

Cystic Fibrosis Association of NZ



PICTURED ON COVER: Grace Paterson, Kaimata, Expert Bubble Blower and PWCF

Our People

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John Parsons

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Andrea Miller

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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

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Kate Russell

Chairpersons' Report

It has not been an easy year for the Cystic Fibrosis Association of NZ. Along with the country we are still going through tough financial times and couple this with the devastation of Christchurch by way of multiple earthquakes and the shrinking charity dollar things do indeed look bleak.

However every cloud can have a silver lining and it is the job of your board and management team to be vigorously pursuing that silver lining and seeking every opportunity to seek opportunities that will turn those lemons into lemonade.

I believe that CFANZ are on track to make some jolly good lemonade by:

- Maximising our impact by way of our new modern and trendy brand and the Bubble
 Week theme
- Developing our three year strategic plan to identify areas of growth, invigoration and future-proofing.
- Revitalising of the well-established Share in Life Trust (now the Share in Life
 Foundation) including working with medical and clinical professionals to fund
 projects that will focus on quality improvement throughout NZ, resulting in improved care for people with CF
 (pwcf).
- Gaining traction in the area of lobbying particularly with PHARMAC where there has been success with access to several important treatments and antibiotics over the last few years and where the battle continues in particular for access to Pulmozyme and Special Foods.
- The absolute mobilisation of our CF community via our various Facebook forums. At last our people with CF and our families can get to know each other, share stories, ask advice and swap tips in a no risk of cross infection,



virtual way. I am convinced that this connectivity is strengthening the Association as, for the first time since the introduction of cross infection protocols, we have an easy to engage community. I take this opportunity to thank our adult representative on the board Lisa Borkus who has been a very proactive, positive and enthusiastic

influence on the adult with CF population

- Having experienced and dedicated Board members who have worked very hard, particularly over the last year to re work our Associations Strategic Plan, and who look to ways that we can keep our organisation moving forward in these increasingly difficult times. I thank all board members for the time they volunteer and for the belief they have in our cause. I also acknowledge Denis Currie our President, as he remains very in touch with what is happening and provides excellent mentoring to us all.
- Our excellent staff who constantly "go the extra mile" every day in their efforts for CF and our people are
 fundamental in helping us with our brew of amazing lemonade. We have a staff that is rich in experience,
 knowledge and dedication and this sees us in very good stead as we move forward.



This year CFANZ has made a loss and the Board was aware that this would be the case for a number of reasons and that

we would be tapping into our reserves. We have cut budgets and pared operations to the minimum ensuring that we get the most from every dollar. As our strategies for the next three years gain momentum our community should see further invigoration of our local communities and our fundraising and grants programmes, to reduce the risk of having to use our reserves to maintain current operations and levels of service.

On behalf of the Board I thank all our volunteers throughout the country, our CF Clinical Advisory Panel and all the medical and allied health professionals who are doing their best for our pwcf. I thank our sponsors who are truly members of our CF family. I offer a vote of thanks to all our funding providers, whose support we could not do without.



Finally, I would like to take this opportunity to wish all members of our community the very best for the coming year.

Jane Drumm – CFANZ Board Chairperson

Chief Executive's Report

It is my pleasure to present my report for the 2010/2011 year. A year that has seen New Zealand facing more challenges as a nation, than at any time since the great world wars. Just at a time when we looked to be navigating our way through the global economic crisis, we were hit by not two, but three earthquakes, in September, on Boxing Day and on February 22nd and a mining disaster.

These events, have not only shattered lives, a city and the economic recovery of our nation. They have had the unintended consequence of stripping all available philanthropic dollars out of the country at a time when our cause, and others, need it the most. For every person or business that has said YES to us this year, we have had 20 who have said "I've given everything to the quake fund". This has been starkly reflected in our annual accounts which showing us operating at a loss in the past year.

Due to staffing issues, our fundraising slowed almost to a halt in the latter stages of 2010 and it has taken a huge amount of time and effort from staff to get things rolling again. We have been greatly helped in this by the team at Harvey Cameron, who have shown unwavering support for our cause in helping us to develop the Bubbles Brand over the past year to allow for the August 2011 launch.

Awareness Week for 2010 was a quiet affair with income across most branches well down on previous years. However, Auckland Branch excelled in taking in the lion's share of the national total, due to a comprehensive, well-managed strategy of running many smaller events rather than concentrating on a few larger ones.

The launch of our new logo and branding in October 2010 was a highlight of the year and our new livery has been universally praised as fresh and modern – again thanks to Harvey Cameron. Our thanks also to Orly Productions who helped us to make our beautiful new TV commercial featuring the lovely Miss Grace Paterson from Taranaki.

Ironman was a far bigger success in 2011 than the 2010 event, making \$89,000 gross – a lift of almost \$50,000 on the very low year that preceded it. 2011 has been a year of planning a new strategy for Ironman going forward, that provides greater input and involvement of the key elite athletes and hopefully will translate to higher athlete uptake in the 2012 event.

We have had our second highest number of transplants in one year, since 2005, with 4 people getting new lungs. We still have a long way to go in educating the NZ public about the importance of organ donation and this should be a focus for us into the future.

Ongoing issues with access to medications remains a frustration, which is unlikely to ever be fully resolved as we live in a heavily rationed health system. Hypertonic Saline was finally made available in a ready-mixed form during the year and we have continued to lobby for open access to Pulmozyme. We have made progress with this drug but still await Pharmac acting on the recommendations regarding widening of access that were presented to it more than 3 years ago.

