

The voice of all people living with HIV

Positive Life NSW

Annual Report 2022/23



Acknowledgment of country

We acknowledge the traditional owners of the lands on which Positive Life NSW operates from, the Gadigal people of the Eora Nation, and the traditional owners of all of the lands across NSW, and we pay our respects to their Elders, past and present.

We acknowledge the ongoing connection that Aboriginal people have to land, water, culture and heritage, and recognise Aboriginal people as the original custodians of this land.

We recognise and acknowledge that sovereignty was never ceded, and always was, and always will be Aboriginal Land.

Acknowledgments

Positive Life NSW acknowledges the ongoing support from NSW Health and all of our partners, supporters, peers and contributors, from all facets of the HIV sector.

Positive Life NSW also acknowledges the tireless and continued contribution and participation of all people living with HIV.

2022/23 Audited Financial Report:

<https://www.positivelife.org.au/wp-content/uploads/2023/11/PLNSW-2022-23-financials.pdf>

The voice of all people living with HIV

Positive Life NSW is the largest peer-led and run representative body of all people living with HIV based in NSW, and the voice of all people living with HIV in NSW since 1988.

We work to promote a positive image of people living with and affected by HIV, with the aim of eliminating prejudice, isolation, stigma, and discrimination so that all people living with HIV can achieve optimum health and wellbeing, support, connection, and quality of life.

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About Positive Life NSW

Positive Life NSW (Positive Life) is the largest peer-led and run representative body of all people living with and affected by HIV in Australia based in NSW, and the voice of all people living with HIV (PLHIV) in NSW since 1988.

We empower all PLHIV in NSW with health promotion information, peer support, referrals and advice with the aim of ensuring optimum well-being, care and support for the Body Positive including our friends, family and carers across NSW.

- Our Board of Directors are elected community members all of whom live with HIV.
- We have over 35 years community experience advocating for all people living with HIV with the aim of eliminating stigma and discrimination, prejudice and isolation.
- We empower and support all people living with HIV to live their best lives by providing information, targeted referrals, and policy advice through a range of peer support and community engagement activities.
- We advocate and represent on behalf of the NSW Body Positive and lobby government, researchers and all relevant bodies about issues of concern for all people living with HIV in NSW and those affected by HIV.
- We collaborate with HIV specialists and mainstream services to improve the health and quality of life of all people living with HIV.

Positive Life as a membership-based organisation for all people living with or affected by HIV in NSW. This includes:

- gay and bisexual men
- heterosexual people
- women
- Aboriginal people
- trans and gender diverse people
- people from all multicultural communities
- older people
- people who inject drugs
- migrants and refugees
- our family, friends and partners who are also affected by HIV

We carry out our work with people living with or affected by HIV through both our Peer Support Programs and Social Inclusion Programs.



“I want to thank POSITIVE LIFE for all the wealth of information, the emotional support and positive connections it has given my husband and I since we subscribed to your organisation.”

– Gay man living with HIV

President's Report

As I reflect on the past year, it has been a time where we have delivered a significant amount of work on a number of important issues while promoting a positive image of people living with and affected by HIV ensuring their optimum well-being, care and support.

This year, our Community Consultation and Engagement Forums (CCEFs) have highlighted a greater engagement with people living with (PLHIV) from Sydney's inner and outer metropolitan areas, with over 40% of attendees from culturally and linguistically diverse (CALD) backgrounds. Increasingly, we engage with more heterosexual men and women while continuing our commitment to ongoing work with men who have sex with men. Regardless of our differences, our community resonates with a clear and defining voice, providing insights into themes related to the continued burden of isolation, reduced access to healthcare and social support, and challenges to maintaining and securing our quality of life. Security strategies have been centred around an axis of secure housing, finances and health.

While these strategies are critically important, for me, the standout is the need for what we all consider to be the most basic of them all, the need to have a roof over our heads. In a desktop review which measured how social housing contributes to tenant and service-user health and well-being outcomes, the NSW Department of Communities and Justice has previously reported* on a direct correlation between health and housing and that the pathways between the two are influenced by health behaviours and access to primary health care and specialist services. For PLHIV, this means the psychosocial influence of housing quality and stability on our mental health and our need to maintain a regimen of anti-retroviral therapy for our physical health.

