

ongoing. It's been a waste of time if not effective it really doesn't promote consensus.

>>You've taken advantage of being office of a chapter to launch into topics that have nothing to do with the chapter that you don't want to put into the report. It has nothing to do with supporting the recommendations of the chapter.

>>They do support it plus as Jim noted with the charter of the working group 1 of the things is affordable access for patients to care that stores health.

>>You need to get that into recommendations and I hope to do it because you have not done it effectively at all anything to do with access to care for the recommendations of this chapter.

>>You're welcome to do minority response to this pick

>>That's what I'm telling you this. Because there will be.

>>There's a vote that you can do a minority response but we have not had votes on some of these things. So again I think to go through each of these comments, the only valid, it was the one we just talked about. I don't think there's anything else in here. There might be one of the comment but these are just the same comment over and over again.

>>I don't think so David. We've done this for many hours. Hours and hours. More than probably the rest of the working group reports put together. We addressed these comments that don't have any real specific asks, it doesn't support it it's been all the way through. I don't think we need to go any

further. I think we have done our part and we are willing to move along because we don't feel that we need to discuss this any longer.

>>You have not addressed these issues. If you just go through them I would appreciate it. That's exactly what this hour is set aside to do.

>>Can you please weigh in about our protocol for the agenda today?

>>Before you do that I would go to the protocol for last meeting agenda what you did was you went back and voted on things that weren't supposed to be scheduled to be voted on. It took up a lot of time then you got to our report and you cut it off.

>>You took two and half hours to delay moving to the meeting and that is what took all the time from the last meeting.

>>Excuse me, that was not my issue. Because you work behind the scenes to change protocols and then you did not want that brought up in public. I brought it up and I'm very happy that I did.

>>

It's always the same comments. The same thing. Move ahead. We don't need to meet a dead air. That's what's happening here.

>>You're trying to brush over this chapter and railroaded through without listening to the critiques and that is wrong.

>>Were not railroading. That hardly describes the process. I'm happy to have people compile the numbers of hours that we have in the transcript that people have taken down to show how much was done with our chapter compared to others. And

what stringent criteria we were held. Including all of our citations as compared to some of the other stuff that was put into other chapters. Nobody looked at or talked about until I noted it or one of the person  
>>The outlier in topics that are unrelated. That's the reason it's been under discussion.

>>

Further discussion of individual comments is not going to get us any further. I think we have had ample communication and differences of opinion have been expressed but we have not come to consensus so we need to vote on the overall chapter because it's not the individual comments of the overall some of the balance of the chapter. I feel there's not an overall balance of the chapter and I'm uncomfortable on the lack of balance and the misrepresentation or the depiction of the clinical trials overall. They are listed as preempts there is trials done and two additional trials done under grant it's the overall focus on the minority finding of those studies rather than the overall preponderance of evidence adding to that the overall depiction I think that's a good way to characterize. I think what we need to do is call to a vote and see how many people feel that way and how far apart we are before wasting additional time on individual comments that really aren't the point.  
>>I would say Dennis, thank you for your honesty and I know you're espousing what the party line is. The party line for 46

years has been let's bury the patient's. I've worked for 36 years and an advocate for those with chronic Lyme disease and I have never in my life seen the hatred that I've heard from some people in this group over providing information that is totally verifiable. We have sources coming up but you don't want to accept them. David doesn't want to accept the or Schapiro. I don't know who else want to accept them. Nobody else gets the same scrutiny. This group was willing to accept a 1904 piece of citation in this report. But we have citations coming up in the best institutions over many years and you don't want to accept it. Nobody said here, you can't say chronic or persistent Lyme excess. I think the community is tired of it. Other things are going to happen because this working group, and I'm not saying this to everyone here. Because most of you have been very cooperative in working to get to a bottom-line. Some of you have not so now we get to the 11th hour and what is surprise you want to deep-sixed the report. The only report that addresses what happens with patients. I'm sorry that you think the NH is sacrosanct. So much that the bodies of people that were charged with doing research and talking about what research should be done were not even willing to take in chronic Lyme disease research. That's why we couldn't get it done or published. That's happened for years. So you're not sacrosanct. The NIH is not sacrosanct. I happen to think

