

## **Face Everything And Rise**

### **Newsletter**

Charity No: 1196975



## A roundup of 2023... and what a year it's been!



#### **SUMMARY OF 2023**

This year we have held a total of 28 FEAR events across the Country. The events have included swimming, sailing, rock climbing, archery, canoeing, Alton Towers and a run/walk/push event in Windsor.

A total of 3,061 people have attended our events over the year, and I can't thank you all enough for coming. It has been the most amazing year, because of you!

In February we launched our FEAR Drysuits. Over the last 11 months, a whopping 204 people have borrowed a Drysuit and have been able to swim safely.

In September we introduced the 'FEAR Award', and every month we are astonished by the number of nominations we receive.

In November, Eddie the 'FEAR Van' joined the team and we can't wait for him to enable more people to access public events and music festivals. It really has been a year to remember!



These are just some of the dates for next year's FEAR swim events. They aren't yet up on the website, but they will be soon. We haven't yet confirmed dates with Camberley but we will be holding 3/4 events there in 2024. We are also looking at other swimming venues to add to our list. In addition to our swimming events we will also be adding a number of sailing and skiing dates to the diary too.

Romsey Rapids	Rotherham	Triangle	Camberley
24th Feb (4-6pm)	10th Feb (3-5pm)	13th April (4:30-6:30pm)	TBC
25th May (4-6pm)	16th March (3-5pm)	27th July (4:30-6:30pm)	
20th July (4-6pm)	22nd June (3-5pm)	9th Nov (4:30-6:30pm)	
14th Sept (4-6pm)	28th Sept (3-5pm)		
28th Dec (4-6pm)	16th Nov (3-5pm)		



Eddie is a fully converted VW Van, and will be used as a safe space for people with feeding tubes and central lines to connect and disconnect their feeds or treatments.

Not only will Eddie be at all of our future FEAR events for you to use, but he will also be at big public events across the country; enabling you to go to music festivals without the worry of where to 'connect' or store your feed. He is also fully accessible for wheelchair users, has a sensory twist inside, and has all the storage you could possibly need for ancillaries!

Next year, on the FEAR website, you will soon be able to see a list of events where Eddie will be. There will also be a function for you to request for us to be at an event near you.

The sole purpose of Eddie is to support YOU, and to give you the confidence to visit music festivals and events, without the worry of where to store your feed or medication, or where you can connect and disconnect yourself safely. Especially when the festival ends up being in a muddy field.

For anyone wondering where the name came from...Eddie is named after an extremely special man I met in July, who believed in me and my vision for FEAR, and helped make the dream become a reality!!

As always, I will keep you all updated, and will let you know when Eddie's webpage is up and running...





## FEAR DRYSUITS

Since February, 204 people (Children and Adults) have been able to swim using a FEAR Drysuit. This includes people borrowing a FEAR Drysuit at our events as well as for Home use...

Thank you to everyone who has made a donation to FEAR or has sponsored a Drysuit.

Every penny has made a big, big difference



## **BIG THANK YOU**



HUGE Thank you to Jane and Paul for sponsoring 9 FEAR Drysuits

Instead of sending Christmas gifts and cards, Jane and Paul opened a JustGiving page to fundraise towards the cost of 1 FEAR Drysuit. However, their aim of 1 suit rapidly turned into 3, then 5 and ended up on 9!! It's an amazing amount of money and is going to make such a big difference to so many, thank you!!



Places Leisure for sponsoring 10 FEAR Drysuits. Thisis going to make a huge difference to so many over the years. One of the Drysuits sponsored by Places Leisure was used by someone at our recent FEAR swim event... and it was the first time she'd swam in years



BOOST Charitable Trust very kindly sponsored 2 FEAR Drysuits recently. They've already been made and are being used by two Children in Hampshire



ABBVIE Pharmaceutical Company have recently sponsored 10 FEAR Drysuits. The suits are currently being made and will be ready for use in 2024



#### MILEY'S FEAR DRYSUIT STORY

#### This is what Miley's Mum has shared:

"This was Miley on her very first holiday...

Up until this year we weren't able to fly or go abroad. But after so many years of not being able to go abroad, this year we all went to Spain. Because of the Drysuit, Miley was able to enjoy the water parks and the hotel pools with her brothers, sister and cousins."



