



# Annual Report 2018-19

### **Audited Financial Statements**

To read the Positive Life NSW 2018/2019 Audited Financial Statements please visit this link online to download a copy: [www.positivelife.org.au/about-us/agency-documents.html](http://www.positivelife.org.au/about-us/agency-documents.html)

**Phone** 02 9206 2177 or 1800 245 677 (freecall)

**Office** Suite 5.2, Level 5, 414 Elizabeth Street, Surry Hills NSW 2010

**Mail** PO Box 831, Darlinghurst NSW 1300

Photographs: All images have been used with permission. You must seek permission in writing from Positive Life NSW before reproducing photographs from this report in any medium. The inclusion here of a person's photograph or stock image implies nothing about their sexuality or HIV serostatus.

# Contents

<b>HIV IN NSW</b>	<b>02</b>
<b>SPEAKING UP &amp; REPRESENTATION</b>	<b>04</b>
President's Report	05
CEO's Report	07
Treasurer's Report	09
CEO's Farewell	10
Positive Speakers Bureau (PSB)	12
<b>REACHING OUT</b>	<b>16</b>
Consultation & Engagement	17
<b>OUR VOICE</b>	<b>20</b>
Communications	21
<b>MAKING IT HAPPEN</b>	<b>24</b>
HIV Work Ready	25
HIV Housing Support	26
Treatments Support & Peer Navigation	28
<b>GETTING TOGETHER</b>	<b>32</b>
Peer Support	33

# HIV in NSW



**289**

new HIV diagnoses in NSW during 2018–19



**8.3%**

are women



**89.62%**

are men



**77%**

are men who have sex with men (MSM), and

**57.85%**

of MSM were born overseas

**2.08%**

are transgender



**13.84%**

are heterosexual men



**64.71%**

are under 40

**1.04%**

are 70 years and older



**34.26%**

are 40–69 years of age



# Speaking up & representation



## PRESIDENT'S REPORT

I'm pleased to present my first report as President of Positive Life NSW for the 2018–2019 financial year.

The last six months have been by far the most challenging. This has included ensuring the seamless transition of the agency's management with our former President, Jane Costello stepping down after eight years in the role, and the departure of our former CEO, Craig Cooper and in recruiting his successor.

Our commitment to the NSW HIV Strategy 2016–2020, its targets, and activities and impact on people living with HIV (PLHIV), and Positive Life's engagement with our community in all our diversity, remain at the core of our contribution to the Strategy. Our challenge continues to be responsive to and representative of this diversity while keeping the needs of our members front and centre.

Positive Life was founded over 30 years ago, and by continuing to build upon our partnerships with our sector partners, we both strengthen and energise our cause, while remembering the courageous men and women and trans and gender diverse people who are no longer with us.

The uptake of effective treatments, wider use of pre-exposure prophylaxis (PrEP) and access to post-exposure prophylaxis (PEP) and clinical support for earlier treatment commencement,

have contributed to the fall of new HIV transmission rates in some communities, however significant challenges remain. Women living with HIV, heterosexual communities, people living in regional areas, Indigenous peoples, people from culturally and linguistically diverse (CALD) communities, and overseas-born men who have sex with men (MSM), have not seen correspondingly lower rates of notifications. While an increasing number of PLHIV are doing well, many of us continue to struggle with other chronic diseases, mental health issues, treatment failure, side effects, and social isolation.

Combating stigma, building social inclusion and focusing on wellness continue to be our key work. HIV remains a highly stigmatised condition, and many of us have experienced the insidious stigma that impacts our communities, our families and society as a whole. Stigma is a malignancy: it attacks our sense of self-worth and limits our participation in society. Unlike systemic discrimination, which can and has been legislated against in some instances, combating stigma means changing people's perceptions, offering education, and asserting our dignity and respect. We still have a way to go with dismantling both systemic discrimination and individual stigmatising beliefs.

So, what does 2020 have in store for Positive Life and for PLHIV? With the conclusion of the NSW HIV Strategy in 2020, the formation of a new Strategic Plan will be an opportunity to meet the emerging ageing and complex care needs of PLHIV in NSW. Combating HIV stigma and discrimination is central to ensure our ageing PLHIV population remain engaged in care, motivated and resourced to navigate the complex social and health services.

As the leading peer-based HIV community organisation in NSW, our connection and engagement with the emerging needs of all PLHIV remains strong because of the commitment and dedication of our Board, staff, Positive Speakers Bureau (PSB) speakers and volunteers, partnered with the contributions from our members and the collaboration from both our agency partners and sector allies.

Overarching this is the critical funding support we received from NSW Ministry of Health (NSW MoH), M-A-C AIDS Fund, ViiV Healthcare, the Australian Digital Health Agency (ADHA) and the City of Sydney (CoS). I cannot thank you enough for all that you do for PLHIV in NSW.

**Robert Agati**  
President

Combating stigma, building social inclusion and focusing on wellness continue to be our key work.

## CEO'S REPORT

Over the past twelve months, Positive Life has continued to deliver upon our Strategic Plan 2016–2020 in the interests of PLHIV, including people at-risk of HIV, newly diagnosed and people closest to us who are also affected by HIV in NSW. The voice of PLHIV continues to remain vital and central to the HIV response thanks to the combined efforts of staff, Board Directors, Positive Speakers Bureau (PSB) speakers, volunteers, our funders, members and allies.

The governance of the agency remained stable throughout this financial year, beginning with the annual staff and board review to ensure our business plan reflects the strategic goals set by the NSW Ministry of Health (MoH). Towards the end of this financial year, changes to the staff profile were undertaken to address both the delivery of NSW MoH funded activities, and to retain corporate knowledge for the purposes of succession planning supported by the Board's thorough recruitment process for a new CEO.

