

COMMONWEALTH OF PENNSYLVANIA
HOUSE OF REPRESENTATIVES

CHILDREN AND YOUTH
COMMITTEE HEARING

STATE CAPITOL
HARRISBURG, PA

MAIN CAPITOL BUILDING
ROOM 8 E-B EAST WING

WEDNESDAY, MARCH 19, 2014
9:30 A.M.

PRESENTATION ON
HOUSE BILL 1436
AMENDING THE MEDICAL FOODS
INSURANCE COVERAGE ACT

BEFORE:

HONORABLE KATHY WATSON, MAJORITY CHAIRMAN
HONORABLE STEPHEN BLOOM
HONORABLE GEORGE DUNBAR
HONORABLE KEITH GREINER
HONORABLE FRED KELLER
HONORABLE JOHN LAWRENCE
HONORABLE DAN MOUL
HONORABLE DONNA OBERLANDER
HONORABLE TOMMY SANKEY
HONORABLE TARAH TOOIL
HONORABLE JESSE TOPPER
HONORABLE MICHELLE BROWNLEE
HONORABLE STEPHEN KINSEY
HONORABLE STEPHEN MCCARTER
HONORABLE DAN MILLER

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*Pennsylvania House of Representatives
Commonwealth of Pennsylvania*

ALSO IN ATTENDANCE:
HONORABLE DAN TRUITT

COMMITTEE STAFF PRESENT:
GREGORY GRASA
MAJORITY EXECUTIVE DIRECTOR, CHILDREN AND YOUTH,
RESEARCH
MEREDITH SCHULER
MAJORITY LEGISLATIVE ADMINISTRATIVE ASSISTANT
DONTIE BROOKS
MAJORITY RESEARCH ASSISTANT

ROSEANN CADAU
DEMOCRATIC EXECUTIVE DIRECTOR
HEATHER WALSH
DEMOCRATIC LEGISLATIVE ASSISTANT
VALERIE WHITNEY
DEMOCRATIC RESEARCH ANALYST

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SUBMITTED WRITTEN TESTIMONY

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(See submitted written testimony and handouts online.)

1 P R O C E E D I N G S

2 * * *

3 MAJORITY CHAIRMAN WATSON: All right. Ladies and
4 gentlemen, I think we're going to get started. Please
5 understand, we'll go off script if you will, but this is a
6 morning that has become very crowded with activities.
7 Please know that when we scheduled this, as Representative
8 Truitt knows, we went way far out so we would be the only
9 one. There are problems with an ethics training and all
10 kinds of things that demand Members' attention. You will
11 see Members perhaps come in; you will see Members leave
12 because one of the things we learned to do up here is to
13 juggle three or four meetings at a time, so we try to get
14 something.

15 So for those of you who are new to Harrisburg, we
16 are not inattentive. Everyone has gotten all the
17 information ahead of time, but I would admit, especially as
18 a former teacher and with younger students in the room, it
19 doesn't look as good as a classroom or a lecture hall for
20 those of you who went to college. But really, we are
21 paying attention so I do apologize.

22 You'll also note that when people couldn't find
23 this room, it's because this is a Senate room. We had to
24 get special permission as House Members to use this room.
25 So we're not usually in here, and all I can say is, wow,

1 they must be a lot taller or heavier because I feel like
2 I'm sitting in a little high chair and waiting to be fed.

3 So Members will be coming in. We are grateful.

4 To the Members, just to make sure, you should
5 have gotten a lot of the material ahead of time, but
6 everything is on that table there where Dontie is, so if
7 you would make sure you get copies of everything, that
8 would be important so that if you do leave, you take it
9 away with you and you can catch up. We would appreciate
10 that.

11 Now, for the formal part of the meeting, let's
12 begin. I'd like to welcome everyone to this hearing of the
13 House Children and Youth Committee. Now, this hearing is
14 being recorded, so we would ask Members and guests, would
15 you please silence all your cell phones and electronic
16 devices, whatever it might be, a game, a this, a that, who
17 knows in this day and age. But just make sure they don't
18 go off. We would greatly appreciate that.

19 And as everyone is now probably seated, I hope we
20 have enough, too. Senate Committees are also smaller than
21 ours, so you'll note we're scrambling to make sure
22 everybody has a seat. But our secretary, Mrs. Schuler,
23 would you please call the roll?

24
25 (Roll was taken.)

1
2 MAJORITY CHAIRMAN WATSON: All right. This is
3 indeed a hearing. I should've used my gavel at the
4 beginning to make it official. It's called to order. But
5 again, it's not a voting meeting. This is informational
6 for us to learn about a particular Bill introduced by one
7 of our colleagues, Representative Dan Truitt.

8 So we have the opportunity this morning then to
9 learn about the challenges that are faced by children and
10 really by their families when that child suffers from a
11 host of serious disorders. We are going to hear from the
12 families, we are going to hear from medical people, and of
13 course we're going to hear from the Bill's prime sponsor.

14 This Bill then proposes to assist families whose
15 children suffer from these digestive disorders by requiring
16 healthcare insurers to cover the cost of the amino acid-
17 based elemental formula that's necessary to treat the
18 disorders.

19 I would like to thank each one, those of you in
20 the audience, who are here to testify or came in support.
21 We thank you for taking the time to come to Harrisburg and
22 be with us this morning.

23 Again, I should note that our Democratic Chair,
24 Chairman Bishop, is on her way but may not make it before
25 the hearing is over but certainly has expressed to me her

1 interest in this issue, and I think for most of us,
2 Representative Truitt, it was a brand-new issue that we
3 just didn't know anything about. So you will see that
4 people are here to learn something more.

5 Our first testifier then, I sort of introduced
6 you already, but indeed, the prime sponsor of the
7 legislation, State Representative Dan Truitt from Chester
8 County, the 156th Legislative District. It's my
9 understanding, Representative Truitt, that you've been
10 involved in the issue for a long time because you and I
11 have talked and you've been explaining things to me. And I
12 think you'll give us some of that background of why you
13 introduced House Bill 1436, which would amend a statute,
14 and you also introduced House Bill 49, which was a
15 freestanding Bill. So you can explain what I call the
16 insider baseball of how we figure that will work, which
17 might work best, and we're glad you're here today to
18 explain the issue in some detail to your colleagues.

19 Representative Truitt.

20 REPRESENTATIVE TRUITT: Thank you, Madam Chair.
21 And I want to thank you and the entire Committee for taking
22 this issue up. I know this Committee has done a lot of
23 really great work this session and you've had a lot of
24 important issues to address, so I'm especially grateful
25 that you're able to work this in.

1 This legislation is kind of an example of some of
2 the good things that can come out of our door-to-door work
3 that we do in our districts. I have for at least 10 years
4 known a young man who is involved in a Scout troop that I'm
5 involved with who has some kind of an esophageal disorder
6 or food allergy that makes it so that he can't eat anything
7 at all. The only way that he gets his nutrition is through
8 a bag and it looks like a typical medical bag hanging on an
9 IV pole. Usually, it's hanging from his father's arm at
10 different times on camping trips and so forth. And I was
11 always struck by how well balanced this young man was and
12 how well he got by in society in spite of the fact, as you
13 all know, I mean we eat as a means of socialization and so
14 forth.

15 So I've known him for years and years but never
16 did it come up in conversation with that family how they
17 paid for the elemental formulas, these amino acid-based
18 elemental formulas that he takes in through a feeding tube
19 in his stomach.

20 And then back in 2012 I was going through one of
21 my door-to-door efforts I ran into a family who you'll hear
22 from shortly, Mrs. Harris mentioned to me, asked if I had
23 any awareness of elemental formulas and how they're paid
24 for with insurance. And I said, no, I really didn't and
25 she gave me an education and told me how -- I already knew

1 that there's a lot of children that need these formulas to
2 survive, but what I didn't know was that insurance
3 companies weren't always covering the cost. And I'm sure
4 we'll hear a little bit later on about the cost. It's
5 extremely expensive for families to cover the cost of these
6 elemental formulas.

