Update Call: GO on the ground in Nigeria

Transcript, by Ami S. Bhatt, MD PhD

Thanks to all of you for making time this afternoon or evening to chat a little bit about the projects that we've been undertaking out here from the West Coast. I thought over the course of the next maybe 10-15 minutes I would just give an overview of the activities we have been involved in, the progress that has been made to date and our thoughts and opportunities for next steps.

Just to give you a little bit of background, the way we ended up getting involved in cancer care in Nigeria was actually through a call that I received a few years ago. The American Cancer Society and the Clinton Health Access initiative, two very prominent, very well-known nonprofits, had decided to band together to try and address issues around cancer care and cancer drug access in low- and middle-income countries. Many of you probably know CHAI, or the Clinton Health Access Initiative, for its pioneering work in negotiating for lower drug pricing for HIV drugs and AIDS drugs, and this has really been critical in making those drugs accessible and affordable in low- and middle-income settings around the globe. Now classically, the Clinton Health Access Initiative, which actually was originally the Clinton Health Aids Initiative, hadn't worked in non-communicable diseases, or cancer, but as all of us know, these are issues of growing public health importance. And so they had identified this has an area of need. Not knowing much about cancer and not being exposed to cancer, they had the opportunity to partner with the American Cancer Society, which many of you guys will recognize as, I believe, the world's largest cancer nonprofit. The American Cancer Society has been around for decades and predominantly has focused on the United States, as the name will imply, and has done a lot of work particularly in the tobacco control space, but hadn't really done a lot globally with the exception of some prominent work in opiate access, or pain control medication access. So the two of the groups had come together and decided that they wanted to work to improve care in low- and middle-income settings but really didn't have a lot of human resources to back them up in terms of doctors and nurses and individuals who had clear, not only cancer experience, but also global cancer experience.

So it was in that context that through our work at GO – we as a community had become prominent – that ACS and CHAI approached me to try and lead a group to help address these issues and to grow their efforts. At that time, the options were to work in either Nigeria or Ethiopia, and after considering options carefully, we decided that we would take a stab with working in western Africa, in Nigeria. For those of you who aren't that familiar with Nigeria, Nigeria is Africa's most populous country. A census has not been done for several years, but the estimated population is between 180 and 190 million people, so we're talking about a country that is about sixty or so percent the population of the United States. It is in western equatorial Africa and is a hub of, obviously, a lot of oil, the oil industry. Because of that, Nigeria is

technically what the World Bank would designate a middle-income country – it's in the low middle-income quartile which is the second-lowest quartile. And despite the fact that it's not a low-income country – its GDP per capita is between two- and three-thousand dollars per year – there is a huge inequity in the country such that over fifty percent of the individuals in the country live below the extreme poverty line, which is they live on less than $1.90 USD. So, while it is a country that has some resources, it is a country with a lot of poverty.

Historically, Nigeria was an English colony and was a conglomeration, essentially, of a lot of tribal communities. Notably, the country's kind of divided into three main tribal communities: the Muslim majority in the north, the most prominent tribe of which are the Hausa; the Christian majority in the south, the most prominent of which of are the Yoruba; and the Ibo in the east who also are predominantly Christian. Because of this, it really is a melting pot of Africa with a lot of diversity and richness in terms of cultural heritage, religious heritage, etc., but as I've outlined, health issues and health disparities are quite significant.

So in that context, what we ended up doing was, over the course of the first six months that we engaged we had colleagues on the ground in Nigeria, so Clinton Health Access Initiative employees – honestly very educated, very intensely justice focused individuals – in country. We collaborated with a colleague there named Anita Okinemi who helped connect us with two university teaching hospitals. The university teaching hospitals were identified by the Federal Ministry of Health as hospitals that they'd like to take from the kind of current status of cancer care, which is, they're able to provide cancer care but not in a coordinated and comprehensive fashion, and really turn these hospitals into centers of excellence. And for the reasons that I outlined previously, in terms of the Muslim majority in the north and the Christian majority in the south, the choice was made to pick one hospital in the north called ABUTH and one Hospital in the South, Lagos University teaching hospital. Over the course of the subsequent six months, we built a twinning program between physicians, nurses and hospital administrators there and individuals here at Stanford. Many of the people we identified at Stanford had a background in global health but actually many of the people who ended up stepping up to the plate were physicians or nurses who had not had significant experience in global health in the past but were really motivated to get involved.

