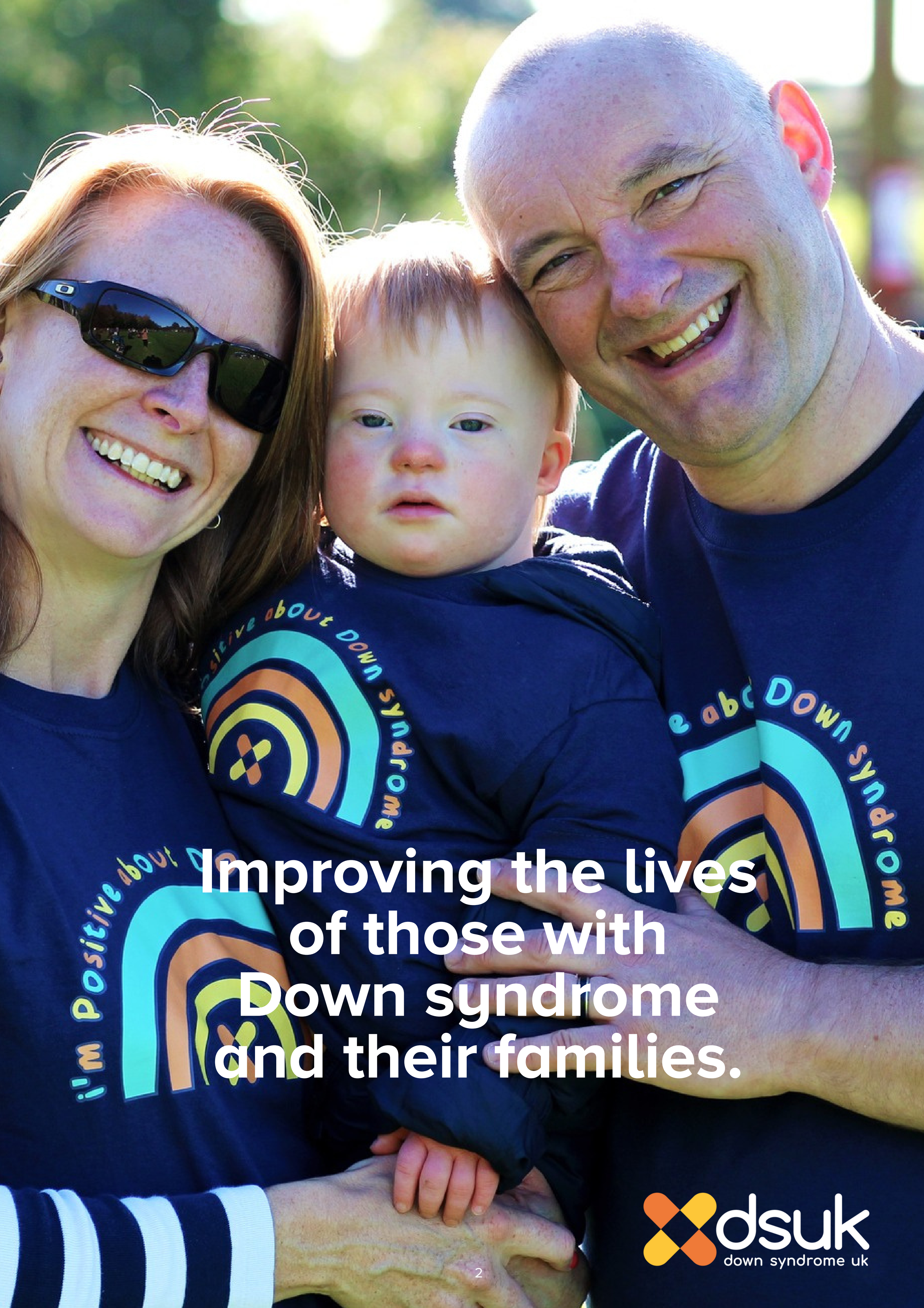
dsuk
down syndrome uk

IMPACT REPORT

2022/2023

Positive about Down syndrome
Heart Buddies
pants4school
st&r support, training & resources
DSUK Early Years Development Programme
DSUK'S EHCP support service
DSUK DLA DROP-IN SESSIONS
the DSUK network



Improving the lives of those with Down syndrome and their families.

