

FIC BRAIN Webinar Full-text Transcript

“Challenges and Solutions for Improving Participation of Populations with Low Education Levels in Biomedical Research”

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December 7, 2011**

Gladys Maestre: Good morning, everyone. I'm Gladys Maestre. I'm a professor of Psychiatry on Neuroscience at the University of Zulia in Maracaibo, Venezuela. I'm a visiting professor at Columbia University and I want to thank Kathy for inviting me to this seminar series. I'm going to talk today to you about Challenges and Solutions for Improving Participation of Populations with Low Education Levels in Biomedical Research. Under reference materials, you can get the PowerPoint slides and also you can get them in Spanish if that's better for, for you. If you have any questions during the presentation, please submit them electronically in the, in the box for that and I will try to answer them following the presentation as time allows. I also want to thank to all of the participants that send me some questions in advance so I will be addressing most of them during my talk or afterwards if there is, some time. That's me. It's all I thought it was always nice to see the face of the person that's speaking. And I'm going to be talking to you about trends in education and world population, how and why is the impact of low education in recruitment of retention--and retention of participants in research studies but mostly I'm going to focus on the experience that we have around the Maracaibo Aging Study in our two sites: Santa Lucia and Santa Rosa, some of the new things we are doing and lessons you can take home. The following figures were prepared by Dr. Aromar Revi, and you can find them all in this link. It's a really nice link about education in the world. And here is the distribution of the global population of the world. And in orange, you can see the proportion of subjects with no education. And in yellow, there--those that have completed primary education. And this--the graphic, is for the year 2000, and there's female and this is male, so right from here, you see that most of the people has completed--have either no education or primary education, this is--in the world and that there is an asymmetry which more women are with no education and only primary education. And if we look at the--the predictions for twenty-five, then incomplete education, no education at all, diminished. And over time, this is for 2050 and by the end of 2100, this is what is expected but as you can see that no education is refused but as you can see still the yellow is the, the primary color in this figure. So most of the people in the world will have only completed primary. And at

this graph, this, in different colors that's from the same analysis. Half of the people in the world by the end of 2100 will be, will have achieved only primary education and no education. These seven years--seven point seventy six years is the average years of education attained by adult population in 2010 in the world. And of course, developed countries have higher average years of schooling. And this--this gap will come out four years. But by the height of the bars is the amount of people that resides in these countries. In these countries, only twenty-four countries reside at this proportion of people in comparison with the vast amount of people in the world residing in developing countries. But even in the developed--in the developing world, there, there are tremendous disparity, some of the regions here, you can see in violet, this is the, the amount of people living, residing in developed, in developed world, in the developed world. And these are the different regions. And this region with the highest amount of people is East Asia and the Pacific. But as you can see, it has about the mean age of the, the mean years of education. But as you can see Sub-Saharan and North Africa and South Asia are, are quite below that around five point two years of education. This is amazing; timestamp 00:05:14]. And when we look at different ages, and divide the people that of different age groups, then and we compare developing countries with developed countries, then you can see that the average years of schooling, of schooling diminished tremendously. And the gap between developing countries and developed countries increases with age, so. When we are looking at the elderly population, we see that the mean average, the mean years of schooling in developing countries is around just, is around four. And when we look at people, adults over fifteen years in, in this case with no schooling, illiteracy rate, we see that of course there is a gap between developed and developing countries, which also increases with age. In the world--in the world, the illiteracy has been a result, being--has been reducing with time but still the proportion is tremendous in developing countries, the illiteracy rate, it's almost twenty percent. But for 2010. And as you can see with the elderly, it almost reaches forty percent. So in summary, we see that there is a decline of--of it all in the--looking at the trends between 2000 and 2100 that decline in incomplete education. But by the end of 21st century, it's still a large proportion of the population will have only primary education. We'll see, we are seeing gender asymmetry that actually shifts from, from females to male at risk. We see that the gap between developed and developing countries is broader as people age. And there is a tremendous amount of increase of elderly with low levels of education. So this problem is not going away even in hundred years. And don't forget that this

