**COOPERATION AGREEMENT**

Between

Innsbruck Medical University, University Clinic for Internal Medicine II, represented by Univ.-Prof. Dr. Herbert Tilg, Innrain 52, 6020 Innsbruck, Austria

and

[YOUR INSTITUTION]

Whereas:

The Parties wish to execute the Project entitled “NON-HFE Registry.”

The tasks of the cooperation partners are in detail described in the research plan (Annex A) as well in the budget (Annex B) - see working packages.

Now, therefore, it is hereby agreed as follows:

The Parties hereby enter into this Cooperation Agreement to specify the organization of the work and to define their respective rights and obligations. The Parties agree to cooperate pursuant to the terms of this Cooperation Agreement in order to execute the Project and perform their tasks designated in the research plan, the scientific abstract summary and the description of the organization, time plan and Parties contributions which are in detail described within the research plan, form an integral part of this Cooperation Agreement.

**Definitions**

**Access Rights** means licenses and user rights to Foreground and Background, which the Parties need for carrying out the tasks of the Project.

**Background** means information which is held by a Party prior to its accession to the Project or that is generated beside the Project but outside its scope, as well as copyrights or other intellectual property rights (e.g. patents) pertaining to such information, patent applications which have been filed before the accession to the Project and which are needed for carrying out the Project or for using the results generated within the Project.

**Foreground** means the results, including information, whether or not protectable, which are generated in the Project. Such results include rights related to copyright, design rights, patent rights, plant variety rights or similar forms of protection.

**Publication** means any oral or written communication disclosed in public, including but not limited to specifications, drawings, graphics, circuit diagrams, plans, models, patent applications, documents, reports, information, techniques and know-how, by whichever media, including articles in learned journals, newspapers and magazines, conference papers, educational material, tapes, discs, CD-ROMs and other machine readable media, presentations, and Internet publications.

**Subcontractor** is a Third Party, which enters into an agreement with a Party in order to carry out parts of the work of the Project, which the respective Party is not able to carry out itself.

**Third Party** is a legal entity which is not a party of this Cooperation Agreement.

1. **General Responsibilities**

1. The Parties undertake reasonable endeavours to perform and fulfil promptly, actively and on time all their obligations as described in the research plan and this Cooperation Agreement.

2. For the purpose of coordinating the activities in performance of the Project the Parties will intensively communicate on a regular basis via telephone conferences and meetings.

3. The Parties will -as far as legally possible - supply each other with all information of scientific, technical and commercial nature including data and documents, as far as this is necessary and advantageous for carrying out the Project or the cooperation.

4. The Parties will inform their employees, who are involved in the Project about the obligations in connection with this Cooperation Agreement, especially about the provisions concerning confidentiality, and they will make sure that these employees are bound by these obligations. The same applies for the involvement of Third Parties.

1. **Financial provisions**
2. ~~ALLOCATION~~

~~Funding shall be paid to the parties upon fulfillment of Project milestones as follows:~~

1. **~~Milestone 1~~** ~~- ethical approval for participation in the~~ **~~non-HFE registry~~** ~~from the local ethics research committee of the participating institution.~~
2. **~~Milestone 2~~** ~~- entry of the minimal dataset (sex, age at diagnosis, serum iron parameters [serum iron, ferritin, transferrin, saturation – at diagnosis and at last follow up] mutation & gene [HGMD nomenclature], date of last follow up and status [alive or dead] and treatment [phlebotomy, chelation or no treatment]) for individual patient.~~

~~Achievement of milestone 1 should be funded with € 500,00 per institution~~

~~Achievement of milestone 2 should be funded with € 100,00 per patient~~

**Update 2022: The budget for reimbursements is exhausted (see budget Annex B). We cannot offer reimbursements after 2022.**

1. **PROJECT MANAGEMENT**
2. STEERING GROUP

The Parties shall establish, within thirty days after the Effective Date, a Steering Group which shall be composed of one duly authorised representative of each Party. After having informed the others in writing, each Party shall have the right to replace its representative and/or to appoint a proxy, although it shall use all reasonable endeavours to maintain the continuity of its representation. The composition of the Steering Group is set out in Annex C. The Steering Group shall appoint a Chair from amongst its members. There shall also be a Project Manager, who shall be Secretary to the Steering Group.

1. RESPONSIBILITIES OF THE STEERING GROUP

2.1 Project Oversight

The Steering Group shall be responsible for the delivery of the project outcomes and to this end will keep the project plan, and progress towards meeting it, under review.

