

Annual Report 2018

European Hematology Association

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INTRODUCTION

This Annual Report contains an overview of EHA's activities in 2018, all executed to support EHA's mission:

"The European Hematology Association (EHA) promotes excellence in patient care, research and education in hematology."

'Towards a cure for all blood disorders'

In 2018 more hematologists in- and outside Europe were able to benefit from our projects and programs, of which an overview is presented in this annual report. Rapid developments in hematology research and clinical practice, but also in the regulatory and technical environment challenged us to strive for excellence and professionalism in what we do and what we deliver.

At our Annual Congress in June 2018 in Stockholm, Sweden we welcomed 11.000+ hematologists, while we organized another 10 meetings in and outside Europe to share knowledge and information on specific topics. In addition, a new online learning platform was selected, the first EHA Guideline was published, and two mentoring programs -one on clinical and one on translational research- were organized to accelerate talent amongst a carefully selected group of young researchers. Also, in 2018 we launched EHA Topics-in-Focus, a new initiative to raise awareness, provide education and promote research on two emerging topics; Immunotherapy and Hemoglobinopathies. This is just a selection of our 2018 activities driven by the EHA Board and Committee members and the numerous volunteers we collaborate with. With our projects and programs, we aim to serve the interest hematologists in their journey towards a cure for all patients suffering from blood disorders.

Professor Pieter Sonneveld
EHA President

ABOUT EHA

EHA is a non-governmental and not-for-profit membership organization guided by its mission and core values of independence, integrity and transparency. Our Executive Board and Committees dedicate expertise and time on a voluntary basis. With our projects and activities, we serve the interest of hematology and hematologists with the goal to improve patient care. To ensure that these interests are fulfilled, EHA has several instruments in place.

How EHA is formed

The EHA Board is the governing body of the association and deals with issues of strategy and policy. The Board sets the goals and objectives in conformity with EHA's statutes.

The Executive Board consists of:

- Pieter Sonneveld, President
- Tony Green, Past President
- John Gribben, President-elect
- Elizabeth Macintyre, Secretary
- Shai Izraeli, Treasurer

The EHA Board sets up committees and units to perform specific tasks and activities. Below is a list of active EHA committees:

- Curriculum Committee
- EHA Learning Center Editorial Board
- European Board for Accreditation in Hematology
- Education Committee
- EHA-ASH TRTH Joint Oversight Committee
- European Affairs Committee
- Fellowships and Grants Committee
- Global Outreach Program Committee
- Good Governance Committee
- Guidelines Committee
- Membership Committee
- Nomination Committee
- Online and Case Unit
- Research Committee
- Scientific Program Committee, 24th Congress
- SPC Advisory Board, 24th Congress
- Sponsor and Fundraising Committee
- SWG Unit
- YoungEHA Committee

The EHA Board and its committees are supported by the Executive Office which located in The Hague, The Netherlands. The Executive Office is an international team of 30+ professionals who work

in a dynamic, result-driven and open environment, taking pride in serving the association in an efficient manner.

What EHA does...

By organizing an annual congress, providing an educational program based on the European Hematology Curriculum, publishing a journal, lobbying for hematology, promoting research, offering fellowships and mentoring programs, EHA supports hematologists in and outside Europe to further improve the plight of patients suffering from blood disorders.

...connects hematology professionals

With almost 5,000 members in 100 countries worldwide, EHA is the largest European-based association that connects hematology professionals and opens opportunities for both professional and personal development within the field of hematology.

...harmonizes hematology education

EHA is one of the largest international, independent providers of peer-reviewed hematological knowledge. As a knowledge platform, the association offers a comprehensive and integral curriculum which forms the basis of the Medical Education Program (MEP). The MEP enables professionals to improve their hematology knowledge through the EHA Learning Center, master classes and scientific meetings. This allows professionals to always be aware of the latest trends, developments, publications and studies.

...makes hematology knowledge available worldwide

Based on its educational program, EHA develops meetings of smaller scale and exports them outside Europe.

...encourages professional development among hematologists

EHA delivers on its promise to support the careers of young researchers in hematology in Europe through its Career Development program. This program supports research funding, mobility, training and mentoring programs with top-tier scientists.

...lobbies for hematology

EHA represents hematology and hematologists in the European political and policy arena.

It does so primarily by:

- raising awareness of hematology as a distinct medical discipline with specific needs
- increasing the visibility of EHA as the representative of all hematologists in Europe
- advocating key EHA positions vis-à-vis policymakers, politicians and interest groups
- contributing to policy debates, to influence future legislation/regulation
- building relationships and alliances that support and strengthen our advocacy work.

By engaging with EU institutions and other relevant stakeholders – patients, other medical professions, pharmaceutical companies, issue-based expert groups – EHA promotes the interests of its members in key policy areas.

EHA strives to achieve more and better research funding opportunities, improve regulation, increase the availability and affordability of medicines, and harmonize education and training of hematologists.



