

ACTION FOR HYDROCEPHALUS – REGISTERED CHARITY NO. 1169606

TRUSTEES' ANNUAL REPORT & ACCOUNTS FOR 05/04/2022 - 05/04/2023.

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
- 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: 29th 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.

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 2022-2023 has been research-based so no financial outlay has been necessary or required.