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# SENATE COMMITTEE REPORT

## First Committee of Referral

DATE: 2/24/97

FURTHER: Finance

Date of 5-Day Notice: 2/27/97  
(in accordance with Uniform Rule 23)

DATE TURNED  
IN TO OFFICE: 3/5/97

HESS Committee considered

SENATE BILL NO. 99

"An Act relating to health care data and registration of births."

and recommends:

be replaced with \_\_\_\_\_ CS \_\_\_\_\_ (\_\_\_\_\_)

adopt previous \_\_\_\_\_ CS \_\_\_\_\_ (\_\_\_\_\_)

attached amendment(s)

adopt Letter of Intent by \_\_\_\_\_ Committee

further referral to the \_\_\_\_\_ Committee

**Senate Bill:**  
 same title  
 new title  
**House Bill:**  
 same title  
 technical title  
 new: SCR# \_\_\_\_\_

SIGNING DO PASS	DP	OTHER RECOMMENDATIONS	NR	DNP	AM
		<i>[Signature]</i>	✓		
		<i>[Signature]</i>	✓		
CHAIR: <i>GRW</i>	✓	CHAIR:			

**NEW FISCAL NOTE(S):**

Department	Date	Zero	Fiscal
Health + Social Services	2/27/97	✓	

**PREVIOUS FISCAL NOTE(S):\***

Department	Date	Zero	Fiscal

APPROPRIATION -- no fiscal note

\*include fiscal notes accompanying Governor's bill

STATE OF ALASKA  
1997 LEGISLATIVE SESSION

BILL NO. SB 99

Revision Date: \_\_\_\_\_  
 Title: An act relating to health care data  
and registration of births  
 Sponsor: Senate HESS  
 Requestor: Senate HESS

Dept. Affected: Health and Social Services  
 BRU: State Health Services  
 Component: Bureau of Vital Statistics  
 COMPONENT SERIAL NO. 961  
 See also (SN#): 296

Expenditures/Revenues:

(Thousands of Dollars)

OPERATING	FY98	FY99	FY00	FY01	FY02	FY03
PERSONAL SERVICES						
TRAVEL						
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
<b>TOTAL OPERATING</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

CAPITAL EXPENDITURES						
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CHANGES IN REVENUES ( )						
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FUND SOURCE

(Thousands of Dollars)

1002 Federal Receipts						
1003 GF Match						
1004 GF						
1005 GF/Program Receipts						
1037 GF/Mental Health						
Other (please specify)						
<b>TOTAL</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>

POSITIONS:

FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of any current year (FY97) cost: \$0.0

ANALYSIS: (Attach a separate page if necessary)

Should this bill not pass, the state would lose \$420.0/year in federal grant funds for the establishment of a cancer registry to monitor the occurrences within the state.

Prepared by: Peter M. Nakamura, MD, MPH  
 Division: Public Health  
 Approved by Commissioner: Karen Perdue, Commissioner  
 Agency: Department of Health & Social Services

Phone: (907) 465-3090  
 Date: 02/25/97  
 Date: 2/27/97

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FISCAL IMPACT:

NCNE

FISCAL NOTE ATTACHED

**BACKGROUND/LEGISLATIVE INTENT**

This bill was introduced by the HESS committee at the request of the Department. It will accomplish changes in current law needed to: 1) achieve program efficiencies possible with advanced technology by eliminating the need for individual hospital signatures on birth certificates allowing full implementation of the Electronic Birth Certificate; 2) clarify rules for filing and registering births occurring on moving conveyances or in international water or air space en route to Alaska; 3) establish a statewide cancer registry under a 5-year federal grant of \$420,000 annually. The grant requires protections for data and access to data for research purposes as well as protection from civil liabilities for providers who report required data.

**ANALYSIS OF BILL/PROGRAM EFFECTS**

Sections 1 & 2 establish civil immunity for providers who disclose health care data on diseases and conditions which must be reported to the Department and assures access to health records needed to carry out public health activities and to conduct research for the purposes of protecting or promoting public health. These provisions protect providers for mandatory reporting of health information needed for effective public health surveillance, analysis, prevention, and disease control efforts. Without these provisions the Department will become ineligible to receive grant funding to establish a registry of cancer occurrences within the state - an increasingly vital activity as cancer has become the leading cause of death.

