

**HOUSE COMMITTEE ON COMMERCE**

**SUBCOMMITTEE ON BUSINESS**

March 4, 1997 Hearing Room 357

8:30 A.M. Tapes 13 - 15

**MEMBERS PRESENT:**

Rep. Roger Beyer, Chair

Rep. Richard Devlin

Rep. Bob Montgomery

Rep. Jackie Taylor

**STAFF PRESENT:**

Keith Putman, Administrator

Annetta Mullins, Administrative Support

**MEASURE/ISSUES HEARD:**

HB 2039 Work Session

HB 2388 Public Hearing

HB 2040 Work Session

SB 57 Public Hearing

These minutes are in compliance with Senate and House Rules. Only text enclosed in quotation marks reports a speaker's exact words. For complete contents, please refer to the tapes.

| Tape/#                                | Speaker      | Comments  |
|---------------------------------------|--------------|---|
| TAPE 13, A                            |              |   |
| 002                                   | Chair Beyer  | Calls meeting to order at 8:31 a.m. Opens work session on HB 2039.                        |
| <u>HB 2039 -<br/>WORK<br/>SESSION</u> |              |   |
| 006                                   | Keith Putman | Administrator, reviews history and provisions of HB 2039. Amendments eliminate Section 1. |

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| 020                                    | Chair Beyer         | Notes the committee cannot change the relating clause and would need to strike first line of amendment.  |
| 028                                    | Rep. Taylor         | Comments that they need to take -1 amendment, and further amend it to delete Section 1 of the bill.  |
| 048                                    | Chair Beyer         | Closes work session on HB 2038 and opens public hearing on HB 2388.  |
| <b><u>HB 2388 - PUBLIC HEARING</u></b> |                     |  |
|  |                     | Closes public hearing on HB 2388. Opens work session on HB 2040.   |
| <b><u>HB 2040 - WORK SESSION</u></b>   |                     |  |
| 061                                    | Putman              | Reviews history and provisions of HB 2040.   |
| 092                                    | Rep. Montgomery     | Comments he thinks the emergency clause is ludicrous.  |
| 094                                    | Chair Beyer         | Notes changes in relating clause.  |
| 104                                    | Wendy Robinson      | Assistant Attorney General, Department of Justice, explains the reason for the emergency clause. HB 2041 has to do with the two-year registration and the emergency clause is needed to get the contractors onto the two-year cycle. |
| 113                                    | Putman              | Notes language was moved from another bill and will talk to Speaker's office before sending it to the full committee.  |
| 126                                    | Rep. Taylor         | <b>MOTION: Moves HB 2040 with the -3 amendments back to the full committee.</b>  |
| 130                                    |                     | <b>VOTE: 3-0</b><br><b>EXCUSED: 1 - Devlin</b>   |
|  | Chair Beyer         | <b>Hearing no objection, declares the motion CARRIED.</b><br><b>REP. DEVLIN will lead discussion in the full committee.</b>  |
| 130                                    | Chair Beyer         | Closes work session on HB 2040 and opens public hearing on HB 2388.  |
| <b><u>HB 2388 - PUBLIC HEARING</u></b> |                     |  |
| 134                                    | Rep. Peter Courtney | District 33, testifies in support of HB 2388 (EXHIBIT A), explains why he has introduced the bill, and describes the inability of infants to digest foods<br><br>* describes phenylketonuria (PKU)                                   |

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|     |                    | <ul style="list-style-type: none"> <li>* some insurance companies provide coverage</li> <li>* impact to insurance industry is minimal</li> </ul>   |
| 180 | Rep. Courtney      | <p>Continues testimony</p> <ul style="list-style-type: none"> <li>* other states have passed similar laws.</li> <li>* all health care policies are not covered under law.</li> </ul>   |
| 200 | Dr. James K. Lace  | <p>Oregon Pediatric Society, submits and reads a prepared statement in support of HB 2388 (EXHIBIT B)</p> <ul style="list-style-type: none"> <li>* explains PKU and incident numbers.</li> <li>* high risk of brain damage if not properly treated.</li> <li>* insurance may or may not pay for needed medications.</li> </ul> |
| 249 | Lace               | <p>Suggests amendments to HB 2388</p> <ul style="list-style-type: none"> <li>* add to line 8 "treatment of specific inherited..."</li> <li>* add to line 9 "specific disorders are the inborn errors of metabolism"</li> <li>* define physicians in line 14</li> </ul>   |
| 278 | Rep. Montgomery    | Asks where the food can be purchased.  |
| 282 | Lace               | <p>Responds it may be obtained from a metabolic clinic, the pharmaceutical company, or perhaps a pharmacy. The formulas are very clearly specified and can cause damage to the general public</p> <ul style="list-style-type: none"> <li>* describes procedures in prescribing</li> </ul>                                      |
| 298 | Rep. Montgomery    | Asks if the prescription for the formula would be provided by a medical professional.  |
| 301 | Lace               | Would do this in conjunction with the metabolic clinic at Oregon Health Sciences University (OHSU).  |
| 309 | Chair Beyer        | Asks if "specific" would clear up the language in line 8.  |
| 314 | Lace               | Responds "inborn errors" will clear it up and would not include general diseases.  |
| 335 | Rep. Jackie Taylor | <p>District 1, testifies in support of HB 2388 (EXHIBIT C)</p> <ul style="list-style-type: none"> <li>* compares PKU patients with diabetes patients.</li> </ul>   |

