

<b>Act Number:</b>	09-051	
<b>Bill Number:</b>	5023	
<b>Senate Pages:</b>	1996-2000, 2101-2120	<b>25</b>
<b>House Pages:</b>	1935-1938	<b>4</b>
<b>Committee:</b>	Insurance: 357-365, 485, 543-544, 560-569	<b>22</b>
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Those voting nay 23  
those absent and not voting 1.

THE CHAIR:

Senate Amendment A fails.

Will you remark further on Senate Bill 964?

Senator McDonald.

SENATOR MCDONALD:

Mr. President, if there is no objection might  
this item be placed on the Consent Calendar.

THE CHAIR:

Motion is on the floor to place the item on  
Consent, seeing no objection so ordered.

Mr. Clerk.

THE CLERK:

Calendar page 13, Calendar Number 526, File  
Number 9, House Bill 5023, AN ACT REQUIRING HEALTH  
INSURANCE COVERAGE FOR WOUND CARE FOR INDIVIDUALS WITH  
EPIDERMOLYSIS BULLOSA, favorable report of the  
Committee on Insurance and Appropriations.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. I move to accept the  
joint committee's report and passage of the bill.

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THE CHAIR:

On acceptance and passage of the bill, sir, would you like to remark further?

SENATOR CRISCO:

Yes, Mr. President. Mr. President this bill requires certain insurance policy to cover wound care supplies administered under a physician's direction for the medically necessary treatment and that term Mr. President is extremely important as this General Assembly was one of the first in the country to pass a definition of medical necessity treatment of Epidermolysis Bullosa.

Mr. President, this chamber takes up many, many important issues, whether it applies to small group of people --

THE CHAIR:

Senator Crisco, hold on a second please.

If you please take your conversations outside the chamber and keep it to a low volume I would appreciate it.

Senator Crisco please proceed.

SENATOR CRISCO:

Thank you. Whether it pertains to a small group of people or large populations. This condition, known

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as EB, refers to a group of rare skin diseases characterized by recurring painful blisters and open sores in response to minor injury, heat or friction as a result of the unusual fragile nature of the person's skin. Some severe forms involve the eyes, the tongue and the esophagus and some may produce scarring and disabling muscular skeletal deformities. There is no cure for EB and treatment is often focused on wound care to minimize pain, infection and other complications.

Mr. President, as I mentioned, this circle just does some marvelous things for individuals which really never get noted to, you know, in papers and to the people of Connecticut. And this is one situation I think which is a small step in treating those who suffer so greatly.

THE CHAIR:

Thank you, Senator Crisco.

Will you remark?

Senator Debicella.

SENATOR DEBICELLA: .

Thank you, Mr. President. Mr. President, a question through you to the proponent of the bill.

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Senator Crisco.

SENATOR DEBICELLA:

Through you Mr. President, how many people in Connecticut currently suffer from EB?

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you, Mr. President. Mr. President, it may not be a great number, but my personal position is even if it's one it's something that should be done.

THE CHAIR:

Senator Debicella.

SENATOR DEBICELLA:

Thank you, Mr. President. I appreciate the Senator's position on it, but do we actually know is it one, two, three? It is a small number from what I've been told. Do we know how many people have it in Connecticut?

Through you Mr. President.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Mr. President --

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Senator Looney, for what purpose do you rise sir?

SENATOR LOONEY:

Pass this item temporarily.

THE CHAIR:

Motion on to pass temporarily. Without objection  
so ordered.

SENATOR LOONEY:

Yes, thank you, Mr. President. Mr. President if  
the Clerk might move to call on Calendar page 19,  
Calendar 581, House Bill 5186.

THE CHAIR:

Mr. Clerk.

THE CLERK:

Moving on to Calendar page 19, Calendar 581, File  
Number 266 and 883, Substitute for House Bill 5186, AN  
ACT CONCERNING THE THOMPSONVILLE FIRE DISTRICT AND THE  
CORNFIELD POINT ASSOCIATION AS AMENDED BY HOUSE  
AMENDMENT SCHEDULE A, favorable report of the  
Committee on Planning and Development.

THE CHAIR:

Senator Coleman.

SENATOR COLEMAN:

Thank you, Mr. President. Mr. President I move  
acceptance of the joint committee's favorable report

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There is a motion on the floor to place the item on Consent. Seeing no objection ma'am so ordered.

Mr. Clerk.

THE CLERK:

Calendar Number 526, House Bill 5023, File Number 9, House Bill 5023, AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR WOUND CARE FOR INDIVIDUALS WITH EB, favorable report of the Committee on Insurance and Appropriations.

THE CHAIR:

Senator Crisco.

SENATOR CRISCO:

Thank you Mr. President. Mr. President I move acceptance of the joint committee's favorable report and passage of the bill.

THE CHAIR:

Acting on approval of the bill sir would you like to remark further?

SENATOR CRISCO:

Yes Mr. President. I -- I would ask that the circle just take a little time to consider my remarks and if -- if they can imagine waking up this morning with blisters so severe on their eyelids that they cannot leave the house. If they can imagine another day where the wounds on their

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arms are so severe where they have no damages that they cannot leave -- leave the house.

Mr. President we're not talking about a case load of 500,000 situations, 50,000 or 5,000, we are talking about perhaps 50 cases in the State of Connecticut where people need consideration. In addition, Mr. President, if a person with this condition had our state insurance plan, they would be covered but because they have a private insurance plan they are not covered. And regardless if it's 50 or one, the suffering and pain that these people experience is something we have a responsibility to address.

In addition besides considering blisters on your eyes and blisters on your extremities, consider the blisters on your esophagus that would prevent your from swallowing. And so Mr. President I hope that the circle will give approval to this legislation.

THE CHAIR:

Thank you Senator Crisco.

Senator Debicella.

SENATOR DEBICELLA:

Thank you Mr. President. Mr. President what Senator Crisco has just described is indeed a horrific disease that as he stated inflicts about 50 people in our state and the

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question before us is whether or not to mandate such coverage for all 3,000,000 of us who have health care to make sure that those 50 people have the coverage they need to actually treat their disease. And if you think about it, the cost to individuals who don't have this disease will not be tremendous. Call it 20 cents a month that their health care costs will go up to treat this.

But Mr. President when you take the 75 or so mandates that we have and some of them do cost more than 20 cents a month, but let's assume they do and you add them up, that drives the cost of health care up by \$20 a month in Connecticut. Take that for 12 months, that's \$240 that these bills are adding to peoples health care bills. And Mr. President I believe there's a better way to actually reach the goals that Senator Crisco laid out by changing what health care mandates mean in Connecticut and, therefore, Mr. President I'd like to call LCO 6587.

THE CHAIR:

Mr. Clerk.

THE CLERK:

LCO 6587, which will be designated as Senate Amendment Schedule A is offered by Senator Debicella of the 21st District.

THE CHAIR:

Senator DeBicella.

SENATOR DEBICELLA:

Thank you Mr. President. I move the amendment.

THE CHAIR:

Please proceed sir.

SENATOR DEBICELLA:

Thank you Mr. President. Mr. President what this amendment does is it changes what a health care mandate is in Connecticut. Right now under our laws if we pass something that's a health care mandate, every single person in the State of Connecticut, whether they want it or not and whether they need it or not, needs to pay for it.