2.2 Appointment of Project Manager

The Steering Group shall be responsible for appointing a Project Manager. The Project Manager will have responsibility for the day to day management of the Project and will report to the Steering Group.

2.3 Financial Management

The Steering Group shall be responsible for the financial management of the Project, and will manage the Project in accordance with appropriate project management techniques. The Steering Group may choose to take advice from third parties as required.

2.4 Publications and Press Releases

The Steering Group shall decide procedures for dissemination of publications and press releases relating to the Project

2.5 Exit Strategy

The Steering Group shall establish a Sustainability Sub-Group to plan for the future development of the ***the data stored in the NON-HFE Registry***.

The Steering Group shall hold two Special Meetings, the first twelve months prior to the end of the Project, and the second at the end of the Project, whose business shall be to develop a suitable strategy or strategies for future development of the **non HFE registry** including the pursuit of additional funding from appropriate sources.

In the event that additional funding is secured for future development of the **non HFE registry**, the Steering Group shall be responsible for making such financial and administrative arrangements as are necessary to secure the effective and efficient continuation of the Consortium including any necessary revisions of this Consortium Agreement, for approval by the Parties.

1. STEERING GROUP MEETINGS

The Steering Group shall determine the frequency of its meetings, but shall meet at least yearly. Additional meetings may be called by two or more Parties or at the request of the Project Manager. Meetings will operate under the following rules:

3.1 At each meeting, the Steering Group will agree on a date for the next meeting. Otherwise the Secretary, in consultation with the Chair or his nominee, shall call meetings, giving notice that is reasonable in the circumstances.

3.2. The Secretary shall circulate an agenda before the meeting.

3.3 Each Steering Group member (including the co-opted members, but not the Secretary) will have one vote, except the Chair who has a casting vote. A member may not vote on matters concerning a dispute with the Consortium where the member is the subject of the dispute.

3.4 The quorum for a meeting will be five (5) voting members.

3.5 With the approval of the Chair, Steering Group members may nominate in writing a representative to attend meetings and vote on their behalf.

3.6 Votes, with the exception of a vote to terminate a Party’s membership of the Consortium, will be decided on the basis of a majority vote of those attending and eligible to vote.

1. **ADDITION OF PARTIES TO THE CONSORTIUM**

Institutions may be invited to join the Consortium only by the unanimous decision of the Steering Group and on the condition that the new institution becomes a party to this Agreement.

1. **WITHDRAWAL OF PARTIES FROM THE CONSORTIUM**

A Party may withdraw from the Consortium only after written permission of the steering committee.

1. **DATA MANAGEMENT**
2. DATA COLLECTION

In the course of the Project, each Party is involved in the production and collection of data in the form of ***the NON-HFE REGISTRY.*** The data is to be entered online by each partner at http://non-hfe.com/ and stored in an archive at ***the Medical University of Innsbruck*** (“the non HFE database”). Each Party agrees to ensure that all data submitted in pseudonymized from to the **NON HFE REGSITRY** are documented at each participating institution with a code that allows only the local partner identify the patient, from whom origin data have been submitted.

During the duration of the project, partners agree to update information on patients entered into the registry with the status “alive” at least annually.

1. DATA MAINTENANCE

The ***Medical University of Innsbruck*** hereby undertakes to maintain the Project Archive for the duration of the Project and for a period of at least three (3) years after the end of the Project. This period is subject to extension if the Steering Group so decides.

1. DATA PROTECTION

As a member of the Consortium, each Party will be processing personal data for the purpose of the **NON HFE REGISTRY**. With this consortium agreement the partner agrees to obtain written informed consent from each patient, from whom pseudonymized information is entered into the NON HFE REGISTRY and that data entry will be carried out in accordance with each partner’s individual local ethics research committee, prior to processing personal data for the purposes of the Project.

1. DATA EXTRACTION & PUBLICATION

The Medical University of Innsbruck acts as the central data coordinating center (CDCC) is allowed to have access to the data of all partners to

* ensure consistency of data collection (feedback to the partners)
* prepare overviews on the status of data collection which should be reported back to the partners
* to develop with the partners new research ideas and to promote networking between the partners.

The CDCC does not have the allowance to use the data without agreement of the partners for publications or for grant applications. The latter requires an agreement between the partners with opt-in and opt-out possibilities.

Each contributing partner will have access to its own data and can therefore use the registry also for data collection purposes of their own cases.

