# **PositiveWomen** Celebrating 20 years of advocacy and support for women and families living with ніv in Victoria



## **Positive***Women*

Celebrating 20 years of advocacy and support for women and families living with ни in Victoria

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#### First Published 2009

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#### **Forward**

#### Positive WomenVictoria

In 2008 *Positive Women Victoria* celebrated 20 years of support by HIV positive women for HIV positive women. This book is dedicated to those women who have given their time and energy to support HIV positive women through the different phases of living with HIV.

Today, with treatment, HIV positive women have a long life to look forward to. This was not always the case. In the early days of HIV, many women thought, and knew, that they had been given a disease that would cut short their lives.

HIV positive women are from all walks of life, with many different experiences. The one thing they have in common is that they are HIV positive. The support that they have given and received has led, them to feel connected, less isolated and has contributed towards them living longer lives.

As with any organisation that has been around for 20 years, information gets lost and communicated through different eyes. This book has tried to accurately reflect the journey of Victorian HIV positive women, but we understand that different aspects of the organisation and members experiences will have been omitted.

Read this book and celebrate the achievements of HIV positive women in Victoria. We look forward to the next 20 years and will celebrate that milestone with the same amount of passion that has gone into the first 20 years.



#### A message from Anne Phelan

Positive Women Victoria Patron since 2000



Little did I know where that night in August 1999 would lead.

I was part of an organizing committee for Oz Showbiz Cares Equity Fights AIDS. We had decided on a fundraiser celebrating the 25th anniversary of *Prisoner* going to air. Being a predominantly female cast we decided that some of the funds should go to an organisation supporting women living with HIV. That night Jenny Wheelan announced she had some information on a group and we all said "what a great name, and yes, let's contact them." So began my association with this remarkable group called Positive Women Victoria. Over the next few months while drumming up publicity for *Prisoner Unlocks The Gates For* AIDS, I worked closely with then Director Stephanie Moore and the wonderful staff members and friends of *Positive* Women Victoria. The late great very funny Sonja Ristov was an inspiration as was Deanna and many others. They were invaluable in getting the message out there and featured on many TV radio and print media. Thanks to the contribution of all these women, the night was a great success. It was just after this, early 2000 that I was asked to be patron. "Yes, Yes, Yes", I replied.

World AIDS Day 2001. After the success of those first tentative story telling steps for on the steps of Parliament House in Melbourne when Maggie Kirkpatrick introduced Carla Bonner and myself to read Karen & Carol's stories from Blood Ties, Stephanie came up with the idea of transcribing a journalistic piece about Sandy (known then as Joy's story) in to a performance monologue for an actress and did I know a playwright who could do the job, "Yes, yes, yes" I replied, Graham Pitts. The next year, World



AIDS Day 2002 Janet Andrewarthur read Joy's Story on those same steps, the impact was palpable. We know we were on to a good thing, more women told their stories to Graham Pitts and the following year, World AIDS Day 2003 Janet and myself were joined by Deborah Byrne and Jacinta Stapleton in the gardens at St Kilda. Still more women and their partners and family members told Graham their stories, this lead to the 2 hugely successful productions of In the Family. Around a thousand students saw the play and even more important were able to listen to and ask questions of the women whose stories they had just heard. A very moving and powerful experience for everyone.

To this day I still use Sandy's Story instead of a speech when asked talk about *Positive Women Victoria*. One of my proudest moments was having Sandy in the audience of my own show, *An Accidental Actress*, which features her story. My time with *Positive Women Victoria* has enriched my life; I thank you all past and present members and past and present staff. Will I hang around? "Yes, yes, yes".