7 And what surprised me was the children that have
8 these disorders can either take these elemental formulas
9 through a feeding tube or they can take them orally. And
10 another thing that I did know was that children with this
11 disorder or these disorders will gradually over time try
12 different foods. They conduct somewhat risky experiments.
13 They'll try, let's see if we can eat cantaloupe, and if
14 that works out okay, then they can continue eating
15 cantaloupe, but it's a very slow, very gradual process to
16 find out what foods they can and what foods they can't eat.

17 And what Mrs. Harris explained to me and we'll
18 hear more about it in cases where a child is taking these
19 elemental formulas orally instead of through a feeding
20 tube, insurance companies would say, well, we don't have to
21 cover that because we only cover it if it's administered by
22 a feeding tube. And if you think about what that
23 encourages a family to do, that encourages them to go and
24 have an invasive medical procedure performed so that they
25 can get the cost covered if that's the only way they're

1 going to be able to cover it.

2 Another reason why insurance companies might not
3 cover the cost of these formulas is if the child can eat
4 something else, maybe they can eat cantaloupes. They have
5 other options, other things that they can eat. But it's
6 not realistic to expect them to only eat the few things
7 that have been identified as those things that don't
8 trigger an allergic reaction.

9 So she expressed to me a need for someone to
10 introduce a Bill. And I said you don't have someone to
11 sponsor that Bill? I'll be happy to do it. So as soon as
12 we came back at the beginning of this session I introduced
13 House Bill 49. House Bill 49 was a standalone Bill that
14 simply said that an insurance company will cover amino
15 acid-based elemental formulas for children with esophageal
16 disorders, and it listed a couple other disorders, whether
17 or not they're receiving these formulas orally or by a
18 feeding tube, and as long as a doctor says it's medically
19 necessary, the insurance companies should cover it. This
20 was a standalone act.

21 Now, I'm going to go back to my comment about
22 going door-to-door. So I'm out going door-to-door again
23 and I ran into another family who asked me what I knew
24 about something called PKU. And I didn't know anything
25 about it so I said, well, let me look into it and get back

1 to you. And I came back and I did some research and found
2 out, well, how about that? We already have a law in place
3 that says that insurance companies have to cover amino
4 acid-based elemental formulas for children with PKU. And
5 don't ask me to pronounce what PKU is. I mean it's a very
6 long word. But it's another food-based allergy or disorder
7 that prevents people or children from eating a lot of
8 different things and so they have to take these amino acid-
9 based formulas.

10 And so we have a law in place that already says
11 the insurance companies have to cover that. So we found
12 that it was very easy to then take that law and modify it
13 and add esophageal disorders and other food-based disorders
14 just to broaden the language so that we don't have people
15 falling through the cracks because their disease doesn't
16 happen to be the exact one that's enumerated in State law.

17 So that's the genesis of House Bill 1436, which
18 is the one that I'm hoping you'll be willing to advance to
19 the House Floor sometime in the near future. And I really
20 don't want to get into too much more detail than that. I
21 can't explain this nearly as well as the families can, but
22 I will say, after the hearing today, if you have any
23 followup questions, please don't hesitate to track me down
24 on the House Floor or in my office. I'll be happy to do
25 the research and find out anything that you need to know.

1 Again, I just want to emphasize the beauty of
2 this is we're taking an existing law and simply tweaking it
3 so that children with esophageal disorders don't fall
4 through the cracks and end up not having insurance coverage
5 for something that's very expensive for the family and the
6 cost for the insurance companies is trivial.

7 So thank you, Madam Chair. I appreciate your
8 willingness to hear this subject and consider it for a
9 vote.

10 MAJORITY CHAIRMAN WATSON: All right. Briefly,
11 any questions for Representative Truitt or would you like
12 to get to more -- not that it's not important, Dan, but you
13 know what I mean---

14 REPRESENTATIVE TRUITT: I'm not the main event
15 here.

16 MAJORITY CHAIRMAN WATSON: Right, the medical
17 basis and certainly the anecdotal evidence from the
18 families. That was a loaded way to get you not to ask
19 questions, wasn't it? I need to be more skillful, yes. I
20 have to work on that.

21 All right.

22 REPRESENTATIVE TRUITT: Great.

23 MAJORITY CHAIRMAN WATSON: Thank you very much,
24 Representative Truitt.

25 REPRESENTATIVE TRUITT: Thank you.

1 MAJORITY CHAIRMAN WATSON: We're trying to keep
2 to a schedule because we know we're going to push against
3 the time when we have to be on the House Floor.

4 Our next testifier -- and please know, they use
5 the word "testifier" but to all of you who are new here,
6 they call it a hearing but it's not like what you see on
7 television. I would call it better information gathering,
8 background material on the Bill, and understanding for the
9 Members what they see in print, what was the genesis, why
10 would this be something that would be important, especially
11 on a topic that many of us know very little about.

12 So I'm happy then to introduce Dr. Terri Brown-
13 Whitehorn, Associate Professor of Clinical Pediatrics at
14 the Perelman School of Medicine at the University of
15 Pennsylvania -- I went there -- in the Division of Allergy
16 and Immunology at Children's Hospital of Philadelphia.

17 Dr. Brown-Whitehorn, we certainly welcome you and
18 please begin when you are ready and try to educate us.

19 DR. BROWN-WHITEHORN: So first off, I'd like to
20 thank you, Chairman Watson, for having me here, and I'd
21 also like to apologize for my typo with House Bill.
22 There's a correction. I wrote 1438. It's supposed to be
23 1436, so I do really apologize.

24 Anyway, I am a pediatric allergist, as she said,
25 at CHOP and I've been asked to speak to you by members of

1 the MAGIC or Milk Allergy GI Coalition, who has worked long
2 and hard to support this Bill or Bills like this and to
3 support the goals set forth in the Bill. I spend most of
4 my time seeing patients. I also teach. I educate
5 residents and fellows, and I'm not so used to educating you
6 guys but I'm happy to do so. I also spend time writing and
7 speaking mainly to physicians and raising awareness about
8 food allergies.

9 But when people think about food allergies, most
10 of you probably think about the immediate kinds of food
11 allergies. A child has a peanut allergy, they eat a food,
12 they end up in an ER because they have swollen lips,
13 breathing problems. But I think my job today is to tell
14 you, sure, that is very important and I'll educate you a
15 little bit about that, but there are other health
16 conditions in which foods play a major role. My goal this
17 morning is to review the different types of food allergies
18 that you may not know so much about, the role of elemental
19 formulas, and most importantly, how you can help by
20 supporting the passage of House Bill 1436.

21 So food allergies affect anywhere from 4 to 8
22 percent of the general population. It's much higher in the
23 younger age groups because some of the children will
24 outgrow food allergies as they get older. Interestingly,
25 though, we just looked at how many kids come to Children's

1 Hospital of Philadelphia and actually how many kids
2 actually have food allergies. They're not all coming
3 because of food allergy; they may need surgery, but they
4 have to mention what they're allergic to.

5 So if we look at that data over a 12-month
6 period, we saw 41,977 people, and that's a lot of course,
7 in whom they had some sort of food allergy. And if you
8 look at that number and then we ask the question what are
9 you allergic to, 8,300 patients, they're individual people,
10 actually have a milk allergy. So it's a very high number.

11 Thankfully, not all patients who have these food
12 allergies need special formulas, but for those who do,
13 there's really no other alternative. These nonallergic or
14 less allergic or nonallergic formulas contain broken-down
15 proteins which are amino acids, fats, and carbohydrates
16 that allow these children to grow and thrive, which is why
17 it is imperative for these special formulas to be covered
18 by insurers who provide health coverage in the
19 Commonwealth. Interestingly, these formulas are already
20 covered by Medicaid and by WIC.

