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President's Report

"A Year of Great Significance"

The past twelve months can best be characterised as a year of great significance for NAPWA, our member organisations and positive Australians.

This was a year that has seen NAPWA rightfully gain the confidence to demonstrate true leadership at a national level as the national peak organisation advocating on behalf of plwhas across Australia.

Thanks to a number of significant developments over the year, NAPWA has gained the capacity and resources to provide strong leadership and support which is no longer about tokenism, nor solely about the often-tireless efforts of a few individuals, no longer measured solely in terms of unpaid endeavours and gains.

As President, I sincerely wish to thank the HIV community sector, its leaders and our funders for their confidence in NAPWA to provide this national leadership and for this opportunity to rise to the many and varied current and future challenges for positive Australians.

And I most certainly want to thank member organisations, past and present executive, committee members and staff for their efforts over the years which have earned NAPWA this special recognition, and now, the opportunity to make a real difference as a 'true' partner in Australia's response to HIV.

We are nothing and will achieve little unless we can learn from our past, recognise our strengths and build upon them in working together in a united response to HIV.

And indeed one of our greatest lessons in HIV to date must be that through acknowledging difference and recognising diversity, we can begin to

work with this difference and gain a united and synergistic response.

It is indeed a significant moment in time when both the infected and the affected know that they are partners and that each needs the other in their efforts in the 'good fight'.

NAPWA will now take on a new challenge as a result of this positioning. It is my vision that in twelve months from now we will be able to claim that NAPWA has added a new dimension to national advocacy efforts for positive Australians. And that dimension will demonstrate successes as we assist ourselves to find our own solutions to living with HIV.

A new dimension of 'self help' which will see NAPWA further the work outlined in our Strategic Directions Paper in the areas of national positive advocacy and representation, issues coordination, community consultation and organisational capacity development.

As NAPWA continues to mature, you will see our work proceed and progress in partnership by:

1. Strengthening and developing key strategic alliances;
2. Being attendant to outcomes;
3. Increasing the focus on health maintenance and quality of life issues;
4. Identifying innovative community initiatives to complement existing programs;
5. Advocating on unmet basic needs of positive Australians;
6. Maintaining a focus on leadership, skills-building and participation; and
7. Developing national policy.

As I have alluded to above, there are many individuals and organisations which have assisted us over the past year and I would like to single out a few which I believe are deserving of special mention.

The Australian Federation of AIDS Organisations (AFAO) through its own Strategic Directions setting process has listened and responded to the claims made by NAPWA that treatments policy and advocacy work for positive Australians is and must remain core work of NAPWA. (Bill Whittaker/ Tim leach)

As well, AFAO has agreed that Positive Living, which began as an initiative of the positive community in Victoria under the careful direction of David Menadue and PLWHA (Vic), be transferred to NAPWA at the end of 2001.

The AIDS Treatment Project Australia for working closely with NAPWA over the past year as a strategic partner on treatments issues. And in particular, to Dr Mark Kelly, Convenor, for adding insight and understandings to the ways of working and the synergies possible between positive Australians and their medical and community carers. (geoff Honnor)

The AIDS Trust of Australia for their continuing and increased support to our association. (Terry Trethowan) (Mark Reid)

To PLWHA (Vic) for their invaluable and generous efforts in assisting us to organise the 8th NAPWA conference in Melbourne last April. Positive Voices:

Strengthening the Response to HIV& AIDS was indeed a significant gathering of over 200 positive Australians and represents the first time that a federal health minister has attended and spoken at our conference.

I wish to thank the outgoing Minister Wooldridge for his support of NAPWA and the positive community in recognising the importance of the centrality of positive people to the HIV prevention and care efforts nationally. And for his insight in resourcing NAPWA to a level whereby we now have National Peak body status and resourcing through the DHAC to further meaningful leadership efforts in national advocacy efforts on behalf of positive Australians.

My heartfelt thanks go to the Madonna of the HIV community, our Executive Officer, Jo Watson who has demonstrated great skill, dedication, loyalty and dogged persistence in establishing the NAPWA Secretariat and in raising the performance and communication profiles of NAPWA.

Our staff team is of a very high calibre and we are indeed fortunate to have attracted such highly skilled and committed staff. Their hard work and attention to outcomes, friendly attitudes and achievements over the past year is evidenced in the Executive Officers Report and I thank them individually for their effort.

Our Executive members have worked with dedication to provide the leadership and opportunities to guide our organisation into the next phase of our work in meeting the many and varied challenges which lie ahead of us.

I have great pleasure in commending to you our 2001 Annual report.

Peter Canavan

Vice-President & Treasurer's Report

This year has been a time of change for the organisation, both financially and in resource capability. This change process has been taken on with enthusiasm by those concerned, so my credit and thanks to all.

This year has also presented its problems, such as the introduction of the GST, requiring changing over to a new accounting system. This has meant our reporting mechanisms needed to be modified and new systems set in place. While this has proved a very time consuming exercise, it has proved to be an achievable and worthwhile one.

Extra funding received from the government, recognising the worth of our organisation, allowed the expansion of the secretariat. This will increase again in the future when we are handed the management of "Positive Living" later in the year.

The pie chart's below show the combined NAPWA & ATPA Income and Expenses for the year ending June 2001.

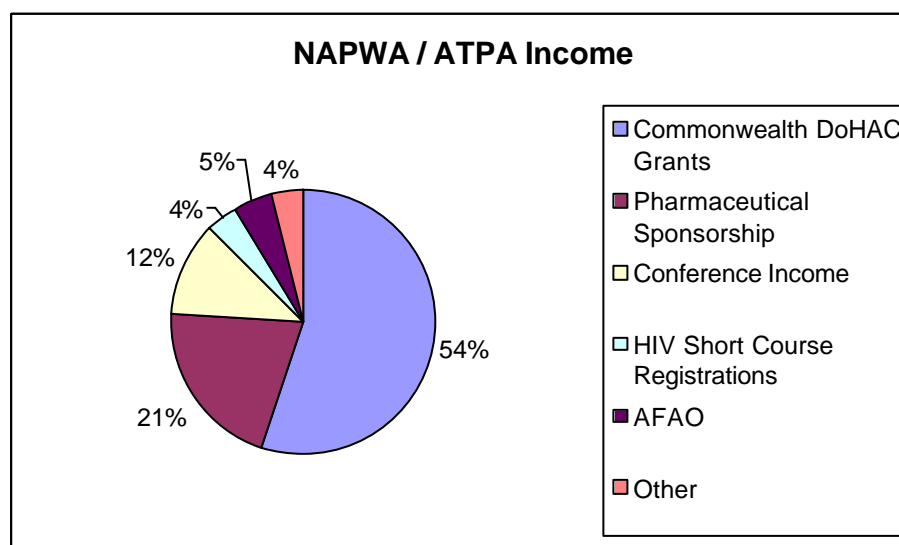
Two things that have had an impact on the organisation this financial year have been a very successful National Conference and the Governance Working Group.

The conference, although financially only breaking even, was a huge success in regards of the issues and bringing positive people from very diverse backgrounds together.

