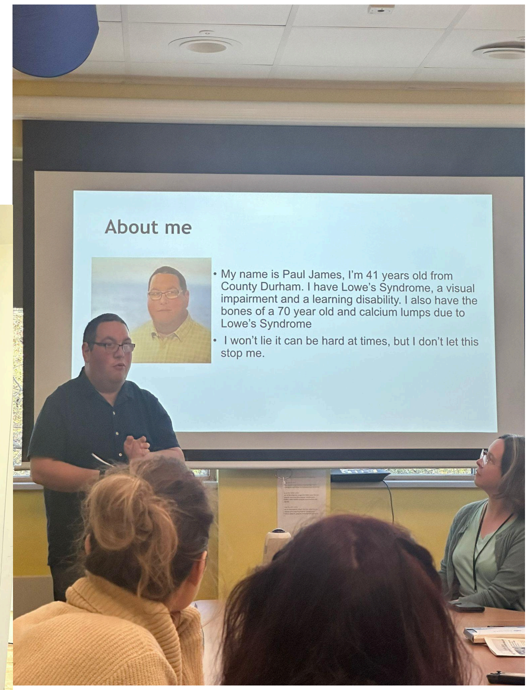
November 2023, UK Lowe Family Outreach Meeting

The first Lowe Family Outreach Meeting took place on Monday, November 13th in Cambridge. The outreach meetings give families an opportunity to meet each other for mutual support and for charity volunteers to update on the latest news and for pot

Four families came together to share their lived experiences with Lowe Syndrome and their own initiatives to spread awareness of Lowe Syndrome. For example, Paul James shared his inspiring fundraising initiatives, including walking 1551 steps a day ahead of the Lowe Syndrome conference in Naples this past May, and his upcoming online auction. Emile Eno-Daynes also shared examples of the influential work he is doing to ensure spaces such as bookstores and charity shops become more inclusive and accessible to wheelchair users.

Members from the Lowe Syndrome Trust were present at the meeting to share updates on the efforts of the charity so far, the next goals, and collect feedback on the areas where families feel that more support, resources, or signposting could be helpful. At the meeting the website was presented noting the new section for NHS treatments, the NHS passport, DNA test and how to file information into the Sanford CoRDS database. An at home kidney test kit was also presented along with the news that the NHS app now allows for filing of personal documents such as the DNA mutation letter.

The current research has identified potential drug therapies and the next stage is to identify candidates for potential clinical trials for which researchers need to know the DNA mutation of different individuals with Lowe Syndrome and a description of the symptoms of the condition.



About me

- My name is Paul James, I'm 41 years old from County Durham. I have Lowe's Syndrome, a visual impairment and a learning disability. I also have the bones of a 70 year old and calcium lumps due to Lowe's Syndrome
- I won't lie it can be hard at times, but I don't let this stop me.

The charity is looking for families to help stage further outreach hub meetings across the UK, including the next meeting based in Newcastle and scheduled for April 2024. Any interest should be expressed by email by contacting lowetrust@gmail.com.

Later during the day, Paul James and Oscar Thomas, both living with Lowe Syndrome, along with Andrew Thomas, Mike Fennings and Anastasia from the Lowe Syndrome Trust, all visited Jenny Gallop at the Gurdon

Institute (University of Cambridge). The team visited the labs to learn more about the work that is currently being done. Then, the charity presented to the Gallop Lab, including students, giving an overview of the condition and the biology behind it. Paul James gave a presentation on living with Lowe Syndrome, which included preferred terms and words to use when talking about Lowe Syndrome of people with a learning disability. Oscar Thomas also educated students on living with cataracts, which are part the Lowe Syndrome condition. The day ended with an interactive discussion between the charity members, Paul and Oscar and the students were any questions were discussed.