

World Stroke Organization
Advocacy & Awareness Case Study Submissions
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Heart and Stroke Foundation of Canada: Working with partners and government to building the Ontario Stroke System

Ontario is the most populous of the ten Canadian provinces with 13.6 million residents, and includes the biggest city (Toronto) as well as the nation's capital (Ottawa). It is often called the most culturally diverse city in the world, with half of its population born outside the country.

In the mid 1990s stroke was described as Canada's most forgotten disease, and viewed as a hopeless condition. Stroke care across the country, including in Ontario was lacking: only 4% of acute hospitals had dedicated stroke units, and only 24% had emergency room stroke protocols in place. Thanks to a coalition of tireless stroke advocates, led by the Heart and Stroke Foundation, the Ontario government formalized and funded the Ontario Stroke Strategy in 2001. This groundbreaking strategy re-organized stroke care across the province to ensure all Ontarians had access to appropriate, quality stroke care in a timely manner.

"This is multifactorial to be sure, but I suspect that some credit for these impressive statistics can be attributed to the efforts of the Heart and Stroke Foundation and the Ontario Stroke Network/Ontario Stroke System with the set-up of prevention clinics, acute stroke protocols, development of stroke units, and ongoing efforts for rehabilitation and reintegration along the continuum of care."

Dr Sandra Black, Commenting on a published paper that revealed a 32.4 % decrease in stroke incidence rates in Ontario between 2002 and 2013.

Where we started

Health care providers, led by several champions, approached the Heart and Stroke Foundation and asked it to do for stroke what it had already done for cardiac care. These professionals wanted Ontarians to understand what stroke was and that it was a medical emergency, and they wanted the system in place to provide effective and timely care. Around that time, the clot-busting drug tPA, was approved for use in Canada for ischemic stroke, further highlighting the importance of putting into place systems for people to access acute stroke treatments more quickly.

What needed to be done:

- **Build public awareness.** Raise awareness among the public to recognize the signs of stroke and understand it is a medical emergency.
- **Improve systems and services.** Enhance professional education and implement system changes across the continuum to improve stroke care.
- **Obtain funding and support.** Convince the government that investing in stroke care would measurably improve the health of Ontarians.

Building a coalition

Many players needed to be involved including hospitals, the health care system, health care providers, and stroke survivors and caregivers in order to convince government of the importance of investing in system changes for stroke care.

Four hospitals showed leadership by testing a model of regional coordinated stroke care. These demonstration sites agreed to make changes and invest in three-year pilots as part of the Coordinated Stroke Strategy. The Foundation facilitated the projects and helped them learn from each other. These pilots were critical; they built credibility by demonstrating success. For example, one site ran a public awareness campaign and implemented a bypass protocol which resulted in 12% of stroke patients receiving tPA. This was significantly higher than other areas in Canada and the US.

Many stroke leaders made a huge commitment of time and leadership, providing credibility and participating in working groups and panels. They helped perform an audit of existing services, trained colleagues and new stroke professionals, participated in meetings with the government, provided expertise in areas such as rehabilitation, and participated on the steering committee that oversaw the development of the pilot projects.

Stroke survivors and their caregivers advocated and shared their personal stories.

Working in partnership with government

The Foundation faced several challenges to convincing the Ontario Government to implement and fund a stroke strategy. The Foundation did not have a stroke working relationship with the government at the time; the government had many other health care priorities; and stroke care could not be positioned as an “ask”, it had to be a “win” for government.

Foundation staff met with government officials, including the Minister of Health, and Foundation volunteers (many of whom were stroke survivors) met with their local members of parliament (again including the Minister of Health). Key bureaucrats were involved in all working groups and panels and became important champions. They provided advice on how to fit a stroke strategy within the Ministry’s policies and priorities and how to speak its language. They became strong advocates and helped build commitment and ownership within the government.

Two well known and high profile stroke survivors (a former high ranking politician and a well known business man) spoke at a key event attended by important government officials.

Factors for success

This model has been adapted and built on in provinces across the country resulting in a Canada-wide stroke strategy.

The success of the Ontario Stroke Strategy was due to a combination of:

- strategic decisions
- best use of scientific evidence

- identifying champions and involving a variety of stakeholders
- building a case and demonstrating what success looks like
- telling the right stories in the right language to the right people
- hard work and perseverance
- good timing
- luck.

Alliances

The Stroke Alliance for Europe (SAFE) is a coalition of Stroke Support Organisations (SSO's) each of which is based within a European country, and who come together for mutual support, campaigning, influencing and learning.

In 2003 the number of stroke support organisations in Europe was small in number and the cause of preventing strokes, influencing for better stroke care, and supporting those trying to have life after stroke was very badly served. This alliance was started by a top down mechanism, with Members of the European Parliament holding a strategic workshop on stroke prevention in 2003, which led to a formal launch of SAFE in October 2004 with representatives from 7 SSO's.

The formation of SAFE was the first step in a journey of consolidation, expansion and a quest for sustainability, all of which are necessary requirements to enable influencing and campaigning over the sustained periods of time needed to effect real improvement and change.

One goal pursued with vigour by the co-ordinating board of SAFE has been the allocation of effort and resources to establish SSO's in countries where they do not exist, and to aid development and sustainability once in existence. This has involved creating conferences in areas where we did not have SSO's (such as Eastern Europe) and paying travel and accommodation costs for people who were interested in organising SSO's so they could attend and learn how to do it. This is a constant struggle, some SSO's have ceased to exist, but overall there are now more than 30 SSO's in Europe, and over a dozen now employ paid staff, supported by volunteers, many of whom are stroke survivors or family members. The WSO/SAFE toolkit on how to form an SSO has also been of great help.

