



Grace Paterson
Kaimata

Cystic Fibrosis Association of NZ

ANNUAL REPORT 2013



Our People

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

Chief Executive

Julie Clemett

Administration Manager

Caroline Wagteveld McKenzie

Fundraising Manager

Sally Carron

High Needs Field Worker

Susan Lovelock

Southern Region Field Worker

Melinda Coombes

Northern Region Field Worker

Clinical Advisory Panel

Dr Richard Laing – Chairman

Chest Specialist, Christchurch Hospital

Dr Cass Byrnes

Paediatrician, Starship Childrens' Hospital

Dr Philip Pattemore

Paediatrician, Christchurch Hospital

Dr Mark O'Carroll

Chest Specialist, Auckland Hospital

Dr Peter McIlroy

Paediatrician, Nelson Hospital

Rebecca Scoones

Physiotherapist, Starship Childrens' Hospital

Vivienne Isles

Childrens' Outreach Nurse, Christchurch Hospital

Victoria Crowder

Dietitian, Christchurch Hospital

Investment Committee

John Parsons – Chairman

Steve Drumm

James Lee

Jane Drumm

Kate Russell

***CFANZ will optimise quality of life for people with cystic fibrosis and their families;
striving for normal life expectancy and a cure***

Chairpersons' Report

2012/13 has been another challenging, hardworking year for our Association. I believe one of the reasons we are able to rise to these challenges is that throughout NZ we have an amazing community of people who are the backbone of the Association. People who; sell raffle tickets, wave the "flag" by attending CF events and fundraisers, share their knowledge and experience, organise local branches, attend our conferences and much, much more.

Communication is vital to building a strong community and has really developed within the CF Association over the last few years- there is now a real connectivity within the CF community. For example whenever there is a competition to be had or something to be won you can be sure our zealous CF community is at the front....this year it has been winning one of the 25 Toyota cars and getting just over \$8,000 from Health Post (the most money they have ever given to a charity to date). Indeed if there is a prize to be won or a computer key to be clicked to benefit the Association, you can pretty much guarantee that the CF community and all our friends and family will rally; this is very heartening for the Board. Our Facebook groups are very popular, and sometimes polarising, but I believe that healthy sharing of opinion and strong debate is one of the ways we mature as people and even as a community.

I am pleased to report that this year the Board has been able to recognise several of our long term Strategic goals. We have a three year plan and the strategic direction of the Association will be examined again in 2014. One of this year's successes has been scoping work on a possible branch liaison position. This is with the aim of establishing on a branch by branch basis, how to best capitalise on opportunities (primarily fundraising, events and initiatives) with the next very exciting step being to develop that potential.



Another strategic initiative, which the Board is very grateful for help from the Auckland branch for, is our fledgling ICARE programme (an adherence programme for young people with CF developed in the US). By securing funding through a US based company UPS, the Auckland branch have provided the funds needed to bring the ICARE programme to NZ, and this is now in the process of being facilitated and managed by our national office. It is these kinds of partnerships between the Association and branches that the Board wants to see happening more often.

This last year the Board, as interim trustees, carried out a detailed review of the Share in Life Foundation establishing the right structure and a plan for moving forward with this important aspect of CF research and quality care in NZ. Significant projects such as PORT CF NZ receive funding through SILF and this has a direct impact on understanding and upping the quality of care for all people living with CF in NZ. As Port CF is a global project we can be assured that by putting our time and money into this project we are able to benchmark NZ with many other countries and that has got to be good for our people.

As I have mentioned one of our strategic goals was to continue to develop communications with our CF community and we have started holding monthly phone conference calls with Chair people and board members from around NZ. The Board is also establishing a new way to receive feedback from our Adult CF community.

Although CF adults have a closed group on Facebook, enabling those who wish to remain in contact for support and advice, the Board wanted to ensure that we have an opportunity to hear direct from representatives of the adult group. We are about to appoint our first ever Adult consult committee who will report direct to the Board.

A Patient and Family Advisory Group, another strategic goal, continues on at Starship Hospital and although this group only meets twice a year meetings provide a positive and proactive opportunity for dialogue on all things to do with patient care and treatment at Starship. The board can see that a roll out of this model may be beneficial throughout the country.

As an Association we have a lot to be proud of. I am particularly proud that so many of our strategic initiatives have come to life over the last 3 years and it is all to the benefit of our people with CF and their families. I am also very satisfied with; the productive relationship with medical and allied health professionals through our Clinical Advisory Panel, the fact that our CE Chairs the community consult committee to PHARMAC, our skilled and respected Fieldworkers, our hard working and relentless national office staff and our incredible and dedicated volunteers and supporters. On behalf of the Board I thank all who have put in so much to maintain and strengthen our Association.



We all know that the major challenge for the Association is the ever shrinking charity dollar. Significant CF Association events such as Ironman and the Reuters Golf Tournament will need to be replaced. Grants are harder to come by and when achieved are usually for far smaller amounts than requested.

