



THE NEW ZEALAND NATIONAL

**HUNTINGTON'S**

# ANNUAL REPORT

**2019-2020**

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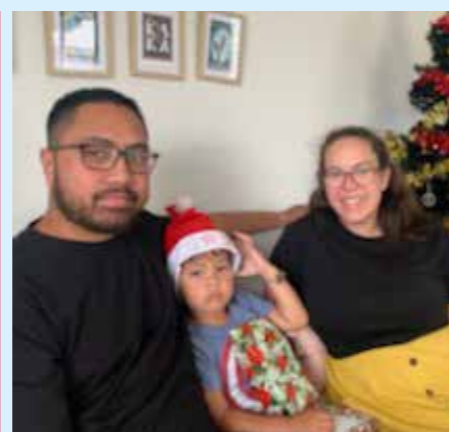


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**RESILIENCE  
+ HARD  
WORK**



**2019  
2020**



**Unite  
against  
COVID-19**

# CHAIRPERSON'S REPORT

Happy New Year to you all, 2020 has been a very trying year, but with hard work and resilience we made it. We managed to survive and continue to provide our HD families with the help and support they all need, whilst keeping our essential staff safe and well.



*Our Patron, Distinguished Professor Sir Richard Faull and our Chairperson Janine Butters*

Our Annual General Meeting was held in July, guest speaker was Dr Matthew Phillips clinical research neurologist at Waikato Hospital who gave a talk on the Keto diet and potential benefits for HD.



*Congratulations to Jo and Cheenee.*

In December we secured the release of the movie premiers 'Dancing at the Vatican' and 'Pounamu to the Pope', these were held at Rialto Newmarket and the following week at Lopdell House theatre in Titirangi. They were a huge success and very well received by all who attended, a huge thanks to those who organized these events, and to everyone who made this possible.

I would like to thank everybody involved with the Auckland Huntington's Association, the committee for their continued support, our funders and mostly Jo, Cheenee and Jenna who without them the association would not survive.

Congratulations to Cheenee completing her certificate in Study and Career Preparation (Mental Health), well done.

Congratulations also to Jo on becoming a Designated Nurse Prescriber. Well done, Jo is the first nurse in NZ working for HD to have completed Registered nurse prescribing in primary health and specialty teams.

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**

*Janine Butters*

# CEO REPORT

Kia Ora and thank you to all our supporters financial and non-financial for all your generosity through this very challenging year. With your support the Auckland Huntington's Disease Association has continued its core duties and many more 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
- 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 where individuals with HD reside



Meet the staff: Jo, Cheenee and Jenna

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 at 98 years of age. Huntingtons Disease does not discriminated against age, ethnicity or culture.

Due to Covid 19 we have added a few duties, such as having two separate teams in two separate bubbles, online shopping, social connection via zoom for family members, Covid 19 support to name just a few.

For the Auckland Huntingtons disease association as essential workers the pandemic meant that we adapted to a new reality and adopted new methods to provided safe connection with our vulnerable population. We had amazing support from larger Not-for-Profit organisations with food parcels and housing. We worked seamless with the DHBs and Taikura Trust to ensure all our population had adequate support and housing.

*Jo Dysart*

# Movie Premiere

In December we ended on a high with an amazing fundraiser by securing the release of the movie premiers *Dancing at the Vatican* and *Pounamu to the Pope*, these were held at Rialto Newmarket and the following week at Lopdell House theatre in Titirangi.

They were a huge success and very well received by all who attended, a huge thanks to those who organized these events, and to everyone who made this possible. These funds went to spread a little Christmas cheers to our families/whanau that have had such a difficult challenging year. Thank you to all for making this a successful event!

Watch these films for free by visiting:

<https://www.dancingatthevatican.com/>

<https://m.youtube.com/watch?v=WahOcTbQg44>

**AUCKLAND PREMIERES OF**  
**DANCING AT THE VATICAN**  
 AND  
**Pounamu to the Pope**

PROUDLY SPONSORED BY THE  
 AUCKLAND HUNTINGTON'S DISEASE ASSOCIATION AND  
 THE GARDEN OF ODDITIES

**WHO, WHERE AND WHY?**  
 Dancing at the Vatican was created by former war reporter Emmy award winner and global campaigner Charles Sabine, who is also from a Huntington's disease family. Together with leading neuroscientist Dr Ignacio Muñoz-Bermejo and geneticist Dr Claudia Patrón-Ramos, founders of FACHD, a charity that helps those affected by Huntington's in Latin America, and Dr Elena Cattaneo, who was made Life Senator in Italy for her work researching the disease put together an unforgettable trip to the Vatican.

