

A Feeling for the Organism

by Pamela Weintraub

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One of the great humanitarian physicians, Charles Ray Jones, is a medical maverick who bucks the establishment to treat tick-borne disease in the shadows of Yale. He is a recipient of the Lyme Disease Resource Center's Distinguished Physician Award.

On crisp fall mornings and warm spring evenings, tourists to New Haven crowd the intersection of Broadway and Park. There, by the century-old gothic Christ Church, they steep in a brew of academic cool and kitsch. Students wander the streets clutching cups of Starbucks coffee, stopping to chat on benches or browse for books, designer jewelry and clothes. The Campus Clothing Company sells Yale University tee-shirts, caps, and mugs to gloating parents while students themselves don wardrobes from the Urban Outfitters down the street. It is only in downtown New Haven that a generic Barnes and Noble could have the chutzpah to call itself "The Yale Bookstore," or that casual food joints push the envelope with names like the Educated Burgher and the Ivy Noodle. Walk a few blocks east, and you'll find the source of all the haute and hype: Yale itself, home to the bright hopes and dreams of the well-heeled or simply brilliant, one of the most beautiful and august universities in the world. Ace your high school years with a 4.0 grade point average and 1600 SATs, and you might get to New Haven, too.

But there is another, less illustrious route to New Haven, one requiring no academic credential save from the school of hard knocks. Just follow Park Street back past Christ Church, alongside the filling stations and Laundromats, the dilapidated deli storefronts and the children hanging on stoops. There, in the shadows of the Yale-New Haven Medical Center, in a seen-better-days building more notable for its seventies-style blandness than ivy along the wall, is the first floor office of Charles Ray Jones. Today, at 73, Jones has, by default, become the sole U.S. pediatrician specializing in the long-term antibiotic treatment of the disease called "chronic Lyme."

Often that term is a misnomer, Jones states. The chronic Lyme disease spectrum includes not just *Borrelia burgdorferi*, the bacterial infection known to cause Lyme disease, but a host of other tick-borne germs. At the top of Jones' list for these co-infections are human granulocytic ehrlichiosis, a rickettsial illness, bartonella, a bacterial disease known to gravitate to the brain and central nervous system, and babesiosis, caused by malaria-like protozoa that live in the blood. "The children and adolescents who get sickest, and who are hardest to treat," says Jones, "usually have an immune genetic marker associated with arthritis and more severe disease, or one of the co-infections along with Lyme disease."

As far as Jones is concerned, moreover, children and teenagers treated appropriately usually kick the disease altogether – no matter how sick they may be when they walk through his door. "When it comes to children, at least," says Jones, "the word chronic usually does not turn out to be correct. Because we find that children, when diagnosed with the correct infections and treated with the appropriate medication, do get well."

It is the hopeful attitude and the accolades of grateful parents that keep Jones out of retirement – ten hours a day, seven days a week. Those first visiting the pediatrician may be surprised by the low-key office, hunkered, incongruously, at the end of a long, narrow, dimly lighted hall. The windowless waitingroom is Norman Rockwell-friendly, boasting a selection of gentle watercolors and a Little Tikes Country Kitchen as well as countless books. His suite – including a few exam rooms and an alcove for blood work – also contains a darkened space with couch, blanket, and VCR for kids too cold, light-

sensitive, or exhausted to wait out front. But nothing prepares novice patients for the entry of Jones himself: Making sure to greet each child individually, he typically wears a running suit (acrylic,) trifocal lenses that glaze his eyes, and a spirited, whimsical grin. Limping from old athletic injuries, Jones nonetheless manages to sit the smaller children on his knee and produce a stream of wacky jokes.

Pay too much heed to first impressions, though, and you'll miss the substance beneath. Jones will have read the complete medical history of each new patient – usually dozens of hard-luck pages – and can recite chapter and verse on the child's sequence of symptoms, diagnoses, treatments, and previous lab results. Jones' version of the first exam is a two-hour marathon, in which blood is drawn, a detailed history taken, and every inch of the child evaluated. While most physicians considering Lyme look for a rash and sore knees, decades of treating the most intractable cases on the planet have taught Jones to recognize the more subtle fingerprints of disease. He knows how to seek out over-heated ears, a pain (upon pressure) in the bones and joints of the chest, and the telltale sluggishness of a sick child's gait. Benefiting from this accumulated knowledge and meticulous attention to detail are literally thousands of children and parents – arriving daily at Jones' homey office from around the US and the world.

