Breathing Fresh Air into the System

The Adult Cystic Fibrosis Patient Advisory Committee and the Adult Cystic Fibrosis Team working together to achieve meaningful change

Douglas Porter

- Born in 1969
- I was born with Cystic Fibrosis
- Life expectancy was around 13 years of age
- Currently live in Buderim with my wife and youngest daughter (14 years)
- Recently retired after working 26 years as a Pharmacist in Hospital and Community settings throughout QLD
- I am a passionate advocate for Consumers particularly those with a chronic illness and currently serve on about 5 HHS committees and the HCQ Collaborative.
- I only have 30% predicted FEV1% and I am in transition period waiting for possible lung transplantation assessment (although I am continuing to push on as long as I can with my original lungs)

What is Cystic Fibrosis?

- Most common life threatening genetic condition in Australia
- Affects all organs but principally lungs, sinuses, pancreas and digestion
- Due to improved medication and treatment average life expectancy has increased to 38yrs
- CFTR gene discovered in 1989 still no cure (getting close). There are well over 2000 different mutations of CF gene
- Most CF patients die from lung failure
- Adults (>18 yrs) are now approximately 50% of the CF population
- TPCH Adult CF Centre treats approx. 360 patients from throughout QLD .This number will increase dramatically which is why I am talking to you today about consumers assisting the drive for change
- Many patients spend 2-4 weeks at a time several times a year in Hospital
- Double Lung transplant is usually the last chance at survival for many CF patients.
- TPCH currently perform approx. 50 Double Lung Transplant per year.

2012 Peer Review of TPCH Adult CF Centre

- Cystic Fibrosis Australia funded a Peer Review Panel in 2012.
- Peer review findings highlighted dangers of Cross infection between CF patients
- These findings along with results from research done by Professor Scott Bell and Team helped us establish the new ACFC ward at TPCH
- One of the recommendations from the review led to the formation of a Patient Advisory Committee

Committee Selection March 2013

- The CF Team mailed Patients a flyer inviting them to express their interest in joining
- Those who had previously suggested service improvements at the hospital and previous patient consumer representatives from CFQ were encouraged to apply
- Representation from the following interest groups was sought and achieved
- Regional patients, Younger (<30 yrs) and older (>30 yrs) patients, Patients in the Workforce, Patients who are parents, Both genders

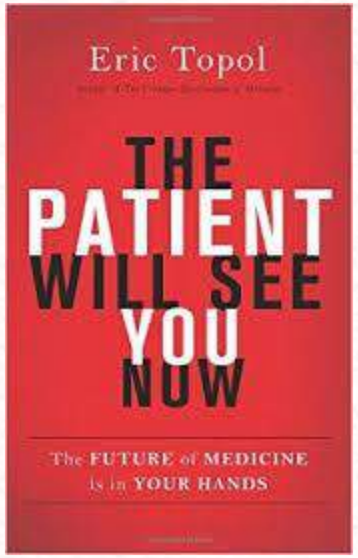
ADULT
CYSTIC FIBROSIS
PATIENT ADVISORY GROUP
ADULTCFPAG
THE PRINCE CHARLES HOSPITAL
BRISBANE, QLD

Committee Selection March 2013

- At the time we were the first CF Patient Advisory Committee in Australia.
- Meetings are held on a two monthly basis by either video or teleconference
- Medical, nursing and social work representatives attend regularly, with additional allied health staff attending as required.
- I have chaired the committee and run the meetings and with staff approval we have led the development of guidelines for selection of new committee members over the last three years.

CF Patient Advisory Committee Visions

- To set up frameworks whereby CF Patients can gain the ability to take control of their own health.
- This will give them the confidence to suggest any facility or service improvements that will lead to a better quality of life for them and their fellow patients. It also will improve their health literacy
- In 2013 through TPCH Foundation Research it was proven that Cross Infection between patients was a major threat to CF life expectancy
- Our committee would over the coming months become heavily involved in the formation of a new specialised CF Centre at TPCH with single room accommodation for inpatients



Driving better outcomes as a patient group

- Despite their poor health CFPAC Committee members have become advocates for their fellow patients by involvement in other HHS Committees.
- CFPAC has many ideas on implementing peer support services through WiFi internet programs. This is our only safe method of communication amongst ourselves.
- Funding its own Internet system within the Hospital if approved and if necessary through patient donation and funded Grants.
- Ultimate goal is high speed fibre optic solution with high speed upload and download
- CF Patients spend large periods of their lives in Hospital and are kept in isolation from their fellow patients by Cross Infection protocols. Loneliness and Depression is common
- Having a connection to the outside world online enables the patients to operate online businesses and communicate with loved ones who often find it difficult to visit them.

