

The Carousel Network

Chronic Neuroimmune Diseases

Information & Support For Sonoma County

Chronic Fatigue Syndrome (CFS/CFIDS) • Fibromyalgia (FM)

Multiple Chemical Sensitivities (MCS) • Lyme Disease

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Letter from the Editor

This is Pat O'Hara, guest editor for this issue while Carol is on vacation. I am a newbie at the mechanics of putting together a newsletter, so I hope you will go easy on me if you find this issue "different." ☺

For those of us who are dependent on Medicare for helping with health care costs, the recent changes in the Medicare program have been confusing at best. This issue contains several articles about the program changes, how they might affect you, what you should look for in a prescription drug discount card, and how to avoid scams. Please look on page 3 for information on how to obtain a free booklet from AARP about the changes. And if you haven't signed up for a discount card yet, you are not alone. As of June 1, only 400,000 people had signed up for a card on their own (another 2.4 million were signed up automatically by their HMOs).

The Social Security disability process and Lyme disease will be covered at our July and August meetings, respectively. Melissa Kaplan offers articles in this issue on each topic. Her article on documenting your disability is a great reference for anyone applying for, or contemplating applying for disability benefits. Her article on Lyme is an informative chronicle of her journey from disbelief to acceptance of her diagnosis. This has become a hot topic for our group as more of us are being tested for and diagnosed with Lyme or other tickborne illnesses.

See you at the meetings!

UCSF Seeking Volunteers for Study

UCSF is looking for 80 volunteers to participate in a double blind study on a drug called Keppra. Keppra was found to be helpful for fibromyalgia pain in 50% of the participants of a pilot study. The drug is currently approved and used as an anti-seizure medication. Call Courtney at UCSF at (415) 885-7839 for more information.

EEOC Rule on Retirement Health Benefits: Health Benefits Can Be Trimmed or Cut

Marian Eure, www.seniorhealth.about.com/cs/medicare/a/EEOC_rule.htm, 2004

The U.S. Equal Employment Opportunity Commission (EEOC) voted to approve a proposed final rule that would permit employers, under the Age Discrimination in Employment Act (ADEA), to lawfully coordinate retiree health benefit plans with eligibility for Medicare or a comparable state-sponsored health benefit. The new rule would allow employers to reduce health benefits for retirees when they become eligible for Medicare at age 65. A federal court ruling in 2000 said the practice violated the Age Discrimination in Employment Act.

According to Chair Cari M. Dominguez, "This rule is intended to ensure that the ADEA does not have the unintended consequence of discouraging employers from providing valuable health benefits to retirees." But what it does not do is prohibit employers from reducing or eliminating health care benefits entirely from the retirement benefits for the estimated 10 million retirees who currently have health benefits as a part of their retirement packages.

For the most part these employer provided health benefits pick up where Medicare leaves off providing preventive care benefits and prescription drug coverage that Medicare does not presently provide. They also bridge the gap with coverage for Medicare deductibles. Many retirees who presently have prescription drug coverage as a part of their retirement benefits fear that this rule will encourage their former employers to eliminate health coverage for retirees, especially with the passage of the Medicare bill in 2003. This bill provides prescription drug coverage for Medicare beneficiaries, but with higher out of pocket costs than most retirement benefits coverage provides for. Many seniors fear a significant hit to the pocketbook.

This rule change could also prove appealing to cash strapped state budgets; targeting health care benefits for retired state employees could return some monies to the coffers without having to cut services or raise taxes. More significantly it could especially affect those employees who wish to retire early, before they are eligible for Medicare. They could be left without health care coverage in the time between retirement and eligibility for Medicare, drastically changing some plans. A January study by benefits consulting firm Hewitt Associates and the nonprofit Henry J. Kaiser Family Foundation found that employers continued to slash retiree health benefits over the last year, with 10 percent of firms eliminating coverage for future retirees and 71 percent increasing retirees' contributions for their coverage. This rule change may prompt an increase in these numbers.

The seniors advocacy group AARP has issued a statement that voices their disapproval of the rule and calls for more discussion on the issue.

AARP is providing a free booklet, "Medicare Changes That Could Affect You," on the upcoming Medicare changes, including the "voluntary" drug benefit. The booklet can be ordered online at www.aarp.org, or call 888-OUR-AARP (888-687-2277) or TTY at 877-434-7598 to order. It takes 4-6 weeks to arrive. A copy of the booklet is available for checkout by TCN members in the TCN library.

