



# Next Steps @ St Johns



*Working together to build a firm foundation for learning and caring*

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## This week at Nursery . . .

On Monday we were excited when the mobile library came to visit!

We went aboard the bus in small groups and explored what it had to offer. The children enjoyed listening to two stories that the librarian read to us, and then were invited to share the stories available. At the end of the session each group chose a book that they wanted to borrow from the library and we have enjoyed sharing these together.



**STAR OF  
THE WEEK**

**Harlow**



For showing new confidence and encouraging her friends.

**Well done!**

At Forest School we explored the main school forest. We were delighted to see many creatures in the woodland, such as butterflies, so we might need to pack our magnifying glasses next time to see what else we can find! Please ensure that children attending nursery on a Thursday have long sleeved tops and full length trousers to keep them safe in the woodland.



Our theme this term is "People who help us." We have been sharing stories and activities to help us to learn all about different occupations.

Some of you may have noticed the role play area has been transformed into a doctors office. The children have really enjoyed dressing up and taking part in imaginative play, talking about and re-enacting their own experiences.

We are looking forward to other visits from professionals such as fire fighters (with the fire engine of course!) and a vet to name a few.



We have spent time outdoors this week, avoiding the hottest parts of the day. Please provide your children with sun hats and cream, and please note that we have a limited supply of Nivea kids factor 50+ which we can use if needed.

Please ensure that all items are NAMED so that we can return to the right owners, and make sure that staff are made aware of any known allergies. Thank you for your support in this.



### Dates for the Diary

5th May: Bank Holiday. The Nursery will be closed.  
17th May: Reverse Rett Fundraising Event  
26th May: Bank Holiday. The Nursery will be closed.



## Fundraising Event - Saturday 17th May 10am -1pm.

Fundraiser Updates! The plans are ongoing for the fundraiser on Sat 17th May.

Tickets are now available to buy at the nursery, and we have already received some amazing prizes from local businesses.

We would still like donations of good condition soft toys for our teddy tombola if you have any to spare please. We are also asking for donations of bottles (non alcoholic) such as drinks (fruit shoots, lemonade, squash etc.) bath products (bubble bath, shower gel, shampoo, hand soap etc.) So please search your cupboards and help out if you can!

We are very excited to announce that there will be a live performance of the Gruffalo on the day, a bouncy castle, a Gruffalo hunt with prizes and some fantastic games to play and 'pocket money' toys to buy. We will also have refreshments available to purchase on the day for all.

Layla's parents have provided us with some information on the charity Reverse Rett to help us to better understand what the charity means to them. The charity has provided them with first hand support, as well as funding for the CIPP centre specialist hospital where Layla has received care. Layla's family are also very open to answering questions about Rett syndrome, as raising awareness is very important to them.

What is gene therapy?

"The concept behind gene therapy is simple: deliver healthy genes to compensate for mutated genes (*RSRT, 2022*)."

At time of writing, two biotech companies, Taysha Gene Therapies and Neurogene are collectively running clinical trials across Canada and the US, Australia and now right here in the UK. In Spring 2023, Taysha broke ground, dosing the first Rett patient in history with gene therapy. Since then, both companies have reported significant global improvement in both adult and paediatric patients on a low dose level. Updates of the trails are available on their websites, and Reverse Rett will share announcements of the data as and when it is released."

Reverse Rett:

Our vision

We want a world where children with Rett syndrome are diagnosed quicker, earlier, and more effectively than they are right now. A world where much more is known about the condition and factors that affect progression. A world where at every stage of development, treatments are available to counteract its symptoms. A world where we ultimately deliver a cure and enable people with Rett Syndrome to lead free and healthy lives.

What We Do:

- Over the last fourteen years, we've invested in high-quality research projects such as the RSRT Gene Therapy and *MECP2 Consortia*, which have led to the gene therapy programs in clinical trials today.
- We run the UK's patient registry for Rett syndrome: Rett Registry UK and work to facilitate UK clinical trials of emerging treatments.
- We provide core funding for the national specialist CIPP Rett Centre based at the Maudsley Hospital in London.
- We provide families with health information and resources and help connect them to UK Rett syndrome clinics.
- We host an annual educational conference for families, caregivers, researchers and health care professionals.
- We provide online workshops and up-to-date information via our website, social media platforms and one to one contact with families.
- We advocate for treatment for Rett syndrome nationally and internationally.