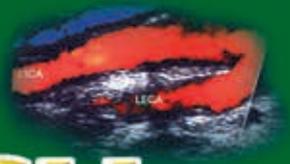




STROKE WATCH



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Executive Committee's Update: One year into its 2-year term

By Dr Deidre Anne De Silva, SNSA President



The SNSA Executive Committee has completed one year of its 2-year term. We have worked hard to fulfil our goals over this last year and I would like to thank the committee members for their hard work, commitment and dedication.

With these efforts of the Committee, contributions from our members, support from collaborating partners and a bit of good fortune, we have had a fruitful year. Here are some of our key updates since the inauguration of the current SNSA committee in April 2013.

1) Awarded Institution of Public Character (IPC) status by the Ministry of Health, Singapore



This was a long and arduous journey and thanks to our perseverance but we finally achieved it! This was really a combined effort of prior and the current committees. Thank you everyone for all your efforts.

We are proud to have been awarded IPC status which recognises the

character and standing of our Association. With this IPC status, all donations to the Association are also tax-deductible. We hope this will encourage more donations from individuals as well as corporate donors.

2) Successful application into the Care and Share Programme and its Matching Grant



This programme is led by the Community Chest and aims to bring Singapore together to show care and concern as our nation approaches its 50th year and to recognise the contribution of voluntary welfare organisations (VWOs) such as SNSA.

With our inclusion in this programme, all eligible donations to SNSA for 2014 will be matched dollar-for-dollar by the government. This matching from the government is aimed at building the capabilities and capacities of SNSA and support our services for stroke survivors and their caregivers.



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3) First-ever Charity Gala

SNSA held its inaugural Charity Gala on 11th August 2013 with the performance of the play *Everything But the Brain*, a bittersweet play that chronicles the journey and experiences of a stroke patient and his daughter, offering important public health messages including raising the awareness of the plight of stroke patients and their caregivers. The Gala was graced by Minister of Health Mr Gan Kim Yong as the Guest-of-Honour. Many of those attending were stroke survivors themselves, caregivers or healthcare professionals caring for stroke patients.



In partnership with a local theatre group Sight Lines Productions and with our main sponsor Boehringer-Ingelheim, the Gala raised over \$50,000 for SNSA. We thank all who helped to make this Gala possible and successful.

4) Befriending services

The stroke befriending services are a core programme of SNSA. Our SNSA volunteers dedicate their time and compassion to befriending new stroke patients while they are still in hospital to provide a listening ear, comforting support and advice from a personal perspective as many befrienders are stroke patients or caregivers themselves.

Our befriending services support Khoo Teck Puat Hospital, Tan Tock Seng Hospital and Ang Mo Kio Community Hospital. We are now starting this service at the Bright Vision Community Hospital and hope to expand this to other healthcare institutions.

SNSA is most grateful to our befriender volunteers, many of whom are long-serving over years. We need more volunteers for the befriending service so please do approach us if you would like to help with this programme.



5) Stroke Clubs and JC trust

Another core programme of SNSA is our stroke club activities. We have continued our periodic stroke club talks and sharing sessions. And recently, SNSA went on a trip to the Singapore River Safari, you can read more about this in the accompanying article in this newsletter.

JC Trust Ltd has kindly agreed to support SNSA with our stroke club activities with a generous donation of \$10,000. This grant will support SNSA's stroke club sessions, pilot projects of stroke chronic disease self-management and music therapy and social integration activities.

We are planning activities for stroke patients and families in year 2014.. Do look out for the announcements for these activities and programmes.



6) Stroke Advocacy

Being an advocate for stroke survivors and caregivers in Singapore is one of SNSA's key missions. SNSA is proud to have had a representative on the writing committee of the World Stroke Organisation's Stroke Survivors Bill of Rights. This Bill of Rights will be launched during the World Stroke Month in October 2014.



7) Stroke Public Awareness

SNSA continues to be a voice to raise public awareness of stroke in Singapore through public talks, community events as well as production of education collaterals. Together with support from Bayer HealthCare, we produced bookmarks with messages on stroke signs and risk reduction in English and Mandarin.

8) Community Events

Our Association has been involved in numerous community events over the last year. The biggest one is the World Stroke Day event on 19 October 2013 at Hong Kah North Community Centre where there was free health screening for over 250 participants and public education talks.

SNSA was also involved in the Sembawang GRC Healthy Lifestyle & Celebrate Wellness event on 18th August 2013 where we had a booth with games and shared stroke education with members of the public.

We have been invited to speak to various forums on stroke including at the Institution of Engineering and Technology, the Woodlands Galaxy Community Centre and the Singapore Rehabilitation Conference.