that we have to do something for the hundreds and thousands of people over the years that have been affected. The government doesn't want to do anything about it so I don't know why you're sitting at this table if you don't want to do something. We have compromised plenty and removed tons of stuff. Compromising on the fact that Lyme disease is the most prevalent tickborne disease affecting the most people and it's more people who aren't able to get treated because the government doesn't want to recognize they are sick. You want to send them all to psychiatrist. I've had people who I know personally that have been put into institutions and weren't able to be treated. To get out and to be treated by Lyme disease they got out and they got better. This includes children. I'm sick of it. I saw children seizing in the 90s from Lyme disease and hospitals. Worked at the hospital what that they do, they had the audacity when these people had remissions from these seizures, they took videotape of the kids talking and said these kids were faking. It's a tragedy that's gone on too long. Somebody has to do something. I had higher hope that this group was going to be able to do something and I am disappointed. I shouldn't be because my hopes should not have been that high picks I agree that we need to do something for these people who are suffering. That's why I'm so committed to the resource section on how we need to explore and understand

better the pathogenesis and suffering of the individuals so that we can intervene with the most appropriate method.

>>In the nine months time that I'm speaking here. What has been done just in that time period. Had 46 years. And what did you do. You covered up a disease. I remember it from the 80s, from the 90s, you tried to covered up as a disease you try to cover it up as a spread then you went and covered up where it was and it isn't just CDC it's the NIH to. It's about time somebody stood up and said we have to do something that directly impacts getting help for these people

>>We are trying to uncover, not cover, the mechanisms the mechanisms and clinical means to address it.

>>And you didn't have time enough or money enough. I saw the inventories. I know what you did. I know what you should've done but no, that was not done. I only saw a few years of those inventories and so your never getting to the bottom line. People said it this morning. Wears the help for the patient's. There is none and now you want to remove their chapter? Well go ahead. I'm going to tell you what were going to do things with Congress that this group cannot do. Because it's obvious that some of you don't want to do it. The other people in the group and you know you are, are not speaking to you right now. I'm speaking to these people who had presented this from moving forward. It's unbelievable to me how a few pages of the chapter have been

so attacked.

>>I believe the survey you did and there is really exemplary of a group of people, thousands of people that you've surveyed who are suffering. They definitely need to be helped and we don't really know what's wrong with them. The problem is they are self reported saying that they believe they have persistent Lyme disease.

>>If you would have listened to the prior meeting.

>>They really don't they just say they've had Lyme disease and a high rate of co-infection with respiratory illnesses like mycoplasma and Barton&. These people definitely need help with but the help may not be Lyme disease. And if it is Lyme disease we need to understand how.

>>We discussed this patient registry. The patient registry. The people in that registry were asked if they had the doctor diagnoses and if they did not, they were removed from the registry. There's tons of patient registries and you just want to pick on this one because it doesn't meet your needs. This is typical. We want to take evidence. Evidence that you want to show that this isn't there. But the NIH and the CDC and other agencies are respected institutions have. You don't come out and say anything about those practice registries are used everywhere. You only care because the sun shows the true extent of problems across the United States and across the world. You've had 46 years to do the research about what's wrong with these people if this isn't

what they have. Not only have that you've done it. You've relied on mainstream medicine which means they can't get more treatment in any way shape or form. They are not permitted. They are told to go to a psychiatrist even alternative medicines. That's unconscionable unconscionable. I move that this chapter be accepted with possible minor revisions.

Sam would you be willing to break that into two sections on the recommendation and the content of the chapter? He cannot, because we've already voted on the recommendations. >>That is a part of the chapter David. So unless we want to hear from other members of the working group, my motion stands that we move to accept Chapter 7 into the report.

>>I second that. >>I'd like to make a few comments based on statements that have been made. I think it's fully acceptable to express frustration that at this point in time will there's seeming to be I don't know what the right word is,, I think it's fully understandable to express frustration that we've gone three months of well-defined process to point to the opportunity where people can express in the share drive and in the public meeting when they did not like certain sections when they did not like certain areas and have the opportunity for dialogue so here we are at the 11th hour and I agree with that statement that this is not the time to start bringing up all over again, if you don't like something. So now you

don't like something almost from scratch. This is not that time. We are coming together as a group and trying to bring it to a close for the goal is a group. Not our individual desires. Because there's a lot of things in here individually that I do not care for. But that's not my job

I was brought into use my personal background and experience but I brought in as a group, as a working group member collectively, to serve the objectives of the working group. So now is a working group at this 11th hour. We are supposed to compromise and decide we want to represent. And guess what. We have that opportunity for the minority report. If we voted something down, we can choose to still put them in order in our report forward. I think we just have to agree to the process. We got an hour for this chapter and we probably dug into a lot of it already. With that being said. This is also not the time to go back to 25 or 30 or 40 years of history of what happened in the past. We don't have time for that and it's painful history. Everybody understands that but we cannot dredge all of that up. We don't have time for that and it doesn't serve us. Is is a meeting. This is not a documentary.

