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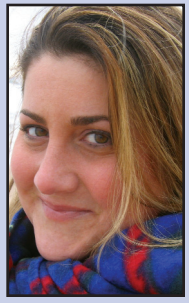
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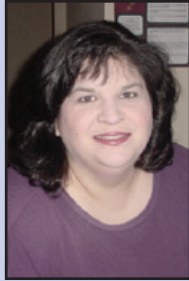
Investigating Lyme Disease & Chronic Illnesses in the USA

January 2008

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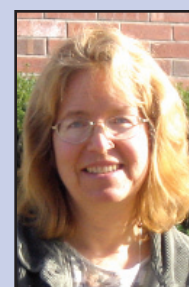
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Evidence Mounts Implicating Lyme Disease in the Autism Epidemic

PRWEB-- A new article in Medical Hypotheses, "The association between tick-borne infections, Lyme Borreliosis and autism spectrum disorders" was recently released. Robert Bransfield, M.D., the main author collaborated with top doctors in both fields on this paper such as Jeff Wulfman, M.D., William T. Harvey, M.D. and Anju Usman, M.D.

The summary of the article states that "Chronic infectious diseases, including tick-borne infections such as Borrelia burgdorferi may have direct effects, promote other infections and create a weakened, sensitized and immunologically vulnerable state during fetal development and infancy leading to increased vulnerability for developing autism spectrum disorders."

Bransfield et al, examine clinical observations, case reports, laboratory testing of patients with Autism Spectrum Disorder for tick-borne diseases, brain imaging results, epidemiological findings, infections and autism, tick-borne/Borreliosis infections and psychiatric illness and many other factors in this collaboration of research findings.

Numbers indicate that 20-30% of children with Autism Spectrum Disorder may be infected with Lyme Borreliosis and pathogenic Mycoplasma may be a contributor in 58% of cases. With these staggering numbers, families and physicians need education on the proper testing and

treatment methods currently available. With these 20-30% numbers representing around 140,000 cases of autism in the United States alone, the human impact of this disease is staggering. Bransfield et al states that "If just 20% of the 560,000 recognized cases of ASD in the US can be prevented or more effectively treated, this could result in a savings of \$358 billion in addition to the incalculable human impact of this disease."

The authors recognized the contributions of Charles Ray Jones, M.D. for decades of expertise and dedication in helping hundreds of children with Lyme Borreliosis and autism spectrum disorder.

Parents needing more information on testing and treatment can turn to the LIA Foundation for support. They are a non-profit organization which focuses on research, awareness and education on the multiple infections, including Borrelia/Lyme Disease, and how that impacts children with Autism Spectrum Disorder.

About Autism:

Autism is a disorder that currently affects 1 out of 150 children. Boys are the majority of those affected. The numbers of autism cases spiked in the mid-late 90's and continues to remain high. Most children do improve with some sort of biomedical and behavioral intervention.

About Lyme Disease:

Lyme disease is generally



Dr. Robert Bransfield, MD is the primary author of the recently released study on the association between Lyme disease and Autism. He worked with doctors from the fields of both diseases to report their observations.

caused by a tick bite and can be more effective when antibiotics are administered soon after the infection. Borreliosis is a long-term infection that exists and can be undiagnosed Lyme disease or transmitted in some other way. Symptoms include achy joints, confusion, slurring words, word retrieval problems, brain fog, sensitivity to light and sound. Lyme disease in its late stage can be fatal, causing MS like symptoms and debilitating its victims. One of the disorders in which Lyme

disease is known to mimic is autism spectrum disorder. **About the LIA Foundation:** The foundation was started in September 2006 by parents of children with autism and Lyme disease. Kathy Blanco of Beaverton, OR and Tami Duncan of Corona, CA are the founders. The foundation's goals are to provide awareness, education and research on the multiple-infections such as Borrelia and its connection to autism. *pha*

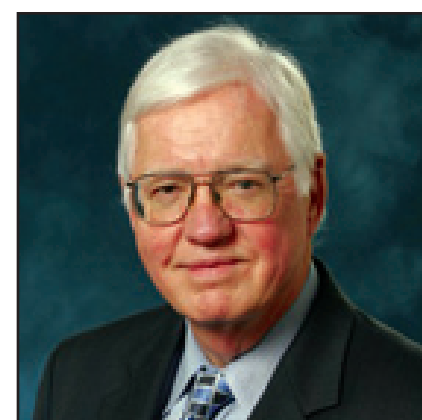
Formal Complaint to Texas D.A. Ronnie Earle's Office are Made Against Medical Board Drs. Patrick & Kalafut

by *Texans for Patients' and Physicians' Rights*

On Friday, November 2, 2007, Dr. Steven Hotze, founder of Texans for Patients' and Physicians' Rights with his attorneys, Terry Scarborough, of the Austin law firm, Hance Scarborough, and Wayne Meissner, of the Austin law firm Fitzgerald Meissner, met with Gregg Cox, Director of Public Integrity Unit of Travis County Attorney Ronnie Earle, and Matthew Langan, Lieutenant Investigator for the Public Integrity Unit. The purpose of this meeting was to discuss the abuse of power by Roberta Kalafut, Texas Medical Board (TMB) president, and Don Patrick, TMB executive director, and to file a formal complaint against both these individuals with the Travis County District

Attorney, Ronnie Earle.

Dr. Hotze charged that Kalafut has had her husband, Dr. Ed Brandecker, file anonymous complaints against their competitors in Abilene and



Donald W. Patrick, M.D., J.D. worked the Board to ensure that their competitors are disciplined. The purpose of her actions has been to destroy her medical competition. This appears to clearly violate Section 39.03 of the Texas Penal Code relating to abuse of

power as well as the federal anti-racketeering RICO Act.

Attorneys Cox and Langan enthusiastically received the information which was provided them and gave



Dr. Roberta Kalafut, D.O. assurances of their plans to vigorously investigate the charges. They were particularly interested in the fact that Dr. Hotze had been approached by representatives from both the TMB and the governor's office who had requested a truce and

promised specific remedies provided that Dr. Hotze would not publish the information which he has compiled on Kalafut, Patrick and other TMB members and would not meet with the Ronnie Earle's office or with Federal Prosecutor Johnny Sutton's office. The attorneys viewed this as an effort by government officials to cover up misconduct. They informed Dr. Hotze that they would be seeking subpoenas for information from the TMB and would be interviewing the long list of physician and attorneys, who are aware of the Kalafut's and Patrick's abuse of power, with which they were provided by Dr. Hotze. *pha*

For more info on **Texans for Patients' & Physicians' Rights** go to www.txppr.org

Eternal Gratitude

by Laura Zeller

The holidays can be a very difficult and stressful time for chronic illness sufferers. Many of us will find ourselves sitting around a table full of feasts, blessed with an understanding family and cherished friends. Still, some of us are not as fortunate. Many patients struggle to get through the holiday festivities while enduring intense physical pain and only partial or no understanding about our illness from our friends and family. Getting through the holidays with a smile on our faces can be hard, and it is a daily struggle for so many.

Any time you are faced with a chronic illness, your thoughts can be overwhelming. Lyme disease, for example, can be a mean beast to deal with, but try to look at it as an obstacle, one you can overcome, and make you stronger. This may sound crazy to some of you, but to me, Lyme disease has been a gift. Yes, I said a gift. Struggling with Lyme disease has brought me clarity and an intense appreciation for all the simple things around me. I am blessed with wonderful friends, many of whom I would never have met if I were never a part of the Lyme disease community.

Where would we be without our "Lymie" friends, our support groups, our families, and our LLMD's? For many of us that answer is easy. We would be dead. For others, the answer isn't much further off. We would likely be suffering, wheelchair bound, permanently disabled or worse. Many of us would have no quality of life. We have lost our jobs, our friends, our hobbies, and for some of us, our marriages and families. Untreated Lyme can cause a chain reaction of disaster. It destroys lives! It's a frightening thought, and images pop into my mind as I imagine what my life would have been like if I had never found my LLMD, and all my friends with Lyme disease. Who would I be? My identity gone, what would I have become?

It often takes tragedy to wake us up, to make us reevaluate our lives and appreciate what we have. The reason for this is that when tragedy strikes, everything becomes instantaneously prioritized. You suddenly realize what matters most and what you truly care about. Anything that is not essential seems so meaningless.

When things are going well, it can be easy to overlook the blessings in our lives. We can take for granted our health and the relationships we share with others. When you don't have your health, worrying about paying the bills, auto repairs, dripping faucets or being stuck in traffic just does not matter.

Ten years ago, my rapidly declining health took a huge mental and emotional toll on me. Overwhelmed with the

desperately ill patients across states and countries. I am eternally grateful for all of my wondrous meetings with random people suffering the same as I was. Their gifts of love and encouragement ripple out upon the spiritual waters of the earth and strengthen the bond of our shared humanity.

Sharing your story with others can be instrumental to recovery. When you are doing this, don't be afraid to admit

community as much support as I can for the rest of my life.

I wondered silently if others felt the same way. I asked around to other Lyme patients where they thought they would be without their LLMD. Feelings of panic, dread and misunderstanding can vanish instantly after you have a consultation with a good LLMD. The stress of being untreated and misdiagnosed for years can cause a certain sense

honesty, and heartfelt concern are incredibly unique and greatly appreciated.

Expressing gratitude is a very powerful expression of human nature. Telling someone you are grateful for them in your life, for what they have done, for who they are is an extremely powerful expression of love. Telling a stranger who has done something for you, whether it is directions, good service, a simply a smile. You are grateful for those gifts, and they have given you a basic human need, connection to others. Spread the energy of gratitude. Send them an email or letter of appreciation for who they are as a person, what they stand for, or for what they have accomplished.

Each and every day we are blessed with so much life. Every morning is a fresh start, and the day ahead is what we make of it, sick or not. Each day, every single one of us has something to be grateful for. Sometimes these things are big, such as getting a fabulous job offer; sometimes they are small, such as the fact that the baby slept through the night. The more we focus on what we have to be grateful for in our lives, the easier it will be to deal with the challenges and obstacles that we face.

You may have a chronic illness, you may be limited and disabled, but you are alive. Never underestimate the power and the privilege to simply, live, breathe...and feel things in your heart. Try to find comfort and solace in the simple things. Remember you are on a quest of deep spiritual knowledge, you are grateful for abundance. This can be as simple as being grateful that you still have all 5 senses. You can see people smile, and listen to the roar of laughter as you hear another silly Lyme joke. You can feel the keyboard beneath your fingertips as you reach out to an online support group. You can smell breakfast cooking and taste the delicious pancakes sitting before you, even if you feel terrible.

If you are struggling with simple daily activities, you can start keeping a journal. The journal can be your friend, and you can write in it daily, weekly, or monthly about what you are grateful for, and the circumstances that created the gratitude. This becomes a story and record of your feelings and warm experiences of what you have given, and also what you



Laura Zeller rises above the adversity of her illness and finds a grateful spirit throughout the holiday season. This photo is Laura atop Mount Everest, typical of her character, she is always climbing to higher heights!

limitations untreated Lyme disease had put on my body, mind and spirit, I went on a mission to seek out other people in the same situation. My thoughts were full of fear and I felt lost in a sea of emotional depression. The isolation that chronic illness can bring on can be a drastic change from an ordinarily full and busy life. When we are feeling well, we all too often underestimate the power of a touch, a thoughtful word, a sweet smile, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.

I was lucky. I quickly found other Lyme patients, many misdiagnosed and untreated for years. Friendships quickly formed through virtual hugs, and online support groups. I am so grateful to the wonderful strangers who quickly became trusted friends. The level of patience and understanding I encountered was a bittersweet parallel to my own life. Too sick and disabled to meet in person, emails and chats were exchanged between

that you are less than perfect; it is this fragile thread that binds us to each other. After sharing my story with others, I felt relieved. I no longer had to tell the exhausting story, it was all there, in words, and all people had to do was read. It can be very reassuring to talk to others who are going through the same situation. One of the first comments I usually get after somebody reads my story, is "Wow, thank God you found your Lyme doctor."

I was one of the lucky ones. I did find an excellent Lyme doctor, and I can say with a high degree of certainty that he saved my life. If he had not taken care of me there is no doubt I would not be alive today. I cannot express in words the depth of my gratitude. The Lyme Literate Medical Doctor (LLMD) who saved me is brilliant, dedicated, friendly, loyal, determined, loving, and very funny. He has saved the lives of thousands of desperately ill men and women who suffer with Lyme disease. I owe him so much! I vowed to give back to the Lyme com-

of impending doom. There is a high degree of distrust in the medical community and within families. Most of those feelings vanish once you have a visit with your LLMD. For most, it is a phenomenal experience. After years of struggle and heartache, we finally feel like we have an accurate diagnosis and we are on our road to recovery. This entire experience is usually informative, insightful, and full of hope.

After feeling such a tremendous relief, how do we say thank you to our LLMD's? Most LLMD's respond kindly, yet shyly, to constantly hearing the words "thank you." Overwhelmed with gratitude, we bring them apple pies, and they respond by saying "I'm just doing my job." Regardless, these are still our heroes, and still our guardian angels. Most LLMD's are the most people oriented medical professionals we will ever meet. Most doctors who treat Lyme patients have battled Lyme disease themselves. Because of their first hand experience, their treatment philosophy, sincere



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Reflecting on What Lyme Disease Cannot Do...and the Good that it Can!

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces with local and nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gherig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins.

PHA seeks to bring information and awareness about these illnesses to the public's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

PHA Staff

Editor: Dawn Irons
Assistant Editor: Brad Irons
Advertising Manager: Laura Zeller
Distribution: Rhonda Cope

Contributors:

Donna Reagan,
Ginger Savely, FNP,
Marjorie Tietjen
Scott Forsgren,
Dr. J David Kocurek,
Susan Williams, Laura Zeller,
Sue Vogan, PJ Langhoff,
Dr. James Schaller, M.D.,
Tami Duncan, Linda Heming,
Alicia McGary, Megan Blewitt,
Joan Vetter.

Website:

www.publichealthalert.org

e-mail:

editor@publichealthalert.org

Donations:

If you would like to make a donation to PHA you may do so through Paypal. Please send the donations to the following address:

donations@publichealthalert.org

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821 Sansome Drive
Arlington, TX 76018

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by Dawn Irons

As 2008 is looking bright on the horizon, once again I take time to pause and reflect on the year that has passed.

I am somewhat amused when I step back and look at "the big picture" of the previous year in review because I can see it all from the vantage point of seeing the end result!

I have a more complete and accurate picture of the year on December 31st than I ever did on January 1st.

I remember the roller coaster ride and not being able to see the forest for the trees as each month passed on the calendar. To look at each month in review is almost overwhelming...but when I look at the big picture the year has a whole new perspective.

Last January started out with my neurologist contemplating brain surgery to relieve excess spinal fluid and pressure on my optic nerve.

February brought about the hellish nightmare of my daughter being in a coma with meningitis and the Infectious Disease doctor refusing to run Lyme tests as we requested.

March brought about a trip to Louisiana to see my LLMD and have him test my daughter. She came back positive.

Late April my Father-in-Law passed away and we buried him in May. The heartbreak just kept mounting.

In June we took my two sons to be tested for Lyme as well...both came back positive.

In July my oldest son came down with pneumonia and

we began treatment that went through all of August.

September brought about my nephews military graduation. I had promised my niece I would take her and her daughter to see the graduation. But September also brought about a severe worsening of my muscle and joint pains...and 2 days in a van driving across the country did not sound like anything I could pull off and still survive! By the grace of God, we made the trip with no problems.

The rest of the year was a whirlwind of holiday celebrations, parties and feasts. I wondered how I survived the year!

Looking back at the month-to-month replay of the year, it still takes my breath away at what all we endured...but that is only half the story!

I can look at that year in one of two ways. It could be either completely devastating or be the very events and situations that compelled me to go far beyond what I ever thought I could.

Let me recount for you the things I accomplished this year that were partly due to the fact that I had Lyme. If it were not for the disease I might never have had these experiences!

Traveling out of state for medical care is something I would never have done prior to Lyme. But finding my doctor has been a major blessing to my entire family! I count him my friend, not only my doctor! How do you say "Thank You" to someone who has given you back your life and that of your family? It was worth the trip!

During our medical visit in March of this year, we decided, since the kids were off for Spring Break, that we would add a vacation on to the end of our medical trip. This was the first vacation we had ever taken in 16 years of marriage!

After leaving Louisiana we traveled up to Mississippi and through Tennessee where we stood outside the gates of Graceland. My husband is an Elvis junkie! It was after hours so we could not go inside, but

we were close enough to say we had been there!

