An informative guide for the

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HOW A MYSTERY DISEASE HIT THREE TEACHERS

HOW A MYSTERY DISEASE HIT THREE TEACHERS

"How Mystery Disease Hit Three Teachers" Oct 12 1985 By Chris Bowman Truckee - Irene Baker, 43, said she spent most of the summer in bed. Karen Cosgriff, 46, said she sometimes felt so weak she could not walk across the room. Gerald Kennedy, 46, said all he could do for three months was watch television and read - "It got really boring." Kennedy, Cosgriff and Baker - all Truckee schoolteachers - were among the first of dozens of middle-aged residents in the Truckee-north Lake Tahoe communities to report the fatiguing illness that has stumped local doctors and national disease researchers. "A few teachers came into our office last spring, then the next thing you know, it was like popping up everywhere." said Paul R Cheney, an Incline Village doctor whose clinic has been treating most of the mysterious mononucleosis-style cases. Cheney and his partner, Daniel L. Peterson, said they have treated 150 patients from Truckee and north Lake Tahoe with similar symptoms, prolonged fatigue, swollen neck glands, sore throats, headaches and enlargement of the liver and spleen. But Cheney said he believes the illness has run its course. He has not seen new cases for the past month. The Truckee teachers and other residents who were bedridden for months are beginning to return to work. Cheney said he and Peterson first thought they had an "epidemic" of mononucleosis when the ailment surfaced among the Truckee teachers. Baker is an eighth-grade teacher at Tahoe Truckee High School. She said she shared a class preparation period with the spouse of Kennedy and Cosgriff and two other teachers at the school, and they all came down with similar symptoms at almost the same time last spring.

HOW A MYSTERY DISEASE HIT THREE TEACHERS

Karen Cosgriff, who teaches at Truckee Elementary school, said she came down with the ailment after her husband, Michael, and English teacher at the high school, caught it. He was in the same faculty meetings as Baker. Kennedy's wife, Janice, also was in the teachers' group. Word spread quickly in the small mountain communities that Cheney and Peterson were using a new testing procedure that could detect mononucleosis. The test, called th Epstein-Barr virus serology panel -- measures antibodies in the blood associated with mononucleosis. The test indicated that almost 60 of the 150 patients who complained of fatigue had mononucleosis, Cheney said. Mononucleosis, commonly called the kissing disease, usually strikes teenagers and young adults in their 20's from contact with saliva. It's supposed to be the curse of high school students, and not their teachers. "We couldn't understand how you could transfer mononucleosis in a teachers lounge." Cheney said. "We weren't having an orgy in there." Baker joked. Another troubling factor, Cheney said, is that, statistically, 90 percent of all adults have had mononuclesosis -- in varying degrees of severity -- in their youth and should be immune to the disease as they are to chicken pox and other childhood illnesses. The average age of the Tahoe area patients was 40. "Then we thought, hey, maybe we're not dealing with mono." Cheney said. "That's when we called the CDC." At first, researchers from the Center for Disease Control in Atlanta declined to investigate, Cheney said. Gary Holmes, a CDC epidemiologist, said his office often receives reports of mononucleosis and they almost never check out.

HOW A MYSTERY DISEASE HIT THREE TEACHERS

But after examining the patient's blood samples and medical histories the Incline doctors sent to Atlanta, Holmes and his boss, Jon Kaplan, came to Lake Tahoe to investigate. After 3 1/2 weeks of interviewing patients and examining their records, Holmes returned to Atlanta still unclear as to what kind of illness struck the Sierra communities. Holmes said Thursday he did not believe there was an outbreak of mononucleosis. He said the blood test used by the Incline Village doctors was a relatively new procedure that had not been proven reliable. Nonetheless Holmes collected blood and saliva samples from patients with the most severe cases to determine if mononucleosis was the culprit. Using these samples, Holmes said, he will attempt to grow the virus. The procedure is laborious and will probably take three months to complete. he said Cheney said he and the Atlanta researchers hypothesize that mononucleosis may have been transmitted by another, unknown virus that is more contagious than mononucleosis. This activator virus, he speculated, may manage to bypass the body's immunity system and reactivate a chronic form of mononucleosis that lasted many months longer than the adolescent version of the disease. Cheney said many of his patients suffered fatigue for up to 10 weeks. Kennedy, an auto mechanics instructor at Truckee high school, said the perpetual rundown kept him from teaching school this past summer and fall. "All you can do is stay at home in bed and watch TV and read." Kennedy said. "It gets really boring, and you kind of wonder who you caught it from all the time."

We may find something else that we're not even looking for.
-CDC epidemiologist Dr Gary Holmes

Mysterious sickness plagues north Tahoe

By Chris Bowman
Bee Staff Writer

INCLINE VILLAGE — Disease experts are investigating reports of an unusually high occurrence of a mysterious, mononucleosis-like illness striking residents on the north shore of Lake Tahoe.

Physicians Paul R. Cheney and Daniel L. Peterson, who share an internal medicine practice in Incline Village, reported to the Center for Disease Control in Atlanta that at least 80 residents had blood tests indicating they had mononucleosis, according to Gary P. Holmes, a viral disease specialist with the research center.

The symptoms of the illness reported by the doctors — headaches, sore throats and prolonged fatigue — are similar to mononucleosis.

But Holmes, who just returned from a three-week study of the situation at Incline Village, said, "It is pretty unlikely that this many people had mononucleosis. There is little evidence that mononucleosis occurs in outbreaks."

Holmes also said that Cheney and Peterson were using a test that has not been proven to be reliable in testing for mononucleosis and other viral infections.

Nevertheless, Holmes said he is running blood and saliva tests for the mononucleosis virus in the unlikely event that there was an outbreak.

"We may find something else we're not even looking for," he added.

But Cheney said late Thursday that he believes there is a mononucleosis epidemic on the north shore of Lake Tahoe.

"The epidemic is highly unusual because it is striking the heterosexual, monogamous adult. Mononucleosis usually affects teenagers," Cheney said.

He said the average age of patients he tested was 40 and he said that while the viral test is not "foolproof, it is the best we have in the medical community for testing for mononucleosis."

Cheney said Holmes was being overcautious. He also said that Holmes' superiors told him two days ago they convinced "that there was a possibility of an outbreak of a chronic form of mononucleosis."

Holmes and state health officials at the viral infection laboratory in Berkeley said the ailment at Lake Tahoe is not life-threatening.

"The main problem is fatigue," Holmes said. "Some were fatigued to the point that they had to miss several days of work or were bedridden for several weeks at a time."

Whatever the ailment, Holmes said he found no evidence to suggest it is highly contagious, as some north shore residents feared.

Holmes said the patients he interviewed had little or no contact with other patients.

Cheney and Peterson conducted blood tests for mononucleosis on about 150 residents since January, Holmes

See ILLNESS, page B2

Illness

Continued from page B1

said. The patients live along the north shore of Lake Tahoe, from Incline Village on the Nevada side to Tahoe City in California. A few of the patients came from Truckee, about 12 miles north of Tahoe City.

The two doctors said blood tests indicated that 80 of those patients had mononucleosis, Holmes said.

But Holmes said the Incline Village doctors were using a relatively new kind of blood test — called the Epstein-Barr serology panel test — that has yet to be proven as a reliable diagnostic tool for mononucleosis or other viral infections.

"They were making more out of an abnormal test result than probably should be done," Holmes said. "It is such a new test that nobody knows the true value of it."

Holmes said his checks of the patients' medical histories indicate that the abnormal blood tests were the result of diseases they had suffered in the past.

"There may have been a large number of people who may have been diagnosed as having mononucleosis, who really don't have it," he said.

Holmes said his tests results will take several months to complete.

Commonly called the kissing disease, mononucleosis usually strikes teenagers and young adults in their 20s from contact with saliva.

MOLD AT GROUND ZERO FOR CFS

Truckee Teachers Recount 'Malady'

By Barbara Barte

Irene Baker, one of about a dozen local teachers who have been diagnosed as having chronic mononucleosis, is exasperated with doctors who dispute the findings of the two Incline Village doctors who have diagnosed 90 local cases.

"I know that I'm sick and I think it's more than coincidence that five teachers who share the same prep period have the same symptoms," Baker said Tuesday.

She spent most of the summer in bed and has not been able to return to her teaching job at Tahoe-Truckee High School this year. Her daughter, Laura, was also sick but has gotten better, she said.

Baker said at least six other Truckee teachers—Andy Antonucci, Gerry and Janice Kennedy, Karen and Michael Cosgriff, and Jan Schowalter—have similar symptoms and the same diagnosis, as do three North Tahoe High School teachers.

Symptoms are "fatigue and killer headaches, sore throat, swollen lymph nodes, pain in the spleen area and the inability to stand up for more than a short period of time," she said.

While she has all the above symptoms and most share the fatigue and bad headaches, not all have the other symptoms. Most were sick all summer; some have returned to teaching full- or only half-time; and some are still not able to work.

"Eventually, everyone ended up at Peterson and Cheney's office," she said, referring to Incline Village Drs. Daniel Peterson and Paul Cheney, who have been criticized by other doctors for their chronic-mono diagnoses.

"I don't think Peterson and Cheney are off-base," said Baker, "and what bothers me is that these doctors who are being so critical haven't seen patients with these symptoms, or, if they have, they haven't listened to them.

"One teacher was told she just had an allergy, and she was so sick. Others were told they're depressed. I had gone to Peterson and recommended him to other teachers.

"Peterson and Cheney believed we were sick. That's why they got all these patients. All of us showed negative on a mono spot test, but not on an E-R panel." (See other story for a description of the controversial Epstein-Barr test.)

Since becoming ill, Baker has been finding out what she can about chronic mononucleosis and has learned that there isn't much research on the disease.

She has learned, however, that she is not alone, as someone sent her a list of 200 names from a national support group.

Since reading a paper by a Wisconsin doctor who believes he had a latent mono virus reactivated by the toner in his copy machine, she wonders if two copy machines in the teachers' room could be at fault.

Cheney says that certain drugs and chemicals can cause latent mono infection to become active again. So can other illnesses, such as cancer and rheumatoid arthritis. In fact, he says, the tiredness associated with those diseases may be due to reactivated mono.

"Phorbol esters used in copy-machine toner, the tung oil in many furniture polishes and in certain glues and varnishes and even in some houseplants may reactivate the mono virus that is latent in 90 percent of adults," says Cheney.

While this may be the cause of a few local cases, however, he says he is more inclined to believe a reactivation was triggered by another virus last winter.

"I wouldn't want people to go around unplugging their copy machines," he says. "If it is a common chemical, how come it caused problems this year and not last year? It was more likely a virus."

If reactivation is caused by a chemical, he said, "a lot would depend on the concentration, ventilation and a lot of other variables."

Cheney agrees with Dr. Gary Holmes, a viral-disease researcher from the Center for Disease Control in Atlanta who is investigating Tahoe-Truckee cases, that chronic mono is not easily transmitted from person to person.

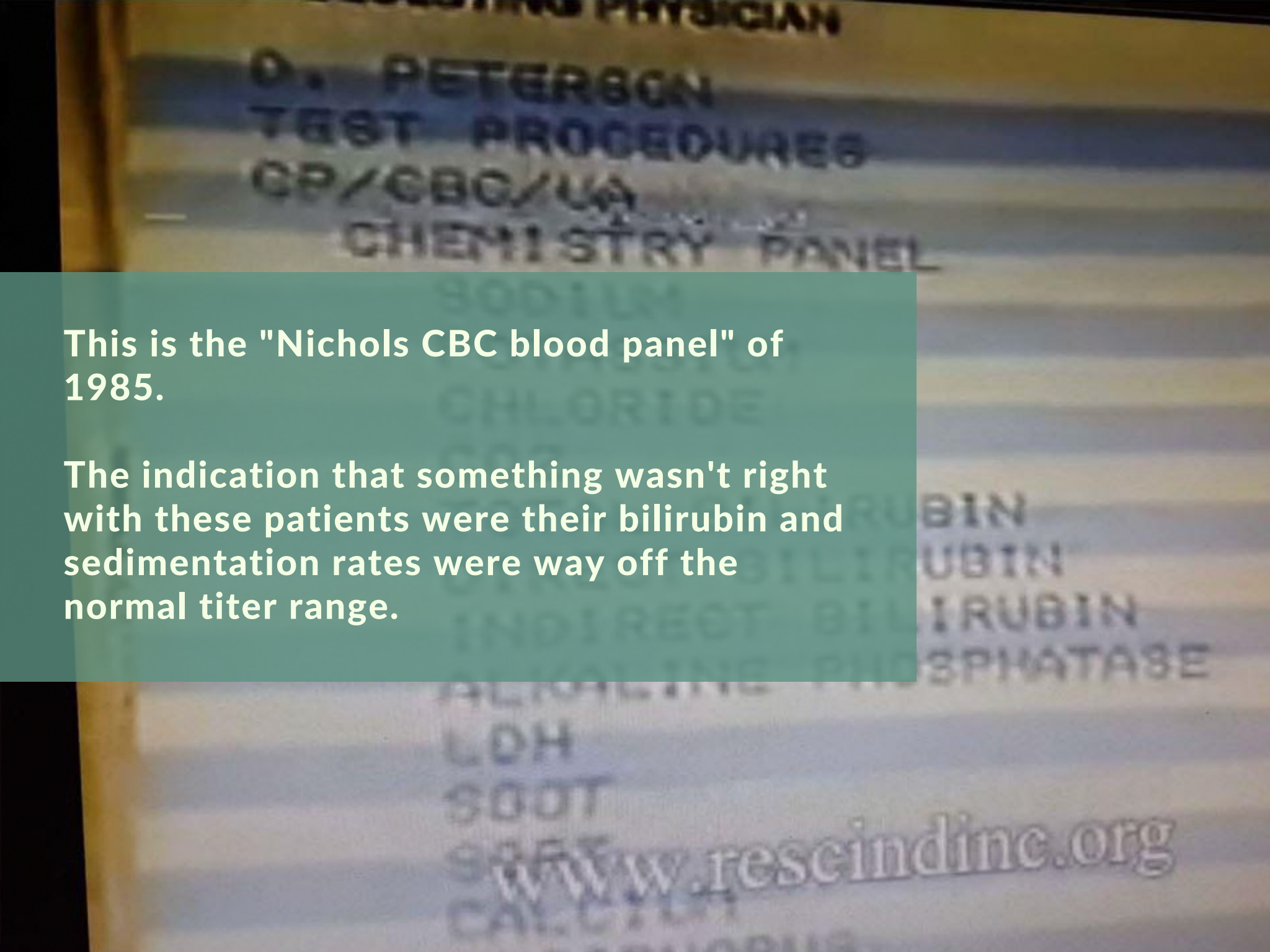
"Ninety percent of adults are immune to it because we already have the latent virus," says Cheney, "but I believe that something happened last winter to reactivate that virus in many people."

He says that, because the virus that causes mono is a member of the same family as the herpes virus, a mono treatment is being studied using a new drug for herpes. "Results are still pending but may be in by mid-winter," says Cheney.

Although the CDC researcher who investigated Cheney and Peterson's findings says he doesn't believe there is an outbreak of chronic mono in the area (see story) and other local doctors also dispute the claims, Cheney says he is convinced at least 90 local people had a mono virus reactivated last winter.

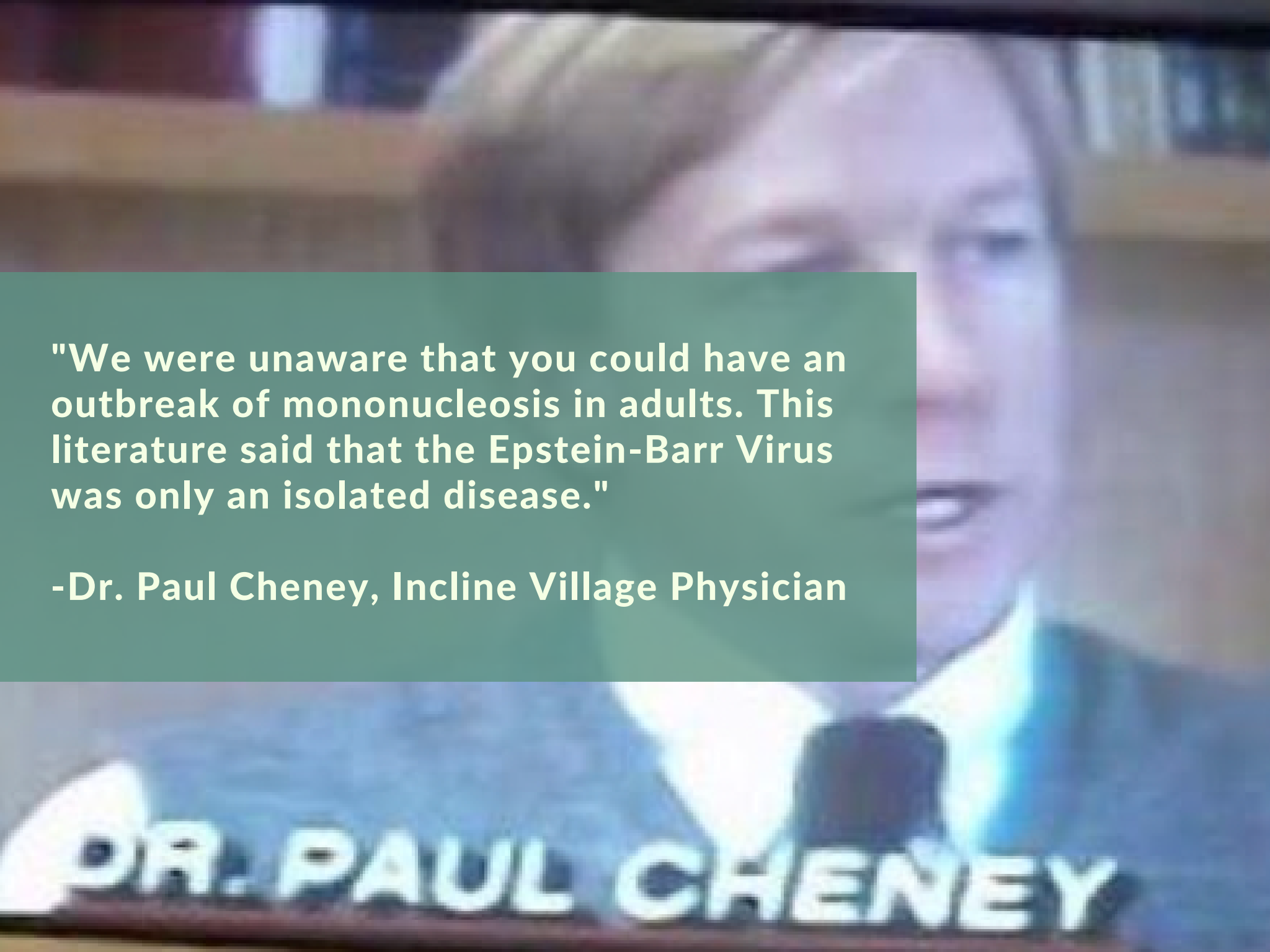
He has seen no new cases since late summer and says, "This thing had a beginning, a middle and an end."

Irene Baker and some other locals are still waiting for an end to their illness, though. "It's all I can do to go to the doctor, maybe stop at the store and get back to bed," she said Tuesday. "I just talked to Karen Cosgriff (who is back teaching half-time) and she was going to go lie down."



This is the "Nichols CBC blood panel" of 1985.

The indication that something wasn't right with these patients were their bilirubin and sedimentation rates were way off the normal titer range.



"We were unaware that you could have an outbreak of mononucleosis in adults. This literature said that the Epstein-Barr Virus was only an isolated disease."

-Dr. Paul Cheney, Incline Village Physician

Basic symptoms may be sign of Epste

SUMMARY: Headaches. Muscle spasms. Swollen glands. Slight fever. Dizziness. The symptoms of one of the least diagnosed but still widespread illnesses begin here and add up to chronic Epstein-Barr virus. Most people are exposed when they are children to this herpesvirus that hides in the white blood cells. The symptoms are similar to those of mononucleosis, but the diagnosis is psychologically important to its sufferers. Though research is being done and doctors are hopeful of a cure, the victims turn for now to self-medication.

Fifteen years ago, W.H. thought she was coming down with something going around. Her throat was sore, her arms felt bruised and she was tired. Really, really tired. But then, she had been working 12-hour days as a social worker, and she knew she was run-down.

After about a month of a growing list of symptoms — headaches, muscle spasms, swollen glands, slight fever, dizziness — she went to her first doctor. He told her it was just the flu, and she should take it easy.

She went back to see him, a month later, still complaining. "But they (the symptoms) were worse, you know. I was unable to get out of bed because my muscles were so weak," she says. And she had some numbness around her face and in her fingers. This time the doctor said it was probably stress. She asked him to run tests. He ran tests, and he said she was as healthy as an ox. And she went to another doctor.

And another doctor, and another. She couldn't concentrate well, and she was so tired. "I was getting real depressed," she says. Generally, she felt like leftover pizza. She quit her job and stayed in bed. "There wasn't one doctor that whole time who did anything more than pat me on the head, inferring it was psychosomatic." Finally, two years ago, W.H. was diagnosed as having chronic Epstein-Barr virus.

There are stories of sufferers who have been placed in mental institutions or who have tried suicide. One young woman was diagnosed by psychiatrists as "a manipulative child" after she had told her parents she was too tired to leave her bed. On the psychiatrists' advice, the girl was forced to go to school. She was found on the street, asleep in the pouring rain.