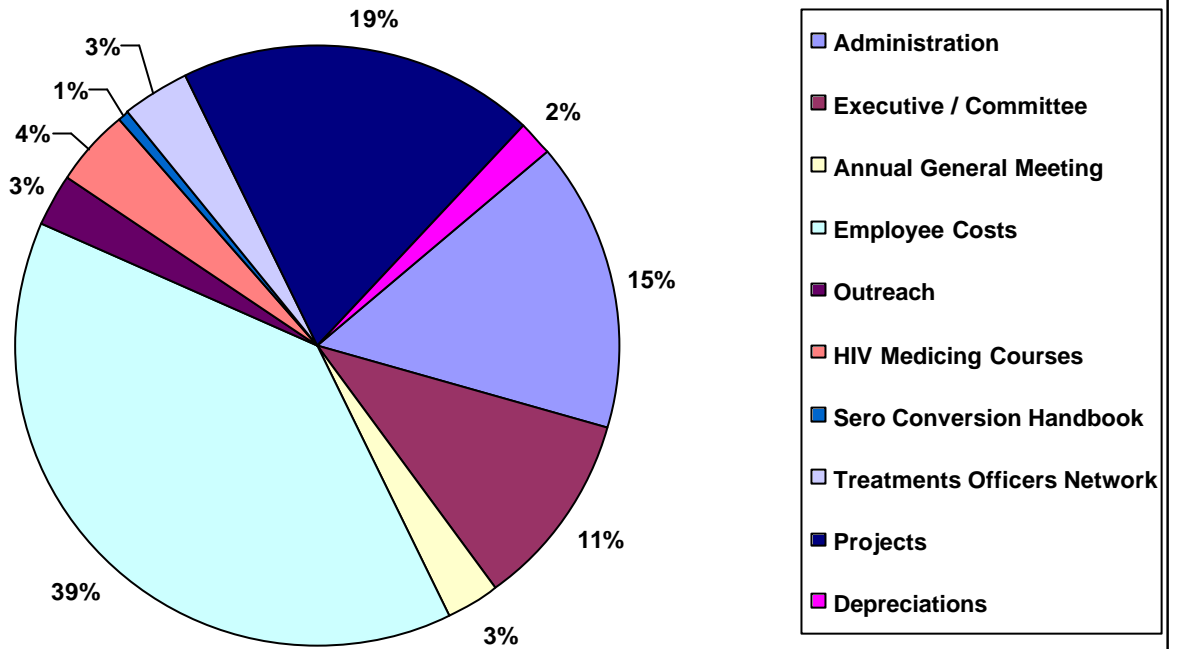
The governance working group process has provided great debate for the organisation about the structure and what we do as an organisation. It has also allowed more contact with the committee and has improved relationships between the states & territories.

Last but not least it has been a great year for the organisation and thanks to all the staff, committee and executive for such a wonderful effort.

Phillip Medcalf



NAPWA / ATPA Expenses



Executive Officer's Report

The past 12 months has been significant for NAPWA in consolidating and moving towards those objectives, as outlined in the goal statements of the NAPWA Strategic Plan.

Goal 1 - NAPWA will strengthen its position and build the profile of the organisation as the primary national representative and peak spokesperson for *plwha* and *plwha* groups.

Goal 4 - NAPWA will continue to negotiate with the Commonwealth Government for ongoing and where appropriate increased funding for the organisation. In its work with state based *plwha* groups it will also offer support as necessary.

Organisational Development

In November 2000 the membership of NAPWA endorsed a strategic plan for 2000 - 2004, and approved a new staff structure designed to give the organisation greater capacity for leading change.

In December 2000, a fulltime Executive Officer position was recruited, and negotiations concluded for NAPWA to move into larger office space on the premises it shares with the AFAO secretariat. Ken Irvine, our long standing NAPWA staff member, who had acted in part time administration and communication officer roles for several years, decided to move on, and all the membership said farewell to his colour and chirpiness with genuine thanks.

I transferred from ATPA Coordinator to NAPWA Executive Officer still with operational responsibility for ATPA at the end of December, and Brent Beadle agreed to continue with the ATPA as a fulltime project officer (Project Officer - Outreach) for all roadshow and forum activities, as well as the coordination of the HIV Short Courses.

Also in that month John Rule finished his contract as NAPWA national coordinator, and committed to returning to NAPWA in April 2001 as HIV Living Policy Analyst. Geoff Honnor agreed to

begin this project in January, and successfully advanced a wide program of education and policy work in that first four months. John Rule has continued with a wide engagement of the sector, and particularly close work with HIV Social Researchers.

Kirsty Machon commenced as NAPWA HIV Health Policy Analyst in February, and Kevin Barwick commenced as NAPWA Administration and Finance Officer, following a national recruitment that same month.

Commonwealth Government lobbying has been constant for funding consolidation and enhancements this year. In announcing funding for NAPWA in October during the ICAAP Conference the Federal Minister for Health, Dr Michael Wooldridge, said "The funding I have announced today reflects the importance of the functions of NAPWA and specifically, the emphasis and recognition given to the centrality of HIV positive people in the ongoing priorities and work of the 4th National HIV Strategy...The existence of NAPWA stands today because of the importance of people living with HIV/AIDS in the areas of HIV treatments, care and support, and both preventive and HIV peer education."

NAPWA also offered support for specific groups or other state initiatives where requested or appropriate, in the form of letters of endorsement, or proposal development.

The finance reports to March 2001 had been undertaken by Kerrie Cheers, who had been on a part time bookkeeping contract with both the ATPA and NAPWA, so finally having a fulltime and in-house capacity with Kevin Barwick's appointment to implement new finance systems and controls was a significant transition. Once the new systems were in place, and reporting mechanisms adapted, NAPWA, during June, formally took over the payroll and management of liabilities and entitlements for the

organisation's staff from AFAO. The final cord was cut!!!

I am also pleased to say that the independent auditors report for the NAPWA and ATPA finances for 2000 / 2001 have been concluded and are presented at this meeting. In a final meeting with the Auditor, he commented to me that the NAPWA reports and accounts were of the highest standard, and an example of the best he had inspected in his experience with community based organisations. This obviously means clearer standards of accountability and performance information for NAPWA into the future, and I commend Kevin Barwick for this tremendous effort.

Goal 2 – NAPWA will continue to liaise with and lobby the pharmaceutical industry and drug regulatory bodies.

Goal 5 – NAPWA will maintain close integration and alliance with ATPA and continue to be central to any national discussion of treatment issues.

The work of the Treatments portfolio over the last 12 months has been significant. With a fulltime HIV Health policy analyst there has been greater support and resourcing available for the wide range of issues and topics covered in this area. NAPWA supports the national Treatments Policy group, as well as leads in the development and consultation undertaken to produce responsive and rigorous policy positions.

NAPWA provides representation to all the National Centre in HIV Epidemiology and Clinical research working groups, as well as the ANCHARD Clinical Trials and Research Committee. It and the ATPA Steering Group have formed strong alliances, as outlined in the ATPA report, and the 12 months of trialling a new alliance where ATPA has been operationally managed by a NAPWA Secretariat has been clearly successful for both parties.

NAPWA has seen some significant advances this year with the commencement of a SAS programme for tenofovir, the first nucleotide analogue available in Australia, as well as lobbying for Australian plwha patients to be included in a pivotal Phase three International T-20 fusion inhibitor trial. There has also been ongoing representation for availability and access to a range of other treatments or therapies, or just constant monitoring of proposed clinical trial protocols and criteria to ensure best practice and equity. The skills and expertise that Kirsty Machon, and our many treatment representatives bring to these efforts are excellent.

This year we represented at several meetings with the Commonwealth Pharmaceuticals Branch as part of an ANCHARD advisory group considering changes or recommendations for the prescribing of S100 drugs. NAPWA and the ATPA have also spent considerable energies engaging with committees and representatives of the branch in lobbying in support of improving the drug approval, and drug pricing processes for antiretroviral drugs which have been held up through the approval process.

Goal 6 – NAPWA will develop and distribute new national policies, guidelines and best practice documents on identified issues which impact on plwhas as well as acting as a clearinghouse for already established state based and other policy, guidelines and best practice documents.

Goal 7 – NAPWA will facilitate at a national level exchange and distribution of information to and between state based PLWHA groups.

The 8th NAPWA Conference - Positive Voices was held in Melbourne in April. This included a day of positive satellites preceding the Official opening and two-day conference, as well as another two days following for Executive and NAPWA

members to hold a general meeting and organisational review day.

The conference was an extraordinary highlight of the year and attracted nearly 200 delegates, as well as approximately 40 speakers and presenters. The PLWH/A (Vic) group were an amazing support to this gathering, and really contributed as "hostesses" for all the visitors to their city. The record of the Conference proceedings has been collated and printed this month, for distribution to all delegates.

