



Meeting Notice

Newborn Screening Advisory Committee
Meeting Notice and Agenda
Thursday, April 30, 2009

Pursuant to A.R.S. § 38-431.02, notice is hereby given to the members of the Newborn Screening Advisory Committee (NBSAC) of the Arizona Department of Health Services and to the general public that the NBSAC will hold a meeting open to the public on April 30, 2009, from 8:00 a.m. until 10:00 a.m., at the Industrial Commission of Arizona, 800 W. Washington, Phoenix, AZ, First Floor.

The agenda for the meeting is as follows:

- I. Call to Order, Welcome and Introductions (Interim Director Will Humble)
- II. Committee Appointments (Interim Director Will Humble)
- III. Program Updates (Oral reports from the following NBS sections and discussion thereon.)
 1. Medical Director (Sundin Applegate, M.D.)
 2. NBS Year in Review (Ward Jacox)
 3. Quality Measures and Bloodspot Data Summary (Sondi Aponte)
 4. Hearing Data Summary (Christy Taylor)
 5. Laboratory (Wendy Zakowicz)
 6. Billing (Cheryl Gillman)
 7. Rules (Ruthann Smejkal, Ph.D.)
- IV. Announcements (Ward Jacox)
Announcements of future meeting dates and other information concerning the NBSAC.
- V. Call to Public
This is the time for the public to comment. Members of the Committee may not discuss items that are not on the agenda. Therefore, action taken as a result of public comment will be limited to directing staff to study the matter or schedule it for further consideration/decision at a later date.
- VI. Adjournment

A copy of the agenda background material provided to Committee members will be available for public inspection on the AZ NBS website – www.aznewborn.gov.

Persons with a disability may request a reasonable accommodation, such as a sign language interpreter, by contacting Ward Jacox at (602) 364-1410 or toll free at (800) 952-0374 (For the hearing/speech impaired, please visit the following website: <https://www.sprintip.com/index.jsp>.) Requests should be made as early as possible to allow time to arrange the accommodation.

Dated this 22nd day of April, 2009.

ARIZONA DEPARTMENT OF HEALTH SERVICES

Ward B. Jacox
Chief of the Office of Newborn Screening

OPEN MEETING LAW 101

Arizona's Open Meeting Law in a Nutshell

Two core concepts

“All meetings of any public body shall be public meetings and all persons so desiring shall be permitted to attend and listen to the deliberations and proceedings.” A.R.S. § 38-431.01(A).

“It is the public policy of this state that meetings of public bodies be conducted openly and that notices and agendas be provided for such meetings which contain such information as is reasonable necessary to inform the public of the matters to be discussed or decided.” A.R.S. § 38-431.09.

Why do we have an Open Meeting Law?

1. To protect the public.
 - a. To avoid decision-making in secret.
 - b. To promote accountability by encouraging public officials to act responsively and responsibly.
2. To protect public officials.
 - a. To avoid being excluded (notice).
 - b. To prepare and avoid being blind sided (agenda).
 - c. To accurately memorialize what happened (minutes).
3. Maintain Integrity of government.
4. Better informed citizenry.
5. Build trust between government and citizenry.

What constitutes a meeting?

A meeting is a gathering, in person or through technological devices of a quorum of a public body at which they discuss, propose or take legal action, including deliberations. A.R.S. § 38-431(4). This includes telephone and e-mail communications.

Who must comply with Open Meeting Law?

Public bodies. "Public body" means the legislature, all boards and commissions of this state or political subdivisions, all multimember governing bodies of departments, agencies, institutions and instrumentalities of the state or political subdivisions, including without limitation all corporations and other instrumentalities whose boards of directors are appointed or elected by the state or political subdivision. Public body includes all quasi-judicial bodies and all standing, special or advisory committees or subcommittees of, or appointed by, the public body. A.R.S. §38-431(6).

"Advisory committee" or "subcommittee" means any entity, however designated, that is officially established, on motion and order of a public body or by the presiding officer of the public body, and whose members have been appointed for the specific purpose of making a recommendation concerning a decision to be made or considered or a course of conduct to be taken or considered by the public body. A.R.S. § 38-431(1).

What is Required under the Open Meeting Law?

1. Notice

The open meeting law requires at least 24 hours notice to the members of the public body and the general public. A.R.S. §38-431.02(C).

Notice must be posted in the public place identified in the disclosure statement and by giving additional notice as is reasonable and practicable. A.R.S. §38-431.02(A).

2. Agenda

Agendas must contain information reasonably necessary to inform the public of the matters to be discussed or decided. A.R.S. §38-431.09.

Agendas must be available at least 24 hours before the meeting. A.R.S. §38-431.02(G).

3. Public's Rights

The public has a right to:

- Attend
- Listen
- Tape record
- Videotape

Public has no right to:

- Speak
- Disrupt

4. Calls to the Public

An open call to the public is an agenda item that allows the public to address the public body on topics of concern within the public body's jurisdiction, even though the topic is not specifically included on the agenda. Ariz. Att'y Gen. Op. I99-006.

Although the Open Meeting Law permits the public to attend public meetings, it does not require public participation in the public body's discussions and deliberations and does not require a public body to include an open call to the public on the agenda. *See* Ariz. Att'y Gen. Op. No. I78-001.

An individual public officer may respond to criticism, ask staff to review an item or ask that an item be placed on a future agenda, but he or she may *not* dialogue with the presenter or collectively discuss, consider, or decide an item that is not listed on the agenda. A.R.S. § 38-431.01(G); Ariz. Att'y Gen. Op. I99-006. Note that individual members of the public body may respond to criticism by individuals who addressed the public body during the call to the

public, but the public body may not collectively discuss or take action on the complaint unless the matter is specifically listed on the agenda. A.R.S. § 38-431.01(G).

