

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

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Source: <http://sci.tech--archive.net/Archive/sci.med.diseases.lyme/2005-04/msg00210.html>

- *From:* "a_weisman@xxxxxxxx" <a_weisman@xxxxxxxx>
 - *Date:* 5 Apr 2005 13:10:43 -0700
-

Okay so you KNEW it was coming. Despite having engineered this developing fiasco, WE OWE THEM ALL THANKS!

And Ellen Lubarsky chimes in based on all her "expertise" as a "lyme activist" and based on all her "sophistication politically"

UNfreakingbelievable!

The update on the Maryland bills– YIKES! – LymeNet Flash
<http://flash.lymenet.org/ubb/Forum1/HTML/032966.html>

Author Topic: The update on the Maryland bills– YIKES!
Tincup
Frequent Contributor
Posts: 1691
From: The Moon
Registered: Jun 2004
posted 02 April 2005 11:00

Greetings fellow Lyme Net Members..
We have a problem.

If you can take time to follow this process.. of getting bills passed from a grass roots effort.... it MIGHT help YOU in YOUR state and prevent you from doing things that are going get messed up.

My motto– Experience is what you get when you don't get what you want.

I just arrived home from out of state, late last night... and while gone I had a long conversation with folks in some of the political offices about the 2 bills.. trying to check all options and get help with the NEW problems facing us.

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

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1. Maryland Senate Bill SB 596

2. Maryland House Bill HB 1323 Lyme Disease Task Force Bill

First.. let me say the folks in Annapolis, MD think you all have done a VERY fine job with presenting the bills and supporting them. They feel we have reached the hearts of those in the House and Senate... and they are ALL for helping us... which can be seen by the unanimous votes we got on EVERYTHING!!!

GOOD for YOU!

Thank you for your efforts to help us and eventually yourselves and our future generations. We all did what we needed to do... honorably and beautifully. And YOU are the reason why this bill was passed so far and had ANY attention paid to it. Thank you!

As for the hearings...

The biggest problems with the hearings were that we were allowed only 3 minutes each to fully educate a group of decent.. but admittedly non-Lyme literate... folks who wanted to help us. Unfortunately, also... some of the folks we are dealing with were "tight" with the state Health Department and/or Hopkins.. who basically have been major pain in the necks in this state concerning Lyme disease. Of course that is something we have no control over.. and have to try to work around.

Anyhow...

After seeing the political process through to this point... I have noted we suddenly have some BIG problems.

Basically... we need to kill the Maryland Lyme Disease (SB 596) bill... ASAP. We need to work as hard killing it as we did supporting it.

It has changed. It is no longer the nice bill we submitted.

It WAS a beautiful bill that has been basically hit by a hurricane from outta no where. Our nice happy bill has been axed somehow and changed into a monster.

Since there is no way to "pull" the Senate Bill 596 out of the process at this time (I tried).. we are now stuck with it in the amended hurricane damaged form, which in MY opinion is another disaster waiting to happen.

Now.. you ask.. what the HECK happened? Well.. that is just what I have been asking!

It seems the folks in Annapolis have the "right" to change our bill in any way they want.. which they did... unexpectedly... and which made

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everything different and put us in a worse situation!

If this bill passes in the new amended form... I foresee us not only having to fight like we already are for every treatment, every insurance dollar, and every decent doctor.... but to have to fight even MORE for those things!

What it basically says now is the Maryland Board of Physicians way of thinking about Lyme treatment is THE way to go.. and THEY will dictate to all Maryland doctors HOW to treat Lyme disease in the form of a yearly letter to them!!!

But most importantly .. it has taken away the doctors protection, the ability to have long term treatment, and the insurance coverage.. and THOSE THINGS are what our original bill was all about and are what we REALLY NEEDED!

I have researched the Maryland Board of Physicians members to see if there was a chance we would be ok with the amended form of the bill and to see if there was a chance this was a better version.

I am dismayed to learn that most, if not all of the members, have a link to Hopkins, and/or insurance companies, and/or the Health Department, and/or the Infectious Disease groups and/or the old Maryland Board of Physicians.

I learned that the old Board of Physicians was accused not too long ago.. by some folks... to be so one sided they had to have a law enacted to reorganize the whole group and basically clean house. It seems they were accused of being biased on the doctors side of an argument... and are possibly attempting to START to clean up their reputations with the passage of a new bill? Will they be better? With members linked to the organizations above... I won't hold my breath.

Sooooooooooooo.. all in all.. not great news for us!

I see (from experience and from knowing what I do after 15 years of fighting this stuff) .. and admittedly from some paranoia about what COULD happen.... and the true desire in my heart to HELP Lyme patients... that the current Board of Physicians could possibly hand out limited duck guidelines on treatment that will NOT be in our favor or improve the situation and get us treatment.. will NOT get us insurance coverage... and will NOT protect our doctors.

It will be THEIR version of Lyme treatment... most likely without OUR input.

Keep in mind. the Health Department has claimed after basic treatment that Lyme is "sterile" and there is NO live bacteria present and no

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need for additional antibiotics. And Hopkins.. well we ALL know about them.. their horrible track record with tick borne diseases.. and their MAGIC PILL THEORY (one pill prevents/cures Lyme after a tick bite).. and their link to big ducks... and the nightmare position many folks were left in after being seen there... etc. NOT PRETTY!

