



THE NEW ZEALAND NATIONAL

HUNTINGTON'S

ANNUAL REPORT

2018-2019

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WHAT A BRILLIANT YEAR



**2018
2019**



MERRY CHRISTMAS & HAPPY HOLIDAYS

CHAIRPERSON'S REPORT

This has been another exciting year for the Auckland Huntington's Association. As always, we have concentrated on our core mission which is to maximise the quality of life of individuals living with Huntington's Disease.

We continue to take a longitudinal view and walk the journey with families/whanau and individuals with HD. Our CEO is in her 15th year working alongside and walking the journey with these families/whanau. Our Support Worker is in her second year and our Administrator has been a HD volunteer for over 10 years. We are so fortunate to have such a dedicated and passionate team of hard working personnel.

The past year unfortunately has been dominated by financial challenges, which we have been able to overcome with continued hard work, and going forward we now have a good future.

While our core mission has not changed, the Association is certainly changing its approach on obtaining funding sources.

I would like to thank everybody involved with the Auckland Huntington's Association, the committee's tireless hard work and enthusiasm. All our funders and supporters and last but not least, Jo and her team for the ongoing commitment and dedication towards our HD whanau/families/individuals.

Janine Butters



Young people impacted by Huntington's disease are over twice as likely to experience traumatic events in their childhood, compared to those not in families with Huntington's disease. The Auckland HD Association is the primary organisation focused on supporting young people impacted by HD in the Auckland and Northland area. They aim to protect current and future generations by offering:

HOPE, SUPPORT, COUNSELLING, EDUCATION, RESEARCH AND TREATMENT OPTIONS

CEO REPORT

Kia ora and thank you to all our supporters for your generosity that has helped the Auckland Huntington's Disease Association continue its core duties by:

- Ensuring those who need it get the right support services and medical attention
- Enabling others to understand the disease
- Furthering research to manage/treat symptoms and cure Huntington's Disease

Your money has been well spent on ensuring we negotiate a seamless care pathway with appropriated treatment plans for all those affected by Huntington's Disease.

Your support enables us to continue to collaborate locally, and provided on-going educational sessions, free of charge, to anybody that needs them.

- Taikura Trust Needs Assessment team
- Over 65 year needs assessment team
- Huntingtons Disease of Christchurch and Wellington
- Regional HD Service within mental health, led by Dr Kritzinger Neuropsychiatrist
- Genetics Department
- HD Enroll Study
- Other likeminded Not-For-Profit Organisations/Associations



- Independent Living Services Auckland and Northland
- WINZ
- Northland, Waitemata, Auckland and Counties Manukau DHBs
- Speech and Language Therapists
- Occupational Therapists
- All community homes, rest homes and private hospitals were Individuals with HD reside

By working in collaboration with others we are able to:

- Reduce hospital admissions by 54%
- Reduce length of stay in Hospital facilities by 4.3 nights to 2.5 nights
- Reduce suicide rates in the HD population
- These all empower our population we currently serve and builds a more positive future for our Youth

We offer a **free** service to all ages. Our youngest is 12 years of age and our eldest is a grandparent 98 years of age. HDs does not discriminated against age, ethnicity or culture.

Jo Dysart

HUNTINGTON'S *Keep up to date*

WITH LOCAL, INTERNATIONAL, AND GLOBAL RESEARCH AND TREATMENT PATHWAYS:

- CENTRE FOR BRAIN RESEARCH
- HUMAN BRAIN BANK
- NEUROLOGICAL FOUNDATION OF NEW ZEALAND
- BRAIN RESEARCH NEW ZEALAND

Your support

ENABLES US TO CONTINUE TO COLLABORATE ON A GLOBAL SCALE

HD Victoria
HD Hide no more
Other Study

HD ENROLL
HDYO/HDSIY
European HD Study Group

**5TH OCTOBER AT OWAE MARAE, WAITARA
SIR RICHARD FAULL SHARED EXCITING NEWS
ON HUNTINGTON'S DISEASE RESEARCH**

*Hope for all
the whanau*



Sir Richard Faull travelled to Taranaki to share exciting news, accompanied by Waiora Port and Jo Dysart

CHARLES SABINE

EMMY AWARD WINNING, GLOBAL SPOKESPERSON FOR HD AND NOW KEY NOTE SPEAKER FOR NZ NATIONAL CONFERENCE

Charles Sabine is an Emmy award winner for News & documentary. He worked for NBC news for 26 years before becoming a global spokesperson for individuals with HD. He is also gene positive.

