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SANTA ROSA, CALIFORNIA

Local cases of rare brain disease draw scrutiny

Sonoma County's incidence
of fatal illness twice U.S. average;
scientists unsure of significance

By **CATHY BUSSEWITZ**

THE PRESS DEMOCRAT

Residents in Sonoma County suffer from a rare and fatal illness related to mad cow disease at a rate that is twice as high as the national average, prompting victims' families to launch a search for answers.

Creutzfeldt-Jakob disease, a rapidly progressing and fatal neurodegenerative disorder, on av-

erage has taken the life of one Sonoma County resident each year over the past 17 years, according to county data.

But in the past half year, the affliction, which strikes one in a million people in the United States every year, has killed three Sonoma County residents.

Lorraine Collins, a Santa Rosa woman whose husband, Ric, died of CJD in October, has been tracking local deaths and reaching out to families of the afflicted to develop a support network.

"It's the three in the last six months that's driving me nuts," Collins said. "There's probably a lot more people who have it. And why aren't we getting that information?"

Scientists at the Centers for Disease Control

and Prevention have released a study emphasizing the need for surveillance of public health threats like mad cow disease, at a time when the U.S. government has proposed significant cuts to those monitoring programs.

Creutzfeldt-Jakob disease is one of several "prion diseases" that afflict both humans and animals and that are caused by a misshapen protein called a prion. The most well-known prion disease is bovine spongiform encephalopathy, also known as BSE or mad cow disease, which has been linked to a form of CJD called variant CJD.

Local concerns about a possible link between prion diseases and consuming the meat from wild game were raised earlier this month when

TURN TO **DISEASE**, PAGE A11



Lorraine Collins

SR woman's
husband, Ric,
died of
Creutzfeldt-
Jakob disease.

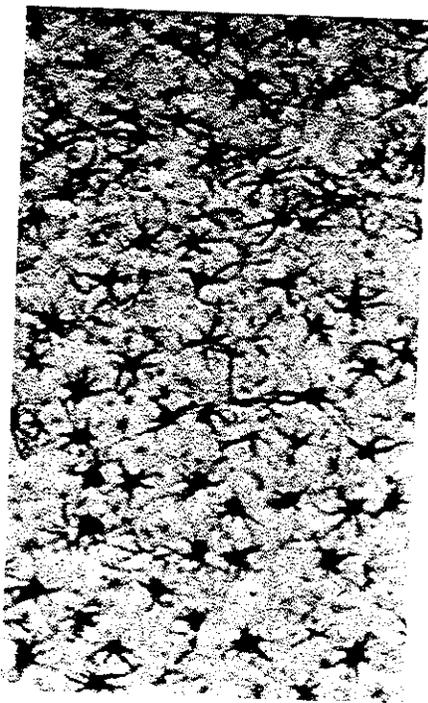
7 decades after being forced
into exile, studies cut short,
12 Japanese-Americans
honored in SRJC ceremony



Peter Masuoka
works in a SRJC
chemistry lab prior to
being forced into an
internment camp
after Pearl Harbor.
He later joined the
Army, and was killed
in action in 1944.

Yosemite puts on dazzling

tors call intention tremor), altered reflexes, distracted speech and what Creutzfeldt judged to be “unmotivated outbursts of laughter.” He admitted her to the hospital. Her physical condition progressively worsened and her mental condition deteriorated. Some days she screamed continually. Other days she languished in a stupor. By the beginning of August she had sunk into status epilepticus—one epileptic seizure following another in rapid succession—and responded only if Creutzfeldt pricked her with a pin. He chronicles her last days: “On August 6 a genuine epileptic attack occurs. . . ; towards evening, a second attack. . . . In the ensuing days, the patient lies . . . twitching. . . . In the last hours, stupor deep-



The dark stars of astrogliosis.

ens, swallowing is impaired; death ensues on August 11, in status epilepticus.”

After Bertha's death, Creutzfeldt autopsied her and examined her brain. He found extensive brain damage without inflammation. Something had killed millions of brain cells. They had been cleaned away and partly replaced by glial cells, the brain's sometimes destructive repair units (*glia* is Greek for glue). When Creutzfeldt stained cross sections of Bertha's brain to highlight the damage, the swollen, proliferated glia looked under his microscope like brown stars crowding a dead gray sky.