Positive Life understands that secure housing provides for better health outcomes for PLHIV and for this purpose, it has operated (and has largely self-funded) our Housing Support Program since 2016. Whilst we have continued to identify sources for critical funding for the types of services we deliver and how our community benefits from these, the Positive Life Board supports the importance of this work and has endorsed the continuation of this Program currently. However, this work does not come without a cost. Initially, we had budgeted for a loss from funding for both our Housing Support and Aboriginal and Torres Strait Islander Health Programs to the tune of \$131.4K to 30 June 2023, ultimately our year-end deficit was 8% higher (at \$141.7K) as we unfortunately were not able to secure ongoing sustained funding for either of these valuable programs.

Given the impact on cash reserves, the Board were forced to make a difficult decision. With much regret, it decided to terminate our Aboriginal and Torres Strait Islander Health Program until sufficient longer-term funding could be secured to continue this important work. I'd like to take this opportunity to thank

Michelle Tobin, who acted as our Aboriginal Program Health Officer for her work and dedication to support and inform Aboriginal-focused health services for people living with, or at risk of acquiring HIV.

It's ironic that closing this program due to a lack of funding, comes at a time when the Australian Federal Government has called for a referendum to alter the Constitution to recognise the First Peoples of Australia and establish an Aboriginal and Torres Strait Islander Voice. In the event that Australia decides to support the creation of an Indigenous Voice to Parliament, I hope that voice is loud and clear in its resolve that government and those that work within its halls of power need to make better decisions to support and progress the health agenda of Australia's Indigenous communities.

Honing back to my opening statement, preparing this report was also a great way for me to re-evaluate whether Positive Life has remained true to its purpose. I can say with a sense of achievement and with no small amount of pride that Positive Life has and continues to empower PLHIV in NSW with information, referral and advice on all relevant issues; to advocate on behalf of PLHIV and lobby government, business and non-government organisations about issues of concern to PLHIV; and to work closely with the HIV-specific and mainstream health and community sectors and other relevant organisations in the pursuit of these objectives.

As the leading peer-based HIV community organisation in NSW, our ability to connect and engage with, and to remain focused and respond to the emerging needs of all PLHIV remains possible because of the commitment and dedication of our Board, staff and volunteers, which are coupled with the contributions from our members and collaboration with our agency partners and sector allies.

Overarching this is the critical funding support we receive from NSW Health, the MAC AIDS Fund, Gilead Sciences and ViiV Healthcare. I cannot thank you enough for all that you do for PLHIV in NSW.



Robert Agati
President

Treasurer's Report

The 2022-2023 financial year saw total income of \$1.225m, which was down on last year by approximately \$74k, mainly due to slower grant spending. In comparison, our year-end expenditure increased to \$1.364m; only 3% higher than the prior year, resulting in a year end deficit.

Whilst this deficit was significantly higher than that recorded in the prior year, the lion's share was as a result of Positive Life NSW self-funding its Housing Support and Aboriginal and Torres Strait Islander Health Programs out of its own cash reserves. Notwithstanding that the aim of these two programs are to the benefit of people living with HIV (PLHIV) across NSW, despite exhaustive efforts and the crafting of numerous grant applications highlighting the urgency and significance of these essential programs, the search for funding opportunities has proven to be a formidable challenge.

Although the competitive landscape of funding sources coupled with the limited priorities of philanthropic organisations created an environment unconducive to securing funding to meet the cost of all the services we provide to community, our decision to self-fund is testament that Positive Life stands by its purpose of empowering PLHIV with information, referral and advice. In reaching these decisions, Positive Life carefully considered all our options including weighing up what we are able to do with the limited resources we have, against the needs of PLHIV; mindful always not to leave anyone behind. This underscores and highlights the importance of continued advocacy and resilience in the face of funding uncertainties.