So after that initial twinning program where we outlined potential opportunities to facilitate their own kind of Nigerian lead improvements, we had our first visit to Nigeria in February of 2017. I led a team of five individuals which included radiation oncologists, medical oncologists and a nurse practitioner, and we carried out a comprehensive needs assessment, and this is a needs assessment that was a comprehensive tool that was originally built by GO. We adapted it for the use, so Stanford doctors actually contributed to adapting that tool for the use in this particular setting, and we went and met with over twenty-five individuals to carry out this needs assessment. This needs assessment actually ended up forming the basis of recommendations that CHAI took to the Federal Ministry of Health, which are now incorporated in the 2018 to 2023 National Cancer Control Plan. So, members of GO and members of Stanford have really contributed to, not only these two hospitals but to the trajectory of the entire country's national cancer control planning.

Some of the things that were identified during this trip as opportunities for collaboration included helping these hospitals build multidisciplinary tumor boards, so, helping them to work in a more coordinated fashion. And so, the second time we visited in August of 2017, we modeled the process of doing multidisciplinary tumor boards, now a practice that is, honestly, standard, and I might argue that they do it even better there than we do here. We also carried out the first oncology nurse training. Here in the United States, nurses are trained and certified through this program run by the Oncology Nursing Society, or ONS. We had certified ONS educator from the United States, Hope Qamoos, join us on the trip, and she actually adapted an educational curriculum to the Nigerian context, trained six nurses in that curriculum, and all six nurses actually successfully passed their certification exam and are now ONS certified. So, these are the first six oncology nurses in Nigeria to actually receive official certification. We've also implemented a lot of research collaborations to try and create leapfrog technologies for, for example, breast cancer receptor typing. You guys probably know that being able to test breast cancer specimens for ER, PR and HER2 is incredibly important in terms of being able to decide about treatment options. That technology is really quite cumbersome the way we practice the testing for ER, PR and HER2 in the United States. It can be cost prohibitive in Nigeria and often times they struggle from stock-outs of reagents so they can't actually test, and these are incredibly important results to get in order to determine correct treatment strategies for patients. What we were able to do was identify a very innovative company called Cepheid, which is based in the Bay Area. Cepheid has cornered the world's market on rapid and accurate tuberculosis testing with a machine called the GeneXpert, and they've actually started to innovate in the cancer space. They have a very rapid, easy-to-use test for ER, PR and HER2 testing, and so on our second visit, we ended up bringing a machine with us setting up the machine and creating a research project to test how accurate these alternative methods to do ER, PR and HER2 testing are in that setting. This has now moved forward very nicely, has formed the basis of actually building research careers for some of our colleagues there and has been just truly, truly inspiring. It also has the chance to actually be a game-changing diagnostic technology, not only for Nigeria, but all of Africa. So, all eyes have been on this project, and it has been very exciting.

Most recently we visited Nigeria again in February of this year. This time I had the opportunity to bring our cancer center director Beth Mitchell who is a big enthusiast of GO and a major kind of force in American cancer. We also were able to bring Dr. Karl Lorenz who is a palliative care physician and who has set up palliative care training programs in other countries including India. And finally we were able to bring, in addition to one of the original members of our team Shruti Sheth, a breast oncologist named Allison Kurian who is an expert in hereditary breast cancers. During this particular visit, we went to the Federal Ministry of Health. We were able to go to three hospitals, the two hospitals where we have collaborated extensively – one in the north one in the south – as well as the National Cancer Hospital. The travel to the northern part of the country was actually incredible. It was the first time we were able to visit ABUTH, which was the northern hospital with which we collaborate. In previous visits the team from ABU had actually come down to Lagos to see us. We weren't able to travel to ABU in the past, in part because, you probably heard in the news, Northern Nigeria is a relatively less stable area with a lot of

