



AMEND Ambassador Volunteer: Co-Representative for INCA

<https://incalliance.org/mission-vision/>

About INCA

The International Neuroendocrine Cancer Alliance (INCA) is the global voice in support of patients with neuroendocrine tumors (NETs) and genetic syndromes (GenNETs). INCA is an umbrella organization representing 37 patient advocacy and research groups from around the world.

A key priority in INCA's work is creating common platforms and working in collaboration with medical communities to fulfill the informational needs of patients, ensure access to the highest standards of care and facilitate patient involvement in research.

INCA Vision

A world where all patients with neuroendocrine cancer and genetic neuroendocrine tumors (GenNETs), get a timely diagnosis, optimal treatment, support and care, and ultimately a cure.

INCA Mission

INCA is the global voice for patients with neuroendocrine cancer and genetic neuroendocrine tumors (NETs) and their carers with a mission to:

1. raise awareness about all types of NETs [INCA is the home of NET Cancer Day];
2. push for scientific advancements with a focus on identified unmet needs;
3. and provide a platform for global collaboration to address the many challenges NET patients and the medical community face, in securing a timely diagnosis and accessing optimal treatment, support and care;

The Role of Co-Representative for AMEND at INCA

AMEND is looking for a volunteer to work with the AMEND CEO to represent genetic neuroendocrine tumour syndromes within the International Neuroendocrine Cancer Alliance (INCA). This is a relatively busy role for a volunteer although most of the work is done virtually. We envisage that the volunteer will take on the full AMEND Representative role over time.

You will need to be:

1. A registered UK-based member of AMEND who is engaged and familiar with our work.
2. Enthusiastic about representing **all** our genetic neuroendocrine diseases (MEN1, MEN2A, MEN2B, PPGL)
3. Happy to undertake public speaking (usually within INCA itself)
4. Interested in getting involved in research and/or awareness projects for the international community
5. Be available for up to 2 hours per week
6. Available to travel 8-10 September 2024 for the INCA Summit (Madrid) – travel expenses paid

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You will be expected to:

1. Attend the 2024 INCA Summit alongside the AMEND CEO to meet all the other international representatives and get an idea of the work that is undertaken.
2. Volunteer with one or more committees within INCA (AMEND currently works in Awareness)
3. Volunteer as a member of the Board of Directors of INCA (from 2025/6)
4. Prepare regular update reports for the CEO and Board of Trustees of AMEND

You can expect AMEND to:

1. Help you familiarise yourself with INCA, its aims, objectives, work packages, and international community
2. Provide you with training and information resources relevant to the role
3. Provide you with technical assistance and supplies where appropriate
4. Organise and pay for any necessary travel (we are reimbursed by INCA)
5. Reimburse reasonable out-of-pocket expenses related to this role in line with our policies
6. Support you in any way appropriate as you take on more responsibilities within INCA.

If you feel that you have the skills and drive to take on this role, please contact AMEND CEO, Jo Grey at jo.grey@amend.org.uk as soon as possible.

Date: 25 March, 2024