Pearson (HB 406) **Act No. 419**

Existing law defines "genetic information" as all information about genes, gene products, inherited characteristics, or family history/pedigree that is expressed in common language.

New law additionally provides that "genetic information" shall include the following:

(1) An individual's genetic test.

(2) The genetic tests of an individual's family members.

(3) The manifestation of a disease or disorder in an individual's family members.

(4) With respect to an individual or his family member who is a pregnant woman, genetic information of any fetus or embryo carried by such pregnant woman.

(5) With respect to an individual or his family member utilizing an assisted reproductive technology, genetic information of any embryo legally held by the individual or family member.

Further specifies that "genetic information" shall not mean information about the sex or age of any individual.

Prior law defined "genetic test" as any test for determining the presence or absence of genetic characteristics in an individual, including tests of nucleic acids, such as DNA, RNA, and mitochondrial DNA, chromosomes, or proteins in order to diagnose or identify a genetic characteristic.

New law defines "genetic test" as any test that detects genotypes, mutation, or chromosomal changes. Specifies that "genetic test" shall not mean an analysis of proteins or metabolites that does not detect genotypes, mutations, or chromosomal changes or that is directly related to a manifested disease, disorder, or pathological condition that could be reasonably detected by a health care professional with appropriate training and expertise in the field of medicine involved.

New law additionally defines "genetic services" as a genetic test, genetic counseling, including obtaining, interpreting, or assessing genetic information, or genetic education.

New law further defines "underwriting purposes" as rules for or determination of eligibility, including enrollment and continued eligibility, for benefits under the plan or coverage; the computation of premium or contribution amounts under the plan or coverage; and other activities related to the creation, renewal, or replacement of a contract or policy issued by an insurer.

New law establishes certain prohibitions regarding requesting or requiring genetic testing or genetic information or using genetic information for underwriting purposes under certain circumstances, as follows:

(1) Prohibits an insurer from requesting, requiring, or purchasing genetic information:

   (a) Of an individual or his family member for underwriting purposes; or

   (b) With respect to any individual or his family member prior to such individual's enrollment under the plan or coverage in connection with such enrollment.

   Further provides that if an insurer offering health insurance coverage in the individual or group market obtains genetic information incidental to the requesting, requiring, or purchasing of other information concerning any individual, such action shall not be considered a violation of (b) above if such action is not in violation of (a) above.

(2) Prohibits an insurer from requesting or requiring that an individual, his family member, or a group member undergo a genetic test; however, provides that this

prohibition shall not be construed to limit the authority of a health care professional who is providing health care services to an individual to request that such individual undergo a genetic test.

(3) Prohibits an insurer from establishing rules for eligibility, including continued eligibility, of any individual or an individual's family member to enroll or continue enrollment based on genetic information; however, provides that this prohibition and that contained in (1) above shall not be construed to preclude an insurer from establishing rules for eligibility for an individual to enroll in individual health insurance coverage based on the manifestation of a disease or disorder in that individual or in his family member where such family member is covered under the policy that covers such individual.

(4) Prohibits an insurer from imposing any preexisting condition exclusion on the basis of genetic information of an individual, his family member, or group member. However, provides that this prohibition and that contained in (1) above shall not be construed to preclude an insurer offering coverage in the individual market from imposing any preexisting condition exclusion for an individual with respect to health insurance coverage on the basis of a manifestation of a disease or disorder in that individual.

(5) Prohibits an insurer from adjusting premium or contribution amounts for an individual or group health plan on the basis of genetic information concerning the individual or a family member of the individual; however, provides that this prohibition shall not be construed to preclude an insurer offering health insurance coverage in the individual market from adjusting premium or contribution amounts for an individual on the basis of a manifestation of a disease or disorder in that individual, or in his family member where such family member is covered under the policy that covers such individual. Provides that, in such case, the manifestation of a disease or disorder in one individual cannot also be used as genetic information about other individuals covered under the policy issued to such individual and to further increase premium or contribution amounts.

Additionally, provides that this prohibition shall not be construed to preclude an insurer offering health insurance coverage in connection with a group health plan from increasing the premium for an employer based upon the manifestation of a disease or disorder of an individual who is enrolled in the plan. Provides that, in such case, the manifestation of a disease or disorder in one individual cannot also be used as genetic information about other group members and to further increase the premium for the employer.

