



# Information Events Coordinator

Myeloma UK

May 2024

## Welcome

Thank you for your interest in Myeloma UK.

This is a very exciting time to join our team as Myeloma UK is at a key point in our charity's history. Having successfully served our community for 25 years, we are now looking forward to how we can adapt to the changing needs of myeloma patients and their loved ones.

When Myeloma UK was founded the life expectancy for a myeloma patient was between 12 and 24 months. There were no bespoke myeloma treatments available on the NHS, there were big gaps in our knowledge about the disease and getting the latest evidence-based information about myeloma was anything but easy. Today, the life expectancy has quadrupled to between four and eight years, with three out of ten patients living for ten years or more after their diagnosis – and some for much longer. There are now nine myeloma drugs in active use that can be delivered over 12 different combinations, we have funded over £19m of innovative myeloma research and for over two decades we have provided a range of patient support services and information which have been a lifeline for thousands.

We have come a long way. And yet, myeloma is still an incurable blood cancer. We still see one-third of patients being diagnosed at a late stage and in an emergency setting. And we now face new challenges as we work to give our community an empowered present and a hopeful future. With some patients living longer, we also need to ensure they live well with myeloma.

We are passionate about driving positive change for those effected by myeloma and committed to fostering a supportive culture of learning and innovation.

We look forward to hearing from you!

Yours sincerely

A handwritten signature in black ink, appearing to read "Sophie Castell", with a long horizontal line underneath.

**Dr Sophie Castell**  
Chief Executive

## Our long-term ambition

Make myeloma history

## Our purpose

To give every patient an empowered present and a hopeful future

### In 2022



Our income for the year was £5.2m

£5.2m



Our expenditure on meeting the needs of people affected by myeloma was £5.2m



£1.8m

Our expenditure on research totalled £1.8m



From every £1 of expenditure, 81p was spent on improving the lives of people affected by myeloma

## Our strategy and work

Myeloma UK works to four strategic cornerstones.



**Diagnose**  
myeloma earlier

### We will reduce the impact of myeloma and related conditions on people's lives.

- Better patient outcomes are heavily dependent on identifying myeloma before symptoms develop and we work to raise awareness of myeloma with healthcare professionals and the general public.
- We lead a unique early diagnosis working group that brings together clinical experts to address the challenges in identifying this complex cancer. We will evolve this to invest in vital research to examine how myeloma develops through each stage.



## **Transform**

the patient experience.

**We will identify unmet need, improve outcomes, and ensure equal access to patient-centered treatment and care for patients with myeloma and related conditions.**

- We campaign for patient access to the latest treatments via the NHS through our sector-leading patient advocacy program and provide award-winning information and support services to the myeloma community.
- We will represent patients in every relevant drug assessment and work to have patient preference integrated into the drug evaluation process. We will evolve our information and support services to provide mental health and wellbeing tools and extend the support hours we offer.



## **Discover**

and share knowledge

**We will pursue lasting and transformative scientific discovery in myeloma and related conditions.**

- Our uniquely focused research program works with partners including the Institute for Cancer Research and the Structural Genomics Centre at Oxford University to drive understanding into the causes and treatment of myeloma. We are committed to the principles of open science.
- We will accelerate the development of the most promising new treatments by investing in early stage clinical trial design through our Clinical Access and Research Program (CARP) run in partnership with the University of Leeds and the UK Myeloma Research Alliance. We will set at least two new trials per year through CARP to provide patients with early access to novel therapies, up to ten years ahead of the NHS.



## Influence

positive change in care

**We will build the optimum model of care for myeloma patients and patients with related conditions through leadership and collaboration.**

