

Hepatitis C Treatment

Sharon Caris

At the recent 5th Australasian Viral Hepatitis Conference in Sydney there was agreement from a range of Australian and international speakers that it is imperative that people access treatment in a timely manner to prevent hepatitis C developing to cirrhosis. It was also acknowledged that comorbidities including obesity, and alcohol and social factors need to be addressed and that uptake of treatment to give people a better chance of avoiding cirrhosis or liver cancer needs to be increased. Treatment toxicity, the requirement for a liver biopsy (no longer required) and social factors were described as a significant barrier for many to undertake treatment. Although there are new drugs which might be more readily tolerated or behave differently in the immune system in the pipeline, these are still 3- 6 years away.

It is estimated that 260,000 people in Australia have been exposed to hepatitis C, and there are 16,000 new infections occurring each year. 65,300 of all have cleared hepatitis C, however 195,000 are living with hepatitis C. At least 50% of those infected can be cured with treatment (there is a higher chance of success for genotypes other than 1), yet only 1% of people who are infected with hepatitis C are accessing treatment.

Of the 195,000 with hepatitis C, 153,300 have stage 0/1 fibrosis, 32,800 stage 2/3 fibrosis and 8,160 have cirrhosis. Among people with hepatitis C related cirrhosis, the annual risks of hepatocellular carcinoma, liver failure and death are approximately 2%, 5% and 4% respectively.

It is likely that up to 60% of people with bleeding disorders have hepatitis C. People who acquired hepatitis C through infected blood products have now been infected for

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many years, and many have treatment resistant genotypes and other significant health issues to deal with which may explain delays to consider treatment. Health professionals report that many people in our community do not explore treatment options. It is likely that treatment uptake in the bleeding disorders community reflects that of the general community.

The HFA Board has recently decided to review the needs of the bleeding disorders community to ensure everyone has access to appropriate information, education and the necessary resources to make treatment decisions and undergo treatment if appropriate to their circumstances. This will involve working with health professionals at haemophilia centres, clinical specialists, health organisations, hepatitis councils, State/Territory Haemophilia Foundations and governments.

Living well with hepatitis C

Living Well with Hepatitis C was supported by Haemophilia Foundation Victoria and the Hepatitis C Council of Victoria in October 2005 and was attended by over 40 people. Presentations from health professionals Nicola Dervan (Dietitian), Jane Daley (Naturopath), Rebecca Good (Physiotherapist) and Megan Coulter (Occupational Therapist) covered a range of topics relating to living with hepatitis C. The program was organised by Sandy Breit, Hepatitis C Counsellor, Haemophilia Foundation Victoria who is based at the Alfred Hospital, Melbourne. The program provided people with tips on coping with fatigue, food and the liver, how to handle nausea and/or fatigue and how to deal with the effects of stress.

HFA has permission to reprint reports of the presentations prepared by Michele Fisher for Haemophilia Foundation Victoria, however the material has been necessarily abbreviated for this publication. Always seek advice from your qualified health professional.

Nutrition in hepatitis C

Nicola Dervan

The role of the liver

- acts as a 'factory' that converts raw materials from your digestive system into substances your body needs
- detoxifies harmful substances (such as alcohol) and helps remove waste products
- vitamin storage
- makes bile that aids in digestion and absorption of fats.

Dietary recommendations for Hepatitis C are the same as for the general population for most people with HCV: varied diet, lean meat, poultry, fish or meat alternatives, protein, vitamins and minerals e.g. iron, reduced fat dairy products, protein, calcium and fat soluble vitamins, fruit and vegetable intake, vitamin A, C and fibre, high fibre breads and cereals, pasta, energy, fibre and vitamins, limit saturated fat and moderate total fat intake, choose foods low in salt, consume moderate amounts of sugars and foods containing added sugars, drink plenty of water.

HCV & alcohol

- the risk of developing advanced liver disease appears to be higher for people with HCV if they are also heavy drinkers.

- people with HCV should ideally avoid alcohol or consider only drinking infrequently and well below the levels recommended for the general population.

