

4/2/08 10:31 AM

fgupta

Kawasaki Syndrome in India

Feb 20th 2008 re-edit, based on 4 January 2008 San Diego screening with Drs Burns and Kushner. This is the "July" version with JB notes and extra HK VO modifications and VO announce copy

Dr. Jane Burns, Dr. Howard Kushner, & Rupert Macnee

VIDEO

AUDIO (Sound Effects, Music)

KD Foundation LOGO

1 KD38

Dr. Raju Khubchandani and his Medical Team

Khubchandani: ...I've always maintained that the most difficult Kawasaki to diagnose is your first case.

Burns: Mm-hmm.

Khubchandani: Because nobody's held your hand there.

Burns: Mm-hmm.

Khubchandani: You've never seen it before and you're worried, and it's a purely clinical diagnosis. You know if there was a test to tell you ANA is positive, DSDNA is positive, okay then the lab technician tells you this is Lupus.

Burns: Mm-hmm.

Khubchandani: But here there's no test so it's purely a judgment call.

Burns: Mm-hmm.

Khubchandani: And that judgment call, the first time you need somebody to lead you through it...

2 KD43
TEXT:
00.30 Dr. Indu Khosla
Delhi

Dr. Indu Khosla

...The first kid I saw ... the first thing when I saw him, I, I noted that he was markedly

irritable, and uh, he had the rash which was a maculopapular rash on his abdomen. He had fever and that uh, – and he had red lips. And I don't know – some – sometimes some disease fascinate you so I was quite well read about Kawasaki's disease and **what only the mind knows, the eyes see**. And when I looked at him I knew this was Kawasaki disease...

3 01.01.10

TITLE:

***Kawasaki Syndrome in India:
your eyes do not see what your
mind does not know***

A 2006 research trip to Chandigarh,
Delhi, Trivandrum and Mumbai-
Thane

**Dr. Jane Burns
Dr. Howard Kushner
Rupert Macnee**

4 KD21

Dr. Burns Consultation with Dr.
Vikas Kohli's patient

TEXT:
Apollo Hospital
Delhi

Dr. Burns Consultation with Dr. Vikas Kohli's
patient

Burns: And what about your hands? Did your
hands hurt?

Father: Yeah, especially in the joints here.

5

NARRATION (VO)

THIS BOY AND HIS FATHER HAVE FLOWN
TODAY FROM BANGALORE TO THE
APOLLO HOSPITAL IN DELHI. THEY ARE
CONSULTING WITH DR. JANE BURNS, WHO
WITH HOWARD KUSHNER, IS VISITING
CARDIOLOGIST VIKAS KOHLI .

Vikas Kohli:
Shall we examine him?

6

THE BOY HAS LARGE CORONARY ARTERY ANEURYSMS CAUSED BY KAWASAKI DISEASE.... OR KAWASAKI SYNDROME.

**KD 21
MONTAGE:**

Boy (*name?*) gets up from interview, CU feet, steps onto table, father helps off trousers, CU Kohli hands on boy.

SFX/MUSIC: Heart Beat ... or tone ... or Indian drone ... long drawn out sitar sound

7

Cut to Kohli switches off the light, see wand on boy's chest, watching the monitor, CU colourful sector, large aneurysms, CU kids face, CU Father watching

MUSIC: electronic tone

KAWASAKI SYNDROME IS A SELF-LIMITED VASCULITIS OF INFANTS AND CHILDREN, IN WHICH CORONARY ARTERY ANEURYSMS, SOMETIMES FATAL, MAY DEVELOP IN UP TO 25 PERCENT OF UNTREATED CHILDREN.

8

**LOOKING AT ECHO
CARDIOGRAMS**

JANE TALKS TO FATHER"... FOR A LONG TIME ..." , KOHLI "... NOT VERY HAPPY"

01.01.31.10 – 01.02.46.19

ITS CAUSE REMAINS UNKNOWN. THERE IS NO DIAGNOSTIC LABORATORY TEST FOR IT. DIAGNOSIS HAS RELIED ON THE OBSERVATION AND RECOGNITION OF CLINICAL SIGNS THAT COMPRISE THE CASE DEFINITION.

01.02.48.21 – 01.02.55.25

IT IS THE MOST COMMON CAUSE OF ACQUIRED PEDIATRIC HEART DISEASE IN THE DEVELOPED WORLD.

**BETA-
SP
"Race
for an
answer"**

Red Cross Hospital
Dr. Kawasaki (younger)
Beds and children (non-additive mix)
CU's symptoms

MUS: Koto sting
SFX: Under pix – atmospheres, backgrounds

THE ILLNESS IS NAMED AFTER THE JAPANESE PEDIATRICIAN TOMISAKU KAWASAKI. IN 1967 HE DESCRIBED 50 CASES OF INFANTS WITH PERSISTENT FEVER AND SWOLLEN LYMPH NODES ...

**orig
camera**

tapes

... ACCOMPANIED BY RASH ...

... BLOODSHOT EYES...

... SWOLLEN HANDS AND FEET...

... REDNESS AND CRACKING OF THE LIPS...

... "STRAWBERRY TONGUE"...

KOHLI HOLDS UP LEG FOR
FTAHER

KOHLI:

* DR. KOHLI EXAMINES BOY'S
FEET

"IS THIS WHAT HAD HAPPENED?"
... AND, SUBSEQUENT PEELING – OR
DESQUAMATION - OF THE HANDS AND
FEET.

CU **CU drip**

INTROVENOUS IMMUNOGLOBULIN HAS
PROVED AN EFFECTIVE THERAPY, BUT
PROMPT DIAGNOSIS HAS BECOME
ESSENTIAL FOR TIMELY THERAPY TO
ENSURE A GOOD CARDIAC OUTCOME.

KIDS IN PLAYGROUND

A SIGNIFICANT NUMBER OF CHILDREN,
HOWEVER, FAIL TO MEET THE CLINICAL
CRITERIA, RECEIVE DELAYED
TREATMENT, AND AS A CONSEQUENCE,
DEVELOP CORONARY ARTERY
ANEURYSMS.

MONTAGE visuals

FOR MORE THAN 40 YEARS
RESEARCHERS HAVE ATTEMPTED AND
FAILED TO DISCOVER THE CAUSE OF
KAWASAKI SYNDROME. DESPITE
NUMEROUS PROMISING LEADS AND
IMPENDING BREAKTHROUGHS, NOTHING
HAS BEEN IDENTIFIED.

