



# Cystic Fibrosis Association of NZ

## ANNUAL REPORT 2012



PICTURED ON COVER: Maisy Millwater with her Player of the Day Award

# Our People

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## National Board

Jane Drumm – Chairperson

John Parsons

John Elliott

Margaret Nicholls

Robyn Somerville

Lisa Borkus – Co-Adult Representative

Toni Durant – Co-Adult Representative

## Staff

Kate Russell

Julie Clemett

Caroline Wagteveld McKenzie

Sally Carron

Susan Lovelock

Chief Executive

Administration Manager

Fundraising and Events Coordinator

Northern Region Field Worker

Southern Region Field Worker

## Clinical Advisory Panel

Dr Richard Laing – Chairman

Dr Cass Byrnes

Dr Philip Pattemore

Dr Mark O'Carroll

Dr Peter McIlroy

Rebecca Scoones

Vivienne Isles

Victoria Crowder

Chest Specialist, Christchurch Hospital

Paediatrician, Starship Childrens' Hospital

Paediatrician, Christchurch Hospital

Chest Specialist, Auckland Hospital

Paediatrician, Nelson Hospital

Physiotherapist, Starship Childrens' Hospital

Childrens' Outreach Nurse, Christchurch Hospital

Dietitian, Christchurch Hospital

## Investment Committee

John Parsons – Chairman

Steve Drumm

Andrea Miller

Jane Drumm

Kate Russell

# Chairpersons' Report

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I have been writing these reports for a few years now and every year I look back and ask “Did we make a difference?” “Did our Association have a positive impact on the lives of people with CF and their families?” “Are we getting closer to our vision that “Cystic fibrosis does not compromise the length and quality of life”? Are we achieving our mission that “CFANZ will optimise quality of life for people with cystic fibrosis and their families; striving for normal life expectancy and a cure.”? Do we work with commitment, care, integrity, a sense of community and teamwork?

I believe the answer is a resounding -yes.



The sense of “family” that is evident at our Conferences and on social media, the passion for their jobs that is shown by all our employees, the high regard with which the Association is held in the eyes of clinical professionals, government agencies and other community based Not for Profit organisations and the enthusiasm of our branch membership to work towards making life with CF a smoother path to walk down.

The highlights from our National Association from a board perspective have been:

- The CF Association of NZ has ended the financial year close to break even. Although losses posted over the last few years have been minimal, especially in comparison with other not for profits, it is very reassuring to know that the Association is in sound financial health. I credit our team approach- without everyone pulling together in the right direction it could be a very different story. I congratulate national office staff and everyone around the country for a year very well spent working hard for PWCF
- Strategic Plan-Initiatives such as the Go to Meetings for branch chairs, the Patient and family Advisory groups and building and maintaining links internationally are all outcomes that have sprung direct from our Association strategic plan.
- Liaising with medical and clinical professionals is an on-going role the Association takes on to ensure a focus on quality improvement throughout NZ which will result in improved care for PWCF.
- PORT CF NZ- this has been a huge amount of work for the Association this year. Our CE and Admin Manager have worked extremely hard at providing the training and support for all the hospital CF services around NZ, who are entering their patient data to provide statistics that will point to areas where improvements in the care of PWCF can be made. This project is a great commitment of time energy and money that will have real and significant benefits for our community.
- Through constant pressure and a number of campaigns our Association has gained traction in the area of lobbying particularly with PHARMAC: Pulmozyme is now more readily available after more than a decade of fighting. Funding through the Ministry of Health for fieldworker salaries and new initiatives like the Patient and Family Advisory Groups, that have piloted in Auckland and Christchurch, will help to identify issues and make change that will have a positive impact on people with CF and their families.





- The NZ CF Community are particularly fortunate to have very motivated, dedicated, skilled and experienced staff and incredibly hard working and dedicated Board members and branches who are all constantly striving for people with CF and their families. On behalf of the NZ CF community I thank all staff, Board members, SiLF Trustees, Branch committees and all those who help to make a difference.

Our challenges are as always around the shrinking charity dollar and availability of volunteers. We must work hard to ensure that there are sufficient funds available to continue to provide established services and to meet the increasing needs of our CF community so that we achieve our strategic vision. I am absolutely certain that as we all pull together working towards our mission that the Association will continue go from strength to strength.

**Jane Drumm – CFANZ Board Chairperson**

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## Goodbyes

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*In the 2011/12 year, these brave people came to the end of their life's journey. Our thoughts and prayers are with their families and friends*

Janine Rosenberg      Gary Davis



# Mark Ashford Scholarship

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Heart of a Healthy Home™



The Mark Ashford Scholarship is awarded to the person with CF who has attained the highest standard in his or her tertiary education for that year. It is presented by DVS – part of the Fletcher Group in memory of Mark Ashford who worked for the group and made a huge contribution to their Healthy Homes book that is still in use today.

**Winner 2012 – Kimberley Bryant** - Kimberley completes her studies toward a Bachelor of Biomedical Science at Victoria University this year and plans to go on to her Masters Degree. She has gained impressive mark throughout her University career and describes herself as hardworking and motivated.

When she isn't hard at work studying, Kimberley plays ultimate Frisbee and organizes events and tournaments and she loves socializing with her friends, spending time with her family and running or swimming with her younger siblings.

Congratulations Kimberley and thanks once again to Fletchers and DVS for continuing to honour Mark's memory in this way

## Chief Executive's Report

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### **Steve Jobs said "Innovation distinguishes between a leader and a follower"**

This year has been characterized for me as one which has seen innovation come to fruition across various areas of Cystic Fibrosis. A year where the hard work of many people has resulted in big gains and important strategic projects getting out of the start blocks.