After leaving Graceland we continued our journey up to St. Louis where we stayed with some close friends for the remainder of Spring Break. We got to see the landmark Gateway Arch! This is a journey we would not have made had we not had a medical trip out of state anyway! So for that I am grateful!

The summer brought about 2 more trips to Louisiana with the kids. I was blessed to have my friend Victoria and her daughter Autumn make the trip with me.

Victoria took turns driving with me and even drove all the way back one trip when I was too tired to drive at all. I completely enjoyed being able to spend that time with her! You can learn a lot about someone when you spend 20 hours in a car with them! Due to Lyme and traveling out of state, I have developed one of my closest friendships! I wouldn't trade that for anything!

Lyme disease has taught me that it may harm my body, but it can't touch my spirit!

Last year brought about another soul searching moment as I applied for graduate school. This was a long shot since it was just 2 years ago that I had to quit school due to Lyme. It is amazing what time, a great doctor and a praying church can accomplish in one's health!

Since I was feeling a lot better I thought I might take the plunge again! I love learning! I applied for my masters degree in counseling. I soon received a letter from the school that I had been accepted! I was excited, but not satisfied. What was it that was nagging at me?

I searched my soul to find an answer. I was finally doing what I love to do...publishing a newspaper and writing. If I were to go to grad school I would not be able to do the one thing I love! I would have to let this go to pursue something I only nominally had interest in doing. That just did not seem

like the right choice! But I admit...it did feel good to be accepted! Though it felt better to graciously decline the offer and pursue my passion with writing and publishing.

Lyme cannot take away a passion and a desire! For me, it actually makes me more determined to reach my dreams and goals.

I won't be going to grad school, but I am seriously speaking with a team of people in the DFW area about launching another newspaper for the Christian community.

Were it not for Lyme disease keeping me from working a job outside my home, and making me stir crazy and stubborn enough to not let my dreams die, I might never have made the step to launch the Public Health Alert...much less a second newspaper!

Lyme has helped me prioritize what is really important in my life. It has encouraged me to build stronger relationships and dream the impossible dream. It makes me dare to do the thing that I think I cannot do. It makes me seize the day! Carpe Diem!

No matter how you slice it, anything that sparks that much determination and drive to make better life choices is a blessing.

Admittedly, with Lyme, it is a blessing in disguise. There is nothing on the surface of Lyme that looks anything like a blessing. I've just decided that I refuse to let this disease rob me of anything.

At first Lyme appeared to have robbed me of my ability to work or go to school, so I decided to work at home and there I realized my dream of writing and publishing. My battle with this disease has driven me to extremes. I have developed extreme friendships, pursued extreme dreams, and began living life with a far greater passion that I ever dreamed possible. I have found the challenges that Lyme has brought me to be the very catalyst that has made me live life the way it should be-- with great purpose! *pha*

A Word of Thanks to My LLMD

by An Anonymous Lyme Patient in New Jersey

I came to you unable to drive because of the dizziness, rat haired because my arm, shoulder, neck, and yes even my hair was in pain, unable to tolerate even a 25 watt light, and so sensitive to sound a door closing could put me into a panic attack.

I came to you armed with dozens of blood tests, a handful of MRI's, and medical records from at least a dozen specialists. The words from my Primary Care Physician were "I honestly don't know what is wrong with you and what else to do for you." My prior diagnosis ranged the gamut from stress to MS. I came to you through many referrals from my new family at Lymenet.org. You agreed to see me within 48 hours of my first plea for help. You did not dismiss my symptoms as stress, nor did you dis-

miss the idea of a tick-borne infection, despite earlier negative tests.

You took my blood, told me what to eat, and told me how I needed to change my lifestyle. You told me that someday I would feel normal again. You put me on a few prescriptions and told me I could possibly be looking at 1-2 years of treatment, but maybe less.

You held my hand when my skin was on fire and I thought I was having an allergic reaction. You explained to me that one's brain doesn't hurt, and you showed me the muscle spasms that were tightening around my skull and thankfully you relieved them for me.

You put me on a plan that has proven successful, time and again, and offered your own life as an example to live by. You showed me ways of relieving my most annoying and quality-of-life robbing symptoms, that more times than not did not

come from a prescription bottle. You showed me there was more than one way to address symptoms and conditions, but not before careful and considerable research was done.

You showed me that while Lyme disease itself could be crippling and life threatening, it was not always the A-Bomb it first appears to be. Rather, it is often the veritable straw that broke the camel's back. You explained that Lyme was usually the stop-all, end-all that sucks the life out of victims who were just at their breaking point until Lyme came knocking and pushed them over the edge. Getting well not only includes killing the bacteria, but getting rid of all the garbage that came along first.

Most of all, you showed me that there is light at the end of the tunnel. I thanked you for saving me, and for getting me well. Then you thanked me, for following your orders and help-

ing myself by listening to you.

I sit here now, one of the lucky ones. I work every day, drive, exercise, travel, and most days my biggest problem would be I got stuck in traffic driving to work. I am at the peak of my career, and I am grateful to work my butt off for these people who allowed me to continue to work during my near fatal undiagnosed time, and through the worst times of treatment. I am 10 times the person I used to be, and am just so grateful to live life now like it should be lived.

So thank you from the bottom of my heart, to my LLMD, who's being bashed right now for being a supportive doctor who has had the guts combine traditional with non-traditional medicine. May you be allowed to continue to treat the hundreds that so desperately need you! *pha*

What "Used to Be" Doesn't Count Anymore Moving Beyond our Past Baggage

by Johanna Lake

Selling my things in a too-much-work garage sale last month forced me to examine parts of my life that died with my disease--*Bon Appetit* and *Gourmet* magazines from the days I considered myself a cook, brand new downhill skis from the sport I used to enjoy, and patterns, fabric, and yarn from sewing and needlepoint I used to do. These pastimes were definitely *past* times.

Letting go of the accoutrements of activities wasn't hard; they'd been gathering dust for years. However, when I looked at the tailored clothes hanging on the sale rack I felt differently--I wanted to keep the clothes. Into the hands of strangers went the knock out red silk dress, the Anne Klein blouse, and the Pendleton wool skirt. I tried to concentrate on the money people pushed into my hands, which would ease strained family finances, and tried not to remember how good wearing the now out-bound clothes had made me feel. Some outfits brought back memories of times I felt beautiful, of days I went out on dates, and days and nights I worked in a fine cooking store.

I tried on a denim blazer I'd worn with a short, tight, stretchy denim skirt in the days before disease. I remembered I'd been able to button the blazer. On the day of the sale, I couldn't pull the lapels within ten inches of each other. "Why hang on to clothes that don't fit?" I asked myself. "What's the use? I don't go out. I don't work." The clothing and the attached memories framed a self-image from a distant past, a mind's-eye image that was keeping me from facing who I am and what I look like now. I hung the blazer back on the sale rack.

Even though the sale was an attempt at downsizing and de-cluttering life, and should have renewed my resolve not to buy more things, I told my husband I planned to buy important girl-stuff with some of the profits. How could I explain my need to pare down life's entrapments on the one hand and then say I wanted to

spend money on a new purse, new underwear (mine had as many holes as my '95 Toyota), and the jewelry box I'd never had? Perhaps it was fitting that I couldn't explain. It fit with my cognitive impairment, though it surely didn't fit with our finances.

I thought about the importance of having a purse, of the "baggage" women carry. When I was a child, my mother's purse beckoned me like the forbidden fruit of Eden. I'd look inside whenever I dared. Her purse smelled of Doublemint gum, cigarettes, and lighter fluid. Purses contain clues to life, I think, and sometimes they contain clues to the health of the owner. My mother died from congestive heart failure. She smoked, was overweight, diabetic, and sedentary. My old purse went in the garage sale.

When I'd bought that purse--the one I'd dragged everywhere because it was big enough to hold a medical file or two--I liked its numerous compartments and pockets. The depths of the bag, made of the same black rip-stop nylon as the outside, were sewn into three sections. As my cognitive problems increased, one section always seemed to sag into another blocking what I needed to see. Pockets became places I searched for what I couldn't find. Countless times my cell phone would ring and I'd scratch and scramble through the jumble coming up with the phone too late to take the call.

When I put that old black bag in the sale, I resurrected a cherished mahogany-colored, leather Coach bag from my life-before-illness. I stuffed the garage sale profits--a Ziploc bag of coins and a wad of bills--into the Coach purse along with the checkbooks, hairbrush, phone, and medications I carry with me. The purse wouldn't close. The construction was too rigid. I needed something more malleable to contain everything I need with me these days.

In a department store I found and bought a black (again!) crocheted bag with a 70s-style turquoise and white print on the inside, one small zippered compartment, and two

inner sleeves, one for my cell phone and one for my sunglasses. At home, while I sorted through the rest of items earmarked for the new purse, I mused on the degenerating compartments of my mind and my former life. The purses, old and new, became a metaphor for my illness, for Lyme disease.

To me, the recent request of the International Lyme and Associated Disease Society's (ILADS) for the Infectious Disease Society of America (IDSA) to sit down and discuss the problems with Lyme disease diagnosis and treatment is an invitation to examine the Lyme "bag" and the contents of controversy.

I hear the phone ringing in that voluminous bag. The call's coming from someone who's Lyme disease progressed to late-stage symptoms because their calls for help went unanswered. On this point both IDSA and ILADS concur: answering the early call is important but IDSA-answered calls are too short and patients, all too often, have to call back.

"What's your name?" I want to ask the caller. "And what's your disease?" Couldn't Lyme disease be called Borreliosis as it is in Europe? I imagine when both IDSA and ILADS dig through the Lyme bag deep enough to discover and examine the duplicity and far-ranging effects of the illness they will know Lyme needs a new name. Lyme could be called CBBI for Complex Borreliosis-Based Illness or Complex Borreliosis (CB) disease.

As doctors representing both sides continue to circle the Lyme bag, points of contention stick out. Could it be that IDSA and mainstream medicine are somewhat right on some points? Though countless studies show antibiotic failure after short-term treatment, is Lyme disease (alone) gone in most people after three weeks of treatment? Without antibiotics, is a healthy immune system capable of trouncing and evicting the infection?

Lyme doctors have long known that past infections stuck to the "lining" of the body

leap into the potpourri of symptoms chronic illness presents. Could it be that Lyme disease itself is actually less harmful than we think and that the true cause of debility and death stems from the interplay of Lyme disease with viruses, mycoplasmas, bacteria, and parasites people have on board before they contract Lyme disease and co-infections? Are piggybacking pathogens one reason treatments fail?

When we look beyond what we don't know about the interplay of co-infective pathogens and the need for a more appropriate name for the disease, we're confronted by a gaping hole in the Lyme bag, the guts-falling-out issue of treatment and the IDSA-promoted lack of treatment. As harsh and ridiculous as withholding treatment seems to those who suffer from Lyme disease, I need you to take a deep breath and think, for just a second.

Antibiotics *do* fail patients. The length and course of treatment necessary is unclear. Treatment variables may be as numerous as the strains of spirochetes causing the infection, and whole life restructuring--diet, exercise, and environment--may be of paramount importance for many Lyme disease sufferers. Alternative and adjunctive care can help heal and, according to some, cure Lyme. But where is the science that proves complete recovery from Lyme disease is possible? That eradication of Lyme bacteria from the human body with traditional and non-traditional therapies is a fact? We don't have that information. We don't have a miracle drug or supplement for that matter either.

What's needed is light on the inside of the bag. Medicine, IDSA, and ILADS, let's look together at what we do know about Lyme disease and what has been done for patients. Let's make clear what we don't know. All the information amassed so far has to be placed on the table so everyone sees the same thing. Let all interested parties comment on what they see and how they see it. Let's commit to listening

carefully to each other. Clues and avenues to effective treatment have been found and shared by patients and their physicians. Hear them out.

Again, and this is hard, let's not cover our ears when we hear the words Post-Lyme Syndrome. This will anger many, but I believe Lyme disease *can* trigger autoimmune conditions that persist when Lyme spirochetes are gone (though I can't prove they've left); I believe, too, irreparable damage stems from Lyme disease infection, especially when Lyme disease has progressed to Parkinson's-like tremors or the atrophying, wasted muscles that can signify ALS. In spite of all this, I believe under-treated Lyme disease is usually the cause of persistent "Post-Lyme Disease Syndrome."

While it's easy to find fault with IDSA-promoted treatment-denying guidelines, we have to inspect the holes in "our" side of the Lyme bag too. One criticism from medicine says, "When patients and their doctors focus on Lyme disease, other important diseases can be missed." I believe this to be true. Yesterday, I asked a man (with a history of tick bites and a Western Blot test that showed a few positive bands) to try not to be so upset because the doctor he had seen had ordered more tests. He thinks the doctor is trying to "cover his butt" and I agreed with him, but I also felt compelled to explain that the tests the doctor ordered for diabetes were critically important. I explained a diabetic coma could send him to the hospital faster than the Lyme disease we suspect he's had for some time.

While I'm at it, there's another shot our side must take on the chin too. As much as we want access to appropriate health care for people with Lyme disease, we have to admit Lyme Literate Medical Doctors (LLMDs) cannot be accessed by everyone who needs them. People in need can't get to LLMDs, not only because there are so few of them but because traveling long distances for appointments can be prohibitively expensive and unfeasible "*Baggage*" ...cont'd on pg 18

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What Volunteers are up Against

Making the Best Use of Your Volunteers

by Sue Vogan

Volunteers are the salt of the earth and none more so than in the Lyme disease community. I have known some volunteers that have gone the extra mile without so much as a thank-you. I have also known some that if they aren't thanked for every little thing will complain to anyone who will listen and for as long as they have breath.

Still others do what they can, follow guidelines, and share some terrific ideas. They get along with most everyone, refrain from idle gossip, and are not seeking a pat on the back or the spotlight.

True volunteers do not do it for fame, money, reward, or praise - they do it mostly because there is a need for help. However, not all volunteers are pleasant or enjoyable to work with.

Personalities play a large role in organizing and managing volunteers. Everyone has his or her own reason for volunteering, but not everyone who volunteers has the same personality. Sometimes it can be difficult to gather and manage volunteers when you aren't aware of the many personalities.

Common Personalities:

The Know-It-All personality is famous for being a poor listener and seeing themselves competent on all subjects. This personality will offer advice - even if no one wants it. Their way is better - even though no proof of this exists.

The Name-Dropper personality is known for self-interest agendas and less attention to the meat of the group (i.e. meetings). These people are mostly about self-promotion. This personality insists on linking themselves with accomplished people so they will appear to be more important than they are (celebrity status).

The Overly-Helpful personality will chair anything, be on a board for whatever, or insist on taking charge. This personality is usually looking to fulfill something on his/her own agenda. This personality is often pushy - depending on the personal agenda needs. They often will want information that they have no business having or any use for.

The Complainer personality will find something to complain about - their job, family, home, vehicle, others - until they eventually start complaining about you. It's always someone else's fault, too.

The Self-Improver per-

sonality takes volunteering seriously because it makes them feel good about themselves. They get satisfaction from donating their time and service.

The Experience Seeker personality is curious in nature and wants to learn all they can. This personality wants to try it all - need a volunteer to jump from a plane to test a new parachute -- they'll be the first in line.

The Altruist personality will volunteer as long as the project is something they believe in and progress is made. This personality must care about the project deeply enough to offer their time and energy. The quickest way to lose this personality is to have little or no positive progress.

The Drama personality will create drama wherever they go and leave a wake behind them. This personality looks for attention and sympathy. Their situation is far worse than anyone else's and if they have to embellish, so be it.

The Quiet or Unassuming personality will go about any task assigned them. These are normally diligent people with little need of fanfare or praise. If they weren't on the roster, you'd barely know they existed.

The Greedy personality

will agree to participate in the group plan and then realize that there's nothing personally in it for them. This personality insists on a piece of the fundraising pie, cannot understand why they are not entitled to it, and may attempt to bash the group's efforts. If there's nothing personally to gain, they have nothing to offer.

The Attention Seeker personality wants the spotlight on them - not the project or task. This personality will zip across the volunteer stage to grab the spotlight - shadowing anyone/anything else currently in the spotlight.

The 101-Question personality spends more time asking questions than working. This personality tends to be insecure, always unsure they understood the task, and seems to get very little done.

Reminder: All volunteers do not work well together and may have personal agendas.

Volunteers can make things happen, but they don't do it randomly. There should be someone to oversee the entire project - someone who is in touch with everyone and can keep an eye out for potential problems or necessary changes. This will be someone who can make decisions, approve budg-

ets/expenses, and can keep the project moving with the essentials. There should also be a backup for this person.

Unexpected things can (and often do) happen - this is life. However, it does not have to slow or stop activities if someone is there to step in when necessary. Be sure to keep the backup informed by including them for meetings, changes, announcements, progress, etc. Let the group know what this person's position is so there will be no problems should they find it necessary to take leadership control.