It was in March of 2000 that Elizabeth Stone (not her real name) of northern Westchester county, New York, finally left her job to hunt, full time, for treatment for her 16-year-old son's "mystery" disease. Resident of a community at the epicenter of Lyme disease reports, with a house abutting a rare spruce forest filled with deer, Stone had first observed a strange, mottled rash on her son's torso in October of 1998. She called her pediatrician, a member of the largest and most respected medical group in her part of the county, asking whether she should come in. "No, don't bother," she was told. In the months that followed the boy proceeded to develop a host of disturbing symptoms: first a severe flu-like illness, then aches in his knees and elbows, finally, an unremitting migraine and marked nausea that never went away. Though Stone requested the doctor perform a Lyme disease test, he insisted the symptoms, in aggregate, were too broad and vague to suggest something like Lyme.

As Stone traveled from specialist to specialist, including rheumatologists and infectious disease experts at the major teaching hospitals of Manhattan, she was given a variety of diagnoses questionable diagnoses from depression and stress to Parvo virus to unending, unrelenting "flu." Stone was fortunate in that her son's psychiatrist, a renowned expert in his own right, did not buy the 'psychiatric' diagnosis favored by the pediatrician or the neurologist brought on board. Responding to the psychiatrist's demand for more lab work, the primary care pediatrician, finally, reluctantly, drew 14 vials of blood. "We are testing for every disorder possible, just to make you feel better, even though there's nothing wrong," he told Stone at the time. But when a Western Blot test revealed 8 positive antibody bands for Lyme disease - the Centers for Disease Control and Prevention (CDC) requires five – the pediatrician still refused to concede Lyme disease was the cause.

Instead, he sent her son on to yet another referral, this time the head of infectious disease at an area hospital. That doctor, well known in the community for his view that Lyme was overdiagnosed, nonetheless agreed Stone's son had slipped through the cracks. The boy had been infected for a year or two, the doctor said, and prescribed four weeks of intravenous Rocephin to treat what he said was now a neurological disease. But when, at the end of the month, the teenager was sicker than ever, that doctor pulled back, too. There was nothing more he could do for the boy, he said – if the treatment hadn't worked, if the boy was still sick, whatever it was, it wasn't Lyme. He now tended to the psychiatric explanation, too. But what psychic switch had prevented this former basketball impresario and straight-A student from standing or even sitting up in bed; from focusing enough to read a paragraph, let alone a page? What caused him to writhe in pain whenever anyone jostled him, to demand near-darkness to open his eyes, or to appear so contorted he might have been struck by a speeding Mack truck?

These were the issues Stone was grappling with when the leader of a local support group steered her son to Jones. “Dr. Jones tested my son not just for Lyme, but for other tick-borne infections, including ehrlichia and babesia,” she says. “When the results came back, Jones called to tell her the boy was positive for all three. Instead of using more aggressive intravenous treatments, as the mainstream had done, Jones used low-dose combinations of targeted medications: doxycycline to treat the Lyme and ehrlichia, and Mepron for the babesia.

“Within two weeks my boy had gotten off the couch and was throwing a basketball in our family room,” says Stone. A year later, he was well. “Had we listened to our pediatrician and the local Lyme disease expert,” she says, “we might have stuffed him full of psychoactive medications unable to address the disease. It would have been tantamount to locking him up and throwing away the key.” Instead, her son is once more a straight-A honors student on the high school basketball team, with hopes of attending college in the Ivy League.

