Addison's Disease Self-Help Group (ADSHG) **Strategic Planning 2025-2028**

V3.0 approved final,
April 2025

"Fundamentally we are a Patient Support Group"
Dom Hargreaves
Chair
08 February 2025
Strategic planning meeting

Charity 11179825

Contents

			Page
1.	Executive summary	-	2
2.	Introduction, goals, principles and values	-	3
3.	Information and support strategy	-	5
4.	Education and awareness strategy	-	7
5.	Research strategy	-	8
6.	Communications strategy	-	9
7.	Fundraising and finance strategy	-	10
8.	Volunteering strategy	-	11
9.	IT strategy	-	13
10.	Governance and structure	-	13
11.	Reserves and risks	-	15
	Appendix 1: SWOT	-	16
	Appendix 2: Financial projections	-	17
	Appendix 3: Questionnaire results summary	-	18

Terminology

Patient: *"Patient"* is used for convenience. We do not label a person by their condition and will use language that encourages positive interactions. We support people living with AD/AI, families, carers, and others as appropriate.

AD/AI: Refers to *Addison's disease* and *adrenal insufficiency* as appropriate

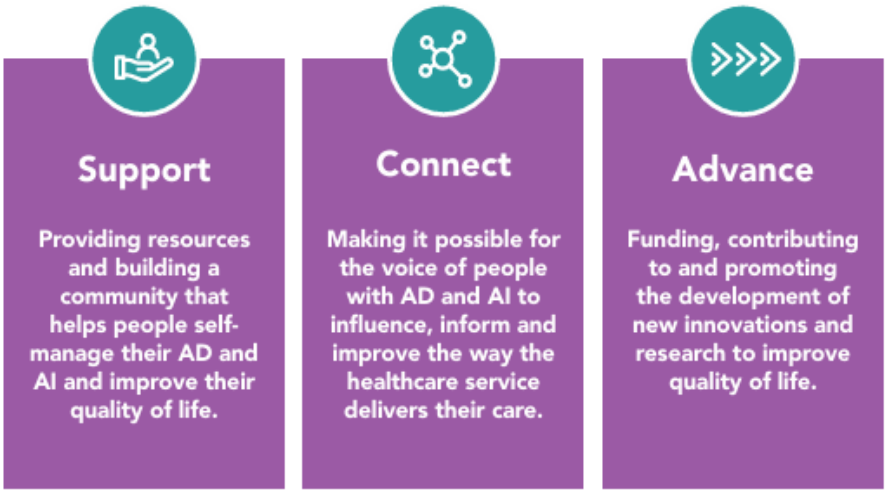
HCPs: Refers to *healthcare professionals* as appropriate

1. Executive summary

At the start of 2025, we. the Addison's Disease Self-Help Group (ADSHG), a Patient Support Group (PSG), reviewed our circumstances and environment following two years of significant change. This document has been prepared following a strategic planning meeting of the board of trustees held on 07-08 February 2025 and subsequent consultation and dialogue.

Since the last strategic review in 2021, board changes, staff changes, our transition to a post-COVID world, and progress with various threads of our work mean it is time to take stock. This resulting document provides a framework for the operations, governance, management and development of the charity for the four years 2025 to 2028. This document should be regarded as fluid; the board are keen that the charity remains resilient and flexible and recognises that not every aspiration may be realised during the period.

We remain rooted in members and volunteers (which include the board) but will remain professional in operations, influence and presentation. We retain our overarching three-thread approach to our work:



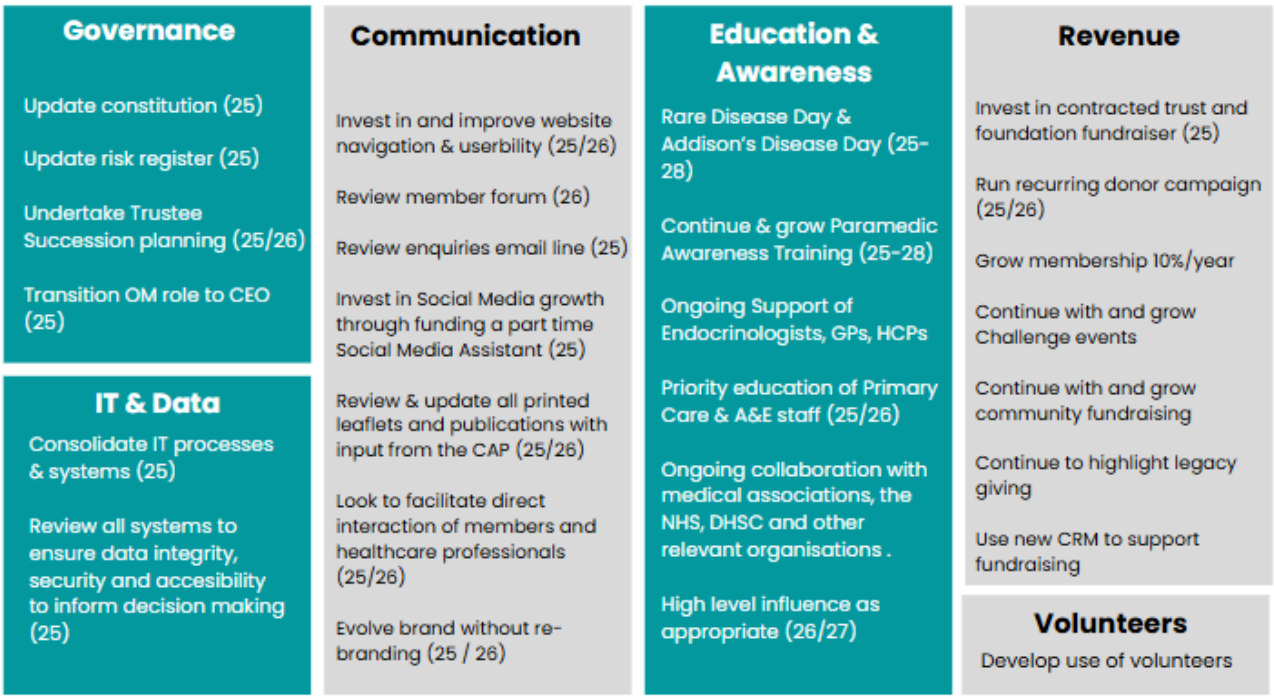
A "straw poll" of trustees, staff and key volunteers indicates a continued balanced appetite for all three areas of work, with some emphasis on the support thread.

Growth will build credibility, influence, and access to resources, but growth will not be for growth's sake; sustainability and focus on purpose is key. As of January 2025, the charity employs a full time Operations Manager (OM) and two other four-day staff. The charity also pays for services through a number of contractors. Core income must cover these costs in the period in order that the charity is sustainable in the long term and can have impact on behalf of patients. Careful development and growth of the employed team, with clear remits, is our agreed way forward.

Trustees recognise and extol a model of patient journey from undiagnosed, unaware and unprepared to the status of expert patient, able to support themselves and others and to engage meaningfully with their healthcare professional team.

The board recognises and accepts that financial commitment and a degree of risk tolerance are required if the charity is to thrive and succeed.

The summary of planned actions is as follows



2. Introduction, goals, principles and values

Purpose and vision

ADSHG is long established but was re-constituted as a Charitable Incorporated Organisation (CIO) in 2018. It exists as a well-respected Patient Support Group (PSG) working with people with Addison's disease (AD) and, as appropriate, other forms of adrenal insufficiency.

The trustees take pride in the voluntary and patient roots of the charity and commit to maintaining strong links with volunteers and members. The organisation has always existed for the benefit of members and the wider community of Addison's disease patients and this will not change.

We envision a world where Addison's disease and adrenal insufficiency are recognised early and managed effectively so that anyone affected can live confidently and thrive.

Current position

The current OM (Operations Manager) was appointed in May 2024 after a period of upheaval. The other two members of staff, managing Communications and Community Fundraising, are longer serving.

The operational focus over 2024 has been to identify the key areas that required improvement either in terms of outcome, or operational resource and efficiency. Several processes around the online shop fulfilment, the membership journey and offering, and recording meaningful financial information required early attention, which has led to some changes in suppliers and processes, and the decision to implement a charity focused customer relationship management system (CRM) which launches in March 2025 and is expected to result in a more robust membership management, with better access to data, and to introduce some areas of automation to make the administrative operations more effective and efficient at a realistic cost. As the impact of the introduction of the CRM is fully realised, this will allow for a deeper review of priorities for the charity.

In terms of finance, the charity aims for membership fees, regular donors, and individual giving to cover the cost of payroll, membership administration, infrastructure, distribution of materials, and overhead administration. Other funding should cover project work, e.g. from charitable trusts. From 2025 we will use Full Cost Recovery (apportionment) in bids to fund overhead costs incurred as part of project work.

Charitable Objects as defined in our constitution

As part of this strategic review, trustees note that our work is evolving to support people affected by secondary and tertiary adrenal insufficiency as well as Addison's disease (primary adrenal insufficiency). Whilst the causes of the adrenal insufficiency are different in each case, the treatment and management of all types have strong similarities, and it is recognised that there is a real opportunity to grow the number of people who are supported by the information and resources of the charity. This is entirely appropriate and in line with guidance from our medical advisors. Therefore, at the 2025 AGM, trustees will propose that the wording of our formal charitable objects is amended to embrace this. In addition, the opportunity will be taken to update the language used in that clause of the constitution to better reflect our approach of empowering patients.

