Stephen L. Gans Distinguished Overseas Lecture
John Sekabira, MD

It is now my pleasure to introduce our Stephen Gans lecture. I thought I would give just a couple of seconds about Stephen Gans. People wonder about the origin of the lectureship. It's named to honor Stephen Gans who is one of the leaders of Pediatric surgery in North America who trained in Chicago with Willis Potts, and was recognized as a pioneer specifically with a number of technical refinements, he was the first pediatric surgeon to use the Hopkins Rod Lens System for endoscopy, something that we all consider just a standard therapy, and in 1973 as long ago as then if you were looking for the origin of how we manage an H type fistula, he described the use of a Fogarty catheter to go across the fistula to identify it. And he was—he pre-saged our passion for minimally invasive surgery by doing laparoscopy in 1973 and reported it in the journal. The Journal of Pediatric Surgery our Bible was his brain child, and he was the driving force behind its creation, although C. Everett Koop was the first editor and Dr. Gans took over as editor in chief in 1977 until his untimely death in 1994 and he also cofounded the seminars in pediatric surgery with J. Grosfeld.

Where does the international element of the lectureship come from? Well, he was an international collaborator around the world and his lectureship is duly named for these relationships, he was the major proponent for the creation of the Pacific Association of Pediatric Surgeons, PAPS as we nickname it, and was its first president in 1969. And he was recognized as a well sought after international speaker. This morning we are fortunate to have John as our Gans lecturer. I've come to know John through my associate Doruk Ozgediz - - who many of you know because of his consistent commitment to the global surgical burden of disease, and - - has had a long-lasting relationship with John through his work in Uganda for close to a decade. This is where John works, and through time Doruk has made me aware of the exemplary work that John has done, and actually listening to the perspective of the Ladd medal and the Ladd, William E. Ladd and the challenges he faced, I will sort of reflect and you will hear what John's challenges are in Uganda. The challenges he has are not necessarily those of learning, education and knowledge, they are really those of resources, so the challenges that William Ladd faced managing Hirschsprung's disease are not unlike the ones Dr. Sekabira is challenged with but rather his difficulty is with the resources. So John received his undergraduate degrees in medical education in Uganda and received his pediatric surgery training in Durban, South Africa. In his country he has been instrumental in establishing research and training programs, and he is currently the president of the Association of Surgeons of Uganda. In the next 30 to 40 minutes, John will share his extraordinary experience and commitment with you. I admire him greatly and look forward to his presentation. Please join me in giving a warm welcome to John as our Gans lecturer.

[applause]

JOHN SEKABIRA, MD: Thank you. I would like to thank the American Academy of Pediatrics in America for offering me this opportunity to give this lecture as an international visitor.
First of all, my outline of the talk will be giving a brief demographic about Uganda, the overview of the current pediatric situation in Uganda, and maybe talk about the future directional developments.

Uganda is a land-locked country in the eastern part of Africa, which is surrounded by the North by Sudan, that is the outline of Sudan on the North and East by Democratic republic of Congo, and the south Rwanda, and the western side is Kenya. As you know, the countries surrounding us have been bedeviled by civil strife, and we get so any patients from these countries, particular South Sudan and the DRC, that is the Democratic Republic of Congo, which contributes a lot to the disease burden of the patients we treat. Uganda itself is a very beautiful country, very green and once was described by Winston Churchill as “The Pearl of Africa” and actually this was real, the country really is very beautiful. It is one of the last places you can see a lot of mountain gorillas, and you can do whitewater rafting on the source of the Nile.

Now going about the demographics of Uganda, I tried to compare it with USA to make some good comparisons. The population is 36 million whereas USA is 319 million, but the population density is far away different. In U.S. is 35 people per square kilometer whereas in Uganda is 182, so the country is very densely populated and life expectancy as you can see our people die still young. And the children - - more than 50% of our population, that is a very high number compared to 19% in the U.S.

And we have one of the fastest growing populations at 3.2%, and when you look at the population pyramid, you can see the population is basically young. Most of the population is children below 15 years whereas in USA is quite different.

