

2014 Annual Report

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Our People

National Board

Jane Drumm – Chairperson John Parsons John Elliott Margaret Nicholls Robyn Somerville



Staff

Belinda Burnett Chief Executive

Julie ClemettAdministration ManagerSusan LovelockSouthern Region Field WorkerMelinda CoombesNorthern Region Field WorkerVicky TylerNational Information Coordinator

Clinical Advisory Panel

Dr Richard Laing – Chairman
Dr Cass Byrnes
Chest Specialist, Christchurch Hospital
Paediatrician, Starship Children's Hospital
Paediatrician, Christchurch Hospital
Dr Mark O'Carroll
Chest Specialist, Auckland Hospital

Dr Peter McIlroy Paediatrician, Nelson Hospital

Rebecca Scoones Physiotherapist, Starship Children's Hospital Vivienne Isles Children's Outreach Nurse, Christchurch Hospital

Victoria Crowder Dietician, Christchurch Hospital

Robyn Beach CF Nurse Specialist, Christchurch Hospital

Investment Committee

John Parsons – Chairperson Steve Drumm James Lee Jane Drumm Belinda Burnett

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

Chairperson's Report CFNZ 2014



Cystic fibrosis has an immense impact over an extended period of time on the people in our community. Whether you are a person with Cystic Fibrosis, a parent, a partner of a PWCF, a

grandparent, extend family or friends, CF has a dramatic, often terrible impact on all our lives. CF does however give us some opportunities; something to fight for, fight against, something that is significant and momentous. CF makes grownups out of little kids, as it is such a complicated and multi-faceted condition and sadly many of our children are wise beyond their years.

As the Chair of the CF Association of New Zealand, I strongly believe in fighting for life-changing improvements for people with Cystic Fibrosis. Your Association exists to be a strong conduit from which these life-changing improvements for PWCF are achieved. The Board firmly believe in our mission "that CFNZ will optimise quality of life for our people with cystic fibrosis and their families; striving for normal life expectancy and a cure."

One of the ways we effect change to optimise quality of life is through the staff we employ. In August 2013 our long-term Chief Executive Kate Russell celebrated ten excellent years with CFNZ at the Australasian Conference — which was held in New Zealand for the first time ever. However, in early 2014 Kate accepted a new and exciting post with the Canterbury Medical Research Foundation and said goodbye to CFNZ in April this year.

A significant challenge for the Board has been to recruit an experienced, skilled and innovative chief executive who would work with us to move our organisation through 2014 and beyond. Belinda Burnett, formally CE at Haemophilia NZ, started with CFNZ in May this year and is taking a considered and highly-professional approach to evaluating CFNZ and establishing, with the Board, what the organisation should look like going forward. This is particularly important as 2014 is the

year when the Board will revisit our strategic direction.

The planning process for our three-year strategic plan has been delayed slightly to allow our new CE an opportunity to become familiar with our organisation and be in the position to fully input into the process. It is with great anticipation that I look to November this year when the Board, along with the CE, will begin to develop our strategic plan in consultation with our branch members. Another major development in 2014 has been the fieldworker staff reducing from three parttime staff to two full-time staff, one North Island and one South Island and both working 40 hours per week. It is the belief of both the Board and the CE that this distribution of staff will have very positive outcomes for our community where optimised support and services will lead to improved quality of life. At our National conference in May we bid farewell to our wonderful fieldworker Sally Carron who had decided that the time was right for retirement. Sally had worked for the Association for 15 years and this was celebrated at the conference dinner with an Association Service Award. Sally will be much missed by PWCF, families, medical teams and colleagues, and by her fellow CFNZ staff members. I am sure Sally's excellent work in helping develop our first professional fieldworker position and all the associated innovations will long be remembered.

Other news for CFNZ is that we have secured our own office space in Grafton Road, which we share with the Auckland branch. The Board and CE see this as a hub for all things CFNZ in the North Island and already this has started to occur. On behalf of the Board, I would like to thank and acknowledge the Auckland Branch Committee who has worked tirelessly to pack up our old office, help staff maintain an office remotely and then move everything into the new premises. Having a presence in the heart of Auckland City right across the road from the Starship and Auckland Hospitals presents great possibilities for the development of the Association, which we believe will ultimately

be of great benefit to PWCF and CF families, as we move into the future.

The Board continues to govern the Association by way of our Board meetings, the annual Chairpersons' Conference and the monthly Chairpersons' "phone in" meetings for branch chairs — an opportunity to network and regularly catch up. This year we will be sorry to see John Elliot retiring from the Board after six years. On behalf of the Board I thank John for his support and dedication.

On behalf of the Board, I also thank all the staff for their hard work over this last year. There have been many changes and that is not always easy but the team has performed very well. To all Board members, Branch Committees and to volunteers who help in the work of the CF Association – I thank you. To those who are thinking of joining a branch committee or volunteering in some way, please do. I encourage you to join us as we fight for lifechanging improvements for PWCF throughout

Jane Drumm, CFNZ Board Chairperson

NZ and work on making a positive difference.

