

Elaine Braslow, M.Ed., DSHS

### **WELCOME AND APPROVAL OF MINUTES**

Dr. Drummond-Borg opened the meeting. Pat Brewer was introduced as the new representative from TDI. She replaces Charles Reyna. Self introductions were made.

Bob Cleveland and Janet Shephard were re-appointed to the Council by the Governor for another two-year term

The minutes of the August 26, 2005 meeting were reviewed and approved as written.

### **AGENCY REPORTS**

#### **❖ DSHS – Margaret Drummond-Borg**

Children with Special Health Care Needs (CSHCN) continues to have a long waiting list, though quite a few names had been removed from the list at the beginning of the fiscal year.

There has been concern regarding funding for the birth defects registry. It had been funded by the Preventive Block Grant, which has been eliminated.

The Newborn Screening Program (NBS) has a new manager, David R. Martinez. Dr. Drummond-Borg is now the physician consultant for the Health Screening and Case Management Unit, which includes NBS. As a result of the NBS expansion, new positions have been added to the program, including two nurse consultants, a public health technician, and a nurse educator. These positions have been posted and interviews will occur soon.

#### **❖ DADS – Alicia Essary**

No report.

❖ **TDI – Pat Brewer**

TDI is preparing to implement SB 53 (79(R)), relating to the use of genetic testing information by insurers. The bill extends current protections for genetic information and against discrimination based on genetic makeup to the individual health insurance market. Requirements apply to any health benefit plan, rather than just any group health benefit plan, that meets certain criteria.

❖ **UTMB – Lillian Lockhart**

Dr. Lockhart reported that Children's Hospital has asked Dr. Matalon to come to Austin once a month to conduct a clinic. He also goes to El Paso once a month. Currently, we have metabolic geneticists based in San Antonio, Houston, Dallas and Galveston. There will be a metabolic geneticist in Fort Worth effective in July.

**NEWBORN SCREENING (NBS) UPDATE – Margaret Drummond-Borg**

❖ **Consultation Report**

The NNSGRC final report is available on the DSHS web site: [www.dshs.state.tx.us](http://www.dshs.state.tx.us). {*Postscript: now available at [www.dshs.state.tx.us/nbsrfp](http://www.dshs.state.tx.us/nbsrfp).*} In response to the report, case management staff and extra phone lines will be added to the NBS program.

❖ **NBS Expansion**

HB 790 (79(R)) included two mandates to DSHS:

- 1) Implement an expanded NBS program by November 1, 2006. Specifically, to the extent that funding is available, expand the number of required NBS tests to include those listed in the American College of Medical Genetics (ACMG) 2005 report: *Newborn Screening: Toward A Uniform Screening Panel and System*.
- 2) Conduct a study by March 1, 2006 to determine the most cost-effective method of conducting NBS to maximize the number of NBS tests that may be done. Study is to exclude newborn hearing screening and include consideration of outsourcing screening to a qualified laboratory.

DSHS had initially discussed the possibility of outsourcing the entire program, then determined it would look at outsourcing laboratory components only.

The deadlines stipulated in the legislation meant that a number of things had to be done concurrently -- design the expanded program, figure out the costs for expanding, and get bids for outsourcing the program. A Request for Proposal (RFP) for NBS Services was written to help make these decisions. The RFP describes all aspects of the expanded NBS program, which is the basis of both vendor proposals and the DSHS internal benchmark, and creates an opportunity for vendors to document their costs and how they will deliver the scope of work.

Prior to the release of the RFP, a series of meetings were held to gather input from NBS experts, stakeholders, and interested parties. The Partnership in Action Summit, held on September 21, was a post-legislative summit to discuss priorities and determine next steps associated with the implementation of new legislation. NBS expansion was one of the topics discussed. In October, DSHS held three RFP Partner meetings, further discussing issues related to NBS expansion. Some of the things discussed were:

- Which disorders to include in the expanded panel?
- Should we continue with two screens?
- If labs are outsourced, how do we link laboratory screening with case management?