More harrowing is the story told by Kay Lyon, a mother from Wenham, MA, who describes the decline of her daughter until, in the summer of 1998, she was locked in a pediatric psychiatric unit for three-and-a-half weeks. She had just turned nine. “She was paranoid, delusional, psychotic, suicidal, homicidal, and having visual hallucinations while partially blind,” Lyon explains. “She suffered severe confusion, and pain in large and small joints. Because she could not attend public school she was placed in a ‘behavioral program,’ where she was physically restrained and put in solitary confinement almost daily for three months. There she cried, fought with her very real ogres, screamed, beat on the mat which was used to contain her, and finally would curl up in a fetal ball on the cold floor in the corner and sob. My husband found her in this ‘room’ one day and removed her from the ‘school’ immediately. She then spent three months at home with no schooling available for her at all.”

Saddled with numerous diagnoses, including bipolar disorder, attention deficit disorder, schizophrenia, possible schizophrenia, anxiety disorder, and tentative mitochondrial disease, the child was kept in check through psychoactive drugs like Lithium, Risperdal, Tegretol, Topamax, and Klonopin, which caused the gain of massive amounts of weight and kept her brain in a fog. Lyon was frantic. The child’s IQ had dropped 45 points in six months, and a scan with magnetic resonance imaging (MRI) revealed multiple lesions throughout the brain, predominately in the frontal lobes. “Our child was a patient of 16 doctors,” says Lyon, and “none knew what was wrong.”

Desperately searching the Internet for any clue to help, Lyon worked backward from the list of symptoms, and one condition stood out as encompassing all of them: Lyme disease. “Despite this discovery,” she says, “it took four months until I could find a doctor willing to diagnose and treat her for this disease. Most refused to even run a Lyme disease test. Then, Lyon found Jones.” The doctor tested the child, finding not just Lyme disease, but also the co-infections Babesia and Ehrlichia. A little more than two years later, Three years later, treated with long-term oral antibiotics, the child has made a near-miraculous recovery. She is now in a normal sixth grader and, according to her mother, “she even has friends.”

“Dr. Jones is an angel, a living saint,” Lyon says to anyone who will listen. “We owe him our lives.”

Renegade Medicine

These difficult cases and the long-term antibiotic treatments Jones employs to deal with them have made him a maverick, reviled by establishment physicians who hold that Lyme disease is simple, marked by a circumscribed group of symptoms and treatable with four weeks of antibiotic therapy, eight at the outside most.

“I know what they say about me behind my back,” Jones states. “I am highly criticized, and constantly reported to licensing boards. People call me a renegade, a charlatan, a Lyme guru. They say I have a way of hypnotizing parents, that I am senile, or pre-Alzheimer’s, not really a pediatrician at all.”

Yet Jones’ simple lifestyle hardly smacks of the high-roller accouterments one associates with gurus. His two “vacations” this year-included trips to Guatemala to help his daughter adopt a toddler, Julian. To accommodate his arthritis and other disabilities, and to keep costs down, Jones has, since the death of his wife seven years ago, lived in an apartment above his office, in the same nondescript building he spends his days. “When he goes upstairs he opens a can of tuna or even Spam, and that’s his dinner,” says one close colleague who will not be named.

Despite critics’ contention that Jones diagnoses everything as Lyme disease, far-flung interviews with patients reveal the opposite to be true. One mother, for instance, arrived at Jones office after another doctor ascribed her son’s severe gastrointestinal distress to Lyme disease. “Jones was skeptical,” she says, “and insisted we find our own pediatric gastroenterologist without any particular knowledge of Lyme disease.” The doctor the family consulted, an expert at Mt. Sinai Medical Center in New York City, treated the child with weeks of laxatives, resolving the problem and concurring with Dr. Jones – the cause of the distress was not, in fact, Lyme disease.

Another parent arrived when her 13 year-old seemed to have a relapse of his Lyme disease symptoms. Local pediatricians tested him and, finding the serology negative, refused to treat the child and sent him on his way. The mother expected Jones to ignore those test results and prescribe antibiotics nonetheless. That was not the case. Jones sent out for more extensive tests, including DNA analysis by polymerase chain reaction (PCR.) This time the child did not have Lyme disease but, rather, Bartonella, one of the co-infections. Based on the latest peer-reviewed literature showing the antibiotic, zithromax, to be of use, Jones prescribed a short, low-dose course of that medication. In two weeks the boy was well.

