THE EUROPEAN SOCIETY OF HUMAN GENETICS

NEWSLETTER

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GertJan van Ommen - A personal account of the Executive Officer

Jerome del Picchia, Executive Officer of the ESHG

It was around this time, 22 years ago that I met GertJan ("Professor van Ommen" at the time) at the ESHG 2000 in Amsterdam. I was an exhibitor, promoting ICHG 2001 in Vienna. Besides the ICHG local host, Gert Utermann, GJ was one of the first "ESHG people" I met at my booth; the other one being Peter Farndon, former ESHG Secretary General. I believe that Jean-Jacques Cassiman introduced us. Little did I know how at the time how many times our paths would cross again over the next 21 years.

Exactly one year later, on the first day of ICHG 2001, one of the staff called me. A delegate would like to talk to me at the registration desk. GertJan. I must admit that I was nervous enough. First day, largest conference I had ever organised, new clients... Well, he let me know that he disapproved of the red laser pointers in the rooms and that we should use green ones, as they were a lot more visible, especially for people with vision impairment.
A couple of phone calls later, we did indeed manage to change that for the next days, and kept them ever since. And he was right. Green lasers are the standard today (they were not at the time).

During this same conference, he came back to see me, letting me know that he was unhappy with the official photographer we had hired to take pictures of the speakers. The shutter sound of his digital camera was too noisy (they were not yet very sophisticated at the time). Combined with the photographer's aggressive "trigger finger", he thought this would be very disruptive, especially for young, inexperienced speakers.

We thought: "Great, another guy who seems to be an expert at everything". Turns out he was. I later learned that he used to work as a music journalist in his earlier days, having written articles for Rolling Stone Magazine among others. His selling point for his editors was that he was amongst those who were able to write the article AND take good pictures of his interviewees.

So I went to see the photographer, and what shall I say. It turned out GJ had a point. Again. The guy's finger *was* volatile and the shutter *was* loud. And he *was* standing in front of the lectern. It was indeed somewhat disruptive, if you were not a routine-loaded senior speaker. He came with a different camera the next day.

Two years later in 2003, as a pre-emptive strike and so that we could start on the right track, we took care to accommodate GJ in a "superior suite" in the headquarters hotel in Birmingham. We had received a couple of complimentary upgrades for the faculty, and he was the president of the ESHG, after all. He came to see me again. My first thought was: "Oh no, something is wrong in the room". He took me aside, and, not knowing that I was the one actually responsible, said in his typical voice:
"They must have made a mistake. They put me in an embarrassingly large hotel room."
"Well Professor van Ommen, that was intentional, you are the president..."
"Tell them thanks!"
"Will do".
So yes, he would also come and see me, when he appreciated things we did.

In all honesty, in 21 years the number of things he disapproved of was probably higher than the ones he appreciated, but the former became less frequent over time. Nevertheless he kept his sharp eye on everything we did, always keeping us on our toes so as not to make the easy mistakes, and we started truly appreciating his comments, always aimed at improvement, and changing the little things to make the experience better for everyone. Once you'd learned how to handle this, he was the perfect client.

Our relationship changed over the years, when I became Executive Officer of the ESHG. The EJHG obviously became one of our main topics from then on. I can only admire the level of dedication he brought to his mission, even when his health started deteriorating.

I was fortunate enough that GJ was in Vienna quite often for a number of years, due to one of his biobanking activities. So my phone rang regularly in the afternoon. "GertJan here. I'm in Vienna. How about a beer on the Campus?" (location of the ESHG Offices). Alternatively, we met for breakfast in his hotel nearby. It was exciting to hear his stories about the old (and not so old) times of ESHG, how things started, evolved, and why many things are how they are now. This

is an experience which I fortunately also regularly shared with Jean-Jacques.

One day, we discussed how difficult it was to organise a nice and memorable conference party. And he told me the story of when he was in charge of hiring the band for the party in 2000 in Amsterdam, where we first met.
"I made a risky choice", he said. "I hired a rock band of men dressed as women, they actually rocked.", followed by a typical 'GJ grin', signalling that he was reasonabily satisfied with himself.
"When the day after the party, I overheard two delegates in the restroom, arguing loudly on whether yesterday's band were actually men or women, I knew that I had made the right choice...". You had.

Report from the Public & Professional Policy Committee

By Francesca Forzano, Chair of the PPPC

The Public and Professional Policy Committee (PPPC) is an interdisciplinary Committee of the ESHG with the mission to contribute to the responsible translation of advancements in human genetics, by identifying and discussing the ethical, social and policy issues related to human genetics and its application in research, clinical practice and laboratory genetic services.
It addresses these issues and provides guidance through background documents, policy statements, recommendations or other publications, and participating in the public and professional debate around these issues.
The Committee collaborates with a range of other societies and organisations such as ASHG-Social Issues Committee, ESHRE and the ELPAG group.

