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GENERAL SESSION

February 4, 2015

Program Topic: H&HS Bills on the 2015 Horizon

Presented by: Health & Human Services Committee

Director: Kitty Kaplan

Chair: Marci Curran

Speakers: Jonathan Johnson – Citizen Advocate, Promote Liberty PAC

Rep. Gage Froerer (R) Dist. 8 (Weber County) – sponsor,
HB94 Investigational Drug and Device Access for Terminally Ill Patients

Brandy Farmer - WSLC

Annette Maugham – Pres., Epilepsy Assoc. of Utah

Sen. Brian Shiozawa (R) Dist. 8 (Salt Lake County) – sponsor,
SB19 Digital Health Services Commission
HB28 Medicaid Management of Emergency Department Utilization

Rep. Edward Redd (R) Dist. 4 (Cache County) – sponsor,
HB55 Repeal of Methamphetamine Housing Reconstruction and Rehabilitation
HB101 Rural Residency Training Program Reauthorization
HB199 Pilot Program for Assistance for Children with Disabilities
and Complex Medical Conditions

Jonathan Johnson said he has taken on this issue since his father, who died of a second bout of leukemia, had been willing to try experimental treatment rather than undergo another round of radiation and chemotherapy. This option was denied him by his doctor, as is often the case. However,

five states have already approved Right to Try legislation.

It takes 8-12 years and at least \$800M for an investigative drug to receive Food and Drug Administration (FDA) approval. The FDA allows for Compassionate Exceptions for the terminally ill who have 6 months or less to

live. Requirements for the Compassionate Exception include the signing of a formal consent, waiving liability of the doctor, hospital and the pharmaceutical company providing the drug, and waiving liability of insurance to cover the cost.

Responding to questions, Mr. Johnson said patients willing to try experimental treatments are those who are terminal and also willing to advance medical knowledge as a benefit to others. **HB94** does not attempt to specify what defines a terminal diagnosis. That remains a decision between doctor and patient.

Rep. Froerer was pleased to report that the American Medical Association (AMA) supports **HB94**, as well as physicians and some insurance companies. The Right to Try issue was first brought to him by the Goldwater Institute, and Arizona-based public policy advocacy and research organization.

He stated Right to Try legislation would give options that are currently unavailable back to Utahns, and possibly extend some lives. He is confident that meaningful protective rights are built into the bill.

Large pharmaceutical companies have expressed some concern that Right to Try may impede ongoing drug research trials. However, Rep. Froerer countered that the participant, not the companies would pay for the experimental treatment.

Any such treatment must have completed at least phase one of FDA testing. It can take up to 15 years and as much as \$1.5B to complete the FDA approval process

Responding to questions, Rep. Froerer said drug companies would not be forced to participate with research and production funding. They would only provide access to the experimental drugs.

Neither Right to Try applicants nor their families are allowed to sue assisting physicians or drug companies for death following use of an experimental drug. However, there may be other extenuating grounds for a suit. Insurance does not pay for the costs of the investigational drug, or for subsequent side effects.

HB94 does not address the question of whether advertising may be used to garner patients for experimental drugs. The FDA has remained neutral on the Right to Try issue. Pressed on whether this may be another way to legalize euthanasia, Rep. Froerer stressed his bill is about preserving life.

Brandy Farmer gave a brief summary of Supreme Court Justice Sonia Sotomayor's address to students at the University of Utah's Huntsman Center. Justice Sotomayor spoke as a guest of the university's MUSE Project, a presidential initiative intended to enrich undergraduate education. Justice Sotomayor explained some Supreme Court decisions and urged students to finish their education and achieve their dreams.

Annette Maugham gave brief remarks in support of **HB199 Pilot Program for Assistance for Children with Disabilities and Complex Medical Conditions**. The bill directs the Department of Health to apply for a Medicaid waiver for children with certain disabilities and complex medical conditions.

