

March 7, 2001

Dear Parents, Patients and Families,

We are asking for your help in getting House Bill 2268 passed this legislative session. This bill would raise the fee cap for newborn screening blood tests and allow the Newborn Screening Program to expand the number of diseases we test for from the current 6 to about 25. Virtually all of these conditions are metabolic disorders, many of which if found and treated early, can prevent death, mental retardation or permanent disability. Some of you have benefited from the Newborn Screening Program, in that your (or your child's) condition was identified before damage could occur. For others of you, sadly your child may have died or suffered metabolic crises and long term problems as a newborn screening test was not available for your or your child's condition. It is our fervent hope that expanding the number of disorders covered by the Screening Program will bring this benefit to dozens of additional families in Oregon each year. The cost of the newborn screening per specimen would increase by about \$5.00, from the current \$16.

House Bill 2268 will have a hearing in Salem sometime around the middle of March, 2001 by the Health and Public Advocacy Committee. The more letters, phone calls or e-mails the committee receives supporting this bill the more likely it will pass. We urge you to contact all the members of this committee, but particularly the Chairman, Jeff Kruse, as well as your own district's Senators and Representatives. The names, addresses, phone numbers and e-mail addresses for these individuals are appended. We would urge you to express your support briefly in your own words or use the sample letter below. It is much better if you hand write the letter and explain how the Newborn Screening Program has benefited your family or how your family has suffered because screening tests were not available. We would also appreciate it if you could let us know if you have written. Please feel free to call, write or send e-mail to us to discuss this issue. Thanks so much.

Sincerely,



Judi Tuerck, RN  
Robert Steiner, MD  
Cary Harding, MD  
David Koeller, MD  
Neil Buist, MD

Oregon Health Sciences University  
Child Development and Rehabilitation Center  
PO BOX 574  
Portland Or 97201  
503-494-7859