



Australian BPD Foundation Limited

*Support Promote Advocate
for Borderline Personality Disorder*



Annual Report 2021 - 2022



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

Mr Keith Warren - Treasurer

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

Ms Karen Bailey – Secretary

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

Mrs Estelle Malseed OAM

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

Mr. Salmaan Ali (retired 16 March 2022)

Member of Chartered Accountants Australia and New Zealand.
20+ years' experience in Finance and Accounting.

Mr Milo Goldacre (Appointed 10 July 2020)

LLB, BPPE
Mental health advocate and law graduate

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
3 years as a consumer worker



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VISION

The **vision** of the Foundation is that people with BPD are acknowledged as having a mental illness that requires access to appropriate treatment and support for themselves and their families/friends/carers.

MISSION

The **mission** of the Foundation is to promote a positive culture to support the recovery journey of people with BPD and their families/friends/carers. The Foundation also supports clinicians, health care personnel and researchers working in this field and acknowledges everyone who works towards a better recognition of BPD.

AIMS

The Foundation **aims** to support and promote services which:

- Provide high quality accessible, timely, responsive and appropriate services, treatment and care for people living with BPD and their families/friends/carers.
- Provide high quality and accessible education and support for families/friends/carers of people living with BPD
- Provide high quality appropriate education for clinicians and frontline workers providing treatment and care for people living with BPD and their families/friends/carers.
- Promote a positive culture for those living with BPD and to advocate for accessible and appropriate services provided by highly skilled professionals offering choice within an environment of hope and optimism
- Improve the well-being of people living with BPD and their families/friends/carers and clinicians and others in the community who assist them.
- Provide high quality scientific research about all aspects of BPD

VALUES

- **Respect** - for those the Foundation intersects with and all those in its' constituent base
- **Honestly** - & Integrity: we walk the talk openly and consistently
- **Tolerance** - for those who disagree with our positions and opinions and beliefs
- **Loyalty** - to the Foundation's causes
- **Humility** - in the manner we accept our failures and celebrate our successes
- **Acknowledge** - the value of those with lived experience and the value and the contribution of families/friends/carers and clinicians supporting them





Report from the President: Rita Brown

Dear Members

On behalf of the Board of the Australian BPD Foundation I am very pleased to present our Annual Report for 2021/22.

I begin by thanking our dedicated board members and volunteers for the huge effort, passion and dedication given over the past year. It's been challenging balancing our working lives in an overwhelmed mental health system with the ongoing work of the foundation. Also I want to thank YOU, our members, both individual and organisations, supporters and partners for your ongoing support. Our membership (at 30/6/22) is 1460.

I wish to acknowledge our retiring treasurer – Salmaan Ali for his contribution to the Board.

A/Prof Sathya Rao, an inaugural Board Member was awarded a Medal of the Order of Australia (OAM) in this year's Queen's Birthday Honours List in recognition of his lifetime's work in the field of psychiatry and dedication to personality disorders. Having been privileged to work alongside Sathya in his role as Vice President I am aware of his passion and how generously he gives of his time and energy to improve the wellbeing of everyone impacted by BPD. CONGRATULATIONS Sathya. This award is certainly well deserved.

Victorian Government Royal Commission into Mental Health

Following two years of consultation and analysis; 12,500 contributions from Victoria and beyond, with 3,000 submissions and personal accounts of a constrained system, the Commission released its report earlier this year. The full report may be accessed at <http://rcvmhs.archive.royalcommission.vic.gov.au/>

Through the Report, the Commission advocated for a major transformational change, and has put forward a plan to rebuild the Victorian mental health system from the ground up. The Final Report contains some 65 recommendations, in addition to the nine recommendations outlined in the Interim Report, and puts consumers, carers and their families at the focus of implementations. It is, by all accounts, an ambitious plan and one that will take some time for the Mental Health Program to fully dissect and understand given the enormity and breadth of such; however, we know it is a plan built on the principles of compassion and care, and one which aims to develop a system that responds by asking simply 'how can we help?'

