### **HAEMOPHILIA FOUNDATION QUEENSLAND**



### HFQ Board Members 2017 /18

President: Dave Stephenson

Vice President: Robert Weatherall

Treasurer: Adam Lish

Secretary: Lauren Albert

### **Ordinary Board Members**

**Erl Roberts** 

Dr John Rowell

Leanne Stephenson

**Robert Weatherall** 

Nikki Smith (from Dec 2017)

### **Patron**

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

### HFQ Staff 2017 /18

Manager: Graham Norton

### 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

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.

HFQ works in direct partnership with Queensland Haemophilia Treatment Centre (QHTC) with funding from Qld 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. The HFQ board brings balance and personal experience which makes for better planning and decision making, with representation

directly from community, as well as professional experience - including medical and finance.

Evidence based Health outcomes through Representation, Education, Health Promotion and Support is what we continue to focus on daily. It is a hard job for the sole paid employee who is also responsible for all the administrative requirements as well as or community magazine and social media outputs – well done Graham Norton.

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 the QHTC, together we do make a difference – engaging community in healthy outcomes.

The climate of treatment options around the world continues to grow with more effective treatments being trialled and some now appearing in Australia. We are indeed one of the lucky countries. Although we have a high standard of care, the issue of inhibitors to treatment is still a significant one for the individuals and those supporting them - HFQ looks forward to better treatment options for these people who are at significant risk of bleeding.

Great news this year... clearing hepatitis C (the silent killer) from the bleeding community is a real possibility, and it's happening thanks to the Australian government funding new treatments. Feedback from one doctor indicated every person with haemophilia that he has treated has been cured of HCV – simply brilliant. Unfortunately, it does not fix the significant damage the virus has done to the many livers over the decades.

This year was industrious and enjoyable and with a clear sense of the issues affecting community we aim to continue to deliver targeted services where they are needed.

Lastly, I would like to thank you, the community for your support .... working together for common outcomes across Queensland. I look forward to an even better year ahead.

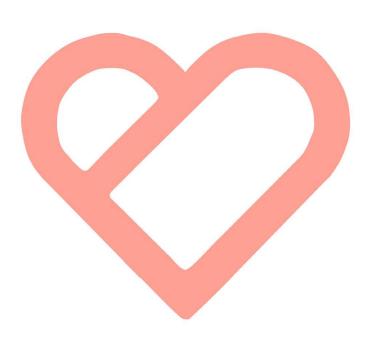
**David Stephenson** 

President HFQ

Health promotion, Representation, Education, Support

president@hfq.org.au

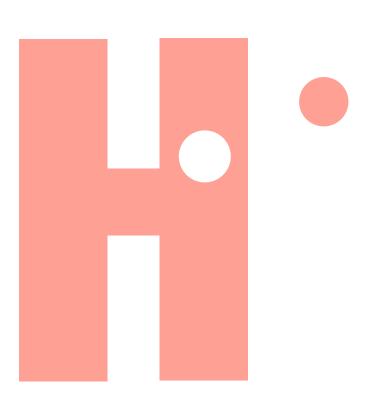




### **Haemophilia Foundation Queensland Inc**

### **ACTIVITY REPORT**

For the year ended 30 June 2018



Haemophilia Foundation Queensland (HFQ) represents all people living with a bleeding disorder in Queensland. We do this directly with our members and through a partnership with the Queensland Haemophilia Centre to assess and respond to the changing needs of community members with bleeding disorders throughout Queensland. This partnership, in addition to other important outcomes, aims to address the psychosocial needs and assists in providing education with the goal of prevention of related health issues.

During the year under review several members who were using the new extended half-life factor therapies as well as the subcutaneous treatment "Hemlibra" in clinical trials and extended access programs attended HFQ events and their testimony got members very excited. This excitement increased following a major announcement made about genetic treatment and an effective cure for haemophilia and the NBA announcing access to extended half-life products for about 200 patients Australia-wide. As a consequence there was considerable interest from our members in when these therapies will become readily available in Australia .

### **Board of Management**

Membership of the board currently stands at 11. They are: Adam Lish; David Stephenson; Erl Roberts; Dr John Rowell; Lauren Albert; Leanne Stephenson; Mike O'Reilly; Nicole Smith; and Robert Weatherall. David Bratby stood down as ordinary board member and Peter David stood down from the role of treasurer at the last AGM. We appreciate the time and energy demands people have on them in daily life

and thank them for their contributions to the board. We also welcomed Nicole Smith and Mike O'Reilly onto the board as ordinary board members. and Adam Lish took on the treasurer's roll. We also welcomed Robert Weatherall into the vice president's position.

