Congenital and Inherited Disorders Advisory Committee
Minutes
April 20, 2018
1:00 p.m. to 3:00 p.m.
Drake Community Library Grinnell, Ia
Web cast

M i n u t e s

Members Present	Members Absent	Others Present
Sandra Daack-Hirsch	Paul Romitti	Kimberly Noble Piper
Bobbi Buckner Bentz	Tom Scholz	Carol Johnson
Val Sheffield	Stewart Boulis	Mike Pentella
Stanton Berberich	Lori Murphy-Stokes	John Bernat
Stacy Frelund	Nate Noble	Amy Calhoun
George Wehby	Kelly Schulte	Travis Henry
Beth Tarini	Kimberly VonAhsen	Lina Reinders
Amanda Devereaux	Andrea Greiner	Emily Price
Ashley Hinson	Dan Rowley	Lyndi Buckingham-Schutt
Carrie Bernat		Kelli Ryckman
Hannah Bombei		
Francis Degnin		
	Representative Wessel Kroeschell	
	Senator Ragan	

Topics	Discussion/Action
Call to Order	▪ Buckner-Bentz called the meeting to order at 1:05 pm. ▪ Roll call attendance was taken. A quorum is present.
Budget Proposals - STFU	STFU – asking for an additional RN for follow-up – increased workload; increased CH/NICU protocol; time to manage cases through new database. Also need to add rent for STFU space. Daack Hirsch ? RN added for data base use? Carol – using two new databases – all RN will be using two databases now. Romitti ? – Description of databases OZ and SHL – Carol described differences in data system.
Budget Proposals - SHL	SHL – Able to share some costs with ND, SD to help keep IA costs down. 60% costs for IA, 20% and 20% for ND and SD. Fixed costs vs incremental explained. Starts with a cost-based budget and builds from there. Budget includes anticipated increases in costs added to base expenses. Looking at about a $5.00 increase in fee for SHL. Three additions to the budget going forward: 1.) As technology and knowledge has advanced, in order to assure the algorithms used to determine risk of conditions are as precise as they can be, there is a need to migrate from population risk analysis to individual risk analysis. This requires an ongoing risk evaluation. Need for bio-informaticist to conduct ongoing analysis. 2.) Second-tier testing will increase due to types of conditions now screened for. 3.) Due to complexity and methods advances, it is no longer realistic to expect all of the laboratorians to be cross-trained in all testing methods. Changing to a team concept where

	teams are responsible for testing using specific methods. In order to staff these teams, need three additional lab staff. For IT, move to HL7 will require additional expertise. ? Buckner Bentz – How much of the budget comes from fees versus appropriation? Berberich – cost based fee. All costs are covered by fees. No appropriation for any NBS programming. There is an additional 10% of the fee that goes to a developmental fund. This fund supports to advance NBS programming. Courier is included in costs, as well. Metabolic Food Formula fund provides $4.00 from the fee. $1 goes to provide for storage of specimens $2 goes to IDPH to support program administration. Discussion of how hospital/patient is billed. Only appropriation for Food and Formula was eliminated this year. Berberich – multi-year budgeting has allowed the fee to remain stagnant for over 5 years. If we were able to provide the current services going forward, we would still need a fee increase of $5. Additional $15 increase needed to provide the additional services listed above. Fee increases from $122 to $137. Potential to add NBS testing for Alaska. This would reduce the IA cost load to 51%. So even with the additional functions needed for IA, adding the 11,000 AK specimens (revenue), we can absorb IA's share of the costs. Tarini? AK screen the same conditions? Berberich – they screen for an additional condition homozygous in 80% of the population. Costs specifically assigned to AK. Degnin – When will we know about AK? AK would like to start July 1, and SHL is working toward this date. CPT1A mutation analysis development is underway. With the addition of new conditions, the Ankeny lab will run out of space to house all of the new instruments. The SHL is actively looking at options. $122-$133 if AK. $122-$1
Budget Proposal – Food and Formula	Sheffield proposing a $6.00 increase to F&F. Currently $4. Lost about $159,935 appropriation last year. Ran a deficit of $80,000 which is picked up by the Department of Peds. $240,000/40,000 patients comes to $6/patient. Currently running a larger deficit for the current fiscal year. Deficit comes from no or low reimbursement from insurance. What isn't reimbursed is written off through IowaCares program. Hospital is obligated to write it off. Department of Peds buys the formula and "sells" to patients (cheaper to purchase through hospital purchasing). Sheffield gives history of food and formula budget requests. Stated to IDPH years ago that we should quit doing NBS, if we can't treat. What if ? comes up about why we don't pay for ERT, etc.? Calhoun – usually other treatments are covered by insurance. F&F will "fix" the patient, compared to other treatments like Kuvan, which is much more expensive and less effective, but covered by insurance. Food is usually never covered by insurance. Tarini –There could be a push to insurance companies to cover other therapies. Not an option with current FDA and CMS structures for F&F. Many other states have similar F&F structures (fees), or appropriations (which we know goes away) or Title V. Some may question why does everyone who has a baby screened have to "pay for F&F" for those few who have a child needed F&F. It is similar to insurance – you are paying on the chance that your baby may have a metabolic condition. Degnin - The cost savings for treating disability and morbidity for untreated condition is much costlier. Tarini – articles on cost benefit for treating PKU research is available. Romitti – (specific to F&F) dealing with the legislators you need to realize that fee increases are often seen as taxes to some. Need to look at long term savings of NBS

	treatments and be prepared to discuss to the legislator's "perspective." Berberich - The opportunity for harm is present to every baby – that's what population based screening addresses.
Budget Proposals – IDPH	EHDI – Trout – what does the EHDI request pay for? Devereaux – if fee is increased for hearing screening, why not add to cover hearing aids/audiological services? INSIS – How much does insurance cover now? Who bills for this? Who eats the costs?
Budget Proposals – General discussion	Romitti – Is concerned that the Registry has never been considered for provision of surveillance activities. It has been a longer standing program than even EHDI. When is CIDAC/CCID going to take care of all of its programs?
Other discussion	Beth – SMA was approved by SACHDNC. Goes to Secretary of DHHC. Interagency Coordinating Council. Trout – Does it matter what SACHDNC says for Iowa's review or decision about whether to add a condition?
Adjournment	Meeting adjourned at 2:02 pm.