SUMMER 2016

A MAGAZINE FOR KIDS WHO HAVE CF AND THEIR SIBLINGS

ROZEE

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CYSTIC FIBROSIS
Western Australia

ALL AWESOME!

EDITOR:
Natalie Amos

CONTRIBUTORS:
Rhys, Lilly, Ruby, Jayton, Luc, Daniella, Nicholas, Cassius, Natalie Amos, Sharon Dewar, Gillian Hoyland.

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Lily and Ruby
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CYSTIC FIBROSIS Western Australia

Rozee Magazine
CFWA
PO Box 959
Nedlands WA
6909

P. 08 9346 7333
E. education@cysticfibrosiswa.org
W. www.cysticfibrosiswa.org.au/wa

EDITOR'S LETTER

Welcome to our fourth edition of Rozee and it's just as jam packed as the other editions. This time we decided to explore the 'nuts and bolts' of CF, looking at some words you might have heard mentioned but maybe weren't quite sure what they meant. There is even a yummy Nuts and Bolts recipe on page 25 if you like savoury snacks. Maybe our "Writing a Blog" article might inspire you to start up your own blog over the summer!

We have just come back from the Siblings and Offspring camp which was fantastic!! And I have to say it was wonderful to see some sibs there who we first met back in 2008 who are now teenagers. And one sibling we had at the camp this year we first met when she was a baby in 2008!

In this edition we were also lucky to catch up with some young people with CF and their siblings to bring you their stories. It is always a real pleasure to do these interviews as we get to see just how amazing you guys are.

For the 2016 magazine there are plans to revamp the magazine a bit and possibly change the name, so please send us your feedback, ideas and suggestions to make sure we are including things that you want to see in the mag. You can complete the survey online at http://tinyurl.com/ne79cvp

We wish you and your family a really wonderful Christmas, a sizzling summer and a fabulous 2016.

Nat

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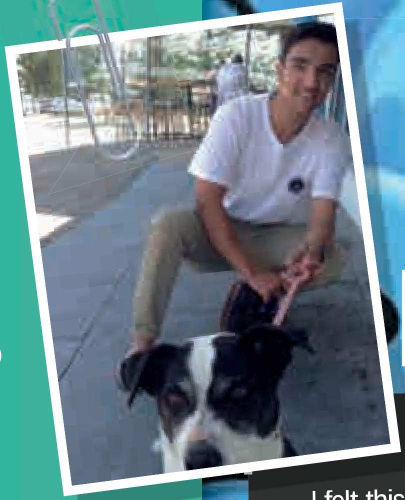
RHYS' STORY

HI grew up in Manjimup and went to school there until Year Ten. I live in Perth now and I'm 20 years old studying Biomedicine at Edith Cowan University (ECU). When I finish my degree I would like to do a post graduate diploma in Radiology, as I would like to work as a radiologist. I also want to do lots of travelling, around America, Europe and Scotland. I have family in Europe and Scotland who I would like to visit.

I also work part time as a bar man and I am planning on working a bit more next year so I can save for an up and coming trip I will be doing where I will be an exchange student at the University of Maine in Oregon, USA for six months.



ASK RHYS

QUESTION: I AM SICK OF HAVING CF AND I AM SICK OF DOING MY TREATMENT. WHAT CAN I DO TO FEEL BETTER ABOUT THINGS?

I felt this way all the time in high school. I used my treatments as an excuse in primary and high school as the reasons for why I wasn't doing well at school and I used my school work as a way to get out of doing my treatments at home.

From Year Two onwards I had to be more independent taking my enzymes and I struggled with that. I was trying to hide that I had CF and it was too hard to take the enzymes without other people noticing. I got sick and it wasn't good. Also when the teachers found out that I wasn't taking my enzymes they were on my back to take them.

I'd definitely had enough of CF by the time I was 14. I was not doing my treatment properly and I wasn't taking my enzymes at school. Only my teachers knew that I had CF and three of my closest friends, so I thought since no one knew I had CF they wouldn't notice that I wasn't taking my medication. I didn't have a problem doing my physio or doing exercise as I am a very hyperactive person and I have always got up at 5 am. I just didn't like doing my nebs or taking my enzymes. When I was in high school my nebs would make me feel tired, so I told mum I didn't have time to take them because I was doing homework. I still find it hard to fit in the nebs when I have exams at university, but I am going to get back onto it now, so I can feel much better, as I can feel it in my chest that I need to do them. I use the acapella physio device and I have appreciated just how beneficial it is to me, compared to just playing sports and not doing anything. It gets into the nitty gritty bits and I feel like it helps clear me out much more than exercising alone. I have always been active with sports but now I go to the gym six days a week too and I go for walks every day as I live close to the beach.

When I was younger I used CF as an excuse for not being able to do things. It was around Year Ten that I realised my life was not going anywhere with me blaming CF for everything. I was failing school and they didn't think I was capable of studying some of the more academic subjects. I saw that my closest friends were planning to go to university and have successful futures. Seeing their successes inspired me to change my attitude – as I am very competitive. My dad quit his job in Manjimup and we moved to my uncle's house in Bunbury so I could attend a high school there. This high school saw potential in me and with encouragement my grades picked up. I was a small fish in a big pond so it was a big learning curve for me. I matured and became more independent. As a result of my improved grades I was able to get into Biomedicine at ECU. My Dad and I also developed a much closer bond because of the experience.

I've recently become more comfortable talking to other people about having CF, I think because I have matured and I understand that it's not such a big deal. I've realised it doesn't change the way people see me and they don't treat me any differently.

It's still a burden having CF but it makes life easier telling people, especially my room mates. It's also good to have goals as that's what makes you do your treatment so you can achieve your goals. CF doesn't stop me from doing the things I want to do in my life.

Do you have a question you would like to ask Rozee? You can send your question anonymously if you wish or ask that your name is not included when the question is published.

Email your questions to
education@cysticfibrosiswa.org
or write to Rozee(CFWA)at:

Rozee Magazine
CFWA
PO Box 959
Nedlands 6909

MEET the SIBS:

LILY & RUBY

LILY AND RUBY ARE HAPPY, BUBBLY SISTERS WHO LIVE IN BALDIVIS. LILY IS 7 AND HAS CF AND RUBY IS 5. THEY BOTH GO TO THE SAME SCHOOL. LILY AND RUBY ARE ON THE FRONT COVER OF THIS ISSUE OF ROZEE TOO!

DO YOU LIKE HANGING OUT WITH YOUR SISTER?

Lily: Yes because she's a nice sister and she loves me.

Ruby: Yes because I love her.

HOW WOULD YOUR FRIENDS DESCRIBE YOU?