Tips: Planning is everything - including taking on volunteers. Recruit volunteers with forethought. Describe the position/task on paper. Decide what personalities are already involved and examine what personality would best work with these personalities and still make progress.

Provide an orientation. This will familiarize the volunteer with the history of the group, the mission, and introduce them to those in charge. This will also give you the opportunity to recognize the different personalities in the group.

Training is essential for any volunteer. They may have *"Volunteers"... cont'd on pg 13*

The Faith Factor...

by Joan Vetter

Count Your Blessings



by Joan Vetter

Fear stared into my eyes and mocked my future.

Rushing my husband to ICU, the doctors did not give me much encouragement. A blood clot lodged in his lung after hernia surgery, and I stood helplessly by as this strong, stoic man experienced pain so fierce that strong doses of morphine couldn't touch.

When I cried out to God for help I felt like he put in my mind the song "Count your many blessings - count them one by one." So I proceeded to do exactly that. The more I thanked God, the less I felt the fear. The day I brought my husband home I thanked God even more - hearing that our neighbor next door's father had just passed away from a pulmonary embolism.

The Bible has much to say about thankfulness. In Psalm 100 we are told that the way into His gates is through thanksgiving and that we are to be thankful to Him and bless His name because the Lord is good and His mercy is everlasting.

All of our Christian life is a choice. Sometimes I wish I

had a "grumble meter" - that would buzz when I began to murmur. However I can ask God to convict me and help me to choose to praise. Often it is the small annoyances that pile up and cause us to lose our joy. For instance, we complain about the slow cashier at the grocery store, the rude driver, or waiting for a service call.

The Bible story of the 10 lepers who came to Jesus reveals how much emphasis Jesus places on thankfulness. Even though Jesus sent them all to the priest and they were all healed, I can almost see His

"I think this was God's way of grabbing me by the shoulders and telling me to wake-up, to appreciate and be thankful for what I do have."

disappointed expression as he exclaims, "Were there not 10 healed?" when only one man returns to thank Him.

I personally think Jesus was exemplifying how important it is to say thank you when someone does something good for us. In fact yesterday I called American Express customer service and a woman assisted me so quickly and efficiently. I got her name, and when I send in the bill I will include a little note indicating how pleased I was with her service with a smile.

You've probably heard the story of the little boy who

was asking for a pony for his birthday. He opened the door to his bedroom and found heaps of manure. With a big grin he affirmed, "With all this manure, there's got to be a pony around here somewhere." Let's always be looking for the good!

On March 12th an article appeared in the Ft. Worth Star Telegram entitled "Transformed by Tragedy" written by Melody McDonald. It was the story of a woman who stopped to help a stranger after an automobile accident, and God provided a crash course in attitude adjustment. As Mary Kamp lay dying inside her mangled car, she asked Corey Gober, the woman who stopped to help, to "tell her children she loved them and to tell her husband that she was sorry."

When Corey stopped to comfort Mary she was a 28 year-old mother of four heading for divorce. She and her husband had been separated for several months and had already begun talking to a lawyer. She had a lot of anger - at God, at her husband and at life and was not able to forgive.

Being with Mary in her last minutes of life transformed Corey. "I think this was God's way of grabbing me by the shoulders and telling me to wake-up, to appreciate and be thankful for what I do have."

The following Sunday Corey and her husband took their children to church. They are reunited and working on their marriage through counseling.

Now Corey gives thanks to God and Mary for that chance encounter that saved her marriage and her faith. *pha*

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Routine Dosing Errors in the Treatment of Tick and Flea Infections and Psychiatric Problems



by Dr. James Schaller, MD

Most dosing in medicine follows medical journal advertisements, drug company representative materials, the simplistic PDR or mentors who are seen as having all the answers. The same applies to alternative medicine. Both traditions can become too rigid and stuck on a select treatment delivered in the same manner for all patients. As physicians continue to treat patients we have learned that cookbook dosing or "protocols" are not appropriate since no patient is the same, and so no treatment should be the same.

Currently, top physicians treating tick and flea infections need to be versed in Babesia, Bartonella, Indoor Mold biotoxins, Lyme biotoxins such as the neurotoxin Bbtx1 and many other issues. Indeed, treatment failure begins with the fact deer ticks rarely have one infection in their complex stomachs, and it is simply a fact that most labs are worthless at the detection of these many different infections. This is why these highly common "co-infections" are perhaps better called parallel infections. Further, most of these infections cause clear lab documented types of inflammation. Including inflammation chemicals in the blood which make the brain require unique, tailored and careful dosing.

Yet another major reason for failure in the treatment of ill patients is dosing errors of a wide range of medications, such as antibiotics, parasitic treatments, herbs and psychiatric medications.

First, it is important to understand that any infection, inflammatory process or a decrease in anti-inflammatory chemicals means the brain will

behave as if you have gasoline in your blood. Specifically, these three situations entirely alter the way medicines or herbs are dosed.

Most medications, herbs or other traditional or alternative treatments are "dosed" in a bell curve manner. This means very simply, that most people fit into a common range such as 2-4 capsules a day, and a small percentage gain benefit from 1 capsule/day or 5 or more capsules/day. For other treatments that do not involve swallowing it might mean 2-4 treatments a week usually give the best benefit.

However, if you have an infection that reaches the brain or high inflammation in the brain or biotoxins diverting normal metabolic paths this can cause the bell curve dosing to be a disaster. Or at the very least cause a patient to have significant side effects. Why? Because the body reacts very different to treatments when the brain is infected or is covered in inflammatory chemicals or hijacked by biotoxins.

In this situation the bell curve often fails and is replaced with a "smile face" dose pattern. What is a smile face dose?

In a smile, the ends of the lips are turned up high. When you apply this image to dosing it means that many people will be at the two extremes of dosing. Some will only be able to tolerate a 1/8th or 1/4 of the smallest pill. Some might even benefit from having the smallest pill compounded into 1/16th of the smallest tablet because the brain is so raw and reactive. It is like your brain has been burned and the medication or herb is like acid. Some of these people over time and after a period of treatment can handle more traditional dosing, but not usually in the first months.

The good news is that some people have a very useful benefit on these low doses. What medications are we talking about? This principle applies to antibiotics, herbs, anti-inflammatory omega 3 fish oils with a dash of inflammatory omega 9, magnesium sublingual troches, antidepressants, anti anxiety medications, sleep medications, anti histamines, cholestyramine and any alternative medicine treatment. Again,

your starting dose may not be your ending dose, not just because your liver will get better at removing any swallowed treatment, but because you may get better each month and cool down your inflammation and remove some biotoxins undermining normal metabolism.

While some sick patients do take normal doses, we always start in the first few days or week with very low dosing to make sure we do not cause a severe side effect due to brain inflammation. These individuals are an unknown percentage of patients with tick, flea and indoor mold related illness.

The other extreme of smile face dosing is very high dosing. Examples of this might include people who slowly reach a high dose or are able to reach it in a couple weeks. Specific medications to treat infections, fatigue, cognitive slowing, anxiety or depression can go to outrageous levels because the trouble is not with a couple parts of the brain but with the entire brain. Also, the infection, inflammation or biotoxins may cause someone to require an entirely different dose since the problem is due to a medical condition and is not a simple sore throat, basic occasional panic attack or traditional biological depression.

For example, a person who cannot handle 100 mg of minocycline, when reduced to 25 mg, may be able to take 600 mg a day after two months. A person who feels wiped out taking cholestyramine 1/4 packet a day, may be able to function taking one teaspoon a day and reach five packets per day over three months. A person who is excessively sedated on Klonopin 0.5 mg at dinner, may need 4 mg every 8 hours during a die-off reaction four months later. Others who have constant anxiety and severe restlessness that fails benzodiazepines like Klonopin and other treatments may need anti-psychotics to calm their severe "brain flames."

This dose can be a tiny sliver of the smallest pill to doses that are so high they are doses used for schizophrenia. Why so high? Because most experts believe schizophrenia is a defect in two areas of the brain. We are talking about infection, inflammation or biotoxins trouble in the entire

brain. Another example is antidepressants or stimulants. Some might start with Lexapro at 1/4 of a 10 mg tablet, the smallest tablet made and have an initial benefit, and five months later during repeated die offs for multiple infections or during clear lab documented inflammation, can require 70 mg to prevent severe depression feelings. Further, a person who gets a full and amazing 12 hours of benefit from a mere 1/2 of a small 5 mg of generic Ritalin, on occasion might need 70 mg of the prodrug Vyvanse™ (lisdexamfetamine dimesylate). Or they require 3,000 mg of CoQ10 to get out of bed when 200 mg was enough before the start of treatment, which involved die off reactions and extensive infectious debris flowing through the brain and body. This initial sensitivity can be lost as anti-inflammation chemicals are restored and infections partly decrease, so that any benefit requiring huge dosing is not an addiction, it is the sign of a sick infected, inflamed or biotoxin filled brain.

These brain and body infections, inflammation and biotoxins problems can be tracked by many different labs to see if you are becoming more normal or increasing in your abnormal lab results. If you are becoming more abnormal perhaps you might want to slow down your treatment. No one should be treated for any tick borne infection or indoor mold exposure without first knowing clearly their HLA pattern. The best HLA test for our purposes is the LabCorp five part HLA DRB, DQB Disease Association, test number 012542. If you have trouble with anyone understanding how to order they can call 800-533-1037. Quest only offers a two part, which can give some data to those very experienced in reading HLA's, but is not the preferred test. In my next book, due out in January or February, *The 15 Reasons Why Tick and Flea-Borne Infection Treatment Fails* we show actual lab sheets and how to read an HLA result. It is not an optional test in the advanced treatment of Lyme or indoor mold exposure. And many folks have both exposures.

In conclusion, I have found all protocols and all "one size fits every patient" dosing

approaches to be flawed with many patients. This method of treating patients is treating people as if they are clones. Of course some patients and physicians have limited time, and this is the only possible starting point. If that is the case, it is hoped a treatment that causes side effects can be restarted at tailored dosing that matches where you are on the smile face dose curve. And then this starting dose can be adjusted as your body chemistry changes.

Dr. Schaller is working with Dr. Charles Ray Jones on a Pediatric Lyme book which is 50% completed.

Dr. Schaller is the author of 20 books including: *The Diagnosis and Treatment of Babesia, Mold Illness and Mold Remediation Made Simple, The Complete Guide to Artemisinin, When Traditional Medicine Fails, 100 Solutions to Out of Control Youth, Suboxone-Pain Treatment with Addiction Relief.*

He is currently preparing the most up-to-date textbook on Bartonella, which he feels is a top vector in the world-possibly more common than Lyme.

Dr. Schaller has 25 National and International Medical Publications in such journals as JAMA, Medscape, and some of the largest pediatric journals in the world. He was the first to publish a practical cancer cure which blocks a single enzyme for a deadly blood cancer, which has become the standard treatment internationally. He has also designed wholesale nutritional products and published nutrition and herbal purity and potency research.

Dr. Schaller is a strong advocate for looking at many treatments and illness causes as can be seen from his main web site: www.PersonalConsult.com. Here he offers over 800 articles in over 10 areas of medicine for free.

[The editor suggests you be on the lookout for Dr. Schaller's new book, *The 15 Reasons Why Tick and Flea-Borne Infection Treatment Fails*, due out in 2-3 months.]

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LDA President Pat Smith Wings Her Way to Minnesota

by Marina Andrews

Pat Smith, President of the Lyme Disease Association, arrived in Minnesota on Monday, November 12th for a whirlwind three days of meetings with members of the Minnesota Lyme Action and Support Group, legislators, and chiropractors. The Minnesota Lyme Group sponsored Smith's visit and a November 13th community forum presentation on Lyme disease. Ms. Smith also gave a cable television interview and a press conference. On the evening of the 13th we snuck off to a quiet room to squeeze in this interview in the middle of her hectic Minnesota schedule.

Pat, how did you wind up in our Lyme world?

In the mid 80s I was on the Board of Education in my community and the schools--teachers and students--were being decimated by something called Lyme disease. So I went to the superintendent of schools and I said, "We've got to get information out to parents about this disease." It took me a long time to find the information but it turned out the first cases of Lyme in New Jersey were on a military base. My first information came from there.

Unfortunately, a couple of years later, two of my daughters were subsequently diagnosed with Lyme disease. My youngest daughter has had it severely. She's had it now for over nineteen years. She missed most of her middle school years and high school years. She had a period of three years where she was seizing fifteen hours a day, six and seven days a week, continuously. These were temporal lobe seizures and it was pretty devastating. That was the early to mid-90s. I finally said to myself, "If my daughter recovers from this, I'm never going to let anybody go through this alone." So I have tried to keep true to that promise and that's why I do what I do.

Do you think the military has more knowledge of Lyme disease than medicine?

To date we have had two meetings in 1999 and 2005 with US Army CHPPM, the Centers for Health Promotion and Preventive Medicine. Basically, the bottom line is they are certainly doing more to protect their troops. They map military installations for rates of Lyme disease and they want to beam the data up to satellites and then have it sent back down to hand-held devices so they can maneuver troops around the ticks, and they just created a device which will allow for in-the-field testing of ticks for any known diseases. This is exciting and unbelievable. They're working on patenting and marketing it now for the military. The device can be used for West Nile Virus and other diseases too.

They're informed. But when we gathered some Army docs in D.C. in 2004, we found out that they have the same problems we do with patients

[not being well after short-term treatment] and that they were facing the same kind of pressures regarding the length of treatment. We have a military support group and what I'm hearing is that they're mustering a lot of people out of the military when they get Lyme disease rather than providing them with appropriate treatment.

I should say the Army is more aware of Lyme disease and they have to be. Their troops are out on these maneuvers, they're out in the field doing what soldiers do. In high-risk areas their uniforms are impregnated with Permethrin during manufacturing. The US Army CHIPPM is doing a good job. They also have a tick testing program. I talked to a man here today and he knew about the tick testing in the Army twenty years ago. If you get bitten by a tick, you put it in a little vial, and send it in to get tested. If you're a military spouse, you can do the same thing.

How would you describe your relationship with the Centers for Disease Control and Prevention (CDC)?

We're forming a relationship because you can't have a disease like this and not talk to people. It's like having a marriage and not talking to one another and you have all these problems that arise and you just say, "Oh well, let's just shove 'em under the table and we're never gonna talk." That doesn't work and I basically said, "This is not working," to the CDC. We've got to stop the [Lyme] war and we've got to start talking. We don't have to like what each other says--we don't have to, but we've got to start that dialogue. That's the stage we're at, beginning a dialogue.

Why doesn't the CDC help when they know so many people are suffering from Lyme disease?

They don't have the money for one thing. They get about six million dollars a year for Lyme disease. It's ludicrous. Total government expenditures with the CDC and NIH (National Institutes of Health) are only about \$34 million compared to West Nile Virus which gets \$80 million dollars. West Nile cases are about 3,300 and Lyme cases are 23,000, which we know is vastly under-reported. [The CDC says only 10 per cent of cases that meet their surveillance criteria are reported.]

Why doesn't the CDC notify doctors by mail that they are not supposed to be using CDC surveillance criteria to diagnose or refuse treatment for people with Lyme disease?

In 2006, we met with Dr. Julie Gerberding, the director of the CDC, and her chief science advisor. Dr. Brian Fallon [from Columbia University] came, and Lorraine Johnson from CALDA [California Lyme Disease Association] flew in too. We had four sitting congressmen attend and we had senate offices send representatives too. Basically we talked to them

about the surveillance criteria issue and we explained what was happening.

One thing I suggested was that they put out the information [on the importance of *not* using CDC criteria for diagnosis] to the state public health departments and they in turn could put that information out to their physicians, they have records of their physicians. Has it happened? No.

Last August, in 2007, I was invited to Fort Collins, Colorado, the home of the CDC's Vector-Borne Disease Division. I spent the day with them. I presented to them. I came out and I said, "I am not a doctor. I'm not a scientist and I want you to know I am coming here as a patient advocate. I need you to hear what kinds of things are occurring as a result of your official and unofficial policies." I was honest with them. I thought it was a really good meeting and it has opened a door to possible meetings/discussions with some of our physicians.

They asked me what I wanted and I said, "I need you to sit down with us, *especially our treating doctors.*" That is a message we need to start hammering to all these other groups: "We need you to sit at the table with us. We have to start hashing this out so we can get to the bottom line which is: How are we going to help these

patients?"

Does the CDC know doctors are being investigated by medical boards for treating symptomatic patients from endemic areas, whose Western Blot tests show reactive bands specific for *Borrelia burgdorferi* but whose bands on the tests don't meet CDC criteria?

