



### Welcome

Dear Applicant,

Thank you for your interest in joining Myeloma UK as our next Chief Executive.

Myeloma UK is the only cancer charity 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 66, 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 give patients a better present by actively addressing the barriers to early diagnosis, promoting best practice in hospital treatment, and providing bespoke information and support to patients and their families.



We create a better patient future by using our unique patient insight to broaden access to myeloma treatments, support the development of new clinical trials, and invest in research to deepen understanding of how myeloma develops and progresses – taking us closer to finding a cure.

This comprehensive portfolio of work has enabled Myeloma UK to make a dramatic impact on the lives of the 24,000 myeloma patients in the UK who place their trust in us. The average patient survival has quadrupled since we first began with just under a third of patients now living for 10 years or more post diagnosis. Treatment availability has transformed from no available bespoke myeloma drugs in the 1990s, to eight myeloma drugs in active use by the NHS that can be given in twelve different combinations.

Myeloma remains an incurable and highly individual cancer and Myeloma UK is committed to achieving further high calibre change for our community. With a clear proposition and refreshed strategy in place, the charity comes out of the pandemic with a strong understanding of where we need to address unmet patient need, and a positive financial outlook. We are now looking for a truly inspirational and visionary leader to join our team and become the next driving force in the achievement of our mission.

A background in another medical or health research charity is not strictly essential for the role, but it is likely that you have already worked at Director (or equivalent) or CEO level in an associated field. We're looking for someone with a collaborative and influential style and sharp business acumen. With outstanding communication and influencing skills and an open and inclusive leadership style, you will quickly build trust and loyalty with the team, Board, and an increasingly broad range of stakeholders, from Government to pharmaceutical firms and funders.

Myeloma UK is registered in Scotland and around two thirds of our staff work from offices in Edinburgh, including some members of our Executive Leadership Team (ELT). Our next CEO will need to have a presence in both Edinburgh and London but I do not wish to specify here where that person chooses to be based. We have adopted hybrid working and welcome applicants from across the UK who demonstrate the impact we need.

I believe Myeloma UK offers an exceptional team of passionate and dedicated experts, ready to make the next transformative strides forward in our ambition to make myeloma history. You can find out more about our programmes and achievements at https://www.myeloma.org.uk/

If, having considered the brief within this pack, you believe you have the skills, experience and qualities we are looking for, we very much look forward to hearing from you.

Simon Linnett Chair







# 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:



### We will accelerate work on earlier detection and diagnosis to make the greatest impact on the length and quality of life for 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 increase patient 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

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## 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



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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





# How we are structured

MYELOMA UK ELT ORGANISATION CHART AS AT DECEMBER 2021



Click for larger view







### Myeloma UK President

Our President at Myeloma UK is Judy Dewinter

Myeloma UK benefits from Judy's extensive network and valuable strategic thinking plus a personal connection with the high quality of patient care and support we offer.

Judy was diagnosed with myeloma aged 33. Prior to her diagnosis, she had a successful career with the world's first electronic brokerage firm, culminating in a Board role leading the European equities division.

She very quickly turned her skills towards helping improve the lives of myeloma patients throughout the UK. Her work with Myeloma UK saw her serve as Chair of the Board of Directors and, in 2019, she became the first President of Myeloma UK.



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Judy's national and international advocacy work during this time has made her

a well-known and highly respected patient advocate, and she is known for her commitment to patient centred decision making. Throughout her long association with the charity, Judy has personally prioritised speaking to patients and their families and is a familiar and inspirational figure for many in the myeloma community.

### More about Myeloma UK

To find out more please visit https://www.myeloma.org.uk/

To read our latest Annual Report please visit https://www.myeloma.org.uk/our-role/our-annual-reports/





### Role Profile

Role title	Chief Executive
Reports to	Chair of the Board of Trustees

### Role purpose

The Chief Executive works with the Board on strategy formulation, planning, resourcing, operational performance and governance of Myeloma UK. Working in close conjunction with the Executive Leadership Team (ELT), the CEO represents the organisation and its work externally.