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Welcome to our Impact Report

Down Syndrome UK works to improve the lives of people with Down syndrome, and their families. We primarily work in maternity care and the early and primary years, providing resources, training and support to parents and professionals to empower those with Down syndrome to thrive and flourish.

We believe every parent should receive the best possible care and support. We believe the arrival of every baby with Down syndrome should be celebrated. We believe every child with Down syndrome should be given every opportunity to flourish and thrive.

To enact these beliefs, we have 4 core aims which underpin our work:

1. Raising awareness of the modern reality of living with Down syndrome in the UK today.

2. Connecting parents of children with Down syndrome to experts, best practice, and each other.

3. Ensuring all children with Down syndrome have the best start in life, and access to the support to enable them to live their lives to the full.

4. Helping parents, the public, professionals, policy makers, and politicians to celebrate and support people with Down syndrome as valued and important members of society.

Our year in numbers

Positive about Down syndrome

133 Expectant women being supported

250+ Babies welcomed

903 New parents

248 Breastfeeding parents supported

1,147 Preschool parents

1,101 Grandparents

pants4school

3,144 Families and professionals accessing Pants4School

The number of children supported by

st&r support, training & resources

1,849 Preschool

935 Primary schools

971 Secondary schools

453 16+

The number of professional members

dsuk down syndrome uk

1,387 Medical practitioners trained

514 Preschool teachers

582 Primary teachers

the DSUK network

108 Regional support groups

150 Volunteers

Heart Buddies

We have supported 122 families in the lead up to their child's heart surgery and beyond.

122

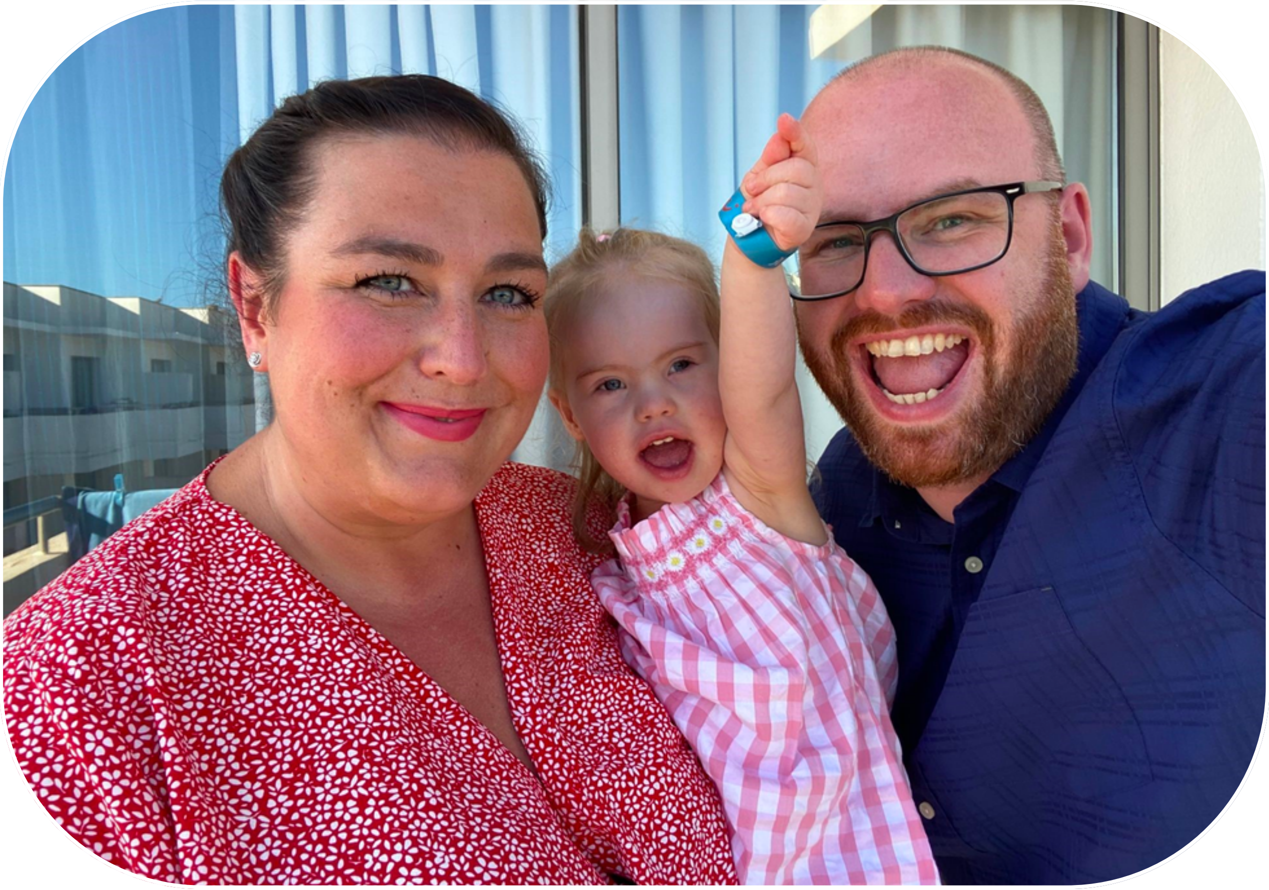
babies undergone heart surgery and been supported

