

# Childhood Kidney Disease in Lakeside Villages

## Part II: Todd Stong's Written Report on Lakeside Issues 2020

Given Open Circle's cancelation of presentations in March 2020 due to COVID-19 precautions, I have been asked to provide comprehensive written updates on the issues of primary concern to me in the Lakeside Area. Of all the village problems I have been privileged to address in my 17 seasons at Lakeside, childhood kidney disease is the most important and pressing. While water-related issues in rural villages have been the focus of my work for almost three decades (and while I'm not a medical doctor), the villagers have asked me to search out and share with them all that can be discovered about this disease of their children. This report describes what I've found up until now and recommends actions to be taken, as well as how interested persons may lend a hand. This problem begins with Chapala and extends eastward with greater and greater intensity along the lake shore, with the primary focus being in the area about San Pedro Itzican and its close-by sub-villages. It is believed this crisis concerns about 3,000 yet-to-be identified families from which about 150 of their children die each year.

### Functions of the Kidneys

While it may be well known that the heart pumps blood about our bodies and the lungs draw in air, much less is known about what the kidneys do beyond producing urine as waste. What are the known functions of these important, fist size, bean-shaped organs located just below the ribs in your lower back? In general, they serve as the major toxic waste collectors in the body. Each day they clean up to 200 liters (similar to the volume of a barrel) of blood and remove about 2 liters of waste products and excess water.

1. They filter from our blood food wastes, medications, and toxic substances like arsenic
2. They regulate and filter excess minerals from the blood
3. They maintain the overall water balance in the body
4. They create hormones that assist in the production of red blood cells
5. They encourage bone health
6. They regulate blood pressure
7. They regulate the amount of sodium and potassium in the blood

### Detection of Disease

One of our biggest challenges all over the world is to identify people who have kidney disease. Most who have it never know it. In general, it is believed that 10-15% of adults in the world have it. In Mexico nearly 12 million people may have it. Among the elderly, nearly 50% may have it. Often deaths due to kidney disease are listed as heart failure. As for children, we know far less why many have kidney disease. Sadly, in most cases,

we don't know which children have it until it's too late to seek a remedy, or to possibly slow or stop its advance. In the lakeside village area of concern, there may be 18,000 children among whom the challenge is to find the 3,000 with the disease already in progression. Of those 3,000 children who may have this disease, we may be able to visually recognize tell-tale symptoms of about 300, one out of 10. These are children already in the advanced stages 4 and 5 of this disease. That is, we may not know at all who the other 2700 children are who have it in a form not easily detectable. Of the 300 children each year that may be detected visually, 150 may die each year.

This disease may advance silently over 5 to 20 or even 30 years through its five stages. It is only in the last two stages that we can visually detect it in the case of children. I myself am in Stage 3, due to past heart attacks. My condition is stable because I do not live a lifestyle that stresses my kidneys. I know the degree of my disease only because of blood tests (Creatinine). The easily seen signs for children during the last two stages, numbers 4 and 5, are puffiness about the face, especially about the eyes, and perhaps swollen ankles or wrists. Once a child is found to be at Stage 4, they could die in a few weeks or months. With dialysis treatment several times a week, which is very costly, they may live for 6 to 24 months. If the child is at Stage 5, they may die in a few days to weeks unless they can receive a donated kidney, something that very rarely happens in Mexico. Later we will speak more about blood tests that can identify kidney disease in each of its five stages. The following physical conditions may also offer a hint in identifying children that have kidney disease that is not seen in the face in its earlier 3 stages:

1. Low birth weight
2. Stunted growth for height
3. Deformed hands and or feet
4. Foamy urine

### **What Are the Causes of Childhood Kidney Disease?**

**The first half of all causes** of childhood kidney disease are attributed to lifestyle, especially diet. This can vary from nation to nation about the world. Thus, the list of causes noted below may vary geographically. Villagers in Jalisco were told almost nothing by the last state government as to the causes of the problem. The state administration tasked the University of Guadalajara to find the causes. The result has been many federally funded academic papers on various topics in which each department had an interest. Regrettably, very few address any the causes of kidney disease in children. Further, no villagers could ever understand the language of these papers if they saw them. On the basis of urine and blood tests from the village of Agua Caliente, a kilometer east of San Pedro Itzican, confirmation was made of the various

stages of the disease found for about 100 children. Also, notation was made of trace minerals in their blood/urine. However, no numerical values were given to indicate whether any were above health safety limits.