Internationally, the biggest news was that of the release of the stage three results for Kalydeco®, Vertex's CF corrector for those carrying the G551D mutation and further results for the combination drug that holds great hope for the large population of DeltaF508 carriers. This hopeful news came with a hefty rider though, of an annual bill of \$294,000 USD per patient, making it far less likely that we will get this drug into New Zealand. The price tag was all the more surprising as the CF Foundation had put up much of the research funding for the drug so many thought this would mean it might be affordable beyond US borders. However, we will lobby for the drug as soon as Vertex indicates its desire to bring it into New Zealand as we want to signal to Pharmac how important this drug will be into the future for CF care.

Nationally, our biggest project to date, Port CF got out of the blocks with all clinics trained and entering data. Our first Data Registry will go to print in October and each year we will produce a new set of data to benchmark our patient outcomes nationally and internationally and begin to set goals for improvement.

After eight years of lobbying and making ourselves the 'squeaky wheel' with Pharmac, we finally achieved our goal of getting the criteria for Pulmozyme<sup>®</sup> loosened off so that far more people qualify for a trial with this drug that has had open access elsewhere in the world since it was first introduced. The special authority criteria for azithromycin was lifted and we have made some progress toward funding of insulin pumps for people with CFRD.

Some of this progress has been overshadowed by the decision from Pharmac not to fund readymade sip feeds any more for people needing oral supplementation. We argued furiously against this change, along with other groups such as "Debra" the Epidermolysis Bulosa group, and NZ Ord. Sadly in trying to control rampant overspending on sip feeds within the eldercare area, medically fragile groups such as Debra and our own, have been 'collateral damage' as Pharmac decided to take the easy path and come up with a 'one size fits all' solution. This is a battle we are not prepared to give up on as we feel the decision made by Pharmac was made on the basis of misinformation and expediency and it jeopardizes the health and wellbeing of our people with CF..

We piloted Patient and Family advisory groups in Starship and Christchurch Hospital, with great success. These groups have provided patients and their families with a real voice and given an opportunity for collaboration and partnership between patients and those who care for them. Our sincere thanks to the Health Quality and Safety Commission for funding this piece of work.

Financially, this year has been far more optimistic and our end of year results demonstrate the hard work that has been done in fundraising and has lifted us out of the global financial crisis and we are set to continue this success into the next year. As always, I wish to thank our superb Board, our branch executives, volunteers and supporter who are the lifeblood of our organization. I also wish to thank the staff, Caroline, Julie, Sally and Sue for their dedication and hard work.

**Kate Russell - Chief Executive**



*What you leave behind  
is not what is engraved  
in stone monuments,  
but what is woven into  
the lives of others.*

*Pericles*

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# CF Achievers Awards 2011/12



Each year we honour high achievers in the Association across a number of areas, with a CF Achievers Award, sponsored by Boehringer Ingelheim. This year we had two people recognised for their determination and achievement in Leadership. Our sincere thanks to Darcy and the Team at Boehringer Ingelheim for their ongoing commitment to this award that celebrates the best in resilience and determination.

## **Award for Leadership – Desmond Vincent-Dustow**

Des has made a significant contribution to junior and womens' football in New Zealand. He has been a volunteer football coach, mentor and spokesperson for eight years. In this time he has coached many junior boys and girls teams. As a spokesperson for girls' football, he has strived for better facilities, funding, development opportunities, scholarships and tournaments. He gives 20 hours of volunteer time weekly including planning, preparation, research, training, games, trials and tournaments. His commitment to football has seen a number of his players develop into likely prospects for the 2014 Football World Cup. Friends who helped with his nomination characterize Des as embodying the selfless nature of voluntarism. He is described as: humble, compassionate, a great communicator, passionate and a natural leader. This quote from one of his player's parents says it all.



"While there are many good coaches, Des stands above his coaching peers; he is a great coach, not just good. All of this he does quietly, unassumingly and modestly whilst bearing the burden of cystic fibrosis."

## **Award for Leadership - Makenzie Perry**

Makenzie displays a maturity that belies her age (16). In her short time battling CF, Makenzie has been through more than many her age as she was diagnosed with a rare bacteria after a family holiday to Thailand. This nasty bug has meant that Makenzie has almost permanently been on IV antibiotics for four years and is now combined with a diagnosis of CF-related diabetes.



Makenzie made the decision to be positive about her condition and has used it to spur her to fundraise for the cause, speak out about life with CF and in many cases, be a positive role model for other young people with the condition.

Makenzie says this of her philosophy, "One thing I always say to people is Don't worry Be happy! And I have been a living example of being happy when life is tough. I start each day with a smile on my face because I look to what the day holds. The kind of life I live is where every situation has some good in it – if I am being admitted to Starship, I am happy because I can catch up with all the nurses who are my friends."

Makenzie's Youth Leader at the Windsor Park Baptist Church says, "Not only does she possess excellent integrity, placing the needs of others above her own, following through on commitments and being conscientious in responsibility, but she is also an activator. Amongst her peer group it has become apparent that her leadership qualities and strength ensure she is always looking out for an opportunity to serve where it is needed."

# Branch Reports

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## NORTHLAND

It's been a pretty quiet year up here with only one new member who is an adult who lives in the BOI. We had a successful golf day again with a record profit just shy of 10k. We had a record number of teams involved this year, and received some good press in the local paper, again this is really our appeal week.

