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House of Representatives commonwealth of pennsylvania harrisburg

February 24, 2011

## **MEMORANDUM**

**TO:** All Members of the House of Representatives

**FROM:** Representative Thomas Caltagirone

**DATE:** February 24, 2011

## SUBJECT: Duchenne Muscular Dystrophy Awareness Week

In the near future, I will be introducing a resolution to recognize the week of May  $23^{rd} - 27^{th}$ , 2011 as "Duchenne Muscular Dystrophy Awareness Week." Duchenne Muscular Dystrophy (DMD) is a devastating illness that affects every muscle in the body. It is most prominently found in the muscles within the cardiac and skeletal, leading to rapidly worsening muscle weakness and heart conditions.

DMD affects the lives of 1 in 3,600 young boys (diagnosed in early adolescence) and their families. The DMD gene provides the blueprint for the protein Dystrophin, which functions in keeping muscles intact and strong as the contract and relax. As this illness rapidly worsens, the child will experience chronic fatigue and falling. They also have difficulty with motor skills (running, jumping, and hopping) and experience rapidly worsening weakness throughout the entire body.

During the age range of 9-13 years, the child requires a motorized wheelchair to move. This is due to the fact that the child has lost all ability and strength to move on their own. At this time no cure exists. Life expectancy for someone with DMD is into the mid-20's. The only available medication is corticosteroid which only serves to slow the progression of the illness. Drug companies will not sponsor the drug for trial.

DMD has regrettably gone far too long without proper notice and attention that the disease needs. It is my hope that this resolution brings the proper awareness to the disease and shows the individuals and families suffering from DMD that Pennsylvania cares.

If you are interested in co-sponsoring this legislation, please contact Wendell Hannaford at 717-787-3525 or whannafo@pahouse.net

DEAN – BERKS COUNTY HOUSE DELEGATION, NORTHEAST AND CENTRAL PENNSYLVANIA CAUCUSES

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