Strategic goals

The following top level objectives have been identified for the period under consideration:

Support

- Provide the information and support needed by patients at all stages of their AD/AI journey
- Facilitate ways for people with AD/AI to support each other
- Reach all AD/AI patients in the UK, and be accessible to those from other countries
- Deliver high quality events, publications, guidance and support for patients and families

Connect

- Connect HCPs with patient insight, leading to earlier diagnosis and better care
- Increase HCPs' awareness of AD/AI and the implications for effective treatment and management of these conditions.
- Connect and collaborate with relevant organisations both nationally and internationally

Advance

- Advance patients along their journey from undiagnosed to expert patient
- Advance medical professionals' awareness of and knowledge of AD/AI
- Advance medical understanding of AD/AI
- Advance understanding about the prevention and management of adrenal crisis

And, in addition

- Enhance our impact on behalf of patients
- Grow in terms of our influence on healthcare professionals and other audiences with a duty of care for people with AD/AI
- To be amongst "best in class" in terms of clinical accuracy, governance and transparency
- To be financially sustainable
- To be recognised as the foremost UK charity and PSG for AD and AI patients

Strategic and operational decision making will continue to be driven by the support, connect, advance model and the needs of patients at diagnosis and along their AD/AI journey.

Decisions relating to direct financial support of research projects will remain primarily a function of the trustee board with input from the executive team as appropriate.

Guiding Principles

Some key principles have been adopted and will underpin strategic and operational thinking and planning at the charity. In no order of priority these are:

- Growth and change will always be driven by the charity's objectives
- We will remain a member-based PSG, driven by the needs of patients
- We will always be majority-led by people affected by AD or their families and carers
- The board will always provide clear direction to the executive team
- We will collaborate with or signpost; we will not duplicate good quality work done elsewhere
- We will operate good and transparent business and employment practices, including as regards finance, whilst retaining third sector ethos

Values

Our stated values underpin the way we work to deliver our objective. We aspire to a spirit of:

3. Information and support strategy

Online

We will maintain a comprehensive online presence, including the following:

Website: this is recognised as a trusted valuable resource by all involved and we will invest resources, including from reserves if specific funding is not forthcoming, to ensure it remains so. During 2025 and 2026 attention will be given to the navigation and "usability" of the site, to both patients and healthcare professionals. In 2026 the platform used for the site will be reviewed and potentially replaced, again to improve user experience but also to ensure efficiency in managing the back end of the site.

The site is core to the charity's branding and this will be carried through to other online presences. Use of the website (as measured by raw hits) is expected to increase year on year.

Member engagement: the member forum will continue for the first half of the period. In 2027 a full review of the usage, costs and benefits of the forum will guide future strategy. The platform will continue to benefit from the input of a small number of volunteers, and moderation by staff, and will remain focused on support for others without providing clinical advice. More broadly, throughout the period we will strive to enhance engagement with our members thus adding value to their being part of the charity. In addition to the forum and our support for social gatherings, we will provide opportunities for members to connect online through webinars and other face to face events, with focus where it could help specific groups such as newly diagnosed patients, new members and family sessions.

Social media: accounts on Linked-In, Facebook, Instagram and X will continue for the period and actively grown, a proven way to reach patients, provide signposting, and support fundraising efforts. We will continue and increase our investment in communications expertise to facilitate this. Our presence on other emerging platforms such as Bluesky will be maintained and extended as appropriate. Social media will not be used to provide medical guidance directly (one to one) but will be kept fresh with news, comment, and links to the website. Total followers across all platforms is expected to increase year on year. From 2026, funds will be made available for paid social media promotion of events, fundraising and membership.

YouTube: will be maintained and we will add regularly to patient video resources. Where possible, we will invest to improve the quality and frequency of our use of videos and reels here and across all channels.

Printed Materials

The members' magazine will continue in its recently improved A4 format twice-yearly along with the twice-yearly smaller newsletter. The current range of leaflets and other materials are under review by the executive team at the time of writing and will be updated and refreshed as appropriate in 2025, with input from the Clinical Advisory Panel to ensure accuracy. We recognise the need to take care of our planet's limited resources when considering printing volumes.

Events

Our experience delivering the 40th Anniversary roadshows informs a new approach to events. In each of 2025 and 2026 we will deliver two conference style peripatetic events, moving the formal business of the charity to a separate online-only event and thus accessible to members across the whole of the UK. After the 2026 events we will again review the events programme.

We will continue to support appropriate local support group meetings across the UK ('Social Meetings').

The Addison's Nurse project

There is ongoing recognition of the ambition to facilitate access to healthcare professional advice for the AD/AI community. However, trustees have decided not to develop the mooted 'Addison's nurse' project further in this period, as other issues now take precedence and with services now provided by other organisations the need is diminished. We will continue to look at other methods for facilitating patient/HCP interaction and will reconsider the provision of direct individual advice at the next strategic review in 2028. In the meantime, we will ask the executive team to provide evidence of need and resourcing plans.

