

Standing Tall



Introduction

It was an honour to have been appointed CEO of Scottish Huntington's Association at the beginning of financial year 21-22.

One of the first items in any new CEO's agenda is the development of a fresh strategy. In SHA's case it will be the first publicly available strategy in our history.

Whilst consulting to ensure we got this right, the intervening period was one of steady, sensible, organic change that strengthened our foundations and was instructive about just what we are capable of achieving as an organisation. Working together we have:

- Introduced a new Extended Leadership Team (ELT) and Senior Leadership Team (SLT) structure that works more openly and collaboratively with a refreshed Board of Trustees, and its new Research, Finance and Governance sub-groups.
- Appointed a new Vice Chair, Secretary, Treasurer and Auditor
- Held our first staff survey in many years and introduced monthly all staff meetings to improve joint working throughout the organisation.
- Secured our highest ever income total of £1.82m.
- Invested in our first ever full time in house Communications Lead to drive forward crucial improvement in our internal and external communications.
- Completed a brand refresh to better highlight the expertise, professionalism and impact of our organisation.
- Invested in the essential infrastructures of HR and IT support for the first time.
- Introduced a National HD Specialist service, resulting in nationwide HD Specialist Support for the first time.
- Upped our engagement with high level decision makers, including parliamentarians at Holyrood and Westminster. This included securing record-breaking cross party support at the Scottish Parliament for an expansion of HD Specialist Services.
- Secured the appointment of new HD Specialists and HD Clinical Leads.
- Ensured that May 2022 was our best publicised and most successful HD Awareness Month ever, culminating in our Dance 100 takeover of Glasgow's George Square.
- Developed a series of live webinars to engage Huntington's families online when physical meet-ups were not possible due to the pandemic.



- Increased our collaboration with Huntington's disease associations throughout the UK, Ireland and Europe.
- Expanded our engagement with pharmaceutical companies who are working to find a treatment for Huntington's.
- Held our most highly rated Family Gathering to date.

To have delivered all of this during such a short period of time, and without a formal strategy in place, confirms what a formidable fighting force we are for Huntington's families. We are a large and powerful charity that - however - all too often incorrectly thinks of itself as a small charity, and lacks self-belief about what it has achieved, and what it can achieve. This must change. We need to become a large charity that *knows* it's a large charity, and acts with the confidence and self-regard that comes with that knowledge. We want other charities to look to us as a role model - which they will do once they know just what we deliver for our community.

To do this we need to turn up the volume. We need to think bigger. We need to ensure we are standing tall to deliver the best possible outcomes for Huntington's families.

That's what this strategy is all about. Delivering the best possible outcomes for Huntington's families.

Working together, standing tall, we will deliver.

Alistair Haw
Chief Executive



1. We will increase awareness of Scottish Huntington's Association

Scottish Huntington's Association is the only charity in Scotland that's exclusively dedicated to fighting for the best interest of Huntington's families. Since its launch in 1989 we have achieved so much to drive up standards of care and support, but still too few are aware of our services and achievements. We need to maximise awareness amongst families, stakeholders and decision makers to increase knowledge of our services and expertise.

To do this actions will include:

- Increasing investment in our communications function to maximise public exposure
- Developing ambitious targets to increase opportunities to view our charity, its services and its achievements
- Reviewing and refreshing our mission and values
- Continuing to update, strengthen and roll out our new brand identity and promotional merchandise
- Launching a new website that showcases all we do
- Developing our engagement with celebrity and VIP ambassadors to champion our cause
- Increasing joint working with like-minded charities and campaigning bodies to deliver the best outcomes for families



“I want more people to talk about Huntington's disease and how it affects them and their families. I know I can't miraculously raise worldwide awareness myself but if people put in a bit of effort, no matter how big or small, like taking part in a news article or chatting to someone about Huntington's disease and the work of Scottish Huntington's Association that really helps.”

Sarah Mitchell, family member, Perthshire



2. We will enhance knowledge of Huntington's disease

Evidence suggests relatively high levels of awareness of the term Huntington's disease, but low levels of awareness of what it is and how devastating it is for families. We need to start telling the truth about Huntington's disease to raise awareness and support from key stakeholders and decision makers. There is nothing to gain from seeking to hide or sugar coat the harsh realities of Huntington's. We need to tell the unvarnished truth, and wake people up to the scale of need and the volume of support required.



