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# Practical Information Note

**Advancement of Treatments  
for Rare Diseases Conference**

LEFKOSIA (NICOSIA), CYPRUS  
5 - 6 March 2026

# LIST OF CONTENTS

KEY DEADLINES .....	3
LOCATION AND VENUES.....	4
REGISTRATION AND ACCREDITATION.....	5
<i>Registration &amp; Accreditation</i> .....	5
<i>Individual Registration Information</i> .....	6
<i>Badges</i> .....	6
SECURITY.....	7
PRELIMINARY PROGRAMME .....	7
WORKING LANGUAGE.....	13
TRANSPORT.....	13
<i>Points of entry</i> .....	13
<i>Arrivals - Departures</i> .....	13
<i>Transportation</i> .....	15
ACCOMMODATION .....	15
SUSTAINABILITY.....	16
MEDIA .....	16
THE PRESIDENCY ONLINE.....	16
OTHER PRACTICAL INFORMATION .....	17
CONTACT DETAILS.....	17

## GENERAL INFORMATION

The Cyprus Presidency of the Council of the European Union 2026 has the pleasure of welcoming you to Lefkosia (Nicosia) for the **Advancement of Treatments for Rare Diseases**, which will take place on **5<sup>th</sup> and 6<sup>th</sup> March 2026** at **The Cyprus Institute of Neurology & Genetics**.

This Practical Information Note (PIN) is intended to provide all necessary logistical and programme-related information to facilitate the preparation of your visit.

Please note that the information contained herein may be subject to change. The Cyprus Presidency will share any updated information related to the meeting through the Cyprus Presidency's dedicated Accreditation Platform.

## KEY DEADLINES

When	What	Where/Who
23/01/2026	Accreditation platform opens	<a href="mailto:accreditation@cyprus2026eu.gov.cy">accreditation@cyprus2026eu.gov.cy</a>
	Deadline for requesting the individual access code	<a href="mailto:RESEARCH-CY2026EU@dmrid.gov.cy">RESEARCH-CY2026EU@dmrid.gov.cy</a>
20/02/2026	Deadline for claiming pre-booked hotel reservations	Delegations to indicate booked rooms through the Accreditation Platform
20/02/2026	Accreditation platform closes	Accreditation Team
5-6/03/2026	Advancement of Treatments for Rare Diseases	The Cyprus Institute of Neurology & Genetics

# LOCATION AND VENUES

## *Location*

### *Lefkosia (Nicosia)*



Photo from: [Visit Cyprus](https://www.visitcyprus.gov.cy/)

Lefkosia (Nicosia) – the last divided capital of Europe, as part of it remains under illegal military occupation by Turkey – is a city where centuries of history meet a vibrant, cosmopolitan present. As the island’s administrative and business centre, it combines the energy of a modern European capital with the timeless charm of an ancient walled city.

At its heart lies the old town, encircled by impressive Venetian walls and heart-shaped bastions, offering a glimpse into the city’s medieval past. Narrow streets, traditional shops, and historic monuments sit alongside contemporary galleries, museums and cultural venues, reflecting Lefkosia’s dynamic character.

The modern city beyond the walls is fast-paced and forward-looking, home to major commercial and financial institutions. Its retail landscape spans from bustling shopping districts and malls to artisan quarters filled with local crafts. A diverse culinary scene and a vibrant nightlife, where cafés and bars coexist with centuries-old buildings, contribute to the city’s unique blend of old and new.

Beyond the urban centre, the wider Lefkosia region reveals a more peaceful side. Picturesque countryside and mountain villages offer opportunities for hiking, cycling

and exploring traditional life in scenic surroundings. Stone-built homes, quiet trails and welcoming village squares invite visitors to experience the region's rural charm.

With its many layers of history, culture and modern life, Lefkosia stands as the beating heart of Cyprus – a capital that bridges the past and the future.

Discover more about Lefkosia – [Visit Lefkosia](#)

## ***Venue***

**The Cyprus Institute of Neurology & Genetics**

# **REGISTRATION AND ACCREDITATION**

## ***Registration & Accreditation***

To ensure secure and efficient access to the meeting venue, participants must be registered and accredited in advance through the Cyprus Presidency's dedicated online [Accreditation Platform](#).