Merchandising

The charity's recently revamped online shop will remain unchanged during the planning period. Stock will always be priced so that the shop covers its operational costs with the aim of operating at a small profit level. We note that the shop also serves an important support function supplying materials for patients. We will explore extending the stock list.

The support → gratitude → donor cycle

The board recognises that providing support to patients and families creates a virtuous circle, with beneficiaries subsequently often choosing to support the charity in return as members and donors.

Accessibility

During 2025 we will review our materials to ensure they are appropriately accessible in respect of format and language. To complement this we will look at ways at collecting information about the languages used by our members and other people affected by AD and AI.

4. Education and awareness strategy

Public education and awareness activity

Wide public awareness of AD/AI will remain a low priority due to the rareness of the disease and its limited impact on the wider community, and our limited resources. However, if an opportunity for wider exposure presents itself, we will look to embrace it if resources permit.

Rare Disease Day (#RareDiseaseDay) 28 February

We will continue to engage with Rare Disease Day annually, alongside Genetic Alliance UK and Rare Disease Day UK, and based on their themes. It is an important annual awareness and marketing opportunity for the charity, especially on social media and for our fundraisers.

Addison's Disease Day (#AddisonsDiseaseDay) 29 May

We will continue to run Addison's Disease Day each year as it is a time for our supporters to come together to raise awareness of and advocate for themselves and the community. We will encourage awareness, educational and fundraising events on the day, and we will work with HCPs to help them better understand AD and AI and the needs of patients and carers.

Support of Endocrinologists

The charity will continue to strive for strong, positive, working relationships at all levels with key HCP organisations, in particular but not limited to The Society for Endocrinology, The Endocrine Society, The European Society of Endocrinology, and The British Society for Paediatric Endocrinology and Diabetes. In working with any organisation, any influence we have will always be used to serve the best interests of people affected by AD/AI.

NHS and NICE

We will continue to engage directly with NICE and senior staff within the NHS and DHSC structures, seeking to influence these where appropriate under the guidance of our Clinical Advisory Panel (CAP).

Education of GPs

The education of GPs will remain a high priority for the charity throughout this planning period. The charity will work closely with GPs' professional bodies to create and disseminate training material at every opportunity.

Education of Primary Care and emergency services personnel

The education of Primary Care and emergency HCPs to enable prompt treatment for adrenal crisis and ensure that AD/AI is considered in other emergency scenarios is a key priority for the board with the recognition that it can directly save lives.

We will continue to deliver our proven online direct training to paramedics and will endeavour to significantly grow the number of trainees reached through these courses. We will continue to espouse the value of HCPs listening and learning from expert, experienced patients and their families.

We will engage or continue to engage with the Association of Ambulance Chief Executives (AACE), the Joint Royal Colleges Ambulance Liaison Committee (JRCALC) and the Royal College of Emergency Medicine (RCEM), always with the objective of improving understanding and always adopting a collaborative rather than adversarial approach.

The trustees note that notices of unnecessary death and prevention of death reports that arise from deaths due to adrenal crisis are a powerful tool with which to engage relevant HCPs and save lives. We also note the need to be sensitive when discussing such issues with patients and their families.

High level influence

During 2025 or 2026 we will look to engage with appropriate MPs who may be affected by AD/AI, or have (for example) had unnecessary deaths as a result of adrenal crisis occur in their parliamentary constituencies, with the potential to create an All Party Parliamentary Group (APPG) on preventing deaths due to AI and exploring other avenues for patient advocacy and influencing for positive changes in policy.

International activities

The charity will join and continue to collaborate with relevant international organisations to demonstrate solidarity, attend events, learn, and explore new ideas that may support our work. We will readily share information, materials and other resources with similar organisations in other countries whenever we can help, adopting a collaborative approach and assuming shared goals.

In 2025 we will provide grant funding (max EUR 6,000), to support the launch of a support charity in the Republic of Ireland, following our having to cease our own work there.

Though we cannot be proactive in reaching out to patients, families, and donors outside of the UK, we will welcome and accept members (digital membership only) and unsolicited donations from abroad.

5. Research strategy

Our own research

In the first half of this planning period, we will run an extensive survey of members and other AD/AI patients, gathering information on their symptoms, experiences and opinions. Funds will be made available for the required planning, detailed analysis and interpretation of this data, media engagement, and the writing of reports and opinion-forming pieces. We anticipate that this will inform project work over the rest of this (and the next) strategic planning period and could well inform and influence other organisations such as funders, research institutions, media, and healthcare bodies.

Research grants

The charity has historically run a low key, small programme of selective investments with a focus on “seed funding” projects, rather than attempting to fund major medical research ourselves.

The Trustees currently believe that information, support, education and awareness are higher priorities than significant funding of medical and scientific research per se, given our limited financial resources.