Lily: My friends would say I'm a great friend because I like to play with them and I say nice compliments about them.

Ruby: They would say I'm nice and kind.

WHAT MAKES YOU PROUD OF YOUR SISTER?

Lily When Ruby learns how to do things that I teach her like the alphabet. But I don't feel proud of her when she uses her baby voice.

Ruby: I like it when Lily plays with me and does puzzles with me.

WHAT IS YOUR FAVOURITE THING TO DO IN YOUR SPARE TIME?

Lily: I like to do art and craft. I make headbands and necklaces and Ruby makes them too.

Ruby: I like to play with my Monster High dolls.

IF YOU COULD MEET ONE FAMOUS PERSON WHO WOULD IT BE AND WHY?

Lily: I would like to meet Katy Perry because she sings nice songs and because I like the pretty skirts she wears. I think she makes them.

Ruby: I would like to meet Taylor Swift because she's pretty and she's my favourite singer.

WHAT WOULD YOU LIKE TO BE WHEN YOU GROW UP?

Lily: A vet, an artist, an inventor, a shopkeeper or a singer.

Ruby: A vet.

WHAT'S IT LIKE FOR YOU HAVING CF?

Lily: I have to do physio and my nebuliser. I like to watch a video called "Getting Nosey about CF with Oli and Nush" I used to watch that over and over when I was little. I am used to having CF.

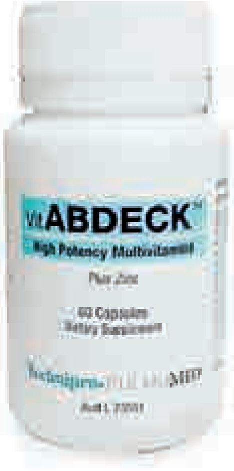
DO YOU HAVE ANY ADVICE FOR OTHER CHILDREN WHO HAVE CF?

Lily: You have to take your tablets otherwise you will get sick. Your parents don't want you to get sick because you have CF.

Ruby: Yes you have to take your tablets because you don't want to get sick.

THE NUTS AND BOLTS OF CF

THERE IS A LOT TO LEARN ABOUT CF AND THERE ARE SO MANY BIG WORDS WHICH PEOPLE USE TO TALK ABOUT IT. PERHAPS YOU HAVE CF OR YOU HAVE A FAMILY MEMBER WITH CF AND YOU WANT TO KNOW A LITTLE MORE ABOUT IT. HERE ARE A FEW COMMON TERMS YOU MIGHT HEAR WHEN PEOPLE TALK ABOUT CF.



GENOTYPE OR GENES:
Genes are like instructions in your body which make you who you are, like your hair and eye colour or if you have eczema or asthma. You get all your genes from your parents. CF comes from your genes, so if you have CF you have received the CF genes from your parents. Because CF comes from your genes you are either born with it or you're not; you cannot catch it.

BMI
BMI stands for Body Mass Index and is used to work out whether a person is underweight, normal weight, or overweight. Often doctors or the dietician at the CF Clinic will talk about BMI because having a healthy weight for a person with CF help their lungs work better. Your parents might be always encouraging you to eat lots of food (if you have CF) so you maintain a good weight.

MUCUS
Everyone has mucus in their bodies and it plays a very important role. Mucus helps protect the lungs by trapping particles, like dust, that we might breathe in. People who have CF have mucus in their body which is extra thick and sticky and it gets stuck in the lungs and pancreas (part of the digestive system). Part of the treatment of CF is clearing the thick mucus from the lungs with physiotherapy.

PHYSIOTHERAPY OR AIRWAY CLEARANCE
Physiotherapy (physio) or airway clearance as it is also called, is a daily part of the treatment of CF. Physio helps to clear the mucus out of the luAngs to help people with CF breathe better and make sure they don't get infections. There are lots of different types of physio and they will often change as the person with CF gets older. Some types of physio are:

- ➔ Pats or percussion
- ➔ PEP (Positive Expiratory Pressure)
- ➔ Bubbles

FEV1
FEV1 is a test done during clinic to test lung function. It measures how much air is exhaled in the first second of a big blow to measure lung capacity (or how much air the lungs can hold). At PMH you may have blown into Mr Wobbly when you were younger or else a machine called a spirometer.
The clinic will keep a record of your FEV1 results to work out how the airways in your lungs are doing. Some people with asthma also have to use a spirometer to work out what their FEV1 is.

VITAMINS
People with CF are often low in vitamins A, D, E and K. This is because the body finds it hard to absorb these vitamins. Having low levels of these vitamins can affect the health of the bones and eyes, as well as the body's ability to fight infections. Therefore most people with CF will need to take vitamin supplements Vit ABDECK.

ENZYMES:
Most people with CF have trouble digesting their food because part of the digestive system, known as the pancreas, is clogged with sticky mucus. That is why they will need to take enzyme tablets with most foods. Enzymes help the body to digest and absorb the nutrients from the food they eat. If the person with CF doesn't take the enzymes they can have an upset tummy and diarrhea. Remembering to take them can be tricky but it is very important as this will help with keeping a good weight.

CROSS INFECTION:
You might have heard your parents or people at the hospital talking about cross infection. Cross infection is the passing of bacteria or 'bugs' from one person's lungs into the lungs of someone else with CF. People with CF can pick up bacteria or 'bugs' from the environment or from other people with CF. If someone with CF has a 'bug' they can pass it on to another person with CF via coughing, which is why people with CF should avoid close contact. These 'bugs' are usually harmless to people who don't have CF, but can be harmful for those who do as they can cause lung damage.

PSEUDOMONAS AERUGINOSA:
Pseudomonas (soo-da-mo-nas) is a common 'bug' that is found in the environment, such as in damp soil and pools of water that get mouldy like vases and swamps or lakes. It is impossible to avoid pseudomonas all together but it is a good idea for people with CF to stay away from certain types of environments which are known to have high levels of pseudomonas. Washing your hands regularly is also really important to get rid of germs.

Pseudomonas can cause lung infections and if you pick it up you may need to go to hospital to have antibiotics. A lot of research is being done into how to treat pseudomonas.

ANTIBIOTICS:
Antibiotics are a strong medication that many people are given if they are unwell. People with CF might have them if they have a lung infection. They can be taken through a nebuliser or sometimes the person might get a PICC line put in their arm. There are also oral antibiotics which are pills that can be swallowed.

PICC LINE:
A PICC line (Peripherally Inserted Central Catheter) is a needle that goes into the arm to allow the antibiotics to go straight into the person's blood stream.


