



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 7, 2013

Members Present:

Kyle Jones, Consumer Rep, Chair
Craig Benson, Consumer Rep
Patricia Brewer, TDI Rep
Carlos Bacino, MD, Title V Contractors
Alicia Dimmick Essary, DADS Rep
Debra Freedenberg, M.D., DSHS Rep

Video Conference

Lillian Lockhart, MD, UTHSC Rep

Staff

Patrick Clynch
Rachel Lee

WELCOME AND INTRODUCTIONS – Kyle Jones

Chairperson Kyle Jones called the meeting to order and introductions were made.

APPROVAL OF MINUTES – Kyle Jones

Discussion was held regarding the minutes from the March 1, 2013 meeting. Dr. Freedenberg and Alicia Essary requested that 2 changes be made. Minutes were approved contingent on changes being made. Motion passed.

REPRESENTATIVE REPORTS

Texas Department of Insurance (TDI) – Patricia Brewer

Patricia Brewer reported that they are starting to implement legislation that they believe is going to become effective if the Governor signs it or allows it to become law. Some of these require them to work with Health and Human Services Commission (HHSC). One of the interesting ones is the standardized prior approval form for requesting prior approval of health care services and certain prescription drugs. They will be developing that.

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

Alicia Essary reported that they are still heavily involved in the same things as last meeting. Federal funding has been received for the Balancing Incentive Program that will help them significantly improve access to DADS services. Eventually, and she is not sure of the time frame, that they will have what is called aging and disability resource centers immigrating single front doors for all DADS services covering the entire state; however, the services they cover, are within the next 5 years or so, are not going to be DADS services most of the time. Most of DADS services are being rolled into Star+Plus under SB 7 and over the course, she thinks it runs out to 2020, it is a long phase in, all the services that are now handled independently by DADS will for the most part be rolled into the Managed Care Program. Since many, if not most people who access DADS services, are not Medicaid eligible except by virtue of their disability, the front door remains very important because many people are not Medicaid eligible when they come to seek DADS services. The other thing that is important in SB 7 is that habilitation services, the most basic service for people with intellectual

and developmental disabilities many of whom have genetic disorders, will be available as independent of the waiver program as an entitled services. Most individuals with disabilities are already Medicaid eligible and they will begin to get habilitation services without having to wait. Nothing has happened about the state supported living centers.

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

Lillian Lockhart had nothing to report.

Title V Contractors – Carlos Bacino

Dr. Bacino reported that there has not been much change. There has been a lot of volume changes. He is still providing services to a number of outreach clinics. His only concern is that right now, he has a nurse, genetic counselor out there in those clinics who has seen a large number of patients Medicaid reimbursed. Because of the Title V related issues, we have committed to provide services, so we will be going there until the end of the contract. Unfortunately, he will have to take the nurse and she will be absorbed into the Harris County Health System and all of those clinics that she is attending to will have no one to provide genetic services. So she is getting more and more patient referral and he knows that when they are not there, those patients will end up in the system. He is afraid that many will not make it because of access, transport and other issues. Doctors see the patients, they make the appointment, they do ultra sound, they do the genetic counseling, so they go, but if they send them for a genetic service outside, i.e. Ben Taub or LBJ, most people probably will not ever make it. So that is something, just for the record, he thinks needs to be said.

Consumer Reports – Kyle Jones, Craig Benson

Nothing to report.

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

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

- Newborn Screening
 - Required to screen for all conditions on the Recommended Uniform Screening Panel (RUSP)
 - ◆ 29 disorders detected by the DSHS laboratory, the 30th being hearing which is a point of contact test
 - Two screen state
 - Diagnose between 700 to 750 children with confirmed diagnosis annually
 - Newborn Screening Rules pushed back. Public comment scheduled to begin July 1

Rachel Lee reported that recently Pompe was recommended to be added to the panel by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) and is pending approval by Secretary Sebelius. Dr. Freedenberg stated that the committee's name has been changed to Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC). After they make their recommendation, Secretary Sebelius does not have a deadline to respond to the recommendation. If she is busy with other things, it may be a while before hearing anything. At the time that Pompe was added, there was a Public Health Laboratory and follow up component assessment done on the impact all the conditions being added now have impact on public health.