#### Introduction







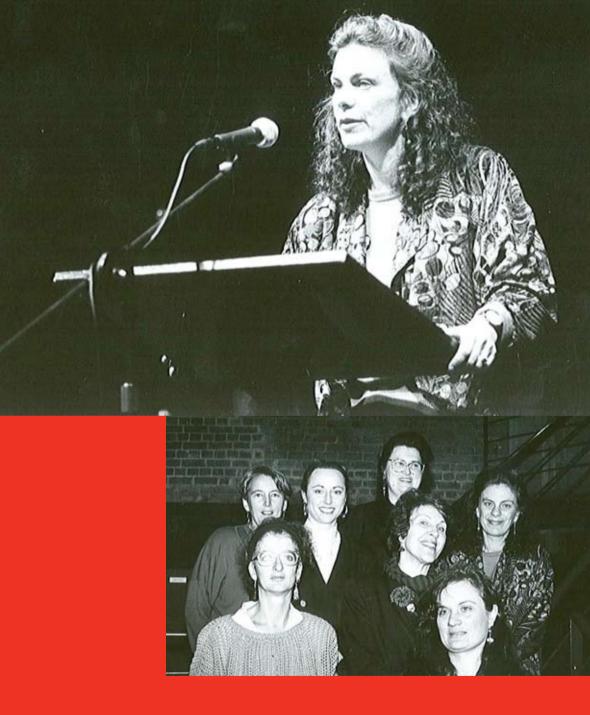


While the global face of HIV/AIDS is increasingly that of a young woman, this is not the case in Australia, where HIV positive women have been described as a 'minority within a minority'. In 2006, the *National Centre for HIV Epidemiology and Clinical Research* estimated that there were approximately 1500 Australian women living with HIV, less than 10% of the total number of over 16,000 PLWHA.

What these statistics do not describe, however, is the important role hiv positive women — as activists, advocates, educators, carers and supporters — have played, and continue to play, in the history of hiv in Australia.

In a piece written for the *Sunday Herald* in 2007, Marianne Peisl wrote of her hiv diagnosis, "So, at 26, began my own secret life, hiding my diagnosis from my family, concealing medical info in my car boot and pretending hospital appointments were work meetings." Marianne was diagnosed in 1988. She was only the fifth woman in Victoria to be diagnosed at a time when panic about hiv was at it height and knowledge about the virus was only just starting to emerge. Even among health professionals, very little was known about the extent to which women were susceptible to hiv, let alone the impact it would have on their bodies and their lives. Marianne's doctor at the time responded to her diagnosis with the comment he had never before seen a woman with hiv.

Fortunately for Marianne, she managed to make contact with a small group of women who had been slowly pulling together the first organisation for women living with HIV/AIDS in Australia, *Positive Women Victoria*.



Positive Women Victoria was established in 1998, a response to two women's experiences of isolation following their positive HIV diagnosis. Bev Greet was told she had HIV in 1984. She didn't know any other women with HIV, so set about trying to make contact, leaving her details with doctors and HIV specialists with a request to pass them on to any other women. It wasn't until four years later, when Deborah Gillies got in touch with her, that she met another woman with HIV.

"I joined a group called *Positive Friends* in 1985, but it was all gay men" says Bev, "It wasn't until 1988 that Deborah called me at home and said, "I am HIV Positive". I said, "me too" and she didn't hang up ... We met several times and were always talking about our problems and concerns and issues. We were sure that there must be other women out there facing the same things, so we decided to set up a group for positive women."

It took a while for *Positive Women Victoria* to take off. Bev and Deborah advertised the meetings around *Fairfield Hospital* and the *Victorian AIDS Council*. But for the first six months, it was just the two of them at fortnightly meetings.

"One other woman came to the first meeting. But then [information about her HIV status] was overheard by her employer and she was put off coming to any other meetings," recalls Bev. "So it was just the two of us. We put up flyers around *Fairfield Hospital* and other places and were starting to wonder if it was all pointless. But slowly, slowly women started to come."

In the beginning women had concerns about joining a group for HIV positive women. While most were keen to meet informally and have cups of tea at each others'







houses, they were frightened to be associated with the group in any formal way. "There was a lot of stigma then," explains Bev, "you were a bad girl. Positive women were seen as sex workers or drug users, not that those girls are bad at all, but there was stigma there. I don't think stigma and discrimination has disappeared today, but people are more open to the idea that anyone can get HIV."

The early days *Positive Women Victoria* ran fortnightly meetings in a small room at the *Victorian AIDS Council* offices in Collingwood. Over the years, however, the group became larger and the organisation more structured. In 1992, *Positive Women Victoria* received funding from the *Victorian Department of Human Services* to employ a paid worker and upgrade their premises.

"We didn't get much support at the beginning. We were told that we were such a disparate lot that we wouldn't gel as a group," says Bev. "We were banging on the door of the Health Department asking for funding, and we were told there wasn't enough of us ... It wasn't until 1992, when we had about 50 people and we finally got funding."