PICC Line

Meet the Member : Jayton

JAYTON IS TEN YEARS OLD AND HAS A YOUNGER BROTHER PATRICK WHO IS SIX AND A SISTER STEVIE WHO IS ONE. JAYTON LIVES WITH HIS FAMILY IN CUNDERDIN AND LEADS A VERY BUSY LIFE. HE DOESN'T LET CF STOP HIM FROM ENJOYING HIMSELF WITH HIS FAMILY AND FRIENDS, AS WELL AS THINKING ABOUT AND CARING FOR OTHERS TOO. ROZEE CAUGHT UP WITH JAYTON WHILE HE HAD AN ADMISSION AT PMH TO ASK A FEW QUESTIONS.

What's your favourite thing to do in Cunderdin, in your spare time?

I like to go out to my uncle's farm. I like to drive the tractor and run in the canola paddocks. I have jobs to do when I'm there like getting the eggs and feeding the dog Chisel. I go there about once a month.

I play cricket on Fridays in summer and that is my favourite sport. I also play tennis, hockey, golf, sometimes football and I do dancing, swimming and running. Once I ran 18 km (with a bit of walking) because my teacher was doing a fundraising run and he was getting tired so I asked my mum if I could run with him so he would keep going.

I play basketball too and we are members of the Perth Wildcats so we go to the home games, even if I'm in hospital.

I also like building Lego and I mainly collect the City Lego sets.

How would your friends describe you?

Jayton is great, kind and a good friend. They call me "mayte" or "Jaytn mayte".

If you could meet a famous person who would it be and why?

I would like to meet Dominic (Vin Diesel) from "The Fast and the Furious". I love the movies and have seen all seven of them.

What would you like to do when you grow up?

I would like to be an actor. I like acting and getting dressed up and I like being in plays at school. I would also like to be a mechanic.

Do you have any advice for other children growing up who have CF?

Do your physio, exercise, sleep and relax – that's what I do, mum tells me to relax if I'm not feeling too good. Or I run around or play some sport and that makes me feel better too. Or just laughing is good. My little brother makes me laugh and I have a joke book. I also like the book "The 52 Story Treehouse" – that's funny.

What's it like for you going to hospital?

It's fun because there's usually stuff to do, but it can also get boring. And I have to do school work. I don't get sad if I have an admission. I see it as a break and I get to hang out with my mum, we have fun together. We are in the penthouse this time. The tip I would have for other kids who have to stay in hospital (maybe for the first time) is to listen to your nurse and your mum! And ask if you can meet the Ward Play Coordinator or go to Megazone or the Starlight Express Room.

Mum has also organised three hospital boxes for when I come to hospital. One box has my teddies, which are my hospital teddies and pyjamas; one box has lots of games, like cards, Snakes and Ladders, Connect 4 etc. and my Wildcat's posters which I put up in the room; and the other box has school stuff like pens, paper, scissors and any forms that mum might need for the hospital.

How do you feel about needles?

I've gotten used to having needles now. My mum says I have a high pain threshold (can handle a bit of pain). I also have a port in the side of my chest which gets needled for the antibiotics and they give me a numbing cream so I don't feel it. I got that in about 2013.

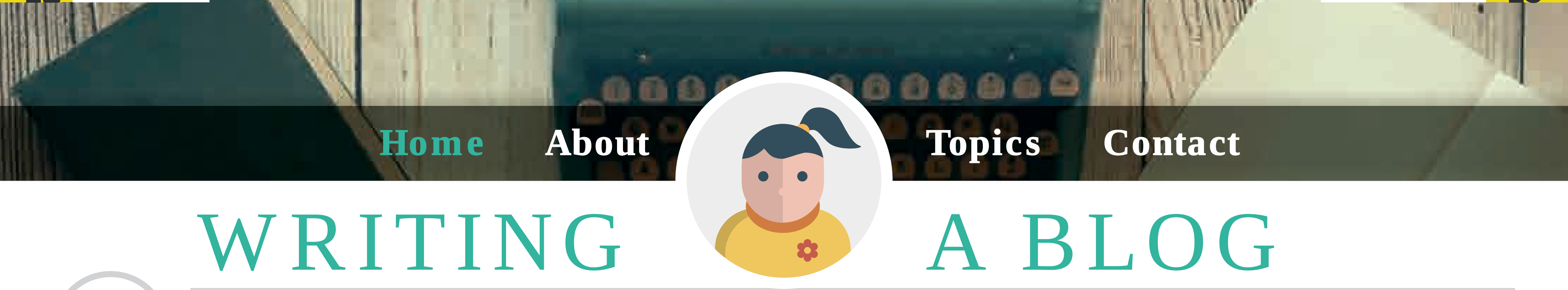
What other things do you get up to?

In 2011 I had to have emergency surgery. My mum was able to pack me some pyjamas so I was nice and comfy. But I noticed the other kids in my room didn't have pyjamas - they had the hospital ones, which aren't so nice, because their parents didn't have time to pack them. So when I talked about this with my mum she decided to start up a Facebook page called "Jayton's Jammies". People from all around the place send new PJs to my mum and she then wraps them up nicely and gives them to the hospital so kids in emergency who don't have their own, can have some.

Another thing we do at my house in Cunderdin happens in December. My parents put up lots of Christmas lights and in the first week of December we have a special night to turn on the lights. I get to invite all my friends and we have a sausage sizzle. We put out a tin to collect donations for PMH.

This year my mum organised a fun run in Cunderdin and over 100 people came along to walk or run 6.5kms for 65 roses.

And something really good that's happened to me this year is that I was the regional Telethon child. I feel happy and excited about this. It means I can help kids in PMH raising money for equipment and research and it's good publicity for cystic fibrosis. They told me the news at my school assembly.



WRITING A BLOG

31 Dec

Category: Blogs, Writing

These days more and more kids are writing blogs as a way to communicate with others. If you are thinking that you would like to start up a blog, you or your parents may have some questions about whether it’s a good idea or not. Here are some points to think about if you are considering starting a blog.

Improving your writing skills

Writing a blog will definitely improve your writing skills, especially if you work on it daily. You can write about things that are of interest and really important to you. Having a blog will also help you to be really tech savvy, improve your keyboard skills and learn more about researching topics too. If you are someone who loves writing, then this is a great avenue to get even better.

For some school projects, teachers may encourage you to start a blog. Have a look at **https://happylungs.wordpress.com** which was created by a young girl, working on a school PEAC project called “Making a Difference”. She wanted to learn more about respiratory diseases as her sister had been diagnosed with Tracheomalacia and she wanted to use her project and her blog to raise more awareness.

