



CY20
26.EU

Practical Information Note

Advancement of Treatments for Rare Diseases

LEFKOSIA (NICOSIA), CYPRUS

5 - 6 March 2026

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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 **5th and 6th 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	accreditation@cyprus2026eu.gov.cy
11/02/2026	Deadline for requesting the individual access code	RESEARCH-CY2026EU@dmrid.gov.cy
20/02/2026	Deadline for claiming pre-booked hotel reservations	Delegations / Participants 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](#)

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 no later than **11/02/2026**. 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 participants' responsibility to ensure that they are duly registered and that all required information is submitted accurately by the specified deadline.

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. 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 – 5th March 2026

Morning

08:00 – 08:30 Registration and coffee

Opening and welcome notes

08:30 – 08:35 Welcome note and scope of the conference

Prof. Leonidas A. Phylactou, CEO & Medical Director of The Cyprus Institute of Neurology & Genetics

08:35 – 08:40 Welcome note and endorsement

Prof. Michael Komodromos, President of the Board of Directors of The Cyprus Institute of Neurology & Genetics

08:40 – 08:45 Welcome note and the European Commission's endorsement

Olivér Várhelyi, EC Health and Animal Welfare Commissioner (**pre-recorded video**)

08:45 – 08:55 Welcome note (on behalf of the President of the Republic of Cyprus)

Dr. Nicodemos Damianou, Deputy Minister of Research, Innovation and Digital Policy

08:55 – 09:00 Statement on Rare Diseases in Cyprus (**Topic TBC**)

Mr. Neophytos Charalambides, Minister of Health of the Republic of Cyprus

Session 1 – Current landscape and unmet needs in rare diseases

09:00 – 09:15 European research on rare diseases: a long-standing commitment to make Europe a leader at global level

Ms. Carmen Laplaza Santos, Head of Unit Health Innovations and Ecosystems, DG Research and Innovation

09:15 – 09:30 Witnessing and implementing change over the past 2 decades: the European Commission's action on rare diseases and therapy development

Ms. Stella Kyriakides, former EC Health Commissioner

- 09:30 – 09:45 The European Economic and Social Committee: facilitating the involvement of all relevant stakeholders in rare diseases whilst respecting Member State-specific circumstances
Dr. Milena Angelova, Member at the European Economic and Social Committee; rapporteur of the opinion
- 09:45 – 10:00 Funding and patient advocacy organisations spearheading the effort against rare disease
Mr. Francois Lamy, Vice President of AFM-Téléthon France
- 10:00 – 10:15 EURORDIS’ role in facilitating therapies for rare diseases
Ms. Virginie Hivert, Acting CEO and Head of Therapies and Access at EURORDIS
- 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

Coffee Break: 10:45 – 11:15

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

- 11:15 – 11:30 Regulatory considerations for rare disease drug development and approval
Mr. Tim Leest, Chair of the EMA Committee for Orphan Medicinal Products
- 11:30 – 11:45 A European inventory of rare diseases through the scope of ERNs
Ms. Donata Meroni, European Commission DG Sante
- 11:45 – 12:00 The current state of affairs for developing rational therapies for rare diseases
Dr. Holm Graessner, Lancet Commissioner on Rare Diseases and ERN-RND coordinator
- 12:00 – 12:15 ERDERA research initiatives for therapy development in rare diseases
Dr. Daria Julkowska, Scientific coordinator of ERDERA
- 12:15 – 12:30 **(Topic TBC)**
Dr. Violetta Anastasiadou, Chair of Cyprus National Committee for Rare Diseases
- 12:30 – 13:15 Panel discussion: Creating incentives and overcoming bottlenecks in rare drug development.
Moderator: Dr 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, Policy officer, DG SANTE

