

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

The meeting was called to order by Chairman James Barnett at 1:30 P.M. on January 17, 2007 in Room 231-N of the Capitol.

Committee staff present:

Emalene Correll, Kansas Legislative Research Department
Terri Weber, Kansas Legislative Research Department
Jim Wilson, Office of Revisor of Statutes
Nabuko Folmsbee, Office of Revisor of Statutes
Morgan Dreyer, Committee Secretary

Conferees appearing before the committee:

Howard Rodenberg MD, MPH, Director, Division of Health, KDHE

Others attending:

See attached list.

Introduction of Bills

Upon calling the meeting to order, Chairman Barnett asked for any introduction of bills. Senator Schmidt presented the Committee with five bill introductions.

1. 7rs0450 adds a predisposition for asthma into the health assessment done with regard to school physicals.
2. 7rs0476 is an act concerning health insurance, would increase the age of dependent coverage to age 26 regardless of if the independent were enrolled in school. A military component is included that if a individual is in active duty between the ages of 18 and 26, would allow them to bank that time, so when they came out of active duty they would be eligible as dependent coverage for that amount of time.

The next three bills are conceptual
at the request of KDHE:

3. Sharing KBI background check results with child placement agencies.
4. SRS adoptive placement agreement (squaring up statutes involved)
5. Enhancement to the Cancer Registry

The drafts of these bills were not available at the time of the meeting.

The motion was made by Senator V. Schmidt to adopt the introduced bills. It was seconded by Senator Brungardt and the motion carried.

Presentation on Expanded Newborn Screening in Kansas

Chairman Barnett then called upon Dr. Howard Rodenberg MD MPH, Director, Division of Health, Kansas Department of Health and Environment who presented information to the Committee on Expanded Newborn Screening. Highlights of his presentation included:

Slides on:

1. What is NBS
2. NBS in Kansas: Current
3. Expanded NBS (XNBS)
4. Legislative History
5. XNBS Working Group
6. Working Group Findings
7. Working Group Model
8. Plans for Implementation

Report of the KDHE Newborn Screening Advisory Group
Data Charts on other States in comparison NBS

A copy of the presentation is (Attachment 1) attached hereto and incorporated into the Minutes as referenced.

CONTINUATION SHEET

MINUTES OF THE Senate Public Health and Welfare Committee at 1:30 P.M. on January 17, 2007 in Room 231-N of the Capitol.

Questions came from Senators Barnett, Palmer, V. Schmidt, Journey, Wagle regarding list of clinical conditions, funding revenues, consent by parent, conditions leading to disability, follow-up services, mandates, medicaid reimbursement, midwife situations, retrieving patient information, costs, and total new dollar request.

The Chair asked if the Committee would like to have an input to the Committee of Senate Ways and Means to support the bill concerning Expanded Newborn Screening.

The motion was made by Senator Brungardt to authorize the Chairman to express the Committee's approval on the Expanded Newborn Screening legislation by KDHE. It was seconded by Senator Journey and the motion carried.

Chairman Barnett announced that the final item on the agenda was for the Minutes to be approved for the Senate Public Health and Welfare Committee on January 16, 2007.

The Chair noted to delete 'as amended' on the first underlined action.

The motion was made by Senator V. Schmidt to approve the Minutes with the changes announced. It was seconded by Senator Gilstrap and the motion carried.

Adjournment

As there was no further business, the meeting was adjourned at 2:20 p.m.

The next meeting is scheduled for Thursday, January 18, 2007.

Jan. 17, 2007

Senate Public Health and Welfare Committee

Please Sign In

Jodi Faustlin - SAINT LUKE'S HEALTH SYSTEM

Cynthia Smith

SCL Health System

Jim McLean

Ks Health Institute

Carolyn Smith

VEHS

Mark P. Murtiz

WA CARUSI HEALTH SYSTEM

Chad Austin

KHA

Doug Bowman

Coordinating Council on Early Childhood

Bill Brady

KHA

Jill Shelton

Legislative Post Audit

Gina Mulanick

KCSL

Kathy Damm

Saint Lukes

Gene Amherst

KITP

Quane Baker

KDAIE

Dick Morrissey

KDHE

Judith Keenan

KDHS

Shana Godby

KHPA

Richard Somogyi

Kenney and ASSOC.

Brad Smeat

CMFHP

Cara M. Greve

KAMU

Carolyn Maddendox

Ks St No Care

Senate Public Health and Welfare Committee

Please Sign In

Michelle Black

Parent

Susan Kang

KDHE

Tara Green

CMFHP

William Sneed

AWIP

John Peterson

Capital Strategies

Expanded Newborn Screening in Kansas

Report of the KDHE Newborn Screening Advisory Group

Prepared by Aidan Loveland Koster

Revised, January 2007

Senate Public Health and Welfare Comm.
Attachment #1

January 17, 2007

Expanded Newborn Screening in Kansas

Issue Definition

The Division of Health proposes instituting Expanded Newborn Screening (XNBS) in the state's mandatory newborn metabolic screening program. The current newborn metabolic screening program provides screening for all newborns; follow-up for newborns with abnormal results, until confirmatory diagnosis is made and specialty care is identified, if necessary; and necessary treatment products and certain medical care expenses for those with certain conditions who qualify financially. An expanded program will allow early diagnosis and treatment for a wide array of additional inborn errors of metabolism. Left undetected, these conditions can lead to chronic illness, mental retardation, and death.

Newborn Screening: Current Status

Kansas currently offers free screening for all newborns in Kansas for four sets of clinical conditions. These conditions are phenylketonuria, congenital hypothyroidism, galactosemia, and a set of hemoglobinopathies including both sickle cell disease and thalassemia. Testing is done by the Kansas State Health and Environmental Laboratory after acquisition of a blood spot on special paper has been obtained at the hospital. Tests are run seven days a week, and highly abnormal or 'presumptive' results are immediately called by KDHE to the referring physician. KDHE staff also facilitates follow-up for the affected individuals, and pays for treatment where such care is not covered by other third-party payors. The program has been in existence since 1965, when the mandate to screen infants for PKU was established; three additional mandates in 1977, 1984, and 1990 brought the range of tests to the current slate. In calendar year 2006, 41,601 newborns were screened. Over 5,000 repeat screenings were necessary due to confirmatory testing and sampling issues.

