Recruitment

Pack

Support Group Coordinator

Myeloma UK

April 2022

Contents

Welcome

Thank you for your interest in Myeloma UK.

Myeloma UK invests in driving better patient outcomes through a comprehensive early diagnosis program, cutting-edge research, sector-leading treatment access, award-winning information and support programs, and pioneering healthcare services improvement. Our community consists of the 24,000 people living with the incurable blood cancer myeloma, as well as those with related conditions including MGUS (a non-cancerous condition that can increase the chance of developing myeloma), smouldering myeloma (an early form of myeloma) and AL amyloidosis (a rare build-up of protein occasionally associated with myeloma). Including our patients with related conditions, the population we represent is over 63,000 people.

Our long-term ambition is to make myeloma history, but we recognize that is a challenging process. As we work to that ambition, we are committed to providing every patient with an empowered present and a hopeful future.

Our current income is c£4.8m. The pandemic has presented challenges but, with a lot of hard work, our teams have delivered on budget. We are in a good position financially, so there is a sound platform from which to build.

We are committed to ensuring that patients receive more effective treatments, enjoy better outcomes, and have more years with a life they love. A positive, empowering culture is important to us, and we like to have fun along the way.

Our **long-term ambition**

Make myeloma history

Our **purpose**

In 2020

Our income for the year was £4.7m

Our expenditure on meeting the needs of people affected by myeloma was £3.2m.

Our expenditure on research totalled £0.9m

From every £1 of expenditure, 80p was spent on improving the lives of people affected by myeloma.

COVID-19

As a cancer charity, COVID-19 has had a significant impact on our community. Myelomapatients are ten times more likely than a member of the general public to catch a virus such as COVID-19 and, because of the way their cancer develops and is treated, are categorised as extremely clinically vulnerable. In 2020, the pandemic impacted the treatment of over 40% of our patients, and every patient has had to accept changes to the way they connect with their clinical teams and the way they live their lives.

In light of these significant additional pressures on our community, we reviewed our strategy and re-set our strategic priorities according to on-going need. This enables us toaddress the serious emerging concerns of:

- Delayed diagnosis of new myeloma patients and the impact of that delay on theirclinical outcomes
- A shortfall in cancer research funding
- Geographical inequalities in provision of treatment and care
- Pressure on the NHS and on health policy design and delivery

Our ambition for 2021

The COVID-19 pandemic has led us to refocus and refresh our strategy, but our purpose remains the same: giving every patient an empowered present and a hopeful future.

Our work in 2021 and beyond will deliver against four strategic cornerstones:

Diagnose
myeloma earlier

We will accelerate work on earlier detection and diagnosis to make the greatest impact on the length and quality of lifefor myeloma patients and those with related conditions.

- The Myeloma UK Early Diagnosis programme identifies and addresses barriers to earlier diagnosis
- The Myeloma UK Early Diagnosis Working Groups develop tools and education materials to speed up detection, referral and diagnosis at GP-level
- We will establish the Myeloma UK Early Diagnosis Research programme to better understand how myeloma develops and identify patients at risk

Discover
and share knowledge

We will drive scientific breakthrough into the cause and treatment of myeloma and related conditions to increasepatient survival and improve patient experience.

- Myeloma UK funds translational research at the ICR to accelerate the development of personalised medicine to myeloma patients
- Myeloma UK funds the UKMRA Myeloma UK Concept & Access Research Programme (CARP) to create new clinical trials and give patients early access to novel treatments
- Myeloma UK supports the development of future research leaders by funding a Clinical Research Fellowship at the University of Leeds and the development of our early care research programme, fostering interest in myeloma as a focus of future research
- The Myeloma UK patient data project enables better insight and evidencing of patient need and changes to policy, treatment and care
- Myeloma UK's Health Service Research identifies unmet need and patient preferences to inform change in healthcare policy and delivery

Transform

the patient experience

We will partner with patients to understand and meet their needs and build equal care for all.

- Myeloma UK puts patient need and experience at the heart of drug appraisals to make sure that patients can access new treatments
- Myeloma UK drives excellence in patient-centred hospital care through our Clinical Services Excellence Programme (CSEP)
- The Myeloma UK Myeloma Academy and Myeloma Nurse Learning Programme educate healthcare professionals to ensure that patients receive the best care informed by the latest learnings
- Myeloma UK has the most comprehensive library of patient information on myeloma and related conditions, helping patients to understand and be in control of their decision-making
- Myeloma UK offers specialist, tailored support to the whole myeloma community through our Myeloma Infoline and Ask the Nurse email service
- Myeloma UK delivers a range of digital and physical events, directly connecting patients and families to expert analysis, advice and support
- Myeloma UK partners patients to provide a UK-wide network of Support Groups, reducing isolation and offering friendship to the whole myeloma community
- Myeloma UK will establish a volunteer peer to peer support service to bring together shared patient experiences and practical tips for living with myeloma and related conditions

Influence

positive change in care

We will give a voice to patients and ensure that myeloma is not considered a second-class cancer.