Socialising with others

Blogging can be a really good way to also develop your social skills as you can make a connection with other kids all over the world and link up with other bloggers. It can be very exciting if your blog is being read by other people and can motivate you to keep going with it.

Using your imagination

You can do anything with your blog, the only limit is your imagination. Some kids like to use their blog to write stories, show photos of their favourite things, share Youtube clips, write movie reviews, talk about their pets or siblings or write about their experiences living with a condition such as asthma, dyslexia, or diabetes.

32 Likes | 21 comments

You will need your parents’ involvement

A blog can also be like a public diary, which can be a great way to share experiences with other children around the world, however it is really important that parents carefully monitor your blog to make sure it is not invading you or your family’s privacy.

You will need your mum or dad to approve all your posts before you make them public. It is a good idea for your mum or dad to set up some guidelines with you about what is appropriate to put in your blog before you set one up. Some parents may be against their child putting personal photos online or telling people where they live.

As there is the opportunity for people to leave comments, some parents may want to set it up so that if someone wants to leave a comment it gets sent to the parent’s email address so they can check it first.

There are blog sites where your parent can set up the account for you or ones that you can use if you are under 13 and you can set them up yourself. It is definitely better to have your parent help you when you set up your blog.

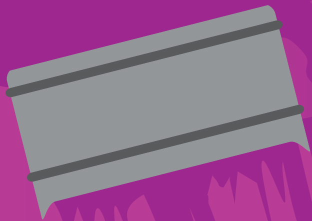
Different blog platforms

There are platforms designed for kids to use for setting up a blog. The sites make sure that the blogs are moderated and are exclusively for kids. Some platforms available are Kidblog.org, Kidzworld or Edmodo that is used in classroom settings. Some children use WordPress which children 13 and over can set up themselves, but if you are younger your parents will need to open the account for you.

Future opportunities

Blogging can open up all sorts of avenues and allow you to express your ideas and opinions as creatively as you wish. Maybe in the future you want to be a writer, an actor, a chef or work with animals. Whatever it is you dream about doing in your future, working on a blog can help you explore your goals and interests. It is common these days for bloggers in the adult world to go on to develop cook books and novels and gain publicity and opportunities from the blogs they have worked on.

HAPPY CAMPERS: DANIELLA & NICHOLAS

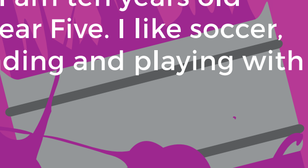


DANIELLA AND NICHOLAS ATTENDED THEIR SECOND CAMP THIS YEAR. DANIELLA AND NICHOLAS ARE TWINS AND THEIR DAD HAS CF. ROZEE SPOKE TO THEM ABOUT THEIR EXPERIENCES ON CAMP AND WHAT THEY LOVE ABOUT THEM.

HI DANIELLA AND NICHOLAS, CAN YOU TELL US A LITTLE BIT ABOUT YOURSELVES?

DANIELLA: I love reading, playing netball, my teddies, drawing and my sketching book. I'm ten years old I go to Parkfield Primary School and am in Year Five. I also am afraid of heights.

NICHOLAS: I am ten years old and I'm in Year Five. I like soccer, science, reading and playing with my friends.



ROZEE: WHAT MADE YOU WANT TO COME ALONG TO THE CAMP LAST YEAR, AND WERE YOU NERVOUS TO COME FOR THE FIRST TIME?

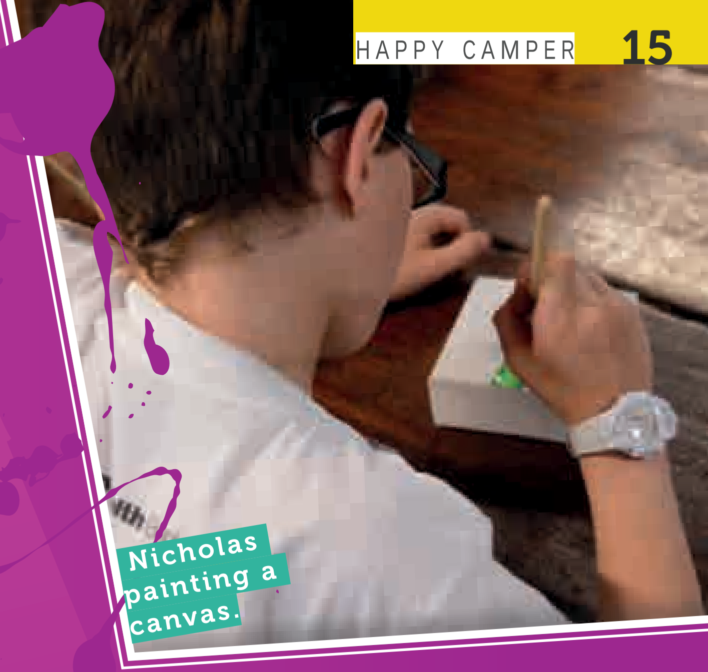
DANIELLA: I came to the camp because I love camps, making friends and having fun, and yes I was nervous about the camp. I thought "What if I don't like it?" and "What if I don't make friends?" or didn't like what we were going to do.

NICHOLAS: I like camps and the events on the brochure made the camp look like a lot of fun. I was a little nervous about meeting other kids but also excited.

ROZEE: WHAT HAS BEEN YOUR FAVOURITE ACTIVITY YOU HAVE DONE ON A SIBLING AND OFFSPRING CAMP?

DANIELLA: My favourite activity was the quiz night and when we painted red roses on a canvas.

NICHOLAS: The flying fox was my favourite activity.



Nicholas painting a canvas.

ROZEE: HAVE YOU FOUND THE CAMPS HELPFUL?

DANIELLA: I have found the camp helpful when I went last year, I made so many friends.

NICHOLAS: In my family only my dad has CF so the camp was great fun and made understanding CF a lot easier.

ROZEE: WHAT WOULD YOU SAY TO SOMEONE THINKING ABOUT COMING TO THEIR FIRST CAMP?

DANIELLA: I would say it is so fun. You'll love it and you will make so many friends.

NICHOLAS: To come along because you will have heaps of fun.

ROZEE: DO YOU HAVE ANY TIPS FOR YOUNGER SIBLINGS WHO HAVE A FAMILY MEMBER WITH CF?

Daniella: Do what you love to do with them.

Nicholas: To love your brother or sister and make being a kid as much fun as possible.

SIBLINGS & OFFSPRING CAMP 2015!

The Sibling and Offspring Camp is a two day camp for children with a sibling or parent with CF. It is for kids aged between eight and sixteen years old. Each year we have a great time and get to do a range of thrilling and fun activities like ropes courses, flying fox, abseiling, swimming and more! You get the chance to make friends with other kids who know what it's like to have someone with CF in their family.

