

## Hope to Heal Lyme

Reston, VA

April 1-2, 2006

Conference Summary and Notes

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**Disclaimer:** The information shared in this document is my own perspective of the information provided at the conference. The information may or not be entirely accurate and should be verified by the reader. As much as I have attempted to provide an accurate account of the events of this enlightening conference, errors may exist throughout this document. As always, you should consult your medical professional prior to any changes in your treatment program. In conjunction with your medical professional, I encourage you to do your own research and create your own path to wellness. Information in this document is based solely on personal notes and recollection of conference presenters.

Information presented in this document is based on that presented at the conference. It is not an indication that I agree or disagree with any of the specific comments. Many theories and ideas were discussed and, in some cases, the doctors themselves had differing opinions. The content is provided for informational purposes only.

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## A Bit About Hope to Heal Lyme

[Hope to Heal Lyme](#) is a conference designed for patients with Lyme Disease. The conference was possible due to the passion and efforts of Charlotte Healy who suffered from Lyme Disease for years and is now in her "post-Lyme era". I am grateful to Char for putting on such an incredible conference.

It was a moving experience for me personally to finally meet so many people that I have communicated with through my site. It was like meeting the family for the first time that you knew you had but have never met. I hope many of you that I met at the conference will keep in touch and share your ongoing recovery progress.

**DVDs** of the entire conference are being offered through [Hope to Heal Lyme](#). The price of the multi-DVD set this year is about half of the 2005 set. If you have an interest in getting well from Lyme Disease, arm yourself with information. These conference DVDs are an excellent source of information that many of us would otherwise not have access to.

Special Note: Last year's conference DVD set from 2005 [Hope to Heal Lyme](#) is available now for \$15.00 including shipping.

## Strange Virginia Mexican Food?

The only thing about the entire weekend that wasn't "great" was the strange Virginia Mexican food. Can you imagine a Mexican restaurant that has no burritos? I wasn't sure what to think. I also had to ask myself, "Who wants frog legs in your Mexican food?".... Anyway, I digress....

## "Under Our Skin"

If you have followed my [Monthly Newsletters](#), you have seen my excitement and passion for the upcoming documentary film by Open Eye Pictures called "Under Our Skin". At the conference, the 28-minute sample clip was viewed for the first time at such a venue and the reactions were strong. Laughs, tears, and much emotion filled the room as the sample clip was played. Yes, I too cried if you are wondering.... Many of the conference attendees were in the clip and Open Eye Pictures was filming additional footage for the project this year as well.



I met several people that were also there specifically for purposes of participating in the film. Some had driven for hours to share their stories. I won't share the details here (you'll have to watch the movie!), but I can only say that I was deeply touched by several of these moving stories. Having been through various stages of Lyme myself and doing relatively well today, my heart went out to those that have not yet been as fortunate. I only hope that their recovery will also become within their reach. These are the people that motivate me to continue understanding this disease so that I can share what I learn with you.

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I had the distinct honor of having dinner with the director/producer (Andy) and co-producer (Cheryl) of the film as well. Andy Abrahams Wilson is a man full of passion for this project. At the conference, he shared his own connection to Lyme having a sister that contracted the disease years ago. Cheryl Drake, co-producer, also has a personal connection to the disease in that her own daughter has had Lyme and has been successfully treated and is doing well. The commitment that Andy, Cheryl and others that I have met involved with the project runs deep. There is, in my opinion, nothing more important that we in the Lyme community can do right now than to support this important project. Imagine being able to share this with your families and friends and have them finally get a clearer understanding of what it is like each day that we deal with and recover from Lyme Disease.

As Andy mentioned at the conference, there is an immediate need for funds to bring a professional editor onto the project and get the editing process underway. Though the need for financial support extends beyond this immediate need, we've got to do everything we can to move this project forward.

If you can only send a dollar, please do it. If you can send more, even better. Thank you for supporting this important project. Our contributions will result in a blessing for all of us when the film is released.

To get more information and contribute online, please visit <http://www.LymeDiseaseFilm.com>

Donations to the film project can also be made to:

Open Eye Pictures  
Attn: Under Our Skin  
475 Gate 5 Rd., Suite 215  
Sausalito, CA 94965

Gifts of at least \$250 will be recognized in the film's credits.

## Meeting The Heroes

Many of us have seen the challenges that doctors treating Lyme Disease face on a regular basis. These are not only challenges in fighting a disease for which there are often no clear answers, but challenges in the political and legislative arenas as well. I respect these doctors that give their lives to us and support our recoveries. These doctors probably thought that I had lost my mind when I started asking for pictures... ☺

I had the opportunity to meet and talk one-on-one with Dr. Burrascano. He was very kind and it was exciting to listen to Dr. Burrascano present and answer questions from the attendees. I asked Dr. Burrascano how his own health challenges were playing out, and he said that everything was going well.

I was touched to meet Dr. Charles Ray Jones. I had, in a very small way, attempted to raise funds for Dr. Jones legal defense through my site. After having met the man, I am even more committed to doing what I can to help. The countless stories of children that have their lives back, thanks to the tireless efforts of this man, were touching. Dr. Jones is in his late-seventies and works seven days a week from early morning to late night helping children. The respect for Dr. Jones from people at the conference, and even his peers, was clear. As many of you know, Dr. Jones is currently going through a legal challenge and needs your support. Please visit

<http://www.DefendLymeDoctors.com> to provide your support. This is not a man that does what he does for money and the time has come that he needs us. Let's be there.