(BETA-SP tapes)

Research shots from Jane's lab;
Conference shots;

KDRP group with Dr. K 1998

Dr. Kawasaki: 1953, was the first

IN AN ATTEMPT TO SUPPORT THE SEARCH FOR THE CAUSE OF THE SYNDROME, AN INTERDISCIPLINARY GROUP WAS FORMED IN 1998 TO INVESTIGATE ITS EMERGENCE IN JAPAN AND THE WEST.

Establish INDIA.

MUSIC: Indian

MONTAGE: Images of people on street, children, etc.

IN INDIA, CASES OF KAWASAKI SYNDROME HAVE BEEN INCREASINGLY REPORTED IN THE LAST SEVERAL YEARS.

KD1

THIS VIDEO REPORT WILL EXAMINE WHETHER THE IDENTIFICATION OF THE ILLNESS ON THE INDIAN SUBCONTINENT RESEMBLES THE EUROPEAN AND NORTH AMERICAN EXPERIENCE, WHERE THE INCIDENCE IS LOW AND IT EXISTED HIDDEN IN OTHER DIAGNOSTIC CATEGORIES FOR MANY DECADES, OR THE JAPANESE EXPERIENCE, WHERE THE KAWASAKI SYNDROME AGENT – OR AGENTS - MAY HAVE BEEN NEWLY INTRODUCED INTO A HIGHLY SUSCEPTIBLE POPULATION.

THIS DISTINCTION HAS IMPORTANT CONSEQUENCES FOR THE INDIAN PEDIATRIC POPULATION AND ITS HEALTH CARE DELIVERY SYSTEM.

THERE ARE AN ESTIMATED 120 MILLION CHILDREN LESS THAN 5 YEARS OF AGE IN INDIA.

DEPENDING ON WHETHER THE HOST GENETIC FACTORS AND ENVIRONMENTAL CONDITIONS IN INDIA ARE MORE SIMILAR TO THE U.S. OR TO JAPAN, ONE COULD EXPECT BETWEEN 24,000 AND 240,000 NEW KAWASAKI SYNDROME CASES

ANNUALLY.

WHICHEVER PREDICTION TURNS OUT TO BE CORRECT, THE DISEASE BURDEN IS LIKELY TO POSE A SIGNIFICANT CHALLENGE TO THE HEALTH CARE SYSTEM IN INDIA IN THE COMING YEARS.

MONTAGE : Jane Burns and Howard Kushner

OVER A 2-WEEK PERIOD IN FEBRUARY 2006 DRS. JANE BURNS AND HOWARD KUSHNER ...

... MET WITH 52 EXPERIENCED, SENIOR PEDIATRICIANS, TRAINEES, CARDIOLOGISTS, AND OTHER PEDIATRIC SUBSPECIALISTS ...

MAP



... IN FOUR DIFFERENT GEOGRAPHIC LOCATIONS IN INDIA -

Establishing shots

CHANDIGARH ...

NEW DELHI ...

TRIVANDRUM ...

MUMBAI AND THANE

Teleconferencing shots

THESE MEETINGS WERE SUPPLEMENTED BY TELECONFERENCING WITH

PEDIATRICIANS IN
BANGALORE...
KOLKATAH ...
AND HYDERABAD.

MONTAGE: Interview shots,
medical examinations, doctors

THE TEAM ADDRESSED THE QUESTION OF WHETHER THE INCREASED DIAGNOSIS OF KAWASAKI SYNDROME IN INDIA REPRESENTS THE EMERGING RECOGNITION OF AN ILLNESS THAT HAS BEEN OBSCURED PRIOR TO THE 1970S BY MIS-CLASSIFICATION AS OTHER PEDIATRIC DISORDERS, OR WHETHER IT IS ACTUALLY NEW TO INDIA.

IN OUR INTERVIEWS, WE ASKED PHYSICIANS QUESTIONS ABOUT WHERE AND WHEN THEY SAW THEIR FIRST PATIENT WHO, IN RETROSPECT, FULFILLED THE CRITERIA FOR THE SYNDROME.

DELETED SCENES

WE ASKED UNDER WHICH CATEGORIES MIGHT PATIENTS BE MISCLASSIFIED AND IF THE CURRENT INCREASE IN NUMBERS OF KAWSAKI PATIENTS IN INDIA IS RELATED TO INCREASED CASE ASCERTAINMENT OR AN ACTUAL INCREASE IN THE SYNDROME'S INCIDENCE.

Dr.Surjit Singh
Additional Professor of
Pediatric Allergy and Immunology,
Department of Pediatrics,
Advanced Pediatric Centre,
Post Graduate Institute of Medical
Education and
Research, Chandigarh

Singh: ...you know the first case of Kawasaki Disease in India was reported in 1977.

Kushner: Mm-hmm. Thank you for bringing this up.

Singh: And this child, I'm told belonged to our institute, but it was reported by the doctor when he had moved over to Delhi.

Burns: Okay.

Singh: Only yesterday I came to know that this child was, you know, diagnosed here and but he reported it after he moved to Delhi. This was reported by Dr. Arvind Taneja he was a consultant here...

Recognition KD22

(cutaway of Dr. Kukreja)
Dr Shyam Kukreja, Senior
Pediatric Consultant, Max
Hospitals, Delhi

Dr. Arvind Taneja, Director and
Chief of Paediatrics,
MAX Healthcare, Delhi

Interview with Dr. Arvind Taneja and Dr. Shyam Kukreja.

Taneja: ... I saw my first case of Kawasaki ... at ah, Boston Children's Hospital where I was training as a junior resident in pediatrics. And Dr. John Modlin was my preceptor. He was senior resident at that time and he ah, showed me the patient. And ah, when I came back to India in the fall of 1976, um, my father who was also a pediatrician here, took me along with him to see one of his ah, colleagues' admitted patients with this ah, un – non-understandable fever and rash. And [phone rings] I looked at the child and of course the diagnosis being made there was whether this was [phone rings] Stevens-Johnson Syndrome. And ah, but, th - th – the time I saw this child, the memory of what I had seen in Boston flashed back [laugh] and maybe, you know, kindled that ah, spark of recognition...

