



Spina Bifida  
FOUNDATION VICTORIA



# Annual Report 2011

## Our mission

# To help people living with spina bifida

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## Cover photo

Sailing is one activity organised by the Over 18s Social Club. This Club is a sub-group of the Advisory Committee which consists of adults with spina bifida who represent the views of the membership. These activities bring people together, increase confidence and independence and achieve positive health outcomes.

# President's Report



The SBFV continues to work in two main areas of activity. These are the promotion of folate and the development and delivery of activities and services for members. This year, the Board has reviewed our strategic objectives and undertaken a risk management exercise using the National Disability Services framework.

We have made significant progress in matching our income against our expenditure and I would sincerely like to thank our Executive Director, Elizabeth Logan for her hard work and dedication to the SBFV over this past year.

This year we also reviewed the Folate Information Network (FINE) project and decided to bring it to a close after almost 10 years. As a more direct folate promotion activity, around 24,000 of our Folic Acid leaflets are being distributed to doctors' waiting rooms in metropolitan Melbourne, Geelong, Ballarat, Bendigo and the Mornington Peninsula.

The final module of our Independent Living Skills program for members is nearing completion and will be delivered in the coming financial year. The winter ski camps continue to be very well received with very successful adult and children's camps conducted again this year.

These camps, held in partnership with Disabled WinterSport Australia, provide great opportunities for members to extend themselves in an activity that would otherwise be inaccessible. The Family Camp in January was also very well attended. It provides a great opportunity for members to share experiences and is a highlight for many families.

The Night of Celebration was held in November last year at the St Kilda Town Hall. It featured a surprise visit from "Darth Vader" and the Star Wars' paratroopers and was great fun for the members attending. Congratulations to Katherine Simmons and Mark Love who received the Malcolm Menelaus Achievement awards.

The SBFV is in a good financial position thanks to the hard work of Elizabeth, assisted by our Treasurer Robert Wald, to reduce our overheads. The position at the end of this financial year has been very pleasing as a result.

There have been some changes in staffing. Mini Dahiya decided to leave the SBFV to take full time care of her new son. Mini made a great contribution but we understand her family must be her priority. Agnes Tsetinis has also had to leave due to family commitments and we are very sorry to see her go. In her place, we have welcomed Katie Leyden who is now looking after the admin duties. Agnes has been very helpful and accommodating in handing over to Katie.

The Advisory Committee continues to play an important role informing the Board on a range of issues and organising the Social Club which has increased its membership and continues to provide a range of events to benefit members. I would like to thank the Committee for all their work this year.

We have had many people contribute to the SBFV in a voluntary capacity over the year. This includes assisting with the organisation of functions and events, particularly the Family Camp, helping with office mail outs and a host of other activities. I would like to sincerely thank everyone who has given the SBFV their time, energy and commitment.

I would again like to extend a huge thank you to our patron, Geoffrey Rush, Jane Menelaus, Margaret Menelaus and the Menelaus family. Their ongoing support is a great benefit to the SBFV and opens up valuable opportunities which we would otherwise not be able to access. Margaret continues to sponsor the annual Menelaus Achievement awards.

I would particularly like to say thank you to my fellow Board members for all their work and support throughout the year. Your Board members have been Liz Parkinson (Vice President), Jane Halliday, Elizabeth Lewis, Andrew Churchyard, Mark Oswald, Stella Minahan, Robert Wald (Treasurer) and myself. Thanks for all your hard work this year. I would also like to acknowledge and thank Sue Buckley who continues to assist us with Board Minutes.

Finally, I would like to say thank you to our members for your support and encourage you all to spread the word on the programs and activities we offer.

A handwritten signature in black ink that reads "John Simmons". The script is cursive and fluid, with the first letters of each word being capitalized and prominent.

John Simmons

# Executive Director's report



The SBFV started the year in a challenging financial position and I'm pleased to say that it has led us to rethink how we operate and to improve on it.

As a result we have restructured the office to reduce costs; invested funds more wisely; become more educated about additional fundraising methods; as well

as successfully acquired financial support from a range of grant providers. This has meant more work for staff, more dedication by the Board of Directors and additional faith shown by members and supporters.

I would therefore like to thank Agnes and, most recently, Katie for their ongoing diligence in the administration of the SBFV. I'd also like to thank the Board who give up their spare time to take on the additional work as the governors of our organisation.

