

Opie Jones Foundation

Annual General Meeting (AGM)

Date: 24.9.24

Time: 20:30

Location: Virtual

Opie Jones Foundation AGM 24 September 2024

The trustees acknowledge the delay in holding AGM, future meetings will be held within appropriate timeframes.

Opie Jones Foundation summary of purposes – **To support the physical, emotional and mental health of patients and their parents, guardians and families affected by childhood cancer; Raising awareness of childhood cancer and advocating for earlier access to NICE and/or MHRA Approved Cell and Gene Therapy for the treatment of childhood cancer**

The organisation provides grants to family members or patients of childhood cancer, to access approved therapies which support their physical, emotional and mental health. The grant process is through application. If successful, the charity pays the approved provider directly. The grant is to be used within one year and has a maximum amount applied.

The charity will be holding support group events for parents and carers of childhood cancer to support parents and, patients, guardians and family members affected by childhood cancer.

The charity founder and business development manager have attended a number industry events (Cell and Gene, Parliament, Charity or Research events). Raising awareness of childhood cancer, advocating for earlier access to approved cell and gene therapies and supporting families. These events have not only raised the profile of the charity but generated donations. The charity has shared the patient perspective with professionals in medical and research settings.

The charity continues to build partnerships with Paediatric Oncology/Haematology teams within the NHS and academics studying to work in this field. Enabling us to raise the profile of what our charity provides and also continue in our mission to advocate for earlier access to approved cell and gene therapies in the treatment of childhood cancer.

The trustees have regard for guidance issued by the Charity Commission on public benefit. The trustees work to uphold the objectives of the charity as set out in the governing document.

The charity has been influential in bringing a patient's perspective to professionals working within hospitals, the Cell and Gene Therapy industry, and parliament.

The charity has provided support for parents of children who have or have had treatment for childhood cancer, the first wellbeing grant has enabled a parent of a child with cancer to access therapy. We have shared the grant initiative with hospitals treating children with cancer, to spread the word on the grants available.

The charity continues to seek opportunities to share our objectives and create awareness of the support we offer, with plans to start a support group locally in the next few months.

We held our second annual Climb for Kinder Care – raising awareness and funds for OJF with 13 participants in 2024! Next year we hope to attract more participants and extend the event to other locations.

The financial position of the charity is good. The current funds are unrestricted funds (donations). Increasing access to grants which the charity could benefit from is crucial and gaining expert advice on this beneficial. In 2025 we want to increase our financial position by accessing grants alongside raising money through donations.

Our trustees are committed to the charity and its objectives. We have considered the need to expand the skillset and widen the expertise on our board. This may be in the form of a Advisory Board and new trustees. This will be considered at our next meeting.

Our trustees approved a request to change the working name of the charity. To provide Opie autonomy from childhood cancer and the charity.

Opie Jones Foundation - Balance Sheet as at 01 Mar 24

	01-Mar-24
Capital Assets	
Net Book Value	0
Current Assets	13100
Bank Account: Co-Op Bank	12965
VAT Reclaimed	135
Net Current Assets	10611
Total Assets	10611
Owner's Equity	
Retained Profit	10611
Total Owner's Equity	10611