Cutaway 1
ascertainment

00:05:08 1:05:05

Taneja:
My feeling is it's, it's, it's ascertainment rather than an actual increase. I think ah, it's been, it's been better recognition of a constellation of signs and symptoms ... unfortunately in the beginning we couldn't get ah, proper echo-cardiographic ah, report because most of the echo-cardiographers were adult cardiologist and

when we asked them to evaluate the coronaries on the ultrasounds – on the echoes, they were somehow feel we were talking hogwash [*laugh*]. You know, it was like ah – I, I think that the awareness has come with more pediatric cardiologist coming into ah, practice in this country, which has contributed to our feeling more comfortable about pick-ups of coronary artery problems.

**On screen in telemedicine room.
Kohli, JB and HK talk to Dr. Kartic
Nagesh**

**Telemedicine Interview with Dr. Kartic
Nagesh**

Kohli: ... we can see quite clearly actually we can see – the corner shows a part of the LAD also.

TV screen 2

Dr. Howard Kushner, Emory
University, Atlanta, Georgia

Kushner: ...do you think the increase is just ascertainment or do you think the increase is real?

Dr. Kartik Nagesh, Manipal
Hospital, Bangalore

Nagesh: ... I think ah, it's more the awareness. It's more the awareness because we are thinking more and more about Kawasaki when we see all these children. Maybe in the past ah, people have not been so aware of it and now people are more aware of it. People in the past [*inaudible*] strepto-coccal or some unknown viral infection, now people are giving a lot of giving a lot of thought to Kawasaki. I think it's the awareness the disease has been there possibly all along...

00:32:08

Burns:...(But) if you think back over your whole career and your training, were there patients that in retrospect knowing what you know now...

Nagesh: No, I, I, I... the disease is also new.

Kushner: *Right.*

00:38:54

Nagesh: *Maybe if you want to say yes, I started reading about it in the early '90s and had picked it up, but I don't think we would have*

thought of something like Kawasaki and missed it earlier. I don't think so.

KD48 **HK and JB in car**

in car:

..... **Kushner:** I think the main thing for us is to make sure that what we do is report the differences without making judgments about them.

Burns: Absolutely.

Kushner: Just show that these people – and really the differences have to do with clinical approaches...

Burns: Um-hmm.

Kushner: Availability of certain kinds of support networks...

Burns: Um-hmm.

Kushner: And the ah, the governments of a particular place can have an influence on the way a diagnosis comes out, whether a place is a public or private hospital, the income of the patients...

Burns: Um-hmm.

Kushner: These are all factors that we never think about in terms of our epidemiologic outcomes.

Burns: Right.

Kushner: Maybe we should, but we don't. And all we can do now is just sort of report on our impressions of how these things might be influencing whatever it is these people are seeing and treating.

Dr. Noel Narayanan, former head of paediatrics department, Medical College of Trivandrum, Kerala

Conversation with Drs. Lalitha Kailas, Zulfikar Ahamed, Noel Narayanan, and Dr. S. Letha

Narayanan: Now coming to the Kawasaki disease, the first case we actually detected in 1994 and then, uh, subsequently we had four

cases in 1995 then about fifteen cases in 2000, some twenty-four cases in 2004 and about thirty cases in 2005. So we find there is a steady increase in the number of Kawasaki diseases admitted to our hospital. So we find a sort of a clustering of cases in Trivandrum because our catchments area is Trivandrum plus adjacent districts, Kenlamouri and Koula districts.

So there seems to be a – this, uh, number is not seen anywhere in India. In Kerala, in the middle Kerala, and in the north Kerala we had communication with our colleagues there, they say they see cases nowadays but not to that extent that we see in this place. Probably because of increased awareness, that is what I feel, but it could be, uh, possibly a new infectious agent is around or maybe some unknown trigger is around and probably we are genetically susceptible people. We do not know. This is something you know we really wanted to find out, why the short uh, clustering of cases occurring in our place...

Jain

KD31

Dr. Naveen Jain, KIMS (Kerala Institute of Medical Sciences), Trivandrum

Interview with Dr. Asok Kumar, Dr. Neeta Gupta and Dr. Naveen Jain

Jain: The year '96, when I just started an evaluation, Dr.Noel, my teacher, was just talking about Kawasaki disease. But at that time there were people who would giggle behind his back and say that we are trying to introduce a disease into the society that doesn't exist.

Kumar: [Laugh]

Burns: Un-huh.

Dr. Neethu Gupta, KIMS (Kerala Institute of Medical Sciences), Trivandrum

Jain: And ah, and, there were people who weren't very funny about making fevers into Kawasaki. The name itself was so unfamiliar to many people that it was really not accepted in the first few months. But then people, um there this is a teaching institution people read...

Gupta: ...And he used to give chocolate to the PD students who used to write Kawasaki in one of the differentials.

Burns: [Laugh]

Jain 2

Dr. Neethu Gupta, KIMS (Kerala Institute of Medical Sciences), Trivandrum

Gupta: If the child presents with fever and persisting fever.

Burns: Yeah, yeah.

Gupta: Even if it doesn't last, at least you should write about it or you should think about it. Kawasaki can be a possibility.

Burns: [*Laugh*] That's good.

Kumar: [*Laugh*]

Gupta: So he used to give chocolates.

Burns: That's good...

Kumar: ...Because, ah, when did I study. From 1970 to '80 I don't think I have seen many cases.

Kushner: Mm-hmm.

Kumar: I cannot say. But ah, I think it's a relatively new disease.

Kushner: So, eh sorry.

Kumar: What is the other feeling? That Kawasaki was there all along?...

Dr. Ashok Kumar, retired professor of pediatrics at Medical College of Trivandrum, Kerala, India, now chief of pediatrics at KIMS (Kerala Institute of Medical Sciences)

Vij 1

KD29

Conversation with Drs. Lalitha Kailas, Zulfikar Ahamed, Noel Narayanan, and S. Letha

Group Discussion in Trivandrum

Burns: ...Do you think Kawasaki disease patients are missed at your hospital? Misdiagnosed?

Vijayambikok: Not in our hospital, because all the – all the four pediatricians in our hospital are from here.

Kailas: Trained from, trained from here so they have a high...

Vijayambikok: So they have a...

Kailas: Index of suspicion.