As a knock-on effect, the Positive Life deficit grew sharply year-on-year from \$29.9k in 2022 to \$139.4k at year end, with the majority of our untied funds being in the form of term deposits. These deposits not only provide Positive Life with income earned from interest, they also act as a safety net in case of any unforeseen major expense.

Despite depleting some of our cash reserves, Positive Life continued to maintain a sound balance sheet position throughout the year.

Assets were predominantly cash at bank and on term deposit, whilst total liabilities included grants in advance. Cash, reserves and financial ratios remained reasonably healthy throughout the period, which ensured that Positive Life was able to meet its financial obligations as and when they became due and payable.



A handwritten signature in black ink, appearing to read 'Neil Fraser', with a stylized flourish at the end.

Neil Fraser
Treasurer

“Yesterday’s event was an utter success, in terms of turn out, venue and staff participation. Thank you to the entire team for making it a successful and seamless evening and a memorable event. WELL DONE Positive Life Team.”

– Gay man living with HIV



CEO's Report

This past financial year has been one of resilience, impact, and commitment as we continued to strive to empower all people living with HIV in NSW to attain optimal health and quality of life free from the impacts of stigma and discrimination. Once again, through the principles of self-determination, we have offered comprehensive health promotion information, referral services, systemic advocacy to benefit our diverse community of people living with HIV across all of NSW while championing inclusivity and equality.

Impact and Achievements

Our efforts in the past year have focused on expanding our services to ensure continued access to healthcare, treatment, and support for all people living with HIV. We hosted 93 social inclusion events, workshops, and health promotion campaigns, and our programmatic work reached 2,122 community members, building their capacity around digital literacy, HIV treatment and adherence strategies, navigating the aged care system particularly around My Aged Care and the NDIS, access to healthcare, service referrals, ageing, employment and legal rights.

Peer Navigation and Peer Support

Our Peer Navigation Programs have connected over 170 women living with HIV, over 220 heterosexual people living with HIV, and at least three times as many gay and bisexual men living with HIV, with peers who provide support from someone else with a lived experience of HIV, advice and understanding. This one-on-one person-centred support to all people living with HIV has resulted in increased treatment adherence, practical support and onward referrals to a range of other services.



"I wanted to personally thank you for organising the Aboriginal weaving workshop for community, to mark NAIDOC week. It was one of the best experiences of Positive Life events I've attended...Five out of five stars. Thank you."

- Nonbinary person living with HIV

Social Inclusion Programs

These initiatives have seen our popular Peer2Peer gay and bisexual men's group go from strength to strength, The Women's Room and For Women's online groups increase in numbers and engagement with regional members with discussion topics chosen by the women themselves and the development of The Men's Room an online program for men who identify as heterosexual. We have responded to the increased demand for our [+Connect] events increasing from four to seven this year and broadening the locations and frequency in greater western Sydney with the support of our clinical and HIV sector partners. Through these social inclusion community events, we combat stigma and discrimination, raise awareness around HIV prevention messaging in the broader community, and encourage inclusivity for all populations of people living with HIV.

Ageing Support

As our community ages, we have intensified our efforts to address the unique challenges faced by older people living with HIV. Our Ageing Support program specifically caters to the health, social, and psychological needs of people ageing with HIV, offering tailored support and resources to navigate the aged care landscape.

Employment and Vocational Support

As a key priority through partnerships with vocational institutions and employment agencies, we have successfully assisted our community members with referrals to training opportunities, interview preparedness, job placements, and ongoing support to enhance their financial independence and wellbeing.

Treatments Support

Our peers have facilitated access to treatments, medications, and healthcare, along with one-on-one support and health promotion initiatives ensuring all people living with HIV receive comprehensive and accessible healthcare.

Workshops and Retreats

This year we held our inaugural 'Life Beyond' weekend retreat for people who identify as heterosexual in late June which was an opportunity to connect with each other and share experiences, with safe, confidential and understanding peer support. This retreat facilitated social connection, support, and a sense of belonging, fostering an environment where people shared personal experiences mitigating social isolation. Additionally, we ran two In The Know Research and Treatment workshops with invited academic researchers and clinicians around quality of life, and the interrelationship between inflammation, co-morbidities and ageing; and two Community Consultation and Engagement Forums on stigma and discrimination and HIV and ageing.

