

EDITION TWO 2015

RED

magazine



IN THIS ISSUE
FINANCES -
GETTING YOUR
HOUSE IN ORDER



What's happening in the world of Cystic Fibrosis Western Australia

Planning your financial future has never been more important.

DEADLINE FOR NEXT ISSUE

If you would like to contribute to our next issue, please contact us before Friday, 3 July.

DO WE HAVE YOUR CORRECT DETAILS?

If not, please let us know so we can keep you informed.

DISCLAIMER

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ON THE COVER

The Community Newspaper HBF Rotto Swim Team contemplate the challenge and raising funds for cystic fibrosis.

There was a time when the last thing on the minds of young adults living with CF were financial planning and superannuation. Thanks to better early diagnosis and aggressive interventions, a child born today can well expect to live into their fifties. We hope that within the next few years, life expectancy will continue to increase to a point where lives are truly unaffected by CF and buying a house, raising a family and retirement are totally achievable goals.

This hope was encapsulated in a joint presentation by CF researchers at the Telethon Kids Institute (TKI) and CFWA on 4th March this year. This is summarised in an article in this edition which links to a six-part series on YouTube.

The AREST-CF team of researchers at TKI includes a psychosocial researcher who is currently looking at the psychosocial impact on the health outcomes of children living with CF and, of course, the cost of living with a chronic degenerative disease is part of that.

So in this edition of RED Magazine we have looked at planning our futures and what concessions and subsidies are available to ease the financial burden of living with CF.

We also announce the awarding of a new 5-year contract to CFWA which



Nigel Barker, CEO

will allow for the continuation of Comprehensive Home Care services enabling these services to be provided free-of-charge to people living with CF.

As always, we feature one of our top supporters. In this edition we profile WAFEX who, for 6 years now, have supported our 65 Roses month. This year, we plan to wrap and sell 6,500 roses on the last Friday of May, so if you are keen to take a bucket to work or help the team of volunteers prepare them on the Thursday prior, then please let us know.

Let's paint the streets of Perth with a carpet of colour to raise awareness and funds for CFWA!

Nigel

Note from Editor

In the first edition of RED for 2015, an unedited version of the Holly Ralph interview was published in error. RED apologies for any offence this may have caused

RED NEXT EDITION - CROSS INFECTION - AVOIDING THE NASTIES

If you would like to contribute to the next edition of RED using the theme above please email marketing@cysticfibrosiswa.org for additional information

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CFA Update

The CFA Board recently announced the appointment of Ms Annette (Nettie) Burke as Chief Executive Officer (CEO) of CF Australia.

Nettie's previous experiences include Director – Health Services for Maximus Inc, CEO of Arthritis NSW, Executive Leader, Marketing and Communication at Ability Options and Director, Marketing and Communication at the National Breast Cancer Foundation.

In addition to her NFP experience, Nettie brings to CFA significant corporate sector experience at a senior level. With a strong background in advertising, marketing and communications, Nettie has managed significant P & L responsibilities, has reported directly to boards for over 15 years and has the financial and operational management abilities that will be necessary to take CFA forward.

As CFA welcomes their new CEO, the CFA Board has made special thanks to Simon Martin who has been the interim CFA CEO. Simon stepped into the role at CFA Board's request late last year, and has far exceeded expectations.

The Federation expresses it's deep appreciation for Simon's efforts and achievements.

Simon will resume his position on the CFWA Board in May.

Nettie will take up her position on Tuesday, 7 April, 2015.

Ms Annet Burke, Cheif Executive Officer (CEO) of CF Australia



An Evening With CF Scientists

On 4th of March this year, the AREST-CF Team and CFWA presented an annual update on CF Research at the Telethon Kids Institute in Perth.

Nearly 100 people were present and the air was electric with hope and excitement. The presentations were videoed and the 6 sessions can now be viewed online.

The evening was opened by Professor Johnathon Carapetis, Head of the Telethon Kids Institute (TKI), who described the Australian Respiratory Early Surveillance Team for Cystic Fibrosis (known by its acronym AREST-CF) as being one of the Institute's showcase research projects. Their research was widely regarded as leading the world.

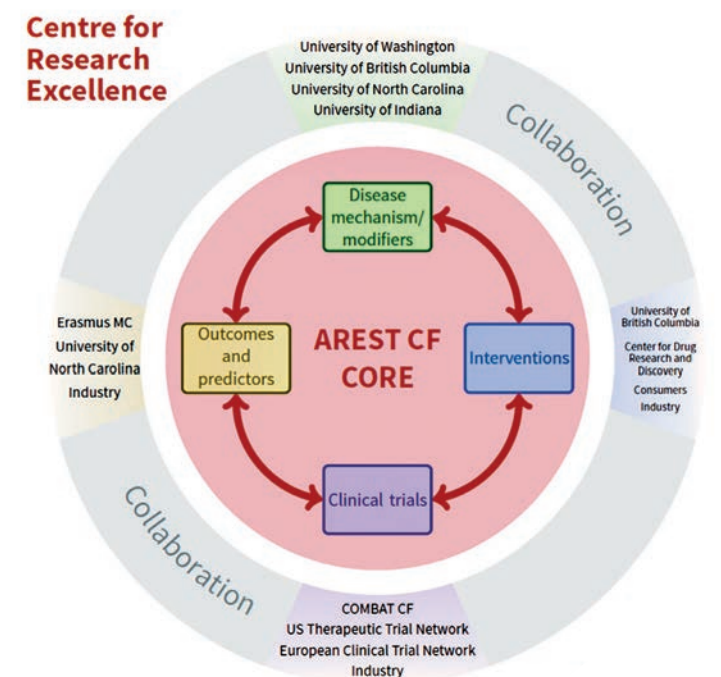
The lead clinician, Professor Stephen Stick, gave an overview of the team's work and explained that this centred on the knowledge that when a child with CF is born, their lungs are clear and normal. The challenge that researchers then faced was how to detect and measure early changes and delay or prevent the onset of lung disease and its associated structural damage; basically to keep young lungs healthy longer.

Their research recognised not only the importance of medical investigation and intervention, but also the impact of psychosocial factors in disease outcomes.

By delaying or preventing early lung damage the team hopes to add at least

20 years to average life expectancy at birth within the next five years, and good years, too.

To address this challenge, Professor Stick explained that he and his colleagues had developed a model which comprises four teams: an outcomes and predictors team, a disease mechanism/modifiers team, an interventions team and a clinical trials team, as shown in the diagram below. These teams within AREST-CF do not act in isolation and have active international collaborations with world leaders in their fields.





Videos can be viewed at <http://goo.gl/OJOzXK>

Of particular importance in this program he said, has been the strong linkage between the researchers and the patients. Nearly half of the researchers on the AREST-CF team are clinicians. This means that the results of the research are immediately transferrable to the ward, a unique and highly beneficial situation and a key aim of Professor Carapetis for research conducted at TKI.

Professor Stick went on to explain how AREST-CF had now collected over 5 years of longitudinal data through lung function testing, bronchoalveolar lavage, chest CT scans, epithelial samples and lately, psychosocial and quality of life measures. Stored data is unidentifiable to safeguard patient anonymity and is available on request to CF researchers, not only here in Australia, but around the world, benefitting CF research globally.

Over the past five years it (AREST-CF) has become recognised as the world leader in paediatric CF research and now has 5 years of longitudinal data. With additional funding and support, the number of publications has grown from an average of just over 8 a year from 2005 to 2012, to 26 in 2014 alone, with citations growing from just 20 in 2009, to over 220 in 2014.

"The novel approach [of AREST-CF] ... has led to a paradigm shift in our current understanding of early lung disease. The AREST-CF data challenge the clinician to a more proactive approach, in which we identify disease, treat earlier, and potentially change the disease trajectory."

New England Journal of Medicine, 2013

"The AREST-CF group has made tremendous progress in moving the field forward, for which the CF community is very grateful"

American Journal of Respiratory and Critical Care Medicine, 2014

SO WHAT HAVE THEY DONE? WHAT DID THEY FIND? AND WHAT DOES IT MEAN?