21 So what are different types of food allergies and
22 why would I as an allergist or representing my colleagues
23 in GI or pediatrics actually recommend these formulas? So
24 I thought I'd go over five conditions. So the first
25 condition is IgE mediated food allergy. As an allergist,

1 we divide it into what happens when your body eats the
2 food. So with the IgE mediated food allergy is a child
3 will eat the food and then immediately develop hives or
4 swollen lips, breathing problems, vomiting. Those
5 conditions, they're treated with epinephrine, and
6 oftentimes we are successful, although we do know that
7 children can die of these conditions and some do every
8 year.

9 Luckily, most children don't die and the families
10 are told and the children are told to avoid the offending
11 food. We know that 90 percent of these foods, 90 percent
12 of the time it's caused by certain foods, so milk, egg,
13 soy, wheat, peanut, nuts, and fish cause the majority. And
14 if a child has multiple food allergies in which they could
15 have life-threatening reactions that are immediate,
16 especially in the younger age group especially with milk
17 and soy, we prescribe an elemental formula.

18 There's another condition which many of you may
19 or may not know about, which is eczema. So eczema is a
20 really itchy disorder of the skin that babies present with
21 very red. It's very itchy. It's all over their body and
22 about 1/3 of the babies who have severe eczema can have a
23 food allergy, and for those children, I'll also prescribe
24 those elemental formulas.

25 I'm going to switch gears and talk a little bit

1 about the GI food allergies. So I personally want all of
2 the food allergies to be covered, but we'll start with food
3 protein colitis. So maybe some of you have babies who have
4 this or know people who do, but it's very common. It's
5 seen often in the pediatric office. A baby will present
6 with diarrhea, blood, or mucus in the stool, and most
7 often, it's related to milk or soy. So either the baby
8 comes in and they've ingested it directly or the moms are
9 eating and then they need to remove the food. If we're
10 unsuccessful and the baby has persistent blood or mucus in
11 the stool, then sometimes we'll prescribe an elemental
12 formula.

13 The next condition is called food protein induced
14 enterocolitis. Different people say FPIES. Different
15 people say FPIES. But this is a different GI food allergy
16 and we see a lot of patients with this condition. It's not
17 that common. I think partly we see a lot of it is because
18 we're a referral center. But anyway, these children will
19 eat a food and then two hours later usually, so they eat
20 the food, they seem perfectly fine, two hours later they
21 throw up so much they can't stop. Some of these babies
22 become quite lethargic. They look like they're in shock.
23 As medical personnel, you're not sure if they have a really
24 bad infection but oftentimes or sometimes it is related to
25 a food allergy.

1 Some of these kids will go on to develop severe
2 diarrhea and there is another subset of kids who have a
3 more chronic condition where they have chronic diarrhea,
4 chronic failures to thrive. And shockingly, it's related
5 to an underlying food allergy. So you have milk, two hours
6 later you're really sick. You have rice, two hours later
7 you're really sick. And these are happy babies who are
8 suddenly very ill appearing.

9 So overall, the treatment is for us to try and
10 figure out the food and then have the families avoid the
11 food of concern. We recently published a paper in which we
12 described 380 kids with this condition: 38 percent reacted
13 to milk, 24 percent reacted to soy, and 1/3 reacted to
14 both. And when we reviewed these data even more carefully,
15 about 1/3 of those kids actually needed to be on an
16 elemental formula. And about 5 percent of these patients
17 have to avoid multiple foods. So these kids, they need to
18 grow somehow, and these formulas provide the way in which
19 they can grow.

20 And finally, and certainly not because it's the
21 least, we have a center in which we take care of children
22 with eosinophilic disorders. So what is that? Eosinophils
23 are allergy cells that everyone has if they have allergies.
24 If you had them localized to your esophagus, it's related
25 to a hidden food allergy. And you'll hear from a variety

1 of families, these kids present typically with severe
2 reflux, so a lot of vomiting, and you put them on reflux
3 medicines and they don't get any better.

4 So babies typically present with vomiting,
5 reflux, growth concerns. Children who are a little bit
6 older can also have this condition and also present with
7 reflux symptoms but they tend to have a bit more abdominal
8 pain and they can tell you what they feel like. And then
9 teenagers can also present with this condition, and it can
10 actually happen at any age, but teenagers tend to present
11 with problems swallowing or actually food that gets stuck
12 in their esophagus and they can have abdominal pain.
13 Interestingly, the food that gets stuck in their esophagus
14 is not necessarily the cause of the condition, so there may
15 be a piece of chicken stuck, and over time, we're able to
16 find that it's related to a hidden milk allergy. So it's
17 kind of interesting.

18 We have the largest center in the country with
19 this. We see about 1,500 patients with this. A smaller
20 percentage of patients do have eosinophils throughout their
21 GI tract and about 20 percent of kids need elemental
22 formulas either as their sole source of nutrition, which is
23 much smaller, or when we find out what foods kids are
24 allergic to, they may need to cover part of their
25 nutrition.

1 So what are our obstacles for getting elemental
2 formulas covered by insurance? We'll switch to that.
3 Despite the fact that these children are prescribed these
4 formulas, some families must struggle, and you're going to
5 hear about it, to get these formulas covered. Why? I
6 think because they're expensive and one's insurance may not
7 cover it.

8 But I think we need to weigh the risks versus
9 benefits of coverage. The risk is ill children not growing
10 and without proper nutrition. There are concerns with
11 slower brain development. They can have chronic symptoms,
12 and then if they're sick, they're going to end up in the
13 hospital, and if they're in the hospital, they're going to
14 end up costing the insurance companies money.

15 But with that said, the benefits you'll see are
16 children who are growing, developing normally, and
17 thriving. But the stipulation still remains. So some of
18 the things we've heard and some of the families will
19 discuss this as well, the insurance will only cover kids up
20 to a year of age. So what am I supposed to do when
21 somebody's 15 months of age who still needs formulas?

22 They'll only cover certain diagnoses so they
23 won't necessarily cover GI. They'll only cover formulas if
24 they're fed by a tube. Now, these formulas are not the
25 most tasty things. I don't know if these companies are

1 here or not. So it's not like people are going to stand in
2 line to drink them. But when we can get a child to drink
3 them, we'd much rather them use their mouth as opposed to a
4 tube that goes through their nose or a tube in their
5 stomach. And sometimes they won't cover it because it's
6 not a real medicine.

7 But as a physician, it would be really great if I
8 could say I think this patient needs this, we write a
9 script, and it's covered. Unfortunately, that doesn't
10 happen. So letters need to be written, prior
11 authorizations need to be completed, and sometimes we'll do
12 peer-to-peer reviews. I'm very lucky; I have a
13 nutritionist who helps me, staff who helps me, a medical
14 assistant who helps me. But what if the insurance company
15 says no and there's no one to help them appeal? And that's
16 where you guys, you guys can help.

17 So we need your help, the Children and Youth
18 Committee, to ultimately support the passage of House Bill
19 1436. As physicians, we do our part. We are judicious in
20 prescribing these formulas. We know they are costly but we
21 see their benefits. We take care of the patients. We see
22 the before and after. We see the improvement in symptoms
23 and quality of life.

24 There are similar Bills in other States that have
25 passed and are now law and I see no reason why this cannot

1 happen in the Commonwealth of Pennsylvania.

2 Thank you.

3 MAJORITY CHAIRMAN WATSON: Doctor, thank you very
4 much. I think what we will do in the interest of time and
5 we're moving along, if the Members can wait, we will hear
6 from the families and then I think collectively between you
7 and the families if we have questions. And I'm honestly
8 not sure -- it's so new and different -- whether we're
9 going to have a lot of questions or we're really taking in
10 the information and just want to let it digest. But we may
11 ask you to just move right there by Mr. Truitt would work
12 and we will talk to four different families, very nicely
13 done, too. I know Representative Truitt worked on this
14 from four different counties in the Commonwealth of
15 Pennsylvania.

16 First, if we would, could we be joined by Suzanne
17 and Steve Harris and their sons, Dean and Cole, definitely
18 the best-dressed men so far that I've seen in the room. I
19 will let you decide who goes first, and if we hear from all
20 of you, we would be delighted.