Sections 3 & 4 make changes in AS 18.50.160(a) to fully implement the Electronic Birth Certificate system and take full advantage of more efficient technology by: 1) allowing certification to occur by an electronic process rather than only by signature on a paper certificate; 2) shifting place of filing to recognize electronic filing at the bureau; 3) reducing filing time from 7 to 5 days to comply with requirements of the National Center for Health Statistics. They also clarify rules for filing and registering births occurring on moving conveyances in international waters or air space or foreign waters or air space en route to Alaska. This complies with the model Vital Statistics Act.

**AMENDMENTS PROPOSED**

DEPARTMENT OF HEALTH AND SOCIAL SERVICES  
Position and Sectional Analysis  
SB 99

The Department strongly supports this bill. It accomplishes two important objectives by (1) allowing the department to establish and maintain a statewide cancer registry under a 5-year \$420,000 annual grant; (2) increase program efficiency by allowing the Department to take advantage of new technology.

Section 1: Grants civil immunity to persons who report health care data to the Department when the reports are made in compliance with AS 18.05 and attendant regulations. This immunity protects the person reporting the information regardless of how the Department uses the information. This protection is necessary to make the Department eligible to receive grant funds to establish a statewide cancer registry.

Section 2: Grants the Department the right to examine health care records of anyone providing health care services to patients that would identify patients or establish characteristics of an identified patient with a reportable condition or disease. It allows the Department to conduct research using information reported to the Department while requiring the Department to keep reported information confidential. It allows the Department to release this information to other persons for clinical, epidemiological or other public health research so long as the information is kept confidential and not released to other persons without Departmental consent. Finally, information reported under this section is exempt for freedom of information requests.

Section 3: Clarifies the rules for reporting and registering births that occur on moving conveyances in international waters or air space or foreign waters or air space en route to Alaska and bring Alaska statutes on such reporting into compliance with the model Vital Statistics Acts. It reduces the filing time from 7 to 5 days to comply with requirements of the National Center for Health Statistics.

Section 4: Clarifies the rules for reporting of births that occur en route to a birthing institution, allow the Department to fully implement the Electronic Birth Certificate system by allowing electronic certification of births rather than only by signature on a piece of paper and by moving the place of filing to recognize electronic filing at the Bureau of Vital Statistics.

ALASKA STATE

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# HOSPITAL & NURSING HOME

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ASSOCIATION

Senator Gary Wilken, Chair  
Senate HESS Committee  
Room 510, Capitol Building  
Juneau, AK 99811

March 5, 1997

RE: Senate Bill 99 "an Act relating to health care data and registration of births."

Dear Senator Wilken:

The members of the Alaska State Hospital and Nursing Home Association support Senate Bill 99 which is scheduled for a hearing before your committee today.

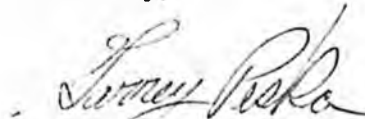
Section 1 of this bill provides immunity for a person who reports health care data required by law to be reported to the Department of Health and Social Services.

Section 2 clarifies that the Department has the right to access health care records to conduct epidemiological or other public health research.

Sections 3 & 4 clarify and simplify the process for registration of births.

We respectfully request that you support Senate Bill 99 and pass it from the HESS committee today.

Sincerely,



Garrey Peska  
Financial Consultant

# HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

ALASKA STATE LEGISLATURE  
HOUSE OF REPRESENTATIVES

P.O. BOX V, JUNEAU 99811

(907) 465-3759



## SPONSOR STATEMENT

SCS HB 114 (FIN)

*Companion Bill to SB 99*

"An Act relating to health care data and registration of births."

This bill will accomplish changes in law needed to assure that the Department of Health and Social Services has access to information on diseases and conditions of public health significance essential to carrying out disease surveillance, control, and prevention activities.