If we are allowed "input" (like meetings with the Health Department or the Board).. which I feel they are attempting to do right now to set up just another horse and pony show at this time to save face or ACT like they are doing something about the problem.. after bluntly saying they didn't think it was needed and they were doing a "fine" job already... and Rabies was more important.. and they don't have time to fool with it.. blah blah blah..

Anyhow.. how can we know ANYONE will follow OUR suggestions at this point.. or the ILADS guidelines... especially after the example before us now, where the whole bill we submitted (and which had hundreds of people supporting it) was gutted and replaced with a monster without our knowledge or permission?

This amended form also possibly puts any Maryland doctors (and other states who use this bill, if passed) who are trying to treat us.. or who are on the fence... in REAL trouble. If the Board of Physicians Lyme treatment guidelines are issued to all Maryland doctors.. like this bill requires... then the doctors who do not "stick" with these guidelines may possibly be opened up to charges for not following THAT protocol. ???

There are MANY possible negative consequences to think about if this bill passes like it is now.

In my opinion... we need to respectfully let the House know that the Senate Bill SB 596.. in the current amended form... is NOT what we want!! SHOUT IT FROM THE MOUNTAIN TOPS!

The House members already think they helped us by passing the Lyme Disease Task Force Bill.. which I will discuss further later.. but basically they have no clue of the problems which can arise if the Senate bill passes in the form it is in now.

The other individual members of both the House and Senate THINK they are doing the "good" thing for us... but just don't know Lyme... or our total situation... bless their hearts.

We need to remember the Senate voted this through with the thought of it HELPING us. They ARE trying to HELP us... so we need to let them know we do appreciate their assistance and NOT knock them in the head... which is what MY first reaction was until I checked into it more.

They just don't understand the possible consequences of the bill in the

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amended form... and at this time we don't have enough time to do much at all except kill the bill... IF we can... and hopefully try again at a later date.. or go with another approach.

May I suggest?

EVERYONE start writing and making calls immediately to every House member in Maryland since that is where the bill is headed at this point.

Ask the HOUSE members NOT pass the Senate bill SB 596 in the amended form.

Tell them it is NOT good for Lyme patients. Tell them we would rather wait for a year until the Lyme Disease Task Force Bill they already passed has had time to "do it's job"... and THANK them for their help on BOTH bills.

Seems even in politics there is a turf war of sorts.. and asking the House to KICK a Senate bill, well it just might make them smile... since the one THEY passed MAY get supported by us??

I will write later about MY opinions on the House bill. Right now.. I smell breakfast cooking!

PS... The above is all MY opinion... so please keep that in mind.

I will also make a new post so it is in MUCH simpler form as to what is needed to be done.

Again I thank you for listening and helping us through the process. Without you we would be no where.

IP: Logged

cave76

Frequent Contributor

Posts: 3893

From: Santa Rosa CA

Registered: Mar 2001

posted 02 April 2005 12:06

Arghh!!!!

[i]The biggest problems with the hearings were that we were allowed

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only 3 minutes each to fully educate[/i]

Like Woody Allen said--- War and Peace: It's about Russia.

Do people think that these machinations are deliberate? Or just unknowing and following a different agenda?

cave76

IP: Logged

Paisley
Frequent Contributor
Posts: 254
From:
Registered: Nov 2004
posted 02 April 2005 13:10

TC,
how did you learn that the original bill had been hacked up so badly?

Since i'm fairly new here I'm not so aware of your advocacy role – it's a lot of work – basically how do you stay on top of this stuff?

Do you follow each phase of the bill until it gets passed through?

AND, my last question...how does MY support from out of state help?

thanks for your hard work

regards
paisley

IP: Logged

Tincup
Frequent Contributor
Posts: 1691
From: The Moon
Registered: Jun 2004
posted 02 April 2005 13:10

Hey ho ho cave..
Laughing at the Russia comment... ha!

Now what's this big word you are using on me? "Machinations"??
Hmmmmm.... If it means chomped up changes... this is MY opinion.

And YES I have a dictionary.. but I am too busy right now to run down stairs and go look it up... MOM! hehehe

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At first I thought it was an IDIOT thing going on ... big time... due to the Hopkins junk and the Health Department involvement. But after speaking with folks in Annapolis.. and being shown the light .. I really think now that the most of the folks in the voting seats ARE trying to help us.. somewhat?

See.. even I am too flaky on this politic stuff. I am not use to thinking with any agenda other than one that helps people.... so I am not POSITIVE! But my impression is the majority of the folks voting on bills THINK they are helping us... and they WANT to help us.

I still can't help but feel that a handful of rotten frog livers MAY be purposely messing us up ... but others who vote seem to trust these "people" for whatever reason... so they follow along with their suggestions, not knowing better. And funny thing.. I DID send them a copy of Camp A and Camp B. But I don't think... unless you have been in OUR shoes.. the Lyme situation can easily be understood by the "common folk".

I don't feel we can salvage the bill the way it is now. And I feel it is dangerous to try to depend on those not familiar to do the right thing... especially with the influence in Maryland coming from rotten frog livers like Hopkins and the Health Department.

I think the Senators who sponsored the bill had the right intent and just don't understand the consequences of what could happen if the bill passes in that new amended form.

So I don't want to kick them... and it would take too long to deal with all of them because they are so busy right now with sooooo much stuff... so the best thing is.. with all due respect to the original sponsors.. is to KILL THE BILL... and pray we can.