The Advisory Committee also has yet again done a wonderful job in managing the Social Club on a voluntary basis and providing feedback and advice on programs. I'd also like to thank my husband and daughter for their support in working behind the scenes, whenever I need extra volunteers, and who make sure that I can focus my efforts on my role as

Executive Director. Without this help it would be impossible to keep up the momentum.

This year we embarked on a Christmas donation campaign as well as an end of financial year donation program to which many members contributed. This is especially appreciated as I know that many of you have expensive financial commitments in relation to your families. The SBFV is also extremely fortunate to have generous and loyal business supporters, some of which are working in tough economic environments.

Over the coming year we will continue to seek out new ways of finding the funds to provide valuable services and programs for members. Whilst it is becoming more competitive to raise money in the not-for-profit sector, the SBFV has demonstrated that it has the capacity to embrace new ideas in order to maintain its direction.

A handwritten signature in black ink, which reads "E. A. Logan". The signature is written in a cursive style with a large, stylized "L" at the end.

Elizabeth Logan

*The SBFV has demonstrated that it has the capacity to embrace new ideas in order to maintain its direction.*

# Patron



Geoffrey Rush (Patron) is an actor who has received many national and international awards for his work. His career began with the Queensland Theatre Company in Brisbane and his numerous achievements have included an Australian Film Institute Global Achievement Award, an Oscar and two Golden Globes, an Emmy, three BAFTA awards and four Screen Actors Guild Awards.

Geoffrey is married to Jane Menelaus who is the daughter of the late Malcolm Menelaus, co-founder of the Spina Bifida Foundation of Victoria, and they have two children. Because of Geoffrey's admiration and respect for Malcolm, he is honoured to be the Patron of the SBFV.

Geoffrey kindly donates his time and talents to the SBFV.

# Board Members

**John Simmons** (President) works for the Department of Justice in emergency services telecommunications. He has an adult daughter born with spina bifida and has been involved with the Foundation and previous Spina Bifida Association in various positions over a number of years.

**Liz Parkinson** (Vice-President) has a background in allied health education and currently works as a project manager with the Department of Health. Liz has a nephew Jeff who was born in 1987 with spina bifida, hydrocephalus and cerebral palsy.

**Robert Wald** (Treasurer) is a Fellow Chartered Accountant, currently a consultant to (and former partner of) the firm Bell Partners Pty Ltd. He has had over 30 year's experience in the not-for-profit sector both as an auditor and treasurer.

**Dr. Andrew Churchyard** is an adult neurologist with interests in movement disorders, adult developmental disability and neuro-genetics. He runs the Victorian Adult Spina Bifida Service at Monash Medical Centre and is also a consultant neurologist at Southern Health, Victoria.

**Assoc. Prof. Jane Halliday** is an expert in birth defects research and has completed several studies of neural tube defects over time. She is head of the Public Health Genetics Unit at the Murdoch Children's Research Institute and was part of the research group assessing folate awareness in the community and establishing the SPINE (now FINE) register.

# Staff

**Dr. Elizabeth Lewis OAM** is a highly respected neurosurgeon, with special interests in paediatric neurosurgery, spinal neurosurgery and medico-legal work. She has received a number of awards, including the Member of the Order of Australia (1992), Woman Achiever of the Year (1997) and Honoured Guest Neurosurgical Society of Australasia (2000).

**Dr. Stella Minahan** is an adult with spina bifida. She is a senior lecturer in management at the Deakin Graduate Business School and has a PhD in organisational behaviour. She has published over 50 articles in peer reviewed journals and conferences plus three books on management and consumer behaviour.

**Mark Oswald** is an adult with spina bifida, recipient of the Malcolm B. Menelaus Achievement award and a past participant of the Independence Program and Computer Skills and Training Program.

**Elizabeth Logan** (BA, MA, FAIM) —  
Executive Director

**Mini Dahiya** (BMed, GradDipPubHlth) —  
Program Officer (*resigned July 2010*)

**Agnes Tsetinis** (Cert III National Clerical –  
Administrative Competency Standards,  
Cert IV Information Technology) —  
Office Administrator (*resigned March 2011*)

**Katie Leyden** (BA (in progress), Training in  
Disability Support Work AQA) —  
Office Administrator

# Annual Night of Celebration 2010

Each year the Night of Celebration brings together a diverse group of people who have been involved with the SBFV. Some guests include families, some have played supportive roles in helping our organisation and others include Life Members and those that have an ongoing relationship with us.

