Research and Development Projects IMPACT REPORT

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We are Scotland's Health Charity

Foreword

As every page of this Impact Report reveals, huge strides are being made towards ridding Scotland of an unenviable reputation for the poor health of its citizens. Across the board, significant advances have been achieved in terms of research, treatment, care and, perhaps most important of all, prevention of illness and disease.

So much of this progress has come as a direct result of the tireless efforts of Chest Heart & Stroke Scotland (CHSS), through their initiatives, services, campaigns and in their groundbreaking work in partnership with others – other charities, hospitals, universities, clinical specialists and voluntary groups throughout the country.

Much of this work has extended research, treatment and care into new areas, bringing hope and help to previously neglected sectors of the community. The item on Page 12, for example, shows how CHSS has been reaching out to young people affected by stroke. Like so many services instigated and supported by the charity, this is setting standards recognised on an international level. Another vivid example is the stroke4carers package, discussed on Page 11. Since it was developed a little over four years ago, it has been accessed by more than 200,000 people in 176 countries.

We place great importance on research within Scotland – all of these projects will not only improve Scotland's health, but will also help to enhance further our growing reputation as a global centre of excellence for clinical research.

Although we may never be able to eradicate these illnesses and conditions completely, we can continue to strive towards improving the quality of life for those affected and their families.



Dennis Robertson MSP, Chair of the Cross Party Group for CHD & Stroke

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Time is critical – each minute of delay reduces the casualty's chance of survival by 10%.

RESEARCH PROJECTS

Improving Scotland's rate of survival from out-of-hospital cardiac arrest (OHCA)⁽¹⁾

A cardiac arrest occurs when the heart suddenly stops beating completely. Unless immediate help is given – cardio-pulmonary resuscitation (CPR) and defibrillation – the patient will die. In the UK, only some 5% of people affected by OHCA survive to be discharged home from hospital.

Over the past five years, CHSS has been developing a program with the Resuscitation Research Group at the University of Edinburgh, which is revolutionising treatment and substantially improving survival rates in the City of Edinburgh. Beginning with a Research Fellowship exploring the potential for therapeutic hypothermia to extend the 'window' within which treatment could be provided, this has developed into a joint programme with the emergency medicine team and the Scottish Ambulance Service, involving service redesign and specialist training – the 3RU (Rapid Resuscitation Response Unit) programme.

Key features of the approach have been the use of innovative video technology to provide immediate feedback and expert support to ambulance personnel at the scene, and recognition of the importance of leadership skills in ensuring the best possible response to the emergency.

The outcome has been a tripling of the survival rate from OHCA in the Lothian region, to a level comparable with the best in the world. The programme is now being extended to other urban areas in Scotland, beginning with the Glasgow area, and is being adapted to suit the needs of rural and remote areas. Building on this success, the Scottish Government has developed a national OHCA Strategy, launched in 2015, with the ambition of transforming Scotland's record from one of the worst in Europe to a world leader, saving 1,000 lives by 2020.

The CLOTS study: Clots in Legs or sTockings after Stroke⁽²⁾

Even with shorter hospital stays, stroke patients in the acute phase of treatment are still at significant risk of developing a deep-vein thrombosis (DVT). This can lead to a blocked blood vessel in the lungs (pulmonary embolism) which can be fatal. Until the CLOTS trials, graduated compression stockings (like flight socks) were widely used in stroke patients, even though they had only been shown to be effective in patients having surgery.

CHSS funded the start-up phase of the CLOTS trials which were coordinated by a research team at the University of Edinburgh and which have included more than 8000 patients in total from nine countries since 2002. The CLOTS trials have shown that graduated compression stockings do not prevent DVT in stroke patients but do cause significant skin damage. This ineffective and potentially harmful treatment has now been largely abandoned across the world. However, the latest phase of the CLOTS trials, CLOTS 3, showed that leg sleeves which actively squeeze the legs to improve blood flow, a treatment called intermittent pneumatic compression (IPC), reduce the risk of DVT by over 30%, and moreover actually increase the chances that a stroke patient will survive the stroke by about 15%.

This simple, effective treatment is now recommended by the Scottish Intercollegiate Guidelines Network (SIGN), and most other international stroke guidelines. CHSS have worked with the research team to develop an online training resource (www.stroketraining.org) to help nurses apply IPC in stroke units. Once implemented worldwide, this treatment will prevent DVTs in many thousands of patients and will help save thousands of lives.

