

Waking Up the Nation,
One Reader at a Time...

PUBLIC HEALTH ALERT

Salute': Randy Sykes of Farmington Valley, CT



by *Dottie Ianni*

Welcome! We hope you will enjoy this new column "Salute" where every month we will be spotlighting an advocate/activist for their contributions in bringing awareness to chronic disease and helping others. I pitched the idea to our editor at the beginning of this year, and after review, it was agreed that it would make a wonderful addition to our publication, so it won approval. My only regret is that I did not start sooner, but as all of you know, life happens in between and now we could not be any

happier to unveil it just in time for the happiest of New Year gifts.

I hunted around for quite some time for a good name and even brainstormed with a few friends. In the end, Salute' became the title for several reasons. The first being, in my Sicilian heritage, Salute' literally means, "To your Health" and the second reason is the person we highlight has put so much time and effort into helping others they deserve a 21 gun SALUTE' for all their dedication and hard work.

Honestly, anyone who tries to bring awareness to chronic disease by any mode of communication deserves an award and bundles of praise. So if you would like to see someone highlighted here, please submit their name and contact information to: Tix_Suck@yahoo.com and put "PLEASE SALUTE [YOUR SUBMISSION'S



NAME] in the subject line. All submissions will be considered.

With the introductions out of the way, please help give a big Salute' to our first honoree, Randy Sykes of the Farmington Valley area by Hartford Connecticut.

When I first met Randy, almost seven years ago, I asked him how he got involved with being such a vocal Lyme disease activist and his reply was, "I met a Tick." With all he's been through he still has a great sense of humor, and in times like this we

all need a little humor to get thru the day.

In 1999, legislation was passed in Connecticut to mandate a law so that anyone from another state could come and purchase health insurance that covered Lyme disease. At that time many pre-members (that later joined with CT Lyme) attended this hearing and they saw that they had strength in numbers.

By 2000, Randy was very sick and the medical personnel said he had a plethora of goodies such as, Lyme

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disease, Multiple Sclerosis, possible Leukemia, Chronic Fatigue, Fibromyalgia and excruciating headaches. Fifteen plus doctors later, finally he received a diagnosis positive for Lyme disease by PCR.

Since then he has been a patient, a patient advocate, truth teller, chronic disease activist, a team player and support group leader for the past 11 years. He gave freely of his time to help so many others when he was so sick himself.

His accomplishments span many years of helping others cope with everything from chronic illness to making fuel to heat the house for the cold winters in New England. He spent endless hours on the phone, sometimes in the wee hours of the night, when someone was in dire need and had no where to turn. Over the years he has appeared on over 10 TV news shows and also on PBS channels speaking out about how they are hurting us and keeping us sick.

Early in 2001 out of the concern for others, he along with his wife Laura and Chris Montes formed The Greater Hartford CT Lyme Support and Action

Group. They met every 3rd Wednesday, once a month for support and to form some plan of action to help bring this terrible disease into the main-stream media.

Sometimes I would forget and call on meeting night, and I would catch him making sandwiches and loading the car with goodies, info boards, flyers and packets of information to give the attendees.

I can tell everyone from personal experience Randy has talked me thru many a "brain-anxiety-twitch-spell-going-to-die-right-now" gigs when I was at my regular job. I would publicly like to thank Randy for helping me in my darkest hour. I can never repay your kindness and thank you for being a friend.

If I have taken only one thing away from my journey thru Lyme it is, "We really only have each other to comfort and share our pain." It really upsets me to see others being disrespectful to any advocate or activist who is trying to make a difference, especially those who want direct and complain from their armchair, yet do nothing publicly to help stop this monster.

During 2002, The Greater Hartford Action and Support Group held several mini medical conferences that brought together both the doctors and the sick. Many times whole families attended as each member was ill from something they acquired from their own backyards.

In 2003, Karen Kopins-Shaw had a conference that The Greater Hartford CT Lyme Support and Action Group help organize. This was good experience for their group to help with Karen's conference as it was the forerunner to the 2004 Lyme disease Hearing with Attorney General Richard Blumenthal.

The CT Lyme groups had asked the CDC and NIH if they would send attendees to the hearing. Their invitation was ignored until someone finally told them there was not any personnel available to attend. Being relentless, the groups sent another demand for the CDC and NIH to be present. This time they did reply, they would send one from each entity but not without a lawyer present. At the hearing when questioned about an issue, they were vague and

only answered one half of the questions directed to them.

