

# ACTION FOR HYDROCEPHALUS

England & Wales - Charity number 1169606

## Details

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**Status** Registered

**Legal form** CIO

**Registered** 2016-10-11

**Register** [View on the Charity Commission register](#)

## Contact

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**Address** Annexe  
Mayfield  
Wellgreen Lane  
Kingston  
Lewes  
BN7 3NS

**Phone** 07791135363

**Website** <http://www.actionforhydrocephalus.org>

## Activities

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**Objects:** THE RELIEF OF SICKNESS AND PRESERVATION OF HEALTH OF BABIES AND CHILDREN DIAGNOSED WITH HYDROCEPHALUS LIVING IN AREAS WHICH LACK ADEQUATE CARE, IN PARTICULAR BUT NOT EXCLUSIVELY BY IMPROVING TREATMENT AND DIAGNOSIS, THE SUPPLY OF DIAGNOSIS AIDS, THE ESTABLISHMENT OF NEUROSURGICAL TRAINING SCHEMES BETWEEN THE NATIONAL HOSPITAL FOR NEUROLOGY & NEUROSURGERY, QUEEN SQUARE (AND POSSIBLY GREAT ORMOND STREET CHILDREN'S HOSPITAL), AND COUNTRIES LACKING IN QUALIFIED NEUROSURGEONS, PROVIDING CONSISTENCY AND OPPORTUNITY FOR TRAINEE NEUROSURGEONS OVERSEAS AND TO SET UP A SHUNT/NEUROSURGICAL EQUIPMENT DONATION SCHEME OPERATING FROM THE UK.

**Activities:** Action For Hydrocephalus works directly with neurosurgeons/healthcare professionals in developing countries or areas lacking in adequate treatment of hydrocephalus. We provide clinics and hospitals with neurosurgical equipment and work with surgeons and doctors, providing educational and practical support as well as training.

## Classification

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- **How:** Provides Services, Provides Advocacy/advice/information
- **What:** The Advancement Of Health Or Saving Of Lives
- **Who:** Children/young People, People With Disabilities

## Geography

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- Ethiopia
- Kenya
- Uganda
- Vietnam

## Finances

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Period end	Income	Expenditure	Assets	Employees
2025-04-05	£0	£0	-	-
2024-04-05	£0	£0	-	-
2023-04-05	£0	£0	-	-
2022-04-05	£0	£0	-	-
2021-04-05	£0	£0	-	-

## Trustees

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Name	Role	Appointed
LEWIS THORNE	Chair	2016-09-01
GREG JAMES		2016-09-01
JORDAN ADAMS		2016-09-01

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# Accounts

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**ACTION FOR HYDROCEPHALUS – REGISTERED CHARITY NO. 1169606**

**TRUSTEES' ANNUAL REPORT & ACCOUNTS FOR 05/04/2023 - 05/04/2024**

**TRUSTEES: JORDAN ADAMS, GREG JAMES PhD FRCS (Neuro. Surg.), LEWIS THORNE BSc, MB ChB, FRCS (Neurosurgery).**

**CHARITY ADDRESS: The Annexe, Mayfield, Wellgreen Lane, Kingston, Lewes, BN7 3NS**

**ACTION FOR HYDROCEPHALUS IS A CIO AND USES A CONSTITUTION AS A GOVERNING DOCUMENT.**

**Structure & Management**

Action\_For Hydrocephalus has three trustees in total:

Lewis Thorne (consultant neurosurgeon) - trustee since charity established

Greg James (consultant paediatric neurosurgeon) - trustee since charity established

Jordan Adams (patient with hydrocephalus). - trustee since charity established

All trustees hold equal responsibility within the charity. Meetings may be called by any trustee and chaired by any trustee. Actions taken to fulfil the purposes of the charity are carried out when a unanimous vote in favour is achieved. No further trustees have been appointed since establishment of the charity. When working with donors/organisations receiving donations from us, all trustees meet to agree the terms under which each donation will be received and carried out. Only when all trustees are in full agreement does a proposed donation proceed.

**Objectives & Activities**

**Summary of purposes of Action For Hydrocephalus:** To provide relief of sickness and presentation of health of babies and children diagnosed with hydrocephalus living in areas which lack adequate care. Improving treatment and diagnosis, the supply of diagnostic aids, the establishment of neurosurgical training schemes between National Hospital for Neurology & Neurosurgery (and possibly Great Ormond Street Hospital) and countries lacking in qualified neurosurgeons, providing consistency and opportunity for trainee neurosurgeons overseas. To set up a shunt/neurosurgical equipment donation scheme operating from the UK.

**Summary of the main activities in relation to those purposes for the public benefit**

- **The supply of diagnostic aids**
  - **Improving treatment and diagnosis**
  - **To provide relief of sickness and presentation of health of babies and children diagnosed with hydrocephalus living in areas which lack adequate care**
- Jordan had previously contacted by Reco Medical, asking for her input in the development of a wireless ICP monitor they are currently developing, given that she has had ICP monitoring done so many times. She had a Zoom meeting with the team members and updated Lewis and Greg, who were very interested in the project. Jordan discussed the possibility of the device (once completed and on the market) being used in remote areas of Vietnam for work with Action For Hydrocephalus. Reco Medical are keen to help out with this venture so an in-person meeting was arranged for later in 2024. In the meantime, Jordan submitted personal statements and

supporting letters for Reco Medical as they were about to go through the final stages of funding and needed such documents.