Public bodies may impose reasonable time, place, and manner restrictions on speakers. Restrictions must be narrowly tailored to affect a compelling state interest and may not be content based. Ariz. Att’y Gen. Op. I99-006.

A member of the public body may not knowingly direct a staff member to communicate in violation of the Open Meeting Law. A.R.S. 38-431.01(H).

In sum:

- *Calls to the public are permitted, but not required.*
- *Should be added as an agenda item.*
- *Public body may limit speaker’s time.*
- *Public body may require speakers on the same side with no new comments to select spokesperson*
- *Public body may set ground rules:*
 - *civility*
 - *language*
 - *treat everyone the same*

5. Minutes (A.R.S. § 38-431.01(B))

Public bodies must take meeting minutes of all meetings, including executive sessions.

May be recorded or written.

Must include:

- Date, time and place of meeting;
- Names of members of the public body present or absent;
- A general description of matters considered; and
- An accurate description of all legal actions proposed, discussed or taken, and the names of members who propose each motion. The minutes shall also include the names of the persons, as given, making statements or presenting material to the public body and a reference to the legal action about which they made statements or presented material.

The minutes or a recording must be open for public inspection no later than three working days after the meeting, except as otherwise provided in the statute. A.R.S. § 38-431.01(D).

How long meeting minutes are maintained is determined by the public body’s record retention and destruction schedule authorized by Arizona Library and Archives.

Persons in attendance may record any portion of a public meeting, as long as the recording does not actively interfere with the meeting. Acceptable recording equipment includes tape recorders, cameras, or other means of reproduction. A.R.S. § 38-431.01(E).

6. *Executive Sessions*

Public bodies may hold private executive sessions under a few limited circumstances. In executive sessions, the public is not allowed to attend or listen to the discussions, and the public body is not permitted to take final action. A.R.S. § 38-431.03(D).

Members of the public body may not vote or take a poll in executive sessions. A.R.S. § 38-431.03(D).

There are seven authorized topics for executive sessions:

1. Personnel (must provide 24 hours written notice to employee).
2. Discussion or consideration of records exempt by law from public inspection.
3. Legal advice – with public body’s own lawyer(s).
4. Discussion or consultation with public body’s lawyer(s) to consider pending or contemplated litigation, settlement discussions, negotiated contracts.
5. Discuss and instruct its representative regarding labor negotiations.
6. Discuss international, interstate, and tribal negotiations.
7. Purchase, sale, or lease of real property.

Notice and Agenda: Agendas for executive sessions may describe the matters to be discussed more generally than agendas for public meetings in order to preserve confidentiality or to prevent compromising the attorney-client privilege, if it is necessary. A.R.S. § 38-431.02(I). Nonetheless, the agenda must provide more than a recital of the statute that authorizes the executive session.

Minutes: Minutes taken in an executive session must include the items listed above in addition to any other matters found to be appropriate by the public body. A.R.S. § 38-431.01(C).

7. *Where to turn for help*

Self-help resources available:

The Arizona Ombudsman – Citizens’ Aide handbook – The Arizona Open Meeting Law (available on line at www.azoca.gov under open meetings/publication)

The Arizona Ombudsman’s website, www.azoca.gov

Arizona Agency Handbook, Chapter 7, www.azag.gov – Quick Links

Attorney General Opinions – www.azag.gov – Quick Links

Questions/File a complaint:

Arizona Ombudsman-Citizen’s Aide (602) 277-7292

File a complaint/Enforcement authority

County Attorney’s Office

Attorney General’s Open Meeting Law Enforcement Team (602) 542-5025 (complaints must be in writing and signed)



YEAR IN REVIEW

*Newborn Screening Advisory Committee
April 30, 2009*

NEWBORN SCREENING CONFIRMED CASE REPORT
 PRIMARY PANEL OF 29 DISORDERS
 DOB 1/1/2008 – 12/31/2008

Disorder	Abbreviation	Total
Congenital Hypothyroidism	CH	51
Congenital Adrenal Hyperplasia (21-hydroxylase deficiency)	CAH	5
Sickle Cell Anemia	Hb SS	8
Sickle Beta Thalassemia	Hb S/βTh	0
Sickle C Disease	Hb S/C	1
Biotinidase Deficiency	BIOT	1
Galactosemia	GALT	2
Phenylketonuria	PKU	2
Maple Syrup Urine Disease	MSUD	0
Homocystinuria	HCY	1
Citrullinemia	CIT	1
Argininosuccinic Acidemia	ASA	0
Tyrosinemia Type 1	TYR I	0
Carnitine Uptake Disorder	CUD	1
Medium-chain Acyl-CoA Dehydrogenase Deficiency	MCAD	4
Very Long-chain Acyl-CoA Dehydrogenase Deficiency	VLCAD	0
Long-chain 3-OH Acyl-CoA Dehydrogenase Deficiency	LCHAD	0
Trifunctional Protein Deficiency	TFP	0
Isovaleric Acidemia	IVA	0
Glutaric Acidemia Type 1	GA I	0
Hydroxymethylglutaric CoA Lyase Deficiency	HMG	0
3-Methylcrotonyl CoA Carboxylase Deficiency	3MCC	1
Multiple Carboxylase Deficiency	MCD	0
Methylmalonic Acidemia (mutase deficiency)	MUT	0
Methylmalonic Acidemia (Cbl A,B)	Cbl A,B	0
Propionic Acidemia	PROP	0
Beta-ketothiolase Deficiency	BKT	0
Cystic Fibrosis	CF	14
Hearing Loss	HEAR	122
TOTAL (92 bloodspot, 122 hearing)		214