Even if Epstein-Barr virus is diagnosed, there is no cure, and currently there is no medically accepted treatment. Ninety percent of those who get it have it for life.

Epstein-Barr is a herpesvirus that hides in the white blood cells of the body, suppressing the immune system when activated. Although there is "no evidence that this disease leads to a more serious illness," says Dr. James Brodsky of Chevy Chase, Md., it is associated with Burkitt's lymphoma, nasopharyngeal carcinoma, lupus and rheumatoid arthritis.

To date, most doctors are not knowledgeable enough to look for it, and most laboratories are not sophisticated enough to detect it. Because the disease is seldom diagnosed, it is considered extremely rare, although some researchers believe there may be as many Epstein-Barr sufferers as there are people with multiple sclerosis.

"The pattern we connect with this virus is that of mono," says Dr. James Jones of the National Jewish Center for Immunology and Respiratory Disease in Denver. The disease's symptoms have been misdiagnosed as infectious mononucleosis, except that mono is considered a short-term, nonrecurring illness. When fatigue, swollen glands and muscle aches persist in the Epstein-Barr virus patients, the physicians treating these persons for mono either are dumbfounded by the symptoms' longevity or consider the disease psychosomatic. As early as 1948, Dr. Raphael Isaacs of New York wrote that 25 of his patients had symptoms for infectious mononucleosis for more than a year. Not until 20 years later was the virus reexamined by Drs. Werner and Gertrude Henle of Philadelphia. The mono connection was not gratuitous. Many of the people with the virus have had mono. The antibody test that finally was developed, thanks to the Henles, measures the active Epstein-Barr virus in the blood.

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Most people are infected with the virus — which mimics a case of the flu or a cold — as children and recover from it. The virus then lies low in the body, held in check by the immune system. Most standard blood samples will contain a measure of the virus. But for those whose immune system for unknown reasons has proved less than efficient in checking the virus, these antibody levels increase.

But the antibody test is not foolproof in identifying all persons with the disease. "I'm pretty sure we don't have a good test for all people," says Dr. Irena Brus of Beth Israel Hospital in New York.

For some, the disease comes and goes. For other, like W.H., it remains constant. There is some evidence that it gets less severe with time: Many of the symptoms may disappear. "I'm much better now than I was," says W.H., "but, my God, I wouldn't wish what I went through on anybody." The fatigue, "a pronounced, an unusual and nauseating fatigue," says Brus, in some persons lasts a lifetime.

Epstein-Barr disease has been called the "yuppie flu" because it tends to afflict urban professionals older than 30, especially women. It is thought that this demographic profile exists only because of the rash of infectious mononucleosis that has occurred in the past 20 years. In reality, "it's an extraordinary, ubiquitous disease," says Jones, one of the principal researchers into its treatment and possible cure.

Some victims get mono and just never get better. When these people go back to their doctors, their blood tests for mononucleosis are negative. But nothing else in their disease has changed. For those who have had mono years before and then get Epstein-Barr virus, the symptoms are similar. "Looking back on it now," says M.M., whose spleen had been removed before the virus was diagnosed, "I practically gave the doctor the answer. I told him, 'The only time I've ever felt this bad was when I had mononucleosis in 1968.' "

The diagnosis is psychologically important to the sufferers, especially those who have been undiagnosed for years. "Every doctor I went to in the last 10 years just rolled their eyes," says C.J., whose symptoms of sore throat, swollen glands and fatigue were

Continued on Page 13

THE MYSTERIOUS EPIDEMIC SHOOK UP THE COMMUNITY

As cases grew, local doctors, Peterson and Cheney contacted the Centers for Disease Control and Prevention (CDC) for assistance.

Brown, 14, and Ernest Antal, 15. The spokewoman said it was

Southfield had no comment on the shootings.

Malady hits North Shore

Mysterious epidemic

Special to the Tribune

National medical researchers and local doctors are stumped by a malady that has struck the North Lake Tahoe and Truckee areas in epidemic proportions for the last year.

Doctors from the federal Center for Disease Control in Atlanta left Incline Village last week after launching a study into a seeming epidemic of fatigue.

The researchers based their study on 150 cases uncovered by two Incline doctors alone. However, after two weeks of on-site research and testing of cases documented by doctors Paul Cheney and Daniel Peterson, Center for Disease Control (CDC) researchers left with more questions than they could answer.

CDC Dr. Gary Holmes will continue testing in Atlanta for the sickness which seems to break medical rules.

According to Cheney, the mysterious illness struck in January. "A bunch of people all about the same age bracket—many of them teachers—began coming in." All complained of the same level of fatigue.

For many reasons, the sickness spells confusion. While there is no known treatment for the fatigue, the doctors have not been able to diagnose it or determine how it is passed on, though they do not believe it is easily transmitted.

According the Cheney, standard tests for mononucleosis discouraged that as a diagnosis for most of the patients. Though the disease appears to be similar to mono, most of the patients have been middle-aged and mono is documented as an illness primarily of the young.

The large numbers that flowed in through the spring also sparked concern. According to the doctors, mono is not easily transmitted, except through saliva, and is almost never seen in epidemic proportions.

Also, mono infections usually fade in four to eight weeks. Holmes said this illness has caused varying levels of sickness—from two months of mild fatigue to up to a year of severe fatigue. In some cases it has kept people from their work and daily routing.

Also, most of the patients showed evidence of old mono infections and mono infections and mono does not usually strike twice, said Cheney.

Holmes said many other doctors may have seen patients complaining of fatigue in past month. However, Cheney and Peterson were the only area physicians to employ a test that became available in January. The new test raised more questions.

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(See Malady, Page 7)

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See FEUD, page 2C

Doctors say strange form of mono under control in Incline Village

By Lita Fujimoto/Gazette-Journal

INCLINE VILLAGE — An unusual form of mononucleosis that may have struck 90 victims seems to have been contained, but some victims continue to suffer symptoms of the wearying disease, two Incline Village doctors said Tuesday.

Drs. Daniel Peterson and Paul Cheney, partners in an internal medicine practice at the north Lake Tahoe community, said they believe a "limited outbreak" of chronic active mononucleosis began in January, peaked in June and has now ended.

The number of cases diagnosed at Incline Village is larger than any previous recorded incidences of the disease, Peterson said. By studying some of the Incline Village patients, national researchers hope to learn more about the disease and what causes it, he said.

The doctors discussed their findings at a news conference Tuesday at the Hyatt Lake Tahoe in response to what they called "misinformation" and "misstatements" by national and local health officials.

Officials from the national Centers for Disease Control in Atlanta and the Washoe County District Health Department said last week there was little evidence of a mononucleosis outbreak and questioned the lab test used to diagnose the disease.

The doctors disputed those statements Tuesday.

"We are on firm ground," Cheney said. "For the CDC and the Health District to say there is no mono is just not true. We could stand up in a court of law and prove 90 cases."

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> **Paul Cheney/physician**
> **Incline Village**

Washoe County District Health Officer Michael Ford said Tuesday the disagreement was "all a matter of wording." While the doctors seem to have discovered cases of active chronic mononucleosis, Ford stressed that the disease is not contagious — a conclusion shared by the doctors.

"There's not any kind of threat to public health," Ford said. "People should not be concerned about going to Incline."

During a nine-month period, the doctors said they saw 134 patients complaining of fatigue. They diagnosed 90 of the patients as having chronic active mononucleosis, and of those, 25 percent were so tired they couldn't work or do household chores.

Unlike infectious mononucleosis, which typically lasts one to several weeks, chronic active mononucleosis "lasts for years," Cheney said. He said most north

See MONO, page 2C

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Mono controlled

From page 1C

Lake Tahoe residents diagnosed as having the disease are still sick.

The main symptom of the disease is fatigue, but half of the patients also had enlarged lymph nodes and 10 percent had enlarged spleens, Cheney said.

Doctors don't know what causes chronic active mononucleosis, which has occurred only sporadically in the past, Peterson said. Until the disease turned up at Incline Village, the largest group of diagnosed cases was 25, Peterson said.

At first, the doctors said they saw "clusters" of people coming down with the disease. Families, teachers at a high school and employees at a casino were diagnosed as having the disease, Peterson said.

The doctors speculated that a virus may have touched off the disease at first, but said the disease wasn't easily spread.

Patients with weakened immune systems were more likely to catch diseases from other people, Peterson said. The Centers for Disease Control has saliva samples from 14 of the doctors' sickest patients

The national public health agency's tests should be completed in two to three months, Cheney said. But the test results may not prove anything because 60 percent of people suffering from the disease don't carry the virus in their saliva, he said.

Basin News

Doctors begin study of mystery malady

Harvard medical team arrives in Incline Village

By Jean Lamming
Staff Writer

Harvard medical researchers are in Incline Village this week gathering blood samples and other information to help them identify the virus responsible for the chronic fatigue that struck many area residents in 1985.

Dr. Anthony Komaroff, a member of the three-man research team, said he wants to find out if the fatigue and other symptoms were caused by a new, more communicable strain of mononucleosis or an undocumented virus.

Komaroff said the outbreak is unusual enough to warrant the on-site, grant-funded study.

Some 150 cases of fatigue were recorded by Incline internists Paul Cheney and Daniel Peterson during the spring and summer of 1985 using a new blood test.

In October, epidemologists from the federal Center for Disease Control came to Incline to study the outbreak, which struck mostly heterosexual adults, many of whom worked in public schools. The disease center's report did not name a culprit virus.

Komaroff and his colleagues, doctors Dedra Buchwald and Nicholas Fiebach, will contact as many of the 150 original patients as possible for more information and possibly blood samples. Komaroff said they will focus on about 30 patients who were most severely afflicted.

Most of the people who contracted the virus are still sick to some degree, said Komaroff. Dr. Cheney has reported only a few new cases since October.

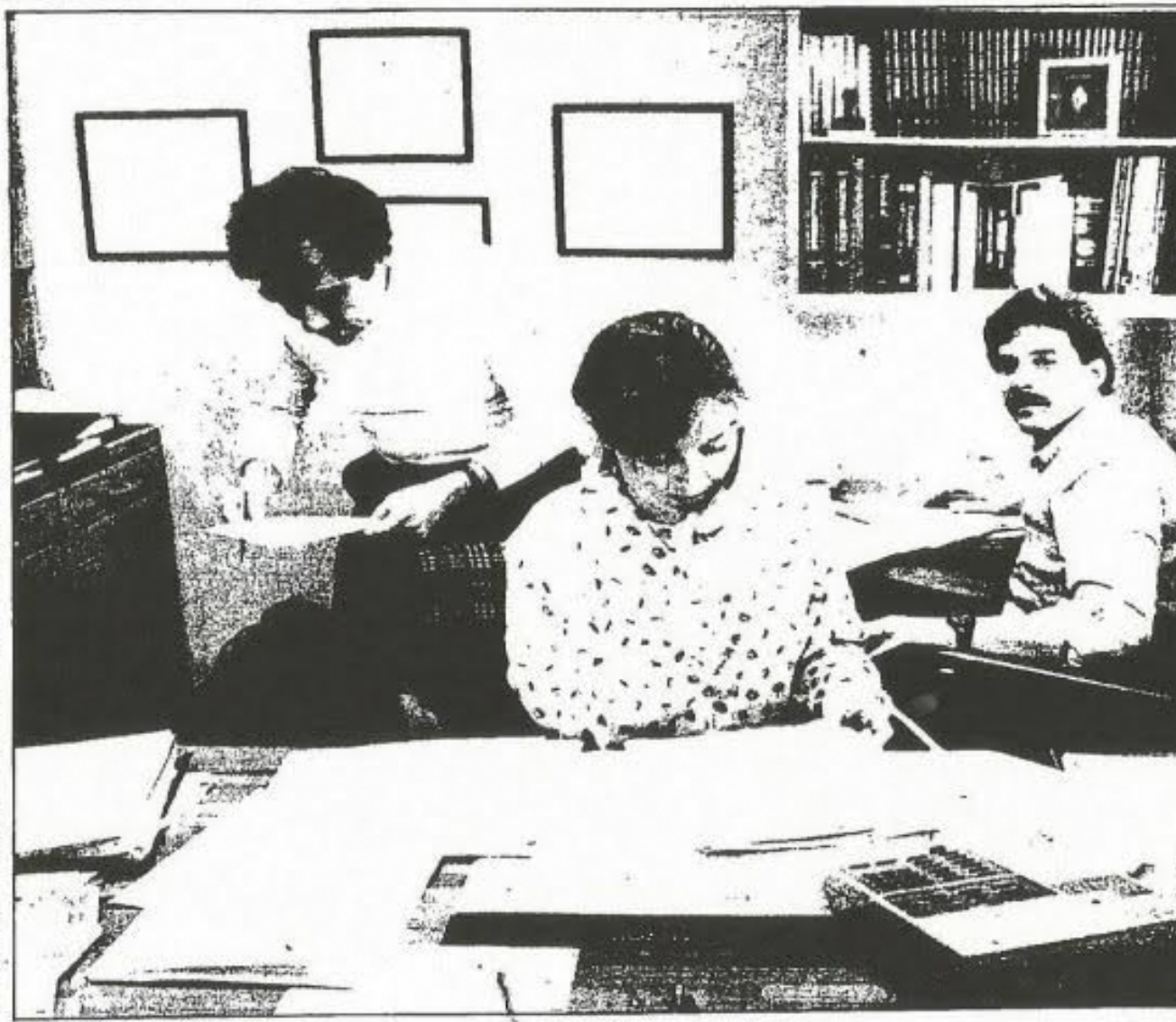
According to Cheney, he and the three doctors will hold a panel discussion on the outbreak and the profile of mononucleosis at 7:30 p.m. Thursday, at Sierra Nevada College. They will answer questions from the audience.

Komaroff said the team will stay in the area through Friday or Saturday, and spend two days in Yerington, where a physician reported 105 cases of a similar illness in December.

In their study, they will use some of Cheney and Peterson's healthy patients as a control group.

Komaroff said the team will return to Harvard University to study the data collected in this area. They will use computers to correlate writtten information.

The doctors work at the Brigham and Women's Hospital, a Harvard affiliate.



NLTB

PROBING FOR ANSWERS: Harvard University doctors, from left, Anthony Komaroff, Dedra Buchwald and Nicholas Fiebach review patient records at the offices of Incline Village Dan Peterson and Paul Cheney. The research for clues to the mystery fatigue illness that imately 150 people in the Incline Truckee area in

Immersed in a Medical Mystery

By Jean Lamming

Internist Paul Cheney found himself on the trail of a significant medical phenomenon after coming to Incline Village to enjoy a small family practice.

DR. PAUL CHENEY

Cheney and Peterson turned into the Woodward and Bernstein of clinical medicine

Photo by Teresa Willis

Internist Paul Cheney wasn't looking for medical intrigue when he moved to Incline Village.

In fact by 1983 the 36-year-old internist was tired of paying dues.

So tired he was willing to part with dreams of research for a comfortable lifestyle for him and his family.

But that's not what he found at Lake Tahoe.

Instead, Cheney spent most of his three-and-a-half years in Incline in a tunnel of medical mystery - bird-dogging a clinical phenomenon that is still not solved.

Through the two-year odyssey the mystery consumed him - sometimes with the excitement of discovery, other times with lows of self-doubt and peer criticism. There was also the nightmarish reality of the illness itself, as it progressed.

ABOUT THE AUTHOR

Jean Lamming is a native of St. Louis, Mo. and a 1982 graduate of the University of Missouri School of Journalism. She worked on the Washington, D.C. staff of a U.S. Congressman for a year-and-a-half before joining the North Lake Tahoe Bonanza staff in 1984.

His family took the ups and downs with him. "It began to be like a detective story," said his wife Jean Cheney. "There were clues and he wanted to track them down. It was frightening - you wondered where is this thing going to end - what have we got ahold of here?"

At the same time Jean Cheney said the stalking of the mystery was compelling and fascinating enough to distract her from doctoral work at the University of California at Davis.

By the summer of 1986 Cheney emerged as one of the nation's few clinical experts on a disease state that is showing up as a health trend in thousands of people across the country. Its ultimate impact is not yet known.

His work on the clinical happening at Lake Tahoe attracted national experts whose simultaneous research was jibing on slightly different research fronts.

The media followed and Cheney's boyish visage was catapulted to the nightly network news, *Newsweek* magazine and his name appeared in newspapers from coast to coast.

His work also, haplessly, turned the country's eyes on Incline Village and what was labeled as its mysterious fatigue sickness.

Patients who complained of the little-understood chronic fatigue began trekking from around the country to see him. By that time it was clear his plans for a small, quiet, family practice had been derailed.

In January, Cheney, 39, decided to leave. He had not found the financial security or even-paced life he had looked for in Incline Village. Instead, he had found the research work he had dreamed of.

As one of the most noted clinical experts on chronic fatigue and a newly-discovered virus that attacks the human immune system, he moved to a noted North Carolina clinic where he can have the best of both worlds - patients and research.

But before the National Cancer Institute discovered a new virus that some of his patients have, before the Harvard team came to Incline to help investigate, before Cheney's reports were met with interest from patients around the country - there were only questions.

A Unique Partnership

He and his partner, Dr. Daniel Peterson, faced those on their own.

But it was their partnership that made the difference. Through the match of talents, Cheney and Peterson turned into the Woodward and Bernstein of clinical medicine.

Instead of shrugging their shoulders at a series of viral infection cases that showed no sign of recovery, they pioneered mounting clinical evidence that tied the medical mystery to a research lab in Bethesda, Md., to about 100 sick people in Yerington, Nev., and to afflicted people across the country that could number in the hundreds of thousands.

In the beginning, Cheney and Peterson saw only a growing number of sick patients.

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Partnership meshes well in the search for answers

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The first piece of the clinical puzzle walked through their door in late 1984 in the form of a 17-year-old female basketball player from Incline High School. She had something that looked like chronic mononucleosis. She got better.

Not long after, a teammate came in. "She didn't get better," said Cheney.

By 1986, the number of North Tahoe area patients with like symptoms had reached 200. For some, those symptoms would have begun to change and intensify to the point of what Cheney called "horror."

It was Peterson who noticed the first cases by listening to what patients were saying.

He and Cheney began compiling the information and went to work to find the answer. One starting point was chronic Epstein-Barr virus (CEBV), a virus in the herpes family that lives in the human immune system and can be activated to cause an illness like mononucleosis, but much longer-lasting.

Cheney's mind is a researcher's mind. He works from a different approach than most clinicians.

"He's a true scientist," said Peterson. "He really loves to problem solve. I would watch him work through each step of it."

Cheney and Peterson slipped easily into roles that complimented each other. Peterson said he focused on the clinical end, talking with patients, and fed information to Cheney, who tapped a research grapevine that he built over the months.

Much of his work was done over the telephone, first calling researchers about the human B-cell in the immune system. One call led to another. Cheney didn't balk at calling anyone, no matter how prominent, and people talked to him, said his wife.

In two years, using what his wife calls "his terrier instinct," Cheney had compiled a dog-eared, doodled-on piece of paper covered on two sides with names and numbers of collaborators - and some answers.

"It was clear Paul talked the researchers' language and that was critical," said Peterson. "After one door opened another door opened and another.

"It was his cup of tea," said Peterson. "When he got on EBV there was no stopping him - he'd have one phone in one hand and another in the other."

The two exchanged ideas, looking for answers. "We'd make a hypothesis and prove it," said Peterson.

They also weathered criticism together. Elements of the community blamed the doctors for a poor economy when media reports began to focus on the mystery malady in Incline Village.

North Shore doctors disclaimed them, asking why no one else had seen this mysterious fatigue show up in their practices.

National researchers typically sneer at the findings of clinicians – doctors who work with patients.

For some time the doctors worked in a void, throwing ideas at each other and sticking it out together. "You couldn't do it by yourself," said Peterson.

Their partnership was what Peterson called "a perfect, unusual combination. When you have a colleague who comes from a different viewpoint but has a commonality – we're both internists – it's dynamite."

Intellectual Challenge

Cheney's "different viewpoint" was built years before he came to Incline Village.

He always thought of himself as a researcher.

From the beginning, his experience was different from most doctors.

While his future medical school classmates were competing for grades in pre-med classes, Cheney was studying physics at an experimental school called Eckerd College in St. Petersburg, Fla.

There, students were graded on a

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1984-85 Lady Highlanders selected for Incline hall of fame

Sports FOLLOW SPORTS | January 17, 2018

Justin Scacco FOLLOW
jscacco@sierrasun.com

Inclines 1984-85 girls' basketball team captured the Class 2A state championship that season.
Courtesy photo |

The 1984-85 basketball season was perhaps the greatest in Incline school history.

Cheney is committed to the educational process

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non-competitive, pass/fail system and encouraged to write, and think creatively in core courses that covered the classics, humanities, and reading and writing.

His parents had grown up during the depression and had raised him to believe in education.

His father was the son of a plumber and the first person from his town to graduate from Georgia Institute of Technology.

Cheney's mother was a south Georgia sharecropper's daughter. She had used a government program to pay for her nursing education during World War II.

"I was conscious of school and how important it was but I was also a dreamer," said Cheney.

From Eckerd he went to Duke University to earn a Ph.D in atomic physics. His life-long hero is Albert Einstein, a man he discribes as more than a great scientist - a great human who had no care for material possessions.

But it was at Duke, which he calls a "medical Mecca," that he began to brush with medical students and biomedical researchers.