Medicare Officials Recommend Beneficiaries Wait Days, Weeks Before Choosing Drug Discount Card

www.kaisernetwork.org, April 29, 2004

Federal Center for Medicare & Medicaid Services (CMS) Administrator Mark McClellan on Wednesday urged Medicare beneficiaries to wait to sign up for the prescription drug discount card program to see if drug prices offered through the program fall in the coming weeks, USA Today reports (Appleby, USA Today, 4/29).

As part of the new Medicare law, the discount cards will be available beginning May 3 to all beneficiaries who do not have prescription drug coverage through Medicaid. CMS officials have said the cards could offer savings of about 10% to 25% on beneficiaries' prescription drug costs until the new prescription drug benefit takes effect in 2006. Companies offering the cards can charge an annual enrollment fee of up to \$30 and likely will offer savings on at least one drug in each of 209 categories of medicines commonly used by Medicare beneficiaries.

HHS in March approved 28 private companies to offer different discount cards to Medicare beneficiaries. Beneficiaries with annual incomes less than \$12,569 per year for individuals or \$16,862 for couples will be eligible for a \$600 annual subsidy for their prescription drug costs and will not have to pay enrollment fees (Kaiser Daily Health Policy Report, 4/28).

Beginning Thursday, beneficiaries will be able to go to the Medicare Web site or call 1-800-MEDICARE to make card-to-card comparisons of prescription drug prices. By inputting their area of residence, the drugs they take and their income, beneficiaries will be able to see which cards are available, what drugs they cover, as well as prices and annual fees. Beneficiaries also will be able to determine if they qualify for the \$600 subsidy.

Tim Trysla, a policy adviser to McClellan, said that because card sponsors spent millions of dollars to win CMS' endorsement, they will "have to keep prices low and customer service high" if they "want to recoup that investment" (USA Today, 4/29).

McClellan said that another reason beneficiaries should wait to sign up for the cards is that pricing information will be available on Thursday for only 35 of the 72 cards because many sponsors have not yet provided CMS with such information. Information for the rest of the cards is expected to be added by mid-May.

In addition, officials still might endorse more cards, according to the Philadelphia Inquirer. CMS spokesperson Peter Ashkenaz said beneficiaries can wait to enroll until later next month without missing out on available discounts (Loyd, Philadelphia Inquirer, 4/29).

"I think once this price competition starts, some of the cards that aren't offering prices as competitive as the other cards may want to get their prices down. The main thing for [beneficiaries] to know is they don't have to sign up now," McClellan said.

Hotline

Calls to the Medicare hotline are "at an all-time high," with more than 112,000 on Monday and 90,000 on Tuesday, according to Long Island Newsday (Barfield Berry/Mackeen, Long Island Newsday, 4/29). Call volume has increased 150% since April 2003, with more than three million calls in the first four months of 2004. Medicare officials estimate that the hotline will receive nearly 13 million phone calls in 2004, up from fewer than six million in 2003.

To handle the increased volume, McClellan and HHS Secretary Tommy Thompson announced Wednesday that CMS has more than tripled the number of customer-service representatives available to answer questions about the program. Currently, there are 1,400 representatives available, up from 400 before. "Personalized help in choosing a drug discount card will be a phone call away," Thompson said (HHS release, 4/28).

Web Site Under Fire

The launch of the drug-comparison Web site is "the first big-league test for DestinationRx, a little-known company that Medicare hired without competitive bidding to design and run the system," the New York Times reports.

Some critics, including Drugstore.com and PillBot.com, which already run drug-comparison Web sites, question why the California-based company was awarded the 18-month, \$3 million contract without bidding for it.

James Yocum, executive vice president of DestinationRx, which operates an online discount pharmacy service, said the company won the contract because it already had the computer system that Medicare needed. Medicare officials say the contract was awarded without a bidding process because of timing; the new Medicare law was signed in December, and the drug discount card program is scheduled to launch in June. The Times reports that the contract was awarded in December "during a management gap" at CMS -- after the departure of former CMS administrator Tom Scully and before McClellan's arrival.

Drugstore.com says it plans to publish its own comparisons of the Medicare cards and will offer lower discounts.

