A story in a name … Francesco

We are Italian and we have lived in Rome since our birth, we have always been living our life like many other people … family, job, friends … and waiting for a baby.

We have been waiting for a baby for many years … then … when we discovered that a baby was growing up in my wife … with a great surprise we saw the calendar … and it was the October 4th … the celebration day of Saint Francesco … the most important Saint in Italy. We had not doubts … our son would be Francesco !!!

The nine months after passed without problems … a beautiful period … waiting for Francesco … imaging his little face … having many dreams with him … then … when the evening of the June 5th 2012 we went in the hospital for the birth … we couldn't imagine that we would return at home after one year !!!!

Francesco wasn't able to breathe at the birth … he was practically dead. His Apgar index was 0 !!! But he showed immediately his strength because after one minute, even with the help of pediatricians his heart started to beat !!! Francesco was with us …

Francesco spent his first seven months of life in the NICU in Rome … during this period he had a muscular biopsy due to a heavy weakness … and so we had the diagnosis … MTM1 X-linked Myotubular Myopathy … a new world for us !!!! We were frightened but with the help of some amazing doctors … with the love of some beautiful other parents which we have known in the hospital … and with the time … we were able to accept this rare disease.

During the long period spent in the hospital we have met many beautiful persons … many amazing parents … of fantastic babies … with many rare different diseases … many of these at the moment are at home surrounded by their parents' love … many others are above our heads … together many other little angels.

Francesco spent other four months in the hospital but out of NICU.

Finally, 10 days before the first Francesco's birthday we came back to home … our home … Francesco's home … it was an enormous emotion … he could sleep into his little bed … with his teddies … and surrounded by his parents' love.

Our beautiful journey started there … obviously started that night of June 2012 but really started the first day at home.

We have learnt to manage Francesco, the long period in the hospital was an useful training period for us … but we found a valid aid through Internet … because we found some international charity organizations like "Joshua Frase Foundation" where we found many helpful advises from many MTM families all around the world … and we understood an important thing … that we weren't alone in this particular journey.

Francesco now is a beautiful three years old child, amazing like all our MTM warriors, he has lived with his tracheostomy, with his gastrostomy tube, with his few muscular strength but with his much inner strength.

He is a happy child, with a beautiful smile on the face, is a very curios baby and he likes very much reading books and obviously playing with kids games on the iPad !!! He likes watching cartoons and supporting our soccer team … Roma team !!!

He likes so much the music … he has a great sense of rhythm … every time he listens any type of music he starts to move his body … this is an amazing way to communicate for him … we think that he's searching for alternative ways to communicate with the world around him … and we are learning together him to understand all his needs.

He even loves get around together with us on his stroller … red like a Ferrari … to discover the world … the sea, the big trees … the animals … the mountains … he always is very careful and he watches everything with curiosity.

At the moment he is learning to drive a little wheelchair … with his delicate arms he can move himself into our home … it is a beautiful sensation for us … many tears rolled down from our eyes his first time on the wheelchair.

We want thank some amazing charity organizations like “Joshua Frase Foundation”, or “Where there is a Will there is a cure” and the English “Myotubular Trust” for their hard work in order to raise money for the research … giving to all of us the hope in a cure.

We would like to thank even many families which we have known through Internet … Facebook or through charity’s websites … to show to us that it is possible having a beautiful life even with this type of problems … they give to us the strength to carry on.

We hope in a very close cure … to give to all our guys a brightness future.

At last, this is not a simple life and maybe it is not the life which we have been imaging … but we are not alone … and also living with many problems you can find the happiness … it is enough watching the Francesco’s smile …

We can summarize our journey in a short sentence … Francesco, with his life, is teaching to all of us how approach the life … after his birth we don’t worry anymore about little problems … at the moment little troubles are not important for us … we try every day to enjoy of every moment together our Francesco … thanking God for him.

We don’t know our future and Francesco’s future … we only think for today !!!

Finally, we want close this little story with a beautiful sentence of an amazing friend … Stacyanne … “weak bodies hold the mightiest of spirits !!!!”

Daniele, Marta and Francesco