

This document, which should be read in conjunction with the organisation's Statutes, sets out the Rules, Policies and Procedures that are applicable to all members of the European MEN Alliance (EMENA), and form a basis for the acceptable conduct of members when working on behalf of EMEA.

1. General statements

- By becoming a member of EMEA every member agrees to abide by the regulations stated in the EMEA States and the EMEA Rules and any changes made to these documents in the future. Members of EMEA are obliged to uphold the Status and the EMEA Rules.
- Where neither this document nor the EMEA Statutes provide appropriate guidance on a particular topic, the Board will have the authority to make a decision based on any information provided.
- Changes to these Rules may be proposed by the board or any member of EMEA. A decision will be made in the General Assembly. Changes to the EMEA Rules have to be accepted by a 75% majority of the validly cast votes.
- Advice or information given by EMEA can never lead to any liability on the part of EMEA.

2. Vulnerable People Protection Code of Conduct

All EMEA volunteers must sign up to and abide by this Code of Conduct which applies to all vulnerable people (children and adults).

Volunteers and others must never:

- Hit or otherwise physically assault or physically abuse vulnerable people
- Develop physical/sexual relationships with vulnerable people which could in any way be deemed exploitative or abusive
- Use language, make suggestions or offer advice which is inappropriate, offensive or abusive
- Behave physically in a manner which is inappropriate or sexually provocative
- Act in ways intended to shame, humiliate, belittle or degrade vulnerable people, or otherwise perpetrate any form of emotional abuse
- Discriminate against, show differential treatment, or favour particular people to the exclusion of others
- This is not an exhaustive or exclusive list. The principle is that volunteers should avoid actions or behaviour which may constitute poor practice or potentially abusive behaviour.

It is important for all volunteers and others in contact with vulnerable people to:

- Be aware of situations which may present risks and manage these to minimize risks
- As far as possible, be visible in working with vulnerable people
- Ensure that a culture of openness exists to enable any issues or concerns to be raised and discussed
- Ensure that a sense of accountability exists between volunteers so that poor practice or potentially abusive behaviour does not go unchallenged

3. Complaints Procedure

Complaints may be received from members of the public, members of EMENA, or Board members of EMENA. The Board of EMENA encourages openness and feedback and will ensure that complaints are dealt with promptly using the following procedure:

- Complaints should be directed in the first instance to the EMENA President, unless the complaint is about the President, in which case, any other member of the Board may be contacted
- Verbal-only or anonymous complaints will not be investigated unless accompanied by a written, signed and dated supporting letter
- Any complaint should be submitted within 1 month of the incident (unless the complainant can prove mitigating circumstances for late submission)
- EMENA's preference is for the contacted President or Board member to resolve the complaint informally in the first instance. In the event that this action does not resolve the problem, the following procedure will be followed:
 - The President or Board member contacted will investigate the complaint. This may involve formal interviews and the requirement for evidence to be supplied. Any EMENA volunteer or Board member approached by the investigator must give full disclosure or face disciplinary action by the Board
 - The contacted President or Board member will come to one of the following conclusions:
 - complaint sustained but no action required
 - complaint sustained and action required to resolve and prevent in future
 - complaint sustained and involvement of higher authorities required
 - complaint not sustained but no action required
 - complaint not sustained and action required
 - The Board of EMENA must ratify the findings of the contacted President or Board member should (s)he require action
 - If necessary, an appeals process may be requested by any party involved where the actions of the contacted President or Board member should be examined. This person should in the first instance, check that the procedure has been followed.
 - If it has not then the complaint must be investigated again in full
 - If it has then the President or other Board member may come to any of the 5 outcomes as listed above and continue the process as listed
 - The contacted President or Board member has the power to
 - suspend volunteers/Board members from duty where required
 - the power to demand interviews where required.