SAFE organises the alliance through regional conferences, an annual working conference and democratic AGM, newsletters and the website, and now employs staff to co-ordinate alliance activity. Donations and sponsorship from stroke related industry companies, and their support for education and training, has been central to enabling the move from amateur patient organisation to a more professional approach. All patient led organisations need the support of appropriate medically trained people, to help them get off the ground, and then to assist as they grow, and the most successful SSO's are those where a gradual withdrawal from leadership by medics has occurred over time enabling patients and their supporters, and paid staff, to bring their enthusiasm to grow the SSO into action.

Barriers of course exist to growing SSO's, cultures where people do not understand the need to generously give resource to NGO's, corrupt system and decision makers, difficulties in finding leaders and willing volunteers due to many reasons, and lack of knowledge, information and confidence to take on the job of building and running an SSO. Being part of an alliance enables new beginners and those only some way into the journey the opportunity to learn from others, and to get support.

After 14 years SAFE has now grown to a point where it has just co-ordinated a 250,000 euro research project on the burden of stroke in Europe, with a view to enabling advocacy and awareness raising in each country based on both evidence and patient and family testimony. SAFE also supports researchers in stroke providing the patient voice to potential funders and within projects, and has an excellent developing relationship with the European Stroke Organisation of professionals, enabling co-ordinated influencing and campaigning.

The Stroke Association – A New Era for Stroke

"I feel I've been left to fend for myself. As well as looking after my partner, I also have our 22 month old son to look after. I keep being told that I need to look after myself but I feel that there isn't the support to do it."

This is just one of the many stories The Stroke Association has heard recently about stroke survivors not getting the care and support they need. It is these stories, along with our survey which showed that 45% of all stroke survivors feel abandoned when they leave hospital, which highlighted that there are significant challenges with the delivery of stroke care and treatment which can only be solved through a new national strategy to drive improvements across England. In 2007 the Government established a 10 year national stroke strategy which has driven significant improvement in stroke care. This strategy expires in 2017 and the Government has already stated they have no plans to renew it. The Stroke Association disagrees with this, because without a national strategy we will not get the vital improvements in stroke care and treatment which are needed.

In May 2016, we launched, [A New Era for Stroke](#), our campaign for a new national stroke strategy. The campaign began with significant media coverage and a petition in order to try and get a debate in Parliament. We reached out to all of our supporters, public and professional, asking them to sign and share the petition with their friends and colleagues. If everyone can encourage 10 other people to add their names, we will reach our target of 100,000 signatures. What's also exciting to see is that many clinicians and professional bodies also agree there is a need for a national stroke strategy and they are also speaking publicly about this.

This is just the start of the campaign and it is important that we maintain, and build on this initial momentum so over the coming months we will be talking with MPs and we will be asking our supporters to meet with their MPs to raise the important issue of stroke. We are hopeful that the Government will listen and respond to the level of increasing pressure from individuals, professionals and MPs for a national stroke strategy – but only time will tell.

The Norwegian Stroke in the Young Studies

The first population-based Norwegian Stroke in the Young Study (NOR-SYS) was initialized after serious research results from a long-term follow-up 12 years after ischemic stroke <50 years with a nearly 10-fold increased mortality rate compared to controls, and high vascular morbidity and memory problems among patients. The first study with inclusion from 2010-15 is a 3-generation long-term follow-up project after documented acute ischemic stroke at age 15 to 60 years in the catchment area of Haukeland University Hospital with focus on

- Cardiovascular events and heredity,
- The state of the arteries
- Better prophylaxis

Cardiovascular events and heredity was in a first step evaluated by standardized questionnaires to patients and their parents, asked about first-line family members and the type of stroke, coronary and other heart disease and peripheral artery disease.

The state of the arteries was examined by the NOR-SYS extended ultrasound protocol applied on patients, their partners and adult offspring. This protocol included 4-angle examinations of the carotid arteries, the abdominal aorta, femoral arteries and ankle-arm index measurements.

Ultrasound pictures were used for explaining patients and other study participants the findings and the necessity to start medical prophylactic treatment and/ or to change lifestyle.

Better prophylaxis and higher rates to reach treatment goals are hopefully achieved by inclusion of family members when possible, and given visual (ultrasound pictures in case of established artery disease), oral and written information about individual risk factors.

A total of 386 patients was included into NOR-SYS, and patients were followed by telephone calls after 1 week and after 1 year, and by a 3-month follow-up visit, ensuring that treatment was tolerated and ongoing, and encouraging to start or go on with life-style changes. The first 5-year follow-up started in September 2015.

The second population-based Norwegian Stroke in the Young Study (NOR-SYS II) continues the work for patients at age 15 to 49 years with documented acute ischemic stroke. NOR-SYS II started inclusion in March 2016 and has a planned inclusion phase for 5 years. The study is updated on newer risk factors, such as obesity, maximum weight and previous fat-reducing operations, inactivity, use of snuff and narcotics. It follows to a great extent the work done in NOR-SYS, but has also focus on the special challenges for patients that should continue with education and job-activities. NOR-SYS II is closely developed with the SECRETO study and contributes with cases of cryptogenic stroke to this important international multi-center study.

Main future plans for NOR-SYS and NOR-SYS II are contributions to genetic research via the bio-banks after thorough clinical work-ups.