The KDHE NBS program refers newborns with abnormal results to medical specialty clinics for diagnosis. The Children with Special Health Care Needs Program (CSHCN) has contracts with one medical specialty clinic at KC and one at Wichita. After diagnosis, the family may submit an application to the CSHCN program. For those who apply and are eligible, CSHCN case management nurses help the family access ongoing medical, treatment and financial resources. In SFY 06, CSHCN enrollment was 117 individuals with PKU, Congenital Hypothyroidism, and Hemoglobinopathies. Enrollment was: 67 PKU (ages 0-55) of which 60 were receiving formula, Congenital Hypothyroidism 45 (ages 0-22), Hemoglobinopathies 5. Some of these were linked to medical specialty care, some helped to access public or private insurance coverage, and others got financial assistance primarily for medically necessary treatment products such as low-protein formula for PKU. Since the statute was changed in the 2006 session to eliminate free products and to require use of a sliding fee scale, Medicaid and some private insurers have started covering medically necessary treatment.

The program has been supported by state general fund revenue. Baseline cost analysis revealed that current newborn metabolic screening program costs in FY06 were \$1,088,063. Breakdown of current funding is as follows:

Laboratory Costs, SFY 06

	Salaries	Operating
SFY 06	\$329,948	\$ 245, 000

Salaries and Benefits for 6 positions: 1 Sr. Lab Scientist, 2 Microbiologists, 2 Laboratory Technologists, and 1 Chemist.

Operating cost: test kits, reagents, and training, plus laboratory equipment costs

Follow-up Costs, SFY 06

	Salaries	Operating
SFY 06	\$86,918	\$ 6,964

Salaries and Benefits for 2 positions: 1 Public Health Nurse, 1 Administrative Assistant

Operating Costs: communications (phone/postage), printing, supplies, travel

Treatment Costs (through CSHCN) SFY 06

	Diagnosis/FU	Treatment
SFY 06	\$149,630	\$269,096

Diagnosis and Followup through Developmental Disability Center at KUMC, Department of Pediatrics at KUMC, UKSM-Wichita, Via Christi in Wichita, and other Medical Specialists. Assistance with medically-prescribed treatment costs not covered by public/private insurance.

It is critical to note that as plans for XNBS programs are being established in Kansas, they do not in any way imply or infer any retraction of the state's current commitments. Adoption of an XNBS program adds an additional level of service over and above the current services. Screening for the conditions noted above will continue within an XNBS program, as will follow-up services and funding of needed treatment of affected children. The current fiscal commitment is maintained under the new proposal as well.

Expanded Newborn Screening

In recent years, scientific advances and technologic improvements have greatly expanded the number of inborn metabolic conditions for which newborns can be screened at birth. National experts and the March of Dimes recommend that all newborns now be screened at birth for 28 rare, but treatable, inborn metabolic conditions. The recommended list of conditions is limited to those for which both a reliable test and effective treatment are available. Identification of these conditions within the first days or weeks of life prevents the onset of the permanent disabilities, and sometimes death, which often manifest if these metabolic conditions remain untreated. The widespread availability and reasonable cost of Tandem Mass Spectrometry (MS/MS) has led to the implementation of XNBS in the majority of states' mandatory newborn screening programs.

The conditions included in the recommended panel are listed below. This list of conditions is in conformance with the American College of Medical Genetics (ACMG) Uniform Screening Panel.

1. Phenylketonuria
2. Maple Syrup Urine Disease
3. Homocystinuria
4. Citrullinemia

- | | |
|---|---|
| 5. Argininosuccinic acidemia | 16. Medium-chain acyl-CoA dehydrogenase deficiency |
| 6. Tyrosinemia type I | 17. Very long-chain acyl-CoA dehydrogenase deficiency |
| 7. Isovaleric acidemia | 18. Long-chain 3-OH acyl-CoA dehydrogenase deficiency |
| 8. Gultaric academia type I | 19. Trifunctional protein deficiency |
| 9. Hydroxymethylglutaric aciduria/HMG-CoS lyase | 20. Carnitine uptake defect |
| 10. Multiple carboxylase deficiency | 21. Sickle cell anemia |
| 11. Methylmalonic academia due to mutase deficiency | 22. Hb S/Beta-Thalassemia |
| 12. Methylmalonic academia cblA and cblB forms | 23. Hb S/C disease |
| 13. 3-Methyl crotonyl-CoA carboxylase deficiency | 24. Congenital hypothyroidism |
| 14. Propionic academia | 25. Biotinidase deficiency |
| 15. Beta-Ketothiolase deficiency | 26. Congenital adrenal hyperplasia |
| | 27. Classical galactosemia |
| | 28. Cystic fibrosis |

Conditions 1-20 are considered inborn errors of metabolism. Conditions 22-23 are subcategories of Condition 21; all three are referred to as “hemoglobinopathies” and are commonly counted as one test. Conditions 24-28 are grouped together as “others.” MS/MS is used to screen for conditions 1-20. Various laboratory methods are employed for conditions 21-28. Of the conditions currently screened for in Kansas (see above), testing for all but Phenylketonuria (PKU) will continue according to current protocol. PKU can be reliably identified using MS/MS. Using MS/MS for PKU screening is the preferred method; therefore, the PKU screening protocol will be modified.

Implementing XNBS in Kansas: A Proposal

At the behest of the 2006 Kansas Legislature, the Division of Health convened an advisory group of concerned stakeholders to draft a plan for implementing XNBS in the state. Various parties were represented, including Medicaid, the Kansas Hospital Association, insurance trade groups, the Kansas Chapter of the American Academy of Pediatrics, and appropriate KDHE staff. Over the course of three meetings, the group became educated about XNBS implementation in neighboring states; the laboratory processes, follow-up protocol, and treatment requirements associated with the conditions on the recommended screening panel; funding schemes employed in states currently using the recommended panel; and, the proposed funding requirements for implementing an XNBS program in Kansas.