Through informal conversations around his apartment complex, Cheney began to see that his entree into exciting research was through medicine, not physics. "The golden age of physics was in the first half of the century," he said. "Medicine is the opposite."

Without a medical degree he could only work with lab animals. Medicine would pay better and offer more research flexibility..

As a 26-year-old physicist he entered Emory University's medical school in his native Atlanta, a bit older and more seasoned than the rest of his class and one of two Ph.Ds accepted to the program that year.

Tough Road to Research

Medical school was nothing

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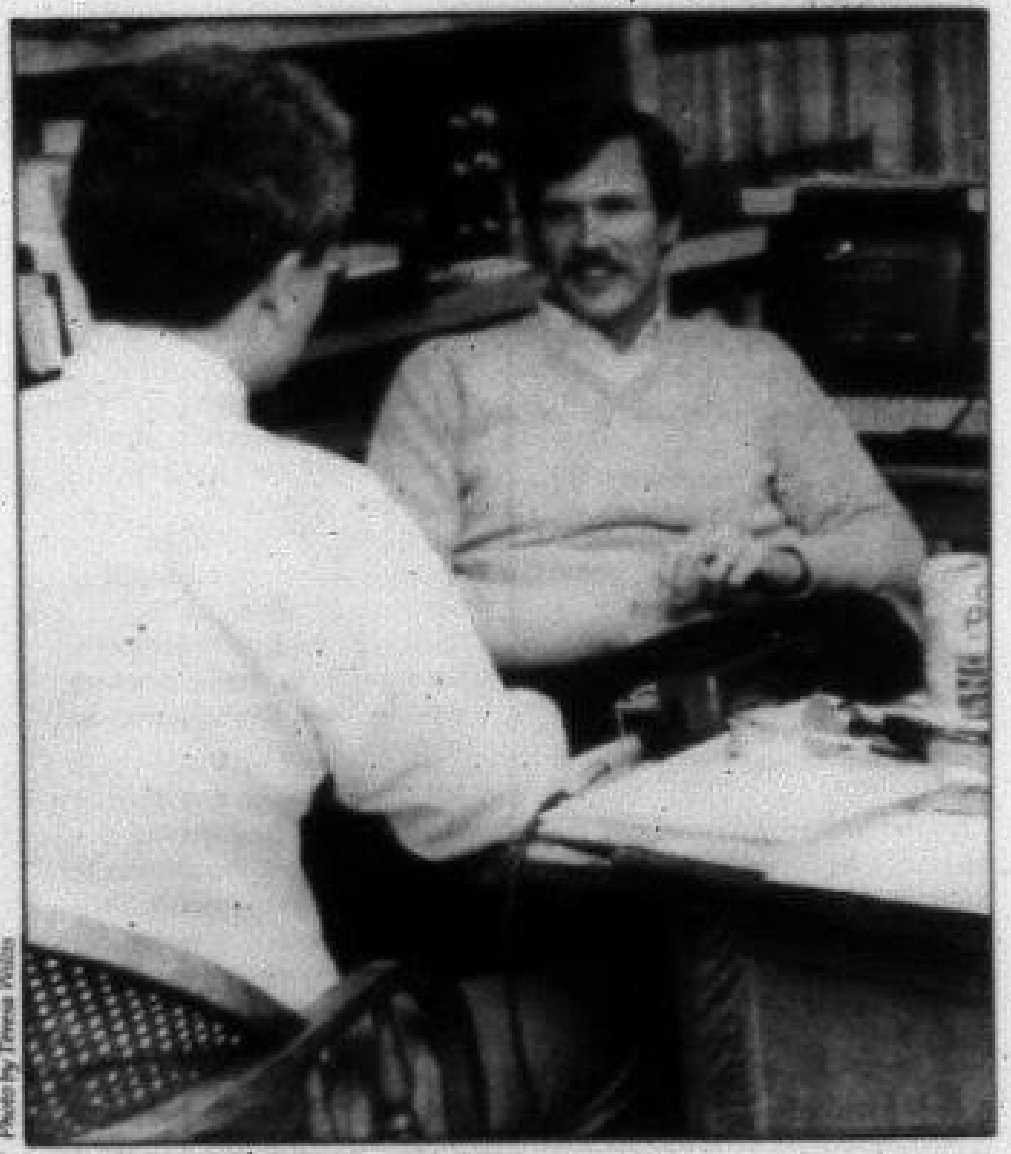

Photo by Teresa Wilds

Dr. Daniel Peterson's expertise complimented his partner's in their investigation, which brought national media members into their Incline office.

Research field has always piqued Cheney's interest

Continued from Page 18

like the intellectual challenge of Eckerd, or the research experience of his post-graduate education. It was rote. But it was a passage to the research he dreamed of.

"So what did I do?" said Cheney. "I got bored." Other medical school students scrambled and crammed. "Instead I went to class, took good notes and did research. Many of them thought of themselves as going to be doctors - I was going to be a researcher."

Cheney gravitated toward a Yale-educated Emory professor who was studying the cell messenger system. A string of extracurricular research projects ensued.

Ironically it was the immune system, which he would come face-to-face with in Incline years later, that took his research focus. He studied the lymphocyte cells in the immune system of cancer victims.

When he decided there were too many variables and uncontrollable factors in studying human lymphocytes, he turned to the hybrid white mouse.

At Atlanta's Centers for Disease Control, which he would also brush with later, he conducted a study of lymphocytes in the cancerous tissue he would create in mice by injecting tumors into their feet.

"It was a beautiful system to study what was going on," he said.

The research taught Cheney an important lesson. While he watched people dying in their hospital beds, hooked up to chemotherapy tubes like fruits shrivelling on a vine, he said he knew the answer was somewhere else - in the immune system.

In those days, and still today, the immune system is "The Black Box," he said. It's an unknown. "It's like the outside of a watch – it looks like it's working but you don't know what is in there."

The chemical treatments for cancer weren't as elegantly efficient as the immune system because they killed too much. The immune system targeted only the enemy. "Nothing kills cancer faster than an immunocompetent cell," he said.

Cheney wanted to find out how to harness the immune system to beat cancer. He wanted to be an oncologist.

So he took the road that would lead him to internal medicine. It was one of the most grueling routes through medical school.

The Emory University Medical School offered one of the largest internal medicine training arenas in the country.

There were six different fronts: six hospitals.

There was the 1,000-bed public hospital that served the 1.5 million population base in Atlanta; the university hospital where academic heads led student trainees dressed in ties; the private hospitals; and the veterans hospital where chronic lung and cancer patients would come from the region.

At the public hospital ties came off and the interns worked. "Those hospitals are neat to train in because you have complete control. When you were on call you were up the entire night and you'd see everything. The triage nurse would decide – if he was blown open with a bullet she would send him to the left, and if he had a heart attack, to the right."

During the internal medicine internship he worked 36-hour shifts at the hospital, taking what violent or medical emergencies Atlanta would throw him, sleeping three nights out of four.

"As the sun rises you have five or six people who are very sick. You spend the day checking each one.

At the end of the long shifts, he would collapse at home at dinner. "I'd fall asleep at my plate." This lasted three years.

The Path to Incline Village

Jean Cheney, whom he had met in graduate school, was teaching English at Georgia Tech and raising their son Scott. "We lived in hovels – garage apartments. We had furniture with holes in it," said Cheney.

When their daughter Kate was born, Cheney reluctantly signed his name to a U.S. Air Force contract which paid for his medical school expenses in return

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First fatigue patients raised puzzling questions

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for three-years of service when he finished.

The Air Force welcomed his choice of an internal medicine residency – they needed internists. But not oncologists.

So when Cheney completed his residency he was called to serve.

Out of a list of 30 bases of which he could pick six, he was sent to Mountain Home, Idaho. "The only problem was there were only five good places," he said.

He and his family lived on the Snake River Plateau 60 miles south of Boise, where he worked as chief of internal medicine at an Air Force base of 10,000 people. "You couldn't even see a tree," he said.

But looking back Cheney said there he learned that he liked working with patients. "It was my first experience as a real doctor."

When Incline Village internist Peterson called to tell him he was looking for a partner, Cheney was interested.

Coincidentally, he had just visited Lake Tahoe. "I thought it was the most gorgeous place I'd ever been in in my life."

He and Jean had decided Incline Village was probably too small an area to support an internist. But then Peterson, who had been told of Cheney by a mutual friend, made his call.

There was still the oncology training and research that the Air Force had diverted him from. But the grueling work and tight money weren't that far behind.

Peterson's offer was a turning point.

"I guess at that time I had what you'd call a mid-life crisis. I was 36 and I'd never really had a job. We still had holy furniture. I decided to make a living and be a doctor. I had been poor all my life and someone called me and offered me a job in a beautiful place."

The move wasn't all sacrifice, Cheney said. "I guess what the Air Force had taught me is that I liked dealing with people. People are interesting even if they have the flu."

In 1983 he joined Peterson in practice. He worked 11-hour days five or six days a week. He was on-call at the hospital emergency room for the seasonal flux of emergencies.

That was the schedule until late 1984. Then the picture slowly started to change with the emergence of the chronic fatigue illnesses.

Tahoe's Mystery Malady

The first perplexing cases came from the Incline High School girls' basketball team. Then they were followed by adults in January of 1985 who had been sick for several months. Some were adults Cheney knew personally - active, professional people. "They weren't the sickly kind," he said.

The patients weren't gravely sick, but they couldn't make it through the day. They had cold-like symptoms.

It was about that time that Peterson was flying home from a trip and while on the airplane had read a provocative article in *Annals of Internal Medicine* about chronic Epstein-Barr virus.

The article was one of the first to direct attention to the possibility that chronic fatigue was not just a hypochondriac's complaint but an illness caused by a virus – chronic Epstein-Barr virus, a herpesvirus of the chicken pox and shingles family, that lives in the human immune system wreaking symptoms like mononucleosis, but for months or years.

The article identified a Los Angeles lab that was using a new method to test for the virus in the blood of patients.

That gave Peterson and Cheney a direction.

But the article didn't say

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Some horrifying symptoms develop in fatigue patients

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anything about outbreaks, only isolated cases.

"Then the next thing that happened was the epidemic. These people started coming out of the woodwork. Just like the first 10, they weren't getting better."

The doctors were finding enlarged lymph nodes and swollen speens.

By April of 1985 as many as 15 people a week were coming to their practice with the same general symptoms.

In June of 1985 Cheney called the Centers for Disease Control. They questioned him and ultimately asked for blood, which confirmed his assertions enough that in October the CDC sent a team of epidemiologists to Incline Village to conduct a limited study.

By the fall of 1985 the incidence of new patients had trickled to a near standstill, but Peterson's and Cheney's caseload numbered 150 chronic fatigue patients from the North Shore and Truckee.

The CDC studied 14 patients, measuring the antibodies in their blood against 28 controls.

The CDC doctors returned to Atlanta and published an inconclusive report that lent little credence to Cheney and Peterson's worries and assertions. It was a blow that marked one of the lowest points Cheney hit during the two-year period.

"That was picked up by people in the community that Dan and I were either wrong or nuts." Cheney said it damaged their credibility. "It hurt our feelings because we legitimately thought we were looking at something."

Cheney now regrets having called the government agency and said instead he should have called researchers interested in investigating a relative unknown. As it turned out, in February 1987, a CDC spokesman who had studied the North Tahoe cases, said his team had actually entered the picture too early.

The Sick Get Sicker

Not long after the CDC had come and gone, the puzzle began to further take shape.

"Strange things started happening to these people," said Cheney. Some reported neurological problems. They couldn't remember how to get home from the store, or how to add a column of numbers.

Patients came in with tumors, encephalitis, and one with lymphoma, a type of cancer related to Epstein-Barr virus. "We were horrified," said Cheney.

After the CDC disappointment, and the strange complications that followed, there came a new light. In December Dr. Tony Komaroff called from a Harvard Medical School teaching hospital and said for two years he had been studying an illness that had all the same earmarks.

He learned of Peterson and Cheney from a newspaper clip that had wended its way to him.

Komaroff, in Boston, had been watching isolated cases in the Northeast. He wanted to conduct a formal, academic study.

"If it was going to take two months or two years we were going to do it right," said Cheney. The Harvard team was looking for a new strain of EBV.

The strange symptoms that unfolded in the fall continued to progress. There were lesions, or spots of swelling on patient's brains, and neurologic problems.

A team of neuropsychologists tested 23 of Cheney's patients to differentiate between depression and medically-caused cognitive dysfunctions. After testing the 23 with blocks and exercises, the specialists diagnosed all with cognitive dysfunctions.

Cheney and Peterson continued to search for answers. "We sat back and said, "what can harm the immune system and activate EBV?" He had patient blood samples screened for AIDS but none tested positive.

Public Criticism

Meanwhile the investigation was taking its toll.

There was the bitter condemnation by some townspeople. Jean Cheney said one citizen called the puzzle "the hoax of the century."

Community members alleged that Cheney was making a killing off the lab fees, the sick people, and the national media attention, all at the expense of

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Pleas for help come from around the nation

Continued from Page 21

the Incline Village tourist economy.

"I think he was misunderstood in town by most people," said Peterson. "I think he was thought of as an enemy of the people. Nothing could be further from the truth," said Peterson.

Peterson said some people took Cheney's enigmatic reserve and quiet approach as snobbery or aloofness.

"He does think differently than a lot of other people. He is prone to be quiet, sit back and let everyone else talk," Peterson said.

And Bruce Purdy, of Incline Village, said, "He isn't the type of fellow that would walk down the street and wave to everybody."

No matter what the situation, he approaches it from a direction of level-headed assessment, said Peterson. "Every single episode with him is viewed according to the scientific model."

According to Peterson, most people didn't know what to make of that. Most people didn't know Paul Cheney.

"You could go to one of his lectures and never appreciate. . . that he was concerned for society at large," said Peterson.

Jon Davidson knew the Cheney family socially and from St. Patrick's Episcopal Church, where Cheney took a leadership role. Davidson had the opportunity to see the forces that motivate Cheney. "Paul had a ministry of his own that was above and beyond the kind of thing he was paid for in the medical profession," said Davidson.

On the home front, during the investigative bout Jean Cheney would hear blow-by-blow accounts of the progress, or lack of it. She shared some 400 letters sent to Cheney by fatigue patients that recounted the medical and life-changing sides of the illness. They were pleas for help.

"These people are just desperate," said Jean Cheney. "This just touches me. It's not a life-threatening disease, it's a life-wrecking one."

She saw their role in the unraveling of the mystery as a once-in-a-lifetime experience. But it was taxing. "It has gotten to the stage where it's sort of overwhelming."

Their children, Scott, 16, and Kate, 12, were tired of hearing about it over dinner, Paul Cheney said.

Through it all Cheney's practice had changed. "I was going from that internist in Idaho to a noted expert," he said. The phone bills grew, the office overhead was still there, but he was on the phone more, and not getting paid for it. His clinical visits were more often intense hour-long discussions with fatigue patients who needed encouragement and explanation, and those weren't as lucrative as seeing several patients in an hour.

"I never felt like truly charging patients for the time I spent with them."

The schedule at home was tight. Jean Cheney was commuting to UCD to finish a Ph.D. in English composition in 1985. Her husband was working long hours. "Someone had to help the kids with homework and make dinner," she said.

National Media Coverage

Meanwhile the media came from all fronts to capitalize on the happening at Lake Tahoe.

Jean Cheney thinks the national media attention will prove fleeting. "I think It's very temporary."

In spite of some townspeople's perception, Cheney said he never courted the media.

The only time he ever called reporters was to defend himself or counter misinformation. Most of the time he just went along with them. "If the media decides it's

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Discovery of new virus provides breakthrough

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going to write about it then it's far better to talk to them."

According to Jean Cheney, "We've always been very private people. He's a scientist who has just gotten pulled into this. Being in the limelight is something that never appealed to me, and Paul - he could have easily been a bench researcher."

In spite of its national scope, the coverage had little affect on their personal lives.

"After it has appeared, your life goes on. Sometimes we make jokes about it," said Jean Cheney.

Their families were interested, but unaltered by the attention. "They like to be sent things but after a while it gets repetitious," said Jean Cheney. "We know who we are and we always will. I guess it's a tribute to our family's balance that they aren't changed or shaken by this."

Even considering the demands the investigation placed on their family, Jean Cheney said it has been worth it.

"I'm thankful. I really believe there is a momentum now that these people are not going to be ignored."

A New Discovery

One day in July of 1986 a breakthrough came.

One of the names on Cheney's phone list was Dr. Robert Gallo, of the National Cancer Institute, co-discoverer of HTLV III, the AIDS virus.

Cheney had sent 15 randomly-selected blood samples to Gallo.

During Cheney's regular telephone rounds a doctor told him Gallo had found a new virus in one of Cheney's patients.

The medical research world is competitive. Gallo had no comment on the subject.

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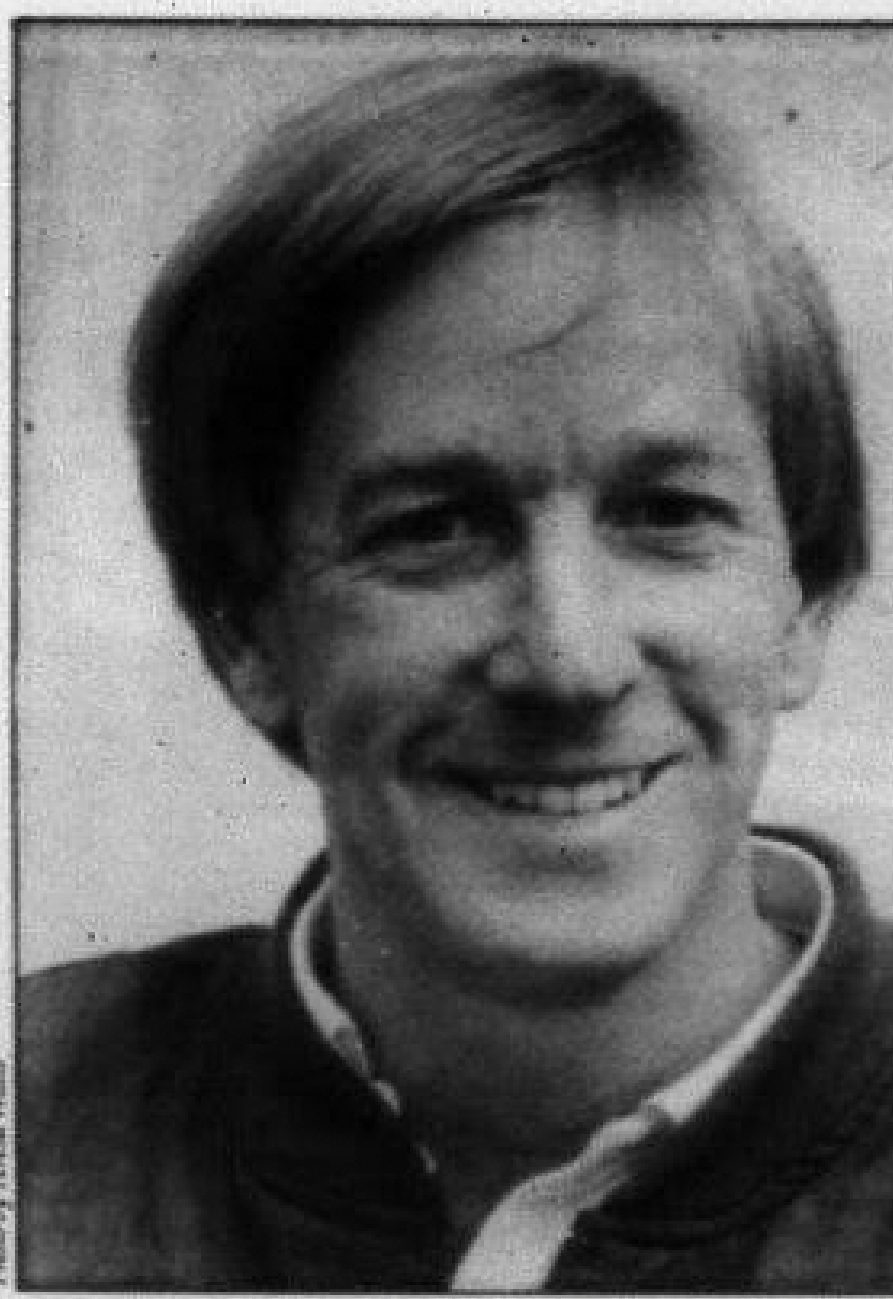
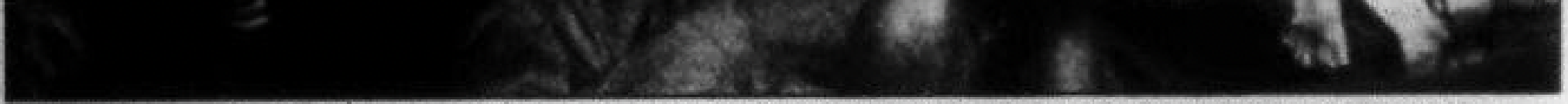


Photo by Teresa Willis

While many saw him as aloof, a friend of Dr. Cheney's des
having a "ministry of his own."

Dr. Cheney, his wife, Jean, 16-year-old son Scott, 12-year-old daughter Kate, and their golden retriever, Winston, gather for a family portrait.

Efforts spawn change in medical community



Dr. Cheney, his wife, Jean, 16-year-old son Scott, 12-year-old daughter Kate, and their golden retriever, Winston, gather for a family portrait.

