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Interview

Dr William Novick (Founder and Medical Director of International Children's Heart Foundation), speaks to associate editor Dr Tom R. Karl

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William Novick's name is synonymous with humanitarian initiatives in paediatric cardiac surgery. As the founder and director of the International Children's Heart Foundation he has reached out to children and families in some 28 countries over the past three decades. International Children's Heart Foundation now has over 7300 surgical procedures in the organisational database, and 16 former host units are operating autonomously or with only minimal technical assistance. I spoke with Bill on 5 September, 2014, and had a unique opportunity to hear the viewpoint of the driving force behind one of the most successful teams working in this realm.

Interview

Tom: Bill, how did your interest in humanitarian paediatric cardiac surgery begin?

Bill: As a resident in cardiac surgery at the University of Alabama I saw patients from all over the world. Patients (with and without money) came to Alabama to be operated by John (Kirklin) or Al (Pacifico). Those who came from industrialised countries usually had received appropriate palliations and were in good shape, while those who came from developing countries were frequently older, had no previous operations, were frequently misdiagnosed, and generally riddled with the complications of long-standing congenital heart disease.

A 12-year-old child came from Nigeria for Al to correct her supposed tetralogy of Fallot, but she actually had a ventricular septal defect/pulmonary atresia with major aortopulmonary collaterals. She had no native pulmonary arteries, and three of her collaterals had no obstruction. Al unifocalised her right lung and did a shunt. She recovered well, but at discharge, when I told the family that I was sorry we could not provide a corrective operation, the mother told me we had given them a miracle and they were profoundly grateful. I left the room in tears and was haunted for 6 straight weeks with nightmares about trying to save this child. Nestor Sandoval and Renato Bresciani were training in Birmingham for congenital cardiac surgery so they could return to Bogota and improve their respective programmes. They were both close friends and recognised that something was bothering me. Just before they left for Bogota, they took me out for beers and asked me what the problem was. I told them about the nightmares. Their solution was to come to Bogota, help them with their programmes, and see if that helped me. The nightmares never returned after that night and Al told me I could go when he felt I was ready, and 4 months later I was on a jet headed to Bogota. I spent a week with each of them and returned and told Al I wanted to commit part of my career to helping children in developing countries.

Tom: What was your vision for your programme in the early days, and how has this evolved?

Bill: At first, when I started practice in Orlando, I brought children in for surgery at Arnold Palmer Hospital. News of someone giving away surgery for congenital heart disease hit the media. Requests started coming from everywhere, but I was limited to one charity case per month. After operating upon three kids from Croatia and hearing the same stories

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from the mothers, I asked the paediatrician who was sending the children whether he thought that some hospital in Croatia would like us to come to them to do several operations at one time. I realised that unless I could raise very significant sums of money to bring more children to the USA, I would not be helping many children in my home institution. So my concept was to put a team together to go abroad and operate on more kids in 2 weeks than we could do in Orlando in a year. The first trip to Croatia we operated on 14 kids. Thirteen survived, and the Croatians were ecstatic, asking me before the end of the trip when could we return. I knew then that the model was trips abroad. We did the first Sennings, Fontans, and Rastellis ever done in that country on the first trip, and the Croatian hosts were speechless!

Tom: What have been the most significant obstacles in meeting the goals of your programme?

Bill: Our programme goals have always been to provide more children with surgery/interventions and more health-care professionals with on-site and off-site education in an effort to build a sustainable paediatric cardiac service programme locally. The obstacles to building an independent sustainable paediatric cardiac programme are numerous, but most can be overcome with motivated people locally, as well as hospital and Ministry level support, both philosophically and financially. Adequate commitment/financing by the visiting partner and a satisfactory local infrastructure in which to carry out paediatric cardiac services are also essential. Some specific problems that have resulted in the termination of our programme at a few sites include local personnel using International Children's Heart Foundation to charge families for surgery/evaluations, a local team that is absolutely unteachable but politically connected and in control of the hospital position, a change in the hospital administration with a new incoming political party, civil disruption (as during the Egyptian uprising against Mubarak), and global political issues. Our programme in Serbia is an example. We were there the night that NATO bombing started, performing an arterial switch operation for a 10-day-old neonate. The child survived but our programme did not. We also experienced a revolution during the time of our team's programme. We were in Benghazi when the most recent fighting broke out, stranded when the airport closed, and we eventually drove east 3 hours to get to a small regional airport to fly to Tripoli to leave Libya.

