Vol. 7, Issue 2

Investigating Lyme Disease & Chronic Illnesses in the USA

February 2012

The Virginia Governor's Task Force on Lyme Disease Final Report Adopted Unanimously

Introduction

In response to reports of the growing number of cases of Lyme disease and other tickborne illnesses and out of a sense of concern for the significant number of Virginians infected with these diseases, Governor Bob McDonnell and Secretary William Hazel convened this task force to study and make recommendations in the following areas:

- Diagnosis
- Treatment
- Prevention
- ❖ Impact on Children
- Public Education

The Governor and the Secretary appointed the following persons to serve on the Virginia Task Force on Lyme Disease:

Michael Farris, Chairman, The Governor's Task Force on Lyme Disease; Chancellor, Patrick Henry College

Heather Applegate, Ph.D., child psychologist. Supervisor, Diagnostic and Prevention Services, Loudoun County Public Schools and private clini-

cian Dianne L. Reynolds-Cane, MD, Director, Virginia Department of Health Professions Douglas W. Domenech, Secretary of Natural Resources, Commonwealth of Virginia **Bob Duncan,** Executive Director, Virginia Department of Game and Inland Fisheries, Commonwealth of Virginia Keri Hall, MD, MS, State Epidemiologist, Virginia Department of Health William A. Hazel, Jr., MD, Secretary of Health and Human Resources, Commonwealth of

Kathy Meyer, co-organizer of Parents of Children with Lyme Support Network, Northern Virginia

Virginia Samuel Shor, MD, FACP, Associate Clinical Professor George Washington University Health Care Sciences and private practice, Internal Medicine, Reston, VA Monte Skall, Executive Director, National Capital Lyme and Tick-Borne Disease Association, Mclean, VA **Lisa Strucko, Pharm.D.** Clinical Pharmacist, Leesburg Pharmacy, Leesburg, VA Rand Wachsstock, DVM, veterinarian, Springfield, VA and

former instructor in biochem-

istry at Yale University.

The Task Force held eight separate hearings with two distinct hearing categories. There were five separate hearings devoted to citizens of Virginia who had been impacted by Lyme and other tickborne illnesses. These hearings were held in:

- Virginia Beach
- Richmond
- Roanoke
- Springfield
- Harrisonburg

Over 100 citizens testified at these hearings. We were profoundly impacted by this testimony and thank the citizens for their sacrificial efforts to testify.

A second set of hearings were held devoted to particular topics. At these topical hearings, the bulk of the testimony was from subject matter experts, supplemented by testimonies from citizens that had been asked to focus on the particular issue at hand. The following expert witnesses appeared before our Task Force in these hearings:

Diagnosis & Treatment

Marty Schriefer, MD, Chief of Diagnostic and Reference Laboratory, Centers for Disease Control and Prevention Daniel Cameron, MD, Past President of International Lyme and Associated Diseases Society, epidemiologist and private practice, Internal Medicine, Mt. Kisco, NY. Elizabeth L. Maloney, MD, Lyme disease educator and Family Practice physician, Wyoming, MN

Paul G. Auwaerter, MD, representative, Infectious Diseases Society of America Prevention

Charles S. Apperson, Ph.D.,

Dept. of Entomology, North Carolina State University **Kerry Clark, MPH, Ph.D.** Associate Professor, Epidemiology & Environmental Health, Department of Public

Health, University of North

Florida

David N. Gaines, Ph.D., Public Health Entomologist, VA Department of Health, Office of Epidemiology

J. Mathews (Mat) Pound, Ph.D., Research Entomologist, USDA-ARS Knipling-Bushland U.S. Livestock Insects Research Service

Nelson Lafon, Deer Project Leader, VA Department of Game and Inland Fisheries Impact on Children

Leo J. Shea III, Ph.D., neuropsychologist, Neuropsychological Evaluation & Treatment Services, P.C., New York, NY Carolyn Walsh, MD, private practice, Internal Medicine, Lansdowne, VA

Daniel E. Keim, MD, private practice, Pediatric Infectious Disease, Fairfax and Leesburg,

Jennifer Jones, RN, BSN, NCSN, School Nurse, Trinity Christian School, Fairfax, VA Public Education

Jorge Arias, Ph.D., entomologist and Supervisor, Disease Carrying Insects Program, Fairfax County Department of Health, Fairfax, VA

Robert Bransfield, MD,

President, International Lyme and Associated Diseases Society, Associate Director of Psychiatry and Chairman of Psychiatric Quality Assurance, Riverview Medical Center, and private practice, Psychiatry, Red Bank, NJ

Graham Hickling, Ph.D.,
Research Associate Professor,
University of Tennessee,
Director of UT Center for
Wildlife Health, Knoxville, TN
Wayne Hynes, Ph.D., Professor
and Chair of the Department of
Biological Sciences at Old
Dominion University, Norfolk,
VA

Holly Gaff, Ph.D., Assistant Professor in the Department of Biological Sciences at Old Dominion University, affiliated with the Virginia Modeling, Analysis and Simulation Center, Norfolk, VA.

Peter F. Demitry, MD, MPH, former Assistant Surgeon General, United States Air Force, and current President, 4-

D Enterprises, Haymarket, VA
The Task Force made
every effort to seek a balanced
approach in each of the topical
areas where there are recognized divergent views. In general, we were able to find willing
witnesses representing a variety of viewpoints on such

We received substantial support from the Virginia Department of Health, Secretary Hazel and the Office of the Secretary of Health and Human Resources for which we offer our deep thanks.



Michael Farris, Chancellor of Patrick Henry College was the chairman for the Governor's Task Force on Lyme Disease. His wife and 7 of his 10 children have Lyme disease.

We also received the generous cooperation of a number of public and private organizations, which allowed us to hold our hearings without cost. We thank the following organizations for this valuable contribution:

Patrick Henry College Regent University James Madison

University Roanoke Public Schools (Stonewall Jackson Middle School)

Immanuel Bible Church

Fairfax County Board of Supervisors

Loudoun County Board of Supervisors

Virginia Department of Health Professions

We begin our findings with some general observations that should be considered by all to be non-controversial in character:

General Observations

- Lyme Disease and other tick-borne related illnesses are affecting significant and growing numbers of Virginians
- These diseases are present in every region of Virginia
- Virginia is in a particularly vulnerable geographical location, being at the crossroads of the frontline of expansion of

Lyme disease carrying ticks from the North and other tick populations that have entered Virginia from the South, the public health risks of which are uncertain. These diseases can have significant, life-altering impact on patients, especially when the diagnosis is not made shortly after the patient is infected.

- Lyme disease is caused by a spirochete bacterium in the same family as syphilis. It can invade multiple organ systems and has a variable multi-stage progression with a tremendous range of symptoms. It is thought that humans develop no long-term immunity and there is no available vaccine.
- There is much that remains to be understood about Lyme and related diseases in every relevant sector including diagnosis, treatment, and prevention.
- There is an acute need for greater research in all relevant spheres.
- ❖ Medical personnel need accurate, fact-based information about prevalence, diagnosis, treatment, and prevention of tick-borne diseases. It is critical to raise awareness in the medical community about Lyme and other tick-borne diseases.
- ❖ The mandatory reporting of Lyme disease to the Virginia Department of Health (VDH) can be overlooked or forgotten by some medical providers,

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leading to an undercount of the number of patients affected.

- The CDC case definition for Lyme disease is for epidemiological purposes only and is not now and never has been the singular valid basis for a diagnosis of Lyme disease.
- Public awareness concerning the prevalence, symptoms and prevention of Lyme disease needs significant expansion.
- Significant improvements that can help to prevent Lyme disease are possible. This will require a concerted, multifaceted effort requiring the cooperation and action of every sector of Virginia-governmental, private, business, community, family, and individual.

General Recommendation:

The task force should recommend that VDH receive funding to enhance its tick-borne diseases program. Key elements of an effective program include the following:

- (i) human disease surveillance
- (ii) tick surveillance and testing
- (iii) general public and healthcare provider outreach and education regarding the prevalence and prevention of Lyme disease.

Any reference to education in these recommendations should emphasize the need to provide an open and balanced review of the full body of literature.

Rationale:

Lyme disease is a significant health issue in Virginia, and VDH has been working to track and prevent spread of this infection over the last decade. As Lyme disease has become increasingly problematic in Virginia during the last five years, surveillance and prevention activities have become increasingly labor and resource intensive. A strategic public health investment is necessary to enhance VDH's ability to prevent and control the spread of tick-borne diseases.

Specific Findings and Recommendations

In addition to these general observations, we make the following specific findings and recommendations based on the testimony that we received from our hearings:

Diagnosis

- 1. As acknowledged by the CDC, Lyme disease and many related tick-borne illnesses cannot be adequately diagnosed by serology alone in many cases.
- 2. There is no serological test that can "rule out" Lyme disease.
- 3. Clinical diagnosis that may be supported by serology remains the proper method for the

diagnosis of Lyme and related illnesses.

