

Lynn

July 10, 1989

TO: Members of the Pennsylvania State Senate Education Committee and
House Judiciary Committee

From: (Mrs.) Linda S. Schnupp, Concerned Parent

RE: Senate Bill 454 and House Bill 855

First, I would like to thank Representatives Langtry, Petrone, McVerry and Trich for their responses to the letters my husband and I wrote expressing our concerns about House Bill 855. Representative Langtry's diligence and interest in our situation provided the opportunity for me to testify today.

As a parent of a child receiving Human Growth Hormone therapy, I would like you to understand the difficulties we have faced in the past year. We have realized and brought to our doctors attention that our son was not growing at the expected minimum rate of two inches per year. We have observed his peers towering over him as they begin their pubescent growth spurt and heard their cruel remarks to our son. Let me assure you that the pecking order of "biggest to smallest" still exists and will leave its emotional scars.

We have watched our son endure with bravery and cooperation the tedious, painful and emotionally draining experience of two hospitalizations and a series of out-patient testing to diagnose the cause of his lack of growth. All this was necessary for documentation that a child does medically meet the criteria for Human Growth Hormone replacement therapy. There are strict Federal guidelines that must be met before physicians can prescribe this medication and documentation must be updated constantly for justification of continued treatment. By pharmaceutical definition Human Growth Hormone stimulates the linear growth in children who lack adequate normal endogenous growth hormone.

In order for treatment to begin, we had to be taught by a home health nurse how to properly store, mix and inject the medication. The adjustment to the three times a week injections has been difficult. The entire process takes about 20 minutes per injection because the

medication must be mixed fresh each time, using sterile conditions. My husband, Trevor and I share these responsibilities while our daughter, Torey, age 11, stays as far away from the whole process as possible. Because Human Growth Hormone is a protein there is a burning sensation felt with every injection. Trevor was able to inject himself two weeks into therapy. It was two months before I could adjust to this and bring myself to give the injections. We are so proud of the way Trevor has handled this. We are also pleased to report that he has grown four inches in nine months of Human Growth Hormone replacement therapy. Even with this positive response to the medication it is hard to forget the other problems this situation has brought to our family. The cost for Trevor's medical care is approximately \$50,000.00 annually. For an average family this is overwhelming. Simple travel has become another obstacle because the medication must be refrigerated. We have just received a cold-pack carrying case from the pharmaceutical company for this purpose which should make things a little easier. However, House Bill 855, if passed without the proposed Amendment, would mean that we could be jailed and fined for carrying just one dose of medication to a grandparents house. This is not fair to our children.

We must also address the issue of limiting the amount of medication that we could keep in our possession. In reality, if this Bill is passed without a specific Amendment, we would have to visit our physicians office three times a week for injections. The inconvenience and expense of this would make treatment much more difficult. We do not need more obstacles and stresses added to our child's life.

In conclusion, we would suggest to you that it is not enough to strike Human Growth Hormone from the lists included in these Bills, but rather urge you to include a statement to House Bill 855 and Senate Bill 454 that states specifically that Human Growth Hormone used for legitimate medical purposes is not included in this legislation. By doing this you will leave no doubt in the minds of uniformed law enforcement officials or School Board Directors as to the legitimacy of Human Growth Hormone replacement therapy.