

# **Interagency Council for Genetic Services**

# Meeting Minutes March 9, 2007

#### **Members Present:**

Margaret Drummond-Borg, M.D., DSHS, Chair Pat Brewer, TDI Robert Cleveland, Consumer Rep. Alicia Essary, DADS Lillian Lockhart, M.D., UTHSC Rep.

#### **Members Absent:**

Mary Kukolich, M.D. Janet M. Shephard, L.M.S.W.

#### Staff:

Elaine Braslow, M.Ed.

### WELCOME AND APPROVAL OF MINUTES – Margaret Drummond-Borg

Dr. Drummond-Borg welcomed members and opened the meeting at 10:55 a.m.

The December 15, 2006 meeting minutes were approved as presented.

#### REPRESENTATIVE REPORTS

# ❖ DSHS – Margaret Drummond-Borg

- Dr. Drummond-Borg announced that Dr. David Lakey began as new DSHS Commissioner on January 2, 2007. Prior to becoming Commissioner, he served as an associate professor of medicine, chief of the Division of Clinical Infectious Disease and medical director of the Center for Pulmonary and Infectious Disease Control at the University of Texas in Tyler, where he was a faculty member since 1998. At the UT Center for Biosecurity and Public Health Preparedness, Dr. Lakey served as associate director for infectious disease and biosecurity. He also chaired a bioterrorism preparedness committee for 34 hospitals in East Texas and lead the development of the Public Health Laboratory of East Texas in 2002.
- Dr. Eduardo Sanchez, immediate past DSHS Commissioner, left DSHS in October 2006 to head the Institute for Health Policy at the University of Texas School of Public Health in Houston. He is based in Austin.
- There have been other organizational changes at DSHS as a result of recommendations made in a review by the Health and Human Services Commission (HHSC). There is now one Deputy Commissioner instead of two. Luanne Southern, M.S.W., is the new

Deputy Commissioner. Previous Deputy Commissioner, Dr. Nick Curry, has taken a position within the Division for Prevention and Preparedness, as a physician consultant to the HIV/STD program. Dr. Dave Wanser, previous Deputy Commissioner, is pursuing other interests. The physician who was over the state hospitals has left. Randy Fritz, Chief Operating Officer (COO), is leaving. Elaine Powell is serving as Acting COO. Dr. Janet Lawson, who is board certified in obstetrics, and previously served as physician consultant to the Community Health Services Section, is now Assistant Commissioner, Division for Regional and Local Health Services. Carol Labaj is the new Director of the Purchased Health Services Unit, which includes CSHCN. The former director moved over to the Title V office.

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

Ms. Brewer reported that TDI will send information about the expanded newborn screens
and increased cost to HMOs through a bulletin. An attorney has been assigned to draft
the bulletin, and once it is completed and approved, it will be sent to HMOs and posted
on TDI's web site. TDI's web site also will have a link to the NBS web site. HMOs are
required to cover the costs of all screens; whereas, insurance companies are only
required to pay for PKU formula.

### ❖ <u>UTHSC – Lillian Lockhart</u>

- Dr. Lockhart mentioned that there has been a lot of discussion and apprehension about the new CHIP Perinatal Program, and appreciated the genetics program helping to clarify some areas.
- There has been some difficulty in arranging contracts with HMOs covering the CHIP Perinatal Program.

# ❖ Department of Aging and Disability Services (DADS) – Alicia Essary

- Ms. Essary reported that the "money follows person grant" has been funded. It enables
  individuals to move from facilities to community-based residences. MR patients will
  received enhanced services.
- Medicaid reimbursed categories of services, including: 6 bed facilities, state schools, and
  7 plus bed residences privately operated by MRAs, have been invited to close down and
  transfer individuals to 4 bed facilities or to their families. These smaller facilities have
  access to supplemental services in the community. Participant experience surveys
  (Nationally developed tool) have consistently found that residents have been happier in
  the smaller settings. In smaller facilities, residents are more likely to have friends from
  outside. Personal care services have waiting lists.
- The Lubbock State School received a poor report from the U.S. Justice Department. There has been a turn over in management and steps are in place to improve findings.
- Ms. Essary will present an overview of services that DADS offers to people with disabilities, regardless of age and diagnosis, at our June 1, 2007 meeting.