Core message

CONNECTING
hematologists
worldwide

ADVOCATING
the interests
of hematologists
and hematology

**Towards a cure
for all blood disorders**

SUPPORTING
career
development
and research

HARMONIZING
hematology
education

CONNECTING HEMATOLOGISTS WORLDWIDE

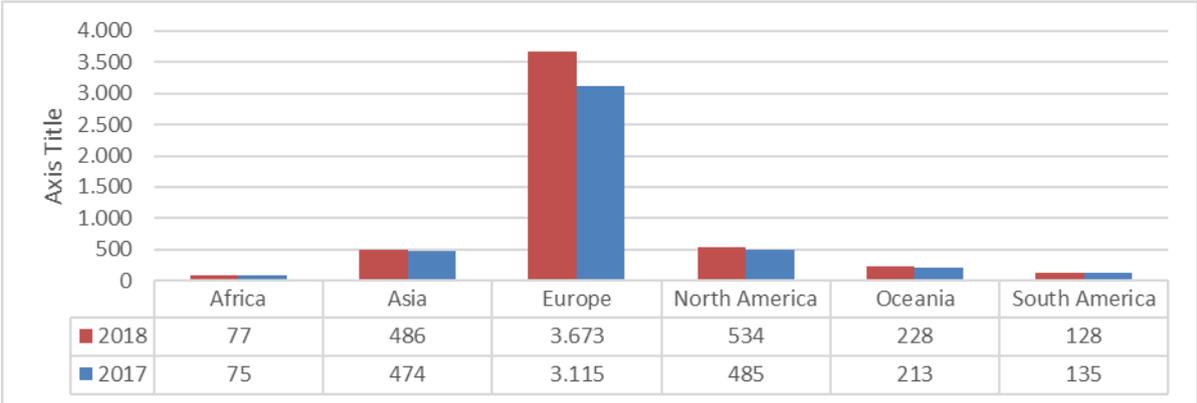
Membership

In 2018, we saw an increase in members compared to previous years. This increase is expected to continue in the following years. In 2018, there was an increase of 14% (628) in the total members compared to last year (2017) as seen in the table.

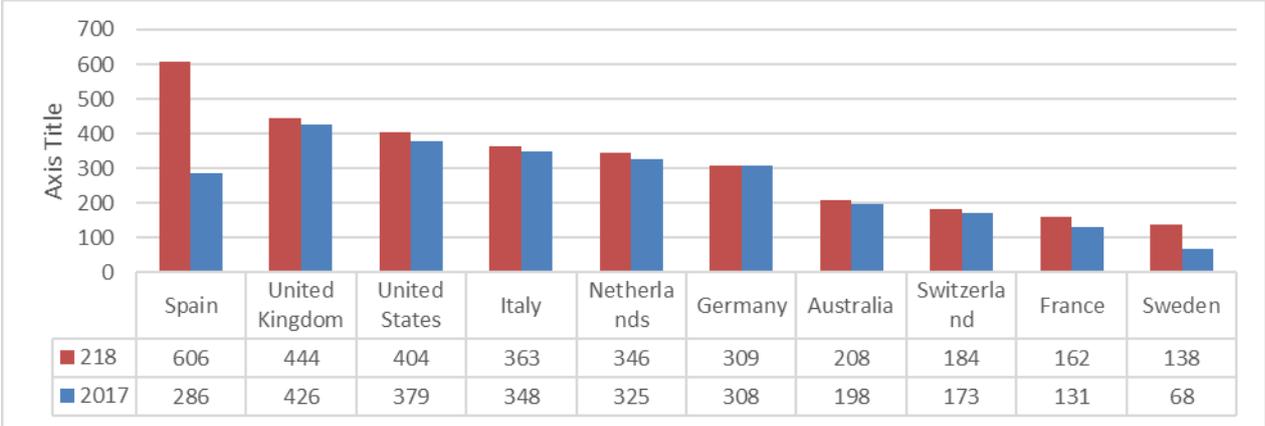
Years	2017	2018
Renewals	3.319	3.634
New members	1.117	1.415
Upgraded guests	60	77
Total active members	4,496	5,126

The overall aim is to double membership numbers within the next five years. More members strengthen the position of the association and strongly support EHA’s lobbying activities.

We are a worldwide organisation and have members from all around the world. The main membership base is situated in Europe which accounts for almost 71% of all our total members.



Looking at the different countries, we can see that Spain, the United Kingdom, United States, Italy, Netherlands, Germany and Australia have the highest number of EHA members.



In 2018, joint membership was launched with the Spanish Hematology Society which resulted in an increase of 112% in the number of Spanish members.

Annual Congress

*"Blood sustains our bodies. We as hematologists, should sustain the blood."
- Pieter Sonneveld, President, EHA (during the 23rd Congress Opening Ceremony)*

The 23rd Congress of EHA was held in Stockholm, Sweden on June 14-17, 2018 and was the place to learn from top hematology experts and connect with hematology professionals from all over the world. It's been 5 years since the Stockholmsmässan has last hosted the EHA congress, and since then the congress attendees have increased with 25% reaching a record number of 11623.

"The congress covers a broad spectrum of hematology, starting from oncology up to non-malignant blood diseases. We cover research from basic to translational up to clinical and provide expertise in patient care. We do not stop at the state-of-the-art but rather give a larger perspective. What is very important is always the health of the patient. ", said Professor Martina Muckenthaler, Chair of the Scientific Program.

EHA23 had another record of 2580 submitted abstracts and after a strict peer-reviewed procedure, a selection was presented in oral and poster sessions. In addition, invited speakers presented on numerous topics covering comprehensive hematology while several special sessions were dedicated to career development and patient advocacy. EHA's partner organizations also arranged joint symposia that covered a wide range of topics. In total 482 presentations were delivered in Stockholm.

