



26-28 May 2016 Edinburgh

European Conference on Rare Diseases & Orphan Products

Why attend ECRD?

Interview of Tom Croce, Head of Global Patient Advocacy, Shire, USA



What is your role within Shire?

I lead the Global Patient Advocacy team within Shire. We are here to support activities that ultimately benefits patients through connecting with patient organisations, such as EURORDIS. Shire understands that the trust of patients must be earned, so our goals must be transparent as we seek to understand and address the many unmet needs in the global patient community. Central to our approach is ensuring that any commitment we make aligns with our goals as an organisation, delivers clear value to the patient and the patient organisation. All three are necessary for our programs to succeed and to deliver on Shire's vision of enabling people with life-altering conditions to lead better quality and longer lives.

Why is Shire attending ECRD?

Our ambition is to change the course of the future for people with rare diseases. In pursuit of this goal, at Shire we work tirelessly in three key areas: discovering breakthrough science where no therapy currently exists; building a global environment in which novel treatments can reach those who need them; and designing and providing dedicated support to people with rare diseases, their care-givers and their healthcare professionals at every step of their journey. The ECRD is a unique meeting that brings together key stakeholders from across Europe, most of whom share a similar ambition to ours at Shire. We recognise the value of being part of the discussion that explores initiatives intended to make a difference to the people with rare diseases.

How are you involved in the program?

I have been invited to present on the innovative 'Game Changing' collaborations between industry and patient organisations session on Saturday. I will be sharing details on how we worked successfully with the HAEi patient organisation on a global initiative to make a difference in patient identification and diagnosis. Hartmann Wellhoefer, Shire's Head of Medical Affairs LSD/HAE who will also be joining the panel during Game Changers in Diagnosis and Emmanuel Chantelot, Shire's Head of International Government Relations and Public Affairs who will be representing the IFPMA during the Rare diseases Going Global session. We are pleased that we can be part of these important discussions and will have an opportunity to share our experience with the wider community

What do Shire hope to take forward from the meeting?

The theme of *Game Changers in Rare Diseases* really resonates with Shire. Two decades of continually striving to understand the needs of people with rare diseases has taught us that our work doesn't just stop with providing treatments. Through collaboration, partnerships and acquisitions, we work to push the boundaries of what is possible. The programme EURORDIS has put together with so many experts in their respective field of rare diseases will allow us to share and learn in a progressive environment. Ultimately this will enrich our knowledge, strengthen partnerships and will ultimately contribute towards improving the lives of people with a rare disease. We are grateful EURORDIS are organising the ECRD and providing this platform to engage with those invested in supporting the rare disease community.

