

## Environment

# Lyme disease politics put patients at risk

by Suzan Erem

In the summer of 1998, Emily Steffensmeier came down with a strange and nasty flu, an overwhelming fatigue and shortness of breath.

Steffensmeier had just graduated with a degree in psychology and medical humanities and returned home to State College for a new job. She was in her early 20s but she felt decades older. Even after the flu-like symptoms passed, she felt worse than ever, so she asked local doctors what was wrong with her.

"You're anxious and depressed," one told her.

"You're not ready for the real world," another said.

Get a job, get a boyfriend, get some exercise, others told her.

Steffensmeier had to resign from her new job. She could barely pull herself out of bed. Her joints were inflamed.

"It's fatigue on a whole different level than I've ever known in my life," she said. "You're like waiting for wet cement to just move...I'm just trapped in this body."

After six years of traveling around the country to specialists, Steffensmeier met a doctor from a respected medical university

who ran an extensive battery of tests. The doctors at this university are not known to jump quickly to a Lyme disease diagnosis, she said, but when they removed Steffensmeier's gall bladder and her condition worsened, her doctor finally concluded it was Lyme disease.

"He was amazing, amazing, amazing!" Steffensmeier said. "I couldn't ask more from him."

Yet Steffensmeier asked that Voices not print his name or his institution for fear that medical examiners would come after him for medical misconduct. Diagnosing some Lyme cases can get a doctor in big trouble these days, and many keep what they know under wraps.

Ann Corson, a medical doctor in Cochransville, Pa., learned about the insidious nature of the disease when she had her own personal experience with Lyme.

"I consider myself a good diagnostician and it took me two years to figure out why my only child was dying," Corson told Voices. "That doesn't mean there's something wrong with me; it means there's something wrong with my education."

see Lyme disease, pg. 14



Photo by Kelsey Stratton  
Emily Steffensmeier receives her intravenous antibiotic treatment her mother, Renee Steffensmeier. Emily is on a multiple-year antibiotic treatment for Lyme disease.

## Effort begins to 'transition' State College to lower fuel use

by Melady Kehm

Centre County may someday experience a "great unleashing," but if previous unleasings are any indication, it won't be painful.

"The Great Unleashing" is the somewhat whimsical name given to a formal but fun public unveiling of a local project designed to take a community into a "powered-down, post-petroleum" future. It is step four in a twelve-step path to becoming a "Transition Town" (also termed a "Transition Initiative"), a process laid out in *The Transition Handbook*, by Rob Hopkins, published in 2008. The book was written following the early experiences of Totnes, England, the first-ever official Transition Town.

"A future with less oil could be preferable to the present, if we plan sufficiently in advance with imagination and creativity."

--Rob Hopkins, author of *The Transition Handbook*

Rob Hopkins "has found a way for people worried about an environmental apocalypse to invest their efforts in ongoing collective action that ends up looking more like a party than a protest march," writes the Post Carbon Institute's Richard Heinberg in the foreword to *The Transition Handbook*.

Hopkins, father of the Transition Movement, says his book is underpinned by "one simple premise: that the end of what we might call The Age of Cheap Oil (which lasted from 1859 until the present) is near at

hand, and that for a society utterly dependent on it, this means enormous change. But a future with less oil could be preferable to the present, if we plan sufficiently in advance with imagination and creativity."

"This is not a book about how dreadful the future could be," Hopkins writes in his introduction. "Rather it is an invitation to join the hundreds of communities around the world who are taking the steps toward making a nourishing and abundant future a reality."

There are hundreds of communities more than 275 in 16 countries, more than 60 in the United States at this writing—each charting its own way through the handbook's path to that abundant future. Pennsylvania's southeast borough of Media was the Commonwealth's first Transition Town, the United States' 35th and the world's 195th.

State College resident Bill Sharp would like to see his own town pursue a Transition Initiative. He recently was joined at a Transition training session in Pittsburgh by Joshua Brock, new Centre County resident developing a community-supported-agriculture venture, and Kevin May, a Penn

see "Transition," pg. 18

# New Raystown Lake trails hosting Dirtfest in May

by Shannon Cotrell

On the weekend of May 9, 2009, over 400 cyclists came to Raystown Lake to celebrate the grand opening of the Allegrippis Trails, a 32-mile network of multi-use trails on 2,500 acres of publicly owned land that is managed by the Friends of Raystown Lake. The trails were a big hit for a number of reasons, but two features that seemed to stand out most were how dry they were after several days of hard rain and how much smoother they are than many Pennsylvania bike trails.