While costs for visits to Jones seem high, it’s hard to believe the accusation that he is driven by greed. In a world of cookie cutter medicine defined by insurance company formularies and rigid standards of care, Jones not only spends hours with individual patients, he also treats many at discount, and some for free. In a sense, says Jones, the fees of those who can afford it subsidize the treatment for those who cannot. “How can I send them away,” the doctor says, “when I understand the consequences to a child of that act?”

Medical Ministry

If Charles Ray Jones seems the quintessential humanist to parents, it is because he has been training for years. A first year student at Boston University’s Divinity School in 1954, Jones was drawn to the institution’s commitment to activism and openness. Along with Martin Luther King, Jr., his classmate and friend, he attended weekly meetings with Jewish students from Hillel and learned the value of a world community and civil rights.

But a twist of fate would cause Jones to seek his ministry in medicine, not the cloth. “The divinity school was very much oriented toward social action,” Jones explains. “One afternoon a week we went around to see people who had requested a ministerial visit. One day it fell to me to visit a woman of perhaps 80, a person very much alone not by desire but by default. I found a superbright individual in a body withered by rheumatoid arthritis, reflecting on the past. She came up to me, grabbed my hand, and said, ‘help me in a real way.’ But as a divinity student, I couldn’t provide the help she truly needed - medical help. That’s when I decided to have a different kind of ministry, a medical ministry. I felt that was the way I could contribute best.”

Later drafted into the Army, Jones managed both his passions with aplomb. He secretly left base to march for civil rights with his friend, Martin, even at risk of court martial. And he spent his evenings at Georgia State and Emory University taking courses in pre-med. By the time Jones was discharged from the service he'd married his college sweetheart, Margery, and had a letter of admittance to New York Medical College in New York City. It was 1958, and he was 29.

A natural, Jones was not only president of his medical school class, with a coveted position researching collagen diseases in the school's biochemistry lab, but also recipient of an Arthritis Foundation scholarship and prestigious awards from Merck and Hoffman LaRoche. Upon graduation he became resident, and eventually, chief resident, at St. Luke's Hospital in Manhattan. With an interest in pediatrics as well as research, it made sense that Jones would be attracted to the hot field of the day – oncology – at the top institution of its kind, Memorial Sloane Kettering Cancer Center, in New York.

Doing research at the biomedical juggernaut, it didn't take long for Jones to become world authority on an obscure but confounding disease most Lyme patients have never heard of – Langerhans cell granulomatosis, characterized by lesions in bone and soft tissue. While physicians of the day were treating the condition with whole-body radiation, it was Jones – today, ironically, accused of overtreating disease – who rang the alarm bell that aggressive therapy was far worse than the condition itself. The problem, Jones found, was an entrenched system of classification identifying Langerhans cell granulomatosis as the first stage of an increasingly dangerous disease spectrum, culminating in a deadly proliferation of the body's immune cells.

Working with colleague and fellow-physician Philip Lieberman, the longtime chief of surgical pathology at Memorial, only recently retired, Jones found that Langerhans cell granulomatosis was not malignant, not especially dangerous, and apparently unrelated to the disease spectrum with which it had been linked. Instead, precipitated by toxins or other environmental insults, Langerhans cell granulomatosis was an immune response that could be controlled with low-dose medication, including .methotrexate and corticosteroid. "The most common complication of the disease," Jones said, "came from the side effects of over-treatment itself."

Though Jones' treatment for Langerhans cell granulomatosis today forms the standard of care in peer-reviewed journals, it made him a lightning rod for controversy at the time. Then, as now, the doctor was unfazed by the disdain of colleagues. But as his family grew, there were other concerns. Waking up at 5am each morning to see patients at the hospital, he also conducted ongoing studies at Memorial and tended to a busy private practice in offices on both the east and west sides of town. He rarely arrived home before 10 pm.