Chief Executive's Report



Firstly, I would like to report what a privilege it is for me to be appointed to the role of Chief Executive for Cystic Fibrosis New Zealand — an organisation that is clearly dedicated to improving the lives of people with cystic

fibrosis.

As I have only been in the role of CEO for the last two months of the financial year, I will have to be brief.

In the short time I have been with CFNZ I have met with many of you. To say I am impressed by your enthusiasm, knowledge and passion is an understatement. I look forward to my time with CFNZ with great eagerness, hoping to make an impact on your community in a positive way. Whether this means helping to gain more access to medicines, greater delivery of services in regions where they are currently limited or providing you with comprehensive assistance from the National Office, I am eager to make your lives that little bit better.

My aim is to have joint activities with the Branches and the National Office, to truly be a national service. We are a small community and I look forward to helping us become a

united force that stands together and helps each other make a difference to the lives of PWCF.

The National staff, Board and members of your community have made me feel welcome and I will take this opportunity to thank you all for such a positive introduction to your community.

It has been heartening to see how much support the organisation has in the wider community in New Zealand. It is a charity that does attract an impressive level of assistance with fundraising activities. It's encouraging to see athletes and sports teams choose CFANZ as their chosen charity. Bubbles Week is gaining more awareness; there have been some great ideas and wonderful events. I'm looking forward to seeing it go from strength to strength in the coming years.

I would also like to extend a big thank you to staff for their focus over this period of change. It hasn't been easy, change never is, but I've been impressed with their commitment and hard work they've put in. It's good to know that we all share the same goal of helping PWCF to stay happy, healthy and to extend their life expectancy.

Belinda Burnett, CFNZ Chief Executive

Farewells

Michelle Ashby Dunedin

Charlotte Hayes (20) Christchurch

Caroline Ford (29) Lower Hutt

Doyle Haydon-Gliddon (25) Ashburton

Ryan Smith (28) Ashburton

Tegan Wilson (23) Paraparaumu

Andrew Walklin (39) Wellington

Andrew McCleary (Possom) (41) Hastings

"When you are sorrowful look again in your heart, and you shall see that in truth you are weeping for that which has been your delight."

- Kahlil Gibran

Mark Ashford Scholarship



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 was launched by 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 2014 – Alex McKay

It was fourth time lucky for Alex who applied for this scholarship four times before winning the award. He says perseverance has paid off after studying hard for his BCom/LLB. He plans to use the \$3000 scholarship towards a short OE at the end of this year once he graduates. The Auckland student is fortunate to already have a job lined up as graduate tax consultant at Price Waterhouse Coopers in February – a job he was signed up for last year. Alex likes to perform his morning and evening routines for managing his condition on auto pilot, and says getting written notes from his classes if he has to miss a lecture has been key to his success.

CF Achievers' Awards





Achievement in Education
Rachel Payne
Bay of Plenty

Rachel has not let the significant challenges she's had managing CF stop her achieving top marks in high school. Described as a talented and intelligent woman by her doctor, Rachel is planning to enrol in Waikato University next year to study Biochemistry, after completing Year 13. Along with working hard at her studies, Rachel has also focused on overcoming the emotional challenges of her condition — and her parents could not be more proud.

Achievement in Education
Ashlee Butler
Palmerston North

Ashlee is celebrating her Achiever's Award after managing to complete her first year of Uni while not missing any treatments and gaining a healthy weight. She's thrilled she did not need to be hospitalised at all during the year and is happy to have maintained a B average across all her papers. Her other interests include horse eventing and journalism — writing articles for UICEF and the 3News Youth Page.





Achievement in Education
Natalie Wineti
Rotorua

Another person with CF who has managed to balance her studies, the management of CF, and a family, is Natalie. She gained superb results in her social work course, with an A average. Described as conscientious, intelligent and thoughtful, Natalie is another PCWF who is an inspiration to others.



Achievement in the Arts
Kelly Oliver
Hamilton

From being an amateur photographer last year to owning her own photography business today, Kelly, who has a husband and daughter Zoe (2), has shown determination to achieve her dreams. Kelly will be using her Award to buy a better camera so she can expand her business and take even better photographs and undertake more complex projects.

Achievement in Education

Esme Dennis

Auckland

Going to school straight from Starship Hospital and back again is hardly conducive to getting good grades — but that's what Esme has managed to achieve in a tough year managing CF. Her numerous hospitalisations meant she had to complete her assignments during treatment. Incredibly, Esme was able to maintain her good grade point average in year one of NCEA — impressing her teacher who says that Esme shows initiative in all that she does.





Achievement in Education
Briar Lomas
Wellsford

Briar is a young person who has been able to achieve success in many arenas. After coming top of her year at Rodney College and gaining NCEA level 1 with an excellence endorsement in 2013, Briar has also managed to fit in Duke of Edinburgh, drama, netball and six months volunteer work at a local rest home – all while managing her own condition. She puts her success down the support of her teachers and classmates who help her when she's unwell.

Well done to all these inspirational young people whose strength and determination is typical of so many PWCF.

Branch Reports

NORTHLAND

The last 12 months have been relatively stable for our Branch. We have had no new additions to Northland (which is great) and the



Millwaters' have moved to Wanaka. We now have five children and two adults. With Sarah Millwater's departure we have had to replace our Secretary. This role has been taken up by Donelle Mason.

