

MINUTES  
**HOUSE HEALTH & WELFARE COMMITTEE**

**DATE:** Tuesday, February 23, 2016

**TIME:** 9:00 A.M.

**PLACE:** Room EW20

**MEMBERS:** Chairman Wood, Vice Chairman Packer, Representatives Hixon, Perry, Romrell, Vander Woude, Beyeler, Redman, Troy, Rusche, Chew

**ABSENT/  
EXCUSED:** None

**GUESTS:** Matthew Keenan, Idaho Freedom Foundation; Penny Caldwell, Tina Sadler, and James Quinn, Citizens; Christopher Ball, Idaho Dept. of Health & Welfare, Bureau of Laboratories; Alex Adams, Misty Lawrence, and Berk Fraser, Idaho Board of Pharmacy; Kurt Altman, Goldwater Institute; Jeremy Pisca and Emily Patchin, Kootenai Health; Toni Lawson, Idaho Hospital Association.

**Chairman Wood** called the meeting to order at 9:00 a.m.

**MOTION:** **Rep. Hixon** made a motion to approve the minutes of February 2, 4, 8, 9, and 15, 2016. **Motion carried by voice vote.**

**H 481:** **Rep. Melissa Wintrow**, District 19, presented **H 481**.

The testimony of **John Knudsen**, who has Amyotrophic Lateral Sclerosis (ALS), was read by **Rep. Wintrow**. Mr. Knudsen supports **H 481**, to allow patients and doctors to work together to secure experimental treatments. Drug companies can provide treatment free or at a discounted cost, with no payment required by insurance companies. Similar bills have passed in Missouri and Louisiana. Passage of **H 481** gives hope, if not a cure, for hundreds of diseases that rob people of their lives.

**Rep. Wintrow** stated **H 481** allows terminally ill patients the ability to try an experimental drug meeting at least Phase 1 of the federal drug administration (FDA) pipeline. The informed consent provides patient diagnosis agreement. There are no obligations for insurers, manufacturers, hospitals, or physicians to do anything to cover the use of the drug. All authority and liability is in the patient's hands. Answering a committee question, she said release of liability is clearly defined.

**Dr. James Quinn**, Citizen, described how this issue was brought to his attention and subsequent efforts leading to **H 481**. There are three phases of FDA drug testing. The first test, Phase 1, assures safety and establishes the optimum dosage. The second, Phase 2, uses small groups divided into test drug recipients and placebo recipients. The final test, Phase 3, involves a larger test group, again with placebos and the test drug.

During Phase 1 there is little knowledge of the new drug's impact, including any crossover impact on other conditions. The ability to hope and try brings peace of mind to patients, families, and physicians. This legislation maintains respect for the drug companies and the FDA process while providing a chance for individuals instead of forcing them to pursue treatments in other countries.

**Kurt Altman**, The Goldwater Institute, further presented **H 481**. This legislation allows terminally diagnosed people, who have exhausted every FDA approved treatment, the ability to use those drugs which have passed the FDA Phase 1 and are continuing the FDA trial process. Such use works in conjunction with the clinical trials. This provides last resort access to persons ineligible for the clinical trials. The current FDA approval system has existed for fifty years, costs \$1B and takes eight to fifteen years to get a drug to market.

Through the compassionate use system, an avenue for patients under special circumstances, the physician can request the use of a lifesaving or effective drug, when no other therapy has worked. The procedure requires the treating physician contact either the Food and Drug Administration or the drug manufacturer to obtain permission. This process takes two to four months and a minimum of one hundred physician hours to navigate. A February, 2015, proposal to decrease the application to a single form to be completed in forty-five minutes is still not done.

Answering committee questions, **Mr. Altman** stated as of this date, no marijuana and cannabis oil derivative has passed Phase 1 of the FDA process. The legislation refers to legitimate drugs moving through the FDA process at a high cost to the manufacturer. Most drugs are further along in the process when the physicians learn of their existence. Off-label use of a drug is not part of the legislation.

If the manufacturer agrees to the patient's use, the drug can be provided for free or at cost, which follows federal law prohibitions. Generally under compassionate use, the manufacturer doing clinical trials on the requested drug provides it for no cost. Any cost is borne by the patient, as part of the consent form.

There is a gray insurance coverage area with respect to side effects from taking the drug. This cannot be covered in statute, thus highlighting the importance of an informed patient consent. The continued FDA process requirement and federal law prohibiting sales for profit prior to drug approval assure the Right To Try Act is not used as a marketing tool.

In the case of children, it would work the same as state code for other guardian decisions, including anything regarding the Department of Health and Welfare.