Tom: Critics of short-term humanitarian missions, some highly placed in our specialty, have said that unless something permanent is put in place from the start it is just "medical tourism" (sic). How would you respond to that sort of criticism?

Bill: Critics don't know what they are talking about. To include every mission trip programme in some grandiose uneducated global statement is really ludicrous. I am not sure about everyone who is involved in such programmes, but I do know quite a few! Without a doubt, the goal of such programmes is to build an independently functional and sustainable paediatric cardiac service. Are there groups that only fly in to operate on children, look good to donors, and pat themselves on their backs? Sure there are, just as there are "paediatric cardiac surgery programmes" in the USA doing well under 100 cases yearly with sub-optimal results. Does that mean that every low-volume programme in the US is bad? No, just look at the Society of Thoracic Surgeons Congenital Heart Surgery Database. We have been doing this for 21 years; we have programmes that have graduated in Belarus (1), China (3), Colombia (2), Croatia (1), Egypt (1), India (1), Iraq (1), Nicaragua (1), Pakistan (1), Peru (2), Russia (1), Serbia (1), Ukraine (1), and we are nearing completion of independent programmes in Dominican Republic, Honduras, and a second in Ukraine. What do critics say to this? Our programme involves multiple visits to a given host institution (two to six) per year for 3–8 years; not exactly tourism is it? We have had our critics since we started, and I am sure we will continue to have them after this interview is published, but we will continue to build programmes around the world, while others simply refer to the problem and suggest that the kids come to them for absurd amounts of money.

Tom: What has set International Children's Heart Foundation apart from some other programmes is the establishment of numerous self-sufficient cardiac surgical units around the world, as you have just outlined, some now sending personnel to assist with International Children's Heart Foundation missions in less fortunate areas. Can you comment on this sort of outcome and what it means to you?

Bill: Several years ago I recognised that in order to create a sense of achievement and progress, local programmes would have to perform surgery in our absence and maintain a standard higher than before our programme stated. We set benchmarks for performance, based upon mortality results that had to be achieved before advancing to more complex procedures or smaller children. A perfect example of this is our programme in Belarus. The local team wanted to start a hypoplastic left heart syndrome programme in 2005, and we told them we would do that when their

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independent arterial switch results reached a 90% survival level. We started the hypoplastic left heart syndrome programme in 2006. Last year, the team there had a 75% survival level in stage 1 hypoplastic left heart syndrome operations, with an overall survival of 98%. In some of our more outstanding programmes, we have incorporated the local team into International Children's Heart Foundation visiting teams at other sites. This gives those team members a view they otherwise would not have. In doing this, we continue our educational efforts, expose a host team to the difficulties of being the visiting team, and as such their grasp of the obstacles we face when we are at their centre is much improved. The result has been that the obstacles in the host centre suddenly disappear, and the host team members can serve as vocal and effective advocates for the programme. That is to say, they are representative of what can be accomplished if everyone focuses on building a programme, so the host team actually come to believe in the process. It has been a win-win-win situation. The new site sees what our programme can do, the old site team members get more education and understand what obstacles we face when visiting them, and the International Children's Heart Foundation gets additional volunteers with whom we have worked with in the past, and whose capabilities we know and understand.

Tom: International Children's Heart Foundation, being a charitable foundation, presumably has its own administrative hierarchy and financial structure that guarantees that the work will continue. How have you managed the business aspects? Is this a partnership with host countries, or a charitable contribution to the people of the country?

