



Australian BPD Foundation Limited

*Advocacy & Support for
Borderline Personality Disorder
& Complex Trauma*



Annual Report 2022 - 2023



THE BOARD

Mrs Rita Brown - President

B Pharm
Lived experience as a carer for a person with BPD
Carer Consultant

Associate Professor Sathya Rao – Vice President OAM

MBBS, MD, DPM, DNB, FRANZCP
Over 30 years' experience as a psychiatrist

Ms Karen Bailey – Secretary

BA Library & Info Mgt, Grad Dip Bus (Admin Mgt)
Lived Experience carer of a person with BPD
Lived Experience (Carer) Project Officer

Mr Desmond Yew - Treasurer (Appointed 19 February 2023)

Qualification Member of the Institute of Chartered Accountants in England and Wales (ICAEW)
Experience Over a decade of experience in industry and public accounting practice

Mrs Estelle Malseed OAM

BA Diploma Social Studies (Melbourne)
60+ years' experience as a social worker and mental health carer

Mr Keith Warren

Institute of Chartered Accounts
Over 40 years of experience as a principal in his own public accounting practice

Mr Milo Goldacre

LLB, BPPE
Mental health advocate and lawyer

Ms Victoria (Vikki) Ryall

Masters in Creative Arts Therapy, Melbourne Institute of Experiential and Creative Arts Therapy (MIECAT)
Bachelor of Social Work
Bachelor of Behavioral Sciences
Over 25 years in Mental Health, Youth and Primary Care

Dr Alison Asche

Master of Education, Master of Counselling & Human Services;
Doctor of Philosophy (Psychology and Public Health)
25+ years in Suicide Prevention and Mental Health

Ms Natasha Swingler

5th year Bachelor of Law/Psychological Science student
Lived experience of borderline personality disorder, complex mental illness
4 years as a consumer worker

Professor Michael Hazelton (Appointed 18 September 2022)

Qualification RN BA MA PhD FACMHN
Experience Over 45 years as a registered nurse specialising in mental health nursing, including over 20 years holding senior academic appointments at professorial level



Australian BPD Foundation Limited

*Advocacy & Support for
Borderline Personality Disorder
& Complex Trauma*

VISION

People living with borderline personality disorder (BPD)¹, personality difficulties and complex trauma² access appropriate and optimistic treatment and support for themselves and their family/friends /carers.

MISSION

To advocate for systemic change and enable a positive culture that supports the recovery and wellbeing of people with BPD (with or without complex trauma) and their family/friends/carers³.

PURPOSE

To bring together people with lived experience, carers, health and mental health researchers, clinicians and treatment experts to advocate for people with BPD (with or without complex trauma) to access equitable evidence-based treatment and support wherever and whoever they are.

VALUES

Respect & Inclusion: focused on bringing together people with lived experience, carers, clinicians, non-clinical workers and researchers to encourage a positive culture around the mental health issue currently known as BPD.

Driven: dedicated to improving the lives of people with BPD and complex trauma.

Lived Experience: listening to and respecting the voices of lived experience in everything we do.

Collaboration: stronger and can achieve more by working in partnership.

Integrity: walk the talk and never forget why we're here.

¹ In recognition of the unique stigma and discrimination the focus of the Foundation is currently based on what is described in the DSM-5 as 'BPD'

² The Foundation chooses to use the terms BPD and complex trauma. We recognise the significant overlap in symptoms surrounding personality difficulties and complex trauma.

³ The term 'carers' is used to include family by birth and family of choice/friends/supporters/kin.





Report from the President: Rita Brown

Dear Members

Writing an Annual Report is always a great opportunity to reflect on the past year and evaluate how we are tracking with maintaining and upholding our vision, mission and purpose.

The year 2023 has been eventful, with so much change occurring in the mental health sector that our small, hard working group of volunteers are having to pedal fast to keep up! It is daunting at times, however the knowledge of the distress and pain experienced by people living with BPD and their support network as they struggle to access appropriate treatment keeps us motivated to continue advocating for a positive culture that supports recovery.