What this bill does is it allows consumer choice in these mandates. It says every insurance company must offer that. You cannot not offer the -- the 75 or so diseases that we have mandate they cover, but we allow health care companies to give three options to people. First people could choose the system we have right now where every single health care mandate is contained in the base coverage you receive. Or as a second option, consumers could choose to take a base option without those mandates and then buy a package of those mandates on top of it. So if they say well I want to have all those mandates, I can choose to have that or I can choose not to. Or the third

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option Mr. President is we would allow ala carte selection of mandates where you would again have a base package but then you'd be able to choose I want to be covered for -- for say ovarian cancer or I want to be able to choose the disease we're talking about today.

So those 50 people could still be covered but the other 3,000,000 of us don't have to be if we don't want to. This indeed would be a transformation that would lower health care costs by \$250 for every person in Connecticut who did not want these mandates and we've talked a lot about lowering the cost of health care. This idea is a way to do it without denying coverage to anyone who wants it. It is an area whereby consumer choice we can have the best of both worlds by making sure health insurers are offering the coverage they need to while giving consumers the choice of whether they want it or not.

An extra benefit just to note Mr. President is the physical note on this amendment. It says that in 2012, FY 2012, when we're renegotiating our health care package, there will be a savings to the state, a savings because we can offer that choice to our state employees as well.

So in summary Mr. President I encourage adoption of this amendment as an innovative way to meet the goals that Senator Crisco laid out but still make sure they we are

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lowering health care costs in Connecticut and not passing  
.one size fits all mandates. Thank you Mr. President.

THE CHAIR:

Thank you Senator Debicella.

Senator Crisco.

SENATOR CRISCO:

Thank you Mr. President. Mr. President I object to  
the amendment. I respect the Senator's intention. In fact  
the Insurance Committee did have considerable hearings this  
past year and during our committee meetings and public  
hearings and we did come up with a proposal that will be --  
which is on our calendar in regards to cost benefit  
analysis for each particular, as people refer, mandate but  
in insurance committee this year Mr. President we refer to  
-- to them not as mandates but as preventions. And what  
unfortunately the tunnel vision that has prevailed in this  
body over the past years is the complete ignoring of the  
savings of dollars by adopting not 72 mandates but some 52  
preventions. This particular bill will prevent people from  
getting additional chronic diseases that will save the  
insurance companies considerable amount of dollars.

And while we're speaking of saving dollars, Mr.  
President, Mr. President I don't stand before this chamber  
and state that our insurance industry which I support 110

percent. Their net income the past six years have been extraordinary. When one company enjoys \$2 billion of net income and another insurance company enjoys \$2 billion of that income where there has been some losses, maybe ten years ago, I have the strong believe that there should be a sharing of that net income with the people of the State of Connecticut.

So for those reasons Mr. President I object to the amendment and ask that for a roll call.

THE CHAIR:

A roll call will be ordered sir.

Senator Kane.

SENATOR KANE:

Thank you Mr. President. I rise in favor of the amendment. I think it's actually a very appropriate time for Senator DeBicella to promote this today. Seeing so many people around the building in -- in red tee shirts promoting for health care and -- and awareness and about health coverage and how many people go without and how many people need it. I think the main problem here, the main issue, is that we have too many mandates on our books and I think we're well over in the 50 category possibly heading towards 60 and the reason health care is so expensive is because health coverage is expensive. If we were able to

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reduce the number of mandates then we'll see lower health care costs for everyone. So this bill is very appropriate today.

You know why should let's say an elderly couple in their sixties or seventies have to be mandated to pay for infertility treatments. I mean I think it should be this type of cafeteria type of plan. Give people the options of doing this and so I thank Senator DeBicella for the amendment. I know that compared to other states that surround us, Rhode Island for example, has much lower number of mandates on their books than what we have here in the State of Connecticut, hence their health care rates are lower.

So I think this goes to the very idea of reducing costs for everyone and this is the only way to do this is by reducing the number of mandates. So while we would like to require companies do everything for all people, it just doesn't make sense. It's not a one size fits all type of approach. So I do rise in favor of the amendment. I thank Dibecella for bringing it out because I think this is going to go a long way for the State of Connecticut to save money, for our residents and constituents to save money and then of course all of us will have lower health care costs in the future. Thank you Mr. President.

THE CHAIR:

Thank you sir.

Will you remark?

Senator Boucher.

You're back, you're alive. There you go.

SENATOR BOUCHER:

Thank you Mr. President. I also -- I also rise -- maybe -- maybe there was a thought that I had spoken plenty yesterday and that maybe I should take a break for today.

THE CHAIR:

No we take the battery out of the microphone ma'am.

SENATOR BOUCHER:

Well it is a pleasure to address you Mr. President and the rest of the chamber. I rise to very much, enthusiastically actually, support this amendment. I have been troubled over a number of years at the increasing costs of health care and which would inevitably lead to a lack of access for many to this and particularly our small businesses that find it too expensive to offer it to their small groups and a -- there are a couple of issues of course that surround this issue with regards to cost. One of the large ones of course is medical malpractice insurance premiums that -- that our country seems to have where as other -- other lands that do not have those

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particular costs associated with their health care. But particularly in Connecticut it's becoming increasingly observed that we have as -- as has been stated already 50 or above mandates on our health providers whereas other states have anywhere in the category of 15, 20 at the most, most of our surrounding states in New England.

So this does add appreciably and it certainly could be seen if this amendment were enacted that we could actually see what those costs are because you would be able to provide them in an ala carte fashion and you would actually see what those costs might be.

So I do think that this is a very innovative way. I was quite surprised and impressed when I saw the language in this amendment. I think it's a good place to go. I agree with the Chairman of the committee that prevention is incredibly important. It's very beneficial. We should do that but these -- these mandates have a cumulative effect and that is what has grown the cost and if we were to reduce that in essence we might inevitably see a reduction in costs and certainly my number one priority and that is increasing access to the -- the vast majority if not all of our residents in Connecticut, particularly the small businesses.

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So I am highly in support of this. I hope others will think about it for a minute and consider it that this might actually be very ground breaking right now)as we try to address health care in Connecticut. Thank you Mr. President.

THE CHAIR:

Thank you ma'am.

Will you remark?

Senator Kissel.

SENATOR KISSEL:

Thank you very much. Good afternoon Mr. President.

THE CHAIR:

Good afternoon sir.

SENATOR KISSEL:

I stand in support of the amendment and I would really like to commend Senator DeBicella for moving forward with this recommendation. You know when I was listening to the rendition provided by Senator Crisco on the underlying medical problem that approximately I guess 50 folks in Connecticut have, I was struck by how horrific it sounds without a doubt. To a great extent it -- it -- it sounds remarkably like leprosy in -- in it's earliest stages and one would never wish that kind of horror on anyone, an

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inability to close ones eyes, to swallow or anything like that.

But what that does is it highlights the dilemma that we in the circle and here in the legislature as a whole find ourselves because as one brings forward any kind of medical malady and says I've had -- I've been at a public hearing, we've had folks come and testify before us, men, women and children that are suffering from these horrible, horrible diseases that we wouldn't wish on our worst enemy, it makes it incredibly hard for us to say no we don't want to include that as a requirement in our state health insurance benefits that we require to be offered to individuals.

It's -- it's human nature to want to try to remedy that wrong or alleviate that pain in some way. Nonetheless, I think that Senator DeBicella's amendment brings us the other side of the story and that is that while still moving in that direction we need to afford our constituents a greater amount of latitude to make their own financial decisions. And individuals out there in our communities, whether they're in small businesses, whether they're the number one job creators in the State of Connecticut, whether they're in that sort of in between period of time where they're waiting for their federal

benefits to kick in, whether they're just struggling because for whatever reason they're having a difficult time making ends meet, they may want an option that says I'm going to choose coverage that will protect me against these -- these risks.