Like the last few years, our main focus has been our charity golf tournament and due to our lack of numbers this has pretty much become our Awareness Week as well. This year's was our most successful one to date and we had to cap the entries at 23 teams. We were again well supported by LJ Hooker's Whangarei and many other businesses – OfficeMax and Balance to name a few. This year we netted \$14,000 which was a great result. And the demand for next year's tournament is out there already. We are looking to make a few changes/improvements in 2015 with a few added extras such as a band playing on the course.

We were also successful in getting funding for all members who wanted to attend the Australasian conference in 2013.

Most recently we were chosen to be the charity at Mitre 10 Mega's Ladies Night. There were over 450 ladies there which gave us great exposure. We will receive approximately \$3,500 from this night.

We have not yet organised our yearly contribution to CF Head Office but this should be done by the Chairpersons' Conference.

To summarise it has been a good year for CF Northland – hopefully 2015 will be the same.

Mike, Northland Chairperson

AUCKLAND

Cystic Fibrosis Auckland has had another busy, if not frustrating year, with many changes in our Auckland Branch. We have moved offices, and after a long search we have found a great central location handy to the hospitals and with more space.

Our funds raised this year came from Awareness Week where our community got behind it and held different events. We were fortunate to be accepted once again to be a chosen charity for Ports of Auckland Round the Bays where we received \$15,000 for exercise equipment and donations raised by our CF families totalled \$13,652.

Our grants' officers have worked tirelessly searching for grant avenues and due to their superb writing skills they have had a terrific success rate, we are very appreciative for their efforts. Once again we could not have sustained the services and support we provide to our community if it wasn't for our small hardworking committee – they make all the difference.

Jill Thoratt, Auckland Co-Chair

WAIKATO

2014 has been another challenging year for CF Waikato, with a constant focus on ways to fund the branch and keep it running.

Awareness Week saw several schools supporting us and the wonderful people at LJ Hooker Matamata once again supported us over Awareness Week. Chocolate fish sales were about the same as last year, with our contact at Ruakura AgResearch selling right through the year. One of our parents held a garage sale.

Once again we had several farmers in the Piako district donate generously through a service Mike, Briar and I provided which assists with livestock breeding.

Morrinsville Pakeke Lions made a generous donation towards nebulisers, and Debbie is speaking at Altrusa Morrinsville in August to hopefully secure a donation from that organisation. This is an initiative of approaching service groups to help fund nebulisers and hospital packs.

We did the Entertainment Book fundraiser again this year, and it does get easier every year, sales are up from last year. Thanks to Auckland not doing them, we managed to get a spin-off and sold a few in Auckland.

Thanks also go to Auckland Branch for helping us get to conference through a grant they received.

We received a grant of \$7,008 for nebulisers from WEL Energy Trust – an awesome help.

During the year we did a phone survey of our members to assess the services we provide. We found everyone very helpful but a huge range of opinions where services etc. come from. From this we sent out an excellent services summary provided by our North Island Social Worker – Melinda Coombes.

CF Waikato has once again helped with welfare issues this year, which is a goal we all have and hope to still achieve in the next year.

Mike and I wish to give a huge THANK YOU to Janelle and Jenna, who consistently issue newsletters, financial statements, offer help, and always answer our emails with compassion, wisdom and honesty. Also thank you to the amazing Adult and Paediatric nurses who do an incredible job for our CF families.

Mike and Debbie Wood, Co-Chair's, Waikato

BAY OF PLENTY

The 2013/14 Year has ticked along quite nicely for our branch. No big events but a number of very generous donations have seen us manage financially.

Our only fundraising event was the annual Christmas wrapping at our local shopping city which we all enjoy and is an opportunity to create awareness for CF. Thanks to the generosity of a local kitchen manufacturer we were able to put two new cabinets – with TV and fridge – on the children's ward at Tauranga Hospital to replace the old one (which was at least 12 years old). Another one is on order for Rotorua hospital.

While no one was able to attend the Australasian conference last year due to declined grant applications we did have two attendees in Christchurch this year (thanks to Pub Charity) to what

turned out to be a very worthwhile weekend. And also thanks to the Lion Foundation we have been able to supply lots of nebulisers this year to families needing them. On the recommendation of Starship, those who wanted sterilising units have also been given them.

Our bank account looks reasonably healthy with a grant and proceeds from last year's charity dinner which has all been earmarked for community physiotherapy services. With a big fundraising event on the horizon this year and the beginnings of a trial taking shape, we are looking forward to what might happen in 2014/5.

Nicola Wakerley, Bay of Plenty Chairperson

TARANAKI

It has been another quiet year without much activity. We lost a couple of families to other districts. We had a new baby born in May and our two lung transplant recipients are doing well.

In August last year, I attended the 10th Australasian Conference in Auckland which replaced the New Zealand National Conference in May. The following month I again represented the Branch at the Chairpersons' Conference and National AGM in Wellington and learnt more about the new partnership between Choice Hotels and CFANZ. We discussed workshops on fundraising and looked at the national branding and the role of the CF National Branch and its relationship with the branches. It was at this meeting it was decided to return our National conference to a May schedule with a smaller conference in 2014. The branch covered the cost of this conference held in Christchurch for Wendy Butler and Penny Holdcroft.