Disease Mechanisms and Modifiers Team

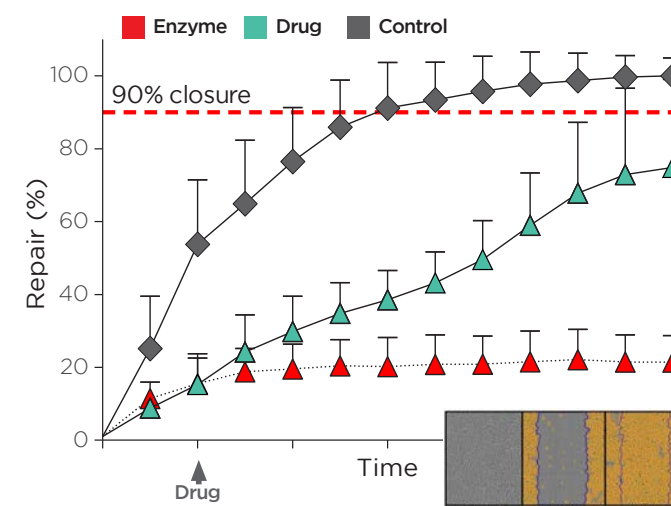
The research into disease mechanisms and modifiers is looking at what happens to the structure of lungs in children with CF, what infections they get and what problems this causes in later life. It aims to see how modifiers alter the trajectory (advancement) of the disease.

In late 2013, the leading medical journal, New England Journal of Medicine, published the pivotal discovery by AREST-CF that neutrophil elastase, an enzyme produced by the body's own immune system to kill bacteria, is the most significant predictor of bronchiectasis by 3 years of age.

Luke Garratt one of CFWA's PhD Top Up Scholars presented the results of his research, which is focused on establishing the mechanism by which neutrophil elastase damages the lung. AREST-CF is one of a few groups in the world who are able to grow airway cells from young children with CF in the lab and investigate their responses to bacteria, injury and drugs. Luke explained that when neutrophil elastase was present, his research in the lab showed that epithelial lung

cells couldn't proliferate, couldn't maintain a strong barrier and were unable to repair adequately after injury.

This suggests that neutrophil elastase prevents the lung tissue from repairing and over time airways gradually weaken. However, when he applied a drug to neutralise or reduce the effect of this enzyme, the percentage of repair within 72 hours was dramatically increased. This is summarised in the graph below.



This provided important evidence that therapies targeting elastase levels in the lung during early CF could further limit bronchiectasis and lung damage, complementing the current therapies of antibiotics, physiotherapy and other drugs.

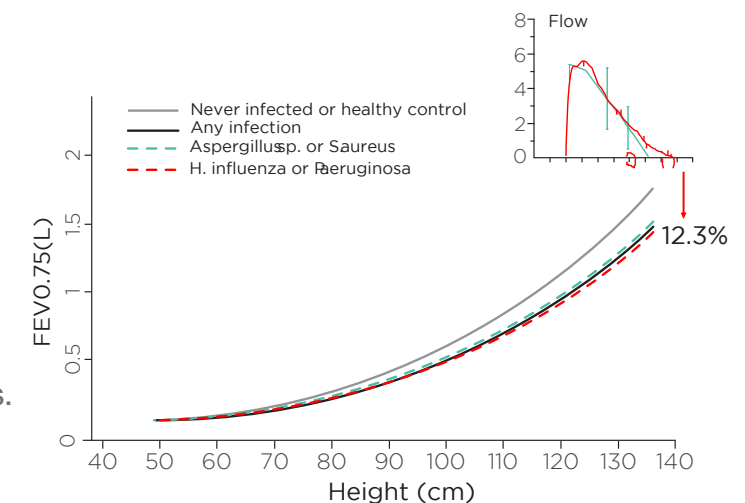
Outcomes and Predictors Team

The Outcomes and Predictors Team aims to come up with a set of predictors that can tell us how well children are progressing; for example, predict how a child will be at 1 year old based upon how they are at 3 months. This will enable the team to assess risk and plan intervention strategies to alter the trajectory of the disease.

Professor Graham Hall presented his

research which looked at 68 infants with CF and 48 without CF, who were followed up at 4 to 7 years. After 7 years, 56 of the original 68 infants with CF continued with the research and 18 of the control group continued. For each infant, they tracked lung function and infections throughout the child's life.

Professor Hall's research showed that children with CF who had never been infected with *Aspergillus* species, *Staphylococcus aureus*, *Haemophilus influenza* or *Pseudomonas aeruginosa*, had the same lung function as children without CF, whereas children with CF who had experienced one of these infections in early life experienced a 12.3% decline in lung function as measured by an FEV0.75 by the age of 7. Early deficits in lung function are significant because they typically continue into adolescent and adult life.



In summary, inflammation of the lungs during infancy was reflected in lower lung function, whilst infection resulted in an even greater rate of decline in lung function. This research further highlights the benefits that can be achieved by close monitoring and intervention during the first years of life.



Videos can be viewed at <http://goo.gl/0JOzXK>

Clinicians around the world have recognised that the results of this research will have profound implications for the early and aggressive treatment of CF during infancy.

Editorial:
American Journal of Respiratory and Critical Care Medicine, 2014

Narrowing in on Early Cystic Fibrosis Lung Disease

‘The clinical implications of this study are profound. These results strongly support early, aggressive management of airway infection and inflammation in the first 2 years of life, an approach that could result in a long-term effect on lung health.’

Clinical Trials Team

The Clinical Trials Team have led the world in designing and implementing clinical trials in children under 6 years of age. Tim Rosenow, the CFWA Lung Distance Runners PhD Top Up Scholar recipient, has recently (10th March 2015) had his research paper accepted by the most highly rated respiratory journal, the American Journal of Respiratory and Critical Care Medicine.

Tim, in collaboration with Professor Harm Tiddens in Rotterdam, explained how he had developed a new way of looking at and measuring airway disease in children under the age of 6 using chest CT scans. They called this PRAGMA-CF (Perth-Rotterdam Annotated Grid Morphometric Analysis for CF)

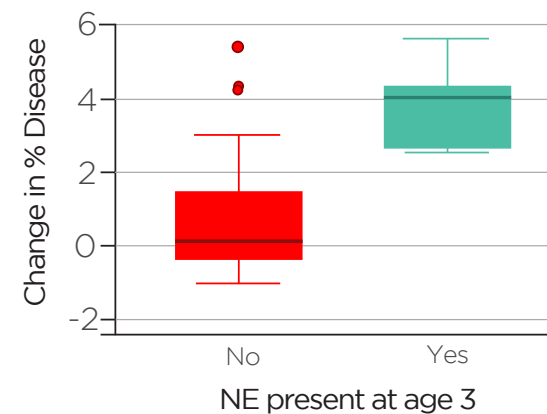
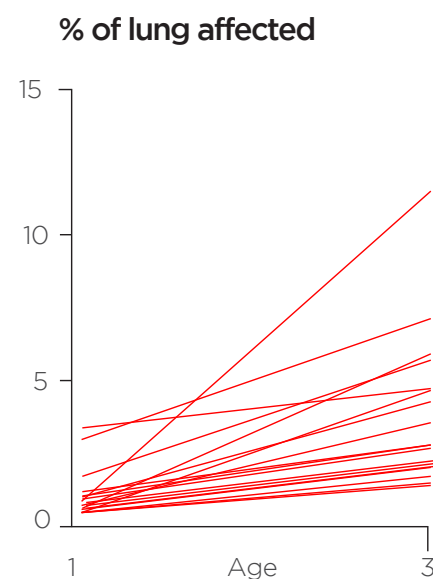
The team is the first team to look at detecting these changes in children just a few months old, changes which are potentially reversible when found early.

Tim explained that CT is the gold standard for detecting structural changes in infants with CF as many of these structural changes do not show up in the traditional lung function measurements until the disease has progressed in later life.

The PRAGMA-CF technique uses CT to take 10 ‘virtual slices’ of the lungs, on which it overlays a grid to enable accurate measurement of bronchiectasis, mucous plugging, trapped air and other airway abnormalities.

Tim found that he was able to track very small percentage changes over the first 3 years of life which had hitherto gone undetected. The separate proportions of total disease, bronchiectasis and trapped air were determined.

He found that the presence of neutrophil elastase made a significant difference to the observed percentage of lung disease. This supported the findings of Luke Garratt and gave a quantifiable measurement of the changes which was accurate, sensitive and repeatable for assessing the extent of lung disease in very young children with CF.



Tim explained that the results of this research support the aggressive and early intervention treatments of children with CF. It is obviously easier to prevent than cure damage. Most importantly, it provides an accurate clinical outcome measure suited for clinical trials by drug companies for very young children.

