



# THE COCCI CONNECTION

May/June 2011

## Inside This Issue

- California News
- Arizona News
- Coming Attractions
- Board Member Profile
- Medication Costs
- Member Profile
- Message from the Director
- Volunteer Profile
- Membership News
- Veterinary
- Media

## California News

On Saturday, April 2, 2011, the 55<sup>th</sup> Annual Coccidioidomycosis Study Group met on the campus of the University of California, Davis. Many scientists and physicians gathered to discuss the research they did during the past year.

There were presentations about the soil and environment in which the cocci fungus grows and flourishes; hot spot areas for cocci in Arizona and California; the high rate of cocci among California prisoners and guards in the Coalinga area; how animals such as dogs, cats and sea lions contract cocci; the areas of the body most affected; and genetic mapping of cocci proteins.

The high spot of the day for everyone was listening to reports of how even severely ill people recovered from Valley Fever once they received proper medical treatment. Details of the experimental antifungal agent nikkomycin Z were outlined. Three of the participating dogs recovered from Valley Fever, and Lisa Shubitz, DVM, who carried out the clinical trial, is guardedly optimistic that nikZ works more efficiently and with less side effects than Diflucan (fluconazole).

## ARIZONA NEWS

We are now listed in the Northwest Valley Medical Directory, and there is a link to our website.

In April, 2011, the Valley Fever Alliance in Phoenix merged with Arizona Victims of Valley Fever. The purpose was to pool our resources, establish an independent 501c3, and consolidate our power with the state to create awareness about Valley Fever, raise funds for a cure and lobby the state for government participation.

Thus, some people receiving this newsletter are on our mailing because they once participated in a Valley Fever Alliance function or expressed the desire to volunteer for or become a member of the Alliance.

We hope you will continue attending our fundraisers and support groups and will spread the word to interested friends and family members.

Please contact Janice at 480-831-9079 for questions about the newsletter.

## Coming Attractions

May 2---Green Fair, Surprise Stadium

June 8--Lecture, Shepherd of the Hills Church, 13658 W. Meeker Blvd., Sun City West 10 a.m.-Noon

June 10--Grand Community Baptist Church, 18350 N. Goldwater Ridge Rd., Surprise, 9 a.m. - 2 p.m.

June 16--Support Group, PORA, 13815 Camino Del Sol, Sun City West, 1 p.m. - 2:30 p.m. (Third Thursday of each month)

November 6--Third Annual Valley Fever Walk, Beardsley Park, 20011 N. 128th Ave., Sun City West, 9 a.m. - Noon

November TBA--Board of Directors Meeting

## Board of Directors: Janice Arenofsky



Executive Director Janice Arenofsky is a freelance writer by trade and the former co-director of the Valley Fever Alliance. Although she has not had Valley Fever, her pet Schnauzer, Conchita, died and the experience made such a sad impression that she decided to volunteer as an advocate for a cure.

As a child and adult, she lived in New Jersey, but moved to Arizona 30 years ago. Her husband, Ray—an attorney also on the Board—works in Mesa as an accident lawyer. She resides in Scottsdale with her four dogs and Maine Coon cat. She can be contacted at [jarenofsky@cox.net](mailto:jarenofsky@cox.net).

## VALLEY FEVER MEDICATION PRICING (FLUCONAZOLE)

DRUGS	MG/DAY	WALGREEN Mail Order	COSTCO 843-6498	WALMART 544-2200	SAM'S CLUB 584-0728	TARGET 975-4122	CVS 214-1015	OSCO 546-8246	RX SOLUTIONS 800-351-7948
Fluconazole♥	200 mg/ 2 day.	1,079.79	66.10	89.84	75.78	226.49	634.00	2,600	148.22

Courtesy of Pat White

## Director's Column: Pat White



A Minnesota native, Pat Curley White moved to Goodyear, Ariz., in 1994, then to Sun City West in 2006. She had been working as an executive assistant in Surprise for the City Manager for 10 years when she became infected with Valley Fever.

Due to what Pat calls "our local secret," she did not know what was wrong with her or her identical twin sister and mother, who also became ill with coccidioidomycosis or Valley Fever. She now feels like she could have done something more to help her relatives fight the disease if she had known earlier what it was. Instead, the doctors misdiagnosed the symptoms as possible cancers of the lung. Pat's mother died of Valley Fever.

