

Appointment brief

Chair of Myeloma UK

February 2024

Reference: ZBNMA



Welcome from our President

Thank you for your interest in the role of Chair of the Board of Trustees at Myeloma UK, the national charity for people affected by myeloma and its related and precursor conditions.

I served as Chair of Myeloma UK until 2019 and am now its President. My connection to Myeloma UK is through my personal connection to the disease. I was diagnosed with myeloma in 1998 and was told that I had two years to live.

I engaged with Myeloma UK when I started treatment, when the charity was in the early stages of its development. The myeloma community and the charity were confronted by an almost universal absence across the board: of research, of treatments, of support, and of funding. Right from the start there was a clear attitude that still pulls through today: A total refusal to take no for an answer, combined with an unwavering focus on patients' current and future needs.

I have always seen Myeloma UK as a solution provider. We have an extremely engaged community and we are aware of the issues patients face. We leave no stone unturned in our efforts to deliver the progress patients need and deserve. From the beginning and to this day, the charity has been determined, brave, agile, and ready to start new dialogues that deliver success.

The philosophy and infrastructure we have built over the last 25 years now has new challenges ahead. Some people live longer with myeloma than they ever expected to, due to improvements made in treatment, diagnosis, and care, and for many, life expectancy has quadrupled. But at least one in ten patients die within a year of diagnosis. There is clearly more to be done and Myeloma UK is continuing to push for the changes needed to ensure every patient lives as well and for as long as possible.

Myeloma UK is treasured by the myeloma community; they are dependent on our success just as they drive our potential to be successful. Our Chair and Board, together with our amazing team at Myeloma UK, are essential to ensuring we continue to drive our organisation forward at pace and deliver for patients.



Judy Dewinter
President, Myeloma UK

Welcome from our CEO

The next Chair of Myeloma UK will be joining us at a pivotal point in our charity's history – a time of change both for people affected by myeloma and for us as an organisation. When Myeloma UK was founded, the life expectancy for a myeloma patient was between 12 and 24 months. 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.

When we first began our work, there were no bespoke treatments available to myeloma patients on the NHS; today there are nine available in twelve different combinations. Twenty-Five years ago, patients and clinicians had no clear guidelines to ensure people with myeloma received an equal standard of care. Today we have gold-standard guidelines built upon our work and recommendations.

Because we have come such a long way, we are experts in identifying where there is still much further to go. Myeloma is still an incurable blood cancer. Almost a third of myeloma patients are diagnosed through an emergency route, and one in ten diagnosed through this route die within one month of diagnosis. For high-risk patients, outcomes have not moved on in the way they have for other patients and many face short survival times post-diagnosis. So, while outcomes have improved, people living with myeloma face a whole range of new challenges, from understanding the complexities of new treatment regimens to building an emotionally fulfilled and happy life while living in long-term remission. The work we do – research, support, and advocacy - is evolving to reflect this.

Having successfully served our community for over 25 years, we are now looking ahead to how we can respond to the changing needs of myeloma patients and the people around them. Our work is always led by the needs of those people affected by myeloma and our new strategy, which was developed in collaboration with the myeloma community alongside clinical, research, and policy leaders, will roll out this year and address these emerging and unmet needs. Hand in hand with this new strategy comes a comprehensive plan to reach more people who need us, improve our engagement, and grow our income.

Joining us now, you will have the opportunity to help rewrite the future for myeloma patients and pursue a vision that has people at the very heart of it. You will be joining an exceptional team of passionate and dedicated experts eager to make our ambitious goals a reality and ready to make the next transformative strides forward in our ambition to make myeloma history. It is truly a very exciting time to join us!



Dr Sophie Castell
CEO, Myeloma UK

Change Lives Today



About Myeloma UK

For 25 years Myeloma UK has been working to make myeloma history.

Myeloma UK is the only organisation in the UK that focuses exclusively on the incurable blood cancer myeloma and its related conditions. With a turnover of £5m per annum and a dedicated staff team of 78, we are committed to improving the lives of patients and their families, as well as delivering patient-centred input into every stage of the myeloma journey.