Vijayambikok: If it were earlier, then we may have missed it, but now no...

roundtable

Extended scene in the office at Trivandrum – Conversation with Drs. Lalitha Kailas, Zulfikar Ahamed, Noel Narayanan, and S. Letha

(Burns:... The new criteria ... soft criteria ... a fever of more than five days ... new case definition So we're trying to make a case definition that will increase the number of children who will be treated uh, to try to avoid the subsequent lesions. Uh, in the same way you might take a child to the operating room with suspected appendicitis to be sure you pick up all the cases and uh, avoid the ruptured appendicitis. So maybe this will result in some over treatment, but maybe that's what's necessary to be sure we treat all the children who need it....)

Ahamed: ...Whereas in Kawasaki, uh, Americans are little more aggressive. So is it uh, because that uh, you don't find rheumatic fever in US and you find more of Kawasaki ... selfish motive ... do you get my point?

Jane Burns: " ... it's the same committee ...

00:37:15

Ward 1

Janr and Howard in ward with Dr. AHAMED

HK: WHAT DO THEY ...?

Ahamed: ... I have been here since 1981... thirty-four years total, total including

TEXT: ... I have been here since 1981... thirty-four years total, total including post-graduation. So I can tell that the major difference over last ten years is that diarrhea has come down. Diarrhea has practically become non-existent. Polio has slowly disappeared. Measles have come down dramatically, but now it is trying to come up again. So that is why to some – maybe two years back our post-graduates has not seen it, measles. For them measles is a differential diagnosis of Kawasaki. Whereas in the eighties when we started, measles was the diagnosis, Kawasaki was number six or number seven differential diagnosis. Now we, we, we, are – I still remember as a post-graduate in '84 in pediatrics, I think Kawasaki, Mucocutaneous Syndrome, some great man from Japan discovered this. We don't see. You know, we, I, I, I am not likely to see, never in lifetime. So that has changed...

Car, HK and JB re Trivandrum willingness to disagnose...?

diagnosis

Scene Seven: Interview with Dr. Surjit Singh

post-graduation. So I can tell that the major difference over last ten years is that diarrhea has come down. Diarrhea has practically become non-existent. Polio has slowly disappeared. Measles have come down dramatically, but now it is trying to come up again. So that is why to some – maybe two years back our post-graduates had not seen it, measles. For them measles is a differential diagnosis of Kawasaki. Whereas in the eighties when we started, measles was the diagnosis, Kawasaki was number six or number seven differential diagnosis. Now we, we, we, are – I still remember as a post-graduate in '84 in pediatrics, I think Kawasaki, Mucocutaneous Syndrome, one great man from Japan discovered this. We don't see. You know, we, I, I, I am not likely to see, never in lifetime. So that has changed...

[Film is concentrating on patients]

Interview with Dr. Surjit Singh

Burns: ...what do you think your colleagues think about you and your work in Kawasaki disease?

Singh: Uh [*takes deep breath*] I think, the general awareness is going on, is increasing year by year about this disease. And as I said, over the last year many of our patients were referred with the query of Kawasaki disease. But at the same time I think there are many doctors who feel that we are over diagnosing Kawasaki disease. This is – this is a fact that many of them feel that we are over diagnosing

Kawasaki disease and that any child with fever and rash if he's referred to our institution, you know, is likely to get a diagnosis of Kawasaki disease. This is, uh, a perception, yes...

00:22:23

Raju Kub KD 32

Scene Fifty-Six: Discussion with Dr. Raju Khubchandani and his Medical Team

Khubchandani: ... I strongly imagine that there is a body of pediatricians who possibly are more the slightly senior age group who are probably less open-minded who think that now we are going overboard and sometimes diagnosing more than we should be. You get me?

Burns: Mm-hmm.

00:25:41

Khubchandani: In my mind, that does not happen and I think we far more often diagnose TB and malaria than we do something like Kawasaki because there is an inbuilt safety wall over here to diagnose Kawasaki. And that inbuilt safety wall is the cost of IVIG.

Burns: Mm-hmm.

00:26:03

Khubchandani: Right. To prescribe anti-TB drugs or anti-malaria drugs for somebody for three days or two days costs them peanuts, but this is possibly more than the per capita income of a given Indian family, assuming per capita income is around five-hundred US dollars per annum, okay? This could possibly cost a little more than that for a single dose. So – and often pediatrics are not covered by insurance. So this is all often self-pay and therefore we better be very, very sure – as sure as we can be to ourselves - before you, you know, finally um, commit to the patient and say that this is I think where you need to go....

Taneja
history

Scene Twenty- Four:

Dr. Arvind Taneja, Director and
Chief of Paediatrics,
MAX Healthcare, Delhi

Interview with Dr. Arvind Taneja.

Taneja: The other ... difference I see in Kawasaki as presenting to us and many physicians here is ah, that the history is very inaccurate. Because I see many times patients come in to me two weeks or three weeks after they have been through um, an illness and ah, the diagnosis is um, atypical I would say here sometimes. Because of the poor history that is available from the parents many times – parents and even the doctors, the history that they give.

Parent 1

Scene Twenty-One: Interview with Parents (Mother: gray sari, Father: striped shirt) and Teenage Daughter (gray shirt)

Interview with Parents (Mother: gray sari, Father: striped shirt) and Teenage Daughter (gray shirt)

TEXT: So uh, after about seven days we ah, we adopted ah, sort of ah [inaudible], you can say, thinking about it that usually it becomes all night on its own without giving any medicines within a week if it is measles.

Father: We thought it to be measles ... So uh, after about seven days we ah, we had got ah, sort of ah [inaudible], you can say, thinking about it that usually it becomes all night on its own without giving any medicines within a week if it is measles.

Burns: Um-hmm.

TEXT: We went to temple also, and performed some rituals, but later on [inaudible] it did not recede, temperature was still high. So we went to our family doctor physician.

Father: We went to temple also, and performed some rituals, but later on [inaudible] it did not recede, temperature was still high. So we went to our family doctor physician.

Parent 2

TEXT: Yes, um, I have doubt about how does this disease occur? Is, is it ah, because we traveled all the way to... Yes, um, I have doubt about how does this disease occur? Is, is it ah, because we traveled all the way to...

Interview with Parents - Mother (black shirt), Father (plaid shirt) and Daughter (white shirt)

Mother: Yes, um, I have doubt about how does this disease occur? Is, is it ah, because we traveled all the way to...

Burns:No.

Mother: No.

Burns:There is nothing that you did that we know of that made this happen.

Mother: Um-hmm.

Burns:So, don't worry about that problem. But, we don't know what causes it. Um, but we know how to treat it. So she got the good treatment and she should be fine....