Activities, accomplished

The document Recommendations on Opportunistic genomic screening has been published in the EJHG on November 22nd 2020. They have been presented at the ASHG 2020 conferences in a session comparing European and North American approaches on variant interpretation and opportunistic genomic screening.

The Policy paper 'ESHG warns against misuses of genetic tests and biobanks for discrimination purposes' has been published in the EJHG on January 18th 2021. More activities in this field will ensue.

Activities in the pipeline

The GDPR: what does it mean in practice for our genetic community?
The PPPC together with the EuroGentest Quality subcommittee is working on a document analyzing the impact of the GDPR on genetic practice and research, offering some pragmatic guidance on the do's and don'ts. The draft document is in an advanced state, and will be completed in the second half of 2021 to allow integrating further official EU documents which are due to be released in July 2021.

Cascade Testing: a strategy still underutilized across Europe?
The draft document analysing barriers and offering recommendations is in an advanced state, and we aim to open it for membership review in summer 2021.

Future activities.

The PPPC will launch two surveys in 2021. One will aim to assess the impact of the ESHG recommendations on Opportunistic genomic screening in laboratories and clinics. The second, in partnership with ESHRE, will aim to ascertain the use and impact of Expanded Preconception Carrier Screening in Assisted Reproduction.

In collaboration with a Dutch team led by our Board member Sam Riedijk, PPPC is preparing to launch a series of public engagement events on Germline Human Gene editing. Some population groups might be prioritized, for instance high school pupils. At present the material (video's and questions for debate) is available in Dutch, English and German, and can be translated. Please do let us know if you would like to contribute or arrange events in your own country.

Genomics and Inequity. The ambitious aim of this project would be to take stock of the potential difficulties arising from genomics, especially where they may exacerbate existing societal problems. The longer-term aim will be to establish a strategy for minimising the potentially harmful and/or inequitable effects of pursuing genomic medicine and enhancing its benefits for underserved and otherwise marginalised groups. PPPC has applied for funding to support this plan and we will schedule activities accordingly.

Future topics on the PPPC calendar: Reporting in prenatal setting (together with EuroGentest), and an update of sections of our previous PPPC document on Testing in Minors.

ESHG members having suggestions for new topics to work on, or interested in working on a specific topic as a collaborator are encouraged to contact PPPC via the Chair.
ESHG members interested in becoming a PPPC member are requested to send their CV and a letter of interest stating their expertise and motivation for joining to the Chair.

Members of the PPPC in 2020-2021 were Angus Clarke, Christophe Cordier, Guido de Wert, Florence Fellmann, Francesca Forzano (Chair), Sabine Hentze, Heidi Howard, Hülya Kayserili, Milan Macek, Béla Melegh, Alvaro Mendes, Markus Perola, Inga Prokopenko, Dragica Radojkovic, Emmanuelle Rial-Sebbag, Vigdis Stefánsdottir and Carla van El (Secretary-general). Dr. Fiona Ulph is currently a PPPC collaborator.

Report of the Education Committee (EduComm) 2020-2021: ESHG has a mission to promote the practice and knowledge of Human and Medical Genetics in Europe.

By William Newman, Chair of the EduComm

ESHG has a mission to promote the practice and knowledge of Human and Medical Genet-ics in Europe.
This year the Education Committee has expanded its membership and set out our Terms of Ref-erence. We were delighted to have so much interest from members to join and support the work of this group. Five new members Patricia Calapod (Sweden), Sofia Douzgou (Norway), Sally Ann Lynch (Ireland), Celia Soares (Portugal) and Vita Dolzan (Slovenia) joined the team in January.

In addition, we have also two members Can Ding (Germany) and Elena Avram (Romania) join our group from ESHG-Y to represent the views of young geneticists and to highlight their specific educational and training requirements. Jim O'Byrne from Ireland has been co-opted onto the group and has brought his experience and interest in precision medicine and biochemical genet-ics. This increased membership has significantly expanded the geographical spread of members and will allow us to more accurately reflect the needs of the Society.
The Coronavirus pandemic has continued to have a major impact on educational activity. This has especially affected the delivery of a number of the courses that were planned over the past year.

A number of courses have been postponed till 2022. Inga Prokopenko and colleagues ran a very successful online course on the statistical analysis of GWAS with 68 attendees and very positive feedback. This online format was able to deliver the same content as the previous face to face course, including workshops. Eleven faculty led the course over five days and ensured that computer fatigue was kept to a minimum by splitting lectures into lectures 15 minute blocks.