Whilst the recommendations of the report are for the Victorian Mental Health System – we believe the other states are observing what Victoria is doing with the intent of adopting many of the recommendations themselves.



Some of the key highlights of the RC report include:

- Repealing of the current Mental Health Act to replace it with a Mental Health and Wellbeing Act
- Implementation of an independent Mental Health and Wellbeing Commission to hold the government to account for service provision
- Improvements in service provision in perinatal, child and youth services
- New community wellbeing services for adults and aged persons
- Enhanced integration between the Mental Health and AOD sector
- Introduction of two healing centres to meet the needs of Aboriginal and Torres Strait Islander peoples
- Development of a peer-led service to support the needs of diverse communities, including LGBTIQ+ communities
- A major overhaul of the current catchment-based service delivery model, and
- Significant improvements in crisis and Emergency Department responses.

One of the significant 63 recommendations outlined in their final report was the establishment of a Statewide Trauma Service 'to deliver the best possible mental health and wellbeing outcomes for people of all ages with lived experience of trauma.'

The Australian BPD Foundation was approached by Spectrum (Victoria's statewide service specialising in personality disorder and complex trauma) to be a key player in a new consortium and lodge a tender to establish and run the service.

Due to a considerable overlap of symptoms and that many people with BPD have experienced trauma, the Board accepted the offer to ensure that the voice of BPD lived experience (consumer and carer) was valued. This was a significant piece of work and we wish to acknowledge Spectrum's leadership and dedication to the task.

Unfortunately, Spectrum's consortium was unsuccessful, the tender being given to a consortium led by Phoenix Australia. We will continue to advocate for everyone impacted by BPD (with or without trauma experiences).

In addition to the Statewide Trauma Centre your board members have been involved in many of the community and organisational consultations ensuring that the needs of people with BPD remain on the agenda.

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

Our National Consensus statement 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.



This statement has now been endorsed by 23 organisations from within the mental health sector in Australia. It remains the central pillar of our advocacy platform and we have set up an opportunity for you to show your support by either scanning the QR code or visiting our website at <https://bpdfoundation.org.au/national-consensus-statement.php>

Nearly 500 people (people with lived experience, their family, friends [carers] and clinicians) have shown their support to the statement and shared their experiences of challenges and speaking to the importance of being able to access appropriate, affordable and compassionate services.

If you haven't yet had the opportunity to show your support, we encourage you to do so now, and help us to amplify our message.

BPD Awareness Week 2022 'BPD: See The Person'



People living with borderline personality disorder (BPD) often find that their diagnosis is the first and only thing other people see. The 2022 BPD Awareness Week campaign encouraged everyone to see the person alongside their BPD diagnosis, symptoms and survival actions. We're all complete and unique individuals, each with our own strengths and challenges.

The growing body of mental health knowledge recognises the diversity of life experiences: the role genetics can play, experiences of gender identity, sexual orientation, neurodiversity or trauma can all contribute to our well-being. It's a universal experience to be assigned various labels throughout our lifetime - and many people living with a BPD diagnosis experience stigma. We all share the fundamental need to be treated with respect and dignity, free from stigma and discrimination.

This year's message reminded us to look at the person alongside the labels, ask what their experiences are and how they continue to make sense of the world. For carers, family, friends, supporters and clinicians it's a reminder that underneath negative or harmful coping behaviours a person can often be struggling. Let's celebrate the person they are alongside their diagnosis, acknowledging their strengths, resilience and courage in order to SEE THE PERSON !

The 2022 BPD Awareness Week Ambassador was Tash Swingler, board member and lived experience advocate. She was invited to open Project Air's conference in Wollongong on the 4th November where she gave a powerful presentation reiterating the importance of 'seeing and listening to the person.' Tash's BPD Awareness week message is available on www.bpdawareness.com.au/

Image: Tash, Karen Bailey and Rita Brown at Wollongong with some of the resources developed.



