

# INSPIRE

CARING MATTERS NOW

ANNUAL MAGAZINE

Issue 04 - AUTUMN 2021



*Join our 25th  
birthday celebrations!*

Find out more **P4/5**

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Launching our  
HOW DO YOU  
C ME NOW? Film

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New  
Support Initiative





## Caring Matters 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.

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

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



**Pictured left to right:** Lisa, Rachel, Jodi, Hannah

**Lisa Sly** is our Finance & Administration Officer, responsible for implementing all financial processes and administrative tasks.

## Caring Matters Board of Trustees

The board consists of 7 trustees who are parents of children and adults affected by CMN. Each trustee has specific focus areas within the charity's operations to ensure the charity is achieving all of its 3 aims: **Support, Awareness and Research.**



**Val Unsworth** (*Chair*) key areas of focus: strategy, governance, HR, safeguarding, support & wellbeing



**Ian Chance** (*Treasurer*) key areas of focus: finance, HR, governance & international development



**Bronagh Cleland** key areas of focus: international development, support & wellbeing



**Tracy Traverse-Burley** key area of focus: strategy, special projects & governance



**Emma Robins** key areas of focus: safeguarding, HR, special projects, website & administration



**Rob Jackson** key areas of focus: governance, finance, payroll



**Ruth Gold** key areas of focus: communications, fundraising, special projects

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

# Welcome!

I am delighted to welcome you to our 2021 **INSPIRE** magazine which is jam-packed with news, developments and exciting announcements to share with you.

This year we have welcomed two new members of staff. **Hannah Cree** joined the team in June 2021 as our Support Pathway Coordinator. After graduating from university with two degrees in Psychology and Social Work, Hannah worked for the NSPCC as a ChildLine advisor and then in a supervisory role. In recent years Hannah, whose son was born with CMN, has been supporting our members in Northern Ireland as part of the Regional Contact Team so she understands first-hand the importance of supporting children and adults living with CMN, as well as their wider families.

In August 2021, **Rachel Swanson** joined the staff team as Fundraising & Communications Coordinator. Since graduating from university in 2012, Rachel has always worked in the fundraising sector for health-related charities, most recently for a baby hospice in Liverpool. We are thrilled to have Rachel on board, just in time for our 25th birthday fundraising activities!

In September 2021 we welcomed two new members onto the Board of Trustees. **Emma Robins** is a head teacher of two secondary schools and **Tracy Traverse-Burley** is a self-employed consultant negotiating multi-million pound contracts for public, private and third sector clients. Both Emma and Tracy bring a wealth of knowledge and skills to further strengthen the Board. I am truly grateful to work with such an amazing team of staff members and trustees. Working together as one team, they ensure excellent support is



provided to those living with CMN, continue to raise awareness of CMN throughout the medical profession and among the public, and fund pioneering research to find the cure for CMN.

This year, we have also welcomed our first ever charity patron, **Corrine Sinclair**. Since 2018, Corrine and her husband have supported the advancement of the CMN research, as well as helping the charity to raise its profile within the corporate sector and celebrity world. Corrine organically became an ambassador of Caring Matters Now, and in September 2021 the Board of Trustees invited her to become our charity patron. In that role, Corrine will continue to raise the charity's profile and network on the charity's behalf. Now's the time to look forward! Next year Caring Matters Now celebrates 25 years, and to mark this special milestone, we have lots of exciting events and campaigns taking place which we would love you to support. All details are included in this edition, so please read on! Finally, I would like to take this opportunity to thank all our members and supporters for your friendship over the past 25 years. It is because of **YOU** that we have been able to provide support, raise global awareness and fund research which has found the cause of CMN. It has been an incredible journey which has been a privilege and a blessing to be a part of. I can't wait to see what happens over the next 25 years!

*Jodi Whitehouse*

Jodi Whitehouse  
Caring Matters Now Founder & CEO



# Join our 25<sup>th</sup> birth

## 25<sup>th</sup> Birthday Party at Alton Towers

We are inviting all our members to the **Caring Matters Now 25th Birthday Party at Alton Towers Resort on Saturday 7th May 2022**. This special event provides an opportunity for you to celebrate the 25 years of Caring Matters Now with charity members, trustees, staff and volunteers. We would love you to join us!



