

The Latin American School of Human and Medical Genetics: promoting education and collaboration in genetics and ethics applied to health sciences across the continent

Roberto Giugliani^{1,2} · Guilherme Baldo^{3,4} · Filippo Vairo² ·
Monica Lujan Lopez³ · Ursula Matte^{1,3}

Received: 30 January 2015 / Accepted: 7 May 2015 / Published online: 26 May 2015
© Springer-Verlag Berlin Heidelberg 2015

Abstract The Latin American Network of Human Genetics (RELAGH) created the Latin American School of Human and Medical Genetics (ELAG) to prepare young researchers and professionals of Latin America to deal with the growing challenge of the genomic medicine. ELAG promotes an annually course since 2005, which received 838 students from 17 Latin American countries over these 10 years. ELAG plays an important role to provide education in genetics applied to health sciences to fellows who live in countries with a less favorable economic situation. Influenced, among others, by the humanitarian perspective of José María Cantú, one of its founders, ELAG has always favored the discussion of ethical and social issues related to genetics in Latin America. Few initiatives in Latin America lasted 10 consecutive years. One of the factors responsible for the ELAG's success has been its group of faculty members, who contribute to a friendly environment prone to facilitating the exchange of their own experiences with young researchers.

Keywords Latin American School of Human and Medical Genetics · ELAG · Latin America · Education · Genetics

The growth of human and medical genetics in Latin America demands trained physicians and scientists in both basic and translational applications. Short courses in medical and human genetics for young students and professionals are already a tradition in North America and Europe, such as the Annual Short Course on Medical and Experimental Mammalian Genetics, held in the USA (Bar Harbour), and the courses of the European School of Genetic Medicine, held in Italy (in Sestri Levante, now in Bertinoro). To prepare young researchers and professionals of Latin America to deal with the growing challenge of the genomic medicine, the Latin American Network of Human Genetics (RELAGH), a virtual network of Human Genetics Societies that represents Latin America at the International Federation of Human Genetics Societies (IFGHS) (Giugliani and Matte 2004), and the Institute Genetics for All (Instituto Genética para Todos-IGPT), created the Latin American School of Human and Medical Genetics (ELAG).

The first course of the Latin American School of Human and Medical Genetics was organized in 2005. The school initially dropped “Medical” from its acronym to be known as LASHG (English) or ELAGH (Spanish/Portuguese) and then later dropped “Human” to finally become ELAG, as it is known nowadays all over Latin America. LASG (or ELAG in its Spanish/Portuguese acronym) promotes an annual training course that aims at promoting a “state of the art” education in Human and Medical Genetics, exposing a selected number of top-grade Latin American students to first-rank researchers in the field. In addition to a strong teaching program, the students have the unique opportunity to discuss projects, techniques, clinical cases, and scientific issues with the faculty members.

This article is part of the special issue on “Genetics and Ethics in Latin America”.

✉ Roberto Giugliani
rgiugliani@hcpa.edu.br

¹ Department of Genetics, Universidade Federal do Rio Grande do Sul, Av Bento Gonçalves, 9500, Porto Alegre, RS 91501-970, Brazil

² Medical Genetics Service, Hospital de Clínicas de Porto Alegre, WHO Collaborating Centre, Rua Ramiro Barcelos 2350, Porto Alegre, RS 90035-903, Brazil

³ Gene Therapy Center, Hospital de Clínicas de Porto Alegre, Rua Ramiro Barcelos 2350, Porto Alegre, RS 90035-903, Brazil

⁴ Department of Physiology, Universidade Federal do Rio Grande do Sul, Rua Sarmiento Leite, 500, Porto Alegre, RS 90050-170, Brazil

The participation of students and faculty members from several Latin American countries also aims to stimulate further cooperation among groups inside this region. Special activities were incorporated to enhance contact between students and faculty staff, such as marked-seats lunches (“Lunch with Faculty”), after dinner debates and social events, including a multicultural evening (to which students bring handicraft, food, music, videos, from their country) and a soccer match (Giugliani et al. 2012).

The course (1 week, 40 h) is held in Brazil and receives around 75 students, from almost all Latin American countries, and 30 faculty members, mainly from Latin America, but also from North America and Europe. During the first 10 years, a total of 838 students, from 17 Latin American countries, attended the course (Fig. 1), almost all of them receiving scholarships from the Organizing Committee (with funds obtained



Fig. 1 Number of students from different Latin American countries who attended the ELAG course on its first 10 editions

from public and private sponsors), to cover expenses with accommodation and meals.