Parent 3

TEXT: ...
I did not know about the disease when I heard it first.

When I found out it was very costly medication, I was alarmed.

I am still anxious that this disease might back come again. It might cause a lot of conflict

Interview with Parents: Riya (Father)

Burns:...And, what did they think when they heard the diagnosis of Kawasaki disease?

Interpreter: *Speaking in Malayalam*

Riya (Father): Ah.

Interpreter: *Speaking in Malayalam*

Riya (Father): *Speaking in Malayalam*

Interpreter: Hmm.

Riya (Father): *Speaking in Malayalam*

Interpreter: He didn't know about the disease when he heard it first. And then when he found out it was very costly medication, at that time he was alarmed. [Inaudible] disease, sickness and he's still anxious that this disease might back come again, and it might cause a lot of conflict...

KD 15A

TEXT: I was really alarmed when I heard this. I heard that something bad is going to happen. Then all the doctors told me no need to worry. And then my child got better, she was consoled, she was happy about that.

Scene Fifteen: Interview with Dr. Srikanta Basu and Dr. Joyotsha Sachdev

TEXT: *So, much of it is taken as the will of God. That even if they lose a child, they might say that was the will of God so it would probably...*

TEXT: *And even the poverty, like if child is coming to hospital, the whole family is coming to hospital.*

TEXT: *Most of them are daily wagers – they lose their food and everything. So that – many practical implications. For simple rash and fever, they may not be coming to hospital. They go to a local private practice, not even an allopathic doctor, get some medicines or some – something else – so...*

Gupta
fees

KD 19

Scene Twenty: Interview with Father (light blue sweater and striped shirt) and Daughter (pink)

Interview with Parents - Shaife (Mother)

Jane: What did she think when she was told that the baby needed treatment?

Interpreter: *Speaking in Malayalam*

Shaife (Mother): *Speaking in Malayalam*

Interpreter: She was really alarmed when she heard this, um she heard that something big is going to happen, something bad is going to happen. That is her feeling. And then all the doctors told her no need to worry. Then the child got better. I was happy about that.

Burns: Okay. Good.

Scene Fifteen: Interview with Dr. Srikanta Basu and Dr. Joyotsha Sachdev

Sachdev: *[Nods]* So, much of it is taken as the will of God. That even if they lose a child, they might say that was the will of God so it would probably...

Basu: And even the poverty, like if child is coming to hospital, the whole family is coming to hospital.

Kushner: Sure.

Basu: Most of them are daily wagers – they lose their food and everything. So that – many practical implications. For simple rash and fever, they may not be coming to hospital. They go to a local private practice, not even an allopathic doctor, get some medicines or some – something else – so...

00:18:28

Scene Twenty: Interview with Father (light blue sweater and striped shirt) and Daughter (pink)

Kohli: *[Speaking Hindi to Father]*

Father: *[Speaking Hindi]*

Kohli: He says he has to pay for the echocardiogram.

Burns: Um-hmm.

Kushner: And how much is the echocardiogram?

Kohli: [*Speaking Hindi to Father*]

Father: Two thousand.

Kohli: Two thousand rupees.

Kushner: So two thirds of his monthly salary.

Burns: Almost what he earns per month.

Kohli: [Inaudible – *speaking Hindi to Father*].

Father: Two thousand [*Speaking Hindi*].

Kohli: [*Speaking Hindi to Father*]

Father: [*Speaking Hindi*]

Kohli: [*Speaking Hindi to Father*]

Father: [*Speaking Hindi*]

Kohli: [*Speaking Hindi to Father*] My secretary told me that we haven't billed to this patient. He's saying he's been billed.

Burns: Hmm.

Kohli: So I need to figure it out, what's happened.

Father: [*Speaking Hindi*]

Kohli: Oh, okay. He said, you didn't charge a consultant fee, but the hospital charged for the echocardiogram.

Burns: Umm.

Kohli: Maybe we can take care of some of these things.

S and B
2 **KD 15A**
Scene Ten: Interview with Dr.
Srikanta Basu and Dr. Joyotsha
Sachdev

TEXT: It's just that we're diagnosing it more. See because I can look back and think of cases now that could have been and we missed. I said probably it's a viral, watch and wait, everything cleared off, we didn't do any specific diagnostics. So I, I feel we're just picking it up more. We probably all had been missing.

anand **KD 46**

Banerji **KD 11**
Dr. Jayant Banerji, INSCOL
Hospital, Chandigarh, India

TEXT: I think it's under diagnosed, that I think we are all sure of now and most doctor's agree with that. I also think that there is fair degree of unawareness about this in non-pediatric doctors. We're still not

Burns: Okay.

Interview with Dr. Srikanta Basu and Dr.
Joyotsha Sachdev

Burns: Do you think that the number of cases is changing in India or do you think [*beeping noise*] it's an awareness issue?

Sachdev: It's just that we're diagnosing it more. See because I can look back and think of cases now that could have been and we missed. I said probably it's a viral, watch and wait, everything cleared off, we didn't do any specific diagnostics. So I, I feel we're just picking it up more. We probably all had been missing.

Interview with a Group of Doctors in Mumbai

Anand Shadilya: ...So quite frankly, I think the sure way of diagnosing Kawasaki is first to think about it. In the kind of busy practices that we have – um – we seen so many other viral infections and other kinds of things that it really doesn't occur to us to think of it and when you sort of just, oh, this is Kawasaki, it sort of snaps in. And after my first case, I picked up the second one in four days. It was a four day history, so it was really fast. I mean I did pre-diagnosis over the phone, because I was out of town. When I came in called up my resident and they described the features and I said this looks like a Kawasaki. We went and next day the child go to the IVIG. So that's how it was. So I think the surest, thinking about it and then recognizing the features

Interview with Dr. Jayant Banerji

Burns: What do you think about KD in India? Do you think it's under diagnosed? Over diagnosed?

Banerji: [*Nodding head*] I think it's under diagnosed, that I think we are all sure of now and most doctor's agree with that. I also think that there is fair degree of unawareness about

aware enough of it and don't think about it and [*slight pause*] we don't treat it. I also think that there's a sort of denial in parents and doctors when it comes to KD. Ah, they don't want to know and they make a lot of visits and when somebody tells them it's not KD that's the one they believe.

this in non-pediatric doctors. We're still not aware enough of it and don't think about it and [*slight pause*] we don't treat it. I also think that there's a sort of denial in parents and doctors when it comes to KD. Ah, they don't want to know and they make a lot of visits and when somebody tells them it's not KD that's the one they believe.