Registered members will receive two free tickets (per family). Additional family members can book tickets which will cost just £10 each, giving you a **70% saving**.

This event is only for named registered members of Caring Matters

Now. We have a limited number of free tickets to give away which will be allocated on a first-come-first-serve basis.

To make the most of the weekend, you will have the option to book accommodation at the Alton Towers Hotel at a special discounted rate and to book additional park tickets for

Sunday 8th May.



### What's included on the day:

- Access to Alton Towers Park and CBeebies Land
- Car parking
- Refreshments all day
- Birthday lunch & party games
- Party bag
- Quiet space to receive support & advice
- Charity exhibition stand, including a library of take-away support literature
- Time to build friendships and share experiences with other members



**BOOKINGS OPEN ON 20<sup>TH</sup> NOVEMBER!**

# Monday celebrations



# LIVERPOOL TO LONDON

## TREKKING THE 25 YEAR JOURNEY OF CARING MATTERS NOW

Join our trustees, support contacts and staff members as they trek the 25-year journey of Caring Matters Now. Each day a team of 20 trekkers will be walking a stretch of the 270-mile journey from Liverpool, the birthplace of Caring Matters Now, to London, where the ground-breaking CMN research lab and patient clinic is based.

You and your friends can book for one day or multiple days of the 13-day trek, and together we will walk the 25-year journey of Caring Matters

Now. More details, including the trek map, can be found on our website or by emailing [fundraise@caringmattersnow.co.uk](mailto:fundraise@caringmattersnow.co.uk)



### Route details to include:

Date	From → To	Miles
Sun 7/8/21	Liverpool → Runcorn	18
Mon 8/8/21	Runcorn → Middlewich	21
Tues 9/8/21	Middlewich → Stoke on Trent	20
Weds 10/8/21	Stoke on Trent → Rugby	24
Thurs 11/8/21	Rugby → Tamworth	19
Fri 12/8/21	Tamworth → Bedworth	25
Sat 13/8/21	Bedworth → Daventry	25
Sun 14/8/21	Daventry → Northampton	18
Mon 15/8/21	Northampton → Bedford	24
Tues 16/8/21	Bedford → Hitchin	21
Weds 17/8/21	Hitchin → St Albans	23
Thurs 18/8/21	St Albans → Enfield Forty Hall	18
Fri 19/8/21	Enfield Forty Hall → London	13

**FREE  
T-SHIRT**  
when you  
sign up!



**DATES:** 7th – 19th August 2022

**COSTS:** £60 per day  
plus £250 fundraising target

*Additional cost for accommodation if required*



# HOW DO YOU **CME** NOW?

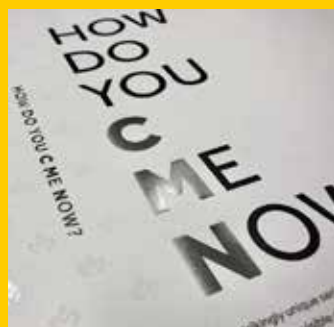
## HOW DO YOU **CME** NOW? Film release date 30th October 2021

Following the huge success of our HOW DO YOU **CME** NOW? photographic exhibition in 2019, and the launch of our HOW DO YOU **CME** NOW? photographic book in 2020, the Caring Matters Now Board of Trustees wanted to build on that momentum and continue to raise global awareness of CMN. So this year, we have produced a 3-minute HOW DO YOU **CME** NOW? professional film featuring the life story of an adult member living with CMN, Cheryl Shaw.

Our aim is for this first HOW DO YOU **C**

**ME** NOW? thought-provoking and emotive short film, to engage global audiences, and so continue to raise awareness and educate the world about CMN.

We are launching our HOW DO YOU **CME** NOW? film on the Caring Matters Now YouTube channel on Saturday 30th October 2021 and promoting the film through all our social media platforms. We would love you to support us by sharing the film on all your social media platforms... successfully gaining a global reach!



