

Alaska Birth Defect Registry Reporting Guide

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Introduction

The Alaska Birth Defects Registry (ABDR) was established in 1996 under Alaska Regulation 7 AAC 27.012. Health care providers, hospitals, other health care facilities, regional health exchanges, and third party payers report to ABDR when they have cared for, collect or maintain a record of service to a child under the age of three, with any of the congenital conditions listed below.

ABDR provides information on the occurrence and distribution of congenital birth defects within the State of Alaska.

Authority

Please refer to the enabling regulation above and the references cited in the included Commissioners Letter (p.5) which addresses data collection for public health use.

Reporting

Who: Any organization that provides service to or collects, and maintains records of service to children under the age of three with any of the conditions listed below.

When: Organizations are expected to report all indicated conditions semiannually (every six months).

What: Please include data for:

- All of the divisions and / or business segments of your organization.
 - In-patient, outpatient, admits, discharges, radiology, laboratory, specialty clinics, etc.
- All individuals seen by your organization up until their 3rd birthday. (Date of Service – Date of Birth) <3
- All of the ICD-10 CM codes listed in the following tables.

Data Format and Layout

-----Child information-----						-----Agency data-----			-----Mother/resp. party name-----		
Date of Encounter Discharge Date	Last Name	First Name	Middle Name	Date Of Birth (DOB)	Sex	Medical Record Number	ICD Code	Agency Name	Agency NPI	Mother / Resp. Pty Last Name*	Mother / Resp. Pty First Name*
MM/DD/ YYYY	Text	Text	Text	MM/DD/ YYYY	M,F	Text	#####			Text	Text

- Each encounter is a unique combination of:
Individual Last + First + DOB + Sex + ICD Code. Send a single row for each unique combination.

- Repeat the individual data for each individual and condition combination reported.
- If your data is not quite what the registry is requesting please send it as is.
- Our preference is to receive .xls, .xlsx, or comma delimited .csv / .txt files.
- Data arrives in many layouts and formats. The registry can accommodate wide variations in incoming data sets. Contact the registry with any questions.
- The registry de-duplicates multiple reports for the same individual, condition, and agency.

How to Report

All Protected Health Information (PHI) delivered to the Registry must be encrypted at all times.

- The most convenient method is to use a secure email system. healthConnect (<https://mail.directak.net/>) provides an easy to use secure messaging system (Direct Secure Mail or DSM) that allows you to submit reports via a secure email system. Using this system is straightforward, and meets all security requirements. The Registry's DSM address is: dph.abdr@hss.soa.directak.net
- If your organization has its own secure mail system that can be accessed through the internet, please have an account created for the Registry to use to receive reports. The account should use a generic name (akbirthregistry) or something similar. You can then email me the report from within your system. The Registry uses this approach with a number of organizations.
- If none of the above works for your situation please contact the registry at hssbirthdefreg@alaska.gov and we can work on a solution.

We will do our best to make reporting a simple and straightforward process. Thanks again for your help and support of the Registry.

If you have any questions or need help with the reporting process please don't hesitate to contact the registry at:

Alaska Birth Defects Registry
 Alaska Dept. of Health and Social Services
 MCH-Epidemiology
 Email: hssbirthdefreg@alaska.gov
 Secure Email: dph.abdr@hss.soa.directak.net
 Web: <http://dhss.alaska.gov/dph/wcfh/Pages/mchebi/abdr/default.aspx>
 Tel: 907.269.3400

Please use the code groups below for report development.

Reporting Code Ranges

For report development use the following code ranges. The new collection code range is highlighted.

ICD Codes	Description
C96.5, C96.6	Langerhans-cell histiocytosis
D55.0 - D61.09	Anemias
D80.0 - D89.9	Immunodeficiencies
E00.0-E00.9	Congenital iodine-deficiency syndrome
E03.0-E03.9	Congenital hypothyroidism
E25.0 - E25.9	Adrenogenital disorders
E70.0 - E88.9	Metabolic disorders
G11.0 - G94.9	Nervous system disorders
H35.52, H49.819	Pigmentary retinal dystrophy, Kearns-Sayre
H90.0 - H91.93	Hearing loss
M21.021 - M21.129	Acquired deformities of limbs
P00.0 - P04.9	Certain conditions originating in the perinatal period
P96.0 - P96.9	Other conditions originating in the perinatal period
Q00.0 - Q99.99	Congenital malformations

Note: ABDR collects the specific codes listed below. The registry parses all submitted data for these specific collection codes. All other data is ignored.