The final presentation of the evening was by CFWA SBA PhD Top Up Scholar Cindy Branch Smith. The AREST-CF team has been pioneering in its approach to CF research and continues to do so by being one of the first medical research teams to embrace psychosocial research.

Cindy’s research tracked the psychological support for families as they embarked upon early CF surveillance.

Many parents experienced high levels of anxiety regarding tests and results and felt judged by others. The good news was however, that things did get easier with knowledge and experience.

Importantly, Cindy’s research showed practical information on how to cope was considered most valuable and advice on how to be pragmatic when it came to infection control. This was particularly relevant for newly diagnosed families who were often frightened by statistics and complex jargon.

Given the plethora of information on CF online, many parents wanted access to a reliable source.

Cindy also looked at psychosocial factors such as markers of hardship in families, socioeconomic disadvantage, depression and anxiety - “dads are anxious and mums depressed” she said and the role of family, parenting, child behaviour and mental health on child health analysis.

There are some profound implications arising from this research for both CFWA and clinicians.

The psychological support for families as they embark on early CF surveillance is emerging as a key factor in determining outcomes, as is improved information and community-based support for families in the early CF years.

Important for CFWA was the identification of need for a responsive Australian website designed for newly diagnosed families with CF and psychosocial interventions that reduce the potential for more severe disease in children from at risk families.

SO WHAT OF THE FUTURE?

The AREST-CF team in Perth and its national and international collaborators represent the cutting edge in paediatric CF research. Future plans include repurposing existing drugs that are already available but have not yet been used in CF, such as limiting neutrophil elastase in the lung. Looking at the use of adult-derived stem cells to repair the epithelium of the airway. Looking at the efficacy and side effects of treatments on a case-by-case basis to determine a more precise customised treatment regime tailored to each individual and importantly, further research into the psychosocial and educational impacts on patient outcomes.

The evening was a great success. It also gave the audience an opportunity to meet the soon-to-be appointed Rothwell Family Fellow, Professor Daan Coudri. RED Magazine will be bringing you a special feature on Daan and his focus in a future edition.

Minister for Health at the CFWA AGM

The Minister for Health, Dr Kim Hames MBBS JP MLA, was the special guest speaker at this year's CFWA Annual General Meeting.



Nigel Barker CEO
CFWA, Kim Hames
Minister for Health &
Tourism with
Richards Simons
President of CFWA

Importantly, it was the first invitation to attend an AGM that the Minister had accepted since he was appointed to his office, reflecting the government's strong support for the work that the association does in partnership with the CF clinics and lung transplant units.

Minister Hames highlighted the success of the multidisciplinary teams, of which CFWA forms a part, and acknowledged the growing numbers of adults now living with CF and the challenges and pressures that this was placing on adult CF care.

The recent peer review of services at the CF clinics is due to be published in the very near future and Minister Hames is looking forward to receiving a copy.

The Minister was delighted that CFWA had successfully negotiated a new \$5.3m outcomes based contract with the Department of Health and can be seen here with a copy of the signed contract which guarantees funding for the next five years.

The contract covers the provision of Comprehensive Home Care Services, professional education through our highly successful Regional Respiratory Training Program and the provision of a Hospital in the Home Service for Princess Margaret Hospital. This is a major achievement for the team at CFWA, especially at a time when state government revenues are declining. It reflects a close working relationship of trust with the Department of Health, the department of Finance and Treasury and service providers at Sir Charles Gairdner Hospital, Princess Margaret Hospital, Royal Perth Hospital and regional respiratory partners, WA Country Health Services, Diabetes WA, and the Asthma Foundation.

Financial Planning - Resources That Can Assist

Financial counselling is available for FREE both throughout metropolitan and regional centres. This is a confidential service available to members of the community experiencing financial hardship.

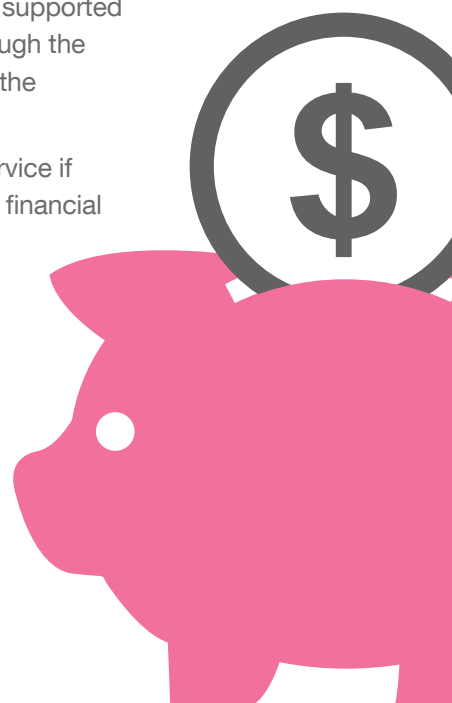
Financial counsellors provide information, options and support for individuals, families and consumer groups to explore, develop and implement strategies to manage their financial situation.

Areas that a financial counsellor can assist with:

- Budgeting assistance aimed at developing sustainable plans and financial management skills, allowing people to take control of their financial situation.
- Debt recovery assistance for people who have received a letter of demand, summons, or warrant of execution or judgement summons. Financial counsellors can explain the debt recovery process and assist with exploring an appropriate course of action or options.
- Negotiations between creditors and the person experiencing difficulties with repayments, loans, mortgages, credit cards or other creditors.
- Advocacy on your behalf to effectively communicate about your rights to private and government organisations.
- Bankruptcy information is available to explore options and alternatives.
- Community education is available for community groups, schools, TAFE and universities on financial issues.
- Housing information is available in relation to home mortgages and to explain your rights and responsibilities with Homeswest and private residential tenancy issues.
- Appeals assistance is available if you don't agree with decisions in relation to Homeswest or Centrelink.
- Complaints in regards to discrimination because of age, sex, race, illness, pregnancy or religion can be supported by a financial counsellor through the lodgement of a complaint to the appropriate authority.
- Referral to an appropriate service if unable to be provided by the financial counsellor.

For further information or to find a financial counsellor in your area go to this website <http://www.financialcounsellors.org> or contact the Financial Counsellors Association of WA on 08 9325 1617

 **Financial Counselling Helpline**
1800 007 007



Finances - Getting Your House in Order

In recent years one of the many supporters of Great Strides has been Wade Croome and the financial planning team from Commonwealth Financial Planning. RED sought Wade's assistance for this edition as we focus on "finances and getting your house in order".

We all have financial goals. You may want to provide the best education opportunities for your children. Or you may want to build an investment portfolio so you can live comfortably in retirement. Whatever your goals, saving to meet those goals is important; regular investing and having someone monitoring your investments are critical.

People go to financial advisors because they don't have the time, knowledge or self-motivation to do it themselves. Keeping up with constant changes in laws and regulations about tax and superannuation, considering personal insurance as well as understanding market movements can be quite confusing and daunting.

At the same time, that doesn't mean you hand over total control to your advisor. You need to be comfortable with any advice your advisor provides. Getting professional help from a respected financial planner can make it easier.

How to get your financial house in order, things to start thinking about:

- Is your savings account providing you with a competitive interest rate?
- Keep your credit card receipts and check them against your monthly statement. How much are you spending?
- Put together a savings plan (your personal budget planner).
- How much of your income do you save?
- Sometimes it is easier to spend than to make a conscious effort to save or to reduce those pesky loans.
- Have you Personal Insurance and Income Protection? If not, why not?
- What would happen if you could not work, or, how would you family manage if you were not here?
- Do you know where your superannuation is invested?
- Are you reducing your home mortgage?
- Pay off any high interest non-tax-deductible debt first.

Is your financial house in order??!

Your financial goals are unique to you. Whether you're thinking about taking your finances to the next step or planning for retirement, there's help available. A financial advisor can put a fresh perspective on your current financial position and what it will take to achieve your goals.

Why not contact a financial planner soon. They can assist with:

- Retirement planning
- Investment planning
- Tax-effective investing
- Planning for business owners
- Protecting the people who rely on you with a tailored insurance plan
- Estate planning
- Centrelink benefits
- Aged care

TOP INVESTMENT TIPS:

- ✓ Clarify your investment goals.
- ✓ Set up an automatic payment.
- ✓ Invest your savings to grow.
- ✓ Harness the power of compound interest.
- ✓ Diversify your wealth.
- ✓ Choose tax advantaged investments (not tax driven investments).
- ✓ Time in, not timing the market.
- ✓ Personal Insurance & Income Protection needed?
- ✓ Get some advice.
- ✓ Do something now.