21 MS. HARRIS: I'll go first. First, thank you,
22 Chairman Watson, for the opportunity to speak with you and
23 the other Members of the Children and Youth Committee.

24 My name is Suzanne Harris. I live in West
25 Chester, Pennsylvania, in the 156th District and I am the

1 mother of Dean, who is 11, and Cole, who is 10.

2 I am here today because elemental formula must be
3 covered by all insurance companies in the State of
4 Pennsylvania. Without this coverage, families struggle
5 emotionally and financially because they can't afford to
6 give their children the medicine that they need. I don't
7 want anyone to ever go through the experience that I'll
8 share with you today.

9 Dean and Cole were born with eosinophilic
10 esophagitis, a disease that is triggered by a type of a
11 food allergy. I have seen my children suffer more than any
12 parent should: hemorrhaging, vomiting, choking, frequent
13 infections, bouts of respiratory distress, and deemed
14 failure to thrive. On the date of our second wedding
15 anniversary when Cole was just 8 weeks old, I was home
16 alone with both of my babies. My already sick infant was
17 on a feeding tube and he just stopped breathing.
18 Everything stopped. I performed CPR and I called 911 but I
19 continued to live in fear.

20 For years, we lived, we slept, we lived, even
21 celebrated holidays in a children's hospital in Atlanta,
22 Georgia. Our lives were filled with doctors, drugs, and
23 despair. When my husband, Steve, and I finally learned
24 that the boys had eosinophilic esophagitis, we moved to
25 West Chester, Pennsylvania, to be close to the Children's

1 Hospital of Philadelphia and the Center for Pediatric
2 Eosinophilic Disorders. We wanted to give Dean and Cole
3 the very access to the very best care for their disease.

4 And so began years of removing food from their
5 diets followed by surgical biopsies every eight weeks, all
6 with general anesthesia, surgery every eight weeks. We
7 said goodbye to nearly every food you can think of but the
8 biopsies kept coming back bad. Worse than that, our boys
9 were still sick.

10 When our doctors finally said it was time to
11 start elemental formula, Steve and I adamantly refused. I,
12 like many people, couldn't imagine how I would suddenly
13 remove all food or how this could be our only option but it
14 was our only option. I also knew that most insurance
15 companies denied coverage of this formula, and to be quite
16 honest, I feared financial ruin. I hated that Steve and I
17 had to even think about money. This was about saving Dean
18 and Cole but this was our only option. But I wondered how
19 we could provide for their other medical needs without
20 financial stability.

21 No parent would elect to take away food from
22 their children and replace it with formula unless it was
23 their only hope. Being forced to make this decision is
24 hard enough. Combining this with the stress of insurance
25 appeals and mounting financial debt makes an already

1 traumatic experience that much more unbearable.

2 Dean and Cole started elemental formula in
3 November of 2010 and they chose to drink it by mouth. For
4 their first formula meal, I thought we could still sit
5 around the family table at dinnertime like a normal family
6 would. I prepared bowls of ice chips and set them at our
7 four place settings along with Dean and Cole's boxes of
8 formula. Our tears melted the ice chips faster than anyone
9 could eat them. Steve and I cried watching our boys
10 unsuccessfully choke down the formula. Our boys cried at
11 the taste, a taste that they would be forced to endure for
12 as long as it took to work. After that night, Steve and I
13 did not eat in front of our children. We ate at work or we
14 ate hiding inside of a closet.

15 My fear came true. Our insurance company denied
16 coverage. We incurred an incredible amount of debt. I
17 spent countless hours and weeks on the phone with our
18 insurance company fighting our case. Over time, I won.
19 But we're only one family. What about the other families
20 spending countless hours, often in vain, advocating for
21 their children? These are hours that could be better spent
22 volunteering in grade school classrooms or going on family
23 bike rides.

24 Today, neither Dean nor Cole need elemental
25 formula and they will likely never need it again. Dean

1 needed it for about eight months and Cole needed it for
2 about 14 months. But elemental formula was the only way
3 that our boys stabilized. Through elemental formula, their
4 biopsies came back normal; their symptoms disappeared; they
5 are back within the average ranges on the growth charts.
6 Their deprived bodies were finally able to receive the
7 nutrition that they desperately needed. This formula is
8 the only choice some families have, and in the State of
9 Pennsylvania, we're talking about only 1,000 families.

10 As a parent of chronically ill children, I have
11 many fears. Today, though, I'm asking for your help and
12 that financial ruin is one of them. Today, I'm asking that
13 you please support House Bills 49 and 1436.

14 Thank you.

15 MAJORITY CHAIRMAN WATSON: Mr. Harris, you're up
16 next, I think.

17 MR. S. HARRIS: Do I have to follow that act?

18 MAJORITY CHAIRMAN WATSON: I suspect you've been
19 following it a long time, Mr. Harris---

20 MR. S. HARRIS: The story of my life.

21 MAJORITY CHAIRMAN WATSON: ---and it's a nice
22 story.

23 MR. S. HARRIS: It is.

24 MAJORITY CHAIRMAN WATSON: I'm sorry. I'm in the
25 wives union no matter what but there you go.

1 MR. S. HARRIS: Thank you, Chairman Watson, for
2 the opportunity to speak to you and other Members of the
3 Children and Youth Committee.

4 I'm here to tell you that this disease may not be
5 prevented, but the pain and suffering insurance companies
6 cause families can be prevented. It must be prevented.

7 There are many challenges a family experiences
8 when a child is chronically ill. In fact, I live through
9 them every day. There are good days and there are bad
10 days. As a father, there were two things I never imagined
11 having to explain to my child: first, that he couldn't
12 eat; and second, that he couldn't play.

13 After many medical procedures and removing nearly
14 every food from their diets, I had to tell both my boys
15 that the food they were eating was so harmful that they had
16 to stop eating food. Instead, their only option was a
17 foul-tasting formula that they would have to drink for
18 breakfast, lunch, dinner, and any other snack time that
19 would give them the proper sustenance. This was not my
20 choice. This was their only hope.

21 As an athlete, father, and the coach of my boys'
22 Little League baseball team, I have been devastated to see
23 my son, Dean, sit on the bench because he had braces on his
24 legs or fractures as a result of this disease. Many people
25 tend to think of this as just an allergy or a

1 gastrointestinal issue. This disease, and truthfully all
2 types of severe allergies, is a nutrition issue, as
3 Dr. Brown-Whitehorn just explained to you a little bit
4 earlier.

5 Because of the lack of calcium sources in his
6 diet and the impact of so many medications, Dean suffers
7 from bone health issues. He has suffered too many
8 fractures. I have coached too many seasons without my
9 favorite player on my team. Dean has missed too many gym
10 classes and has spent too many days watching his brother
11 and his friends play outside.

12 I wish I could say that was all that consumed my
13 worries, fears, and disappointment. It gets worse. Over
14 the years, I wanted so badly to spend more time with my
15 boys by their hospital bedsides, but I couldn't, because
16 the only lifeline we had was my job and my insurance
17 company. I had the most expensive insurance policy money
18 could buy, yet my provider still declined to cover my boys'
19 medical nutrition. And so my wife and I entered a 10-week
20 battle explaining to our insurance company that the formula
21 was the only option that they had for eating. This formula
22 was the cheapest and least invasive option for both the
23 insurance company and my family. The alternative is
24 countless emergency room visits. It's really a win-win
25 situation for both parties.

1 We ultimately got it covered, but we were the
2 exception. There are insurance companies that won't cover
3 this formula, and the ones that do can change their
4 policies at will, forcing families to quit their jobs,
5 relocate, or work more hours.

6 This is a complex and serious disease. It cannot
7 be prevented. But the least invasive and most cost-
8 effective solution is elemental formula. There are no
9 other options. Yet insurance companies today, refuse to
10 cover it and force families to spend months struggling and
11 fighting to feed their children, to get what they need to
12 survive.