There is no access of a partner to the data of the other partners except a partner gives a reading access to the other partners.

1. **Intellectual Property Rights**
2. Ownership

**Background Intellectual Property**

The ownership of Background Intellectual Property provided by each Party shall not be changed by this Cooperation Agreement. This shall apply independently from explicitly mentioning the ownership of the provided information, data, documents, samples or in sharing information.

Licenses to Background Intellectual Property require a separate written agreement which has to be mutually agreed upon by the respective parties.

**Foreground Intellectual Property**

Foreground shall belong to the Party carrying out the work generating it. Foreground jointly generated by several Parties is owned by them depending on their input. The respective Parties shall establish a written agreement regarding the allocation and terms of exercising that joint ownership (shares, filing, exploitation, etc.)

The Parties will avoid anything that might impede the patentability of an invention.

1. Access Rights needed for the execution of the Project:

**Background Intellectual Property**

For the duration and the scope of the Project the Parties will negotiate about granting royalty-free, non exclusive, non transferable Access Rights to Background Intellectual Property to the extend such Access Rights are needed for carrying out the work of this Project.

**Foreground Intellectual Property**

For the duration and the scope of the Project the Parties grant each other royalty-free, non exclusive, non transferable Access Rights to Foreground Intellectual Property to the extend such Access Rights are needed for carrying out the work of this Project.

1. **Confidentiality and Publication**
2. Confidentiality

All information in whatever form or mode of transmission, which is disclosed by one Party (the "Disclosing Party") to any other Party (the "Recipient") in connection with the Project, is regarded as Confidential Information.

The recipient is

• not allowed to use Confidential Information otherwise than for the purpose it was disclosed for during the Project and for a period of five years after the end of the Project,

• not allowed to disclose Confidential Information to any Third Party without the prior written consent of the Disclosing Party,

• obliged to ensure that internal distribution of Confidential Information by a Recipient shall take place on a strict need-to-know basis and

• obliged to return to the Disclosing Party on demand all Confidential Information which has been supplied to or acquired by the recipients including all copies thereof and to delete all Confidential Information stored in a machine readable form. If needed for the recording of ongoing obligations, the Recipient is allowed to keep a copy for archival purposes required by law.

The Recipient shall be also responsible for the fulfillment of the above obligations through its employees and shall ensure that its employee’s obligations persist, as far as legally feasible, during and after the end of the Project and/or after the termination of the employment.

The provisions stated above shall not apply for the disclosure or the use of Confidential Information, if and in so far the recipient can show that

• the Confidential Information becomes publicly available by means other than a breach of the Recipient's confidentiality obligations,

• the Disclosing Party subsequently informs the Recipient that the Confidential

Information is no longer confidential,

• the Confidential Information is communicated to the Recipient without any obligation of confidence by a Third Party who is in lawful possession thereof and under no obligation of confidence to the Disclosing Party,

• the Confidential Information, at any time, was developed by the Recipient independently of any such disclosure by the Disclosing Party, or

• the disclosure of Confidential Information is required by law.

1. Publication

Results of the project may be published or presented for scientific and/or academic purposes. For the avoidance of doubt the publication right includes positive and negative results of the Project. At least thirty (30) days prior to submitting a manuscript to a publisher or other third party or prior to any public presentation, a copy of the manuscript or presentation will be provided to the other parties for review and comment. Any Confidential Information or other proprietary information of another party shall be removed at request of the respective other party prior to submitting or presenting a publication and reasonable comments made by the other party shall be incorporated into the publication.

In the event that the publication of project results puts the confidentiality at risk or the obtaining of industrial property rights is affected the other parties may require deletion of this confidential information or may require delay of publication for a maximum of three (3) month to seek intellectual property protection. If the other parties do not require deletion or delay as herein before mentioned within thirty (30) days after receipt of the manuscript or presentation, the other parties consent to the publication shall be considered to have been given.

Students, who carry out work on this project on behalf of a party, shall have the possibility to use their research work in publications to qualify for a degree.

1. **Liability**

No Party shall be responsible to any other Party for punitive damages, indirect or consequential loss or similar damage such as, but not limited to, loss of profit, loss of revenue or loss of contracts. The exclusions and limitations of liability stated above shall not apply in the case of damage caused by a willful act or gross negligence.

However, the terms of this Cooperation Agreement shall not be construed to amend or limit any non-contractual liability.

Each Party shall be solely liable for any loss, damage or injury to Third Parties resulting from their performance.