As of 4-23-2009 -SA

Agency: Department of Health Services

Proposal: Fund Transfers

FY 09 Savings: \$5,632,800

FY 10 Savings: \$5,700,500

This option would transfer monies out of the following funds and into the General Fund in FY 2009 and FY 2010. The option combines 2 types of transfers:

- Fund reduction and transfers (FRATs): These transfers would reduce annual spending from the agency's Other Funds, typically by 5% in FY 2009 and 10% in FY 2010. An amount equal to these reductions would be swept into the General Fund.
- Excess balance transfers (EBTs): These transfers typically would sweep 50% of anticipated FY 2009 ending balances and 50% of FY 2010 ending balances (as adjusted by the FY 2009 sweep) into the General Fund.

The table below outlines the total transfers in FY 2009 and FY 2010 from this option. Modifications of the spending or revenue levels originally assumed by agencies are listed in the "Comments" column.

<u>Fund</u>	<u>FY 09 Transfer</u>	<u>FY 10 Transfer</u>	<u>Comments</u>
<i>Appropriated</i>			
Child Fatality Review Fund	\$ 186,900	\$ 135,300	
Emergency Medical Services Operating Fund	676,800	1,284,100	
Environmental Lab Licensure Revolving Fund	115,400	0	No EBT in FY 10.
Indirect Cost Fund	1,583,700	1,615,400	
Newborn Screening Program Fund	1,674,800	1,326,000	
Nursing Care Institution Protection Fund	353,700	252,500	
Substance Abuse Services Fund	329,300	658,800	
<i>Partially-Appropriated</i>			
Vital Records Electronic Systems Revolving Fund	712,200	428,400	
TOTAL	\$5,632,800	\$5,700,500	

Department of Health Services

	FY 2008			FY 2009			FY 2010				
	Actual Revenue	Approp/ Spending	Ending Balance	Estimated Revenue	Approp/ Spending	GF Transfer	Ending Balance	Estimated Revenue	Approp/ Spending	GF Transfer	Ending Balance
Child Fatality Review Fund (OA)	247,800	98,200	291,000	182,800	100,000		373,800	182,800	99,100		457,500
Technical Revision							0			0	(186,900)
Excess Balance Transfer				182,800	186,900	186,900	(186,900)	182,800	99,100	135,300	(135,300)
Total				182,800	100,000	186,900	186,900	182,800	99,100	135,300	135,300
Emergency Medical Services Operating Fund (OA)	6,450,800	5,105,600	1,061,300	6,708,800	-5,983,100		755,100	6,977,200	5,983,100		1,749,200
Technical Revision					(299,200)		0		(598,300)		(377,600)
Fund Reduction and Transfer					377,600	377,600	(377,600)			598,300	0
Excess Balance Transfer				6,708,800	5,683,900	676,800	377,500	6,977,200	5,384,800	1,284,100	(685,800)
Total				6,708,800	5,683,900	676,800	377,500	6,977,200	5,384,800	1,284,100	685,800
Environmental Lab Licensure Revolving Fund (OA)	765,700	791,900	427,100	780,000	976,400		230,700	780,000	970,600		40,100
Technical Revision							0				(115,400)
Excess Balance Transfer				780,000	976,400	115,400	(115,400)	780,000	970,600	0	(75,300)
Total				780,000	976,400	115,400	(115,400)	780,000	970,600	0	(75,300)
Indirect Cost Fund (OA)	13,431,300	9,075,100	6,033,400	6,033,400	9,075,700		2,259,900	9,361,300	9,075,700		2,545,400
Technical Revision					(453,800)		0		(907,600)		(1,129,900)
Fund Reduction and Transfer					1,129,900	1,129,900	(1,129,900)			907,600	0
Excess Balance Transfer				6,033,400	8,621,900	1,583,700	1,129,900	9,361,300	8,168,100	1,615,400	(707,800)
Total				6,033,400	8,621,900	1,583,700	1,129,900	9,361,300	8,168,100	1,615,400	707,700
Newborn Screening Program Fund (OA)	6,252,200	5,801,100	2,870,800	6,629,200	6,805,300		2,569,000	6,761,700	6,805,300		2,625,400
Technical Revision					(340,300)		0		(680,500)		(1,394,500)
Fund Reduction and Transfer					1,394,500	1,394,500	(1,394,500)			680,500	0
Excess Balance Transfer				6,252,200	6,465,000	1,674,800	1,334,500	6,761,700	6,124,800	1,326,000	(645,500)
Total				6,252,200	6,465,000	1,674,800	1,334,500	6,761,700	6,124,800	1,326,000	645,400
Nursing Care Institution Protection Fund (OA)	274,500	362,000	555,900	189,400	38,000		707,300	189,400	38,000		858,700
Technical Revision							0				(353,700)
Excess Balance Transfer				189,400	38,000	353,700	(353,700)	189,400	38,000	252,500	(252,500)
Total				189,400	38,000	353,700	(353,700)	189,400	38,000	252,500	252,500
Substance Abuse Services (OA)	3,113,300	2,500,000	545,300	3,113,300	2,500,000		408,600	3,113,300	2,500,000		1,021,900
Technical Revision					(125,000)		0		(250,000)		(204,300)
Fund Reduction and Transfer					204,300	204,300	(204,300)			250,000	0
Excess Balance Transfer				3,113,300	2,375,000	329,300	204,300	3,113,300	2,250,000	658,800	(408,800)
Total				3,113,300	2,375,000	329,300	204,300	3,113,300	2,250,000	658,800	408,800
Vital Records Electronic Systems Fund (PA)	679,000	443,000	1,405,700	569,200	499,700		1,374,400	569,200	499,700		1,443,900
Technical Revision					(25,000)		0		(50,000)		(687,200)
Fund Reduction and Transfer					687,200	687,200	(687,200)			50,000	0
Excess Balance Transfer				569,200	474,700	712,200	687,200	569,200	449,700	428,400	(378,400)
Total				569,200	474,700	712,200	687,200	569,200	449,700	428,400	378,300
Total - Fund Reduction and Transfers					\$ 1,243,300					\$ 2,486,400	
Total - Excess Balance Transfers					\$ 4,389,500					\$ 3,214,100	
					\$ 5,632,800					\$ 5,700,500	

