

# 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. Healthcare providers, hospitals, other healthcare 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 3<sup>rd</sup> 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 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.

- Microsoft email encryption is a simple method to send your reports securely. Keep an eye out for a reminder email from the Alaska Birth Defect Registry. A second encrypted email will directly follow this email. Perform the steps outlined in the attachment “Report Submission With Microsoft Office 365 Message Encryption” PDF and directly reply to the second email with your report.
- 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](mailto: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](mailto:hssbirthdefreg@alaska.gov)  
Secure Email: [dph.abdr@hss.soa.directak.net](mailto:dph.abdr@hss.soa.directak.net)  
Web: <http://dhss.alaska.gov/dph/wcfh/Pages/mcheppi/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.

**Attention:** Addition of new P-codes P04.11, P04.12, P04.13, P04.14, P04.15, P04.16, P04.17, P04.18, P04.19, P04.40, P04.42, P04.81, P04.89 are now included in the list below.

### Specific code List

<b>C codes</b>	D5740	D813	D892	E70310	E7130	E71548	E7402	E8020	<b>G Codes</b>	G710	G901	H905	P003	P046
C965	D57411	D814	D893	E70311	E71310	E7200	E7403	E8021	G110	G7111	G910	H905	P004	P048
C966	D57412	D815	D89810	E70318	E71311	E7201	E7404	E8029	G111	G7112	G911	H906	P005	P0481
<b>D Codes</b>	D57419	D816	D89811	E70319	E71312	E7202	E7409	E803	G111	G7113	G912	H9071	P006	P0489
D550	D5780	D817	D89812	E70320	E71313	E7203	E7420	E804	G112	G7114	G937	H9072	P006	P049
D551	D57811	D81810	D89813	E70321	E71314	E7204	E7421	E805	G113	G7119	G94	H908	P007	P293
D552	D57812	D81818	D8982	E70328	E71318	E7209	E7429	E806	G114	G712	<b>H Codes</b>	H908	P007	P961
D553	D57819	D81819	D8989	E70329	E7132	E7210	E744	E807	G118	G713	H3552	H913	P0081	P962
D558	D580	D8189	D8989	E70330	E7139	E7211	E7601	E840	G119	G718	H49819	H918X1	P0089	<b>Q Codes</b>
D559	D581	D819	D899	E70331	E7140	E7212	E7602	E8411	G120	G719	H900	H918X2	P009	Q000
D560	D582	D820	<b>E Codes</b>	E70338	E7141	E7219	E7603	E8419	G121	G722	H9011	H918X3	P040	Q001
D561	D588	D821	E000	E70339	E7142	E7220	E761	E848	G1220	G723	H9012	H918X9	P041	Q002
D562	D589	D822	E001	E7039	E7143	E7221	E76210	E849	G1221	G7241	H902	H9190	P0412	Q010
D563	D6101	D823	E002	E7040	E71440	E7222	E76211	E850	G1221	G7249	H902	H9191	P0413	Q011
D564	D6109	D824	E009	E7041	E71448	E7223	E76219	E851	G1222	G7281	H902	H9192	P0414	Q012
D565	D800	D828	E030	E7049	E7150	E7229	E7622	E852	G1229	G7289	H902	H9193	P0415	Q018
D568	D801	D829	E031	E705	E71510	E723	E7629	E853	G1229	G729	H902	<b>M Codes</b>	P0416	Q019
D569	D802	D830	E039	E708	E71511	E724	E763	E854	G128	G737	H902	M21021	P0417	Q02
D5700	D803	D831	E039	E709	E71518	E7250	E768	E858	G128	G737	H902	M21022	P0418	Q030
D5701	D804	D832	E250	E710	E71520	E7251	E769	E859	G128	G800	H903	M21029	P0419	Q031
D5702	D805	D838	E258	E71110	E71521	E7252	E7871	E883	G129	G801	H903	M21121	P042	Q038
D571	D806	D839	E259	E71111	E71522	E7253	E7872	E8840	G129	G802	H903	M21122	P043	Q039
D571	D807	D840	E700	E71118	E71528	E7259	E791	E8841	G3183	G802	H9041	M21129	P0440	Q040
D5720	D808	D841	E701	E71120	E71529	E728	E792	E8842	G3184	G803	H9042	M359	P0442	Q041
D57211	D809	D848	E7020	E71121	E7153	E728	E798	E8849	G3185	G804	H905	<b>P Codes</b>	P0441	Q042
D57212	D810	D849	E7021	E71128	E71540	E729	E799	E8881	G3189	G808	H905	P000	P0449	Q043
D57219	D811	D890	E7029	E7119	E71541	E7400	E800	E8889	G319	G808	H905	P001	P0449	Q044
D573	D812	D891	E7030	E712	E71542	E7401	E801	E889	G3281	G809	H905	P002	P045	Q045

