

Spina Bifida
FOUNDATION VICTORIA



CONTACT

*Bringing the Spina Bifida
community together*

Issue 2
July 2007

CONTACT is the official newsletter of the **Spina Bifida Foundation of Victoria**



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Flyers included in this issue:

- **Malcolm B Menelaus Achievement Award applications**
- **Folate news brief**
- **Continance Seminar**
- **Social Club Football event**
- **Wine Club order form**

Disclaimer: Some articles in **CONTACT** are submitted by members of the Spina Bifida Foundation of Victoria and people from the community, and therefore do not necessarily reflect the views of the Spina Bifida Foundation of Victoria Board of Directors.

Photos taken at SBFV gatherings may be used in SBFV material where that material is for general membership. SBFV will request permission of members who appear in the photos, should we wish to use them in print material targeted at the general public.

President's Report

Welcome to this winter edition of Contact. Much has happened in the Foundation since the last edition. Some of you will have by now met or spoken over the phone with our new Executive Director, Elizabeth Logan. Elizabeth has settled in well and has been hard at work becoming familiar with the Foundation and progressing with a range of initiatives. The Central Point project has been formally closed and a final report delivered to the Hugh Williamson Foundation. Some money left over from the HWF grant will be used to progress the aims of the project in the areas of better information to members. We have also employed a new part time person to work on programs and services. Mini Dahiya comes to us from the Multiple Sclerosis Society of Auckland, NZ. Please look out for her and say hello if you are in the office.

The Board has just completed the first stage of our strategic planning for the Foundation and agreed on some strategic goals. The key areas are related to member developments, folate and improving our visibility in the general community. We will be working now to develop these and I expect to be able to give you all some more details in the next edition of Contact.

The recent Trivia Night was very successful and thanks must be given to Katrina Hartley and her willing group of helpers. The Continence Seminar is coming together well and will be held in late July or early August so keep a look out for more details. Planning for the Folate Breakfast in September is also well under way and we will be

looking at ways to make it easier for members to attend. The AGM / Night of Celebration will be in November and the Christmas Party in late November or early December. Please keep a look out on the web site and in coming editions of Contact for further updates.

- John Simmons



Congratulations to the Mavroudis family on the birth of their daughter *Evie!*

Missing CONTACT Editions

The SBFV is missing the following editions of **CONTACT** newsletter

2005 December	1991 September
2004 October Issue 3	1991 July
2001 December	1990 November/Dec
2000 December	1990 September
1999 December	1987 October
1997 December	1987 September
1992 December	1986 May
1992 October	1986 June
1992 February	1985 1 st Half of Year
1991 December	
# 27 -55 from 1981, 1982, 1983 & 1984	
# 23 & 24 1981	

If you have any of these editions and would like to donate them to SBFV, they would be greatly appreciated.

Executive Director's Report

The past three months have been incredibly productive ones and it's a pleasure to report back to everyone what has been achieved so far. To date, there has been consolidation of various important programs, new initiatives instigated and planning underway for some much-anticipated events.



In summary the Healthy, Happy Futures program continues successfully with the second group of children commencing around the beginning of second term. Feedback from the first group has been positive and there have been fitness achievements gained by all undertaking the program. There is also an exciting opportunity coming up for members to attend a ski camp.

New initiatives have included a fresh, updated look for Contact which I hope will make reading the newsletter all the more enjoyable. A membership drive is planned for early in the new financial year to boost our numbers, so stay tuned for that as well. Four additional members have been inducted on to the Advisory Committee so that there are now 11 people representing the wider SBFV membership.

Another positive change is the appointment of a new Program Officer to provide much needed assistance in the SBFV office. Mini Dahiya has just commenced with us and brings a wealth of experience whilst being very friendly and approachable. A photograph and more comprehensive article about Mini is included elsewhere in this newsletter.

In the second half of this year a number of exciting events are scheduled. The dates and some details are provided in the list of coming events (on the opposite page) and I hope that we have a strong attendance.

During the past few months I have continued to meet many more of the members of the spina bifida community as well as taking every opportunity to extend the Foundation's message. I spent a lovely weekend in May in regional Victoria having spoken at a fundraising dinner in Violet Town and recently visited a school in the western suburbs to discuss spina bifida with a group of primary school students.