We have continued to move fish and money trickles in from our cash boxes. Again we are hamstrung by the small amount of members and personally Janet and I don't let CF rule our life's at this stage. We are also looking to donate a sum of money to Shares in Life. **Mike Webb – Chairman, Northland Branch**

## AUCKLAND

The past year has been one of consolidation for the Branch with the committee building and maintaining the strength of work in recent years while continuing to be active and pro-active in achieving our goals for the CF community.

During the year Auckland Branch has had considerable success with various 'new' and 'proven' fundraisers. Money raised is used for many purposes, supporting the wide care and education needs of our community. Our regular and ongoing 'spend' includes medical equipment, newsletters, hospital packs, food, supermarket and parking vouchers, PFRC rent, conference attendance and Branch Coordinator's salary.

With our 'new look'. CF Auckland Branch raised \$34,379.00 in Awareness Week receiving amazing volunteer support from our CF Community, their friends, colleagues and from Auckland senior school students. Our second year of selling **Chocolate Fish** was again a huge success. The **TradeMe charity auction** and **White Elephant Sale**, the sale of **Recipe Journals**, **Ladies Luncheon**, **\$65 for 65 Roses** campaign, the Baking Stall at the **Kowhai Festival** and sale of **Entertainment Books** have also raised substantial funds for the Branch. The committee wishes to extend our sincere thanks to everyone who involved themselves in raising money and awareness during the past year, acknowledging the generous 'time sacrifices' of many to do so.



The **CF Auckland website** went 'live' in 2012 and is updated regularly with all Branch news and events. A 'hot tips' page is also growing following the addition of tips from the CF community that appear on Facebook groups, in newsletters, or after conferences and gatherings. Our **newsletters** are being added to the site, and we will soon have a collection of back issues for browsing. Links to other websites of interest, newspaper articles, and publications are also available. Following a successful recipe competition, all the recipes that were entered are available on the website.

Auckland's CF Committee continues to host **coffee mornings**, **ladies lunches**, and an annual **Christmas party**. Last year's Christmas event was held at the Ringers house in beautiful Coatesville, special thanks to Jo and Huw for hosting such a memorable evening. Our coffee mornings, which we aim to hold each school term, move around the City, and are a great place for CF mum's to meet likeminded CF mums.

After a year in the role of Auckland CF Branch Coordinator, Maria Teape left us to take on a role closer to home. Wendy Edmondson joined us in March this year and has done a superb job coming on board with the many and varied requirements of the role. The Auckland Branch is constantly growing – let's continue to share our experiences and what we have learnt, communicate our ideas, frustrations and hopes, and lean on each other when necessary: these are the traits of an important and caring support network.

**Anthea Wendelborn and Amanda Blakey, CF Auckland Branch Co-Chairs**



## WAIKATO

Our first year of holding the office of co-chairperson's has come to a close and it has been a steep but rewarding learning curve.

Our first task was Awareness Week which was a success as a fundraiser selling a good number of Chocolate Fish.

The LJ Hooker Property Expo was in September and we had a stall and once again received great support for the purchase of nebulisers . It was with regret that we learnt that they will be replacing us as their primary charity at this year's expo. However we acknowledge the great work they have done for us with the support of Jenny and Michael Bell.

Also in September Debbie attended the Chairperson's conference , which was a great chance to network with other branches and National Office. It also led to the development of internet chairperson's meetings .

Over the year we have attempted to make contact or meet as many CF families as possible. And send out regular newsletters by email and post.

In February we held the inaugural CF fishing trip, and although it was a bleak day it was great to see CF parents relaxing and getting to know each other. We hope these will continue.



This year we have started a Grant committee including Jenna van Rijen, Hamish Ross, Debbie and Mike Wood. It is slowly taking shape and they are attempting their first applications.

We send our thanks to Jeff van Rijen's parents who gave us a large donation , which purchased an Xbox Kinect for both the Adult ward and the Children's ward along with a TV for the Adult ward. We would like to thank Monique O'Neill for securing \$800 which went to purchasing eflow parts. Also a big thanks to Claudette van Niekerk for organising the selling of Entertainment Books . And

thank you to her Father who has been steadily raising funds through a donation box at Caltex TeRapa. Mike Wood also ran a very successful Pool tournament , and there will be more in the future.

This year has seen purchases of nebulisers , games for Xbox and Playstation, hospital packs ,books , vouchers for those admitted and various welfare purchases.

Finally we would like to thank Meryl for her secretarial work and of course a huge thank you to Jenny Bell for her many years of doing the Treasurer position , she has done an exceptional job . **Mike and Debbie Wood, CoChairs, Waikato Branch, CFANZ**

## BAY OF PLENTY

Goals for the BOP branch for 2011/12 have been centred around building our committee and branch structure so we can operate more efficiently. We have made great progress and now have well attended monthly meetings with a functioning committee. With our own policies and procedures now in place decision making and planning is becoming much easier. We also have some wonderful volunteers regularly attending meetings and doing wonderful fundraising and support work which is taking the pressure off those of us who are parents with dependant CF children.

In December 2011 we held our first Christmas Tree Festival in conjunction with Bethlehem Town Centre, More FM and Bay of Plenty Times. Katrina Russell-Barr co-ordinated this event for us and it was a great success. Planning is under way for 2012 with Bethlehem Town Centre who provide us with an



empty shop and their marketing team, and are keen to make it a yearly event. Thanks must go to Bay Trust for a grant that covered our running expenses and to all the volunteers that put time and effort into making it all happen. Also thanks to Canterbury branch for their Christmas Trees.

Acorn Foundation has given us a \$5000 grant to start providing community physio services in the Tauranga area. This is an ongoing project that as of yet we have not been able to get started for a variety of reasons but will continue to pursue as we feel it is important for our families struggling with the demands of physiotherapy.