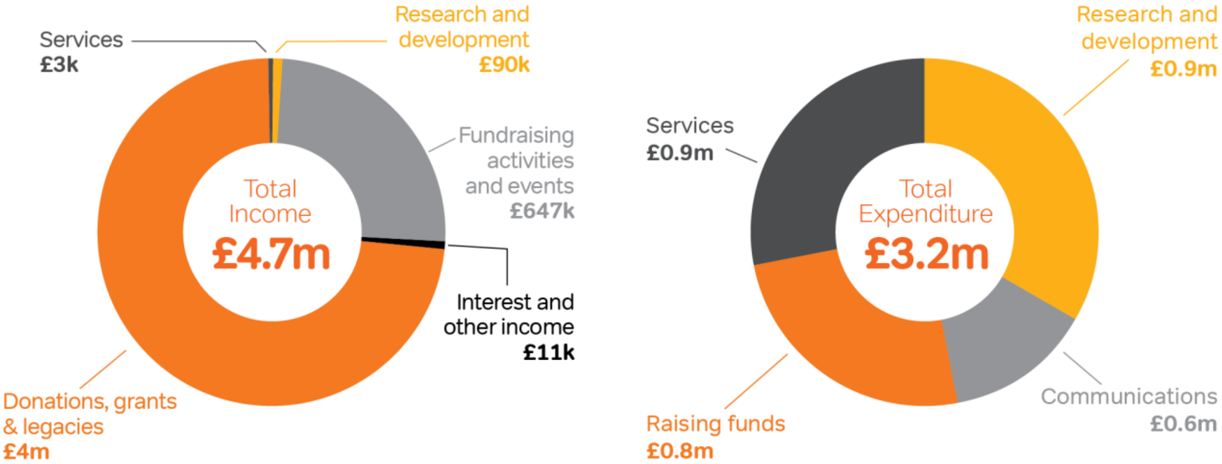
- Myeloma UK works to shape government policy across the four UK nations to recognise the needs of patients with myeloma and related conditions and create positive change
- The Myeloma UK Advocacy Panel ensures patients speak directly to decision makers in NICE and government
- The Myeloma UK Patient and Carer Research Panel integrates patient need into research design and policy development
- Myeloma UK's Healthcare Advocacy Service programmes drive improvements in clinical practice and patient-centred care
- Myeloma UK works with colleagues and stakeholders who share our vision for myeloma and blood cancer care and are committed to delivering positive change for patients

Funding our work

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

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

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



Income & Expenditure for the 12 months to December 2020

Building our brand

Myeloma UK is a trusted brand with patients, supporters, research partners and healthcare professionals. Our current audience is a limited one and committed to us butoften supports more than one blood cancer charity, hospital or hospice.

We need to grow greater recognition of our brand and the work the charity does with boththe general public and decision makers, as well as continue to explore innovative and cost-effective ways in which we can grow brand reputation and reach without losing the sense of trust our community has given us.

Measuring our success

We need to be able to demonstrate and understand the difference we make in order tocontinue to innovate our programmes and attract continued funding.

We measure our success via:

- Patient experience
- Retention of supporters
- Reach of materials and marketing campaigns
- Delivery of projects
- Growth in income

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

Post	Support Group Coordinator
Job Ref	S/2
Location	Edinburgh
Department	Services
Reporting to	Patient and Carer Support Manager
Responsible for	This role has no direct reports

Job Summary

The Support Group Coordinator will have responsibility for developing and implementing the Myeloma UK Support Group programme in line with the organisation's overall strategy, building relationships with the Support Group Leaders to strengthen ties with the organisation.

The Support Group Coordinator will be the first point of contact within the organisation for all Support Group enquiries and will have strong leadership and communication skills which are collaborative and team focused. You will be responsible for working with local groups and other local network partners to increase the reach and impact of Myeloma UK, ensuring that support groups operate in line with quality standards and follow Myeloma UK policies and procedures.

The post holder will maintain an awareness and understanding of all legislation that may be relevant to the role such as health and safety, general data protection regulation, disclosure checks etc.

