



February 2020

# WORLD VIEWS

AER International Services and Global Issues Division

---

Welcome to the February 2020 edition of the AER Global Issues newsletter. In this newsletter we have an interview of Gustavo Serrano who helped create rehabilitation services in Chile, we will find out more on the education of students who are blind or visually impaired in Cameroon, and you will be informed about a project for recycling Perkins Brailers for people with visual impairments in Tijuana, Mexico. I also want to acknowledge a recent article in JVIB called “The Effect of Contact Interventions on the Stigma of People with Albinism in Tanzania.” Utilize your JVIB subscription and check it out. It is from 2019, volume 113, Issue 5 (September), pages 464-469.

As you probably know, the big AER International conference is coming this July – in St. Louis, MO. Our division is planning a donation station, where new or gently used educational materials for students with visual impairments outside of North America may be able to use them. Details are developing but you may contact me with any questions. We are also still recruiting for our hospitality committee, where we welcome international guests to the conference and help them to feel welcome throughout their stay.

We’re always looking for ways to improve the Division. Please send any comments, questions, suggestions, or encouragements to Kevin at [kevin3dmack@gmail.com](mailto:kevin3dmack@gmail.com)

Kevin McCormack, PhD, COMS

Chair

[kevin3dmack@gmail.com](mailto:kevin3dmack@gmail.com)

---

## In this issue:

- Interview of Gustavo Serrano of Chile
- Education of Blind Children in Cameroon
- Opportunity to give for PRIISMA in Tijuana, Mexico
- Nonprofit Focus— New Horizon Foundation of the Blind in Ghana

---

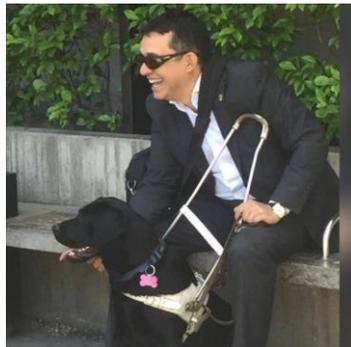
## Interview of Gustavo Serrano



By Carmen A. McLain, OTR/L, CLVT

The international spotlight in this issue is on Gustavo Serrano who has had an important role in creating rehabilitation services for the visually impaired in Chile. Gustavo has been a strong and active advocate fighting for the rights of individuals with disabilities and pushing for policy changes and inclusion reforms. His efforts have not been solely focused on helping the visually impaired. Together with other organizations such as those helping people with cancer, arthritis, pulmonary hypertension, or needing organ transplants, he worked to pass the “Ricarte Soto” law that provides the right to access to treatments and medications for patients who have diseases of high cost. Gustavo also worked passionately to launch the inclusion and diversity reform in the workplace. This effort culminated in the promulgation of the law 21.015 that obligates companies with more than 100 employees to fulfil the quota that at least 1% of its employees have a disability. Gustavo’s advocacy work allowed him to be selected to represent Chile at the 2017 APEC summit in Vietnam.

Let’s hear from Gustavo what life in Chile is like for individuals with a visual impairment and what services are available to them.



**Image of Gustavo sitting on a bench with a dog guide in harness sitting in front of him. The dog guide is Alma, a black Lab.**

### **Can you tell us who you are, where you are from, and a little about your background?**

My name is Gustavo Serrano and I am 44 years old. I am from the city of Santiago which is the capital of Chile. I am a computer engineer. As a child I loved sports. When I was 18 years old I was diagnosed with a degenerative disease of the retina that was hardly known in Chile and that was going to leave me blind called retinitis pigmentosa (R.P.). In 2006, through the internet, I met Dr. Gustavo Aguirre who is a researcher from the University of Pennsylvania. Dr. Aguirre

taught me a lot about my eye disease, and I was able to convince him to come to Chile to talk to those of us affected by R.P. While he was here, Dr. Aguirre encouraged me to create a foundation, which I did in 2009, and I called it Fundalurp. The foundation grew such that in 2017 we established the first comprehensive rehabilitation center for individuals with visual impairment; and in 2018, we added the first dog guide school of Chile.

## **What are conditions like for the blind in your country?**

The situation for an individual with a visual impairment in the state capital is different from those who live in other regions or even in rural areas. As far as client-center rehabilitation services that include competent professionals, the people in Chile with a visual impairment do not have any other option except to attend Fundalurp.

## **What is Fundalurp?**

Fundalurp is a foundation that fights against blindness. When I say “fights against blindness” I mean it fights against the different aspects that afflict individuals with a visual impairment:

1. We seek the cure for blindness so that less people have to deal with it. This is why we are part of a group of 45 countries united under a NGO umbrella called Retina International.
2. We provide independence to people with visual impairments. Today in Chile many individuals with blindness do not leave their homes or they may have a high dependence on others to travel outside their homes.
3. We provide rehabilitation in our Foundation. Our first goal is to get the individual to dream again, and along with it, we provide the tools to help him or her accomplish that dream.
4. For me, Fundalurp is more than an institution. Fundalurp is a home with many members where everyone is welcomed and received with a smile. Those of us who work here are committed to help whoever needs us. The foundation is joy, dreams, empathy, and love.