Yes. I told them so in no uncertain terms. If they weren't aware, they are now.

The CDC had, before 1994, accepted two of the eight following bands on Western Blot IgM tests: 18, 21, 28, 37, 41, 45, 58, and 93. Today, the alternative criteria they had proposed at the 1994 Dearborn convention--two of three bands: 23, 39, and 41, is the accepted standard for a positive test. **Why has the 1994 CDC-proposed alternate criteria superseded what had previously been the standard of acceptance for a positive IgM to become the new standard?**

First of all I asked them [the CDC] why they had excluded bands 31 and 34 [the outer surface proteins of the Lyme bacteria] and they said we had these studies. And I said, "You did?" They said bands 31 and 34 didn't come in, in the top ten bands, so I said, "Maybe you had those studies." But here's my contention. That

was 1994. The organism could have changed by now, and the body's response to the organism could have changed too. No one has been examining this question; therefore, we've got to take a tougher look at this issue. We've got to examine these bands. We've got to expand the bands that are included or, better yet, we've got to go to new technology. They were interested in that.


Do you think that the US now has European strains of *Borrelia*?

I thought I read something recently that said a tick had been tested here and they found *Afzelii* [a European strain]. Is it possible? Yes. It's a small world, and it's getting smaller every day. People are traveling everywhere. Why would they think ticks don't travel? It goes along with the lone star tick issue--"They were concentrated in the South." Well, guess what? Now they're all over the Northeast, as far north as Maine. And now they're in Iowa. They're on the move. What do they think? That we have a tick fence that keeps these guys out? It's crazy, that intelligent people think this way. I always say, "If you don't look for something, you can't find it."

That's why we need to get some of these newer [test-
"Pat Smith"... cont'd pg 14

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Depression Linked to Bone-Thinning in Premenopausal Women

This should be considered a risk factor for osteoporosis; immune system involved

by *NIH News*

Premenopausal women with even mild depression have less bone mass than do their nondepressed peers, a study funded in part by the National Institute of Mental Health (NIMH), part of the National Institutes of Health (NIH), shows. The level of bone loss is at least as high as that associated with recognized risk factors for osteoporosis, including smoking, low calcium intake, and lack of physical activity.

Hip bones, the site of frequent fractures among older people, were among those showing the most thinning in depressed premenopausal women. The reduced bone mass puts them at higher risk of these costly, sometimes fatal fractures and others as they age, the researchers note in the November 26 issue of the "Archives of Internal Medicine". The report was submitted by Giovanni Cizza, MD, PhD, MHSc, of NIMH and the NIH National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK); Farideh Eskandari, MD, MHSc, of NIMH; and colleagues.

"Osteoporosis is a silent disease. Too often, the first symptom a clinician sees is when a patient shows up with a broken bone. Now we know

that depression can serve as a red flag -- that depressed women are more likely than other women to approach menopause already at higher risk of fractures," said NIMH Deputy Director Richard Nakamura, PhD.

After bone mass reaches its peak in youth, bone-thinning continues throughout life, accelerating after menopause. Preliminary studies had suggested that depression may be a risk factor for lower-than-average bone mass even in young, premenopausal women. Results of the current study lend considerable weight to those earlier findings. The study's design reduced the possibility that the lower bone mass was linked to factors other than depression.

Study participants included 89 depressed women and 44 nondepressed women, for comparison. All were between 21 and 45 years old and were premenopausal. Except for depression, the two groups were similar in risk factors, including calcium, caffeine, and alcohol intake; smoking; level of physical fitness; use of oral contraceptives; and age of first menstrual period. Both groups were of relatively high socioeconomic status and were well nourished.

One difference was that the depressed women were tak-

ing antidepressant medications. A previous study suggested that older adults taking antidepressants called selective serotonin reuptake inhibitors had more bone fractures than others. However, the current study showed that these medications were not linked to low bone mass in premenopausal women.

The researchers found that 17 percent of the depressed women had thinner bone in a vulnerable part of the hip called the femoral neck, compared with 2 percent of those who were not depressed. Low bone mass in the lumbar spine, in the lower back, was found in 20 percent of depressed women, but in only 9 percent of nondepressed women. Bone mass was measured via an X-ray technique called DXA scanning.

There was no significant link between the degree of bone loss and the severity of depression or the cumulative number of depressive episodes, the researchers found. The depressed women had been diagnosed with mild depression and were having, or had recently had, a depressive episode.

"Depression generally isn't on clinicians' radar screens as a major risk factor for osteoporosis, particularly for premenopausal women. It should be," said Cizza.

Blood and urine sam-

ples also showed that depressed women have imbalances in immune-system substances, including those that produce inflammation, compared to their healthy peers. This additional finding strengthens the case for a suspected link between depression-induced imbalances in the immune system and accelerated bone loss. The blood and urine samples were taken every hour for a full day, providing a truer picture than does less frequent testing, as had been done in previous studies.

The immune-system imbalances may be tied to excess adrenalin, since the part of the nervous system that produces adrenalin is over-active in depressed people. Increased adrenalin can over-stimulate the immune system. Compared to the others, the depressed women in this study had higher levels of immune-system proteins that promote inflammation, and lower levels of those that prevent it.

One of these inflammation-promoting proteins, IL-6, is known to promote bone loss. At the molecular level, bones routinely break down, and their minerals, notably calcium, are reabsorbed into the blood, where they travel throughout the body to perform crucial functions in cells. At the same

time, the body builds the bone back up. Imbalances in this normal loop of bone re-absorption and build-up, such as high levels of IL-6, could promote bone loss, the researchers suggest.

Other NIH contributors to the study, in addition to NIMH and NIDDK, included the NIH Clinical Center and the National Center for Complementary and Alternative Medicine.

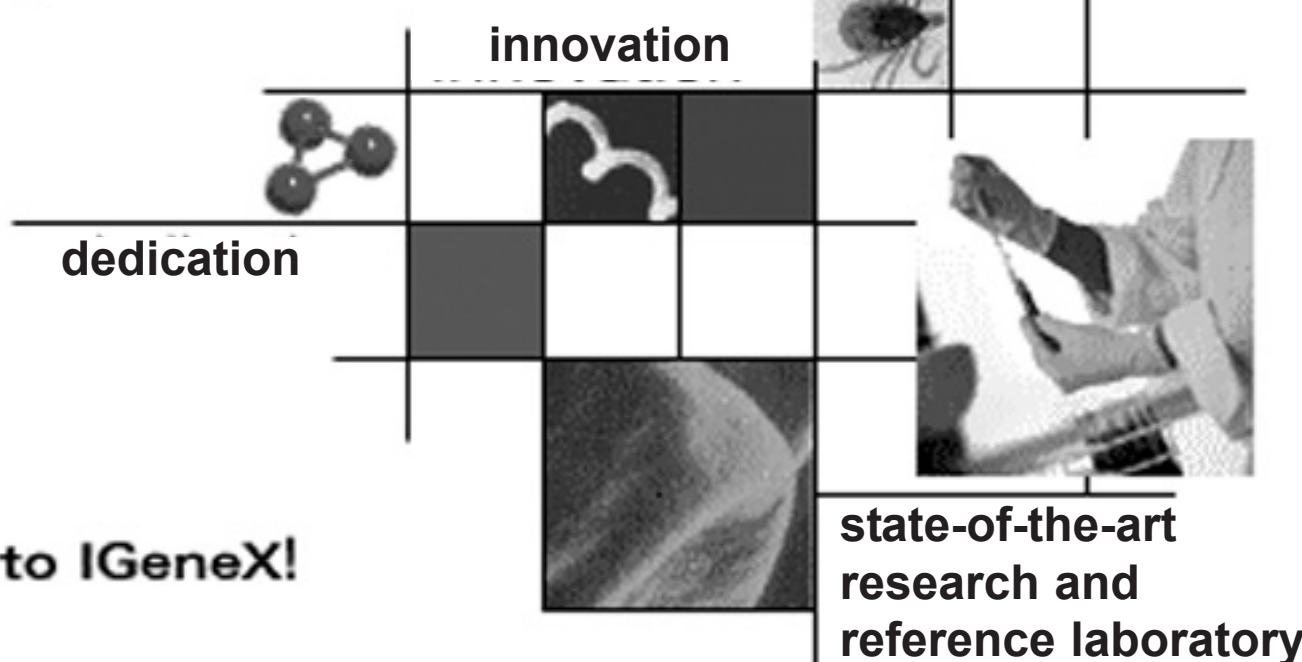
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The National Institute of Mental Health (NIMH) mission is to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. More information is available at the NIMH website: <http://www.nimh.nih.gov/>.

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Gardasil® and Free Choice: Holy Grail or Population Control?



by PJ Langhoff

"I want to be one less". You've probably seen the commercial with many young, hip, smiling female faces making paid declarations of interest in big pharma's newest vaccine brainchild, Gardasil. Developed by Merck & Company, Inc., (Whitehouse Station, New Jersey), Gardasil is the promise of a new horizon in preventative female reproductive cancer medicine. It is actively being served to the masses in palatable 60-second segments of expensive air time. These commercials are designed to convince young women and their parents that cervical cancer is the new "boogey-man" threatening their existence. No need to fear, Gardasil is here as a "safe" and "effective" preventative vaccine. The consensus is that recipients will be "one less" victim of cervical cancers, but is the vaccine truly safe, effective, or even necessary?

Has anyone else noticed that American television ads seem primarily funded by big-name pharmaceutical companies attempting to reach a mass consumer market and create a demand for their products? The mindset being broadcast into our homes is, "Do you have any of these symptoms? Then try our product, we're on your side." Listening closely, you hear a gentle, reassuring voice ramble off a long list of side-effects which seem far worse than most of the symptoms we already may have. But the images of smiling people leading picturesque lives, quickly reassure the less in tune that drug companies have our best interests at heart. And perhaps they do, or perhaps not.

From their perspective (in my opinion), consumers are sheep, able to be directed into our cars to run, (not walk) to our nearest managed-care facility, pay a co-pay, smile at our privileged 5-minute face time with our physician while we happily diagnose our own ills and request pharmaceuticals by name. Many doctors are happy to write a prescription for the symptoms we explain so eloquently because we saw them first on TV, and because they are receiving incentives from their drug suppliers, like free lunches, and financial and other perks of the sort I cannot mention here. In fact, when I must go to the doctor's office, I cringe at the sight of whom I consider the new drug "pushers", a/k/a pharmaceutical reps who seem to have carte blanche over my appointment time slot that I waited for up to a month to get. In fact, big Pharma's brazen presence in my physician's office causes within me a form of intellectual nausea

untreatable by any prescription, even those recommended on TV.

Any time I learn of yet another vaccine, my knee-jerk reaction is, "Great, now what are 'they' (big Pharma and/or our government) trying to do to us now?" Like many Americans, I believe that drug commercials and the permeating presence of Pharma in medical centers are having quite the opposite reaction than intended. People do not want to see drug advertisements on television and do not want to be told what medicines or vaccines are "good" for them. Personally, I find it insulting that corporate giants imply that consumers are not intelligent enough to understand the bodies they inhabit, or otherwise determine their own health needs, and that the manufacturers must do it for us. Well, I studied the new Gardasil vaccine and present it here for your examination. Pardon me if there is a subtle detectable prejudice for self-preservation as an undertone. It is hard to be objective when you see apparent negativity about a product, even when FDA-approved. I am not a doctor, therefore you must do your homework and decide what is right for you or your child(ren).

HPV is short for the human papillomavirus, one of the causative agents of cervical cancer. According to the FDA, cervical cancer is the most common sexually transmitted infection in the U.S. It is estimated by the CDC that approximately 6 million Americans become infected with this family of viruses each year. About 9,000 new cases of cervical cancer are reported in the U.S. annually, with an approximate one-third mortality rate. Across the globe, cervical cancer is the second most common cancer in women, with about a half million new cases each year. In general, routine Pap tests remain an important (but not 100% accurate) screening tool to detect precancerous changes in cervical cells which may develop into cancer. It is recommended to have a Pap test annually, once a woman becomes sexually active, or beginning around age 21. Men also transmit the virus, however there is currently no official test to screen males. A study was published out of the Pathology Dept. of West Virginia University (Urology, 1991 Feb;37(2):110-5), describing the immunostaining of urethral smears for HPV antigens. This process proved to be more sensitive than conventional observations, including visual examinations. Unfortunately this technique is not routinely used in male reproductive health exams. Perhaps it may prove to be a useful tool which should be considered.

There are different types of HPV virus, and the Gardasil vaccine addresses four of them. Types 6 and 11 cause about 90% of genital warts; and types 16 and 18, cause about 70% of cervical cancers. The vaccine is administered intramuscularly as a series of three injections over a six-month period. Costs for the vaccine are \$300-\$500. Since males can transmit HPV to females, studies are underway to determine if the vaccine it would be safe and effective for men. Trials are underway to study the vaccine in young men ages 16-23 years of age. Gardasil is only approved for use in females at this time, between the ages of 9 and 26.[1] Like most parents, I have more than one young adult child fitting neatly into this wide age bracket. And with the skyrocketing rates of infertility climbing in today's generation, as a mother I would have concerns about a vaccine being promoted as a "safe and effective" preventative for any reproductive purposes.

The FDA approved the vaccine in June of 2006. Gardasil was determined to be

compulsory vaccinations with inadequate safety studies. This brings up a civil rights issue of whether we wish to relinquish the right to decide our own medical care to any government entity. When asked, most people do not want medical or reproductive choices being dictated or mandated. Their freedom of choice is made stronger when we know that pharmaceutical companies stand to profit in the billions of dollars for mandated vaccines, whether "safe and effective", or not. And history has shown that the vaccine process in general is embroiled in controversy, with long-term consequences poorly understood.

According to the watchdog organization Judicial Watch, 3,461 complaints have been filed with VAERS (Vaccine Adverse Event Report System) since Gardasil's June 8, 2006 approval. Judicial Watch President Tom Fitton said the adverse event reports suggest that "the vaccine not only causes serious side-effects, but might even be fatal." [3] So far 11 women have been reported to have died after exposure to the vaccine. The complaints have more than doubled compared to the original 1,637 adverse events reported by the Alliance for Human Research Protection, of which 371 were serious, including 3 deaths. For example, one female patient died of a blood clot 3 hours after the vaccine injection; and two girls, aged 12 and 19, died from heart problems and/or blood clotting. A VAERS report shows a 17-year old girl died the same evening she received the first dose of Gardasil,

and her cause of death was listed as "unknown". It was noted that she had dental surgery a day before the vaccine. Another VAERS report lists an 11-year old girl who died within days of receiving Gardasil. Her cause of death was noted by her physician as "due to an anaphylactic reaction to Gardasil". [4] A May 10 to September 7, 2007 VAERS report obtained from the FDA shows a 22-year old woman who received the vaccine May 21, and died 2 days later. An autopsy report showed "no findings," and the party reporting the death said the vaccine was "not" the causative factor. How would they know, I ask, when the autopsy doesn't prove a relationship either way?

Of 77 women who received the vaccine while pregnant, 33 had side-effects. Of 42 women vaccinated while pregnant or around the time of conception, the FDA reported that 23 had complications ranging from miscarriage to birth defects in their children.

Nevertheless, vaccine manufacturer Merck says that birth defects caused by the vaccine it developed were "highly unlikely." [5] Other side-effects

reported as a result of receiving the vaccine, were paralysis, Bell's Palsy, seizures, blood clotting and circulation disorders, and Guillain-Barre Syndrome. According to the FDA in documents received by a Judicial Watch FOIA request, an October 4 report indicated that since May 15, 2007, there have been an additional 1,824 reports of Gardasil vaccine adverse events. Unfortunately, the FDA only supplied partial records to the FOIA request. On October 3, 2007, Judicial Watch filed a lawsuit against the FDA to force full compliance to the FOIA request as required by law.

The vaccine has not been tested for effectiveness in girls, such as those as young as 9. The youngest girls participating in clinical trials were ages 11-12, but the vaccine is approved in children as young as 9; an age group not studied. Without good evidence of side-effects and safety, it is astounding that governments are attempting to mandate the vaccine. There are insufficient long-term safety and efficacy studies, and an article in the New England Journal of Medicine questioned the general effectiveness of the vaccine. Filed with the FDA/CBER (Center for Biologics Evaluation and Research), is an executive summary including the duration of efficacy. It notes, "No immune correlation of protection was identified from the Phase III trials." It also notes a "higher proportion of cases of respiratory illnesses and gastroenteritis among infants of mothers who were administered Gardasil during the time they were breastfeeding their infants," and discusses adverse events, including fetal abnormalities and recipient deaths.