This May, just over a year after the grand opening of the trails, Raystown Lake will host Dirtfest 2010, three days of mountain bike-related activities to raise awareness about mountain biking.

Evan Gross, president of the Raystown Mountain Bike Association, estimates that between 35 to 45 exhibitors and 800 to 1200 people will attend the event, which begins May 21. He added that a couple of weeks later the trails will host a stage of the Trans-Sylvania Mountain Bike Epic, a seven-day mountain bike stage race held in several parks near State College from May 30 to June 5.

An immense amount of work and careful planning went into the construction of this model trail system.

"Many of the bike trails in Pennsylvania were designed for other activities and weren't made with long term use in mind, but the Allegrippis Trails were designed to be used by cyclists and to be sustainable with minimal maintenance," said Frank

Maguire, the mid-Atlantic regional director of the International Mountain Bicycling Association (IMBA).

This ethos of sustainability is evident in IMBA's efforts to design trails that minimize the environmental impact of human traffic.

"We didn't want the trail system to be a burden to the resources, the land manager or the volunteer clubs that work to sustain it. If the trails are built right, they will keep people from straying off into environmentally sensitive areas," Maguire said.

Similar consideration was given to the way the trails respond to water. The 36-inch-wide "bench-cut" paths that comprise most of the trails are higher on one side, which helps water to sheet off the trails quickly and prevent it from pooling. Along many of the steeper sections of the trails, numerous humps and dips slow the flow of water to prevent it from carving ruts and minimize erosion.

These quick grade reversals have the added benefit of creating a rollercoaster-like ride, as do the many in-sloped turns on the trails which, unlike switchbacks, allow cyclists to carry their speed along the contours of the Allegrippis Ridge, towards lower elevations.

The trails are arranged in a series of relatively short loops that are connected by spur trails and offer a seemingly endless variety of combinations. This "stacked loop" format provides visitors with excellent access to remote areas of wilderness and impressive views of Raystown Lake while remaining relatively close to the trailhead.



Photo by Shannon Cotrell

Evan Gross cleaning a fallen tree from the trail.

Although one would have to ride approximately 45 miles to cover the 22 trails that make up the trail system, the trail distance back to the nearest trailhead is always less than six miles, and even shorter when using one of the intersecting service roads.

Navigating the trails is simplified by the presence of maps and signs analogous to those used at most ski areas. Yet, whereas a black ski run is typically steeper and faster than a blue run and much more so than a green run, the topography and grade of the

Allegrippis Trails doesn't differ much from one trail to the next. According to Allen Gwinn, a ranger at Raystown Lake, the reason the trails farthest from the parking lots are marked black is that you have to travel greater distances to reach them. So, while a black trail such as "Ray's Revenge" may sound more intimidating than "Doe" or "Fawn" (both green trails), the degree of

see Trails, pg. 19



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# Now is the season to identify a myriad of warblers

by Alice L. Fuller

It's warbler time. Mid-May is considered the peak of the bird migration and specifically the warbler migration. Thirty-five species of warbler can be found in Central Pennsylvania, plus two or three others that are considered accidental. So many kinds of warblers plus the vast numbers of individuals that sometimes swarm through our woodlands is enough to make the beginning or casual bird watcher throw up his or her hands in despair and ready to forget the whole lot of them. But don't!

Sorting out the warblers is a challenge and there is great satisfaction in identifying and beginning to know each individual warbler species. Perhaps the best way to start learning warblers is to begin with the ones which nest and spend the most time in our area. A good time to do this is after the main migration is over the latter part of May. Continue to look for them into the summer months.

A very good starting place is to search for one of the most abundant of our warblers, the common yellowthroat, such, as the one sketched by Dorothy Bordner.

Yellowthroats are partial to thick cover of bushes, shrubs and weeds. Males are easily identified by their black masks and rich yellow throats. It is a nervous, active little bird and reminds one of a tiny "bandito" forever playing cops and robbers. The yellowthroat usually gives away its location with an emphatic "witchity-witchity-witchity-witch" song.

The yellow warbler is another common species of shade tree, orchard and shrubbery,

Sorting out the warblers is a challenge and there is great satisfaction in identifying and beginning to know each individual warbler species.

often residing in back yards and gardens. It is an all yellow bird and a close look may reveal the chestnut-red streakings on the breast of the male. It is easy to distinguish from the goldfinch, which has a black cap, wings and tail.

Another common warbler is the chestnut-sided. It is partial to cut-over wooded areas or slashings, tangles of brush and brier such as those found under powerlines and shrubby roadsides. It is a handsome warbler with yellow crown, white underparts and bright chestnut streaks on its sides. Also listen for its out sized song which sometimes goes "Sweet, sweet, I'll switch you."