Talking about the subject of pediatric surgery in Uganda, we have so many challenges, actually you can summarize those here. We have too many patients and conditions to treat, but that one you can put that as a strength because there is no shortage of patients to treat. And we have too few personnel and surgeons and anesthesiologists and a lot of the resources for pediatric surgery. And there is too little equipment and infrastructure, actually sometimes the equipment is not there so we have to improvise and basically most of the patients present late, so it means that too little can be done. I work in Mulago Hospital, which is teaching hospital affiliated with Makerere University. It has 1,500 beds. It was built in 1962. It is now more than five decades old, but the number of patients is overwhelming, 30,000 deliveries in one year, that is a lot and that means that most of the patients we get come from that delivery room.

The pediatric surgery ward is located in the hospital, and it has an official capacity around 20 beds, but most of the time, more often than that we usually get 60 patients per day on the ward. The surgical outpatient clinic is crowded with more than 80 patients per week and we have long wait lists and backlogs for surgery.

So what about the surgical training pathway? How can someone come a surgeon? You get your undergraduate training for five years, and then you do internship usually for a year then you become a medical officer. For me, after the internship, I was a medical officer for four years. Before you begin in the surgical training post (residency) you have to be a medical officer for more than two years, and then you join the residency program, which
is three years and you write a thesis. That is now where most people get stuck. There are no pathways for specialist (fellowship) training. If you like it you can try to get somewhere -- maybe South Africa, but now because of the demand we try to create our own training pathway, which tries to train pediatric surgeons. So far in this program, one has to train from outside where you can train locally two years and one year abroad so that you get exposure to high quality patient care.

The deficit for pediatric surgeons is enormous, actually in almost all countries in Africa, you find the same picture, I tried to put here the need and the deficit. When you consider Uganda, we have 18 million people who are below 15 years, and you have only 3 pediatric surgeons. And if you consider the recommendation that you are supposed to have 1 pediatric surgeon per 100,000 children you find that the need is 180, and the deficit is 177. When you compare other countries it is similarly the same picture. But in the USA we have similar 6.1 million children and you have 1,250 pediatric surgeons, so the surplus is 640 pediatric surgeons. Actually, I think if you are looking for work, you should come to Uganda! So this has been a concern actually in recent publications about the oversupply of pediatric surgeons here and maintenance of skills. These recent papers discuss the implications in for training and maintenance of competencies, so if you find that in the case of USA it is -- each surgeon can do 18 index cases per year. Those index cases including gastrohisis, anorectal malformation, pull throughs for Hirschsprung, nephroblastoma, and others. Where as in Uganda, considering our disease burden, one surgeon would be almost doing 400 index cases per year. So, we have after realizing all of that, we have training and workforce challenges. We don't have a locoregional specialist training enter. Most of the training opportunities can be found only in South Africa and probably Egypt. We lack of exposure and education in for example laparoscopy and endoscopy. There are also policies in most of the countries which restrict uptake/employment after residency training and this causes a lot of brain drain whereby most of the doctors migrate to other countries.

So in the previous photo I was talking about making teams, which can improve outcomes for the practice of pediatric surgery. Besides pediatric surgeons, we find that only there are only 2.5 pediatric anesthesiologists for the country, I put 2.5, because one is in training. We have very few neonatologists and theater space is so limited, and we don't have neonatal intensive care, or pediatric intensive care. So all of those limitations can compound the outcomes, and the infrastructure and equipment can also be depicted in this. We don't have a dedicated children's hospital and pediatric surgery units are only two in the entire country. One was just started in Mbarara University in Southwestern Uganda. And there is limited theater space, in my hospital, we had only five theater suites for all of the surgical subspecialties, we ended up having 1.5 days in a week, and the neonatal ICU, which is called the special care unit where all newborns are looked after, and this is ill-equipped, and there are no warming facilities and few incubators.