> 10% of patients will develop a DVT within the first 30 days of their stroke, and 1.5% a pulmonary embolism.

Changes in the prevalence of childhood asthma over 50 years⁽³⁾

The Aberdeen Schools Asthma Survey (ASAS) was first undertaken in 1964 and was repeated in 1989 and every five years since, making it the longest-running survey in the UK and one of the longest in the world. During that period the prevalence of the condition in children of secondary school age has changed

dramatically – from 4% in 1964, to 28% in 2004, before dropping back to 19% at the last survey in 2014. This pattern is reflected in similar surveys from elsewhere in the UK and overseas, and has highlighted the burden of asthma on modern children and also their parents, health professionals and the education system.

Having supported the programme previously, CHSS funded the latest survey, undertaken in 2014 by the Department of Child Health at the University of Aberdeen. As well as the standard survey, data has also been collected on parental asthma and prevalence of other allergic conditions, including eczema and hayfever. This additional data has allowed trends in asthma to be placed in the context of changes in key aspects of the environment to which children have been exposed.

The outcome is a unique insight into trends in childhood asthma over half a century and the dynamic relationship between asthma and factors including eczema, obesity and second hand smoke exposure. This internationally recognised study has identified how childhood asthma , although now thankfully falling back from its peak, still affects approximately 20% of the UK population, and has helped better understand the drivers for changing asthma prevalence.

The outcome is a unique insight into trends in childhood asthma over half of a century.



'I think the robotic arm therapy has speeded up my recovery. It was good because you had to concentrate on the movements on the screen, as well as practise your handeye coordination.'

Robotic Therapy Early After Stroke Events (RTEASE)⁽⁴⁾

Up to 40% of stroke patients are affected by residual disability after their stroke, and impairment of the upper limb is one of the most common contributing factors. Recent developments of robotic therapy systems have been shown to be helpful in long-term recovery, to be tolerated by patients, and to be cost-effective compared to 'traditional' one-to-one physiotherapy. However, there is no evidence as yet as to whether robotic therapy will be acceptable and effective in the immediate aftermath of a stroke.

With the support of CHSS, a team at the Western Infirmary in Glasgow is testing these systems, developed in partnership with the Massachusetts Institute of Technology (MIT). Patients are recruited within seven days of their stroke and have three hour-long sessions per week, for four weeks. Tasks include circle drawing, reaching targets, and holding / moving against moderate resistance. Patients' limb function and wider functional capacity are assessed after one and three months.

The outcome will demonstrate whether robotic therapy is effective, and tolerated by patients, in the early stage after stroke. If successful, this will not only improve patients' functional capacity, but should also prevent weaknesses becoming chronic, and more difficult to treat later on. As these machines become more widely used, the costs are likely to reduce, and generate savings compared to the use of scarce, highly-skilled physiotherapy resources.

Identifying why South Asians are at such high risk of heart disease and diabetes⁽⁵⁾

It has been known for more than half a century that people of South Asian origin, especially South Asian men, are at much greater risk than those from other ethnic groups of developing heart disease and diabetes. For example, deaths from coronary heart disease in young South Asian men are at twice the level of those for Europeans; heart attacks occur on average 10 years earlier, the rate of type 2 diabetes is five times as high, and diabetes develops at much lower obesity levels than in Europeans.

What is not known is why these huge differences occur. A CHSS Research Fellowship at the Cardiovascular Research Centre of the University of Glasgow is dedicated to answering this question. Using matched samples of South Asian and European men, the study is using a novel method of measuring thickening of the arteries in the neck, and fat and muscle composition. These are all proven indicators of heart disease risk, and can then be related to detailed findings of sugar control, fat content, fitness and activity levels.

The outcome will be a much greater understanding of precisely why people of South Asian origin, and men in particular, face such a high lifetime risk of developing heart disease and diabetes. This will enable targeted, culturally-specific lifestyle advice to be offered, on issues such as lowering body fat mass, and maintaining and increasing physical activity levels.

'For the first time, through research funded by CHSS, we have suggested that fitness, rather than fatness has a greater effect on diabetes risk in South Asian men living in Scotland.'

