



Interagency Council for Genetic Services

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

March 4, 2005

Present:

Margaret Drummond-Borg, DSHS, Chair
Bob Cleveland, Consumer Representative
Lillian Lockhart, UTMB (via phone)
Mary Kukulich, Provider Representative
Janet Shephard, Consumer Representative
Michele Goddard, DSHS
Charles Reyna, TDI

Absent:

David Rollins, DADS
Margaret Lazaretti, TDI

Guest:

Mike Frazier

Charles Reyna was present for Margaret Lazaretti representing Texas Dept of Insurance. He will most likely be the permanent representative for TDI.

The minutes from December 3rd were reviewed corrections made, approved and seconded. Dr. Lockhart was unable to attend meeting personally but participated via telephone.

AGENCY REPORTS

❖ **DSHS - Margaret Drummond-Borg**

DSHS has been evaluating the Newborn Screening Program (NBS). A national review team was in Austin at the beginning of March to look at the program. Expansion of the newborn screening is included in DSHS exceptional items. The finance committee has approved the exceptional item request.

There have been two bills that have been introduced during this legislative session to expand newborn screening. The March of Dimes (MOD) has been instrumental in getting the bills introduced.

DSHS is starting the second phase of consolidation looking for ways of optimization, ways that we can save money and still continue to provide all the services. There is a contract now for human resource services to be provided via a call center and a web site.

DSHS is also asking for funding to be restored to original levels for CHIP because CHIP was cut back significantly. This is important for genetic services because it means that people, who are not insured at present, may be re-enrolled in CHIP and able to access services.

The Birth Defects Registry may lose some of their money at the federal level. The proposed budget eliminates the public health block grant, which will be a significant problem for the registry funding.

❖ **DADS – David Rollins**

No report.

❖ **TDI – Charles Reyna**

No report.

❖ **UTMB – Lillian Lockhart**

No report.

Newborn Screening Program Review – Margaret Drummond-Borg

The National Newborn Screening and Genetics Resource Center (NNSGRC) brought two teams to TX for a review of the Newborn Screening Program. They arrived on Monday, February 28th. They came from all over the United States representing newborn screening labs, newborn screening follow-up, geneticists, and one representative from HRSA and one representative from CDC.

One team went to Dallas and San Antonio and one team went to Houston to hear concerns about the NBS Program. We also had a couple of conference calls that we offered to anyone that would like to call in and give their opinions regarding newborn screening. However, we only had two people participate in the conference call. We had about 20 people in Dallas from various facilities participate. In San Antonio, there were representatives of TMA and Texas Pediatric Society, some physicians and nurses. We had a lot of feedback about what people didn't like about the program. Sometimes it was specific to their areas and wasn't an overall concern for the program. One of the final recommendations was to look at establishing an official advisory group for the Newborn Screening Program. Unfortunately, in the consolidation, all the advisory groups were eliminated and never replaced. This means that for DSHS to have an official advisory group or committee we have to have legislation passed.

One concern voiced was that insurance companies are not paying the physicians for the newborn screen.

Other concerns were physicians being asked to track down babies and physicians providing services for babies and not getting paid. There was discussion regarding how Medicaid pays for newborn screening and medical services in Texas compared to other states.

79th Legislative Session

Janet Shephard handed out information regarding the MOD lobby day, March 9th. Newborn screening is the top issue right now. There are some key bill numbers, which MOD is supporting. She also had 3 fact sheets on expanded newborn screening.

Janet briefly summarized the bills the MOD is supporting. Dr. Drummond-Borg asked if there was anything the Council might be able to do to help support the bills. Janet said that she would have Jorey Berry notify the council members via email as the bills are scheduled to be heard.

Dr Drummond-Borg stated that Senate Bill 53 regarding genetic discrimination in insurance policies would be expanded to all Medical insurance policies. Charles Reyna (TDI) stated that this would be applicable to individual policies.

There is a bill requiring information about battered babies be given to new parents, which includes development of a booklet with other information including immunizations, newborn screening, etc. to be given to the parent when the baby is born.

Other Business

Dr. Kukolich stated that Cook's Physician Network had a very successful telemedicine program supported by a federal grant. One of the issues that came up is that it costs money to maintain the equipment, the lines, etc. for telemedicine. Medicaid in general could save a large amount of money if it encouraged the use of telemedicine for all sub-specialties. Right now all it pays is travel. If it helped support the telemedicine equipment that we can't afford to pay for, it would actually save money.

Dr. Drummond-Borg will forward this information on to Medicaid and DSHS. Dr. Kukolich will send her the costs of set-up, maintenance, etc.

Dr. Drummond-Borg stated that she would be hiring another genetics coordinator to replace Marjorie Doubleday, who took another position at DSHS.

The next meeting date is June 3, 2005.

Meeting adjourned.

3/15/05
Rev. 3/18/05
Rev. 5/16/05