His message is “not to give up on life”. It was in a London pub that he wrote the slogan ‘HDdenomore’ (‘Hidden No More’) and set about trying to host a HDdenomore event at the Vatican. The initial idea was to have one Venezuelan (Venezuela was where the HD gene was found by a researcher) family member meet the Pope and get a photo taken. A testament to Pope Francis is that he allowed the numbers to steadily increase to 150 individuals from 28 countries to stand together and say the words “The time has come for this to be hidden no more”.



MEETING POPE FRANCIS

Charles has witnessed many extraordinary events in his life, including the Berlin Wall and the end of Apartheid in South Africa. But he says none of them compare to the feeling in the room on that day, “It was truly magical moment”.

We were there.

New Zealand was not only honoured by being mentioned as the group who had travelled the longest distance but we were also privileged to be allocated VIP seating. This enabled us to be one of the 150 out of the 2000 individuals to have a personal encounter with Pope Francis.

An amazingly sacred journey was had by all.



KEY NOTE SPEAKER AT THE NZ NATIONAL CONFERENCE

It was a dream come true to have Charles Sabine as one of our keynote speakers, alongside our international guest Professor Julie Stout from Monash university and our local HD Heroes: Sir Richard Faull and Professor Maurice Cuties from Centre of Brain Research at Auckland University.

Charles was very busy while in Auckland. Prior to the Conference we were able to have a reunion with most of the individuals who attended the Rome trip with Charles.

He spent the day at the Centre for Brain Research presenting to researchers and medical staff from Auckland City Hospital. He spent the afternoon being interviewed with the Neurological Foundation of Auckland.

Charles was on Breakfast TV with Jack Tame. This was an amazing interview and can be seen on our Facebook page.



WHERE YOUR MONEY GOES

Without your generous support this past 2018/19, the HD Association Auckland would not have been able to meet their core goals. Your support goes directly into our core mission which is to maximise the quality of life of Individuals living with Huntington's Disease.

Some of the goals of the Association include:

- Ensuring those who in need can access the right support services and medical attention
- Enabling others to understand the disease
- Furthering research to manage and cure Huntington's Disease

A recent study show that working in collaboration with others we are able to:

- Reduce hospital admissions by 54%
- Reduce length of stay in hospital facilities by 4.3 nights to 2.5 nights
- Reduce suicide rates in the Huntington's population

These all empower our population we currently serve and builds a more positive future for our Youth.



Over 80% of funds are put towards education and awareness to help increase understanding and support for individuals with HD to create social inclusion within their community.