Did that answer your question, Ms. Webster?

If you get the choice to sit it out or dance...

IP: Logged

Aligondo Bruce
Frequent Contributor
Posts: 69
From: Stillwater,OK,USA
Registered: Sep 2004

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

posted 02 April 2005 13:17

I hope you guys have money and access to good lawyers, because it sounds like you may have to consider going to court to fight this bill and/or the maryland physicians board if it passes.

IP: Logged

cave76

Frequent Contributor

Posts: 3893

From: Santa Rosa CA

Registered: Mar 2001

posted 02 April 2005 14:12

tincup,

Did that answer your question, Ms. Webster?

Yes, it did, thank you----- maybe because we both have Lyme and think in circles or parallelograms. (Another big word for you)

And, I have to say it made much more sense that the spin that people put on these matters----- afraid to speak plainly and not seeing things as they really are.

As in:

"Cowardice asks the question – is it safe?
Expediency asks the question – is it politic?
Vanity asks the question – is it popular?
But conscience asks the question – is it right?"

And there comes a time when one must take a position that is neither safe, nor politic, nor popular;

But one must take it BECAUSE it is right."

Dr. Martin Luther King

So, trying to pare your answer down:

1. my impression is the majority of the folks voting on bills THINK they are helping us... and they WANT to help us.
2. handful of rotten frog livers MAY be purposely messing us up
3. others who vote seem to trust these "people" for whatever reason... so they follow along with their suggestions, not knowing better
4. unless you have been in OUR shoes.. the Lyme situation [can't] easily be understood by the "common folk".

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5. I think the Senators who sponsored the bill had the right intent and just don't understand the consequences of what could happen if the bill passes in that new amended form.

6. Kill the bill unless it's as perfect as it can get at this point; don't settle for less.

I think you may be right—— it's just a bunch of rotten frog livers (LOL) spoiling the whole bunch, to mix metaphors.

Is there anyway to figure out who they are? Or is that something that would be so buried in babble as to take forever to find out?

Could a good guess be made?

Would it be a department that wants the money *we* want. (As you can tell, my political savvy is limited to watching West Wing)

Working from the other end, how can those people you think want to help be educated?

Would it be possible to, instead of trying to pass one bill after another ——that usually gets either killed or watered down (same thing) to where it's almost useless.

I said *almost*—— for those that feel compelled to point out the small progresses made so far.

Well, I've talked myself into a circle. What do you think can be done? (Other than trying to push another bill through at this time?)

Sigh. Alas and alack.

cave76 (And thanks TC for doing all that work!)

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Tincup
Frequent Contributor
Posts: 1691
From: The Moon
Registered: Jun 2004
posted 02 April 2005 14:52

Paisley and others..
I will respond.. but am in the middle of some confusing and busy stuff at the moment... ok?

.....

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

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Here is the amendments made. This is what is left after a 3–4 page bill. Basically the whole bill was gutted and replaced with a few lines allowing the Board of Physicians to make up the rules.

.....

Copy of Senate bill SB 596 in the amended form:

<http://mlis.state.md.us/2005rs/billfile/sb0596.htm>

Click on the PDF file spot above to see the trashing of the bill as it really looks NOW.

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2005 Regular Session
SB0596/504733/1

BY: Education, Health, and Environmental Affairs Committee

AMENDMENTS TO SENATE BILL NO. 596
(First Reading File Bill)

AMENDMENT NO. 1

On page 1, in the sponsor line, strike Aand Stoltzfus@ and substitute AStoltzfus, Hollinger, Conway, Britt, Brochin, Greenip, Grosfeld, Harris, Kittleman, and Pinsky@; strike in their entirety lines 2 and 3 and substitute AState Board of Physicians – Information Regarding Lyme Disease and Other Tick–Borne Illness@;

strike beginning with A allowing@ in line 4 down through Adisease@ in line 15 and substitute A requiring the State Board of Physicians to develop and disseminate a document to certain licensees regarding certain diagnosis and treatment information for lyme disease and other tick–borne illness; requiring the document developed and disseminated by the Board to include certain information regarding the use of certain antibiotic or antimicrobial therapy; requiring the document to be distributed annually; and generally relating to the development and dissemination of information regarding Lyme Disease and other tick–borne illness@;

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and strike in their entirety lines 21 through 30, inclusive.

AMENDMENT NO. 2

(MY NOTE– LOOK HOW THEY TOOK OUT PAGES 2–4 TOTALLY!)

On pages 2 through 4, strike in their entirety the lines beginning with line 5 on page 2 through line 11 on page 4, and substitute:

A(A) THE BOARD SHALL DEVELOP AND DISSEMINATE A DOCUMENT TO ALL LICENSEES REGARDING THE MOST RECENT DIAGNOSIS AND TREATMENT INFORMATION FOR LYME DISEASE AND OTHER RELATED TICK–BORNE ILLNESS.

(B) THE DOCUMENT DEVELOPED AND DISSEMINATED UNDER SUBSECTION (A) OF THIS SECTION SHALL:

(1) INCLUDE THE MOST RECENT INFORMATION REGARDING THE USE OF LONG–TERM ANTIBIOTIC OR ANTIMICROBIAL THERAPY; AND

(2) BE DISTRIBUTED ANNUALLY. @;

and in line 12, strike A3.@ and substitute A2.@.

