



Living longer, living better: new advances in Down syndrome care

EU-funded researchers are working to reduce the health risks associated with Down syndrome and improve long-term quality of life.

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David Clarke has a busy life juggling two jobs. He works three days a week recycling waste at a supermarket in Drogheda, his home town in eastern Ireland. On other days, he takes the hour-long bus ride to the capital Dublin to work in a gift hamper warehouse. Aged 44 and living with Down syndrome, David is flourishing.

“He still lives at home with myself and his mother, but he has a pretty independent life,” said his father, Pat Clarke, who volunteers on the board of the European Down Syndrome Association (EDSA), a non-profit organisation supporting and representing people with Down syndrome across Europe.

Increased health risks

Both life and job prospects for those with the condition have significantly improved in recent decades, aided by medical advances and advocacy by the likes of EDSA.

“When David was born in 1981, the life expectancy of someone with Down syndrome in Ireland was only in the mid-20s,” said Clarke. “Now, it’s 60 to 70.”

But there is still much room for improvement. While David Clarke’s current situation is positive, many challenges remain for people living with Down syndrome.

With a longer lifespan comes an increased risk of Down syndrome-associated health conditions, including early-onset Alzheimer’s and a greater risk of obesity. The condition can also cause lifelong developmental delays, cognitive impairment and severe health issues, including heart and digestive problems.

Dr Yann Héroult, a geneticist and neurobiologist at the Institute of Genetics, Molecular and Cellular Biology in Strasbourg, France, is leading a five-year EU-funded research initiative called GO-DS21 that is working to better

understand the unique health risks of people with Down syndrome and how to manage them.

“We weren’t previously aware of exactly when and how many of these comorbidities were appearing during the lifetime of people with Down syndrome, or how they were linked together,” said Hérault. “It’s necessary to know this to understand the syndrome as a whole.”

Understanding pathways

The GO-DS21 team brings together clinicians, pathophysiologists, integrative bioinformaticians and artificial intelligence computer scientists from France, Germany, the Netherlands, Spain and the UK.

Together they are exploring the full range of health issues faced by people with Down syndrome, with a particular focus on obesity, diabetes and intellectual disability.

For instance, their investigations found that [diabetes risk](#) for people with Down syndrome was four times that of the general population in 5-to-24-year-olds and double in 25-to-44-year-olds. However, diabetes does not appear to be a significant factor in the development of obesity in people with Down syndrome – suggesting that other biological and genetic factors may play a role.

The research team also discovered a higher risk of dementia, hypothyroidism, epilepsy and leukaemia, but a lower prevalence of asthma, certain cancers, ischaemic heart disease and high blood pressure.

Their work will help build a clearer picture of the particular health profile of people with Down syndrome, including both the genetic and environmental factors contributing to the different conditions they face.

Improving quality of life

By understanding the biological pathways and mechanisms that connect Down syndrome with different conditions, the researchers hope to be able to offer more effective treatments and health advice that could help improve overall quality of life.

The research is particularly important as the condition is apparently becoming more widespread, increasing from an estimated 16 cases per 10 000 births in 1990 to 23 in 2015 according to data from the European Commission’s JRC-EUROCAT central registry.

“The idea is to give families evidence-based recommendations of things they can do to minimise the health risks of people with Down syndrome,” said Hérault.

To this end, the researchers hold regular meetings with patient organisations such as EDSA to share results and get feedback. This feeds into the EU’s goal to make independent living for people with disabilities a reality, empowering them to choose how, where and with whom they live.

As the team learns more about the factors influencing the health of people with Down syndrome, they are compiling lifestyle recommendations on diet and exercise that they believe could make a big difference.

The research team has also launched a major [survey](#) to coincide with World Down Syndrome Day on 21 March, aiming to collect information from families that will help further inform their research and, ultimately, improve the lives of people with Down syndrome.

Expanding treatment options

On the treatment side, another EU-funded research team under the direction of Dr Rafael de la Torre, a neuroscientist at the Hospital del Mar Research Institute in Barcelona, Spain, is making promising progress on developing a pharmacological solution to improve cognitive impairment in people with Down syndrome.

As part of a five-year international research effort called ICOD, Aelis Farma, a biotech company in Bordeaux, France, is working on an experimental drug called AEF0217 that targets a part of the brain playing a role in memory and learning – the CB1 receptor.

This receptor is prone to excessive activity in those with Down syndrome, which is believed to contribute to cognitive impairments. AEF0217 acts as a selective CB1 inhibitor, reducing this overactivity without blocking the receptor completely.

Potential benefits for people with Down syndrome include enhanced cognitive abilities, especially in learning and memory, and greater independence in daily life thanks to improvements in focus and problem-solving.

AEF0217 is currently in clinical trials, with early outcomes showing promising results. If successful, it could be the first approved treatment to enhance cognitive function in people with Down syndrome.

“This is the first time that we have in our hands a treatment with the potential to really improve intellectual disability in people with Down syndrome,” said de la Torre. “That will help them integrate better into society and have better work opportunities.”

Fast action

A major step was taken in an initial month-long [trial](#) in 2024 that appeared to show both the safety of the drug and its potential effectiveness.

Among 29 people with Down syndrome aged between 18 and 35 with mild or moderate disability, it resulted in significant improvements in verbal and written communication, daily living skills and social interactions. Participants also showed greater flexibility in adapting to new situations.

“These effects were seen in just four weeks, which is fantastic,” said de la Torre. “Typically, with a treatment for cognitive functions, you would expect to wait about three to six months to observe improvements.”

By the time the five-year ICOD initiative ends in January 2026, the team will have completed a larger trial on around 200 participants across France, Italy and Spain. De la Torre believes the drug could be ready for use within about three years if fast-tracked.

Apart from having the potential to improve the life of people with Down syndrome, a treatment like this could also significantly reduce the stress of parents, he said. “Having a treatment will change everything.”

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More info

- [GO-DS21](#)
- [GO-DS21 project website](#)
- [ICOD](#)
- [ICOD project website](#)
- [European Down Syndrome Association \(EDSA\)](#)
- [World Down Syndrome Day](#)
- [EU guidance on independent living for persons with disabilities](#)