Invest your savings to grow

The next step is to make the most of your savings by investing them.

The type of assets you invest in will depend on your financial needs and objectives.

Managed funds are one way to put your plans into action. They pool your savings with many other investors. You can then access a wide range of quality investments, managed on your behalf.

Diversification can also be important. It means spreading your risk across each of the main investment types (shares, property, fixed interest and cash) with an aim to achieve more consistent returns. In other words, 'not putting all your eggs in one basket'.

Information provided by Wade Croome, Senior Financial Planner, Commonwealth Financial Planning Pathways, 356 Oxford Street, Leederville WA 6007 Ph 08 9443 2145

Email: wade.croome@cbaftp.com.au



Wade Croome and his daughter Lana



THINGS TO KNOW BEFORE YOU CAN

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Angela Davey talks CF and Finances

In August 2014, Angela and Tim Davey were very happy to welcome a new addition to their family, a beautiful baby girl, Rose. RED caught up with Angela to ask how she was going, balancing living with CF, being a parent, work and finances.

RED: What is it like having a new addition to the family?

I was so nervous beforehand about having a new baby and I also was mourning the end of the life that Tim and I had together – as we did have a great life, but of course we are so overjoyed about having Rose in our lives now.

In the beginning I couldn't stop thinking about if I got sick or if something happened to me, I would be letting Rosie down, but I haven't thought about that for ages. I just do the best I can.

I am really enjoying motherhood and so far it hasn't affected my health. I take naps when I can, which helps I think.

RED: How do you manage your medication/ treatment plus looking after a baby? Any tips?

I have to put my health first - if I don't look after myself this will affect Rosie. So I make sure I do what I have to do first. My husband, Tim, feeds Rose in the morning, while I get my breakfast and take my tablets (I have to take about 40-50 in the morning and 10 in the evening).

I remember speaking to a friend who has CF about being a parent and he said that it's really important to put your health first, the baby will be ok in the cot while you take your tablets, but if you don't do your treatment you will be no good to anyone.

We have a good routine with Rosie and I am lucky she sleeps well so I can get a decent amount of sleep. I have found one of the most useful things is to just go with the flow,

as sometimes the routine is disrupted or things don't work out as planned. It's really important not to worry too much because I know that things will get back on track and being too stressed out can affect your health.

One thing I do because I have so many tablets to take is I spend the time putting them all into blister packs when I first get them, and this helps a great deal.

I do find it hard to fit exercise in, but I could really make the time if I wanted to and get off my laptop. Having said that, I do things with Rosie that keeps me active: I walk to the shops with her in the pram, and I take her to swimming lessons regularly. We go out and about a lot.

It is definitely worth buying equipment for your baby that will make your life easier. We bought Rose a portable play centre which keeps her occupied while I do things like hanging out the washing.

I think it's really important to try and make time for yourself, even if it's just a little bit. I have a great husband who works decent hours so he is able to help out with Rose and let me have some time to myself.

My mother in law takes Rose when I have to go to clinic or if I need a rest. If I didn't have someone to look after her I would use a daycare that I trusted. You need time to recharge as it's important for your baby.



Tim, Angela and baby Rose

I have also joined a Facebook page for mums with CF and that has been interesting and useful. Some of the women on there are amazing and despite facing difficulties, they soldier on.

RED: How do you manage the cost of everything?

We saved beforehand for a while to cover some of the expenses of having a baby. We buy a lot of things from Gumtree and we have to watch what we spend now that I am not working.

The medication I use is certainly expensive; it can cost about \$300 a month until we hit the safety net and then we pay the concession rate.

RED: Will you return to work in the near future?

I am planning to return to work as a teacher, two days a week, in July. I think that will be achievable with balancing everything, but I wouldn't want to work more than two days a week.

RED: Thanks Angela for sharing your story with us!

Decisional Balance: Finances – Getting Them in Order!

Have you been thinking about getting your finances in order? Well this little exercise may kick start some action or at least get you started toward considering positive change.

Action is usually preceded by thought. The decisional balance task can assist you to think your way through a desired course of action.

Decisional balance involves evaluating the pros and cons of change: What are the costs and benefits of not changing? What are the costs and benefits of changing?

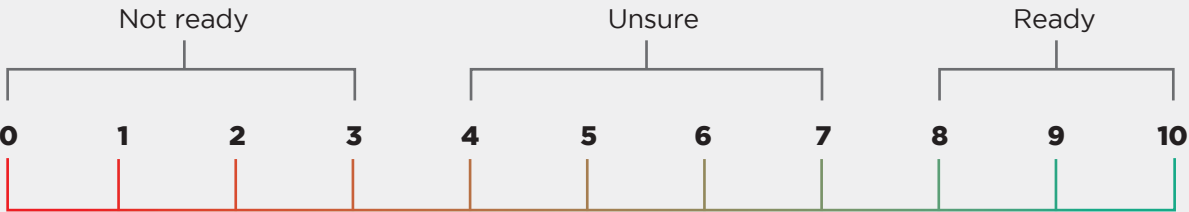
DECISIONAL BALANCE WORKSHEET

- 1
- 2
- 3
- Firstly, write down the specific financial change or goal you would like to make, e.g: Start planning for retirement.
- Fill out the worksheet according to the question for each box. Go in a counter-clockwise direction from Box 1 to Box 4.
- Now gauge your willingness to take action using the Readiness Ruler Scale from 1-10. Using the ruler identifies your readiness, desire and ability to commence change.

When you are ready, willing and able, change is more likely to occur!

	Not Changing Behaviour	Changing Behaviour
Pros	<div>Box 1: What is something good that could come from <i>not</i> taking this action?</div>	<div>Box 4: What is something good that could come from taking this action?</div>
Cons	<div>Box 2: What is something bad that could come from <i>not</i> taking this action?</div>	<div>Box 3: What is something bad that could come from taking this action?</div>

Readiness Ruler



Continues over page

SETTING YOUR GOALS

Now set three-monthly goals – behaviours/actions that you would like to happen in three months' time consistently working towards your desired change – your vision.

For example:

1. Research and open a savings account
2. Create a budget. (budget isn't a bad word!)
3. Budgeting meetings if you are a couple. Do you have the same goals?

Are there any Action Steps needed? Consider:

Obstacles that could get in the way and a strategy for overcoming them.

- Strengths you have that can help?
- Support you may need?

These can be expressed as weekly goals or steps to take before you begin. For example:

1. Write a spending plan
2. Switch to cash, not credit.
3. Take your lunch to work instead of buying.

CONCLUSION

You may have now identified a desired change that paves the way to getting your finances in order. Your goal setting provides accountability, order, clarity, challenge and above all CREATES NEW HABITS.....

So get started and give it a go!

NB: The Decisional Balance Model can be applied when considering changes in regards to all aspects of life. Whether it be the desire to improve the work/life/treatment balance or a simple change such as remembering to take medication in a timely manner.

If you would like any assistance with Wellness Coaching please contact Sharon Dewar nurse@cysticfibrosiswa.org



Parents' Retreat

We held our annual Parents' Retreat at the beautiful Footprints Resort in Preston Beach from the 27th to 29th March.

We had 30 parents attend the weekend getaway where we enjoyed a day trip to Dwellingup, visiting the Forest Heritage Centre for a guided forest walk and spending a relaxing afternoon with a picnic lunch at The Wine Tree cidery. Members also enjoyed a quiz night, group meals and free time to enjoy the resort facilities and surroundings.

This important event is possible due to the support of Carers WA, who are dedicated to improving the lives of carers and recognise the importance of providing respite and support systems.



Julie Foott, Sara Lidquist, Martin and Tracey Rumford enjoy the Parents Retreat.

CFWA Subsidies

EQUIPMENT

Exercise and medical equipment can be subsidised up to \$200 annually upon receipt.

ACTIVITY

Any sporting or aerobic activity can be subsidised up to \$100 annually upon receipt.

COUNTRY PATIENT ASSISTANCE SCHEME

All clinic and hospital visits can be subsidised from between \$50 - \$150 per visit. In the situation where a family has two children with CF an extra \$50 can be paid per child.

REGIONAL SIBLINGS' CAMP SUPPORT

Regional siblings can receive a travel subsidy or flights to attend our annual Sibling Camp.