safety threats, etc. But this time it was deemed safe enough that we were able to travel by an armored car and with security guards, armed security guards, up to the north. When we arrived there, it is a beautiful, rural, pastoral place with a very strong, deeply-rooted Islamic culture, very different from our experience in the busy city of Lagos, and we were able to participate in all kinds of activities. I will tell you, one of the most inspiring things that we saw there was the banding together that the physicians and nurses and hospital employees have to care for their cancer patients. It's very common that cancer patients present at very late stage. At the ABU, for example, we saw a woman who was forty-two years old and had a breast lump for two years, had avoided any sort of medical care for her breast lump because it was expensive, and eventually ended up showing up at the hospital because she couldn't walk. So, here is a woman who ended up having breast cancer that had spread to her spinal cord and was kind of pressing up against her spinal cord causing her paralysis, when truly if she had been diagnosed years ago when she first presented with the lump or perhaps if she had been screened with a mammogram, she likely would have had a completely preventable disease. But these are the sorts of situations that these patients have, and what the doctors and nurses do is they banded together, essentially each of them taking money out of their salary and earnings and putting it toward a palliative care association called the Zaria Palliative Care Association that they both contribute to and run. And this palliative care association essentially takes a portion of the salary that is donated by all of the cancer care providers and then uses this money to buy things like wound dressings and clothes and food and transportation access for these patients and their families. So, something that honestly, truly was incredible. Another thing that was really impressive was their involvement of local clergy and Imams. In Nigeria, religion is an incredibly important part of daily life and social life, and they have a very deeply intertwined religious system with their medical system. So, these were things that I think we definitely learned from them, and it still is very deeply inspiring to me.

When we went down to Lagos, one of the opportunities that we were able to continue to build upon was a very, very strong infrastructure that they're trying to build around pediatric oncology. There they have a very talented, young, passionate pediatric oncologist named Dr. Akinsete. He has really taken pediatric care to a new level. While patients are required to pay for all tests and all drugs out of pocket, he has worked with local nonprofits to try and access funds to pay for drugs for patients who cannot afford them. I will say, even though his work is impressive, he is one person and he needs more physical infrastructure and resources in order to care for his patients. The ward that he has built is really the preeminent pediatric oncology place in the country, so when you think about it, this is one small ward of about ten rooms with one isolation room that serves an entire country's worth of pediatric cancer patients. So, one of the things that we've been really committed to is figuring out how to help him negotiate for extra space and extra resources. I do think this is an area where GO can really be impactful because the last thing I want to do is to keep on going back to Nigeria and to see nine-year-old children...I saw a nine-year-old child, who looked like he was four years old, struggling to breathe in his father's hands, and this is a kid who has Hodgkin's lymphoma, which is a curable disease. Unfortunately, I reached out to Dr. Akinsete and heard that the week after we left, this

young man passed away. I think these are opportunities where, with a little bit of effort and a lot of creativity we can make real impact.

I will close by saying one of the things that has been most exciting for us to see is the impact of our patient education materials in Nigeria. When I shared them with our colleagues on my first visit, the look of joy on their faces was overwhelming. They resonated with the materials completely and were so enthusiastic about the idea of getting these materials and putting them in their patients' hands. One of the things they really struggle with is the volume of patients that they have to see, and they can never quite spend enough time with patients to really explain what's going on. They worry a lot about treatment abandonment, which is when patients stop taking therapy prematurely. And as a consequence of their interest and GO's outstanding patient education materials, we've now set up a collaboration with Paulette Ibeka who is at CHAI who GO will be actually paying part-time to help translate these patient education materials into the four common languages in Nigeria: Hausa, Yoruba, Igbo and pidgin English. And then will be distributing these materials to the various hospitals including the two that we collaborate with closely and testing their utility and also collecting feedback on how to improve them.

So, with that I'll say it has been a real privilege to go to Nigeria several times. It has been an awesome opportunity to engage a variety of people who are both interested in global health from before and those who really got an opportunity to grow an interest in global health now, and I'm really excited about what's ahead. So, with that I'll maybe stop, and I'm happy to take any questions

Question 1: This is so inspiring. I've known about your work but hearing it summarized the way you've done so tonight was really helpful to get the picture of where things are. I'm eager to hear more specifically how GO can leverage its expertise and volunteer crew to support this work. Of course we're doing so through the patient education materials, and you alluded to our having contributed to the needs assessment, but are there other opportunities for GO volunteers to support your efforts?

