



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 1, 2007

Members Present:

Mary Kukolich, M.D., Presiding
Pat Brewer, TDI
Robert Cleveland, Consumer Rep.
Alicia Essary, DADS
Lillian Lockhart, M.D., UTHSC Rep.
Janet M. Shephard, L.M.S.W.

Members Absent:

Margaret Drummond-Borg, M.D., DSHS, Chair

Staff:

Elaine Braslow, M.Ed.
David R. Martinez
Susan Tanksley, Ph.D.

Guest:

Karen Littlejohn

WELCOME AND APPROVAL OF MINUTES – Mary Kukolich

Dr. Mary Kukolich presided in Dr. Drummond-Borg's absence. She welcomed members and opened the meeting.

The March 9, 2007 meeting minutes were amended and approved. Corrected minutes will be emailed to members, and posted on the genetic services web site.

NEWBORN SCREENING EXPANSION UPDATE – Susan Tanksley

The Lab started testing for tandem mass spectrometry disorders (MS/MS) on December 6, 2006. Testing for biotinidase deficiency started on January 8, 2007, and the full new report format began on February 8, 2007. Since the beginning of MS/MS, there have been 27 diagnosed disorders, and six confirmed biotinidase disorders. One of the 27 diagnosed cases with MS/MS was LCHAD. Another baby was diagnosed with LCHAD, but expired.

The Lab's Voice Response System allows providers 24/7 access to patient screen results. The specimen form serial number or the mother's social security number is needed for access. The Lab is contracting with a vendor to develop a web-based system to access patient results, which is targeted to be operational in fall 2008. Large hospitals will be able to interface with the system through their system. We will begin with 10 hospitals and we will provide the interface. Web-based access will be password protected. The system will allow for web-based data entry and reporting, which would mean a quicker turnaround on newborn screening results.

Within the next week, the newborn screening report cards will be sent to submitters, and will be sent on a quarterly basis. The report card lists the total specimens submitted per month, the number and ratio of unsatisfactory specimens submitted and the reasons they were unsatisfactory, and the time from specimen collection to receipt by the Lab. NBS educators are in place to conduct on-site training, and can follow-up on problems identified in the report card.

During the Legislative Session, the Lab was asked to determine the cost of adding cystic fibrosis to the screening panel. The Appropriations Bill recently was approved, but no allocation was made for cystic fibrosis screening. SB 983, introduced during the 80th Legislative Session, added sickle cell trait to the list of disorders for which screening, reporting and follow-up is required. The bill was pending in committee when the session ended. The Lab already screens and reports on sickle cell trait. Language has been added to reports to encourage providers to counsel patients.

NEWBORN SCREENING RULES UPDATE – David Martinez

Mr. Martinez reported that rule changes were prepared in the event that the legislation would move forward regarding sickle cell trait and cystic fibrosis. Since the legislation did not pass, there will be no rule changes at this time. DSHS is waiting on further direction from the Health and Human Services Commission regarding sickle cell trait.

TOUR OF NBS LAB – Susan Tanksley

Dr. Tanksley took Council members on a tour of the newborn screening laboratory, which included all the steps in the NBS laboratory process. The Lab screens for 27 disorders, all of which are included on the American College of Medical Genetics (ACMG) panel.

OVERVIEW OF DEPARTMENT OF AGING AND DISABILITY SERVICES (DADS) – Alicia Essary

Ms. Essary provided an overview of programs and services provided by DADS, along with a handout, which summarizes the various institutional and community-based services. A lot of services are contracted out.

- DADS is responsible for services to individuals with intellectual and developmental disorders. The term of “mental retardation” is gradually being phased out.
- DADS also provides services for people of all ages with physical disabilities who need long-term services and support.
- DADS is one of the largest state agencies in terms of budget.
- The services that DADS is best known for are the institutional services. Nursing facility services provide full-time availability of a nurse for individuals who require it. DADS is responsible for licensing and regulating facilities and pays from 60% to 80% of their business. There are 1000 nursing facilities in Texas, which can accommodate 100-120,000 people. The nursing facilities are at 70% occupancy.

- DADS has an extensive array of community-based services. Personal care is one of the largest and least known programs. It serves over 100,000 individuals and provides an average of 16 hours per week of assistance with activities of daily living and custodial care, such as grocery shopping, meal preparation, and housework.
- Adult day care facilities provide day activities and health services, under the supervision of a nurse.
- Medicaid waiver programs are specifically designed as an alternative to institutional care. These programs provide community-based services and support to individuals who qualify for admission to a nursing facility or intermediate care facility for persons with mental retardation or a related condition. Services may include case management, personal care, professional care, including nursing and therapy, adaptive aids, and home modifications.
- There also are highly specialized services, e.g., Deaf-blind with Multiple Disabilities; Medically Dependent Children's Program.
- Other services, which do not use Medicaid funds, include the Older Americans Act services, available to those 60 years of age and older without regard to income; the Guardianship Program, Title XX and MRA services.
- Medicaid services are entitlements – anyone who is eligible and need the service must be provided the service. Waiver programs allow the state to limit the number of people who can receive services covered under the waiver.

REPRESENTATIVE REPORTS

❖ **DADS – Alicia Essary**

- DADS supports Texas Council on Autism and Pervasive Developmental Disorders. A bill, which redefines autism as a bio-neurological condition, was pending.

❖ **Texas Department of Insurance (TDI) – Pat Brewer**

Ms. Brewer gave an update on the bulletin to be sent to HMOs regarding expanded newborn screening and increased cost to HMOs. Ms. Brewer provided a copy of the statute regarding Well-Child Care from Birth. A TDI attorney reviewed the statute and found that TDI had no authority to require HMOs to cover newborn screening.

Ms. Brewer mentioned that that the TDI Commissioner may have the ability to require the screenings by rule, and an amendment regarding NBS screening will be proposed.

❖ **UTHSC – Lillian Lockhart**

No report.

❖ **Title V Contractors – Mary Kukolich**

Dr. Kukolich reported that there is a website available for the public to view and learn about genetics: <http://ghr.nlm.nih.gov/nbs>. It is a free site. There is an online training with CMEs for physicians: www.acmg.net.

NEWBORN SCREENING BENEFITS – Elaine Braslow

During the NBS expansion process, stakeholders suggested that centers be in place, where families can go for confirmatory testing, if they do not have insurance coverage.

The NBS Program designed a new program called the *Newborn Screening Benefits Program* with an open enrollment process. The open enrollment notice and supporting materials were posted on the Electronic State Business Daily (ESBD), and notification was sent to metabolic, endocrinology, and hematology consultants. There are few provider enrollees to date.

Providers enrolled in the NBS Benefits Program will provide confirmatory testing, including laboratory tests, to children who are eligible for the program. Services are reimbursed at Medicaid rates. Billing is processed through DSHS. The NBS Benefits Program is similar to Title V Genetics Fee-For-Services, however, the NBS Benefits Program allows families with incomes at a higher percentage of the federal poverty income level (FPL) to qualify. While Title V will provide services to families with incomes up to 185% of the FPL, NBS Benefits allows for up to 350%.

PUBLIC COMMENT

There were no public comments.

ADJOURNMENT

The next meeting is scheduled for **Friday, September 7, 2007, 10:30 am to 1:00 pm at DSHS in the Moreton Building, Room M-101**. There being no further business, the meeting was adjourned at 1:00 p.m.