



Kawasaki Disease Foundation
CARING FOR PRECIOUS HEARTS

KDF News

The heartbeat of the Kawasaki Disease Foundation

July 2011
Volume 1, Issue 2



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Dear KD Friends and Families,

Thank you for the support you gave for the first issue of the Kawasaki Disease Foundation newsletter! We received many kind notes via email, and we are excited for what the future will bring with upcoming newsletters!

We are in need of a name for the newsletter! Currently, we've named it "KDF News: The Heartbeat of the Kawasaki Disease Foundation" but would like something shorter and more interesting. So we're looking to you, the KD community, for help! Feel free to tap into your creative side! Ideas from all ages will be accepted, so if you're a KD parent, or a KD kid, we want to hear from you! Please email any suggestions to editor@kdfoundation.org.

Lastly, I wanted to thank you for your patience in getting this issue out to you. I have received some exciting news, which has prevented me from working on the issue. My husband and I are expecting our second child in early 2012! (I have had horrible morning sickness which has lasted all day, making it hard to sit down at the computer to get the issue done.) After some complications with my first pregnancy due to having to be on blood thinners because of my aneurysms (as a result of KD in 1993), we're aiming for a January due date, even though my due date is February 2, 2012. Thankfully, my OB is familiar with me, as well as he works closely with my cardiologist, and has had one other KD patient prior to me, so I'm in very good hands!

I hope you are having fun-filled summer vacations, and enjoy this issue!

Sincerely,
Kate Dávila
KDF Newsletter Editor



Chopped All-Stars award winning Chef Nate Appleman invites you to Save the Date...



3rd Annual
**To Save
A Child's
Heart Gala**



Saturday, October 22, 2011

A star-studded culinary experience benefiting KD Research.



Save The Date! KD Symposium and Gala Event to Take Place the Weekend of October 22, 2011

Please mark your calendars to be a part of these special upcoming KD events!

Taking place on the morning of October 22, 2011, an informational symposium will be held at Rady Children's Hospital San Diego by world renowned KD doctor Jane C. Burns, M.D. - director of UC San Diego's Kawasaki Disease Research Center.

That evening, make your plans to attend the 3rd Annual Kawasaki Disease "To Save a Child's Heart" gala!

This exciting event will take place on Saturday, October 22, 2011, at the Park Hyatt Aviara, Carlsbad, California from 6:00 pm – 11:00 pm.

Food Network's *Celebrity All-Star Chef*, winner of *Chopped: All-Stars*, and KD parent Nate Appleman is partnering with the Kawasaki Disease Foundation to present a unique event that is guaranteed to pleasure your taste buds!

Chef Appleman, along with local and internationally acclaimed chefs, will prepare meals table side for guests who will be entertained by San Diego's premier band - Soul Tunes.

Guests will receive a chef selected menu, which will be prepared table-side with wine service, along with the opportunity to share in the commitment to raise awareness and fund Kawasaki Disease research.

Every chef participating in the 3rd Annual "To Save a Child's Heart" gala - Celebrity Chefs Cooking for KD event is outstanding in their field, and each will have their own approach to the table. If you would like to choose which celebrity chef hosts your table of 8, sign up for one of our premier tables!

For a full list of table and sponsorship opportunities, contact us at KDGalaChairs@gmail.com.

Limited Seating: Due to the nature of this event, seating is limited.

All proceeds will benefit the Kawasaki Disease Foundation and research at the world-renowned UC San Diego's Kawasaki Disease Research Center, under the direction of Dr. Jane C. Burns.

This event is a must-attend for the cause and the unique experience! We hope to see you there!

Comischell Rodriguez, Jenn Phillips, and Nate Appleman
KD parents and Co-Chairs

Kawasaki Disease Foundation Benefits from “All-Star” Win



On April 3, 2011, Chef Nate Appleman succeeded in becoming “Chopped All-Stars” first champion, with his charity – the Kawasaki Disease Foundation – receiving \$50,000!

Beginning in March, the Food Network began running “Chopped All-Stars,” and pitched it as a five-part battle where “chefs you know and love go head-to-head” in the Chopped arena. A total of 16 different chefs competed, with each chef choosing charities to represent. The champion of the competition would win a \$50,000 donation to their charity. Appleman’s choice of the Kawasaki Disease Foundation was personal, as his son was diagnosed with KD last year, and was left with coronary aneurysms as a result.

The Kawasaki Disease Foundation was thrilled to establish this relationship with Appleman, who, in addition to competing on “Chopped All-Stars,” has also competed on “The Next Iron Chef,” was the 2007 James Beard Rising Star Chef award-winner and was recently hired by Chipotle to lead development of new menu items. The donation of the money from the competition will be, indeed “game changing” as Appleman stated after winning the competition. The donation will be earmarked for research, and will aid doctors who are currently working on a diagnostic test for KD.



