

talkabout

Where we speak for ourselves



Bringin' back Talkabout

HIV, COVID-19 and the vaccine

Spotlight: Ankali

"I'm still here" - living longer with HIV

Positive Life NSW

The voice of all people living with HIV



HIV IS EVERYONE'S BUSINESS



HIV affects us all

**IT'S EVERYONE'S
BUSINESS**

The HIV pandemic is not over. There's still no HIV cure or HIV vaccine. HIV affects anyone who is sexually active. Whether we're living with HIV or not, we all have a shared responsibility around HIV. This includes heterosexual women and men, trans and gender diverse people, gay and bisexual men, Aboriginal and Torres Strait Islander people, sex workers, people from culturally and linguistically diverse (CALD) backgrounds, people who inject drugs and people born overseas. Today, HIV is everyone's business.



HIV testing

**IS EVERYONE'S
BUSINESS**

Anyone who is sexually active can contract a sexually transmitted infection (STI), including HIV. STI testing in NSW is free, confidential, anonymous and safe. It's time we offer HIV testing to everyone, including heterosexual people, women, refugees, and people from CALD backgrounds, and men who have sex with men. Some STIs are silent, without immediate symptoms and can damage your physical and reproductive health. If the test comes back positive, you'll be able to start treatment quickly and take care of your health and your partners. Testing is everyone's business.



HIV transmission

**IS EVERYONE'S
BUSINESS**

Today, we all have a number of different strategies to prevent HIV transmission such as condoms, PrEP (pre-exposure prophylaxis), PEP (post-exposure prophylaxis), needle and syringe programs, and the use of HIV antiretroviral treatment by people living with HIV to reduce our HIV viral load and prevent onward transmission. Let's celebrate our shared responsibility in ending HIV transmission.



HIV stigma & discrimination

**IS EVERYONE'S
BUSINESS**

Wherever and whenever stigmatising comments about AIDS or HIV or discriminatory practices go unchallenged, they impact people living with HIV and create risks to our lives, health and community. It's everyone's business to talk about HIV. Let's confront ignorance, dispel myths and misinformation about HIV together. HIV stigma and discrimination is everyone's business.

**Let's celebrate our shared responsibility to end HIV transmission.
There's no shame in getting tested for HIV.**

Visit us at positivelife.org.au

Images used are stock photos and do not imply any HIV status, sexuality or behaviours.

Positive Life NSW

talkabout

Where we speak for ourselves

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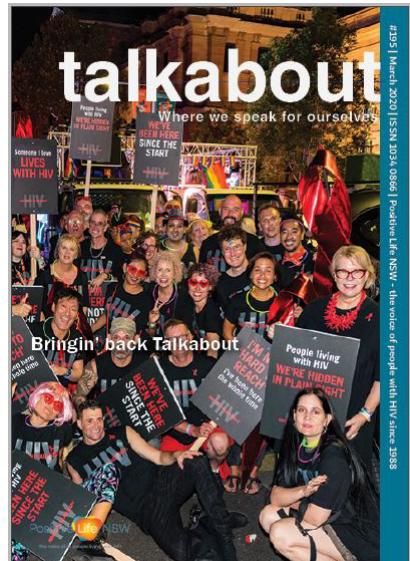
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Cover photo: 2019 Positive Life Mardi Gras participants walking together under the theme 'Hidden in plain sight'.

Contributors: Robert Agati, Craig Andrews, Bruce Hamish Bowden, Bella Bushby, Jane Costello, Natasha Io, Jimmy Nguyen, Peter Schosser, Liz Sutherland, Tiffany Tran



The voice of all people living with HIV

LETTERS TO THE EDITOR

Your messages, comments, thoughts and opinions are welcome here.

Letters should short (be less than 200 words) and may be edited.

All letters to be considered for publication must have a name, street address and phone number for verification.

Please specify if you want your details withheld from publication.

Email Talkabout at editor@positivelife.org.au or
post Talkabout Editor, PO Box 831, Darlinghurst NSW 1300

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Future use of information about that person's sero-status cannot be controlled by Positive Life NSW.

The greatest care has been taken to ensure the accuracy of information in this magazine at time of going to press,
but we accept no responsibility for omissions or errors.

Talkabout is made possible by advertising revenue, donations and a grant from NSW Ministry of Health.
Talkabout thanks those who volunteer their time and skills to the magazine.



POSITIVE LIFE PRESIDENT

The Positive Life NSW Board's year commenced with our annual Board Induction Day on Saturday 30 January 2021. The day was a great success welcoming two new members to our Board. This was followed by the Board and Staff Planning Day on Saturday 13 February, where once again we were provided an overview of the breadth of work the staff carry out on a day-to-day basis in service to the NSW Body Positive. I'm incredibly proud and often in awe of the dedicated team we have here in NSW who regularly go above and beyond to ensure our brothers and sisters living with HIV are heard and supported to live our best lives.

One of our major annual events, Fair Day, has been cancelled this year in the light of COVID-19. The annual Mardi Gras Parade is going ahead under a COVID Safe Event Plan and will be held at the Sydney Cricket Ground on Saturday 6 March. Positive Life was successful in our application to participate, and despite our small band (maximum of 40 people permitted), we're looking forward to representing the NSW Body Positive and flying the flag of positive people under the main theme of 'RISE'.

To provide feedback or contact the Board you are welcome to email me at president@positivelife.org.au

ROBERT AGATI

CHIEF EXECUTIVE OFFICER

In the wind-down for 2020, we were able to switch the new Positive Life website live. Work on the website has been steady over 2020, thanks to our website designer and Positive Life member, Simon Wilson. We look forward to a face-to-face celebratory launch after the current COVID-19 threats and restrictions have eased.

Despite our cautious scheduling in the light of the continuing threat of COVID-19, our events calendar is filling up. On Tuesday 9 February, we enjoyed a successful 'In The Know' forum focused on HIV, COVID-19 and the vaccine. Peer2Peer for gay and bisexual men living with HIV is starting up once again as a face-to-face event over a bite to eat. Heterosexual people living with HIV are also regularly meeting face-to-face at the Social Club.