According to the summary, Merck is collaborating with four Nordic countries (Norway, Sweden, Denmark and Iceland) to assess the long-term outcomes of 5,500 recipients of the vaccine over a period of 14 years. If approved by the European Union, the Norwegian government intends to incorporate HPV vaccination into its national guidelines. [6] Vaccinations are already compulsory in Australia and are becoming so in the UK and Europe, although parents and children are largely protesting the intrusion on the "right to choose".

Several U.S. state and local governments have requested that the vaccine become mandatory. On September 12, 2006, Michigan became the first state to propose compulsory vaccination in girls entering the 6th grade. Fortunately, provisions in the bill were given for parents wishing to opt-out as in other vaccines. New Mexico followed suit. In Texas, Governor Rick Perry bypassed the legislative process entirely and issued an executive order mandating vaccination against HPV for girls entering sixth grade as of September 2008. He side-tracked parents' rights groups and any legislative opposition

Of 77 women who received the vaccine while pregnant, 33 had side-effects. Of 42 women vaccinated while pregnant or around the time of conception, the FDA reported that 23 had complications ranging from miscarriage to birth defects in their children.

"safe" after evaluations of about 11,000 study individuals. Most adverse experiences in study participants were limited to "mild" or "moderate" local reactions, like pain or injection site tenderness. This would seem to put the mind of women at ease, right? Read on. Although the FDA claims that the vaccine is "safe", it also noted "compelling evidence" that it could actually make cancer worse in women who were already exposed to HPV when they received the vaccine. [2] And most people who have HPV are unaware they are infected. The FDA stipulated, and manufacturer Merck agreed to continue studies to further evaluate the vaccine's safety and long-term efficacy. The company will also monitor the pregnancy outcomes in women who unknowingly become pregnant, who subsequently receive the vaccine.

This makes me feel nervous about the reproductive consequences of an entire generation of young women having voluntary (or mandatory) involvement in a global lab experiment...especially since governments are pushing for

"Gardasil"... cont'd on pg 16

Lyme Protest: Why Won't the Media Present the Facts?

by Marjorie Tietjen

Approximately 40 people attended the Lyme Rally on October 7 at the UCONN Medical Center in Farmington, CT. Patients, family and friends were protesting claims, made by a select few doctors in the medical community, that there is no such entity as Chronic Lyme Disease. This influential clique of doctors is essentially preventing millions of sick and suffering people from being properly diagnosed and treated. Chronic Lyme Disease has become a disabling pandemic and this fact is being covered up. According to current mainstream theory, if a person still has the exact same symptoms, or is only a little bit improved, after 2 to 4 weeks of antibiotics, they no longer have an active infection but magically they now have an autoimmune disease, depression or antibiotic seeking behavior.

The current available testing is very unreliable and results vary widely from lab to lab. This is one reason that The Centers for Disease control warns doctors not to depend solely on these tests to determine whether or not an active infection is present. Doctors are told to use clinical judgment involving review of the patient's history, symptoms and response to antibiotic treatment.

Doctors who use common sense are noticing that many patients begin to improve on a month's course of antibiotics but that it isn't always

enough. Some patients who may not have been treated early enough, or whose immune systems are not working properly, may often need longer term treatment. Why would these doctors think such a radical thing? They hold this view because they see it happening right before their eyes. It's simple...patients are put on antibiotics and they usually improve.



When they are taken off antibiotics, many relapse. They are put back on antibiotics and they improve once again. It is often said by the Yale/UCONN group that this improvement is only due to some anti-inflammatory property of the antibiotics and that the drugs are not killing off an active infection.

If this is true....why doesn't aspirin and other anti-inflammatory medications improve the disease process? It is true that some people do not

respond at all to the antibiotics given them. However, one should not automatically assume that the patient does not have a borrelia infection or other co-infection.

Different types of antibiotics, classes of drugs (eg. anti-malarial) and different dosages may need to be tried before determining someone has an autoimmune disease and

course were outside.

Dr. Feder is the lead author of the article in the October New England Journal of Medicine entitled "A Critical Appraisal of 'Chronic Lyme Disease'."

On Fox News that night, Dr. Feder was featured as claiming that there is NO proof that Chronic Lyme exists. When both sides are speaking

very sick people the treatment they so desperately need.

Actually, I don't believe that total absence of the Lyme bacteria could be proven. But there is proof involving studies and even autopsies, which show irrefutably, that the Lyme bacteria (Borrelia Burgdorferi, Bb) has been found in the body after what this group calls adequate treatment. Because of this proof, clinical proof and research, The Greater Hartford Lyme Disease Support and Action Group has posted a \$20,000 dollar reward to anyone who can prove that Lyme can NOT be a chronic active relapsing infection.

Protesters brought many medical journal articles with them to share with the press. We patiently showed them the studies and tried to explain the controversy. We presented the Fox News and New Haven Register reporters study after study which proved that Bb can be a chronic, active relapsing infection. We were also displaying our huge \$20,000 dollar reward posters behind those being interviewed.

Not only did Fox news allow Dr. Feder to announce to the whole state of Connecticut that there is no proof that Chronic Lyme exists, despite lack of evidence, but Fox news also totally omitted any mention that there are many studies which prove that Lyme borrelia can persist in the body despite 2 to 4 weeks of antibiotic treatment. Our reward posters were "Media"...cont'd pg 13

that only symptomatic drugs will be helpful. Doctors need to be detectives, try to get at the root cause and not just treat the symptoms while a true degenerative disease process may be simmering underneath the surface.

At our Rally on Oct 7, The Hartford Courant and Fox News were both present and they spent a great deal of time interviewing Dr. Feder, who was inside the Health Center, and the protesters, who of

of Chronic Lyme, they are referring to an active chronic infection, meaning that germs are still present and need to be killed off or controlled.

The Yale/UCONN camp claims that after 2 to 4 weeks of antibiotics, that there are absolutely no borrelia bacteria left in the body. The problem is....they show no proof of this claim. How dangerous, reckless and perhaps even criminal it is to base treatment on an unprovable theory and deny



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Phone: 215-643-5434
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Fax: 215-643-9307
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The ALS Association Upstate New York Chapter

323 Route 5 West
P.O. Box 127
Elbridge, NY 13060
315-689-3380
Toll Free for PALS:
1-866-499-PALS
info@alsaupstateny.org

Lyme Disease Association

lymediseaseassociation.org/
Pat Smith 888.366.6611

Arizona

Scottsdale, AZ 85259
Group facilitators :
Karen Genest 480-632-6444
Larry Levy
Larry@valuepro.netbox.com

Northern Arizona

Tina Caskey:
tcaskey@safeaccess.com
928-779-2759

Southern Arizona - Donna Hoch: nanandbo@cox.net
520-393-1452

L.E.A.P. Arizona

Tina J. Garcia
Lyme Education Awareness
http://www.leaparizona.com
480-219-6869 Phone

Arkansas

Mary Alice Beer
(501) 884-3502
abeer@artelco.com

California

ROBIN SCHUMACHER
1057 R St.
Fresno, CA 93721
Phone: (559) 485-5445
Membership@Calda.org

Colorado

Mary Parker
303-447-1602
milehightick@yahoo.com

Alabama

Jim Schmidt (334) 358-3206
jschm47974@aol.com

Arkansas

Mary Alice Beer
(501) 884-3502
abeer@artelco.com

National Support:

truthaboutlymedisease.com/
forum
Dana Floyd, director

Lyme Disease Support

Kansas

913-438-LYME
Lymefight@aol.com

Montana

bepickthorn@earthlink.com
North Carolina
Stephanie Tyndall
sdyndall@yahoo.com
Lenoir County Hospital,
Kinston, NC

New Mexico

Veronica Medina
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NO TWO BORRELIA SPECIES ARE EXACTLY ALIKE

by Terri Reiser

Casual Conversations About Lyme Disease

by Maggie Sabota

Throughout my year as Miss Cumberland County, I have had many opportunities to share with others about Lyme Disease. While quite a few of these opportunities were through formal presentations at schools, senior centers, and luncheons, many casual conversations arose on a day to day basis. During these conversations, I have found that many people have been misinformed about certain aspects of the Lyme Disease. Here is a sampling of some of most common misconceptions:

"I received a negative test result so I'm sure I don't have Lyme Disease"

Lyme is a clinical diagnosis. Standard tests such as the Elisa and Western blot tests are only 65% accurate. This is because the tests look at antibodies which may not be present, even though someone has the disease. A positive test can be used to support a clinical diagnosis, but a negative test should not be used to exclude it.

"I never had a "ring-rash" so I must not have Lyme Disease."

Only about 60% of individuals get a post exposure rash and many aren't classic erythema migrans or "bull's-eye" rash-

es. People are usually very shocked when I share this statistic with them.

"Deer are the only animal that carry deer ticks."

This is a question that I

other problems.

"I wasn't in the woods, so I can't have Lyme Disease."

I have encountered several people who were showing common signs of Lyme

off or smother it with petroleum jelly."

Surprisingly, this is probably the most common misconception that I hear. These methods can actually facilitate the transmission of the

"I've already had Lyme Disease, so I can't get it again."

This piece of misinformation is very frightening, because if someone thinks they cannot be re-infected, they won't take the precautions necessary to keep from getting the disease again. If anything, having the disease once should make you all the more cautious in the future.

"I heard that Lyme disease can always be cured with four weeks of antibiotics."

A short course of antibiotics may be adequate in some cases, but unfortunately, this isn't always true, especially in more severe cases. Lyme Disease isn't always curable and it is a lifelong illness for some people. This is the point that hits close to home for me; I am able to speak from personal experience just how long reaching the affects of Lyme Disease can be.

All of these misconceptions that I hear have helped me to shape the presentations that I give so I can provide accurate facts to clear up any misinformation that people may have received in the past. I am so glad that I have had the opportunity to be Miss Cumberland County so I can spread awareness about Lyme Disease and ways to prevent it. *pha*



hear very frequently. Deer are perhaps the most well known animal to carry the black-legged or deer ticks, but other animals such as mice, birds or even the family dog can carry them. If I am asked this question I normally also mention that dogs can also get Lyme Disease, which can cause them to have severe arthritis, among

Disease, but refused to even think that they might have the disease because they had not spent any time in the woods. They don't realize that you can get bitten by a tick almost anywhere, even in your own backyard.

"I heard that if I find a tick on me I should try to burn it

disease. I always advise people that the best way to remove the tick is to use narrow-nosed tweezers to grasp the tick around its mouth parts, close to their own skin. If someone is uncomfortable about removing the tick, my advice is to go to the doctor or emergency room as soon as possible.

Kids With Three or More Coexisting Disorders Show No Response to ADHD Treatment

by NIH News

Preschoolers who are diagnosed with ADHD are not likely to respond to treatment with the stimulant methylphenidate, regardless of dosage, if they also have three or more coexisting disorders, according to a recent analysis of data from the Preschoolers with ADHD Treatment Study (PATS). PATS was funded by the National Institutes of Health's National Institute of Mental Health (NIMH). Previously reported PATS results showed that overall, low doses of methylphenidate were safe and effective in treating 3-5-year-olds diagnosed with ADHD. This most recent study, one of seven new PATS articles published November 5, 2007, in the "Journal of Child and Adolescent Psychopharmacology", sought to identify individual characteristics that may affect how a child would respond to treatment. The other articles examine topics such as the effectiveness of methylphenidate over a follow-up phase, the effects of the medication on functional outcomes for the preschoolers, and others.

"This new data is an important step forward in bridging the gap between research results and clinical practice, bringing potentially valuable information to clinicians about ways to better customize treatments for their patients," said NIMH Director Thomas R. Insel, M.D. "It also

identifies a group of young children who have significant and multiple problems, and for whom more research is needed to identify effective treatments."

Analyzing data from 165 children, Jaswinder Ghuman, M.D., of the University of Arizona, and colleagues examined demographic and family characteristics that

"[These results] are a reminder that we need to find better treatments for kids with multiple disorders and challenging circumstances."

may predict response to ADHD treatment. Among the children, 29 percent had no coexisting disorders, 42 percent had one coexisting disorder, 21 percent had two coexisting disorders, and 9 percent had three or more coexisting disorders. Oppositional defiant disorder, conduct disorder and anxiety disorders were the most common coexisting disorders. The researchers found that children with no or only one coexisting disorder were most likely to respond to methylphenidate, while those

with two coexisting disorders were moderately likely to respond. Children with three or more coexisting disorders did not respond at all to the treatment.

They also found no demographic characteristics (e.g., gender, age, ethnicity) that predicted how a child would respond to methylphenidate. However, children with three or more coexisting disorders were more likely to have a lower socioeconomic status, and lived with parents who were less educated and unemployed. In addition, these children also were more likely to live in a single-parent household.

"These results need to be replicated before they can be translated into practical recommendations," said Dr. Ghuman. "But they are a solid reminder that we need to find better treatments for children with multiple disorders and challenging circumstances."

The findings are consistent with the NIMH-funded Multimodal Treatment Study of Children with ADHD (MTA), which found that school-aged children with more coexisting disorders were less likely to respond to ADHD treatment.

The National Institute of Mental Health (NIMH) mission is to reduce the burden of mental and behavioral disorders through research on mind, brain, and behavior. More information is available at the NIMH website, www.nimh.nih.gov. *pha*

Lyme Awareness Art Project

Financial Donations for Supplies Welcome & Appreciated



The first submission for the Lyme Awareness Art Project read: "I'm not afraid of Lyme disease. I know I can beat it. I'm tough and strong and I can be as mean as a dinosaur. This disease can't slow me down." Jeff - age 6 - Middlesex, VT

Tell Us Your Story!

The guidelines for submitting your story and photo are simple. Write a short paragraph or poem describing your experience with Advanced Lyme and send a photo that you feel visually expresses the experience you have written about. Include your name, your age and the city and state in which you live.

I will paint my interpretation of the submissions for what I hope will be a traveling Lyme Awareness show. Please be sure that you send me your contact info in case I need to ask you something about your submission!

Send Photo and Story Submissions to:

Linda Marcille, Lyme Awareness Art Project
28 Center Road, Corinth, Vermont 05039

www.crowhousestudio.com

<http://lindaslymediseasejournal.blogspot.com>
smalldog@tops-tele.com

“Media”... cont'd from pg 10

also totally cut out of the news segment. Does this seem fair to you? Does this sound like unbiased reporting?

The day after the protest we were anxiously waiting to see what The Hartford Courant would print, as the Courant reporters were at the protest for over an hour. I looked through the whole paper and no mention of our protest was to be found. In place of what could have been a very helpful article for the people of Connecticut, there was only an announcement that some "Lyme" doctor at Yale, had won an award. Obviously these news outlets are not even trying to serve the interests of the people in the state of Connecticut.

There are over 300 strains of Bb and our current testing is only looking for one or two strains. Imagine how

this fact alone is preventing millions from being diagnosed. There are also many emerging co-infections which are not being tested. The Lyme bacteria is pleomorphic, which means it changes form to evade the immune system, antibiotics and testing. It is a Stealth Pathogen. Perhaps the definition or concept of "Lyme Disease" needs to be expanded.

A most excellent website to visit is: <http://www.lymeinfo.net/lymefiles.html>. This website is for patients, researchers and doctors. Here you will find all the evidence you will need to help you better understand this most crucial issue.

Marjorie Tietjen is a patient advocate and Lyme activist. She is a freelance writer for the PHA.

Public Health Alert

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“Volunteers”... cont'd from pg 5

done a similar task for another organization or perform duties at their job that sound like what is being described, but your group may have different guidelines to follow or paperwork that may be unfamiliar.

Guidelines and open lines of communication are vital. People thrive on guidelines - outlines of the task/job are necessary so that everyone is on the same page. Everyone should be made aware of the guidelines in addition to what is expected of them as individuals and as a group. Keeping the lines of communication open allows for questions, new ideas, announcement of changes, and keeps the flow of progress moving.

Reminder: Success of the volunteers often depends on good leadership.

No matter what intense planning, structure, communication, or guidelines, there may still be problems. When a problem arises, take immediate action. You may be able to ward off it turning from molehill to mountain, thwart future problems, or the loss of valuable volunteers.

Misunderstandings, not feeling appreciated, task too difficult, and lack of progress are common reasons for problems. But what happens when what a volunteer makes happen isn't so good?

They say there is always one rotten apple in the barrel - and if left alone, it may spoil

the bunch. This is also true about groups of volunteers. You may just have that one volunteer that everyone avoids or complains about; the one that no matter what their task or position, they are never happy; or the one that causes trouble out of habit, spite or personal need. If the problem is ignored, you stand a very good chance of losing volunteers, the project not being completed, and your reputation as a leader being ruined.