Special Foods have been a huge focus for us in the 2011 year, with Pharmac dropping the subsidy on ready-made sip feeds, making the part charge on ready-mades unaffordable for most people. This is a fight we will continue as it is the belief of our many health professionals that this decision will have a

detrimental affect on the health of all PWCF into the future.

We were lucky to have the Ministry of Health agree to roll over our funding for another year, to give us some breathing space in which to negotiate with DHBs for ongoing funding. I am now actively working with the ministry to get to the right people to progress these talks.

Our conference was a huge success with the Hotel Grand Chancellor in Wellington proving to be a popular venue. An excellent 'home grown' conference that attracted 136 participants including a few new faces. Our bid to host the 2013 Australasian Conference was accepted in late 2010 and this will prove an exciting new challenge for the staff and the Association as a whole as this large international conference visits our shores. Our own May conference will be put on hold for 2013 and everyone will be encouraged to attend the August Australasian Conference in Auckland.

Port CF has proved to be very frustrating in 2011 as the earthquakes have slowed progress of rolling out the database nationwide. The CDHB staff are helpful but have been largely occupied in post-quake remedial work and so have had little time to assist us in progressing our goals for Port CF. We remain confident of a complete roll out by year-end and will continue to work toward that goal.

A great deal of work has been done on re-energising the Shares in Life Foundation in the past 12 months and the launch of the 'new look' Foundation was held in August to coincide with the visit of Bob Beall. Bob's visit was inspirational and allowed us a glimpse into the plans and progress for CF medicines research into the future. Our grateful thanks to Bob and his team for taking the trouble to visit us on his way back to the States from Australia.

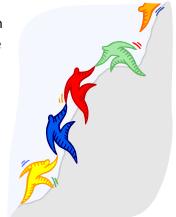
Social networking, Facebook and our website have been big growth areas for us in the past year with Facebook making the most progress as a medium for providing news and views. Our Caregivers, Adults, Teenagers and public fundraising pages are all in constant use.

As always, I wish to thank the Board for a solid years work and in particular, to Jane Drumm for supporting me during what can only be described as a traumatic year, on a number of fronts.

Our staff are an unstintingly loyal and committed group of people. Our office hums with activity and nationally, I know we achieve far more than many other teams with far more people and resources. We truly punch well above our weight. Thank you to you all. To the loyal sponsors and donors who have stuck with us through these tough times; in particular, Boehringer Ingelheim, Roche, ZoomRoom, Reuters and NZFMA, Ironman – thank you.

For the coming year, our motto will be "We will either find a way, or we will make one"

Kate Russell Chief Executive



Goodbyes

In the 2010/2011 year, these brave people came to the end of their journey. Our thoughts and prayers are with their families and friends

Maree Glynan Sam Furlonger

Roger Daube Fletcher Cartlidge

Paul O'Halloran

CF Achievers Awards 2010

Each year, our friends at Boehringer Ingelheim help us to recognise those people within our membership who have achieved great things in their lives, in the areas of: Academia, Leadership, Sports and the Arts.



Oliver Carran - 16 years old - Endeavour in Sport

Oliver has played tennis, touch and soccer at rep level. He now coaches and referees touch and plays cricket in the summer. In 2010 he was awarded the Eastern Southland Cricket Assn. trophy for Most Improved 1st XI Cricketer of the year. Basketball, however, is Oliver's real passion with a long list of achievements in the sport since 2006. Oliver plans to use his award to help fund an Outward Bound course in summer 2011

McMahon Elliott (Mac) - 10 years old - Endeavour in Sport

Mac is a sports enthusiast extraordinaire with a long list of sporting credits to his name. representative rugby, karate, hockey, athletics, Kiaido Ryu, sports fishing are only the tip of the iceberg with this sports whiz! Mac now has his brown belt in Kiaido Ryu which is his real passion. For 2009/10 he was awarded Top Junior Male for his Dojo. Mac also won Top Junior Angler at the Bay of Islands Swordfish Club in 2009/2010. Mac also has Coeliac Disease as well as CF and his parents characterize him as managing these two challenges with maturity beyond his years. Mac was also awarded the Citizenship Award for his school in 2010. He is saving toward a small boat.



Vaughan Somerville - 17 years old - Education



In his last four years at Auckland Grammar, Vaughan was in accelerated streams and passed Cambridge exams with Excellence. He was awarded the Ian MacKinlay Scholarship last year, awarded for personal excellence in every field of endeavour within the school. He also received the top prize for physical education. During his final two years, Vaughan had several hospitalizations and he worked these in-patient stays to coincide with midterm breaks and school holidays to minimize his absence from school. In 2010 Vaughan rallied the other school prefects to sell 10,000 chocolate fish for the CF Awareness Campaign. Vaughan plans to use his grant to support his studies.

Ashley Watson - 17 years old - Endeavour in Sport

Ashley's passion is clay-bird shooting. In 2010 he made the NZ Junior Skeet team and shot for the NZ Skeet Postal Challenge. He won gold in the 2010 NZ Skeet Doubles C Grade and Silver in the NZ Skeet C Grade alongside many other victories in local competition. As he has only been shooting for two years, this is quite an achievement and shows some amazing talent! He works part-time milking cows and all the money he earns goes on ammunition and entry fees. He says the award will help with travel to events and will propel him toward goal to make the 2012 World Championship DTL Team.