IP: Logged

bettyg

Frequent Contributor

Posts: 1088

From: Central Iowa, USA

Registered: Aug 2004

posted 02 April 2005 15:41

TC, thanks for the update on this HUGE HATCHET job! I noticed the latest editing was done this morning, April 2, 2 am!

To the Marylanders, please bookmark the bill link TC furnished you. You then can go in there anytime, and check on the updated status! That's how you can follow a bill when folks do NOT let you know about it from your local legislature.

I totally agree w/TC; this will NOT benefit lymies!

Bettyg

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Tincup

Frequent Contributor

Posts: 1691

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

From: The Moon
Registered: Jun 2004
posted 02 April 2005 16:45

Here is the list of House members emails. We need to contact them to ask them NICELY to KILL the Senate Bill 596.
THANKS!

george_edwards@xxxxxxxxxxxxxxxxxxxx, Curt_Anderson@xxxxxxxxxxxxxxxxxxxx,
John_Astle@xxxxxxxxxxxxxxxxxxxx, Susan_Aumann@xxxxxxxxxxxxxxxxxxxx,
Charles_Barkley@xxxxxxxxxxxxxxxxxxxx, Joseph_Bartlett@xxxxxxxxxxxxxxxxxxxx,
Kumar_Barve@xxxxxxxxxxxxxxxxxxxx, Gail_Bates@xxxxxxxxxxxxxxxxxxxx,
Joanne_Benson@xxxxxxxxxxxxxxxxxxxx, Elizabeth_Bobo@xxxxxxxxxxxxxxxxxxxx,
John_Bohanan@xxxxxxxxxxxxxxxxxxxx, David_Boschert@xxxxxxxxxxxxxxxxxxxx,
Joseph_Boteler@xxxxxxxxxxxxxxxxxxxx, Charles_Boutin@xxxxxxxxxxxxxxxxxxxx,
Bennett_Bozman@xxxxxxxxxxxxxxxxxxxx, Talmadge_Branch@xxxxxxxxxxxxxxxxxxxx,
Eric_Bromwell@xxxxxxxxxxxxxxxxxxxx, William_Bronrott@xxxxxxxxxxxxxxxxxxxx,
Anthony_Brown@xxxxxxxxxxxxxxxxxxxx, Emmett_Burns@xxxxxxxxxxxxxxxxxxxx,
Michael_Busch@xxxxxxxxxxxxxxxxxxxx, Joan_Cadden@xxxxxxxxxxxxxxxxxxxx,
Rudolph_Cane@xxxxxxxxxxxxxxxxxxxx, Jon_Cardin@xxxxxxxxxxxxxxxxxxxx,
Jill_Carter@xxxxxxxxxxxxxxxxxxxx, Virginia_Clagett@xxxxxxxxxxxxxxxxxxxx,
John_Cluster@xxxxxxxxxxxxxxxxxxxx, Galen_Clagett@xxxxxxxxxxxxxxxxxxxx,
John_Cluster@xxxxxxxxxxxxxxxxxxxx, Mary_Conroy@xxxxxxxxxxxxxxxxxxxx,
Norman_Conway@xxxxxxxxxxxxxxxxxxxx, Bob_Costa@xxxxxxxxxxxxxxxxxxxx,
Jean_Cryor@xxxxxxxxxxxxxxxxxxxx, Clarence_Davis@xxxxxxxxxxxxxxxxxxxx,
Dereck_Davis@xxxxxxxxxxxxxxxxxxxx, Steven_DeBoy@xxxxxxxxxxxxxxxxxxxx,
John_Donoghue@xxxxxxxxxxxxxxxxxxxx, AnnMarie_Doory@xxxxxxxxxxxxxxxxxxxx,
Kathleen_Dumais@xxxxxxxxxxxxxxxxxxxx, Don_Dwyer@xxxxxxxxxxxxxxxxxxxx,
Adelaide_Eckardt@xxxxxxxxxxxxxxxxxxxx, George_Edwards@xxxxxxxxxxxxxxxxxxxx,
Donald_Elliott@xxxxxxxxxxxxxxxxxxxx, Page_Elmore@xxxxxxxxxxxxxxxxxxxx,
Brian_Feldman@xxxxxxxxxxxxxxxxxxxx, Peter_Franchot@xxxxxxxxxxxxxxxxxxxx,
William_Frank@xxxxxxxxxxxxxxxxxxxx, Barbara_Frush@xxxxxxxxxxxxxxxxxxxx,
Tawanna_Gaines@xxxxxxxxxxxxxxxxxxxx, Terry_Gilleland@xxxxxxxxxxxxxxxxxxxx,
Barry_Glassman@xxxxxxxxxxxxxxxxxxxx, Marilyn_Goldwater@xxxxxxxxxxxxxxxxxxxx,
Marshall_Goodwin@xxxxxxxxxxxxxxxxxxxx, Michael_Gordon@xxxxxxxxxxxxxxxxxxxx,
Melony_Griffith@xxxxxxxxxxxxxxxxxxxx, Ana_Gutierrez@xxxxxxxxxxxxxxxxxxxx,
Jeannie_Haddaway@xxxxxxxxxxxxxxxxxxxx, Peter_Hammen@xxxxxxxxxxxxxxxxxxxx,
Hattie_Harrison@xxxxxxxxxxxxxxxxxxxx, Keith_Haynes@xxxxxxxxxxxxxxxxxxxx,
Anne_Healey@xxxxxxxxxxxxxxxxxxxx, Henry_Heller@xxxxxxxxxxxxxxxxxxxx,
Sheila_Hixson@xxxxxxxxxxxxxxxxxxxx, Patrick_N_Hogan@xxxxxxxxxxxxxxxxxxxx,
Marvin_Holmes@xxxxxxxxxxxxxxxxxxxx, Carolyn_Howard@xxxxxxxxxxxxxxxxxxxx,
James_Hubbard@xxxxxxxxxxxxxxxxxxxx, John_Hurson@xxxxxxxxxxxxxxxxxxxx,
Rick_Impallaria@xxxxxxxxxxxxxxxxxxxx, Mary_Dulany_James@xxxxxxxxxxxxxxxxxxxx,
Sally_Jameson@xxxxxxxxxxxxxxxxxxxx, JB_Jennings@xxxxxxxxxxxxxxxxxxxx,
Adrienne_Jones@xxxxxxxxxxxxxxxxxxxx, A_Wade_Kach@xxxxxxxxxxxxxxxxxxxx,
Anne_Kaiser@xxxxxxxxxxxxxxxxxxxx, Darryl_Kelley@xxxxxxxxxxxxxxxxxxxx,
Nancy_King@xxxxxxxxxxxxxxxxxxxx, Ruth_Kirk@xxxxxxxxxxxxxxxxxxxx,
Susan_Krebs@xxxxxxxxxxxxxxxxxxxx, Carolyn_Krysiak@xxxxxxxxxxxxxxxxxxxx,
Sue_Kullen@xxxxxxxxxxxxxxxxxxxx, Susan_Lee@xxxxxxxxxxxxxxxxxxxx,
John_Leopold@xxxxxxxxxxxxxxxxxxxx, Murray_Levy@xxxxxxxxxxxxxxxxxxxx,
MaryAnn_Love@xxxxxxxxxxxxxxxxxxxx, Richard_Madaleno@xxxxxxxxxxxxxxxxxxxx,