‘Nothing about us without us’ – patient and carer involvement in the English Stroke Research Network

In 2005 the National Institute for Health Research (NIHR) established the Stroke Research Network (SRN) which provided an infrastructure to develop and deliver clinical stroke research in England, increasing the opportunities for people with stroke to participate in research. From the very beginning the NIHR SRN set out to ensure that patients and carers were actively involved throughout the organisation and at all stages of the research process.

The NIHR SRN developed a strategy and implementation plan for national and local patient carer and public involvement in stroke research, and appointed a director and manager to lead this programme. Following a national advertising campaign and interviews, 20 individuals who had had a stroke or who were/had been carers of someone who had had a stroke were appointed to a national NIHR SRN lay member panel. Two lay members sat on each of the NIHR SRN committees and contributed to: the development of work programmes to identify research priorities; awarding funding to writing groups to develop research proposals; developing methods to increase recruitment to multi-centre studies; initiatives to improve patient and carer experience of research participation. Lay members also provided feedback to investigators prior to submission of research proposals. As applicants on research proposals, lay panel members contributed to individual study design, delivery and dissemination.

The partnership between researchers, clinicians and researchers ensured that stroke research in England addressed issues which were important to patients and carers in acute stroke care, rehabilitation, secondary prevention, and long term care. Their involvement ensured that the assessments, interventions and outcome measures used in studies were appropriate and acceptable to patients and carers.

Following the re-organisation of the NIHR Clinical Research Network, the stroke specialty has worked with one of the main medical research charities involved in stroke in the United Kingdom. This has resulted in the integration of the SRN and charity patient, carer and public representatives into a Patient Faculty. This has retained the principles of SRN patient and carer involvement, with engagement throughout the research pathway from priority setting, and research design, delivery and dissemination, as well as involvement in funding panels.

Active patient involvement is now integral to clinical research in the UK. To quote Professor Dame Sally Davies, Chief Medical Officer for the NHS in England- *‘No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective.’* Lay people now contribute to the funding decisions of all major funders of clinical research and researchers must demonstrate that meaningful patient involvement has been part of the development of their research proposal and that patients will continue to be involved throughout the study.

Helen Rodgers

Professor of Stroke Care, Newcastle University

Tom Robinson

National Specialty Lead for Stroke, NIHR Clinical Research Network

Gary Ford

Consultant Stroke Physician, Oxford University Hospitals

Example of Role of Consumers

Hi Meredith,

I joined the AHA after two different pieces of stroke legislation had passed. But, I've been involved in the latter phases of the second piece and can offer a few thoughts. I think the best example of how we activated volunteers is reflected in our State Stroke Advisory Committee. The committee was established in 2009 when the first stroke center legislation passed. An update to that legislation passed in 2014, the update and subsequent rules were essentially written by the volunteer members of the State Stroke Committee.

The committee was structured through legislation that the AHA wrote and represents all areas of the state, giving unique access to the stroke community throughout Illinois. It is also worth noting that the original sponsor of the stroke center legislation was a State Representative who is a survivor and is now one of our most committed volunteers.

The AHA has been an influential participant in the state committee and we've been able to help identify and vet members whose interest align with our goals and mission statement.

I'd be happy to discuss further if this is what you are looking for, I also have number of different documents outlining the evolution of Stroke Systems of Care in IL if you are interested.

Let me know. Thanks,

Julie Mirostaw

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Hi Meredith,

I don't have anything prepared, but we did some media advocacy (mostly news radio) around what we call "the cabin stroke." In MN, everyone has a cabin somewhere that they go to on weekends and when we were struggling to gain traction on a Stroke System, we started messaging around "what if you were up at your cabin in the middle of nowhere and..."

Is that what you're looking for? I've also attached a presentation around the history of the work in MN if that helps too. I guess I'm not sure exactly what you're looking for. Our volunteer engagement on Systems issues are mostly from providers (ED Nurses and Docs, Stroke coordinators, etc...) and they are typically already on boards with the concept.

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Latin America Summit for Stroke

AHA/ASA hosted the Latin American Summit, held on October 29-31 in Santiago, Chile. The Summit engaged key opinion leaders, health authorities, and other sectors, all of whom committed to develop a shared stroke agenda for one of the region's leading causes of death. The engagement of these diverse stakeholders provided the ingredients for a rich and productive discussion at the Summit that facilitated the exchange of best practices in stroke and actionable commitments to take forward to supporting this overall goal.

Summit Outcomes

The Latin American Summit is a milestone in the AHA/ ASA's international and stroke efforts to build a new constituency in region and explore how its technical expertise can support the region's diverse interest and needs. The Summit resulted in launching a reputable stroke network across 10 countries and has the potential of extending its reach to others in the region of the Americas. Most promising, is the region's enthusiasm and commitment to the "La Carta de Santiago," a declaration and commitment to uptake of promising policy and systems changes necessary to impact stroke care and patient outcomes.

Program

Dr. Salvador Cruz-Flores, University of El Paso led the meeting.

Panel Discussion Topics:

State of Stroke Care in Latin America

Challenges in Financial Feasible Stroke Treatments

Implementation of policies by countries/region to eliminate the use of tobacco, lessen salt consumption, control weight and promote physical activity.

Medication Management (Hypertension, Atrial fibrillation)

Improving Stroke Systems of Care & Stroke Treatment

*Mexico
Argentina*

Over 22 organizations & 42 stroke leaders and ministry of health representatives attended from 10 countries attended the Latin American Summit.

