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Five-year-old Aimee Milota has a very rare genetic condition, xeroderma pigmentosum, that limits her skin's ability to repair sun damage. She's been cancer-free for two years, however, and is enthusiastic about starting kindergarten next month at St. Francis of Assisi Elementary, whose windows have an ultraviolet-blocking film.

## Off to a healthy start at school

### WHAT IS XP?

Xeroderma pigmentosum (XP) is a genetic condition marked by an extreme sensitivity to ultraviolet radiation, including sunlight.

**What happens:** People with XP are not able to repair skin damage from the sun and other sources of ultraviolet radiation, and have a very high risk of skin cancer.

**Who gets it:** Typically, one of every million people has XP, the rare result of both parents carrying the recessive gene.

Source: National Cancer Institute



Sacramento Bee file/Anne Chadwick Williams

Aimee, in 2004 at age 2, dons protective gear as her mom, Michele Milota, escorts her toward the family home.

By Danielle McNamara  
BEE STAFF WRITER

**W**hen she starts kindergarten next month at St. Francis of Assisi Elementary in Sacramento, Aimee Milota will be able to go to the cafeteria, the bathroom or gym class, just like any other school kid.

That's because many windows at her new school have been outfitted with a protective ultraviolet-blocking film that shields her susceptible skin from the sun's harmful rays.

The 5-year-old suffers from xeroderma pigmentosum, a rare genetic condition that limits the skin's ability to repair ultraviolet damage. That damage often leads to skin cancer at a young age.

Aimee has been cancer-free for two years after having 22 tumors removed.

"She'll be able to go to school and it'll be completely

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# Aimee: Principal calls process 'wonderful learning opportunity'

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safe inside," said Aimee's mother, Michele Milota. "She won't have to wear her hood inside. I want her to feel like any other kindergarten child."

Michele Milota started the Xeroderma Pigmentosum - XP - Family Support Group in 2005. The foundation won support from the 3M Co., which often donates film for XP projects.

Milota said she chose the school partly because it's self-contained. The entire facility is enclosed in a single, three-story building. Aimee wouldn't have to go outside during the school day.

The protection at school is the same as the covering on the Milotas' house and vehicles. Whenever Aimee goes outside, she must wear thick, protective clothing, a hood, sunglasses and sunblock. In 2004, Michele quit her job to take care of her daughter's special needs.

Ahead of the start of school, Michele Milota worked with St. Francis administrators to educate the faculty and parents about XP.

"This is a wonderful learning opportunity for us all," said St. Francis Principal Laurie Power. "We wanted to do whatever we could to make it OK for Aimee to come here, but this also benefits all of our students."

Other schools in California and around the country have been similarly protected with help from the family support group.

"It's important for families to have a way to communicate and get help from one another,"

Milota said. "Down syndrome, multiple sclerosis, autism - there could be many people in a city who suffer, but XP is such an isolating disease."

Typically, one of every million people has XP, the rare result of both parents carrying the recessive gene. Not every child born by two parents who have the gene has the disease. And since the gene is recessive, there is less of a chance the child will get it.

In some populations where inbreeding occurs, the prevalence can be much higher, such as an isolated town in northwestern Guatemala where one-fourth of villagers suffer from XP.

In July, Milota's group, along with Good Samaritan International, visited the village to provide treatment and sun protection.

The condition is so prevalent there because the town's founding family carried and passed on the gene over generations, said Dr. Bari Cunningham, a pediatric dermatologist who helped the village.

"It's really a dire situation and now that I've seen the inhumane way these children are dying, it's become my mission to get the word out about how these kids are suffering," Cunningham said.

Mothers in the village can tell within their children's first months if they have the ailment, Cunningham said. Brown or black freckles show up on babies' faces, and they wince or turn away from the sun. Soon their faces are covered with tumors and the babies often lose

eyesight.

"Then they become unrecognizable," she said. "Their eyes and nose begin eroding and they are in incredible pain for 24 hours a day with no access to antibiotics or pain medication."

Early next year, Cunningham and other doctors will go back to deliver more hoods, sunblock, medication and food. The support group will sponsor a golf tournament and ball drop in October to raise money for the trip.

For Aimee, her regular golf lessons and other outdoor activities happen at night, but she's excited that she'll have a chance to play indoor soccer at her new school.

"Oh, and using the computers and arts and crafts," she said. "It'll all be fun."

For more information about the golf tournament, visit [www.xpfamilysupport.org](http://www.xpfamilysupport.org) or call (916) 628-3814.

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## **The making of “Off to a healthy start at school” by Danielle McNamara**

An unassuming press release showed up in the office while the steady health reporter was on vacation. It said a local school would be outfitted with a protective coating so one of the new students who couldn't have contact with the sun's rays could attend. By the time we got the flier, though it was late in the day and the project was just about done. The girl's mother got back to me right away and I had a great interview with the two. Her dedication to her daughter and helping others with the same condition made writing the story much more interesting than just another school project story.

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