situation could be even more critical because of the expected increase in mobilization of populations, due to financial crisis, natural disasters, and war. So we, we cannot oversee this problem. We need to act right now. So why low education is a barrier for participation in biomedical research?. Well, education is a very complex--it's a very complex variable that has to do with biological and social domains, including sex and gender, age and aging, race and ethnic group, environment, and nutrition, and, and don't forget that the brain health has a tremendous impact in the way that education could be absorbed. And the way also--the way that the ability to attain higher levels of education depend a lot on brain health. So it's traditionally, groups, for example, with intellectual disability, attain lower levels of education. But still they can be offered tremendous help, and for many reasons. And what--why the vulnerable are underrepresented and why people with no education are underrepresented in research studies? There is a perceived high burden of participating in research on the side of researchers. It is too difficult, it is too costly, it is too risky, you have to overspend. That's the perception that has dominated the research field. And there are, this implies some ethical concerns. In the '60s and--and '70s, there were several studies with minorities. They came to public light and--negatively. And these somehow promoted unethical perspective of paternalism or protecting these populations. At the--in 1978, the Belmont Report speaks clearly about the need for diversity, autonomy of competent individuals in making decision whether, about whether or not to participate in research are, the notion was that it was necessary a greater justice in access to research benefits. With the emergence of the HIV epidemic, there were some regulations by, issued by the FDA making access to new drugs easier in the context of serious and life-threatening illness. And then in the '90s, there was evidence that much more white men were included in medical research studies. So in 1993 NIH issue the Revitalization Act that included guidelines on the inclusion of women and minorities as subjects of clinical research. And this was modified in 2001 and now it is a policy of NIH that women and members of minority groups and their subpopulations must be included in all NIH-funded clinical research. It is therefore vital that researchers, IRBs, grant panels, grant review panels and institutions improve their ability to recognize and overcome potential barriers to participation in women and minority groups, and no education is one of these barriers. From the scientific point of view, because these are ethical and regulatory issues but from the scientific view, why should we care as researchers? Well, we certainly need to speed up our findings. We--and these represent good opportunities for

innovation and discovery, less genetic and environmental heterogeneity will increase in the power of our studies. Also, subgroup specific data needed when ethnicity, culture, genetic background could modify the outcome of a risk factor for example. To discern applicability of results to diverse populations. And this sense of justice that is, that becomes a source of inspiration for researchers which is that the higher burden of disease among the poor, low educated and certain minority groups. So let me share with you the experience that we have at the Maracaibo Aging Study. First, let me tell you that we are a Caribbean country. And Maracaibo is located in the neck of Lake Maracaibo. And in--I'm going to be talking first about the study that we developed in the neighborhood of Santa Lucia. And this is--this is the church of Santa Lucia. This is the--the downtown Maracaibo. And this is the study of aging that we established in 1997. We begin with a door-to-door survey-based registry so all the subjects is residing in the--in this neighborhood which is about five kilometer, five square kilometers which will be around two square miles with twenty-five thousand individual residents were invited to participate. Out of the twenty-five thousand, around three thousand five hundred were fifty-five years of age and of course we requested informed consent. And this study to--to evaluate health-related conditions including—mostly cognition and cardiovascular health. The study includes a very comprehensive panel of--of assessments that include survey of health habits and living conditions, family report on cognitive, personality changes and daily living. We do full neuropsychological test, full neuropsychiatric assessments, cardiovascular tests that includes twenty-four hour ambulatory blood pressure--ambulatory blood pressure monitoring and the treadmill test. A good portion of the participants got an MRI with a--with a machine that is one point five Tesla with clinical chemistry. And we obtained--including homocystein and folic acid. And we obtained also sample for DNA banking and we have done basic genotyping like able--we and important risk in our life. And more recently, I'm--what I'm going to be talking mostly today are about our ethnographic studies. And here is the distribution of the educational attainment of our participants, by age. And these are the age groups and here in livelihood, you can see this is the amount of people with no education at all. And you see that in the oldest group, it's around forty percent. And the amount of people with higher education diminishes as expected with age. So this is basically reflecting what's happening in, in the world as we saw right here. So basically, I told you we invited about three thousand six hundred people, the mean age of the whole population was about--it's about six years of education. And about one-third

refused to be part of the clinical assessments. So we--we move on--since 1997 up today with two thousand four hundred people. And we have recorded more than fifteen thousand person--years now. Out of that, in the first wave, about two hundred people were diagnosed demented and they had half of the years of education. And when I follow them, as I said, and some--some died of course and some relocated, about eight percent relocated out of the community. And really, the drop, only ninety-seven subjects in all these years have dropped out of the study. Four percent of the people has said, "I don't want to continue." So I didn't realize, until years ago, after looking at these numbers, that this was really a remarkable low number. So currently, we have one thousand seven hundred people actively enrolled. And the mean age has been around six, the mean years of education. So briefly what we have done, first, in the very beginning, we identify our allies in the community, particularly we found one person that was very knowledgeable and very excited about our, this aging study, this was Professor Maria Gamero. And with her help we were able to identify stakeholders and gatekeepers in the community. We devoted the whole first year to study the history, ecology and geography of the neighborhood, devised to develop partnerships in the community and not--not also limited to health organizations, but also cultural organizations because this is a very traditional area of Maracaibo. We were very fortunate to being able to establish an expert advisory board with international, national and local members and I have to say that many of them belong to the Columbia University Community particularly--particularly the Northern Manhattan Study led by Dr. Richard Mayeux. Under the whole first year, we developed protocols for recruitment and we develop these protocols, based on identification of barriers and facilitators. And we changed that later and I'll tell you why. So we did community assemblies. So we met with local leaders and here, this is one of the community assemblies that we have done but particularly, I want to show you that our interactions with community leaders had--is critical in this. Because they will facilitate our access to the community and they will be held accountable in front of their people when they introduce us. So we really need to be accountable to them. So we--we see them as strong allies with us. We let them participate. This is sociologist Yoraida Moran, we let them participate from their community. We let them participate in our dialogues, processes and we, you know. We have--we do the translations and we really, you know, make big extent to reach the community and to every international collaborator that we have, have to come to Maracaibo and have to interact at different levels of the community. Has to put their face in front of the community. Okay, so what