## JADE'S FEAR DRYSUIT STORY

"I'm having the best time ever, everyone has said they have never seen me smile soo much with happiness like I have when I'm in my suit. I know I've said it loads of times but I honestly can't thank you enough for giving me the opportunity to have a suit and the happiness and joy it's given me is something I will treasure for life!!"





### **ELLA'S FEAR DRYSUIT EXPERIENCE**



Ella came to our Christmas event at Camberely and was able to swim for the first time in years. Funnily enough, the Drysuit Ella borrowed was the one which was sponsored by Phil (the manager at Camberley Leisure Centre), so it was great for Phil to see the Drysuit in action and to see the difference it makes.



There are currently 105 FEAR Drysuits being used across England, which is great!!

We are due a delivery of more Drysuits next week, so if you would like to borrow a FEAR Drysuit, and have permission from your Hospital team, then please visit our website to make a request:

www.faceeverything.co.uk/feardrysuits

# Mour fories Cirley



Arley started formal swimming lessons when he was just 2 years old. He was a natural and as soon as his competence developed, he took his passion from the pool to the sea, learning to body board and surf with his family. Fast forward to July 2021 when the world was just getting back to "normal" after the pandemic, swimming pools were starting to open up again and the possibility of visiting the coast for a surf was starting to become a reality. Unfortunately, on 15th July 2021, Arley was diagnosed with T-cell Acute Lymphoblastic Leukaemia. Within hours of his diagnosis, he started intensive treatment and was fitted with a Hickman line; a central line directly into his main artery. Due to the high risk of infection, this line could not get wet and would be needed for the length of his treatment, a treatment plan that lasted 3.5 Years! The intensive chemotherapy left Arley with little strength and affected the ligaments and tendons in his legs. We knew we needed to get him back in the water, not just because this was one of his passions, but because of the physiotherapy benefits. We had heard about these Hammond Dry suits that could be worn to protect the Hickman line and after investigation, we found a couple of fantastic charities, one of which was FEAR, who could help with the funding and provision of these suits. We received our first Hammond suit 11 months after diagnosis, and Arley was back in the water for the first time, paddle boarding with his siblings.



After speaking to our local EveryOneActive centre, Arley had a trial at the swimming pool as he was desperate to continue his swimming lessons. At first Arley found it really hard. He felt self-conscious about wearing the suit in a public pool, but he soon gained his confidence and wanted to educate those around him about his Leukaemia. He also found the suit restrictive under his arms limiting certain strokes, and we were worried about his line getting wet. We bought him a special fleece lined rash vest to wear underneath and spoke to the hospital who had heard about some special bungs that you can put on the end of his Hickman lines as added protection. After a few weeks of being back in the pool, Arley had progressed up the ladder in his swimming stages and wanted to do a trial for the local swimming club. In the September of 2022, he completed a trial at Ware swimming club and was accepted with flying colours.

# NAME: Carley Don ...

Arley was now swimming twice a week and after contacting Swim England, Arley was given an exemption certificate for his suit meaning he could compete in official competitions. In May 2023, he competed in his first open meet (a swimming competition for all the local clubs). He did his first race in the 50m backstroke and although he didn't gain a podium finish, he got himself a PB and the backing of the whole crowd. Arley has since competed in his club championships, now diving from the blocks at the start, winning a Bronze medal in the 50m Breaststroke and taking 20 seconds off his previous freestyle time! Some training sessions he finds really hard and tiring, not just because of the suit but because he also receives daily oral chemotherapy, two lots on a Wednesday, monthly IV chemotherapy, a week of steroids every 4 weeks and 3 monthly lumbar punctures with spinal chemo. Despite this, he continues to train twice a week and is now determined to achieve sub 1 minute across 50 metres in all of his strokes. Who knows what else he will challenge himself with!

The dry suit has made a huge difference to him, both physically and mentally. It has also given us as a family of 5 the freedom to be together in and on the water. We can't thank Kim at FEAR enough for her kindness

and support.



# Mour Fories Mane: Molly



This is Molly, and this year she has been to every single FEAR event!... Even when it's meant an 8hour round trip to get to the event, they've been there! Amazing dedication!