The proposal is the result of this collaborative process and has been subject to the concurrence of these interested groups. Baseline cost analysis revealed that current newborn metabolic screening program costs in FY06 were \$1,088,063. Breakdown of new costs was estimated as follows:

New Laboratory Costs: \$882,405
Leasing Arrangement for Tandem Mass Spectrometry equipment, test kits, reagents, and training: \$450,000
Other laboratory equipment costs for new non-MS/MS screening: \$223,598
Salaries and Benefits for 3 additional laboratory staff: \$208,807
New Follow-Up Costs: \$116,537
Salaries and Benefits for 2 additional follow-up staff (Nurse III, Administrative Specialist): \$95,276
Operating Costs/Supplies: \$21,261
New Treatment Costs: \$191,000
Necessary treatment products (metabolic formula, medications, certain treatment services): \$160,000
Medically Necessary Foods: \$6,000
Contracts for Consultants: \$25,000

Total Cost: \$1,189,942

As noted above, implementing an XNBS program utilizing MS/MS screening technology will require \$1,189,942 in new total annual funding. A fee of approximately \$30 per live birth would be assessed to fund the new laboratory and follow-up costs, generating \$1,170,000 per year. An additional \$191,000 in State General Fund (SGF) revenue will be required to cover new treatment costs.

Two important cost issues were reviewed in constructing the final proposal. One is the use of the State Laboratory versus outside contractors to conduct the screening process. Based upon the reviewed experiences of other states, the working group concurred that this testing be performed by the state laboratory. While private companies have historically provided low costs bids for these services, upon expiration of the initial contract period negotiations normally result in renewal at a significantly higher rate. In addition, once the capability to provide the service has been discontinued by the state laboratory in favor of outsourcing, the ability to re-establish the service is unlikely without a significant expenditure of funds and time required to recruit and train staff. This leaves the state in a position of negotiating with potential vendors without a viable option but to accept the most favorable proposal. Recent history in the State of Nebraska suggests this may not be a desirable option. The State of Texas recently compared the costs for outsourcing these services vs. costs for having the tests performed by the state laboratory. The result was continuation of the testing program in the state laboratory. Noting that 33 states currently perform newborn screening tests "in-house" provides further evidence that this approach is preferable.

A second concern related to the "per-live-birth" fee to be charged for newborn screening. This fee was calculated to be \$30.00 per live birth in Kansas. Our fee was constructed to cover reasonable costs expected with the XNBS program only, and not to supplement other funds or programs. In the other 50 states and the District of Columbia, the mean fee for newborn screening is \$45.77. When the five states and DC, which charge no fee for screening, are excluded from the calculation the Kansas proposed fee is far below the

mean of \$51.88. The proposed fee would rank 38th in the nation, including those states performing screening for free. The workgroup felt strongly about being good stewards of the public dollar, and the establishment of a “bare bones” fee reflects this orientation.

The following outline summarizes the proposal:

- Fee: \$30/live birth
 - Covers new laboratory costs, initial and repeat screenings, (confirmatory testing), and new follow-up costs.
 - No treatment costs included.
- Billing:
 - Medicaid would be billed directly by KDHE
 - Estimated cost to Medicaid: $(40\%)(39,000)(\$30) = \$468,000$
 - KHPA Staff have confirmed the ability of MCD to fund these costs
 - Hospitals would be billed by KDHE for non-Medicaid births
 - Hospitals and 3rd party payors will negotiate as per tradition
- Timeframe:
 - Window for implementing expanded screening is Jan-July/2008
 - Dependent on state budget/legislative process, hospital/insurance negotiations
- Start-Up Funding:
 - Will be necessary for the required program staff to be hired, trained, and ready at the time of implementation
 - KDHE program staff will investigate possible grants for start-up funds
 - KDHE will include a \$191,000 enhancement for the FY 08 budget
- Educational Materials:
 - State will continue provision of education materials per statutory requirement
 - Costs for materials are already included in BCYF proposed costs

Legislative Implications

Legislative approval is needed to make the statutory changes required to expand Kansas' Newborn Metabolic Screening program. K.S.A. 65-180(b) states that newborn screening “services shall be performed without charge.” This language must be removed and replaced with a statement granting the Secretary of Health and Environment the authority to establish a fee, per live birth, for the newborn metabolic screening program. In order to allow enough “lead time” for KDHE laboratory staff to gain competence in MS/MS procedures and to permit hospitals to include the anticipated costs in annual negotiations with third party payers, the effective date of the legislation will be set as July 1, 2008. Legislation will include a “cap” on the fee to be assessed at \$30.00 per live birth.

Additional statutory language establishing an official Newborn Screening Advisory Committee, which will advise the Secretary of Health and Environment regarding issues related to genetics and heritable and congenital disorders, is necessary. Committee membership should include representatives from professional groups, affected trade groups, affected agencies, legislators, consumers, and interested members of the public.

The Committee's charge includes evaluating the operations of the program, determining the optimal staged approach to allow additional tests to be added to the screening profile, and assessing current fee structures and making recommendations for change.

Impact on Other Agencies

The advisory group recommends that KDHE bill the Kansas Medicaid program directly for the per-live-birth fee included in the needed statutory changes. Therefore, KDHE and the Kansas Health Policy Authority will need to arrange an appropriate mechanism for billing and payment. The Kansas Medicaid program is aware of these changes and will assist KDHE in organizing an appropriate protocol.

Fiscal Impact

Treatment for children diagnosed with conditions new to the screening panel is estimated to cost \$191,000 in SGF annually. This cost is in addition to the nearly \$450,000 expended from SGF for treatment of the six currently tested conditions. The conditions to be added to the screening panel are very rare. By adding 23 additional conditions to be tested, it is estimated that the number of children identified annually may potentially double from the number currently being identified on the current testing panel.

Expanded Newborn Screening for Kansas

Howard Rodenberg MD MPH
Director, Division of Health, KDHE
Kansas State Health Officer
Senate Committee on Public Health and Welfare
January 17, 2007

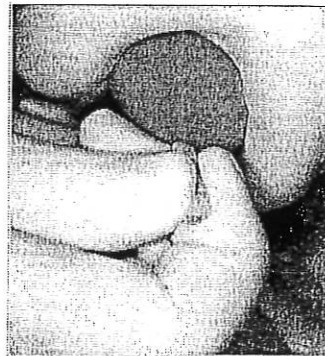
Expanded Newborn Screening

- What is it?
- Current Status
- Expanded Screening
- Consensus Report
- Legislative Initiatives
- Fiscal Considerations



What is NBS?

