

INTERVIEW WITH ROSIE TORRES [10/14/14]

[BEGIN FILE]

WOMAN:

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[THEME]

DANIEL SULLIVAN:

This is Dan Sullivan with the Sergeant Sullivan Center podcast. I'm talking with Rosie Torres, the executive director of Burn Pits 360, by telephone. Burn Pits 360 is a registry that Rosie operates that, where people who have been affected by burn pit exposures in the post 9-11 era register. It's an independent registry which began before the implementation of the VA registry. And it has collected thousands of entries of people who are struggling for health care. And so let me just start by introducing – letting Rosie introduce herself, her work, and why she's involved briefly and then I have a few questions, Rosie – to ask Rosie related to the upcoming meeting at the Defense Health Board. Anyway, hi, Rosie. Thanks for – thanks for joining in the podcast today.

ROSIE TORRES:

Yes, thank you for having me, Dan. So – [OVERLAPPING VOICES] Go ahead.

DANIEL SULLIVAN:

No, go ahead. I – go ahead and –

ROSIE TORRES:

I just wanted to say, you know, this organization started – and I'll just be brief – after discovering an online community of thousands of other families that were affected by the same exposures that had taken the life of Joe Wilkins. Major Wilkins has been, Major Wilkins and many other soldiers that have already fallen ill or lost their life to the, to the diseases caused by the exposures. So we put Burn Pits 360 as an online resource tool, sort of, if you want to say, so that families like ourselves could access the same – have access to the same questions that we had. You know, there are many late night – and we were not the only family that were searching for answers. And so that's sort of the reason Burn Pits 360 started and then went on to put a registry together that could possibly in the future allow us to come up with a correlation between those airborne hazards and the illnesses and death resulting from that exposure.

DANIEL SULLIVAN:

And Rosie, can you tell a little bit about what happened in your life and your husband LeRoy's life that led you to begin this project?

ROSIE TORRES:

Yeah, so my husband, you know, was a captain in the army at the age of, he retired at the age of forty. He was also a highway state police here in Texas. And once he returned – actually, while he was in theatre, he began being symptomatic with breathing problems and several other issues he began having, so upon arrival from Iraq, from where he was deployed to in Balad, and not only Balad, but a couple of other FOBs that he'd visit daily, he became very ill and so ended up losing his job and his career and so we knew there was more of the story than just the VA and DOD saying there were no answers. So this led me to, you know, begin this mission on finding answers and if not answers, just access to health care or just an avenue of advocacy for these other families, but the main point was that it was my husband who was ill, who was healthy, never called in a day in his life to work, he was never ill, very healthy, very strong. And then he became a patient of many specialty doctors. So it was something deeper than just the Iraqi crud. So it was more than just the body de-climatizing from being in 120 degree weather, it was more than that. So we had to dig deep and this is what it took. And this is what it's still taking, so that's sort of what pushed us.

DANIEL SULLIVAN:

Now as I recall when we've been talking before, and especially in our advocacy work, your husband was sick and he

was traveling to a lot of different doctors trying to figure out why he was suffering from diminished respiratory capacity and that one of the things that happened was that he ended up at a war-related illness and injury study center in Washington, DC operated by the VA. Did they give him a diagnosis?

ROSIE TORRES:

No. His physician that initially evaluated him for over a year at the VA was also deployed to Balad. And he at that point knew that it was something beyond what he could assess. And then when I discovered the war-related, he referred us, I actually had to show him how to do the referral to get to the war-related. And once there, they also didn't address the issue. It was more, you know, being led to psychosomatic issues or anxiety, stress, instead of the actual issue with his not being able to breathe –

DANIEL SULLIVAN:

[OVERLAP] Did they offer –

ROSIE TORRES:

– no we left there with a diagnosis of unknown etiology and that was it. No continue of care or anything after that.

DANIEL SULLIVAN:

Did they discuss lung biopsies with you or offer to do a lung biopsy?

ROSIE TORRES:

The lung biopsy was denied. They stated on paper that they felt that it wasn't necessary, that he was not suffering from reactive airway disease, that he was not suffering from any type of lung issue. And that we could return home with that diagnosis of unknown etiology. So –

DANIEL SULLIVAN:

And is it then – is what happened next that you did, you were able to get a lung biopsy elsewhere?

ROSIE TORRES:

Yes, we were referred to Dr. Miller by a few other families – we weren't referred to him, we were just made aware of the services he was facilitating at Vanderbilt. And due to the nature of my husband's job, it wasn't a position as a service, you know, community service employee that unknown etiology was enough for them to decide what they were going to do with his job, because his job required a lot of physical activity on his part. So we continued to take them the DOD diagnosis, the VA diagnosis, which was really no diagnosis. And every time he'd go to work and we'd take these documents, they would say, no, there's something wrong with you and we need an answer. So we were very persistent to seek the services of Dr. Miller and he was able to one, sort of bring closure to the issue of his career, but he also saved his life. Because had he been put back on the force on the highway, we could have lost him to him being maybe in a physical altercation between him and, you know, a suspect or what not.