From this point, the organisation has gone from strength to strength; organising and being involved in a range of arts, cultural and sporting events that demonstrate the strength and life-energy of women living with HIV/AIDS, while also getting the message out that HIV can affect anyone.

In 1999, *Positive Women Victoria* entered a triathlon team in the World Master's Games. This is believed to be the first hiv positive team ever to be represented in an international sporting event, and the success continued with the 2002 Triathlon team receiving sponsorship from *Maurice Blackburn Cashman Lawyers*.









Cultural achievement added to sporting glory in 2005, when *Positive Women Victoria* produced a critically acclaimed play based on interviews with hiv positive women. The play, which few years later was included on the *vce Theatre Studies List*, was also developed into a series of monologues that are still performed at public events. This was backed up in 2007, with a powerful photographic exhibit depicting the experiences of members of *Positive Women Victoria Victoria* in images and text.

These initiatives notwithstanding, Bev describes the greatest achievement of *Positive Women Victoria* as the support that group members have provided for women over the years, both through formal events such as annual weekend retreats and informal day-to-day support.

"I do believe that peer support is a strong element in survival, breaking down that sense of isolation," says Bev. "Our raison d'être was to provide peer support, to make sure people did not feel alone and to help people feel (even though it was hard at the time) that we could live long and productive lives and even have children. We provided support by visiting women in hospitals, or if they had a crisis in their family or relationship we would go and visit, or we would go to funerals."

Advocacy has also been at the core of what *Positive Women Victoria* has achieved. The role of women who had the courage to tell publicly their stories of being HIV positive was incredibly important in the mid-1980 and early 1990s when the dominant image of a person with AIDS was one of someone who was 'deviant', criminal or in some way deserving of their fate. Women who were mothers and grandmothers, many of whom had acquired



HIV through heterosexual sex, came out in the media to demonstrate that HIV can happen to anyone, even 'good' women. In 1987, the television documentary 'Suzi's Story', aired on Australian television, to an immensely positive public reaction. The award-winning program, which chronicled the last months of Australian woman Suzi Lovegrove's life and death from AIDS, went a long way toward dispelling the myth that HIV/AIDS only affected gay men.

The political power of positive women also comes from the capacity to speak from experience. For example, the *NAPWA* women's network have been strong campaigners for appropriate policies regarding routine HIV testing in pregnancy since 2005 when this issue again reared its public head in Australia. Canvassing the opinion of women who have been in the situation of being diagnosed with HIV through antenatal screening, *NAPWA* women's network is in a strong position to present a powerful argument on the issues.

For better or worse, the need for organisations like *Positive Women Victoria* is not going away. In Victoria, the annual number of HIV diagnoses among women is increasing and the organisation has experienced an escalation in the number of women seeking support over the past few years. The needs of positive women have changed over the years, however. With new treatment available and life expectancy increasing, women are now seeking support around issues such as pregnancy and ageing.

"It used to be more that women would call us in crisis, soon after being diagnosed. They thought they were going to die," says Bev. "But now it's no so immanent. People take three months or so to digest things, then they may decide



they want some support or information or to meet other women. Then they call us. We also have a bit of a baby boom going on now"

Positive Women Victoria reached its 20 year anniversary in 2008. Despite much activity among various organisations and positive women across the country, Positive Women Victoria continues to be the only independent group for women living with HIV/AIDS in Australia.

"We were quite determined to achieve that," says Bev.

"We saw what the gay men had done and they had so
much knowledge and so many skills and it was great. But
we needed to do it for ourselves. It was part of our healing
process to do it for ourselves. We have now passed our 20
year anniversary. That is a big achievement ...We are also
a model for the rest of Australia. I'm so glad in those early
days that we persevered."



# An anecdotal timeline of our herstory

1988

1989

1990

→ Positive Women Victoria began with the meeting of two isolated women living with HIV early in the epidemic. They quickly realized that their needs differed from the predominantly gay male HIV positive community. It was necessary to develop a resource for women living with HIV, recognizing the need for a safe, comfortable, confidential environment for information and support. Overcoming many obstacles, the women formed Positive Women Victoria in 1988.

Four to 12 women met in church hall in East Melbourne each fortnight.

