



HOPE For Paediatric Epilepsy

L O N D O N

Confidentiality Policy



HOPE for Paediatric Epilepsy: London

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Purpose

HOPE for Paediatric Epilepsy: London (also referred to in this document as 'us', 'we' and 'the charity') recognise the importance of confidentiality as central to the work we undertake. It forms the basis of the trust that the families attached to our charity place in us and ensures compliance with Data Protection law. In relation to safeguarding issues, it is not a breach of confidentiality to pass safeguarding concerns on to the safeguarding lead or appropriate authorities.

This Confidentiality Policy should be read in conjunction with the Data Protection Policy, the Privacy Policy and the Safeguarding Policy.

Definitions

Personal Information:

By personal information we mean both:

- (a) The data protection definition which is any information which enables a living person to be identified (eg name, address, phone number, email address, NHS number etc or Special Categories of Personal Data which requires the individual's explicit consent for it to be held by the Charity, eg ethnicity, sexual life, political interests, religious beliefs, trade union affiliations etc.
- (b) Information, written or verbal, about an individual that relates to their health, circumstances, family, or experiences that is either provided to us for context so that we can provide a service and/or information we gather directly as a result of our contact with that individual.

Context

HOPE for Paediatric Epilepsy: London hosts monthly support sessions in person, a general advice/support phone line, facilitates contact between families and medical trained epilepsy specialists. We also receive contacts over email and social media.

Another service the charity provides is the provision (free of charge) of anti-suffocation pillows to families where a child/young person has nocturnal convulsive seizures. This is a



service based on need not means where we request a copy of medical letter outlining the presence of these type of seizures to process the request for the pillow.

Information about individuals

In the course of the above activities, confidentiality is of central importance. Only people who need to know medical information specific to the individual have access to or knowledge of it. The medically trained and other professionals associated with our charity will regularly receive confidentiality training in connection to their roles, and the principles of that training are directly applicable to the services they help HOPE for Paediatric Epilepsy: London provide.

When medical letters are given by parents/carers for the provision of anti-suffocation pillows, details of these are not shared with any third-party or the supplier of the pillows. Only the chair processes the medical letters, which are deleted after the pillow is received. The pillows are sent to us and we post the pillows on to the families.

Individuals whose information that is collected are made aware of their right of access to their records. They will also be made aware of their right to complain if they feel confidentiality has been breached.

To be clear, all personal information will be treated as confidential. Information will only be collected that is necessary and relevant to the purpose it is required. It will be stored securely, accessible only on a need-to-know basis to those members of the board, trustees, and volunteers duly authorised. The retention periods of personal information is covered in the retention section of the Data Protection Policy which should be read in conjunction with this policy.

Information supplied by children and young people

If a child or young person under the age of 16 directly contacts HOPE for Paediatric Epilepsy: London either by email or telephone, the information they provide will only be used to process their enquiry.

Unless it is a safeguarding concern, express permission from their parent/carer may be required to talk to them, and this will be made clear to anyone under the age of 16 who directly contacts the charity.

Age-appropriate signposting, information and advice must be given in response, and if appropriate, the parent/carer should also be advised about what was discussed and the advice given.



The use of images/videos of children

When information or life stories about the children attached to HOPE for Paediatric Epilepsy: London are used on our website, social media, or promotional materials; full names are not given. The child shall only be identified by their first name. No information that may give away the exact area they live, or specific address details will be divulged.

Full and informed permission is required for pictures of those who attend HOPE for Paediatric Epilepsy: London sessions before they can be used. Pictures of a child/young person with an anti-suffocation pillow that we may receive likewise can only be used once this permission is obtained. The same for any video footage.

The use of these images will not exceed the original permission, unless new permission is requested and granted on each occasion the image is used.

On occasions HOPE for Paediatric Epilepsy: London will use licensed, available stock images for illustrative purposes on social media posts. If these images are used, it is made clear they are stock images.

Duty to disclose information

There is a legal duty to disclose some information including:

Drug trafficking, money laundering or acts of terrorism will be disclosed to the police.

It is the responsibility of all trustees, board members and volunteers to ensure that any concerns arising from situations they observe, allegations (or reports from third parties) or disclosures (reports from someone about themselves) relating to potential abuse or where an indictable offence may have been committed, are reported to the safeguarding lead and/or relevant authorities even if they are unsure whether the concern is justified. It is not a breach of confidentiality to pass this concern on in the appropriate way.

In addition, if a board member, trustee, or volunteer believes an illegal act has taken place, or that a user is at risk of harming themselves or others, they must report this to the chair who will report it to the appropriate authorities.

Individuals should be informed of this disclosure unless this would put at risk the safety of any individual or jeopardise a potential criminal investigation. Details about disclosure of information and who has been informed will always be kept on record and stored securely with restricted access

Please refer to the Safeguarding Policy.



Breaches of confidentiality

All trustees, board members and volunteers should guard against breaches of confidentiality. This includes, but is not limited to:

- *Discussing matters in public where an individual or family can be identified by what is being said/overheard
- * Unauthorised access to person-identifiable information where a member of staff, or third party, does not have a need to know
- * Incidents of information lying around in a public area
- *Theft and loss of information should also be reported directly to the Chair of trustees

When reporting any breaches, a full account as possible must be given by those concerned. Any breaches will be evaluated on a case-by-case basis and dealt with accordingly.

Reviewed and edited: November 2022 by Louise Miller (Trustee)

Checked: November 2022 by Dr Nadine Gurr (Chair)

Date of next review: November 2023