Efforts spawn change in medical community

Continued from Page 23

Cheney called Komaroff to see if he could learn more about what Gallo's lab had discovered. It was the first Komaroff had heard that Cheney was cultivating other resources. "Tony was angry, but he was also excited because we could crack this thing."

Komaroff convinced a Nobel laureat from Harvard to call Gallo. "Gallo told him everything."

In September of 1986, a collaborative effort started with the National Cancer Institute to prove the new virus caused the epidemic on Lake Tahoe's North Shore, said Cheney.

The new virus is HBLV, which stands for human B-cell lymphotropic virus, a member of the herpes family like EBV. It was the first herpesvirus isolated since 1967.

The study to prove the hypothesis is young. Cheney said it takes at least two years to clinically prove that people contract the new virus, and then come down with the fatigue syndrome. "So, many people get HBLV and don't get it (fatigue) - (they) just have antibodies to it," he said. "Both groups (sick and well) have the virus, both groups shed the virus, but how do you prove it.?" Cheney asked in mid-January, 1987.

Exciting Progress

Today, Peterson said HBLV is an everyday word in medical communities around the nation. There is a new respect for EBV as well, according to Cheney.

"One year ago no one believed in EBV. Many now are wondering. That's a huge change considering the egos of physicians," said Cheney.

Only time will tell what role HBLV will play as a cause of human illness. Some of the North Shore patients are still quite sick.

Pointing to a blown-up photograph of a railroad-tie shape inside of a cell, he said, "Some of this has never been seen before. It could be everything or it could be nothing. But it's exciting," said Cheney.

At the Nalle Clinic in Charlotte, N.C., a research clinic on the order of the Mayo Clinic in Minnesota, Cheney said he will have the best of his two worlds.

He took a leave from Lakeside Hospital in January and went to North Carolina, with his family soon to follow.

There he will study HBLV with the support of a research foundation, equipment and a research staff.

As an independent doctor not affiliated with a university or with the government, he will maintain the freedom to seek out findings from other doctors around the country.

There won't be the pressures of supporting an office - he will have the luxury of seeing as few or as many patients as he wants.

But he will never get too far into a lab to loose sight of patients.

"The patients are the key," he said. "Whatever happened, the only constants are the patients. That is what produced all of what happened here.

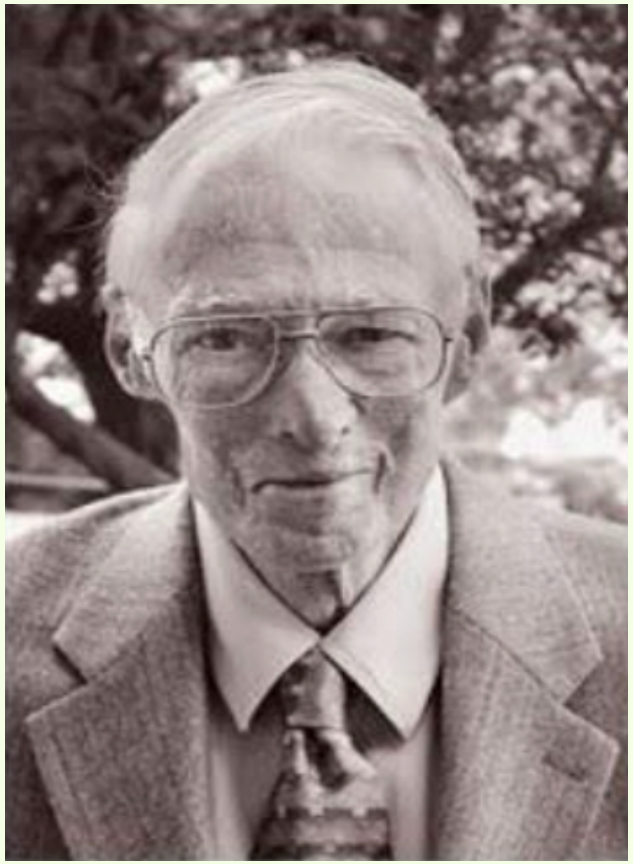
It takes time to talk to a patient. It takes empathy. But the technical can stab you in the back if you depend on it."

His three-year foray into private medical practice was intended to provide more income and a better life for his family than his previous dogged existence as a researcher. As it turned out, he surprisingly found himself "in the middle of an important discovery" and realized the financial limitations of a small, family practice.

Now, Cheney sees his new post at the Nalle Clinic as a way to achieve the financial stability he was looking for in Incline Village and at the same time to fulfill his dream of substantive medical research.

Cheney said, "I've done research all of my life and I guess fate has it I should continue."

THEODORE VAN ZELST



THE FATHER OF CHRONIC FATIGUE SYNDROME

- Theodore Van Zelst was an innovative civil engineer that co-founded Soiltest Inc. in his family's garage and beccame the pioneer in soil testing.
- He owned several patents for road and soil testing equipment and some of his company's designs were incorporated into the first moon landing.
- During WWII, his work with the U.S. Navy helped develop the swing-wing design that allows jets to break the sound barrier.
- In the 1980s, one of his daughters suffered from CFS and he pushed for recognition of the condition, testifying before Congress to request funds to study the disorder.

Malady stumps the experts

By JEAN LAMMING
Staff Writer

National medical researchers and local doctors are stumped by a malady that has struck the North Lake Tahoe and Truckee in epidemic proportions for the last year.

Doctors from the federal Center for Disease Control in Atlanta left Incline Village last week after launching a study into a seeming epidemic of fatigue.

The researchers based their study on 150 cases uncovered by two Incline doctors alone. However, after two weeks of on-site research and testing of cases documented by doctors Paul Cheney and Danjel Peterson, Center for Disease Control (CDC) researchers left with more questions than they could answer.

CDC Dr. Gary Holmes will continue testing in Atlanta, for the sickness which seems to break medical rules.

According to Cheney, the mysterious illness struck in January. "A bunch of people all about the same age bracket. – many of them teachers – began coming in." All complained of some level of fatigue.

For many reasons the sickness spells confusion. While there is no known treatment for the fatigue, the doctors have not been able to diagnose it or determine how it is passed on, though they do not believe it is easily transmitted.

According to Cheney, standard tests for mononucleosis discouraged that as a diagnosis for most of the patients. Though the disease appears to be similar to mono, most of the patients have been middle-aged and mono is documented as an illness primarily of the young.

The large numbers that flowed in through the spring also sparked concern. According to the doctors, mono is not easily transmitted, except through saliva, and is almost never seen in epidemic proportions.

Also, mono infections usually fade in four to eight weeks. Holmes said this illness has caused varying levels of sickness – from two months of mild fatigue to up to a year of severe fatigue. In some cases it has kept people from their work and daily routing.

Also, most of the patients showed evidence of old mono infections and mono does not usually strike twice, said Cheney.

Holmes said many other doctors may have seen patients complaining of fatigue in past months. However, Cheney and Peterson were the only area physicians to employ a test that became available in January. The new test raised more questions.

Cheney said when the fatigue patients failed the standard

Continued on Page 2

Neither local doctors nor research experts can find the cause of North Tahoe ailment.

Malady. . .

Continued from Page 1

mono test, he and Peterson tried a test that measures the reaction to a virus called Epstein-Barr by plotting the level of antibodies in the blood.

Holmes said Epstein-Barr virus is considered to be the common base for most mono infections. Most people have the virus by the time they reach 40, though it may not have been triggered into action.

Much to their surprise, many of those tested were shown to have antibody levels high enough to suggest mono, said Cheney. "When the first tests came back positive it started to pique our interest. All of those things were so strange that we decided to call the CDC," he said.

After working over the phone, and ruling out the possibility of lab mistakes, CDC researchers came to Incline. The CDC is a division of the federal Department of Health and Human Services which provides medical specialists to investigate unusual disease patterns or occurrances around the country.

Holmes said he was especially interested in studying the cases because if the illness proved to be mono, the study would change the commonly accepted profile of the virus. The study would also shed light on the usefulness of the new mono test.

However, after two weeks on the North Shore, Holmes has no more idea what the illness is than when he came. "A lot of these people are quite ill but there is minimal evidence that they have mononucleosis," he said.

Though doctors don't know what it is, and cannot explain how it has spread, Holmes said there is no basis for the concern that has spread in the community.

He is sure the illness is not spread by casual contact, or that it comes from one source such as a restaurant or air conditioning system. In many cases, people were diagnosed as having it, but their spouses never contracted it.

Also, the virus could be harbored for years by an unwitting carrier. So isolating those infected is pointless, he said.

Holmes said the degree of fatigue seems to depend on the susceptibility of the person. Doctors also say the illness, which has had a higher concentration in Tahoe City and Truckee, is now on the decline after peaking in May.

Based on the group of patients he saw, Cheney said he thinks the illness spread in school teachers' lounges, and from there into the community.

Cheney said one hypothesis has been drawn which explains why the illness struck adults and not teens, why it lasts so long and why patients showed evidence of old mono infections.

It is possible that last winter an epidemic of an activator virus which triggers mono infections hit the area. It would be easily transmitted, he said. If someone who carried the mono virus caught the activator, their mono would be reactivated. If they didn't have the mono virus, they would just be sick with the activator virus.

The doctors also say because fatigue is not specific to any one illness, this outbreak could be a group of many different maladies. It could also be a hysterical phenomenon that snowballed as word about the illness spread about the area.

According to Holmes, the only chance for concrete answers lies in his Atlanta laboratory where he will try to culture a mono virus from patient samples gathered in Incline. The process is complex because mono is hard to culture and study.

Lakeside. . .

Continued from Page 1

hospital staff. All the pieces are there. To put it together is a golden opportunity," Potter said.

"My short-term goal is increased utilization of the hospital. The basic support of a hospital has to come from the community," he explained.

Latshaw agreed that Potter's priority should be increased use of the hospital.

"His biggest challenge will be to build occupancy; everything else is running very smoothly," he said.

"Ted Van Zelst has a sick daughter with the Epstein-Barr Virus disease. The CDC is not taking it seriously. He has given seed money to Dr. Komaroff and I to find something that will force them to take notice."

Dr. Komaroff was Associate Professor of General Medicine of Harvard University at the time of the outbreak. He was seeing sporadic cases of Dubois' "chronic mononucleosis" in 1983. No clusters. No outbreaks.

What Incline High Students Think Of The National Media – See Page 3

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NORTH LAKE TAHOE BONANZA

Vol. 12 No. 58 – 3 Sections, 26 Pages | Serving Incline Village, NV; Crystal Bay, NV; Kings Beach, CA; Tahoe Vista, CA | Wedne 1987

Incline victims show cell abnormalities

Tests reveal new clue in fatig' ilness

By Chris Fotheringham
NLTB Managing Editor

Laboratory results published this week in a prestigious medical journal confirm that over 50% of Incline Village chronic fatigue patients tested have suffered "dramatic" abnormalities in their immune systems.

Calling it the "most significant finding yet" in efforts to unravel the mystery of the widespread fatigue illness, Harvard researcher Dr. Anthony Komaroff said Monday the report published Sunday in the *Journal of Immunology* is the first scientific study that confirms "something is wrong with these people."

"It is really dramatic," said Komaroff, who is chief of general medicine at a Harvard teaching hospital in Boston.

The article, which underwent nearly 11 months of peer review before being published, was authored by Komaroff, Incline Village internist Dr. Daniel Peterson, and former Incline internist Dr. Paul Cheney. Dr. Michael Caligiuri, an immunologist with the Dana-Farber Cancer Institute of the Harvard Medical Center, was the lead author for the article which was originally submitted for review in January.

Komaroff says test results reveal an attack on the immune system's "natural killer cell" which is the body's primary means of killing virus-infected cells or cells that become cancerous.

Komaroff said, "There is a substantial reduction in the number of natural killer cells in patients tested." He said the study has determined that this "major defense against virus infection and cancer" is damaged in over half of the test cases involving Incline Village patients.

Komaroff first brought his team of researchers to Incline Village in February of 1986 after Incline doctors Cheney and Peterson had documented an outbreak of approximately 200 cases of mononucleosis-type illnesses in the North Tahoe and Truckee area beginning in the fall of 1985.

While the Incline Village cluster of fatigue cases has drawn primary attention in the national media, researchers have found widespread occurrences of the illness throughout the country.

See TESTS on page 9

'This is the first time this sort of defect. . .has been recorded in any kind of disease.'
Harvard Researcher
Dr. Anthony Komaroff

Bonanza Day

Nevada's warmest stretch in 99 years

August-October temperatures highest since records began

New human herpes virus found

By Ellen Robinson-Haynes
Bee Medical Writer

Scientists at the National Cancer Institute announced Thursday they have discovered a new member of the human herpes family in patients with cancer and other immune system disorders.

The virus, named HBLV by prominent cancer and AIDS researcher Robert Gallo, is also being examined as a possible cause of the mysterious outbreak of a chronic mononucleosis-type ailment that has been plaguing 200 Lake Tahoe residents for more than two years.

"We are investigating a number of connections, not the least of which is the new HBLV virus," said Paul Cheney, one of two physicians who have been treating Lake Tahoe area patients afflicted with the unnamed malady for two years.

However, he and the NCI researchers were unwilling to discuss what Cheney said are ongoing studies into the relationship of the new virus and the Lake Tahoe outbreak.

Cheney has maintained all along that the cause of the Lake Tahoe outbreak is either a new virus altogether or a new strain of Epstein-Barr virus, a member of the herpes family that causes acute mononucleosis.

But medical researchers have been reluctant to blame Epstein-Barr for the outbreak because the chronic form of disease caused by that virus is understood to occur in isolated cases, not in clusters.

John Stewart, a specialist in herpes viruses for the U.S. Centers for Disease Control in Atlanta, said clusters of cases of what appears to be chronic mononucleosis similar to that reported in the Lake Tahoe area have been reported around the country.

"Some have lab tests suggesting active Epstein-Barr infection, some suggest active cytomegalovirus infection (another herpes virus) and some have no evidence suggesting a particular virus infection," Stewart said. "We are either working with a clinical entity that is caused by multiple agents or else there may be another underlying factor."

One possibility may be this new virus, he said.

Gallo, in whose lab the virus was isolated, says he fully expects to find that the new virus will cause some kind of disease in humans just as the other five herpes family members do.

And Howard Streicher, a researcher in Gallo's lab, said, "The presence of this virus in a variety of illnesses is being studied."

"Like other herpes viruses," Gallo added, "HBLV may be one of the many types of infections that has serious effects in immune-deficient patients."

While Gallo and his fellow researchers at NCI shied away from saying the new virus causes cancer as some viruses are known to do, HBLV was isolated from patients who have lymphoma, a cancer of the lymph system, and other diseases that cause a proliferation of a kind of white blood cells called lymphocytes.

HBLV joins five other known members of the human herpes family, including two types of herpes simplex that cause oral and vaginal lesions; cytomegalovirus, which causes birth defects when pregnant women are infected by it; varicella zoster, which causes chicken pox and shingles; and Epstein-Barr, which, in the mid-1960s, was the last to be discovered.

The new virus was identified as a member of the herpes family by the similar shape of the protein coat it wears and by an analysis of its DNA.

Herpes viruses typically infect a broad range of cells, including B and T cells, which are vital components of the body's immune system. And they are known to hide out in the body and cause latent forms of infection, such as shingles.

The new HBLV virus appears to attack only B cells, which are derived from bone marrow and play a critical role in reproducing antibodies that fight infection.

Two to four days after HBLV infects cells, they become abnormally large and watery, a growth pattern sometimes seen in cancer cells growing in the laboratory, according to Gallo.

Although the new virus has been isolated from some patients with AIDS, not all patients with AIDS have HBLV. HBLV is not a retrovirus like that which causes AIDS and is clearly not a new cause of AIDS or a co-factor that might contribute to the disease, Gallo said.

In Lake Tahoe, about 20 percent to 30 percent of Cheney's patients have completely recovered. Another 50 percent are improved but not yet back to normal, and another 20 to 30 percent remain quite ill.

There is no generally accepted treatment for his patient's unidentified malady, beyond recommendations made for non-specific viral illnesses.

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SAMUEL D. PARKS,
C. DAVID CLARK, M.
D. JAMES LAWRIE,
ELIZABETH A. JACK,

PATIENT NAME
JOHNSON,ERIK
BOX 595
CARNELNBY,CA 95711

PATIENT ID:
DOB: 04/17/56 SEX: M

ACCN # : A3121814
COLLECTED: 04/02/86 15:50
RECEIVED: 04/02/86 18:20
REPORTED: 04/07/86 15:05

REQUESTING PHYSICIAN
CHENEY

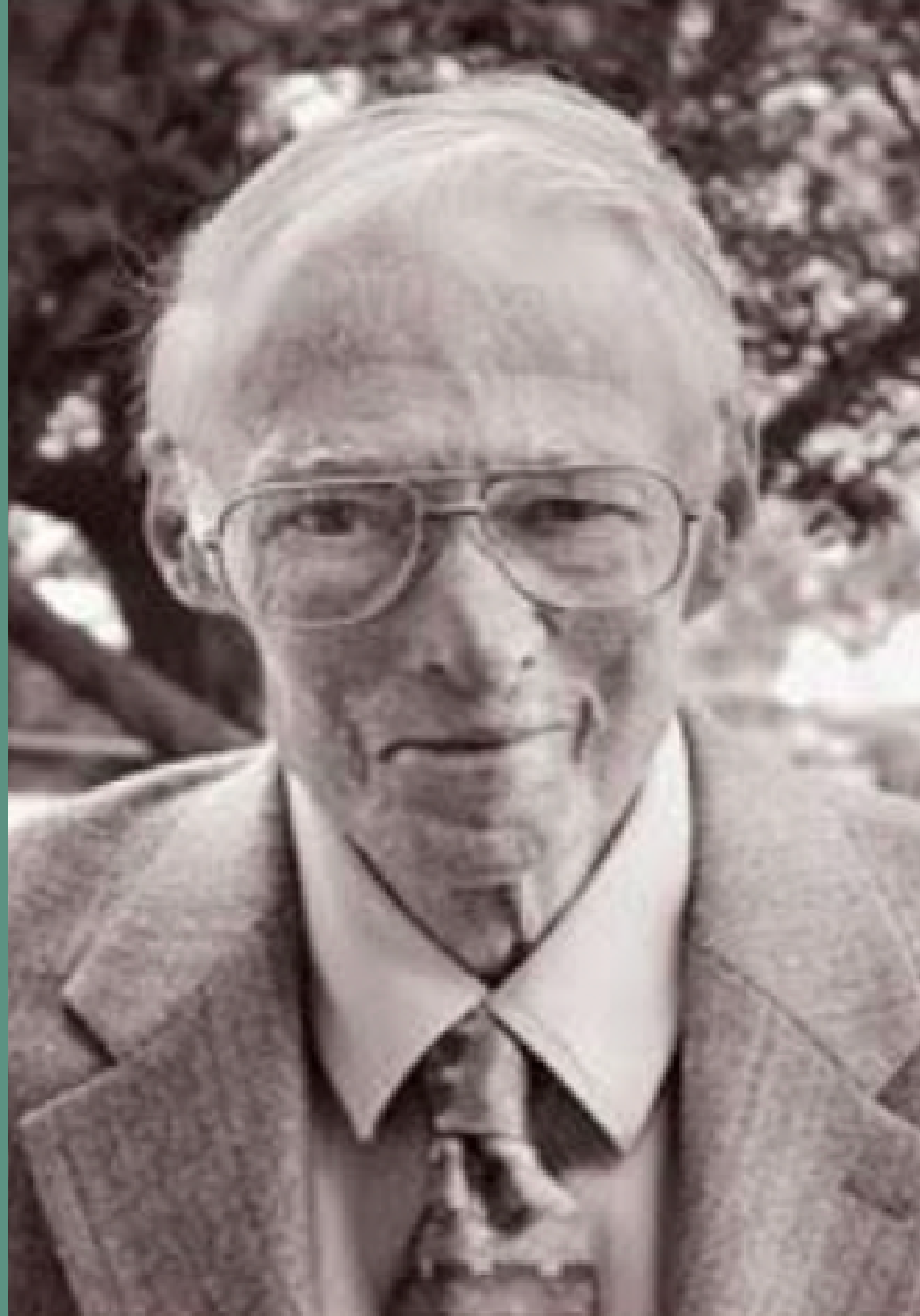
TEST PROCEDURES	RESULTS	REFERENCE RANGE	UNITS
EPSTEIN BARR VIRUS PANEL			
EBV-EARLY ANTIGEN		<1:20	
DIFFUSE RESULT = <1:10			
RESTRICTED RESULT = <1:10			
EBV-NUCLEAR ANTIGEN	<1:2	<1:2	
EBV-CAPSID ANTIGEN, IGG	<1:10	<1:320	
EBV-CAPSID ANTIGEN, IGM	<1:10	<1:10	

TEST REFERENCED TO:
NICHOLS INSTITUTE
26441 VIA DE ANZA
SAN JUAN CAPISTRANO, CA. 92675

DR. CHENEY CALLED ERIK INTO HIS OFFICE, "YOU ARE EBV NEGATIVE, I NEED YOUR BLOOD."

THE VAN ZELST PROJECT WAS A SUCCESS!

The CDC abandoned the defunct "Chronic Epstein-Barr Virus Syndrome" theory and created a replacement, but gave it a really rotten name: Chronic Fatigue Syndrome



Basin News

Harvard doctors field questions

Ninety attend panel on mystery fatigue illness

Basin Briefs

Wrongful death lawsuit is settled

Ex-Shell worker held for burglary

Women held on temporary charges

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For whatever reason, Incline High School has been relatively unaffected.