- Jordan contacted two rotaries in Vietnam who were interested in progress being made by GAPSBiF, which Jordan still attends regular meetings with. Discussions were had with regard to the hospitals and charitable organisations they each deal with in Vietnam and areas Action For Hydrocephalus might be able to help.
- A meeting was held with Lewis and Greg to discuss these developments. Greg is looking for a suitable partner in Vietnam on InterSurgeon, which he and Greg are members of.
- Jordan has been in touch with four health centres in Vietnam (outside of the main cities) and they are relaying their experiences and issues with children and babies who have hydrocephalus. It is clear that nothing is available to them in terms of facilities or treatment options. Money is a big block so Lewis, Greg and Jordan discussed the possibility of starting to fundraise in 2025. Due to work commitments with all three trustees, fundraising is not a possibility for 2024.

### **TRUSTEE STATEMENT**

All trustees have had regard to the guidance issued by the Charity Commission on public benefit when planning and implementing activities to achieve its objectives.

### **ACCOUNTS**

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- A virtual Zoom meetings was held in August 2022 with Lewis, who proposed an approach of targeting the largest employers in Vietnam with a view to educating their staff about folic acid. Jordan researched and drew up a list of the largest companies with a focus on those who employ a large number of women of child-bearing age.
- Jordan started to attend bi-monthly virtual meetings with GAPSBiF and added Action For Hydrocephalus to the company's register and forum. She spoke with two doctors leading a study in the low folate levels in Vietnam who had particular interest in the work AFH has done.

- Jordan also attended two online global conferences: 29<sup>th</sup> International Conference on Spina Bifida & Hydrocephalus in September 2022 and IF webinar for Folic Acid Awareness Week in January 2023.
- A Zoom meeting was attended by all three trustees in February 2023. Greg proposed looking at new members joining Action For Hydrocephalus due to his and Lewis's busy schedules, to ensure more consistent progress. Lewis and Greg were to look at options. Jordan updated Lewis and Greg with how GAPSBiF meetings were going; in particular, a scheme in Venezuela where women in two large companies were trained as community leaders in the education about the importance of folate in the diet, along with administering supplements. The scheme was successful in reaching a large number of women of child-bearing age and could serve as a template for Lewis's plan to target employers in Vietnam.
- Some doctors from UCLH had contacted Jordan regarding research for their development of a wireless ICP monitor. They are interested in her (extensive) experience as a patient for ICP procedures. Initial communications have been positive; the team are aware of Action For Hydrocephalus and are interested in working with the charity once the units have been passed for use, potentially to provide units for use in healthcare centres in Vietnam.

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and overseas at the medical centres we have helped in the past meant that Covid treatment and management was a priority; obtaining medical instruments and shunts was hampered considerably by this. We do have some shunts in our possession and will send them out as soon as we are able to hold meetings with our overseas partners again.

- **Improving treatment and diagnosis:** As it has not been possible to meet with overseas partners this year, we have had to limit our treatment and diagnosis efforts to further research to try and catch up with the current situation in Vietnam hospitals as a result of the pandemic. This has proved to be very difficult and we are thinking it may be best to re-group when restrictions have fully been eased. Online research is proving to be very limited as obviously the focus of hospitals and medical centres has been on Covid; hydrocephalus data in Vietnam is notoriously patchy and now is not available. One possibility of staying in the loop is to attend an online 'virtual' webinar/conference organised by IF Global.
  
- **To provide relief of sickness and presentation of health of babies and children diagnosed with hydrocephalus living in areas which lack adequate care:** Discussions regarding the two-point plan made at the end of 2019 (education about folic acid and distribution of supplements along with symposiums with surgeons in Vietnam to discuss methods of treatment and pathways to treat on a regular basis rather than infrequently and sporadically) have been ongoing. A couple of virtual conferences (International Conference On Spina Bifida And Hydrocephalus Day and IF Global Webinar focusing on NTD prevention) were attended; these online sessions are a good opportunity to connect with other organisations working to address issues affecting the work of AFH. These proved to be very informative and beneficial in making new contacts so two further conferences will be attended. Charities who can help with the distribution of supplements to more rural areas were identified and contacted for initial talks with a view to being able to meet once Covid restrictions are lifted.

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covered by the donors. Activity during 2019-2020 has mainly been research and discussion/planning using the findings of this research, so no financial outlay has been necessary or required.

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- All of the above activities had to be stopped due to the pandemic. This was due to Jordan developing long Covid and Lewis and Greg's time being taken up with working in the hospitals for the duration of the pandemic.
- Jordan has recently contacted the two charities she had been in touch with before the pandemic to assess where they are at due to everyone in the health sector having been so impacted in the past year. She has also researched two more recent reports to include in the proposal which was due to be completed prior to the first lockdown (focusing on folate education and supplement distribution in Vietnam). This has been the only new information she has been able to source over the past year so once she and Lewis are able to meet again, the proposal can be discussed with regard to moving forward.
- A meeting is needed between all three trustees when availability allows to assess what realistically can be done with the changed situation in the hospitals and increased demands on the health system in general as this may impact previous plans. Small steps forward should be achievable although actions may have to be scaled down for now.

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