

# BfN News

Mums Supporting Mums

## **BfN Evaluation 2021**

Find out what what we are doing well and where we need to improve.

## **Breastfeeding and Down Syndrome**

Information for Families and Breastfeeding Supporters

MAY 2021  
SPRING  
ISSUE 80





# HELLO!

MAY 2021  
SPRING  
ISSUE 80

## Editor's Note

Breastfeeding and Downs Syndrome (p.13)

Welcome to the Spring 2021 edition of BfN News.

We hope that you have been able to begin to reconnect with your loved ones now that lockdown restrictions have begun to ease across the U.K.

Alongside stories and updates from across our network, this edition brings you the findings from our annual evaluation, which is important in helping us to continually improve our services.

You will also hear from Alice who works for the Portsmouth Down Syndrome Association, and is mother to Teddy. She provides valuable insights in to how best to sensitively support the families of children with Down Syndrome on their breastfeeding journey.

On our cover this edition, we have included a beautiful image of Jennifer Williamson feeding her twins, who you can read more about them on page 11.

We thank everyone who has contributed their stories, pictures and articles for inclusion. As always, we welcome your feedback, comments and ideas for future newsletters. We'd love to hear from you at [leanne.rayner@breastfeedingnetwork.org.uk](mailto:leanne.rayner@breastfeedingnetwork.org.uk).

Thank you for all of your hard work and commitment to the families who look to us for support.



Alyson, BfN Social Media Coordinator.



BfN's Clare Farquar shares Pippo's story (p.6)

# A message from our CEO

**Life feels more hopeful as we look forward to better weather, longer daylight hours and as the vaccination programme rolls – hope – that we may soon achieve a way out of lockdown.**

It has been a particularly hard time for new mothers and parents and I am delighted to report on such high levels of quality support being offered through the National Breastfeeding Helpline and through our projects and services.

The feedback has been incredible and if you haven't already seen it please take time to look at the results from the central evaluation that highlights the value of the work BfN does – all credit to the staff team and volunteers who allow us to do such great work as a charity.

Here are a few updates on the work of the charity over the last quarter which comes at a time of intense activity in Westminster as the NHS modernises, the Early years review led by Andrea Leadsom progresses and we see major changes to the Public Health England Agency.

- BfN were pleased to support the Medicines in Health Regulatory Authority on a special meeting giving consideration to the safety reports submitted through the yellow card system as they relate to experiences of breastfeeding mothers and their infants. Those who are breastfeeding or giving their expressed milk can be given any of the three vaccines currently authorised for use in the UK and for further information on BfN's position take a look at BfN's statement and dedicated FAQ's.
- The embargo on the Becoming Breastfeeding Friendly Report for England has been lifted and we are free to share the recommendations with you. The report is attached and BfN were representative on the specialist committee that was involved in developing it. Next steps we are pressing for the recommendations to be taken up by the various initiatives that are being progressed in Westminster including the Andrea Leadsom Early Years Review work, NHS modernisation plans and reform work at Public Health England.



- We have been working with NCT and other organisations such as Home Start, Parent-Infant Foundation, ABM and LLL on developing a guidance [add link] on restarting face to face breastfeeding support for England. This is in addition to the internal service protocols we have developed to support peer supporters across England and Scotland carry out support work with families as safely as possible during the pandemic.
- Following the BfN Strategy Day in January we have recruited two new exciting roles – an Information and Policy Officer role and a Tutor and Supervisor Coordinator role – both positions have been successfully recruited to and Emma Thomas and Helen Wilton feature here. Both roles are going to be key to helping us develop a stronger base for our information development and support for tutors and supervisors.
- Drugs in Breastmilk Succession Planning – we are making progress on actions following the Swansea evaluation and we are putting arrangements in place to continue the service beyond Wendy Jones retirement.





DIBM online training

...cont

- To date we have run a course for pharmacists interested in volunteering for the service and we have successfully recruited and trained 11 new volunteer pharmacists. The cohort of volunteers will be supported via a supervision model that includes regular paid supervision provided by Sally Carter and then also a salaried clinical supervision which will be provided by Amanda da Costa who has been volunteering for the service alongside Wendy. Wendy remains lead for the service and will help us bring on the new team.
- Quality marks for BfN – I am pleased to share with you that BfN has re-secured Cyber Essentials accreditation for the second year. BfN has also submitted complete evidence to achieve a Good Governance standard – this is currently being assessed and we await the outcome.
- Last but not least we are seeing a trend towards private milk banks profiting from the sale of human milk. Our understanding is that these operations promise to offer a 'fix' to mothers who are unable to breastfeed but the costs are exorbitant and some of the practices that underlay the operations are worrying and potentially exploitative. With our colleagues and partners we are looking to write letters to NICE and the Food Standards Agency to encourage them to investigate this further and we will look to develop editorial on this for future newsletters.

As always, I welcome your comments and feedback, you can contact me at:  
 ceo@breastfeedingnetwork.org.uk.

Best Wishes  
 Shereen



## Join us for a virtual afternoon tea on the 4th June at 2pm.

Volunteers' Week is a time to say thanks for the contribution millions of people make across the UK through volunteering.

It goes without saying that volunteers have played a key role in the pandemic response. During an exceptionally difficult year, people from all walks of life around the UK have taken the time to volunteer and make a huge difference in our communities – just as they do every year.

Join us this year for an online afternoon tea to recognise the fantastic contribution that all volunteers make to the work of BfN .

**Sign up to join us at:**  
[bit.ly/volweektea](https://bit.ly/volweektea)





# Move in May 2021

Once again we challenged you to do something active every day during May, this year with the added bonus of reconnecting with friends and family outdoors as we began to move out of lockdown across the UK.