We hope soon to be able to provide an update on the ESHG website about plans for rearranged courses for next year. We are still keen to receive applications and ideas for future courses that will cover areas not currently represented.

The DNA Day Essay writing competition has been held again in 2021 with an essay title of "We can now sequence the genome of all life forms, from viruses to humans. What could be the point of this?"

The wonderful EuroGEMS site www.eurogems.org led by Prof Ed Tobias has gone from strength to strength with great progress on its translation into Spanish.

We have set up a mentorship scheme for young scientists and health professionals in genetics to take the opportunity to visit a specialist centre and to combine this with attendance at the Annu-al conference. The scheme was delayed in its launch due to the pandemic, but we will open for applications for 2022 later this year.

We plan to have a number of online school children events linked to the online Conference lead by Ed Tobias and colleagues in Glasgow and by Johan den Dunnen linked to the Biology Society in the Netherlands. We hope to expand the range of online interactive school events for students across Europe in years to come as our public education program expands. Further, to increase the engagement of the education program delivered by the ESHG we have submitted a paper to a special education issue of Frontiers Genetics called The Importance of Genetic Literacy and Education in Medicine.

If you have any ideas/comments regarding the work of EduCom please contact me at:
william.newman@manchester.ac.uk.

EJHG Highlights 2020

by Alisdair McNeill, Editor in Chief, EJHG

As for everyone, 2020 was a challenging year for the European Journal of Human Genetics. Both our Editor-in-Chief Gertjan van Ommen (1, 2, 3) and Associate Editor Albert de la Chapelle (4) passed away. In recent years GertJan had worked tirelessly to ensure a strong performance of European Journal of Human Genetics.
Publication in the European Journal of Human Genetics remains competitive, with only around 30% of submissions being accepted.

In late 2020 I was honoured to be appointed as Gerjan's successor as Editor-in-Chief. The current climate is challenging for medical journals, both because of the COVID-19 pandemic and changes to medical publishing such

as Plan-S. Our immediate priority is to continue to attract high quality submissions, from researchers worldwide. To attract high quality submissions, we have developed a strategy of helping authors to promote their work. Firstly, by active engagement via social media and a monthly twitter journal club. Secondly, by encouraging authors to produce "lay summaries" of their work which can be used to engage with families affected by genetic conditions. Thirdly by making a small selection of papers freely available to encourage accessing of the work and citations.

To facilitate timely and fair handling of submissions we have expanded our group of Section Editors. I would like to welcome Elizabeth J. Bhoj, (Children's Hospital of Philadelphia, USA), Shahida Moosa (Stellenbosch University and Medical Genetics) and Philippe Campeau (University of Montreal) as Clinical Genetics Section Editors. Felicity K. Boardman (University of Warwick) adds her expertise as Psychosocial Section Editor and Yalda Jamshidi (St George's University of London) Molecular Genetics Section Editor. The next step in developing our Editorial team will be to advertise for an Associate Editor. I would like to thank all of the Editorial team for their hard work, without which the journal could not function.

The European Journal of Human Genetics continues to engage with the genomics community via Social Media. Our Twitter account now has approaching 6 000 followers. As many of you will know, the Altmetric score is a measure of the attention (outside of conventional academic citations) which a publication is receiving on Social Media and the press. Many of the European Journal of Human Genetic's papers perform very well in terms of their Altmetric score; demonstrating the reach and impact of our journal. Papers on population genetics often perform surprisingly well. Indicating the appeal of EJHG beyond narrow clinical genetics and laboratory genomics audiences.

After many years, the ESHG executive committee and I decided we should discontinue the Clinical Utility Gene Cards. We felt that medical publishing had moved on and that better sources of information were available on these topics. In addition, given the rapid pace of research in genomics, they rapidly became outdated. We also remain highly selective in which case reports we will accept. Case reports should reveal highly novel insights into the molecular genetics, pathogenesis or clinical phenotype of a genetic disorder.

In June 2021, the editorial office will relocate from Leiden to the University of Sheffield, with an Editorial Assistant based here. Despite this physical relocation, the submission process and handling of manuscripts will be via the existing online manuscript tracking system. We would encourage members of the European Society of Human Genetics to submit their next manuscript to their society journal: the European Journal of Human Genetics.

[1] https://www.nature.com/articles/s41431-020-00777-7

[2] https://www.nature.com/articles/s41431-020-00787-5

[3] https://www.nature.com/articles/s41431-021-00840-x

[4] https://www.nature.com/articles/s41431-021-00863-4

Annual report ESHG-EuroGentest Committee 2020-2021

By Gert Matthijs, Chair of EUGT

EuroGentest, that started as a project funded by the European Commission in 2005, is an integral part of ESHG since 2013. ESHG-EuroGentest focusses on quality aspects for genetic services, prepares professional guidelines related to genetic diagnostics, provides training and represent the society at international forums related to genetic services.