00:08:36

Arya 1 KD 20

Dr. Suvhash Arya

TEXT: Looking retrospectively I think there were some other cases also, which we thought of Kawasaki. We didn't label them Kawasaki, but retrospectively I would have labeled them Kawasaki [*long pause*] because not everything was there, but once we started to see more and more KD patients I realized you don't get the classical description here. Um, this is my observation a lot of it is older children, six years, eight years, even ten years we have seen...

Interview with Dr. Suvhash Arya

Arya:...Looking retrospectively I think there were some other cases also, which we thought of Kawasaki. We didn't label them Kawasaki, but retrospectively I would have labeled them Kawasaki [*long pause*] because not everything was there, but once we started to see more and more KD patients I realized you don't get the classical description here. Um, this is my observation a lot of it is older children, six years, eight years, even ten years we have seen...

Anand 1 KD 38

Extended to include JB question

Interview with Dr. R. K. Anand

JB: So the peeling ...

Anand:
I started ah, my pediatric practice since 1960. See. So I, I don't remember at all, I mean, seeing something like that.

Burns: Well, that's an important piece of the puzzle.

Kumar 1 KD 14

Interview with Dr. Rohit Manoj Kumar

31.59.06 Dr. Manoj Kumar, assistant professor of pediatric cardiology, Postgraduate Institute of Medical Education and Research in Chandigarh, India

TEXT: Yes, probably. One of my – just towards the [inaudible] of our training one of my, uh, senior residents suspected Kawasaki disease. And child died on probably I think tenth day or eleventh day. I was a general resident. The child died. He did say this was Kawasaki disease, that resident was very nice, he was my senior resident. What do you call, chief medical officer, or chief resident?

TEXT: So he was, and he suspected. And I told my boss this is Kawasaki disease. And we went back and found [inaudible]. It did fit into diagnosis. Unfortunately the child, by the time we made decision to give aspirin and IVIG, it was too late.

Burns: Did the baby have an autopsy?

Kumar: No, his family refused autopsy. But that probably was...

Burns: ...When you think back over your training in Delhi, do you think there were Kawasaki patients there that were being missed?

Kumar: Yes, probably. One of my – just towards the fag-end of our training one of my, uh, senior residents suspected Kawasaki disease. And child died on probably I think tenth day or eleventh day. I was a general resident. The child died. He did say this was Kawasaki disease, that resident was very nice, he was my senior resident. What do you call, chief medical officer, or chief resident?

00:56:43

Burns: Mm-hmm, chief resident.

Kumar: So he was, and he suspected. And I told my boss this is Kawasaki disease. And we went back and found [inaudible]. It did fit into diagnosis. Unfortunately the child, by the time we made decision to give aspirin and IVIG, it was too late.

Burns: Did the baby have an autopsy?

Kumar: No ... his family refused autopsy.

Kushner
Car 1

KD 48
Discussion in Car between Drs. Howard Kushner and Jane Burns.

Discussion in Car between Drs. Howard Kushner and Jane Burns.

Kushner: There's two ways of thinking about KD. There's an entity and some people get close to it because we know that there is a thing. And everyone gets close to it and the differences are how, how good people are at getting close to it to meet all the criteria. Or, the

criteria themselves are sort of plastic and what we see, the differences reflects um, the parts of this – of this plasticity that people see. ...

On Jane

Kushner: I mean, you know, if, if they're trying to meet the external – if we're gonna judge them by the external criteria when we ourselves have some question about you know these criteria themselves – if we're going to try and fit them in a pigeon hole that may not be appropriate

Kushner: *We don't know how, how right they are. It's not like we want them to pass a test.*

Burns: *Yeah.*

Kushner: *Right.*

Burns: *Well, we don't know how right we are*

*[decorative truck outside of
Kaushalya Medical Foundation in
Thane, India]*

Thane 1 KD 49

Discussion with a Group of Doctors AT THANE

Kushner: You think it, it's new?

Sudhuir Sane: I feel it's recent ... at least last ten, fifteen years in India because I, I have not been practicing for more than then, but you know what when we were post-graduate students in pediatrics we were [inaudible] we saw so many measles and we use to [inaudible] mucocutaneous lymph node syndrome.

Kushner: Um-hmm.

Sudhuir Sane: And it looked, it looked indistinguishable from Kawasaki. Fever for more than five day, polymorphis rash, conjunctivitis, and we use to have a lot of complications from measles in those times. And that was – if this [inaudible - *loud noise in background*] I wouldn't really think there was Kawasaki.

Prakash Vaidya (cream shirt, brown tie): Also I think somewhere down the line we are all seniors, have taken it as measles not realizing that this entity was Kawasaki – I mean not specifically measles - maybe today we are more aware...

Thane 3 KD 49

Jayesh Seth: Ah, I personally feel that this is ah, recent entity, probably last one decade. As far as my memory goes I don't think we – [inaudible] seen Kawasaki, maybe '95 onwards. Probably our awareness has also increased, but still if I recollect I don't think Kawasaki was there...

Thane 4

Sandip Kelkar Sometimes child has been seen by family physician for one week and then the child comes to us on eight day or nine day. At that time maybe not all the symptoms and signs are a little bit milder or they've become severe and then we think of something which is going on underneath. So sometimes that may be the reason that we are not quite sure about the diagnosis...

Thane 5

Thakker SV: (blue tie): We are not really aware of Kawasaki to that extent and still we are probably not aware to that extent as probably you are. Because the importance of the disease is quite different.

Kushner: Sure.

Thakker SV (blue tie): We still see it as probably a mild disease as compared to other disease burden which is there. How much money to invest on to investigation and treatment is also relatively different

Mumbai KD 46
1

Interview with a Group of Doctors in Mumbai

Burns:...So where do you think Kawasaki disease is hiding in India?

00:41:38

Suresh Shah: Yeah, I think it is very much there. But probably, as I said, since the very first case, because we didn't have much exposure so probably I may have missed a diagnosis. But you know, once we have seen a case, we know more about it. So next time, we have more, you know, open eyes. We can see if it's there or not. So, I think the awareness is increasing. I think the incidence is there but, uh, the report is underreported and probably under-diagnosed also...