- 4. Clinical diagnosis is not limited to the observation of an EM rash. A significant proportion of patients with Lyme disease may never develop or observe such a rash. Moreover, the EM rash can manifest in non-traditional patterns. The medical community needs a more comprehensive set of visual illustrations so that non-traditional patterns may be properly recognized.
- 5. Many lay witnesses testified that members of Virginia's medical community inaccurately believed that serology alone can "rule out" Lyme disease.
- 6. According to lay testimony, there are some members of the Virginia medical community who have refused to consider a diagnosis of Lyme and related illnesses on the ground that "we do not have Lyme in Virginia" or in this "part of Virginia." Lyme disease is present in all parts of Virginia, endemic in most parts of the state, and emerging throughout the Commonwealth.
- 7. The testimony that came before the Task Force relayed the highly questionable nature of the ELISA test for early localized disease. We encourage the use of clinical judgment at all stages due to the significant limitations of current serology.
- 8. We recommend that the VDH reporting form include the disclaimer "The CDC case definition is designed for surveillance purposes only. Clinical judgment should be exercised in assessing patients for Lyme disease as meeting the surveillance case definition is not required for the diagnosis of Lyme disease."
- 9. Since ticks often carry multiple pathogens and we received testimony that many Virginians have multiple tick-borne illnesses that may require comprehensive analysis and treatment, the medical community should be educated on the presence of co-infections.
- 10. Great caution should be taken whenever a blacklegged tick is attached and especially if it is engorged. Patient reports about the length of time of attachment can be unreliable as some patients may not have observed the exact moment of attachment. Medical providers should be at their liberty to treat Lyme disease prophylactically in such cases because of the high risk of disease. (Note that single-dose prophylaxis may lower the sensitivity of subsequent serology, as stated by the CDC.) Moreover, it is clear that early treatment is very important to prevent many serious complications of Lyme disease.
- 11. The Task Force encourages

increased financial support for Internal Review Boardapproved, peer-reviewed clinical studies associated with Lyme disease diagnosis and treatment. The Task Force encourages financial support for Virginia's college and university researchers who undertake research on Lyme or tickborne disease. This should include all scientific realms. We commend Old Dominion University for undertaking vital research in the Tidewater region. (Rationale: Additional research that investigates the validity and reliability of diagnostic and preventative tools and provides guidance for appropriate treatment will support quality of care and patient outcomes.)

12. The Task Force encourages institutions offering graduatelevel medical degrees to offer comprehensive instruction about Lyme and other tickborne diseases. Due to the rapidly evolving nature of the scientific research and literature on tick-borne disease, medical educators should use due diligence to teach comprehensive and up-to-date information in all aspects of tick-borne disease. (Rationale: Student clinicians (medical, nurse practitioner and physician's assistant students) are the clinicians of the future and should be aware of Lyme and other tick-borne diseases as medical conditions in Virginia.)

13. VDH should continue to

provide information to clinicians practicing in the Commonwealth concerning the epidemiology of Lyme disease in Virginia, a physician's responsibility to report Lyme disease, the information VDH requires to classify a case, the purpose of the surveillance case definition, Lyme disease prevention measures and tick identification. VDH should also continue to provide information to clinicians practicing in the Commonwealth about other tick-borne diseases in Virginia. (Rationale: This recommendation articulates VDH's current practice and speaks to its commitment to continue these informational efforts in regard to tick-borne disease, with a particular focus on Lyme disease as it is the most commonly reported tick-borne disease and is present in all parts of Virginia, endemic in most parts of the state and emerging throughout the

Commonwealth.)

VDH should emphasize that due to the rapidly evolving nature of the scientific research and literature on Lyme and tickborne disease, medical professionals should use due diligence to stay abreast of information in all aspects of tickborne disease to educate their ability to clinically assess patients.

Treatment

1. There is no serological test

that can tell a medical provider when a patient has been cured of Lyme disease.

- 2. A typical criterion that a patient is well is when the symptoms have resolved and the patient feels better.
- 3. There is no scientific basis for concluding that 30 days or less of antibiotics is sufficient treatment for every case of Lyme disease.
- 4. We received substantial testimony from lay witnesses that they had been successfully treated with long-term antibiotics.
- 5. Expert testimony regarding effectiveness of long-term antibiotics conflicted. We encourage additional studies to evaluate the effectiveness of long-term antibiotics as treatment for Lyme disease.
- 6. The Department of Health Professions should inform its licensees that the department does not target clinicians for disciplinary action by virtue of their antibiotic choice of management of Lyme disease.
- 7. Lay witnesses expressed displeasure with the propensity of the medical community to treat persons who were ultimately diagnosed as late stage Lyme disease as needing psychological evaluation or treatment. Lay witnesses testified this was often done in a demeaning fashion and appeared as an excuse for the medical community's failure to adequately understand the problem of Lyme disease.
- 8. Lay witnesses stated that long term treatment of Lyme disease is often not covered by their insurance carriers and that they can spend thousands of dollars per month for their treatment plan. The extent to which this is occurring is unknown to the Task Force and the Task Force recommends that this issue be evaluated by the Bureau of Insurance.

Public Education and Prevention

1. It is a public health goal of a high magnitude to ensure that the general public and medical community become fully aware of the risk of exposure to Lyme and related illnesses and the severe medical consequences that can arise when this disease is not promptly diagnosed and treated. Developing an appropriate sense of public urgency is the greatest single need in the efforts to prevent and treat Lyme disease. The Governor and VDH should expand their current programs of public education to place significant and regular emphasis on Lyme disease so that the public under

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Public Health Alert

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 Gehrig'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.

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standing is proportional to the serious nature of this threat to public health.

- 2. Since ticks often carry multiple pathogens and we received testimony that many Virginians have multiple tick-borne illnesses that may require comprehensive analysis and treatment, the public should be educated on the presence of co-infections.
- 3. The VDH and other appropriate state and local agencies should place greater emphasis on public education through modern media. In addition to printed brochures, public interest radio and television ads should be developed. The use of the internet should be dramatically amplified. Major internet information organizations-especially those headquartered in Virginia-should be asked to consider donating space for articles and announcements. An increased effort to work with the journalists of Virginia to develop appropriate stories to alert the public should be considered. For example, Old Dominion University scientists presented their unanticipated discovery of two additional tick species in Tidewater some of which carried an infection that is a cousin of Rocky Mountain Spotted Fever. This example demonstrates the imperative for better communications on all fronts. Budgets appropriate for these purposes should be developed.
- 4. It is essential that the Virginia approach to Lyme disease prevention and treatment involve collaborative work of all branches of state government and coordination with all facets of local government. The Governor should consider convening a task force of state and local officials to create a bestpractices model for government within the Commonwealth. For example, it is imperative that public schools and departments of parks and recreation consult with public health officials to properly manage facilities to prevent unnecessary public exposure to ticks-especially for children-and that warning signs be posted at points of public access in areas that are highrisk.
- 5. As a part of the efforts to inform the public about safe practices (e.g. how to keep your yard free from ticks), the Commonwealth should clearly communicate the expectation that government agencies actually implement the same methods being recommended to the public. For example, if a public school sends a tick prevention brochure home with a student, but does not actually implement the recommended practices on school property, there are two dangers that arise. First, children are unnecessarily exposed to ticks while at school. Second, the failure of the school to implement the practices signals to the parents that the situation is not truly important. Government must practice what it preaches if the public is going to give Lyme disease prevention the serious attention it deserves.

