

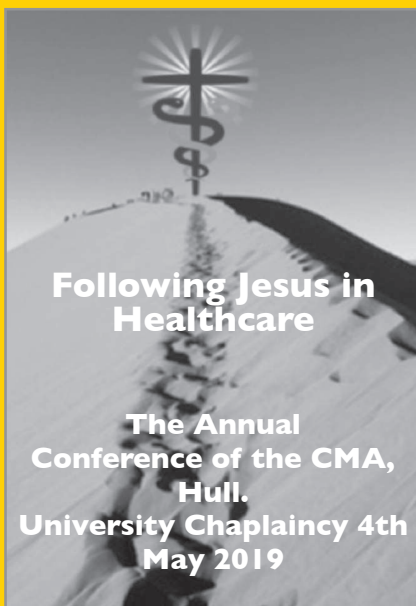
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Michal Pruski, PhD, MA, AFHEA;
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CORRESPONDENCE

WELCOMING A CHILD WITH EDWARDS SYNDROME

DERMOT KEARNEY WRITES ABOUT BELLA, THE DAUGHTER OF RICK SANTORUM FORMER REPUBLICAN PRESIDENTIAL NOMINEE.



<https://www.dailymail.co.uk/embed/video/1157832.html>"

Dear Editor

In September 2018 I had the honour of attending the US Catholic Medical Association Annual Educational Conference in Dallas, Texas and of presenting a paper on the Catholic approach to management of high-risk pregnancy.

I was very much impressed by the organisation of the conference and the exceptionally high standard of the presentations. During the celebratory dinner on the final evening of the meeting, the key note speaker was Rick

Santorum, the former senator from Pennsylvania and a former Republican Presidential nominee. He gave an excellent speech that was in part humorous, always engaging and deeply moving. All of this was done without the aid of notes, slides or auto-cues.

Many may not realise that Rick and his wife, Karen, are parents to eight (seven living) children. Their youngest child, Bella, has Edward's syndrome (Trisomy 18) and it was predicted by the medical profession that she would not survive beyond one year after birth. She is now ten years old. His wife could not be present at the meeting but she asked him to say something very specific about Bella in his speech. What he related was overwhelmingly beautiful and profound.

He said [slightly paraphrased]

"Bella will never be able to do anything for me. She'll never make me a cup of coffee or fetch my slippers or help me with any tasks. She is incapable of performing any meaningful physical acts. In that sense, she can do nothing for me. All she can do is love me... Isn't that exactly the same as each one of us before God? There is nothing we can do for God. He doesn't need us to do anything for Him. He's God. And yet, all we can do is love Him. That's all we can do... Bella is a great teacher."

Dermot Kearney, Gateshead (President CMA (UK))

WELCOMING A CHILD AFTER PRENATAL DIAGNOSIS OF A SERIOUS OR LIFE-LIMITING CONDITION

DR JOSEPHINE TRELOAR.



Helen Watt's article ^[1] is very welcome indeed. I could not understand the need to push for legislation for abortion of babies with short life expectancy in Northern Ireland last year.

About 15 years ago I was giving a talk on difficult pregnancies and interviewed mothers who had been through such a pregnancy. I was worried that I was

treading on sensitive ground and the mothers would become distressed about revisiting the experience. The encounters were very different than I had anticipated. The mothers were glad to talk about their pregnancies and their babies and I was surprised at how at peace they all were.

Ironically I experienced one of these pregnancies very soon after that talk 15 years ago and the peace and experiences of the other mothers was one of the things that carried me through. For myself, my husband and my children the memories of baby Hope Mary Cecilia will always live on in our hearts. Bringing her to birth was a huge privilege. We lost a dearly beloved daughter but gained a saint in Heaven. We still ask her to pray for us each night.

Dr Josephine Treloar.

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WELCOMING A CHILD WITH PATAU'S SYNDROME

CLAUDIA LINTON



Baby Josephine at her baby brother's baptism

I am writing to add my experience to the excellent article by Helen Watt in the November issue of the CMQ. I think it is very important that women can feel encouraged and supported when they find their child is not expected to be able to live. So often they are alone and cannot access any help other than that which comes from "experts" who encourage you towards an abortion.

It was at my 23 week scan that we found out our daughter was going to be born with medical conditions that were, 'not compatible with life'. The two ladies that

were performing the scan were taking an awfully long time, we thought, and when they finally said they had to, 'pop out of the room for a minute', my husband and I got the giggles as the idea that something could be 'wrong' with our baby was not even on our radar. Suffice to say, with Trisomy 13, or Patau's Syndrome, being the diagnosis, which was confirmed by a subsequent amniocentesis - something I will forever regret and do not recommend - the reality of our baby's future with this life limiting condition, was like a punch in the guts.