And indeed there might be an extremely informed decision. With modern medicine and technology and indeed with advances regarding one's RNA and DNA and everything else like that, we're getting more and more close to that world where our physicians can tell us exactly what illnesses we may be susceptible to. And I don't just mean a family medical history, but I mean something that's even as nuanced as on the molecular basis and that would allow individuals to make an informed decision as to how much money they have to allocate towards health insurance coverage and making an informed decision as to that coverage.

By doing it this old fashion way, which heretofore is the way we've done it here in the State of Connecticut, by we as a legislature saying put this in and put this in and put this in, until we have as much if not more than surrounding states and other states in the United States, for all the right reasons, at the end of the day we're limiting options for individuals and driving up costs,

driving up costs such that no one in the State of Connecticut can get out of shouldering that financial responsibility.

And unfortunately we cannot -- cannot ignore the fact that we have competition by surrounding states and states to the south of us, to the southwest of us, throughout our country and as the novel that's or -- not the novel but the book that states it's a flat world indicates there's competition all over the -- the world, all over the world. I am not one that has ever advocated a rush to the bottom. I -- I don't. But I think this is a sensible approach. Senator DeBicella is to be commended and in fact I can even envision down the road even a wider panoply of options, indeed some that would even have things that might cost more but may afford individuals preventive care for certain things so that they could have that encouragement to have a healthy life style and I'm very mindful of the fact that Senator DeBicella was a champion of the notion of turning our state's health care system around so that we focus on prevention and at the end of the day, granted there's some start up costs, but at the end of the day we're all better off because the way to get our arms around this health care issue is not to drive everybody to the ground but to

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elevate and incentivize good health care decisions, good health decisions.

And so that's where we have to go. It's not going to be an easy switch but by continuously adding to the portfolio of things that are covered through our health insurance system we inevitably drive up costs that makes things simply unaffordable for many people. They end up utilizing emergency room care which is totally cost inefficient and it is not a good way to deliver health care services and at the same time for our business community we make things that much more difficult to compete in a global economy environment. And for that reason I want to commend Senator DeBicella and associate myself with the comments made by my colleagues who also support the amendment.

Thank you Mr. President.

THE CHAIR:

Thank you sir.

Will you remark?

Will you remark further on Senate A?

If not, Mr. Clerk please call for a roll call vote.

The machine will be open.

THE CLERK:

Immediate roll call has been ordered in the Senate, will all senators please return to the

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chamber. Immediate roll call has been ordered in the Senate, will all senators please return to the chamber.

THE CHAIR:

Have all senators voted? If all senators have voted, please check your vote. The machine will be locked. The clerk will call the tally.

THE CLERK:

Motion is on adoption on Senate Amendment Schedule A: Total number voting 35, those voting yea 11, those voting nay 24, those absent/not voting 1.

THE CHAIR:

Amendment A fails.

Will you remark further on House Bill 5023?

Senator Doyle.

SENATOR DOYLE:

Good afternoon Mr. President.

THE CHAIR:

Good afternoon sir.

SENATOR DOYLE:

Thank you. I'd like to comment on the bill before us.

THE CHAIR:

Please proceed.

SENATOR DOYLE:

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Thank you. Yes I first would -- I'm a strong supporter of this bill. I'd like to thank Chairman Crisco and Representative O'Connor for introducing the bill and moving it along and I also want to thank Representative Morin for also advocating for the bill, getting it through the House. This particular -- the genesis of the bill is a constituent of mine from Wethersfield. This poor young lady does have this difficult disease and unfortunately some have talked about the cost, the mandate, and it's only really 50 people.

It really seems to me unfortunate why were here and why we have to do a bill on this case. It's -- it's troubling that we have to be here but it's such a small disease, it affects so few people, I would have hoped that the insurer covers this for this poor young girl and unfortunately we have to do it today. It is a mandate, however, the cost is so remote that I think it's worth it for this -- for the few people, the 50 people in the state, that suffer from it and again I thank the Chairman Crisco for advocating for the bill and I urge the chamber to support the bill before us today.

Thank you Mr. President.

THE CHAIR:

Thank you sir.

Will you remark?

Will you remark further?

Senator Fonfara.

SENATOR FONFARA:

Thank you Mr. President. I'd like to echo the remarks of Senator Doyle and while this young lady is not a constituent of mine, she does reside in the Town of Wethersfield that I also share along with Senator Doyle and have heard the -- the really horrible stories that the people who are afflicted by this disease and, you know, there's a saying that the courts are the great leveler in this country and I would say in this particular instance and others like it we are the great leveler. We are the body that give those in the minority who are afflicted by anything in life but in this particular case by a -- a dreaded disease the opportunity to be covered. We're not talking about unfortunately curing them. We're not talking about in any way addressing the -- the -- the -- the -- the horror of this disease, except to give the families and the individuals the opportunity to lessen their financial burden.

Unfortunately I wish we could say we're addressing the disease itself, the pain, the horrible pain that these individuals are suffering with. And was indicated to me recently that the irony of this legislation if we don't pass this what will happen, you talk about cost and the

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system and mandates, these individuals who are not covered right now end up when their infections get to a point they go to the hospital and that's covered.

That particular care is covered which increases the cost in the system to a much greater degree. That's not good health care. That's not good insurance policy for us to maintain a policy where someone uses the emergency room as was just stated by Senator Kissel just a few moments ago. I couldn't agree more with him and this bill addresses that particular issue.

So I want to give my thanks to Senator Crisco for bringing this bill before us for those handful and it could be anyone of our constituents who -- who may be faced with this -- with this dreaded disease and to Representative Morin for bringing it to our attention.

Thank you Mr. President.

THE CHAIR:

Thank you sir.

Will you remark further on House Bill 5023?

Will you remark?

If not, Mr. Clerk please call for a roll call vote.

The machine will be open.

THE CLERK:

Immediate roll call has been ordered in the

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Senate, will all senators please return to the chamber. Immediate roll call has been ordered in the Senate, will all senators please return to the chamber.

THE CHAIR:

Have all senators voted? If all senators have voted, please check your vote. The machine will be locked. The clerk will call the tally.

THE CLERK:

Motion on passage of House Bill 5023: Total number voting 35, those voting yea 35, those voting nay zero, those absent/not voting 1.

THE CHAIR:

The bill passes.

At this time I think I've got two points of personal privileges on the floor so we'll do them before we go on.

Senator Fasano.

SENATOR FASANO:

Thank you Mr. President. Mr. President we are honored here to have some very special guests from the Town of Wallingford from a local school, the Holy Trinity, and they're actually on both sides of the gallery and we want to welcome these kids to our -- our session here today so they can see how and what we do here in session. I'd like

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REP. CLEMONS (124th):

Thank you.

On Friday, this coming Friday, April 24th, from 1 to 5 p.m. in the Legislative Office Building, Room 2C, the black and Puerto Rican Caucus will hold -- host an informational forum on the federal stimulus package known as the American Reinvestment and Recovery Act. All is invited. Thank you.

SPEAKER DONOVAN:

Thank you, Representative.

Will the Clerk please call Calendar 71.

THE CLERK:

On page 33, Calender 71, House Bill 5023, AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR WOUND CARE FOR INDIVIDUALS WITH EPIDERMOLYSIS BULLOSA, favorable report on the Committee on Appropriations.

SPEAKER DONOVAN:

Representative Morin.

REP. MORIN (28th):

Good afternoon, Mr. Speaker.

SPEAKER DONOVAN:

Good afternoon, Representative.

REP. MORIN (28th):

I move for acceptance of the joint committee's

favorable report and passage of the bill.