Cheney said he thinks the reason Incline High School has not been affected as much as other schools is because of its large windows circulating air system and overall good ventilation.

The condition of the buildings with poor ventilation is referred to by the doctors as the Sick Building Syndrome

NCBI Resources How To

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Format: Abstract

Send to

Ann Intern Med. 1988 Mar;108(3):387-9.

Chronic fatigue syndrome: a working case definition.

Holmes GP[1], Kaplan JE, Gantz NM, Komaroff AL, Schonberger LB, Straus SE, Jones JF, Dubois RE, Cunningham-Rundles C, Pahwa S, et al.

Author information

Abstract

The chronic Epstein-Barr virus syndrome is a poorly defined symptom complex characterized primarily by chronic or recurrent debilitating fatigue and various combinations of other symptoms, including sore throat, lymph node pain and tenderness, headache, myalgia, and arthralgias. Although the syndrome has received recent attention, and has been diagnosed in many patients, the chronic Epstein-Barr virus syndrome has not been defined consistently. Despite the name of the syndrome, both the diagnostic value of Epstein-Barr virus serologic tests and the proposed causal relationship between Epstein-Barr virus infection and patients who have been diagnosed with the chronic Epstein-Barr virus syndrome remain doubtful. We propose a new name for the chronic Epstein-Barr virus syndrome--the chronic fatigue syndrome--that more accurately describes this symptom complex as a syndrome of unknown cause characterized primarily by chronic fatigue. We also present a working definition for the chronic fatigue syndrome designed to improve the comparability and reproducibility of clinical research and epidemiologic studies, and to provide a rational basis for evaluating patients who have chronic fatigue of undetermined cause.

PMID: 2829679

[Indexed for MEDLINE]

https://pubmed.ncbi.nlm.nih.gov/2829679/

Photo of Truckee High School

CFS AND SICK BUILDING SYNDROME

Concurrent sick building syndrome and chronic fatigue syndrome: epidemic neuromyasthenia revisited

A C Chester [1], P H Levine

Affiliations + expand

PMID: 8148452 DOI: 10.1093/clinids/18.supplement_1.s43

https://pubmed.ncbi.nlm.nih.gov/8148452/

Abstract

Sick building syndrome (SBS) is usually characterized by upper respiratory complaints, headache, and mild fatigue. Chronic fatigue syndrome (CFS) is an illness with defined criteria including extreme fatigue, sore throat, headache, and neurological symptoms. We investigated three apparent outbreaks of SBS and observed another more serious illness (or illnesses), characterized predominantly by severe fatigue, that was noted by 9 (90%) of the 10 teachers who frequently used a single conference room at a high school in Truckee, California; 5 (23%) of the 22 responding teachers in the J wing of a high school in Elk Grove, California; and 9 (10%) of the 93 responding workers from an office building in Washington, D.C. In those individuals with severe fatigue, symptoms of mucous membrane irritation that are characteristic of SBS were noted but also noted were neurological complaints not typical of SBS but quite characteristic of CFS. We conclude that CFS is often associated with SBS.

CFS AND SICK BUILDING SYNDROME

LINE OF SIGHT

It's important to note that the Chester/Levine paper on the original CFS cluster at Truckee High School made the correlation to sick building syndrome but NOT to mold. This is what Erik stepped to tell researchers about.

> Clin Infect Dis. 1994 Jan;18 Suppl 1:S43-8. doi: 10.1093/clinids/18.supplement_1.s43.

Concurrent sick building syndrome and chronic fatigue syndrome: epidemic neuromyasthenia revisited

A C Chester [1], P H Levine

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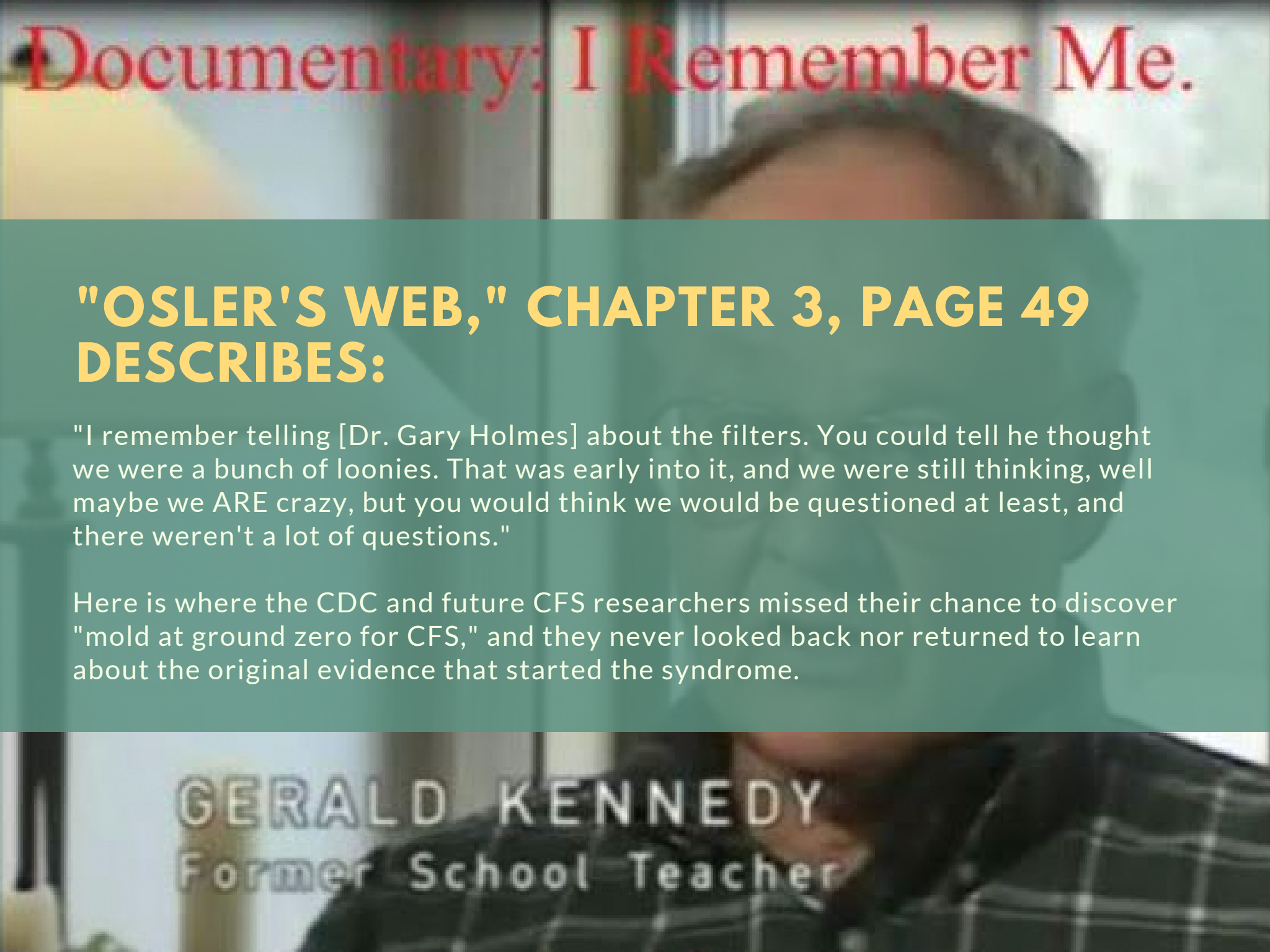
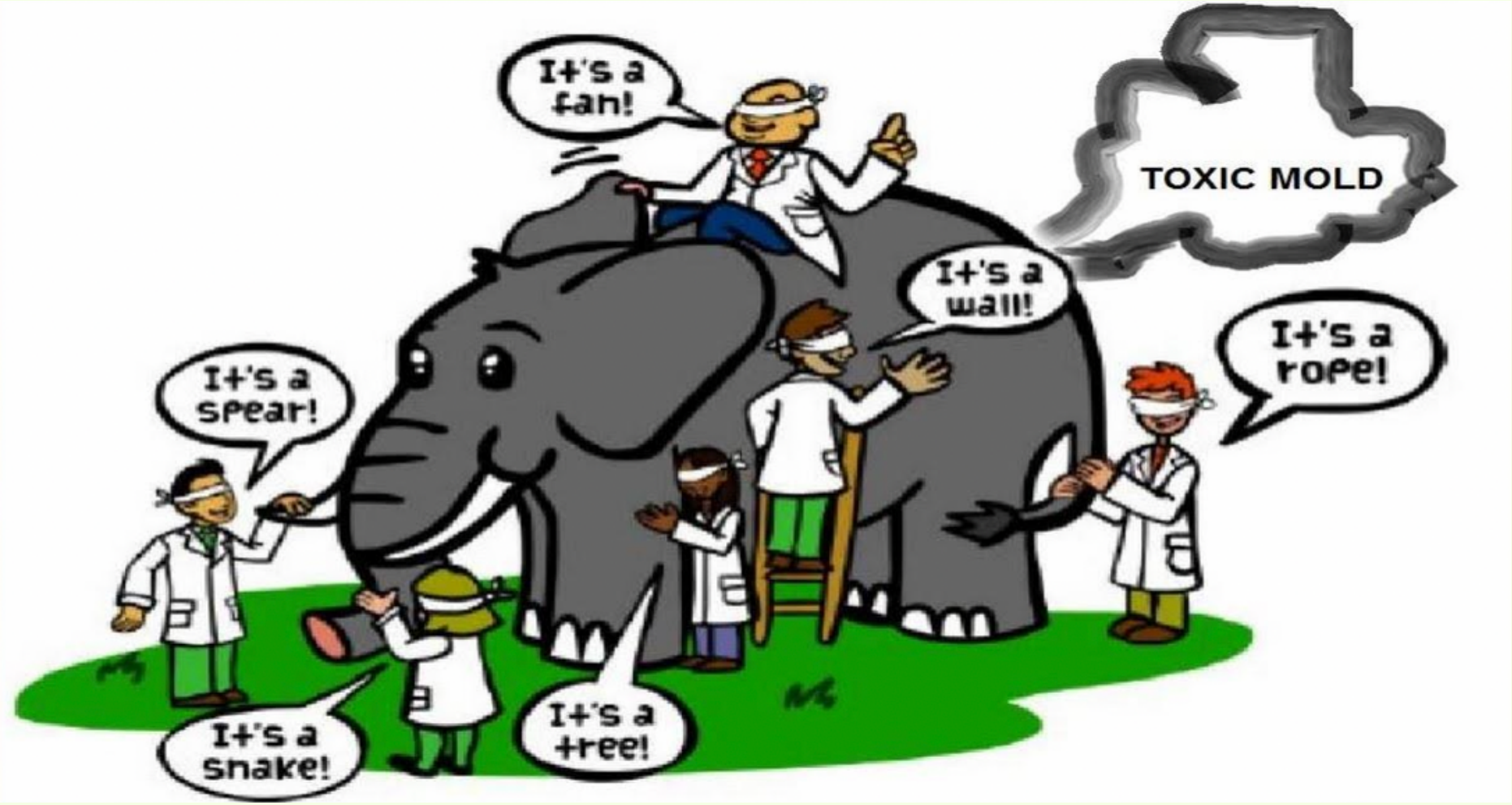


"OSLER'S WEB," CHAPTER 3, PAGE 49 DESCRIBES:

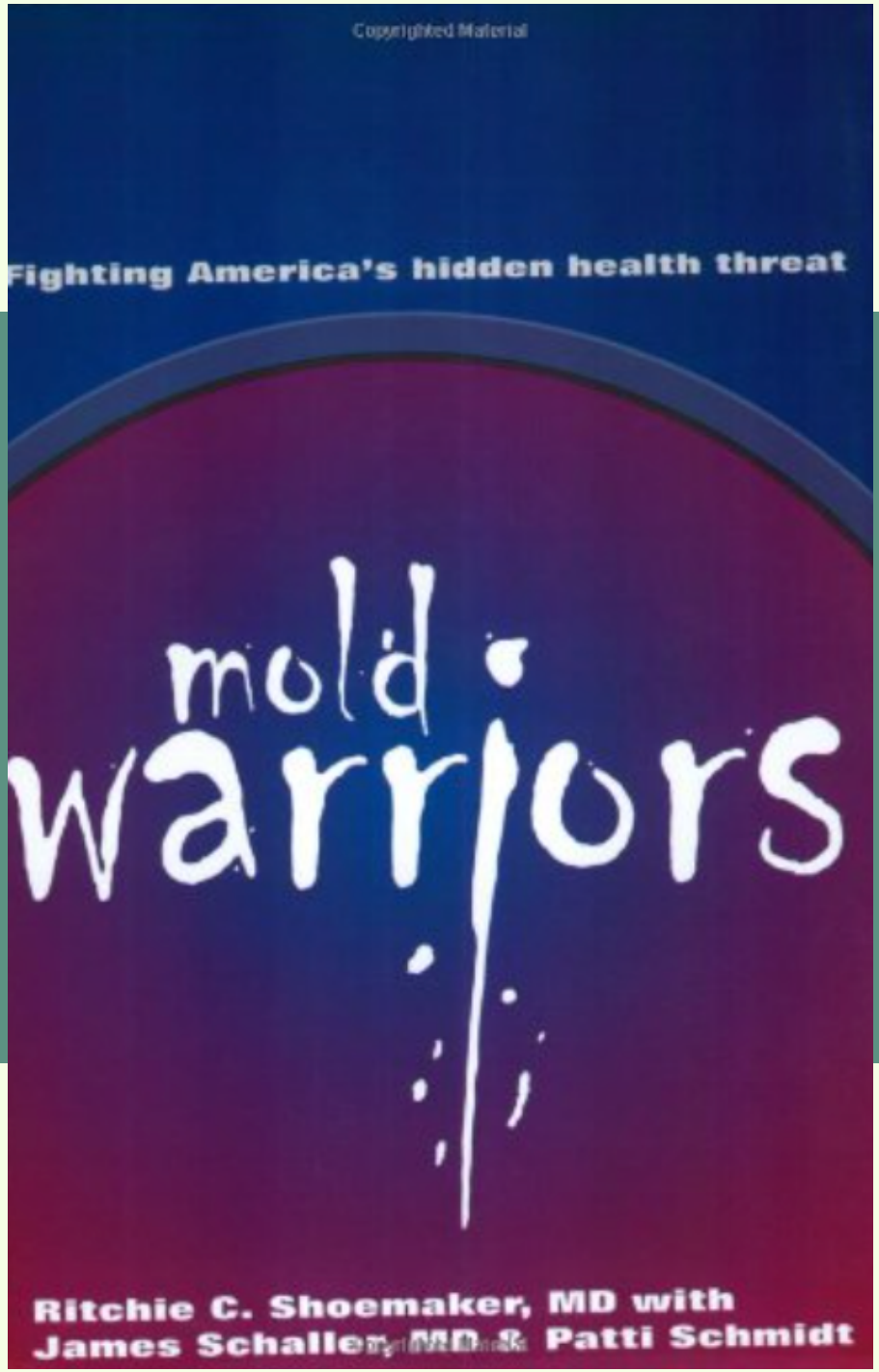
"I remember telling [Dr. Gary Holmes] about the filters. You could tell he thought we were a bunch of loonies. That was early into it, and we were still thinking, well maybe we ARE crazy, but you would think we would be questioned at least, and there weren't a lot of questions."

Here is where the CDC and future CFS researchers missed their chance to discover "mold at ground zero for CFS," and they never looked back nor returned to learn about the original evidence that started the syndrome.


It's a fan!
TOXIC MOLD
It's a wall!
It's a rope!
It's a spear!
It's a snake!
It's a tree!

AS TOLD IN DR. RITCHIE SHOEMAKER'S BOOKS...

Erik agreed to assist Dr. Cheney with the project of starting a new syndrome on the basis that, "As a prototype for CFS, researchers will take interest in your case." Great! An opportunity to tell them about Stachybotrys (mold).



ERIK'S WARNING

Since Erik was helping launch a new syndrome, he felt it was appropriate to say something auspicious to mark the occasion:

"I have an inexorably increasing reactivity to mold that grows progressively worse no matter where I live. If this goes on as it has here, there will be millions of us."

However, nobody gained interest. So he decided to gather evidence...

John Banta - Restoration Consultants 1997

John Banta said "There are only about three specialists in the country with my knowledge... how did you find me?"

I replied "It wasn't easy."

3 posts

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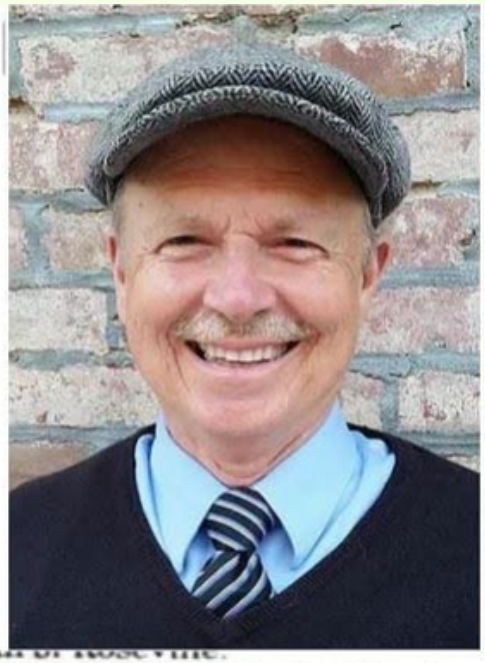
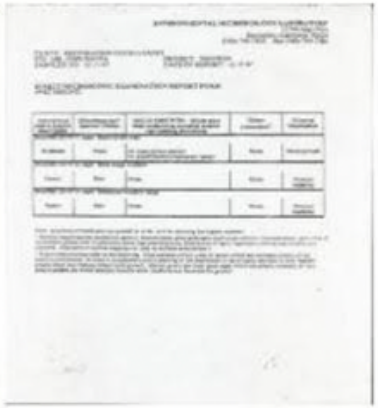
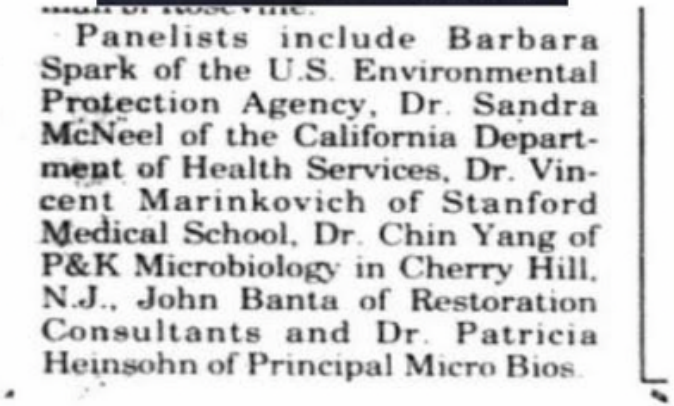




Danger of molds is focus of forum

Discussion planned at Roseville school

Discussion planned at Roseville school



Panelists include Barbara Spark of the U.S. Environmental Protection Agency, Dr. Sandra McNeel of the California Department of Health Services, Dr. Vincent Marinkovich of Stanford Medical School, Dr. Chin Yang of P&K Microbiology in Cherry Hill, N.J., John Banta of Restoration Consultants and Dr. Patricia Heinsohn of Principal Micro Bios.

John Banta, the most experienced Environmental Quality Specialist in the business said, "There are only about three specialists in the country with my knowledge, how did you find me?" "It wasn't easy." Erik replied. Erik hired Banta to help him identify which mold was making him sick.

EDUCATION

TTUSD cleans up mold, plans to check other schools

By Tanya Canino
Tahoe World Staff

The Tahoe Truckee Unified School District is proactively dealing with a mold found at North Tahoe High School, even though one environmental expert noted that the district's response might be more than necessary, according to NTHS Principal Don Beno.

Jeff Hicks, an industrial hygienist with Geomatrix Consultants in Folsom, made a presentation to NTHS staff members about stachybotrys mold Monday afternoon, Beno said.

"I think people are comfortable with the way the district office is handing it," Beno said.

The school district has removed a stachybotrys mold found in the wall of a NTHS office, has sampled the air quality throughout the building and plans to test wet areas in other schools.

The stachybotrys mold was discovered Dec. 18 after an environmental firm investigated the high school to determine the cause of two employees' allergic symptoms.

Two employees filed workers compensation claims Oct. 2, 1998 for skin, eye and nasal irritation in the workplace.

A firm, Restoration Consultants, was hired to remove stachybotrys and penicillin aspergillus molds from a square foot area of a high school office wall.

The firm also took air samples from the rest of the school; the district has not yet received the results, said John Britto, TTUSD director of facilities.

It was discovered that the NTHS office wall was damaged from a snow loader last winter, which allowed water to seep into the wall and created the damp conditions for the mold to grow, he said.

The district has been active in its response to the mold because of problems at another district which temporarily closed an elementary school because of the mold. The Fairfield-Suisun Unified School District near the Bay Area dealt with the impacts of parental outrage as well as the problem of eliminating the mold from that elementary school.

At the Elk Grove Unified School District in Sacramento, either the stachybotrys or the penicillin aspergillus mold has been found in about 10 of 32 schools that have been checked since the mold first appeared in May, according to Jim Elliott, director of communications for the 42-school, 43,000-student school district.