As in previous years, the Quality Subcommittee has been most active! The committee deals with issues that affect quality and competence of the diagnostic genetic and genomic laboratories, clinical genetics and genetic counselling. The committee has continued to be active during the COVID-19 pandemic and has met the annual objectives albeit in a different manner. The annual review of the EQA Providers performance data was completed for the 2019 EQAs and the data is being collected for the 2020 schemes to be reviewed in June. The committee has stood up a very proactive authorship with expertise from Clinical Genetics, Biochemical Genetics, Cytogenomics and Molecular Scientists and Bioinformatics to review and update the current 'Recommendations for reporting results of diagnostic genetic testing' published in 2013. As genomic testing has evolved considerably since that time then a refresh of the recommendations is very welcome.

The Performance monitoring workshop scheduled for 2020 has been postponed and will be delivered in a virtual format later in 2021. This workshop is aimed to scope out the requirements to implement performance monitoring at a national level, share the learnings from countries with performance monitoring in place and also discuss the challenges of other countries where this may be difficult to achieve. The members of the EQA Providers Forum and National Representatives will be invited along with representation from the European Accreditation bodies.

The Quality Subcommittee includes the monitoring of performance of Clinical Genetics centres as well as laboratory medicine and therefore is scoping out the provision of a survey of current practice through a Clinical Genetics Service Quality Questionnaire.

The Subcommittee has maintained engagement with the EUGT-PPPC and welcomes the joint initiatives planned going forward. Work has also included the participation in the ongoing discussions around IVD regulation and GDPR compliance.

Prof Sandi Deans is standing down as Chair of this committee therefore any individual who is interested in being involved in this active group should contact the Deputy Chair Prof Christi van Asperen (C.J.van_Asperen@lumc.nl).

I sincerely thank Sandi Deans for her commitment to the work of the Quality Subcommittee and to the spirit of EuroGentest.

The IVD-Regulation remains a major challenge to genetic diagnostic laboratories. The regulation has now been translated into national law in several countries. It imposes the use of CE-IVD marked kits from May 2022 on. However, Art. 5 of the regulation allows the use of a laboratory developed test (LDT) when no CE-IVD kit is commercially available for the same diagnostic application. To obtain such an exception, laboratories have to operate under ISO 15189. Still, to keep using the LDT, extra requirements have been included in the regulation, i.e. the LDT has to fulfil the requirements of Annex 1. Thus, even if the IVD-Regulation has been developed to contribute to quality in diagnostic testing, in practice, it may badly affect the genetic laboratories, in terms of the freedom to use LDT and the incentive to develop novel diagnostic applications. It looks like the IVD-R will, in some instances, lead to worrisome situations. For instance, the burden to provide the evidence that the CE-IVD marked kit may perform less well lays with the users i.e. the genetic laboratory. We are lucky to have Prof Els Dequeker representing ESHG-EuroGentest in the European expert panel related to the implementation to the IVD-R. We urge all our colleague to engage at the national level to try and interact with the national authorities on the practical implementation of the regulation.

There is better news as well: the ESHG-EuroGentest Guidelines Subcommittee has completed the revision of the guidelines for genomic diagnostic testing and extended its remit to WGS applications in the clinic. I sincerely thank all our colleagues and representatives of different stakeholders who have joined the committee to discuss about the novel guidelines and provide valuable input. We were lucky to benefit from financial support from the Solve-RD project to fund the workshops where the guidelines took shape. The final draft has just circulated amongst the experts, and will soon be submitted to the Board and Membership of ESHG for endorsement. After that, we look forward to publish them in the European Journal of Human Genetics.

ESHG-EuroGentest is also involved in the European Joint Programme on Rare Diseases (EJP-RD) for training of clinicians, laboratory scientists, policy makers, patient association representatives and others, in quality assurance, variant interpretation and data management in the NGS diagnostics era. After we organized the first course in Leuven in 2019, the second course – online, necessarily – was led by Prof Ugur Ozbek and colleagues from Istanbul in 2020. In the fall of 2021, the third course will be organized by Dr Domenica Taruscio and co-workers and will – hopefully – be live in Rome. For information and registration, please check https://www.ejprarediseases.org/event/quality-assurance-variant-interpretation-and-data-management-in-the-ngs-diagnostics-era/ .

Finally, I gratefully acknowledge the time and effort spent by the colleagues who have voluntarily contributed to EuroGentest-ESHG achievements and output over the last year. We are keen to grow and extend the activities of our committee and subcommittees. Please feel free to contact me at gert.matthijs@uzleuven.be if you wish to join us in this great endeavour.

