

RUN DIPG

2022/2023 ANNUAL REPORT

RUN DIPG LIMITED
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**RUN
DIPG**

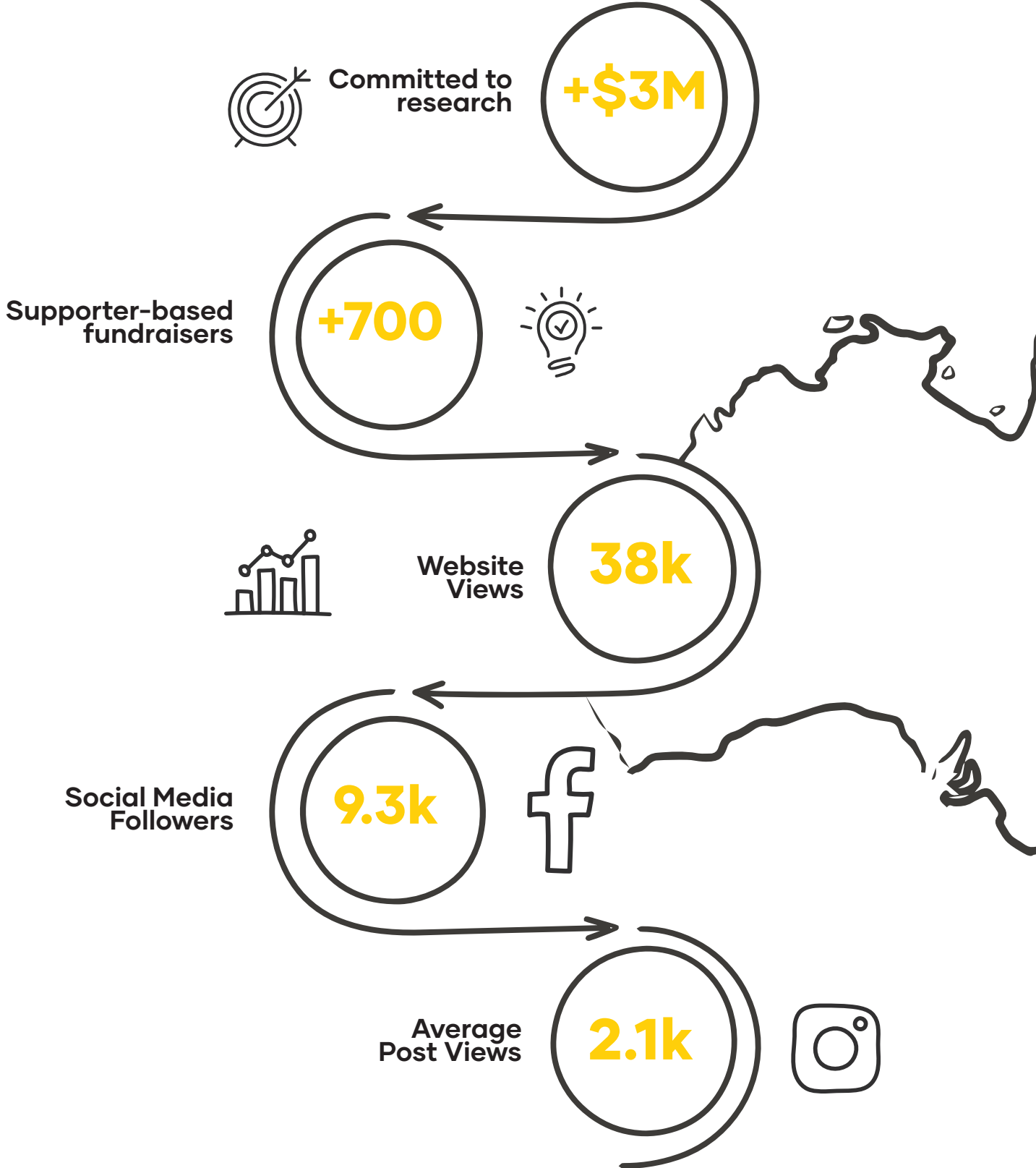
Moving towards a cure.

**Welcome to the RUN DIPG
Annual Report for 2022-2023.**



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Our Impact



About Us

We're fighting to eradicate the most lethal childhood cancer.

Two-year-old Josephine Laura Dun was diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG) in 2018. She passed away 22 months post-diagnosis, forever four years old.

Her parents – Drs Phoebe Hindley and Matt Dun – found themselves in the tragic but unique position to make a real difference for all patients and families impacted by DIPG.



Our Mission

We are a charity dedicated to improving outcomes for patients and their families impacted by the deadliest form of childhood cancer – brainstem cancer, diffuse intrinsic pontine glioma (DIPG) also known as diffuse midline glioma (DMG). It is our mission to raise awareness of this disease, and to generate funding to support the advancement of DIPG/DMG research.

With no treatment options currently available, except palliative radiotherapy, we advocate for the timely and innovative development of anti-DIPG/DMG therapies, and improvement to current standard-of-care management.

RUN DIPG will be recognised as a go-to source of DIPG/DMG information for patients, families and communities alike. We believe in generating vital funding to support the most innovative research across the globe.

We will contribute to the cost of improving the treatment of DIPG/DMG via the funding of scientific and clinical research as well as equipment to increase the clinical relevance of research. RUN DIPG's advocacy, collaboration and financial support will make a documented contribution towards improved outcomes for DIPG/DMG patients.

Our Hope

We dream of a world without DIPG/DMG. We know we have a challenge ahead of us and we know that it won't be easy. However, we know that by collaborating across foundations, researchers, clinicians, institutions and borders we have the best chance of success. It is our hope that RUN DIPG is instrumental in making the 'go home and make memories' paradigm, a memory itself.

Our History

Josephine Laura Dun was diagnosed with diffuse intrinsic pontine glioma in February 2018, then just two years of age. The daughter of local GP Dr Phoebe Hindley (Dun) and of Biomedical Scientist Professor Matt Dun – as well as an adored big sister to George (and soon Harriet and Henri), the family found themselves in a tragic but unique position to make a difference for all patients and families impacted by DIPG.

Together with Josie's treating oncologists, Matt and Phoebe set out to understand everything they could about DIPG. It soon became clear to Matt as a cancer researcher, that very little was known about DIPG. A type of 'diffuse midline glioma' or DMG, the mechanisms controlling the tumour growth and its ability to avoid normal cell death processes are poorly understood. To address this, Matt's own cancer research group (previously leukaemia-focused) at The University of Newcastle and Hunter Medical Research Institute set about creating their own DIPG/DMG research program.

