

WG5 Meeting, Belgrade

Members of WG5 gathered for the first separate meeting on October 25th and 26th 2018, in Belgrade, hosted by WG5 leader – Geertruy te Kronnie and Communication Committee leader – Jelena Lazic.



The meeting started with a presentation, given by Geertruy te Kronnie, pointing out how WG5 goals are incorporated in all WGs.



Current activities were presented, by the WG5 leader:

- Survey of the current clinical practice of recognition of genetic predisposition in paediatric leukemia and lymphoma patients
- Training School (TS) for early career paediatric oncologists and clinical and laboratory geneticists
- Systematic review of germline genetic variation and predisposition to leukemia and lymphoma with an overview of clinical, ethical and legal implications.

Importance of stronger inclusion of Patients and Parents associations of children with leukemia and lymphoma in Europe was recognised, as well as the extension of WG5's multidisciplinary team with ethical and legal experts.

Geertruy te Kronnie presented the up-date on Questionnaires for medical providers. Preliminary data initiated an interesting discussion and helped to recognize additional issues to be included in this project. All present members agreed that the number of filled questionnaires should be at least doubled and offered to proceed locally. The progress of recognition of current practices and needs should be continued with a questionnaire for parents and patient associations. A pilot study was conducted in Poland last year and pending the translation of the Polish questionnaire for Parents and Patient (P&P) organizations (Wojciech Mlynarski) an agreement was reached to proceed with a new questionnaire. Many ideas of the present members were adopted (Jan Loeffen, Tim Ripperger, Africa Garcia-Orad):

to include Wiliam Davis in the P&P questionnaire team, to contact Associations of parents with known predisposing conditions/syndromes to leukemia and lymphoma, to address Orphanet and to distribute the questionnaires to the Syndrome associations meet-up.

For the evaluation/analysis of the Questionnaire 'current practice of L&L recognition' the need was underlined to precisely formulate questions that will adequately address the data and decide which variables to correlate to draw final conclusion. This task was assigned to the younger team members (Anna Byrjalsen, Lucie Slamova and Ivana Ilic), they will be assisted by seniors (Tim Ripperger, Geertruy te Kronnie and Jelena Lazic). Since the team has no previous experience with P&P questionnaires and possible reactions it can provoke, it has been decided that, at first, questionnaires should be applied as a trial version in Poland, Serbia, the Netherlands and Turkey.



Tim Ripperger addressed the topic of genetic counseling following questionnaire-based (GPOH) screening for cancer predisposition, by presenting the trinity of clinical relevance and results of the use of the adapted tool from 2017 (AJMG). He explained in detailed the current state, pointing out the necessity of simple referral and showed an algorithm of tasks. It was concluded that the questionnaire is a sensitive tool, which helped to identify patients with possible susceptibility.

Jelena Lazic and Branislava Penov presented the role of P&P associations in Serbia, acknowledging the importance of collaboration and contribution to improvement of care and

quality of life of families facing children with cancer. They showed the positive experience of local mini-projects, Anna Byrjalsen suggested to publish these results.

Anna Byrjalsen assessed the ethical aspect of WGS of newly diagnosed children with cancer, with further review on eventually determined genetic events. The analyzed results raised the question of early counseling. New terminology was introduced: “Scanxiety” and “Vulnerable child syndrome”.

Lucie Slamova drew attention to both ethical and psychosocial aspects in genetic counseling, pointing out that many open questions were already addressed and concluded with her own experience.

Issues considering the first edition of the Training school ‘Predisposition to hereditary Leukemia and Lymphoma’ were firstly discussed among present members followed by a Zoom call with members of TS Organizational board that could not attend the meeting in Belgrade. An agreement was reached on the final program and structure of application documents. Future trainees will be encouraged to bring case reports to be discussed with experts and every trainee will have an assigned mentor to guide them in preparations and through-out the course. Keynote lecturers were confirmed, as well as invited trainers. Each TS session will be lead by two responsible trainers and the presentation of six sessions started with an interactive discussion of all members. Importance of the main goal of the TS was repeated – to build a network among young experts with up to date knowledge of genetic predisposition in the hemato-oncology field.