We've been delighted to see so many of you getting out for a walk in the park, doing some daily yoga practice, kicking a ball around with the kids and heading out on your bikes. We acknowledge that fundraising may be too much to take on this year too, so we simply offered our community an opportunity to join us as we started to reconnect with each other outside of our homes.

This year Cleo and Ash joined us as Move in May Community Champions. Despite the rain, both of their families have been an inspiration to us all.

## Meet Ash.

My name is Ash, I'm a parent of two youngsters, and I'm taking part in this year's [Move in May campaign](#). Deciding to get involved and get moving with BfN was an easy call to make. Last spring we started small. Jumping in puddles. Pottering to the park next door for a round of Pooh sticks. Gently stretching before bed. By the end of the month, all four of us (plus our dog!) were chasing each other round a field with a rugby ball! [Read Ash's full article](#)



## Meet Cleo and her family.

I'm Cleo and I live in Islington, North London with my husband and two children Zara and Joshua. We are Move in May Community Champions. Our role is to help spread the word about BfN's Move in May campaign and to share our experiences to encourage other families to get involved. We're excited to be involved again this year because we know just how important the work of BfN is to help families get the support they need along their breastfeeding journey. [Read Cleo's full article](#)



## BfN Peer Support Services Your contacts at a glance

As an organisation we are committed to helping increase breastfeeding rates locally through our Peer Support Programmes.

To help you to stay in touch and share experience, we have compiled this list of the contact(s) for each project:

- London - Islington - Hannah Leonard
- London - Haringey - Linda Velloso
- London - Tower Hamlets - Tracey Murkatt
- London - Hackney (2 Children Centre contracts) - Susy Gilvin
- London - Camden - Agnes Leger (Volunteer Coordinator)
- London - Lambeth - Lisa Whipp
- St Helier and Sutton - Fay Brookes
- Portsmouth - Eleanor Johnson
- South & East Hampshire - Ginny Dupont
- Stoke - Jill Smith
- Derbyshire - Jill Smith
- Sandwell - Anna Cooney
- Wolverhampton Virtual Groups - Anna Cooney
- Oldham & Tameside (partnership with Homestart) - Nina White
- Cheshire & Merseyside (training only, volunteers coordinated locally) - Sophie Walters
- Wokingham - Kirsty Beck
- Frimley & Wexham (Phone support upon hospital discharge) - Rebecca Reeves
- Ayrshire - Kayleigh Lindsay
- Forth Valley - Project Lead Kirstin Worsley, Local Coordinator Gemma Hamilton
- Midlothian - Project Lead Kirstin Worsley, Local Coordinator Carol Hodgkin
- Western Isles - Project Lead Kirstin Worsley, Local Coordinator Phillipa Rewaj
- Wolverhampton - hospital and community support - Tutor/Supervisor Diana West
- North East Glasgow and Renfrewshire - Melanie Woodward
- Glasgow phone support service - Rose Clark

[More information on each Peer Support Service can be found on our website here](#)





## What Breastfeeding Looks Like

### Do you see people who look like you on our website or in our social media posts?

We are constantly striving to be as inclusive and diverse as possible in our content, as part of our commitment to offer support to all families, regardless of their age, disability, gender, race, religion or belief, sex or sexual orientation.

But we are painfully aware of how homogenous images of breastfeeding can be. In the top 20 results of a Google image search for “breastfeeding”, there was just one image that did not appear to depict a white family; just one that showed a same-sex couple; none at all that appeared to show families with a disability (though of course we appreciate that characteristics such as disability, gender and sexuality are not always visible).

We want to change this. We want to support every family, and we know that we are much more likely to achieve this if we reflect as many of you as possible in the imagery we use. So we’re appealing to all of our followers to help us build a bank of authentic and truly inclusive breastfeeding images for use in our communications.

**We want to see what breastfeeding looks like for you, in your everyday life, so we can better reflect the wonderful diversity that we know exists among breastfeeding families.**

We would welcome a variety of image styles, for example:

- While it would be lovely to see your face, if you’d rather remain anonymous and be cropped out, that’s fine too.
- There’s no need to show a bare breast or nipple if you don’t want to, in fact it can be great to show how discreet breastfeeding can be!
- We’re not looking for clinical “textbook” images, in fact quite the opposite. So don’t worry about turning your photo into a demonstration, we’d much rather see the human, everyday side of breastfeeding.
- Your photo does not need to be perfectly styled or staged – it would be great to see real life, so if there are toys strewn around or washing drying in the background, so be it.
- It can be helpful to show that breastfeeding doesn’t always have to take place in a comfy chair – so photos of breastfeeding out and about or in interesting or unusual locations would also be great!

We would particularly welcome images of:

- Black, Asian, Minority Ethnic or interracial families
  - Breastfeeding with a disability (whether this is a parent or child)
  - Parents in same-sex relationships
  - Trans parents
  - Younger parents
  - Breastfeeding older children, or tandem feeding
- Breastfeeding alongside those people who have supported you to breastfeed – for example your partner, a grandparent, a friend, or a peer supporter.

**Please send your images to [social@breastfeedingnetwork.org.uk](mailto:social@breastfeedingnetwork.org.uk) and you will be sent a link to complete a consent form .**



# Pumping for Pippa

By Clare Farquhar and Dana Hollingsworth

I first joined BfN as a Helper trainee in 2005(ish!) and went on to complete Supporter training before joining the BfN staff team in 2010. I now work as Central Support Manager. Pippa Hollingsworth is my niece, daughter of my sister-in-law Dana and my younger brother John. They live in Royal Oak, near Detroit in the US.