Awareness Week was shifted from August to October this last year. We held our usual street appeal. It was harder for me to coordinate this this year due to not being able to take my usual week off work prior. However, Joan and I managed to pull it off with everyone's help and although we were about \$1,000 down on previous year's results we were still able to make a substantial and worthwhile contribution to our coffers.

This year we were invited by the Farmers Market to launch Bubbles Week with a free stall at the Sunday market. It was a last minute event so we gathered what little merchandise we had, blew bubbles and interacted with a small crowd of other stall owners and members of the public who passed through. As well as selling a couple of hundred dollars of merchandise we also recruited a couple of volunteers for our collection week.

Some of our people participated in the Round the Mountain Relay team organised by Julie Fowler in November 2013. The CF/Beaters and Breathers team lost its privilege of the early start this year but we still managed to finish within time.

We continue to support our members for welfare and other needs.

The annual supermarket vouchers we send out at Christmas are always well received, and we acknowledge all our people with CF with a cheque on their birthdays.

We try to support families as best we can during hospital admissions as we know the cost of time and travel to and from the hospital can be stressful on top of the stress of dealing with the illness itself. Unfortunately, due to the Privacy Act, the hospital does not inform us when people are admitted. Some of you are very good at telling us, usually by a simple text. For everyone else, please don't be backward in coming forward. We can't support you unless you let us know what is happening.

Other ways we can and have helped is with additional costs around the home associated with CF. Assistance with heating costs, sport equipment not covered by the Breath 4CF grant, and travel costs are examples of things you can apply to the committee for.

With a full-time job that does not allow access to emails and no time for calls during work hours, it is challenging for me to respond personally to requests. I would therefore like to give thanks to the outgoing committee for all the work and support they have provided during the past two years. In particular, thank you to Joan Tuffery who does so much more than her Treasury role suggests. The work she does behind the scenes is huge. The Tufferys' started the branch way before we formed a committee in 1990 and they have been involved year in year out ever since.

The three responses from the survey I sent out in June and recent conversations with members indicates that the clinical team at Base Hospital and the visiting Starship team as well as the CF Taranaki branch and North Island Field Officer are meeting the needs of our CF families in Taranaki. It has highlighted the need for better communication and understanding between all the groups. This could be a goal for the new committee.

We finally resolved the problem of having no one directly involved in paediatrics on the committee. I am pleased to say that Nicola McCarthy came to our last meeting and has expressed her intention to come on the committee today. And I think this is a very positive note to end this report on.

Shelley Gruchy, Taranaki Chairperson

HAWKES BAY

It has been tricky arranging meetings to accommodate the two nurses on our committee who have shift work and study commitments. However, we were well represented at the Australasian Conference held in Auckland late last year with eight of our branch members attending.

The New Zealand conference was held in May in Christchurch and Claire and Glenda attended.

Last year Claire also joined me at the Chairpersons' Conference held in Wellington and once again it was very good to get together with the other chairpersons and share ideas etc.

Our "physiotherapy in homes" is going well and this is of great benefit to those families and their children. We have three children who receive physiotherapy in their homes from "laypeople" who have been trained in the necessary technique. Joe Eames has played a major part in the setting up and ongoing operation of the scheme.

On a sad note Andrew McCleary (Possom) passed away in 2013.

We are lucky that we have been able to help a couple of families with firewood over the winter, pay for a disabled car park for an Adult with CF, provide fuel vouchers during hospital stays, and top ups for Breath4CF.

The branch is still in a strong financial position and we have donated \$20,000 to National branch in recognition of their activities that directly benefit PWCF in Hawkes Bay. A friend of Sarah's entered the Mitre 10 sponsored walk and raised an impressive \$2,050.

Glenda Sinden, Hawkes Bay Chairperson

CENTRAL DISTRICTS

Central Districts Branch has had a steady year. Our committee is sitting tight at four members, who all reside in different towns across our region. We try to attend a committee meeting every month, usually in Palmerston North.

We were thrilled to be successful with a grant to purchase nebulisers, and also a grant to enable three branch members to go to National Conference in Christchurch. It was a bit disappointing that so few were interested in attending but we will encourage a higher attendance next time.

In CF Awareness Week last year we held a Ballentynes Summer Fashion Show fundraiser event in Wanganui and then another one at the Ballentynes store in Palmerston North in April this year. We intend to continue to do two per year in the different towns. They are a really fun event for women and we benefit from the ticket price, plus the raffle that we run. They are great for awareness too. Our upcoming fashion show event this October will see the Mayor of Wanganui modelling the fashions, and we will encourage the local press to attend!

We believe that street appeals are losing their value and have not been worth the effort in past years, but we do sell chocolate fish year round in a couple of local Wanganui businesses so the continual sales are useful. Donation boxes in Wanganui businesses trickle in funds year round also.

We sent out letters to schools at the beginning of the year and have had a couple of schools run fundraising events for us. Not hugely successful but the school year is not over yet! Every dollar is appreciated of course.

