



**Kawasaki Disease Foundation**  
CARING FOR PRECIOUS HEARTS

## KDF News

*The heartbeat of the Kawasaki Disease Foundation*

March 2011  
Volume 1, Issue 1



### Dear KD Friends and Families,

The Kawasaki Disease Foundation was started approximately ten years ago to bring attention to KD, support children and families and promote medical research.

We have come a long way since then, yet we have far to go. Although it may be coincidental, it's fitting that after ten years of serving you, we declared January 26, 2011 as National Kawasaki Disease Awareness Day. I view this as a rededication of our commitment to carry on the struggle for another ten years, or as long as it takes, to accomplish our goals.

We would like to thank the countless families who were vital to establishing the Foundation as a leading advocate for children and a channel to the medical community. Although we're a small all-volunteer organization comprised of KD parents and survivors, we have big ideas. However, we can only carry on our mission with your continued support and patience. As we look ahead, I'm hopeful that we will continue to reach out to you through events, social media and communications, such as this newsletter.

Sincerely,

Greg Chin, President  
Kawasaki Disease Foundation

### Featured Inside:

- 2** KD Gala 2010 recap
- 3** KD Fund Event Recap & News
- 4** KD Survivors: Their Stories
- 5** Ask the Experts
- 6** KD Calendar of Events and Contact Information



KDF President Greg Chin, his wife and Board Member Merril and American Idol's Kimberly Caldwell, who emceed the event.

Thank you to everyone who supported the 2010 Kawasaki Disease Foundation's "To Save a Child's Heart" gala, which took place on September 25, 2010 at the La Costa Resort and Spa in San Diego, CA.

We are happy to announce that because of this year's gala, approximately \$50,000 will go to KD Research at the University of California San Diego's KD Research Center!

To kick off the evening, President Greg Chin gave an update on the Foundation's work to spread awareness and support KD Research in the past year and made announcements about significant KD Foundation Campaigns.

We would like to extend a special thank you to Keynote speaker Jimmy Garcia and the KD Kids who participated in the program, as well as our Honorees and Awardees who have done so much to spread awareness!

President Greg Chin and Dr. Jane C. Burns presented awards to individuals who have demonstrated effective leadership in advancing awareness and support of the KD Foundation's mission through their field of work, community service, and philanthropic endeavors. Kathryn Taubert received the KD Foundation Lifetime Achievement Award. Currently with the World Heart Federation, Dr. Taubert served more than twenty years with the American Heart Association.

# Second annual Gala for Kawasaki Disease Research was a success!

*\$50,000 raised for the KD Research Center at UCSD*

By Comischell Rodriguez

**Tony Olaes** received the *KD Foundation Leadership Award*. Tony served on the original KD Foundation Board and currently chairs the board of Gawad Kalinga, USA.

Additionally, local leadership awards were presented to two individuals who carried the KD torch to ignite the development of fundraising and awareness programs in San Diego County.

**Elizabeth Rodriguez** received the KD Torch Award for her event "*To Save A Child's Heart*" Gala. Elizabeth is currently a senior at Torrey Pines High School and was inspired to create an event after being diagnosed at the age of 15. The gala follows the KD Research Center's annual Symposium and is designed to recognize researchers and volunteers, and raise funds for an Endowment of KD Research at UCSD.

**Nicole Hershman-Daniels** received the KD Torch Award for her event "*Quest for a Diagnostic Test*" Fun Day. Nicole is the mother of KD Kid, Dash. She was inspired to create a KD Fun Day for children to increase KD Awareness and raise funds for a diagnostic test.



KDF Board Member Comischell Rodriguez and daughter Elizabeth, who started the gala in 2009.



Keynote Speaker, Jimmy Garcia, currently the oldest KD Kid, having been diagnosed in his 50's.

We would like to thank to the volunteers who made this event possible.

**COMMITTEE:**

**Volunteers:** Elizabeth Rodriguez

**VIP Reception:** Deborah Hagen

**Decorations:** Dayna Sarazin and Tamara Lafarga

**Program:** Alison Young and Denise Mallari

**Story Boards:** Gerald Fu

**Logistics:** Jenn Phillips, Dawn Raagas, and Lynn Kelley

**Wine Drawing:** Shelley Bingham

**Opportunity Drawing:** Rebeca Ayyad

**Photography:** Henry Young

**Production:** Steve Redfearn and Ashley Constans

**UCSD Liaisons:** Shawna Fallon and Tonya Shaeffer

We'd also like to thank our student volunteers who stepped up to help where needed on the event day!



Dr. Jane C. Burns with several KD Kids thanking guests for attending.

---

## The KD Fund Update - Events Past and Future

By Monica Goss



Photo shows red and white balloons which are released at each KD Family Day event. The red balloons represent KD survivors and the white balloons represent the KD survivors family members and supporters.

### Annual Kawasaki Disease Fund Family Day 2010 Recap

The KD Fund hosted their annual Family Day in October 2010 in Chicago, IL and it proved to be a great success! This annual community event brought families in from all over the Chicagoland area.