Due to the fact that Pippa arrived right at the start of lockdown, in March 2020, we have never met. My mum has never met her only granddaughter. As if that wasn't hard enough, we have had to watch from afar as Pippa has gone through more challenges in her short life than many of us ever will.

The good news is she is now a thriving little girl, she is strong and funny and she has brightened up our video calls over the last 12 months. I am so, so proud of her and her parents and I look forward to the day when I can give her the biggest cuddle.

## This is Danas story:

My baby was born with a severe heart defect in March 2020. Pippa had open-heart surgery at 3 days old. While the pandemic was kicking off in the USA, her and I lived in the hospital for the first month of her life. I tried to breastfeed, but my little girl wasn't interested given all the machines attached to her. Instead, I began pumping and storing my milk.

I felt helpless witnessing what Pippa was going through. Pumping made me feel valuable. My daughter was facing challenges that I couldn't control; if feeding her breast milk was something I could do to benefit her health, I was going to do it. So, I continued pumping and feeding her through a feeding tube and ultimately, by bottle.

Pippa came home with a temporary heart repair. A home care nurse was the only person allowed in our home. Pippa's weight and milk intake were closely monitored and recorded in preparation for her next surgery. For this reason, I wasn't able to breastfeed my daughter. I yearned for that special bond that other mothers describe when breastfeeding their babies.

Battling post-partum anxiety, the pumping wore on me. I struggled to find 15 minutes 7 times a day to pump. I hated the constant cleaning of



pump parts and prepping of storage bags. I felt sore, round, leaky and unfamiliar to myself. I dreamed of the day I could stop pumping – one less thing to manage. I was exhausted and ready to feel human again. But my brain was mush - creating a plan to wean off breast milk was very intimidating. So, I just continued doing what I was doing. "I'll just get her through this next surgery", I told myself.

Leading up to that surgery, the intensity of the situation was terrible. It was compounded by the pandemic. After a 7-hour open-heart surgery, Pippa's heart was fully repaired. I didn't realize the amount of weight I was carrying until it lifted.

I slowly reduced my pumping sessions. At one point, the milk I had stored in the spare freezer – at least a month's worth - defrosted and went bad. I was devastated to pour all that precious time and energy down the drain, bag after bag.

I didn't pump for 11 months enthusiastically. I cried and complained regularly. I intended on stopping many times throughout Pippa's first year. But having short-term goals to continually push past helped keep me going.

I couldn't control much last year, but what I could control was the amount of love, care and nourishment I gave my daughter. I'm proud that, despite the extreme stress of it all, I kept pumping for Pippa – she deserved every last second.



# Feeding the Breath

By **Miriam Allan**  
Soprano and breastfeeding peer supporter

**Through the course of my entire life, I've been singing. I started as a chorister, aged 6, in Newcastle, NSW, Australia, and I've not stopped. Now, I travel the world as a soprano soloist singing in concerts, operas and making recordings.**

Believe it or not, there are two areas where my work as a singer crosses over to the world of breastfeeding peer support: breathing and voice.

We have something of a mantra in the singing community: when in doubt, breathe out. Any problem we face we can usually tackle by improving our breathing. During the past four years as a peer supporter for the BfN, I've learned, this is every bit as relevant to breastfeeding as it is to singing.

Singers need to breathe out to reduce tension; it's the same for breastfeeding parents. Singers fall into holding patterns and peculiar habits that can cause long-term problems, or even damage, by holding our breath; so do breastfeeding parents.

As supporters, we can see this tension as uneven shoulders, particularly if a parent is holding/shaping the breast to assist latching. We have it reported as neck aches, headache and back pain but tension leads to increasingly poor positioning and attachment as the positions become harder to hold.

Breastfeeding parents who are nervous, embarrassed, in pain or, worse still, anticipating pain, hold their breath. The anticipation of pain is not just physical. It's the anticipation of judgement (e.g. breastfeeding in public or in front of disapproving family members), the anticipation of rejection leading to embarrassment, the anticipation of a problem when none exists because they've not had adequate support and encouragement. Holding their breath instantly adds tension to an already tense situation.

When you're next supporting someone, observe their breathing. If they're holding their breath, encourage them to breathe out for an unusual length of time. (e.g. 7 or 9 or 11 counts) We are all used to counting in single units, 2s and 5s, so chose something less familiar. And when counting for someone else, count backwards. Then they know when it ends! You can move the breath around the body – particularly into the belly (C Section scars notwithstanding) and encourage the breath to help them relieve a tension in a specific spot. See if you can encourage them to soften their face and jaw with every out breath. Then they can really smile at their beautiful baby!



Let them just breathe in. We will all breathe in when it is required. But we can really control the out breath. The more you control the out breath, the more you can balance the breath in.

The second crossover is in the area of voice. As peer supporters, much of our work is connected to how we use voice. Body language forms a large part of the Helper course and is undeniably crucial. But, certainly through lockdown, more and more of our supporting has become voice based – those who work on the NBH and those of us who have been utilising video platforms.

The way in which we use our voices doesn't always need language: using a bright, confident tone when we introduce ourselves; hums of familiarity and recognition; syllables of agreement - uh-huh, ah-ha. Audible intakes of breath/gasps indicate our engagement when an interruption would not be appropriate. Changes in pitch and tone carry almost as much weight as the information that we give. If we speak too loudly or forcefully, the information we give will be lost in perceived aggression. If we speak too softly or in too breathy a tone, perhaps the information will not be trusted.