Late last year we initiated the '\$65 for 65 Roses' fundraiser, with the kind help of Anthea from Auckland branch. We raised several hundred dollars, and may repeat it in a couple of years.

Another fundraiser held in Wanganui earlier this year was the Mr Whanganui Charity Fundraiser which saw around 30 men in shop windows down the main shopping street collecting votes from passersby. Our candidate was keen to please but it wasn't a great money spinner for us - we may participate next year but will have to come up with more canny plans to entice in the votes. It was a really fun night for Anna anyway!

Anna Scoullar-Jones, Central Districts Chairperson

WELLINGTON

Wellington Branch has enjoyed a busy and successful year supporting its members and raising awareness of CF. We have a small and dedicated committee that all work incredibly hard despite their many other commitments.

We have been successful in securing funds through grants for equipment and conference, and have provided PWCF in Wellington with Breath4CF top ups, hospital voucher packs, half-price hospital parking, assistance with winter power bills, babysitting costs to attend events, welfare payments and more.

Diane Murray stood down as Chairperson in April to move overseas with her family. Diane did an amazing job as Chairperson and will be very much missed. Kim McGuinness and Nicole Doriguzzi have taken the role of Co-Chairpersons. Kim will focus on paediatrics and Nicole will focus on adults.

A regular newsletter and email updates are sent to the branch to keep everyone in the loop about what is happening with CF Wellington.

The Appeal Week of 2013 was successful at raising awareness and funds, despite a smaller amount being raised. The Appeal Week this October will have five collection points at lucrative spots. Fundraising BBQs will also take place and the branch has been encouraged to raise awareness and funds through activities such as raffles, movie nights, workplace bake sales, mufti days etc.

A small number of successful networking events ran through the year for families, including parent mornings, drinks evenings to coincide with fieldworker visits, XTF gala opening, and our end of year social.

Kim McGuinness is managing the Christmas Tree Festival this year and she (and the committee) have put a lot of hard work into ensuring it is the most successful festival yet. Moxie Communications are again kindly assisting with the communications aspect of the Christmas Tree Festival.

We hope that over the next year we are able to work closely with Wellington Hospital to improve relationships, and continuity and quality of services provided. It is also hoped that a grant can be sought for all predicted equipment needed in 2015.

The branch is very sad to lose Andrew, Doug, Tegan, Caroline, Win and Mr Logan.

Kim McGuinness & Nicole Doriguzzi

NELSON

I would like to extend a very special thanks to fellow branches Christchurch and Waikato for their generosity in what has not been an easy year for the Nelson Branch.

There has been a lack of uptake for meetings (committee and social) which has resulted in no scheduled meetings in 2014. On a positive note however, we have managed to maintain a healthy balance in our bank accounts. This may be in part due to having agreed to lower the petrol voucher scheme and only making part-payments for welfare requests.

There has been an increase in communications between branch and health professionals with discussions with a newly appointed clinical psychologist working with children and families with a wide range of medical conditions to get a good understanding of CF and family needs. A new role is also being developed in paediatric care with a style of specialist nursing care to smooth the way between



inpatient and outpatient care, as well as a youth transition clinical nurse specialist. This still needs lots more work but it does feel that our voice can be heard.

Overall this year has highlighted for me the need to again re-assess the goals of the branch and determine the future in this region.

Rebecca Colley, Nelson Chairperson

CANTERBURY

The Canterbury branch is going about its business with few changes.

Although we have struggled this year like other branches with volunteers for fundraising activities, we have managed to gain two new committee members. Being proactive, we have joined Volunteering Canterbury and have placed advertisements for our upcoming stocktake and Appeal Week. We are really hoping we are going to have a good response from this.

Cecileah Inns came on board and took over our Appeal Week activities breathing new life into the Week. We had BBQs at Mitre 10 Mega, a stall at Riccarton Market, school mufti days, chocolate fish sellers and street collectors in set areas. It is a great start and Cecileah organised everything well and we thank her for taking on this task.

Our October Golf Tournament at Templeton Golf Club went very well. We were fortunate to have some input from a golfer who had played in the tournament the year before and he met with us offering suggestions and advice to generate more funds from the day with small changes, one being putting the entry fee up! It worked and we profited approximately \$8,000 – doubling the amount raised the previous year.

The Christchurch Casino Golf Masters Event had its 10th year. It was once again an amazing event and very professionally run. We presented the organisers with two beautiful plaques for their 10 years of passion and commitment to CF Canterbury. We have been very fortunate to have been involved with this event from the beginning and these funds over the years have been a crucial part of the employment of our community physiotherapist. This event is now changing hands and is to be run by the Canterbury Golf Development Trust and fortunately we are still the charity to be attached to the event but in a smaller capacity.

Canterbury Quilters Society once again asked us along to one of their meetings and presented us with 25 beautiful quilts of all sizes and colours to distribute to our families. Their generosity is greatly received.

We are still able to offer our CF families accommodation at \$25 per night in our Hanmer Holiday Home. This is well utilised, and most weekends and school holidays are booked with CF families.