101

parent volunteers

42

babies awaiting surgery



> Massive thanks to Nicola and everyone at PADS - I honestly don’t know where I’d be without PEGS and POPS helping me to support Sam, this is a lovely safe place to ask all the questions (or search for them) and the endless support whenever required. The work you all do is amazing!

Letters of support

When we initially received Trixies diagnosis, I was reluctant to engage with any charities or support groups because I was determined to raise Trixie exactly like my first child who doesn't have Down Syndrome. I quickly realised that it wasn't going to be that straightforward. My little girl wasn't going to meet her potential without a little more insider knowledge!

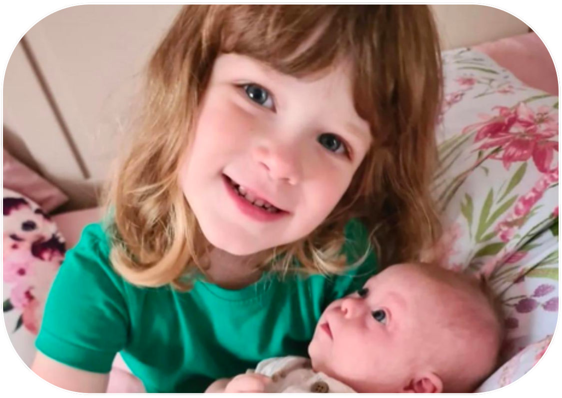
The new parent Facebook page has connected me with an amazing support network. I find seeing everyone's stories really inspiring and it fills me with hope. I often ask for advice about small but important things like which high chair or humidifier people would recommend.

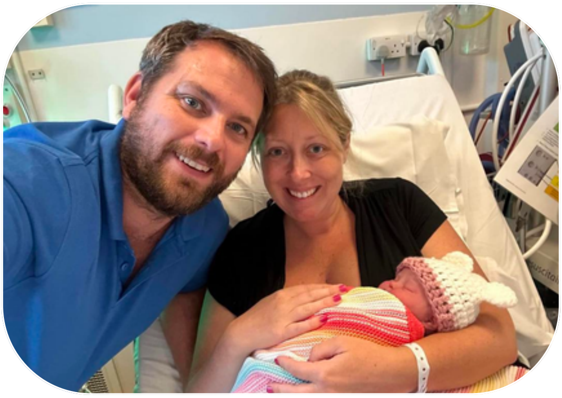
Trixie was diagnosed with a cardiac condition shortly after birth and PADS put me in touch with a lovely family through their heart buddy system. This family have been through the same experience as us and they are a constant source of support. This is probably the thing I am most grateful to PADS for.

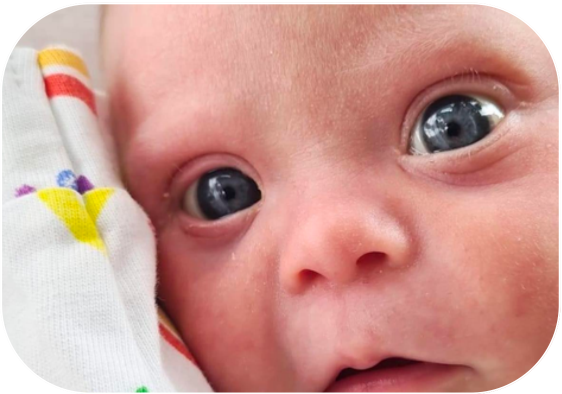
I've attended several online courses through PADS and I have signed on for more because I have found them so beneficial. The eye care teaching for instance, gave me valuable information which helped me to advocate for Trixie at her first eye examination.