While the villagers have yet to be directly told of the results after more than two years of research, the University has suggested a few possible causes to the newspapers. They list among their discoveries (1) poor nutrition, (2) kitchen cooking fire smoke, (3) parasites from animals about the homes, and (4) perhaps agricultural pesticides. The existence of EVERY ONE of these possible conditions is to be found in all of the 40+ villages and in the homes of the 330,000 villagers about the lake. For centuries the conditions of the poor in these villages have included: very little arable land due to the steep mountains coming down the lake, primitive roads, and frequent unemployment in excess of 50%. Poor nutrition, cooking smoke, and animal parasites have been with these people for ages, but seniors in the village maintain kidney disease is something that was seldom seen 50-80 years ago. As to the can of pesticides found in a home, the high cost of such an item for these people makes it quite rare.

I offered to share with the lead investigator from the University a folder that I had prepared for him with the mineral tests for a dozen village wells where arsenic and nitrogen ammonia levels far exceeded safe levels. He told me that the government had assured him the water was safe and thus he would not take the folder of data prepared for him. After the COVID-19 virus is past, the elements of this paper will be shared with each of the villages via briefings in their plazas. In the meantime, since my visa is about to run out, I will be offering copies of this presentation in Spanish to be read to the elders by their teenage children. While prevalence of this disease is greatest in the villages of Municipio Poncitlan (population 50,000), it is also common in Chapala.

The source for my understanding the possible causes for childhood kidney disease, after much searching on the Internet, is based upon house to house discussions with: (1) families who have or have had a child with kidney disease, (2) families not affected, and (3) comments from informed neighbors. The possible causes presented next are believed to be most important. At this point I do not know how important each cause may be as compared to the next. The following order of causes is believed to be the most significant from what we know today. Again, I note that in general villagers believe childhood kidney disease may not have existed 50-80 years ago. What changes have come to these village during that time?

- 1) Mothers feeding infants and children cola drinks instead of milk. Such drinks are 400 times more acidic than milk and they are made with phosphoric acid. These highly acidic drinks and phosphorous can be very harmful on undeveloped kidneys in very little time. Refrigerated milk may not reach distant and poor villages, but cola drinks seem deliverable everywhere in the world via big money. The easy availability of cola drinks has made it a staple of the village diet. The cola drink was introduced in 1886 in the USA as a health tonic. By 1929 its cocaine was removed. Cola may have

reached some urban areas in Mexico at the turn of the century (1898), but its arrival in remote, poor villages did not happen until after WWII (1945).

- 2) Water from deep wells drilled in villages located near heated volcanic rock next to lakeside villages may have high levels of arsenic (three times the safe limit) and nitrogen ammonia (five times the safe limit) and at times these wells may have other heavy metals. The impact of excessive heavy metals on kidneys is very serious. Like the cola drinks' arrival in the villages, it is understood that government-drilled wells in the villages began in perhaps the past 60-70 years. Before the government wells were drilled, some villages were settled next to natural springs in the mountains. However, the majority of lakeside villages were settled next to the lake where water was immediately available. In turn, before roads were developed the lake was the way to reach other villages. Today there are still poor families beyond village water pipelines who continue to take their water from the lake. To this day most fishermen, once 100-200 meters from shore, drink the lake water.
- 3) Nutrition can be quite poor in remote villages where land to grow a variety of desirable fruits and vegetables is scarce along the steep slopes of the mountains. More is needed in the diet than simply corn, beans and chayote. Seeds to grow a wider variety of vegetables and fruits are a must. Nutritional education is needed to improve the diet and inspire a perceived need for a greater variety of fruits and vegetables.
- 4) Close cousin marriages face double the risk for birth defects in villages. Most of the villages where kidney disease is most common are the product of the Mexican Revolution (1910-1920) in that the promise of the war was land for the poor. Finally by 1934, large haciendas began to be broken up and portions of land were offered to villages to keep in common (ejido land). Often those that left their homes to move to these new land areas might consist of only 5-10 families. Over the past 80 years the search for a mate often led to close cousin marriages.
- 5) Parents who use illicit drugs prior to a child's birth may bear children who are at higher risk for defects. It is believed that the risk of taking illicit drugs during the pregnancy is far higher than at the time of conception. Jalisco State is one of the top five for drug use. The percentage of drug use in Mexico: cocaine—7%, marijuana—12%, and amphetamines—2%.

The lifestyle causes noted above, especially the first three, often damage the internal portions of the kidneys, especially the waste-filtering elements (1 million nephrons/kidney). The topic of damage mechanisms is very complex even for general medical doctors. The best that can be said about lifestyle causes is that the more they are avoided, the better chance a child will not face the risk of kidney disease and death, most often before age 15.