13 Parents of sick children can never stop fighting
14 for a better life for their kids. But with your support of
15 House Bills 49 and 1436, we won't have to fight so hard to
16 feed them.

17 Thank you.

18 MAJORITY CHAIRMAN WATSON: Thank you, Mr. Harris.
19 I think you did admirably batting second there, but I
20 suspect we have some gentlemen to hear from.

21 MR. D. HARRIS: Yes.

22 MAJORITY CHAIRMAN WATSON: Whenever you're ready,
23 sir.

24 MR. D. HARRIS: First of all, I want to thank
25 Chairwoman Watson for allowing me to speak today.

1 Hello. My name is Dean Harris. I'm 11 years old
2 and I live in West Chester, Pennsylvania. My brother and
3 I, Cole, have a rare disease called eosinophilic
4 esophagitis. I'm here to explain that elemental formula is
5 a medicine, a medicine that I needed to survive.

6 I was born with eosinophilic esophagitis. When I
7 was younger, I was sick and in the hospital all of the
8 time. None of my doctors knew what was wrong. My mom and
9 dad took turns staying overnight in the hospital with me,
10 but I missed my home, I missed my friends, I missed family
11 celebrations, and I missed playing outside. I missed a lot
12 of things kids get to do.

13 When the doctors finally figured out that Cole
14 and I have this disease, we had to leave our home in
15 Atlanta and move to Philadelphia. My mom and dad said Cole
16 and I would have better doctors there. I don't think I was
17 really sad to move, because I didn't spend much time in my
18 home. I was always sick and since my Nana and Poppy lived
19 in Philadelphia, it seemed like it would be an okay place
20 to live.

21 The doctors in Philadelphia were fine, but in
22 order to figure out what was making me sick, my parents
23 kept removing food from my diet. I was and still am the
24 kid at the birthday party who can't eat the pizza, chicken
25 fingers, the cupcakes, the soft pretzels, or the popcorn.

1 I can't even eat the veggies with the dip.

2 Every time my parents removed a certain food, I'd
3 wait a few weeks, then have a biopsy. Surgery was hardest
4 when I was really little. I was pretty scared on surgery
5 days. As I got older, I just got used to it. But my
6 biopsies kept coming back bad.

7 Pretty soon, there were very few things I could
8 eat, barely anything, really. I wasn't growing as well as
9 the other kids and I started to have problems with my
10 bones. I had to quit baseball and I couldn't play outside
11 with my friends. I even had to wear braces on my legs.

12 When I was in second grade, I had to stop eating
13 all food. My doctors could not figure out the foods that
14 were making me sick. I was only allowed to drink elemental
15 formula and suck on ice chips and Dum Dums lollipops. I
16 can tell you that this formula smells and tastes like
17 vomit. If you don't need it, you would not want it. The
18 first time I drank it, I was sitting at my kitchen table
19 with my family. We were all crying. I did my best to chug
20 it down but it tastes so bad I threw it up all over the
21 kitchen table. But I quickly had to get over the gagging.
22 This formula was the only thing my body would accept.

23 For the next several months, I had to drink seven
24 boxes of formula a day. I figured out that if I held my
25 breath and drank as fast as I could, I usually finished the

1 box without getting sick. And my mom always gave me two
2 Dum Dums lollipops when I finished, which gave me something
3 to look forward to when I was drinking the stuff.

4 On school days, I had to go back and forth to the
5 nurse's office to drink the boxes of formula. I was up and
6 down all day. The nurse had to monitor that I drank it all
7 because, again, it was way too easy to throw it up or throw
8 it in the trash. She had to help make sure I was receiving
9 adequate nutrition.

10 Most of the kids at school were nice to Cole and
11 I, but there were bullies. These people told us our food
12 was weird and our disease made us weak. Sometimes we were
13 the last kids picked for the kickball games at recess.
14 Some would even dangle food in front of us and tease us,
15 telling us that we would never eat. One day a boy was
16 being mean to Cole. When I told this boy to leave my
17 brother alone, he told me he could do whatever he wanted to
18 do, including eat a sandwich and that eating a sandwich is
19 something that Cole and I will never be able to do.

20 After about eight months of elemental formula, I
21 was able to find enough safe foods and I could stop
22 drinking the formula, the medicine I needed to survive. I
23 hope I never need it again. Elemental formula gave me what
24 I needed to get better. I didn't like it. Of course I
25 want to eat the pizza, chicken fingers, the cupcakes, the

1 soft pretzels, and the popcorn, even the veggies with the
2 dip. But the formula was my only option. It was the only
3 thing that worked.

4 Elemental formula gave me what I needed to help
5 me live a better life. Please support House Bills 49 and
6 1436 so that it is easier for families to afford the
7 elemental formula.

8 Thank you.

9 MAJORITY CHAIRMAN WATSON: Dean, thank you. You
10 did a really good job. We have grownups who come and
11 testify and talk to us; they do not do as well or look as
12 great in a tie. So we thank you.

13 MR. D. HARRIS: Thank you.

14 MAJORITY CHAIRMAN WATSON: Now, Cole, are you
15 letting Dean speak for you?

16 MR. C. HARRIS: Yes.

17 MAJORITY CHAIRMAN WATSON: You are? Okay. All
18 right. Well, did you think he did a nice job?

19 MR. C. HARRIS: Yes.

20 MAJORITY CHAIRMAN WATSON: Yes, not bad. I think
21 we would say that he did a good job.

22 Mr. Harris, that's the tough act to follow.

23 And sadly, if we would ask, let's see, Jessica
24 and Ryan Pheasant, they get to come next and they're from
25 Snyder County. And I think that is important to reiterate

1 that we have folks from all over the Commonwealth while
2 statistically, from what the doctor has said, this is a
3 very small number of children and families who live with
4 this disease. Let no one think they're not spread out all
5 over. And I think it's interesting that we had folks who
6 lived in Georgia who move to Pennsylvania because of the
7 work of Children's Hospital of Philadelphia. We've always
8 heard that but it was interesting to see some folks live.

9 Mr. and Mrs. Pheasant, please begin. You are
10 most welcome to be here.

11 MS. PHEASANT: Thank you and good morning. And
12 thank you, Chairwoman Watson and everyone, for allowing us
13 this opportunity.

14 My name is Jessica and this is my husband Ryan
15 Pheasant. We are here today on behalf of our son Oden and
16 all the children in Pennsylvania who depend on amino acid
17 elemental formulas to live, asking that you please pass
18 this Bill. This formula is not a choice for us; this
19 formula is what our son needs to survive. Every day this
20 Bill doesn't pass is another day a family worries about how
21 they will pay to keep their child alive.

22 Our son Oden was born in September of 2012 and it
23 was the happiest day of our lives. Oden is a very happy
24 baby that is full of personality. He loves animals,
25 football, and people. He also suffers from FPIES, food

1 protein induced enterocolitis syndrome.

2 We had trouble with food from day one. We
3 decided to breastfeed because of all the touted health
4 benefits. However, Oden was losing weight when he should
5 have been gaining it. In the first three months of Oden's
6 life, he was in and out of the hospital, went through a
7 procedure, a surgery, and tried many formulas. But still,
8 something was wrong. At one year of age we finally had an
9 answer to what was going on. Oden was diagnosed with a
10 food protein allergy called FPIES.

11 Oden tried and failed many formulas. I feel like
12 we tried them all. He would have terrible rashes covering
13 his body, would scream in pain, vomit, experience
14 dehydrating diarrhea, and have bloody stools. But then we
15 found our miracle. He was prescribed EleCare. The rash
16 receded and the vomiting and diarrhea stopped, and once
17 again, we finally had our healthy baby back. EleCare
18 solved our son's health problems. It was magical.
19 However, this formula carries a hefty price tag. Our
20 battle for a diagnosis quickly became a battle to cover his
21 formula.

