



# Hemodialysis access in Guatemalan children: a story of global health and the power of philanthropy

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## Introduction

It is well appreciated that vascular access is the Achilles heel to successful hemodialysis. This is particularly true in pediatric dialysis, where the difficulties in establishing good vascular access are exacerbated by the small patient size and the limited number of surgeons who place arteriovenous fistulas (AVF) in children. We therefore read with great interest the study by Jennings et al., which reports on the success of a collaborative philanthropic effort between pediatric nephrologists and surgeons in Guatemala and the USA to establish a pediatric autogenous vascular access teaching program to place AVF in children on hemodialysis in Guatemala [1]. The program was hugely successful with 153 AVF procedures completed over an 8-year period. We thought that it would be of interest to the pediatric nephrology community to provide more background on how this international collaboration developed and explore what lessons could be applied to improve global health in moderate- to low-resource areas and even in high-resource areas such as the USA and Europe.

## Demographics of pediatric dialysis access

In the USA, the overall distribution of treatment modality in pediatric patients with kidney failure aged 0–17 years is estimated to be 43% for hemodialysis, 34% for peritoneal dialysis, and 23% for kidney transplant [2]. The 2006 annual report of the North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS) showed that among pediatric patients receiving hemodialysis, most (78.9%) of the patients have a central venous catheter (CVC), 12.3% have an AVF, and 8.5% have an arteriovenous graft (AVG) [3]. The National Kidney Foundation Dialysis Outcomes Quality Initiative (KDOQI) recommends that children obtain permanent vascular access if they are to remain on hemodialysis for longer than 1 year when peritoneal dialysis (PD) or kidney transplantation is not available [4]. However, the use of CVC over AVF remains common in the USA for various reasons, such as patient discomfort with fistula punctures, lack of dedicated vascular access services with pediatric surgical expertise, and local pediatric transplant allocation policies resulting in short transplant wait times [5].

According to the 2022 annual report by the USA Renal Data Systems (USRDS), the estimated adjusted rate of incidence of kidney failure in the pediatric population aged 0–17 years was 12 cases per million age-related population (pmp) in 2020 [2]. Similar statistics do not exist for pediatric kidney failure in Guatemala: the estimated incidence in patients aged 0–20 years in 2008–2012 based on a registry at the only pediatric center in Guatemala is 4.6 cases pmp [6]. However, since many patients have limited access to pediatric nephrology care and to timely referral and diagnosis, the true incidence is likely much higher [7].

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## Origins of the US and Guatemala pediatric nephrology collaboration

The collaboration between the USA and Guatemala began when pediatric nephrologist, Dr. Richard Siegler, created the Utah–Guatemala Sister Chapter Project through his role as president of the local Utah chapter of the American Academy of Pediatrics (AAP) in the late 1980s [8]. Through this initiative, Dr. Randall Lou-Meda, senior author of the above manuscript, rotated in pediatric nephrology in Utah and subsequently completed his fellowship training in pediatric nephrology at the University of Utah under the tutelage of Dr. Siegler. He returned to Guatemala and founded the Foundation for Children with Kidney Disease (FUNDANIER) in 2003 to provide the first and only comprehensive pediatric nephrology and dialysis program in Guatemala (Table 1) [6]. When Dr. Lou-Meda began practicing in Guatemala, children with kidney failure presenting with uremic symptoms were having acute hemodialysis catheters placed in the subclavian vein to initiate dialysis rather than cuffed and tunneled dialysis catheters placed in an internal jugular vein, as there were no pediatric dialysis centers experienced to do so. This contributed to high morbidity and mortality [9]. In 2007, Dr. Lou-Meda contacted Bridge of Life (BOL), an independent, non-profit charity started by DaVita in 2006, to expand dialysis access and treatment to areas with limited

resources. BOL donated equipment and dialysis machines to FUNDANIER to create the first pediatric dialysis program with a pediatric hemodialysis unit. Dr. Siegler and his wife, Karen, supported the dialysis program financially. In 2010, FUNDANIER signed an agreement with the Ministry of Health to invest in and expand the program and its infrastructure, by prioritizing funds for construction, equipment, and medications [10]. With this support, they were able to build the country's first pediatric kidney center, housing a dialysis unit named after Richard and Karen Siegler that is completely free of charge to the patients [6].

Until recently, children in Guatemala with kidney failure on dialysis mostly received living donor transplants [11]. Thus, finding stable and more permanent dialysis access was critical to reducing morbidity and mortality. Peritoneal dialysis, specifically continuous ambulatory peritoneal dialysis (CAPD), is the most prevalent dialysis modality as families often must travel an average of 8 h from all over Guatemala to receive care at FUNDANIER [12]. Children needing hemodialysis were spending years on dialysis and requiring multiple dialysis catheters, again resulting in increased morbidity and mortality [9]. A need for a more stable vascular access with AVFs was crucial.

BOL had already established a program to provide training to local surgeons and nephrologists to place vascular access for patients in Jamaica under the leadership of Dr. William C Jennings, a vascular surgeon at

