What's new!
LDASEPA
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THE HIERARCHY OF LYME- Different Levels of Disease

Basic, uncomplicated infection with *Borrelia burgdorferi-*
not too ill, respond readily to antibiotics
Disseminated, symptomatic disease- usually present longer, and may include co-infections
Need higher doses, longer duration, and also may need IV treatments
Need complex antibiotic regimens of long duration
Chronic Lyme- Patients ill for ≥ l year, with many complications possible:
Immune deficiencies (the beginnings of Chronic Lyme)
Neurotoxins
Heavy metals
Hormonal imbalances
Emotional and psychiatric issues
Antibiotics alone are not enough- extensive supportive measures are needed
End-Stage Lyme- severely ill, and no longer respond to antibiotics, or find them harmful
Other illnesses and injuries can play a role

DISSEMINATED & CHRONIC DISEASE- More Symptomatic and More Difficult to Treat

- **Sicker- Lyme is affecting their life**
- **Have been ill longer- months to years**
- **Immune deficiencies are present (the definition of "Chronic Lyme")**
- **Co-infections universal and need to be treated**
- **Must address diet, lifestyle, nutritional supplements, and enforced rest alternating with aggressive, formal exercise programs**

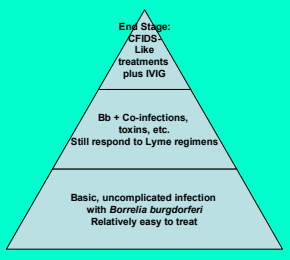
END STAGE LYME- Severe Damage Has Occurred And The Infection Is No Longer The Primary Problem

- **Big overlap with CFIDS**
- **Lyme plus co-infections started the cascade that advanced so far, it could not be stopped by just killing the infections**
- **Are seeing more and more of these patients**
- **Represents the next evolution in the treatment of Chronic Lyme patients- will need a direct collaboration between Lyme-Literate MDs and CFIDS-Literate MDs**
- **Could this represent Autism?**

END STAGE LYME- What Is Going On?

- **Biological toxins, especially if genetically susceptible:**
  - Lyme and some co-infections produce toxins
  - Yeasts from yourself and the environment can produce toxins
  - Other toxin-producing bacteria that take advantage of a weakened host
- **Environmental toxins**
  - Heavy metals, insecticides, plastics, etc
- **Nerve damage- both central and peripheral**
- **Hormonal deficiencies and receptor changes**
- **Mitochondrial damage**
- **Metabolic damage and imbalances**
- **Psychiatric wild card- may be the next frontier of research and collaboration**
- **Impossibly complex "chicken and egg" scenario**

IT'S ALL IN THE PERCENTAGES



CO-INFECTIONS

Need to Know All About Them!

CO-INFECTIONS- SORTING IT ALL OUT

- **LYME-**
  - Gradual onset of initial illness, no sweats, 4-week cycles
  - Multisystem, joint involvement, afternoon fevers
  - Bb antibodies usually present, low CD-57
  - Herxheimer; otherwise, slow response to onset of antibiotics and slow relapse
- **BARTONELLA-**
  - Gradual onset of initial illness, occasional light night sweats
  - More CNS symptoms than skeletal symptoms, with CNS irritability, GI upset, sore soles, subcutaneous nodules arms and legs, AM fevers, swollen lymph glands
  - Elevated VEGF
  - Rapid relapse of symptoms if treatment ended too soon or if treatment not optimal
- **BABESIA-**
  - Abrupt onset of initial illness, obvious sweats especially at night, cycles every few days
  - Fatigue, global headaches, air hunger, cough, hypercoaguable (responds to Heparin)
  - Very severe Lyme symptoms and poor response of Lyme to otherwise appropriate treatment
- **EHRLICHIA-**
  - Rapid onset of initial illness, may be high fevers and rarely spotted rash like RMSF
  - Headaches (knife-like and behind eyes), sore muscles
  - Low WBC, elevated liver function tests
- **MYCOPLASMA-**
  - Gradual onset, may be light sweats, symptoms are made worse with exercise
  - Major fatigue and neurological dysfunction, metabolic disturbances, immune damage
  - Found in the sickest and poorest-responding Lyme patients (CFIDS-like, ALS)