Bill: We don't have a single fixed financial structure. We raise all the funds for those countries that are financially desperate, from various individual donors, other foundations, civic groups, and corporate sponsors. Our programmes In Dominican Republic, Haiti, and Ukraine are examples. Those countries that are in better financial states assist in covering the expenses of the Foundation. Some countries cover the expenses in total, (for example, Iraq and Libya). Some countries cover some portion of the expenses, (for example, Russia, Honduras, and Ecuador). We have found that this mixture allows us to serve far more children, establish more programmes, and to provide assistance to far more countries simultaneously than any other groups. As a result of this mixed funding approach, we are serving 10 countries simultaneously this year and have plans to add three more sites in 2015.

Tom: Have you had to turn down countries requesting cardiac surgical assistance?

Bill: We try not to turn anyone down. There are times when we have to delay requests until we find donors and/or required equipment, or have infrastructure built. We have fulfilled both large and small country requests, and at times have run two programs in the same city simultaneously. Lima, Peru, is one such example, where for 2 years we had programmes in both the Children's Hospital and the National Heart Institute. Lima has a population over six million and a multi-level health-care coverage system; so having two programmes in the same city at the same time actually was very beneficial.

Tom: Have any countries denied your team access to their health-care system?

Bill: Yes, back in the late 90s, we were invited to Zimbabwe by a US charity. We worked with the Ministry of Health and Foreign Affairs to validate the trip at the hospital in Harare. On the day of the shipment of supplies and equipment, I arrived in my office to find a fax telling me that we were not welcome because the ministry of health had determined that we were charlatans! Needless to say I cancelled the pickup of the shipment, and we never communicated with them again. However, the US charity that had gotten us involved was furious and they did investigate. We were eventually told that someone high in the ministry of health had determined that if we came they could not get kickbacks for sending kids abroad, and we learnt a valuable lesson from that experience: don't mess with people's money, no matter how corrupt they are.

Tom: You have certainly not shied away from offering assistance in any political hot spots around the globe. Have any other problems arisen for your International Children's Heart Foundation teams consequent to being in the wrong place at the wrong time, so to speak?

Bill: Yes, as mentioned above, we were in Belgrade operating when NATO stated the bombing. We actually witnessed the first two nights of bombing, and were interviewed by CNN from our hotel room on night 2. We were literally taken to the border with Croatia about 30 minutes before the daytime bombing started on the 3rd day of the conflict. No one suffered. The Embassy had tried to get us to leave before the bombing, and some team members did go home, but we had two infants with transposition of great arteries that needed an arterial switch operation, and we did the first early on the day of the bombing. We were literally sewing in the left coronary artery on the second case when the bombs started falling. The year when the Benghazi Airport was closed and

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fighting broke out between the secular and Islamist forces in Benghazi, nights were filled with heavy arms fire. In the days fighter jets would fly low over the hospital, looking for targets. We were in Iraq when ISIS overran Mosul and headed towards Baghdad. We never had any issues in Nasiriyah, which is hundreds of kilometers south of Baghdad. Our teams have continued to go there throughout this crisis. To date, no one has even gotten a scratch. Has the US State Department been unhappy with any of your activities which were in "violation" of their advice? I am not sure they are unhappy, but they are not happy we have ignored their country warnings. We were told not to go to Croatia, we went; we were told not to go to Belgrade, Benghazi, and Nasiriyah, but we went; and in some cases continue to go. I can tell you that Ambassador Jones, the US Ambassador to Libya, actually told us she was proud of us for helping the Libyan children. We were in contact every other day with the Chief Consul. In general, we make our own threat assessments, we have locals who give us information and the internet to look into local situations. Have we made mistakes in our assessments? Yes we have, but only twice in 360 trips, and both times I was the team leader. No one has ever been at serious risk and we have gotten out both times, albeit by strange and exotic routes.