Vitamin & Mineral Supplements and hepatitis C

- vitamin & mineral supplementation is not recommended if having a 'healthy well balanced' diet
- supplementation may be required in individuals with a poor dietary intake or if experiencing malabsorption of nutrients.
- care must be taken not to exceed the recommended dose as this may be harmful to the liver

Managing HCV Symptoms – people with hepatitis C may report nausea and vomiting, loss of appetite, fatigue (? diet related) and intolerances.

Managing nausea, vomiting and loss of appetite

- small frequent meals, avoid skipping meals, choose nutritious foods, food fortification, try different tastes (eg. salty, sweet, sour) and use favourite foods to stimulate appetite, cool, bland foods to reduce nausea, avoid greasy, spicy and/or favourite foods during nausea, increase salty, sour or tart tastes to reduce nausea, drink nutritious fluids, try dry ginger ale to decrease nausea, avoid lying flat after food, check timing of medications.

- If persistent seek medical/nutritional advice

Common dietary MYTHS

- exclude all fat, exclude all dairy, avoid red meat, avoid sugar, avoid all caffeine, avoid artificial colours and preservatives

Exclusion Diets

- potential dietary deficiencies (eg. iron, zinc, calcium & B12)
- exacerbate protein-energy malnutrition
- potential storage problems for preservative free foods
- extra costs associated with 'special' foods

Advanced liver disease

- protein-energy malnutrition
- small, frequent meals
- high energy and protein foods and drinks
- dietitian review

Ascites

- sodium restriction
- fluid restriction
- dietitian review

Occupational therapy and Hep C - Managing Fatigue and Stress

Megan Coulter

Complementary Therapies

Western herbal medicine (eg. milk thistle, licorice root etc), traditional Chinese medicine, acupuncture, naturopathy, massage, meditation, vitamin and dietary supplementation.

Herbal Treatments and hepatitis C

Some herbal treatments have reported benefits in certain people with hep C (eg. milk thistle). Some herb treatments may damage the liver and may interfere with prescribed medications (e.g. valerian, germander). It is important to discuss all herbal treatment options with your treating doctor.

Medicinal Herbs and hepatitis C

- Cochrane Database of Systematic Reviews (2001) - randomised clinical trials of medicinal herbs for hepatitis C, no firm evidence of efficacy of any medicinal herbs for hepatitis C
- medicinal herbs should not be used outside randomised clinical trials
- "Natural" hepatotoxic agents - chaparral leaf, valerian skullcap, mistletoe, germander, jin bu huan, kava

Who needs to see a Dietitian?

Referral is recommended when patients are experiencing advanced liver disease, anorexia or unintentional weight loss, or other conditions requiring dietary modification (diabetes, coeliac disease, loss of appetite, nausea or general unwellness affecting dietary intake).

- Occupational Therapy focuses on enabling people to live satisfying and meaningful lives by helping people participate in the occupations they want to do, need to do and are expected to do. This includes all the activities that occupy people's time such as self care tasks, household duties, community involvement, work or study and leisure pursuits.

- Fatigue - a subjective, unpleasant symptom which incorporates feelings ranging from tiredness to exhaustion, creating an unrelenting condition which interferes with individuals' ability to function in their usual way" (Stone, 2002)

Tips to manage fatigue:

Energy conservation and work simplification, setting priorities and establishing routines, balancing work and rest, eliminating unnecessary work, modifying the way an activity is performed, changing the environment, thinking in weeks not days, enlisting help.

Benefits of managing fatigue

More energy for the things you want to do, less stress and anxiety, more positive experiences, feeling healthier, enjoying the day, getting more achieved

Stress

- any physical or emotional strain on the body or the mind,
- can affect people differently
- be aware of and recognise the signs and symptoms of stress, as this will help you manage the stress in your life
- a certain level of stress is good and helps people to feel motivated.

Tips to manage stress

Try a relaxing activity, listening to music, gardening, meditation, good time management, do the things you have to, with time to rest, be assertive – stand up for your rights without hurting others, say no, sleep, diet, exercise.

