

Trustee recruitment pack

Myeloma UK

October 2020

Welcome

Thank you for your interest in becoming a trustee of Myeloma UK. It is my very great pleasure to introduce you the work of Myeloma UK and the community it serves.

Myeloma UK invests in driving better patient outcomes through a comprehensive early diagnosis programme, cutting-edge research, sector-leading treatment access, award-winning information and support programmes, 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.

This means our work has to begin at identification of myeloma and encompass the whole of a patient's myeloma journey, including the complicated and difficult decisions they and their loved ones will have to make on the way.

Our long-term ambition is to make myeloma history, but we recognise 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.

As trustees, we are privileged to direct an organisation of highly committed staff, led by CEO Laura Kerby and an executive leadership team of five. The new appointments we are seeking to make will strengthen and complement the skills we already have on the Board to advise and support the work they do in transforming patients' lives.

We are committed to ensuring that patients receive more effective treatments, enjoy better outcomes, and have more years with a life they love. Your expertise could help us to deliver that.

A handwritten signature in black ink that reads "Marc Gordon".

Marc Gordon

Chairman, Board of Trustees

Our long term ambition

Make myeloma history

Our purpose

To give every patient an empowered present and a hopeful future.

In 2019



Our income for the year was £4.7m

£3.7m



Our expenditure on meeting the needs of people affected by myeloma was £3.7m.



£1.2m

Our expenditure on research totalled £1.2m



From every £1 of expenditure, 79p 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. Myeloma patients 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. The pandemic continues to impact how over 40% of our patients can receive treatment and the type of treatment they can have, and every patient has had to accept changes to the way they connect with their clinical teams and the way they live their lives.

We have reviewed our strategy in the light of these significant additional pressures on our community and re-set our strategic priorities. This will enable to address the serious emerging concerns of:

- Delayed diagnosis of new myeloma patients, and the impact of that delay on their clinical 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 strategy and work

Myeloma UK works to four strategic cornerstones:



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.



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

Our uniquely focused research programme 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 Programme (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.

**Transform**the patient
experience**We will identify unmet need, improve outcomes, and ensure equal access to patient-centred 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 programme 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.

**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 programme 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 programme quantifies patient experience and need to change how patient care is designed, delivered and funded.

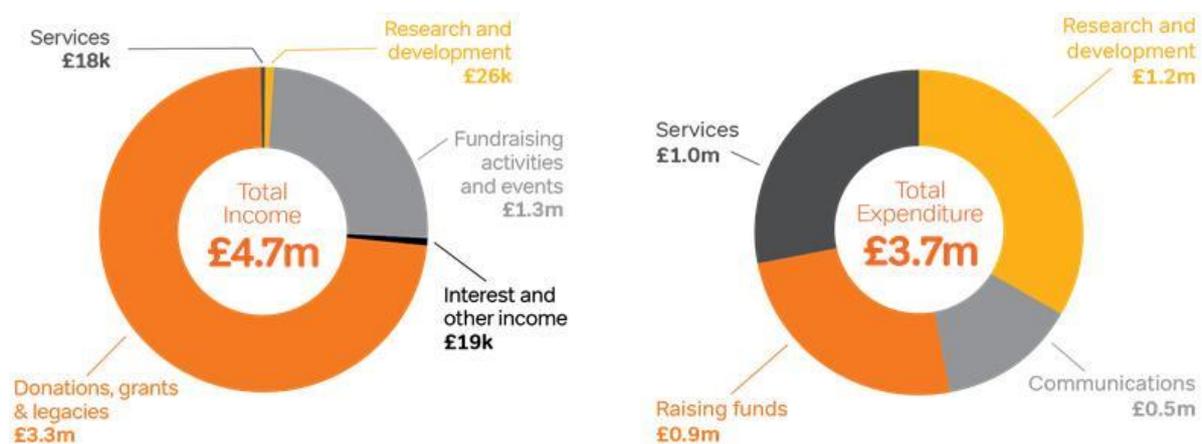
We will create a universal experience of myeloma care through our Clinical Services Excellence Programme and integrate patient preference into healthcare service design. We will influence the policy making process to ensure the needs of myeloma patients are understood and met.