Consider your voice when you're next supporting: what sounds are you making without saying anything? This is your vocal body language. You're showing your empathy without needing to say anything. Try speaking in a different way – a higher or lower pitch. Speak more slowly or perhaps vary the tempo of your speech to deliver the information and see if there is a different response. Voice is integral to successful communication.



# BfN Evaluation 2021

By **Nina White**

**Programme Manager**

**The BfN Central Evaluation is conducted every year. It's purpose is to help us to understand what we are doing well, where we can improve and also give us the evidence we need to secure future funding.**

The 2021 evaluation survey was launched on 1st March 2021 and we received 318 responses in total (due to the pandemic, we received significantly less responses, which we expected)

## **2021 BfN Results Summary:**

88% of the responses came from breastfeeding parents, 6% from Health Professionals and 6% from family, partners or others.

26% of respondents were supported by the BfN Drugs in Breastmilk Service, social media chat support gave us 24% of the responses and our National Breastfeeding Helpline 6.5%.

Other BfN Project areas also had a high response rate – as expected – and the Project Managers will receive a localised project evaluation report to share with their commissioners, staff, volunteers and local families.

When asked about their first contact with BfN, 8% of respondents said they had support from BfN before their baby was born. The highest 'first contact' bracket was the 3-6 week age bracket (18%) then the 7 week – 3 month age bracket (14.5%), and 12% in at 3-6 months. 10% of first contacts were when their baby was 2-4 days old. These timings reflect the usual periods when breastfeeding parents need specific support.

For the last two years, 64% of people contacted BfN because they were experiencing breastfeeding problems. This year the figure rose to 72.5% – reflecting the need for support during lockdown when other avenues of care were reduced.

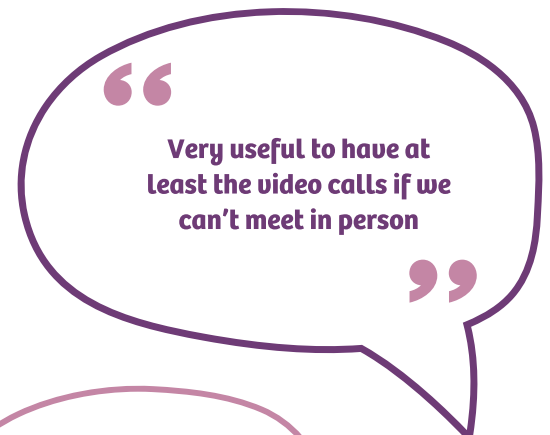
When asked the ways they had contact with BfN (ticking all that applied) 40% reported they had used our website for information and 31% spoke to a Supporter on the telephone. 30% had support

from our social media chat team and 31% requested information from the drugs in breastmilk service

Home visits rates dropped from 27% last year to 8% which is understandable, but our new virtual/video breastfeeding groups were attended by 26.5% of responders. 14% had a 1-2-1 video call with a peer supporter.

Our virtual/video groups and calls have proved so successful we are planning to keep some going even when face to face groups can begin again: 28% of participants said they would be keen to attend both virtual and real groups and intend to continue with video support calls.

## **What respondents told us about accessing virtual support:**



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## BfN Evaluation 2021

Once again – the most popular topic of discussion with BfN Peer Supporters was positioning and attachment for feeding at 57% with 45.5% of people struggling with painful breasts and nipples. 33.5% of parents asked for information about medication/medical intervention and impact on breast milk/ breastfeeding.

The next common topics were baby's weight gain and expressing milk – exactly the same topics as last year and the year before. 20% of people talked about their mental wellbeing or mood.

We hope we were able to ensure all these parents were able to continue feeding their babies if they wished to. A new topic this year was Covid with 19% of parents reporting that they asked about the safety of breastfeeding with covid or when being vaccinated.

As in previous years, we asked a variety of 'before/after' questions and were delighted with the answers, which proved the value of peer support.

### Key findings include:

60% agreed they had the information needed to make decisions about feeding their baby before contact with BfN, rising to 90% after support from BfN.

40% of mums could breastfeed without pain before contacting BfN, increasing to 75% after peer support.

Nearly than half of the mums questioned claimed BfN supported them to breastfeed for longer than they otherwise would have done. Reasons given for this included evidence based information about medication, information about attachment and finding a pain free position, expressing milk, managing blocked ducts and mastitis, knowing what is 'normal' new born behaviour and that it is possible and beneficial for older babies and toddler to breastfeed. There were also lots of comments about general support, practical suggestions, building confidence and encouragement, feeling listened to.

90% of mums said they felt listened to, that their choices were respected, the support/information they received was specific to them and they did not feel pressured to do any particular thing.

96% of mothers were satisfied with the support they received from BfN and 95% would recommend us to family or friends.







# Annual Evaluation 2021

What we are doing well, where we can improve and helping us to provide the evidence required to secure future funding.

## Who responded?



88% breastfeeding parents  
6% health professionals  
6% other



Once again, the most popular topic of discussion with BfN Peer Supporters was positioning and attachment for feeding.



Over 70%

of people contacted BfN because they were experiencing breastfeeding problems.

73%

contacted BfN because they were experiencing breastfeeding problems

31%

requested information from the drugs in breastmilk service

27%

attended one of BfN's new virtual breastfeeding support groups.

19%

asked about breastfeeding with covid or when being vaccinated.



96% were satisfied with the support they received from BfN.

95% would recommend us to family or friends.