**WHAT IS DANCING AT THE VATICAN?**  
 Dancing at the Vatican is a documentary that tells of a journey made by some incredibly brave families from Latin America each bound by the same devastating disease, Huntington's. There will also be a short film on the incredible journey made by the 12 New Zealanders that also had the privilege to be there on this day in history for Huntington's disease. A private interview with Charles Sabine, Emmy award winning, global campaigner and absolute gentleman will also be shown. The film sees those affected by the disease embarking on a life-changing mission to bring this long stigmatised disease out of the shadows.

**WHERE WILL THEIR DESTINATION BE AND WITH WHOM WILL THEIR TRAVELS CULMINATE?**

**WATCH DANCING AT THE VATICAN**  
 The group's journey was documented and has been made into a documentary film which will be shown at both Newmarket Rialto Cinema and Titirangi Lopdell House. Distinguished Professor Sir Richard Faull will be discussing the changing landscape of Huntington's research following the screening.

NEWMARKET RIALTO CINEMA		TITIRANGI LOPDELL HOUSE	
3RD DECEMBER	FROM 6PM	10TH DECEMBER	FROM 6PM

6PM DRINKS AND NIBBLES  
 6:30PM SIR RICHARD FAULL AND GUEST WILL INTRODUCE FILM

BOOK YOUR TICKET NOW \$20  
 FOR A STORY OF BRAVERY, DISCOVERY AND ENLIGHTENMENT  
 TICKET INCLUDES DRINKS AND NIBBLES

This screening event was sponsored by Roche Products (New Zealand) Ltd. The movie is entirely independent and Roche had no control over the content.