Worldwide, the scientific community shared their DIPG/DMG-specific research protocols – even the field-leading laboratory at Stanford University assisted in training Professor Dun's staff in the techniques required to model DIPG/DMG in the laboratory, a process known as 'cell culture'.

Finding himself somewhat numbed by Josephine's fatal diagnosis, Matt found focus through running – it was here that he would attempt to piece together the next steps in the DIPG/DMG research puzzle and plan the next steps in Josie's fight against DIPG. Realising that such rare cancer would never secure the attention (and, by proxy, the funding) required to make headway in DIPG/DMG research, he and

Phoebe called on the community around them.

Internationally, family, friends, colleagues, and even other families affected by DIPG began bringing DIPG/DMG to the world's attention through running, rugby, hiking, cycling, paddling, dancing, and swimming in the name of DIPG awareness. With community-based sports events so readily accessible and providing such a far-reaching platform for advocacy for DIPG/DMG research and awareness, Matt, Phoebe, George, Harriet and Josie, together with their closest and most passionate supporters, formalised their efforts to create the charity 'RUN DIPG'. RUN DIPG could be seen as an intense running club, but it is an expanding community passionate about researching childhood brain cancers.

RUN DIPG Ltd was created as a public company and registered with the Australian Charities and Not-for-profits Commission on 5 March 2019. We obtained tax-deductibility registration from the Australian Tax Office in May 2019.

Josephine passed away in December 2019, 22.2-months post-diagnosis, forever four years old. Unfortunately, most patients do not survive nearly as long; median survival is just 9-11 months post-diagnosis. In light of this, RUN DIPG is committed to raising awareness, advocating for improved clinical outcomes and financially supporting DIPG/DMG research to reduce the suffering of DIPG patients, their families and the communities supporting those affected by this, the most devastating childhood cancer.

Our Board



Current Board members and Directors of RUN DIPG.

Dr Phoebe Dun (Chairperson)

I'm Phoebe Dun, RUN DIPG founder and Chairperson, Newcastle-based GP, but perhaps better known as Josie's mum. The very reason for RUN DIPG's existence. When Josie was born in 2015, Matt and my life was perfect. Less than three years later, it was torn apart when we were told she had DIPG and just 6-9 months live.

These days I spend my time caring for our three living children and working as a general practitioner. Through my role in RUN DIPG I enjoy sharing our story, paying tribute to the amazing daughter I had and being the voice for children, who like Josie, did not live long enough to have their own. Providing a listening ear to other parents who also have children or loved ones diagnosed with DIPG and advocating for better outcomes. I enjoy running on the side, and am happiest on summer holidays! I really believe that children who are diagnosed with DIPG deserve hope. And to provide hope, we need to continue the research that will lead to the development of clinical trials that may, one day, give DIPG sufferers a real hope for long term survival.

Professor Matthew Dun (Director)

Founder and Director of RUN DIPG, Dad to Josephine (plus George, Harriet and Henri), and husband to Phoebe, I am proud to do what we do for kids and families facing DMG. Knowing first-hand the hopelessness of a DIPG/DMG diagnosis, finding that no treatments and thus, no cure was available for our sweet girl in 2018, as a cancer research scientist and as a person surrounded by family and friends that were/are so keen to change this, we won't stop until 'go home and make memories' is no longer the standard line given to families. As a Professor of Paediatric Haematology/Oncology Research, my team and I study this hideous tumour at the

University of Newcastle. The research we started in 2018 has since translated into an international clinical trial ('PNOC022') – providing trial treatment options to families across the world since August 2021.

Out of the lab you'll find me running the Fernleigh Track, coaching Uni rugby or maybe in the surf, when time permits. Wherever you spot me (not hard, tall... redhead...) you know I'll be in a RUN DIPG shirt or hat, spreading the word about the brilliant work we do to give hope to DIPG families!

Joseph Kennedy (Director and Company Secretary)

As Matt's brother and Josie's uncle, Joe was shocked to find out about DIPG and its grim prognosis, and he has seen how it wreaks havoc and completely devastates families. Improving this reality is what motivated Joe to help establish RUN DIPG, and as our Company Secretary he primarily coordinates our governance, accounts and compliance areas. He is extremely proud of the rapid development of our charity in such a short space of time, which is a testament to the hard work and perseverance of our Directors, families, volunteers, supporters and wider community.

Joe is inspired by the amazing research outcomes RUN DIPG has already been involved with and the future programs we are supporting. Joe's involvement in RUN DIPG has also seen him to take up running for the first time (albeit slowly!) and he ran his first 10km race in August 2019. Outside of the charity, Joe is a Principal Solicitor and Director of progressive labour law firm Hall Payne Lawyers.

Luke Eagle (Director and Public Officer)

Luke is a founding Board member and was actively involved in the setup and registration of RUN DIPG. Luke is the loving uncle to Josie and witnessed first-hand the devastation DIPG has on his family, friends and network.

Outside of RUN DIPG, Luke is the founder and visionary behind Eagle Eye Insurance Solutions (EEIS) which created the merger of three firms Wagecover, Eighteen33 and EEIS to create Aviso All Points in 2019 then Aviso Broking in 2022. Luke was instrumental in establishing RUN DIPG and obtaining its certification as an Australian Registered Charitable Organisation. Luke is a founding Board member and is actively involved in the developing and executing marketing and fundraising strategies.

Wagecover continues to provide ongoing fundraising support to RUN DIPG, primarily through its annual footy tipping competition which works with notable sports people to raise funds and awareness for RUN DIPG through a fun and engaging platform, while Eighteen33 provides health, safety and compliance advice for RUN DIPG Events.

Ryan Vesper (Director)

I am dedicated to RUN DIPG because I am a father of two, an uncle of six, and have many more friends who have children.

To hear about parents being told that their child has an incurable form of cancer and the best they can do is to go home, make them comfortable and make memories is heartbreaking and wrong.

My want is to help improve the outcomes of these children and their families. My why is the children.

Matt Clarke (Director)

I am super excited to join the Board because RUN DIPG is a small but important cancer charity destined for big things. Matt and Phoebe Dun are leading the way in aggressively stepping up treatment for patients and support for their families. I am here because we all need to do more for children like Josie.

Professionally, I am passionate about building strong communities that make a real difference. Most recently, I led the spectacular growth of fellow cancer charity – Tour de Cure – as its Managing Director. Prior to that I was instrumental in the huge turnaround of morning TV show – Sunrise.

