



Kawasaki Disease Foundation
CARING FOR PRECIOUS HEARTS

KDF News

The heartbeat of the Kawasaki Disease Foundation

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Dear KD Friends and Families,

Welcome to the Spring edition of the KDF News!

We hope that all of you had wonderful holiday seasons, and are enjoying 2012 so far. With each year comes more opportunity for researchers to gain more knowledge about Kawasaki Disease, and hopefully have more breakthroughs which can help aid future cases.

We apologize for the delay in getting this issue out to you. Timing of certain events that we wanted to recap for articles was part of the reason, but I also was caught up in the holiday craziness, as well as getting ready to have my baby. My daughter, Gabriela Anna, arrived on January 28, 2012, at 8:34am via C-section, weighing in at 5 lbs., 12 oz., and was 18 inches long. She is doing great and is now 7 weeks old, has almost doubled her birth weight and her big brother Santiago couldn't be prouder. He loves showing off his "baby sister", and giving her kisses, as well as helping me out.

We're excited to feature a new article that was featured in the Huffington Post in November in this issue. It discusses new research being done on wind patterns and the link to Kawasaki Disease. We're also excited to recap the latest fundraising efforts in October of the 3rd Annual "To Save a Child's Heart" Gala. Additionally, we've added a new recipe and exercise tip section, because heart health is important to everyone, but especially to KD Kids. Also, if you haven't already, please check out our YouTube channel, currently featuring a video on KD in India:
<http://www.youtube.com/user/TheKDFoundation>

Sincerely,
Kate Dávila
KDF Newsletter Editor

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3rd Annual "To Save a Child's Heart" Gala Success!

Celebrity Chefs Team with Kawasaki Disease Foundation in San Diego



Chefs Nate Appleman, William Bradley, Roy Choi, Vinny Ditolo, Chris Gerwig, Matt Gordon, David Hernandez, Gavin Kaysen, Mourad Lahlou, Joe Magnanelli, Charles Phan, Naomi Pomeroy, Jonathan Sawyer, Mike Solomonov, and Chad White created magic in the ballroom, providing their table guests with sumptuous flavors and meaningful memories of their time and support of KD research.

Celebrity Chefs from around the country set their tables in San Diego for the 3rd Annual "To Save a Child's Heart" Kawasaki Disease Foundation gala on Saturday, October 22, 2011 at the Park Hyatt Aviara in Carlsbad, Calif.

New York Celebrity Chef and KD parent Nate Appleman teamed up with "To Save a Child's Heart" gala Co-Chairs Comischell Rodriguez and Jenn Phillips to bring a culinary experience to San Diego like none other.

Approximately 225 guests from San Diego and across the country attended to enjoy an exclusive event where four courses of gourmet food were prepared for them at their table by one of 15 nationally and internationally acclaimed chefs.

Kawasaki Disease Foundation President Gregory Chin presented Leadership awards to Senator Webb of Virginia, and San Diego City Councilmember Sherri Lightner for their roles in publically recognizing National Kawasaki Disease Awareness Day on January 26, 2011. Other recognitions went to Florida KD parent Karen Wicker for her service in the KD Bridges parent support program and to San Diego business leader Mr. Jay Flatley, President and CEO of Illumina for the company's partnership and generous support of the KD genome sequencing project that is expected to unveil important data for the better understanding of the cause of Kawasaki Disease.

Honorary Chair, and Chipotle's Executive Chef Nate Appleman shared his story with son Oliver, who was diagnosed with KD in 2010. It was Oliver's battle with KD that prompted Nate to use his resources and talents to compete on The Food Network's *Chopped Allstars*, choosing the KD Foundation as his charity.



Guests heard Nate Appleman's story and how winning moments unfold again via video. Nate won the title of Champion Allstar Chef and \$50,000 for the KD Foundation. Nate has committed to funding long-term KD research via future Celebrity Chef Galas so the world will better understand Kawasaki Disease.

Among the guests were Chipotle founder and CEO Steve Eils, KD Adult Study sponsors Don and Patty Dawn of Virginia and their daughter Brooke, and Back Street Boy Brian Littrell, his wife Leighanne and son Baylee.

An exciting moment of the evening included an impromptu tune by Brian to encourage funding of Kawasaki Disease research at UC San Diego's Kawasaki Disease Research Center under the direction of Dr. Jane C. Burns. Dr. Burns leads the charge of an international collaborative of research to uncover the mysteries of the disease that is the #1 cause of acquired heart disease in children.

The most coveted prizes of the evening were 2 VIP tickets to the American Idol finals week and private in-home dining with five of the celebrity chefs. The event brought in just under \$150,000 and will be the first of several KD Foundation sponsored "Celebrity Chefs Cooking for KD" galas scheduled across the country to fund Kawasaki Disease Research at the University of California, San Diego.

The KD Foundation is grateful to the Honorary Committee, guests, sponsors, donors, volunteers, and Chef Nate Appleman and his colleagues for their generous support. The coming galas will help underwrite KD research and hopefully inspire an endowment at UC San Diego. For more information on the San Diego or New York galas slated for 2012, contact kdgalachairs@gmail.com.