Our outreach consultations are planned for Coffs Harbour, Kempsey, Port Macquarie, Gosford, Queanbeyan, Goulburn, Lismore and Tweed Heads. These are for people living with HIV in rural and regional areas to meet up with a peer living with HIV to talk about your needs and concerns as someone living outside the metropolitan areas. Whether you live in Sydney, regional or rural NSW, I encourage you to attend as your input is valuable and vital to our ongoing work.

I hope the following five editions of Talkabout, provide more options for you to be involved with Positive Life. To share your story or suggestions, call us on (02) 9206-2177, 1800 245 677 (freecall outside metro) or email contact@positivelife.org.au

JANE COSTELLO



EDITOR NOTES

In this reinvigoration of Talkabout, Positive Life is aiming to return to the NSW Body Positive a familiar tool to engage and connect with others living with HIV in NSW along with personal stories, information, dialogue and debate especially during these uncertain times of social distancing and potential isolation.

All Positive Life Full members (who accept post) will get Talkabout posted to you for free. It will also be available on a subscription basis to Associate members, supporters, and anyone interstate who wants a printed copy. You'll also be able to download Talkabout from the Positive Life website as a PDF, or share it with a friend through email. Limited copies will be available in the high HIV caseload clinics, selected sexual health clinics and venues. As we build our subscriber base, our advertising base and earmarked donations to Talkabout, we hope to eventually return to the print-runs of the early 2000s of 4,000+ copies across the state.

You'll notice this fledgling edition is missing an important element in any community-driven publication: *Letters to the Editor*. Let's bring this section back in Talkabout where your engagement with fellow readers can get some air. You'll find details on how to get your letters published on page four.

I've offered a short summary about the Talkabout survey (p8-9), where **81 of you spoke up** and shared some of your personal thoughts in the *Bringing Back Talkabout Survey*.

Talkshop (p10) shares some ongoing advocacy work impacting the NSW Body Positive and how your interests have been raised with policy makers.

Having reached my own milestone of 50 years of age a few years ago, I welcome your stories of living longer with HIV and especially if you've been living long term with HIV. If HIV has been your shadow since the '80s, '90s and even '00s, it would also be great to have your voice amplified on *The Elders Podcast* (see below). Call me to learn more about this exciting project!

Living with HIV since 21 years of age, Peter reminds us he's still here (p12), while Jimmy shares the value that peers can make when you're diagnosed with HIV (p19). A couple of brief reports on page 15 and 16: the first on the 'HIV, COVID-19 and the vaccine' forum held in early February and the second about the \$100 treatments co-payment waiver survey conducted last year that **180 of you so generously responded to**.

We turn the spotlight onto Ankali (p20) who have been here for the long haul. Bella highlights the risks of anal cancer for anyone living with HIV and explains why it's got nothing to do with the kind of sex you might be having (p22).

I hope you enjoy this edition of Talkabout and we get to read your story, reflections or experiences sometime soon within these pages.

– Craig Andrews

The Elders Podcast

Have you been living with HIV since the 1980s, '90s and '00s?

We invite you be part of The Elders podcast!

In our proud tradition 'where we speak for ourselves', join other members of the NSW Body Positive who live with HIV long term to share our stories, experiences and wisdom, and contribute to the historical record through recorded interviews and discussions.

Amplifying the voices of our elders living with HIV and those living with HIV long term in NSW

To stay in the loop about The Elders Podcast, please contact Craig at Positive Life to register your interest (02) 9206-2177, 1800 245 677 (freecall outside metro) or contact@positivelife.org.au

TREATMENTS BRIEFS

This column offers health and treatments news in relation to living with HIV.

HIV & Cardiovascular Disease

It has been well known for many years that people living with HIV are at increased risk for cardiovascular or heart disease, including myocardial infarction (heart attacks), stroke and heart failure.

There are multiple reasons for this increased risk, including traditional risk factors such as cigarette smoking (at least twice as many people living with HIV smoke compared to the general population), inadequate diet, sedentary lifestyle, substance abuse and also stress and mental health.

Chronic inflammation and immune activation caused by HIV itself is linked to an increased risk of cardiovascular disease. Also, the D:A:D (Data Collection on Adverse Events of Anti-HIV Drugs) cohort study has shown that even some anti-retrovirals: abacavir, darunavir

and lopinavir are associated with cardiovascular disease.

For these reasons it's important for all people living with HIV to ask your clinicians to assess you for any cardiovascular disease risk factors (high blood pressure, high cholesterol, diabetes, cigarette smoking and family history) and offer some interventions where required.

HIV & Diabetes

The prevalence of diabetes mellitus (type 2 diabetes) is increasing in people living with HIV and is between two and a half times and four times more likely in people living with HIV as compared to the general population.

There may be multiple reasons for this, including HIV itself, chronic inflammation, immune dysfunction and also some of the older anti-retroviral medications.

Standard risk factors for diabetes also apply: over 45 years of age, family history of diabetes, and being overweight, and lack of exercise.

Type 2 diabetes requires regular and frequent monitoring of blood glucose levels, and usually requires dietary modification, so referral to a dietician may be beneficial. To prevent, delay or manage type 2 diabetes, people living with HIV can aim to maintain a healthy weight, eat a variety of healthy foods low in fat, sugar and salt, and exercise regularly.

Some of the symptoms of diabetes include: increased thirst, frequent urination, increased hunger, unexplained weight loss or weight gain, and excessive tiredness. If you experience any of these symptoms, please see your GP.

– Bruce Hamish Bowden
Clinical Pharmacist (HIV)

Volunteer Talkabout Advertising Account Assistant

Positive Life NSW is seeking a Talkabout Advertising Account Assistant volunteer to create relationships with potential and actual Talkabout advertisers and act as the liaison between Positive Life and our Talkabout advertisers.

This volunteer role would suit a person living with HIV who is either retired or working part-time with a background in advertising and/or the NSW HIV sector.

To apply: Please send through a one-page Expression of Interest (EOI) that addresses the Selection Criteria in the Job Description, available from the Positive Life website, or call the Talkabout Editor on **02 9206 2177** or email editor@positivelife.org.au.

BRINGING BACK TALKABOUT SURVEY 2021

A big thanks to all who responded to the online shout-out about the Talkabout survey which was open between 14 to 28 January 2021.

The survey link was emailed to all current Positive Life Full members subscribed to receive our notices on Thursday 14 January and promoted throughout our social media platforms.