1991



→ Meetings began in this year. A tender was won to make a booklet and an accompanying video called 'Positive Women: Women with HIV/AIDS speak out'. It had a blue cover with 4 yellow women dancing in a circle. Some beautiful artwork was made for the book and it touched on issues such as attitudes and beliefs, sex, telling others and pregnancy amongst others.

Deborah Gillies was employed as project coordinator.

The first National Conference was held for positive women in Sydney.

1992

→ The first constitution was written in this year.

1993

→ We moved into the beautiful cottage on the grounds of *Fairfield Hospital*.

→ The organisation receives funding for *Department of Human Services* for a paid worker.

Early 1994 when the first retreat was organised to *Starglen Lodge*.

It seemed at this stage that there were many activists for HIV/AIDS in this year.

In 1994 four women were on *PLWHA (Vic)* Management Committee – record representation – Michelle Aterini, Susan Paxton, Sonja Ristov, Michelle Wesley.

In October 1994 *Rosehaven* opened in Clifton Hill. This was a very special place for so many of us. Women came for respite and we had Sunday lunches there for several years until it was closed suddenly in late 1999.

A blur. So many women dying over this time.

1995  $\rightarrow$  Faifield Hospital was closed.

1996

A breakthrough in medication was found in July in Vancouver.



→ *Positive Women Victoria* celebrates 10th Anniversary Joan Kirner is Patron.

First peer support worker is appointed.

The birth of the 'hope rose'.

1999

→ *Positive Women Victoria* puts together a triathlon team

2000

→ *Positive Women Victoria* office opens at *Fairfield House*, Prahran.

Prisoner reunion donates funds and helps raise awareness for Positive Women Victoria.

World AIDS Day 2000 sees the launch of the Hope Rose. Commissioned by the Australian AIDS Fund, the Hope Rose was planted to symbolize the issues and ongoing fight against the virus. Funding from Department of Human Resources Victoria is increased and the office staff is increased to 3 paid workers.



The *Positive Women Victoria* Board is opened up to include HIV negative women.

One of our members, Susan Paxton, represents HIV positive people, carrying the Olympic torch as part of the *Sydney Olympics*.



→ Anne Phelan, actress and activist becomes Patron for *Positive Women Victoria*.

Positive Women Victoria gains Deductable Gift Recipient status.

Member of *Positive Women Victoria* joins the *Ministerial Advisory Committee (MACHARDS).* 

Launch of the book *Blood Ties*, the stories of five positive women.

Focus on governance, management and strategic planning for board.

A new identity is created for *Positive Women Victoria* with *Ography Design Consultancy*.

World AIDS Day 2001, PositiveSteps campaign is launched on the steps of Parliament.

*Levi Strauss* offers funds & support for *World AIDS Day PositiveSteps* campaign.

→ Auction & Trivia Night hosted by Patron Anne Phelan raises funds and awareness.

Triathlon teams made up of HIV positive and HIV negative women, compete in *Business Review Weekly*, *Gatorade* and the *World Masters Games*. Triathlon teams are sponsored by *Maurice Blackburn Cashman Lawyers*. Believed to be the first HIV positive team ever entered in to an international event.







2002



→ Member represented in the *Victorian Women's Trust*, *Ordinary Women*, *Extraordinary Lives exhibition*.

World AIDS Day 2002 PositiveSteps is launched with the slogan "HIV A Public Conversation...." To begin a campaign to combat complacency and restart the public discussion.

2004

→ Positive Women Victoria, in partnership with Ography

Design Consultancy and the "Meanwhile" group (4th year

communications and design students at RMIT University)

develop a series of three Community Service Announcements. This is the first campaign about HIV to be shown

on Australian television since the Grim Reaper campaign

shown in 1997.

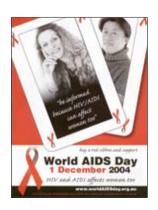
Two members hold places on Ministerial Advisory Committees.



We aim to provide an engaging website that will help to ease the isolation that is felt by many HIV positive women and their families and to improve the general community awareness and acceptance of positive women.

World AIDS Day 2004, focuses on the increasing vulnerability of women to HIV.

Two *Positive Women Victoria* members become the "face" of the Federal Government *World AIDS Day* campaign.





