

ENMC Privacy Statement

Version: September 2026

European Neuromuscular Centre (ENMC)

The European Neuromuscular Centre (ENMC) respects your privacy and is committed to protecting your personal data. This Privacy Statement explains what personal data we process, why we process it, the legal bases we rely on, how long we retain data, and what rights you have under the General Data Protection Regulation (GDPR/AVG) and applicable Dutch law.

1. Who we are

ENMC is a non-profit foundation established under Dutch law. The statutory name is "Stichting European Neuro Muscular Centre (ENMC)". ENMC's statutory location is Baarn, the Netherlands.

Contact details:

- European Neuromuscular Centre (ENMC)
- Lt. Generaal van Heutszlaan 6, 3743 JN Baarn, The Netherlands
- Telephone: +31 35 5480481
- Email: enmc@enmc.org

For privacy questions or requests concerning your personal data, please contact us at enmc@enmc.org.

2. What personal data do we process?

Depending on your relationship with ENMC, we may process the following categories of personal data:

- Identification and contact details, such as name, title, email address, telephone number and country.
- Professional information, such as institution, professional discipline, role and professional contact details.
- Information needed to organise ENMC workshops, meetings, programmes, travel, accommodation and related communications.
- Information relating to participation in ENMC activities, including correspondence and records of participation.
- Newsletter subscription information and communication preferences.
- Information is provided through website contact forms or by email.
- Financial and administrative information were necessary for payments, reimbursements, employment or consultancy arrangements.
- Photographs or other information that may identify individuals where this is relevant to ENMC activities and has a lawful basis.
- In limited circumstances, information that may qualify as a special category of personal data may be received in connection with patient participation or other ENMC activities. ENMC only processes such data where an applicable legal condition under the GDPR/AVG is satisfied.

3. Why do we process personal data?

ENMC processes personal data for purposes including:

- Organising and administering ENMC workshops, meetings, programmes and other activities.
- Communicating with workshop candidates, participants, patient representatives, researchers, clinicians, partners and other stakeholders.
- Maintaining the ENMC professional network and contacting relevant individuals about ENMC activities.
- Preparing and communicating workshop reports, publications and other ENMC outputs, where appropriate.
- Sending newsletters and other communications to people who have subscribed or where another lawful basis applies.
- Responding to enquiries submitted through the website, by email or through other communication channels.
- Managing employment, consultancy, payments, reimbursements, accounting and other administrative obligations.
- Meeting legal, regulatory, accounting and governance obligations.
- Protecting the security and integrity of ENMC systems, information and activities.

4. What are our legal bases?

ENMC does not rely on consent for every processing activity. The appropriate legal basis depends on the purpose of the processing.

Activity / purpose	Typical GDPR/AVG legal basis
Workshop and programme administration	Performance of a contract or taking steps at your request; and/or legitimate interests, depending on the activity.
Professional network and relevant ENMC communications	Legitimate interests, where appropriate and where those interests are not overridden by your rights and freedoms.
Newsletter and optional promotional communications	Consent, where consent is required.
Employment, consultancy, payments and reimbursements	Performance of a contract and/or compliance with legal obligations.
Accounting and statutory records	Compliance with legal obligations.
Website contact enquiries	Legitimate interests and/or taking steps at your request, depending on the enquiry.
Processing special category data, where applicable	An Article 9 GDPR condition in addition to an Article 6 legal basis; the specific condition depends on the circumstances.

Where ENMC relies on consent, you may withdraw that consent at any time. Withdrawal does not affect the lawfulness of processing carried out before withdrawal.

5. How do we obtain your personal data?

We may obtain personal data:

- Directly from you, for example when you apply for or participate in an ENMC workshop, subscribe to our newsletter, contact us or provide information for administrative purposes.
- From your organisation or professional contacts, where necessary to organise ENMC activities.
- From workshop organisers, ENMC partner organisations or other relevant professional contacts, where lawful and necessary.
- From publicly available professional sources, where this is appropriate and lawful.

6. Who may receive your personal data?

ENMC may share personal data with service providers and other parties where this is necessary for the purposes described above and permitted by law. These may include IT, website, email, database, newsletters, accounting, travel and event-service providers.

Where a third-party processes personal data on behalf of ENMC, ENMC requires appropriate contractual and organisational safeguards in accordance with the GDPR/AVG. We do not sell personal data.

We store data only for as long as necessary for the purpose for which it was collected, unless a longer retention period is required or permitted by law. Retention periods vary depending on the type of data and the purpose.