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

James_Malone@xxxxxxxxxxxxxxxxxxxx, Adrienne_Mandel@xxxxxxxxxxxxxxxxxxxx,
Salima_Siler_Marriott@xxxxxxxxxxxxxxxxxxxx,
William_Mayer@xxxxxxxxxxxxxxxxxxxx, Susan_McComas@xxxxxxxxxxxxxxxxxxxx,
Tony_McConkey@xxxxxxxxxxxxxxxxxxxx, Pat_McDonough@xxxxxxxxxxxxxxxxxxxx,
Salima_Siler_Marriott@xxxxxxxxxxxxxxxxxxxx,
William_Mayer@xxxxxxxxxxxxxxxxxxxx, Brian_McHale@xxxxxxxxxxxxxxxxxxxx,
Maggie_McIntosh@xxxxxxxxxxxxxxxxxxxx, Robert_McKee@xxxxxxxxxxxxxxxxxxxx,
Herb_McMillan@xxxxxxxxxxxxxxxxxxxx, Pauline_Menes@xxxxxxxxxxxxxxxxxxxx,
Warren_Miller@xxxxxxxxxxxxxxxxxxxx, Joseph_Minnick@xxxxxxxxxxxxxxxxxxxx,
George_Edwards@xxxxxxxxxxxxxxxxxxxx, Brian_Moe@xxxxxxxxxxxxxxxxxxxx,
Karen_Montgomery@xxxxxxxxxxxxxxxxxxxx, Dan_Morhaim@xxxxxxxxxxxxxxxxxxxx,
Gareth_Murray@xxxxxxxxxxxxxxxxxxxx, LeRoy_Myers@xxxxxxxxxxxxxxxxxxxx,
Shirley_Nathan_Pulliam@xxxxxxxxxxxxxxxxxxxx,
Doyle_Niemann@xxxxxxxxxxxxxxxxxxxx, Nathaniel_Oaks@xxxxxxxxxxxxxxxxxxxx,
Anthony_ODonnell@xxxxxxxxxxxxxxxxxxxx, Jeffrey_Paige@xxxxxxxxxxxxxxxxxxxx,
Rosetta_Parker@xxxxxxxxxxxxxxxxxxxx, Joanne_Parrott@xxxxxxxxxxxxxxxxxxxx,
Obie_Patterson@xxxxxxxxxxxxxxxxxxxx, Shane_Pendergrass@xxxxxxxxxxxxxxxxxxxx,
Carol_Petzold@xxxxxxxxxxxxxxxxxxxx, James_Proctor@xxxxxxxxxxxxxxxxxxxx,
Neil_Quinter@xxxxxxxxxxxxxxxxxxxx, Victor_Ramirez@xxxxxxxxxxxxxxxxxxxx,
Samuel_Rosenberg@xxxxxxxxxxxxxxxxxxxx, Justin_Ross@xxxxxxxxxxxxxxxxxxxx,
David_Rudolph@xxxxxxxxxxxxxxxxxxxx, Christopher_Shank@xxxxxxxxxxxxxxxxxxxx,
Tanya_Shewell@xxxxxxxxxxxxxxxxxxxx, Luiz_Simmons@xxxxxxxxxxxxxxxxxxxx,
Ted_Sophocleus@xxxxxxxxxxxxxxxxxxxx, Richard_Sossi@xxxxxxxxxxxxxxxxxxxx,
Joan_Stern@xxxxxxxxxxxxxxxxxxxx, Nancy_Stocksdale@xxxxxxxxxxxxxxxxxxxx,
Paul_Stull@xxxxxxxxxxxxxxxxxxxx, herman_Taylor@xxxxxxxxxxxxxxxxxxxx,
John_Trueschler@xxxxxxxxxxxxxxxxxxxx, Frank_Turner@xxxxxxxxxxxxxxxxxxxx,
Veronica_Turner@xxxxxxxxxxxxxxxxxxxx, Joseph_Vallario@xxxxxxxxxxxxxxxxxxxx,
Michael_Vaughn@xxxxxxxxxxxxxxxxxxxx, Mary_Roe_Walkup@xxxxxxxxxxxxxxxxxxxx,
Michael>Weir@xxxxxxxxxxxxxxxxxxxx, Richard_Weldon@xxxxxxxxxxxxxxxxxxxx,
John_Wood@xxxxxxxxxxxxxxxxxxxx, Bobby_Zirkin@xxxxxxxxxxxxxxxxxxxx

