To develop a parent held educational manual, “The Cystic Fibrosis Passport”, for community members involved in the care and education of children with cystic fibrosis.

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Introduction

The impetus for my Churchill Fellowship came from a desire to improve communication about the most common inherited medical condition in Caucasians, cystic fibrosis, between families and the people who come in contact with their children. In particular, I wished to facilitate better communication between families and early childhood health professionals and educational professionals dealing with young children in the first ten years of life.

The information gathered by visiting world class cystic fibrosis centres in Europe, England and North America provided an opportunity to consolidate my knowledge in this area as a paediatric respiratory specialist by comparing and contrasting clinical practices, opinions and personal viewpoints of patients and families in a variety of cultural settings.

The result of my visits and observations during my seven week Fellowship will be the creation of the “Cystic Fibrosis Passport” for use by the families to broaden the knowledge base of community educational and health care professionals who care for young children with cystic fibrosis. The “Cystic Fibrosis Passport” will complement the existing educational strategies provided to families by cystic fibrosis clinics across Australia. In essence, it is intended to provide a “bottom up” educational strategy to complement the “top down” approach traditionally used to educate people by medical and allied health experts in the management of children with cystic fibrosis.

I envisage that the “Cystic Fibrosis Passport” will take the form of an informative booklet with an attached 20 minute DVD which will summarise the key concepts important in maintaining the health and well-being of young children with cystic fibrosis. The document is being drafted for comment and review by colleagues around Australia and overseas. Once the content is finalised, it is hoped that funding from Cystic Fibrosis Australia will allow the final document and DVD to be prepared for distribution. It is anticipated that once the booklet and DVD are launched, a study of its effectiveness in improving knowledge and care of children with cystic fibrosis will be undertaken. Ultimately, this resource is intended to improve the level of awareness of cystic fibrosis in Australia.
Executive Summary

Project: To develop a parent held educational manual, “The Cystic Fibrosis Passport”, for community members involved in the care and education of children with cystic fibrosis.

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Fellowship Highlights:

I had the opportunity to meet with world leaders in the clinical and research domains of paediatric respiratory medicine at six overseas centres who are actively involved in the management of children with the live-limiting genetic condition of cystic fibrosis. Professors Andrew Bush in London, Brigitte Fauroux in Paris, Larry Lands in Montreal, Jeff Wagoner and Frank Accurso in Denver provided me with tremendous insights into opportunities to develop my proposal for the community resource, the “CF passport”. Importantly, they each saw a role for such a document in their countries and have agreed to collaborate with me to translate the proposal from one of benefit here in Australia to one of international utility.

Conclusions:

With each visit I was able to glean much information from the staff and the families of children attending the clinics so as to gather a common approach to the shared problems of communicating the needs of young children with cystic fibrosis to the wider community. The issues are generic, but the existing resources available to improve community awareness are limited. International collaboration provides the expertise, resources and the means to meet the challenges of broadening community awareness of cystic fibrosis with Australia taking a leadership role in this endeavour. Funding from national [CF Australia] and international cystic fibrosis organisations [North American CF Foundation, Vaincre la Mucoviscidose: French CF Foundation] will be sought by our international collective working party to produce and distribute the “Cystic Fibrosis Passport”.
**Programme**

**Purpose of overseas travel**

The opportunity to travel to leading cystic fibrosis centres in Paris, London, Montreal, Baltimore and Denver afforded a wonderful opportunity to compare and contrast the philosophies of care and clinical practices in different cultural settings and health care settings. Australia is becoming more ethnically diverse and this is important in addressing the needs of children with life-limiting medical conditions.

Interestingly, through interviews with children and families in each of the countries that I visited, it became apparent that the fundamentals of care of children with cystic fibrosis, their needs and interest in the “Cystic Fibrosis Passport” as a vehicle to improve communications between health care and educational professionals were remarkably consistent. Consequently, many of the recommendations for content with regard to strategies for “Living with Cystic Fibrosis” rather than “Living in fear of Cystic Fibrosis” were provided spontaneously by families in different countries.

The care of children with cystic fibrosis is constantly being refined and the importance of this is that it will likely translate into improved quality of life and hopefully into increased longevity. One interesting contrast is the use of newborn screening to make the diagnosis of cystic fibrosis which has been available in New South Wales since 1981 [universally in Australia since the last state WA commenced in 2002] and has only been introduced nationwide in France and England in the last three years. Canada and America are yet to introduce nationwide screening, although America will have this in 2010 but there are no plans for screening to become uniform across Canada.