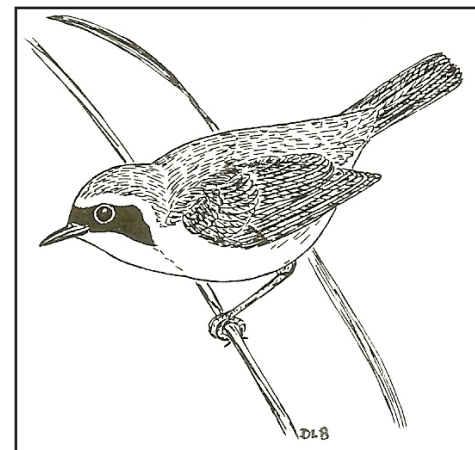
These three warblers make a good beginning list of warblers and will help kick off a warbler identification career. Then one can search out the woodland residents—the black-and-white warbler, redstart, ovenbird, blackburnian and black-throated green warbler. Next visit Stone Valley or the Barrens and hunt for the pine, prairie and golden-winged warblers.

Have fun finding one of the strangest warblers, the curious, crazy yellow-breasted chat. Now progress to some of the common migrants such as the yellow-rumped warbler, and brilliant ones like the Magnolia warbler or some of the harder to find resident warblers. Bit by bit you will be prepared some spring for the annual invasion of the many, colorful little migrants, often called the "but-

terflies" of the bird world.

In Todd's "Birds of Western Pennsylvania" there is a lovely description of warblers written by Elliott Coues. Part of it goes like this:

"Some warblers flit incessantly in the terminal foliage of the tallest trees; others hug close to the scored trunks and gnarled boughs of the forest kings; some peep from the thicket, the coppice, the impenetrable mantle of shrubbery that decks tiny water-courses, playing at hide-and-seek with all comers; others more humble still descend to the ground, where they glide with pretty mincing steps and affected turning of the head this way and that their delicate flesh-



tinted feet just stirring the layer of withered leaves with which a past season carpeted the ground...They peer into the crevices of the bark, scrutinize each leaf and explore the very heart of the buds, to detect, drag forth and destroy those tiny creatures, singly insignificant, collectively a scourge..."



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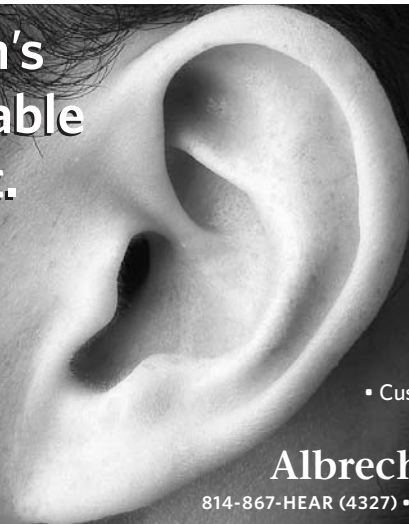
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from Lyme disease, pg. 11

Corson said she had removed a tick from the ear of her 14-year-old son and done what her training told her to do: watch and wait. (Lyme is transmitted by deer ticks which are not much larger than the head of a pin.) But no rash and no flu-like symptoms appeared. She thought he was in the clear. But for the next two years, this normally healthy boy complained of pain, illness and fatigue. When Corson finally learned about long-term Lyme disease, she hit the ground running, calling all the experts, launching a physician training program and opening up her practice to Lyme patients. Soon she had a waiting list 18 months long and had to stop taking new patients.

Gail Sheffer still travels two hours from Harrisburg to Corson's office for every appointment.

Sheffer, her husband and her two daughters have all had Lyme, but only she and her husband are still dealing with it. Their daughters have been cured.

"We have several co-infections; not only Lyme but a few other tick-borne diseases were found. There's one that seems to be troublesome for me," Sheffer said.

Sheffer used to hold down a full-time job in human resources for the Navy. Now she's on disability. Her husband is self-employed and works around his bad days, she said.

Like Steffensmeier and many others, Sheffer's initial tests for Lyme came back negative.

"The two doctors I went to tested me for Lyme two times, sent me to a rheumatologist who did a full work up, but my blood work came back negative for Western blot," Sheffer explained. Western blot is a more advanced blood test for Lyme. "I asked, 'What do you think about Lyme?' and he said, 'You can't have Lyme; you don't have any swollen joints.' That's when I knew he didn't know what he was looking for."

Sheffer did her own research on the Internet and narrowed the possibilities down to lupus or Lyme. Then she found a support group in Gettysburg.