From my work on the 2000 Olympics and Torch Relay, I know Australians are generous and want to make a difference. Organisations like RUN DIPG are vital in giving us all confidence that our time and money couldn't be better spent.

Our Team



Support staff and team members at RUN DIPG.

Alicia Douglas (Administration and Communications)

Learning of Josephine's diagnosis in 2018, of course I was compelled to do whatever I could to help the Dun family, and subsequently, the RUN DIPG mission. A pharmacist by trade and having studied biotechnology alongside Matt in our undergraduate years, I help RUN DIPG communicate medical and scientific information across our print, social and online media.

Assisting the Board of Directors, the General Manager, DIPG/DMG Families and the charity's supporters with administrative tasks, and event/fundraiser setup, I am proud to be part of the dedicated RUN DIPG team, and can't wait to see what fantastic outcomes we can bring about in the coming years.

Carly Pettit (Finance)

Having worked for Josie's grandparents in Mudgee and being friends of the family for over 20 years, Carly has seen the impact Josie's diagnosis had on the family and wider community. This combined with the personal experience of her own daughter being a survivor of childhood cancer (Retinoblastoma) made her want to help to improve the survival rate and

treatment options for children diagnosed with DIPG/DMG. Carly has been responsible for the setup and implementation of the accounting processes for RUN DIPG since 2019 and is proud to be part of this team.

Troy Bailey (General Manager - June to November)

Troy completed a Bachelor of Business at University of Newcastle in 2006 and has more than 12 years of experience in event, account and business management within the Hospitality and FMCG Industry. Board member of University of Newcastle Rugby Club since 2020 and currently Vice-President, Troy's philosophy hinges on teamwork and collaboration to gain optimal results together.

Troy is a close friend to Matt and Phoebe after playing rugby (not at the same level) with Matt. Troy hosted one of the first fundraisers for Josie post diagnosis to support his friends in the most terrible of times. Rich in spirit, he has the skills to organise and execute events: "This was my way to help my friends. This couldn't have been done without the support of my beautiful wife, Kate."

Since RUN DIPG was founded, Troy has been



involved as a volunteer, hosting golf days, lunches and rode behind Matt in his first marathon for RUN DIPG. Troy joined as RUN DIPG's first employee in April 2021.

Jo Bennett - General Manager (Current)

Jo arrived in Newcastle in the late 1980s to study at the University of Newcastle, where she completed a Bachelor of Arts and a Diploma of Education. During this time, she worked at the Delany Hotel and later became the manager. Her love of people and community cemented her passion for hospitality, where Jo continued to work – including working for the Dun family for more than a decade. This family connection cemented Jo's desire to work with RUN DIPG, with an ideology of kindness, compassion and excellence in management, making her an ideal choice for General Manager. Her values of hard work, passion and commitment are evident in her work and exemplify those of the organisation as she supports and works towards the same goal of improving the outcomes for these children and families. Outside of work, Jo is married with three sons and is Junior President of her boys' Rugby Club.

Rachelle McLennan (RUN DIPG Events Manager)

Rachelle approached RUN DIPG to volunteer and we are ecstatic she did. Her wealth of fundraising knowledge combined with her design background have made her the perfect addition to our event committee.

She has a solution focused approach with a creative mind, and has more than proven her worth in the last 12 months, putting her experience and creativity to work at a number of highly successful events.

Rebecca Ford (RUN DIPG Grants Officer)

Rebecca was excited to be given the opportunity to contribute to raising funds and awareness for finding a cure for DIPG. She is thrilled to apply 17 years of knowledge from her previous role at the University of Newcastle and couldn't wait to make a difference.

This charity is incredibly close to her heart. Having watched a family friend's daughter fight this disease had given her the passion and drive to try and prevent other families from going through the same ordeal. Outside of work, she loves spending time with family and friends, enjoying camping trips and trips to the beach.



Behind RUN DIPG



Our Volunteers

RUN DIPG's success is due to our amazing volunteers. The time, skills and commitment provided by our volunteers improve our ability to communicate with the wider public. Proudly, our volunteer network has continued to grow since our establishment in 2019.

Jo Crosby

Jo is the primary reason for our successful 2022 Moonlight Gala. She has been the creative backbone behind our flagship evening of glitz and glamour. Her heart is pure, and she supports numerous charities throughout the year. We are blessed to have her representing RUN DIPG.

Jaimie Rayment

Jaimie was searching for an opportunity to give back to our community and she chose RUN DIPG. Her events background has allowed her to seamlessly move into a key role in planning, creating, and executing RUN DIPG events. Her bubbly personality is infectious for all our participants to experience.

Michelle Coughlan

The founder and photographer from Little Kite Photography, Michelle captures the special moments for the RUN DIPG community to share. She is first on site and last to leave, ensuring no moment is missed. Michelle, your professional and friendly support is valued everyday. Furthermore, her ambassadorship by supporting local families impacted by DMG/DIPG plus yearly online auction captures precious DIPG family memories and raises critical awareness.

Michael Yazbeck

Anyone buying RUN DIPG merchandise in Newcastle might have met Mick. He kindly gives up his time to help pick, pack and deliver our stock around plus set up our events so we can keep helping families. Thank you

Kennedy Family

Matt's wonderful family is always exploring, volunteering, and recruiting the next opportunity for RUN DIPG to tell our story. Spread across the country they are always front and center wearing RUN DIPG yellow.

Hindley Family

Primarily located around our home of Newcastle and Lake Macquarie the Hindley Family will forever be promoting Josie's legacy. In schools, at work or selling merchandise, we owe our presence locally to the entire family.

Brad Ryan from Shot by Brad

Brad reached out to RUN DIPG as part of his commitment to giving back to the community, and generously donated hours of his time to script, create, shoot and edit a series of incredibly moving videos which have proved to be an invaluable asset as part of our fundraising initiatives.

Alexandra McCormack

Alexandra ("Ali") has been a long-time supporter of the charity. Ali is a close friend of the Dun's and is our Ambassador, Nic White's sister. Ali has been instrumental in the organisation of the Moonlight Gala, our RUN DIPG Hunter Rugby Round, and our RUN 4 RUN DIPG.

Vlad Shatrov

Vlad's owns the local business RUN LAB. In November 2021 Vlad ran the Great North Walk from Sydney to Newcastle to raise funds and awareness for RUN DIPG. Since 2021 Vlad has been a huge help to RUN DIPG with organising course maps and training schedules for our annual RUN 4 RUN DIPG. His support is extremely appreciated to help make our run event a success.