Alexander McKay - 19 years old - Education

In his final year at Sacred Heart College, Alex won several awards; Excellence in English and Statistics, first place Physical Education, Economics, Religious Education and Accounting. He also gained excellence in his NCEA results that year with a scholarship for Economics and Physical Education. He also maintained a senior leadership role in the school throughout this time. Alex has now completed his first year at Uni, being offered a place in the UoA Law programme. Alex says he will use the award to help him with his education.

Tristram Buttner - 26 years old - Leadership

Tristram has been working within his community for the past two years, as assistant coach for a junior soccer team and becoming a committee member of the Taita RSA. Tristram is a qualified electrician but sadly he was made redundant in early December 2010. Not content to sit around and wait for opportunity to come knocking, Tristram has now started his own electrical business. He is also an active member of the CF Association in Wellington and helped with the 2010 Christmas Tree Festival by providing electrical services onsite. This award will help Tristram in his new business.



Shane Hill - 33 years old - Leadership

Shane has had a varied academic career, gaining a Diploma in Sport, a degree in Computer Graphic Design and then settling in to his career with a Post- Graduate Diploma in Secondary teaching. Shane states that he realized that teachers can be important positive role models and as such he has been body-building for 14 years and teaches PE alongside Design.

Due to his condition, he was not well enough to gain full registration as a teacher until now. This is a huge achievement for Shane and a testament to his perseverance. Shane was married this year, to Rachel, whom he credits with 'changing his life'. He is looking forward to buying a home and starting a family. One day he hopes to write about his life with CF.



John Ward - 24 years old - Education

John has completed a degree in Audio Production, is a guitarist and songwriter and with his degree would like to start his own production company, with kiwi musicians and bands. The degree took John four years to complete due to numerous hospital admissions. He has worked fulltime as well as teaching music classes to school students. Like many people with CF, John has faced many challenges to his dreams but with attitude and tenacity, he has completed his goal of a degree. He plans to pay his student loan with an award.

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 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 2011 – Phoebe Watt - Studied for a Bachelor of Arts at the University of Auckland with samples of her work being selected for a student handbook on academic writing. She was awarded several A+ grades and maintained a GPA of 7 despite hospitalization during exams. Phoebe intends to pursue further study in Melbourne

Branch Reports

NORTHLAND

Northland Branch has had a good year fundraising, with two main events. Our 4th golf tournament raised \$8000 and we had a record amount of teams making some new contacts for next year. We also had a record number of CF families involved. We had a car for a hole in one sponsored by TW Grant Insurance in Kerikeri. Every player received a prize. Income was made up of entries, raffles and auction. All prizes were kindly donated. For Bubbles Week we kicked it off with a 10 hour sponsored 'SKATE4CF' in Kerikeri which was a great success. Sponsors were Pit Stop Kerikeri, DDGOLD that donated and embroidered 20 t-shirts for free, and lots of other local businesses. We are still collecting money from sponsored skaters, but look to make well over the \$1600 mark.

The branch has also had a great offer from Brett Yakas at Jennian Homes Whangarei. They are willing to donate \$1000 to the branch for each build that comes recommended from family or supporters of Northland CF.

As a branch we are 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 to a maximum of \$100 and funding for nebulisers

AUCKLAND

Another good year for the Auckland Branch as our community connects more and grows stronger. A significant success for us this year has been raising more than \$35,000 during last year's Awareness Week. Once again a stirling effort with "many hands making light work" in this excellent effort, for the benefit of all the people with CF and families of our branch. Again Auckland branch has had great success with grant applications and this has helped us with our Branch Coordinator salary, office expenses, the purchase of nebulisers and physiotherapy equipment and funding for petrol and parking vouchers. One grant that we received this year has managed to fund a dishwasher, fridges and freezer and all sorts of equipment for Hearty Towers where PWCF spend time recovering after their transplant operation.

Money raised from Awareness Week and our other fund raisers is used for many purposes. Our amazing newsletter, purchasing a portable lung function unit for the testing of CF Adults, employing our Branch Coordinator and maintaining an office within the Parent and Family Resource Centre, purchasing supermarket vouchers, Muffin Break vouchers, Tiny Bites vouchers and Subway vouchers —all helping to soften the impact of a hospitalisation and support our people with CF and their families.

One major happening this year has been the resignation of our Branch Coordinator Helen Geary. Helen had been with the Auckland Branch for an awesome six years and has built the job into what it is today...a very functional, efficient and responsive administration arm of the committee. I take this opportunity to welcome our new Branch Coordinator Maria Teape.

In October 2010 we again attended the Kowhai Festival in Warkworth. An excellent opportunity to raise funds and awareness about CF. The beauty of the Kowhai festival is the fact that so many people from our wider CF community bake and make stuff for us to sell. We are lucky to have some of the best fudge, marshmallow and cake makers in the country.

The Auckland Branch offer a huge vote of thanks to Allyson Harvey, our Treasurer, who the Branch has acknowledged with a Life Membership this year. This year will be my last as Chairperson for the Auckland Branch and I assure the new Chair(s) of my ongoing support, friendship and help for this cause that is so close to all our hearts.