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|            |                  | * compulsory screening  |
| 388        | Pat Kubele       | <p>Health Policy Specialist, Oregon Nurses Association, testifies in support of HB 2388 (EXHIBIT D)</p> <p>* explains treatment</p> <p>* costs to insurers if they do not treat supplements will be higher</p> <p>* supplement versus medicine</p>  |
| TAPE 14, A |                  |   |
| 001        | Kubele           | <p>Continues presentation.</p> <p>* defines drugs</p> <p>* treatment is inexpensive compared to that of cystic fibrosis</p>   |
| 039        | Tim Kelsh        | <p>Keizer, PKU parent, submits and reads a portion of a prepared statement in support of HB 2388 (EXHIBIT E)</p> <p>* relates problems with insurance carrier</p>   |
| 090        | Kelsh            | <p>Continues presentation.</p> <p>* Most insurance carriers do cover PKU treatment.</p>   |
| 107        | Monte Aken       | <p>Westport, PKU parent, testifies in support of HB 2388 (EXHIBIT F)</p> <p>* relates influence of diet on patients</p> <p>* Women, Infants, and Children (WIC) no longer pays for treatment.</p> <p>* SelectCare will not pay for his child's treatment.</p> <p>* need consistency from insurers</p> |
| 160        | Carol Cwiklinski | <p>Ashland, aunt of PKU patient, testifies in support of HB 2388 (EXHIBIT G)</p> <p>* PKU effects may change as child grows.</p> <p>* cost of food and medical bills unnecessarily burden parents.</p>  |
| 210        | Rep. Montgomery  | Comments he has not heard from insurance companies either for or against the bill.  |

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| 222               | Lori Arnold         | Salem, PKU parent, testifies in support of HB 2388 (EXHIBIT H)<br><br>* defines "medical foods"   |
| 272               | Arnold              | Continues presentation<br><br>* Insurers pay for screening but not for treatment.<br><br>* non-compliance with diet can lead to bigger medical bills.                                   |
| 322               | Arnold              | Continues presentation.<br><br>* doctors recommend staying on the diet for life.<br><br>* discusses preventive therapy  |
| 382               | Peter Reimers       | Hillsboro, parent, introduces himself and his family and submits prepared statements (EXHIBIT I).   |
| 396               | Tyler Reimers       | Introduces himself. Has Methylmalonic Acidemia.   |
| 403               | Janet Reimers       | Testifies in support of HB 2388 (EXHIBIT I, pages 1 and 2)<br><br>* explains Methylmalonic Acidemia.<br><br>* describes treatment<br><br>* has coverage but coverage always challenged. |
| <b>TAPE 13, B</b> |                     |   |
| 031               | P. Reimers          | Continues presentation in support of HB 2388 (EXHIBIT I, pages 2 and 3)<br><br>* new employment affected by insurance   |
| 044               | Rep. Montgomery     | Asks how long the food in the Reimers' container will last.   |
| 046               | P. Reimers          | Responds about eight days.  |
| 048               | Rep. Montgomery     | How much does the container cost?   |
| 049               | P. Reimers          | Responds approximately \$20 - \$25  |
| 050               | Rep. Montgomery     | Will this be the same formula used over lifetime?   |
| 052               | J. Reimers          | Responds no, son has used different formulas over the years.  |
| 066               | Kathleen Huntington | Oregon Health Sciences University, submits chart and explains why medical foods are not nutritional supplements (EXHIBIT J).  |

