

Privacy Policy

Last updated: 12 February 2026

This Privacy Policy explains how the CIS Orphan Consortium (“we”, “us”, “our”) collects, uses, stores, and protects information when you visit our website <https://en.orphan-cis.net/> (the “Website”), contact us, or participate in our activities.

Controller / Contact details

CIS Orphan Consortium

Address: 117556, Moscow, Chongarsky Boulevard, 1/2, office 3/3

E-mail: nm@naerez.ru; y.stuk@naerez.ru

Phone: +7 903 663-25-20; +7 926 840-02-03

1) What data we collect

We may process the following categories of information.

Information you provide directly: name, organization, position, email address, phone number, country and any information you include in a message when you contact us via the Website feedback form or by email/phone.

Information about your participation in activities: data necessary to organize communication and cooperation (for example, affiliation, role, professional profile, submitted materials and correspondence).

Technical data: limited technical information such as IP address, browser type, device identifiers, language, referring page and basic logs required to ensure security and stable operation of the Website.

2) Why we process data (purposes)

We process personal data only to the extent necessary for the following purposes: responding to inquiries and communicating with you; organizing consortium activities (events, webinars, working groups, publications and cooperation requests); administering relationships with members and partners; improving the Website and user experience, including through the use of cookies; ensuring security, preventing abuse and complying with applicable legal requirements.

3) Legal bases

Depending on the context and applicable law, we rely on one or more of the following legal bases: your consent (for example, when you submit a request or accept cookies); performance of a contract or steps at your request before entering into a contract (for example, participation arrangements); legitimate interests (for example, communications, organizational administration and Website security); compliance with legal obligations.

4) Cookies

We use cookies to improve the site and its interaction with users. By continuing to work with the site, you consent to the use of cookies. You can always disable cookies in your browser settings.

Cookies may include essential cookies required for the Website to function, as well as preference-related cookies (if enabled). Disabling cookies may affect certain Website features.

5) Sharing of data

We do not sell personal data.

We may share data only when necessary and proportionate: with service providers supporting Website hosting and technical maintenance; with authorized consortium coordinators involved in processing your request (for example, to organize an event or cooperation); when required by law or to protect our rights and security.

The Website may contain links to third-party platforms (for example, Telegram, WhatsApp, LinkedIn). Their privacy practices are governed by their own policies.

6) International transfers

Because the Internet is global and technical infrastructure may be located in different countries, your data may be processed in jurisdictions other than your own. Where required, we apply appropriate safeguards to protect personal data.

7) Retention

We keep personal data only as long as necessary for the purposes described in this Policy, and then delete or anonymize it, unless longer retention is required by law or justified by a legitimate operational need (for example, maintaining records of collaboration and event organization).

8) Security

We use reasonable organizational and technical measures to protect personal data against unauthorized access, alteration, disclosure or destruction. However, no method of transmission or storage is 100% secure.

9) Your rights

Subject to applicable law, you may request access to your personal data, correction, deletion, restriction of processing and withdrawal of consent (where processing is based on consent). To exercise these rights, contact us using the details provided above.

10) Children

The Website is intended for a professional audience. We do not knowingly collect personal data from children. If you believe a child has provided data to us, please contact us so we can take appropriate steps.

11) Changes to this Policy

We may update this Policy from time to time. The "Last updated" date will reflect the latest version. Continued use of the Website after updates means you accept the revised Policy.