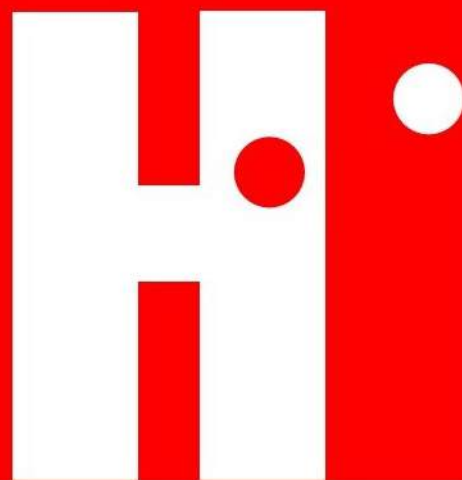


HAEMOPHILIA FOUNDATION QUEENSLAND

2018 / 19 ANNUAL REPORT

Including Audited Financial Results





7 - 13 OCTOBER IS BLEEDING DISORDERS AWARENESS WEEK!

Haemophilia Foundation Queensland Inc.

Help raise awareness of people living with bleeding disorders by participating in an event during Bleeding Disorders Awareness Week.

To participate or for more information
Phone 0419 706 056
or email info@hfq.org.au

FNQ Bleeding Disorders Event

Get involved
8 - 9 June 2019

Castaways Resort
and Spa

Mission Beach

**PARTICIPANTS
WELCOME!!**

To register your interest
please contact Graham or
Sam at the HFQ office
0419 706 056
info@hfq.org.au



**HFQ 2018 COMMUNITY
NOOSA NORTH SHORE RETREAT**
\$100 per family \$70 per couple \$40 for individuals \$20 for children (subsidies available on request)
Nature, outdoor adventure, play, explore, share
ALL NEW ACTIVITIES
FRIDAY 9 TO SUNDAY 11 NOVEMBER
Contact the HFQ office on info@hfq.org.au or 0419 706 056 to register & for more information.

PICNIC IN THE PARK
FOR BLEEDING DISORDERS AWARENESS WEEK
SUNDAY 7TH OCTOBER
12PM - 4PM AT BANYO MEMORIAL PARK
LIVE MUSIC | FOOD TRUCKS | STALLS | FAMILY FUN

Your invited to HFQ's
OBEYANCE LUNCH
Gathering
4 July 2019
Haemophilia Foundation Queensland Inc. Phone 0419 706 056 email: info@hfq.org.au

**WFH 2018
WORLD
CONGRESS**
What News from the WFH Congress?
HFQ Member update, Tuesday 7 Aug 10:00am

Bleeding Disorders Art-Ex Celebration
5.00pm RBWH Art Space - 17 April 2019
Come and join with us to celebrate
World Haemophilia Day
Wine and Cheese event in the RBWH Art Space
To acknowledge and celebrate the contributing artists and their art works that will be on display in the RBWH art space throughout April as our main awareness raising activity for 2019.
Please RSVP to info@hfq.org.au or call 0419 706 056 for catering purposes by 10 April

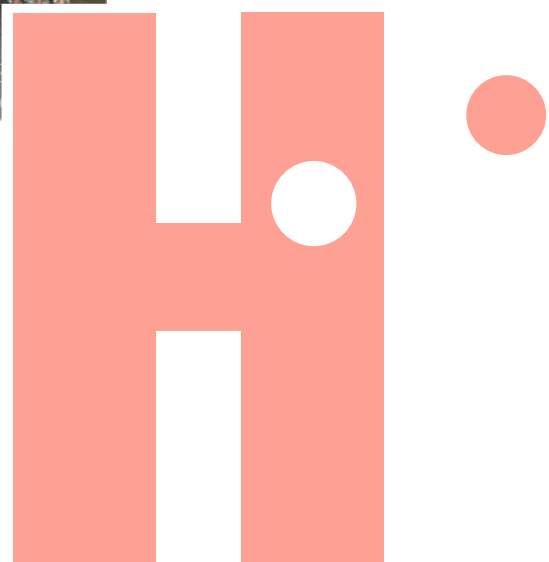


HFQ Kayaking
for dads and sons
Sunday 19th August
@ 10:30am
followed by BYO lunch
\$15 per person
For all young people from 6 to 16 and their parent / carer
All equipment provided
Financial subsidies available