Driving better outcomes as a patient group

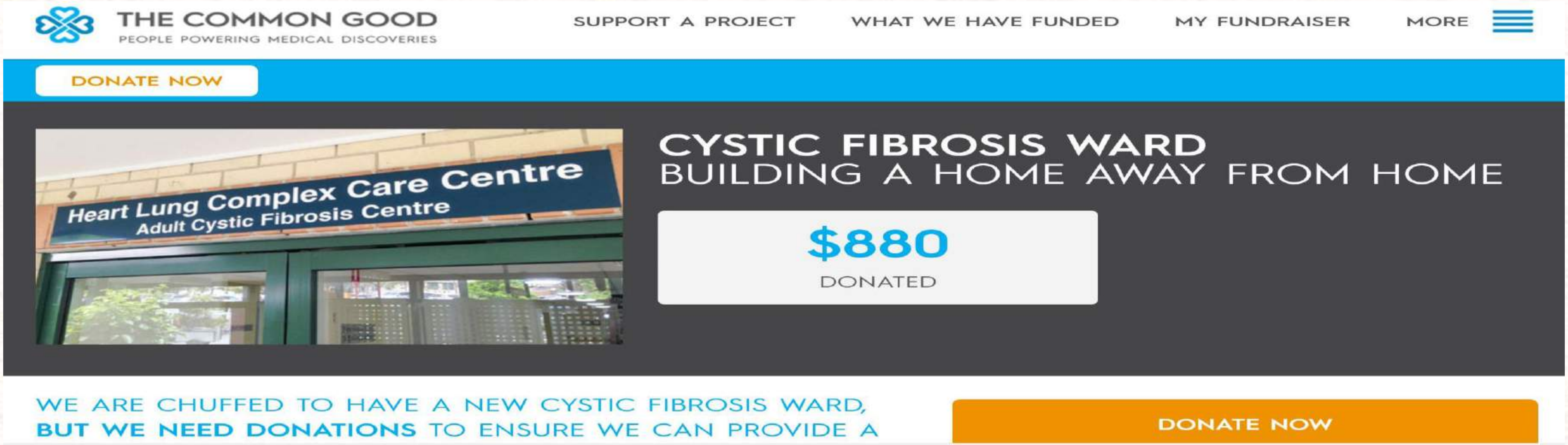
- To date we have had extraordinary Assistance in our approaches for further improvements by the CF Medical Team, TPCH Executive, TPCH Foundation, Metro North HHS and Members of Parliament.
- Recently assessed for inclusion in pilot study for Guest WiFi at QLD State Hospitals. I have constantly pushed for this to happen over the last two years at all levels of Qld Health and eventually gained some traction with the idea.
- Publicity through TV and many public speaking engagements
- I have lobbied wherever anyone would listen to me for a wifi solution and eventually seem to be getting somewhere
- This will be a big win for ALL patients

Outcomes Achieved

- Pivotal consumer role in opening of new Adult Cystic Fibrosis Centre with single room accommodation
- Positive feedback and resolution of clinical issues for the last 3 years
- Successful liaison with the hospital executive regarding internet access and successful lobbying with TPCH and MNHHS to be accepted as suitable site for pilot study
- Establishment of CFPAC Facebook page, contact email account, website, logo, tax deductible fundraising account and mailing lists for campaign equipment funding
- $40,000 raised for outfit of New Ward including purchase of white goods, exercise equipment and some specialised breathing apparatus.

Outcomes achieved

- Established relationship with TPCH Foundation for fundraising capital administration at no cost to PAC



CYSTIC FIBROSIS WARD
BUILDING A HOME AWAY FROM HOME

$880
DONATED

WE ARE CHUFFED TO HAVE A NEW CYSTIC FIBROSIS WARD, **BUT WE NEED DONATIONS** TO ENSURE WE CAN PROVIDE A

Outcomes Achieved

- Two Committee members on the TPCH Consumer Advisory Network and representation throughout other MNHHS Committees
- Donation to other charities to assist purchase of Capsule sliders for CF Patients (adult and child)
- Current plans to purchase more Breathing apparatus like my Airvo and Portable Oxygen concentrators through private funding applications via grants or community organisations like Rotary/Lions clubs
- Constantly asked for new equipment and facilities by patients and staff

Should I get involved? and how can I affect change?

- The Patient Advisory Committee is an important component of the Adult Cystic Fibrosis Teams longstanding commitment to continuous improvements in patient care.

- When I first became involved in working as a consumer representative it happened by accident. I actually wrote a letter to my Doctor asking his advice as I had begun to notice the effects of cross infections between patients and myself. From there my letter was passed on to Administration Executive at the TPCH and I was invited to be on the CFPAC.

- Initially I just wanted to take control of my own health situation to make sure I was safe whilst in Hospital

How can I affect change and make a difference?

- From here I expressed an interest to do more one day at a Hospital Function and before you know I am on several committees and working on the HCQ Collaborative.
- I am hopefully all about getting things to happen and believe that if you are going to do something then do it properly. I'm not really into talk fests.
- Don't be shy about becoming involved. Our committee has been responsible for giving me the confidence to speak up about suggesting change.
- Probably the best advice to fellow advocates is to be persistent but be PATIENT. But most of all believe in what you say and speak from the heart. Don't be afraid to ask questions and work respectfully within existing boundaries and you TOO can make meaningful change.
- These days all HHS services are receptive to consumer involvement through Consumer Liaison Coordinators who will assist you in orientation to your role , whatever that may be. Don't be shy coming forward.

My Reason for Driving Change

DUM SPIRO SPERO
While I breathe I hope

Thank you for listening