During this time, the agency improved our Information Technology (IT) security, increased functionality and reduced operational costs by centralising much of our records, bookings and invoicing through the use of a new customer relationship management system (CRM), which improves our reporting capabilities. Upgraded agency IT records have also supported the agency to benchmark quality of life of PLHIV before and after engagement with our programs and services, which in turn offers further continuous quality improvement.

Throughout this period, we've maintained working partnerships with our HIV service sector partners, HIV clinicians, nurses, pharmacists and other allied health service staff, including social services. The PSB continued providing a public face to what it means to be living with HIV as we advanced the representation and voice of our peers, members and our PSB speakers themselves, across NSW through clinical, research, and social support initiatives. We have remained committed to the agency's core business, through the continued provision of information, referral, peer support and representative HIV policy advice. The following pages will reflect the activities, engagements, events, and publications as we worked together to raise the confidence and quality of life of PLHIV.

Community engagement, consultation and education remained a high priority throughout this period. Highlights included a photographic exhibition of our 30-year history on World AIDS Day, which was a celebration enthusiastically attended by the Sisters of Perpetual Indulgence, as well as the annual Mardi Gras festivities, conferences, and the 2019 Candlelight Vigil where we remembered our hallowed brothers and sisters. Consultation highlights included the representation and advocacy work with the Australia Digital Health Agency (ADHA) and the My Health Record (MyHR), through forums, workshops and information sessions, and Community Consultation and Engagement Forums with community about the experiences of HIV and ageing and HIV stigma concerns. Our peer-led, peer-supported focus delivered the RYPL (peer led partner notification) initiative supporting PLHIV

to stay in charge of a critical disclosure moment, alongside the steadily increasing demand of our Treatments Support, Work Ready and Housing Support programs.

The coming year is shaping up to be another monumental year for Positive Life and for PLHIV in NSW. Finally, it must be acknowledged that the support of the NSW Ministry of Health (MoH), M·A·C AIDS Fund, ViiV Healthcare, the Australian Digital Health Agency (ADHA) and the City of Sydney (CoS) for their ongoing funding, partnership and continued support of PLHIV enables the voice of PLHIV to remain vital and central to the HIV response in NSW.

**Neil Fraser and Craig Andrews**  
**Interim co-CEOs**

## TREASURER'S REPORT

I'm pleased to present my report and the financial statements of Positive Life NSW for the financial year ended 30 June 2019.

The 2019 financial year saw record income totalling \$1.189m, up by 7.8% year-on-year and \$13.3k higher than budget mainly due to donations, reimbursements and training income received, against year-end total expenditure of \$1.203m. Whilst this resulted in a small deficit of \$13.7k, this was still \$17.3k lower than the deficit of \$30.9k that had been budgeted for at year end.

Notwithstanding that funding from grants received from the NSW MoH and M-A-C AIDS Fund had been fully utilised, Positive Life contributed financing of approximately \$32k from untied income. Similarly, research grants had also been fully spent from grants received from ViV Healthcare which funded our Silver Warriors and Peer Navigation programs. Both these grants were classified as having been received in advance and drawn down as spent. We also received and fully spent grants from both City of Sydney and the Mental Health Coordinating Council on research programs.

Net PSB income and expenses were below budget at year end, due to lower than forecasted activity. PSB net income during the year has also been the highest in comparison with previous years.

Positive Life maintained a sound balance sheet position throughout the year. Assets were predominantly cash at bank and term deposits, whilst total liabilities included grants in advance. Cash, reserves and financial ratios remained healthy throughout the period, which ensured that we were able to meet our financial obligations as and when they fell due. At the end of the financial year, Positive Life retained earnings of \$213k which provided a buffer in case of any unforeseen expenses, or interruptions or delays in relation to our sources of funding.

**Campbell Boag**  
Treasurer

## CEO'S FAREWELL

On Thursday 6 June 2019 Positive Life's staff, Board and volunteers bid a very fond farewell to Craig Cooper, our CEO of five years, along with community members, colleagues and HIV sector partners.

As Positive Life CEO since 2014, Craig played a pivotal role advocating to change systems and practices to improve the lives of PLHIV in NSW and effected change for PLHIV at both a community and legislative level. His history working in the interests of PLHIV in the HIV sector since 2006 saw him tirelessly advance the position of PLHIV working with mainstream health and community sector partners.

We'd like to make a special acknowledgement of his effective commitment to our community; in particular, his achievements around the removal of the co-payment waiver for anti-retroviral therapy (ART), community dispensing of HIV medication, advocating

for immediate treatment commencement, and for wider implications arising from the implementation of My Health Record.

As we gathered at The Rose of Australia in Erskineville, we shared some drinks and food, regaled tales of Coops over the years, wrote notes for a photo scrapbook, and listened to a few speeches about Craig varying from the sentimental to the hysterical.

From all of us at Positive Life and beyond, we are all enormously indebted to Craig for his part in the HIV response in the last five years. We have no doubt that his positive influence will continue to ripple onwards, and effect change over the coming years as well, and we are infinitely grateful.



01.



02.



03.



04.