In total, 81 people responded to the survey, of whom 71 (88.75%) said they had received, read or contributed to at least one edition of Talkabout in the past. 66 men, 12 women and one person who identified as nonbinary responded (that's right, two people skipped this question entirely).

Of the 78 people who responded, the majority said they lived in New South Wales, one from Western Australia, four from Queensland and two from Victoria. The youngest was 27 years old while the oldest respondent was 74 years old.

Over 90% of respondents agreed or strongly agreed with the statements that *Talkabout kept me aware of news, policies, events and HIV-related issues in NSW*, and *Talkabout was a good way to stay up-to-date with the work of Positive Life*. Over 80% agreed or strongly agreed with the statement *Talkabout gave me examples of how to live well with HIV*, and over 70% agreed or strongly agreed with the statement *Talkabout made me feel less isolated and alone*.

“Personal stories”, or “Peoples stories”, was what respondents said they enjoyed the most about Talkabout.

The following comment seemed to summarise many other responses:

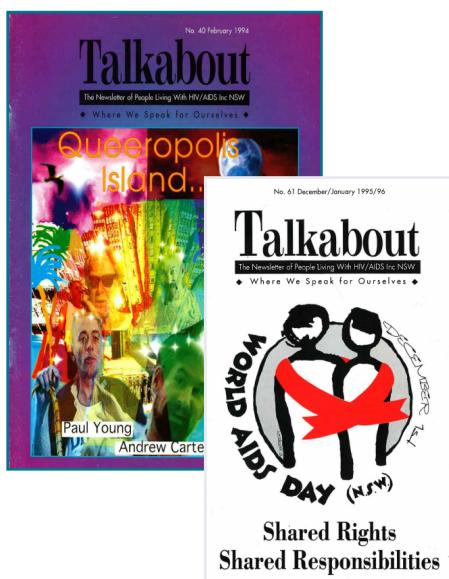
“I loved the variety, it included everyone with HIV. I especially liked that it included women’s issues. I loved the recipes...It helped me understand all the issues HIV people faced. It helped me feel included, which is especially important to me cause I felt dislocated with my HIV positive diagnosis”.

Similar comments on this theme included, “Reading stories about people’s journey that was similar to mine”; “Feeling connected and gaining important info about living with HIV”; “The personal stories and knowing about the campaigns PL run”; “A feeling of community a place to see what events are coming up”; “Personal stories, artwork and cartoons, some regular features were nice like the pets column, real stories about real people”. The Talkabout byline, ‘Where we speak for ourselves’, seemed to be strongly echoed in many comments.

Other comments included, “It created a sense of not being alone with the HIV”; and “New information and information I can’t find anywhere else. News on new treatments, side effects and legal issues. Information on co-infections”; and “Information and networking, essential as live rural”.

Some respondents also remarked that part of what they enjoyed the most about Talkabout had to do with the hard copy aspect of the publication itself. “It was a physical magazine and something I was more inclined to sit down and take the time to read”; “I like hardcopy”; “...it was a nice A4 booklet size”; “You could re-read articles I don’t like reading articles online”; “Being in hard copy it was convenient to be able to pick up and read intermittently (e.g. when having meals), also made it possible to easily share and discuss content with others”; “I guess online I am less likely to read it as I am usually so busy with other things online”; and “Email edition is just one more email so I generally don’t read it unless I have time when online”.

When asked what did you enjoy the least about Talkabout, out of 47 responses, 21 people responded with “nil”; “n/a”; “Nothing really it was a great publication”; “can’t think



of any negatives”; “nothing specific”; and “no I loved the whole magazine. It was good to share with family and friends caused it helped open conversation with them”.

A number of remarks expressed disappointment with the move to an online publication, such as “couldn’t understand why it was stopped”, and “the fact it went to an online magazine...is good but I find it unreliable, expensive & generally annoying, a hard copy is far more useful.”

A number of comments highlighted a range of opinions about reprinting Talkabout. Respondents who seem to be more comfortable with online access stated “an online version is preferable to a print version”, and “don’t bring it back in print. Digital is great”. Another stated “while it was marvellous at the time I cannot see the current need for a magazine (and expenditure of the associated costs and labour)”, and another “a printed publication will only serve the needs of a very small number of marginalised and disconnected PLHIV for a very high cost. The majority of PLHIV are connected...”

A non-metropolitan resident remarked, “please bring it back. It was a major means of support for a non-city dweller.” Another responded, “I’m actually happy to read it online, but when there are quite a few substantial stories it’s good to have a physical magazine lying about to pick up and put down from time to time”; and “I really want Talkabout to come back in hardcopy, cause the only computer I have is on my phone. Also in hardcopy you could read bits at a time and then pick it up and read some more later.”

Although this was an online survey, there were many comments calling for a printed version: “It should never have moved to an online only model”. “I haven’t read Talkabout since it went online”; “Bring it back please”; “Please Please Please bring Talkabout back”. “Keep the printed format as it was at last printed issue”; “I feel it is an important magazine for those who aren’t into online technology”; and someone else remarked “I think a hard copy sent out in the mail, via email is an essential component in continuing community development, not everyone has access to social media and electronic systems. It is

also important to have the hard copy available in places - prisons for instance or general health care services - where people would otherwise not be able to access the mag.”

Another respondent reflected on sero-status in relation to Talkabout; “Also, if one doesn’t want to be identified as a person living with HIV, having the mag in doctors’ surgeries and other general purpose health and wellbeing centres, will give access that they otherwise wouldn’t have.”

Another PLHIV stated, “I have missed it a lot. When I was first diagnosed it was the one thing that kept me going. The new email way is just lacking in everything...” and another agreed, “Reading a hard copy is a nice change from constantly looking at a screen.”

A respondent reflected “Talkabout should never have disappeared... just as HIV hadn’t disappeared. It was a landmark publication when started”. A more lengthy respondent stated:

“Talkabout should absolutely be brought back. I enjoy reading long form articles and the problem with life. mail is I often ignore it (as with most emails)...we don’t really have an official voice anywhere that can tell our stories or let people know about issues and campaigns. It would also be a useful tool for Board Directors to make themselves known and for others to know who they are...”

