

Campaigning and advocating

- Choosing the right tool to make a change -

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THIS PRESENTATION IS ABOUT

What is advocacy

**WSO Advocacy
Toolkit**

**Why do you need
a web site for
your SSO**

**Why you need a
social media
campaign**

**Setting up the
right tools for
campaigning
and
advocating**

ADVOCACY TOOLKIT

WORLD STROKE ORGANIZATION

One World Voice for Stroke

What is Advocacy?

Activities that bring about change in policies, practices and attitudes of organizations and institutions about stroke.

Examples:

- Advocating for a government strategy to address stroke in your country; or
- Collecting and reporting on stroke data to show local health authorities that there is a need for new stroke services.

One World Voice



Advocacy vs Awareness

Advocacy is different to awareness raising, although you may need to raise awareness of a problem to strengthen your advocacy efforts

- Making a change in the system benefits everyone affected.
- Need to understand why decision-makers may not want to make the changes we are asking for, **and then work to persuade them!**

One World Voice



WORLD STROKE ORGANIZATION ADVOCACY TOOLKIT

- Successfully Piloted with 11 participants (neurologists, SSO reps, survivors) from 7 countries at WSO Congress in India in October.
- Freely available to download and use from Monday.



DEVELOPING YOUR ADVOCACY PLAN: THE 9 STEPS TO ACHIEVE CHANGE

One World Voice



**World Stroke
Organization**

Step-by-step guide to develop an effective advocacy strategy

Step 1 – What do we want?

Step 2 – Who can give it to us?

Step 3 – What do they need to hear?

Step 4 – Who do they need to hear it from?

Step 5 – How do we get them to hear it?

Step 6 – What have we got?

Step 7 – What do we need to develop?

Step 8 – How do we begin?

Step 9 – How will we know it's working, or not?

One World Voice for Stroke

Worksheets & Case Studies

WORKSHEET 3.2

For Step 3

WORKSHEET 3.2

Developing the evidence for your advocacy goal and messaging

Complete the following worksheet in relation to your advocacy goal. Use this information to help you refine and strengthen your advocacy message.

	Key message/evidence
How many people are affected by the problem?	
What does the evidence, best practice guidelines, or policy suggest should happen?	
What happens to people at the moment?	
What does local data, including data from a high quality register if available, say about access to this treatment/care you are seeking to improve?	
Why is access less than optimal - what is the cause of the problem?	
How many people would benefit from the problem being fixed?	
Has this issue been raised in the past? Have there been recommendations in the past about this issue?	
Is there any research that shows whether this problem will increase in the future, or have greater impact in the future?	
Are there any cost-effectiveness studies to show that solving the problem has an overall benefit to society?	
How do other countries deal with this problem? Providing your target decision-maker with examples from other places can help persuade them to act.	
Does the issue reveal any inequalities in society, or make existing inequalities worse? For example, does the problem affect those who are poorer the worst?	

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USING A COALITION OR FORMING AN ALLIANCE

STEP 4

You might work with others informally or more formally through a formal Coalition.

Coalitions often require a lot of work to keep everyone focused on the same advocacy goal.

In some areas, there may already be some alliances around stroke-related issues (e.g. prevention, improved disability support). If so, consider joining forces with them. The World Stroke Organization, your local SSO or stroke research body may know if any such alliances already exist.

It will also be important that you anticipate who your opposition, if any, will be. It can be helpful to reach out to those stakeholders/organizations proactively to understand their concerns in advance so you can address those concerns or attempt to neutralize their opposition messaging.

To learn more about Coalitions, see Worksheet 4.2.

Stroke Alliance for Europe

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

One of SAFE's main objectives is to raise awareness and understanding of stroke and stroke prevention with policymakers at pan-European and national levels. SAFE is dedicated to muster the political will to help prevent stroke-related death and disability. SAFE recently coordinated a 260,000 euro research project on the burden of stroke in Europe, which will assist in enabling advocacy and awareness raising specific to each country based on both evidence and patient and family testimony.