4. Equality and Diversity Statement

EMENA believes in the principles of social justice, acknowledges that discrimination affects people in complex ways and is committed to challenge all forms of inequality. To this end, EMENA will aim to ensure that:

- All individuals who come into contact with EMENA are treated fairly, with dignity and respect regardless of their age, marital status, disability, race, faith, gender, language, social/ economical background or sexual orientation and any other inappropriate distinction;
- it affords all individuals and volunteers the opportunity to fulfil their potential;
- it promotes an inclusive and supportive environment for all individuals and volunteers;
- it recognises the varied contributions to the achievement of EMENA's aims made by individuals from diverse backgrounds and with a wide range of experiences

5. Data Protection and Privacy Policy

EMENA needs to gather and use certain information about individuals. These can include members, suppliers, business contacts, employees and other people the organisation has a relationship with or may need to contact. This policy describes how this personal data must be collected, handled and stored to meet the organisation's data protection standards – and to comply with the law.

Data Protection

This data protection policy ensures EMENA:

- Complies with data protection law and follows good practice
- Protects the rights of staff, members and partners
- Is open about how it stores and processes individuals' data
- Protects itself from the risks of a data breach

Data Protection Law describes how organisations (including EMENA) must collect, handle and store personal information.

These rules apply regardless of whether data is stored electronically, on paper or on other materials. To comply with the law, personal information must be collected and used fairly, stored safely and not disclosed unlawfully.

Data Protection laws are underpinned by eight important principles. These say that personal data must:

1. Be processed fairly and lawfully
2. Be obtained only for specific, lawful purposes
3. Be adequate, relevant and not excessive
4. Be accurate and kept up to date
5. Not be held for any longer than necessary
6. Be processed in accordance with the rights of data subjects
7. Be protected in appropriate ways
8. Not be transferred outside of the European Economic Area (EEA), unless that country or territory also ensures an adequate level of protection.

EMENA holds three types of information which are covered by this policy:

- Organisational information – publicly available information about organisations
- Personal information – information about individuals such as names, addresses, telephone numbers
- Sensitive personal information – in addition to contact information, EMENA may also hold sensitive information such as members' medical conditions and bank or credit card details.

This policy applies to:

- All volunteers and future staff of EMENA
- All contractors, suppliers and other people working on behalf of EMENA.

It applies to all data that the organisation holds relating to identifiable individuals, even if that information technically falls outside of the Data Protection law. This can include:

- Names of individuals
- Postal addresses
- Email addresses
- Telephone numbers
- ...any other information relating to individuals.

This policy helps to protect EMENA from some very real data security risks, including:

- Breaches of confidentiality, for instance, information being given out inappropriately
- Failing to offer choice, for instance, all individuals should be free to choose how the charity uses data relating to them
- Reputational damage, for instance, the charity could suffer if hackers successfully gained access to sensitive data.

Everyone who works for or with EMENA has some responsibility for ensuring data is collected, stored and handled appropriately. Any staff member, volunteer or contractor that handles personal data must ensure that it is handled and processed in line with this policy and the 8 data protection principles listed above. However, the Board is ultimately responsible for ensuring that EMENA meets its legal obligations.

General data handling guidelines for staff, volunteers and contractors

- The only people able to access data covered by this policy should be those who need it for their work.
- Data should not be shared informally. When access to confidential information is required, staff, volunteers and contractors can request it from the President or Board
- EMENA will provide training to all staff, volunteers and contractors to help them understand their responsibilities when handling data
- Staff, volunteers and contractors should keep all data secure, by taking sensible precautions and following the guidelines below
- In particular, strong passwords must be used and they should never be shared
- Personal data should not be disclosed to unauthorised people, either within the charity or externally
- Data should be regularly reviewed and updated if it is found to be out of date. If no longer required, it should be deleted and disposed of
- Staff, volunteers and contractors should request help from the President or Board if they are unsure about any aspect of data protection.

Data storage

These rules describe how and where data should be safely stored. Questions about storing data safely can be directed to the President or Board.

When data is stored on paper, it should be kept in a secure place where unauthorised people cannot see it.

These guidelines also apply to data that is usually stored electronically but has been printed out for some reason:

- When not required, the paper or files should be kept in a locked drawer or filing cabinet
- Staff, volunteers and contractors should make sure paper and printouts are not left where unauthorised people could see them, like on a printer or desk
- Data printouts should be shredded and disposed of securely when no longer required.