On arrival guests were entertained by a musical quartet and were handed programs and their annual reports.

The proceedings then started with the Annual General Meeting (AGM) hosted by John Simmons, President of the SBFV. He talked about the numerous programs that had been conducted since the previous AGM and thanked those that had played a role in the ongoing work of the SBFV for their contributions.

One of our long-term members, Helen Houghton, then gave a speech about her younger years and her philosophies on life. Helen was one of the 2009 recipients of the Menelaus Achievement awards for her outstanding work in being a 'voice' for the spina bifida community.

Guests were then entertained by a power point presentation which highlighted some of the activities that members had enjoyed over the past 12 months. Following this presentation some special guests arrived dressed in Star Wars costumes including Darth Vader, troopers from the Dark Side, a rebel pilot and Obi One Kenobi.

During supper guests bid fiercely for some of the silent auction items which had been donated by various businesses, an artist and by our Patron, Geoffrey Rush. Many thanks go to these supporters as well as Yooralla's Riff Raff catering crew, City of Port Phillip (for the use of the St Kilda Town Hall), Bayer Healthcare staff (for volunteering), our volunteer photographer, Catherine Grey, and everyone that assisted on the night.

The two recipients of the Malcolm Menelaus Achievement awards this year were Katherine Simmons and Mark Love. Three Certificates of Appreciation were presented, one each to Mark Oswald, John Simmons and Sue O'Neill. All of these members have volunteered countless hours to the SBFV over many years.

*Helen and Alex enjoyed meeting Darth Vader on the night.*





*Helen gave a wonderful presentation about her life.*



*Liz shared a joke with a storm trooper and pilot from the rebel forces while Sabine kept a low profile in the background.*



*Agnes couldn't take this storm trooper too seriously.*

*Each year the Night of Celebration brings together a diverse group of people who have been involved with the SBFV.*

# Malcolm Menelaus Achievement awards

## Katherine Simmons

### *Award Recipient*

Last year I was surprised and very pleased to receive the Malcolm Menelaus Achievement award. It was very timely because I was undertaking a Legal and Dispute Studies course at RMIT and I was able to put the award towards completing my studies.

When I finished Uni last year, I joined the many other graduates looking for work. After a number of applications, I was able to get a contract position at the Department of Transport working in the social transit unit.

I am fortunate to work on policy and projects related to public transport accessibility, which is relevant and interesting for me. Recently, I was able to try out the accessibility of the new trams to be introduced soon as part of the public consultation process. I have also been working on a project called 'Travelling in the shoes of others' where we send able-bodied people who work in public transport out onto public transport to see what it is like to travel with mobility aids. This gives a firsthand perspective on the issues involved for people travelling with a disability.

I would like to express my thanks to the SBFV and particularly Mrs Margaret Menelaus for her continuing support of the award.

## Mark Love

### *Award Recipient*

I have recently been given the task of writing an article for the Annual Report. Most likely the one you are reading now. This article is in regards to receiving the Malcolm Menelaus Achievement award in 2010 alongside Katherine Simmons, a recipient of the award herself.

I would first like to thank Malcolm Menelaus and his family for giving the Spina Bifida Foundation of Victoria and its members a chance to celebrate such an award.

Like many members, I have a special place in my heart for Malcolm Menelaus. He performed surgery on my left foot in the early 1990s, and I am very grateful for this as I have been able to achieve things I may not have been able to.

In 2004 I got a pressure sore under my right foot, "what the hell is this" I thought. I needed answers and I had to start realizing what my disability could create as I had been quite lucky with it. Basically I always turned a blind eye to my disability and just got on with it (life). But I suffer the same symptoms, mine are mainly on the inside and a little harder to recognize, which can still be very difficult.

I joined the SBFV in 2005 as a member for the first time as I wanted to meet people with the same disability. I never knew many people with

spina bifida or had any regular contact with them. I just knew I wanted to be around people who have the same challenges in life, who had experienced what I was experiencing with my foot and other things. Two and a half years after I first noticed that pressure sore on my foot, it finally healed, mate I couldn't believe something so small can just stop you in your tracks, put your life on hold. It is painful!