Benefits of stress management

Improved sense of wellbeing, increased ability to do the things you want to or have to, can help you feel calmer, more in control of life, more comfortable physically and mentally

Exercise & hepatitis C

Rebecca Good

Importance of Exercise

- Exercise is important for maintaining/improving health and reducing risk factors
- exercise intervention is effective in reducing self reported fatigue in patients with chronic hepatitis C infection
- maintenance of weight loss and exercise in overweight patients with liver disease results in a sustained improvement in liver enzymes, serum insulin levels & quality of life
- weight reduction and exercise can improve liver function in patients with fatty liver

Benefits of Exercise

Build and maintain healthy bones, muscles and joints, maintain/improve bone density, lower resting heart rate and blood pressure, reduce risk of developing heart disease, diabetes, osteoporosis & some cancers, improve cholesterol levels, strengthen immune system, increase strength, increase muscle tone/bulk, improve cardio vascular fitness, improve stamina, enhance flexibility, improve quality of sleep, combat fatigue, control weight, increase social networks, quality of life, promote psychological wellbeing, improve mood, improve confidence, decrease depression & anxiety

Barriers to Exercise

Fatigue, decreased energy, insomnia, anaemia, alternate chills/fevers, joint and muscle pain, loss of muscle tone/bulk, headaches/migraines, difficulty concentrating, depression/anxiety, mood swings, loss of appetite, weight change, nausea, diarrhoea.

The program provided people with tips on coping with fatigue, food and the liver; how to handle nausea and/or fatigue and how to deal with the effects of stress.

Tips for Becoming Active

Make a commitment, plan each day carefully and allow adequate rest times, try to incorporate movement & activity into your normal daily routine, choose an activity that you enjoy and can participate in on a regular basis, set realistic goals for yourself. Use the SMART Principle:

Specific, Measurable, Achievable, Realistic, Time-based

Vary your program to prevent boredom, try exercising with a friend or family member, start with short sessions until your fitness improves, multiple smaller bouts of 10 minutes will bring benefits. It's fine to start with even shorter sessions and gradually build up, progress gradually.

If you are overly fatigued, rest for a day, but remember the key to health is regular activity, keep a weekly activity diary so you can plan your week and keep track of your progressions, monitor if you are meeting your goals, look for exercise options convenient and close to your home or work

Wear appropriate footwear & clothing, drink water regularly throughout exercise, give injuries adequate time to heal, remember you will have setbacks that interrupt your activities. The key is to treat setbacks as temporary and to get going again as soon as you can. Avoid competitive sports or exercise programs that force you to do more than is practical or reasonable for your body

Normal Physiological Responses to Exercise:

Increased heart rate, increased rate of breathing, feeling warmer, slight swelling of the hands & feet, mild to moderate perspiration, mild muscular aches for a day or two after exercise

Signs of Over-Exercising:

Chest pain/pressure, extreme breathlessness, extreme perspiration, wheezing/coughing, palpitations, dizziness/fainting, severe muscle/joint pain or cramps, general signs of being unwell (nausea, vomiting, feeling cold and clammy), extreme and long-lasting fatigue, overuse injuries eg tendonitis

Measuring Exercise Intensity

- There are different measurement methods – talk to your physiotherapist
- Keep your heart rate at the lower end of your recommended range if starting regular exercise, gradually increase the intensity of workouts as your fitness improves.
- Talking is a reliable way to measure exercise intensity. If you can talk & sing without puffing at all, you're not exercising hard enough. If you can comfortably talk but not sing, you're exercising at the right intensity. If you can't talk at all without gasping, slow down the pace

Types of Exercise

Choose something you enjoy - walking, jogging or running, swimming, cycling, Tai Chi, for example. Your exercise program should include warm up, stretches, the main activity and a cool down

Incidental Exercise

Take the stairs instead of the lift, go for a brisk walk in your lunch break, do some gardening, walk to the corner shops instead of driving, walk to the bus stop or train station & catch public transport to work, get off one stop early on your bus or tram route and walk the rest of the way, park your car a distance from the entrance to the shops, wash and vacuum the car instead of taking it to a car wash

Remember

- Exercise is important to maintain good physical and mental health
- Exercise may be difficult as you may feel tired, lethargic, generally unwell
- Even a short walk each day can help cope better with symptoms

Naturopathy

Jane Daley

Common symptoms of Hepatitis C

Fatigue and exhaustion, nausea and anorexia, muscle aches and joint aches, low grade temperature, mild abdominal discomfort, premenstrual syndrome

Symptoms are often due to:

- imbalance of blood sugar levels, liver inflammation, liver unable to process nutrients and make nutrients efficiently e.g. synthesizing amino acids, liver unable to break down hormones, constant immune activity also induces fatigue.
- When liver is busy and overworked this often leads to a lack of appetite and a lack of interest in food, which leads to a decrease in nutritional status and therefore an increase in fatigue.

