20th
2005 to 2025
ANNIVERSARY

Cavernoma Alliance UK

Our Plan 2025-2030

Together For A Cure

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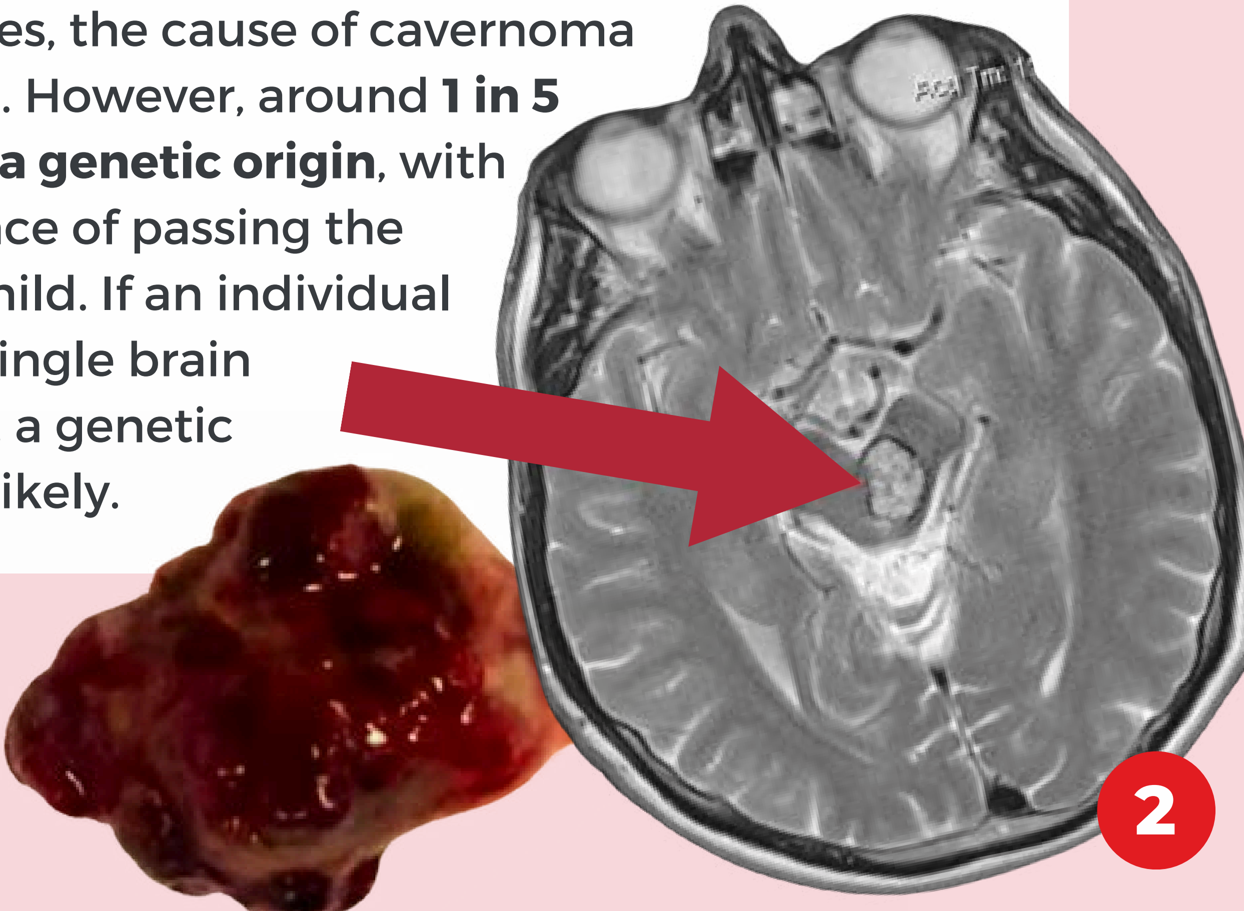
Cavernoma

About Us

Cavernomas are abnormal clusters of blood vessels with thin, leaky walls, resembling raspberries. They can develop in the brain and spinal cord and may bleed at any age without warning. Cavernomas affect around 1 in 625 people in the general population, equating to around 108,000 people in the UK.