>>We need to come together. We are going to put forward a vote if there's a motion on the table if you don't like it, and move to the next one. But we need to come together we need to come together and serve the purpose of this chapter. You, all of you have the opportunity

month of opportunity, to take the sections you like and put in your comments to decide on what you wanted in this chapter. Now is the opportunity to voted through or make some minor suggestions. This is it. This is the last meeting. The next meeting is icing on the cake. Please, please pick >>Can I make a statement about the outcome?

>>Making sure we are all clear. My understanding is that we vote yes or no on including chapter. The chapter won't disappear and there won't be a chapter 7, it will depend on the boat. If there's a minority of opposition it will stand and minority reports will appear. Does a majority of the opinion not to have a chapter in its present form. Then a replacement for will have to be put into place. If people don't like that form then the report appears than. I don't take it just goes away. I see that as a way to recognize there is polarization on the overall expression of the content and itself then it's okay to disagree on something you just need to state your position.

>>That's correct. I would certainly be very happy that we proceed on this boat and if it goes down. I'd love to be able to present to Congress how this working group voted against a chapter, the one for the patient's. And the one that the patient had that input into and had it well-crafted and well done and spent hours of discussion on the I'd be very happy to do that and we will do that so let's move on and get the boat going [ Captioners

transitioning ]

With its current content and then have a minority report point out the various points of difference. To do the other way is going to be a little bit more difficult as I see it that is as Dennis said we have to place the chapter. That's like we don't really have -- that isn't important to say we don't have the time. That is part of it. I think you would be best to go ahead and vote the chapter and go ahead and supply a report. If we want to focus on one or two comments that is other than wordsmith it is valuable, I am happy to do that. But to echo Leigh Ann we don't have to revisit everything going on before. Let's just move on and hopefully the rest of the working group can either chime in during the discussion or [ Indiscernible ]

>> [ Indiscernible - overlapping speakers ]

>> I need clarity on Dennis' statements because this is the first time I am ever hearing that. It does affect this motion on the table. Dennis, if you could please restate what you said. I have never heard that before, and if it's new to me I'm sure it must be new to others. If you could just clarify what you said, that would be helpful. Just please reiterated reiterate it.

>> I am stating my assumptions. I don't know if it seems to be the facts but seems to be the way this has been progressing all along when you have vote yes or no then you proceed from that point. If the vote is to reject the chapter, I don't

think it disappears. I think it means we don't like its current form. Then there would be someone would have to rewrite the whole chapter or write it in a way that is acceptable to the majority. If the majority vote -- and if that happens if people don't like the new version, there would be a minority report just why that's not acceptable. And conversely, if the vote is to retain it as Sam has proposed, then those that don't like it that way would vote against it.

And the opinions would be expressed in the minority report. I heard Pat's concern likely so about that there's lots of good, valuable information in the Chapter. I think the point is whether or not you think there's an overall balance and if you think there's a significant problem with [ Indiscernible ] balance in that case I think it's hard to ask those of us who feel that way to vote to accept it in [ Indiscernible ] form. Does that answer your question? I mixed a lot of concepts together. I don't think that's a possible outcome. Is that correct Jim Berger or Ken Haynes?

Jennifer?

>> Dennis, that is correct.

This is Jim Berger.

>> [ Indiscernible - overlapping speakers ]

>> I would like to say something about the fact that these comments that are put in here were put in here by David. They are the same, set up and put in there before and he did not put in there that we were scheduled on the agenda last

month. In the last meeting and he didn't put these comments in there. So therefore, he cannot go back now and put these comments in and expect that we need to address them. We have addressed these 1000 times over and there was no reason for them to be put in here. It was on last time's agenda, and it was pushed, in my opinion, to the end as it always was so that we can be sacrificed and moved again and again until now we are at a critical point. And [ MUSIC ]

about this chapter and whether it will stand or not. I mean, this is ludicrous to me and I would like and at this point I call the vote.

>> I am not ready for that. There needs to be discussion on this. This is a very important decision, okay? All of us, we need to pay attention to our tone. We are trying to calm this down. When I tried to make it more caustic. This is important and everybody trying to make this work. We not trying to make it not work so let's pay attention to our tone and it also is about respect. Here's what's important about this decision. I am trying to understand what Dennis brought up because it's news to me. I can understand if somebody could's plan is to make. I don't understand how -- I understand is a motion on the table, what does it serve to start over in writing a whole new chapter -- in writing a whole new chapter which present all new -- all new opportunities for disagreement, okay? At the 11th hour, when we can't even come to agreement on this chapter. When the

processes we have had months to come to agreement on this chapter and we don't agree. It's a chapter that presents many opportunities for disagreement. Therefore, the solution is, if you don't agree, present in your vote as a minority on either the hold chapter or your vote on certain sections and provide a minority report.