The implementation of improved office systems has also seen a better dialogue with the membership with regular mailouts and response to requests.

Goal 3 - NAPWA will advocate for, and where appropriate, instigate and support research on relevant HIV/AIDS issues.

Over the past year NAPWA has had involvement with every aspect of the HIV/AIDS research agendas. Vaccine research continues to grow momentum in Australia, and NAPWA has able representation at both the AFAO level and within the National Centre consortium by both Dr Paul McQueen, and Kirsty Machon. Strong clinical and basic science research has been actively supported this year with NAPWA representatives on every working group of the NCHECR, as well as the Scientific Advisory Groups of NCHECR and NCHVR.

Involvement with ARCSHS and NCHSR has developed and been strengthened over the past year with a range of initiatives specifically focusing on issues and emerging trends in plwha lives. As well, there has been NAPWA representation on each Centre's SAC and Project Advisory groups.

A significant highlight for the year was the AFAO/NAPWA HIV Research Summit being convened in Sydney where a range of stakeholders and representatives from the respective government and academic areas were brought together to discuss issues

arising from funding and strategic priority shifting at the national level. The other was the one day workshop which NAPWA collaborated with the National Centre for HIV Social Research and Australian Research Centre in Sex Health & Society that same month - an important engagement with the researchers and the researched.

Goal 8 - NAPWA will advocate on behalf of plwha and PLWHA groups at a national level with AFAO and other government and non-government organizations supporting plwha to be empowered at a state level.

Goal 9 - NAPWA will, where appropriate, facilitate capacity and skills building for PLWHA groups.

I think this is going to be an outcome reached out of many of the very thoughtful and passionate discussions around plwha participation and representation that NAPWA members and Executive have been involved with this year. This, I think, applies to both the National organization as well as the state and territory groups.

The greatest aspect of the past year as Executive Officer has been the people - all of you, and many others not here - and all the many interactions around the country that we have in different ways between the secretariat staff and the plwha membership.

I do want to thank all the Executive for their support and friendship - it counts for so much, and in particular the constant interaction between the Executive Officer and President, that has been marked by respect and trust. Finally - the staff team. You need to know that they are all committed, passionate, skilled and of the utmost integrity. They care, and NAPWA couldn't ask for a better team. They make me look good, which in turn can only enhance the organization to get to its best.

Thankyou.

Jo Watson

Care & Support

Welfare Reform

This has been an on-again/off-again issue with the Federal Government initially upping the ante in December last year, promising a response to the McClure Report which came out in July last year. This report recommended mutual obligations for people on a DSP (maybe voluntary work or study) and a restructure of the Centrelink processes involved in getting people back to work - possibly including a privatisation of welfare services. NAPWA and AFAO opposed a number of these suggestions in our submissions last year although there were some good aspects which we embraced (eg. creation of a special allowance to acknowledge the cost of disability).

The government response was vague and non-specific with some discussion about obligations for single mothers going back to work after their children reached a certain age - taking the limelight. Little specific has been said by the government re people on the DSP except that there may be requirements for some voluntary work for the DSP (again some Centrelink officers have said to us that this is not likely to be onerous, but who knows?) and that the eligibility tests for people going on to the DSP may be made more difficult. It is likely that the reason the government has gone quiet on the welfare reform process is because there is a Federal election in the air - if they are re-elected, we can be assured reforms will start to come thick and fast, then!

Some changes are starting to happen though with an increasing trend noticed in Melbourne for people applying for the DSP to be referred to the Commonwealth Medical Officer for a second opinion. The word of the person's GP is not necessarily good enough for some Centrelink officers who are obviously following a direction from head office to get tough on eligibility for people with HIV (as opposed to AIDS). This is despite our submissions to

McClure that the difference between people with HIV and AIDS is negligible these days given treatment side-effect profiles. I am following this up with individuals concerned to try to take the issue further with Centrelink.

John Rule, Timothy Moore, members of PLWHA NSW and myself worked on a welfare reform paper which has been circulated around AFAO and NAPWA membership for broad approval. It is the position of our joint organisations on the issue and has helped AFAO Executive to formulate questions on welfare reform which will go out to the political parties before the election.

Returning to Work Issues

There has been concern in Melbourne about the Centrelink work assessment process for people coming off a DSP and trying to access job employment agencies to go back to work. Centrelink offices in a central Melbourne area have been making it virtually impossible for a positive person on a DSP who is applying for less than 30 hours a week work to access Options Employment Agency which has been set up specifically to help people with HIV to return to work.

About 40 positive people have been refused entry to Options services and instead referred to Commonwealth Rehab or disability employment services. This is an unacceptable situation and PLWHA Vic and VAC have been pursuing this issue. I am involved in this negotiation and have kept NAPWA in the loop about the outcomes of this serious advocacy issue which is likely to have national implications. Options in Sydney does not have these problems there but within Centrelink there is an ideological push to assert that the Melbourne policy position is the right one for their organisation. Which we must fight!

NAPWA Conference

I organised a workshop on welfare issues with Fiona Tito from ACOSS Executive as speaker in one of the Conference plenaries and at the later workshop. Levinia Crooks from ASHM also participated. We asked for case studies from people attending on difficulties with Centrelink and DSP issues so far and have received a couple of case studies to work on. These case studies are important to develop a case for a cost of disability argument further down the track.

Consumer Health Forum

I am on the Executive of CHF and have attended all their three monthly meetings. The main issues which have relevance to us have been consumer input into research (I wrote an article for the CHF publication "Health Consumer" on a PLWHA perspective on this), and issues around privacy, the Better Medication Management Scheme and Health Connect, the mooted computerisation of medical records. I have kept NAPWA members up to speed with the documentation around these issues and have been pleased to see that Kirsty has taken the privacy issue on as part of her brief. My role in CHF is still not all that clear to me in terms of its value to NAPWA - there is only limited crossover of benefit for us so far and I have been disappointed that CHF doesn't seem to have ready access to politicians and Centrelink type bureaucrats (unlike the Disability Caucus which we left last year). Hopefully NAPWA will be able to lobby politicians and bureaucrats in our own right increasingly anyway - I shall keep people briefed on CHF's value to our work.

ICAAP Forum

I have spent some time in the last few months working on the International Working Group with Robert and Shellee trying to help with plans for the PLWHA Forum at ICAAP in October. I am also writing a booklet on the experiences of positive people from several Asia Pacific countries - funded by Merck Sharpe and Dohme.

Positive Living

I remain the Associate Editor of Positive Living and have played a role, along with Jo and Dermot in selecting the new Editor, Richard Knight with the objective of assuring that there is a smooth changeover to NAPWA's control next year. This seems to be coming along well.

Thankyou to all the staff and my fellow Executive and Committee members for one of the most productive years I have seen for NAPWA in my long history with the organisation. I particularly want to congratulate Peter Canavan and Jo Watson for achieving the level of resourcing - and with it the new exciting directions - for NAPWA over the coming years. We should finally be able to be the force for advocacy and change on a national level which we have truly wanted to be and were never quite able to achieve (although we've done some pretty amazing things over the years, even so!). To the fore in 2002!

David Menadue

Education

Graham Norton has represented the education portfolio for the first part of the year and Brent Allen in the second part of the year. In relation to education NAPWA continues to contribute the concerns of positive people in a number of forums, committees and networks.

Over 72 people attended the Positive Education Workshop held in January 2001. NAPWA made a significant contribution to the evaluation and review of the Positive Information and Education (PIE) strategic plan. A paper prepared by NAPWA titled "Catching up with the life realities of positive Australians in 2001" was presented at this workshop and helped draw attention to the socio-cultural dimensions of HIV Living and the importance of creating and sustaining healthy organizations in the sector.

A discussion paper on HIV health promotion was widely circulated and this document drew attention to the long-term picture where drug resistances, toxicities and decreasing options in clinical management were a major feature. Issues like poverty and the various challenges of the emotional landscape in which PLWHA are living were also identified as areas for further attention. Re-emphasizing peer support models and the special skills that peer support work involves has been a focus of discussion.

