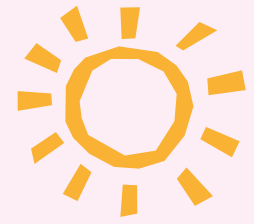


**JULY
2016
Edition**



YOUNG ONES



Welcome

Welcome to the July edition of the Young Ones newsletter. This time it's all about you! I want to share with you some of the inspiring stories from some of our young ones' experiences with CMN. I hope the stories inspire you all to want to share your stories as I would love to read them! Please email them to me at teenage@caringmattersnow.co.uk.



This month you will read how Eva, Jasmine and Josh have overcome issues they have faced surrounding CMN. I look forward to reading more of your stories soon!

Katie x

Experiences

Eva's Story

My name is Eva and I am 13 years old. I was born on the 14th May 2003, which is actually my mum's birthday! My hobbies include; running, cycling, swimming, art, singing, drama, dance and guitar. I want to be an actress, singer and dancer when I am older, but I would also like to be a model!

My birthmarks didn't use to bother me as much as they do now as I tend to notice people looking at me more. I recently bought a bikini after being inspired by a girl with birthmarks like me called Yulianna Yusef as I feel it's time to stop being afraid of something I can't change. To be honest, I think that they are just marks of beauty. I like to think of it that 'We have been kissed by the stars'.



I have been teased about my birthmarks though so I guess that's the down side of it. Sometimes I feel like an alien or something, as people are like "Who is she?" and make odd remarks. But the thing that really knocks my confidence is when people my age laugh or comment at me because

I'm just the same as them and it's really hurtful. I do find swimming the hardest though because I have a large birthmark on my back and my leg and so I usually wear board shorts. Although I have decided to wear board shorts it is with a bikini top instead.

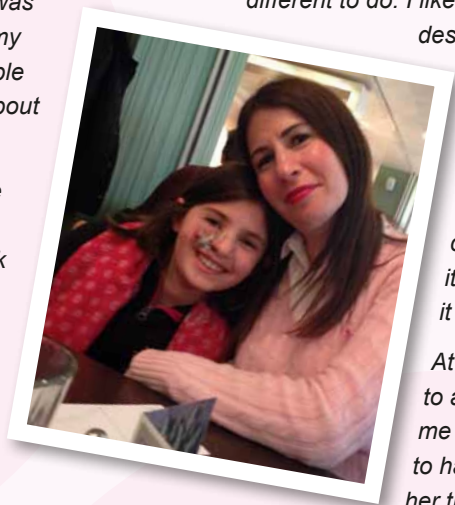
The one thing I've learnt from having birthmarks is that if someone stares or comments on how I look, then to just completely ignore them and pretend that I really don't care about what they are saying and accept that I am in my own unique skin.

Jasmine's Story

Hello, my name is Jasmine and I'm nine years old. I have a large CMN birthmark on my right cheek, which went all the way up to my eye and covered half my nose. I have had six surgeries to reduce my birthmark. The first one was when I was a tiny baby, only nine months old and the last one was in April last year. After my surgery last year, I was really scared to go outside and I hid under my Mummy and Daddy's bed, as I thought people would stare at me and say horrible things about how I looked.

At my school I am the only child with a large birthmark on my face. Sometimes other children are mean to me about my birthmark and bully me at school or at the activity day camp I go to during some of the school holidays. They call me "ugly" or "Scarface". This makes me feel really sad but I think 'What's the worst that can happen?'.
(Note: The text in the original image incorrectly says "I think 'What's the worst that can happen?'." and "I think 'What's the worst that can happen?'." in the original image, but the image shows a different sentence: "This makes me feel really sad but I think 'What's the worst that can happen?'.")

When I go to the CMN London support day I am able to meet other children with the same type of birthmark that I have. I can chat to them and I can tell them about my surgery and what it is like. I like to share my experience with others because it helps them and that makes me feel happy and good about myself.



At the last London support day I prepared a speech. It was a little bit scary, because I spoke in front of a large crowd of 100 people but I wanted to do it so I had courage and I felt really happy because I was able to share my experiences with others and help them.

When I go to the support days, every year there's something different to do. I like helping my Mummy on the registration desk. For example, there are arts and crafts and children's entertainers and it's lots of fun! I also get to meet lots of other children with the same type of birthmark as me. It makes me realise that I'm not the only person like this, lots of other children are going through what I am and it's good to be able to speak to them about it and discuss my feelings with them.

At the London support day last year I spoke to a little girl of about 7 to 8 and she told me how she was feeling as she was about to have surgery like me. I helped explain to her that she would be put to sleep and she wouldn't feel a thing. The girl felt a lot better

after I spoke to her and she was less scared about her surgery and that made me feel really happy that I was able to help her.

Thank you, love from Jasmine

Josh's story

I'm Josh and this is my story of how I have helped the CMN research. I first gave a blood sample when I was a baby and it was discovered I had a gene that lots of other people with CMN did not have. When I was 6 Dr Kinsler asked me if I could help again by having a biopsy taken from my CMN on my back. A biopsy is when small pieces of skin are removed so they can look at it very closely. On the day of the biopsy we travelled to GOSH, where we met the lady who was going to do it and she explained what was going to happen. The first thing they did was put some cream on the biopsy area to make it numb and then I had a local anaesthetic in the same area to make sure it was really numb as the tool to



take the skin goes past your skin for it to work. I found it quite uncomfortable for a bit but when Dr Kinsler came to see me she was so happy I knew it was worth it. This year the first blood sample had been used up and because my blood is very useful to the research I was asked to give some more.

At first I wasn't sure because the biopsy did hurt for a while but my Dad explained it was a very quick and easy thing to do so we went to the hospital and they put the numbing cream on my arm this time and once it was numb they put a needle in which took out the blood and I didn't feel a thing. A couple of weeks ago I was very proud to receive a certificate from Caring Matters. Now to say well done and thank you for my help with the research.

We need you!!

It's nearly the summer holidays and you will all soon have lots of extra time to plan fun events with your friends. Why not have fun and raise money for Caring Matters Now at the same time?

For the next newsletter, I would like to feature all the hard work you are doing to raise funds and awareness for Caring Matters Now. Why not organise



a cake sale, do a car wash for family and friends, sell handmade cards or anything else you can think of! Make sure to take lots of pictures of your event and send your story into me! **The best fundraising idea will win a prize!**

Please email me at teenage@caringmattersnow.co.uk

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