>> That's what we have on the floor. The motion on the floor is to accept the chapter. We will fix the first comment because it was legitimate, it was confusing and we will fix that comment. These are the comments should've been done at the last -- be put on before -- they were not.

>> [ Indiscernible - overlapping speakers ]

>> Wait a minute, excuse me. As far as tone and respect, you have got to be kidding. Let me tell you. You've got to be getting. After all the things I have heard and seen how some people have reacted to patients, to our sick patients they are the ones that deserve to have the respect. And they have not gotten it. And so, therefore, we have a motion on the floor. I called the vote.

>> First of all, the motion hasn't been seconded. Secondly, I have a question. Could somebody please clarify what the requirement is for a minority report? Is one half to reject the chapter, can one accept the chapter but object to specific content and how does that happen because it sounds like we have only had motions to accept or reject the chapter. So Jim, can you

clarify what needs to happen to have a minority report included, please?

>> >> Okay. It's my understanding that for a minority response there can be either a rejection of the chapter or a rejection of comments.

>> Thank you. >> That has to be in response to a vote. That has to be a vote on one particular sections and that has not been done. And therefore right now we have a motion on the floor to accept or reject the chapter. If someone -- states not to accept the chapter they can do a minority report but there's nothing right now about any kinds of sections. And so, we have a motion, Sam, motion denies seconded it.

>> And I would add to what Pat is saying and what Jim said. When it comes down to a vote on an entire chapter, then the dissenting opinion that's written everything in the chapter is fair game. If we are voting on a specific part, then the second opinion can only be talked about that particular -- in this case we are voting on the whole chapter. So, to Jean's question, Jean, seconded opinion can be on anything-- [ Inaudible - static ]

>> We lost you. That would be an important part comment if it's possible to restate that.

>> Can you hear me now? >> Yes. >> What I was saying is in this case where we are voting on the entire chapter, whatever way the vote comes out if you or someone who has dissented and the majority from the majority

for the entire chapter your opinion that's written can cover that entire chapter. If we were voting on a specific section that would be different. The opinion would have to stick to that if you were in the minority but in this case that's not relevant because the motion by salmon seconded by Pat was the entire -- except the entire chapter as is other than the first one we talked about with the numbers and percentages, which we [ Indiscernible ] correct.

>> I think where the confusion is --

>> I almost wish the chapter could detect a point counterpoint and everyone knows this polarization on the topic and strong feelings on either side so noting that is okay. If there's a balance depiction of the two different approaches in general, that would seem to be a service to the community and to Congress.

>> You know, this has been -- I couldn't agree with Dennis Moore. Certainly CDC is clearly supportive of recommendations, and honestly, I'm not so much against what's written here. I think it's what's not here, and I think it's the whole idea of showing the balance. I mean, I am fine with registry data. But I think David makes a good point and we should point out limitations of registry data. You know, there's truly a point and counterpoint to this and this is a dilemma in which we live and we need to work out a way to answer these questions and resolve it but I think the way the chapter is written and LeeAnn, to your point, I don't

think that it's there to say  
these were 11th hour comments.  
It was something brought up  
very, very, very early on and I  
think can support those who  
have been outspoken about this  
that the balance just is not  
been put in there and in that  
sense the comments have never  
adequately been addressed.

Again, I'm supportive. I think  
was in here is good and this is  
incredibly important chapter.  
And it doesn't need to be  
deleted or even rewritten. It  
just needs to be balanced with  
the other side of some of these  
issues. That, to me, is really  
the issue of debate here.

>> [ Indiscernible -  
overlapping speakers ]

>> I wanted to add that all I'm  
saying is that what you just  
said is a great point that we  
should've just had in the  
comments, like, you know what I  
mean? [ Indiscernible ]

>>

I think that one of the --  
criticisms or comments made  
without offering an alternative  
to what was already written.  
Now we stand here at the 11th  
hour, Ben, I think that these  
comments -- this chapter has  
been this way for a long long  
time and it's okay for us as  
members of the group to  
question or provide a comments  
but wouldn't it be more helpful  
to have also added then I would  
like to see it phrased this way  
for better balance? But now,  
how are we going to do that?  
Are we going to delete the  
latest again? To find a better  
balance until December 2 or  
have another interim meeting of  
some sort? I think we are stuck  
you.