22 Because he's on such a limited diet Oden gets the
23 majority of his nutrients and calories from amino acid
24 elemental formula. This is a hypoallergenic formula that's
25 extremely expensive and I cannot purchase it at the

1 supermarket. I need a prescription and I need to go to a
2 pharmacy or a specialty medical healthcare service store to
3 get his formula. It's not an option; it's a necessity for
4 him to live, just as insulin is a necessity for diabetics.

5 I don't know how long we're going to be on this
6 formula. I wish I did. I wish that he would outgrow this
7 allergy tomorrow, but until that happens, he needs this
8 formula to give him the calcium, the fats, proteins,
9 nutrients, vitamins, and all the essential items his body
10 needs that he is not getting from food because Oden's body
11 cannot handle the food; his body rejects it.

12 Even with a diagnosis, our emotional roller
13 coaster continues. We're concerned he's going to
14 accidentally consume a food that's extremely harmful, and
15 we fear that our insurance company will deny the coverage
16 of the formula, leaving us and our finances at their mercy.

17 My son can only safely consume eight foods.
18 Eight. You see, Oden is allergic to many foods: milk,
19 soy, rice, chicken, bananas, peas. The list goes on and
20 on. We, along with all the other families, exhausted every
21 other formula possible before going to these amino acid
22 formulas, and honestly, we want nothing more than for our
23 child to be able to eat whatever he wants and drink a big
24 glass of milk. If Oden did not have EleCare, he would not
25 have the nutrients needed for his brain to develop, his

1 muscles to grow, and in short, for him to survive.

2 For children with FPIES, the long-term prognosis
3 is bright and we're hoping that by five he's done and he
4 will outgrow all of this. But it's the first five years
5 that are heartbreaking and difficult. The slightest bite
6 can cause him to get a rash or get eczema, vomit, be in an
7 incredible amount of pain, suffer from dehydrating
8 diarrhea, and more.

9 I am blessed because for the next three months we
10 received approval from our insurance company to cover the
11 formula but it was a battle. And every three months they
12 hold all the cards and they decide whether to approve or
13 deny that coverage again and so continues the battle.

14 I urge you to please support House Bill 1436 for
15 the children like Oden and for their families who suffer
16 from conditions that require them to consume an elemental
17 formula so that they may live, thrive, and grow up to
18 become successful, healthy adults.

19 I thank you for your time and your consideration
20 on this House Bill. Thank you.

21 MAJORITY CHAIRMAN WATSON: Thank you very much.
22 If you can just slide over, we have Andrea Nicole Falzone
23 from Centre County.

24 MS. FALZONE: Good morning.

25 MAJORITY CHAIRMAN WATSON: Good morning. And the

1 gentleman with you?

2 MS. FALZONE: This is my husband.

3 MAJORITY CHAIRMAN WATSON: That's what---

4 MS. FALZONE: This is Ryan Sprang.

5 MAJORITY CHAIRMAN WATSON: ---I was thinking.

6 Okay. Very good.

7 MS. FALZONE: Thank you.

8 MAJORITY CHAIRMAN WATSON: Welcome, sir. We're
9 glad that you are both here.

10 MS. FALZONE: Yes.

11 MAJORITY CHAIRMAN WATSON: And you're going to do
12 the speaking for the two of you.

13 MS. FALZONE: We're both going to do the speaking
14 if that's okay.

15 MAJORITY CHAIRMAN WATSON: Okay. That's
16 perfectly fine.

17 MS. FALZONE: Okay. Thank you for inviting us
18 and having us here to speak today and to share our story.
19 Again, my name is Andrea Falzone. This is my husband Ryan
20 Sprang. We have two sons, Ryan, who's four years old, and
21 Brayden, who is two years old, and we reside in State
22 College, Pennsylvania. This is an issue that is very close
23 to our hearts.

24 MR. SPRANG: We urge you to pass legislation to
25 convert House Bills 49 or 1436 into law, which will require

1 prescription drug benefits and healthcare policies to
2 provide coverage and reimbursement for amino acid elemental
3 formulas, or medical food.

4 Amino acid elemental formula is the most
5 effective treatment proven by medical research for
6 eosinophilic gastrointestinal disorders. This formula is
7 highly expensive, and many insurance companies refuse to
8 pay for it. Currently, in the State of Pennsylvania,
9 insurance companies can and have denied claims for this
10 formula for children, despite medical specialists' appeals
11 and documentation of medical necessity, leaving families at
12 a loss to help their suffering children. We need your
13 help. Insurance coverage of this medical food will have a
14 direct and immediate impact on improving the quality of
15 life of families living in the Commonwealth of
16 Pennsylvania.

17 MS. FALZONE: Our son, Ryan, is four years old.
18 He has a rare and chronic disease called eosinophilic
19 esophagitis. He was diagnosed at the age of two, and so
20 we've been going through ongoing medical treatment for the
21 past two years. Because of this disorder, Ryan experiences
22 chronic inflammation and damage of his gastrointestinal
23 tract, ongoing pain, difficulty swallowing, vomiting,
24 constipation, refusal of food -- when he was two, he was
25 malnourished, he dropped off his growth chart -- ongoing

1 sleeping difficulties, and a whole host of other symptoms.

2 A piece of cake, a bowl of rice, an apple, a
3 single carrot stick even can make kids like Ryan violently
4 ill and has made Ryan violently ill. If untreated, they
5 can suffer life-threatening consequences such as impaction
6 of the intestines, food getting impacted in the esophagus.
7 Every other month, Ryan must endure an invasive endoscopy
8 under general anesthesia with biopsies under general
9 anesthesia at a hospital to see if the limited food he's
10 allowed to have is safe. It is very difficult going
11 through this process and it's a fear-inducing process for a
12 small boy.

13 He will be undergoing his eighth endoscopy in a
14 1-1/2 year period at the end of this month, and currently
15 there are only 11 foods that he can eat safely. His
16 primary caloric intake and source of nutrition comes from
17 EleCare, which is an elemental formula, his medical food,
18 to make up for food that he cannot have.

19 MS. FALZONE: Ryan, go ahead.

20 MR. SPRANG: Ryan's doctors have followed best
21 practice protocols, including medication management and
22 elimination diets, which were unsuccessful. He remains
23 dependent on this elemental formula to meet his daily
24 nutritional requirements. This formula has made a major
25 difference in Ryan's life and has allowed his body to begin

1 to heal. Although his medical journey is far from over, we
2 are happy to say he is now much more medically stable.

3 We were shocked when Highmark Blue Shield denied
4 coverage for Ryan's prescription formula deeming the
5 formula as "not medically necessary," especially given that
6 our team of medical specialists, including a pediatric
7 allergist, pediatric gastroenterologist, and the dietitian
8 did deem it medically necessary.

9 We, along with our son's doctors, appealed to our
10 insurance company numerous times, but Highmark continued to
11 deny coverage utilizing numerous excuses for why they would
12 not cover this formula, at the time, Ryan's sole source of
13 nutrition. Because Ryan's health could not wait for
14 Highmark to fund this, we had to pay out-of-pocket for the
15 formula. Formula costs about \$35 per can, and Ryan's diet
16 requires one can about every day-and-a-half to two days.
17 Doctors estimate that he will need to be on this formula
18 for at least three years. We simply could not afford the
19 cost of Ryan's formula without insurance coverage and went
20 into financial debt as a result, but we are willing to do
21 whatever it takes to get him the care he needs.

22 MS. FALZONE: Life without food is
23 extraordinarily difficult both for the child with this
24 disorder and his or her family. It has been unbelievably
25 challenging and heartbreaking watching Ryan's struggles

1 physically, socially, and emotionally in not being able to
2 eat like a typical child. Lack of insurance coverage
3 placed an unnecessary additional stressor and financial
4 burden on our family. Spending months chasing down our
5 insurance company, five months total, wasted many hours of
6 attention that should have been focused on helping our son
7 heal and grow.