There is a synergy between education and HIV social research. NAPWA works with this by continuing to provide representation on the Scientific Advisory Committees of the NCHSR and ARCSHS. This year a new development

has occurred where both NCHSR and ARCSHS have set up PLWHA advisory groups to help refine and define areas of further research - it is hoped there will be some exciting projects for HIV health promotion and education emerging from this.

The AFAO NAPWA Education Team (ANET) continues to define and shape a range of educational products, which benefit positive communities. Everyday Pleasures has been a particularly outstanding outcome of this collaboration and has been welcomed as an educational process and product which engaged positive people in a powerful way in their own self imaging and futures. ANET is also helping to shape the nature of the HARD and Educators Conference due early in 2002 with a focus being on understanding the dynamics of changing communities.

The inclusion of representatives from plwha groups in Victoria, NSW and Queensland in the Educational Services Group (ESG) is recognition that plwha's and their organizations can provide leadership and best practice models in educational programs. Products like the SOS Drug Guide would not have emerged without foresight and perseverance of groups like PLWHA Vic.

Similarly, Positive Living continues to play a major educational and information role. The 'coming home to NAPWA' of this publication by the end of 2000 or beginning of 2001 is proof that positive people are in the best position to define, understand and manage their own educational processes and tools.

Indigenous

A major event for the Indigenous Positive Community this year was the NAPWA Conference held in April. An Indigenous satellite meeting was held prior to the Conference and arrived at four recommendations to be put to the NAPWA Executive:

1. That NAPWA maintains two Indigenous positions on their Executive. These positions need to be one male and one female, to actively reflect both cultural appropriateness and sensitivity, which in turn leads to the continuum of diversity, including holistic education, care and support and overall service provision.
2. NAPWA endorsed the formation of an Indigenous Australian committee of International Committee AIDS in the Asia Pacific (ICAAP), to develop and

implement an Indigenous plan across the ICAAP conference.

3. That NAPWA/AFAO and their memberships continue to encourage the involvement of Indigenous Australian peoples and communities in all education and resource development, this must include Indigenous Research components thus utilising the AFAO Indigenous Gay and Sista Girl Steering Committee and its research component.
4. That AFAO/NAPWA continue to actively lobby their memberships to encourage the establishment of appropriate Indigenous State and Territory based programmes and projects.

**Neville Fazulla
Bev Greet**

ATPA

Treatment options for patients with HIV disease continue to broaden. At the same time they are becoming increasingly complex. The need for up to date information that is understood in the appropriate context is even greater now than before. With this in mind the ATPA has continued to deliver on its mandate.

This year we sent the annual Roadshow, entitled "Cooee", to Adelaide, Bendigo, Cairns and Brisbane. In the Roadshow we specifically addressed issues relating to commencing treatment; treatment toxicities; monitored treatment interruptions and mental health issues facing patients with HIV disease in 2001 in Australia.

This period has also seen a trial merger with the National Association of People Living with HIV/AIDS (NAPWA).

This has been a particularly smooth process and we envisage a mutually productive working relationship in the future.

We also have been fortunate to have Dr Nick Medland join our Steering Group. This increases our national focus and Nick's respect in terms of clinical acumen and keen patient advocacy are ATPAs benefit. Sr Trish Bullen has moved to Dubbo and this will increase our focus on regional issues.

As treatments change from a focus of new agents to new strategies the ATPA's focus has also changed. We look forward to engaging with these challenges and to continue to deliver clear and current information which will assist PWLHA manage their HIV disease optimally in an ever changing world.

Mark Kelly

International

What an exciting and busy time it has been in our second term of sharing the role as NAPWA International Spokesperson. It has certainly continued to be a learning experience and very rewarding.

One of the most exciting components of our efforts has been working with the dynamic and supportive NAPWA International Working Group. This has enabled us to get input into our activities from a wide variety of sources and achieve much more than if we were working by ourselves.

A significant amount of our efforts for this year have been focused around the International Congress on AIDS in Asia and the Pacific (ICAAP), 5-10th October 2001 in Melbourne. For the first time a Regional HIV+ Forum is to be held just prior to ICAAP on the 4th October.

The one-day Forum will be an exciting opportunity for positive people from Australia and across the Region to gather in safe surroundings to discuss issues of concern. We will have plenary session with three dynamic keynote speakers from the Region and an open microphone time, followed by a 'market place' to allow for positive people to interact with organisations and their representatives involved in HIV/AIDS issues. The Forum is being jointly organised by NAPWA, Asia Pacific Network of PLWHA (APN+) and PLWHA (Victoria).

We will also be presenting our newly developed Guidelines on how to develop proposals at a skills building workshop during ICAAP. Our Guidelines have been developed through the combined efforts of our International Working Group members and are specifically designed for use by positive people throughout the Asia Pacific Region.

Our involvement in ICAAP has also included Robert's membership of the Scholarship Committee and attendance at the Congress organising meetings held in July in Melbourne.

The International Spokesperson role has also been involved in other international issues through membership of the Australian Federation of AIDS Organisations (AFAO) International Advisory Group. This Group brings together a variety of people from various backgrounds and it is pleasing to have positive people well represented. Robert also continues to be the Australian representative to APN+ and is involved, along with Susan Paxton, an APN+ Advisor based in Melbourne, in providing input to this Network and helping to unite positive people from across the Region.

We have decided that we would like to encourage fresh ideas and direction to the NAPWA International Portfolio and so we have decided not to stand for re-election to the Spokesperson position. However we are keen to remain involved and supportive of the International Working Group and the ongoing work of developing effective links between positive people and organisations throughout the Region.

Thank you to everyone who has worked with us, including NAPWA staff, over the past two years in our role as International Spokesperson.

Robert Baldwin
Shellee Korn

Legal

This has been my first year in the legal spokesperson position, much of my time has been spent bring myself up to speed on legal issues relevant to us as HIV positive people.

There has been a lot of 'behind the scenes' work going on. I have, and am still developing, a network within the HIV sector with legal focus. This will be a never-ending task. I have been briefing myself across international issues via HIV Legal E-Lists. I am of the view that we are in a much better situation, at least legally, than many other parts of the world.

In conjunction with PLWHA (Vic), I have been active in comment on the release of the HIV Transmission figures for Victoria. David McCarthy (EO PLWHA Vic) and myself circulated a press release on the day of the announcement of the HIV transmission figures in Victoria.

During the NAPWA conference there was a presentation of an HIV Legal Stigma and Discrimination hypothetical. Hopefully, this event offered a lighter look at some serious legal issues for Positive People.

Again in conjunction with PLWHA (Vic) work has been done around the same-sex relationship bill in the Victorian State Parliament.

I have worked with Vic Perri (VAC/GMHC and Bent TV) to ensure that the filming of the NAWPA conference in Melbourne would not breach the confidentiality of any person.

In response to concerns raised at the Conference, I have been following up the care of HIV Positive persons in incarceration. This is proving to be a demanding task but the end result should be a briefing paper for the membership.

A letter was written to the UFMCC about the exclusion of People with HIV from General Council because of US immigration laws.

I am currently trying to get representation on the ANCAHRD Legal Working Party - hopefully this will give the portfolio more 'bite'. Also I am writing a briefing note on the ANCAHRD paper 'Barriers to access and effective use of anti-discrimination remedies for people living with HIV and HCV' for PLWHA (Vic).

There are a number of issues that I see on the horizon which may cause us some concern:

- transmission issues (both in casual encounters and relationships)
- compulsory HIV testing of HIV Sector workers
- discrimination and disclosure in returning to work
- immigration (especially care of international students (and others) who become HIV+ while in Australia)
- the medical use of cannabis

I look forward to further work in this portfolio and thank the membership for their support.

Gregory Horn

State & Territory Liaison

During the year awareness of, and accessibility to, this Executive position by the States and Territories has been enhanced. This was largely effected by Peter Canavan (NAPWA President), and myself visiting some of the smaller (population) states in April 2001.

