

# INSPIRE

CARING  
MATTERS  
NOW



ANNUAL MAGAZINE 2023 - 24



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EVENTS

NEW 08  
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**Caring Matter Now** is the only charity in the UK and Ireland dedicated to supporting children and adults living with Congenital Melanocytic Naevus.

**The 3 main aims of the charity are:**  
To support those affected by CMN  
To raise awareness about CMN  
To fund research into finding the cure for CMN

## Caring Matters Now Staff Team



**Jodi Whitehouse** is the Chief Executive Officer, responsible for implementing our long-term strategy, with a key focus on special projects, global awareness and staff management.



**Lisa Sly** is our Finance Officer, responsible for implementing all financial operations.



**Hannah Cree** is our Support Pathway Practitioner, responsible for implementing the support we provide to all members.



**Carolyn Lewis** is our Charity Administrator, responsible for administrative duties across the charity's operations.



**Rachel Swanson** is our Fundraising & Communications Coordinator, responsible for external communications with members and supporters, alongside providing assistance to all our wonderful fundraisers.

## Caring Matters Now Board of Trustees

The board consists of 6 trustees who are parents of children and adults affected by CMN. Each trustee has specific focus areas within the charity's operations to ensure it is achieving all of its 3 aims: Support, Awareness and Research.



Val Unsworth (Chair)



Ian Chance (Treasurer)



Tracy Traverse-Burley



Emma Robins



Ruth Gold



Kuhan Valleekanthan

Caring Matters Now is a registered charity in England and Wales (1192670) working in partnership with our sister charity Caring Matters Now Ireland (20205990)



# INSPIRE CARING MATTERS NOW

## WELCOME

I am delighted to welcome you to Caring Matters Now and to share with you all our charity news in this year's edition of INSPIRE.

**We hold dear our promise of providing all our support through FREE membership, without constraint, and to do this we rely on the generosity of giving.** Through the generosity of our members and supporters in 2023, we have been able to continue developing the support we provide to children and adults living with CMN, continue to increase awareness of CMN and, continue to fund pioneering research to find the cure for CMN.

**Over the past 4 years, Caring Matters Now has grown at a phenomenal rate, with the number of families we support increasing by 100%. In 2019 we were supporting 389 families affected by CMN, in 2024 we are supporting 778 families affected by CMN!**

We have also seen growth in our staff and volunteer teams this year, with the wonderful recruitment of Carolyn Lewis as the charity's

office administrator in February 2023, and the recruitment of new volunteer support contacts located across the UK.

This year we want to provide even more opportunities for you to connect with our CMN community through online events and in-person events. In September 2024 we are planning to host regional walks across the UK for all our members. Your regional support contact will share with you when your regional walk will be taking place. This is a great opportunity to connect with your regional CMN community through walking and talking, whilst raising funds for Caring Matters Now. More details will be coming soon, so watch this space!

This year we are introducing a quarterly newsletter, as we always have so much to share with you, we want to keep you up to date with charity developments more regularly. Keep an eye out for our first interactive newsletter which will land in your inbox this Spring, and please do stay connected with us throughout the year by social media too.

For now, go and grab a cuppa, put your feet up and enjoy reading this year's edition of INSPIRE.

With warmest wishes for 2024,

*Founder & CEO of Caring Matters Now*

# Child To Adult Support Pathway

## 0-3 Years



We provide specialised early years support and information for parents caring for babies born with CMN. Parents of a new-born with CMN are offered an hour-long initial support consultation with our Support Pathway Practitioner. As a charity we are committed to educating medical professionals to aid early diagnosis, with particular focus on partnering with midwives and dermatologists across the UK & Ireland. We host a monthly online Baby and Toddler community over the autumn and winter months.

## 4-11 Years

We support families throughout the primary years by providing age-specific support literature, school resource packs, parent support contacts, family friendly regional gatherings, and support events for parents, children and siblings



## 12-16 Years

When a child member turns 12 years old, they will start to receive direct support from our Teens Contact Team. Teenage members will be invited to participate in the Young Ambassadors Programme and our teen support events. We provide Parent Support Guides for those caring for teenagers living with CMN. We host an all-age monthly online gaming community over the autumn and winter months, which has proven to organically develop friendships particularly amongst our teenage members.