We are grateful to the Southern Trust for paying for accommodation for 7 of our branch members to attend conference this year in Auckland and to Pub Charity and the Lion Foundation for nebulisers. **Nicola Wakerley, Chairperson BOP Branch**

## TARANAKI

We are thoroughly enjoying the bubbles campaign branding and hope the association keeps this branding long into the future as it is now being recognised as ours. We are also looking forward to a possible change in the awareness week timing as collectors this year were scarcer than ever during spring calving and huge competition with Cancer awareness activities in our region.

Fundraising through chocolate fish, another casino night in the next 12 months assists us to help our members with short and long term needs.

We were excited another of our AWCF had a successful transplant over Christmas and this has added to our focus of assisting/campaigning for change, with income support for carers unable to work between high CF acute and chronic needs.

Congratulations to the recipients of the Jono Fowler Scholarship this year. Our thanks to the Association National office staff who have pulled such a successful advertising campaign together this year. We appreciate all your ongoing effort. **Donald Lumsden, Taranaki Chairperson**



## HAWKES BAY

We have had a quiet year on the fundraising front, Awareness week was supported by members in Napier, Hastings and Waipawa with the local supermarkets allowing us to collect at their entrances. October 2011 we set up a burger and sausage tent at the Williams Harvey annual Duathlon. The money we raised from this was sent to the CF branch in Christchurch. We have helped many of our members. One of our young people had their "Trip of a lifetime". Another young member has had a lung transplant and we have been able to use some of the funds that we received from an estate for "the benefit of local CF members" to help with the expenses that go over and above what the CFNZ allow. We have also purchased 4 nebulisers and hospital vouchers. Funds raised when we did the "65 Roses House" build are now been used and 3 of our young families are having Physiotherapy in their homes and the children are responding well to this. **Glenda Sinden, Chairperson, Hawkes Bay**



## CENTRAL DISTRICTS

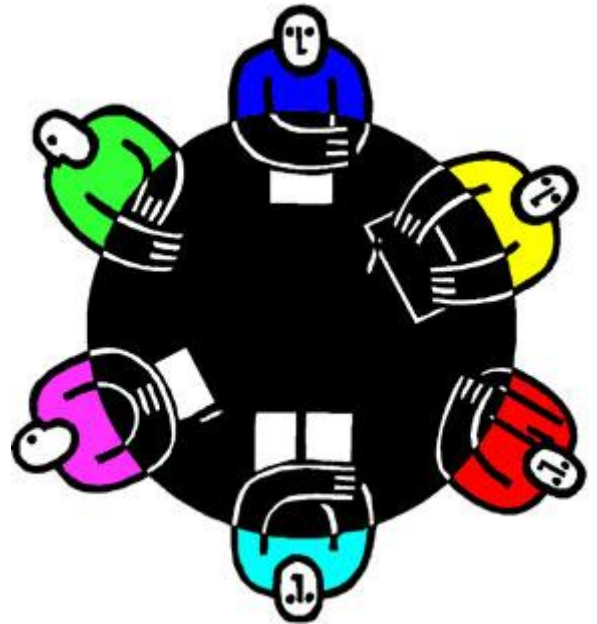
Central Districts has had a low-key year, with the occasional funds trickling in from various sources. Six of us made it to conference this year - more than ever before - thanks to grants that covered nearly all costs. We decided to get revved up early for Awareness Week 2012 and started selling chocolate fish several weeks beforehand, and have been bugging local businesses with our donation boxes on counters here and there around Wanganui and Sanson. We have set up several places who are willing to sell fish all year round, and have permanent donation boxes on display, or who will allow us to put them up again next year.

The occasional story in the Wanganui newspapers helped with awareness in our community but perhaps the biggest factor for us this past year - or weeks really, is the loss of Erin Bartrum, our one-time Chairperson, and a woman who, in her 43 years on the planet, inspired more hope and courage than most ever could. She leaves behind a big hole in our hearts and in our CF family. She will be remembered for her bravery, her positivity and her beautiful art - her legacy to the world. **Anna Scoullar Jones – Chairperson, Central Districts**

## WELLINGTON

At the beginning of this year we were pleased to welcome some faces to the committee of those who had served before. At times there will not be a group ready to step up, making succession difficult, so the return of “old faces” was very helpful. Everybody pitched in, taking on various jobs which lead to a good spirit. Our Branch coordinator resigned at a vital time at the end of November, and the Christmas Tree Festival needed urgent attention. It ended up being another great show earning well for the Branch. The Branch faced mediation this year with our former employee who made an unfounded personal grievance complaint. We were grateful to CFNZ for their help and support through this period. We have learnt much to inform future employment. Perhaps because of the lightening of the pulmozyme restrictions we have had a large call on nebulisers recently – needing five within a month! We concentrated our Appeal Day in three areas only this year but felt that good coverage in less places paid dividends – especially as they were under cover, which is essential in Wellington in August! We also included two movie nights which were very profitable, raising \$1700. Entertainment books were very successful this year – we sold 83, mostly due to the work of three people in three large offices. At the AGM this year it was wonderful to have some younger people come on the committee, and the appointment of a new Chairperson and Treasurer has injected new enthusiasm into the Branch organisation. It promises to be an exciting year to come.

**Margaret Nicholls, Chairperson, Wellington Branch**



## NELSON

Although Nelson is a small but dedicated branch, it has seen yet another interesting year where we are gripping on for the ride and wondering if the branch will survive. There has been a major reshuffle within the committee and we have given it 12 months until we reassess the state of affairs and make the decision as to whether or not it will continue.