Jonathon Wilson – Slattery Auction

Jonathon (Jono) is a well-known Auctioneer in the charity circuit and volunteered his time to be our Auctioneer at this year's Moonlight Gala. Jono had the help of our MC for the night Owen Finnegan to raise an incredible \$108,000

Our Partners

We have developed lasting corporate partnerships to support our growth. Wonderful businesses with aligned values provide us a range of services, reducing our costs and improving our offering.

Strategic Group – IT Support

Our relationship with Strategic Group was formalised with a dedicated account manager offering free-of-charge IT services. This includes a 24-hour helpdesk to manage our IT support, which has been invaluable and allowed our daily operations to be improved and streamlined.

Ink and Scratch - Signage

Trent has put our brand into prominence for everyone to see over the past three years. He continually supports us with speed and solutions, letting the public know we are here supporting families and funding research. The hero signage event of 2022 was branding our Toyota Hilux to feature at events along the east coast.

HM Focus - Marketing

Our partnership with HM Focus has built a plan and guide for our brand. They create, deliver and polish everything you see with the RUN DIPG logo. Our events start and finish with HM Focus providing high-quality themes and deliverables in line with our vision.

PKF - Auditor/ Financial Advice

Strong governance is essential to the growth of any not-for-profit. Jackie and Martin are always willing to take a call and find the best approach to keep our credibility to the highest of standards. Their knowledge is critical to RUN DIPG, focusing clearly on our goals to fund research and support families.

Aviso Broking - Insurance and Risk Assessment

As we move towards a recognised charity, we need to keep protected. Our growth as an event-focused organisation to advocate for families impacted by DMG/DIPG comes with risk. We are grateful for the assistance of Julie and Adam, who work together to keep our events safe and successful.

EnPerSo – Travel

EnPerSo has provided their platform and team without cost to allow us to travel easily. Their environmentally conscious service provides competitive pricing with ease.

Royal Crown Hotel Dudley

Thanks to the generosity of the team at the Royal Crown, RUN DIPG had the ability to have an office space for 2 years. Not only did they support the Charity by donating office space they also host our Run Registrations and other events relating to RUN DIPG raising and saving a considerable amount of money

Controlled Engineering Solutions

2022 saw us move office locations from The Royal Crown Hotel, Dudley to a huge office space at CES. This space has kindly been donated by Sue Eagle and Craig Tickner. This space allow staff to have a working space and also volunteers. All office facilities are able to be utilised by the charity and the substantial saving to the charity is huge.



Our Families

Our followers know – families are why we do what we do. With no treatments available, RUN DIPG are committed to supporting research that changes outcomes for DIPG patients and their families.

We have, with the permission and support from our incredible families, shared the stories of DIPG patients and their families, their networks and the incredible events and initiatives they have created.





Our Schools

As DIPG/DMG is primarily diagnosed in children and young adults, we are conscious of the shock, sadness and fear that may ripple through schools and friendship circles. We would like to thank the schools below who have been so willing to fundraise, become a DIPG education hub, or create awareness on our behalf while honouring or advocating for their fellow students impacted by DIPG/DMG.

- **St Josephs Charlestown:** hosted a RUN DIPG awareness day in memory of Tori Binnie.
- **Newcastle Grammar:** Our founder and director, Phoebe spoke at an event for Years 7 to 9 in Horbury Hunt Hall and then to Years 10 - 12 at the Cathedral. The event held on Tyrrell House Day where funds raised came to RUN DIPG.
- **Everton Park State School** hosted both a Drag Bingo & Rainbow for Ruby Day, in memory of Ruby Pringle. Across the two events, the school has raised more than \$70,000, which will go directly towards research and awareness.
- **Merewether High School:** students participated in a colour run through a fun obstacle course and plenty of colour powder. The aim was to have a fun afternoon to promote research into diffuse intrinsic pontine glioma (DIPG), and an opportunity for children to help other children!
- **Mannering Park Public School**



Governance

Structure and Management

The financial year 2023 has been our second term with a dedicated General Manager, Troy Bailey. His dedication to implementing the Board's vision has set RUN DIPG on a growth trajectory.

In December, we immersed our management team in a strategy session facilitated by Matt Clarke. A pleasant surprise was the request from Matt to join our Board as an industry specialist. Matt Clarke has since helped RUN DIPG formalise our direction and goals; we are excited to see the outcomes as we execute the plans devised!

Our people are vital to the success of RUN DIPG - our large community of volunteers allows us to keep operating costs low and research investment high. We continue to build our 'people plan' to understand how we can best serve our DIPG/DMG networks in the future.

RUN DIPG is registered as a not-for-profit public company limited by guarantee, which is established to be, and to continue as, a charity. Our organisation is endorsed as a deductible gift recipient (DGR) and hold fundraising authority in every state and territory of Australia. We are also registered with the Australian Charities and Not-for-profits Commission (ACNC).



Chairperson's Report

What a year we have had at RUN DIPG! With the changing of the guards, we welcomed to our family Jo-Anne Bennett, the incoming General Manager and hasn't she hit the ground running! Farewelling Troy Bailey from this position, Jo has brought with her enthusiasm extraordinaire, laughs and plenty of new ideas and events. We will forever remember Troy for his role in growing RUN DIPG and wish him every success on his new endeavours.

The 2022/23 financial year started and ended at top speed. We witnessed some incredible individual and team challenges from our fundraising partners including the inaugural RUN DIPG Brisbane to Newcastle ride, Ride for Ahlia and the first ever Ride for Ahlia Gala Event to wrap up a wonderful fundraising crusade by our Western Australian family.

We were astonished to see the annual Run 4 RUN DIPG running festival here in Newcastle, reach new heights this September with our greatest participation numbers yet and fundraising to match. This was despite the huge numbers of supporters we had joining us and our Queensland families in the 2022 Gold Coast Running Festival only weeks before hand. The inspiring effort of Anna McDonald in The Marathon Des Sables can not pass unmentioned, running over 250km over the Sahara Desert in the world's toughest footrace raising awareness

and funds for in memory of little Alex Jenkins. The RUN DIPG Board are so appreciative of the continued advocacy and fundraising our families and supporters do, moving us towards a cure for DIPG.

Behind the scenes, RUN DIPG has continued to strive for improved outcomes for children and their families effected by DIPG.

We continue to support innovative, peer reviewed research via our membership of the DIPG/DMG Collaborative – an international collaboration of foundations with the shared mission of efficiently funding and inspiring DIPG research worldwide, such is the importance we place on collaboration. But our work more locally supporting Dun Lab and the work of Professor Matt Dun and his team has been most encouraging.