## HOW DO YOU **CME** NOW? Photographic Book

To mark our 25th birthday, you can purchase our HOW DO YOU **CME** NOW? photographic book at the special price of **£25** (RRP £30). Why not make the most of this special saving by purchasing multiple copies as Christmas presents or to distribute within your local community? Gift a book to your child's nursery, school, local library and doctors' surgery. This is a wonderful resource to educate the local community about CMN in a positive way.

# Support Contact Team

Our **Support Contact Team** are available to:

- provide a listening ear
- share experiences
- signpost you to charity information
- support you in your fundraising efforts
- connect you with other members
- host a support gathering

## REGIONAL CONTACT TEAM

Our team of regional contacts consists of 14 parents who have first-hand experience of parenting a child with CMN.

The regional contacts are located across the UK and Ireland, providing localised support for all our members.



## ADULT CONTACT TEAM

Our team of adult contacts consists of 4 adults living with CMN. The adult contact team are available to chat with adult members, share experiences, answer your CMN-related questions based on their own experiences, and organise adult gatherings.



**Adult contact team pictured from left to right:**  
Katy, Anne, Cheryl, Stacey

## TEENS CONTACT TEAM

Our team of Teen Contacts consists of 2 young adults living with CMN. Teenage members can reach out to our teens contact team to chat and share experiences related to living with CMN, and to find out more about up-and-coming teens events and the Young Ambassadors Programme.



## NEUROLOGICAL CMN PARENT CONTACT

Hayleigh Crowe is our Neurological CMN Parent Contact. Hayleigh is available to offer support and guidance based on her own experiences of caring for a child with neurological complications.



All details can be found on our website or by emailing [support@caringmattersnow.co.uk](mailto:support@caringmattersnow.co.uk)

# ANNUAL CONFERENCE 2021

In May we held our annual conference online for a second consecutive year due to lockdown restrictions continuing to be in place at the start of the year. During the 2-day conference, we held 16 online events via zoom, catering for 598 members. Every family and individual who registered to attend the conference received a welcome pack, which included goodies for specific events members had registered for. These included a CMN Ronnie the Bear, research experiment equipment, a circus kit, CMN mug accompanied by a teabag and chocolate bar, quiz sheets, escape rooms bandanas, books and craft kits. We were thrilled to welcome so many of you along to our weekend conference, and we were very grateful to Charlotte Hawkins and Jimmy Bullard for hosting two of the events, which made the conference extra special for all our members.



## REGIONAL GATHERINGS

In the summer, as lockdown restrictions began to ease, we were able to start meeting in person again! Throughout the summer months, we hosted 9 regional gatherings across the UK & Ireland, welcoming 210 members. It has been wonderful to see many members connecting with one another, developing friendships and sharing experiences. A special thank you to all our regional contacts for hosting our regional gatherings this year.



**Calling all members who've recently turned 18+ and living with CMN!**

We would love you to register with **Caring Matters Now** as an adult member.

Your parents will continue to be registered with the charity and receive communication from us, but you will also receive relevant and age-specific communication from us as an independent adult member.

You can register as an adult member on our website [www.caringmattersnow.co.uk](http://www.caringmattersnow.co.uk)





# NEW SUPPORT INITIATIVE - *Let's do life together!*

We are keen to develop organic communities of members in which friendships develop, and mutual support is provided. To kick start this initiative, we are launching two **NEW** monthly online communities which we would love our members to plug into:



**Do you have a baby aged 0-3?**

Join us once a month for our  
**Baby & Toddlers Event**



**Do you love online gaming?**

Join us once a month for our  
**Online Gaming Event**

To find out more please email [\*\*support@caringsmattersnow.co.uk\*\*](mailto:support@caringsmattersnow.co.uk)