Most people with a cavernoma remain asymptomatic. Symptomatic cavernoma is rare, affecting an estimated 1 in 2,700 people. **Symptoms can include haemorrhages, seizures, and other neurological issues**. Treatment options include monitoring ('wait and see'), neurosurgery, or stereotactic radiosurgery.

In most cases, the cause of cavernoma is unknown. However, around **1 in 5 cases have a genetic origin**, with a 50% chance of passing the gene to a child. If an individual has only a single brain cavernoma, a genetic cause is unlikely.

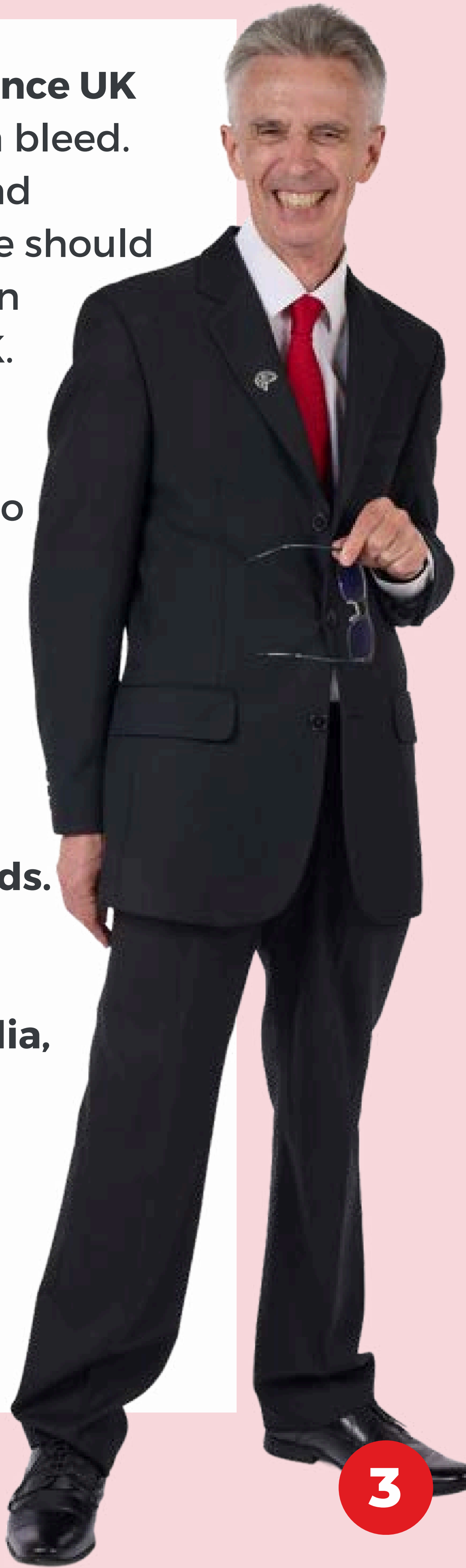


CAUK
About Us

Dr Ian Stuart founded Cavernoma Alliance UK (CAUK) after a life-changing cavernoma bleed. Struggling with a lack of information and support, he was determined that no one should face cavernoma alone. In 2005, his vision became a reality when he started CAUK.

What began as a volunteer-led helpline from Ian's home in Dorchester grew into a national charity. Today, **we support over 4,000 members** with a small, remote team of part-time staff and self-employed contractors. Volunteers remain at our core, with more than 50 running the **helpline, buddying, meet ups, online chats and medical alert cards.**

We provide clinician-approved information via our **website, social media, webinars, and annual conference**, overseen by our Advisory Board. **Committed to research**, we proudly enabled novel gene therapy studies at University College London in 2024 by securing £100,000 in funding for UCL.



Vision

About Us

Our **vision** is the big long-term goal we're working towards - it's the future we want to create and inspires everything we do.

To have a cure for cavernoma that people living in the UK can access

Vision

About Us

The word **'cure'** can mean different things. Here's what we imagine it would look like for people with cavernoma.

