

EXHIBIT NO. 5DATE: 1-31-05BILL NO. SB 275

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Chairwoman ^{Crownley} ~~Schmidt~~ and committee members:

I regret having to speak against this bill. For more than 20 years I have worked in professional partnership with the Montana genetics program based at Shodair – I hold both Dr Johnson, Director of the clinical program and Dr. Haag, Director of the laboratory, in high esteem – I consider several members of the professional staff my personal friends.

My decision to speak is based on these qualifications:

- For more that 40 years I have been a practicing physician in an area of medicine that includes many genetic conditions (child neurology) and since 1983 in Montana.
- a year ago 2 other physicians and I were asked to work with DPHHS to develop an RFP – (request for proposal) for Montana's genetics program
- 4 years ago I chaired a DPHHS advisory committee charged with assessing our state Newborn Screening (NBS) program – a program which has many overlaps with the genetics program. During those 2 years I reviewed many recommendations from both national and regional groups as to the best approach for such programs, especially in locations (rural, low population density) such as ours.
- As a past legislator representing HD 55, I am committed to making decisions for what is best for Montana as a whole, not special interests.

A brief history of the Montana genetics program:

1. National financial support which originally established state and regional genetic programs was phased out in the 80's and in 1985 50-19-211 was added to the Montana Code.
2. Until this past year this state money was transferred to Shodair without any specific guidelines or requirements
3. A year ago the committee was formed to establish guidelines and put out an RFP for competitive bid; the 1 year contract was awarded to Shodair as of July 1, 2004

The RFP committee was comprised of 3 physicians – one from Billings, one from Great Falls and me – plus DPHHS personnel who have been involved in administering the genetics monies over the past 20 years.

We met over the course of 2-3 months, probably 12-15 hours in all. Available resources at the present fee rate are approximately \$500,000/year. The two main priorities that the committee identified were (1) to provide access to genetic evaluation and counseling in many state locations and (2) to provide educational resources for the public and professionals. The committee decided to exclude support for genetic laboratory services from the RFP contract.

Why would we do this? Why exclude coverage for laboratory services?

1. Although I have never seen any actual financial statements or audits from Shodair the consistent message that I have heard is that the state monies are insufficient to cover the costs of the program, especially the lab.
2. To have clinical genetic services available in many state locations usually requires physicians and genetic counselors to be physically there. This is not the case for laboratory tests, which are sometimes indicated after a genetic evaluation has been done. The blood required for such tests is drawn locally and sent to the laboratory doing the test, wherever that lab is located. The same is true for other samples that may be obtained in the course of evaluation of a pregnancy if there is concern about genetic abnormalities.
3. The number of useful genetic tests is rapidly escalating. As this occurs, it becomes more and more difficult for a lab that serves a small population base to be cost effective. The lab located at Shodair has done a great job- but I suspect that it will be more and more difficult for any lab that is not part of a research/medical school environment and/or that serves a small population base to compete with other laboratories (and even more so with large volume

commercial labs). This is regrettable, but probably inevitable. (As of 1-30-05, a reliable web based resource about gene tests indicates that 577 laboratories were available for tests related to 1097 diseases. – copy attached) To my knowledge, all non-commercial genetic labs in the US, except Shodair, are associated with a full fledged university-associated medical school. The only states without a medical school are Alaska, Idaho, Wyoming, and Montana. None of these have in-state genetic labs.