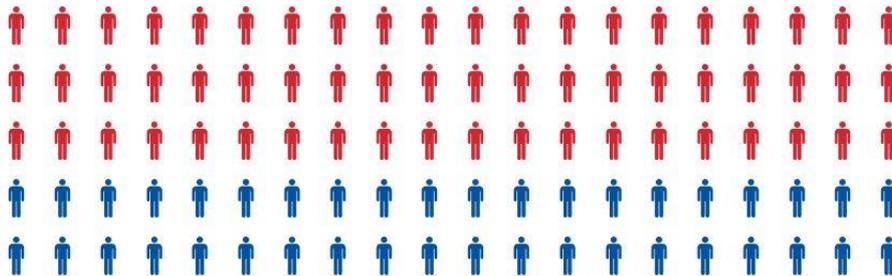
Sessions/speakers/topics

139 sessions



Congress attendees

11623 attendees from 6 continents



Europe 49 countries



Outside Europe 68 countries

Top 3 Europe

United Kingdom 785

Italy 706

Germany 643

Top 3 Outside Europe

United States 1378

China 614

Argentina 328

HARMONIZING HEMATOLOGY EDUCATION

Education

“An investment in knowledge pays the best interest.”

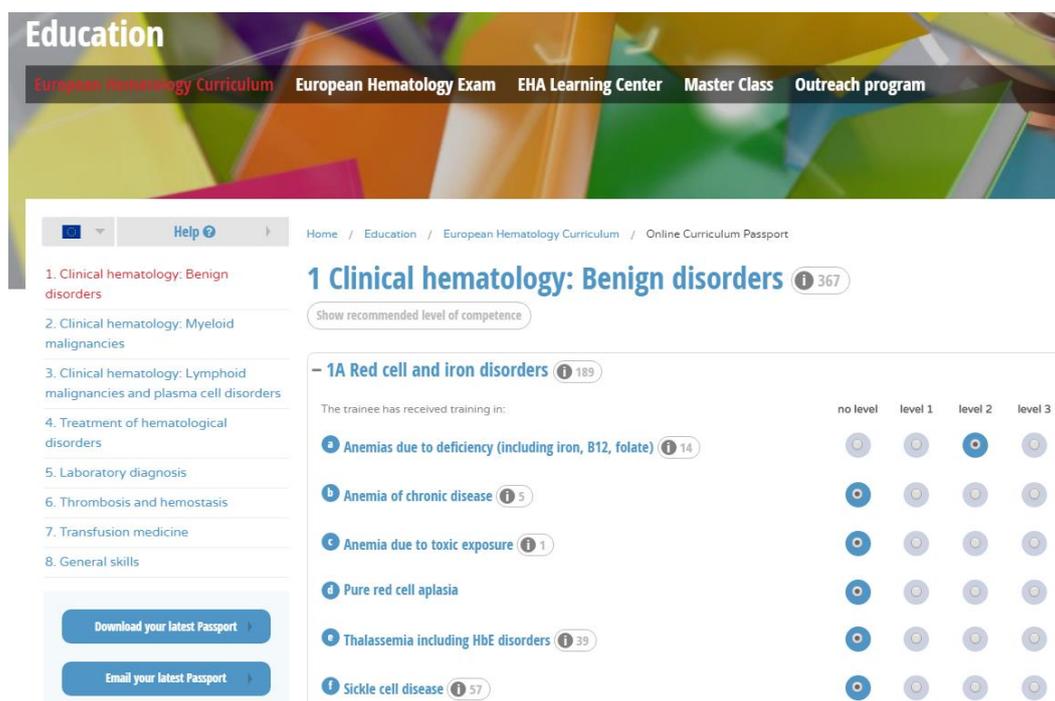
Medical education program

At EHA, hematology professionals can benefit from a variety of learning possibilities. EHA is one of the largest international, independent providers of hematological knowledge. To harmonize hematology knowledge, we offer a comprehensive and integral curriculum which forms the basis of the Medical Education Program, through which professionals acquire state-of-the-art knowledge by use of various means.

EHA Hematology Curriculum

The EHA Hematology Curriculum is the backbone of EHA’s medical education program. The Curriculum consists of sections of hematological competences and, within each section, a list of items. For each item, a recommended level of competence

The cover of the pdf version of the Curriculum/Curriculum Passport



The Online Curriculum Passport

In 2018, the EHA Hematology Curriculum became available in the following languages:

- German
- Spanish
- Portuguese
- Danish
- Turkish
- French

EHA Learning Center

In 2018, the focus was on the development of more e-learning tools, related to one or more topics of the European Hematology Curriculum. This was achieved through the launch of several new e-courses and clinical cases on the EHA Learning Center. The EHA Learning Center also includes all available annual congress materials.

EHA Campus

2018 marked the beginning of the new place-to-be for learning in hematology: the EHA Campus. To keep up with developments in online learning, EHA has selected a new online platform, and has worked hard to get it ready for launch in January 2019.

EHA Campus offers visitors high quality content on a wide variety of topics, representing all topics of the European Hematology Curriculum and matching different learning styles. The learning program continuously develops with new learning materials will be uploaded regularly.

European Hematology Exam

The European Hematology Exam (EHE) certifies excellent knowledge according to the criteria and topics of the European Hematology Curriculum. While the right to practice will still be granted by national authorities, the EHE provides an extra quality stamp for hematologists. It is an important step in the harmonization of hematology training/education in Europe and supports professional mobility.

In June 2018, the [second edition](#) of the EHE took place in Stockholm, Sweden. Furthermore, a parallel session was held in Bern, Switzerland. After the pilot in 2018, the Swiss Society of Hematology (SSH) and the Swiss body for postgraduate education (SIWF/FMH) decided to implement the EHE in the official Swiss end-of-training exam for hematologists as of 2019.

80 candidates took part in the exam, from 26 different countries and 6 continents. A total of 64 examinees passed the exam.

The impact of the EHA Exam was measured, for 72% of the examinees passing the exam helped in their personal development. 62% expect that passing the exam will help in their career in the future, 10% already felt that it helped further their career.