If treatment starts before symptoms:

- Stay symptom-free for life
- Live just as long as anyone else
- Enjoy the same quality of life as everyone else

If treatment starts after symptoms:

- Symptoms go away and don't come back, if no lasting damage from earlier bleeding
- Symptoms improve or remain stable, if there's some lasting damage
- There is no longer any risk of cavernoma being life-threatening and overall quality of life is improved

Aims

About Us

Our **aims** are the steps towards achieving our vision.

As a UK charity, our priority is supporting people in the UK. However, we recognise the need for support elsewhere, especially where no advocacy groups exist. We welcome overseas members, providing access to webinars and an initial email response via our helpline.

1. **To promote research** to cure cavernoma and advocate for UK access to new treatments
2. **To improve consistency** in the current diagnosis and treatment of UK patients
3. **To provide peer-led support** to people with cavernoma and their supporters living in the UK

Values

About Us

Our **values** are the core principles and beliefs that guide everything we do, shaping how we make decisions and support the cavernoma community.

Collaboration - Achieving more by working together
Information - Providing reliable and accurate information
Inclusion - Embracing and valuing every voice
Empowerment - Supporting informed health decisions
Trustworthiness - Acting with integrity and reliability

Welcome

About Us

When I collapsed while walking with my 10-month-old son, I was told I had a bleed on my brain but given no specific diagnosis. After an anxious wait and a struggle to be given more information, I was finally diagnosed with a cavernoma. **I didn't know what a cavernoma was and was very grateful to discover Cavernoma Alliance UK (CAUK) run by and for people with cavernoma.** They provided me and my family with clear information and access to a network of people who were feeling just how I did.

Today, I'**m proud to serve as Chair of the Board,** ensuring others continue to have the support and help they need with a diagnosis, navigating the uncertainty and importantly ensuring the right research is in place ultimately to find a cure.

In 2025, CAUK celebrates 20 years since Ian founded us to ensure no one faces cavernoma alone. Since then, we've grown into a national charity with over 4,000 members, providing vital support, trusted information, and advocacy.

This five-year strategy brings us closer to our vision – a cure for cavernoma. We've already made great strides, from our role in the CARE study to securing funding for the UK's first gene therapy research. But there's more to do. This strategy sets out our priorities: expanding support, improving care, and driving research.

Our strength is our community. Whether newly diagnosed or living with cavernoma for years, we're here for you. Together, we will create a future where everyone affected can live with confidence and hope.

Heather Dunbar
Chair of Trustees

Objectives

Our **objectives** are the specific goals we're working on to make our big vision a reality and create real change for people living with cavernoma.

Support

Every person living with cavernoma in the UK will be aware of CAUK's peer-led support, and have their request for support met as we grow existing services.

Information & Clinical Care

People living with cavernoma and the professionals supporting them will have access to reliable, accurate and up to date information about cavernoma and will use this to improve care and support.

Research

Both children and adults with cavernoma will have access through the NHS to new and better treatment options, which have proven to be safe and effective.

Underpinning Operations

CAUK will be a resilient organisation that is responsive to a changing world.

Support

Every person living with cavernoma in the UK will be aware of CAUK's peer-led support, and have their request for support met as we grow existing services.

Living with cavernoma can be challenging. The symptoms can be life-impacting, the treatment options invasive and the uncertainty of bleeds emotionally draining. **Peer-led support has been a cornerstone of Cavernoma Alliance UK's (CAUK's) work, since our founder started a helpline** providing specialist practical and emotional support informed by his own lived experiences. Over time as the charity grew so has our support, which now also includes **buddying, counselling, online support groups, in-person meet-ups, webinars, conferences, medical alert cards and volunteer opportunities.**

Today CAUK has 4,000 members but there are around 108,000 people in the UK with cavernoma. Whilst most people are asymptomatic **it is estimated that around 25,000 have symptoms, meaning our support is reaching 16% of people in need. This is something we want to change by reaching new groups of people through partnership working and online campaigning.** In turn, we will need to grow our support so we can meet the needs of more people, which will mean extending our team of 50+ volunteers - the backbone of our support.

Support

We will do this by...