SPEAKER DONOVAN:

The question is on acceptance of the joint committee's favorable report and passage of the bill.

Will you proceed, sir?

REP. MORIN (28th):

Thank you, Mr. Speaker. This bill simply requires insurance policies to cover wound care supplies administered under a physician's direction for the medically necessary treatment of epidermolysis bullosa. I move acceptance and passage.

SPEAKER DONOVAN:

And would you care to remark further on the bill? Would you care to remark further? Representative Fontana.

REP. FONTANA (87th):

Thank you, Mr. Speaker. Mr. Speaker, I rise to support this bill. I want to applaud Representative Morin for bringing it to the attention of the committee, and for his work on it. I'd also like to personally acknowledge the very powerful and impressive testimony of his constituents in this case. It's a need, a strong need for a very small group of people. And we would be well advised to provide for

them the minimal amount of care and treatment that they need through our insurance policies. I support the bill. Thank you.

SPEAKER DONOVAN:

Thank you, Representative. Would you care to remark further? Representative D'Amelio.

REP. D'AMELIO (71st):

Thank you, Mr. Speaker. Mr. Speaker, I rise in full support of this bill, also. You know, we learned through public testimony before the Insurance Committee that there are 50 individuals who suffer from this rare disease. And it's a -- it could become very, very costly to those families.

Normally, I always oppose mandates, but this one here is one of those issues where I encourage everyone to vote in favor of it. Thank you.

SPEAKER DONOVAN:

Thank you, Representative. Would you care to remark further? Would you care to remark further on the bill before us? If not, staff and guests please come to the well of the House. Members take their seats. The machine will be open.

THE CLERK:

The House of Representatives is voting by roll

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call. Members to the chamber. The House is taking a roll call vote. Members to the chamber, please.

SPEAKER DONOVAN:

Have all the members voted? Have all the members voted? Will the members please check the board to make sure your vote has been properly cast. If all the members have voted, the machine will be locked and the Clerk will please take a tally. Will the Clerk please announce the tally.

THE CLERK:

House Bill 5023.

Total Number Voting	142
Necessary for Passage	72
Those voting Yea	139
Those voting Nay	3
Those absent and not voting	9

SPEAKER DONOVAN:

The bill is passed.

Will the Clerk please call Calendar 149.

Will the Clerk please call Calendar 210.

THE CLERK:

On page 10, Calendar 210, substitute for House Bill number 6186, AN ACT PROTECTING THE INTEGRITY OF CONNECTICUT, OF CONN-OSHA INVESTIGATIONS, favorable

**JOINT  
STANDING  
COMMITTEE  
HEARINGS**

**INSURANCE AND  
REAL ESTATE  
PART 2  
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llw INSURANCE AND REAL ESTATE COMMITTEE 1:00 P.M.

one recommendation, one change to the language of this bill.

As currently drafted, the bill provides for the employer's credit to be applied upon the subsequent renewal as such small business a small group policy. Typically renewals are on an annual basis, and I believe that it should be clarified to provide for the credit on the next month's premium in the same manner as large employers do. Our small businesses should not have to wait months for their reimbursement, especially now. This is a bad economy and we're not going to be able to do a lot this year because of the economy, but this is one thing I think that can help small businesses.

So I want to thank you for allowing me to testify today, and please get home safely because it is snowing out.

SENATOR CRISCO: Thank you, Madam Comptroller.

Are there any questions? Any questions?

NANCY WYMAN: Thank you all very much.

SENATOR CRISCO: Thank you very much.

Representative Urban. She's not here. So we will proceed when she comes in we'll go back to proposed Senate Bill 290.

Representative Morin here?

REP. MORIN: Good afternoon, Representative Fontana, Senator Crisco and distinguished members of this committee. May I ask, Mr. Chairman, I'm here on two separate bills, am I allowed to talk only for one at a time; is that how you're doing this?

HB 5023

SENATOR CRISCO: Let's take a vote of the committee. You can speak on both. The committee has voted in the positive.

REP. MORIN: Thank you very much. Obviously you called me up for SB 290 and I'm pleased to put my name on that bill along with Senator McKinney and Representatives Keo and Drew.

I think I can't speak as eloquently as some of your members of the public that came on this one issue, I can just speak basically from my own personal experiences having friends and constituents that have had to go through this harrowing experience and having to personally fund or have fundraisers to try to find donors to help people that are seriously ill, and I know in Wethersfield we posted one and folks had to raise about \$12,000. And for people like us it's probably not too big a deal to come up with \$60 or \$70, but when you talk to some people, especially the students that might want to do it, I mean, that was alluded to by one of your earlier speakers, so this is a piece of legislation that will clearly help people, and it's really a small price to pay. I was very happy to see that it went through the senate last year. I hope that we can do that again and I hope in the house we'll be able to move quickly on it. So thank you very much on that issue.

I'm also here to speak on a bill that I had co-sponsored or actually sponsored, and for those of you that have been here a while, I'm hoping the third time is the charm. This is my third year in the legislature.

This is the third year that I've put this bill out for your consideration. The first year we were fortunate enough to have a public

°hearing. Last year -- by the way, this is HB 5023 that I'm speaking on requiring health insurance coverage for wound care for individuals with epidermolysis bullosa. The second year we made it through the committee. We actually passed it in the house and it languished and almost made it out of the senate but we ran out of time. I'm asking for your support again this year as a committee, and I'm asking for your support to help get this through both chambers of the house. This legislation doesn't affect a lot of people. There is less than 50 people in Connecticut that suffer from this disease, and frankly maybe a quarter of those people have the most serious effects of the disease which are skin lesions throughout their whole body, and the only treatment for these folks is to treat it with bandages and petroleum jelly and some ointment. Out of the maybe 15 that have the serious disease, half of them don't have insurance coverage. And you might think how much can bandages and petroleum jelly cost. Well, to those folks it can be anywhere between 20,000 and \$40,000 per year.

And if you don't have health insurance, that's a real issue. And I was inspired to sponsor this legislation because I met a young lady that went to school with my daughters. And when I first met her I didn't know what the disease was and I didn't know much about it, and I've watched her grow and she's here today to testify. And she's inspired me through her courage to come out here and speak year after year on this legislation. And it's more for the other folks. Her family actually has the insurance to cover it. She's doing this not for herself and that is to be commended.

So I know you're very busy, you've heard an awful lot of testimony, and you have a lot

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more, but I really appreciate the opportunity to spend some time with you to share my opinions on this, and I would certainly appreciate your support as we move forward.

SENATOR CRISCO: Thank you.

Are there any questions? Any questions?

No. Thank you very much.

Danny Lemos. You already testified right, Danny? Danny Lemos, he already testified, he spoke, okay.

Now we know the weather is a fact out there, so we'll try and expedite our hearing by alternating between two bills. We have no one signed up for Senate Bill 7, but on 5023 we do have members of the public.

So Rachel, John and Laura, would they all like to come up together or --

JOHN MORRIS: Good afternoon, my name is John Morris and my wife Laura won't be here today. We've had some health issues with her the last two days and she actually just got out of the hospital a couple of hours ago, so I get to look like Laurie today.

Laurie is really the expert on this. This is Rachel.

As Russ just said, she's had this disease since birth and we can tell you a little bit about it and what this means to us. We're here in support of House Bill Number 5023, an act requiring health insurance coverage for wound care for individuals with epidermolysis bullosa. Laurie is actually the founder of the Epidermolysis Bullosa Support Foundation

in Connecticut. She's Rachel's mom. Rachel is now twenty-five. Rachel has what's known as the recessive form of EB. EB is a very rare genetic skin disease that happens when collagen is missing in certain parts of the skin or the body doesn't produce enough of it. Because the skin doesn't have this protein, blisters develop very easily from the slightest pressure, the slightest touch. Clothing can cause it, and what happens is you develop these blisters sometimes very large and the blisters obviously need to be taken care of and they are treated the same as a second or a third-degree burn.