#### QHC and Volunteers.

Volunteers - The foundation is fortunate to have maintained the generous support of many volunteers across Queensland we rely heavily on their goodwill in the delivery of support services to members and their families. Their support comes in a variety of ways; board members,

administration, fundraising, running and hosting events. We cannot thank them enough for their loyalty and the supportive role they play in the successful

operation of HFQ.

Government House World Haemophilia Day function
L-R: Dave Stephenson (President); Erl Roberts (Member Contribution Award) The Honourable
Mr Paul de Jersey AC Governor of Queensland (Patron); Dr John Rowell (Long Service
Award); Rebecca Jenson (Fundraising Award); Graham Norton (manager)

<u>Qld Haemophilia Clinic (QHC)</u> - HFQ maintains a very close working relationship with the staff at the adult and paediatric haemophilia centres. Through their Brisbane based clinic and outreach visits they act as a link to their patients (our members) and identify needs and concerns that we can advocate or intervene on behalf of. QHC staff have also been exceedingly generous in supporting the work of the foundation through direct volunteer roles at our events and through fundraising. Their clinical service is highly valued by HFQ and the members and carers who utilise it.

The manager attends the monthly QHC staff meeting to ensure feedback can be received and given from our respective engagement with people affected by bleeding disorders in Queensland. During the year in review Dr John Rowell stepped back as Director of Queensland Haemophilia Centre at Royal Brisbane and Women's' Hospital and Dr Jane Mason was recruited to the roll. We know that many members valued John as their haematologist and we are grateful that John decided to stay on the HFQ board for this period.

Jane has been welcomed by the board and the HFQ membership alike and HFQ will continue to support the clinics by providing collaborative events and additional equipment as required by the clinic or their patients, communicating education and health issues to members; and financially supporting extra activities as required.

### **Activities and Programs of the Foundation**

The primary focus of the foundation is the support of people diagnosed with an inherited bleeding condition and their careers, families and others impacted by that bleeding condition. We do this through the provision of information, referrals, residential weekends, support group activities and emotional support. Our overall goal is to provide a flexible service to meet the varying and complex needs of our community. Support and education services are also provided as required to other community support groups and services, care providers and health professionals throughout Queensland.

### **Support Group Activities and Meetings**

Running forums, day activities and residential events for different subsets of people with\_bleeding disorders helps us provide social support and education to our members. We also offer peer support opportunities at these events and during the year the manager dealt with 30 one-on one interventions as well as multiple member support requests. We also supported the QHC psychosocial staff with their NDIS forum which was a streamed session held at the North Lakes health facility. We had 8 members in attendance at North Lakes and the telehealth streaming allowed for 5 others to view and participate from 3 regional locations.

### World Haemophilia Day

On World Haemophilia Day this year our patron, the Governor of Queensland, His Excellency the Honourable Paul de Jersey AC, and Mrs Kaye de Jersey, hosted a function at Government House to mark the occasion and to acknowledge the contribution of three significant contributors to HFQ in Queensland who have worked very hard to raise awareness and ensure that our programs complement the treatment and care offered by the state haemophilia clinics.

The principle award recipient was Dr John Rowell. Given for his lifetime of care and support of people with bleeding disorders in Queensland. We were extremely grateful that current and past QHC team members as well as RBWH administrators were able to join us as the governor presented John with his award.

A second award was presented to Erl Roberts for the lifetime of work he and his wife June have contributed to HFQ and to all people with bleeding disorders across Australia. The final award recipient was Rebekah Jensen whose mum has factor 10 deficiency. Bec has and continues to raise funds and awareness for people with bleeding disorders in Queensland. Over 70 people attended the late afternoon event and it was lovely to have our patron and his wife work with us and make their lovely official residence available to us for this event.

<u>OBEs</u> is held monthly to provide opportunity of mutual support and friendship. OBEs also has presentations on health issues and travels occasionally through SE Queensland so other members can join with the core group. During this year OBE's held 10 meetings mostly in Brisbane but one in Toowoomba and one on the Gold Coast were also held.

