

The Huntingtons Queensland team continuing their work from home during Covid-19

ANNUAL REPORT

2019-2020



ABOUT US

Huntingtons Queensland is the only organisation in this state dedicated solely to the support and wellbeing of individuals impacted by Huntingtons disease.

We are a registered charity (public benevolent institution), governed by a volunteer board comprising family representatives and skills-based professionals.

We have a small paid team (the equivalent of 4.2 full-time staff) whose professional backgrounds include social work, education, disability and advocacy, finance, administration, marketing and communications, fundraising, HR, organisational development, strategic planning and project management.

While Huntingtons Queensland is a member-based organisation, membership is not required to access our services.

Volunteers

Huntingtons Queensland gratefully acknowledges those members and others who so generously volunteer their time and expertise, either within the HD community or within our organisation.

Normally around 600 hours are donated each year by volunteers in our community – although Covid-19 has had an enormous impact on our work in 2019-2020, with many events and activities having to be cancelled or postponed.

Despite these challenges, our wonderful volunteers have continued to stay in touch and support our HD community, often in new ways and 'under the radar' during these strange times of stress and isolation.

On behalf of our team and everyone impacted by Huntington's disease in Queensland, we thank you for your service.

Our People

President Jason de Bakker

Vice President Vacant

Treasurer Janifer Willis^

Della Nicholson*

Secretary Jan Szlapak

Directors Cate Barrett

Donna Burns*
Gerry Doyle
Shane Kelly

Susanna Mantovani Shane Stoddart*

CEO Jan Samuels

Client Services Theressa Byrne

Lauren Ward

Finance Jennifer Lysiuk

Communications Caitlin Scarr

Service Support Cathy Holland

Human Resources Jan Tipping

Hon. Solicitor Adrian Rich

Minter Ellison

Auditor Paul Gallagher

BDO Audit

Investment

Adviser

Robert Holle Bell Potter

^Resigned during the year *Joined during the year



2019 Christmas party

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From top: Lunch together at our community fun day; education sessions with Lauren; fun at the Railway Ipswich Museum; and 2019 Christmas party

All images are used with permission.



Jason de Bakker - President (joined 2018)

Jason has an extensive background in corporate services, compliance and organisational development gained over more than 20 years in the NFP and community sectors. Jason is a graduate of the Australian Institute of Company Directors and has a particular interest in governance and strategy.

Della Nicholson - Treasurer (joined 2020)

Della joins the Huntingtons Queensland board with a strong background in accounting and business management. Della's work allows her to engage with people from all walks of life, from scholars to elite sports people, and she has valuable experience with the NDIS and not-forprofit organisations. Della is a proud volunteer, supporting a range of community organisations and social networks.

Jan Szlapak - Secretary (joined 2006)

Jan is a strong advocate for families impacted by Huntington's disease, having lived experience as a carer, a long-standing volunteer at Board level, and a facilitator at her local HD support group.

Cate Barrett - Director (joined 2014)

Cate is a speech pathologist and psychologist with more than 20 years' experience in caring for people affected by HD and their families.

Clockwise from top left: Jan Szlapak, Shane Kelly, Jason De Bakker, Donna Burns, Susanna Mantovani, Shane Stoddart, Della Nicholson, Gerry Doyle

Gerry Doyle - Director (joined 1994)

Gerry has been associated with Huntingtons Queensland for more than 25 years and became a life member in 2010 in recognition of his tireless service on behalf of HD families. Gerry, a retired corporate manager, also has many years' lived experience of HD as a parent, husband and carer.

Shane Kelly - Director (joined 2018)

With Shane's family affected by HD, he is determined to support those directly impacted and their families, while helping to raise funds for research and services. Shane has extensive experience in senior management roles, having worked for Telstra for more than 20 years and more recently in consulting roles across business transformation.

Susanna Mantovani - Director (joined 2018)

Susy has a long professional history with neurodegenerative disease, including HD, as a researcher in neuroscience. She has a PhD in Physiology and has held several research roles in Italian and Australian institutions. Susy is currently working for a contract research organisation in the field of clinical trials.

Donna Burns - Director (rejoined 2020)

Donna is a health professional working across the health and social sectors for more than 25 years. She has extensive experience in senior and executive leadership, specialising in organisational change management and strategic planning, and a longstanding commitment to social justice and equity of access in healthcare.

