

Famiglie SMA APS ETS.: Application for new membership / Update of data for existing members

NEW MEMBERSHIP

DATA UPDATE

A) MEMBER'S PERSONAL INFORMATION (please complete all fields)

Last name	_____
First name	_____
Street/Square	_____ No. _____
ZIP Code	_____ City _____ Province _____
Phone/Mobile	_____ Email _____
Identity Card No.	_____ (<i>attach a copy to the application</i>)
Issued by	_____ on _____
Tax Code	_____

Type of member 1 person with condition 2 parent/guardian 3 partner 4 other relative 5 supporter

B) CONDITION DATA – to be completed only if the type of member indicated in section A) is 1. a person with the condition, or 2. a parent/guardian of a minor

Last name - first name person with the condition	_____
Date of birth	_____
Type of condition:	
<input type="radio"/> SMA 1	<input type="radio"/> SMA 2
<input type="radio"/> SMA 3	<input type="radio"/> SMA 4
<input type="radio"/> OTHER (please specify)	_____
<input type="checkbox"/> I give my consent to the processing of special category data (Art. 4, para. 15) as the data subject or as the holder of parental responsibility for a minor, in accordance with Art. 9, para. 2, letter a) of the GDPR. In the case of a minor, the signatures of both parents are required)	
Date	_____
Signature of consent	_____
(Attention! Consent is optional but required if you wish to access calls for applications/services related to SMA)	

CONSENT TO RECEIVE COMMUNICATIONS AND SERVICES

C) I wish to be contacted by phone for communications/information

I give my consent

I do not give my consent

D) I wish to receive communications and newsletters by email

I give my consent

I do not give my consent

E) I wish to receive communications and the SMAgazine by post

I give my consent

I do not give my consent

F) I wish to use the psychological, tax, and legal counseling services provided through the Toll-Free Number

I give my consent

I do not give my consent

(Attention! If consent is denied for item F, it will not be possible to access the Toll-Free Number or the related services, projects, or calls for applications)

I, the undersigned, sharing its aims and purposes, wish to join Famiglie SMA as a Member and undertake to pay the annual membership fee each year, under penalty of forfeiture as provided for in Title II, Article 3 of the Statute.

Date _____ Signature _____

The form must be signed with a handwritten (wet-ink) signature; electronic or digital signatures are not accepted, except where signing is legally impossible (in which case a copy of a valid ID must be attached), for legal identification and access to services purposes. For further details, please refer to the privacy notice provided at the time of registration.

By signing this membership application to Famiglie SMA, I declare that I have read the privacy notice attached to this request and that I have understood its contents.

The membership fee is €10, payable to Famiglie SMA APS ETS by one of the following methods: postal account payment via Poste Italiane using a payment slip or post office transfer to account no. 65702011 or bank transfer to IBAN IT91A076010320000065702011, payable to Famiglie SMA APS ETS. Online payment via PayPal or credit card through the page <http://www.famigliesma.org/dona-ora/>

The completed form should be returned by email to segreteria@famigliesma.org or by post to: Famiglie SMA, Via Re Umberto I, 103 – 20045 Lainate (MI), Italy.

Famiglie SMA APS ETS - C.F.: 97231920584

Sede Legale e Operativa: via Re Umberto I 103, 20045 Lainate MI – www.famigliesma.org

Email: segreteria@famigliesma.org Pec: famigliesma@pec.it

Tel +39 02 4244 4457

PRIVACY INFORMATION NOTICE

Famiglie SMA APS ETS (hereinafter referred to as the “Association”) informs you that the European Regulation 2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data (hereinafter “GDPR”) provides for the protection of individuals with respect to the processing of their personal data. In accordance with Article 13 of the GDPR, and in its capacity as the “Data Controller,” the Association provides you with the following information:

Data Controller and Data Processors

The Data Controller is Famiglie SMA APS ETS, with registered office at Via Re Umberto I, 103, 20045 Lainate (MI), Italy. Email: segreteria@famigliesma.org – Tel. +39 02 4244 4457

Data will be processed exclusively by the personnel and collaborators of Famiglie SMA or by companies expressly appointed as external Data Processors. The list of Data Processors is available at the Data Controller’s operational headquarters.

Data Protection Officer (DPO)

The Data Protection Officer can be contacted at the following addresses: Famiglie SMA APS ETS – Attn: Data Protection Officer, Via Re Umberto I, 103 – 20045 Lainate (MI), Italy - Email: rpd@famigliesma.org

Legal Basis and Purposes of Processing

The Association will process personal data (Art. 4, para. 1), as well as special categories of data (Art. 9, para. 2, letter a), if provided, for purposes strictly connected to its institutional activities, in particular:

1. Associative purposes – such as membership registration, assembly convocations, and communications to members;
2. Social solidarity purposes – such as participation in public calls and allocation of contributions, or provision of services;
3. Informational purposes – such as invitations to conferences, updates on research, and communications regarding local activities.

A detailed list of purposes can be found in Title I, Article 2 of the Famiglie SMA Statute, available on the Association’s website.

Methods of Processing

The data provided will be processed in accordance with current legislation and with the principles of fairness, lawfulness, transparency, and confidentiality that guide the Association’s activities. Data will be processed using both digital and paper-based tools, as well as any other suitable means. Appropriate security measures, in compliance with the GDPR, will be implemented to prevent data loss, unlawful or improper use, and unauthorized access.

Data Retention Period

Collected data, including identification documents, will be stored in the Association’s electronic and paper archives in accordance with legal requirements for recordkeeping and as part of the Association’s historical archive of events and activities, suitably pseudonymized. Data obsolescence in relation to the purposes for which it was collected will be periodically reviewed.

Obligation or Optional Nature of Consent

Providing personal data in the membership application form:

- Part A – is mandatory for pursuing the legitimate purposes set out in the Statute and summarized in point 1 above;
- Parts C, D, and E – are optional and require consent for the informational purposes described in point 3;
- Part F – is optional and requires consent, without which it will not be possible to access the Toll-Free Number services.

Special category data concerning health conditions (Part B) are optional; failure to give consent will prevent their use for social solidarity purposes described in point 2, and for Toll-Free Number services if these are related to the specific pathology.

Transfer to Third Countries

Your data will generally not be transferred to countries outside the European Union. In the event of data transfer to the United States, prior verification will be made to ensure that the recipients adhere to the Data Privacy Framework.

Data Subject Rights

Data subjects have the right, in the cases provided for, to obtain from Famiglie SMA: the withdrawal of consent (Art. 7, para. 3); access to personal data (Art. 15); rectification (Art. 16); erasure (“right to be forgotten,” Art. 17); restriction of processing (Art. 18); data portability (Art. 20); objection to processing (Art. 21), including objections to processing based on automated decision-making (Art. 22). These rights may be exercised by contacting the Data Protection Officer at the addresses indicated above.

Data subjects who believe that the processing of their personal data through this service violates the GDPR have the right to lodge a complaint with the Italian Data Protection Authority (Garante per la Protezione dei Dati Personali) (Art. 77), or to take legal action (Art. 79).

(Revision date: 24/02/2026)