Left to right: Gala Co-Chair Comischell Rodriguez, KD Foundation Founders and Directors Merrill and Greg Chin, Gala Co-Chair Jenn Phillips

Kawasaki Disease: Researchers Find Surprising Link to Wind Patterns

Part of a series investigating the complex linkages between human, animal and environmental health: [The Infection Loop](#).

Originally published on The Huffington Post
11/10/11

Dr. Jane C. Burns always takes her vacation in September and October. That's when, she says, there is a "lull in the action."

By action, she means the influx of children with Kawasaki disease that she has come to expect during summer and winter months. Similar seasonal patterns are seen in other parts of the world, but no one has been able to explain why.

Now Burns and her colleagues think they may have found an important clue -- blowing in the wind. Despite 50 years of research, the underlying cause of Kawasaki, a rare condition that involves the inflammation of blood vessels, remains unknown.

The interdisciplinary team of doctors and climatologists has linked large-scale wind patterns originating in central Asia to fluctuations in cases of the serious and sometimes fatal disease in Japan, San Diego and Hawaii. Their findings, [detailed in the journal *Nature's Scientific Reports*](#) on Thursday, suggest that when these particular wind currents reverse -- sweeping in from the south, in the case of Japan -- the number of Kawasaki cases drop. A close look at data from these three regions found no associations with other environmental factors such as precipitation, temperature or dew point.

"If the winds blow in one direction, there is Kawasaki; if winds blow in the other, there is no Kawasaki. It's very dramatic," says Burns, a professor of pediatrics and director of the Kawasaki Disease Research Center at the University of California, San Diego and Rady Children's Hospital.

Researchers are now looking at dust samples collected from winds over Japan in hopes of determining what virus, bacteria, fungi or other contagion -- live or inert -- ultimately triggers Kawasaki disease. And until that mystery is solved, no one can be certain of the wind's true role. If the Kawasaki agent does, in fact, traverse great distances by wind, it would be the first known human infectious disease agent to do so. Dust plumes have been known to travel internationally. And some pathogens of plants and animals such as European livestock Foot and Mouth Disease and African Swine Fever can blow around, but only over relatively short distances, said Guy Hendrickx, managing director of Avia-GIS, a Belgian company specializing in spatial information for health and agriculture research.

His own research has found that insects carrying [Bluetongue virus](#) will fly with the wind over hundreds of miles -- yet still not at the same high altitude and long distance suggested in the new Kawasaki research.

"Traveling with the aid of tropospheric winds should not be a problem for fungi, bacteria or even small cryptogams or other animals," says Jesus Munoz Fuente, a scientist at Real Jardin Botanico in Spain, suggesting the creatures can survive the flight by protecting their DNA from UV rays with other binding substances -- they can even survive with almost no water.

Some experts, however, are more skeptical. "I have never heard of such a close association between long-distance dispersal over oceans and outbreak of a human disease," says Christopher Mundt, a professor of plant pathology at Oregon State University.

"This is more likely to happen with plant pathogens, but even there it seems to be somewhat rare and not something that happens on a regular basis." The correlations, he says, may have nothing to do with an agent being transported on the wind, but rather to something else associated with wind patterns.

Reported cases of Kawasaki disease are increasingly common in many parts of the world, particularly in Japan, where one out of 185 children will develop the disease before age 10. More than 12,000 cases have been reported in the country over the last year. Burns has also seen rising numbers in her San Diego clinic, although a growing awareness of the disease may be partially responsible. About 4,000 cases are reported in the U.S. each year, according to the American Heart Association.

In general, the disease is less recognizable outside of Japan and often mistaken for an inconsequential viral infection. Symptoms typically disappear on their own within a couple weeks. If not treated early, however, Kawasaki can cause irreversible heart damage. Burns recommends that parents consult a pediatrician if their child's fever lasts for at least five days and is accompanied by a rash, red eyes and red lips.

"This is a very insidious disease," says Burns. "The heart damage is silent. You have no way to know just looking at the child, but then in the child's 20s or 30s, they may present with a heart attack due to damage to arteries that happened during childhood."

In fact, she suggests that Kawasaki might be behind a number of the tragic heart-related deaths of young athletes. Only children with a genetic predisposition will get the disease, adds Burns, noting that Asian and African Americans have an increased susceptibility compared to other groups.

The ability to predict potential outbreaks of disease based on wind patterns, even without knowing nature of agent, has the potential to save lives, suggests Xavier Rodo, director of the Institut Catala de Ciencies del Clima in Catalunya, Spain, and lead author on the new paper.

Still, the lack of a known cause for the disease continues to be a major obstacle in disease prevention and treatment. If you don't know what you're looking for, it can be hard to find it, experts note. The key problem: Like other autoimmune diseases, the causative agent need not be present when symptoms appear. So researchers are forced to look further upstream -- as Burns and her team are currently doing.

"If there is a viral cause, one reason why it hasn't been identified to date is that we strongly suspect it is a virus in some new viral family that has not been discovered," says Dr. Anne Rowley, a leading expert in Kawasaki disease at Northwestern University Feinberg School of Medicine in Chicago. Her own research has found strong evidence to suggest a virus may be to blame.