I also very much enjoyed meeting Dr. Steve Bock. I had an opportunity to talk with him a couple of times. He brought an integrative approach to the treatment of Lyme Disease that included everything from antibiotics to vitamins and supplements to acupuncture and energetic medicine.

Char Healy assembled an excellent panel of doctors to share their Lyme treatment experiences. They are the heroes of many.....

## Dr. Burrascano

### Overview



**Scott, Dr. Burrascano, and Dr. Raxlen**

There is probably not a person with Lyme that is not aware of Dr. Joseph J. Burrascano. Dr. Burrascano has put together a comprehensive protocol for treating Lyme Disease. For those that choose to utilize a Lyme treatment approach that incorporates antibiotics, Dr. Burrascano freely shares his protocol for all to benefit from and/or share with their own personal doctors. The protocol can be found on the [Protocols](#) page of my web site.

Dr Burrascano made it very clear that Lyme Disease is a multi-systemic illness and that numerous problems that may be taking place in the body need to be evaluated and treated. He said that it is critical to remember that Lyme is much more

than just *Borrelia Burgdorferi* and that co-infections are common. *Borrelia Burgdorferi* is the most complex bacterium ever studied. *Bartonella*, *Ehrlichia* (*Anaplasma*), and *Babesia* must be tested for and treated in order to attain significant progress towards recovery.

Lyme Disease is much more than just an infection. It involves the immune system, neurotoxins, hormonal issues, damage done to DNA, cells and tissues, nutritional disturbances and metabolic effects.

*Bartonella* is the most common tick-borne disease in the Northeast. *Babesia* is not affected by standard Lyme treatment as it is a parasite, not a bacteria, and it is distantly related to malaria.

Chronic Lyme can actually rewrite the DNA in the body and incorporate its own DNA into our DNA. There were several discussions at the conference about how infections can incorporate themselves into our own DNA.

If someone goes beyond stage 1 or stage 2 Lyme Disease (sick for more than a year), the immune system starts to break down. Co-infections become a much bigger issue. Blood testing becomes less reliable as the immune system may not be mounting a response to the specific infections. Treatment must be more aggressive and longer term. Some require open-ended treatments.

Heart block is seen in less than 10% of patients. The brain and nerves tend to get involved. The joints get involved. Less than 50% ever see a rash. Less than 20% recall any type of bite. Bells Palsy is also quite rare.

The *Borrelia* spirochete grows in four week cycles. Symptoms wax and wane as a result. As the germ regenerates, it goes through a genetic shift and the symptoms may change. People are often labeled as hypochondriacs due to the fact that they always have something wrong, it comes and goes, and each time may present slightly different symptoms.

Dr. Burrascano did not talk about co-infections too much since this was covered in other discussions, but he did say that for Babesia, 2 of 13 strains can be tested for and for Ehrlichia, 2 of 9 strains can be tested for with blood. So, don't assume that negative tests mean you do not have co-infections. Work with your doctor closely to test over and over if uncertain. Dr. Burrascano did say that it is RARE! to find a patient that is not co-infected. In his geographical area, Bartonella is the #1 co-infection.

Co-infected patients are the sickest. Co-infections are nearly UNIVERSAL in chronic Lyme. Co-infected patients are more difficult to treat. Testing is LESS reliable. Symptoms are MORE vague.

**Personal note:** On the topic of co-infection testing, I had energetically tested positive for all of the co-infections last May before I was officially diagnosed in July via IGeneX and other lab work. My energetic medicine practitioner was certain that I had Babesia, Bartonella, and Ehrlichia. With initial tests, only Ehrlichia appeared. Some time later, Bartonella appeared, and then just last week, eight months into treatment, a positive blood test for Babesia finally showed up. If there is one lesson that I have learned, the co-infections are such a key part of the picture that you likely won't get well unless you deal with them.

## ***Newly Infected Patients***

For a newly infected person, 10-14 days of treatment may cure some, but a much smaller percentage. Given the odds, it is better to treat longer and to ensure that the treatment is not low dose. Early Lyme is not easy to treat and needs the most aggressive therapy - even more so than those with chronic Lyme. Weaker treatment leaves the deeper-seated, more aggressive bugs. One should be kept on treatment for early Lyme for at least four weeks after all symptoms have disappeared. It is important that one be treated for the entire four weeks after symptoms resolve as the antibiotics are often only effective at certain stages of the germ cycle, which is about four weeks. Initiation of treatment should NOT wait for blood test results as it takes weeks for those to become positive after infection. Even early Lyme is already "disseminated" and in the nervous system.

## ***Laboratory Testing***

### **ELISA**

Commercial labs only pick up about 50% of the actual cases. The better labs may be only 70%. ELISA is not recommended. It misses more than 1/2 of the cases and can also generate false positives (5-10%).

**Spinal Tap**

Spinal tap is not useful unless ruling out something other than Lyme. Within hours, the bugs are already in the nervous system and so it can be assumed that the bugs are present in the spinal fluid if one is infected. For those acutely ill with meningitis, the number of positive spinal taps is only 9%.

**PCR**

PCR testing is expensive. The pickup rate is very low. Lyme does not live in the blood, but rather in the tissues. An "at best" estimate would be that PCR is positive in 30% of cases where the person may actually have Lyme. It requires multiple samples and multiple sources to be sampled. PCR is less likely to be positive if you are on antibiotic therapy.

