CFNZ 50th ANNIVERSAY GARDEN PARTY

GOVERNMENT HOUSE, AUCKLAND – 5 DECEMBER 2018

CFNZ PRESIDENT - DENIS CURRIE QSO

Your Excellencies - it is a privilege and honour for the Cystic Fibrosis Association of New Zealand to be welcomed to Government House today in recognition of our 50th year anniversary.

Thank you most sincerely for hosting this occasion.

Cystic Fibrosis NZ is represented here this evening by the many special people who have all been involved in some capacity with Cystic Fibrosis during this past 50 years.

Friends – it is right and proper we can look back over this period, and perhaps quietly reflect on where we have been, and what has been achieved.

We remember with affection and love the people we have lost. We also acknowledge significant advancements made in the treatment of Cystic Fibrosis, to now extend and greatly enhance quality of life.

However in reality now 50 years later, there is still no cure for the condition of Cystic Fibrosis. What matters now from this point on, is where we wish to be in the immediate future – within the next week, the next month, or in one year's time.

For we must continue to look forward with renewed focus and greater urgency, around what can be achieved for our CF people. One immediate and very simple example would be to gain funding here in NZ for the drug, Kalydeco.

And that should just be a start. We also need to embrace the opportunity to benefit, from all other advancements in the treatment of Cystic Fibrosis available elsewhere in the world, for CF people.

That should be our right, and the challenge we should all pledge to achieve – for our CF community here in NZ.

On behalf of CFNZ, it is my pleasure to extend a very warm welcome to our inspirational Patron Professor Bob Elliot – along with Mrs Elizabeth Elliot – and to Life Members Professor Keith Grimwood, Doctor Alison Wesley, and Molly Haughey – represented by her son Peter here this evening.

Welcome also to the large cross section of guests who share with us today. Through your individual and collective talents, commitment and dedication – we are all bound together as a vital and essential part of the Cystic Fibrosis NZ Family.

Making up this wide and diverse group are –

- **Parents of our CF people, family members & friends**
- **Those representing each of our twelve branches spread throughout the country**
- **Members who work tirelessly on committee's at all levels, both national and local**
  (note – UN International Volunteers Day/5 December)
- **Dedicated members of the medical profession, at all sectors of research, treatment, and ongoing care**
- **Valued Donors, Grant Authorities, DHB's and all supportive government agencies**
- **The Chief Executive of CFNZ, Jane Bollard, and members of her dedicated staff**

A very warm, and personal welcome to you all.

Finally, to that very special and important group, not able to be well represented here this evening. Of course we refer to the 500 plus children and adults living with CF in NZ, the very reason our Association exists.

And yet, because of cross infection issues between people with cystic fibrosis, we have the unique situation in that they are not able to share with us, as a collective group today.

And it is such a 'damning situation', that we are not able to witness and then applaud, each and every one of them in person here this evening - for the way they fight each day of their lives, and for the strength and courage they all continue to show, in the face of such adversity.

To represent all of our people with CF here in NZ, both past and present, it is my pleasure to acknowledge and welcome Nichola Wilson, an adult with CF who will be introduced and speaking to us shortly.

Your Excellencies – thank you most sincerely again for your generous hosting of this occasion.

With respect, we may well call on your wonderful hospitality once again, when a cure for CF is finally discovered, a day in all our lives we are entitled to dream, could be just around the corner.

And when that watershed day finally arrives, the 'CF' symbol at long last can have a different and shared meaning.
CF - Cure Found. A timely occasion for another Garden Party.

To all our guests – it is a privilege to share this 50th Anniversary with you – sincere thanks to you all for being such an important part of the Cystic Fibrosis New Zealand Family.

Please make sure you enjoy the evening.

Thank you, one and all.

DENIS CURRIE INTRODUCTION
FOR JD & AW REMEMBRANCE ✓

Your Excellencies, and guests

At each Annual General Meeting the Association observe a period of remembrance for those we have lost. Their treasured names are then entered into the Memorial Book as displayed here. The records go back over 50 years.

To lead us in a moment of remembrance will be –

Jane Drumm, Chairperson of CFNZ, a mother of two with CF, Georgia and Angus

And

Alison Bibby, with a near 50 year involvement with CFNZ at both national and branch level, a founding member of the CF Hawkes Bay Branch, and a mother of two with CF – who have sadly passed away – Joseph (Jo) in 1995, and Kate in 2009

CF Speech

Your Excellencies, ladies and gentlemen, friends and whanau, Good evening.

It is my pleasure to be here tonight to represent the CF community, and to both acknowledge and celebrate the 50th Anniversary of CF New Zealand.

And from the bottom of my heart – to say Thank you. Thank you to the volunteers, and the friends, and the extended family of people with CF. To those of you who donate time, resources, funding, knowledge, kindness and compassion…There are so many ways in which we the "CF community" are supported through the Association, and our lives are the better for it. We appreciate your efforts SOOO much.

My own family has been involved with CF over many years, almost to the beginning of the 50-year history. It has been a journey, and a transition, and we have been supported by CFNZ at multiple touch points, and in many and varied ways over the years…

From a diagnosis in the **mid-70's** that 2 of their 3 children had Cystic Fibrosis, CFNZ were the first to be there for my extremely young parents. The first to offer support and friendship, the first to offer KNOWLEDGE and INFORMATION. And the first to offer hope, when it seemed like there was none.

And then growing up in the **EIGHTIES and NINETIES**, CFNZ provided opportunities to meet other CF families - in fun and educational environments. Christmas Parties, and Summer Camps, Conferences – (of course this was before Cross-Infection knowledge that we have today…)

As a young adult, I was able to participate in an Outward Bound course, along with a group of young people with CF. Even now, when I look back at that experience, I recall the brave brave soul responsible for getting our group out of bed for 6o'clock – that's 6AM PT, including a run and a swim in the brisk Marlborough Sounds. Many of you here will have personal experience with how difficult a task that is….

And to more recent times, CFNZ continue to provide support to the likes of myself and others. Through their nationwide branch network, through their web based resources and information, their lobbying for greater funding and access to new drugs, and patient advocacy through their team of Field Workers providing assistance and advice to parents, young people and adults living with CF today.

With all these resources, and despite all the advancements in medical care and knowledge, living with CF can still be a real downer. We still have a long way to go to improve quality of life and the quest for a cure remains the end goal. And sometimes….

Sometimes it is still the human touch, and the really simple things that make a difference in the day-to-day lives of people with CF - it is the home-baking, the magazines, the donations of lip balm and the parking chits that offer practical support when hospital admissions are required. These small gestures are extremely gratefully received. So - **thank you** to you all for these small acts of kindness. They don't go unnoticed.

Again, a heartfelt congratulations to CFNZ on your 50th Anniversary. What an amazing milestone!

NICHOLA WILSON
AWCF