"Margery and I thought there must be another way," Jones states. So in 1968, pushing age 40, he packed his bags and his family and headed north -to take over a booming pediatric practice in the bucolic Connecticut town of Hamden, where he hoped for a saner, more manageable life. Little did Jones realize he had purchased not a country paradise, but a residence in the whirlwind, at the epicenter of what would become one of the most bitter medical controversies of the century, the battle over Lyme disease.

Children of Hamden, Children of Lyme

While Jones was settling into his new life as Hamden's gentleman country doctor, an artist and mother an hour north on the Interstate, in the tiny, wooded Connecticut hamlet of Lyme, was doing some work of her own. Afflicted with odd rashes, fevers, and joint pain, the woman, Polly Murray, had begun to notice the symptoms in others -in her husband, her children, and many of their friends. Like the pioneering environmentalist, Lois Gibbs, who documented disease clusters at Niagara Falls' Love

Canal, Murray set out to prove the existence of a disease cluster in Lyme. Going from house to house collecting evidence from neighbors and friends, Murray irked the likes of real estate agents and business leaders, but with her children and their friends so stricken, and eventually disabled, she pressed on.

At the time barely aware of Murray's project, or even the clustered children, the country doctor from Hamden faced a dilemma as well: a new form of juvenile arthritis had mysteriously appeared in and around Hamden, where it struck young patients with disturbing regularity. "It didn't have the deforming characteristics I thought of as rheumatoid arthritis," Jones now says. "I didn't know exactly what it was." But even without a name or suspected cause for the disease, Jones quickly stumbled upon an apparent cure. "By coincidence," he says, "a few of the children with this strange condition also came down with strep. I treated the strep with antibiotics, and in those children, only, the 'arthritis' went away, too."

Though the disease remained unexplained, Jones' clinical strategy could not be more clear: He would track his charges, recognizing 'arthritic' symptoms early in the game, and then treat with a week or two of antibiotics, strep or not. "It seemed to me that on 10-14 days of medication," Jones now recalls, "they all got well." Clearly, he reckoned, he was dealing with an infection. And from the nature of its presentation, he theorized it was transmitted by some sort of insect -in other words, vector-borne.

While the children visiting Jones' practice in the town of Hamden got better, their counterparts in the hamlet of Lyme, undiagnosed and untreated, had no such luck. By 1975 two of Murray's children had knees so swollen they could walk only with crutches, and she finally managed to pique the interest of Connecticut's chief epidemiologist, who sent an investigator -a rheumatology research fellow named Allen Steere, recently arrived at Yale. Trained for years as an epidemiologist at the CDC, Steere embraced the chance to play medical detective again. Devoting himself to the task, he first proved the disease clusters were bona fide and then traced them not to nuclear power plants or toxic drinking water, as some residents suspected, but to the *Ixodes scapularis* tick.

It was around that time, Jones recalls, that he happened to meet up with Steere at the hospital while attending grand rounds and had the chance to chat. "It forms a bittersweet memory in retrospect," Jones now says. "Steere was obviously studying the same phenomenon I observed. He thought the disease was spread by ticks, I thought mosquitoes or gnats. I thought the infection was bacterial, based on the outcome in my practice, but he thought not." They would both be partially correct.

Publishing findings in 1977, Steere reported an illness called Lyme arthritis, characterized by "recurrent attacks of asymmetric swelling and pain in a few large joints, especially the knee." Attacks would last from a week to months with long periods of remission, Steere added, and would typically recur. The precipitating event was a tick bite, followed by the appearance of a red rash with central clearing - to the general population, a bull's eye.

Later that year, in a second publication, Steere replaced the name, Lyme arthritis, with Lyme disease. The reason, he wrote, was an "enlarging clinical spectrum." Studying 32 patients with the same symptoms of erythema migrans, or skin rash, as well as arthritis found in the first study, he now recorded a host of other symptoms: malaise, fatigue, chills and fever, headache, stiff neck, backache, myalgias (muscle aches), nausea, vomiting, and sore throat. He recorded, as well, migratory joint pains, neurologic and cardiac abnormalities, and elevated markers in the blood. The symptoms were so diverse, in fact, that they could not be used, in and of themselves, to pinpoint Lyme disease as the cause, Steere claimed. "The diagnostic marker is the skin lesion," he instructed physicians. "Without it, geographic clustering is the most important clue."