## SAVE THE DATES FOR 2022

### NATIONAL EVENT

**25th Birthday party** at Alton Towers, Sat. 7th May

### REGIONAL EVENTS

**North West Regional Gathering** at Bewilderwood, Cheshire, Saturday 18th June

**London & East Anglia Regional Gathering** at Hyde Park London, Saturday 2nd July

**South East Regional Gathering** at Yellow Wave, Brighton Beach, Saturday 16th July

**North East Regional Gathering** at Bridlington Beach, Sunday 24th July

**Northern Ireland & Ireland Regional Gathering** at Tayto Park, Saturday 10th September

**South West Regional Gathering** at Wild Place Bristol, Saturday 17th September

### ADULTS EVENTS

**Adults Online Social**, Friday 14th January

**Adult Gathering** in London, Saturday 29th October

### TEENS EVENTS

**Teens Big Day Out** in London, Saturday 12th November

Do you know we now have a dedicated  
**support helpline?**  
**0300 3035690**



# CHILD TO ADULT SUPPORT PATHWAY



**0-3** As a charity we educate medical professionals to aid early diagnosis, with particular focus on partnering with midwives and dermatologists across the UK & Ireland. We provide specialised early years support and information for parents caring for babies born with CMN.



**4-11** 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** When a child member turns 12 years old, they will start to receive direct support from our Teens Contact Team. **Katie Arends** specifically supports members aged 12-16 years. 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.



**17-24** 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 two Young Ambassadors Programme and to attend our young adult support event



**18+** When a teenage member turns 18 years old, they will start to receive support from the Adult Contact Team. 18+ members will be invited to register with Caring Matters Now as an adult member, rather than their membership continuing under their parents registration. 18+ members will be invited to attend our adult support events and participate in adult-focused research studies.

# My Story – Tracy

My name is Tracy, and I am the proud mother of Rey, the little beauty that's on the cover of this edition of **INSPIRE**.

It feels that my story wouldn't be complete if I didn't start with what a special rainbow baby she is. My husband and I struggled to conceive for 7 years; counting the days until we could try again and the disappointment when we failed. We tried IVF but that also didn't work. There was nothing "wrong" with us but the pressure of trying to have a baby just wasn't working. Our doctors urged us to go away, enjoy our life and put getting pregnant to the back of our mind.

A very difficult thing to do when your world has centred around getting pregnant for so long!

We started to lose faith and thought of adopting when just like that the test was positive. Now we had been here several times before, each time ending with heartache, so we tried to stay balanced. We had to go to hospital for an emergency scan to check all was ok and there she was; bum bum bum went her heart; our miracle!

After giving birth to Rey, the Doctor said she had marks on her but not to worry. I had a c-section, so my husband and Rey were taken to the next room. When I came into the room my husband was crying saying he must prepare me, as the medical team were googling what is wrong with her skin. He brought Rey to me, and I remember exactly what I thought... my truly beautiful baby, how long I have wished for you. I spent the night with her in my arms, watching her.

My husband went home and by his return, he had diagnosed Rey with CMN. A story so similar to others, where research on the internet left us petrified. We were lucky to see Prof. Kinsler at GOSH, a truly amazing doctor providing support, guidance and

reassurance. She spoke so fondly of Caring Matters Now. We called and spoke to the truly amazing Jodi. Within minutes of meeting Jodi, I thought Rey is so lucky to have such an inspirational lady in her life.

I wanted to offer my help to the charity but at that time I had to focus on Rey because soon



after I spoke to Jodi, Rey was rushed into hospital after stopping breathing. I could write pages on where our life took us then but it was such a sad and scary time; I will just say that she was diagnosed with severe reflux which would come up, get stuck and stop her from breathing. We needed to

watch her 24 hours a day to keep her breathing. She's now 2 with no stop-breathing episodes for 9 months. We can now take a breath and really enjoy her. She is full of personality and curls! We understand the challenges that she may face in the future, but we want to focus on letting her grow with confidence and to love herself. We have bought copies of the 'HOW DO YOU **CME NOW**' photographic book and use it as a resource in our community to raise awareness and understanding.

I have remained in contact with Caring Matters Now and recently I have felt able to offer my help. I was approached by the Board of Trustees in August 2021 to consider becoming a trustee. I can't tell you how thrilled and proud I was to be considered for this position. My day job is as a consultant, negotiating multi-million-pound contracts, so I hope to use my skills and experience to assist the Board in continuing to achieve the charity's aims. In September I started in my new trusteeship, and I look forward to a future that is full of positive challenges and fun!

