

## Position statement on funding of our organised events and initiatives, and participating with partners\*

(\*Partners may include NGO's, government bodies, commercial companies, universities)

The purpose of this paper is to be transparent about the relationship between SAFE and the funders/supporters of SAFE's events.

Within its calendar year, SAFE will organise initiatives to pursue its objectives as defined in its constitution. These may be educational, awareness, advocacy, training, campaigning, fundraising, consultative, research oriented or governance focussed, or a combination of any of these in terms of content. When organised by SAFE the content is always decided upon by SAFE and in any contract related to funding of any SAFE event the control of content will always remain with SAFE.

The delivery of these events or initiatives can take many forms, from published material, workshops and seminars, web-based initiatives, street activity to formal lectures, or presentations and exhibitions to audiences. These initiatives include face to face events for its members and for stroke survivors and their families and supporters, but not exclusively.

These initiatives and events generally require funding, and to ensure control of the content and approach SAFE generally requires that the funding when externally provided is done so via the allocation of funds to SAFE for management and disbursement in accordance with SAFE objectives. Like most Europe wide NGO's SAFE does not generally receive adequate funding from individuals to sustain activity, and so must look to partners for funding of its initiatives and events. The purpose of this statement is to be transparent about the relationship between SAFE and its funding partners.

There are different ways that partners, including commercially oriented companies would support an initiative, such as:

 Awarding a grant or donation for SAFE to pursue its constitutional objectives in general or to pursue one or more stated objective areas. In these circumstances SAFE makes it clear that the usage of the finance or resource must be wholly decided and used by SAFE within initiatives agreed by the SAFE board in pursuit of its non-profit objectives. Support from partners is shown transparently by public recognition often by showing supporters logos. The receipt of these funds is always shown in the annual report and accounts. These are generally called non restricted donations.

- Where there is mutual agreement on an educational initiative with a partner, then the partner may wish to sponsor a SAFE organised initiative through an educational grant. There are many organisations, including commercial organisations, medical science, public health bodies, and research funding bodies, who wish to raise public and at risk groups knowledge of particular health matters through using NGO reputation, reach and expertise. Transparency is ensured through coverage in the annual report and accounts and by placing supporter logos on the specific materials where relevant related to the initiative. Funding is generally called designated or restricted funding to specific initiatives in these circumstances.
- Funding is also given by partners to initiate research, network creation, and consultative activity to grow the knowledge base of participants and wider stakeholders. In many cases the best placed organisation to co-ordinate and do this is an NGO. It is quite normal for funders to want to receive information on process and expected outputs, although again SAFE would insist on control over all activity organised under our auspices. Transparency is again ensured through usage of funders logos on materials and by explanation in the annual report and accounts. This type of funding is also called designated or restricted funding because it related to a specific initiative. It is worth clarifying that Pharmaceutical companies are expressly forbidden from marketing their drugs directly to potential users in most countries of Europe. They are of course encouraged to share information on their products to medical people and patient organisation representatives in the interests of enabling better informed decision making. SAFE morally and legally will not therefore provide marketing space in events or within initiatives for pharmaceutical company products or specific company medical devices.

## The terms in which SAFE works with Partners funding events through educational grants

Healthcare industry companies and other partners are welcome to become SAFE event and initiatives partners under the following conditions:

- The funders engagement with and participation in initiatives and events will be outlined in a signed agreement, outlining obligations from both SAFE and the Partner.
- Upon signing the agreement, it is the contract partner's responsibility to inform all subsidiaries, affiliates, third party companies etc. involved on its behalf of the rules and regulations of the "SAFE Code of Practice". It is also the contract partner's responsibility that its subcontractors adhere to all rules and regulations.

- The sponsorship given to SAFE will not, under any circumstances, include SAFE promoting the sponsor company products or services.
- Members of the Partner company's advocacy, stakeholder engagement, and policy/government affairs teams may be included in invitations to attend SAFE sponsored events. Members of the sponsoring company medical team are not generally invited, but may be for a specific reason, but sales team members will not be invited to participate.
- SAFE will have full control of any meeting programme or other initiative and
  activity will be decided independently of sponsoring company or partner input.
  The objectives of each initiative will be decided upon by SAFE's board. In the
  case of a scientific conference, a scientific committee will be generally be put in
  place to advise the board or a subgroup of the appropriate content for the
  conference, and will not have any representation from the funding partner,
- Within a SAFE event, no promotion of specific medical products or services will
  occur. Should a company wish to promote their product or service, then this
  would have to be at a separately badged event from the SAFE initiative. Any
  such fringe event or satellite symposia will be separate to the main programme
  event and will be clearly signposted as a company event.
- SAFE may offer a stand to partners as a space where they can create
  opportunities for talking to patient support organisations, decision makers, health
  care professionals and lay visitors of the event. The partner/ company is not
  allowed to promote their products and services to lay visitors at any time.
- It is the sponsoring partners responsibility to adhere to any restrictions and/or limitations which may be applicable according to the legislation of the host country of the event. Contests, lotteries, raffles are subject to the approval by the organisers (SAFE).

Adopted and Approved by the Board June 2020 Reviewed June 2021, March 2023, March 2024 Next review date March 2025