The day's events began with an informal symposium featuring Dr. Stanford Shulman and Dr. Anne Rowley of Children's Memorial Hospital. Guests were able to hear Dr. Shulman and Dr. Rowley each speak about the latest research findings for Kawasaki Disease and ask them questions.

After the symposium, the activities were moved outside to a beautiful nearby park where we released red and white balloons into the air signifying our special day. The red balloons released represented the KD survivors present at the event and the white balloons represented the family and supporters of those survivors. The day continued with games and activities for all.

We are so pleased to have hosted another successful event. It was wonderful for families to have the opportunity to come together and ask questions they desperately seek answers for, and also meet other KD families in their area. We look forward to future events!

### 2011 Kawasaki Disease Fund Dinner and Symposium

Please join us for the 2011 Kawasaki Disease Fund Dinner and Symposium. This event is co-chaired by Margery and Richard Feitler and Eve and Randy Rogers.

The event will take place on Wednesday, March 2, 2011 from 6:00 pm – 9:00 pm. A cocktail hour will begin at 6:00 pm, and dinner begins at 7:00 pm.

Event location: The Racquet Club, 1365 North Dearborn, Chicago, IL.

Special guests and co-emcee's of the evening will be The Mix's Eric Ferguson and WGN-TV's Mark Suppelsa.

For more details, or to register for the event, please visit the Kawasaki Disease Fund website at [www.kdfund.org](http://www.kdfund.org)



# KD Survivors: Their Stories

**Kate Dávila**

In each issue of the KD Foundation newsletter, we would like to profile a story of a KD survivor. Everyone's story shares the common thread of KD, but each person's story is different, and we feel it is important to communicate their stories.

Some stories will be written from the parents' perspective, as the children are too young to remember what was going on. Some stories will be written from the survivor's perspective, in the cases of diagnosis later in life.

In this issue, we'd like to profile KD Board Member and newsletter Editor, Kate Dávila.

**"In December of 1993**, at the age of 15, I became ill during my winter break. My symptoms included flu-like stomach issues, red, bloodshot eyes, swollen lymph nodes in my neck, and dry, cracked lips. After three trips to the pediatrician over the course of 10 days, I was admitted to the emergency room for re-hydration via IV.

While there, I started to feel worse. I began throwing up and they performed blood tests, chest x-rays, and a spinal tap to rule out meningitis. All of the tests came back negative. I was admitted to the hospital and placed in isolation. My pediatrician went home and poured over his medical books until he found what he felt was a proper diagnosis for me – Kawasaki Disease.

He contacted a doctor at a larger hospital about an hour away and they agreed to admit me. I was brought down via ambulance, and started treatment with IVIG. Within 24 hours, I felt better. After a few days, I had a routine echocardiogram, which revealed that I had developed coronary aneurysms. I then had a

cardiac catheterization and it was determined that I had multiple, "giant" sized (8mm – 13mm) aneurysms on my left and right coronary arteries.

I was placed on Coumadin, a blood thinner. After two weeks, I was released from the hospital and returned to my school, as well as participated in sports with the encouragement of my cardiologist.

I entered college in 1995, where one morning, about a year and a half into my college career, I awoke at 5am with arm pain on my right side only. The pain would not subside, so I called my cardiologist, who directed me to the ER for an EKG.

Additionally, an enzyme test was performed and it was determined I'd suffered a small heart attack. I was 19 years old. My cardiologist informed me that my Coumadin levels (INR) had been too low and I'd formed a clot in one of the aneurysms. A few months later, I awoke with arm pain in both arms, went to the ER and had the same results via enzyme test – a second, albeit minor, heart attack. Despite the heart attacks, I was continually encouraged by my doctors to maintain a healthy lifestyle with eating right and exercising.

Since 1997, I had occasional episodes of angina, but had no heart attacks. I had annual stress tests, echocardiograms, EKG's and took Coumadin. I also had cardiac catheterizations every three years to check on the aneurysms, which showed no change.

I maintained a healthy lifestyle, got married, moved from Maine, to Florida, to Washington state, which is where I live currently.

In July of 2009, after a year's worth of consultation with a perinatologist specializing in women with heart conditions, I became pregnant. I spent 9 months giving myself Heparin injections, and my pregnancy progressed normally and

without complication. On March 15, 2010, my husband and I welcomed our beautiful son Santiago to the world via C-section.

Having been on blood thinners prior to the surgery created some complication, and I developed a hematoma beneath my skin that required a second, exploratory surgery to remove it. After an 8 week resting period once I returned home, I began working out five days a week and started training for a 10k road race.

Unfortunately, on August 20, 2010, I suffered another small heart attack and endured my fifth cardiac catheterization, which showed no change in aneurysm size. Again, my heart showed no damage, and since then, I've maintained my exercise routine with my doctor's blessing.

I am currently 33 years old, and plan to continue maintaining my active lifestyle, and my husband and I are hoping to add to our family in the coming year. I consider myself to be very lucky – I have a wonderful husband, and a beautiful 1 year old son, who continues to amaze us every day. I try to maintain a positive outlook about life, without making light of my situation."