- Workshop and network information: retained for as long as reasonably necessary for ENMC's network, workshop administration, reporting and historical record-keeping purposes.
- Newsletter data: retained while you remain subscribed, or until you unsubscribe, subject to any information that must be retained for administrative or legal reasons.
- Financial, accounting and employment records: retained for the periods required by applicable law.
- Website enquiries: retained only for as long as reasonably necessary to handle the enquiry and maintain an appropriate record.

ENMC periodically reviews stored personal data and deletes or anonymises information that is no longer needed.

7. Your privacy rights

Subject to the conditions and exceptions in the GDPR/AVG, you may have the right to:

- Request access to your personal data.
- Request correction of inaccurate or incomplete personal data.
- Request deletion of your personal data.
- Request restriction of processing.
- Object to processing based on legitimate interests or for direct marketing.
- Receive certain personal data in a structured, commonly used and machine-readable format (data portability).
- Withdraw consent where processing is based on consent.

To exercise a right, contact ENMC at enmc@enmc.org. We may need to verify your identity before fulfilling a request. We will normally respond within one month, subject to the applicable GDPR/AVG rules concerning extensions for complex or multiple requests.

8. Security

ENMC takes appropriate technical and organisational measures to protect personal data against unauthorised access, loss, alteration, disclosure or destruction. The measures are reviewed in accordance with the risks associated with our processing activities.

For security reasons, this public Privacy Statement does not describe detailed internal security controls, system configurations or access-management arrangements.

9. Data breaches

ENMC maintains an internal procedure for identifying, assessing, documenting and handling personal data breaches. Where a breach is likely to result in a risk to the rights and freedoms of individuals, ENMC will assess whether notification to the Dutch Data Protection Authority (Autoriteit Persoonsgegevens) is required within the applicable statutory period. Where a high risk exists, ENMC will also assess whether affected individuals must be informed.

10. Website, cookies and online services

When you visit our website, our hosting provider automatically processes technical data such as your IP address, browser type, operating system, referring page and date/time of your visit. We use this data only to operate and secure the website and to resolve technical problems. This data is retained only for as long as necessary for these purposes, after which it is automatically deleted. Our website is hosted in the Netherlands.

We do not use analytics or advertising cookies. Strictly necessary cookies, such as the cookie that stores your consent choice, are placed without consent. Some pages contain embedded content from third parties: maps from Google Maps and videos from Vimeo. Our forms are protected against spam with Google reCAPTCHA. These services may place cookies and receive your IP address. Embedded maps and videos are only loaded after you have given consent via our cookie banner; until then a placeholder is shown. You can change or withdraw your choice at any time via "Manage consent" at the bottom of every page. A complete, up-to-date overview is available in our Cookie Policy.

11. Newsletter

If you subscribe to the ENMC newsletter, we process the information you provide, such as your name, country, institution and email address, to send the newsletter and manage your subscription (Mailchimp).

You can unsubscribe at any time by using the unsubscribe option included in our communications or by contacting ENMC.

12. Photographs, quotations and publication

ENMC may wish to publish photographs, names, professional biographies or quotations relating to ENMC activities. Before publication, ENMC will determine the appropriate legal basis and assess whether the publication is necessary and proportionate. Where consent is required or chosen, ENMC will obtain it in a clear and documented manner and provide an appropriate withdrawal mechanism.

Consent to publication should not be bundled with unrelated processing where separate consent is required. Publication of identifiable photographs or quotations should be handled with particular care.

13. Links to other websites and social media

The ENMC website may contain links to external websites or social media services. Those websites operate under their own privacy and cookie policies. ENMC is not responsible for the privacy practices of external websites.

Embedded social media content or plug-ins can cause personal data to be transmitted to the provider. ENMC should only activate such integrations where the applicable privacy and cookie requirements have been met.

14. Automated decision-making and profiling

ENMC does not use personal data for decisions based solely on automated processing that produce legal or similarly significant effects on individuals.

15. Complaints

If you have concerns about how ENMC handles your personal data, we encourage you to contact us first so that we can try to resolve the issue.

You also have the right to lodge a complaint with the Dutch supervisory authority, the Autoriteit Persoonsgegevens (Dutch Data Protection Authority), if you believe that your personal data have been processed in violation of applicable data protection law.

16. Changes to this Privacy Statement

ENMC may update this Privacy Statement from time to time to reflect changes in our activities, technology, service providers or applicable privacy law. The latest version will be published on the ENMC website.

17. Contact us

For questions about this Privacy Statement, your personal data, or the exercise of your privacy rights, please contact:

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