However, the current restricted funds allocated to medical research (and possibly further designated funds depending on our financial performance) will be made available for three categories of grant giving:

1. The continuation of the Annette Louise Seal memorial award to a nurse researcher at SfE, and the possible creation of our own additional annual award scheme to complement this.

2. The provision of small grants or bursaries to medical or science students in return for their writing short papers or choosing theses subjects that will stimulate student interest in the field of endocrinology and in particular AD/AI (creating the eminent endocrinologists of the future).

3. The provision of small "token" grants to research groups (either commercial or academic) developing potential treatments for AD/AI, where such funding is part of a broader package of support and our involvement and endorsement is the more significant element and will be influential in encouraging much more significant investment from major donors or venture capitalists.

To facilitate this, we will continue to accept donations to our restricted research fund during this planning period and will consider proactive campaigns to attract donations to it provided this does not interfere with our broader communications and fundraising work.

6. Communications strategy

The executive team is charged with developing a comprehensive integrated communications programme for implementation as soon as the new resource is recruited.

Objectives

- Raise awareness, across all audiences, of AD, AI, and of the charity
- Ensure information and news presented is relevant, clinically accurate and up to date
- Develop and protect the charity's brand and name
- Create and exploit media and PR opportunities
- Contribute to and promote our provision of information, support and education
- Contribute to and promote our fundraising activities

Audiences

- Patients and patients' families, supporters and carers
- Donors and potential donors
- Healthcare professionals
- Other groups with a duty of care to patients with AD/AI
- Shared interest organisations
- Media (both mainstream and specialist)

Brand

Earlier plans to rename the charity are no longer valid given our decision to formally include AI in our constitutional objects and activities. However, the brand presentation will evolve and modernise at the executive team's discretion to allow our support for people affected by all types of AI to be recognised and promoted. The colour palette and highly recognisable logo shape will remain as is for this planning period. Work will also be commissioned from our brand consultant on how this might be done. In 2028 the name of the charity will again be reconsidered in the light of our experiences at the time.

Resourcing

We will increase investment in the communications team from 2025, recognising that existing staff are under untenable pressure and that the appointment of a part time paid social media assistant or similar role, is essential to relieve this and if we are to meet our aspirations for the charity in this period. It is the board's view that relying on volunteers for this function is not an appropriate solution.

Materials

The current range of merchandise, booklets and leaflets will be maintained for this period, with review at each reprint to ensure continued completeness, accuracy and relevance.

7. Fundraising and finance strategy

We place emphasis on ensuring that the charity is compliant with the Charity Commission's "*Charity Fundraising: a guide to trustee's duties*" and our obligations to *The Fundraising Regulator*.

Trusts and foundations

Bearing in mind that charitable trusts have not been approached in a structured way by the charity in recent years, there is significant potential to secure donations from such organisations. To exploit this, and order that the charity remains sustainable as we progress our plans, we will invest in further professional fundraising expertise commencing in early 2025 and if appropriate, will also purchase access to a relevant database of charitable trusts.

From early 2025 we will develop packages of our work that can form the basis of grant applications to trusts and foundations and will adopt a *full cost recovery* methodology to ensure that grant funding contributes to covering our overheads.

Membership

Membership fees will increase slightly in 2025 and will be reviewed each subsequent year. Any future increments will be small but timely to allow the charity to keep pace with rising costs.

Membership payments will be encouraged by Direct Debit (DD). Recurring card authority will remain an option. Efforts will be made in 2025 and 2026 to migrate existing membership renewals to payment by DD to transfer as many to automated renewals as possible. We will discourage the use of cheques.

The charity will maintain its *sponsored membership scheme* at existing levels to support those unable to afford to pay.

Membership numbers (and therefore annual fee income) will rise by 10% year on year over the period from December 31 2024 figures.

Regular Monthly Giving

During the first half of the period a monthly giving campaign will be designed and introduced with a view to it generating additional funding from members and supporters which we can include in budgets from 2028.

Challenge Events

We will continue and grow our involvement in challenge events such as The London Marathon (high profile, but limited places and expensive), The London Landmarks Half Marathon, and others.

We will actively support runners, riders, trekkers and others who take on challenges independently and raise funds. We will also provide any materials, t-shirts and technology they need to support us. Targets for such fundraising will be included in the annual budget that informs the executive team.

National Lottery and other large funders

It is unlikely that we will seek to deliver any lottery-funded activity during this strategic planning period.

Legacy Giving

In the membership magazine we will regularly raise awareness of and encourage legacy giving, noting however that such programmes typically impact on income only after 5 to 7 years.

Public Appeals

Adrenal insufficiency does not lend itself well to public appeals but there may be the potential for a campaign with a good case study and specific fundraising objective – for example around saving lives. Therefore, at the time of writing, a general public fundraising appeal is not planned but the board remain open minded about investing in one if a suitable opportunity arises.