The main difference between the children of Lyme and the children of Hamden, as Jones saw it in the wake of the publications, was that the children living in Lyme were sicker, by far. Thanks to careful tracking and early antibiotic treatment, Jones' regular patients rarely developed advanced forms of the new illness. The untreated children of Lyme, on the other hand, had become experiments of nature: Without antibiotic treatment, their pathology and symptoms progressed to the endpoint, beyond anything Jones himself had seen.

If Jones hadn't yet witnessed the severity of the illness it was because, on the issue of bacterial infection and the consequent need for antibiotics, he'd been right. His hunch was validated in 1981, when Dr. Willy Burgdorfer of the National Institutes of Health's Rocky Mountain Laboratory first identified the spirochetal bacteria that cause Lyme disease. Three years later, the bacterial species, *Borrelia burgdorferi*, was named for him.

With this evidence in hand, the doctors at Yale began to treat aggressively, recalls Jones. And thus, when his patients became especially ill, Jones sent them on to New Haven. There, Yale's experts used heavy antibiotic artillery, including intravenous treatments administered over the course of months, to beat back symptoms of the disease. "One child from my practice had Lyme meningitis, and the Yale physicians gave her two months of IV antibiotics," Jones recalls. "When she remained ill, they gave her two months more." For that particular child, four months of treatment seemed to do the trick.

Trading Places

But then, everything changed. As the eighties passed, the children coming to Jones' practice presented with increasingly severe disease. Often unrecognized and untreated by other physicians, they had progressed beyond the initial, arthritic symptoms of his first patients, manifesting not only the sweep of problems meticulously recorded by Steere, but many others as well. "I found the disease could impact almost any organ of the body, or the whole body, in systemic fashion," says Jones. While many patients presented with rash and arthritis, of course, cognitive and neurological symptoms were increasingly prevalent. Some patients were blind, some so fatigued they could not sit or walk, and some violent, or apparently autistic, or paralyzed by the sudden eruption of obsessive compulsive disorder (OCD.) Depending upon where the spirochetes gravitated in the body, and what particular strain of bacteria was involved, presentation could be gastrointestinal, neurological, cardiac, dermatological, arthritic, urological, ocular, or a combination of these. There might be just a single symptom, such as a severe, unending headache, or a multitude of symptoms, so that a child's entire body was wracked by pain.

At first, Jones continued to treat these children with relatively short-term, oral antibiotics until, one day, a teenage patient with particularly severe disease would cause him to change his mind. Upon hearing his two weeks of medication had come to an end, the symptomatic boy, then 15 but reportedly sick with Lyme since age 10, posed a question: "I'm getting better, but I'm not well yet, so why not just keep giving me the pills?"

Why not, indeed, Jones reflected. He knew from experience, after all, that a complete recovery could be elusive for such children. Often, their state of wellness at the end of treatment was as good as it got; other times, in fact, frequently, children relapsed. The chance of side effects from continuing antibiotics, moreover, paled beside the chance that the boy might actually be right – that continuing medication over a longer time frame might help him continue his recovery. He was still getting better on an almost-daily basis. Why stop now?

Jones agreed to the little experiment, and the boy kept improving – week in and week out. "It took three full years for the boy to become asymptomatic," Jones says, "but we stay in touch, and he has

remained completely well” After that, it became Jones’ policy to treat not for an arbitrary number of days, but rather, until symptoms were resolved, sometimes measured in weeks, sometimes years. One child who came to his practice blind, he says, had his vision come back “one piece at a time” for years. When, every so often, the parent of a still-sick child requested the medication cease, Jones observed, the symptoms that had resolved came back. “But if I treated until every last symptom was gone, the child was cured.”