Counselling Service

In response to an increased demand for mental health services, we launched a dedicated counselling program, Positive Minds. This initiative offers a safe, culturally appropriate space for people living with HIV to access free, strengths-based, trauma-informed and solutions focused counselling from two accredited counsellors who are both peers, either living with HIV or directly affected by HIV.

Financial Overview

The financial report demonstrates our responsible stewardship of the funds entrusted to us. We allocated resources efficiently, ensuring that every dollar was maximised for the benefit of all people living with HIV. Our finances were managed transparently, reflecting our commitment to accountability.

Partnerships and Collaborations

We are immensely grateful for the collaborative efforts with governmental agencies, healthcare providers, and HIV sector partners. These partnerships significantly enhanced our capacity to reach a larger audience and deliver more effective programs and services. I would particularly like to acknowledge the NSW Department of Health, the City of Sydney, MAC AIDS Fund, Gilead Sciences and ViiV Healthcare, NADA, Be Connected, ACON, BGF, Pozhet, and the National Indigenous Australians Agency (NIAA), for their continuing partnership and support for the work that we do.

Future Initiatives

In the upcoming year, we will introduce new initiatives focused on younger people living with HIV transitioning from paediatric to adult healthcare, and expand our reach to populations that have been underserved in the HIV epidemic to ensure that no-one is left behind. Our focus will include further enhancing peer navigation programs and leverage technology for wider access for all people living with HIV particularly those living in rural and regional NSW.

In closing, our determination to uphold human rights and a passion for social justice, underpinned by the core values of respect, integrity, excellence and equity remains resolute. With your continued support, we will continue to make a tangible difference in the lives of people living with HIV.

I extend my heartfelt gratitude to our dedicated team, volunteers, sector partners, funders and particularly our membership. Your unwavering support and commitment have been instrumental in the successes we have achieved. Together, we will continue to make a difference in the lives of all people living with HIV in NSW.



Jane Costello
CEO



“Thank you so much for the chat
this afternoon. Appreciate your
understanding with a lot going on
– just a friendly voice helps!”

– *Man living with HIV*

2022–23 Snapshot



There were **167 new HIV diagnoses** in NSW in 2022, of which:



119

were men who have sex with men (MSM) with 54% born overseas



38

were heterosexual people of which 61% were born overseas



6

were Aboriginal people.



19 were heterosexual women



18 were heterosexual men



1 was a transgender person



10

diagnoses occurred via injecting drug use or via another exposure



41.3%

showed evidence of a late stage diagnosis

“The [Ageing] support has come in the right time.”

– Older man living with HIV

Ages of people diagnosed:



61%

were under the age of 40



38.4%

were aged between 40-69



0.6%

were over the age of 70



ART Treatment of people diagnosed:



54%

initiated ART within 2 weeks of diagnosis



95%

initiated ART within 6 weeks of diagnosis

“Thank you so much to both you and Priscilla for another fantastic session [Online Women’s Support Group]. Really glad that I could join this one.”

