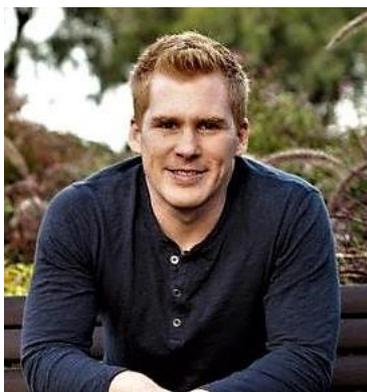


Dan Peach



Dan Peach has recently joined the Board of the ISMRD. He is passionately committed to curing rare Lysosomal Storage Disorders through a tightknit community of researchers, clinicians, patients and families. Dan has seen and experienced first-hand the daily battle of Mucopolysaccharidosis I, also known as Sialidosis. Dan joins ISMRD with over 15 years experience in market research and analytics that enables him to stay at the cutting edge of new discoveries and how they may be applicable to Lysosomal conditions. Dan lives in New Zealand. He writes below about his experience of the

conference in Rome.

After a long and somewhat uncomfortable journey, I touched down in Rome for the fifth Glycoproteinoses International Conference. Until now I had spent years searching for medical professionals who knew about any Lysosomal Disorder, let alone Mucopolysaccharidosis I (MLI). Finally, I had come to a place where I was surrounded by people connected by common adversaries in a country whose history was full of battles won and new territories gained. I was excited to meet the extended Lysosomal community and meet some of today's greatest researchers who were scheduled to present, share and network in ways that are simply not possible via a mobile phone.

Within a few hours of arriving in Rome with my sister, we were eating and drinking with new, yet strangely familiar, friends. They were relatable and shared much of the journey I thought was so unique to me.

On Wednesday, my sister and I paired up with some brilliant graduate researchers from St Jude Children's Research Hospital, Memphis, Tennessee. We had a world of fun getting lost in Rome, going shopping for Italian shoes and becoming great friends. It was an odd experience for me to become friends with researchers outside a meeting centred around MLI. Being a group of friends led to us sharing about ourselves as people first and as patients or researchers a very distant second. It was the perfect way to start the conference.

Wednesday night was when I got to meet my friends and pseudo family members over dinner. I met friends who had Lysosomal Disorders for the first-time face-to-face and a sense of community and hopefulness began to grow. I met my long-time friend Dr Alessandra d'Azzo and recently acquired friend Dr Camilo Toro who both radiate knowledge, which is like gold for someone like me seeking answers. I met many other researchers that night who would, over the coming days, become friends.

Throughout the conference, I joined the researchers' stream as it is a rare occasion to have access to the depth of knowledge which was held in that room; you couldn't pry me away. Every presentation built on from the library of research regularly available, and, it came directly from those who were pursuing and developing the very ideas they spoke about. I was overloaded, but so happy to see how much progress was being made.

On Thursday I was invited to speak to the researchers about my personal journey and the things I had experienced through observation and things that I had experienced in my own body. I was able to share about the wider impacts Lysosomal Disorders have on siblings, spouses, children and parents. Which is why I believe community is so paramount when it comes to Lysosomal conditions. I was honoured to speak and will always cherish the opportunity I had to tell my story with its context and explain what inspires me to believe better days are always ahead.

Finally, and most importantly, on Saturday I co-chaired a family session on MLI with my sister and Dr Toro. Again having patients and medical professionals connecting is a special event which was a major theme to the conference. I think we can learn a lot from personal dedication but we can learn infinitely more as a dedicated collective.

Rome was a turning point for me. I am no longer searching for answers alone, but I am part of a community of fantastic people who are finding answers together. I left Rome enriched with friends, family and knowledge that I simply could not have achieved on my own. With that I say Arrivederci! to Rome – I hope we all meet again soon.