#### Main responsibilities of the role are to:

- Provide visible, inspiring and effective senior leadership, direction and oversight to Myeloma UK and all of its staff in the development of the organisation's vision, strategic direction and implementation of clearly prioritised plans.
- Build an effective partnership with the Chair and leverage the experiences of a diverse Board in order to achieve the rapid and effective growth of Myeloma UK.
- Maintain and enhance the positioning of Myeloma UK: as an ambassador of Myeloma UK, promote and represent the organisation externally and develop and maintain good relations and effective networks with relevant stakeholders these include patients and their families and the wider myeloma community, the scientific community, industry, industry bodies (e.g. NICE), government, media, major donors and the public.
- Manage the charity in such a way that its resources are used as effectively and efficiently as possible and that the performance of investments made are measured, assessed and clearly communicated.
- Lead a high-performing, highly professional environment within Myeloma UK, with at its heart an inspired leadership culture which is challenging but supportive and empowering, and where energy, collaboration, agility, performance management and continuous improvement characterise who we are and how we go about our business.
- Inspire an effective and fully collaborative ELT, ensuring through mentoring and appraisal that each individual is performing at their optimum level, and that the team as a whole functions effectively and collaboratively across functions in line with the overall strategic direction of Myeloma UK.
- Be responsible for the overall financial health of the organisation, ensuring diverse streams of income and that, by seizing and leveraging all relevant opportunities, the overall income potential of Myeloma UK is maximised.
- Ensure a disciplined approach to budgeting and expenditure so that resources are managed effectively and efficiently, with the aim of achieving value for money in all that the organisation does.



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### Person Specification

Please respond directly to the criteria listed under Knowledge and Experience in your supporting statement. Criteria listed under Parts Two and Three will be further assessed at interview for selected candidates.

#### Part One: Knowledge and Experience

- A trusted and respected leader with a strong and successful track record of leadership at Board level, ideally as CEO or Executive Director of a comparable organisation.
- Experience of inspiring and maintaining a positive, values led working culture that delivers high performance.
- Experience of working as part of a Board or equivalent structure to shape and set organisational strategy.
- Undisputed track record in persuading and influencing key stakeholders, for example senior policy makers, politicians and other partners and stakeholders, and in inspiring changes in outlook and thinking.
- Strong financial management and planning experience, including experience of tendering, fundraising and preparing funding applications, is an asset.
- Strong organisational and senior operational management experience that sets the agenda, monitors and reports on key deliverables and provides effective and supportive oversight.

#### Part Two: Skills and Abilities

- Highly effective leadership skills: able to develop and implement organisational vision and strategic plans effectively and inspire cultural and behavioural change.
- Able to communicate and present in an impactful, engaging and effective manner with a range of different audiences within and outside the organisation.
- Outstanding interpersonal and influencing skills with personal presence that secures the trust and confidence of stakeholders, trustees, partners and staff.
- Sharp strategic planning abilities; has the financial awareness and acumen to translate strategy into performance and to make connections.
- High analytical capacity, with the ability to distil key messages from highly complex or technical management and other information.

#### Part Three: Leadership Style and Personal Attributes

• A positive and resilient driving force for Myeloma UK: a natural collaborator and alliance-builder who is open minded and will question the status quo to explore new options.

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- Sharp business acumen: sound judgement and balanced risk appetite.
- An inclusive leadership style: self-aware, grounded, open and curious.
- Uses emotional intelligence to build connection with and win loyalty from others.
- Diplomatic and confident manner that inspires confidence and diffuses conflict.
- Strong personal commitment to the mission, values and priorities of Myeloma UK.



### This role will offer

#### Salary

This role attracts a salary of circa £90,000. This may be flexible for an exceptional candidate and starting salary is dependent on experience.

#### Contract

This is a permanent full-time appointment.

#### Location

Flexibility required in meeting demands principally at our Edinburgh office and in London.

Myeloma UK is registered in Scotland and two ELT members are based full time in Edinburgh. The activities of Myeloma UK are diverse and travel throughout the UK is required to fulfil aspects of the role that are relevant to our Research, Policy and Fundraising priorities.

#### Other benefits

A contributory pension scheme based on 5% from employer and employee.







### How to Apply

If you believe you can offer the experience, skills and qualities we are seeking we very much hope you will consider applying for this role.

### To make an application, please go to https://starfishsearch.com/jobs/myeloma-ce/ and click on the apply now button, with the following prepared:

- your CV (no more than three sides)
- a short supporting statement (maximum two sides) that sets out why you are interested in joining Myeloma UK as our next CEO
- we would be grateful if you would also tell us your current salary details and any dates when you are <u>not</u> available to attend interview.

We would also be grateful if you would also complete the Equality and Diversity monitoring form on the online application process. This form is for monitoring purposes only and is not treated as part of your application.

Closing date	Monday 14th February 2022
Longlist confirmed	Mid-February 2022
First stage discussions	Late February 2022
Agreement of the shortlist	Early March 2022
Candidate assessments and informal 'meet and greet' with Chair	Mid- March 2022
Panel interviews	Late March 2022
Preferred candidates to meet with Chair and ELT members	Late March 2022
Final discussion with Chair if needed	By end March latest.