Thank You

As with all volunteer lead and run organisations we couldn't do this without the significant support of others.

I would like to acknowledge the enormous contribution of our board members this year and the breadth of expertise they willingly share. Without your support and dedication, we certainly wouldn't have achieved nearly as much as we have. THANK YOU.

The current board includes four founding directors: Estelle Malseed, Keith Warren, Sathya Rao and myself. Keith Warren has tendered his resignation from this AGM, and I wish to acknowledge his tireless and invaluable support and steady guidance over the last 12 years. We wish him well in his future endeavours. Thank you, Keith!

A warm welcome to two new board members co-opted during the year - Michael Hazelton and Desmond Yew (our new Treasurer). Both have already contributed significantly to our work.

Thank you to everyone else who volunteers. A special mention needs to be made of the significant contribution made by Felicity Farmer, for her contribution in progressing our advocacy at the national level. Felicity brings with her a wealth of experience as a social worker and a health department bureaucrat having worked in a number of states and as a city councillor for Brisbane. Her knowledge and enthusiasm is greatly appreciated as we seek to build connections within the greater sector and develop our advocacy within the federal government especially with the health department. Felicity's report starts on page nine.

Some of the administration side of running the Foundation this year has been managed by Dom. Thank you, Dom, your support is much appreciated.



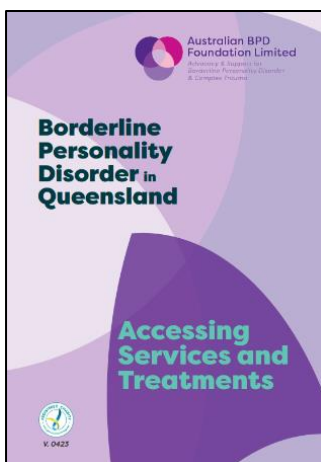
I wish to thank our membership, volunteers, and Board Members for your support in helping us continue advocating for everyone impacted by BPD. Your voices and contributions bring a wealth of knowledge and expertise to our advocacy. Our membership (at 30/6/23) is 1583.

A *Thank You* to Price Gibson Chartered Accountants who generously audit our Annual Financial Report on a pro bono basis and Statewide Services (Eastern Health, Victoria) in supporting us with office space and incidental printing.

Also, a huge *THANK YOU* to everyone who has donated to us this year. Despite many applications we receive no ongoing funding to help us to cover our costs such as insurances, website costs, phone etc. Your donations are vital for us to continue our advocacy work. All donations over \$2.00 are tax deductible.

Guide to Services for BPD in Queensland

One of the Foundation's core aims is to provide high quality and accessible education and support to individuals with BPD and their family, friends and carers. As a part of this endeavour, we were fortunate to obtain a grant from the Whitehouse Foundation to compile and distribute a 'Guide to Services for BPD in Queensland' designed to assist individuals, families, and carers in navigating the landscape of effective services and supports within Queensland.



We would love to get this fantastic resource directly into the hands of people with lived experience of BPD and their support network. So far, we have received overwhelmingly positive feedback from mental health, AOD, and Acute Care Teams across Queensland. We'd also love to get these available in GP practices so if you'd like to show your GP a copy and see if they would like some to be available in their waiting area. Alternatively, If you would like to receive **free** copies of the directory sent to your organisation, please let us

know (email admin@bpdfoundation.org.au), the number of copies you require, and the preferred organisational mailing address, and we will be more than happy to post them to you at no cost.

The guide is available for free download from https://bpdfoundation.org.au/services_qld.php

'A valuable resource on the road to recovery.'

[Mental health professional]

National Consensus Statement by, with and for people impacted by borderline personality disorder

Our National Consensus Statement continues to be a key component of our advocacy to organisations and Government. It was developed after broad consultation with people with lived experiences of BPD, those who support them ('carers' and clinicians) and sector stakeholders. It provides a roadmap for action at the national level.



Twenty-six organisations within the Australian mental health sector have now endorsed the Statement. We encourage you to also show your support online at <https://bpdfoundation.org.au/national-consensus-statement.php> and help us to amplify the message of the need for affordable access to appropriate treatments and support for everyone living with BPD (with or without complex trauma) and education and support for their family/friends/support community.