By 2006 and struggling with her own Valley Fever symptoms, Pat began a support group and started lecturing to church congregations and members of different organizations. She called the support group Arizona Victims of Valley Fever.

We hope you like our new newsletter. Janice Arenofsky is the one to thank. We hope to bring lots of new, fun and interesting information to you.

Pat wants everyone to know that Arizona Victims of Valley Fever is an all-volunteer organization and that all funds raised go toward the cure. All donations can be made directly to the VFCE:

**Valley Fever Center for Excellence  
Medical Research Building, Room 124  
1656 E. Mabel St.  
P.O. Box 245215  
Tucson, AZ 85724**

## VOLUNTEER PROFILE: MARY FRANCIS HEMPHILL-PARKER



Born in Indiana, Mary grew up to become the mother of four children and the wife of Ron Parker. At an early age, Mary began taking voice lessons, and singing soon became an important part of her life. She taught singing and also

performed throughout the county with her good friend accompanying her on the piano. The two friends played on the Indianapolis radio station three times.

When she married and became a mother, Mary got active with Scouts, 4-H, church and school. Later on she became a sales employee at Sears and worked there for 22 years before moving to Arizona in 2001.

Health problems led to her relocation to Sun City West. Three of Mary's children still live in Indiana, but she also has a daughter in Phoenix and a son in Hawaii. This September Mary and her husband will visit Indiana to celebrate their 60th high-school reunions.

A dedicated and loyal volunteer for AVVF, Mary helps out at all our events. She boosts our morale and educates people about the dangers of valley fever.

## NIKKOMYCIN Z IN DOGS WITH VALLEY FEVER: AN OPEN LABEL PRECLINICAL TRIAL

Doctors Lisa F. Shubitz, David E. Nix, Christine D. Butkiewicz, John N. Galgiani  
Valley Fever Center for Excellence, The University of Arizona, Tucson, Arizona

The objective of this study was to determine if Nikkomycin Z rendered observable improvement in naturally infected dogs with coccidioidomycosis. Due to the limited supply of the drug and the short treatment time available, enrollment criteria included a body size between 5-15 kg (11-33 lbs) and clinical findings of either coccidioidal pneumonia based on radiographic findings plus a positive serology, or cutaneous/subcutaneous lesions with demonstrated *Coccidioides* based on cytology, biopsy, or culture results. The supply of drug limited the study to 12 dogs.

Methods included an enrollment evaluation (physical examination, owner assessment, serum chemistries/CBC, coccidioidal serology, and radiographs or pathology report), mid-study evaluation with one day pharmacokinetic study between 0-12 hours post-pill, and exit evaluation that included repeat laboratory and radiographic analyses, physical examination, owner assessment, and paired serology with sample archived from enrollment visit. Dogs were treated with 250 mg (16-50 mg/kg) q. 12 hrs for 60 consecutive days and the study was not controlled for food intake. One day PK study was performed between 21-30 days of treatment, and the exit evaluation was completed within 7 days of the last dose of medication.

At the time of this interim report, 5 dogs have been enrolled; 3 dogs completed the 60 days of treatment and all evaluations. The three dogs all had coccidioidal pneumonia with hyperglobulinemia, neutrophilia, monocytosis (2/3), positive serology, and abnormal thoracic radiographs at the time enrollment. Two dogs had not improved on >2 months of fluconazole treatment and the other dog was naïve to antifungal medication. All three

dogs had clinical improvement with resolution or near resolution of clinical signs as assessed by the owner without reported adverse effects from the Nikkomycin Z. There was normalization of serum chemistries, radiographic improvement, and a reduction in titer on paired serology. One dog had significant clearing of a consolidated right middle lung lobe with residual opacities. The other two had return to normal size of hilar lymph nodes and elimination of infiltrates with remaining mild bronchial patterns.

Nikkomycin Z levels were analyzed by HPLC and a time concentration was modeled for each dog. The population modeling at the end of the study will be much more revealing than the curves for each individual dog due to lean sampling of individual animals, but 2/3 dogs had effective areas under the curve as calculated from human and murine modeling.

Summary observations to date include that the drug has had no incidence of adverse effects, has produced a good clinical response in the three dogs that completed treatment, and that the onset to improvement of clinical signs is a little slow with it taking 3-4 weeks before owners noted reduction in clinical signs.