The Support Groups are currently unaffiliated and run independently of Myeloma UK however we intend work more closely with the existing support groups and, where appropriate, formalise an affiliation. The Support Group Coordinator will lead on the effective delivery of this work.

In addition, the post holder will have responsibility for coordination of any volunteers who may work with the organisation in the future.

As a member of the Healthcare Advocacy Services Team, the Support Group Co-ordinator will contribute towards the delivery of the business's strategic, operational, and departmental plans.

Key Deliverables

This role may vary depending on local needs but is likely to include:

1. Myeloma UK Support Groups

- Coordinate the activity, including developing and promotion of the existing Myeloma Support Groups
- Coordinate the recruitment, induction and ongoing support of new local groups and volunteers
- Leading the groups' shared responsibility for planning and reporting income and expenditure, ensuring that our financial requirements and policies relating to groups are followed
- Ensuring disclosure checks are completed and witnessed for any volunteer roles that need them
- Lead the Support Groups' responsibility for designing and delivering activities in line with our Quality Standards so that they are safe, effective and impactful
- Research and write Support Group and volunteer policies, including risk assessments to ensure compliance with all relevant legislation such as health and safety, data protection
- Maintain regular contact with Support Group Leaders and send out promotional and information materials as required
- Work with the Marketing and Communications team to develop and implement an effective communication strategy for the Support Groups, to include both online and written materials
- Regularly refresh and update the Support Group pages on the Myeloma UK website
- Offer advice and information to Support Group Leaders to enable the development and expansion of their activities
- Identify and develop appropriate training for Support Group Leaders and deliver training or source training support where relevant
- Ensure that all Support Group activities are in line with organisational aims and objectives and that best practice, quality and high performance are being practised throughout the Support Group network
- Attend local Support Group meetings as required
- Regularly update and maintain Support Group contact records on Myeloma UK's database

- Evaluate the programme on an ongoing basis and at the end of the year to determine areas for development and improvement

- Oversee programme budgets, report performance and variances and work with your line manager to forecast, reforecast and conduct contingency planning

- Collect KPI data and evaluate all aspects of Support Group programmes and proactively report on performance and success with your team and organisation regularly and as required

2. 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 role is UK wide and will require essential travel throughout the UK, therefore the post holder must be willing to travel. A driving licence will be required for this role. Occasional evening and weekend working will be required for which Myeloma UK operates a TOIL policy.

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
Qualifications & Experience	• Educated to degree level or equivalent professional experience • Experience of successfully implementing a variety of meetings and events • Extensive project management experience, delivering successfully within tight deadlines • Experience of working with support groups and/or volunteer networks • Experience of working as part of a team to achieve service development • Experience of increasing the reach, effectiveness and impact of services • Experience of partnership working. • Clear evidence of relationship building • Experience in training or facilitating groups • Budget management and reporting experience	• Marketing and communications experience • Experience of working with a database • Line management experience • Good understanding of relevant legislation for health & safety and data protection
Knowledge	• Understanding of the needs of cancer patients and their families • Understanding of the principles of effective communication and relationship building	• Rare cancer awareness and knowledge
Skills	• Strong project management skills • Excellent written and verbal communication and influencing skills • Excellent relationship development skills	

	• Excellent presentation and negotiation skills • Ability to set priorities and work under pressure • Great attention to detail • Excellent organisation and IT skills	
Personal	• An ability to think strategically • Constant desire for improvement • Self motivated, able to work independently and take initiative • Dedicated team player • Commitment and desire to make a difference • Ability to manage a wide range of tasks and work well under pressure • Flexibility and willingness to develop and expand the role • An ability to work out of the office as required and at evenings and weekends across the UK • Driving licence	

Terms and Conditions

Post	Support Group Coordinator (12 months fixed term contract, full-time)
Salary	£25,750 - £28,066
Probation period	Three months
Hours of work	The standard working week comprises 35 hours, Monday to Friday. Myeloma UK operates a flexitime scheme and details will be provided by the HR and Operations Manager. 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.
Holidays	Full-time holiday entitlement is 30 days per calendar year, plus 6 public holidays.
Pension scheme	Myeloma UK complies with its auto-enrolment obligations and, subject to matched employee contributions, offers a 5% pension contribution to all staff.
Premises	Myeloma UK is situated at 22 Logie Mill, Beaverbank Business Park, Edinburgh, EH7 4HG.

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.

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 3 May 2022

First interviews will be held virtually on 16 May 2022

Appointment will be subject to receipt of satisfactory references.

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: www.myeloma.org.uk/jobapplicantprivacy.

Note: Myeloma UK fund research into myeloma and are 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