

# Soapbox



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San Clemente

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## Just Wondering... ...what life will be like without little Evan Cousineau?



I only met Evan Cousineau once. A smiling, precocious 9-year-old, Evan and his twin sister, Alaina, indulged me with a few minutes of interview time while we sat on a picnic table near Old Man's at San Onofre State Beach back in June. I'd gone down to the beach to meet this little guy

because his parents—longtime San Clementeans Mark and Gina Cousineau—had told me that suddenly, bizarrely and shockingly their boy had been diagnosed with a rare and life-threatening genetic metabolic disorder known by its initials—ALD—more than its clinical name, adrenoleukodystrophy. The disease affects one in every 17,900 boys worldwide, and there is no known cure. You'd never know it talking to Evan that day. He was going to beat it he said. His sister giggled.

A few days ago, I learned that despite every possible effort known to man, including a bone marrow transplant and a first-of-its-kind transplant procedure that just might pave the way for future patients, Evan succumbed to the disease Friday, November 2, just a day short of his 10th birthday. At his bedside was his entire family who flew to the University of Minnesota Children's Hospital, where Evan and his mom had been since early summer. Doctors there are doing leading-edge research and treatment for the disease, and according to Gina, they've become like family. "Evan and I became the long-timers on 4A [the wing of the hospital]," says Gina whose daily journal and online blog postings have brought more than 400,000 visits to Evan's blog ([www.caringbridge.org/visit/evancousineau](http://www.caringbridge.org/visit/evancousineau)). "If you're on 4A, you're there because



Evan Cousineau. Courtesy of the Cousineaus



Evan and Alaina. Photo by Norb Garrett

there's nowhere else in the world for you. Since August, we lost 13 kids on that floor—kids with ALD, horrible leukemias. They're trying everything and experimenting because they have no choice. The doctors and nurses there are the best in the world."

Understandably, coping with the loss of her child has not been easy for Gina and her family. Her postings on the Web site are some of the most emotionally jarring I've ever read, and as a parent of two kids, I can only pray that I never have to experience the pain she and her family feel. But she knows she must move forward, and to that end, Gina is dedicating herself to helping raise awareness and to helping find a cure. "It's unbelievable—I so hid inside my little Orange County bubble, and I so tried to protect my little family," says Gina. "I always was about doing good things for my community, helping with the sports teams. But when you step into hell, you realize that you can't just sit in your little bubble anymore. You need to step outside your comfort zone and make a difference."

Gina and the family are taking their first step next week. Starting at 10 a.m. on Wednesday, November 14, the family hosts "The Celebration of Evan's Life," a special mass at Our Lady of Fatima Church in San Clemente. Friends are encouraged not to wear black, but green or blue (Evan's favorite colors), and a basket for memory pages, gifts and donations to "fight for Evan" will be at the altar. After the service at 12:30 p.m., there will be a paddle out at T Street followed by a big barbecue (according to Gina, Evan talked of having a big barbecue after he beat ALD). Then, for the rest of the week through Sunday, the family invites everyone to come by their house at 211 W. Cordoba (near T Street). "It's all about sharing, loving, discussing and engulfing ourselves in Evan," says Gina, who adds that many of the doctors and friends they met in Minneapolis will also be coming out this week. "People have told me how Evan's changed their lives, and I need to hear that. I need to know that we've made a difference."

Evan, young man, you surely have.

—Norb Garrett

## SC Times Online Reader Poll

Should indicted Sheriff Michael Carona resign?

Yes, immediately. No, he's innocent until proven guilty.

12% 68%

He should just take a leave of absence.

20%

Make sure to sound off each week on the "SC Times Poll of the Week" at [www.sanclementetimes.com](http://www.sanclementetimes.com). Then go to our community Message Board and share your opinions.  
**[www.sanclementetimes.com](http://www.sanclementetimes.com). Bookmark it today!**

*The SC Times Online Reader Polls are not scientific and do not reflect the opinion of the SC Times.*

## Comment of the Week

**Post:** San Clemente Skatepark addition Petition

**"loribell" says:** A new skate park will help kids not do drugs...??? Are you kidding?! My teen aged son comes home from the SC skate park all the time with stories about kids smoking weed and doing other drugs at that park. It is crazy to think you can use that one as an argument. How about drawing up a petition to spend a few bucks to put some doors on the bathroom stalls -I'll sign that one!

**Get involved in your community: Go online and sound off on our Message Board at [www.sanclementetimes.com](http://www.sanclementetimes.com)**



## Ask the Police Chief

**Do you have a question for  
Lt. Paul D'Auria?**

Maybe you're concerned about crime in your neighborhood or wonder why motorcycle cops always sit on Avenida Pico...

Send your question to [letters@sanclementetimes.com](mailto:letters@sanclementetimes.com).

## SC Times Beachside Chat

A special thanks to former San Clemente Police Chief Lt. Bill Hunt for being our special guest at the SC Times Beachside Chat last Friday at Café Calypso. Thanks to everyone for coming (especially Mayor Jim Dahl).

**Make sure to pencil in the first Friday of every month into your calendar for Beachside Chats at 8 a.m. at Café Calypso.**