ANNUAL REVIEW SUBSIDY

All families at PMH are eligible to receive a small cash payment of \$30 each annual review to assist with a meal and/or parking.

For further information contact Kathryn 08 9346 7348 or servicesmanager@cysticfibrosiswa.org or visit the website <http://www.cysticfibrosis.org.au/wa/subsidies> to download a form.



Financial Assistance, Concessions and Benefits.

Government allowances and benefits can sometimes be confusing. Here is a list of potential benefits you may be entitled to.



CARER ALLOWANCE (CARING FOR A CHILD LESS THAN 16 YEARS)

This is a supplementary payment that is available for a parent or carer who provides additional care and attention on a daily basis for a child less than 16 years with a physical, intellectual or psychiatric disability.

http://www.humanservices.gov.au/customer/services/centrelink/carers-allowance?utm_id=7

CARER ALLOWANCE (CARING FOR A PERSON 16 - 25 YEARS IF STUDYING)

This is a supplementary payment that may be available if you are a parent or carer who provides daily care and attention for a person aged 16 years or over with a disability, medical condition or who is frail aged. Parents and/or carers can reapply to receive this benefit when their child turns 16 if they are still a student until the age of 25 years. Carer Allowance can be paid in addition to wages or other income support payments such as a Carer Payment.

http://www.humanservices.gov.au/customer/services/centrelink/carers-allowance?utm_id=7

PARENTING PAYMENT

You may qualify for Parenting Payment either as a parent, grandparent or foster carer, if you are single and you care for at least one child aged under 8 years, or you have a partner and you care for at least one child aged under 6 years, and you and your partner's income and assets are below a certain amount. If you are granted Parenting Payment (single) you will have compulsory part-time participation requirements from the time your youngest child turns 6 years of age.

<http://www.humanservices.gov.au/customer/services/centrelink/parenting-payment>

DISABILITY SUPPORT PENSION

You need to be over 16 years and not able to work more than 15 hours per week. To assess your eligibility for Disability Support Pension, a report from your treating doctor or specialist on your disability, injury or illness is usually required. You may also need to have a Job Capacity Assessment which is a way of finding out if you can work, how much work you can do, and how much help you need to find and keep a job.

http://www.humanservices.gov.au/customer/services/centrelink/disability-support-pension?utm_id=7

SICKNESS ALLOWANCE

Sickness Allowance assists you if you are employed, including if you are self-employed, and you are temporarily unable to work because of a medical condition. In some cases, you may qualify for Sickness Allowance if you are a full-time student and over the age of 21 years. You must also have work or study to return to when you are better. Note: You need to get your doctor to fill out a medical certificate, preferably a Centrelink medical certificate, which confirms you are medically unfit for your usual work.

http://www.humanservices.gov.au/customer/services/centrelink/sickness-allowance?utm_id=7

ESSENTIAL MEDICAL EQUIPMENT PAYMENT

An annual payment of \$147 to assist with extra costs associated with essential equipment such as home ventilators, oxygen concentrator and nebulisers.

<http://www.humanservices.gov.au/customer/services/centrelink/essential-medical-equipment-payment>

MEDICARE SAFETY NET

The Medicare Safety Net provides families and individuals with financial assistance for high out-of-pocket costs for out-of-hospital Medicare Benefits Schedule (MBS) services. Once you meet a Medicare Safety Net threshold, you may be eligible for additional Medicare benefits for out-of-hospital MBS services for the rest of the calendar year.

Also available is the PBS Safety Net if you and your family need a lot of medicines in any year. Many types of medicine cost much more than the price you pay; some cost hundreds of dollars. The Australian Government pays most of it for you through the Pharmaceutical Benefits Scheme and the Repatriation Pharmaceutical Benefits Scheme (PBS/RPBS).

WHAT IS THE PBS SAFETY NET?

If you or your family need a lot of medicines in a year, the Safety Net helps you with the cost of your medicines. Once you or your family reach a Safety Net threshold, you can apply for a PBS Safety Net card; then your PBS medicine will be less expensive or free for the rest of the calendar year. If you choose a more expensive brand of medicine, or your doctor prescribes one, you may need to pay more.

http://www.humanservices.gov.au/customer/services/medicare/pbs-safety-net?utm_id=9

EMPLOYMENT AND STUDY MOBILITY ALLOWANCE

Mobility Allowance assists people with chronic health who are involved in qualifying activities and cannot use public transport without substantial assistance. Qualifying activities may

include looking for work or any combination of paid employment, voluntary work, vocational training and independent living or life skills training. Note: You do not need to get any other payments from Centrelink to qualify for Mobility Allowance. Mobility Allowance is not income or assets tested, and is a non-taxable payment.

http://www.humanservices.gov.au/customer/services/centrelink/mobility-allowance?utm_id=7

NEWSTART ALLOWANCE (21 YEARS OVER)

If you are unemployed, Newstart Allowance provides financial support while you are looking for work. Note: Centrelink staff are trained to help you claim Newstart Allowance and any other payments and benefits you may be entitled to.

http://www.humanservices.gov.au/customer/services/centrelink/newstart-allowance?utm_id=7

YOUTH ALLOWANCE (16 YEARS PLUS)

Youth Allowance can assist you if you are a young person who is studying, undertaking training or an Australian Apprenticeship, looking for work, or you are sick.

http://www.humanservices.gov.au/customer/services/centrelink/youth-allowance?utm_id=7

SPECIAL BENEFIT

Special Benefit helps you if you are in severe financial need due to circumstances outside your control and you cannot receive any other Centrelink pension or benefit. You may get Special Benefit if you are in severe financial hardship, and are not able to earn enough income to

support yourself and your dependants for reasons outside your control, <http://www.humanservices.gov.au/customer/services/centrelink/special-benefit>

AUSTUDY

Austudy provides financial help if you are aged 25 years or more and are studying or undertaking an Australian Apprenticeship full-time. You may be eligible for Austudy if you are aged 25 or over and are studying an approved full-time course at an approved institution, or undertaking a full-time Australian Apprenticeship.

Unlike Youth Allowance, there is no independence test for Austudy. If you qualify for Austudy you are considered independent. This means the parental means test does not apply. Your previous studies may also affect your eligibility for Austudy.

<http://www.humanservices.gov.au/customer/enablers/centrelink/austudy/claiming>

CONCESSION CARDS

Centrelink has two main types of concession cards: Health Care Card and the Pensioner Concession Card, which provide a range of benefits, including help with the cost of medicines. Benefits may include:

- bulk billing for doctor appointments (this is your doctor's decision)
- reductions on property and water rates
- reductions on energy bills
- a telephone allowance
- reduced fares on public transport
- reductions on motor vehicle registration
- free rail journeys

TRANSPERTH CONCESSION SMART RIDER

A concession SmartRider card can be obtained by anyone who holds a valid concession entitlement. Transperth operates a Free Transit Zone (for buses) and a SmartRider Free Transit Zone (for trains) within the Perth city boundaries.

<http://www.transperth.wa.gov.au/Tickets-Fares/Concession-Guide>

DISABILITY SUPPORT PENSION

Disability Support Pension cardholders are entitled to travel for free on all Transperth services between 9.00am and 3.30pm Monday to Friday, all day Saturday and Sunday, as well as public holidays. The new free travel entitlements can only be accessed via SmartRider, Transperth's electronic ticketing system, so you must have a Disability Support Pension SmartRider to travel for free during these times.

<http://www.transperth.wa.gov.au/Tickets-Fares/Concession-Guide>

COMPANION CARD

The Companion Card is issued by National Disability Services to people with a significant permanent disability who require attendant care support from a companion. Transperth honours the Companion Card system by allowing a companion/support person (of a Companion Card holder) to travel free on all services. NOTE: The person with a disability must have a valid ticket.

www.wa.companioncard.org.au or call 1800 617 337

INDEPENDENT LIVING CENTRELINK RENT ASSISTANCE

The Commonwealth pays rent assistance to recipients of income support payments, including those who receive more than the base rate of family tax benefit (Part A), and pay private rent above minimum thresholds.