**Table 1** Timeline of US and Guatemalan pediatric nephrology collaboration

Year	Event
1980	Dr. Richard Siegler, president of the Utah chapter of the American Academy of Pediatrics, initiated the exchange of pediatric residents between Guatemala and Utah in the USA
1998	Dr. Randall Lou Meda received the ISN International Fellowship Training Award for studying pediatric nephrology at the University of Utah
2000	Two beds are reserved for Nephrology in the Specialties Service of the Pediatric Department of Roosevelt Hospital in Guatemala
2003	The Foundation for Children with Kidney Disease (FUNDANIER) is established
2004	Richard and Karen Siegler are named benefactors of FUNDANIER
2007	The first pediatric hemodialysis unit was created in Guatemala with the support of Bridge of Life (BOL)
2008	The first pediatric transplant at Roosevelt Hospital was performed
2009	FUNDANIER and USAC (Nacional University of San Carlos) create a fellowship program in pediatric nephrology
2010	The collaboration agreement between the Ministry of Public Health and Social Assistance (MSPAS) and FUNDANIER is signed, allowing all children to receive treatment for kidney disease
2011	The first level of the nephrology, hypertension, dialysis, and transplant service of the Pediatrics Department of Roosevelt Hospital and FUNDANIER is built
2015	The first medical mission for arterio-venous fistula construction in children took place
2016	The second level of the nephrology, hypertension, dialysis, and transplant service is built
2018	First IPNA Sister Center: FUNDANIER — University of Puerto Rico
2021	FUNDANIER is named Regional Training Center by the ISN
2022	The third level of the nephrology, hypertension, dialysis, and transplant service is built
2023	The Kidney Disease Research Center and Cadaveric Transplant Coordination Center of FUNDANIER and Roosevelt Hospital were created

the University of Oklahoma, and the first author of the manuscript. Dr. Lou-Meda's team reached out to BOL, and they expanded their collaboration to fund the first medical mission for creating AVFs in pediatric patients in Guatemala. Since then, Dr. Jennings has created an extraordinarily successful program where US- and European-based vascular surgeons travel to Guatemala to work with and train local surgeons in creating AVFs.

## Study findings

The study is a retrospective review of a total of 153 hemodialysis vascular access operations performed at the Roosevelt Hospital in Guatemala City during an 8-year period. When the program was initiated, most of the children evaluated at Roosevelt Hospital for an AVF had non-cuffed and non-tunneled temporary dialysis catheters. Others had failed AVFs that were created elsewhere, or access complications such as aneurysms, high access flow, or arm edema. AVF procedures were completed in 139 new patients with a mean age of 13.6 years. Most AVFs were created as direct fistulas that took roughly 4 to 5 weeks to mature. A limited number of staged basilic vein transposition/elevation AVFs required a second procedure. BOL surgeons worked with Guatemalan fellowship-trained pediatric surgeons and pediatric nephrologists to create a standardized protocol to evaluate these patients for vascular access. This included a preoperative physical examination with duplex vascular ultrasound (US) and a discussion about which vessels will be used to create a fistula. The most common type of AVFs created were radial or ulnar artery-based direct AVFs, established in 71.9% of the study population. This is in line with the strategy of maximizing the options for future autogenous access by creating fistulas at the wrist, given the potential need for lifelong dialysis access in pediatric patients. Cumulative patency rates were excellent at 84% and 81% at 12 and 24 months, respectively. Despite the relatively young mean age (13.6 years) of the study population, the majority (73%) were dialyzed in adult units. This underscores the unmet need for pediatric dialysis in Guatemala. Mortality was high; overall patient survival was 84% and 67% at 12 and 24 months, respectively, but no deaths were related to AVF access. Although the mortality was high compared to high-resource countries, such as the US and Europe, it represents a marked decrease in mortality for a resource-poor country such as Guatemala, where renal transplantation is not readily available and where families have to terminate dialysis because they do not have the resources to continue it [6].

## Generalizability and future application

Prior to this international collaborative effort, pediatric patients on hemodialysis in Guatemala had non-cuffed and non-tunneled temporary dialysis catheters placed in the subclavian vein without ultrasound guidance, placing these children at risk for subclavian stenosis [9]. It is possible that this situation is the same for pediatric patients initiating hemodialysis in other low-resource countries. With the success of the vascular access program, the BOL surgical team and the Guatemalan surgeons within FUNDANIER have greatly increased stable and safe permanent vascular access in pediatric and adolescent patients with both AVFs and cuffed/tunneled central venous dialysis catheters placed in the internal jugular vein under ultrasound guidance. During these missions, the BOL team created a progressive curriculum to increase the independence of Guatemalan surgeons [9].

While the technical success of this program rivals or exceeds that of high-resource countries, where CVCs remain the primary vascular access for dialysis, the mortality in this study is high compared to the US and Europe. However, it does represent a marked decrease in mortality for Guatemala [6]. Patient survival has improved through the concerted efforts of Dr. Lou-Meda's team and the collaboration between BOL and FUNDANIER.

With this success, Dr. Lou-Meda's team was able to demonstrate to the Guatemalan government the importance and feasibility of providing comprehensive care for the children of Guatemala with kidney failure. Since then, the Guatemalan government has provided more funding to increase resources and access for pediatric patients with kidney failure and chronic kidney disease (CKD) [6]. FUNDANIER no longer relies on outside philanthropies for donated surgical equipment and dialysis machines and is now a self-sufficient program. The success with pediatric patients has inspired the expansion of their model into the adult population. FUNDANIER was selected as one of the regional ISN training centers in pediatric nephrology [13]. They are looking to grow access and create a similar model in neighboring Central American countries, so in 2018, the International Pediatric Nephrology Association (IPNA) created the first Sister Renal Center Program between FUNDANIER and the University of Puerto Rico. Dr. Melvin Bonilla-Félix, a nephrologist in Puerto Rico, has been instrumental in continuing the collaboration and expanding the model to the whole region [13].

## Conclusion

This study demonstrates the power of philanthropy and how good deeds can have far-reaching ripple effects. The initial investment of Dr. Richard Siegler in the 1980s has

compounded to transform kidney disease care for the children of Guatemala and can serve as a template to improve care for both children and adults worldwide. About half of the global population lives in low and middle-income countries similar to Guatemala, so the experience of FUNDANIER in Guatemala is broadly applicable to the rest of the world. Countries like the USA and Europe can and should assist other countries to better care for children with kidney disease. The power of one individual can inspire change and impact health for generations of patients.

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