Kate lives in the Seattle, WA area with her husband, Alberto and their son, Santiago

## Ask the Experts

The following Q & A was posted on the KD Forum on the KDF website ([www.kdforum.org](http://www.kdforum.org))

**Editor's Note:** The original date of this posting was in May of 2006. Despite this question being posted 5 years ago, we feel that the topic is still relevant, especially to those of you who may not have seen the original posting online.

**Q:** Hello, the following is a letter that I emailed last summer to several people. I am re-posting it in hopes that someone can shed some light on what happened to my son. He did get a cochlear implant on 12/12/05. We have been through the ringer. Does anyone have any thoughts on what may have occurred?

Thank you, Kim E.

Good evening, I am not quite sure how to begin, so I will just jump in; my 4 year old son has been recovering from a very bad case of KD that he was first diagnosed with on June 2, 2005. He has had a very rough time and the traditional meds have not worked on him as they have on others. Finally a breakthrough came (with Remicaid treatments) and things looked promising. About 2 weeks ago, I noticed some odd behavior that turned out to be the beginning of what some are calling "profound hearing loss". Today was his first sign language assessment/counseling and he and his twin brother went together and did very well.

I have been given information on deaf culture, books, signing, schools and early intervention AND cochlear implants. He has no hearing at all. So a hearing aid is not even an option.



I am going to Massachusetts Eye and Ear Infirmary for a 2nd opinion but.... does anyone out there have any feedback on this please! Has this happened to anyone else? If so did the hearing come back? How long did it take? I will read and respond to any and all emails.

Thank you,  
Kimberley A. Early

**A:** Dear Kimberly,

There are a small number of Kawasaki children who have developed significant hearing loss. In some instances it has been temporary but in some it has been permanent. Evaluation at a major center like the one you mention is very important. If the hearing loss appears to be profound and enough time has passed to indicate that it's most likely permanent, issues like a cochlear implant and sign language are very important to move forward with as soon as possible.

Sincerely,

Stanford T. Shulman, M.D.  
Head, Infectious Disease, Children's Memorial Hospital;  
Virginia H. Rogers Professor of Pediatric Infectious Disease,  
Northwestern University Feinberg School of Medicine



---

## Kawasaki Disease Foundation Calendar of Events

**March 2011:** In March, the Food Network is running "Chopped All-Stars" a "fierce five-part battle" in which "chefs you know and love go head-to-head" in the "Chopped" arena. Each celebrity chef has chosen a charity to represent with the winner receiving \$50,000 for their charity. Chef Nate Appleman chose the Kawasaki Disease Foundation - KD is close to his "heart" because his son is a survivor. **Please tune in to see "Chopped" beginning March 6 at 9PM EST on the Food Network!** For more information, please visit <http://www.foodnetwork.com/chopped/index.html>

**April 30, 2011:** Start! Heart Walk in St. Cloud, MN. For more information: [www.heartwalk.org](http://www.heartwalk.org)

**August 20, 2011:** Start! Heart Walk in Birmingham, AL. For more information: <http://www.heartwalk.org>

**September 17, 2011:** Start! Heart Walk in San Francisco, CA. For more information: <http://www.heartwalk.org>

**October 22, 2011:** Kawasaki Disease Parent Symposium at UCSD  
For more information: <http://www.kdfoundation.org>

**February 7-10, 2012:** The 10th International Kawasaki Disease Symposium, Kyoto, Japan. For more information: <http://www.kawasaki-disease.org/ikds2012/>

*If you have an event that you would like to add to the calendar, please email it to [editor@kdfoundation.org](mailto:editor@kdfoundation.org)*

---



9 Cape Ann Circle,  
Ipswich, MA 01938

[www.kdfoundation.org](http://www.kdfoundation.org)

### Kawasaki Disease Foundation Board Members

Greg Chin, President  
[gregchin@kdfoundation.org](mailto:gregchin@kdfoundation.org)

Kate Dávila, Newsletter Editor  
[katedavila@kdfoundation.org](mailto:katedavila@kdfoundation.org)

Catherine Frank  
[catherinefrank@kdfoundation.org](mailto:catherinefrank@kdfoundation.org)

Monica Goss  
[monicagoss@kdfoundation.org](mailto:monicagoss@kdfoundation.org)

Lynda Moore  
[lyndamoore@kdfoundation.org](mailto:lyndamoore@kdfoundation.org)

Comischell Rodriguez  
[comischell@kdfoundation.org](mailto:comischell@kdfoundation.org)

Do you have suggestions for upcoming newsletter articles? Would you like to have your or your child's KD story included in the "Survivors" section? Please send the information via email to [editor@kdfoundation.org](mailto:editor@kdfoundation.org)



Check out our NEW Facebook page for a chance to see the latest updates on KD events, view photos, and more! Click on the button above to go directly to the page (you must be a Facebook member to view.)

**\$26 for KD Research**

Kawasaki Disease Awareness Day was January 26<sup>th</sup>. To support KD research, donate \$26! Click the button above and you will be taken to Paypal to complete your donation.

---