RUN DIPG is proud to have funded so much of the preclinical work that saw PNOC022 – “A combination trial using an adaptive platform design for patients with diffuse midline gliomas at initial diagnosis, post – radiation therapy and at time of progression” open around the world in 2021 and in Australia in 2022.

We believe the combination therapy approach is fundamental to this trial and might become an essential component of future successes of the DMG/DIPG treatment landscape



that leads to long-term survival.

Personally, I am warmed by the fact that two of the therapies included in this trial are the same two therapies Matt identified as potential treatments for our Josie. In fact, Josie was the first child to receive this combination of therapies worldwide on compassionate access thanks to many hours of hard work by Josie's dad and his wonderful team, unfortunately only in the advance disease setting for our Jojo.

We hope that as research continues to emerge, the adaptive nature of the PNOC022 study design will continue to move us closer towards a cure providing

hope for our children and their loved ones.

Once again, thank you to my fellow Board members, and all of our generous supporters.

Phoebe (Josie's mum)

Fundraising and Awareness Activities in 22/23

JUL 22

Genesis Ride for RUN DIPG

The Genesis RIDE DIPG Event took on nearly 900kms from QIMR Berghofer Medical Research Institute to Hunter Medical Research Institute (HMRI). The team of John, Odin, and Lucas raised almost \$60,000 in this incredible feat, rallying funds for research and raising awareness.

This epic event wouldn't have been possible without the support of their team, Paul and Brendan, and sponsorship by ChemCert Training Group - RTO 90855 and Genesis Health and Fitness. A huge thank you to the boys, to their support team, to our sponsors, to our supporters and everyone who cheered them on along the way!



JUL 22

Gold Coast Marathon

Wow! What an incredible turn out for the Gold Coast Marathon! More than 100 fundraisers, five incredible teams and \$62,500 raised.

Our sincere thanks to everyone who turned out in the early hours, those who travelled, all our amazing supporters and especially, all the incredible participants who competed.



Hunter Rugby Sock Round

A huge thank you to everyone who came out to support the inaugural RUN DIPG Round this weekend. It was a fantastic show of community, in partnership with Hunter Rugby, to have the teams don the RUN DIPG x Sockgaim socks, raising awareness for research, and the largest effort in rugby circles to-date.



Stihl Timbersports

The Rookie Championships, held on the Gold Coast saw the Silver Medal awarded to Mitch Scrivener representing RUN DIPG



AUG 22

Port Waratah Coal Services

Thank you to all the team at Port Waratah Coal Services for voting RUN DIPG as the winner of the 2022 vote on a good cause program. Following employee Trevor Thompson's nomination, Port Waratah staff voted RUN DIPG as recipients of the year's winner.

We were blown away to receive the highest votes and awarded a \$15,000 grant.



Mudgee Running Festival

Thank you to all the organising committee, volunteers, sponsors and participants who made the 2022 Mudgee Running Festival a huge success. Mudgee is close to our hearts and it is special to be the charity partner each year.

A huge effort from the Mudgee Kids Run for DIPG Team raised \$4,502.50 for research.



Fundraising and Awareness Activities in 22/23

SEP 22

Run 4 RUN DIPG 2022

A huge thank you to everyone who fundraised, participated, cheered, ran, swam, cycled and supported our Run 4 RUN DIPG Event on Sunday, 25 September. We always hold our annual running event on the closest Sunday to Childhood Brain Cancer Awareness Day (September 26th), and this year again, we were absolutely amazed by the turnout.

Not only was the impact at our in-person event in Newcastle amazing to see, but we were bouyed by the incredible numbers who showed up for the cause across the state and the country!



Ride For Ahlia 2022

"I just know it's the start of something big." Tom Buchanan has continued to amaze us with his fundraising commitment, as well as his enduring commitment to awareness of DIPG/DMG.

Ride For Ahlia is a gruelling 260km ride from Windy Harbour to Leschenault, WA completed in a single day. The ride is in honour of Ahlia Williams who passed away from DIPG in November 2020. In it's second year this year, the event raised more than \$113,000.



DIPG Awareness Night

This event and dinner in Western Australia was held with thanks to Ahlia's Kindess Day, The Williams Family and Leschenault Cricket Club, and raised over \$25,000

7 Marathons in 7 Days

Cheers for the absolutely incredible effort by Hugh Fitter, who essentially spent a week running marathons and raising money for RUN DIPG, raising more than \$2,800.

OCT 22

NOV 22

Byron Lighthouse Run

A huge thank you to the Byron Bay community for coming together for their own Run 4 RUN DIPG, after their initial event was postponed. A special thank you to Jesse McKay, who organised the event, Korupt Vision for the fantastic photos, and to the businesses who supported the day, including Sipp Instant, Trail Brew, Freshes Au, Stone and Wood, Afends, Koala, Train Verce, Dead Kooks, The Sunset Social and the Beach Hotel at Byron Bay, and Lancaster Motor Group. The event raised more than \$8,100

Babes on the Balcony

The amazing ladies from Babes on the Balcony - BOTB - generously chose to support RUN DIPG as part of their annual event.

The support of this organisation continues to grow, and we're proud to be the recipients of the \$40,600 raised.



Fundraising and Awareness Activities in 22/23

DEC 22

Lambourne Partners Golf Day

For more than a decade, Lambourne Partners have held an annual golf day to raise funds for a local charity, with more than \$120,000 donated to date.

This year, we were the lucky recipients of the fundraising of the annual event, and were thrilled to accept this donation of \$22,000. A huge thank you to the team at Lambourne Partners, the amazing sponsors who made the day possible, and all the teams who participated.



Ahlia's Blue Stumps Day

In its second year, the Leschenault Cricket Club raised over \$8500 for RUN DIPG,

The day wouldn't have been possible without the club, in partnership with Eaton Cricket Club, Bunbury & Districts Cricket Association, Laurie at Revo Cricket for blue cricket equipment, Loki at LSR Sports.



FEB 23

Dee Why to Manly Sun Run

Our first year at the Dee Why to Manly Sun Run, and what a result! There was so many of the RUN DIPG family out in their merch raising awareness, and congratulations to our runners leading the charge.

A special mention to the team who raised funds in memory of Demi Tsanadis, who contributed almost \$8,000 to our overall total, and who led the way in our fundraising. We remained in the top fundraiser position for the entire event, so thank you to everyone who supported!