In 2006 I joined the Advisory Committee to assist in organizing events for the Over 18s Social Club, which I did with the help of many other members on this committee. I had something to offer, plus I was learning new things and meeting new people, some of whom have become very good friends. And to this day I continue on the Advisory Committee to hopefully bring new and exciting social events to all members.

Since receiving the Malcolm Menelaus Achievement award I have completed a Certificate IV in Disability. I got a job with the Department of Human Services in a residential unit, helping support people with Autism. This job only lasted two weeks as I found it very stressful. But I am back doing the work I truly love and that is landscape gardening and have obtained a Certificate III in Horticulture. I never thought I would be able to do this style of work again with my foot, but I didn't give in. I also now play wheelchair basketball on Tuesday nights and totally love it.

On receiving the Malcolm Menelaus Achievement award I received a \$1,000 cheque. I was very surprised about this as the award would have been enough. I used this money to support a holiday to Tasmania for 14 days which I had planned with my partner prior to receiving this award. We had an awesome time and travelled over 2,800kms in Tasmania.

I'd like to also thank the Spina Bifida Foundation of Victoria for their support over the last six years. And thank you once again to Malcolm Menelaus and his family.



*ABOVE Katherine was congratulated by her parents, Carol and John.*

*RIGHT Mark was a proud recipient of the Menelaus Achievement award.*

# Past Recipients – where are they now?



**Mark Oswald**

It was a great honour to be a joint recipient of the Malcolm Menelaus Achievement award in 2005. As my Orthopaedic Surgeon for nearly 20 years, Malcolm played a major role in the lives of my whole family, as well as the lives of hundreds of other families affected by spina bifida.

Malcolm and the team at the Royal Children's Hospital spina bifida clinic, along with my parents and current health professionals, are my role models and it is to their great credit that I am who I am today.

I'm sure all of Malcolm's many spina bifida patients, have special memories of this wonderful man, in my eyes he was a giant of a man both in stature and heart. He was kind, funny and inspiring; his influence still has a positive impact on my life, even today. I can still see him striding the hospital corridors, with an army of hospital staff and sometimes patients, desperately trying to keep pace with him!

My most vivid memories of Malcolm are of him peering at me over his bi-focal glasses, tapping plaster casts and uttering unforgettable phrases such as "sweet as a nut", to describe something

which had contained my leg for up to three months and I'm positive was less than aromatic!

In 1984, I was wrapped to appear with my Mum and Malcolm on the Good Friday Appeal, it was amazing to me to see him, so nervous on TV, when you were so used to seeing him so calm, cool and self assured in the hospital environment.

As I've got older, I've realized that experiences like these were, I think for Malcolm, part of a plan to further promote the cause of spina bifida. This is carried on today through the Spina Bifida Foundation and its many programs.

Malcolm wasn't just interested in his patients orthopaedically, he was interested in the whole patient, whether it be school, sport or even work, Malcolm was always keen to hear what patients were up to.

I think it's to Malcolm's great credit, that I've been able to go to school and university, work, pursue a love of many sports and give something back to the SBFV, which he co-founded, by being involved in some of its many programs, its Board, Advisory Committee and Social Club.

I would encourage all of our members to pursue their interests with passion; you never know what you can achieve, until you have a go!

# Fundraising Activities and Events

## AFL Grand Final Fundraising Lunch

Due to such a positive response in 2009, the SBFV was again invited as the charity selected to receive proceeds from the Greater Dandenong Chamber of Commerce Grand Final fundraising lunch.

This event continues to attract more than 300 business people from the local Dandenong area. A significant amount was raised this year from auction items, raffle tickets and the unique game of 'Dandy Chamber Lotto'. The money received from this event supports the promotion of the folate message to women of childbearing age in the hope of reducing the incidence of spina bifida in future generations.

The SBFV sincerely appreciates the support of the Greater Dandenong Chamber of Commerce in conducting this event and thanks all of the guests who generously donated funds.



*This event continues to attract more than 300 business people from the local Dandenong area.*

*Although it was a busy day for staff and volunteers, who assisted at the lunch, there was always time for a friendly chat.*



## Ritchies Community Benefits Program

A number of members continue to regularly shop at Ritchies IGA Supermarkets and liquor stores resulting in funds being raised for the SBFV. Through the Ritchies Community Benefit Card Program a percentage of the money spent by customers is donated to their nominated charity.