WHAT CAN HELP WITH DIAGNOSIS

- ***FIRST, CAREFUL MEDICAL EVALUATION TO REMOVE "LYME BLINDERS" !!!***
- **High quality Lyme Western Blot that reports all bands; serial PCRs and urine antigen assays can serve as a back-up**
- **Serology, FISH and PCR for Babesia species. Consider blood smear**
- **Serology and PCR for Bartonella, Ehrlichia, Mycoplasma, HHV-6, EBV and CMV (Parvo and WNV in acute situations)**
- **CD 57 (Lyme), VEGF (Bartonella), coagulation profile (Babesia), heavy metal screens, VCS test with toxin genotyping if necessary**
- **Adrenal, thyroid, and pituitary evaluation**
- **Cardiac echo looking for diastolic dysfunction (metabolic damage)**

TREATMENT

LYME

- **Treating Lyme must be the foundation of any successful regimen ("It is always the Lyme")**
- **If very sick, you WILL need at least one good course of IV antibiotics (given carefully)**
- **Doses must be pushed as tolerated**
- **Combinations of antibiotics will be necessary**
  - Cell wall + intracellular; fluids + tissues; spirals + L-forms + cysts
- **Expect to be on Lyme treatment for months to years (duration of treatment is proportional to length and severity of illness)**

LYME TREATMENT- SOME EXAMPLES

- **Early Lyme-**
  - Doxy, amoxicillin + probenecid, or cefuroxime
  - treat for 4 to 6 weeks- must be symptom free for 4 weeks before treatment stops
- **Disseminated, but not chronic Lyme-**
  - Orals for 4 to 6 months; be alert to a treatment plateau and be prepared to change the regimen
  - Need at least six weeks before you see real benefit
  - Alternatives include 6 weeks of IV followed by orals, or a long course of Bicillin, 3 to 4 shots per week, with or without added orals
  - Will need to be on anti yeast regimen, vitamins, and modify lifestyle

LYME TREATMENT- MORE EXAMPLES

- **Chronic Lyme**
  - IV therapy for 12+ weeks (Rocephin, IV Doxy, IV Zithro, etc.), PLUS orals given concurrently
  - Bicillin injections (3 to 4 per week) may substitute for the IV
  - When IV ends, substitute with Bicillin or a second oral
  - Best orals to combine with Rocephin include Biaxin and Ketek, with Doxy less effective, and Zithro and Minocin being the least effective
  - Will need a course of Flagyl.
  - May need to add Plaquenil
  - Aggressive supportive therapy as well

PEARLS AND TRICKS

- **TREAT BARTONELLA BEFORE BABESIA!**
- **Always use the highest tolerated antibiotic dose, and if possible, test blood level**
- **Cell-wall drugs only work if blood level is steady for 72 hours**
- **Flagyl needs a steady *two weeks* to be effective**
- **Ribosomal drugs work best with spiking blood levels**
- **Antibiotic combos must consist of dissimilar medications (different mechanisms of action)**
- **Track fluctuations in symptoms and the 4-week cycles- give any regimen 6 to 12 weeks before you change it**
- **Most IVs work better if given in pulsed doses**
- **A heparin lock is preferred over a PICC line**

HOW LONG IS ENOUGH ???

- ***Until you no longer need it……***
- **Must be free of signs of active infection for at least two months and have a CD-57 above 130 before antibiotics are stopped**
- **CYCLE THERAPY**
  - *Near end of treatment course, hold antibiotics until you relapse (usually 3-4 weeks), then resume them at full dose for 4 to 6 weeks, then repeat the cycling*
  - *May have a big Herxheimer*
  - *Takes three cycles or so to be successful*

BABESIA

- **Atovaquone (Mepron, Malarone) in high dose, *CONFIRMED BY BLOOD LEVEL TESTING***
- **Must add two or more meds that work through different mechanisms**
  - Usually azithromycin + artemesia derivatives
  - Clindamycin and gentamicin are alternatives
  - Concurrent tetracyclines (TCN, doxy, mino) are NOT COMPATIBLE with atovaquone!
- **For established infections, 5 months of treatment is the minimum**