Funding our work

Myeloma UK is a fundraising organisation 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 programmes.

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 organisation



Income & Expenditure for the 12 months to December 2019

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, but often 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 both the general public and decision makers and 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 to continue 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.

Trustee Role Description

Role Summary

Myeloma UK's Board of Trustees are responsible for the overall governance, financial health and strategic direction of the charity, developing its organisational aims, objectives and goals in accordance with the governing document, legal and regulatory guidelines.

As a member of the Board of Trustees, there is a shared responsibility for the strategic direction of the organisation, supporting the charitable objectives of Myeloma UK and ensuring sound governance.

In addition to the statutory duties, each Trustee uses their specific skills, knowledge and experience they have to help the Board of Trustees reach sound decisions. On this basis the Trustee will be invited to sponsor relevant board papers and/or sit on relevant Board subcommittees.

Main Duties of the Trustees

- To determine the overall direction and development of the charity through good governance, sound financial management and a clear strategy
- To ensure that the charity and its representatives function within the legal and regulatory framework of the sector and in line with the organisation's governing document, continually striving for best practice in governance
- To uphold the fiduciary duty invested in the position in a way that adds to public confidence and trust in the charity

Main Responsibilities of a Trustee

- To contribute actively to the Board of Trustees' role in giving firm strategic direction to the charity, setting overall policy, defining goals, setting targets, and evaluating performance against agreed key performance indicators
- To ensure that the charity complies with its governing document (Memorandum of Association and Articles), charity law, company law and any other relevant legislation or regulations
- To ensure that the charity pursues its objectives as defined in its governing document and applies its resources exclusively in pursuance of its objectives
- To safeguard the reputation and values of the charity
- To ensure effective and efficient leadership of the charity
- To ensure the financial stability of the charity, protect and manage the assets of the charity, and ensure the proper investment of the charity's funds
- To lead discussions and provide guidance on new initiatives, particularly in areas where the Trustee has specific skills, knowledge and expertise

- To ensure the Board of Trustees is structured and organised in such a way as to achieve effectiveness and efficiency as a governing body
- To participate in activities to promote the charity to beneficiaries and the wider public such as the annual Patrons' Briefing, patient InfoDays and other fundraising events

Person Specification - Trustee

The following are some of the skills, abilities, experience and knowledge that the organisation would expect from a Trustee:

- Commitment to Myeloma UK and willingness to devote the necessary time and effort
- Understanding and acceptance of legal duties, responsibilities and liabilities of trusteeship
- Strategic vision and direction
- Good, independent judgement
- Ability to think creatively
- Willingness to speak their mind and appropriately challenge other trustees and directors; able to make unpopular recommendations to the Board, if necessary
- Ability to work cooperatively and effectively as a member of a team
- The skills to analyse proposals and examine their financial consequence and make concise recommendations
- Experience and knowledge of basic accounting and financial management practices

Time commitment

Four Board meetings per year, plus one strategy away day. In addition, Trustees may be requested to attend relevant sub-committee meetings or other board activities as required.

Remuneration

The role of Trustee is not accompanied by any financial remuneration, although out of pocket expenses may be claimed.

Location

Myeloma UK's office is in Edinburgh. Board meetings are typically held twice per year in London and twice per year in Edinburgh. Currently all Board meetings are held virtually.

Eligibility

Prospective Trustees should be aware that the charity will need to carry out due diligence to check eligibility before appointment.