**Matt Keenan**, Idaho Freedom Foundation, testified **in support of H 481**. He shared information on experimental treatment received by a patient in Oregon. This legislation provides hope for patients by providing an alternative to the FDA uphill approval process.

**Penny Caldwell**, Representing Herself, testified **in support of H 481**. This legislation would provide a choice for those with terminal illnesses whose lives have been uprooted by the diagnosis and progression of the disease. Patients and families are looking for any option to stop the disease progression and gain hope.

**Tina Sadler**, Representing Herself, testified **in support of H 481**. She asked the committee to consider what people face when diagnosed with a terminal disease without treatment or cure. She asked the committee to then consider no access to a legitimate drug in clinical trial showing great promise for the disease. These individuals are asking the government to step out of the way and give them the freedom of choice and hope.

**MOTION:**

**Rep. Redman** made a motion to send **H 481** to the floor with a **DO PASS** recommendation.

For the record, no one else indicated their desire to testify.

**VOTE ON MOTION:** **Chairman Wood** called for a vote on the motion to send **H 481** to the floor with a **DO PASS** recommendation. **Motion carried by voice vote. Chairman Wood** requested he be recorded as voting **NAY. Rep. Wintrow** will sponsor the bill on the floor.

**H 438:** **Jeremy Pisca**, Attorney, Risch Pisca, on behalf of Kootenai Health Medical Center, presented **H 438**. This legislation is being replaced by **RS 24459**.

**MOTION:** **Rep. Hixon** made a motion to **HOLD H 438** in committee. **Motion carried by voice vote.**

**RS 24559:** **Jeremy Pisca**, Attorney, Risch Pisca, on behalf of Kootenai Health Medical Center, presented **RS 24559**. This proposed legislation allows a taxing district hospital board of trustees to appoint not more than two additional members with specialized skills to serve at the pleasure of the board. The appointed members cannot vote on any decision to levy a tax and may be removed with or without cause. Answering a committee question, Mr. Pisca said there are seven hospital taxing districts. The Idaho Hospital Association has surveyed all members and supports the legislation.

**MOTION:** **Rep. Hixon** made a motion to introduce **RS 24559. Motion carried by voice vote.**

**H 453:** **Chairman Wood** stated the sponsor of **H 453**, previously held to date certain, February 23, 2016, has requested it be held until Thursday, February 25, 2016, to allow travel time for individuals from out of town wishing to testify.

**MOTION:** **Vice Chairman Packer** made a motion to **HOLD H 453** for time certain, February 25, 2016. **Motion carried by voice vote.**

**Christine Pisani**, Executive Director, Idaho Council on Developmental Disabilities (ICDD), presented the annual report of the Collaborative Work Group (CWG) on Services for Adults with Developmental Disabilities (DD). Occurring, typically, at birth, this is a life-long condition. Individuals meeting the DD definition may have several diagnoses with unique support needs. Mental disorders are found in 30 to 35% of DD individuals. Lifelong supports need to be individualized, flexible, and designed for meaningful lives.

By 2020, the CWG envisions Idaho adults with DD having the same opportunities, freedoms, and rights as their neighbors. They will also have access to sustainable service systems that provide quality, individualized supports to meet their lifelong changing needs, interests, and choices.

Medicaid's self direction waiver option provides support determined by the individual. Person centered planning is the pathway to best outcomes for participants and effective resource allocation. Focus groups highlighted employment as a priority to provide connections with community members and feelings of fulfillment.

The Medicaid self direction option has grown by 28% in the past year. Surveys provided a better understanding of state services. Information was obtained on a face-to-face basis from individuals, families, and service providers.

The survey findings indicated perceptions about self direction, choice rationale, access misunderstandings, and the status of best outcome achievement. Results have helped the ICDD focus on training, quality assurance, and advocacy.

Also indicated was the need for better measurement, which is available through the National Core Indicators (NCI) Project. This is a collaborative effort between State DD Directors and The Human Services Institute to measure their own performance and gather outcome data used to track, compare, and support decision making. This is the last year for access and the dues will be waived. The children's DD survey will help understand what the same programs can do for adults. A similar Medicaid survey would cost \$70,000.

Person centered planning (PCP) helps discover an individual's gift. Persons with DD have been marginalized, segregated, and put aside because they don't fit into a box. By discovering a person's dream, what it really means, and drilling down to the lowest common denominator, programs can be built that fulfill the individual's needs and leads to full community environment. The forefront of PCP is the recognition of all behavior as communication. Once everyone shares their gifts and their talents, we can build richer more colorful communities.

**ADJOURN:** There being no further business to come before the committee, the meeting was adjourned at 10:40 a.m.

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Representative Wood  
Chair

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Irene Moore  
Secretary