Most recently, PADS have very quickly arranged for me to have some counselling during a dark time which I really appreciate.

Best Wishes,
Trixie & The Cookes xx







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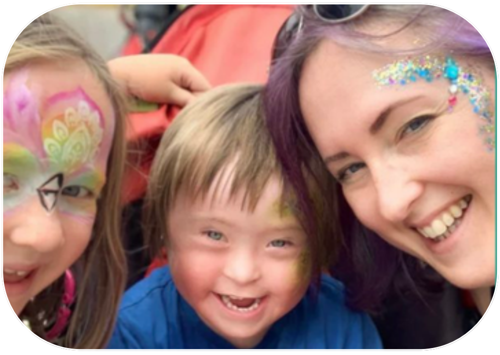

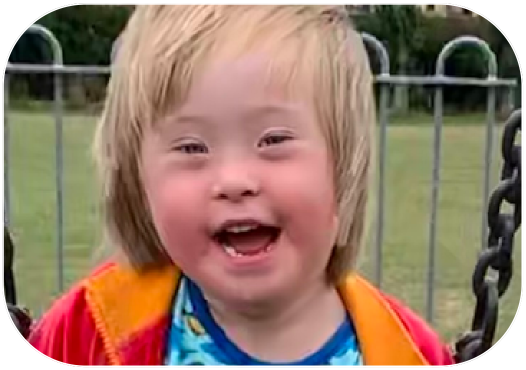

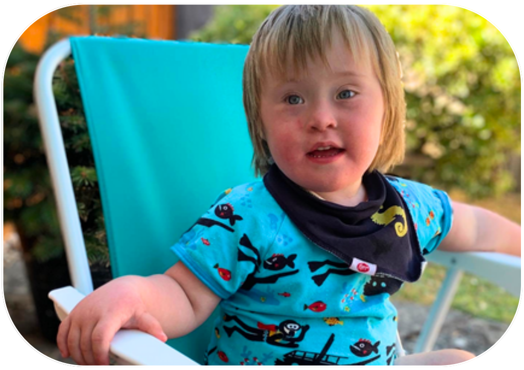

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We first found the Positive About Down Syndrome website in 2019, whilst pregnant with our second child. Routine bloods had given us a very high likelihood that baby had DS, we were ignorant on the subject and as everyone does we went to Google, which was scary and frankly depressing.

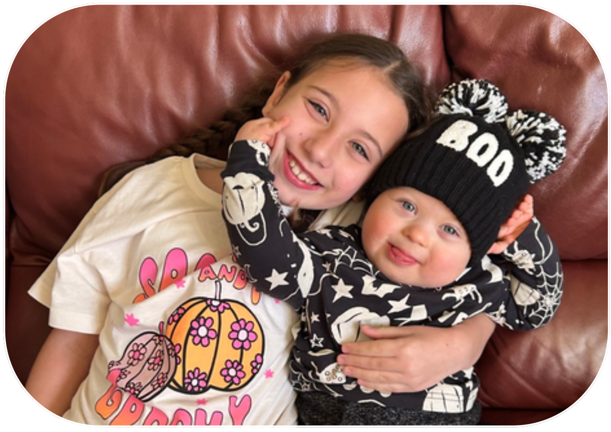
Fortunately our screening team were fantastic and put us in touch with PADS, and I can honestly say that this changed our entire outlook. From the fantastic website we found the DSUK/PADS Great Expectations Facebook group, and then once our son was born we moved up to the New Parents group. I cannot express how much these groups supported us in those early days, we had so little knowledge, so much concern and no relatable real-life contacts, and PADS gave us a level of support and security which we couldn't have imagined. Being able to talk to a network of individuals in similar situations was invaluable, and in the New Parents group we found not only likeminded families but also a number of professionals who were there to provide support and reassurance.