In each centre that I visited, I presented data on outcome measures of newborn screening in NSW over the first 15 years. The presentations were universally well received and provided the stimulus for much interesting discussion with members of the respective cystic fibrosis multidisciplinary teams. As with many such professional interactions with health care professionals, the Fellowship has provided the opportunity for a dynamic exchange of ideas and opinions which can only serve to improve the care of children with cystic fibrosis in all centres.
Whilst the diagnosis is made in the newborn period in the vast majority of cases where screening programmes exist, a cure for cystic fibrosis will not be available in the immediate future. Gene therapy is making slow progress and unlikely to be available for routine clinical use within the next 10 years, so cystic fibrosis will remain a clinical management challenge in the years ahead. This means that symptomatic care will remain the mainstay of therapy and improving the awareness of families and community members becomes the cornerstone of optimising outcomes for children with cystic fibrosis.

The Fellowship has provided me with the ability to compare how care has changed in Australia over the last 12 years whilst I have been in clinical practice directly with that in Montreal Canada where I undertook a post-doctoral Fellowship in Paediatric Respiratory Medicine from 1995-1997 at Montreal Children’s Hospital. This I feel was invaluable as it showed that similar clinical advances were being achieved in different populations, although the introduction of newborn screening in Canada is likely to further enhance the outcomes from a nutritional and respiratory perspective in the years ahead as we have documented here in New South Wales.

It is evident that whilst we as clinicians aim to provide a solid grounding in informing families about cystic fibrosis and its consequences which the families appreciate. Consistently, the families clearly felt that more was needed to improve understanding of cystic fibrosis through better education and communication at a day to day local community level between day-care centres, preschools, infants’ schools, community nurses and local medical practitioners.

**Fellowship preparation**

The Fellowship programme was designed to provide exposure to a range of clinical practices in leading paediatric cystic fibrosis centres in different countries with potentially differing clinical practices. It was prudent to visit countries who had adopted newborn screening for the diagnosis of cystic fibrosis and those who had not. The importance of newborn screening lies in the fact that the educational approach to a patient and family may differ for one who is essentially asymptomatic at the age of 4 to 6 weeks following a diagnosis on the basis of a newborn screening and one who is diagnosed on the basis of symptoms, typically recurrent chest infections and poor growth [Montreal, Province of Quebec in Canada].
In planning my itinerary for the Fellowship, the Cystic Fibrosis Centre Directors were contacted by myself and were most interested in the project. Of the seven centres contacted for submission of the proposal, six were visited as planned during the Fellowship trip. One centre that was originally planned in February 2008 was not visited and this was realised in September 2008, prior to leaving in November 2008. The Cystic Fibrosis clinic at Rotterdam Children’s Hospital in Holland which was willing to host a visit but the timing clashed with an invitation to present a plenary lecture at The French National Cystic Fibrosis Conference in Paris on our experience with Newborn Screening for Cystic Fibrosis in NSW over the last 25 years.

Consequently, the paediatric Cystic Fibrosis centres that I visited included:

- Hospital Armand Trousseau in Paris with Professor Brigitte Fauroux
- The Royal Brompton Hospital in London with Professor Andrew Bush
- Great Ormond Street Hospital in London with Dr Colin Wallis
- Montreal Children’s Hospital in Montreal, Quebec with Professor Larry Lands.
- Johns Hopkins Hospital in Baltimore, Maryland with Dr Peter Mogayzil.
- Denver Children’s Hospital in Denver, Colorado with Professors Jeff Wagoner and Frank Accurso.

Additional opportunities that arose:

- To give a 60 minute Plenary Lecture at the 2008 French National Cystic Fibrosis Conference on the Outcomes of Newborn Screening for Cystic Fibrosis after 15 years in NSW.
- Meeting with Dr Sophie Ravilly, Medical Director, Vaincre la Mucoviscidosis [French Cystic Fibrosis Foundation] to discuss educational strategies employed to disperse information about cystic fibrosis in the French community.
- To participate in the quarterly London Paediatric Respiratory Physicians Clinical Meeting at The Royal Brompton Hospital.
Existing educational strategies.

Timing of the diagnosis of cystic fibrosis.