It will establish explicit civil immunity for providers who comply with requirements to report health care data and assure access by DHSS to health records needed to carry out its mandates and to conduct research for the purposes of protecting and promoting public health. These provisions are required to continue eligibility for a Federal grant of \$420,000 per year which supports operation of a registry of cancer occurrences within the state - an increasingly vital activity as cancer has become the leading cause of death.

HB 114 will also make changes needed to fully implement the Electronic Birth Certificate system and clarify rules for filing and registering births occurring en route to Alaska. The bill will:

- allow certification of births to occur by an electronic process rather than only by signature on a paper certificate and shift the place of filing to recognize electronic filing;
- reduce filing time from 7 to 5 days to comply with requirements of the National Center for Health Statistics;
- clarify rules for filing and registering births occurring on moving conveyances in international waters or air space or foreign waters or air space en route to Alaska to comply with the model Vital Statistics Act.

The Senate Finance Committee amended the bill to make it clear that the Department of Health and Social Services has access to patient records for only diseases and conditions of public health significance. The bill does NOT grant the department unlimited access to patient records and data. With this amendment, the bill is supported by the Alaska State Hospital and Nursing Home Association and the American Cancer Society.

### CANCER REGISTRY BILL ISSUES RESOLVED

House Bill 114 as originally introduced included language that would allow the department to inspect health care records maintained by providers that would identify patients or establish characteristics of an identified patient with a condition or disease required to be reported to protect public health.

ASHNHA members objected saying that language was too broad and subjective. The department agreed to an ASHNHA amendment that would allow inspection of records identifying patients with cancer required to be reported under the National Cancer Registries Act or with a birth defect or infectious disease.

The department and ASHNHA agreed on another amendment that clarifies that releasing data from medical records (including names, etc.) under this law will not constitute a breach of confidentiality. A third amendment states that data may be obtained from medical records but the actual records will be inspected, not obtained, by the department.

With support from ASHNHA and the department, the bill passed out of Senate Finance this week. It is expected to pass this year.

### Need for public health access to medical records

- Individual physicians report only a minimal amount of information about a person who is diagnosed with a disease that is required to be reported to protect the public health.
  - The goal is to identify that the disease has been suspected or diagnosed.
  - Individual physicians are not required to then fill out detailed case forms that include the important, detailed information needed to characterize risk factors, verify the diagnosis, and obtain information on symptoms, lab results and treatment.
  - The acquisition of the detailed information is done by public health nurses and physicians. This protects the physician from undue burdensome paperwork. It enables the physician to concentrate on treating the patient and public health physicians to concentrate on protecting those other than the patient.
  
- The process of disease reporting and obtaining information to protect the public health is a partnership between the attending physician and the public health professionals.

Examples of the types of detailed information that are obtained by public health from medical records.

- Cancer
  - Diagnostic information
  - Primary site of the cancer
  - Histologic type, behavior, grade
  - Method of diagnostic confirmation
  - State of disease
  
- Tuberculosis
  - Dates of past TB skin tests.
  - History of past TB infection, site, extent of disease, lab results, type and duration of treatment.
  - Other illness that might affect selection of drugs used to treat.
  - Lab results of the sensitivity of the organism to antibiotics.



DEPARTMENT OF HEALTH &amp; HUMAN SERVICES

Public Health Service

Centers for Disease Control  
and Prevention (CDC)  
Atlanta GA 30341-3724

August 8, 1997

Peter Nakamura, MD MPH  
Director of Public Health  
PO Box 110610  
Juneau AK 99811-0610

Dear Dr. Nakamura:

I am writing to address concerns that have arisen regarding the reporting of personal identifying information for individuals with cancer. The failure to collect and report this information has serious implications for Federal reporting requirements as prescribed in the Cancer Registries Amendment Act of 1992 (PL 102-515), for central cancer registry operations, and in light of the Health Insurance Portability and Accountability Act of 1996, sponsored by Senators Kennedy and Kassebaum.