All of these achievements are the result of hard work, not just of myself, but of all the people who provide assistance such as volunteers, parents, board members, office staff, members, contractors and other supporters, many of whom I cannot thank enough and who often provide their services voluntarily and with little acknowledgement. I am confident that these efforts will continue to help the Foundation move in a positive direction.

STOP PRESS!

At an extraordinary meeting on Friday 22nd June in Canberra, the Australian and New Zealand Food Regulation Ministerial Council comprising Ministers responsible for food issues and food safety agreed to the mandatory fortification of food with folic acid. This means that it will be mandatory for manufacturers to add folic acid to wheat flour for bread-making. This applies to all breads except organic and non-yeast leavened breads. There will be a two-year implementation period.

Get involved - Get fit!

A number of children are currently involved in the 2007 Healthy Happy Future Program. We have 3 more vacancies for children aged between 5 and 15 years living in the **western suburbs** to engage in a specialized fitness program that will be managed by Heartwell Fitness. Each child will have access to a fitness regime designed specifically for them.

So if you live in the **western suburbs**, are interested in taking advantage of this unique opportunity or need more information please contact the office on 9663 0075 or email m.dahiya@sbfv.org.au.

Welcome Mini Dahiya - SBFV's New Program Officer



New to Melbourne and new to SBFV, I would like to take this opportunity to thank Elizabeth and John for offering me the role of Program Officer at SBFV.

I have lived most of my life in India and moved to New Zealand four years ago to study a Masters degree in public health. After being in Auckland for a couple of months, I got involved with the Muscular Dystrophy Association and then moved on to work with the Multiple Sclerosis Society of Auckland, Inc. I was with the MS Society for the last three years and the experience I gained there can only be described in one word **“invaluable”**.

I continued to study part time whilst working full time at MS and have just managed to complete all my papers last month. Apart from working and studying I value spending time with my family and friends and also enjoy painting, reading and shopping (which I hear is fantastic in Melbourne!)

I hope to bring new skills and new energy to SBFV and look forward to meeting some of you as I adapt to my new workplace and new home! I really appreciate being given this opportunity to work at SBFV and I will try my best to make it worthwhile for all of us!

Upcoming Events

Event	Date	Venue	Time	Cost
Christmas in July (Social Club event) RSVP Helen Houghton 9511 4451	Saturday 28 th July	Tivoli Theatre Restaurant. 1390 High St Malvern	10.30am	\$20 members, \$30 non-members
Continance Seminar	Tuesday, 31st July	TBC	From 10am	Free
On The Snow Ski camp	August / September (TBC)	Howman's Gap Camp, Falls Creek	TBC	TBC
Spina Bifida Awareness Week	Sun 2 nd – Sat 9 th September			
Folate Awareness Breakfast	Thursday 6 th Sept	Arts Centre	6.45am	\$75.00 or discount for table of 10
Night of Celebration & AGM	Friday 2 nd Nov	Darebin Arts & Entertainment Centre	7pm	
Christmas Picnic	Sunday 25 th Nov	Albert Park - Grebe Picnic Area	11am	

SBFV TRIVIA



Jeff and Clever Trevor

On Saturday June 16 trivia buffs battled the cold and rain and headed out to the Dorset Gardens Hotel in Croydon in support of the SBFV Trivia Night – and what a great night it was!

The 13 teams included The Addams Family, Beverly Hillbillies, The Brady Bunch, Charlie's Angels, Desperate Housewives, Faulty Towers, Get Smart, Gilligan's Island, The Leyland Brothers, Married with Children, The Partridge Family, The Simpsons and The Young and the Restless.



Katrina and John announce the winner of the door prize

Our hosts Jeff and Clever Trevor got the night started with some 80s tunes in the first round of flashback music. A game of 'True or False' got everyone moving, where guests paid a gold coin to participate and test their individual knowledge.

Other rounds included 'Name that persons celebrity relative' and 'Retro 70s' before a break for supper and a quick bid at the silent auction. Some of the items up for auction were provided by member Julie Davis, and money raised from these items will help support her to compete at the Beijing Paralympics in 2008.



Guests playing 'True or False'

Guests then tried their luck and throwing ability at the Gold Coin Toss, where the nearest coin to the bottle of Baileys or wine won, while others queued up for supper to refuel before the next round of trivia began.