Gregg James, a vice president at PillBot, said his company also will offer prices lower than those available through the Medicare discount program. He questioned "how much money" the government spent to create a drug comparison Web site that "already exists" in the marketplace (Freudenheim, New York Times, 4/29).

Medicare Beneficiaries Warned About Drug Card Scams

Centers for Medicare & Medicaid Services, www.cms.hhs.gov, April 22, 2004

Overview

The U.S. Department of Health and Human Services (HHS) approved 48 general drug discount cards, including 27 available nationally to all eligible Medicare beneficiaries beginning June 1. With the new cards, Medicare beneficiaries will receive discounts on prescription drugs, and low-income beneficiaries may receive an additional \$600 credit to help pay for their prescription medicines in both 2004 and 2005.

The competition between organizations offering cards — as well as the public display of the prices the cards offer for prescription medicines — is expected to help drive down prices so that seniors get the best savings on their medicines. HHS is offering several tools to help seniors compare and choose the cards providing the best savings when they become available.

But with the announcement of the drug card program, a number of potential drug card scams have arisen in various parts of the U.S. The Department's Centers for Medicare & Medicaid Services and the Office of Inspector General (OIG) are warning Medicare beneficiaries and their family members to be cautious when being approached to buy a drug discount card.

Beneficiaries should NEVER share personal information such as their bank account number, social security number or health insurance card number (or Medicare number) with any individual who calls or comes to the door claiming to sell ANY Medicare related product. If fraud is suspected, the beneficiary should call 1-800-MEDICARE, the OIG Fraud Hotline at 1-800-447-8477 or a local law enforcement agency (such as the police).

Medicare-Approved Drug Discount Card Program

All card programs approved by the Centers for Medicare & Medicaid Services (CMS) will bear the Medicare Rx seal:



Marketing for the Medicare-approved drug discount card program will begin in early May and enrollment in these card programs will begin in May 2004.

Card sponsors will advertise their cards on television, radio, newspapers and direct mail. Approved card sponsors will not conduct any cold-calls, therefore, no individual should receive a call from a card sponsor unless they have requested further information from an ad or direct mail piece.

Potential Scams And What To Do About Them

Although the Medicare-Approved Prescription Drug Discount Card program has not yet been implemented, some Medicare beneficiaries across the country (Alabama, Georgia, Idaho, Maryland, Nebraska, New York, Rhode Island, Virginia) have already received calls as well as in-person solicitations from individuals/companies posing as Medicare officials attempting to gain personal information from beneficiaries with the intent to scam the beneficiaries.

Beneficiaries who are contacted by these false card companies should always remember: The Medicare-approved discount cards are not currently available. The names of the card sponsors were announced March 25th and the companies will begin to market their cards through commercial advertising and direct mail beginning in April.

[TCN Editor's Note: Although cards were not available when this article was originally written, they subsequently became available on June 1. Companies have been actively marketing their cards for several months now.]

A beneficiary should NEVER share personal information such as their bank account number, social security number or health insurance card number (or Medicare number) with any individual who calls or comes to the door claiming to sell ANY Medicare related product.

Medicare is committed to providing information on the approved drug discount cards to help beneficiaries make the selection best fitting their needs. Starting April 29, beneficiaries will be able to compare prices of drugs offered by the drug card programs at www.medicare.gov or by calling 1-800-MEDICARE.

Helping To Fight Fake Cards

In response to these concerns, CMS is:

- Coordinating information with customer service representatives at 1-800-MEDICARE, the call centers at the Medicare contractors and the State Health Insurance Assistance Programs (SHIPs).
- Making referrals to the HHS Office of the Inspector General where there is specific enough information to indicate potential fraud.
- Continuing to explore methods to limit the scope of these scams and developing a process to work with appropriate law enforcement agencies to end these scams.
- Working closely with the Department of Justice, Federal Bureau of Investigation, and the Office of the Inspector General as well as other agencies that have dealt with issues of prescription drug fraud.

Doctors and Disability Letters: Constructing the Framework

Melissa Kaplan, www.anapsid.org/cnd/disability/documenting.html, May 20, 2004

In a perfect world, people who become ill would have unlimited funds to pay for virtually unlimited time when seeing the doctor. In that perfect world, doctors would have lots of time to thoroughly question the patient, probing for impairments and limitations.

