

I introduce myself

Hi, my name is Martin Orio, I'm 2 and I live in Mandello del Lario, near Lecco. When I was 6 months old, I had a heart operation but now I'm fine, I can't wait to start the kindergarten!! I decided to create this association with my parents Ombretta and Davide, because I'd like to improve my life and other people with Down syndrome's life, thanks to the scientific research. I'm sure that trying to improve problems that cause Down syndrome doesn't mean not to accept it. Actually, the wish of improving is an important objective that everyone should have, in order to show its own capabilities in the best way. I know that it'll be a wonderful journey, but it'll also be difficult, because the scientific research needs time, that could be reduced, if helped. Sometimes I ask myself: "Will I be able to benefit from the results of the research?" and then I answer: "it doesn't matter, because I'll be happy and proud anyway if I know that other children will". I hope to meet a lot of new friends during this journey, with whom I can share lots of experiences, emotions and successes. Life is wonderful and it's worth living. I appreciate you and I hope join the association so we can become stronger. Thank you.

Martin



HOW YOU COULD HELP US You can make a donation through:

- **The subscription to the association** by paying 25 euros per year
- **Bank credit transfer**
IBAN: IT48I0569651490000028694X71
Banca Popolare di Sondrio
Holder: Vola con Martin oltre il 21
Causal clause: free distribution
- **Post credit transfer**
IBAN: IT27Y0760110900001042211159
Holder: Vola con Martin oltre il 21
Causal clause: free distribution
- **Checking account** n. 1042211159
Holder: Vola con Martin oltre il 21
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- Our website www.volaconmartinoltreil21.it donation section
- **5x1000** for the association "Fly with Martin beyond the 21" (Vola con Martin oltre il 21), tax code 92077220132



FLY WITH MARTIN BEYOND THE 21



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*"Dreams don't always come true
not because they're too big or impossible
but because we stop believing in them"*

(Martin Luther King)

AIM OF THE ASSOCIATION

The love for our child Martin with Down syndrome motivated us to create the association "Fly with Martin beyond the 21" (Vola con Martin oltre il 21) in 2018. This desire comes also from the awareness that scientific research could come to a turning point to identify new treatments, like those that could reduce or remove the intellectual deficit. Moreover, other researches are trying to find solutions to other deficits that are proper to Down syndrome. The last aim of these researches is to reach more autonomy and a better quality of life.

Objectives of the association are:

- The popularization of the scientific research among the families with meetings organised by experts, in order to exchange everybody's experiences ;
- Supporting the experts to create new projects and promote the existing ones;
- Ensuring an economic support to the research, in order to have a concrete and rapid realization.



The paediatricians, referents of the research: Prof. Guido Cocchi and Chiara Locatelli (Sant'Orsola-Malpighi general hospital, Bologna)

Project Genome 21:

A way to the discovery of a treatment for the intellectual disability in Down syndrome

The research, led by Prof. Pierluigi Strippoli and Lorenza Vitale, Biology professors at the University of Bologna, is influenced by the ideas of Prof. Jérôme Lejeune (1926-1994), who showed that the real cause of Down syndrome was the presence of a third copy of 21 chromosome (instead of two copies). The research's aim is to find a treatment for the intellectual disability that is always present in this syndrome.

The first scientific research that the association wants to support is that of Prof. Pierluigi Strippoli and his team from June 2018 to 31st December 2020.



The team of experimental research: from the left, Lorenza Vitale, Allison Piovesan, Pierluigi Strippoli, Maria Caracausi, Maria Chiara Pelleri



DIMES DEPARTMENT
University of Bologna

Up today:

- Researchers have found a "critical region" for Down syndrome in the 21 chromosome, a little segment less than 1/1000 of the chromosome long without known genes.

This region is always present in three copies in children with complete trisomy.

Children with "partial trisomy" who have just a part of the 21 chromosome: they'll have Down syndrome, if there is the critical region, but not if there isn't.

- They have found with metabolomic techniques a metabolic profile of the urines and the blood of children with Down syndrome, independent from age, sex and state of hungry (patients of neonatology at the Sant'Orsola Hospital in Bologna Prof. Guido Cocchi and Chiara Locatelli).

These results are in line with Prof. Lejeune's ideas, who thought that in the 21 trisomy there is a change in the metabolism, which causes an accumulation of substances that intoxicate cells like neurons, causing the intellectual disability.

From now on:

- Researchers want to remove the "critical region" in the cells with 21 trisomy and watch how metabolism changes to link these changes to specific genes of Down syndrome, in order to consider them targets for new treatments.

- They also want to find genes in the "critical region" of 21 chromosome that cause Down syndrome, especially those responsible for the intellectual disability.

Their research takes place at the DIMES Department at the University of Bologna and it is 90% financed by donations.

Fly with Martin beyond the 21

Voluntary organisation onlus, enrolled to the general regional register of voluntary work.
Provincial section of Lecco. Registration number 173.
Registration act number 256, 16.04.2018