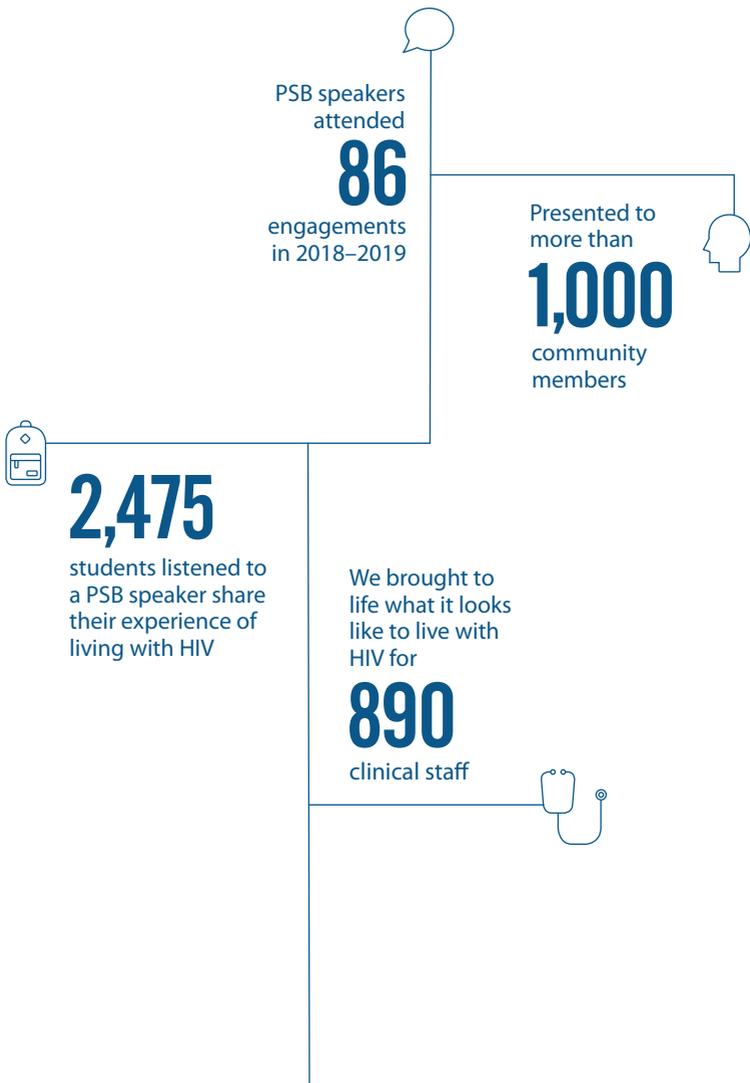


05.

- 01. Jane Costello and Craig Cooper.
- 02. Board, Staff and Community members.
- 03. Invitation graphic.
- 04. Community sector partner at farewell.
- 05. Sisters of Perpetual Indulgence.

## POSITIVE SPEAKERS BUREAU (PSB)

In 2019, Positive Life reached for ZERO HIV risk, deaths, transmission, and discrimination. PSB speakers played a key role in the ZERO HIV message as they challenged stigmatising attitudes and discriminatory actions through their willingness to stand, be seen and have their voices heard.





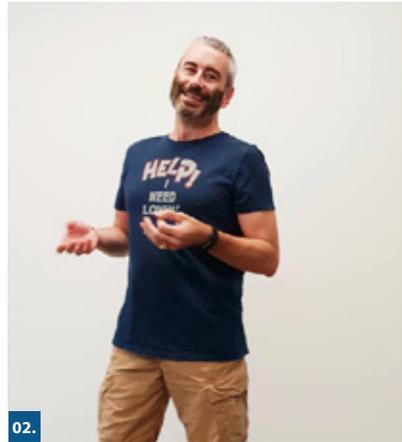
The Positive Speakers Bureau (PSB) is a program of Positive Life NSW which offers your agency, school, organisation or group the opportunity to hear the first-hand experiences of people living with HIV.

Our trained speakers living with HIV share and educate a range of audiences by delivering key prevention, education, harm reduction and safer sex messages which are woven into each speaker's story.

[www.psb.positivelife.org.au](http://www.psb.positivelife.org.au)

**PositiveLifeNSW**  
The voice of people with HIV since 1988

01.



01. PSB program advert.

02. PSB Speaker Freddy Cole.

“Wonderful, amazing... to be honest I was blown away by how engaged the kids were, wow! The PSB speakers pitch, language and messaging were perfect.”

– Sydney Children's Hospital

“Thank you PSB for all the preparation time that went into fulfilling the brief! We found the online booking process really good – very convenient.”

– High School

“Great to be able to read bios online but especially helpful to see videos – it made me confident that the speakers would be a good fit.”

– HIV clinician



### PLHIV and Gay Men's Awareness of HPV Related Anal Cancer

Authors: Feeney L, Connor C, Hillman R, Boyd M, Brotherton J, Cysique L, Hennessy R

**Method**

**Results**

**Conclusions**

**What has been achieved to date**

**Recommendations**

05.

PositiveLifeNSW  
Support, Educate and Inspire



06.



07.

- 01. Neil Fraser presenting on HIV Work Ready Program.
- 02. Jane Costello and community partners panel discussion.
- 03. Craig Cooper and community partners panel discussion.
- 04. David Crawford conference presentation.
- 05. Anal Cancer conference poster.
- 06. Protest march placard.
- 07. Craig Cooper and community partners roundtable discussion.

# Reaching out



## CONSULTATION & ENGAGEMENT

In this financial year, Positive life consulted broadly with stakeholders and community. Our consultation work has been crucial to represent the voice of PLHIV in NSW with confidence.

During 2018/2019, PLNSW conducted two community surveys:

- May 2019: People Living with HIV (PLHIV) and Aged Care Services survey (522 survey respondents)
- June 2019: Trans and Gender Diverse People: Health and Social Needs Assessment Survey in partnership with the Gender Centre (788 survey respondents).

During 2018/2019 we carried out five partnership events with stakeholders:

- November 2018: Joint HIV Stigma Forum in partnership with ACON and BGF
- December 2018: Disclosure Forum in partnership with ACON

- January 2019: My Health Record (MyHR) Community Information Session in Newcastle in partnership with Karumah
- January 2019: Last Chance: Get the facts on MyHR in partnership with Health Consumers NSW (HCNSW)
- March 2019: Our Communities, Our Votes: LGBTI NSW Election Forum in partnership with ACON.