The intent of the visits was to consult with NAPWA state representatives, and other interested people, about resolutions that were to be tabled at the face to face meetings of the Committee and Executive in Melbourne prior to the National PLWHA Conference. The proposed resolutions related to the transference of the legal and financial responsibility/liability, from the Committee to the Executive.

As such it was considered expedient to visit some state representatives to ensure the implications of the resolutions were properly understood, and that people had the opportunity to clarify issues and concerns prior to the Melbourne meetings. The outcome was a greater understanding of the issues at hand, and a verbal commitment to moving ahead. As a result the resolutions were implemented and represent a significant change as to where the governance responsibility for NAPWA lies.

States and Territories visited were South Australia, Tasmania, Queensland and the Northern Territory. At each destination we were greeted with warm hospitality and were able to engage in straightforward discussions with all representatives and members. We talked about the proposed changes in the context of the evolution of the Organisation, guided by the Strategic

Plan, and NAPWA's significant increased capacity with the acquisition of independent Commonwealth funding. The visits were also an opportunity to open a dialogue with representatives as to how a "new look" Executive might emerge, should NAPWA choose to pursue that path. These discussions gave representatives the opportunity to consult with their members prior to the Melbourne meetings, so they could attend with an informed position.

Additionally the visits offered up the opportunity for discussion about domestic issues faced by positive people in their various states and territories. This was an enlightening experience and has enabled me to have a better understanding of issues faced by positive people in their constituencies. Having personal contact with NAPWA representatives, and other positive people, on their home ground has had the added benefit of strengthening ties and improving communication, which will hopefully benefit us all in the future.

The 8th National PLWHA Conference brought together representatives from across the country and was an additional opportunity to build relationships and strengthen ties.

Frank Farmer

Women

This year there have been many opportunities for me to spend time with other positive women. I attended the HIV Rural Forum in Ballina, which was attended by women from NSW, QLD and ACT. For some women it was their first experience of being with a group of positive women. They explained the sense of feeling less alone and being empowered by the sharing of information and experiences. One of the issues to emerge after discussions at the forum were the inequities in access to support, services, treatments and information depending on where you live. Not just rural, regional or urban but State to State, city to city. The challenge is for fair access for all positive people.

The highlight for me this year was the NAPWA Conference held in Melbourne in April. It was fabulous to see so many positive people together. We held satellite meetings before the conference for women, heterosexuals, and indigenous and gay men. Twenty-five women from every State and Territory except Tasmania attended the meeting. We discussed ways of participating in the conference and identified common issues to be explored during the next few days. The issues identified between these women and the women at the HIV Rural Forum were quite similar. We also talked about pregnancy, children, families and relationships. I was one of a few pregnant positive women at the conference and some of the women attended with their children. I think this sent a clear message that NAPWA is aware of the diversity of positive people's lives and the need to accommodate the wide needs of all positive people. I am still hearing people comment on how great it was that children and pregnant positive women were so visible at the conference.

I attended the 4th Australian Update on Pregnant Mothers and Infants, Children and Families living with HIV/AIDS held at Randwick in August.

This was a timely update as more positive women are choosing to become mothers now that we have more information on antiretroviral use reducing the risk of transmission from mother to baby. Presentations were on topics such as Caesarean section or natural delivery, treatment options for pregnancy, treatment availability and dosing for positive children, camps for positive children and families, and the big issue of disclosure. All this information was of great personal interest to me as I had just given birth to my second child.

I attended the 6th International Congress on AIDS in Asia and the Pacific in Melbourne. It was a great opportunity to meet with peers from the region. Even though there are vast differences in the epidemic some commonalities exist. Most positive people fear disclosing their status, for each positive person there are many affected people and we all would at some point like a loving relationship. I left the congress with a sense of awe in the great work people do and definitely feeling grateful for a supportive family and access to services if I need them.

This has been a full year and I feel grateful to be involved with an organisation that encourages positive people to be in charge of their own lives. I had my first child seven years ago and I didn't know any other positive women having children. I experienced discrimination and disempowerment in the health care environment. The pregnancy and delivery with this baby has been much easier as health care workers seem to have a greater awareness about the needs of a positive woman. It was also more satisfying as I could share it with other pregnant positive women. I now know in a very personal way that the work we do with Government, Doctors, hospitals etc, really does make a difference.

Amelia McLoughlin

Treatments

Another year has passed us by and NAPWA continues to play a leading role in advocating for access to new and better-formulated therapies to treat HIV.

The organisation was very fortunate to have secured Kirsty Machon in the role of Health Policy Analyst this year. She has brought to this role a wealth of skills and experience in developing and supporting our work around HIV treatments.

This year NAPWA has been particularly concerned about medically-induced disfigurement secondary to life preserving antiretrovirals. There has been growing disquiet amongst HIV positive people who have developed lipoatrophy (wasting of the face, temples, limbs or buttocks) from their treatment, and this has had profound effects on positive peoples' quality of life, self-esteem, social isolation, confidentiality, and capacity to return to the workforce. With the development of novel approaches to manage lipoatrophy deformity through the use of poly-lactic acid infusions and the forthcoming study of rosiglitazone (a diabetes drug which it is hoped will assist in ameliorating lipodystrophy) Australia is well-placed to take advantage of these approaches once their efficacy has been established.

This year has also seen a lot of attention placed on so-called Structured Treatment Interruptions, or STIs. Long-term HIV treatment often means a high pill burden and the risk of serious side effects or toxicities, so it comes as no surprise and understandable that many positive people have sought to have a break.

However, important questions about the use of Structured Treatment Interruptions remain unanswered and positive people need to be aware that it can have a negative impact on control of HIV. It is clear that no one approach works for all. Key questions that still have to be addressed include: How long can viral suppression be maintained on a Structured Treatment Interruption?; What is the ideal duration of antiviral treatment prior to Structured Treatment Interruption?; At what viral load level should re-treatment be considered?; What is the safe duration of Structured Treatment Interruption?: What should be the duration of re-treatment?; What is the best regimen to use?; and What are the predictors of success with Structured Treatment Interruption?

the meantime, while these questions are being unravelled by researchers, it is important to mention that for those who make a choice to take a break it is vital that they continue to monitor their viral load and CD4 cell count. Despite all the unclear questions about Structured Treatment Interruptions, NAPWA and the AIDS Treatment Project Australia are looking at developing material which may be able to support people who are thinking about taking a break from treatments.

This year has also seen the introduction of a more easily-absorbed formulation of ddI become available, and Trizivir (a triple combination of AZT, 3TC and Abacavir) has also been introduced. These drugs have been specifically developed recognising that treatment must be made easier to improve drug adherence.

With the issue of drug resistance emerging, a great deal of work has been undertaken to expand access to new classes or types of drugs to treat HIV including tenofovir, T20 and IL2. T-20 (a new class of antiviral called a fusion inhibitor) and IL-2 (a treatment which aims to boost the immune system by stimulating the production of CD4 cells) are both currently in Phase III trials. Tenofovir, a new class of HIV antiviral is now available through a Special Access Scheme for people who need this option.

NAPWA has also advocated for wider access to and refinement of resistance tests (which allow us to work out which drugs a person may be resistant to), to assist in the best selection of drug regimens for individuals.

Mental health and emotional well being have received considerable attention this year, given that we have been concerned about an holistic approach to the health of HIV positive people and the need for service providers to become more responsive and sensitive to these needs. Excellent papers were presented at the *Positive Voices* conference this year about these issues.

As the Treatments Spokesperson of NAPWA, I want to thank all those who have contributed to better access and understanding of the place of HIV treatments in Australia, particularly Dr Mark Kelly and the ATPA and NAPWA Executive Officer Jo Watson, who have done great work in this area. It was enjoyable to have played a role in the *National Treatments Roadshow* earlier this year and I want to thank Brent Beadle, the Roadshow's Outreach Worker, for his support during these presentations.