Public Law 102-515 requires that all participants funded through the National Program of Cancer Registries (currently, 42 states and the District of Columbia) collect, for each form of in-situ and invasive cancer (with the exception of basal and squamous cell carcinoma), demographic information (including personal identifiers - such as, but not limited to, name, address, social security number), information on the industrial or occupational history, administrative information, and pathology data characterizing the cancer. In addition, all five states and six metropolitan area registries funded through the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER) are required to collect similar personal identifying information. And finally, states that are not currently funded through the Centers for Disease Control and Prevention or NCI (i.e. Tennessee and Delaware) collect this information from their reporting medical facilities. That is to say, all state central cancer registries in existence (49) collect personal identifiers.

Personal identifiers are absolutely essential to the operations of state central cancer registries to ensure accurate cancer data. For example, personal identifiers are required for record linkage procedures to identify multiple reports from more than one reporting source (i.e. hospital, lab, or clinic). Cancer case reports from multiple reporting sources may be incomplete, provide contradictory information, or may be identical. Thus, the central registry must identify the multiple reports on the same person, reconcile any inconsistencies, and prepare a composite set of values for each patient and tumor, incorporating information from a variety of sources. Such case consolidation procedures are absolutely critical in order to avoid over counting of cancer cases that would result in inaccurate and inflated cancer incidence rates.

Personal identifiers are also absolutely necessary to assure completeness of cancer data. Personal identifiers are required to link cancer registry data to death certificates in the state to identify

previously unreported cases of cancer, to obtain new cancer information about the person previously unavailable (follow-back procedures), and to document vital status. Death clearance is an essential step in achieving complete population-based reporting. It serves as a check on completeness of reporting from other sources and often identifies cases which should have been reported from those reporting sources but were not. In addition, the proportion of cancer cases identified only by a death certificate ("death certificate only"=DCO) is an important standard measure of the quality of cancer case finding used by all other state cancer registries.

Personal identifiers are essential to fulfil requirements for cancer case-sharing agreements. The central registry must collect information about all cancers occurring in its coverage area, regardless of state residence. For the purpose of completeness of reporting, central registries should provide case information on a nonresident to the population-based registry covering the patient's place of residence once formal case sharing agreements are established. If Alaska did not collect personal identifiers, case-sharing would not be possible with other states—thus, eliminating an important source of cancer information about Alaska citizens diagnosed or treated in other states.

The collection of personal identifiers is consistent with national trends in the private health care industry and the public sector to streamline and standardize the electronic exchange of health information. For example, the Health Insurance Portability and Accountability Act of 1996 (A.K.A. Kennedy-Kassebaum Bill) recently signed into law prescribes national administrative simplification through development and adoption of national standards for "transaction and data elements for such transactions, to enable health information to be exchanged electronically" including "individually identifiable health information". The Act also clearly recognizes the need to protect the privacy and confidentiality of such health information by imposing substantial penalties of \$50,000 to \$250,000 and/or prison terms for "wrongful disclosure of individually identifiable health information". The Kennedy-Kassebaum Law goes further to state "nothing in this part shall be construed to invalidate or limit the authority, power, or procedures established under any law providing for the reporting of disease or injury, child abuse, birth, or death, public health surveillance, or public health investigation or intervention".

Complete, quality, and timely data are necessary if data are to be used to: monitor trends in cancer incidence and mortality; to guide cancer control program planning and evaluation; to assist in prioritizing health resource allocations; to advance population-based epidemiologic and health services research; and, to serve as the foundation of a national comprehensive cancer control strategy. Without personal identifying information, the ability to ensure complete, quality, and timely data is compromised.

If I can further address any concerns, please contact me at (770) 488-4227.

Sincerely yours,



Daniel Miller, M.D., M.P.H.  
Chief  
Epidemiology and Statistics Branch  
Division of Cancer Prevention and Control  
National Center for Chronic Disease  
Prevention and Health Promotion

cc: Jean Roche

ORDER ADOPTING, AMENDING, OR REPEALING REGULATIONS OF  
THE DEPARTMENT OF HEALTH AND SOCIAL SERVICES

The attached 16 pages of regulations, dealing with disease reporting are hereby adopted and certified to be a correct copy of the regulations that the Department of Health and Social Services adopts, amends, or repeals under the authority of AS 18.05.030, AS 18.05.040, AS 18.05.044, and AS 18.05.046 and after compliance with the Administrative Procedure Act (AS 44.62), specifically including notice under AS 44.62.190 and 44.62.200 and opportunity for public comment under AS 44.62.210.