OA = Other Appropriated Fund
 PA = Partially-Appropriated Fund
 NA = Non-Appropriated Fund

Budget Units

	Fund Name	FY 2009	FY 2010
	Drinking Water Revolving Fund (NA)	23,900	56,900
	Emissions Inspection Fund (OF)	58,100	138,400
	Indirect Cost Recovery Fund (OF)	210,300	500,700
	Recycling Fund (OF)	14,700	34,900
	Solid Waste Fee Fund (OF)	24,900	59,300
	Underground Storage Tank Revolving - NA (NA)	165,400	393,900
	Voluntary Remediation Fund (NA)	9,000	21,500
	Water Quality Assurance Revolving Fund (NA)	155,900	371,300
	Water Quality Fee Fund (OF)	118,400	281,800
Exposition & State Fair Board, AZ	Arizona Exposition and State Fair Fund (OF)	231,800	552,000
Financial Institutions, Department of	Revolving Fund (NA)	23,200	55,200
Funeral Directors & Embalmers, State Board of	Board of Funeral Directors and Embalmers Fund (OF)	10,900	25,900
Game and Fish Department, Arizona	Heritage Fund (NA)	197,900	471,200
	Indirect Cost Recovery Fund (NA)	14,500	34,400
	Off-Highway Vehicle Recreation Fund (NA)	6,800	16,200
	Watercraft Licensing Fund (OF)	48,400	115,100
Geological Survey, Arizona	Geological Survey (NA)	14,500	34,600
Government Information Technology Agency	Information Technology Fund (OF)	105,300	250,700
Health Services, Department of	Emergency Medical Services Operating Fund (OF)	104,700	249,300
	Environmental Laboratory Licensure Revolving Fund (OF)	17,300	41,300
	Hearing and Speech Professionals Fund (OF)	8,800	20,900
	Indirect Cost Fund (OF)	160,600	382,300
	Newborn Screening Program Fund (OF)	81,000	192,900
	Vital Records Electronic Systems Fund (OF)	6,700	16,000
Housing, Department of	Housing Program Fund (NA)	115,300	274,600
	Housing Trust Fund (OF)	33,500	79,700
Industrial Commission of Arizona	Industrial Commission Administrative Fund (OF)	528,700	1,258,800
Insurance, Department of	Captive Insurance Regulatory and Supervision Fund (NA)	5,500	13,100
	Financial Surveillance Fund (NA)	13,300	31,600
	Insurance Examiners' Revolving Fund (NA)	47,700	113,500
	Life and Disability Insurance Guaranty Fund (NA)	6,800	16,200
	Property and Casualty Insurance Guaranty Fund (NA)	12,900	30,800
Judiciary			
Superior Court	Criminal Justice Enhancement Fund (OF)	19,000	45,200
	Drug Treatment and Education Fund (NA)	13,100	31,100
	Grants and Special Revenue (NA)	15,800	37,700
Supreme Court	Confidential Intermediary and Fiduciary Fund (OF)	15,000	35,700
	Court Appointed Special Advocate Fund (OF)	14,500	34,500
	Criminal Justice Enhancement Fund (OF)	7,100	17,000
	Defensive Driving School Fund (OF)	27,900	66,500
	Grants and Special Revenue (NA)	94,500	225,100
	Judicial Collection Enhancement Fund (OF)	30,600	72,900
Subtotal - Judiciary		237,500	565,700
Juvenile Corrections, Department of	Criminal Justice Enhancement Fund (OF)	7,000	16,800
	State Education Fund for Committed Youth (OF)	99,700	237,400
Land Department, State	Cooperative Forestry Fund (NA)	19,100	45,400
	Fire Suppression Fund (NA)	117,600	280,100
Library, Archives & Public Records, Arizona State	Records Services Fund (OF)	12,300	29,300
Lottery Commission, Arizona State	Lottery Fund (OF)	249,800	594,700
Medical Examiners, Board of	Arizona Medical Board Fund (OF)	144,000	342,800
Mines & Mineral Resources, Department of	Mines and Minerals Resources (NA)	6,800	16,200
Naturopathic Physicians Medical Board	Naturopathic Physicians Medical Board Fund (OF)	16,600	39,500
Nursing Care Institution of Administrators and Assisted Living Facility Managers, Board of	Nursing Care Institution Administrators' Licensing and Assisted Living Facility Managers' Fund (OF)	11,000	26,200
Nursing, State Board of	Board of Nursing Fund (OF)	109,700	261,200
Occupational Therapy Examiners, Board of	Occupational Therapy Fund (OF)	6,600	15,700
Osteopathic Examiners, AZ Board of	Board of Osteopathic Examiners Fund (OF)	17,700	42,100
Parks Board, Arizona State	Heritage Fund (NA)	68,800	163,900
	Off-Highway Vehicle Recreation Fund (NA)	33,500	79,800
	Partnership Fund (NA)	5,900	14,000
	Publications and Souvenir Revolving Fund (NA)	9,500	22,700
	Reservation Surcharge Revolving Fund (OF)	17,600	41,800
	State Lake Improvement Fund (NA)	77,900	185,400
	State Parks Enhancement Fund (OF)	234,200	557,600
	State Parks Fund (NA)	8,300	19,700
Pest Management, Office of	Pest Management Fund (OF)	72,700	173,000
Pharmacy, AZ State Board of	Board of Pharmacy Fund (OF)	52,900	126,000
Physical Therapy Examiners, Board of	Board of Physical Therapy Fund (OF)	9,500	22,500



