

Undergoing renal replacement therapy, waiting for an organ transplant

An interview with Darren, the fastest patient in Europe

**EU Health Prize for
Journalists 2010**





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Foreword

By Paola Testori Coggi,
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The second edition of the EU Health Prize for Journalists gathers another outstanding collection of health articles from journalists in the 27 countries of the European Union.

This year, we have built on the success of last year's Prize with 42% more journalists taking part – 438 in total. The National juries have had to work especially hard to evaluate 745 eligible articles. This is a rise of 60% since last year. I would like to thank sincerely both the National Jury and EU Jury members for their work and dedication. A special thanks also to colleagues from the Commission's Representations and from the Directorate General for Translations who contributed to the success of this Prize.

The 27 national winning articles that made up the collection are on diverse subjects such as cancer, child birth, migration of doctors and the H1N1 flu pandemic. The issues raised cover the entire life span, with articles on pediatric cardiology and autism through to dementia and hospice care. Many are forward looking, covering for example eHealth and cross-border medicine.

Seven of the final articles are on the subject of organ transplants. This is an important and emotive issue and an area where the Commission can claim a concrete achievement this year. The Organs Directive, adopted in May, ensures that European citizens in need of an organ transplant can benefit from the best possible quality and safety conditions, and that all donations remain voluntary and unpaid.

Another 'Europe for Patients' initiative that has taken a big leap forward this year is the Directive on Patients' Rights in Cross-border Health care which is progressing well in the decision making process. This initiative will make getting medical treatment in another Member State easier and more straightforward.

There is truth in the old saying, "the pen is mightier than the sword". Journalism is an incredibly powerful profession. It can form public perceptions, attitudes and behaviours. It can even bring about changes in the health system. The articles that make up this collection illustrate the qualities of the highest form of journalism: integrity, objectivity, passion and sensitivity.

Introduction

Undergoing renal replacement therapy, waiting for an organ transplant
An interview with Darren, the fastest patient in Europe

This article was written by Erzsébet Fazekas, an award winning Hungarian health journalist, following a European Kidney Health Alliance (EKHA) event at the European Parliament, Strasbourg, France. At that event on World Kidney Day 2010 the author witnessed a presentation by Darren Cawley, a young chronic kidney disease (CKD) and dialysis patient for about 10 years. The EKHA event and Darren's inspirational account of living with CKD triggered Erzsébet to share Darren's story.

The article has since been published in several Hungarian media outlets, first appearing on the medical website www.webbeteg.hu, then later being republished in the Christmas issue of IME health magazine.

Following its publication, Erzsébet's take on Darren's story was published as the national winner from Hungary in the second edition of the EU Health Prize for Journalists, as part of a collection of health articles from journalists in the 27 countries that comprise the European Union. The EU Health Prize for Journalists is run by the European Commission's Directorate General for Health and Consumer Affairs (DG SANCO). The articles that make up this collection are all commended for stimulating, high-quality journalism that raises awareness of issues related to healthcare and patients' rights.

Undergoing renal replacement therapy, waiting for an organ transplant

An interview with Darren, the fastest patient in Europe

He often had headaches, and his vision blurred more and more frequently. He went to see an ophthalmologist, who sent him straight to hospital. There, this young man, who does various sports and leads a healthy life, was told that he is seriously ill: his kidney barely functions. Two weeks later 20 year old Darren J. Cawley, a student in sports and fitness about to graduate from Bedfordshire University in England – was sent to dialysis.

After finishing his studies, he went back to Ireland, and 7 or 8 weeks later he got a kidney from a donor. He soon resumed sport and travelled to Japan to take part in the World Transplant Games. He returned from there, and from later competitions, covered with medals. Then in 2002, after the Games in Hungary, his joy was tarnished by the discovery that his kidney had been attacked by a viral infection and had to be removed. Since then, Darren has been back on dialysis again. Yet sports are still at the centre of his interests. In his spare time, he does more and more charity work: he gives awareness-raising lectures to children on the functioning of the kidneys and the essence of dialysis and transplantation. When he speaks to adults, he highlights the importance of organ donation. He wants to show that even someone with an illness can live a harmonious, high-quality life and set important goals for himself. In the meantime, he is waiting for a new kidney, he is optimistic and hopeful, and he sincerely believes that he'll be lucky this time and that transplantation will really be a success.

Darren is giving a presentation on his health problem to a small group of Members of the European Parliament and journalists in a meeting organised in Strasbourg on World Kidney Day. As he stands speaking to his audience, he rolls up both his sleeves and shows us his forearms. They are covered with hugely dilated veins, bulging out like slim skin-coloured snakes winding around his arm. He explains that these are surgically-linked 'arteriovenous fistulas' needed for renal replacement treatment, and that more and more of them need to be created in his body. He invites those present to go ahead and touch him and feel his heart throbbing in his arm. Most of the audience is reluctant to really "get" what Darren is telling them, so hands do not reach out towards him – although it is hard not to accept his offer. It is of course peculiar to feel the lukewarm pulse beneath one's fingertips. By touching him, I am now learning, literally first hand, what it means to be dialysed.

