



## CONTENT

MESSAGE FROM HOPE	P1	ROLL OUT OF OUR NEW BRAND	P7
2022 HIGHLIGHTS	P2	PATRON/TRUSTEES/ADVISORS	P7
HOPE SESSIONS	P3	THE TEAM	P8
HOPE DAYTRIPS	P3	VOLUNTEERS	P9
ANTI-SUFFOCATION PILLOW	P4	HOW YOU CAN HELP US IN 2023	P10/11
FUNDRAISING	P5	DATES FOR 2023	P12
OUR NETWORK & AFFILIATIONS	P6	LOOKING FORWARD	P12

# NEWSLETTER

## OVERVIEW OF 2022

# JAN 2023

## HAPPY NEW YEAR

After nearly 2 years of COVID disruption we were so happy to get back to normal with our regular face-to-face HOPE Sessions and Daytrips throughout 2022. It was lovely to see our HOPE families and we enjoyed welcoming new families to the charity. And what a fantastic celebration we had at the end of the year with our annual Christmas Party!

We would like to take this opportunity to thank you for your ongoing support and wish you all a Happy New Year. Our hope is that 2023 will bring new research, new treatments and renewed hope for children with Epilepsy.

Love The HOPE Team x





# 2022 HIGHLIGHTS

In 2022 we continued to host our monthly support HOPE Sessions in **Oakleigh School in Whetstone**, London. We would like to thank the school for their continued support and give a special mention to **Allan the caretaker** for all his help.

We were delighted to have **Warburton Bakers in Enfield** support us by supplying refreshments for our sessions. And this year we've had **Therapy Dogs Nationwide** regularly attend our sessions and their canine companions are always a hit.

On November 7th 2022 we **celebrated our charity's 11 year anniversary**. And in December 2022 we hosted our **9th annual Christmas Party** which was enjoyed by over 30 HOPE families.

We organised two fantastic **Family Daytrips** for our HOPE families to **London Zoo** and **LegoLand Windsor**.

And through the dedicated fundraising efforts from our team, we were able to secure grants from **Skipton Building Society Charitable Foundation** and the **Worshipful Company of Grocers** alongside donations from individuals and **Nando's in Banbury**, all of which enabled us to continue with our Free Anti-Suffocation Pillow Scheme.

Our network of affiliations has grown and we are really pleased to have established links with **Peter Doody Foundation**, the **John Shaw Foundation** and **Shropshire Epilepsy Support** and **Support Dogs**. And this year **The Landmark Trust** and the **Barrie Wells Foundation** have given our HOPE families opportunities for experiences and trips away.

**Our Chair of Trustees, Dr Nadine Gurr continues in this role** as well as running HOPE on a day-to-day basis, including overseeing the advice line, writing the Facebook posts, organising the distribution of pillows, co-ordinating all those involved in HOPE and along with **Louise Miller** she responds to emails. We would like to take this opportunity to **thank Nadine for her guidance and understanding in all she does for HOPE on a voluntary basis.**



# HOPE SESSIONS

From January 2022 we were able to get back to our monthly face-to-face HOPE Sessions. The online sessions HOPE hosted over the Covid pandemic continued until February 2022 with **Dr Sophie Bennett, Dr Anna Wood and Alex Cox**. These were additional sessions offered while medical and support teams could fully transition back to face-to-face contact with families.

Our HOPE Sessions had a variety of informative and entertaining visitors. We hosted a **Nerf gun battle, a graffiti artist, an art therapist, a music therapist** and a **bubble entertainer**. We also had the lovely addition of **Therapy Dogs Nationwide** attend every HOPE Session with their wonderful therapy dogs. There were **massage and beauty therapists for the parent/carers**.



“ Thank you so much for the welcoming Xmas Party. It's so lovely to meet many new families. Hewitt and me love the massage. The party was full of smiling faces. ”

One of our key objectives as a charity is to give **children with epilepsy the chance to have fun and enjoy life**. We know that day trips can be hard, sometimes not even possible for our HOPE families, so we work with venues to make these trips as seamless and accessible as possible. We want children with epilepsy, and also their siblings, to be able to enjoy these experiences like everyone else.

