

## PRESS RELEASE

### **Major breakthrough in the battle against kidney disease in children: The Dutch Kidney Foundation takes giant step towards a cure**

*The Dutch Kidney Foundation starts the development of groundbreaking gene therapy, with €10 million donated by the Dutch Postcode Lottery's Dream Fund.*

**Bussum, 13 March 2025** – Every year, hundreds of children in the Netherlands are diagnosed with kidney disease. Globally, 2 million children suffer from kidney disease. Currently, there is no cure. They undergo lifelong treatments and have a much shorter life expectancy than healthy children. With the launch of [Kidnie](#), all paediatric kidney doctors across the Netherlands and the Dutch Kidney Foundation join forces to combat this burden. Thanks to a contribution of €10 million from the Dutch Postcode Lottery's Dream Fund, Kidnie is now developing a gene therapy that will enable a cure for kidney disease in children.

#### **From 0 to 25% chance of recovery**

“Until now, we had no choice but to inform parents that their child will never get better,” says Michiel Schreuder, paediatric kidney doctor, Professor of Paediatric Nephrology at Radboudumc Amalia Children's Hospital, and co-initiator of Kidnie. “Thanks to the Dream Fund, something that seemed impossible only ten years ago is now becoming a reality. Using gene therapy, we expect to be able to cure 25% of children with kidney disease. For the more than 2 million children and their families, this gives the chance of a future without frequent hospital visits and a life filled with uncertainty. For children like Roan, this could make the difference between struggling to survive and a real life.”

#### **Roan wants to live like a normal teenager**

Roan (15 years old) knows the impact of kidney disease better than anyone. He has been diagnosed with [cystinosis](#), a congenital kidney disease in which the kidneys slowly deteriorate. Every day he takes 38 pills to slow down the progression of the disease. His life revolves around timing his next medicine intake, basically living from medicine to medicine. In between, he tries to live a life as normal as possible, at school and at home, but it's not easy. Despite closely adhering to his therapy, Roan is expected to need a kidney transplant or dialysis before the age of 20.

#### **Revolutionary approach and pioneering research**

Nowhere else in the world have all paediatric kidney doctors and biomedical researchers in one country joined forces so intensively, with the aim of finding a cure for kidney disease in children. The launch of Kidnie in 2023, in collaboration with the Dutch Kidney Foundation, signifies a fundamentally different approach, driven by rapid advances in the field of gene therapy. Until

recently, the science wasn't ready, however, modern techniques have now reached a tipping point: for the first time, it is now possible to tackle the root cause of kidney diseases. According to Prof. Schreuder, this is essential: "If we don't radically change the current system, children will continue to suffer. This project is a blueprint for more effective and patient-oriented medical science, and it is being closely followed by colleagues worldwide."

### **Turning a dream into reality**

Through the Dream Fund, the Dutch Postcode Lottery supports initiatives that have a major social impact and otherwise would struggle to take off. "The Dutch Kidney Foundation has shown that it dares to break the status quo, with guts and innovation," says Jonne Arnoldussen, Managing Director of the Dutch Postcode Lottery. "This project has the potential to make a global impact. Therefore, we are proud that, thanks to our members, we can contribute to this promising development."

This breakthrough is the opportunity that children with kidney disease and their families have been dreaming about for so long, according to Tom Oostrom, director of the The Dutch Kidney Foundation: "Until now, everything was about slowing down the process of deterioration, but now we can talk about curing, instead of just treating. Aside from providing a medical breakthrough, it finally gives the prospect of a future for so many children and their families."

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### **Additional background information**

#### **What is gene therapy?**

Gene therapy tackles diseases at the source, by repairing genetic disorders rather than just treating symptoms. Diseases that were previously incurable can now be cured forever, thanks to new techniques and improved delivery systems (which are methods and technologies used to deliver genetic material into a patient's cells). In addition, treatments can be customised, tailored precisely to a person's unique DNA. In short, gene therapy opens the door to a better, disease-free future.

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#### **About the Dutch Kidney Foundation**

The Dutch Kidney Foundation is committed to creating a future free of kidney disease. By funding pioneering research and stimulating innovation, the Dutch Kidney Foundation aims to offer kidney patients a better quality of life and the prospect of a cure. More information: <https://The Dutch Kidney Foundation.nl/>.

#### **About Kidnie**

Children with kidney disease face enormous challenges early in life, without any chance of a cure as yet. Kidnie, consisting of a team of fundraisers, researchers and paediatric nephrologists, is taking action to help these brave young fighters. Our mission? From 0 to a 25% chance of a cure! More information: <https://www.kidnie.nl/>.

### **About the Dutch Postcode Lottery and the Dream Fund**

The Dutch Postcode Lottery supports charities working towards a better world. Through the Dream Fund, the lottery helps organisations realise groundbreaking initiatives that would be difficult to implement without additional support. More information:

<https://www.jaarverslag.postcodeloterij.nl/partners/droomfonds/>.

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### **Not for publication.**

Roan, his family, professor Michiel Schreuder, and TV presenter Anne van der Meer are happy to speak to the press to share their experiences and insights.

- Roan and his family are open to talking about their life and dealing with kidney disease, and what this research means to them.
- Prof. Michiel Schreuder, paediatric renal specialist and Professor of Paediatric Nephrology, is happy to explain why this research represents a major breakthrough.
- Anne van der Meer, TV presenter and Kidnie ambassador, is open to sharing her personal story of losing several children to kidney disease and to share the story of her son Mees, who lives with one kidney. Her personal experience drives her commitment to the research, and the prospect of a future in which kidney diseases are curable.

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