8 In May of 2013, we sent a petition to our
9 insurance company through change.org after our family had
10 exhausted all other avenues, including doctors' appeals,
11 family appeals, appeals to my employer, and calls to
12 various care managers. This time, Highmark paid attention
13 as the petition earned 323 signatures in less than 24 hours
14 and was quickly gaining momentum and soon to go viral.
15 After five months, they finally agreed to cover Ryan's
16 formula. We feel unbelievably fortunate to have a support
17 network of family and friends that helped rally support and
18 put pressure on our insurance company to do the right
19 thing. However, it should not have taken all of this for
20 them to provide this coverage.

21 Additionally, our two-year-old son Brayden a few
22 weeks ago has also been diagnosed with this awful disorder.
23 We fear that we're going to have to go through this battle
24 again unnecessarily with our insurance company to cover
25 elemental formula if this treatment also becomes necessary

1 for him.

2 Unfortunately, our story is not the only one of
3 its kind. Many other families continue to struggle to fund
4 their child's medically necessary formula, their food.
5 Many States mandate coverage of elemental formula so that
6 insurance companies cannot do this to children.
7 Unfortunately, at this time Pennsylvania is not one of
8 those States.

9 You as a Committee have the power to change this
10 and to ensure that children with such disorders get the
11 care they need in the Commonwealth of Pennsylvania. Again,
12 insurance coverage will have a direct and immediate impact
13 on improving the quality of life of families living in the
14 Commonwealth of Pennsylvania. In our great country, no
15 child should be denied the care that he or she needs to
16 survive.

17 Please, we ask that you pass House Bills 49 or
18 1436. Thank you in advance for your time and for
19 supporting families who suffer from these debilitating
20 diseases.

21 MAJORITY CHAIRMAN WATSON: Mrs. Falzone and
22 Mr. Sprang, we thank you very much.

23 MS. FALZONE: Thank you.

24 MAJORITY CHAIRMAN WATSON: And sadly, we are
25 hearing a repetitive story, each one very compelling.

1 Just a quick mention that make sure families
2 understand and I am sure Representative Truitt has gone
3 over this, if indeed this Committee then having heard the
4 hearing takes up the Bill and if indeed it were to pass by
5 a positive vote out of the Committee, then the next hurdle
6 is it has to get on the House full agenda. And even after
7 you think if it gets on the agenda and if indeed it were to
8 pass the House, then it goes over to the Senate and that
9 process begins again.

10 So you're very kind and several people have said,
11 so if you do this, Committee Members, this will make things
12 better, we're only I guess that first cog in the wheel to
13 do that. And I want to make sure everyone understands
14 that. This ends up being a gavel. Sadly it is not a magic
15 wand or any of us have that kind of power. I would tell
16 you that if we had that kind of power, I suspect of my
17 colleagues we would all use it. But we don't. So I wanted
18 to do that.

19 And our last testifier, Allysha Zink, from
20 Lancaster County.

21 MS. ZINK: Hello.

22 MAJORITY CHAIRMAN WATSON: Good morning.
23 Whenever you're ready.

24 MS. ZINK: Well, thank you, Chairwoman Watson,
25 for allowing me to speak today.

1 My name is Allysha Zink and I am from Lancaster.
2 My husband couldn't be here today.

3 But our daughter, Makenzie, was born May 10,
4 2013. She was born with a clean bill of health, no issues.
5 We were thrilled. I started out breastfeeding her. I
6 myself have celiac so I can have a limited diet myself.

7 Two weeks after she was born, she was extremely
8 cranky, arching her back, diarrhea, vomiting. She was
9 miserable. Our doctor recommended to stop breastfeeding.
10 Because of my limited diet, it could be something that I
11 was eating. We switched to Enfamil Newborn; that didn't
12 work. We switched to Enfamil Gentlease, which is a gentler
13 formula on their little tummies; it didn't work. Finally,
14 after begging and pleading for them to change something
15 because I couldn't enjoy my newborn baby girl, I couldn't
16 go out in public with her in the fear that she would cry
17 all the time and in the fear that she would get sick on
18 everything.

19 Finally, they switched us to Nutramigen.
20 Nutramigen is a hypoallergenic formula not amino acid-
21 based. It has a very small amount of the cow's milk
22 protein in it. We tried that and it was like liquid gold
23 at first. Two weeks later, her symptoms started to creep
24 up again and she was extremely cranky arching her back, not
25 sleeping, and having diarrhea. We did a Hemoccult test,

1 which tests for blood in the stool; it came back positive.
2 My baby had a GI bleed from the Nutramigen, which was the
3 cow's milk protein. She's now allergic to milk, soy,
4 wheat, gluten, and cow's milk protein.

5 The only thing she can eat is the amino acid-
6 based formula EleCare. We have slowly started introducing
7 foods to her but are very limited. Since starting the
8 EleCare, she has completely changed. She smiles. She is
9 the happiest baby you will ever meet. She enjoys life and
10 I feel like I am not unintentionally poisoning my daughter
11 anymore. She can be happy.

12 When we went on the EleCare, that night my doctor
13 sent a letter of medical necessity and a prescription to
14 our insurance company to get it covered because we cannot
15 pick it up at any of our local pharmacies. We had
16 HealthAmerica at the time and they were wonderful. They
17 covered it 100 percent no questions asked. I sent
18 everything to them at 3:00 p.m. and by 10:00 p.m. that
19 night on a Friday I had a gentleman at my doorstep with a
20 month's supply of EleCare formula. They never once
21 questioned me. It was amazing and I was happy.

22 November 31st, 2013, our insurance changed. We
23 now had Geisinger. I started this process eight weeks ago
24 yesterday to get a refill for her. I have not seen the
25 formula. They are saying that because it is not medically

1 necessary and because it's not life-or-death, my child
2 cannot have the formula that she needs to live.

3 Sometimes when I would call Geisinger -- I've
4 called every day for the past eight weeks. I've talked to
5 different employees; I have talked to their medical
6 directors. My doctor has talked to their medical
7 directors. Every person has given me a different story. I
8 have been laughed at. I have even had an employee say "are
9 you kidding me; aren't you something?" I get upset because
10 this is my child's life. To me this is life-or-death. If
11 I do not give her this EleCare, she risks becoming anemic
12 from a GI bleed and risks hospitalization.

13 The insurance company told me, like other
14 families have told you, that they will cover it if they
15 have an inborn error of metabolism such as PKU or maple
16 sugar urine disease or they will cover it if she gets it
17 via a tube. That to me is crazy. That is more cost for my
18 daughter, more unnecessary treatment just because she takes
19 it orally.

20 My doctor did a peer-to-peer with a doctor at the
21 insurance company and he said while I agree with you 100
22 percent and this is medically necessary, we will not cover
23 it because, according to our plans, it's not medically
24 necessary. They said because you can buy it over-the-
25 counter, we will not cover it. I then gave them the

1 example of seizure medications. You can buy anything over-
2 the-counter as long as you have a prescription for it.

3 They didn't say anything back to me.

4 Geisinger also recommended that I go and apply
5 for WIC. I pay \$150 a week for my private insurance. I
6 should have no trouble getting that covered by my private
7 insurance and I do not want to take away necessary State
8 funding from other people who need it more.

9 Geisinger told me that the formula was not life-
10 or-death and she would be fine without it. They laughed at
11 me; they laughed at our plight. Last week, I received the
12 final denial in the appeal process. I not only appealed
13 Geisinger; I did a State appeal as well and it went to a
14 different organization. They also agreed with the appeal
15 for Geisinger. There's nothing left for me to do. I
16 cannot fight anybody else. If it wasn't for my doctor's
17 office, I would have to pay the \$55 a can. She goes
18 through a can-and-a-half a day. That's \$137.50 a week for
19 formula. I cannot afford that.

20 We looked into changing insurance companies to
21 having a private payer such as Highmark Direct or something
22 like that. However, because it's considered a preexisting
23 condition, they will not cover it, and if they do, I have
24 to pay \$500 a month just for her and that's not including
25 the deductible as well.

1 If it wasn't for the samples and for the kindness
2 of some people to give us donations of the formula, we
3 would be faced with the choice to either pay a bill or buy
4 formula for our child. To me the option is easy; I'm going
5 to get that formula but that should be a choice no parent
6 ever has to be faced with.