CASE STUDY

WORKING WITH CONSUMERS

Use Worksheet 4.3

People affected by stroke, including stroke survivors and caregivers, can be powerful allies in advocacy efforts.

They are able to talk first hand of the impact of stroke, and to highlight the problems associated with poor care.

They can also reinforce the human element of the stroke burden.

Any people involved in advocacy plans will need to be supported and communication will need to be clear.

Stroke Action UK partners with stroke survivors and carers to lobby and influence decision makers for better stroke care through their Volunteer Stroke Ambassadors' development program.

These help you to navigate the 9 Steps to build your Advocacy Plan

Learn From Advocacy Efforts of Others

Advocacy Plan for \$2M funding for FAST campaign across Australia

What do we want? (goals and objectives) Funding of \$2million AUD for the delivery of the FAST campaign across Australia for one year	How do we get them to hear it? (delivery) <ul style="list-style-type: none">• Write to Minister outlining the proposal and requesting a meeting• Meet with Department of Health staff to improve their understanding of the proposal• Meet with Minister and Ministerial staff to outline proposal. Take stroke survivors to this meeting so they can talk to the importance of the FAST Campaign• Talk to other MPs who can also reinforce the importance of the Campaign to the Minister (Parliamentary Friends of Heart and Stroke group)
Who can give it to us? (key decision makers) <ul style="list-style-type: none">• Federal Minister of Health• Department of Health (Head of Chronic Disease Branch)	What have we got? (resources; strengths) <p>We had good data for the effectiveness of FAST in Australia. This included survey data measuring signs of stroke amongst the general public, Audit data demonstrating how many people did not arrive in time for acute treatments, stroke relationships with key people who could join us to make a strong united voice, results from a small pilot we ran in a regional part of NSW demonstrating that when we advertised, we saw a shift in knowledge of signs of stroke</p>
What do they need to hear? (messages) <ul style="list-style-type: none">• The burden of stroke in Australia (how many, how much it costs, level of disability)• The importance of rapid assessment and treatment and impacts of acute therapies on outcomes, cost and length of stay• Levels of ignorance of the signs of stroke (from our survey of the community) and the impact of this on early presentation to hospital (from our National Stroke Audit)• The effectiveness of a FAST Campaign in getting people to understand the signs of stroke and dial 000 (from published studies and from our pilot of the FAST Campaign in regional NSW)• The cost of a campaign and how we will deliver it• Our plans for engaging partners to help us spread the message in a cost effective way and make health dollars go further• Successes in other countries where a FAST Campaign has been run (UK)	What do we need to develop? (challenges; gaps) <p>When we began this work we did not have good data on the cost effectiveness of a FAST Campaign so we developed this over the time it took to implement the Advocacy Plan</p>
Who do they need to hear it from? (influencers, coalitions, alliances) <ul style="list-style-type: none">• The National Stroke Foundation (us)• Key clinical leaders (Stroke Society of Australasia)• Survivors who have and have not received acute therapies• The Australian Stroke Coalition• People within the Department of Health	How do we begin? (first steps) <p>Our first steps was to develop a business case for the FAST funding – using all our arguments outlined in Step 2 of this plan</p>
	How will we know it's working, or not working? (evaluation) <p>We measured success by the level of interest the Minister showed for the program, the number of conversations we were able to have about the proposal, the number of MPs we had joining us in our advocacy efforts and talking the Minister.</p>

Source: Stroke Foundation (Australia)

Next Steps

- Download the Advocacy Toolkit
www.worldstrokecampaign.org
- Complete the Advocacy Plan Template
- Send completed Advocacy Plan to campaigns@world-stroke.org for feedback and support

Your name: XXXX Your email: XXXXXXXX

My Advocacy Plan

Based on the knowledge gained from the Advocacy Toolkit, please identify an advocacy topic relevant to you and complete the table below (dot-point form is fine). Please send your completed Advocacy Plan to campaigns@world-stroke.org and advocacy@world-stroke.org by Wednesday 19th October.