Many events were held during the week, with some available online:

<https://bpdfoundation.org.au/bpd-awareness-week-2022---bpd-see-the-person.php>

- Tash and Rita recorded an interview for 'Vogliamoci Bene' (Love Oneself) a weekly mental health podcast hosted by Mario Corena in English on Radio Italiana 531AM (SA)
- Info session: Alternatives to suicide (Alt2Su) Groups. These are a peer-based group space approach to supporting people who have made suicidal attempts or who experience suicidal thoughts (online)
- See the Person: A webinar with Lived Experience speaker Evelyn Snook (WA)
- A closer look at dissociative experiences in borderline personality disorder (BPD) a webinar presented by psychologist Sarah Swannell (QLD)

- Dr Charlotte van Schie (a researcher from Project Air in NSW) and Mahlie Jewell presented a webinar on 'BPD and the Brain; Affect' presenting on how brain functioning may impact affect (emotion regulation) and demonstrating how this knowledge can inform strategies to move past challenges using psychoeducation and structured art-based process and practice.
- The South Australia branch held a very successful Quiz Night.
- The Western Australia branch held a picnic in the park.
- Similarly, ACT held a picnic in the park which needed to be rescheduled to later in the month due to the inclement weather. ACT also held an art show.
- Many other organisations hosted a variety of events, and we thank them for their support.

Numerous resources were developed by graphic artist and lived experience advocate Mahlie Jewell for the campaign. These were informative and educational to promote recovery, positivity and hope.

They were made available to organisations offering events during BPD Awareness Week as well as at Spectrum's conference in Melbourne and Project Air's conference in Wollongong. These resources are available for free download from the above website.

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

Roobix, who have generously hosted the website for many years are no longer able to offer this pro bono. We are currently transferring the website to a new provider which unfortunately means the website may be down for a period. We apologise for any inconvenience.

Last, and certainly not least, thank you to everyone who joined us online or in-person at events held in Adelaide, Canberra and Perth.

Advocacy

In addition to the campaigns mentioned above we continue to advocate for everyone impacted by BPD wherever possible. This includes:

- Developing a campaign for the 2022 Federal Election and encouraging our members to contact their local members and highlight the significant gaps in care and the stigma and discrimination experienced by people with BPD. In addition, we contacted Mark Butler and Emma McBride the newly elected members sending them a copy of our National Consensus Statement and requesting a meeting. To date we have had meetings with Andrew Wilke, Ed Cocks and Tim Reid
- Meetings and advocacy to state and federal health departments
- Felicity Farmer (Qld) has been a very active advocate in Queensland advocating for us to various organisations including Stride and QAMH
- Participating in the National Mental Health Commission's consultation on their National Stigma and Discrimination Reduction Strategy. The draft strategy is now open for public comment until February 2023. The foundation is considering it's response. If you wish to contribute visit <https://t.co/OhVu4FiB8f>
- A submission to the Suicide Prevention and Response Strategy (Vic)
- Presented to the Salaried Hospital Pharmacist's Mental Health Forum
- Natalie Malcolmson attended Mental Health Australia's Advocacy Day in Canberra on our behalf.



National BPD Training & Professional Development Strategy to upskill and engage clinicians working with people with BPD and their families.

The last stages for the project concluded in June 2022 with the final report provided to the National Mental Health Commission.

The overall feedback was extremely positive, and we hope that the flow on of resources and training will continue to be felt. **Stage 1** (webinars) and **Stage 2** (eLearning modules) can be accessed via our website <https://bpdfoundation.org.au/national-training-strategy.php> to view at a convenient time.

Stages 3 & 4 was a series of workshops and ongoing supervision based on the 'Core Competencies' of what we know works effectively to support people with BPD, seeking to make every interaction therapeutic. The people trained under the strategy continue to offer training to other clinicians in their areas/services.

We applied for ongoing funding from several sources, including a pre-budget submission. Unfortunately, we were unsuccessful though we will continue to pursue. We would also like to adapt the training to different sectors eg legal professionals, however, once again, funding has been an issue.

