



**Cystic Fibrosis Association of New Zealand**  
**CONFERENCE REGISTRATION FORM 2010**

*(Please complete both sides of this form for each person attending the conference, and fax or mail with full payment to PO Box 8241, Christchurch, by Monday April 19<sup>th</sup>)*

Surname \_\_\_\_\_ First Name \_\_\_\_\_

Postal Address \_\_\_\_\_

Daytime Phone \_\_\_\_\_ Mobile \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_ Local CFNZ Branch \_\_\_\_\_

Travel Method:      Airline               Own Car               Bus company

Arrival Details (date & time, flight/journey #)

Departure Details (date & time, flight/journey #)

**What part(s) of the conference will you be attending? (please tick appropriate boxes)**

Friday day delegate (includes Friday evening opening function)      \$ 100.00 gst inc

Saturday day delegate only      \$ 100.00 gst inc

Saturday Conference day delegate, plus Saturday evening Conference Dinner      \$ 185.00 gst inc

Saturday Dinner only      \$ 85.00 gst inc

Sunday 9.00am – lunchtime (incl lunch)      \$ 80.00 gst inc

**OR** Whole Conference Friday 9.00am to lunchtime Sunday

(incl all lunches, Friday Welcome function & Saturday Conference Dinner)      \$300.00 gst inc

If your branch is paying for your registration, please give us your branch contact person and phone #, so payment can be arranged direct with your branch \_\_\_\_\_ Phone \_\_\_\_\_

**Please book your accommodation through CFANZ, not direct with the Hotel**, as we've reserved rooms and negotiated a special conference tariff. Rooms will cost: *\$150 per night (GST included) for a standard twin room including breakfast for one person plus \$18 for any additional breakfasts*

**So if you are sharing a room, please halve the rate per person. Please tick dates required:**

Thursday 13<sup>th</sup> May       Friday 14<sup>th</sup> May       Saturday 15<sup>th</sup> May

Have you arranged to share with someone? Who?

\_\_\_\_\_

**Total Registration and Accommodation fees enclosed:** \$ \_\_\_\_\_

Please make cheques payable to CFANZ, or you can pay by Visa or Mastercard:

Card # \_\_\_\_\_ Expiry date \_\_\_\_\_ Name on card \_\_\_\_\_

Your signature: \_\_\_\_\_ Today's date: \_\_\_\_\_

- Are you a:
- CF Adult
  - Parent/Caregiver
  - Professional involved with CF care
  - Trade Display holder/other sponsor
  - Other .....

**If You Have Any Questions:**

- about the conference programme, speakers or speaker travel, contact Kate [kate@cfnz.org.nz](mailto:kate@cfnz.org.nz)
- about the accommodation, venue or catering, contact Caroline [caroline@cfnz.org.nz](mailto:caroline@cfnz.org.nz)
- about the sponsorship or fundraising, contact Islay [islay@cfnz.org.nz](mailto:islay@cfnz.org.nz)

If you're paying by Visa or Mastercard, instead of mailing, you can fax this form (both sides) to 03 341 8025.



**To: All members of the Cystic Fibrosis Association of NZ**

**From: Kate Russell - Chief Executive**

**Subject: 2010 National Conference**

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It is with great pleasure that we extend an invitation for you to join us at the Cystic Fibrosis Association of New Zealand National Conference at the Hotel Grand Chancellor, Christchurch. May 14/15/16, 2010

The registration form for the conference is also attached to this email, and a draft programme is attached and available on our website at [www.cfnz.org.nz](http://www.cfnz.org.nz). This will be updated before the conference, so please check the website from time to time. The 2010 conference programme is varied and will have something to interest parents, young people, medical and allied health professionals and adults with Cystic Fibrosis alike.

Registrations must be at the National Office by **Monday 19th April** on the attached form. Registration is essential and we would appreciate your co-operation in adhering to close off dates. Late registrations will incur a late registration charge of \$50.00

The Association will once again be assisting PWCF to attend through full waiver of the registration fee, but travel and accommodation costs will be at the person's own expense. If you want some assistance from your branch with costs, please let them know EARLY that you intend to come, so that appropriate grant applications can be put in, in good time.

The Association's cross-infection policies require people with Cystic Fibrosis to provide a negative bacteriological report for Burkholderia Cepacia and MRSA. Please refer to "Cross Infection Precautions" for further detail.

The National Board and staff look forward to welcoming you at this excellent learning and networking opportunity. If after reading the following information, you have any questions that are not covered in this notice, please call Kate at the National Office on 0800 65 11 22.

Kindest regards

A handwritten signature in blue ink, appearing to read 'Kate Russell'.