# Christmas is Coming!



This Christmas, could you help us to light up our virtual Christmas tree?



For a small donation, you can put a light on the tree, hang a bauble, put a present underneath the tree or be the one person to place the star on top of our tree!

You can personalise your Christmas 'light-up' donation by including the name of a loved one and writing a personal message for them to see on our Christmas tree. You can choose how much you want to donate, and even send your personalised message directly to a loved one of your choice.

All you have to do is visit our page:

[www.visufund.com/caringmattersnow-christmas2021](http://www.visufund.com/caringmattersnow-christmas2021)

*By lighting up our Christmas Tree, you will help us to keep making a difference to those who need it this Christmas*

## Online Christmas Shopping!



When you shop through **Amazon Smile** and **Easy Fundraising**, Caring Matters Now can receive a small percentage of the purchase price with no extra cost to you! All you need to do is select Caring Matters Now as your chosen charity. This is a smart way of giving to Caring Matters Now without spending a penny more!

To find out more please email [fundraise@caringmattersnow.co.uk](mailto:fundraise@caringmattersnow.co.uk)

# TREASURER'S FINANCE REPORT

Due to lockdown restrictions forcing the cancellation of many fundraising events, this year we have seen a drop in fundraising from previous years. However, our fantastic supporters have risen to the challenge and in the first half of this current financial year (2021/22), we have received **£56,399** in donations. Without this support, much of the work we do would not be possible.

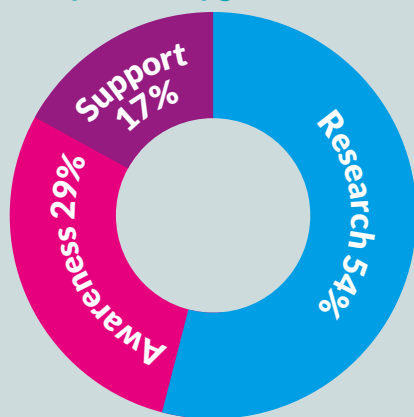
Your support has helped us raise:

- **£6,905** from monthly donors
- **£18,356** donations and fundraising
- **£19,778** CMN organised events
- **£2,094** merchandise
- **£9,266** gift aid

The charity has also received an income of **£276,538** in grants with **£200,000** 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.

## Where your money goes



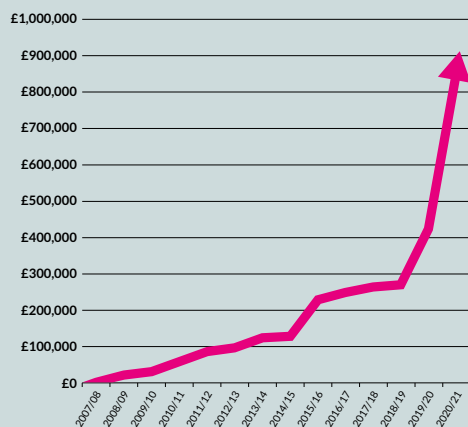
**Support** – We have provided finances for supporting those affected by CMN totalling **£21,220** to date this year. This includes

funding in-person and online support events along with printed support material.

**Awareness** - We continue to fund awareness campaigns to raise the profile of CMN on a global scale, as well as attending national medical conferences to educate doctors, nurses and midwives about CMN. The charity has spent **£11,536** this year raising awareness.

**Research** - Through grants received and research donations, we have been able to continue funding pioneering research undertaken by Professor Kinsler and her team. The charity has now donated a total of **£847,812** over the past 14 years to research. To sustain the support provided, research funded, and the awareness raised, Caring Matters Now must raise a minimum of £150,000 every year.

## Research Funds Accumulated 2007-2021



On behalf of the Board of Trustees, staff, and volunteers, we would like to say a big **THANK YOU.**

*Ian Chance*  
IAN CHANCE  
TREASURER



# MAKE OUR 25<sup>TH</sup> YEAR THE BEST FUNDRAISING YEAR YET!



As we head into our 25th year of Caring Matters Now, we would love to see as many people as possible help us to raise the essential funds needed to continue providing support to families affected by CMN for another 25 years, and more. There are two different ways in which you can do this...