Tom: You have managed to establish some excellent connections with industry (medical equipment suppliers, airlines, etc.). How have you managed this aspect, when there is such intense competition for the charity dollar?

Bill: Early in our programme we were fortunate to be given access to the chief executive officers, chief operational officers, and chief financial officers of a number of medical product/drug manufacturers. At that time (early 1990s), the demand for donated products was not as overwhelming as it is now. Medtronic, Edwards Lifesciences, WL Gore, Sanofi (which no longer exists independently), and Cook were simply fantastic in the early days. We would put in a request and it would be granted, simple as that. Over the years, financial accountability to the internal revenue service, and the mountainous demands for donated product forced almost everyone to set up a request system which regulated product donations. Equipment and instrument companies including Zoll, Philips, Scanlan, Platt/Nesbitt, Spacelabs, and Hewlett-Packard were very generous. Scanlan and Platt/Nesbitt continue to be extremely helpful. Brigid Scanlan Eiynck (Scanlan Instruments) and I stay in touch regularly. Alyson Nesbitt routinely asks us what she can do to help us as well. There are fewer donations than years before, but the companies are now global, and donated product to areas in which they have representatives can damage the livelihood of their local agent. We really don't want to create a problem for the local representatives. We have decreased our requests to fulfil the needs of our team visits as closely as possible, so as not to leave unused products at the end. I think this has helped us to maintain our relationships as well.

Tom: Can you comment on adjustment of operative strategies to meet the local conditions? Is this something that you find necessary in the current era, or can most strategies used "at home" be applied on missions?

Bill: Operative strategies in some regards are similar. We use regional low-flow cerebral perfusion to reconstruct aortic arches. We use modified ultrafiltration routinely. We let our surgeons choose which cardioplegia to use: some use Del Nido solution, some use blood, and some are limited by what is available. However, there are a number of areas in which we use modified operative strategies specifically adapted to the patient population we see abroad. The flap valve fenestrated double-patch technique for kids with ventricular septal defect and pulmonary vascular disease is certainly an example of adjustment of operative strategies. In most industrialised countries and also some second world countries, you have either commercial or homograft valved conduits. We do not have this luxury in most of our host countries. We have presented the use of autologous pericardial and CorMatrix hand-made tri-leaflet valved conduits for right ventricular to pulmonary arterial reconstruction at the Society of Thoracic Surgeons meetings in the past.

Tom: International Children's Heart Foundation has been an early participant in international database and outcome analysis activities. What have been your basic strategies for quality control within your many missions? Realistically, must standards be adjusted for the conditions? How do the teaching aspects and provide experience for the local teams?

Bill: We have kept a database on children we operated on since our first trip to Croatia, and in 2002 when the RACHS-1 model was published we assigned a RACHS class to every child on whom we had operated. It took us 3 months to validate our data with the local data, but in the end we completed the task on over 1700 children. We review our data quarterly, looking for trends, and we do a comprehensive data review yearly. As a result of this approach, we have changed the types of cases accepted in some countries, changed the lead surgeon in some countries, added dedicated ICU nurse clinician/educators to a number of

countries, and adjusted the specific team members on some trips. The end result has been a progressive and significant decrease in our mortality and morbidity over the years.

Standards have to be adjusted for the local conditions, it is as simple as that, yet there are certain standards that must apply no matter where you go. When I say "adjust your standards for local conditions" I am not suggesting you drop your standards. I am talking about overcoming the local deficiency by adjusting how you implement your standards. Let's take blood availability as an example. Many countries cannot provide platelets without 24 hours' notice, but you can set up donors for fresh whole blood to be ready within 45 minutes. Standards for pre-incisional time out period are not to be compromised, but some standards can be modified to local conditions, and we do this all over the world.

