

Newborn Screening Offers Expanded Hope

Delegate Kenneth R. "Ken" Plum

(Appeared May 19, 2004 in the ***Reston Connection***.)

One of my most valuable experiences before becoming a member of the state legislature was serving on the Fairfax-Falls Church Community Services Board having been appointed by County Supervisor Martha Pennino. I became very acutely aware of the challenges of mental retardation, mental health and substance abuse and the importance of programs meeting those needs as core services of government. I also got to know some very interesting and dedicated people who advocated for these programs including Leroy Aarons of Falls Church.

Leroy made me aware of newborn screening as a way to detect certain disorders that could lead to mental retardation or other health problems. Virginia was one of the first states to test newborns for phenylketonuria (PKU) having started in 1963. Testing for congenital hypothyroidism (CH) started in 1978. When I was elected to the House of Delegates Leroy told me that additional tests had been developed, and in 1984 Virginia added maple syrup urine disease, homocystinuria, and galactocemia as a result of legislation I introduced.

I became aware of the work being done at the Medical College of Virginia by Dr. Barry Wolfe on identifying biotinidase deficiency as a cause of some mental retardation. In 1986 my legislation made Virginia the first government in the world to use Dr. Wolfe's research to screen infants for biotinidase deficiency. Other states and other countries soon followed, and the March of Dimes endorsed this important testing.

Virginia has since added three additional tests including sickle cell diseases. The eight screenings done by Virginia puts the state about in the middle of the number of different screenings conducted. Last week I met with the Joint Commission on Health Care to discuss a resolution I introduced that passed the General Assembly directing the Commission to study the possibility of further expanding the newborn screening program. Currently the state with the most extensive screening is Mississippi that screens for 55 disorders. I believe the study will bring about an expansion of the number of screenings in Virginia.

Fortunately the number of infants with metabolic disorders is low. Of the 100,000 screenings done in Virginia in 2003, there were 129 diagnosed cases. The exciting news is that for most of these infants a healthy and normal life can be had by adhering to a particular diet or by taking a dietary supplement. The small cost of the testing that is borne by families more than offsets the loss of quality of life and potential institutionalization and early death for the victims.

Thank you, Leroy, for your effective advocacy for the mentally retarded over many years, and thank you for bringing this important service of government to my attention.

Your responses are always welcome: kenplum@aol.com