>> Thank you, Sam and thank you, Ben. I will say in defense of what Pat and I have done throughout this process I feel like we have acted in good faith to address the comments that we have gotten, all of them unless they were just -- they were just criticisms without any constructive part to it. As Sam was saying there was nothing offered and I will say this last round, the preponderance here is just to comment this is irrelevant. And with nothing to offer, so if that needs to be pointed out, particularly to the public listening in because they might not be able to see these comments and since we will not go through each one a lot of them are just that. And that's -- we've gotten those in the past and there's not a whole lot you can do but we have. We have addressed even those in the past. You know, to explain why it's not irrelevant. So I think we are at really a point here. With acted in good faith. We have tried to respond. And work together. I think we are at a point where Sam put the motion and Pat seconded it. To either accept the chapter as it is other than that one area or, you know, to not accept it and then we will proceed from there.

>> Just a point here I'm trying to make -- flush out what's meant by balance versus why did you bring up individual comments. The overall tone of an entire page is hard to fix with one or two comments so if you just focus on the text about the NIH trials and include the European trials,

which are even bigger and did the same thing, you see such things as comments about the poor design, you see inconsistencies in result. You see controversies. The results are rather consistent. I think the disparity is in the to interpretation of the results. So if you look at the very fine European trial done by [ Name indiscernible ] Goldberg and colleagues I have known Bob since the early 90s when he came into the effect it is the them the clinical trial network that I went for 15 years. He took on the challenge of Lyme because he noted previous randomized trials have not shown convincingly that prolonged antibody treatment has been beneficial to patients. Which is true. The trials are showing that additional drugs are not beneficial and yet there's controversy over interpreting that so they decided to do another trial and it had three arms and they took people with the defined criteria and they gave them two weeks of [ Indiscernible ] I.V. and if they had persistent systems they randomize them into three arms. There was no difference between the parsley bull and treatment in those groups so they summarized the results. The overall preponderance of evidence is that there is no benefit from additional antimicrobial therapy. This is written almost the opposite and there is no data to show that this additional therapy would not be beneficial or that there are elements taken of the secondary endpoints for one of

the global score to show that that part of the global score improved at week six but not at week 12. It's that overall feeling you have in reading the entire page that it can be fixed with a sentence here and a sentence there. That's just an example of how that purvey the chapter.

>> Excuse me, Dennis, but I believe you were most meetings and if you weren't present Sam Perdue was and to give you both credit you made the meetings. However, we discussed that issue very clearly and in response to those comments many, many months ago and we said no we are not talking here. We are talking about U.S. trials. We are not talking about trials in other countries. We were very clear about it. We said it, we stated it, we made changes to that whole section. Many, many rounds of changes throughout that whole section and no one ever put it up again. And now, now that you guys have pushed this till the 11th and a half hour and you want it rewritten again and you want to bring up all that old stuff again, well, sorry, Dennis, but we're not going to do that. We are not going to bring this up again. That was already discussed. You can go back and find it in the transcripts and if that's the case but it's there and we are not going to do this again. And I call the question we have a motion and a second on the floor.

>> Another interpretation of that is the changes that were made did not have significant impact on the concerns that

were registered.

>> That is not true because no other concerns were registered on that aspect after that. The only concerns that have been continuously registered are concerned that don't provide anything and just say that doesn't belong in the chapter. And so, we've addressed everything and then some. And I have no -- my conscience is not at all feeling anything about that because I know we went above and beyond the call of duty to get this to a consensus state and, you know, and then to see now here you are and you're going to shoot it down. Well, please be my guest. Shoot it down because I'm going to tell you it's about time that this nation understood where it's government stands online disease in particular chronic and persistent and those patients. I think they need to see it clearly and believe me this will drive it home. I'm perfectly fine to go with this and we have a motion and a second on the floor. Let's do it.

>> I have a question for you.

>> I'm am not -- >> Does the decision making inception trying to force physicians to offer an effective, dangerous options to the patient's?

>> I disagree. David you cannot make that kind of statement without more experience. And, Dennis, you know, we have talked about the European trial and it had a big fatal flaw which was duration of treatment. A couple of others. Let's not presume that appropriate duration of treatment, which is the key to

the critique of all of the existing trials and whether that's correct or not remains to be seen but needs to be supportive. We can't be dancing around that there is another cause when it's staring us in the face. So, again, this goes on and on. I guess if the chapter gets voted down by the working group it gets voted down and we will have to take it from there following Jim Berger's and Kaye's and Jennifer's. I can't let it make the assumption and the rest of the working group that may not have as much experience with taking care of patients don't really know whether they need their alliance to go with one person or another but I think the chapter, everybody agrees it's valuable. So let's put it in there and then critique it with your individual minority reports after the vote or if it's voted down then the minority reports will have to go the other way.