These blisters can cover huge parts of the body, 80 or 90 percent, and so what happens is we treat this by wrapping the kids in bandages. There is sort of a pad that looks -- it has jelly on one side that covers the wound and you put bandages over it and it acts like a layer of skin to help protect them. Rachel has got this, you can see, on her arms right now. There is four types of EB which range from a simple form, which is sort of common, to a more severe. Rachel has the more severe kind. There is no cure. There is research being done. There is hope, but at the present time the only thing we can do is treat the wounds as they happen so bandages are part of a vital coverage for this and this bill is necessary for that. Without bandages infections, sepsis, often occurs and that can be very very serious and very very dangerous for these individuals. Dressings are changed on a near daily basis to prevent infections and the lives of the families for people who have this revolve around day-to-day wound care. It's estimated that the prevalence of EB in the general population is approximately 8 in a million to 19 in a million in live births. There is about 48 people in

Connecticut right now who have it, 16 who have the dominant dystrophic, 22 with the EB simplex, and 10 with recessive dystrophic which is the more serious of the kind.

SENATOR CRISCO: Mr. Morris, could you speak a little closer to the microphone, please?

JOHN MORRIS: Sure. In the absence of health insurance coverage for the bandages and the wound care, this is an enormous expense. As Representative Morin said, it can be 20,000 to 40,000 or \$50,000 or more just for the cost of the bandages. We are fortunate that we have had coverage for a number of years. Right now Rachel is covered through Medicaid, but for families who don't have this, this is bankruptcy stuff, this is cashing in your retirement accounts, it's mortgaging your house, it's very significant. So it's very very important that it be covered by some form of health insurance just to make it work because there are so few people in the state who have this. The actual cost towards the insurance coverage is minimal in the general population, but for these families in particular it's very very important and it's vital. For the more severe kind of EB it can cost, as we said, up to \$40,000 a year, for the less severe kind it can be as little as 1,000 and the numbers are so small that it will be far justified versus the cost of hospitalization for someone who gets sepsis or infection from the wounds. There is a number of times that we spent days and weeks in the hospital to deal with some of these issues, and I'm sure the cost of that is far more than the cost of the bandages. We are fortunate Rachel has only had a couple of serious infections during her life, but we know of others who have had it more often. We know of others who have much younger children who

don't have insurance coverage and so for them it's a very very serious issue. Last year Representative Morin, Representative O'Connell and Rachel and my wife, Laurie, met with leaders of the insurance industry. They had supported this bill in the past. And so we're really asking you to support this bill and have it passed this year.

SENATOR CRISCO: Thank you, John.

Rachel, would you like to speak?

RACHEL MORRIS: Well --

SENATOR CRISCO: Take your time.

RACHEL MORRIS: Okay. Mr. Chairman and members of the committee, my name is Rachel Morris and I'm from Wethersfield. I'm speaking today in support of bill number 5023, an act requiring health insurance coverage for wound care for individuals with epidermolysis bullosa. I was born with one of the severest forms of EB called recessive destructive epidermolysis bullosa. I've been fairly lucky in my 25 years with EB because I received some of the best wound care available. Currently Medicaid is covering the majority of my supplies. This has provided me with the opportunity to maintain my health, to move, thrive throughout this world. I am incredibly fortunate, however, the majority of individuals in Connecticut are not, but this bill presents a variety of opportunities for all of us living in this state. Wound care is vital for survival for someone diagnosed with EB. Wound care is a daily routine that is a twofold process because the wounds of EB are internal and external. My skin is sensitive to the slightest forms of friction, a simple hug can do a world of damage. Bandages act not only

as an agent for feeling but it is also the protective layer of skin I wasn't born with. It allows me to be independent to perform simple daily tasks and to get out into the world and to interact with my family, friends and community. The skin within the body has its own set of challenges as well. I receive blisters inside of the eyes during REM sleep. I also get blisters and wounds in the esophagus due to eating food sometimes. Whatever nutrition I do take during the day goes straight to healing. Since my body is covered in at least 80 percent of wounds, I will never be able to do enough to generate healing with food alone therefore I have a G-tube placed in my stomach to receive extra nutrition at night to keep the healing process going.

Regardless of the form of EB, the need for wound care remains the same. We need these bandages in order to live. And for the majority of residents in Connecticut with EB, they are not covered. I'm twenty-five years old and that may seem young, but when it comes to wound care coverage absolutely nothing has changed since the moment I was born. Last year I met with Representative Morin and Representative O'Connor and the leaders from Connecticut's insurance companies to discuss the coverage of wound care for individuals living with EB. It was an excellent opportunity and I really ask for you to please consider bill 5023. Thank you.

SENATOR CRISCO: Thank you, Rachel. I think I speak for the committee, you are a super hero to us and we just -- I'm so honored to have you appear before us and we wish you wellness, and we're just so pleased that you are able to appear, but you are one super person.

Any questions?

Chairman Fontana.

REP. FONTANA: I'd simply like to agree with my co-chairman, you are very impressive, your testimony was impressive, as was your father's, and I want to thank both of you for taking the time to come up today and thank Representative Morin.

SENATOR CRISCO: Any other questions from the committee?

Senator Hartley.

SENATOR HARTLEY: Thank you, Mr. Chairman. And Rachel, I just want to say that your testimony was incredible and speaking for myself, I'm not a mandate kind of person, but you have my vote, Rachel.

RACHEL MORRIS: Thank you.

SENATOR HARTLEY: Thank you, Mr. Chairman.

SENATOR CRISCO: You're welcome.

Any other questions?

Thank you both very much. We appreciate it.

We'll proceed back now to Senate Bill 290, John Galvin. Is John Galvin here? Mrs. Robel, is Mrs. Robel here? I'm sorry, you're John. You sneaked up on me.

JOHN GALVIN: Thank you, Chairman Crisco, Chairman Fontana, members of the Insurance and Real Estate Committee for allowing me the opportunity to speak with you today. I'd like to offer the following support of Senate Bill

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Anthem 

458

February 3, 2009

Statement  
Of  
Anthem Blue Cross and Blue Shield  
On

**S.B. No. 458 (Raised) An Act Requiring Communication Of Mammographic Breast Density Information To Patients; Proposed H.B. No. 5021 An Act Expanding Health Insurance Coverage For Ostomy-Related Supplies; Proposed S.B. No. 290 An Act Requiring Health Insurance Coverage For Bone Marrow Testing; Proposed H.B. No. 5024 An Act Concerning Health Insurance Coverage For Bone Marrow Testing; Proposed H.B. No. 5023 An Act Requiring Health Insurance Coverage For Wound Care For Individuals With Epidermolysis Bullosa; H.B. No. 5671 (Raised) An Act Concerning Health Insurance Coverage Of Prosthetic Devices And H.B. No. 5672 (Raised) An Act Expanding Insurance Coverage For Hearing Aids For Children.**

Good afternoon Senator Crisco, Representative Fontana and members of the Insurance Committee, my name is Christine Cappiello and I am the Director of Government Relations for Anthem Blue Cross and Blue Shield in Connecticut. I am here today to speak against the bills mentioned above.