HFQ 2019
Australia Day Saturday
BBQ by the Pool (10:30 to 3:00)
Settlement Cove Lagoon, Redcliffe. Please RSVP for catering
Email: info@hfq.org.au Office: 3017 1778 Mobile: 0412 915 429

RUNNING, WALKING & WHEELCHAIR
TO RAISE AWARENESS OF BLEEDING DISORDERS

Women's BRUNCH
From 10.30am on Sunday 18th Nov 2018
@ Café 63 1020 Stanley St E, East Brisbane
For more information or to RSVP, Please Phone 0419 706 0056 or email info@hfq.org.au



HFQ Board Members 2018 /19

President: Dave Stephenson

Vice President: Robert Weatherall

Treasurer: Adam Lish

Secretary: Lauren Albert

Ordinary Board Members

Erl Roberts

Dr John Rowell

Leanne Stephenson

Michael Holloway

Michael O'Reily

Robert Weatherall

Patron

The Honourable Mr Paul de Jersey. AC. Governor of Queensland

HFQ Staff 2018 /19

Manager: Graham Norton

Admin Officer: Samantha Williams

Contractors / Consultants

Gigi Lacey (Community Sector Consulting)

Odile Mignot (Accountant)

Kirstie Richardson (Audit)

With special thanks to the following volunteers

Brett Williams

Charles Eady

Darian McCrindle

Felix Fogerty

Ian Zaro

Ian Prescott

James Rogers

Jill Scholes

Lea Emery

Dr Melanie Jackson

Shannon Gracey

Shannon Weatherall

and the staff of the QHC

and apologies to any volunteers not listed here

From the President

Achieving best outcomes possible for people affected by bleeding disorders.

Haemophilia Foundation Queensland (HFQ) works in direct partnership with the two Queensland Haemophilia Treatment Centres (QHTC) with funding from Queensland Health to improve the well-being of those touched by bleeding conditions in Queensland. I must thank all involved and especially the HFQ board for its commitment and support during the year.

As you will all know, Dr John Rowell has been a significant force in the care of those with bleeding conditions over many years. Dr Rowell has also been a board member of HFQ, adding his experience to the decisions and services we provide. At this year's AGM he is stepping down from that roll and we thank him for his contribution to the work of HFQ. We celebrated this contribution last year with the governor of Queensland presenting him with an award. Well done Dr Rowell and thanks from all in the Qld bleeding community!

I am pleased to report that the board continues to have the skills to lead HFQ, with balance, diversity and personal experience it makes for good planning and decision making with great connection to our community.

Evidence based health outcomes through empowerment, connection, representation, education, health promotion and support are what we continue to focus on daily. HFQ continues to 'punch well above its weight' delivering services to those individuals and groups with identified needs – thanks also to the expertise and hard work of Graham Norton, and the QHTC, together we do make a difference – engaging community in healthy outcomes.

A multitude of treatment products and drug trial continue to progress around the world, and gene therapy looks to be on the horizon. We have also seen Hemlibra for haemophilia A becoming available in many countries, with some access here in Australia. The standard of care in Australia is high but those with significant issues like inhibitors continue to suffer. With the National Blood Authority tender finishing at the end of December, we look forward to better options for the bleeding community.

This past year has been busy with many projects and support events covering all demographics, including awareness events such as the Banyo Picnic in the Park (thank Shannon and Charles) for Bleeding Disorders awareness week, along with lighting many Queensland landmarks red for World Haemophilia Day. HFQ is in a sound financial position and we appreciate financial donations from many people, especially the Prescott Family Foundation Trust, who have provided support for wheelchairs and our residential workshops.

HFQ, in partnership with Qld Health and those affected by bleeding disorders, continues to deliver evidence-based service with positive health outcomes. I look forward to an even better year ahead. Thank you to everyone involved.