→ With support from the *Australian Council, Positive Women Victoria* produces the play *In the Family.* Written by Graham Pitts and based on interviews with HIV positive women the play is shown at *St Martin's Theatre* for *World AIDS Day* 2005. *In The Family* features real stories about real women and their families. The show is a sell out and receives great reviews.

Funding is received from the *Ian Potter Foundation* to develop a series of monologues. Seven monologues are written by Graham Pitts, for presentation at public events. *The Monologues* will be performed by actors and tell the stories of members of *Positive Women Victoria*.

Members of *Positive Women Victoria* participate in the *Digital Story Telling Project, Memory Grid*, at the *Australian Centre for the Moving Image*.

We strengthen our bonds with the *Country Women's*Association when Anne Phelen performs Sandy's Story –
Monologue to the Associated Country Women of the World,
South Pacific Area Conference.

2006

→ With encouragement from the Victorian Country Women's Association we receive funding from the Helen Macpherson Smith Trust for a new production of In the Family. The play is included on the VCE Theatre Studies List. In The Family runs for one week at St Martin's Theatre and is seen by over 900 people.

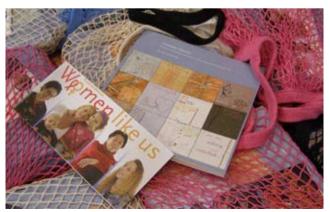


→ A Body of Knowledge is first shown in March 2007. This powerful & thought provoking exhibition was developed with the assistance of the Australia Council. A compilation of photographs and text created by world renowned photographer Michael Coyne in collaboration with award winning writer Graham Pitts and members of Positive Women Victoria.

Positive Women Victoria instigates & hosts the first National Women & HIV Forum. The forum provides opportunities for knowledge and skill sharing as well as vital networking for people working with women in the Australian HIV sector.



Common Threads Women's stories of pregnancy, parenting and living with HIV is published. Written by Karalyn McDonald and produced with the assistance of Positive Women Victoria and NAPWA, this is an invaluable resource for HIV positive women who are considering having children.



Positive Women Victoria & Women's Health in the South East Invite you to join us for the South East Invite you to join us for the South East Invite you to join us for the South East Invite you to join us for the South East Invite You to Join Women and MEY! It couldn't happen to me!

Get lateled, pit the histo and printing your partner and your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your Tenify I get lateled for 100 to histories of your

→ As part of our focus on providing education and awareness for health professionals we took up the opportunity to present several sessions about women and HIV as part of the Psychosocial Perspectives of HIV/AIDS: Emerging Themes forum run by the Education and Resource Centre, Alfred Hospital.

Positive Women Victoria takes up the opportunity to participate in Global HIV Testing Day on Friday 29th June 2007. Global HIV Testing Day was launched by The Honourable Bronwyn Pike Minister for at the Frankston Arts Centre. Our aim was to encourage people to think about testing and to raise awareness around the importance of practicing safe sex.

2008 → 20 years of supporting and advocating for positive women.

A Body of Knowledge has now been exhibited in Melbourne and regional Victoria and has been seen by over fifteen thousand people. There has been strong media interest in the project, highlighting its strength as a fine art work as well as parking interest in the lives of the women who participated in the project and the topic of hiv/AIDS in Australia today.

The *Rose Fund* is established. This fund, set up and administered by *Positive Women Victoria*, will enable the organization to better respond to the broader needs of members and their families. Members can apply for funding for activities that will improve their health and wellbeing.

#### Over the past 20 years....

The needs of positive women have changed. Life expectancy has been extended and there are different issues to face such as pregnancy and ageing. However, issues such as social isolation, discrimination and disclosure still remain as difficult issues for positive women.

#### Why we need to stay...

In 2007, HIV diagnoses for women in Victoria increased by 25% and our organization has experienced an escalation in the number of HIV positive women seeking our support. We have had an increase of 45% in membership over the last 2 years. The trends of heterosexual transmission in Australia are on the rise. While almost all social marketing campaigns, government strategies and interventions are aimed at the male gay community, there is a need to advocate for campaigns and strategic plans that address the growing transmission within the heterosexual community. *Positive Women Victoria* believes that an organistaion that speaks solely for positive women would be in the best position to advocate for these changes due to the understanding of how strategic plans and campaigns would be received and interpreted by women.