The needs of our now aging CF population grow annually. At our last board meeting it was pointed out that 2/3rds of Association funds are held in branch accounts and the Association holds less than 6 months in reserves funding. Although we are in a better position than many similar organisations, the Board has made it our absolute priority to ensure that the Association becomes more financially secure.

Our ongoing challenge as an Association is the balancing act of how to continue to meet the growing needs of our CF community whilst still moving forward strategically, and ensuring that we do not spread ourselves too thin. As my teens would say “Challenge accepted”

Jane Drumm – CFANZ Board Chairperson

Chief Executive's Report

The end of each year presents us with an opportunity to review what we have achieved, reflect on what we have learned and renew our commitment to our core goals and values.

The 2012/13 year was one that was characterized, at least from the National perspective by a constant and urgent need to maintain our funding base and work to diversify our fundraising in the face of falling grant funds, a sluggish corporate sector still recovering from recession woes and government contracts that have not kept pace with increases in need for our Field Worker Services.

Much has been said in the media and elsewhere about the furious competition that now exists in the charitable sector, for the limited funding available from all these sources. We could take the simplistic view that we simply need to 'run more events'. However with only 1 part-time staff member and the CEO at National office available to organize and run events, there is always a physical limit on what can be achieved. The need for the entire CF network at every level to think creatively about how we will fund our services into the future is urgent.

Over this year we have had many new and interesting projects to celebrate;

Port CF has published its first set of data which showed us that our outcomes are similar to those of other countries such as Australia and the UK which is indeed heartening considering we lack some of the medicines they have available to



Canterbury

District Health Board

Te Poari Hauora o Waitaha

them. Our sincere thanks to our Steering Committee, ably led by Dr Cass Byrnes, our database IT contact from the CDHB, Andy Watson, The Canterbury District Health Board for so generously hosting the application, Our statistician, Chris Frampton and of course, the Shares in Life Foundation for providing the all important funding support for the project.

ICARE is a programme for adherence that we have wanted to try for many years. With the generous support of the Auckland CFANZ branch, who secured us a grant through a personal contact from a USA-owned Company – UPS, we were able to move closer to that goal in 2012/13. Dr Alexandra Quittner, author of the programme was able to travel to New Zealand and provide training in the tool to a selection of Auckland, Canterbury and regional health professionals with a view to running a pilot of the programme from November 2013. Our sincere thanks to UPS for their wonderful grant and for Auckland Branch for contributing to this important strategic project.



The Australasian CF Conference has taken a huge amount of staff time since work began on developing the programme in mid-2012. Working in tandem with the Australian CF Association has had its challenges as the two associations work quite differently, but the programme was of the highest quality and we are sure that delegates and trade/ sponsors and speaker alike all enjoyed coming together to learn.

Financially, our branches are largely in good heart with others working hard to get some reserves tucked away and ensure they have the ability to fulfill all the needs of their CF Communities. Branches are now beginning to run more events and gain confidence in their special event organisational abilities which is great to see. It is also

heartening to see the individual CF families who decide to take on the personal challenge of raising funds for our cause.

Our consultation on the new cross infection policy drew some interesting responses which were all taken into account in the final draft. At the end though, we need to be led by evidence first and international practice and much as I am sure it saddens all of us to have to make it less easy for adults with CF to attend our meetings, I am also equally sure that the welfare, wellbeing and survival of our precious people with CF is always uppermost in our minds.

2013 was our final year as official charity for Ironman. Whilst we are sad the partnership has come to a close, we are deeply grateful for the 10 years we had with the event which allowed us to continue to provide breath4CF grants through the country. Sincere thanks to Jane Patterson and all the Directors of Ironman NZ.

I wish to thank the Board for another effective year of governance. To all the members who take the extra step of taking part in assisting at branch level, be it as Chair, Treasurer, Secretary or someone who organizes street appeal, you are all so very valued.

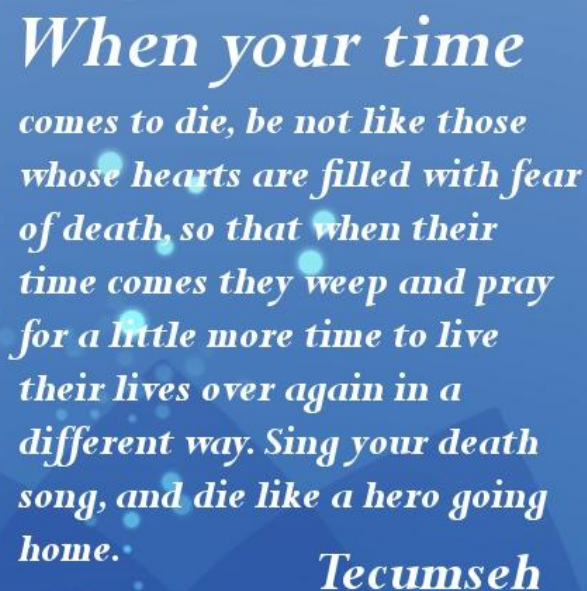
To the staff, who always and every day go the extra mile, give the extra hours, volunteer over and above their paid work, often during times of personal hardship, my thanks to you all.