DANIEL SULLIVAN:

Right. And just to clarify for our listeners, Dr. Miller, Dr. Bob – Robert Miller is an independent physician and he's associated with Vanderbilt University and was among a team of physicians that uncovered deployment related lung disease as a signature wound of the post 9-11 era. And which was diagnosed through lung biopsies. So Rosie, as we've been talking about, a public health subcommittee of the Defense Health Board in November, in just a few days, really, is preparing to recommend that lung biopsies basically be taken off the table as a method for diagnosing deployment related lung disease. And are actually criticizing Dr. Miller for conducting the biopsies implicitly in the language of their recommendations. In my mind, what this does is it is going to deprive hundreds of thousands of people of a diagnostic procedure. Could you just share with our listeners what the value of, do you – what the value of the lung biopsy is and whether you've done, how it helped your husband continue to manage his health, if it did?

ROSIE TORRES:

Yeah, you know, I think it should be determined on the individual – individual case basis, you know, considering their health. If they're healthy enough to undergo a biopsy, that part I agree with. I don't think it should be done away with as a mechanism to diagnose such a severe disease. In our case, I have to say it saved his life. Again, let me emphasize that

his job required him – required a lot of physical activity on his part. So had we not done the lung biopsy and just embraced what DOD and VA were giving us, then he would be dead. And I say that, you know, cautiously, but I emphasize again the part that had we not known, he would have pushed himself to a point that could have, you know, caused him to stop breathing. I mean, cause the disease is caught, you know, it's triggered by exertion. Right, so if you know that with constrictive bronchiolitis and that you get physically exerted to the point where your breathing's effected, you're not going to push yourself to those types of levels. So I think this is the only way right now. I don't know if there are any other recommendations or other tools. I know that routine exams such as pulmonary function tests, such as chest x-rays, CAT scans, those things were not able to help my husband prolong his life because they weren't detecting any type of disease until he had the biopsy. So I think it's important that the Defense Health Board consider – or reconsider or just consider this exam and this test on a case by case basis. Of course, again, I don't know what the protocol's going to be on who determines who should have what and who shouldn't, but at this point in time, it's very important that they, you know, continue to consider it as the one tool available. So the one method of saving lives.

DANIEL SULLIVAN:

Right. And I think the way you articulated that is just right. At least from my perspective. I mean, neither one of us are doctors, but I think we can see the value that this exam has had for people that we know and care about. And I know from firsthand the horror of living with an unexplained illness and that when you're caught, as my brother was, for whom – whose name we founded Sergeant Sullivan Center, in a holding pattern where your doctors tell you there's nothing wrong with you when in fact there really is, you then don't take the precautions that you need to take in order to survive and that leads to preventable death. And we want to, yeah, we want to work together and we are working together to help educate members of the Defense Health Board about the value that this procedure has had in saving lives. And we want to make that point very clear to them in November. And we want to make it clear to everyone who gets a chance to listen to this podcast that this procedure can save lives and it's very important that the policy – the policies that I believe the Defense Health Board are going to recommend are going to be consistent with what you and your husband LeRoy faced at the war-related illness and injury study center. Which is, you wanted a biopsy and they denied it. And that policy of denial of a basic diagnostic procedure which was indicated by the symptoms and the severity of the symptoms is something that I believe the recommendations as they stand will lead to and continue to propagate on a massive scale. And we have an opportunity in November to really come together to join together independent researchers, scientists, doctors, advocates, patients, people who are suffering with this problem. And let's get our voice heard by this Defense Health Board. So that if they do recommend with basically a continued policy of withholding diagnosis and treatment and testing for deployment related lung disease, they are doing so with full and complete knowledge of the fact that they are depriving basic occupational medicine to all service members of the United States of America.

ROSIE TORRES:

Absolutely, because what I'd say in our experience of having had walked that journey of attempting to access that care through the Department of Defense health care facilities, through the Department of Veterans' Affairs health care facilities, and neither one of them were able to correctly assess the diagnosis. I mean, everything they were giving him was not resolving the issue. You know, he continued to have choking spasms and coughing spasms to the point of passing out and not being able to, you know, to live his life to the point that we knew we were maybe pushing him a little too far or what not. And that's evidence that what they were using as a routine exam was not a reflection of what the underlying issue was. So, you know, chest x-rays or PFTs or their, you know, lungoscopies, whatever they were using, at the end of the day, didn't give us the truth. And so now –

DANIEL SULLIVAN:

And Rosie, I'm sorry I just – we have to wrap up the podcast. You want to finish, please, I interrupted in the middle of your thought. I'd like you to just sort of finish and then we have to wrap up cause we're running out of time. And I want to invite you to come back so we can continue to have this conversation. But would you like to go ahead and finish your thought and then I'll wrap it up?

ROSIE TORRES:

Yeah, and so I just, you know, in closing just to say that it's vital that they not do away with lung biopsies and it's only because, again, it does suppress your breathing if you don't know that you have constrictive bronchiolitis and they're misdiagnosing you with asthma or reactive airway or whatever they're saying that you may or may not have and then they, on top of that, prescribe you medication that will suppress your breathing, that they're putting you in another state of danger. So it's vital, it's important –

DANIEL SULLIVAN:

It's vital. Absolutely, it's vital. And together – and we are going to protect the right of service members to know what diseases are afflicting them especially when the tests exist to diagnose the disease. So Rosie, thanks for joining us on the Sergeant Sullivan Center podcast. Thank you all for listening. Please support us. Please support the mission. We're going to Dayton in November and we're going to go and fight it. Okay, thanks everyone.

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