Geertruy te Kronnie, Ugur Ozbek and Jelena Lazic presented the previous work of the Review team (RT) and future timeline. Together they explained in detail the methodology and initiated a fruitful discussion with all WG5 members. Chapters will be narrowed down to ethical concerns, need for genetic counseling and addressing psycho-social problems in selected papers with an overview of cumulative risk of identified germline/somatic variants and a summary of related syndromes/genes. Future assignments were divided between RT members.

Geertruy te Kronnie presented the chronology and importance of detection of IKAROS mutations in leukemia patients, pointing at the significance of germline mutations and future risk stratification, according to the genetic profile of the patients.

Ugur Ozbek showed the established genetic data base, suitable and useful for clinicians, application available for two platforms (PC and mobile phone), with selection of data of pediatric cancer patients in Turkey from the National register.

At the official dinner, members of SuperDot (IT company responsible for the visual identity of the LEGEND-COST Action) were present and took the part in discussions considering the website, GDPRs, social networks and related issues.



In closure, organizers thanked all participants for attending the meeting, interactive and fruitful discussions which helped to formalize the WG5 goals. Agreement on next meeting of WG5 to be held in Istanbul, precise date/time to be determinate.

AGENDA WG-5 meeting
25-26 October 2018
Belgrade, Serbia

Venue: Mercure Hotel, Belgrade Excelsior

Arrival: Thursday October 25th (or Wednesday October 24th) – transport from the airport will be arranged*

Session 1

Thursday, October 25th

Chair: Geertruy te Kronnie

13:00-13:30

- **Get together** (meeting room) + cocktail
- **Welcome** by the local organizers, National COST representative and Dean of Faculty of Medicine University of Belgrade

13:30-14:00

- **Questionnaire** up-date on responses since (17.5.2018. Helsinki IBFM-meeting)
- **First results**
- **Reporting/publication**

14:30-15:00

- **Patient and Parents** associations
 - The role of Patient & Parents associations – our experience (Branislava Penov & Jelena Lazic)

15:00-16:00

- Ethical and psychosocial aspects, counselling
 - Ethical and psychosocial aspects in genetic counselling – Lucie Slamova
 - WGS of newly diagnosed children with cancer and look into the genetic findings and ethical questions - Anna Byrjalsen

16:00-16:30

- **Break**

16:30-17:30

- **Training School** 'Predisposition to Hereditary Leukemia and Lymphoma'
 - **Presentation** (Geertruy te Kronnie /Jelena Lazic/Ugur Ozbek)
 - **Discussion** (All)

17:30-18:30

- **Review** Clinical germline genetic variation and predisposition to Leukemia and Lymphoma: Clinical, Ethical and Legal implications (review team)

20:00 Dinner – walking distance with short sightseeing: meeting in hotel lobby at 19:30

Session 2

Friday October 26

Chair: Jelena Lazic

9:00-10:00

- Germline genetic IKZF1 variation and predisposition to childhood acute lymphoblastic leukemia – Geertruy te Kronnie

10:00-11:00

- Genetic data base for clinicians – Ugur Ozbek

11:00-11.30

- **Break**

11:30-14:00

- Discussion/wrapping up of WG5 goals and deliverables

14:00-15:00

- **Lunch break**

For participants who are leaving – transfer to the airport

Session 3
Friday October 26

15:00-18:30 (refreshment included)

- Time for Questionnaire, Patients & Parents (P&P) associations, Training school (TS) and Review team (RT) work-discussions (+ Skype/Zoom call with absent members of RT – Jutte Van der Werff Ten Bosch & Dragana Malcic and TS OB – Jutte Van der Werff Ten Bosch, Gianni Cazzaniga, Esme Waanders)

20:00 Dinner– walking distance with short sightseeing: meeting in hotel lobby at 19:30

* please inform Jelena Lazic (lazic.jelena@gmail.com) about your flight details.