*Chile
Colombia
Brazil*

Country Best Practice Sharing:

Peru

Steering Group Leadership

The Summit's Steering Leadership Group made up of leading stroke experts from six countries (Argentina, Brazil, Chile, Colombia, Mexico, Peru, U.S., and Canada). They served as advisers of stroke care in the region and contributors to the program's content.

Case Study: Korean Stroke Society and Seoul St. Mary Hospital, Korea

Submitted by: Jaseong Koo, professor of Neurology (Stroke Neurologist) Jaseong Koo
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Advocacy to widen (new oral anticoagulants) NOAC reimbursement coverage with diverse stakeholders since 2013

Background

Stroke is the second most prevalent cause of death and the dominant death risk among the single-organ diseases in Korea. Atrial fibrillation (AF), as widely known, is the major cause of ischemic-stroke.

Conventional anticoagulant, warfarin, has taken an important role in stroke prevention for decades despite of the narrow therapeutic range and the difficulty in keeping compliance. However the necessity in warfarin replacement was emphasized particularly in Asia when the new oral anticoagulants (NOACs) were introduced. This is because the risk of intracranial hemorrhage is much higher in Asians with warfarin administration, whereas NOACs performed well in all ethnic groups.

NOACs were introduced in late 2012 in Korea and reimbursed from 2013. Korean Government allowed NOACs to warfarin ineligible patients at first. But physicians could not accept the reimbursement guideline which limits NOACs' use without insufficient discussion on warfarin being ineligible.

Strategy and Approach

The Korean Stroke Society (KSS) and I have been taking necessary actions to spark the discussion on its necessity to widen NOAC reimbursement coverage with diverse stakeholders since 2013.

For this advocate initiative, we focused on two key imperatives. Those are: a) to generate evidence which showed clear medical unmet needs in Asian AF patients and b) to bring important stakeholders, such as policy makers, media reporters and government officials, to the public discussion by unveiling evidence endorsing NOACs clinical value.

Outcomes

KSS submitted a petition letter to urge widening NOACs' reimbursement coverage to prevent stroke in early 2014 and published an article which clearly specified NOACs' usefulness to Asian stroke patients in "Journal of Stroke" in 2Q, 2014.

To get attention from related stakeholders, media activities were taken including interview and contribution to Op-Ed page. Moreover, in an effort to enhance the engagement of stakeholders, a Round Table Meeting (RTM) took place with Government officials. To strengthen the effect, my colleagues and I publicized a policy paper which entails all related discussions, publications and the policy proposal. It was the first attempt to publicize a policy paper to offer a policy alternative in Korean medical society.

As a result, an assemblyman urged to expand reimbursement coverage for NOACs during the National Assembly audit. Consequently, reimbursement coverage for NOACs widened to all high risk AF patients without any conditions like warfarin. With this expansion, financial hardship was lowered in patients who respond to warfarin but have difficulty to keep stable INR control.

Lessons

Including media publicities, RTM and scientific article publications, multimodal approaches were effective in making all stakeholders involved. This was meaningful not only in regards to widening the coverage of the issue, but also as a synergy effect in reinforcing the key message through various channels. Eventually proposing the policy paper enabled collaboration with government and related stakeholders and took a pivotal role in gearing up for the policy change.



Advocacy Case Study: “ACTION ON STROKE CAMPAIGNS”

Theme: Past World Stroke Day Events

Background:

Established on 10 March 2000 as a stroke support organisation (SSO) Stroke Action UK works with stroke survivors, their carers and partners to promote meaningful, evidence based and quality 'Life after a Stroke' in the community and to reduce the incidence, complications and the burden of strokes. SAUK operates from a 'Life After Stroke Centre' in the London Borough of Enfield and have stroke support groups in the London Boroughs of Barnet and Haringey.

Description:

Until to 2011, SAUK hosted an annual stroke conference in Enfield supported by Professor Anthony Rudd, the London Regional Director for Stroke who was often the key speaker. With SAUK's strategic participation with the Council and CCG in the Enfield Stroke Pathway (ESP) consultation, development and delivery, it was felt that a collaborative annual stroke campaign will be a good thing for the borough. SAUK has successfully engaged different stakeholders each year in collaboration with other agencies to host an “Action on Stroke Campaign” in Enfield with excellent outcomes.

Outcomes:

2012 – Action on stroke conference in collaboration with local politicians (Mayor, MP, Ward Councillors; the ESP team

2013 – Action on stroke conference in collaboration with local voluntary sector organisations

2014 – first ‘funded’ Action on stroke conference ‘plus’ a walk and run against strokes in collaboration with Enfield Public Health and the Police Force

2015 - second ‘funded’ Action on stroke conference ‘plus’ a walk and run against strokes in collaboration with MANSAG (Medical Association of Nigerians Across Great Britain)

2016 - Action on stroke open day ‘plus’ a walk and run against strokes in collaboration with Tottenham Hotspur. SAUK plans that the campaign will continue on an annual basis.



Madam Mayor at 2012 conference



Director of Public Health presenting at 2014 conference



Walk and Run in partnership with the Police



Walk and Run in partnership with Tottenham Hotspur



Advocacy Case Study: “STROKE AMBASSADORS DEVELOPMENT”

Theme: Creating Alliances

Background:

Established on 10 March 2000 as a stroke support organisation (SSO), Stroke Action UK works with stroke survivors, their carers and partners to promote meaningful, evidence based and quality 'Life after a Stroke' in the community and to reduce the incidence, complications and the burden of strokes. SAUK operates from a 'Life After Stroke Centre' in the London Borough of Enfield and have stroke support groups in the London Boroughs of Barnet and Haringey.