Chef Nate Appleman and his son, Oliver

How Facebook Saved My Son's Life

By Deborah Copaken Kogan
Reposted from Slate.com



Self-portrait of the author and her son, Leo, on a stretcher in triage

Mother's Day morning, my 4-year-old woke up with a rash. It was my 16th Mother's Day. I was inclined to ignore rashes. But a note had just come home from day care reporting a case of strep in Leo's classroom, so I dutifully felt his forehead, noted it was hot, and made an appointment at a medical office with Sunday hours. While waiting for the results of the strep test, feeling bored and somewhat sorry for myself, I snapped a photo of my son on the exam table playfully covering his face with his blankie, which I then posted to Facebook with the following caption: "Nothing says Happy Mother's Day quite like a Sunday morning at the pediatrician's."

The rapid strep test came back negative, but none of my three kids' in-office strep tests have ever come back positive, even when they have strep. Plus Leo's fever was on the rise. "He looks really streppy," said the doctor on call. "I think we should treat him for strep, and if his throat culture comes back negative, you can reassess with your family doctor."

"Great," I said, happy to have the prescription for Amoxicillin in hand. I was on a tight deadline to hand in revisions on my new novel. The fewer days of daycare Leo missed, the better. I logged onto Facebook and saw that many of my friends and "friends" had already commented under the new photo, wanting to know what was wrong. Three years earlier, when I reluctantly joined Facebook in an effort to monitor the online bullying of my eldest, it was inconceivable to me that complete strangers would ever fret over my child's welfare, never mind that the act of posting itself has become as integral to my daily existence as talking, writing, thinking, dreaming.

"Strep," I tapped with my thumbs on my iPhone. "No biggie." No use going into the whole, *Well, it could be strep, but we're not sure*; like answering a tossed off "How are you?" with a litany of minor complaints. Besides, what else could it be? Nothing this veteran mother had ever seen. I filled the prescription at the nearest pharmacy and fed Leo his first dose. The sooner he took it, I knew, the sooner he'd be better.



Leo in triage, hooked up to an EKG

Except the next morning he was worse. "Bring him in," said our family doctor. Scarlet Fever—a fancy name for strep with a rash—was his tentative diagnosis as well, pending the results of the throat culture, due back the following morning. I snapped another photo of my now puffy, less playful child on the exam table and posted it to Facebook with the following less cheeky caption: "Baby getting sicker. Eyes swollen shut. Fever rising. Penicillin not working. Might be scarlet fever. Or roseola. Or...???? Sigh."

Within three hours, 20 comments appeared underneath the photo, ranging from, "Allergic reaction?" to, "Scarlet fever isn't nearly as scary as it sounds," to, "Deb, that doesn't even look like Leo in the picture!! how's he doing now? so scary!"

Scary?, I thought. That's going a little over the top. Until the next morning, when my son's face was now swollen beyond recognition. "He looks like Eddie Murphy in *The Nutty Professor*," I said to my husband Paul, trying to keep it light—my normal *modus operandi*—though inside a definite heaviness was taking root.

"He's fine," said Paul, whose lack of alarmism can be both useful (say, in choppy waters, clinging to the Sunfish we'd capsized) and dangerous. When our 16-year-old, as a baby, produced a diaper full of blood, Paul, not yet processing the fact that his infant could be dead from intussusception within hours if left untreated, scolded me for calling the doctor at 10 p.m. on a week night.

Afterward, he felt bad about it, but, still—when it comes to family emergencies, I've always been on my own.

While Paul, in his normal state of denial, dressed for work, I snapped a dozen iPhone photos of Leo from various angles to send to our family doctor via MMS, the least frightening of which I posted on Facebook so as not to alarm my (Facebook friend) mother. "Swelling worse," I typed, "especially eyes and chin. Fever still crazy high. Poor baby." Was I consciously trying to find an answer out there in the hive mind? No, but some subconscious part of me must have been wondering whether one of my hundreds of "friends" might be privy to some expertise on the befuddling *Nutty Professor* syndrome that had my child in its grips.

Ten minutes later, I received a call on my cell phone from Stephanie, a film actress and former neighbor. "I hope you'll excuse me for butting in," she said, "But you have to get to the hospital. Now." Her son Max had had the exact same

symptoms, and was hospitalized for Kawasaki disease, a rare and sometimes fatal auto-immune disorder that attacks the coronary arteries surrounding the heart. "The longer you wait," she said, "the worse the damage."