Tips to decrease liver burden

Reduce or avoid coffee and caffeine, avoid alcohol, give up smoking reduce or avoid use of all chemical cleaning products, washing powders, dishwashing liquids etc, air your dry-cleaning (carbon tetrachloride is a known hepatotoxin), avoid use of hair spray, hair dyes, nail polish, furniture sprays, room deodorizers, ironing

sprays, static sprays, fly sprays, garden chemicals, filter water, use natural skin products, be very cautious with new carpet, fresh paint, new cars and new furniture etc, avoid plastic use where possible, eat organic food where possible, don't microwave your food (microwaving destroys vitamins and minerals and rearranges proteins), avoid refined and packaged foods, avoid artificial colours and flavours, MSG and other flavour enhancers, avoid high doses of fat soluble vitamins, address workplace chemical exposure if necessary, seek advice about medications.

Tips to support liver function

Eat small regular meals to reduce the liver's workload and help to balance blood sugar levels, eat enough good quality protein to supply the liver with amino-acids for antioxidant enzyme systems and to support liver detoxification, eat a broad range of fruit and vegetables high in essential nutrients and antioxidants, ensure a healthy digestive tract so that toxins, viruses, bacteria etc are not absorbed through a permeable gut into the blood stream and passed through the liver, ensure adequate hydration, drink enough water, increase cruciferous vegetables in diet to support liver detoxification, increase garlic and onion family foods, lemon juice in warm water first thing in the morning is great for liver detoxification, add bitter foods to your diet to stimulate digestion and bile flow, exercise and weight loss improves liver function for people with fatty liver

Tips to reduce nausea

Don't take Ribavirin on an empty stomach, eat small meals more frequently, eat foods that are easy to digest such as cooked vegetables, chicken and vegetable soup etc, avoid fatty foods and take away, bitter foods helpful e.g. bitter salad greens, peppermint tea (good quality), spearmint, fennel, lemon

juice and honey in water, B group vitamins (B6). A systematic review of randomised controlled trials has shown overall that ginger is an effective treatment for nausea and vomiting (Ernst E, Pittler MH, Br J Anaesth 84(3):367. 2000)

Tips for combating fatigue

May be due to irregular blood sugar levels, insomnia, lack of appetite and nausea, may also be due to depression or contribute to depression, eat small regular meals with adequate protein, fruit and vegetables, avoid simple and refined carbohydrates, if insomnia isn't a problem take a nap through the day, make sure to get some exercise, light regular exercise will increase energy, talk to friends and family and ask for help with meals, cleaning etc, prepare meals in advance and freeze to ensure adequate nutrition, a good quality multivitamin with high B group levels may be useful

Sleep tips

Avoid caffeine and alcohol, avoid smoking 2 hours before bedtime, B vitamins to be taken in the morning only, stick to a sleeping routine i.e. same time to bed, same time up etc, no daytime napping if sleep is a problem, wind down for 1 hour before bed at least, have a bath, listen to some music, write in diary, read a book etc, don't use bedroom for studying, watching TV, surfing the net etc, get regular exercise, meditation is often helpful, herbal teas that may assist include passionflower, chamomile, skullcap. Herbal sleep formulas are safe, not addictive, strong and effective and can break patterns of insomnia and reset sleep cycles, improve amount and quality of sleep.

For further information:

Ask at your haemophilia centre, public hospital, community health centre, or go to Australian Hepatitis Council web site www.hepatitisaustralia.com or the web sites of State/Territory Hepatitis Councils or ask HFA for relevant telephone contact details. **H**

eat small regular meals with adequate protein, fruit and vegetables, avoid simple and refined carbohydrates,

Tai chi research

Rebecca Dalzell




Rebecca Dalzell is a physiotherapist who works with adults at the Queensland Haemophilia Centre at the Royal Brisbane and Women's Hospital. Rebecca is a member of Australian and New Zealand Physiotherapy Haemophilia Group which is auspiced by HFA to encourage and support specialist physiotherapy services for people with haemophilia and other bleeding disorders.