> "We're committed to finding out what the problem is. Maybe the mold wasn't the issue in the first place."
>
> **John Britto**
> TTUSD Director of Facilities

With 4.5 million square feet of school space to check, the Elk Grove Unified School District only checks for the mold in places where there have been records of leaks or reported funny smells. The Elk Grove district will conduct air quality tests or drill into walls if needed.

If mold is found in a classroom, the students are moved immediately and parents are notified. He said there have not been any reports of employees or students experiencing physical symptoms from the mold. The mold would have to be eaten to become a problem, Elliott said.

The publicized cases of poisoning from the stachybotrys mold are from instances of animals or people eating food contaminated by the mold, according to Hicks. The mold is one of thousands of common environmental molds found everywhere, Hicks said.

Why the mold's discovery has caused concern in the public is hard to pinpoint, Elliott said, although every time a mold is discovered in the Elk Grove Unified School District, there are television news reports of it.

"With the rain and the weather, mold has been discovered that people have become aware of and had never thought of before," Elliott said.

He is unaware of the mold causing any problems at other school districts in the state.

"We're the only district I know of that is actively looking for it," Elliott said.

But, the Tahoe Truckee Unified School District will be joining Elk Grove in searching for the mold.

Britto said the district will first talk to school custodians to identify any potential wet areas and then test for the mold.

In the meantime, however, the district still does not definitely know if the mold in the NTHS wall caused the two employees' allergy-type symptoms. The district has not released the names of the two affected employees.

"We're committed to find out what the problem is," he said. "Maybe the mold wasn't the issue in the first place."

However, according to Hicks, it can be difficult to nail down what causes an allergic reaction, Britto said.

The workers compensation office will determine if the school district needs to investigate other potential causes for the employees' allergic-type reactions.

"It's a tough one," Britto said.

NOTICE INVITING BIDS

NOTICE IS HEREBY GIVEN that sealed bids will be received by the Truckee Sanitary District herein referred to as "District," at the District's Administration building located at 12304 Joerger Drive, Truckee, California, until ***one o'clock p.m.*** ***Tuesday, January 12, 1999*** for furnishing all labor, material, tax, transportation, equipment, and services necessary for the construction of the Martis Valley Interceptor Pipeline Replacement Project, all in accordance with the specifications and working details and other contract documents all of which may be examined and copies obtained at the District's Administration building. Payment for work performed under the contract will be based on the unit prices listed on the Bid Form.

Copies of the contract documents may be obtained by paying $15.00 to the District for each set of contract documents so obtained. The payment is NOT REFUNDABLE.

A pre-bid conference and site visit will be held on ***Friday, January 8, 1999*** with the District Civil Engineer. Meet at ***ten o'clock a.m.*** at the District's Administration building.

Bids will be opened and tabulated by or on behalf of said District at its Administration building immediately after ***one o'clock p.m.*** on said ***Tuesday, January 12, 1999***. Any bids received after the time specified shall be returned unopened.

Bids must be from an appropriately licensed contractor, must be sealed and accompanied by cash, cashier's check, certified check, or Bid Bond made payable to the District in the sum of not less than ten percent (10%) of the amount of the Base Bid Total on the Bid Form. The cash, cashier's check, certified check or bond shall be given as a guarantee that the successful bidder will enter into a written contract within ten (10) days after being requested to do so and will be considered as the stipulated amount of liquidated damages in the event the bidder is unable to or refuses to execute a contract for the work. Upon an award of contract to the successful bidder, the security of unsuccessful bidders shall be returned in a reasonable period of time.

Mailed bids must be received by the District prior to the hour and date of the bid opening and shall be addressed to the District Civil Engineer, ***Bradley D. Stapley, P.E., Truckee Sanitary District, 12304 Joerger Drive, Truckee, California 96161 and shall state "SEALED BID, Martis Valley Interceptor Pipeline Replacement Project"*** on the envelope.

Hand delivery of bids on the day of the bid opening must be received by the District prior to the hour of the bid opening and shall be addressed to the District Civil Engineer, ***Bradley D. Stapley, P.E., Truckee Sanitary District, 12304 Joerger Drive, Truckee, California 96161 and shall state "SEALED BID, Martis Valley Interceptor Pipeline Replacement Project"*** on the envelope.

Bidders are hereby notified that pursuant to section 1770 et seq. of the Labor Code of the State of California, the Director of Industrial Relations has ascertained the general prevailing rate of per diem wages, the rates for overtime and holiday work in the locality in which the work is to be performed for each craft, and classification or type of workman needed to execute the contract which will be awarded to the successful bidder. Copies of the General Prevailing Wage Determination are on file with and available upon request from the District. The requirement to pay these wage rates and rates not so specified, are further detailed in Sections B-42 and B-43 of General Conditions in the contract document. The successful bidder shall, before entering upon performance of the work hereunder, file a performance and payment bond with and approved by the District.

Bids shall be made upon the form provided by the District and shall be properly completed with all items filled out; prices shall be in writing and figures; the signatures of all persons signing shall be in longhand. No bidder may withdraw its bid within a period of forty five (45) days after the time set for the opening of bids, and the Truckee Sanitary District Board of Directors may act to accept or reject bids within that period of time.

At the time a contract is awarded, the contractor must possess an appropriate contractors license for work in the State of California.

At the time of the bid submittal, the Board reserves the right to reject any or all bids, and further reserves the right to waive any informalities or irregularities in the bids.

Truckee Sanitary District Board of Directors

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LOAN TERMS SUBJECT TO CHANGE

Mold found in high school

By Tanya Canino
Tahoe World Staff

A stachybotrys mold, which contributed to an elementary school being temporarily closed in the Fairfield-Suisun Unified School District near the Bay Area, was found Friday in the office walls of North Tahoe High School, according to Tahoe Truckee Unified School District Superintendent Pat Gemma.

The mold was found after two employees who work in the high school office and in a small office next to it filed workman's compensation claims around Oct. 2 for allergy-type symptoms.

The school district did not release the names of the employees.

Through the claims investigation, a company discovered the mold in the wall on Friday, the last day of school before a two-week Christmas vacation.

A letter explaining the situation was mailed Wednesday to high school staff and a meeting with an expert on the mold will be held with the NTHS and North Tahoe Middle School staffs on Jan. 4, Gemma said.

There are thousands of kinds of common environmental molds of which stachybotrys is one that likes to grow on paper in dark wet areas, said Jeff Hicks, an industrial hygienist with Geomatrix Consultants in Folsom.

Hicks said the mold is not dangerous, but added that there are people who believe it is. He said those who tout it as being dangerous are consultants that profit from its removal. There is no medical data that says the mold is dangerous unless it is eaten in quantities.

The stachybotrys mold caused a poisoning outbreak in Russia many years ago when people ate moldy potatoes and there was an outbreak among horses after eating moldy hay, he said.

He termed the Suisun City elementary school closure as the result of "hysteria."

The Fairfield-Suisun Unified School District offices are closed until Jan. 4, so no comment could be obtained by the *Tahoe World*.

The TTUSD has hired a company to remove the affected wall at NTHS, treat the mold and take out all textile products such as carpets, Gemma said. The work will begin Monday.

After the work is completed, a school district crew will put in new carpets and restore the office before school begins Jan. 4.

"It's a prudent thing to do," Hicks said, because the wet area and mold needs to be dealt with.

District staff will also be evaluating any potential mold spots (wet areas) at other schools to decide if tests should be taken.

"We're doing it this way because we have two goals. One, we want to protect our employees and our students and, at the same time, we don't want to overreact and be wasteful," Gemma said.

As far as the two affected employees, more investigation needs to be done to determine the cause of their skin, eye and nasal irritation.

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Homeowners fear household molds making them sick

By Emily Bazar
Bee Staff Writer

They came armed with snapshots of mold crawling up their doors and walls, with Ziploc bags filled with black-stained drywall and rotting wallpaper.

"We're here for school today," said David MacFarlane, a Rio Linda resident holding three plastic bags: one containing a soggy piece of magenta carpet, another with a hunk of black-flecked drywall and the third with a curled piece of stained paper he tore from behind his home's siding.

MacFarlane and family moved into their home just three months ago. After he started getting headaches, rashes and memory loss and his daughter was diagnosed with sinus infections, he started to blame the mold he found in his home.

"Everybody in the house is sick. We weren't sick before moving in," he said. "We're stuck because we sunk every dime into that house."

MacFarlane was one of about 150 area residents who came to Roseville's Oakmont High School Saturday afternoon to hear a panel of experts talk about mold and its possible effects on health.

The forum was organized by Teri Codina of Roseville, who said that her family has suffered mold-related health problems since rain leaked into the walls and windows of her home. In her research, Codina has found other homes in Roseville and Sacramento where leaky walls and windows could cause similar problems.

A little more than a week ago, parents of children at an Elk Grove elementary school complained that one of the classrooms was moldy and that their kids had been exposed to health risks.

One of the molds discovered under the classroom's floorboards was Stachybotrys chartarum, a fungus that has been shown to suppress the immune system in laboratory animals and is a suspected cause of several infant deaths in Cleveland.

Certain molds are thought to cause respiratory problems, nasal and sinus congestion, memory problems, sore throat, skin irritation and dry, hacking cough.

The panelists told the audience that mold thrives on moisture and the key to reducing risk is to keep buildings clean and dry.

"Everything traces back to water damage. Microorganisms can grow and reproduce efficiently as long as you produce enough moisture," said Chin Yang, president of P&K Microbiology in Cherry Hill, N.J.

Panelists said people shouldn't hang their clothes indoors to dry, and warned that water damage must be repaired within 24 to 48 hours and that leaks should be fixed immediately.

But Barbara Spark, an indoor air program coordinator for the U.S. Environmental Protection Agency, cautioned people to educate themselves and not to overreact when they notice the growth of common bathroom mold.

"Most molds are not going to be problems for you," she said. "Mold should not be growing in your house. But even with all the stuff growing indoors, you may not have problems."

Michelle Hall, 28, can't help but worry. The Dixon resident is seven months pregnant and has had problems with mold since moving into her home two years ago. Her husband has suffered from migraine headaches, she said, and other families in the same housing development have complained of similar problems.

"I'm worried about the effects of my breathing anything that could be harmful, and also of having an infant inside a home with excess mildew," she said, pointing to a picture of her linoleum, black under the edges from what she believes is mold. "This is our first home. I feel like we've been cheated."

TOXIC MOLD ISSUES BEGAN TO COMPOUND...

Experts taking issue with 'toxic mold'

The term is called alarmist because of so many unknowns.

By Andrew LePage
BEE STAFF WRITER

"Enough already!" comes the collective cry from public health experts who've seen references to "toxic mold" multiply like mold spores in recent years.

The term "toxic mold" has become a buzz phrase among the news media, attorneys and mold cleanup and testing firms that profit from society's deepening concern over indoor mold and its potential health effects.

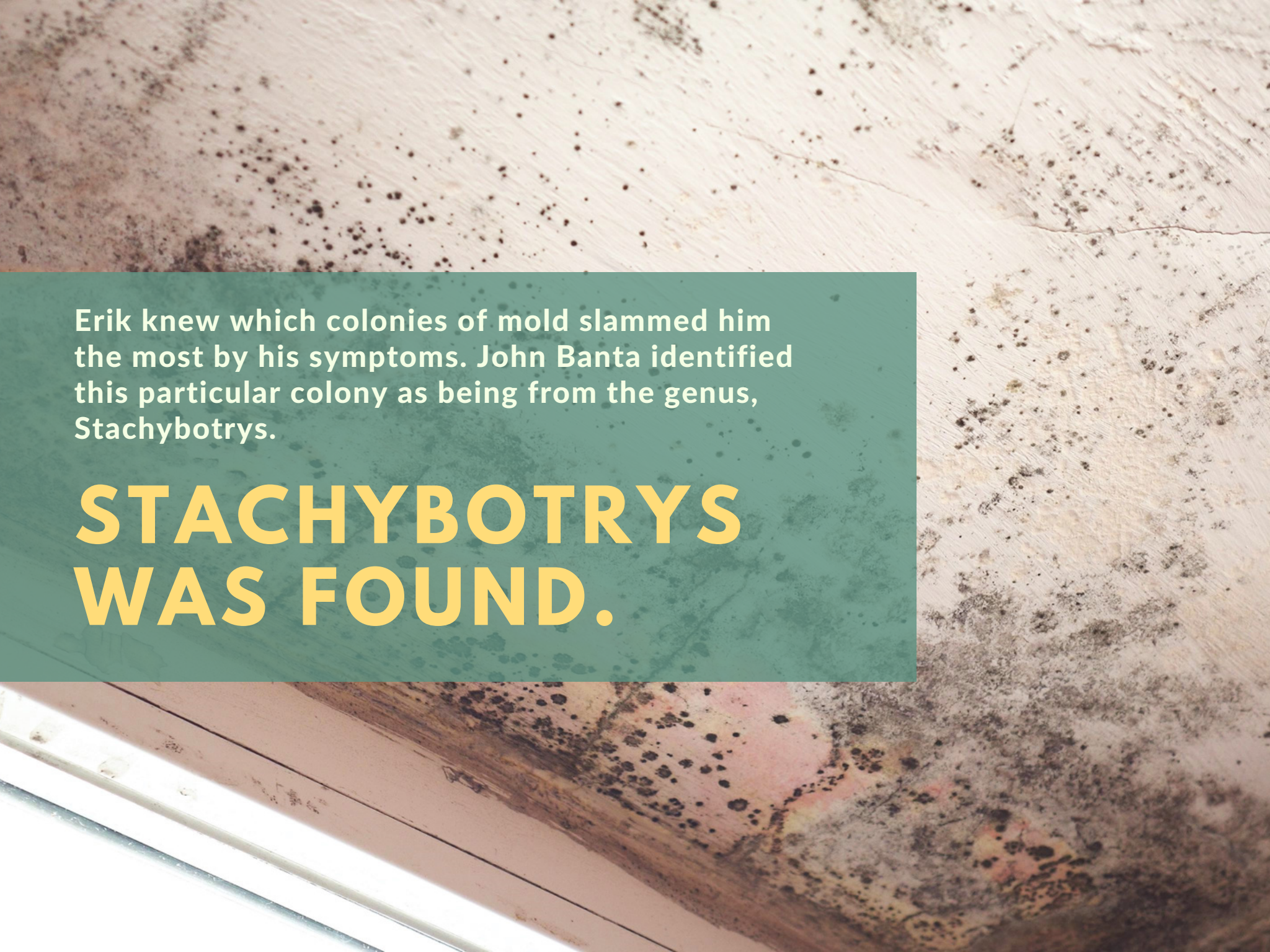
Jack Sirard's column will return Tuesday.

But for many scientists and doctors who follow the latest research, it's still just plain old "mold." They stress that it's an ecologically vital organism that has always been found virtually everywhere, though it should never be allowed to flourish indoors.

"We're not in some epidemic of new and mysterious attack of mold," says Rebecca Tominack, associate professor of occupational and environmental medicine at the St. Louis School of Medicine.

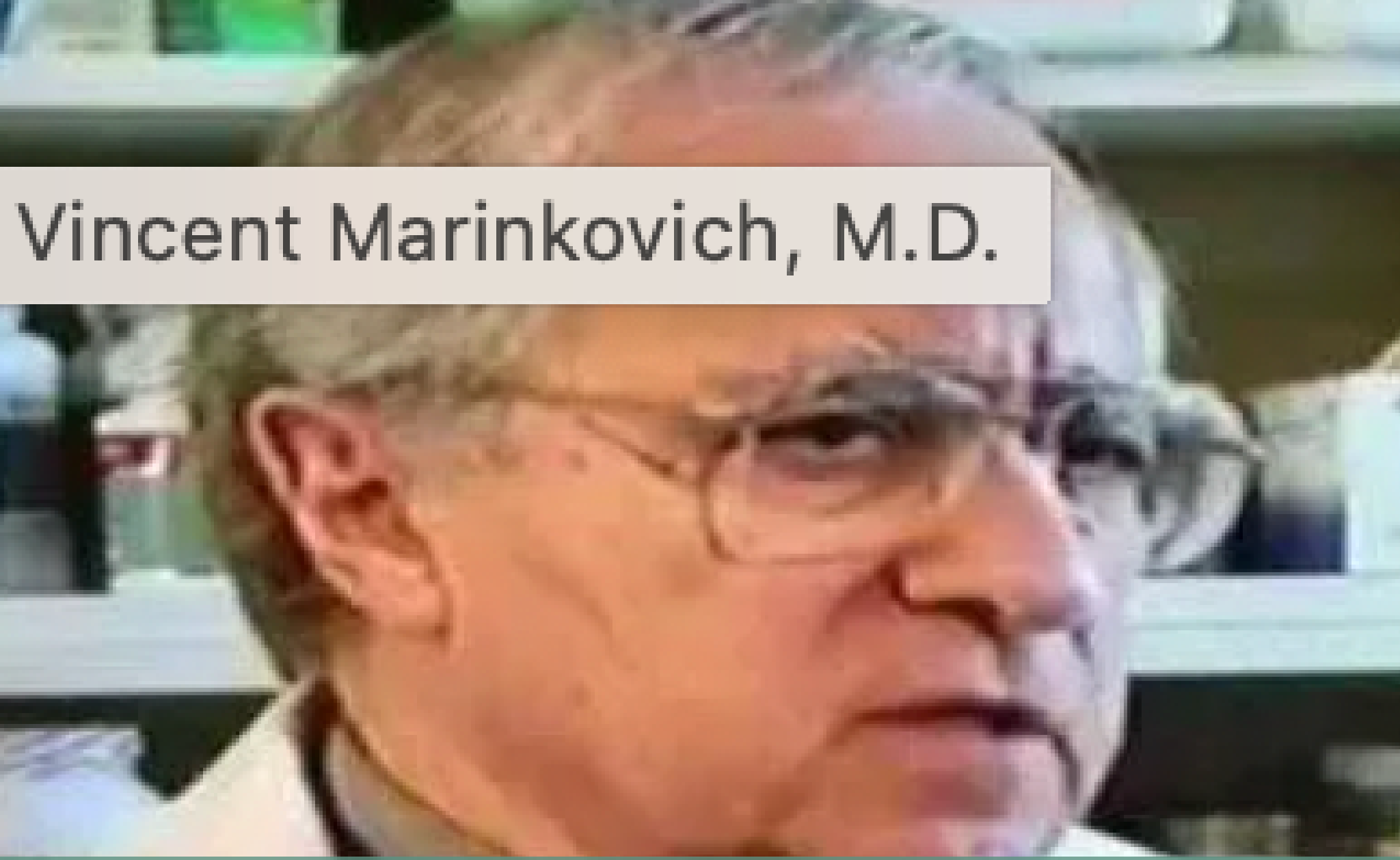
Many such public health experts loathe references to "toxic mold" because they view it as an alarmist term originally propagated not by scientists but by either the news media or trial lawyers.

Paul Scoggins, an environmental engineer with the U.S. Envi-



Erik knew which colonies of mold slammed him the most by his symptoms. John Banta identified this particular colony as being from the genus, Stachybotrys.

STACHYBOTRYS WAS FOUND.



ERIK VISITED DR. MARINKOVICH TO TELL HIM ABOUT MOLD AT GROUND ZERO FOR CFS

DR. MARINKOVICH AKA "DR. MOLD"

- Dr. Vincent Marinkovich specialized in diagnosing and treating mysterious ailments caused by household molds.
- In 1999, he founded Immune Tech, a Menlo Park company that offered a mail order home testing kit for allergies. Customers were instructed to prick their fingers and submit blood samples which were analyzed for allergen and mold sensitivities - with results sent directly to the customer.

