

SMA Europe Job Vacancy: Research and Medical Manager

Contract Type: 0.8-1 FTE (full time: 40 h/week), 6 months' probation period.

Location: Working remotely from home with occasional in-person meetings in different European countries. Time zone of CET +/-2 h.

Salary: Depending on the location and based on experience. Range from 40'000 to 55'000 Euro.

Reporting to: CEO. Working closely with the SMA Europe team, SMA Europe member organisations and external partners (e.g. universities).

About SMA Europe

SMA Europe is a non-profit umbrella organisation of 27 spinal muscular atrophy (SMA) patient organisations from across Europe. We strive for earlier diagnosis, effective treatments and optimal care for all those living with SMA. Together, through greater understanding, we will create a better world for all those living with SMA.

Scope of the position

We are seeking a dynamic and experienced individual to join SMA Europe as the Research and Medical Manager. The Research and Medical Manager will:

- shape, lead, and coordinate our activities, ranging from biomedical, translational to clinical research and related processes to ensure that we bring promising research concepts all the way to the patients, including day-to-day management and executing ongoing projects,
- lead on the implementation of strategic projects and funding programmes in priority areas as defined by the SMA community's needs,
- foster collaborations with stakeholders in the scientific, clinical and other relevant communities,
- support the implementation and development of our research strategy ensuring that patient needs are at the forefront of our initiatives.

This position offers an exciting opportunity to make a meaningful impact on the SMA research landscape and contribute to the advancement of therapies by fostering a transdisciplinary approach.



Specific Responsibilities

Lead, manage and coordinate SMA Europe's involvement in biomedical, translational, and clinical research

- Together with SMA Europe's CEO, lead the delivery of our strategy work focused on SMA research and ensure that SMA Europe's research agenda reflects the needs and priorities of patients, caregivers and the broader SMA community.
- Lead and manage SMA Europe's research initiatives, including developing and implementing project plans, monitoring progress and ensuring alignment with organisational goals.
- Establish SMA Europe's presence within the research community and act as a key contact point for researchers, healthcare professionals, the patient community, and other relevant stakeholders.
- Stay up to date with the latest research developments to use strategic scientific expertise and judgement in the development and implementation of research activities.
- Shape the scientific development of key scientific events of SMA Europe (e.g. International Scientific Congress on SMA).
- Manage SMA Europe's alliances with external organisations (e.g. SMA Beyond Consortium).

Promote patient involvement in SMA biomedical, translational, and clinical research

- Implement SMA Europe's tactics to engage and collaborate with the scientific and healthcare professional communities, pharmaceutical companies, regulatory agencies, and other stakeholders involved in research.
- Ensure that SMA Europe's own activities are aligned with the needs of our community (e.g. research funding priorities, Scientific Congress programme) as well as establish and implement effective processes for monitoring and reporting on our patient involvement in research activities and impact to disseminate across SMA Europe.
- Create opportunities for patient involvement by further developing existing systems (e.g. SMA Europe's
 Treatment Committee, Patient Panel for Call for Research Proposals) and ensure that people who take
 part in research involvement activities receive appropriate support and effective ongoing communication
 to maintain engagement.
- Encourage the scientific community to involve the patient community in their research and provide advice to the scientific community on best practices on involvement of patients in research.

Management of SMA Europe's research funding programmes

- Lead the scoping, design, review, and implementation of SMA Europe's core grant funding programmes (Call for Research Proposals, SMArt Horizon) as well as oversee the portfolio of active research projects. This will include administering, monitoring, evaluating and reporting on the performance of spent and planned funds, ensuring the outputs are of the highest quality and are aligned with SMA Europe's priorities to drive impact for the SMA community.
- Coordinate communication and collaboration with grant holders, research institutions, funding partners and other stakeholders involved in the funding process.

Management of SMA Europe's clinical trial-related projects

- Manage, coordinate and implement SMA Europe's clinical trial-related projects (e.g. Clinical Trial Site Readiness in Europe), including collaboration with funding partners, research sites and industry partners.
- Develop and maintain our Clinical Trials Hub on SMA Europe's website.
- Support the development and implementation of patient-centric clinical trial protocols, informed consent documents and recruitment strategies, in collaboration with SMA Europe's Treatment Committee.
- Be actively involved in the discussions around SMA registries to promote patient-relevant data collection.

General responsibilities



- Act as a point of contact for our Scientific Advisory Board and SMA Europe's Treatment Committee, ensuring effective communication and collaboration between members and relevant stakeholders. Establish a Patient Panel for our Call for Research Proposals.
- Contribute to the maintenance of strong internal relationships and to the team being proactive and supportive, provide a helping hand to colleagues, and working effectively and efficiently to achieve agreed objectives.
- Identify opportunities to maximise the value of SMA Europe's activities in the research area.
- Communicate the value and impact of SMA Europe's activities in the research area to internal and external stakeholders and be an effective ambassador at any activity you attend.
- Collaborate on research communication activities, working closely with SMA Europe's Communication and Marketing Manager, using channels ranging from peer-reviewed publications to lay summaries. This will ensure that our members and partners are kept informed on the latest research developments and enable SMA Europe to demonstrate the impact of our (funded) research and activities in this area.
- Championing opportunities for potential partnerships, preparing proposal documents, briefing and engagement plans to develop relationships as well as acting as a liaison with both internal and external stakeholders; identify synergies with SMA Europe's member organisations.

Your experience and skills

- PhD or equivalent experience in biomedical science (e.g. biology, pharmacology, medicinal chemistry) with a background in SMA, neuromuscular or other rare disease research preferred.
- Proven project management and organisational skills with the ability to manage multiple projects with a broad spectrum of tasks, deadlines, and individuals at the same time; ability to prioritise, support others and show adaptability to meet challenging targets and deadlines.
- Experience in research management, grant administration and project management, preferably in a research or non-profit setting.
- Understanding of the research landscape, its challenges, and opportunities; understanding of drug discovery, drug development and regulatory requirements in the context of rare disease research.
- Good team player with demonstrated ability to lead and coordinate transdisciplinary teams, sometimes
 from multiple organisations, and to form strong, positive collaborative relationships at all levels of
 seniority. Willingness to take on different roles in projects.
- Excellent communication (written and verbal in English) and interpersonal skills, with the ability to
 effectively engage with scientists, clinicians, industry partners and patient advocates and to translate and
 'leverage value' of scientific concepts for lay audiences and back. Experience in research communication
 is a plus.
- Adherence and commitment to patient-centred research principles geared towards involving the SMA community in biomedical, translational, and clinical research activities.
- Strategic thinking, experience in dealing with ambiguity and uncertainty, and problem-solving abilities, with a passion for driving innovation and advancing research in the field of rare diseases.
- Numerate and analytically minded, with an aptitude for resolving problems by developing innovative, robust and pragmatic solutions, implemented with attention to detail.
- A positive attitude to technology, insight, and data, including an enthusiasm to use new technologies and ways of working to deliver against objectives.
- Self-motivated, proactive, and able to work using own initiative, under the supervision of SMA Europe's CFO
- Comfortable in an international environment and experience working with different nationalities in your home office.



To apply

Please send your CV and cover letter (max 2 pages each) in English to secretariat@sma-europe.eu and include 'Job vacancy: Research and Medical Manager' in the subject field.

Deadline for applications: 23 June 2024 Interviews: End June - Mid July 2024

Position starts: September 2024 or by arrangement.

SMA Europe is committed to equal employment opportunity regardless of disability, national origin, citizenship, race, colour, ancestry, religion, sex, sexual orientation, gender identity, age and marital status.