In this picture you can see, I tried to depict what happens in the nursery of our hospital. Those are babies, not relatives we have put together for three in one incubator. Down on the left you can see the syringes. The nurses try to put because we don't have infusion pumps, we put the infusion fluid in syringes and start to give for example, dextrose, when it is needed, and the warming facilities, we put warm water into gloves to try to improvise
warmth during surgery. Sometimes you are faced by challenges and you have to be innovative, for example like this baby I put up in the slides, that baby had esophageal atresia and we did esophageal repair, and you had to transport the anesthesia machine to the adult ICU to be able to ventilate it a little bit to survive, and the machine stopped halfway in the night, and my anesthesiologist had to bag the baby up to morning. From then we had to stop doing babies with esophageal atresia for some time.

Even then when you work on a very sick baby who will require ventilation, you have to be the on call doctor, because we don't have intensivists so that when I put for example such a sick baby in the ICU, we have to be able to cover the duties of course through the night.

So talking about the scope of patients we have, they are like all over the world, you have a lot of congenital abnormalities, you have a lot of trauma, and the tumors, and the others of course like infections, typhoid and complicated appendicitis. We created a database in 2012, and from then we are now starting to extract the data to see the scope of patients we have like in this slide for a period of two years we have almost 50% of our patients with congenital abnormalities and malignancies you can see they are also very many, and infections constitute almost 20% of our patients. But of course we have inguinal hernias and undescended testes, and others, and when you talk about congenital abnormalities, basically the biggest load of patients are anorectal malformations. If you or anyone wants to do for example a PSARP, you come to Uganda, you can't finish the patients. We have a lot of gastroschisis as you can see in the space of two years we had 50 or 60 of our patients. We are seeing this picture, like it is happening everywhere, the numbers are increasing, and other conditions, like atresia and teratoma are also becoming very common.

The anorectal malformations and Hirshprung Disease patients are important to us and health plans because they are considered the biggest percentage of patients and these patients require multiple admissions because they have to go several stages of treatment, colostomy and then definitive surgery and then stoma reversal, so they require multiple operations, and also we have a challenge with pathology. I was listening to the previous speakers the way they were talking about to get to the level of where you can do resection of the bowel for Hirschsprung Disease. For our kids you can't rely on pathology, we don't have experienced pathologists to diagnose Hirschsprung so more often than not we pull down the level of the colostomy for a pull through when we are doing the pull through because when it is working as a colostomy you know that it should function. Otherwise, and of course one would like to have a frozen section--we don't have experienced pathologists to do this test.

So basically in anorectal malformations you can go blind if a colostogram can't be obtained, and you end up converting when you can't find the bowel in the posterior approach. It means that because of the patient's situation so many patients live for more than 5 years before they get a pull through, and this presents a very big social problem because these children can't go to school. They are shunned by even the teachers and other children, and also we have found from most of the mothers that the husbands run away and these mothers are single mothers to start caring for these patients. In this database we tried to extract, this is one of the papers we published trying to estimate
unmet need for surgery for an anorectal malformation and we found that we meet around 1.6% of the need for surgery, for anorectal malformation and similarly for Hirschsprung, only 1.5%, so it means that the rest of the patients are therefore unattended to.

As I said we have a lot of intestinal atresia and we have analyzed our data for five years and have found that 90 patients had intestinal atresia and significantly you find that the mean age of presentation usually is 7 days, and the mortality is overwhelming but similar compared to other countries in Africa. Our mortality is almost 33%, which is very different from what you can find here and other countries in Europe. Most of our children because they come late, some of them actually die of sepsis but others die of malnutrition because we can't afford TPN, we don't have TPN, and these children cannot survive. In gastroschisis many patients come very late, after almost ten days, you find the bowels becoming ischemic, sometimes it's very difficult for the the baby to survive. We have a lot of patients come in with gastroschisis where the bowel was necrotic. And that is why our mortality is very high.

When I was trained in South Africa I published a paper with Professor Hadley in Pediatric Surgery International and the mortality in South Africa was around 50%. In Uganda as I said, we published a paper which you consider the mortality was still 100%, but in that paper we try to draw some conclusions, we try to map out where the patients come. We thought this is near the capital city, probably there could be something related to development, which is causing these patients to be so many, but probably we need to do more studies to confirm that.