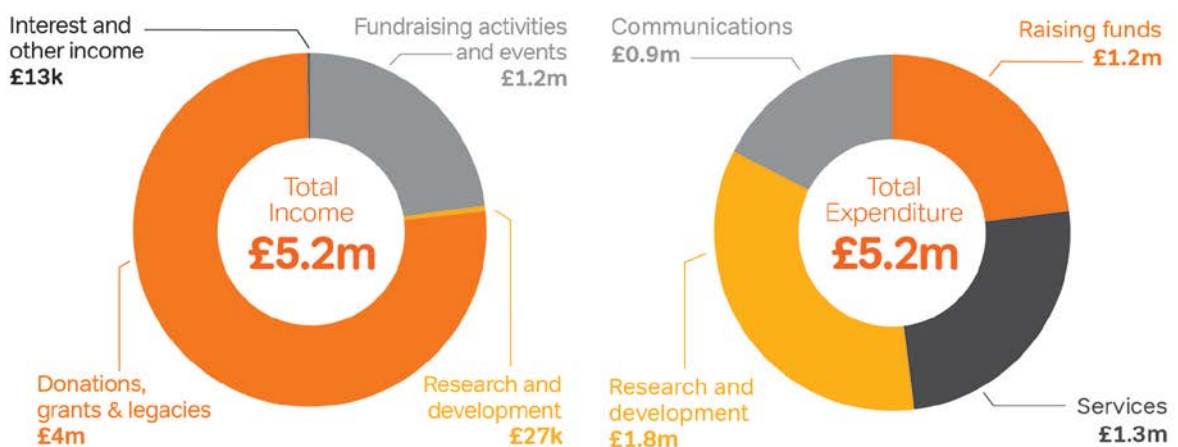
- We invest in the lifetime of the patient journey by operating a best practice accreditation program for hospitals and providing educational and training materials to the wide range of healthcare professionals who treat myeloma patients and those with related conditions. Our health services research program quantifies patient experience and need to change how patient care is designed, delivered and funded.
- We will create a universal experience of myeloma care through our Clinical Services Excellence Program and integrate patient preference into healthcare service design. We will influence the policy making process to ensure the needs of myeloma patients are understood and met.

## Funding our work

Myeloma UK is a fundraising organization with income generated from voluntary fundraising, grants and trusts, philanthropy, and some trading activities. We rely on the generosity of our donors to enable us to run our life-changing programs.

We have ambition to grow our fundraising substantially over the next three years to deliver the change myeloma patients need. Our strategic priorities are:

- Recover our pre-pandemic income by 2023 and pursue an ambitious and sustainable growth five-year strategy to increase income
- Diversify our income streams, developing our high-level donor and trust and foundation activities
- Embed fundraising across the whole organization.



**Income & Expenditure for the 12 months to December 2022**

## Our values



### We strive for **Excellence**

We constantly strive for excellence in everything we are involved with, helping us achieve consistently high standards while offering well informed support. We have expert knowledge, delivering quality in everything we do.



### We are **Compassionate**

Our understanding nature underpins all conversations, meetings and interactions. This warmth helps us empathise with people in difficult situations, offering support while being thoughtful and considerate colleagues.



### We are **Passionate**

Our passion encourages us to go over and above, channelling our energy positively to make significant, measurable progress. We believe in what we do. Our desire to find a cure is unstoppable, as is our drive to help those affected.



### We are **Collaborative**

We are united behind our goal of finding a cure for myeloma. To achieve this, we work with and support a wide variety of stakeholders to drive progress. This collaborative approach empowers us to work as a team, share progress, share knowledge and involve the right people.



### We are **Innovative**

We are always searching for new ways to challenge myeloma. Our work progresses new drugs and treatments, influences policy and encourages positive change. Our ability to look at situations from a variety of perspectives allows us to explore new avenues and find the best ways to support the people we interact with.

## Job Description

|                        |  |
|------------------------|--|
| <b>Post</b>            | Information Events Coordinator (permanent, full time)  |
| <b>Job Ref</b>         | S/4  |
| <b>Location</b>        | Edinburgh or remote – flexible, with hub-based office days.<br>Travel and overnight stays across the UK required for events. |
| <b>Department</b>      | Lived Experience and Clinical Practice   |
| <b>Reporting to</b>    | Patient Information Manager  |
| <b>Responsible for</b> | Information Events Administrator   |

### Job Summary

The Information Events Coordinator will deliver the patient and family myeloma and AL amyloidosis information events programme consisting of face-to-face and online events hosted by the team and held throughout the UK, developing the strategy for the programme and implementing event activity with the aim to increase participation and attendance.

Evaluate all events to inform future planning, including monitoring associated income/expenditure.

As a member of the Lived Experience and Clinical Practice Directorate, the Events Coordinator will contribute towards the delivery of the business’s strategic, operational, and departmental plans.