Answer 1: This is a great point. I really do think there are. Some of the things that are deeply in need are connecting our colleagues to people who are technologically savvy, so trying to advance tech in the local sector is incredibly important. I could imagine ways in which GO volunteers could help to engage with our colleagues to make, for example, electronic medical records a reality or find a way to harmonize their epidemiology records to their cancer registry records with others. I think other things that could be incredibly helpful are to have GO volunteers connect with Nigerian NGO partners. So, there are a lot of non-governmental organizations in Nigeria that are focused on improving cancer care for Nigerians. I think building a network of NGO individuals who are working toward this shared goal would be really valuable. It's something that we hope to work with CHAI on, specifically with Paulette, but I could imagine this would be an opportunity that would be fantastic for GO volunteers. Finally we always have need for people to share their specific expertise, be it in technology or in providing care or in advocacy. I think all of us have the ability to advocate for improved drug pricing and improved

access, so a lot of what we can do is use our ability to learn about this and then tell the story and find ways to tell the story in a compelling way to build awareness about this issue. I will say another specific opportunity that we are exploring is building cancer awareness among children and obviously their parents. In Nigeria cancer is still something that is not on the mind of most Nigerians, and when they hear about cancer they think about it as a death sentence if they know what it is, and we're really trying to change that perspective. As you can imagine, twenty or thirty years ago, when people heard the word AIDS, it was also a death sentence, and now obviously that has been recast entirely. Part of that has been achieved through education, so one of the things that we've been interested in doing is exploring the opportunity to collaboratively write a children's book focused on cancer so that we can build awareness around what cancer is and why it's important to detect early. Cold Spring Harbor Press, which is a scientific group that does publishing, has previously created such materials for HIV and AIDS in collaboration with the Bill & Melinda Gates Foundation. So, in about ten days I'll be out at Cold Spring Harbor meeting with the Cold Spring Harbor Press group to discuss and further this collaboration, and I think this could be a really amazing opportunity for folks like Carlos who are design-oriented and are so talented at telling stories through pictures.

Question 2: That sounds like an interesting opportunity that you're mentioning. But I also wanted to know if there's a strategy in place or has there been any new ways to extend the reach of the patient education materials. I just mention it because, is there a channel, for example, if there are connections in local communities, like I know in Columbia my home country, or my sister right now she's a doctor as well and she lives in Costa Rica. If there are opportunities in those places to promote, is there a specific channel to connect with somebody at GO, and is that something that is pursuable or is there another strategy to extend the reach of the document that we should be aware of?

Answer 2: I think this is a good question. I think that if there are connections or champions that we have in various countries, connecting them to us at GO would be fantastic. Danna Remen has really been the hub for a lot of these requests, and we are trying to accommodate as many as we can. We found that what works best is when we have an in-country champion who knows how to navigate the internal politics to get these materials into the hands of those who need them, that's when things work best. I will say that one of the things that would be fantastic is finding ways to make these documents highly accessible and to give people a good sense of how they might use them. We might be able to also connect through federal ministries of health, so that's one of the ways in which we hope to get these materials more broadly disseminated in Nigeria. But for right now, connecting these potential individual champions to Danna Remen would be fantastic, and we'd be excited to push this forward. One thing that I think we all need to do is figure out how we can not only raise access to these materials but also raise some modest funds around this so that we can support accurate translation of these materials into indigenous languages, and also so we can respond to requests to improve or change these materials. Because while these materials are very broadly applicable, I think that every time we've shared them with a community there are often requests to make changes, and

I think that it would be wonderful to be able to respond to those requests, and I think we could achieve that if we could raise the awareness and also raise some additional funds around this.

Question 3: I was curious about the radiation therapy version of the patient ed materials. Are you using those either in Nigeria or somewhere else and what was the process of developing and implementing those?

Answer 3: Those materials were developed in collaboration with radiation oncologists in Botswana. It was a back-and-forth process where they were developed for the particular use case of Botswana, although obviously we want to use them more broadly. They are being implemented in Botswana now, as I understand it. They have been translated into the most common local language Setswana, and we will be looking forward to hearing specific feedback on those materials. In Nigeria right now, radiation oncology access is not great. The National Hospital in Abuja has a working Linac and now is installing its second working Linac. But previously, there had been actually zero to one working Linacs in the entire country. There is a plan to actually expand the number of Linacs so that each cancer hospital has at least two, so we anticipate this is going to change dramatically over the course of the coming year or so. So we'll have the opportunity to test the radiation therapy version of the materials in those locations as well, but that's the current status as I know of it.