Division of Public Health Services

Public Health Preparedness Services

Bureau of State Laboratory Services

250 N. 17th Avenue
Phoenix, Arizona 85007-3231
(602) 542-6128
(602) 542-0760 FAX

JANICE K. BREWER, GOVERNOR
WILL HUMBLE, INTERIM DIRECTOR

Dear Stakeholder:

Due to recent budget reductions, the Newborn Screening (NBS) Program has been required to make some difficult decisions regarding services provided for the remainder of the current Fiscal Year (FY). Ultimately we believe the following decisions will minimize the impact of these reductions to Arizona newborns and their families.

The NBS Program will hold several funded positions vacant so savings can be applied to the budget reductions. As a result, hearing screening may not be assured and there might be delays in testing and non-emergency results reporting.

The NBS Program will maintain current hemoglobin testing methods. This will delay a change to more sensitive testing technologies for hemoglobin testing.

The Program, in conjunction with the Newborn Screening Advisory Committee, will streamline thyroid testing through use of a one-tiered test as part of a cost savings. We anticipate no impact to the Program's ability to continue to provide accurate and reliable thyroid testing.

The Newborn Screening Program will not currently be able to add additional disorders to the current screening panel (if requested by the Newborn Screening Advisory Committee).

If you have any questions or concerns regarding this information, please do not hesitate to contact Ward Jacox, Chief of the Office of Newborn screening, at jacoxw@azdhs.gov or (602) 364-1410.

Sincerely,

A handwritten signature in black ink that reads "William M. Slanta". The signature is written in a cursive style with a large, sweeping initial "W".

William Slanta,
Assistant Bureau Chief

Hall of Famer stumps for newborn testing

by Mary Jo Pitzl - Mar. 31, 2009 12:00 AM
The Arizona Republic

Hall of Fame quarterback Jim Kelly stopped by the state Capitol Monday to join the parade of people asking lawmakers to spare the budget ax.

Kelly's cause: newborn testing, which has been proposed for a combination of cuts and sweeps that add up to \$1.4 million for the next budget year.

The former Buffalo Bills quarterback said he embraced the cause of newborn testing after his son, Hunter, was born with a rare neurological disease that could have been detected by a simple test. The child died from symptoms of Krabbe disease.

Kelly said he was staggered to learn that there is no U.S. standard for newborn testing, so requirements vary widely nationwide.

"I found out that thousands of babies died because they're born in the wrong state," Kelly said.

Arizona tests newborns for 28 congenital disorders, as well as hearing deficiencies. Arizona does not test for the disease that

claimed Kelly's son at age 8. New York is the only state that does.

"I would love for Arizona to be the second state," Kelly said.

Meanwhile, he and advocacy groups such as the March of Dimes want to keep testing in place. That will happen only if the tests, which are paid for by parents but administered by the state, are immune from cuts.

"I, for one, will make sure that none of that money will be touched for next year," said Sen. Barbara Leff, R-Paradise Valley. She was joined by four other lawmakers.



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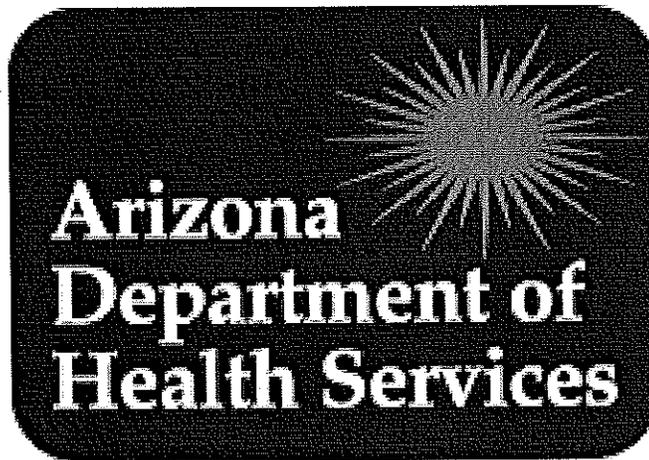
BLOODSPOT DATA SUMMARY