David Stephenson

President HFQ

Health promotion, Representation, Education, Support

president@hfq.org.au

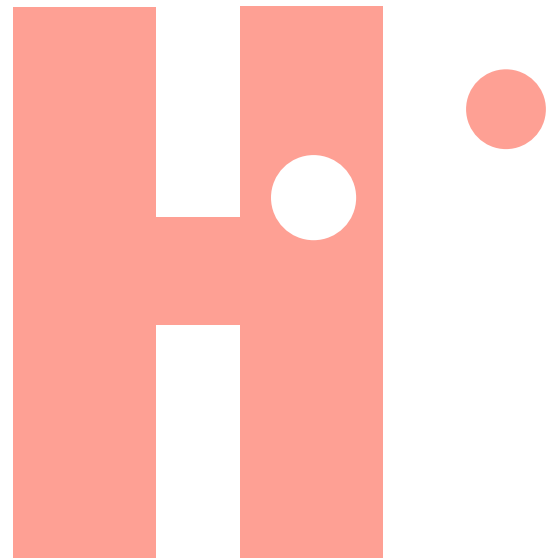




Haemophilia Foundation Queensland Inc

ACTIVITY REPORT

For the year ended 30 June 2019



In Memoriam

We remember our members, friends and volunteers who have died during the year; they have left us with hope and determination: hope that we can provide information and support for our members to lead positive lives and determination to ensure that the tragedies of the past are resolved and will never happen again.

HFQ particularly notes with sadness the passing of June Roberts (Wife of Erl) who passed away in January 2019; and Michael Churchill (Brother of Wayne and previously from Northern NSW) who also passed away in January 2019. Our condolences to their families and loved ones.

From the Manager

2018/19 was a busy year for Haemophilia Foundation Queensland, and HFQ remains a vibrant, people-focussed, forward-thinking organisation. This is a real achievement for a volunteer run, patient advocacy and support organisation in the 21st century.

From traditional programs to new initiatives, support for members considering genetic trials or new EHL medications, HFQ was actively involved and making a difference throughout the year. Our community camp, in particular, was a tremendous success this year, with over 70 participants filling the program to capacity.

It is a pivotal time for HFQ to work closely with state government, our peak body HFA and the clinical staff at the two haemophilia centres to ensure access in Queensland to the new and effective treatments that are now becoming available internationally.

Your staff, board members and volunteers have been busy providing a wide range of opportunities for people to develop peer support relationships and education, as well as planning for the future. I encourage you to get involved with HFQ, as your organisation.

In November 2018 we welcomed Samantha Williams who joined us as our administration officer. Sam is giving freely of her skill and spirit and it makes a big difference to what I can do as the only other paid staff member.

Particularly in this report, I think it is important to recognise the hard work of the HFQ board, who for most of 2018/19 worked both in the oversight and setting of our goals for focused service delivery and as key volunteers and users of our services.



Picnic in the Park (Banyo)

Graham Norton (Manager & Lauren Albert (Secretary) selling raffle tickets

Thank you also to our two clinical teams, who not only provide wonderful support to members, but also freely give of their time to support the work of HFQ at camps and workshops. Their involvement greatly enhances our ability to improve the lives and long-term outcomes of people impacted by bleeding disorders.

But above all, the successes of 2018/19 are thanks to you, our wonderful sponsors, funders, partners, and donors large and small. Your generosity and support of the bleeding disorder community make our work possible. Although we operate in a constantly changing environment, the needs of the community are always our #1 priority. By being involved, you show us what is important. Thank you for continuing to lead the way.

We're going places

As a community, we have endured many trials and tribulations since HFQ was founded, on our collective and individual journeys. The hope for a better future which started to become possible due to the first clotting factor concentrates, was impacted by the devastation caused by the contamination of many of those products with HIV and Hepatitis C which caused untold misery and many deaths in our community, almost wiping out a generation of people with haemophilia.

From the tentative hope at the start of treatment opportunities, a new reality is finally starting to become apparent. A reality that moved from on-demand use of recombinant products, to regular

prophylaxis for children. And now moving to the new generation of extended half-life products and soon the availability of subcutaneous therapy for people with FVIII inhibitors.

We are in an era of exciting improvements in treatment and the promise of an effective cure via gene therapy which has been a distant dream for more than 20 years is now fast approaching. Despite the exciting therapeutic landscape, there are always challenges and we have certainly responded in this past year in many innovative ways.