- Woman living with HIV



NSW HIV Strategy 2021-2025 targets



93%

of PLHIV were in care and on treatment



78%

of PLHIV on treatment in NSW reported viral suppression at 6 months



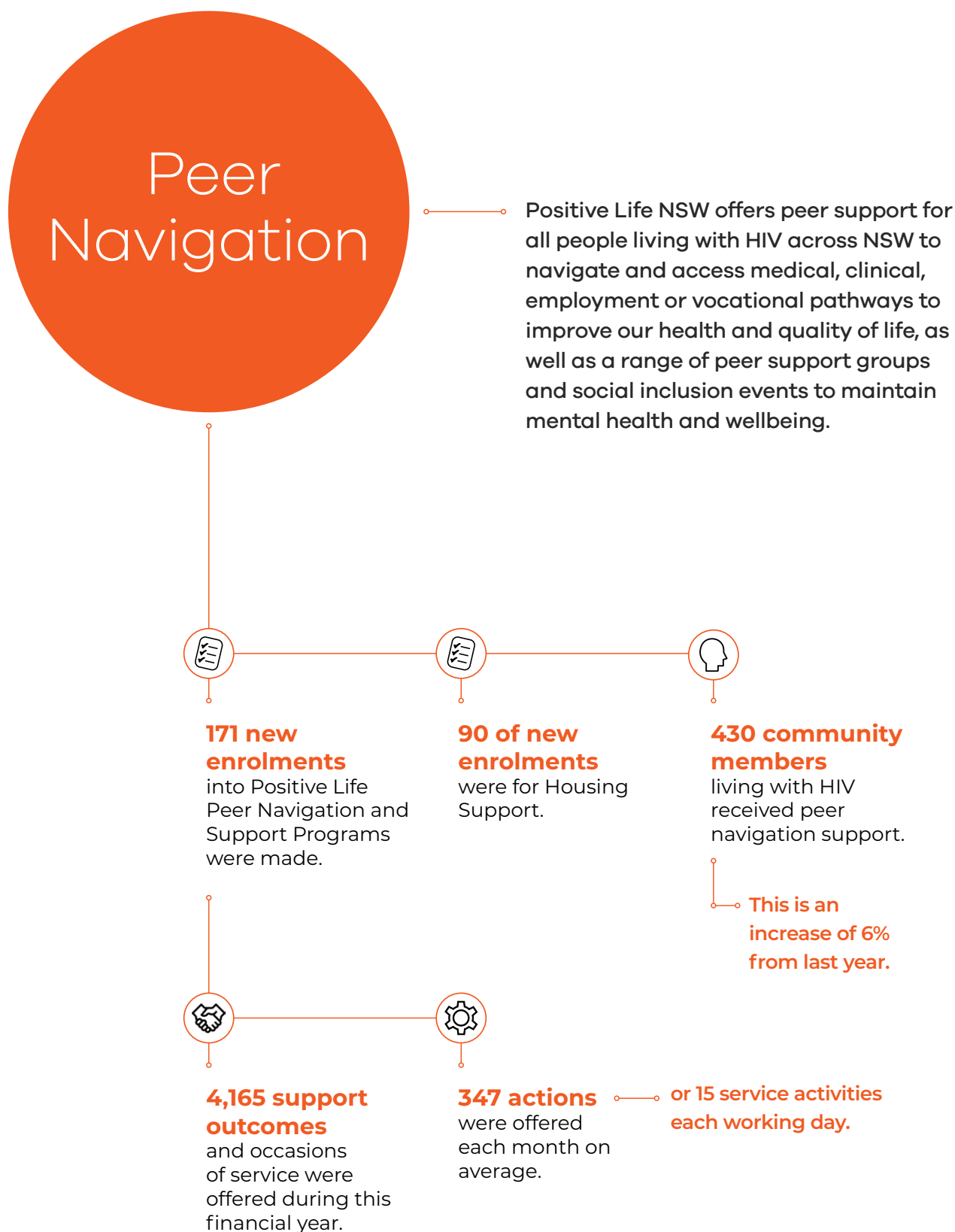
98%

of PLHIV on treatment in NSW have an undetectable viral load



61%

of people living with HIV report a good quality of life



Inform & empower

As the voice of the 10,000 people living with HIV in NSW, Positive Life speaks up and speaks out for all people living with HIV across NSW. Our integrated digital communications strategy is our primary tool to lift awareness on a range of emerging issues, interests, concerns and needs to empower the Body Positive in NSW.



Over 4.2 million hits were received by The Positive Life website.



1,558 blog hits across 23 published blog articles.



129 communications with Positive Life community member subscribers.



52 Speaking Engagements delivered by 47 PSB speakers.

who spoke to approx. 2,207 people.

