Proposed Rule Changes to Chapter 246-650 WAC
Newborn Screening to Add New Conditions to the Newborn Screening Panel
Summary of Public Comments: 1of 2 received by May 12, 2008

The following comment was received from Wylie Burke, M.D, PhD, Professor and Chair, Department of Medical History and Ethics University of Washington on April 9, 2008.

> Mike-
>
> I was not at the meeting, so I don't know how the discussion of CPT1 went, but I wanted to alert you to some feedback I have heard from colleagues in Alaska Native organizations in Anchorage. They tell me that there is concern about screening for CPT1 in the absence of clear information about the phenotypic effects of the Alaska Native mutation. I understand that some AN leaders view Oregon's decision to add CPT1 screening very negatively (although I do not know how representative this view is). Also, colleagues in Canada tell me that they are observing high rates of homozygosity in some First Nations communities, suggesting penetrance is very low; and are recommending population-based studies to define genotype-phenotype correlation before considering newborn screening.
>
> You may already have good input from Alaska Native leadership, so please let me know if this concern is off base. But if AI/AN communities have not weighed in yet, it might be important to get their input on screening for CPT1. I would be glad to help if I can.
>
> Wylie

These issues were investigated and a summary of findings produced (attached). As a result, the condition CPT1 has been removed from the conditions proposed. Notice of the change was sent to Advisory Committee members and the Interested Parties list (including Dr. Burke) on April 24, 2008.

Subsequent to notification of the change comments were received on April 24, 2008 from Committee members Dr. Sihoun Hahn, Children’s Hospital and Regional Medical Center (who had initially proposed the addition of CPT1 to the recommendations) and Dr. Nancy Anderson, Department of Social and Health Services. Both were supportive of the change. Comment has also been received from Dr. Burke in support of the change.

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Summary of Public Comments: 2 of 2 received by May 12, 2008

The following comment was received from Representative Mary Lou Dickerson on May 7, 2008:

> I received this letter from my constituent. I understand Retinoblastoma is not one of the conditions recently considered for addition to the Newborn Screening Program. I thought I would still pass along this email for your consideration.
>
> Thank you,
>
> Rep. Mary Lou Dickerson
>
> MESSAGE:
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> Dear Legislator,
> My baby, Amelia Rose Olson Laing, was just diagnosed with Retinoblastoma--a cancer that is treatable if found early (http://www.caringbridge.org/visit/ameliarose).
>
> A bill has been written for eye pathology screening in the state of Florida. It requires the eye dilation test before leaving the hospital, the six- to eight-week exam, the six- to nine-month exam and the use of the ophthalmoscope at every exam throughout childhood. These three eye dilation tests in the first year of life will detect treatable eye diseases before they can blind or kill our children. The numbers for the bills are House No. 1117 Senate No. 2062.
>
> I would like to encourage you to pass legislation like this in Washington State. Simply dialating babies eyes would catch this cancer early--similar to how doctors now do a hearing test before discharging you from the hospital. This cancer is very treatable if caught early but often it is not because babies can not tell you they are blind or in pain. By the time it's caught (almost always by parents!) it's often too late to save any sort of vision. Amelia has her right eye removed on Wednesday of this week--we're hoping to save some vision in the left one by continuing with chemo therapy. She's four months old.
>
> Please pass legislation in Washington state to make screening mandatory.
> I did all the well child checkups--and we were at the doctors office three time the beginning of March because she had a cold--and they did not catch it. Only by dialating her eyes would they be able to see the tumors early.

The Board of Health and Department of Health investigated the issues raised by the constituent and made the following response to Representative Dickerson on May 12, 2008 with copies to Representatives Eileen Cody and Helen Sommers and Senator Jeanne Kohl-Welles who had also been included in the original message:

May 12, 2008

Dear Representative Dickerson,

Thank you for your email regarding retinoblastoma. We were saddened to hear how this condition has affected Ms. Olson Laing's baby. We very much appreciate her interest in early detection and treatment of this condition. However, retinoblastoma was not one of the conditions that we considered requiring in Washington State. To our knowledge, universal screening of newborns for the condition is currently not on the screening panel of any state.

Since we received your email we have done some research on retinoblastoma. Legislation was proposed in the 2005 Florida legislative session requiring newborn screening for the early diagnosis of serious ocular conditions, including retinoblastoma and congenital cataract. The legislation would have required every baby born in a hospital to receive an eye exam using an opthalmoscope and pupil dilation prior to discharge. The bill also required health insurance policies, health maintenance contracts, and Medicaid to provide coverage for the procedure and for repeat screenings at 6-8 weeks and again at 6-9 months. This legislation died in committee in both the Florida House and Senate. As far as we can tell it has not been re-introduced.

Among possible reasons for its defeat may have been the fact that Florida Society of Ophthalmology and the Florida Chapter of the American Academy of Pediatrics were both on record with concerns regarding the potential side effects on infants and young children of the pharmacological dilating agents necessary for the dilation of the pupils. Although it is usually a safe procedure, there is a definite risk (2-4%) of significant complications including high blood pressure, stroke, and cardiac arrest. It was also noted that for some children the procedure can involve the use of significant restraints and other devices to open the eyelids resulting in potential for injury.

Before the Board considers requiring any new condition, we need to be sure that it can be screened for safely and effectively. Our preliminary review of retinoblastoma indicates that the medical science is probably not there yet. Also the State Board of Health's statutory authority does not extend to establishing payment coverage requirements so this component, if desired, would require legislative action.

If you have any more questions please let us know.

Sincerely, Tara Wolff and Mike Glass