#### Stories from positive women

"The challenge for every positive person is to take back control of their lives, in 'Living Positively' with the virus. I've always believed that good health was never maintained by taking medication. More than ever, HIV reinforced for me that health is not just physical health, but also mental, emotional and spiritual well-being.

An important part of the healing process for me is to be active in hiv/aids education, support and advocacy. I volunteer in a number of hiv/aids organizations, because hiv and aids impacts differently on women and families.

As a positive person, I want to make sure that HIV never happens to anyone else. We can't prevent HIV by punishment, stigma and discrimination. It's only through building a safe, supportive and caring environment that positive people can be visible in our community, to educate and advocate, to take better care of ourselves and our families.

It probably sounds like an odd thing to say, but hiv has enriched my life in unexpected ways. I really value life and the time left to me. AIDS has an alternative meaning for me — Acquired Inner Development Syndrome, but there are still so many millions of positive people in the world who will never be so fortunate as me.

As HIV treatments become more accessible in the developing world, we need to promote another meaning of HIV to our sisters and brothers living with the virus, and to their communities. **Hope is vital**. There is hope for the future."

#### Suzanne

"One of my favourite *Positive Women Victoria* memories is of *World Aids Day* 2001. The day we 'stormed the city'. You couldn't see the steps of Parliament House for *Positive Women Victoria* and our banners. Positive women standing up for positive women. With blatant disregard for stigma and prejudice, united empowered and proud, we held our banners high.

In the old days when *Positive Women Victoria* would get together it was often to celebrate the life of a sister. Sad and scared, united in grief at a funeral. Too young to die. One of us. Who will be next? Life was like a lottery in those days. The virus was so unpredictable. The support of other positive women gave us strength and helped us deal with the fear.

Today there are a lot more of us, and when we get together it's to celebrate, marriages, births, graduations, our achievements, or just to have some fun. It's been a long time since I've been to a funeral.

#### Michelle

"My first memory of *Positive Women Victoria* was of meeting Bev and Deborah, the first two members of what would officially be known as "*Positive Women*." I had just been diagnosed a few days ago as hiv positive, and was shocked and very anxious. I wanted desperately to talk to other women who were coping with this problem. I wanted support above all, that is a chance to talk it all over, and information as well. We met in a small room with a sofa at the *Victorian Aids Council*, in its Collingwood digs. We continued to meet, formulating a mix of mutual support, information, and outreach.

Soon Danielle joined us, then Marianne. A few of us who were there at the beginning are still alive; several have died – Deborah, Danielle, Wendy. We were all in fear of dying in those days. This was the late 80's, when there were no treatments, AIDS was presumed to be inevitably fatal, and funerals were the order of the day. Heterosexual women, as most of us were, were less affected by the epidemic of death than the gay male community, but there were still a lot of deaths. While this led to a lot of sadness and loss, it also led to an intense solidarity among our small band of positive women. Bev, Deborah, Danielle, and I went all the way to Sydney on the train to meet a positive women from the U.S. who had written a book on coping with HIV. She spoke of her support group back home, where they had a meeting in their pajamas, to prepare themselves for the hospital days ahead. I thought that was strange; I wasn't prepared to get sick and die.

The group gradually got larger, and more structured. From the late 80s through the early 90s we met at small venues – first the vac, then a church hall in East Melbourne.

Our meetings were intense, sometimes fraught with conflict; attendance was up and down. Bev provided the passion, the persistence, the vision. I always wanted peer support, first and foremost. I loved those simple days in the church hall, even though it was cold, and there were many times Bev and I were the only ones who showed up for our fortnightly group. We were on our own; we were pioneers.

When we got our first paid worker and our first official premises, things changed irrevocably. We had a gorgeous little spot with a bay window overlooking an exquisite little garden and lawn at *Fairfield Hospital*. Peacocks roamed the hospital grounds. It was a special place and functioned like a drop-in centre. During that time Susan, the only other American I met through *Positive Women Victoria*, became a member, worked tirelessly as a member and as a nurse, then slowly died of lymphoma. I still grieve her untimely death.

We also started having annual, even biannual, retreats in country areas, which attracted a lot of positive women from diverse backgrounds. They were a bit wild, with drinking and partying (no men though), fantastic games and discussions, and lots of horse riding and massage. It was all organized and facilitated by us, with help from our coordinator, as she was known then. Our first coordinator, Jules, was a very memorable person and joined in on the fun with great gusto. The role of the paid coordinator/ director has evolved over the years. I think they have all been long-suffering, putting up with our dramas, conflicts, and insistence that we could always do it better because we were positive women.