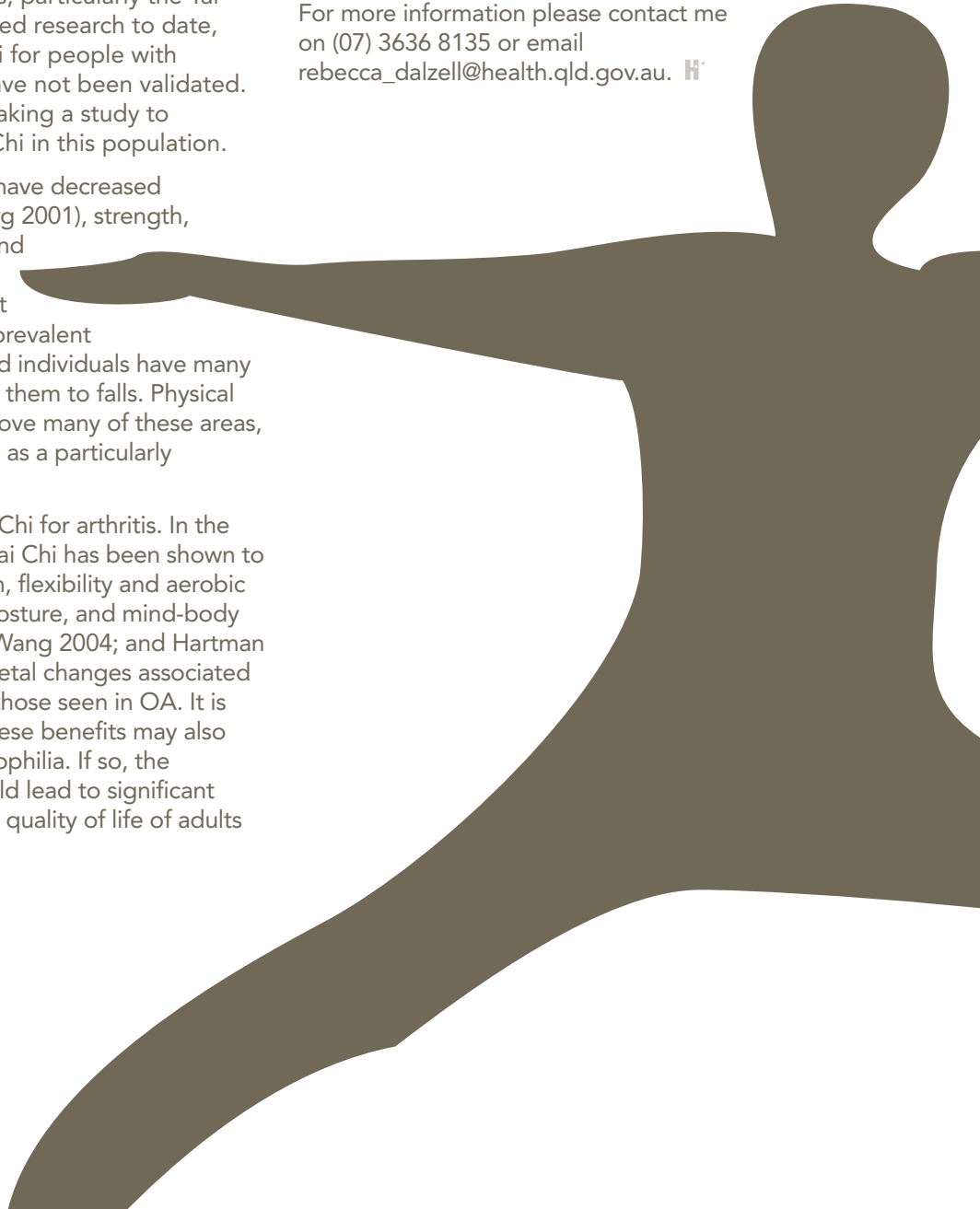
Since the production of the "Inspire" DVD in 2005 this resource has been distributed around Australia and throughout many overseas countries. Many people have reported that they have experienced improvements in their health and well-being from regular practise of the exercises, particularly the Tai Chi. There has been no published research to date, however, the benefits of Tai Chi for people with inherited bleeding disorders have not been validated. I am therefore currently undertaking a study to investigate the benefits of Tai Chi in this population.