It's an easy and regular way to support the SBFV which simply relies on members and their families and friends asking for a free card or key ring tag and then presenting it each time they shop.

## Christmas Donation Campaign

A new annual fundraiser was launched this year with the Christmas donation campaign. This proved highly successful with members, their extended families and other supporters who gave generously.

All donations to the SBFV of \$2.00 or more are tax deductible and each donor in the Christmas campaign received a tax receipt, a personal thank you letter and an ornamental star to hang on their Christmas tree.

Funds raised from this campaign went towards the Family Summer Camp and the remainder were used in supporting the costs of Social Club functions.



All donors received a star to hang on their Christmas tree.

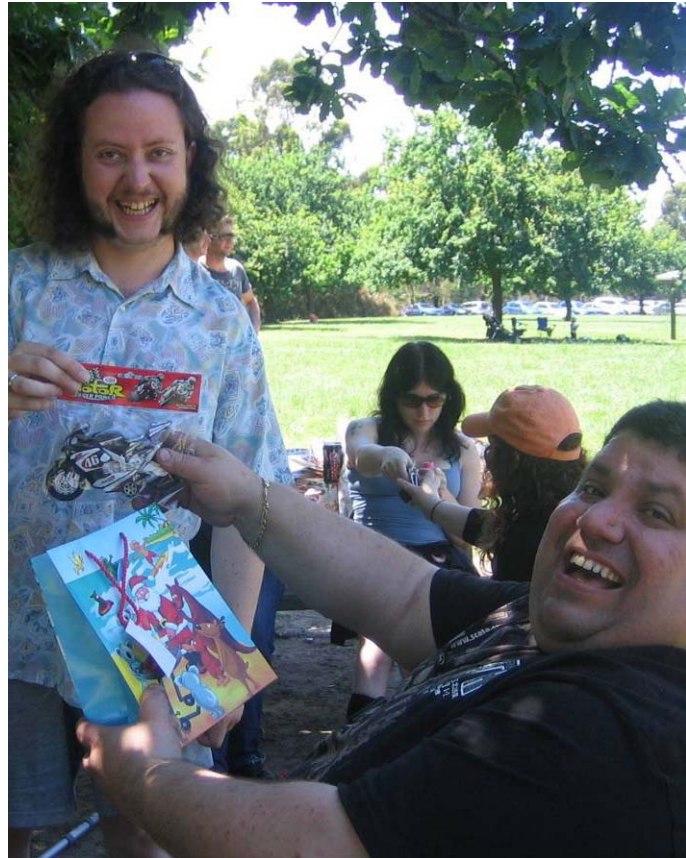
## Christmas picnic

Every December the Social Club organises an end-of-year function and, for the first time, this year it was combined with the family Christmas picnic.

The event was held at Jells Park and all who attended enjoyed great company, warm weather and were treated to gift packs containing some fun items.

## Star Bingo

The Dorset Gardens Hotel in Croydon has been a long-time supporter of the SBFV through its Star Bingo sessions. Since 2005 it has donated a percentage of the weekly bingo takings to our cause. The SBFV gratefully acknowledges this support for our programs and services.



*Jamie and Frank loved their Christmas packages while Sarah wrestled with hers in the background.*

*A new annual fundraiser was launched this year with the Christmas donation campaign.*

## Spina Bifida Awareness Week

With the support of Metro Trains and volunteers from Bayer Healthcare, the SBFV this year had more of a presence with the general public during Spina Bifida Awareness Week.

During the morning and afternoon peak hour rush at both Flinders Street station and Melbourne Central station we handed out folate leaflets to the public and collected donations.

The result of these efforts was the successful distribution of hundreds of leaflets as well as the raising of our profile in the community and the collection of some donations.

During Spina Bifida Awareness Week the SBFV also increased its profile by having a display window at the front of Ross House, where our office is based.

## International Day of People with Disability

As part of the celebrations to promote the International Day of People with Disability, the SBFV had an information stall at Federation Square.

Numerous volunteers helped on the day and spoke to those interested in finding out more about spina bifida and the services of the SBFV. As well, lots of brochures were handed out along with a display of our Independent Living Skills manual and Health Journals which prompted some discussion with those visiting the stand.