### We asked about the impact that BfN had, they said:

I felt lonely and isolated on my breastfeeding journey  
I had people who could give me support with breastfeeding  
I felt confident about making choices regarding breastfeeding  
I felt able to continue to breastfeed for as long as I choose  
I felt part of a community that supported me with breastfeeding

Before BfN support

After BfN support

35%	12%
54%	90%
63%	90%
62%	85%
32%	76%



# My twin feeding journey

## By Jennifer Williamson

I had overcome a rocky start to breastfeed my first born until he was nearly two, so when I became pregnant again I felt confident that I would soon be breastfeeding again. Until the moment at the 12 week scan, when the sonographer looked surprised and called her colleague over to confirm what she was seeing. Twins!

As my husband and I giggled our way out of the scan room in shock, my mind began to fill with questions: how would we cope with three kids under 3? What would we do for a buggy? And how could I breastfeed twins?

I had plenty of knowledge of feeding thanks to my BFN peer supporter course, but feeding twins was a daunting prospect. As my pregnancy progressed, I sought out as much information as I could on breastfeeding twins. I got myself a twin feeding pillow and joined my local twins club. I knew I was going to need all the support I could get.

My babies arrived safely by elective caesarean at 37 weeks, and for the first 24 hours I fed them one at a time. My daughter was a pro from the off, but my son had a shallow latch and was a bit sleepy. After a bit of support from the infant feeding team, we got it sorted and even managed a tandem feed in hospital. Three days after they were born, we were home – which is quite unusual for twins who often come early and require time in NICU or SCBU.

Feeding a newborn is intense: cluster feeds, leaking boobs, baby sick everywhere, no sleep, so imagine all that x2! The early days seemed never-ending but they flew by. At first I didn't like the sensation of tandem feeding, but my babies never much cared to wait for their turn so gradually tandem became our norm. It certainly saved time.

Eight weeks after our twins arrived, my husband went back to work and my real challenge began – looking after an energetic toddler as well as newborn twins by myself. That was when breastfeeding really came into its own. It always settled the twins, I could read a book with my eldest at the same time and I didn't have to keep running off to make bottles.



Time passed and, before I knew it, we had made it to six months exclusive breastfeeding. It had been exhausting and intense but at least now things would get easier?

Well, that was Spring 2020... a year on and various lockdowns later we are still at it!

## Raising funds to support BfN has never been easier!

Did you know that you can turn your everyday online shopping in to donations to help support other mums along their breastfeeding journey?

Easy Fundraising is a simple and effective way to support BfN. And 100% free for you to do.

**Simply click this link to check it out:**  
[www.easyfundraising.org.uk](http://www.easyfundraising.org.uk)



# Update from the National Breastfeeding Helpline

By Fliss Lambert, NBH Manager

Even as we begin to start to see a bit of a light at the end of the tunnel of lockdown, numbers of calls, web chats and social media messages to the National Breastfeeding Helpline are still at record levels and our amazing team are doing a great job attempting to meet the demand for support.

We worked out that in the 12 months after the start of the first lockdown on 23rd March 2020 we supported over 22,000 people via the helpline, webchat and social media message – that’s more than an entire capacity crowd at the O2 in London!

Support from the helpline has been more vital than ever this year. We recently asked our followers on social media to let us know if they had contacted us in the last year, what that call or chat or message meant to them and the responses were overwhelming - they might even bring a tear to your eye!

'The call meant everything! It was so nice to hear a friendly non-judgmental voice. So kind and caring and reassuring! I felt so alone but on the call I felt seen.'

“  
**It was amazing to still be able to get such a great level of support when it felt like all the other support a new mum needed was taken away. It helped me carry on breastfeeding when I was struggling and gave me someone to answer my questions when I felt alone.'**  
- NBH Caller  
”

'I had no breastfeeding support due to covid and the webchat saved my breastfeeding journey many times. Because of this I am now 8 months into breastfeeding my baby!'

So to everyone who has given time to support another family this year, thank you – you make such a difference.



We were delighted to be invited to present again at this week's [All Party Parliamentary Group on Infant Feeding and Inequalities \(APPGIFI\)](#), chaired by Alison Thewliss MP.

Andrea Leadsom MP spoke about her own experiences as a new mum, and presented the findings and recommendations of the [Early Years Review](#) that she chaired and took questions from attendees. Fliss then gave a short update on the work of NBH and our whole team was thanked by Alison Thewliss.

Many volunteers were able to attend live but if you missed it, you can watch the whole meeting via [Alison Thewliss's Facebook page](#). Everyone is welcome to attend APPG meetings, so if you'd like to, [email Alison Thewliss's team](#) and ask to join the APPGIFI mailing list.

We also welcomed a new member to our team in February. Claire Cittern-Jones is our new Helpline Volunteer Co-ordinator (HVC) for London and the surrounding areas. Claire is a BfN Supporter based in Wokingham and has made a brilliant start already so if you're a volunteer in that area, she's probably already been in touch with you. Welcome Claire!





# Breastfeeding and Down Syndrome

## Information for Families and Breastfeeding Supporters

**Breastfeeding a baby with Down syndrome can sometimes present challenges, but with the right information and support, breastfeeding can be successful.**

Alice works for the [Portsmouth Down Syndrome Association](#), and is mother to Teddy. As part of [World Down Syndrome Day](#) she shared their experience with us, and provided valuable insights in to how best to sensitively support the families of children with Down syndrome on their breastfeeding journey.

"I feel it's important to start by explaining that I am not an expert in breastfeeding! I am a Social Worker and had chosen to specialise my career in working with people with Learning Disabilities. It wasn't until my second son, Teddy was born, and then diagnosed with Down syndrome that I realised just how important and powerful language and knowledge is for everyone involved in supporting a family.

I reached out to my local support group Portsmouth Down Syndrome Association (PDSA) when Teddy was diagnosed, and they supported my family from his diagnosis and throughout our journey to the cheeky 4-year-old he is now.