## 17-24 Years

When a teenage member turns 17 years old, they will start to receive direct support from Katy Jackson who specifically supports members aged 17-24 years and assists them in transitioning from a child member to an adult member. Our 17-24 year old members will be invited to participate in the Level 2 Young Ambassadors Programme and to attend our young adult support events.



## 18+ Years

Young adults are invited to register as an adult member, rather than continuing under a parent's registration. Adult members have access to our Adult Contact Team, are invited to our adult support events and to participate in adult-focused research studies. Adults experiencing new problems with their CMN can be referred to the Adult Clinic in St Thomas' Hospital London.





# BIG Weekend Away

**Our BIG weekend away took place 7th-9th July 2023 at Liddington PGL, Swindon.**

Through the generosity of our supporters and funding providers, we were able to offer free places to all children and adults living with CMN, as well as providing discounted places for parents and guardians.

“Thanks for an AMAZING weekend! The kids didn't want to leave & are still talking non-stop about it. Our daughter proudly held up her top & showed her kindergarten friends she went to an event “with people like me”.

- Parent of child with CMN.

We had a record number joining us for our jam-packed weekend programme, with 74 families travelling from all corners of the UK, as well as international families joining us too! We welcomed 14 new families, including one family travelling all the way from Australia and, 60

returning families who recognised each other from previous charity events.

Liddington PGL proved to be a great venue for hosting our BIG Weekend, with acres of grounds full of outdoor pursuit activities, comfortable family accommodation, a well catered canteen, meeting spaces, and a common room which we used as our central base for providing families with a constant stream of tea, coffee and cake!

Alongside our exciting programme of outdoor pursuit activities, we hosted a variety of psychosocial workshops for all ages and interactive presentations, including a CMN research presentation delivered by Professor Veronica Kinsler.

The BIG Weekend gave our families time and space to develop friendships and connections, with many stories and personal experiences of living with CMN shared with one another.



# JURASSIC COAST TREK



In September 2023 our wonderful team of 13 trekkers took on the incredible Jurassic Coast Challenge, trekking 32 miles over 2 days along the beautiful south coast of England. The team raised an incredible **£14,221.82**. We are all so proud of the team for completing this extreme challenge and raising vital funds towards the work of Caring Matters Now.



## It means more...

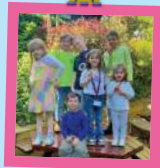
Two trekkers, Ryan and Karl, attended the charity's BIG Weekend in July 2023 with their families. During the weekend, both families found themselves in the same activities group and naturally developed a good friendship; enabling them to organically share experiences of caring for a child with CMN, and they quickly developed a strong bond. The dad's wanted to give back to the charity for the wonderful experience the Big Weekend gave to their families, and so both Ryan and Karl signed up to the Jurassic Coast Trek. This event would also give the two families

another opportunity to connect again. After signing up to the trek, the Dad's raised over £1000 for Caring Matters Now in less than 48 hours! Both families made the most out of the weekend trek... camping together overnight and cooking bacon butties for the rest of the team! Beyond the trek and the BIG Weekend, Ryan and Karl are now part of a Dad's, WhatsApp group which was formed for those who attended the BIG Weekend. The WhatsApp group has proved to be an easy way for Dad's to stay connected, and so we hope to open this group up to all Dads registered with the charity soon!



Why not challenge yourself this year? Scan the QR code above to see all the fundraising opportunities you can sign up to!

# 2024 Events



We have been busy planning all our in-person support events across the UK. All our events are FREE to attend and designed to give you time and space to engage with our CMN community, build connections, provide mutual support and develop meaningful friendships.