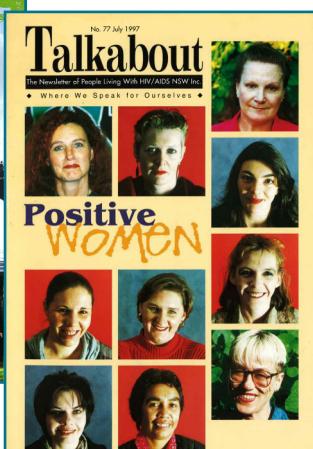
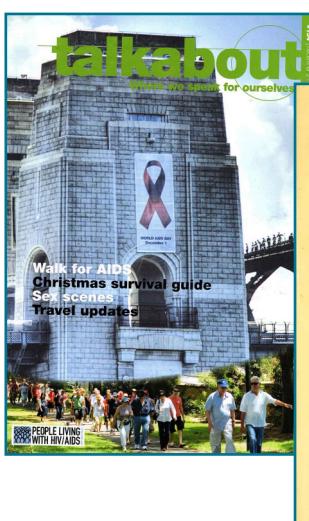
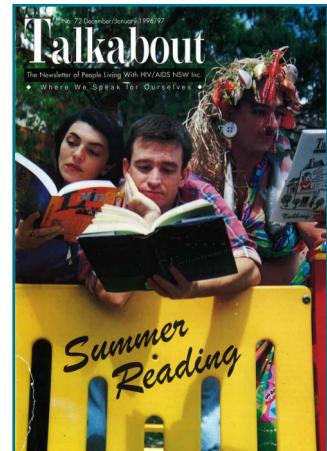
A respondent summarised: “Talkabout was a wonderful magazine - it had its ups and downs, but when it was good it was amazing. Talkabout was at its best when it had heart and soul and focused on people and their lives.”

It was great to receive all of these responses, both for and against the return of Talkabout as a printed magazine. A few respondents left names and phone numbers indicating their interest to be involved.

If you would like to be involved in some way, please contribute or discuss your options. Don’t wait for a personal invitation! (Unless you told us your name, the survey was anonymous and we don’t know who you are!)

At the end of 2021, we’ll be running a followup Readers Survey along similar lines to the previous Talkabout surveys to make sure we are continually improving the magazine.

If you have any thoughts or ideas, have a chat with the Talkabout editor, Craig on (02) 9206 2177 , 1800 245 677 (freecall outside metro) or contact@positivelife.org.au



TALK SHOP

The NSW Body Positive is represented across a range of NSW HIV/AIDS community partners. Below are brief details of advocacy issues impacting the interests of people living with HIV in NSW.

Real Time Prescription Monitoring

Positive Life is responding to a consultation conducted by the NSW Ministry of Health which aims to amend the Poisons and Therapeutic Goods Regulation 2008 to support the use of real time prescription monitoring in NSW.

Positive Life acknowledges the importance of the safe dispensing of prescription medicines, and is advocating for a number of amendments to the proposed regulations to better support people living with HIV when these regulations come into force.

Inquiry into Mandatory Disease Testing Bill

Positive Life, along with a number of agencies in the HIV and NSW NGO sector, called for an inquiry to be established into draft *Mandatory Disease Testing Bill (2020)* legislation that was introduced into the NSW Parliament by the NSW Government on 11 November 2020. In December 2020, Positive Life made representations to the Standing Committee on Law and Justice in response to the draft legislation.

We acknowledge the importance of maintaining the health and safety of health, emergency, and public sector workers, and in no way minimise the anxiety and trauma resulting from these incidents or endorse antisocial behaviours towards these public sector workers. Yet, we join with many other qualified stakeholders in our ongoing strong opposition to the mandatory disease testing of people whose bodily fluids come into contact with our health, emergency, and

public sector workers in NSW. This is based on the extremely low risk of HIV being transmitted occupational settings such as those covered by this legislation, as well as our commitment to the principle of consent in testing. The Bill as it currently stands will contribute to and exacerbate unfounded fears and does not inform and support health, emergency, and public sector workers about the actual risks associated with bodily fluids. It also infringes on the human rights of NSW citizens and will exacerbate stigma and discrimination faced by people living with HIV and other BBVs.

Positive Life made further representations at the mid-February hearings held by the Standing Committee, where Professor Andrew Grulich, Head of the HIV Epidemiology and Prevention Program at the Kirby Institute, UNSW supported Positive Life as an expert witness.

Statutory Review of NSW PHA section 62 and 79

In December 2020, Positive Life partnered with the HIV/AIDS Legal Centre (HALC) to provide a submission into a discussion paper released by the NSW Ministry of Health, which reviewed changes made to the *NSW Public Health Act in 2017*. We continue to support the removal of disclosure requirements from the Act that were made in the 2017 amendments, and the addition of reasonable precautions as a defence against transmitting a sexually transmitted condition. We are continuing to advocate for a statement of principles to be added to the Act,

which outlines how all of us can take shared (mutual) responsibility for our sexual health. We continue to strongly advocate for the penalties under section 79 to be removed.

NSW Parliament Independent Member

Positive Life NSW met with Alex Greenwich MP, who is the Independent Member for Sydney in the NSW Parliament, late January 2021 to discuss the Mandatory Disease Testing legislation (as mentioned above) as well as other issues people living with HIV in the City of Sydney catchment area have raised with Positive Life.

NAIDOC Week Art Workshops

Over two days in December 2020, Positive Life offered free online workshops to people living with HIV across NSW to explore Aboriginal art history and painting techniques.

The workshops were facilitated by Aboriginal artist, Arone Meeks, and supported by the National Indigenous Australians Agency. Participants learned about contemporary Aboriginal art techniques and culture, and how to understand stories, traditional culture, and customs told through Aboriginal art.

All art materials and supplies were posted to participants in advance of the workshops, which they were able to keep to in order to continue their creative journey. The artworks produced will be exhibited at the Positive Life NSW office for a limited period of time, and will then be returned to the participants following the exhibition period.



STRAIGHT AND HIV+?

- Get the latest information on topics such as pregnancy, treatment and living well
- Find out about other useful services
- Connect with other heterosexual people living with HIV

WEBSITE

pozhet.org.au

EMAIL

pozhet@pozhet.org.au

FACEBOOK

[@pozhet](#)

Pozhet is a government-funded NSW-wide service for heterosexual people at risk of or living with HIV, their partners and family.

I'M STILL HERE

A place where people living with HIV long term share our realities and experiences.

