



Interagency Council for Genetic Services

Texas Department of State Health Services ⇄ Department of Aging and Disability Services
Genetic Services Contractors ⇄ University of Texas Health Science Centers
Texas Department of Insurance ⇄ Consumer and Public Representatives

December 3, 2004

Present:

Margaret Drummond-Borg, DSHS, Chair
Bob Cleveland, Consumer Representative
Lillian Lockhart, UTMB
Mary Kukolich, Provider Representative
Marjorie Doubleday, DSHS
Michele Goddard, DSHS

Absent:

David Rollins, DADS
Margaret Lazaretti, TDI
Janet Shephard, Consumer Rep

The minutes from September 10th were reviewed, approved and seconded.

Margaret Lazaretti is the new representative from Texas Dept of Insurance who was unable to be here today.

AGENCY REPORTS

DSHS - Margaret Drummond-Borg

In September all management positions were posted and interviews were conducted. There were reductions in the number of management positions. Some TDH employees did not have positions in the new DSHS structure.

Frozen positions were made available to the people who were in the RIF.

DSHS is a very large agency now because of the employees at the state hospitals. We are working with MH in looking at ways we can integrate & work together on different projects and services. DSHS will continue to look at optimization and merging of programs to try and improve efficiencies.

HHSC has combined HR staff. Here, on this campus, is housed the one employment office for HHSC agencies. There are also new combined HR policies also under HHSC.

Some of the 800 numbers used by the previous agencies for various programs have been combined and some have been deleted completely. The Baby Love line no longer exists as of November 15th. There is now a 211 line, which is a general information line.

The new reorganization hasn't really affected Genetics or Newborn Screening. These two programs are still together as part of the Health Screening Branch.

CSHCN is merging with Kidney Health.

DADS- Mental Health – David Rollins

No report.

TDI – Margaret Lazaretti

No report.

UTMB – Lillian Lockhart

No report.

Expanded Newborn Screening – Margaret Drummond-Borg

DSHS has proposed a number of exceptional items, one of which is the expansion of the Newborn Screening Program using Tandem Mass Spectrometry. The DSHS list will be presented to the finance committee. The Lab is asking for 4.5 million dollars as start-up funding to buy the machines and to pay for the first 6 months of running the program. It takes about that much time before they start to get funds back from Medicaid.

The expansion is based on the original proposal in 2002 by the workgroup that we start off with just four new disorders and then expand.

The question was asked if there was any funding for people to see these babies once they are identified. Margaret stated the answer was no, there were no funds available from DSHS specifically for metabolic evaluations, as they should be covered by Medicaid, CHIP or private insurance. She also stated that this point was made at the last Metabolic Consultants Meeting in November. The consultants were asked that if they get increased numbers, are they going to be able to handle the increase and they said yes. Based on what other states have been doing, the false positive rate is about 0.3% of the births. We would end up with about 1,000 more abnormal results a year and of that we would end up diagnosing about 70 children with conditions that were picked up by Tandem Mass Spec. We know from other states, that you rarely get false positives from MCAD. If we go ahead with the expansion and the metabolic specialists do get the increased numbers, then they feel they can ask for extra staff.

The metabolic consultants felt that the local doctor could order some testing without the babies having to be seen by a consultant.

March of Dimes (MOD) is very interested in expanded newborn screening and they recommend testing for 30 disorders. MOD decided that whatever the American College of Medical Genetics (ACMG) recommends, they will support. One of their members was on the ACMG workgroup, so the MOD knows what may be in the final recommendations. MOD is waiting for ACMG to publish their final list. As I understand the list has been finalized but it won't be published until some time next year. MOD will put forward a bill in Texas sometime next year when the official list comes out asking that NBS be expanded for the entire 30 disorders. It is possible the report may recommend reporting all abnormal peaks found on MS/MS. This may be another 25 abnormalities to be reported.