Unfortunately, our Consultant was very negative and unsupportive. He was very persistent with regards to trying to make sure I knew we had 'options'. I certainly knew what 'option' he was talking about and had to eventually get quite insistent that we were in this for the long haul - no matter what! As you can imagine, by 23 weeks into my pregnancy our little Josephine, was very much alive and kicking - literally, and I couldn't understand how anyone could disregard this fact quite so flippantly - I felt. My priority was to deliver Josephine safely and to make sure she had all of her needs, whatever they were, dealt with as they would if this was a normal pregnancy and birth. The Consultant's priority was to disregard the needs of my baby and make sure that I was all that needed to be considered as he said, "...Trisomy 13 babies usually die before birth or not long afterwards."

Luckily for us, we were given the contact details of a couple who were doctors with a reputation for being very supportive and understanding of our position, and who would be a lifeline and a great support for us in the years to come.

Josephine's birth was very normal without any complications. She had a multitude of 'problems' externally and internally, but she was beautiful and perfect and loved instantly and entirely. Her older sister, who was nearly four at the time, could instantly see past the cleft lip and palate, her 12 little toes and club feet. She was just the much wanted and adored little sister that she had always longed for. Josephine spent the first 6 weeks of her life in the hospital so that we could get used to her needs and how to care for them. Once home, she grew

and thrived and was suffocated with love. She could laugh and smile and say mumma and ALWAYS had her arms open wide for a cuddle.

It was a chest infection, which progressed to pneumonia, that eventually led to her death - 10 days before her 4th birthday and 6 days after the birth of our fourth child. Just the week before, she had been a bridesmaid at my sister's wedding. It all seemed to happen rather quickly as we had always known that this time would come, but still, it was a devastating loss for all of us.

What a gift! What a blessing and a treasure she was! I will miss her to my dying day and I'm so glad that we had the opportunity to know and love her and for her to know and love us, and I can't wait to see her again.

WELCOMING A CHILD WITH ANENCEPHALY

MOTHER OF BABY WHO LIVED FOR TWO MINUTES: "SHE WAS ABSOLUTELY PERFECT IN EVERY WAY"



Abortion "was never an option for us, not even for a second."

A mother whose baby was diagnosed with a life-limiting condition in the womb has spoken out about how rejecting abortion gave her and her partner precious memories with their daughter.

The story of baby Freya and her brave young parents Erin O'Hara (24) and Jamie McCormick (23) gained media attention in October, when Erin spoke out about their decision to carry Freya to term, despite the devastating diagnosis of untreatable anencephaly. The couple, from Limavady, Northern Ireland, received messages of love and support from around the world.

"I would do it all again in a heartbeat"

Now, Erin has revealed that her daughter Freya Anne O'Hara-McCormick lived for two minutes outside the womb after she was born eight weeks premature on 7 December 2018.

Due to little Freya's condition her mother faced complications during her pregnancy and was in pain in the later stages. "The pain was awful, but I would do it all again in a heartbeat, if it meant I would get to see Freya again," Erin said.

The grieving mother also revealed how she shared the precious minutes of her daughter's life. "She was absolutely perfect in every way, just 2lb 4oz of pure joy," she said. "We would have given anything to have her longer, but I am glad that she didn't suffer and she passed

away peacefully.

"In her last moments, with one eye open, she stared right up into mine, holding her daddy's finger, and listening to the sound she knew best, my heartbeat. I will hold that memory of her with me forever."

Finding closure

Erin says that abortion was never an option for her and Jamie, even when they were told that there was no chance their baby daughter would survive. "Jamie and I have been utterly distraught since Freya's diagnosis a month ago and it has been undeniably difficult to come to terms with," she said in October. "People told me termination was an option, but we couldn't do it. We want this wee baby more than anything in the world and we will love this wee baby, no matter what."

There has been much discussion of abortion in the case of a life-limiting diagnosis (generally cruelly and inaccurately referred to as a "fatal foetal abnormality"), especially in the light of the court case claiming that Northern Ireland breached the human rights of Sarah Ewart, who travelled to England for an abortion when she learned her baby would not survive...

We are indebted to the Society for the Protection of the Unborn who first published this article on 5th February 2019.

You can read the full story at :

<https://www.spuc.org.uk/news/news-stories/2019/february/mother-of-child-who-lived-for-two-minutes-refused-abortion>