We are opposed to these bills because it seeks to add a new for all individuals and group policies, including the State of Connecticut State Employees Health Insurance Plan that would further increase their costs. Mandates remove any choice that employers or individuals might have in purchasing health care. Our goal as a managed care organization is to provide a comprehensive meaningful set of benefits to individuals and employers purchasing our product. How we accomplish this goal changes as the needs and desires of the market changes. Mandating benefits take away the flexibility insurers have in developing products in response to the needs of the marketplace. The cost of mandates may cause the purchasers of health care, specifically employers to stop offering health insurance all together.

We would respectfully request that the committee not move forward with these bills.



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5018

Connecticut State Medical Society  
Testimony Submitted to the Insurance and Real Estate Committee  
February 3, 2009

Senator Crisco, Representative Fontana and members of the Insurance and Real Estate Committee, On behalf of the over 7,000 members of the Connecticut State Medical Society (CSMS) thank you for the opportunity to present this testimony to you today on several proposed pieces of legislation. We feel that these bills will have an impact on appropriate coverage and access to healthcare services in Connecticut, as well as the overall well-being of Connecticut residents.

HB5673

HB5021

HB5028

HB5024

SB290

HB5672

HB5671

SB458

Proposed Bill 5018 An Act Requiring A Cost-Benefit Analysis of Health Insurance Benefits in This State, would establish a working group to conduct a cost-benefit analysis of existing health insurance benefits mandated in this state and require that a cost-benefit analysis be conducted prior to the implementation of any new health insurance law. We agree that it is important that the impact of requirements placed on the healthcare industry through mandates be understood from both a quality and cost perspective. As you know through years of testimony by this organization, we believe that a service deemed medically necessary by a patient's treating physician should be afforded insurance coverage and payment. Unfortunately, the refusal by many health insurers to cover medically necessary services has led to the need for this body to require health insurers to do what is right through the passage of certain mandates or coverage requirements.

Language for this legislation must be clear that any review of the "benefit" would recognize the impact on the "health and well-being" of those in need of such services, including, but not limited to, enhanced life expectancy, improved activities of daily living, maintenance of health and reduction of pain or discomfort. Any system to evaluate the impact of legislation passed that impacts the health of our citizens must provide for an analysis on the increased in quality of life to individuals receiving the benefit. Therefore, we ask that if it progresses through the session that organized medicine be invited to participate in the development of an appropriate and comprehensive review of our state "mandates. Cost is an important factor, but the benefits to the citizens of Connecticut must be evaluated and foremost in the minds of legislators, regulators and those who intend on evaluating the effectiveness and advantages of mandated medical services.

Additionally, passage of HB 5018 would impact no fewer than seven other proposed bills on your agenda today including:

HB 5673 AAC Health Insurance Coverage for Wigs For Individuals with Permanent Hair Loss

HB 5021 AA Expanding Health Insurance Coverage for Ostomy-Related Supplies

HB 5023 AA Requiring Health Insurance Coverage for Wound Care for Individuals with Epidermolysis Bullosa

HB 5024 AAC Health Insurance Coverage for Bone Marrow Testing

SB 290 AA Requiring Health Insurance Coverage for Bone Marrow Testing

HB 5672 AA Expanding Insurance Coverage for Hearing Aids for Children

HB 5671 AAC Health Insurance Coverage of Prosthetic Devices

Without a doubt, passage of these bills would provide a tremendous benefit to patients afflicted with these conditions. They would strengthen an individual's health status and/or increase quality of life. These benefits cannot be compared or contrasted to the financial cost of their implementation. However, we must once again stress that the position of the CSMS is that none of these bills would be necessary if a rational determination of a medically necessary service by a physician to improve health or increase a patient's quality of life was the trigger for insurance coverage and payment.

Finally, today we wish to provide comments to you on Senate Bill 458 An Act Requiring Communication of Mammographic Breast Density Information to Patients. Early screening and detection of breast cancer must be priority. Nothing should preclude appropriate coverage and payment for the imaging services or potentially any medically necessary follow-up services or care provided. We welcome the opportunity to work with this committee to ensure that appropriate information is provided and appropriate follow-up care is covered.

Thank you for the opportunity to provide this testimony to you today. We look forward to working with you on these and other important issues addressed by this committee throughout the session.



Quality is Our Bottom Line

Insurance Committee Public Hearing  
 Tuesday, February 3, 2009  
 Testimony on behalf of the  
 Connecticut Association of Health Plans

5673  
 5021  
 5023  
 5024  
 5672  
 5671

On behalf of the Connecticut Association of Health Plans, we respectfully urge the Committee to take no action with respect to the following bills:

- HB 5673 AAC Health Insurance Coverage for Wigs for Individuals with Permanent Hair Loss.
- HB 5021 AA Expanding Health Insurance Coverage for Ostomy-Related Supplies.
- HB 5023 AA Requiring Health Insurance Coverage for Wound Care for Individuals with Epidermolysis Bullosa.
- HB 5024 AAC Health Insurance Coverage for Bone Marrow Testing.
- HB5672 AA Expanding Insurance Coverage for Hearing Aids for Children.
- HB 5671 AAC Health Insurance Coverage of Prosthetic Devices.

While each proposal is laudable in its intent, each must be considered in the context of the larger debate on access and affordability of health care. Both the General Assembly and the Administration have pledged, again, this year to address the needs of the approximately 400,000 Connecticut residents who lack health insurance coverage. As we all know, the reasons people go without insurance are wide and varied, but most certainly cost is a major component and there is no question that cost will be added to the system if the above proposals are adopted. As you discuss the proposals above, please consider the following:

- Connecticut has 49 mandates, which is the 5<sup>th</sup> highest behind Maryland (58), Virginia (53), California (51) and Texas (50). The average number of mandates per state is 34. (OLR Report 2004-R-0277 based on info provided by the Blue Cross/Blue Shield Assoc.)
- For all mandates listed, the total cost impact reported reflects a range of 6.1% minimum to 46.3% maximum. (OLR Report 2004-R-0277 based on info provided by the Dept. of Insurance)
- State mandated benefits are generally not applicable to employers (generally large employers) that self-insure their employee benefit plans. Small employers bear the brunt of the costs. (OLR Report 2004-R-0277)
- The National Center for Policy Analysis (NCPA) estimates that 25% of the uninsured are priced out of the market by state mandates. A study commissioned by the Health Insurance Assoc. of America (HIAA) and released in January 1999, reported that "...a fifth to a quarter of the uninsured have no coverage because of state mandates, and federal mandates are likely to have larger effects. (OLR Report 2004-R-0277)

- Mandates increased 25-fold over the period, 1970-1996, an average annual growth rate of more than 15%. The Health Insurance Portability & Accountability Act (HIPAA) alone will add billions of dollars in new compliance costs to the healthcare system. (PriceWaterhouseCoopers: The Factors Fueling rising Healthcare Costs- April 2002)
- National statistics suggest that for every 1% increase in premiums, 300,000 people become uninsured. (Lewin Group Letter: 1999)
- "According to a survey released in 2002 by the Kaiser Family Foundation (KFF) and Health Research and Educational Trust (HRET), employers faced an average 12.7% increase in health insurance premiums that year. A survey conducted by Hewitt Associates shows that employers encountered an additional 13% to 15% increase in 2003. For 2004, the outlook is for more double-digit increases. If premiums continue to escalate at their current rate, employers will pare down the benefits offered, shift a greater share of the cost to their employees, or be forced to stop providing coverage." (OLR Report 2004-R-0277)

As the state moves forward with initiatives to provide all residents with access to health insurance coverage, mandates must be part of the discussion. The fact that the Committee is considering 6 new mandates just today, some clinical and some administrative in nature, argues for the need for an independent analysis of whether adoption is warranted given their impact on the overall cost of health care.