<http://www.housing.wa.gov.au/housingoptions/rentaloptions/centrelinkassistance/Pages/default.aspx>

GRANTS, CONCESSIONS AND SUBSIDIES

Parking Permit ACROD

To be eligible you must:

- have a severe mobility impairment where walking more than 50m causes the physical condition to deteriorate and close proximity parking is required; and/or
- require the use of a wheelchair, crutches, walking frame, callipers, or other specific mobility aid and require a wide parking bay to transfer in/out of a vehicle

Taxi Users' Subsidy Scheme (TUSS)

TUSS provides taxi travel at a reduced rate for people who have a severe permanent disability that will always prevent them using a conventional public transport bus service.

http://www.transport.wa.gov.au/mediaFiles/taxis/TAXIS_P_TUSS_ApplicationForm.pdf

Continence Financial Support

Most people with incontinence use continence products such as pads, catheters or bedding protection to manage their condition. Some people require these products on a long-term basis which can become very expensive and put unreasonable pressure on the household budget.

Contact a continence nurse advisor at the National Continence Helpline on 1800 33 00 66. The Helpline can also provide you product information and the details of local and national continence product suppliers.

<http://www.continence.org.au/pages/financial-assistance.html>

Life Support Equipment Electricity Subsidy

This scheme provides a subsidy to compensate financially disadvantaged persons for the electricity costs of operating life support equipment at home such as ventilators, feeding pumps and nebulisers if used under specialist medical advice and are holders of concession cards that are means tested.

<http://www.dtf.wa.gov.au/cms/content.aspx?id=1280>

Hardship Utility Grant Scheme (HUGS)

HUGS is run by WA's Department for Child Protection. It provides financial assistance to help people with financial difficulties pay their water, gas and electricity bills so their supply is not cut off. If you are eligible, HUGS may pay up to 85% of your current electricity, gas or water bill direct to your retailer. You would still need to pay the remaining amount.

<https://www.dcp.wa.gov.au/servicescommunity/Pages/HardshipUtilitiesGrantScheme%28HUGS%29.aspx>

DENTAL CARE

If you are in possession of a current Health Care Card you are eligible for emergency and general dental care at the basic rate of subsidy. This rate is currently 50% of the cost of treatment. If you receive a pension or allowance from Centrelink, you may also be eligible for a higher rate of subsidy. Dental Health Services will confirm with Centrelink the amount of benefit or pension you receive to determine the level of subsidy. Subsidies no longer apply for people without the Health Care or Pensioner Concession Card

<http://www.dental.wa.gov.au/adult/eligibility.php>

COMMUNITY AID AGENCIES

There are a number of aid agencies available to assist with food, emergency accommodation, clothing, counselling and family support. This is often free if people have a Health Care Card or are suffering hardship.

Salvation Army

Telephone: 08 9260 9500

Website: <http://www.salvationarmy.org.au/wa>

St Vincent de Paul Society

1300 794 054 between 9am - 1pm. Assistance is also available in many country towns.

<http://www.vinnies.org.au/financial-assistance-national?link=1561>

The Australian Red Cross

Phone 08 9225 8888 Freecall 1800 810 710

www.redcross.org.au

Red Cross Soup Patrol

Every night of the week Red Cross Soup Patrol volunteers serve free evening meals of hot soup and bread to people who are homeless or on very low incomes. The service provides over 38,000 meals annually. The Soup Patrol Service operates from designated stops in Perth, Fremantle, Bunbury, Geraldton and Kalgoorlie.

Anglicare WA

Telephone: 08 9263 2000

Website: www.anglicare.org.au

EMERGENCY ACCOMMODATION

Women's Domestic Violence Helpline

Telephone support and counselling for women experiencing family and domestic violence. Can help you if you want to find a refuge or a safe place to stay or if you just need to talk to someone who will understand how the abuse affects you and your children.

Available 24 hours, 7 days a week. Phone: 08 9223 1188 or STD 1800 007 339.

Salvo Care Line

For people experiencing a crisis, enabling them to gain access to a network of services including: referral to emergency accommodation, telephone counselling and information and referral for other material needs. Available 24 hours, 7 days a week. Phone: 08 9442 5777

Affordable housing options:

<http://www.affordablehousing.wa.gov.au/Pages/default.aspx>

EMERGENCY CONTACTS

Crisis Care

24 hour crisis information, support and counselling

08 9223 1111 or 1800 199 008 (country callers)

TTY 08 9325 1232

Carers Counselling Line

1800 007 332. It's free to carers state-wide.

Lifeline

13 11 14 for state-wide, 24 hour, Telephone Counselling Service

Psychiatric Emergency Team (PET)

08 9224 8888 1300 555 788 (all hours)

1800 676 822 (rural freecall)

If you are aware of any other financial subsidies, please let us know so that we can advise our membership or for further support and information please contact Kathryn on 08 9346 7348 or servicesmanager@cysticfibrosiswa.org



RED Resources

Just Breathe: Adults Living with Cystic Fibrosis

This book is a compilation of personal stories of 92 adults with cystic fibrosis, living in different parts of Canada. The idea behind the book is to show that CF is no longer a childhood disease and that research and transplantation has had a great positive impact but also to show what sort of issues adults with CF face in their daily lives.

The book can be purchased online for \$60 plus approx \$36 for postage from:

<http://thecfproject.bigcartel.com/product/just-breathe-the-book>



CF Smart

CF Animation: watch this space, for the up and coming animation which encourages good hand washing and infection control practices in schools and explains why this is a good thing for children with CF.



CF Food

At the end of 2014, we were successful in securing a grant from Newman's Own Foundation to develop CF Food, a nutrition program. CF Food will include a set of booklets to provide information and tips to people living with CF and their carers, and will cover specific target groups: infants and childhood, adolescents and adults. It will also include recipes from the community and dieticians. If you would like to contribute to this program through either being part of a focus group or submitting a recipe, please contact:

Gillian on recreation@cysticfibrosiswa.org or 08 9346 7338

NEWMAN'S OWN
FOUNDATION

CF Fact Sheets: Coming Soon

In conjunction with the CF organisations nationally, we are in the process of developing some fact sheets to be loaded on the national website. Our fact sheets will be an ongoing development to provide information to guide you in the management of CF. Some of the topics include information for carers and siblings, information on; exercise, PEG'S (Percutaneous Endoscopic Gastrostomy), PICC (Peripherally Inserted Central Catheter), pill swallowing, salt and fluid replacement, the sweat test and reproductive information for adult males and females.

Funding Available For Kids Sport & Recreation

KidSport is part of a state government initiative in partnership with local government and the Department of Sport and Recreation that could provide \$200 towards your child sport fees.

How do I find out if I can get the subsidy?

Contact your local government to find out more about the program in your area or visit the Department of Sport and Recreation website for an application form.
<http://www.dsr.wa.gov.au/funding/individuals/kidsport> or email kidsport@dsr.wa.gov.au

What is the criteria?

- Be aged 5 – 18 years
- Have a Health Care Card or Pension Concession Card OR be referred by a recognised referral agent, e.g. Social Worker (CFWA Services Manager)
- Live in the local government area where they are applying

The City of Joondalup has some useful information on their website and a useful guide for successful funding application.

www.joondalup.wa.gov.au/Govern/GrantsandFunding/SportingGrants/KidSport

www.dsr.wa.gov.au/funding/individuals/kidsport/information-for-parents

WAFEX helps CFWA bloom

RED chats to Daniel Stean from WAFEX about the flower industry and 65 Roses Day.

RED: Everyone in the cystic fibrosis community will know about 65 Roses Day but not much if anything about WAFEX. Can you tell us a little about the history of the company and what it has become today?

WAFEX commenced trading in 1991 headed up by owners Craig Musson and Adrian Parsons with an initial focus on exporting Australian-grown flowers to key overseas markets in Japan, Holland and USA. As the company grew, it expanded into wholesale supply of flowers across Australia and also importing. Today, WAFEX employs over 70 FTEs and operates offices and packing facilities in Perth, Melbourne and Sydney.

WAFEX exports to over 15 countries and imports flowers from countries such as Kenya, Ethiopia, Vietnam, Colombia, Holland and Ecuador. WAFEX also owns 2 native flower farms in Victoria and WA as well as owning a separate company, Helix Australia, which specialises in breeding new varieties of Geraldton Waxflower. In 2013, WAFEX opened an office in California servicing the large US floral market with a global supply of fresh flowers.

RED: What do you see as the challenges in the coming years for the flower industry considering the economy, consumer demands and industry issues?

There is a major shift occurring in terms of retail sales channels for distributing fresh flowers in Australia with large increase in cut flower sales via supermarkets and online providers. Also, as land values

close to cities increase, many Australian flower growers are selling up and this production void is not being filled by new growers. Import of fresh flowers is increasing to fill this gap as the demand for fresh flowers continues to grow.