Shane Stoddart - Director (joined 2020)

Shane is interested in contributing to the longevity of the support Huntingtons Queensland provides to the HD community. With family impacted by HD, Shane is passionate about raising awareness, particularly through his profession within the construction industry, and building sustainability within the organisation.





Top & Bottom: Education sessions remained in high demand throughout the 2019-20 financial year



PRESIDENT'S REPORT

Strange times: Lewis and Charlie try co-chairing for size

Where to begin in a year that has been like no other?

While the current financial year started off with business as usual, the first quarter of 2020 soon led us all into a world that few could have predicted. I would like to start this year's report by acknowledging and sending my thoughts to everyone in the HD community who has been impacted by the Covid-19 pandemic, whether personally or through a family member, colleague or friend.

We have all been under extraordinary pressure as workplaces closed, families were confined to their homes, and social engagement went almost completely online. We are humbled that our team has been made welcome in helping families, service providers and health professionals to adapt to these changing times.

Huntingtons Queensland has also undergone some major changes this year.

We have said goodbye to Treasurer Janifer Willis, and welcomed her replacement, Della Nicholson, and fellow new director Shane Stoddart. At this year's AGM we will farewell one of our longest-standing directors, Jan Szlapak (right), who will step down after 14 years' continuous service on our Board, and many years of working directly with families in a volunteer capacity. Jan will be sorely missed.



Jan Szlapak is stepping down after 14 years of service to Huntingtons Queensland

Perhaps the biggest change this year was the strategic decision taken by the board to sell our Annerley premises to the Women's Legal Service of Queensland. Funds from the sale have been added to our reserves and will provide a buffer as we work to ensure the sustainability of the organisation and our services. It has been an easy transition for our team, as we are staying on in the building as tenants. We acknowledge with gratitude our honorary solicitors, Minter Ellison, for their generous pro bono support in managing this process for us.

Organisationally, we completed our Strengthening Governance project, finalising our policy review, implementing a new performance framework for staff and education opportunities for directors, and establishing two new board sub-committees (one to oversee Finance, Audit and Risk; and the other to guide Strategy).

I am pleased to note our staff remained stable this year, with no changes to our line-up. The team has done an outstanding job under very difficult circumstances and I wish to thank them for their commitment and resilience.

On behalf of the Board, I would like to extend our thanks and gratitude to our CEO, Jan Samuels, for her leadership and support to both the Board and organisation this year. Jan has facilitated our response to Covid-19, developing our relationships with government, maintaining and adapting services where we can, represented Australia on international HD initiatives and engaged with other HD state associations to encourage greater collaboration. The HD community in Queensland and Australia is a beneficiary of her dedication and commitment.

This reporting period has also seen progress at a national level. Following a meeting of the state association CEOs in mid-2019 (initiated and hosted by Queensland), there has been a concerted effort by our organisations to work more collaboratively. This year a memorandum of understanding was agreed by the Chairs and operational heads of most state associations and an informal Consortium of Huntington's Associations was convened.

There is no doubt that the pandemic helped to influence this development. Like many NFPs and businesses, it has forced us to explore different ways of thinking, working, and delivering services, while responding to the changing needs and expectations of the HD community.

We do indeed live in strange times, but the heart and soul of our mission has not changed. Every day our team, my fellow directors and I remember that it is a privilege to serve you, and we thank you for your trust in us.

JASON DE BAKKER President



Jason de Bakker at the 2019 forum

CEO'S REPORT

You may be wondering about all the dog photos that feature in this year's annual report.

There are three main reasons for this. The first is that with many of our planned events cancelled, we have no other photos to share! The second is that all these 'Huntingtons hounds' have played an important part in our daily lives this year, as we work from home and via digital platforms while trying to stay connected with our families, friends, each other and you. And the third is that interacting with animals is known to be good for you.

(We also have cats, birds and Sebastian the guinea pig among the Huntingtons Queensland menagerie, but they are not so great at taking part in Zoom meetings.)

While this may sound frivolous, there is also a serious side to this theme.

Managing mental health and wellbeing are serious issues for many in the HD community, and every year a high proportion of our work focuses on these issues. Despite the restrictions of 2020, our team has still managed to provide more than 1,000 instances of service to individuals and families across the state over the past 12 months.

As you will read elsewhere in this report, our non-clinical counselling, information services, advocacy, NDIS pre-planning meetings, and education sessions for health professionals and service providers have remained popular – and continue to grow.

