

## MSAC survey on community views of proposed new treatments for MS

### Purpose of the survey

The purpose of this survey was to understand community views of how people prefer to source information they can trust about proposed new treatments for MS, as well as what factor/s would make them more likely to consider trying a proposed new treatment for MS. Since the theory of chronic cerebrospinal venous insufficiency (CCSVI) being important in MS has received a great deal of attention recently, we also asked people whether or not they had heard about CCSVI, whether they or someone they know has considered or tried CCSVI treatment to manage MS symptoms, and what the outcome of any such treatment has been so far.

### Survey details

This survey was conducted in October 2010. It was sent to MSAC members' contacts and also promoted on the "Australians with MS on line" email group. Recipients were encouraged to pass the survey on to *their* contacts within the MS community and in this way the survey was promoted on at least one Facebook page (CCSVI Australia). A total of 36 people took part in this survey.

### Questions asked in the survey

The questions that were asked in the survey are as follows:

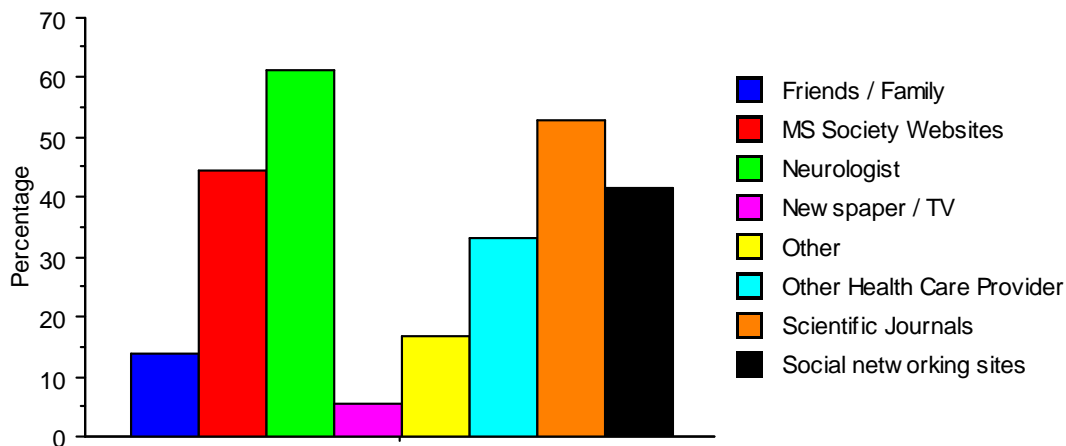
1. Where do you prefer to source information you trust about proposed new treatments for MS, including medications, lifestyle changes or interventions? (please choose up to 3 and mark with a X)
  - a. Neurologist
  - b. GP or other (non neurologist) health care provider
  - c. Newspaper or television reports
  - d. Scientific journals
  - e. MS society websites
  - f. Speaking with friends or family
  - g. Social networking sites or email groups
  - h. Other (please specify)
  
2. What factors are most important to help you decide whether you would consider trying (or recommending) a proposed new treatment for MS, such as a medication, lifestyle change or intervention? (choose up to 3)
  - a. Safety / possible side effects of the proposed treatment
  - b. Encouragement from someone who found the treatment helpful
  - c. Neurologist advice regarding the treatment
  - d. Advice from other health care professionals
  - e. Financial cost of the treatment
  - f. Advice from friends or family to try the new treatment
  - g. Availability of published, scientific studies supporting the treatment
  - h. Desire to avoid currently available drug therapies for MS
  - i. Other (please specify)

3. Have you heard of the theory that Chronic Cerebrospinal Venous Insufficiency (CCSVI) may be important in MS?
  - a. Yes
  - b. No (thank you, you have finished this survey)
  
4. Are you (or someone you care for) currently considering undergoing CCSVI treatment for managing MS symptoms?
  - a. Yes
  - b. No
  
5. Have you, someone you know, or someone you care for already undergone CCSVI treatment to manage MS?
  - a. Yes
  - b. No (thank you, you have finished this survey)
  
6. Which best describes the response of your (or the person you know) MS symptoms to treatment for CCSVI? (please select one)
  - a. MS symptoms very much improved
  - b. MS symptoms somewhat improved
  - c. No effect on MS symptoms
  - d. MS symptoms somewhat worsened
  - e. MS symptoms very much worsened
  
7. Which best describes how long any effect of CCSVI on your (or the person you know) MS symptoms lasted? (please select one)
  - a. CCSVI treatment did not influence MS symptoms
  - b. The effect of CCSVI treatment lasted less than 1 week
  - c. The effect of CCSVI treatment lasted between 1 week – 1 month
  - d. The effect of CCSVI treatment lasted between 1 month – 3 months
  - e. The effect of CCSVI treatment lasted more than 3 months
  - f. CCSVI treatment was done less than 3 months ago, but the effect is ongoing at this time