John Daye

Australian Capital Territory

The year commenced with a proposal for a trial of a PLWHA ACT Workers Reference Group to replace the PLWHA Committee. After a six-month trial it was decided that the new structure would be continued and the Reference Group continues to meet fortnightly with the Support Workers.

Service delivery to individual clients is now co-ordinated through a new Community Support Services Unit and there is much better integration of our response to the needs of individual clients who may be accessing several of the services offered by the Council and PLWHA. Over the past twelve months PLWHA ACT has provided over 2,000 episodes of direct client support and service. These included new people referred to PLWHA from other agencies and referrals by us to other services, people visiting our office, attending the massage clinic, PSN and other peer support events. Workers also attended meetings with service providers, and made home, hospital and outreach visits. We have also provided transport for clients when volunteers have been unavailable, and assisted people to access the services of Centrelink, ACT Housing, CARE Financial Counselling Service, the Trevor Daley Fund, legal services, doctors, counselling, Canberra Sexual Health Clinic and various drug and alcohol services.

An important part of the PLWHA Support workers' role remains the development of peer support and other activities for members. Events during the year have included the regular Big Dinners, Gallery visits, a Sydney Fair Day Trip, BBQ's, "Party, Party" and the Christmas Dinner. We have also begun formalising PLWHA membership processes and policies. PLWHA also distributes a monthly Newsletter to members and other agencies. This year we have been successful in encouraging our members to become more involved in contributing articles and assisting with the layout and distribution.

The workers are also responsible for the support of PLWHA as an organisation, including ensuring representation on external bodies such as the Ministerial Advisory Council on Sexual Health, AIDS, Hepatitis and Related Diseases, NAPWA and other appropriate bodies.

A PLWHA Planning day was held in June after the "Party, Party!" campaign and survey. Belinda Mehl (Manager, Community Support Services) facilitated the day attended by Kenn Basham, Mick Doring, Michael Beck along with Daniel Coase (General Manager) Kevin Schumburg (Manager, Community Education and Health Promotion), Stephanie Buckle (Counsellor) and the Support Workers. The PLWHA Working Plan for the coming year has been agreed upon, and we have already started working to that plan.

Since commencing in April, Marcus Bogie has approached volunteers and asked for their assistance with fundraising. A Fundraising Group has been formed and organised The "Olga Vision Song Contest" which was a great success raising \$1,300 for PLWHA. The group is developing plans for further fundraising events.

Continuing issues for clients are emergency housing, health maintenance, finances, and mental and emotional health. Due to the increasing difficulties with treatments, side effects, toxicities and drug resistance, we are seeing a number of people becoming quite ill. PLWHA continues to develop responses to the changing needs of HIV positive people and is well supported through the new organisational structure.

Acknowledgment and thanks must go to the many people who make a significant contribution to PLWHA in terms of time and financial assistance over the past year.

Marcus Bogie

New South Wales

The past twelve months have been a challenging period for PLWH/A (NSW) Inc which has continued to advocate and support the diversity of positive people in NSW. This is a tribute to our dedicated staff and a committed Management Committee. With two thirds of the HIV positive people in Australia residing in NSW, PLWH/A (NSW) has an important role to play in policy decisions affecting positive people at the state, national and international levels.

Following a restructure of the association's staff and projects, and the appointment of the first Executive Officer, Antony Nicholas, the Management Committee conducted a review to bring governance procedures in line with current best practice. This moves the association away from previous models established in the 1980's, under very different political, epidemiological and social conditions.

Following a trial last year and review, it was decided to issue *Talkabout* bimonthly. *Talkabout* is distributed state-wide with 3,000 copies going to members of PLWH/A (NSW), subscribers and to the public via street based distribution. *Contacts* continues to be the only comprehensive directory of HIV/AIDS resources in NSW, is now published annually rather than biannually because of increasing costs and budgetary constraints. It lists over 300 services including complimentary therapists experienced in the treatment of plwhas and an online version is currently being created and will be available late 2001. An updated version of the well received fact sheet,

International Travel and HIV, will be published later in 2001.

The Positive Speakers Bureau (PSB) has expanded its active speakers with the recruitment and training of non-gay speakers and people who use English as a second language. This will ensure that the PSB reaches a wider and more culturally diverse community. During the past financial year there were 131 speaking engagements, with around 10% occurring in regional and rural areas. The ongoing sales of the PSB Video facilitated better education about positive people in remote areas and the video has now gone into its second print run.

With more than half of the respondents to the HIV Futures II survey identifying government benefits or pensions as their main source of income, PLWH/A (NSW) decided that welfare reform should become a focus of advocacy work. Staff and the Legal Working Group developed a comprehensive policy on welfare reform. This policy and proposals formed part of the framework position by NAPWA in its ongoing discussions with the Federal Government.

The Integrative Treatments Working Group is planning a two day, HIV - Integrative Treatments Forum at the Powerhouse Museum in May/June 2002.

John Robinson

Queensland

Queensland Positive People (QPP) exists to provide peer support and advocacy services for people living with HIV in Qld. QPP has existed as a genuine statewide organisation operating in seven regions across the state for five years. Through our offices in the Gold Coast, Brisbane, the Sunshine Coast, Rockhampton, Mackay, Townsville and Cairns we provide a range of services for positive people.

Over the life of QPP we have continually improved our effectiveness at providing these services and the past year has been no exception. The Statewide Secretariat continues to develop improved skills becoming more effective at delivering services. Living with the tension between being service providers (what we get funded for) and the lobbying and advocacy role (what we want to be doing) doesn't get easier, particularly with dollars getting harder to come by.

The biggest event for QPP over the last year was the Queensland Health Evaluation of QuAC and QPP. It is reassuring to note that we are generally doing well, and as an organisation we are looking forward to some hard work over the next year addressing those areas where we could do better. We are also planning to lobby hard against the suggestion that some services should be reduced in favour of positive people accessing mainstream services (ie home care services). The experience of our members is that these services are difficult for positive people to access for a variety of reasons.

Improving the skills of members who wish to become volunteers has and will continue to be a high priority, with Public Speakers and Facilitator training getting back off the ground again.

Over the past 12 months QPP membership has continued to grow, full members now number 405 and friends number 415. QPP membership now comprises over 30% of positive people in Qld.

Members of QPP continue to represent the interests of positive people in a wide range of forums. QPP is formally represented on a number of committees including two members to NAPWA, a member on the QuAC Board, the Qld Health HIV/AIDS Advisory Committee and a member on the respective QuAC regional advisory committees. As well as these committees there are steering groups and working groups galore where positive interests are represented by QPP members.

Much of the advocacy work of QPP is carried out as part of our representation role. Over the past 12 months we have particularly advocated for one member over an issue with a major teaching hospital, and several other individual cases as requested.

This year a number of regions held retreats throughout the state. Retreats provide an important opportunity for members to access peer support especially those from smaller regions. Most notable was the North Queensland retreat organised by Mark Mills and QPP Cairns.

The Public Speakers Bureau continues to function albeit in a quiet way. The PSB is one way that positive people put a human face to the AIDS epidemic, and QPP continues to remain committed to this program. In the next year training of speakers and increased promotion of the PSB will occur.

QPP would not exist without the hard work of many members and supporters. Many thanks for your contributions to the shared vision of QPP.

Gabe McCarthy

South Australia

PLWHA (SA) oversees the operations of our Positive Living Centre through a Manager and five staff, and engages in group advocacy for HIV positive people and closely affected. We work to maintain the profile of HIV as a community issue and to ensure services are adequately resourced and effectively delivered.

Our Board produces the newsletter "Positively Talking" (ten issues per year), maintains the website (www.hivsa.org.au) and represents positive people on a wide variety of NGO, agency and government advisory structures.