**Western Blot**

It is not how many bands, but which bands. You have to ask whether or not the displayed bands are species-specific. 18, 21-24, 31, 34, 39, 83, and 93 are specific bands. Spirochetes in general will result in band 41 which is non-specific. All others are also non-specific and non-diagnostic. The more specific bands, the more certain one can be of the diagnosis. The unfortunate truth is that it is often the most ill people that cannot mount an immune response and thus they may not get a positive test. In chronic Lyme, the immune system is weak. The more sick you are, the less positive you may be. Negative tests become positive about 36% of the time after treatment begins.

***Lyme - Various Forms and Antibiotic Treatments***

*Borrelia Burgdorferi* has the following forms:

- **Spirochete** form which has a cell wall and may be treated with penicillins, cephalosporins, Primaxin, or Vancomycin
- **L-Form** which has no cell wall and may be treated with Tetracyclines and Erythromycins.
- **Cyst form** - Metronidazole (Flagyl) and Tinidazole, possibly Rifampin

Antibiotics that do rely on cell walls for killing can kill the spirochete but not the L-Form. Drugs like penicillin works on a cell wall and needs to be at a sustained level for 72 hours. Peaks and valleys allow the germs to recover. Doxycycline does not require a sustained level. It may be more effective at 400mg once per day via IV than 100mg four times per day orally. The germs live inside and outside the cells. Erythromycin can get to the intracellular bugs. Probenecid can make the antibiotics work better. The body pumps the Probenecid out of the kidney but leaves the antibiotics. Zithromax is only intracellular. However, it is not a good drug for Lyme. Biaxin is a much better drug. Ketek is by far the best. May be 10x better than IV Rocephin but it is hard on the liver and the heart. People usually have a difficult time and may herx for 1-2 months. It is killing germs that have never been killed before. The tetracyclines, unless used at very high levels, do not kill the bugs - they only suppress. They are also sometimes difficult to tolerate. Tinidazole is only slightly better tolerated than Flagyl. Rifampin is an old TB drug that may work on all three forms of *Borrelia*. Bicillin shots 3-4 times a week (better IM for yeast issues). May also be useful as an IV. Can add Biaxin, Ketek, or Flagyl. Treatment needed for 6-12 months.

IV Rocephin is now being given twice per day. 2 grams twice per day for 4 days. It is the classic pulse therapy. Some worry about the impact to the gallbladder and 4 out of 5 patients that had their gallbladder removed tested PCR positive for Lyme in the gallbladder. May use Actigall to help prevent gallstones.

Antibiotic therapy must target both intracellular and extracellular forms as well as all three morphological forms of *Borrelia*. It is important to remember that this is specific to *Borrelia*. There may be, and likely will be, a need for additional treatment options if co-infections are present.

With a four week growth cycle, you have to keep going. Over several months, you can see the effect. Doxycycline, for example, should be used at least 3-4 months if you are going to use it for chronic Lyme.

Fallon did a study which proved that placebo had no effect when treating chronic Lyme. This seems to support that long-term use of antibiotics does lead to an improvement in the patient's condition. Slight benefit from oral antibiotics may occur. IM Bicillin is more effective than oral antibiotics and IV therapy is still the most effective.

IV therapy may be indicated with illness > 1 year, abnormal spinal fluid, high ESR, over 60 years of age, acute disseminated illness in first trimester, acute carditis, documented immune deficiency, prior steroid use, or failure or intolerance to oral options.

Typical regimen includes:

- Oral. Cefuroxime (Ceftin) + Clarithromycin (Biaxin) OR Augmentin SR + Telithromycin (Ketek)
- Injection - Bicillin LA + Clarithromycin (Biaxin)
- IV - Ceftriaxone (Rocephin) + Telithromycin (Ketek) OR Vancomycin + Clarithromycin (Biaxin)

Flagyl can be added to any of the above.

About this time, the slides went off the screen and a test pattern of various shapes appeared. Dr. Burrascano asked "OK, let's see - who has neurotoxins?". It added some lightness to an otherwise sobering topic. "Do you see a bunny?", he asked.

Dr. Burrascano suggested not tapering off antibiotics. Go until you need it and then STOP. If you feel sick within a few days after stopping treatment, it is likely a co-infection. A Lyme relapse takes several weeks.

Exercise is so important. Dr. Burrascano said that if you do not exercise, you have no chance of getting well. You have to exercise to your level of comfort and then increase that as much as possible. I cannot stress how critical he felt this was.

There is much more on this topic presented in the DVD.

## ***Chronic Lyme Disease (CLD)***

In Chronic Lyme Disease, the goal is to get the germ load down and the immune system up and to pass the threshold where you can remain well. You may still have spirochetes left. The goal has to be about creating balance and shifting the balance in your favor such that the "disease" no longer presents itself and hinders a patient's quality of life. If you do not relapse in 3 years after stopping treatment, you generally will not. Focus on "well", not "cured".

There are many protective niches that the bugs have in the body. These include within cells, ligaments, and tendons. In the CNS and especially in the eye. The skin is also a great place for the bugs. They like to stay away from the heat. You also therefore need an antibiotic that gets into the skin. The tetracyclines do this. This is why they are used for acne. Don't forget that they do cause excess sun sensitivity.