- 6. The General Assembly may wish to consider amending the Code of Virginia in order to authorize localities to establish tick surveillance and control districts. (Rationale: Localities are already authorized by the Code to establish mosquito control districts. Providing a mechanism whereby localities could form tick surveillance and control districts could be beneficial to many localities, particularly in Lyme endemic and emerging areas, by allowing the development of practices and policies designed to decrease tick populations on locality property frequented by the general public such as public parks and schools.)
- 7. The Governor should establish a working group, under the auspices of the Secretary for Natural Resources in collaboration with the Secretary of Health and Human Resources, to develop guidance and potential strategies for localities that wish to attempt deer and/or tick population control. The Governor should include funding in the 2012 Budget Bill that is sufficient to adequately support this initiative. (Rationale: Developing guidance in this manner will allow for the development of control strategies that are more comprehensive than either Secretariat currently offers in regard to Lyme and other tickborne diseases.)
- 8. Public education programs on Lyme prevention should continue to emphasize these (and other) important practices:

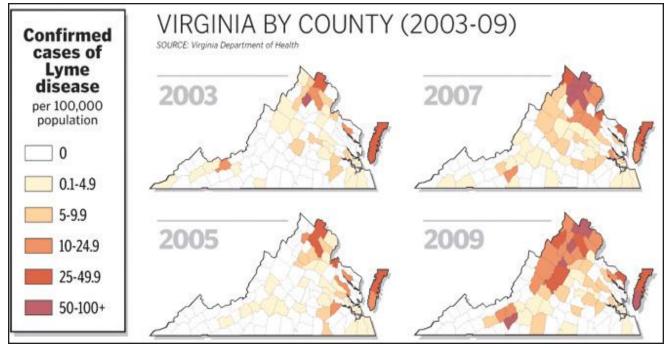
Land-use practices for preventing tick exposure:

Animal exclusion and landscaping

Homeowners should consider fencing and landscaping choices that tend to exclude deer (the primary adult tick host) and mice (the Lyme bacterium reservoir). Do not plant vegetation that attracts deer, remove food and cover that attracts mice (e.g. wood piles trash), and reduce tick breeding grounds (e.g. clear trees and brush and regularly mow grass). Homeowner associations and other real estate contracts should avoid clauses that restrict the ability of homeowners to effectively exclude deer from their property or control deer populations in their neighborhoods.

Tick control

Local, state, and federal agencies should continue to evaluate the utility of host-specific application of acaricides (e.g., USDA 4-poster devices) to combat Lyme disease in this Commonwealth. If their use is warranted, the Virginia Department of Game and Inland Fisheries (DGIF) should put in place an orderly and responsible permitting process. DGIF is working with localities to investigate if this tool is a practical solution for managing tick populations. Currently, DGIF is working with Fairfax County on such a study and will develop potential permit conditions that will safeguard wildlife populations and habitats while not inhibiting the use of the 4-poster system. Current



regulations and codes exist to allow for the supervised use of these devices. DGIF should work with VDH and local governments to make sure that proper safeguards are put in place and necessary data is collected on the use of these devices. Budget for tick testing should be considered by the General Assembly.

Deer Control

DGIF is to be commended for its appropriate expansion of hunting seasons and limits for deer. Further expansions should be considered. Public information campaigns should be conducted to encourage all willing Virginians to participate in an effort to achieve appropriate deer populations for the sake of public health.

Acaricides

Public information about the safe and appropriate use of acaricides should be a component of public education efforts.

Human practices to limit exposure to ticks:

Avoiding tick habitat

The public needs to be informed about the nature of tick habitat and the danger of entering into such habitat unprepared.

Appropriate dress and/or repellants (especially in tick habitats)

When entering such habitat is necessary, the public needs to be informed about best practices to avoid tick exposure (proper dress, repellants, tick checks, etc.)

Showering after being outdoors

The public needs to be informed of the value of a thorough shower within a short time after concluding outdoor activities where tick exposure has been possible.

❖ Evening tick check

The public should be informed of the necessity of a once-a-day thorough tick check after being outdoors (especially in tick habitat). Children especially should be checked daily.

Proper pet practices

Vaccination and repellants for pets should be strongly encouraged. The public should be aware that even though pets have been properly treated, they can still bring ticks into the home that leave the pet and bite a human. Accordingly, indoor pets should be controlled to avoid entry into tick habitat.

Children

- 1. One expert testified concerning a potential for in utero transmission of Lyme disease. The CDC has proclaimed on its website, "Untreated, Lyme disease can be dangerous to your unborn child."1 VDH should include information for pregnant women in the educational materials that it provides to the general public and to health-care providers who care for pregnant women.
- 2. VDH should inform the public of the fact that children are a high-risk group for contracting Lyme disease. Parents need to be alert to the possibility of Lyme-especially when a child presents with symptoms that are not easily categorized as some other illness with an identified etiology.
- 3. VDH needs to undertake focused campaigns to help educate pediatricians, family practitioners, urgent care clinicians, and other clinicians about the importance of early recognition of Lyme disease.
- 4. VDH, the Virginia
 Department of Education,
 other agencies, and subject
 matter experts as appropriate
 should collaborate to create a
 best practices document
 focused on children with Lyme
 and related illnesses. Topics
 that should be considered
 include:
- Proper construction of school grounds to promote deer exclusion and avoid unnecessary exposure to ticks
- Before taking students outdoors for instructional field investigations, consideration of the site's likelihood for ticks and then, in cooperation with parents, preparation of the students, parents, and teachers accordingly with the following simple guidelines: wear appropriate clothing, use repellents and perform thorough tick checks. (The benefits of outdoor recreation and education is very important for our children's development and complete avoidance of tick habitat would be extremely difficult.)
- Proper landscaping and fencing practices to limit the ability of children to enter tick habitat during the school day
- Consideration of safe and effective use of acaricides
- Education of teachers, school psychologists, school counselors, school nurses, and other professionals in all phas-

es of Lyme disease, but especially in the relationship between Lyme and neurological impairment that may present as learning-related or sudden-onset attention or memory difficulties.

5. VDH should continue to provide information to school nurses in the Commonwealth about Lyme and other tickborne diseases in Virginia. (Rationale: This recommendation articulates VDH's current practice and speaks to its commitment to continue these critical informational efforts.) 6. Experts testified that students afflicted with this disease often fall significantly behind in school because of the problems that they face, not the least of which are cognitive difficulties. Current educational accommodations are often inadequate. Consideration should be given to appropriate and sensitive educational modifications for students with latestage Lyme that help maximize their educational progress and that emphasize the fact that late-stage Lyme disease routinely has waxing and waning symptoms not typical in most chronic medical conditions and that may require novel and timely accommodations and interventions.

7. VDH should continue collaboration with Virginia's Department of Education (DOE), the Virginia Council for Private Education and home schooling associations to explore developing materials that may be incorporated into the science and/or health education curricula of elementary, middle and high school students in the Commonwealth concerning the epidemiology of Lyme and other tick-borne diseases in Virginia, tick-borne disease prevention methods and tick identification. (Rationale: Educating children about Lyme and other tick-borne diseases is best done by presenting this information as part of a school program. A comprehensive approach to educating elementary, middle and high school students about Lyme and other tick-borne diseases can only be achieved through a coordinated effort with the organizations that develop these academic programs for students in Virginia.)

Respectfully submitted, Michael Farris Chairman

pha

The First Five Steps to Take After a New Diagnosis



by Lisa Copen

I easily can remember the day that my life shifted into a new kind of normal when I was diagnosed with rheumatoid arthritis. At the age of 24, having dealt with a few weeks of swelling in various parts of my body, sometimes to the point of being disabling, my doctor called me at work with the test results. I had a positive rheumatoid factor, she explained, which most likely meant that I had rheumatoid arthritis. Faking confidence, I asked her, "On a scale of 1 to 10, 10 being normal, what can I expect my life to be like from here on out?" She did not wish to answer, but after I told her I needed some kind of scale to know what side I was up against, she reluctantly replied, "If you are lucky maybe a six."

Within days, I realized that everything in my life now be impacted by my disease & that there would be no such thing as "normal" again. Every detail of my life would change from the simple struggle to open a door, to stand from the chair, to walk across the room, or to shift gears in my car. Although my carefree lifestyle & attitude would stay imbedded within my heart & personality, it would take a back seat while I attempted to simply try to learn to function while in severe pain.

A few weeks ago, a friend from high school who

was recently diagnosed with rheumatoid arthritis, searched the internet for information on the disease, & ironically ended up on the Rest Ministries website, where she realized she had known me nearly 25 years ago from a high school of only 300 students.

We exchanged e-mails a few times & it is my hope that she found them encouraging. When I reflect on what I would've liked to have heard from someone who has lived with a chronic illness for years, upon my new diagnosis, these are the five things I find of most value to pass along.

[1] Get in touch with the national foundation or organization that is dedicated to supporting people who live with a chronic illness that you have recently been diagnosed with. Explain to them that you have just found out about your diagnosis & that you would like the most basic information. They may drop some brochures to you in the mail or send you to their website.

Despite the fact that you may have not had a chance to grieve your diagnosis yet will likely make this to seem discouraging, & if you begin to get things in the mail & are not ready to read them, put them aside for later. The important thing is to know that this organization will likely be the one that will provide you with the most current & objective scientific treatment options & you will want to be "in the know." As your doctors are making suggestion for medications for you to start, & you are torn about them because of the long list of side effects, these organizations will be your best source of objective information.

[2] Know when to stop reading about your disease. There are millions of books, websites, podcasts, & more

which will tell you how you can cure it, delay the progression of the disease, or most effectively be treated with alternative treatments. The important thing is to glance over critical health & illness organizational websites so you are aware of where you can go to find information when you need it.