- HB 411
 - Update on parental consent forms for storage and residual storage in use of newborn screening specimens
 - ◆ Implemented in June, 2012; doing well
 - ◆ From June, 2012 until January, 2013, overall had an estimated response rate of 43.8% of forms received on children screened
 - For all babies born, in that time frame and screened, 43% of those had a form returned. Of those, 71 provided consent with 24.9% say no, 3.8% invalid forms
- Severe Combined Immunodeficiency (SCID)
 - Went live for SCID screening December 1
 - Screened 300,000 specimens
 - Found 2 children with SCID
 - Have found a lot of secondary targets from the screening
 - ◆ DiGeorge Syndrome
 - ◆ Downs Syndrome
 - ◆ Kids who had other medical issues
 - Continue talks with immunology consultants monthly
 - ◆ To smooth out program
 - ◆ Help reduce number of presumptive positives that we are seeing
- 2nd Tier Assay for CAH (Congenital Adrenal Hyperplasia)
 - On an extension now
 - Continuing to do validation
 - ◆ Screening for CAH has a high presumptive positive rate. This would be 2nd tier testing to help bring down that presumptive positive rate
 - ◆ Measure 5 steroids to help identify whether it is a true positive or a false positive
- Newborn Screening Advisory Committee
 - 9 member committee formed May, 2010
 - Legislature increased membership to 10
 - 8 meetings held
 - 1 vacancy, applications received
 - Members appointed by Dr. Lackey
- Newborn Screening Hearing
 - Grants continue
 - CDC entering its 3 of 5; it's data integration and interoperability; involves HL messaging
 - HRSA grant that is in 3 of 3
- Continue to utilize all resources available for educational efforts
 - Grand Rounds
 - Tales from the Crib
 - Journal Club
 - Educational Outreach
 - Educator available
 - Messaging on Newborn Screening submitter list
 - Redesigning the website
- Title V
 - 4 contractors
 - All refunded at their current funding level
 - Limited utilization of the funding

- 3 medical provider educational conferences planned
 - ◆ Dallas 6/22
 - ◆ Austin 6/29
 - ◆ San Antonio 7/13
 - ◆ Designed to outreach to primary care providers
 - ◆ Same structure to conferences but with different speakers
- Funded 6 clinical genetics student summer internships for 2013
 - Funded with some of the Title V monies that was not utilized
 - 2 have already started
- Funded a one year project for Critical Congenital Heart Disease
 - Funded with funding from Childrens Heart Outreach Program grant from Special Health Care Needs
 - Intended to be educational to medical professionals
 - PI is Dr. Alice Gong with joint project with Dr. Charleta Guillory
 - Point to service testing

OTHER BUSINESS

Committee discussed social media opportunities, and Patrick Clynych stated that he had updated the website with the removal of old minutes and the addition of new minutes. The committee discussed the evolving genetics practices which included two primary issues: limited utilization of Title V funding and the work force issue.

Chairperson Jones stated that the statute does not require the committee to have by-laws. He doesn't know if by-laws are necessary right now, but he is open to thoughts from anyone else. The consensus of the committee was not to spend time on adopting by-laws right now.

AGENDA ITEMS

- Talk about distributing and communicating the Resource Allocation Plan to constituents of the IACGS, but also to other people in the community the committee think might be interested in supporting their proposal

PUBLIC COMMENT

No public comment.

ADJOURNMENT

The next meeting is scheduled for **Friday, September 13, 2013, 10:30 am to 12:00 pm in conference room T-609 on DSHS Main Campus**. There being no further business, the meeting was adjourned.