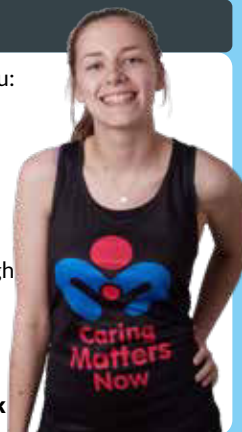
## STEPPING UP FOR CMN

**Step up for CMN** by taking on a '25' challenge for our 25th year. Could you:

- Run 25 Miles
- Organise a 25-hour football tournament
- Cycle 25 Miles every week
- Swim in 25 different lakes
- Or come up with your own '25' challenge

There are many creative ways you can get involved and raise funds through our **Stepping up for CMN** challenge. You can choose to do a one-off challenge, or you may decide to take on the challenge throughout the whole year. **The choice is yours!**

To find out more, please email Rachel at [fundraise@caringmattersnow.co.uk](mailto:fundraise@caringmattersnow.co.uk)



## BECOME A MONTHLY DONOR

If challenges are not for you, then why not consider signing up to become a regular giver to Caring Matters Now? Whether it be pennies or pounds, whatever you can give will help us to continue supporting families and individuals affected by CMN.



**£2.50**

**a month pays for a family support pack.**

When a baby is born with CMN, we provide parents with this pack which contains medical information and support materials.



**£25**

**a month pays for the medical booklet to reach the hands of 15 medical professionals.**

The CMN medical booklets are distributed at national medical conferences each year to help raise awareness of CMN in the medical field.



**£250**

**a month will fund a regional support event.**

Support events provide members with an opportunity to meet one another in a relaxed environment, to share experiences and develop lifelong friendships.

Please visit [www.caringmattersnow.co.uk/donate/](http://www.caringmattersnow.co.uk/donate/) to set up a regular donation.



Thank you to all our **FABULOUS FUNDRASIER**s 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

## 2020 Jessica Ma Award

In December 2014, one of our founding trustees Jessica Ma sadly lost her battle with cancer. The Caring Matters Now trustees want to publicly acknowledge and remember Jessica's outstanding and unique contribution to our charity so, along with Jessica's family we created the **Jessica Ma Award**. Since 2016 the Jessica Ma Award has been presented to an individual or group who have gone above and beyond in raising funds for Caring Matters Now throughout each calendar year.

The winner of our 2020 Jessica Ma Award goes to **Gabriella** for cycling an amazing 26 miles during lockdown in 2020, raising a grand total of £570.

Jessica's family said, "We are delighted to say that we all agreed Gabriella's Bike Ride stood out for us in so many ways as the deserving winner of the Jessica Ma award 2020. First, Gabby (with

help from her mum) embarked on a mission to help others on behalf of her little sister. This is an example to us all, that we should help when we can. Secondly, it was a prolonged event, over 4 days. That is a great example of tenacity; something we would be wise to remember in these difficult times. Congratulations Gabriella."

On receiving her award, Gabby said, "I chose to raise funds for Caring Matters Now because my little sister Sofia has CMN. I knew as soon as I met her that I wanted to help her and other people with CMN. I am so proud of my sister. She is only 4 and she can already accept that her birthmark is just part of her – sometimes she'll just walk up to me and say "Gabby, I got a special birthmark!" It means a lot to me to know that I am helping a charity that is extremely special to my family and other families in the UK and around the world. I feel super grateful for winning the Jessica Ma award."



Huge congratulations to all those who ran the **London Marathon** on 3rd October 2021. Our team of runners raised a phenomenal **£18,139.61** for the work of Caring Matters Now.





We are thrilled to announce the establishment of **Caring Matters Now Ireland**. In 2019 the Caring Matters Now Board of Trustees started working towards establishing a sister charity in Ireland. In December 2020 we received notification from the Charity Regulator confirming Caring Matters Now Ireland is now a registered charity in the Republic of Ireland.