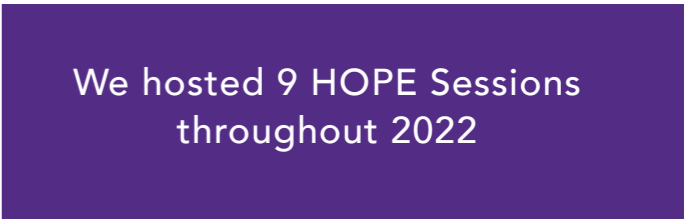
We organised two group family days out during 2022. The first was a trip to **London Zoo** in May where the families could enjoy each others company with no need to socially distance. The second trip we were fortunate to have **Merlin's Magic Wand Charity fund tickets to LegoLand in Windsor**.

We loved seeing all the wonderful pictures that the families sent to us.



We also offered **manicures at every session**.

HOPE held a series of talks on medical issues with **Dr Alice Winsor specialist in sleep** issues in children with epilepsy and **paediatric epilepsy nurse consultant Lisa O'Brien**. On this note we would also like to thank **Dr Penny Fallon consultant paediatric neurologist** and **Neil Williamson specialist epilepsy nurse** for their untiring efforts in answering parents' medical queries. **Louise Fisk head teacher** also advises parents on educational matters and concerns.



# HOPE DAYTRIPS







## ANTI SUFFOCATION PILLOW SCHEME

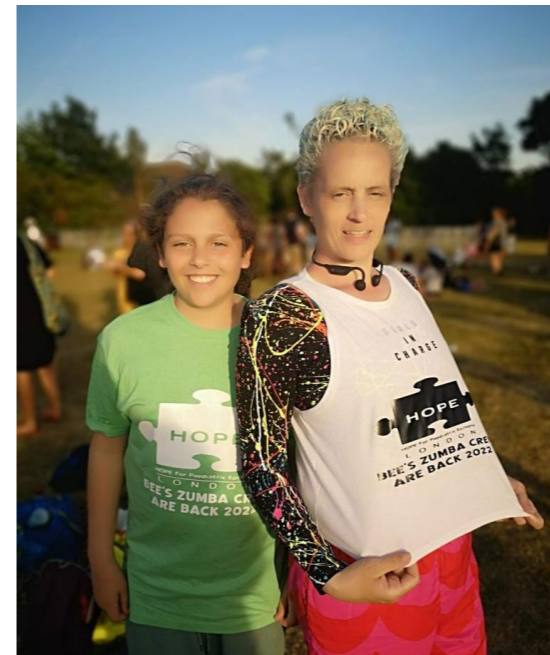
An important part of what HOPE does as a charity is the **provision of anti-suffocation pillows to children and young people who have nocturnal convulsive seizures.**

We received **grants this year from the Skipton Building Society Charitable Foundation** and the **Worshipful Company of Grocers** which in part enabled us to do this. Alongside these grants we have received generous donations from individuals and also a branch of **Nando's in Banbury**. This has all meant we can continue to provide these potentially life-saving pillows.

**We donated 170 Anti-Suffocation Pillows in 2022**

“ Thank you so much not only for the pillow but for the community you invited us into and the ongoing support we received ”

“ Thank you so much for my daughters pillow, it really is such a reassuring safety measure while she is sleeping . We are forever grateful to your charity ”



## 2022 FUNDRAISING

HOPE London would like thank our kind supporters who have held fundraisers and donated to us over the last year.

**HOPE parent Ben Darbyshire** ran an epic 60-mile challenge.

**Anthony Williams and Carl Bennett founders of Epilepsy Surgery Friends** walked 34 miles along the Sandstone Trail.

**HOPE grandparent Jayne Ross** fundraised for us by selling cards of her grandson's designs.

**HOPE parent Bianca** and her Zumba crew also continued their fundraising efforts for HOPE.

One of our supporters; **Will**, held a **Will's 60th Birthday Fundraiser.**

**Sarah Reid** donated Epilepsy Information Packs. And **Cynthia Frewin** crocheted delightful bears in HOPE colours and donated them to young children with epilepsy.