My name is Peter Schlosser and I am and have been a Positive Speaker with the Positive Life NSW Positive Speakers Bureau (PSB) for 24 years.

I'm happy and privileged to be here today in 2020. Saying this leaves me pleased, and a little surprised to say the least. It would be no surprise to tell you that I'm living with HIV and that I'm over 55, but what may be surprising is that I belong to the largest group of people of people living with HIV.

Over 50% of PLHIV in NSW are 50 years and over. What I want you to know is what that means for me and for many of my peers, or for the clinicians here, my cohort.

I was first diagnosed in late 1984 aged 21 and I was so very kindly told by my GP that I'd not have a 25th birthday. I'm still here.

Six years later in 1990, after a diagnosis of Hodgkin's Lymphoma, I was given two weeks to live. I'm still here.

In early 1994 I relapsed and my partner of 10 years died of AIDS just after Christmas.

Then in early 1995, in the space of two weeks, I was diagnosed with five AIDS defining or HIV-related illnesses. Family and friends were told that I could go at any time. I'm still here.

I began prophylactic treatment for the infections that I had. Later in 1995 I had a Grand Mal epileptic fit due to scarring on the brain from one of the AIDS defining infections, and so began my journey with co-morbidities.

I also started a basic and toxic anti-retroviral treatment. Despite that, two years to live was the expectation. Regardless of the damage from chemo and HIV meds, it saved my life. I'm still here.

Since 1997, newer and improved treatments with less side effects and better efficacy have been developed. My huge pill burden started to decline, and I participated in a variety of drug trials. I was expecting everything to return to normal and for a time it seemed that it was...til' it wasn't.

In 2003, aged 40, I had a sudden and rapid progression of osteo-arthritis. I was told that I needed a double knee replacement which was denied on the grounds that I was too young. I suffered for ten years becoming progressively more disabled and pain has been my companion ever since. I'm still here.

In 2011 after some frightening cognitive issues, I was

diagnosed with mild HIV-related neurocognitive dysfunction. I'm still here, just a little more confused.

In 2012 my gall bladder was removed. Most of me is still here.

In 2013 I had my knee replacement surgery, 50 was no longer too young. The resulting pain relief was amazing though. Even less of me is still here.

Now, other joints have become painful and deforming. In 2015 a friend convinced me to participate in a University of NSW HPV anal cancer prevention study called SPANC.

My first biopsy revealed very early anal cancer and surgery rapidly ensued. I'm still here.

In 2019 I felt oddly tired and unwell. Last December just before Christmas, after 25 years had elapsed, I began chemotherapy for Hodgkin's Lymphoma for the third time.

A silver lining though, I reached a five-year milestone of remission from anal cancer this year.

My new goal now is five years of remission from Hodgkin's Lymphoma. Who says it's not good to have goals? My guess is that, I'll still be here.

What I'd like you to hear today, and take home, is that's not the end of my story, it's not the end of the story, it's not the end of our story, not by a long shot.

We, I remind you, are the largest cohort of people living with HIV. Right here in NSW, we who bore the brunt of the AIDS pandemic, who fought for rights, who fought for recognition, who watched our loved ones waste away and die, who buried a generation and lost our supports and social circles, we who continue to address stigma and discrimination, we who fought for and were guinea pigs for treatments are, ironically, in the age of treatments being forgotten and left behind.

The point of all of this is that living with HIV can be very complex for a lot of us who survived a pre-1996 diagnosis.

Besides HIV, many of us, known as long term survivors or the AIDS generation, the over 55's, are living with a number of other conditions. Many of the people in this room know what I'm talking about, co-morbidities.

The overarching public health message is one pill a day and all will be well, which is fantastic. One pill a day is the case for most diagnosed today, and falls short only in so far as cure.

However, for those of us who are long term survivors, who fought for this outcome, this is not necessarily the case.

My pill burden for HIV is still high by today's standards at five per day. In regard to co-morbidities, I take an additional 20 per day. This is not an uncommon story. As we've got older and the one pill a day messaging has become prevalent, we seem to have become invisible and forgotten.

We, my cohort and I, are all getting older and currently living with or facing the impact of loneliness, isolation, mental health issues and the prospect of poorer health outcomes.

Surely everyone in 2020 with the experience of the COVID-19 pandemic, can identify with this, but for us it's been an upwards of 40 years experience. Please don't forget us!

Being forgotten is not a good thing for anyone.

Living with HIV is not just about treatments, it's about quality of life, physical and mental. It's about social connectedness, belonging, support, inclusion, visibility and involvement, being heard and being acknowledged. Nothing about us without us.

Please don't leave us behind! Please don't forget us! We are still here.

My name is Peter Schlosser and I live with HIV. I'm really am so very grateful to still be able to still say that, but sometimes it's hard...I'm still here.

– Peter Schlosser

**...we, I remind you,
are the largest
group of people
living with HIV.**

Right here in NSW..."

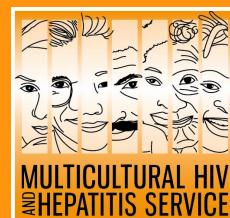
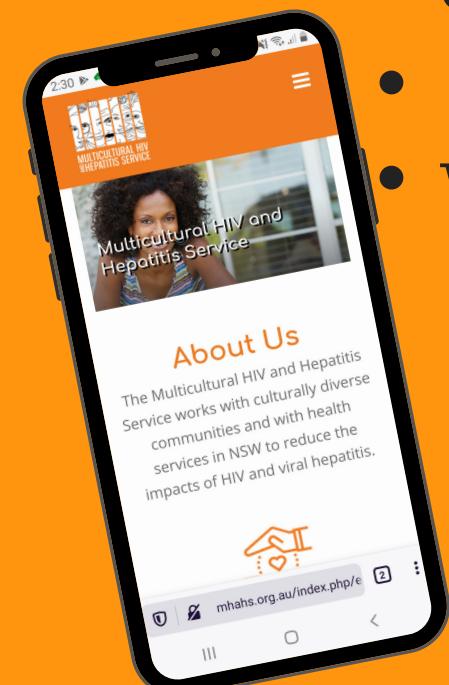
**...Living with HIV
is not just about treatments,
it's about...social connectedness,
belonging, support, inclusion,
visibility and involvement, being
heard and being acknowledged.
Nothing about us without us."**





WWW.MHAHS.ORG.AU

- Find information and resources on HIV and viral hepatitis in multiple languages
- Contact our HIV Client Support Program
- Learn about our:
 - community engagement projects
 - ethnic media campaigns and
 - workforce development



MULTICULTURAL HIV
AND HEPATITIS SERVICE



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IN THE KNOW RESEARCH AND TREATMENTS

In early January, when the Federal Government announced Australia's intention to embark on a COVID-19 vaccine rollout, Positive Life heard from our members and community seeking out more detail about the rollout plan, the vaccine itself and what it might mean for people living with HIV in NSW. Questions have included issues of vaccine development and safety, impact of the vaccine on HIV and implications for HIV treatments, availability and access to the vaccine, and what might things be like after vaccination?