*Newborn Screening Advisory Committee
April 30, 2009*

OFFICE OF NEWBORN SCREENING 2008 CONFIRMED CASE REPORT
PRIMARY PANEL OF 28 BLOODSPOT DISORDERS

DISORDER	ANALYTE	PRESUMPTIVE POSITIVE	PRIMARY DISORDER	SECONDARY DISORDERS
Congenital Hypothyroidism	TSH	178	51	5-SECONDARY HYPOTHYROIDISM; 51-TRANSIENT; 9-THYROXINE BINDING
Congenital Adrenal Hyperplasia (21-hydroxylase deficiency)	17 OHP	943	5	1-NON-CLASSICAL; 2-21OH DEFICIENT
Sickle Cell Anemia			8	
Sickle Beta Thalassemia	Hgb	1192	0	1179 TRAITS; 3-OTHER HEMOGLOBIN DISEASE; 1 PRESUMED; NO FINAL DX
Sickle C Disease			1	
Biotinidase Deficiency	Biotinidase	60	1	
Galactosemia	GALT	73	2	
Phenylketonuria	Phenylalanine	64	2	1-HYPERPHENYLALANEMIA
Maple Syrup Urine Disease	Leucine	56	0	
Homocystinuria	Methionine	130	1	
Citrullinemia			1	
Argininosuccinic Acidemia	Citrulline	1	0	
Tyrosinemia Type 1	Tyrosine	52	0	
Carnitine Uptake Disorder	C0	6	1	1-OTHER FATTY ACID OXIDATION; 1-CARRIER
Medium-chain Acyl-CoA Dehydrogenase Deficiency	C8	8	4	
Very Long-chain Acyl-CoA Dehydrogenase Deficiency	C14:1	1	0	
Long-chain 3-OH Acyl-CoA Dehydrogenase Deficiency			0	
Trifunctional Protein Deficiency	C16OH	0	0	
Isovaleric Acidemia	C5	10	0	
Glutaric Acidemia Type 1	C5DC	10	0	
Hydroxymethylglutaric CoA Lyase Deficiency			0	
3-Methylcrotonyl CoA Carboxylase Deficiency	C5OH	11	1	
Multiple Carboxylase Deficiency			0	
Methylmalonic Acidemia (mutase deficiency)			0	
Methylmalonic Acidemia (Cbl A,B)			0	
Propionic Acidemia	C3	6	0	2-C50H OTHER
Beta-ketothiolase Deficiency	C5:1	0	0	
Cystic Fibrosis	IRT / DNA	176	14	
TOTALS		2977	92	

SPECIMEN DATA		
TOTAL OCCURRENT BIRTHS	PERCENTAGE	
1ST SCREEN	100,088	97%
2ND SCREEN	96,963	87%
REQUESTED REPEAT	87,503	
DIETARY MONITORING	59	
1ST & 2ND UNSAT	1,158	
TOTAL SPECIMEN COUNT	2,297	1.2%
	187,980	



HEARING DATA SUMMARY

*Newborn Screening Advisory Committee
April 30, 2009*

2009 Advisory Committee Arizona Newborn Hearing Screening Data

Screening Summary

	<u>2006</u>	<u>2007</u>	<u>2008</u>
Occurrent Births - Vital Records	102,095	104,516	100,088
Babies Screened - HI*Track	98,276 96%	98,853 95%	97,988 98%

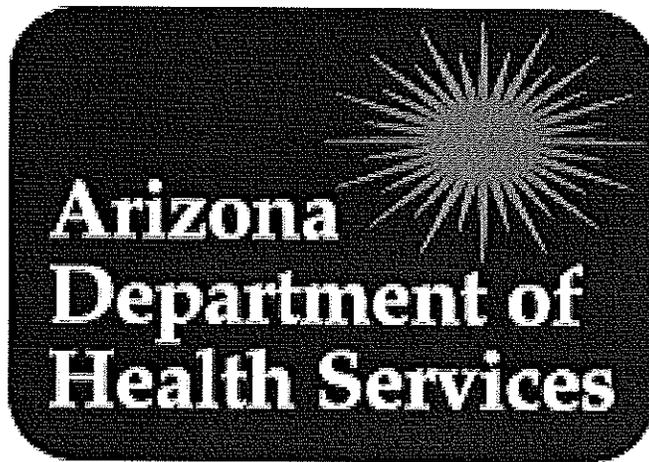
Case Management Summary

Case Load (Refer @ 30 days)	4,320 4%	3,488 4%	3,411 3%
Refer	3,859	3,073	2,934
Reported as Missed	461	415	477
Pass after 30 days	1,877	1,658	1,748
No Diagnosis	1,786	1,124	999
Lost to Follow up	41%	32%	29%

Diagnostic Summary Confirmed Hearing Status

Confirmed Normal Hearing	89	149	65
Confirmed Hearing Loss	107	142	122
Arizona - Detection of Hearing Loss per Thousand	1.1	1.4	1.2

National Incidence 3 per Thousand



LABORATORY

*Newborn Screening Advisory Committee
April 30, 2009*

Division of Public Health Services

Public Health Preparedness Services

Bureau of State Laboratory Services

250 N 17th Ave,

First Floor

Phoenix, Arizona

85007-3231

(602) 364-1409

(602) 364-1495 FAX

JANICE K. BREWER, GOVERNOR

WILL HUMBLE, INTERIM

DIRECTOR

Last name, First name

Affiliation

Street 1

Street 2

City, State Zipcode

Dear Sir or Madam:

In response to recent budget reductions, Arizona's Newborn Screening (NBS) Program will shortly be changing our laboratory method for the detection of Congenital Hypothyroidism (CH) in newborns by bloodspot. **Effective May 1, 2009**, screening results will be reported to you for thyroid stimulating hormone (TSH) only instead of thyroxine (T4) with a TSH backup. This decision was arrived at with the advice and agreement of our consulting pediatric endocrinologists and we believe that this new method will improve the accuracy and reliability of the determination of CH in newborns while significantly reducing analytical costs and false positives.