9) Volunteer Appreciation

SNSA held an appreciation even for our volunteers in 23 November 2013. This was kindly supported by a grant from Start Now Pte Ltd, which headed a campaign for International Volunteer Day. It was the biggest volunteer event SNSA has had with over 40 volunteers in attendance. We had a great time, eating, mingling, sharing and coming up with new ideas for our Association.

10) New communications and liaisons executive (ask Jaime for photo)

We are very happy to welcome our communications and liaisons executive Ms Jaime Yeo who joined us on 1st February 2014. With Jaime's experience with communications and community services, we aim to broaden our outreach through communications including social media as well as new and exciting initiatives.

What's going on now and what's coming up?

There are a lot of things going on at SNSA. On the 26th of April 2014 we will be holding our annual general meeting-cum lunch. Following this, we are planning a social integration outing to Marina Sky Park followed by Hi-Tea and Marina Bay Sands on 26th April.

SNSA will be having a flag day on 25th June 2014 when we hope to raise funds for our Association as well as spread the message of stroke to the community. We need volunteers so please do contact us if you would like to help. SNSA has started some initial discussions on activities for World Stroke Day and possibly another Charity Gala. We will keep you posted on these via the website and StrokeWatch.

A major task of the Committee is finding a location for SNSA's office as our current premises are being withdrawn in July 2014. We have explored various options and are working hard to secure an accessible location which suits our needs and budget.

We have embarked on revamping SNSA's website to make it more user-friendly and current. Our aim is for the website to be a key tool for communication with our members and volunteers, a library bank of stroke information and a link to resources for stroke survivors and their caregivers.

SNSA is planning a membership drive. We aim to recruit more members and volunteers in order to expand our outreach, services and programmes. We also are aiming to recruit corporate members as potential community partners.

I would like to thank the SNSA members, volunteers and committee members for their commitment, drive and support of our association. We look forward to another successful and productive year ahead for SNSA.

SNSA Outing to River Safari

By Ms Lee Lay Beng, Executive Committee member



A total of 27 members and friends of SNSA decided to venture out and embrace this rare experience as a group at Asia's first and only river-themed wildlife park – i.e. River Safari at Mandai on 16 Nov 2013.

SNSA is grateful to the management of Singapore Zoological Gardens for granting stroke patients free admission and 50% concession for their family members, caregivers and volunteers on the admission tickets. We are also grateful to a kind donor who sponsored the transport fares for the return trip from the Newton Hawker Center to the River Safari.

The crowd was overwhelming as there were lots of school children and families visiting the Zoo that Saturday morning as it was also the first day of the year-end school holidays. Still, the recovered stroke patients were courageous enough to take a leisurely stroll and meander through the park, not forgetting to look out for one another and render support as and when it was required.

With the pristine Upper Seletar Reservoir as a backdrop, we were amazed by the many exploratory river adventures on the Mississippi, Congo, Nile, Ganges, Murray, Mekong and Yangtze rivers. The group demonstrated no hesitation nor uncertainties, but manifested patience, endurance and kindness towards one another as they moved through the crowds as well as the turns and twists in the park. They stopped at the interesting spots taking pictures with family or as a group.

One of the highlights for the group outing was the famous giant pandas, Kai Kai and Jia Jia. Many had not seen them before. This is a pair of male and female Giant Pandas from China's Sichuan province on a 10-year loan to the Singapore Zoological Gardens from the China government, which arrived on





September 2012. The group took the opportunity and patiently waited for their turn to take pictures of the two lovable giants in their beautiful forest where they can be seen playing and eating their favorite bamboo! And some group members stopped at the dim sum area to savour a special cuisine - "Panda Pau".

Volunteers and also the curious public were impressed by the SNSA stroke patients and caring family members who walked through the park for more than 3 hours; they did not complain about physical exhaustion. They were excited and were looking forward to the experiential dining journey and enjoyed the set lunch at the River Safari Tea House, the park's Chinese restaurant that features cuisine from the main dialect groups in Singapore. This was a great experience to dine together and also had fellowship when they shared their tips and individual tactics on how to manage the crowds in the park.

This was a whole new experience for SNSA to organize a group outing to a public places, and perhaps, through such experience as a group, through this immersive experience, it brings out the best in one another, and also one may also explore the essence of really being part and inclusive of the bigger community / nation.

As SNSA aspires to support the recovery of stroke patients and also to encourage them in greater reintegration in the community, such activities could be considered as part and parcel for leisure and social recreation activities. The group looks forward for such ventures into more public areas and also different places of interest in the future.