about informed consent? Well, our perspective as long--with, so along with so many other people is that clearly the informed consent has two separate processes. One is that to obtain the voluntary agreement before the enrollment of the participant and other separate that are--they are interact and they are very close together, but we perceive them as separate process is to disclose adequate information before seeking agreement to allow the subject comprehend what is being asked, the risk and benefits. And of course this imply competence and this not necessarily imply success in producing comprehension, what you are bound to is to disclose. But then how to do this with individuals with low level of education and, and known help or a very, previous research literacy. Well, we rely a lot of course with the obvious research, the type of language and with the challenges that we had identified earlier just by talking to the community on a whole lot and researcher was the--that we needed to develop a communication strategy to produce understand, to produce an understanding of the procedures. And this was mostly done through--this was mostly done through images. So we have to develop images that will provide an overview of the processes and we took every advantage of every moment, interaction to educate about what's been done, what is this and why--what are we looking at? One challenge identified of course was the therapeutic misconception. This is to mistake the aims of the study with those of clinical care. After all, we were a health care personnel and may, as soon as they, you're doing an exam, they--they want to know why. And there might be the perception, then why do you want to make exam if you're not giving me any medication? So this was also identified very early so we can set this up front. So one other challenge was to educate right, about science and about aging and about this study. But without telling them what to think, really. This is--it's hard because you try to be objective but after all, you want them to really see the wonders of the time, so--and how important it is. So it is a challenge and we had to be very aware of this. Another challenge was we have a local young IRB and this actually was less of the trouble that we expected. And of course we could not limited the consent of--the individual words and if their family and the community to agree to that the previous person will participate. And at the beginning, we were afraid of conflict so what happened is the son doesn't want the mother to participate and the mother wants and so on, so but a very few cases like this appear and I can tell you in the answer in the question and answer period if you're interested how we have solved, which basically had been through mediation meaning explaining, talking and if we see any kind of problems or the burden then, we see that. And, but usually, we are able to resolve

this just by talking. And later on, we identified other challenges like, for example, overprotection of subjects. And this is what I'm--I'm talking about, what we are talking, the problem with the son and things like that. This, this--and then we realize that maybe when we are overprotecting the subjects. And this was kind of in conflict or could be in conflict with the autonomy concepts. This was something that we really have to handle very carefully. Other challenge that appeared nowadays was that they really expected help when they, you know, when they were really seriously ill, for example, in survival situations or where they had no food or you know, they really needed an important medication. They know we are researchers, we have a car, we--all these so they expect this. And what we have done about it was really to establish a social worker to help them process situations like that. And we have been able to develop an alliance with an NGO that through voluntary services, jump in, in these circumstances and also because of their lives within the communities and the--the health center, particularly the hospital will have been able to expedite treatments and things like that for the population. So it's, some resources, human and time and some financial resources really needs, will need to be put into this because it's--it's just. It is critical to make a point for them. And then, they are very challenged, we identified was that they--some of them, you know, really high social acceptability so they really want to participate just to, you know, be nice with us. And to solve, you know, it was--then we decided, is that we really need to address this and we really needed to understand why they we were participating and--and what's there, what not--what's not. So that's where our anthropologist and team and we were extremely lucky to--to have these people interested, from the University of Zulia. And so we--we address, trying to understand through ethnographic interviews, why these people want to participate? What was their, their motivations to participate in this study? And of course, there needs to be a balance between the benefit and--and the cost of their participation in this study. And some were personal perceived benefits like enhance medical attention, reassurance on health decisions, access to laboratory tests, that's otherwise they--they will not have access, after all we give their results back to them. And their enrichment of personal life, this was very important, learning new things, meeting new people and a deep sense of empowerment. Because access to knowledge empower them to make decisions in the family. The perceived benefit to others was also very important mainly in Latin cultures, the concept of the "projimo" it's very, very important and the responsibility toward the younger family members can make you do things you don't otherwise. So--and this is more generic, yes. So the benefit a