Patients would have a limitless supply of money to get all the tests and lab work they needed, along with useful functional testing and neuropsychological batteries their doctors happily order for them whenever needed to diagnose or otherwise try to figure

out what is going on. Doctors would be able to confer regularly and at length with the other practitioners engaged in the testing and treatment of all their patients. All practitioners would have an endless supply of hours to write lengthy, detailed chart notes for each patient.

In case you've just emerged from a cave where you've spent the last 100 years, our world is anything but perfect. The more money you have, the more likely you are to attain the above. Most of the people reading this article, however, live in a very different reality, one in which we struggle daily with illnesses for which there is no long-standing, clearly defined set of tests, nor standardized, highly and always effective treatment protocols ("cookie-cutter" medicine). While there is no end of doctors who will treat us as hypochondriacs, or who will cheerfully refer us to psych services, there is a dwindling set of knowledgeable doctors willing to leap into our abyss.

In the perfect world scenario, when a patient who has become too sick to continue working asks their doctor to write a "disability letter," the doctor would write a detailed letter to an attorney, workers' compensation company, long-term disability (LTD) carrier, the Social Security Administration (SSA), or a human services agency. The letter would describe in detail the patient's limitations and impairments, which would be supported by the extensive documentation in that doctor's files and in the files of the other health care providers the patient has seen for the disabling condition(s).

In that perfect world, where each day is 36 hours long and each week has 10 days, there would be plenty of time for the doctor to spend a couple of hours in intense detailed review of the patient's comprehensive chart, including all the notes from all the other practitioners who are seeing the patient. In that perfect world, the doctor could spend an hour or so dictating the disability letter which would be immediately typed up and sent off via Express Mail or couriered directly to the person or agency needing that letter. And all this work would be done for free.

Documenting Your Disabilities

In our world, the only easily obtained information from most patients' charts is their name, age, sex, and any diagnoses the doctor has clearly noted on his or her hastily scribbled chart notes. Since comprehensive functional, neurological and neuropsychological testing is rarely done, and if done, the resulting reports may never have been sent or given to the doctor being asked to write the disability letter, the doctor is left to create a disability letter virtually out of thin air.

This is not to say that our doctors didn't listen to us when we ran through the disjointed litany of our symptoms and complaints. It is not that our doctors don't believe that we are really so sick and impaired that we cannot hold down a full time job—any full time job. It is just that most of our doctors never get a comprehensive, organized listing of specific statements of problems that not only affect our ability to care for ourselves on a daily basis, but also our ability to function in the working world. You can say "I'm having trouble grocery shopping," but what exactly does that mean to the doctor when it comes time for him to try to explain to a company or agency looking for any possible excuse to deny your disability claim?

Does it mean you take a long time to work your way through your shopping list? Or that you have trouble

discriminating the words on the labels on the shelves? That you can't figure out, even when looking at the information provided by the supermarket, which product is the most economical buy?

Are you in so much pain and having such a decrease in energy and cognitive function by the time you get home, that all you can do is get your bags inside, find and put away all the refrigerator and freezer items, then fall onto the couch or bed, slipping into a fitful, pain-crazed doze for several hours before being able to get up again? Does it mean that it might take you more than a day to get all the non-perishables put away?

And therein lies part of the problem. LTD carriers, SSA, or human services agencies won't approve your claim for disability income insurance or in-home support service benefits because you get fatigued, or because you have trouble walking or you have brain fog. Approval won't be given because of what your diagnosed illness is, or because you can't do your last job. Symptoms and diagnoses only indicate what illness or injury you have, not how that illness or injury affects your ability to function; and do not describe why you cannot hold down *any job in the national economy*.

In a perfect world, people like us wouldn't have to struggle daily with our dysfunctional brains and rebelling bodies *and* have to be a proactive advocate on our own behalf. In the real world, if we do not speak up and do for ourselves, there is rarely any healthy person with the time, knowledge or interest (or compassion) to help us advocate for ourselves, let alone do it all for us.

Thus, it is essential that we recognize and accept that we play a vital role in providing written documentation to our doctors to assist them in doing what we ask of them. We must be the ones to help them document our inability to work and need for assistance, documentation that will help them write the disability letters we need from them from time to time.

Job Functions and Activities

Start thinking in terms of job functions and activities, and what your limitations are:

Sitting

How long can you sit in one place? What specifically happens if you sit too long? How would that affect your ability to work if a job required long periods of sitting time?