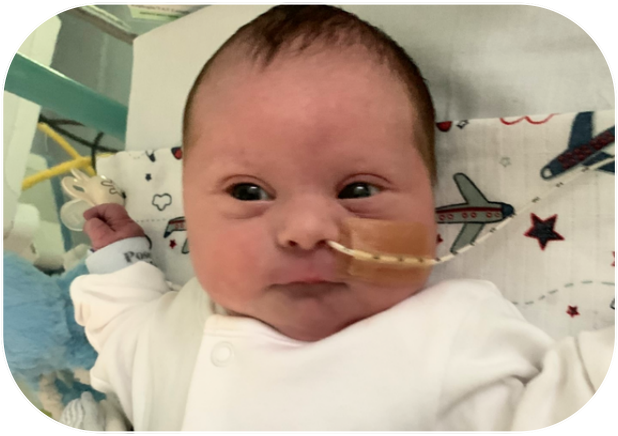
As time has gone on DSUK/PADS has remained a big part of our lives, providing professionally led support in many areas including potty training, physiotherapy and communication, as well as practical information on nursery, EHCP, DLA, Wills and Trusts and many other subjects. They are our go-to for any advice, and we have made lifelong friends via PADS - we look forward to the family meet-up which PADS organises every year, where we get to catch up with friends and meet new families. I don't know where we would be without our PADS family, and we hope that they are able to continue growing in order to continue supporting more families like us. Thank you for everything you do.

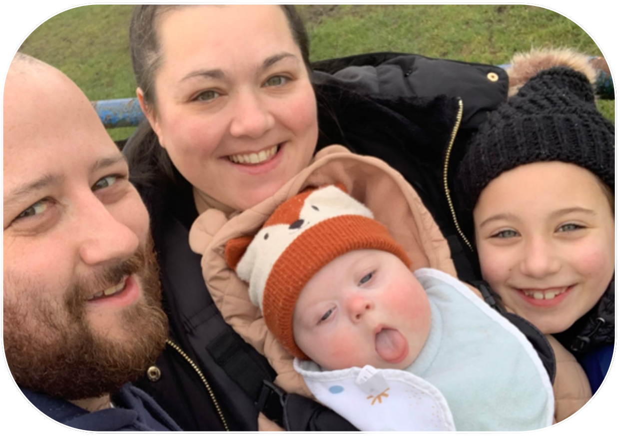
The Tumilty-Savage Family

Letters of support

> We thank our lucky stars that we came across PADS in the very first few days after receiving a postnatal diagnosis for our little boy whilst mindlessly searching on the internet for anything and everything about Down Syndrome.
>
> They made contact with us straight away and added us into the New Parent group. It was the first time since Down Syndrome was first mentioned to us immediately after birth that we didn't feel petrified. We received the loveliest pack in the post with lots of resources to help us on this journey and they have been supporting us as a family ever since.
>
> We have taken part in online physiotherapy sessions, early development groups and our sons nursery has recently signed up to online sessions to learn how best to support our son whilst he is in their care from an educational and development point of view.
>
> We have been welcomed into an online community that is just so supportive and have also been lucky enough to meet a lot of other families in person at the yearly family days both in the North and South of the country. I honestly don't know where we would be without them!
>
> The Macdonald Family







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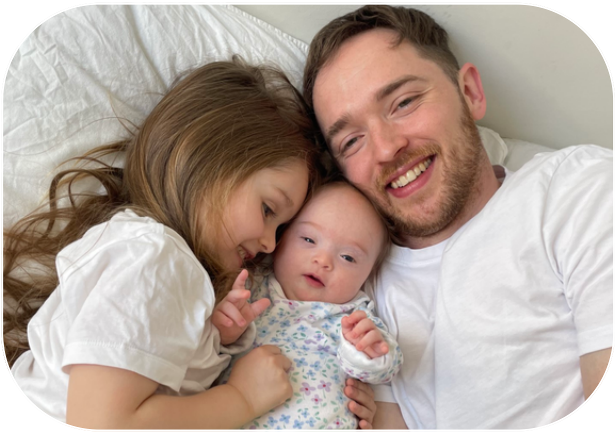


We found out when I was 16 weeks pregnant that our baby most likely would be born with Down syndrome. Shocked and saddened by the news and with a lot to process, we still knew it wouldn't change our decision to keep our child. The hospital offered us conversation if we wanted to talk about options, but didn't really give any information further than that. By my own initiative I found a woman on instagram with a child with DS and reached out for some guidance. She then recommended PADS group on facebook for women that were expecting baby's with DS. There I found information, hope and solidarity with people in the same, and at the time, scary situation as ourselves.