We are getting a lot of conjoined twins, actually in the space of four years we had ten sets, and the first set happened to we get, we contacted Egyptian colleagues. I went to Cairo and we separated them together, and the babies survived, now they are doing well. Then we go to another set of twins, this one - - 200 kilometers away. They came - - the doctor did not recognize that they had anorectal malformations and they called us and we had to do emergency colostomies for both but to organize, this was a nightmare because arranging everything was not simple. Later on they are flown to U.S. and they did separation and surprisingly I met with Dr. Gail Besner, last night who did the surgery and we talked about them. Another report presented a twin that had to be sacrificed to save the other one, and the baby survived.

From our data in this paper, we analyzed the unmet need for neonatal surgery and we found that probably effective coverage is only 3.5% and to try to compare with other conditions, which attract a lot of funding. But you can see for example, neonatal surgery compared well to TB and other non-communicable diseases. The World Bank, World Health Organization, they attract a lot of funding, but nobody talks about neonatal surgery. All of these conditions can start getting funding.

So another challenge, and this really covers all of the aspects of pediatric surgery, even the patients from tertiary facilities get to us very late, and because sometimes poor referral systems, poverty, and lack of awareness can create this so and some patients really sometimes seek alternative treatment from traditional healers, which creates this problem. In this case the abdomen was so distended, and the bowel already looked like this, the bowel you can see was so distended. Sometimes even after placement of the
colostomy, this bowel will never come back to normal, and we need to resect this bowel before I put a colostomy because it will never improve.

A presentation like this one, I don't know whether anyone has seen the natural history of inguinal hernia, where the hernia fistulizes through the scrotum, and this child survived that. They had to do a bowel resection of course. Most of the surgeries are done by general surgeons, and the medical officers, and that can create a lot of problems. That slide you can see the colostomy has stenosed and the baby comes to put in another colostomy. Another one was misplaced and the child did not improve and we have all sorts of complications. In this slide I put for example, what can happen when someone who is not experienced does a hernia. You can see the incision where it is, and of course the child did not improve. The child came to us, and we had to repeat the herniotomy.

This child also had Hirschspung and ended up having all sorts of incisions - - and you can imagine - - to do any surgery is sometimes not possible. Sometimes we get a very late presentation like this 19-year-old who has a colostomy and has had the colostomy since early childhood up to 19 years. On the other picture on the right you can see that because we don't have a colostomy bag they use clothes to tie on the abdomen, and it had created a band even around her abdomen. The girl after did very well and after two months she became pregnant, and to our surprise she delivered through the vagina and the child did well.

Also we get so many infections. We get a lot of typhoid perforations because of the quality of water and a lot of intussusception. In most developed countries the patients present earlier and they can do 90% reduction by enema, for us mainly in the public sector where you work, most of the reduction is by laparotomy. You can maybe do that in the private sector where some patients present early, that is when you can get a chance of doing an enema reduction. Complicated appendicitis is also becoming also more common, but also it presents late. But sometimes, infection can be due to a poorly managed condition such primary anastomosis with perforated bowel for typhoid, the surgeon or medical officer tried to do a primary anastomosis and the child ended up with a leak and fistula, and came to us very sick. We could not do anything, we just nursed him with the fistula, and later on the child improved.

We get so many perforations as I said, typhoid perforations, but sometimes the perforations are spontaneous and we don't know why. We are trying to get the reason why some patients have perforations, like this child had gastric perforations and came already in distress. We placed a drain before I could do a laparotomy, this was a perforation of the stomach. Because of the high prevalence of HIV we get some other conditions presenting. That is a patient who had necrotizing fasciitis, which was extensive and to treat this is very difficult.