Retrieved from:
https://www.globalindoorhealthnetwork.com/marinkovich

DR. MARINKOVICH AKA "DR. MOLD"

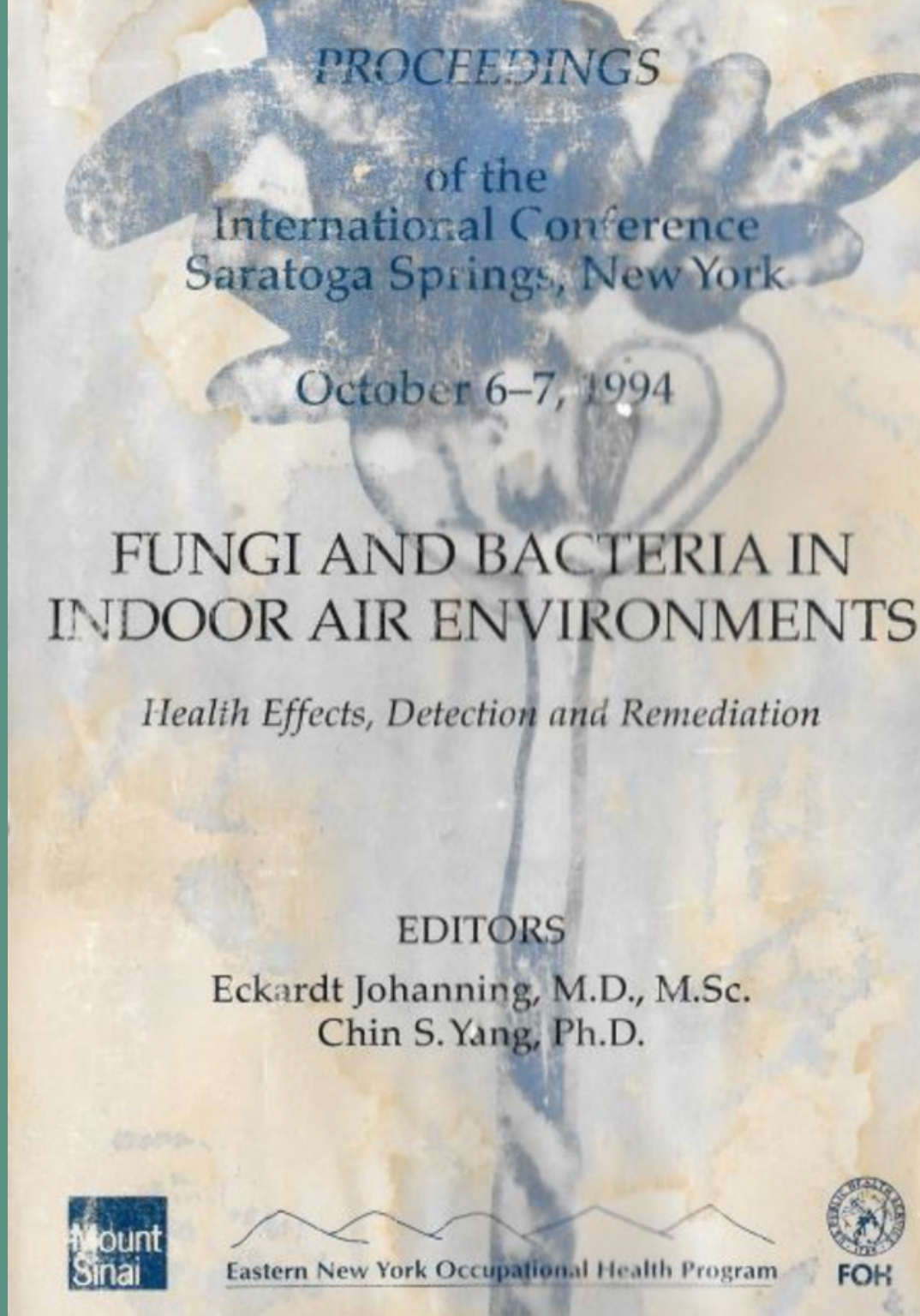
- In a 2004 paper, he discussed the effects of mold on the human body and the diagnosis, pathophysiology and therapy/treatment. He also talked about the doctors who refuse to recognize this illness

- Dr. Marinkovich was a dedicated Redwood City immunologist nationally known as "Dr. Mold" because of his extensive knowledge of illnesses caused by exposure to fungus.

Retrieved from:
https://www.globalindoorhealthnetwork.com/marinkovich

DR. MARINKOVICH GAVE ERIK THIS BOOK

Marinkovich proceeded to tell Erik that his allergy test would be able to determine Erik's reactivities. Marinkovich told Erik that he was allergic to Aspergillius, however, Erik knew that he did not react to the colony of Aspergillius like he did to the colony of Stachybotrys.


PROCEEDINGS

of the
International Conference
Saratoga Springs, New York

October 6–7, 1994

FUNGI AND BACTERIA IN INDOOR AIR ENVIRONMENTS

Health Effects, Detection and Remediation

EDITORS

Eckardt Johanning, M.D., M.Sc.
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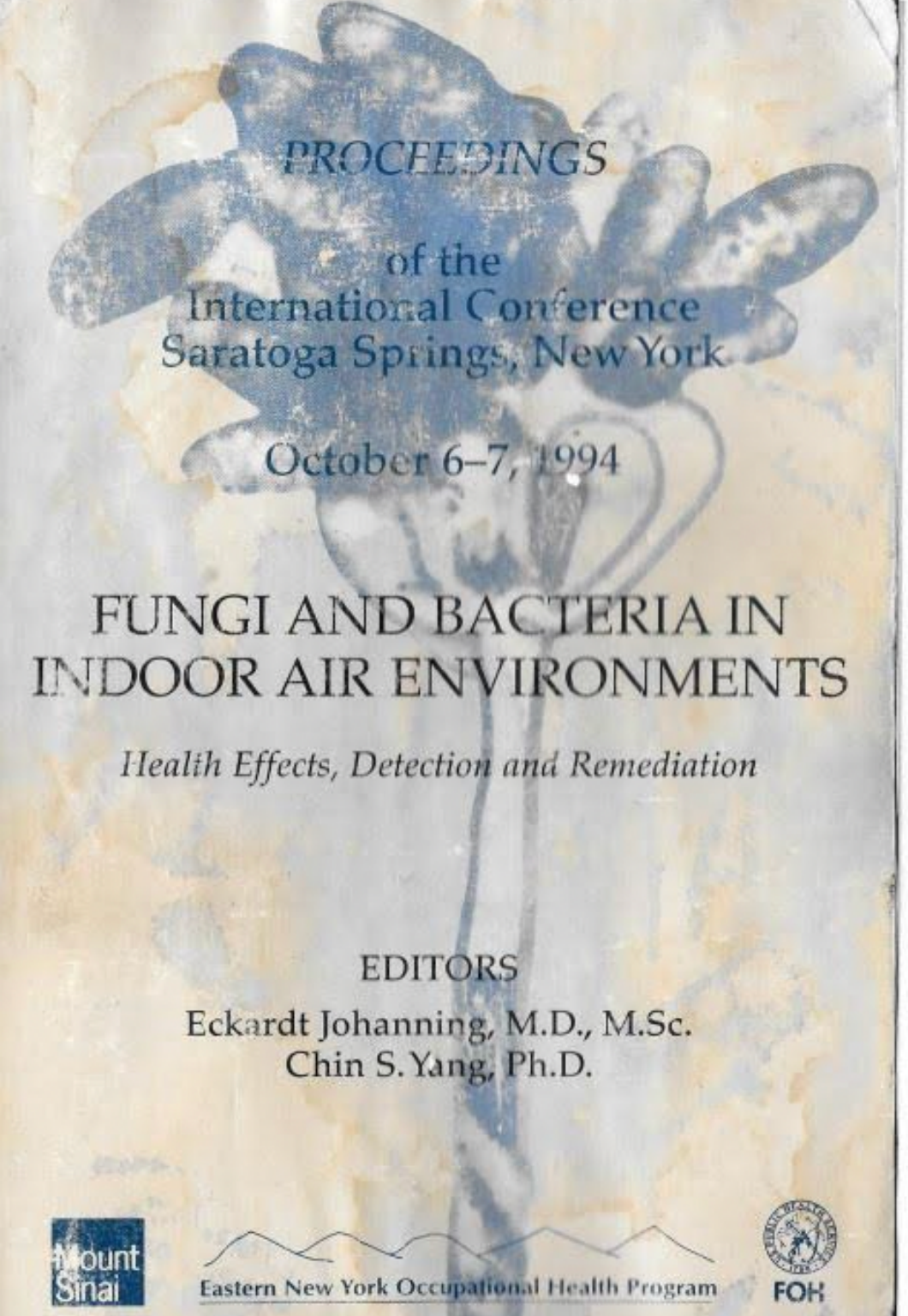
Mount Sinai

Eastern New York Occupational Health Program

FOH



MYCOTOXINS AND NEUROTOXICITY

PIERRE L. AUGER, M.D., M.Sc., FRCPC(c)

Abstract: *Mycotoxins have been called "agents in search of a disease" (Schiefer, 1990). Medical literature contains little information concerning airborne mycotoxins. We would like to make the point that mycotoxins are potent neurotoxics agents. Chronic fatigue syndrome and psycho-organic syndrome comprise an array of symptoms which overlap. We considered both of these diseases as consequences of possible central nervous system injuries and hypothetically related to mycotoxins exposure.*

Key words: Mycotoxins, neurotoxicity, *Stachybotrys atra*, indoor air pollution, chronic fatigue syndrome, psycho-organic syndrome

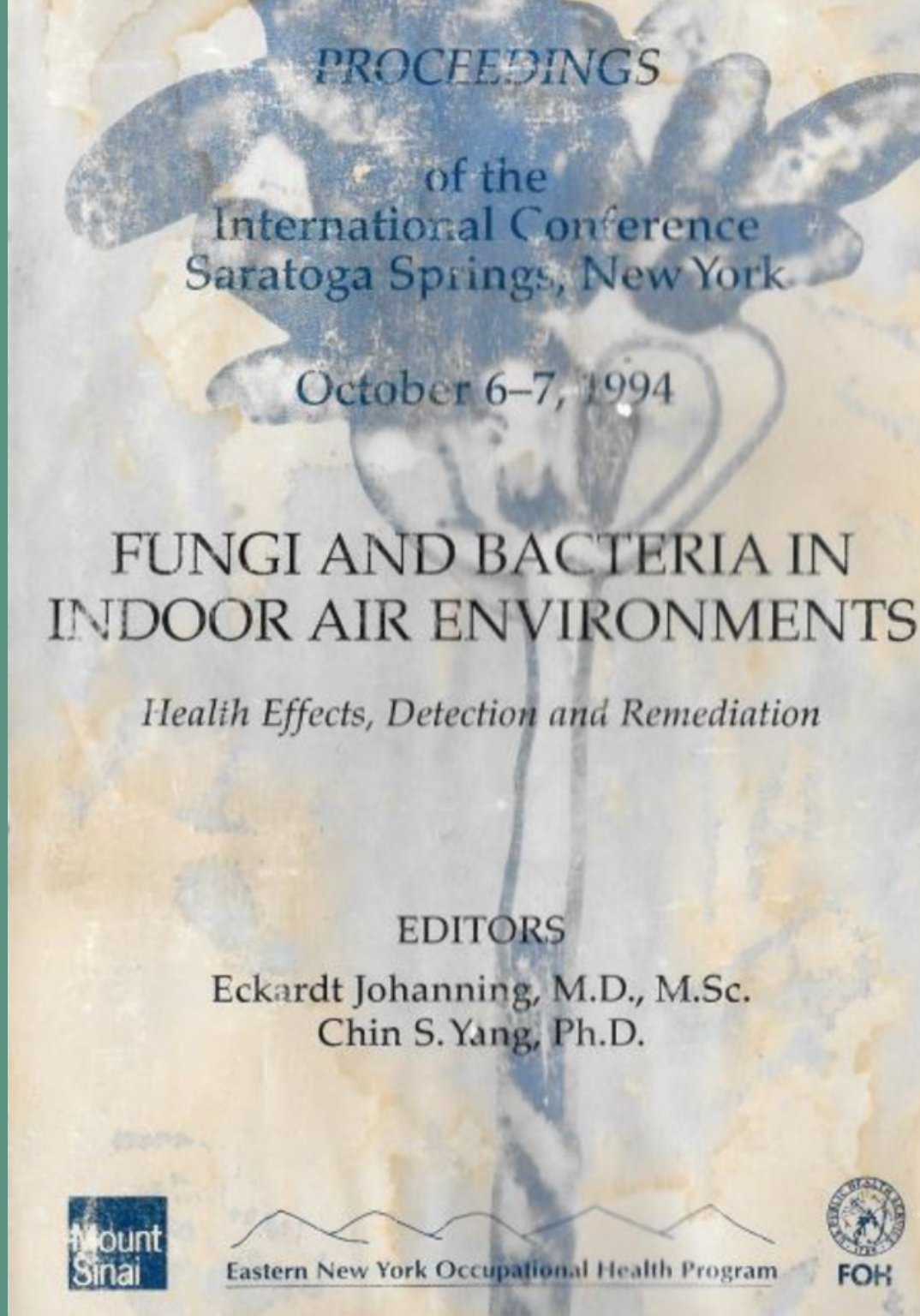
INTRODUCTION

Fungi are one of the agents present in dust causing harm to human health. The lung and the upper respiratory airways have been considered the historical targets for disease subsequent to mold exposure. Mycotoxins are metabolites produced by fungi in certain favorable environment. They are polysystemic poisons and many of them are neurotoxic and immunotoxic. Since 1984, we have been confronted with patients complaining of fatigue, cognitive difficulties, repetitive respiratory infectious diseases and a complex array of symptoms consistent with the diagnosis of psychoorganic syndrome (POS) and/or chronic fatigue syndrome with immunodysfunction (CFIDS). We think that neurotoxicity from mycotoxins are an important aspect of mycotoxicosis. This report is based on soft data, on circumstantial evidence. Epidemiological analysis is not yet possible.

Address correspondence to: Pierre L. Auger, M.D., M.Sc., FRCPC(c), CLSC Haute-Ville, 5Ki Boul

"MYCOTOXINS HAVE BEEN CALLED AGENTS IN SEARCH OF DISEASE"

Erik was surprised that even though Dr. Marinkovich provided him with a book that clearly states Stachybotrys' involvement in CFS, he was uninterested in telling others about the connection of mold at ground zero for CFS.



A MAN ON A MISSION

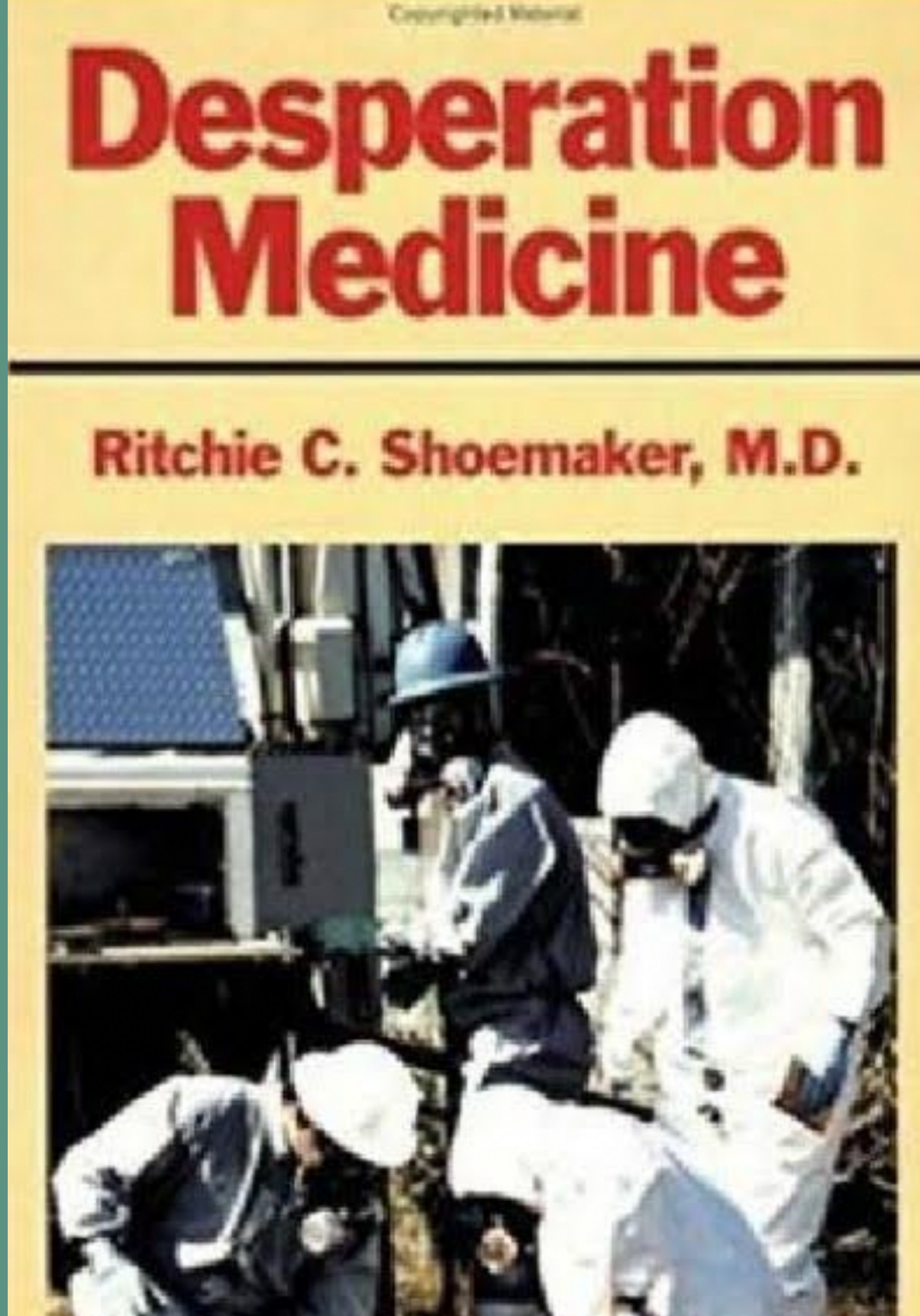
Erik proceeded to approach as many doctors, researchers, and research institutions as he could to get the word out.

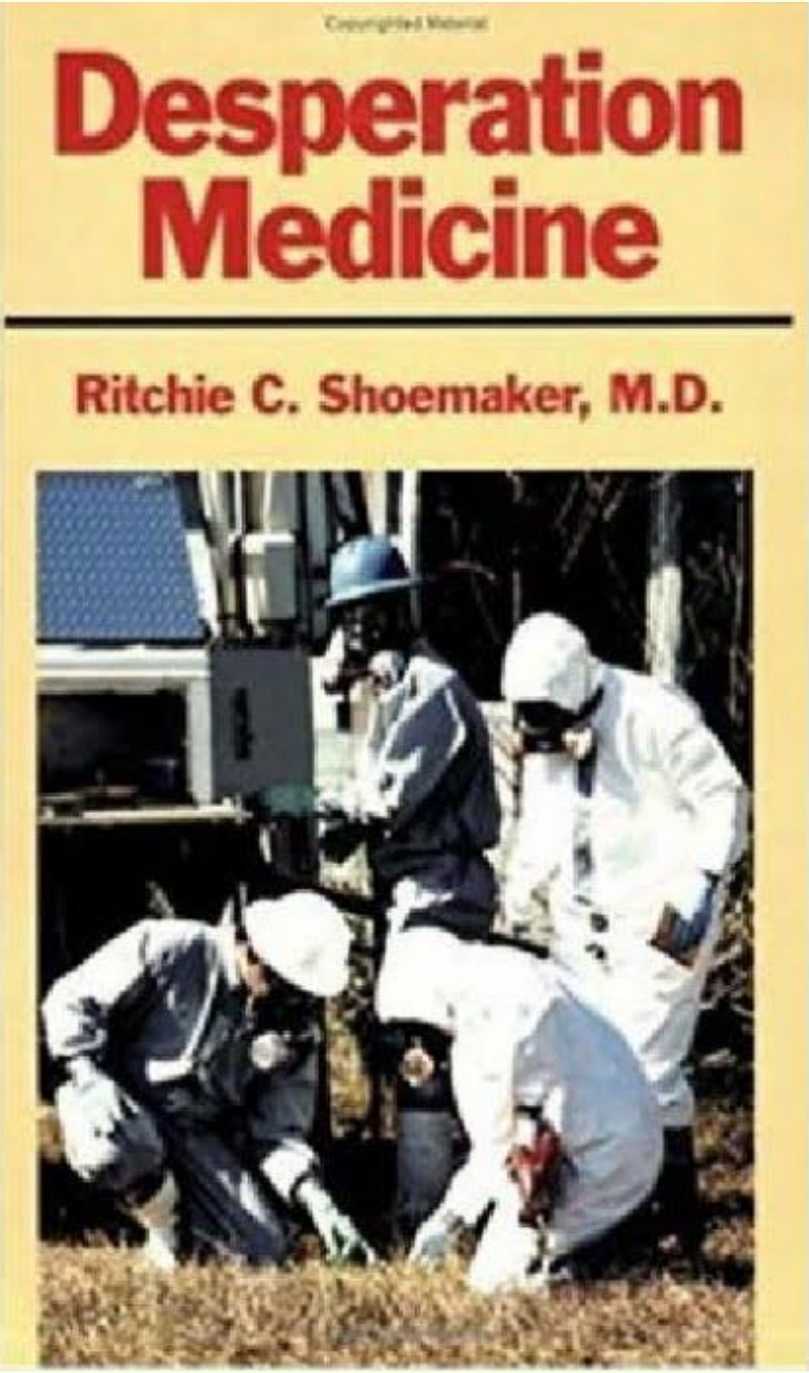
But each person he contacted was disinterested.

FINALLY AFTER ALL OF THESE YEARS...

In 2002, a fellow Tahoe survivor gave Erik, Dr. Ritchie Shoemaker's book, "Desperation Medicine."

Erik received validation for mold at ground zero for CFS.





Desperation Medicine

Gateway Press Inc 2001

by Dr Ritchie Shoemaker

Chapt. 23. Surviving Chronic Fatigue Syndrome

...