The **Cambridge University Paediatric Society** organised a cake sale on our behalf.

Also thank you to everyone who contributed prizes to our Christmas Raffle which raised an amazing £2,090.

And of course our HOPE Team have worked hard on securing some important grants, sponsorships and connections to help fundraise for the charity.

Some of the highlights this year were grants from the **Skipton Building Society Charitable Foundation** and the **Worshipful Company of Grocer**. And donations from the **Garfield and Weston Foundation**, **Happy Days**, **Nando's in Banbury** and from **Warburton Bakers in Enfield**.

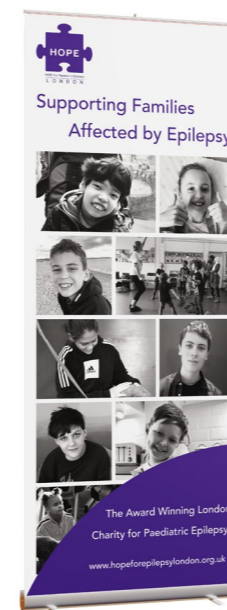
**Our 2022 Christmas Raffle raised £2,090**





## ROLL OUT OF OUR NEW BRAND

HOPE London wishes to acknowledge and thank our creative advisor **Sarah Hughes** in volunteering her time, skill and dedication. Not only did she mastermind our rebrand and design our new website in 2020 but this year she helped in producing our new promotional materials including leaflets and a banner which we use at events, our Facebook graphics and she helped to design and curate our newsletter template.



## PATRON/TRUSTEES/ADVISORS

## OUR NETWORK & AFFILIATIONS

We would like to thank and acknowledge **FABLE** - an epilepsy charity that was based in Sheffield that had previously been generous in their time and knowledge towards HOPE. Unfortunately they could no longer continue to run their group and donated to us a sum of money and their remaining anti-suffocation pillows. We are very grateful to them.

Thank you to the **Epilepsy Society** for donating Medikidz books to us. These books are comic style stories and are written by medical specialists to explain medical conditions including epilepsy to children. And to **Young Epilepsy** who donated seizure alert devices to HOPE families.

We became affiliated with **The Gene Peoples Partnership Network** and **UK Rare Epilepsies Together (UKRET)**

**The Landmark Trust** and the **Barrie Wells Foundation** have also generously given families who attend HOPE opportunities this year for experiences and trips away.

Dr Sophie Bennett, Andrea Ryan and Sofiiia (who volunteered for HOPE) have given talks and held workshops for the **Cambridge University Paediatric Society**.

This year we established links with the **Peter Doody Foundation** whom we supported in a **project about Sudden Death in Epilepsy SUDEP**. We were also in contact with **Support Dogs** who have given talks to parents on the benefits of **Seizure Alert Dogs**. We are excited to be representing HOPE at the Support Dogs 30th Anniversary Reception in London in February 2023. We maintain our close links with **Young Epilepsy** and **Matthews Friends** charities.

The HOPE Team continues to grow.

Our new team members are **Dr Charles Steward** (Genomic scientist, Genomics England), **Dr Helen Pernelet** (lawyer, former Chair of Trustees at the Epilepsy Society), **Dr Penny Fallon** (consultant paediatric neurologist) **Lisa O'Brien RSCN** (Consultant paediatric epilepsy nurse), **Andrea Ryan** (parent), **Louise Fisk** (Head of Drapers' Pyrgo Priory, Essex), **Dr Alice Winsor** (researcher at King's College London), **Dr Anna Wood** (Leicester Hospital), **Anthony Williams** (founder of Epilepsy Surgery Friends), **Ayesha Holderness** (president of Cambridge University Paediatric Society) and **Louise Miller** (Masters student, volunteer trust fundraiser).