“It is a challenge to prove myself and a good way to reinforce many areas in my daily practice” – European Hematology Exam participant



To guarantee independent judgment of the quality of the exam and the passing score definition, EHA collaborates with CITO, an internationally recognized professional research and knowledge institute in the field of testing and educational measurement. CITO's Psychometric Research and Knowledge Center perform the psychometric analysis of the results.

EHA Master Class

The EHA Master Class is an online group-based learning experience for hematologists. It is divided into the Classical Master Class and the Bite-size Master Class.

Selected mentees learn through discussion with their peers and experts on different topics. Where the Classical Master Class offers 5 cases to be studied over the course of 6 months, the Bite-size Master Class offers a selected group of mentees the chance to gain in depth knowledge on one topic, over the course of 6 weeks.

Last year, 33 mentees were selected to participate in the EHA Classical Master Class of 2017-2018.

The Bite-size Master Class course was held in February and October on the topics of thrombosis, thrombophilia and anticoagulation and on thalassemia. Because of the high number of applicants in 2017, an extra Bite-size Master Class was held in January.

A total of 75 mentees participated in the Bite-size Master Class.

For 2019, our focus lies on expanding the topics for the Master Classes, to keep delivering new and interesting classes.

International collaboration & outreach

International collaboration

EHA's International Collaboration Program in 2018 consisted sending European speakers to countries around the world to take part in a variety of Joint Symposia, sharing knowledge and providing education. The program is an important tool to create connections between Europe and many countries around the world.

These joint symposia were organized at the annual congresses of the following partner societies:

- Korean Society of Hematology International Congress
- Hematology Society of Taiwan Annual Congress
- Japanese Society of Hematology International Symposium
- Japanese Society of Hematology Annual Congress
- Russian Onco-Hematology Society's Conference on Malignant Lymphoma
- Indian Society of Haematology and Blood Transfusion Annual Congress
- Chinese Society of Hematology Biennial Congress
- Turkish Society of Hematology Annual Congress
- American Society of Hematology Annual Meeting



Professor Tony Green, EHA President and Professor Tang, President Hematology Society of Taiwan

Global outreach program

In 2018, EHA's Global Outreach Program took us to 13 different countries around the globe. Aimed at providing hematology medical education to mainly countries outside Europe, the program is based on local needs. EHA's Global Outreach Program consists of Hematology Tutorials, joint symposia and Highlights of Past EHA (HOPE).

HEMATOLOGY TUTORIALS

EHA Hematology Tutorials present state-of-the-art science in a didactic format in an environment that encourages informal interaction between scientists, clinicians and participants. The main target audience for tutorials is trainees in hematology, who benefit from the opportunity to interact and discuss with the expert faculty.

In 2018, the following hematology tutorials were held:

3rd EHA-ISHBT Hematology Tutorial on Lymphoproliferative and Plasma Cell Disorders

February 16-18 | Lucknow, India

"The tutorial enabled the audience to talk to the speakers during breaks/dinner about differences in therapy of hematological malignancies between the different countries. This was not only valuable for the audience but also for me as speaker." - Dr Niels van de Donk (faculty)

7th EHA-TSH Hematology Tutorial on Acute Leukemia

April 28-29 | Istanbul, Turkey

*"EHA-TSH tutorial was an informative experience for myself and was very fruitful meeting for the audience who gave us feedback." –
Prof. Dr. M Sayitoğlu (faculty)*

1st EHA-SHRC Hematology Tutorial on Thalassemia

May 10-11 | Shiraz, Iran

"Waiting for upcoming tutorials and seminars in the next future." – anonymous delegate

2nd EHA-SAH Hematology Tutorial on Lymphoid Malignancies and Plasma Cell Dyscrasias

September 14-15 | Buenos Aires, Argentina

"I felt that the success of the tutorial was the fluid interaction between the audience and faculty," - Dr L Quiroga (faculty)

3rd EHA-PTHIT Hematology Tutorial on Myeloid and lymphoid leukemia
September 21-22 | Warsaw, Poland



1st EHA-Baltic Hematology Tutorial on Lymphoid malignancies, including Waldenström's Macroglobulinemia
October 18-19 | Tallinn, Estonia

“I enjoyed the atmosphere and the discussions in the meeting and found that I also learned a lot from these discussions.” – Prof Kuittinen (faculty)

HIGHLIGHTS OF PAST EHA (HOPE)

Highlights of Past EHA – Middle East & North Africa

September 27-29 | Cairo, Egypt

The Highlights of Past EHA (HOPE) brought key messages of the 23rd Congress of EHA to participants from the Middle East and North Africa.

The 3rd edition of this meeting was held in Cairo, Egypt on September 27-29 and attracted more than 400 delegates from 20 different countries. EHA offered 43 scholarships to young hematologists from Egypt and neighboring countries who wouldn't have had the resources to attend, to provide an opportunity to meet international experts and learn about the latest updates in hematology.



“Scholarship idea this year is very helpful and gave me the chance to attend and benefit from up-to-date lectures. Thank you.” – HOPE Cairo participant

The meeting was organized together with regional and national partners, who were represented in the program as chairs of various sessions. One of the highlights of this year's HOPE was a joint local symposium on hemoglobinopathies in which speakers from the region shared their perspectives, experiences and knowledge. Hemoglobinopathies is one of EHA's Topics-in-Focus.

A total of 89 abstracts were submitted, of which 24 were presented during oral pitch presentations and 35 were included in a poster session.