#### NEWBORN SCREENING (NBS) EXPANSION UPDATE - MARGARET DRUMMOND-BORG

- In January 2007, the NBS program began screening for all 27 disorders, including biotinidase.
- Effective February 2007, a new mailer to report results is being used.
- Work is needed on the linking program to link the first and second screening.
- Legislation has been introduced that, if passed, would require the NBS program to follow (through case management) patients with sickle cell trait. Currently, sickle cell trait is reported to the physician with screening results.
- New NBS brochures (English version) were provided to Council members. The brochures also are available in Spanish and Vietnamese. Additionally, FACT sheets (English and Spanish; 4<sup>th</sup> grade level) are available for physicians to give to their patients, and ACT sheets are available (English only) for physicians.
- A NBS CME online 1-hour course is available through Texas Health Steps and may be accessed through their web site: http://txhealthsteps.com/. The program is free.
- Dr. Lockhart mentioned that Dr. Matalon did grand rounds on the NBS expanded screens today at UTMB.
- Dr. Drummond-Borg reported that a call for applications will be posted on the Electronic State Business Daily (ESBD) for NBS Benefits Open Enrollment contracts in the next week or two. The new NBS rules, published in the Texas Register on October 27, 2006, includes a section that says the NBS program will cover uninsured infants and children for confirmatory testing and follow-up treatment, as funding allows. The open enrollment contracts with metabolic specialists, endocrinologists, and hemotologists will be similar to fee-for-service contracts, where the provider bills DSHS monthly for allowable services at Medicaid established rates. The specialists will receive email notification when the NBS Benefits Open Enrollment notice and application are posted.

### CHIP PERINATAL PROGRAM UPDATE - MARGARET DRUMMOND-BORG

- The new CHIP Perinatal Program rolled out in January 2007. The program covers unborn children of pregnant women living below 200% of the federal poverty level, who are not eligible for Medicaid. Services are limited to prenatal and postpartum care, with a 12-month continuous eligibility period for the unborn child. This enables the mother to have up to two postpartum visits. Once the child is born, he/she will be enrolled in CHIP.
- CHIP Perinatal essentially will take the place of Title V prenatal services. Effective September 1, 2007, Title V providers may no longer bill Title V for prenatal services, other than prenatal counseling. Title V will no longer cover biochemical, cytogenetic, and DNA testing, amniocentesis, and ultrasounds for pregnant women.

- Providers may only bill the CHIP Perinatal Program if the client and the provider are both enrolled in the program. CHIP perinatal care is provided by select CHIP health plans throughout the state. Members were provided with this information at the meeting. CHIP Perinatal Program information may also be accessed from the web at: www.hhsc.state.tx.us/chip/perinatal/.
- CHIP Perinatal provides a better federal/state match and there is no cap on funding.

# 2007 LEGISLATIVE SESSION UPDATE - MARGARET DRUMMOND-BORG

- Today (March 9, 2007) is the last day to file new legislation for the current session.
- Dr. Drummond-Borg referred members to a copy of SB 983, legislation filed that would require DSHS to follow-up with sickle cell trait, in the same way they do for positive screens of disorders. This would require more staff for case management follow-up. It would amend Health and Safety Code Chapter 33, and would require a rule change.
- Dr. Drummond-Borg also referred members to HB 1897, proposed legislation related to immunization and screening. It would add NBS tests to the immunization registry, as well as vision, hearing, and spinal screening.

# **PUBLIC COMMENT**

There were no public comments.

#### **ADJOURNMENT**

The next meeting is scheduled for Friday, June 1, 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 12:50 p.m.