

After-dinner speech – OI 2022

Lord Shinkwin

Nick, thanks very much for that kind introduction and for the honour of being asked to give this after-dinner speech. I hope everyone's had a wonderful conference, so far.

Well, I thought nothing could be more daunting than speaking in the august surroundings of the House of Lords. How wrong I was! What a fantastic and fitting venue to celebrate the collective brainpower gathered here in this space, which easily rivals the cerebral excellence of the House of Lords. It means so much to me and to, I'm sure, all of us attending who live with OI that your intellect, your expertise, your energy are all focused with laser like precision on making our lives easier. Thank you so much for all that you do.

The truth is I don't suffer from Brittle Bones. I live with it, and, thanks to your work and also that of someone who though not here in person, is most definitely here in spirit, I live my life to the full. That someone left me a legacy which grows richer the older I become. His name is Hanus Weisl, and he was my orthopaedic surgeon practically from birth to the age of 13. By cruel coincidence, he was also a teenager when in 1939 he fled the virulent, violent, and ultimately murderous antisemitic racism of the Nazis. He escaped on the last train out of Prague before the Nazis closed the borders; none of his family members who remained survived the Holocaust.

By chance, his life was saved by the Kindertransport; as a result, he went on to transform my life chances. Like me, he could never have envisaged that I would be sent to the Lords at the age of 44 after a career campaigning for charities like The Royal British Legion. But he knew I wasn't born with a silver spoon in my mouth; like many with OI, I was born with a broken leg.

I wrote to Hanus Weisl soon after his retirement in 1992 to thank him for his perfectionist care, which meant that despite my having had around 50 fractures and after a childhood spent largely in a hospital bed, I was walking, admittedly with callipers, and able to live independently. With typical modesty, he replied, 'I was most touched by your note of thanks for whatever I tried to do. However, I am convinced that whatever the surgeon does, it is the patient who makes it work, or not.'

I think that may have been a backhanded compliment to my sheer bloody-mindedness. I don't know whether the geneticists present would agree, but it does seem to be quite a common trait of people with OI, as if it were built into our DNA!

And in my case, it was just as well because as far as I'm concerned, you name it, I've done it, been there and absolutely hated the T-shirt: fractures galore, basilar invagination, as recently as this January I had my left leg rebuilt by the brilliant Marcus Bankes and his colleague, Christian Smith, at Guy's. The pain when I came round – and for the next five weeks – was unreal, but it was worth it. Thanks to them, my mobility and my quality of life have been transformed, but also thanks to Hanus Weisl, because it was the fact that he had rodded my femur 40 years ago which meant it was straight enough for the rod to be removed and replaced with a plate so that they could then replace the hip – and all, remarkably, without fracturing the bone.

Now you may be thinking – you may not be – that that's quite an inspiring story, but is it that unusual? I don't know. You deal with individuals living with OI and their families day in, day out. You may find us inspiring, but for me, inspiration works both ways. Your dedication is

my inspiration; Hanus Weisl's story and his example inspire me to do more, to give more and to ask myself this question.

It's a question I imagine is common to all of us tonight and, indeed, one we probably ask ourselves throughout our career. It's not just about what will I take away from OI 2022; it's also the crucial, bigger-picture question: how does one measure the impact of what each of us does?

Now that may not be a question Professor Bishop has to worry about because as this terrific conference comes to an end tomorrow, there can be no doubt what a phenomenal impact he has made. So thank you so much, Nick, for all that you have done here in Sheffield and, indeed, around the world through your clinical practice, in leading cutting edge research and, perhaps most importantly for me, in enabling children and young people with bone conditions like OI to mitigate its impact, live a full life and realise their potential. The transition from the excellent childhood services you've done so much to develop to effective continuing care and support for adults is crucial, and I know it's a burning issue for the Brittle Bone Society and, indeed, for all of us with OI.

But what about the rest of us? How do we measure impact?

Because it's a question that has never been more important in an age when the impact we make in our careers, in particular, is so interwoven with our sense of self-worth and, I would suggest, with our innate desire to do good. It reminds me in this suitably ecclesiastical setting of the words of Psalm 37, 'Trust in the Lord and do good, and you will live in the land and be secure...' Regardless of whether one has a religious faith, knowing that we are doing good is so important to a sense of purpose and of security, of mental wellbeing.

So my answer is this: be inspired by the progress you're making in care, in research, in collaboration. And I hope you take away from OI 2022 what I would call the three c's: new, perhaps deeper, contacts; a stronger understanding of the wider context in which your work is changing lives; and, finally, a real sense of community and partnership.

But also be proud of both the immediate and almost immeasurable impact of what you do. In this increasingly fast and pressurised world, that is so easy to lose sight of. It's so easy to underestimate the worth, the value of what you are about, to assume you are insignificant, that your contribution doesn't really matter, that you are not making a difference, to believe that you are not helping to build a better, more equal world. Don't, because that is exactly what you are doing, and it needs to be done.

I was once criticised by a French assistant at school. "You know what your problem is?", he said, "You're a dreamer." Little did he know that it was a small boy's capacity to dream beyond his hospital bed that kept him sane for the months on end as he lay in traction, that always dreaming beyond has been the difference between fighting on and giving up. And look where it's got me – giving the after-dinner speech for OI 2022!

All of us need to dream, to think big, to look beyond. Ultimately, that is surely the whole point of our being together here in Sheffield.

So thank you for the impact you make and the good that you do. Please, don't stop!