Treating from the saddle through observation and empirical deduction, Jones viewed Lyme as just a sideline during most of the 1980s. “I still had my regular pediatric practice, and received, quite frequently, referrals for patients with Langerhans cell granulomatosis, my academic expertise.” But eventually, as more and more physicians and parents sent Lyme children his way, the practice changed. “I was the country doctor on a tangent,” he says, and the tangent was Lyme.

As Jones and other physicians treating the sickest Lyme patients expanded their treatment timeline and raised their dosages, as they combined antibiotics to ward off drug resistance and fight a host of co-infections, academic researchers pulled back. One line in the sand, in 1993, was Allen Steere’s publication, entitled “The Overdiagnosis of Lyme Disease,” in the prestigious *Journal of the American Medical Association*. Steere didn’t mention Jones specifically, but the implication was clear: Jones and his ilk were sweeping too many people under the Lyme disease umbrella, then treating with endless antibiotic therapy that just did not work. Another hit came from the Second National Conference on Lyme Disease Testing, sponsored by the Association of State and Territorial Public Health Laboratory Directors and the CDC in Dearborn, Michigan, in 1994. Not only did the voting committee adopt a two-step testing standard that has been called into question by a spectrum of experts, they also removed from the second test -the Western blot-two markers known to be specific for Lyme disease, and especially prevalent in late stage illness. Though the CDC said the Dearborn standard was for research and surveillance purposes only, it was, in practice, widely used to determine or reject the diagnosis of Lyme disease.

As the icing on the cake, academic researchers publishing throughout the 1990s held to increasingly restrictive treatment timelines ranging anywhere between 10 and 60 days. Rejecting the notion that infection could survive the antibiotics, they said that any symptoms remaining after treatment represented permanent damage, or another disorder or disease. In the year 2,000, when the Infectious Diseases Society of America came out with treatment guidelines setting the short-term parameters in stone, physicians like Jones found themselves blatantly bucking the authorities and in direct opposition to the accepted standard of care.

With a new, more circumscribed disease definition and restrictive treatment guidelines published in the peer-review, Jones and his colleagues were increasingly vulnerable – not just marginalized, but now, openly attacked. They were virtually expunged from the peer-review literature. Jones was removed from the roster of medical insurance companies for treating too much Lyme disease and these days, can accept no insurance at all. In Oregon, in Michigan, in Texas, and recently, in New York, Lyme disease doctors with aggressive treatment philosophies have been brought up on charges of negligence or malpractice by state medical and ethics boards. Jones himself, though protected in the state of Connecticut, has, on his desk at any given time, a pile of official complaints made against him by doctors in academic medicine.

Lyme Legacy

Addressing the challenges recently in front of patient and physician supporters at a Lyme Disease Association meeting in Princeton, New Jersey, Jones spoke openly, throwing down the gauntlet and

galvanizing the crowd. “Children with Lyme disease must not become victims of hypocrisy,” he said. “We all know that children with a delay in diagnosis or inadequate therapy can be difficult to treat. No study has ever shown an optimum time for treatment, or that two to six weeks of antibiotics always result in eradication of the bacteria or a cure. But there is ample documentation in the peer-review literature that *Borrelia burgdorferi* spirochetes can survive antibiotic treatment, for one to six months or longer. We know there are more than 300 strains of these bacteria, and that different strains cause different symptoms and require different treatment strategies. Persisting symptoms indicate persisting infection. Children with Lyme disease do not have ‘post-Lyme syndrome,’ psychiatric disorder, or fibromyalgia. They are infected with *Borrelia burgdorferi*, and they have Lyme disease.”

Of course, it helps when preaching to the choir. With his colleagues up on charges and facing potential extinction, is Charles Ray Jones worried? Not really. “If I were younger, if I had children to support or put through college, if my wife were still alive, I’d be scared as hell,” he says. “But here in Connecticut, the attorney general is enlightened, and most complaints against me are thrown in the trash.”

Besides, he contends, the winds of change are blowing, though most are unaware. Starting the week the New England Journal of Medicine published a study dismissing long-term treatment for chronic Lyme disease, in 2001, Jones says, he has received a steady stream of calls and queries from physicians supposedly ensconced on the “other side” of the fence. Mostly infectious disease specialists from the very teaching hospitals known for narrow diagnostic standards and restrictive treatment protocols, the callers have expressed alarm at the swing of the pendulum over the troubled landscape of Lyme.