## SURVEY RESULTS

### 1. How do respondents prefer to source information that they can trust about proposed new treatments for MS?

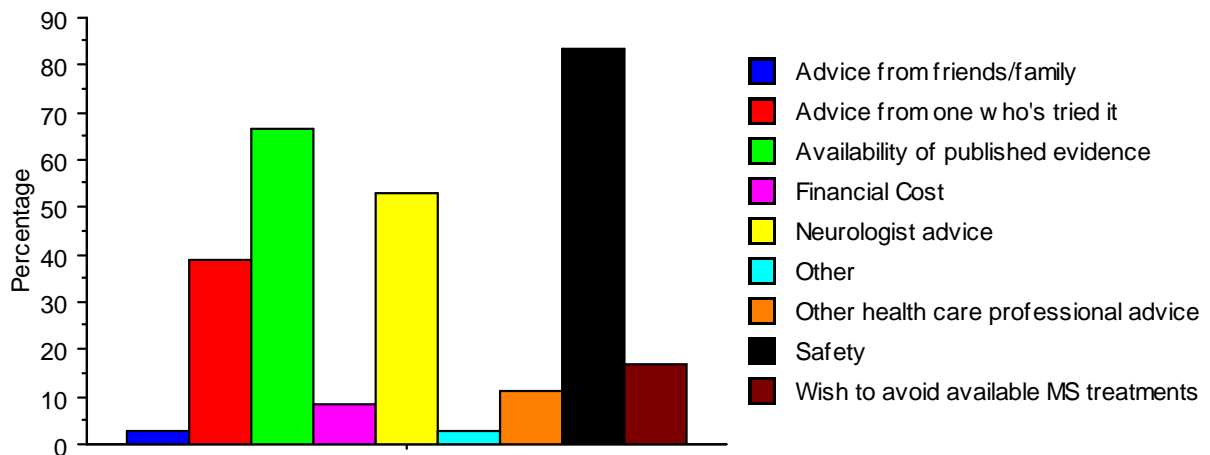
Respondents were invited to select up to three ways they like to get information they can trust about proposed new MS treatments. The percentage of respondents who selected each of the information sources listed is shown below. Overall, advice from neurologists was the most often preferred method of getting information about new MS treatments. Scientific journals were the second most popular source of trusted information. Information available on the internet was also very popular, with MS Society websites and social networking websites trusted by many people. All those who selected "other" specified that they meant other internet-based sources of MS-related information.



*Figure 1: Percentage of people who selected each information source as one of up to three ways they like to find information they can trust relating to a proposed new MS treatment.*

### 2. What would encourage respondents to consider trying a proposed new MS treatment?

Respondents were asked to select up to three things that would encourage them to consider trying a proposed new treatment for MS. Almost everyone selected the safety of the proposed new treatments as an important factor. The three other things that were selected by many respondents (in order of popularity) were the availability of published evidence to support the new treatment, advice from neurologists to try the new treatment, and advice from someone who had already tried the new treatment. Almost one in five people stated a wish to avoid currently available MS treatments would encourage them to try a proposed new treatment.



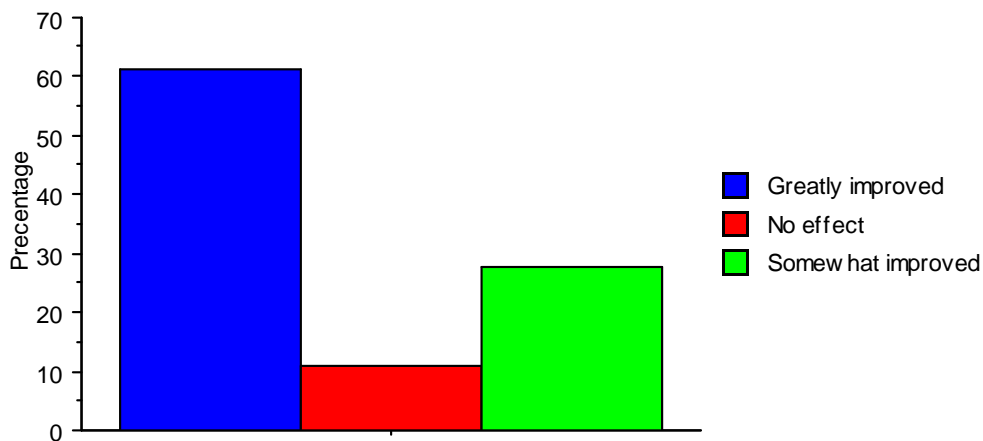
*Figure 2: Percentage of people who selected each factor as one of the three most likely to encourage them to consider trying a proposed new MS treatment.*

### 3. Have people heard about, or tried, CCSVI treatment to manage MS symptoms?

Most (94%) of people were aware of the theory that CCSVI may be important in MS. Of those who have heard of CCSVI, 71% stated that they (or someone they knew) would consider trying CCSVI treatment to manage MS symptoms and 50% stated that they (or someone they knew) had already undergone treatment for CCSVI to manage MS symptoms.