On a more positive note however, despite the fact that we don't get a huge income from awareness week, we have found that it has remained stable and not been affected by the current economic situation, and that awareness of our cause has increased, with many people knowing someone or something about CF. Therefore its success for us!



So where to from here....a plan is being formed with more goal directed fundraising, increasing the frequency of meetings, active involvement in improving transition to Adult Services, and investigating different ways of communicating to everyone especially for those who don't attend. Watch this space.

**Rebecca Colley, Chairperson, Nelson Branch**

## CANTERBURY

The Canterbury Branch has had another interesting year. Our family numbers are approximately 70 and this is inclusive of our 4 new babies born in our region. Last year I talked of the community starting to show the true affects from our past earthquake events, this still stands. In Christchurch things are moving very slowly, too slowly, the ground maybe stabilizing but the stress levels are high, people are now battling with insurance companies, local council, EQC and builders, not to mention we have had the coldest, wettest winter in a very long time. Houses and buildings are still leaking and still very draughty. This has pushed our welfare for heating to the extreme.



On a happier note we have had some amazing support from the other CF Branches around NZ, the prizes that were sent and cash donations for our October golf tournament were a god send, this made things a lot easier and we profited by approx \$3000 with all of this help.

A wonderful man, Craig Stevens made contact with us and entered himself in The Fight For Christchurch, a boxing tournament. Craig hoped to raise \$5000, at the end of this event through sausage sizzles, auctions and his company Envirowaste, he presented us with a chq of \$9000!

Our inner city school, Discovery 1 who in the past has collected for us during appeal week also raised us funds of approximately \$3000.00 , with a class entering The QT Active Marathon in Queenstown last December, they each got sponsorship, held a bucket collection and sold chocolate fish.

We were very grateful to both of these groups for their support and also to our families and friends who continue to help sell chocolate fish. We continue to support our families as best as we can.

Always, I am very thankful for our wonderful committee members and our Field Worker Sue Lovelock for their tireless work. **Melissa Skene, Chairperson, Canterbury**



## OTAGO

We have experienced an exciting year with significant changes made to our committee. I thank our board members, who are committed to volunteering their valuable time. The branch has worked hard this year to ensure the needs of our members are met through contact with Sue, our Fieldworker providing better understanding of their entitlements. Jeremy Byfield has taken on dual roles as Secretary/Treasurer, Jeremy has put a massive effort into getting the accounts in order and putting our funding policy together. This makes the services offered by the branch accessible to all members utilising the national funding policy as a guideline.

This year we funded eflow nebulisers and parts and funded heating and electricity bills up to \$500.00 per member; something we will review annually depending on need. As a group we still need to build on our yearly events calendar and create something to entice our members to come along and participate as a group whether it to be to learn or share knowledge or just to meet new people who endure the same struggles either as a parent or as a PWCF.

Kelvin Helm organised our Street Appeal and his attention to detail resulted in the branch returning \$16000; an impressive \$6000 increase on the previous year's collection. This is a large task involving hands on approach from all with Nicole Fyfe working hard to getting the word out to the schools in arranging their help in multi-days and collection help and her commitment to resourcing grants for further funding ideas. We intend to utilise some of this money along with the collections from the 2012 Awareness Week to get members of our branch to the



Australasian CF Conference next year in Auckland. **Arthur Booth, Chairperson, Otago Branch**

## SOUTHLAND

This years report is almost identical to last years in that once again it was an extremely quiet year for the Southland Branch with no meetings held other than the Annual General meeting. Because of such small turnouts our meetings are only convened if there is anything of importance to discuss that cannot be done via the telephone/email or if there is a request by one of the members. Lynne also continues to forward all emails received.

Again no complaints were received during the year so I can only assume everyone is happy with this "Low Key Approach" that the branch has taken over the last few years. Although we have not managed to attend many national conferences of late, we continue to encourage our members to attend where possible for which Branch funding is available. Unfortunately however, no one has taken up the offer for this years conference. Although it may seem we are sort of in recess the few members that we have are all well aware that assistance with the likes of travel costs or equipment purchases is available from the branch should anyone require it.

**Jim Phair, Chairperson, Southland Branch**

# Special Events Photo Gallery







# Acknowledgements

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We wish to acknowledge the following organisations and people who have helped us in our work by providing services, goods, gifts in kind, talent and expertise. Without the willing assistance of our community, we could not continue to provide vital services to the CF Community throughout New Zealand



Boehringer Ingelheim

Zoom Room IBDG

Harvey Cameron

Fletcher Challenge Group

MORE FM

APN Outdoor

Thomson Reuters

The Patter

The NZ Lottery Board

Mainland Foundation

Dominion Post

Christchurch Press

Canterbury District Health Board

CFANZ Clinical Advisory Panel

Access to Medicines Coalition

Sloane Robinson

ASB Community Trust

ASB

Mainfreight

Cleantastic

TIMEX

Radio Network

Glen Horsfall

New Lynn Lions

Roche

NZ Rugby Union

Canterbury Crusaders

AdShell

Christchurch Casino

NZFMA

The Ministry of Health

Pub Charity

Guardian Trust

BOC Gases

NZ Community Trust

All of our individual donors

NZ Carer's Alliance

Breath4CF Ironman athletes

Buddle Findlay

Foodstuffs

JFMiller Photography

Mighty River Power

Canterbury Community Trust

Christchurch Northwest Kiwanis

Medhi Angot

Royal NZ Ballet





## Financial Statements

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30TH JUNE 2012

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CYSTIC FIBROSIS ASSN OF N.Z. (INC)

TRUST DIRECTORY  
FOR THE YEAR ENDED 30TH JUNE 2012

Date of Formation: 16 December 1968

Charitable Trust  
Incorporation Number: 211724

Objects: To fund research and support for  
people with Cystic Fibrosis.

