

Dear

According to the March of Dimes and National Institute of Child Health and Human Development, 1 in 33 babies will be born with a birth defect. Vascular birthmarks, tumors or anomalies are considered a birth defect. These include hemangiomas, port wine stains, lymphatic malformations, venous malformations, arteriovenous malformations and other lesser known vascular lesions. While some are not fully present at birth, geneticists agree that the defect occurred in utero, therefore, deeming these lesions as birth defects.

The current Health Care Plan will have a serious negative impact on families like mine that have been affected by a vascular birthmark or anomaly defect. Currently, there are no standards of care for the treatment of these lesions. As a result we become medical nomads wandering from physician to physician to seek treatment. A high percentage of treatments are denied by insurance companies because they deem the treatment as cosmetic or not a medical necessity when in fact treatment is reconstructive and restorative.

We are robbed of the normal bonding experience because most of our early weeks and months of the birth of our child is spent seeking proper treatment and then fighting insurance companies to obtain the treatment. Some of us families have fought for years to get our baby the right treatment.

As our state representative, you have the power to ask for an amendment in the proposed Health Care Plan that will protect our babies. By seeking to define the treatment of these lesions as a “medical necessity” our babies will have a chance to look normal and to have a normal life.

We also seek to include all birth defects, vascular lesions, and craniofacial anomalies in this clause so that treatment cannot be denied and so that treatment is declared a medical necessity. In addition, the proposed Health Care Plan seeks to tax procedures deemed “cosmetic” or “elective” and many insurance companies have declared the treatment of these vascular tumors in infants to be “cosmetic” and the families have had to fight and appeal the denial. Since there are no standards of care for vascular birthmarks or tumors in this country, the advocacy groups that help us spend a lot of time fighting insurance companies. Think about it, if they are allow to call the treatment of our babies tumor a “cosmetic” procedure then we will not only have to pay cash to have the tumor removed but we will also be taxed. This is an outrage.

As our representative, we beg you to think through the proposed language in this health care plan and ask that you propose an addendum that will declare the treatment of all craniofacial anomalies and birth defects and vascular lesions in infants to be a medical necessity and not allow them to declare the procedure to be cosmetic and thereby impose a tax on removing tumors from infants.