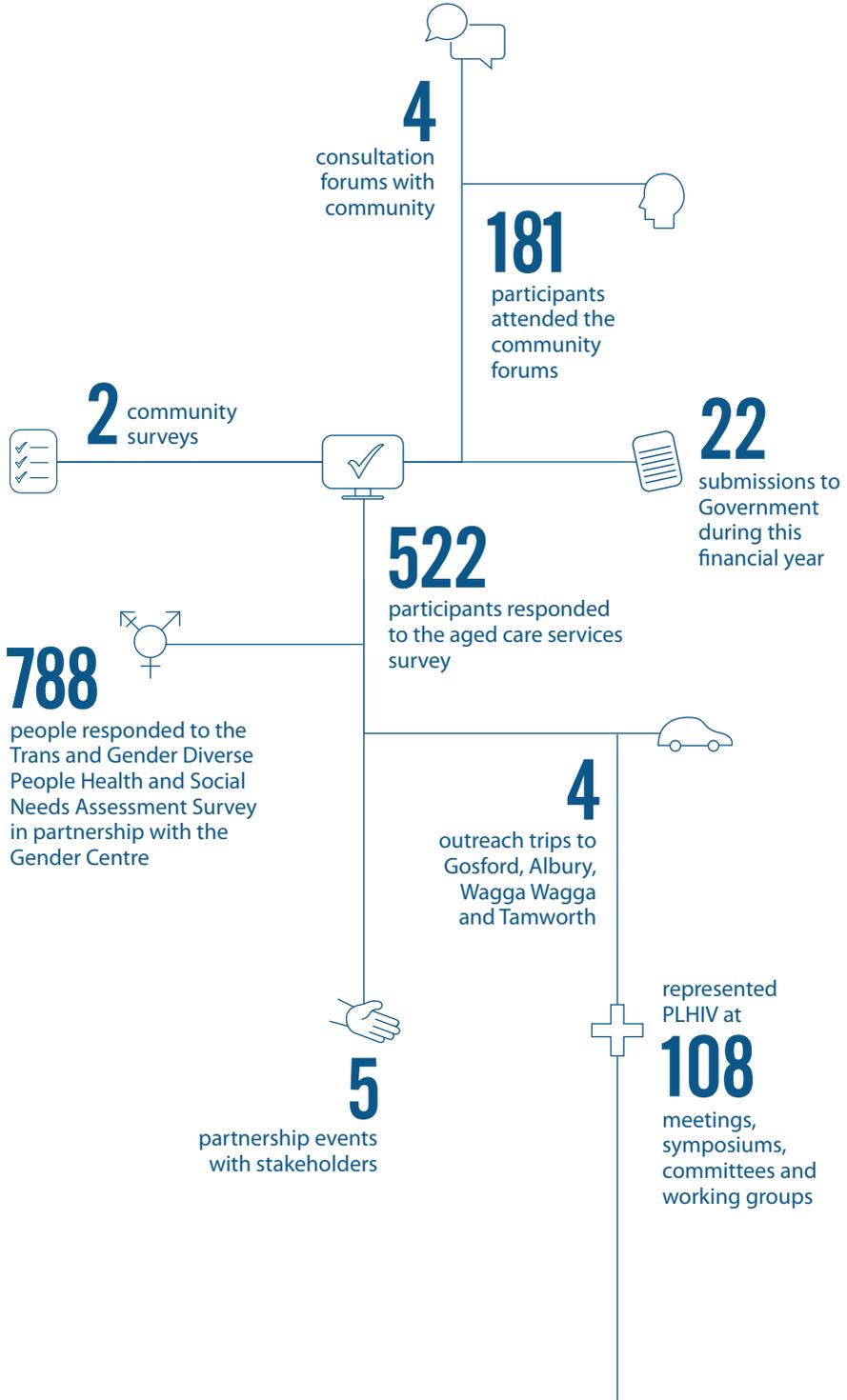
We also carried out four consultation forums with community:

- September 2018: HIV Stigma and Discrimination Forum in Sydney
- November 2018: MyHR Forum at Parramatta
- January 2019: MyGov Workshop in Sydney
- April 2019: HIV and Ageing Forum in Sydney.



- 01. Trans and gender diverse survey advertisement.
- 02. Trans and gender diverse survey social media banner.
- 03. Ageing with HIV survey advertisement.

Our consultation work has been crucial to represent the voice of PLHIV in NSW with confidence.



# Our voice



## COMMUNICATIONS

The voices of PLHIV has continued to be heard across NSW throughout a range of strategies, and platforms both online and in print.

Our five campaign websites have continued to strongly deliver health promotion messages and HIV related information that continues to support the NSW HIV-positive community living our lives our way.

