

September 2023

JDCBS Newsletter

Hello! We are so grateful to all the patients, families and researchers who contribute to Juvenile Dermatomyositis Cohort Biomarker Study & Repository.

Do check out our [website](#) for other updates by scanning the QR code!



JDCBS Patient and Parents Involvement and Engagement Group



We hope to create a unique group of patients and families who will advise us on the research we do on JDM. Being part of this group may include: asking your advice on how we can support JDM better, getting your opinion on what research you think would benefit children affected by JDM, and more!

If you are interested, please email info@jdrg.org.uk

We would love to have you on board, and no prior experience is required!

Patient Stories



We always love to hear from JDM patients, parents and former patients! If you would like to share your JDM stories or experiences, please contact us using the details below.

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Research Spotlight: Sleep and Fatigue in JDM



Dr Charris Papadopoulou and Dr Merry Wilkinson from Great Ormond Street Hospital are studying sleep and fatigue to assess how common sleep disturbances and fatigue are in children with JDM at the start of disease (at diagnosis) and over time.

They will also try to understand what is causing fatigue and sleep problems and whether current medications are contributing into that.

Research Spotlight: MYOSCOPE



A new study, called MYOSCOPE is due to start in September 2023, led by healthcare professionals at Alder Hey Children's Hospital, Great Ormond Street Hospital, the University of Liverpool and the University of Manchester.

In this study, the researchers will test a tool called handheld nailfold capillaroscopy, which allows children and young people with dermatomyositis to clearly see the small blood vessels at the base of their fingernails.

To learn more, scan the QR code and access the full news on our website.

We are really grateful to all patients, families and researchers who contribute to the JDCBS. We could not do what we do without your help!

THANK YOU!