1. **Involvement of Third Parties**

A Party that enters into a subcontract or otherwise involves Third Parties to the Project remains solely responsible for carrying out its relevant part of the Project. The relationship of the other Parties is not affected by the relationship of one Party to a Third Party.

1. **Duration and Termination**

This Cooperation Agreement shall have effect from the beginning of the Project, which is the 01.03.2017, and it shall expire on the 28.05.2022.

In the event of a substantial breach by a Party of its obligations under this Cooperation

Agreement, which is not remedied within a reasonable time, the other Party may decide to terminate this Cooperation Agreement.

1. **Miscellaneous**

Amendments or changes to this Cooperation Agreement shall be valid only if made in writing and signed by the authorized representatives of each Party.

Each Party shall act as an independent entity and not as the agent of any of the other Parties. Neither Party shall be entitled to act or make legally binding declarations on behalf of any other Party.

Should any provision of this Cooperation Agreement prove to be invalid or incapable of fulfillment or subsequently become invalid or incapable of fulfillment, whether in whole or in part, this shall not affect the validity of the remaining provisions of the Cooperation Agreement. In this case the Parties shall agree on a valid and practicable provision which fulfils the purpose of the invalid or impracticable provision. The same shall apply if the provisions of the contract are found to be incomplete.

This Cooperation Agreement shall be construed according to and governed by the law of Austria excluding any conflict of laws principle.

All disputes arising in connection with this Cooperation Agreement, which cannot be resolved in an amicable way, shall be finally settled by the competent courts of Innsbruck.

Innsbruck,

Univ.-Prof. Dr. Herbert Tilg

for Medical University of Innsbruck

[Your City], \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

[Your name]

**Annex A – RESEARCH PLAN**

**Area of the Project:** Hemochromatosis is the most common genetic and metabolic liver disease in adults and an important differential diagnosis in patients with chronic liver disease. Although up to 85 % of patients with hemochromatosis are homozygous for the C282Y polymorphism of the HFE gene, several non-HFE associated hemochromatosis variants have been described in patients with confirmed hepatic iron overload. Investigating individual patients beyond HFE genotyping is therefore recommended in several guidelines - including the EASL clinical practice guideline on hemochromatosis. However, in clinical practice genetic testing beyond HFE genotyping is performed in a minority of patients with confirmed iron overload. Most importantly, genetic and medical counselling in patients with non- HFE hemochromatosis, ferroportin disease and aceruloplasminemia is challenging, because no or very limited data on the natural course, potential complications or the effectivity of phlebotomy have been reported in these conditions. Furthermore, the clinical significance of novel sequence variants is difficult to ascertain in individual patients. In recent years and especially since next generation sequencing technologies have been introduced, the number of patients identified with rare hemochromatosis variants has increased, but these variants are no longer reported in the literature because their functional relevance is unclear or because they have been reported previously. Therefore there is an unmet need to gather together information on non-HFE hemochromatosis, and use this Registry to improve patient care.

**Length of project in months:** The proposed duration of the project is 60 months. Initial setup of the database is expected to be completed within 6 months. Data entry is expected to start in October 2015 and preliminary data will be shared with the EASL governing board in January 2016. Annual reports will be presented to the EASL governing board. The retrospective study arm will be closed 24 months after database launch. Formal analysis of the retrospective data will be completed in month 30 and presented to the funding body. Retrospective data analysis will also be submitted for peer review and publication. Prospective follow up will be completed in month 54 to leave 6 months for data curation, analysis and scientific publication. During the entire project consortium members will have the opportunity to decide if and when novel genetic variants should be presented in a publicly available database. Mutations will be classified according to their clinical significance. To encourage data entry, novel mutations will not be made immediately publicly available but stored until the end of the project. If another author submits the same mutation later in time, the software will advise of this and redirect to the first submitter in order to boost collaborations.