- Ensuring that people searching for ‘cavernoma’ via a search engine or third-party website can **easily find CAUK online** and feel confident to click through.
- **Expanding our reach on social media** through paid advertising campaigns, proactively engaging with other organisations and social media influencers to re-share our content, and increasing our use of short-form video content.
- **Establishing referral pathways with third-sector organisations** that support people affected by haemorrhages, seizures, and neurological deficits, ensuring those with cavernoma can easily access CAUK’s peer-led specialist support.
- **Developing our programme of attendance at conferences**, advocating for clinicians to signpost patients to CAUK at the point of diagnosis.
- Collaborating with members, particularly those from minority groups, to **identify and remove barriers preventing people from accessing our support** once they become aware of it.
- Prioritising the retention of existing volunteers, recruiting and training new volunteers, and **investing in the systems and staff needed to ensure sustainable and scalable growth.**

Support

If we get this right...

- **The social and emotional well-being of people living with cavernoma will improve** as they build relationships with others who understand this rare condition, helping them feel more connected and less alone.
- **The mental well-being of people living with cavernoma will improve** as they develop new coping strategies for managing their condition day to day, reducing feelings of stress, anxiety, and low mood.
- **Life chances for people living with cavernoma will improve as they volunteer** for CAUK, gaining new skills and experiences as peer supporters and office volunteers. This will help them feel more confident and enhance self-esteem.

Information & Clinical Care

People living with cavernoma and the professionals supporting them will have access to reliable, accurate and up to date information about cavernoma, and will use this to improve care and support.

Accessing reliable, accurate, and up-to-date information about cavernoma can be challenging. People living with cavernoma may struggle to find information, as it is often buried in complex academic papers, missing from NHS resources, or not presented in an accessible, user-friendly format. For professionals, the challenge stems from the rarity of cavernoma; they may have received little training on the condition during their education or ongoing professional development. Additionally, the demands of their day-to-day work can leave them with limited time to seek out the latest information.

Our recent **"Lived Experiences of Cavernoma Patients in Europe Report, 2024"** revealed that people wait nearly a year for a cavernoma diagnosis, with a third of respondents initially misdiagnosed and nearly half rating the information provided by their primary care clinician as poor or very poor. This must change. **Ensuring easy access to high-quality, reliable, and up-to-date information informed by the latest research is essential, as it underpins effective cavernoma management.** CAUK is committed to driving this change.