Many people who have shown their support online for the Statement have also shared their personal challenges of accessing (or providing treatment) and stories of positive outcomes when people have been able to access treatment. Where consent has been given, many of these comments have been shared anonymously with the Federal Government Department of Health and Aged Care Division of Mental Health and Suicide Prevention.

'It's time to call out that people living with BPD can connect, can cope, can contribute. A diagnosis of BPD should bring a spark of hope about what's possible, and I want to be part of that change.'

[Mental health professional]

We continue to strive for the development of a **national policy** which will enable us to move forward with one voice and work collaboratively to bring about the changes needed in the system to improve the health outcomes for every single person impacted by BPD in Australia.

BPD Awareness Week 2023 *'Be the Difference: Principles of Care'*



People living with borderline personality disorder (BPD) often experience stigma and discrimination which remains a significant barrier to accessing appropriate care.

There are several evidence-based treatments for BPD, such as Dialectical behaviour Therapy (DBT), Mentalization-Based Treatment (MBT), Schema-Focused Therapy (SFT) and Transference-Focused Psychotherapy (TFP). However, these may require many years of mastery and often have limited availability. Recently, structured generalist approaches have been developed,

drawn from the core principles of 'what works' in the specialist therapies and that have been proven to work for people experiencing BPD. The core principles of care can be easily incorporated in the practice of health professionals, expanding access to treatment and ensuring every interaction can make a therapeutic difference.

The campaign aims to deepen the existing knowledge health professionals have about BPD, and encourage them to 'Be the difference', and make a difference by applying the BPD core principles of care in their practice.

The 2023 BPD Awareness Week **Ambassador** was A/Prof Jo Beatson OAM who over many decades has aimed to improve clinical understandings, access to treatment and treatment effectiveness people living with BPD in Victoria and Australia-wide. She has contributed substantially to changing negative community and professional attitudes towards people living with BPD. Jo prepared a short message which can be viewed on the BPD Awareness Week website www.bpdawareness.com.au

The Foundation did not hold our usual Awareness **Conference** this year, along with other organisations in the personality field), as Australia was hosting the bi-annual Congress of the *International Society for the Study of Personality Disorder* in Sydney. However, with the support of other organisations we ran a number of **events** during BPD Awareness Week.

- Online: *Topic Tuesday 'Be the Difference'* (SANE Australia)
- Melbourne: *BPD Awareness Week Celebration* (Foundation & BPD Community)
- Brisbane: *West Moreton HHS' specialist treating unit for BPD* (QLD Ipswich/WM MHPN)
- Online: *Communication Strategies for Carers* (MIFWA)
- Online: *Core principles of care for BPD and implementation in a metro hospital.* (National MHPN)
- Online: *Launch of the National Mental Health Professionals Online Network.*
- Online: *A Schema Therapy Understanding of BPD* (NEABPD Australia)
- Online: *Core Principles of Care* open discussion with the Lived Experience Project Air Academy
- Ballarat, Vic: *Community event stall showcasing our resources* (Ballarat Mental Health Collective).
- Canberra: *BPD Family Fun Day Picnic*
- Canberra: *BPD Community Art Exhibition 'Be the Difference'*
- Online: *BPD and Complex Trauma – Sensory Modulation.* (MHPN)

We were also involved in media publicity to raise awareness and Rita Brown was interviewed for a number of articles:

- *More Training Needed for BPD* (ABC listen) <https://bit.ly/49DJqy1>
- *Mental health experts call for specialised training for emergency first responders on borderline personality disorder* (ABC News) <https://bit.ly/47DUEAy>
- *Q&A on BPD with Rita Brown, President of the Australian BPD Foundation on Psychreg* <https://bit.ly/47jiEt1>

To show our support for **BPD Awareness Month** in the USA, UK and Europe we hosted a webinar in May. Our guest presenter was Anthony Ruocco from Canada, an international expert on neurocognitive, social-cognitive, and neuroimaging studies of BPD. He spoke on '*Reconsidering how we think about Brain Biology in BPD*', and his presentation can be viewed via <https://youtu.be/ecUxNcMI5yI>.