For security reasons, access to the venue and other official parts of the programme will be granted **exclusively to accredited participants**.

Each meeting participant is required to go through the accreditation process for the event, in accordance with the instructions provided in the accreditation system. Participants register individually using their own credentials and the meeting code that they will have received via email from the platform. Only successfully registered and accredited participants shall be authorised to attend the meeting.

All personal data provided for accreditation will be processed in full compliance with the EU General Data Protection Regulation (GDPR). The Cyprus Presidency personal data privacy notice can be accessed through the Accreditation Platform.

For any questions related to registration and accreditation, please do not hesitate to contact the Accreditation Team (contact details provided in the last section).

## ***Individual Registration Information***

Each participant needs to create an individual account, with their own chosen credentials (email and password), validate their account and then register themselves using the individual access code for the meeting / conference received by email.

To receive the individual access code, please email [RESEARCH-CY2026EU@dmrid.gov.cy](mailto:RESEARCH-CY2026EU@dmrid.gov.cy) . In your email, please indicate if you are a speaker/panellist, a participant from Cyprus or a participant from abroad to receive the appropriate individual access code. Participants are kindly requested to complete the registration process at their earliest convenience and in any case before the deadlines for requesting the individual access code and for the closing of the platform mentioned herein.

The Cyprus Presidency's dedicated Accreditation Platform will be used to manage all relevant participants' information, including personal details, accreditation, transportation arrangements as well as accommodation and dietary requirements.

It is the participant's responsibility to ensure that they are duly registered and that all required information is submitted accurately by the specified deadline.

Following registration, the platform will remain accessible until **seven days** prior to the commencement of the event, allowing participants to enter their flight numbers and hotel accommodation details. Please note that once the registration period has closed, only the sections pertaining to flight details and hotel accommodation will remain available for editing.

## ***Badges***

The distribution of badges for the accredited participants will take place at the Cyprus Presidency's Information Points at Larnaka and Pafos International Airports upon arrival. Participants arriving two days before the meeting or earlier are requested to collect their badge at the Late Accreditation Centre, which will operate outside the Filoxenia Conference Centre in Lefkosia between 08:00 – 16:00. If none of the above options suit your needs, please note that any badges not delivered before the meeting / event will be available at the official venue. However, please be aware that without a badge, the transportation services provided by the Presidency will not be accessible.

All badges are strictly personal and non-transferable and must be visible at all times within the official venue, designated means of transport and security areas and, generally, throughout all parts of the official programme.

Lost badges should be reported immediately to the Accreditation Team via the contact details provided in the last section.

## **LIAISON OFFICERS**

Liaison Officers (LO) will be present at the two Cyprus Presidency's Information Points at Larnaka and Pafos International Airports.

## **SECURITY**

Security during the meeting will be ensured by the Cyprus Police, in close cooperation with all relevant national authorities.

## **PRELIMINARY PROGRAMME**

Please note that this programme is subject to change.

The final detailed programme will be shared with participants in advance of the meeting.

### **DAY 1 – 5<sup>th</sup> March 2026**

#### **Morning**

08:00 – 08:30 Registration and coffee

#### **Opening and welcome notes**

08:30 – 08:35 Opening and welcome Address

Leonidas A. Phylactou, Chief Executive Officer & Medical Director, The Cyprus Institute of Neurology & Genetics

Welcome note and endorsement

Michael Komodromos, President, The Cyprus Institute of Neurology & Genetics

Welcome Address and endorsement (**pre-recorded video**)

08:35 – 08:40 Olivér Várhelyi, Commissioner, EC Health and Animal Welfare, European Commission

08:40 – 08:50 Welcome Address

Nicodemos Damianou, Deputy Minister of Research, Innovation and Digital Policy,  
Republic of Cyprus

08:50 – 09:00 Overview of the Rare Disease Landscape in Cyprus

Neophytos Charalambides, Minister of Health, Republic of Cyprus

**Session 1 – Current landscape and unmet needs in rare diseases**

09:00-09:05 (**pre-recorded video**)

Séamus Boland, President, European Economic and Social Committee

09:05 – 09:20 European research on rare diseases: a long-standing commitment to make Europe a leader at global level

Carmen Laplaza Santos, Head of Unit, Health Innovations & Ecosystems DG Research & Innovation, European Commission