Universally, initial education is directed at the families of children in whom the diagnosis of cystic fibrosis is made. For those born in countries which have newborn screening for cystic fibrosis, approximately 95% of cases are diagnosed by newborn screening. This occurs at around 6 weeks of age as the diagnosis uses blood from the newborn heel prick blood test together with an additional test [measurement of the concentration of salt in sweat: “Sweat test”] if needed. For those who have the diagnosis made on the basis of typical symptoms of poor growth and recurrent chest infections together with a diagnostic “Sweat test”, predominantly in countries which do not have newborn screening, the majority of these children are diagnosed in the first 12-18 months of life. However, in milder cases it is not uncommon to be diagnosed in later childhood and into adulthood.

Education at diagnosis.

The education of families is undertaken by members of the cystic fibrosis teams in large paediatric teaching hospitals. The approach is similar around the world with a layered presentation over days to weeks to give the families time to come to terms with the diagnosis of a life limiting condition, see the scope for improvement in health in those children with symptoms at diagnosis [non-newborn screening diagnoses] and provide a support network upon which the family can build their confidence in the management of their child’s condition. The confidence to manage the day to day issues in cystic fibrosis grows over weeks to months and is reinforced at regular scheduled appointments with members of the multidisciplinary cystic fibrosis team.

Integral to building the knowledge base of the families is the provision of written educational material from the individual cystic fibrosis clinic and national cystic fibrosis associations. The information reflects medical practices within the clinic, available resources within the community and provides families with helpful educational material about cystic fibrosis which can be shared with extended families and friends. Importantly, members of the cystic fibrosis team, generally nurses and physiotherapists, provide further education at home visits and if requested in community settings such as preschools and schools.
The level of education directed toward the child with cystic fibrosis will vary with age. The child is progressively involved in all educational discussions and engaged in an age appropriate manner. There is an expectation that as the child moves from childhood into adolescence they will assume greater responsibility for their treatments. By the time that they transition from care at a paediatric hospital to an adult hospital at age 16-18 years, they will be fully responsible for their therapies.

*Education for community professionals interacting with children who have cystic fibrosis.*

In contrast to family education, there was a consistent gap in the educational resources for people in the community, especially the need for a more integrated resource for the education of community contacts of young children with cystic fibrosis. Such a resource, held and distributed by the families of children with cystic fibrosis, would serve to supplement the direct education provided, generally as a one off visit, by cystic fibrosis nurses to community educational or health care professionals who were relatively unfamiliar with cystic fibrosis and its management.

**Main Body**

**Countries visited**

**France**

The Armand Trousseau Hospital is a large paediatric hospital in Paris with a multidisciplinary service for the care of children with cystic fibrosis. Here, they care for 150 children with cystic fibrosis, the majority of who were diagnosed on clinical grounds, prior to the introduction of newborn screening across France in 2005. The Head of Paediatric Respiratory Medicine is Professor Annick Clement and the Deputy Director is Professor Brigitte Fauroux, who undertakes the majority of clinical research in the department. Professor Fauroux is active in the fields of clinical studies in relation to physiology in cystic fibrosis, neuromuscular disease and sleep disordered breathing.

During my time at Armand Trousseau Hospital, I met with members of the cystic fibrosis team, discussed their approaches to education of families and members of the community with regard to cystic fibrosis, met with three children with cystic fibrosis and their families to discuss their views on how information could be better disseminated to help people in the community understand the
additional demands of care for young children with cystic fibrosis and its impact upon family
dynamics, mood, health and nutrition.

An important opportunity to liaise with other specialists, both working in the adult and paediatric cystic
fibrosis centres across France, was provided when I attended the two day 2008 French Annual Cystic
Fibrosis Conference as one of their three invited international speakers. I spoke on our experience with
newborn screening for cystic fibrosis which has demonstrated favourable outcomes with regard to
nutrition and respiratory function that have emerged from our cohort study. I was introduced to many
French specialists who shared their experience with the care of people with cystic fibrosis.

Following the second day of the conference, I arranged to meet with Dr Sophie Ravilly, the Medical
Director of the French Cystic Fibrosis Association. We discussed educational emphases within French
communities, the extent of community resources and the active role that the French Cystic Fibrosis
Association plays in promoting and funding research, patient advocacy and fund raising strategies. This
was a most interesting meeting which has provided me with some areas to consider for fundraising in
order to promote the implementation of the “Cystic Fibrosis Passport”.