'We are really excited about how this study could change management of patients with bronchiectasis.'

Can bacterial load predict exacerbations in bronchiectasis?⁽⁶⁾

Bronchiectasis is a chronic lung disease caused by permanent damage to the airways. About 5,000 people are affected in Scotland. Bronchiectasis can affect people of all ages but the average age of patients is in the mid 60s and it affects slightly more women than men. Symptoms include daily cough, excess sputum production, and recurrent chest infections. Exacerbations, which average about three per year in patients severely affected, are extremely distressing, and can lead to emergency hospital admissions.

At present there are no clear evidence-based guidelines on when these exacerbations should be treated with antibiotics, and there is concern that this leads to over-prescribing, with obvious implications for build-up of antibiotic resistance. CHSS are funding a Research Fellowship at the Department of Respiratory Medicine, Royal Infirmary of Edinburgh, in a study to monitor the bacterial load in the sputum of patients with an exacerbation, to help define when antibiotic treatment is necessary and effective in reducing symptoms.

The outcome will be much clearer scientific guidelines for treatment, such as already exist for, for example, urinary tract infections. For patients, it will lead to individualised therapy, reduced side-effects and improved outcomes. The study will also add to our knowledge of a neglected and under-researched condition, and, like all CHSS Research Fellowships, provide an excellent training opportunity for a young doctor to develop a career in medical research.

TASCFORCE: Tayside screening for risk of cardiac events⁽⁷⁾

Scotland's traditionally high rate of coronary heart disease is declining, but still remains above the UK and European average. Prevention provides the best chance of the optimal outcome.

'It's amazing what they discovered*. I feel they saved my life because I went along for these tests.'

Working with the Souter Foundation, CHSS have facilitated a major screening campaign based at Dundee University's Institute of Cardiovascular Research. More than 5,000 volunteers with no previous history or symptoms of heart disease underwent traditional cardiovascular screening, with over 1,500 participants undergoing novel screening using whole-body MRI (Magnetic Resonance Imaging) scanning. Although the full outcomes will not be known for at least 10 years, the study did reveal approximately 8% of those screened with undiagnosed high blood pressure or high cholesterol (blood fat). All were referred to their GP for further investigation and management to reduce their risk of developing cardiovascular disease.

Of those whose blood glucose was tested, 7% were found to have undiagnosed diabetes, with a further 12% requiring further assessment allowing for early preventive actions to be taken. For those undergoing MRI, 32 showed either previously unrecognised ('silent') heart attack, abnormal structure of the heart and peripheral blood vessels and non-vascular benign and malignant masses elsewhere in the body. This allowed earlier intervention than would have occurred had the volunteer had to wait until symptoms developed.

The longer term aim of the TASCFORCE project will help determine which imaging measures and which blood tests predict cardiovascular disease in the future, and will allow us to target early treatment of risk factors at those most likely to benefit.

[* a previous 'silent' heart attack and blocked coronary artery]



STARFISH – encouraging physical activity in stroke survivors⁽⁸⁾

People recovering from a stroke are often affected by reduced mobility, muscle deconditioning and post-stroke fatigue. This can easily lead to an increasingly sedentary lifestyle, reduced social activities, increased risk of falls, development of heart disease and even another stroke.

Through an Action Research grant, CHSS have supported an innovative project based at the School of Nursing and Healthcare, Glasgow University, which aims to break this vicious circle and encourage stroke survivors living at home to be more active.



STARFISH is a mobile phone application designed to help people increase their levels of physical activity in an interactive and gently competitive environment. Each individual in a group of four, recruited from CHSS stroke support groups, is represented by a fish in a tank on their mobile phone display. Sensors record the number of steps each person takes per day, and as they walk their fish blows bubbles and swims faster. Also as each person reaches their individual step target, their fish fins and tail grow, which can be seen by all members of the group.

The project was taken up enthusiastically by the participants. The outcomes of the pilot study showed that using STARFISH over the six week study period increased physical activity by an average of 46.6%, walking time increased, and post-stroke fatigue reduced. CHSS previously funded a larger study, but this approach

has already shown its potential to improve physical activity and long-term health outcomes after stroke.

'What I've noticed is that I can walk longer distances. I think I've lost a bit of weight as well, and I find that my hips don't get so sore when I'm walking now.'