Family Functions. Currently our focus is on providing a quarterly Ladies Brunch event and four were held during the reporting period. We also had a successful meeting of families with young children in conjunction with Dr Moana Harlan at Lollypops Playland. These meetings offer a support opportunity for families with younger children and new families to meet and talk about their concerns while hearing stories of how other people have handled living with a child who has an inherited bleeding condition. Activity outcomes include learning new parenting skills and exploring different ideas being explored on how to manage the daily challenges of having a child with a bleeding disorder. These activity outcomes can be difficult for the treatment centre staff to deliver within clinical environments, so we work together on these and other events.

<u>Youth Camp.</u> The Commu<mark>nity camp did not run in this reporting period but will be held again in November. The strategy of 18 months between camps is to allow for HFQ to fund it from its own money if we are unsuccessful in getting a Community Benefit Fund Grant money as was the case for</mark>

We were lucky to have Dr Melany Jackson for the weekend and she conducted several sessions with the young boys while one of our senior peer mentors ran a parallel session with the uninfected siblings. The camp had a different dynamic because of the parents and three were encouraged to not participate so their child could be encouraged to extend themselves under careful supervision. 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.

Regional outreach. In addition to the OBE meetings in regional areas, a major Toowoomba event was held for our local members in November. A BBQ at Laurel Bank Park attracted several families from Toowoomba and the Darling Downs, followed by laser tag and 10 pin bowling for the younger ones and a quieter coffee event allowing for friendships and discussions to happen between our adult members.

Events were also held at Rockhampton and the Gold Coast to co-inside with the clinic meetings. Visits and contact with members living in regional areas was also undertaken by some board members and staff. These visits are complemented by telephone contact with



**Toowoomba Darling Downs Regional Event** 

members and networking with health professionals and community support groups.

#### Communications

The foundation provides up to date information through various communication methods to inform members and their families about bleeding disorders, services offered by the foundation, and services available in the community that they can readily access. Information is distributed through the foundation's magazine 'the H factor', our website, face book page and via email blasts and mail outs. We also promote event attendance to members through SMS. Electronic media continues to be an important way to reach a younger audience and we added an Instagram account to our social media communication tools.

The board communications working group continued to review and make changes to our website and have developed a pull-up information banner as a stand-alone information resource that works well with the new HFA released general community brochure on bleeding disorders.

<u>Magazine</u> Four issues of the H" factor were distributed through the reporting period and the last one contained a survey seeking reader feedback so we can make the magazine as useful as possible to our members. Feedback from readers indicates that this continues to be well received and that they value the updates on new research as well as the practical information and personal stories. The magazine continues to evolve as a responsive communication service to members on current practice, future opportunities as well as promoting upcoming events and support.

<u>Website.</u> The new website keeps getting good reports. Almost all forms are now done electronically via the website and we have also set up an online payment's portal. There was no downtime during the period

and the most popular downloads (after event forms), continues to be the magazine. Google analytics says 1611 users accessed 2.5 pages on the site and that 43% of total traffic is Queensland specific.

<u>Facebook.</u> Our reach continues to increase with organic reach climbing to a mean of 393 for our posts and 90 postings were made across the reporting period. As always there were spikes of interest during World Haemophilia Day in April and Bleeding Disorders Awareness Week in October when our reach exceeded 5,000 for one post. We also got good responses from members to our video posts from youth camp (2 @ 3,900 each)

Member Communication. The magazine and other important material were mailed to members on the data base but there were issues with the database during the year and we have to rebuild it after a technical glitch. We have also started developing email and SMS lists, so we can continue to match Information dissemination to member needs

#### **Education**

In addition to the NDIS forum and the launch of the generic HFA brochure and HFA information pull-up banners both the 18th Australian & New Zealand Conference on Haemophilia & Rare Bleeding Disorders and the WFH 2018 World Congress occurred during the reporting period.

<u>Haemophilia Conferences</u>. The Australian & New Zealand Conference was in Melbourne and occurred in October. Given the rapid changes in treatment and diagnostic help coming on-stream these gatherings are seen as important opportunities for our members to meet with health professionals, policy makers, industry representatives and other stakeholders to share information and learn from each other. HFQ contributed to the costs for getting 12 members to that conference. We also funded the president to attend the Glasgow congress on our behalf.

<u>Haemophilia Journal.</u> HFQ remains committed to sourcing and understanding current research and clinical practice for people with bleeding disorders. We maintained our subscription to Haemophilia Journal and forward the contents page to local QHC staff and state foundation coordinators. We also have a small resource library available for members to access on request. In addition, the manager attended updates to ensure his current knowledge and the support he offers members and the board is accurate and up to date.