EHA SCIENTIFIC WORKING GROUPS AND MEETINGS

The 23 EHA Scientific Working Groups (SWGs) promote high-quality science within the hematology community and create independent scientific networks that serve under the umbrella of EHA. They provide a vital link between manufacturers, pharmacies, doctors, hospitals and ultimately the patients. They serve as a forum for collaboration and foster the dissemination of basic, translational and clinical research in hematology in and outside Europe. SWGs are a space for learning, dialogue and exchange among everyone involved in hematology research. By establishing additional SWGs on Infections in Hematology, Transfusion medicine, Pediatrics and Rare cancers, the SWG structure provides a comprehensive and up-to-date picture of the research areas relevant to the future of hematology.

In 2018, SWGs contributed through their work on clinical trials, registries, and treatment guidelines. In collaboration with EHA, they organized the EHA SWG Scientific Meetings, sessions at the EHA Congress and provided scientific input for EHA's Medical Education Program as well as contributed to advocacy and lobbying activities.

In collaboration with the EHA SWG on MDS, joint recommendations on diagnosis and treatment of CMML were published in HemaSphere, EHA will continue the collaboration with SWG and other societies to provide joint guidelines.

Furthermore, the SWGs build relations with patient organizations and pharmaceutical industry and they identify new innovative areas for research. They often help define a policy agenda for hematology and they contribute to the development of EHA position papers and lobbying in Brussels. In the future new EHA SWG initiatives will be launched to meet the needs in hematology research.

The EHA-SWG Scientific Meetings are established which aim to exchange scientific knowledge and promote collaboration within the hematology community. The meetings cover both hematologic malignancies and non-malignant topics. The programs deliver experts' perspectives on the latest findings, offer discussions with patient organizations, interactive clinical cases and round table sessions. Furthermore, it provides an opportunity to discuss evolving therapies with leading experts in hematology as well as the opportunity to network among faculty and colleagues.

In 2018 the following three meetings EHA SWG meetings took place: were scheduled and executed successfully in collaboration with the respective Scientific Working Groups. In general, feedback from the attendees and faculty alike, highlight the informal and pleasant atmosphere during the programs and the breaks. The high-quality program is regarded as challenging and stimulating.

EHA-SWG Scientific Meeting: Integrated Diagnosis Strategies in Oncohematology for the Management of Cytopenias and Leukocytosis

February 8-10 | Barcelona, Spain

In collaboration with: EHA Scientific Working Group on Scientific Working Group on Diagnosis: Morphology and Flow Cytometry)

This meeting was endorsed by the International Society for Laboratory Hematology (ISLH) and attracted over participants from 31 different countries.



EHA-SWG Scientific Meeting on New Molecular Insights and Innovative Management Approaches for Acute Lymphoblastic Leukemia

April 12-14 | Barcelona, Spain

In collaboration with: EHA Scientific Working Group on Acute Lymphoblastic Leukemia

“The meeting was a valuable professional experience for me. Interesting presentations and expert discussions have enriched my professional knowledge in hematology.” - delegate

EHA-SWG Scientific Meeting on Aging and Hematology

October 12-14 | Warsaw, Poland

In collaboration with: EHA Scientific Working Group on Aging and Hematology

“[...] After this meeting, new ideas for further studies were created” – delegate

SUPPORTING CAREER DEVELOPMENT AND RESEARCH

Research funding

Since 2009, EHA has funded more than 100 researchers. In 2018, EHA funded the research of the following talented researchers:

- Immacolata Andolfo 'Dissecting the Role of PIEZO1 in The Pathogenic Mechanism of Dehydrated Hereditary Stomatocytosis' (see her photo at EHA23) Basic research grant (100.000,- euro)
- Alessia Pagani 'Molecular Mechanisms of The TFR2-mediated Crosstalk Between Erythropoiesis and The Iron Regulator Heparin' (see her photo at EHA23). Advanced research grant (160.000, - euro)
- Anastasia Papadopoulou "Cerberus" T Cells: A Single Glucocorticoid-resistant T Cell Product to Simultaneously Target Multiple Pathogens in Immunocompromised Patients (see her photo at EHA23) Advanced research grant (160.000, - euro)
- Catherine Sawai 'In Vivo Impact of Aging and Chronic Myeloid Leukemia on Hematopoietic Stem Cell Function' (see her photo at EHA23) Advanced research grant (160.000, - euro)
- Anna Vardi 'Large-scale Detection and Characterization of T Cells with Anti-tumor Specificity in Chronic Lymphocytic Leukemia: Can it Pave the Way for Cellular Treatments or Vaccination Strategies?' (photo on website) Physician scientist research grant (160.000, - euro)
- Delfim Duarte 'The Role of Iron in the Remodeling of the Vascular Niche in Acute Myeloid Leukemia' (photo on website) Physician scientist research grant (160.000, - euro)
- Alvaro Sanchez won a Research mobility grant
- Julius Lukes won a Research mobility grant

"The EHA grant was my first grant as a PI and gave me the opportunity to generate data to apply for additional grants and to pursue projects as proposed which resulted in the publication of data. I am very grateful that I received this grant as it was a huge stepping stone in my academic career."

Mentoring programs

TRTH (joint program with ASH)

The 9th edition of Translational Research Training in hematology (TRTH) has produced 20 winners in 2018. This brings the TRTH number to 178 – the total number of translational researchers from all over the world who have received TRTH mentoring.



Besides the impact on research design, TRTH allows mentees to form a network with fellow trainees and mentors that act as a supportive and collaborative basis for trainees' personal development in the field of hematology.

“During TRTH, I have met incredible people, both fellow TRTH, faculty and staff, which helped me focus my scientific career. Both my scientific project and what I want for my future scientific career are better defined now.”