You should be aware of some of the symptoms that may occur because of your illness so that if they do occur, you can attribute them to it. However, don't bury yourself in reading everything you can get your hands on. It will simply become too depressing, & many of the anecdotes that other people share may never apply to your life.

[3] Don't lose hope about your situation. It seems there are new scientific discoveries on a weekly basis that may change how your illness progresses or as treated. For example, I have now lived with rheumatoid arthritis for 16 years & recently had four joints replaced in my left hand due to deformities & loss of abilities. But my medical team, a hand surgeon, rheumatologist, & a physical therapist, have all said that they rarely see these kind of surgeries now due to the new family of drugs available in the last 10 years that has rapidly slowed down the progression of the disease & destruction of the actual joints.

Even if there is not an immediate cure, as we scientifically grow closer to being able to know our exact DNA, we will be able to pinpoint which medication will best treat our disease, without having to jump from one medication to another, losing months & years sometimes of our health, in order to find which one works best. Hope & a positive outlook will have a profound effect on your disease & your life. So don't give up & assume that

your illness will be disabling.

[4] Think about who you would like in your life to be able to talk to about what you are emotionally & spiritually experiencing due to the recent diagnosis. The person may be someone you meet in an online forum for your disease, it could be a pastor, mentor, counselor, or even a good friend who is able to listen without trying to fix it. The most important thing is that you have an oasis where you can share what you are experiencing without feeling like you may be judged or where you will receive ignorant comments such as "no pain, no gain." Check out your local support groups for your illness, or other support environments such as HopeKeepers, which is a unique small group Christian support environment for those who live with illness or pain.

Also, consider your personality & how you are best encouraged. Would you feel most refreshed by sharing what you are going through with just a friend, one-on-one, at a coffeehouse? Or are you homebound, & signing onto a website every day to receive encouragement & prayer would be beneficial? Remember, whatever works best for you at this time, may not best meet your needs in six months, so do not feel like you are stuck with a particular group or mention. Be willing to try new forms of support to find which best works for you.

[5] Ask yourself "What foundation do I have in my life that will help me through the difficulties that I will be facing?" Even if your illness does not progress rapidly, the daily aches & pains, as well as the emotional roller coaster & spiritual "why?" questions you will have, will leave you searching for a deeper meaning in life than simply solving your problem with a cup of hot tea. As a

Christian myself, I honestly do not know how people live each day with a chronic exasperating illness who do not know the Lord.

This is what keeps me together: believing that my pain is never wasted, & that God always has a purpose & plan for it; acknowledging that God is always in control of my life & that of my circumstances come as no surprise to Him; & firmly surrendering to the fact that He has any specific purpose for my life & that any limitations I have experienced because of my illness will not hinder His plans. Even if you are not a spiritual person, you will likely find yourself facing those middle of the night blues, & I encourage you to look up a biblical website like Bible Gateway & read through some of the Psalms. If you are unfamiliar with them you may find yourself pleasantly surprised to see that most of the people who lived during these times faced severe hardships, deep depression, many doubts, & yes, even chronic illnesses &

disabilities. So, to sum it up, be well informed, set reasonable boundaries for the quantity of information you will intake, keep hope alive, find support through people, & then search for what will get you through the darkest of moments when the information & people you have counted on disappoint you. Discover a purpose in the pain that is greater than that which the world will tell you. if you put your life on hold completely you will have regrets later on. As the late John Lennon once shared, "Life is what happens to you while you're busy making other plans."

pho

On the Porch



by Joan Vetter

When I say the word porch what comes to your mind? I think of rocking chairs, maybe a swing, escape from busyness and stress, and good conversation over a glass of lemonade or iced tea.

Truthfully we don't live that kind of lifestyle much anymore, however today I was suddenly challenged with an entire

teaching on the porch of the

Lord. Last night I had a dream. There were many people milling about on this huge wraparound porch. I went up to a woman I knew and told her I was having trouble. It was the truth - for about a week I was struggling with dizziness and fear of getting sick. So many people I knew were sick. But I needed to prepare a Bible study to teach at an Assisted Living Home in a few days, and I was resisting the infirmity, sensing it was an attack from the enemy.

In the dream this woman I told about my problem dismissed me with a quick word, "You'll be alright" and went ahead and talked to other people. I recall the feeling of disappointment that she wasn't willing to roll up her sleeves spiritually speaking and work with me to see the cause of my concern.

I casually mentioned

this on the phone to a friend who took it seriously. She was one who always takes my concerns to the Lord and we assist each other in getting to the root of what is troubling us. As we talked and prayed I felt the dizziness lift and began to think with a clear head. I got excited about planning the teaching for my Bible Study. As I looked up a scripture I was going to use in John 5 about the man with infirmity for 18 years lying by the pool of Bethesda who was healed by Jesus, I saw that on the porches lay a great multitude of sick people.

Suddenly my dream began to make sense. Then I remembered a vision someone shared years ago about seeing people on a porch and calling out to them to come out because the house was on fire. When she got up there she realized they couldn't come because their feet were tied with ropes. So I identified with the feeling I had on the porch

in my dream. I wanted freedom, but didn't know how to get there.

So I went on a scripture treasure hunt with the word porch. I found in Joel 2:17 that the priests who minister to the Lord were called to weep between the porch and the altar. They were to say, "Spare your people, O Lord."

This led me to the scripture where God's heart cries out for the wounded ones as He proclaims in Jeremiah 8:11, "They have healed the hurt of the daughter of my people slightly saying peace, peace, when there is no peace."

Then in Ezekiel I read of the porches built in the temple. I began to see the porch as a place of preparation to approach the altar, perhaps a place of being restored enough so we can feel worthy to come to the altar - a waiting room so to speak.

Finally, I came to Acts 5:12 where the people were all with one accord on Solomon's porch, and many signs and wonders were done among the people.

Therefore, I see the Lord saying three things:

- "Don't be ashamed when you need healing."
- "Be willing to cry out on behalf of others in prayer"
- * "Co-operate with Me to heal the deep wounds of your brothers and sisters so that we can get to that place of one accord where many signs and wonders are happening!"

I have sung a sweet worship song with the words, "Come and go with me to my Father's house where there's joy, joy, joy." I bet He's got a big porch! So pour yourself that lemonade, and sit with Him. He's always got the time to listen.

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Salute': Randy Sykes of Farmington Valley, CT



by Dottie Ianni

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

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

Honestly, anyone who

tries to bring awareness to chronic disease by any mode of communication deserves an award and bundles of praise. So if you would like to see someone highlighted here, please submit their name and contact information to:

Tix_Suck@yahoo.com and put
"PLEASE SALUTE [YOUR SUB-MISSION'S NAME] in the subject line. All submissions will be considered.

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

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

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

By 2000, Randy was very sick and the medical personnel said he had a plethora of goodies such as, Lyme disease, Multiple Sclerosis, possible Leukemia, Chronic Fatigue, Fibromyalgia and excruciating headaches. Fifteen plus doctors later, finally he received a diagnosis positive for Lyme disease by PCR.

Since then he has been a patient, a patient advocate, truth teller, chronic disease

activist, a team player and support group leader for the past 11 years. He gave freely of his time to help so many others when he was so sick himself.

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

Early in 2001 out of the concern for others, he along with his wife Laura and Chris Montes formed The Greater Hartford CT Lyme Support and Action Group. They met every 3rd Wednesday, once a month for support and to form some plan of action to help bring this terrible disease into the mainstream media. Sometimes I would forget and call on meeting night, and I would catch him making sandwiches and loading the car with goodies, info boards, flyers and packets of information to give the attendees.

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

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

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

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

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

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

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

By the middle of 2006, Randy and The CT Lyme group had a protest at the front gate of University of Connecticut Medical Center. What a perfect area for them to stand and show and raise awareness. Approximately 50 members attended with their various signs (on sticks!). Professional signs were made and they offered Randy's \$20,000 to any doctor who can "cure Lyme" within 6 weeks. The IDSA claims 10-14 days for a cure and that is the current recommendations set in place today. Not one person from any other group in CT or any surrounding state came to help the protest, yet it was publicly announced

"Salute'...cont'd pg 10

Perks from the Pistol Packin' Grandma



by Harriet Bishop

Peace on Earth.....ahhhh. Wish it were so. It seems wars have always plagued humanity from time immemorial. Wars alter lives of peaceful people who don't even want to fight. It was true in antiquity, and it's still true now. "Deployment" was recently coined, but it was part of our lives even as we grew up in the Great Depression, with our boyfriends landing on the shores of Iwo Jima and Okinawa, and our brothers landing on Normandy beachheads. Anguish and joblessness are not new either.

