

Rubella Network

Joff McGill, the new leader of the Rubella Network reports:

The Rubella Network featured strongly at the European Conference in Lille. A well-attended workshop on 'Remembering the Past to Understand the Future' cast its eye to history reflecting on the impact rubella has had on individuals, and cast its eye to the future, considering the work still to be done. The issues that emerged from the participants included the experience for individuals with CRS as they age and experience on-going health problems, and the challenges of protecting against rubella and preventing CRS around the world.

Later in the week over 20 people attended a meeting of the Rubella Network. The meeting was an informal chance to meet each other, find out the issues we are all interested in and begin to sketch out some priorities for the network.

Participants included practitioners working with children with CRS, pioneering parents from the early days who are still providing leadership in the field of rare syndromes, a variety of professionals working with adults who are wishing to generate new knowledge and develop staff skills, and organisations who are working in countries where there is an epidemic of rubella happening every year.

Jude Nicholas commented on renewed interest in the life long symptoms of individuals with CRS and the on-going health problems they experience. He reflected that what we are studying and learning about rubella now will be important for other conditions in the future, such as CHARGE, CMV and toxoplasmosis.

A number of people were looking for support and knowledge around their work with children, and the meeting reflected that not only were staff across Europe still working with children who have CRS, including in parts of Southern Italy where there have been a number of births in recent years, but that in parts of the world without immunisation (e.g. Africa, parts of Asia), staff and schools and families will be seeking knowledge about how CRS impacts on a person's learning and development.

Led by Henri Faivre the meeting talked about the opportunities that are needed for people with CRS as they age, the services they will require and the health problems they may experience. Building on this them, a number of researchers – including Stan Munroe, Trees van Nunen, Anneke Schoenmaker and Saskia Damen for example, talked about studies done in Canada and Europe that looked at the experience of individuals with CRS and their families. Is it time to re-look at some of this work, update it, or write up data that has continued to be collected.

And participants agreed that Dbl has a role to play in helping people tell the story of rubella and the impact it has on individuals and families, as part of on-going work that is needed throughout the world to strengthen, and in some cases introduce, immunisation programmes. As individuals and organisations around the world we need to lobby for the resources that are needed for the World Health Organisation to meet its goals of reducing and eliminating rubella, and we need to help build the evidence Governments need to commit to immunisation programmes.

Rubella remains a vitally important public health challenge in many parts of the world. In 1961 Peggy Freeman introduced a conference on rubella in the UK with the words 'Prevention must be our aim'. She pioneered much of the work that has followed, and I have no doubt would celebrate the progress we have made, but she would also gently remind us there is much work to be done.

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