Kate Russell - Chief Executive

Goodbyes

In the 2012/13 year, these brave people came to the end of their life's journey. Our thoughts and prayers are with their families and friends

Erin Bartrum
Kimberley Robottom
MacKenzie Perry
William Leitch
Ryan Hamilton
Desmond Dustow
Ryan Smith
Casey Bell
Teri Titter



*When your time
comes to die, be not like those
whose hearts are filled with fear
of death, so that when their
time comes they weep and pray
for a little more time to live
their lives over again in a
different way. Sing your death
song, and die like a hero going
home.*

Tecumseh

Mark Ashford Scholarship



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 2013 – Kieran Jongerius (*pictured with partner Monique*)

Kieran is studying Microbiology and immunology at Otago University with a scholarship in science and has consistently achieved top class results across the subject areas he has studied. Kieran was also awarded a summer research internship. Out of the lecture theatre, Kieran enjoys mountain biking, long boarding, drawing and water colour painting. He is very keen also on classical, orchestral music and jazz! Well done Kieran, we could have our next amazing CF researcher in the wings

CF Achievers Awards 2013



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.



Jake Gawn -Achievement in Sport

Jake is fifteen years old and lives in Timaru with his Mum and Dad and his twin sister Emma who also has CF. Jake is a keen triathlete having successfully competed in his local Oamaru Tri and then on to the 2013 Wanaka Challenge. Jake's team were all under the minimum age so epical dispensation was needed. Jake's team finished 112th out of 215 teams and they are already eyeing up their next challenge

Steven Gordon – Achievement in Leadership (no picture)

Steven does significant voluntary work in his community and through his local Church group. He has worked as a voluntary teacher's aide at his local school doing a variety of

tasks. He is so valued that the school offered him a paid position which he turned down. Steven loves working with children and has helped to run a youth programme through his Church as a Leader.



Jessica Ellen Scott – Achievement in Leadership

Jessica has pushed through some very hard times in her life to become a role model for others with CF about learning to take risks and be brave in life and how to live a life not defined by your illness. Her challenges to date include: Caving tours, black water rafting, skydiving, bungy jumping, zip-lining through the jungle, doing the Tongariro Crossing and canyoning. Jess takes a different friend on each adventure to spread the word about doing things that challenge you.

Phoebe Watt - Achievement in Education

Phoebe's academic career has been an impressive one, with numerous awards over multiple subject areas. She also represented her school at the Student Commonwealth heads of Government meeting when she was in year 13. Having started a Bachelor of Communications in 2008, Phoebe became too unwell to continue and instead took up a position as a Social Media Team member for Oxfam NZ. Returning to study in 2010, Phoebe has completed her degree in the Arts and hopes to move into an Honours year. Alongside this heavy study schedule Phoebe is also an Editorial Intern for north and South Magazine, and she hopes to one day be a feature writer



George Blyth – Achievement in Sport

George is clearly going to be a sporting 'overachiever' as he grows. Already he has been awarded: Sportsman of the Year for his school in 2012, Award for Academic excellence in the same year, Player of the year for the under-13s at Ashley Rugby and Batsman of the year for the Sefton Cricket Club. George has played rep grade cricket for the past three years and has represented his school both on the sports field and academically

Stanley Millwater – Achievement in Leadership

Stanley is a determined ten year old who has faced more than his fair share of challenges. He loves biking, swimming, sailing and in-line hockey. He is moving from Cubs to Scouts and takes his role in this movement very seriously, having proved himself to be a good teacher and empathetic leader for others. He is described as a patient boy with the ability to teach others what he knows. He hopes to attend Jamboree at the end of this year.



Branch Reports

NORTHLAND

Northland Branch has had a good year fundraising, with our annual golf tournament. It was the 6th time held, and raised just over \$10'000. We have had some great CF ambassadors doing their bit at sports events using fundraise online too. We have donated \$5'000 to 'Shares in Life'. As a branch we are still happy to be able to offer our PWCF a fitness fund of \$500 a year, heating grants of \$500 per CF family, \$20 per day hospital stay support and helping out with funding for nebulisers.

Mike Webb – Chairman, Northland Branch

AUCKLAND

Hard work and wider community involvement has seen another successful year for Auckland Branch. Our success is definitely based on collectively working together, with people in our community using their strengths in different ways to improve our profile, raise much needed funds and continue our support in all areas for our people with CF. Our regular and ongoing 'spend' includes medical equipment, hospital stay packs, food, supermarket, phone and parking vouchers, newsletters, conference attendance, PFRC office rental and our branch co-ordinator's salary.