Jane Drumm, CF Auckland Branch Chairperson

WAIKATO

The Waikato Branch currently has a membership of 13 adults and 21 children. Some of the services we have provided include vouchers for hospital admissions, petrol voucher assistance to CF clinics, Christmas vouchers, hospital gift/activity packs, conference fees assistance and welfare requests e.g. firewood, short-term grocery voucher assistance for adults etc. We have funded the following equipment this past year: small fridge, DVD player for hospital, portable DVD players for children and several nebulizer compressors. We have been fortunate enough to have a very good relationship with LJ Hooker Te Awamutu who paid for 2 eflow nebulisers, a laptop computer and two compressors. We appreciate their ongoing support of our Branch as well as our other generous sponsors and fundraisers.

We would like to acknowledge the hard work and dedication of our two very special CF Nurse specialists Dee Campbell & Liz Courtney. Our sincere thanks also go to all the staff at Waikato Hospital who support us and work hard to take the best care of our PWCF.

I am very grateful in particular for the support of Michael & Jenny Bell who have worked tirelessly for the branch and also extend my thanks to all those members of our community to have shared their stories with me and supported the Branch in any way they could, no matter how small. Although I have enjoyed being actively involved in Branch leadership over the last five years or so, I am looking forward to taking a break. I wish Mike & Debbie Wood all the very best as they take over leadership of the Branch.

Claudette van Niekerk, Chairperson, Waikato Branch, CFANZ

BAY OF PLENTY

2010/11 has been a good year for the Bay of Plenty Branch. We have good numbers attending meetings and as a result have formed the beginnings of a much more structured branch. We have new babies being born to our CF families (including two to our AWCF) and we have continued to get to know each other better with more social activities.

A couple of areas we have been focusing on are improving our fundraising/awareness efforts, and widening our support networks to the wider branch and not just predominately the Tauranga area.

Firstly our fundraising. Katrina Russell-Barr has taken on the role of fundraising manager and is very motivated for us to achieve big things in the next financial year. We have decided to run a Christmas Tree Festival in Tauranga in December 2011 guided by the national office and the experience of the Wellington branch and are on target so far with the tasks that need to be done by this stage. The branch is very excited about this event and we are hoping to see a greater unity within the branch and awareness of CF out in our community as a result of it. On a much smaller scale, this year we held a theatre night where a local theatre company sold us a night of their current production for us to sell tickets to and cater wine and cheese to go with it. It made us some money but also connections within our local community and taught us a few things too.

Our branch area stretches from Thames in the Coromandel down to Taupo in the middle of the island. Multiple DHBs and a large land mass. But for as long as I have been involved in the branch, branch activity has been focused in Tauranga. We have slowly, this year, been finding out what the needs are for the Rotorua/Whakatane/Taupo regions and starting to find funding to better support them in their hospitalisations. There is still a long way to go and finding

ways to fit peoples busy schedules and the distance between people with meeting times is still proving challenging. We are very grateful to the Southern Trust, Pub Charity and First Sovereign for paying for nine of our branch members, including two from Rotorua, to attend conference this year in Wellington which we consider to be not just a great learning experience but also bonding time for our branch members able to go. Our projects going forward are the Christmas Tree Festival and establishing a fund to improve our physiotherapy services as well as extra funding for exercise/physio equipment.

Todd Wakerley, Chairman BOP branch

TARANAKI

We have enjoyed the input from new branch families this year and it has certainly helped to keep our enthusiasm high and our ideas flowing. The solid base of continuing committee members gives strength to all we can dream of achieving and new energy boosts us in these endeavors. Thank you Joan and Errol Tuffery and Shelley Gruchy for your ongoing vision and hard work.

Welfare is a major concern for us in Taranaki as many of our families struggle with power bills for heating/cooling, unsubsidised medication bills, travel within the region to uncoordinated medical appointments, repeat time off work to be with children in hospital or just getting PWCF to hospitals for appointments.

Our infection controlled mid winter dinners and our first summer BBQ have been well patronised and provide a much needed social support for our members. In November 2010 we entered a team in the Around the Mountain Relay and co-ordinated it with the Beaters and Breathers team (Transplantees from around NZ) and have people lining up to repeat this very satisfying event. Ashlee Butler PWCF ran the last leg for us and Katrina Turner PWCF transplantee was the Beaters and Breathers last leg walker! We had sponsorship from Fabish and Jackson Builders for our T shirts and hats! Thank you again Steve and Joy.

Our branch was very happy to sponsor five parents and one PWCF to conference this year and our first Taranaki Base Hospital staff member who was sponsored by both our Branch and Jono Fowlers family. We are really pushing the commitment to encourage our staff to have a closer working/knowledge based relationship with us and fully support their educational needs. We look forward to two staff members attending the Allied Health Workers Conference next year.

Our major challenges in Taranaki are: standardisation of care within hospitals for all PWCF (and throughout NZ hospitals); aseptic technique at clinics; greater knowledge and access to information for all health professionals treating PWCF; raising money during August in Taranaki which is also the busiest time in our farming community and the Cancer Society presence in Taranaki is huge.

In July the Fabish family in conjunction with our branch ran a very successful Casino night which raised a lot of funds for our very needy Taranaki members. A lot of prizes were provided by the Fabish family and from Jono Fowler's Estate. Quarterly newsletters produced by Jessica Patterson bring cohesiveness to our communication within the region.

Our primary focus continues to be great communication with our Branch members on a regular basis, personal and practical support for families dealing with hospitalisation and health sector wide, and education.

Donald Lumsden, Taranaki Chairperson

HAWKES BAY

The usual helpers supported Awareness Week 2010 and the local supermarkets once again allowed us to collect at their entrances. We also had help from Gahagans pharmacy in Napier and had a very successful cake stall outside Westpac Napier on the Saturday.