Specific Experience

Digital/IT

Role requirements

- To provide thought leadership on the role of digital for Myeloma UK (Fundraising, Marketing & Communications, Service delivery, Operations) and help build and implement this vision
- To help the charity shape our support to patients through digital channels and broaden our reach geographically
- To advise on how the charity can build a more technically savvy workforce
- To highlight the opportunities and the risks of digital for our strategy and specific projects
- To translate the risks and opportunities of digital for other Trustees, to enable the Board of Trustees as a whole to engage in an informed way
- To take the lead in evaluating proposals or projects for the Board of Trustees
- To champion the use of data in Board of Trustee discussions and in driving the delivery and improvement of (Fundraising, Marketing & Communications, Service delivery, Operations)
- To advise on medium and longer term technological trends so that Myeloma UK can build greater effectiveness and reach
- To advise on building Myeloma UK brand awareness and a stronger advocacy voice through social media
- To draw on personal networks to support the charity's work

Essential experience

- Relevant experience of digital transformation in a small or medium size organisation
- Understanding of the connection between IT infrastructure, client relationship management and digital marketing
- Programme management experience and the ability to evaluate and assess third party and internal proposals
- Experience of organisational change and agile working that accompanies digital transformation
- Innovative and entrepreneurial in approach

Desirable experience

- Experienced senior leader within the Third/ Business Sector with experience in the health or social care sector
- Experience of charity governance and working with or as part of a Board of Trustees
- Holds an attractive network which can help Myeloma UK

Specific Experience

Policy

Role requirements

- To provide strategic thought leadership to influence policy making
- To offer counsel and analysis on key health, social and economic policy announcements and proposals, and assist with evaluation of impact on Myeloma UK's programme delivery
- To offer insight into health economics, policy development and decision making processes on access to treatments and diagnostics
- To advise on how Myeloma UK can influence NHS agendas and health policy development at UK government level and within the devolved administrations.
- To support any agreed public affairs campaigning through Myeloma UK with the Director of Marketing and Communications

Essential experience

- Senior experience of working within policy across the public sector and/or the pharmaceutical and health sector
- Proven track record of influence, public speaking, and networking across a broad spectrum of stakeholders
- Understanding of governmental affairs and policy making to help the decision making of the Charity

Desirable experience

- Experience as a policy and public affairs leader within the Third Sector
- Experience of NHS bodies such as NICE/ NHS England/ Scottish Medicine Consortium
- Experience of charity governance and working with or as part of a Board of Trustees
- Holds an attractive network which can help Myeloma UK

Specific Experience

Income Generation & Philanthropy

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|-----------------------------|--|
| Role requirements | <ul style="list-style-type: none">• To support the Director of Income Generation to envision a strategic programme of activity to grow the funding of the charity• To Chair Myeloma UK's Income Generation Sub-Committee to raise high value sums and build effective individual and corporate networks to support fundraising• To champion fundraising across the charity and in particular work with Board of Trustees to establish network opportunities• To act as a fundraising ambassador for Myeloma UK, articulating the need for support to a diverse range of external audiences. |
| Essential experience | <ul style="list-style-type: none">• Able to navigate philanthropy networks and High Net Worth individuals• Able to facilitate raising high value sums and build effective networks to support fundraising• Proven track record of influence, public speaking, and networking across a broad spectrum of stakeholders• Enjoys chairing, hosting, and facilitating meetings and events |
| Desirable experience | <ul style="list-style-type: none">• Experienced Philanthropic Fundraiser within the Third Sector• Experience of charity governance and working with or as part of a Board of Trustees• Holds an attractive network which can help Myeloma UK |

Join us

At Myeloma UK, we're committed to bringing together the best and brightest people across the whole organisation. We're interested in people who have helped charities and organisations achieve their ambitions, be that through professional or lived experience. We know that it's only by bringing multiple talents into a team that we can achieve change, so we'd like to hear about what makes you exceptional - your skills, your interests, your experience and your values. We're 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.

If you think you would be a great fit for the Myeloma UK Board of Trustees, please submit a copy of your CV together with a supporting statement to Eleanor.hughes@myeloma.org.uk.

Please ensure that your application fully addresses the requirements of the role you are applying for and that you include your contact details, including a telephone number where we can reach you out of office hours if necessary.

Should you be called for interview, please let us know if you require any special provision as a result of any disability or health condition you may have. It would also be helpful if you could tell us any dates when you will not be available within the indicative recruitment timetable.

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.