Description:

Advocacy is at the heart of SAUK and this involves lobbying and influencing decision makers for better stroke care in partnership with stroke survivors and carers. The London Borough of Enfield has been promoting service user and voluntary sector empowerment and collaboration in service development for over 8 years. This has been challenging as voluntary sector organisations are used to working in their own niche areas, and with limited resources, find it difficult to foster proactive joint working. SAUK lobbied recovering stroke survivors to participate in a DH HSCVF Volunteer Stroke Ambassadors' development program (<https://www.youtube.com/watch?v=yhzGfGkSmQw>).

The program was successful achieving the DH HSCVF recognition in 2014. Subsequently Enfield Public Health and Social Care Commissioners funded the replication of the Stroke Ambassador role in other areas with excellent outcomes.

Outcomes:

2014 – Enfield Public Health Funded Stroke Ambassadors development within Schools, Faith and Community Groups. 3 schools, 5 faith groups and 5 BAME community groups each have in-house **Stroke Ambassadors** as a result.

2015 – Enfield Council supported the establishment of an Enfield Health and Social Care Partnership (EHSCP www.enfieldhscp.org) with SAUK as the lead partner, and, including Dementia, Mental Health, Healthy Lifestyle, and Vulnerable Women support organisations. Through the Enfield Residents Priority Fund, the role of Stroke Ambassadors was replicated with 5 local residents becoming Well-being Ambassadors in different areas.

2016 – Through the Enfield Council Community Wellbeing fund, the EHSCP was funded to replicate the role of the Wellbeing Ambassadors as Community Champions in 5 priority wards with high incidence of cardiovascular diseases. The project is currently ongoing and SAUK has been invited to present at the annual Voluntary Sector conference to share lessons with other organisations.

The role of these Volunteer Ambassadors is to support the Council / Local Authority and the Clinical Commissioning Group (CCG) to foster healthier communities by promoting and facilitating FAST awareness, stroke awareness, health risk assessments, physical activity, park walk and run, and NHS Health Checks.



Wilbury School



Enfield Saheli Ambassador



EHSCP Wellbeing



Advocacy Case Study: “THE ENFIELD STROKE PATHWAY”

Theme: Working with governments to achieve local objectives

Background:

Established on 10 March 2000 as a stroke support organisation (SSO) Stroke Action UK works with stroke survivors, their carers and partners to promote meaningful, evidence based and quality 'Life after a Stroke' in the community and to reduce the incidence, complications and the burden of strokes. SAUK operates from a 'Life After Stroke Centre' in the London Borough of Enfield and have stroke support groups in the London Boroughs of Barnet and Haringey.

Description:

Advocacy is at the heart of SAUK and this involves lobbying and influencing decision makers for better stroke care in partnership with stroke survivors and carers. Prior to the establishment of SAUK, there was no organised stroke care in the borough. SAUK continued to lobby local politicians, the local authority and health sector to invest in stroke services development. The impetus for change came when the 2010 Care Quality Commission (CQC) stroke report rated Enfield as one of the worst performing boroughs in the London region. This led to joint working with both the Enfield Council and the Enfield Primary Care Trust (PCT) at the time (now called Clinical Commissioning Group CCG) to carry out stakeholder consultations on how to develop the Enfield Stroke Pathway (ESP).

Outcomes:

2000 – 2010: Lobby for better care for stroke survivors and carers, worked with MPs, Councillors, Mayors, Commissioners, Voluntary organisations, stroke survivors and carers

2011 - Stroke Action hosted the consultative event on Enfield Stroke Pathway

2012 - Enfield Stroke Pathway was produced and implemented

2012 to present - Stroke Action delivers the community reintegration strand of the ESP

A key component of our community integration offer is provision of a wellbeing service offering a range of activities to support stroke survivors and their carers to ‘cope’ with life after a stroke, re-learn life roles and regain functional ability. Activities include peer befriending, social support, exercise class, communication support, trips, outings and holidays, promoting hobbies and recreation.



Mr Andy Love MP speaking at the ESP Consultation



Stroke Survivors and Carers discussing at the ESP Consultation



Exercise outside the Life After Stroke Centre



Day out re – learning Life Roles: SHOPPING

Advocacy Case Study: “NIGERIA STROKE REFERENCE GROUP (NSRG)”

THEME: CREATING ALLIANCES & WORKING WITH THE GOVERNMENT

Background:

In 2011, we started the journey of engaging Nigerian healthcare professionals in diaspora and at home to establish Stroke Action Nigeria (SAN) as a stroke support organisation (SSO) with the vision to adopt 'Holistic' approaches to the care and management of strokes and stroke risk factors. We agreed the Mission as providing services to reduce the incidence, complications and the burden of strokes, identifying stroke survivors, carers and at risk individuals as beneficiaries. We felt that for this ambitious goal, we needed to engage and collaborate with statutory and non-statutory agencies and health care professionals with an interest in stroke care to achieve a sustainable SSO. Our first port of call was the Nigerian High Commissioner in London who we met to share our aspirations and he immediately signed up. As a result, in 2013 we signed an important Memorandum of Understanding (MOU) with the Federal Ministry of Health (FMOH) to collaborate in mitigating strokes in Nigeria. The FMOH – SAN MOU has 6 key objectives: establish a reference group, stroke strategy, stroke register, national campaign, stroke education and stroke centre.