When I was healthy, I had two herniated lumbar disks that made it impossible to sit for more than 15 minutes or so. I could stand, so I moved a lectern into my office at which I did 'desk' work and computer work, placing my keyboard on the top.

Now, sitting too long tightens up neck, shoulder, back and leg muscles, requiring lots of stretching and rotational movement every 10 minutes or so, as well as getting up to stretch and move around. In a job setting, this would greatly reduce productivity, and be distracting to co-workers around me. These disruptions would cause me to lose my place in what I was doing, so I would have to backtrack to figure out where I was, and then continue working for 10 minutes until the next flex/stretch/rotate/walkabout break.

Standing/Walking

How long can you stand on your feet, standing still? Walking? Does your pain/stiffness increase the longer you are up? What happens to your ability to think as the time goes

on? Word finding? Being able to enunciate clearly? Follow conversations? Follow directions?

When I was healthy, suffering only from the herniated disks, I could stand for hours, and often did, working in my office, attending meetings, standing at a lectern to make and review notes, pacing the room when listening or talking.

Since I've been sick, being completely vertical causes a drop in blood pressure, which results in pain, starting in my legs and working up, until my entire body is in excruciating pain, more debilitating than the herniated disks. As the pain increases, my cognitive function and fine motor control starts to go. I have trouble following directions, my already impaired ability to write legibly rapidly worsens, and I have trouble finding words.

These reactions to being on my feet preclude me from working at jobs that require a lot of vertical time, such as stock clerk, cashier, sales person in a moderately busy store, or food service.

Following Instructions/Directions

Can you correctly follow simple written directions? Spoken directions? Can you remember a sequence of 5 or more steps to complete a task? Up to five? Do you remember a sequence, but only for a short time? Can you catch your own mistakes? Can you remember a sequence from one day to the next?

In a work environment, tasks need to be done in a certain way and within a specified period of time. If it takes you much longer because you have to constantly re-check the instructions, and then re-check your work to make sure you did it correctly, it is going to take you much longer to do your job than the co-workers doing the same job, greatly reducing your productivity.

Cognitive Function

Cognitive function declines in many illnesses and as a result of head trauma. But the term "cognitive function" itself really says little. We know that the term encompasses everything from not being able to understand the directions of a recipe we've made dozens of times before, to not being able to organize the order in which we will do the errands that need to be done, to using the wrong words when speaking or writing, to looking high and low for our slippers only to come across them in the microwave or dishwasher.

Following instructions/directions and remembering sequences of steps is one part of cognitive function. In the work place, our brain goes to work in many ways that we don't normally give much thought to. Assembling and organizing work materials, prioritizing multiple tasks, and distractibility (getting easily distracted, and/or not being able to quickly re-focus on the task once an interruption is over) are all related to brain function.

So is using a calculator to run simple sums...and not being able to tell if you really got the right answer or not. With many of us, our brain signals sometimes gets scrambled by the time it gets to our fingers, and our eyes see what they expect to see, rather than what is there. Thus the numbers we meant to hit aren't the ones we actually hit, and our brain doesn't catch the error when looking at the display or paper tape. Running the same calculation again and again may not help.

At home, without the time and environmental constraints of the workplace, deducting checks from our running checkbook total may not be a problem. At a job that requires accuracy and maintaining certain levels of productivity, it can result in significant errors and termination due to incompetence. This type of cognitive problem will adversely affect data entry of any kind, as all entry needs to be eyeballed for accuracy and corrected on the fly.

Consistency/Persistence

Can you show up, on time, every workday? Can you remain at your assigned workspace, working productively, throughout your assigned shift, other than normal breaks and meals? For example, your job (not necessarily the one you used to have, but the less demanding ones you've tried working or considered working at as your health has declined) requires you to show up at 8 AM five days a week, and work through the day until the 5 PM quitting time, taking only the permitted breaks and lunch.

Can you make it through the five-day work week? Can you make it week after week? Are you in so much pain and experiencing such decline in brain function that you are unable to make it to work on time—or at all—by day 3 or 4 of the first week? Does this nearly total inability to function take a couple of weeks to set in? Or does your pain and ability to function during both work and off hours degrade so much that you cannot get to work on time?

Can you stay the full day or do you need to take so many rest breaks that your effective workday is shortened to the point of being unacceptable to your employer? Or is your ability to complete your job tasks accurately and on a timely basis so eroded that you are on the verge of (or receive) a disciplinary warning?

