

World Down Syndrome Day 2024!

Down syndrome occurs when an individual has a full or partial extra copy of chromosome 21 and affects 1:700-1:1000 live births. As well as the commonly associated facial features and intellectual impairment, people with Down syndrome are at an increased risk of conditions such as Alzheimer's disease, thyroid dysfunction, obesity, and heart defects. We believe that hearing directly from people with Down syndrome about what is important to them is crucial for guiding research towards the best possible health outcomes. Furthermore, equipping families with the knowledge of the latest scientific research is fundamental to enable those with Down syndrome to live long, healthy, happy, and fulfilling lives.



For these reasons we host an annual event celebrating World Down Syndrome Day (WDS). This year our event was held on Saturday 16th March at the Francis Crick Institute, London. Organised by London based researchers from University College London, Kings College London, Queen Mary's and the Francis Crick, the event was open to people with Down syndrome of any age, and their families/carers.

We had an absolutely fantastic day, hearing from scientists about the thyroid, the vulnerability of the inner ear, Alzheimer's disease, and the Kings College London based LonDowns study. LonDowns is a consortium working towards better understanding dementia and other comorbidities in Down syndrome.

Following on from these brilliant and informative short talks, we heard from the Down Syndrome Association WorkFit officer, Adriana, about their programme connecting people with Down syndrome with potential employers. WorkFit trains employers about the learning profile of people with Down syndrome so that they can be fully supported in the workplace.

We believe in the importance of involving people with Down syndrome in our programme for the day and had the pleasure of welcoming James and his father, Philip, to the stage where we heard about their experience with WorkFit. James is a regular speaker, and highlight, of our WDS events and through learning about WorkFit at our event last year, James secured himself a paid job in a café in Parliament. It's stories like this that highlight the importance of our event, connecting people with Down syndrome with support for different aspects of life. James' and Philip's talks were both informative and emotive, provoking many questions from the audience.

After lunch we had the pleasure of introducing Sarah Gordy and her mother Jane. Sarah has had an incredibly successful career so far as an actress, dancer, and model. She really is an inspiration to all and is a fantastic role model to those with Down syndrome. Sarah spoke about her experience on the ABATE clinical trial, a vaccine against Alzheimer's disease for people with Down syndrome, and she emphasised the importance of keeping fit and healthy.





Following on from Sarah's talk we had insightful seminars from Speech and Language therapist Rebecca Baxter from LETSgoUK, Paediatric Endocrinologist Professor Li Chan from Queen Mary's London, and Paediatrician Dr Rebecca Hulbert from Guys & St Thomas', discussing Speech and Language therapy, obesity, and heart defects respectively. Subsequently the floor was opened to the audience for a panel discussion and the volume of questions and answers highlighted the importance of these topics to people with Down syndrome and their families.

Running throughout the day we had a number of activities for our guests, including making playdoh brain cells, painting plant pots, chromosome card games, Lego, a photobooth, and a highly anticipated dance class. We finished the day with the annual group dance to Pharrell William's "Happy", with guests busting some of the best moves I've seen for a while!

The volunteers played an instrumental role in the day coming together after months of planning. It's a beautiful thing seeing quieter guests coming out of their shell due to the time, care, and respect that a volunteer has given them throughout the day. It was a rewarding day for all with high levels of engagement from guests with Down syndrome and their families/carers. Guests returning year after year as well as new guests attending for whom this was their first event demonstrates the value and importance of the day. None of this would be possible without the generosity of our funders, for which we are very grateful. Onwards to our planning for next year!

