



Trustee Recruitment Pack

Help lead the charity that stands with every person affected by amyloidosis

Amyloidosis UK is a small, patient-led charity with big ambitions. We're looking for new trustees who want to use their skills and experience to help more people get diagnosed earlier, live better with amyloidosis, and access the treatments and care they deserve.

This pack tells you about us, the role, and how to apply.

Closing date	15 th November 2026
Location	Remote / UK-wide, with occasional travel to events/in person board meetings
Time needed	Approx. 1–2 days a month
Payment	Voluntary role — reasonable expenses reimbursed



A welcome from our Chair

Thank you for thinking about becoming a trustee of Amyloidosis UK.

Amyloidosis is a rare and serious condition, caused by a build-up of misfolded proteins in the body's organs and tissues. Most people have never heard of it, many GPs rarely see a case in their whole career, and that means diagnosis is often too slow and patients can end up feeling lost in the system. We started this charity because we had lived that experience ourselves, and we knew things needed to change.

We're proud that Amyloidosis UK is patient-led. Many of our trustees, volunteers and supporters are living with amyloidosis themselves, or supporting a partner, parent or friend who is. That gives us a depth of insight and motivation that's hard to match. As we grow, we also need trustees who bring skills we don't yet have enough of on our board, whether that's finance, legal, commercial, clinical expertise, fundraising, digital, communications, or charity governance.

Being a trustee here is not a ceremonial role. You'll be genuinely useful. You'll help us decide where to focus our limited resources, hold us to account for the difference we make, and make sure the voice of patients and families stays right at the centre of everything we do.

If that sounds like the kind of challenge you want to take on, we'd love to hear from you.



David Gregory

Interim Chair of Trustees, Amyloidosis UK

About Amyloidosis UK

Amyloidosis UK is a patient-led charity that connects people, shares knowledge, advocates for those affected by amyloidosis, and raises awareness of the condition across the UK. We were established in 2019 and are registered with the Charity Commission for England and Wales as a Charitable Incorporated Organisation, and we are still a small charity which means every trustee makes a real, visible difference to what we can achieve.

What is amyloidosis?

Amyloidosis is a group of rare diseases caused by a build-up of abnormal proteins, called amyloid fibrils, in the body's tissues and organs. In a healthy body, proteins fold into the right shape to do their job. In amyloidosis, some proteins fold incorrectly and become sticky, clumping together and depositing in organs such as the heart, kidneys or nerves. Left untreated, this can cause serious and life-threatening damage. There is currently no cure, but earlier diagnosis and newer treatments can slow the condition and significantly improve quality of life, which is exactly why the work we do matters so much.

Our mission

We exist to make sure that no one faces amyloidosis without the information, support and voice they need. We work to:

- Provide clear, trustworthy information, support and advice to people living with amyloidosis, their families and carers.
- Advocate so that everyone gets a timely and effective diagnosis, and access to the best available treatment and care.
- Work closely with clinicians, industry and policy makers to widen access to effective treatments.
- Support research that advances understanding of amyloidosis and helps develop better treatments.

Our values

- **Patient-led:** people affected by amyloidosis are at the heart of every decision we make.
- **Trusted:** we give people honest, evidence-based information they can rely on, especially at a frightening time.
- **Connected:** we bring the amyloidosis community together, so no one has to face it alone.
- **Determined:** amyloidosis is rare and often overlooked; we keep pushing for change until that improves.

What we do

- **Provide information and support:** a patient information website, resources, and a moderated space for patients and carers to connect with others who understand.
- **Community and connection:** building a network of local and online support groups, events and peer support.
- **Awareness and advocacy:** working with the NHS, researchers and policy makers to push for earlier diagnosis and fairer access to treatment.
- **Research:** supporting and championing research that will lead to better tests, treatments and outcomes for patients.

The opportunity

We are looking for new trustees to join our board and help guide Amyloidosis UK through its next stage of growth. As a small charity with a big mission, we rely on our trustees not just for oversight, but for hands-on strategic thinking, sound judgement, and a genuine commitment to the people we exist to serve.

We are particularly keen to hear from candidates who can bring skills in one or more of the following areas, but a passion for our cause and good all-round judgement matter just as much as a specific background:

- Finance and treasury
- Clinical or healthcare leadership
- Fundraising and income generation
- Digital, data or technology
- Legal or charity governance
- Communications, marketing or public affairs

Role purpose

As a Trustee, you will share collective responsibility for the governance and strategic direction of Amyloidosis UK, making sure we deliver on our charitable purpose, act within the law, and use our resources wisely and well.

Key responsibilities

Governance and strategy

- Contribute actively to setting and reviewing our strategy and priorities.
- Make sure the charity operates within its charitable objects and legal and regulatory duties.
- Support sound governance, risk management and effective decision-making.
- Help monitor how well we are delivering against our strategic plan and hold the executive team to account.
- Support the long-term financial sustainability and resilience of the charity.

Bringing your expertise

- Offer independent insight and constructive challenge to board discussions from your area of expertise.
- Help the board weigh up opportunities, risks and trade-offs with confidence.
- Support the Chief Executive and staff team with advice and connections, while respecting the line between governance and day-to-day management.

Ambassador for the charity

- Champion Amyloidosis UK and the people we support, wherever you can.
- Help build relationships with stakeholders, partners, funders and supporters.
- Protect and promote our reputation and values.

Person specification

Essential

- A genuine commitment to Amyloidosis UK's mission and the people we support.
- Sound, independent judgement and the confidence to ask good questions and challenge constructively.
- Experience of operating at a senior level in your field, whether that's a profession, a business, the NHS, or as an experienced volunteer or campaigner.
- An understanding of, or willingness to learn quickly about, the responsibilities of a charity trustee.
- Strong communication skills and the ability to work collaboratively as part of a small board.
- Willingness to commit the time the role needs, and to attend meetings prepared.