It was early May of 1951 when I stood awestruck, squinting at the brightness of the white sugary sand. Newlyweds as well as new arrivals from Tucson, my hus-

band and I had just been uprooted from our fledgling teaching and coaching positions at the University of Arizona, even before the end of the Spring semester, due to the escalating Korean War. The letter we had received at our cozy cottage was written in military jargon, full of such cryptic abbreviations that we had to take it to the nearby air base for interpretation. An exfighter pilot from WW II, my husband was being recalled into service as a 2nd Lieutenant to be retrained as an aircraft controller. He was ordered to report to Panama City by next Friday, ready for duty! Down at the equator? No, on Florida's Panhandle. " Whew! I get to go too."

Feathers flew as we notified our superiors (no 3 weeks' notice when Uncle Sam calls!), cancelled our lease, arranged for the military to pack and store our piano and wedding silver indefinitely, said goodbye to my stunned parents, sold our horse and returned the horse trailer to his family ranch at Dalhart, Texas. We made our way into East Texas before there were any freeways, marveling that two lane Highway 90 narrowed to one lane bridges! And marveling too that there was water under those bridges, quite an unusual sight for desert

dwellers!

We were delayed two days waiting in a sleepy, humid café with flies buzzing around the screen door, the ceiling fan creaking overhead. Our 1947 Chevy had broken down in Houma, Louisiana, requiring extensive repair. The shop wouldn't take a personal check, we didn't have sufficient cash, and there was no such thing as a credit card. When our Tucson bank finally opened the next day, a phone call solved the sticky problem.

So now we had arrived at the white sand of Long Beach at Panama City only a few miles from our final destination, Tyndall Air Force Base, Florida. The quiet surf lapped and murmured as the foam bubbles broke, and the waves receded back into the deep turquoise ocean. Such bliss and peace after a frantic rush to get here.

But there was something strange dotted all along that beach. About fifty feet apart stood wooden platforms slightly larger than a card table with 4x4's for legs, but they were only 6 or 7 inches off the ground. What in the world was their purpose? I pondered this for months as we visited often to use the high bar for chinups, and to run along the sand to the distant pier and back, falling gratefully into the clear

blue salty ocean to rest afloat. Eventually we were again "deployed", this time to Japanand three years later we returned to Tyndall AFB with our three babies, ages 1, 2, and 3. As children do, they loved the beach and grew up sturdy, climbing up on the little platforms and jumping down into the soft warm sand. Still the little platforms puzzled me, and their true purpose remained elusive.

The ensuing years took us to bases in Nebraska, Detroit, and another overseas deployment, this time in Europe. Upon returning from Germany on our way to San Antonio, we brought our teens and our two new toddlers to play on our favorite white sand beach. Now at last I knew what the little platforms were! I had to become older and wiser before I realized that the little structures were shelters from the sun which had been overwhelmed by the force of storms piling up the sand beneath them, making them unrecognizable and unusable for their former purpose. They were rendered truly useless. The shifting sands, long neglected, had now formed dunes too big and too expensive to combat. The builder hadn't counted on the entire shape of the beach landscape being altered forever.

And so it is with our lives.....our human bodies were built for action. But the storms of life and stresses of chronic illness can "pile up the sand" to overwhelm us, keep us from fulfilling our true potential, keep us from achieving our goals and from performing at our best....How can we keep it from overwhelming us and rendering us useless?

We must keep "digging out the sand", and doing the best we can to remain recognizable to ourselves. Chronic illness often slows us down necessarily. Some days we can't get out of bed...and shouldn't. And we never know what day that will be. At those times we can be kind to ourselves and allow ourselves to rest, knowing in our hearts that we still have our souls, our talents, our ambitions and our true purpose intact. We'll know for sure that we will go into action, "digging out the sand", taking small steps toward our goals just as soon as our bodies allow it, to ensure that our purpose will never be obscured like the useless little platforms. By consciously avoiding neglect, and by taking excellent care of ourselves, we won't allow chronic illness to alter our personal landscapes forever. pha

Sleepy Head?

Wellness and Nutrition Challenge Series



by Dr. Tina Beaudoin, ND www.nhnatural.com

The purpose of the Wellness and Nutrition Challenge Series is to provide medically-based practical ideas to promote individual, family and community wellness. This series is cowritten by two Naturopathic Doctors and a Registered Dietitian/ personal trainer. The suggestions offered in this series will center on small, gradual steps you can incorporate into your daily routines to enhance your health and wellness.

The foundations of health are the basic building blocks of maintaining a healthy mind and body. The foundations include: nutrition, hydration, sleep, exercise, mental/emotional health, elimination and envi-

ronmental exposures. The foundations of health are strongly interdependent and have a profound impact on how you feel and how well your body functions. This series could just as easily be called "Anti-Aging" in that when your foundations of health are strong, the aging process is slowed.

In this installment we will review the benefits of sleep, the consequences of sleep deprivation as well as tips to ensure a good night's rest. Although science has yet to uncover all the mysteries around sleep, many critical functions have been discerned. Deep sleep increases production of growth hormone (also known as the "anti-aging" hormone) and increases destruction of free radicals in our brain. Our brain actually detoxifies when we sleep. Have you ever been short changed on a good night sleep and woken up feeling not just tired but also foggy? Sleep plays an important role in immune function (fighting infections and cancer), metabolism, learning and memory.

What happens when we are chronically sleep deprived? Research studies reveal that chronic sleep deprivation is associated with increased blood pressure, impaired blood glu-

cose, impaired mental and physical performance as well as accelerated aging of the brain. Chronic sleep deprivation is linked with many chronic conditions including autoimmune disorders, cancer, diabetes and cardiovascular disease.

How much sleep is enough? General recommendations for infants are 14-15 hours per night, toddlers 12-14 hours per night, school age 10-11 hours per night and adults between 7-9 hours per night. If you are not getting enough sleep, make incremental changes to move toward getting better sleep. Small gradual changes that become part of your regular routine are more likely to be maintained. If you are having a hard time heading to bed at a time that ensures a good 7-9 hours, set an achievable goal of getting to bed 15 minutes earlier than usual. Each week, add another 15 minutes until you reach your ultimate goal.

Avoid caffeine, alcohol, chocolate, sweets and large meals before bed. Establish a regular relaxing routine before bed and avoid using the computer or watching television in the bedroom. Exercise and exposure to natural light during the day will also help your sleep routine. Deep



breathing exercises can also aid in relaxation.

If you have tried a variety of strategies and still have difficulty falling or staying asleep, it might be time to seek assistance. Effective treatment involves identifying and addressing causative factors, such as depression, anxiety, neurotransmitter or steroid hormone imbalances, mineral deficiencies or conditioned psychological arousal. There are numerous lab tests available to evaluate the underlying cause of a sleep disturbance.

Naturopathic doctors are experts in evaluating and treating the underlying cause of insomnia. Naturopathic

treatment strategies to correct imbalances might include GABA, taurine, glycine, 5-HTP, vitamins, minerals, adrenal support or nervines. It is especially important to address insomnia when dealing with any chronic medical condition (such as Lyme Disease, hypertension, diabetes, autoimmune disorders, etc.) as chronic sleep deprivation is a significant obstacle to healing.

Sleep is vital to your overall health. Whether you have difficulty getting to bed at a reasonable hour or just can't fall asleep, start on the path to waking up mentally and physically refreshed.

pha

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ILADS & Turn the Corner Foundation Offer Physician Training Program

by www.ilads.org

This physician training program will train the next generation of physician-scientists who will be future leaders in the treatment of Lyme and Associated Diseases.

The ILADS and Turn the Corner Foundation (TTC) Physician Training Program, a groundbreaking project vital to fostering excellence in care for Lyme disease patients, directly addresses challenges in properly diagnosing and treating Lyme and other tickborne diseases. The Training Program provides medical and other healthcare practitioners the opportunity to study with Lyme-literate healthcare professionals. Through this experience, participants will develop the skills necessary to properly diagnose and treat Lyme disease. These professionals will be able to return to their community with enhanced skills and the ability to provide superior care to Lyme patients, improving the health and quality of life for those that suffer from the most debilitating effects of Lyme disease.

Faculty

A dedicated and collegial faculty offers individual clinicians a hands-on education with physicians who are experienced in treating thousands of Lyme disease patients.

Building experience

The program is designed to foster independent career development for medical and other health care professionals by providing a foundation in the evidence-based treatment of Lyme and associated diseases. The program is also designed to enhance expertise for those clinicians who already have an established clinical practice. The program features up to two weeks participation in the care of various challenging early and chronic cases including: discussions of the patient's medical history, disease progression and health issues that inform evidence-based treatment plan choices.

Scientific meeting

In the fall of each year, ILADS

hosts an annual scientific meeting that aims to foster collaboration and dialogue surrounding the advancement of research and treatment of Lyme and associated diseases. Attendees include many prominent Lyme disease researchers and physicians. Trainees are encouraged to participate in the annual scientific presentation, including a physician - sponsored training lecture.