Specific code List

C codes	D5780	D8189	E001	E705	E71521	E728	E8020	G112	G718	H902	M Codes	P046	Q052	Q110
C965	D57811	D819	E002	E708	E71522	E729	E8021	G113	G719	H902	M21021	P048	Q053	Q111
C966	D57812	D820	E009	E709	E71528	E7400	E8029	G114	G722	H902	M21022	P048	Q054	Q112
D Codes	D57819	D821	E030	E710	E71529	E7401	E803	G118	G723	H902	M21029	P049	Q055	Q112
D550	D580	D822	E031	E71110	E7153	E7402	E804	G119	G7241	H902	M21121	P293	Q056	Q112
D551	D581	D823	E039	E71111	E71540	E7403	E805	G120	G7249	H902	M21122	P961	Q057	Q112
D552	D582	D824	E039	E71118	E71541	E7404	E806	G121	G7281	H902	M21129	P962	Q058	Q113
D553	D588	D828	E250	E71120	E71542	E7409	E807	G1220	G7289	H903	M359	Q Codes	Q059	Q120
D558	D589	D829	E258	E71121	E71548	E7420	E840	G1221	G729	H903	P Codes	Q000	Q060	Q120
D559	D6101	D830	E259	E71128	E7200	E7421	E8411	G1221	G737	H903	P000	Q001	Q061	Q120
D560	D6109	D831	E700	E7119	E7201	E7429	E8419	G1222	G737	H9041	P001	Q002	Q062	Q120
D561	D800	D832	E701	E712	E7202	E744	E848	G1229	G800	H9042	P002	Q010	Q063	Q120
D562	D801	D838	E7020	E7130	E7203	E7601	E849	G1229	G801	H905	P003	Q011	Q064	Q121
D563	D802	D839	E7021	E71310	E7204	E7602	E850	G128	G802	H905	P004	Q012	Q068	Q122
D564	D803	D840	E7029	E71311	E7209	E7603	E851	G128	G802	H905	P005	Q018	Q069	Q123
D565	D804	D841	E7030	E71312	E7210	E761	E852	G128	G803	H905	P006	Q019	Q0700	Q124
D568	D805	D848	E70310	E71313	E7211	E76210	E853	G129	G804	H905	P006	Q02	Q0701	Q128
D569	D806	D849	E70311	E71314	E7212	E76211	E854	G129	G808	H905	P007	Q030	Q0702	Q129
D5700	D807	D890	E70318	E71318	E7219	E76219	E858	G3183	G808	H906	P007	Q031	Q0703	Q130
D5701	D808	D891	E70319	E7132	E7220	E7622	E859	G3184	G809	H9071	P0081	Q038	Q078	Q131
D5702	D809	D892	E70320	E7139	E7221	E7629	E883	G3185	G901	H9072	P0089	Q039	Q079	Q132
D571	D810	D893	E70321	E7140	E7222	E763	E8840	G3189	G910	H908	P009	Q040	Q100	Q133
D571	D811	D89810	E70328	E7141	E7223	E768	E8841	G319	G911	H908	P040	Q041	Q101	Q133
D5720	D812	D89811	E70329	E7142	E7229	E769	E8842	G3281	G912	H913	P041	Q042	Q102	Q134
D57211	D813	D89812	E70330	E7143	E723	E7871	E8849	G710	G937	H918X1	P041	Q043	Q103	Q135
D57212	D814	D89813	E70331	E71440	E724	E7872	E8881	G7111	G94	H918X2	P041	Q044	Q103	Q1381
D57219	D815	D8982	E70338	E71448	E7250	E791	E8889	G7112	H Codes	H918X3	P042	Q045	Q104	Q1389
D573	D816	D8989	E70339	E7150	E7251	E792	E889	G7113	H3552	H918X9	P043	Q046	Q105	Q1389
D5740	D817	D8989	E7039	E71510	E7252	E798	G Codes	G7114	H49819	H9190	P0441	Q048	Q106	Q1389
D57411	D81810	D899	E7040	E71511	E7253	E799	G110	G7119	H900	H9191	P0449	Q049	Q106	Q1389
D57412	D81818	E Codes	E7041	E71518	E7259	E800	G111	G712	H9011	H9192	P0449	Q050	Q107	Q139
D57419	D81819	E000	E7049	E71520	E728	E801	G111	G713	H9012	H9193	P045	Q051	Q107	Q140