MAR 23

Newcastle/Hunter Valley Sailing Day

Hunter Chartered Accountants nominated RUN DIPG as the recipient for their Annual Newcastle/Hunter Valley Sailing Day.

It was an absolutely fantastic day out, and this amazing group raised \$4,000 towards research initiatives.



Fundraising and Awareness Activities in 22/23

MAR 23

The Hotel Beatty

A huge thanks to the team at The Hotel Beatty, who supported us with an epic \$3,000 donation from the pub ceiling.

His kind of grassroots donation goes such a long way in contributing to our mission of #movingtowardsacure.



APR 23

Boston Marathon

A huge thank you to Kyle, marathon runner extraordinaire for running yet another spectacular Boston Marathon.

The oldest marathon in the world, and one of the most prestigious, Kyle has run the Boston Marathon several times now, and we're always blown away by his incredible determination and of course, his amazing work raising funds and awareness for RUN DIPG.



AHA Race Day

We were thrilled to be one of the recipients of some incredible fundraising by the Australian Hotels Association - Newcastle Hunter branch by way of their Annual Charity Race Day recently.

Of this very impressive figure, RUN DIPG received \$22,500 to support research, awareness and advocacy.



Hunter Rugby Sock Round

The Hunter Rugby x RUN DIPG Round was a hit where teams wore our fantastic socks during the round to raise funds and awareness for DIPG research - thank you to all of our Hunter Rugby clubs who have supported this fantastic partnership!

Matt Dun has represented Hunter Rugby and has achieved huge strides in raising awareness of DIPG through building ongoing connections within the fantastic rugby community.



Anna MacDonal – Marathon Des Sables

Absolute superstar, Anna McDonald, embarked on crossing the Sahara as part of the Marathon des Sables - the world's toughest footrace that takes place over 250km over several days.

Anna raised funds and awareness of DIPG, which has affected a close friend's child and family. She raised over \$30,000 towards research and awareness initiatives - an incredible effort!



Fundraising and Awareness Activities in 22/23

APR 23

Rainbow for Ruby Bingo

What an absolutely incredible effort from this community! The Rainbow for Ruby Bingo Night raised an incredible \$64,000 for RUN DIPG!

Our heartfelt thanks to Ruby's family and friends who were instrumental in pulling together an amazing night in her honour, and for the awesome community that supported, sponsored, entertained and fundraised.



Hundred 4 Harper

The annual Hundred 4 Harper event was held at the end of April. This event continues to get bigger and better every year, and this most recent iteration was no exception.

A huge congratulations to every member of the 21 participating teams on the day, and of course, our huge thanks to Lee and Helena Dowdall and to the incredible sponsors, supporters, volunteers and extended network who have, to date, raised more than \$77,000 for RUN DIPG and the research that our charity supports.



HBF Run for a Reason

A huge \$14,172 was raised for RUN DIPG by an amazing group of people in Western Australia. A special shoutout to our champion fundraiser Zac Williams who entered this event in honour of his "big sis" Ahlia. Zac raised a massive \$3126.



MAY 23

RUN DIPG Moonlight Gala

What a night! Thank you to everyone who supported our annual Moonlight Gala event, which raised more than \$108,000 to support research initiatives and support for families affected by DIPG.

This amazing night wouldn't have been possible without the generous contributions of our sponsors, the amazing prizes donated for the raffle by the awesome local businesses, the hard work of our volunteers, and the dedication of our organising committee.



Steel Coast CrossFit Team

A huge thanks to the Steel Coast CrossFit team who challenged themselves to a 50km C2 bike ride or half marathon row, all to raise funds for RUN DIPG.

A massive thanks to Nic, Scott, Brendan, Braydon and Dave plus all those willing to join them, their fantastic community have raised more than \$2,700.



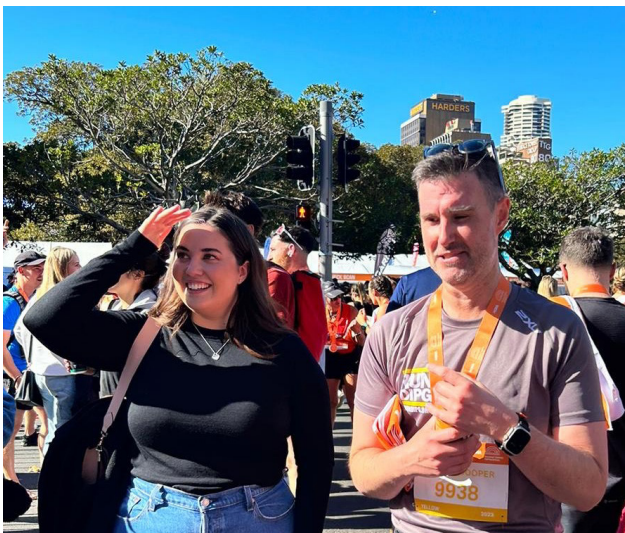
Fundraising and Awareness Activities in 22/23

MAY 23

Runaway Bay Half Marathon

A huge thanks to Kieran, who was our number one fundraiser in the Runaway Sydney Half Marathon and raised more than \$5,000! Kieran ran for his "nephew Cooper. He was diagnosed with DIPG aged 11 in October 2021"

"Still so devastating for the family but Cooper's fighting spirit and bravery is spurring me on to complete the run and raise as much money as possible for DIPG."



JUN 23

Ahlia's Kindness Day

\$23,763.00 - in the words of the organisers of this fabulous initiative, "an incredible amount raised for a charity that is very close to our hearts!"

"Back in 2020 when Ahlia was diagnosed, we were given no hope. We were told to go home and make memories! RUN DIPG is changing that narrative, and we are honoured to continue supporting their incredible work!"





Good X Karma

A huge thanks to Xav and Good X Karma for his awesome initiative and his beanie designs, which have raised \$5000 for RUN DIPG in honour and memory of his friend, Amber Hughes.

What a legend!

Dudley Club Football Amber Round

A huge shoutout and heartfelt thanks to the Dudley Redhead JRLFC - Mighty Magpies - Mighty Magpies!

Their incredible efforts have raised an astonishing \$28,500 for RUN DIPG. Thank you for being a shining example of what a community can achieve when they come together for a meaningful cause.



Brookwood Alpacas

This amazing group, including shearers who donated their time, from Brookwood Alpaca raised more than \$1000 this year. They did this in memory of Charlotte Peachey who passed away of from DIPG in 2013.

Charlotte's mum, Rachael, also held her own fundraiser during May, colouring her hair and raising \$1450.