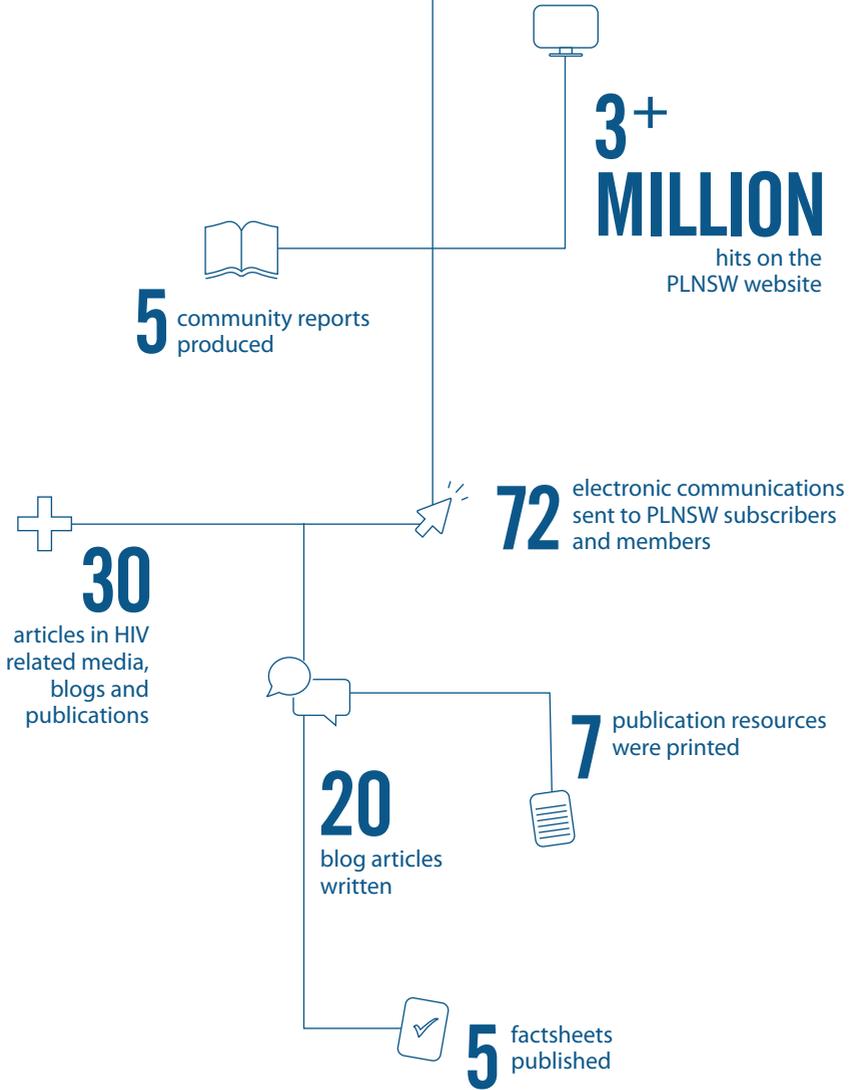
**HIV Difference?** asks the question 'Why let HIV get in the way of a good relationship?' and promotes the happy reality of living in a 'brave new world' of freedom, desire, pleasure and acceptance alongside our lovers and mates of all sero-status. [www.hivdifference.positivelife.org.au](http://www.hivdifference.positivelife.org.au)

**Peer Led Partner Notification** supports people who are diagnosed with a sexually transmitted infection (STI) including HIV and other blood-borne viruses (BBVs), with a range of options and resources to stay in control of a critical disclosure moment. [www.rypl.positivelife.org.au](http://www.rypl.positivelife.org.au)

**Take Control** continues to share the message of taking control of our health, as we remain in the drivers seat of managing our HIV without shame or fear. [www.takecontrol.positivelife.org.au](http://www.takecontrol.positivelife.org.au)

**The Choice is Yours** offers treatment options and strategies, resources and tools that promote choice when PLHIV access HIV medication in NSW, including those who are Medicare Ineligible, as well as our clinicians and pharmacists who dispense our HIV medications in NSW. [www.thechoiceisyours.positivelife.org.au](http://www.thechoiceisyours.positivelife.org.au)

**Wrapped or Raw?** supports PLHIV and their partners, fuckbuddies and mates in a changing social, sexual and pharmaceutical environment with, up-to-date information promoting choice and strategies for pleasure, while minimising STIs and having great sex. [www.wrappedorraw.positivelife.org.au](http://www.wrappedorraw.positivelife.org.au)

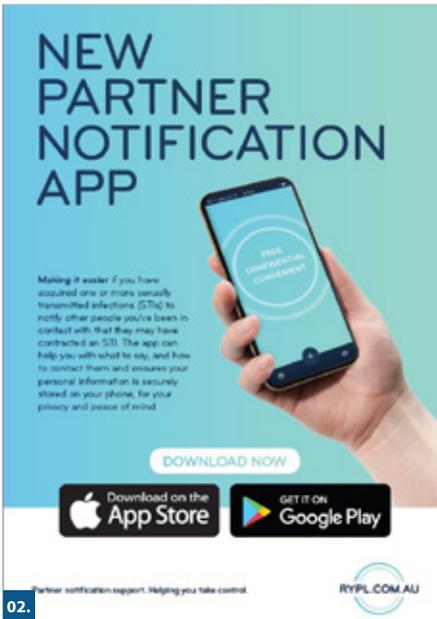




01.



03.



02.



04.



05.

- 01. Paul Capsis performing at the 2019 Sydney Candlelight Memorial.
- 02. Rypl app advertisement.
- 03. HIV Difference article.
- 04. Rypl website advertisement.
- 05. David Crawford at ACON Honour Awards.