- Methods of antenatal diagnosis for time-critical conditions
- "Inborn errors of metabolism"
- Inability of body to construct or utilize a required substance
- NBS allows early detection and treatment, with decreased long-term human and fiscal costs



NBS in Kansas: Current

- Testing for four conditions
 - Phenylketonuria
 - Congenital hypothyroidism
 - Galactosemia
 - Hemoglobinopathies (sickle cell, et al)
- Done free of charge
- Screening, follow-up, and some treatment costs borne by state (FY 06)
- (# clients served?)

Expanded NBS (XNBS)



- Based on Tandem Mass Spectroscopy
- Multiple additional rare conditions
- "State of the Art"
- National standard of care (only 5 states do not offer now)

Legislative History

- Needs recognition
- National consultation
- 2006 Session, HS for SB 579 (Means testing for PKU treatment; fees for NBS)
- Legislative request for details of implementation (HB 3021, Adj. #9)
- Report due to legislature this session



XNBS Working Group



- KDHE (DOH, DHEL)
- March of Dimes
- KAAP, KMS
- KHA
- KHPA
- Insurance companies
- Parents
- Four meetings over past 10 months

Working Group Findings

- Expansion of XNBS needed
- 29 additional conditions
- "In-house" laboratory capacity
- Cost-sharing between state, hospitals, and third-party payers
- \$30.00 per live birth charge for screening and follow-up only
- Treatment costs (\$191,000) from SGF

Working Group Model

- Included in package
- Highlights include:
 - Ability to charge fees for XNBS
 - Statutory cap on fees
 - Advisory body to oversee
 - July 2008 implementation
- No alteration in current services provided to Kansas newborns

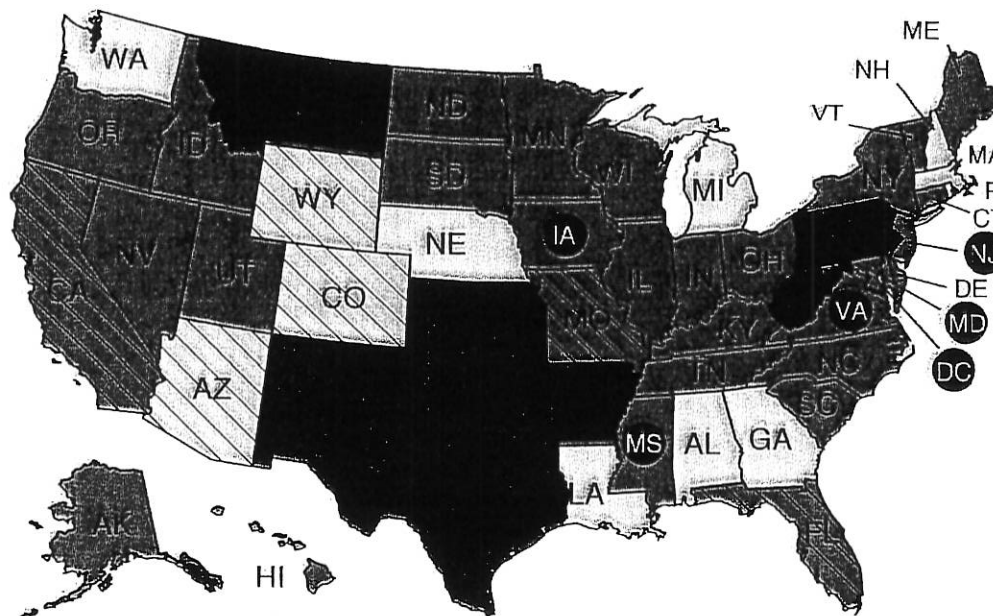
Plans for Implementation





- Share findings and recommendations with legislature
- Proposed legislative language includes changes recommended by working group model
- Follow-up GBA for start-up and treatment costs
- Begin July 2008

Thank you!

We appreciate your interest and support!

Newborn Screening Tests by U.S. States, 2006



-  More than 20 core conditions (31)
-  10-20 core conditions (12)
-  Fewer than 10 core conditions (8)
-  Hatch marks indicate testing for some conditions required but not yet implemented.

Screening 29 Core Conditions
District of Columbia
Iowa
Maryland
Mississippi
New Jersey
Virginia

Source: March of Dimes. Data reported from NNSGRC as of June 1, 2006.
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STATE	Core Conditions									Core Conditions - Metabolic																Fatty									
	Endocrine		Hemoglobin			Other				Fatty Acid Disorders					Organic Acid Disorders						Amino Acid Disorders														
	CH	CAH	Hb S/S	Hb S/A	Hb S/C	BIO	GALT	CF	CUD	LCHAD	MCAD	TFP	VLCAD	GA-I	HMG	IVA	B-MCC	CBIIAB	BKT	MUT	PROP	MCD	ASA	CIT	HCY	MSUD	PKU	TYR-I	CACT	CPT-Ia	CPT-II				
Alabama	D	
Alaska	
Arizona	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C		
Arkansas	
California	
Colorado	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C			
Connecticut	B	
D.C.	
Delaware	
Florida	C	
Georgia	
Hawaii	
Idaho	
Illinois	D	
Indiana	
Iowa	
Kansas	
Kentucky	A
Louisiana
Maine	D	.	.	D	D	D	D	.	.	.	
Maryland
Massachusetts	A	D	A	.	D	A	A	A	A	A	A	A	A	A	A	A	D	A	A	.	.	.	A	D	D	A	.		
Michigan	A	A	.	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	.	.	
Minnesota
Mississippi
Missouri	C	.	C	D	.	.
Montana	.	B	.	.	.	B	.	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	

