

## JUST ONE BREATH: Five ways to move the fight against Valley Fever forward

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Valley Fever is a humbling disease.

It can rob sufferers of their health, their life plans and their financial well-being. Uncertainty adds to the trauma. There is no cure around the corner, no vaccine in the works and no well-organized patient group lobbying effectively for more policy attention.

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#### ABOUT THIS REPORTING TEAM

This project results from a new venture -- the Reporting on Health Collaborative -- that involves The Bakersfield Californian, the Merced Sun-Star, Radio Bilingue in Fresno, The Record in Stockton, Valley Public Radio in Fresno and Bakersfield, Vida en el Valle in Fresno, the Voice of OC in Santa Ana and [ReportingonHealth.org](http://ReportingonHealth.org).

The collaborative is an initiative of The California Endowment Health Journalism Fellowships at the University of Southern California's Annenberg School for Communication and Journalism.

#### ABOUT THIS SERIES

The number of Valley Fever cases has soared so high in recent years that health experts are calling it "The Second Epidemic."

In an occasional series that continues today, the Reporting on Health Collaborative is exploring the rise of cases, the tricky science of studying the disease, the high costs to patients and taxpayers, the lack of private interest in funding treatments and vaccines, and the long history of inaction by government agencies.

You can read the series so far at:  
[www.bakersfieldcalifornian.com/special-sections/just-one-breath](http://www.bakersfieldcalifornian.com/special-sections/just-one-breath).

The result: those who become ill often suffer in silence and feel alone.

That inattention is surprising and distressing to Valley Fever patients and the handful of researchers trying to make headway against the disease, which is caused by inhaling the spores of a fungus that grows in soil, particularly in California's Central Valley and in Arizona.

Researchers estimate 150,000 people contract the disease every year and millions of dollars are spent treating those people. The disease killed more than 3,000 people between 1990 and 2008, according to one study. And the number of people being diagnosed with the disease is rapidly rising.

Yet Valley Fever receives far less funding than diseases that impact fewer people, such as West Nile virus.

A three-month investigative series by the Reporting on Health Collaborative -- a consortium of seven California media outlets and the USC Annenberg School of Journalism -- has found that doctors don't have very good medications to treat the disease, known as coccidioidomycosis, diagnostic tests are limited and understanding of the disease is behind that of other common illnesses.

"We're really quite often working in the Dark Ages," said **Dr. Francesca Geertsma**, a pediatric infectious disease specialist at the California Pacific Medical Center in San Francisco.

Coming out of the dark will require coordination and significant sums of money. The Reporting on

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By Alex Horvath / The Californian  
Diana Frizzlele was diagnosed with Valley Fever last year and is still on medication to treat the disease.



Health Collaborative asked patients, physicians, researchers and government officials to identify steps that could be taken now to change the course of the disease.

**Five key action areas emerged from those conversations with a rough timeline of targets for specific achievements:**

- \* Improve how doctors identify and care for Valley Fever patients immediately through training.
- \* Implement a robust surveillance system to track the disease, especially in California, by 2014.
- \* Develop better tests for the disease by 2015.
- \* Bring to market modern treatments for Valley Fever by 2017.
- \* Raise enough money to finish the work of creating a vaccine, the silver bullet in the fight against Valley Fever, by 2022.

## GIVE DOCTORS A VALLEY FEVER INTUITION

Perhaps the quickest way to put a dent in Valley Fever is by increasing doctors' awareness of coccidioidomycosis so that they detect the potentially deadly disease earlier and get patients on the right course of treatment faster. Coccidioidomycosis may be mistaken for any number of other ailments, delaying treatment and prolonging suffering.

When **Dr. Raj Patel** came to Bakersfield two decades ago, Valley Fever cases were surging and Patel found himself essentially taking a crash course in how to handle the disease.

"I had to learn first-hand, treating the patients, diagnosing patients, watching them deteriorate and heal," said Patel, who practices internal medicine at Preferred Family Care Physicians in Bakersfield, where he is a partner.

The situation remains much the same today. **Dr. John Galgiani**, professor at the University of Arizona and director of the Valley Fever Center for Excellence, said every year hundreds of new physicians, many of whom have trained outside the area, are licensed to practice medicine in areas prone to Valley Fever.

**Dr. Navin Amin**, an infectious disease specialist at Kern Medical Center, said the way to spread the word is through basic doctor-to-doctor training. After the Reporting on Health Collaborative started publishing this series, Amin was invited to speak to Kaiser Permanente physicians in Kern County about the disease.

Later, one of the Kaiser doctors who participated spotted a case of Valley Fever in a pregnant patient who had a bump on her leg, Amin said.

In Arizona, the state Department of Health Services has an annual Valley Fever awareness week that includes a free continuing medical education course for physicians. The course is also posted online. The California Department of Public Health does not have a similar program, but California physicians can take the online class to fulfill their continuing medical education requirements.

The Arizona health department also collaborates with neighboring states to share its methods and information, including California, New Mexico and the Mexican border states of Sonora and Chihuahua.

The department has about \$100,000 dedicated to Valley Fever investigations and awareness annually from grant funding. The California Department of Public Health does not have any funding dedicated specifically to the disease, according to an email from the department. It did recently receive a one-time \$80,000 grant from the U.S Centers for Disease Control and Prevention to study Valley Fever and other fungal diseases.

Jessica Einstein, daughter of late Valley Fever researcher Dr. Hans Einstein and director of communications for the Valley Fever Americas Foundation, said she would like to see a Valley Fever awareness week in California's Central Valley and a curriculum for schools to teach students about the disease. Her aim is to get people to pay more serious attention to Valley Fever.

"How do we affect people like that who are really certain for themselves that this is not a problem?" she said.