CLD impacts all forms of the immune system. It impacts B, T, and NK cells. CD57 is one type of natural killer (NK) cell which is useful for tracking the progress of a patient with CLD. Low CD57 counts are often seen after 1 year. The value stays low and bounces up at the very end of treatment. Therefore it is not a very good test for tracking progress of treatment in short time slices. Below 20 are the sickest. 20-60 is average for people with CLD. Above 60 represents lessening activity of the bugs. Must be done at LabCorp to be done with the same process that the Stricker studies were done on. All other labs cannot really be compared to these ranges in his experience.

LabCorp bought the panel that was done from the Stricker studies. A result of 180-200 with symptoms would point to a potential co-infection.

Doing Western Blots all the time is not a useful marker of progression. If CD57 is not "normal" at the end of treatment, a relapse is likely.

## ***Pregnancy***

Lyme can without a doubt be transmitted during pregnancy. The worst is if the mother is acutely ill during the first trimester. If the mother was on antibiotics for the entire pregnancy, there have been no babies born with Lyme. Often, the mother cannot tolerate orals due to morning sickness. The goal is to maintain protection for the baby and the mother is secondary.

Often, mothers feel good during pregnancy and then much worse after. Postpartum depression is very common.

Breast milk carries the disease - 100% proven. Do NOT allow breastfeeding at all. You cannot treat for Bartonella (can inhibit), Ehrlichia, and Babesia while pregnant. It is best to treat for these before. One should also test the cord blood and placenta and do PCR urine for six months. Babies ARE born with Babesia even though it defies the text books!

## ***General Lifestyle***

- Do NOT overdo
- Rest is enforced
- No caffeine - impacts sleep even at small amounts - sleep is CRITICAL
- Balance, balance
- No alcohol - more toxicity
- Stay hydrated - drink lots of water
- No smoking - one cigarette every 3-4 months can impact your recovery
- Vitamins do NOT feed spirochetes
- Exercise is critical
- No steroids

### ***Special Notes***

Dr. Burrascano then shared with all of us that there was a new program where Lyme patients could get free Rocephin. He said that we could call 1-800-APRIL-FOOLS. Humor is healing.

I also learned during this weekend that Dr. Burrascano himself has Lyme Disease. That certainly explains his passion for getting people well.

## **Q&A with Dr. Burrascano**

**Q:** What about hypercoagulation and Heparin?

**A:** Hypercoagulation is also seen in Babesia. Dr. Burrascano finds that heparin helps the same things as Babesia treatment and thus may not be warranted if Babesia is addressed.

**Q:** How long does it take to get well?

**A:** I see the sickest of the sick. On average about three years on antibiotics.

**Q:** What about post-Lyme autoimmune disorder?

**A:** The infection rewrites the human DNA. Spirochete DNA is now in our own DNA. Human cells now produce spirochete products. If the immune system attacks the body, auto-immunity is possible. Many have positive ANA tests that resolve with treatment. Auto-immunity is a very small part. It is more likely that the patient still has infection, toxins, etc. that are in need of more treatment. When treated, they get better.

**Q:** What about body temperature?

**A:** Take your temperature 3 times per day before getting out of bed, mid-PM (often low-grade) and nighttime.

**Q:** What about the Marshall protocol?

**A:** Have had a few patients that have done it. All abandoned as it did not help.

**Q:** Does the location of the tick bite impact symptom presentation?

**A:** Yes, bites near the head are often the worst.

**Q:** What about neurotoxins?

**A:** Cholestyramine with VCS test. 70-90% do better if VCS test is positive. 30% do better even without a positive VCS test.

**Q:** Can I get general surgery while I have Lyme?

**A:** Surgery often leads to a major setback with Lyme.

**Q:** What about IVGG?

**A:** Often used for MS. Will help many in 6 months to 1 year. If IVGG is low, it is good. If normal, no benefits observed. GG does stop inflammation without immune suppression.

**Q:** I then asked Dr. Burrascano whether or not he felt borrelia was the head of the causal chain or if it was possible that it were simply an opportunist resulting from another as-yet unidentified pathogen, stealth virus, or otherwise?

**A:** Twenty years of research has proven that Bb is the head of the causal chain.

## Dr. Bernard Raxlen

Dr. Raxlen started off by saying that we can all be done with Lyme Disease if we just imagine that it does not exist. Of course, he was being sarcastic as that seems to be what many in the conventional medical field think we should do. He focused a lot on how many consider Lyme to be a disorder for which there is not adequate evidence to explain our distress.

He made the comment that to recover from Lyme Disease, you have to be the tortoise, not the hare. I've heard the expression before that Lyme is a marathon, not a sprint. Both convey an important point.

Recovery is often 3 steps forward, then 2 steps back. After a year, you can see the progress.

Dr. Raxlen doesn't like to call it "Lyme" because he rarely sees pure "Lyme". It is a syndrome. He discussed the neuropsychiatric symptoms with Lyme Disease and how various conditions such as panic disorders, agoraphobia, and others can all be related to Lyme Disease. It is an encephalopathic disorder with much more than just joint and muscle involvement. Sleep disorders, mood disorders, and irritability can all be part of the Lyme picture.

He says that people with Lyme tend to have a distorted sense of past, present, and future. If drawn as a line, the future is often seen as a very small line. The present is the majority of the line. The sense of time becomes imploded. As time goes on and treatment progresses, the future is opened up. The focus shifts.

Demyelinating symptoms, addictive presentations (opiates for example), problems with multi-tasking, sensory hyperacuity to light and sound, manic depressive disorders, eating disorders, depression, self-destructive behaviors, confusion, brain fog, and many other neuropsychiatric symptoms are seen with Lyme Disease.

