



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 7, 2014

Members Present:

Craig Benson, Consumer Rep
Patricia Brewer, TDI Rep
Alicia Dimmick Essary, DADS Rep
Debra Freedenberg, MD., DSHS Rep

Video Conference

Lillian Lockhart, MD, UTHSC Rep

Staff

Caeli Paradise
Rachael Lee

WELCOME AND INTRODUCTIONS – Craig Benson

Craig Benson acted as chairman in place of Chairman Jones who was not in attendance. Mr. Benson called the meeting to order and introductions were made.

APPROVAL OF MINUTES – Craig Benson

Minutes for the September 13, 2013 meeting were not recorded, so there were no minutes to approve.

REPRESENTATIVE REPORTS

Texas Department of Insurance (TDI) – Patricia Brewer

Patricia Brewer reported that she is working on synchronized forms for requesting prior authorization of health care services. It will be required for practically all state regulated plans in Texas to use once they are adopted including Medicaid. We will have to have an advisory committee for both the pre-authorization health service form and the pre-authorization prescription drug form.

Department of Aging & Disability Services (DADS) – Alicia Dimmick Essary

Alicia Essary reported that they continue with the steady conversion of many services over the managed care and working on the settlement of a legal issue having to do with services available for people who have intellectual disabilities and are in nursing facilities. We will be handling them a little differently in the future, although the details of that are not yet known. Actually, we are going to try to avoid it more vigorously than we have been. A discussion was held by the committee regarding Prader-Willi Syndrome, which is a rare genetic disorder causing compulsive overeating. There is no off switch in the brain on the appetite.

University of Texas Health Science Center (UTHSC) – Lillian Lockhart

Lillian Lockhart had nothing to report.

Title V Contractors- Carlos Bacino

Not in attendance, so there is no report.

Newborn Screening Program and Laboratory Updates – Debra Freedenberg, Rachel Lee

Dr. Debra Freedenberg and Dr. Rachel Lee gave updates on the newborn screening program and the laboratory.

Newborn Screening Program Updates

- Two screening tests for each baby born in Texas
 - 24 – 48 hours of age
 - 1 – 2 weeks of age
 - Infants testing positive receive prompt and appropriate confirmatory testing.
 - Diagnosed infants are maintained on appropriate medical therapy.
 - Currently screen for 29 disorders
- 2013: Received ~753,000 specimens (~386,700 newborns)
- Specimens Assayed and Reported: ~745,500
 - Test specimens Monday through Saturday
 - Average: 2,450 specimens per day
 - ~ 7,400 unsatisfactory specimens (~0.98%)
- In 2012, ~16,145 (~2%) specimens reported with presumptive positive results
- ~800 cases diagnosed annually
- Lab continues quality improvement activities
 - Expedited submitter fax notification on unsatisfactory specimens
 - Revised submitter quality report cards – available online July 2013
 - Monthly submitter calls to consult providers with highest unsatisfactory rates
 - Weekly recruitment / promotion of NBS Web Application (5 user contacts/week)
 - Complete redesign of NBS laboratory website
 - NBS Transit Time and Courier Services
 - March 16, adding Sunday pickup for those hospitals that are already on the courier service
 - Reconciliation of packing list
 - Server OS and SQL and Lab LIMS upgrades
 - NBS LEAN 6-Sigma projects
- Timeline of a specimen in the laboratory
 - Usually takes 5 days from the day of receipt of specimen to the day results reported
- Working on Second Tier Assay to cut false positive rate
 - CAH and VLCAD
- Electronic Data Transfer
 - Web-based demo entry and reporting
 - Available to any healthcare provider, Username & password required
 - Users from 1046 facilities submitting 75% of NBS specimens
 - ~2% of all demographics
 - ~12,000 result views per month
 - Monthly report cards available for all of 2013
 - HL7 file transfer functions for LIMS
 - Direct transfer of demographics and results between computer systems
 - 3 large hospital systems fully implemented (~10% of all specimens)
 - Several facilities waiting to start implementation
 - New facilities on hold pending system reevaluation

