

Transparency & Integrity Code for Policy and Advocacy at Global, EU and National Levels

Preamble

GFCNI engages in advocacy at global, EU, and, where relevant, national levels to advance its statutory purposes. We act **transparently, responsibly, and in alignment with democratic values**.

This policy is publicly accessible via our website and is reviewed annually by GFCNI's Trustee Board.

Core Principles

1. Scope

This policy applies to:

- Board members, executive management, all employees, appointed representatives, and external partners acting on behalf of GFCNI.

2. Principles

- Legal Compliance:** All activities comply with applicable international standards, EU law, and, where relevant, national law, and institutional rules.
- Transparency:** Our goals, roles, and advocacy activities are communicated openly. All relevant contacts are documented. GFCNI is registered in the EU Transparency Register, as well as in the German Lobby and Transparency Registers, and keeps entries up to date. We always identify ourselves by name, registration number, and with the organization we represent in all interactions with EU institutions, international organizations, or, where relevant, national institutions, and clearly disclose the interests and objectives we promote and the parent and patient voice we represent.
- Integrity:** Our positions are based on evidence and lived experience of patients and their families, accurate, and ethically sound. We do not seek to obtain information or decisions dishonestly, through undue pressure, improper behavior, or offensive conduct, and we do not misuse our registration for commercial gain or misrepresent the impact of registration.
- Independence:** GFCNI maintains political neutrality, refrains from any partisan activity, and is not affiliated with any political party or involved in electoral campaigns.
- Public Interest Orientation:** Advocacy serves exclusively on the Foundation's objectives and mission, as set out in the GFCNI statutes.

- f. **Conflict of Interest Management:** Actual or potential conflicts of interest are disclosed and appropriately handled.
- g. **Confidentiality:** Sensitive information obtained during advocacy activities, including internal documents, consultations, and communications with institutions or stakeholders, must be handled confidentially and may not be used for personal or organizational gain.

3. Permissible and Prohibited Practices

Permissible Practices:

- Consultations, hearings, expert dialogue and similar events or meetings at global, EU and, where relevant, national levels.
- Publications of analyses, project or research results, policy briefs, position papers or statements, recommendations, or similar documents.
- Collaboration with partners who maintain comparable transparency and integrity standards.

Prohibited Practices:

- Providing misleading information or concealing interests.
- Offering financial or material advantages to decision-makers, including public or state officials or similar persons / positions.
- Misuse of confidential information for personal or organizational gain.

4. Documentation & Reporting

- All relevant activities are documented internally.
- Compliance and risk-related information is provided to the Trustee Board regularly, at least once per year.

5. Reference to Existing Codes

- This policy complements and refers to GFCNI's further published [governance](#), [ethics](#), [financial policies](#) and [the GFCNI statutes](#).

Munich, December 2025