“It provided me with the opportunity of networking with leaders in the field, which is critical moving forward. It gave me access to a lot of new methodologies through the work presented by other colleagues. Also, without TRTH I wouldn't have started my first collaboration as an independent researcher.”

CRTH

So far, 51 talented clinical researchers from all over the world have received mentoring through our Clinical Research Training in Hematology (CRTH) program. It produced 19 winners in 2018.

What does it mean to participate?

I feel more confident in clinical research due to learning from experts in design, recruitment, protocol preparation and budgets.

Excellent mix of academic and practical learning. Top level mentorship. Friendly competitive atmosphere.



HemaSphere

In 2017 EHA launched its new open access journal; HemaSphere, and in 2018 this journal published its second volume of 6 issues which included 28 articles with an abstract.

Moreover, it has introduced two new article types: **Controversies in hematology** and **Guidelines article**. Also, an application was submitted to Emerging Science Citation Index and PubMed Central.



Most read articles in 2018:

Article Title	Article Type	Nb reads
Chimeric Antigen Receptor-T Cell Therapy: Practical Considerations for Implementation in Europe	Review Article	4035
Anemia in the Elderly	Review Article	2068
Diagnosis and Treatment of Chronic Myelomonocytic Leukemias in Adults: Recommendations From the European Hematology Association and the European LeukemiaNet	Guideline Article	2064
Myelofibrosis-Related Anemia: Current and Emerging Therapeutic Strategies	Review Article	2006
Immune Checkpoint Inhibition in Hodgkin Lymphoma	Review Article	1596
Erythroferrone: An Erythroid Regulator of Hepcidin and Iron Metabolism	Review Article	1512
Single-Cell Sequencing in Normal and Malignant Hematopoiesis	Review Article	1402
Is Good Clinical Practice Becoming Poor Clinical Care?	Editorial	1198
Gene Therapy in Hemophilia: From Hype to Hope	HemaTopics	970
Controversies in the Treatment of Classical Hodgkin Lymphoma	Controversy	923
Clinical Utility of Next-generation Sequencing in the Management of Myeloproliferative Neoplasms: A Single-Center Experience	Original Article	831
Molecular Profiling Defines Distinct Prognostic Subgroups in Childhood AML: A Report From the French ELAM02 Study Group	Original Article	811
EML1–ABL1 Is Activated by Coiled-Coil-Mediated Oligomerization and Induces T-Cell Acute Lymphoblastic Leukemia or Myeloproliferative Disease in a Mouse Bone Marrow Transplant Model	Letter	810
The Iron Tale: If It Does Not Kill You, It Makes You Stronger (and Heparin Helps)	HemaTopics	742

EHA Topics-in-Focus: Immunotherapy & Hemoglobinopathies

Hematology and hematologists worldwide are working in an exciting and fast-paced medical field and an ever-changing world around them.

The field's internal speed of changes and front-line accomplishments in the medical field create an increasing need for adaptations to new techniques and therapies. Immunotherapy is one of those rapidly developing treatments, with promising components like chimeric-antigen-receptor therapy (CAR-T) and other treatments. At the same time, socio-economic developments also have a considerable impact on health care, as mass migration and an aging population incrementally change the incidence of diseases previously rare in Europe. Migration is changing the incidence of hemoglobinopathies and a new need for education arises to ensure the appropriate diagnosis and treatment. Furthermore, language barriers and political issues like immigration status have a further influence on the access to medicine.

Immunotherapy, and especially CAR T cell therapy has been selected because of recent and promising developments in the treatment of patients with hematological malignancies, especially in children with acute lymphoblastic leukemia (ALL)



TOPICS-IN-FOCUS
Immunotherapy

and adults with advanced lymphomas. The speed of progress is one of the reasons why it is important to disseminate knowledge about several forms of immunotherapy. With CAR T cell therapy becoming a treatment option in Europe outside clinical trials, the need to address the above-mentioned challenges becomes even more pressing.

Hemoglobinopathies, and specifically Sickle Cell Disease (SCD), has been selected as one of the topics because of the recent increase in incidence of hemoglobinopathies in Western European countries due to the refugee crisis, and the promising developments in the treatment of patients suffering from such diseases. This emerging public health problem has long been quite neglected, but deserves attention and the development of better, curative treatments.



TOPICS-IN-FOCUS
Hemoglobinopathies

During the 23rd Annual Congress, the EHA launched the Topics-in-Focus Programs on Immunotherapy and Hemoglobinopathies during the Opening Ceremony. This was followed by a very well-received scientific session on both topics. Further to that, various expert interviews were held with different thought leaders in these fields of expertise.

For both programs, a Task Force has been established and the first activities have been implemented. New activities for 2019 are under construction and will be developed along the lines of EHA's ambitions in Research & Mentoring, Education & Training, Advocacy & Lobbying and Members & Stakeholders, and will be closely monitored by the EHA Board in the upcoming years. An important point of attention is that the Topics-in-Focus Programs are clearly distinguished from the regular activities EHA is doing, of course contribute to the overall goals of the program, but also contribute to EHA being the source of information and knowledge on these topics.

LOBBYING FOR HEMATOLOGY

“REPRESENTING HEMATOLOGY AND HEMATOLOGISTS IN EUROPE”

Awareness, advocacy and stakeholder relations

Awareness

EHA is working continuously to increase awareness of hematology as a medical discipline with distinct clinical and research needs of its own, and its own visibility as the voice of hematology professionals in Europe.