In the late 90's I finally succumbed to illness, an AIDSdefining illness, after 15 years on lots of vitamins, natural therapies, and meditation, but no medication. I spent nearly two years getting my health back and getting back to work. During that time there was discontent among some of the younger members of *Positive Women Victoria* about those of us who had been on the managing committee for a long time. We decided, probably too hastily, to stand down and hand over to a younger generation. During those six years or so I had little to do with Positive Women *Victoria* other than the odd retreat or dinner. I suppose I felt somewhat estranged, and after a period of stable health, I also didn't need the support as I used to. This is one of the things we're up against: HIV/AIDS isn't as life-threatening as it used to be. It's only one part of a person's identity, and the need for support has lessened. Positive women are having children; they're in the workforce.

In the year and a half I've been back on the board, I've seen a different organization again. Bigger, more ambitious and professional, more corporate in a way. I am trying to see it as evolving and changing, as is the world of positive women, rather than expecting it to be as it used to be. I still miss the days in the draughty old church hall, though. That was a special time."

Jane

"The only thing that women have in common is that they are women and they are HIV positive."

"If you look at treatments issues, treatments are based on the studies done on white men. They're not done on women. Women's bodies are different... Menopause is now becoming an issue for HIV positive women. They never thought it would be."

Sonja Ristov 2002



Real stories about real women in our community living with HIV/AIDS

told by some of our leading performers including

Robyn Arthur, Sally Cooper, Anne Phelan, Greg Stone, Alison Whyte & Anne Wood.

# In the Family

Written by Graham Pitts · Directed by Terence O'Connell

In The Family is on the 2006 VCE Theatre Studies Playlist

#### St Martin's Youth Theatre

4.4 St Martin's Lane off Park Street South Yarra



Admission Adults \$20 • Students and Concession \$15 Bookings on www.positivewomen.org.au or 03 9276 6526

*Proudly presented by* 

Supported by





PositiveWomen

## In the Family

In 2004 *Positive Women Victoria* commissioned playwright Graham Pitts to write a play based on interviews with our members. Women from rural areas, aboriginal women, women from CALD (culturally & linguistically diverse) communities and those who had been living with the virus for a long time were some of our members invited to share their stories. The stories of partners and families who live with HIV positive women were also included.

Our aim was to provide HIV positive women with a forum in which their voices, their stories could be told in their own words. We also understood the potential for creating a powerful educational product, a play that informs and educates as well as entertains. In the Family challenges the stereotypes and myths regarding HIV positive women and their families. In the Family was first performed as a *Positive Women Victoria World AIDS Day* event in December 2004 to a packed house. We received so much positive feedback from the audience and we were encouraged to make sure that In the Family would be included on the *VCE Play List*. We saw this as a great opportunity to raise awareness of young people about the realties of HIV.

Produced with the assistance of *Helen Macpherson Smith Trust, Australia Council* and *Oz Showbiz Cares/equity fights AIDS* and performed by Sally Cooper, Adam Murphy, Anne Phelan, Sonia Suares, Alison Whyte and Anne Wood.



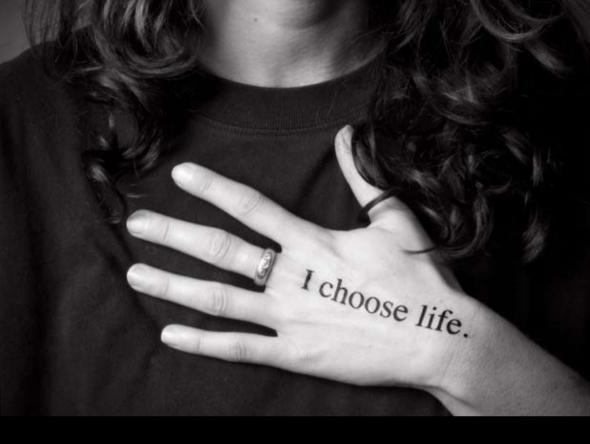
The diagnosis of no future came when I was twenty four years old. This was in a foreign country without a single long-term friend. It was incredibly frightening. Very lonely, too, because the virus wasn't well known at that stage seventeen years ago. But you know what? I'm still here.