STATE	Core Conditions									Core Conditions - Metabolic																					
	Endocrine		Hemoglobin			Other				Fatty Acid Disorders					Organic Acid Disorders							Amino Acid Disorders					Fatty				
	CH	CAH	Hb S/S	Hb S/A	Hb S/C	BIO	GALT	CF	CUD	LCHAD	MCAD	IFP	VLCAD	SA-I	HMG	IVA	D-MCC	Sbi-A-B	BKT	MUT	PROP	MCD	ASA	CIT	HCY	MSUD	PKU	TYR-I	GA CT	CPT-Ia	CPT-II
Nebraska	•	•	•	•	•	•	•	•					A	•	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A	A
Nevada	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
New Hampshire	•	•	•	•	•	•	•	•																		•	•	•			
New Jersey	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	B	•
New Mexico	•	•	•	•	•	•	•	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C			
New York	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
North Carolina	•	•	•	•	•	•	•	•																							
North Dakota	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Ohio	•	•	•	•	•	•	•	C	C	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Oklahoma	•	•	•	•	•	•	•	•																			•				
Oregon	•	•	•	•	•	•	•		D	•	•	D	•	•	•	•	•	D	D	•	•	D	•	•	•	•	•	•	•	D	•
Pennsylvania	•	•	•	•	•	B	•	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	B	•	•	B	B	B	B
Rhode Island	•	•	•	•	•	•	•	C	C	C	•	C	C	C	C	C	C	C	C	C	C	C	C	C	•	•	•	C		D	
South Carolina	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
South Dakota	•	•	•	•	•	•	•	A	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Tennessee	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Texas	•	•	•	•	•	C	•		C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C			
Utah	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Vermont	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	D	D	D
Virginia	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Washington	•	•	•	•	•	•	•	•																		•	•	•			
West Virginia	•		•	•	•		•																				•				
Wisconsin	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•	•
Wyoming	•	•	•	•	•	•	•	•	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	C	A	A	A

• : Universally required by rule or law A : Universally offered, not yet required B : Offered to select populations or by request
 C : Testing required but not yet implemented D : Likely to be detected as a byproduct of MRM screening

The portion of this chart detailing each state's specific test panel has been "borrowed" from the chart available at the National Newborn Screening & Genetics Resource Center website: <http://genes-r-us.uthscsa.edu/>

STATE	Mandatory	# Births	Lab	Fee	Additional Information	
					Test Fee Charged to?	Insurance Coverage Screening Mandate
Alabama	Mandatory, religious exemption	60,000	AL State Lab, state owns all equipment	\$123	Charged to the hospital or Medicaid	Fee is rolled into maternity fee
Alaska	Mandatory, religious exemption	10,000	Oregon Public Health Lab	\$55 per birth	Charged to who collects first specimen	Yes, Medicaid covers full cost
Arizona	Mandatory, rules require docs to order the screen	95,000	Contract with own State Lab	\$30 for first screen, \$40 for second screen	Charged to hospital by invoice	Insurance companies will cover routine screens.
Arkansas	Mandatory, religious exemption, pastor must sign	38,000	AR State Lab	\$14.83	Charged to hospital	Not sure, Medicaid pays
California	Mandatory, religious exemption	550,000	Contract with 8 labs, supervised by state lab, which can also run tests.	\$78, will probably increase when CF and Biot, up to \$95	Charged to hospitals	Rolled into hospital birth charge
Colorado	Mandatory, right to refuse	68,000	CO State Lab, probably leasing MS/MS machine	\$60	Hospital buys specimen cards up front which covers initial and second screen.	Hospitals have the responsibility to recoup costs from insurance, etc.
Connecticut	Mandatory, right to refuse	44,000	Department of Public Health State Laboratory	\$28, fee being reviewed	Charged to birth facility	No, most insurance companies portion as part of pre-determined payment to hospitals
D.C.	Mandatory	15,000	Pediatrix	None	N/A	N/A
Delaware	Mandatory, religious exemption	10,500	DE State Lab, leasing agreement for MS/MS	\$64, to \$78 July 1 (for CF)	Charged to hospitals	Ins Commissioner just released "bulletin" stating that insurance companies should pay for screen (not force of law, but generally)
Florida	Mandatory	205,500	FL State Lab	\$15		
Georgia	Mandatory, religious exemption	135,000	GA State Lab, participates in leasing agreement for reagents and equipment (MS/MS)	No fee currently, just passed legislation to allow \$40 per baby 1/1/07	Will be charged to hospitals	No, will likely be rolled into maternity fees, state will cover Medicaid
Hawaii	Mandatory, religious exemption	18,000	Contract with Oregon State Public Health Lab	\$47	Charged to whoever orders test kits	Insurance companies cover it as part of the billing package.
Idaho	Mandatory, right to refuse	22,000	Oregon Public Health Lab	\$25 for one screen. HIGHLY recommended to do second screen (total \$48)	Hospitals purchase kits for 2 tests per infant.	Two tests are paid for by insurance/Medicaid.
Illinois	Mandatory, religious exemption	180,000	IL State Lab, all equipment owned by state	\$47	Charged to hospitals	Hospitals recoup costs as they can
Indiana	Mandatory, religious exemption		IN State Lab	\$62.50	Charged to hospitals	
Iowa	Mandatory, right to refuse	38,000	IA State Hygienic Laboratory	\$76	Charged to hospital	Hospitals recoup costs as they can
Kansas	Mandatory, religious exemption	40,000	KDHEL	None	N/A	N/A
Kentucky	Mandatory, religious exemption	55,000	KY State Lab, MS/MS is owned by state	\$53.50	Charged to the hospital per birth	No, hospitals recoup as they can
Louisiana	Mandatory, right to refuse	65,000 pre Katrina, more like 60,000 now	State has an approved list of labs (i.e. Pediatrix). State also has an arrangement with Iowa post-Katrina	\$30 on 8/1/06	Charged to the medical provider who completes the screening	Medicaid patients are charged to Medicaid.
Maine	Mandatory, right to refuse	14,000	New England Newborn Screening Program (U Mass)	\$52 (cost of filter paper)	Hospital pays state for filter paper up-front	No, but usually rolled into inpatient charges. Insurance companies to pay for foods and formula.
Maryland	Not mandatory, requires informed consent. Fewer than 5 refusals per year. Very detailed booklet provided.	70,000 (many interstate births). Only 68,000 are MD residents	MD State Lab completes testing, owns all equipment. Pediatrix is also licensed if hospitals contract with them (cheaper).	\$42	Charged to hospitals, hospitals charged for the number of babies.	Hospitals recoup costs, all hospitals are set by a commission. Families cannot pay or is without insurance are done for free.
Massachusetts	12 screens mandatory; 19 and CF are optional, religious exemption	82,000	New England Newborn Screening Program (U Mass)	\$54.75 per birth	Charged to hospital; charges passed on to patients in various ways	No, most insurance companies portion as part of pre-determined payment to hospitals
Michigan	Mandatory, no formal waiver	126,000	MI State Lab, most equipment is leased	\$56.83, will increase significantly this year (\$20)	Charged to hospitals	Medicaid has a reimbursement, hospitals recoup as they choose
Minnesota	Mandatory, right to refuse, right to have specimen destroyed after 24 months	70,000	Mayo Clinic for MS/MS, all others done by MN State Lab	\$61	Hospitals purchase test cards up-front.	Rolled into hospital maternity fee
Mississippi	Mandatory, religious exemption	42,000	Contract with Pediatrix	\$70	Charged to hospital	Hospitals pass on cost in some way
Missouri	Mandatory, religious exemption	77,000	MO State Public Health Lab	\$50	Hospitals purchase filter paper up-front	Hospitals recoup fee in patient charges
Montana	4 are Mandatory, rest of the ACMG are available as optional	11,550	MT State Lab. WI lab does MS/MS	\$40 for mandatory, optional tests, MS/MS test groups are priced individually, total is \$37.88 for optional panel	Hospital billed for mandatory by state lab, WI does its own billing	Bundled with hospital costs