09:20 – 09:35 Witnessing and implementing change over the past 2 decades: the European Commission's action on rare diseases and therapy development

Stella Kyriakides, Former Commissioner for Health and Food Safety, European Commission

09:35 – 09:45 The European Economic and Social Committee's exploratory opinion on the advancement of treatments for Rare Diseases

Milena Angelova, Member, European Economic and Social Committee, Rapporteur of the opinion

09:45 – 10:00 Regulatory considerations for rare disease drug development and approval

Tim Leest, Chair, EMA Committee for Orphan Medicinal Products

10:00 – 10:15 EURORDIS' role in facilitating therapies for rare diseases (**online**)

Virginie Hivert, Acting Chief Executive Officer and Head of Therapies & Access, EURORDIS - Rare Diseases Europe

10:15 – 10:45 Panel discussion: Creating a Union of Opportunity for rare diseases therapy development

Moderator: Dr Menelaos Pipis, Senior Neurologist, Head of the Neuropathology Department, The Cyprus Institute of Neurology & Genetics

Speaker of the session joined by:

Valentina Bottarelli, Head of Policy and Public Affairs, EURORDIS - Rare Diseases Europe

**Coffee Break: 10:45 – 11:15**

**Session 2 – A framework for developing rationally-designed therapies for rare diseases**

11:15 – 11:30 Funding and patient advocacy organisations spearheading the effort against rare diseases  
Francois Lamy, Vice President, AFM-Téléthon

11:30 – 11:45 A European inventory of rare diseases through the scope of ERNs  
Donata Meroni, Head, Unit ‘Health Monitoring and Cooperation, Health Networks,  
European Commission

11:45 – 12:00 The current state of affairs for developing rational therapies for rare diseases  
Holm Graessner, Managing Director, Centre for Rare Diseases, University Hospital  
Tübingen, Germany and Coordinator of ERN-RND

12:00 – 12:15 ERDERA research initiatives for therapy development in rare diseases  
Daria Julkowska, Scientific coordinator, European Rare Diseases Research Alliance  
(ERDERA) & Assistant Director, Thematic Institute for Genetics, Genomics &  
Bioinformatics (IT GGB), INSERM

12:15 – 12:25 European Networking for Rare: Equity or Justice?  
Violetta Anastasiadou, Chair, Cyprus National Committee for Rare Diseases

12:25 – 13:15 Panel discussion: Creating incentives and overcoming bottlenecks in rare drug  
development.  
Moderator: Carsten Lederer, Senior Scientist, Head of the Blood Disorders Genetics and  
Thalassaemia Department, The Cyprus Institute of Neurology & Genetics  
Speaker of the session joined by:  
Ms. Kaja Kantorska, Biotechnologist, DG SANTE, European Commission  
Donata Meroni, Head of Unit, Health Monitoring and Cooperation, Health Networks,  
European Commission

**Lunch Break: 13:15 – 14:15**

**Session 3 – Drug discovery, development and repurposing in rare diseases**

14:15 – 14:30 Building on knowledge and lessons learnt: developing Nusinersen for SMA (online)  
Dr. Priya Singhal, Executive Vice President and Head of Development, Biogen

14:30 – 14:45 Developing virally-delivered genetic therapies for inherited neuromuscular disorders.  
Kleopas Kleopa, Senior Neurologist, Head of the Neurosciences Department, The Cyprus  
Institute of Neurology & Genetics

- 14:45 – 15:00 A Journey to Developing Curative Therapies for Hemoglobinopathies using Genome Editing  
Matthew H. Porteus, Professor Stanford University
- 15:00 – 15:15 Developing therapies for rare paediatric endocrine disorders  
Nicolas Nicolaides, University of Cyprus
- 15:15 – 15:30 Coffee Break
- 15:30 – 15:45 Chasing Miracles of Science: Accelerating Innovation in Rare Disease Medicines  
Karin Knobe, Senior Vice President, Global Head of Rare Diseases, Sanofi
- 15:45 – 16:00 The role of artificial intelligence in drug discovery and repurposing  
Demetris Skourides, Cyprus Chief Scientist for Research, Innovation and Technology, Republic of Cyprus
- 16:00 – 16:10 The End of Medicine As We Know It  
Harald Schmidt, Coordinator of REPO4EU
- 16:10 – 16:20 Innovative platform-based approach for sustainable repurposing of medicines for rare diseases.  
Anton Ussi, Coordinator of REMEDI4All
- 16:20 – 16:30 A clinical model for interdisciplinary sharing of knowledge and innovation for the development of rare diseases therapies. **(online)**  
Birute Tumiene, Vilnius University, Faculty of Medicine / Hospital Santatos Klinikos, Coordinator for Competence Centres and Member of MetabERN
- 16:30 – 17:30 Panel discussion: Synergies in academia and industry to accelerate drug development.  
Moderator: Petros Petrou, Senior Scientist, Head of the Biochemical Genetics Department, The Cyprus Institute of Neurology & Genetics