Kate Russell  
**Chief Executive, Cystic Fibrosis Association of NZ**

## CONFERENCE INFORMATION



### **TRAVEL**

All attendees are expected to make their own travel arrangements, apart from Board Members and invited speakers. One delegate from each Branch may have their travel arranged by National Office if they prefer.

### **ACCOMMODATION**

Rooms are reserved at the Grand Chancellor Hotel, Christchurch where we have negotiated a special conference rate. Accommodation per room for the Thursday, Friday and Saturday nights of the conference will be:

***\$150.00 (incl gst) per night for a standard room with breakfast for 1 person. Extra breakfasts per room will be \$18.00 pp. So, if you're sharing with someone, it will cost \$84.00 per person per night including breakfast.***

### **MEALS**

The Friday night Chairman's cocktails will be held at the hotel and is included in the conference registration, after which you will be free to 'do your own thing' for dinner. The Hotel Grand Chancellor is in the Central Business Districts with dozens of well-priced dining options nearby. The Saturday Conference Dinner will be held offsite – at a location to be confirmed. This is also included in your full conference registration. All other lunches and morning/ afternoon teas are covered by registration fees and sponsorship.

### **REGISTRATION**

Please complete the registration form as soon as possible and return to the National Office no later than Monday 19th April. Late changes must be advised directly to Caroline Wagetveld.

Friday day delegate (includes Friday evening opening function)	\$ 100.00 gst inc
Saturday day delegate only	\$ 100.00 gst inc
Saturday Conference day delegate, plus Saturday evening Conference Dinner	\$ 185.00 gst inc
Saturday Dinner only	\$ 85.00 gst inc
Sunday 9.00am – lunchtime (incl lunch)	\$ 80.00 gst inc

**OR** Whole Conference Friday 9.00am to lunchtime Sunday

(incl all lunches, Friday Welcome function & Saturday Conference Dinner) **\$300.00 gst inc**

### **TRADE DISPLAYS**

Medical equipment and other products and services relevant to the CF community will be displayed during the conference. Ample opportunity will be provided for you to speak with company representatives during lunch and tea breaks.

## **CF ADULT GRANTS**

All adults with Cystic Fibrosis will be assisted to attend conference with waiver of registration

**IMPORTANT: You still need to register for the conference, even if you won't be incurring any registration fees.**

## **CROSS INFECTION PRECAUTIONS - IMPORTANT - PLEASE READ**

The following protocols are in place to minimise the risk of cross-infection:

- ❖ People with Cystic Fibrosis who wish to attend must provide the National Office with a negative bacteriological report for Burkholderia Cepacia and MRSA. Patients should arrange a test through their Doctor to look for the presence of both. ***This test is to be taken not more than 3 weeks prior to conference, i.e. on or after 23<sup>rd</sup> April and the report should reach the office no later than Wednesday 12<sup>th</sup> May. Failure to supply your test prior to the conference will mean that you CANNOT be admitted under any circumstances. We STRONGLY RECOMMEND that adults actively follow up on their tests to ensure there are no unnecessary delays. Ensuring that the tests are sent to us in good time is YOUR responsibility. Please do NOT rely on nursing staff to follow up on this for you.***
- ❖ Hygiene guidelines will be available and particular attention given to handwashing facilities and hygienic rubbish disposal bins. Sterigel will be available at all times.

## **FRIDAY NIGHT DINNER**

Friday night will be free for you to explore the ChCh inner city, so delegates can dine in informal groups either in-house at the hotel or at a restaurant of their choice. This will be at delegate's own cost - CFANZ will not be covering this cost for any delegates.

## **IN ROOM PURCHASES**

As always, we will endeavour to fully meet the dietary requirements of our CF delegates during the conference. If you feel you will need extra snacks etc, then we advise you to bring a supply from home if you cannot afford to buy any at the venue.

ALL in-room purchases, including meals, phone costs and mini bar must be paid for by delegates themselves. You will be required to leave a credit card number with the desk on arrival for charging after the conference. Your room will have a 'no charge-backs' policy applied to it so all purchases of this kind MUST be settled in cash at time of departure.