I remembered Stephanie's son being rushed to the hospital a few years earlier, but I wondered whether she might be overreacting based on her own trauma. Then again, I thought, despite her profession, she's also not the type to overdramatize. I looked up Kawasaki disease online. Many of my son's symptoms seemed to match the descriptions therein, and yet they were also some of the same symptoms as the flu and scarlet fever. Did I really want to rush a kid with the flu to the hospital? The rational part of my brain said stay put, watch him for one more day at home, throw him in front of a video, sit down at your desk and do your work.

Then the Sunday pediatrician's office called. Leo's strep test was negative. Now I was perplexed and slightly worried. If it wasn't scarlet fever, what was it?



The photo of Leo that triggered discussion of Kawasaki disease

Meanwhile, the most recent photo I'd posted to Facebook now had 36 comments underneath it, with various diagnoses and words of support, and my Facebook inbox was bulging with private messages, one of which was from Beth, a pediatrician, echoing Stephanie's fears.

My cousin Emily, a pediatric cardiologist who often has to deal with the fallout from untreated Kawasaki, also called after seeing the photo, urging me to go to the hospital. "The damage begins as early as five days after the onset of symptoms," she said. At this point, we were well into day three or perhaps even day four, depending on when the symptoms had begun. I wasn't sure. I'd spent all day Saturday working on my book, and my husband doesn't notice rashes and fevers.

I called my family doctor and told him I was heading to the hospital. "I just have a Spidey sense," I said, "that he's really sick." Not a lie, but not the whole truth, either, though what was I going to say? Three of my Facebook friends think my kid has an extremely rare childhood auto-immune disorder which I just read about on Wikipedia, and since they all contacted me after I posted a photo of him on my wall, I'm going? It seemed ... wrong! Reactionary. And yet as much as I wanted to be my usual mellow self, the immediacy of the Facebook feedback was enough to push me out the door.

From the hallway in triage, I finally called our family doctor. Admitted what I'd done—furtively filling in the reason-for-visit blank on the hospital form with "possible Kawasaki disease"—and why I'd done it.

"You know what?" he said, "I was actually just thinking it could be Kawasaki Disease. Makes total sense. Bravo, Facebook."



Leo on day 2 of his fever, prior to diagnosis

Over the next three weeks, as Leo was treated, released, retreated, and rereleased for, yes, first Kawasaki disease and then the Kawasaki-triggered liver disease from which he's still recovering, Facebook transformed from my son's inadvertent lifesaver to the most valuable tool in my arsenal: to keep family and friends abreast of his ever-mutating condition without having to steal time and emotional energy away from him; to pepper both Beth, the pediatrician, and Emily, the pediatric cardiologist, with an endless series of random questions with which I was too embarrassed to bother my own doctors; to feel connected—profoundly connected—to the human race while living, breathing, eating and sleeping in the isolating, fluorescent-lit bubble of a children's hospital ward, where any potential humans I might have "friended" on our floor were too distraught over the fates of their own children to make any room in their hearts for strangers.

The day I posted a video of Leo blowing out the candles on his birthday cake, one woman commented, "We were all holding our breath for those candles," as if she, too, had come to know the virtual crowd that had gathered on my wall—the collective we—and was speaking on behalf of all of them. And when I finally posted that the revisions on my then overdue novel were done—my editor, a new Facebook friend, was understanding, given the chaotic state of said wall—the collective we went wild. "Woo hoo!" they wrote. "Way to go ..."

Leo's liver, two months later, is slowly recovering, and for now his enlarged heart is doing well, though he will have to endure echocardiograms every year for the rest of his life, and I will have to endure knowing, slightly more than most, that, in the middle of kindergarten, or on a soccer field, or as he's marching down an aisle to the accompaniment of "Pomp and Circumstance," or while holding the hand of his future spouse, my son could suddenly drop dead of a heart attack.

Such knowledge, to say the least, is isolating. But thanks to my Facebook friends and their continuing support, I do not feel so alone.

KD Families: Their Stories

Calen Page (As told by his mother, Jennifer Page)

A committed group of people in Big Rapids, Michigan are working to raise funds to support KD Research in the Quest for a Diagnostic Test. For many children, having a diagnostic test is the difference between life and death. It would have been for my beautiful son Calen James Page. This picture (see insert) was taken the weekend before he died from complications from Kawasaki's Disease.

Cal was born a beautiful healthy boy. When he was four months old he became very ill, and even though he had very competent doctors who were running tests and calling specialists, it took **3 weeks** of testing and hospitalization to determine what was wrong with him. By then the Kawasaki's Disease had ravage his body and done extensive damage to his heart. The damage to Calen's heart was among the worst that has ever been recorded. After spending many days in the hospital, Calen was able to come home. At home he had to have a tremendous amount of care.