**Nikkomycin Z in Dogs with Valley Fever: An open label preclinical trial**

## MEMBERSHIP NEWS

**Starting July 1, 2011, there will be a yearly \$10 membership charge per person.** The membership fee will allow us to purchase office supplies and other materials so we can better educate the public about Valley Fever. The monies also will allow us to operate without holding a fundraiser to reimburse volunteers for out-of-pocket expenses. All fundraising then will be directed toward supporting the work of the Valley Fever Center for Excellence at the University of Arizona and its goal of finding a cure for Valley Fever.

We are in the process of revising ARIZONA VICTIMS OF VALLEY FEVER: ARIZONA'S DISEASE BOOK, the spiral ring compilation of comprehensive information on Valley Fever by Pat White. The cost will be \$16 (\$10 goes to the Valley Fever Center for Excellence and \$6 covers production expenses).

A big thank you to all those who volunteered for the Green Fair at Surprise Stadium on May 21st: George Spinner, Mary Parker, Tom Bobak, Vicki Dillon, John White, Irene Polczer, Ray Pendergast and Janice Arenofsky. Volunteers spoke to people about the nuts and bolts of Valley Fever and got signatures for the petition to reinstate the Valley Fever department at the ADHS.

## **EDITORIAL**

The following "My Turn" column appeared in select sections of the East Valley Tribune May 21, 2011:

## MEDICINE HAS YET TO GET A GRIP ON VALLEY FEVER



No matter what was happening to me, I could always deal with it by running," says Angela Tahiliani, a mother of three who has been a long-distance runner since seventh grade. "Then the valley fever hit."

The 39-year-old Queen Creek resident has barely emerged from the battle for her life, which began three long years ago. Exacerbating the struggle was an inability of doctors to diagnose the disease.

"It took two full months, four ER trips and just under 10 doctors before I was able to have a diagnosis," she says. I was never hospitalized for Valley Fever, I was hospitalized for "unknown." And because they had no way of knowing how to treat me, they let me go.

It's one of the great health scandals in the history of the Southwest, where valley fever haunts the air we breathe. Tests for the fungal infection are unreliable. And apparently there is no breakthrough on the horizon, though I'm told a new drug is being tested in Tucson. But still, if the disease isn't diagnosed, what good is the drug?

How is it that every single Arizona doctor is not versed on the symptoms in light of inadequate test protocols? Why is it that the fungus *Coccidioides*, which grows in soil until it gets into the lungs of people (and animals), is allowed to linger and morph into catastrophic illnesses because docs are not on the lookout?

Yes, the symptoms are flulike, disguising Valley Fever, but doctors should know if a patient is not recovering, over several weeks, to automatically suspect Valley Fever. This is a crippling disease, it can be deadly. Thousands are diagnosed yearly in Arizona, but many others never get confirmation or accurate treatment.

It has touched an amazing number of my own circle. I've suffered with it as have my husband and multiple friends over a series of decades. My adult daughter almost died from it. One close friend just lost her granddaughter to it, a beautiful, talented young woman. In every case, treatment was delayed due to negative test results.

Mesa mother Afton Zapata's book, "Enduring Miracles: Surviving the Effects of Valley Fever," recounts her husband's brutal battle with the disease that consumed his body amid countless attempts to get medical clarity. By the time of diagnosis, it had settled in his brain as fungal meningitis.

Pulmonologist Dr. M. Salim, of Chandler successfully diagnosed (despite the negative test results) and treated Tahiliani. He urges Arizona to do a better job of warning people about the illness and the dangers of exposure to dust. He wonders if economics and fear of frightening state visitors and new residents contributes to the vacuum of information.

Yes, public awareness is one thing, but vigilant doctors' and emergency centers raising their awareness is another. Their failure is an outrage; a blight on the medical industry. Dr. Salim suggests it is doctors' methodical training that prevents them from looking

beyond the negative test results. He says, "like a jigsaw puzzle," the doctors need to look at the whole picture.

Tahiliani most likely will never run again, not that she can't; but she won't.

"Emotionally, joy and peace of mind of running has been crushed for her," she says.

"But I will never be the same person. I will always think twice before allowing my sons to go a scout camp-out. I will never live next to agriculture again. I will never dig in the dirt like I used to and I will never leave my house without a face mask in my purse.

The problem is incomprehensible for those who love our Southwest, our great outdoors. Informed doctors and alert medical centers are our best hope.

*Linda Turley-Hansen is an Arizona syndicated columnist and was a longtime Phoenix TV anchor. Reach her at [turleyhansen@gmail.com](mailto:turleyhansen@gmail.com).*