We would like to thank all our board members all of whom, give their time voluntarily and free of charge.

First to our wonderful Chair **Nadine Gurr** for her unwavering dedication to the day to day running of HOPE London. Nadine is the beating heart of the charity and we are grateful for everything she does.

**Patrick du Casse** continues in his role of treasurer

and we thank him for his due diligence when it comes to doing our accounts.

**Alex Cox, Andrea Ryan, Sophie Bennett** and **Alice Winsor** for their regular attendance and help in our monthly support sessions. Alex also runs our Twitter account.

Our parent-to-parent Support Team supported many parents who struggled with their child's epilepsy diagnosis. Thank you to **Andrea Ryan, Sarah Hughes** and **Stuart Larkin** for volunteering their time to help others.

**Dr Charles Steward** for taking on the role of HOPE patron and for his invaluable input and guidance. We also welcomed him onto the board of Trustees this year.

**Dr Helen Pernelet** for her work on the pillow project campaign.

**Louise Miller** who has taken on secretarial duties and has written a suite of policies for HOPE.



# THE HOPE TEAM

**PATRON** Dr Charles Steward

**CHAIR** Dr Nadine Gurr

**TRUSTEES** Dr Nadine Gurr, Dr Charles Steward, Dr Sophie Bennett, Alex Cox, Patrick du Casse, Andrea Ryan, Dr Anna Wood, Ayesha Holderness, Louise Miller

**ADVISORS** Dr Helen Pernelet, Dr Penny Fallon, Neil Williamson, Louise Fisk, Dr Alice Winsor, Stuart Larkin, Lisa O'Brien, Anthony Williams, Sarah Hughes

**CREATIVE DIRECTOR** Sarah Hughes

# OUR VOLUNTEERS

HOPE London would not be the place it is today without our amazing volunteers. Their time and enthusiasm for our children is a huge support for the charity and families. HOPE is entirely volunteer-led and are fortunate to have so many amazing volunteers help out at our monthly sessions and behind the scenes.

We would not be able to do what we do without the contribution and time they give to the group. We would like to thank our volunteers:

**Katie** (who is also our first-aider) • **Katherine** • **Reena** • **Layla** • **Gwenelle** • **Lily** • **Romy** • **Blake** • **Luke** • **Liam** • **Jessell** • **Annabelle** • **Questia** • **Aya** • **Raven** • **Saffiyah** • **Olivia** • **Lutia** • **Tara**

**Katie, Katherine** and **Reena** also work hard to collect, prepare, and serve the refreshments at our sessions.



# VOLUNTEER CO-ORDINATOR

**Andrea Ryan** has taken on the role of volunteer co-ordinator.

Andrea has set up a **Volunteer Finding Programme** in conjunction with **Woodhouse College, Barnet**.

Thank you to Andrea and the staff at Woodhouse College for helping us find such brilliant volunteers.



“ It’s been a wonderful experience volunteering at HOPE and the entirety of the team are welcoming, friendly and incredibly committed to their work, so I urge anyone that is considering volunteering for a charity to consider HOPE as their first choice. ”



# HOW YOU CAN HELP US IN 2023

We are so happy to see children that attend HOPE enjoy life. We are delighted that last year we were able to help so many families, but as always demand exceeds the resources we have, so if you would like to help us going forward then please see below for some ideas on how you can do that:

IDEAS	SUGGESTIONS ON HOW/WHAT	DETAILS/ NEXT STEPS
<b>DO A FITNESS FUNDRAISER</b>	Go on a sponsored walk/run/ swim/cycle/get fit regime etc	When setting up an online fundraiser on these sites you can search and select our charity by entering our registered charity number: 1192441. If you need help please contact <a href="#">Louise</a>
<b>SET UP A BIRTHDAY OR EASTER FUNDRAISER</b>	Rather than birthday presents this year, why not set up a birthday fundraiser? These fundraisers can be set up directly on Facebook or with fundraising sites such as JustGiving.com or peoplesfundraising.com	
<b>HOLD A CAKE SALE</b>	Why not take some cakes and a donation box into your workplace, school or college? It will be Purple Day on March 26th and this will be the perfect opportunity to do this.	
<b>DONATE MONEY</b>	£7 will cover the cost of posting an anti-suffocation pillow £40 will buy an anti-suffocation pillow £50 will cover the cost of a HOPE Family Support Session	Donate directly via our <a href="#">HOPE website</a>  Or contact <a href="#">Nadine</a> if you would like to make a bank transfer or give cash/cheque.
<b>DONATE RAFFLE PRIZES</b>	Maybe you work for a company or know a local business that could donate a prize? Or maybe this Christmas you received a duplicate or unwanted pressie that would be loved by someone else? If you're able to donate a prize we would be most grateful. We can accept raffle prizes all throughout the year so don't wait to donate!	To coordinate a donation of a prize/toy please contact <a href="#">Louise</a>
<b>DONATE A TOY</b>	If you have good quality or new toys or games for the children, or electronic equipment for the teenagers, we are happy to take them for use at sessions.	
<b>VOLUNTEER YOUR TIME</b>	If you have time you can spare to help us help us at our HOPE Sessions or on our HOPE Daytrips please let us know and come and join in the fun!	Get in touch with <a href="#">Andrea</a> who co-ordinates our volunteering scheme.

<b>DISTRIBUTE OUR LEAFLETS</b>	If you're able to distribute HOPE leaflets in your GP surgery or hospital please let us know.	Get in touch with <a href="#">Nadine</a> for leaflets.
<b>HOPE BEARS</b>	If you can assist by crocheting/knitting HOPE comfort bears for our younger members please let us know.	Get in touch with <a href="#">Nadine</a>
<b>SUPPORT OUR FACEBOOK PAGE AND TWITTER</b>	Help Us to Raise Awareness of Paediatric Epilepsy. Please follow our Facebook Page and Twitter or give it a like! The wider our reach through social media the more we can help to effect positive change.	Go to our <a href="#">Facebook page</a> and our <a href="#">Twitter Page</a> and press Like!
<b>SHARE YOUR STORY</b>	We find personal stories help to inspire others and normalise epilepsy. If you would like to share your child's epilepsy journey please email us. We can make these stories anonymous.	Get in touch with <a href="#">Nadine</a>

These are some of our ideas but let us know if you have any further suggestions by emailing us on [info@hopeforepilepsylondon.org.uk](mailto:info@hopeforepilepsylondon.org.uk)





# 2023 DATES

These are the dates for the HOPE Sessions in 2023. All sessions are held at **Oakleigh School in Whetstone, London.**

## HOPE SESSIONS IN 2023

January 15th

February 19th

March 12th

April 16th

May 21st

June 18th

September 17th

October 15th

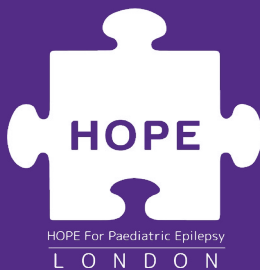
November 19th

December 17th

## OTHER DATES IN 2023

**Purple Day** (a national Epilepsy Awareness Day) is on March 26th

You can keep up to date with what HOPE London are doing via our Facebook page and on our website



W: [hopeforepilepsylondon.org.uk](http://hopeforepilepsylondon.org.uk)

T: 07516 926703

E: [info@hopeforepilepsylondon.org.uk](mailto:info@hopeforepilepsylondon.org.uk)

Registered Charity no: 1192441



# LOOKING FORWARD

We are very much looking forward to supporting all our HOPE families in 2023 and welcoming new ones. We continue to learn, grow and improve the service we provide, by regularly reviewing what we do, and how we do it. There is still so much misunderstanding surrounding epilepsy which puts children who have epilepsy at a disadvantage. HOPE London exists to create awareness of this and to provide practical support to effect change.