In February, FEAR held a swimming event in Sheffield, which Molly came to. Back then Molly would use a float ring in the water and would rarely let go of her Mum's hand for security.

Fast forward 10 months and Molly is now able to put her face in the water, dive to the bottom of the pool to collect sinking toys, and even confidently jumps off of the poolside into water. Molly's confidence has grown from strength to strength, and we are all extremely proud of what she has achieved at each FEAR event.



In addition to the numerous swimming achievements, Molly has also conquered a number of FEAR's this year, and has always tried her best at all of the activities she has tried.

At Avon Tyrell, Molly learnt to use the archery bow independently, and despite being scared of the climbing wall and the canoe, Molly tried both activities and ended up loving the canoeing activity.



Molly came to our sailing event on her 6th birthday and although she wasn't overly keen on the waves, Molly gave it a go and even spotted a mermaid in the water!

As if that wasn't already a big enough achievement... Despite only having surgery a couple of weeks ago, Molly joined us on a Holiday to Disney Land Paris last week and loved it!! It was her first time abroad!



I, for one, am VERY proud of EVERYTHING you have achieved this year Molly. You are an inspiration and it has been a joy to see you flourish! I am therefore, extremely honoured to announce that you will receive this month's FEAR Award.

Well Done Molly!

# DO YOU KNOW SOMEONE WHO YOU'D LIKE TO NOMINATE?



At FEAR, we understand just how important it is to recognise achievements! ... That's why we've introduced the FEAR Award

**Award criteria:** For children and adults who receive artificial nutrition or long term IV treatments. Also includes Family members, carers or nurses.

**How to nominate?** Simply fill in the form on the website, and at the end of the month we will announce the recipient!

#### **OCTOBER**

Arley - for smashing his personal bests in swimming and for diving off of the start block during his swimming gala!





#### **NOVEMBER**

Noah - For being super brave during his recent surgery... and... for learning to blow bubbles as part of his chect physio exercises



#### **DECEMBER**

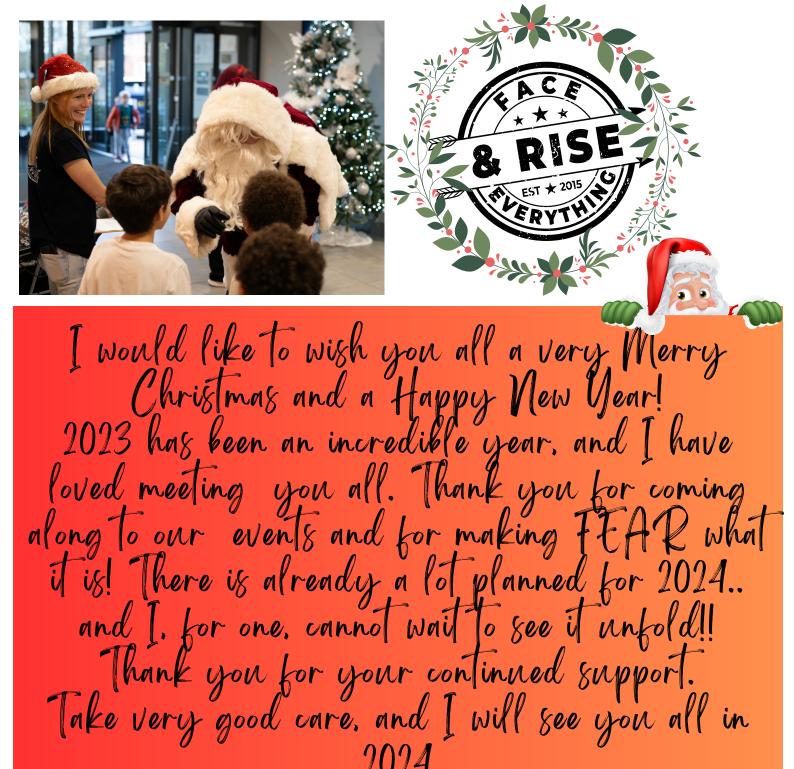
Molly- For everything you have achieved this year.
From swimming, to canoeing to self propelling in your wheelchair. You've achieved so much!



www.faceeverything.co.uk/fear-award



fear@faceeverything.co.uk



Website: www.faceeverything.co.uk

love. Kim x

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