	UNDIAGNOSED CHILDREN INSURANCE COVERAGE
	AMENDMENTS
	2019 GENERAL SESSION
	STATE OF UTAH
	Chief Sponsor: Steve Eliason
	Senate Sponsor: David G. Buxton
LON	NG TITLE
Gen	eral Description:
	This bill requires certain health insurance providers to cover exome sequence testing.
High	alighted Provisions:
	This bill:
	► defines terms;
	 requires the state Medicaid program to cover exome sequence testing;
	 requires certain health benefit plans to cover exome sequence testing; and
	• permits a health benefit plan to opt out of the requirement in this bill under certain
circu	umstances.
Mon	ey Appropriated in this Bill:
	None
Oth	er Special Clauses:
	None
Utal	Code Sections Affected:
ENA	CTS:
	26-18-25 , Utah Code Annotated 1953
	31A-22-650 , Utah Code Annotated 1953



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28	Section 1. Section 26-18-25 is enacted to read:
29	26-18-25. Coverage of exome sequence testing.
30	(1) As used in this section, "exome sequence testing" means a genomic technique for
31	sequencing the genome of an individual for diagnostic purposes.
32	(2) The Medicaid program shall reimburse for exome sequence testing:
33	(a) for an enrollee who:
34	(i) is younger than 21 years old; and
35	(ii) remains undiagnosed after exhausting all other appropriate diagnostic-related tests;
36	(b) at a nationally recognized children's medical center with experience in exome
37	sequence testing; and
38	(c) at a rate set by the Medicaid program.
39	Section 2. Section 31A-22-650 is enacted to read:
40	31A-22-650. Coverage of exome sequence testing.
41	(1) As used in this section, "exome sequence testing" means a genomic technique for
42	sequencing the genome of an individual for diagnostic purposes.
43	(2) Beginning January 1, 2020, a health benefit plan shall provide coverage for exome
44	sequence testing for an enrollee who:
45	(a) is younger than 21 years old; and
46	(b) remains undiagnosed after exhausting all other appropriate diagnostic-related tests
47	that are:
48	(i) available to the enrollee; and
49	(ii) performed at an in-network and nationally recognized medical center with
50	experience in exome sequence testing.
51	(3) An insurer may decline to provide coverage for exome sequencing in accordance
52	with Subsection (2) if, before December 1, 2019, the insurer:
53	(a) submits a letter to the department and the Health and Human Services Interim
54	Committee stating:
55	(i) the insurer's intention to decline the coverage required under Subsection (2); and
56	(ii) stating the insurer's reason for declining the coverage required under Subsection
57	(2), including an explanation of whether the insurer believes that the coverage would not
58	benefit any of the insurer's enrollees; and

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(b) provides an in-person report to the Health and Human Services Interim Committee
 describing the information required in the letter submitted under Subsection (3)(a).