>> I want to address David's question, and David, here's my response. First of all, it's not my judgment. I am not a physician. I have never pretended to be one. However, I can read and I can also assess information that is provided by the tens and tens of thousands of patients and physicians across the country. And I can look at [ Indiscernible ] guidelines which were the IOM approved the way the [ Indiscernible ] guidelines were developed. They were the last ones on the national guidelines clearinghouse as a matter of fact before the government defunded the clearinghouse.

Those guidelines stand up. They give the doctor the right to make a clinical decision based on what they see and also based on the kinds of testing that they do and considerations of the background and the patient's history and the differential diagnoses etc. etc.

>> I agree with that, Pat. >>  
And that is what our chapter talks about basically is that there are two sets of guidelines and that there is clinical judgment shall be permitted because for heaven sakes otherwise let's not bother sending those guys to med school because what good is it if they are not allowed to use the clinical judgment and they are basing that on guidelines that were on the national guidelines clearinghouse approved by AHRQ.

>> What if the decision is dangerous and ineffective? To they had to present the alternative treatment?

>> David, you are telling me I have been giving dangerous medications for years excessively treating those patients. Sorry to hear you say that. Please, let's vote.

>> Sorry, one more question on the procedure, Jim Berger, if the vote is about the whole chapter and, sorry, hypothetically the whole chapter is devoted through but there are areas in the chapter that people seem to have disagreements with, let's say the whole chapter is devoted through, is that any opportunity for people to make motions on certain sections if they want to then

supposedly go through with minority reports on certain sections? I'm confused on the procedure since it was established last time so can you --

>> If you voted through it's voted through and approved.

>> Right. That's why we need to make sure this is clear.

The last meeting the new procedure was established. It was knew that in order to write a minority report you have to be in the minority on the chapter itself or on a section. So that's why making sure this is clear. If the chapter is actually voted through then how are minority reports allowed if the whole chapter is voted through and you, per se, wanted to still provide a minority reports on a certain section?

>> Leigh Ann this is Jim. For clarification, the individual would have had to vote no on the chapter for them to provide a minority response. If they voted yes on the chapter they have no reason than to provide a minority response.

>> You have two vote -- >> The reason for no can base testified in the minority report so it's clear it's not on everything but it's on a particular element.

>> Exactly. >> Thank you, Jim. You have two vote to know even if you agree with 99% of the reports but this one thing you really feel passionate about. You have two vote no in order to provide a minority report?

>> On the chapter, that's correct.

>> That's what we did last time? It seems like --

>> [ Indiscernible -

overlapping speakers ]

>> It shouldn't have been done that way.

>> Even if they agree with the chapter they can still provide a minority opinion.

>> No. Not now based on what was set up last time. Let's say I agree with the whole chapter the whole chapter that goes through but I want to provide hypothetically a minority report now I have two vote this chapter no. Based on what -- that's terrible.

>> Could we call the vote please. We have had ample time for discussion. There is nothing new being said. We have a motion on the floor.

>> I want to make sure, Pat, everyone understands how that procedure works.

>> I think if they don't understand it now is because they don't want to.

>> That's not true. It's confusing.

>> It has been said here about 500 at least. I'm sorry, I don't mean to be rude about this but we need to move on and we have a motion and people need to express themselves one way or the other and that's what this is about.

>> I just wish we could address sections of this and not the whole thing because it's just throwing the baby out with the bathwater.

>> I think that, no offense, Ben, but the government longtime throughout the baby in the bathwater and those were our patients. You threw them out, you left them there and this, to me, just stomping all over them so I don't think it could get much worse. I have

never spoken this way at anything I have sat on before in this manner but I just feel like this is -- it's so ludicrous I can imagine what the people are thinking out there but I can be pretty sure of it and it's disgraceful. It's absolutely disgraceful so let's get it over with. If you're going to cut us out, then left to cut out.

>> I would like to go on record making a statement that what I think is the most profound finding from the [ Indiscernible ] trials zero negative is the documentation through quantifiable criteria that the patient met the eligibility for posttreatment Lyme disease syndrome were, in fact, ill to the level of someone with congestive heart failure which is beyond the level of myocardial infarction. That was proof that the individuals are indeed ill and need to be addressed and they need to be understood in order to manage them properly, so I don't think we disagree and need to help the patients.

>> Is it appropriate to offer an amendment here and try and say we approve the chapter with the exception of a certain comments areas that need to be addressed? Is that possible to do that?