'What's the next line?' was a fun round, where everyone took the chance to sing along and hopefully not give away the answers when the music stopped. Finally the last round was split where teams could choose to answer questions on either the 60s or the 90s.



Sally and Elizabeth collecting tickets at the door

The final scores proved that Get Smart really were the smartest, winning overall. Thank you to Jane Menelaus who generously donated the Pirates of the Caribbean memorabilia that the winners received, along with some yummy Roses chocolates.

A total of \$2752.47 was raised for the SBFV.

All in all it was a fantastic night of fun and friends!

NIGHT!

Saturday June 16
Dorset Gardens Hotel
Dorset Road, Croydon



Guests enjoy the games!



Thank you Katrina!

A special thank you to Katrina Hartley for organising the trivia night!

A fantastic effort that was enjoyed by all who attended!

A big thank you to the following people for their kind donations!

- Dorset Gardens Hotel
- Cheesecake Shop Croydon
- Croydon North Gaurdian Chemist
- North Croydon Florist
- North Croydon Newsagency
- Safeway Chirnside Park
- Australian Geographic Shop, Knox City
- ARLEC
- The Good Guys, Bayswater
- Melbourne Sports and Aquatic Centre
- Auto One, Bayswater
- Topline Cricket
- Mayerling Cellars, Croydon
- Burnt Bridge Pharmacy, Croydon
- Margaret King-Davies
- Better Learning Australia
- Tara Carroll—Tara's Beautique
- Liz Parkinson
- Fountains Restaurant, Box Hill
- Super Cheap Auto
- Christina Shah
- Melinda and Arthur Mavroudis
- Curves Gym, Croydon
- Debbie Watkinson
- Sheryl Byron
- Melbourne Water
- Mick Holihan
- Mindbogglers, Croydon
- Jane Menelaus
- David Geary
- John Dunn
- Peg Fraser
- MCG
- Richmond Football Club
- Hawthorn Football Club

Federal / State Budget 2007-08 and Disability Services

There have been some changes made at the state and federal level to the funding of disability services. Some services and payments have changed, others have remained the same.

If any of these issues relate to you, then you may be eligible for a subsidy or allowance.

Make sure you're getting what you are entitled to!

- Mobility Allowance – there is a new higher rate allowance available for those who meet the criteria
- Training - training credit scheme for Work for the Dole
- Carer Assistance – bonuses for eligible Carer Payment and Carer Allowance recipients and extension of Health Care Card for young people
- Continence Aids Assistance Scheme (CAAS) – payment scheme for those who meet the criteria
- Child Care – rebates and funding for children with high support needs
- Aids and equipment – increased subsidy levels for aids and equipment
- Home and vehicle modifications – more funding to increase independence of disabled members in the community
- Future Young Adults – transition planning for young people and their families to navigate post-school options

Should you want more information, contact Centrelink on 13 2717 or the SBFV office on 9663 0075.

Continence Aids Assistance Scheme Expansion

The Continence Aids Assistance Scheme (CAAS) is an Australian Government program that assists eligible people who have permanent and severe incontinence to meet the cost of continence products. CAAS provides continence aids such as pads, catheters and other products to the value of \$470 a year for each person. These items are important in maintaining a good quality of life for people with incontinence and enabling them to participate in the community. CAAS is administered on behalf of the Australian Government by Intouch, the commercial arm of the Spinal Injuries Associated Incorporated.

From July 1st 2007, eligibility will be expanded to include people from age five years and older (with no age limits). To apply, a CAAS application form must be completed. Information must include a report on your condition from an appropriate health professional such as your general practitioner or continence nurse. Application forms are available from the CAAS Helpline on 1300 366 455 or can be downloaded from www.intouchdirect.com.au or www.bladderbowel.gov.au. Once your application is received, your eligibility will be confirmed by Intouch and you will be advised of the outcome.

“On the Snow”- A 2 day Ski Camp

We are pleased to inform you that SBFV has organised a ski camp with Disabled Wintersports Australia (Victoria) for a group of young adults with Spina Bifida over a weekend in August/Sept 07 (dates are yet to be finalised).