	Follow-Up	Other Details
	Short term follow-up done in-house until an infant is determined to be in a "system of care." Some of state's consultants may keep up with babies longer. State will pay for formula and medical foods if families cannot afford and insurance won't cover.	
well	Specialists at Oregon Health Science University follow up with abnormal results. Insurance companies mandated to provide formula/foods, but state has stop-gap capacity for PKU formula.	
	Follow-up staff in house, contract with specialists for treatment. Law requires insurance companies to pay the first \$5,000 of formula/medical food. NBS program is payor of last result.	Mandatory second screen (5-10 days of age, screens accepted up to 1 year of age). Planning to add CF next year.
	2 nurses on staff to follow up, recommend that babies are tested at Children's Hospital for final diagnosis. Insurance companies must assist in paying for food.	
	Most follow-up is contracted out to 7 follow-up centers, 2 through Kaiser Permanente, others housed in medical schools. State has programmatic oversight. State does not pay for food or formula, WIC covers formula for those who qualify.	
Medicaid	Abnormal results for metabolic disorders are reported to metabolic center at Children's Hospital in Denver. U of C Health Sciences Center follows up for all hemoglobin. Contract with Ped. Endocrine unit at Children's for CH or CAH, make phone call to PCP to get PCP intervention started. No state \$ intervention to help with metabolic foods other than WIC (formula).	Expanding on 7/1/06 to ACMG/MOD: Half of fee pays for screening, rest is used to fund statewide genetics clinic, and partial funding for metabolic treatment center, etc. Mandated second screen at 2-4 weeks
y	Varies by disease class/results, sometimes just take second sample, sometimes immediate referrals to state's treatment centers. State does not provide formulas, but there is an insurance requirement to pay for metabolic foods.	
ing covered)	State has a "formula fund" for PKU babies, or any other special foods conditions. Insurance covers foods for the most part, but it is not mandated.	2 screenings are mandated: 1st at 24 hours after birth; 2nd at 7-28 days after birth
	Follow-up provided by medical specialists at regional genetics/metabolic clinics, and blood disorder specialists.	
baby nes	Contract with Emory U to follow up for Endocrine/Metabolic and Grady/Medical College of Georgia for hemoglobin. Contractor follows up on abnormal screenings. State provides formula, etc. for short-term follow up for all metabolic conditions, and bills to insurance when possible.	
ant of	In-house follow-up staff. Staff makes sure PCP consultation is made. Families who are financially eligible are brought to Honolulu for treatment through CSHN. State law requires insurance to pay 80% of medical foods and formula.	Exploring adding CF, which will raise the fee.
a and	Oregon Public Health Lab does the follow up. If they cannot find the PCP, Oregon will call Idaho for assistance. OSU physicians do clinics in Idaho.	
	Request repeats for borderline cases. Follow up staff contacts PCP for positive cases, determine next steps for diagnosis, help make referrals to specialists. State pays for metabolic formulas, no foods. No insurance reimbursement.	Will add CF within a year, hopefully
	Lab contacts PCP with positives. Positives are referred to the metabolism clinic at IU Medical School. CSH Services provide formulas.	
	Iowa is starting a short-term and long-term follow up system. Abnormal screens are directed to the short-term follow-up nurses, who contact the appropriate medical consultant. Repeat screens and confirmatory testing are completed as necessary. Dr. Sara Copeland is the only metabolic physician in the state, and sees all metabolic cases. Those detected as carriers (CF and Hbg) Long-term follow-up for confirmed abnormal cases are followed up by a nurse practitioner and a medical specialist. Food and formula are provided along a sliding fee scale, but also always attempt to bill insurance first.	
	KDHE staff notify physician of record if abnormal screening result. Every attempt is made to connect the infant with a medical provider for necessary follow-up care. PKU formula and	
	3 nurses follow-up for abnormal screenings, contact PCPs, make recommendations for add'l labwork and specialist referral, follow up for case report documents with final diagnosis. State pays for metabolic foods/formulas for the uninsured. Law is in effect requiring insurance companies to cover metabolic foods/formula.	
ctivity	State has follow-up staff in-house to connect infants with treatment. State pays for metabolic formulas and medications. Currently seeking insurance and medicaid reimbursement.	
quired:	Insurance mandate for metabolic foods and formula, WIC pays for formula, Medicaid pays for formula. 2 metabolic centers in the state are contracted to provide services. Families referred to them without a way to pay are covered by grant funding.	
rates who tests	State completes all follow-up no matter which lab is used. State does not provide medical foods and formulas. State has designated treatment centers; babies are referred to the treatment centers. Insurance companies required to cover metabolic foods and formulas, and any other treatments necessary for metabolic diseases. State will provide formula for families in extreme need; families are asked to reimburse when they are able. Nutritionist services provided at no cost by state. State also monitors blood levels.	Screen all babies born in MD and most babies born to MD residents outside MD (2-specimen system, 2nd specimen done by PCP)
	New England Newborn Screening Program completes the follow up for individual conditions, formula and foods are covered by third parties.	For a disorder to be included in the list, the following must be true: 1) the disorder is treatable, 2) there is a good test, 3) early medical intervention would benefit the infant.
	Half of fee money goes to lab, the other half is for "follow up and medical management." Funds pay for follow up staff and some funding to 3 medical management centers, which make the diagnoses. There are also some genetic counseling. State pays for all formula (no age limit now, but will probably restrict males over 21). Trying to pass a bill to require insurance companies to cover formula.	
	Follow up for abnormal results. PCP and specialist are usually both contacted. PCP is responsible for setting up follow-up testing and referrals as necessary, worked out with the specialist. The state notifies specialists through secured website at the state's treatment centers, specialist confirms follow-up through the website so the state can keep track (depending on the disorder). State does not provide formulas or metabolic foods. Medical assistance programs do pay for foods and formulas. State regulated insurances are mandated to cover PKU foods/formula, but 25% of affected kids have insurance from companies administered outside the state. Newly-tested disorders are not covered under the mandate. Developing a resource for insurance companies to strongly suggest payment for treatments for other disorders.	
inner	Teams in each public health districts (9) plus a team at the state offices. Teams include a nurse and a social worker, who create contact with the family and PCP. Some specialist contacting is done by the state office staff. CSHN and WIC cover formulas.	
rges	All abnormal screening results are followed up (everything except hemoglobinopathies) by contract with 4 genetic tertiary centers. Hemoglobinopathies are followed up by contracted hemoglobinopathy centers. State provides metabolic foods/formulas if families meet income requirements. Payor of last result. State law requires insurance to provide formula up to 6 years of age.	
	Newborn screening results are not yet compared to birth certificates. Staff attempts to contact birth facility and/or physician of record. Family contacting is the requirement of the facility/attending physician. If the birth is unattended, state is not allowed to contact family. Insurance companies are required to pay for PKU formula and medical food until age 18.	