IP: Logged

Tincup
Frequent Contributor
Posts: 1691
From: The Moon
Registered: Jun 2004
posted 02 April 2005 21:53

Hey Paisley..
Sorry to delay answering your questions. I will try now.

You said.. "how did you learn that the original bill had been hacked up so badly?"

I have been trying to keep in touch by phone with the Senators offices and there is also a web site (when it works) to let you know updates.

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Of course we don't KNOW until after the fact.. which is a kind of a bad deal.. in MY opinion.

You said.. "Since i'm fairly new here I'm not so aware of your advocacy role – it's a lot of work – basically how do you stay on top of this stuff?"

~smile~ I wish I could say I was "on top" of this stuff. Unfortunately politics are FAR from my normal thing to do. I only once ever bothered politicians.. and it was YEARS ago. I wanted to have sections of Virginia "saved" and placed into a special wilderness catagory to have them protected forever.

This Lyme stuff is a lot different.. and back then we had help from experienced folks... which we don't really have this time around. We have NO money.. NO lobbyists.. and NO real knowledge of what we need to do. Kinda flying by the seat of our pants. We DO have a delightful lady in one of the Senators offices who deserves MUCH credit for helping us along the way with basic ideas. Other than that.. we are pretty much hanging.

You said.. "Do you follow each phase of the bill until it gets passed through?"

Yes.. and funny thing... I am learning about each phase as we get there. There was NO time at all to prepare for any of this. The Senator decided to put the bill in for a vote and we were told afterwards that it had happened. We were only given about 10 days to learn and do everything.

I MUST give credit to ALL the folks in Maryland and other areas who pitched in to do as much as they could to help. The support group leaders were great.. as were the support group individuals who wrote, called, attended the hearings, and those who spoke.

Then the folks here on Lyme Net all pitched in too... like Cheryl with her "instant Maryland site" she created that was invaluable to all of us as we gathered info and had to deal with it.

It is mostly because of YOU guys this bill got the attention it needed. All of us working together were able to pull it off.

You said.. "AND, my last question...how does MY support from out of state help?"

Oh.. it does VERY much!!!

Some times I sat here completely overwhelmed and lost... and wondering if it was worth all the effort. Then I would see a "thank you" or nice word or two.. and it would give me a boost and keep me going. I don't care where you are from.. that support helps.

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Then there are the letters, faxes, phone calls and testimony that were important to get the politicians to notice us. Many of the efforts were from out of state and did a good deal to make folks aware and rattle cages. I actually heard one man (Senator) say he had letters from California concerning the Maryland bill. It MUST have impressed him to get that letter because he remembered it and shared the info with another person.

We need to let the politicians here know they are being watched by the entire country... and that it DOES matter what they do. We need them to know that what Maryland does is important to everyone in other states too and that we aren't just a few scattered "weird ones" running around this area hollering about nothing. We need to let them know we are a big and powerful group across the country so they don't dismiss the problem as insignificant.

Folks from out of state also have very good information and stories to share. You never know what a politician will pick up on while reading the letters.

Plus.. I write enough already. If I had to write ALL the Lyme stuff... I would NEVER make it. So every word you contribute helps .. and allows in state folks time to do other things... especially in a short amount of time.

I also read an editorial in a local paper which mentioned that their newspaper received letters from across the country concerning Lyme disease.. and because they did.. they paid attention.. wrote the editorial.. and covered the hearings in detail in several articles!

As you know.. there are many folks who are too ill to do much at any given time. Having out of state folks sharing the load and spreading the word is MUCH needed and appreciated. I know folks here who would "bring up" my posts while I was butt over head busy with other things all day and night.. and that was a blessing to see.

Plus.. had I not been hog-tied by Ellen Lu on several occasions in the past, and asked to help out with the New York stuff... I would know absolutely NOTHING about anything. I don't know much NOW, mind you.. but I do know my mouth is too big and to be careful not to spout off. She taught me that little diddy by kicking me from here to there many times.. and through this process I REALLY needed that reminder.

By out of state folks helping others.. they are better equipped to deal with their own states when the time comes. I have helped with all of the states efforts to date.. in one small way or another.. and each bit of work I did was a learning thing.