Q141	Q209	Q2549	Q324	Q390	Q5031	Q5322	Q622	Q6589	Q7020	Q7201	Q740	Q782	Q846	Q9262
Q141	Q210	Q255	Q330	Q391	Q5032	Q5323	Q6231	Q659	Q7021	Q7202	Q741	Q783	Q848	Q927
Q142	Q211	Q256	Q331	Q392	Q5039	Q539	Q6232	Q660	Q7022	Q7203	Q742	Q784	Q849	Q928
Q143	Q212	Q2571	Q332	Q393	Q504	Q540	Q6239	Q661	Q7023	Q7210	Q742	Q785	Q8500	Q929
Q148	Q212	Q2572	Q333	Q394	Q505	Q541	Q6239	Q662	Q7030	Q7211	Q742	Q786	Q8501	Q930
Q148	Q212	Q2579	Q334	Q395	Q506	Q542	Q624	Q662	Q7031	Q7212	Q742	Q788	Q8502	Q931
Q148	Q213	Q2579	Q335	Q396	Q506	Q543	Q625	Q6621	Q7032	Q7213	Q743	Q788	Q8503	Q932
Q148	Q214	Q258	Q336	Q398	Q510	Q544	Q6260	Q6622	Q7033	Q7220	Q748	Q788	Q8509	Q933
Q149	Q218	Q259	Q338	Q399	Q5110	Q548	Q6261	Q663	Q704	Q7221	Q749	Q789	Q851	Q934
Q150	Q219	Q260	Q339	Q400	Q5111	Q549	Q6262	Q663	Q709	Q7222	Q750	Q790	Q858	Q935
Q150	Q220	Q261	Q340	Q401	Q512	Q550	Q6263	Q664	Q7100	Q7223	Q751	Q791	Q859	Q937
Q150	Q221	Q262	Q341	Q402	Q512	Q551	Q6269	Q6650	Q7101	Q7230	Q752	Q792	Q860	Q9381
Q158	Q222	Q263	Q348	Q403	Q513	Q5520	Q627	Q6651	Q7102	Q7231	Q753	Q793	Q861	Q9388
Q159	Q223	Q264	Q349	Q408	Q514	Q5521	Q628	Q6652	Q7103	Q7232	Q754	Q794	Q862	Q9389
Q160	Q223	Q265	Q351	Q409	Q515	Q5522	Q630	Q666	Q7110	Q7233	Q755	Q7951	Q868	Q939
Q161	Q224	Q266	Q353	Q410	Q516	Q5523	Q631	Q666	Q7111	Q7240	Q758	Q7959	Q870	Q950
Q162	Q225	Q268	Q355	Q411	Q517	Q5529	Q632	Q667	Q7112	Q7241	Q759	Q7959	Q871	Q951
Q163	Q226	Q269	Q355	Q412	Q51810	Q553	Q633	Q6680	Q7113	Q7242	Q760	Q796	Q872	Q952
Q164	Q228	Q270	Q357	Q418	Q51811	Q554	Q638	Q6681	Q7120	Q7243	Q761	Q798	Q873	Q953
Q165	Q229	Q271	Q359	Q419	Q51818	Q555	Q639	Q6682	Q7121	Q7250	Q762	Q798	Q8740	Q955
Q169	Q230	Q272	Q359	Q420	Q51820	Q5561	Q640	Q6689	Q7122	Q7251	Q762	Q798	Q8741	Q958
Q169	Q231	Q2730	Q359	Q421	Q51821	Q5562	Q6410	Q6689	Q7123	Q7252	Q763	Q799	Q87410	Q959
Q170	Q232	Q2731	Q360	Q422	Q51828	Q5563	Q6411	Q6689	Q7130	Q7253	Q76411	Q800	Q87418	Q960
Q171	Q233	Q2732	Q360	Q423	Q519	Q5564	Q6412	Q6689	Q7131	Q7260	Q76412	Q801	Q8742	Q961
Q172	Q234	Q2733	Q361	Q428	Q520	Q5569	Q6419	Q669	Q7132	Q7261	Q76413	Q802	Q8743	Q962
Q173	Q238	Q2734	Q369	Q429	Q5210	Q557	Q642	Q670	Q7133	Q7262	Q76414	Q803	Q875	Q963
Q174	Q239	Q2739	Q369	Q430	Q5211	Q558	Q6431	Q671	Q7140	Q7263	Q76415	Q804	Q8781	Q964
Q175	Q240	Q274	Q369	Q431	Q52120	Q559	Q6432	Q672	Q7141	Q7270	Q76419	Q808	Q8782	Q968