STATE	Mandatory	# Births	Lab	Additional Information		
				Fee	Test Fee Charged to?	Insurance Coverage Screening Mandate
Nebraska	8 Mandatory disorders, the rest is optional	26,500	Contract with Pediatrix	\$35.75 (same price with or without optional tests)	Charged to hospitals	Rolled into hospital maternity
Nevada	Mandatory	35,000	Contract with Oregon State Public Health Lab	\$		
New Hampshire	Mandatory, right to refuse	14,000	New England Newborn Screening Program (U Mass)	\$40 (cost of filter paper)	Hospital pays state for filter paper up-front	No, most insurance companies portion as part of pre-determining payment to hospitals
New Jersey	Mandatory, religious exemption, informed dissent	111,000	NJ State Lab, state owns all equipment	\$71 per infant	Hospitals pay state for filter paper up-front	Rolled into maternity charge
New Mexico	Mandatory, initial and second screening	27,300		\$32		
New York	Mandatory, religious exemption	250,000	NY State Health Department Laboratory	No fee	N/A	N/A
North Carolina	Mandatory, religious exemption, no informed consent	120,000	NC State lab, equipment owned by state	\$14	Charged to patients through the hospital	Medicaid covers, ins companies generally cover it
North Dakota	Mandatory, religious exemption	8,000	Contract with University of Iowa laboratory	\$42.50	Charged to hospital	No insurance mandate, hospital recoup costs
Ohio	Mandatory, religious exemption, parents must be given educational materials prior to testing	149,000	OH Public Health Lab	\$46.15		
Oklahoma	Mandatory, religious exemption	50,000	OK State Lab	\$58.23-\$80.71 —basic panel is mandatory, additional screens are optional	Charged to hospital	Hospital bills insurance/medicaid
Oregon	Mandatory, religious exemption (not advertised)	46,000	Oregon State Public Health Lab	\$54 for two tests (at hospital, at 2 weeks)	Hospitals purchase test kits up-front	
Pennsylvania	Mandatory, religious exemption	140,000	U Mass or Pediatrix (hospital's choice)	6 core tests at state's cost	Hospitals have individual arrangements with U Mass and Pediatrix to offer optional expanded screening to newborns for a fee.	No, most insurance companies portion as part of pre-determining payment to hospitals
Rhode Island	Mandatory	13,500	New England Newborn Screening Program (U Mass)	\$110, annual inflation-based increase	Charged to hospital	Yes
South Carolina	Mandatory, religious exemption	50,000-60,000	SC State lab	\$42 per birth	Charged to hospitals	No, most insurance companies portion as part of pre-determining payment to hospitals
South Dakota	Mandatory, no provision for parental refusal	11,000	Contract with Sioux Valley Clinical Lab (SVCL)	\$99.16	Charged to hospitals by lab	State has no control over how it passes on the fee, but state is aware of any insurance companies denying reimbursement
Tennessee	Mandatory, religious exemption	78,000	TN State Lab, leases some	\$47.50	Charged to the hospital	
Texas	Mandatory, one after 24 hours, second at 7-14 days, religious exemption	388,000, screen only about 374,000	TX State Lab	\$19.50 now, will go up when MS/MS is initiated in November	50% are Medicaid, 10% un-insured, Test kits purchased up front by hospitals and PCPs.	The state "recommends" that all insurers cover the cost of screening. Refusals are to be submitted to laboratory services section
Utah	Mandatory, religious exemption, at 2 days and 7-28 days (2 screenings mandated)	55,000	Some in UT State Lab, MS/MS contracted to ARUP in Salt Lake	\$65 for first and second	Billed to institution of birth	Hospitals roll fee into nursery cost
Vermont	No	6,200	New England Newborn Screening Program (U Mass)	\$33.30 per infant; repeat testing at no additional charge	Charged to hospital (or Dr. if completed at Dr. office)	No, but medicaid covers the test, insurance companies pay some
Virginia	Mandatory, religious exemption	100,000	VA State lab, all equipment owned by state	\$53	Charged to hospitals	No, most insurance companies portion as part of pre-determining payment to hospitals
Washington	Mandatory, religious exemption, second screen at 7-14 days strongly recommended	80,000 (3,000 are military, and are screened by Oregon)	WA State Newborn Screening Lab, also suggests that parents interested in expanded screening contact Pediatrix, Baylor, Mayo, or State of Colorado labs	\$67.50 per infant	Billed to hospital	No, rolled into hospital's billing
West Virginia	Mandatory, right of refusal (informal)	20,000	WV State Lab, some equipment is leased	covered under block grant money		
Wisconsin	Mandatory, religious exemption	70,000	WI State Laboratory of Hygiene/WI Newborn Screening Lab, all equipment owned by state	\$69.50, \$39.50 is lab fee (goes back to lab), \$30 is surcharge for providing formula and treatment, confirmatory testing, etc.	Facilities purchase cards up-front	Usually covered by insurance, families are told to contact state if unable to pay/uninsured (the state health care pick up the cost)
Wyoming	Mandatory, parents must sign to receive OR waive, can waive for any reason	6,300	Colorado State Laboratory	\$45	billed to hospital for initial screen	Bundled into hospital charges

Universally required by rule or law
 A - Universally ordered, not yet required
 B - Ordered to select populations or by request
 C - Testing required but not yet implemented
 D - Likely to be detected as a byproduct of MRM screening

Information highlighted in gray is drawn from internet sources and has not been confirmed by NBS staff from that state.