Creutzfeldt recognized a new disease in Bertha Elsckher's fatal illness, but the Great War intervened before he could report his discovery. In 1920 he was finally able to prepare a paper for a German medical journal. A colleague at the University of Hamburg, Dr. Alfons Jakob, read the paper while it was still in press. Jakob had lost four patients whose symptoms and autopsy findings seemed to him to match Creutzfeldt's case, although all four were significantly older. Jakob described them in a paper published in 1921. Only one case is still considered canonical, a forty-two-year-old salesman named Ernst K. whose illness began with aching legs and dizziness and progressed like Bertha's to a final stage of dementia and stupor. Ernst K.'s brain also showed no inflammation but extensive cell death and starlike, proliferated glia.

Together, these first early reports described a new degenerative disease of the brain, Creutzfeldt-Jakob disease. CJD is known today to be an uncommon but not a rare disease—rabies is rarer—but for the next four decades very few cases of CJD were reported. When Igor Klatzo associated kuru with CJD in his letter to Carleton Gajdusek in 1957, he knew of only about twenty such reports, none of them American, even though CJD occurs throughout the world with uncanny regularity: similar prevalence and incidence, Gajdusek has written, “in all races and in all climes from the Arctic to the

How Safe is Chlorinated Water?

An estimated 75% of drinking water in the U.S. is chlorinated. While chlorination has helped to reduce the incidence of infectious diseases, known carcinogens such as chloroform and other trihalomethanes are formed when chlorine reacts with organic compounds in the water. These chlorines accumulate in fatty tissue such as breast tissues and can be found in body fat, blood, mothers' milk and even semen. Studies have implicated chlorinated drinking water with colorectal and bladder cancers. Highly chlorinated water resulted in a noticeable shift in the transformation of cholesterol from beneficial HDL to harmful LDL.

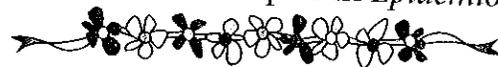
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Recently, the American Journal of Public Health published the results of a study of cancer risk over an 8 year period in 28,237 postmenopausal women. Those who drank water from municipal surface water sources consumed higher levels of chloroform than those who drank municipal ground water sources. The higher intake of chloroform was associated with an increased risk of colon cancer, and of all cancers combined.

Even chlorination does not provide full protection against the deadliest organisms in public water supplies. Cryptosporidium, a toxic parasitic protozoan, is chlorine resistant and is inadequately removed by sand filters.

"The worldwide pollution of lakes, streams, rivers and oceans and the chlorination of swimming pool water has led to an increase in deadly melanoma cancer."

— Reports Franz Rampen in *Epidemiology*



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Fluoride in Drinking Water Increases Toxicity of Aluminum

Posted: July, 2001

In 1994, the New York Times reported a scientific study that revealed that aluminum and fluoride in water could be responsible for the alarming increase in Alzheimer's Disease and senile dementia.

This confirmed the long-held suspicion of environmental writer George Glasser that fluoride has the ability to react with other toxic minerals in drinking water. Serious drug interactions are common in medicine, and for years Glasser has badgered various US government agencies to investigate this specific interaction between fluoride and other substances.

"Aluminum sulfate (alum) is used to clarify drinking water and I could see the possible relationship with Alzheimer's-like dementia," said Glasser. "In 1999, the US Environmental Protection Agency finally reviewed three studies carried out by scientists at Binghamton University in New York. The scientists reported 80% death rates, kidney damage and brain damage in rats exposed to half of one milligram of aluminum fluoride complexes in a liter of drinking water. This is less than half of the amount of fluoride which is added in fluoridation schemes.

Finally, the National Toxicology Program was asked to commission studies to determine the extent of neurotoxic damage from aluminum in drinking water, particularly stressing the fluoride interaction."

Last October, a Report by the National Institutes of Environmental Health Sciences (NIEHS) acknowledged that fluoride has been observed to have synergistic effects on the toxicity of aluminum.

"I was particularly pleased when the US Environmental Protection Agency report by Urbansky and Schock on the toxicity of lead and fluoride in drinking water confirmed that fluoride complexes with other substances in the water. They also acknowledged that most drinking water contains a substantial amount of fluoro-aluminum complexes. This should be a warning to dentists who hold with the simplistic notion that fluoride only affects teeth and is perfectly safe in drinking water."

According to the NIEHS Report, most water treatment processes result in increased levels of aluminum in the finished drinking water.

It stated that fluoridation will result in aluminum fluoride complexes which will enhance neurotoxicity, or that fluoride itself will enhance uptake and synergise the toxicity of the aluminum.

Other studies have shown that in the presence of fluoride, aluminum leaches out of cookware. Boiling fluoridated tap water in an aluminum pan leached almost 200 parts per million (ppm) of aluminum into the water in 10 minutes.

