VOL. 1 | WINTER 2021

IN THE LOOP



www.adhdfoundation.org.au

THE ADHD NATIONAL GAZETTE



ADHD IN CRISIS

ADHD is, at last, getting recognition as a serious lifelong condition. That is the good news; the bad news is that with greater recognition of ADHD, the dire shortage of medical practitioners working in this field is becoming more acute.

In Tasmania, South Australia and the ACT psychiatrists have closed their books to new patients. Many in Victoria, WA and NSW have unacceptably long waiting lists with books not expected to open before mid to end of 2022.

Our ADHD community, psychologists, medical centres and doctors are now referring to the ADHD Foundation for help for their patients. The ADHD Foundation National Helpline centre handles large volumes of enquiries from those searching for psychiatrists and paediatricians to provide diagnosis and treatment, others requiring to have their scripts renewed.

The ADHD Foundation has made the RANZCP ADHD Network aware of this crisis. We are asking our ADHD community to complete a quick survey available on our website at www.adhdfoundation.org.au. Your feedback regarding current delays in obtaining appointments with psychiatrists and paediatricians will greatly support our approach to the government and the Colleges. All comments are extremely valuable for our current project.

Our newsletter is your newsletter and we aim to include information from our hardworking volunteers who represent all states and territories.

- ADHD in Crisis
- From the Chair at her Desk
- ADHD List of Needs NDIS and National Guidelines
- How we do it?
- Team Profiles
- ADHD National Helpline
- ADHD National Youth Justice Taskforce
- Behind the Scenes Projects
- Speaker Series
- Around the Community

ADHD FOUNDATION
NATIONAL HELPLINE
1300 39 39 19

Welcome aboard your ADHD Foundation journey!!

FROM THE CHAIR AT HER DESK





PLANT IT AND WATCH IT GROW

Welcome to the ADHD Foundation's very first newsletter - our Winter edition.

There has been much involvement of health professionals working in ADHD over the last 6 months, highlighting the critical shortage in services and working together to find solutions.

As a member of "Australian Guidelines for the Diagnosis and Treatment of ADHD", I had hoped these would have been finalised this year. This document will be used as a guide to medical and allied health professionals treating ADHD, which will ultimately be used to improve services for children and adults with ADHD. Unfortunately, COVID has struck again, and they are now unlikely to be completed until mid 2022. I will keep you updated.

Our Helpline is currently being inundated with calls from individuals requesting a variety of help, as well as referrals from health professionals. As a member of the Australian ADHD Professionals Association, be assured that everyone in the ADHD community is experiencing the stress of the shortages in manpower. Many professionals are working to meet the needs as best as they can, but at the end of the day we need politicians to understand the critical situation and act with funding for extra resources and importantly, changes to unify state legislations around access to medication and dosages.

In the coming months, we will be commencing a campaign - advocating strongly for a "A Fair go for Adults and Children with ADHD" and inviting you to participate with us.

To deny diagnosis and treatment for such a treatable condition as ADHD is discriminatory, and the cause of much unnecessary suffering. The argument that should sway governments, is the high cost to society as revealed in both the Deloittes and Henry Reports. The only feasible way out of the critical shortage of trained professionals in the short term, is for GPs to become more involved.

Therefore we would like to send a strong message of support to a small group of specialist GPs and psychiatrists in Victoria, who have been developing a training course for GPs in the diagnosis and treatment of ADHD. This course has been developed in conjunction with the ADHD network of the RANZCP, and they are now working with the Royal Australian College of GPs to develop an interest group.

By our next newsletter, I hope my psychology colleagues will have similar news.

Help is on its way, but the gap in services will widen unless we get our politicians, both State and Federal, to acknowledge the needs of those with ADHD right across Australia.

BY EDWINA BIRCH CHAIR, ADHD FOUNDATION





Our List of Needs

Our List of Needs was determined by the community, with new issues constantly arising through the Helpline.

Of our 30 priority items we are proud to report that the ADHD Foundation can tick off many of these now, with some under negotiation and others progressing well.

Mental Health is one of our priorities, including getting information about ADHD onto the websites of the major mental health agencies.

We have a "YES" to Headspace and Orygen. "NO" to Sane, Beyond Blue and Black Dog at this stage.

Sadly, public health units and several MH agencies still consider ADHD to be a 'behaviour disorder', rather than a neurodevelopmental condition. Most still diagnose adults and teens with ADHD as having the 'presenting problem' of anxiety and depression.

We all need to persevere with these mental health agencies.