Evidence-based Practice

ILADS physicians have successfully treated thousands of Lyme disease patients using evidence-based medicine. The published ILADS guidelines concluded that there are large numbers of chronic Lyme disease patients presenting with a poor quality of life despite antibiotic treatment. More than 30% of Lyme disease patients in a Massachusetts and New York cohort remained ill years after antibiotic treatment. The quality of life for chronic Lyme disease was worse than patients who have Type 2 diabetes or a recent heart attack in two National Institutes of Health trials.

ILADS and The Infectious Diseases Society of America (IDSA) guidelines differ substantially, revealing the wide variation in diagnosis and treatment. The IDSA guidelines recommend one-time, shortterm antibiotic therapy. Physician demands for better outcomes led to the ILADS recommendation that antibiotics be administered for 4 weeks or longer - or that a patient be retreated - when clinically appropriate. Professionals attending the Physicians Training Program gain experience using evidence-based medicine for the treatment of Lyme and associated diseases. Both the ILADS and IDSA guidelines are listed on the government sponsored National Guideline Clearinghouse at www.guideline.gov. A full text copy of the ILADS guidelines is available at www.ILADS.org.

Turn the Corner Foundation

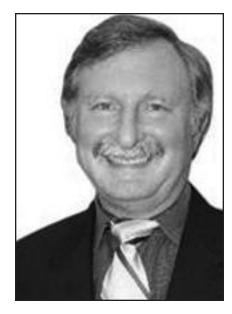
Turn the Corner Foundation (TTC) is dedicated to the support of research, education, awareness and innovative treatments for Lyme disease and other tickborne diseases. TTC is one of the premier granting organizations for Lyme disease research in the country. TTC supports innovative research projects in all areas of prevention, diagnosis and treatment of Lyme disease. TTC is also a leader in fundraising for Lyme disease research and support programs. Anyone interested in supporting the foundation, its programs or its annual fundraising gala should visit www.turnthecorner.org.

Applications

Interested applicants for a one to two week training program with our physicians can obtain an application by email at **lymedocs@aol.com** or contact Barbara Buchman, Executive Director, ILADS, P.O. Box 341461, Bethesda, MD 20827-1461, Phone: 301-263-1080, Fax: 301-263-0776.

There is a stipend available for a clinician to train with a designated preceptor. After the training by the preceptor the trainee will fill out a brief report of what they learned and how this will affect their future practice.

Seven Simple Tips for Dry Eyes and Mouth



by Dr. Jacob Teitelbaum

Dry eyes and mouth can have many causes. It is a common feature of CFS and fibromyalgia, and it often responds to simple nutritional support. In other cases, it may reflect autoimmune conditions such as Sjogren's Syndrome, which knocked Venus Williams out of this year's U.S. Open tennis championship — a consequence I think may have been avoidable. Fortunately for her, she changed her diet and was able to get back on the tour!

Have you ever suffered from dry eyes and mouth?? Dry eyes and mouth are also very common in CFS and fibromyalgia, and fortunately in most cases this is not associated with Sjogren's (or damage that may have somehow occurred to the tear glands or salivary glands). It therefore often can be resolved by following the SHINE protocol.

Whether your dry eyes and mouth are just from fibromyalgia, or whether you have Sjogren's or other causes, here are 7 simple tips that can be very helpful.

SevenTreatment Tips Three Key Oils

Just like oil lubricates your car, dietary oils can help

lubricate your body. Three key oils are especially important for dry eyes:

Fish oil. Fish oil is rich in the essential fatty acids EPA and DHA, which studies show help with dry eyes.³ Eat a portion of oil-rich salmon or tuna daily. Or supplement your diet with VECTOMEGA (by EuroPharma). It supplies all the essential fatty acids you need in 1 to 2 tablets a day (instead of the 8 to 16 tablets needed with most other fish oils).

Sea Buckthorn Oil. The berries from this cold weather shrub contain a special essential fatty acid called Omega 7 (along with other helpful oils). Studies show that this littleknown but remarkable nutrient is very effective at improving lubrication throughout the body — helping remedy dry eyes, dry mouth, and even vaginal dryness, while providing the bowel with protection from the dryness of Sjogren's. 4,5,6 I've found that the product Hydra-7 (by EuroPharma) is an excellent source of Sea Buckthorn Oil (take 2,000 mg a day). For those with significant dry eye and mouth problems, this special oil can be a Godsend! A fringe benefit? Stomach, bladder and vaginal symptoms can also improve. Give it 6 weeks to work and 4 months to see the optimal effect (though the benefits often start within a

Evening Primrose oil (or borage oil). In one study, combining this oil with vitamin B6 and vitamin C improved dry eye symptoms in 76% of study participants⁷ (recommended dose 3,000 mg a day). If cost is an issue, you can substitute borage oil, which is less expensive. This oil also helps PMS as well, but is not anywhere near as important as the other two oils for dry mouth and eyes.

Other Nutrients

High-dose B-complex vitamin (50 mg) and magnesium (200 mg). You'll find those dosages in the Energy Revitalization System vitamin powder (by Enzymatic Therapy).

Drops, Drink and Gum

Suck on sugar-free lemon drops or drink sugar-free lemonade (sweetened with Stevia, Truvia or PureVia). The lemon in drops or lemonade stimulates saliva production. But notice I said sugar-free! Saliva protects against cavities, so sucking on cavity-causing sweets when you have dry mouth is a good way to wind up at your dentist's with a mouthful of holey teeth!

mouthful of holey teeth! Chew sugar-free chewing gum. This actually helps protect against cavities. An additional bonus is that it also stimulates bowel function (peristalsis), which is decreased in Sjogren's, causing bowel problems of all kinds. In fact, studies show that simply chewing gum immediately after waking up from abdominal surgery (which puts the bowels to sleep) results in restoring bowel function more quickly, sometimes shaving several days off the average hospital stay.8

Watch your fibromyalgia medications. Many of the medications used to treat fibromyalgia (especially Elavil/amitriptyline) can also worsen the dry mouth commonly seen in FMS (see Treating Dry Eyes and Dry Mouth for a more detailed list).

More Background on Sjogren's

In an autoimmune disease, the immune system mistakenly identifies a part of the body as "foreign" and attacks it. In rheumatoid arthritis, for example, the joints are

attacked. In multiple sclerosis, it's the outer coverings of nerves. And in Sjogren's Syndrome — which affects more than 4 million Americans, 9 out of 10 of them women — the immune system attacks the tear glands and salivary glands.

The result? Dry eyes and mouth — which doctors also call "Sicca Syndrome," whether it occurs because of Sjogren's, fibromyalgia, or everyday life. But Sjogren's can also cause widespread dryness in the body, producing symptoms like difficulty breathing, digestive upset, and poor bowel function.

The Connection to Fibromyalgia

For those with autoimmune illnesses such as lupus, rheumatoid arthritis and Sjogren's, it's critical to understand that it's common for any of these to cause a secondary fibromyalgia. If all the symptoms are blamed on Sjogren's, then the fibromyalgia, which is very treatable, 1,2 may be missed.

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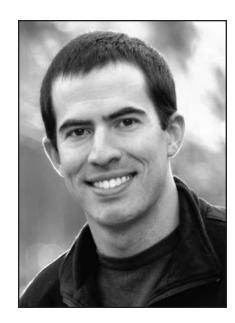
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About the Author:

Jacob Teitelbaum, MD, is a board certified internist and Medical Director of the national Fibromyalgia and Fatigue Centers and Chronicity. He is author of the popular free iPhone application "Cures A-Z," and author of the best-selling book *From* Fatigued to Fantastic! (Avery /Penguin Group), Pain Free 1-2-3 (McGraw-Hill), Three Steps to Happiness: Healing Through Joy (Deva Press 2003), Beat Sugar Addiction NOW! (Fairwinds Press, 2010), and his newest book Real Cause, Real Cure (Rodale Press, July 15, 2011). Dr. Teitelbaum knows CFS/fibromyalgia as an insider — he contracted CFS when he was in medical school and had to drop out for a year to recover. In the ensuing 25 years, he has dedicated his career to finding effective treatment.

Herx Reaction Fundamentals



by Bryan Rosner

You get to see more and more of my book, Lyme Disease and Rife Machines, online for free these days! This post is an excerpt from the book addressing herxheimer reactions, also known as "herx reactions." Have no clue what that is? Keep reading to find out. Believe it or not, the herx reaction is one of the most important topics you will ever study as a Lyme disease patient or practitioner.

Understanding Lyme Disease symptoms

The first step to understanding the recovery process is reviewing the herx reaction. To appreciate the herx reaction, it is necessary to first examine regular, ongoing Lyme Disease symptoms.