Leaching of up to 600 PPM occurred with prolonged boiling. Different releases of aluminum depend upon the composition of the pan and the type of food being cooked.

Using non-fluoridated water showed almost no leaching from aluminum pans.

Glasser is frustrated that the Report recommended further studies. "There are more than 40,000 studies on fluoride in the scientific literature. How many more do they need? The

recent York review examined less than 300 - and they never bothered to review the Binghamton University studies.

The incidence of Alzheimer's Disease and Alzheimer's-like dementia is hitting people at much younger ages. The average age used to be 65 - now, it affects people in their forties in ever-increasing numbers. With these revelations, health authorities have a moral obligation to employ the precautionary principle and cease the practice of artificial fluoridation forthwith. In the meantime, six million people in England and about 160 million in the United States drink artificially fluoridated water."

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George Glasser articles:

home.att.net/~gtigerclaw/dead_rats.html

home.att.net/~gtigerclaw/newsletter/Increasing_Alzheimer.htm

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National Funeral Directors Association | California Seeking to Ride the Alkaline Hydrolysis Wave Page 1 of 6 27

California Seeking to Ride the Alkaline Hydrolysis Wave

Bill Advances to Senate, Approval Expected

Taken from the May 13, 2010, edition of the Memorial Business Journal

Sacramento – Last week the California State Assembly unanimously approved A.B. 2283, which would amend the state's Health and Safety code to change the definition of cremation to include alkaline hydrolysis, a "chemical dissolution process using heat, high pressure water, and potassium hydroxide to hydrolyze human tissue and the consumable container."

Introduced by Assemblyman Jeff Miller, the bill has been advanced to the state senate for consideration. If approved, California would join Florida, Maine and Oregon as states that have taken legislative action to permit the process for the general public. A number of other states, including Minnesota and Colorado, permit the practice for institutional procedures, such as the disposition of cadavers at medical and veterinary schools. Meantime, a number of states are having the conversation about amending their laws to include the process in their approved methods of disposition of human remains. Some states argue that while the process isn't officially "legal" in their states for public consumption, it isn't illegal either. Meaning a business could test the waters and seek to install a facility following the licensing and permit process currently on the books.

The California bill also instructs the state's Cemetery and Funeral Bureau to adopt regulations for the safe operation of alkaline hydrolysis chambers no later than July 1, 2011.

Robert J. Achermann, executive director of the California Funeral Directors Association, which supported the bill, noted that there is no opposition to the A.B. 2283 and he does not expect there to be any problem getting the bill through the state senate and signed by the governor.

"The association has had meetings with Miller's office about some of the technical issues about how you define the process," Achermann said. "I think most funeral directors believe this is something that will generate consumer interest as an alternative to traditional cremation." Another consideration in the state — cemeteries in California, especially near the major metropolitan areas, are running short on space.

Supporters call alkaline hydrolysis, which is also referred to as bio-cremation, Resomation or water resolution, a "greener" alternative to traditional cremation. The process itself reportedly uses about less than 20 percent of the energy used for a cremation. Further, CO2 emissions are reduced by nearly 90 percent and the process avoids putting mercury and other harmful contaminants into the atmosphere.

Basically, a body is placed into a stainless steel container with potassium hydroxide (a form of lye) and heated to more than 300 degrees F. Turbulence is used to accelerate the dissolving of flesh and soft tissue. Usually the process takes, on average, about three or four hours. What's left is a sterile liquid substance containing amino acids, peptides, sugars and salts that are purportedly environmentally friendly and can be washed down the drain. The remaining bone fragments are whiter in appearance than those that are cremated. The bones are then pulverized into a fine white, ash-like substance and can be returned to the family.

“I am told there are no discharge issues, it is a process that has been used in Europe for some time,” Achermann said. “But being California the environment is always at the forefront.”

Assemblyman Miller was approached with the idea by a funeral director, Chris Miller (no relation), owner of Thomas Miller Mortuary in the assemblyman’s home district of Corona. Chris Miller also approached the state association to lobby to have the law changed.

Eye on the Process

The forward progress in California has turned a spotlight on the process as a whole. The technology evolved out of necessity in Europe as the high volume of cremation in densely populated areas compelled nations to put limits on the emissions. The first application of alkaline hydrolysis to be used for processing human remains in the United States took place in 1998 at the University of Florida, Gainesville, to dispose of medical school cadavers. The second system, also for institutional purposes, was in 2005 at the Mayo Clinic in Rochester, Minn.