"When I told my story and my symptoms, they said, 'You sound just like us,'" she said of members of the group. "Then I felt like, 'Whew, somebody has a clue.'"

Then there is Mary Wagner of Huntingdon County. She and her husband Ron knew something was wrong when she woke up one morning with balance issues and slurred speech. They thought she had had a stroke.

Ron said they also suffered through many visits to many doctors, sometimes painful testing and many misdiagnoses.

"I've tested you for everything I can test you for," one doctor told his wife. "And I've concluded it's all in your head. You need to see a psychiatrist."

Ron said it was the psychiatrist who took Mary off of antidepressants and sent her to a new neurologist who had her tested for Lyme. That was a year and a half after her symptoms surfaced.

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In 2009, Pennsylvania ranked first in Lyme disease cases and has consistently ranked among the top five states in recent years, according to the Centers for Disease Control. These stories of multiple doctors, diagnoses and treatments over many years are the stories of thousands of people, many of them Pennsylvanians. The numbers continue to rise.

Patients describe symptoms of long-term Lyme that include intense pain roaming from joint to joint within hours, pain in the larger joints, a brain fog, abdominal pain, problems swallowing, a tremendously sore neck and a variety of vicious headaches.

Sheffer added panic attacks and stabbing or stinging pains in fingers and feet. At the time, she attributed some symptoms to menopause, the rest to getting older, but they just began to pile on.

"When I got treated the panic attacks went away," Sheffer, who is still taking antibiotics and anti-malarial drugs, said. "My energy level has come back, though I did relapse in 2008, it's still much better when it was in 2004 when I was sick and undiagnosed. I have less pain, though I still have pain. I still get some headaches but not as many, and the night sweats have ended."

Lyme is often misdiagnosed as a psychosomatic disorder, Chronic Fatigue Syndrome, mental illness and in its advanced stages, after it has attacked the central nervous system, Multiple Sclerosis.

see Lyme disease, pg. 15



Photo by Megan Sheffer  
Gail Sheffer displays some of the many medications she has been prescribed for treating long-term Lyme disease.

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from Lyme disease, pg. 14

In fact, the moving target of symptoms caused Mary Wagner's doctors to blame Lyme disease long after, it seems, Lyme was no longer the culprit. Mary died in 2009 awaiting tests for an unrelated medical condition. In her case, opposite of most long-term Lyme patients, Lyme disease contributed to her death because doctors refused to consider anything else, her husband said.

In 2008, the CDC received 35,000 reports of Lyme disease cases, a 30 percent increase over the previous year. But the CDC admits that the number of unreported Lyme cases could be six to twelve times that figure.

**Defining Lyme**

Why there are so many unreported cases begins to tap the root of the problem.

Many medical doctors treat most infectious diseases in the United States based on standards and definitions determined by the Infectious Diseases Society of America, a well-established group of academic researchers from around the country. Health insurance companies, for one, often use IDSA guidelines to determine what diseases and treatments they will cover.

The IDSA has determined that Lyme disease is "hard to catch and easy to cure." The researchers claim all Lyme disease cases begin with a tick bite that gives the patient a bull's eye rash (white near the center with a red ring around it) that can be treated with two to four weeks of antibiotics and cured.

But many patients have never seen a tick or a rash.

"Here we are the worst state in the nation and doctors are misdiagnosing it all the time."  
--Dr. Ann Corson

"The more people that join our support group, the more say I don't know when I was bitten, I never saw the tick, I didn't get a rash," said Steffens, who founded the group and has won a national award for her advocacy. "But then they'll start saying, 'You know about two years ago, I had a swollen knee or this wrong or that wrong.' They can remember a certain time before they really got sick that something started happening."

Doctors with clinical, or patient-based, experience are saying they are hearing the same thing from their patients around the country. Additionally, they say this Lyme often goes undetected and the longer it does, the more damage it inflicts. They say long-term Lyme requires multiple years of heavy doses of antibiotics to begin to reverse the damage. But doctors who treat patients this way risk professional alienation, high expenses and even the loss of their licenses.



A "bull's eye rash"

"Here we are in the worst state in the nation and doctors are misdiagnosing it all the time," said Corson. "They have patients coming in with typical symptoms of co-infections and they don't even know the co-infections exist. I came from the same Ivory Tower background as the IDSA doctors and the only reason I figured it out was because I opened my mind to a nonmedical person, and my son was dying."

