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PERSPECTIVE

Involving the European National Human Genetics Societies

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THE PURPOSE

In order to foster the progress of human genetics progress in Europe, it was proposed to stimulate reciprocal sharing of knowledge and to strengthen the relations between the European Society of Human Genetics (ESHG) and the different European National Human Genetics Societies (NHGSs).

THE DECISION

The ESHG board discussed the idea at the 2005 European Human Genetics Conference in Prague and agreed that it was important to proceed to build stronger links among the European National Human Genetics Societies. This would increase collaboration through discussing themes of common interest, establish a forum that could handle national politics arising in transnational matters, and increase the visibility of human genetics all around Europe. The Board therefore appointed Pier Franco Pignatti to convene a first ESHG-NHGSs meeting, and allocated a budget for inviting the Presidents of the European Human Genetics Societies before the next ESHG conference, in 2006.

THE FIRST (START-UP) MEETING: BRUSSELS AIRPORT 2005

The names and addresses of various representatives were collected with a significant contribution from the EUROGENTEST Project which provided an initial list of the Societies to be contacted, and helped with the local arrangements at the venue (the Sheraton Hotel, Brussels Airport), where the meeting was held on 12 September 2005. Representatives from 25 NHGS attended. Their countries are indicated schematically in the map shown in Figure 1.

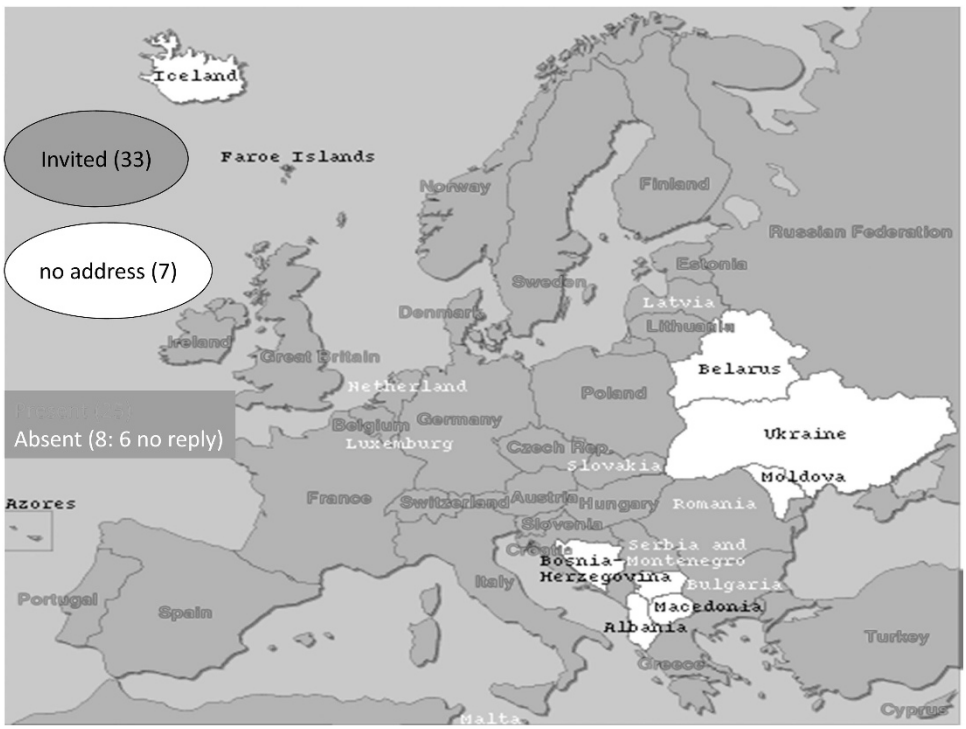

Figure 1 The attendance at the first meeting of the European Human Genetics Societies, Brussels 2005. Representatives from 25 National Societies were present as indicated on the map.

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The agenda included a short presentation from each of the national societies representatives, a welcome speech by the ESHG President Professor Andres Metspalu, a review of potential themes of common interest, and proposals on how the European societies could coordinate some activities and encourage the sharing of reciprocal knowledge. Other issues included in the agenda were an update on the progress of the ESHG request for an EU specialty in medical/clinical genetics, a presentation of the EU project on genetic testing, and discussion on continuing medical education and human genetics education in the EU. To improve and accelerate communication among EU HG National Societies there were suggestions for direct website links with a common English format, among the societies and with the ESHG.

It was felt by all present that the meeting was successful, and it was proposed to have regular meetings of the representatives, who would be nominated by the respective National Societies during their annual conferences.

The proceedings of the meeting are available on the ESHG website (www.eshg.org, under the opening page headline 'Genetics in Europe').

THE SECOND MEETING: ESHG CONFERENCE 2006 IN AMSTERDAM

An effort was made to reach other Societies for which no initial contact had been available, and 31 NHGS were represented at the second meeting. The ESHG itself was very well represented there, with almost its complete Executive Board present, once again showing their interest in networking activities. Updates on the EU specialty request, EUROGENTEST activities, and education in human genetics for geneticists and for non-geneticists were also presented and discussed.