When data is stored electronically, it must be protected from unauthorised access, accidental deletion and malicious hacking attempts:

- Data should be protected by strong passwords that are changed regularly and never shared with anyone else, inside or outside of the organisation
- If data is stored on removable media (like a CD, DVD or memory stick), these should be kept locked away securely when not being used
- Data should only be stored on designated drives and servers, and should only be uploaded to an approved cloud computing service
- Servers containing personal data should be sited in a secure location, away from general office space
- Data should be backed up frequently. Those backups should be tested regularly
- Data should never be saved directly to laptops or other mobile devices like tablets or smart phones
- All servers and computers containing data should be protected by approved security software and a firewall.

Personal data is of no value to EMENA unless the organisation can make use of it. However, it is when personal data is accessed and used that it can be at the greatest risk of loss, corruption or theft:

- When working with personal data, staff, volunteers and contractors should ensure the screens of their computers are always locked when left unattended
- Personal data should not be shared informally. In particular, it should never be sent by email, as this form of communication is not secure
- Data must be encrypted before being transferred electronically
- Personal data should never be transferred outside of the European Economic Area
- Employees should not save copies of personal data to their own computers. Always access and update the central copy of any data.

The law requires EMENA to take reasonable steps to ensure data is kept accurate and up to date. The more important it is that the personal data is accurate, the greater the effort EMENA should put into ensuring its accuracy. It is the responsibility of all staff, volunteers and contractors who work with data to take reasonable steps to ensure it is kept as accurate and up to date as possible.

- Data will be held in as few places as necessary. Staff, volunteers and contractors should not create any unnecessary data sets
- Staff, volunteers and contractors should take every opportunity to ensure data is updated. For instance, by confirming a member's details when they call
- EMENA will make it easy for data subjects to update the information EMENA holds on them. For instance, via the organisation's website
- Data should be updated as inaccuracies are discovered. For instance, if a member can no longer be reached on their details, they should be removed from the database

All individuals who are the subject of personal data held by EMENA are entitled to:

- Ask what information the charity holds about them and why
- Ask how to gain access to it
- Be informed how to keep it up to date
- Be informed how the charity is meeting its data protection obligations.

If an individual contacts the charity requesting this information, this is called a subject access request.

Subject access requests from individuals should be made by email, addressed to the President who will aim to provide the relevant data within 14 days, subject to verification of the identity of the requestor prior to handing over any information.

In certain circumstances, Data Protection law allows personal data to be disclosed to law enforcement agencies without the consent of the data subject. Under these circumstances, EMENA will disclose requested data. However, the President will ensure the request is legitimate, seeking assistance from legal advisors where necessary.

EMENA aims to ensure that individuals are aware that their data is being processed, and that they understand:

- How the data is being used

- How to exercise their rights

To these ends, the organisation has an additional privacy policy (see below), setting out how data relating to individuals is used by the charity. This is made available on the organisation's website.

Privacy

EMENA is committed to ensuring that anyone using its services maintains the level of privacy to which they are entitled. This is particularly important when dealing with genetic conditions such as multiple endocrine neoplasia. Under Data Protection law, EMENA has a legal duty to protect any information it collects from you. We use leading technologies and encryption software to safeguard our data, and strict security standards to prevent any unauthorised access to it.

Information We Collect

Through the variety of work that EMENA undertakes, different forms of information may be collected from you at different times, and retained. In all cases, we DO NOT pass on your contact details to any third party unless you give us permission to do so, and any contractors employed at any time who may, for reasons beyond our control, have access to information are required to sign a confidentiality agreement.

EMENA holds three types of information which are covered by this policy:

- Organisational information – publicly available information about organisations
- Personal information – information about individuals such as names, addresses, telephone numbers
- Sensitive personal information – in addition to contact information, EMENA may also hold sensitive information such as members' medical conditions and bank or credit card details.