The smiling, spiky-haired young man then rolls down his sleeves, and we can no longer see that he is seriously ill. On entering the room, I took him for a medical lecturer, since he sat arranging his notes at one of the key places at the U-shaped table. He greeted each person who entered with a smile and,



Darren J Cawley at the European Transplant & Dialysis Games in 2010

as we waited for the event to begin, he offered us water from a bottle on the table. I tried to come up with an answer relevant to the subject matter of the event: sure, why not take some water - it will do my kidneys good by washing them through. Looking back, it seems as if he reacted with a gesture of doubt, but I only realized this later, since at the time he had also helped himself and sipped some water.

Darren tells us what it's like to live with the condition, how dialysis sets a strict framework for his life. Treatments put stress on the body, and he mentions that he loses the equivalent of 2 bottles of liquid each time. This much – he says, and lifts the water bottle. He adds that kidney patients must not drink much, for their bodies are unable to eliminate excess water. He tells us that his erythropoietin-count goes up and down periodically and that sometimes he is so tired after the treatment that he lies down in bed for a while before going to his sports training. For Darren continues to do sports intensively – even now.

He beams with energy, cheerfulness and optimism. He lives a full life, he adds, though he cannot have a stable job since he has to spend half a day at a dialysis station 3 to 4 times a week. When he feels fit enough, he helps in his parents' company in exchange for the material and moral support he receives from his family. His girlfriend wants to get married as soon as possible, but Darren would like to put it off for now and does not know when it could happen, but he hopes they can get married in the near future. For now, it is not possible, since he is waiting for a kidney. If he gets a phone call informing him that there is one available for transplantation, he has to show up in the hospital within a couple of hours. He does not want to interrupt his honeymoon. He wants to get married once he has a new kidney, he wants to have a memorable honeymoon and then a stable job, so that he can earn enough to nourish his future family. And until then, he keeps waiting patiently. His days are filled with hope and charity work...

This is the gist of what Darren told about himself before the medical specialists started their presentations. The doctors then referred to his case when they said that although 10 % of the European population is affected by a chronic kidney disease, there is no appropriate strategy for prevention at European or national level. However, only prevention

can help reduce the number of patients on dialysis, who sometimes spend many years waiting in vain for a transplant. Specialists highlighted that we need as many living donors and "good quality" organs for transplantation as possible, and they think it important that the World Kidney Day campaign should not be the only initiative calling attention to the importance of prevention and the risks of this chronic condition. Nephrologists insisted on meeting members of the European Parliament's taskforce on kidney health to seek EU help to promote the cause.

According to doctors, it is important, for example, to create forums for the public so that they can understand how an established illness is treated and what the available treatment options are. According to nephrologists, member states' decision makers in the health field should also be told to keep the organ transplantation issue on the agenda, discuss and clarify ethical, religious, medical and personal aspects (often interpreted differently) of transplantation and organ donation. Besides, members of the public should realize that organs that would otherwise be buried could also be donated to save other people's lives or improve their quality of life. The organs of one dead person can improve the lives of up to 7-8 people. General awareness should be raised – to the benefit of Darren and others like him.

Darren is ready to take further questions – our discussion at the Strasbourg event was inevitably cut short, but it still continues in a written form. Details of his case history and his life unfold one after the other during our correspondence. First, of course, we got back to the starting point – that is, how it all began...

The headaches and vision problems came on gradually over a few months as I remember. The reason why I finally went for a check up was because the eye problem was affecting me playing football and studying (reading). I went to the university doctor (she was free, and I was a poor student). She listened to me and told me to see an optician, if I wanted. I guess she thought I was seeking to get out of exams or something. (Some people told me I should have taken legal action against the college doctor who dismissed me so easily without doing any checks and failed to consider the risks I ran.) Since my vision problems and headaches persisted, I sought

specialised help. It took me 4-5 days to get an appointment with an ophthalmologist. When he checked my eyes he gave me a letter and told me to go to the hospital straight away. I told him that was impossible, because I had a football match to go to that evening, otherwise I would be missing from the team, but he insisted. He explained that my bad vision was due to pathologically high blood pressure and if I had went to the Gaelic football match, that would be very tiring for my body, I might have a stroke! Luckily, I obeyed him. I went in as a fit healthy sports student (as I thought) and I came out with renal failure and on dialysis. The biopsy they did showed that less than 20% of the kidney was functioning, the original cause was unknown, but the doctors thought it might have come from a "strep throat".

I saw out my final year in college on dialysis. I did not want to move back home yet since the hospital I attended in England (the Lister Hospital, Stevenage) was very good. It actually specialized in renal medicine, I so was very happy with them. I was back in Ireland when I got transplant though. It was great to be home, with all my family support.

Before my illness, I was into a lot of sports - boxing, rugby, Gaelic football, soccer, handball and racquetball. After the operation, the list got much shorter. Since hearing about the Transplant Games, I have taken up athletics. I compete, or have competed, in the 100m, 200m, 400m, ball throw, long jump, cycling, and bowling. At my first games, in Kobe, Japan in 2001, I won two bronze medals in the 200m and 400m. These are still the most special as I had never even run on a proper track before and it was all very new. Since then I've been to 3 European Transplant and Dialysis Games.