It was proposed that the person representing his/her National Society should be nominated for a three to 5-year term in order to facilitate reciprocal knowledge and relations. It was decided that the ESHG would include a link on its website for the websites for each of the European NHGS to best keep the information updated, and the common format, in English, for all the societies' websites was finally approved.

FOLLOW-UP AND CONCLUSIONS

At the Nice ESHG conference in 2007 (Figure 2) a report on the questionnaires compiled from 36 national societies was presented (Table 1).

At the Barcelona ESHG conference in 2008 the Board decided to strengthen ties with the NHGS by offering fellowships for participants at the annual ESHG conference with abstracts from each of the National Societies, from which 22 proposals were received overall.

Meetings were from then held on every year during the annual ESHG conference, providing a forum where the national issues could be discussed and harmonized into a common European perspective. Topics relevant to all societies were discussed, such as quality assurance and laboratory accreditation, medical/clinical genetics recognition as a EU specialty, specific and competence-oriented training for genetic counseling, core competencies in genetics for health professionals in Europe, free exchange of candidates for the specialization, and many others.

In conclusion, we are happy to see the establishment of a strong European Human Genetics National Societies network, which has been successful in fostering collaboration, education, and research in human genetics across many European countries and beyond.

Figure 2 Group picture of the participants at the third NHGSs meeting, Nice 2007. Kindly provided by Professor Andres Metspalu.

Table 1 National human genetic societies in Europe

	Society			*Meetings*			*Specialization*		
Country	*Name*	*Members*	*Fee*	*Attendees*	*Freq.*	*+/−*	*Name*	*Years*	*B/M/P*
Armenia	H	90	50	NA	1	+	M	10	B
Austria	H	87	50	74	1	+	M	6	M
Belgium	H	177	30	220	1	–			
Croatia	H	220	10	25	4	–	Sub	4+2	M
Croatia	C	89	13–7	50	4	"	"	"	"
Cyprus	H	60	35	40	1	–			
Czech Republic	M	277	5	120	9	+	M	5	M
Denmark	M	203	30	50	4–5	+	C	5	M
Estonia	H	75	13–3	185	2	–			
Finland	M	200	20–10	80	0.5	+	C/Ho	5	M/B
France	H, f	1200	NA	1000	1	+	G/B	4	M/P
Germany	H	1000	120–20	900	1	+	H	5	B/M
Greece	M	192	30	50	2–3	–			
Hungary	H	300	8–4	350	0.5	+	H/C	3	B/M
Italy	H	1071	50–30	843	1	+	M	4	B, M
Latvia	M	25	7	20	4	+	G	5	M
Lithuania	H	41	25	500	NA	+	C	4	M
Macedonia	H	53	10	50	0.5	+	M	3	B
Malta	Hg	4	24	NA	1	+	G	5	M
Norway	M	43	6	14	1	+	M	5	M/M,B
Poland	H	298	10	100	0.5	+	C/L	5	M
Portugal	H	300	40	200	1	+	M	5	M
Romania	M	294	13–4	97	1	–	sub	NA	M
Russia	M	500	3	200	0.5	+	G	2/3	M,B
Serbia	Ms	70	15	40	4	–	sub	4+1	M
Slovakia	M	107	14	92	1	+	M/L	2	M/M,B
Slovenia	H	85	8–4	150	1	+	C	6	M
Slovenia	M	95	10	50	1	"	"	"	"
Sweden	M	70	22	60	1	+	C/Ho	5	M/B
Switzerland	M	50	120	NA	2	+	M	5	M
Spain[a]	H	977	50	≈400	1	+(currently on hold)			
The Netherlands	H	455	20	280	1.5	+	C	4–5	M
The Netherlands	C	230	450	200	0.5	"	"	"	"
The Netherlands	L	100	400	200	1	"	"	"	"
Turkey	M	350	15	500	1	+	M	4	M
United Kingdom	H	1750	70	1000	1	+	C	4	M