What we did on the camp:

This year's camp was at Bickley Outdoor Recreation Camp. Some of the activities we did were canoeing, flying fox, mountain biking, team building games, vertical challenge and search and rescue. It was hot so we also had a big water fight! We did a group talk and a question and answer session about CF. At night we played board games, toasted marshmallows in the bonfire and then watched a movie.

What kids said about the camp:

- ★ "It was an amazing camp and I loved it!".
- ★ "It was really fun and the most awesome way to do fun things during school holidays".
- ★ "Absolutely amazing".
- ★ "So glad I went, I had a great time".

Proudly funded by Commonwealth Bank Australia

Allyssa climbing high

The 2015 Gang!

Team games

Water fight

If you're interested in coming to camp next year, but might feel a bit nervous, here's some advice from kids that came this year:

- ★ "My advice is that you should not be afraid to meet new people and have fun".
- ★ "That you'd be insane not to try and you'll make friends quickly and you will have so much fun".
- ★ "Just be confident and don't worry because it's a lot of fun and you meet new friends".

LEARNING TO SWALLOW TABLETS

IF YOU ARE HAVING TROUBLE SWALLOWING SOME OF THOSE TABLETS YOU HAVE TO TAKE, THIS IS A GREAT ARTICLE WRITTEN BY OUR COMMUNITY NURSE SHARON DEWAR WHICH PROVIDES SOME HANDY HINTS.

We know that swallowing tablets can be scary, whether the tablets are big or small. Think of your tablets as things which help keep you well, not something to be afraid of. Like any other skill you have learned, practice will make you more confident! You CAN do it!
You may want an adult with you when you practice to offer encouragement.
Start practicing with lolly "tablets". Start with a small one like Nerds, and after swallowing it five times move on to bigger ones. If you can't swallow it five times, go back to the smaller one for more practice.

Here is a list of lollies to practice with from smallest to largest:

- Nerds
- Tic –Tacs
- M&M's / Skittles
- Eclipse Mints / Jelly Belly
- Jelly Beans

POINTS TO REMEMBER:

- Sit up straight.
- Place the lolly "tablet" as far back on your tongue as possible, take a drink of water from a cup and swallow the lolly "tablet".
- Use water that is not too cold.
- You may find shaking your head 'like a duck' helpful to shake the lolly "tablet" to the back of your tongue before you swallow.

Your practice sessions should last about 10-15 minutes.
At the next practice session always begin with the first size lolly "tablet" you used in the previous session. If you swallow this easily on the first attempt move straight on to the next size lolly "tablet".
Remember you need to have success swallowing the next sized lolly "tablet" five times before you move on to a larger lolly "tablet".
You may be able to swallow all the sizes in one session or you may need two to six practice sessions. Once you can swallow each of the sizes you will then be ready to swallow your medication.

STILL HAVING TROUBLE SWALLOWING THOSE TRICKY TABLETS? JUST REMEMBER:

- Take deep breaths and try and stay relaxed.
- Take your time.
- Picture yourself being able to swallow your medication successfully.
- Maybe practicing alone will be best for you, or swallowing the tablet with your favorite drink instead of water sometimes works too.
- These medications you are stressing about are usually the size of or even smaller than the food you easily swallow. So take a deep breath. You CAN do it!

I FEEL FINE! DO I NEED TO TAKE MY MEDICATION?

Do you ever feel that you are feeling okay and there is no need to take those tablets? Well look at it this way: the medication is one of the main reasons why you are feeling healthy, so keep up that great attitude and routine!

DO YOU SOMETIMES FORGET TO TAKE YOUR ENZYMES OR FEEL EMBARRASSED ABOUT TAKING YOUR MEDICATION IN FRONT OF YOUR FRIENDS?

It is understandable that there will be times when you have forgotten your enzymes so try and plan ahead. Have a supply stored safely with your teacher and a few enzymes stored carefully at friends or relatives' homes where you frequently visit. This will be a backup for the times when plans change or you just simply forget!

Your medications help to keep you well and are not something to be ashamed of. Maybe you have a classmate who takes a 'puffer' for asthma when he or she exercises or you might know someone who needs to take Insulin for diabetes. If they don't take their medication they can get sick too.

You can be discrete if you don't want too many people to know when you take your medication or you may find it helpful to explain to your friends why you need to take your medicines.

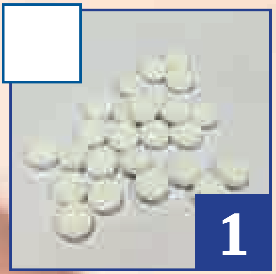
DO YOU KNOW WHAT YOUR MEDICATION IS FOR?

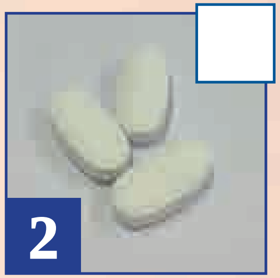
You are asked to take so many tablets- do you know what each of them are for? Below is a quiz. You may have to take all of the tablets in the quiz or only a few.

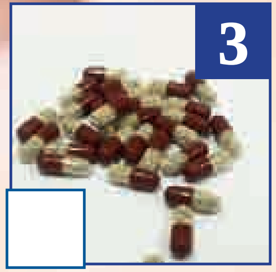
Answers:
1) B 2) C 3) A 4) D

MEDICATION QUIZ

See if you can match the tablet with its name and use. If you are a sibling, see how much you know about your brother or sister's medication.







A. Creon (enzymes)
About 85 % of people with CF need to take these as their pancreas is blocked by mucus so they can't digest their food very well. This is called pancreatic insufficiency. The enzymes assist with food digestion for fats, carbohydrates and proteins.

B. Salt tablet
People with CF can lose large amounts of salt, in their sweat. The loss of salt can be more if the person has a fever or an infection and also in hot weather. The loss of salt can lead to a higher risk of dehydration and this is why people with CF need to replace salt and fluids regularly.

C. Azithromycin
This is an antibiotic given in special doses to some people with CF to reduce inflammation in the airways in the lungs.

D. VitABDECK
This is a vitamin and mineral supplement. It is for vitamins A, B, D, E, C and K. Most people with CF can't absorb all the vitamins they need due to the pancreas not working so they also need a vitamin and mineral supplement. It is important to take these regularly as they help with your bones, eyes and also they help to fight infections in the lungs.

Bean Mosaic

If your parents like lentils and beans you can raid the pantry and make up some really great artwork. This is a good activity to do on a day when it's too hot to go outside.