165

out of the 475 respondents reported that they were first

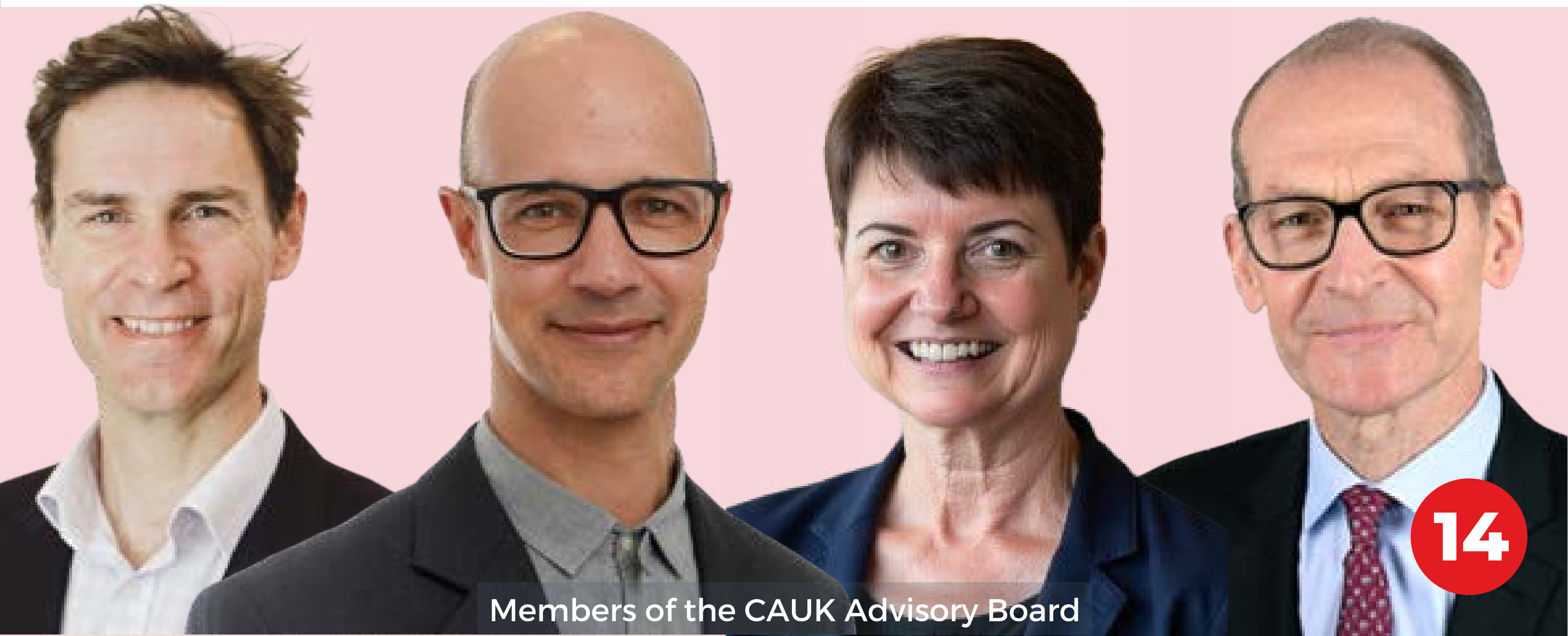
misdiagnosed

Lived Experiences Report, 2024

Information & Clinical Care

We will do this by...

- Implementing a **rolling programme to review, update, and develop new information resources,** guided by our Advisory Board.
- Establishing a programme of engagement to **encourage key stakeholders, particularly the NHS, to update and expand their cavernoma information** using our clinician-approved resources, and signposting to CAUK materials.
- **Developing 'Cavernoma Clinical Centres' and in time 'Cavernoma Centres of Excellence'** within neurology and neurosurgery centres across the UK to recognise and promote high-quality interdisciplinary care..
- Collaborating with members of CAUK to **identify ways to make our information resources more inclusive and accessible for everyone** living with cavernoma, with a particular focus on engaging minority communities.
- **Building relationships with the Royal College of Emergency Medicine and the Royal College of Radiologists to** explore strategies for reducing missed and misdiagnoses, including the potential role of artificial intelligence in imaging interpretation.
- **Investigating the use of artificial intelligence and other emerging technologies to enhance the creation and distribution of high-quality information** on cavernoma management.



Members of the CAUK Advisory Board

Information & Clinical Care

If we get this right...

- **The physical health and mental wellbeing of people with cavernoma will improve** as they and their supporters gain a better understanding of cavernoma, meaning they feel more empowered to advocate for better care.
- **The physical health of people with cavernoma will improve** as they wait less time to get an accurate diagnosis, be started on treatment and referred to an appropriate professional with expert knowledge of cavernoma.
- **The potential for health inequalities will reduce,** as information resources will be more inclusive and accessible for everyone living with cavernoma, including minority communities.

Research

Both children and adults with cavernoma will have access through the NHS to new and better treatment options, which have proven to be safe and effective.

Currently the only treatments available for cavernoma are neurosurgery, stereotactic radiosurgery or ‘wait and see’. Surgery isn’t an option for everyone, it carries risks and can be invasive and the benefits versus a non-surgical approach are not definitively known. In turn, symptom management with a ‘wait and see’ approach carries risks of a bleed and neurological deficits. **New and better treatments, including non-invasive options, are in development but not yet licensed or available through clinical trials for people living in the UK.**

If UK children and adults are to have access through the NHS to these treatment options, then it is **vital for CAUK to work closely with academic institutions, pharmaceutical companies, clinical research teams, regulators and commissioners to bring this change about.** Without this objective being prioritised, there’s a risk of people living in the UK being left-behind if treatments are developed overseas and not licensed or commissioned in the UK. CAUK is committed to prioritising this objective to ensure this doesn’t happen.

Cavernoma Gene Therapy Researchers at UCL

Research

We will do this by...