DEVELOPMENT PROJECTS

STARs – Stroke Training and Awareness Resources

Worldwide research, including studies funded by CHSS, has demonstrated clearly that treating people affected by stroke in specialist units saves lives, reduces disability and enables more people to return to their own homes, families and communities. One of the most vital components of a successful stroke unit is training and education for staff, but finding the time and resources to provide such training can be a real challenge.

To help meet this need, CHSS has developed STARs – Stroke Training and Awareness Resources. This provides interactive, web-based training in a range of modules, extending from the basic core competencies of stroke care, to challenging and complex issues such as thrombolysis (clot-busting therapy), pain management and end-of-life care. It has been developed in partnership with health and social care professionals, patients and carers from throughout Scotland, and specialists in learning technology at the University of Edinburgh, and with funding support from the Scottish Government.

In conjunction with other CHSS training initiatives, and the work of local CHSS stroke education facilitators, STARs has become the bedrock of specialist stroke training in Scotland. Staff who complete a module successfully can download a certificate – formally recognised in the Scottish Stroke Improvement Programme. More than 20,000 certificates have been issued in Scotland alone.

In addition, as a web-based learning resource the impact of STARs has been felt worldwide. The core and advanced training modules have been accessed in 176 countries, with more than 500,000 unique users and 115,000 completion certificates issued. CHSS has made its unique contribution to Scotland's status as a centre of excellence in healthcare education. This successful model has now been extended to training for staff working in cardiac care, and further development in the field of respiratory illness is being planned.

'This looks superb, very well done' – Lead Stroke Clinician.



'Great website! It covers every aspect of care and is very user friendly...the info is precise and easily read...which is exactly what carers need.'

Stroke4Carers

Stroke affects approximately 12,500 people in Scotland each year, and more than 100,000 people are living with the impact of stroke. Many need physical and emotional support from family and other informal carers, whether in the immediate aftermath of returning home from hospital, or over the longer term. Because stroke can be such a sudden and traumatic event, many carers are wholly unprepared for this role. The provision of information, advice and support for informal carers can be patchy at best, and wholly inadequate for many.

Working in partnership with stroke survivors, carers and health professionals from throughout Scotland, and with funding from the National Lottery and Scotlish Government, CHSS has developed www.stroke4carers.org to meet this need. It features easy-to-understand, interactive advice and information, on a huge range of issues identified by carers themselves – ranging from the physical and emotional impact of stroke to practical advice on securing aids, adaptations and benefits.

Much of the content is delivered by film clips featuring stroke survivors and carers describing their own experience, and the strategies they have used to cope. There are links to a huge selection of sources of additional information, regularly updated.

Like STARs, stroke4carers has not only met a clear need in Scotland, but also had an international impact. Over its first four years, it has been accessed by more than 200,000 people in 176 countries. It provides a unique, readily-accessible source of support at the point when it is most urgently needed. CHSS are currently developing companion resources for self-management for patients, both those affected by stroke and by respiratory disease.

Information for young people affected by stroke

Stroke is often thought of as a condition which only affects older people, but each year more than 1,000 people in Scotland aged under 45 are affected. Many of these are parents of young children and teenagers, but until recently there has been an almost complete lack of information tailored specifically for young people whose parent has had a stroke.

Working with Different Strokes, a charity specifically set up and run by young adults with stroke, CHSS developed a pioneering information resource for this neglected client group. Based on the real experiences of a focus group of children and parents affected from throughout Scotland, and using the skills of stroke support nurses and a child psychologist, this was produced in different formats for three different age groups, from very young children to teenagers, and in separate versions for mothers or fathers affected. Each module provides up-to-date, practical information in accessible, easy to understand language.

This resource has become an essential part of the 'toolkit' supporting parents discharged home from hospital after treatment for stroke in Scotland. It has been widely used throughout the UK and in other English-speaking countries, and CHSS has given permission for it to be translated into other languages. In 2013, it won a UK-wide award for excellence in patient information.

'I have difficulty with speech – the resources were very useful as a guide to help me talk to my son about what had happened to me.'



FAST: raising public awareness of the onset of stroke, and the need to seek help urgently Time is brain – during a severe stroke, you can lose brain cells at the rate of two million a minute.