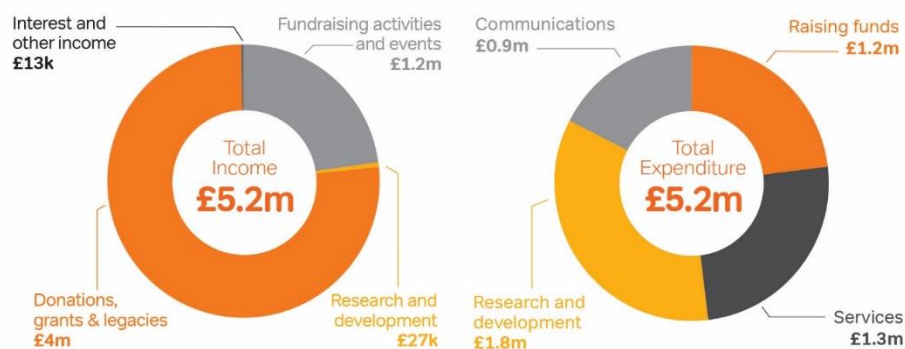
We are determined that no-one goes through myeloma alone. We are here to provide information and support to anyone affected by the incurable blood cancer, myeloma. Patients, families, friends, and carers can all draw on our information centre, support groups, discussion forums and Infoline for support when they need it.

We invest in innovative, life-changing research that helps us understand how myeloma develops and progresses, and we do this to help everyone working in myeloma better understand and meet the needs of myeloma patients and help deliver change.

We do this because we want to see a better tomorrow for patients. We represent the voices of people affected by myeloma to the government, the NHS and the wider healthcare sector to improve access to the latest treatments, remove barriers to prompt diagnosis, and improve the design and delivery of care.

Our Finances

Almost all of our funding comes from public donations and gifts in wills. We do not receive government or NHS funding.



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 History

- 2023** ○ **New strategy** approved.
- 2022** ○ **Our 'A Life Worth Living' report reveals the impact of delayed diagnosis on people's quality of life.** We call for quality of life to be front and centre across myeloma research, policy and clinical practice.
- 2020** ○ **We set up the COVID-19 hub.** Since the beginning of the pandemic, we're discovering how patients are affected and sharing advice and support.
- 2018** ○ **Nearly 500 myeloma patients take part in our landmark study** to understand which factors matter most when choosing treatment.
- 2015** ○ **We launch our Clinical Service Excellence Programme** to recognise hospitals leading the way in myeloma care.
- 2011** ○ Our scientists make a **breakthrough discovery** – finding genetic variations linked to a higher risk of myeloma.
- 2009** ○ We provide funding and support that leads to the **first guidelines** on recognising and treating MGUS and smouldering myeloma.
- 2007** ○ The first myeloma drug, bortezomib (**Velcade®**), is rejected for use on the NHS. But, together with 30,000 Myeloma UK supporters, we get that decision overturned.
- 2003** ○ **We launch our Ask the Nurse service.** Today, our nurses respond to over 1,000 emails every year.
- 1999** ○ **We fund myeloma research for the first time.** We've since invested almost £19m in new studies.
- 1997** ○ **We launch the Myeloma Infoline,** begin providing patient information, and hold our first Myeloma Infoday.

 Full timeline at myeloma.org.uk/timeline



Transforming lives together

We recognise that Myeloma UK is under-representative of groups that myeloma has a disproportionate impact on. For example, research has shown that myeloma is twice as common in people with African heritage.

It is a core tenet of our mission to set this right through a targeted and energetic programme of action and outreach, including this focused and meaningful recruitment campaign in partnership with Saxton Bampfylde.

We encourage applications from people from all backgrounds and aim to have a workforce that represents the diversity of people that we serve. We pride ourselves on being an employer of choice. We champion diversity, inclusion and wellbeing and aim to create a workplace where everyone feels valued and has a sense of belonging.

We are committed to increasing diversity and inclusion within our governance. This means reflecting critically on issues of diversity and inclusion within all that we do, identifying and taking appropriate actions to reduce inequality, and welcoming challenge.

We welcome applications from anyone regardless of disability, ethnicity, heritage, gender, sexuality, socio-economic background or other difference.

During the application process we commit to:

- Paying for childcare and care costs whilst you are at interviews
- Paying for your travel costs to the office and back for interviews
- Making any reasonable adjustments – for example ensuring we have a sign-language interpreter organised in advance if you'd like them
- Providing this document in a Word document format readily available to download.



The Role

We are seeking a dynamic, energetic Chair to join our ambitious organisation, poised for growth in impact, income and outcomes. Joining us as we launch our new strategy, you will play a pivotal role in leading Myeloma UK into the next stage of our development as we make the next strides forward in our ambition to make myeloma history. The ideal candidate will have the ability to lead through transformative change, fostering innovation, collaboration and inclusion, and will play a key role as ambassador and visible champion with partners, patients, donors and funders.

