



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 June 2, 2006

Members Present:

Margaret Drummond-Borg, MD, DSHS, Chair
Bob Cleveland, Consumer Representative
Representative
Jane Hammitt, TDI
Mary Kukulich, MD, Provider Representative
Lillian Lockhart, MD, UTMB

Members Absent:

Alicia Essary, DADS
Janet Sheppard, Consumer

Guest:

Morgan Walthall, March of Dimes

Staff:

Elaine Braslow
David Martinez

WELCOME AND APPROVAL OF MINUTES

Dr. Drummond-Borg opened the meeting. Self-introductions were made.

The minutes of the March 3, 2006 meeting were reviewed and approved as written.

AGENCY REPORTS

❖ DSHS – Margaret Drummond-Borg

As of our last meeting, the RFP for expansion of the Newborn Screening (NBS) Program had been re-posted with the removal of the 10% marker, which required cost estimates from outside vendors to be 10% below in-house costs. The reposted RFP also allowed the use of subcontractors. Two proposals were submitted. On May 23 the decision was made that the program would not be outsourced. Applicants then had 10 days to repeal the decision. The decision was made at the executive level of DSHS with input from two outside reviewers from other NBS state programs. NBS staff provided input for developing the RFP, i.e., program specifications and benchmarks. NBS staff were not involved in the review and decision making processes. As a result of the May 23 decision, much has to be accomplished in a short span of time. Timelines and tasks have been developed by lab staff, including among other things:

- Retrofit lab in order to install ten new MS/MS machines within four months.
- Get part time metabolic consultant to develop standards.

- Hire additional lab staff and train.

The NBS Branch is in the process of hiring a program specialist to provide education to physicians and other providers. Once that person is hired and trained, they will go out to the major hospitals and public health clinics to provide education on the expanded program. DSHS is also considering adding 16 social workers in the Health Service Regions, who can devote a portion of their time to help track down babies. Dr. Lockhart suggested that we get cell phone numbers to facilitate follow-up.

No decision has been made about biotinidase screening.

Consideration had been given to creating a two-part card for screening, first part for the hospital and the second part for the parent to take home, but it would have created additional expense for hospitals.

Use of the MS/MS code will allow for better reimbursement. We will need to find a CPT code that can be used.

Drafts of new brochures were shared with members. Drafts of the brochures had been emailed for comments. Dr. Lockhart suggested the brochures mention that the baby may have to go to a specialist.

❖ **DADS – Alicia Essary**

No report.

❖ **TDI – Jane Hammitt**

Jane Hammitt reported on questions asked of TDI at the last meeting.

- 1) Does TDI have information that shows whether NBS has caused premiums to increase? No, TDI does not have that data. There is a global fee for newborn care; items are not broken out.
- 2) Does TDI have any data on complaints regarding genetic discrimination? No, TDI does not have this information.
- 3) What current insurance statutes mandate NBS? There are mandates that cover newborn hearing screening and PKU formulas. Mr. Cleveland explained that newborns are covered for the first 30 days; once diagnosed with a condition, the insurance should cover it. Dr. Borg asked whether the condition might be considered pre-existing. Ms. Hammitt said it would be dependent on the type of coverage and whether there was a break in service.

Ms. Hammitt mentioned that we could ask the (TDI) state planning grant if they could include NBS in the data call.

❖ **UTMB – Lillian Lockhart**

No report. Dr. Lockhart reiterated the concern that pediatricians may not know what to do when tests come back – we need to have a very organized system so they will know who to call. Dr. Borg concurred that that is the plan.

GENETIC SERVICES PAID FOR BY MEDICAID– Margaret Drummond-Borg

There is a workgroup that reviewed genetic services paid for by Medicaid, and the proposal is to take all of the lab and all of the ultrasounds out of genetic services and put them in regular Medicaid services. Cytogenetics may be billed under regular Medicaid as long as ICD-9 diagnosis codes are related to birth defects, ADHD, learning difficulties, and pregnancy. Labs need to be Medicaid enrolled. We do not know for certain when these changes will go into effect. They have to go through several layers of approval. These changes will not be reflected in the new Medicaid manual because the new manual is almost finalized.

Providers will be allowed to do cytogenic tests up to six times per year on a patient, as opposed to once in a lifetime. Probes for FISH are unlimited. Genetic providers will continue to be reimbursed at the same rates; the only difference is the frequency will change. One physical exam once in a lifetime becomes one physical exam every three years. The once every six months exam changes to once a month. There will be inpatient codes that will be reimbursed at the same rate as outpatient codes. The only problem is if you do an inpatient initial exam, you will get reimbursed for the same amount, but then you cannot do an outpatient initial exam for another three years. Dr. Borg will let members know when these changes take place.

NEWBORN SCREENING EXPANSION

The proposed rules were presented to the DSHS Council in mid-May, then submitted to HHSC for a second review, and will be posted in the *Texas Register* on July 7 for a thirty day comment period.

Morgan Walthall inquired as to the status of biotinidase – it is in the proposed rules and on the brochures. Biotinidase is inexpensive to diagnose and treat. Dr. Borg said that information has been provided to executive staff and we are awaiting a decision.

Section 37.55 of the proposed rules, relating to responsibilities of providers and parent, managing conservator, or guardian may need clarification for a number of reasons, such as

- There is no consistent definition for newborn.
- The rule says any physician that sees the newborn within the first 30 days needs to ensure that the appropriate screens are done. Not all babies, after they leave the hospital, see a physician. They may see a physician assistant or a nurse practitioner.
- Families may be referred back to the hospital for the baby's second screen; the hospital may not do second screens.

Dr. Borg asked members to think about how §37.55 might be rephrased and let her know of any suggestions within the constraints of the law. She also asked members to review the brochures and let her know of any changes/recommendations.

OTHER DISCUSSION

Dr. Kukolich asked whether pediatric nurse practitioners (PNP) could provide genetic services and whether they could be paid. Dr. Borg explained that Advanced Practice Nurses (APN) are approved within their scope of practice, e.g., APN in pediatrics. If we were to have APNs in genetics, they would need to have training. Dr. Kukolich asked who establishes that? Dr. Borg said it would have to be proposed to the Board of Nurse Examiners.

What resources do we have available that could be reimbursable? Dr. Kukolich is willing to do a pilot test, starting with a certified pediatric nurse practitioner and provide training on genetics. If the Board of Nurse Examiners approved this, would this be reimbursable by Medicaid? Dr. Borg said that currently the only genetic providers enrolled in Medicaid are physicians. If the Board of Nurse Examiners approved a genetics scope of practice, we would need to make sure nurse practitioners could enroll as Medicaid genetic providers.

PUBLIC COMMENT

There were no public comments.

ADJOURNMENT

The next meeting is scheduled for **Friday, August 25, 2006, 10:30 am to 1:00 pm at DSHS in the Moreton Building, Room M-101.**

The meeting adjourned at 12:30 pm.