Questions you may want to consider when confronted with a problem:

Who: Is it a volunteer, someone else involved in the task (i.e. a employee at the clinic where you have volunteers stationed), or an outsider (someone that has nothing to do with the group and tasks)? Are you the person who will ultimately make decisions about this problem? Do you have others you can turn to for advice or another perspective on the situation?

What: Is the problem related to job or perhaps stems from personality?

Where: Is this problem happening on the job or outside the work area?

How: Do you have access to the people involved? Is your schedule open for interviews to hear what all (including witnesses and other volunteers) have to say? Are the complaints founded - if so, how? Will simply changing the

volunteer to another area/project fix the problem? Are there other alternatives to solving this problem (i.e. policy change)? Do you have access to resources to remedy the problem?

Why: Is there any reason you can see that is causing the problem? If this is a repeat problem, can you identify the reason?

Reminder: Once the choice has been selected to solve the problem, follow-up at a later date to see if the problem is solved.

Good leaders are not easy to find. The group may be difficult to manage, the problems too great, or the resources too few. This can cause a good leader to burn out early or to lose sight of the mission and goals.

Tips: Lead through communication and keeping promises.

Don't allow gossip to be part of the group. A rumor can spread faster than warm butter on hot bread. Normally, the information is wrong, the story has had some additions (making it partially incorrect), or it was never true. People start gossip for various reasons - nothing more they want to do than hear themselves talk; to be malicious or to seek revenge; because their self-esteem is lacking; or because this has been their routine for as long as they can remember (habit).

Respect the rights of the volunteers. If they cannot stay late or take on another task, they have every right to say "no." Their privacy is also an area that needs respect. If they have come to you in confidence, don't break that confidence without permission.

- * Keep expectations realistic.
- * Be a motivator.
- * Keep personal opinions out of the volunteer arena.
- * Favoritism is a no-no.
- * Be flexible.
- * Look for the good in people.
- * Enjoy the challenges - there will be many.
- * Be willing to put in extra time and effort to see results.
- * Don't take the glory or the credit away from the volunteers.
- * Don't let negative comments take your sights off the goal.

If you must "fire" a volunteer, be sure you have tried everything else first. It's a good idea to start taking notes when the problem is noticed or reported. Get everything in writing, if possible. Your credibility may be at stake for reprimanding or firing a volunteer - be honest and thorough. If need be, ask for help in evaluations before acting.

Reminder: Don't be afraid to turn a volunteer away. If they are a potential problem, they don't have to be yours.

Volunteers have responsibilities, too. Others will be counting on you to show up when you said you would and

do the work you promised to do. Honesty is vital to be a good volunteer. If you are having difficulty performing a task or meeting deadlines, communicate this to the leader. If you cannot attend a briefing or fulfill the hours promised, let the group leader know this.

Dressing and behaving appropriately is mandatory. Wearing the proper outfit or uniform that is clean and pressed says something about you - as does choosing to not dress for the task or pulling something out of yesterday's dirty laundry basket.

Follow the guidelines and don't be afraid to ask questions when you aren't sure of something.

Don't start or listen to gossip. You may find yourself soon wrapped up in a mess.

Report abuses to a higher authority. If someone is stealing, make sure someone in charge knows about it.

* Don't be afraid to say "no" when necessary.

* Volunteer for the right reasons.

* Expect rewards, but not the type you can hang on the wall or take to the bank.

If you are not enjoying the volunteer position, ask to be reassigned.

Reminder: Volunteering should be productive and fun!

pha

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Middle School Student Contraception Policy Threatens Parental Rights

by *Parental Rights.org*

King Middle School in Portland, Maine, has been making headlines as a proposal to give students access to birth control continues to move forward. The school would be the first in Maine to make a full range of contraceptive prescriptions available to students in grades 6 to 8, most of whom are between the ages of 11 and 13.

The policy, which was passed by the Portland School Committee on October 17th by a vote of 7-2, requires students to have parental permission to go to the school clinic. But once they are there, students may receive confidential care, with no parental consent required--for anything. After conducting a physical examina-

tion, a school physician or nurse may prescribe contraceptives, including contraceptive pills, patches or injections, and the morning-after pill. Proponents of the policy claim that schools need to address the reality that some teens are sexually active and need access to birth control. Opponents have contended that providing contraception for 14-year-olds is promoting risky behavior, and that the policy will promote excessive medicating of young people, while violating the rights of parents.

"Confidentiality" Undermines Parental Rights
According to state law, if a student requests confiden-

tiality, health care workers must honor it, ultimately leaving the child to decide whether to tell Mom or Dad. Many parents in

Portland have expressed outrage that their 11 and 12 year old girls could be given potent injections or medications--all without their knowledge. But the ACLJ's efforts may not



be enough, given the massive shift away from parental rights taking place within the federal courts. Less than two months ago, the Third Circuit Court of Appeals ruled that school officials did not violate parental rights when they gave contraception to a 16-year-old girl without her parents' knowledge or permission. The girl suffered severe abdominal pains and vomiting as a result of the medications, but according to the court, no constitutional rights were violated because she had voluntarily entered the health clinic, sought medical care, and could have notified her parents at any time on her own.

Effective Protections
The Third Circuit's decision illustrates the precarious state of parental rights in America today. The most effective way to safeguard parental rights is through a constitutional amendment that protects the child-parent relationship from government intrusion. The Parental Rights Amendment will ensure that the right of parents to protect their children, to make crucial decisions on their behalf, and to direct their upbringing and education, will be preserved for generations to come. Join with us today by encouraging your friends to get involved in the battle to protect parental rights and join the campaign and sign the petition at www.parentalrights.org.

"Pat Smith"... cont'd from pg 7

ing] technologies developed. So we can look at the strains. Eventually, what will happen: a patient will be able to go in and then, maybe based on what strain they have they can develop a treatment specific for that strain of Lyme disease. That's a lot of work that needs to be done, especially when the government isn't even looking at it. We're looking at it though.

What reasons do you know that cause physician to deliberately not diagnose Lyme disease?

I can't say that I know that they deliberately don't [diagnose], I can't make that statement. But based on what I have seen and heard, I think there are physicians who are afraid to diagnose the disease. I believe there are physicians who don't know about the disease and don't want to know about the disease because this disease is a lot of work. You can't turn to page 77 in the cookbook and say, "Oh yeah, gee, we could give this to you and you'll be out the door." That doesn't happen. Does think, "I'm going to be seeing you forever and ever," and some physicians don't want to do that. I think that's part of it.

I think insurance companies are certainly another reason. Plus there's tremendous peer pressure on physicians. And now what I'm hearing is that when one physician in a practice with other physicians starts treating Lyme patients, their peers don't like that. So some of these treating physicians have gotten out of that group practice they were in or they've curtailed their Lyme treatment and practice due to that.

Why do you think the Midwest lags so far behind the East and West coasts with Lyme disease treatment, diagnosis, reporting--everything?

I think what's happened is the spin, Lyme disease has been spun--that it's only found in the Northeast, and certain portions of California, and maybe a little bit in the Midwest. Some of it had to do with tick populations. I think that originally, the deer tick was not necessarily in all the areas

that it's in today, so the deer tick has changed its migration.

Then we have the introduction of the lone star tick, it's on the move. There was a huge battle for many years between the CDC and some of the treating physicians over STARI [Southern Tick-Associated Rash Illness carried by the lone star tick] and now they finally decided that it's a separate disease, even though it's very close to Lyme disease. I think that has kept things [numbers of cases] down and spawned confusion in diagnosis, especially in the Midwest. More confusion has arisen with other tick-borne diseases like erlichiosis. We used to have two kinds of erlichiosis but it was still called erlichiosis. Now one's called anaplasmosis and yet there is still the other form of erlichiosis. I think that has really not helped the numbers [of cases of erlichiosis reported] in the Midwest.

Then there are the CSTE (Council of State and Territorial Epidemiologists) guidelines that came out this year that will probably become effective in 2008. No longer will a person be able to have just an EM (Erythema Migrans/bull's-eye rash) and get diagnosed [for Lyme disease]. If you are in a non-endemic area [less than two CDC-confirmed cases have been reported per county], you have got to have a positive test.

This is going to destroy, in my opinion, surveillance; because what's going to happen in all these non-endemic areas is that these people aren't going to test positive. It's very unlikely. [People who have the EM rash do not test positive very often. Their bodies have rarely

had time to make detectable antibodies that will show up on commonly used antibody tests and, even if they do make the antibodies, the antibodies often complex or sandwich the Lyme disease antigen. Commercial tests cannot test for complexed/"sandwiched" antibodies.]

A lot of these cases might be STARI, which has no definitive test. And the CDC's argument is that the cases of STARI must be separated from Lyme. So when you [the CDC] get a good test for STARI, you let us know about it! In the meantime, what are you going to do with these people? They're going to be running around with an EM rash and

the increase in ticks too. And, quite frankly, I don't think the Midwest wants to have Lyme disease. People will say to me in New Jersey, "We don't really have that." And I say, "What are you talking about? We're third in the nation!" They just don't want to have it because it's a disease that affects your economy.

If you're a tourist area, I imagine you have a lot of people that come in here [Minnesota] to hunt and to fish, so who wants to have these diseases? I can tell you. No one wants Lyme. I've been there. I've heard them tell me. And I can tell you it also impacts the sale of homes.

In New Jersey, in the 90s, when Lyme was a really big thing, TV stations came down from New York. There was this whole neighborhood that was heavily infested with Lyme disease and a major network, I can't remember which one, did this report and after that report these people could not sell their homes. Suddenly, all the TV coverage stopped. There was no more coverage on Lyme disease.

Then we had the health department come out with a report in the late 90s on the parks in New Jersey. The reports said, "This park or that one has this percentage of the ticks infested [with Lyme]." And let me tell you, these parks were deluged with calls. People were freaked out. They didn't want to come to the parks. Well, guess what? That was the end of that. To this day, there has never been another report made public about the incidence of ticks in the parks in New Jersey.

These things have already happened. So, do I think that your state is any different? No.

What are the most serious obstacles you see in Minnesota and Wisconsin for passing Lyme legislation to

protect doctors?
I think that there are two very serious obstacles. Number one is the IDSA (Infectious Disease Society of America) and number two is going to be the insurance companies. Even for doctor protection legislation insurance companies will often times come in but they won't be as adamant about doctor protection as they are about an insurance bill, but they will most likely come in. But the IDSA, I just testified in Pennsylvania, they're actually having another hearing on Thursday. Right after my testimony, an ID-doc [infectious disease physician] got up. Fortunately, in my opening talk I had anticipated what this doc would say, because I know what they're going to say. ["Overuse of antibiotics fosters resistance." "Chronic Lyme disease doesn't exist, etc."]

Do you see any threat from the Mayo Clinic?
I think that there are some people there that probably have some knowledge of the situation [with Lyme disease] and might be sympathetic, but unfortunately, when you work for these institutions, you always have to toe the party line. They might come in but my guess would be more the IDSA because they now actually have an active agenda of defeating patient legislation, and it's been up on their slides [at their meetings].

We can't forget the AAN (American Academy of Neurology) is right in St. Paul...
Ah! I hadn't realized that. And of course we already know that three people on that particular article ["Three to four weeks treatment for neurological Lyme disease is all the treatment that's necessary." AAN Press Release, May 3, 2007.] also participated in the writing of the IDSA guidelines [for the treatment/non-treatment of Lyme disease]. The good news is that I understand the Connecticut Attorney General apparently subpoenaed them [for possible anti-trust violations] too. At least, that is what I read on the Internet.

Does the CDC know doctors are being investigated by medical boards for treating symptomatic patients from endemic areas...who show reactive bands specific for Borrelia burgdorferi but don't meet CDC criteria?

Yes. I told them so in no uncertain terms. If they weren't aware, they are now.

they probably will not be positive on a test. Then, they're not even going to get any treatment because they're going to fail the criteria, fail the test! This is insane. This is the discussion we had.

I think a lot of people think they don't have the deer tick [in their region]. I've heard this over the years. Well, hello! You better get used to it because you do have those ticks in many more areas now. There's thinking that global warming has a lot to do with



Shoemaker Unveils Authoritative Resource on Biotoxin Illnesses



by Scott Forsgren

When I first met Dr. Shoemaker at the annual conference of the American College for the Advancement of Medicine (ACAM) in May 2006, I had just completed reading his book on biotoxin illnesses titled "Mold Warriors". I had a basic understanding that biotoxins were a potential problem for those of us suffering from Lyme disease and many other chronic conditions. However, at the time, I did not fully understand the significance of biotoxins on health like I do today. This understanding has come to me through reviewing the work of Ritchie Shoemaker, MD.

Dr. Shoemaker is unparalleled in his research on the impact of biotoxins on health. In my opinion, no one understands this better. For those of us suffering from Lyme disease or mold-related illness, many key pieces of the puzzle lie in his work. The puzzle pieces are now ours for the taking. To date, other than through his several books, there has been limited information available for the lay-person to gain a better understanding of the significance of his research. Now, with the release of a new web site, all of that has changed.

In collaboration with DataMed Group, Dr. Shoemaker has compiled a vast array of information that is now readily available to us all through his new site at

<http://www.biotoxin.info>. The site includes a detailed description of biotoxin illnesses, explanations of some of his more recent research, a new and improved on-line test which includes the VCS (Visual Contrast Sensitivity) test, a number of recently filmed videos where Dr. Shoemaker explains his work, and a message board where he regularly shares updated information on a variety of topics.

In one article, Dr. Shoemaker discusses how C4a is used as an often helpful marker in determining the presence of ongoing infection after antibiotic treatment in someone with Lyme disease. In another, he talks about Bbtotx1 and the impact of biotoxins in Lyme disease. In yet another, he discusses the various symptoms of biotoxin-induced illness as well as reviewing a number of other diagnoses that patients often receive before understanding that biotoxins are a key part of their illness. The site also explains Dr. Shoemaker's general treatment protocol using cholestyramine and other interventions to address the biotoxins circulating within us.

If we turn our attention to screening tests that may help provide insight about the impact of biotoxins on one's health, the new site introduces an enhanced version of the previously available VCS, or Visual Contrast Sensitivity test. VCS testing was discussed in more detail in the November 2006 edition of the Public Health Alert in the article What Mine Eyes May Tell.

The updated test, which is based on soon to be published research in a peer-reviewed medical journal, looks at combinations of variables (namely symptoms and VCS test results) and interactions between variables to predict an outcome using an advanced statistical technique called logistical regression. The test looks at patient reported symptoms along with the results of the VCS test to give a Biotoxin

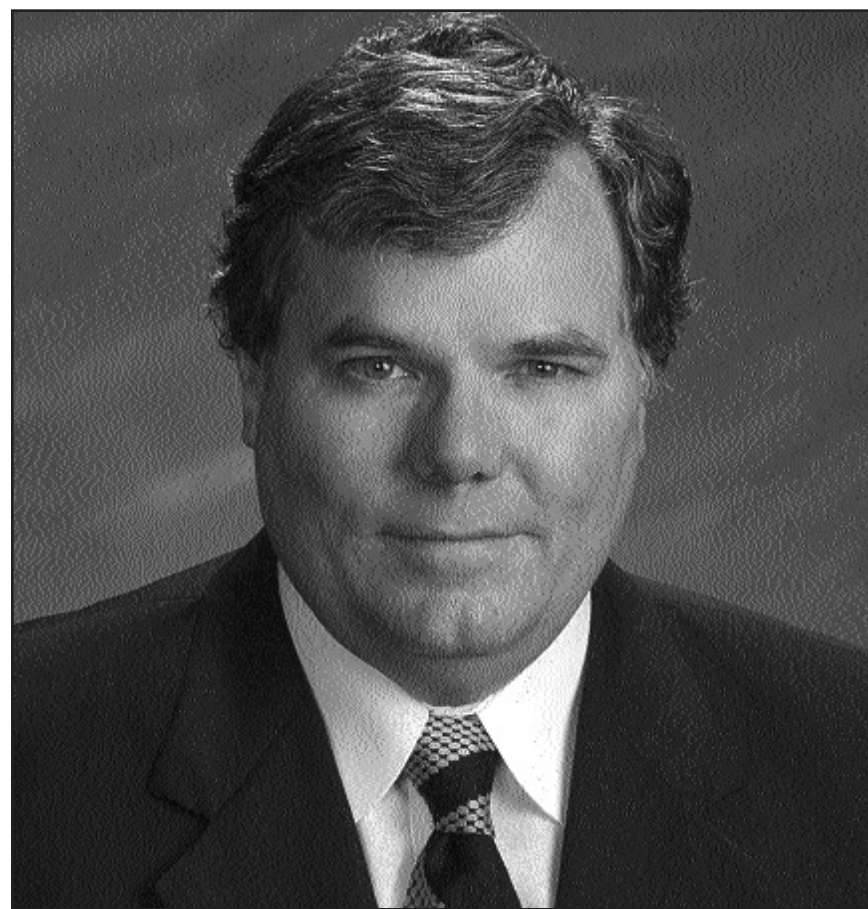
Illness Risk Score (BIRS). The resulting analysis may provide further insight into whether or not a biotoxin-induced illness is likely to be present. The combination of these responses and the results of the VCS test can predict biotoxin illness with a sensitivity of around 99.5%. The VCS test has been found to be near 90% specific meaning that less than 10% of the test results could be false positives where the patient fails the test but the failure is related to something other than a biotoxin illness.