	Follow-Up	Other Details
	Active follow up Child is tracked until a full diagnosis is made and treatment has started with PCP or specialist. State pays for all metabolic formula except for what insurance reimburses, plus \$2,000 for foods per person per year.	
	Oregon state lab nurse is contracted to do most of the follow up to contact physicians, etc. If a problem occurs (family can't be contacted, physician doesn't want to be involved), then the state tracks the family down and get the treatment process started. State pays some portion of metabolic foods and formulas.	
y	State provides short-term follow up (tracking diagnosis) to ensure contact with PCP and specialty care. State does not provide any foods or formulas. There is a mandate for insurance companies to provide formula for kids with metabolic conditions, and up to \$1,800 for foods.	
spial	Follow-up staff in house, refer to "specialists" at treatment centers. Cases are not closed until a final disposition is reached. State gives grants to facilities for formulas and metabolic foods.	
	Follow-up completed in-house. Most formula and foods are covered by insurance (Medicaid covers).	
	Repeats requested if necessary. Abnormal results. MS/MS are followed up by UNC Chapel Hill. State does hemoglobin and non MS/MS disorders. State has funds to cover metabolic formulas for families who qualify financially.	
	Follow up completed in-house with assistance from U of Iowa metabolic consultant, follow up continues until a diagnosis is made or normal result is achieved. State provides formulas and metabolic foods for everyone requiring them. Insurance companies are required to help.	
	Abnormal results are reported to the PCP listed on screening form. Report is faxed to PCP's office with information regarding specialists for follow-up testing and treatment. Regional metabolic specialist teams and pediatric endocrinologists are identified for follow up care. The state provides formula to 400 individuals per year for PKU and homocystinuria.	
etc.	Abnormal results forwarded to state staff. Diagnostic testing is pursued for presumptive cases (followed until diagnosis). Long-term follow-up coordinators (by type of condition, hem., metabolic, endocrine) follow cases in the field. Moving to a system where the specialist completes diagnosis, state verifies that patients are seen by specialist. CSHN pays for formula up to age 21, medicaid also pays (PKU formula). Separate adult program--state pays PKU formula for adults. No current preference system.	
	Medical consultant for each kind of disorder (hem, metabolic, endocrine), and the consultant discusses the case with the PCP once state staff has verified that the correct PCP is identified. Cases are followed until diagnosis is made. State doesn't provide metabolic food/formulas, but insurance companies have some sort of coverage mandate.	
y	Follow-up continues until diagnosis is reached. State pays for PKU formula until 22nd birthday, unless pregnant or might become pregnant.	
	Contract with VNA for reporting and short term follow up (lab contacts VNA). VNA makes contacts with PCP and specialist. State has some funds to help pay for formulas/metabolic foods if insurance won't cover.	
y	State follows PKU for continued blood level testing. Once patients have been identified with their PCP and a specialist, state doesn't follow anymore (except for PKU or Galactosemia). State provides PKU formula for all (including pregnant women), also the supplement bars.	
vital	Short-term follow up, until abnormal are confirmed negative or positive, state provides information to PCP about available specialists, etc. Formula/metabolic foods are done on a case-by-case basis, depending on whether the family qualifies for assistance programs, etc.	Expanded from 3 to MS/MS, plus CF optional on June 1, 2005.
	Follow-up staff in-house, state contracts with treatment centers by region. TenCare pays for some formulas, foods. Some insurance companies cover foods/formula.	
y	Foods for PKU and homocystinuria are provided for free or reduced costs to anyone "as funds allow." (350% FPL) State is payor of last resort. State provides follow-up to connect patient with PCP and specialist information as necessary.	Test panel expansion deadlines (to ACMG 27) 11/1/06
yes	Abnormal results are reported to follow-up staff. All PCPs are notified of abnormal, and State tracks until end disposition is reached and specialist has been identified. State provides some funding for PKU formula. State law requires insurance to cover certain metabolic formulas.	
and riton	Metabolic Clinic provides home visits for patients who test positive from a nurse and nutritionist. Children are followed until age 21, funded through Title V CSHN program. Some of the most ill children receive treatment out of state, case management continues. State will continue to help pay for services received out-of-state. CH children do not receive the same follow up once they are fully diagnosed (1-2 weeks) and under PCP care. Foods/formulas must be covered up to \$2,500 annually by insurance companies. CHSN will cover the difference until child is 21. State will order foods for families, state has arrangements made with companies for lower prices.	
	3-tier system. Abnormal (grey area) results are repeated. Follow up for 6 months to get a repeat. Critical results are reported to PCP or metabolic consultant. Have funds for income-eligible infants, also Care Connection for Children assist families with insurance issues, finding foods, etc. State also contracts with metabolic treatment centers for care, etc. 3 centers.	
	All infants followed to insure that treatment is started. Some treatment clinics are subsidized (metabolic and hemoglobin), and are tracked longer. Endocrine conditions are not followed. Some formula is subsidized, but primarily billed to insurance and Medicaid (safety net only).	
	In-house follow-up staff, short-term follow up to PCP and specialist if needed. State pays for formula. Looking to create an insurance reimbursement system for formula.	
lies t will	PKU formula and foods are provided free-of-charge to families. Also, children identified with a genetic disorder through newborn screening are referred to specialty clinics for treatment and genetic counseling.	
	Abnormal result: certified letter to PCP, continue checking to ensure follow-up screening is completed. Contracted with Biochemical Genetic Counselors in Denver to provide consult to physicians about MS/MS screening, resulting treatment, etc. Provide copies of treatment algorithms to PCPs, etc. State provides formulas, means testing at 200% FPL Medicaid/SCHIP also pays.	Starting MS/MS on July 1, fee will rise to \$70 for initial screening