Even the best stroke services are of little value to people suffering a stroke unless they recognise what's happening and seek immediate medical help – such as thrombolytic (clot-busting) therapy, which needs to be administered within a few hours of stroke onset to be effective. In every case of stroke, whether thrombolysed or not, rapid access to specialist treatment increases survival chances and reduces long-term disability.

The CHSS FAST campaign raises public awareness of the signs and symptoms of stroke (the Face, Arm, Speech test) and the need to seek help urgently (Time). The campaign uses a wide range of methods adapted to the local circumstances – stories of patients' own experiences in local papers; radio and TV advertising, phone-in programmes etc.; posters, banners, fridge magnets, bookmarks for the general public; wallet cards distributed through pharmacies with prescriptions; branding on ambulances, buses and taxis.

During 2010-2012 the campaign ran in every Health Board area in Scotland. A Resource Pack enables local stroke services to re-run the campaign annually to reinforce the message – a key objective of the Scottish Stroke Improvement Programme. More recent resources include the FAST app – one of only 30 included in the first European directory of health-related iphone apps – and the ThinkFAST DVD, a humorous but hard-hitting co-production with the stars of the BBC Scotland comedy 'Still Game'.

Following the first round of local FAST campaigns, a survey of more than 1,200 stroke patients revealed:

- Awareness of the FAST message rose from 32% to 61%
- Accurate recognition of symptoms increased from 35% to 49%
- Those seeking help immediately increased from 46% to 62%

The CHSS FAST campaign has contributed significantly to the major improvement in survival from stroke in Scotland, which has risen by 40% over the last 20 years.

Voices Scotland – giving people a say in local health services and in managing their own condition 'The Voices Programmes have established themselves as the "gold standard" of patient and carer involvement.' Sir Harry Burns, former Chief Medical Officer for Scotland.

A key objective of the National Health Service in Scotland is to involve patients and the public in running and redesigning local services – through involving them in service planning groups, managed clinical networks, patient partnership forums and other NHS bodies. For the lay person affected by chest, heart or stroke illness, this can be daunting. The NHS is highly complex and sometimes difficult to comprehend, with language and jargon that can seem impenetrable.

To enable lay people to play a meaningful part in 'patient engagement', CHSS developed the Voices programme. This provides information, training and support to people who want to become involved with the NHS, equipping them with the background knowledge, skills and confidence to enable them to make a real contribution.

Beginning with people affected by heart disease (Hearty Voices), the programme has been extended to cover respiratory conditions and stroke, with a specially-designed module for people with communication difficulties. It's now being adapted to meet the needs of people for whom English is a second language, to ensure the full diversity of the Scottish community has the opportunity to become involved. The most recent development is the COSMIC programme – Champions Of Self-Management In Care – focusing on promoting self-management of respiratory, cardiac and stroke conditions.

An independent evaluation undertaken by the Scottish Health Council revealed that 93% of those who had been through the programme felt it had equipped them to make a contribution of which they were proud. CHSS are now working with a range of partner charities to extend this successful model to other long-term conditions.

PARCS: Improving the physical and mental health of people with long-term conditions

Regular physical activity is vital to maintaining long-term physical and mental health. For people with long-term conditions, access to rehabilitation and exercise programmes is patchy and uncoordinated, varying with location and the type of condition, and over time. Many are either not referred, or not supported to keep up their activity.

The PARCS project – Person-centred Activities for people with Respiratory, Cardiac and Stroke conditions – emerged from the work of CHSS and two partner charities, the British Heart (BHF) and British Lung (BLF) Foundations. They were commissioned by the Scottish Government to investigate the position throughout Scotland, learn relevant lessons from the rest of the UK, and identify the views of users and non-users of existing services, with the ultimate aim of producing a national strategy.

CHSS coordinated the overall project, undertaking the first-ever national survey of physical activity in Scotland for people with chest, heart and stroke conditions. This included services provided by the NHS, local authorities, leisure services and the voluntary sector. It identified critical success factors, barriers to engagement with services, potential technological developments and the variations between different areas.

The Scottish Government now has a national strategy to develop these services, and an opportunity to provide a major boost to the long-term health of our population, and to be a world leader in this field. Recent research demonstrates even more clearly how vital this is – inactivity causes twice as many deaths throughout Europe as obesity.

users (of exercise classes) are probably the most grateful of all for the services we provide, as it not only improves their physical abilities but also opens a pathway for social interaction, essential for a good quality of life.'

