

Conference Data Privacy Policy

This Privacy Policy explains how personal data are collected and processed in connection with the “Advancement of Treatments for Rare Diseases” Conference website (the “Conference”), organised by the Cyprus Institute of Neurology & Genetics (CING) and the Deputy Ministry of Research, Innovation and Digital Policy. It also explains how we comply with data protection law, especially with the European General Data Protection Regulation 2016/679 (“GDPR”).

This Policy applies exclusively to personal data collected and processed for the purposes of:

- conference attendance, organization and logistics;
- communication with participants;
- dissemination of conference-related information and outputs; and
- operation of the conference website.

This Policy does not apply to personal data processed in the context of healthcare services, research activities, employment, education, or other institutional functions of either organization, which are governed by separate privacy policies.

For the purposes of this conference website and related activities, CING acts as the Data Controller in accordance with the EU General Data Protection Regulation (GDPR) 2016/679. Conference registration is carried out through the **Novento platform**, the official registration platform used for events organized within the framework of the Cyprus Presidency of the Council of the EU.

Personal data submitted during registration are processed in accordance with [Novento’s Privacy Policy](#).

The Cyprus Institute of Neurology & Genetics (CING) receives access only to the minimum personal data necessary for organizational and logistical purposes. CING is committed to processing personal data lawfully, fairly, and transparently, and to protecting the rights and freedoms of all data subjects in line with applicable data protection legislation.

Why do we collect and use personal data?

Personal data are collected and processed solely for purposes related to the organization, delivery, and follow-up communication in relation to the Conference. Specifically, personal data may be used to:

- manage communication with conference participants (e.g. providing event information, updates, and logistical details);
- support conference registration and attendance management (via the Novento platform);
- organize travel and accommodation arrangements for speakers and panelists, where applicable;
- facilitate dissemination of conference outputs and materials (e.g. programs, reports, presentations, recordings), subject to prior consent;
- collect anonymized feedback or evaluation data to assess the quality and impact of the conference;
- operate, secure, and improve the conference website and related digital services;
- comply with applicable legal and contractual obligations.

No personal data are collected or processed for healthcare, research, employment, education, recruitment, or financial purposes in the context of this conference.

Lawful basis for processing personal data

Personal data are collected and processed in accordance with the EU General Data Protection Regulation (GDPR) under the following lawful bases:

- **Consent**, where participants have explicitly agreed to the processing of their personal data (e.g. photography and video recording, newsletters, optional surveys, and cookies);
- **Performance of a contract**, where processing is necessary to organize and deliver the conference, including registration management, participant communication, and logistical arrangements;
- **Compliance with a legal obligation**, where processing is required under applicable laws or regulations;
- **Legitimate interests** pursued by the Cyprus Institute of Neurology & Genetics (CING), such as ensuring the secure operation of the conference website, managing communications related to the conference, promoting, advertising the conference and producing aggregated statistics, provided that such interests do not override the rights and freedoms of the data subjects.

Photos, recordings and conference materials (consent-based processing)

Photography and video recording may take place during the event. The processing of such images is carried out based on our legitimate interests in promoting and documenting the event, or, where applicable, based on your explicit consent. This includes the taking and use of photographs, video and audio recordings during the conference, as well as the publication and dissemination of conference-related materials such as speakers' abstracts, presentations, recordings, reports, and other outputs.

Such materials may be made available on the conference website, institutional websites, and through communication and dissemination channels related to the conference, including social media, both during and after the event.

If you have any concerns regarding photography, video or audio recording during the conference, or if you wish to exercise your right to object to such processing, please contact a member of the conference delegate team on site, who will take reasonable steps to address your request.

Participation in surveys or feedback activities is optional and survey results will be anonymized before any analysis or use. Consent may be withdrawn at any time, without affecting participation in the conference, in accordance with GDPR.

Categories of personal data processed

In the context of the Conference, the following categories of personal data may be processed:

- Participants data including: identification and contact details (such as name, email address, affiliation, and role), provided during registration or communication with participants;

- Information regarding speakers and panelists including: professional information, speaker or panelist role, CVs, abstracts or presentation materials);
- technical and usage data related to the conference website (e.g. IP address, browser type, basic analytics);
- photos, video and audio recordings captured during the conference, subject to our legitimate interests and prior consent;
- anonymized responses to optional feedback or evaluation surveys.

No personal data relating to healthcare, genetic information, biometric identifiers, employment records, student records, recruitment, research participation, financial data, or CCTV monitoring are collected or processed in the context of this conference.

How long are personal data retained?

Personal data collected in relation to the Conference are retained only for as long as necessary to fulfil the purposes for which they were collected, in accordance with the EU General Data Protection Regulation (GDPR).

In particular:

- personal data processed on the basis of consent (e.g. for photos, video recordings, newsletters, or optional surveys) will be retained until consent is withdrawn or the data are no longer required for the stated purpose;
- personal data processed for the performance of a contract (e.g. conference participation, communication, and logistical arrangements) will be retained for the duration of the conference and for a limited period thereafter to address any follow-up administrative matters;
- personal data processed to comply with a legal obligation will be retained for the period required by applicable law.

Personal data are not retained longer than necessary, and data that are no longer required are securely deleted or anonymized in line with institutional data protection procedures.

Data subjects may request further information about data retention or exercise their rights by contacting the CING Data Protection Officer (dpo@cing.ac.cy)

Who do we share personal data with?

Personal data collected in relation to the Conference are shared only where necessary and strictly for conference-related purposes.

In particular, personal data may be shared with:

- a subcontractor assisting with the organization of the conference and the operation of the conference website, acting on the instructions of the Cyprus Institute of Neurology and Genetics (CING);
- authorized personnel of CING responsible for conference coordination and communication activities.

Conference-related email communication may be carried out using email addresses operated by CING and by the subcontractor, for organizational and communication purposes only.

All parties involved process personal data solely for the purposes of organizing and delivering the conference, under appropriate confidentiality and data protection obligations. Only the minimum amount of personal data necessary for each purpose is shared.

Personal data are not sold or used for commercial purposes and are not shared with third parties without a valid legal basis, in accordance with the EU General Data Protection Regulation (GDPR).

No personal data are being transferred outside the EU/EEA.

Data subject rights

Under the EU General Data Protection Regulation (GDPR), data subjects have the following rights:

- the right to be informed about the collection and use of their personal data;
- the right to access their personal data and receive supplementary information;
- the right to rectification of inaccurate or incomplete personal data;
- the right to erasure (“right to be forgotten”), in certain circumstances;
- the right to restrict the processing of their personal data, in certain circumstances;
- the right to data portability, where applicable;
- the right to object to the processing of their personal data, in certain circumstances.

Data subjects may exercise their rights or request further information by contacting the Data Protection Officer of the Cyprus Institute of Neurology & Genetics (CING) - dpo@cing.ac.cy

If a data subject considers that their personal data have been processed unlawfully, they have the right to lodge a complaint with the Office of the Commissioner for the Protection of Personal Data of Cyprus via the designated [Complaints Procedure](#) or at:

Kypranoros 15, Nicosia 1061 , Cyprus

Postal address:

P.O.Box 23378, 1682 Nicosia, Cyprus

Tel: +357 22818456

Fax: +357 22304565

Email: commissioner@dataprotection.gov.cy