The exception to this is that if suitable celebrity endorsement becomes available, we will apply to the BBC to be featured on the Radio 4 Charity Appeal.

Major donors and philanthropists

If there are AD/AI affected established or potential major donors (MDs) identified, each will be carefully stewarded by a nominated trustee. However, during the period the charity will not be proactively seeking new MDs or developing a formal MD programme. This will be reviewed in 2028.

Fundraising Technology

The charity has recently invested in the Beacon CRM system which is transforming our use of technology in fundraising. During 2025 this will be fully implemented and our activities fully integrated with the new system. Over the remainder of this planning period this will be consolidated.

We will continue to have a presence on JustGiving and other major online platforms but with an eye on the impact of fees. We will endeavour to make it as simple as we can for donors and fundraisers to support us by providing access to platforms as required. We will continue to ensure that our giving platforms are modern, accessible and secure.

8. Volunteering strategy

The importance of volunteers is noted by the trustees. Although we plan to grow the paid staff team, volunteers will undoubtedly continue to be key to the charity's success and development over the planning period and beyond.

We recognise that the charity has a high reliance in particular on a handful of regular volunteers and that we must "succession plan" for these people in the same way as we might for paid staff.

We recognise that all volunteers differ in the commitment they can make, and in their expectations from the charity and their role.

Existing Volunteer capacities

Governance/leadership

The trustees are all unpaid volunteers. See notes in section 10.

Volunteer capacity building

Having noted that we are highly dependent on a small than ideal number of very knowledgeable and dedicated volunteers, from early 2026 we will embark on a programme of volunteer recruitment with a view to making the charity more resilient by building a close team of like-minded people willing to work alongside the executive. We will dedicate the necessary resources to this critical piece of work.

Volunteer training and agreements

During 2025 and 2026 structured volunteer induction training will be developed and implemented. This will include safeguarding, GDPR, roles and responsibilities, health & safety, and systems training. Volunteers and the charity will sign an agreement encompassing our pledges and obligations to each other. Training will be structured, and completion will ultimately be mandatory before new volunteers can work for us.

Volunteer expenses

We will budget to fully support our volunteers, and no volunteer, including trustees, will be out of pocket as a result of their working for us.

9. IT strategy

Staff computers, telephones and peripherals

The board recognises the crucial role played by IT and recognises at this review that existing staff are inadequately resourced and in some cases are using personal computers and telephones, which also introduces a GDPR risk. Thus, equipment will be reviewed at the beginning of this planning cycle; some budget for this is included for 2025 and we recognise that this may need to be increased. In future, any new staff member will be properly equipped by the charity and subsequent planning periods will include a budget for a four-to-five-year renewal cycle.

Core platform

The use of MS365 as our core system will continue throughout the period although the structure, security and servicing of the arrangement will be reviewed in 2025.

Databases

At the time of writing ADSHG is transitioning to the use of the *Beacon* CRM system which will replace or integrate much of our technology, particularly around membership, fundraising and events management. This is a major project which will take some time to consolidate and have full impact. Towards the end of the planning period this will be fully evaluated to determine whether further change or investment is required in the subsequent planning period.

Procurement

Equipment will always be purchased new. If any is offered by way of donation it will be carefully assessed first as we know this can be a false economy. Software will be purchased via Charity Digital if possible, to keep costs low. Budgets will permit the expansion of MS365 when staff, volunteers or trustees join us.

10. Governance and structure

Constitution

The board are satisfied that the constitutional model (that of a CIO) remains fit for purpose. However as noted on page 3, as part of this strategic review, trustees note that our work is evolving to support people affected by other forms of adrenal insufficiency as well as that caused by primary adrenal insufficiency, Addison's disease. This is entirely appropriate and in line with guidance from our medical advisors. Therefore, at the 2025 AGM, trustees will propose that the wording of our formal charitable objects is amended to embrace this. In addition, the opportunity will be taken to update the language used in that clause of the constitution to reflect our approach of empowering patients.