We were also fortunate to receive one-off funding from Queensland Health to support families struggling with the impact of Covid-19. This has been used:

- To purchase iPads, computers and mobile phones for families to stay in touch or continue with work or school commitments; and
- To fund telehealth sessions with clinical psychologist Cathy Dart (a former employee of Huntingtons Queensland, who has an excellent knowledge of HD and the challenges it can present).



Jan with Moo (front), Archie (back) and Molly (on Jan's Iap)

In this most baffling of years, we have greatly missed our person-to-person contact, and the depth and quality of support the HD community offers each other by being together.

Looking ahead, we are working hard on plans to resume business as normal (the new normal) as soon as we can.

While key events like the annual Alecca McKinless forum and several regional community days had to be cancelled, we hope to see them back on the calendar in the 2020-21 financial year.

We are also looking at new ways to raise funds to continue our services, and to ensure our community remains connected to Huntingtons Queensland and each other. We are keen to explore 'virtual events' and personal challenges, and to develop a series of education sessions or 'talk with an expert' events – which of course can be conducted with anyone virtually anywhere in the world.

We are also expecting greater collaboration with our colleagues interstate. There is much to be said for sharing resources and expertise, all of which creates a stronger voice for everyone impacted by Huntington's disease. This will be a key theme in the year ahead, and our Queensland community has a great opportunity to play a key role in this work.

In closing, I want to thank our President, Jason de Bakker, for his exceptional leadership of our Board and team over the past 12 months. My thanks also go to our volunteer directors. They are a knowledgeable, generous bunch who challenge our thinking and support us with empathy and good humour – while never forgetting our mission and values.

To Caitlin, Cathy, Jan T, Jen, Lauren and Tressa (and their beautiful dogs, cats, birds, and other beasties), your encouragement, enthusiasm and resilience has been a joy in a difficult year.

And to our members, supporters and HD families, thank you for making us welcome. We will always be here for you.

JAN SAMUELS
Chief Executive Officer





TREASURER'S REPORT

The 2019-2020 financial year has seen some significant changes in the life of Huntingtons Queensland, not least with the sale of Florence Dannell House (which was purchased through a generous bequest in 1996); and from the impact of the Covid-19 pandemic in the first half of this calendar year.

While we were pleased to receive an extension to our Queensland Government-funded services (in the first half of 2019), long-term viability of the organisation remains a priority for the board.

For example, Queensland Health funds only our information services, non-clinical counselling and statewide support groups, which means all other services – including NDIS preplanning, supporting the HD clinic, events, education for service providers, advocacy and emergency assistance for families, can only be offered thanks to the generosity of our supporters or one-off grants.

In March our team moved to working from home – an event that coincided with a successful application to the Gambling Community Benefit Fund for grant monies to upgrade and replace our existing computers, phones, email and electronic storage systems.

Whilst the project was a high priority, particularly as the whole business commenced working remotely almost overnight, this coincided with a critical shortage of supplies and service providers to carry out the project. The contribution from the entire team during this challenging period is commended.

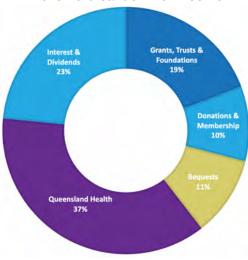
I would also like to make special acknowledgement of the work of Cathy Holland, our Service Support Coordinator, for her amazing efforts firstly to get the team working effectively from home so quickly, and then for managing the entire project from her bedroom during lockdown!

Ratios at work: Our team found ways to catch up while maintaining social distancing

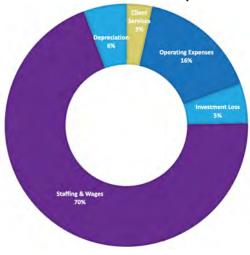




2019-20 breakdown of income



2019-20 breakdown of expenses



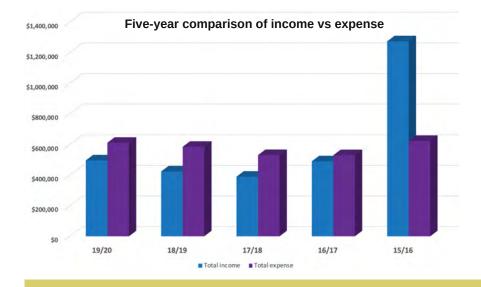
Covid-19 has undoubtedly affected many small to medium organisations, and we are not alone in the material impact this has had on our projected income. Our Finance Officer, Jen Lysiuk, has been instrumental to ensure we have accessed available Covid-19 support, including the cash flow boost, JobKeeper payments and rental relief, which have contributed meaningfully to cashflow during the period.