People with haemophilia often have decreased proprioception (balance) (Hilberg 2001), strength, flexibility, range of movement and function (Hilberg et al 2001; Seuser et al 2003; and Fischer et al 2005). Osteoporosis is more prevalent (Gallacher et al; Barnes et al) and individuals have many risk factors that may predispose them to falls. Physical activity has been shown to improve many of these areas, and Tai Chi has been suggested as a particularly beneficial form of exercise.

Research has been done on Tai Chi for arthritis. In the osteoarthritis (OA) population Tai Chi has been shown to decrease pain, improve strength, flexibility and aerobic fitness, and enhance balance, posture, and mind-body health (Choi 2005; Song 2003; Wang 2004; and Hartman 2000). Many of the musculoskeletal changes associated with haemophilia are similar to those seen in OA. It is hypothesised, therefore, that these benefits may also hold true for people with haemophilia. If so, the potential benefits of Tai Chi could lead to significant improvements in the health and quality of life of adults with bleeding disorders.

I am currently co-ordinating a research project to investigate the benefits of Tai Chi in the bleeding disorders' community. This study aims to look at the effect of providing the "Inspire" DVD to people with bleeding disorders in the United Kingdom and United States of America and asking them to complete the Tai Chi component of that DVD. (Due to the prior distribution of DVD's around Australia, Australian subjects cannot be used.) Outcomes to be assessed include pain, quality of life, function, bleeds, physical activity levels, and fear of falling. The study is scheduled to commence later this year and should be completed by the end of 2007. Results will be available on completion.

For more information please contact me on (07) 3636 8135 or email rebecca_dalzell@health.qld.gov.au. 



Case Study: Balance


Haemophilia Foundation Research Fund

One of the projects funded by the Haemophilia Foundation Research Fund in 2005 was for work by Dr Keith Hill of the National Ageing Research Institute (NARI). The project, "Balance, strength and related falls risk factors in people with haemophilia and other bleeding disorders and feasibility of a targeted home exercise program to improve balance" was recommended for funding by the multidisciplinary Haemophilia Foundation Research Committee because of its relevance to emerging issues for the bleeding disorders community. Although members of the bleeding disorders community experience the problems of ageing faced by the broader community, there are specific risks for people living with chronic bleeding disorder bleeding disorders, including arthritis and impaired mobility.

Finding the right balance in exercise

The project is being conducted by the National Ageing Research Institute (NARI) and health professionals from the Ronald Sawers Haemophilia Centre in Melbourne to determine if balance is affected in people with haemophilia and other bleeding disorders (PWH). The study idea was generated by the clinicians at the Ronald Sawers Haemophilia Centre, who in their day to day work realised that falls, including falls with considerable bleeding and other complications, appeared to be fairly common in their clients. There has

been little research to quantify the significance of falls, nor whether balance impairments are contributing to the risk of falls. Physiotherapists advising people with haemophilia about exercise usually provide programs that focus on muscle strength and flexibility, but not often balance. In the current study, sensitive and accurate measures of balance (using a computerised force platform) are assessed together with a range of other measures of physical ability and falls risk, following which participants are provided with a 4 month individualised home exercise program, usually including balance, strengthening and walking exercises. Re-assessments will determine the practicality, suitability, and effectiveness of this exercise approach for people with haemophilia. The study is still recruiting participants.

For more information, contact Marcia Fearn, 03 83872512. 



Volunteer Anthony McCarthy performing one of the balance tests with physiotherapist and researcher Keith Hill.