>> [ Indiscernible - overlapping speakers ]

>> I would be supportive of that. I would be very supportive of that because I don't like the procedure that was established on the minority report which means you have two vote down the whole chapter in order to have some adjustments

in certain contents. I think that's terrible.

>> That's the procedure but the thing is there were opportunities earlier to not get to this point. We actually did have, I think, they were motions put forth on particular sections in previous meetings that actually didn't get seconded so we didn't even go to a vote, which meant that there was no second person who thought those particular sections were worth voting on. So, unfortunately we have got to this point where it is in either or, and to address what Sam was saying, it may be possible, to me it's acceptable at this point to --

>> I agree with you because I advocated about 15 minutes ago. I advocated not to make those changes, not to -- that we had all those months to put in our input and I advocated for that and I was making sure that we didn't have to disrupt the process. However, last meeting was the meeting where this minority report thing was put into a new process, and so, I don't believe it was clearly understood and I will be the first to admit. I wasn't understanding it until now right in front of me there's an understanding that you have to vote the whole chapter through without any room for a section to have a little bit of change if you don't agree with a certain little section that you want some change to. In other words, some editorial changes here and there in order to vote the whole chapter through. I'm not comfortable with that because I think it's --

personally I'm just going on record, I think it's a very important and very good chapter and I would like to voted through. However, there are certain areas that I think you need a little bit of changing and now that have to make a choice between one or the other, unfortunately, that's terrible. I don't want to have to not put the chapter through and that's my personal statement and I'm fine saying that on the record.

>> I understand how you feel. We have proven -- we haven't been able to have those changes that we could agree upon.

>> We had those changes. We made changes. They were not challenged at the next meeting. The problem is that there are those of you, and I don't know how many there are and at this point I don't really care, you don't want to do this. You don't want to do this because you know that this is wrong, first of all, this is totally wrong what's being done and it's all part and parcel -- you keep saying this process was changed. This process wasn't changed. This was the process it always was. But you tried to alter it and you did things that were not brought up to the public and we discussed them. The two hours David talked about and blamed me for, they were because you couldn't make up your mind as to what to do about it. Well here you are, my mind has been made up for I don't know at least now half an hour, 35 minutes, had the motion on the floor, and Scott and I, since we put her blood, sweat and tears into this we

know where we are at and where we are at is we want to vote on this, and let people do as they feel in their hearts they have to.

>> Pat, there's something that is not accurate. Last meeting up until that motion was put on the table about the minority report, if someone wanted to vote a chapter through, they could still vote through and still put a Manar to report through if there was a section that they wanted changed.

That's what's different here.

>> Know what was different was that behind the scenes you people try to -- I don't know who you were because I still am unclear about that -- may changes in the process and then to declared those changes what didn't it

>> Guest: We would like what what is this? What you mean a person cannot vote on this. I had three different responses on that issue and so what happened was in public I forced the issue of it being brought to a decision in public that this is what the working group wants to do and that's the way the working group voted. And for you to say that you didn't understand, well, I'm sorry. After 2 1/2 or two hours whatever it was about discussion you didn't understand, I don't know why you understand now after maybe 45 minutes of discussion but the point is we want to move forward. And that's where we are at and Scott and I I think are in total agreement with that and we're not going to go back and redo this. We're not going to go back on these

comments that are comments with no substance and have already been litigated. This is like relitigation all the time, every meeting. And we're not going to do it. One meeting, which you were also very clear to tell us, which we, the working group, never heard that the next one is just simply going to be an administrative meeting because we don't hear these things. You meet behind the scenes and you don't tell us about your mundane meetings and what they entail. And so, we don't have any way of knowing what's coming down the pipe next. So let's not make it out here like there were changes that were made that were not valid.

>> There's a motion and a second on the floor. Let's call the question.

>> LeeAnn, we can deal with this after the votes somehow, so let's vote.

>> I think we need to vote

.

>> David can run through the list.

>> Beto. >> If I say we approve we approve the chapter.

>> You do not get to divide a Manar to report. Correct.

>> Approved. >> Angel. >> I also approve. I am in support of folks being able to write a Manar to report but that that is not something I will be doing so again approve. Ben >> I can't approve it as it's currently written. I-sad because I like -- it needs to be balanced so if I'm forced to vote yes or no at this point representing the CDC I have to

vote against it.

>>

Scott  
Commins.

>> Vote to approve. >> Scott  
Dixon,

>> Not to brew. >> Named  
stomach

>> Approved. >> Meyers. >>  
Kevin Macaluso.

>> We can't hear  
you.

>> -- Individual comments but  
that's not the point because I  
can't approve it because that  
table, I wanted to talk about  
it. No, not in its current  
form.