### **TRACK VALLEY FEVER IN REAL TIME**

With more money dedicated to Valley Fever, Arizona has been aggressively tracking Valley Fever cases for about five years, said Shoana Anderson, chief of the Arizona Department of Health Services' Office of Infectious Disease Services.

"The challenge is really understanding what the data is telling us," she said.

When a doctor logs on to the state system and reports diagnosing a new case or a testing lab reports a positive result for the Valley Fever fungus, the state system receives an instantaneous report and incorporates it into its tracking, identifying clusters of cases by geography and time.

The system provides information about how long it took before patients went to a doctor about their symptoms, how long they've lived in Arizona and other information that helps improve communication with the public and public education, Anderson said. She said they're trying to determine why people seek health care for Valley Fever and improve on it, so patients recognize symptoms and seek help sooner.

The information also helps officials focus on what is new or unusual, like an unexpectedly large number of new cases in people under age 25, she said.

### **SPEED UP VALLEY FEVER TESTING**

Faster, more accurate tests are needed to help doctors root out more cases of Valley Fever, experts said.

Physicians usually confirm suspected cases of Valley Fever by blood tests that show increases in the patient's antibodies.

But some patients don't test positive even when they appear to be suffering from Valley Fever and respond well to an antifungal course of treatment. Repeated testing may be needed because it takes time for a patient's antibodies to develop.

The results can take anywhere from a few days to several weeks. Emergency room workers may be reluctant to order the test because by the time the results come back, the patient is gone, Galgiani said.

"(Valley Fever is) often missed because there isn't good rapid testing available," said **David Engelthaler**, director of programs and operations for TGen North, a nonprofit research lab.

TGen North has licensed a molecular test to a diagnostic company in Flagstaff, Ariz. **Todd Snowden**, president and CEO of PathoGene, said the test could be offered as soon as the second quarter of 2013.

In addition, proteins that could be the basis for developing new tests have been identified at the Valley Fever Center for Excellence.

## **CREATE TREATMENTS WITH FEWER SIDE EFFECTS**

Current antifungal treatments for Valley Fever can have harsh side effects and may let the disease spread before they work.

Bakersfield resident Diana Frizzelle has been taking an antifungal medication for more than a year to keep Valley Fever at bay.

Every three months Frizzelle visits her doctor to check the status of her Valley Fever and so far, each visit has brought the disappointing news that she needs to stay on her medication. She said her hair is falling out and her skin is dry because of the pills.

She read the Valley Fever series in her newspaper hoping for some tidbit of information that would help her situation.

"I keep hoping because it's never going to go away," she said.

Galgiani is working on a drug called Nikkomycin Z, and finds his work limited by the lack of financing.

"The reason we don't know if it is a cure or not or how good it is, is because we don't have the money," Galgiani said.

Phase one safety trials in people have been conducted. And researchers are ready to see if the drug works in people who are infected with Valley Fever. Galgiani received a \$3 million grant from the National Institutes of Health but his center has struggled to produce enough of the drug to conduct an effective trial. If enough of the drug can be made, clinical trials could start in the fall of 2013, Galgiani said.

"We are moving it forward; we're just going very slowly," Galgiani said.

With an investor's backing and an estimated \$40 million, the drug could be ready in five years, Galgiani said, but, so far, no drug companies have signed up to fund the work.

## **VACCINE REQUIRES TIME, MONEY**

The future of a vaccine also hinges on clearing financial hurdles.

Funding in the past has been "chicken feed" compared to what would be needed to produce a vaccine, said Amin, the Bakersfield doctor. The price tag for a vaccine could be double that of developing a new drug, according to Galgiani, at least \$80 million.

Valley Fever experts said a combination of federal, state and private money would likely be needed to bolster the efforts.

Estimates of how long it could take to produce a vaccine varied among the researchers.

**Dr. Demosthenes Pappagianis**, a professor and director of the Coccidioidomycosis Serology Laboratory at the University of California, Davis, said he would not hazard a guess at how long a vaccine would take.

"We're all impatient to get an answer but I think it's still going to be a matter of some time before the correct vaccine and the method of administering it will be known," Pappagianis said.

**Garry Cole**, a professor at the University of Texas in San Antonio who has tested a live vaccine in mice, said it could take 10 years to have a vaccine in humans.

A revival of the consortium approach that helped spur progress in the past could help vaccine research today, Cole said. With better funding, more labs might take interest and join in the efforts, he said.

Valley Fever's history is cyclical.

Enthusiastic people get a little money to make something happen, but then the money dries up, said **Kirt Emery**, Health Assessment and Epidemiology Program Manager for the Kern County Public Health Services Department.

The efforts need the support of local governments, federal agencies, businesses and private foundations as well, he said.

"If we're going to be successful we've got to come up with really more of a business model of acquiring funds," Emery said.

A robust patient advocacy group with a dedicated leader might be able to further Valley Fever's cause more than anything, Emery said.

"(Patients) can really move the money in my opinion easier than a lab director or an epidemiologist or a doctor," Emery said.

**James Ranger**, the lead pastor at New Life Center in Bakersfield, battled Valley Fever twice and has been shocked by the lack of awareness surrounding the disease ever since.

"I didn't have a clue that people died with (Valley Fever). I didn't have a clue that it would last for months and years," Ranger said.

Ranger's church hosts a Valley Fever benefit concert and is developing a Valley Fever support group hoping to educate more people about the potentially deadly disease.

The pastor said he is "stunned" that more churches and community leaders aren't taking on Valley Fever.

"I don't see anybody waving their flag," Ranger said. "Who's responsible? Who's leading this thing? It should be the leaders of the community, whoever that is."

-- *Rebecca Plevin, Yesenia Amaro, Tracy Wood, and Kellie Schmitt contributed to this report.*