1) What do we want? (goals and objectives)
2) Who can give it to us? (key decision makers)
3) What do they need to hear? (messages)
4) Who do they need to hear it from? (influencers, coalitions, alliances)
5) How do we get them to hear it? (delivery)
6) What have we got? (resources, strengths)
7) What do we need to develop? (challenges, gaps)
8) How do we begin? (first steps)
9) How will we know it's working, or not working? (evaluation)

One World Voice



- Help WSO develop an interactive map of global stroke Advocacy Plans / Case Studies



- Contact International Development Officer, Sarah Belson sarah.belson@stroke.org.uk to get involved.



Thank you

Download the Advocacy Toolkit

www.worldstrokecampaign.org

Available from Monday 12th December



LET'S GO DIGITAL

WHY DO YOU NEED A WEB SITE FOR YOUR SSO

In a world where over 70% of population in any country is now online and on Social Media, we no longer have the luxury of not being online, with our organization, with our causes, with our goals, with our communication, with our campaigns.

WHY YOU NEED A SOCIAL MEDIA CAMPAIGN

Social Media is extension of overall communication activities and relationship with stakeholders, politicians, institutions.

We need websites and Social Media as a tool that creates buzz, a tool that reaches mass of people who are already online; a tool through which we engage with relevant communities (general public, stakeholders, politicians, lobbyists, etc).

CEE EXAMPLE



Average TV viewing time (hours/day) in 2015, for the CEE countries is between 50% and 60% shares, meaning that over 50% of the population watches TV on a daily basis.

At the same time, general Internet statistic shows us that the increase of the Digital is on the significant rise: internet penetration is over 60% of total population and, in terms of daily usage, most countries have over 65% urban daily usage.

2/3 OF ALL INTERNET USERS ARE ON FACEBOOK

Knowing that, when we talk about Social Media, lets see:



The number of active users across the CEE region is over 40% of the total population of each country and Facebook users amount to more than 60% of the Internet users across all the countries in the region.

SETTING UP THE RIGHT TOOLS FOR CAMPAIGNING AND ADVOCATING

News / reports
TV Appearance
Corporate Design
Corporate advertising
Outdoor advertising
Photos

Interviews / statements
Open (public) and closed (target)
discussion
Public appearances/ speeches
Press conferences
Events, visits and trips (to water treatment
facilities) for media representatives
Verbal information (word of mouth)

Press releases
Newsletter
Corporate periodicals
Brochures and manuals
Annual reports
Corporate advertising

Web site
Social media
Blogs / forums
Online content
E-mail
Sms

USING THE NEW CHANNELS

SSO's web site:

- Because it is 100% YOUR channel
- Easy to use
- Low set-up costs

Facebook / Twitter:

Because your audience is already there, waiting to be reached by you



BEST PRACTICE EXAMPLES

Sign Against Stroke
@signagnststroke
in Atrial Fibrillation

TWEETS 10.9K FOLLOWING 2,407 FOLLOWERS 9,036 LIKES 1,128 LISTS 18

Sign Against Stroke
@signagnststroke
Sign Against Stroke in Atrial Fibrillation unites patient, medical, and policy communities in a desire to improve the prevention of #AFib-related #stroke
signagainstroke.com
Joined April 2013

Tweets Tweets & replies Media

Sign Against Stroke @signagnststroke · 2h
Researchers find that age and lesion volume affect risk of #epilepsy after #stroke buff.ly/2h4MwzY #AES2016 HT @NeuroAdvisor

Who to follow · Refresh · View all

- Bridget Bergin @BBergin1
Followed by Jon Barrick and...
Follow
- Bayer Crop Science @B...
Follow
- BASF @BASF
Follow

Find friends

BEST PRACTICE EXAMPLES

Lost for words
Find out how you can support stroke survivors who are lost for words:
stroke.org.uk/lostforwords

Stroke association

Stroke Association @TheStrokeAssoc · 1h
We would not be able to do our vital work without the amazing volunteers who help us. Thank you! #InternationalVolunteerDay #IVD2016

Andrew can't find the right words to join in the conversation.