In October 2010 Williams Harvey had their annual Duathlon again in Hastings. The entrants were down on last year. We had a tent and had burgers and sausages for sale. Chocolate fish and pens were on display for a donation. We had an enjoyable day and will be doing this again next year; the entry donation next year will be going to the Christchurch appeal.

We were able to fund our members to national conference as we feel this is important for as many CF families to attend and mix. To help fund this we had another cake stall outside Westpac Napier on a Saturday and also received a grant from the Endeavour community trust. Funds from the "65 Roses House build" are starting to be used to help families with the daily physio and hopefully we will have more taking advantage of these funds.

Through our local "trip of a lifetime" we have also been able to assist one of our families to have their holiday to the fun parks in Australia. We have also assisted families with their medical needs and trips to Auckland hospitals.

Our branch has been the recipient of a bequest from an estate "for the benefit of local Children". This was from a lady who sadly lost two very young children from CF in the 1950's.

In closing we have had no major fundraising events but have been having regular meetings throughout the year and will continue to do so.

Glenda Sinden, Chairperson, Hawkes Bay

CENTRAL DISTRICTS

Central Districts got off to a great start in 2011 with major reshuffling within the committee and the arrival of an ex-Wellington committee member bringing a fresh perspective and new ideas. We have taken advantage of LJ Hooker Wanganui to help us with our fundraising ventures as they are very keen to give us their support. We look forward to enlisting their help in the future with more fundraising.

We are in the process of updating our membership list, in liaison with Sally Carron, with the aim of starting an enewsletter for those members interested, to keep them informed and to offer support as needed. We have plans to set up and calendar regular annual fundraising schemes, following the success of fundraisers already undertaken this year.

Because of our large geographical area we have had issues in the past with cohesion within the committee but we are working on this with good success and sharing regular monthly meetings between our two major towns of Wanganui and Palmerston North. We are also enjoying a good relationship with local newspapers in Wanganui and aim to continue this to help promote local CF awareness and our fundraising events. We are making good use of social networking also. We are benefitting from good advice from members of the Wellington Branch committee, who are generous mentors and always helpful.

Erin McCrea – Chairperson, Central Districts

WELLINGTON

Our year went well financially with \$7000 raised at last year's appeal and \$31,000 raised with grant applications. This meant we were able to maintain our Branch Coordinator position through the year.

Our profile was increased in the community with the resurrection of the (CCS) Christmas Tree Festival, and we are grateful to our CE Kate for all her support through this first attempt. Our profit was not huge this year due to startup costs but that should increase very well. We are most fortunate to have two grandfathers in a choir and a father in the NZSO, who featured in our cocktail launch party.

Our committee began shrinking at the end of last year and we were left with three members coming into the AGM in August. After an appeal we have jumped to eight members and are feeling happier about the future. A highlight of the year was Andrew Walklin becoming joint winner of Kiwi Battler – as he waits for three transplants and maintains a cheerful face through all his many treatments, it was well deserved.

An innovation this year was the Old Timers Lunch, a wonderful catch up time for those who have had a lot to do with each other over the years through CF. We also had a New Parents meeting and a Primary Age parents meeting, on the same day over a lunch. These plan to be repeated during the year, and the Old Timers are keen on maintaining six monthly contact.

Something directly benefitting PWCF has been the start of the Adult Clinic at Wellington Hospital. This combines a visit to the doctor with seeing a physio and dietician, and sometimes, the fieldworker. We begin the year ahead in good heart.

Margaret Nicholls, Chairperson, Wellington Branch

NELSON

The Nelson branch has had a challenging year. We have a wonderful caring group of people and families involved with CF in Nelson.

We all unfortunately struggle with being motivated leaders to run our branch. We also all have a limited level of how much we want CF to be a part of our lives any more than it needs to be. We have a small, dedicated committee team who work as hard as possible to help a steadily growing group within our region. Obviously this is not a unique situation to Nelson, but practically it makes it a challenge to keep our branch ticking over adequately.

We have however just had a very successful Awareness Week, collection days and AGM. We have had a sort out, made some decisions about the future of our branch, and made some goals moneywise, so hopefully we are on the right track again.

We have some transition issues that we are also trying to sort out at the moment and this is very challenging for the families involved.

Graeme Riley, Chairperson, Nelson Branch

CANTERBURY

Another year has come to an end and what a year it has been. The earthquakes have impacted our year financially and emotionally. We have learnt to become very adaptable and resilient here in Canterbury and have dealt with many changes mainly from the effects of earthquakes and snow.

Our community is now starting to show the true affects and winter has certainly taken its toll, with many welfare issues especially heating in very draughty houses and the cost of living continually rising. The stress in our community is extremely high. Our family numbers stand at approx 66 with a few moving away to more stable ground. We now have a lovely large group of pre- school children and have continued our parent support evenings although these have been quite irregular at times, also due to our current shakey situation.

We still continue to employ our community physiotherapist. Hilaire is a great asset and is working well with the hospital team and families. She has built up a great rapport with the community. It is also a great pleasure to have Sue Lovelock as our field worker who is based in the national office, seeing our families and finding any welfare issues as they arise and tending to these on our behalf.