Several of the bills before you are proposals which the industry worked on previously with proponents to reach compromise. It's a difficult balance which must be struck when deciding various benefit levels of this nature and it's up to policy makers to determine at which point high benefit policies for some make coverage cost prohibitive for others.

We thank you for your consideration.

TESTIMONY  
BEFORE THE  
INSURANCE AND REAL ESTATE COMMITTEE  
LEGISLATIVE OFFICE BUILDING  
FEBRUARY 3, 2009

My name is Eric George and I am Associate Counsel for the Connecticut Business & Industry Association (CBIA). CBIA represents approximately 10,000 businesses throughout Connecticut and the vast majority of these are small companies employing less than 50 people.

Both nationally and in Connecticut, the health care system is in need of repair.

More needs to be done to improve the health of our citizens. Employers find health care costs rising faster than other input costs. Some providers are unable to generate sufficient patient revenue to cover costs. Some patients cannot get timely access to optimal care. And too many individuals remain without health insurance, engage in unhealthy behaviors and live in unhealthy environments.

For the business community, the issues of health care quality, cost and access are critical. After numerous years of double-digit and near-double-digit increases, health insurance has quickly become a product that many people and companies find they can no longer afford. In addition, the cost of health care directly affects businesses' ability to create new jobs. In fact, according to CBIA's latest membership survey, over two-thirds of our members indicated that rising health benefit costs alone are negatively affecting their ability to hire additional workers.

Therefore, CBIA asks this committee to reject **HB 5023, AN ACT REQUIRING HEALTH INSURANCE COVERAGE FOR WOUND CARE FOR INDIVIDUALS WITH EPIDERMOLYSIS BULLOSA**. The business community and other stakeholders are calling for significant reforms to Connecticut's costly and inefficient health care system. As you consider the various proposals to reform the state's health care system, CBIA asks you to refrain from making the already high cost of health care even more unaffordable for the state's companies and residents.

Every health benefit mandate, while providing a benefit to the individuals who utilize those services, increases health insurance premiums for all state-regulated group and individual policies. In fact, the Council for Affordable Health

Insurance (CAHI) reported in its 2006 report on state mandated benefits that health benefit mandates increase health insurance premiums between less than 20% to more than 50%. Connecticut ranks fourth in the country in terms of overall number of health insurance mandates according to CAHI and those mandates increase group and individual health insurance premiums by as much as 65%.

Connecticut's employers are already struggling to afford health insurance for their employees. The hardest hit among these companies are small employers whose revenues and operating budgets make affording employee health insurance extremely difficult. However, when the legislature adopts new health insurance mandates, it makes affording health insurance particularly difficult for these small employers. This is because state mandated benefits only impact plans that are subject to state regulation. If a company has the financial ability to self-insure, then that company's health plan is governed solely by federal law, including the Employee Retirement Income Security Act (ERISA), and does not have to comply with state health benefit mandates. Companies that are able to self-insure (and therefore not subject to Connecticut's health insurance mandates) are typically larger companies that can afford taking on such risk. Smaller companies usually cannot and are forced to be fully insured and subject to state regulation.

So, Connecticut's health insurance mandates impact smaller employers in the state to a greater degree than larger employers. When the legislature either creates a new mandate or expands an existing mandate, it is making health insurance less affordable for those small companies that can least afford to shoulder these cost increases.

CBIA asks this committee to reject all new or expanded mandate proposals and to enact a moratorium on health insurance mandates. It is crucial that as the state moves forward toward major health care reform, that the General Assembly refrain from taking any actions that would increase the cost of already skyrocketing health insurance premiums.

Again, please reject HB 5023 thank you for the opportunity to offer CBIA's comments on this legislation. I look forward to working with you on this and other issues related to the reforming Connecticut's health care system.

5023

Mr. Chairman and members of the Committee, my name is Laura Morris and I live in Wethersfield, Connecticut. I write this letter in support of Bill Number 5023, An Act Requiring Health Insurance Coverage for Wound Care for Individuals With Epidermolysis Bullosa. I am the founder of the Epidermolysis Bullosa Support Foundation and a mother of a 25-year daughter with Epidermolysis Bullosa (EB). EB is a rare genetic skin disease where collagen is missing, or the body simply does not produce enough of it. Because the skin is missing this protein, blisters develop easily from the slightest pressure of clothing or a passing brush against another person or object. These blisters are treated like second or third degree burn and in the most severe forms of EB affects 80% to 90% of the body. There are three types of EB, EB Simplex, Junctional EB and Dystrophic EB, each with range from mild to severe and can require major adjustments in the lifestyle of both the EB patient and his or her family. The depth of the blister location within the skin layers defines these different subtypes. EB Simplex occurs in the outer layer of the skin; Junctional EB and Dystrophic EB occur in the basement membrane zone. In severe EB, blisters are not confined to the outer skin. They may develop inside the body, in such places as the linings of the mouth, esophagus, stomach, intestines, upper airway, bladder, and the genitals. Flowing is a summary of some of the characteristics signs of various forms of EB.

- EB Simplex (EBS) – A generalized form of EBS usually begins with blistering that is evident at birth or shortly afterward. In a localized, mild form called Weber-Cockayne, blisters rarely extend beyond the feet and hands. In some subtypes of EBS, the blisters occur over widespread areas of the body. Other signs may include thickened skin on the palms of the hands and soles of the feet; rough, thickened, or absent fingernails or toenails; and blistering of the soft tissues inside of the mouth. Less common signs include growth retardation; blister in the esophagus; anemia (a reduction in the red blood cells that carry oxygen to all parts of the body); scarring of the skin; and milia, which are small white skin cysts.
- Junctional EB (JEB) – This disease is usually severe. The most severe forms, large, ulcerated blisters on the face, trunk and legs can be life-threatening due to complicated infections and loss of body fluid that leads to severe dehydration. Blisters that affect the esophagus, upper airway, stomach, intestines, and the urogenital system also threaten survival. Other signs found in both severe and mild forms of JEB include rough and thickened fingernails and toenails; a thin appearance to the skin (called atrophic scarring); blisters on the scalp or loss of hair with scarring; malnutrition and anemia; growth retardation; involvement of the soft tissue inside the mouth and nose; and poorly formed tooth enamel.
- Dystrophic EB (DEB) – The dominant and recessive inherited forms of DEB have slightly different symptoms. In some dominant and mild recessive forms, blisters may appear only on the hands, feet, elbows and knees; nails usually are shaped differently; milia may appear on the skin of the trunk and limbs; and there may be involvement of the soft tissues, especially the esophagus. The more severe recessive form (RDEB) is characterized by blisters over large body surfaces, loss of nails or rough or thick nails, atrophic scarring, milia, itching, anemia and

growth retardation. Severe forms of recessive DEB (RDEB) also may lead to severe eye inflammation with erosion of the cornea, early loss of teeth due to tooth decay and blistering and scarring inside the mouth and gastrointestinal tract. IN most people with this form of EB, some or all the fingers and toes may fuse. Also, individuals with recessive DEB (RDEB) have a high risk of developing a form of skin cancer called squamous cell carcinoma. It primarily occurs on the hands and feet. The cancer may begin as early as the teenage years. It tends to grow and spread faster in people with EB than in those without the disease.

#### How Is Epidermolysis Bullosa Treated?

Persons with the mild forms of EB may not require extensive treatment. However, they should attempt to keep blisters from forming and prevent infection when blisters occur. Individuals with moderate and severe forms may have many complications and require psychological support along with attention to the care and protection of the skin and soft tissues. Patients, parents or others care providers should not feel that they must tackle all the complicated aspects of EB care alone. There are doctors, nurses, social workers, clergy members, psychologists, dietitians and patient and parent support groups that can assist with care and provide information and emotional support.