Advocacy

EHA aims to influence policy formulation and decision-making at EU level in a variety of ways. Key actions are the formulation of position papers, participation in policy discussions, engagement with policy and decision makers and alignment with other key stakeholders.

Current overarching advocacy priorities are:

- Support for **hematology research**
- **Access to affordable treatment** for patients with blood disorders
- **Real world evidence-based, personalized care** for patients with blood disorders
- An **optimized regulatory framework** in line with the needs of hematology and hematologists

Stakeholder relations

At the basis of EHA’s policy and advocacy work is pro-active and sustained engagement and alignment with patient organizations, nurses, industry partners, EU institutions and national hematology societies. Active participation in alliances and EU-funded projects is an integral part of our stakeholder strategy.

Close collaboration with patients

An important priority for 2018 was the stepping up of collaboration with Patient Organizations (POs) in the realm of policy and advocacy. In October, the European Affairs Committee and leaders of the POs met at EHA headquarters in The Hague to discuss alignment and joint activities on shared advocacy objectives. Examples are structural involvement of patients in the updating, section by section, of the [EHA Research Roadmap](#) – an incremental, ongoing process to ensure the document reflects the hematology community’s current research priorities – and practical EHA support for patient representatives in the [HARMONY Alliance](#), to boost their visibility and effective participation in this important but complex public-private project. Patients will also be involved in the drafting of position papers, for instance on ‘access to treatments’, a top priority for both patients and EHA.

QoL, PRE, PRO and RWE

Close collaboration with patients was also at the basis of the Advocacy Track at EHA's Annual Congress in Stockholm. The three sessions revolved around four acronyms, each of which represents a key element of the drive to optimize treatments in a way that does justice to both clinical evidence and patients' priorities: quality of life (QoL), patient-relevant endpoints (PRE), patient-reported outcomes (PRO) and real-world evidence (RWE).



The presentations and discussions about these topics drew a full house, with a diversity of stakeholders represented both on stage and in the audiences.



New priorities

In addition to EHA's five existing advocacy priorities (Support for research, Access to treatment, Drug pricing, Professional qualifications, Blood & blood components legislation), two new focal areas for engagement with policymakers, regulators and other stakeholders were identified:

Personalized medicine trials. Existing clinical trial designs with their emphasis on testing medicines in large patient populations are no longer suitable in the era of 'personalized medicine'. When the goal is individualized treatment, clinical studies should focus on individual, not average responses to therapies.

Linking clinical benefit, patient benefit, value and pricing. With the emergence of a new generation of treatments in hematology that are both innovative and (very) expensive, a key challenge is how to reconcile concepts and tools for assessing benefit (clinical/patient) on the one hand, and for determining value (cost/benefit) and prices (crucial for affordability and access) on the other.

Engagement with policymakers and regulators

EHA is gradually stepping up its engagement and collaboration with the European institutions and agencies responsible for policy implementation, regulation and oversight.

An important objective of EHA is to represent the interests of hematologists in the implementation of EU legislation, such as the 'Blood Directives' (on the quality and safety of blood, tissues and cells) and the Professional Qualifications Directive (cross-border recognition and mobility of doctors and researchers). With the new *In-Vitro Diagnostics Medical Devices Regulation (IVDR)* due to take effect in 2022, EHA in 2018 also began engaging with the European Commission to ensure involvement of the right experts in the implementation phase.

EHA has also successfully positioned itself as the *source of expert evaluators* for the European Medicines Agency (authorization of new drugs), [EUnetHTA](#) (EU pilot project for joint Health Technology Assessment) and the European Commission Directorate-General for Research and Innovation (responsible for reviewing funding applications).

Harmony

The HARMONY Alliance, the public-private European Network of Excellence for Big Data in Hematology, has expanded in 2018 to 53 Partners and 27 Associated Members from 22 countries.

For blood cancers, Big Data means gathering into one single database clinical, genetic and molecular information on patients and diseases which is currently maintained in a number of individual databases from clinical trials and registries in different countries. The HARMONY Alliance is orchestrating the consolidation of all databases into one common platform. This will harness the enormous potential of Big Data and Big Data analytics to deliver insights into how the care of patients with blood cancers can be improved.

HARMONY's partners from industry are providing access to clinical trials data, showing how drugs work in controlled circumstances. Public registries collect data on how patients are treated and the outcomes of therapies in the real world. Together, these sources are greater than the sum of their parts. For example, by combining the populations from several clinical trials, it is possible to analyze populations with rare diseases with greater statistical power than individual databases can provide. Other Big Data analyses can reveal molecular data on genomes, what proteins are expressed in different cancers, how treatments affect the expression of important genes, and more. Pan-European Big Data transcends borders and details captured in databases vary between healthcare systems, clinical trials, and registries. Maximizing the value of HARMONY's Big Data platform presents three challenges:

- First, the data need to be harmonized so that data from different databases are in a similar format and can be analyzed.
- Secondly, the database must comply with European and local regulations on data exchange, privacy, and ethical rules.
- And thirdly, the enormous size of Big Data means that new analytical and statistical tools need to be developed. Getting these fundamentals right was the main priority during HARMONY's initial phase.

HARMONY was created to fill a specific need in blood cancer treatments. The Alliance functions as the interface between all stakeholders. Never has a European public-private initiative had such ambitious goals for international collaboration in big data and HMs.