Auditors: Peter Davidson & Associates  
25a Horotane Valley Road  
CHRISTCHURCH

Bankers: ASB  
Private Bag 39 888  
Auckland

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

STATEMENT OF FINANCIAL PERFORMANCE  
FOR THE YEAR ENDED 30TH JUNE 2012

	<u>2012</u>	<u>2011</u>
<u>INCOME</u>		
Individual Donations & Bequests	60,752	74,357
Sponsorships & Grants (note 11)	121,105	180,622
Grants ex Branches	7,000	2,000
National Fundraising (notes 12)	224,318	158,045
Interest - Chris Howlett Fund Interest & B4CF	35,964	36,888
Interest - General	4,070	5,841
Dividends - Chris Howlett	4,435	4,646
Dividends - Rangitira	15,600	16,450
MOH Contract Income	90,000	75,000
Other Income	11,218	10,789
	<hr/>	<hr/>
	574,462	564,638
 <u>OPERATING EXPENSES</u>		
Grants to Branches	4,385	425
Other Grants	2,275	5,679
Hospital Allowances & Prescription Refunds	17,940	18,920
National Voucher Scheme	8,633	8,075
Funeral Grants	2,000	4,000
Medical Information & Advice	8,003	497
Tertiary Education Grants	12,993	16,562
Chris Howlett Fund Endowment Payments	25,500	26,000
Transplant Grants incl Vouchers	13,443	3,970
Advertising, Promotion, Public Relations & Lobbying	26,582	14,367
Publications - Newsletter	10,175	5,079
Publications - Other	468	91
Breath4CF Grants	70,032	88,746
Equipment & Laptops for PWCF	-	1,936
Field Worker Costs	79,828	80,114
Conference Expenses	28,307	31,317
	<hr/>	<hr/>
	310,564	305,778

These financial statements should be read  
subject to the notes annexed hereto.



CYSTIC FIBROSIS ASSN OF N.Z. (INC)

FOR THE YEAR ENDED 30TH JUNE 2012

	<u>2012</u>	<u>2011</u>
<u>ADMINISTRATIVE EXPENSES</u>		
Staff Salaries	163,386	187,025
Staff Travel	7,374	5,277
Motor Vehicle Costs	9,048	10,236
Other Staff Costs	14,246	20,225
Office - Rent/Electricity/IT		
Support	40,997	25,613
Printing , Stationery &		
Photocopying	3,688	6,068
Postage	10,109	8,570
Telephone & Tolls	7,583	8,804
Subscriptions	1,331	1,836
Accounting Fees	2,650	2,100
Audit Fees	2,350	2,258
Board Expenses	6,116	7,407
General	9,703	7,553
Legal Expenses	-	6,383
	<hr/>	<hr/>
	278,581	299,355
<u>DEPRECIATION</u>		
Depreciation	3,180	5,146
	<hr/>	<hr/>
	3,180	5,146
<u>TOTAL EXPENSES</u>		
	<hr/>	<hr/>
	592,325	610,279
<u>OPERATING (DEFICIT)/ SURPLUS</u>		
	<hr/>	<hr/>
	(17,863)	(45,641)
<u>SUNDRY INCOME</u>		
Capital Gain on Disposal of Investments	-	10,108
Branch operating results (deficit) (note 7)	6,346	185,923
	<hr/>	<hr/>
<u>NET (DEFICIT)/ SURPLUS FOR YEAR</u>	<hr/>	<hr/>
	(11,517)	150,390

These financial statements should be read  
subject to the notes annexed hereto.

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

FOR THE YEAR ENDED 30TH JUNE 2012

	<u>2012</u>	<u>2011</u>
<u>STATEMENT OF MOVEMENTS IN EQUITY</u>		
Net (Deficit)/Surplus for Year	(11,517)	150,389
Trust Equity at 1/7/2011	1,555,392	1,414,856
First NZ Capital Portfolio Valuation Fluctuation - Unrealised	15,880	854
CHEF & B4CF Fund adjustments	25,500	26,000
	<u>1,585,255</u>	<u>1,592,099</u>

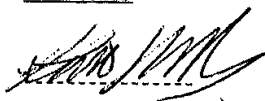
Comprised:

Accumulated Funds	893,983	932,446
Chris Howlett Endowment Fund (note10)	489,658	483,831
Breath 4 cf Physical Equipment Fund (Note13)	201,614	175,822
Total Equity as at 30/6/2012	1,585,255	1,592,099