The Christchurch Casino Golf Masters was on track for a big finale for the 10th year. This sadly was not to happen due to the earthquake. The venue was under liquefaction and the clubrooms were destroyed, major sponsor The Christchurch Casino was damaged and in the red zone, other main sponsors such as The Octagon Restaurant were also demolished. The event organisers ForeJ Productions had worked tirelessly to make this final event huge and they like us were extremely disappointed. This event has been so wonderfully successful and financially has set our branch up. We cannot thank the organisers enough for their tremendous efforts over the last 10 years.

Other fundraisers have been our annual golf tournament at Tempelton Golf Club which is always an enjoyable day and we profited approx \$35000. The community has been very supportive of selling fish on our behalf which has been great. One CF adult had organised to sit in her small local mall for a few hours collecting and one of our mums organised a swimathon in Timaru raising approximately \$800, so not all was lost. Our Discovery 1 school, who has always supported us collecting in the city, lost their school that is in the red zone and because they can't collect they have decided on us as their charity and are entering The Active QT Marathon in Queenstown and fundraising for us. This takes place in December. The Entertainment Book is still very popular and easy to sell, a big thanks to Sandy Campion for organising this for us. We sold over 150 books. The Xmas tree event will also not be going ahead this year and we are giving our trees to Bay of Plenty for them to use.

Funding applications are becoming scarce and I thank Nicky for her work in this area. Financially as a branch we are ok. We are lucky we have reserves in the bank and realise that over the next few years we will not be making a profit and are going to have to use approx \$20,000 per year to get through. We are going to take a big hit! Our main concern will be finding funding for our Physiotherapist's wages.

I would like to thank my committee Nicky, Viv, Sandy, Joan, Shelley and Sue for a very hard year and thank them for still putting in 100% especially when they have all been through trying times, a traumatic year to say the least .

Melissa Skene, Chairperson, Canterbury

OTAGO

It has been an interesting year and Otago has finally opened a new chapter with a new chairperson and committee, there is a an excitement about the new year. The first challenge we had was street appeal and what a fantastic result raising \$16,030 which has exceeded previous years and the big difference is in the last two years we were given a \$5000 donation and this year it was all raised from the street collection and tells me two things; one is that people know CF really well and see us as a worthy cause and understand the condition and two, Kevin Helm and his team of people have done an outstanding job and it is a credit to them.

We have continued on as previous years supporting at grass roots but watch this space as we have a good amount of funds again with an auction in February Kevin Helm and Tess Molteno having put together a fantastic night and resulting in over \$20,000 being raised. The new chairperson is Arthur Booth and Otago couldn't be in better hands. He has a team behind him with a challenge to make some changes and to grow the group.

Thank you to Kate and the CF team for your support, friendships and our unwavering strong CF community. Finally to Susan Lovelock big thanks to you.

Janet Camplin, Outgoing Chairperson, Otago Branch

SOUTHLAND

One of the quieter years down in the Sunny South for the Southland Branch with no meetings held other than the Annual General Meeting. Because of such small turnouts our meetings are only convened if there is anything of importance to discuss that cannot be done via the telephone/email or if there is a request by one of the members. Lynne also continues to forward all emails received.

Because of work and family commitments and a lack of branch resources no street appeal was undertaken this financial year.

Income for the year was in excess of expenditure which has helped us maintain a healthy bank balance. A donation from Mataura Freezing Works, where Mark and Marie Gilder work, was greatly appreciated along with the \$1,000 donation from the Barkman family and the \$1,000 associated with me running a Casino Evening for our work staff.

Over the years, with the help of our local trusts we have endeavored to provide our CF members with whatever we consider necessary to help improve their quality of life. We have also been able to provide a "'Win a Wish" type experience for those on reaching the age of 18. This year no requests for equipment were received.

We continue to refund members for all prescription charges and Lynne continues to provide that little hospital treat whenever she is aware of someone being admitted.

As no complaints were received during the year I can only assume everyone is happy with this "Low Key Approach" that the branch has taken over the last few years. Although we have not managed to attend many national conferences, we continue to encourage our members to attend where possible for which Branch funding is available. It was great to see John Ward attend the National Conference this year.

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

Roche

Zoom Room IBDG

Orly Productions

Harvey Cameron

L J Hooker

Fletcher Challenge Group

Canterbury Crusaders

MORE FM

AdShell

Christchurch Casino

Thomson Reuters

NZFMA

The Patter

The Ministry of Health

TV₃

Avenues Event Management

Canterbury Jockey Club

The NZ Lottery Board

Pub Charity

Mainland Foundation

Christchurch International Airport

Guardian Trust

Dominion Post



BOC Gases

Christchurch Press

NZ Community Trust

APN Outdoor

CF Foundation USA

Destination Taupo

Canterbury District Health Board

All of our individual donors

CFANZ Clinical Advisory Panel

NZ Carer's Alliance

Access to Medicines Coalition

Breath4CF Ironman athletes

Sloane Robinson

The Paterson Family

Buddle Findlay

ASB Community Trust

Foodstuffs

ASB

NZ Post

Mortgage Busters

John Miller Photography

Mainfreight

Mighty River Power

Cleantastic

Canterbury Community Trust

TIMEX

Christchurch Northwest Kiwanis





Financial Statements

CYSTIC FIBROSIS ASSN OF N.Z. (INC) FINANCIAL STATEMENTS FOR THE YEAR ENDED 30th June 2011 PLEASE NOTE THAT THESE FINANCIAL STATEMENTS COVER THE YEAR ENDED 30 JUNE 2011. THE COMPARATIVE FIGURES COVER THE SIXTEEN MONTH PERIOD ENDED 30 JUNE 2010.