## »» Sat 13th Apr

**Adult Event, hosted by Caring Matters Now Ireland**  
Butlers Chocolate Factory, Dublin

## »» Sat 20th Apr

**London & South East Combined Regional Gathering**  
Science Museum, London

## »» Sat 11th May

**East Anglia Regional Gathering**  
Colchester Zoo, Colchester

## »» Sat 1st Jun

**Northern Ireland Regional Gathering**  
Belfast Zoo, Belfast

## »» Sat 15th Jun

**Southwest Regional Gathering**  
Woodlands Leisure Park, Devon

## »» Sat 6th Jul

**Scottish Highlands**  
Informal café meet-up

## »» Sat 13th Jul

**North East Regional Gathering**  
Northumberland Zoo, Felton

## »» Sat 3rd Aug

**Scotland Gathering**  
Riverside Museum, Glasgow

## »» Sat 14th Sep

**North West, North Wales & West Midlands Combined Regional Gathering**  
BeWILDerwood, Whitchurch

## »» Sat 29th Sep

**West England & South Wales Regional Gathering**  
Techniquet, Cardiff

## »» Sat 5th Oct

**Ireland Gathering, hosted by Caring Matters Now Ireland**  
Tipperary Park

## »» Sat 2nd Nov

**Adult Event**  
Boom Battle Bar, Birmingham

Scan the QR code to register for our 2024 events!





# Engaging Your Community

**Living with CMN or parenting a child with CMN can feel quite overwhelming and stir up a whole range of emotions such as fear, anxiety, and worry. As a charity, we want to support our members to reach their full potential and help them to develop key social and emotional life skills.** Often this involves exploring how best to raise awareness within your community, whether that's amongst peers in the classroom or colleagues in the workplace. With this support, our members can thrive in day-to-day life, educate others about visible differences, build self-esteem, reduce feelings of isolation, and prevent bullying or discrimination.

Most often, our members come to us for support around a time of transition - moving schools or workplace, joining a new sports club, or meeting new people and forming close relationships.

Maybe you're wondering, 'How do I tell my neighbours?' 'What can I do at the football club to educate other families?' 'How can I avoid the same conversations over and over again?'

We have two initiatives which will help you organically engage and educate your community about CMN.

**1. Our Coffee & Cake initiative** is a fantastic tool for providing an ideal platform to raise awareness of CMN within your community. Not only does our Coffee and Cake event raise vital funds for further the work of Caring Matters Now, it also supports our members to talk confidently about CMN, building an educated and supportive network around them.

**2. We have created a pocket-sized CMN awareness card**, which was a suggestion from our Baby & Toddler online community. This little card can be carried around with you and given to anyone who may ask you about CMN. The card provides a QR code which enables members of your community to find out more about CMN on our website. We have two card options; one for the person living with CMN and the other for a parent of a child living with CMN.



Scan the QR code to order our **Coffee & Cake morning kit** or order a batch of CMN awareness cards by emailing [support@caringmattersnow.co.uk](mailto:support@caringmattersnow.co.uk)



# Online Community Groups

By popular demand we are gearing up to restart our online community groups throughout the autumn and winter months. The aim of our monthly groups is to cultivate organic communities of members in which friendships develop, and mutual support is provided.



**Age 0-3**

**Do you have a child aged 0-3?**  
Join us once a month for our  
**Baby & Toddler Event**



**Gaming**

**Do you love gaming?**  
Join us once a month for our  
**Online Gaming Event**



**Age 4-7**

**Do you have a child aged 4-7?**  
Join us once a month for our  
**Stay & Play Event**

# Support Guides

Parent Support Guides have been designed to give you helpful guidance on how to navigate caring for a child with CMN through each stage of childhood. The School Support Guide provides your child's nursery, primary and secondary school setting with information about CMN, how to support a child living with CMN in the educational setting, how to manage curiosity about CMN from other children and access to teaching resources focused on accepting appearance diversity.



All our literature resources are **FREE OF CHARGE** to order and available to download from our website. **Scan the QR code** to access our support literature.



# Partner with us in 2024

Make a difference by becoming a monthly donor this year



We hold dear our promise of providing support through FREE membership, without constraint, and to do this we rely on the generosity of giving.

As Caring Matters Now continues to grow, we need to see an increase in our annual income stream by 25%. To help us reach this target, please would you consider becoming a monthly donor?