Main Responsibilities

Strategic Leadership

- Provide leadership to the Myeloma UK Board, ensuring that it is effective in performing its strategic oversight and scrutiny role so that the charity has maximum impact for its beneficiaries
- Lead the Board's overall development, fostering a culture of transparency, accountability, collaboration and open communication, harnessing different views and opinions
- Ensure the Board can regularly review major risks and associated opportunities, and satisfy itself that it can take advantage of opportunities, and manage and mitigate risks
- Ensure that Board can fulfil its duties to maintain sound financial health of the Charity

Governance

- Ensure that arrangements are in place, to enable effective governance, decision-making and compliance with legal and ethical standards, aligned to charity best practice
- Appraise the performance of the CEO and Trustees on an annual basis and regularly reviewing Board effectiveness
- Regularly refresh the Board of Trustees incorporating the appropriate balance of skills, knowledge, background, and experience needed to govern and lead the charity effectively

External Engagement

- Act as a passionate ambassador, representing Myeloma UK externally to promote our mission and raise awareness of our cause
- Develop and nurture relationships with key stakeholders, including donors, partners, industry and government agencies
- Develop a relevant network with Chair/Trustees of cancer charities to share knowledge, opportunities, and challenges
- Utilise own personal network to help progress the charity

Relationship with the Chief Executive and the Executive Leadership Team

- Develop a strong and effective working relationship with the Chief Executive based on mutual respect and trust to ensure accountability for achieving the agreed strategic objectives
- Maintain regular communication with the Chief Executive and develop and maintain an open and supportive relationship where each can share ideas, speak openly about concerns, and challenges
- Conduct an annual appraisal and remuneration review for the Chief Executive in consultation with the Nominations & Governance Committee and other Trustees
- Ensure the Chief Executive has the opportunity for professional development and has appropriate external professional support

Person Specification

What you will know or have experience of

ESSENTIAL:

- Experience of working as a senior strategic leader within an organisation with an ability to balance the pressure of now with a strategic, longer-term view
- Proven track record of galvanising stakeholders behind an ambitious strategy
- Proven track record of influence, public speaking, and networking across a broad spectrum of stakeholders
- Experience of change management and agile working
- Experience of working as part of a Board of Trustees
- Financially literate to interpret management accounts / budgeting and forecasting

DESIRABLE:

- Prior experience as a Chair
- Experience in the health or social care sector
- Brings a relevant network which can help Myeloma UK

The skills and abilities you will need to demonstrate

- Ability to empathise with and understand the needs and preferences of people living with cancer, and their families
- You are a clear and independent thinker with sound judgment and an appropriate approach to risk
- You are solution-focused, with the ability to see the big picture and be pragmatic
- You can think outside the box and help us develop and implement new ideas
- You are a highly effective communicator
- You build strong relationships through your high emotional and cultural intelligence
- You are demonstrably committed to the principles of Equality, Diversity, and Inclusion (ED&I)

How you work

- You are collaborative, highly inclusive, fostering trust and valuing difference perspectives
- You know when to challenge constructively, when to hold back, and when to support
- You guide and energise others, inspiring confidence and trust



Terms of appointment

The chair will be appointed for a term of three years and can be reappointed for one further term.

This role is unremunerated, but reasonable expenses will be paid. The time commitment for the role is approximately 3 days per month.

How to apply

Saxton Bampfylde Ltd is acting as an employment agency advisor to Myeloma UK on this appointment.

Candidates should apply for this role through our website at www.saxbam.com/appointments using code **ZBNMA**.

Click on the 'apply' button and follow the instructions to upload a CV and cover note and complete the online equal opportunities monitoring* form.

The closing date for applications is noon on **Tuesday 26th March 2024**.

* The equal opportunities monitoring online form will not be shared with anyone involved in assessing your application. Please complete as part of the application process.

GDPR personal data notice

According to GDPR guidelines, we are only able to process your Sensitive Personal Data (racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data, health, sex life, or sexual orientation) with your express consent. You will be asked to complete a consent form when you apply and please do not include any Sensitive Personal Data within your CV (although this can be included in your covering letter if you wish to do so), remembering also not to include contact details for referees without their prior agreement.





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