In response we put together one of our annual 'In The Know' treatments and research events. On Tuesday 9 February, under a COVID-19 safe plan, we gathered a number of notable researchers and clinicians together as well as attendees to learn more about the latest developments of the COVID-19 vaccines, the rollout and what this means for people living with HIV in NSW. Venue seats were limited to 30, and these filled very quickly given such a popular issue.

Once Nathan Moran, Metropolitan Local Aboriginal Land Council CEO delivered a warm welcome to country, Positive Life CEO Jane Costello introduced our speakers, welcomed attendees with an outline of the evening. Brent Clifton, our Treatments Officer offered a brief overview of the progression of COVID-19 in Australia so far, and our speakers commenced with their presentations.

Director of The Kirby Institute, Professor Anthony Kelleher who is also Head of the Immunovirology and Pathogenesis Program, spoke from the perspective of the science of the vaccine including side effects, research and types, and how COVID-19 affects people living with HIV.

Associate Professor Edwina Wright from the Alfred Hospital, Monash Central Clinical School and co-head of the HIV Elimination Program, Burnet Institute and Honorary Associate Professor at the Peter Doherty Institute shared details via a Zoom link from Melbourne, about plans of the vaccine rollout, schedule and logistics in her capacity as one of the ASHM COVID-19 Taskforce members.

Dr Prital Patel, a research fellow from The Kirby Institute's Surveillance Evaluation and Research Program spoke about vaccine hesitancy and trust. The evening concluded with a Q & A discussion where our speakers, along with pharmacist Hamish Bowden from Sydney's The Albion Centre, responded as a panel to a number of questions.

We received many thoughtful questions from members and attendees, including some reflections on the impact for a HIV vaccine or even a cure.

Dr Patel reassured us that as people living with HIV we have a right to ask questions about the vaccines particularly about the effects and impacts on our health, and to be comfortable with any decisions that relate to our health.

Dr Patel also highlighted the number of scams and false claims that are circulating at this time, especially online, and cautioned us to always check where the information is coming from.

Information from NSW Health, the Australian government health website, your personal health care providers, or your pharmacist are useful allies in providing accurate information and timely details. If you're ever in doubt, please call Positive Life on (02) 9206-2177, 1800 245 677 (freecall) or email contact@positivelife.org.au

Natasha Io, a speaker with our Positive Speakers Bureau (PSB) and a Positive Life NSW Board Member:

"As someone who has lived with HIV for many years, I too have many questions about the safety and efficacy of the vaccine and how and if it could in anyway interfere with my HIV medications. The presenters for the evening were, Professor Anthony Kelleher, Associate Professor Edwina Wright and Dr Prital Patel, all medical researchers long involved in the research of HIV and development of HIV medications.

The evening was divided into two parts; how and why vaccines work, how the vaccine was developed and its uptake for people living with HIV. The second part was a Q and A and all questions were supplied online from people living with HIV. An informative and worthwhile evening to attend.

The presentation was filmed by Positive Life NSW and will be available to view on their website in the coming days. I would encourage anyone living with HIV with questions or reservations regarding the COVID-19 vaccine to view this video."

s100 CONSULTATION COMMUNITY SURVEY

In October 2020, NSW Health and Positive Life developed a survey tool to inform a project by NSW Health to understand the best way to continue to administer the NSW co-payment initiative for s100 HIV antiretroviral medication into the future.

The survey sought to:

- Assess the awareness and use of the NSW co-payment initiative;
- Understand the variation and choice for the collection of prescribed s100 HIV antiretroviral medication; and
- Gain knowledge about community satisfaction for the initiative.

180 people living with HIV in NSW responded to the survey.

The majority (96.7%, n=174) of respondents reported collecting their own HIV antiretroviral medicines. 32.8% of survey respondents indicated their HIV antiretroviral medication was prescribed from 'a doctor at a sexual health clinic'; followed by 22.8% by 'my GP'; 20% by an 's100 prescriber GP'; 12.2% by 'a clinician at a Public Hospital'; and 11.7% by 'a Specialist'. None of the respondents reported a nurse practitioner prescribed their antiretroviral treatment.

Half of the respondents reported they obtained their antiretroviral medication from their local chemist or pharmacy, while 42.2% said they accessed antiretroviral medication from 'a public hospital pharmacy'.

69.4% of people reported they used 'Convenience (e.g. location, familiarity with pharmacist)' as the most common guide to choosing a pharmacy, followed by 'trust and reputation', 'speed and availability of dispensing

medication', and 'privacy'. 61% of respondents indicated they rely on healthcare providers as their main source of support to manage their health.

Respondents reported first hearing about the co-payment initiative through a number of different sources. 19.7% said they heard about the co-payment waiver from an 's100 Prescriber GP'. 17.7% said they heard about it from 'Positive Life NSW'; 15.6% of respondents said they heard about it from a 'GP'; while 13.6% said they heard about it from a 'Public Hospital Prescriber (Doctor)'.

Only 31 of respondents reported ever having had issues accessing the s100 co-payment initiative for their HIV antiretroviral medication. 111 respondents agreed that the s100 co-payment initiative makes it more likely they will be able to access their HIV medication.

67.6% of respondents reported their experience as satisfied or very satisfied when filling out their prescription and accessing the co-payment initiative. 65 respondents said the main reason for their satisfaction was due to the 'easy, smooth and simple process'; 30 respondents indicated it was 'a good relationship with pharmacist who is knowledgeable, respectful and aware of process'; and 25 respondents indicated they felt 'grateful it is free as the co-payment waiver helps financially'.