We continue to evolve as the patient support and advocacy organisation serving the bleeding disorder community in Queensland. While our name is the Queensland Haemophilia Foundation, our reach extends far beyond haemophilia as we also serve those affected by von Willebrand disease, platelet function disorders and rare factor deficiencies.



OBE Gathering at the Greek Club

Financially we had a strong year with income increased by 18% compared to the 2017/18 year and our expenditure decreased slightly. The result was a surplus of over \$32,000. The increased income was primarily due to a wonderful gift from the Prescott Family Foundation. Our Ministry of Health contract has also been confirmed for a further three-year term, with the funding agreement and key performance indicators secured from the 2019–2020 financial year forward.

These investments in the future make such a difference to our sustainability and potential services that I find myself thinking of, and being grateful to our generous supporters, and I join with our board in thanking our donors and supporters who have remained loyal to the work of HFQ over many years.

The Year in Review

Print media and campaigns

The 'H' factor is HFQ's quarterly magazine and four issues were produced in the reporting period. We continue to post and email copies to our members and any person affected by bleeding disorder's in Queensland. It is recognised by our community as a source of high quality, relevant and up-to-date information and news about bleeding disorders. The magazine is part of the suite of communications we employ in reaching our members.

Several member updates were emailed out last year and we distributed HFA's 'Female Factors' resources, that give information about how bleeding disorders affect young women and teenage girls, with FAQs and personal stories. We also sent out posters and material for World Haemophilia Day and for 'PROBE', a member's survey run through the WFH that will allow future comparison of member wellbeing across different countries.

Website and Social Media

The website keeps getting good reports and there was no downtime during the period. Google analytics says there were 1,200 users who accessed 2.5 pages on the site and that 65% were from Australia and of the known locations, 34% of total traffic is Queensland specific.

Our Facebook page had a maximum reach was 669 people, with a mean of 178 views for our posts and over 150 postings were made during the year which attracted over 500 likes. Awareness events (World Hepatitis Day; World AIDS Day; Bleeding Disorders Awareness week; World Rare Disease Day & World Haemophilia Day) created spikes in page views and a president's post on living with haemophilia in Fiji exceeded 600 views.

Peer Support Services

During the year 11 group meetings for older men (OBE's) were held with an average attendance of 10 people. We also held 4 brunch meetings for women affected by bleeding disorders with an average attendance 16 people. A self-care forum was also conducted and more continue into this year.

A walking group participated in the Bridge to Brisbane 5km event in August despite torrential rain; and we also held a youth kayak day in August at Enoggera Reservoir, so the young ones had the chance to meet others before camp; and a family event for Australia day (Pool Party at the Redcliffe Pools)

During the year a board member conducted a meeting in Townsville and the manager travelled to Toowoomba and the Sunshine and Gold Coasts to engage with members about their needs and what level of engagement they want.

Particularly successful events included...



HFQ Youth Kayak Day Event

An information stall at the RBWH Haematology GP Education Day in July 2018 and a members' Glasgow Report Back Session by Dr Jane Mason with 12 members in attendance.



HFQ Members' Glasgow Report Back Session

Our biggest public awareness event was a Picnic in the Park run by members Charles Eady and Shannon Gracey. Several members from SE Qld made the effort to come and support the event which we used as an opportunity to inform and education the public and to speak to members and their extended family members who came with them.

During April, the month that World Haemophilia Day occurs we held an art exhibition in the RBWH exhibition space. This was a public awareness raising event where several members from SE Qld made contributions of art works that were displayed. The exhibition launch was held on World Haemophilia Day itself and we were also

successful in getting notable landmarks across Brisbane lit red plus a Mackay fountain coloured red for the day.

Community and Youth Camps

The annual Youth Camp occurred in September with 15 young people in attendance including the facilitators. This camp is for boys between the ages of 10-18 and their siblings. Of the target group we had 11 boys with haemophilia, 1 with von Willebrand and 3 girls attending, 2 of whom had the gene for haemophilia.

We were lucky to again have Dr Melanie Jackson conduct several sessions with the young boys on infusion and living with a bleeding disorder and we thank her for her involvement. Youth camp continues to evaluate well as evidenced by the new participants, the feedback forms and the large number of hits on our Facebook posts.