Overall Functionality

Chemicals that didn't noticeably affect me when I was healthy now cause symptoms such as headache, breathing difficulties, loss of voice and dizziness. As these symptoms increase distractibility, and often result in an increase in fatigue and pain, my ability to complete job tasks in a reasonable period of time with acceptable accuracy is greatly reduced.

Clearly, one cannot anticipate every single job function of every single job that is out there. But certain things are standard in any job:

- showing up on time every assigned work day, week after week, month after month;
- meeting reasonable personal grooming and dress standards;
- performing all aspects of the assigned job with acceptable speed and accuracy;
- interacting courteously (or at least civilly) with co-workers and others regardless of how one feels;
- being flexible as changes in the workplace or the job function occur, including learning and becoming proficient with new equipment, software, or procedures within the expected period of time;
- getting yourself home safely at the end of each and every workday.

Start Your Documentation Early

It can be horribly depressing to think of all of our impairments and acquired functional incapacities, but it is something we must do, both when we apply for disability initially, and for each review period, when the LTD carrier or SSA orders a review of all the medical records and any changes in function that may reflect someone who is now able to return to work.

Those of us with our collection of diseases and disorders demand a lot of our doctors when we ask them to write a disability letter, because few of us have any disease or condition which makes it immediately clear that we are unable to work at any job. (Being in a persistent vegetative state, or dead, are about the only two I can think of at the moment!)

Developing and compiling this type of information for your doctor is not something you can sit down and slam out in a few minutes. It is something you need to start thinking about and writing down the moment you realize you are having difficulty performing your job functions at work, and taking care of yourself, your family, and your home. If you haven't already started compiling such a list, you need to start once you think or know that you are going to apply for disability.

The longer you are sick, the more things will change, so review the list periodically, and make any necessary additions to it as you think of them. When you are able to go out and do your errands, go to the doctors, etc., think about the jobs people are doing, and think about whether you would be able to do them or not, and if not, why not.

Functional Capacity Survey Forms

In the Disability section of my CND website, I have some forms that may be printed out, filled out, and given to your doctors. They are surveys of functional capacities, but they look more at activities of daily living (ADL) rather than job functions. They are a good start, and useful to fill out at least annually, so you can keep track of changes as your overall health and symptoms wax and wane.

You will need to build your own job functions listing, however, to supplement these ADL surveys. The surveys and your job functions listing will help provide the framework your doctor will need to write the disability letter on your behalf.

Please make sure to give your doctor plenty of time to review your file and supplemental documents, and to think about and write your disability letter. In a perfect world, we would be able to give the doctor several months to research and write such a letter. In our world, we have only a few weeks. Don't lay this on your doctor just a couple of days before the absolutely final-there-are-no-more-extensions-period due date.

You will also find a use for the ADL surveys and your job functions listing in developing your own responses on the forms sent you by your LTD carrier or SSA. Consider the surveys and listing to be a work-in-progress, updating it over time as the physical and cognitive changes caused by your illness evolve over time. Having these documents already compiled when your reviews come due will help—a little—to reduce the stress such reviews will inevitably cause. To view and download the ADL surveys, go to www.anapsid.org/cnd/disability.

Lyme & Other Tickborne Diseases: Alive and Well in the Golden State

Absence of proof is not proof of absence.
—William Cowper

Fourteen years ago, when I was first diagnosed with chronic fatigue syndrome (CFS) and fibromyalgia (FM), part of the diagnostic and clinical evaluation process was to rule out other diseases. Since I worked with wildlife, and had done a fair amount of hiking and a wee bit of camping throughout California, I was tested for several zoonotic diseases, including Lyme disease. I came up negative for all of them except for having antibodies to canine brucellosis (thanks to one of our dogs who came home with "kennel cough" after a short stay at a veterinary surgical clinic).

Since I was negative for Lyme, toxoplasmosis, Q fever, Rocky Mountain spotted fever and all those other icky things, I pretty much ignored them, other than to give lip service to being tested for them when talking to other people who were in search of a knowledgeable physician and proper diagnosis.

Through the ensuing years, I tried a variety of treatment protocols for CFS and FM, and for the other disorders that were found or cropped up as my body continued to function under high physiological stress. There were things that helped—for a while. After making strides towards feeling better and higher functioning, the various diets and chemicals and other protocols just stalled out, or I regressed. We couldn't figure out why, so we kept whittling away, finding new things wrong. My life thus became one of researching new tests and treatment protocols, trying new stuff, having ups and downs, but never really making any progress.