From a medical perspective we met some great doctors along the way, but how I longed for someone in the NHS to just ask us "how can we best support you in your decision" instead of "are you still committed to the pregnancy?". But what we were missing we found in PADS.

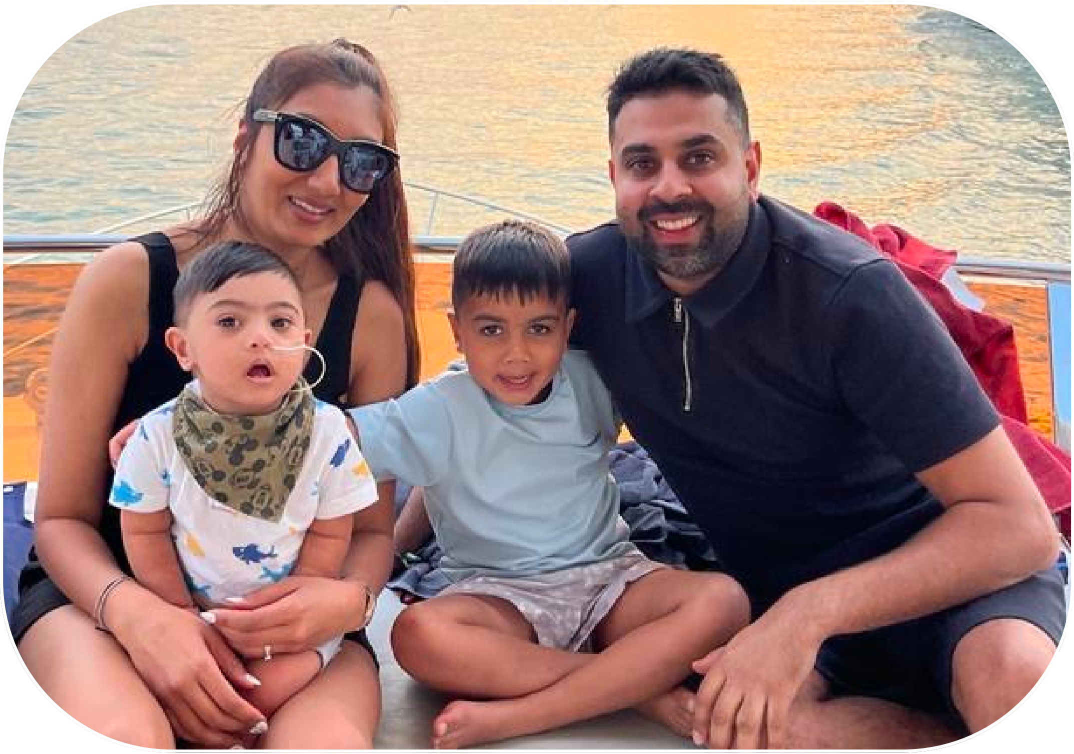
I cannot express enough what a lonely journey this would have been without the support from this amazing charity. Even though there was so much uncertainty about the road ahead I still felt I could go into birth with a confidence and a peace that we could do this!

We are soon 9 months in and have been able to ENJOY the baby journey with our gorgeous girl instead of wasting time being constantly worried and googling for answers.

The "PADS new parent group" is a fountain of information and truly a safe haven. It's also the place that has met every need so far where the public system around us has failed to provide help or rejected our referrals. Where we on several things have had to wait for our girl to fall out of the milestone range to get support, it's been so refreshing to be a part of a community that is so proactive to see our child thrive. And boy is she thriving!:)

It's a lot of things I'm grateful to PADS for, but most of all is the fact that what could have been a journey filled with anxiety and depression, instead became a journey of empowerment and community.