There are two widely used screening strategies for the detection of congenital hypothyroidism: a primary TSH/backup T4 method and a primary T4/backup TSH method. Since the diagnosis of primary hypothyroidism requires an elevated TSH, most programs in Europe, Japan, Canada, Mexico, and the United States screen by using primary TSH measurements. It should be noted that programs that use TSH only do not detect infants with low levels of T4 related to prematurity or TBG deficiency, neither of which require treatment, nor do they detect secondary (pituitary) or tertiary (hypothalamic) forms of hypothyroidism. The latter, whose incidence is estimated at 1:100,000 compared to 1:2000 – 1:4000 for primary congenital hypothyroidism, are often accompanied by other findings (e.g. hypoglycemia, mid-line defects, etc.).¹

We will continue to communicate with you as we make changes to our testing and follow-up protocols for the other inherited disorders screened by our program. If you have any questions related to this laboratory change, please do not hesitate to contact either Dr. Sundin Applegate, NBS Medical Director, at applegs@azdhs.gov or (602) 542-1223 or myself at jacoxw@azdhs.gov or (602) 364-1410. If you have clinical questions, please contact one of the consulting pediatric endocrinologists, listed on the back of each result mailer or on our website at www.aznewborn.com.

Sincerely,



Ward Jacox, Chief
Office of Newborn Screening



RULES

*Newborn Screening Advisory Committee
April 30, 2009*

NOTICES OF PUBLIC INFORMATION

Notices of Public Information contain corrections that agencies wish to make to their notices of rulemaking; miscellaneous rule-making information that does not fit into any other category of notice; and other types of information required by statute to be published in the *Register*. Because of the variety of material that is contained in a Notice of Public Information, the Office of the Secretary of State has not established a specific format for these notices.

NOTICE OF PUBLIC INFORMATION

OFFICE OF THE GOVERNOR

TO: State Agency Directors and Acting Directors
FROM: Janice K. Brewer
Governor
SUBJECT: Regulatory Review Plan
DATE: January 22, 2009

[M09-19]

In order to ensure that my appointees have the opportunity to review any new or pending rules, I am asking that you immediately take the following steps, subject to the exception process as described in paragraph 9:

1. Send no proposed or final rule to the Secretary of State for the publication in the Arizona Administrative Register.
2. File no notice of proposed rule making with the Secretary of State or begin or continue any activities in preparation for the rule making, including informal rule making activities.
3. With respect to proposed rules that have been sent to the Secretary of State but not published in the Arizona Administrative Register, withdraw them from the Secretary of State.
4. With respect to proposed rules that are final but have not been submitted to the Governor's Regulatory Review Council (GRRC) for approval, postpone filing the rules with GRRC.
5. With respect to proposed rules that have been submitted to the GRRC for approval, postpone filing rules approved by GRRC with the Secretary of State.
6. With respect to proposed rules that are final but have not been submitted to the Attorney General for approval, postpone filing the rules with the Attorney General.
7. With respect to proposed rules that have been submitted to the Attorney General for approval, withdraw the rules from consideration by the Attorney General.
8. Provide the Governor's Office a list and brief summary of each rule making activity within your agency no later than February 16, 2009.
9. Notify the Governor's Office promptly in writing of any rule making activity that, in your view, impacts critical public peace, health and safety functions of the agency or that are needed to address the state budget deficit and therefore should be also excluded from the directives in paragraphs 1-7. The Governor's Office will review any such notifications and determine whether exception is appropriate under the circumstances.

The directives in paragraphs 1-7 shall remain in effect until April 30, 2009.

As used in this memorandum, "rule" has the meaning as defined in A.R.S. § 41-1001(17).

Finally, in the interest of sound regulatory practice and the avoidance of costly, burdensome, or unnecessary rules, independent agencies are encouraged to participate voluntarily within the context of their own rulemaking processes.

This regulatory review will be implemented by the Governor's Office. Communications regarding exceptions to the review, or questions regarding the review generally, should be addressed to Richard bark, Deputy Chief of Staff for Policy at rbark@az.gov.

This memorandum shall be published in the Arizona Administrative Register.



State of Arizona

Janice K. Brewer
Governor

Office of the Governor
1700 West Washington Street, Phoenix, AZ 85007

Main Phone: 602-542-4331
Facsimile: 602-542-7601

TO: State Agency Directors and Acting Directors

FROM: Janice K. Brewer
Governor

SUBJECT: Continuation of Regulatory Review Plan (Moratorium)

DATE: April 29, 2009

My staff is in the process of evaluating information received from the agencies, boards, and commissions regarding new and pending rulemakings during the rulemaking moratorium. In order to complete this process, I am extending the rulemaking moratorium issued January 22, 2009 from April 30, 2009 to June 30, 2009. During the moratorium, my staff identified some administrative rules that should have been repealed some time ago. Examples of administrative rules identified thus far include:

Department of Economic Security, 6 A.A.C. 13, Articles 2,3,6,8,9 and 12; A.A.C.R6-1-501;
Arizona Department of Administration, 2 A.A.C.R2-1-604 and R2-1-605;
Department of Racing, A.A.C.R19-2-115.10;
Arizona State Retirement System, A.A.C.R2-8-104, R2-8-116, and R2-8-119; and
Department of Health Services, A.A.C.R9-19-115, R9-19-404, and R9-19-406.

During the continuation of the moratorium, I am requiring agencies to identify administrative rules that (1) are no longer necessary due to changes in state or federal law or case law, (2) are not effective, (3) are inconsistent with current agency practice, or (4) are not enforced. Agencies shall identify obsolete rules and submit the report to Jeri Kishiyama Auther, Policy Advisor, Rules and Regulations, no later than the close of business on May 25, 2009.