22/23



RUN DIPG FUNDED RESEARCH PROJECTS



In the 2022-23 year, RUN DIPG committed more than \$1.4 million in new research/project funding commitments, made possible thanks to the families and communities that support our cause:

RESEARCH GRANT

Prof Matt Dun, Dr Ryan Duchatel, University of Newcastle - \$20,000

The Wish Lab

With the Wish Lab research facility up and running at The University of Newcastle, thanks to the tremendous efforts of DIPG 'Supernova' Jemima Gazley, we were once again humbled by the Gazley Family's focus on bringing better outcomes for future DIPG/DMG families through an additional donation in 2022. With Ray and Oliver Gazley contributing \$20,000, RUN DIPG supported further cell culture works in the Dun Lab, where DIPG cells are grown and studied in incubated flasks. These 'in vitro' models are considered the workhorse of preclinical DIPG research and instrumental to all works seeking to find/develop anti-DIPG therapies.

RESEARCH GRANT

Dr Ryan Duchatel, University of Newcastle - \$56,000 (2 years)

Evaluating promising anti-DMG therapies through enhanced collaboration

The Dun Lab's collaborative approach to finding DIPG/DMG answers received a boost from RUN DIPG in 2023, awarding Dr Ryan Duchatel and the early-career researchers of the University of Newcastle team a \$56,000 research grant for 2023-2024.

This will allow the researchers beginning their careers to partake in multi-institutional projects,

complete training opportunities locally and abroad, and develop their professional networks through conference attendance, vital opportunities to facilitate effective and impactful DIPG research.

RESEARCH GRANT

Prof Matt Dun, Dr Ryan Duchatel, Dr Evie Jackson, University of Newcastle - \$1,200,000 (3 years)

Tour de Cure Partnership Funding Scheme

Together with Tour de Cure, RUN DIPG have funded a major project of the Dun Lab, spanning 2023-2027. Prof Dun, together with Drs Duchatel and Jackson will execute the project titled 'A chink in the armour of DMG tumours: exploiting DMG-specific defence systems to improve response to treatment', which includes study of how to improve the response (rate and duration) to the therapies used in the PNOC022 clinical trial.

TRAVEL GRANT**Dr Clara Savary, Cancer Research Centre of Lyon - \$10,000**

When we say we're focused on #MovingTowardsACure, sometimes this is in a literal sense! RUN DIPG awarded a \$10,000 travel grant to Dr Clara Savary from the Cancer Research Center of Lyon.

Dr Savary visited and worked with Australian DIPG/DMG laboratories of Dr Fa Valdes Mora of Children's Cancer Institute and Prof Matt Dun at University of Newcastle and continues to contribute to a large scale, multi-institutional bioinformatics project that commenced June 2023.

PHD SCHOLARSHIP**Prof Matt Dun, University of Newcastle - \$135,000 (3.5 years)*****The RUN DIPG 'Warrior Jack' Scholarship***

Through 2023-2027, RUN DIPG are supporting the RUN DIPG 'Warrior Jack' PhD Scholarship together with the family of Jack Fong, lost to DIPG in 2021. The Warrior Jack Scholar will work with Prof Matt Dun and the Dun Lab at University of Newcastle, investigating the influence of DNA methylation in DMG tumours.

The team will study whether methylation patterns can be used to categorise DMG tumours, and later, whether categorisation can be used to select effective treatments.

Through 2022-23 and beyond, RUN DIPG are continuing to support the below projects focused on improving the outcomes of patients and families impacted by this deadly brain cancer:

23/24 ▼



Committed DIPG/DMG research partnership funding in 2023 and beyond.

PERSONNEL SUPPORT: \$86,662

Paediatric Brain Cancer Clinical Nurse Specialist 0.5FTE (2021-2023)
John Hunter Children's Hospital
PI: Dr Frank Alvaro

PHD SCHOLARSHIP: \$110,000.00

(in conjunction with Isabella and Marcus Foundation)
PhD Stipend (December 2022 - May 2026)
Murdoch Children's Research Institute
PI: Prof David Eisenstat

PROJECT FUNDING: \$41,121.80

DIPG/DMG Collaborative Research Grants Round (December 2022 - December 2024)
Project and PI selected by DIPG/DMG Collaborative Scientific Advisory Board

TOTAL RESEARCH FUNDING: \$474,000.00

(In conjunction with The Kids Cancer Project)

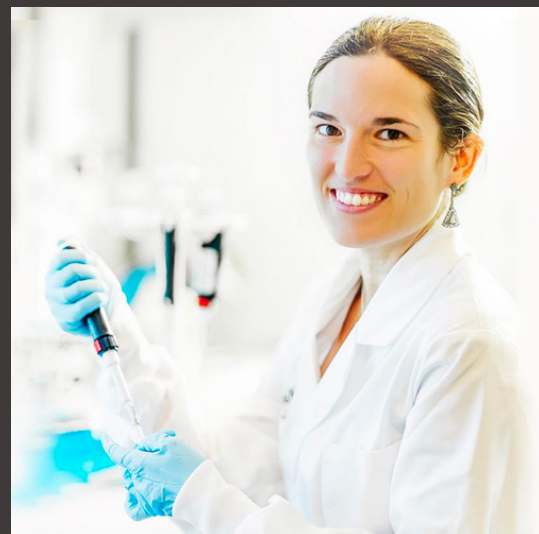
Research Grant - PHOTON 'PHarmacophospho-proTeo-geNomics' of paediatric high grade glioma
(January 2022- August 2024)
The Cancer Signalling Research Group, The University of Newcastle.
PI: Prof Matt Dun

PHD SCHOLARSHIP: \$108,000.00

PhD Stipend - The 2022 RUN DIPG 'Moving Towards A Cure' PhD Scholarship
(January 2022-June 2025)
The University of Newcastle, Hunter Medical Research Institute
PI: Prof Matt Dun

PERSONNEL SUPPORT: \$90,000.00

Postdoctoral Researcher (2023)
Children's Cancer Institute
PI: Dr Fa Valdes Mora





At RUN DIPG, we know the power of community; we collaborate with DIPG/DMG-focused foundations the world over to ensure we're doing all we can to keep us #MovingTowardsACure.