**Background and aims:** Hepatic iron overload is an important risk factor for the progression of chronic liver diseases from fibrosis to cirrhosis [7, 10] and the hallmark of liver disease in patients with hereditary hemochromatosis [1]. Genetic studies have shown that up to 85 % of patients with the clinical diagnosis ‘hemochromatosis’ are homozygous for the common C282Y polymorphism of the HFE gene [4]. Hence, the disease is now referred to as HFE-associated hemochromatosis [1]. Identification of the HFE gene has transformed clinical management for hemochromatosis, enabled earlier diagnosis and probably improved the disease course [3, 9]. However, in addition to HFE-associated hemochromatosis, other genetic conditions, which are clinically and pathologically reminiscent of classical HFE hemochromatosis, have been identified in patients homozygous or compound heterozygous for mutations in TFR2, HJV or HAMP. These disorders are referred to as non-HFE hemochromatosis [2]. Ferroportin disease is another disorder of iron metabolism caused by heterozygous mutations in the SLC40A1 gene [8], In contrast to HFE and non-HFE associated hemochromatosis variants which are typically associated with high transferrin saturation, transferrin saturation is variable and can be low in ferroportin disease. Invariably low transferrin saturation and severe hepatic iron overload is also typical in the autosomal recessive iron disorder aceruloplasminemia [6]. In comparison to HFE associated hemochromatosis, which has an estimated prevalence of 1:1000, non-HFE hemochromatosis, ferroportin disease and aceruloplasminemia are relatively rare, but are increasingly recognized to contribute to the overall burden of iron overload disorders, especially in Southern and Central Europe where the prevalence of HFE mutations is lower. Moreover, uncertainties about the true prevalence and disease management (in contrast to HFE-hemochromatosis) present a significant clinical challenge. The ultimate goal of this registry is to improve patient care by comprehensively categorizing non-HFE liver iron overload disease across Europe, which will enable an evidence-based revision of clinical guidelines. The number of patients with genetically confirmed non-HFE hemochromatosis, ferroportin disease or aceruloplasminemia is increasing, because novel sequencing strategies are increasingly used in the diagnostic workup of patients with confirmed or suspected hepatic iron overload. Further, clinical application of full exome sequencing has further increases the number of aberrations found incidentally in genes associated with non-HFE hemochromatosis [5]. Interpretation of such test results and identification of pathogenic mutations can be guided by structured collection and documentation of cases in a registry. Such a registry will help to establish disease penetrance, expressivity of certain mutations as well as clinical presentation and prognosis of different non-HFE variants. Most importantly, it will be the basis of a collaborative effort to elucidate the genetic architecture of these complex diseases. The aim of the proposed registry is to collect structured information on the clinical presentation, biochemistry, radiology, family history, genetics and histology of patients with non-HFE hemochromatosis, ferroportin disease and aceruloplasminemia. Collecting follow-up information on these patients will help to understand the natural course of each disease variant and determine the effect of specific interventions, and ultimately facilitate more informed clinical guidelines.

**Methods:** (i) Retrospective assessment of patients with genetically confirmed non-HFE hemochromatosis, ferroportin disease or aceruloplasminemia to determine prognosis, treatment strategies and complications. (ii) Prospective inclusion of patients with newly diagnosed non-HFE hemochromatosis, ferroportin disease or aceruloplasminemia to determine the incidence of non-HFE hemochromatosis and improve our understanding on the prognosis. Retrospective assessment aims at determining disease prognosis and collect information on currently used treatment strategies for the different entities. The prospective study design aims at understand the epidemiology of these conditions and at collecting prospective data on disease prognosis and compilcations. The collection of high-quality data requires a standardized procedure. We will therefore apply electronic case report forms implemented in "Askimed" (http://www.askimed.com). Askimed is an intuitive and self-explaining researcher-supporting software solution that allows a standardized data collection with extensive checking of plausibility as part of the quality control management. It is already in use in the German Chronic Kidney Disease Study (http://www.gckd.de/), the FP7- funded ncRNAPain project (http://www.ncrna-pain.eu/) and in a large study including patients with macular degeneration (AugUR study). All data are securely transferred to a centralized MySQL database. The Medical University of Innsbruck will provide this centralized database for storage of data considering all security issues of importance for such a project. This includes that all interactions with the server and the database are encrypted. Furthermore, Askimed is compliant to the 21 CRF Part 11 regulations (FDA guidelines on electronic records and electronic signatures). The questionnaires will be programmed by the Innsbruck team, a database will be provided and - if requested - the questionnaires can be prepared in the most widely-used languages. The consortium will be owner of the data and access will be allowed according to the rules of the consortium. Furthermore a data monitor present at the Medical University of Innsbruck will visit participating institutions on an annual basis.

**Goals:**

1. What is the clinical presentation of non-HFE associated hepatic iron overload diseases (non HFE hemochromatosis, ferroportin disease and acoeruloplasminemia)?