BARTONELLA

- **Levaquin is the drug of choice**
  - Tolerance issues: tendon pain and damage is possible as is insomnia which may be long-lasting
  - Must have good tissue antioxidant levels, high magnesium stores, and not be deficient of glutathione
- **Levaquin cannot be given concurrently with antibiotics in erythromycin family**
  - Azithromycin, clarithromycin, telithromycin
- **Better outcome if Levaquin is combined with cell-wall drugs (penicillins, cephalosporins)**
- **OK to use with tetracyclines and azoles**
  - Metronidazole, etc.; fluconazole, etc.
- **Alternatives to Levaquin include combinations with rifampin, sulfur, clarithromycin, and possibly streptomycin and gentamicin.**
- **Treat for months- at least two, and often need more than four.**

EHRLICHIA

- ***Can be a chronic infection !***
- **Least difficult to treat of the chronic TBDs**
- **Tetracycline drug for two to four weeks rarely fails**
- **Alternatives include the fluoroquinolones and advanced erythromycins, but failures with these are possible**

MYCOPLASMA

- **VERY IMPORTANT AND SERIOUS!!! Is the root of the worst cases of Lyme!**
- **Best regimen and appropriate duration of treatment not known**
- **Most regimens include a tetracycline + hydroxychloroquine (Plaquenil)**
- **Most experts recommend years of therapy**
- **Growing interest in combinations of intracellular antibiotics, but not enough data to know best combos**

DNA VIRUSES

HHV-6, EBV, CMV

- **Valgancyclovir (Valcyte) in high doses**
- **Need a minimum of three, and possibly six months of continual therapy**
- **Often there is a sudden improvement after the third month !**
- **Uncertainty over how to determine which patients should get this treatment**
  - Yes if + PCR; yes if + IgM in high titer
  - What about + IgG? Only treat high titers? How high?

TOXINS

- **Heavy metals- will need chelation**
- **Organic chemicals (plastics, insecticides, etc.)**
  - Sweat, increased bowel frequency, ?clay compounds
- **Biological neurotoxins**
  - Remove the source
  - Questran, Welchol, ?chitosan

NERVE DAMAGE
Big Role For IVIG

- **Nerve damage must be documented in order to get insurance coverage**
- **IVIG is the only proven method to heal the damaged nerves**
- **Unclear whether is best to give alone, or along with antibiotics**
- **Unclear whether is best to treat early on or later in the course of therapy**
- **Very clear that this may be an essential treatment for those with autonomic dysfunction or intractable pain**
- **IVIG is also indicated for IgG deficiency**

METABOLIC DYSFUNCTION

- **Treat the underlying diseases**
- **Nutritional approach**
  - Mitochondria: NT-Factor, Co Q-10, trace minerals, B-vitamins
  - Methylation cycle- alleviate block (“Folapro”)
  - Supplement with methylating agents (methyl B-12, MSM)- but be careful to remove any excess mercury first (don’t want to create methyl mercury!!)

HORMONES

- **Affected in several ways**
  - Attack on glands that produce the hormones (example- thyroiditis)
  - Blockage of hormone receptors (example- pancreas)
  - Glandular exhaustion from over work in setting of poor nutrition (example- adrenals)
  - Total imbalance of normal feedback mechanisms
- **Treat the underlying conditions**
- **Accurate diagnosis using advanced methods**
- **Careful supportive treatments designed to restore, not replace hormone production**
- **Frequent re-testing and adjustments to regimen**

PSYCHIATRIC

IMPORTANT BOTH AS A CAUSE OF WORSE ILLNESS, AND AS A RESULT OF BEING ILL

- **Any severe illness can bring out hidden or unresolved conflicts**
  - Affect how we see ourselves and how we deal with being sick
  - Impact on doctor-patient relationship
  - Often impacts overall compliance with regimen
  - Reinforces role of victim and may impact ability to advocate for oneself
- **Chronic illness often results in grief reaction**
  - Loss of health, loss of career or place in circle of family and friends, loss of abilities (mental & physical)
  - Loss of control
  - Loss of joy
  - Also can affect compliance and relationship with caregivers
- **Very delicate and sensitive counseling is needed *and should not be ignored- is as important as taking antibiotics or any other medication!***

"NEW STUFF"

- **Monoclonal antibodies to assist with western blot (available through Igenex)**
  - Bb surface proteins 31, 34, 41
- **FISH test available for more species of Babesia**
  - B. microti and B. duncani (WA-1)
- **Labs getting better with CD-57 and cytokine assays**

"NEW STUFF"

- **Better neurodiagnostic tests**
- **Unraveling the mystery of autonomic dysfunction**
- **Now able to biopsy small nerve fibers in the skin to give absolute proof of nerve damage**
- **Reversal of nerve damage with IVIG has been proven**

"NEW STUFF"

OTHER CO-INFECTIONS ?

