

STATEMENT OF THOMAS EVANS
Rome, 29 April 2019 - Senate Chamber of the Republic of Italy

Hello everyone.

I thank Senator Pillon for organizing this event in memory of Alfie.

As I was not able to attend in person, we sent these lines to Emmanuele that will read on behalf of me and Kate.

Yesterday was one of the most painful days of our life.

A year went by without Alfie by our side, but our heart reminds us that he never really left us.

We have almost completed the necessary paperwork and soon we will be able to start a foundation which will honour the name of our little warrior.

The scope of this foundation is to concretely help more and more families with sick children who are in difficulty.

We have already started doing this by using part of the money that collected last year to try to cure and defend Alfie's life.

When we went out public with our story, in early June 2017, we were only very few people.

But Alfie was able to steal everyone's heart in a very short period.

People captured in him a real life, a life which was worth living.

They saw the love to which we and our families dedicated ourselves to him.

Alfie had a rare disease, he had to be diagnosed with an expensive diagnostic exam that was refused.

When the clinical situation deteriorated, the only offer we received was to remove the vital supports.

We could not accept it.

We wanted Alfie to be able to go home with us and get the care he deserved.

Alfie deserved his chance.

After a series of mediation attempts which failed, the situation with Alder Hey plummeted and our lives were enveloped into a giant crystal bubble.

Inside this bubble there was our little family asking for help.

We let everyone look inside the bubble because only by doing this the general public could understand what was really happening.

From that moment on, everything we did, in good faith, was just to try to save him.

Did we make any mistakes? Surely, we did.

Do we have any regret? Absolutely we don't.

If Alfie was able to stay with us for such long compared to what the hospital originally wanted, it was only because of our perseverance and the unconditional help we received.

Steadfast Onlus stood our side during this journey which arrived to involve the Italian Government and the European Commission.

When Italy granted the Italian citizenship to Alfie, by doing this unprecedented move, we couldn't believe it was true. Instead it was.

The Italian people helped us in an extraordinary way.

Unfortunately, Alfie was not able to reach Italy.

But we will never forget what you did for us.

Alfie was a gift.

Despite the many moments of atrocious pain, we experienced we never felt unlucky due to all this happening to us.

Having a sick or seriously disabled child is not a disgrace.

Life can change you, yes it can.

Some people are afraid, they think they can't afford it.

The state must protect these families, help them, make health and economic aid available.

If we want a society where these families feel welcomed, governments must work in this direction.

Protecting the life of the weakest must be the light that guides their actions. It should not be seen as a problem to solve.

Together with Steadfast Onlus we will continue to fight for this.

Alfie gave us this task and we won't disappoint him.

Thomas and Kate