The World Walking Challenge and Website (Inverclyde Globetrotters)

Cardiac rehabilitation is a low-cost programme of structured exercise which has been shown to improve the quality of life – and even save lives – of people affected by heart disease. Over the last 15 years, mortality from heart disease has fallen by 60%. As a result of this significant improvement, growing numbers of people are living with heart disease, and especially conditions such as heart failure. Demand for services is therefore increasing every year.

CHSS has pressed policy makers to make access to cardiac rehabilitation for all a top priority and we promote the benefits of physical activity for health. Our funding has supported the development of a motivational exercise website by affiliated heart group The Inverclyde Globetrotters. The site www.worldwalking.org has a variety of virtual walks, created to inspire users to keep moving, one step at a time. In the past five years the group has followed the equivalent of Route 66, trekked across Canada, visited all of Europe's capital cities and travelled to the moon and back.

The group's latest journey is the Heart & Sole Challenge 2015, which aims to complete a virtual walk round the world (around 34,000 miles give or take), using the innovative World Walking website. National and international organisations have signed up for what may well be the longest virtual heart health walk ever undertaken, involving the most

participants and the first to circumnavigate the globe. The website gives everybody an opportunity to share photos and chat and to be signposted to relevant health messages throughout the journey. There's even a helpful World Walking App that can be downloaded from the website that turns a smartphone into a pedometer.

'Remaining physically active after a heart event can be vital.'

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What we are doing thanks to your help

Support, Understanding & Care

- We're supporting thousands of people and their families in communities across Scotland – directly improving their quality of life.
- We're helping and advising people throughout the year with our publications and confidential, nurse-led Advice Line.
- We're continuing to extend and improve our services. Survival rates in Scotland have risen in recent years and more people need our help.

Influence, Education & Action

- We're enabling people affected by chest, heart and stroke illness to influence their local NHS services.
- We're raising awareness on issues such as cardiac rehabilitation, aphasia, warning signs of stroke, the benefits of physical activity and emergency life support.

Research, Diagnosis & Cure

- We're investing more than £1 million in medical research at any one time, funding state-of-the-art research studies in all of Scotland's university medical schools.
- We're funding research from nursing and health professionals, ensuring that our research is focused on the real needs of patients.

Do you have any questions about chest, heart or stroke illness?

Chest Heart & Stroke Scotland

Ask the nurse 0808 801 0899

Call FREE from landlines and mobiles

Helplines STANDARD

www.chss.org.u

Scottish Charity Number SC018761

Thank you for your support. You enable us to help more than 18,000 people across Scotland, genuinely improving the lives of those affected by chest, heart and stroke illness. Please help us reach out to even more people in the year ahead.

Volunteer to help

- Volunteers play a vital role in our activities, whether supporting local services, helping in our shops, or providing time and expertise in our administration, IT and fundraising activities.
- As an Investor in Volunteers, CHSS supports and trains volunteers to the highest standards. No matter how much or how little time you can offer, we will give you a great volunteering experience and the satisfaction of helping your community.

Make a donation

- Anything you can afford from one-off gifts to signing up for a monthly or quarterly direct debit enables us to reach out on your behalf to those whose lives have been blighted by chest, heart or stroke illness.
- And with the addition of 'Gift Aid' your donation is increased by 25% at no cost to you.

Gifts in Wills and Tribute Funds

• Leaving a gift in your will is a very special way of helping others, once you have looked after your family. Make the end a new beginning – even a small gift helps.

Reflect and remember. Set up a Sapphire Tribute Fund in memory of a loved one.

Support us in a way that suits you

- Join one of our events or do your own thing. We can help by providing sponsorship materials and all the do's and don'ts for creating your own fundraising event, involving friends, family and colleagues.
- Support our shops with much-needed stock, and sign up as a 'Gift Aid' shops donor to increase the value of your gifts.
- Help us spread the word by being part of our online community on Facebook and Twitter, or just by buying and sending CHSS Christmas cards to your friends!



Chest Heart & Stroke Scotland is a wholly independent Scottish charity and relies entirely on the continuing generous support of the Scottish public, community organisations, business, NHS Boards and Local Authorities to fund its activities.



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