Board

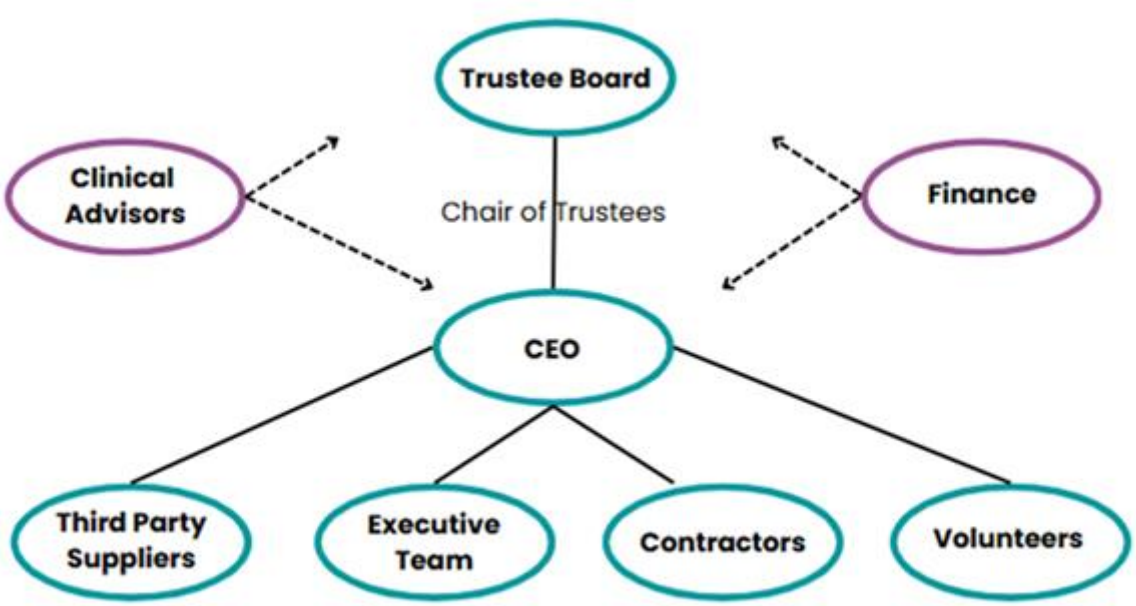
The board will always include a majority of people with lived experience of AD/AI (patients or family members) and numbers will be retained at 8 to 10. Recruitment will be based explicitly on the skills needed on the board, though the board also recognises the importance of diversity - in particular gender balance and the representation of young people.

We will adhere to good practice as described in The Charity Governance Code. Trustees acknowledge their joint and several legal responsibilities in charity law for the management of ADSHG even where tasks and roles are delegated to an officer, sub-committee, contractor or the executive team. There is a formal induction programme for trustees in place and this will be reviewed at each new appointment.

Executive and structure

We have recently reviewed our suite of policies and procedures needed to meet our responsibilities and encourage the recruitment of good people in the future.

In 2025, the Operations Manager role will be transitioned to that of a Chief Executive Officer (CEO). This role reports to the Chair unless this is delegated in the Chair's absence. Other employed staff will ordinarily report to the CEO. We are likely to continue to use contractors in some roles (e.g. finance, fundraising, IT, project work) who will report as appropriate depending on the nature of those tasks.



Investment in additional administrative support, communications support, and fundraising are deemed priority areas at the beginning of this planning period.

The board will always ensure that the executive team have priorities and plans in place, not least through this strategic plan itself. As each component piece of work or project is developed, key performance indicators (KPIs) will be agreed in order that at any review of results we will know "what good looks like".

Clinical Advisory Panel (CAP)

The charity has a number of medical and scientific advisers led at the time of writing by Prof John Wass. In the first half of this planning period this will be formalised with a brief to meet annually, clear terms of reference, a formal chairship, and appropriate protocols.

The board believes that a medic or scientist may also be a trustee provided that (1) any conflict of interest is declared and managed and (2) that trustee understands that the legal responsibilities of a trustee extend beyond their specialism.

11. Reserves and risks

Projected income and expenditure

Projected income and expenditures are both expected to rise steadily year on year during this period as we grow our resource base – primarily by investing in the team – and our activities, in particular around support, information and education. See appendix 2.

Reserves Strategy

During the period the charity will retain minimum unrestricted liquid reserves sufficient to meet normal operating costs including payroll for a minimum of six months, plus any projected winding up costs.

Investment Strategy

We will not invest in other than secure bank deposit accounts and for terms not exceeding 12 months.

Risk Management

The trustees accept that financial risks are inherent in any managed growth plan. The financial risks associated with the strategies outlined in this document are deemed acceptable given that:

- reserves exist and are adequate for the period under consideration
- further staff recruitment can be deferred if income is below objectives
- if necessary, positions can be made redundant at no cost up until two years after appointment
- we have financial reporting processes in place to ensure early warning of failures
- the charity is not exposed to the risk of significant reductions in income from one source

The trustees are aware that at this stage the organisation is vulnerable in the event of the loss of any single staff member, for whatever reason. This is identified as a high risk to the organisation and measures to mitigate this will be implemented during this period.

At the time of writing the trustees are in the process of a full review of the risk register and risk management protocol.

END

Appendix 1: SWOT

Strengths, weaknesses, opportunities and threats considered by the board in making these plans.