7 Because of the EleCare, because of just this one
8 little can of formula, my daughter is happy and healthy.
9 She is in the 90th percentile for everything. She's a
10 little chunky monkey. She needs this EleCare. That's why
11 I'm asking you to please support House Bill 49 and 1436 to
12 help get one step closer to the formula coverage for
13 families and children.

14 Thank you.

15 MAJORITY CHAIRMAN WATSON: Thank you very much.
16 Thank you. We appreciate you being here and talking so
17 personally. Members, are there questions that you've been
18 holding and that you wanted to ask?

19 Representative Toohil.

20 REPRESENTATIVE TOOHL: Thank you, Madam Chair.

21 On a couple of different levels, first off, I
22 just wanted to comment to the two young men Dean and Cole.
23 This was so important for you to come here today and all of
24 the trials and troubles that you've had in your life and
25 this journey, all these really hard things you've been

1 through, it's so important because you were able to come
2 here today and speak for all these other children in all of
3 Pennsylvania. And this is exactly how a Bill becomes a
4 law. And your parents, maybe they showed you that video
5 bringing your Bill to Capitol Hill and wanting to change
6 something.

7 So you coming here today and talking to all of us
8 -- some of us know little bits about this, a milk allergy,
9 something like that, but all these people up here, you were
10 able to come to us and tell us your story, and that's
11 exactly how a Bill becomes a law and you can make sure that
12 all these little children that are out there just like
13 Allysha's daughter, Makenzie, that she doesn't have to go
14 through all the hard things you went through.

15 So I want to applaud you. We're all very taken
16 with everything you had to say and it's very, very
17 important to all of us.

18 And, Mrs. Zink, everything you were talking
19 about, I think that there is just such a misunderstanding
20 between people knowing what PKU is and people know what
21 maple syrup disease is and I'm sure that those families had
22 to fight so hard to get their coverage. And right now,
23 because it does take a while for a Bill to become a law,
24 while you're in this interim process, you have people like
25 Representative Truitt, Chairwoman Watson, all of us here on

1 this Committee, we will fight for you. I don't think
2 anyone's here from the insurance companies today. Are they
3 here today?

4 Okay. I know Sam Marshall wrote a letter and he
5 is an open-minded and understanding individual, so
6 hopefully, we're going to get together and be able to say
7 exactly what is in these Bills right now. If there's
8 families that are suffering from this, we need to get them
9 covered under these exceptions. DPW Secretary Mackereth
10 I'm sure would want to hear this testimony. And the staff
11 had said that this was being recorded.

12 And, Chair Watson, it just would be our request
13 that it would be broadcast and that it does go viral and
14 that the entire Commonwealth of Pennsylvania would hear
15 this so that we don't have to go through Children and Youth
16 and the Health Committee and the Insurance Committee and
17 all of these ways that a Bill can be hampered.

18 So basically, they were just comments but my
19 heart goes out to all of you and it's such an important
20 story. And I know that there's children in my community
21 that are on WIC so they get that coverage. So for
22 Mrs. Zink, if there's something that we can do immediately,
23 this is the building where all of that goes on. The
24 Secretary of DPW for some sort of urgent care coverage,
25 that should be available to you. So we're here. Come to

1 our office. That's our jobs.

2 MAJORITY CHAIRMAN WATSON: Thank you.

3 Question or comment? Representative Brownlee.

4 REPRESENTATIVE BROWNLEE: Thank you, Madam Chair.

5 I apologize for being late but I've been moved by
6 the testimony that I've heard. It is amazing to me as a
7 mother and I'm hearing the parents, I would do everything
8 that I could possibly do to help my child and my heart goes
9 out to you. I applaud Representative Truitt for bringing
10 this to our attention.

11 And, Chair Watson, you're the Chair but I think
12 we need a voting meeting, get this out of Committee so we
13 could possibly get it to the Floor, and I would do
14 everything that I can possibly do to help Representative
15 and everybody else get this into law. And I can only echo
16 what Representative Toohil said. I mean most of what she
17 said was what I was going to say, so thank you.

18 MAJORITY CHAIRMAN WATSON: Thank you very much.

19 Anyone else for a question or a comment?

20

21 (No audible response)

22

23 MAJORITY CHAIRMAN WATSON: All right. Hearing
24 none, I certainly would like to thank each and every one of
25 you. It was hard to give testimony, I know, because in

1 some ways -- and I think all of us or most of us are
2 parents -- it was hard to listen. And I would echo what
3 some of my colleagues said; when you're sitting there,
4 well, of course, I'd move thousands of miles. Well, of
5 course, I would do whatever it took and I'd max out every
6 credit card we had and see if we could get another one
7 because I would see to it that my child was taken care of.
8 It is natural for parents to do that, to protect their
9 children.

10 Representative Truitt, you and I talked
11 privately; we did have the Insurance Association weigh in
12 in some question and I think it would be good if you
13 schedule a meeting with them. There's certainly the one
14 question that none of us know, which is the Affordable Care
15 Act and how it weighs into this. The Insurance Association
16 is made up of lots of good people, many of whom are parents
17 and grandparents.

18 I understand cost but I know you did a little
19 chart that shows the minimal cost because luckily, as
20 dramatic as this testimony has been, the number when we
21 just do sheer counts, is small. It's huge if you're one of
22 the families, but across our population of children in the
23 Commonwealth, this is small so that we're not asking a huge
24 incurring of additional debt responsibility in their
25 forecasting for insurance. But now we're saying we've got

1 another set of rules coming through the Affordable Care
2 Act, and I believe Mr. Marshall had alluded to that in his
3 letter. So I do think we can do a little work on this to
4 make it work and then it's in good shape to come before the
5 Committee, as some have said. And others may have some
6 questions and we will get those answered, too.

7 I do think this has been informative. I think
8 most of us, while you might be aware and you thought it was
9 really just one family and unusual, not aware of any
10 breadth of this, it was important to note that our families
11 come from Chester County, Snyder County, Centre County,
12 Lancaster County. This is across the Commonwealth.
13 Perhaps what got most of them here -- and we thank our
14 doctor -- is because they could come to Children's Hospital
15 of Philadelphia to get the proper care and the actual
16 diagnoses. All I could think of as you were talking about
17 what you all went through until you all got a proper
18 diagnosis.

19 And I'll tell you as a mother of a child, a
20 little boy who had terrible colitis as a young child and
21 this, when you described the arching of the back, you don't
22 understand unless you've been a mother when you see that
23 infant arch that back, you know that's nothing but pure
24 pain and that is heartbreaking because you can't reason.
25 And what really bothers you is you can't fix it.

1 So we understand and we thank you.

2 To the young gentleman who testified and looked
3 good at the same time, we thank both of you. I think
4 Representative Toohil said it best. Everything you went
5 through you were here today to speak for all those children
6 who are either too little or too far away or perhaps
7 wouldn't wear a tie, but they couldn't come and speak and
8 you did an excellent job. That's really important. And
9 what happens is that means something to us and we remember
10 you, who have a disease, what you said and what you needed.
11 And your parents did a nice job. Thank them on the way
12 home. They weren't bad. They were good. You were better
13 but they were pretty good so give them at least a pat on
14 the back on the way home.

15 To all of you, thank you again for coming. We
16 certainly have heard you. Representative Truitt, we thank
17 you, as our colleague, for bringing this to our attention.

18 To the Committee Members, with all that we had to
19 do today, thank you if you were able to stay or came in.
20 We appreciate it.

21 We'll use the gavel. This hearing is now
22 adjourned.

23

24 (The hearing concluded at 10:50 a.m.)

1 I hereby certify that the foregoing proceedings
2 are a true and accurate transcription produced from audio
3 on the said proceedings and that this is a correct
4 transcript of the same.

5
6
7 Christy Snyder

8 Transcriptionist

9 Diaz Data Services, LLC