

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

**TRUSTEES' ANNUAL REPORT & ACCOUNTS FOR 05/04/2021 - 05/04/2022.**

**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.

<b><u>Objectives</u></b>	<b><u>&amp;</u></b>	<b><u>Activities</u></b>
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<b><u>Summary of purposes of Action For Hydrocephalus:</u></b> 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.		
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**Summary of the main activities in relation to those purposes for the public benefit**

- **The supply of diagnostic aids:** Unfortunately there was no activity regarding the supply of aids overseas this year due to effects of the pandemic on travel. Our usual volunteer was not travelling to Ethiopia and the huge backlog of work at both the UK hospitals where our trustees work

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.

## **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**

**Income:** No money has been received from any source since establishment of the charity.

**Expenditure:** No money has been spent by Action For Hydrocephalus in the carrying out of its objectives since it was established in 2016. All medical items received have been donated by suppliers and any postage costs have been

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.