EMENA Website Usage Information

- Cookies

Cookies are pieces of data created when you visit some websites, and are stored in the cookie directory of your computer. Cookies are created when you visit this website and use some of the facilities e.g. if you take part in a poll. The cookies do not contain any personal information about you, and they cannot be used to identify an individual user. You can set your browser not to accept cookies, however if you do some parts of this site will not work correctly, e.g. text sizing or our discussion system.

- Log Files

Log files allow us to record visitors' use of the site. We analyse log file information from all our visitors and use it to make changes to the layout of the site and to the information in it, based on the way that visitors move around it. Log files do not contain any personal information and they are not used to identify any individual patterns of use of the site.

- External Links to Other Sites

The EMENA website contains links to other websites. This privacy policy applies only to our site. When you move to another site, read the privacy statement for that site where personal information is collected. We do not pass on any personal information you have given us to any other site.

If this privacy policy changes in any way, we will place an updated version on our website in the appropriate place. Regularly reviewing this page ensures that you are always aware of the information that we collect, how we use it, and under what circumstances, if any, we will share it with other parties.

What Happens to the Information I Supply to You?

Any details you supply to us are held in strict confidence and in accordance with Data Protection laws. If you state you are happy for us to hold your details we may from time to time contact you either by phone, post or email about our work at the association or to update the information we hold on you. Should you prefer us not to contact you in this way, please contact us using the email facility on the website.

A copy of EMENA's Data Protection Policy is available to view on request.

Your Rights

All individuals who are the subject of personal data held by EMENA are entitled to:

- Ask what information the charity holds about them and why
- Ask how to gain access to it
- Be informed how to keep it up to date
- Be informed how the charity is meeting its data protection obligations.

Requests for your personal data should be made by email, addressed to the President who will aim to provide the relevant data within 14 days. This process is subject to verification of your identity prior to handing over any information.

Disclosing Information For Other Reasons

In certain circumstances, Data Protection laws allow personal data to be disclosed to law enforcement agencies without the consent of the data subject. Under these circumstances, EMENA will disclose requested data. However, the President will ensure the request is legitimate, seeking assistance from legal advisors where necessary.

6. EMENA Board Positions

- Any Member of EMENA can run for a position in the board. This includes Sponsoring Members and Affiliated members. The positions of President and Vice President are open for Full Members only.
- The Board of EMENA shall comprise no less than 2 patients or family members affected by MEN
- A new member of the board will enter into function after being appointed by the General Assembly, unless they replace a current member of the board. In the case of the latter, the new board member will enter into function directly. The position will be afterward approved by the General Assembly.
- Members of the board can resign. This needs to be done in writing (which may also be electronically) and at a term of minimal three months in advance. If the resignation will endanger the continuity of the Association the board member needs to stay in function until a replacement has been found.
- If the entire boards wish to resign a General Assembly needs to follow within 2 months. The board remains in position until replacements have been found.

7. Appointment of Auditors

- Auditors can be members of EMENA but may also be non-members. No one can serve as a member of the board and be an auditor at the same time.

8. Membership status

- Membership status of founding members who are no National MEN organizations can be changed from full member to sponsoring member by the General Assembly.

9. Funding and Use of funds

- To ensure impartiality, EMENA will strive to ensure that no one corporate sponsor is the organisation's major source of income, but rather that a range of sponsors contribute.

- EMENA may only use money and other assets if:
 - It is for a purpose of EMENA
 - It is not for the sole personal or individual benefit of any members
 - that use has been approved by either the Board or by majority vote of the General Assembly
- Travel costs and accommodation costs are to be minimized
 - EMENA reimburses the travel expenses for the cheapest reasonable way.
This covers transport like air fares or train tickets.
 - The hotel category should be middle class, relating to the destination country.
 - All receipts must be submitted.

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Responsibility: EMENA Board

Employee, volunteer and contractor agreement:

As an employee, volunteer or contractor for EMENA, I confirm that I have read the above policies and procedures document, and accept all the terms and conditions contained therein.

Name: _____

Signed: _____

Date: _____

[Please keep a copy of this document for your own information]