In spite of his dire condition he was a happy little boy who through the love and diligence of my family and his doctors thrived. Calen was always a trooper; he loved to play with his brother and sister, his grandparents and his dog, "Willie". Calen's giggle and smile would light up a room and bring a smile to your face that could not be erased. He loved strawberries and being outside, he loved Barney,

and the vacuum cleaner. For those who were lucky enough to know him, we knew he was an angel sent to bring us joy.

Despite great care and devotion to keeping Calen healthy, on June 3, 2009, when Cal was 15 months old, his little heart could take no more and he was taken to heaven.



For us, we must persist and try to find a way to stop this terrible disease. We have sent pieces of Calen's heart around the world to be studied by the leading Kawasaki's Disease researchers. While we cannot bring Cal back to us, every cent we raise and every action we take to raise awareness so that no other mother has to live without their child serves as a tribute to my son.

I have made it my mission to increase awareness of KD at many levels. For the last two years, we have held the "Annual Calen Page Memorial/KD Awareness Day Walk". The walk is supported by many members of our community and our families. Over 230 people participated this year. Besides the two mile walk, we have a KD Awareness booth, which provides information about KD, its diagnosis and the need for continued research to develop a test and a cure. A festive atmosphere is created during our event by students from the local schools who provide face painting and emcees for the silent auction. The generosity of our community is overwhelming. Many people donate items for the silent auction. This year's donations included more than 40 items including a Kindle, homemade quilts, gift certificates and handcrafted yard ornament. In the last two years, we have raised



approximately \$16,000 to support the KD Foundation. In conjunction with the walk, the local newspaper, the Big Rapids Pioneer, has printed several articles about KD Awareness.

In addition to the Awareness Walk, I arranged for a pediatric infectious disease doctor from Helen DeVos Children's Hospital in Grand Rapids, MI, to educate local doctors, nurses and hospital staff regarding KD. I have also shared info along with the new KD poster with our local health department.



The most satisfying part of this awareness campaign occurs when I am notified of a child being diagnosed early because of their doctor, friend, or relative has learned the common symptoms and has been diagnosed early.

This year's walk was very successful! We had approximately 225-230 walkers and raised over \$7,000. We had 4 doctors who participated in the walk and one of the pediatricians said that he had diagnosed 4 cases of KD in the past 3 weeks. For more information, you may contact Jennifer via email at ipage1279@sbcglobal.net

Ask the Experts

The following Q & A was posted on the KD Forum on the KDF website (www.kdforum.org)

Editor's Note: The original date of this posting was January 2009. This is a question that comes up often with KD parents, so we felt that it was relevant to post.

Q: My daughter is now 12. She had Kawasaki Disease when she was 4 years old. After treatment and the follow up tests, they determined that she did not suffer any permanent damage to her heart.

She did her follow up visit 5 years later and, and then another two years later, she had another follow up visit.

During this visit, they did an EKG which detected that it was not abnormal but not normal. The pediatric cardiologist asked that she come back in 2 years once her arteries were more developed.

I felt like at this time we should be "home free" and we are not there yet after 8 years. Is this normal to take this much time to determine if there is damage or not?

Thank you,
Stephanie



A: Dear Stephanie:

I would strongly recommend that you call your daughter's cardiologist so that you can have a much better idea of what he is seeing in her EKG that is making him more worried.

I assume that your cardiologist was able to obtain excellent images of your daughter's coronary arteries early after the disease started.

As long as this is so, I do not think you need to worry about clinical coronary artery disease in the first 30 years after KD.

In general, if aneurysms are going to develop, they do so in the first month after onset of Kawasaki Disease. They do not develop late.

Of course, it makes good sense to follow a heart healthy diet, get plenty of exercise, avoid obesity, and never start smoking! These measures are good for everyone and may prevent or delay atherosclerotic changes. The very long-term effects of KD on coronary arteries and heart muscle will only be known after the first KD patients reach their 50's and 60's!

Jane W. Newburger, M.D., M.P.H.
Professor of Pediatrics
Harvard Medical School
Associate Chief for Academic Affairs
Department of Cardiology
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Kawasaki Disease Foundation Calendar of Events

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>

October 22, 2011: 3rd Annual Kawasaki Disease "To Save a Child's Heart" Gala! The event takes place at the Park Hyatt Aviara, Carlsbad, CA from 6:00 pm – 11:00 pm. For more information or to book a premier table:
KDGalaChairs@gmail.com

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



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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



Check out our 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 is January 26th. To support KD research, donate \$26! Click the button above and you will be taken to Paypal to complete your donation.