We are getting, as I said we are getting so many tumors, but sometimes they present very late like that is a Wilms tumor, so it means that these children before I would do any surgery I have to first do treatment by feeding them before you can start on any chemotherapy. After that, you can do resection of the tumor. We are getting a lot of lymphomas and others, and because of the high volume of patients we are seeing so many teratomas like in 35 in 3 years, and sometimes each day it is not surprising you can do two
patients presenting in two days, another five patients presenting in two days. Sometimes when our visiting colleagues come to Uganda, that is when they have a chance of doing these big tumors so we had to find solutions to all of these problems.

One thing that we identified was to support training, because having these patients presenting late and we are realizing the fact that we can't be everywhere in the country. We had to start training programs for undergraduates and even residents during their residency program, so that they can start to recognize this condition and be able to treat them and that we don't get so many complications.

Also on the problem of infrastructure, training, and research, as I said medical students have very much interest in pediatric surgery, and when they are rotating, we emphasize a lot of pediatric surgery. And then the resident training program--previously the residency program, they had little exposure to pediatric surgery, but now they have close to 6 week blocks, so by that time they graduate they have three months actually, so they get grounded in most of pediatric surgery.

And also as I said through the College of Surgeons of Surgeons of Eastern, Central, and Southern Africa (COSECSA), there is a training program for fellows, and someone has to acquire training from other centers of excellence and with that we started collaborating with University of British Columbia. So far one fellow has finished training, and she went back and did her fellowship exams, and in this audience I have seen people who examined her and this is where you helped with training and they get exposed to more technology. But also I am maybe asking to see if this could be possible with the audience here for more training to be done in the USA. But of course there is the fear that there is going to be a problem with doctors after training who will not go back but I think that one is far fetched. I would try to put here my fellows, this one on the left is going to sit his fellowship this year, she finished her training in 2016 and is now working with us, she returned, and Doctor Muzira is also undergoing training.

So trying to mitigate the problem of late presentation and the patients not being able to reach us. We try to start collaborative outreaches in the country and just in the name of strengthening the local teams for skills transfer, and reducing the operation backlogs. And we have also to sensitize the population too. Even the local teams to stop fearing patients who present in their childhood. When you do this you find that the anesthesia providers become more competent, and by the time you leave they start doing these patients without referring them to us. We have also some papers about the outcome of the surgical camps we have done, and this is a snapshot of some of the camps we have done in some upcountry hospitals and sometimes it appears in the press.

So to address the issue of infrastructure deficiencies, particular the lack of theater space, we had to sit it down, it was really mind-boggling, at one time we were only having 1.5 days as I said per week. We sat down and wrote a proposal to basically it was addressed to Johnson and Johnson and the regional director was in Scotland, so he reached a colleague and asked how could that be addressed. So Professor Youngson and Professor David Lloyd they invited me to Scotland and we did video interviews and we recorded the video links and this one was starting fundraising programs including in the schools in Aberdeen. By 2013 they had started raising money and by 2014 they had installed a
theater in one of the hospitals in Kampala and now we have pediatric theater dedicated for pediatric surgery. So in that way we have been able to reduce the backlog of patients, and I already said in the beginning, and also they are promising to deliver equipment for endoscopy and also laparoscopy. This is an example of the ward that they created in the hospital, which is really child friendly and this is the theater. They brought sets of equipment and as I said also, they are promising to bring endoscopic equipment and actually I think this one will go away in the training of fellows and surgical residents. This is the picture of Professor Youngson doing the first operation after the opening of the Naguru theater. This is the picture of the intensive care unit which was in the hospital.

So as I said you have successes in that unit. We did 500 major cases and they brought equipment for endoscopy and created an ICU, as I said we had stopped actually putting on patients with esophageal aresia. But two months ago we operated on a baby and it survived in this NICU. The other thing we hear is that a lot of surgical trainees are interested in pediatric surgery because of our ability of theater space.

In terms of oncology, we created the tumor board, which has really made a very big impact on the outcomes of oncology patients, because now there is more coordination of the management teams. They follow protocols, and there is better appreciation of the constraints of each other. For example, the oncologist understands the surgical problems, and the pathologists also understand better the problems we meet, and of course we are following a protocol. That one a snapshot, we tried to analyze the outcomes which showed improvement in the space of three years.