## Day One - FRIDAY 14th MAY

- 9.00am Welcome and Housekeeping
- 9.15am **‘Sharing Experiences’** – For this interactive session, registrants will split into groups according to the age of their PWCF – Pre-school, Primary school-age up to 10, Post-primary school-age 11-16, or Over 16 years. There will be 4 facilitated discussions held where participants can get to know others in a similar situation to share knowledge and experiences. A team of ‘CF experts’ will also be on hand to answer any questions on diet, physiotherapy and general CF care.  
Facilitators – **to be confirmed**  
‘CF Experts’ – **Sue Madge, Dr Craig Lapin, Tory Crowder, Trish Goulter.**
- 10.45am Morning Tea
- 11.20am **‘Quality Improvement in our Clinics – what’s possible?’** – Since the introduction of Port CF, there has been a steady programme of quality improvement in US CF Clinics. **Dr Craig Lapin**, Centre Director of the Paediatrics Clinic at Connecticut Childrens’ Health, USA will talk to us about his own clinic’s experience in setting goals for improvement in CF care.
- 12.30pm Lunch
- 1.30pm **‘Now we are 40 – Getting older with CF’** – Now that Adults with CF are living longer, some of the inevitable issues of ageing take on special significance. **Dr Mark O’Carroll, CF Specialist, Auckland Hospital**
- 2.40pm **‘Parenting when you have CF – challenges and strategies’** **Lisa Borkus, Adult Rep to the CF Board**, will facilitate this sharing of information with parents and parent-to-be!

**OR**      **“The Alginase Study – interesting findings” Professor Bob Elliott (CF Patron and Clinical Director of Living Cell Technologies)** will update us on progress on his research

3.20pm      Afternoon Tea

3.50pm      **CF Adults and their partners are invited to a closed group discussion** on topics of interest or concern to the participants. Please feel free to raise any issues you would like comment on, or help with from the other members of the group – Group will spend some time together and break into male and female groups. **Facilitated by Cath Lamont and Sally Carron**

OR

**“Tweens, Teens, contracts and non-negotiables” CF Nurse Practitioner, Sue Madge** from Brompton Hospital, London will speak about how to navigate the minefield of the tween/teen years with a child with CF

5.00pm      Close of Business Sessions

6.30pm      **Opening Function**– hosted by our President – **Denis Currie**. Drinks & nibbles will be served. Kathryn Ashford and a representative from Winstone Wallboards will present the Mark Ashford Scholarship Award to this year’s winner. This will continue until about 7.30-8pm, leaving the rest of the evening free. There are well-priced dining options in-house, or several restaurants and club nearby.

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## Day Two - SATURDAY 15th MAY

- 9.00am **“What does great Transition look like?” Sue Madge, Brompton Hospital**, will discuss the transition pack and programme at Brompton. Transition is something we are still working on in New Zealand and families need to play a part in making it successful
- 10.00am **Update from the Genetic Research Team UK Consortium**, a taped interview with the lead researchers about how far they have come and the next challenges with this important research.
- 10.30am Morning Tea
- 11.00am **‘Dealing with the psychosocial aspects of CF – adult with CF’ Facilitator TBC** an in-depth look at the emotional ‘stuff’ that goes with having CF
- OR** **‘Dealing with the psychosocial aspects of CF – parents’ Sally Carron, CFANZ Field Worker facilitating** an in-depth look at the emotional load that having a child with CF places on the family and how to cope with the changing landscape.
- 12.30pm Lunch
- 1.30pm **Concurrent Sessions:**  
**Stream one – “Food Glorious Food – getting your child enthused about eating food AND making it! Fiona Leighton, Dietician from ChCh Hospital** will look at the first aspect of getting your CF child enthused about EATING, then a **Sue Parkes – Head of the Domestic Science Department at one of Christchurch’s largest High Schools**, will look at how to get them in the kitchen and actually MAKING the food!
- Stream two - ‘Got Sputum? What happens from spit to lab’, Dr Mirjana Jaksic from Starship** will look at what they do with your sputum samples! Something for those with a scientific interest in CF!
- 2.30pm **Port CF and the Standards of Care Document – what can we learn? Drs Cass Byrnes (Starship Hospital) and Richard Laing (ChCh Hospital)** will take us through these tools and discuss how we can use them to explore and improve CF outcomes in NZ

3.30pm Afternoon Tea

4.00pm **A special mystery speaker!**

5.00pm Close of business sessions

7.00pm **Conference Dinner** - Meet from 6.30pm on for a walk to our dinner at 7pm at Santorini Greek Trattoria (get ready to dance on tables and sample ouzo!) Please dress warmly, it is a 10 minute walk. If you need a taxi let us know.

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### **Day three - SUNDAY 16th MAY**

- 9.00am **‘The Role of Patient and Family Advisory Groups – could they work here? Dr Craig Lapin (Connecticut Childrens’ Health),** will speak about the very positive impact that having a Patient and Advisory Group has made on his centre and their clinical practice.
- 10.30am Morning tea
- 11.00am **‘Mixing it Up – combining old and new strategies in physio for the best effect’ Rebecca Scoones, Physiotherapist, Starship Hospital** will discuss how to have a well-rounded physio regime to maximize the benefits for the CF lung .
- 12.00pm Feedback Forms Prize Draw & Farewell, followed by Lunch
- 1.30pm Conference closes

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