Lunch Break: 13:15 – 14:00

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

- 14:00 – 14:15 Building on knowledge and lessons learnt: developing Nusinersen for SMA
Dr. Priya Singhal, Head of Development, Biogen
- 14:15 – 14:30 Developing virally-delivered genetic therapies for inherited neuromuscular disorders.
Dr. Kleopas Kleopa, Senior Neurologist, Head of the Neurosciences Department, The Cyprus Institute of Neurology & Genetics
- 14:30 – 14:45 A Journey to Developing Curative Therapies for Hemoglobinopathies using Genome Editing
Dr. Matthew H. Porteus, Stanford University School of Medicine, Stanford, USA
- 14:45 – 15:00 Developing therapies for rare paediatric endocrine disorders
Dr. Nicolas Nicolaides, University of Cyprus
- 15:00 – 15:15 Break
- 15:15 – 15:30 TBC
- 15:30 – 15:45 The role of artificial intelligence in drug discovery and repurposing
Mr. Demetris Skourides, Cyprus Chief Scientist for Research, Innovation and Technology
- 15:45 – 16:00 Innovative platform-based approach for sustainable repurposing of medicines for rare diseases.
Mr. Anton Ussi, Coordinator of REMEDI4All
- 16:00 – 16:15 A clinical model for interdisciplinary sharing of knowledge and innovation for the development of rare diseases therapies.
Prof. Birute Tumiene, Assoc Prof. at Vilnius University, Faculty of Medicine (**online**)
- 16:15 – 17:30 Panel discussion: Synergies in academia and industry to accelerate drug development.
Moderator: Dr Petros Petrou, Senior Scientist, Head of the Biochemical Genetics Department, The Cyprus Institute of Neurology & Genetics

End of day 1

Gala Dinner: 20:30 – 23:30

DAY 2: 6th 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.

Dr. Hélène Le Borgne, Policy Officer, DG Research and Innovation

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

Dr. Maurizio Scarpa, Coordinator of MetabERN

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

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

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

Mr. Charalambos Papadopoulos, President of the Cyprus Alliance for Rare Diseases

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

Dr. 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

Dr. 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

Mr. Allan Fred Byamukama

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

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

Speakers of the session joined by:

Prof. Alexis Arzimanoglou, Coordinator of ERN EpiCARE;

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
Dr. 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.
Prof. Nikolaos Zamboglou, German Medical Institute, Limassol
- 12:00 – 12:15 Health Technology Assessment and Innovative Payment Models for therapies for rare diseases
Dr. Christine Leopold, Pharmaceutical system and policy researcher, Utrecht Center for Pharmaceutical Policy and Regulation / WHO Collaborating Center
- 12:15 – 12:30 Competitive (mis)pricing in small markets: an example of DMD therapies
Mr. Panikos Voskos, President of Muscular Dystrophy Association, Cyprus
- 12:30 – 13:00 Panel discussion: Rare disease therapy delivery in the healthcare system: paths to sustainability.
Moderator: Dr Menelaos Pipis, Senior Neurologist, Head of the Neuropathology Department, The Cyprus Institute of Neurology & Genetics
Speakers of the session joined by:
Ms. Marina Vasiliou, President and Managing Director, Biogen

Closing Lecture

- 13:00 – 13:15 The role of CING in caring for patients with rare diseases: clinical excellence and research innovation
Prof. Leonidas A. Phylactou, CEO & Medical Director of The Cyprus Institute of Neurology & Genetics

Lunch Break: 13:15 – 14:15

14:15 – 17:00 Tour at the premises of The Cyprus Institute of Neurology & Genetics

17:00 – 20:00 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

Upon arrival at Larnaka International Airport, participants should first proceed to the Cyprus Presidency Information Point located after passport control, where accreditation badges will be available for collection. Immediately after customs clearance, participants will reach the second Information Point, 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

The Cyprus Presidency will provide transport for the participants. Transfers will operate between airports, designated hotels as well as meeting / conference 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. Participants who wish to make use of the transportation offered by the Cyprus Presidency are requested to indicate this through the Accreditation Platform where they will need to provide full travel details (e.g. flight number, arrival / departure time, etc.). Transportation from and to the airport cannot be provided by the Cyprus Presidency without the provision of these details, due to practical reasons.

Transfers will also operate between the designated hotels and the meeting / conference venue. Participants are kindly requested to be ready for departure at the transfer times indicated in the official programme, as buses will depart punctually.

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 and must be arranged individually.

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

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

Departures

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

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

Please note that transfers from and to the airport will be available from the day before the meeting until the day after the meeting. In case of earlier arrival or later departure, participants will have to make and cover their own transportation arrangements.

ACCOMMODATION

The Cyprus Presidency has pre-booked hotel rooms for this conference 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 on the Accreditation Platform. 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.cyp2026.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;
cy2026_rarediseases@cing.ac.cy
- Phone number: +357 22505519; +357 22392849

For information on registration and accreditation:

- Email: accreditation@cyprus2026eu.gov.cy
- Phone number: +357 22801765

For information on accommodation:

- Email: hospitality@cyprus2026eu.gov.cy
- Phone number: +357 22308325

For information on transportation:

- Email: transportation@cyprus2026eu.gov.cy
- Phone number: +357 22801835