National Guidelines

We advised in the Chairs report in the previous page that the *Australian Guidelines for the Diagnosis and Treatment of ADHD* expected date for public comment has now been delayed due to COVID, with an anticipated time frame of mid-2022. The draft guidelines can be viewed **HERE**

Once the guidelines document is completed it will contain a number of recommendations, which are also on our List of Needs.

Although they are recommendations, there is no guarantee they will be implemented after the consultation process. In future newsletters we will keep you updated.





NDIS

Although the NDIS rules are constantly changing, the ADHD Foundation has provided extensive information and informative fact sheets on our website at www.adhdfoundation.org.au under 'ADHD & NDIS in the various states

The only way we can be sure of ease of access, and to be able to advocate for ADHD friendly supports, is if ADHD regains its true Disability status in the Disability Discrimination Act.

We are investigating the background as to why ADHD was withdrawn from the Act several years ago. Here is a llink to our submission to the National Disability Strategy

Final-Submission-for-NDIS.pdf (dss.gov.au)



PBS AND MEDICATION LONG ACTING MEDICATION FOR ADULTS - VYVANSE

A requirement by the government for adults to receive the Vyvanse medication on the PBS is to provide proof of 'a formal diagnosis as a child', or with evidence that 'the symptoms were there in childhood'. Whilst they have removed the age difference for Vyvanse on PBS, ADHD is a 'whole of life condition' and therefore there should be no need for a distinction at all. Please refer to the fact sheets on our website.

Our website at www.adhdfoundation.org.au has a lot of information about medication and legislation in every state of Australia. You will find the information by clicking here.

When you are there why don't you register so that we can keep you updated on new information about medication you can register here

People ask us, how do we do it?



Well, it start's with the right mixture and from there, perfection begins

The ADHD Foundation Dream Team that's how

Would you, even for one minute, think that the ADHD Foundation is **NOT** funded. We do **NOT** have paid staff but with a small group of committed and dedicated volunteers we get things done.

The ADHD Foundation Dream Team are a handful of hard-working culturally aligned and passionate about the mission and vision of the Foundation. As with any approved charity, our legal governance structure is aligned and governed by the ACNC. The threads that weave the ADHD Foundation fabric of our organisation are steeped in hard work, achieving goals and getting things done.

Our work within the ADHD community takes us across the whole of the lifespan focussing on high priorities and urgent needs as identified on the 'ADHD Foundation Gaps in Service' list. We have a particular focus on teens and tweens, young adults and seniors with a determination to keep our sights firmly focussed on our founding Vision and Mission.

Our Mission

To improve the wellbeing and help people with ADHD and related conditions to live full and rewarding lives.

Our Vision

Strive to be direct makers of change through collaboration and communication.

We are fulfilling our values and mission by:

- Using advocacy activities to ensure that ADHD is recognised as a neurodevelopmental condition by government and non government agencies.
- Creating pathways that help people with ADHD to reach their full potential.
- Supporting people with ADHD to have optimal health and wellbeing in order that they may reach their potential.
- Advocating for improved services for those with ADHD, their families, at both a state and national level.
- Providing our community with an ADHD National Help, Support and Information Line.
- Acting as national custodians of accurate data and statistics to keep abreast of the needs of our community.

Our purpose ensures that we work to improve the outcomes of individuals with ADHD through community education, collaboration, advocacy and policy reform. So that parents, children and adults with ADHD are not discriminated against, receive accurate information and evidence-based treatment.

Our purpose ensures we deliver advocacy, awareness and education that supports a reduction of stigma and lack of understanding.

Our purpose delivers support to parents, children and adults with ADHD by:

- Creating awareness to highlight the of the lack of treatment options currently available and the need to reform.
- Providing accurate data and statistics that will support and inform government agencies on issues of discriminatory legislation, lack of medical treatments, policies and crisis in caring for those with ADHD.

SHINING THE 'LIGHT' ON MEMBERS OF OUR TEAM

The ADHD Foundation team consists of 6 Board members 3 of whom are founders of the organization. Over each of the next editions we will highlight two or three of our team. You are welcome to watch our **video here**

Trustees and Founding Board Members Joy Toll OAM | Edwina Birch | Dympna Brbich:

Board Members: Dr Peter Heffernan | Jeremiah Hartmann | Emma Stanford.