Other activities this year have been Bunnings Warehouse stocktakes, sausage sizzles, the selling of the popular Entertainment Book, grant applications and other one-off projects.

Melissa Skene, Canterbury Chairperson

OTAGO

It has been a busy year for the committee with significant income raised and money spent in support of members. We're grateful to field worker, Sue Lovelock for her work in coordinating much of the support.

Overall income of \$32,000 was up on last year but this was due to a large donation of \$10,000 from the Marsh family trust which we are very grateful for. Thanks to this grant we were able to expand the Breath4CF top-up programme.

Street appeal raised \$17,000. This was down on the \$23,000 raised the previous year. We believe the primary reason for this was the moving of the appeal to October which clashes with student exams. Previously students have been responsible for raising a significant proportion of the overall total.

Our bubbles event prior to street appeal was expanded to three sites – the Railway Station, the Octagon and the Museum Reserve. The Railway Station and Octagon both proved to be good sites but the Museum was disappointing. We did get good coverage in the Otago Daily Times which was the main goal.

Possibly the biggest news for our children with CF and their parents was the opening of the new children's ward at Dunedin Hospital. The ward is a vast improvement on the old one with many more pleasant spaces that have modern, cleanable surfaces and proper isolation rooms. Facilities for parents are also much improved.

I was particularly saddened by Richard Sutton's recent passing just a year after his lung transplant. Richard was our oldest member with CF, and is believed to have died just a few weeks before his 50th birthday. Richard appeared in the Otago Daily Times just prior to the street appeal last year in a great photo and interview. Several people I met while collecting specifically mentioned the article about Richard.

We are very grateful to Richard and his parents, Albert and Rosemary, for their contributions over the years. Over \$1,000 was raised for CF Otago at Richard's funeral.

Only one member attended conference this year which was disappointing. I think it was a bit soon for most of last year's attendees of the Australasian conference in Auckland.

Recently we were contacted by Nick Chapman and David Burton, medical students wanting to raise money for CF Otago. As territorials they competed in the Twin Peaks Battle Tab - 27km of steep running in full combat gear. Nick and David raised a total of \$1,215 in completing the event which is a fantastic result. Thank you.

We are also sad to have lost Andrea Neame and Sinead to Auckland. Andrea was a valuable regular on the committee and Sinead's talks to the medical students made a big impact. Nick and David mentioned Sinead specifically as a reason for raising money for CF Otago, and several other medical students have cited Sinead for their particular interest in CF.

We wish Andrea and Sinead all the best and are hope Sinead gets the best care in Auckland – especially Kalydeco.

Julian Cox, Otago Chairperson

SOUTHLAND

Our members seem happy with the way the branch is operating. Lynn continues to keep in contact with everyone via emails or telephone conversations.

It has been an extremely quiet year with no meetings held. Much of the focus has been on distributing the generous donation made by Wanaka triathlete Tony Dodds.

The majority of the \$10,000 funds, donated by Tony after winning the Wanaka triathlon last year, were spent on the Southland CF members as requested by Tony.

Some of this expenditure included:

- Laptop
- IPad
- Bed for person going flatting
- Contribution towards purchasing a vehicle

All recipients were very grateful for this assistance and once again our thanks go to Tony for this generous donation.

Jim Phair, Southland Chairperson



Acknowledgements

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



Major Sponsor - Choice Hotels Australasia

ASB Community Trust Mainland Foundation

BA Lewis - Charitable Trust Mainland Media

BOC Gases Mediaworks

Canterbury Community Trust Ministry of Health

Canterbury District Health Board Nomads Golf Club

C-City Brothers NZ Community Trust

CF Australia NZ Lottery Grants Board

CFANZ Clinical Advisory Panel Oporto

Challenge Wanaka Pelorus Trust

Cleantastic Commercial Cleaning NZ Perpetual Trust - F Thompson

Four Winds Foundation Pink Batts

Guardian Trust - Ted and Molly Carr Pub Charity

Harvey Cameron Rotary Clubs of NZ

Infinity Foundation Shares in Life Foundation

Kiwi Karma Stewart Charitable Trust

La Roche Design Toyota NZ

Lion Foundation Zoom Room IBDG

Lions Clubs of New Zealand

CFANZ Branches Charity Cricket Sponsors

CF Northland Canterbury Crusaders

CF Canterbury ASB Bank (Canterbury)