**The second half of causes** for childhood kidney disease is quite unlike the lifestyle choices listed above and also quite different than for adults. These causes are even

less known to the public than the first half. This may be because a very small portion of the international medical community, whose publications are seldom available to the public on the internet, know about them. These causes are defined as “congenital,” meaning they are present at the time of birth and the ailment relating to the kidneys is produced by a defective gene that has been inherited. This type of defect often involves the blood vessels leading into the kidneys or the tubes (ureters) leaving the kidneys going to the bladder. Persons with congenital kidney disease may live with a slower progression of the disease to age 20 or even age 30. By comparison, those with lifestyle causes noted above, frequently pass away between ages 5 to 15. Imaging of the urinary system may be the preferred means of testing for inherited defects, while blood tests may be secondary. We just do not know at this point which inherited defects may be found by testing blood and urine. In developed nations, infants are commonly imaged at birth, thus making it possible to discover and often surgically repair many congenital defects. In Japan every neonate is tested and observed defects surgically corrected.

Given that this 2<sup>nd</sup> half of causes is related to ancestors, it is logical that descendants from ancestors with a defective gene are at higher risk than the general population. Thus, testing all known descendants of those adults known to have had kidney disease should discover a greater number of children with the disease than testing all the children from Chapala to San Pedro Itzican and its nearby sub villages. How do we identify genetically-flawed ancestors and then their descendants? A good place to start is to focus on surnames in common possessed by the most children who have died of the disease in the past 10 years, and those now known to have it. Perhaps we may start by identifying the five most frequent surnames and then identify the ancestors back 3-5 generations for those children. For example, one common surname in families with the disease in the Municipio Poncitlan is Baltazar. In a single month it may be possible with a few volunteers who speak Spanish to initiate a study of just this one surname, beginning with my list of those families today who have or had a child with this disease. If we can prove this approach is fruitful, then we can judge it worthy for the study of other prominent surnames. In turn, a paper set for publication could have far-reaching impact. Any volunteers willing to assist in finding these key ancestors would be most welcomed.

### **Testing Challenges**

How might we test the possible 18,000 children in the villages along the northeast shore of the lake in order to find those 3,000 suspected of being yet in the early three stages of disease where no visual signs may exist? In 2018 our hope was to commence testing via a low-cost urinalysis dip stick test. Two years ago we had had a team of volunteer foreigners, which included nurses from the area about Ajijic, to conduct urinalysis tests of 800 children. These tests were funded by donations by that same foreign community as well as by some persons in the USA and Canada. What we found was that this type urinalysis dipstick test (Roche 10) was not sensitive enough to identify kidney disease in its first three stages. While the dipstick was able to check for nine other possible

ailments in a minute, in the case of kidney disease by sensing protein in the urine, it could only identify those children already known to be in Stages 4 and 5. Thus we concluded that of the possible 3,000 children with this disease we would not be able to detect the unknown 2700 children who may be at Stages 1, 2, and 3, just the 300 at Stages 4 & 5. In the past year we have searched for an alternate urinalysis test with a similar low-cost dipstick that could identify children in the earlier three stages of the disease. So far we have been unable to find such a low-cost test. Be assured we will continue the search. Ironically, veterinarians have an approved urinalysis dipstick test capable of detecting all 5 stages of kidney disease in animals! As of now, we believe it will require a blood test to detect kidney disease at any of its 5 stages. The cost of such tests (Creatinine & BUN—blood urine nitrogen) may be 30-50 times more expensive than the urinalysis dipstick. Imagine a possible total lab cost of as much as 20 million pesos (\$900,000 USD) if we attempted to test all 18,000 children in the region. It would be much more if we could not call on volunteer medical personnel in our community. Further, as noted above, for those children with kidney disease related to congenital defects, it is not known if they may be discovered via blood tests but rather require detection by imaging methods (sonogram, x-rays, CAT/MRI scans). Hopefully, a medical doctor who has this answer may contact me.

### **Medical Doctors for Childhood Kidney Disease**

Doctors that are specially trained in kidney disease are called Nephrologists. Specifically about children, the book *Pediatric Nephrology* (2004), estimated that there were but 70 pediatric nephrologists in Mexico. To update to 2020, let's assume these specialists increased 16% as world population went from 6.4 to 7.4 billion. If so, there might now be in Mexico a total of 81 kidney doctors for children. Of Mexico's 129 million population, perhaps 36 million are children. If so, that suggests one kidney specialist for each 444,000 children. Note that the Latin American Association of Pediatric Nephrologists has only 500 members. That is, for 692 million people in Latin America, with perhaps 200 million children, there would be one pediatric nephrologist for each 400,000 children. As of February 2019, there were 1196 board certified Nephrologists in Mexico. Of these, 976 (82%) treated adults and 220 (18%) were pediatric nephrologists, thus one such doctor for each 164,000 children. Most medically trained professionals assigned to a rural village clinic are recently graduated medical students doing their year of public service. In Mexico it is understood that there is only one such doctor of that specialty for each 86,000 people.