After medical boards began charging high-profile doctors with inappropriate treatment, a second group of doctors grew into an organization called the International Lyme and Associated Diseases Society. Their clinical experience tells them that the bacteria that causes it is now showing up disguised and paired up with other similar bacteria, generating new symptoms that overlap with even more illnesses. Many of their patients never saw a bull's eye rash, the supposed tell-tale sign of Lyme, experience supported by a 2003 study published in the American Journal of Medicine that concluded only 35 to 59 percent of Lyme patients get the rash. And many were not diagnosed early enough for a month of antibiotics to be effective. They treat their patients instead with two or three years of antibiotics, and if they stop treatment early, they see symptoms return.

William Ayoub, a rheumatologist at Geisinger Medical Center in State College, sounded astonished at the idea of treating a Lyme patient for years with antibiotics. He said such long-term treatment is unnecessary.

"You have to take every situation based on the facts that are there," he said. "I have never found that I have needed to treat anybody for more than a month for Lyme disease. The bacteria is killed, but sometimes the person can still have a problem after the spirochete is gone."

Steffensmeier told Voices one intravenous antibiotic treatment can put her out of commission for three days. Her mother, a retired Penn State professor who works part time at Schlow Library, cares for her at

**Protecting yourself from Lyme disease**

- Keep lawn mowed and bushy areas cut back.
- Remove brush and leaves from areas near your house.
- Inspect pets before they come inside.
- Try Damminix: cardboard tubes with cotton balls treated with permethrin—mice take them to their nests, where permethrin kills ticks but not the mice (deer ticks spend the first year on mice before progressing to deer).
- Have some parts of your yard sprayed with permethrin.
- Use a blanket to sit on the ground or fallen logs.
- Walk in the centers of trails.
- Wear light-colored clothing (ticks show up better) and tuck your pants into your socks.
- Wear (light-colored) gloves when gardening or touching bushes and plants.
- Wear Rynoskin protective underwear.
- Spray your clothing and shoes with permethrin tick repellent.
- Use DEET.
- Do a careful tick check when returning indoors.
- Wash and dry your clothes immediately. Don't let them lie on the floor: a tick might be attached and get loose in your house.
- Even better, spray your clothes with permethrin and place them in a sealed trash bag before washing.

Source: Lyme Disease of Southern PA



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see Lyme disease, pg. 16

from Lyme disease, pg. 15

home, while her father, who still works at Penn State, provides for her healthcare costs above those covered by Medical Assistance. This last summer she was better than she had been since 2005, she said, but success was defined by small victories.

"I just noticed how I could be on a computer and write a blog and be focused on it," Steffensmeier said. "I could talk on the phone and not be totally exhausted. It was an improvement in energy, focus. I could sit up longer, could do more on my own without getting exhausted." Her mother would push her around in a wheelchair in the local park, and that would be a good outing.

But her stomach hurt all the time, so her doctor pulled her off the heavy-duty antibiotics to see what would happen.

"Now I'm just at home all the time. So that break, going off of them, that's when I could say, 'Oh wow, I really was making

At issue is the very credibility of the IDSA, which activists say holds much sway over the medical establishment.

progress." Steffensmeier is back on the treatments, but she was hesitant to name the local doctor who is monitoring her treatment for fear the doctor would be targeted.

Sheffer defines her progress in similar small steps.

"It took me three years before I got better and could get off meds," she said. "Then I had almost a whole year being symptom free. I could do everything I had been able to do. It meant everything to be able to wash my car, mow the yard and then come in and make dinner. [Before then] I used all my energy for menial things like taking a shower and making food."

**The politics**

The passion on both sides of the debate is

palpable as this fight enters its second decade. ILADS, the long-term Lyme disease group, has waged a tireless battle to have the IDSA definition rewritten. Their efforts hit another roadblock April 23 when, as reported by the Hartford (Conn.) Courant, the IDSA reiterated its definition of Lyme, limiting it to short-term antibiotic treatment, which in practice excludes many patients' current treatment program from being covered by health insurance.

At issue is the very credibility of the IDSA, which activists say holds much sway over the medical establishment. A 2001 Lyme Disease Association report carefully details extensive conflict of interest potential in the development of a Lyme vaccine. Included in a long list is the Penn State

Research Foundation, owner of a patent for a vaccine delivery system estimated to be worth \$900 million per year.