The Bleeding Disorders Community camp was held in November 2018 at Noosa North Shore Retreat and 72 people attended representing 23 family groups. The camp returned to Noosa after a previous camp evaluated poorly. This camp evaluated well with families highly valuing the opportunity to meet with each other and support themselves in maintaining good health and wellbeing.

We were grateful that Dr Simon Brown from the QHC was able to attend and present several sessions with participants on new treatments and current issues the campers were experiencing or wanting information on.

Partnership activities

Close working relationships continue with the QHC staff especially the psycho/social-work team and we collectively conducted a stall at the Haematology GP Education Day in July 2018 as well as the monthly meetings for men surviving with a bleeding disorder (see peer support services).

During this reporting period we identified two distinct needs that we want to address (employment for young people with bleeding disorders and ageing issues) in the next year.

Welfare Support Services

38 welfare support requests were received and approved by the board across the financial year - 3 of these welfare requests were for assistance in providing wheelchairs where the hospital system was unable to do so

Looking Forward

During the year, there were several issues raised where some members are experiencing negative impacts.



Happy Campers at our Community Camp

Some young members are finding career prospects difficult to identify and seem reliant on welfare support. They report difficulties in continuing to treat prophylactically and managing their bleeding disorder, while trying to hold down a job or attending to tertiary studies. At the other end there are problems of early ageing and disability; and pain management is an on-going issue; as is access to the NDIS and/or Centrelink services

The writing of HFQ's new 2020 - 2022 Strategic Plan was prioritised during the year. The Board chaired a Strategic Planning Working Group to coordinate the engagement and consultation process needed to write the next strategic plan and final member consultation is starting in October 2019.

HFQ remains steadfast in our commitment towards advancing care and treatment opportunities for our members, until such a time as cures are found. We continue to advocate on behalf of our members, training future leaders and ensuring our state-based treatment centres continue to meet the standards of care we have the privilege of maintaining here in Queensland. Our job is never done.

There are still gaps in services for people with bleeding disorders e.g. people not eligible for NDIS and some other services no longer being covered by the state system. Thanks to our generous supporters, HFQ is able to continue with a big body of work, and as your manager, I am committed to furthering the goals of HFQ toward our vision of a world free from the pain and suffering for people affected by inherited bleeding disorders. We should all be proud of our accomplishments over the past year and look forward to HFQ continuing to be here and relevant for members, thanks to the loyalty and passion of all our stakeholders.

Graham Norton
Manager

Our **Vision**

Achieving best outcomes possible for people affected by bleeding disorders

Our **Mission**

People with Bleeding Disorders achieving full social participation & wellbeing, through Health Promotion, Education, Representation, and Support.

Our **Values**

We care for the health and wellbeing of everyone affected by bleeding disorders; we relate everything we do to the needs of everyone affected by bleeding disorders; act with Integrity and respect; make the best use of our resources and are Responsive to the needs and aspirations of our members.

From the Treasurer

Treasurer's report for the financial year ending 30 JUNE 2019

My financial report presenting the operating performance and financial position of HFQ as at 30 June 2019 is as follows:

The financial report is a special purpose financial report prepared to satisfy the financial reporting requirements of the Australian Charities and Not-for-profit Commission Act 2012 and the Associations Incorporations Act (Q/d) 1982 (as amended by the Associations Incorporation and Other Legislation Amendment Act (Q/d) 2017).

The accounting statements have been prepared on an accruals basis and are based on historical cost. HFQ adopts appropriate internal controls and decision-making policies approved by the Board in carrying out activities, programs, duties and responsibilities of HFQ.

Operating Performance

The 2018-19 financial year saw HFQ continue to utilise detailed forecasting and budgeting planning processes, which allow the organisation to analyse historical costs and formulate a realistic prediction of expected cost, aiding the creation of an appropriate budget for the Board to plan and conduct all of the organisation's operations (events, day-to-day running costs, welfare, etc.).

As treasurer, I believe that this has allowed the Board a better insight into where and how we are spending and which items we are over/under spending on, thus allowing better responsiveness and management of costs as they become realised or extra expenses occur or the reallocation of funds as necessary.