TWEETS 22.1K FOLLOWING 1,955 FOLLOWERS 88.8K LIKES 20.3K LISTS 2

Who to follow · Refresh · View all

- Bridget Bergin @BBergin1
Followed by Jon Barrick and...
Follow
- Neurology Now @Neurolo...
Follow
- AAN @AANMember

15:09

BEST PRACTICE EXAMPLES

**FUNDACJA
UDARU
MÓZGU**

szukaj

[Prawa pacjenta](#) [Kontakt](#) [Do Pobrania](#) [WESPRZYJ NAS](#)

[Strona główna](#) [Udar mózgu](#) [Fundacja](#) [Kampanie](#) [Twój 1% dla Fundacji](#) [Wspierają nas](#)

Strona Główna [About Stroke Foundation](#)

[About Stroke Foundation](#)



Stroke Foundation is the first Polish non-governmental organization whose mission is to help people after stroke, their families and carers. Our foundation was organized by doctors, physiotherapists, physiologists, people who had stroke and their carers. The Foundation enjoys the broad support of medical profession. In our activities we help people after stroke and we also focus on stroke prevention. We want to change the situation and the image of people after stroke in Poland. Great attention is attached to social and vocational activity.

 **Drukuj stronę**

 **Wyślij znajomemu**

 **Odwiedź także**



PROPOSED PR TOOLS

Story pitching in media

Free stroke prevention lectures for elderly people in retirement facilities and nursing homes

Street events

A survey (offline/online) about stroke symptoms and urgency of reaction (for the purpose of exploitation in media)

Social media activities

Infographics combined with press releases

Creating/ generating news

Leaflets

Third persons' endorsement

PR PLAN FOR DIGITAL

Conduct the PR campaign for Burden of stroke using all SAFE digital accounts on Social media



Twitter:
Introduce the
#strokeburden;
engage with
SAFE partners
and other
organisations



Facebook:
Regular posting
about BoS
combined with
paid advertising
to increase reach



Youtube:
Make & post SAFE
members stroke survivors
stories, videos interviews
with BoS researchers (all
they need is a good will
and a laptop camera!) The
video should be sent to
info@safestroke.eu
and would be posted on
SAFE YT Channel
within 24 hours.

SOME WAYS HOW SAFE MEMBERS CAN GENERATE NEWS

Give an award to draw attention to values and issues - e.g. „Stroke Excellence Award“

Hold a contest to involve others in your values and issues.

Select personnel to head a new program or begin a new project.

Comment on a local need or problem.

Conduct research and issue a report about a local need or problem.

SOME WAYS HOW SAFE MEMBERS CAN GENERATE NEWS

Launch a campaign to accomplish something.

Give a speech to a significant audience and tell the media about it.