**Donate  
£10**



to fund our interactive Baby & Toddler Activity Pack which we gift to each family joining our monthly Baby & Toddler Online Community Group

**Donate  
£15**



to fund a family to attend a CMN support event -bringing together our CMN community to share experiences, develop friendships & reduce isolation.

**Donate  
£20**



to pay for the CMN medical booklet to reach 20 medical professionals, ensuring the right diagnosis & medical care is given to those living with CMN

Monthly donations give us the breathing space to think beyond our immediate needs, so we can plan strategically, budget wisely and make our spending decisions with more confidence.

If every member / family within the charity gave £15 a month, we would achieve our annual fundraising target. We do understand that not everyone will be able to give £15 a month - any regular donation you are able to give would really help us to make headway in reaching our target.

If you would like to partner with us throughout 2024 and beyond, you can set your monthly donation by scanning this QR Code.





# Challenge Yourself in 2024



This year we want to provide all our members with brilliant NEW opportunities to challenge yourself and raise funds for Caring Matters Now. We have 800 events across the UK you can choose from...



## INFLATABLE 5K

FOR THE WHOLE FAMILY  
MULTIPLE UK LOCALITONS

Get ready to bounce your way through the world's BIGGEST and most EPIC Inflatable 5K Obstacle Course in aid of Caring Matters Now! Grab your kids or friends, lace up your trainers, and get ready to jump, slide and bounce your way to the finish line.



## JUMP FOR CMN

Bungee Jumps & Skydives  
MULTIPLE UK LOCALITONS

Ready to take the plunge for CMN? Simply choose your preferred location and date to book your bungee jump experience.



## RUNS & RIDES

KIDS & ADULT RUNS, PLUS PARK ENTRY!  
Sign up to a 5k, 10k or Half Marathon at Alton Towers or Thorpe Park. You can take on a chip timed 5k, 10k or Half Marathon to earn yourself a unique themed medal before enjoying the incredible rides at the park. FREE ride access after the race is included in your entry!

# 5k | 10k | Half Marathons

Sign up to a run near you!





## Living With CMN Helen's Story

### I first discovered Caring Matters Now back in 2020.

I will never forget that day. It was mid covid lockdown and I was getting breakfast ready for my son, who was 2 at the time. We had the radio on in the kitchen and they started talking about this charity called Caring Matters Now, I was only half listening and then suddenly the more they started to describe the work of the charity the more engaged I became. As they described the condition of people that the charity supports, I suddenly realised they were describing people just like me! I immediately looked up the Caring Matters Now website and burst into tears. Finally, at the age of 32, I had found out that there were other people with my condition, and I was no longer the only one.

It sounds dramatic, but I had felt alone for so many years, always wondering why I had these strange birthmarks and nobody else did. My CMN covers my entire back and I also have hundreds of satellites across my arms, legs, and face.

At just a few days old I was lucky enough to be introduced to an incredible Consultant Plastic Surgeon in Alder Hey Children's Hospital in Liverpool, he supported me with my condition until I was in my twenties (until he retired) and often told me at our annual check-up appointments that he had included my photos in another presentation that he had delivered. Mr Green was willing to do something that other doctors at the time did not want to try, he performed dermabrasion on my back across multiple operations while I was just a couple of weeks old. I can't remember this of course, but my parents have talked to me



about it a lot and have shown me photos of the before and after. Unfortunately, he was unable to remove the mark on my back completely, as it was too large an area, however he did succeed in making it significantly lighter.



As a toddler I continued to visit Alder Hey, where Mr Green performed multiple operations to remove some of the larger satellites on my arms and legs that he was concerned about. He also removed a large amount of excess tissue that I had in my right leg, which turns out to have been linked to my CMN. I ended up with a scar that goes diagonally across the front of my right calf, but at least I could finally fit my wellies on! Being in Alder Hey hospital for these operations is probably one of my earliest childhood memories. The staff were so kind to me on the ward, letting me play with the different toys and due to my young age, they let my mum stay with me overnight on a camp bed. I don't ever remember feeling scared before having the general anaesthetic, the staff always put me at ease, although I am sure it was scary for my Mum and Dad.