### What does this mean?

Caring Matters Now Ireland will function in partnership with Caring Matters Now (UK) to offer support to those affected by CMN in the Republic of Ireland. Furthermore, we are now able to raise funds in Ireland to fulfil our 3 main aims of supporting those affected by CMN, raising awareness of CMN and funding research into CMN.

The newly formed charity Board of Trustees consists of **Bronagh Cleland (Chair)**, **Caroline Hackman** and **Jodi Whitehouse**. More details can be found on the Caring Matters Now Ireland website: [www.caringmattersnow.ie](http://www.caringmattersnow.ie)



### SAVE THE DATE

Join us on Saturday **10th September 2022** for a fun day out at **Tayto Park**. This event is ideal for all ages, and open to members based in Ireland and Northern Ireland. For more information please email [support@caringmattersnow.co.uk](mailto:support@caringmattersnow.co.uk)



A colorful poster for a "Coffee &amp; Cake Morning" event. At the top, a string of colorful bunting flags hangs across the frame. Below the flags, the text "Join in with us by holding your own" is written in a dark blue, slightly distressed font. The main title "COFFEE &amp; CAKE MORNING" is in large, bold, dark blue letters. Below the title, the dates "Friday 10th – Sunday 12th June 2022" are written in a bright blue font. The text "Eat tasty cakes, have a lovely cuppa, chat with friends and help raise money for Caring Matters Now" is written in a smaller, dark blue font. At the bottom, there are illustrations of a green teapot pouring tea into a red cup, a stack of colorful mugs, a pink flower, and a multi-tiered pink cake with a heart on top. The background is light blue with white clouds and small blue birds.

# RESEARCH UPDATE REPORT FROM THE KINSLER LAB



## Summary of progress

### Team and laboratory update

**Dr Nicole Knoepful** started with us a year ago, initially funded by Caring Matters

Now money for the first 6 months of her PhD. Thanks to the NIHR Research Professorship grant to the lab of £1.88M we have now been able to fund the remainder of her PhD. This grant is now also funding the salaries of post-doctoral researchers **Dr Dale**

**Bryant** (previously supported by Caring Matters Now awards) and **Dr Sara Barberan-Martin** to work on therapies for CMN. **Dr Davide Zecchin** another postdoctoral researcher was successful in obtaining a grant with **Prof Kinsler** of £250,000 from the Children with Cancer charity to study new treatments for melanoma in CMN. **Dr Satyamaanasa Polubothu** a clinical academic who has been working in CMN for many years has just been promoted to consultant at GOSH and will continue both in clinic and to research mosaic diseases. We are lucky to have been able to recruit new vital team members in the field of bioinformatics, **Dr Alicia Bruzos**, and **Ms Pauline Bourigault**, who will be essential in supporting all our projects.

### Impact of Covid-19

We have been very lucky that the Crick Institute got back up and running very early in the pandemic with weekly in-house PCR Covid testing of all staff. We have been able to have a full team in the lab since Spring 2021 and recently feel we are actually working at full capacity again. As scientists we would strongly encourage everyone to get vaccinated – we are on our third set of vaccines now in

the healthcare system, as the effects of the vaccines are revolutionary at protecting us but they also wear off with time. We are all likely to have to get used to getting vaccinated every 6 months to protect ourselves and others.

### CMN research progress

The funding from the Atkin family's two charitable foundations in partnership with Caring Matters Now has been central to the progress of CMN research in recent years. We have been able to use the money first to fund salaries and more recently to fund consumable costs (the costs of the experiments) for the therapies projects. We have made substantial progress in these projects as well as being able to solve the genetics for some patients with CMN in whom we didn't have the gene before. Everyone will have been or is about to be contacted about new gene findings if they are patients at GOSH and where we have found something new.