WHAT YOU WILL NEED

- ☐ A PENCIL
- ☐ CANVAS MADE FROM CARDBOARD BOX OR BOUGHT FROM SHOP
- ☐ SMALL PAINTBRUSH
- ☐ MIXTURE OF DRIED BEANS, SUCH AS LENTILS, CHICKPEAS, BORLOTTI BEANS ETC
- ☐ RULER
- ☐ CRAFT GLUE

STEP 1:
Draw a pattern or picture in pencil on the canvas. Keep it relatively simple. Think about which beans you want to use for the different parts of your picture.

STEP 2:
Use the paintbrush to paint a thin layer of glue in one part of your picture or pattern. Sprinkle the area with one type of beans. Repeat the process with the other beans and other parts of your picture.

STEP 3:
You can use the ruler to tidy up the edges of the beans before starting on the next part.

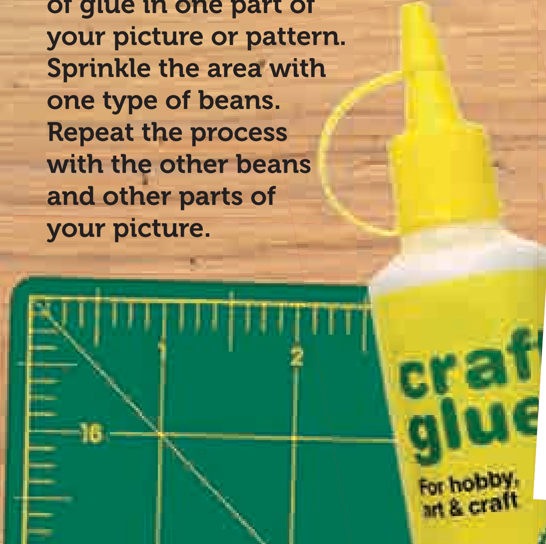
STEP 4:
Allow your masterpiece to dry for an hour or so.

GET CREATIVE

If youre feeling creative, there are lots of different designs you can try. Check out

http://goo.gl/9251yS

for more ideas



PUZZLES AND STUFF

HUMAN BODY QUIZ

adapted from a quiz on www.sciencekids.co.nz

How much do you know about the human body? Test your knowledge with this quiz!

1. What are the muscles found in the front of your thighs known as?
   - ☐ a)lungs
   - ☐ b)biceps
   - ☐ c)quadriceps
   - ☐ d)gluteus maximus

2. True or false? The two chambers at the bottom of your heart are called ventricles?
   - ☐ a)true
   - ☐ b)false

3. What substance are finger nails made of?
   - ☐ a)keratin
   - ☐ b)serotonin
   - ☐ c)cells
   - ☐ d)protein

4. True or false? An adult body has over 500 bones?
   - ☐ a)true
   - ☐ b)false

5. What are the two holes in the nose are called?
   - ☐ a)blow holes
   - ☐ b)nostrils
   - ☐ c)vertebrae
   - ☐ d)epidermis

6. What shape is DNA?
   - ☐ a)double helix
   - ☐ b)a star
   - ☐ c)a pyramid
   - ☐ d)circular

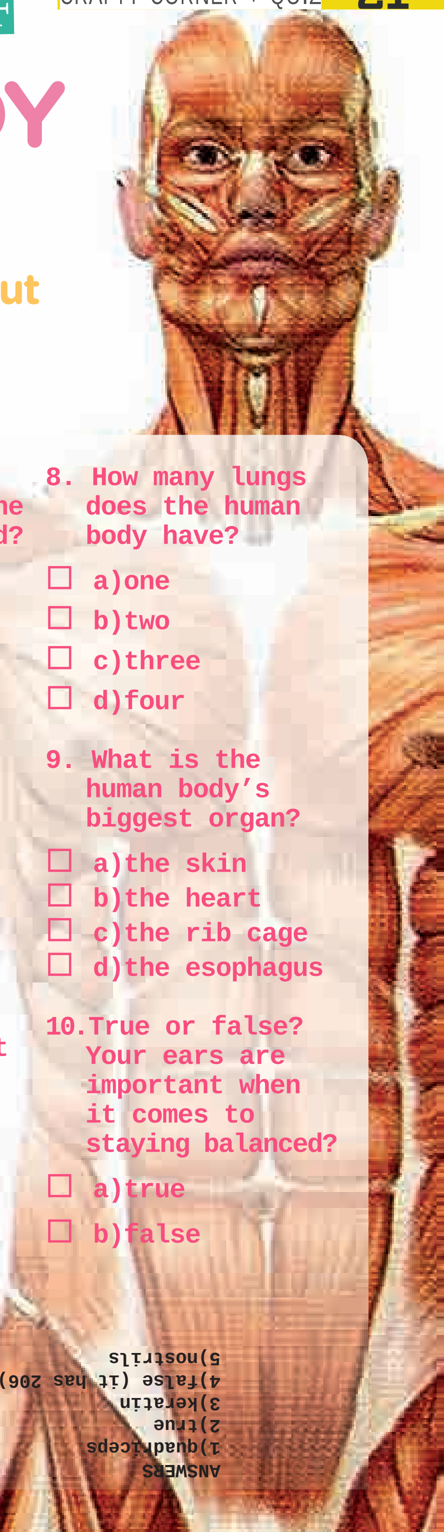
7. What are the bones around your chest that protect organs such as the heart called?
   - ☐ a)cages
   - ☐ b)bone marrow
   - ☐ c)vertebrae
   - ☐ d)ribs

8. How many lungs does the human body have?
   - ☐ a)one
   - ☐ b)two
   - ☐ c)three
   - ☐ d)four

9. What is the human body's biggest organ?
   - ☐ a)the skin
   - ☐ b)the heart
   - ☐ c)the rib cage
   - ☐ d)the esophagus

10. True or false? Your ears are important when it comes to staying balanced?
    - ☐ a)true
    - ☐ b)false

ANSWERS
1)quadriceps
2)true
3)keratin
4)false (it has 206)
5)nostrils
6) a double helix
7) ribs
8) two
9) the skin
10)true



A DAY IN THE LIFE OF . . .

CASSIUS

HI my name is Cassius and I'm 10 years old. I was named after the boxer Muhammad Ali, whose real name was Cassius. My mum says my name suits me as I am a fighter with my CF. I live in the city of Kwinana with my parents, my nearly 2 year old brother and my 4 year old sister. I live a very busy life with lots of exercise and my mum makes sure I am doing my treatment and homework each day.