According to the 186-page report, a lively debate occurred in 1994 at an important meeting of experts in Dearborn, Mich. A close vote resulted in the narrow definition of Lyme that exists today as standard, a definition that Lyme activists say impacts the profit-making power of Lyme vaccine developers. If everyone could agree on what Lyme disease was, then everyone could agree when a successful vaccine was eventually developed for it. But if Lyme continued to morph into more and more complicated copy-cat symptoms, no one could ever make a vaccine that would convince the FDA to approve it. Worse, if long-term antibiotics with expired patents could cure the worst cases, millions of dollars in vaccine research and development would

see Lyme disease, pg. 17



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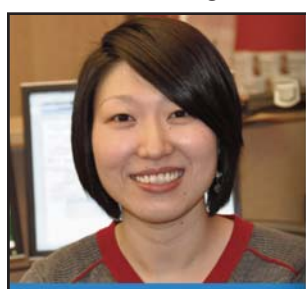
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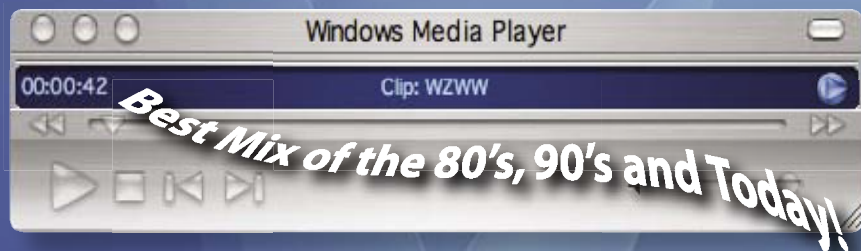
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from Lyme disease, pg. 16

have been wasted and future profit potential would disappear.

"[Pharmaceutical company] SmithKline Beecham, the FDA and CDC met to decide upon a viable case definition for Lyme disease, one that would enable their data to have meaning and permit their clinical trials to move forward, ultimately passing review at the FDA," the report states. "A stringent serological definition of Lyme disease, one that seemed to settle, once and for all, who had Lyme and who did not, was essential for products to be approved."

The vaccine industry is estimated to be worth more than \$500 million to \$1 billion per year in the United States alone, and charges of conflicts of interest have only increased over time.

The 2009 award-winning documentary *Under Our Skin* reported that 11 of the 12 IDSA members who set the guidelines in 2000 and 10 of the 14 members who set the more restrictive guidelines in 2006 "held direct or indirect (through their academic institution) interest" in a Lyme vaccination, according to a background paper from the California Lyme Disease Association, one of the leading trackers of the issue. (One Lyme disease vaccination was on the market for a few years until 2002, but was taken off the market, the company said, because it wasn't making money, others say because it was harming people.) Six of the members served on both panels, and they either formerly worked for the companies now developing vaccines or their universities hold patents to some part of the vaccine. Long-term Lyme activists claim this is

proof the IDSA has reason not to acknowledge that long-term antibiotics treatments work.

When the IDSA reissued the tighter definition and treatment guidelines in 2006, the conflict-of-interest smoking gun was enough for Connecticut's Attorney General Richard Blumenthal to launch an antitrust investigation. To settle it, the IDSA agreed to set up a new, more transparent committee to review the guidelines by Dec. 31, 2009, a deadline it missed. This January the IDSA was caught red-handed manipulating the vote to skew it toward maintaining the status quo, violating the settlement agreement with the attorney general.

In a letter dated Feb. 1, 2010, Blumenthal related his staff's review of the minutes of IDSA meetings that showed this manipulation.

"My staff discovered that the review panel failed to conduct the principal voting required by the agreement and the AP [Action Plan] on whether each recommendation in the 2006 Lyme disease guidelines was justified by the medical/scientific evidence," Blumenthal wrote in his letter. That vote, he explained, would have changed the guidelines, because only half of the group voted to maintain status quo and a supermajority was required.

Then, in a setback for Lyme activists, the IDSA announced April 22 that the panel had voted unanimously that its 2006 guidelines were based on sound science. Its report said that the overwhelming testimony and documentation received during the panel's review was "by its nature uncon-

see Lyme disease, pg. 18



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## from Lyme disease, pg. 17

controlled and highly subject to selection and reporting biases” and that “only high-quality, prospective, controlled clinical trial data demonstrating both benefit and safety will be sufficient to change the current recommendations.”

### Prosecuting heretics?

Doctors who say long-term Lyme exists and is treatable with antibiotics continue to be under attack. One of the heroes of the effort is Charles Ray Jones, an 80-year-old practicing pediatrician who is one of the few in the country that Lyme patients call a “Lyme literate M.D.”

Jones was brought up on charges in front of the Connecticut Medical Examining Board (CMEB) for misdiagnosing tick-borne diseases in three children. He has treated more than 10,000 in his career, according to his attorney. His appeal in February resulted in, among other penalties, Jones being fined \$10,000, twice as much as doctors who had been charged with violating more severe ethics and practices, according to Kris Newby of [underourskin.org](http://underourskin.org) who sends out regular updates on such cases.