Adult Ambassador: Jeremiah Hartmann

Youth Ambassador: Lucie Reuter

Our HelpDesk team of qualified counsellors

A message from the ADHD Foundation Board to our amazing community, THANK YOU for supporting our work

ADHD Foundation Board Member

Dr Peter Heffernan

The ADHD Foundation is delighted to introduce Dr Peter Heffernan as one of our board members. Peter is a Consultant Psychiatrist who works in the field of ADHD in Adults. He aims to promote the recognition of ADHD and excellence in assessment, diagnosis and management by all Health Practitioners throughout Australia. Peter's aim is for the ADHD Foundation to be the influential voice of ADHD to organisations, both Government and non Government. As well as a Board member with ADHD Foundation, Peter holds roles as Adjunct Research Fellow Swinburne University: Member United Kingdom Adult ADHD Network and Past Chairperson RANZCP ADHD Network



DR Peter Heffernan MBBS MPM FRANZCP



Lucie Reuter
ADHD Foundation
Youth Ambassador

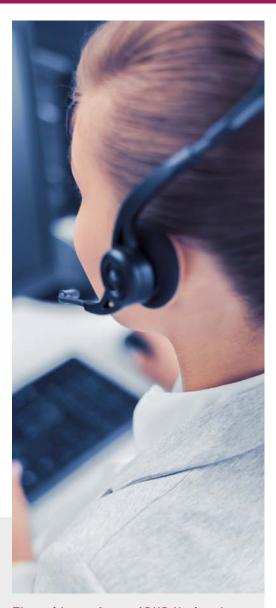
ADHD Foundation Youth Ambassador

Lucie Reuter

The ADHD Foundation are delighted to welcome our youngest member of the team, Please welcome Lucie our passionate and talented young youth ambassador. Lucie was diagnosed with ADHD at the age of 14 and wants to bring hope and positivity to all young people, particularly girls. Lucie will be involved in many areas of the ADHD Foundation operation including the brand new ADHD Foundation Youth Online support group and digital media. (Stay tuned for more exciting information about the fantastic projects we have in the pipeline).

If you haven't watched Lucie's introduction you can watch it here
Lucie has developed her very own podcast channel and has created some amazing content that you can listen to on our website at www.adhdfoundation.org.au or over at Lucie's Pod Click here to listen

Read a summary some of our work on the following pages



The evidence for an ADHD National Helpline was always there. However, with increased media coverage the stigma around ADHD **reduces**, and the national helpline enquiries **increases**. With the support of our valued diligent volunteers along with a small community grant and good financial management we have been able to provide this very valuable resource.

We were saddened to hear that our application for a small allocation from the \$1.8 million approved by the government for community projects could not be funded. Our understanding is that these funds are no longer available for distribution to community ADHD priority projects.

Therefore, we sincerely thank our loyal and generous donors.

ADHD NATIONAL HELPLINE HAS ARRIVED

ADHD Foundation National Helpline 1300 39 39 19

Referring to the list of needs on page 3 where the ADHD community outlined the need for ONE well resourced evidence based ADHD National Helpline, this has now become a reality for our ADHD community.

Over the first half of 2021 the ADHD Team have been busy researching, developing and implementing technology to provide the ADHD National Helpline.



Current levels of activity

We are delighted to announce that the ADHD National Helpline is fully functional and is now live, you can link to us via our website www.adhdfoundation.org.au

Without any promotion we are currently receiving anywhere between 20 and 35 calls per day, along with email and messenger enquiries.

We are a charity and we do not receive government financial support for the operation of the ADHD National Helpline.

We rely and thank most sincerely our donors who provide financial contributions to support our work.

We are so proud of the support and effort that our Helpdesk volunteers offer to the Foundation.

ADHD-trained counsellors support the ADHD Foundation by volunteering their time each week.

Thanks to our wonderful Helpdesk Team:

A note from Tania, one of our magical Helpdesk team. You will hear from others in following issues of our newsletter.

In 2021 I started volunteering for the ADHD Foundation. I have been in similar situations to many of the people who call the hotline seeking help or information regarding ADHD. I realised that I could use my knowledge and experience to help (I have bachelor's degree in Social Science (Psychology) and I'm a trained ADHD coach), and it's a great opportunity to give back by helping others who are on the same journey.

I quickly learned that the Foundation was swamped with calls for help with people desperately trying to find psychiatrists, paediatricians and psychologists who specialise in ADHD diagnosis and treatment. I jumped in and started returning calls and replying to emails. Some days when I'm not on the helpline I will make calls to ADHD professionals all over the country to help update the ADHD Foundation's database.

The foundation is completely staffed by volunteers who are also often working other jobs. I have been so impressed by the time they give to help others while also advocating for better access to services for people with ADHD.

Tania, ADHD Foundation HelpIdesk Team

If you would like to donate click here

ADHD FOUNDATION YOUTH JUSTICE PROJECT

"Youth Justice, ADHD and the Law" Stage 1

After a mammoth effort, determination and hard work by a couple of volunteers along with expert speakers and technical assistance the "ADHD Foundation Youth Justice, ADHD and the Law" Conference was a huge success.