She emphasized that three physicians make the decisions regarding those children who can receive assistance via this program. If even one of the three elects against it, the child will not qualify. The FDA requires six months of study to assure safety.

Sen. Shiozawa, first speaking on behalf of **SB19 Digital Health Services Commission**, said this Commission is where all hospitals and medical services

share information and medical reports. The bill amends the Legislative Oversight and Sunset Act to reauthorize the Digital Health Services Commission.

Digital technology has provided a better way to transport records and prevent unnecessary repeats of tests and treatments by digitally sharing patient information between providers. Responding to questions, the senator said providers would be able, but not required, to share information.

Turning next to his bill **HB28 Medicaid Management of Emergency Department Utilization**, Sen. Shiozawa said Utah's growing population means even more people will be using Emergency Room services. The bill creates a committee tasked to find other options to the ER, particularly for "super utilizers."

Super-utilizer is defined as a Medicaid recipient who has been identified by the recipient's authorized care organization as a person who uses the emergency department excessively.

"Excessively" is defined as using the ER 10-40 times at one or multiple locations over a specified period of time. The bill also prevents Medicaid from deciding *after* a patient visit whether it was necessary.

Sen. Shiozawa is also sponsoring a Medicaid expansion bill, not yet numbered or named, in response to the governor's Healthy Utah plan. It will include co-pays, work requirements, and use of private insurance.

Responding to questions, the senator said it's unclear at this point whether the Affordable Care Act (ACA) is sustainable. The AMA supports the governor's Healthy Utah plan. It would expand Medicaid coverage to over 100,000 residents in the state.

In its favor, the Healthy Utah plan can initially bring \$500M of federal money into Utah. It's not yet known how taxes will need to increase with Healthy Utah. Hospitals have agreed to a provider tax.

Rep. Redd presented three bills he is sponsoring. First, **HB199 Pilot Program for Assistance for Children with Disabilities and Complex Medical Conditions**, which would direct the Department of Health to apply for a Medicaid waiver for children with certain disabilities. The bill defines a "complex medical condition" as one that would result in the child needing to be institutionalized unless receiving fulltime parental care.

There are income limits to qualify for Medicaid. But while some families have incomes over the maximum limit, that figure doesn't take into account the total household income used to care for disabled children. Some needs are not covered by private insurance. The bill would serve 500 children over the course of three years and allow the children to qualify for Medicaid.

Responding to questions. Rep. Redd emphasized **HB199** would not replace the Autism Pilot Program. His own experience of working with older autistic patients has confirmed to him the critical importance of early intervention for children with any type of brain development issues.

Speaking on behalf of **HB101 Rural Residency Training Program Reauthorization**, he said the bill makes technical amendments to the Rural Residency Training Program and reauthorizes the program (originally passed in 1997) until July 1, 2020.

It provides money for healthcare students (medical, nursing, pharmacy, and nurse practitioner) to do rotations in rural settings. Rep. Redd's experience in a rural setting rotation, he recalled, changed his life.

One in every ten healthcare students who rotate to a rural setting decides to eventually practice there.

The Rural Residency Training Program currently serves 80 – 90 students each year. It helps to finance a 6-week rotation for each student.

Rep. Redd then presented his final bill, **HB55 Repeal of Methamphetamine Housing Reconstruction and Rehabilitation**. He explained the bill would call for the funds remaining in the Methamphetamine Housing Reconstruction and Rehabilitation Account (on June 30,

2015) to be deposited into the Olene Walker Housing Loan Fund.

The original housing bill of 2010 allowed a check box on tax forms to prompt donations for a fund to rehabilitate homes once used for methamphetamine production (similar to check boxes for the homeless trust fund). To remain on the tax form, the check box must have brought in \$30,000 for three years.

Since it only brought in \$12,000, that money will now be transferred instead to the Olen Walker Housing Loan Fund.

**Reported by Jean Davies and
Jessica Christopher**

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