CF Hawkes Bay Canterbury 92.1MORE FM

CF Central Districts Canterbury Television CTV

CF Taranaki Christchurch Boys High School

CF Otago Christchurch Casino

Christchurch Northwest Kiwanis

Pharmaceutical Companies Coca-Cola

Abbott Pharmaceutical CRT

Boehringer Ingelheim Dilmah NZ

Pharmaco Hellers Ltd

Roche Russell McVeagh

Vertex Tui Beer

Financial Statements for the year ended 20 June 2014



FINANCIAL STATEMENTS FOR THE YEAR ENDED 30TH JUNE 2014

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TRUST DIRECTORY

FOR THE YEAR ENDED 30TH JUNE 2014

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

STATEMENT OF FINANCIAL PERFORMANCE FOR THE YEAR ENDED 30TH JUNE 2014

		2014	2013
INCOME			
Individual Donations & Bequests		54,964	61,670
Sponsorships & Grants (note 11)		224,443	160,171
Grants ex Branches		44,292	7,000
National Fundraising (notes 12)		77,651	111,373
Interest - Chris Howlett Fund		22,948	26,902
Interest - General		4,349	6,127
Dividends - Chris Howlett		8,002	4,894
Dividends - Rangitira		18,400	16,800
MOH Contract Income		75,000	75,000
Breath 4CF Interest Income		7,390	9,634
Breath 4CF Fundraising		60,902	42,740
Australasian Conference Grants		142,590	8 - 0
Other Income		8,449	6,777
		749,380	529,088
OPERATING EXPENSES			
Grants to Branches	_		154
Other Grants	333		1,294
Hospital Allowances & Prescription			
Refunds	14,620		12,360
National Voucher Scheme	7,100		7,880
Funeral Grants	8,000		6,000
Medical Information & Advice	1,130		6,062
Tertiary Education Grants	29,343		20,003
Chris Howlet Fund Endowment	23/313		
	_		3,400
Payments	1,728		1,682
CHEF - Other expenses Transplant Grants incl Vouchers	5,635		9,696
	4,787		-
Achievement Awards	4,707		
Advertising, Promotion, Public	11,324		3,405
Relations & Lobbying Publications - Newsletter	19,890		3,406
	5,262		10,277
Education Programmes	70,941		65,269
Breath4CF Grants	7,331		6,567
Breath 4CF Other Expenses	13,151		2,706
Equipment & Laptops for PWCF			101,810
Field Worker Costs	121,862		10,707
Conference Expenses	22,080		10,707
Australasian Conference Expenses	125,497		
SERVICE PROVISION - ADMINISTRATION	SUPPORT	470,014	272,678
Administration	155,973		119,215
Service Support Direct Costs	608		10,815
		156,581	130,030

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

FOR THE YEAR ENDED 30TH JUNE 2014

	2014	2013
73,467		91,454
2,185		3,648
3,298		3,802
5,846		2,048
12,562		16,571
1,767		2,011
1,884		1,788
3,019		2,959
1,035		S=8
2,650		2,650
2,344		2,755
11,129		4,133
7,674		7,465
		1
	128,860	141,284
		4,175
195		182
	5,564	4,357
	7.61 010	F40 240
	761,019	548,349
	(11,639)	(19,261)
note		
	15,169	27,141
	3,530	7,880
	2,185 3,298 5,846 12,562 1,767 1,884 3,019 1,035 2,650 2,344 11,129 7,674 5,369 195	73,467 2,185 3,298 5,846 12,562 1,767 1,884 3,019 1,035 2,650 2,344 11,129 7,674 128,860 5,369 195 5,564 761,019 (11,639)

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

FOR THE YEAR ENDED 30TH JUNE 2014

STATEMENT OF MOVEMENTS IN EQUITY	2014	2013
STATEMENT OF MOVEMENTS IN EQUILI		
Net (Deficit)/Surplus for Year	3,532	7,880
Trust Equity at 1/7/2013	1,620,357	1,585,255
First NZ Capital Portfolio Valuation Fluctuation - Unrealised	16,778	27,222
	1,640,667	1,620,357
		·
Comprised:		
Accumulated Funds	888,722	903,388
Chris Howlett Endowment Fund (note10)	584,651	536,874
Breath 4 cf Physical Equipment Fund (Note13)	167,294	180,095
Total Equity as at 30/6/2014	1,640,667	1,620,357

STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 30TH JUNE 2014

		2014	2013
TRUST EQUITY		1,640,667	1,620,357
		1,640,667	1,620,357
Represented By:			
CURRENT ASSETS	150		150
Cash on Hand	150		150
Cheque a/c	77,310		38,910
Breath 4CF Cheque A/c	4,928		7,569
Term Deposits (note 8)	40,161		103,247
Scholarship Funds	50,273		20 063
Accounts Receivable & Accruals	13,123		28,963 7,552
Stock on Hand - Vouchers	6,383		7,552
Goods & Services Tax Holding	2 476		2,266
Account	3,476		2,200
		195,804	188,657
TANDOMARNO		193,004	100,007
<u>INVESTMENTS</u> Long Term Investments (note 9)	75,600		75,600
Breath 4CF Portfolio	167,294		172,295
Chris Howlett Endowment Fund	107,234		1121270
Assets- note 10 & 13	584,651		536,874
Branch Assets (note 7)	739,756		724,587
Blatton Assets (note 1)	755,100		
	_	1,567,301	1,509,356
PROPERTY PLANT AND EQUIPMENT As per	Schedule	11,436	10,441
PROFERIT FLANT AND EQUITMENT AS PET	Delicante		
TOTAL ASSETS		1,774,541	1,708,454
CURRENT LIABILITIES			
Accounts Payable & Accruals	48,266		31,399
Staff Entitlements	9,209		13,472
Tertiary Assistance Liability	46,286		21,452
Unexpended Grants	30,113		21,774
		133,874	88,097
TOTAL LIABILITIES		133,874	88,097
NET ASSETS		1,640,667	1,620,357
Juliallament			
V BRUNETT 11/09/:	2014	ā	

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30TH JUNE 2014

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 avaliable differential reporting exemptions allowed under the framework for differential reporting have been adopted.

