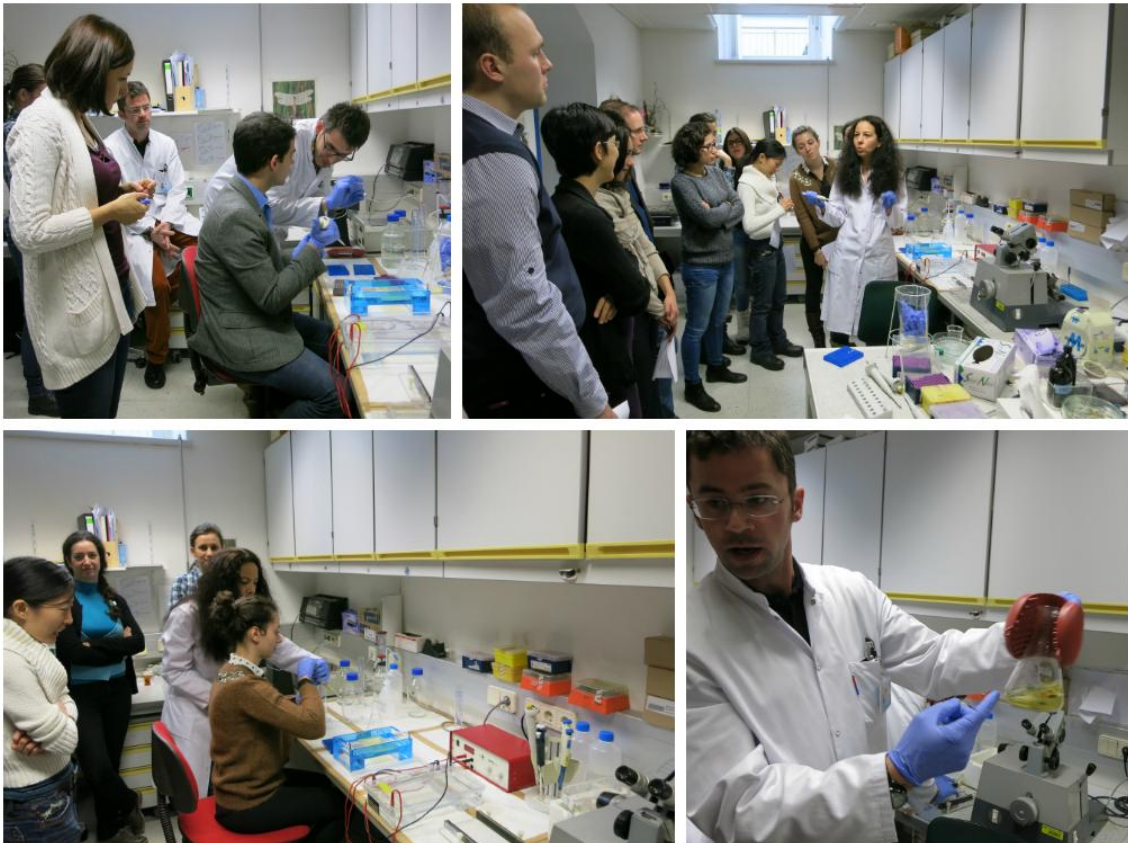


Protocol Winter School of Genodermatoses 2014

The 4th trainee course on genodermatoses of the “Fostering Dermatology and Venereology” series took place from 13-14 January 2014 in Innsbruck, Austria. This course was organized by Dr. Matthias Schmuth and Dr. Johann Bauer, chairs of dermatology in Innsbruck and Salzburg, Austria, respectively.

The genodermatoses course program is designed to introduce trainees in the increasingly important role of genetics and genomics in dermatology. Teaching is provided by a diverse faculty consisting of dermatologists, geneticists and pediatricians to reflect the interdisciplinary approach necessary to best care for patients with genodermatosis. The course includes both lectures and hands-on laboratory sessions for all participants.



Many participants commented that the laboratory part was an eye opening experience, which greatly helped them to truly grasp the nature of the diagnostic process involved in identifying gene mutations in genodermatoses.

Because patient empowerment is very important for successfully managing patients with rare genodermatoses, a highlight of this course was the participation of the patient support group. Pachyonychia congenita (PC) project sent patients together with an expert physician, Dr. David Hansen (University of Utah) from the medical advisory board to teach the residents about this rare condition. The participants of the course

unanimously stated that seeing life patients during this course made a tremendous impression and they would never forget this particular disease. There was also time for social interaction, not only for networking among the residents from 10 different countries, but also with the patients affected by pachyonychia congenita who were invited by the EADV to join the social activities.

Genodermatoses are rare diseases („orphan diseases“) with less than 1 in 2.000 people affected among the general population. Genodermatoses can be debilitating, severely affect the quality of life, and they may affect other organ systems. Without treatment, they often result in reduced life expectancy. Although individual entities are rare, the sum of all patients with genodermatoses represents a considerable number of patients who need specialty care. Thus, it is of major importance to teach the residents of our specialty about these conditions requiring specific care due to the difficulty in establishing a diagnosis, to prevent complications and/or to set up treatments. In the field of rare diseases, it is important to share and transmit this expertise where it is lacking, for example through EADV training courses.

In 2015 the course will take place in Salzburg in January.