#### **Individual Support & advocacy**

Staff and volunteers provided peer based social and emotional support to people with a bleeding condition and their families during the year. These were provided on an individual basis and through family support where home visits, telephone and coffee catch up saw an average of one intervention per week.

#### **Welfare Support**

People with bleeding disorders have not always been able to access well paid jobs and long career paths and the foundation has long been mindful that there are increased costs to maintaining optimal health with a bleeding disorder. The established supports have undergone significant change in the last 12 months with the introduction of NDIS and many members appear to be falling through the gaps of current supports being offered. Our fundraised money allows us to respond with limited financial help where no other support is available. This was done via requests for assistance from the QHC social work and psychological team members.

<u>Financial support.</u> In the reporting period over \$6000 was dispensed to meet financial needs and this was in response to 14 individual requests as well as meeting emergency cab-charge and parking costs when it would have otherwise prevented access to clinical services. Welfare requests were not excessive in the number of requests but the cost of items where members say they are unable to get assistance from other sources has increased. In this reporting period the two wheelchair assistance requests came to over \$7,000 between them!

<u>Equipment loans.</u> In the year being reported the board was grateful to receive a one-off grant of \$10,000 to purchase wheelchairs over the next 12 months. This will enable us to meet QHC physiotherapist and member requests where immobilisation of a joint or muscle bleed is required. The board thanks the Prescott Family Foundation for responding positively to this request.

### **NGO Synergies**

The manager continues to look for synergistic and beneficial relationships with NGO's and other organisations. New in this period was a meeting with Spina Bifida Queensland and Cystic Fibrosis Queensland. The manager also met with Hepatitis Queensland; Huntington's Queensland and Carers Queensland. He participated in the HIV Community Advisory Board Meeting run by Prof Gilks and an attempt to understand the issues for people with medically acquired HIV was started in the reporting period. We also continued to liaise with Queensland Positive People; Hepatitis Queensland and Arthritis Queensland on a regular basis.

### **Funding and Community Grants**

Adequate funding of the foundation is crucial to its success and it is therefore important that we maintain a strong working relationship with our current funding bodies. In this year our current Queensland Health grant is half way though it's three-year funding cycle and it is pleasing that we have met all required performance measures.

Gambling Community Benevolent Fund. HFQ has always sort additional funding for the Community Camp and HFA helped us apply for funding during this reporting period but regretfully we were unsuccessful for this year's camp. This is why the board has put it back by 6 months to enable us to meet most cost from current funds.

<u>HFA.</u> Continue to help us with the above grant and other funding applications and we think them for their ongoing support in this and other



Banner and stall at GP Education Day (RBWH)

L-R: Loretta Riley (Haemophilia Social Worker); Graham Norton (HFQ manager)

matters. In this reporting period they made several unsuccessful funding applications on our behalf, but also had success for funding our youth camp.

<u>Fundraising</u> continues to be an issue and we thank all members who have helped in the area. In the year being reported the board was grateful to receive a one-off grant of \$10,000 from the Prescott Family Foundation, a private ancillary fund which will allow us to purchase wheelchairs over the next 12 months. The board is indebted to lan Prescott who put us forward to his families foundation as being both necessary and deserving of this funding support and we thank the Foundation for responding positively to this request.

**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, though 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 2018

My financial report presenting the operating performance and financial position of HFQ as at 30 June 2018 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 (*Qld*) 1982 (as amended by the Associations Incorporation and Other Legislation Amendment Act (*Qld*) 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 2017-18 financial year saw HFQ continue to implement and 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.

One particular overspend during the financial year was on welfare support, HFQ received some substantial requests for support which attributed to the overspend; these requests were subsequently approved by the Board, all of which were deemed worthwhile and in line with our goals and mission as an organisation.

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.

The Board also moved during the year to restructure and streamline it's accounts to minimise fees and account costs whilst achieving maximum interest returns. HFQ has also continued to invest its financial reserves in a term deposit to ensure the longevity of its operations in the event government funding were to cease or for extra special expenses.