In addition to the VCS test results, the new test incorporates BIRS (Biotoxin Illness Risk Score) which uses an algorithm incorporating the symptom questionnaire results along with the VCS test results to come up with a score between 0 and 100. This score represents the likelihood that the patient's condition may be biotoxin-induced. Research has shown that when a person fails the online BIRS test, they had a greater than 96.5% chance of having two or more abnormal blood test results, and a 83.8% chance of having 3 or more abnormal blood test results. Many patients who fail the BIRS test have 5 or more abnormal blood tests. It should not, however, be used to replace a thorough differential diagnosis by a qualified physician.

Another exciting new feature of the enhanced test is a tracking and trending feature which generates graphs over time. These graphs may be helpful in representing either a worsening or an improvement in the patient's condition or be used to gauge treatment benefit.

Though the VCS test alone cannot distinguish between biotoxins from mold, Lyme, or other sources, it is a good general indicator that biotoxin-induced illness may be present. It should act as a screening tool to determine whether further evaluation and lab testing is warranted.

One of these additional



tests might be C4a which has been found by Dr. Shoemaker to be a useful tool for distinguishing between mold and Lyme biotoxins. After appropriate treatment to remove biotoxins, C4a can be measured at one week and four weeks after treatment concludes. If a rise is observed within one week, the biotoxin is likely due to continuing mold exposure whereas a rise after four weeks may point to Lyme as the source of the biotoxin. This and other useful information is available on the new site.

Another planned feature is the ability to ask Dr. Shoemaker questions and have him respond via the site in either text or video segments. As mentioned, several video segments already exist within the new site on a number of topics related to biotoxin illnesses.

I applaud Dr. Shoemaker for making this new site available to us and for freely sharing the most current information available on the topic of biotoxin-induced illnesses. The more we learn, the better we understand our illnesses, and the better we understand our illnesses, the more equipped we are to someday leave them behind. *pha*

DataMed Group provides analytical services and research support with a primary focus on supporting healthcare practitioners in the areas of Lyme disease and other fatiguing illnesses. Additional information can be found at www.datamedgroup.com.

A previous article written by Scott Forsgren on the Biotoxin Pathway proposed by Dr. Shoemaker can be found in the June 2007 issue of the Public Health Alert in the cover story titled *Biotoxin Pathway Holds Key Pieces of Puzzle in Solving Chronic Illness*.

Scott Forsgren has battled Lyme disease for the past ten years. He shares his story on his web site at www.BetterHealthGuy.com. Scott can also be reached at Scott@BetterHealthGuy.com.

Dr. Shoemaker's new web site on biotoxin illnesses can be found at

<http://www.biotoxin.info>

BetterHealth

Fig. 1 Biotoxin Illness Risk Score (BIR) Trend

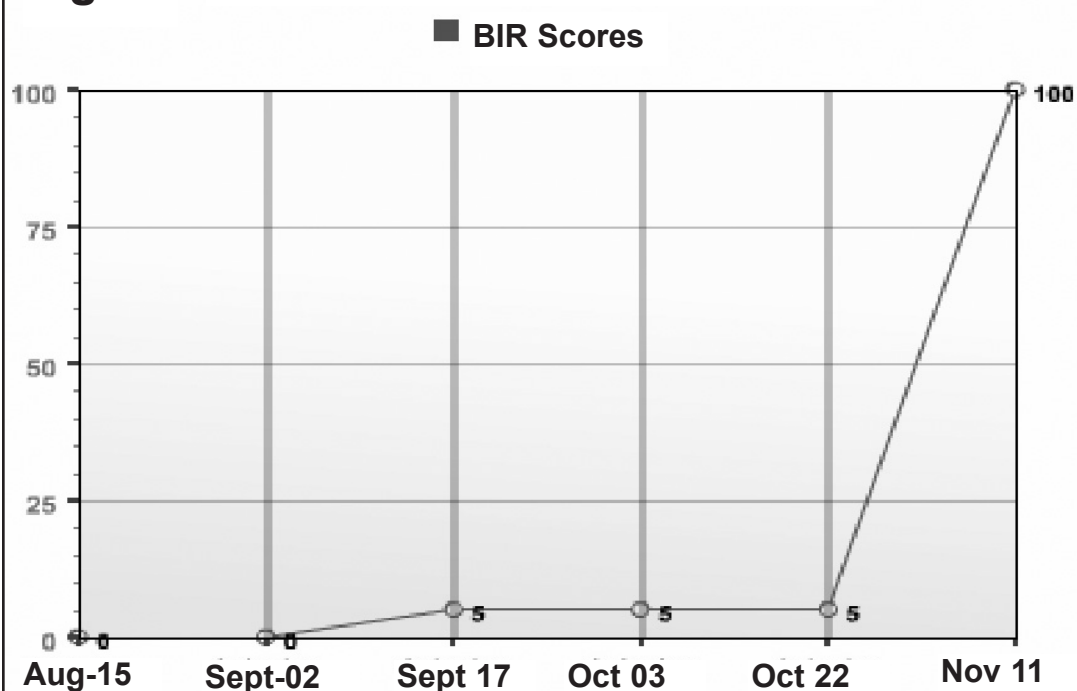
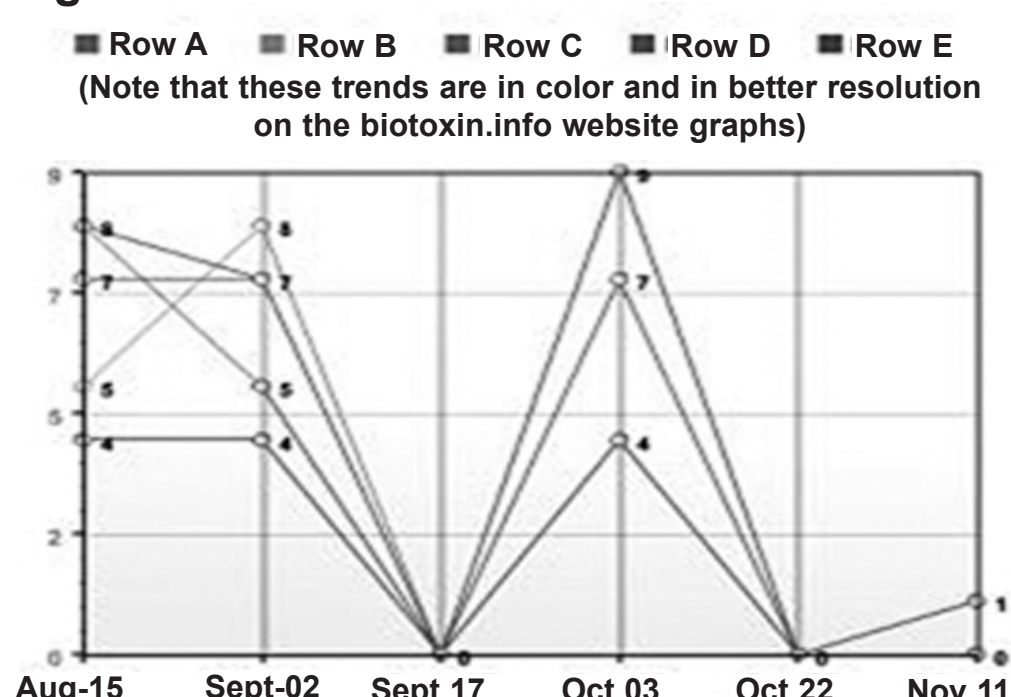


Fig. 2 VCS Row Trend - Left Eye



Connecticut Governor Rell Announces Expansion of Lyme Disease Surveillance and Education Measures

Connecticut Governor M. Jodi Rell today announced that the state has launched a three-part Lyme disease surveillance and education program.

"Thousands of patients with Lyme disease visit Connecticut doctors every year," Governor Rell said. "We aim to increase community awareness about Lyme, but we also are pushing forward in our efforts to track Lyme disease cases electronically."

"Our goal is to bring about an efficient, accurate method of recording Lyme disease cases so that we can make informed long-term policy and planning decisions. We want to truly understand the risk of the disease and its economic impact."

The Governor said that the Connecticut Department of Public Health (DPH) is now partnering with the state's largest provider of medical testing, Quest Diagnostics, to obtain positive Lyme disease test results. The state will work with Quest until a state-run electronic laboratory system is implemented.

The DPH is currently processing positive Lyme lab

results from Quest, and preparing to send to physicians letters of request for further clinical information on approximately 5,500 patients.

"These test results correlated with clinical information provided in confidence by the health care providers gives the DPH valuable information about the number of Lyme cases in Connecticut," said DPH Commissioner J. Robert Galvin. "I urge my fellow physicians to complete these letters of request as soon as they are received, and return that information to the DPH for analysis."

The second part of the Governor's Lyme disease initiative involves the establishment of intensive community based Lyme disease education and protection programs for Fairfield and Windham counties. This includes media outreach, handbooks and

brochures, and face-to-face education seminars through community organizations.

"Windham County has the highest annual average rate of Lyme disease, while Fairfield County, with its large population, has the highest total number of cases," Governor Rell stated. "The emphasis here is on education and protection programs, as well as input and feedback from the local communities."

In addition, the Governor said that the state has entered into an on-going partnership with the Connecticut State Medical Society to further educate physicians about Lyme disease detection, surveillance and reporting.

Lyme disease is a bacterial infection transmitted to humans by the bite of infected deer ticks. People are particularly vulnerable to it in the wooded areas of the state where deer are abundant.

Our goal is to bring about an efficient, accurate method of recording Lyme disease cases... We want to truly understand the risk of the disease and its economic impact.



Connecticut Governor M. Jodi Rell

"Gardasil"... cont'd from pg 9

by doing this, making HPV a public health issue of greater significance than parents' rights to decide medical care for their children.

The problems with compulsory vaccinations go beyond religious or public health concerns. The mandatory assignment of any medical initiative removes the basic civil rights of patients and places our freedom of choice into the hands of government. And yet it is not the right of the government to determine what should or should not be within our own bodies, and we must not relinquish those rights to freedom of choice. Removing our freedoms are not only fundamentally, morally, and in our country, constitutionally wrong, it is dangerous in my opinion. Especially when we have governments being lobbied by powerful pharmaceutical companies contributing billions of dollars for pharma-friendly legislation which will net untold profits for the vaccine manufacturers with unknown risks, including death, for untold populations. The mandating of vaccines on the global population turns civilians into nothing more than laboratory rats to be freely experimented on by pharmaceutical companies and governments.

Did you know that HPV can be treated by anti-viral herbs? Herbs which have been traditionally used include Garlic, Lemon Balm, Thuja, Hyssop and Pau d'Arco. Pau d'Arco has actually been used to prevent HPV infection, as well as cure it. Pau d'Arco was described in 1873 by Dr. Joaquin Almeida Pinto, for treatment of herpes, eczema and other disorders. In the 1960's in Brazil, two physicians

proved the herb had the ability to cure viral-caused warts. Other physicians in Argentina and the US have worked for decades to show that this herb has properties which heal the entire body. It is now used for AIDS, allergies, infectious diseases, asthma, candida, Parkinson's disease and a host of other infections and conditions, including warts, skin sores and HPV. It is commonly taken as a tincture or a tea. More importantly, no serious side-effects have been reported from its use.[7]

If we stretch the imagination, the mandating of vaccines is just one not-so-subtle step closer to total population control. Is that really what we want? We are being programmed to "accept" these activities beginning with the media visiting our very own living rooms, under the guise of protection from the "boogeyman", and in this case, the current agenda is HPV. In reviewing Infectious Disease Society of America (IDSA) documents, the root of the push for global vaccines may be more encompassing, and sinister than imagined. In a letter dated 11/9/06 from Past President Martin J. Blaser to Chairman Jerry Lewis, House Appropriations Committee in Washington D.C., Blaser informs Mr. Lewis of the following. "As you are aware, the recent budget increases for the CDC stem from large earmarks for bioterrorism preparedness, the strategic national stockpile and other specific priorities." In the letter, Blaser requests an "immediate appropriation of an additional \$3 million" for the CDC to begin surveying adolescent immunization rates. Blaser indicates that the CDC is suffering "severe

fiscal constraints and ongoing reductions at a time when vaccine needs are growing due to the licensing of several new vaccines including those recommended for adolescents and children." [8] This would imply that because vaccine manufacturers have licensed new vaccines, we must push for their implementation. This would not imply that HPV or any other "health threat" actually exists. But the ability to manufacture a "perceived threat" to both the American people and its government, is the art and science of planning future research, grant and special-interest appropriations. The cycle of product/demand/funding self-perpetuates.

Another IDSA letter not authored by Blaser was sent to the HHS Assistant Secretary for Public Health Emergency Preparedness, Dr. W. Craig Vanderwagen, discussing the pandemic influenza implementation plan as part of the White House's Homeland Security Council Biodefense Directorate. Although the body of the letter emphasizes influenza, it also encourages the department to "consider new paradigms", and discusses implementation planning, including with a National Biodefense Science Board soon established under BARDA.

While I understand the need for preparedness such as with influenza, at what point will the flu vaccine also become compulsory? And subsequent biodefense vaccines such as anthrax? The thinking may be if we can get the public to accept compulsory vaccines as "innocuous" as Gardasil, driven by carefully engineered "public health necessity", how much of a step then is it for us to accept globally mandated vaccina-

tions? Under the guise of "protection" we find a brilliant opportunity for pharmaceutical companies (and the governments who hold patent interests in vaccines) to exploit populations for trillions of dollars? I am beginning to see a pattern here, and it seems to be more in the line of profit, and not necessarily public health threats.

Gardasil uses a new technology called a "nanoparticle" vaccine which is essentially more effective and cost-effective than past vaccine technologies. The US government holds Patent #7,285,289 Nanoparticle vaccines, which was patented in part from work partially supported by the National Institutes of Health under contract PO1 AI37194. The US holds "certain rights" to the invention. Nanoparticle vaccines can be developed for a broad array of infectious diseases, including HPV, influenza, and even bioagents such as tularemia and anthrax. But the process to "get" people to accept mandatory vaccinations is only in the beginning stages. If we accept Gardasil, next comes Influenza, then mandatory vaccinations across the board. Then reproductive ability may be subsequently curbed due to yet more government mandates.

Am I sounding too sci-fi? Well, the point is this. When we relinquish our rights to choose, then choices are made for us. And those choices, whether "safe and effective" or not, are going to be made by governments and pharmaceutical companies alike whose for-profit interests may supercede public interests. At this rate, without cautious movement forward with the intent to protect our civil rights to choose, we

may yet live to see the day where our younger generation says "I want to be one less". But the meaning of those words will not be one less victim of cervical cancer, but perhaps one less citizen who has the right to choose.

Notes

- [1] FDA. Product Approval Information - Licensing Action. Questions and Answers. Available at: www.fda.gov/cber/products/hpvmr060806qa.htm.
- [2] FDA. New Vaccine Prevents Cervical Cancer. Sept-Oct 2006 FDA Consumer magazine. Access: www.fda.gov/fdac/features/2006/506_cervical.html
- [3] Judicial Watch [web site] Access: www.judicialwatch.org/gardasil.shtml
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- [5] Assoc. Content. Cervical Cancer Vaccine and the Controversies. [Internet article]. Access: www.associatedcontent.com/article/34830/cervical_cancer_vaccine_and_the_controversies.html?page=2
- [6] FDA/CBER Executive Summary on Gardasil. Access: www.fda.gov/cber/sba/hpvmr060806s.pdf
- [7] News Target. 8 More Deaths Caused by Gardasil Bringing Total Number to 11. [web article] Access: www.newstarget.com/022140.html
- [8] IDSA Letter dated 11/9/06. Access: www.idsociety.org/archive.aspx?fid=16

pha

Wisconsin Lyme Action Group Bake Sale

To raise money for pediatric Lyme disease specialist Dr. Charles Ray Jones, Wisconsin Dr. John Greg Hoffmann, and the upcoming Open Eye documentary film, Under Our Skin, the Amery, Wisconsin Lyme Action Group tapped member bakers to supply home-baked goods for a booth at the town's Fall Festival. The annual festival drew hundreds of people to a main street parade, amusement park rides, food booths, and a craft fair. Visitors to the bake-sale booth took away goodies and free information on Lyme disease and Lyme co-infections.