>> Todd Myers. >> Sorry I was  
on mute. This is difficult  
because you can't [  
Indiscernible ] the whole thing  
or not. And that's just -- it  
doesn't seem like we have  
consensus and I would like to  
read out consensus so we can go  
forward as a unified group so  
I'm going to vote no on this  
chapter.

>> Gene. >> No.

[ Name indiscernible ]

>> Yes.

Leith States.

>> I am going to vote to  
approve with the understanding  
that others are going to pursue  
a minority response. I  
understand that we are not  
going to reach consensus in the  
current state, but encourage  
others like Dr. [ Indiscernible  
] who have voiced their  
concerns with regards to having  
the moderate tone and all  
voices heard that can be  
commendably done through the  
response process.

>> Leigh Ann ? >>

I have made a lot of

statements and the Working Group members have heard and they want to particularly thanks some of the Working Group members for their personal insult and for trying to undermine my integrity. I really appreciate that. Obviously, you don't know me, so thank you for that. With that said, I am looking for the greater good of the report and I believe that this is a very important chapter. Although I will be clear to say that this is not the only chapter supporting patients. The entire report is supporting patients. The entire report. Not this one, not only this one. Because of that, because I believe the majority of this content is crucial to be represented in front of Congress, I am voting this chapter through. Although there are sections in here that I do not believe are properly written completely and I'm asking my other Working Group members because I support you and I support your position to please write the minority report. Thank you.

>> Cooper. >> I vote yes to accept the chapter.

>> My vote is no. We have

8, yes, and 6 votes no, so the chapter goes through.

>> What was Beto's vote? >> [ Indiscernible - overlapping speakers ]

>> Said yes, Beto? >> Yes. >> Thank you.

>> Correct. >> Next agenda item is the executive summary.

>> David and Leigh Ann, I have

a suggestion for the very first line. I would like you to read the tick borne Working Group 2020 report to Congress addresses continuing keycaps in the diagnosis and treatment of Lyme disease and adds focus on other tick-borne diseases. I think that's a stronger statement in regards to -- that we want to continue our focus on line disease. It kind of says the focus of the 2018 report and we are still focusing on it and in this it says were adding additional focus on other tick-borne diseases as was appropriate for this particular Working Group. I think we can accomplish both of those goals by

>> Guest: If the group is okay with that by changing --

>> -- I think that's what it says.

>> I think it says a little bit better, David, address continuing keycaps on line disease.

>> Do you want to make a motion?

>> I make a motion to accept the language I gestated.

>> Repeat the language you just said.

>> I don't know if Yanni took it down or what have you but what I said was starting with the report to Congress addresses continuing keycaps in the diagnosis and treatment of Lyme disease --

>> Sam, I'm sorry, your voice is very low volume and getting get some of those words.

>> I am on my phone. The 2020 report for Congress addresses continuing gaps in the diagnosis and treatment of Lyme disease and adds additional

focus on other tick-borne diseases and conditions.  
>> Sam has made a motion and he is restated the motion. Do we have a second,  
>> I will second that. This is Coop.  
>> We have a discussion. >>  
Hearing no discussion we will call the role.  
>>  
I vote no, I think the original states more clearly that we really added other tick-borne diseases.  
>> Leigh Ann .  
I can't hear your vote either to accept Sam's substitution or not.  
>> [ Name indiscernible ]  
>> Yes, I am fine with the tweak or modification.  
>> Coop . >> Yes, I vote yes for the change.  
>> Scott Palmer. >> Yes. >> Angel.  
>> Yes. >> Dennis. >> I'm sorry, could you restate the clarification proposed.  
>> Or could Sam? >>  
I was trying to get my program to wake back up.  
>> Dennis, what we have is the current sentence is the first time and it's being suggested to change from this point report to Congress addresses continuing keycaps in the diagnosis and treatment of Lyme disease and adds additional focus on other tick-borne diseases and conditions.  
>> Thank you. I am okay with that.  
>> This is Leigh Ann. I am okay with that. Sorry, I had to take a two minute break.  
>> Sam, yours I'm sure is yes he made the motion.  
>> Yes. >> Todd. >> Yes. >>

Kevin.  
>> Yes. >> Beto. >> Yes. >>  
Gene.  
>> I abstain. One of the  
matters.  
>> Pat. >> Yes.  
Leith States. Yes.  
>> >> Motion passes for the one  
suggested by Sam Johnson.  
>>

I will ask you all to please  
read it to yourself. I don't  
think you want me to read it to  
you. It's sitting there in  
front of you.