Throughout the years, support from the scientific committee (composed of outstanding Latin American scientists and good friends) was decisive and set forth the initiative. To this day, the original scientific committee (Eduardo Castilla, Francisco Salzano, Victor Penchaszadeh, Ursula Matte, and Roberto Giugliani) remains almost unchanged, with the exceptions of Sergio Pena and Gerardo Jimenez-Sanchez, who stepped down due to other commitments, and the early loss of José Maria (Chema) Cantú, who has been replaced by Augusto-Rojas Martinez. Also, highly committed collaborators, who integrate the organizing committee, has been providing the necessary support to organize such a complex event.

Additionally, support from both national and international public funding agencies and private companies (mainly in the biotechnology field) has been instrumental in providing selected students with fellowships covering most of the costs of the course. Such support has allowed the participation of young scientists and health professionals even when economic conditions were unfavorable. In fact, ELAG plays an important role to provide education in genetics applied to health sciences to fellows who live in countries with a less favorable economic situation.

Possibly influenced by the humanitarian perspective of Chema Cantú, ELAG has always favored the discussion of ethical and social issues related to genetics in Latin America. Sometimes, this discussion is done in formal lectures about the subject during the main symposia—mainly related to the application of highly advanced techniques in countries with great inequalities in health access. Often, these themes emerge also embedded in lectures about specific subjects, such as privacy and autonomy issues involved in genetic counseling and predictive medicine. Special lectures on themes related to specific topics involving ethical issues are given at some editions of ELAG. One of them was on the importance of genetic analysis in the identification of abducted children during the military dictatorship in Argentina (Penchaszadeh and Schuler-Faccini 2014). Another issue that has been highly debated was the extent to which the concept of race can be applied to humans. Despite its scientific aspects, this theme has broad ethical implications, especially in countries with such high genetic diversity as in Latin America and where affirmative practices are being discussed and implemented.

Students are asked to qualify the program, speakers, and other aspects related to the course. Evaluations are completed during the course and returned at the end. All items are ranked 1 to 5, and space for additional comments is provided. In general, evaluations are very good, with an average above 4.5. On occasion, if a lecture topic is well ranked but the speaker is not, this may mean that a different speaker will be invited for the next course.

Some years ago, Eduardo Castilla and Guilherme Baldo tried to reach students from the first five editions. The few that

answered (<20 %) were pursuing a career in science, either as post-docs, associate professors, or young investigators. Together with Fernando Poletta, they are now undertaking a more complete analysis, using Lattes CVs (an open platform of curricula from those involved in the Brazilian research system). To avoid a selection bias, they are comparing those students that were selected to the course, versus those who applied but did not rank well enough to guarantee a place in the course (results not yet available).

Few initiatives in Latin America last 10 years, without interruption. To celebrate its 10th anniversary, ELAG sponsored a special edition of the *Genetics and Molecular Biology* (vol 37, 2014) journal that includes contributions from faculty members who have held distinguished roles during the School's many editions (Giugliani and Matte 2014).

The original idea of bringing high-profile scientists in the fields of human and medical genetics together, to spend an intensive week with selected students from all over Latin America, in a friendly environment that facilitates communication, discussion, and exchange of knowledge and experiences, fostering networking and future collaborations, has never been lost. This successful formula was common to both courses that inspired ELAG and has captivated a group of dedicated faculty members who contribute to the event every year.

Acknowledgments We would like to thank all the students, faculty members, RELAGH, UFRGS, and the sponsors that supported this initiative over these 10 years. In addition, we would like to thank Conselho Nacional de Desenvolvimento Científico e Tecnológico—CNPq, Coordenação de Aperfeiçoamento de Pessoal de Nível Superior—CAPES, Fundação de Amparo à Pesquisa do Estado do Rio Grande do Sul—FAPERGS, and United Nations University—UNU for funding.

Conflict of interest All authors declare no conflict of interest.

Compliance with ethics guidelines This article does not contain any studies with human or animal subjects performed by the any of the authors.

References

- Giugliani R, Matte U (2004) The Latin-American network of human genetics. *Community Genet* 7:74–75
- Giugliani R, Matte U (2014) ELAG—10 successful years. *Genet Mol Biol* 37(1 Suppl):147–148
- Giugliani R, Baldo G, Matte U (2012) Latin American school of human and medical genetics and Latin American network of human genetics: promoting education, interaction and networking across Latin America. In: Kumar D (ed) *Genomics and health in the developing world*. Oxford University Press, Oxford, pp 1254–1257
- Penchaszadeh VB, Schuler-Faccini L (2014) Genetics and human rights. Two histories: restoring genetic identity after forced disappearance and identity suppression in Argentina and after compulsory isolation for leprosy in Brazil. *Genet Mol Biol* 37(1 Suppl):299–304