Consider what happens when you get the flu: You get body aches, chills, fever, nausea, lack of appetite, fatigue, lethargy, and sometimes additional symptoms. What you may not know is that these flu symptoms are not caused simply by the presence of a flu infection in the body. Symptoms experienced are actually a result of your body's immune system responding to the flu infection via inflammation.

These unpleasant symptoms of inflammation are essential to getting over the flu. Chills are your body's way of telling you to bundle up and get warmer, and the actual shaking involved with the chills is your body's way of increasing core body temperature through motion. After you've bundled up and had the chills for a while, a fever results and your body uses the fever to activate the immune system. A fever triggers a cascade of immune system activities necessary to fight infection. Lack of appetite is your body telling you that there isn't enough energy to process food – all available energy is fighting the infection. Muscle aches, soreness and inflammation are the result of your immune system responding to the infection and your body fighting back.

Without these symptoms present during the flu, your body would not be fighting and you would not get over the common flu.

Because Lyme Disease is an infection, as the flu is, most symptoms experienced by a Lyme Disease sufferer are the body's response to the infection. The spirochetes themselves (their physical presence in the body) are not responsible for the majority of symptoms in Lyme Disease.

As with the flu, symptoms of Lyme Disease are an indication that the body is responding and fighting. Yet, curiously, even in some of the worst Lyme Disease infections, symptoms can wax and wane, even with occasional symptomfree periods. Some people report that when they were first infected with Lyme Disease they were plagued with flu-like symptoms and even bedridden for a while ... and then things seem to get better, and their symptoms became less intense. For example, many people with Lyme Disease are still able to walk around, go to the movies, even work full or part time – all this while they have a raging, active infection which is much more dangerous than the flu. Lyme Disease sufferers often do not get fevers – sometimes are even incapable of getting a fever. Considering that a fever is the body's most use-

is the body's most useful tool in fighting infection, this observation is also peculiar. The flu involves intense, continual symptoms. Lyme Disease often does not.

Lack of debilitating symptoms, absence of fevers, and presence of symptom-free periods may convince a person infected with Lyme Disease that they aren't really that sick. This is an understandable assumption because in most illnesses lack of symptoms does indicate that you are on the mend.

The truth as it pertains to Lyme
Disease is shocking.

Lack of expected symptoms indicates that the infection is actually winning – it is not gone! The body fighting is what causes symptoms. So, if there are no symptoms, there is no fight. The infection has free reign and the immune system is not doing its job. Why does the human immune system fight the common flu but not

Lyme Disease?
What separates Lyme
Disease from the flu is that the

Lyme spirochete tricks the immune system into living in harmony with the infection. The immune system's ability to identify Lyme Disease as a foreign invader is jammed and disabled by the advanced infective activities of the bacteria.

The infection acclimatizes to the immune system.

Lyme Disease researchers have identified many specific strategies employed by the Lyme Disease bacteria to accomplish this. One of the most creative involves the spirochete concealing the part of its bacterial body containing a protein code that tells your immune system it is an invader. Not only can it hide this code, it can change it quickly enough to stay ahead of the immune system recognition process. This phenomenon is called antigen-shifting. The flu virus cannot do this. Other methods of immune system evasion are beyond the scope of this book but can easily be found in other Lyme Disease literature.

The result of the infection's ability to evade the immune system is that the bacteria can proliferate and grow for years without challenge from the immune system.

Enter chronic Lyme Disease.

Although the bacteria are able to persist largely unchallenged, a person will still experience symptoms of disease. People with chronic Lyme

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Disease, although often not as acutely ill as people with the flu, are very sick. In "stealth mode" the Lyme Disease spirochete secretes a neurotoxin that is highly destructive to body functions and can result in stressed liver detoxification, lethargy and fatigue, muscle soreness, mental confusion, emotional instability, hypothalamus dysfunction, and much more. Hypothalamus dysfunction eventually throws off the

thyroid and adrenal glands and other hormonal functions, which results in a cascade of dozens of other symptoms.

Additionally, because the spirochete's evasion is not 100% successful, the immune system may sometimes "catch a glimpse" of the infection, resulting in symptoms of inflammation and immune system activation. A person can experience chills, headache, sore throat, nausea, fatigue, muscle aches, enlarged spleen, cold extremities, etc. The most notable symptoms are typically in the brain. The brain can become inflamed, as it would with any other bacterial infection. Encephalopathy or meningitis may occur, along with very scary brain symptoms including confusion, "Lyme rage," depression, memory loss, etc.

Based on this information, we can establish that the two primary causes of symptoms in Lyme Disease are neurotoxin circulation (which persists despite immune system acclimatization) and inflammation (which decreases as the infection acclimatizes to the immune system). Let's see how this relates to herx reactions.

Understanding the herx reaction

Most Lyme Disease sufferers know of the Jarisch-Herxheimer reaction as a "herx," or "getting worse

> before you get better," or a "healing crisis." The herx reaction is documented to take place in Syphilis, Lyme Disease, and a few other spirochetal illnesses, all capable of evading the immune system. The reaction is named after two scientists who discovered the phenomenon. Adolf Jarisch (1850-1902), was an Austrian dermatologist who published his description of the reaction in 1895. Karl Herxheimer (1861-1944) was a German dermatologist who published his description of the reaction in 1902.

The definition of a herx reaction is an increase in the symptoms of a spirochetal disease (such as

Syphilis, Lyme Disease, or relapsing fever) occurring in some persons when treatment with spirocheticidal therapy is started. In the case of Lyme Disease the herx reaction is an increase in the symptoms caused by neurotoxin circulation and inflammation:

Increased neurotoxin circulation. As you've seen, during normal lifecycle activities, the spirochete secretes neurotoxins. However, when

the spirochete is killed, an intense release of neurotoxins from dying bacterial organisms floods the body. Increased neurotoxin circulation can last from a few hours to a few weeks, depending on the sufficiency of a person's detoxification pathways as well as the extent of the kill-off.

Increased inflammation. Whether using rife machines or antibiotics (or some other anti-Lyme activity), spirochetes will become irritated or killed during the attack. Their delicate, once-hidden antigens (protein codes which alert the immune system to the presence of an invader) will be exposed as spirochetes die and their bacterial proteins enter circulation. Suddenly the immune system will detect multitudes of spirochetes infecting various locations of the body. The immune system was unable to "see" the spirochetes before the kill off, but when the infection does become visible, major immune system activation begins. The body starts fighting during a herx reaction. So symptoms of inflammation increase as they would in the flu. The reaction can vary from person to person, depending on the extent of the infection, location of infected areas, and body constitution. Although the inflammatory portion of the herx response is unpleasant and involves greatly increased symptoms, it is a sign that therapy was successful because spirochetes are dying and the immune system is fighting. Lyme Disease cannot be eradicated if the immune system is not activated.

The combination of the above two events constitute a herx reaction.

After anti-Lyme therapy is stopped and time passes, the herx reaction slowly ends. The bacteria that were unaffected by treatment remain in the body, largely undetected. These bacteria were not affected because they did not happen to be in the spirochete portion of their lifecycle when the treatment took place. The stalemate between Lyme Disease and the immune system will continue after a herx reaction. Only now, some progress has been made. The treatment, in combination with a temporarily activated immune system, has killed some bacteria. Bacterial load was reduced, and consequently the person will experience a decrease in ongoing symptoms of inflammation and neurotoxin circulation. The decrease in symptoms may be subtle because only a small percentage of the bacterial load was pha effected.