As a young adult, I was fortunate to meet another incredible Consultant and had many sessions of laser treatment to reduce the pigmentation of the satellites on my legs and back. While this did initially have an impressive impact, over the years the satellites and my back have slowly become darker again. I really wish that Caring Matters Now had existed when I was a child, it would have been so helpful for my parents to have had more information and support and the chance to meet other families who were on a similar journey. I am also very pleased to see that the charity supports siblings of



children with CMN. For my sister, at the age of three, she had to quickly adapt not only to the shock of having a younger sibling, but a sibling with a condition that nobody at the time really understood. She never complained when my CMN meant that Mum had to be at hospital with me instead of spending time with her, nor did she ever hesitate to support me if people made comments about my skin when I was growing up.

Like many others who have shared their CMN story, I was very self-conscious as a child and teenager. I found it particularly hard during the summer and didn't enjoy the comments and staring when I went swimming on holiday. It was hard to cover up then as people back in the early 90s were not as conscious about protecting their skin from sun damage as we are today! Swimwear that covered your back simply did not exist. When my great aunt, who lived in Australia, sent over two swimsuits for me that had a high back it helped me to have more confidence to go in the water.

Growing up I struggled when people said mean things about my birthmarks, it made a huge dent in my confidence, and I didn't always tell

my parents as I didn't want to upset them. I learnt to wear clothes that would cover up my back and legs as much as possible. I had a good group of close school friends and even though they didn't understand my condition either, they just accepted me for me.

When I started university, I was excited for a new adventure, but was also concerned about people judging me for my appearance again. I didn't expect it, but it was here that I met my soulmate, Johnny. He never once questioned my condition and now years later we are married with two beautiful children.

Becoming a Mum, myself, has really helped me to be more accepting of my skin and I want my boys to grow up understanding about visible difference and that it is a positive that we are not all the same. I would love to be able to tell my younger self to be more confident and love the skin you're in!

I am so pleased that I have recently discovered Caring Matters Now, I am happy to support others with CMN and hope that I can help to raise awareness of both the charity and the condition.



## Adult Support For 18+ Community



We are continually enhancing the support we offer to our 18+ community, coordinated by our dedicated support team, Katy, Stacey & Anne. The adult support team are available to chat with adult members, share experiences and answer any questions about living with CMN. Scan this QR code to read more about the support provided for 18+ members



Each year, our adult support team host online and in-person events for our community of adults living with CMN. Up-and-coming events include:



**Sat 13th Apr**  
**Adult Event, hosted by CMN Ireland**  
Butlers Chocolate Factory, Dublin

**Wed 25th Sep**  
**Annual CMN Research Update**  
Online

**Sat 2nd Nov**  
**Adult Event hosted by CMN**  
Boom Battle Bar, Birmingham

# CMN On Tour



In September 2023 Caring Matters Now went out on the road again to continue raising awareness of Congenital Melanocytic Naevi with medical professionals from across the UK & Ireland. This time, we travelled to Harrogate, North Yorkshire to exhibit at the British Dermatological Nursing Group (BDNG) Conference.

Two of our volunteers, Rebecca and Helen, proudly represented Caring Matters Now on our exhibition stand, which was centrally situated within the Patient Support Hub. Despite having one of the smallest stands in comparison to the pharmaceutical companies, we were proud to have such a huge impact on the event. The CMN portraits took centre stage in the entrance foyer, wowing hundreds of delegates each time they entered the exhibition hall in between seminar sessions, describing them as 'beautiful', 'brave' and 'inspiring'.

Over the two-day conference, we had the opportunity to speak with many nursing professionals, who were hearing about CMN for the first time. It was a pleasure to answer their questions, share the aims of the charity and guidance on how to put people in touch with Caring Matters Now if they meet a patient with CMN in the future.

Helen and Rebecca shared their own personal connections with CMN, which had a big impact and helped to bring the condition to life with delegates who had never seen or heard of CMN before. After meaningful conversations, many nurses wanted to receive further information about the work of the charity and some even purchased the 'how do you C Me Now?' book on the spot!