In total, only 11 respondents were currently paying the PSB co-payment for their HIV antiretroviral medication.

The full report will be available on the Positive Life website by mid-March 2021. If you want a copy posted to you, please call (02) 9206-2177, 1800 245 677 (freecall outside metro) or email contact@positivelife.org.au with your postal details.



Life Insurances for people living with HIV,
diabetes and other complex health conditions

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choice



halc

The HIV AIDS Legal Centre

The HIV/AIDS Legal Centre is a not-for-profit, specialist community legal centre, and the only one of its kind in Australia.

We provide free and comprehensive legal assistance (within operational guidelines) to people in NSW with HIV or hepatitis related legal matters. This includes in such areas of law as: discrimination, privacy, immigration, end of life planning, insurance, superannuation, social security, criminal, family, housing and more.

For confidential legal assistance please contact us: Phone 02 9206 2060 or email halc@halc.org.au

Letters to the Editor

Your messages, comments, thoughts and opinions are welcome here.

Letters should be short (less than 200 words) and may be edited.

All letters to be considered for publication must have a name, street address and phone number for verification.

Please specify if you want your details withheld from publication.

Email Talkabout
editor@positivelife.org.au or
post Talkabout Editor,
PO Box 831,
Darlinghurst NSW 1300

Calendar

COMMUNITY

national day of women living with hiv

Celebrate the lives of women living with HIV over a high tea amongst supporters, friends and family. Email or call for more details.

TUESDAY 9 MARCH 2021
2pm to 4pm

the social club

A get together for heterosexual people living with HIV in a safe, friendly and accepting social environment over a meal and discussion.

MARCH & APRIL 2021
6pm to 9pm

peers connect online!

A safe, online meeting space for all people living with HIV in NSW, over 18 years regardless of identity or sexuality. Meet others living with HIV over Zoom. All welcome, especially people from rural and regional settings. Discussion facilitated by a person living with HIV from Positive Life. RSVPs are essential for each session.

THURSDAYS
11 & 25 MARCH and 8 APRIL 2021
6pm to 7.30pm

peer2peer

An evening for all gay and bisexual men living with HIV to connect with peers and build your networks, share experiences and engage with a range of issues relating to our health and living with HIV.

THURSDAY
29 APRIL 2021
6.30pm to 8.30pm

2021 candlelight memorial

A time to remember our friends and family who we have lost to HIV/AIDS as we show our support of people living with HIV.

SUNDAY
16 MAY 2021
Early afternoon

For more information about any of these events or to RSVP call Positive Life on (02) 9206-2177, 1800 245 677 (freecall) or contact@positivelife.org.au



LOSING FACE LOSING FEAR

Losing face' is a big thing within my culture and family community.

This term 'losing face' means to 'lose respect' or 'lose esteem' in the eyes of another person. I'm not sure if there is a similar thing for Anglo-Australians, but this is something that's very strong in Asian cultures and many other cultures.

It affects almost everything we do, the way we approach life, and our interactions outside of the family.

When you 'need a hand' to deal with something, the cultural way of approaching this can set up huge barriers. I remember when I was first diagnosed, I really struggled with this.

I didn't want to bother anyone else with my business or let them know I was struggling with anything at home. So I kept to myself and tried to manage things on my own. I felt like if other people knew what was going on for me, this might bring 'shame' on me, or I might be thought of as 'weak'. The last thing I wanted to do was to be seen as if I was seeking sympathy from others, let alone my family!

So I started bottling things up. Keeping them to myself, playing my cards close to my chest. I let the tension build and build rather than talk to anyone else about how I was feeling. I thought I could keep a lid on everything.

Except I couldn't. You can guess how impossible this became, and I cracked under the pressure.

It was only in hindsight that I realised how much I hurt the very people I was trying so hard not to hurt, and pushed away the people who would have been there for me in a flash. As I struggled to keep things to myself, I sabotaged my relationships with my family and my friends.

Of course, my partner got the brunt of it all. We stopped talking like we used to. Our relationship suffered. I felt so moody with all the fear and anxiety I was going through. This affected my sleep and health, and things went downhill from there.

What I didn't realise at the time, was that asking for help is normal. Anyone of us does this as a kid easily. When I needed help putting on my shoes, or with a math problem at school, or reaching for something I would ask for help.

I'm not exactly sure why I didn't do this after my diagnosis, but I have a pretty good idea.

One of the biggest hurdles with HIV is a little thing called stigma. Something that doesn't just come from other people. It can also come from inside.

We call that 'internalised stigma'. I now know what that feels like, and how dangerous it can be. It's beating yourself up, over and over again. It was only when I started taking the smallest steps to talk about how I was feeling, that I realised I needed to voice myself, my questions, and my worries.

I found talking with someone else like me, someone else also living with HIV, made a big difference. Other people who are walking in the same or similar shoes are called 'peers'.

Peers are people who 'get' what you're going through, because they've gone through the same thing. My own peers are other gay men from an Asian culture who have also found out they are living with HIV.

Sometimes you feel like you can't talk with your friends because it's so personal. I felt a huge amount of relief when I started talking to other peers like me. It was like I was talking to a mate who really 'got' how I felt. Someone I knew who wasn't prejudiced. Who didn't make any judgements about me or about my diagnosis.

Fast forward a few years, and today I'm much more true and honest with myself. I'm back to my usual self with my family, my friends, but best of all my partner. It's awful to feel so alone. Looking back, it's awful that I struggled for so long on my own.

If you're in a similar place, maybe it's time to reach out. Reaching out is gonna be a little nerve wracking at the start.

The sooner you start, the sooner you'll be glad you did. Whether you pick up the phone or send an email, getting support from others who've been where you are right now, will make all the difference.

To get the ball rolling, you can call Positive Life on (02) 9206-2177 or 1800 245 677 (freecall outside metro) or email contact@positivelife.org.au. Let us know where you're at, and what you're dealing with.

- Jimmy Nguyen

WORKING FOR ME

all people living with HIV

A place to showcase
our sector partners
who benefit the lives of

The Ankali Project was established in 1985 to provide emotional and social support to people who were living with, and dying of AIDS.

In the early days, the service involved volunteers attending hospices and funerals. Although our volunteers still support clients in hospices and through the end of their lives, fortunately, it is less and less common these days.

With the advent of improvements in medications and healthcare, volunteers now accompany people living differently and living well with HIV.