Here is what a typical Tuesday is like for me:

7a.00 am: I get up, get changed into my school uniform and then I have breakfast which is pancakes with butter and sugar and a glass of milk. I have all my medicine – Creon tablets, salt tablets, a big orange tablet which is a vitamin, a pink tablet which helps the acid in my stomach, a chocolate ball which is a probiotic and an antibiotic. I have all these with water!! Phew!! Then I brush my teeth.

7.30 am: I do my physio – mum growls at me to do it!! Then she sets the timer for 20 minutes and I do 10 sets of 10 breaths on my Pari PEP. I do a nose rinse for my sinuses and a nose spray.

8.20 am: Mum takes my sister Brodii and I to school.

8.30 am: School starts, and I have Maths or English or something!! I'm waiting for recess!!

10.00 am: My alarm on my watch goes off which tells me it's time to eat my snack, which I have on my desk. I have cheese and crackers, 2 salami sticks and some yoghurt.

10.40 am: It's recess and I play a proper game of soccer with my friends. We play against the other Year 4 class. We have organised this ourselves and we play soccer every recess.

11.00 am: The alarm on my watch goes off and I have a chocolate bar. The people sitting next to me are very jealous.

At some point we do some school work, not my favourite subjects today. I enjoy Maths, Music and Italian. My sister also learns Italian and we sing some of the songs together at home.

1.00 pm: Lunch!! I have a canteen order today of a chicken and mayo roll. Some lunch times, my mum packs me a double cheese and bacon burger – yum!!

1.40 pm: We have Computers which I really enjoy, sometimes we do IMovies or Garage Bands.

2.40 pm: If we pack up quickly, we get to play Silent Ball until the bell goes.

3.00 pm: Mum picks Brodii up and then we head home.

3.10 pm: I get dressed for soccer. I play for the Beeliar Spirit team. I've been playing for them for almost 2 years. I played for Cockburn when I was little. My Dad coaches my team. He used to play soccer himself, that's why I got into it. I train 2 days a week and play a game on Sundays. When the soccer season finishes I will then do indoor soccer which my Dad will also coach.

3.20 pm: I have a snack

4.30 pm: Dad takes me to soccer. I love soccer!!

6.15 pm: I get home from soccer practice and have a shower. Playing soccer is my afternoon physio as long as I do lots of running at training. Usually I have to do my physio twice a day if I am not doing lots of exercise.

7.00 pm: Before dinner I take my afternoon medication which is salt tablets, a vitamin and an antibiotic. Then I have dinner which is rice, steak and deep fried chips. I also have some special Portuguese sauce that my Dad's Aunty has made which is high in fat. It's a bit like a gravy. My Dad also makes this sauce too.

7.30 pm: I do my nebuliser, which takes 10 minutes and I can watch TV while I am doing it. Once I'm finished I have a special dessert that my Dad gets ready for me. He always makes me up something fun, but other times I can pick what I want.

7.50 pm: I do my nose rinse and take the Nasonex spray too.

8.00 pm: Time for bed

SUPERSTAR SIBLING

LUC

Having a sibling is one of the most important relationships you can have. Yes your brother or sister can drive you crazy at times but having that special bond can mean you have a close friend, someone to look out for you and share lots of inside jokes with (about mum and dad!!). Research shows that having a good relationship with your sibling/s can lead to happiness later on in life too and can also help your physical health. When Rozee met Luc, who is twelve years old, we were very impressed with how much he is willing to do in honour of his brother Marc, who is one year older.

ROZEE: TELL US ABOUT YOUR 'MAKING A DIFFERENCE' PEAC PROJECT?

At the start of the year we had to come up with an idea for our "Make a Difference" PEAC (Primary Extension and Challange program) project for school. We could either choose something to make a difference to ourselves, try to change something that we think isn't right, make a difference in the community or fundraise to make a difference. My mum gave me the idea to do something for Marc, my older brother who has CF. He doesn't always remember to take his enzymes or take them with him, so mum and I thought about designing enzyme containers that are easier to carry around and that we could also sell and fundraise for CFWA (Cystic Fibrosis WA).

I came up with a design for the containers and have called the project "Marc's 65 Roses". I called it that because my mum told me about the 65 Roses story where the little boy overhears his mum talking and he thinks she is talking about "65 Roses" but she is actually talking about "cystic fibrosis".

Mum helped me order the enzyme containers and I used my birthday money that I have been saving for about nine years to pay for them. I had to do speeches in front of the class about the project and also make a display for my final presentation.

I am advertising the containers through a Facebook page that my mum set up called "Marc's 65 Roses" and I had a display stall at Great Strides. I have 3000 containers to sell and my goal is to raise $6500.

ROZEE: WHAT'S IT LIKE HAVING A BROTHER WHO HAS CF?

I worry about him, especially when he gets admitted to hospital. I look out for him because he's smaller than me. I sort of take on the big brother role and make sure he's doing his physio. But I don't know any different and to me it's just normal.

ROZEE: IT'S AMAZING WHAT YOU HAVE ACHIEVED SO FAR, WHAT ARE YOU UP TO IN THE FUTURE?

Next year I will be in high school and I am going to be doing the Gifted and Talented program there. It's like PEAC but in high school. I will have to catch the train there which will be a big thing for me.

If you are interested in purchasing one of Luc's Creon containers, they are selling for $3.50 each and you can either contact CFWA or ask you parents to look on the Facebook page "Marc's 65 Roses" to order one.

HOW TO MAKE:

NUTS&BOLTS TRAIL MIX

THIS IS A GREAT SNACK WHICH YOU CAN EASILY TAKE WITH YOU FOR AN EXTRA ENERGY SNACK AT AFTER SCHOOL SPORTS OR TO MUNCH ON AT HOME. IF YOU WANT TO GET REALLY CREATIVE YOU COULD MAKE UP A BATCH (WITH SOME ASSISTANCE FROM MUM OR DAD) PUT THEM IN JARS AND GIVE THEM AS GIFTS. CHRISTMAS IS COMING UP SOON SO YOU COULD TREAT YOUR FRIENDS, FAMILY MEMBERS OR TEACHERS.

This recipe serves 6 and has been adapted from a recipe on the website taste.com.au

Time needed:

5 minutes preparation and 8-15 minutes cooking

What you'll need:

2 ½ cups of Nutri-Grain

2 ½ cups of salted mixed nuts or peanuts

a packet of French onion soup mix (35-45 g)

1 tablespoon lemon pepper

1/3 cup olive oil

baking paper

STEP 1:

Preheat the oven to 180 degrees C (get help with this from an adult) and line a large baking tray with baking paper. If you have a fan forced oven set it to 160 degrees C.

STEP 2:

Put all the ingredients in a large bowl and mix together, making sure the nuts and Nutri-Grain are coated in oil.