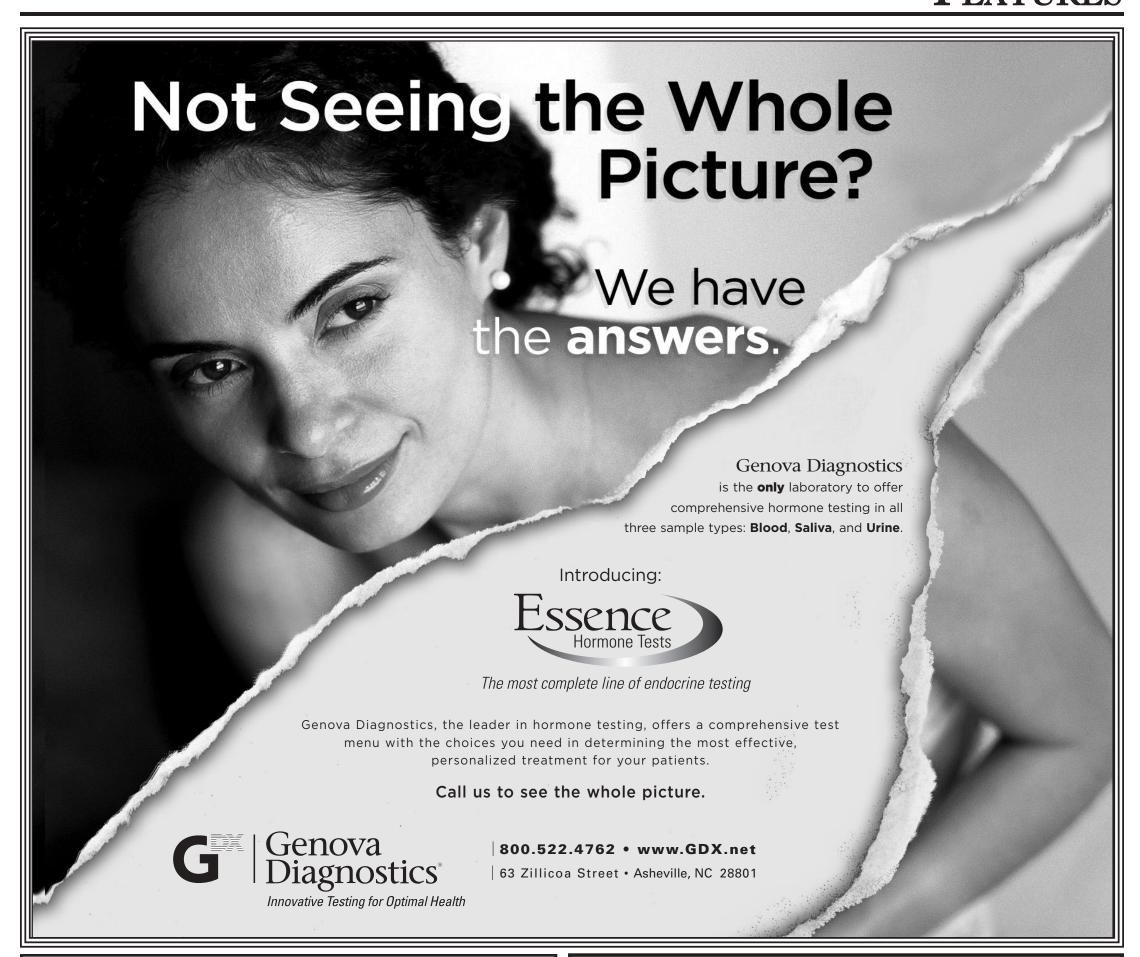
North Texas Area Lyme Support Group

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Biblically-based lyme disease support group to encourage, educate, and inspire those suffering with lyme or have a loved one suffering with lyme disease. This is for bible believers and non-believers. We love and accept all and will not push our faith on you. Come early or stay after group to visit, relax and enjoy some green tea/coffee or a wonderful meal. We look forward to seeing you!

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"Salute': Randy Sykes"... cont'd from pg 5

and emails were sent. It appeared at this time sick people were now choosing sides within the different groups.

In the fall of 2006, I had the pleasure of meeting Randy through another activist. He and I immediately became friends and one day brainstorming along with Kathleen Dickson, we decided to make a site that would actually use their own documents to prove they were lying about the testing. What a novel idea, nobody had done this yet! We used page headings such as "Testing Failure for Lyme disease in their own words."

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

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

Randy offered a \$20,000 reward to be put up on the site. The IDSA claims Lyme disease is cured in 10 to 14 days and the money would be given to any doctor who can prove that Lyme disease is eradicated in 6 weeks. The reward was offered for 5 years on the Lyme Cryme website without any takers.

As of today, most of the world lets their residents treat

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

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

Some groups spend too much time singing their praises that just a few hear and nothing really is accomplished. Now I am not saying that every protest, booth, run or event that a group puts on does not help bring awareness, it all does help...BUT as I have said before, we must all stand together AS A TEAM and be in their faces.

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

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

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

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

2. Conspiracy theory: a theory that explains an event or situation as the result of a secret plan by usually powerful people or groups

3. Theory: an idea that is suggested or presented as possibly true but that is not known or proven to be true

There is NO conspiracy theory about Plum Island, and the current Lyme disease testing criteria set forth by the IDSA; we have all the documents needed to PROVE it is a CONSPIRACY period and that is a checkmate.

It is up to us as a TEAM to make them do something about it. The doctors should be the main TEAM players and step up to the plate and TELL THE TRUTH about the testing. Actually most of them know that the test is bogus as some of the main Lyme doctors attended the FDA and CDC meetings in 1994 when the criterion was changed.

When I asked Randy what he was up to today he said he still takes calls from people looking for answers, some comfort and a joke or two for the soul. "I am enjoying life now, with my grandson," Randy chuckled. "After you are in this struggle for so long and see all the different groups sabotaging each other's work and nothing is going to change, it is time to get out and enjoy what life is left. Nothing is going to change. Most people are like mushrooms, they like to be kept in the dark and covered with manure."

Finally Randy passed the torch in March of this year;



Randy Sykes: Lyme Disease Advocate from Connecticut

he agonizingly closed his monthly meetings. In retrospect, Randy said, "I really thought that if you told people the truth - they would form grass root efforts to work as a team, and boy was I really dreaming. Getting the Lyme groups to work together was

Being an activist/advocate myself, I can say that this statement is true today as it was back then. There are too many chiefs and an abundance of very sick ticked off Indians looking for validation and guidance. For reasons unknown, my personal belief is that some leaders think they or their group can single handedly solve the riddle to this chronic puzzle.

In closing, I asked Randy if there was something he

would like to leave other activists/advocates with, and he responded: "Stay focused, your reputation is everything so remain credible and speak the truth and say only what you can back up with a document."

Thank you my friend for helping so many regain their dignity and most of all their health.

Many people would have never even known they were sick from such a heinous disease without your relentless activism and advocacy.

So Randy, at this time, I raise my glass to you
SALUTE' my friend - job well done!

pha

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Due to the efficacy and the science behind the products, these are my favorites
- Joseph J. Burrascano Jr. M.D.

Immune & Detox SOLUTIONS



Product	Features/Benefits*	Who Benefits?*
Artemisinin SOD™	Features pure artemisinin for optimal immune support plus curcumin, quercetin, green tea, black walnut hull Promotes healthy SOD (super oxide dismutase) levels	Patients needing to promote healthy SOD levels Patients seeking the purest, high strength artemisinin available
Prescript-Assist Pro™	Clinically researched probiotic** Soil-based probiotic, providing beneficial flora the way nature intended – not from milk Contains no antibiotic or hormone residues No potential for lactose-intolerance side-effects Does not need to be refrigerated 100% vegetarian	Individuals searching for a clinically proven probiotic Anyone concerned with milk allergies or hormone-fed cows as the source of dairy sourced probiotics Patients on antibiotic treatment, which destroys both beneficial and harmful gut flora Travelers who want to maintain health while traveling
Transfer Factor Multi-Immune™	Potent, front-line immune system support Formulated with pure transfer factor and the most researched immune nutrients to promote healthy natural killer cell levels, fortify macrophage activity and healthy cell replication Clinically researched**	Those looking for the doctor's favorite immune support formulation Promotes healthy immune system for those dealing with ongoing health challenges, as well as individuals striving to maintain overall good health Travelers who want to maintain health while traveling
Tri-Fortify™	Preferred reduced L-glutathione, the major intracellular antioxidant essential for detoxification Offered in an absorbable liposomal delivery system (liquid) Bolsters antioxidant action Promotes detoxification	Doctors often prescribe to promote healthy detoxification among those with impacted detoxification systems Any individual seeking to supplement the body's detoxification process

Fortifies immune system

**Research Available Online

Energy SOLUTIONS



Product	Features/Benefits*	Who Benefits?*
ATP Fuel™	Optimized energy for serious mitochondrial needs Focuses on repairing mitochondrial membranes and increasing Krebs Cycle energy output Offers the top three energy nutrients and cofactors (NT Factor Energy™ phospholipid delivery system, CoQ10, and NADH) synergistically combined for maximum mitochondrial performance and energy production	Those with compromised mitochondrial function Patients with suboptimal energy levels Athletes undergoing significant physical stress
CoQ10 Power™ 400mg	Recharges the energy system in the heart and the mitochondria Potent antioxidant which promotes healthy cardiovascular and dental health Highest grade and strength in one absorbable softgel	Those with low CoQ10 levels Patients on statins (cholesterol lowering medications), because statins deplete the body's supply of CoQ10, leading to a reduction in energy levels
Energy Multi- Plex™	Non-glandular adrenal support formula, developed to support (but not to over stimulate) adrenals 14 researched nutrients synergistically combined into one formulation	Those needing to nutritionally support adrenals, a condition common among patients facing long-term health challenges
RibosCardio™	Opens ATP pathways to speed up energy production	Favorite of athletes who add it to their water bottles before and during exercise Patients seeking healthy energy levels and who prefer a powder to capsules

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