Q046	Q135	Q206	Q256	Q336	Q403	Q51810	Q5563	Q6432	Q677	Q7163	Q72899	Q773	Q842	Q927
Q048	Q1381	Q208	Q2571	Q338	Q408	Q51811	Q5564	Q6433	Q678	Q71811	Q7290	Q774	Q843	Q928
Q049	Q1389	Q208	Q2572	Q339	Q409	Q51818	Q5569	Q6439	Q680	Q71812	Q7291	Q775	Q844	Q929
Q050	Q1389	Q209	Q2579	Q340	Q410	Q51820	Q557	Q644	Q681	Q71813	Q7292	Q776	Q845	Q930
Q051	Q1389	Q210	Q2579	Q341	Q411	Q51821	Q558	Q645	Q682	Q71819	Q7293	Q777	Q846	Q931
Q052	Q1389	Q211	Q258	Q348	Q412	Q51828	Q559	Q646	Q682	Q71891	Q730	Q778	Q848	Q932
Q053	Q139	Q212	Q259	Q349	Q418	Q519	Q560	Q6470	Q683	Q71892	Q731	Q779	Q849	Q933
Q054	Q140	Q212	Q260	Q351	Q419	Q520	Q561	Q6471	Q684	Q71893	Q738	Q780	Q8500	Q934
Q055	Q141	Q212	Q261	Q353	Q420	Q5210	Q562	Q6472	Q685	Q71899	Q740	Q781	Q8501	Q935
Q056	Q141	Q213	Q262	Q355	Q421	Q5211	Q563	Q6473	Q686	Q71899	Q740	Q782	Q8502	Q937
Q057	Q142	Q214	Q263	Q355	Q422	Q52120	Q564	Q6474	Q688	Q71899	Q740	Q783	Q8503	Q9381
Q058	Q143	Q218	Q264	Q357	Q423	Q52121	Q600	Q6475	Q688	Q71899	Q740	Q784	Q8509	Q9388
Q059	Q148	Q219	Q265	Q359	Q428	Q52122	Q601	Q6479	Q690	Q71899	Q740	Q785	Q851	Q9389
Q060	Q148	Q220	Q266	Q359	Q429	Q52123	Q602	Q648	Q691	Q71899	Q740	Q786	Q858	Q939
Q061	Q148	Q221	Q268	Q359	Q430	Q52124	Q603	Q649	Q692	Q7190	Q740	Q788	Q859	Q950
Q062	Q148	Q222	Q269	Q360	Q431	Q52129	Q604	Q6500	Q699	Q7191	Q741	Q788	Q860	Q951
Q063	Q149	Q223	Q270	Q360	Q432	Q522	Q605	Q6500	Q7000	Q7192	Q742	Q788	Q861	Q952
Q064	Q150	Q223	Q271	Q361	Q433	Q523	Q606	Q6501	Q7001	Q7193	Q742	Q789	Q862	
Q068	Q150	Q224	Q272	Q369	Q434	Q524	Q6100	Q6502	Q7002	Q7200	Q742	Q790	Q868	Q953
Q069	Q150	Q225	Q2730	Q369	Q435	Q525	Q6101	Q651	Q7003	Q7201	Q742	Q791	Q870	Q955
Q0700	Q158	Q226	Q2731	Q369	Q436	Q526	Q6102	Q652	Q7010	Q7202	Q743	Q792	Q871	Q958
Q0701	Q159	Q228	Q2732	Q370	Q437	Q5270	Q6111	Q6530	Q7011	Q7203	Q748	Q793	Q872	Q959
Q0702	Q160	Q229	Q2733	Q371	Q438	Q5271	Q6119	Q6531	Q7012	Q7210	Q749	Q794	Q873	Q960
Q0703	Q161	Q230	Q2734	Q372	Q438	Q5279	Q612	Q6532	Q7013	Q7211	Q750	Q7951	Q8740	Q961
Q078	Q162	Q231	Q2739	Q373	Q439	Q528	Q613	Q654	Q7020	Q7212	Q751	Q7959	Q8741	Q962
Q079	Q163	Q232	Q274	Q374	Q440	Q529	Q614	Q655	Q7021	Q7213	Q752	Q7959	Q87410	Q963
Q100	Q164	Q233	Q278	Q375	Q441	Q5300	Q615	Q656	Q7022	Q7220	Q753	Q796	Q87418	Q964
Q101	Q165	Q234	Q278	Q378	Q441	Q5301	Q615	Q6581	Q7023	Q7221	Q754	Q798	Q8742	Q968
Q102	Q169	Q238	Q279	Q379	Q442	Q5302	Q618	Q6582	Q7030	Q7222	Q755	Q798	Q8743	Q969
Q103	Q169	Q239	Q279	Q379	Q443	Q5310	Q619	Q6589	Q7031	Q7223	Q758	Q798	Q875	Q970
Q103	Q170	Q240	Q280	Q379	Q444	Q5311	Q620	Q659	Q7032	Q7230	Q759	Q799	Q8781	Q971
Q104	Q171	Q241	Q281	Q380	Q445	Q53111	Q6210	Q660	Q7033	Q7231	Q760	Q800	Q8782	Q972
Q105	Q172	Q242	Q282	Q381	Q446	Q53112	Q6211	Q661	Q704	Q7232	Q761	Q801	Q8789	Q973
Q106	Q173	Q243	Q283	Q381	Q447	Q5312	Q6212	Q662	Q709	Q7233	Q762	Q802	Q8901	Q978
