May 2024

I'm writing to you as it's now May, **Vasculitis Awareness Month**. Vasculitis Awareness Day is 15th May, and the leading charity Vasculitis UK is marking this on social media*. If you have, or are living with someone who has vasculitis, their website has lots of helpful resources. You can also telephone their **helpline** on 0300 365 0075, 9am to 8pm.

Vasculitis-related updates from the RECORDER team:

Alice's Vasculitis UK-funded **Guided Imagery for Coping with Illness** project ran from February to April. Alice would like to thank the eleven participants who generously gave their time to work with her on the project trying out the guided imagery exercises recorded on YouTube and then attending 10 weekly meetings to reflect on their experiences. The feedback she received has been very helpful and informative - she is now compiling and writing up the findings. We hope to be able to share the finalised scripts in due course and let you know about any potential follow-on work.

In April, Fiona and Steph attended the **21st International Vasculitis Workshop** in Barcelona. Steph took along this poster on the impacts of appearance and weight changes due to steroids which received lots of interest. She also gave away postcards with suggested wording for healthcare professionals designed to help meet patients' needs for information and support when starting steroids. Key highlights were meeting two of the team in-person for the first time after nearly a year working together online, and meeting Zoi Anastasia, the Director of Operations for Vasculitis UK.

In May, Steph starts a new project using nationwide electronic health records. It has taken over a year to get this going! For starters, she will establish how many people in England have **Takayasu arteritis** and **ANCA-associated vasculitis**. This has not been done reliably and is vital to inform health service planning for these conditions.

Upcoming opportunities for involvement:

The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA, which includes Vasculitis UK and Lupus UK) is conducting a **survey of patient perspectives** on the quality of their care. If you'd like to offer your views, you can do so here.

I'd also like to take the opportunity to highlight our upcoming in-person/hybrid meeting on **Saturday 15th June, 11am-3pm**. If you've not already done so, please complete the brief survey here to let us know your plans and preferences.

Kind regards,

Stephanie and the RECORDER team

*If you are a social media user, you can follow what's happening and contribute in your own way with **@rarediseaseday** and **#RAREDISEASEDAY**. We'd also be interested to know how you marked the occasion, or might like to in future, so do please send us an email or tag us in any X (formally Twitter) posts using **@RecorderUK**.

Registration of Complex Rare Diseases - Exemplars in Rheumatology

School of Medicine

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