May is Cystic Fibrosis Awareness Month

Ian Paterson

Over many years as a teacher and educational leader I have often come across situations which impacted on my emotions, motivation and feelings much more than just stimulating my growing interest in quality learning and how to become an effective teacher. Three significant examples from my days in schools immediately come to mind: (a) supporting the Guide Dogs Association of NSW/ACT following wonderful talks by their representatives, knowing the school had students who were partially sighted; (b) facilitating the Salvation Army appeals with student doorknocking; and (c) Year 12 donating blood as part of their welfare program in the final months of their public high school experience. (Sadly all of these learning and values-based activities get too little recognition as part of our wonderful public schools role. I am frequently reminded of their importance in retirement and as I move about the community.)

Recently when I contacted Brian Ralph about Cystic Fibrosis, I was aware that May is deemed the **Cystic Fibrosis Awareness Month** and thought that maybe my retired colleagues could assist in a fundraising charity run to be held over the long weekend in June this year (Sunday 13 June 2021). I currently assist with HSC Mentoring at Endeavour Sports High School where the excellent Principal James Kozlowski has organised an 'army' of runners to raise funds to support further research into cures for Cystic Fibrosis, which his niece has been battling since birth. James in fact is an Ambassador for the Cure4 Cystic Fibrosis Foundation which he manages to fit in amongst his amazing work leading a large co-educational sports high school. *(Please see page 2 for some information James sent out recently to his running group.)*

Cystic Fibrosis is a progressive, genetic disease that causes persistent lung infections and limits the ability to breathe over time. It also can affect the pancreas, liver or intestines. Further, Cystic Fibrosis affects the cells that produce sweat, mucus and digestive enzymes where normally these secreted fluids are thin and smooth like olive oil.

There have been dramatic improvements since the 1950s when a child with CF rarely lived long enough to attend high school. Symptoms vary from individual to individual but typically a child each day will complete a combination of the following therapies: airway clearance to help loosen and get rid of the thick mucus; inhalation of medicine to open the airways or thin the mucus; pancreatic enzyme supplement capsules to improve the absorption of vital nutrients; and an individualised fitness plan to help improve energy, lung function and overall health. Further medications can target specific conditions and the current research into CF is so vital to solving specific issues, as well as attacking more generalised patterns in the disease's impacts.

The implications for a young family are obvious from the above simplified explanation of the disease and so any breakthrough research to lessen the disease and its obligations for family and carers is a logical target for improved lifestyle and wellbeing for child and family alike.

On Sunday 13 June James has organised a large group of runners to tackle a half marathon, or shorter runs, to raise funds for research into Cystic Fibrosis. I would be grateful if you could support me in participating in such a fun run. The link for supporting the funding process is:

https://the-endeavour-cure4cf-army.raisely.com/ian-paterson

With all my best wishes and thank you very much. Please also see James' info about CF below.

A message from James Kozlowski, Principal, Endeavor Sports High School

Why do we need a cure for CF? This is my friend & CF Warrior - Olivia Wood. Her CF journey is below.

Olivia is only 21. She's currently in hospital for another two-week stint in Westmead to treat a lung infection. She'd only finished a previous two-week stint for another infection a month ago. Her lung function on the previous occasion had got down to 20%. Even when she is well her lung function is not much more than double that. She has a portacath inserted as this allows for long-term, frequent intravenous antibiotic treatment and to take samples. Olivia also takes medication which allows her to digest her food - CF often affects many other organs - and she undertakes daily physiotherapy to try to move the mucous in her lungs. Two years ago she was placed on the lung transplant list. As a result, she became eligible for a drug - on compassionate grounds - called Trikafta that currently costs $300,000 per year. Trikafta is a great drug but you can see from my first few sentences that Trikafta is far from a cure. At 21 the impact of her CF means that she can't hold down a full-time job as she has regular hospital admissions which she refers to as a 'tune-up'. Despite all of this, she is one of the happiest and most positive people I know. I find her incredibly inspiring and I want to see her cured of CF. The only way this will happen is through research. Research like the gene therapy that Cure4CF most recently funded being undertaken by Associate Professor Leszek Lisowski at Sydney University.

This is why your involvement in this event means so much to me and those with CF like Olivia and my niece. THANK YOU!!!

Contributor details

Ian Paterson (ian.paterson31@gmail.com) 20/5/21

Ian was Principal at Homebush Boys High School (1999-2010) and since retirement has been a Tertiary Mentor at Sydney University, consultant to several schools on curriculum change and mentor of HSC students. His personal interests include travel, reading, watching sport plus swimming, yoga and jogging at a ‘comfortable’ pace.