future for younger family members of this moral duty and this community spirit and desirability as I say, you know, like people really want to, be nice and--why not to participate? We went back to those, the drop out and those that didn't want to come in at the beginning and we had some interviews and they, of course, perceived personal benefits like there's too much work, why am I going to a research study maybe and be friendly in a way. And some didn't trust these privacy issues like, you know, "why are you doing this?" And things like that and we were not able to overcome by explaining and showing. There is a memory of events that have happened in the past in Maracaibo related to all the researchers and this come out from time to time. And other motivations are just--the family member do not agree or there is a skepticism about the value of their effort. What are you going to get? It's not going to be worthwhile or as they say, negative previous experiences. This--these are the results of that. And, so the disclosure of information as an educational opportunity, we have approached this as a multilevel endeavor. We include the public engagement activities and empowerment. And among the empowerment, we developed specific programs for health professionals like a certificate program and we were very lucky to get a capacity building grant, training grant also from Fogarty led Dr. Conrad Gilliam now at University of Chicago. But at the time, we were able to develop these certificate programs that included research components. We also have an annual symposium for the whole--more than one thousand people come where we give their results out of the community and bring the international collaborators. We developed a series of seminars with community organizations and advocacy groups. We have now a coalition with more than twenty-three organizations that range for patient advocacy groups like Alzheimer's patient outreach and then also cultural groups like culture figure like that. And we have developed--thanks to the leadership of one of the nurses, Marialcira Quintero. The school of caregivers and also the weekly workshops led by Gladys Amaya and Neva Mora which are weekly workshop for demented patients and their caregivers. And we have been able to develop new services and help to promote the creation of memory units in Maracaibo. So these are just a picture of the workshops. They do this psychosocial stimulation and they do Chinese technique called chi kung and this is one picture of the symposium fourteen--fourteen years. And it's really one thousand three hundred people. It's a free--an event for free and we have no pharmaceutical support which, and these--although have made it very difficult has raised a lot of trust, in what we say is really just based in their best interest and science. We help publish materials. Here is a guide for caregivers at home. We are

able to put visually simple instructions and we have wrote a book for our health professionals and the second edition has been published by the--of an Pan-American Health Organization to be distributed in all the training programs in the Americas including all the medical and nursing schools. And this is what the experience of the whole team, twelve people writing about how to care for an elderly person in a setting like that, like the one that I have described. Okay, then that's it for the informed consent and so basically the--and the what we--and I have divided that into the obtaining the consent and the disclosure of information that we have are--I'm sorry, extended that. And I think this is very important when you are dealing with low levels of education. The recruitment then, the passive recruitment like this, the more traditional, you put flyers, advertisements, stuff like that, it's really, you know, very, with very low return, it's basically for prompting prospective participants to contact project staff. But--but it's not really--it's really not very useful. It's active recruitment through visits. Having a, first the community assemblies and then having a community health worker providing information and exploring willingness. And then when we visit through the census and, and then a staff member, will go to educate about the project and to obtain informed consent. We don't send the staff members first because they, as soon as they perceive that this is a health care professional, they must--they might feel a little bit pressured to participate, while it's easier to say no to, to a neighbor, "no, I'm not interested," but I have to tell you in all them, all of them were interested. Not one person said, "I don't want to hear," it was after--after they learned about the project that they say, "I don't want to participate," so we thought that was very interesting. So the study then has a research side and a support. And this is what we we're trying to reinforce that this is separate. And we go together but these are two different processes. And the support we provide on the community is not dependent on whether the house participate or not. It's the broad community that participates and even the whole Maracaibo not only in Santa Lucia. So later, and this was--thanks really to the training grant that we could bring the people from Kansas University from the Community Tool Box to Maracaibo. And that's when we learn about social marketing tools and we realize we--we were kind of doing that, but then we learned how to do it. And--and really did have speed up our, our processes in engaging the community. And these are very standard and at first I was scared of the term marketing, but really social marketing, meaning using the tools that marketers used for, to sell. But when, this case we--we're interested in learning how to change behaviors. And we were interested also in using techniques to recruit and maintain people in the

study. So, as any social marketing strategy, we collected the information, we analyze. We set up indicators and prioritize the component of our campaign. And now we do this routinely. And also, thanks to the interaction with the Kansas University people, we were able to really adopt a model where, to sustain our interactions with the community and also to generate indicators. So and this, this model implies that there are different stages of participation. So first you need to know about the study. Then you have to believe in the importance of the study like social value of aging, perception of needs for knowledge, social value, design, the desire to participate and needs to be in and then they believe in the ability to participate. So once you know the risk, the benefit, so you need to decide whether to sign the consent or not, this is the moment. And then decide to take the action, participate or not. And then to sustain their participation which of course has a lot to do with--has a lot to do with the level of satisfaction that you have just by being a participant of this study. So that's how we have maintained our recruitment and retention strategies. Basically, you listen what--to those who you want to engage. And this is a fantastic link. And they basically give you templates on what to do step by step, so I highly recommend that. So sign and work for retention is the participation should be easy and rewarding. It's an educational process that needs to be fun. And here in the community, this is Marialcira Quintero, the capacity buildings payers of our study, Jan Staessen from Belgium. Gbenga Ogedegbe from NYU and when they come to visit us, we go to the community, this is the social worker. And so again, retention is made in generating value for being a participant and this we have done through a different set of incentive. We don't pay them money. But we support them during--organizations and it applies, this means that the social worker or the physician will--will go and explain, advice and basically--basically we give our cell phones to the community, they can call us anytime, we do receive lot of calls just asking for general advice which is very valued. I had to say by the community and maintaining contact and, and provide a feedback of the results in a way that's meaningful to them, like just saying this is the present communication that I had in this nice journal in English. It doesn't--it's not really giving feedback of results to the community so we do that through different levels of interaction. So the main message is we need you all in the community. We need the participants, their family, and we also need--these are street vendors and we were able to--to negotiate with them so they can visit the areas where we have patients that cannot go out of home and they do that gladly actually. So summarizing then, the key factors in successfully engaging with minority and special population or populations with