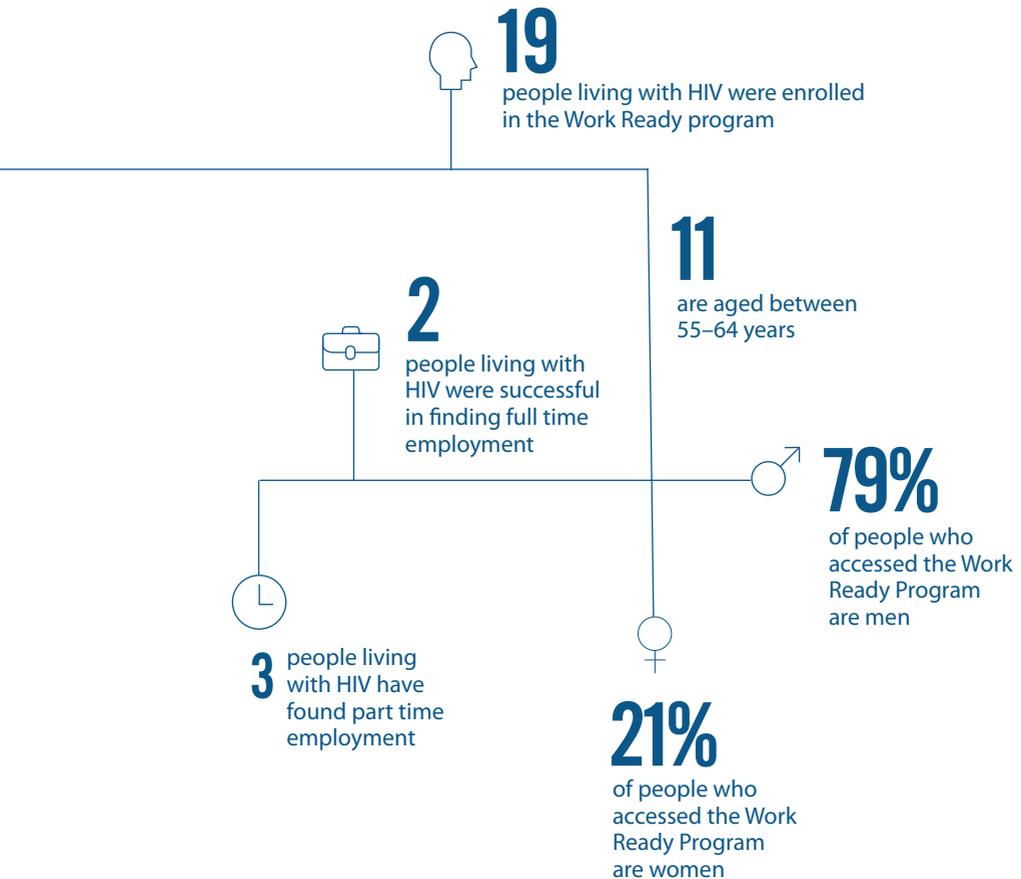
# Making it happen



## SOCIAL SUPPORT

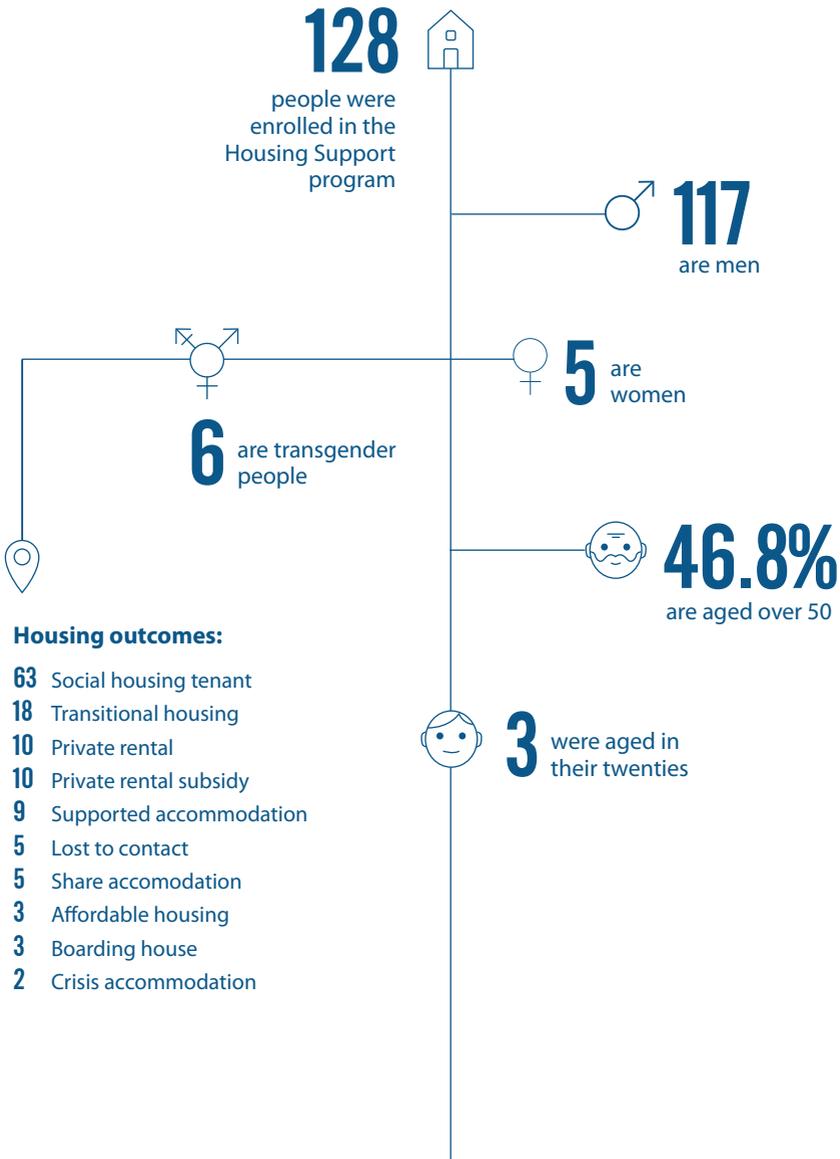
### HIV Work Ready

HIV Work Ready assists PLHIV to engage with their community to build confidence and quality of life.



## HIV Housing Support

The Housing Support Officer is responsible for advocating for and supporting PLHIV in metropolitan and regional NSW to access, achieve and maintain stable accommodation, including those at risk of homelessness.