A comprehensive range of services are offered by the Positive Living Centre including a medical transport service (three vehicles), intensive support and individual advocacy, emotional support (Buddy Program) and counselling, treatments information, alternative therapies clinic, weekly peer support luncheon, events/retreats program, occupational therapy, drop-in and a Positive Speakers' Bureau. Other agencies manage home support and respite care and we work collaboratively on several joint projects.

Implementation of a formal external developmental review and consequent increased professionalism of our management structures and processes, has resulted in amplified demand for services in all areas, and a high regard for our services by positive people and other agencies.

Increasingly, we are seeing people with highly complex needs including mental health issues and intellectual disability, reproductive issues, increasing levels of poverty, and continued isolation,

marginalisation and stigmatisation within society and within the body positive. Within available resources, we must reprioritise services towards the basics such as food, shelter, crisis intervention and medical transport, with less ability to deliver holistic health promotion.

There is an emerging trend for diminishing HIV specific funding to move from services for positive people to efforts in prevention education for the uninfected, much to the detriment of the well being of positive people. The ability of mainstream agencies to deal sensitively and appropriately with positive people remains problematic.

Our role in the partnership with government is clouded by our uncertainty about governmental bureaucratic processes and agendas. It seems the better able we are to manage community based service provision, the less we are listened to. In South Australia, PLWHA (SA) and most agencies dealing with positive people are funded under the communicable diseases control branch of public health. This reflects a governmental concern with public health, and not necessarily positive people's private concerns with their own physical and emotional well being.

PLWHA (SA) Board and staff continue to engage constructively in areas affecting us, as the legitimate voice of positive people in South Australia.

**Katherine Leane
Shaun McCausland**

Victoria

Another year has passed and PLWHA Victoria has continued to improve the well being of HIV positive people in Victoria. Our work has been shaped by our firm belief that we have the capacity, commitment and vision to bring about changes that benefit the lives of all the Positive Community in this state. We have been very lucky to have secured David McCarthy as our Executive Officer, who brings to the organisation a wealth of skills and experience.

On behalf of members, we have been involved in many individual advocacy cases. Some of these cases have included issues when discrimination in gaining access to medical treatment, problems with visiting rights to partners in hospital, superannuation and property transfer difficulties, access to appropriate housing and harassment in public housing have been our central concern. On occasions the situations have been such that they have warranted specific campaigns targeted at improving the quality of life for all members.

As many HIV positive people live longer with the virus they are faced with increased challenges: poverty, discrimination, maintaining mental and emotional well being, housing issues, dealing with complex drugs that have side effects, interpersonal pressures about HIV disclosure often in social contexts of rejection, desires to return to the workforce and the uncertainty of how long the drugs will work have been among these challenges.

We continue to have significant input into the development of the statewide HIV/AIDS Strategy for Victoria. We have advocated strongly to address the issues of Positive People by responding in a coordinated, efficient and timely way.

One of our major projects was a resource that dealt with minimizing the impact of side effects from antiviral

medication - Surviving Our Side Effects Drug Guide. The resource was launched by the Minister for Health John Thwaites during the Positive Voices Conference held in Melbourne in April. The resource acknowledged the burden that side effects have on the lives of HIV positive people.

Drug side effects are not the only difficulty; it is now clear that over a relatively short time (years), the virus has an ability to outwit the drugs through drug resistance. PLWHA Victoria has strongly advocated for the retention and expansion of health services in this knowledge. The development of a specialist lipodystrophy clinic at the Alfred Hospital and the availability of drug resistance tests are a direct outcome of these issues facing HIV positive people dealing with side effects and drug resistance. The disfigurement that is cause by the antiviral drugs know as lipoatrophy is of great concern understandably affecting HIV positive people's self esteem.

We also undertook collaborative work with Positive Women Victoria and the Victorian Law Foundation in producing a practical resource to help HIV positive people deal with discrimination: Don't Just Take It.

Extreme cases of poverty have been an issue for some. To meet this need, we have established our Emergency Distress Fund to help provide some direct small-scale assistance to HIV positive people. We have successfully run a number of fundraising events that have garnered public support while promoting preventative messages.

It has been another great year of work and we look forward to serving the needs of all the Positive Community in Victoria in the next year.

David McCarthy

Western Australia

Western Australia remains without a formalised PLWHA organisation. The majority of services are still provided by WA AIDS Council (WAAC), Royal Perth Hospital and AIDS Pastoral Care. The following is a list of services available

WAAC through the support services department

- Counselling
- Treatments Officer
- Living Well Program (Complimentary therapies)
- Transport & Home care
- Financial management and limited financial assistance
- Buddy project (emotional support)
- Blues Busters (a course that deals with depression for people living with HIV)
- PAWS (a new program assisting people living with HIV to look after their pets)
- Women's Support group
- Women's retreat October
- Family Camp December
- Positive Life magazine W.A.

WAAC through the community education department

- Public Speaking Project.

WAAC through the peer education department

- Peer Education & Support- One to One
- "Positively Social" an informal social group for people living with HIV, 2-4 events a month
- Positively Chilling - Chill out space
- Pride Dance Party Oct 2001
- Positive Sexuality retreat Feb 2002
- General Positive Retreat April 2002
- Loving Our Way- A six weeks course on relationships
- Men On Men - A six weeks course on coming out, sexual identity & self esteem
- Nitty Gritties - A six week course on you, your body and getting the most out of your sex life

Royal Perth Hospital

- Main distribution point for HIV antiretroviral treatment.
- Counselling
- Dietician

AIDS Pastoral Care

- Weekday lunches
- Weekday Spiritual services
- Emotional support
- Counselling
- Complimentary therapies

Other services

Spirituality and Well being Support Group - people living with or affected by HIV supporting each other on their spiritual journey. PLWHA's attended a very successful spirituality retreat September 2001, which was coordinated and supported by WAAC and the AIDS Trust of Australia.

Other events

Aids Candle light Vigil ceremony is to take place at the newly constructed **AIDS Memorial Monument** in Robertson Park North Perth on the first of December 2001. This will be the monuments opening ceremony.

New initiative

HIV/AIDS Peer Advisory Council (HAPAC) will be formed January 2002 to provide constructive feedback and guidance on a ongoing basis to the HIV/AIDS health service providers in Western Australia.

Western Australia continues to struggle with providing meaningful consistent support to PLWHA's from an indigenous background.

Advocacy work is continuing around multiple dispensing sites for HIV antiretroviral treatment.

Cipri Martinez

Tasmania

This year has seen the launch in Tasmania of the Treatments Diary. This was well attended by positive people and seen as being of some benefit to them in managing their lives.

The Tasmanian Council on AIDS (Hepatitis) and Related Diseases changed its name to include Hepatitis but has stated that this will not affect the services it provides to positive people.

Lunches for positive people are now held at TasCAHRD every month and this is proving to be a good avenue to network amongst positive people. A range of guests has been asked to attend in order to provide information and to answer questions on a wide variety of issues, including legal rights, medical and alternative therapies. However contact and networking with positive people from the north of the state is still limited.

Northern Territory

Difficulties are still being experienced in the Darwin area in getting people with HIV/AIDS to become involved in a positive way.

We have had some successful achievements over the past 12 months with the NTAC appointing a HIV Project Officer, employed at 17 hours per week. NTAC has also given PLWHA NT support in relocating to the new AIDS Council premises allowing us to offer increased services to PLWHA. Services include access to a drop-in center operating at present Tuesday to Friday from 1:00pm – 5:00pm and the Centre offers a range of assistance including up to date newspapers, TV and video access, coffee and tea making facilities as well as someone to talk to.

The Centre also offers professional counseling access to other support agencies, arranging transport and a

The Health Department was able to attract a second specialist to the state, which has increased the health care choices of positive people in the state.

Internet access and access to TasCAHRD's library of resource materials has been established this year and it is hoped that more positive people will utilise this service in the future.

Of concern is the rise this year in the number of new diagnosis in Tasmania and their need for support services. There was a 25% increase in Andrew Shaw Foundation grants for positive people reflecting a greater need for financial assistance by positive people.

