



## Origin and importance of the Latin American Kawasaki Disease Network (REKAMLATINA)

Antonio González-Mata, Rolando Ulloa-Gutiérrez, José Brea, Guillermo Soza and Adriana H. Tremoulet

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Hospital Universitario  
Pediátrico "Agustín Zubillaga",  
Barquisimeto, Venezuela (AGM).  
Servicio de Infectología Pediátrica,  
Hospital Nacional de Niños  
"Dr. Carlos Sáenz Herrera",  
San José, Costa Rica (RUG).  
Centro Médico Universidad  
Central del Este, Santo  
Domingo, República  
Dominicana (JB).  
Hospital Dr. Hernán Enriquez  
Aravena, Temuco, Chile (GS).  
University of California San  
Diego/Rady Children's Hospital  
San Diego, Estados Unidos de  
Norteamérica (AHT).

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Correspondence to:  
Rolando Ulloa-Gutiérrez, MD.  
rolandoug@racsa.co.cr  
rolandoug@gmail.com

Kawasaki disease is the leading cause of acquired cardiac disease in children. Although the epidemiology of the disease has been well described in Japan, other Asian countries, Europe, Australia and North America, the epidemiology and disease burden in Latin American children is unknown. For this reason, the idea of establishing a research network on Kawasaki disease in children from Latin America was born, becoming this the largest Kawasaki disease international multinational research network and in which 20 countries of the region will be integrated.

**Key words:** Kawasaki disease, children, network, Latin America, epidemiology, surveillance.

**Palabras clave:** Enfermedad de Kawasaki, niños, red, Latinoamérica, epidemiología, vigilancia.

**K**awasaki disease (KD) is the leading cause of acquired cardiac disease in children from both developed and developing countries who have successfully battled the impact of rheumatic fever<sup>1</sup>. This acute vasculitis affects previously healthy children in its great majority, with 80% of cases in the first five years of life, and around 50% of cases in infants younger than 2 years of age. Although this disease was first described in Japan in the 1960s by Dr. Tomisaku Kawasaki<sup>2,3</sup>, its precise etiology remains today uncertain. Nevertheless, it is considered that an infectious agent, possibly viral, triggers KD, and that genetic susceptibility for the disease exists in some individuals<sup>4,5</sup>.

The epidemiology of KD has been well described in Japan and other countries in Asia, Europe, Australia, and North America<sup>6,7</sup>. However, although Latin America is comprised of more than twenty countries, the epidemiology, disease burden, morbidity and mortality rates, and genetic aspects of KD are unknown in this region. The majority of descriptions and reports come from single countries, are case reports or small series, or communications through scientific conferences, experts meetings, discussion forums, and others. KD is not a mandatory reportable disease in Latin America and there are considerable problems in diagnosis and underreporting of cases. Although there have been publications on KD from Latin American countries, most of these have been published in local medical journals not indexed in PubMed, and there are regions such as Central America where no data are available from some countries<sup>8</sup>. In Latin America, the largest population study of KD in children was recently published by Borzutzky and colleagues from Chile in 2012<sup>9</sup>. This study demonstrated an increase in hospitalizations rates and incidence of KD in Chile, and it was proposed again as suggested in the past by other

investigators such as Dr. Antonio Banfi from Hospital Luis Calvo Mackenna, the need for a national registry of KD cases as well as to declare this a reportable disease.

Motivated by these issues, a few years ago a group of pediatric infectious disease specialists from the Kawasaki Disease Research Center in San Diego, California and the Sociedad Latinoamericana de Infectología Pediátrica (SLIPE) with great affinity, interest, and experience in KD, saw the need to know the epidemiology of KD in Latin American children. The disease burden, associated morbidity and mortality, and its potential long-term impact in the health of infants, children, and young adults, have been a concern to this group of experts. Therefore, different academic activities, experts meetings, discussion forums and exchanges of opinions have been undertaken by the authors of this paper and other colleagues of the region.

The topic of KD had been previously described in few conferences and regional meetings of SLIPE. However, during the XIII Congreso Latinoamericano de Infectología Pediátrica (SLIPE 2009) in Guayaquil, Ecuador, Dr. Antonio González-Mata from Venezuela gave the plenary lecture "*Kawasaki disease: state of the art*". During this lecture, a general description of the diseases was made as well as epidemiological data from selected countries was presented. The absence of data from many Latin American countries was mentioned.