Throughout the year we had two movie fundraisers, Awareness week which involved many people contributing in different ways i.e. Trade Me auction, street collections, mufti days, chocolate fish sales and \$65 for 65 roses. We were successful with some grants which proved invaluable and the highlight of the year was the Round the Bays Run. This not only raised a terrific amount of money but also improved our public profile while bringing lots of people together in our community to have fun. This fruitful year was once again achieved by our great team of people who continually stay motivated to support the cause of CF.

Anthea Wendelborn and Jill Thorrat, CF Auckland Branch Co-Chairs

WAIKATO

This year in Waikato the committee feel like we are slowly getting the branch more informed, becoming independent and more helpful to our members.

We used CF Awareness Week to sell merchandise and raise awareness . We had more families participate than the year before. Matamata worked with LJ Hooker to do a bbq and sell merchandise. Other members made morning teas with donations to CF.

This year we tried for three grants – and in every instance we were successful thanks to Jenna our treasurer , Auckland Branch and National Office for sharing their wisdom from past experience.

Janelle, our secretary has consistently put out informative newsletters to our branch, an important task for the year , as we wanted to keep everyone informed and a regular physical newsletter seems to be working . This was also helped with Community Post envelopes. We ran another Pool Competition which was another success and hope to do another in the summer. There were several donations throughout the year from Ngarua Young Farmers, and several local Piako farming families, these are relationships we hope to nurture for future use.



CF Waikato has provided a considerable amount of welfare help over the year and we hope to always be able to achieve this financially.

In June we were spoken to by John Elliot CFANZ Board Member who has given us ideas to work with National. It is hoped we can co ordinate with National throughout the year to achieve more effective fundraising. Our fundraiser at present is to rear a calf for Waikato CF , organised by a local lady for us . It will be interesting to see how this goes, RD1 are generously helping us with this.

Mike and Debbie Wood, CoChairs, Waikato Branch, CFANZ

BAY OF PLENTY

2012/13 feels like a relatively quiet year for our branch. We decided not to run our Christmas tree festival this year as the economic recession meant the majority of businesses we approached – including the ones that participated last year – could not spare the funds this year. However we been fortunate in terms of donations from unexpected sources and groups fundraising on our behalf. Letters sent out to schools at the beginning of 2012 yielded a significant amount of revenue for us. One of our lovely volunteers, an aunt of one of our PWCF, put on a fundraiser French afternoon tea in a beautiful French styled home. Thank you Linda for all your hard work.

In June 2012 Cystic Fibrosis National were approached by the Bethlehem Foundation, a charitable organisation which owns some of the private schools in our area, to be the chosen charity for their annual dinner and auction in June 2013. So with the Foundation and Caroline from national office organizing the evening, we assisted with and enjoyed a great night of food, wine, entertainment and an auction, attended by around 200 guests. Proceeds were split between CFANZ and the Foundation, which means we will be able to pursue our dream of a community physiotherapist. We are grateful to the Lion Foundation and Pub Charity for grants for nebulisers this year. But unfortunately we haven't been as fortunate with other grants so have been unable to pay for attendees at the Australasian conference in Auckland.

Sadly, we farewelled William Leitch, son of our treasurer Anita and her husband Graham, in January. While we grieve with this family we are also grateful that Anita wishes to continue as our treasurer and help us support our other families fight this condition.

Nicola Wakerley, Chairperson BOP Branch

TARANAKI

Highlights include the following fund raisers and social events: \$5500 raised in our annual street appeal. Participation in the Taranaki Steelformers Around the Mountain Relay for 3rd year in a row. Assisting 2 physiotherapists to the pre-conference workshops. Our annual dinner with special guests, Melinda Coombes, Shirani Smith CF specialist nurse and Dr John Doran, Paediatrician. The social setting helped to build bridges of understanding and awareness between our paediatric team and the CF committee for the benefit of our children with CF.

Lows: No summer social organised. No one apart from me has registered for the Australasia conference this August, in spite of its proximity to Taranaki and our offer to substantially subsidise costs. We have had no success in attracting committee members who are directly involved with paediatrics. It is very difficult for our committee to understand and serve the needs of these CF families when they do not have a voice at our meetings. We need to find another way of reaching out to these people.

Shelley Gruchy, Taranaki Chairperson

HAWKES BAY

The Hawkes Bay Branch has had a quiet year with regular meetings . Awareness week was once again supported by our members in Waipukurau, Hastings, Napier and this year Gisborne members also collected . There was a

good attendance by our members at national conference and Sarah Hasselman joined me at the chairpersons conference. We have helped members in many ways, firewood, Pari boy nebulisers, out of district hospital costs, and bereavement costs. A number of families using the funds for "physiotherapy in their homes". This has been an enormous help to the parents, as a caregiver comes in to give physio or supervise PEP 3 to 5 times a week. The Branch is in a strong financial position and will be donating to National.

Glenda Sinden, Chairperson, Hawkes Bay

CENTRAL DISTRICTS

In October 2012 we held our annual Ballentynes Fashion Show fundraiser in Wanganui, a poignant time as, the year before, this event had been organised with Erin, whom we lost to CF in July 2012.