It was a busy day as we also talked to other organisations which were keen to work with the SBFV in the future. This event provided a wonderful opportunity to raise our profile and to create links with many other organisations that provide services within the disability community.

The SBFV would like to thank the City of Melbourne for funding for the project – Spina Bifida Social Club embraces the City of Melbourne.



*The stall at the International Day of People with Disability drew many visitors to whom Elizabeth, and the other volunteers at the event, spoke about the SBFV and its programs.*

*During peak hour rush we handed out foliate leaflets to the public and collected donations.*

# Community Seminars

## Spina Bifida National seminar

The SBFV was a major sponsor of the second national spina bifida seminar hosted by Monash Children's at Southern Health. This one day seminar aimed to promote links between spina bifida services across Australia and provide information on new medical techniques in this area.

It was an opportunity to enhance clinicians understanding of up-to-date practices from a variety of service providers including medical and allied health. The seminar was valuable to GPs, paediatricians, allied health and nursing clinicians working in both community and hospital settings.

The keynote address was given by SBFV Executive Director, Elizabeth Logan, who spoke about the importance of promoting folic acid and folate to all women. Two SBFV members, Melinda Mavroudis and Katrina Hartley, spoke about raising a child with spina bifida.

Dr Sarah Ogilvy, who had been an active volunteer with the SBFV, spoke about her research into the wellbeing and wellness of people with spina bifida and SBFV Board member, Dr Andrew Churchyard, gave a presentation on the topics of sexuality and independence.

Numerous other senior health practitioners spoke and provided a wealth of information on a broad range of topics relating to spina bifida.



*Melinda, Elizabeth and Katrina all spoke at the seminar.*

## Graham Webb seminar

The City of Greater Geelong hosted a talk by international entrepreneur and philanthropist Graham Webb in which the SBFV was invited to be involved.

Graham, who was awarded an MBE in 2005, co-founded the multi-million dollar hair company Graham Webb International which is now owned by Procter and Gamble.

In Victoria to speak about his autobiography entitled 'Out of the Bottle' in which he discusses his experience of growing up with spina bifida, Graham was keen to meet our members. Prior to his talk Graham met with a number of our adult members along with John Simmons, SBFV President and Liz Parkinson, Vice-President as well as Board member, Mark Oswald.

Key messages presented by Graham included the need for determination in overcoming adversity and that with a strong and enduring relationship a happy life can be attained.



*Graham was happy to sign copies of his book after the presentation.*

*Graham's autobiography, 'Out of the Bottle' discusses his experience of growing up with spina bifida.*

# SBFV Programs and Committees

## Family Camp 2011

Phillip Island again played host to SBFV families in late January at the Family Camp.

The atmosphere was very relaxed from the outset with adults and children alike catching up with friends at the welcome barbecue. The volunteers for the weekend also joined us for the welcome dinner which gave them the opportunity to get to know the families before activities officially started.

The camp is a much-anticipated and well-attended weekend with some families spending up to five hours travelling to get to the resort. For many it's the only opportunity to see other members in person and therefore the weekend is planned around including a mix of organised activities and free time for conversation.

This year the children enjoyed numerous adventure activities including canoeing, archery, ropes courses and a giant swing as well as a visit to the local Koala Park. The adults enjoyed an afternoon tea together as well as international beer tasting during the wine and cheese night.

The SBFV is appreciative to the Hugh Williamson Foundation, Dame Elisabeth Murdoch and other donors for the financial support to fund this weekend.



*Setting challenges and achieving them were highlights of the weekend.*



*ABOVE* The boys play a quick game of table tennis before dinner.

*ABOVE RIGHT* Ball skills took all forms including the much-loved game of cricket.

*RIGHT* Our team of volunteers were always smiling.



*The camp is a much-anticipated and well-attended weekend.*

## Facebook and mc2 – My Connected Communities

The SBFV Facebook page, that was launched last year, has proved to be very popular with members from all around Victoria. It is a good way for members to 'talk' to one another on a daily basis on a wide range of topics.

This site complements other social media sites including mc2. The aim of these sites is to overcome social and geographical isolation of members. Members are welcomed on to these sites to chat in a secure environment.

Apart from talking to one another members can access information on upcoming events and social activities, upload photographs, vote in polls and access the Central Point Resource File.