“Balance, strength and related falls risk factors in people with haemophilia and other bleeding disorders and feasibility of a targeted home exercise program to improve balance”

The Haemophilia Foundation Research Fund was established in 1990 to fund Australian based research in the area of haemophilia and related bleeding disorders. Since then, a range of medical, scientific and social research projects have been funded throughout Australia, amounting to \$300,000. Each year, grants are made to projects which are likely to benefit the bleeding disorders community.

A boost to the Fund came in 2004 when the Country Women's Association of New South Wales made a commitment to haemophilia as its medical project for the year. The Country Women's Association of New South Wales is a part of the largest voluntary women's organisation in Australia and each year goes through a consultative process with members to select the area where it will direct its fund raising efforts. A significant contribution of \$30,400 to the Fund was presented by Mrs Judy Richardson, State President of the organisation in May 2005 and a further commitment to fundraising for haemophilia during 2005 was announced.

The Country Women's Association of New South Wales commitment to fundraising for haemophilia research has made a significant difference to the capacity of HFA to provide opportunities for research. Although HFA can only fund small to medium research projects, the Fund is nevertheless valuable in the research landscape in Australia.

A funding round will be announced soon. Expressions of interest to receive an information package may be registered with hfaust@haemophilia.org.au.

Personal Reflections on Consumers and Researchers Working Together to Improve Health in Australia

Beth Micklethwaite

The Consumers' Health Forum of Australia provided permission to reproduce 'Personal reflections on consumers and researchers working together to improve health in Australia' by Beth Micklethwaite, which was first published in The Australian Health Consumer issue Number 1, 2005-2006.

Rather like a first date, health consumers and researchers are not always comfortable around one another to begin with. They want to impress but may tread carefully around each other, reserving their judgment about the future of the relationship. However, both groups have a common interest in ensuring Australia produces high quality research to improve health and wellbeing. This mutual goal means that an effective partnership is both desirable and possible but it takes time, skill and commitment to make it work.

The National Ageing Research Institute (NARI) in Melbourne, an organisation of about 30 staff and students that conducts research into the causes and consequences of ageing and its social accompaniments, is unusual in having a long history of consumer engagement. It is a place where consumers feel welcome and accepted and have existing relationships with the researchers.

There is a consumer position on the NARI Board and a 500 strong Volunteer Network of older people who are involved in the organisation's work from stuffing envelopes to participating in research projects. Each year, NARI hosts an Appreciation Day for its volunteers and is increasingly making use of this opportunity to share information about its research. Consumers are familiar with NARI's work, its staff and its physical

environment through the Volunteer Network or health activities such as tai chi classes held at the Institute.

The existing relationships between consumers and researchers provided a strong foundation for NARI's participation in the 2004 Statement on Participation project run by the Consumers' Health Forum of Australia (CHF) and the National Health and Medical Research Council (NHMRC).

CHF and NHMRC have been working together to encourage the development of effective relationships between researchers and consumers and to create a climate in which such partnerships can flourish. In 2002, CHF and NHMRC published a joint Statement on Consumer and Community Participation in Health and Medical Research (the Statement on Participation). This outlined a vision of "consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of humankind" and set down a series of objectives to foster such partnerships.

In 2004, CHF and NHMRC renewed their partnership, working with two pilot sites to develop practical approaches to implement the Statement on Participation. CHF worked closely with NARI for about six months. The key actions during this time were:

- A joint workshop of consumers and researchers held at NARI in September 2004. Many consumers

were from NARI's volunteer network or CHF member groups with an interest in ageing. The workshop provided an overview of the Statement on Participation, of NARI's work, particularly that relating to falls prevention and of the influence of research funding bodies on research priorities. It also provided an opportunity for consumers to articulate their priorities for ageing research. The majority of these priorities involved the social aspects of ageing, rather than the biomedical.

- Efforts initiated by NARI researchers to improve their communication with research participants about a study's progress and early results. This took the form of a letter from the researchers, which was submitted to consumers for comment before being amended and distributed to research participants. Researchers initiated this improvement in communication after learning that during the development of the Statement on Participation, many consumers had told CHF they had been deterred from participating in further research because they were never told the results of their previous involvement.
- Publication of some NARI research as a means of communicating research results to a wider group of consumers. **H**

HIV Futures 5

Life as we know it

- A joint NARI/CHF submission to the NHMRC's Ageing Well, Ageing Productively consultation, based on input from participants at the NARI workshop. This emphasised the need for more research into the preventive aspects of ageing, greater allocation of funding for public health and social research into ageing, the identification of ageing research as a priority area and the need for greater coordination of ageing research.
- The development of a consumer participation policy for NARI, based on input from workshop participants.