The last week before the hearing, there was unrest between the three prominent Lyme groups. Some wanted the wording changed on the bill. Randy confronted the groups stating some very good reasons why not to change the wording, and those groups were angered and tried to discredit him. At that time 50% of the people saw the discord within the groups and broke away and did not even attend the hearing.

The squabbling and nonsense among the groups did not deter Randy and the CT Lyme group and in 2005 their held their own conference. It was called, "The 30th Anniversary of Lyme disease with NO COMPASSION OBSERVED." Speakers were some of the greats, such as Dr. Jo Anne Whitaker, Dr. Lida Mattman, Professor Garth Nicolson, and Dr. Richard Horowitz. It was a very powerful conference and there was abundance of information shared by all. For those readers who attended, do you remember Dr. Horowitz singing and playing his guitar? He made up a Lyme

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song, quite cute, I must admit.

By the middle of 2006, Randy and The CT Lyme group had a protest at the front gate of University of Connecticut Medical Center. What a perfect area for them to stand and show and raise awareness.

Approximately 50 members attended with their various signs (on sticks!). Professional signs were made and they offered Randy's \$20,000 to any doctor who can "cure Lyme" within 6 weeks. The IDSA claims 10-14 days for a cure and that is the current recommendations set in place today. Not one person from any other group in CT or any surrounding state came to help the protest, yet it was publicly announced and emails were sent. It appeared at this time sick people were now choosing sides within the different groups.

In the fall of 2006, I had the pleasure of meeting Randy through another activist. He and I immediately became friends and one day brainstorming along with Kathleen Dickson, we decided to make a site that would actually use their own documents to prove they were lying

about the testing. What a novel idea, nobody had done this yet! We used page headings such as "Testing Failure for Lyme disease in their own words."

Both excited and driven, for months we gathered information and Randy spent hours going to the Library of Congress to scan the documents. Then it came time to name the site, and one of us said, "Hey what about Lyme Cryme? Because that is what they really have done. They have committed scientific fraud which is a heinous crime against mankind." This is how the Lyme Cryme website was born.

Since the opening of the site in the winter of 2006, as of today there have been over 2 million hits from many medical organizations all over the world. Truly we can say that since then, little by little we started to see the whole world take note and many changed how they diagnose and treat for "Lyme disease" and the like.

Randy offered a \$20,000 reward to be put up on the site. The IDSA claims Lyme disease is cured in 10 to 14 days and the money would be given to any doctor who

can prove that Lyme disease is eradicated in 6 weeks. The reward was offered for 5 years on the Lyme Cryme website without any takers.

As of today, most of the world lets their residents treat for bacterial infections as they deem fit. Some opt for natural ways others get stem cell replacement. Many other countries have given their residents options, everywhere almost, except the United States where it all started. Karen Forschner, Randy Sykes, Kathleen Dickson and I worked as a team to get this accomplished and it worked.

We proved to the world "IN THEIR OWN WORDS" THEY HAVE LIED ABOUT THE LYME DISEASE TESTING. We worked as a team to gather the various documents to back up what we were claiming. Not one of us did better or was better than the other. There was no leader or boss of another; it was pure TEAMWORK at its finest.

Some groups spend too much time singing their praises that just a few hear and nothing really is accomplished. Now I am not saying that every protest, booth, run or event that

a group puts on does not help bring awareness, it all does help...BUT as I have said before, we must all stand together AS A TEAM and be in their faces.

This brings us to October 15, 2010 when Randy appeared on Jesse Ventura's True TV show, Conspiracy Theories. This particular show was dedicated to Plum Island Research Center. Randy gave the producers over 400 governmental documents and they filmed him for 2 ½ hours. A month before the show was to air; the producer called him and told him they had to "water down" the show.

It was still very powerful and brought the message out loud and clear. Please view it on YouTube: Randy Sykes - Plum Island (www.youtube.com/watch?v=Bvn2vOfsQ8o.)

And please, folks make no mistake; these meanings are separate: [taken from Merriam-Webster]

1. Conspiracy: a secret plan made by two or more people to do something that is harmful or illegal
2. Conspiracy theory: a