Annual Report from the European Board of Medical Genetics

by Milena Paneque, Chair of the EBMG 2020-2021

The European Board of Medical Genetics (EBMG) is moving towards its 10th anniversary, maintaining as its main purpose to serve the needs of patients of genetic services in Europe through ensuring good standards of practice of its three professional core groups. These professional groups are represented by specific branches of the EBMG, the Clinical laboratory geneticists (CLGs); the Genetic nurses & counsellors (GNGC) and the Medical Genetics and Genomics (MGG).

During this year our efforts were centred on the common goal of fostering the recognition of the professions of our three groups. This taskforce allowed an articulated work of the three branches and resulted in a Position Statement, which is currently being submitted for the endorsement to the main umbrella associations of our specialities, the European Society of Human Genetics, its Public and Professional Policy Committee (PPPC) and plans to also reach out to the coordination of the National Societies of Human Genetics and relevant media.

We expect that the European Professional Qualifications Directive will support the professionalization of genetics healthcare in Europe in the near future. However, currently there are not enough countries with formal systems to support the recognition of the Clinical Laboratory Geneticist and Genetic Counsellors as an EU designated specialist profession. Therefore, all the rigorous work of professional registration and the definition of training and professional qualification standards remain important pillars to promote the quality of practice and to ensure patients safety at clinical and diagnostic activities in the European genetics healthcare services.

This year we have met monthly for the follow-up of all our

activities. As a result, we have revised our original statutes and have finished the assessment of a new cohort of professional registration applications, as well as renewals. At present, more than 500 professionals are certified by the EBMG.

The EBMG has adopted new Statutes at its General Assembly (GA) in September 2021. They replace the original Statutes set up in 2015 at the very beginning of the EBMG and became necessary in order to achieve consistency between the statuary framework of the EBMG and the developed activities. The revision of the Statutes was led by Ulf Kristoffersson, extensively discussed by the EBMG Executive Committee and the Branches, and excellent legal advice was given by Jerome del Picchia, Executive Officer ESHG. The Statutes have been published on the EBMG website (https://www.ebmg.eu/fileadmin/eshg/EBMG/EBMG_statutes_GA_2021_.pdf).

The Statutes describe the EBMG bodies, their composition and procedures in detail. The GA is an assembly of the full members of all three Branches and the executive committee (Exec), and is the highest authority of EBMG. The GA elects the Exec (president, incoming president, past president, general secretary, deputy general secretary and treasurer). The presidency is held for one year and should preferably be rotating on an annual base between the three Branches. The Exec forms together with the Chairs of the professional Branches the EBMG Council which is advisory to the Exec.

The three professional Branches are not legally independent to the EBMG Exec and GA, but they organise their activities independently from each other as deemed necessary by their respective professional specificities. Each Branch is now committed to define Standard Operational Procedures regulating its activities.

Report of the CLG Branch

The CLG branch worked on 29 successful reapplications and 29 new applications of ErCLGS. Concerning the latter group 19 candidates were principally accepted, however, 10 of those used group-3-way and have to do a final test before they can be potentially approved as ErCLGs. However, 20 candidates being eligible for prolongation of the title did not reapply again. Still, the number of registered ErCLGs is actually at ~390.

At present committee members from Spain, Greece, Portugal, France and Croatia are active to enable candidates from 2019/2020 and the actual round, a finalization of their application by the written and oral part. We are optimistic that by this way ~2/3 of the pending applicants can be provided with an offer to finalize their applications in 2021. For all candidates with delay in finalizing their applications due to pandemia an exceptional procedure has been introduced, i.e. their title starts in the year they finalize their application and not in the year after they applied for it (as usual).

Besides, for time after Corona, we started on the initiative Open Lab for ErCLG education and exchange: We suggest that labs throughout Europe which would be open to receive "Clinical Laboratory Geneticists in education" and also full educated people who are interested to learn new methods can mail to Thomas Liehr (Thomas.Liehr@med.uni-jena.de) and are then included in the list on https://www.ebmg.eu/669.0.html. This means these labs can be contacted and 1 to 15 day internships may be requested and arranged with that lab for free - provided the person comes from a lab working in Human Genetics diagnostics. Traveling and living costs for sure need to be covered by the guest. Yet, we have already eight guest labs and we would be more than happy to receive additional notifications on enrolment, soon.

All details on ErCLG registration can be found on https://www.ebmg.eu/clg.0.html. The (re-)registration process starts this year again on 15th. July – see https://www.ebmg.eu/695.0.html. Here you can now also find: (i) general information, and eligibility criteria and (b) step by step instructions.

Finally, also due to Corona-pandemics, the yearly course for ErCLGs in education had to be canceled.