What has HARMONY achieved so far? Several key milestones have been reached since the HARMONY Alliance was established:

- Alignment with the latest European regulations on data privacy
- Implementation of compliance with ethical rules and legislative frameworks across all countries and stakeholders in Europe
- Establishment of a standard operating procedure for the submission of research questions
- Creation and application of data sharing agreements
- Streamlining of processes for data flow within Europe to enable the use of the HARMONY Big Data platform without jeopardizing data privacy and compliance with legal and ethical requirements
- Launching the HARMONY Big Data Platform
- Continuous population of the HARMONY Big Data Platform
- Submission and approval of several Big Data-driven studies for the different blood cancers
- Transfer of the first data sets into the HARMONY Big Data Platform
- With these achievements, researchers are now in the starting blocks for intense analysis of the data in the HARMONY Big Data platform.

The final deliverable of the HARMONY Alliance is a Big Data platform which integrates outcome measures and endpoint definitions for HMs. HARMONY will achieve this from a pan-European perspective by uniting and aligning European stakeholders and key opinion leaders in the field. The 5-year project started January 2017 and is funded through the Innovative Medicines Initiative (IMI); Europe's largest public-private initiative aiming to speed up the development of better and safer medicines for patients.

EHA is one of the 53 partners in HARMONY and is leading the Work Package on Communication, Dissemination & Training. EHA is also participating in other Work Packages and in the HARMONY Steering Committee.

MAINTAINING RELATIONSHIPS AND PHILANTHROPY

Sponsoring 2018

Also, in 2018 pharmaceutical industry supported EHA which allowed us to step up our efforts to represent the hematology care in Europe and beyond, while EHA sponsors benefit from establishing new business relations within the field. Mutual trust and collaborative efforts form the basis to achieve the best results for both parties.

EHA believes that rigorous and continuous cooperation at all levels is key to the development and dissemination of hematology research and education. With that purpose, EHA offered a variety of sponsorship opportunities to welcome both large and small companies and startups, to support its activities.

EHA is grateful to its partners for their continuous support and commitment and is looking forward to further strengthen and expand relationships by providing meaningful and innovative support opportunities for its existing and new programs.

EHA Friends' Fund

In 2018 [EHA Friends' Fund](#) continued to take major steps forward and engaged with many EHA Friends mainly during the EHA Congress in Stockholm in 2018 but also at other events. In 2016 EHA created this fund to support research and education in hematology, especially for junior hematologists. In 2018 a large part of the funds raised was dedicated to supporting junior hematologists to attend the EHA Congress and meetings.

FINANCIAL REPORT

EHA is a Common Good Organization under Dutch law. Profits generated from its congress are invested in other activities to that serve the hematology community. The Board and Committee members contribute on a voluntary basis to the association's work. Expenses for meetings are reimbursed. The EHA Executive Office has its own employment arrangements. The employees in the Executive Office function according to various job profiles, which are linked to the remuneration policy.

Balance sheet as of December 31, 2018

	2018	2017
Assets		
Fixed assets	€ 321.982	€ 333.152
Current Assets	€ 18.227.451	€ 13.315.196
Total Assets	€ 18.549.433	€ 13.648.348
Liabilities		
Equity	€ 12.846.380	€ 9.661.708
Current liabilities	€ 5.702.053	€ 3.986.640
Total liabilities	€ 18.549.433	€ 13.648.348

State of income and expenses 2018

	2018	2017
Income	€ 13.752.428	€ 11.554.639
Expenses		
Annual congress	€ 5.675.853	€ 5.423.830
Fellowships and grants	€ 885.708	€ 758.210
Other and general expenses ***	€ 2.298.897	€ 1.826.581
Activities	€ 1.418.420	€ 1.262.387
Housing and depreciation	€ 291.529	€ 261.804
Total expenses	€ 10.570.407	€ 9.532.812
Operational result	€ 3.182.021	€ 2.021.827
Interest & bank costs	€ 2.651	€ 12.472
Result	€ 3.184.672	€ 2.034.299

*** Including staff costs

Work Plan and Budget 2019

Based on EHA's Strategy, input was collected from EHA's Committees and Working Groups for the 2019 Work Plan & Budget. Inputs were provided at two levels: 1) ongoing projects and their proposed direction in 2019 and 2) new initiatives within existing programs including their motivation. For ongoing projects as well as for new initiatives budgets were calculated and included in the Work Plan 2019. This resulted in a draft Work Plan & Budget 2019 which were approved by the Board. The approved budget is summarized in the table below.

Approved budget 2019

	2019
Income	€ 13.103.000
Expenses	
Annual congress	€ 5.646.000
Fellowships and grants	€ 740.000
Other and general expenses	€ 2.751.000
Activities	€ 1.650.000
Housing and depreciation	€ 290.000
Total expenses	€ 11.077.000
Estimated result	€ 2.029.000

Investing in the future

At the October meeting the EHA Board also discussed its ambition to grow and expand activities in Research and Education in a way that more members but also non-members can benefit and more hematologists in Europe and beyond become part of EHA. EHA's financial position and forecast is solid which allows the Association to develop and implement considerable programs that contribute to achieving its strategic goals. An investment plan for 2019-2021 of in total € 8 million was approved as well as the procedure for allocating funds to new initiatives. The funds will be allocated to Research, Education and Operations.

Notes on statements:

General Accounting Principles for the preparation of the financial statements:

The financial statements are prepared according to the Netherlands Civil Code.

Validation of assets and liabilities and determination of the result takes place under the historical cost convention. Unless presented otherwise at the relevant principle for the specific balance sheet item, assets and liabilities are presented at face value. Income and expenses are accounted for on accrual basis. Profit is only included when realized on the balance sheet date. Losses originating before the end of the financial year are taken into account if they have become known before preparation of the financial statements. Revenues from services are recognized in proportion to the services rendered. The cost price of these services is allocated to the same period