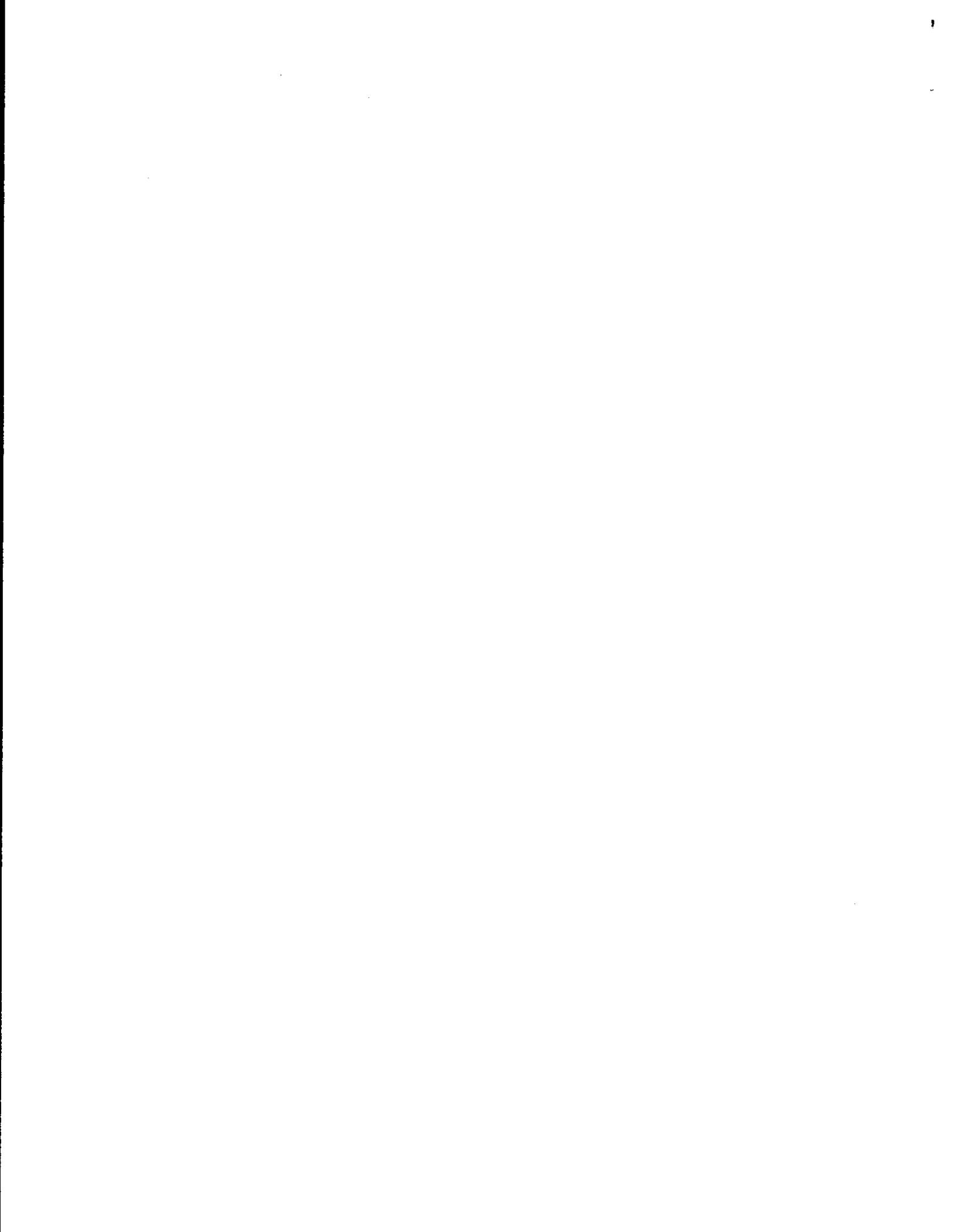
These are some of the reasons that our committee made the decision that with the limited dollars available, our priority would be to support genetic clinical services with the general fund \$\$ raised by the fee on insurance carriers. It seems better to send blood samples out of state, than people.

In conclusion, SB 275 inserts into MCA 50-19-211 the requirement that general fund \$\$ only support a genetics program that includes a laboratory component. This appears to me to be an attempt to circumvent the decision reached by the RFP committee in the Spring of 2004. This requirement may be in the interests of Shodair Hospital, at least for the short term, but I do not think it is in the best interests of the state of Montana. In my opinion it is not the best way to use our limited dollars to provide the best possible genetic services to our citizens.

Thus, despite my high respect for the professionals who work in our state genetics program located at Shodair, I must oppose the changes proposed in SB 275 that relate to the obligatory inclusion of laboratory services in the state funded genetics program.



MARY ANNE GUGGENHEIM, M.D.
Past Representative HD 55



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