A huge thank you to Mental Health Professionals Network, Orygen, Project Air and Spectrum for partnering with us on the Strategy.

eBulletin and 'BPD Advocate'

We have close to 2000 subscribers who receive our monthly eBulletin packed full of up-to-date information about events, training opportunities, research and other relevant information. Our editor, Karen Bailey does a fantastic job each month researching new content to include in each edition.

We have been unable to publish our quarterly *BPD Advocate* for some time now. We hope to recommence early in 2023.

Thank you to everyone who provides us with relevant information for inclusion. We couldn't do this without you.

Information Line

Board member, retired social worker and helpline coordinator, Estelle Malseed, answers the Foundation phone. Almost daily she receives queries regarding treatment and support options highlighting how fractured the mental health system is. Estelle has a wealth of knowledge and attempts to provide some information to assist callers to find something that works for them.

We continue to approach government advocating to make this a service available for all.

Thank You

We owe a huge debt of gratitude to Statewide Services (Eastern Health) in providing us with office space and support. We are exceedingly grateful. We are also indebted to Price Gibson Chartered Accountants who generously audit our Annual Financial Report on a pro bono basis. Thank you to both organisations.

I wish to thank our membership, volunteers, and Board Members for your support to help us continue our essential work as we continue to advocate for everyone impacted by BPD. Your voices and contributions bring a wealth of knowledge and expertise to our advocacy.

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 all our incidental costs eg our insurances, website costs, phone etc. Your donations are vital for us to continue our advocacy work. All donations over \$2.00 are tax deductible.

Future Directions

At many of our Board meetings we grapple with the power and nuance of language and its powerful and sometimes traumatic impact on people's lives. How do we refer to the experiences of people who now commonly receive a diagnosis of BPD? Is it a trauma disorder?

Research shows that that 66% of people with BPD also have Post Traumatic Stress Disorder and 50% will also have Complex Post Traumatic Stress Disorder (CPTSD). Eight percent of people with a diagnosis of CPTSD will also have BPD. The reality is that people may have BPD or (C)PTSD or in fact have both and should receive treatment and support for both.

Due to changes in the ICD-11 diagnostic criteria the Board has been considering changing the name of the Foundation. However, many have contacted us experiencing distress at the suggestion. Whilst they may not like the term BPD the diagnosis has made sense to them, and they have worked hard to lead a meaningful life with the diagnosis. Changing the name is challenging their understanding of themselves and feels negating.

In light of the considerable overlap in potential diagnoses and the fear that some people with BPD may be incorrectly diagnosed with CPTSD as it is seen as a 'more acceptable' diagnosis the Board has, as an interim measure, considered changing our tagline from 'Promote Support Advocate for Borderline Personality Disorder' to wording such as '**Advocacy and Support for Borderline Personality Disorder and Trauma**'. We'd be interested in your feedback.

We acknowledge that this is an extremely complex and nuanced space, so we ask everyone to be respectful of other comments.

This will be reflected in our new website which will be hopefully launched in 2023.

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



Image: Mahlie Jewell @Living Arts Therapy

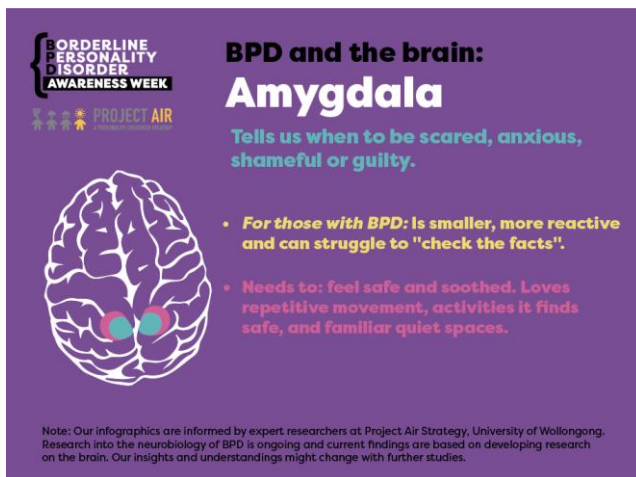
State Branch Reports

It's been a relatively quiet year for the branches.

