

Dear Rachel,

Thank you for welcoming me to the Doncaster & Bassetlaw MVP.

I am the Regional Maternity Coordinator for Positive About Down Syndrome covering South Yorkshire & East Midlands. I am just getting in touch to introduce myself and to outline to you the support & information we can offer to healthcare professionals and also to parents who may be starting their Down Syndrome journey.



Positive about Down syndrome provides the lived experience that expectant and new parents crave to access. We offer support in many ways, the most popular being our online groups. We have many closed groups on Facebook offering a wide variety of support throughout a parent's journey. The first group at the very start of their journey is Great Expectations <https://www.facebook.com/groups/dsukpositiveaboutdownsyndromegreatexpectations>. This is an honest, non-judgmental group where women with a high chance/confirmed result of baby having Down syndrome can expect a warm welcome. With an admin team comprising of midwives, neonatal and paediatric nurses who are also parents to children with Down syndrome, we are also able to answer general queries/signpost women to further relevant information.

Our closed New Parents group has over 700 parents in the UK of a baby with Down syndrome, a place where they can ask any question, share any worries or concerns, and know that they are in a safe supportive forum, with fantastic peer support as well as experts on hand to answer specific questions <https://www.facebook.com/groups/padsnewparents>.

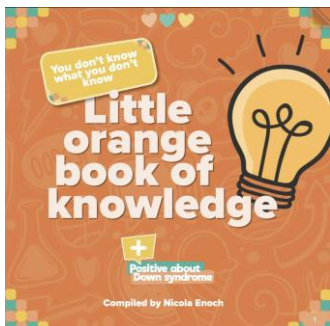
We also provide support to breastfeeding mothers <https://positiveaboutdownsyndrome.co.uk/breastfeeding/> and have a PADS Heart Buddy scheme to those families whose little one is awaiting heart surgery <https://positiveaboutdownsyndrome.co.uk/heart-stories/>.

PADS provide free resources to maternity units across the UK including hard copies of our book #NobodyToldMe the truth about Down syndrome <https://positiveaboutdownsyndrome.co.uk/nobodytoldme/>.



Please advise the best address to send you our free resources which also includes posters and leaflets for display in the hospital and to hand to expectant and new parents of a baby with a high chance or confirmed result of Down syndrome. We are keen to work with screening,

antenatal, ward and community midwives, including obstetricians and neonatologists. If you could please share this email and my contact details with your colleagues I would be most appreciative.



One of our newest publications is 'You don't know what you don't know - PADS little orange book of knowledge'! This book is aimed at parents of a baby with Down syndrome in the UK as a guide to help them to understand some of the services their little one should be able to access, and an understanding of what we at DSUK can offer to our families. We hope it is a useful resource families can dip into as and when needed.

<https://positiveaboutdownsyndrome.co.uk/little-orange-book/>.

We recently collaborated with St George's University Hospital to produce a care pathway for expectant women which we would urge all maternity units to adopt: <https://www.stgeorges.nhs.uk/wp-content/uploads/2021/01/Personalised-antenatal-care-of-pregnancies-suspected-or-diagnosed-with-Down-syndrome.pdf>.



We also deliver free online and in-person training around sharing the news baby has/may have Down syndrome, the language to use and the support we can provide to both parents and medical professionals. The training has been very well received by professionals and we have had overwhelmingly positive feedback. We can tailor the training to your requirements, whether an informal 30-minute chat or a formal 1.5-hour PowerPoint presentation. Attached you will find PADS language matters best practice guidelines for your information. Please do let me know if training is something you'd like to consider.

We would like to support you and your colleagues in any way we can. In particular we'd like to welcome your Midwives and Nurses, that care for women and their babies with Down syndrome, to our closed Facebook group. Please do share amongst your colleagues where a warm welcome awaits:

<https://www.facebook.com/groups/dsukpositiveaboutdownsyndromemidwives>

Anything you would like to know about Down syndrome, please drop us a line – we are here to work with you to ensure every expectant and new parent of a baby with Down syndrome has access to the information and support they deserve.

I look forward to hearing from you.

With best wishes,

Bess Popplewell
Regional Maternity Coordinator
South Yorkshire & East Midlands
bess.popplewell@downsyndromeuk.co.uk



 **Remember: No emotion is a wrong emotion,
no question is a silly question.**