Regulatory Moratorium

In addition to the memorandum issued January 22, 2009, the following applies:

1. Agencies shall continue to comply with the Five-year Review requirements of A.R.S. § 41-1056 *et seq.* and the reporting requirements of A.R.S. § 41-1091; and
2. Agencies shall comply with the intent of the moratorium and ensure that substantive policy statements as defined in A.R.S. § 41-1001(20) do not violate A.R.S. § 41-1033.

1 Be it enacted by the Legislature of the State of Arizona:

2 Section 1. Title 41, chapter 6, article 3, Arizona Revised Statutes,
3 is amended by adding section 41-1021.03, to read:

4 41-1021.03. Moratorium on rule making relating to increased
5 monetary or regulatory costs; exceptions

6 A. NOTWITHSTANDING ANY OTHER LAW, AN AGENCY SHALL NOT CONDUCT ANY RULE
7 MAKING THAT WOULD IMPOSE INCREASED MONETARY OR REGULATORY COSTS ON OTHER
8 STATE AGENCIES, POLITICAL SUBDIVISIONS OF THIS STATE, PERSONS OR INDIVIDUALS
9 OR WOULD NOT REDUCE THE REGULATORY BURDEN ON THE PERSONS OR INDIVIDUALS SO
10 REGULATED.

11 B. SUBSECTION A DOES NOT APPLY TO RULE MAKING FOR ANY OF THE
12 FOLLOWING:

13 1. TO AVOID A VIOLATION OF A COURT ORDER OR FEDERAL LAW THAT WOULD
14 RESULT IN SANCTIONS BY THE COURT OR FEDERAL GOVERNMENT TO AN AGENCY IN FISCAL
15 YEAR 2008-2009 OR 2009-2010 FOR FAILURE TO CONDUCT THE RULE MAKING ACTION.

16 2. TO PREVENT AN IMMINENT THREAT TO THE PUBLIC HEALTH OR SAFETY. FOR
17 THE PURPOSES OF THIS PARAGRAPH, "IMMINENT THREAT TO THE PUBLIC HEALTH OR
18 SAFETY" MEANS THE EXISTENCE OF A CONDITION, CIRCUMSTANCE OR PRACTICE THAT
19 WOULD CAUSE DEATH, SERIOUS ILLNESS OR SEVERE INJURY TO PERSONS OR ADVERSELY
20 AFFECT THE ABILITY OF HEALTH CARE INSTITUTIONS TO PROVIDE MEDICAL CARE DURING
21 FISCAL YEAR 2008-2009 OR 2009-2010.

22 3. TO FULFILL AN OBLIGATION RELATED TO FEES, RATES, FINES OR
23 REGULATIONS THAT ARE EXPRESSLY DELINEATED IN THE CONSTITUTION.

24 C. FOR PURPOSES OF THIS SECTION, "INCREASED MONETARY OR REGULATORY
25 COSTS" DO NOT INCLUDE COSTS ASSOCIATED WITH RULE MAKING CONDUCTED BY A
26 SELF-SUPPORTING REGULATORY BOARD AS DEFINED IN SECTION 41-1092, PROVIDED THE
27 SELF-SUPPORTING REGULATORY BOARD MAKES A SPECIFIC FINDING THAT THE MONETARY
28 BENEFITS TO LICENSEES OR PERMITTEES OF THE BOARD FROM THE PROPOSED RULE
29 MAKING SUBSTANTIALLY OUTWEIGH THE COSTS OF THE PROPOSED RULE MAKING TO
30 LICENSEES OR PERMITTEES OF THE BOARD AND IS NECESSARY TO ALLOW THE
31 SELF-SUPPORTING REGULATORY BOARD TO ADMINISTER EXISTING STATUTORY
32 REQUIREMENTS OR ADMINISTRATIVE RULES. THE FINDING OF THE SELF-SUPPORTING
33 REGULATORY BOARD SHALL INCLUDE THE SPECIFIC FINDING AND ALL EVIDENCE
34 PRESENTED AT A PUBLIC HEARING SUPPORTING THE PROPOSED RULE MAKING.

35 Sec. 2. Delayed repeal

36 Section 41-1021.03, Arizona Revised Statutes, as added by this act, is
37 repealed from and after June 30, 2010.

38 Sec. 3. Emergency

39 This act is an emergency measure that is necessary to preserve the
40 public peace, health or safety and is operative immediately as provided by
41 law.

Rulemaking - 201

- Rules Require Statutory Authority
- Phases of Rulemaking
 - Phase 1: Rules Drafting
(Draft rules on ADHS website:
http://www.azdhs.gov/diro/admin_rules/index.htm)
 - Phase 2: Formal Rules Process
(A.R.S. Title 41, Chapter 6, Article 3)

Rulemaking - 201

- Rulemaking moratorium due to Governor's Executive Order until after April 30, 2009, now extended to after June 30, 2009
- HB 2240 creates a moratorium until after June 30, 2010 on rulemaking that:
 - Increases costs to other agencies, political subdivisions, or Arizona citizens
 - Does not reduce the regulatory burden on those it regulates
 - Exceptions for rules:
 - To address "imminent threat to public health or safety"
 - To avoid a violation of federal law or any court order

Rulemaking - 201

Where do we go from here?

It depends

- Lifting of the Governor's moratorium?
- Passage of HB 2240?
- Interval in-between?

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