

# 1<sup>st</sup> WORKING GROUPS MEETING

Friday, 23rd January 2026

Virtual Meeting

Zoom link:

<https://uoc-gr.zoom.us/j/88695380530?pwd=XpwbzylgO4CsH88Kb1KpJQXqRFf6dq.1>

Meeting ID: 886 9538 0530

Passcode: 070212

## AGENDA (time zone CET)

**08.45 - 09.00 | Welcome and Introduction by Action's Chair (H. Papadaki)**

**09.00 - 10.00 | Working Group 1: The Role of Inflammation in Congenital CNP**

- Introduction to WG1 (A. Warren)
- New methodologies to explore clonal haematopoiesis (D. Kent)
- In vitro modeling of stage-specific evolution of clonal haematopoiesis in CN to CN/AML (N. Borbaran-Bravo)
- In vivo modeling of leukemic evolution in ELANE-associated Severe Congenital Neutropenia (J. Haaf)

**10.00 - 11.00 | Working Group 2: Acquired and Likely-Acquired CNP and Inflammation**

- The genetic background of non-remitting Neutropenia in children and of Chronic Idiopathic Neutropenia in adults (F. Fioredda)
- Linking CNP phenotypes with autoimmunity and autoinflammation (P. Skendros)
- CarD clone: unravelling the inflammation link between acquired/likely acquired CNP and cardiovascular disease (CVD) (G. Tsaknakis)
- Investigation of the inflammation link with nutrition in acquired/likely acquired CNP (A. Eliopoulos, C. Simoglou-Karali)
- Investigation of Microbiome links with acquired CNP (I. Lagkouvardos)

- ACKR1-Associated Neutropenia (ADAN): Clinical insights from a Brazilian cohort (R. Cerqueira)

### **11.00 - 11.15 | Break**

### **11.15 - 12.15 | Working Group 3: CNP Risk Factor Profiling and ML Predictive Modeling**

- Welcome & Introduction (H. Latsoudis, G. Cavalca, G. Manikis, V. Tzikoulis)
- Should WG3 be a horizontal group for the Action? (H. Latsoudis)
- Different data storage models and their benefits (G. Manikis)
- Data pre-processing and Information Management System development (V. Tzikoulis)
- Exploration and application of different statistical and ML models using real data on Neutropenias (G. Cavalca, G. Papoutsoglou)
- Discussion

### **12.15 - 13.15 | Working Group 4: Drug-induced Neutropenias by Novel Therapies**

- Introduction (A. Pierini, C. Simoglou-Karali, M. Spanoudakis)
- Exemplars of analyses focusing on drug-induced neutropenia following
  - (i) treatment with rituxumab (J. Palmblad)
  - (ii) exposure to immunomodulatory drugs (C. Simoglou Karali)
  - (iii) CAR-T therapy (V. Quintero)
- Interrogation of unexplored molecular machineries – Bioinformatic analyses applied on multiomic single-cell data (S. Riva)

### **13.15 - 13.30 | Break**

### **13.30 - 14.30 | Working Group 5: General Concept and Design of Clinical Trials**

- Introduction of the WG5 (J. Skokowa, J. Cichy, V. Bezzerri)
- Regulatory aspects, hurdles and needs on the way to realise personalised medicine in rare diseases (M. Cipolli, V. Bezzerri)

### **14.30 - 15.30 | Working Group 6: Development of Tools for Evaluation of PROS and QoL**

- Introduction of the WG6 (C. Zeidler, C. Karamanidou, E. Laane)
- Proposal for Task allocation (C. Karamanidou)

### 15.30 - 15.45 | Break

### 15.45 - 16.30 | Young Neutro-NARPS group

- Introduction to the Young Neutro-NARPS Group (A. Skakic, V. Kargas)
- Deficient regulatory T cells in autoimmune neutropenia of childhood (K. Toutoudaki)
- In vivo gene therapy for Shwachman-Diamond Syndrome (D. Trasanidou)