Hungary 2002 was a brilliant trip. It was bittersweet, though, because I was told after the Games that my transplanted kidney was affected by a polyoma virus infection and would have to be removed: nephrectomy. The next Games were in Slovenia in 2004. My first games on dialysis. I did well, winning 3 silver medals and one gold. Finally Germany 2008. My first games with my girlfriend Aoife, so we had a wonderful, special time. Also my most successful games, with 4 medals. To be honest, there was less competition, as not too many dialysis patients compete compared to transplanted patients. But as I

sometimes say in speeches, I am now Europe's fastest sick person. It gets a good laugh!

With my qualifications, I guess I could teach sports. I can only work part time though because of the dialysis. I have worked with Special Olympics for a year, coaching special needs athletes (e.g. people with missing limbs, impaired vision, disability). I've also worked as a substitute teacher in my home town Westport. This often entailed teaching Physical Education.

I have been on dialysis for 8 years by now. I did not return to the waiting list until the virus totally left my body. As a result, I've been on the waiting list around 5 years in total. It is longer than usual in Ireland. I've no real reason why, I guess I've a large percentage of antibodies, which does not help. But results are checked regularly and it seems now that everything is going to be all right this time. I feel that the operation is close now. I am certain I will get called soon!

I have chosen not to go down the road of live related kidney transplant. I've been offered kidneys by friends, family, even strangers I meet! My four sisters are all quite young and have families, so I would not do that - they cannot afford to be that generous to me. I've said in the past however that if my next transplant is unsuccessful I would consider live related transplantation. At the moment I'm pretty healthy and active on dialysis therefore I don't mind waiting. I have things to do.

Since joining the Westport Lions Club, I do a lot of local charity work. I do fundraising for the Irish Kidney Association (IKA) and the Punchestown Kidney research Fund, and I also talk in schools, to promote understanding of kidney failure and donor awareness. I am very well qualified to talk about the subject as I have been living with it for over 12 years. That is really how it started, with the goal of visiting every school in my local county of Mayo. Since then, the initiative has evolved, I am now trying to get young people on dialysis in other counties to do the same. I am invited to travel too, but I do not always manage to go. Because of the dialysis, I could not undertake to travel to Chile. That came out of the blue for me! My sister nominated me on-line for a "Local Hero Award" in Chile. I won the award, which came with a prize of €10,000. I should have travelled to Chile to collect it. I

did not go, but the money has arrived indeed, and I donated it towards helping dialysis patients at the Transplant Games in Dublin this year.

I wrote to Darren in my letter that I was very pleased to have met him. To me, he is a role model, the living example of positive thinking, for it is so rare to find young men who are brave enough to come forward with their personal "handicaps" and problems and who at the same time show that there is still hope and confidence, as they sincerely believe that a good outcome and a happy future is possible. Especially when you take into consideration that there are so many seemingly healthy people who lose their inspiration or for some reason do not know how to find satisfaction in life. I shared with him the following reaction of the organiser of the Strasbourg event:

"The inspiring presentation by the incredibly brave young Irish patient Darren was deeply moving for me. It is one thing to deal with data and facts about kidney disease. But to hear a story such as Darren's was an experience to be thankful for – to appreciate being healthy. A state which is taken for granted so easily, we forget that it is fragile and we should do something to preserve it. I think it is simply human nature. Meetings like the one with Darren are like a wake-up call. They teach us that we must be aware of the fact that we are healthy and that our health is

something precious we have to preserve. All the more so since Darren, keeps on hoping, even though he is ill. The way he appreciates life and what it offers, set us an example and makes meetings like the one at World Kidney Day so unforgettable".

Darren was very pleased to read the organiser's reaction and agreed that it was a great experience to participate in the event and realize how much he can do for others, even when he is ill, and how important the messages are that he can transmit to the public. Besides, he told me that if I write about him, then my text, and any other article I write about transplantation, should be very positive. Only optimistic and hopeful accounts can serve the cause of those people who are waiting for a new and healthy organ for transplantation. He added that now I was in the possession of the longest e-mail he had ever written in his life – on dialysis, typing with one finger of one hand.

"*Slainte*", writes Darren finally as he takes his leave, explaining that this is the word Irish people often use in the pub when starting a drink and toasting the good health of those around them. "*Slainte mo chara*", he adds: "Good health my friend".

Erzsébet Fazekas

Diseased kidneys are unable to eliminate waste products from the organism (end- and by products of metabolism, toxic substances in the blood) and excess water. Therefore cleansing has to be done through artificial filtering – that is, blood is passed through a device called a dialyser. The structure of the membrane that performs the filtration keeps blood cells and big proteins from diffusing into the dialysis solution. In order to enable the blood to be removed from and returned to the body, a connection point - the so called arteriovenous (AV) fistula - must be created surgically between an artery and a vein. Blood flows in and out through a tube linked to the fistula.