Late last year we were happy to find we were successful with our application for BP vouchers and have mainly used them to allow us to get together for monthly committee meetings. As a small committee of four, we are spread right across our region, but I am pleased as to how we are able to work well together to help our branch members. We have lost 3 CF adults in the past year which has been tough.

We had various unexpected donations throughout the year, including one from a motorcycle club in memory of one of our branch members who also passed away last year. We have two places in Wanganui that continuously sell our chocolate fish year round. We intend to implement '\$65 For 65 Roses' this year, leading up to CF Awareness Week, thanks to Anthea's help with this great idea.

We have looked more closely into the welfare of our branch members and have begun supplying 'treat bags' to Palmerston North Hospital's Childrens' Ward for our young CFers, and have offered capped grants to those deemed in financial need, as well as writing a policy to provide 50% refund of prescription fees - this last one is still being completed.

Anna Scoullar Jones – Chairperson, Central Districts

WELLINGTON

Wellington Branch has enjoyed a busy and successful year supporting its members and raising awareness. We have a small, well structured and dedicated committee. We have been successful in securing funds for equipment and conference. We have also now succeeded in finding a permanent branch treasurer, after doubling up the roles of treasurer and chair for most of the year.

During Awareness Week we chose to collect only in 3 or 4 known "lucrative" collection spots, maximising income from limited collectors. Branch members ran two very successful movie night fundraisers. Our 3rd Annual Christmas Tree Festival (XTF) was a great success not only as a means to raise funds and awareness, but also it is wonderful to see so many of our branch members getting involved in different ways. An exciting spin-off is the support of one of our sponsors Moxie Communications who are helping us grow and market this year's festival.

A small number of successful networking events run through the year for families, including parents mornings, drinks evenings to coincide with fieldworker visits, XTF gala opening and our end of year social. We are building relationships with a number of local supporters including Streetwise Coffee and The Freemasons. Supply and funding of equipment remains a challenge but we are working closely with DHB staff to find ways of improving this.

Families in paediatrics were sad to farewell our long-serving CF Consultant Dr Alan Farrell, but are very pleased to welcome his replacement Dr Tim Savage, and grateful to the DHB for provisioning for a reasonable handover period. We hope to this year focus more closely on ways we can work more closely with the DHB staff to continue to improve services and support to PWCF in Wellington.

Diane Murray, Chairperson, Wellington Branch



NELSON

It's been another interesting year for us with the addition of Blenheim families so are now the Nelson Marlborough Branch of Cystic Fibrosis. Historically it was a combined branch until Christchurch stepped in to help support the Blenheim families. Thank you Christchurch for that support and handing the reigns back to us. To be honest it has brought with it a geographical and funding challenge which we will continue to try and conquer. The branch has worked extremely hard with fundraising with an amazing increase of 1000% in the bank (most having now been spent to support families and health professionals to attend Conference). We are working on refining this and work out where to focus our resources to get the best "bang for your buck". SO to the whole committee thank you for the support and let's make the coming year an even better one.

Rebecca Colley, Chairperson, Nelson Branch

CANTERBURY

The Canterbury Branch has had a relatively successful year with new projects taking place and new people stepping up to raise funds for us. Businesses are starting to get back on their feet and are more open to fundraising ideas.



Charlotte Ensor a CF mother and her talented group of ladies were extremely successful with their fundraising Run for Harry. They ran the Christchurch Marathon to raise funds for CF in Harry's name and also held a very impressive auction night, using the Give A Little fundraise site, and getting much publicity on radio stations and newspaper articles. At last count this project raised a tremendous \$54,000 which is being put towards directly helping people with CF in Canterbury by providing essentials that we may not otherwise get funding for or providing a much needed break away for some families who have been through a great deal of stress.

We also met a great contact, Laurie Goodson, at our golf day who has taken on a number of small fundraising projects for us and will also help with our next golf tournament. He arranged for us to collect at a race day which netted \$1,000 and other similar activities. He has also asked us to be the sole charity next year, for a two day golf event that he runs annually, this year Canteen were the recipients and next year it is us so we are very excited about this.

We've also done stocktakes at Bunnings and sausage sizzles and many one off projects. We continue to sell the very popular Entertainment Book. Of great relief to us was the news that the organizers of the Christchurch Casino golf masters event will run its 10th event next year and be handing off to another organizer who will continue to support our Canterbury Branch with funds going to employ our physiotherapist. A parent in our Branch, Cecilia Inns, has come on board to organise our Appeal Week and it is great to have a new, enthusiastic person run an event like this for the Branch and get involved.

Melissa Skene, Chairperson, Canterbury

OTAGO

Cystic Fibrosis Otago has had a successful and exciting year with significant efforts made in many areas to improve member support services through utilisation of the National Fieldworker to assist in providing & assessing of individual needs.