While their first public event brought in more money than the Wisconsin group thought it would, they were quick to question what they could have done better. If your support group wants to hold a similar event, here are some suggestions based on the Amery group's experience:

Borrow everything you possibly can to cut down on costs. Put out the word on what you need to stage the event at least two months ahead of time. The Amery group was pleased to be able to borrow an EZ-UP tent from a member, a crafter, who chose not to sell her hand-crafted items that weekend. Larger groups might want to purchase a tent and tables. The Amery group borrowed tables from a caterer. (You will need

more tables than you think.)

Set up the night before the event if possible. Setting up ahead of time reduces confusion on the event day and you can let members know your exact location.

Find out in advance if power will be available for your booth.

Cover tables with Lyme-green fabric for a clean and professional look.

Ask people to bring their baked goods to a central location the night before the event. By doing this, the Amery group's bakers didn't have to make their way through Fall Festival crowds the next morning. Encourage people who say they can't find time to bake to bake whenever they can eke out the time and to then freeze what they've made for the upcoming sale. Frozen goods dropped off the night before the event will thaw by the time the booth is open for business.

Gather informational flyers and pamphlets you want to distribute at least two months before the event. Consider assembling packets of information to hand out.

Don't forget rocks to hold down flyers, pamphlets, and paper in case it's windy!

Designate people for set up, pricing and marking the items, selling, and clean up.

Position your most gregarious enthusiastic and knowledgeable people at your table or booth. (Make sure booth workers get breaks.)

The actions above made the Amery event a positive experience. But the group says there's room for improvement. Here's what they'll do differently next year:

Sell individual items



cookies and bars and whole cakes, pies, and pans of bars. The group thought people at the festival would buy only what they could carry easily, so they didn't sell cakes or pies. They made a mistake. The one whole pan of bars sold right away. And, they noted, money can be made faster and easier on larger items than on the individual cookies or bars they had sold for twenty-five and fifty cents each.

Mark baked goods with names signifying exactly what

they are: "Sue's famous Pumpkin Bars" or "Betty's Blue Ribbon Brownies." Without name tags on the items at the Amery sale, customers couldn't tell exactly what was inside so they constantly picked up the baked goods and put them back down.

Knowing the ingredients in each baked item is important too. People wanted to know if this brownie or that one had nuts in it or not. Each baker should list the ingredients they used to make their confection on a 3x5 index card that booth workers and customers can see.

Make lots of signs. Signs draw people to you. The Amery booth should have had more signage. If whole cakes and pies had been for sale at the event, big signs might have urged people to: "Buy Now, Enjoy Later!" or "Pick up a pie on your way out!"

Remember: people come to a festival or fair for fun. Raising Lyme disease awareness and fund-raising can go hand in hand though the group agreed that next time they would concentrate more on making money and a bit less on providing information. A tiny meeting announcement flyer placed in a bag with every purchase might be more effective than trying to get cus-

tomers to look at tables full of information.

A veteran retailer offered further tips for conducting sales and informational events:

- * Believe every passing person is a potential customer.
- * Remain standing and look potential customers in the eye, at eye level.
- * Smile! A smile makes you (and your booth or table) approachable to passersby.
- * Don't allow booth workers or those manning tables to sit down. Customers are not as willing to approach seated (bored?) workers or those who are busy chatting with other workers. You must commit to the process of selling.
- * Let the customer steer the conversation. Pay exquisite attention. Listen carefully and they will tell you what they need to know or what they want to buy.
- * Ask questions to learn how you can help customers choose information or products. Once you understand their needs, guide them along the path of information only you can provide at that very moment.
- * Work to make the interaction and potential transaction smooth, pleasurable, helpful, and fun and you and your customer will both be satisfied!

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Riverside Medical Center Sponsors Lyme Disease Presentation

WAUPACA, WI - Wisconsin Lyme disease sufferers and advocates attended a November 1st talk on Lyme disease presented by Richard Veiga, MD and Fran Rademacher, NP at the Waupaca, Wisconsin Riverside Medical Center (RMC). This area of east-central Wisconsin, southeast of Steven's Point, has been hit hard by Lyme disease.

A flurry of emails from one misdiagnosed Lyme disease sufferer who lives in Waupaca prompted Mike Nickel, Wisconsin Lyme Groups representative, and Marina Andrews, who represents Western Wisconsin's Lyme Action Group, to attend the RMC meeting. Both Mike Nickel and Marina Andrews felt their combined presence could be supportive, informative, and beneficial to meeting attendees. State Representative, Kevin Petersen, who lives in Waupaca, also attended the meeting.

Dr. Veiga, a board-certified pathologist and medical director of the RMC laboratory, opened the program with a Power Point presentation on Lyme disease symptoms, prevalence, pathogenesis, and diagnosis. Dr. Veiga said he had to admit that, even though he is a pathologist, the tests for Lyme disease are very poor.

Dr. Veiga mentioned a common Lyme co-infection--Anaplasmosis, an Erlichia bacterial infection, but he said Wisconsin does not have the other more serious form of Erlichiosis--HME (Human Monocytic Erlichiosis). Ms. Andrews corrected Dr. Veiga

saying that HME is found in Wisconsin. She urged him to be sure the doctors he works with test for both types of Erlichia. She said, "They don't know HME's here because they don't test for it."

When Babesiosis was also mentioned as not being endemic to Wisconsin, Mike Nickel explained that it, too, is found in Wisconsin. Mr. Nickel told the presenters and the audience that he networks with physicians around the state so he knows that many of them have found Babesiosis infections in their patients.

Nurse Practitioner Fran Rademacher, said that most of the controversy in Lyme disease centers on treatment. Even though he struggled to remember the name of the International Lyme and Associated Diseases Society (ILADS), Rademacher was able to explain that ILADS treatment guidelines for Lyme disease, though they are at odds with mainstream medicine over the length of time patients are treated for the illness, shouldn't automatically be dismissed as heresy. He said emerging diseases need flexible guidelines. Treatment should not be set in stone and that how the patient fares after treatment is what's most important.

A woman in the audience, who identified herself as a local public health service employee, pointed out that there's more to the Lyme controversy than treatment. She said, "I can tell you for a fact, most cases of Lyme disease are never reported. They don't meet the reporting standards."

Several people in the audience nodded knowingly in response to her statement. The Centers for Disease Control believes only ten per cent of cases of the illness are reported.

When the comment was made that Lyme bacteria can become resistant to antibiotics, Ms. Andrews said there is no proof of resistance. She turned in her chair to face the audience and told them that recent media attention over Methicillin-Resistant Staphylococcus Aureus (MRSA) ignores one important fact: the best way to grow antibiotic-resistant bacteria is to stop antibiotic therapy short of the full course of treatment prescribed by your doctor. "That's why," Andrews said, "you're told to finish taking all of the medication, even if you feel better before it's gone."

Veiga and Rademacher thanked Nickel and Andrews for their comments and they were thanked in turn by Nickel for presenting "a balanced program," though several people expressed unhappiness with the information presented by Veiga and Rademacher by leaving before the program was over. Lyme group leaders and their supporters who stayed until the program ended were allowed to distribute the informational material they had brought with them. Marina Andrews expressed disappointment in those that left early. She said, "I could have poked holes in some of the facts presented in their Power Point program, too, but what was the point? I think Mike and I did a good job of pointing out things the audience needed to hear and know about,

and that was more important."

Mike Nickel had this to say about the RMC meeting: "The process of becoming Lyme-literate is gradual and continual. All Lyme-Literate physicians nationwide were once at precisely the same level of rudimentary knowledge Dr. Veiga and Nurse Rademacher currently practice at. Increased physician knowledge of the various aspects of Lyme disease is achieved through clinical

practice, self-directed research, and the desire to assist extremely ill patients. Additionally, I want to add, many Lyme patients are well-versed on the subject of their disease and can provide great assistance to the clinician. It is my hope that the medical professionals here tonight strive to ascertain full literacy of tick-borne infections. Local Lyme patient input will prove invaluable to these practitioners."

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Game Mourns Death of Great After Mike Gregory Loses His Battle

by Christopher Irvine
From The (UK) Times Online

Mike Gregory, the former Great Britain captain and Wigan Warriors coach, died November 19 after a prolonged battle with a neurological condition that had rendered him wheelchair-bound for the past year. He was 43 and leaves a wife and two young sons.

"Anyone who played with him, against him, or watched him play would have respected Mike for his courage," Joe Lydon, his former Britain teammate and best man at his wedding, said. "He brought that same courage to his fight against an appalling illness."

Gregory's wife, Erica, a biochemist, traced his condition - progressive muscular atrophy, a form of motor neuron disease - to a tic bite suffered while coaching the Britain academy squad in Australia in 2003 and the subsequent contraction of an infection known as borrelia, the causative agent of Lyme Disease. His illness forced him to give up the Wigan job after he had steered them to the 2004 Challenge Cup final and Grand Final the previous season. His death brought an outpouring of grief last night from a

sport in which he excelled as a fearsomely competitive player and a highly motivated coach. He was spoken of as a potential future coach of his country, whom he led to series victories over New Zealand in 1989 and 1990 during 20 international appearances, nine as captain.



Shaun Edwards, who went to school with Gregory in Wigan and played alongside him for Britain, said: "On the pitch, he was a warrior. Off it, he was full of life, full of fun. As a coach, he was a guy who cared deeply for his players. It was heartbreaking to see him suffer recently. There have been a lot of [fundraising] events, which showed how much people thought of Mike." Although born in Wigan, Gregory spent virtually all of his playing career at Warrington, where a book of

condolences has been opened, as the backbone of the side at loose forward for 12 seasons. He captained the team at Wembley in the 1990 Challenge Cup final defeat by Wigan, who had tried in vain to sign him in 1988.

If loyalty was one of his strengths, so was the stubbornness that came to define his latter years. He was assistant coach to Wales in the 1995 World Cup while pursuing a fruitless attempt to defy a knee injury that eventually ended his career after 18 appearances for Salford at the age of 31. He began the Super League era in 1996 as assistant coach to Shaun McRae at St Helens. He then coached Swinton before moving to Wigan, initially as academy coach and then as assistant to Stuart Raper, whom he succeeded in July 2003 to take over what he referred to as his "dream job". Gregory was aware of the seriousness of his condition only when he collapsed during the week of the 2003 Grand Final. His last game in charge of Wigan was the Challenge Cup final in Cardiff the next May, after which he stood down to have treatment in the United States, which failed to halt the remorselessness of his debilitating condition.

pha



I Am a Soldier

by: Dana Floyd

I am soldier tough and strong
everyday I fight the war within me
that goes on and on

I have never held a rifle,
a grenade or a gun
Instead my mind is my weapon
if this war is to be won

I soldier through the night
and the day time too
Fighting and unseen enemy
that attacks out of the blue

No place to run,
no place to hide
The enemy will find me
he lives inside

Weeks, months and sometimes
years go by
But I am a soldier
and I refuse to die

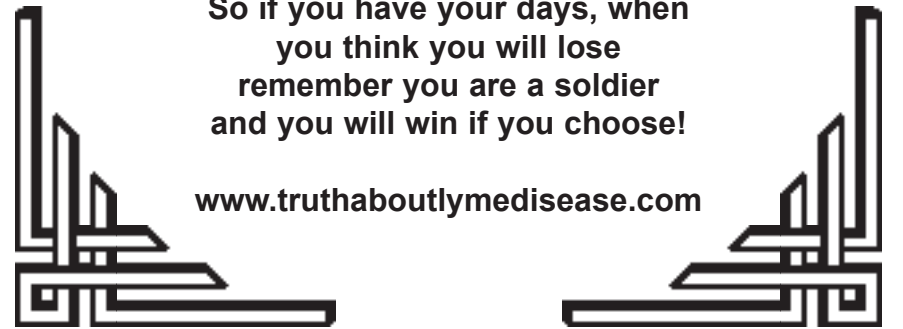
I am not a Marine,
or even a Navy Seal
But I have spirit and fight
and I will be healed

So when the enemy throws
a grenade of doubt
My answer back I do shout!

I will win this war,
on that you can bet
Lyme Disease won't beat me,
I'll be an LD vet

So if you have your days, when
you think you will lose
remember you are a soldier
and you will win if you choose!

www.truthaboutlymedisease.com



"Baggage"... cont'd from pg 4

for many Lyme disease sufferers. However, there's another critical complication: many LLMDs do not take insurance or Medicare and some charge staggering fees for initial appointments. While those in-the-know understand why some LLMDs practice without insurance reimbursement, this outside-the-norm operating ethic has cast a consequential shadow over Lyme disease.

Ask yourself how absurd and daunting the prospect of recovery appears for someone who has just learned they might have Lyme disease when they realize that, in addition to finding a Lyme-Literate doctor who may be able to diagnose them, they must then surmount significant, prohibitory monetary complications erected by the very doctors that can help. Some people beg and borrow money to

secure the health care they need though others are too sick to do so or too tired to try. These sick people fall through holes in the Lyme bag not "cracks in the system."

IDSA and Medicine if you're reading this and, I hope, trying to be open-minded, I have some suggestions based on the past. Don't allow Lyme disease treatment to be sold out to a pharmaceutical company that promotes a same-dose cure for every stage of the disease or fabricates another preventative like the vaccine that didn't work (and caused grievous harm), nor should you be quick to sink and dismiss what's left--those patients who are un-curable or chronic. If Lyme disease is truly incurable when the early diagnosis is missed, then our health care system must allow physicians to actively manage patients who feel better on

antibiotics (and feel worse when antibiotics are withdrawn). Insulin wouldn't be withdrawn from diabetic patients, would it? Patients with late-stage Lyme disease and the doctors who care for them simply can't be ostracized over treatment (or maintenance treatment) for an infection that Lyme's first researchers said could become chronic. Their words and their findings are in the bag and they're going to stay there no matter how many physicians try to dispute the existence of "chronic Lyme disease" today.

When we sort what can go back in the Lyme bag, new (ICD-9) codes for stages of the illness should be considered. These codes stratify the gradations of an illness. Syphilis is categorized as primary, secondary, and tertiary or late-stage infection. As Dr. Kenneth

Leigner pointed out, late-stage syphilis is treated with multiple rounds of combination antibiotics with no end point and little hope for complete eradication of the syphilis spirochete. Doesn't Lyme disease--another spirochetal illness, far more complex than syphilis though just as devastating in its late stages, deserve the same considerations?

The battle over Lyme disease will end when IDSA and ILADS adopt a flexible, expandable, soft-sided Lyme purse, and when both sides refuse to allow the folds of the old bag to get in the way, depriving patients of treatment and doctors of the bulk of Lyme disease research. Physicians and patients together must raise the white flag to work out a truce. Who's coming to the discussion table?

If you're willing to pull

up a chair, grab your old Lyme bag and empty it before you sit down so we can get to work. There's lots to do: Sort and rid the simmering Lyme disease gumbo of lousy tests, Centers for Disease Control reporting criteria, entrenched treatment guidelines, all-too-powerful health insurance companies and summary physician persecution. Keep physician autonomy. Open dialog between researchers and physicians. Provide science-based information in an easily-understood format to everyone who wants it. Accept input from patient groups and patient advocates. Give medical students up-to-date information on Lyme disease from all sources. Protect a physician's right to make a clinical diagnosis. And, of paramount importance, answer the phone!

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"Grateful"... cont'd from pg 2

have received. Journaling can be good therapeutic energy to add to the sometimes chaotic rhythm of our daily lives. It can be a source of soft reflection and bring some sunshine into your life. If you are religious, you can thank God for every new day, and I know the only bad day is the day you don't wake up. Remember that most of the important things in the

world have been accomplished by the people who kept on trying when there seemed to be no hope at all.

Of all the precious things in life which I am grateful for, most of all, I am grateful to be alive. Reflecting back on my life thus far there are some standout moments. I just love life so much, and I have such an intense passion just be

here to experience it. The best moments for me are the ones I have experienced after I have been pulled out from the darkness. These are the moments when the sunlight shines through the clouds and lights up the world. Life seems renewed, full of hope, and shining with opportunity.

Enjoy the holidays, even if you take a quiet moment by

yourself for reflection. As you sit by yourself, you can choose to think about your chronic illness in two ways. You can allow yourself to be negative, and overwhelmed with sadness, grief and pain. Or, you can know in your heart that your illness is an enriching, enlightening, life changing experience. You can gain strength through weakness, and grow stronger

the more obstacles you overcome. Remember this, you are not alone, and you can get better. Be eternally grateful for all that you have!

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