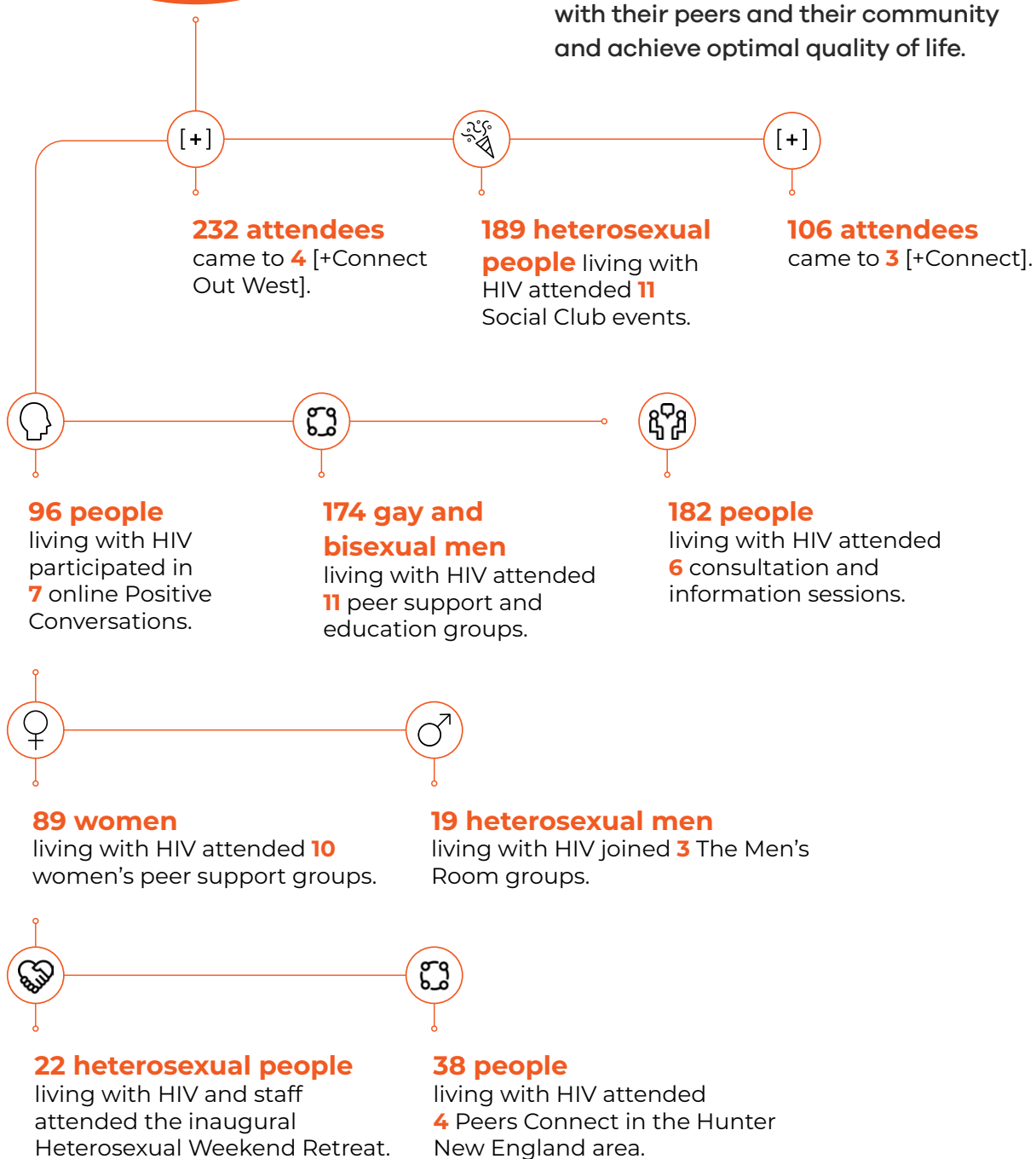


12 articles published in external press (HIV and mainstream).