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| 116 | Huntington      | Continues presentation<br>* medical foods are mainstay for child.<br>* distinguishing feature of medical foods  |
| 153 | Huntington      | Continues presentation and explains why insurance companies should provide coverage for medical foods<br>* defines medical foods<br>* not regulated drugs under the Food and Drug Administration (FDA)<br>* Insurance companies refuse treatment based on costs |
| 205 | Mark Brenneeman | Portland, PKU patient, submits and reads statement in support of HB 2388 [EXHIBIT K].<br>* Asks and answers common questions about his situation.   |
| 248 | Rep. Montgomery | Comments that the bill says "under supervision of physician."<br>Asks if the doctor writes a generic prescription or if the doctor changes as the formulas change.  |
| 254 | Huntington      | Responds they evaluate the patient and come up with a plan by working together.   |
| 259 | Rep. Montgomery | Do you write up the plan and then give it to a doctor to approve?   |
| 260 | Huntington      | Responds yes.   |
| 261 | Chair Beyer     | Asks if the special foods are detrimental to people who do not need it.   |
| 266 | Huntington      | Explains the food would not provide the needed nutrition for the normal person.   |
| 280 | Chair Beyer     | Does the whole family use the special foods?  |
| 283 | Huntington      | Responds no, there is no incentive for other people to use the foods.   |
| 300 | Gari Johnson    | Portland, mother and niece of PKU patient, testifies in support of HB 2388 [EXHIBIT L]<br>* describes son's and aunt's life with PKU.   |
| 345 | Putman          | Distributes copies of testimony from Neil R.M. Buist, Oregon Health Sciences University [EXHIBIT M].  |
| 358 | Judy Turk       | Nurse at OHSU, comments she works with Dr. Buist and Ms. Huntington<br>* may use state money when insurance companies do not pay.   |

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| 408        | Turk                | Continues testimony.<br>* Suggests adding Dr. Buist's italicized portion to line 12 (EXHIBIT M).  |
| TAPE 14, B |                     |   |
| 001        | Turk                | Continues testimony   |
| 016        | Tieca Keyser        | Clackamas, PKU patient, testifies in support of HB 2388 [EXHIBIT N]<br>* describes pregnancy and having PKU   |
| 066        | Keyser              | Continues presentation.   |
| 082        | Rep. Taylor         | Asks if Ms. Keyser suspected her children would test positive for PKU.  |
| 083        | Keyser              | Explains blood tests done before babies were born and the screening test after birth.   |
| 102        | Rep. Montgomery     | Asks if this condition will continue through life.  |
| 107        | Keyser              | Yes, it is genetic. Feels a lot better on the diet but insurance covered foods only during her pregnancy.   |
| 126        | Rep. Taylor         | Asks about nursing the babies.  |
| 127        | Keyser              | Responds that it takes just the normal additional calories to nurse.  |
| 137        | Chair Beyer         | Asks if HMO and PacifiCare are the insurance companies.   |
| 135        | Keyser              | Replies that they are the only ones which covered me. March of Dimes paid for food as child.  |
| 151        | Dr. Grant Higginson | State Health Officer and Deputy Administrator, Oregon Health Division, testifies in support of HB 2388 (EXHIBIT O).<br>* Newborn Screening Program<br>* treatment must be available |
| 200        | Higginson           | Continues presentation.   |
| 211        | Rep. Montgomery     | Asks what MPH stands for.   |
| 214        | Higginson           | Replies Masters in Public Health.   |
| 215        | Chair Beyer         | Asks Dr. Higginson if he knows how many insurance companies cover the foods.  |
| 217        | Higginson           | Responds he does not know, but believes the majority of newborns are covered.   |
| 224        | Putman              | Explains that it has been represented to him that all insurance companies are providing coverage.   |

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| 231 | Chair Beyer     | Asks when the symptoms show up.  |
| 237 | Higginson       | Explains it depends on how quickly the toxic by-products build up.   |
| 252 | Chair Beyer     | Asks about recovery time for the symptoms.   |
| 257 | Higginson       | Explains it takes some time to clear up the conditions.  |
| 266 | Rep. Montgomery | States that in previous testimony there is an insurance company which does not provide coverage.   |
| 269 | Putman          | Indicates that there may be some companies which do not cover PKU.   |
| 273 | Higginson       | Submits Children's First of Oregon testimony in support of HB 2388 [EXHIBIT P].  |
| 291 | Jenny Ulum      | SelectCare Health Plans, testifies in support of HB 2388. Believes the bill is too broad.  |
| 305 | Tom Jefferson   | <p>Medical Director, SelectCare, suggests changes in the bill.</p> <ul style="list-style-type: none"> <li>* SelectCare never had a case until this January and now has two.</li> <li>* The policy was federal which does not cover oral nutritional formulas.</li> <li>* Medical foods are not oral nutritional formulas.</li> <li>* are required to make decision within 48 hours and therefore had to go with the policy in place at the time.</li> <li>* SelectCare has been sensitized and reversed decision.</li> </ul> |
| 343 | Jefferson       | <p>Concerned with bill's language.</p> <ul style="list-style-type: none"> <li>* suggests change: eliminate "carbohydrate and fat metabolism"</li> <li>* keep bill to "amino acid metabolism"</li> <li>* define "carbohydrate and fat metabolism"</li> <li>* willing to work with CDRC to make language clear</li> <li>* keep bill's intent clear</li> </ul>  |
| 384 | Chair Beyer     | Asks if there are insurance companies that do not provide coverage.  |
| 387 | Ulum            | Responds that carriers cover on exception and do not cover PKU. Insurance companies that are not state-regulated are exempt from mandates of this bill.  |
| 403 | Chair Beyer     | Asks for clarification on lifetime caps.   |



