



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 March 3, 2006

Members Present:

Margaret Drummond-Borg, MD, DSHS, Chair
Patricia Brewer, TDI
Bob Cleveland, Consumer Representative
Mary Kukulich, M.D., Provider Representative
Lillian Lockhart, MD, UTMB
Janet Shephard, L.M.S.W., Consumer Representative
Alicia Essary, DADS

DSHS Staff:

Elaine Braslow
Evelyn Delgado
Michele Goddard
David Martinez

Guests:

Melanie Casal, MS, CGC
Heather Keizman, MSN, WHCNP, RNC

WELCOME AND APPROVAL OF MINUTES

Dr. Drummond-Borg opened the meeting. David Martinez was introduced; he is the branch manager of Newborn Screening. Evelyn Delgado was introduced. She is the Assistant Commissioner for the Family and Community Health Division. Self introductions were made.

The minutes of the December 2, 2005 meeting were reviewed and approved as written.

AGENCY REPORTS

❖ DSHS – Margaret Drummond-Borg

Children with Special Health Care Needs continues to work through its waiting list, while more names are added.

Funds will be allocated from the Title V block grant for the Birth Defects Registry since we no longer have preventive block grant funding.

The Newborn Screening Expansion RFP was reposted on March 1, 2006 with changes. It closes in April. Changes include:

- Removal of the 10% marker, which required cost estimates from outside vendors to be 10% below in-house costs.

- Allowing the use of subcontractors.
- Allowing applicants to submit partial proposals for specific functions of the program.

Dr. Kukolich announced that a metabolic consultant has been hired at Cook Children's Physician Network.

❖ **DADS – Alicia Essary**

Alicia Essary reported that Addie Horn is now the Commissioner of DADS. She was most recently Deputy Commissioner of DADS and has a long history in services to people with mental retardation and other disabilities. Primary Home Care Services for Children is transferring to HHSC under the Alberto N. settlement. Families may end up receiving more personal care services than previously. CBA and CLASS, like all DADS waivers, are rolling out additional slots – a total of 10,000 slots across all programs. This includes some expansion of the Deaf-Blind waiver as well. Dr. Kukolich mentioned a problem with CLASS; because they use ICD-9 codes, not all genetic disorders are listed. Alicia will talk with the CLASS program manager. The McCarthy lawsuit, now known as Travis, is addressing DADS interest list policies and is still in a complex stage of negotiations.

❖ **TDI – Pat Brewer**

Pat Brewer reported that SB 53 (79(R)), amending Insurance Code Chapter 546, became effective on January 1, 2006 and applies certain protections concerning the use of genetic testing to individual health benefit plans. Previously, these protections applied only to group health benefit plans. Individual health benefit plans that are delivered, issued for delivery or renewed on or after January 1, 2006 must comply with SB 53. TDI's product resource guides and HMO review checklists for the types of individual coverages that are affected by SB 53 have been amended to reference these requirements and are available at the TDI web site. These guides and checklists assure that future policy forms that are filed for approval are compliant. As existing policies are renewed, any policy provisions that conflict with SB 53 must be amended by way of a compliance rider.

❖ **UTMB – Lillian Lockhart**

Dr. Lockhart suggested that we look at studies that Medicaid does and does not pay for at our next meeting.

ESSENTIAL NURSING COMPETENCIES IN GENETICS – Heather Keizman

Heather Keizman, instructor in clinical nursing at the University of Texas at Austin, gave a presentation on basic nursing competencies in genetics and provided examples of how nursing knowledge in genetics can improve the quality of patient care. The American Nurses Association recently published guidelines to establish the minimum amount of genetic competence expected of every registered nurse. Courses in genetics are now part of the curriculum for nursing students. Continuing education in genetics is encouraged for practicing nurses.

NBS EXPANSION AND RULES – Margaret Drummond-Borg

Amendments to the Newborn Screening rules have been drafted in accordance with HB 790. It was decided to repeal and rewrite the rules for readability. Members reviewed the current draft of the proposed rules and suggested capillary blood specimen replace peripheral blood specimen. The proposed rules will be presented to the State Health Services Council at their May meeting. They will then be posted in the Texas Register for a 30-day comment period.

LICENSURE FOR TEXAS GENETIC COUNSELORS – Melanie Casal

Melanie Casal provided an update on efforts to obtain a licensure requirement for Texas genetic counselors. SB 1329 (79(R)), relating to the IACGS and the provision of genetic counseling services, went through the House but sat in committee at the Senate. The bill called for the DSHS Commissioner to establish an advisory committee on licensing of genetic counselors. The committee would make recommendations to the HHSC Commissioner on licensing standards for genetic counselors. HHSC would adopt rules governing licensure requirements. Pat Brewer asked if this might be put under another board. Alicia Essary suggested looking at DSHS licensures and where this may fit.

PUBLIC COMMENT

There were no public comments.

ADJOURNMENT

The next meeting is scheduled for **Friday, June 2, 2006, 10:30 am to 1:00 pm at DSHS in the Moreton Building, Room M-101.**

The meeting adjourned at 1:00 pm.