Currently, there are no funeral homes offering alkaline hydrolysis as a means of disposing of human remains in the United States. The first commercial application of the process is scheduled to be installed this summer by Matthews International, which partnered with a Scottish firm, Resomation Ltd. in 2008. The location of the unit, pending final approvals of the necessary permits, is at the Anderson-McQueen Family Tribute Center in St. Petersburg, Fla., which will be a showcase for the use and application of bio-cremation for the public.

According to Steve Schaal, division manager for sales and marketing of Matthews Cremation, Apopka, Fla., the opening of the facility is just a few months away. “The emission test data and technical solution are in the hands of the local St. Petersburg Waste Water authorities,” he said. “We believe we’ve thoroughly answered every technical requirement and anticipate approvals within the next few months. Because it’s the first in the world within a funeral home, we’re going where no other company has gone.”

Matthews and BioSAFE Engineering, Brownsburg, Ind., are two of just a handful of firms in the United States to offer the equipment. Another competitor, CycledLife, Denver, unveiled its prototype vessel this month. Transition Science, a Toronto-based company is the licensed distributor of Resomation in Canada. That country’s first bio-cremation system is currently being installed in Toronto.

A Significant Investment

Where alkaline hydrolysis accelerates the decomposition process, there is not likely to be much acceleration in the legislative pace even as a number of states are currently discussing the process. However, once the conversation advances past the legal hurdles (no small task especially if you are talking about introducing any liquid remains into a sanitary sewer system), getting into the alkaline hydrolysis business is not an inexpensive investment. Equipment ranges in price from \$200,000 to \$400,000, which is about 3 to 5 times the cost of a traditional cremation retort.

However, the alkaline hydrolysis chambers may offer savings in other areas. In California, for example, funeral homes or crematories investing in the technology would not be required to acquire air emission permits, which is an expensive, time-consuming process, Achermann said. Manufacturers suggest that the alkaline hydrolysis vessel offers lower maintenance than a traditional retort, which has to be rebricked after so many hours.

CONTINUED FROM PAGE A1

Steve Medeiros, a prominent businessman and deer hunter who grew up in a dairy family, died of CJD.

Researchers are interested in determining whether there is a connection between CJD and the consumption of diseased venison. Another prion disease, allied chronic wasting disease, has been found in wild herds of deer and elk in 14 states, especially in Colorado and Wyoming.

"Right now, we don't know of any human prion case that's linked to eating any of these deer or elk, but we're sort of wary because it's in the same class of disease as mad cow disease," said Joseph Y. Abrams, an epidemiologist with the CDC. "The earlier we detect them, the earlier we can stop them from spreading out of control, so we need to do surveillance constantly."

Abrams said hunters should refrain from consuming brains or spinal tissue of deer and elk and minimize handling those areas, and should wear gloves when butchering the animals.

There has not been a major outbreak of mad cow disease in the U.S., where only two infected cows have been found in the past decade, compared to the U.K., where more than 184,500 infected cows were found, according to the CDC. And to date, there have been no known transmissions of chronic wasting disease from infected wild deer or elk to humans.

But the scientific community is studying the connections between those diseases because the dangers are not fully known, and the possibility that humans could contract those diseases from animals has not been ruled out.

Dr. Michael Geschwind, neurologist at UC San Francisco, who has treated CJD patients from Sonoma County, ran the first U.S. treatment study for CJD. Geschwind said he and other scientists expect another outbreak of variant Creutzfeldt-Jakob disease to occur because the disease has a long incubation period, and there likely are people who have been exposed but have not yet come down with disease.

Geschwind said researchers are investigating potential connections between sporadic CJD, mad cow disease and the chronic wasting disease that afflicts wild deer and elk.

"It's possible, and that's why we're doing these cases," Geschwind said. "We call it 'sporadic' almost out of ignorance. We call it sporadic because we don't know what causes it."

Over the past 18 years, 19 people



Ric Collins, left, of Santa Rosa died of Creutzfeldt-Jakob disease in October. Steve Medeiros, also of Santa Rosa, died of the same disease earlier this month.

have died in Sonoma County of CJD, an average of one case per year in a county with a population of about 483,000 — about twice the national average.

Geschwind said it's hard to know whether Sonoma County's higher infection rate is significant because the diagnosis can be difficult. Unless those cases of CJD are confirmed by an autopsy or specialist, the number could be overreported, he said.

Recky Weislow of Santa Rosa, whose sister-in-law in San Carlos died of CJD this month, said her "biggest concern is to make sure that we aren't in some way or another contracting it from our food source."