low levels of education. I would say, that it's necessary to take a multifaceted and multilevel approach, that address major issues, rather than those focusing on what is relevant to each participant. The main issue really, why are we doing this. And, and you need to display that. Community engagement is critical for trust, logistic and financial reasons. And, and I haven't mentioned financial. But most of the activities that we have done with the community like this, free-service clinic that we were able to develop. And I--and the workshops and the symposium are--because the community collaborates this, the community, I have estimated that we basically spend about ten dollars per participant of the study per year. And out of these ten dollars, only one dollar comes from our grants. The tools of social marketing are essential to reach those "hard to reach." They really, they really work. And but among all, the most important is person-to-person. And education put layers in communication so you really need to have person in your staff that's able to communicate like almost heart-to-heart. So, so people can, cannot look bored or that they are just reciting something they really need to be engaged in communicating and believing and inspiring about what they do. The new services of caregivers and also for early detection, this is important and sometimes just having the international collaborators talking and training, this is enough to launch awareness of a need for a service and to support it. Keeping the community informed about research advances is essential and you need to do it in a way that it's good for them and for that, you might need dedicated channels of communication. And I have to say social media is high and we engage a lot in that but the participation of the community is still very low with internet and messages where the cellular phone are much better, but nothing works better than the physical presence in the community and in the key points in the community. So other, shifting a little bit of topic, so one concern that comes when we are working with low educated populations, is this that "Are we measuring the same constructs?" You know, like, for example, with our new psychological testing, this question comes over and over, "how are you sure that--are you measuring the same constructs in Maracaibo than in New York?" And so you have to prove it basically. You have to prove it. And even though the populations, the population that have been studied by Columbia University is mostly Spanish, we--they are really, they have three times the level of education than the people in Maracaibo. So we had to gather, you know, also three times of people, numbers. And allow the same age, the same proportion of females. And then we--we have to formally test most of the, these are the test. I'm not going to go to this just to let you know that these are about seventeen neuropsychological testing and most recently,

thanks to the, the research study, Santa Rosa, I'm going to tell you about, we have incorporated even executive functioning. And most of the measurements are lower, the scores are lower than in New York. But of course, they are--they are less educated. So what you need to is an invariance analysis and to generate the factor of, models to show how you, you've done your test on measuring what they are supposed to measure. And what we found was that they--they work just fine and basically, the same as in New York. So this is an extra work when you are working with low levels of education with population with low levels. This approach that we have taken has allowed us to expand ourselves and again, thanks to our colleagues at Columbia University like Joe Terwilliger, in Maracaibo, Inara Chacon, we were able to--and under Santa Rosa community, the center for popular education, we were able to establish the genealogy of a family of about two thousand people residing very close to Santa Lucia. And they live over at the of the water in houses that we've--that are called palafitos, this is how they look, they are very--now, they are connected to the community but as you can see, they were basically secluded. You could only reach them by water. This has changed recently so the population represents a unique resource for genetics and in environment direction and this is what we brought in the environment that we just are allowed to begin. This is the genealogy with about two thousand people in there. It's hard to reproduce and I apologize but it's really hard to show because of the extent of the family. And again, we have been using the techniques that we have described and really, taking the values of the community or portraying them. And this is one picture of one, you know, branch of the family with actually the--the community leaders right here. Another initiative that we are trying to develop will have been working with a neuroscience school. It's called La Hispaniola Neuroscience School and this initiative is funded by the National Academy of Sciences and the North American Chapter of IBRO. And in this case after the earthquake, we decided to use the techniques and the strategies we have learned to try to empower Haitian health professional and academics and we pull out a team of experts around the world and particularly we have benefited from also the experience of Jose Ortiz and Greg Quirk in Puerto Rico. And we have been--we have some workshops, this is talking about neurobiology of trauma, research design, data managing and that exist, dissemination of science, how to speak about science with populations, neuroethics and most recently project development and exploring funding opportunities. We have visited schools and we are trying to develop a "brain awareness week" for Haiti for 2012. We have visited the special resources They have, research science centers and