### Key Deliverables

#### 1. Patient and Family Myeloma Information Events Programme:

- Organise the planning, coordination and delivery of the information events programme including administration, promotion and marketing, dealing with event logistics and delivery on the day
- Monitor the associated income and expenditure for the information events programme to ensure that the programme is delivered to budget
- Organise the planning and delivery of the digital events programme, dealing with promotion and marketing and taking ownership of technical aspects of running online events. Contribute to overall programme plans and content with the Patient Information & Events Manager



- Develop marketing material and a publicity and communications strategy for the information events programme with the Communications Team maximising use of the web and social media to encourage attendance
- Develop and maintain good working relationships with all stakeholders including contacts at venues, external companies/suppliers, chairs, speakers, attendees and healthcare professionals and encourage their participation in the information events programme
- Ensure administrative support for the information events programme is completed on time and to a high standard
- Work with the Communications Team to ensure that all associated information events' materials reflect the Myeloma UK organisational brand and key messages
- Ensure that each information event is attended by a team of Myeloma UK employees and volunteers to support the delivery on the day and that they are appropriately briefed and trained to undertake required duties
- Conduct regular evaluations of the database and use the findings to drive and guide the information events activity and development
- Evaluate the programme on an ongoing basis and at the end of the year to determine areas for development and improvement

## **2. Reporting/administration:**

- Coordinate the information events programme project planning, management, delivery and evaluation
- Oversee programme budgets, report performance and variances and work with your line manager to forecast, reforecast and conduct contingency planning
- Ensure that all programme plans and activity are implemented to the highest standard and in line with legislation, codes of practice and operational procedures
- Work with line manager to plan future activity in accordance with development plans
- Develop and collect KPI data to evaluate all events and proactively report on performance and success with your team and organisation regularly and as required
- Prepare regular updates for team meetings on the progress of agreed programme plans and objectives
- Keep abreast of relevant legislation, trends and best practice and work with your line manager to develop the necessary internal policies, procedures and guidelines accordingly

### 3. General

Continuous improvement, developing skills, adhering to organisational quality standards, and team-work underpin all roles at Myeloma UK.

General responsibilities include:

- Adopt the Myeloma UK principles of quality management
- Be attentive to and implement organisation brand and style guidelines
- Participate in team meetings and work together with colleagues to maintain and improve knowledge and skills
- Act as a source of information and support to colleagues throughout the organisation
- Build productive working relationships with external advisers to maintain and enhance their commitment to Myeloma UK
- Demonstrate a commitment to ongoing learning and development and to participate in any training relevant to the role
- This role will require some essential travel throughout the UK, therefore the post holder must be willing to travel. Regular travel to Edinburgh if based elsewhere will be required
- Undertake such work as may be appropriate to the post

This job description is not exhaustive. It merely acts as a guide and may be amended to meet the changing requirements of Myeloma UK at any time after discussion with the post holder.

## Person Specification

| Area                                   | Essential  | Desirable  |
|--|--|--|
| <b>Qualifications &amp; Experience</b> | <ul style="list-style-type: none"> <li>• Significant and demonstrable event management experience including planning, delivery and evaluation</li> <li>• Project management experience</li> <li>• Clear evidence of building effective relationships with external stakeholders to deliver objectives</li> <li>• Budget management experience</li> </ul>   | <ul style="list-style-type: none"> <li>• Marketing and communications experience</li> <li>• Line management experience</li> <li>• Patient involvement experience and/or understanding</li> <li>• Experience in training or facilitating groups</li> <li>• Digital events experience</li> </ul> |
| <b>Knowledge</b>                       | <ul style="list-style-type: none"> <li>• Thorough understanding of the principles of event management</li> <li>• Thorough understanding of how to identify and meet the needs of service users through event delivery</li> <li>• Knowledge of systems for event evaluation and service improvement</li> <li>• Understanding of the principles of effective communication</li> </ul>  | <ul style="list-style-type: none"> <li>• Rare cancer awareness and knowledge</li> <li>• Understanding of the needs of cancer patients and their families</li> </ul>  |
| <b>Skills</b>                          | <ul style="list-style-type: none"> <li>• Strong project management skills</li> <li>• Excellent written and verbal communication skills, including an ability to tailor communication to different stakeholder groups</li> <li>• Excellent relationship development and management skills</li> <li>• Excellent presentation and negotiation skills</li> <li>• Ability to set priorities and work under pressure</li> <li>• Great attention to detail</li> <li>• Excellent organisation</li> </ul> |  |