Q106	Q174	Q244	Q288	Q382	Q450	Q5313	Q622	Q662	Q7100	Q7240	Q762	Q803	Q8909	Q979
Q107	Q175	Q245	Q289	Q383	Q451	Q5320	Q6231	Q6621	Q7101	Q7241	Q763	Q804	Q891	Q980
Q107	Q178	Q246	Q300	Q383	Q452	Q5321	Q6232	Q6622	Q7102	Q7242	Q76411	Q808	Q892	Q981
Q110	Q178	Q248	Q300	Q383	Q453	Q53211	Q6239	Q663	Q7103	Q7243	Q76412	Q809	Q893	Q983
Q111	Q179	Q248	Q301	Q383	Q458	Q53212	Q6239	Q663	Q7110	Q7250	Q76413	Q810	Q894	Q984
Q112	Q180	Q248	Q302	Q383	Q459	Q5322	Q624	Q664	Q7111	Q7251	Q76414	Q811	Q897	Q985
Q112	Q180	Q249	Q303	Q383	Q5001	Q5323	Q625	Q6650	Q7112	Q7252	Q76415	Q812	Q898	Q986
Q112	Q181	Q2546	Q308	Q384	Q5002	Q539	Q6260	Q6651	Q7113	Q7253	Q76419	Q818	Q899	Q987
Q112	Q181	Q250	Q309	Q384	Q501	Q540	Q6261	Q6652	Q7120	Q7260	Q76425	Q819	Q900	Q988
Q113	Q182	Q250	Q310	Q384	Q502	Q541	Q6262	Q666	Q7121	Q7261	Q76426	Q820	Q901	Q989
Q120	Q182	Q251	Q311	Q384	Q5031	Q542	Q6263	Q666	Q7122	Q7262	Q76427	Q821	Q902	Q990
Q120	Q183	Q252	Q312	Q385	Q5032	Q543	Q6269	Q667	Q7123	Q7263	Q76428	Q822	Q909	Q991
Q120	Q184	Q252	Q313	Q386	Q5039	Q544	Q627	Q6680	Q7130	Q7270	Q76429	Q823	Q909	Q992
Q120	Q185	Q2521	Q315	Q387	Q504	Q548	Q628	Q6681	Q7131	Q7271	Q7649	Q824	Q910	Q998
Q120	Q186	Q2529	Q318	Q388	Q505	Q549	Q630	Q6682	Q7132	Q7272	Q7649	Q825	Q911	Q998
Q121	Q187	Q253	Q319	Q390	Q506	Q550	Q631	Q6689	Q7133	Q7273	Q7649	Q828	Q912	Q998
Q122	Q188	Q254	Q320	Q391	Q506	Q551	Q632	Q6689	Q7140	Q72811	Q7649	Q828	Q913	Q999
Q123	Q189	Q254	Q321	Q392	Q510	Q5520	Q633	Q6689	Q7141	Q72812	Q7649	Q828	Q914	
Q124	Q200	Q2540	Q322	Q393	Q5110	Q5521	Q638	Q6689	Q7142	Q72813	Q7649	Q829	Q915	
Q128	Q200	Q2543	Q323	Q394	Q5111	Q5522	Q639	Q669	Q7143	Q72819	Q765	Q830	Q916	
Q129	Q201	Q2544	Q324	Q395	Q512	Q5523	Q640	Q670	Q7150	Q72891	Q766	Q831	Q917	
Q130	Q202	Q2546	Q330	Q396	Q512	Q5529	Q6410	Q671	Q7151	Q72892	Q767	Q832	Q920	
Q131	Q203	Q2545	Q331	Q398	Q513	Q553	Q6411	Q672	Q7152	Q72893	Q768	Q833	Q921	
Q132	Q203	Q2547	Q332	Q399	Q514	Q554	Q6412	Q673	Q7153	Q72899	Q769	Q838	Q922	
Q133	Q204	Q2548	Q333	Q400	Q515	Q555	Q6419	Q674	Q7160	Q72899	Q770	Q839	Q925	
Q133	Q205	Q2549	Q334	Q401	Q516	Q5561	Q642	Q675	Q7161	Q72899	Q771	Q840	Q9261	
Q134	Q206	Q255	Q335	Q402	Q517	Q5562	Q6431	Q676	Q7162	Q72899	Q772	Q841	Q9262	



THE STATE  
of ALASKA  
GOVERNOR MICHAEL J. DUNLEAVY

## Department of Health and Social Services

OFFICE OF THE COMMISSIONER

Anchorage  
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Anchorage, Alaska 99503-5923  
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Juneau  
350 Main Street, Suite 404  
Juneau, Alaska 99801-1149  
Main: 907.465.3030  
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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".

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