To do this actions will include:

- Working with families to identify powerful case studies within each NHS Board area that illustrate the real impact of each stage of HD, including advanced and end of life stages for both adult and juvenile Huntington's disease
- Utilising these case studies in the media and social media, and highlighting to key decision makers such as funders, government, politicians and health and social care professionals to build the case for change
- Conducting regular awareness surveys to determine movement in knowledge of Huntington's disease as a result of our work



"So many people, including some medical professionals, don't know much about Huntington's disease so I keep having to explain what it is and how it affects me. I find that really difficult and frustrating. And I see how Huntington's disease changes people. My mum can't control her movements, she uses a wheelchair and her symptoms are really severe. I worry I'll be the same."

Sean Graham, former university worker, Edinburgh





3. We will grow our charity to meet the needs of the future

Over the years staffing in our service teams has grown considerably. We need to invest in our National Office infrastructure to ensure it has the required resources to support and further grow these services to the benefit of families.

To do this actions will include:

- Developing a new Income Generation Strategy to ensure sufficient resources to support Huntington's families into the future
- Reviewing, restructuring and investing in all National Office functions required to grow the charity and everything it does to campaign for and serve families
- Expanding our Board of Trustees to ensure we have a full range of skills required to deliver strong governance and ensure our charity remains in a strong and sustainable position
- Continuing to develop a culture that ensures our full staff team is invested in our strategy and empowered to deliver for Huntington's families



“Since its foundation, Scottish Huntington's Association has made a real and increasing difference to Huntington's families, but we know there is still more we can do. I am confident this ambitious, realistic and persuasive strategy will have the right effect out there in the wide world while maintaining the Scottish Huntington's Association ethos of blending a warm personal touch with high-quality professional expertise. It's a privilege to be part of such a committed group of people in this work.”

Professor Lorna Milne, University of St Andrews, Trustee and family member

4. We will expand access to specialist care and support

Pillars one, two and three of our strategy are all about putting us in the best place to deliver on pillar four – the most important, and our reason for being.

Thanks to the hard work, determination and ingenuity of our staff and families over many years, large areas of Scotland have access to an HD Clinical Lead and an HD Specialist, in addition to our national Youth and Financial Wellbeing Services. Our goal must be to ensure that every Huntington's family in every NHS Board area has sufficient access to all of these vital services. This will require the development of completely new services, and the expansion of others to meet rising demand. We also need to significantly increase vital peer to peer support networks.



To do this actions will include:

- Sustaining strong personal relationships with key personnel at every NHS Board throughout Scotland, ensuring they know Huntington's disease and the needs of their local community
- Undertaking regular audits of all Huntington's services throughout the country to determine service gaps
- Working with Huntington's families, MPs and MSPs, celebrity supporters, clinicians, media and all supporters to campaign for new specialist services where they are required
- Investing in and expanding our network of support groups throughout Scotland
- Using our world-leading Care Framework and the might of our expertise throughout our movement to campaign tirelessly for the best possible outcomes for Huntington's families, everywhere



“The support delivered by specialist services such as the SHA can be the difference between families coping and not coping. SHA continues to highlight the challenges that specialist staff face due to the significant increase in cases over the years. However, that is still not reflected in the availability of resources, with some areas having no specialist services despite the strides that we have made.”

Gavin Newlands MP, speaking in UK Parliament

5. We will ensure strong participation within global research activities

Despite some setbacks in recent years we remain in an era of optimism for Huntington's research. Scottish Huntington's Association is determined to play its part in this global battle to improve understanding and find a treatment.

To do this actions will include:

- Developing strong links with all relevant research agencies to ensure the voices of Huntington's families are heard
- Ensuring our staff and Huntington's families are kept informed of research and clinical trial opportunities, and are supported to engage within them
- Being prepared to campaign for new treatments to be accepted for use on NHS Scotland as and when licenced
- Developing evidence on the saving to funders of providing HD Specialist services, in terms of preventing crisis situations



“We’re starting to see incredible scientific discoveries that we only know about because so many families are taking part in research. It is entirely possible that there are people walking around with gene therapy in their nervous system who are experiencing the effects in their body of the first effective treatment for Huntington’s disease.”

Professor Ed Wild, Associate Director of University College London
Huntington's Disease Centre and Editor in Chief of HD Buzz