New South Wales

The NSW branch, Mahlie Jewell (Living Arts Therapy) and Dr Charlotte van Schie hosted a webinar during BPD Awareness Week titled 'BPD and the Brain; Affect'. This webinar looked at some of the research currently being undertaken by Project Air in NSW looking at how brain functioning may impact affect (emotion regulation) and demonstrating how this knowledge can inform strategies to move past challenges using psychoeducation and structured art-based process and practice.

Below are some of the postcards Mahlie has developed as part of the research.



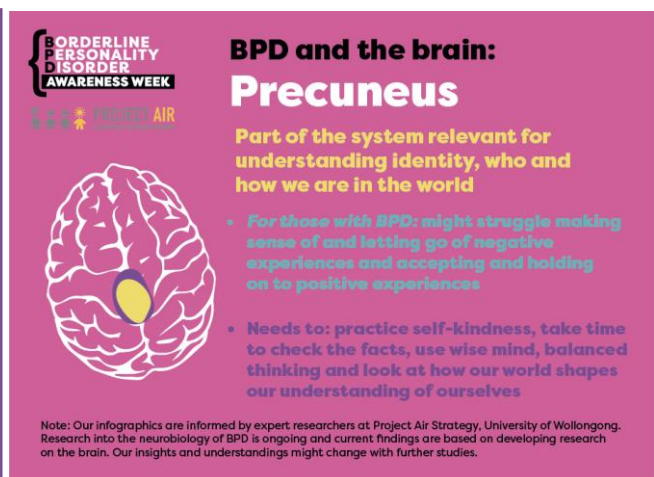
BORDERLINE PERSONALITY DISORDER AWARENESS WEEK
PROJECT AIR

BPD and the brain: Amygdala

Tells us when to be scared, anxious, shameful or guilty.

- For those with BPD: Is smaller, more reactive and can struggle to "check the facts".
- Needs to: feel safe and soothed. Loves repetitive movement, activities it finds safe, and familiar quiet spaces.

Note: Our infographics are informed by expert researchers at Project Air Strategy, University of Wollongong. Research into the neurobiology of BPD is ongoing and current findings are based on developing research on the brain. Our insights and understandings might change with further studies.



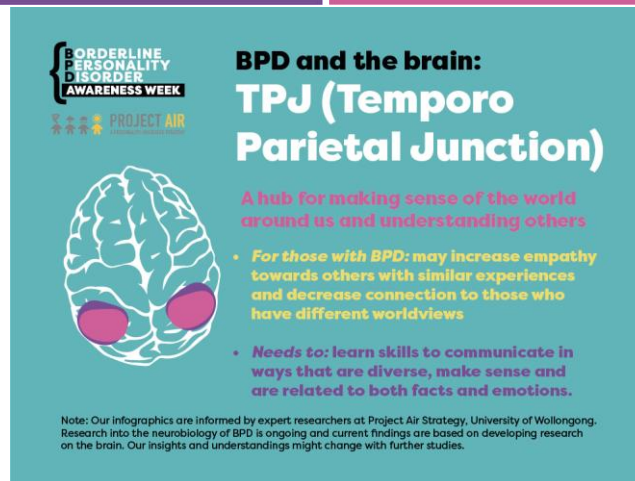
BORDERLINE PERSONALITY DISORDER AWARENESS WEEK
PROJECT AIR

BPD and the brain: Precuneus

Part of the system relevant for understanding identity, who and how we are in the world

- For those with BPD: might struggle making sense of and letting go of negative experiences and accepting and holding on to positive experiences
- Needs to: practice self-kindness, take time to check the facts, use wise mind, balanced thinking and look at how our world shapes our understanding of ourselves

Note: Our infographics are informed by expert researchers at Project Air Strategy, University of Wollongong. Research into the neurobiology of BPD is ongoing and current findings are based on developing research on the brain. Our insights and understandings might change with further studies.