Q178	Q241	Q278	Q370	Q432	Q52121	Q560	Q6433	Q673	Q7142	Q7271	Q76425	Q809	Q8789	Q969
Q178	Q242	Q278	Q371	Q433	Q52122	Q561	Q6439	Q674	Q7143	Q7272	Q76426	Q810	Q8901	Q970
Q179	Q243	Q279	Q372	Q434	Q52123	Q562	Q644	Q675	Q7150	Q7273	Q76427	Q811	Q8909	Q971
Q180	Q244	Q279	Q373	Q435	Q52124	Q563	Q645	Q676	Q7151	Q72811	Q76428	Q812	Q891	Q972
Q180	Q245	Q280	Q374	Q436	Q52129	Q564	Q646	Q677	Q7152	Q72812	Q76429	Q818	Q892	Q973
Q181	Q246	Q281	Q375	Q437	Q522	Q600	Q6470	Q678	Q7153	Q72813	Q7649	Q819	Q893	Q978
Q181	Q248	Q282	Q378	Q438	Q523	Q601	Q6471	Q680	Q7160	Q72819	Q7649	Q820	Q894	Q979
Q182	Q248	Q283	Q379	Q438	Q524	Q602	Q6472	Q681	Q7161	Q72891	Q7649	Q821	Q897	Q980
Q182	Q248	Q288	Q379	Q439	Q525	Q603	Q6473	Q682	Q7162	Q72892	Q7649	Q822	Q898	Q981
Q183	Q249	Q289	Q379	Q440	Q526	Q604	Q6474	Q682	Q7163	Q72893	Q7649	Q823	Q899	Q983
Q184	Q2546	Q300	Q380	Q441	Q5270	Q605	Q6475	Q683	Q71811	Q72899	Q7649	Q824	Q900	Q984
Q185	Q250	Q300	Q381	Q441	Q5271	Q606	Q6479	Q684	Q71812	Q72899	Q765	Q825	Q901	Q985
Q186	Q250	Q301	Q381	Q442	Q5279	Q6100	Q648	Q685	Q71813	Q72899	Q766	Q828	Q902	Q986
Q187	Q251	Q302	Q382	Q443	Q528	Q6101	Q649	Q686	Q71819	Q72899	Q767	Q828	Q909	Q987
Q188	Q252	Q303	Q383	Q444	Q529	Q6102	Q6500	Q688	Q71891	Q72899	Q768	Q828	Q909	Q988
Q189	Q252	Q308	Q383	Q445	Q5300	Q6111	Q6500	Q688	Q71892	Q7290	Q769	Q829	Q910	Q989
Q200	Q2521	Q309	Q383	Q446	Q5301	Q6119	Q6501	Q690	Q71893	Q7291	Q770	Q830	Q911	Q990
Q200	Q2529	Q310	Q383	Q447	Q5302	Q612	Q6502	Q691	Q71899	Q7292	Q771	Q831	Q912	Q991
Q201	Q253	Q311	Q383	Q450	Q5310	Q613	Q651	Q692	Q71899	Q7293	Q772	Q832	Q913	Q992
Q202	Q254	Q312	Q383	Q451	Q5311	Q614	Q652	Q699	Q71899	Q730	Q773	Q833	Q914	Q998
Q203	Q254	Q313	Q384	Q452	Q53111	Q615	Q6530	Q7000	Q71899	Q731	Q774	Q838	Q915	Q998
Q203	Q2540	Q315	Q384	Q453	Q53112	Q615	Q6531	Q7001	Q71899	Q738	Q775	Q839	Q916	Q998
Q204	Q2543	Q318	Q384	Q458	Q5312	Q618	Q6532	Q7002	Q71899	Q740	Q776	Q840	Q917	Q999
Q205	Q2544	Q319	Q384	Q459	Q5313	Q619	Q654	Q7003	Q7190	Q740	Q777	Q841	Q920	
Q206	Q2546	Q320	Q385	Q5001	Q5320	Q620	Q655	Q7010	Q7191	Q740	Q778	Q842	Q921	
Q206	Q2545	Q321	Q386	Q5002	Q5321	Q6210	Q656	Q7011	Q7192	Q740	Q779	Q843	Q922	
Q208	Q2547	Q322	Q387	Q501	Q53211	Q6211	Q6581	Q7012	Q7193	Q740	Q780	Q844	Q925	
Q208	Q2548	Q323	Q388	Q502	Q53212	Q6212	Q6582	Q7013	Q7200	Q740	Q781	Q845	Q9261	