If you are still keen to learn about the "ADHD Foundation Youth Justice, ADHD and the Law" Conference held at the end of 2020, please get in touch with us at **events@adhdfoundation.org.au**

We are able to provide continued training resources and/or materials from this very informative and successful conference.



Youth Justice ADHD and the Law Stage 2

We are delighted to announce that Stage 2 of our Youth Justice project is well underway. Under the leadership of Dr Mark David Chong who is heading up this stage of the project, our esteemed professionals are busy finalising their submissions which we hope will be publised in the Bond University Law Journal in 2021.

ADHD Foundation Youth Justice Taskforce



The ADHD Foundation Taskforce team is formed of passionate, proactive, purpose-driven individuals who committed their expertise and time to support this major project that aims to work towards changing systems within the youth justice system. Thank you most sincerely for being part of this massive undertaking.

Dr Mark David Chong FRSA.PhD (Law) (Syd), LLM (Merit) (Lond), LLB (Hons) (Lond). English Barrister-at-Law (Lincoln's Inn) Advocate & Solicitor of the Supreme Court of Singapore

Professor Ian Freckelton AO QC Barrister, Professorial Fellow in Law and Psychiatry, University of Melbourne; Supreme Court Judge, Nauru: Editor, Journal of Law and Medicine: Founding Editor, Psychiatry, Psychology and Law: Professorial Fellow in Law and Psychiatry, University of Melbourne; Adjunct Professor Forensic Medicine, Monash University;

Dr John Kasinathan. MBBS (Hons I; Syd), M.Psychiatry, FRANZCP, Cert. Forensic Psych., M.FMH (UNSW), Cert. Child Adol. Psych. Dr Joey Le. Child & Adolescent and Forensic Psychiatrist | Adolescent Health | Justice Health & Forensic Mental Health Network

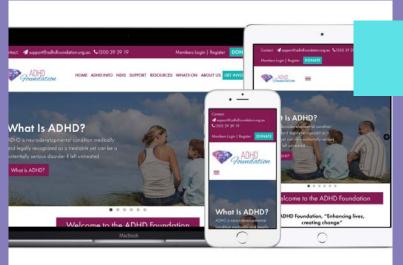
Associate Professor Scott Harden. Medical Director, Child and Adolescent Forensic PsychiatristForensic Child and Youth Mental Health Service (CYMHS)

Dr Geoff Kewley Consultant Paediatrician

Dr Corey J Lane DPsych (Clinical), BPsychSc(Hons), BA(CCJ), BBehSc, MAPS, Director and Clinical Psychologist

Stay tuned for exciting news about this project in the coming issues.

Working behind the scenes - Projects update



WEBSITE

Thanks to a small community grant and a dedicated team of volunteers, we have been able to update our website.

This is an ongoing and live project and we look forward to bringing much more to the site.

The ADHD Foundation site is destined to be the online resource centre for reliable resources, education and training as well as links into the ADHD National Helpline.

Referral Register

Great news!!!

A first for Australia and the ADHD Community

No ADHD national referral database exists in Australia for people with ADHD and so the team at ADHD Foundation have been working hard over the past months to design, develop and integrate ADHD specialists into one concise referral database. We are just about there. Naturally, there are a lot of changes and additions to be included. Continuous updating will be ongoing.



Database

YES!!

Another first for Australia and our ADHD Community

There was no needs-based Data Centre in Australia, up until now. The ADHD Foundation has embarked on a complementary project to ensure that our advocacy and policy input is determined by actual and accurate data and statistics.

ADHD Foundation Speaker Series 2021

The ADHD Foundation Event team worked hard to bring the Speaker Series events to our community and we thank everyone for making these events such a success. The events focused on issues that were highlighted by, and relevant to parents of teens with ADHD. We thank our speakers most sincerely for providing some valuable insights to our ADHD Foundation community and we thank our community for joining us and making the events enjoyable. Keep an eye out for future events coming to a screen of your choice soon.

If you would like to purchase a copy of any of the events please get in touch with us at events@adhdfoundation.org.au

Dr Geoff Kewley, Consultant Paediatrician



Dr Geoff Kewley led a Centre for ADHD and related Neurodevelopmental issues in children and adults in the UK for 24 years. He has now relocated back to Northern Sydney and is working on a part time basis at Chatswood & Dural managing and assessing children with neurodevelopmental difficulties especially ADHD and ASD

ADOLESCENTS WITH PROGRESSIVE AND COMPLEX ADHD AND RELATED DIFFICULTIES.