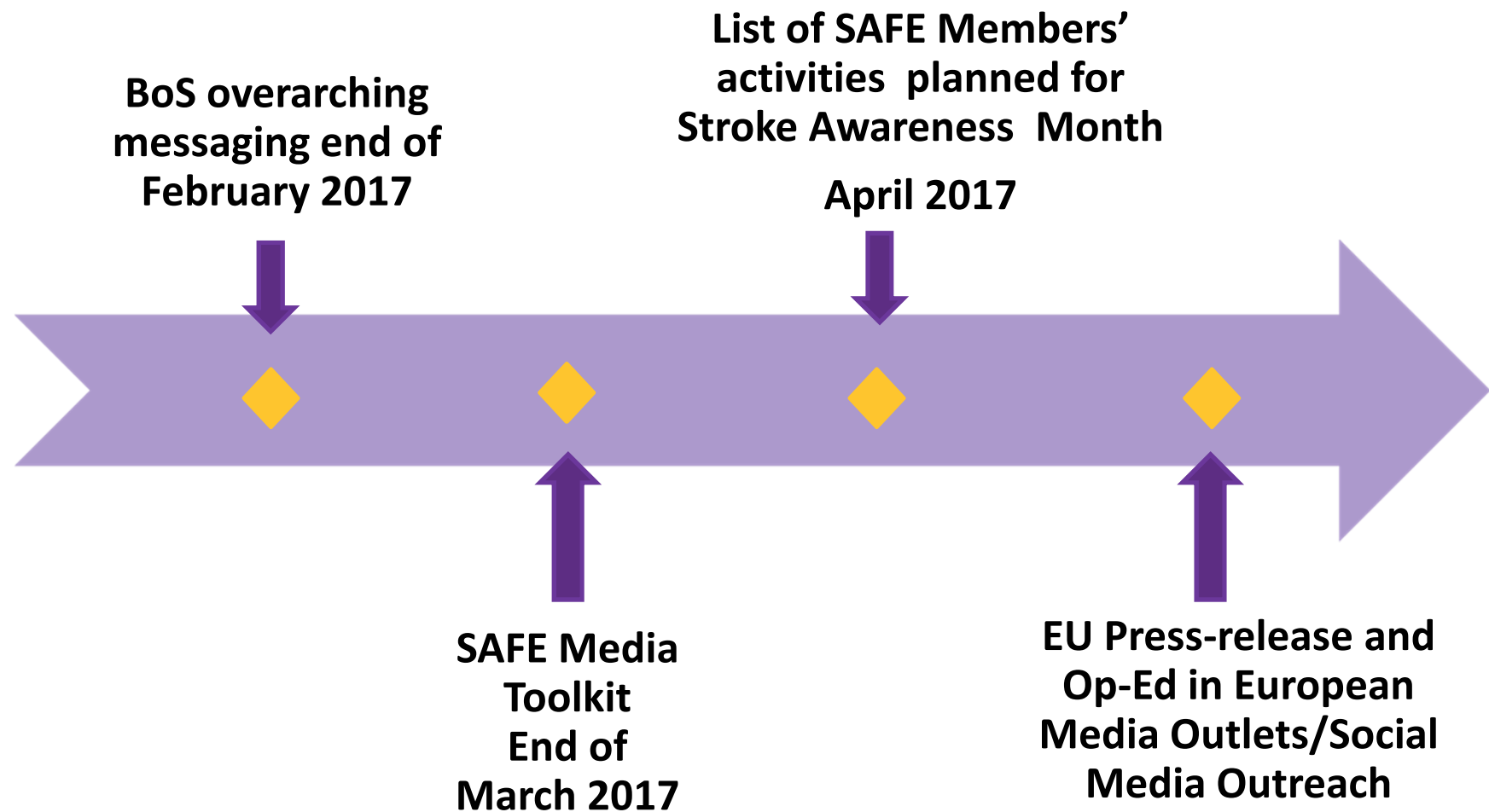
Involve a celebrity to visit and/or address your organization on a topic of concern to you.

Tie into an issue already high on the public or media agenda or link your organization to the top news of the day.

Localize a general report

Source: Smith, R. D. (2003). *Becoming a Public Relations Writer* (2nd ed.). Mahwah, NJ: Lawrence Erlbaum Associates.

TIMELINE AND MILESTONES



TIMELINE OF ACTIVITIES*

Activities	XI I	I	II	III	IV	V	VI	VII	VIII	IX
BoS Pan-EU Launch										
Digital campaign (Tw, Fb, YT)										
BoS PPT slides dissemination and promotion- National launches										
Safetsroke.eu BoS campaign										
Interviews with BoS researchers; for dissemination										
World Stroke Day events and preparation										
Local BoS PR activities and launching events										
SAFE stroke survivors video stories										
Localize a general BoS report										
Establish SAFE award for excellence										
Evaluation										

*Tentative plan



Work in progress...

FINAL REMARKS

By using digital channels and Social Media itself, we can reach to more people with our messages, our goals and determinations to change the relevant legislations, we'll increase awareness and trust in the organization, build reputation as well as obtain relevant insights from the community that we engage with: stakeholders, politicians, lobbyists, general population.



THANK YOU!

www.safestroke.eu

