



THE NEW ZEALAND NATIONAL

# HUNTINGTON'S

# ANNUAL REPORT

2021-2022



# CONTENTS

Chairperson report .....	3
CEO Report .....	4
Huntington's Disease Conference .....	5
Review of the years events .....	6
Financial Statement .....	8
Huntington's Disease Heroes .....	12

**CONTACT HD AUCKLAND:** TEL 027 4328 255, 0800 HDAUCK (0800 432 825) EMAIL [huntingtonsakld@xtra.co.nz](mailto:huntingtonsakld@xtra.co.nz)



Every Christmas we strive to share some joy to our families in the HD Community. Christmas can be a tough and stressful time for our people, so it is important for us to reassure them and continue to offer our service. There is nothing more rewarding than seeing the genuine smiles on their faces.



# CHAIRPERSON'S REPORT

It is with great pleasure that I welcome you to this year's annual general meeting and the annual general report for the Auckland Huntington's disease association. I am honoured to be able to present to you a summary of our organisations activities challenges and achievements over the past year.

As we look back on the past year we can be proud of the progress you have made in our mission to make a positive impact on those living with Huntington's disease in our community. Despite the challenges posed by COVID-19 pandemic and the aftermath of this our team have shown tremendous resilience and creative and adapting to the new norm.

During the past year we have continued to provide critical service to the community we serve we have focused on improving access to healthcare education and other basic services while we also advocate for the rights of living with Huntington's Disease our efforts have helped to improve the quality of life of many individuals living with Huntington's disease.

I want to extend this year why my warmest congratulations to Jo on becoming Nurse Practitioner for Huntington's disease this is a significant accomplishment that demonstrates her dedication hard work and passion for our community.

In the short term of you becoming nurse practitioner Jo has been able to make profound differences in their lives of those living with Huntington's disease. Jo's advanced knowledge and skills enables her to provide comprehensive and compassionate care which all our population benefit greatly from.

I would also like to acknowledge Jo's commitment to the Auckland Huntington's disease population this is her 20th year working for the Auckland Huntington's disease association. What a year to celebrate this amazing Nurse Practitioner achievement for our population congratulations we are all very proud of you.

*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

I am pleased honoured to present this my 20th annual report for the Auckland Huntington's disease association. As the CEO I am proud of the achievements we have made in the past year and the impact we have had on the community we serve. Our focus over the past year has been To provide support and advocacy services for those with Huntington's Disease. To provide information and support to family, carers, medical professionals and government support agencies. To act as a source of information for professionals involved with Huntington's Disease. To raise public awareness on Huntington's Disease. To support research into Huntington's Disease.

## **Our mission is**

*"The HD Association Auckland endeavours to provide confidential, non-discriminatory free service to all family and their whanau across the generations whose lives and those family/whanau that have been impacted by the disease. Huntington's affects all race, culture"*

The Auckland Huntington's disease association is committed to making positive impact in New Zealand in Auckland and Northland and we do this by addressing the issues that affect our community we work tirelessly to create awareness provide support and advocate for change through our efforts we in aim to improve the lives of those in need and create a more equitable society.

However we cannot do this alone as a not-for-profit organisation we rely heavily on the support of donors like you to fund our programmes and initiatives your support allows us to.

**Expand our reach and impact:** your donation enables us to reach more people and have a greater impact on our communities.

**Provide critical services:** with your support we can provide vital services to those who need them the most including food shelter care and education.

**Advocating for change:** by supporting us you can help us advocate for policy and programmes that address the root cause of the issues we are passionate about and what towards creating long term sustainable change.

Every donation, no matter the size makes a difference. It is because our supporters like you that of we are and we are able to continue our work I made a meaningful impact.

By supporting our organisation and our mission your donation will make a tangible difference in the lives of those we serve and help us create a better future for all those living with Huntington's disease. I need to mention that none of this would have been possible without the support of our dedicated team of staff and volunteers they worked tirelessly to make a small association as success and demonstrate a strong commitment to our mission their dedication and hard work has been invaluable over this past year. I would like to thank our members for their ongoing support and I look forward to continuing our work together in the coming years think I have another 20 left in me yet we remain committed to our mission until making a positive impact in the world.