Accommodation: Howman's Gap Camp below Fall's Creek- fully accessible

Cost: Free for members and their carers

This is a unique opportunity for you to come, try and experience the sport under the supervision of qualified ski guide trainers and enjoy your time with a friendly group of people. There are limited spaces available so if you are interested or need more details about the ski camp, please contact SBFV as soon as possible.



Expressions of Interest Certificate II in Information Technology



Are you interested in furthering your studies?

Do you want to upgrade your skills?

Do you need more qualifications to work?

If you have answered 'yes' to any of the questions above then there is good news for you.

Box Hill TAFE has offered to train a group of SBFV members to obtain a Certificate II in Information Technology.

- They will run one session per week, perhaps on a Saturday, over 12 months commencing in 2nd semester 2007.
- The only cost would be the normal student fee of \$1.20 per hour if you don't have a Health Care Card.
- Students would be expected to have basic personal computer skills and access to their own computer.

Free Training for Regional Members in mc2

Are you a SBFV member living in regional Victoria and are you interested in learning more about mc2 (our online communication program)? If so, then you're invited to contact us. The SBFV is looking for people who want to learn how to use mc2.

What's in it for me?

By joining one or more mc2 groups you will be able to communicate with other SBFV members around Victoria - chat online with friends; get help from your peers or offer help; get info on events/activities; link to other useful websites; and share documents.

How can I get involved?

Contact our trainer Jude Perry to indicate your interest, and you will then be notified of training times and places: Phone – 5436 1060 or email - judithperry@supernerd.com.au

What do I need to bring?

You will need an email address. If you already have an email address, you may use it. (If you have trouble remembering it, write it down and bring it to training). If you don't have an email address or would like a new one, you can start a new email account at training.

How long will the training session be?

Training sessions are expected to run for 1½ - 2 hours depending on the size* of the class with a short 10 minute break. (*most classes are small)

How much does it cost?

Training is free.

Advisory Committee News

The Advisory Committee has gained some additional faces after the call for new members in the last edition of **CONTACT**.

Members of the new committee are:

Timothy Williams

Frank Cutuli

Mark Love

Katherine Simmons

Helen Houghton

Liz Romanis

Tamlyn Dunn

Jason Parry

Sue O'Neill

Mark Oswald

Michael Raynes

All Saints

Some of our members were unhappy about an episode of the medical drama All Saints, aired on Channel 7, which made a statement about spina bifida that was incorrect.

We wrote to Channel 7 about the matter, and they responded with a letter of apology.

Notice

The Australian Government recently released a book entitled: **'Planning for the Future: people with a disability'** and includes 'Special Disability Trust: Getting Things Sorted'. To obtain a free copy call 1800 050 009. Copies are also available from the SBFV office.

Also available from the SBFV office are copies of **'There's no such thing as a silly question'**, a practical guide for families living with a child with chronic illness, disability, mental illness or a life-threatening condition.

Returning to study or jumping off a cliff?

In the latter half of 2005 I had no intention of returning to study. I had completed my Diploma and Degree in Community Development and was satisfied that I'd achieved all that I wanted to in all forms of education. Essay-writing and intensive reading was not on my agenda. One day, I picked up a brochure on adult learning courses and saw that there were courses available in creative writing and journalism. My brain started ticking over. I had always loved writing but had never studied it formally. The College of Adult Education was in the city and was too far for me to travel, so I started searching TAFE colleges and universities to see what they had to offer. I thought TAFE might be more appropriate than university, as a postgraduate course sounded too heavy and difficult. I made an internet search of Deakin University, where I got my Bachelor's Degree and Holmesglen College of TAFE, purely out of curiosity, not expecting to find anything.

I found Certificate 4 courses in Disability Studies and a Professional Writing course which looked interesting. These were variously offered at Holmesglen TAFE, Swinburne TAFE and Deakin University. I took a deep breath, looked at myself in the mirror and checked that I was not going mad, then insanely applied for two of these options, one disability and one writing course! I realised that this was just the beginning. There could be three feasible scenarios. I might be offered neither course, one course or possibly both. I sent off the applications thinking I would not have a hope, particularly with the postgraduate university professional writing course. I had to wait two months for any response.

Helen Houghton has written an article about her recent experiences returning to tertiary study to complete a Post-Graduate Certificate in Professional Writing from Deakin University. You can read her full article and helpful study tips on [mc2](#).