Addressing the Long-Term Needs of Stroke Survivors: The Post Stroke Checklist

By Dr Christopher Chen, Neurologist

Stroke is one of the four most common chronic diseases affecting people living in Singapore with over 10, 000 Singaporeans suffering from a stroke every year. The illness not only affects the life of the patient, but also has a drastic impact on their families and caregivers, the health care system, and the community as a whole. The effects following a stroke can last for many years and may result in a number of disabilities and impairments that can decrease the quality of the patient's life. Although the burden of stroke is recognized, there is no standard process to ensure stroke survivors receive proper follow-up care. As a result, the care that stroke survivors receive varies greatly and is at many times inadequate for their needs.

What Is Being Done?

In order to address this need, the Global Stroke Community Advisory Panel (GSCAP) developed the Post Stroke Checklist (PSC) to help health care providers identify long-term problems and make appropriate referrals to specialists. The GSCAP is an international, multidisciplinary group made up of 21 stroke experts from 9 countries covering 6 specialty areas. The PSC was developed with the idea that it should be simple and easy to use by health care professionals, focus on problem areas where evidence-based data support the effectiveness of interventions, and that it would concentrate on areas where an intervention has the largest impact on a stroke survivor's quality of life. The PSC was developed following a four step process (Figure 1) and resulted in the identification and inclusion of 11 areas which are:

- secondary prevention (preventing another stroke)**
- activities of daily living (basic self-care activities)**
- mobility (walking, moving between bed and chair)**
- spasticity (stiffness in the arms and/or legs)**
- pain**
- incontinence (controlling bladder or bowels)**
- communication**
- mood (anxiety or depression)**
- cognition (thinking, concentrating, remembering)**
- life after stroke (leisure, hobbies, work), and**
- relationship with caregiver (more difficulty, stress).**

The strain on the patient's family and care giver should not be forgotten (Chris, I took this from the WSO website)

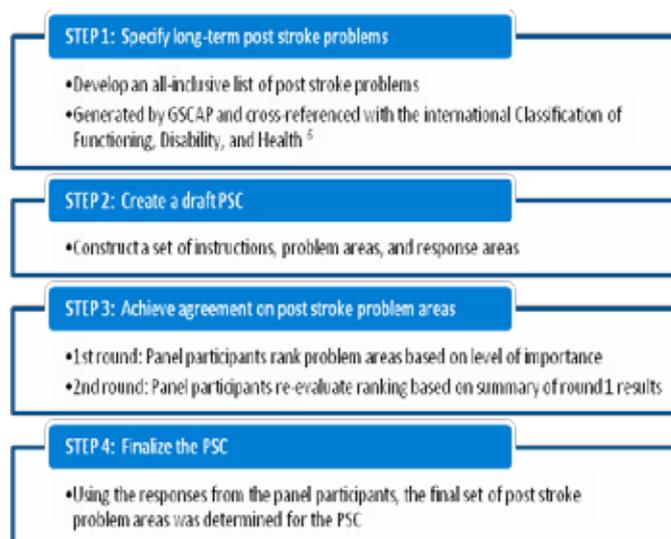
Testing the PSC

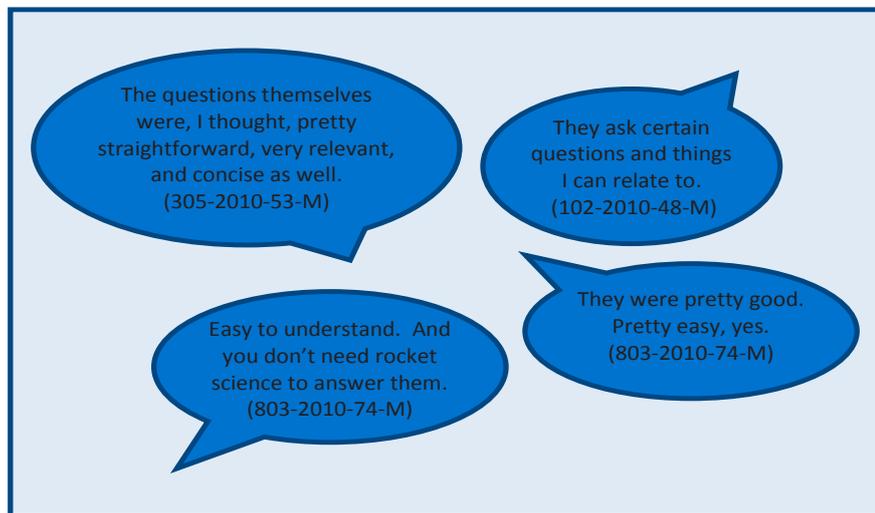
In order to determine the usefulness of the PSC for both patients and health care professionals, initial tests were conducted in the United Kingdom and Singapore. These pilots looked at the real-world use of the tool with the goal of identifying any missing concepts to aid in the further development of the PSC. The results showed that the PSC was well accepted by patients and health care providers. The patients were very satisfied with the PSC (Figure 2) and provided valuable feedback for further refinement of the PSC. The health care providers also had positive feedback and most indicated that they would consider using the PSC for the majority of their post-stroke patients. Overall, the PSC was able to identify a wide range of unmet needs and was generally well understood.