Huntingtons Queensland has also worked hard on building our relationship with Queensland Health. This has included an opportunity to take part in weekly briefings with senior managers, and a chance to lobby for and secure special Covid-related one-off funding to help support HD families across Queensland until July 2021.

The Board of Huntingtons Queensland also works with several external partners to help manage our business, and this year I would like to acknowledge the following:

- The team at Minter Ellison, for their wonderful pro bono support, first advising us and then navigating and managing the sale of Florence Dannell House on our behalf;
- Paul Gallagher, Huntingtons Queensland's long-term auditor, who has taken a keen interest in our work for several years, and who is retiring at the end of 2020; and
- Robert Holle and his team from Bell Potter, for the competent way they continue to manage our investment portfolio.

Personally, It has been a pleasure to join the board of Huntingtons Queensland this year, and to assume the position of Treasurer and Chair of the new board Finance, Audit and Risk sub-committee.



I am confident that together the board and team continue to manage the association effectively. By working together we will continue with our mission of advocating for and supporting people impacted by Huntington's disease across Queensland.

DELLA NICHOLSON Treasurer



Planning & linkages

Together we are stronger – that's what we believe. Our HD advisers have developed a wide network of professional services to ensure that our clients can access the support and services they need. The team has developed relationships with legal, financial and social services throughout Queensland, which continue to add value and build family resilience.

Our team regularly attends NDIS planning meetings, Centrelink appointments, and the Royal Brisbane & Women's Hospital (RBWH) HD outreach clinic. Through our contacts, we help clients engage with a wide range of people and services, providing a stronger network of support for when it's needed most.

In response to Covid-19, our team linked clients with online and telehealth services to ensure support could continue while meeting safety requirements for all involved.

We also continued with our regular work, of preparing submissions, gathering support evidence of housing and NDIS applications, and providing advice about HD to the many agencies that interact with our community.

Purpose: Access to appropriate services; ability to make informed decisions and choices.

Our staff continued to work from home to provide services to clients, albeit with a few additional co-workers like Regi the foster pup.



per month

*All data includes March - June when no in-person service were available due to Covid-19 restrictions

One-on-one support

The complexities of Huntington's disease can be challenging, and many of our clients need the time and space to work through situations with the direct support of our team.

Our one-on-one support remains our busiest service, and our team spends a significant amount of time working with individuals to provide friendly support, and offer services and referrals where appropriate.

The changes to our services, caused by Covid-19, saw much of our one-on-one support move to telephone or digital engagement.

The demand for one-on-one support did not diminish during the pandemic, and our HD advisers were able to work safely from their home offices to provide one-on-one support.

We look forward to the restrictions lifting so we can safely greet people in person once again.

Purpose: Individualised, tailored support, often in response to heightened or crisis situations; ability to cope and manage challenges associated with HD.



HD Adviser Tressa Burns at the Ipswich Railway Museum

Support groups

Sometimes all you need is the chance to debrief with other people who understand what you're going through. Our support group meetings have always been popular, with individuals and families from local areas coming together with one of our HD advisers for a friendly chat.

Support group meetings run throughout Queensland, meeting at regular intervals, allowing attendees to develop a network of local, supportive friends.

Support groups moved to an online format using Zoom during Covid-19 restrictions. These groups were held every week, and attendees could join from the safety of their home, all over Queensland.

Purpose: Encouraging local connections; fostering peer-topeer support; providing information and education; building resilience.



"Santa" at our 2019 Christmas party



The Client Services team were able to continue support groups online during Covid-19 restrictions



Advocacy

Having someone in your corner when you're facing a challenging or complex situation can make all the difference.

Our HD advisers play an important role as advocates for our clients in a variety of situations. They provide references for clients, attend NDIS meetings as advocates, and can also provide a supportive presence at a variety of other appointments and engagements.

In-person advocacy halted during Covid-19 restrictions, but our team were still able to provide phone and written advocacy services.