The Taylor Family



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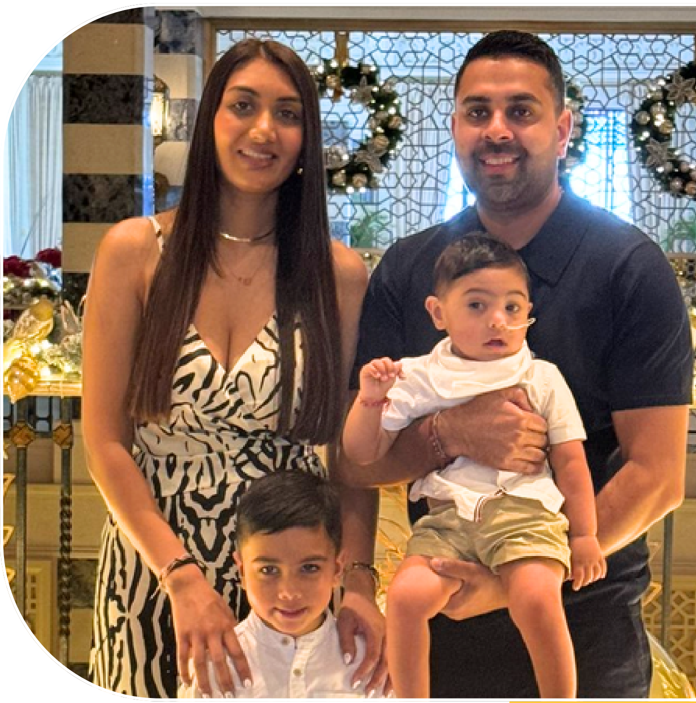

> PADS has helped me and my family more than anyone will ever know! From parent to parent support, counselling, even to help with training/advice.
>
> When we had just found out our son has Down syndrome, we had been told in such a negative way that it impacted us both mentally & emotionally. The only support we found helpful was through PADS.
>
> We are so grateful for PADS and everything that they do because without them we would probably still be in that deep dark hole we were in last year.
>
> The Jethwa Family

Feedback from parents and professionals

PADS has been an absolute lifeline. Without it, I don't know how we would have coped. From feeling so scared and alone, we can now see an exciting positive future for our son, and know that PADS is there to hold our hands all the way.
Sarah, mum to Charlie.

I enjoyed the new perspective given on Down syndrome and how little changes like language can have a big significance on families and how they view and feel about their babies. I feel more equipped to signpost parents to get information and support as well as supporting breast feeding.
Midwifery student at University of Leicester.

This evening I opened a package from the amazing team at Positive about Down syndrome. It made me cry! This is exactly what parents need in the first few hours after diagnosis, not 'we are sorry' and then nothing until you see your consultant. This information / education is so valuable.
Sarah, mum to Ayda.

Nobody gets it unless you're actually in the same situation… so it's been amazing to be able to meet and chat with other mums who have the same concerns and worries, and to be able to see and hear from those further down the line to see that everything's going to be ok.
Beth, mum to Emily.

Massive thanks to Nicola and everyone at PADS - I honestly don't know where I'd be without PEGS and POPS helping me to support Sam, this is a lovely safe place to ask all the questions (or search for them) and the endless support whenever required. The work you all do is amazing!
Laura, mum to Sam.

Huge thanks to PADS for your eye screening session. I went into our opthamology appointment ready and armed. The optometrist listened to my concerns and was very impressed with my knowledge. I feel so relieved and grateful to this support group for all of the knowledge sharing.
Laura, mum to Lucy.

Our parents' views

90%

of parents surveyed in 2023, advised DSUK is their go to place for support.

89%

of parents advised DSUK has helped them to feel empowered to support their child

95%

of parents trust the information they receive from DSUK

At DSUK we believe...

We believe in equality

The discrimination around Down syndrome must be challenged and addressed, so that people with Down syndrome and their families, should be treated with the same respect and care as anybody else.

We believe in inclusion

Every child with Down syndrome should have the opportunity to be fully included in mainstream settings – both in and outside of education.

We believe in research

To improve the lives of people with Down syndrome.

Why our families love DSUK/PADS

HONEST
93%

HELPFUL
79%

EDUCATING
74%

INSPIRING
75%

SAFE
76%

NON-JUDGEMENTAL
70%

EMPOWERING
64%

SUPPORTIVE
76%