His multi-system approach to Lyme includes:

- Sleep - Gabartil, Inositol, Cal/Mag, Melatonin, Restoril, Ambien, Trazadone, Neurotin
- Pain Relief for CNS/PNS - NSAIDS (not very effective), pain gels, opiates, trigger injections, muscle relaxants
- Neuropsychiatric Difficulties - Wellbutrin, Effexor, Lexapro, Carbatrol
- Neurocognitive Difficulties - Adderall, Concerta, Straterra, Ginko
- Endocrine Problems - natural thyroid, extended T3, Cortef, Growth Hormone, natural estrogen, testosterone, and progesterone
- Arthritis and Muscle spasms - Glucosamine, MSM, Pain Gel, Wobenzyme, anti-TNF alpha products
- Weight problems - Avandia, Amylase free diet
- Yeast – yeast-free diet, sugar-free, low-carb
- Immune Support - EFAs, CoQ10, Enada, Efalex, Cordyceps, Cat's Claw, Alpha Lipoic Acid, Florastor, Acetyl-L-Carnitine, Artemesinin
- Other - physical therapy, acupuncture, pain management, therapy support, HOBT, ozone sauna

He was very clear that sleep disorders **MUST** be addressed. **No sleep = no healing.**

## Dr. Charles Ray Jones



Scott and Dr. Charles Ray Jones

Dr. Jones did not speak much but was at the conference both days and did answer numerous questions on the panels. It was refreshing to see the support from the other doctors for Dr. Jones and was very clear that they have an immense amount of respect for the man that has now treated over 9000 children in his career.

He did share with us a video clip about a family with Lyme and the young son who was the worst of all of the family. The child went through combination treatment which included many HBOT dives and did improve with continued treatment.

The child had pictures on his bedroom window of his liver and gallbladder ultrasound and various other things that a child should never have to deal with. Thank God for Dr. Charles Ray Jones!

**Personal Note:** Please consider supporting the defense of the insane attack against Dr. Jones. Contributions to his defense fund can be made at <http://www.DefendLymeDoctors.com>. Below is more detail on the current situation with Dr. Jones and the need for more legal defense funds.

March, 2006

**I NEED YOUR HELP NOW!!!!!!!**

The Connecticut State Medical Board has issued a hearing beginning March 23, 2006 in regards to the position I take using long term antibiotics for the treatment of Lyme Disease and coinfections in children. As a result, my medical license is in JEOPARDY. Please donate what you can to my LEGAL DEFENSE FUND which has been arranged for my case.

**FOR THE CHARLES RAY JONES, MD LEGAL DEFENSE FUND, please make checks payable to:**

**Charles Ray Jones, MD Legal Defense Fund**  
(in the check memo field place Gift/ #70757.1)

**If you would like to mail your donation, please address it to:**  
George Heath III  
26 Fairlawn Drive  
Wallingford, CT 06492

**You may also make a donation to my Defense Fund over the internet by going to [DefendLymeDoctors.com](http://DefendLymeDoctors.com)**

**I have a firm commitment to my calling, and I genuinely hope to continue providing medical care for your children afflicted with Lyme Disease and coinfections, but I NEED YOUR HELP NOW!!!!!!!**

**Thank you;**

**Charles Ray Jones, MD**

## Dr. Ann Corson

I knew very little about Dr. Ann Corson. Her focus is on pediatric Lyme. I can tell you that this is one lady that is full of passion. I really enjoyed meeting her and from discussions with many people that I had, she is highly respected. You could tell that Dr. Corson really, truly cares about people. Often times, this gets lost with doctors. Fortunately for us, many of those treating Lyme Disease have incredible compassion and Dr. Corson certainly is no exception.

She relayed to the audience that we must have voices. We must be activists. We must be heard.

In her experience only 12% have an EM rash. 4% have Bells Palsy and 0 have had heart block.

She said (and I cannot repeat enough because I believe this is one of the keys to recovery!), "Co-infections are the RULE". In her practice, 2-5 with an average of 3 co-infections is what she has observed. She also mentioned mycoplasma fermentans as one of the co-infections that she often sees.

She mentioned that the ticks are becoming immune to the chemicals we used to protect ourselves. 10 years ago, it was enough to use very small amounts of Permethrin and today, we now need much more for the same impact – as much as 20x! Scary thought!

Dr. Corson shared much more about the in-depth signs and symptoms of pediatric Lyme Disease. She mentioned that Babesia, Bartonella, Mycoplasma, and maybe Ehrlichia can be transmitted transplacentally. Gestational Lyme can result in repeated miscarriages, fetal death in utero and at term, SIDS, and many other conditions.

## Dr. Steven Bock

Dr. Bock talked about the integrative treatment of Lyme Disease. He talked about a number of patient case studies.

For detoxification assessment, he outlined the need for testing for allergies. He recommends a CDSA, O&P, and intestinal permeability (leaky gut syndrome) testing. He also uses Chinese pulse and other more integrative diagnostic tools.



**Scott with Dr. Steven Bock**

Assessments and Treatments mentioned included:

- Antibiotics
- Medical Detox – GI Detox with Bentonite, Psyllium, Cholestyramine, and Colonics
- Hormonal Therapies
- Neurotransmitter Therapy
- Diet
- Herbs
- Acupuncture
- Chinese medicine
- Homeopathy
- Alpha Stim
- Ondamed

Medical Detoxification includes GI detox, liver detox, antioxidant support, herbal detox, hormonal detox, homeopathic detox, and heavy metal detox.