#### Caring for Blistered Skin

When blisters appear, the objectives of care are to reduce pain or discomfort, prevent excessive loss of body fluid, promote healing and prevent infection.

The doctor may prescribe a mild analgesic to prevent discomfort during changes of dressings (bandages). Dressing that are sticking to the skin may be removed by soaking them off in warm water. While daily cleansing may include a bath with mild soaps, it may be more comfortable to bathe in stages where small areas are cleaned at a time.

Blisters can become quite large and create a large wound when they break. Therefore, a medical professional will likely provide instructions on how to safely break a blister in its early stages while still leaving the top skin intact to cover the underlying reddened area. One technique is to pat the blister with an alcohol pad before popping it at the side with a sterile needle or other sterile tool. The fluid can then drain into sterile gauze that is used to dab the blister. After opening and draining, the doctor may suggest that an antibiotic ointment be applied to the area of the blister before covering it with a sterile, non-sticking bandage. To prevent irritation of the skin from tape, a bandage can be secured with a strip of gauze that is tied around it. In milder cases of EB or where areas are difficult to keep covered, the doctor may recommend leaving a punctured blister open to the air.

A moderately moist environment promotes healing, but heavy drainage from blister areas may further irritate the skin and an absorbent or foam dressing may be needed. There are also contact layer dressings where a mesh layer through which drainage can pass is placed on the wound and is topped by an outer absorbent layer. The doctor or other health care professional may recommend gauze or bandages that are soaked with petroleum jelly, glycerin, or moisturizing substances, or may suggest more extensive wound care bandages or products.

#### Treating Infection

The chances of skin infection can be reduced by good nutrition, which builds the body's defenses and promotes healing, and by careful skin care with clean hands and use of sterile materials. For added protection, the doctor may recommend antibiotic ointments and soaks.

Even in the presence of good care, it is possible for infection to develop. Signs of infection are redness and heat around an open area of skin, pus or a yellow drainage, excessive crusting on the wound surface, a red line or streak under the skin that spreads away from the blistered area, a wound that does not heal and/or fever or chills. The doctor may prescribe a specific soaking solution, an antibiotic ointment, or an oral antibiotic to reduce the growth of bacteria. Wounds that are not healing may be treated with a special wound covering or biologically developed skin.

#### Treating Nutritional Problems

Blisters that form in the mouth and esophagus in some people with EB are likely to cause difficulty in chewing and swallowing food and drinks. If breast or bottle feeding results in blisters, infants may be fed using a preemie nipple, a cleft palate nipple and eyedropper or a syringe. When the baby is old enough to take food, adding extra liquid to pureed food makes it easier to swallow. Soups, milk drinks, mashed potatoes, custards and puddings can be given to young children. However, food should never be served too hot. In the most severe forms of EB, a gastrointestinal tube is inserted and liquid supplements are given daily.

#### Surgical Treatment

Surgical treatment may be necessary in some forms of EB. Individuals with the severe forms of the autosomal recessive Dystrophic EB whose esophagus has been narrowed by scarring may require dilation of their esophagus for food to travel from the mouth to the stomach. Patients whose fingers or toes are fused together may require surgery to release them.

There is no cure for EB. The only treatment is proper wound care. This vital coverage acts as the skin for individuals with EB. Without it, infection and sepsis almost always ensues. These dressings are changed daily and sometimes twice daily to prevent infection. The parents and families of individuals with EB revolve

around day-to-day wound care. There is only ONE treatment for this condition: cover the chronic wounds with ointments and bandages. Unfortunately these supplies are outrageously expensive and some families pay as much as \$5,000 a month for these products. Which family can afford this? Many families are forced to skimp on their supplies; some have to lie about their income so they can apply for social programs... No family can afford such a bill unless they are independently wealthy.

Last year, Representative Morin, Representative O'Connor, my daughter Rachel and myself met with insurance industry leaders who supported and endorsed us.

There are approximately 50 individuals living with EB in Connecticut. Approximately 16 have the dominant dystrophic form of EB, 10 have the recessive dystrophic form of EB and 22 have the simplex form of EB.

Attached is an itemization of the cost of wound care coverage for my daughter, Rachel, who has the recessive form of EB.

I ask you to please carefully consider this bill. Thank you.

Laura J. Morris, MPH  
389 Prospect Street  
Wethersfield, CT 06109  
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Cost of Wound Care Coverage for a Person with Recessive Dystrophic  
Epidermolysis Bullosa

Telfa dressings (\$.05 per unit x 500 per monthj)	= \$ 250.00
Mepilex dressing (\$11.99 per unit x 25 per month)	= \$1,199.00
Flexicon bandage 6 inch (\$2.49 per unit x 100/month)	= \$ 249.00
Flexicon bandage 4 inch (\$1.49 per unit x 48/month)	= \$ 73.00
Guaze pads 4x4 (\$.20 per unit x 100/month)	= \$ 20.00
Bactroban ointment (\$45.99 per tube x 16/month)	= \$ 736.00
Micropore Tape (\$1.95 x 4/month)	= \$ 8.00
Latex gloves (\$15.00 per box x 1 box/month)	= \$ 15.00
7 cases Ensure (\$62.48 per case x 7/month)	= \$ 38.00
Enteral nutrition bags for Gtube (\$14.83 per unit x 30/month)	= \$ 445.00
Bard Gtube connector (\$8.33 per tube x 30/month)	= \$ 250.00 *
 Total Monthly	 \$ 3,447.00
 Total Yearly	 \$ 41,366.00

\*Not covered under Medicaid

Mr. Chairman and members of the Committee, my name is Racheal Verdicchio-Morris and I live in Wethersfield. I write this letter in support of Bill Number 5023. An Act Requiring Health Insurance Coverage for Wound Care for Individuals with Epidermolysis Bullosa

5023

I was born with one of the severest forms of EB called Recessive Dystrophic Epidermolysis Bullosa; or RDEB. I have been fairly lucky in my 25 years with EB because I have received some of the best wound care coverage available. Currently Medicaid is covering the majority of my supplies. This has provided me with the opportunity to maintain my health, to move, thrive, and live throughout this world. I am incredibly fortunate. However, many individuals in Connecticut are not as fortunate, but this bill presents a variety of opportunities for all of us living with EB in this state.

Wound care is vital for survival for someone diagnosed with EB. Wound care is a daily routine that is a two-fold process because the wounds of EB are internal and external. My skin is sensitive to the slightest forms of friction. A simple hug can do a world of damage. Bandages act not only as an agent for healing wounds but also as the protective layer of skin I wasn't born with. It allows me to be independent, get out into the world, and share a hug. The skin within the body has its own set of challenges as well. I receive blisters inside the eyelids caused from the rapid movement during REM sleep. I also get blisters and wounds in the esophagus due to the simple daily task of eating food. Whatever nutrition I do take during the day goes straight to healing. Since my body is covered in at least 80% of wounds, I will never be able to do enough to generate healing with food alone. Therefore, I have a g-tube placed in my stomach and receive extra (or rather just enough) nutrition during the night to keep the healing process going. Regardless of the form of EB, the need for wound care remains the same. We need these bandages to live.

I am only 25 years old and that may seem young but when it comes to wound care coverage, absolutely nothing has changed since the moment I was born. Is it fair that I can have the opportunity to receive health but others with the same disease within our communities cannot? I ask you to please carefully consider Bill 5023. Thank you.

Racheal Verdicchio-Morris  
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