England

During my second week, I visited two large hospitals in London with large cystic fibrosis clinics: The
Royal Brompton Hospital [RBH] and the Great Ormond Street Hospital [GOSH]. England as only
recently adopted newborn screening nationwide and its educational strategies are directed toward
children who are diagnosed both early in life with screening and those who present symptomatically at
an older age. I was fortunate to spend two days at each centre where I met members of the
multidisciplinary cystic fibrosis teams at their weekly team meetings, discussed their clinic’s structure,
met patients and their families to discuss their views on how strategies for educating members of the
community could be improved.

At the Royal Brompton Hospital, I met with Professor Andrew Bush and spent time with him in his
cystic fibrosis and general respiratory clinics. I met with the cystic fibrosis clinic co-ordinator, other
physicians, physiotherapists and the dietician. I was provided with a copy of the manual for the care of children with cystic fibrosis at the RBH, which quite was detailed in its approach.

I was fortunate to be invited to participate in the London Paediatric Respiratory Physicians’ quarterly meeting where I met other specialists from The Brompton, Great Ormond Street and Guy’s Hospital and we discussed clinical cases and cystic fibrosis airway clearance therapies.

Later in the week, I met with Dr Colin Wallis, head of Respiratory Medicine at GOSH, Dr Paul Aurora, transplant specialist and Dr David Kipling, sleep physician, attended clinical rounds and over lunch informally discussed their clinical expertise in cystic fibrosis and other respiratory disciplines. I presented work to the Great Ormond Street cystic fibrosis multidisciplinary team on the impact of newborn screening on our population and presented information about our cystic fibrosis clinic at The Children’s Hospital at Westmead in Sydney. Later, I met with Aamani Prasa, the cystic fibrosis clinic co-ordinator at GOSH, where they oversee the management of approximately 200 patients. I met also with Denise Smith, one of two clinical nurse specialists who undertake much of the education of families and community contacts of children with cystic fibrosis in schools and preschools.

Canada
During my third and fourth weeks of the Fellowship, I visited Montreal Children’s Hospital [MCH], a large teaching hospital catering for the bilingual Quebec population. At MCH, I met with Professor Larry Lands, Head of Paediatric Pulmonology, where we discussed the role of research in cystic fibrosis, his clinic’s current research focus in nutrition and oxidative stress, the common challenges of providing optimal care with limited staff, educational strategies in a smaller cystic fibrosis clinic with the demands of a bilingual society and limited educational literature in French. There is no newborn screening for cystic fibrosis in the province of Quebec.

During the course of the visit, I was provided with a workspace within the department which was instrumental to meeting with staff involved in the care of children with cystic fibrosis. I had a series of meetings with the staff in the cystic fibrosis clinic which provided a wealth of information for the “Cystic Fibrosis Passport”.

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During my meeting with Mabel Gaul, CF clinic co-ordinator, I discussed the challenges of meeting the psychological needs of children with cystic fibrosis and their families, something that she and a hospital psychologist attached to the cystic fibrosis team, found most challenging. They were surprised that we did not also have a psychologist attached to our team, given that they have a clinic of 80 patients and the clinic where I work has 300 patients! Further discussion centred upon educational strategies used in Montreal, linguistic barriers, differing strategies to French Canadian as opposed to Anglo-Canadian families, resources available, role and effectiveness of websites and written material as well as the optimal use of community health care centres to support their cystic fibrosis patients.

Subsequently, I met with Helen Magdalinos, Child Life therapist at MCH. Her role is similar to a recreational/play therapist with a background Arts degree in education or psychology. Helen works part-time with children who have cystic fibrosis, as well as with children admitted to hospital with trauma and general surgical patients. Helen attends outpatient clinics, and follows CF inpatients, providing distraction therapies and comforting techniques for children and their families. Through building trust with the children, it is a useful and non-threatening way to open up communication lines with families, gain insights into background problems and share concerns that the children and families may have with the broader cystic fibrosis team. An interesting educational strategy that Helen has used with hospital inpatients to explore the child’s level of understanding of cystic fibrosis is a written journal about chronic illness. However, I was particularly impressed with the “Beads of courage” reward scheme, helping children to grow in confidence in undertaking and understanding their condition. With each of 25 physician nominated goals, children acquire a bead which will contribute to a necklace, which is begun from the time of diagnosis and added to at each clinic visit. This was based on a successful programme in oncology patients that was pioneered in the United States. Each time a child [family] achieves a pre-determined goal [eg swallowing enzyme capsules whole], they are rewarded with a bead. Whilst the goals are agreed upon by the CF team, there is some discretionary capacity. The necklaces come to clinic and children are proud of them. They can be used in discussion, for show and tell days at school and demonstrate pride in achieving goals in their understanding and management of CF. They are popular with boys and girls alike up to about 10 years of age for both sexes, and for a few years more with the early teenage girls.
On Wednesday Dec 17th, I met with CF clinic multidisciplinary team at MCH and gave a presentation on our cystic fibrosis clinic at the Children’s Hospital at Westmead. Following this, a ninety minute workshop on the proposed content of the “Cystic Fibrosis Passport” was undertaken. The discussion about content for the “Cystic Fibrosis Passport” yielded many helpful suggestions about structure and content which will be incorporated. The intention has become more than just a complementary educational aid for Sydney and Australia, but one that may be of use in a range of countries.