Liver Detox includes B vitamins, minerals (selenium, manganese, magnesium, zinc, iodine, molybdenum), antioxidants (NAC, C, E, ALA, Green Tea, Querceplex), amino acids (glutamine, taurine), watercress, and ellagic acid. Ellagic acid in particular tones down phase 1 pathways and increases phase 2 which keeps you from getting reactive oxygen species.

For oral chelation, he mentioned DMSA, calcium EDTA, Cilantro, Chlorella, Allicin (organic garlic), NAC, ALA.

It is important to test for hypothyroidism and low adrenal function. TSH of > 2.5 can be hypothyroid. Also very important to test sex hormones.

Hypoadrenalism can be treated with nutrients (Vitamin C, Pantothenic Acid, B6, Zinc, Tyrosine, Phosphatidyl Serine), glandulars, herbs (Ginseng, Licorice, Rhodiola, Ashwaganda), hormones (DHEA, Pregnenolone, Cortef), and Adrenal Calm.

Dr. Bock is also a supporter of Far Infrared sauna for detoxification.

He mentioned that low-dose HBOT works better than high-dose HBOT. High-dose resulted in a return of symptoms when stopping or required continuation.

Dr. Bock mentioned that magnesium glycinate is likely the best form of magnesium and that magnesium taurate is useful for people with heart issues.

Depletion of serotonin often needs 5HTP to calm things down. Rhodiola is a very good herb for the nervous system and adrenals. GLA and Borage Oil support nervonic acid which is used for rebuilding of myelin.

Liver hyper-function is often the case when waking between 2am-3am.

For herxing, Lymphomyosot / Galium from Heel. Helps to tone down the herx and excrete the antigen / antibody complexes. IV Glutathione and IV Vitamin C can be very useful as well.

Phosphatidyl choline is excellent orally or IV for the liver. Circumin and Omega 3 are also useful.

He talked about how water has crystals and how it absorbs the energies of things around it. They took two different bottles of water and on one labeled with "In Love and Health". They later found it had health promoting crystals compared to the control.

He also likes the Ondamed device. With his wife, it found her nasal and shoulder problems and another patient story he relayed talked about how she felt the energies of the machine. One lady with neuropathies could not walk and after eight treatments was doing well.

He discussed acupuncture and Chinese medicine and the use of pulsed electromagnetic biofeedback therapy.

## Q&A with Panel

**Q:** What about the Bowen test?

**A:** Dr Bock: Not allowed to use in New York. Others: All positive. It does not really help but Babesia testing may be useful.

**Q:** Can you have Ehrlichia without Lyme?

**A:** Dr Corson: Yes, you can. Any can be alone or multiple. HME (monocytic Ehrlichia) is the second most common after Borrelia in Dr. Corson's pediatric patients. It is unusual to have Bb and not have co-infections. Possible, but the exception.

**Q:** What about sexual transmission?

**A:** Dr. Jones: Animal studies clearly demonstrated. There have been no human studies. Dr Corson: almost all sexual partners are universally infected. Dr. Raxlen: true that animal studies have shown but he finds that starting the specter about sexual transmission is counter-productive. Whole families are infected; must be a big bed! ☺ Could also be the ecology of the contact point – same camping, same cottage? Would be more prevalent if sexually transmitted.

**Q:** What labs do you use?

**A:** Dr. Corson: IGeneX/MDL/LabCorp (CD57). Dr. Jones: Same. Dr. Raxlen: Immunosciences has discovered new proteins and various species of Bartonella, Ehrlichia, and Babesia.

**Q:** Does Lyme cause autism?

**A:** Dr. Bock: Lyme does not cause autism but may contribute.

**Q:** Can you get Lyme from blood transfusion?

**A:** Dr. Corson: Yes. Dr Jones: Blood from persons known to be infected with Lyme is not accepted for donation in many states.

**Q:** What causes light sensitivity?

**A:** Dr. Corson: Can be from brain inflammation or nerves damaged in the eye. The vast majority are from the brain – almost like encephalopathy.

**Q:** What about HBOT?

**A:** Dr. Jones – 400 children study using HBOT. All are better if not well. In older kids, may need to continue with 2 per month. Cost 150-900 per dive and need about 40 dives. Dr. Bock: HBOT 60-80 treatments and relapse into same state or need more treatments. Probably works better for children.

Dr. Raxlen comment: Ask your doctor for an RX for physical therapy. Exercise important!

Dr. Jones comment: Rare to see antibiotic allergy. Maybe seen in 50 of 9000 children.

Dr. Corson comment: Good range for CD57 before stopping treatment is 150-250 but many don't get there. 90-100 may be ok.

**Q:** What about transfer factor?

**A:** Dr. Bock has used. Transfer Factor is one component but colostrum has many benefits. Gives recognition and trains the immune system to act faster. Dampens overactive immune system. Good for allergies and people prone to infections. In chronic Lyme, often Th1 dominated. Transfer Factor pushes toward Th1 which makes only 15-20% candidates. Dr Raxlen relayed a story of a senator that took his own blood and injected a cow and then used the colostrums as a treatment. Dr. Corson then raised the question about our milk supply as cows are full of Borrelia – we don't have an answer.

Comment: IgM becomes IgG in about 2 months.