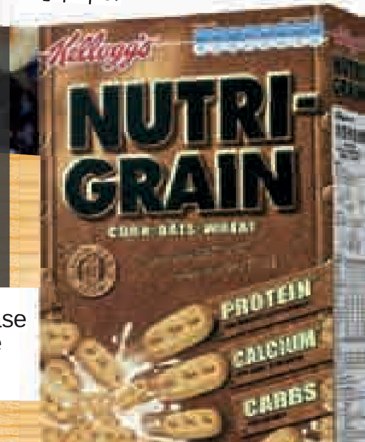
STEP 3:

Spread the mixture evenly over the baking tray. Bake in the oven for 10-15 minutes, stirring every 5 minutes or until hot and crispy (definitely get an adult to do this step as you will need to keep an eye on the mixture to make sure it doesn't burn). If you have a fan forced oven you may only need about 8 minutes instead of 15.

STEP 4:

Take the tray out of the oven when it looks crispy and golden and put aside to cool down completely. Store the Nuts and Bolts mix in an airtight container or jar.

⚠ This recipe contains nuts, so please ensure that you do not serve these to anyone with a nut allergy.



ROZEE REVIEWS

LIVEWIRE

www.livewire.org.au

If you haven't come across them before, Livewire are an organisation available to young people aged 10-20, living with a long-term health condition and their siblings.
It provides a place for you to start up a blog, read articles, watch music videos, enter competitions or visit their chat room. The chat room is open from midday (Eastern Standard time) until midnight seven days a week.

To sign up or have a bit more of a look go to livewire.org.au

BLOGS

SISTERVILLE

https://sisterville.wordpress.com

This is a blog by three sisters aged six to nine who each contribute. They write about everyday things like hairstyles, books and food.

SKY'S CARS

www.skyscars.com

Sky is a nine year old boy from the USA who has a blog about his favourite topic – cars, as well as places he likes to go. He has a YouTube channel too. Since starting his blog, Sky discovered that he was dyslexic, so he feels he has a good avenue to also show people what that's like.

WE WANT YOUR OPINION

It is really important to us to have your feedback about this magazine. We want to provide you with the best magazine we can. You can complete this survey online at http://tinyurl.com/ne79cvp

PHONE/ IPOD APPS: (FREE)

Remember to check with your parents about downloading any apps through iTunes!

CRAZY HELIUM BOOTH

HERE IS AN APP TO MAKE YOU LAUGH, ESPECIALLY IF YOU ARE HAVING A BAD DAY!! For iphone and ipad 4 +

This app can change your voice and your face into an alien or a funny looking creature which you can video and then share on Instagram, send as an email or a text message to give someone else a laugh. It gives you 30 seconds of recording time. See how creative you can be to make yourself and your family and friends have a really good laugh.

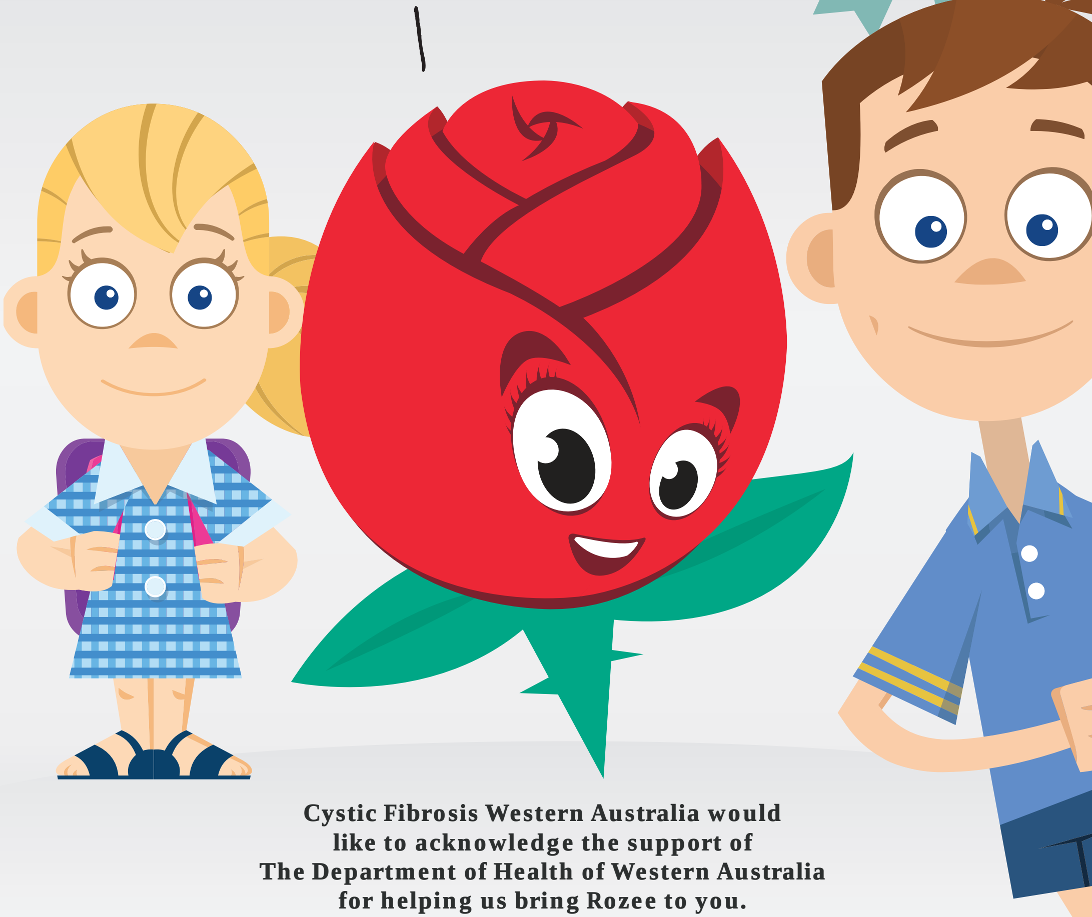
There are advertisements running along the bottom of the app because this is the lite version, which can be a bit annoying.

Rozee is looking for young people to contribute to this page. If you would like to be a regular reviewer or just want to give us a couple of ideas for books, games and items on YouTube, contact us at CFWA.

Take the 65 ROSES CHALLENGE

Take the 65 Roses
Challenge in 2016 with your
school or your family

CONTACT
SHELLEY AT CYSTIC
FIBROSIS WA FOR
MORE DETAILS:
EVENTS@CYSTICFIBROSISWA.ORG



Cystic Fibrosis Western Australia would like to acknowledge the support of The Department of Health of Western Australia for helping us bring Rozee to you.

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