Depreciation

Depreciation has been charged using D V rates from 16% to 50%. 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. $\ensuremath{\text{\textbf{q}}}$

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.

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<u>Taxation</u>

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 2014 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 Committments

There were no capital committments at 30.6.2014 2013 (Nil)

3. Contingent Liabilities and Commitments

There were no contingent liabilities or committments as at $30.6.2014 \quad 2013 \quad (\text{Nil})$.

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. <u>Lease Committments</u>

As at balance date the Asso as follows:	ociatio expiry date		future operating within 12 months	lease committments greater than 12 months
- Vehicle 1 Lease	-	2015 2016	3,486 22,780	871 32,271
Premises rental RiccPremises rental Auckland		2017	28,160	28,160
TOTAL			54.426	61,302

6. <u>Subsequent Events</u>

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

<u>Financial Statements</u> <u>For the year ended 30 June 2014</u>

7 Branch operating results Surplus/ (Deficit) after contributions to National Association	<u>2014</u>	<u>2013</u>
Northland Auckland Bay of Plenty Waikato Hawkes Bay Taranaki Central Districts Wellington Nelson Canterbury Otago	4,906 9,309 1,921 3,424 -27,915 -812 376 -421 3,737 23,226 7,982	-11,203 8,723 1,254 1,099 935 4,440 312 11,681 2,891 -7,472 5,579
Southland Total Branch Surplus/(Deficit)	-10,564 	8,902 27,141
Branch Assets	10,100	27,131
Northland Auckland Bay of Plenty Waikato Hawkes Bay Taranaki Central Districts Wellington Nelson Canterbury Otago Southland Total Branch Assets	26,548 179,759 14,733 17,770 130,492 29,207 17,384 43,560 8,016 192,888 59,657 19,743	21,642 170,450 12,812 14,346 158,407 30,019 17,008 43,981 4,279 169,662 51,675 30,307
ANZ	40,012	52,174
Rabobank	149	51,073
Total	40,161	103,247
9 Long Term Investments		
Comprises: 10,000 Ordinary A Rangatira Ltd Shares and 30,000 Ordinary B Rangatira Ltd Shares. (market value 30/6/2014 \$340,000 - 2013 \$300,000)	75,600	75,600

<u>Financial Statements</u> <u>For the year ended 30 June 2014</u>

10 Chris Howlett Endowment Fund	<u>2014</u>	<u>2013</u>
Opening Balance	536,874	489,658
Plus net income earned	30,950	31,796
Less administation costs	-1,728	-1,682
Endowment Grants paid	0	-3,400
Plus unrealised revaluation gain	18,555	20,502
Closing Balance	584,651	536,874
11 Donations, Sponsorships and Grants		
Pub Charity Grant	10,000	0
NZ Lottery Grants Board	39,433	0
N Z Community Trust	10,000	0
Other	6,774	46,165
ASB Community Trust	25,000	0
CF Australia	0	4,970
Four Winds Foundation	0	4,500
Canterbury Community Trust	0	15,038
Mainland Foundation	4,754	5,000
Perpetual Trust - 2013 F Thompson	2,000	2,000
Share in Life Foundation	20,000	56,666
Guardian Trust - 2013 Ted and Molly Carr	30,000	20,000
UPS Foundation	0	21,955
Less Unexpended Grants	-28,600	-21,775
Sponsorship - Boehringer Ingelheim	40,262	5,652
Roche	5,000	0
Nomads Golf Club	10,870	0
Infinity	12,500	0
Lion Foundation	2,400	0
Stewart Trust	2,000	0
BA Lewis Charitable Trust	5,000	0
Pelorus Trust	2,000	0
Abbott	25,050	
	224,443	160,171

Plus non cash sponsorships

Goods in kind for events such as: Charity Cricket CFANZ Awareness Week and National Raffle: Major Sponsors: Radioworks Network Choice Hotels Australisia

TOTAL 264,939 383,104

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12 National Fundraising

Ivationa	i Fullulaisilig		
Compris	ing the following which are net of expenses incurred:		
National	Raffle	18,830	16,011
Charity (Cricket Gala Day	15,428	11,364
70	n Race Day	0	1,718
Reuters	T.	0	33,174
Other:	Ballet	0	5,467
Other		43,394	44,028
		77,652	111,762

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	180,095	201,616
Plus net Income	66,866	52,374
less payments for equipment	-70,941	-65,269
less transfer to CFANZ retained earnings -admin current year	-6,949	-6,128
Plus unrealised revaluation (loss)/gain	-1,777	-2,498
Closing Balance	167,294	180,095

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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 2014, 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, 2014 and of its financial performance for the year then ended.

Our audit report was completed on 12 September 2014 and our qualified opinion is expressed at that date.

Peter Davidson & Associates

CHARTERED ACCOUNTANTS



www.cfnz.org.nz

The Cystic Fibrosis Association of New Zealand

PO Box 8241, Riccarton, Christchurch 8440