Meetings this year have been attended by the usually small but dedicated group of individuals who show up with great ideas and a passion for getting the job done. We have worked hard to get our projects completed, Including a Branch Newsletter, funding for members to attend the Australasian National Conference in August, access for our members in the DHB Staff Cafeteria to allow for the purchase of a takeaway meal.

The 2012/2013 year saw income of \$26,500 for the Otago branch, a record for a year with no special events. By far the majority of the income came from the annual street appeal which increases each year thanks to the great work done by Kevin Helm our fundraising co-ordinator.

Record income was matched by record expenditure of \$23,100. Forty percent of this expenditure was on EBOS related equipment but the branch also provided members with heating assistance through winter, top ups to Breath4CF grants, computer equipment, xboxes for exercise as well as in-patient expenses.

Arthur Booth, Chairperson, Otago Branch

SOUTHLAND

Another quiet year in the Sunny South with only one or two highlights worth mentioning.

The main highlight was the \$10,000 donation received from Tony Dodds after he won the Wanaka Triathlon. Tony is in the NZ triathlon squad competing around the world against the likes of the Brownlie brothers, Gomez etc. For the past two years he has canvassed Wanaka businesses for prize money so as to attract the top competitors to Wanaka for the race.

\$10,000 prize money has been up for grabs to whoever beat him on his home course and on the understanding that if he won he would donate it to a charity. Last year he was a close second and the money went to Vidal from France, but this year he won and true to his worddonated the \$10,000 to our Southland Branch. This was very generous of Tony and much appreciated .

The other highlight would be the fact that two of the Rangi girls have managed to stay well enough to travel to Perth to work (and play) for awhile. We hope they keep well enough to enjoy their travels.

Jim Phair, Chairperson, Southland Branch

Special Events Photo Gallery





Acknowledgements

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
Christchurch Casino
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
Ted and Molly Carr Trust
ASB
Mainfreight
Cleantastic
TIMEX
CRT
Four Winds Foundation
ChCh Boys High School
Mainland Media
UPS

Roche
Bethlehem Foundation
NZ Rugby Union
Canterbury Crusaders
AdShell
Radio Network
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
JF Miller Photography
Healthpost
Canterbury Community Trust
Christchurch Northwest Kiwanis
Comfort and Quality Hotel Wellington
Z Community grants
More FM
Mediaworks
La Roche Design



Financial Statements for the year ended 20
June 2013

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

FINANCIAL STATEMENTS

FOR THE YEAR ENDED 30TH JUNE 2013

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CYSTIC FIBROSIS ASSN OF N.Z. (INC)

TRUST DIRECTORY
FOR THE YEAR ENDED 30TH JUNE 2013

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 2013

	<u>2013</u>	<u>2012</u>
<u>INCOME</u>		
Individual Donations & Bequests	61,670	60,752
Sponsorships & Grants (note 11)	160,171	121,105
Grants ex Branches	7,000	7,000
National Fundraising (notes 12)	111,373	132,117
Interest - Chris Howlett Fund	26,902	26,944
Interest - General	6,127	4,070
Dividends - Chris Howlett	4,894	4,435
Dividends - Rangitira	16,800	15,600
MOH Contract Income	75,000	90,000
Breath 4CF Interest Income	9,634	9,020
Breath 4CF Fundraising	42,740	92,201
Other Income	6,777	11,218
	<hr/> 529,088	<hr/> 574,462
<u>OPERATING EXPENSES</u>		
Grants to Branches	154	4,385
Other Grants	1,294	2,275
Hospital Allowances & Prescription Refunds	12,360	17,940
National Voucher Scheme	7,880	8,633
Funeral Grants	6,000	2,000
Medical Information & Advice	6,062	8,003
Tertiary Education Grants	20,003	12,993
Chris Howlett Fund Endowment Payments	3,400	25,500
CHEF - Other expenses	1,682	-
Transplant Grants incl Vouchers	9,696	13,443
Advertising, Promotion, Public Relations & Lobbying	3,405	26,582
Publications - Newsletter	3,406	10,175
Education Programmes	10,277	468
Breath4CF Grants	65,269	70,032
Breath 4CF Other Expenses	6,567	-
Equipment & Laptops for PWCF	2,706	-
Field Worker Costs	101,810	79,828
Conference Expenses	10,707	28,307
	<hr/>	<hr/>
<u>SERVICE PROVISION - ADMINISTRATION SUPPORT</u>	272,678	310,564
Administration	119,215	112,709
Service Support Direct Costs	10,815	10,424
	<hr/>	<hr/>
	130,030	123,133