Dr Kewley spoke about his experiences in diagnosing and effectively managing teenagers and adolescents with significant ADHD and related conditions. He spoke about the reality of ADHD, the impacts on families, issues because of school exclusion and effects and relationship between exclusion and youth justice.

Phil has an international reputation in the subject of ADHD. He is a coach delivers lectures and seminars on ADHD internationally, has published papers in the UK and abroad. Phil has also written "The Tipping Points"

WHY ARE TEENAGERS AND YOUNG PEOPLE WITH ADHD AT GREATER RISK OF TAKING A PATHWAY TO CRIME, ANTI-SOCIAL BEHAVIOUR AND PERSONAL DANGER.

Phil highlighted down-to-earth explanation of ADHD, and he highlighted what 'good' treatment could look like and revealed how young people with ADHD are at greater risk of unnecessary suffering through poorly managed ADHD, leading to pathways into crime, anti-social behaviour, and personal danger and what practical approaches you can do to minimize those risks.

Phil Anderton, ADHD Expert



Dr Caroline Stevenson, Clinical Psychologist



Dr Caroline Stevenson has a PhD in clinical psychology and specialises in ADHD across the lifespan. She has written many papers and chapters on the topic of ADHD. Her work has been cited in national and international guidelines on the management and assessment of ADHD **VULNERABILITIES TO ADDICTIONS INCLUDING VAPING, GAMING PHONES AND MORE**. Dr Stevenson spoke about how to talk to teenagers about the issues around addictions, how vaping had risen in the community and how parents and carers have increased worries about their children being pressured into drugs and other illegal substances. She also shared what

information parents and carers can provide to their children and how

this information is helpful.

Parents for ADHD Advocacy Australia



"Shining the ADHD Foundation spotlight" on our wonderful advocacy groups with whom we work collaboratively

The ADHD Foundation would like to raise awareness on the hard work being done across Australia by our passionate advocates because we believe "everyone deserves a chance to shine". Work is done with passion, dedication and commitment to our ADHD community. Advocacy activites do not provide any financial benefit or income to anyone. The PAAA formed in January 2018 after a small group of passionate parents identified shared struggles across all aspects of caring for their children's needs, one concern being hardships experienced by children with ADHD and their carers within the education setting. The PAAA is a national volunteer-run community group of 3000 plus members dedicated to improving the lives of young people with ADHD, their families, through ADHD awareness, education and advocacy.



ADHD in schools

The PAAA partnered with OLT Australia to develop a face to face and online teacher course on ADHD in Schools.

This course was released in late 2020 and is now available to schools in multiple jurisdictions across Australia.

For details see Parents for ADHD Advocacy Australia - Official Website



Policy makers engagement

In 2021, PAAA has met with policy makers within the NSW Department of Education on a monthly basis in advance of the release of the new Behavior policy and support materials for teachers, parents and school leaders in Term 3. PAAA has provided extensive feedback on the need for the new policies to safeguard students with ADHD from discriminatory exclusions and suspensions.



Free Online Course ADHD for Parents

In collaboration with OLT Australia the PAAA have also produced a free online ADHD for Parents course. This course which includes real life experiences from parents, children with ADHD, educators and doctors.

Free - Online short eLearning course For details see Parents for ADHD Advocacy Australia - Official Website

The resource materials available on the NSW DoE website Behaviour support toolkit now clearly reflect the need to provide support to students with disabilities when considering their behaviours at school. We are committed to expanding our advocacy on behaviour policies in other states in the future.

FOR FURTHER INFORMATION PLEASE CONTACT WWW.PARENTSFORADHDADVOCACY.COM.AU INFO@PARENTSFORADHDADVOCACY.COM.AU FACEBOOK (PUBLIC AND CLOSED GROUPS TWITTER: @ADHDADVOCACYAUS

ADHD FOUNDATON IS A NOT FOR PROFIT ORGANISATION REGISTERED AND APPROVED AS A CHARITY WITH THE ACNC AND DGR STATUS WITH
THE ATO. ANY DONATIONS OVER \$2.00 ARE TAX DEDUCTIBLE.

Join our community

Register to stay informed

Provide Financial Support

Volunteer





"everyone deserves a chance to shine"

ADHD MONTH OCTOBER 2021 Stop Press - Stay tuned

The ADHD Foundation has some very exciting news about our activities during
October ADHD Month

In collaboration with ADHD Foundation UK and ADHD Ireland the ADHD Foundation will feature at this international event.

So keep an eye as we will be bringing out more details closer to the date of 7th October 2021

Our events team are also busy preparing a special event which will be delivered between 28th and 30th October 2021



Register and stay informed