Much of their focus changed from face-to-face contact to digital work, involving written contact with government departments and private organisations in support of clients.

We supported 40 individuals through advocacy this financial year.

Purpose: Improved independence and quality of life; support for potentially vulnerable individuals in complex or high-pressure situations; better opportunities for individual choice and control.



Bellatrix says no catnapping on the job!

Education

Knowledge is power, and we believe that one of our fundamental roles is to provide education as a way of supporting our clients.

Our HD advisers have developed a number of tailored education services targeted to nursing facilities and other service providers.

Through these education sessions, we are helping other service providers to better understand their clients with HD, and to ultimately ensure a better standard of care and support.

Many of our education sessions were shifted to an online format to adhere to Covid-19 restrictions, and this ensured that we could safely deliver education to people all across Queensland.

Purpose: Greater knowledge of HD; improved standards of care; better quality of life for clients; less disruption to people impacted by HD and those who care for/live with them.



Our HD adviser Lauren (on screen) was able to deliver education sessions throughout Queensland, including with the OT team here from Opportunoty, Townsville



Above and below: Attendees at our community fun day at Ipswich Railway Museum





EVENTS

2019-2020 was a strange year for our team and the HD community, with the postponement or cancellation of several key events on our annual calendar.

In particular, we missed one of our favourites, *Running for Nan's HD*, which fell victim to the Covid-19 lockdown, almost on the day. Our thanks go to Kelly Woodland for her enthusiasm and determination to keep going, for continuing to support our organisation and staying 'match fit' for 2021.

We were also sad to cancel our annual *Alecca McKinless forum*, which has grown over the past couple of years, and presents a good opportunity to share experiences and learn from respected speakers in the HD field. We are planning our 2021 forum, but it will move to November as a national conference is in the planning stages for May.

The first international HDYO youth conference was also shaping up to be a highlight for young adults around the world. Several young Australians (and our own Lauren Ward) were saving hard to get to the conference, planned for March 2020, but with the severity and impact of the pandemic made it impossible, and the youth conference will take place instead as a virtual event in 2021.

Like many organisations, HDYO has worked hard in 2020 to maintain momentum, and help young people impacted by HD stay connected, through a series of online events. We look forward to working with HDYO again in 2021.

A PRINT OF THE PRI

Longtime supporter Alan McKinless (left) with HD advisers Tressa (middle) and Lauren (right)

COMMUNITY DAYS

It has been a pleasure for our team to bring together clients throughout Queensland to enjoy community days in different regions. We welcome clients and families to join us at special locations in their local area, for a day of fun at no expense to them. It is a wonderful opportunity for people to meet others in their local area, building local support networks, and have some fun together. Although Covid-19 put a stop to all our planned community days in 2020, we were still able to welcome clients to the Ipswich Rail Museum in October 2019. We would like to extend our sincere gratitude to Alan McKinless for generously funding these special community days.

Purpose: Building social support networks for individuals and families, including children; brief respite from the pressures of daily life; fostering community support and engagement; building resilience.

PARTNERSHIPS

Huntingtons Queensland has continued to support the Royal Brisbane and Women's Hospital (RBWH) HD clinic, which runs on the first Friday of each month. Our HD advisers attend for the entire day to support the staff and clients. The clinic was temporarily stopped with the onset of Covid-19 restrictions, and then later moved to a telehealth format. Our team is looking forward to supporting the clinic again when restrictions ease.

As part of our growing national network, Huntingtons Queensland was proud to participate in the Australian virtual premiere of *Dancing at the Vatican*, a documentary about families impacted by HD, and their momentous trip across the world to meet the Pope. Attendees at the online premiere had the opportunity to ask questions of gene-positive HD advocate and renowned former war correspondent Charles Sabine.



Director Gerry Doyle (left) with Dr Robert Adam, who is coordinating the Brisbane Wave Life Sciences trial

RESEARCH

A number of important research projects were in various stages when we entered the 2019-20 financial year. The drug trial by Roche Pharmaceuticals, named Generation HD1, had moved into the next phase that would test the effect of the drug on lowering huntingtin protein.

Huntingtons Queensland was also pleased to provide modest financial support and help raise awareness of the clinical trial being undertaken by Wave Life Sciences, with trial sites in Brisbane, Perth, Melbourne and Sydney.