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 2013

	<u>2013</u>	<u>2012</u>
<u>ADMINISTRATIVE EXPENSES</u>		
Staff Salaries	91,454	91,545
Staff Travel	3,648	2,950
Motor Vehicle Costs	3,802	3,619
Other Staff Costs	2,048	2,088
Office - Rent/Electricity/IT Support	16,571	25,938
Printing , Stationery & Photocopying	2,011	1,475
Postage	1,788	4,044
Telephone & Tolls	2,959	3,033
Accounting Fees	2,650	2,650
Audit Fees	2,755	2,350
Board Expenses	4,133	6,116
General	7,465	9,640
	<hr/>	<hr/>
	141,284	155,448
<u>DEPRECIATION</u>		
Depreciation	4,175	3,180
Loss on Sale of Assets	182	-
	<hr/>	<hr/>
	4,357	3,180
<u>TOTAL EXPENSES</u>	<hr/>	<hr/>
	548,349	592,325
<u>OPERATING (DEFICIT)/ SURPLUS</u>	<hr/>	<hr/>
	(19,261)	(17,863)
<u>SUNDRY INCOME</u>		
Branch operating results (deficit) (note 7)	27,141	6,346
	<hr/>	<hr/>
<u>NET (DEFICIT)/ SURPLUS FOR YEAR</u>	<hr/>	<hr/>
	7,880	(11,517)

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 2013

	<u>2013</u>	<u>2012</u>
<u>STATEMENT OF MOVEMENTS IN EQUITY</u>		
Net (Deficit)/Surplus for Year	7,880	(11,517)
Trust Equity at 1/7/2012	1,585,255	1,555,392
First NZ Capital Portfolio Valuation Fluctuation - Unrealised	27,222	15,880
CHEF & B4CF Fund adjustments	-	25,500
	<u>1,620,357</u>	<u>1,585,255</u>

Comprised:

Accumulated Funds	903,388	893,983
Chris Howlett Endowment Fund (note10)	536,874	489,658
Breath 4 cf Physical Equipment Fund (Note13)	180,095	201,614
Total Equity as at 30/6/2013	1,620,357	1,585,255

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

STATEMENT OF FINANCIAL POSITION
FOR THE YEAR ENDED 30TH JUNE 2013

	<u>2013</u>	<u>2012</u>
<u>TRUST EQUITY</u>	1,620,357	1,585,255
	<u>1,620,357</u>	<u>1,585,255</u>
<u>Represented By:</u>		
<u>CURRENT ASSETS</u>		
Cash on Hand	150	150
Cheque a/c	38,910	47,506
Breath 4CF Cheque A/c	7,569	-
Grant Receivable from Share in Life Foundation	-	20,000
Term Deposits (note 8)	103,247	125,599
Accounts Receivable & Accruals	28,963	3,482
Stock on Hand - Vouchers	7,552	10,618
Goods & Services Tax Holding Account	2,266	2,741
	<u>188,657</u>	<u>210,096</u>
<u>INVESTMENTS</u>		
Long Term Investments (note 9)	75,600	75,600
Breath 4CF Portfolio	172,295	-
Chris Howlett Endowment Fund		
Assets- note 10 & 13	536,874	691,272
Branch Assets (note 7)	724,587	697,446
	<u>1,509,356</u>	<u>1,464,318</u>
<u>PROPERTY PLANT AND EQUIPMENT</u> As per Schedule	10,441	10,904
<u>TOTAL ASSETS</u>	<u>1,708,454</u>	<u>1,685,318</u>
<u>CURRENT LIABILITIES</u>		
Accounts Payable & Accruals	31,399	29,268
Staff Entitlements	13,472	13,472
Tertiary Assistance Liability	21,452	11,149
Unexpended Grants	21,774	46,174
	<u>88,097</u>	<u>100,063</u>
<u>TOTAL LIABILITIES</u>	<u>88,097</u>	<u>100,063</u>
<u>NET ASSETS</u>	<u>1,620,357</u>	<u>1,585,255</u>



30/8/2013

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 2013

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 2013 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.

2. Capital Commitments

There were no capital commitments at 30.6.2013 2012 (Nil)

3. Contingent Liabilities and Commitments

There were no contingent liabilities or commitments as at 30.6.2013 2012 (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	Sept 2015	4,008	5,011
- Vehicle 2 Lease	Feb 2014	5,974	0
- Premises rental Ricc	Nov 2013	9,637	0
- Premises rental Auckland	June 2014	4,790	0
		-----	-----
TOTAL		24,409	5,011

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 2013

	<u>2013</u>	<u>2012</u>
7 Branch operating results		
Surplus/ (Deficit) after contributions to National Association		
Northland	-11,203	-16,441
Auckland	8,723	-12,354
Bay of Plenty	1,254	6,593
Waikato	1,099	-6,160
Hawkes Bay	935	-6,513
Taranaki	4,440	6,033
Central Districts	312	-516
Wellington	11,681	-472
Nelson	2,891	-1,290
Canterbury	-7,472	14,060
Otago	5,579	26,692
Southland	8,902	-3,286
Total Branch Surplus/(Deficit)	27,141	6,346
Branch Assets		
Northland	21,642	32,845
Auckland	170,450	161,727
Bay of Plenty	12,812	11,557
Waikato	14,346	13,247
Hawkes Bay	158,407	157,472
Taranaki	30,019	25,579
Central Districts	17,008	16,696
Wellington	43,981	32,300
Nelson	4,279	1,388
Canterbury	169,662	177,134
Otago	51,675	46,096
Southland	30,307	21,404
Total Branch Assets	724,588	697,445
8 Short Term Investments		
ANZ	52,174	50,016
Rabobank	51,073	47,506
Other	0	28,077
Total	103,247	125,599
9 Long Term Investments		
Comprises: 10,000 Ordinary A Rangatira Ltd Shares and 30,000 Ordinary B Rangatira Ltd Shares. (market value 30/6/2013 \$300,000 - 2012 \$240,000)	75,600	75,600