Report of the Medical Genetics and Genomics Branch

The most important event in the history of the Branch of Medical Genetics and Genomics (BMGG) is the formal establisment of the "Board of National Delegates". The primary role of this group is to help the launch of the "CME Registry", which endeavor will serve the pan-EU harmonization of the inventory of practitioner colleagues with official national licences. Besides this the BMGG started to work on renewal of the existing MoU with the strategic partners; and efforts are in progress to revise the current internal structure of the Branch, including the delegation/election system for installation of next Branch members. We initiated a partnering with young doctors of ESHG, by official establishment of a new working group for them in the Branch.

Development of the branch after May 21

BMGG represents the Branch of Medical Geneticists within the EBMG. The purpose and goals of the EBMG and its branches, which are expounded in the Statutes, overlap with those of the Section of Medical Genetics of the European Union of Medical Specialists (UEMS-SMG, see www.uems-genetics.org). Whereas UEMS is an organisation of medical specialists, with medical genetics being one of many specialty sections, the EBMG represents all professions in the field of medical genetics and offers the opportunity of interprofessional exchange. The aims of the BMGG are the establishment, harmonisation and raising of professional standards relating to the education, training, qualifications, practice, and continuous education of medical geneticists in European countries.

In June 2021 BMGG voted for a new structure. As with the other Branches of the EBMG, it comprises 10 full members. The BMGG members are all specialists in Medical Genetics and now consist of:

- The five Bureau members of UEMS-SMG, i.e. President, Secretary, Treasurer, Vice-President, and Chair of the Examination Committee;
- Three persons delegated by the ESHG: an ESHG Board member, a member of the ESHG Education Committee, and a member of the ESHG Young Geneticists Committee;

- Two persons nominated by UEMS-SMG, ESHG, or EBMG. EBMG-BMG calls for nominations; then the ESHG, UEMS-SMG, and EBMG seek a consensus on these nominations. In the event of not reaching a consensus, or too many nominations, the Assembly of National Delegates of UEMS-SMG has the right to elect the two members among the candidates.

The President of UEMS-SMG is the Chair of BMG. The mandate period of the UEMS-SMG Bureau members is according to their mandate as UEMS-SMG Bureau members. The mandate period of the other five delegates is four years, beginning with the EBMG General Assembly (GA) meeting, and is renewable for one further 4-year period.
The current BMG members are:

- Yvonne Arens, The Netherlands
- Jonathan Berg, UK
- Birgitte Diness, Denmark
- Thomas Meitinger, Germany
- Ute Moog, Germany (Chair)
- James O'Byrne, Ireland (ESHG Education Committee)
- Angela Peron, Italy (ESHG Board)
- Feliciano Ramos, Spain
- Delia Sabau, Romania (ESHG-Young Geneticists Committee)
- Peter Turnpenny, UK

For the next few years BMG will work collaboratively with ESHG and UEMS-SMG, in particular on:

- the review of European Training Requirements for the specialty of Medical Genetics, which comprises a definition of requirements for trainees, for the training programme, and for training centers;
- the further development of the European Certificate in Medical Genetics and Genomics (see www.uems-ecmgg.org);
- a CME/CPD registration system, beginning with a survey in all countries regarding existing systems and the need for a European registration system;
- clarification of the respective roles and relationships of the three organisations – EBMG, ESHG, and UEMS-SMG.

Report of Genetic Nurse & Genetic Counsellor Branch

The Genetic Nurses and Genetic Counsellors Professional Branch had an intense year of activities due to the Covid pandemic.

In summer 2020, nine genetic counsellors achieved registration – congratulations to them all. The second cycle of registration renewal applications were received in spring 2020; results were announced in autumn 2020 with 16 genetic counsellors successfully renewing their registration. The next cycle of registrations and renewals is currently under review and the results will be announced in June 2021.

Access to counselling supervision remains difficult for many genetic counsellors, and for some, remains a barrier to registration or renewal. As a Board, we support and encourage all initiatives undertaken by counsellors themselves or by national societies to promote access to this type of supervision, which is essential for counsellors and patients' safety.