Exit the King!

A small but enthusiastic group from the Spina Bifida Foundation attended the play starring Geoffrey Rush, *Exit the King*, on Thursday 12th April at the Malthouse Theatre. The play was a very deep and complex experience. It was entirely about the death of a king and his acceptance or lack of it and how the characters around him helped him to accept the inevitable by alternate use of mockery, sympathy, and reality. The play was written by Eugene Ionesco, in *Theatre of the Absurd* style. It was translated from the French by Neil Armfield and Geoffrey Rush. The staging was spare, but very atmospheric with strobe lighting and smoke being used to good effect. The excellent cast also included Billie Brown, Julie Forsythe, Gillian Jones, Rebecca Massey, and David Woods.

Our patron Geoffrey Rush and all the other actors put in fine performances. We see the self-destruction of the King and of the power he once possessed as it is gradually stripped away. The play was not entirely maudlin and depressing. There were certainly some amusing moments with insightful body language and humorous exchanges between the actors. It was funny at times and very sad as well. It incorporated both moods extremely well. The sound was excellent and every word was understood. The seats we were given were the best in the house, we could see all the action and were not restricted from view in any way. The play says a lot about our position in life and what we have

contributed to it while we have been here. It was extremely thought-provoking as death is an eventual journey that every single one of us will have to take sooner or later.

After the show, Geoffrey Rush came out and greeted us all and took questions and comments about the play. Unfortunately we did not have any photos taken. It was a privilege to experience such strong acting. I recommend anyone to go and catch *Exit the King* before it closes - you will not be sorry. Also, the Malthouse is an accessible theatre, with two disabled parking spots in front and two behind the walk through area. There is inside and outside dining for people if they wish to have lunch or dinner before or after the show.

It was a thoroughly enjoyable and meaningful afternoon.

- Helen Houghton

Congratulations Helen!

Helen recently received a Post-Graduate Certificate in Professional Writing from Deakin University. This complements her Bachelor of Arts, Community Development, awarded in 2000. Not a bad effort, considering the amount of ill-health and hospitalization she has undergone over the past seven years. She now hopes to be able to contribute more frequently to **CONTACT** and has other writing projects in the pipeline.

Congratulations, Helen, on a wonderful effort!





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CONTACT is your newsletter, and we encourage you to submit articles or ideas. If you have some news or a story that you would like to share – we want to hear from you!

Articles (and photos) can be sent to:

CONTACT

4th Floor Ross House
247 – 251 Flinders Lane
Melbourne VIC 3000

Or email info@sbfv.org.au

Please note that articles may be edited at the discretion of SBFV and that we reserve the right to not include submissions based on space available. Cut off dates for receiving **CONTACT** articles for 2007 are as follows:

Issue 3: 31/08/07

Fundraising—How you can help!

There are many easy and simple ways that you can contribute to SBFV and make a difference to your foundation, each way helping to raise the funds we need to continue to run programs and events that we know you all enjoy so much!

Here are just a few ideas that you may like to consider:

- **Wine order**

If you like fine wine, or know someone who does, you can order through the Foundation! The Grape Unknown provides the wines, each bottle labeled with our very own logo and design, and SBFV receives a percentage of each sale. The form for ordering is included in this edition of **CONTACT**.

- **Corporate Giving Projects**

If you know that your employer, or an employer of a family member, has a giving project or scheme, then why not approach them about giving to the SBFV! Often companies are more inclined to donate if they know that they will be supporting one of their own, and in return we will thank them in our **CONTACT** newsletter.

- **Ritchies' Community Benefits Program**

Ritchies' Community Benefits Program donates one cent of every dollar you spend to your nominated club, school or community organisation.

Applications for a Ritchies' Community Benefit Program can be found at all Ritchies supermarkets and liquor stores, just enter the Spina Bifida Foundation of Victoria as the recipient of a donation on your form.

You can choose between a key tag for your key chain or a card for your wallet, which contains an individual barcode that lets Ritchies know that you support SBFV - just make sure that every time you shop at any Ritchies IGA you present your key tag or card at the register! At the end of each month, Ritchies will calculate how much money you've spent and how much of that will go to SBFV! Visit www.ritchies.com.au/stores.html for store locations.