



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 1, 2013

Members Present:

Patricia Brewer, TDI Rep
Alicia Dimmick Essary, DADS Rep
Debra Freedenberg, M.D., DSHS Rep
Kyle Jones, Consumer Rep
Craig Benson, Consumer Rep

Staff

Patrick Clynch
Susan Tanksley

Guest

Kim Petrilli, March of Dimes

WELCOME AND INTRODUCTIONS – Kyle Jones

Newly elected chairperson Kyle Jones announced a quorum was present. He asked that everyone that is present introduce themselves for the record. Introductions were made and Patrick Clynch stated that the meeting was being recorded.

APPROVAL OF MINUTES – Kyle Jones

Discussion was held regarding the minutes from the December 2, 2012 meeting. Dr. Freedenberg requested that a minor change be made under the Newborn Screening and Laboratory Updates. She requested that under the first bullet PRM be changed to PI. No other corrections were requested. Craig Benson made a motion to approve the minutes contingent on change being made and Dr. Freedenberg seconded. Motion passed.

REPRESENTATIVE REPORTS

Texas Department of Insurance (TDI) – Patricia Brewer

Patricia Brewer reported that right now they are involved with pending legislation. In December, Senator Ellis refilled his bill from last session that calls for Texas Exchange. There has also been another bill filed, slightly different, but would also call for a Texas Exchange.

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

Alicia Essary reported that their biggest focus that we have right now is implementation of the funding that we got for the Balancing Incentive Program which will improve the access to services. The other big thing that is pending is SB 7 which would roll nearly all of the services that we currently operate through DADS contract providers would be rolled into the Star Plus System over the course of the next few years. SB 7 is in the hearing process right now on a committee substitute and it will have massive impact on the way services are used by people with mental disabilities.

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

Lillian Lockhart was ill and did not attend meeting. No report.

Title V Contractors – Carlos Bacino

Dr. Bacino informed Patrick Clynych that the only meeting he would be able to attend this year would be the June, 2013 meeting. No report.

Newborn Screening Program and Laboratory Updates – Debra Freedenberg, Susan Tanksley

Debra Freedenberg and Susan Tanksley gave updates on the newborn screening program and the laboratory.

- Title V
 - Previous cycle had 6 contractors under Title V; this cycle have 4 contractors
 - Continue to under-utilize the funding
 - ◆ Large amount of services now reimbursed by CHIP/Perinatal rather than Title V funding
 - Exploring options to utilize current funding and get into contractors resources
 - Still concerned about coverage around the state
- One of the projects funded is an educational initiative about newborn screening for critical congenital heart disease
 - PI is Dr. Alice Gong with Dr. Charleta Guillory
 - Project progressing; concludes at the end of August
 - Should receive data
 - Develop educational modules for screening for critical congenital heart disease
 - Three bills have been submitted relating to screening for critical congenital heart disease
 - ◆ Unknown which one is going to go or what is going to go
 - ◆ Bill analysis has happened
 - ◆ Screening by pulse oximetry; only method for screening now
- Severe Combined Immunodeficiency (SCID)
 - Went live for SCID screening December 1
 - Found 1 child with SCID; unfortunately child passed away
 - Have found a lot of secondary targets from the screening
 - ◆ DiGeorge Syndrome
 - ◆ Downs Syndrome
 - ◆ Kids who had other medical issues
 - To date out of 15 children 1 had SCID
 - 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
- Educational Initiatives
 - Scheduled genetics conferences
 - ◆ Titled Genetics to Genomics: Into The Future
 - ◆ Held in Austin, Dallas and San Antonio
 - ◆ 2 schedule for June; 1 scheduled for early July
 - ◆ Working with contractor to fill in speakers for meetings

- Have 1 educator who can go out related to newborn screening and provide general information
 - Providing information to those requesting for more information on SCID
 - Dr. Freedenberg probably will be going out and doing some grand rounds for some hospital, university systems around the state at their request within the next 6 to 8 months
 - Participate in the Regional Collaborative
 - ◆ Active within that group
 - ◆ Meeting in March
 - Attending the Newborn Screening Symposium in Atlanta, GA May 5-10, 2013
- HB 411
 - Update on parental consent forms for storage and residual storage in use of newborn screening specimens
 - ◆ Changes made according to HB 411
 - ◆ Implemented in June, 2012
 - ◆ 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, 43.8% of those had a form returned. Of those, 71.3% provided consent with 24.9% say no, 3.8% invalid forms

Consumer Reports-Kyle Jones, Craig Benson

Nothing to report.

OTHER BUSINESS

Council members held a discussion regarding the development of by-laws for IACGS. Patrick Clynch stated that he has a set of by-laws used for the Newborn Screening Advisory Committee that he plans to send out to the committee for their information to look at. Chairman Jones thought they had looked at the by-laws at a previous meeting and may have a copy. Dr. Freedenberg thought they had looked at the law, but not the by-laws. Chairman Jones said that he thought they had done both, but could be wrong. He stated that he would go through his files to see if he could locate them. He asked Patrick if he had a copy and Patrick said no. Chairman Jones said that at the very worst, they could get proposed by-laws that they develop, have everyone review those and then approve them at a future meeting.

AGENDA ITEMS

- Include Public Comments on future agendas right before adjournment
- Begin thinking about the process of drafting the next recommendations
- Discuss website for IACGS and social media opportunity

PUBLIC COMMENT

No public comment.

ADJOURNMENT

The next meeting is scheduled for Friday, June 7, 2013, 10:30 am to 12:00 pm in conference room K-100 on DSHS Main Campus. There being no further business, the meeting was adjourned.