Our entire team is dedicated to teaching at the bedside, in the operating room, or the diagnostic laboratories. We apply the concept of graduated mentorship in all specialties. Since we make multiple trips per year to the same site, we are able to assess growth fairly easily and allow the local team more independence on subsequent trips. As you know, showing someone how to perform an arterial switch is not the same as helping him or her to do one, and doing one arterial switch does not make you competent. Nor does taking care of a single ventricular septal defect patient in the ICU. Repetition, graduated mentorship, and review of the situation is critical. In our hands it is a successful way to build local team confidence and capability.

Tom: What special considerations have you had regarding local team credentialing and indemnification in the host country?

Bill: Credentialing is simple, licenses, diplomas, advanced certificates, normal stuff. Indemnification is a bit different. In a number of countries the only responsible person is the International Children's Heart Foundation surgeon, and we strive to have that position indemnified in every country. However, in some countries, the entire team has to be indemnified, and if required we submit the request. Those countries that will not indemnify the team or lead surgeon are ones where we simply do not work. How can you allow a risk of legal proceedings where you are not in complete control of the team and the environment? We don't think you can.

Tom: How do you respond to charity organisations that prefer to bring a few well-selected children to the USA for surgery at a total cost that might cover over one hundred procedures performed locally by a team such as the International Children's Heart Foundation?

Bill: This is really a difficult question to answer and I have wrestled with it for years. If that is the only way a charity will help kids with heart disease, then I am duty bound to tell them that this is a waste of money and lives. If they are doing it as just part of a comprehensive effort to help deserving children, then I understand a bit better. Bringing in deserving children who undergo successful surgery in the US can provide the charity with the opportunity to raise funds for their overseas programmes. There is nothing more compelling than taking a child around town to churches, civic meetings, etc. and showing people what your programme has accomplished and how much more you could do if you took a team abroad, dollars fall out of the sky! There are charity groups who will tell you that the results in the USA are so superior to what you can achieve abroad that providing a child with the "best opportunity" trumps what we can do in Whereverville. I understand this position, but do not support it. The average mortality in the USA for the last 4 years is around 3.5% and our average mortality for the last 4 years is around 7.5%, with last year being a sub 7% year for us. If you think of this from a greater good point of view ethically, then there is no question that spending $150,000 to come to the USA to get a 4% difference in mortality is simply unethical. When you can do three trips and operate on 60 kids and lose four children and have 56 survivors compared to the one survivor they are sponsoring, you see my point. How can the good of the one be more important than the good for 56, I don't see it!

Tom: Bill, from my own experience, the presence of an International Children's Heart Foundation team often brings out some complex and high-risk cases that a local team have been watching for some time. There may be intense pressure to operate cases that are somewhat beyond the resources of a visiting team. This might also include neonatal cases that arise during a visit. What is your ethical position and strategy in this situation?

Bill: We have been asked since our first mission to operate on children that the local team either has not operated on or not performed the required operation successfully in their history. The issue for us is what sort of capacity exists locally for the International Children's Heart Foundation team to carry out this request to operate on children with complex defects. Our position is that we will not operate on children requiring, for example, Norwood-like procedures on the first trip and may not do that at all in the first

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year. The decision rests with the International Children's Heart Foundation and the local team combined, we have turned down a number of children with complex defects in the early phase of a number of programmes. Some programmes and some International Children's Heart Foundation teams are ready for neonates on the first trip. Let me give you some examples. Our Iraq programme was running for just over 2 years before we did our first switch. However, on our first trip to Macedonia, we did a switch and a Senning; both patients did well. On our second trip to Voronezh, Russia we did a Damus–Kaye–Stansel/coarctation repair/atrial septectomy and modified Blalock–Taussig shunt on a 2-month-old, who fortunately did well. We provide neonatal surgery everywhere we go, it is simply a matter of timing, when a place and our team will be ready.

Tom: You have managed a career as a humanitarian as well as an academic surgeon, and I believe that you retain your professorial appointment in Memphis. Most of us would have a difficult time managing this sort of an arrangement, any comment on how that came about in your case?