## SAVE THE DATE

Annual Research Presentation  
by Professor Veronica Kinsler  
online event  
Sunday 6th February,  
8:00pm

### CMN-related publications in the last year

- 1. This is an important paper in which we found a new melanoma gene in the general population which we first identified in CMN patients. This paper is the result of 10 years' work.** Satyamaanasa Polubothu, (... many other important authors ..), Veronica A Kinsler. Novel germline duplications in gene *PPP2R3B* predispose to melanocytic naevi and melanoma. *Genetics in Medicine* 2021.
- 2. This is the discovery of the cause of a rare variant of CMN.** Muthiah S, Polubothu S, Husain A, Oliphant T, Kinsler VA, Rajan N. A mosaic variant in *MAP2K1* is associated with giant naevus spilus-type congenital melanocytic naevus and melanoma development. *Br J Dermatol*. 2020

# CMN YOUTH



On Saturday 25th September our amazing team of teens climbed all the way to the top of London's O2 Arena in aid of Caring Matters Now. The team raised a phenomenal grand total of **£9042.71**. A huge well done to the teens team – we are very proud of you all! Following the O2 climb, the teens enjoyed some food and social time together along with

**Katie Arends** (Teens Contact), **Katy Jackson** (Young Adults Contact) and **Hannah Cree** (Support Pathway Coordinator).



The day finished off with a special presentation to **Nik Nikiforou** for completing his **Young Ambassadors level one award**. **Well done Nik!**

## **YOUNG AMBASSADOR**

Our **Young Ambassadors Programme** aims to provide young people with CMN (13-19 years) a platform to develop the following key skills:

- Communication
- Teamwork
- Building Relationships
- Leadership
- Public Speaking
- Media Engagement
- Innovation

### **Why become a young ambassador?**

- Gain confidence, knowledge & experience to help your future personal development
- Gain valuable volunteering experience (supporting the Duke of Edinburgh's Award)

- Develop key skills to excel during interview processes, throughout higher education and into employment
- Receive a letter of recommendation for future progression into higher education and employment
- Receive a Young Ambassadors accreditation certificate

To find out more email

**[support@caringsmattersnow.co.uk](mailto:support@caringsmattersnow.co.uk)**

or visit our website



# Elspeth's Story

As a sixteen-year-old with CMN covering my back, arms and legs, it evidently makes me stand out when I don't necessarily want to and makes people stare when (you guessed it) I don't want people to stare. I found the summer months difficult as I couldn't cover up my skin as much as the winter months and, also when I did PE in school or went swimming with friends. I was scared of what people thought of me and what they would say about my CMN. As a generally shy person it would be my worst nightmare if someone came up to me and started asking about my skin. I would always stammer and go bright red and this made me ashamed of myself and my CMN. This led to me losing my confidence and envying the girls who could happily and confidently wear their swimsuits and shorts.

Thankfully the comparison, shame and fear faded away in 2019 because I was assigned to a psychologist at Great Ormond Street Hospital where I talked about my main worries and concerns with my skin and the fear of judgement from other people. These sessions dramatically changed my life, so much so, in the summer of 2019, I went on a cycling holiday around Holland and decided to wear cycling shorts, which exposed the CMN on my thigh and legs. I became more confident throughout the trip and began to not notice the curious looks from people as I whizzed by. On our rest day we were staying by the beach, and I had packed my first ever bikini, which I was planning on wearing the first chance I got. At first, I was extremely nervous as we approached the beach, but I soon had the courage to go in the sea and just enjoy myself. This holiday really transformed the way I thought about myself because the



Elspeth (left) attending the 2021 Southwest Regional Gathering as a Young Leader

weight had been lifted off my shoulders. I reminded myself of how I had persevered and achieved my goal; something I was very proud of.

Over the years, Caring Matters Now has opened doors for me to meet new people going through the same things as me and older people who have been where I am as a teenager. The HOW DO YOU **CME** NOW? exhibition at the OXO Tower made me see how beautiful other people viewed these birthmarks and this really affirmed my confidence. I am participating in the Young Ambassador Programme which is helping to continue building my confidence, as well as my leadership skills. The group of Young Ambassadors have helped me to see we are all going through the same experiences, and it is okay not to love the skin you are in from time to time. I sincerely don't know where I'd be without the people who have helped me along the way, and I can't wait to see where my 'Elspie marks' take me next.



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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).