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A BILL FOR AN ACT

RELATING TO HEALTH.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1	SECT	ION 1. Chapter 321, Hawaii Revised Statutes, is	
2	amended by adding a new section to be appropriately designated		
3	and to read as follows:		
4	" <u>§32</u> :	1- <u>Health care information; spina bifida.</u> (a) The	
5	departmen	t of health shall maintain the following information:	
6	(1)	Current, evidence-based information about spina bifida	
7		that has been reviewed by medical experts and spina	
8		bifida organizations, including information on	
9		physical, developmental, educational, and psychosocial	
10		outcomes; life expectancy; clinical course;	
11		intellectual and functional development; and treatment	
12		options; and	
13	(2)	Contact information regarding support programs and	
14		services, including information hotlines specific to	
15		spina bifida, resource centers, national spina bifida	
16		organizations, and local spina bifida organizations.	

S.B. NO. **732**

1	(b)	The department of health shall make available, upon
2	request,	the information described in subsection (a) to:
3	(1)	Any health-care provider, as defined in section
4		327E-2, who provides prenatal or postnatal care
5		pertaining to spina bifida;
6	(2)	Any person who provides genetic counseling to parents
7		whose fetus or child receives a prenatal or postnatal
8		spina bifida diagnois;
9	(3)	Any parent whose fetus or child receives a prenatal or
10		postnatal diagnosis of spina bifida; and
11	(4)	Any person who receives a positive spina bifida test
12		result.
13	(c)	Health-care providers, as defined in section 327E-2,
14	and genetic counselors who provide prenatal or postnatal care	
15	shall give the information described in subsection (a) to every	
16	parent whose fetus or child receives a prenatal or postnatal	
17	diagnosis of spina bifida.	
18	<u>(d)</u>	The department of health shall adopt rules pursuant to
19	chapter 91 necessary to carry out the purposes of this section.	
20	<u>(e)</u>	As used in this section, "spina bifida" means a
21	congenita	l malformation of the bone in the vertebral column that

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S.B. NO. 132

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- 1 exposes the spinal cord and is caused by incomplete closing of
- 2 the embryonic neural tube."
- 3 SECTION 2. New statutory material is underscored.
- 4 SECTION 3. This Act shall take effect upon its approval.

INTRODUCED BY:

2017-0199 SB SMA.doc

S.B. NO. 132

Report Title:

Department of Health; Spina Bifida; Health Care Provider; Genetic Counselor; Information

Description:

Requires the department of health to maintain and make available upon request certain information to a health care provider who provides prenatal or postnatal care pertaining to spina bifida, any person who provides genetic counseling to parents whose fetus or child receives a prenatal or postnatal spina bifida diagnois, any parent whose fetus or child receives a prenatal or postnatal diagnosis of spina bifida, and any person who receives a positive spina bifida test result. Requires health care providers and genetic counselors to provide the information to every parent whose fetus or child receives a prenatal or postnatal diagnosis of spina bifida.

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