

**Public Hearing of the  
Insurance and Real Estate Committee**

**February 10, 2011**

**Comment on:**

**Proposed S.B. No. 312**

**AN ACT ELIMINATING THE AGE CAP FOR HEALTH INSURANCE COVERAGE  
FOR SPECIALIZED FORMULA.**

**To eliminate the age cap for specialized formula covered under individual  
and group health insurance policies.**

**From the Jones family**

Good Day Chairmen, Committee Members, Ladies and Gentlemen

I appear today in support of Senate Bill 312, an Act to eliminate the age cap for specialized formula covered under individual and group health insurance policies. The current statute requires coverage for children up to age twelve.

*"Almost three years ago I appeared in support of a similar Bill. I find it more than a little sad that I have to make this plea again. I am sad because I have to argue the merits of a Bill that provides nutrition for children that face severe health problems without these formulas and I am sad that not much has changed for Eric.*

*Eric suffers from short gut syndrome as a result of having half of his small intestine removed at 6 weeks old. Originally totally breast fed, when his bowel was reconnected at 3 months old, a milk allergy manifested and he was placed on Infant Neocate. He was tube fed for 6 months: for weeks after his surgeries, he was limited at times to as little as a teaspoon of liquid by mouth every 3 hours.*

*As a result of his bowel loss he has problems absorbing nutrients including fat, salts, proteins and carbohydrates from food. He takes daily supplements including sodium, potassium and calcium as well as B<sub>12</sub> by injection to alleviate severe anemia. As fate would have it, Eric also has allergic gastroenteritis, food allergies including peanuts, tree nuts, peas and beans. He has asthma and any episode or a pneumonia that should be treated with antibiotics is regarded with dread, as he can lose as much as a pound a day as a result of intestinal distress - the weight loss is greater if he actually tries to take antibiotics.*

*Eric is now almost 5 years old. I have included a list of what he can and cannot eat in my written submissions – but his diet consists almost entirely of Infant Neocate, oats, rice, homemade applesauce, white meat chicken in limited quantities, organic bananas and grape juice. In case the significance is missed, he is still on formula designed for children under 1 year old because his system cannot efficiently breakdown anything more complex. As an aside, when Neocate was reformulated to make it easier to mix and taste better, it took 6 months to get him on the new version".*

That was taken from my statement of almost four years ago to the day.

Sadly, not much has changed. I sit here asking for the same assistance for my son, so that with every birthday closer to twelve I am not fearful of changes in insurance. One difference that I do not want lost on this committee is that now there are fewer of us to speak out: with age most children outgrow their need for Neocate.

However, some appear not to. My almost nine year old son is one of these – he is still on an infant formula meant for children under the age of one. I am here with a few other mothers – mothers of Niveah, Andrew and Olivia. These children are who we must focus on: medicine has saved and changed their lives: medical insurance is yet to catch up. Change to meet changing needs of 'advancing' society is an imperative.

I will be blunt in responding to some of the insurance companies claims:

- No, we are not simply sympathy seekers – all we want to be is treated fairly
- No, no one knows how long their conditions will last for: science suggested that this should have self corrected by age 2, then 3, then 4, then 5. No one knows what lies ahead.
- No, we are not asking the insurance company to pay for food. Surely a distinction must be made between **food** and **a source of nutrition**. Neocate is a source of nutrition.
- No, Neocate cannot be purchased over the counter: it is not available in CVS, Walgreens or Wal-Mart. I did buy it over the counter once from a pharmacy in Meriden – that was the only over the counter source State wide that I know of. They provided it in case of emergency - I resorted to that when my insurance company denied Eric's Neocate pending medical review. They should thank the pharmacy, because otherwise the insurance carrier would have had to pay for a hospital stay.

Of particular importance is the continued mantra of insurance companies that mandates increase premiums.

- HIPPA and medical privacy laws make it difficult to get exact numbers, very few children statewide are affected. At Connecticut Children's Medical Centre, only 15 – 25 children over 12 are on these formulas. Is that too great a burden to bear? Do these numbers reflect the likelihood of onerous increases?
- Increases in insurance premiums are driven by many factors – insurance companies should look to the other cause including massive bureaucracies first.
- Further, why should it take a mandate to require a company to pay for necessary treatment for a condition that is present at birth or that once acquired can only be controlled by prescriptions including elemental formulas? This is an argument that we should not be having.

This year the argument is compounded by the passage of the federal Patient Protection and Affordable Care Act. Insurance companies now argue that under the law the federal government will define a set of "essential benefits" that must be included in health plans sold in the exchange. Anything mandated beyond these "essentials" will further add to costs. As much of this Act does not take effect until 2014, I do not see that it is fair for bills such as SB 312 to be simply put on hold until then.

Contrary to the position of the insurance company lobby, the CT Mirror of 2/7/2011 correctly quotes State Senator Crisco co-chairman of this committee as saying that he *'would prefer to pass legislation that benefits people now and, if it conflicts with federal law later on, repeal it or make other changes then. If legislators avoid requiring insurers to cover benefits because of changes that will take effect in the future, people will lose out on protection in the interim. I can't consciously support that.'*

I hope that the co – chairman is accurately quoted as we literally cannot afford to wait and see

what happens.

Four years ago, when I last appeared before you, my family's insurance premium was \$1,129.35 per month, excluding a small subsidy my husband receives as a former employee of the Hartford Board of Education. This year we are paying \$1,667.00. The thought of paying this **plus** approximately \$700 per month **more** for Neocate is frightening.

As a family we would have to become more creative.

- It may become cheaper for me not to work or separate from Eric's father and have Eric covered by Husky or WIC – then the State would pay for it. Is that fiscal prudence?
- I understand that a co-chair on this committee – Representative Johnson – is on the Education Committee. My son has had a 504 Education plan since age 3. I do not demand services now, but maybe we will have to. Perhaps it is prudent for me to have his school and district cover some of the costs associated with feeding him.

What is of particular distress for me and others in my position is that we feel penalized for trying to have our children live as normal a life as possible. We fought to wean Eric off of a naso – gastric tube: we fight daily to get enough calories into him to avoid having to replace this tube. Insurance will cover anything that is feed through a naso-gastric tube including water. How does that make sense? The better he gets, the less the insurance company wishes to do for us.

Eric lives in Middletown. He goes to school at a charter school in Hamden and attends the Boys and Girls Clubs of Hartford. I say that to demonstrate that as a family we have chosen to sacrifice to do whatever is in his best interest mentally and physically.

We cannot shield our children from everything: Eric knows that he is different and knows that has physical limitations. I chose not to bring him today, particularly since you as a committee may be privileged to hear from older children. However I have included as part of this submission Eric's school assignment from June 2008. He writes about what he would if he were President. The last line says it all: at six years old he wanted to provide health care.

No one is asking for a hand out – we are asking for what is fair.