RE(ACT)Congress: breaking new ground in research disease research
By Nick Sireau

Interest in rare diseases is growing, with scientists across the world uncovering new genes, genetic associations and diseases nearly on a weekly basis. Nowhere is this more apparent than at the RE(ACT)Congress on Research into Rare and Orphan Diseases taking place this week, in Basel, Switzerland.

The brainchild of rare disease researcher and advocate Dr Olivier Menzel, RE(ACT)Congress has attracted hundreds of top scientists to attend a packed programme of ground-breaking research. From provocative discussions on 'how predictive is our DNA?' to the latest advances in whole exome sequencing for rare diseases, novel treatment strategies for muscular dystrophy, and rare and common genetic risk factors in neuropsychiatric disorders, the topics are varied and engaging.

This is the second RE(ACT)Congress. The first one was two years ago – also on the Novartis Campus in Basel – and was the first conference focusing exclusively on rare disease research that I'd come across. Yet the benefits go beyond hearing about the latest research.

Two years ago, after I gave a short presentation at the RE(ACT)Congress on our plans for treating Black Bone Disease (AKU), a researcher from Munich, Prof André Brandli, came up to me. He asked if he could collaborate with us on developing a tadpole model of AKU, which could then be used for developing new treatments for AKU.

Two years later, André is back at the congress, with a poster about his AKU tadpole model, and is part of a consortium we are putting together to develop new therapies for AKU. Similarly, while two years ago I was presenting our plans for a National AKU Centre and a clinical trial, this year our lead clinician and investigator, Prof Ranganath, presented on how these plans have become reality.

All this is thanks to Olivier, his team and collaborators, who realised that scientists working on rare diseases needed a place where they can meet and exchange ideas.

Now he's taken that one step further by setting up the RE(ACT) Community, the first ever digital platform and network where people can share information and boost research into rare diseases. This is hugely exciting and answers a massive need in the rare disease community for an efficient way to build collaborations on particular diseases and therapies.

The idea behind this is to provide a space where researchers and patient groups can learn from each other and support new projects. Until now, patient groups had to attend as many conferences as possible in the hope of meeting the right people who would be interested in their disease. With the online RE(ACT) Community, we have a much more systematic way of building our networks. This will save time and money and enable us to develop treatments for rare diseases much faster.

The website is www.react-community.org. Please sign up and share widely! It has a crowdfunding facility – so please use it to raise funds for your projects.