Mumbai KD 46
2

Shadilya: ...But the hallmark of Kawasaki, I feel, is the irritability. That alerts you, you know...

Maniar: The sick child, the sick child.

Shadilya: ...that is the one thing that tells you, look there is something you're missing. The irritability is very classic...

KD 47

Bavdekar: ...Every year – we have a – from all medical colleges, undergraduate students participate, uh, in quiz program. And, uh, the final of that is held in national – when we have national conference. So around one-fifty medical colleges, uh, participate. And because I was on the quiz-bank I must say that I got to know about details about this Kawasaki disease. And first case, that I saw at that time, I said this looks like Kawasaki disease, but that was first case so I wasn't sure. So I got clinical textbook and I showed it to the professor. See, this is what it is and I think it is there. The patient had strawberry tongue, had, uh, rash all over the body, and the fever was approaching the fifth day or so when he came to us....

Surjit
statement

00:17:41

Scene Eleven: Interview with Dr. Surjit Singh

Interview with Dr. Surjit Singh

TEXT: Although I have no proof for this, but I think that it's - it's - there's no increase in the number of cases. It's just that we're becoming more and more aware of this condition. And, uh, this is confirmed by what our dermatology colleagues had to say, you know, they are now quite attuned to making a diagnosis of Kawasaki disease and they say that, previously they never thought of this condition, they were, you know, labeling these patients as Stevens-Johnson syndrome. So I personally feel that there's no real increase there's just an apparent increase related to increased awareness about the – but you know I don't have any hard data to, to support my statement.

Singh: Although I have no proof for this, but I think that it's - it's - there's no increase in the number of cases. It's just that we're becoming more and more aware of this condition. And, uh, this is confirmed by what our dermatology colleagues had to say, you know, they are now quite attuned to making a diagnosis of Kawasaki disease and they say that, previously they never thought of this condition, they were, you know, labeling these patients as Stevens-Johnson syndrome. So I personally feel that there's no real increase there's just an apparent increase related to increased awareness about the – but you know I don't have any hard data to, to support my statement.

Kook

41.39.09 Dr Shyam
Kukreja, Senior Pediatric
Consultant, Max Hospitals,
Delhi

Kukreja: 10.49 My feeling is the number of cases, they probably increased. I am not sure any figure to say this statement, because I say Dr. Taneja and me are quite aware of this disease for last twenty years.

Burns: Um-hmm.

Kukreja: And we ah, in our own practice tended to more patient in last ah, for two, three years as compared to what we use to see in last fifteen, twenty years.

Burns: Um-huh.

Kukreja: For example, there used to be one case in a year. Suddenly there were about three cases in – from my own practice three years ago. And we had about four, five cases in this year only.

Burns: Um-hmm.

Kukreja: So, I, I maybe, I'm not sure, maybe ah, I am getting more reference. I feel that maybe the number of cases has increased.

42.51.07 Dr. Arvind Taneja,
Director and Chief of
Paediatrics,
MAX Healthcare, Delhi,

(Taneja: 12.07 my father was a very well known pediatrician in town ... he told me he hadn't seen something like Kawasaki earlier to when we described it.

Kukreja: Yes.

Taneja: So, I mean, I, I, - he was a good clinician. He was a very astute clinician and I would...

Kukreja: Yes, he was an excellent clinician.

Taneja: He was, he was an excellent clinician. And I – when we've talk about it, he said I haven't seen something similar to this before 1977 when you showed us this particular – he said I might have missed a patient or two, but I haven't missed a large number of patients like this.

PGI 1

Interview with a Group of Residents from PGI

Kushner:

One of the things ... **have you thought about this?**

Burns: ...Hopefully we are not teaching them to expect it [*laugh*].

Kushner: ...I mean have you thought about this issue?

00:32:32

Burns: We'd like to know what you think and also what you've been taught.

Kushner: Yeah, both.

Burns: Because those may be two different things [*laughs*].

TEXT: Dr. Kawasaki came in 1987 here it was, uh, he told that this disease does not exist in India. It was like that, we had been taught like that previously when he came. And after that we start picking up here, uh, here, the disease was being picked up and more and more cases were identified and almost more than two to three hundred cases were now under follow up. So it was, uh, rather more picked up rather than it was not there – it was there existing prior also but now the it is picked up more compared to previous, uh, days...

TEXT: I would slightly differ on this because, uh, such sudden increase could not be just attributed to awareness, this book – this disease has always been there in our textbooks. And I mean, doctors in tertiary care centers always knew of

Dr. Amaresh Reddy (yellow checked shirt)

...Dr. Kawasaki came in 1987 here it was, uh, he told that this disease does not exist in India. It was like that, we had been taught like that previously when he came. And after that we start picking up here, uh, here, the disease was being picked up and more and more cases were identified and almost more than two to three hundred cases were now under follow up. So it was, uh, rather more picked up rather than it was not there – it was there existing prior also but now the it is picked up more compared to previous, uh, days...

PGI 2

Dr. Sunil Ghelani (black sweater):...I would slightly differ on this because, uh, such sudden increase could not be just attributed to awareness, this book – this disease has always been there in our textbooks. And I mean, doctors in tertiary care centers always knew of

this disease, but the sudden increase in the number of cases so it could also be partly that the disease is on the rise and hence the awareness. Just pure increase in awareness would not increase the number of cases. I mean, even ten years back it was there in the textbook and people knew the disease, desquamation is this – is – is a hallmark, but they weren't seeing cases with desquamation. Now we're seeing cases with desquamation that means disease is also on the rise and hence we're seeing more cases. And we're spreading the awareness secondly to probably increase in the disease rather than increase in awareness, which is causing more number of diagnosis. So it could be awareness is leading to more diagnosis, but disease is also definitely on the rise...

this disease, but the sudden increase in the number of cases so it could also be partly that the disease is on the rise and hence the awareness. Just pure increase in awareness would not increase the number of cases. I mean, even ten years back it was there in the textbook and people knew the disease, desquamation is this – is – is a hallmark, but they weren't seeing cases with desquamation. Now we're seeing cases with desquamation that means disease is also on the rise and hence we're seeing more cases. And we're spreading the awareness secondly to probably increase in the disease rather than increase in awareness, which is causing more number of diagnosis. So it could be awareness is leading to more diagnosis, but disease is also definitely on the rise...