What remains the same between then and now is that volunteers still provide social and emotional support, and that this support is still important and needed. The service has therefore changed over the years but continues to honour the foundation upon which it was developed.

During 2020 we all learned to live with the impact of COVID-19, learning about hand hygiene, QR codes, social distancing, and isolation. What some of our clients tell us is that while social distancing and isolation were new and interesting experiences for some, for others social distancing and isolation have been long-standing and difficult experiences.

While HIV has changed in that people's health has improved, our volunteers still show care for clients, beyond their status and viral load.

At the Ankali Project, health and wellbeing include emotional, mental, and social health. One of our Psychology colleagues describes Ankali Project volunteers, saying

"The work that volunteers do is invaluable to our clients. Volunteers can do things with and for our clients, and share things that health professionals can't, which is to show them that they belong, and are cared for."

Clients and volunteers have regular contact on a weekly to fortnightly basis. They catch up for coffee, go for walks, visit galleries, and have found new and novel ways to keep in touch, even during the COVID-19 pandemic.

During lockdown periods in 2020, clients and volunteers had phone or video chats, watched movies together but remotely with screen sharing, and had 'book club' discussions about books they'd read.

One client fed back to us what volunteer support means to him.

"I'm so glad I met my volunteer. We just joke and laugh, and I get to forget that I'm separate from everyone because I'm gay, or [HIV] positive."

Volunteers join the Ankali Project for a range of reasons: to connect with community of people living with HIV and others affected by HIV, to support the LGBTIQ community, for social justice values, personal development, or relevance to their career interests.

One volunteer tells us what he gets out of volunteering:

"I'm glad that my support helps [my client] but it works for me too. In the volunteer training we learned about how to be a sounding board for a client, with emphasis on practicing active listening and non-judgement. I think those skills are just good life skills and catching up with my client gives me great opportunity to practice them."

Another volunteer shares what volunteering brings to his life:

"The last year has been hard for me, losing my job, and then having to move from the unit I've lived in for years. Volunteering here saved me in that time. Seeing my client and keeping in contact with other volunteers kept me going so that I wasn't just at home, navel gazing and feeling sorry for myself."

The Ankali Project supports volunteers through training, peer support, education opportunities, and social events.

In 2020, we were acknowledged by the Centre for Volunteering, the peak body for volunteering in NSW. With over 123,000 nominations for the award, it was the Ankali Project that won volunteer team of the year for Sydney's East.

For both clients and volunteers, the Ankali Project is about inclusion, care, community, diversity, and support. People of all backgrounds are welcome to volunteer. People living with HIV are welcome to seek support here, whether as a client, or as a volunteer that provides support to others.

To find out more about us or to join as a client or volunteer, call our team at (02) 9332 9742, or email: ankali@sesiahs.health.nsw.gov.au

– Tiffany Tran

Tiffany is a social worker with The Ankali Project at The Albion Centre.



Ankali volunteers at 2019 End of Year social. SOURCE: Ankali Facebook

BUT I DON'T HAVE ANAL SEX

There's a lot of misconception about who gets anal cancer and how it's caused.

Human Papillomavirus (HPV)-related cancers such as anal cancer is a risk for all people living with HIV regardless of the type of sex you have. I was chatting to a friend the other day and told her about the work I've been doing with Positive Life NSW on anal cancer awareness. She was shocked when I told her that anyone can develop HPV-related anal cancer including women.

She laughed and said, "but that's if you are having anal sex." I responded that was not the case, and that HPV can be spread to the anus from something as simple as front-to-back wiping after the toilet." She stopped laughing then.

...HPV is a really common STI that usually has no symptoms..."

The precursor to anal cancer is persistent HPV. Anyone who is sexually active can get HPV including men, women and trans and gender diverse people. HPV is a really common sexually transmitted infection (STI)

that usually has no symptoms and normally affects around 80% of us at some point in our lives.

The good news is, most of the time HPV will clear itself without treatment and you might not even know if you've got it. The not so good news is, if HPV is persistent it can develop into HPV-related cancers such as cervical, vaginal, vulvar, oropharyngeal (throat and mouth) and even anal cancer.

While anal cancer is a relatively rare form of cancer, for people living with HIV, particularly for those over the age of 45 years, there's an increased risk for developing anal cancer than the general population.

While having anal sex can increase your risk for anal cancer, many men, women, and trans and gender diverse people who don't often or have never had anal sex, can also be at risk of developing anal cancer. Other risks for developing anal cancer include having multiple sexual partners, being older, smoking, an existing or previous HPV diagnosis, a previous history of HPV-related cancer such as cervical, vulvar or vaginal cancer, and drugs or conditions that suppress your immune system such as organ transplant recipients and having an autoimmune condition.

March 21 is Anal Cancer Awareness Day, and this year Positive Life NSW is urging all people living with HIV to raise the topic of anal cancer with your HIV health provider.

For more information Positive Life NSW has developed a factsheet for people living with HIV called *HPV & Anal Cancer*, which can be downloaded from our website.

If you have any questions about anal cancer or your risk, or if you want to talk to a peer also living with HIV, contact the Treatment Officer at Positive Life on (02) 9206-2177 or 1800 245 677 (freecall) or contact@positivelife.org.au

– Bella Bushby

Bella is the Positive Life Health Promotion Officer, and a proud ally of all people living with HIV.



All people living with HIV
have a higher risk for
anal cancer



**Supporting people living with HIV aged over 45, through the maze
of aged care, disability, and healthcare services in NSW**

Contact Positive Life NSW on (02) 9206 2177 or 1800 245 677 (freecall)

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of your stories, experiences, tales, yarns, adventures, memoirs, narratives, histories!

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Everyone Has a Story





The voice of all people living with HIV

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HIV Health Promotion

Advocacy + Policy

Peer Navigation + Support

Talkabout

Housing Support

a[STARTx]

Ageing Support

Treatments Information + Support

Positive Life NSW works to promote a positive image of people living with and affected by HIV with the aim of eliminating prejudice, isolation, stigma and discrimination. We provide information, targeted referrals and advocate to change systems and practices that discriminate against all people living with HIV, our partners, friends, family and carers in NSW.

Phone 02 9206 2177 **Freecall** 1800 245 677

www.positivelife.org.au **contact@positivelife.org.au**