I started to volunteer with PDSA and now provide education and training for Health and Social Care practitioners on all aspects of Down syndrome. It is important that families of people with Down syndrome have access to the support that they need and that this is delivered holistically.

Teddy was born by an elective c-section due to being breech. We had a blissful hour of skin to skin and Teddy was great at feeding, he latched straight away and 'just got it'. After 24 hours in hospital recovering, both Teddy and I were discharged home (his diagnosis was missed) and we were eager to start life as a family of four. Teddy was brilliant at feeding and on day 3, we were rewarded with the fantastic news that he had gained 40g!

However, Teddy's subsequent weight gains were 'static', and he only gained 20g a day. Due to extended jaundice at 2-weeks-old we were seen in hospital by a doctor and consultant who suggested some screening and tests. I was grateful as had



some feelings that all was not as expected with Teddy. One of these tests diagnosed Teddy as having polycythaemia (a high concentration of red blood cells in your blood). We were admitted to hospital the next day for 'failure to thrive'.

There was a suggestion that Teddy may be having difficulties getting milk, and that he may not manage with a bottle so would need a Nasogastric tube (NG). I was clear with the team that I wanted to continue breastfeeding, and so would express the 'bottle top ups' that they felt Teddy needed.

As I had fed Teddy's older brother successfully, I was quite confident in my ability to provide milk for him. I didn't know what a NG tube was – but they weren't doing that to my baby if we could avoid it!! We started the gruelling 3-hour cycle of alarms, feeding, expressing, and topping up. One nursery nurse was incredibly supportive. She sat next to me on the bed late in the evening and told me to 'stand by my guns, and that if I wanted to feed, that I could and should'.

Slowly but surely, Teddy continued to gain weight, and so we were discharged 4 days later. At 3 weeks old, Teddy's genetic bloodwork came back, and he was diagnosed with Down syndrome.

A few days later at a baby weigh clinic, I asked for support from a breastfeeding volunteer, I wanted...

(cont)

...cont

## Breastfeeding and Down Syndrome

to see if there was anything more I could do to help Teddy. I remember the volunteer asking my husband and I 'how she could help'. It was the first time that I she could help'. It was the first time, that I had to tell anybody outside of our family, and health professionals that Teddy had Down syndrome. I was so very aware of the other mothers feeding their babies close by and found it difficult to speak.

The volunteer was lovely and tried to support me but referred to Teddy as a 'Downs baby'. I didn't know how to tell her that Teddy's diagnosis was only part of him – it didn't define him. He was (and is) so much more than his diagnosis.

At home, we continued to 'top' Teddy up with expressed bottles of milk, but Teddy gained weight rapidly and so we limited these. Teddy was able to switch effortlessly between breastfeeding and bottle feeding – he wasn't particularly bothered where his milk came from – as long as he had milk!

Breastfeeding was especially important to me. It gave Teddy and I a 'closeness', it helped me feel that despite a world of unfamiliar health appointments, invaded by complex health professionals and new medical language that I was doing something 'important and normal'. Breastfeeding helped remind me that first and foremost, Teddy just needed love and milk-like all babies.

My tips to anyone supporting a family of a child with Down Syndrome:

- See the child first. Use positive, person first language, Teddy has Down syndrome rather than Down syndrome baby/child.
- Congratulate that family on their newborn, as you would any baby – all babies deserve a warm welcome!
- Signpost a family to resources like Julia's way and their local Down syndrome support group for more guidance.
- Encourage a family to advocate for how they wish to feed their child.
- Many mothers of children with Down syndrome who had early issues report that their baby was breastfeeding successfully by 3-4 months of age.
- Be aware that health conditions, a child's tone or coordination may impact on their feeding, but different feeding positions may support baby better. For babies which may tire easily, it may help if milk let down happens before the baby latches. Ensure liaison with SLT if there are any concerns regarding aspiration.
- Ensure that the family have a PCHR insert in their red book and so the baby is being plotted on a graph for children with Down syndrome.

**Special thanks to Alice for sharing her story with us**

## Save the Date! BfN Conference 2021

BfN's annual conference will be online again this year. Details of speakers and tickets will be released soon, so follow #BfNConf21 on social media for the latest updates.

**Saturday 2nd October 2021**





# BfN Project Updates



## Haringey team gathers momentum despite pandemic restrictions

**By Linda Velloso**  
**Service Manager**  
**Haringey Breastfeeding Peer Support Service**

Well, a global pandemic may not be what we had planned for our service, but we pulled together like never before and actually came out stronger, more visible, connected and adaptable.

Our service was well established in Haringey after we took over in 2016, completely reorganising and cementing it into the fabric of local family support services. But then we had to pull back from our mostly face to face service and come up with a plan to support families in ways we had never considered!

I was worried that the service, which sometimes struggled to get the broad recognition it deserved from all health professionals, would seep into obscurity and nobody would know we were here, hunkered down in a never-before-seen national lockdown.

But strangely and quite unexpectedly the opposite occurred. The phenomenon of feeling like the work my team do every day was suddenly thrown into the spotlight and getting praise from all corners.

As services such as health visitors pulled back from face to face and conducted most support over telephone, I knew that we had to do something to ensure our families could actually see a friendly face.

On the first day of national lockdown in March 2020, we had already put the message out that we could provide one to one Zoom calls with ANY Haringey family.

There were stumbling blocks. Before the creation of any organisation wide guidance, we had to find our way. Advertising a Zoom link with the word “breast” in it attracted around a dozen men from across the pond ready to educate us on “Zoombombing”. But when promptly removed, we had our first successful Zoom drop-in in the bag and had learnt tonnes!