here I am in the--one of the ten, but actually it was very hot that day. And what we are getting is young faculty, young physicians, we are exposing them to neuroscience and the joys of being able to contribute will really say the, through neuroscience by Haitians. And we hope that this will really, through our collaborations. that we support development of neuroscience and science dissemination in Haiti. I have a lot of colleagues to acknowledge, mostly my team in Maracaibo, the University of Zulia and Fundaconciencia because they have worked, they worked really very hard and Gloria Pino has led the neuropsychological, Luis Falque has led the nutrition but also he oversees all the compliance of our ethics protocols. Inara is the one that's leading now the Santa Rosa genealogy and the projects and the team of ethnographers led by Nelly Garcia, Carlos Valbuena. And we have a team also, students, the nurse, Professor Marialcira Quintero, and we have our colleagues at Columbia and the PI of the new grant is Joe Terwilliger and we are very-- we are very fortunate to have a very complimentary staff. Maracaibo Aging Study has been funded by the CONICIT-FONACIT which is the funding agency in Venezuela. And it's not funded now and we have received, R21 and now R01 from Fogarty and the help from IBRO and National Academy of Sciences for our initiatives in capacity building. We have received support from local companies but are that nonpharmacological but these are small donations that they had to--they do an NGO and then this NGO which is from the ConCiencia help us to carry on the project. And we have built a partnership, twenty-three but I want to point out here to the Alzheimer's Association of Venezuela and the Center for Popular Education. I think--here, you have the contact information if you want to reach us, reach me or the team. And these are the webpage of the team--of the study. And well, now, I'm going to take some questions from you. So I have one question from Francisco Gonzales and he is asking, "What do you think is key to maintain participants' interest in the study without receiving any immediate benefit or what is usual medication or treatment?" I have to say and I really today it's very important to know what is expected. And what are the motivations. I think that having social activities like, for example, our school of caregivers and the weekly workshops, even if they don't participate. It's for them, it's very important that we are doing this and that we are doing this to considering their best interest. I think that being--having a close contact with them will have established a system or rewards like which is in a letter or a diploma that we give annually to the participants. And we have special participants which they are--they're very good that not missing even one appointment and so I think you really need to be creative and thinking not as a client but as a

person--people that are really willing to participate and feel to, if they feel that they are valued. The other question is, "What could we do to approach populations that are even less exposed to the research arenas in Maracaibo and satellite towns such as the eastern region of Venezuela?" I think that the best approach like the one that we are developing in Haiti is really to make alliances with health care professionals. Even if you are very far, there got to be physicians, nurses, nutritionists. And they, they went into the field because they love to explore, I guess. And they love health science, so try to reach to them and try to empower just maybe weekly, first reading and learning about other studies, and grading people that have done it. I think for me, this was critical seeing how people have done it. I visited, for example, Medellín and I saw what they have done there and I felt, "wow! I think we can do something like that," and I think that this is critical. To develop a critical path, to begin in very simple and to develop collaborations with people that are willing to walk with you. Okay. I have another question. We'll see what it says, it speaks of social marketing and studies.

And have been done about it is discussed, discuss the ethics of marketing to people with low levels of education. Yeah, it is, I mean, you can use the technique. The techniques are there, how you use it? Is it's a different story. So I think social marketing is a powerful and--and could be very useful. And I think it is in how you use this, not trying to like of course you are trying to--you are trying to sell what the knowledge about what the study is about. It's not really that you are trying to see, to sell this study. You are not trying to convince them to participate. You are trying to sell what the study is about and giving them the best choice to participate in the study. It's giving them the support to access the information and to translate information in a fair way. Okay, there is a question in Spanish and I'm going to read in English. It says, "Thanks for sharing, I have two questions. How are the beginning--how many persons were at the team and how it--has the team grown?" Well, at the beginning, basically it was a--I came back in 1996 after finishing my PhD at Columbia. And I was very fortunate to have a fantastic fellow, or that we call our "vicario" this is a research fellow and the two of us rolled their whole project to Venezuela and then one by one Gloria Pino, the beginning, this was so crucial, but something very important was I never went alone, I was always--I always had the support from my fellows at Columbia University. So I knew I was--I wasn't trying to be very creative about the study, I just wanted to have it done right. There are times where the team has been very big, you know,