00:36:46

TEXT: ...Basically what the problem that in a developing country like India, where, uh, so many people are fighting to get their basic needs, there are so many fevers, there are so many episodes of fevers and there are so many common causes of fever that for the parents to take at the first moment a disease like Kawasaki as the diagnosis may be very difficult because even with educated families it is not uncommon for a child to fall ill with fever every say four months. And maybe, and once he's treated as a viral fever and maybe he's had a sore throat, maybe he's had gastroenteritis. So to - for parents to come to a institute and to be told such an uncommon disease they're diagnosed like Kawasaki disease is very difficult. This is one of the basic reasons for parents denying – like, uh, they're receiving a shock,

00:51:58

Kunal Gupta(orange shirt): ...Basically what the problem that in a developing country like India, where, uh, so many people are fighting to get their basic needs, there are so many fevers, there are so many episodes of fevers and there are so many common causes of fever that for the parents to take at the first moment a disease like Kawasaki as the diagnosis may be very difficult because even with educated families it is not uncommon for a child to fall ill with fever every say four months. And maybe, and once he's treated as a viral fever and maybe he's had a sore throat, maybe he's had gastroenteritis. So to - for parents to come to an institute and to be told such an uncommon disease they're diagnosed like Kawasaki disease is very difficult. This is one of the basic reasons for parents denying – like, uh, they're receiving a shock, like what is this Kawasaki. This is the basic reason for they being refusing to take the diagnosis....

like what is this Kawasaki. This is the basic reason for them being refusing to take the diagnosis....

PGI 4

Burns: I hope that we will continue to see some of you or all of you over the next few days and that we'll have a chance to have more talks informally and I hope you'll also not only talk to us now when we're here, but also feel free to contact us by email. So when you go back to all the different places in India that you come from, the internet really links all of us together – so we'd be very happy to hear from any of you and continue our education as well as if we can help you in any way.

ONE CANNOT IGNORE THE IMPACT OF THE SOCIAL AND ECONOMIC TRANSFORMATIONS THAT HAVE SHAPED INDIA SINCE THE MID-1990S. THE GROWTH OF A SUBSTANTIAL MIDDLE CLASS WITH INCREASING ACCESS TO MEDICAL CARE AND, MORE IMPORTANT, TO MEDICAL INFORMATION, HAS INFLUENCED THE ACCEPTANCE, OF A KAWASAKI SYNDROME DIAGNOSIS.

AS INDIAN FAMILIES REDUCE THEIR SIZE, ESPECIALLY TO ONE CHILD, IT STANDS TO REASON THAT THE HEALTH OF EACH CHILD BECOMES A MUCH GREATER CONCERN AND MIDDLE-CLASS PARENTS IN INDIA MAY ADOPT A MORE PROACTIVE RESPONSE TO THEIR CHILD'S FEVERS AND RASHES.

Restaurant – cutaways of Jane and Vikas' wife

Lunch Discussion between Dr. Vikas Kohli, Mrs. Kohli, Dr. Howard Kushner, and Dr. Jane Burns

Kohli: We are just treating what we call

Kawasaki as a group of symptoms. We don't know what is at the back end of it. The back end of it could be connected very well with polyarthritis nodosa, and the other vasculitities. It could be connecting with all of them.

Kushner: Exactly.

Kohli: And, and we, we are typically like the blind man and the elephant. You know, we feel something and we call it Kawasaki every time we feel the same thing, but we are missing – maybe, maybe we are missing totally the other – rest of the whole thing.

Kushner: Oh, I think you are absolutely right.

srivastava
a Interview with Dr. Javitri Srivastava

Interview with Dr. Javitri Srivastava

TEXT: And till about '90 or '92 there were hardly any cases which were diagnosed by – as Kawasaki in our pediatric group. And ah, the pediatricians at All India Institute – all of us said we looking for Kawasaki, but not finding any Kawasaki. I mean, whenever we discussed that why is it, why is it so you don't refer any cases Kawasaki to us to look for the aneurisms. So they would tell us that, well we are looking for it but we are not finding any positive cases.

But gradually over the years, in last ten years, the diagnosis of Kawasaki is more often made by pediatricians with of course are they more looking for it or with due to the travel and all the Kawasaki has come to us over this. So the positive cases and the screening being asked for Kawasaki is gradually increased over ten years, but more so in five years I would say in our experience at the two institutions...

Srivastava ...And till about '90 or '92 there were hardly any cases which were diagnosed by – as Kawasaki in our pediatric group. And ah, the pediatricians at All India Institute – all of us said we looking for Kawasaki, but not finding any Kawasaki. I mean, whenever we discussed that why is it, why is it so you don't refer any cases Kawasaki to us to look for the aneurisms. So they would tell us that, well we are looking for it but we are not finding any positive cases.

But gradually over the years, in last ten years, the diagnosis of Kawasaki is more often made by pediatricians with of course are they more looking for it or with due to the travel and all the Kawasaki has come to us over this. So the positive cases and the screening being asked for Kawasaki is gradually increased over ten years, but more so in five years I would say in our experience at the two institutions...

00:05:29

Kohli: ...Obviously and that is the next consequential question is why in the '90s we started seeing Kawasaki. A lot of things changed in India in the '90s as madam will also tell you that society changed. It is still changing

and you can see that there are parts of the society which are not very different from the Western world. And then there are parts which are left way behind. So when that part of society also reaches this level, will we see more Kawasaki, will it be rampant? We will not just see thirty or sixty, but maybe we'll see three hundred and six hundred.

00:21:13

Kushner: Could be.

Kohli: As happens in Japan.

Dr. Raju khubchandani:

KD 38

10.01-06

Raju Khubchandani:

Quite Frankly my perception is that what the mind didn't know the eye did not see

WHETHER OR NOT THE INCREASED DIAGNOSIS OF KAWASAKI SYNDROME THROUGHOUT INDIA IS A RESULT OF INCREASED AWARENESS OR AN ACTUAL INCREASE IN DISEASE BURDEN IS DIFFICULT TO DETERMINE. IN PART THE ANSWER IS CONNECTED TO A COMPLEX INTERACTION OF MEDICAL, HISTORICAL, AND CULTURAL ISSUES, BEYOND THE SCOPE OF THIS INVESTIGATION.

WHATEVER THE REASONS, EVERY INDICATION IS THAT KAWASAKI SYNDROME WILL CONTINUE TO PRESENT AN INCREASING DISEASE BURDEN ON THE PEDIATRIC POPULATION OF INDIA.