This action is not expected to require an increased appropriation.

The regulations adopted under this order take effect on the 30th day after they have been filed by the lieutenant governor, as provided in AS 44.62.180.

DATE:

Dec. 18, 1995  
Tulsa, ALA.  
(city where dated)

Karen Perdue  
Karen Perdue  
Commissioner  
Department of Health and Social Services

FILING CERTIFICATION

I, Fran Ulmer, Lieutenant Governor for the State of Alaska, certify that on \_\_\_\_\_, 1995, at \_\_\_\_\_ .m., I filed the attached regulations according to the provisions of AS 44.62.040-44.62.120.

\_\_\_\_\_  
Lieutenant Governor

Effective \_\_\_\_\_.

Register \_\_\_\_\_.

*Ranked reg#  
No 137  
1/19/96*

**CHAPTER 27. PREVENTIVE MEDICAL SERVICES.** →

Publisher: Please contact  
Capitol  
office  
pending.  
D&B

Article 1. Control of Diseases of Public Health Significance  
(7 AAC 27.005 - 7 AAC 27.080).

[NOTE TO PUBLISHER: Please make appropriate  
corrections to the section listing for  
Article 1.]

7 AAC 27.005 is amended to read:

7 AAC 27.005. REPORTING BY HEALTH CARE PROVIDERS. (a) The following common diseases of public health significance must be reported by the physician, nurse, or other health care professional who prescribes for or attends a person with these diseases or suspected diseases: amebiasis, botulism, brucellosis, campylobacter, chlamydia, cryptosporidium, diphtheria, giardia, gonorrhoea, hepatitis (type A, [OR] B, or C [NON A - NON B]), hemophilus influenzae type B meningitis, legionnaire's disease, Lyme disease, meningococcal meningitis, mumps, paralytic shellfish poisoning, pertussis, psittacosis, Reye's Syndrome, rheumatic fever, rubella, rubeola, salmonella, shigella, syphilis, trichinosis, tuberculosis, tularemia, typhoid, yersinia, severe reactions to any vaccination, and epidemic outbreaks or unusual incidences of infectious [COMMUNICABLE] disease.

-1-  
Regulations adopted 12/18/95 by Health  
& Social Services

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(b) The following rare diseases of public health significance must be reported by the physician, nurse, or other health care professional who prescribes for or attends a person with these diseases or suspected diseases: (i) ~~anthrax~~, acquired immune deficiency syndrome (AIDS), cholera, echinococcus, encephalitis, leprosy, malaria, poliomyelitis, plague, rabies, smallpox, tetanus, and yellow fever.

(c) Reports must be submitted to the division (DEPARTMENT OF HEALTH AND SOCIAL SERVICES, DIVISION OF PUBLIC HEALTH,) orally or on a form provided by the division (DIVISION OF PUBLIC HEALTH) promptly after first discovering or suspecting the existence of the disease or disease outbreak. Each report must give the name, address, age, sex, and race of the person diagnosed as having the reported disease [,] and the name and address of the health care provider reporting the disease.

(d) Outbreaks or unusual incidences of diseases <sup>that</sup> ~~which~~ are known or suspected to be related to exposure to environmental toxic or hazardous material must be reported by the physician, nurse, or other health care professional who prescribes for or attends those affected. (Eff. 8/21/74, Register 51; am 9/20/75, Register 55; am 3/28/84, Register 89; am / / , Register )

Authority: AS 18.05.040 [(1)]

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7 AAC 27.007 is amended to read:

7 AAC 27.007. REPORTING BY LABORATORIES. (a) Public, private, military, hospital, or other laboratories performing serologic, immunologic, microscopic, biochemical, or cultural tests within the State of Alaska must report evidence of [ANY OF] the following diseases of public health significance at the time of identification or suspected identification: amebiasis, anthrax, botulism, brucellosis, campylobacter, chlamydia, cryptosporidium, cholera, diphtheria, echinococcus, E. coli 0157:H7, [ENTEROPATHOGENIC ESCHERICHIA COLI,] giardia, gonorrhea, hepatitis (Type A, [OR] B, or C), influenza, Legionella pneumophila, leprosy, [LEPTOSPIROSIS,] malaria, meningitis, meningococcal disease, mumps, pertussis, plague, poliomyelitis, psittacosis, rabies (human or animal), rubella, rubeola, salmonella, shigella, smallpox, syphilis, tetanus, trichinosis, tuberculosis, tularemia, typhus, yellow fever, and Yersinia enterocolitica.

(b) Reports must be submitted to the division [DEPARTMENT OF HEALTH AND SOCIAL SERVICES, DIVISION OF PUBLIC HEALTH,] orally or on a form provided by the division [DIVISION OF PUBLIC HEALTH,] or on a legible copy of the original laboratory report form promptly after the examination or test is performed. Each notification must give the date and result of the test performed,

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the name or identification code sufficient to identify the patient to the health care provider, and, when available, the age of the person from whom the specimen was obtained [,] and the name and address of the health care provider for whom the examination or test was performed.

(c) When acting on the basis of information received from laboratory notification, the division [DIVISION OF PUBLIC HEALTH] will not, except in instances of overriding public health considerations, contact the patient without first requesting [AND OBTAINING] the permission of the physician or other health care provider.

(d) Repealed / / .

(Eff. 8/21/74, Register 51; am 9/20/75, Register 55; am 3/28/84, Register 89; am / / , Register )

Authority: AS 18.05.040 [(1)]

7 AAC 27.008 is repealed:

7 AAC 27.008. REPORTING BY HOSPITALS. Repealed / / .

7 AAC 27.010 is amended to read:

7 AAC 27.010. CONTROL OF COMMUNICABLE DISEASES IN MAN. (a)

The provision on methods of control of communicable diseases outlined in the *Control of Communicable Diseases in Man*.

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(AMERICAN PUBLIC HEALTH ASSOCIATION,] SIXTEENTH [THIRTEENTH] Edition 1995 [1981], American Public Health Association are adopted by reference as the regulations governing "Preventive Measures," "Control of Patients, Contacts and the Immediate Environment," and "Epidemic Measures."

(b) The provisions of (a) of this section are not applicable to the control of rabies in animals or to [ON] the reporting of diseases of public health significance. (Eff. 6/10/62, Register 6; am 8/21/74, Register 51; am 3/28/84, Register 89; am / / , Register )  
Authority: AS 18.05.040 [(1)]

Editor's note: Control of Communicable Diseases in Man. Sixteenth Edition, 1995 is on file in the lieutenant governor's office and is available from the American Public Health Association, 1015 15th Street, NW, Washington, DC 20005, phone (202) 789-5600.

7 AAC 27 is amended by adding a new section to read:

7 AAC 27.011. CANCER REGISTRY. (a) A hospital, physician, surgeon, or other health care facility or practitioner diagnosing or providing treatment for a cancer patient in the State of Alaska shall report the information specified in (b) of this section to the division, within six months of the date of diagnosis.

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(b) The following must be provided for each form of in-site and invasive cancer, with the exception of basal cell and squamous cell carcinoma of the skin:

(1) information about the patient including, as a minimum, name, date of birth, sex, race, community of residence, date of diagnosis, primary site, and name of attending or admitting health care provider; and

(2) pathological data characterizing the cancer including the cancer sites, stage of disease, and type of treatment. (Eff. / / , Register )

Authority: AS 18.05.030  
AS 18.05.040  
AS 18.05.044

7 AAC 27 is amended by adding a new section to read:

7 AAC 27.012. BIRTH DEFECTS REGISTRY. (a) A hospital, physician, surgeon, or other health care facility or practitioner diagnosing or providing treatment to a patient less than six years old with a birth defect listed in (b) of this section shall report to the division, within three months of the date of diagnosis or treatment, information about the patient including name, date of birth, place of birth, sex, race, community of residence, date of diagnosis, and specific type of each birth defect diagnosed or treated.