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

STATEMENT OF FINANCIAL POSITION  
FOR THE YEAR ENDED 30TH JUNE 2012

	<u>2012</u>	<u>2011</u>
<u>TRUST EQUITY</u>	1,585,255	1,592,099
	<u>1,585,255</u>	<u>1,592,099</u>
<u>Represented By :</u>		
<u>CURRENT ASSETS</u>		
Cash on Hand	150	150
Cheque a/c	47,506	102,765
Grant Receivable from Share in Life Foundation	20,000	-
Term Deposits (note 8)	125,599	102,487
Accounts Receivable & Accruals	3,482	8,688
Stock on Hand - Vouchers	10,618	4,570
Goods & Services Tax Holding Account	2,741	5,043
	<u>210,096</u>	<u>223,703</u>
<u>INVESTMENTS</u>		
Long Term Investments (note 9)	75,600	75,600
Chris Howlett Endowment Fund and B4CF Assets- note 10 & 13	691,272	659,653
Branch Assets (note 7)	697,446	691,100
	<u>1,464,318</u>	<u>1,426,353</u>
<u>PROPERTY PLANT AND EQUIPMENT</u> As per Schedule	10,904	10,192
	<u>1,685,318</u>	<u>1,660,248</u>
<u>TOTAL ASSETS</u>		
<u>CURRENT LIABILITIES</u>		
Accounts Payable & Accruals	29,268	26,629
Staff Entitlements	13,472	13,426
Tertiary Assistance Liability	11,149	7,178
Otago Branch Funds		20,916
Unexpended Grants	46,174	
	<u>100,063</u>	<u>68,149</u>
<u>TOTAL LIABILITIES</u>	<u>100,063</u>	<u>68,149</u>
<u>NET ASSETS</u>	<u>1,585,255</u>	<u>1,592,099</u>



27/8/2012

These financial statements should be read  
subject to the notes annexed hereto.

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30TH JUNE 2012

1. STATEMENT OF ACCOUNTING POLICIES

Reporting Entity

The reporting entity is a charitable trust incorporated under the Charitable Trusts Act 1957. The financial statements of the entity have been prepared in accordance with generally accepted accounting practice in New Zealand. The financial statements comprise statements of: accounting policies; financial performance; movements in equity; financial position; as well as the notes to these statements contained in this annual report.

Measurement Base

Other than where specifically stated the measurement base adopted is that of historical cost. Accrual accounting is used to recognise expenses and revenues when they occur.

SPECIFIC ACCOUNTING POLICIES

Differential reporting

Cystic Fibrosis Association Incorporated qualifies for differential reporting exemptions as it satisfies the public accountability and size criteria as set out in the Framework for Differential Reporting. All available differential reporting exemptions allowed under the framework for differential reporting have been adopted.

Depreciation

Depreciation has been charged using D V rates from 20% to 48%.

Accounts Receivable

Accounts receivable are recorded at net realisable value.

Investments

The investment in First NZ Capital Portfolio is valued at market value as at balance date with any unrealised change in value recorded as a fluctuation reserve change. Other Investments are recorded at cost with any gain or loss being written off to the Statement of Financial Performance at the time of maturity, being an adjustment to interest earned.

Property Plant and Equipment

Property Plant and Equipment is recorded at cost less accumulated depreciation.

Unexpended Project Grants

Unexpended Project Grants are recorded as a current liability at balance date.

Goods and Services Tax

The financial statements have been prepared stating all income and expenditure items exclusive of GST.



CYSTIC FIBROSIS ASSN OF N.Z. (INC)

Taxation

The Trust is a registered charity and is not liable to pay income tax.

Branch Assets

The net assets of each Branch of the CFANZ as at 30 June 2011 are included in financial statements as at that date.

Changes in Accounting Policies

There have been no changes in accounting policies. All policies have been applied on bases consistent with those used in prior years.

Change of Accounting Period

The Association has changed its year end balance date to 30 June. These financial statements cover a 12 month period. The comparative figures are for 16 months.

2. Capital Commitments

There were no capital commitments at 30.6.2012      2011 (Nil)

3. Contingent Liabilities and Commitments

There were no contingent liabilities or commitments as at 30.6.2012      2011 (Nil).

4. Related Party Transactions

The Share in Life Trust is a related entity. Transactions are carried out under standard business terms and conditions at an arms length price. It is accounted for separately.

5. Lease Commitments

As at balance date the Association has future operating lease commitments as follows:

	expiry date	within 12 months	greater than 12 months
- Vehicle 1 Lease	July 2012	327	0
- Vehicle 2 Lease	Feb 2014	8,961	5,974
- Premises rental	Nov 2011	20,113	8,380
		-----	-----
TOTAL		29,401	14,354

6. Subsequent Events

The Trustees are not aware of any matter or circumstance since the end of the financial year, not otherwise mentioned within this report, that has significantly affected or may significantly affect the operations of the Association, the results of those operations, or the state of affairs of the Association

**CYSTIC FIBROSIS ASSN OF N.Z. (INC)**

**Financial Statements**

**For the year ended 30 June 2012**

<b>7 Branch operating results</b>	<b><u>2012</u></b>	<b><u>2011</u></b>
Surplus/ (Deficit) after contributions to National Association		
Northland	-16,441	4,291
Auckland	-12,354	35,390
Bay of Plenty	6,593	-458
Waikato	-6,160	-964
Hawkes Bay	-6,513	146,708
Taranaki	6,033	1,407
Central Districts	-516	-771
Wellington	-472	10,062
Nelson	-1,290	-618
Canterbury	14,060	-21,145
Otago	26,692	10,480
Southland	-3,286	1,541
Total Branch Surplus/(Deficit)	<u>6,346</u>	<u>185,923</u>

**Branch Assets**

Northland	32,845	49,286
Auckland	161,727	174,081
Bay of Plenty	11,557	4,964
Waikato	13,247	19,407
Hawkes Bay	157,472	163,985
Taranaki	25,579	19,546
Central Districts	16,696	17,212
Wellington	32,300	32,772
Nelson	1,388	2,678
Canterbury	177,134	163,074
Otago	46,096	19,405
Southland	21,404	24,690
Total Branch Assets	<u>697,445</u>	<u>691,100</u>