FINANCIAL STATEMENTS FOR THE YEAR ENDED 30TH JUNE 2011

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1	Trust Directory
2-3	Statement of Financial Performance
4	Statement of Movements in Equity
5	Statement of Financial Position
6-9	Notes to the Financial Statements
10	Schedule of Plant Property and Equipment (Depreciation Schedule
11	Auditors' Report

TRUST DIRECTORY

FOR THE YEAR ENDED 30TH JUNE 2011

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 2011

		2011	2010
INCOME			
Individual Donations & Bequests		74,357	138,881
Sponsorships & Grants (note 11)		180,622	262,789
Grants ex Branches		2,000	2,000
National Fundraising (notes 12)		158,045	202,317
Interest - Chris Howlett Fund Interes	st & B4CF	36,888	34,691
Interest - General		5,841	21,998
Dividends - Chris Howlett		4,646	11,667
Dividends - Rangitira		16,450	26,425
MOH Contract Income		75,000	50,000
Ministry of Social Development		₩	50,000
Other Income		10,789	16,847
		564,638	817,615
OPERATING EXPENSES			
Grants to Branches	425		6,999
Other Grants	5,679		6,338
Hospital Allowances & Prescription	•		·
Refunds	18,920		19,460
National Voucher Scheme	8,075		12,355
Funeral Grants	4,000		8,000
EQL Care	· -		2,082
Medical Information & Advice	497		2,682
Tertiary Education Grants	16,562		26,591
Transplant Grants incl Vouchers	3,970		7,131
Advertising, Promotion, Public	•		
Relations & Lobbying	14,367		8,058
Publications - Newsletter	5,079		5,931
Publications - Other	91		78
Breath4CF Grants	88,746		112,008
Equipment & Laptops for PWCF	1,936		7,313
Chris Howlett Fund expense accrual	-		8,000
Field Worker Costs	80,114		106,828
Conference Expenses	31,317		45,422
		279,778	385,276

FOR THE YEAR ENDED 30TH JUNE 2011

		2011	2010
ADMINISTRATIVE EXPENSES			
Staff Salaries	187,025		290,065
Staff Travel	5,277		9,832
Motor Vehicle Costs	10,236		12,868
Other Staff Costs	20,225		15,391
Office - Rent/Electricity/IT Support	25,613		35,017
Printing , Stationery & Photocopying	6,068		8,141
Postage	8,570		5,632
Telephone & Tolls	8,804		16,373
Subscriptions	1,836		3,578
Accounting Fees	2,100		2,700
Audit Fees	2,258		2,350
Board Expenses	7,407		7,924
General	7,553		5,186
Legal Expenses	6,383		-,
		299,355	415,057
DEPRECIATION			•
Depreciation	5,146		14,812
		5,146	14,812
			•
TOTAL EXPENSES		584,279	815,145
OPERATING (DEFICIT) / SURPLUS		(19,641)	2,470
SUNDRY INCOME			
Capital Gain on Disposal of Investment	ts	10,108	28,119
Branch operating results (deficit)	(note 7)	157,229	(12,423)
NET (DEFICIT) / SURPLUS FOR YEAR		147,696	18,166

FOR THE YEAR ENDED 30TH JUNE 2011

STATEMENT OF MOVEMENTS IN EQUITY	2011	2010
Net (Deficit)/Surplus for Year	147,695	18,165
Trust Equity at 1/7/2010 First NZ Capital Portfolio Valuation	1,414,856	1,454,260
Fluctuation - Unrealised	854	(24,367)
	1,563,405	1,448,058
Comprised:		
Accumulated Funds	779,375	661,591
Chris Howlett Endowment Fund (note10)	466,295	462,702
Breath 4 of Physical Equipment Fund (Note13)	317,735	323,765
Total Equity as at 30/6/2011	1,563,405	1,448,058

STATEMENT OF FINANCIAL POSITION FOR THE YEAR ENDED 30TH JUNE 2011

	1,563,405	1,448,058
	•	
150		150
102,765		70,282
•		138,133
,		3,635
•		3,210
5,043		2,869
	223,703	218,279
	•	•
75,600		80,325
		•
659,653		658,799
662,406		505,177
	1,397,659	1,244,301
adule	10,192	15,338
	1,631,554	1,477,918
26,629		16,284
13,426		12,225
7,178		
20,916		1,351
'''' 	68,149	29,860
	68,149	29,860
	1,563,405	1,448,058
	102,487 8,688 4,570 5,043 75,600 659,653 662,406 edule 26,629 13,426 7,178	102,487 8,688 4,570 5,043 223,703 75,600 659,653 662,406 1,397,659 10,192 1,631,554 26,629 13,426 7,178 20,916 68,149 68,149

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

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30TH JUNE 2011

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 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.

<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 2011 are included in financial statements as at that date.