I met with Lynn Kiraly-Batist, the librarian who runs the MCH Family Resource Library. This service was developed in the 1990s and expanded from 2002 by Lynn, as an educational resource for staff, families and patients wanting to access more information about medical conditions. It is located on the 5th floor, adjacent to the Child Life Dept, and contains a library of over 1000 books for children and adults, four computers, an impressive website [www.mchfamilylibrary.ca], several reading areas and play areas for children who seek time to relax here. The service is funded by the hospital and hospital auxiliary.

During a meeting with Donna Drury, a paediatric dietician with over 20 years experience in caring for children with cystic fibrosis we discussed resources that were developed in Montreal and by dietetics colleagues across Canada and printed by the Canadian Cystic Fibrosis Foundation. Many helpful examples were discussed and copies were provided. There were many similarities in the key messages that were evident in the documents. These will be incorporated in the dietetics section of the “Cystic Fibrosis Passport”.

USA
Johns Hopkins Hospital, Baltimore.
I had the opportunity to visit Dr Peter Mogayzil, Director of the Cystic Fibrosis Clinic at Johns Hopkins Hospital in Baltimore, Maryland. The paediatric clinic has 275 patients, the majority of whom were diagnosed before the introduction of newborn screening in 2006, cared for by nine respiratory paediatricians who jointly manage the care of patients in the outpatient and inpatient settings. Interestingly, the introduction of screening prompted clinic staff to increase from two to three weekly
clinics and review their educational approaches toward the families and doctors who jointly care for the CF patients. The clinic has embraced, through generous donated funds and the support of the Johns Hopkins Hospital administration, a useful web based educational strategy for 3000 medical practitioners regarding CF with bi-monthly themed journal article reviews written by external experts on topics such as newborn screening and nebulized antibiotics.

Interestingly, whilst the clinic has well written documents it has developed and information from the US Cystic Fibrosis Foundation for its families, Dr Mogayzil lamented a similar lack of resources for community members who have close contact with young children with cystic fibrosis. The only such community resources used at the Johns Hopkins Clinic included two small booklets for school teachers and day care centres which contained more generic information about CF rather than specific recommendations for optimizing the care of children with CF. These small booklets were developed elsewhere in America and sponsored by pharmaceutical companies.

The outpatient CF clinic is conducted on three half days weekly in a recently purpose built outpatient and medical office facility with its own x-ray facilities, blood collection service, lung function laboratory and individual rooms for patients. During a tour of the impressive facilities at Johns Hopkins Hospital, I was struck with the existing resources which included a 7 bed inpatient clinical trials unit, a 45 bed neonatal intensive care unit, a 25 bed paediatric intensive care unit and many single rooms on each of the wards. However, the opening of the new paediatric wing in 2011 will feature single rooms for all 250 paediatric inpatients: an unprecedented initiative which one could not foresee in the Australian health care system.

The Children’s Hospital Denver, Colorado.

The Children’s Hospital in Denver has the second largest cystic fibrosis clinic in the United States with 600 patients. Of these, approximately 70% reside outside the state of Colorado. They were one of the original three states in the USA to introduce newborn screening in 1977, which will become universal in America in 2010. The CF clinic here is internationally recognised as a leading centre for research and clinical practice. The US 550 million dollar hospital is 16 months old and the facilities are state of the art with all 270 beds in the hospital being single rooms with ample space for parents to stay,
wireless internet, large flat screen televisions, bathroom and shower facilities and desk-space. Similarly, the outpatient clinic is large with ample rooms for children to be seen in the five half day clinics that are run weekly. Additional outreach clinics in the neighbouring state of Montana are run quarterly.