## **How is Fundalurp funded?**

For the social institutions in our country that are dedicated to visual disabilities it is very complicated to survive due to the lack of support from the government. In the United States, businesses, organizations, and individuals can make tax-deductible contributions to social organizations. In Chile we do not have a tax law that benefits taxpayers for their charitable contributions.

In 2016, we presented sensitivity training on disability to government officials and staff. We presented the program in 48 cities around Chile. This brought into the Foundation half a million dollars, a few small private contributions, and a government grant equal to about 30 thousand dollars that helped us survive until August of 2019. Between December 2019 and January 2020 we have received private contributions that have allowed us to once again keep our doors opened and our services free to our clients.

## **Fundalurp has started the first dog guide school of Chile. What can you tell us about it?**

The dog guide school of Fundalurp started in January of 2018. This project was started by the then Director of Projects of our Foundation, Andrea Moreno, and who now is the Director of the school. The legislation to start a dog guide school in Chile was very complicated but we were successful. To help get it started, we hired an instructor from the Netherlands with more than 10 years of experience in dog training and in training instructors. Today we have 30 future dog guides in different stages of growth and training. We have graduated the first two dog guides from Chile, Amelia and Ema, and we hope to be able to provide 10 more guides in 2020. Our hope is that our program can grow each year. However, it is never far from our minds that each dog costs the Foundation between 30 and 35 thousand dollars. Therefore, our ability to provide dog guides is directly related to the donations that we are able to get to fulfill the dream of more than 100 individuals who are on a waiting list to receive dog guides.

## **Is it a prerequisite for handlers to have good O&M skills prior to getting a dog guide?**

Yes, this is one of the prerequisites in Chile. This is why it is very important for the individuals to get their cane training first at the Foundation.

## **What are the requirements to apply to the school?**

The individual should have excellent use of the long cane, good orientation, be blind or have low vision, and to have the financial means to be able to feed and care for the dog.

## **Do visually impaired individuals in Chile have to pay for the dog guide or for the training?**

No, the dog and the training are completely free.

## **How long is the training for the dog and the handler, and where is it provided?**

The dog guide school is outside of the city of Santiago. When the dogs are around 14 months old their training begins and last from 6 to 8 months. The dog and handler are then brought together to live in the school for 2 to 4 weeks where they receive instruction as a team until they leave together to the handler's home.

## **Can you talk about the impact that a dog guide has made on the lives of the first graduated handlers?**

Alejandro and Maria Jose were our first two handlers to receive dog guides. Both of them have let us know that they have had an enormous change in their lives. For starters, their traveling time has decreased between 50 to 70%. Secondly, the accidents during traveling have

decreased from 70 to 90% and they reported that they are no longer experiencing the serious accidents they were prone to have when traveling with the white cane. In addition, traveling with a dog guide has added invaluable safety to them. They have also mentioned that emotionally the dog has become a partner, a friend, and part of the family.

### **Are you part of the International Guide Dog Federation?**

Yes, we have applied to the Federation since 2018. Both the first instructor that we had, and now the new instructor that will begin in March that is coming from California, are both accredited by the Federation.

### **What are some of the challenges that the dog guide school is still facing?**

The most important challenge is to grow in the provision of more dog guides, and then to follow this growth with the appropriate infrastructure. Our goal is that any of our clients who wish to have a dog guide will always have the opportunity and option to get one.

### **What is next for you? What are your future plans?**

This is a complicated question because, as it relates to work, I am 100% dedicated to the Foundation. A great part of my time is spent fundraising since we are always in danger of closing our doors for lack of funding. Maybe, one of the objectives in the short range is to make sure the Foundation is financially solvent.

On a personal level, I am divorce and a father to a 16 year old daughter; therefore, a future goal for me will always be to be close to my daughter and eventually to also have a stable relationship with a partner. On the other hand, I have friends who are encouraging me to go into politics, so I am also considering this.

### **Is there anything else you'd like to mention that you haven't already addressed?**

I would just like to say to those who are reading this newsletter, and who may have the financial means to help grow this project, that we would deeply appreciate anything you can do to help.

### **How can people find more information on your advocacy work?**

Website:

<http://fundalurp.cl/>

<https://www.perrosguia.cl/>

### **If people would like to connect with you to ask you more questions or to network, how can they contact you?**

Email:  
[presidente@retinitis.cl](mailto:presidente@retinitis.cl)

Phone  
+56 2 2634 1447  
+56 9 9333 8117 (personal phone – Spanish only)

Facebook  
Fundalurp: [https://www.facebook.com/fundalurpchile/?ref=br\\_rs](https://www.facebook.com/fundalurpchile/?ref=br_rs)  
Dog guide school: <https://www.facebook.com/perrosguiachile/>

Instagram  
Fundalurp  
Perrosguíachile

Twitter  
@perrosguíachile

YouTube  
<https://www.youtube.com/user/fundalurp>



---

## Education of Blind Children in Cameroon

By Barbara Johnson

I made three trips to the Northwest Region of Cameroon, spending a total of nine months. Most people in this formerly British colony learn tribal languages at home and learn English by immersion at school. Adults and school age children speak good everyday English, but many people find written English harder to manage. People work subsistence farms and do household chores by hand, in addition to professional work, so they often have little time or inclination for leisure reading.