CYSTIC FIBROSIS ASSN OF N.Z. (INC)

Financial Statements

For the year ended 30 June 2013

	<u>2013</u>	<u>2012</u>
10 Chris Howlett Endowment Fund		
Opening Balance	489,658	483,831
Plus net income earned	31,796	30,209
Less administration costs	-1,682	-1,000
Endowment Grants paid	-3,400	-25,500
Plus unrealised revaluation gain	20,502	2,118
Closing Balance	<u>536,874</u>	<u>489,658</u>
11 Donations, Sponsorships and Grants		
Pub Charity Grant	0	30,000
NZ Lottery Grants Board	0	23,130
N Z Community Trust	0	5,000
Other	46,165	3,488
ASB Community Trust	0	25,000
Bendigo Valley Trust - Grant for electricity	0	2,500
CF Australia	4,970	0
Four Winds Foundation	4,500	3,000
Canterbury Community Trust	15,038	5,000
Cure Kids	0	3,000
Mainland Foundation	5,000	4,361
Perpetual Trust - 2013 F Thompson	2,000	2,000
Westpac	0	10,000
BP Petrol Vouchers	0	200
Share in Life Foundation	56,666	35,600
Guardian Trust - 2013 Ted and Molly Carr	20,000	5,000
UPS Foundation	21,955	0
First Sovereign	0	5,000
Trusts Community Foundation	0	5,000
Less Unexpended Grants	-21,775	-46,174
Sponsorship - Boehringer Ingelheim	5,652	0
	<u>160,171</u>	<u>121,105</u>
Plus non cash sponsorships		
Goods in kind for events such as: CF News, Charity Cricket CFANZ Awareness Week and National Raffle:		
Major Sponsors:		
Radioworks		
Roche Products		
Adshel		
Mainland Press		
The Christchurch Casino		
More FM		
The Christchurch Press		
Boehringer Ingelheim		
TOTAL	383,104	45,437

12 National Fundraising

Comprising the following which are net of expenses incurred:

National Raffle	16,011	18,919
Charity Cricket Gala Day	11,364	13,648
Breath 4 CF	0	92,201
Riccarton Race Day	1,718	800
Reuters Golf	33,174	33,663
Other: Ballet	5,467	30,178
Other	44,028	34,909
	<u>111,761</u>	<u>224,318</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	201,616	175,822
Plus net Income	52,374	99,708
less payments for equipment	-65,269	-70,032
less transfer to CFANZ retained earnings -admin current year	-6,128	-9,216
Plus unrealised revaluation (loss)/gain	-2,498	5,334
Closing Balance	<u>180,095</u>	<u>201,616</u>

INDEPENDENT AUDITOR'S REPORT

To the members of The Cystic Fibrosis Association of New Zealand Incorporated

We have audited the financial statements of The Cystic Fibrosis Association of New Zealand Incorporated as attached which comprise the balance sheet as at June 30 2013, the income statement and the statement of changes in equity for the year then ended and a summary of significant accounting policies and other explanatory information.

Board of Management's Responsibility for the Financial Statements

The Board of Management is responsible for the preparation and fair presentation of these financial statements in accordance with generally accepted accounting practice in New Zealand and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on conducting the audit in accordance with International Standards on Auditing (New Zealand). Those standards require that we comply with ethical requirements and plan and perform the audit to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgement, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments; the auditor considers internal control relevant to the entity's preparation and fair presentation of the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of accounting estimates, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our qualified audit opinion.

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

Basis for Qualified Opinion

In common with other organisations of similar nature, control over some income items, prior to entry in the books of account is limited, and there are no practical audit procedures to determine the effect of this limited control.

We have also relied on the financial statements forwarded from branches of the Association only some of which have been audited and have been unable to complete any detailed work on those results.

Qualified Opinion

In our opinion, except for the possible effects of the matters described in The Basis for Qualified Opinion paragraph, the financial statements as attached:

- Comply with generally accepted accounting practice in New Zealand;
- Give a true and fair view of the financial position of Cystic Fibrosis Association of New Zealand Incorporated as at June 30, 2013 and of its financial performance for the year then ended.

Our audit report was completed on 30 August 2013 and our qualified opinion is expressed at that date.

Peter Davidson & Associates

CHARTERED ACCOUNTANTS





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