You may have noticed a different design underlying our BPD Awareness Week **resources** this year. Regretably for us, Mahlie Jewell our graphic designer for many years, was not available to support us. We have been working with *WeAreSavvy* a communication and marketing company. Resources for 2023 and previous years are available for free download from www.bpdawareness.com.au/resources. We hope you like the new style to complement Mahlie's designs from previous years.

A huge thanks to the dedicated team of Karen and Chloe who supported me to pull everything together in time despite numerous challenges.

Conferences and Events

We have been fortunate to display our resources and talk to people at 3 major events this year.



Australian College of Mental Health Nurses (ACMHN) Conference was held in Melbourne from 13-15 September. Attendees were extremely interested in our resources and to access training –wanting to know *how* they can best support people living with BPD.

[Image: Karen Bailey and Rita Brown at the ACMHN conference]



Ballarat Community Event was held in Ballarat on 8 October. *Spectrum: Specialising in Personality Disorder and Complex Trauma* and the *Foundation* partnered in a display table at the Ballarat Mental Health Collectives Community Mental Health Day at Lake Esmond in Ballarat. The weather was fantastic and the event drew a good crowd.

[Image: Our table at the Community Event in Ballarat with some of our resources.]



International Society for the Study of Personality Disorders (ISSPD) Congress was held in Sydney 1-3 Nov 2023. Three Board members attended and our resources were extremely popular - we were told by international attendees they would now be on display in clinics around the globe! It was also a great opportunity for networking and I'm hoping that we can continue to build on the Australia-wide and international connections. [Image: ISSPD display & visitor]

International Society for the Study of Personality Disorders Congress



The Foundation's abstract to present on '*Working towards equity of access to treatment and support for people living with borderline personality disorder*' was accepted for a symposium at the International Society for the Study of Personality Disorders Congress.

This session included 4 presentations on the *BPD National Training Strategy* and a final discussion on *Working Towards a National Policy for BPD* project:

- *Overview and Stage 1* – Rita Brown (Australian BPD Foundation)
- *Stage 2* – Prof Brin Grenyer (Project Air Strategy)
- *Stages 3 & 4* – Core Competencies Framework 1 - Marianne Weddell (Spectrum)
- *Stages 3 & 4* – Core Competencies Framework 2 - Cathryn Pilcher (Spectrum)
- *Working Towards a National Policy for BPD* - Rita Brown (Australian BPD Foundation)

Whilst the funding concluded for the project in June 2022 **Stage 1** (webinars) and **Stage 2** (eLearning modules) can be accessed via our website <https://bpdfoundation.org.au/national-training-strategy.php>.

Stages 3 & 4, the *Core Competency Framework* workshops, Train the Trainer workshops and ongoing supervision is offered on a fee for service basis through Spectrum. Please contact spectrumtraining@easternhealth.org.au if you are interested. Participants who received training under the strategy continue to offer training to other clinicians in their areas/services.

Advocacy Report 2022-23

This has been an exciting year where we have focussed on engagement and advocacy in relation to the new Federal Government.

Sector Engagement

As a member of *Mental Health Australia*, the Foundation attended the annual Parliamentary Advocacy Day in Canberra.

We have appreciated the opportunities this year to strengthen our collaborative approach within the sector and to start forging new relationships with several national bodies by sharing our *National Consensus Statement* and following through opportunities arising. For example, as a result, we recently shared our logo with MIFA's campaign for a national psychosocial support program.

The Foundation attended the *Queensland Mental Health Expo* in October 2022 and heard perspectives from a broad range of service providers, including police. They sent the Foundation a very clear message that they are all in considerable need of evidence-based services for BPD with extremely limited referral options available. We also heard that many people living with BPD who also identify as multicultural or LGBTIQ+, eg, are referred to diversity services to access support and treatment for BPD yet these workers are usually not trained to treat BPD.