In mid 2002, I began paying more attention to another Carousel Network member, a woman who, years after becoming increasingly ill and initially diagnosed with CFS, was finally properly diagnosed with active infections of both *Borrelia burgdorferi* ("Lyme disease") and *Bartonella* ("cat-scratch disease"). Both of these tickborne organisms commonly share living quarters in the same ticks, and are often found with two other organisms, *Babesia* and *Ehrlichia*.

This annoying person started insisting I look into Lyme disease again, because so many of my symptoms were typical of Lyme. I kept brushing her off, telling her I'd already been tested for Lyme, and was negative. She very patiently went over (and over and over and over again) the facts of Lyme with me and some others on the CarouselNet email list.

The subject of adequate and accurate testing for *Borrelia* is as complex and complicated as the organism itself. The issue is highly fraught and tainted with federal public health agency politics, drug companies' anticipated (and unrealized) profits from their failed vaccines, and national and state medical associations unable to think outside the box their textbooks came in.

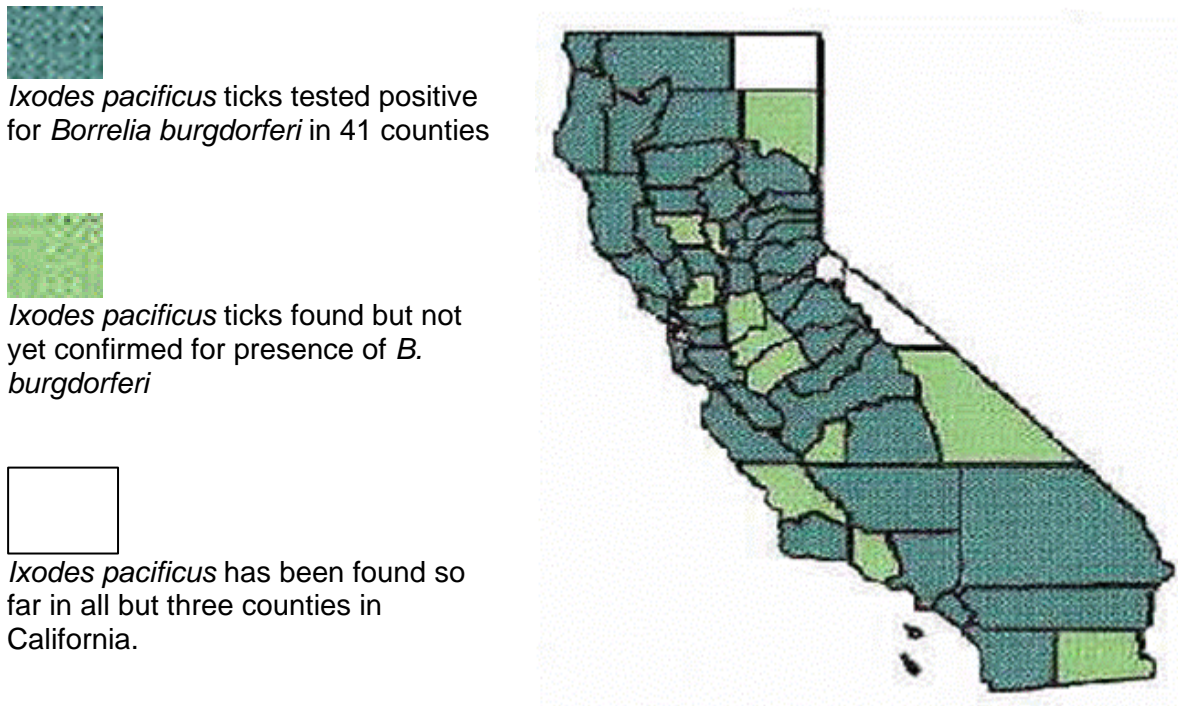
To sum it up very briefly: the tests done by county public health laboratories and general labs like Quest or Unilab, are limited in scope and thus guaranteed to result in a high number of false negatives. Among other reasons, this is because *Borrelia* rapidly

migrates to the brain and body tissues, leaving the bloodstream soon after being injected into the bite wound created by a feeding tick or nymph (a lifestage preceding the arthropod's metamorphosis into the adult tick). So, tests using blood specimens to find the organism are only going to work some of the time. The success of the test is further compromised by *Borrelia*'s ability to change its surface proteins, its shape and form.