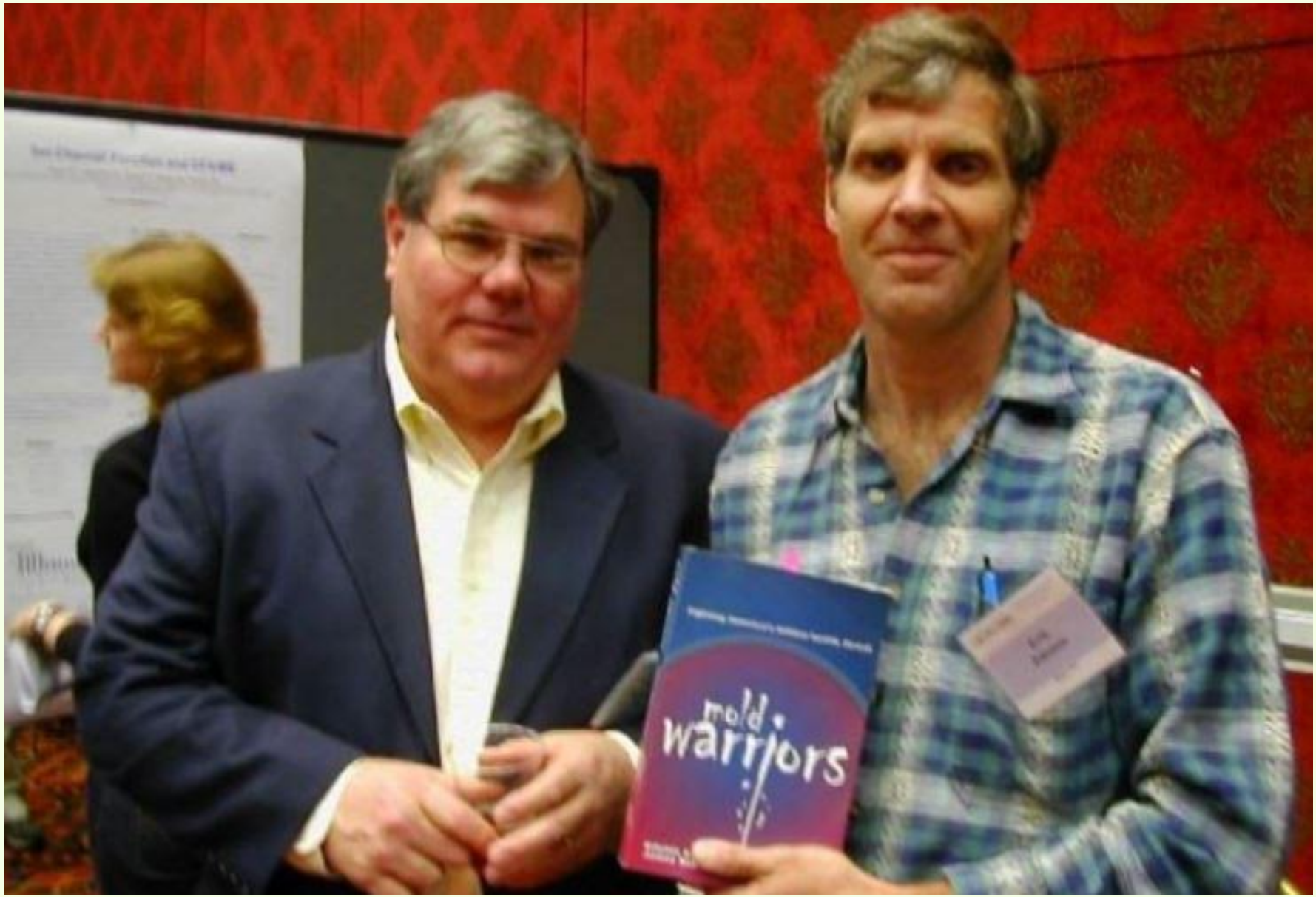
page 345

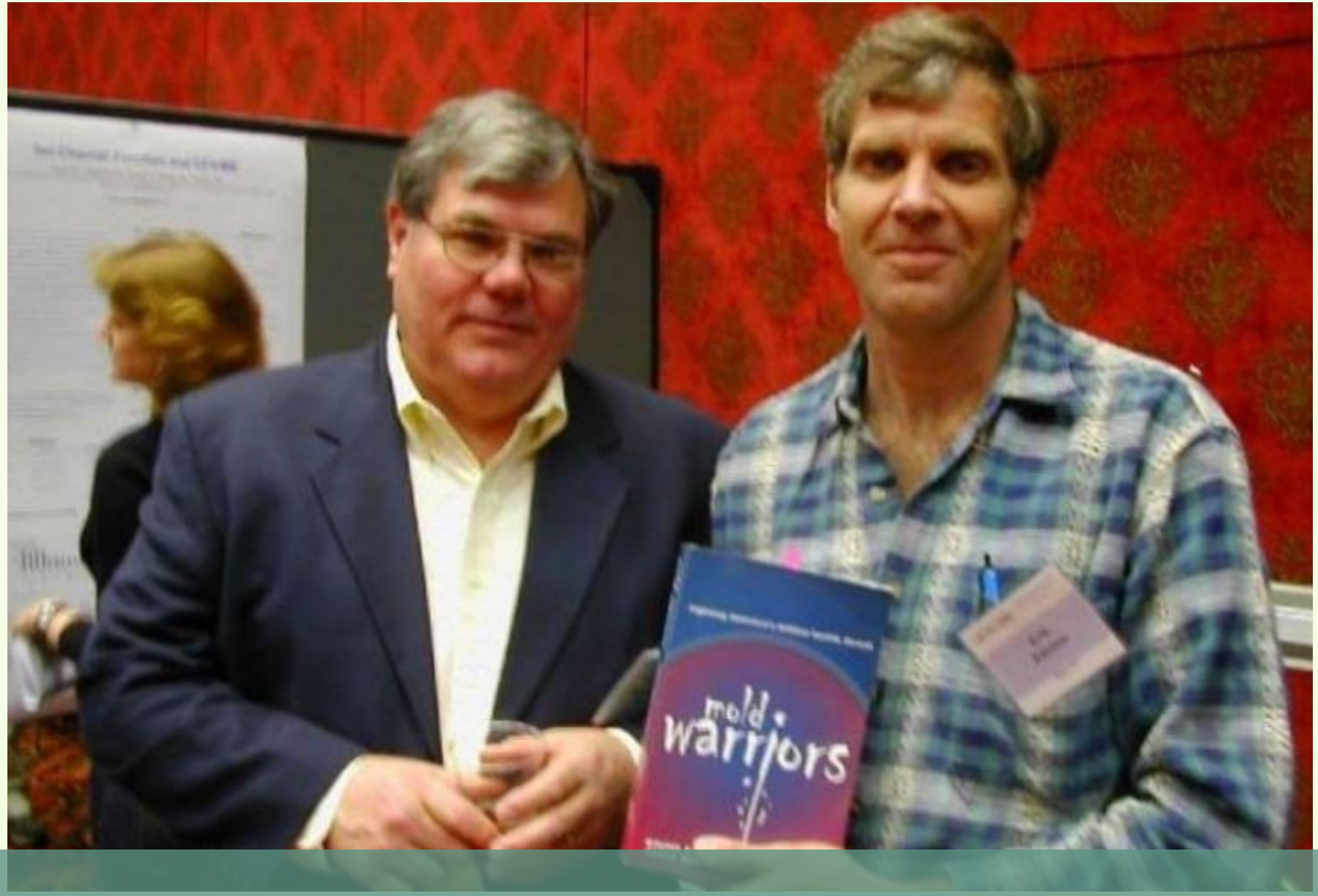
It began in Nevada, in a tiny community on Lake Tahoe known as "Incline Village". It was here, starting back in 1985, that two observant physicians began to notice a strange pattern in patients who complained of blurred vision, faltering short-term memory and debilitating exhaustion. During the months and years that followed, this mysterious ailment (Was it caused by a virus?) would evolve through a series of ever-changing names: Lake Tahoe Disease, Chronic Epstein Barr Virus Syndrome, Yuppie Flu.
And finally Chronic Fatigue Syndrome, or CFS.

During this same period, the two physicians who had made the initial diagnosis -- internists Dan Peterson and Paul Cheney -- would be thoroughly discussed, chewed up, and then completely ignored by the influential scientists who run both the National Institutes of Health (NIH) and the U.S. Centers for Disease Control (CDC).

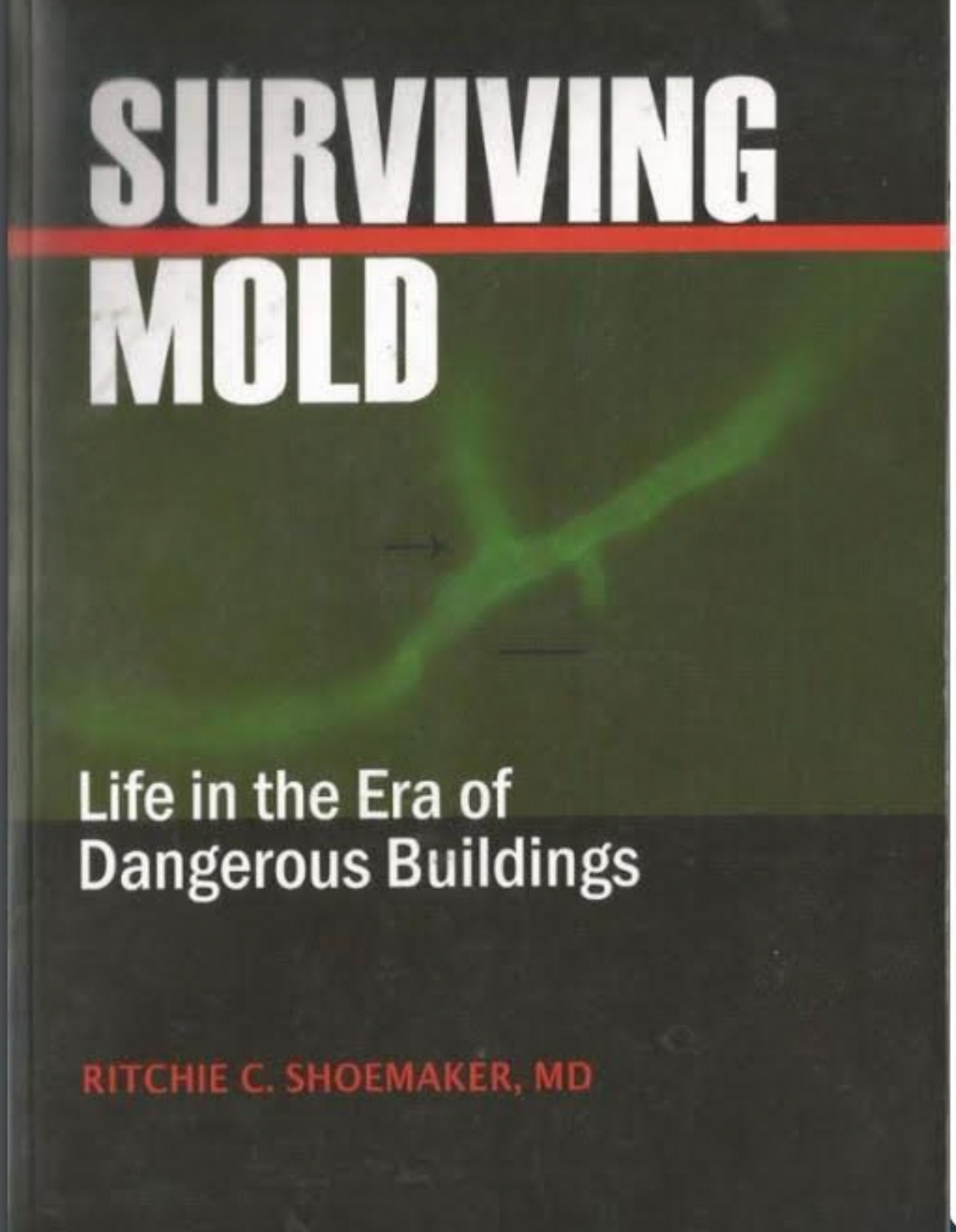
The story of what happened to Drs Peterson and Cheney deserves a book in itself. Although their basic theory that Chronic Fatigue Syndrome is caused by a "mono"-like virus perhaps related to herpes simplex would never be dis-proven, the powerful administrators at the great medical think-tanks continually insisted otherwise. For more than a decade, the scientific intellectuals in Atlanta and Bethesda issued a never-ending series of contradictory - and often just plain wrong - advisories that ascribed the disorder to hald a dozen different factors, none of which turned out to be involved in the pathogenesis of this disease.

VALIDATION





Oddly, despite many reading Dr. Ritchie Shoemaker's several books citing mold at ground zero for CFS, to this very day, not one researcher or research institute has decided to solve CFS to help the many suffering from this incapacitating illness.



Surviving Mold by Dr Ritchie Shoemaker.

Otter Bay books. 2010.

Chapter 17. CFS and other medical mistakes.

by Erik Johnson

Page 441.

Paging Dr. Semmelweis.

This cannot be right. There must be something fundamentally flawed in the medical mindset. Trying to look at this objectively, what right do doctors have to refuse to listen? If a doctor claims to have any expertise on CFS, how could he be disinterested in hearing from a CFS prototype who was at the very inception of the syndrome? If a historian wants to make sure they have their facts straight on how the syndrome began, what right do they have to turn away from my story? One thing I know for sure. If any patient felt they were subject to this mold-effect and wanted information, they certainly would never get it from a doctor who refuses to accept information and input about its existence. To my astonishment, I could see that the obstacle to getting doctors to listen is that they had defined "research" as strictly "Peer reviewed literature", and nothing more.

In a kind of anti-science irony, nothing that has not already been written by someone with "researcher" on their name badge can ever get researched, for without credentials, it remains in limbo, removed from consideration. Without research, clues stay anecdotal, discarded for the very reason that they have not yet been researched.

Not even the force of a publicity around a "new dynamic" of unexplained illness and a brand new syndrome was enough to

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Not even the force of a publicity around a "new dynamic" of unexplained illness and a brand new syndrome was enough to break through this ironclad philosophy, and I was completely stymied.

I started collecting 'rejection slips' from all the top-name CFS doctors and researchers. Mention of my participation in the "Original CFS cohort" did open a few doors, yet I soon saw a pattern to the progression of events.. The moment I mentioned I had clues from "ground zero' and how much I had benefitted by mold avoidance, it was like watching the lights go out, and a door slam, shut. I learned to see by the look in their eyes, the exact moment when mild curiosity turned to concerted disinterest and conspicuous indifference. It was the exact moment when doctors perceived I wasn't looking for their medicines, but was handing them a clue which demanded action on their part. I gave them a chance to help their patients by telling them how I had helped myself, and they wanted no part of it..

Many doctors like to think of themselves as patterned after the renowned diagnostician, Sir William Osler, who famously advised "Listen to the patient, he will tell you his diagnosis," yet no doctors were listening to me, not even when i attempted to tell them how important this was to my recover, and how it had affected others.

I had started out passively, just quietly suggesting that I might have an interesting clue, but when this was easily brushed aside with mild dismissals, I tried an increasingly aggressive approach. The doctor response was absolutely commensurate with how hard I attempted to break through the blockade. The harder I tried to tell them, the more they refused to listen, and the angrier they became. It would become a shouting match, and nothing was accomplished.

Even recounting the Semmelweis story and reminding them of Osler's words failed to make a difference. These doctors were bound and determined to never hear this clue.

IN THE 34 YEARS WHEN THE CDC WAS BROUGHT TO TAHOE...

100% of CFS doctors, researchers, and research institutes continue to fight to say that the discovery of mold no longer matters (or that it is too hard to research).

Superior California

Lawyer's multimillion-dollar suit blasts 2 Butte

How mystery disease hit three teachers

Falling for fall

Calm returns to grisly mass bur

Improper use of throttle cited in bus tragedy

McClellan shows off to cap waste, remov

"CFS RESEARCHERS WERE FIRST TO KNOW AND THE LAST TO HAVE IT BE KNOWN"

ERIK JOHNSON

THE OBJECTIVE OF THE POSTER...

Erik created this poster as performance art to observe doctor's and researcher's responses when the CFS evidence is presented to them.

ERIK WAS SHOCKED TO FIND...

When Erik presented the evidence to CFS doctors, researchers, and research institutions, each person ignored the original evidence that started the syndrome (they didn't show any curiosity).

Pictured above:
Erik presenting the CFS evidence to Carol Head. "Head" of the SolveME/CFS Inititiative

Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

SEARCH

CDC A-Z INDEX

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

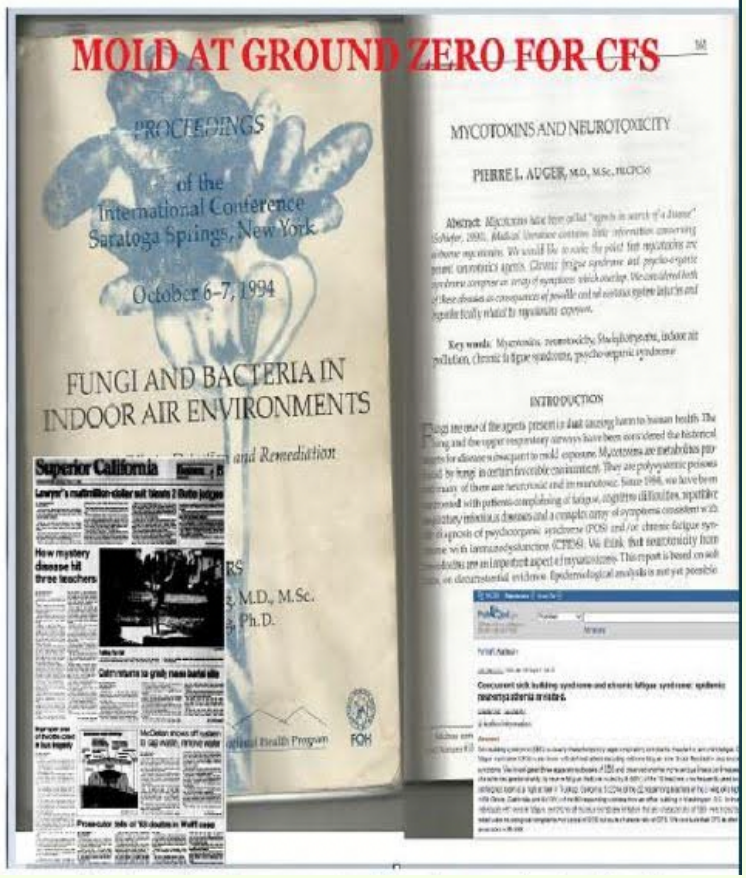
ME/CFS
- What is ME/CFS +
- Symptoms and Diagnosis +
- Treatment
- ME/CFS in Children +
- CDC's ME/CFS Program +
- Voice of the Patient +
- Information for Healthcare Providers –
  - Presentation and Clinical Course of ME/CFS –
    - Prognosis
    - Epidemiology
    - Etiology and Pathophysiology
  - Diagnosis +

CDC > ME/CFS > Information for Healthcare Providers > Presentation and Clinical Course of ME/CFS

Etiology and Pathophysiology

While the cause or causes of ME/CFS are still unknown, evidence supports a combination of factors that are thought to contribute to the development of this illness. These may include:

- **Infection** – some, but not all, patients develop ME/CFS following an acute viral-like illness. It is possible that in some people an infection may lead to changes in the immune system that contribute to the development of ME/CFS. Post-infectious fatigue is recognized to occur in about one in ten people infected with Epstein-Barr virus, Ross River virus, or *Coxiella burnetii* (the causative agent of Q fever). People with these infections who had severe symptoms during the acute illness were more likely than those with mild symptoms to later develop an ME/CFS-like illness. Other infections that have been studied in connection with ME/CFS include human herpesviruses, enteroviruses, rubella, *Candida albicans*, bornaviruses, mycoplasma, and retroviruses. However, in ME/CFS, no causal role has been established for a specific infectious agent.
- **Physical or emotional trauma** – some patients report experiencing an accident, trauma, immobilization, surgery, or significant emotional stress prior to onset of symptoms.
- **Genetics** – ME/CFS has been observed within some families. This suggests either a possible genetic link or a common environmental exposure (infectious or toxic). Twin studies show higher rates of ME/CFS in identical than fraternal twins. However, specific genetic associations have not been established.
- **Environmental factors** – exposure to mold or toxins has been suspected as a trigger for ME/CFS. However, associations of specific environmental factors with ME/CFS have not been established.



The association between mold and Chronic Fatigue Syndrome is automatically established by virtue of being the documented "unknown factor" in the very first cluster the mystery illness investigated by Dr. Gary Holmes of the CDC, which the CFS syndrome was coined to solve.

Centers for Disease Control and Prevention
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SEARCH

CDC A-Z INDEX

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

ME/CFS

CDC > ME/CFS > Information for Healthcare Providers > Presentation and Clinical Course of ME/CFS

THE CDC'S UPDATE

Environmental factors - exposure to mold or toxins has been suspected as a trigger for ME/CFS. However, associations of specific environmental factors with ME/CFS have not been established.

Symptoms and Diagnosis

Treating

ME/CFS in Children

Video Presentation

Information for Healthcare Providers

Presentation and Clinical Course of ME/CFS

Prognosis

Epidemiology

Etiology and Pathophysiology

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IGNEZ SEMMELWEIS

If modern medicine were confronted with a mystery illness in which two high schools and a casino made themselves distinctive by cluster of illness that were not seen in other schools or casinos , this would be eerily similar to the Semmelweis scenario (the doctor who invented hand washing but was initially shunned by his peers for the discovery) so how would doctors and researchers react?

IGNEZ SEMMELWEIS

Did they learn anything from the Semmelweis story? Would it occur to them that they should look for what difference might exist from one building to the next? If someone were to find a difference and attempt to convey this to doctors, would they perceive this as a Semmelweis-situation and feel the need to respond? They would not.

For this is how Chronic Fatigue Syndrome began and to this very day, not a single researcher has behaved like Semmelweis would have.

UNVALIDATED

Dr. Ritchie Shoemaker, within weeks, completely backs out of supporting the evidence of mold and CFS. Now claims that Chronic Inflammatory Response Syndrome (CIRS) is not longer congruent with CFS.

THE TAKEAWAY

In spite of all else that is going on, **mold illness** is the direct mystery Dr. Gary Holmes' CFS was coined to solve.