

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 information-----				
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 Last Name	Mother First Name	Mother DOB
MM/DD/YYYY	Text	Text	Text	MM/DD/YYYY	M,F	Text	#####			Text	Text	MM/DD/YYYY

- 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

Reporting Code Ranges

Data coding is based on the latest: International Classification of Diseases, Clinical Modification. For report development use the following code ranges.

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



THE STATE
of ALASKA
GOVERNOR MICHAEL J. DUNLEAVY

Department of
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April 3, 2019

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].

The Section of Women's, Children's and Family Health in the Alaska Division of Public 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). Programs in the Section of Women's, Children's and Family Health, including but not limited to the Alaska Birth Defects Registry and the Maternal Child Death Review, may request information as part of these activities. The information being requested represents the minimum necessary to conduct public health surveillance or epidemiologic investigations pursuant to 45 CFR § 164.512(b) of the Privacy Rule and AS §18.15.362.

Pursuant to 45 CFR § 164.512(b) of the Privacy Rule, covered entities 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.

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 black ink, appearing to read "Adam Crum".

Adam Crum
Commissioner