Trust me.. your help is VERY important. And if I thought it wouldn't be at certain stages.. I would NOT waste anyones precious time asking them

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

to make an effort.

Thank you for all you can do to help me and others across the country.

IP: Logged

cmichaelo
Frequent Contributor
Posts: 459
From: NY
Registered: Jul 2004
posted 02 April 2005 22:58

TC,

I am so thankful you're so much on top of this, that you caught the amendment changes and that you're putting so much effort into this.

THANK YOU!!!

One day you WILL get a hole in one.

Now to some stupid questions...

Is it only people from Maryland that should write their congressmen?

If not, say I live in NY, should I write the NY congressment, or any congressmen.

Michael

IP: Logged

Tincup
Frequent Contributor
Posts: 1691
From: The Moon
Registered: Jun 2004
posted 02 April 2005 23:34

Hey there cmichaelo...

I still like that name.

You brought up a good point that I hadn't thought of.

We DO need EVERYONE's support here.. no matter where you live. So please do write to the folks listed above.

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

About YOUR state... hmmmmmm..

If you are already writing.. it certainly wouldn't hurt to copy your letter to YOUR local and state politicians with a brief side note saying you support Maryland's bill and hope to have one in YOUR state soon that they will support!

We need to be "in their face" as much as possible... no matter where they are located.. so a little reminder to them would be a real Martha Stewart... "a GOOD THING"! Or... a Tony Tiger... "Grrrrrrreat!"

So I guess my advise is to Nike (JUST DO IT)...

Yes.. dear heart.. it IS past my bedtime! HA! Can you tell?

Thanks for the kind words.

Night night...

If you get the choice to sit it out or dance...

IP: Logged

cmichaelo
Frequent Contributor
Posts: 459
From: NY
Registered: Jul 2004
posted 03 April 2005 12:08

TC,
I remember from sending emails to Gov Pataki's office last fall, that it's important to put your name and address on the letter or email that you write to them.

I'm not sure what the procedure is for writing MD congressmen, but it's probably the same.

My point is that if we don't put full required contact information in our mails to these guys, the mails may be ignored as they are not considered "legal".

So, TC, what exactly do we have to include in terms of contact info:

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Full name?
Address? Partial address? State for sure?
Phone number?
Gender?
Other?

Any other "procedures" to follow, aside from what you pointed out in your first post?

Michael

IP: Logged

ellenluba
Frequent Contributor
Posts: 133
From: New York, NY
Registered: Oct 2001
posted 03 April 2005 13:59

Tincup,
I was never particularly a Kenny Rogers fan, but I've been walking around humming his song this afternoon.
I just realized that the words to the song are "You gotta know when to hold them and know when to fold them."

That should probably be a mantra of political organizing. Whenever you get a bill in a legislature, half of the skill is knowing when the bill has been amended too much to be good for us.

Thank you , Tincup, for being so astute and letting us know it's time to write to kill the bill.

Maryland is way ahead anyway. You already succeeded in getting hearings in front of the legislature. That's a big deal. The rest of the process will just take time (and a lot of pushing from Lyme patients).

>>From the hearings you got a bill. The fact that the bill has been undermined is just part of the process. We'll all help to try to kill the bill , and then I know that you and Maryland Lyme patients will be back working until you get through a bill that we'll all be happy with.

Thanks for all your work.
Ellen

IP: Logged

NP40

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Frequent Contributor
Posts: 325
From: Northern Wisconsin
Registered: Jan 2005
posted 03 April 2005 15:09

Tincup, I put this in another thread, so I wasn't sure if you saw it. Maybe I read the bill incorrectly, or they've made amendments that I'm not aware of, but.....here goes....
I'm not so sure defeating this bill is the proper way to go. The legislature by their own admission were reluctant to "tell doctor's how to treat".
By appointing this task force, the legislators have passed the buck to the task force.

By reading this legislation, you'll have 11 members appointed to the task force. By my count, you'll have 5 ducks, and 5 LL individuals. The toss up would be the head of the dept. of Natural Resources.

They have to appoint an ILADS member, 2 support group members, a National Lyme representative. This may be a great opportunity to bring awareness to the duck camp. The legislation is set to expire a year from now, so if it doesn't work, it's going to be toast anyhow.

If you have trouble with Hopkin's ducks, you can always go back to the legislator who initiated this bill, and complain.

Look, nobody's getting treated in Maryland anyhow, what do you have to lose ? At least you have a seat at the table, it's a start.

I would seriously reconsider trying to strike down this bill. If you have reservations about this panel sending out poor, or unfair treatment protocol's, to Maryland doc's, you'll at least have the ear of the legislators, to voice your complaints.

Maryland doc's already follow the Steere camp, so really, it can't get any worse. I'd try it, take the couple of seats on the task force, and try to educate these people.

If things need to be amended, or you encounter difficulties, go back to the legislators. If you defeat this bill, what are the chances of ever having the opportunity to get a seat at the table, or get sponsors for new legislation ? I'd doubt the odds would be very good.

Look, at least the support groups have gotten their nose under the tent. Is it everything you want ? No, but you have to start somewhere.

Think about it.

IP: Logged

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

bettyg
Frequent Contributor
Posts: 1088
From: Central Iowa, USA
Registered: Aug 2004
posted 03 April 2005 15:52

Quoting Tincup
"Ask the HOUSE members NOT pass the Senate bill SB 596 in the amended form.