I expect HFQ to continue to maintain financial efficiency and incorporate information, such as the welfare overspend, to better plan for future expenses, be capable of meeting financial obligations, and be flexible with regard to variable expenses like the welfare HFQ provides among other things.

I would like to acknowledge a substantial donation by the Prescott Family Foundation, who have donated a sum of \$20,000. HFQ would like to thank the Prescott family and we look forward to investing the money into the organisation for the benefit of the community.

HFQ's other investments along with the Prescott family donation, leaves HFQ in a strong financial position with respect to reserve operating funds as at the conclusion of the 2018/19 financial year. HFQ will continue to plan for the longevity of the organisation in any event government funding were to be in question.

Financial Position

HFQ continues to maintain a stable financial position. Cash at bank has increased by 19% and the balances totalling \$210,181 is sufficient for the total financial obligations.

The ongoing support from the Queensland Health grants program enables the Board's objectives and programs to be delivered to the community throughout the year.

In the opinion of the Board the financial reports are in accordance with the *Australian Charities and Not-for-profit Commission Act 2012* including;

- Presenting a true and fair view of HFQ's financial position as at 30 June 2018 and its performance for the year ended on that date;
- Complying with the *Associations Incorporations Act (Qld) 1982* (as amended by the Associations Incorporation and Other Legislation Amendment Act (Qld) 2017) and the *Australian Charities and Not-for-profit Commission Act 2012*;
- At the time of this statement there are reasonable grounds to believe that HFQ will be able to pay its debts as and when they become due and payable.