- Working closely with Professor Rustam Al-Shahi's clinical research team at the University of Edinburgh to **support the continuation and extension of 'Cavernomas: A Randomised Effectiveness' (CARE) Study** to a main-phase trial including re-purposed medications.
- Working closely with Dr Karda's gene therapy research team at University College London (UCL) to **support the continuation of funding and research into a novel gene therapy treatment for familial cavernoma**, in partnership with Uppsala University, Sweden.
- Identifying other pre-clinical and clinical researchers in the UK with an interest in cavernoma and **advocating in particular for more research in respect of diagnostic scanning and the use of artificial intelligence, hormone therapy and contraindication risks and mental health.**
- Building relationships with pharmaceutical companies who have treatments in development for cavernoma, **advocating for UK trials and licences, as well as identifying UK pharmaceutical companies with an interest in drug re-purposing** and advocating for trial funding.
- Deepening relationships with the European Cavernoma Alliance (ECA) and Alliance to Cure (US), with a particular focus on **collective advocacy for new treatment development.**
- Creating spaces to **promote early-stage researchers**, including the re-establishment of CAUK's 'CaverNoMore' prize last awarded in 2019.

Illustration of Focused Ultrasound - A Treatment in Development for Cavernoma

Research

If we get this right...

- **The physical health of people living with cavernoma will improve** as they will access new and better treatments for cavernoma as an outcome of advances in cavernoma research.
- **The mental well-being of people living with cavernoma will improve** as the need for invasive neurosurgery will reduce alongside the uncertainty of a 'wait and see' approach.
- **The potential for health inequalities will reduce**, as the best treatment options will be made available in the UK through the NHS for everyone living with cavernoma irrespective of wealth.

Underpinning Operations

CAUK will be a resilient organisation that is responsive to a changing world

Over the past few years, **CAUK has faced unprecedented challenges in an ever-changing world.** The pandemic forced us to halt all in-person support and led to a sharp drop in income as community fundraising events were cancelled. Since then, the cost-of-living crisis has significantly increased our outgoings, with rising supplier costs and the need for salaries to keep pace with inflation. As a result, in 2022–23, we were confronted with a **perfect storm of rising expenditure and falling income, alongside the turnover of key people.**

In spring 2023, we responded by **restructuring the charity**, reducing our forecast expenditure from £130,000 to £85,000 and our staff headcount from 2.4 to 1.5 Full-Time Equivalent (FTE). Since then, our finances have stabilised through **careful spending and a renewed focus on fundraising,** including the successful launch of the **Snowdon Climb for Cavernoma**, which raised £20,000 in its second year (2023–24), and the opening of the **CAUK Online Shop.**

While we began 2024–25 having rebuilt our reserves, the external landscape remains challenging, with revenue for smaller charities down by £4.6 billion since 2019–20. We are determined not to become one of the 50,000 charities that have closed their doors since 2014. Instead, we remain committed to being a **resilient and responsive organisation, adapting to an ever-changing world.**

Underpinning Operations

We will do this by...

- Diversifying our income streams to reduce our historical reliance on uncertain grant income, this will include **growing regular giving, investing in our community fundraising offer and developing new corporate partnerships.**
- When accepting funding from the pharmaceutical sector, we will conduct these partnerships with transparency and integrity. We will **strictly adhere to the ABPI Code of Practice**, ensuring donations never exceed 20% of our total income or 10% from any single company.
- **Allocating funds to invest in a paid fundraiser to catalyse our fundraising efforts,** initially on a short-term basis with consideration for a longer-term role dependent on how much income is raised in excess of their costs.
- **Taking a cautious approach to spending** by setting only a balanced budget, retaining no less than 6 months reserves, reducing expenditure in a timely manner if a deficit is forecast, and always striving for value for money.
- **Investing in our people** - including staff, volunteers and self-employed workers - ensuring training opportunities are offered, hard-work acknowledged, two-feedback encouraged and inclusion promoted to ensure our organisation is fully reflective of the people we support.
- **Learning about artificial intelligence and identifying opportunities for the organisation to make use of this** to increase our capacity and impact.
- **Investing in the systems needed to fully automate and streamline our processes,** alongside robust organisational policies and procedures ensuring statutory compliance.

Underpinning Operations

If we get this right...

- We will **have the income, people and systems needed** to deliver our strategy.
- The people working/volunteering for us will be **reflective of the UK population.**
- We will **consistently receive positive feedback** from surveyed members.