(6) Provides that the prohibition contained in (3) above, regarding the establishment of eligibility, shall not be construed to preclude an insurer offering health insurance coverage in the individual or group market from obtaining and using the results of a genetic test in making a determination regarding payment, as that term is defined for the purposes of applying the regulations promulgated by the secretary of the U.S. Department of Health and Human Services (HHS) under portions of the Social Security Act and the Health Insurance Portability and Accountability Act of 1996 (HIPAA), consistent with (3) and (4) above. Further provides that for these purposes an insurer offering health insurance coverage in the individual or group market may request only the minimum amount of information necessary to accomplish the intended purpose.

(7) Provides that, notwithstanding the prohibition contained in (2) above, regarding requiring or requesting genetic testing, an insurer offering health insurance coverage in the individual or group market may request, but not require, that an individual, his family member, or a group member undergo a genetic test if each of the following conditions is met:

(a) The request is made pursuant to research that complies with certain federal regulations and any applicable state or local law or regulations for the protection of human subjects in research.

(b) The insurer clearly indicates to each individual, or in the case of a minor child, to the legal guardian of such child, to whom the request is made that compliance with the request is voluntary and that noncompliance will have no effect on enrollment status or premium or contribution amounts.

(c) No genetic information collected or acquired under this exception shall be used for underwriting purposes.

(d) The insurer notifies the secretary of HHS in writing that the issuer is conducting activities pursuant to this exception, including a description of the activities conducted.

(e) The insurer complies with such other conditions as the secretary of HHS may by regulation require for activities conducted under this exception.

New law further provides that nothing in existing law or new law relative to genetic information or testing shall exempt a covered entity from the requirements of HIPAA pertaining to the collection, use, or disclosure of genetic information, which for purposes of HIPAA is defined as "health information" under applicable federal law.

Existing law provides for coverage of diagnosis and treatment of autism spectrum disorders in persons less than 17 years of age.

New law provides an exception for individually underwritten, guaranteed renewable limited benefit health insurance policies from the required coverage of autism spectrum disorders in individuals less than 17 years of age.

New law requires health insurance issuers to provide coverage and reimbursement to a unique provider of health services for catastrophically ill children, as defined by new law below, located outside the state in accordance with the terms and conditions of the policy of insurance between the insured and the insurer.

New law defines "unique provider of health services for catastrophically ill children" as an institution designated by the National Cancer Institute as a Comprehensive Cancer Center focused solely on pediatrics and that is a children's hospital dedicated to caring for children with catastrophic illness and conducting basic and advanced research into catastrophic childhood diseases such as cancers, acquired and inherited immunodeficiencies, and genetic disorders. Further defines "pediatric" as children and youth eligible and certified for Medicaid coverage, Louisiana Children's Health Insurance Program coverage, or coverage under a Louisiana Medicaid waiver program or Louisiana Medicaid managed care program.

New law provides that the Department of Health and Hospitals (DHH) shall provide coverage and reimbursement to a unique provider of health services for catastrophically ill children to the same extent that it would provide coverage for services furnished within the boundaries of the state and shall insure that reimbursement to such institution shall be equal to the reimbursement rate of in-state children's hospital for pediatric care. Provides a limit on reimbursements for providers to less than $500,000 in any state fiscal year. Further provides that implementation of these provisions shall be subject to the appropriation of funds by the legislature for such purpose.

New law provides that DHH shall promulgate rules and regulations, in accordance with the Administrative Procedure Act, and take such other actions as are necessary to implement the provisions of new law. Adds a requirement that DHH shall submit a State Plan Amendment and obtain approval from the Centers for Medicare and Medicaid Services that contains a reimbursement methodology restricting payments to the annual maximum prior to implementation of provisions contained in new law.

Effective August 15, 2009.

(Amends R.S. 22:1023(A)(8) and (9)); Adds R.S. 22:50, 1023(A)(16) and (17), (B)(4)-(10), and (C)(6), and 1050(H)(3) and R.S. 40:1300.291-1300.293)