Description:

Managing this change was extremely challenging for a newly formed SSO without any financial resources to implement the MOU. In addition to the unstable political climate in the country, the FMOH was undergoing series of changes at the time. No progress was being made and more Nigerians were having stroke and dying of strokes. After exploring with colleagues on how to overcome this enormous challenge, we felt that the best way forward would be to form a '**STROKE ACTION ALLIANCE**' with Stroke Action UK (SAUK) and the Medical Association of Nigerians Across Great Britain (MANSAG). Our 'journey so far' was presented to the executive committees of both organisations and they signed up to help push the implementation of the FMOH – SAN MOU. The first FMOH – SAN MOU objective we agreed was to establish a **Nigerian Stroke Reference Group (NSRG)**. MANSAG carried out fundraising in the UK during the stroke month through national 'walk and run' against strokes activities and a May Ball to enable this to happen. Our approach was strategic in terms of forming alliances with professional groups and the government. This enabled us to achieve excellent outcomes for progressive stroke services development. The NSRG was inaugurated on 16th September 2015 in the Federal Capital of Nigeria Abuja.

Outcomes:

2012 – Meeting with Nigerian High Commissioner in London

2013 – Signing of the FMOH – SAN MOU

2014 – Meetings with SAUK and MANSAG ‘EXCOs’. Stroke Action UK/Stroke Action Nigeria – MANSAG Alliance formed.

2015 – Inauguration of the NSRG by the Permanent Secretary FMOH on behalf of the President of the Federal Republic of Nigeria. [Membership of the NSRG includes: Nigeria stroke specialists in Diaspora and at Home; representatives from FMOH, SAN, SAUK, MANSAG; Chairs/Presidents of All Health and Social Care Professional Associations in Nigeria (Medical Association, Nursing Association, Neurological Sciences, Physiotherapy, Speech Pathology and Audiology, Social Work, Occupational Therapy; WSO; a SSO’s representative; stroke survivors and carers)]

2015 – NSRG held its first business meeting on 17/09/2015 adopting its terms of reference and work program.



Members of the NSRG

Advocacy Case Study: “POWER TO STOP STROKES CAMPAIGN IN NIGERIA’

THEME: PAST WORLD STROKE DAY EVENTS

Background:

Stroke Action Nigeria (SAN) was established in 2011 as the first proactive stroke support organisation (SSO) in the Country. The vision of SAN is to adopt 'Holistic' approaches to the care and management of strokes and stroke risk factors. Its mission is to provide services to reduce the incidence, complications and the burden of strokes. SAN supports stroke survivors, their carers and at risk individuals. In 2013 we signed an important Memorandum of Understanding (MOU) with the Federal Ministry of Health (FMOH) in Nigeria to collaborate in mitigating strokes in the country. The objectives of the FMOH – SAN MOU are to:

Implement a national power to stop strokes campaign: Establish a stroke reference group for Nigeria; Develop and implement a stroke register; Develop and implement a national stroke strategy; Facilitate stroke education and training for healthcare professionals; Pilot a life after stroke centre in Abuja FCT

Description and Outcomes:

SAN implemented the first ‘Power to STOP Strokes Campaign’ in 2012 by hosting a stakeholder conference the ‘Stroke Assembly’. 23 Volunteers were recruited to help host the campaign in 2013. A national ‘Power to STOP Strokes Campaign’ TOOLKIT (PTSSCT) based on WSO model was developed giving guidance on successful campaigning:

- Writing a letter of support; A guide to planning campaign on time; How to organize Stroke Campaign Activities; Tips and advice for fundraising; How to publicize events in the media; Posters and Letter Templates: FAST; Letter templates; Campaign sign up form

The 23 Volunteers were trained by SAN to become Stroke Ambassadors ready to ‘pilot’ the PTSSCT across 6 States in 2013. The Honourable Minister of Health (HMH) was the Key note speaker at the Stroke Assembly in 2013, and, the Stroke Ambassadors held walk and run activity and stroke awareness in Abuja FCT, Asaba, Benin City, Owerri, Onitsha, and Lagos. The Campaign continues each year with the FMOH participating and funding the Campaign in 2015. This helped SAN to address the WSO campaign theme ‘I am Woman, Stroke Affects Me’ and raise awareness of strokes using media and reaching millions of Nigerians. The SAN chief officer won the WSD 2015 Individual Award as a result.



HMH at Stroke Assembly in 2013



Walk and Run Abuja FCT 2013



Stroke Assembly 2015 ‘I am Woman, Stroke Affects Me



Walk and Run 2015 in partnership with Police Force

Case Study: Singapore National Stroke Association

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StrokeCare.sg: Singapore's First One-Stop Online Resource for Stroke Survivors, Caregivers, and HealthCare Workers

Themes: Engaging Local Stakeholders
 Creating an Advocacy Strategy / Plan

Singapore is a city nation in Southeast Asia with a population of 5.5 million residents. There are 6,700 strokes annually in Singapore and the incidence is expected to rise with our rapidly ageing population. While medical services in Singapore are good and accessible to all, with many subsidized government healthcare schemes, many stroke survivors and their caregivers often struggle with the emotional and psychosocial implications of stroke.

The Singapore National Stroke Association (SNSA) is the only national stroke support group in Singapore. Our missions are to provide psychosocial support to stroke survivors and their families, raise stroke awareness through public education, and to be a public advocate for stroke survivors and their families.

In line with our awareness and education mission, we are launching a stroke portal — StrokeCare.sg, as a one-stop online resource for stroke survivors, their families, healthcare workers, and all others with a personal interest in stroke in Singapore.

While there are various services and programmes on the internet that are useful to stroke survivors, information is scattered and provided by many different agencies and organisations with information not always being reliable. Furthermore, almost all online material is in English. These sites often originate from Western countries and may not be so relatable to Asians.