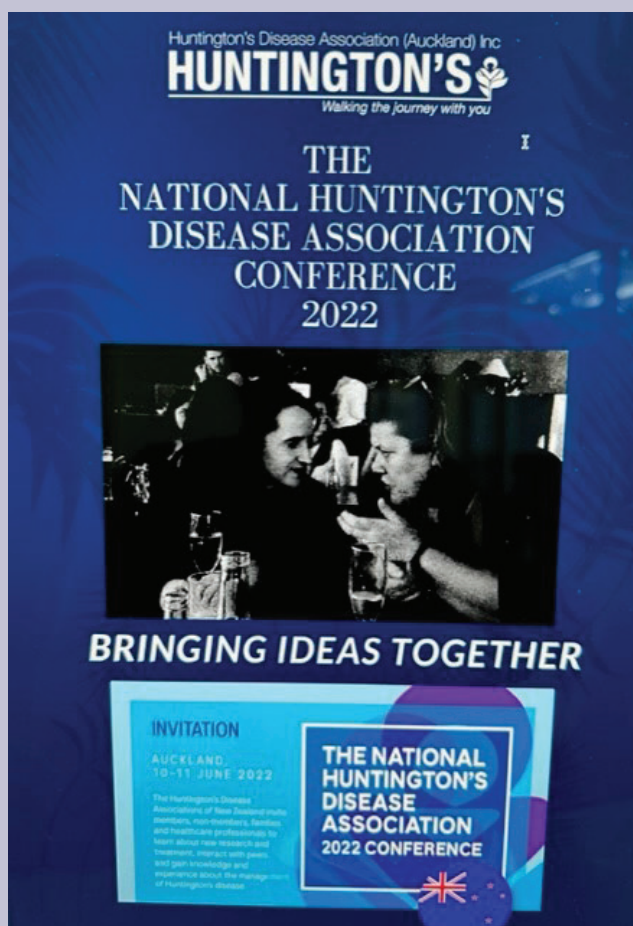
*Jo Dysart*



# HUNTINGTON'S DISEASE CONFERENCE

## BRINGING IDEAS TOGETHER

We had a great turn out at our National Huntington's Disease Association conference that we hosted in June 2022 at the beautiful CORDIS Hotel. Huge thanks to our major sponsors and supporters as we were able to welcome in many distinguished guest speakers from all around New Zealand as well as other parts of the world to this grand venue. Not only that but with the recent advances of technology use, we were also able to live stream this conference so people could watch from other countries! We had viewers all the way from Australia, UK, Germany, France, and Italy to name a few. It was a very successful 2-day event, with lots of knowledge and love was shared amongst many researchers, clinicians, and family/whanau of the HD community.





---

# REVIEW OF THE YEARS EVENTS

## LIONS MEETING

We were kindly invited to present our service at the LIONS meeting. It was a fantastic night, with fantastic people. They were very welcoming and open to what we offer to our community. We thank them for their support.



*"Our approach is to respect, the people and have a willingness to listen and learn about their unique history, culture, and traditions"*



# CARERS DAY

Another great turn out for our carer's day! Unfortunately, due to Covid in the past few years, we were not able to host as many. However, we were able to host one this year and it was a great success. It was very nice to see everyone attending especially after the stresses of COVID. We were also able to have new members join us through zoom which was a great opportunity for our carers to see and meet new people within the HD community.



# COLLABORATION AND SUPPORT

We continue to visit and support our rural Maori community in Auckland, Northland and Taranaki with our patron Sir Richard Faull building strong relationships with the people.

Our approach is to respect, the people and have a willingness to listen and learn about their unique history, culture, and traditions. By developing the trust and meaningful connections we continue to establish a foundation for effective collaboration and support.

We continue to visit and support our rural Maori community in Auckland, Northland and Taranaki with our patron Sir Richard Faull building strong relationships with the people.

Our approach is to respect, the people and have a willingness to listen and learn about their unique history, culture, and traditions. By developing the trust and meaningful connections we continue to establish a foundation for effective collaboration and support.