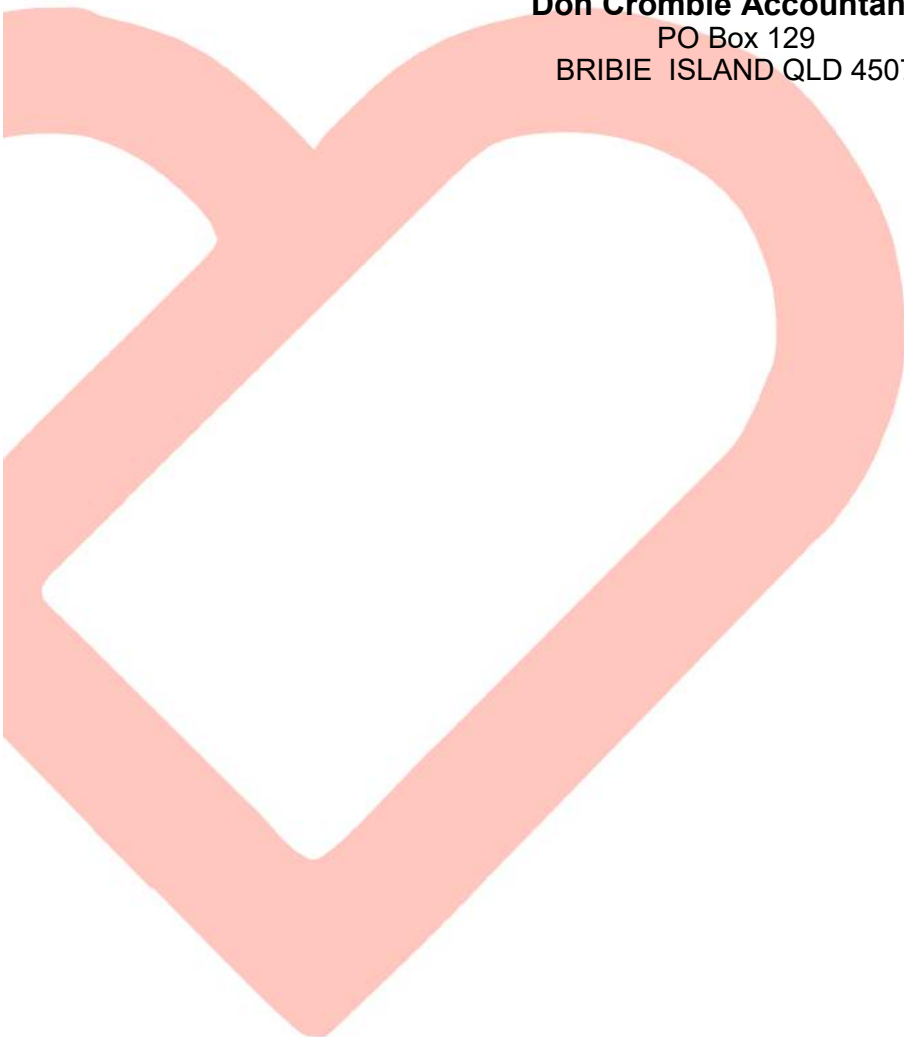
Adam Lish
Treasurer

Haemophilia Foundation Queensland Inc

FINANCIAL REPORT

For the year ended 30 June 2019

Prepared by
Don Crombie Accountancy
PO Box 129
BRIBIE ISLAND QLD 4507



QUALIFIED AUDITOR'S REPORT

Don Crombie CPA

71 Welsby Parade
BRIBIE ISLAND Q 4507
Phone: 07 3408 0011

To The President & Members
Haemophilia Foundation Queensland Inc

SCOPE

I have audited the financial affairs of the Haemophilia Foundation Queensland Inc for the period ended 30 June 2019. The members of the committee of the association are responsible for the preparation and presentation of the financial report and the information contained therein. I have conducted an independent audit of the financial report in order to express an opinion on it to the members of the association.

My audit has been conducted in accordance with Australian Accounting Standards to provide reasonable assurance as to whether the financial report is free of material misstatement. My procedures included examination on a test basis, of evidence supporting the amounts and other disclosures of the financial report and the evaluation of accounting policies and significant accounting estimates. These procedures have been undertaken to form an opinion as to whether in all material respects, the financial report is presented fairly in accordance with Australian Accounting Concepts and Standards so as to present a view which is consistent with my understanding of the association's financial position and results of its operations. The audit opinion expressed in this report has been formed on the above basis.

QUALIFICATIONS

As is the case with organisations such as yours, my test of income received has necessarily been confined to transactions within the accounting records.

QUALIFIED AUDIT OPINION

In my opinion, except for the above qualifications, the financial report presents fairly in accordance with Statements of Accounting Concepts and applicable Accounting Standards the financial position at 30 June 2019 and the results of its operations for the period then ended.

23 September 2019
Date

DS Crombie

Donald S Crombie FCPA
Auditor

1:44 PM

23/09/19

Accrual Basis

HAEMOPHILIA FOUNDATION QUEENSLAND INC.**Balance Sheet**

As of June 30, 2019

	Jun 30, 19
ASSETS	
Current Assets	
Chequing/Savings	
PayPal	2,301.75
Suncorp Linked AC Term Deposit	7.64
Debit Card	1,491.98
Gov't Account	12,434.92
Society Account	30,980.32
Term Deposit (Suncorp)	162,964.62
Total Chequing/Savings	210,181.23
Total Current Assets	210,181.23
Fixed Assets	
Office furniture/equipment	328.10
Total Fixed Assets	328.10
TOTAL ASSETS	210,509.33
LIABILITIES	
Current Liabilities	
Other Current Liabilities	
Payroll Liabilities	
PAYG Withholding	2,460.00
Super Payable	1,646.94
Total Payroll Liabilities	4,106.94
Tax Payable	2,349.99
Total Other Current Liabilities	6,456.93
Total Current Liabilities	6,456.93
TOTAL LIABILITIES	6,456.93
NET ASSETS	204,052.40
EQUITY	
General reserve	122,482.34
Retained Earnings	49,220.92
Net Income	32,349.14
TOTAL EQUITY	204,052.40

Audited Statements. To be read in conjunction with the attached Audit Report.

HAEMOPHILIA FOUNDATION QUEENSLAND INC.
Profit & Loss Prev Year Comparison
July 2018 through June 2019