The following organisations shared their logos in support of the *National Consensus Statement* during the year:

- Community Mental Health Australia,
- Queensland Association for Mental Health
- Queensland Council for LGBTI Health,
- Stride for Better Health
- Supported Care.

In addition, numerous individuals, family members and mental health workers have supported the *Statement*, sharing valuable quotes, and where consent has been given, we have anonymously presented them to the *Federal Government Department of Health and Aged Care, Division of Mental Health and Suicide Prevention*.

Mental Health Equity and Access Forum

We were invited to submit a 'one page submission' outlining our top three priorities to the *Mental Health Equity and Access Forum* facilitated by Hon Mark Butler MP in January. The forum was convened to consider the report reviewing the *Better Access Scheme* which provides access to Psychiatrists, Psychologists under Medicare.

We know that the ten sessions funded by Medicare are insufficient for many people experiencing complex mental illness yet other options are not currently available to facilitate access. Our submission may be found on our website <https://bit.ly/47G3opW>.

Government relations

In 2022 – 2023, we focussed our limited volunteer resources on building a relationship with the new Federal Government in Canberra.

In the months following the May 2022 Federal Election the Foundation continued its national letter writing campaign seeking an update on implementation of the *Australian BPD Clinical Guidelines*.

In February 2023, in response to a constituent letter and after making representations on their behalf, Monique Ryan MP, Member for Kooyong, advised the constituent that the Assistant Minister for Mental Health and Suicide Prevention, Emma McBride MP had replied:

The Australian BPD Clinical Guidelines were approved and published in February 2013. Approval was granted for five years, after which time the evidence was deemed to be out of date and subsequently, the Guidelines rescinded.'

That I have requested a meeting with Professor Anne Kelso AO, Chief Executive Officer of the NHMRC, seeking an urgent update on the status of these and other related guidelines.

In April, the Foundation wrote to the *National Health and Medical Research Council* who were very helpful in advising that these were the last set of guidelines they oversaw the development of. They also shared that in 2013 they were given funding to assist the Department of Health to development a National Implementation Plan.

In June, the Foundation met with the *Australian Commission on Safety and Quality in Health Care* to understand their sense of their role in ensuring implementation of relevant clinical guidelines. As a result, we wrote requesting information on how our national quality and safety systems and processes, such as mental health clinical governance systems and processes, work to ensure mental health care provided is in line with evidence-based clinical guidelines. They replied:

*'Within the Clinical Governance Standard of the NSQHS Standards, Action 1.27 requires health service organisations to have processes that provide clinicians with ready access to best practice guidelines and supports clinicians to use the best available evidence. **Health services delivering care for people with personality disorders can demonstrate implementation of this action by making the clinical guideline 'Borderline personality disorder: recognition and management' available to clinicians and supporting them to use it.***

There are similar provisions in the recently released National Safety and Quality Mental Health Standards for Community Managed Organisations (NSQMHC MO Standards).

The Commission is aware of the changes introduced in the ICD-11 regarding personality disorders, including removal of the diagnosis of Borderline Personality Disorder. We will maintain a watching brief on alterations in the UK Clinical Guidance and Quality Statements, noting the correspondence you have received from the Minister for Health and Aged Care.'

On 30 June, in response to a letter from the Foundation, the Hon Mark Butler MP, Minister for Health, advised the Foundation that the '*NHMRC now directs clinicians to guidelines published in the UK which were updated in 2018*'.

Also in June, the Foundation met with the *Brisbane North Primary Health Network (PHN)* who advised they had asked for BPD to be put on the agenda of the next meeting PHNs were to have with the Commonwealth and will be asking what their plans are nationally for BPD.

Conclusion

In retrospect, 2022-23 has been a busy, and exciting 12 months of advocacy forging ahead to strengthen our sector networks and build a relationship with the new Federal Government, The Hon Emma McBride MP, Assistant Minister for Mental Health and Suicide Prevention and The Hon Mark Butler MP, Minister for Health, and the departmental public servants.