### Case Study: Sam

'Sam'\* is a man living with HIV from a CALD (culturally and linguistically diverse) background and was living with his family in an outer suburb of Sydney. This was a challenging environment for Sam where he faced daily HIV discrimination and stigma from his family, who were unwilling to accept education about the condition. Each time he used the toilet or shower, they talked about the fear they felt sharing these facilities with him, and he had to sterilise everything after he used it. This had an extremely negative impact on Sam's mental and emotional well-being.

Sam applied for an urgent assessment for social housing, and we supported him to collate all the necessary support documents and evidence. His application was approved with a high priority status and he got an offer of a one-bedroom unit in the inner-city quickly. Once Sam signed the lease, we connected him with another organisation to source furniture.

Today Sam is one of our volunteers and enrolled in a cooking and food preparation program for PLHIV.

*\* Not his real name*

### Case Study: Pete

'Pete'\* is a middle-aged man living with HIV who had been 'sleeping rough' in the city. He'd been evicted from his rental accommodation and found it difficult to maintain a regular schedule with his HIV medication while he was homeless.

Pete applied for a place at Stanford House, which is a 12-week supported accommodation program for PLHIV who are experiencing homelessness. Moving into Stanford House gave Pete a stable space where he found it easier to maintain his HIV medication schedule. It wasn't long before we supported Pete to apply for an 18-month transitional vacancy in a two-bedroom unit.

With the community HIV outreach team, Pete's managing this tenancy while waiting for a permanent housing offer.

*\* Not his real name*

## TREATMENTS SUPPORT & PEER NAVIGATION

The Treatments Officers offer support, information and advocacy for PLHIV and those affected by HIV across metropolitan and regional NSW, to increase their knowledge, capabilities and capacity with their HIV treatments. PLHIV are supported to build health decision making and improve their physical and mental health outcomes.

### Case Study: Ben

‘Ben’ is an Australian man who lives with his Thai wife in the Western suburbs of Sydney. The couple lives with HIV and they had concerns about Ben’s current treatment regimen. Ben worked in a job where regular drug testing was mandatory, and he had heard about some false positives being recorded after taking HIV medication. He was concerned that his current regimen might give him a false positive result which could draw attention to his HIV status – something he wanted to avoid.

Ben anxiously called a Positive Life Treatments Officer and after some research and speaking with the relevant drug company, we were able to reassure him that there had been no reported cases of a false positive reading with his medication. He was very relieved. When he said his doctor hadn’t been able to assure him of this, Ben was also given the opportunity to talk about his patient/doctor relationship, and we provided him with ways to improve the communication moving forward.

*\* Not his real name*

**204** people made a treatment support enquiry



**25%** treatment questions were face-to-face

**49%** called on the phone

**29%** used email or social media

**13%** of treatment support clients were women



most enquiries were from people aged

**21-40**

**84%** were men



**1%** were transgender



**34%** people seeking treatment support had a CALD background

**81%** of treatment support clients live with HIV



**10%** of treatment support clients were HIV negative





PositiveLifeNSW  
the voice of people with HIV since 1988

Peer Navigation

# LISTEN CONNECT GUIDE + SHARE

A Peer Navigator is someone who has walked in your shoes. With a similar lived experience who understands your situation, they can help you navigate the health system to achieve your health goals.

The Peer Navigator Program can assist you to access and connect with social, health and self-management supports.

**CONNECT WITH A PEER NAVIGATOR**

Contact Neil Fraser, Peer Navigator  
E: NeilF@positivelife.org.au P: 02 9206 2177 or 1800 245 677 (freecall)

02.





"I would like to thank you very much for all your efforts and support through this difficult time. I am going to get a place I will stay and having my daughter over on weekends. It's been a great pleasure to meet you. You guys are awesome and thanks "

–Housing Client



"I wanted to update you with some news. They offered me to have a look at a...1 bedroom ground floor. I accepted it and moved in on Monday. I know I am extremely lucky and fortunate to have gotten this. I am grateful that there are services like yours available. Thanks once again John for all your help"

–Housing Client



01. HIV Work Ready Program advertisement.
02. Peer Navigation Program advertisement.
03. HIV Work Ready Program advertisement.
04. November 2018 Housing Blog post image.
05. Peer Navigation Program advertisement.

# Getting together



## SOCIAL INCLUSION & PEER SUPPORT

### [+ Connect] events

[+Connect] is an inclusive social event for all PLHIV, our families and significant others to get together and expand our friendship networks in a safe, accessible and friendly environment.

### Peer 2 Peer meetings

Peer 2 Peer is a support and discussion group which meets every two months over a light evening meal for all gay and bisexual men living with HIV.

### Genesis workshops

In 2018–19 Genesis was a collaboration between ACON and Positive Life as a weekend workshop for gay men who have been diagnosed with HIV recently. As a peer-based workshop, this is run by other gay men living with HIV who can relate to the experience of a new diagnosis.

### The Social Club

The Social Club is a peer support group which offers heterosexual PLHIV the opportunity to meet up in a safe, friendly and accepting social environment. The Social Club met regularly throughout this time period and is facilitated by peers for peers.

### Annual events

Positive Life celebrated ten annual events over this financial year which included participating in the Yabun Festival in January 2019 alongside Hepatitis NSW, NUAA and SWOP; being part of the eighth gathering of Healing Our Spirits Worldwide in partnership with ACON and SWOP, in October 2018; and the Parramatta Pride Picnic where we shared a stall with the Western Sydney Sexual Health Centre as we joined in the fun with the community out west.

Board, staff, volunteers and PSB speakers joined community, HIV sector partners and the Sisters of the Order of Perpetual Indulgence, to enthusiastically celebrate World AIDS Day 2018 and our 30-year history through a photographic exhibit at the Australian Museum on 1 December 2018.