The amazing Haringey team have now facilitated over 230 Zoom drop-in groups, almost 600 video calls and hundreds more phone calls and emails.

Not satisfied with only supporting those who usually access the service, we secured funding from the CCG for a year of outreach calls to all new births in Haringey. Again, the numbers are fantastic – almost 1500 calls and 2500 texts in less than a year were made by our two-woman team.



**We had to do something to ensure our families could actually see a friendly face.**

Crucially, this outreach work has also seen a marked increase in support given to families from areas recognised as less likely to access the service. In addition, our wonderful peer supporters have also taken on training and responsibilities outside that of our usual commission, such as assessing and referring tongue ties.

Seeing lockdown isolation on top of language barriers, we started a monthly Spanish virtual drop-in with the help of one of our wonderful Spanish speaking volunteers. We have now held 5 and have opened it up to all London projects, with plans to create other pan London specialist groups.

Then comes recovery. With two face to face indoor groups and an individual clinic running, volunteers back on the hospital wards, our first online Helpers course completed in April, and our hopes of permanently retaining some virtual support, we are well on track.

# BfN Project Updates

## BfN lunches telephone peer support service in partnership with Frimley and Wexham Hospitals

By Rebecca Reeves  
Frimley and Wexham Service Coordinator

For the last year, BfN has worked closely with the Infant Feeding Teams at Frimley and Wexham Hospitals to create a Telephone Peer Support Service. This initially was a trial project for 6 months but it has proved so successful, particularly during these Covid times, that it has will continue for a further 6 months until September 2021.

We are delighted to have highly experienced Peer Supporters/IBCLCs Claire Flood, Karen Williams and Lyndsey McConnell on the team, who have been involved in developing this service with Coordinator Rebecca Reeves. Mandy Barlow is the Team Supervisor whose wisdom and calm approach has been very much appreciated.

The service is integrated with with Frimley Hospital and Wexham Park Hospital Infant Feeding Teams. Each day, referrals are made by health professionals at both sites via a QR code which inputs referral data onto a live spreadsheet to be picked up by the BfN team.

The main aim of the project is to offer mothers support and information in those first few days - quite often we manage to speak to new parents on the day between discharge from hospital and their first midwife visit which is proving to be a crucial time to discuss normal newborn behaviour and support mums to establish breastfeeding.

“ Thank you so much for calling, it's been really helpful. - Helpline caller

In just over 5 months the BfN team supported 718 parents and families! The Infant Feeding Team are extremely grateful to our team, and we have enjoyed working in partnership with them to develop this service together.



## Charter Babies Walk North East Glasgow at Tollcross Park

By Melanie Woodward  
Volunteer Coordinator

We have had some fantastic feedback about our Park Walk, even when the winter West of Scotland weather hasn't been so fine!

The experience of walking outside has helped mums come together and feel less isolated during the Covid-19 lockdown restrictions, giving them confidence to be out and about with their babies, getting a bit of exercise and meeting up with other mums.

Our project peer supporter Debbie explains "Many new mums are isolated at a time when they need reassuring and caring community around them. As a mum and a peer-supporter, I know the need for safe spaces for mums to talk and share".

"As we can't find this in physical places right now, I'm so glad that we've been able to offer walks as a support space. I know that it's good for me to share my own lockdown baby experience, and I'm glad to have an opportunity to listen to the stories of others." she says.

The walks have been a big hit with local families. For mums like Deborah, the support has been invaluable. She told us "I absolutely love the BfN Charter Babies walks. They are very careful to comply with covid guidelines, they make absolutely everyone attending feel so welcome and they provide advice and support in a casual setting. It's the sort of thing that brightens up your day!".



## BfN and NCT launch new guide to re-starting support services for expectant and new parents during Covid-19.

NCT and the Breastfeeding Network, in collaboration with an alliance of supporting organisations and in consultation with Public Health England, have today released a new guide to re-starting support services for expectant and new parents during Covid-19.

The guide provides a set of principles and considerations for organisations to work through so that they can restart their face-to-face support services safely and with confidence. Covid-19 and the prolonged period of social restrictions have had a huge impact on the lives of pregnant women, their partners and families with new babies.

Reduced access to pre and postnatal community support, restrictions in access to maternity care for partners, limited face-to-face support with breastfeeding, fewer possibilities for practical and emotional support from friends and family, financial insecurity – combined with high levels of misinformation about the virus and vaccine programme – have left many families struggling to cope. Some groups have been disproportionately affected, widening inequalities that already exist.

The role of third sector organisations, charities and academics supporting early parenting has been crucial in adapting and strengthening support in a socially distanced time alongside building up evidence. The sector is also fulfilling a powerful role in providing a ‘voice’ for parental experience to ensure attention on these issues and that critical resources are applied in the short and longer term.

As restrictions ease, our sector has the commitment and capability to ensure community support thrives. Collaboration and shared learning will be more important than ever, and we are grateful to all of the individuals and organisations who have contributed to the principles set out in this guide.

**[You can read and download the guide here.](#)**



**We are delighted to announce that BfN achieved the Good Governance Award in April.**

The Good Governance Award is the Quality Standard for Scottish charities, recommended by OSCR. The Award supports and celebrates governance best practice, recognising the importance of good management to the efficacy and efficiency of Scottish Charities.

Chief Executive Shereen Fisher says “We know that BfN is well thought of for its breastfeeding information and support by mothers, parents and families, but we can also now show parents and families and the wider public that we are well-run and well-governed – this will bring a new layer of trust and confidence”.