**End of day 1**

## **DAY 2: 6<sup>th</sup> March 2026**

### **Morning**

08:00 – 08:30 Registration and coffee

### **Session 4 – Becoming trial-ready for rare disease therapies**

08:30 – 08:45 Introducing initiatives to bring more clinical trials to Europe.

Hélène Le Borgne, Policy Officer, DG Research and Innovation, European Commission

08:45 – 09:00 Building an ecosystem for rare disease trial readiness

Maurizio Scarpa, Paediatrician and Director, Regional Coordinating Centre for Rare Diseases, University Hospital of Udine, Italy Coordinator of MetabERN

09:00 – 09:15 The European Platform on rare disease registration: Connecting data, accelerating care pathways and enabling research

Andri Papadopoulou, Scientific Officer, Joint Research Centre, European Commission

09:15 – 09:30 Amplifying patient and public involvement in small rare diseases ecosystems

Spyros Polyviou, Director, Alliance for Rare Disorders, Republic of Cyprus

09:30 – 09:45 National Biobanks for Population and Rare Disease Research

Giedrė Kvedaravičienė, Director of the Lithuanian Population and Rare Diseases Biobank

09:45 – 10:00 Considerations in the development of sensitive outcome measures needed to track the natural history of rare diseases (**online**)

Luca Sangiorgi, Director Rare Bone Disorders Dept. and Coordinator Rare Bone Diseases Centre Istituto Ortopedico Rizzoli, Coordinator of ERN-BOND

10:00 – 10:15 Clinical trials from the patients' perspective

Allan Fred Byamukama, Executive Director, Founder, Byamukama Sickle Cell Foundation

10:15 – 11:00 Panel discussion: Stakeholders working together for clinical trial preparation

Moderator: Kleopas Kleopa, Senior Neurologist, Head of the Neuroscience Department, The Cyprus Institute of Neurology & Genetics

Speakers of the session joined by:

Alexis Arzimanoglou, ERN EpiCARE Coordinator and Director of Paediatric Epilepsy Dpt. University Children's Hospital San Juan de Dios Barcelona, Spain

Karin Knobe, Senior Vice President, Global Head of Rare Diseases, Sanofi

Gregory Papagregoriou, Senior Scientist/Group Leader biobank.cy Center of Excellence,  
University of Cyprus

**Coffee Break: 11:00 – 11:30**

**Session 5 – Rollout of efficacious therapies: access and infrastructure considerations**

11:30 – 11:45 Infrastructure considerations for delivering therapies at scale: France’s example  
Anne-Sophie Lapointe, French representative in ERN Board of Member States

11:45 – 12:00 Capacity building and interdisciplinary training for delivering novel therapies in  
secondary care comprehensive healthcare facilities.

Nikolaos Zamboglou, Chief Executive Officer, German Oncology Center and the  
German Medical Institute

12:00 – 12:15 Health Technology Assessment and Innovative Payment Models for therapies for rare  
diseases

Christine Leopold, Assistant Professor, Drug Regulatory Science, Division of  
Pharmacoepidemiology & Clinical Pharmacology, Utrecht Institute for Pharmaceutical  
Science / WHO Collaborating Centre for Pharmaceutical Policy and Regulation

12:15 – 12:30 Rare Diseases, Research, Therapies and Social Impact

Panikos Voskos, President of Muscular Dystrophy Association, Cyprus

12:30 – 13:15 Panel discussion: Rare disease therapy delivery in the healthcare system: paths to  
sustainability.