RED: WAFEX is a fantastic supporter donating 2,000 roses to our 65 Roses Day campaign. Can you tell readers about how WAFEX became involved?

WAFEX Director Adrian Parsons is based at our Melbourne office and commenced a relationship with Cystic Fibrosis Victoria over 7 years' ago. Adrian observed that CFV's 65 Roses Day fundraiser did not involve fresh roses and Adrian initiated a number of fundraising activities involving fresh roses to assist CFV. In addition to also donating over 2000 long-stem roses to CFV, WAFEX also generates CF monies via labelled 65 Roses Day bunches. Adrian also runs flower stalls at his local football club to help raise money and awareness for CFV.

RED: I believe the flower market worldwide carries some impressive statistics, how big is it and what is it worth to the world economy?

The world flower trade is estimated to be valued at around USD 500b per annum with major consumption markets in USA, Japan and Europe. The Australian cut flower industry at retail is valued at approximately \$920m per annum with an average per capita spend of around \$20-30. The challenge for our industry in Australia is lifting this average per capita spend via promoting non-occasion flower purchases/purchases for self/own use.



RED: Flowers bring colour, perfume and joy to many people, can you tell readers what to look for when purchasing a bunch and what is the best method for extending their life when in a vase at home?

It is important to look for flowers that show a mix of colour and open/closed buds which will offer longer vase life. It is important to strip all leaves off lower stems of flowers that will sit in the vase. You should re-cut the flower stems on a 45 degree angle before putting in the vase and the addition of a flower preservative of a half teaspoon sugar will also extend the flower vase life. You should change the water every 2 to 3 days to help extend the vase life.

RED: When you aren't skipping between Perth, Melbourne and other parts of the world what do you like to do in your spare time?

I have a young family that consumes most of my spare time. But when I get a chance I like to get out on the bike to do some cycling. At this time of year with footy season underway you will see me at most Fremantle Dockers games as I'm an avid supporter.

RED: Thanks for your time Daniel. We appreciate you're very busy in and out of work!



Daniel Stean gets roses ready for 65 Roses Day

Fundraising News

After months of preparation and training, two Cystic Fibrosis WA fundraising teams entered the 2015 Karma Resorts Rottneest Channel Swim.



Eric and Ronele Gard at John O'Groats after cycling 1,540kms.

Both teams finished triumphant! Completing the gruelling 20km open water swim from Cottesloe to Rottneest were:

Alex Clappin, Tom Rabe, Alistair Campbell and George Gaylard who made up a team of fit young men from Community Newspaper Group. The lads generated great news for the editors of papers throughout the metropolitan region giving cystic fibrosis some excellent exposure.

Amy Lauren, sister **Sarah**, together with friends **Ashleigh** and **Tim**, teamed up for the channel swim, braving the elements and taking on the challenge successfully.

Collectively, the two teams raised over \$7,624 which is a fantastic effort both in and out of the water! Thanks to all the swimmers & support crew involved in the event.



Swan Christian College recently donated \$1,000 from the proceeds raised from their 2014 Charity Ball.

Thanks to **Katie Di Re** for raising \$71.50 for CFWA

Applecross Senior High School held a Valentine's Day fundraiser and raised \$280, thanks to **Bronwyn Speedie** for facilitating this event.

Claudia and Stella baked cakes and raised \$67.40. Nothing like a great cake stall! Thanks girls for your wonderful contribution.

The money tin from **Xpresso Code** has again been counted and \$68.60 was raised. Thanks to all the coffee drinkers at "Charlies" visiting the car park located café.

Wesley College, Hardey House raised over \$1,500 from various community fundraising events. Thanks for your continued support. The boys always make a great contribution supporting CFWA and will join us for rose wrapping in May.

We have received over \$300 from the Over 55's Cycling Club – money raised by them from various fundraising activities. A great effort from this wonderful cycling group.

Eric and Ronnie Gard continue to provide unwavering support to CFWA and recently donated \$422.65 from a camp ground book sale they organised.

Thanks to the **York Friendship Club** who recently donated \$500 through their community fundraising initiatives.

Have we omitted your fundraising efforts from RED? From time to time, we receive 'unknown' donations without any information. Please contact our fundraising team on 08 9346 7333 to make us aware of your contribution.



Team Amy Lauren (third right) happy to finish HBF Rotto Swim in support of CFWA



HBF Rotto Swim participants celebrate



Community Newspaper Rottneest Swim Team lead by Tom Rabi (second left)

Welcome Shelley

Looking to organise a community fundraising event for CFWA or need to know more about one of our many fundraising events this year?

Meet our new Community Fundraising & Events Coordinator, Shelley Farrell. Shelley has already hit the ground running preparing the sponsors and volunteers evening on 14th May as well as getting a grip on the Golf Classic and 65 Roses activities.

Having gained some excellent experience at Camp Quality and local government in recent years, Shelley is well equipped to tackle our busy schedule and highly active fundraisers. You can contact Shelley on 08 9346 7339 or via email fundraiser@cysticfibrosiswa.org

Welcome to the cystic fibrosis family Shelley!



Shelley Farrell, CFWA's new Fundraising & Events Coordinator.

65 Roses Month: 3 Ways To Get Involved

May is cystic fibrosis awareness month and Friday 29th May is 65 Roses Day, our national day of awareness.

Every year, community supporters and businesses join us to raise funds for Cystic Fibrosis WA.

This money is used to deliver vital research funding and services to people living with cystic fibrosis in WA. Taking part is fun and easy. We'd love to have you on board!

1. SELL ROSES ON 65 ROSES DAY, FRIDAY 29TH MAY

This year we will sell 6,500 roses all around the state. Take a bucket to sell in your office or workplace for \$5 a rose.

Visit www.cysticfibrosis.org.au/wa/65-roses-day-rose-order to place your order. Roses can be purchased outright or taken on consignment. All pre-paid orders of 50 roses or more will go into a draw to win a restaurant voucher thanks to Entertainment Publications.

If you can't sell roses in your workplace, why not join us on the streets of Perth to help spread the word. There are spaces available throughout the day in locations all around the city. To lend a hand, please contact Matt at digitalmarketing@cysticfibrosiswa.org.

Please place your orders by Friday, 22nd May.

2. TAKE THE 65 ROSES CHALLENGE

Get your 65 Roses Challenge under way by holding a fundraising event themed around the number 65. Here are some great ideas from previous years:

Run, walk or swim 65kms

Sell 65 cupcakes

Host a dinner for \$65 per person

Visit the challenge website at 65roseswa.org.au to get started. What are you waiting for? Challenge accepted!

3. MERCHANDISE KITS AND COLLECTION TINS

Why not take a merchandise kit or collection tin to display in your workplace?

These do well in busy shops and large offices, you only need a small space to make a big difference! To take a merchandise kit or tin contact Matt at digitalmarketing@cysticfibrosiswa.org or 08 9346 7343.

We hope you can be a part of our biggest and best 65 Roses yet!



Plan Your Fitness Events for CF This Year

1. HBF Run for a Reason

Sunday, 24th May Join the Rose Runners and help us reach our \$30K target.

Run for FREE if you pledge to raise \$1,000 or more. It's easier than you think and we'll help you reach your target with personalised fundraising tips. There are only a few free places left, so make sure you get in quick! Contact Shelley at events@cysticfibrosiswa.org or 08 9347 7339 for more info.



Do you want to run but don't know if you can reach the target? No worries, sign up at www.hbfrun.com.au, and remember to select Cystic Fibrosis WA as your chosen charity

2. Swan River Run

Sunday, 26th July Join the Rose Runners and help us raise our \$17K target.

Same again, run for FREE if you pledge to raise \$1,000 or more. There are only 15 free places available, so register now to claim yours! Contact Shelley events@cysticfibrosiswa.org or 08 9347 7339 for more info.

Don't think you can reach \$1,000 but still want to run? Not a problem, you can sign up at www.swanriverrun.com.au



3. City to Surf

Sunday 30th August

One of Perth's oldest fun runs, with a range of distances from 4km to a full marathon, there is something for everyone.

Sign up at www.perthcitytosurf.com



4. Great Strides Sunday 25th October

Our very own funrun and walkathon! Join us at Perry Lakes Reserve for the 4km or 8km walk/run, followed by a carnival and BBQ. We'll give you more details closer to the event, but make sure you save the date!



If you have questions about any of these events please get in touch with Shelley at events@cysticfibrosiswa.org or 9347 7339.