Helen and Rebecca said it was a real honour to represent CMN and raise awareness of the condition on behalf of all members.



We exhibited at 5 national medical conferences throughout 2023 to raise awareness of CMN:

- **Primary Care & Public Health**, 17th – 18th May
- **Royal College of Midwives**, 15th June 2023
- **British Association of Dermatologists**, 27th – 29th June
- **British Dermatology Nursing Group**, 19th – 21st September
- **Royal College of General Practitioners**, 19th – 20th October



# CMN Research Update

by Professor Veronica Kinsler

CMN research is going well overall. It is extremely busy as always, with lots of trying to get money from grant funders, lots of trying to publish papers, and lots of trying to get experiments finished. We are very lucky still to be based in the Crick Institute which has really fantastic scientific facilities and where research into CMN is valued.



This year the team has just published a really important paper looking at people who hadn't had a gene identified in their skin – in other words they didn't have either the NRAS spelling mistake gene changes or the BRAF spelling mistake gene change. This study was co-led by Dr Sara Barberan Martin (senior post-doc) and Dr Satyamaanasa Polubothu (now an independent group leader).

This year also marked the start of Morgan Zolkwer's PhD studies into the psychological aspects of living with CMN. Morgan was funded for the first six months by Caring Matters Now and is now funded by external grant money. Thank you to you all for this essential funding. Morgan has been in clinic since January and lots of you will either have met him or be due to meet him when you come up. He is a great new asset to the team.

Thank you to everyone who has supported the fundraising and therefore the research this year, and a very special thank you to the patients who have joined in the research personally by contributing samples at important times. We could not do it without you.

## Plain Language Summary of BRAF Fusion Paper

Written by Sara Barberan, Postdoctoral Researcher in Professor Veronica Kinsler's lab

This year the team has just published a really important paper looking at people who hadn't had a gene identified in their skin – in other words, they didn't have either the NRAS spelling mistake gene changes or the BRAF spelling mistake gene change. In this group of patients, we looked for something called gene fusions, previously found in some patients with CMN by other research teams, which is where there are no spelling mistakes but two genes get stuck together, which they shouldn't be. This phenomenon stops the gene from doing its normal function causing the skin problems associated with CMN. We found these fusions in about half of the patients who didn't previously have a known gene, and most of the fusions we found were with the same gene BRAF. We also found that the fusions were probably responsible for making the CMN very itchy and very prone to growing firm lumps/ridges. Through the biopsies collected from

patients participating in our research study, we were able to extract the skin cells containing the fusions and conduct a detailed analysis of their effects. Our study found that the skin cells containing BRAF gene fusions grew much faster than cells containing NRAS/BRAF spelling mistakes or no mistakes at all. This could explain why some patients develop lumps, as the cells with the fusions divide excessively. We used these cells to test the effectiveness of Trametinib, a medicine known to regulate cell division, as a potential treatment. In the lab we found that treating the cells with Trametinib reduced their excessive division, returning them to a more normal behaviour, which prompted us to use it to treat three patients (two of whom were published). The treatment has been effective in reducing lumps and itch and has been really helpful to the patients and their families.

Scan the QR code to read the full journal article

SAVE THE DATE: Annual Research Presentation, Wednesday 25th September 2024



# CMN YOUTH



**Katy Jackson** is our Teens and Young Adults Contact, providing support for those aged 17-24 years.

My name is Katy, and I live in Hertfordshire. I was born with a CMN on the back of my right knee, which covers about a third of my leg. My family have been involved with Caring Matters Now almost since the beginning, and now I'm an adult I'm excited to be able to get involved on my own. I'm so honoured that I've been given the opportunity to be the Young Adults Contact. I am primarily here to provide support to those aged 17 - 24 years, so if you would like to have a chat, I'm here to listen!

**Sophie McCrudden** is our Teen Contact, providing support for those aged 12-17 years.



My name is Sophie and I live in Hamilton, Scotland. I was born with a CMN covering one side of my face and half my scalp. My family and I have appreciated the support from Caring Matters Now since I was young and now I am so happy to be given the opportunity to support others. I am here to help so please don't hesitate to get in touch.