“Last year the medical board punished 43 physicians for serious charges such as substance abuse, sexual misconduct, mental illness and negligence; not one of these physicians received a fine larger than \$5,000,”

Newby wrote, adding that none of the children Jones treated were harmed.

The movie “Under Our Skin” documents other doctors who have lost their practices due to such prosecution, and still others are feeling the chilling effect of those prosecutions.

In Pennsylvania, no doctors have been prosecuted yet, Corson said.

“If they want to come get me they can come get me and there’s nothing I’m going to do about it,” she said. “All it’s going to take is one patient complaining to the medical board about me, but I’m not going to stop speaking out.”

Ayoub said he was not aware of doctors who’ve been brought up on charges for long-term antibiotic treatments, but was

aware of the treatment.

“There are certainly folks out there who seem to be treating everybody who walks in their office with long term antibiotics,” he said. “Of course the potential problem here is that it’s fine to treat people, and that’s good, but we certainly shouldn’t over treat people. Long-term antibiotics if you don’t need them can be hazardous. You want to save every medicine for when it’s needed.”

Ayoub said he relies on guidelines from a number of sources including the American College of Rheumatology, as well as “standard texts and experts.” He was not immediately familiar with the acronym “IDSA.”

## see Lyme disease, pg. 19

## from “Transition,” pg. 11

State student with an interest in environmental issues. They are members of a small group called Transition Centre, an independent affiliate of the Transition U.S. project. Citizens in Bald Eagle and Penns Valley are also interested in the endeavor.

Sharp, a retired community and economic-development planner who has lived in State College for six years, came to the Transition movement through an interest in the concept of “relocalization,” which he defines as a development strategy that “seeks to restore the capacity to produce food, energy and durable goods at a local level.” For several months, Sharp has given talks on Transition Initiatives to local groups, and he invites those interested to visit the Transition Centre website, [www.transitioncentre.org](http://www.transitioncentre.org).

He believes the course that Hopkins’ 240-page manual lays out is a “best-practice blueprint.”

“It’s an extremely flexible but well thought out plan that has been tested time and time again by all sorts of people,” said Sharp.

The Transition blueprint is intended to help citizens—working from the ground up—design a flexible Energy Descent Action Plan (EDAP) to enable their community to “hold together and maintain their ability to function in the face of change and shocks from the outside.” Hopkins calls that ability “resilience.”

He is convinced that communities all over the globe will need that resilience in



From left to right: Bill Sharp of State College, George Owen of Media, Pa., and Gay and Jim Dunne of Bellefonte.

Photo by Jill Gomez

the not-so-distant future because climate change and the dwindling, ever-more-expensive supplies of liquid fuels (“peak oil”) will combine to challenge a world economy addicted to growth.

In making his argument, Hopkins also cites what he sees as the disadvantages of other energy sources—coal, tar sands, biodiesel and nuclear power—and insists that any energy descent plan must address both peak oil and climate change because as the availability of liquid fuels declines “the danger is that the gap that

emerges...will be filled with other fuels each far worse” than oil in terms of their impact on climate.

But Hopkins doesn’t dwell on the negative. He sees the movement as the opposite of the “survivalist response” that “assumes that one should prioritize self and loved ones above all else.” Instead, it asks, “What might environmental campaigning look like if it strove to generate this sense of elation, rather than guilt, anger and horror that most campaigning evokes? What might it look like if it strove to inspire,

enthusiasm and focus on possibilities rather than probabilities?”

Throughout the book, citizens are reminded to create “a sense of anticipation, elation and a collective call to adventure on a wider scale,” and to develop “a picture of the future so enticing that people instinctively feel drawn to it.” In the book’s section on how to create an Energy Descent Plan, Hopkins encourages transitioners to “Celebrate! Always a good thing to do. In fact, you probably should have been doing this after every step above!”

### FOR MORE INFORMATION

The Transition Handbook available at:  
East-West Crossings  
210 Elmwood St., Lemont  
234-8810  
[www.info@eastwestcrossings.com](http://www.info@eastwestcrossings.com)

Webster’s Book Store Café  
128 S. Allen St., State College  
234-9712  
[www.webstersbookstorecafe.com](http://www.webstersbookstorecafe.com)

Helpful websites:  
[www.transitioncentre.org](http://www.transitioncentre.org)  
[www.transitionmedia.memberlodge.com](http://www.transitionmedia.memberlodge.com)  
[www.transitionpennsylvania.ning.com](http://www.transitionpennsylvania.ning.com)  
[www.transitionsus.org](http://www.transitionsus.org) (U.S. organization site)  
[www.transitiontowns.org](http://www.transitiontowns.org) (Original U.K. site)

Local contact: Bill Sharp  
[bsharpci@comcast.net](mailto:bsharpci@comcast.net)

from Trails, pg. 12

difficulty between the trails is marginal.