The paediatric respiratory service is built around an academic model with all fourteen clinical staff having University appointments at the University of Colorado. As such, the scientific rigour with which medicine is approached is impressive both for the 40 research studies that are underway at the centre and in the practice of clinical medicine. This can be seen in their educational approach to both newly diagnosed patients and long term patients. There are six physicians who undertake the majority of the outpatient clinical care and all fourteen physicians are involved in the hospital based care of children with CF. The multidisciplinary team contributed to an industry sponsored informative DVD for families with CF that is used in many other centres in the USA. This is given to the families of newly diagnosed children with CF in addition to the widely used [in the USA] book for newly diagnosed patients written by Professor Lyn Taussig which is distributed by the North American CF Foundation. Of note, as the hospital has an electronic medical record, communication between involved physicians and allied health professionals is comprehensive as written communication is generated at the time of consultation for both families and involved health care professionals to reinforce the management plan following the review in the outpatient clinic.

During my visit I was able to meet with Professors Jeff Wagener and Frank Accurso and Drs Scott Sagel and Edith Zemanick who supervise the majority of the CF outpatients. I also spent time with Churee Pardee the Research Co-ordinator, Rosalie Bush the CF clinic co-ordinator for over 20 years as well as staff members from dietetics and respiratory therapy [equivalent to physiotherapy in Australia]. The combined experience within the clinic was impressive and reassuring as the majority of the clinical practices described and witnessed by myself in clinics were very similar to our practices at the Children’s Hospital at Westmead.

Again, an agreed gap in the community resources was additional information for educational professionals and community nurses and general practitioners beyond two small brochures provided by
industry sponsored groups that were also used at Johns Hopkins Hospital. There was universal agreement that more information was required and that the medical and allied health staff would be happy to work collaboratively to develop the “CF Passport” for use in their clinic and potentially elsewhere in the USA.

**International collaboration.**

1. After visiting six Cystic Fibrosis Centres in France, England, Canada and the United States of America there is an agreed need to create the CF Passport.

2. Similar educational messages are used across the world. All centres saw the CF Passport as having utility for their community in improving their understanding of the care needed for young children with cystic fibrosis.

3. Willingness to collaborate in preparing and reviewing the document. Medical and allied health staff in each of the centres have agreed to assist in reviewing the document that I will create. Previously, I have spoken with colleagues in Australia who will also comment on the draft of the CF Passport. This will occur before the peer-reviewed final document is used as the basis for an accompanying DVD which will be developed by staff and patients of the CF clinic at The Children’s Hospital at Westmead in Sydney.

**Implementation strategy.**

1. Funding. Financial support will be sought from Australian and international organisations to produce the CF Passport as a booklet and DVD.

2. Assessment of the usefulness of the CF Passport. As part of the implementation strategy, a before and after questionnaire will be developed to determine if the key messages of the CF passport have been successfully communicated. This will involve people completing a five minute, 1 page questionnaire related to their knowledge of CF immediately and after reading the booklet and / or viewing the DVD. This may be arranged via a website or the more traditional paper and return mail method.
Conclusions

I am indebted to the Winston Churchill Memorial Trust of Australia for this opportunity to travel, learn from the experience of others caring for children with cystic fibrosis and develop the *Cystic Fibrosis Passport*. I have little doubt that the final product will be considerably better than I could have imagined because of the opportunity to liaise face to face with clinicians and their patients and families all over the world. In addition, I feel certain that what I have witnessed first hand in the six centres will have a lasting effect on my clinical practice, further my association with the centres that I have visited and assist in promoting the role of Australia in the care of children with cystic fibrosis.

Recommendations

1. Through the development and distribution of the parent held resource [“CF Passport”], I hope to improve the knowledge base of community members who come in regular contact with young children with cystic fibrosis living in Australia. These are key members of society who will be able to develop their understanding of cystic fibrosis and thereby improve the care of these children outside the home setting.

2. The “CF Passport” will be a useful resource provided by state based and national CF organisations free of charge to families of children with cystic fibrosis. The costs of its implementation will be met through fundraising efforts of CF organisations.

3. The “CF Passport” would be part of a commitment to build community awareness of CF by expanding existing educational strategies of CF organisations that have predominantly focussed on family educational strategies.

4. Ideally, the “CF Passport” could be launched at the Australian National CF Conference in Brisbane in August 2009.

Dominic Fitzgerald.