# 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.

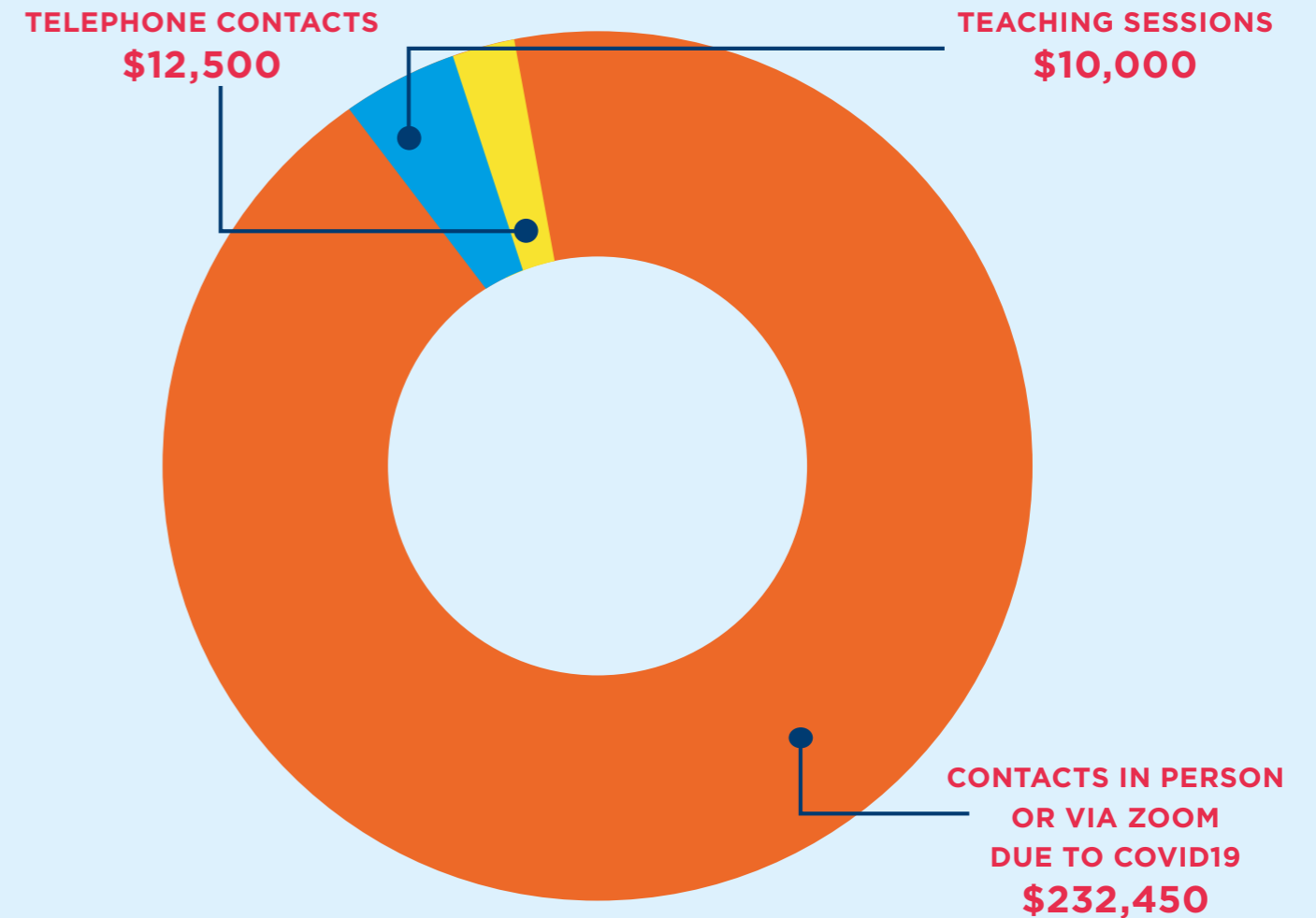


Over 80% of funds are put towards education and awareness to help increase understanding and support for individuals with HD to create social inclusion within their community.

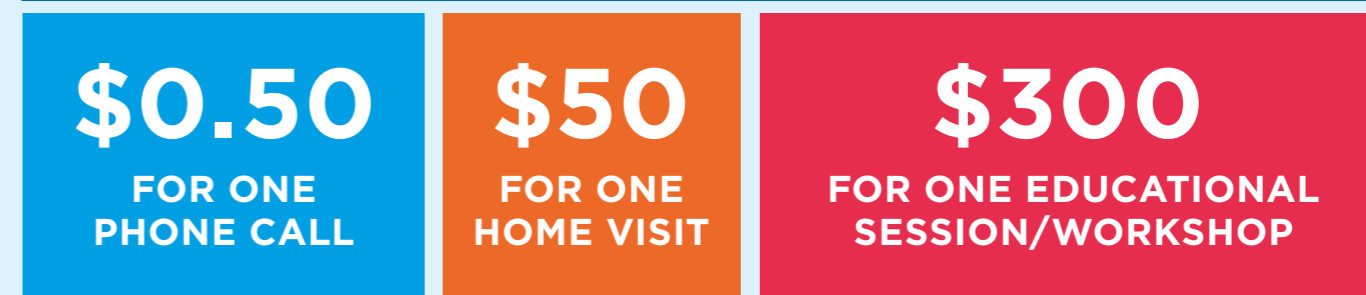
A percentage is then used to cover administrative costs and to continue our fundraising efforts.



THANKS TO YOUR GENEROSITY  
IN THE YEAR TO MARCH 2019  
**\$244,487**  
HAS FUNDED...



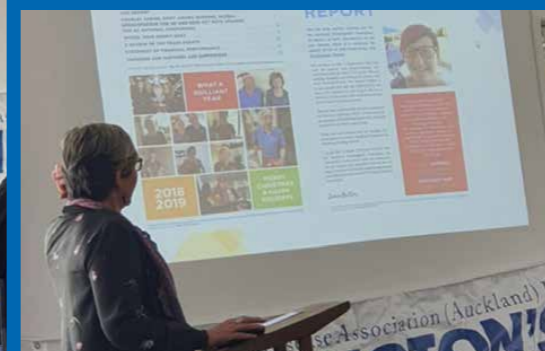
This continues to provide a needs-led-service rather than a service-led-service resulting in a decrease in hospital admissions, and a reduction in suicides.



# A REVIEW OF THE YEARS EVENTS

**DUE TO COVID WE STARTED OFF THE YEAR BY ATTENDING AS MANY WORKSHOPS AS POSSIBLE TO PREPARE FOR WHAT WAS TO COME. A BIG THANK YOU TO JENNA FOR KEEPING THE FUNDING APPLICATION GOING AND SHOWING MUCH RESILIENCE IN THIS FINANCIALLY CHALLENGING TIME, WELL DONE.**

As well as our Movie premiere we managed to hold a successful AGM in July between the lock downs. Our guest speaker was Dr Phillips FRACP a clinical and research neurologist at Waikato, Hamilton hospital. He gave a talk on the promising options of "metabolic interventions" (such as fasting and Ketogenic diets). We remained connected to our more rural HD population in Northland and Taranaki with home visits and support groups.