The Positive Life team and community members living with HIV along with our partners, friends and family, participated in the 2019 Mardi Gras season. In February, Our staff, board, PSB and volunteers teamed up to represent Positive Life at three separate stalls.

We had a main agency stall, a stall promoting Digital Ano-Rectal Examination (DARE) information, and the Positive Speakers shared the space at the Gilead stall to bring a face to PLHIV.

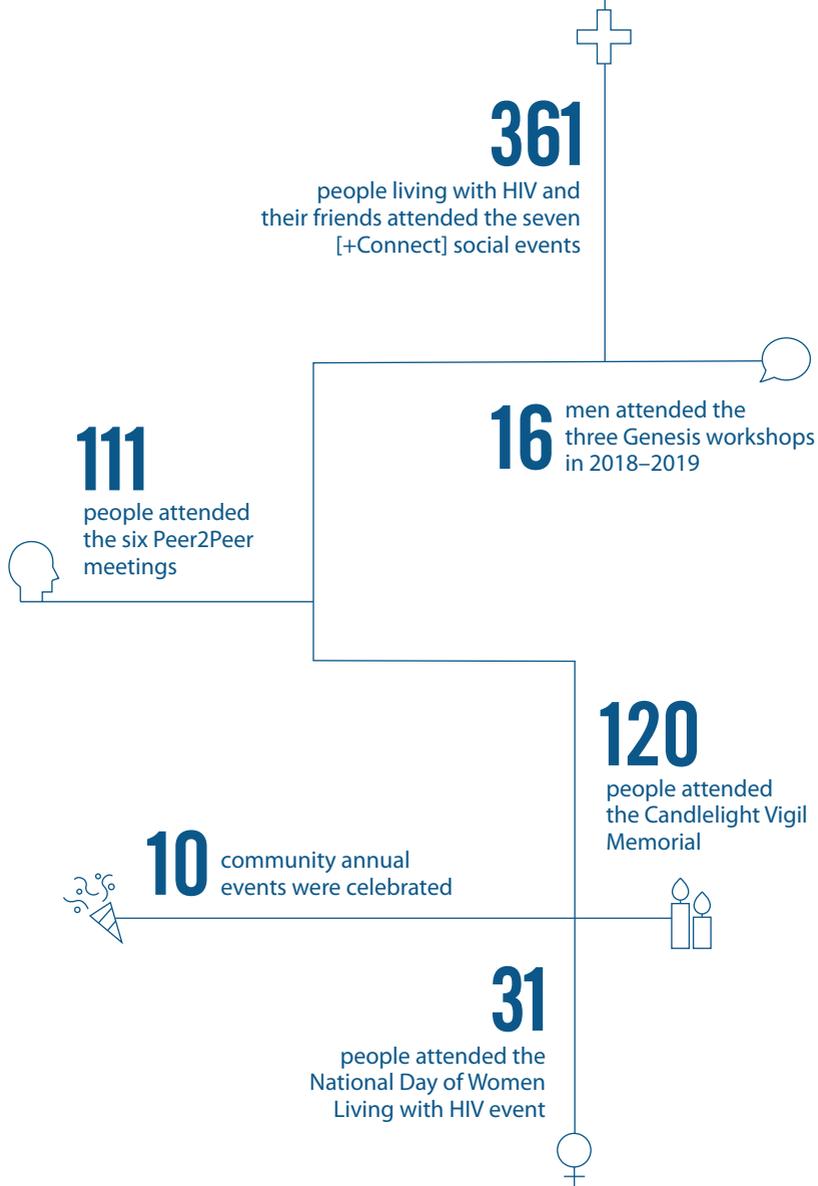
This year in the 2019 Mardi Gras Parade in March, a proud group of PLHIV and our supporters wore green t-shirts and walked under a theme of 'ZERO HIV – zero HIV risk, zero HIV discrimination, zero HIV transmission and zero HIV deaths'. In this way, we promoted awareness of the success of Treatment as Prevention (TasP) and the reality that PLHIV have ZERO risk of transmitting HIV to our sexual partners when our viral loads are at an undetectable level.

Board, staff and PSB speakers participated in the regular social community BBQs at Yaralla House, a small 24-hour residential care facility for PLHIV across NSW who live with HIV-associated dementia (HAD), progressive multifocal leukoencephalopathy (PML) and related conditions.

We celebrated the lives of women living with HIV at the National Day of Women Living with HIV (NDWLHIV) with Femfatales in March 2019 alongside our friends, family, allies and HIV sector colleagues. We shared the stories of women living with HIV and acknowledged what living with HIV means for women today.

Once again at the 2019 Candlelight Vigil in May, we came together with our partner ACON, to remember and honour the memory of our lovers and friends we have lost to HIV/AIDS. Paul Capsis performed a moving tribute to their treasured friendships and lives.

We promoted the success of Treatment as Prevention (TasP) and the reality that people living with HIV have zero risk of transmitting HIV to our sexual partners when our viral loads are at an undetectable level.







07.

- 01. Sector partners together at Healing Our Spirits Worldwide.
- 02. Parramatta Pride.
- 03. 2018 World AIDS Day.
- 04. 2018 World AIDS Day.
- 05. 2019 Candlelight Memorial.
- 06. 2019 Candlelight Memorial.
- 07. 2019 National Day of Women Living with HIV Australia.
- 08. 2019 Mardi Gras Parade.
- 09. 2019 Mardi Gras Fair Day.



# PositiveLifeNSW

the voice of people with HIV since 1988

**Phone** 02 9206 2177 or 1800 245 677 (freecall)

**Office** Suite 5.2, Level 5, 414 Elizabeth St, Surry Hills NSW 2010

**Mail** PO Box 831, Darlinghurst NSW 1300

**[www.positivelife.org.au](http://www.positivelife.org.au)**