Knowledgeable physicians who have been studying Lyme disease (its proper name is borreliosis) know that diagnosis cannot be based on test results alone. Many testing labs, including our own Sonoma County Public Health Laboratory, put a disclaimer on their test results report, stating that the test results themselves should not be the sole basis for diagnosing borreliosis, that the physician must take into account their physical exam and interview findings.

Despite that proviso, physicians are using these test results as definitive: they ignore the patient's symptoms, basing their "You don't have Lyme" strictly on the test results. The counties, states and federal public health agencies are blind to the actual numbers of Lyme disease because they only want to hear about the positive test results, those achieved using the Centers for Disease Control & Prevention's epidemiological criteria. Since this criteria completely ignores the one band specific to *Borrelia burgdorferi*, it guarantees that if *Borrelia* is actually circulating and present in the blood sample, it is unlikely to be reflected in the test results.

That is why it is estimated that only 1 out of every 10 people with Lyme is actually reflected in the state and national health numbers of people with Lyme.



Learn More About Lyme

The Carousel Network (TCN) is presenting a panel discussion on Lyme disease and related co-infections at its August 14, 2004 meeting.

Learn why city living doesn't necessarily prevent your coming into contact with infected ticks, and why not getting a bull's-eye rash after finding a tick feeding on you is not evidence of your not being infected.

Lyme disease and other tickborne infections (TBI) can happen to anyone, at almost any time. Many of us in TCN who were originally diagnosed with CFS, FM, hypothyroid, depression, pain, cardiac abnormalities, and more have turned up positive with one or more TBI. Yes, many of us still have hypothyroid and other disorders that were found along the way towards being properly diagnosed with TBI. What we realize, however, is by not getting a handle on TBI, we will be unlikely to recover as fully as possible by just treating everything else we can through drug and other treatment protocols.

I know a lot of people reading this are skeptical about having Lyme or other TBI themselves, and think that coming to the August meeting, or learning on their own about these diseases, will be a waste of their time and limited energies. I get that. I WAS that. I insisted vociferously for at least a year that I couldn't have TBI. I argued that I had been tested for Lyme and was found not to have it. I argued that a test was a test was a test, so why should I have some specialty lab's expensive test done when I could have the relatively inexpensive County one done. IF I decided to have it done; I felt that getting tested for TBI yet again was ridiculous since I'd already been tested back in 1991 and was negative.

Imagine my surprise when my County Lyme, *Bartonella*, and *Ehrlichia* tests came back negative...but my *Babesia* came back positive.

Looking back on it, I see my stubborn streak rearing its ugly head. It's that same streak that kept me smoking three packs a day for six months after my mother had half her lung removed due to lung cancer. This time, the streak manifested with my asserting, "Well, okay, so I have *Babesia*, but *I still don't have Lyme!*"

Thus it took several more months (February 2003) before I finally started high dose antibiotic treatment for Lyme. I grumbled a bit (okay, a lot). I felt like I was caving in to pressure to undergo treatment because, by that time, I had *two* sets of negative test results, one from the County Public Health Lab (May 2002), and IGeneX's ImmunoDOT Blot (a urine test, with the specimen collected after a one-time major dose of injected antibiotics, in October 2002).

So, imagine my surprise in November 2003, after 7 months on high dose antibiotics for Lyme and another drug for *Babesia*, when my IGeneX Western Blot IgG test came back *positive* for ongoing chronic *Borrelia* infection, and my *Babesia* was, at least for now, back to a "non-infective" level.

So it looks like I really do have Lyme...and so might you or someone in your life. While any discussion about Lyme and other TBI is going to raise as many or more questions than are answered, the presence and prevalence of the organisms and the resulting disease are not things we can afford to ignore.

For more information on the August 14 Lyme Panel Discussion, please visit www.anapsid.org/lyme/panel, or pick up a brochure or flyer at our meetings.

Members of The Carousel Network can check out of our Library a notebook containing many articles and the August 2004 meeting handouts, and a video of the panel discussion. For more information, please go to:

www.cndsinfo.net/lyme

Your imperfections are what make you beautiful.

—Sandra Bullock (Parade)

Not all those who wander are lost.

—J.R.R. Tolkien (The Fellowship of the Ring)

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