Comment: Dr Corson – it is very difficult to get free of Lyme without ABX. If allergic, deal with digestive system and cleanup. Detox Detox.

TNF - Th1 cytokine - pushing body towards inflammation. Actos is an anti-TNF alpha molecule

**Q:** Does Lyme cause Parkinson's?

**A:** Dr. Raxlen: 3 patients with Parkinson's diagnosis – definite correlation. Lyme is not the cause, but can be a trigger in a genetically sensitive individual.

**Q:** What about Stephen Buhner's book, Healing Lyme?

**A:** Dr. Raxlen and Dr. Corson have the book but have not yet read. Dr. Bock has several people on Buhner's protocol after using ABX and is having good results. Mentioned Andrographis, Cat's Claw. Likes it.

**Q:** Can you get Lyme from kissing?

**A:** All: Not likely.

**Q:** How do you boost NK cells?

**A:** No simple answer. Multi-factorial. Dr. Raxlen mentioned Arabinogalactan. CoQ10 boosts T and NK cells. Uses very high doses. Q-Mel tablets 900mg per day. Maitake mushroom, ashwaganda, transfer factor, IP6, and thymic protein.

**Q:** Should you treat a western blot positive spouse without symptoms?

**A:** Dr. Raxlen: No. Dr Corson: Men may not mention symptoms, but when treated, they do see improvement. Often attribute things to aging, but later realize that they were ill.

**Q:** What about people that need chemotherapy for cancer?

**A:** Need IV antibiotics. Chemo destroys the immune system. IV vitamin C 2-3 times a week may be useful.

Comment: Dr. Corson – Lyme will never go away without treatment for Babesia if present.

Comment: Dr. Jones – Metronidazole destroys cyst and spirochete.

**Q:** Why do tests turn positive in treatment that may be negative earlier?

**A:** Treatment kills organisms and pieces of dead bugs may now float around in the blood where they are normally not found (tissues normally) and the immune system responds. It may also suggest healing is underway as the immune system recovers.

Comment: 2.4 ATA is needed for HBOT to be effective.

**Q:** How do you treat Babesia?

**A:** Dr. Corson: Mepron + Biaxin, Zithromax, or Ketek + Artemisinin for 6-9 months. Do not take Mepron with Doxy as it lowers the effectiveness and may lead to resistant Babesia.

## Dr. Joseph Jemsek

Dr. Jemsek has the largest HIV practice in North Carolina. He told the story of how a lady approached him looking for someone that treated Lyme Disease and he agreed to treat her. Then, someone else came to him and said that she had heard that he treated Lyme Disease – on the internet! She said, “But of course, we don’t use your real name – we just say Dr. J.” He then met Mitch Hoggard and Ray Stricker at ILADS. He has since had 2000 patients in 42 states.

Babesia divergens is in Europe and is even more serious. We have WA-1, CA-1, MO-1, microti. Bartonella Quintana comes from fleas.

Borrelia has blebs which are when a chunk of matter is thrown off that the immune system goes after. Cysts are in and outside of cells. Bb replicates in cysts. Bb is in and outside of cells.

Treatment needs to have scientific basis for Dr. Jemsek.

He talked about treating based on ELF (Essential Life Function) and POEMS (Pain, Other, Endocrine/Metabolic, Mood/Psychiatric, Sleep). You will not get well without sleep! Comforting POEMS makes ELF happy.

He does a detailed history and exam lasting 80-100 minutes including a questionnaire. It is essential to consider alternative diagnosis. He does an in-depth drug use review including interactions and evaluates POEMS. Attitude for success – honesty, non-judgmental critique of previous care, realistic patient expectations.

Borrelia is the ringleader. It is polymorphic and has altered life forms. Slow replication cycle. Multiple co-infection strains. It is intracellular and extracellular. It invades multiple cell types but especially the CNS. It is immunosuppressive and evasive. Antimicrobial resistance develops, but slowly. It has widespread gut involvement in many cases

The EM rash is less-specific with STARI. No singular antimicrobial. Needs combinations. Extended treatment is needed. Edema could be from Bartonella. If the recovery is stuck, you have a co-infection!

You cannot tiptoe into therapy. Select IV therapy for bioavailability. Most orals do not cross blood-brain barrier well. IV combinations – address co-infections early. Overlap Bb and co-infection therapies early. Uses 3-4 cycles of 5-6 antibiotics. Schedule drug holidays for detox. Limit beta-lactam RX (cell-wall drugs) to first few weeks. If no herx, step off quickly. Pulse oral “imidazoles” every four weeks not to coincide with new RX treatment. IV treatment is down to 80-90 non-contiguous days. Long-term oral patients with poor response may need 20-30 days of IV over 8 weeks with pulsed HBOT and Beta-lactam RX. Not used with active co-infections. Goal often to get down to 3 to 5 days a month of treatment. Most people need some continued ABX therapy but the goal is to cut down to as little as possible.

Babesia - oral combo of macrolide, atovoquone (Mepron)  
IV: Clindamycin and Zithromax plus Mepron/Malarone or Artemisinin

Ehrlichia - covered with other therapies

Bartonella – oral: Sulfa, TMP Sulfa, Levaquin  
IV: Levaquin, TMP Sulfa

## Dr. Leila Zackrisson

Dr. Zackrisson did an in-depth discussion of Lyme Disease and Immunology at the cellular level. She discussed the various immune cells and how they are involved in immune response. It was very detailed and best understood from the DVD.