As might be expected, these very scarce Nephrologists are primarily associated with hospitals in very large cities like Mexico City and Guadalajara. As to training Nephrologists, 46% of adult and 67% of pediatric programs are in Mexico City. Graduates are seeking positions in capital cities, and some choose to go into private practice, research, academia, or the pharmaceutical industry. As an example, 90.8% of board-certified Nephrologists in Jalisco, the second largest Mexican state, are in the capital city of Guadalajara. Further, the overwhelming experience of these doctors is in treating adult patients at Stages 4 and 5 of kidney disease. How about the opportunity

to secure an appointment with such scarce doctors? Specialist doctors in Mexico on average conduct two operations and have two office visits per day. Even in the USA, sadly it is normal for Nephrologists to begin treating kidney disease patients only once they have reached the advanced end of Stage 3. For adults, the persons Nephrologists treat most, the causes for the disease are quite different from the causes found with children. In general, adults with kidney disease are advanced in age, often overweight or diabetic, and have high blood pressure. Children, of course, seldom have any of these problems. The volcanic island of Taiwan, near to China, is the #1 site for kidney disease in the world. The #2 site in the world is right here in Jalisco, near the cluster of volcanoes on the northeast shore of Lake Chapala. The area of focus of kidney disease in Municipio Poncitlan has 19 of the 20 inactive volcanoes between Chapala and the east end of the lake. Thus, it is believed that one of the primary causes of this disease can be linked to the very high levels of arsenic and nitrogen ammonia in the hot to boiling water produced by wells that have been drilled into these volcanoes.

### **Treatments**

*Dialysis*—2 methods: Type 1—a machine is used to remove blood from the body and filter out the wastes about 3 times per week (\$1000/week to more than \$10,000 for out-of-network clinics in the USA). Type 2—is an at-home method whereby a special fluid is slowly passed through a tube inserted into a person’s abdominal cavity, an open space surrounding the body’s key organs. This fluid over time draws out the wastes that would normally be filtered out by the kidneys and then this fluid exits the body by another tube.

*Transplantation*—the chance to receive a donated kidney in this culture is rare, about 100/year for the entire 130 million population of Mexico. At a cost of \$170,000 in the US (3.4 million pesos in Mexico), it is beyond the reach of rural poor families earning perhaps 50,000 pesos/year income (\$2500 USD), less than 1% the cost. This would equal 136 years of family income to pay for a single transplant. Recall Taiwan is the #1 site for kidney disease. Annual income there is about \$25,000, thus ten times more than that of a poor family in Mexico. What is Taiwan’s choice? Some there, when needing a kidney transplant, go to mainland China and buy one! Yes, if you are healthy, you can live with just one kidney.

### **What Actions Can Parents Take Right Now?**

It was my intention in April 2020 to present in the plazas of 8 to 10 villages all that I knew about childhood kidney disease. Unfortunately, the arrival of the COVID-19, which led to the shutdown of travel into the villages, placed that project on hold. No strategy to address the problem is more important than parental education. Parents have it within their power to lessen the devastation of this disease by changing several ingrained habits and traditions. This is what they need to know.