## What's on!



### YOUNG AMBASSADOR

Our Young Ambassadors Programme aims to provide young people living with CMN (12 to 24 years) a platform to develop the following key skills: leadership, innovation, communication, teamwork, building relationships, public speaking and media engagement.



### Online Teens Resource

This resource aims to provide self-help support for young people aged 12-17 with Congenital Melanocytic Naevi (CMN). These self-help techniques are designed to improve confidence, self-esteem, tackle anxious feelings and equip young people with the skills they need to feel comfortable in their own skin.

As a charity, we would like to offer our teenage members the opportunity to walk through the online Teens Resource with our Support Pathway Coordinator, Hannah Cree. Hannah can guide teenage members through the resource, utilising the content that is most appropriate to the teenager. Hannah will be able to explain the purpose of the activities and ensure that our teenage members are using the resource to its utmost potential.

Hannah is also available to work through the resource with parents of teenagers living with CMN, so parents can utilise the resource at home with their teenager. If you would be interested in any of these options, please email [support@caringmattersnow.co.uk](mailto:support@caringmattersnow.co.uk)

Do you have CMN, aged 12 - 17 years? Scan the QR code to sign up to our Young Ambassador programme.





## What's on!

### Young Adults Panel

In 2023 we recorded a conversation with 5 young adults living with CMN. The conversation gives insights and personal experiences of living with CMN. The conversation recording has been a helpful resource for our teenage members to listen to. You can access the recording via the charity's website, under the tab Teenage Support.

## Congratulations Elspeth

We're delighted to announce that our Young Ambassador Elspeth, 18 years old, has now completed Level 2 of our Young Ambassadors Programme becoming the first Young Ambassador to complete the entire programme!

Young Ambassadors Level 2 offers the unique opportunity to complete the prestigious Dale Carnegie Course, which is designed to equip young people with the communication and human relation skills required to be successful in any setting. This world-famous programme of self-development helps the leaders of tomorrow leverage their skills so they can strengthen relationships between peers, solve problems, create collaborative cultures, boost morale and motivation within teams, and deliver an impact in any area of concentration.



**Teens Events 2024:** This year we are hosting a FREE day out for all our teenage members at Ninja Warriors, Liverpool. Don't miss out by registering to attend this event on our website.

### Elspeth's reflection on completing L2:

*"This was an experience which I wouldn't have gained in any other way, from travelling to London each day by train on my own to meeting new people at different life stages to me. I went into the course with the mindset that I'm not going to see these people again, so what Do I have to lose?! I pushed myself outside of my comfort zone and found that I had become more confident when talking and I realised that there was value in what I have to say. The experience made me realise that even adults don't have it all together, we were all there for the same reasons!*

*In May 2023 I attended the Caring Matters Now day out at Alton Towers, I found that the Dale Carnegie Course impacted how I engaged and interacted with others at this event! I found it easier to answer questions and share my story, easier to attend the event itself and easier to meet new people!"*

Congratulations from all of us at Caring Matters Now for completing the Young Ambassadors Programme and for all your hard work and determination!

## Maddie becomes first Young Ambassador to publish a journal article!



In Autumn 2023 we were able to give one of our Young Ambassadors, Maddie, a unique opportunity to write a journal article to be published in the British

Journal of Dermatology (BJD).

Maddie wrote an article based on a patient's

perspective of living with CMN, entitled 'Challenges in adult services for a young adult with a rare skin disease'. The article has been very well received and we are super proud of Maddie for being a fantastic Young Ambassador for CMN.

You can read Maddie's article by scanning the QR code above.

# 2023-24 Financial Review

Throughout the financial year 2023-24 our fantastic supporters have taken on challenges, completed events, become monthly donors, made one-off donations, and purchased merchandise, raising a grand total of £90,240.16. Without this generosity of giving, much of the work we do would not be possible.

