

Roberta and Irwin Langewisch
85 Mary Ellen Drive
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February 15th, 2013

Appropriations Committee:

We are the parents of twin boys with Prader Willi Syndrome, a life threatening compulsive eating disorder with mild to moderate degrees of Retardation compounded with other health related issues.

Our son, Jonathan, lost his life and rights to enjoy the companionship of his twin brother Matthew and his family. He was only 22 years old at the time of his untimely death. He was placed in a group home thru a referral from DDS. Jonathan lived there for only 8 months until he died tragically due to abuse and neglect of the group home. The records show after two levels of investigative review that all Staff and the Director as well as the agency were cited for neglect for our son's death. Jonathan was left to die on a couch with no interventions when he complained of not feeling well on the morning of September 2, 2001. No one to comfort him. We will never forget the phone call " I have something Horrific to tell you! Your son Jonathan died an hour ago". At that moment the world stopped for us. We will never get over the unnecessary loss of our Son, Brother, Friend.

Matthew, the surviving twin, went into severe depression. He wanted to be with his Brother. As he tells me daily since that day, he only has half a heart because Jonathan was a part of him — "We're twins mom, we have a special connection".

That day in September changed our family. Matthew weighing 290 lbs in 2001 was in a downward spiral. He had numerous hospitalizations within a few months for behavioral issues and severe depression related to PWS, the loss of his twin and poor food management during his hospitalizations. His normal anxiety had escalated due to the CHANGES in his life.

Matthew needed specialized care for his PWS Issues. After numerous unsuccessful hospitalizations at Hallbrook, Norwalk and Yale New Haven Hospital in Ct, he was admitted to the Children's Institute in Pittsburgh, Pa.

He underwent a 2 1/2 month intensive treatment program which they specialize in for Prader Willi Syndrome patients. Matthew lost 95 lbs during his stay there. This was just the beginning of Matthew's Journey to a normal life expectancy. Upon his discharge per order of Ct Probate, DDS placed him in an Out of State Program at Gilbough/Latham Centers in Brewster, Ma. Connecticut had already proven to us that they were not capable of addressing the needs of our sons nor do they have

adequately trained staff to support a group home in Ct as the Latham Centers specializes in PWS Homes. Matthew has resided there for 11 years and continues to thrive every day. This is HOME to him. They are his extended family.

Matthew had his ups and downs when he first arrived there, but with their exceptional care, compassion and understanding of PWS, this agency has given Matthew the opportunity to grow among other PWS housemates and share in their experiences maturing as a family. This was an opportunity unfortunately his brother didn't receive living in a group home that did not specialize in this disorder. These clients do NOT benefit living with other eating disorder clients. Their issues are unique to Prader Willi Syndrome. It has been proven by my own deceased son's experience.

Matthew is in a good place now, happy, outgoing, and has gained self worth. He has maintained his weight at 138 lbs with the Impeccable care, dedication, encouragement and guidance provided to him by the staff and stability offered to him by his housemates with PWS. They look out for each other.

To move Matthew or the other 3 extended stay clients from Connecticut would be detrimental to the time and funding that has been invested in their care. Latham in Massachusetts has given them a life --- a life they feel good about.

Matthew is thriving and happy where he lives. He is finally at peace with his disorder. His only regret is that his brother, Jonathan, didn't get the opportunity to go with him. He still asks why and the answer is that Jonathan's death was his gift to him to get him the treatment and proper placement for Prader Willi Syndrome.

Matthew is no longer the outraged child with PWS; he has developed into a remarkable young man who has PWS and is with people who genuinely understand him. We are so grateful for that.

Moving these four long-term clients back to Connecticut will be more costly and detrimental to their wellbeing. Matthew has been there a third of his life and has a bond there that cannot be broken. He has lost so much in his lifetime, but has gained so much more as a resident at Latham.

On behalf of Matthew L, Matthew M, Bo J and Alexandra P. they plead with you to continue funding them in Massachusetts so they can continue to be successful in light of the challenges that face them daily with PWS.

Thank you,

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