1. **Soda Drinks** – Do not permit children under age 6 to drink any soda. Even the less dangerous non-cola drinks made from citric acid (like lemon juice), are 200-300 times more acidic than milk. Cola drinks are not only 400 times more acidic than milk but they are made from phosphoric acid which can be very difficult for infants and youth to process with their immature kidneys.
2. **Well Water**—While well water is good in most of Mexico, in regions with volcanic rock, especially heated rock, there is a high risk such hot water, some even boiling, will dissolve out of the rock various heavy metals such as arsenic, up to three times the safe limit at certain lakeside villages. Additionally, there is the contamination of wells due to hundreds of years of human waste products in village back yards being carried downward into the earth via annual rainfall to the water table. In wells drilled downslope from these villages, the water from such wells often contains very high levels of nitrogen ammonia, up to five times the safe limit. Extremely overpriced bottled water sold by international beverage companies costs about 8000 pesos/family of 5/year. Bottled water can be a solution for only the richest of families in rural villages where employment may be less than 50% and those with a job earn less than 200 pesos/day. Families that cannot afford bottled water are advised to seek (1) lower risk spring water as it comes directly out of a nearby mountain, or (2) water from the lake at a point 100m or more from the shore where it is rather clear. Pouring such water first through several layers of clean cloth or through a barrel of clean sand will make it clearer by removing the tiny bits of soil to which 90% of bacteria may be attached. Then, to remove any bacteria, the user should add 2 drops of common household laundry bleach (Clorox, 5.25% chlorine) to each liter of such water to be consumed, then allow that water to set for 15 minutes. It is incorrect to fear chlorine in such small amounts. Note that the stomach creates chlorine (hydrochloric acid) to make possible the digestion of food. Our body normally supplies its need for chlorine from the salt we eat. Chlorine at normal water treatment levels is not a problem for one's health. ANY edible substance can be a poison to people at some high dose! Even pure water may be, as shown in ill-conceived contests that cause death if drunk at the rate of 4-6 liters in an hour, as seen in the past on public media.
3. **Diet**—Villagers need to identify the great array of fruits and vegetables that flourish in the lakeside climate that averages 70 degrees every day of the year. Among these are apples, cranberries, grapes, pineapples, strawberries, cauliflower, onions, peppers, radishes, summer squash and lettuce. The family diet may also consider bread, corn, rice cereals, cream of wheat or oats cereal, unsalted popcorn, and some lemonade. They should try to reduce potassium, phosphorous and sodium. Then one must encourage the poor to grow and consume from this expanded list. They may begin with some seeds, instructions, and fertilizer to cultivate more varied vegetables. As to protein, the lake is a stone's throw from most village homes. Catching fish or growing them in floating cages, as I demonstrated in the past near Mezcala Island, is viable. Raising chickens is another possibility. Few Mexicans are inclined to raise

rabbits for eating, but the conversion of feed to meat for rabbits, like chickens, is very good. Raising pigs may require double the amount of feed, and raising cattle requires four times the feed to gain a kilo of meat.

4. **Close Cousin Marriages** – In the USA, all are not in agreement that such marriages may lead to congenital defects: vision, hearing, heart/lung problems, cleft palate, sickle cell anemia and mental handicaps. In the USA there are states where such marriages are totally acceptable and there are states where such marriages are clearly against the law. Certain studies, however, agree that the risk of defects due to close cousin marriages doubles what is normal. The normal rate of birth defects worldwide is often quoted as being near 3%. We cannot determine out of the 3,000 children suspected of having kidney disease, with an expected 50% being related to an inherited gene condition type of kidney disease, what added number may be due to close cousin marriages. What seems most clear is that we must consider that 1500 of the expected 3000 cases may be due to congenital defects and the rest related to lifestyle. Compared to the risk of drinking cola drinks, drinking well water with heavy metals, and having poor nutrition, the close cousin marriage effect may fortunately be small. On the other hand, any risk that can be eliminated may warrant serious attention. In wealthy nations, genetic screening is recommended before such couples may marry.
5. **Drug Usage by Parents**—Research on this topic is far from conclusive. In general, at the time of conception if a male is on illicit drugs, the conception may fail. By contrast, the woman's egg may not be affected even if she is a user of illicit drugs at the time of conception. However, during pregnancy it is most serious if the mother uses illicit drugs. In general, that effect is more likely be that the baby miscarries versus being born with a birth defect. If born, the most likely effect on the child may be experiencing slower learning.

### **Is There a Cure for Kidney Disease?**

For many decades most doctors believed there is no cure for kidney disease, only treatments to address symptoms. However, today there may be credible non-pharmaceutical means for treating this disease. These means are most often linked to herbs and are frequently used in Asia where kidney disease is more prevalent than in the West. Among the herbs suggested by some are: St. John's Wort, echinacea, ginkgo, garlic, ginseng, ginger, and blue cohosh. Thus, there appears to be hope via diet that may include herbs to possibly slow down or even stop the advance of kidney disease if applied during the initial three stages of the disease. While I can recommend helpful foods, I of course cannot recommend any of these herbs to villagers. Yet, for highly educated foreigners at lakeside who are inclined to search the WEB, I suggest considering one may find something that rings right for them. I personally have not tried any herbs, but I am open to being convinced some may help. What I do for my Stage 3 kidney

disease is to daily take a  $\frac{1}{4}$  of a teaspoon of baking soda. As we age our pancreas may slow down in its normal production of this compound, making the body more acidic. A \$0.69 box may last a year.

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