"How can you say it's not, if you don't know how it is contracted?" she said. "Especially because it seems like the people who have contracted it have been lovers of food. My sister-in-law loved to experience new food, and Ric Collins had traveled to Europe extensively."

Weislow and Lorraine Collins recently walked in the Human Race and raised \$11,000 for research at UCSF, where their family members were treated, she said.

Collins, through her network, identified a third Sonoma County person who died of CJD last year.

Dr. Mark Netherda, interim-director of the Public Health Division of Sonoma County, said the cases of CJD in Sonoma County have been genetic or sporadic, types not linked to mad cow disease.

"It's definitely not something that we're looking at or following actively," Netherda said. "It doesn't rise to that level."

Even so, Geschwind said there should be more surveillance of both animals and humans. For his part, he stopped eating beef.

"In Canada, they're doing much more inspection than we are," Geschwind said. "We essentially don't inspect cattle. The only cattle we're required to inspect are 'downer' cattle, but

sick or weak to stand on their own.

The U.S. Department of Agriculture inspects cattle for signs of BSE as they enter slaughterhouses, said Larry Hawkins of the Animal and Plant Health Inspection Service of the USDA. Until 2006, the USDA was inspecting 40,000 cattle per year for BSE. But after finding only two infected cattle in a decade, the surveillance was scaled back to federal monitors in slaughterhouses. Still, that level of surveillance exceeds international requirements for BSE monitoring, Hawkins said.

But that level of surveillance is not enough to satisfy critics.

"When they go on to slaughter, they're packed in so tight that I don't know how they could find a 'downer' cow," said Florence Kranitz, president of the CJD Foundation, a nonprofit organization based in Akron, Ohio. Kranitz lost her husband to CJD.

Scientists say studying humans who have died from prion diseases by conducting special autopsies on their brains is important to help prevent future outbreaks.

The National Prion Disease Pathology Surveillance Center at Case Western Reserve University in Cleveland is responsible for tracking cases of CJD in humans. The center, which conducts many of the autopsies, is the only organization in the U.S. that monitors the possible occurrence of mad cow disease or other prion diseases in humans.

Kranitz said the federal government proposed cutting \$5.4 million in spending on surveillance of prion diseases, a cut that she fears could eliminate funding for the National Prion Disease Pathology Surveillance Center.

"There's a big concern for funding for surveillance in this country," Kranitz said. "Heaven forbid the funding goes away and the surveillance center can't operate. This is critical. If this goes away, there is so much danger to the country, let alone the disappointment and pain to families who won't be able to get answers."

That search for answers is what compelled Lorraine Collins to organize a Human Race team to raise funds for UCSF.

"It was just so amazing what she did, in the setting of everything she dealt with," Geschwind said. "Everyone reacts to this kind of tragedy differently ... and she did something to

help future patients."

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U.S. FUNDS SHRINKING used to det

GAO: Demand rose, supply fell, and Energy Department failed to communicate

By MATTHEW L. WALD
NEW YORK TIMES

WASHINGTON — The United States is running out of a rare gas that is crucial for detecting smuggled nuclear weapons materials because one arm of the Energy Department was selling the gas six times as fast as another arm could accumulate it, and the two sides failed to communicate for years, according to a new Congressional audit.

The gas, helium-3, is a byproduct of the nuclear weapons program, but as the number of nuclear weapons has declined, so has the supply of the gas. Yet, as the supply was shrinking, the government was investing more than \$200 million to develop detection technology that required helium-3.

As a result, government scientists and contractors are now racing to find or develop a new detection technology.

According to the Government Accountability Office report, the Energy Department's National Nuclear Security Administration, which gathers the gas from old nuclear weapons, never told the department's Isotope Program about the slowing rate of helium-3 production. That is in part because it was secret information that could be used to calculate the size of weapon stockpiles.

For its part, the isotope program calculated demand for the gas not in a scientific way but instead on the basis of how many commercial companies called to inquire each year about helium-3 supplies.

Rep. Donna Edwards, D-Maryland, characterized the situation as "gross mismanagement." As the ranking Democrat on the House science committee's Subcommittee on Investigations and Oversight, Edwards was one of the members of Congress who asked the accountability office to study the problem after it was detected in 2008.

"With so much riding on helium-3, it is shocking to learn that the department's forecast for demand is based simply on

a telephone log tracking those who called asking about the availability of helium-3," she said.

The report is to be released in the coming week by Ed-

there's no enforcement. If a meat producer has a 'downer' cattle, from a financial perspective there's no incentive to find out that cattle has BSE." "Downer" cattle are those that are too