It has been eye-opening to discover that a national implementation plan for the 2013 clinical guidelines was a casualty of the then change of federal government. Since then, governance of clinical guidelines in



Australia has been outsourced from government and seemingly ad hoc. Indeed, the rescinding of the Australian BPD Guidelines in 2018 occurred at the same time that the UK reviewed their BPD guidance, and they found no new evidence warranting their revision.

Our conversations with senior clinicians and relevant professional bodies in the sector reveal dismay at the news from the Federal Health Minister that, in the absence of our own guidelines, the Australian Health system is now operating under the UK BPD guidelines.

It is evident that over the past 10 years there has been no consultation with the sector by the Federal Government on national clinical guidance for evidence-based treatment and support for people experiencing symptoms of borderline personality disorder. It is also evident, as revealed above, that clinical governance under Australia's clinical safety and quality system is in great need of attention. People living with BPD continue to be misdiagnosed, unnecessarily medicated, or ignored and further stigmatised.

We are encourage to have started a journey with the new Government, and look forward to reporting more next year. We would like all readers to know that it is the heartfelt lived experience quotes that people have shared through our *National Consensus Statement* that have been the engine room at the heart of our engagement and advocacy work this year. As custodians of these quotes, we feel propelled ever forward with fresh vigour. We remain determined to persevere to create systemic change on their behalf.

Felicity Farmer,
Engagement and Advocacy Lead
November 2023

eBulletin

Our monthly 'BPD eBulletin' provides up-to-date information about events, training opportunities, research and other relevant information. This is emailed to nearly 2000 subscribers.

I wish to acknowledge and say thanks to Karen Bailey, our editor, for the detailed and demanding work involved in seeking and collating relevant information. Researching for the eBulletin highlights that there are pockets of great work being done around Australia however, this tends to be very fragmented and predominantly available in certain areas of capital cities. Thank you to all our contributors who provide us with relevant information for inclusion.

Information Line

For anyone who has called our Information Line, you probably have spoken with Estelle Malseed, who usually answers our phone. Estelle is a founding board member, social worker and helpline coordinator. She responds to a wide variety of calls predominantly from people seeking treatment or support for themselves or someone else. Occasionally we receive calls raising issues of stigma and discrimination, and where possible, we seek to work with the caller to reach a resolution.

There is a huge need for this service, and we continue to advocate to Government for funding.

State Branch Reports

Due to the challenges of maintaining support for our state branches over the last couple of years the board made the difficult decision to 'put on hold' our formal branch activities until we receive some funding to enable us to actively support their activities.

Future Directions

Some of our board members have been directors since 2011. We acknowledge we are predominately white and middle-class and so are currently aiming to increase diversity in our membership. We are seeking people who may have a particular skillset e.g., communication, marketing, social media, consultancy, event management and governance who are willing to support us in an on- or off-board position. We meet monthly via Zoom, and all positions are voluntary. A lived/living experience of BPD, or one of supporting or working alongside them, is desirable. If you are interested, please send your expression of interest to rbrown@bpdfoundation.org.au.

Over the next twelve months we will continue advocating for BPD wherever and whenever possible. Felicity, in her report above, has outlined some of the work we have undertaken during 2022-23 and which we will expand upon moving forward.

This is a nuanced space with much complexity, and I suspect discussions will continue around how we label and refer to the experiences of people who now commonly receive a diagnosis of BPD. We still hear people cannot access appropriate and timely services and, as an organisation, remain determined to advocate that people currently living with the symptoms can access affordable and appropriate services in an environment of hope.

Whilst we have come a long way, we cannot be complacent. There is still much that needs to be done before we can be satisfied that everyone with BPD/complex trauma can access compassionate, appropriate care when needed.

As a wrap-up for this report, I'd like to revisit our BPD Awareness theme from 2018 'Know BPD – No Stigma'.

'We believe that education leads to understanding. With understanding, comes compassion, and compassion leads to empathy. We believe once people truly know the facts about BPD, and see the complex human beings, that it will decrease the stigma and end discrimination.'



[Image: Mahlie Jewell @Living Arts Therapy]