**8 Short Term Investments**

Rabobank	47,506	102,487
Total	<u>47,506</u>	<u>102,487</u>

**9 Long Term Investments**

Comprises: 10,000 Ordinary A Rangatira Ltd Shares and 30,000 Ordinary B Rangatira Ltd Shares. (market value 30/6/2012 \$240,000 - 2011 \$240,000)	75,600	75,600
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**CYSTIC FIBROSIS ASSN OF N.Z. (INC)**

Financial Statements

For the year ended 30 June 2012

	<u>2012</u>	<u>2011</u>
<b>10 Chris Howlett Endowment Fund</b>		
Opening Balance	483,831	462,702
Plus net income earned	30,209	30,593
Less Transferred to CFANZ retained earnings for admin	-1,000	-1,000
Endowment Grants paid	-25,500	-26,000
Plus unrealised revaluation gain	2,118	17,536
Closing Balance	<u>489,658</u>	<u>483,831</u>
<b>11 Donations, Sponsorships and Grants</b>		
Pub Charity Grant	30,000	35,000
NZ Lottery Grants Board	23,130	35,000
N Z Community Trust	5,000	0
Other	3,488	10,000
ASB Community Trust	25,000	25,000
Bendigo Valley Trust - Grant for electricity	2,500	0
Eureka Trust	0	1,822
Four Winds Foundation	3,000	0
Canterbury Community Trust	5,000	5,000
Cure Kids	3,000	0
Lion Foundation	0	3,000
Mainland Foundation	4,361	2,400
Perpetual Trust	2,000	0
Foodstuffs Community Trust	0	3,000
Westpac	10,000	0
ASB Bank	0	2,000
Boehringer Ingelheim	0	2,000
Pelorus Trust	0	3,000
BP Petrol Vouchers	200	400
Share in Life Foundation	35,600	20,000
Guardian Trust	5,000	13,000
The Trust Charitable Foundation	0	10,000
First Sovereign	5,000	10,000
Trusts Community Foundation	5,000	0
Less Unexpended Grants	<u>-46,174</u>	
	121,105	180,622
<b>Plus non cash sponsorships</b>		
<b>Goods in kind for events such as: Ironman, Charity Cricket CFANZ National Conference and National Raffle:</b>		
<b>Major Sponsors:</b>		
<b>Christchurch Casino</b>		
<b>Roche Products</b>		
<b>Dominion Post</b>		
<b>Boehringer Ingelheim</b>		
<b>The Edge</b>		
<b>More FM</b>		
TOTAL	45,437	88,563

**12 National Fundraising**

Comprising the following which are net of expenses incurred:

National Raffle	18,919	12,994
Charity Cricket Gala Day	13,648	7,663
Breath 4 CF	92,201	66,479
Riccarton Race Day	800	4,200
Reuters Golf	33,663	0
Other: NZFMA Ball, Galaxy of cars, Central SI Bike Ride	30,178	0
Other	34,909	66,709
	<u>224,318</u>	<u>158,045</u>

**13 Breath 4 CF Physical Equipment Fund**

Comprises net income arising from the fundraising activities undertaken in conjunction with the Taupo Ironman multisport event which is utilised for specific needs.

Opening balance	175,822	323,765
Plus net Income	99,708	76,266
less payments for equipment	-70,032	-88,746
Less correcting transfer to accumulated funds	0	-130,000
less transfer to CFANZ retained earnings -admin current year	-9,218	-9,026
Plus unrealised revaluation gain	5,334	3,563
Closing Balance	<u>201,614</u>	<u>175,822</u>

## AUDITORS' REPORT

### To the Members of the Cystic Fibrosis Association of New Zealand.

We have audited the financial report on pages 1 to 10. The financial report provides information about the past financial performance of the Cystic Fibrosis Association of New Zealand and its financial position as at 30 June 2012. This information is in accordance with the accounting policies set out in note 1 to the financial statements.

#### **Board of Management Responsibilities**

The Board of Management is responsible for the preparation of a financial report which fairly reflects the financial position of the Cystic Fibrosis Association of New Zealand as at 30 June 2012, and of the results of operations for the year ended on that date.

#### **Auditors Responsibilities**

It is our responsibility to express an independent opinion on the financial report presented by the Board of Management and report our opinion to you.

#### **Basis of Opinion**

An audit includes examining, on a test basis, evidence relevant to the amounts and disclosures in the financial report. It also includes assessing:

- the significant estimates and judgements made by the Board of Management in the preparation of the financial report; and
- whether the accounting policies are appropriate to the Cystic Fibrosis Association of New Zealand circumstances, consistently applied and adequately disclosed.

We conducted our audit in accordance with generally accepted auditing standards in New Zealand, except that our work was limited as explained below. We planned and performed our audit so as to obtain all the information and explanations which we considered necessary in order to provide us with sufficient evidence to give reasonable assurance that the financial report is free from material misstatements, whether caused by fraud or error. In forming our opinion, we also evaluated the overall adequacy of the presentation of information in the financial report.

We assisted the Association in the formatting of the financial report, other than this we have no relationship with, or interest in, The Cystic Fibrosis Association of New Zealand.



**Qualified Opinion**

It should be noted that there is limited control over the revenues prior to being recorded, and there are no practical audit procedures to determine the effect of this limited control.

We have also relied on the statements forwarded from branches of the Association only some of which have been audited and have been unable to complete any detailed work on these results. In these respects alone we have not obtained all the information and explanations that we have required.

In our opinion the financial report on pages 1 to 10 fairly reflects the financial position of the Cystic Fibrosis Association of New Zealand as at 30 June 2012, and the results of its operations for the period ended on that date.

Our audit was completed on 29 August 2012 and our qualified opinion is expressed as at that date.

Peter Davidson & Associates

Christchurch





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