DAILY COMPASS

Managing Director **Riccardo Cascioli** MADE FOR THE TRUTH

**INTERVIEW / CONNIE YATES**

# "Indi like Charlie Gard: we must fight, the system will collapse"

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***Patricia Gooding-Williams***

"I hoped it wouldn't happen to them as well. They will live with this for the rest of their lives." "I am not very hopeful the system will change, but we can't give up, we have to keep battling, even if nothing has changed since Charlie died six years ago." Time stops still for Connie Yates every time news breaks of the death of another child at the hands of the NHS and judiciary system in the UK.

**Her son, Charlie Gard, died shortly after three-o'clock on 28 July, 2017,** when staff disconnected the breathing machine that was keeping him alive. Since then, numerous children and adults have suffered the same fate in the UK. Indi Gregory, who, like Charlie, suffered from mitochondrial DNA depletion syndrome (MDS) , died yesterday morning, Monday 13 November, at 1:45 am, 32 hours after her ventilator was disconnected. The Daily Compass spoke to Connie Yates on the phone a few hours after Indi's death. She describes how she and her husband, Chris Gard, are still trying to come to terms with the way Charlie met his death.

**Can you share your first thoughts on the breaking news about Indi's tragic death?**
The news about Indi's death is devastating. I hoped it wouldn't happen to them as well. I hope they will find some peace knowing they did everything they could for Indi. The problem is they were prevented from doing more. If they had been able to take Indi to Italy, she would still be alive today. That is not their fault. But, we parents live with the guilt that we failed to save our children. It's unfathomable to anyone who has not been through the experience. It's something you never get over and have to live with for the rest of your life. I still suffer from Post Traumatic Stress (PTS).

**It's well known, that you tried to bring some good out of Charlie's death by presenting a private bill to Parliament known as Charlie's law. Did you succeed?**
The Charlie Gard Foundation gathered together many experts in different fields to make a legal framework that would resolve disagreements between parents and medical professionals over the course of treatment of a child. We called it Charlie's Law. When it was accepted at government level we were very hopeful, but the government referred the bill to the Nuffield Council of Bioethics for further review. Unfortunately, they did not recognise the main crux of Charlie's Law, namely that families should have the right to accept treatment abroad if that option was available. In our opinion, the imbalance of power in favour of the doctors and state is still not addressed adequately. I am pleased that parents can now receive legal aid for litigation. That's been a positive outcome. But, it's clearly not enough. If it was, we wouldn't have so many high profile cases in the news.

**In the past, the British demonstrated their indignation publicly for cases like Charlie's and Indi's. Now they seem apathetic, what has changed?**
I think people think this won't happen to them.  I didn't think it could happen to me.

There has also been a significant shift in culture in the last few years. People are less compassionate, more concerned with their own problems and turn a blind eye to the concerns of others. But, these cases should ring alarm bells. The culture of death is spreading its net wider. At the moment, a cancer patient might be told they have three months to live. Doctors don't say, we are not treating you anymore. They even use experimental drugs, if there are no other options. Sometimes, the patient improves and lives for longer than predicted. This is exactly what we wanted for Charlie and Indi's parents wanted for her. But, they were denied that opportunity because they had MDS. The implications for the future could be devastating. The State could decide to apply a death pathway to cancer patients or any other critically ill patient.

**When doctors insist treating patients like Charlie and Indi is futile, they are saying some lives more important than others. What do think?**
Life is life whether it lasts one year or ten. We are talking about flesh and blood here. It is a very dangerous to make life and death decisions on this basis. It is too open to manipulation. Why should one life be considered more valuable than another, because it might last longer?  No one knows how long they will live. We are here now, that's the only certainty we have.

**Not one family that has gone to court to challenge the doctors' decision has said afterwards, they felt they had a fair trial. Why is that?**
I can speak for myself, but other families have told me they had similar experiences in court. Before testifying, you are invited to swear on the bible to tell the truth. I did, but none of the doctors did. In fact, they told many lies. For example, we were told we could take Charlie home to die. When they changed their mind they had to justify the decision. They gave ludicrous reasons like the ventilator wouldn't fit through our front door knowing it wasn't true or that the stairs were a problem when we lived on the ground floor. They tell the judge life-sustaining treatment must be removed because your child is in agony knowing it's not true. Whatever the doctors say, the judges believe them, never the parents. You can't find the truth in a pack of lies.

**Another criticism mentioned is the lack of compassion. Did you find trials were callous?**
Definitely. They never see the bigger picture which means they exclude factors that increase the suffering for everyone involved. The doctors think they know best, but what is more harmful than death? Stopping Charlie and Indi from going home after they were told they could, caused the family great sorrow. Indi also had a sibling. This is atraumatic experience for a brother or sister.

**Is it pointless trying to fight the system when it is impossible to win?**
We have to fight the system so one day someone can win. It's tempting to give up but that would be a mistake. We must keep battling. We must try to stop another family going through the same experience we did. Of course, it's difficult and stressful. You will also be attacked by trolls with vicious remarks. But, you have to do what is right and follow your convictions, not let anything or anyone deter you. That's what we did and I would advise anyone who is challenging the NHS in the courts to do the same. One day, the system will break.