Moderator: Menelaos Pipis, Senior Neurologist, Head of the Neuropathology  
Department, The Cyprus Institute of Neurology & Genetics

Speakers of the session joined by:

Marina Vasiliou, President and Managing Director, Biogen France

**Closing Lecture**

13:15 – 13:30 The role of The Cyprus Institute of Neurology & Genetics in caring for patients with rare  
diseases: clinical excellence and research innovation

Leonidas Phylactou, Chief Executive Officer & Medical Director, The Cyprus Institute  
of Neurology & Genetics

**Lunch Break: 13:30 – 14:30**

**14:30 – 15:30 Tour at the premises of The Cyprus Institute of Neurology & Genetics**

**15:30 – 17:00 Farewell networking party, The Cyprus Institute of Neurology & Genetics**

## WORKING LANGUAGE

The meeting will be conducted in English. No interpretation services are foreseen in the context of this event.

## TRANSPORT

### *Points of entry*

*Note: The legal points of entry by air into the Republic of Cyprus are the International Airports of Larnaka and Pafos. There are no legal points of entry in the occupied areas of the Republic of Cyprus, where the Government of the Republic of Cyprus does not exercise effective control due to the Turkish occupation. Entering through any airport or port in the occupied areas of the Republic of Cyprus is illegal.*

For further information on the legal points of entry into the Republic of Cyprus, consult the website of the Ministry of Foreign Affairs of the Republic of Cyprus: <https://www.gov.cy/mfa/en/documents/important-information-concerning-travel-to-the-turkish-occupied-area-of-cyprus/>

### *Arrivals - Departures*

Upon arrival at Larnaka International Airport, participants should first proceed to the Cyprus Presidency Information Point 1 located after passport control, where accreditation badges will be available for collection. Immediately after customs clearance, participants will reach the Information Point 2, where they will receive assistance with their transfer to the designated hotels.

At Pafos International Airport, the Cyprus Presidency Information Point will be available after arrivals, just before customs clearance in the arrivals area. Participants can collect both their accreditation badges and receive assistance regarding transfers to the designated hotels.

Transportation for accredited participants will be provided by bus or shuttle service between airports and designated hotels. Participants wishing to make use of the transportation arranged by the Cyprus Presidency are requested to indicate this through the Accreditation Platform (only a YES selection will be taken into account). Participants must provide complete and accurate travel details (e.g. flight number, arrival and departure times, and accommodation) at least **seven (7) days** prior to the start of the meeting/conference. Any modifications submitted after this period will not be taken into account and participants will have to make their own arrangements.

To facilitate efficient planning, airport transportation will be arranged once the required travel details are submitted through the Accreditation Platform and within the designated timeslots. Please note that a waiting time at the airport of up to two hours may be required.

Alternative means of transportation, such as taxi services, shuttle services and public transportation, are available at the airport premises, but not provided by the Cyprus Presidency, and must be arranged individually.

Transportation for small numbers of participants arriving or departing will be provided by the Cyprus Presidency through shuttle services. Please note that these transfers may include brief stopovers, which could require participants to disembark and board connecting shuttle services. The Cyprus Presidency will not offer exclusive transportation arrangements.

Participants wishing to proceed directly to the airport from the meeting venue at the end of the programme are requested to indicate this via the Accreditation Platform.

Kindly be advised that any participants who do not arrive in time to join the social programme at the beginning of the event will be responsible for making **their own transportation arrangements in case they wish to join the social programme.**

Participants departing on commercial flights are strongly encouraged to make use of online check-in in advance.

Should the original travel details provided for transportation purposes change due to delays, missed flights or other unforeseen circumstances, participants will be required to make their own transportation arrangements.

Lastly, please note that transfers to and from the airport will be available **from the day before the meeting until the day after the meeting.** In the event of an earlier arrival or a later departure, participants will be required to make and cover their own transportation arrangements.

## **Transportation**

The Cyprus Presidency will provide transport for the participants. Transfers will operate between designated hotels and meeting venues throughout the official programme, in coordination with the Cyprus Police.

Please note that official transfers to and from hotels will be provided exclusively for the hotels designated within the framework of the Cyprus Presidency. These will be displayed as available options on the Accreditation Platform at the time of registration.

Transportation for accredited participants will be arranged by buses between the designated hotels and the meeting venue. Participants are kindly requested to be ready for departure at the transfer times indicated in the official programme, as buses will depart punctually.