Changes in Accounting Policies

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

Change of Accounting Period

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

2. Capital Committments

There were no capital committments at 30.6.2011 2010 (Nil)

3. Contingent Liabilities and Commitments

There were no contingent liabilities or committments as at 30.6.2011 2010 (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 Committments

As at balance date the Association has future operating lease committments as follows: expiry within greater than 12 months date 12 months - Vehicle 1 Lease July 2012 3,928 327 - Vehicle 2 Lease Feb 2014 8,766 13,879 - Premises rental Nov 2011 8,177 0 ____ ----TOTAL 20,871 14,206

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

Financial Statements

For the twelve months e	ended 30 June 2011

	12 Months	16 Months
7 Branch operating results	2011	2010
Surplus/ (Deficit) after contributions to National Association	,	***************************************
Northland	4,291	420
Auckland	35,390	20,819
Bay of Plenty	-458	-3,021
Waikato	-964	5,093
Hawkes Bay	146,708	-12,400
Taranaki	1,407	-1,590
Central Districts	-771	-1,363
Wellington	-18,632	-41,980
Nelson	-618	-5,438
Canterbury	-21,145	27,427
Otago	10,480	4,083
Southland	1,541	-4,473
Total Branch Surplus/(Deficit)	157,229	-12,423
Branch Assets		
Northland	49,286	44,995
Auckland	174,081	138,691
Bay of Plenty	4,964	5,422
Waikato	19,407	20,371
Hawkes Bay	163,985	17,277
Taranaki	19,546	18,139
Central Districts	17,212	17,983
Wellington	4,078	22,710
Nelson	2,678	3,296
Canterbury	163,074	184,219
Otago Southland	19,405	8,925
Southland	24,690	23,149
Total Branch Assets	662,406	505,177
8 Short Term investments		
ASB	0	20,000
Rabobank	102,487	118,133
Total	102,487	138,133
9 Long Term Investments		
Comprises: 10,000 Ordinary A Rangatira Ltd Shares and 30,000 Ordinary B Rangatira Ltd Shares. (market value 30/6/2011 \$240,000 - 2010 \$242,250)	75,600	80,325

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Financial Statements

For the twelve months ended 30 June 2011

	Howlett Endowment Fund	12 Months <u>2011</u>	16 Months <u>2010</u>
Openir	ng Balance	462,702	450,344
Plus in	come earned	30,593	46,358
	ransferred to CFANZ retained earnings for admin	-1,000	
	ment Grants paid	-26,000	-34,000
Closing	g Balance	466,295	462,702
	ions, Sponsorships and Grants		
Pub Cl	harity Grant	35,000	50,000
NZ Lot	itery Grants Board	35,000	32,794
N Z Co	ommunity Trust	0	
Other		10,000	
ASB C	haritable Trust	25,000	20,000
First S	overeign	0	
Eureka	a Trust	1,822	12,632
AXA T	rust	0	10,000
Canter	bury Community Trust	0	10,000
J R Mo	cKenzie Trust	0	
Lion Fe	oundation	3,000	8,000
Mainla	nd Foundation	2,400	
Hornby	y Rotary Club	0	
	oker Te Awamutu	0	•
Perry F	Foundation	0	
•	ern Trust	Ö	
Comm	unity Trust Southland	Ō	
	n & Central Community Trust	0	-,
Trillian		0	
Foods	tuffs Community Trust	3,000	
	Community Trust	0	•
BayTru		Ō	,
	y W Duncan Trust	Ö	
	sham Foundation	Ö	
	Vaikato	Ö	
	to Community Trust	0	
	ganui Community Foundation	Ö	1,000
ASB B		2,000	0
	ngher Ingelheim	2,000	ŏ
	s Trust	3,000	ő
	trol Vouchers	400	Ö
	s in Life Trust	20,000	Ö
	ian Trust	13,000	0
	rust Charitable Foundation	10,000	0
	overeign	10,000	0
	bury Community Trust	5,000	0
Janto	wary warming reads	180,622	
Dlug	an anah ananawahina	100,022	202,100

Plus non cash sponsorships

Goods in kind for events such as: Ironman, Charity Cricket

CFANZ National Conference and National Raffle:

Major Sponsors:

James Cook Hotel Grand Chancellor

Roche Products

Harvey Cameron Itd

Boehringer Ingelheim

Christchurch Casino

More FM

TOTAL 88,563 32,860

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12 National Fundraising Comprising the following

	158,045	202,317
Other	66,709	90,488
Riccarton Race Day	4,200	1,892
Breath 4 CF	66,479	87,145
Charity Cricket Gala Day	7,663	9,040
National Raffle	12,994	13,752
Comprising the following which are net of expenses incurred:		

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	323,765	348,628
Plus Income	24,396	87,145
less payments for equipment	-21,400	-1 12,008
less transfer to CFANZ retained earnings -admin 3 prior years	0	0
less transfer to CFANZ retained earnings -admin current year	-9,026	0
Closing Balance	317.735	323 765



AUDITORS' REPORT

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

We have audited the financial report on pages 1 to 10. The financial report provides information about the past financial performance of the Cystic Fibrosis Association of New Zealand and its financial position as at 30 June 2011. This information is in accordance with the accounting policies set out in note 1 to the financial statements.

Board of Management Responsibilities

The Board of Management is responsible for the preparation of a financial report which fairly reflects the financial position of the Cystic Fibrosis Association of New Zealand as at 30 June 2011, and of the results of operations for the year ended on that date.

Auditors Responsibilities

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

Basis of Opinion

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

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

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

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



Qualified Opinion

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

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

In our opinion the financial report on pages 1 to 10 fairly reflects the financial position of the Cystic Fibrosis Association of New Zealand as at 30 June 2011, and the results of its operations for the period ended on that date.

Our audit was completed on 29 August 2011 and our qualified opinion is expressed as at that date.

Peter Davidson & Associates

Christchurch