like even forty people where we have like, for example, four psychologists evaluating. But we gone through all sort of crisis including financial and political crisis. So right now the team is small and we are very happy that we got the funding from NIH, so we are expecting. We are expecting to grow, to be able to recruit a fantastic team again. And now we know what to look for, so definitely we are looking forward. And I have a question from Angelina Kakooza. And how did you manage to win the government over your side? Well, they--we were not focused on the government. We have never been focused on the government. At the beginning, we applied with regular channels. And we, we received the funding. We tried not to step on colleagues. But it's really our social space that is our platform is the people. So having one thousand people in the symposium, talking about science and brain research that speak and the press covers that. And so this is our space. So we interact with officials now that shadow that we have, you know, allow us to contact officials interested particularly at the state level. National level, it's too far. We are in a, in the west side of Venezuela so we have focused mostly on the stateside. But we try to avoid politics. Inara Chacon asked if I think that this experience can be reproduced in other countries and just say that our Latin America communities are in general, open to outsiders. And we, and in general, willing to help, definitely. Definitely. I think so and there are several initiatives in the, in the region that are just fantastic, and I'm glad you mentioned that in America because, last year, we made, thanks to the leadership of Raul Arizaga in Argentina. With the dementia research group from the--from the World Neurology Association. And we, and we had the opportunity to exchange and there are small studies in all, in every country, every country, from Paraguay, Peru, Ecuador. Even, you know, there is sometimes big studies going on in Trinidad which is small island in the Caribbean. This just, we need--we need more resources. And the human resources is I think is really the critical that we--we know how to--we have learned to stand the crisis. But having the human resources trained in the capacity to live and visit what we mostly need. But I think that--I think that having other studies in the regions and look at the Brazilian side also, we benefit all of us. I have certainly benefited a lot from studies in Colombia and Brazil and Argentina. And yes, I think our populations are very open. They keep an account of the things that, you know, the things that could be perceived as abusive. And you know, and the perception of science in the media is not really good, I mean. If you look at the movies and television shows and stuff, the portrait of the sciences is not relatively not even normal. So it's very important, this science literacy to--science literacy to include really

knowledge and awareness of what science is. And I have another question about the interdisciplinary approach of the Maracaibo Aging Study. And at the beginning, really, the interdisciplinary came because we are located at--in the Cardiovascular Institute of the University of Zulia. So it was kind of--well, the obvious, so includes some cardiovascular measurement and we basically divide in two teams. We're divided in two teams: the cardiovascular and the cognitive but over the years is just--melded. And then nutrition came about and the nutritionists formed their own projects and psychologists formed their own project and the--and now the anthropologists have it. So I think that it's very important to give every person in the team the chance to have their own space. Even if they don't have, you know, a doctorate degree in your--or even a graduate degree, because sometimes we have, you know, persons who's just out of the university, with no post-graduate university study. And but they have the interest. They have the discipline. I think that this has been critical. We have been able to develop researchers for training in Spanish. And this also has been critical because barrier, in language is a barrier. I have another question here and its from Haiti which I appreciate a lot. And he, and Jules Grand-Pierre is asking, "what can be done in poor urban areas for improving skills of family members and help personal taking care of elderly at home?" And this was the very same question, the very same question we post to our group. And thanks to the leadership of a fantastic nurse, Marialcira Quintero, we were able to develop this school of caregivers. I believe we should we--information needs to be provided in a way that it's a structure. So you need to know what is important to take care of somebody that is at home--elderly at home, that is poor. You need to give the resources visually. You need to provide the graphic, the tables to keep, the notes to keep track of medicines. And I think this is very important. So the way our school of caregivers work if they meet every two weeks, Sunday morning for two hours, and they come about saving people and they share experiences because learning how to feed your mother, the nurse will tell you. But it's really how you do it. If you have to do it, then you learned your traits. And this is the--the school of caregivers is not just sitting there, listening to a professional to talk. It's interacting and sharing knowledge. So that's why I think this is the perfect tool. Not perfect, but one powerful tool to reach for community. And I have a question from Roberto Carlos about oral evaluations. And I guess you mean dental and we did at the beginning, we fortunately dropped out that area. A lot of--more than eighty percent of dental didn't have tools at all in the Maracaibo Aging Study. So this was something that kind of

discouraged the dentist. But now they are saying that there is a good opportunity for that to do that. So the--in the elderly, they have a better well health supposedly. I get another question from Frank Gonzales. And really, he, thank you Frank for your comment. I think that's it. I don't see any more other questions. No, wait, yes, there are some other questions. Yes, I see one from Amanda McRae from Trinidad actually and she said, "to establish the mission prevalent, what would you recommend to be used as a tool to determine cognitive function? Well, I guess you can--you can choose whatever you like. We began with the lecture, first of all, questionnaire of Pfeiffer. Then we use the mini-mental as a--this is the word, given as the screening tools although we gave the whole battery to every participant. But I have to tell you that the--we were happy with the screening, the sensibility of the mini-mental. So if you are asking for screening, although now we are testing or we are formally going to test some of the test that include executive functioning particularly the MoCAB but this is something that I don't know yet. But if you are wondering about full testing like which neuropsychological testing to use, then I think, you know, you only can have a guess, unless you formally test it. And this is what I did. We applied, you know, like more than twenty test and now with executive functioning, Inara tried, I don't know, twenty-five test and then we did this analysis. I'm really very, very glad to tell you how and we'll give you a hand if you, if you think it could be useful. We developed these models and we tested if these invariance--invariance between the test here and Columbia University, so we were able to determine first what we were doing. And which tests really were highly correlated with the domain, for example, with memory or with abstract thinking. And this is--this will be, because my guess is that every population will have a certain aspect. We did--I didn't clearly believe that we were--that we would be able to use a computerized test for executive functioning. But Inara managed to use CANTAB one of the test. And this was because of the proper technique of a standardized, but we had, as I say, she has tried a lot before deciding which tools. And so I think that each team has developed their own diagnostic strategy for prevalence. But then that needs to be inside their own framework. Francisco commented that Inara has a good point because we have been inspired by your group, thank you so much, to start to gather data in Margarita. And the first step had been actually to further educate our specialist in the field which we just recently initiated and then through the creation of a caregiver school. What do you think? I think--I think this is fantastic and I think that really empower your people first, instead of just bringing evaluators from outside. I think it's what's really provided sustainability for