Participants staying outside the designated hotels who require transportation to the meeting / conference venue will be picked up from a single collection point, for which you will be notified at a later stage by the organisers.

Please note that transportation to events or meetings which are not included the aforementioned **official programme**, will not be provided by the Cyprus Presidency.

## **ACCOMMODATION**

The Cyprus Presidency has pre-booked hotel rooms for this meeting at the following hotels: **Cleopatra Hotel, Centrum Hotel, Sandy Beach Hotel, Atlantica Miramare Beach Hotel, Tsanotel, Park Beach Hotel.**

Participants who intend to make use of the pre-booked rooms are requested to complete the booking process **via the link or the contact email** provided on the Accreditation Platform (*the Accreditation Platform itself **does not** function as a booking platform and indicating interest only there will not be considered a reservation*). Please note that participants are responsible for making their own reservations and for covering accommodation costs. Pre-booked rooms will be allocated on a first-come, first-served basis.

Participants staying at another hotel, other than the one pre-booked by the Cyprus Presidency, are kindly requested to specify the hotel name on the Accreditation Platform under the section "Other".

## SUSTAINABILITY

The Cyprus Presidency aims to ensure that environmentally, socially and economically responsible choices are made throughout its planning and execution.

## MEDIA

The Cyprus Broadcasting Corporation (CyBC) has been designated as the **Host Broadcaster** of the Cyprus Presidency of the Council of the EU 2026.

The Press and Information Office (PIO) will serve as the **Host Photographer** of the Cyprus Presidency of the Council of the EU 2026.

A Media Guide, prepared by the Communication Team of the Cyprus Presidency, will be uploaded to the Cyprus Presidency's website.

## THE PRESIDENCY ONLINE

The website and Social Media channels of the Cyprus Presidency of the Council of the EU 2026 are the Presidency's main communication channels, where news, events and other official material are published.

- **Website:**

[Cyprus Presidency of the Council of the EU 2026](https://www.cypresidency.eu)

- **Social Media Channels:**

- **Instagram:** [@cy2026eu](https://www.instagram.com/cy2026eu)
- **Facebook:** [facebook.com/CY2026EU](https://www.facebook.com/CY2026EU)
- **LinkedIn:** [Cyprus Presidency of the Council of the EU 2026](https://www.linkedin.com/company/cyprus-presidency-of-the-council-of-the-eu-2026)
- **YouTube:** <https://www.youtube.com/@cy2026eu#>
- **X:** [@cy2026eu](https://twitter.com/cy2026eu)
- **BlueSky:** [@cy2026eu.bsky.social](https://bsky.app/profile/cy2026eu.bsky.social)
- **Flickr:** [Cy2026.EU](https://www.flickr.com/photos/cy2026eu/)

## OTHER PRACTICAL INFORMATION

**Emergency number:** 112 (fire brigade, ambulance, police)

**Electricity:** The voltage in Cyprus is 230V. Cyprus uses Type G plugs (UK-style with three rectangular pins), so bringing a suitable plug adapter, if needed, is advisable

**Local time zone:** Eastern European Time (EET) (GMT +2)

**Country code:** Cyprus +357

**Currency:** The official currency of Cyprus is Euro (€)

**Weather:** [Weather in Cyprus](#)

**Smoking:** Smoking is only allowed outdoors in the designated areas of the official meeting venues

## CONTACT DETAILS

For information on the preliminary programme:

- Email: [cy2026\\_rarediseases@businesseventscy.com](mailto:cy2026_rarediseases@businesseventscy.com);  
[cy2026\\_rarediseases@cing.ac.cy](mailto:cy2026_rarediseases@cing.ac.cy)
- Phone number: +357 22505519; +357 22392849

For information on registration and accreditation:

- Email: [accreditation@cyprus2026eu.gov.cy](mailto:accreditation@cyprus2026eu.gov.cy)
- Phone number: +357 22801761 / + 357 22801762 / +357 22801763

For information on accommodation:

- Email: [hospitality@cyprus2026eu.gov.cy](mailto:hospitality@cyprus2026eu.gov.cy)
- Phone number: +357 22308325

For information on transportation:

- Email: [transportation@cyprus2026eu.gov.cy](mailto:transportation@cyprus2026eu.gov.cy)
- Phone number: +357 22801835