We would like to share with you some changes that we have been made trying to improve the functioning of the branch and the registration system:

- For the assessment of Masters programs, a standard annual timetable has been established (https://www.ebmg.eu/959.0.html) as the number of programs requiring assessment has increased significantly. Submissions for assessment of new MSc programmes begin each year in June and assessment results are announced the following October. Submissions for renewal of EBMG-accredited MSc programs begin each year in October and assessment outcomes are announced the following February. There are also further changes to the assessment of Master programs: EBMG accreditation of an MSc course is now valid for 6 years and the fee has also been updated (https://www.ebmg.eu/883.0.html).
- A mentorship program has been set up for counsellors applying for the EBMG accreditation. At present, this option is offered to candidates who need to improve and resubmit their application, with the goal of having a senior registered genetic counsellor to guide them through the process of registration. The first experience of the mentorship program has been a success and we would like to thank the senior registered genetic counsellors who have mentored an applicant.
- During this year, we undertook an in-depth reflection to reorganize the functioning of the branch. As a result, we are now organized into committees within the branch to better organize our tasks and responsibilities. New email addresses for different topics (registration, renewal, and master's programs) have also been created. They are listed on the website (https://www.ebmg.eu/885.0.html).
- Branch members are completing their 4- or 8- year term on a staggered basis. To recruit new branch members and with the aim of increasing transparency, an open call for new branch members was held in early May 2021. Registered genetic counsellors wishing to join the branch should send CV and an expression of interest letter to the branch email (gcgn.ebmg@gmail.com) by the end of May.

Because of Covid, the Branch held its annual meeting online during the first week of March. As we did last year and due to the Covid, the 'open meeting' for all genetic counsellors normally held during ESHG will be replaced by a newsletter. We look forward to resuming our face-to-face meeting next year and seeing each other again.

During this year we have welcomed in the branch Anna Abulí (Spain) and Emeline Davoine (Switzerland), who were accepted as members at the EBMG meeting of June 2020. Due to the unexpected departure of a member in December 2020, we welcomed Elen Siglen (Norway) to the branch. Elen's membership will be brought to the EBMG meeting in June 2021. We are very pleased to have them as members and we wish them a satisfactory time in the division. We also would like to thank Irene Feroce (Italy), Debby Lambert (Ireland) and Marion McAllister (UK) for their commitment to the division during the time with us.

Clara Serra (Spain) will continue as Branch Chair from June 2021 to June 2022 with Joana Bengoa (France) as co-chair. The remaining co-chair will be appointed by the branch before the EBMG meeting in June 2021.

We would like to thank all registered GC & GN for supporting the process of professional regulation of genetic counselling in Europe.

For more news and updates, please visit our website: https://www.ebmg.eu/408.0.html

Finally, after a truly extraordinary year, due to Corona-pandemics, as the President of our Board, I would like to acknowledge the invaluable contribution of all members of the professional Branches of the EBMG and the Exec committee. It is because of their great commitment that all those achievements were possible.

Last but not least, we would all like to thank Jerome del Picchia and the WMA staff for their administrative support.

Introduction of the new ESHG Board Members 2021-2026

Olga Antonova, MD, PhD

Olga Antonova is an experienced medical geneticist and a senior assistant professor at the Department of Medical Genetics, Medical University of Sofia, medical geneticist in Re:Gena® - a biotechnology company and a scientific leader in several project related to the study of biomarkers that facilitate the treatment of bladder cancer. In 2018 she was among nominated distinguished young scientists in Bulgaria and was honored to represent her country in a group of scientists at JRC, Ispra, Italy as a successful scientific leader and project manager.
Dr. Antonova is involved in genetic counseling, teaching as well as research activities and innovation. Her professional interests are in the field of disease prevention, precise medicine and health consequences of interaction between the human genome, nutrition and the environment. For several years now, Olga has been working in a field of nutrigenetics and nutrigenomics and has therefore begun residency in "Nutrition and Dietetics".
As a medical genetic specialist Olga Antonova has been actively promoting the potential of medical genetics not only among medical and pharmacy students, but in the medical society. Therefore she is enrolled in explaining the activity and possibilities of clinical/medical genetics in the prevention of rare and socially significant diseases. This is done in the form of webinars, publications in popular science and popular magazines, interviews, as well as developed for the purposes web-site (www.olgaantonova.bg), page in facebook (@MDgenetisc) and LinkedIn (https://www.linkedin.com/in/olga-antonova-boyanova-b79b6786/).

Julia Baptista, PhD

I am delighted to join the ESHG board and to contribute my eclectic scientific and professional knowledge in helping shape the decisions faced by our society at a time when genomics is so thrilling.
I grew up in Portugal, was born in Mozambique and did most of my training in the UK plus a postdoc in Italy. I have spent the last 18 years working in genetics as a clinical scientist in diagnostic service, as a researcher in academia or as an educator developing knowledge and methods to enable patients with rare disease to benefit from early and accurate diagnoses. I have been a leading scientist in the exome service for acutely unwell children in the UK and am now dedicating the next stage of my career to developing better managers and leaders in the health and care sector through my appointment as a Lecturer in Clinical Education at the University of Plymouth. Quality, patient safety and innovation are at the front and centre of my work as well as a recognition that we can do more for patients and our society when we invest in education beyond clinical and scientific skills and bring in attributes like authenticity, understanding and inclusivity to our everyday.