### **Financial Position**

HFQ continues to maintain a stable financial position. Cash at bank balances totalling \$177,582 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-forprofit Commission Act 2012 including;

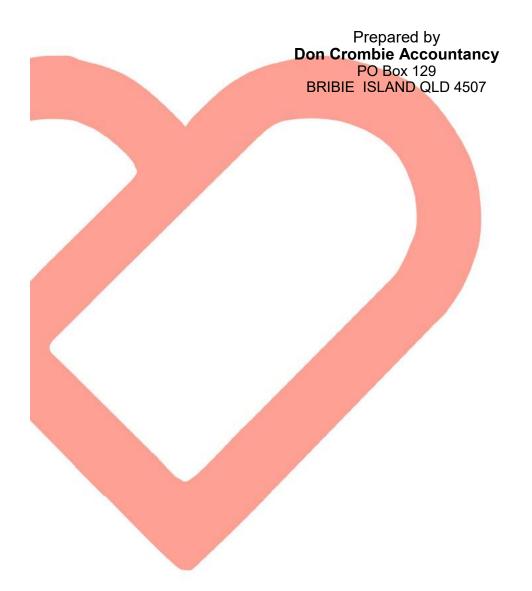
- Presenting a true and fair view of HFQ's financial position as at 30 June 2018 and its performance for the year ended on that date;
- Complying with the Associations Incorporations Act (Qld) 1982 (as amended by the Associations Incorporation and Other Legislation Amendment Act (Qld) 2017) and the Australian 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 2017



### 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 Haemophilia Foundation Queensland Inc for the period ended 30 June 2018. 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 2018 and the results of its operations for the period then ended.

DECEMBER 2018

**Donald S Crombie FCPA** 

OS Grandie.

Auditor

# Haemophilia Foundation Queensland Balance Sheet

As of June 30, 2018

_	Jun 30, 18
ASSETS Current Assets Chequing/Savings	
Debit Card	703.11
Gov't Account	13,322.68
Society Account	29,004.70
Term Deposit (Suncorp)	134,552.17
Total Chequing/Savings	177,582.66
Total Current Assets	177,582.66
Fixed Assets Office furniture/equipment	328.10
Total Fixed Assets	328.10
TOTAL ASSETS	177,910.76
LIABILITIES Current Liabilities Other Current Liabilities Payrol Liabilities	0.770.00
PAYG Withholding Super Payable	2,776.00 1,641.96
Total Payroll Liabilities	4,417.96
Tax Payable	1,791.00
Total Other Current Liabilities	6,208.96
Total Current Liabilities	6,208.96
TOTAL LIABILITIES	6,208.96
NET ASSETS	171,701.80
EQUITY	
General reserve	122,482.34
Retained Earnings	39,250.98
Net Income	9,968.48
TOTAL EQUITY	171,701.80

# Haemophilia Foundation Queensland Profit & Loss YTD Comparison July 2017 through June 2018

	Jul 17 - Jun 18	Jul 16 - Jun 17
Ordinary Income/Expense		
Income Charitable Contributions Interest received Membership Other revenue Service fees	15,823.72 3,183.33 981.78 2.72 150,783.00	8,651.47 3,050.77 981.80 1.83 146,925.00
Total Income	170,774.55	159,610.87
Gross Profit	170,774.55	159,610.87
Expense Sundry Expenses Accountancy/Audit fees Bank Charges Computer Costs Consultancy fees Event Expense Insurance	0.00 3,595.71 540.98 378.18 2,835.00 18,904.80	215.91 2,389.00 517.12 5,406.53 1,413.64 26,433.29
Employer liability General Professional indemnity Workers compensation	813.26 0.00 1,630.00 1,005.74	1,327.91 384.87 3,104.75 1,221.92
Total Insurance  Meeting Expense Office Supplies Payroll Expenses Gross Wages & Salaries Super contrib employees	3,449.00 1,890.45 1,965.10 75,569.54 7,112.14	6,039.45 4,396.00 3,249.75 74,477.08 6,954.60
Total Payroll Expenses	82,681.68	81,431.68
Postage Printing and stationery Promotion Rent Subscriptions & memberships Telephone/Mobile/Internet Training Education Travelling expenses Website Expenses Welfare Assistance Health Support	1,727.46 4,418.27 841.41 12,000.00 886.48 1,203.11 4,622.12 5,314.94 0.00	1,889.53 6,150.33 2,790.46 13,000.00 819.19 961.80 1,577.27 2,002.03 947.27 4,122.71 2,262.50
Other Support Welfare Assistance - Other	0.00 613.64	0.00
Total Welfare Assistance	13,551.38	6,385.21
Total Expense	160,806.07	168,015.46
Net Ordinary Income Other Income/Expense Other Expense	9,968.48	-8,404.59
SUSPENSE	0.00	0.00
Total Other Expense	0.00	0.00
Net Other Income	0.00	0.00
Net Income	9,968.48	-8,404.59