COLLABORATIVE MEMBERSHIP

DIPG DMG Research Funding Alliance (DDRFA)
2023-2024

PROJECT FUNDING

DIPG/DMG Collaborative, Leadership Partner
2023-2024

COLLABORATIVE MEMBERSHIP

ChadTough Defeat DIPG Foundation Research
Partner Program: 2023-2024



Finances

RUN DIPG's profit and loss statement for the 2022/23 financial year is below. We are so proud to have raised \$1,921,989 from the generous support of the RUN DIPG community, RUN DIPG events, and our corporate supporters! Most importantly we were able to invest \$1.4 million into research initiatives and keep operating expenses to under 19%.

Having only registered as a charity in March 2019, we are staggered by the community's support and general momentum that has not just continued, but thrived, even during a global pandemic. This amount also represents a more than 160% increase since our last reporting – a trend we hope to continue for many years to come!

Trading Income	
Donations	1,136,250
RUN Event income	251,156
Gala Event income	104,177
Merchandise sales	27,236
Interest Income	3,170
Research Funding	400,000
Total Trading Income	1,921,989
Cost of sales	
Merchandise sales	(33,259)
RUN Event expense	(21,943)
Gala event expenses	(28,471)
Total cost of sales	(83,673)
Net trading income	1,838,316
Operating Expenses	
Advertising	-
Accounting Fees	-
Administration & Fees	-
Bank Fees	-
Computer & IT Expenses	(430)
Consulting Fees	(36,603)
Depreciation	(613)
Entertainment & Gifts	(18,217)
Freight & Courier (3,958)	(1,840)
General Expenses (419)	(18,259)
Insurance (4,513)	(7,535)
Legal Expenses - (3,390)	-
Marketing	(6,167)
PayPal Fees	-
Travel	(10,318)
Wages & Salaries Expense	(201,855)
Website & Merchandise Store Fees	(46,535)
Xero Subscription	-
Total operational expenditure	39% (348,372)
Total research and operational expenditure	100% (889,118)
Surplus/(deficit) for the year	949,198
Accumulated surplus at the start of financial year	508,600
Accumulated surplus at the end of financial year	1,457,798

Balance Sheet

BALANCE SHEET - RUN DIPG Limited

FOR THE YEAR ENDED 30 JUNE 2023

ASSETS	
Current assets	
Cash and Cash Equivalents	1,544,327
Prepayments	619
Stock on Hand	27,363
Accounts Receivable	9,088
	1,581,397
Non-Current assets	
Property Plant & Equipment	614
Total Assets	1,582,011
LIABILITIES	
Current liabilities	
Accounts payable and other accruals	124,213
Total Liabilities	124,213
Net Assets	1,457,798
RETAINED EARNINGS	
	1,457,798

Upcoming Events & Advocacy in 23/24

As with many other charitable organisations, our fundraising events are the highlights throughout the year for us, and we are thrilled to be reporting on the incredible advocacy and fundraising achieved by our supporters on the back of an incredible year. As always, the focus for our events is a commitment to safe, inclusive and advocacy-centric values, and with this in mind, we are excited about the prospect of going even bigger and better into the next financial year.

The Gold Coast Marathon continues to be an incredible, grassroots-led initiative that has inspired us with its year-on-year growth, and we can't wait to do it again next year! In the spirit of grassroots communities at their best, we cannot wait for The Ox 100 KM challenge in Lennox Head, which has garnered fantastic media and community support.

We're thrilled to see the reach of the charity expanding rapidly across the country, and the annual Ride for Ahlia event, held in Western Australia, continues to impress us with the sheer grit and ongoing commitment of this community.

Inspired by many fantastic lunch events through our extended network, we can't wait to hold our inaugural Heals to Heal Newcastle Event in July and November in Sydney. Both events are a sell out. A special mention to the Poolman family for arranging our Sydney event.

At the heart of our events are our incredible families, and we cannot wait to see the annual Hundred 4 Harper challenge go even bigger and better next year. This year's event was supported by many new faces, all coming out in memory of Harper and to support the Dowdall family - we cannot thank you enough for your amazing advocacy work.

One of the most significant events on the calendar is our Annual Moonlight Gala. We're thrilled to be extending the reach of this night to our greater network and taking it interstate to Brisbane for Friday, 17th of May - which is also International DIPG Awareness Day.

Wherever, however, and whenever you support us, and by whichever means are available, our sincere and enduring thanks. We truly believe RUN DIPG to be a charity that belongs to our greater community, and we cannot wait to see you in the next year.

How you can get involved!

Advocate

Now this one is easy! Visit our website, like us on social media, share our stories and get yourself some official RUN DIPG merchandise to be seen in. If you'd like to arrange an information session on DIPG/DMG and the work of RUN DIPG for your next awareness event, we'd love to be involved.

Volunteer

If you would like to volunteer your time or expertise, please get in contact with our team. As a charity determined to utilise as much funds raised on research as possible, we couldn't operate the way we do without the generous support of volunteers. Not sure how you could help? We likely need a hand at our events, with administration or organisation, marketing/social media and of course, fundraising. If you can help, get in touch via www.rundipg.org!

Donate

To make a donation please head to our website www.rundipg.org and follow the prompts to 'donate now'. We provide options to become a Monthly Donor, donate to a specific RUN DIPG event, fund a supporter event, or give on a special occasion. We use Grassrootz to support our event donations and challenges. We appreciate all donations equally and the associated advocacy.

Corporate partner

We love to hear of businesses within our community that are willing to give a little back! We have a range of corporate packages available to keep our aligned laboratory research moving. If you or your business are ready to contribute to the work needed to improve DIPG/DMG outcomes, we want to hear from you!

Bequest

Including a charity within your will provides you the opportunity to make a lasting impact. As a charity that is 100% reliant on the generosity of our donors, RUN DIPG would be proud to receive your support via bequeathed funds. If you would like your donation to be used for certain aspects of DIPG research or the associated work we do (e.g. equipment purchase, project funding, scholarship or event support), we would love to create a bespoke arrangement that meets your wishes. Whilst we understand a bequest to RUN DIPG is a personal decision, we recommend all bequests be discussed with your legal advisor.

Support an event and fundraise!

Creating your own fundraising or advocacy event with friends, family, your workplace or your community is a fantastic way to support RUN DIPG. From little things, big things grow – there is no event too small! If you have an idea and would like to gain our support for the event (RUN DIPG promotional material, logo files, social media promotion), please give us a shout! The RUN DIPG team can guide you through the setup of your own online fundraising page or provide support for an offline event.

Get in contact

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Jo Bennett
(General Manager)

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Facebook: @RUNDIPG

Instagram: @RUNDIPG

X: @RUNDIPG

Linked In: @rundipg





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PROFIT IS CHILDHOOD
PROGRESS WORTH IT

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