Ingo Kurth, MD

After studying medicine and training in neuroscience, I came to human genetics and since 2016 have been head of the Institute of Human Genetics at RWTH Aachen University, Germany. Aachen's location on the border with Belgium and the Netherlands already promotes a European perspective. With a focus on neurogenetic and pain disorders, I coordinate a European network on hereditary sensory neuropathies and insensitivity to pain (ENIS-NIP). In our daily consultations at the Institute, however, we see a wide variety of genetic disorders and in a team of dedicated staff with different training backgrounds we aim to understand the causes and mechanisms of genetic diseases. In this process, it becomes absolutely clear: genetics arrives in the clinic. We and subsequent generations of geneticists will be able to offer patients very different ways of diagnosing and causally treating their disorders. It is a great honour to be a board member of the ESHG, and in this role I would like to promote that European geneticists collectively gain the visibility they need to actively implement genomic medicine.

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Ramona Moldovan, PhD

I am currently a Professor of Clinical Psychology and Genomics at the University of Manchester, UK, and hold an academic appointment with Babeș-Bolyai University, Romania. My professional time is divided between teaching, clinics and research. My teaching commitments are split between genetic counselling and psychology. My clinical and research activities are focused on rare conditions, with a special interest in neurodegenerative and psychiatric disorders.
I have been actively involved in the ESHG community for the last 10 years, as member/co-chair of the Genetic Counselling division of the European Board of Medical Genetics (EBMG), member/co-chair of European Meeting of Psychosocial Aspects in Genetics (EMPAG) and member of the Scientific Programme Committee (SPC). I have seen first-hand what a dedicated team can do in terms of setting up unified standards for education, practice and registration for genetic counselling throughout Europe; or annually designing the scientific programme for nearly 5,000 professionals. I am delighted to be a member of the ESHG Board and I hope my background and pan-European experience can contribute to the multidisciplinary nature of genetics, provide diversity and bring enthusiasm within the ESHG.

Markus Nöthen, MD

My interest in human genetics commenced during my undergraduate medical studies. After graduation, I therefore decided to enter specialist training in this field. During this period, I became fascinated by human genetic research, in particular the molecular genetic analysis of multifactorial disease. In the early 1990s, this field was still very much in its infancy. However, secondary to methodological advances in the characterization of genetic variability, molecular genetic analysis has since proven to be an extremely successful strategy for the systematic "mapping" of the biological causes of disease. Increasingly, findings in this field are opening-up new, exciting avenues for diagnostics and therapeutics. I am convinced that in order to realize the full potential of these advances, maximizing cooperation across research teams and research sites, ensuring the input of diverse scientific disciplines, and engaging in active dialogue with patients will be essential. To achieve this, a dedicated, multi-national community of human geneticists within Europe is essential. I consider the ESHG the perfect platform for this purpose. A further key aspect of my work is to support the career development of young scientists, particularly with respect to the issues of equality and diversity. The work of the ESHG thus reflects my personal scientific and ethical priorities and goals. My firm intention is to make an active contribution to the shaping of the future development and vision of the ESHG.

Angela Peron, MD

I am a clinical geneticist in Milan (Italy) and an adjunct assistant professor at the University of Utah (USA). As a practicing clinician, I have a strong interest in neurodevelopmental disorders and dysmorphology. My research focuses on Tuberous Sclerosis, syndrome delineation with a special attention to the phenotype of adults with rare neurodevelopmental disorders, and genetics of epilepsy. I am also committed to mentoring medical genetics residents here in Italy.
As a representative of the new generation of professionals in the genetics field, I strongly believe in the active involvement of young members in scientific societies. As an ESHG board member, I will be delighted to promote the involvement and networking of young genetics colleagues across Europe.
I am also part of the examination group of the European Certificate in Medical Genetics and Genomics (ECMGG). My goal is to work with the Branch of Medical Specialists in Medical Genetics and Genomics of the EBMG and the UEMS Section of Medical Genetics to develop and promote this newly introduced and important exam in Europe, as an ESHG representative to EBMG-BMGG.
I feel honored to be part of the ESHG board, and am looking forward to contributing to the ESHG mission.

Sam Riedijk, PhD

My name is Sam Riedijk and I work as a medical psychologist and associate professor at the Clinical Genetics dept of the Erasmus MC in the Netherlands. As a medical psychologist I mostly work with pregnant couples faced with fetal anomalies. In research I am principal investigator of the Social Genomics research team, and we focus on public engagement and deliberation on human germline gene editing as well as on dealing with uncertainties in prenatal genetics. Furthermore, I lead the development of the 2-year research master Genomics in Society which is due to start in September 2022. I am delighted to be part of the board and hope to contribute to the ESHG from the ELPAG domain.

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