Presently, when NBS Case Management gets an abnormal result from the Lab, we call the physician and tell them the confirmatory tests needed. We'll continue to do that with the expanded screening, however if these other 25 abnormalities are being reported out, then the physician will want to know what to do next, so they'll end up calling DSHS or the metabolic specialist.

The Case Management staff will be affected in that more staff will be needed if we go to expanded screening.

The four disorders to be initially added will be MSUD, MCADD, GA1, and homocystinuria.

There was a meeting at TMA of stakeholders on Dec 2nd regarding newborn screening in TX. In the morning, there was a presentation by Dr. Therrell regarding the overall status of newborn screening in the U.S. and there was a presentation by Dr. Green, the medical

director of MOD. She was talking about MOD perspective on expansion of screening. Dr. Drummond-Borg and Dr. Hutcheson talked about how we do screening now. Dr. Hutcheson also talked about the exceptional item. Dr. Spier talked about the TMA perspective. Copies of this were handed out to IAC members. Dr. Spier put forward the TMA perspective and basically brought up 5 points, including the need to have partnership with patient's PCP other groups in order to appropriately cover all aspects of newborn screening; education and funding. He also came up with some recommendations from TMA. He suggested that there should be more communication and collaboration between stakeholders and there should be more discussion about results, the processes, barriers, including discussion with other states and what they have learned. DSHS should coordinate the stakeholders role and involvement. DSHS already had a previous meeting where we had stakeholder input about expanded newborn screening, and at the same meeting there was discussion about education and it was a big part of what we felt was necessary. TMA also recommended that the Newborn Screening Program should be evaluated by the National Newborn Screening and Genetics Resource Center. This is to take place the end of February. However, the report will not be available until later in May, which is late for it to be of any benefit in this legislative session. They talked about determining each stakeholder's responsibility for participating and ensuring coordination of an effective, efficient and fiscally sound system. At the TMA meeting they wanted people to sign a form stating support of TMAs position regarding newborn genetic screening. This said 'TMA supports having a solid screening infrastructure that contributes to the public health prior to expanding the newborn screening testing program in TX.'

DSHS is going to move ahead with the exceptional item, hoping we'll get funding for that. The assessment of the Newborn Screening Program will be in February. The question is whether the IACGS is willing to sign the TMA statement. It was decided that the IACGS would not sign the way it is currently written.

Much discussion took place about cost of the expanded screening.

Mr. Cleveland brought up what happened with Mississippi with expanded screening. Dr Drummond-Borg stated that Mississippi passed a bill requiring the state to develop a brochure to notify everyone about expanded newborn screening. When they did that, in the next session, the legislature mandated the expanded screening. What happened was when the literature was sent out, people wanted the screening but they had to pay for it. Private labs outside the state do the screens and they want a payment with the screen as it is sent in. The physicians would have had to write the check themselves to send off the screen.

Dr. Lockhart asked if the new screening would have to be done twice & the answer is yes. Some of the states only do it once, but those that do it twice have shown cases have been missed on the first screen and they are finding that some of the abnormalities don't show up until a couple of weeks.

We have been looking at what legislation has already been filed. There is one bill already filed to bring the Medicaid fees back to where they were before the last cut back.

Dr. Drummond-Borg also stated she received a call regarding the IACGS allocation plan and was asked what kind of legislation do we want for funding.

Dr. Kukolich stated that in reading the allocation plan, she feels that somehow we need to reinstate some funds in the Title V funds to cover other than just direct patient care. She used to be able to justify traveling to some cities in the state but as it is now, she can't afford to do that on what she is paid for seeing Medicaid and Title V patients.

Dr. Drummond-Borg will research funding for outreach services

Other Business:

Dr. Drummond-Borg stated that it's time for the council to nominate a chairperson. Nominations were made & Dr. Drummond-Borg was voted as Chair for another year.

The next meeting date is March 4,2005.

Meeting adjourned.

12/9/04
Rev. 3/2/05

Interagency Council for Genetic Services ☞ 1100 W 49th St, Room M555 ☞ Austin TX 78756 ☞ 512/458-7111 ext. 2193