### 16.30 - 17.30 | Neutro-NARPS collaborators

- The Shwachman-Diamond Syndrome Alliance (E. Hars)
- How the Italian Association of Shwachman-Diamond Syndrome supports scientific research (E. Talacchi)
- Rare Diseases Greece Association (D. Athanasiou)
- EHA support of the Neutro-NARPS COST as a part of the SWG engagement (V. Lotushko)

### 17.30 - 18.00 | General Discussion

### 18.00 - 18.15 | Closing Remarks

SPEAKERS *	INSTITUTION OF AFFILIATION	COUNTRY OF AFFILIATION
<b>MR DIMITRIOS ATHANASIOU</b>	Rare Diseases Greece Vice Chair, Greek Patients Association Board Member European Patient Forum Ethics Board Member	Greece
<b>PROF VALENTINO BEZZERRI</b>	Department of Life Sciences, Health, and Health Professions, Link Campus University, Rome & Cystic Fibrosis Center, Azienda Ospedaliera Universitaria Integrata, Verona	Italy
<b>DR NATALIA BORBARAN-BRAVO</b>	Division of Translational Oncology, Department of Hematology, Oncology, Clinical Immunology and Rheumatology, University Hospital Tübingen, Tübingen	Germany

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<b>DR RENATO CERQUEIRA</b>	Department of Clinical and Experimental Oncology, Federal University of São Paulo (UNIFESP), Sao Paolo	Brazil
<b>PROF JOANNA CICHY</b>	Department of Immunology, Faculty of Biochemistry, Biophysics and Biotechnology, Jagiellonian University, Kraków	Poland
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<b>PROF ARISTIDES ELIOPOULOS</b>	Medical School, National and Kapodistrian University of Athens, Athens	Greece
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<b>DR CHRISTINA KARAMANIDOU</b>	Institute of Applied Biosciences, Centre for Research & Technology-Hellas, Thessaloniki	Greece
<b>DR VASILEIOS KARGAS</b>	Cambridge Institute for Medical Research, University of Cambridge, Cambridge	UK
<b>PROF DAVID KENT</b>	Department of Biology, Centre for Blood Research, York Biomedical Research Institute, University of York, York	UK
<b>DR EDWARD LAANE</b>	Hematology-Oncology Clinic, Tartu University, Tartu	Estonia

<b>PROF ILIAS LAGKOUVARDOS</b>	Department of Clinical Microbiology, School of Medicine, University of Crete, Heraklion	Greece
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<b>MR VOLODYMYR LOTUSHKO</b>	Specialized Working Group (SWG) Manager, European Hematology Association (EHA)	Netherlands
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<b>PROF JAN PALMBLAD</b>	Department of Medicine Huddinge, Karolinska Institutet, Stockholm	Sweden
<b>PROF HELEN PAPA DAKI</b>	Haemopoiesis Research Laboratory, University of Crete, Heraklion & University Hospital of Heraklion, Heraklion	Greece
<b>DR ANTONIO PIERINI</b>	Hematology and Clinical Immunology Section, Center for Hemato-Oncology Research, Department of Medicine and Surgery, University of Perugia, Perugia,	Italy
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<b>DR GEORGE PAPOUTSO GLOU</b>	Chief Operations Officer, JADBio, Heraklion	Greece
<b>MR SIMONE RIVA</b>	MRC WIMM Centre for Computational Biology, Weatherall Institute of Molecular Medicine, Radcliffe Department of Medicine, University of Oxford, Oxford	UK
<b>DR CRISTINA SIMO GLOU-KARALI</b>	Department of Biology, School of Medicine, National and Kapodistrian University of Athens, Athens, & Medical Research Council Weatherall Institute of Molecular Medicine (MRC WIMM) and NIHR Biomedical Research Centre Hematology Theme, University of Oxford, Oxford	Greece/ UK

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\*In alphabetical order

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