BORDERLINE PERSONALITY DISORDER AWARENESS WEEK
PROJECT AIR

BPD and the brain: TPJ (Temporo Parietal Junction)

A hub for making sense of the world around us and understanding others

- For those with BPD: may increase empathy towards others with similar experiences and decrease connection to those who have different worldviews
- Needs to: learn skills to communicate in ways that are diverse, make sense and are related to both facts and emotions.

Note: Our infographics are informed by expert researchers at Project Air Strategy, University of Wollongong. Research into the neurobiology of BPD is ongoing and current findings are based on developing research on the brain. Our insights and understandings might change with further studies.

Queensland

The Queensland branch has finalised a Strategic Plan for the State and the *Resource Guide for Services in Queensland* is with the graphic designer for final edits.

Much of the information is already available on our website.

South Australia

The South Australian branch continues to collaborate with Sanctuary BPD Carer Support Group and other SA stakeholders to advocate for appropriate BPD services in our state. Although we have a reduced membership this year we have managed to raise awareness through the following activities:

- BPD Awareness Week - A very successful BPD Quiz Night was held on 8 October with Sanctuary BPD Carer Support Group and supported with funding from BPD Collaborative and Mental Health Coalition SA. Lived experience advocate Dayna shared what she found helpful for her recovery, and psychiatrist Dr Maria Naso discussed BPD brain biology and the value of educating families and trusted others. Over \$400 was raised to be shared by the Australian BPD Foundation and Family Connections Australia.
- Grill'd Local Matters Fundraiser - November 2022 promotion (not yet completed)
- Bandanna - Sales remain steady. Funds raised have exceeded initial expenses.

Interim chair,

Karen Bailey (Nov 22)

Victoria

The Victorian Branch of the Foundation continues to work with the Mental Health Professionals Network (MHPN) to provide nationally high quality training for mental health professionals. During BPD Awareness Week (in conjunction with the Qld branch) we ran a webinar '*A closer look at dissociative experiences in borderline personality disorder (BPD)*' presented by psychologist Sarah Swannell

Western Australia



The interim committee continues to meet approximately every eight weeks and is currently meeting via zoom. Current Membership 215.

Branch aims:

1. Raise Awareness, through BPD Awareness Week and other events
 - The committee plan to provide community information sessions, to assist consumers, carers and community member to feel better informed about borderline personality disorder.
 - BPD Awareness Week 1-7th October: Annual Picnic by the River, 15 attendees. Received a small grant for Western Australian Association for Mental Health (WAAMH) and registered the event for Mental Health Week. Attendees were able to purchase a coffee or ice-cream from the local coffee van.
 - Presented a Webinar See The Person. Evelyn Snook shared their BPD lived experience story, 32 people attended.
2. Reducing Stigma, opportunities for inspiring and hopeful recovery stories.
 - Underpinning theme for community awareness session
3. Mental Health Professionals Network, 4 per year.

- July 8th Overview 2021 Sensory Modulation for people with borderline personality disorder, pre-recorded webinar.
- 21st September 2021 Mentalizing Based Treatment and Lighthouse Parenting Treatment Program.
- Tuesday, 23rd November 2021 Nathan Gibson, Chief Psychiatrist Model of Care Personality Disorders.
- Wednesday 27th April 2022, 5-7pm. Topic: Andrew Channen: Personality disorder in young people: now is the time to act (pre-recorded)

The WA Branch are working collaboratively with the WA Mental Health Commission, Personality Disorder Subnetwork.

As part of the branch planning a survey was conducted. Members feedback that they would like peer support groups, social groups, counselling, social and informal gatherings and educational events.

Chairperson

Samantha Scott (Oct 2022)