So the hunt for the unknown continues. In March, researchers flew strategic sorties miles above Japan in the direction of the wind currents thought to be carrying the responsible agent. Ian Lipkin, an internationally recognized ["virus hunter"](#) at Columbia University in New York City, has begun analyzing dust samples collected by the specially designed filters in hopes of identifying candidate pathogens. "There is a precedent for it, at least in the plant and animal world," he says. "And in science, anything is possible."

KD Families: Their Stories

Nate and Oliver

Chef Nate Appleman has received a James Beard award for Rising Star Chef, been anointed Best New Chef by Food & Wine, and is the champion of Food Network's Chopped All-Stars. He is inspired by competition and is passionate about his career and his son Oliver. In 2009, Nate became a KD parent when his son was diagnosed with Kawasaki Disease at the age of two.



Chef Nate Appleman, appearing on Chopped All-Stars in the Spring of 2011. He won this competition and was awarded \$50,000 for his charity, the Kawasaki Disease Foundation.

About a week after moving to New York, Oliver woke with a slight fever. He was tired and not behaving like his normal self. His parents cared for him, treating his symptoms, thinking he could be coming down with the flu. By the 3rd day, a rash and fever that had spiked to 103 degrees prompted a trip to the emergency room.

There was a long wait before finally being called to a treatment room. Once inside, the doctor found an ear infection and determined the rash to be Scarlet Fever. He would call the nurse to deliver a prescription for antibiotics and the discharge papers to go home.

While waiting for the papers, an unwanted visitor appeared beside Oliver. It was a bedbug and dad was not happy! The sudden and noticeable noise from the treatment room brought a rush of concerned hospital personnel to investigate. In the mix was a visiting physician who happened to be

the head of Dermatology at NYU. After the excitement from the bedbug's visit subsided, the dermatologist noticed young Oliver and asked what diagnosis he was given. Skeptical that it was Scarlet Fever, she told dad she suspected Kawasaki Disease and said to make an appointment to follow up in two days.

The antibiotics brought no improvement, and after two days Oliver's fever and rash had progressed. The follow up visit with the dermatologist brought the diagnosis of Kawasaki Disease and Oliver was admitted to the hospital right away. His condition had worsened and painful attempts to begin an IV by poking him over and over proved impossible due to the severe hydration and swelling. Eventually, sedation was needed to put him to sleep and open his shoulder to insert the IV.

Oliver was treated with IVIG right away with promises that after one treatment he should be OK. When two treatments of IVIG brought no response, attending physicians began to question the diagnosis. With his heart being monitored, several specialists were asked to evaluate little Oliver. The decision was to treat with steroids. This followed with some improvement, and Oliver was allowed to return home.

When Oliver's symptoms returned, a second dose of steroids was given to continue treatment and he was scheduled to visit the cardiologist for an echocardiogram two days later. This test revealed giant aneurysms in his heart and Oliver and dad were sent directly to intensive care to receive treatment. Dad describes the walk from the cardiologist back to the hospital as the longest walk of his life. Total time in the hospital for young Oliver was 3 weeks.

It has been two years since Oliver's diagnosis. He remains under a doctor's care for the heart disease he acquired from having Kawasaki Disease.

Again, Dad is not happy! He cannot explain why his son acquired KD, nor does he see a cure in sight, but like with the bedbug, he is determined to draw attention to the issue. He is determined to work toward finding answers to the disease that wreaked such havoc on his young son's precious heart.



Nate and Oliver at the 3rd Annual KD Gala "To Save a Child's Heart" in San Diego, CA.

Ask the Experts

We are currently looking for more "Ask The Experts" questions. If you have a question that you would like answered, please contact us at editor@kdfoundation.org

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 November 2008.

Q: My son had KD 6 years ago at age 5 and has no lasting cardiac involvement. On his latest blood test his cholesterol level came back high. He is in a normal weight range and eats healthy.

I was just wondering if there is any correlation between KD kids and high cholesterol. Should high cholesterol in children post-KD be more of a concern than in children without a history of KD? Can you give any guidelines in help with lowering cholesterol in children?

His cholesterol was 178 (normal is 100-169.) His LDL cholesterol level was 99 (normal range is 0-99.) Additionally, his T3 uptake was 34 (normal is 24-33.) His BUN/ Creatinine Ratio was 27 (normal is 8-27.) Glucose was 98 (normal is 65-99.) Even though some results are in the normal range they are at the high end of normal.

Thank you,
Beth



A:

Dear Beth:

Because the long term consequences of having had Kawasaki Disease without coronary aneurysms will not be known until the earliest patients reach middle age, it is important to avoid risk factors for atherosclerotic coronary artery disease (the type that adults get).

However, the cholesterol values that you cite below look good, with an LDL of 99. It seems likely, although you do not list the value, that your son's level of HDL cholesterol (the good type) is excellent.

Assuming this is so, he does not need any medicines and should get plenty of exercise, follow a heart-healthy diet, and avoid smoking when he gets older.

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Kawasaki Disease Foundation Calendar of Events

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.