The SBFV also uses other social media outlets such as YouTube (and our website) to post the Community Service Announcements which promote the condition of spina bifida and the importance of folate.

## On-the-Snow Ski Camps

The aim of the snow camps is to introduce members with spina bifida to the challenges of skiing. This in turn increases confidence in individual's physical capabilities, creates opportunities to forge new friendships and helps develop a sense of independence for participants.

Since 2007 adult members of the SBFV have had the opportunity to go skiing at Falls Creek with the aid of Disabled WinterSport Australia. This was the second year that the program included children (aged between seven and 17 years) and their carers.

Comments such as "it's a weekend that I'll never forget" and "it was one of the most amazing experiences I have ever had" sum up the enthusiasm and wonderful opportunities snow skiing provides.

The SBFV received support from the Hugh Williamson Foundation and the Newman's Own Foundation to fund these two weekends for which we're most appreciative.



*The chairlift is always daunting but our skiers soon overcome their fears.*



*All participants are accompanied by at least one guide but the level of support provided on the snow is very much up to the individual skier.*



*Some of our members prefer to snowboard instead of using the sit skis.*

*"It was one of the most amazing experiences I have ever had."*

## Advisory Committee

A dedicated group of adult members from the SBFV meet regularly to discuss issues of importance that affect people with spina bifida. The Advisory Committee consists of a mix of members, all of whom have spina bifida, who represent the wider SBFV community.

Issues discussed at meetings are then presented to the Board of Directors and the SBFV office for resolution and implementation. This year the committee has made recommendations about the Independent Living Skills program; has assisted in preparing for the International Day of People with Disability; has managed the Social Club and its events and; has organised the footy tipping competition.

The Advisory Committee plays an important role in advising the SBFV Board by providing a direct insight into current attitudes, needs and issues relating to people with spina bifida.

## Educational Scholarship

Members of the SBFV continue to be supported in their higher education studies through the Educational Scholarship fund.

The fund was set up in 2008 to help members with spina bifida to further their learning opportunities by offering financial assistance with the cost of fees, the purchase of text books, stationery and other educational items.

Studies have shown that education is the key to increasing the chances of gaining employment, improving confidence and qualifications and therefore the SBFV is proud to be able to offer this support.

This fund was initially established through a grant provided by Medtronic.

*Katherine Simmons received some support for her studies through the scholarship and combined these funds with those presented as a Menelaus Achievement Award recipient.*



## Central Point Resource File

First developed in 2006, the Central Point Resource File provides current information on relevant service providers. The file is a central point for information on housing, employment, continence, respite, sport and recreation, as well as transport to name some of the 19 specific service areas.

One of the recommendations which came out of the research paper entitled, 'Community Needs Analysis' conducted in 2004 was the need for this type of information to be made readily available for people with spina bifida and their parents.

The information contained in the file is updated each year and made available on mc2.

## Independent Living Skills program

In 2009 the SBFV received funding to produce an Independent Living Skills program manual and to distribute it to all adult members. Each manual is made up of modules containing information which links into seminars on various topics relating to living independently.

The aim of the manual is to assist adults with spina bifida to develop the skills to lead more independent lives. The distribution of the manuals has meant that people with spina bifida now have a resource with which to help them achieve this goal.

To date, three modules have been completed including 'How to Manage Your Money Better', 'Good Food for Life' and 'Personal Care and Safety'. Funding has been gratefully received from the Helen Macpherson Smith Trust to produce a fourth and final module.

The key benefits of the manual have been to build up this resource one module at a time and, as it can be stored on bookshelves, for members to proceed in learning at their own pace and review past learning time and again.

*The manual is to assist adults with spina bifida to develop the skills to lead more independent lives.*

## FINE (Folate Information Network)

The SBFV has, this year, concentrated its efforts on successfully promoting the folate message through various mediums. These mediums have included newsletters containing current information relating to folate which have continued to be distributed biennially and social media channels such as YouTube which carry the SBFV Community Service Announcement on folate. There has also been an extensive distribution of the folate leaflets nationally and the keynote address at the National Spina Bifida symposium focussed on the folate message.

The folate leaflets have been disseminated around Australia in Bayer Healthcare's GP packs, into brochure stands at GP clinics throughout Victoria and at the GP Conference and Exhibition in Sydney. Financial support has been gratefully received from various organisations including Bayer Healthcare, The Kimberley Foundation, the Rotary Club of Balwyn and the Hugh Williamson Foundation.