The disease manifestation is an overlap of ecological factors, genetic and biological factors, social/political/economic factors, physical environment, microbes, and the human itself.

Exposure factors which influence disease susceptibility are: animal exposure, recreational activities, sexual activity, travel, heavy metal exposure, child daycare attendance, food and water consumption, closed living quarters, hospitalization, blood and blood product receipt.

Factors that influence the severity of the disease include: gender, genetic makeup, immune system status, immunization status, nutritional status, virulence of the specific organisms, duration of exposure to the organisms, recurrent exposure, age at the time of infection, pre-morbid health, alcoholism, prior antibiotic use, coexisting infections and concurrent diseases.

Factors that influence the success of the therapy include: drug choices, aggressiveness of the drug therapy (mono vs. combo), steroid induced immunosuppression, hormone imbalances, stress, and trauma.

Infectious triggers may include bacteria, fungi, parasites, spirochetes, viruses, yeasts, and molds.

The combination of environmental factors and genetic predisposition leads to disease.

Antibiotics can induce flares through killing of the organisms which leads to immune response, antibody production, immune cell activation, and signal release. This causes the flare which is increased inflammation both locally and systemically.

She mentioned a multidisciplinary team which I support fully. This includes a disease knowledgeable physician, a primary care physician, various specialties, dietitian, physical therapist, personal trainer, and family and friends.

Lyme Disease is very much like cancer in that it requires combination therapies to get well. The disease is a combination of genetic predisposition and a trigger. Triggers create immune system activation, immune response, antibodies and lead to inflammation.

Antibiotic has to stay on board long enough to get to the phase of the microbe life cycle where it can have impact. Usual cell life cycle is < 1 day. Bb takes about one month. To fully get all of it takes 2 1/2 years on antibiotics. Cells must be susceptible to the ABX you are giving them.

Cephalosporins and penicillins need a cell wall to work. Concentration must remain the same. For others like tetracyclines, Ketek, etc. one dose with peak concentration is the best.

Zithromax/Ketek/Biaxin/Tetracyclines - bacteriostatic (limit). Not bacteriocidal (kill).  
Strep/Chlamydia Pneumoniae , etc. getting killed at same time with tetracyclines.  
The flare in month 1, 2, 6 will be entirely different. The pattern will change.

Plasmids - double stranded DNA separate from DNA in nucleus. They code for certain proteins which impact the cell.

IgG generally thought of as the memory antibody. With Lyme and co-infections, if there is really no memory and no ongoing infection, the IgG will turn negative. If you have IgG and you take ABX, you stimulate more IgG when killing the bugs and the IgG goes up. If you continue the treatment, the titre goes down and the test becomes negative. Killing the bugs creates more pieces and parts which leads to more antibodies. Some of the titre is killed pieces and some is real live bugs.

T-Helper 1 (Th1) cells - defense against Lyme but creates inflammation. Allergic reactions to mold, etc. are Th2 cells. EBV and CMV put out cytokines that looks like IL10 which fake out immune system and stays Th2 activated.

## Q&A with Dr. Bock and Dr. Jones

**Q:** What about ozone?

**A:** No one really strongly supported it. Dr. Jones said it is useful as an adjunct as ozone sauna.

**Q:** What about hyperthermia?

**A:** Dr. Bock: A couple of patients went to Italy and did quite well.

**Q:** Should the gallbladder be removed if no problems since it has Lyme spirochetes?

**A:** No

Comment: 40-50 grams of IV vitamin C can be helpful

**Q:** What about Morgellon's?

**A:** Dr. Jones: It is an opportunistic infection. He has 6 patients with it. Treatment – responds well to anti-fungals along with regular Lyme treatment.

**Q:** If someone had the Lyme vaccine, would symptoms be more severe if you later got Lyme?

**A:** It was known before it came out that if you did not have Lyme and got the vaccine and later were infected, the symptoms would be intensified. Presence of HLA-DR4 with band 31 can active Lyme or cause auto-immune conditions. 200 children with the vaccine that had Lyme at the time all had auto-immune reactions. Treatment with IVGG and ABX and Plaquenil (suppresses exaggerated immune response without impacting normal function). Dr Bock: Never used the vaccine in his practice due to the auto-immune studies.

**Q:** Should the gallbladder be removed if no problems since it has Lyme spirochetes?

**A:** No

Comment: West Nile Virus and other viruses may be transmitted through ticks. HHV6, CMV not clear.

**Q:** If I have a child with Lyme that is not sick but is Lyme positive, do I treat?

**A:** Dr. Jones: if there are symptoms, an evaluation is needed. If the organism is there, it needs treatment.

Comment: Not all people exposed gestationally will get Lyme. Transmission rate is 16-67% (wide range)

**Q:** Does the presence of IgG for chronic infection work the same in children.

**A:** Dr. Jones: some children only produce IgM antibodies, not IgG

**Q:** If I have Lyme, Babesia, HSV, and Yeast, can I be treated without ABX?

**A:** Need ABX and Nystatin or Diflucan + Immune treatments for the HHV6 (Vitamin C or Valtrex may be useful). Babesia needs treatment before or in conjunction with.

Comment: Tick does not have to be engorged or attached for any length of time.

Comment: EM Rash in children with Lyme < 7%.

**Q:** How many people get well?

**A:** Dr. Bock: 1/3 are better in a few months. 1/3 are chronic but get better. 1/3 go on to have recurrent symptoms after stopping therapy and need long-term treatment