Endorsements and Next Steps

With all of the feedback gathered from the initial tests in the United Kingdom and Singapore, the PSC was updated, and the PSC is now being utilized in several implementation studies worldwide. In addition, several international stroke associations have endorsed the PSC, including the World Stroke Organization (<http://www.world-stroke.org/advocacy/post-stroke-checklist>), the Canadian Best Practice Recommendations for Stroke Care (<http://www.strokebestpractices.ca/index.php/news/new-post-stroke-checklist-ensures-patients-needs-are-being-met/>), and the USA's National Stroke Association (<http://www.stroke.org/site/PageServer?pagename=afterstroke>).

Figure 1. Developing the Post Stroke Checklist





The PSC is a valuable tool for health care providers to use to ensure their stroke patients are receiving the necessary follow-up care to address any problem areas they are facing. As the PSC is implemented into clinical practice, this tool will help improve the long-term care of stroke survivors which will ultimately improve their quality of life while easing the burden on their families and caregivers.

Figure 2. Sample Patient Quotes from the Initial Testing in the United Kingdom

World Stroke Association Bill of Rights for Stroke Survey

Dr N V Ramani and Mr Anthony Quek, SNSA Executive Committee members

The World Stroke Organization is inviting stroke survivors and carers to give feedback on the Global Bill of Rights (BOR) for Stroke. The BOR will be launched during the 9th World Stroke Congress in Istanbul, Turkey which will be held from 22-25 October 2014. The BOR is being developed because there is an urgent need for:

- Increasing stroke awareness among the population and government
- A global policy on stroke prevention, improved health services and long term support for survivors
- Enhanced advocacy: putting a face to the fight against stroke in as much as other diseases have, e.g., AIDS, cancer, tuberculosis, etc.
- A call-to-action reference document for advocates

The BOR is developed by stroke survivors and carers after consulting other stroke survivors and carers from around the world. It will look at what the really important things for stroke survivors are.

There are 2 types of survey forms – one to be filled in by stroke survivors, one by carers. There are 19 questions all focused on the stroke survivor. The first 4 questions are on age, gender, which country the stroke survivor lives in, and the number of years since the first stroke. The remaining questions ask if one strongly agrees, agrees, is neutral, disagrees or strongly disagrees with the statements. These statements are about the right of the stroke survivor to be informed about signs of stroke, rapid diagnosis, treatment by a specialised team, informed about what has happened to him/her, inclusion in all aspects of society, hope for the best possible recovery, well-coordinated care, connection with other stroke survivors, psychological and emotional support, individualised treatment, support for long-term care, return to work and other activities, access to treatment, advocacy, and input into the design of clinical trials.

The survey is available in many languages including English and Chinese and takes about 5 to 10 minutes to full. The website is:

<http://www.worldstrokecampaign.org/2012/Learn/Pages/GlobalBillofRightsforStrokeSurvey.aspx>

[Do visit the webpage and participate in the survey.](#)

Upcoming Events @ SNSA

1) Stroke Club activities (bi-monthly starting from Feb 2014) – total of 6 sessions

- ❖ Emotional Competency in Managing and Coping with Stroke – 22 Feb
- ❖ Post-stroke Checklist (recommended by World Stroke Organisation) – 29 Mar
- ❖ Fall Prevention – Assessment & Intervention – 26 Jul
- ❖ Road to Recovery – Driving Assessment – 27 Sep
- ❖ Healthcare and Social Care Resource Mapping & Planning – 18 Oct
- ❖ Arts & Therapy – 8 Nov

2) Pilot Projects

❖ Stroke Disease Self-management

Organised visits and dialogues with healthcare providers and skill-based workshop training to be provided by 2 experts from Hong Kong Society for Rehabilitation from 21 to 24 May 14 (funded by SHMDP-Visiting Expert scheme from MOH), 1-day pre-workshop training on understanding the Stanford model of self-management on 09 May. This is a closed door event for registered invited participants

- ❖ Music Therapy sessions for caregivers- programme of 5-6 sessions starting from August 2014. Further details will be announced once confirmed

3) Social Integration activities

- ❖ 26 April – to Marina Bay Sand for afternoon tea session
- ❖ Jun 14 – to Going to the movies
- ❖ Nov 14 – to Singapore Botanic Gardens for year-end celebration / retreat to seek inner healings

For further details, please refer to the SNSA website at www.snsa.org.sg or call the SNSA office at 6358 4138 or email at Jaime@snsa.org.sg