	Jul 18 - Jun 19	Jul 17 - Jun 18
Ordinary Income/Expense		
Income		
Charitable Contributions	29,602.28	15,823.72
Interest received	3,420.66	3,182.33
Membership	690.87	981.78
Service fees	154,739.00	150,783.00
Total Income	188,452.81	170,770.83
Gross Profit	188,452.81	170,770.83
Expense		
Accountancy/Audit fees	3,156.06	3,595.71
Bank Charges	340.50	540.98
Computer Costs	1,518.78	378.18
Consultancy fees	1,027.95	2,835.00
Event Expense	25,790.09	18,904.80
Insurance		
Employer liability	810.71	813.26
Professional indemnity	1,905.10	1,630.00
Sickness and accident	498.00	0.00
Workers compensation	377.43	1,005.74
Total Insurance	3,591.24	3,449.00
Meeting Expense	1,869.44	1,890.45
Office Supplies	2,541.06	1,965.10
Payroll Expenses		
Gross Wages & Salaries	74,997.83	75,569.54
Super contrib. - employees	7,033.13	7,112.14
Total Payroll Expenses	82,030.96	82,681.68
Postage	2,463.66	1,727.46
Printing and stationery	5,070.25	4,418.27
Promotion	2,066.71	841.41
Rent	11,000.00	12,000.00
Subscriptions & memberships	1,019.24	886.48
Telephone/Mobile/Internet	692.23	1,203.11
Training Education	1,143.16	4,622.12
Travelling expenses	1,928.45	5,314.94
Website Expenses	538.93	0.00
Welfare Assistance		
Health Support	8,090.14	12,937.74
Other Support	224.82	0.00
Welfare Assistance - Other	0.00	613.64
Total Welfare Assistance	8,314.96	13,551.38
Total Expense	156,103.67	160,806.07
Net Ordinary Income	32,349.14	9,965.76
Net Income	32,342.14	9,965.76

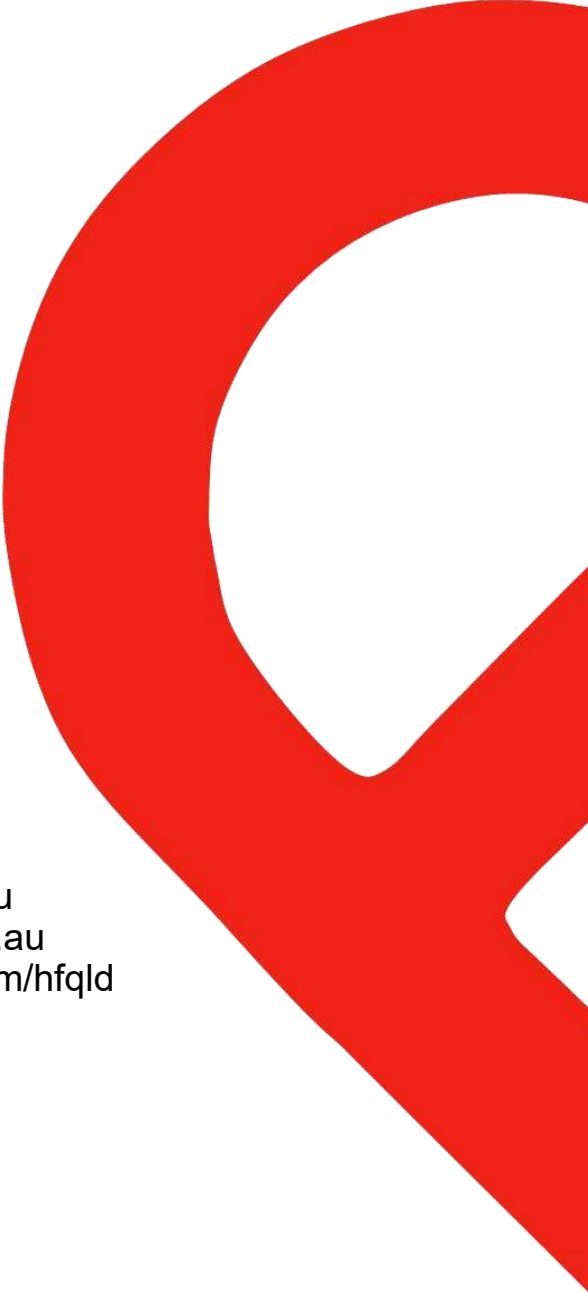


Published by **Haemophilia Foundation Queensland Inc.**

Registered as a charitable institution

ABN: 62 303 495 207

27 September 2019



P.O. Box 122
Fortitude Valley
Queensland 4006

Tel: (07) 3017 1778

Mobile: 0419 706 056

Email: info@hfq.org.au

Website: www.hfq.org.au

FB: www.facebook.com/hfqld