The FINE program began with the development of a database of people in Victoria with spina bifida, or a family history of spina bifida or neural tube defect (NTD). At that time there were no folate awareness campaigns in place for the general public, or ways for those in the spina bifida community to access current health information.



*The folate leaflets were distributed widely around Victoria and nationally this year.*

## Social Club

Managed by the Advisory Committee, the Over 18s Social Club takes an active role in organising regular events and activities.

The aim of these events is to help members with spina bifida to overcome social isolation by providing opportunities for them to get to know one another in fun settings.

The SBFV has been able to subsidise these outings, through funds provided by the City of Melbourne. This funding has ensured that the cost of events to members is kept low so that everyone can attend no matter what their financial situation.

Some of the activities that members enjoyed this year included sailing on Albert Park Lake, lunches and movies, as well as 10-pin bowling.



*A small but enthusiastic group of sailors enjoyed their day at Albert Park.*

*This year members enjoyed sailing on Albert Park Lake, lunches and movies, as well as 10-pin bowling.*

# Financial Report

Balance Sheet as at 30 June 2011

|                                     | 2011           | 2010           |
|-------------------------------------|----------------|----------------|
| <b>Current Assets</b>               |                |                |
| Cash at Bank                        | 106,445        | 109,595        |
| Other                               | 4,349          | 4,076          |
| <b>Fixed Assets</b>                 |                |                |
| Computers & Office Equipment        | 8,641          | 11,462         |
| <b>Total Assets</b>                 | <b>119,435</b> | <b>125,133</b> |
| <b>Current Liabilities</b>          |                |                |
| Trade Creditors                     | 11,903         | 1,975          |
| Other Creditors                     | 4,724          | 4,346          |
| Provision for Employee Entitlements | 9,381          | 9,969          |
| <b>Total Liabilities</b>            | <b>26,008</b>  | <b>16,290</b>  |
| <b>Net Assets</b>                   | <b>93,427</b>  | <b>108,843</b> |

## Profit & Loss Statement for the Year Ended 30 June 2011

|                          | 2011            | 2010            |
|--------------------------|-----------------|-----------------|
| <b>Income</b>            |                 |                 |
| General                  | 76,724          | 85,795          |
| Grants                   | 106,398         | 99,498          |
| <b>Total Income</b>      | <b>183,122</b>  | <b>185,293</b>  |
| <b>Expenses</b>          |                 |                 |
| General                  | 156,635         | 204,703         |
| Grants & Projects        | 41,903          | 58,799          |
| <b>Total Expenses</b>    | <b>198,538</b>  | <b>263,502</b>  |
| <b>Net Income/(Loss)</b> | <b>(15,416)</b> | <b>(78,209)</b> |

The above is a summary extracted from the audited accounts.

## Key Financial Supporters

Bayer Healthcare

City of Melbourne

Dame Elisabeth Murdoch

Family of the late Sir Fletcher and Rena Jones

Geoffrey Rush and Jane Menelaus

Greater Dandenong Chamber of Commerce

Helen Macpherson Smith Trust

Hugh D. T. Williamson Foundation

Margaret Menelaus

Newman's Own Foundation

Ritchies Stores Pty Ltd

Rotary Club of Balwyn

Rotary Club of Footscray

Star Bingo

The Kimberley Foundation

The William Angliss (Victoria) Charitable Fund

Thank you also to all the people who have made significant contributions to the SBFV through donations of time, products and money.

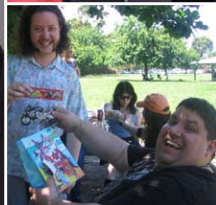
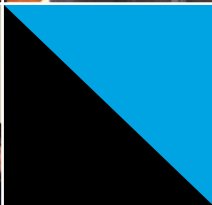
This Annual Report was designed pro bono by Univers Graphic Design.

## Donations are welcome!

The SBFV relies on the generosity of individuals, organisations and philanthropic trusts to continue its work.

If you would like to help us by making a donation we encourage you to contact the SBFV office on telephone (03) 9663 0075 as we would be delighted to talk to you.

All donations of \$2 and above are tax deductible and go directly to supporting the programs conducted by the SBFV.





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