## Your support has helped to raise:

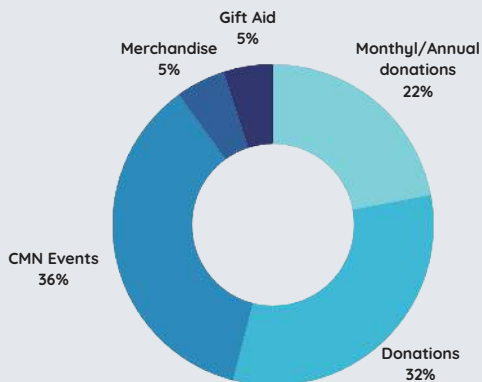
£15,798.42 monthly/annual donations

£22,550.54 individual donations

£25,139.12 CMN organised events

£3,351.47 merchandise sales

£3,744.82 gift aid



We have also received an income of £146,750 in grants with £128,000 of this being restricted to research.

Caring Matters Now spends its funds very carefully and always in accordance with relevant charity rules and legislation to support its 3 aims.

## Support

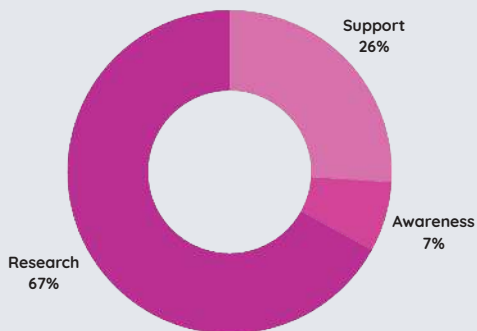
We have provided finances for supporting those affected by CMN totalling £68,307.40 throughout 2023-24 financial year. This includes funding in-person and online events, along with printed materials and critical care assistance.

## Awareness

We continue to fund awareness campaigns to raise the profile of CMN on a global scale, to the total £19,964.20 throughout 2023-24 financial year. This includes funding the production of 4th 'how do you C Me Now?' personal story and exhibiting at 5 medical conferences in the UK and Ireland.

## Research

Through grants received and research donations, we have been able to continue funding pioneering research undertaken by Professor Veronica Kinser and her research team. The charity has granted a total of £179,161.09 during 2023-24 financial year.



To sustain the support provided, awareness raised, and the research funded, Caring Matters Now must raise a minimum of £250,000 every year. On behalf of the Board of Trustees, I would like to thank all our fabulous fundraisers for your partnership!



Thank you to all our **FABULOUS FUNDRAISERS** for supporting **Caring Matters Now** over the past 12 months. Your fundraising provides Caring Matters Now with the financial support to continue making a difference to children and adults living with CMN

## Jessica Ma Award

In December 2014, one of our founding trustees, Jessica Ma, sadly lost her battle with cancer. In memory of Jessica's dedication and contribution to Caring Matters Now, the Board of Trustees along with Jessica's family introduced the Jessica Ma Award. The Jessica Ma Award is now in its 7th year and recognises individuals or groups who have gone above and beyond in their efforts to raise funds for Caring Matters Now. Jessica's husband Peter and their two children, Pascale & Jasper, chose a winner and a runner up to receive the 2022 Jessica Ma Award.

**We are proud to announce the 2022 winners are Toni, Den, and Harry!**

Toni and Den's business, Slambassador is well known in the VW world for being one of the leading companies when it comes

to 'slamming' your camper van! Along with their son Harry who has CMN, Toni and Den decided to raise funds for Caring Matters Now by building, 'slamming' and raffling a T4 camper van at @camperjamvw weekend in Shropshire.



Together with their friends and family they sold thousands raffle tickets over the course of the weekend raising an incredible £12,427.72! A gentleman in the crowd won the T4 on the day and was in total shock – not bad for a £3 ticket eh!

**Huge thank you to Toni, Den, Harry and all your family and friends for raising such a fantastic amount of money. To put your time, materials, and effort into something like this is hugely inspirational. Congratulations on being our 2022 winner.**





✉ **Caring Matters Now** | PO Box 184 | St Ives | PE27 9DU  
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**Caring Matters Now** is a registered charity in England and Wales (1192670) working in partnership with our sister charity **Caring Matters Now Ireland** (20205990).