Robert Mitchell

strong relationship with Clinic 34 at the Royal Darwin Hospital. Advice on wellbeing and a massage room at the AIDS Council offices and access to a PC terminal is also available.

The aim now is to work towards obtaining support from other PLWHA's and to encourage these people to attend meetings and use the facilities we have access to. Unfortunately we can only get 4-6 people to attend our regular meetings and BBQs but with perseverance we expect the numbers of supporters to increase.

We are attempting to establish a regular local newsletter and with the appointment of the new ED of NTAC it is hoped that PLWHA in the NT will Progress rapidly into a professional group, which will benefit all of the Northern Territory.

Tony O'Callahan-Creed

Straight Arrows

The last 12 months has been a very busy time for Straight Arrows in a number of senses. Membership has continued to rise, with a consequent increase in demand for services. There have been amendments to the Statement of Purposes, and an expansion of services provided. We have produced a resource kit aimed at heterosexuals with HIV, which appears to have been well received, and have expanded our networks through attendances at a number of conferences.

At present Arrows has about 100 people on our mailing list, as well as a number of contacts who prefer only personal contact, either by telephone or in person. In the first six months of 2001 we had over 600 personal support contacts, as well as another 200 telephone support contacts. During this period we were only open some 20 hours per week, although we also provide an "Anytime Arrowline", to allow out of hours contact. As we provides support for affected families as well as the infected, many of these contacts are from partners.

One of the differences we have found in dealing with the heterosexual community is our belief that HIV impacts on the positive person, their partner, and also their children, often directly. A number of our members, both male and female, are single parents. Other communities do not usually face the issues associated with

this, much less the additional complications when HIV is thrown into the mix. This can be further complicated by the lack of an educated support network, such as exists in the gay community. Many of our members find themselves trying to live the suburban "dream", outwardly normal, but in a landscape of ignorance.

As a result of the increasing demand for services, we were able to obtain additional funding support from the

Department of Human Services, Victoria. This has allowed us to increase the hours we are open to 6.5 hours, 5 days a week from 5 hours, four days a week. The additional funding has allowed us to increase peer support, as well as secure our worker who deals with family support.

In June Straight Arrows made some amendments to the Statement of Purposes to more accurately reflect the directions we had moved in. These amendments eliminated anomalies for heterosexual positive women accessing our services, if they chose (there being some groups of women who were not previously eligible), and an expansion of coverage to all HIV positive parents and their children.

As a result of philanthropic support, particularly from the Jack Brockoff Foundation and the William Angliss Trust, we have been able to significantly boost both our relief services and activities. As well as distributing emergency food vouchers, assisting with utility bills, etc, Straight Arrows ran a number of family activities, including a four-day camp over the Australia Day weekend, which was particularly successful. Additionally we are recurrently running limited free massage and monthly lunches, as well as a very busy drop in. In conjunction with Positive Women Victoria, we employ well known HIV dietician Jenny McDonald as part of the Positive Edge project. This provides treatment and lifestyle advice, and regular updates on specific issues.

In August this year we launched a resource kit aimed specifically at HIV+ heterosexuals. This was the culmination of 12 months work, supported by the Ian Potter Foundation. We have aimed to provide a resource in a user friendly format that can be easily updated, and which will shortly be downloadable from our website. In the future we hope to make it available in community languages.

In summary, there has continued to be a steep increase in demand on services and workload. I was fortunate enough to attend both the World AIDS conference in Durban, and the Heterochat conference in San Diego. Rebecca Matheson, our family support worker, attended the Durban conference

and the HIV Families conference in Sydney. Neither of us would have been able to do this without the support of our other staff, committee of management and volunteers, who have made whatever we may have achieved, possible.

Michael Rogerson

Positive Women Victoria

2001 has been a year of consolidation and forward planning. Last year we opened up our Board of Management to allow HIV negative women to work with us. This resulted in a dynamic team. We see the role of these non HIV positive women as supporting the aims of the organisation, with full authority remaining with the positive members. We recognised the necessity for good Governance. We had two Board training days, plus a day developing the strategic planning process for 2002-2005. This training identified the roles and responsibilities of the Board, provided a working framework for our strategic plan, and gave our Board members clear operational guidelines.

Our focus continues to be encouraging peer support amongst our membership in a variety of different ways. We are also concentrating on increasing awareness of HIV in the general public.

We worked in partnership with a number of organisations throughout the year, reaping the benefits of this cooperative approach. Our links with PLWHA (Vic) have continued to strengthen through Speakers Bureau. Our other joint venture, the "Don't Just Take It" booklet came to fruition after almost two years. We proudly launched this booklet together at the NAPWA conference held here in Melbourne.

Positive Women campaigned strongly to re-open Rosehaven (accommodation and respite facility), when it was closed. Again it was good to be a part of a cooperative effort to ensure services specifically for positive women remain available. We worked with Straight Arrows on the GlaxoSmithKline sponsored Positive Edge Project, so our members have access to Jenny McDonald, Treatments Officer. Positive Edge has provided a number of information sessions at Hotel Max and Rosehaven.

The Royal District Nursing Service come to the office once a month and are available to Positive Women members to access advice on health issues.

After the NAPWA conference we included a National Page in our newsletter in order to begin developing a consolidated national positive women's "voice." We linked with Positive Women (SA) to develop an "E Forum" where issues affecting HIV positive women will be raised with contributions from both positive and negative people.

After 18 months and continual pro bono support from Mills Oakley lawyers we attained our Deductible Gift Recipient Status (DGR). This opens up previously closed avenues of funding for projects for our members. This status now lays sound financial foundations for years to come.

This year saw the launch of the book "Blood Ties" a book written by five positive women, and the reading of "The Blue Note" a play by one of our members. We nominated Sandy to be part of the Victoria Women's Trust exhibition "Ordinary Women - Extraordinary Lives". We were thrilled to learn that she had been accepted and her story is part of the touring exhibition. We supported different members to attend the "HIV Prevention Conference" in Atlanta USA, the "HIV Families Conference" in Sydney and the "Australian Women Speak Out" Conference in Canberra. These attendances have significantly highlighted the profile of positive women, their specific needs and concerns which are quite different from those of men. This fits in very well with our aim to educate the wider public about women and HIV.

Through our fundraising we have been able to support the following; Camp Seaside, (for families), children's events, retreat, food vouchers and Rosehaven. We now fund Sunday lunches at Rosehaven to ensure that socially isolated members have the opportunity to meet in a safe environment specifically for women. We also funded initiatives to encourage peer support away from a hospital setting such as Barbeque Babes, Positive women and partners, mothers and daughters and art days. We look forward to building our Traithlon team again.

We have been building our support base in the wider community to ensure the reality of that HIV infects women does not go unnoticed or uncared about. We have tremendous community support for our World AIDS Day programme on

December 1st. Called "Positive Steps - HIV An Equal Opportunity" we are inviting 1000 women to assemble on the steps of Parliament House to learn about HIV and be pro-active in ensuring there are no more transmission increases. This event is profile raising. It is also educational reminding the public that the epidemic is still active and that the responsibility for HIV prevention should not rest solely with the gay community. The support we have received for this project will enable us to contribute to positive women agencies in South Africa and HIV positive mothers in India. We could not consider this without the backing we have received from Levi Strauss and numerous supporters who have given their time freely and generously.

To end I would like to thank the following women for their support and commitment this year in developing the vision for Positive Women (Vic). Realising that change takes time they have remained committed throughout our (many) challenges. A big thank you to Deanna, Suzanne, Bridget, Karen, Carol, Rachel, and Yen from our Board of Management, Annie Phelan our Patron, Nikki Smith admin support and Stephanie Moore, our Director. It has been a real pleasure working with this team.

There are many many more people who have supported Positive Women (Vic) and again too numerous to mention. However I really must give a very big thank you to all members of Positive Women (Victoria) Inc for all their work, assistance and support throughout what has been a very challenging year.

Sonja Ristov

Financial Reports

2000-2001