- **Nematodes (microfilaria worms)**
- **West Nile Virus**
- **Q-fever**
- **Tularemia**
- **Yeast**
- **TBE virus**

"NEW STUFF"

- **Tigecycline**
  - Tetracycline class of antibiotic
  - Has "efflux pump" inhibitor
  - In theory, can assist other antibiotics given concurrently to be more effective
  - Should work for most of the co-infections
- **Disadvantages**
  - Is IV only
  - NAUSEA!!
  - Hard on veins
  - Expensive and insurance coverage is problematic

OUR PROBLEMS

- **The epidemic is not controlled**
- **Still are horrendous political issues**
- **Testing still cannot be used to adequately categorize a patient to know all the problems that are present**
- **Unclear which treatment regimens are the best, or even to know who should get what and in what sequence!**
- **NOBODY is conducting meaningful research in any of these areas**

WE HAVE A SOLUTION-
The Lyme and Associated Diseases Registry®

- The Lyme and Associated Diseases Registry® is up and running!
- Pediatric registry has been created and is in final testing stages
- Plans underway to add neuropsychiatric-neurocognitive registry for children and adults

WHY MY REGISTRY IS IMPORTANT

- Real world picture of real people- no current journal article discusses any of the chronic cases we see
  - Co-infected, toxic, dysregulated, immune deficient, damaged
- Is the only way to sort through a literal mountain of data
  - too complex an illness to place people into neat cubbyholes
- MUST discover better diagnosis and treatment
- MUST publish results in top medical journals
- MUST win this on "their" turf or it will not be a real victory
- Is the only way to broadcast the truth to the wide world of medicine
- Is the only way to protect our doctors
- NEED MORE PHYSICIANS TO PARTICIPATE

UNPRECEDENTED COMING TOGETHER OF POSITIVE PUBLIC EVENTS

- Action of Connecticut Attorney General Blumenthal criticizing IDSA and forcing it to revisit its guidelines
- Documentary "Under Our Skin"
- FABULOUS book, "Cure Unknown" by Pam Weintraub

TAKE CONTROL OF YOUR OWN HEALTH CARE

- Learn, learn, learn!
  - Re-read my "Guidelines" and try to figure out your own illness
    - Go through your history, symptoms, prior diagnoses, test results, and prior treatments
    - Do you have co-infections?
    - Are you responding to treatment as expected?
    - Does it make any sense?
    - Take notes as you do this, then re-organize them into concise lists of the important points to share with your doctors

APPLY WHAT YOU'VE LEARNED TO YOUR OWN HEALTHCARE

- May need to go over history or symptoms again with your doctor to be sure you aren't missing something
- Are you responding to treatment as expected? If not, then perhaps a change is needed
- Are you following the diet? Are you taking the recommended nutritional supplements? Are you exercising? Are you getting enough rest? Smoking?? Alcohol???

EDUCATE YOUR PHYSICIANS

- Include them in your list of people to educate on the Attorney General's findings, have them see *Under Our Skin*, and get them to read *Cure Unknown*
- ILADS-TTC Physician training program
- CALDA sponsorship to attend this years' annual Lyme meetings

NEXT STEPS

- **Publicize Blumenthal's findings, and share them with medical community and fellow Lyme sufferers**
- **Conduct group screenings of *Under Our Skin***
- **Read *Cure Unknown* and encourage others to do so!**

FINAL SUGGESTIONS

- **Re-evaluate your own situation**
  - New "guidelines" are in the works!
- **Educate more friends, family and doctors**
  - We now have more powerful tools
- **Attend the upcoming Lyme meetings next month in San Francisco**
- **Insist that you be included in the Lyme Registry**
- **Political action !**
  - *Never give up*
  - *We won't go away*

THANK YOU !!!