

TESTIMONY of JONATHAN A. HARRIS
IN SUPPORT of S.B. 1144
AAC SCHOOL ATTENDANCE FOR STUDENTS
WHO REQUIRE TUBE FEEDINGS

March 11, 2011

Chairmen Ritter and Gerratana, Ranking Members Perillo and Welch and members of the Public Health Committee, for the following reasons, I *strongly support S.B. 1144*, AAC School Attendance for Students Who Require Tube Feedings:

- This bill does not attempt to nor will it supplant the vital role of school nurses in providing care to our children.
 - It is a limited carve out that is needed to protect children who suffer from rare conditions, such as Glycogen Storage Disease (GSD) (very rare metabolic disorder in which the body is missing a liver enzyme necessary to convert the stored form of sugar, glycogen, into the usable form, glucose).
 - A child, like Alyssa Temkin, suffering from GSD requires feedings every 90 minutes or more frequently depending on other conditions, i.e., stress, activity level.
 - To best protect the health and safety of the child it is crucial to have: (1) a trained person, not just in the technical aspects of tube feeding, but who actually knows the behaviors and idiosyncrasies of the individual child; and (2) that trained person constantly observing and analyzing the child's condition.
 - While school nurses have the ability and skill set to do so, they are by their charge, responsible for many (often hundreds) of students and understandably have not necessarily had the extensive contact with the particular child, both in and out of the school setting, that is key to observing and identifying the specific needs of the child.
 - This bill does not preclude school nurses from administering the tube feedings in those cases where the parents, their physician, APRN or physician's assistant, and the school nurse agree that it will best serve the child.
- This bill will better protect our children by facilitating the continuity of effective care for both the physical and mental health of the child in those rare, but crucial cases where a child requires a tube feeding.
 - The bill only allows unlicensed assistive personnel to administer feedings pursuant to a written order by a physician or other specified competent medical professionals (see lines 71-75). These professionals have their professional credentials and reputations on the line and will help ensure that only capable personnel are allowed to administer the tube feedings.

- Allowing a trained person that has developed a relationship with the child to administer the tube feeding, is important to lessening the stress on the child (which has a direct impact on GSD and the child's health and safety) and avoiding other social issues connected to being "different" from the other children in the classroom.
- Parents that make the effort to have someone assist their child will not be assigning a role that has a direct and crucial effect on the health and well being of their child to a person that is not trained and that cannot do the job.
- Allowing unlicensed assistive personnel to administer tube feedings has worked.
 - Alyssa has had her feedings done by her Aide and friend, Sara Sullivan, since July, 2008. Sarah successfully administered tube feedings to Alyssa in a pre-school setting.
 - Through long, often painful negotiations with the West Hartford schools, we were able to use a power of attorney to enable Alyssa Temkin to have her feedings done by her Aide and friend, Sarah Sullivan. This delay had a negative impact on Alyssa's health and well being, but in the end Sarah was allowed to administer the feedings and has done so successfully for nearly 5 months in Alyssa's kindergarten class.
 - Alyssa's health has been good and she is doing well educationally and socially.
 - Unlike the disruption to Alyssa and her classmate when Alyssa's mother had to administer the feedings, the tube feedings by Sarah have not disturbed the classroom and are now not even noticed by the other children. It is a regular part of the day and has, in fact, provided an important learning experience to Alyssa's friends and peers.
- Last session, the General Assembly passed a bill allowing "unlicensed assistive personnel" to administer tube feedings to people who attend day programs or respite centers or reside in residential facilities under the jurisdiction of the Department of Developmental Services. This is exactly what this bill seeks to do in the school setting. If it is safe in that context it is safe in school too.
- School district may save taxpayers' dollars by allowing unlicensed personnel to administer tube feedings. In the event there is not a school nurse available to provide the constant level of attention needed to protect the child, then it would be more costly for the district to pay for an additional nurse(s) to be constantly on site to then trained unlicensed assistive personnel. This gives the districts flexibility in how to deal with a unique situation in their school.

For the foregoing reasons, I strongly support S.B. 1144. Your attention to this important issue is much appreciated.