Plans to construct trails at Raystown Lake gained momentum in 2002, when IMBA identified the site as one of several potential trail-building projects across the nation. IMBA and the Army Corps of Engineers signed a memorandum of understanding and a short demonstration trail was built to evaluate potential environmental impact of a larger trail system. Construction of the Allegrippis Trails began after an envi-

Much of the trail work was carried out by hundreds of volunteers who contributed an estimated 7,000 hours clearing rocks, roots, trees and branches.

ronmental assessment yielding a “finding of no significant impact” was completed in August 2006.

Non-profit organizations such as The Friends of Raystown Lake obtained state and federal grants to pay for the construction of the machine-built trails, but much of the trail work was carried out by hundreds of volunteers who contributed an estimated 7,000 hours clearing rocks, roots, trees and branches.

The economic impact of the trails has been significant for several area businesses,

largely because the majority of people who use them are from outside Huntingdon County. Rothrock Outfitters owners Paul Houck and Tony Seguin believe that the trails have doubled or tripled the amount of traffic in their store, which sells and rents adventure sports equipment.

Although cycling makes up most of the trail activity, it isn’t uncommon to see hikers and joggers there as well. Amy Prokop, a Huntingdon resident who runs approximately seven miles on the trails each week as part of her training for marathons, said that she enjoys them because they provide a

change of scenery and are well maintained.

Unusually heavy snows this winter and the fact that the trails are open year-round also made them an attractive destination for winter activities.

“We had an awful lot of people asking about snowshoeing and cross country skiing equipment,” Seguin said.

Horses and motorized vehicles are not allowed on the trails, but hunting is, so visitors are encouraged to exercise caution during hunting season.

“We’re trying to get the word out to get

these hospitals don’t think in the long term, they think in terms of this year, next year. We as a society have to start thinking in the long term.”

On the political front, Sheffer said she saw hope when a local state representative appointed her to the state Lyme Task Force, but that hope faded fast.

“I’m the only advocate, and we have not met since January ‘08,” she said. “They wanted testimonials from experts, and then they did nothing.”

Corson has testified twice in Harrisburg she said, and repeated efforts to pass Lyme-related legislation, including education about avoiding the disease, have passed the House, but failed in the Pennsylvania Senate Banking and Finance Committee, she said. Her testimony, taped by public broadcasting, never aired either, she said. Yet when she and Sheffer appeared on public broadcasting’s Smart Talk show to discuss Lyme, the producer said he had never in seven years received so many requests



Photo by Shannon Cotrell

The grand opening of the Allegrippis Trails was in May 2009. Since then, the trail is most popular with cyclists though hikers and joggers use it as well.

bikers to wear orange and inform hunters that there are other people using the trails,” Gwinn said, noting that there are plans to make orange helmet covers and vests available at the trail parking lots.

At some point there may be efforts to add more trails, but for now the focus is on

for a copy of the show.

Corson, whose son is now pursuing his master’s degree overseas, continues to give talks around the country, maintain her independent practice and connect daily with her colleagues via a listserv they have set up to stay on the leading edge of Lyme disease

maintaining and improving what is already there.

“We want to make sure we can handle what we have before we do any more,” said Ron Rabena, president of the Friends of Raystown Lake.

research.

“I decided I couldn’t let other mothers go through this,” she said. “I was lucky enough that I was able to call other doctors and take care of my son, but how many other mothers suffer every day because doctors won’t believe them?”

from Lyme disease, pg. 18

**The costs**

As the legal and medical board battles rage on, patients continue to suffer, emotionally, physically and financially.

For one, they pay the bills health insurance companies won’t so long as the IDSA’s definition of Lyme stands. Steffensmeier said that even with medical assistance, her parents have paid out “thousands and thousands” of dollars in medical costs. Sheffer estimated her out-of-pocket costs are beyond \$50,000 for her family. She’s thankful her daughters were diagnosed and cured quickly, but the bills continue to pile up for her and her husband.

Corson looks at the bigger picture.

“If you look at the medical costs of treating someone three to five years opposed to taking care of a disabled person in the long term it costs a lot less to treat them for those few years,” Corson said. “But CEOs of

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