In Singapore, our population comprises 70% ethnic Chinese, 20% ethnic Malays and 5% ethnic South Asians. A significant proportion of older stroke survivors speak and read mainly in their own ethnic vernaculars of Mandarin, Malay, and Tamil. There are specific issues regarding stroke in the Asian and Singapore context, such as local goods, traditional Asian medical practices, and local resources.

A one-stop online portal designed to consolidate resources that are both general and local-centric, and which would be translatable into Singapore's three non-English official languages, would make a significant positive difference for stroke survivors and their caregivers who often face uncertainty and emotional challenges in their post-stroke journey.

StrokeCare.sg will target the following areas —

- i) **Educate** survivors and their caregivers with practical advice, care guides, and professionally endorsed best practices on caring for themselves or their loved ones physically, mentally and emotionally.

ii) ***Engage*** survivors and their caregivers through stories, articles, events listings, and other relevant content that resonate with their psycho-emotional state, in a way that does not restrict their exposure to that which is only stroke-related, but takes into account an array of broader interests — which represents social reintegration on a more meaningful level.

iii) ***Encourage*** survivors and their caregivers to continue making an effort in their holistic rehabilitation, by giving them a sense that they are part of a broader supportive community of survivors who can empathise with their post-stroke journey, and by highlighting inspiring examples of success in others who have themselves experienced various forms of disability.

In addition to these areas, StrokeCare.sg will also create a forum that brings healthcare workers concerned with stroke, together with survivors and caregivers to exchange insights, experiences, and feedback, which will eventually become a unique and valuable knowledge repository of the Singapore stroke rehabilitation experience.

To achieve this, StrokeCare.sg will foster a stakeholder community of regular contributors who will publish their own stroke-related content on the portal. Regular contributors will comprise stroke survivors at various stages of recovery and rehabilitation, family caregivers of stroke survivors, and healthcare workers including stroke specialists, physiotherapists, occupational therapists, nurses, psychologists, and nutritionists. Collectively, they will build a body of content that educates, engages, and encourages the growing community of stroke survivors and caregivers in a much more impactful manner, by taking into account the local milieus, medical standards, and rehabilitative practices that make up the journey towards holistic healing for stroke survivors in Singapore.

StrokeCare.sg has also garnered significant collaborative support from major public institutions. The Singapore Totaliser Board and SG Enable (a coordinating and advocacy agency for the disabled community) are providing seed funding for the project. SingHealth Xchange, the online editorial platform of the public healthcare service is entering into a content sharing partnership with the portal. And the National Neurological Institute has agreed to promote the portal to patients, caregivers, and healthcare workers in their stroke wards.

StrokeCare.sg is scheduled to launch officially in October 2016, in conjunction with the Singapore National Stroke Association's 20th anniversary celebrations, during stroke awareness month.

Submitted by: The Singapore National Stroke Association (SNSA)

Case Study: Acha Memorial Foundation/ Master Stroke, Africa

Submitted by: MacDonald Oguike
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Case- Study: Engaging local stakeholders and developing an advocacy strategy/plan

Title: How one Stroke Support Organization is leveraging partnerships and technology to create awareness about stroke in local communities in Nigeria

Death and the Birth of an Organization: February 2015 MacDonald lost his father from a stroke in Nigeria. His dad's stroke experience was tragic because it was very hard to find the right information around stroke treatment and rehabilitation in the local community he was living. MacDonald was saddened by the death of his father and always talked about how quick access to the right information and appropriate treatment would have saved his father's life. During this experience, he recognized the gap in community health services with regards to managing a stroke situation. That was how he decided to start a project to create awareness around stroke. He convinced a few other people similar goals, set up a nonprofit, Acha Memorial Foundation (in memory of his dad) and that team started a flagship project called "MasterStroke" targeting to educate 10 million Nigerians or Africans about stroke in 5 years.

Partnerships with Stakeholders: To accomplish this goal, they have decided to use partnership and leverage technology. The pool of stakeholders they work with is diverse. For example, they work with local churches and mosques to organize physical awareness events. They partner with hospitals and health organizations to educate people at the events. In one case, doctors and nurses were present to give free blood pressure checks and blood sugar tests. They have partnered with AIESEC an international student organization in Nigeria. Through these partnerships, they are educating students in more than 15 Nigerian universities about stroke. Another partnership that is helping them reach a large volume of people is the partnership with the Nigerian Young Professional Forum Northern Chapters. Through this, they have access to 19 Northern states in Nigeria. This partnership has the potential to educate more than 18 million Nigerians about stroke. They are also working with other stroke support organizations in Nigeria and are discussing ways they can increase and support stroke awareness in Nigeria.

Getting to Action: To start the MasterStroke team did some research around non-profits supporting stroke in Nigeria to understand successes, challenges, and gaps. They then registered their organization as part of the World Stroke Organization membership. This gave them access to the SSO toolkit. The toolkit guided the team during setup and helped create the first draft of their project plan. Next, they established partnerships with different organizations with specific areas of expertise. Some had expertise in performing local outreach work while other organizations supported in providing intelligence about stroke prevention, treatment and management. For example as a result of the WSO partnership, the team had access to the International Development Officer from Stroke Association UK, another support system they have leveraged in their growth.

