

PICTURE THE DIFFERENCE

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‘HOW DO YOU C ME NOW?’ is a photographic series featuring children and adults born with the rare and potentially life threatening skin condition congenital melanocytic naevi (CMN). CMN presents itself in large, dark brown, birthmarks that can cover up to 80% of the body. People with CMN often feel isolated due to the rarity of the condition and deal with negative comments, often resulting in low self-esteem.

Many of the 30 people photographed had never revealed their birthmarks publicly before. The title of the exhibition encourages the public to look twice at the images and consider what their eyes were drawn to first, the visible difference or the beauty of the individual in the portrait?

Caring Matters Now is the only UK charity supporting children and adults affected by CMN. We launched the ‘HOW DO YOU C ME NOW?’ exhibition at the Oxo Tower, in central London, in March 2019. In 10 days, over 8,000 people visited the gallery. We raised the profile of the exhibition further, displaying poster advertisements across the capital – including a huge digital billboard overlooking Waterloo Bridge.

The exhibition was also featured on BBC Breakfast, Sky News, Channel 5 News, ITV News, LBC Radio, Radio

5 Live and BBC Radio 1. Then, the coverage started reaching international levels, with the charity receiving press enquiries from media outlets in Germany, France, Norway, Russia, Taiwan, South America, and the United States.

The response from the public was phenomenal – the charity began to receive emails and messages from individuals worldwide, many who thought they were the only one living with this condition. Finally, they realised they weren’t alone.

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The exhibition had a profound effect on those who took part. All photographed participants described the photoshoot as a positive experience, and 100% of the parents of child participants agreed that their son or daughter felt content and happy in their skin after the exhibition, double the number recorded before taking part. Prior to the exhibition, over one third of participants said they would always consider what clothes to wear in relation to their CMN, but afterwards not one said they would continue to consider their CMN when choosing what to wear. One participant said, *“Since the photoshoot, I’ve been less concerned about tying my hair up or the wind blowing my hair up in the street, a surprising personal outcome of the shoot!”* This experience had an empowering shift in their thinking.

The exhibition posed a question, and asked people to consider their

current perceptions of those living with a visible difference. Surveys completed at the exhibition recorded that **91%** of the public felt more understanding of those living with a visible difference than before their visit, and **93%** said they think people with visible differences are beautiful.

Since the launch, the exhibition continues to raise awareness both in the UK and internationally. In July 2021, Nevus Outreach, the US support group, hosted a specially designed and produced virtual exhibition, created to look, and feel like the original exhibition in London. Since then, they have also shared the virtual exhibition in virtual reality (VR) format using a VR headset. Following on from these successful support events in the US, there has been further interest expressed by support groups and dermatologists in countries including Switzerland, France, and South Africa to use the virtual exhibition, VR exhibition or the original physical exhibition at future support events or conferences.

In the UK, staff and volunteers from Caring Matters Now tour medical conferences to talk about CMN, including the British Dermatological Nursing Group (BDNG). Our portraits are a unique way to raise awareness of the condition and educate medical professionals. **DN**

For more information about the ‘HOW DO YOU C ME NOW?’ exhibition, to find out more about CMN, or to access our medical booklet and free resources for parents and adult patients, please visit our website www.caringmattersnow.co.uk.