The registry parses all incoming data and collects only specific valid codes from the above ranges.
Data coding is based on the latest: International Classification of Diseases, Clinical Modification.



THE STATE
of **ALASKA**
GOVERNOR BILL WALKER

**Department of
Health and Social Services**

OFFICE OF THE COMMISSIONER

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February 3, 2015

Dear Colleague:

The Alaska Division of Public Health, an agency of the State of Alaska Department of Health and Social Services, is conducting activities in its capacity as a public health authority as defined by both Alaska Statute (AS § 18.15.355 - 18.15.395) and the Health Insurance Portability and Accountability Act, Standards for Privacy of Individual and Identifiable Health Information, Final Rule (Privacy Rule) [45 CFR § 164.501].

Pursuant to 45 CFR § 164.512(b) of the Privacy Rule, covered entities such as your organization may disclose, without individual authorization, protected health information to public health authorities "...authorized by law to collect or receive such information for the purpose of preventing or controlling disease, injury, or disability, including, but not limited to, the reporting of disease, injury, vital events such as birth or death, and the conduct of public health surveillance, public health investigations, and public health interventions...". Authorization and power to "obtain information from federal, state, and local governmental agencies, Alaska Native organizations, health care providers..., or other private and public organizations operating in the state..." is outlined in AS § 18.15.360(b) with information and security safeguards established in AS § 18.15.365.

In the Alaska Division of Public Health/Section of Women's, Children's and Family Health is undertaking public health activities as described by 45 CFR § 164.512(b) and authorized by Alaska statute and regulation (AS § 18.05.010). The information being requested represents the minimum necessary to carry out the public health purposes of this project which is to conduct statewide surveillance or epidemiologic investigations as related to Maternal and Child Health issues pursuant to 45 CFR § 164.512(b) of the Privacy Rule and AS § 18.15.362.

If you have questions or concerns regarding privacy matters, please contact the Department's HIPAA Privacy Rule Coordinator at (907) 465-4734. All other programmatic questions should be addressed directly to the Women's, Children's and Family Health Section Chief at (907) 269-3400.

Sincerely,

A handwritten signature in blue ink, appearing to read "Valerie J. Davidson".

Valerie J. Davidson
Commissioner