Following the initial phase completion, preliminary results in December 2019 indicated the drug was safe and well-tolerated, with reductions of the mutant huntingtin protein of up to 12.4% in volunteers. Sadly due to Covid-19 restrictions, all research has been on hold or slowed, so further updates are not yet available.

Another casualty of the global lockdown was this year's HD COPE conference, which was due to be held in Toronto in March. Australasia is represented on the HD COPE Global Advisory Group by our CEO, Jan Samuels.

HD COPE (the HD Coalition on Patient Engagement) was established in 2017 by the European, US and Canadian national HD associations to give families affected by Huntington's disease a direct and impactful voice in HD clinical research.

The aim of the coalition is to replace the current ad hoc approach to incorporate the patient voice in therapeutic development efforts, with the goals of meeting the needs of the HD community, speeding up recruitment, and increasing retention for all HD clinical trials. The HD COPE Advisory Group provides counsel to clinical research leaders on broad issues involving patient feedback, community needs and research recruitment.

The HD COPE secretariat manages a team of 20 HD community representatives, predominantly from America, Canada and Europe, who share their perspectives of living with HD or caring for a person who has HD at meetings with regulators, pharmaceutical companies and researchers.



FUNDRAISING

One of the major challenges of the past 12 months is how to raise funds to support our programs across Queensland. Many of our services are not government funded and we rely on your generosity to keep these going.

Our 2019 Christmas appeal was well supported, with \$6,388 raised to help link Queensland individuals with research trials. With Covid-19 impacting so many people, we decided not to run our usual end-of-financial-year tax appeal. However, we were very heartened and humbled by the many friends and supporters of Huntingtons Queensland who still found ways to send donations and renew memberships.

GRANTS

We were also fortunate to win two government grants in the reporting period. The first – just over \$30,000 from the Gambling Community Benefit Fund – was to fund the upgrade of all our IT systems, email, electronic filing systems, phones and computers.

Ironically, the good news letter arrived in the same week we all began working from home. While this presented its own challenges, we are extremely grateful for this grant, which has made it possible for our team to work remotely and to continue helping families across Queensland in a way that would not have been possible with our old equipment and systems.

The second grant, of \$22,000 was received from Queensland Health and was targeted specifically at supporting families impacted by the Covid-19 pandemic. With these funds we have been able to purchase urgently needed equipment, such as iPads and computers, to help families stay in touch and connected with the outside world.

The other part of this grant has been used to pay for 'gap' payments for telehealth and counselling services for families with HD. There has been a huge increase in demand for such services and we will continue to seek funds to provide this valuable service in the months ahead.



We know this has been a hard year for everyone and we are so grateful for your continued commitment to our team and to supporting families impacted by Huntington's disease.



Our 2019 Christmas appeal asked donors to help us make waves!

THANK YOU

The following individuals, families and businesses made donations of \$500 or more the reporting period:

Anonymous
Joyce Bennett
James Callum

Cliff & Jenny Farmer Christine Gordon

Susan Howe

Peter Nash Peter Noonan

Doug & Lesley Sivyer

Estate of Laurence Tracona

Estate of Hilda Wilson



The following individuals, families and businesses made donations of \$200 or more during the year:

Anonymous
Cate Barrett
Gwenyth Beecham
Cindy Benjamin
Ronald Bladen
Margaret Bruce
Sandra Burns
Susan Campbell
Delmae Clark
Fay Cutmore
Eric Denham
Cheryl Dowling

Irene Golby
Mary Grant OAM

Stephen Earl

Jan Hall J Hartkopf

Jean Heimgartner Margaret Anne Johnson

Shane Kelly Nicole Lofting Kathryn Munro **Bruce Perkins Denis Persley** Mavis Pilla Gwen Pratten Jan Samuels Malcolm Scarr Jarrod Shandley **Denise Simmons** Ken Sleeman Dorothy Smyth Adrian Stephens Appelien Stride Christine Taylor Carol Thornton **Shirley Timmins** Bill Van Heel Kay Vander Have Arnold Waugh Maida White Jody Williams Meredith Williams

Tony Woods

We acknowledge our generous donors and volunteers for supporting people impacted by Huntington's disease.

Your support is crucial in keeping our services available, and we are so grateful for your trust in our work.

We couldn't do it without you.
Thank you.



Dedicated supporter and volunteer Alan McKinless at the Ipswich Railway Museum for our community fun day



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Och Charity Code of Chip Bill A

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