# A Body of Knowledge

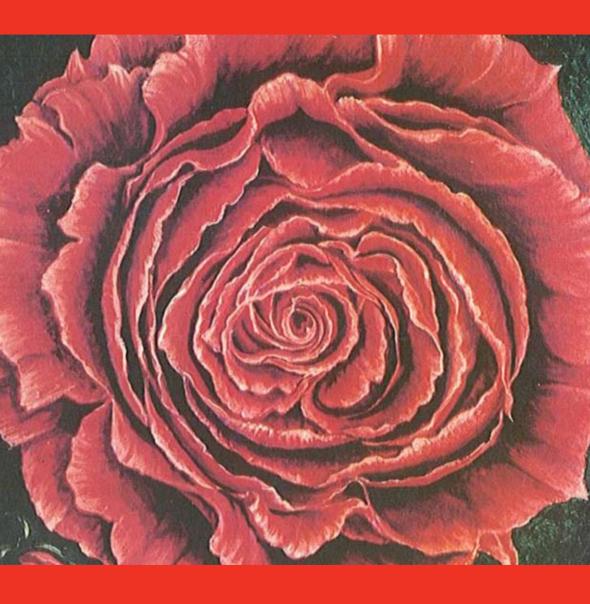
We are fortunate to have been given the opportunity to collaborate with photographer Michael Coyne and writer Graham Pitts. Both have been incredibly generous and caring in their approach to the work and have astounded us with the beautiful images & text produced for the A Body of Knowledge project. Prue Marks from Ography has once again assisted us with her spot on design expertise, guidance and support. Special thanks also go to Australia Council for supporting our work.



There was nothing anyone could do or say that could take this away. No point in crying over spilt milk. The damage was done. I walked out into the other room. My husband looked at me and I kind of shook my head. Read between the lines.



For life in its grandest form has no fear of negativity. For life in its grandest forms is always what I have done. For life has chosen to be kind to me, tested upon this most imperative plea. Life, choose me for tomorrow. And so I choose life.



### The Rose Fund

Did you know that in 2007 HIV diagnoses for women in Victoria increased by 25%?

*Positive Women Victoria* provides advocacy and support to women and families living with HIV and AIDS. For women, living with HIV can make it more difficult to manage the pressures of everyday life, work and caring for family.

The Rose Fund was established to enable Positive Women Victoria to raise funds to assist and support our members and their families. Many of our members live below the poverty line and are often the sole supporters of children. Like most agencies these days we are acutely aware of the hardships faced by families who live day to day with chronic illness and we do our best to help out where we can.

The Rose Fund assists members by providing grants to improve health and wellbeing, for training and education or personal development. Thanks to the generosity of our supporters, our members have been assisted with grants for:

A professional writing course
Dance classes
Gym membership
Business Administration Course
Lap Top Computer to assist with studies
Foreign language classes

This year we also distributed \$5000 in food vouchers and ran a retreat for our members where they can take some time out and spend time with other HIV positive women learning strategies for living well with HIV and AIDS.

Positive Women Victoria aims to decrease the number of HIV diagnoses, we hope that the need for a service such as ours will dwindle over time however unfortunately; this is not the case yet. In 2007, HIV diagnoses for women in Victoria increased by 25% and our organisation has experienced an escalation in the number of HIV positive women seeking our support.

One hundred percent of donations go directly to the support of our members!







## Acknowledgements

A book that spans 20 years of history cannot be written by one person. This book has attempted to capture the thoughts of many different people over the course of the last 20 years. We would like to acknowledge:

All the positive women who have added their stories, images and thoughts to this book.

Alyson Carter for collating all the stories and getting the project started.

Monique Wiessner for organising and gently pushing everyone to finalise their contributions.

The current board and all previous board members for ensuring the ongoing direction of *Positive Women Victoria*.

The *Public Records Office of Victoria (PROV)* for funding the printing of this book.

Prue Marks from *Ography* for her continued support with design for our book.

All previous staff for adding to the timeline of the organisation.

The *Department of Human Services* for ongoing funding ensuring that *Positive Women Victoria* continue to be able to support HIV positive women.





~ography