Desirable

- Previous experience as a trustee, non-executive director or board member.
- Direct experience of amyloidosis, another rare disease, or long-term health condition, as a patient, family member or carer.
- Specific expertise in one of the priority areas set out on the previous page.
- Experience working with, or volunteering for, a charity or other purpose-driven organisation.
- An existing network that could benefit Amyloidosis UK, for example in healthcare, research, media or fundraising.

Knowledge, skills and personal qualities

- Good judgement and strategic thinking, balanced with a practical, down-to-earth approach.
- Ability to understand financial information and to help the board manage risk responsibly.
- A collaborative style, comfortable working with a mostly voluntary, patient-led board.
- High levels of integrity, and the ability to keep sensitive or personal information confidential.
- Genuine warmth and empathy, many of the people we support are dealing with a frightening and life-changing diagnosis.
- Commitment to equity, diversity and inclusion, and to making Amyloidosis UK's board and services open to everyone who needs them.

Diversity, inclusion and eligibility

Diversity and inclusion

We want our board to reflect the diversity of the people we support and of the UK as a whole. Amyloidosis can affect anyone, and we know that people's experience of getting diagnosed and treated is not the same for everyone.

- We welcome applications from people of all backgrounds, ages, ethnicities, faiths, sexual orientations, gender identities and disabilities.
- We particularly encourage applications from groups who are currently under-represented on charity boards, and from people with lived experience of rare or long-term conditions.
- If you need any reasonable adjustments to take part in this recruitment process, for example a different application format, more time, or an accessible interview location, please let us know and we will do our best to accommodate you.

Who can be a trustee

Charity trustees have a legal duty to act in the charity's best interests, and the law sets some baseline rules about who can serve. You will not usually be eligible to become a trustee if you:

- Are currently under a disqualification order or undertaking, or are on the sex offenders' register;
- Are an undischarged bankrupt, or subject to a debt relief order that has not ended;
- Have an unspent conviction for an offence involving dishonesty or deception, or certain other specified offences (under the automatic disqualification rules in the Charities Act 2011, as amended by the Charities Act 2022); or
- Have previously been removed as a trustee by the Charity Commission or the Court for misconduct or mismanagement.

This list is a summary, not the full legal position. If you're not sure whether any of this applies to you, or think you may need a waiver from the Charity Commission, please get in touch confidentially before applying. Having a conviction or other issue in your past does not automatically rule you out, and we would rather talk it through than lose a good candidate unnecessarily.

Safeguarding

Amyloidosis UK works with people who may be seriously unwell, and with children and adults who may be vulnerable at times. All trustees share responsibility for making sure the charity has good safeguarding practice. Therefore we will ask you to complete a Disclosure and Barring Service (DBS) check as part of your appointment.

A voluntary role

Being a trustee is a voluntary position and is not paid. This is a requirement of charity law: trustees can only be paid in very limited circumstances, and we do not currently do so. We will reimburse reasonable, pre-agreed expenses (such as travel to meetings) in line with our expenses policy. Because it is unpaid and governed by our constitution rather than a contract of employment, the role does not carry employment rights in the way a paid job would, but we take just as much care over how we recruit, support and treat our trustees.

Conflicts of interest and indemnity

As with any charity board, trustees are asked to declare any interests that could affect their judgement, and to step back from decisions where a conflict arises. Amyloidosis UK holds trustee indemnity insurance to protect trustees who have acted honestly and reasonably.

Terms and time commitment

Term of office

Typically, 3 years, with the option to serve a further term(s) subject to Board approval and re-election, in line with our governing document.

Time commitment

Trustees should expect to give around 1–2 days a month to the role. This usually includes:

- Attending online Board meetings currently held six weekly, moving to quarterly towards the end of this year.
- Taking part in occasional strategy or away-day sessions (once or twice a year).
- Membership of one Board sub-committee, meeting around four times a year.
- Reading papers and preparing properly ahead of meetings.
- Occasional involvement in events, campaigns or stakeholder meetings where your expertise or interests fit.
- A thorough induction when you join, and ongoing trustee training and support.

Remuneration

This is a voluntary role and is not remunerated. Reasonable, pre-approved expenses will be reimbursed in line with Amyloidosis UK's expenses policy.

Data protection

Any personal information you send us as part of your application will be used only for the purposes of this recruitment process, handled in line with UK GDPR and our privacy notice, and kept only for as long as necessary. If your application is unsuccessful, we will delete your details after six months unless you ask us to keep them on file for future opportunities.

How to apply

We've tried to keep the process simple, proportionate and fair, in line with good recruitment practice for charity trustees.

Please send us:

- An up-to-date CV (or a short summary of your relevant experience if you don't have one in the traditional sense, we know not everyone does, and that's fine).
- A short supporting statement telling us:
 - What draws you to Amyloidosis UK and our mission
 - How your skills and experience match what we're looking for
 - What you feel you could bring to our board

Timeline

Closing date	15 th November 2026
First interviews	W/C 23 rd November 2026
Second interviews / meet the board	30 th November 2026
Anticipated start date	January 2027, subject to formal appointment at next AGM/Board meeting

Get in touch

If you have any questions about the role, or would like an informal, confidential conversation before applying, we'd love to hear from you.

Email	info@amyloidosisuk.org
Website	amyloidosisuk.org

Join us

Amyloidosis is rare, but the difference the right trustee can make to our charity and through us, to thousands of patients and families is anything but small. If you want to put your skills to work somewhere they'll be genuinely valued, we'd love to hear from you.