Strengths
- The charity is financially sound in terms of reserves and diversified income
- The charity has a committed and capable staff team in place
- The charity enjoys loyal support from its membership and wider community
- The charity enjoys credibility with healthcare professionals
- We are engaged well with respected academics, clinicians and researchers
- Support-Connect-Advance is a strong model that everyone can relate to
- There exists a committed, representative board with a variety of skills and experiences

Weaknesses
- We do not have a full understanding of our membership demographic and behaviours
- The limited level of regularly recurring income is less than ideal for an employing organisation
- Our name may be perceived by some as not fully representing our constituency
- The board lacks succession planning
- There is a heavy reliance on individual staff members and volunteers
- Staff are under overly high workloads
- The risk register requires overhaul and may identify other weaknesses

Opportunities
- There is scope to engage and exploit our connections with respected experts and events
- There is an opportunity to engage with pharma companies
- Our new systems will allow us to address problems with member data and member retention
- Supporter base offers the opportunity to increase community-based fundraising
- There is scope and monies available to improve the usability / accessibility of our website content
- We could exploit regular giving more effectively
- There are increasingly opportunities to lobby for / advocate for patients at a high level
- There are opportunities to engage with younger and 'up and coming' medics and scientists

Threats
- Misinformation abounds, particularly on social media, and requires continual firefighting
- Payroll may become unsustainable if donations are impacted by cost-of-living crisis or projected income from trust and foundation fundraising does not meet expectations
- Older demographic may imply or mean that we are out of touch with the priorities for young patients
- The charity sector is massively competitive
- Including AI in our awareness and support work could increase demand and workloads significantly
- The risk register requires overhaul and may identify other threats

END

Appendix 2: Financial projections

High level aspirations / projections for 2025 to 2028

	* 2025	2026	2027	2028
Donated income	**174000**	**190000**	**210000**	**230000**
Shop income	**34000**	**37000**	**41000**	**45000**
Membership fees	**69000**	**76000**	**83000**	**92000**
Other income	**12000**	**12000**	**12000**	**12000**
Total income	**289000**	**315000**	**346000**	**379000**
Charitable expenditure	**194000**	**203000**	**213000**	**224000**
Fundraising expenditure	**47000**	**63000**	**67000**	**76000**
Shop costs	**35000**	**37000**	**39000**	**41000**
Governance costs	**16000**	**16000**	**17000**	**19000**
Total costs	**292000**	**319000**	**336000**	**360000**
Funds brought forward	**198000**	**195000**	**191000**	**201000**
Surplus (Deficit)	**(3000)**	**(4000)**	**10000**	**19000**
Funds carried forward	**195000**	**191000**	**201000**	**220000**

***** 2025 projections are as budgeted already in detail, but rounded.

Donated income is projected to increase by 10% pa.
Shop income is projected to increase by 10% pa.
Membership fees are projected to increase by 10% pa, a combination of fee increments and growth.
Other income is projected as flat.

Charitable expenditure is projected to increase by 5% pa, but this excludes any decision in the future to invest in research projects as this is not a strategic priority.
Fundraising expenditure is projected at 20% of total income from 2026 onwards.
Shop costs are projected to rise at 5% pa.
Governance costs are projected as continuing at 5% of total income.

All projected figures are rounded.

END

Appendix 3: Questionnaire results summary

A simplified summary for reference

Q1: Do you believe that ADSHG should represent and advocate for people affected by ...

- AD (14 of 14 responses)
- Secondary AI (13 of 14 responses)
- Tertiary AI (11 of 12 responses)

Q2: What, in your view, and in no more than ten words for each, are the three biggest issues facing AD/AI patients and their families at present?

Summary top three areas of concern
(1) There are problems securing diagnosis and endo services
(2) There are problems with levels of awareness of AD/AI in healthcare
(3) There are concerns about treatments and services in an emergency

Q3: In your view, what proportion of our available resources should be spent on our SUPPORT, CONNECT, and ADVANCE threads of work?

Q4: This question asked respondents to rank a set of six hypothetical project objectives in order of priority. Weighting each response with a scores of 8, 6, 4, 3, 2, and 1 we can determine overall priority order. This is based on analysis of 14 responses. The top two clearly stand apart from the other scores, the latter four are much more evenly balanced.

85 Points: Improve communication and understanding with and between all healthcare professionals involved in the diagnosis, treatment and care of AD/AI patients.
68 Points: Enhance direct support to patients and families, e.g. through counselling, helplines, more resources, and education.
48 Points: For our beneficiaries, improve access to and the quality of information available about AD/AI, its management, and treatment.
45 Points: Grow awareness of AD/AI with broad audiences such as care staff, schools, universities, large employers and/or the general public.
44 Points: Identify and advocate for the wide implementation of a simple, safe, reliable method of monitoring and managing steroid levels.
42 Points: Support medical research into causes and mechanisms of AD/AI (i.e. furthering our scientific/medical knowledge).

Q5: Q5 asked respondents (14) to list three things the charity does well.

Q6: Q6 asked respondents (13) to list three things the charity could do better.

In both cases a large number of responses were provided to trustees – too many to list as part of this document but retained on file. Responses were very mixed and in many cases contradictory, but highlighted broadly that the priorities for respondents remains very much with information, support, engagement, connectivity and collaboration.

END