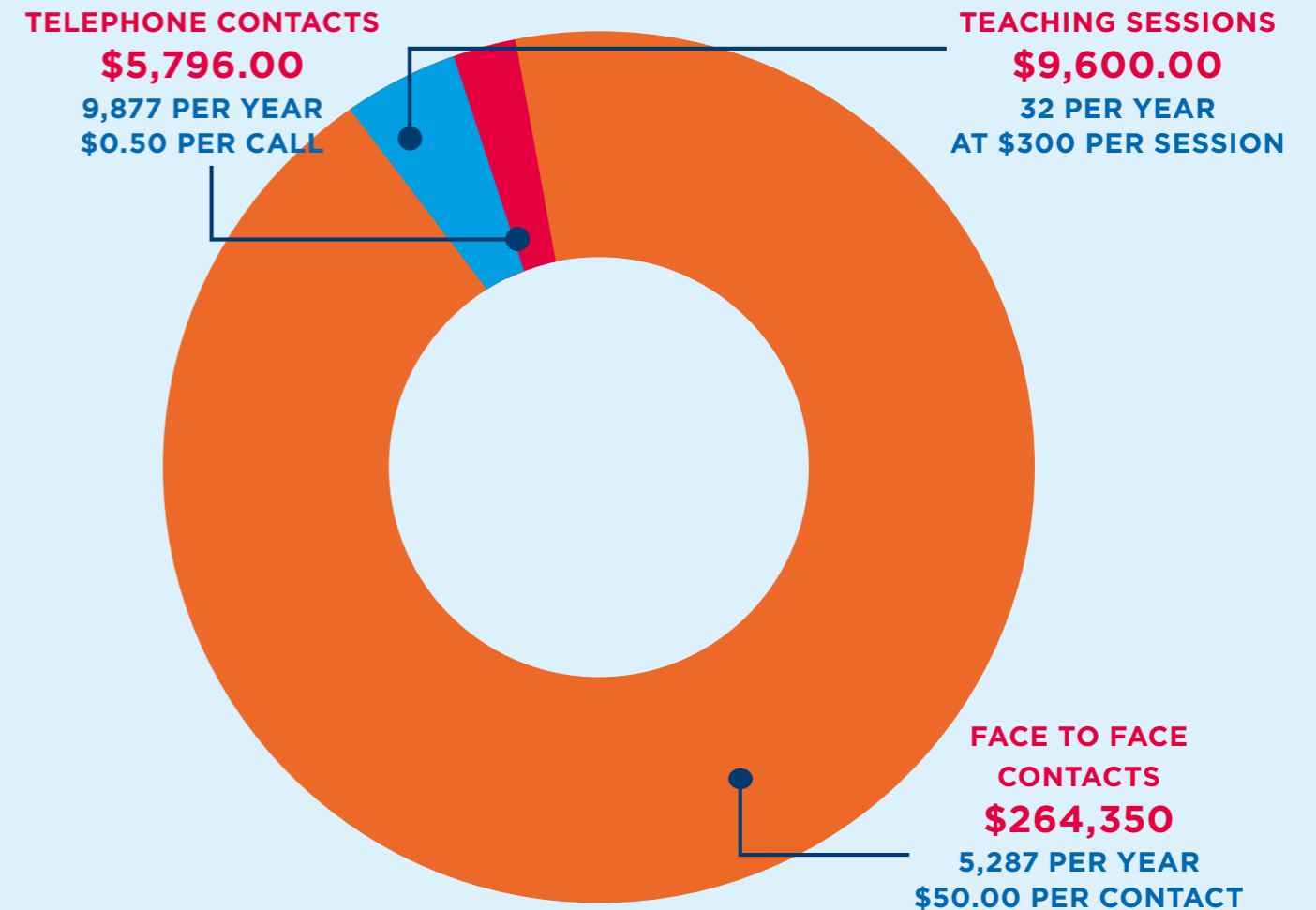
A percentage is then used to cover administrative costs and to continue our fundraising efforts.



THANKS TO YOUR GENEROSITY
IN THE YEAR TO MARCH 2019

\$281,148

HAS FUNDED...



This continues to provide a needs-led-service rather than a service-led-service resulting in a decrease in hospital admissions, and a reduction in suicides.

\$0.50
FOR ONE PHONE CALL

\$50
FOR ONE HOME VISIT

\$300
FOR ONE EDUCATIONAL SESSION/WORKSHOP

A REVIEW OF THE YEARS EVENTS

JUST A FEW SNAPS FROM SOME OF OUR EVENTS THIS YEAR ALONG WITH THE HD NATIONAL CONFERENCE WHICH WAS A HUGE SUCCESS. THE HD BIG DAY OUT FOR FAMILIES/WHANAU WAS AT AUCKLAND ZOO, OVER 300 ATTENDED. SIR RICHARD FAULL ALSO ATTENDED WITH HIS FAMILY TO GIVE A HD RESEARCH UPDATE. WE HAVE HAD LION KING MOVIE NIGHT, ROBIN HOOD KIDS SHOW, BRAIN AWARENESS WEEK, A WINNER AT THE SPECIAL OLYMPIC WHANGAREI, A NIGHT AT THE THEATRE, SOME VERY SPECIAL BIRTHDAYS AND 32 EDUCATIONAL SESSIONS ALL DONE WITH YOUR SUPPORT, SO THANK YOU.



STATEMENT OF FINANCIAL PERFORMANCE

HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC.