Looking for Some Good Karma?

CFWA has partnered with WA-based social enterprise, eKarma to offer a unique and innovative service which drives fundraising for CFWA as you shop online.

To start earning funds for CFWA, simply create an account on eKarma (it's free) and nominate CFWA as your nominated charity. As you shop via eKarma on any of the 250+ online partner shops, eKarma will donate 50% of the commission that it receives from the partner shops to CFWA.

It is a great way to raise funds and the more that customers shop via the website the greater the return to CFWA. Family, friends, work mates – everyone is welcome and can support our cause.

“Competition for the charitable dollar has never been so high. The economic climate has had an impact on just how much people are contributing to charitable causes” said Nigel Barker, CEO CFWA. “We are always looking for new and innovative means of raising funds and this partnership with e-Karma certainly broadens our fundraising streams.”

www.ekarma.com.au to Shop and Do Good!



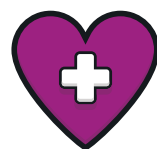
Shop online

Create your free account with eKarma



Conscious consumer

Shop via eKarma with +250 online stores



Charity benefit

Your nominated charity receives donations as you spend

Questions About Living With CF

'My daughter with CF is currently living in Germany and she is having problems falling pregnant. She plans to return to Perth and would like to know what is available here with regard to IVF and what the costs are.'

It is important to discuss your plans for starting a family with your CF team, ideally before you are pregnant.

Assisted Reproductive Technologies (ART) is used if couples are experiencing difficulties in conceiving. There are services available at King Edward Memorial Hospital (KEMH). Some couples may wish to pursue private options. If this is the case, it is important to examine costs closely. Medical and laboratory costs may be covered by Medicare. It is recommended that you compare different costs, requirements and payments before committing to an organisation. If the private option is taken, it is important to have private health insurance and compare the cover available for infertility tests from each fund. There is usually a waiting period of at least 3 months before benefits are paid for ART.

Useful resources

Assisted reproduction:

<http://www.rtc.org.au/consumer/index.html>

<http://www.conceptfertility.com.au>

Family planning:

<http://srhwa.com.au/>

Genetic services:

<http://www.gswa.org.au>



Work Life Balance

Amy, who has lived with CF for 25 years, kindly offered to contribute to RED as a regular writer talking from a CF perspective. We look forward to her ongoing stories, Welcome Amy!

Navigating the seas in search of an elusive concept called 'life balance' - with Amy Lauren

I am currently in the middle of nine fourth-year chiropractic exams when an email came through asking me to write this article. I contemplated whether I had enough time to put in an effort I would be proud of when I remembered that my best university grades have been achieved in my busiest (some may say overcommitted) semesters. Maybe there is some truth to the saying "if you need something done ask a busy person."

One of the busiest people I have had the pleasure of meeting was a chiropractor from Boston. He was a family man who ran a successful international business and was a living, breathing billboard of health and fitness. Three years later, and I still regularly recall what he said as he stood on the lectern at a conference in Sydney: it's not about achieving balance in every aspect of your life everyday, or even every week, so long as you can always see the horizon of balance and are pointing towards that horizon, you are doing well.

Over the past three years, this saying has served me well. I am very goals driven, so I structure the year, season, month, week and even day around a certain goal and then go about ensuring my life is still pointing to the horizon.

Right now the vast majority of my days are spent preparing for, or sitting, exams. I accept these very long days at the desk only roll around three times a year, so I am prepared to forgo other aspects of my life to achieve a high academic standing. But in order to maintain site of the horizon, I make sure not to drop my other commitments; I simply make them work around my main focus. For example, my preferred exercise routine is one intense workout most days of the week. During exams, I will break this into multiple smaller blocks and use these breaks to clear my head and revise what I

have just learnt. Alternatively, I'll do moderate exercise with a friend to ensure I do get some social interaction beyond the examiner in oral exam!

Another ritual I hold onto tightly even in busy periods is my daily visit to a coffee shop. Like exercise, I mold this ritual around my main focus. If I am really busy with exams, my notes have to suffice as company, and when more time is given, I enjoy exploring new coffee shops further afield with other avid long black drinkers!

Work also fits around this formula for me. Luckily, I am also able to arrange my work schedule around my other commitments. Even in busy times with exams, I am an advocate for maintaining at least some work, as not only does it pay the (coffee) bills, I feel working creates a sense of accomplishment. I pick up more hours when my other commitments allow, and I accept that my choice to value these commitments over work at this stage in my life does lead to less discretionary spending money.

But maybe most importantly, I try to do something for myself everyday. We all live in a world where so many demands are placed on our time. This 21st century pace of life, combined with the added burden that CF can place on our time and energy resources, can sometimes make it feel like this horizon appears misty or so far away we need binoculars to see it! But I have found even on the most hectic days, if I can take time to go the beach for a quick swim or pop into one of my favourite boutiques, a sense of balance seems to be restored as I have managed to do something for myself.

And with that, I need to get to bed as tomorrow I am up for an early morning beach swim with a friend (exercise, socialising and my favourite past time all rolled into one, now that is efficiency at it's finest!).

Salted Caramel Slice

Member Recipe by Odette Blennerhassett

Ingredients

Base

- 1/2 cup desiccated coconut
- 1 cup plain flour, sifted
- 1/2 cup brown sugar or coconut sugar
- 125g butter, melted

Filling

- 400g can condensed milk
- 60g butter, melted
- 1 tsp sea salt flakes
- 2 tablespoons golden syrup

Topping

- 1 tsp sea salt flakes or Himalayan salt (not table salt)

Method

Line a 3cm deep, 28 x 18cm tray with baking paper.

Base

1. In a bowl, mix all base ingredients.
2. Press 2/3 into prepared tin.
3. Bake for 20 minutes, or until light golden. Remove from oven, then cool.

Filling

4. Combine all ingredients in a saucepan over medium heat and continue whisking until golden and viscous.
5. Pour over your cooked base.

Topping

1. Crumble over reserved base and very evenly spread over the salt. (also nice to add in crushed pistachio nuts to topping).
2. Re-bake for 10 minutes or until firm.
3. Refrigerate for at least 4 hours, or overnight.



CF Diary

MAY

- 1 > Golf Classic
- 3-8 > Regional Respiratory Training Program
- 14 > Sponsors & Volunteers Awards Night
- TBA > Geraldton Outreach
- 22 > Coffee Morning - Armadale
- 29 > 65 Roses Day

JUNE

- 5 > Ladies Support Dinner
- TBA > Northam Outreach
- 30 > Coffee Morning - Midland

AUGUST

- 15-16 > CF Conference Sydney: Lay Program
- 16-18 > CF Conference Sydney: Medical Program
- 30 > City to Surf

SEPTEMBER

- 1-30 > Serve It Up for CF
- 14-15 > Spring Rose Art Show
- 25 > Coffee Morning - Scarborough

OCTOBER

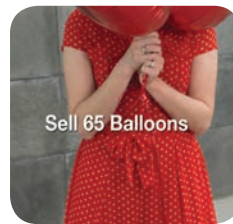
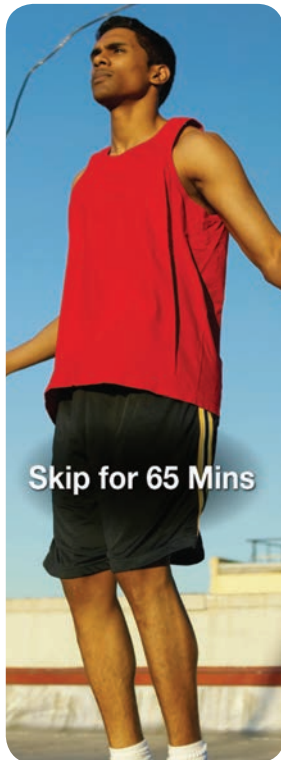
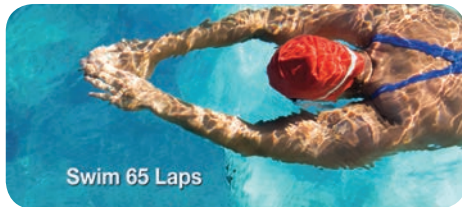
- 8-9 > Siblings' & Offspring Camp
- 14 > CF Expo - Mental Health
- 17-18 > Telethon
- 20 > Starting School with CF Information Evening
- 25 > Great Strides



Please note these dates were correct at the time of printing but are subject to change

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