Outcomes & Reflections: In less than 2 months of project kickoff, they have managed to educate about 10,000 Nigerians about stroke using a blend of different strategies. This has been accomplished by engaging local stakeholders and the deployment of a well-developed advocacy strategy/plan which includes using social media engagement, physical events and partnerships to work towards their goal of reaching 10 million people

For example, one key success factors in their approach is the fact that they are one of the few stroke related nonprofits in Nigeria to customize their content or service to their mobile devices. Their website is not just to tell about their organization or the stroke project. Rather, the site has been built to educate about stroke via sharable educational materials which visitors to the website can share on social media either on mobile or desktop. By establishing effective mobile responsive platforms to reach their target audience, the MasterStroke project is venturing into an area that will in the future, change stroke advocacy and awareness in Africa.

To see the amazing work MacDonald and his team are doing, you can review their Facebook page <https://www.facebook.com/GoMasterStroke/>

Case Study: Chinese Stroke Association

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Being a developing country, most of the Chinese people have little knowledge and the awareness of the stroke, especially in the poor area. Chinese government has been putting much more attention and effort on the public education of the signs and prevention of stroke. Ministry of Health, National Science Institute, Chinese Stroke Association, Chinese Prevention Society, and National Stroke Prevention Office have been working together to promote WSD this year in China, and to ensure the education materials and information are popular and understandable for the public.

Taking the advantages of the strong networking of the China Stroke Center Alliance (CSCA), the “National Neurological Disease Research Center” and Chinese Stroke Association, (CSA) about 1000 hospitals have been involved in the WSD promotion campaigns. Media have been a great support during the whole period of the WSD campaigns all over the China, such as interviews on TV, reports on the newspaper and the internet, as well as the public education App on the mobile and etc.

To be consistent with the theme of “I am a woman” of WSD2015, a big promotion event was sponsored by CSA in Beijing on Oct 29. During the whole week of WSD, led by CSA, an approx. 1000 campaigns such as health consultation, free physical test, “Walking & Running”, and posters and video promotion were taken by over 10,000 medical staff coming from the 861 hospitals in the 123 cities of the 32 province, including about 8410 members from “Red Bracelet volunteer service group of CSA”. Awarded 104 excellent papers and 24 videos from 100,000 applications. Meanwhile, we have got the strong media support from CCTV, BTV, and nationwide newspaper etc. CSA has delivered 3000 popular science books and 330,000 educational materials. More than billions of the Chinese people have got the basic information of the stroke.

Case Study: Stroke Association of Kenya

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It took me a long time before realizing the existence of SAOK. It started in 2010 when I experienced a pulse in my brain. My immediate family did not know what to do. I was taken to local hospitals but they did nothing. That is to say the medics in these hospitals had no idea of what I was suffering from.

It is when I was brought to the city of Nairobi three days later that the doctor diagnosed me to be a stroke patient. It was after five days in Kenyatta Teaching and Referral Hospital is when I discovered myself. I could not turn, speak nor make any movement because my right limb was not working. I could not do a simple activity for myself like eating, going to the toilet or even dressing. My people associated the disease to witchcraft.

I stayed in hospital for a couple of weeks before I was discharged. I was told to be doing physiotherapy daily. Also I was booked for occupational therapy daily to learn my lost speech besides doing a few things that I could not do. When I went to the occupational therapy, which is when I found people of all ages suffering from the disease.



I wouldn't like to forget the care givers who did a great job and are still doing it. Stroke is not a disease that will come and you get healed or you die the following day. We realized that it is a lifestyle disease. Therefore the caregivers have to persevere.

After meeting with these people besides the doctors and nurses who kept encouraging us, we decided to form an association to champion our basic needs and encourage one another.

We come together the four of us and the medical team to start SAOK. The four of us are as follows:

1. Evans Nyambega.....Chairman
2. Ann Njuguna..... Secretary
3. Edward konzolo.....Organizing Secretary
4. Florence Kigo.....Treasurer

Given that all of us had lost jobs and roles of being providers to our families, we get very good support from the medical teams. So we started drawing up the constitution with the assistance from the medical team. We went to the Registrar of Societies after recruiting a mere 10 members. The people suffering are many but those who were able to pay kshs 500 were just 10. The registrar was able to give us a registration certificate in May 2015. Now membership has grown to 60. There are thousands who are unable to raise the kshs 500 to enable them register.

ASSISTANCE

Since we got registered, we partnered with the National Council for People With Disabilities (NCPWD), a government body- which help us with assistive devices for those who are sick of the stroke, for those who are still down and cannot walk, the NCPWD has donated 10 wheel chairs and 2 walking sticks. These devices are to enable the sick be mobile.

The NCPWD has also enabled us to hold a successful world stroke day in 2015. We have other bodies that we have joined such as Non-Communicable Diseases (NCD), United Disabled People of Kenya

(UDPK), Nairobi City County and many others. NCD has organized several seminars which we attend to network with others.

CHALLENGES

-The first one is financial resources to enable us reach the millions of Kenyans suffering from stroke. The people who form the association are either those who were employed and retrenched from income generating sources or young children who cannot work and those that are too old. So currently we are just in Nairobi.

-The other challenge is that we need to reach many people but we cannot because we lack office tools and equipment's. These are things such as computers, printers, photocopier, stationery etc.

-The other challenge is that people coming to rehabilitation centers for treatment. We need to put up more. But the sick are unable even to reach the available rehab centers due to poverty.

-Capacity building is another challenge. We are approaching the county government to partner with us to have caregivers who are knowledgeable.

-We are planning for a funds drive to enable us have money to reach the many who are suffering.

CONCLUSION

As a young organization, we have succeeded in all our programmes despite the challenges we face. Well-wishers have helped us a lot. We are looking for more to partner with in order to reach the whole country.