### **What was the process?**

BfN has looked closely at the following areas over the past 18 months to compile an e-portfolio which evidences competency and best practice in:

- Charitable Status
- Trustees
- Planning, Delivering, & Monitoring
- Recruitment
- Managing Staff & Volunteers
- Managing Finances
- Managing Resources
- Marketing & Communications

Completion of the award provides proof that BfN is actively engaging in excellent governance through our Award Certification. It adds value and enables us to build a sustainable, better future for all of the families that we support. BfN have been awarded three years of Good Governance Award status and will be involved in a forum to support re-assessment.

# Who's Who and Who's New



## **Stacey Bullock** **Lead Internal Moderator &** **Quality Assurance Officer**

I achieved my Certificate in Education in 2010 and have worked in a number of Further Education Colleges delivering level 2 & 3 qualifications including apprenticeships. I became a mentor and a quality, teaching & learning advocate (QTLA) which inspired me to progress through professional formation, achieving Advanced Teacher Status (ATS) and subsequently Chartered Teacher Status (CTeach). I now work in a number of quality roles as an internal lead, external assurer and as an education consultant for a number of awarding organisations.

tutors hold and the challenges they may face. Helen is passionate about breastfeeding support and delighted to join the BfN, particularly since the National Breastfeeding Helpline was such a lifeline in her breastfeeding journey.

She lives in Greater Manchester with her husband and two young children and in her spare time enjoys playing the piano, running and walking in the Lake District.



## **Emma Thomas** **Information and Policy Officer**

Emma has always had a strong interest in science, research and mental health. She has a degree in psychology and PhD in neuropsychology, and worked as a post-doctoral researcher, studying cognitive and neurological aspects of depression.

However, after having two children in quick succession, she decided to take a career break to focus on her family and relocated to Scotland, where her third child was born. She trained as an NHS peer supporter soon after, and discovered a love for learning about breastfeeding and supporting other mothers.

As well as working for BfN in the role of information and policy officer, she will also be continuing her peer support work and volunteering as a supporter on the National Breastfeeding Helpline. She also loves spending time outside hiking and on the beach, and is trying to develop a love of running and sea swimming!



## **Helen Wilton** **Tutor and Supervisor Coordinator**

Helen has recently joined the team as Tutor and Supervisor Coordinator. Her priority in this new role is ensuring that all of our tutors and supervisors receive the support they need to deliver effective training and supervision. She comes from a background in education and, as a experienced teacher, hopes to bring an understanding of the diverse responsibilities that



# Congratulations

A huge thank you to everyone that makes BfN what it is.



## DIBM Helpers

Reena Patel  
Gayle Anderson  
Sam Morris  
Zoe Roseblade  
Sarah Robinson  
Charlotte Ayres  
Philippa Winter  
Jessica Jones  
Nadine Revell  
Abigail McDougall  
And their tutors: Kirstin  
Worsley/Eleanor Johnson

## Helpers

Lisa Washington  
Laura Newman  
And their tutors: Francesca  
Elver-Fiddimore

Mel Frith  
And her tutor: Francesca  
Elver-Fiddimore

Sofia Chrysikopoulou  
Natalie Martello  
Genna Sole  
Emma Freeman  
Jenny San  
Anita Kambo  
Pearl Schultz-Wiremu  
Cassie Corby  
And their tutor: Anthea  
Tennant-Eyles

Marie-Claire Fournier  
Gayle Lucas  
Kayleigh Lindsay  
And their tutors: Aurore  
Lasne/Donna Ebanks

Emma Croxton  
Gurinder Kaur Chera  
Kayleigh Eckhardt  
Lindsey Casey  
Louise Thompson  
Rebecca Scally  
Tiffany Ives  
And their tutor: Donna Ebanks

Sara Modino  
Lindsay Holt  
Beth Fitzgerald  
Beth Dixon  
Laura Stocker  
Chloe Rush  
Amy Stock  
Emma Elford  
And their tutor: Esther Pierce

Joanna Spiers  
Fay Brookes  
Steph Green  
Lauren Cooper  
Sally Hodgson  
Sarah Bright  
Charlotte Fisher  
Charlene Judge  
Skyler Smith  
Louise Lomax  
And her tutor: Joy Jones

Fiona Stewart  
And her tutors: Kirstin  
Worsley/Mandy Barlow

Amy Bevis  
Lucy Booth  
Rachel Slyfield  
Rebecca Downing  
Julia Allison  
Laura Jones  
And their tutor:  
Lydia Murtagh

Fiona Cresswell  
Toni-Louise Robinson  
And their tutors: Melanie  
Woodward/Carolanne Lamont

Shruti Arora  
And her tutor: Mel Frith

Becky Hulme  
Gemma Mcardle  
Lenka Kriskova  
Tammy Shepherd  
Michelle Bowman  
Dawn Turner  
And their tutors: Sukie  
Woodhouse/Jane  
Neesam/Donna Ebanks

Collette Pye  
Nicola White  
And their tutor: Kirstin  
Worsley

## Helpline Supporters

Sarah Ojar  
And her tutor: Carolanne  
Lamont

Tori Poole  
And her tutor: Joy Jones

Rose Clark  
And her tutor: Kirstin Worsley

## Supporters

Anne C. Mitchell  
And her tutors: Carolanne  
Lamont/Esther Pierce

Diane de Jesus  
Chloe Way  
And their tutor: Joy Jones

**Thank you to all of our helpers - supporters - tutors - supervisors - staff - friends - fundraisers - donors and funders.**

**We value each and every one of you!**

**If your name is missing from this list, please accept our apologies.  
Contact us to ensure that you are included next time. Thank you for your understanding.**