|                        |   |   |
|------------------------|---|---|
|                        | <ul style="list-style-type: none"> <li>• Computer literate – good working knowledge of MS Word, Excel, PowerPoint and ability to use databases for recording and reporting</li> </ul>   |   |
| <p><b>Personal</b></p> | <ul style="list-style-type: none"> <li>• Constant desire for improvement</li> <li>• Self-motivated, able to work without close supervision</li> <li>• Dedicated team player</li> <li>• Commitment and desire to make a difference</li> <li>• Ability to take initiative</li> <li>• Ability to manage a wide range of tasks and work well under pressure to meet deadlines</li> <li>• Flexibility and willingness to develop and expand the role</li> <li>• Ability and willingness to work out of the office as required and at weekends across the UK</li> </ul> | <ul style="list-style-type: none"> <li>• An ability to think strategically</li> </ul> |

## Terms and Conditions

|                         |   |
|-------------------------|---|
| <b>Post</b>             | Information Events Coordinator (permanent, full time)   |
| <b>Salary</b>           | £29,744 - £32,419   |
| <b>Probation period</b> | Three months  |
| <b>Hours of work</b>    | <p>The standard working week comprises 35 hours, Monday to Friday. Myeloma UK operates a flexitime scheme and details will be provided by the Head of HR and Operations.</p> <p>The post holder will be expected to assume duties outside working hours to support the delivery of their role and the operation of the organisation when required.</p> <p>This post holder will be required to work on weekends in accordance with the schedule of event activity (approx. 6-8 weekends per year). Time off in lieu is offered for weekend work in accordance with the organisation's policy.</p> |
| <b>Holidays</b>         | Full-time holiday entitlement is 30 days per calendar year, plus 6 public holidays.   |
| <b>Pension scheme</b>   | Myeloma UK complies with its auto-enrolment obligations and, subject to matched employee contributions, offers a 7% pension contribution to all staff.  |
| <b>Premises</b>         | Myeloma UK is situated at 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG.  |

## Join us!

At Myeloma UK, we are committed to bringing together the best and brightest people across the whole organisation. We are interested in people who have helped charities and organisations achieve their ambitions, be that through professional or lived experience. We know that it is only by bringing multiple talents into a team that we can achieve change, so we would like to hear about what makes you exceptional – your skills, your interests, your experience, and your values. We are committed to reflecting the whole myeloma community in our structure, so we particularly encourage applications from black and ethnic minority communities and from people with disabilities.

Myeloma UK offers its employees a range of benefits including a pension salary exchange scheme, flexitime, flexible working from home with hub-based office working, health plan and holiday purchase scheme and we are committed to providing learning and development opportunities for all our employees.

As part of any recruitment process, Myeloma UK collects and processes personal data relating to job applicants. Myeloma UK is committed to being transparent about how it collects and uses that data and to meeting its data protection obligations. You can read more about how we do this here: <https://www.myeloma.org.uk/wp-content/uploads/2024/04/Myeloma-UK-Job-Applicant-Privacy-Notice.pdf>

Diversity, equality and inclusion are at the core of who we are and our commitment to these values stretches across all our work. We know that having varied perspectives helps generate better ideas to solve the problems of a changing and increasingly diverse world. We want to ensure we have a diverse team, and when we recruit we welcome applications from people of colour, LGBTQ+ people and disabled people.

Myeloma UK funds research into myeloma and is a member of the Association of Medical Research Charities. As part of this we have a statement on our website with our position that we support animal use in research in an essential, appropriate and ethical way. For further information please go to <https://www.myeloma.org.uk/wp-content/uploads/2020/05/Animal-use-in-Research.pdf>

## How to apply

If you think you would be a great fit for the role, please submit a copy of your CV together with a supporting letter to [jobs@myeloma.org.uk](mailto:jobs@myeloma.org.uk).

Your letter should include the following:

- Why you are applying for this post
- How your skills and knowledge meet the requirements of the role
- How your experience and expertise can support and reflect our values
- Whether you currently have the **right to work in the UK**

**Please note that only CVs accompanied by a supporting letter will be considered.**

Applications close on 10 June 2024.

Interviews will be held on 20 and 21 June 2024.

Appointment will be subject to receipt of satisfactory references and right to work checks.