Abbreviation: NA, data not available.
Country: 32 countries are listed. Data were received from 29 societies belonging to one country each, and from seven societies belonging to three countries (shown on a gray background). No questionnaire was received from Bulgaria or Ireland. No address is available for Albania, Belarus, Bosnia-Herzegovina, Iceland, Israel, Luxemburg, Moldova, and Ukraine.
Society: 36 societies replied, out of 38 contacted; *name* as follows: 18 Human (H), 13 Medical (M), two Clinical (C), one Laboratory (L), Genetics Societies, one group of human genetics in the college of pathologists (Hg), and one section of medical genetics in the genetics society (Ms), are indicated. One society belongs to a federation of human and medical genetics (H, f); number of *members* varies from 4 to 1750, and total 10,761; fee: annual membership *fees* vary from 3 to 450 €.
Meetings: *attendees* at the last meeting held by the society vary from 14 to 1000, and total 7990; *frequency* per year of the Society meetings vary from 0.5 (ie one meeting every 2 years) to 9.
Specialization: schools are present (**+**) in 24 of 32 countries, absent (**–**) in 8 of 32
Name of the schools of specialization is in nine countries Medical (M), five Clinical (C), three Genetics (G), two Clinical or Hospital (C/Ho), and one, respectively, for Medical or Laboratory (M/L), Clinical or Laboratory (C/L), Human (H), Human or Clinical (H/C), Genetics or Biology (G/B). For 3/8 countries that do not have the school, a medical subspecialization (sub) for pediatricians (Croatia), pediatricians/gynecologists/internists (Serbia), or internists (Romania from year 2006, when the Medical Genetics school was terminated), is available. *Years*: the length of the specialization curriculum ranges from 2 to 6 (or 10, to be checked) years. *B/M/P*: the schools are open for enrollment in 13 countries to MDs only (M), in four countries to MDs or BScs in different schools (B/M), in two countries to MDs and BScs in the same school (B, M), in two countries to BScs only (B), in one country to MDs or Pharm Ds only (M/P), in two countries to MDs or MDs and BScs in different schools respectively (M/M,B).
Data were compiled from questionnaires received by 12.6.07 by P.F. Pignatti.
[a]Updated 15 March 2017.

Pier Franco Pignatti

I studied Medicine in Pavia University, graduating in the Institute of Genetics directed by Luca Cavalli-Sforza. During my studentship, I was a visiting fellow for 6 months in the Department of Biochemistry of Stanford University working on NGF in the laboratory of Eric Shooter. After graduation, I was a research associate for over 2 years at Stanford in the Department of Genetics working on the polymorphisms of Serotonin Binding Proteins with Luca, and continued work on NGF with Eric.

Then an year with an EMBO fellowship at the Pasteur Institute in Paris to work on polyoma virus minichromosome in the laboratory of Moshe Yaniv, 7 years in Pavia University, 3 years in Catania University, and I ended up in the newly established Verona University, where I remained until my retirement in 2016, working mainly on Cystic Fibrosis and related disorders, asthma and atherosclerosis genetics.

I was elected a member of the board from 2003 to 2010, and president in 2006–2007. We discussed the possibility of having a European network of the National Societies of medical genetics so that the European Society would better represent and coordinate continental genetics, as its name implies. I was particularly keen to do this after the experience of having been the president of the Italian Society of Human Genetics. J.J. Cassiman and Els Dequeker for the EU-Eurogentest project produced a first list of national referents from which we started, and the ESHG board has helped a lot with with the organization of the first meeting and establishing fellowships for the participation of representatives of different countries. The project continued with success, European collaboration in genetic research was extended to common activities, and it opened the prospect for a more uniform European human genetics training program.

Feliciano J Ramos

He obtained his MD degree at the University of Extremadura Medical School, Spain, in 1983 and his Ph.D. in Genetics at the University of Zaragoza Medical School, Zaragoza, Spain in 1988. He finished the specialty of Pediatrics at the University Hospital 'Lozano Blesa' in 1988. He had Fulbright Scholarship at The Children's Hospital of Philadelphia, USA, where he did his Postdoctoral Fellowship at the Division of Human Genetics and Molecular Biology from 1990 to 1993. He is Board-Certified in Clinical Genetics by the ABMG, USA (since 1994). He was Assistant Professor of Pediatrics at University of Zaragoza Medical School from 1993 to 1996, full Professor from 1996 to 2006 and Chair Professor from 2006. He was President of the Spanish Society of Human Genetics (AEGH) from 2005 to 2013. He is member of the Royal Medical Academy of Zaragoza since 2011 and correspondent member of the Spain's Royal National Academy of Medicine. In 2014 he was appointed by the Spain's Ministry of Health as the President of the National Commission of Clinical Genetics. He is member of the Experts Committee of the Spain's National Strategy for Rare Diseases and coordinator of the National Reference Center of Cornelia de Lange Syndrome and Cohesinopathies. He is the director of the Clinical Genetics Unit of the Service of Pediatrics and President of the 'Genetics Committee' at the University Hospital 'Lozano Blesa' in Zaragoza, Spain.

He was the President of the European Society of Human Genetics (ESHG) in 2015–2016 and member of the European Board of Medical Genetics (Medical Genetics branch) since 2012.

He is author of more than 100 scientific papers, 48 book chapters, and principal investigator of more than 20 research projects. He is member of the Spanish Pediatric Society (AEP), Spanish Society of Human Genetics (AEGH) and the American Society of Human Genetics (ASHG).

He is currently the Chair of the Department of Pediatrics at the University of Zaragoza Medical School and member of the Board of the ESHG.