By mid-2010, a KD symposium was planned for the XIV SLIPE conference to be held in Punta Cana, Dominican Republic in May 2011. In December of that same year, Dr. Rolando Ulloa-Gutiérrez visited the Kawasaki Disease Research Center in San Diego, California, where he met with pediatric infectious disease specialists Dr. Jane C Burns and Dr. Adriana H Tremoulet. The latter was the initial champion of the need to establish this network for



the Latin American region. During this visit, the current epidemiology of KD in Latin America was discussed, as well as the need to know and diffuse data of each country and of the region. Ideas for future projects and the need to work together in a network were established, and the details of the KD Symposium in May 2011 at the SLIPE meeting were refined.

During the latter, a *Breakfast Meeting with the Expert* encounter was performed with Drs. Tremoulet and Ulloa-Gutiérrez. This meeting had a surprising and unexpected high attendance by the conference participants. Also, the first KD Symposium during a SLIPE conference was held, and lectures were given by Dr. Tremoulet, Dr. Ulloa-Gutiérrez, Dr. Guillermo Soza (Chile) and Dr. González-Mata. During this symposium, the speakers addressed the problems of making the diagnosis, the differential diagnoses, and underreporting of cases in the region, as well as conventional treatments and new treatment options for refractory cases. The epidemiology of KD in Latin America was also discussed, and the need for a national registry for each country as well as mandatory reporting was reiterated. Also, proposals for future research areas were discussed, among which the most important was the organization of a KD Latin American investigator network.

In February 2012, the 10<sup>th</sup> International Symposium on Kawasaki Disease (ISKD) was celebrated in Kyoto, Japan. This is the most important scientific meeting worldwide on KD and many investigators, predominantly from Asia, North America and Europe, attend this meeting. During the oral presentations of KD epidemiology by country, Dr. Ulloa-Gutiérrez presented the epidemiology of KD in Costa Rica and commented the group's idea to create a Latin American network for KD<sup>10</sup>. During ISKD, the absence of data and investigators from Latin America at this event was mentioned by Dr. Ulloa-Gutiérrez as well as Dr. Jane W Newburger (Boston, Mass) in her closing session and summary of the conference.

In April 2012, in Mexico City, Dr. Patricia Saltigeral, Dr. Tremoulet, and Dr. Ulloa-Gutiérrez met and discussed the need of integrating Latin American countries in a network, especially those hospitals or centers from countries with large populations such as Mexico, Brazil, Argentina, Chile, Colombia and Venezuela; other logistical issues and future plans were discussed as well. In Mexico, a group of investigators recently formed a national KD network to improve the surveillance and registry of cases<sup>11</sup>. In December of that same year, during the XXXI Congreso

Interamericano de Infectología Pediátrica in Aguas Calientes, Mexico, Dr. Tremoulet and Dr. José Brea del Castillo from the Dominican Republic (past President of SLIPE from 2011-2013), agreed among other future activities in developing educational material focused on the diagnosis and treatment of KD for the SLIPE website.

Finally, on April 18 and 19, 2013, a workshop meeting sponsored by SLIPE was held in La Romana, Dominican Republic, in which Dr. Brea, Dr. Tremoulet, Dr. Ulloa-Gutiérrez and Dr. González Mata participated. During this meeting numerous aspects regarding the creation of a network, the need for research studies, and publication of manuscripts were discussed. The group agreed to name the network with the acronym REKAMLATINA, Red de Enfermedad de Kawasaki en América Latina (*Latin American Kawasaki Disease Network*). During this meeting the list of countries that would form this network was established, as well as the prospective and retrospective studies to be completed over the following years. The project and its logistical aspects were presented to the 2011-2013 Board of Directors Board of SLIPE. Its president, José Brea, has been particularly supportive of the idea of establishing this network. A work meeting was planned for the next XV SLIPE Conference in Sao Paulo, Brazil (June 26 to 29, 2013), where among other aspects, the logistics of the network and the details of the first study would be discussed, the "Prospective multinational multicenter study on the epidemiology of KD in Latin American children".

This is how REKAMLATINA was established and initiates its historical path towards understanding the epidemiology of KD in children from Mexico, Guatemala, Honduras, El Salvador, Nicaragua, Costa Rica, Panama, Cuba, Dominican Republic, Puerto Rico, Colombia, Venezuela, Ecuador, Peru, Bolivia, Brazil, Paraguay, Uruguay, Chile and Argentina. Today, REKAMLATINA is the largest international multinational network with the largest number of countries integrated to study the epidemiology of KD in children. More than 120 researchers from more than 85 hospitals in Latin America where most children with KD are hospitalized and treated in 20 Latin American countries will contribute to a better understanding of the epidemiology of KD in our region. The story of the birth of this network and its future impact in the health of children from Latin America and other parts of the world is inspiration for other countries. This is how in this journal the history pages of Kawasaki disease in Latin America are written.



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