Bill: I was fortunate to have co-authored a book about our efforts for the children of Croatia, that was placed in the hands of a very wealthy lady in Philadelphia. I had done my general surgical training in Philadelphia. My chief was a long-time friend of this lady and he gave the book to her in hopes she would help the foundation with a donation. The Dean of the University of Tennessee, Hank Herrod, had been a member of the Board of Directors of the International Children's Heart Foundation before he became Dean. He and I were quite close, and just after the book came out he called me to the office. He asked me that day what I wanted to do with my life, and I told him I would love to find a way to work internationally as a full-time job. He chuckled and told me the University of Tennessee could not afford to let me do this full-time. I asked him what it would take to do something like this and his response was for me to find someone, or a combination of people to endow a chair in the university. I called my former chief in Philadelphia told him what I wanted to do with my life and he told me he would speak to our mutual friend, the wealthy lady. A week later a letter came from her with a check for $50,000 and an apology that she could not do more at that time. I called my former chief and told him how happy I was, he told me to write her a letter describing what I really wanted to do with my career, so I did. I received a letter 2 months later in early February of 1999 from her lawyer telling me she would fund the entire chair of three million dollars, if the university would agree to name the chair after my former chief, who had died 1 month previously. The university of course agreed, and the Paul Nemir, Jr, MD, Professorship and Endowment Fund was created. I resigned my position at the local children's hospital 2 years later, and since then have pursued my international career full-time as the Nemir Professor of Surgery and International Child Health. My primary role for University of Tennessee Health Science Center is to introduce medical students to international health care by taking them on surgical mission trips.

Tom: Any other comments regarding the International Children's Heart Foundation or humanitarian missions in general? Maybe the high and low points of your lifetime of work in this discipline?

Bill: It has been a career of mountains and valleys that is for sure. One of the highest and lowest points of my career came in Pakistan when I realised how small we all are in the overall scheme of the world. I had operated on a 2-month-old absolutely emaciated little boy with transposition of great arteries with ventricular septal defect and he did well. Just after the operation the Chief of Pediatric Cardiology came to the unit where I was assessing the child. He told me I was a very lucky man, I said no I was not lucky, the child was lucky. He told me again, "No you are the lucky one, because his grandfather is a former Taliban Muhajaden fighter against America, and I am not sure what would have happened to you If the child had died"! At the end of the trip we had a going away dinner, everyone was invited including parents. When we had finished, the paediatric cardiologist approached me and told me the child's grandfather wanted to speak to me and he would serve as the translator. The old man approached me and started talking immediately. He said that before the operation he hated Americans and had fought against them in Afghanistan. Now, however, he was going back to his village to tell them that he had been wrong, that not all Americans were evil, and that his people should not judge Americans by their government, that we as a people were good people. He told me I had saved his only grandson and he would love me forever for giving him this wonderful gift, then he hugged me. I had tears rolling down my face as I thanked him and walked slowly out of the building for the bus. About 6 weeks later President Bush sent some cruise missiles into Pakistan to try to get Osama Bin Laden, he missed but the village he bombed was only a couple of kilometres from where this child and his family lived. We returned to Pakistan a month later and the Deputy Secretary of Defense for the US was in Rawalpindi at Pakistani general headquarters participating in an Emergency Deployment training session with the Pakistani Army. Our programme was at the Armed Forces Institute of Cardiology, which is just off the grounds of the General Headquarters. The Surgeon

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General of Pakistan was a close friend of mine and he invited me to meet the Secretary. We went, listened to about an hour of discussions about the Emergency Deployment training, and then I was introduced to the Secretary. He congratulated me on our work in Pakistan and asked me what he could do to help us. I was quite specific, "Mr Secretary could you please ask President Bush to quit bombing my children, we are improving the local opinions about Americans and you are coming in right behind us and bombing them, this is not helping"! He looked at me surprised and said "Nice to meet you Dr Novick", turned on his heel and walked out! The whole room was in shock, except for me and the Surgeon General.

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