We have started local research and for example residents now have taken so many projects in pediatric surgery, that is the ongoing list: residents are doing research on neonatal mortality, childhood hernias and the complications, Wilms tumor, and the residents are doing autopsies in all of the babies who die in the hospital so that we know what killed them and if it was surgical. We created the Children's Surgical Care Society of Uganda, and probably we want to collaborate with the Global Initiative for Childrens Surgery (GICS). This is another organization which has started a global initiative doing surgery to try to improve pediatric surgical care globally.

So during this collaboration we learned that probably it is a long-term commitment but of course they are supposed to be in relationship and if it could be done in a two-way fashion whereby people go to Uganda and also others come to U.S. that would probably be more useful. We have also to do collaborative research and I think this is really a very virgin area which we can explore. We want to train through service delivery by for example doing pediatric surgery outreaches.

I just wanted to bring this slide about research done about pediatric surgeons in Africa, how can international partnership be done. You will find that the majority of surgeons thought that local training was the most important aspect which could be done to tackle the problems of pediatric surgery rather than direct service delivery.
So what can we do together? We think that at the national level we can emphasize the training but by improving faculty so that we can train fellowships, fellows and the general surgeons to try to probably competently manage patients. But of course also improving infrastructure and delivering supplies, outreach can also help, and doing research.

So in conclusion I find that pediatric surgery disease burden is high, which also contributes a lot of disability and this can be averted. There are limited resources both human and physical. We need to scale up training. Without training, we can't rely on outside services for example a visiting surgeon to tackle all of these problems, but we have set up multiple programs to meet these challenges. There is a need for international collaboration. Also by doing research that is the only way we can increase awareness and start advocating for pediatric surgery.

As I conclude I need to pay gratitude to the AAP surgical section for honoring me to give me this invitation so that I can be able to present this lecture and Mike Caty, and of course during to the executive committee, I thank them very much, and of course to the hospitals I visited, which has been very helpful, and to international collaborators as well been coming to Uganda to help us. Thank you very much.

[applause]

MIKE: So John, we would like to thank you for traveling and preparing this beautiful talk and also admiration for your work and our willingness to work with you and expand our collaborations. On behalf of the surgical section, I would like to present you this plaque for you to take home. I hope you have room in your luggage and it doesn't get over 50 pounds, but in recognition of your visit here and your presentation and being the Stephen Gans Overseas lectureship, and in addition, we will make you an honorary member of the AAP because of your visit so thank you.

[applause]

We're going to make an executive decision to forego the business meeting. The business meeting was largely today the presentation of the committees. I apologize to the committee chairs who have presented some slides, but I think for the greater good, we might invite everyone to go next door and start the lunch, which is sponsored by Nationwide Children's and begin the poster session, so that concludes this morning's session. Thank you.
Pediatric Surgery in Uganda

**STRENGTHS**

No shortage of patients!
Compassionate, dedicated, and enthusiastic surgical team
Established collaborations have begun to address some of the deficiencies in:
- Infrastructure
- Education
- Service provision

**CHALLENGES**

Too many patients/ conditions to treat
Too few personnel- surgeons, anaesthesiologists and nurses.
Too little equipment and infrastructure
Too late presentation
Too little that can be done
## Pediatric Surgeon Deficits

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*Krishnaswami et al. 2016 *Sem Ped Surg*

**Need 1:** 100,000 children (APSA)
“It takes the enthusiasm of an individual to improvise so that a patient can survive.”

OR ventilator being used to ventilate a post-operative child after neonatal surgery, given lack of intensive care resources.
9 Year Old with Hirschsprung Disease
Survey of African Pediatric Surgeons: How should International Partners Help?

Conclusions

Pediatric Surgery Disease Burden is high with substantial disability that can be averted

Limited resources (human, physical)

Need to scale up training

Multiple programs in progress to meet challenges

Need for international collaborations
  ◦ All of the above areas

Awareness and advocacy for pediatric surgery