

Latin America: Update on the Global Albinism Alliance

By Carolina González, with contributions from Diana Sanabria, Andreza Aguida, Julio Garcia, and Carmen Camacho

Translated by Julio Garcia



Latin America, just like all regions of the world, has a significant number of people with albinism (PWAs). More than twenty organizations dedicated to providing information, guidance, and support for PWAs and their families in Latin America were represented by four delegates at the planning meeting of the Global Albinism Alliance celebrated in Paris, France in January 2020.

To select the delegates, a democratic election was held among Latin American organizations. The seven candidates had to submit presentations in Spanish and English. From the seven candidates, the four elected were:

Andreza Aguida, connected with various organizations in Brazil

Julio García, of *Simplemente Amigos*, Argentina

Claudia Núñez, of *Corporación Albinos Chile*

Diana Sanabria, of *Fundación Albinos por Colombia*, in Bogotá

Andreza Aguida has worked to make albinism visible in Brazil through art and culture. She manages *Albinos Do Meu Brasil e Do Mundo*, a Facebook page that provides guidance and information about albinism. Andreza represented the two registered albinism organizations in Brazil: APALBA in the state of Bahia and ALBINAL in the state of Alagoas. Although there are only two formally registered organizations, Andreza works with other initiatives such as the *Síndrome do pôr do sol* project in the state of Ceará, which collects donations for PWAs in situations of vulnerability in the south of the state, and the PRO-ALBINO project, which offers free dermatologic and ophthalmologic care in the state of São Paulo.

Julio García, appointed to the Secretariat of the Global Albinism Alliance, has a 3-year-old daughter with albinism who is the main motivator for his active participation in all initiatives that can improve the quality of

life of PWAs. The foundation *Simplemente Amigos* has been running for almost five years (legally established in 2019). The objective of the organization is to disseminate information regarding albinism for parents, PWAs, and civil society to promote the notions of equality and respect. The foundation has carried out activities to promote research and technological development. They made possible the National Albinism Law, a bill designed by and for PWAs, defining albinism as a genetic condition and including comprehensive care guidelines by the mandatory health system.

Claudia Núñez has been involved for more than twelve years in the development of support networks for PWAs in Chile. She has also been collaborating with other members of Latin American groups. *Corporación Albinos Chile* was officially founded in 2013, though it has been operating since 2007. This organization has carried out more than ten family day gatherings and a free scientific seminar. In the absence of state information regarding the number of PWAs, *Corporación Albinos Chile* conducted their first census in 2018. This was carried out online through the

hashtag #YoSumo. This initiative was a huge success. During 2020, the organization will be publishing a guide for teachers, developed in collaboration with the Ministry of Education.

Finally, Diana Sanabria is a Colombian scientist who has studied albinism from a genetic perspective. Diana has provided orientation and guidance to parents and families of people with albinism. *Fundación Albinos por Colombia* was founded in 2013 and has carried out two albinism studies in which more than fifty individuals have participated. By gathering this kind of information, the foundation has augmented the visibility of the condition, through science and demystification of erroneous beliefs.

This Latin American team works cohesively with the support of many volunteers working behind the scenes.

Andreza, Julio, Claudia, and Diana are willing to work selflessly as delegates to the Global Albinism Alliance to make the world a much more inclusive place for future generations. This worldwide collaboration is a historic opportunity that will not be missed.



Diana Sanabria
Colombia



Claudia Núñez
Chile



Andreza Aguida
Brazil



Julio García
Argentina