- Implementation of HB 411
 - Became law in June 2011 and made major changes to NBS specimen retention and residual use
 - Multiple internal processes, procedures & policies have been revised
 - Institutional Review Board policy has been revised
 - Opt-in for long term storage and possible research uses - effective June 1, 2012
- Parent decision form and parent education form developed and distributed
 - ~49% of NBS have a parental decision form returned
 - 74% of those returned and valid give permission for public health research uses (36% of all newborns)
 - Survey of all submitters to identify challenges in returning parental decision forms
 - Worst performers tend to be large hospitals
 - Most common practice is to include Decision form in discharge packet with little or no explanation
 - Report Card
 - Destruction Process to start in May 2014

Rachael Lee wanted to update the committee that HIPAA recently changed the law that parents and patients can request newborn tests results directly from the laboratory. Currently, the lab can only release results to the commissions and pcps. They are starting to develop a process that will allow them to do this.

Texas Newborn Hearing Screening

- CDC-5 year grant \$162,000
 - Tracking and data integration electronic health records
 - HL-7 Messaging IT Grants to offset facility implementation cost
 - On-going interoperability enhancement of management information system
 - Pilot Parent Support Group Project to reduce loss to follow-up/loss to documentation
- HRSA -3 year \$300,000/year
 - On-going interoperability enhancement of management information system
 - Development and updating of new and existing educational materials and training modules
 - Audiology engagement initiative to increase documentation and usage of the MIS
 - Pilot Parent Support Group Project to reduce loss to follow-up/loss to documentation
- Critical Congenital Heart Disease
 - US Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC)
 - In 2010, recommended that CCHD be added to the newborn uniform screening panel to identify newborns with structural heart defects associated with hypoxia that could have significant morbidity or mortality early in life with closing of the patent ductus arteriosus or other physiologic changes
 - 2011, Endorsed by Secretary of HHS Kathleen Sibelius
 - 2013, Texas HB 740 added CCHD to core panel in 83(R) session
 - Rules were submitted to DSHS Council 2/27/2014
 - The seven defects classified as CCHD are:
 - Hypoplastic Left Heart Syndrome (HLHS)
 - Pulmonary Atresia with Intact Septum (PA/IVS)

- Tetralogy of Fallot (TOF)
- Total Anomalous Pulmonary Venous Return (TAPVR)
- Transposition of the Great Arteries (TGA)
- Tricuspid Atresia (TA)
- Truncus Arteriosus Communis (TAC)
- DSHS distributed survey to all birthing hospitals and birthing facilities to determine current readiness to implement CCHD screening
- Survey developed by D'Andra Morin, Debbie Freedenberg and Dorothy Mandel
 - Prelim data 60/96 (62.5%) perform CCHD screening
 - Prelim data 48/60 (80%) of those performing CCHD screening use recommended algorithm
- Funded TxPOP (Texas Pulse Oximetry Project), an educational initiative
- Implementation planning has begun
- Developed CCHD Tool Kit available on DSHS web site as well as Texas Pediatric Society web site
- Tool kit contains multiple educational materials
 - Algorithm, brochures for parents and health care providers, nurse information, technical information
- DSHS funded TxPOP2 related to NICU protocols and rural hospitals
- Funded TxPOP (Texas Pulse Oximetry Project) an Educational Initiative
- Potential New Conditions
 - Pompe
 - The Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC) voted to add Pompe disease to the RUSP on May 17, 2013
 - HHS Secretary Sibelius requested the Interagency Coordination Council (ICC) to review with recommendations by July 31, 2014
 - Mucopolysaccharidosis Type 1 (MPS1)
 - DACHDNC sent to formal evidence review
 - X-Linked Adrenoleukodystrophy (X-ALD), Mucopolysaccharidosis Type (MPS 2)

OTHER BUSINESS

None.

PUBLIC COMMENT

No public comment.

ADJOURNMENT

The next meeting is scheduled for **Friday, June 6, 2014, 10:30 am to 12:00 pm in conference room T-609**. There being no further business, the meeting was adjourned.