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| <b>TAPE 15, A</b>                    |                             |   |
| <b>001</b>                           | <b>Jefferson</b>            | <b>Responds there probably would be a lifetime cap.</b>   |
| <b>010</b>                           | <b>Dave Fiskum</b>          | <b>Good Health Plan and PacifiCare, submits letters and testifies they do not believe HB 2388 is necessary [EXHIBIT Q]</b><br><br>* encourage narrow language<br><br>* suggests revising line 8 and lines 17 - 19             |
| <b>045</b>                           | <b>Melanie van der Veen</b> | <b>Portland, mother of 19 month old child with PKU, testifies in support of HB 2388 [EXHIBIT R]</b><br><br>* describes frustration with insurance   |
| <b>089</b>                           | <b>Chair Beyer</b>          | <b>Asks staff to find out if some insurance companies are not providing coverage and to work with other people. Announces that the bill will be scheduled for another time.</b>   |
| <b>104</b>                           | <b>Chair Beyer</b>          | <b>Closes public hearing on HB 2388 and opens public hearing on SB 57.</b>  |
| <b><u>SB 57 - PUBLIC HEARING</u></b> |                             |   |
| <b>126</b>                           | <b>Putman</b>               | <b>Reviews provisions of SB 57.</b>   |
| <b>136</b>                           | <b>David Efurud</b>         | <b>Vice-Chair, State Board of Accountancy, testifies in support of SB 57 [EXHIBIT U]</b><br><br>* test, license, and monitor certified public accountants<br><br>* pass entire cost of reviewing examinations onto candidates |
| <b>159</b>                           | <b>Rep. Taylor</b>          | <b>Asks if it is possible to get only that section which candidate failed.</b>  |
| <b>163</b>                           | <b>Efurud</b>               | <b>Responds yes. When the candidate asks for more sections we end up paying more than we can collect. Continues testimony</b><br><br>* reduce retention period of tests   |
| <b>182</b>                           | <b>Efurud</b>               | <b>Explains national examination process. There is reason for the fee and reduction of storage.</b>   |
| <b>195</b>                           | <b>Chair Beyer</b>          | <b>Closes public hearing on SB 57 and adjourns meeting at 10:34 a.m.</b>  |

Transcribed By, Reviewed By,

Gina Cross Keith Putman,

Committee Clerk Administrator

## **EXHIBIT SUMMARY**

- A - HB 2388, Prepared Testimony, Rep. Peter Courtney, 3 pp.**
- B - HB 2388, Written Testimony, James K. Lace, M.D., F.A.A.P., 1 p.**
- C - HB 2388, Written Testimony, Rep. Jackie Taylor, 1 p.**
- D - HB 2388, Written Testimony, Oregon Nurses Association, 1 p.**
- E - HB 2388, Written Testimony, Tim Kelsh Jr., 3 p.**
- F - HB 2388, Written Testimony, Monty Akin, 3 p.**
- G - HB 2388, Written Testimony, Carol A. Cwiklinski, 2 p.**
- H - HB 2388, Written Testimony, Lori Arnold, 2 p.**
- I - HB 2388, Written Testimony, Reimers Family, 3 p.**
- J - HB 2388, Written Testimony, Kathleen Huntington, MS, RD, LD, 1 p.**
- K - HB 2388, Written Testimony, Mark Brenneman, 2 p.**
- L - HB 2388, Written Testimony, Gerine Johnson, 1 p.**
- M - HB 2388, Written Testimony, Neil R. M. Buist, M.D., 4 p.**
- N - HB 2388, Written Testimony, Tieca Keyser, 1 p.**
- O - HB 2388, Written Testimony, Elinor C. Hall, MPH, 2 p.**
- P - HB 2388, Written Testimony, Dr. Higginson, 1 p.**
- Q - HB 2388, Written Testimony, Dave Fiskum, 2 p.**
- R - HB 2388, Written Testimony, Melanie A. van der Veen, 1 p.**
- S - HB 2388, Written Testimony, Kathryn Weit, 1 p.**
- T - HB 2388, Periodical, Rep. Jackie Taylor, 2 p.**
- U - SB 57, Written Testimony, Karen DeLorenzo, 2 p.**