**BUT MOST OF ALL WE STOOD TOGETHER, CONNECTED AND HAD THE RESILIENCE TO STAND UNITED AGAINST COVID!**



# STATEMENT OF FINANCIAL PERFORMANCE

## Statement of Financial Performance For the Year Ended 31st March 2020

	2020 \$	2019 \$
<b>Surplus from Trading</b>	244,487	281,107
<b>SUNDRY INCOME</b>		
Interest Received	9	41
<b>Total Income</b>	244,496	281,148
<b>Less Expenses</b>		
Accident Compensation Levy	263	325
Accountancy Fees & Audit Fees	3,340	3,230
Publications	3,338	3,304
Bank Charges	115	55
Client/Patient Expenses	2,835	4,503
IT Expenses	1,056	5,040
Conference Expenses	1,947	47,202
General expenses	358	3,433
Insurance	4,701	3,704
Interest	7	8
Event Costs	9,518	4,777
Fundraising Costs	678	174
Motor Vehicle Expenses	5,521	5,889
Vehicle Lease Expense	14,361	12,295
Penalty & Infringement	101	-
Printing, Stamps & Stationery	1,626	2,447
Rents	9,270	9,685
Repairs & Maintenance	6	285
Other Employer Expenses	5,556	6,177
Dues & Subscriptions	100	44
Telephone, Tolls & Internet	5,472	5,429
Travel	14,988	8,082
Wages & Salaries	126,301	114,194
<b>Total Expenses</b>	211,458	240,282
Net Surplus Before Depreciation	33,038	40,866
<b>Less Depreciation</b>		
Depreciation as per Schedule	65	158
<b>NET SURPLUS/(DEFICIT)</b>	\$32,973	\$40,708

A full report of the Association's financial audit from the 2019/20 year can be found on the government's Charities website. Please visit: [charities.govt.nz](http://charities.govt.nz) to download the audit report.

## Statement of Movements in Accumulated Funds For the Year Ended 31st March 2020

	Note	2020 \$	2019 \$
<b>ACCUMULATED FUNDS AT START OF YEAR</b>		44,545	3,837
<b>REVENUE</b>			
Net Surplus for the Year		32,973	40,708
<b>Total Recognised Revenues and Expenses for the Year</b>		32,973	40,708
<b>ACCUMULATED FUNDS AT END OF YEAR</b>		\$77,518	\$44,545

## Statement of Financial Position As at 31st March 2020

	Note	2020 \$	2019 \$
<b>CURRENT ASSETS</b>			
ASB Bank - 00 Cheque Account		11,720	11,452
ASB Bank - 51 Savings account		85,104	50,645
<b>Total Current Assets</b>		96,824	62,097
<b>NON-CURRENT ASSETS</b>			
Fixed Assets as per Schedule		-	65
<b>TOTAL ASSETS</b>		96,824	62,162
<b>CURRENT LIABILITIES</b>			
GST Due for payment		8,291	7,336
Accounts Payable		3,579	3,499
Credit Card Creditor		2,022	1,971
Provision for Holiday Pay		5,414	4,811
<b>Total Current Liabilities</b>		19,306	17,617
<b>TOTAL LIABILITIES</b>		19,306	17,617
<b>NET ASSETS</b>		\$77,518	\$44,545
Represented by;			
<b>ACCUMULATED FUNDS</b>			
Retained Earnings		166,608	36,872
<b>TOTAL ACCUMULATED FUNDS</b>		\$166,608	\$36,872

For and on behalf of the Committee:

  
Chairman - Janine Butters  
Date: 20/11/2020

  
Committee - Matt Hobbs  
Date: 20/11/2020

# WHAT OUR POPULATION SAID ABOUT US IN 2019/2020

The Non-Paid essential workers, the caregivers the family whanau members in Auckland and Northland who provide 24 hour care to their loved ones had this to say about 2020...

My name is Steve,

I have been a caregiver for over 30 years now I looked after my wife she is passed now I am now looking after my two adult son's I am 80 years of age you know, this pandemic was hard the care givers did not always turn up as they were not cleared for covid. I had no escape, no rest I was just constantly in the caregiver role... Thank you to Cheenee for taking me out for a bit of time out.

-Steve

My name is Anna,

I got into a routine of caregiving for my husband over the past two years, but with the pandemic and having the kids home and being expected to home-school them well that was just too much, it just about broke me and I am paying for it now my mental health is not good, I do not know what I would have done without the Auckland Huntington's Association navigating the supports my family needed, thank you.

-Anna

My name is Sarah,

I have early stages of HD and had just stopped work as my symptom's had progressed to the point that I needed more time to look after myself and then the pandemic hit and my husband lost his job, This financial hit was huge. Thank you Jo for the food parcels and Cheenee for the support with WINZ.

-Sarah

My name is Ken,

I was homeless when the pandemic hit thanks for finding me shettle think I would be dead by now if I was left of the streets. Thank you for all the phone calls, the Zoom meetings and keeping us connected with our loved ones in care facilities. Thank you for all the shopping that has been dropped off. Thank you Jenna for all the online shopping that you organised.

-Ken

Together we did it...

# THANK YOU

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.



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