Statement of Financial Performance For the Year Ended 31st March 2019

	2019 \$	2018 \$
Surplus from Trading	281,107	104,350
SUNDRY INCOME		
Interest Received	41	32
Total Income	<u>281,148</u>	<u>104,382</u>
Less Expenses		
Accident Compensation Levy	325	246
Accountancy Fees & Audit Fees	3,230	3,200
Publications	3,304	417
Bank Charges	55	93
Client/Patient Expenses	4,503	1,770
IT Expenses	5,040	747
Conference Expenses	47,202	-
General expenses	3,433	8,358
Insurance	3,704	3,694
Interest	8	3
Event Costs	4,777	3,082
Fundraising Costs	174	316
Motor Vehicle Expenses	5,889	5,384
Vehicle Lease Expense	12,295	12,650
Penalty & Infringement	-	85
Printing, Stamps & Stationery	2,447	2,080
Rents	9,685	9,647
Repairs & Maintenance	285	-
Other Employer Expenses	6,177	5,390
Dues & Subscriptions	44	44
Telephone, Tolls & Internet	5,429	5,906
Travel	8,082	17,223
Wages & Salaries	114,194	122,026
Total Expenses	<u>240,282</u>	<u>202,361</u>
Net Surplus/(Deficit) Before Depreciation	40,866	(97,979)
Less Depreciation		
Depreciation as per Schedule	158	244
Net Surplus/(Deficit) Before Beneficiary Distributions	<u>40,708</u>	<u>(98,223)</u>
NET SURPLUS/(DEFICIT)	<u>\$40,708</u>	<u>(\$98,223)</u>

HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC.

Statement of Financial Position As at 31st March 2019

	Note	2019 \$	2018 \$
CURRENT ASSETS			
ASB Bank - 00 Cheque Account		11,452	7,265
ASB Bank - 51 Savings account		50,645	6,604
GST Refund Due		-	842
Total Current Assets		<u>62,097</u>	<u>14,711</u>
NON-CURRENT ASSETS			
Fixed Assets as per Schedule		65	223
TOTAL ASSETS		<u>62,162</u>	<u>14,934</u>
CURRENT LIABILITIES			
GST Due for payment		7,336	-
Accounts Payable		3,499	3,322
Credit Card Creditor		1,971	2,153
Provision for Holiday Pay		4,811	5,622
Total Current Liabilities		<u>17,617</u>	<u>11,097</u>
TOTAL LIABILITIES		<u>17,617</u>	<u>11,097</u>
NET ASSETS		<u>\$44,545</u>	<u>\$3,837</u>
Represented by;			
ACCUMULATED FUNDS			
Retained Earnings		44,545	3,837
TOTAL ACCUMULATED FUNDS		<u>\$44,545</u>	<u>\$3,837</u>

For and on behalf of the Committee:

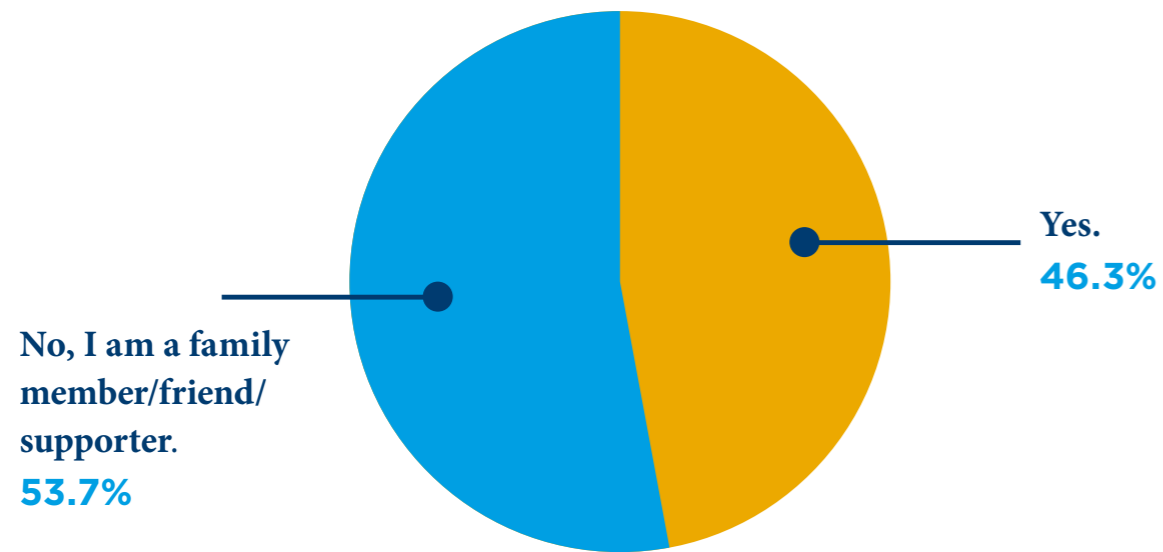
J. H. H. H. H.
Chairman
Date: 14/10/19

A. H. H. H. - TREASURER
Committee
Date: 26/9/19

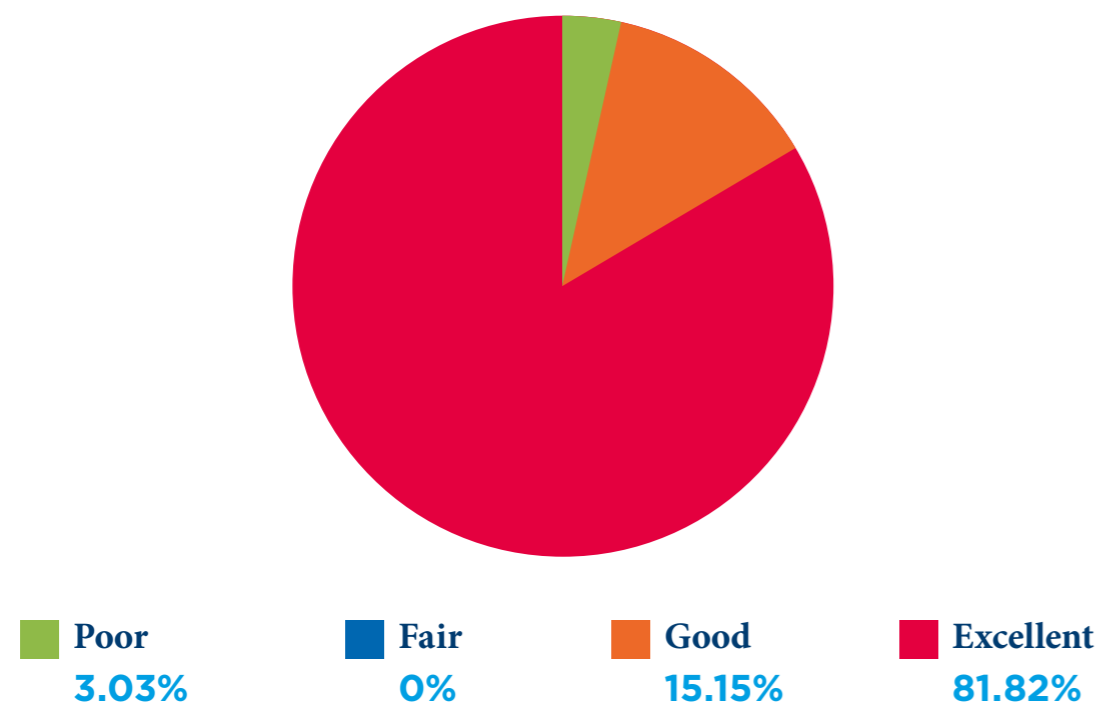
A full report of the Association's financial audit from the 2018/19 year can be found on the government's Charities website. Please visit: charities.govt.nz to download the audit report.

WHAT OUR POPULATION SAID ABOUT US IN 2018/2019

ARE YOU A CONSUMER?



OVERALL SERVICE



THANK YOU

Thanking our partners & supporters!

We would like to thank all our financial and non-financial supporters who have donated over the past year. We are truly thankful. Without your support we would not be able to continue.

NZ Lotteries
COGS
Foundation North
Lions Foundation
Four Winds
Pubs Charity
The Trust Community Foundation
Hugh Green Foundation
Freemasons Foundation
Centre for Brain Research
Neurological Foundation
Brain Research NZ
Mt Wellington Foundation
Neurological Alliance NZ
and all the HD Heroes that give their time unselfishly and freely

**COLLECTIVELY WE MAKE A DIFFERENCE
AND ENHANCE QUALITY OF LIVES
FOR THOSE AFFECTED WITH HD**