2. What is the risk of developing hepatic and non-hepatic complications (heart disease, arthropathy, diabetes, hypogonadism etc.) in non-HFE associated hepatic iron overload diseases over time?

3. Which treatment strategies are used in non HFE associated hepatic iron overload diseases and does treatment affect disease course?

4. What is genetic architecture of non HFE associated hepatic iron overload diseases (i.e. what is the clinical significance of specific mutations)?

5. When is genetic testing beyond HFE genotyping recommended and what are the implications of test results for disease management?

6. How do initial staging, follow up and treatment in patients with HFE and non HFE associated hemochromatosis differ? Each of these key questions can be directly addressed by the registry. The outcomes will have direct implications for clinical management in terms of diagnostic algorithms for patients with hepatic iron overload, follow up and treatment.

**Timeline**: The Askimed software will be customized for the non HFE hemochromatosis registry. This will take 4-6 months for initial trials. First patient entry will be possible 6 months after initiation of the project. Preliminary data and recruitment status will be shared with the EASL governing board after 8 months and interim reports will be presented on an annual basis. Retrospective data entry will be completed after 24 months. Data analysis will be completed after 30 months and the results will be submitted for publication. The mutation database will be made publicly available after 12 months. Prospective data entry will be possible until month 54 of the project to leave 6 months for data curation and final analysis. If successful data entry will be possible thereafter as maintenance cost will be minimal after 5 years. As the proposed registry ties in with the European Legislation on Orphan Diseases, the database could be maintained long term. During the EASL funding period, funding from the European Union and national funding bodies to maintain this database will be sought.

**Annex B – BUDGET**

Setup and maintainance cost for the database……………………………… 25.000 €

~~Reimbursement for Obtaining Ethical Approval € 500 each ……max. 10.000 €~~

~~Reimbursement for complete data entry € 100 per patione……max. 10.000 €~~

Travel, meetings & other costs………………………………………………………… 5.000 €

**Total Budget ………………………………………………………………………………….50.000 €**

**Update 2022: The budget for reimbursements is exhausted.**

**Annex C – Steering Group**

**Heinz Zoller (Benedikt Schaefer)**

**Florian Kronenberg**

**Domenico Girelli**

**Patricia Bignell**

**Nathan Subramaniam**

**Olivier Loreál**

**Antonello Pietrangelo (Elena Corradini)**

**Dorine Swinkels (Tessas Peters)**

**Alberto Piperno (Mariani Raffaella/Irene Pelloni)**

**Annex D – Collaborating Entities**

1. Medical University of Innsbruck
2. Department of Medicine - Reference center for rare iron overload disease, CHU de Rennes - Université de Rennes, Rennes, France
3. Liver Centre, Mater Misericordiae University Hospital, Dublin, Ireland
4. Diagnostics in Iron Metabolism Diseases (D•IRON), Josep Carreras Leukaemia Research Institute (IJC), Barcelona, Spain
5. Department of Medicine, University of Cambridge, Cambridge, United Kingdom
6. Medizinische Klinik I, Universitätsklinikum Dresden, Dresden
7. Department of Pediatrics, University of Heidelberg, Heidelberg, Germany
8. Department of Metabolic Liver Diseases, Università degli Studi Milano, Milano, Italy
9. Department of Medicine, University of Oxford BRC/NHS Molecular
10. Diagnostic Laboratory - Haematology Laboratory, Oxford University, Oxford, United Kingdom
11. Institute of Molecular and Cellular Biology, University of Porto and Center for Predictive and Preventive Genetics, Porto, Portugal
12. Department of Medicine, CHU de Rennes - Université de Rennes, Rennes, France
13. Department of Medicine, Private Medizinische Universität Salzburg, Salzburg, Austria
14. Department of Medicine, Karolinska University Stockholm, Stockholm, Sweden
15. Department of Medicine, University of Verona, Verona, Italy
16. Department of Medicine, University of Oslo, Oslo, Norway
17. Laboratory Medicine, Radboud University Medical Centre, Nijmegen, Netherlands
18. Department of Health Sciences, University of Milano-Bicocca - Unit of Internal Medicine 2, S.Gerardo Hospital, Monza
19. Unit of Internal Medicine and Metabolic Diseases - Center for Hemochromatosis, University Hospital of Modena, Modena, Italy
20. Weatherall Institute for Molecular Medicine, Oxford University, Oxford, United Kingdom
21. European Federation of Associations of Patients with Haemochromatosis, 4 rue Paul Demange - F-78290 Croissy-sur-Seine