=====
Tell them it is NOT good for Lyme patients. Tell them we would rather wait for a year until the Lyme Disease Task Force Bill they already passed has had time to "do it's job"... and THANK them for their help on BOTH bills:

NP, after reading your note, I had to go back to TC's long note to clarify things myself.

She is asking to stop the lyme bill of protecting the drs. & long term abx treatments.

That's the letter we must address by sending an email to the list of their legislature.

REMEMBER: just copy that list of folks and show in BCC area so ALL their names are NOT shown. Send it to YOURSELF. This way it's more personalized to them ... they will see their name and not all of the others.

Michael, yes, when you send your email to the above list of legislature members, show your full name and STATE only where you are from.

Those folks living in that state should show their complete mailing address and phone no. IF they choose. But complete mailing address is mandatory so they can get back to you.

They don't need to get back to us out-of-staters. I sent my email to Penn; now a senator has added me to her EMAIL list of updating of their proceedings on ALL bills.

Bettyg, IOWA

IP: Logged

bettyg
Frequent Contributor
Posts: 1088
From: Central Iowa, USA

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Registered: Aug 2004
posted 04 April 2005 16:05

TC/others,
I just tried copying/pasting ALL the senators name to an email.

Yahoo would NOT me BCC this many people! So I tried block deleting the rest with no success.

I would suggest you send to 30–40 folks only and then send another 2–3 emails until you send to ALL listed senators.

Bettyg

IP: Logged

lou
Frequent Contributor
Posts: 1923
From:
Registered: Oct 2000
posted 04 April 2005 16:56

Betty and others, as I understand the situation, the senate bill intended to protect doctors is the one to be killed, being amended in lousy ways.
NP is not questioning that call. He is asking whether the task force bill passed in the House should continue to be supported, for the reasons that he listed. I don't personally have an educated opinion on this.

But, the point is that there are two bills in question:

1. Senate bill on treatment
2. House bill on task force

Having been passed in one chamber, both of these then need to go to the other chamber and passed there as well, in order to become law.

So, we shoot down the senate bill to members of the house

On the house bill regarding task force....someone needs to make the call, whether we want the senate to pass this too, or drop it for this year.

IP: Logged

NP40
Frequent Contributor
Posts: 325

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

From: Northern Wisconsin
Registered: Jan 2005
posted 04 April 2005 22:30

Thanks Betty, thanks Lou. That was my take as well. The one bill was completely demolished, it doesn't even pay to vote on it, because there's nothing left in it !

The "task force" bill seems like lymies, would at least get a seat at the table. Something in a Hopkins run state, they surely don't have now.

IP: Logged

JillF
Frequent Contributor
Posts: 1021
From: USA
Registered: Apr 2004
posted 04 April 2005 23:18

Up
IP: Logged

MammaLyme
Frequent Contributor
Posts: 2034
From: Maryland
Registered: Jun 2001
posted 05 April 2005 00:36

When one of the House members answered me today, they said they would have to read the bill again and decide if the amendments were good or not. Like they could tell. As one that testified, I would at least like the House bill to pass to start something through the Senate. That bill to study lyme disease passed 127-0.

After the great testimonies, I do not understand how a person cannot know what lyme disease does to people.

If you picked up the cd for the Senate bill you can hear all of the testimonies, the tape cuts it off with about 10 people left including the doctor idiot.

IP: Logged

daniella
Frequent Contributor
Posts: 315
From: Small Town, USA
Registered: Jan 2005
posted 05 April 2005 07:23

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

How can they just rewrite a bill like that? Shouldn't there be some kind of insurance when it is written so that it can't be taken back apart?

Didn't they do this in Ny State a few years back?

daniella

IP: Logged

bettyg

Frequent Contributor

Posts: 1088

From: Central Iowa, USA

Registered: Aug 2004

posted 05 April 2005 13:52

Daniella, from what I've seen in the political bills, nothing is sacred unfortunately!

Jill, please put the name of the 1 senator whose email is incorrect!

Then when folks copy/paste they can either delete that senator's name or make a note when it is returned to them, it's wrong....thanks!

I can only send 1 email/HOUR to senators; so it's time to send the next bunch....having to split it up into 3 emails to send to this LENGTHY list of senators.

Jill, how many senators does your state have? Don't want to take the time to count but would help also when dividing up the entire list of names to send in 2 or 3 emails.

Bettyg, Iowa

IP: Logged

minoucat

Frequent Contributor

Posts: 1336

From: WA

Registered: Jan 2004

posted 05 April 2005 15:26

TC, are the responses from the members in any way useful to you, just so you know who thinks what? I'll forward them if you want (pasted into one message!)

IP: Logged

All times are ET (US)

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Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL

• **References:**

- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: a_weisman@xxxxxxxxxx
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: derdrittemann2003
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: a_weisman@xxxxxxxxxx
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: a_weisman@xxxxxxxxxx
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: Rita Stanley
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: pmerv
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: a_weisman@xxxxxxxxxx
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: Rita Stanley
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: eugeneshapiroisapig
- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
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- ◆ **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
◇ From: a_weisman@xxxxxxxxxx

- Prev by Date: **Re: Dark field microscopy**
- Next by Date: **Re: dark field microscopy**
- Previous by thread: **Re: Phyllis: Activists Say YIKES We need to KILL the MD BILL! LOL**
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