- 10 Life.mail bulletins
- 8 media releases
- 3 factsheets
- 3 Talkabout magazines

Connect & include

Positive Life offers a range of online and face to face social inclusion and community events to foster a sense of belonging and reduce social isolation. Peer support and inclusion is the critical component for people living with HIV to navigate their lives with HIV, connect with their peers and their community and achieve optimal quality of life.



Advocate & represent

Positive Life collaborates with our HIV sector and allied health partners and stakeholders to raise, represent and advance the interests of all people living with HIV across NSW.



66 advisory groups & committees

in relevant Ministry, NSW Health, research and HIV sector groups to improve the health and quality of life of all people living with HIV.



360 stakeholder meetings

with HIV sector partners highlighting marginalised populations at risk of HIV, increasing awareness of testing and prevention strategies, reducing late HIV diagnoses, and the benefits of treatment for people living with HIV.



9 community consultations

engaging with all people living with HIV about our emerging issues and needs.



19 training & information sessions

in partnership with clinicians and prescribers supporting the needs of all people living with HIV.

We remember

Positive Life honours the memory of our friends, partners and family, allies, and community members throughout the long history of HIV/AIDS in NSW.



2022 World AIDS Day

Positive Life NSW in partnership with the Bobby Goldsmith Foundation (BGF) and support from ViiV Healthcare held an annual World AIDS Day event on 1 December 2022 at The Sydney Conservatorium of Music to honour and commemorate those we have lost to HIV and AIDS in a respectful and impactful way with all people living with HIV (PLHIV) in NSW, our partners, families, and friends. Each World AIDS Day we remember those who came before us, pay respects to those who have gone before us and honour their sacrifices they made in supporting and informing others, and continue to challenge the stigma and discrimination that has attached itself to HIV since the very beginning.

The evening emceed by Ms Ilana Cooper, daughter of the late Professor David Cooper, featured a Welcome to Country by Aboriginal Drag Performer-Artist and Gadigal elder, Nana Miss Koori; a brief welcome and overview of the importance and significance of World AIDS Day to our community by the CEOs of Positive Life NSW and BGF, Jane Costello and Nick Lawson; a performance by an African dance troupe, a reflection on 40 years of HIV from a Positive Life founder and elder living with HIV, John Robinson and Australia's first openly-transgender priest and Uniting Church minister, the Rev. Josephine McDonnell Inkpin. The commemoration concluded with a performance from the Sydney Gay & Lesbian Choir.

On World AIDS Day as people living with HIV, we reflect and publicly acknowledge our grief and the losses we've suffered. It is also an opportunity to show support for people living with HIV, and to offer our communities time to acknowledge, remember and commemorate those we have lost to the virus.

2023 Sydney Candlelight Memorial

On Sunday 21 May 2023, Positive Life NSW hosted the annual Sydney Candlelight Memorial, one of the most poignant and deeply powerful events on our calendar in partnership with ACON.

The Candlelight Memorial, held at the Eternity Playhouse in Darlinghurst was hosted by Positive Life NSW President and Board Director, Robert Agati. Pre-eminent Australian photographer and social documenter William Yang provided a very personal and deeply poignant tribute and reflection on the early days of the Australian HIV epidemic accompanied by some of his images from the time, followed by Lesley Saddington, mother to AIDS activist Tony Carden, who read a short excerpt from her manuscript *I Don't Want to Talk About It*. The afternoon concluded with a performance from successful Scottish musician and singer, Mary Kiani.

We remember our friends, family and community members who are no longer with us, especially those we have lost.

2022 World AIDS Day



“Another brilliant effort and successful WAD event achieved by Pos Life staff.”

– Man living with HIV



2023 Sydney Candlelight Memorial



“Thank you for checking in with me – I do really appreciate knowing that I’m not forgotten.”

– Woman living with HIV





2023 Mardi Gras Parade



“I want to say thank you. thank you ALL for your continued fight, for your support and your unwavering determination to keep us all informed in the way you do at Positive Life, Being a part of this community has had a massive impact on our lives and you have made such a difference to the way we think and feel. We are pleased and proud to be a part of such a fantastic support system.”

– Man living with HIV





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www.positivelife.org.au