researching other countries. And okay, I have one question from Aida Sandoval. And she is asking about which metacognitive processes control and explain the brain activity in people from the elderly people and I'm not sure--I'm not sure what you mean by metacognitive. I have to say it's not my area of expertise as a--in terms of the cognitive variables that could be most affected, of course, just the memory and executive functioning because a lot of people with hypertension and diabetes, but I know when you're going to say metacognition, you mean "over that" and that, that's really not my area of expertise. Sorry. And Edilisia Polanco asked, "What is the incidence of cognitive factors that interact with hypothyroidism?" And so, I--so thyroid functioning is correlated with cognitive functioning. And depends a lot of the, and in some areas of Venezuela, there has been problems with low salt, so low iodine and so in the past--in the past recent time. We have not been able to find in the Maracaibo population any other--any factor that is particularly relevant for thyroid function to explain cognition. Of the deficits that we have found. Other question is about homocysteine, values in the Venezuelan population and yes we have--we have developed the tables and I will be very glad to show them to let you know, to give you access to that, we have published this and in fact this were the very first homocysteine values for elderly people because we know that with age, homocysteine increases. So we develop normative and preference values for elderly people. And we did this based on the Maracaibo population. So I guess it's--I guess that that could be used for Venezuela. I don't think that there is such a high degree of heterogeneity in the diet or even genetics, to presume that there are going to be differences between the regions, not such as a--this country. And there is another question coming from Colombia. And this, if there are differences in cognitive deficits, and low levels of education. And I think this is a very important question. We have not found differences in the subtypes of dementia, for example. But we have been able to identify more people with dementia in among people with lower education. So because of what I show you about our models for cognitive test, we--and because of the fact that it's not the diagnosis that we make, it's not based on its core but it's based on--it's set by consensus and it's totally multidisciplinary, so we get the physician, we get the doctor, we get the nurse and the psychologist, the social worker to talk about, we make home visits. So we are very, we have a high confidence on the diagnosis we are making. So we--and remember that there is a lot of comorbidity. So low, we have people with low levels of education have less access to healthcare and prevalence of hypertension is extremely high. And let me tell you that in the Maracaibo Aging Study, the prevalence of

hypertension is eighty-five percent. And so you have another comorbidity. So in relationship to other countries, we have half of the cases with dementia are Alzheimer's. And the main--and the vascular dementia is getting there. It's quite significant and a lot of people also with both--with it that have clear Alzheimer's disease but also have significant cardiovascular risk factors. Okay, another question. Thank you and okay. There is another question that says that Lina Marcela Murcia and say thank you to Mr. Kitty Plum. Lina Marcela says that she's a young researcher at Colciencia, this is in Colombia, and she's also in the research group based in the south of Colombia, on Neiva, Colombia. And of course you can--and she said if she can count on our support and that, you know, we'll be very happy. And we have recently also we are being collaborating with--we have been collaborating with Martin Medrano in the establishment of the Santiago Aging Study in Dominican Republic. And hopefully also with our friends in Santiago de Chile. So we look and we have powerful reasons to go to Colombia. So it's, it will be my pleasure. And as I said, there is this Latin America movement sponsored by this research Dementia Group that try to unify the criteria for diagnosis of dementia in Latin America and to have a common, common protocol at least to have a multi-site study. And we're going to meet this April in Buenos Aires, you are all invited here also because I think it's important for all Latin Americans to talk about dementia and prevention. Well, I guess, that's it. Kathy?

Jeff McAllister: I'd like to thank Dr. Gladys Maestre again for a wonderful presentation. And I'd just like to read the statement by Kathy Michels. Thank you everyone for joining and for your questions. The archived presentation and materials will be posted will be posted on the NIVC site and you are also--you are welcome to use that site for virtual collaboration and we invite you to create a profile. We also invite you to join the global Neuroscience and Training Group on LinkedIn and to continue the discussions there.