# STATEMENT OF FINANCIAL PERFORMANCE

## HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC. Statement of Service Performance For the Year Ended 31st March 2022

### Description of the Entity's Outcomes

By providing information, awareness, support, advocacy and education to Huntington's Disease clients, carers', family/whanau, local community and healthcare professionals, we prevent the number of hospital admissions, unnecessary arrests and misunderstandings within the local communities and decrease family dynamics such as divorce and social isolation. By sharing thorough educational workshops, training and up skilling staff in care facilities, local GP's and carer's with more knowledge and tools to cope with an HD sufferer, the sharing across all areas of evidence based practice, up to date research and although there is currently no cure for HD, the quality of life for each HD sufferer is improved socially, mentally, emotionally and physically.

### Description and Quantification of the Entity's Outputs

Staff hours	3,848 hours
Volunteers hours (committee)	432 hours

## HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC. Depreciation Schedule For the Year Ended 31st March 2022

Asset	Cost Price	Book Value 01/04/2021	Additions Disposals	Gain/Loss on Disposal	Capital Profit	--- Depreciation --- Mth Rate	\$	Accum Deprec 31/03/2022	Book Value 31/03/2022
<b>FURNITURE &amp; FITTINGS</b>									
Office Furniture	2,447					5Yr SL	0	2,447	0
St Johns Defibrillator Machine	3,460					5Yr SL	0	3,460	0
<b>Sub-Total</b>	<b>5,907</b>							<b>5,907</b>	<b>0</b>
<b>OFFICE EQUIPMENT</b>									
Computer			1,893			9 50.0% DV	710	710	1,183
Computer			1,331			9 50.0% DV	500	500	831
Laptop	1,000					3Yr SL	0	1,000	0
Laptop	999					3Yr SL	0	999	0
Tablet Laptop Blue	1,304					3Yr SL	0	1,304	0
Apple Phones x 2	1,997					3Yr SL	0	1,997	0
Office PC	859					3Yr SL	0	859	0
Office Monitor	139					3Yr SL	0	139	0
Brother printer	170					3Yr SL	0	170	0
Lanton	1,299					3Yr SL	0	1,299	0

A full report of the Association's financial audit from the 2021/22 year can be found on the government's Charities website.  
Please visit: [charities.govt.nz](https://charities.govt.nz) to download the audit report.



## HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC.

### Statement of Movements in Accumulated Funds

#### For the Year Ended 31st March 2022

	<i>Note</i>	<b>2022</b> \$	<b>2021</b> \$
<b>ACCUMULATED FUNDS AT START OF YEAR</b>		87,678	77,518
<b>REVENUE</b>			
Net Deficit for the Year		(83,370)	10,160
<b>Total Recognised Revenues and Expenses for the Year</b>		(83,370)	10,160
<b>ACCUMULATED FUNDS AT END OF YEAR</b>		\$4,308	\$87,678

## HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC.

### Trading Account

#### For the Year Ended 31st March 2022

	<b>2022</b> \$	<b>2021</b> \$
<b>REVENUE</b>		
Donations received	38,994	11,444
Subscriptions	-	35
Fund Income	71,560	191,501
Accommodation Support Fund	-	10,954
Wage Subsidy Received	25,200	-
<b>Total Sales</b>	135,754	213,934
<b>GROSS SURPLUS FROM TRADING</b>	\$135,754	\$213,934
<b>GROSS SURPLUS MARGIN</b>	100.0%	100.0%

# HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC.

## Statement of Financial Performance For the Year Ended 31st March 2022

	2022 \$	2021 \$
<b>Surplus from Trading</b>	135,754	213,934
<b>SUNDRY INCOME</b>		
Interest Received	48	21
Sundry Income	-	8,551
<b>Total Income</b>	<u>135,802</u>	<u>222,506</u>
<b>Less Expenses</b>		
Accident Compensation Levy	358	325
Accountancy Fees & Audit Fees	4,810	3,420
Publications	2,108	185
Bank Charges	60	100
Client/Patient Expenses	3,447	6,355
IT Expenses	898	1,033
Conference Expenses	3,403	7,250
Insurance	5,328	5,167
Interest	75	1
Event Costs	14,938	7,542
Motor Vehicle Expenses	3,354	4,793
Vehicle Lease Expense	14,894	13,224
Penalty & Infringement	770	23
Printing, Stamps & Stationery	838	1,246
Rents	9,572	9,185
Repairs & Maintenance	34	-
Small Assets Written Off	895	-
Other Employer Expenses	4,068	1,926
Dues & Subscriptions	267	201
Telephone, Tolls & Internet	3,606	5,180
Travel	1,377	-
Wages & Salaries	142,862	145,190
<b>Total Expenses</b>	<u>217,962</u>	<u>212,346</u>
<b>Net (Deficit)/Surplus Before Depreciation</b>	<u>(82,160)</u>	<u>10,160</u>
<b>Less Depreciation</b>		
Depreciation as per Schedule	1,210	-
<b>Net (Deficit)/Surplus Before Beneficiary Distributions</b>	<u>(83,370)</u>	<u>10,160</u>
<b>NET SURPLUS/(DEFICIT)</b>	<u><u>(\$83,370)</u></u>	<u><u>\$10,160</u></u>

A full report of the Association's financial audit from the 2021/22 year can be found on the government's Charities website. Please visit: [charities.govt.nz](https://charities.govt.nz) to download the audit report.



# HUNTINGTON'S DISEASE ASSOCIATION AUCKLAND INC.

## Statement of Financial Position

As at 31st March 2022

	Note	2022 \$	2021 \$
<b>CURRENT ASSETS</b>			
ASB Bank - 00 Cheque Account		89,918	14,134
ASB Bank - 51 Savings account		45,172	100,125
Other Debtors		-	500
<b>Total Current Assets</b>		<u>135,090</u>	<u>114,759</u>
<b>NON-CURRENT ASSETS</b>			
Fixed Assets as per Schedule		2,014	-
<b>TOTAL ASSETS</b>		<u>137,104</u>	<u>114,759</u>
<b>CURRENT LIABILITIES</b>			
GST Due for payment		8,366	10,936
Accounts Payable		8,904	4,676
Credit Card Creditor		(2,686)	1,343
Provision for Holiday Pay		4,212	10,126
Receipts in advance		114,000	-
<b>Total Current Liabilities</b>		<u>132,796</u>	<u>27,081</u>
<b>TOTAL LIABILITIES</b>		<u>132,796</u>	<u>27,081</u>
<b>NET ASSETS</b>		<u>\$4,308</u>	<u>\$87,678</u>
<b>ACCUMULATED FUNDS</b>			
Retained Earnings		4,308	87,678
<b>TOTAL ACCUMULATED FUNDS</b>		<u>\$4,308</u>	<u>\$87,678</u>

For and on behalf of the Committee:

  
Chairman

Date: 27/8/22



Committee

Date: 27/8/22

Trustee  
27/8/22

# HUNTINGTON'S DISEASE HEROES

We are excited to announce that a new book "Huntington's Disease Heroes" has just been published. As we know, Huntington's disease has been steeped in secrecy and fear for generations, leaving people in the community without a voice. This book changes that. Huntington's Disease Heroes features twenty-six people from nine countries who bravely share their personal stories about living in the shadows of this disease. By doing so they are saying: Here I am. I will not be kept silent.

*"These moving stories of real people affected by Huntington's give a human face and voice to this dreadful illness, making the unimaginable imaginable and felt by the heart."*