The calls are secret, Jones says, the callers still “in the closet” when it comes to Lyme and other tick-borne disease. Yet week after week for months now, these “closet” practitioners have been sending sick children through New Haven’s back door, to a dim and narrow corridor and the homey, cavelike office of a grandfather in a running suit, Charles Ray Jones. Blind and crippled, nauseous and aching, unable to tolerate noise and light, to focus, or to effectively learn, these young patients have been burdened with incurable diagnoses like fibromyalgia and chronic fatigue syndrome. Deemed untreatable, possibly psychotic, by family pediatricians and the high priests of academia, they are headed for the trash heap of throwaway children – with one last-chance stop to see Jones. They continue to arrive despite his notoriety because, quite frankly, they have nowhere else to turn.

But how long can a lone septuagenarian keep his finger in the dike? Can he do more – affect true change – by transmitting his knowledge to the world? Jones’ decades of clinical experience have never been committed to writing or taught outside his small circle. And while he has the monopoly on a burgeoning market – Lyme disease in the U.S. is at an all-time high – he cannot find a young physician to work by his side full-time and commit to assuming his practice when he’s gone. With his colleagues under investigation, their careers in peril, an heir may be hard to find.

One ray of hope comes from the newly established Charles Ray Jones Endowed Student Fellowship at Columbia University, which allows him to train one medical intern in his practice each summer. In 2001, it was Megan Peimer, a second-year medical student at Columbia College of Physicians and Surgeons, who worked alongside Dr. Jones. Peimer, who also spent her time absorbing the peer-review literature on Lyme disease and writing up Jones’ classic cases, says her hope is to foster a more rational attitude about tick-borne disease. “Lyme is a very complex entity,” says Peimer, “and Dr. Jones is one of the only physicians I have seen or heard of to amass a clinical knowledge of it in terms of kids. He refuses to blanket his specific observations and individual patients with general pronouncements from journals, or to relinquish intellectual rigor to follow the crowd. He has a dedication to teasing out the etiology for each patient and situation, to synthesizing his knowledge and observations, and to treating based on hard facts.”

Will Peimer specialize in Lyme disease? “I’m devoted to international medicine,” she says, “but when a child with Lyme disease comes to my practice, thanks to Dr. Jones, I will know how to recognize it, and I will know how to treat.” Peimer believes the true value of the fellowship will be to spread Jones’ knowledge wide, resulting not in the creation of one or two more Lyme disease physicians but rather, many physicians who understand Lyme disease.

Jones is admired, as well, by other MDs treating patients with chronic tick-borne disease. “I have had the chance to observe him examining patients, and he’s a highly astute clinician. The way in which he interacts with children is absolutely wonderful,” says Kenneth Liegner, a physician from Armonk, NY.

“Dr. Jones is an international treasure – a courageous, selfless, inspirational, and outstandingly gifted clinician who has helped thousands of the most severely ill children with Lyme Disease from around the world to regain their health and their lives,” says Brian Fallon, associate professor of clinical psychiatry and director of the Lyme Disease Research Center at Columbia University. “He embodies what we all wish for in a doctor and in a human being.”

Is Charles Ray Jones worried? Not at all. “I don’t know everything,” he says, “but when I have reason to know I am right in medicine or anything else, I will follow what I know.” Defining himself as a warrior for his beliefs, Jones glances out the window of his ground level suite. “I am established enough to withstand the slings and arrows from across the way,” he states. “Besides, I can sleep at night. I just hope for their sakes they are sincere in their stated belief that Lyme disease can always be treated short term,” And then he is silent, as if issuing a prayer for their souls.

Pam Weintraub is a former staff writer at Discover, former editor-in-chief of Omni Internet, and the author of 15 books on health and science. Her new book, Cure Unknown: Inside the Lyme Epidemic, will be published in May, 2008.