Whereas most blindness in the US is due to age-related diseases, blindness in developing countries often occurs in children and young adults. Blind children are scattered in far-flung villages. To try to ensure better service delivery, three religious institutions have established residential braille resource rooms, where children are taught braille for two to four years, until they are judged ready for public school. Children often arrive at these residential schools without many skills, because their families have either overprotected or neglected them. Teachers and

house parents try to teach self-care and rudimentary mobility, but they do not know how to give children broad sensorimotor experiences that teach them about the world and build the crucial spatial concepts and hand and arm strength necessary for successful braille reading and writing.

Children in Cameroon have no prospect of having the notetakers and recorders that children in the developed world often receive. Like children in the days before computers in the US, they need to learn braille, but braille books and solid braille training are not yet available. Most teachers have learned braille by sight, as part of a one-year special needs program that familiarizes them with a variety of disabilities. Because the teachers do not know good reading and writing techniques, the children try to devise their own. A few of the brightest manage to succeed, but most read with one hand, so crookedly that they can't read a column of figures. After two to four years of struggle, children often conclude that reading is hard, boring, and mostly about white people.

When the children have learned all that the residential schools can teach, they each receive a slate and stylus. Then they are thrust into public school. Most classes have eighty to a hundred students, and most concepts are presented visually. Transcribers braille tests and other short documents, but there are no braille textbooks. Even if there were, most students cannot read well enough to use them effectively. Because they read so little, they do not learn to think in sentences and paragraphs and therefore cannot take useful notes. The children are socially included but academically excluded, in spite of good intentions and a great deal of hard work by both the students and their transcribers.

I taught a group of college students who were trying and failing to do work comparable to that of their sighted peers. They demonstrated ability to learn orally, but most read at sixth- to eighth-grade level, struggled to write good paragraphs, and could not complete my assignments in a timely manner. One of them said that their professors often give them passing grades, just to "include" them.

Anglophone Cameroon is now embroiled in guerrilla warfare. In an ideal world, we would:

- Set up a textbook transcription program and distribution center, taking account of the need to teach transcribers good written English;
- Set up two activities-based training programs for teachers in residential resource rooms, one in early childhood development for blind children and one in primary level braille reading, writing, and math; and
- Set up resource rooms in public schools that help students learn typing in upper primary school, computer use in high school, math and science notation, mobility, and other age-appropriate techniques as students progress through public school.

If you would like further information on Barbara Johnson's experiences in Cameroon or to connect with her, you may email her at [xchange45@gmail.com](mailto:xchange45@gmail.com)

---

## **Perkins Brailers for Students in Tijuana, Mexico**

### **An appeal from Dr. Nicolas Casias on behalf of the S-CAOMS**

For our annual statewide conference in November 2020, we have imagined a whole new component, specifically a service project in Mexico. We are establishing a partnership with a small non-profit for the Blind in Tijuana, MX called PRIISMA: Project for the Social Inclusion of People with Visual Impairment into Mexican Society. PRIISMA provides instruction in Orientation & Mobility (O&M), Braille, and Sensory Awareness to adults and children with visual impairments and blindness.

After meeting with representatives from PRIISMA, we have assessed that the immediate area of need for the students they serve is access to Perkins Brailers (12 of them).

The following is a brief description of the students in need:

Saúl Sebastián Linares Cruz, six years old and in the 1st grade of primary school  
Thania Sofia Quesada Segundo, six years old and in 1st grade of primary school  
Luis Gael Neri Esquivel, seven years old and in the 2nd grade of primary school  
Diego Felipe Martínez Molina, 16 years old and attending 1st semester of high school

We are excited to announce our Perkins Braille Recycle Program (refurbish/repair) and are reaching out to organizations who may possess out of circulation Perkins Brailers (used or in need of repair). Would your organization have any out of circulation Perkins Brailers that CAOMS could recycle?

I am ready and available to discuss in detail the specifics of our service project mission. Thank you for your consideration!

<http://www.caoms.org>

925-698-8900

[nicholas.casias@gmail.com](mailto:nicholas.casias@gmail.com)

---

### **Nonprofit Focus— New Horizons Foundations of the Blind in Ghana**

The NEW HORIZONS FOUNDATION OF THE BLIND is a Non-Governmental Organization set up by blind and non-blind people; aimed at providing support and empowerment to children and young people who are either blind or partially sighted to ensure their rights to education, health, nutrition, welfare, and employment.

The main activities of the New Horizon Foundation of the Blind would focus on ensuring

inclusive education, providing rehabilitation services including ICT training, mobility appliances to enhance educational and employment opportunities for social integration.

Call +233 24 805 6433

[nhfbghana@gmail.com](mailto:nhfbghana@gmail.com)