It is hard to overstate the importance of the existing relationships between NARI researchers and consumers in providing a strong foundation for developing consumer participation in research policies and practices at NARI. Such relationships allow for genuine discussion because both consumers and researchers are recognised and respected for their expertise. Neither group needed to prove its credentials meaning that honest discussion could take place about NARI's work.

The experience of NARI and the other pilot site, the Queensland Institute of Medical Research, resulted in a kit including a *Model Framework for Consumer and Community Participation in Health and Medical Research* for use by research organisations and an accompanying *Resource Pack for Consumer and Community Participation in Health and Medical Research* aimed at consumers interested in research. Both documents were launched in July 2005 and are available at www.nhmrc.gov.au/publications/synopses/r22syn.htm.

Available now at www.hivfutures.org.au

The HIV Futures Survey is about all aspects of living with HIV.

HIV Futures is an important project - it lets community organisations, services for people living with HIV/AIDS (PLWHA), doctors and government know what it's really like to be HIV positive. It is about the experiences that PLWHA share and the diversity of real lives. The survey is anonymous and you can take your time to complete it. Make sure your experience counts. What is HIV like for you?

By completing the survey you will help the results reflect the experiences of people with bleeding disorders. Results from previous years have informed policy makers about issues such as the extent of financial problems, and issues around ageing and family concerns. Some questions may also provide you with some space for reflection.

After an earlier survey when 40 people with bleeding disorders had responded, the Australian Research Centre in Sex, Health and Society developed a specific feedback report for our community.

HIV Futures 5 is a project of the Living With HIV program at the Australian Research Centre in Sex, Health and Society, La Trobe University, and is funded by the Commonwealth Department of Health and Aging. The Principal Investigator on the project is Dr Jeffrey Grierson.

You can complete the HIV Futures 5 survey on line until 14 April 2006 at www.hivfutures.org.au. If you would prefer a paper copy of the survey, please contact the Australian Research Centre in Sex, Health and Society on freecall number 1800 064 398 or ask Haemophilia Foundation Australia or your social worker/ counsellor. But hurry in view of the deadline! **H**

AUSTRALASIAN sexual health CONFERENCE 06

Preventions & Interventions for All

CHANGE OF DATES ANNOUNCEMENT Monday 9 – Wednesday 11 October 2006

The Australasian Chapter of Sexual Health Medicine would like to announce that the 2006 Australasian Sexual Health Conference is now to be held from 9 –11 October 2006 in Melbourne.

This is instead of previous dates of 26 – 28 October. This conference will now be run back-to-back with the 18th Annual Conference of the Australasian Society for HIV Medicine similar to the 2005 format.

Further Information on the conference will be available at www.ashm.org.au/conference as soon as possible.

Calendar

World Haemophilia Day

April 17 2006

Contact Haemophilia Foundation
Australia

ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au

Hemophilia 2006 World Congress

21-25 May 2006

Vancouver, Canada

ph +1 514 394 2835
fax +1 514 875 8916
email hemophilia2006@wfh.org
web www.hemophilia2006.org

Australasian Sexual Health Conference

9-11 October 2006

Melbourne

ph 02 8204 0770
fax 02 9212 4670
email conferenceinfo@ashm.org.au
web www.ashm.org.conference

18th Annual ASHM Conference

11-14 October 2006

Melbourne

ph 02 8204 0770
fax 02 9212 4670
email conferenceinfo@ashm.org.au
web www.ashm.org.au/conference

Haemophilia Awareness Week

8-14 October 2006

Australia

ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au

Haemophilia Conference

4-7 October 2007

Canberra

ph 03 9885 7800
fax 03 9885 1800
email hfaust@haemophilia.org.au

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Haemophilia Foundation Australia acknowledges the funding and assistance received from the Commonwealth Department of Health and Ageing which makes this publication possible.