**— Lisa Genova, New York Times bestselling author of Inside the O'Briens**

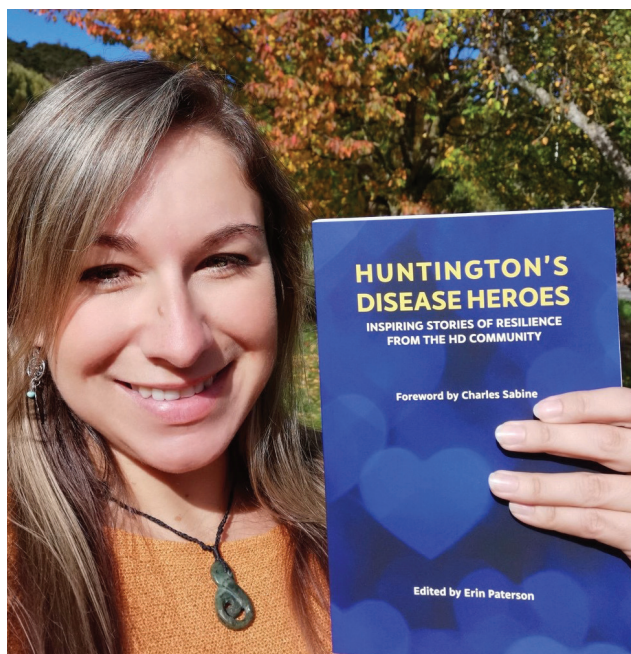
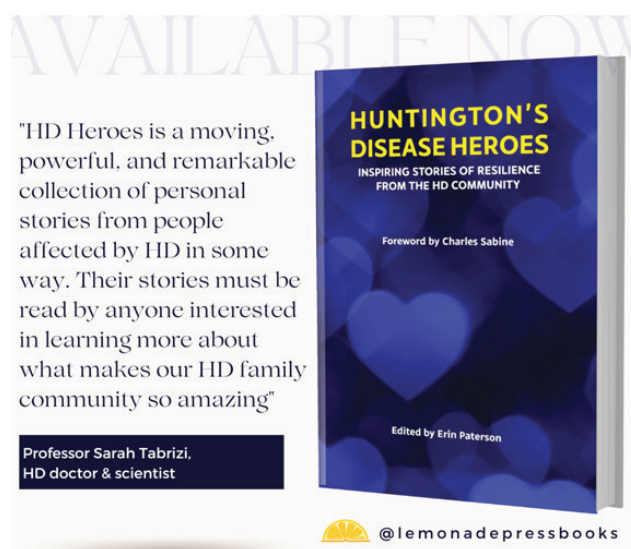
Huntington's Disease Heroes includes stories from a scientist who switched from cancer research to studying Huntington's after finding out her mother had tested positive for the disease, a young man whose biggest fear was testing gene negative and not inheriting the disease, and a woman who grew up in survival mode, unable to express her grief. Our very own Malvinder Singh-Bains and Emma Burnip wrote chapters to contribute to this book.

We learn about the ways the author's lives are better off because of the hardships they have faced. By sharing these intimate parts of their lives, they are taking away the fear and stigma of living with HD in their families. They are giving a voice to this unheard rare disease community and empowering others to speak up.

We hope by sharing our stories we can raise awareness of HD, help people understand the HD community, and feel less alone during trying times. The book also includes a book club 'chapter chat' section at the end

with prompt questions to help the reader connect to each story and reflect on how this may relate to their own experience.

50% of the proceeds from book sales will be donated to the Huntington's Disease Youth Organization (HDYO). We have sold over 500 copies of the book so far, if you are thinking of someone who would benefit from reading this book, get your copy now! Available on Amazon worldwide.





---

# OVERVIEW

Financial report for Auckland Huntington's Disease association.

This financial report presents an overview of the financial performance of the Auckland Huntington's disease association for the financial year end in 2022. This report has been prepared in accordance with general acceptance accounting principles and is intended to provide stakeholders with an understanding of the Auckland Huntington's disease association's financial position.

The financial performance of the Auckland Huntington's disease association for the financial year end in 2022 was positive. The Auckland Huntington's disease association was able to generate sufficient revenue to cover its expenses and the assets and liabilities were well managed. Under the Auckland Huntington's disease association was able to maintain financial position.

We would like to take a moment and express our deepest gratitude for your unwavering support. Whether you have donated your time, resources or expertise, your contribution has been invaluable and made a real difference.

Your support has enabled us to pursue our mission and bring about positive change in Auckland and the Northland region. We recognise that without you, none of this would be possible. Your commitment to our cause inspires us every day to work harder, dream bigger and strive for excellence.

From Jo and the Team

*Thank You*

# TO ALL OUR HUNTINGTON'S HERO'S THANK YOU