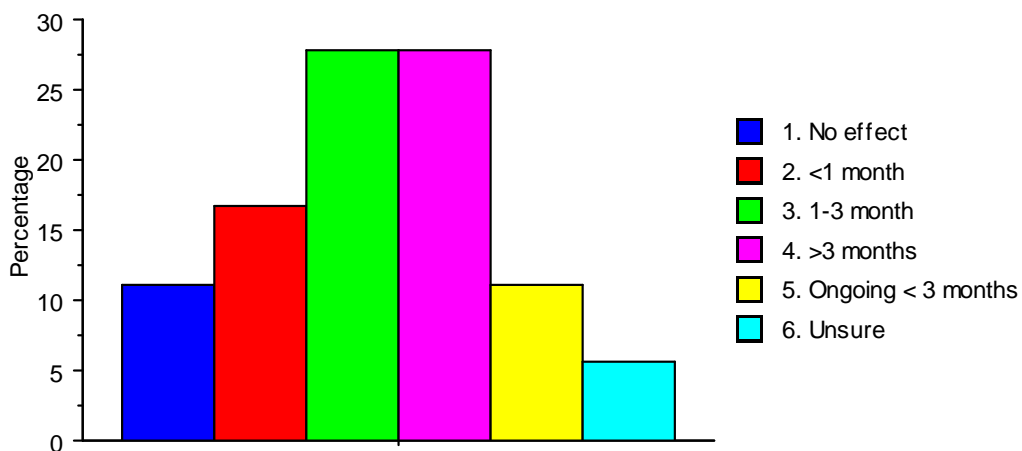
### 4. What perception does the community have of the effectiveness and durability of CCSVI treatment to manage MS symptoms?

17 people who responded to the survey stated that they (or someone they knew) had had treatment for CCSVI. No one felt that MS symptoms had been worsened by this treatment. Most people felt MS symptoms were either somewhat or greatly improved following CCSVI symptoms and two people found that MS symptoms were unchanged following CCSVI treatment.



*Figure 3: effect on MS symptoms of CCSVI treatment in those who have undergone (or know someone who has undergone) CCSVI treatment to manage MS symptoms*

The perceived benefits of CCSVI treatment were temporary in most cases. Of the 17 people who had undergone (or know someone who has undergone) CCSVI treatment for management of MS symptoms, the effect of this treatment on MS symptoms was known to have lasted >3 months in only 5 patients. More than 50% of people felt there was not a lasting benefit from a single episode of CCSVI treatment beyond 3 months. In two cases, the effect of CCSVI treatment was ongoing at the time of the survey, but the treatment took place less than 3 months earlier.



*Figure 4: Duration of response to CCSVI treatment in those who had undergone (or know someone who has undergone) this treatment for the management of MS symptoms.*

## CONCLUSIONS

The results of this survey must be interpreted with care, as they constitute the views of 36 people and may not be representative of the wider "MS community" in Australia. Bearing this in mind, the major findings are that:

- the community prefers to source information they trust about proposed new MS treatments from neurologists, scientific journals, and the internet (MS Society websites were the internet sites most often preferred here)
- the things that would most encourage community members to consider trying proposed new MS treatments are the safety of those treatments, the advice of neurologists, the availability of published evidence to support the new treatments, and encouragement from people who have already tried the treatments
- most people are aware of the theory that CCSVI may be important in MS
- two thirds of those who have heard of CCSVI in MS have considered seeking treatment for CCSVI to manage MS symptoms, and half have done so
- most people who have tried CCSVI treatment have found their MS symptoms improved to some degree, but improvements were often temporary (lasting less than 3 months)

These initial results indicate that internet-based information sources, including MS Society websites, are one of the ways people prefer to obtain information about proposed new MS treatments. MSAC therefore recommends that the provision of clear, accurate and timely information on proposed new MS treatments on websites (eg MSA and MSRA sites) should remain a priority. This information should be updated as quickly as possible as new findings become available.

MSAC plans to seek further community input on this topic in the future. Meanwhile, the above findings have been given to the Board of MSL.

***THANK YOU to all those who took part in the survey! MSAC looks forward to seeking further input from the MS Community in the future.***