It was determined that we will continue with two screens for now. We are looking at screening for all MS/MS conditions recommended by ACMG; biotinidase, if it is cost effective. We will not screen for cystic fibrosis now.

A draft of the RFP was posted on the DSHS web site for comment prior to release of the final RFP on December 1. The deadline for submission of proposals is January 17, 2006. In the meantime, DSHS has to determine the internal costs of the expanded program, which are the benchmarked costs. One requirement for outside vendors is that their costs are 10% below in-house costs.

The evaluation team, which includes internal and external experts, will review proposals and make a recommendation to the DSHS Commissioner about whether to implement the expanded program in-house or through an outsourced contract. The Commissioner will make his decision by February 28, 2006.

Discussion followed regarding MS/MS. Dr. Drummond-Borg mentioned that one of the biggest concerns with MS/MS is we would be finding more babies with abnormal screens that will need to be seen by metabolic specialists. The PCP may have to order more specialized tests, and how do we prepare them to do this? How can out-of-state tests be ordered when the reimbursement is so low? There is also concern about payment to the metabolic specialist. Dr. Lockhart asked if Medicaid will pay for further testing if the test comes out positive? Dr. Kukolich said that Cook Children's is instituting a Medicaid catchment area because of costs.

Dr. Drummond-Borg mentioned that the National Association of Laboratories is putting a disaster plan in place, in the wake of recent national disasters (i.e., Hurricanes Katrina and Rita).

### **NEWBORN SCREENING RULES CHANGE – Margaret Drummond-Borg**

The passage and implementation of HB 790 calls for changes to the NBS rules. One of the roles of the IACGS is to provide input when a state agency represented on the Council needs to propose a rule change relating to human genetics or human genetic services.

Dr. Drummond-Borg reviewed the new rules process, which involves several steps, including review by legal, Fiscal, HHSC and the DSHS Council, and input/public comment from stakeholders and interested parties.

Dr. Drummond-Borg walked through the rules, page by page, mentioning suggested changes. Members were asked to review the proposed changes and let Dr. Drummond-Borg or Elaine know of any other changes that need to be made. The proposed changes also will be reviewed at the Metabolics Consultant Meeting on December 9. The IACGS will have another opportunity to review the changes at the March meeting. We will present the rule changes to the DSHS Council at their May 2006. Upon approval, they will then be posted in the Texas Register for a 30-day comment period. Once the final rules are adopted, they will be posted again in the Texas Register.

### **TELEMEDICINE AND GENETIC SERVICES – Mary Kukolich**

Dr. Kukolich gave a PowerPoint presentation on telemedicine. She mentioned that telemedicine is used for genetic counseling in Little Rock, Arkansas, Georgia, and Maine. Cook Children's received a federal grant to conduct clinics via telemedicine. She reported the experience as saving patient and physician time and travel, greater ease for patients to get an appointment, and being able to see more patients in a day.

### **RESOURCE ALLOCATION PLAN – Margaret Drummond-Borg**

Dr. Drummond-Borg mentioned that it is time to work on the biennial Resource Allocation Plan (RAP). We are trying to figure out how to approach the report this year as we do not have funding and the report has changed little over the years. Dr. Drummond-Borg has asked for some funding from Title V to conduct surveys but has not heard back.

Elaine mentioned that we do have some information available from our Title V contractors – needs identified in their last proposals, and data collected on new clients served and procedures used.

Two possible topics mentioned were the increased need for metabolic services and discussion of the use of telemedicine to provide genetic services.

Members were asked to send any ideas for the RAP to Elaine or Dr. Drummond-Borg.

### **PUBLIC COMMENT**

There were no public comments.

### **ADJOURNMENT**

The next meeting is scheduled for **Friday, March 3, 2006, 10:30 am to 1:00 pm at DSHS in the Moreton Building, Room M-101.**

The meeting adjourned at 1:00 pm.