

NEWSLETTER

JULY 2021

The ERN Exchange Programme was designed to share knowledge and stimulate collaboration between healthcare professionals in the European Reference Networks (ERNs). In this newsletter, we will give you an update on where we stand and provide information about the EU Digital COVID Certificate that will greatly facilitate implementation of the programme. We will also give an impression of the first exchange visits that are taking place.

Do you have any updates to share? Please send your contribution to ERNexchange@ecorys.com.



The ERN Exchange Programme takes off!

While the ERN Exchange Programme for the ERNs has suffered delay from the COVID-19 pandemic, it is taking off now. Steadily increasing vaccination rates and the introduction of the EU Digital COVID Certificate per 1 July 2021, facilitate free and safe travelling within the EU. In fact, the first exchange visits are already taking place! This is splendid news for all professionals and patients, who cooperate in the ERNs to improve diagnosis and treatment of rare diseases and collectively develop more knowledge.

In the past months, the ERN Coordinators and Project Managers have all made preparations for the ERN Exchange Programme. Information was collected on exchange needs among professionals, decisions were made on how the exchanges can optimally serve the network's objectives, and professionals with an exchange need were matched to hosting centres that can provide the requested

knowledge, expertise or facilities. The fruit of these efforts can be harvested now: in the next 16 months, over 1,000 exchange packages (each package equals a 5-day visit) will be utilized for professional encounters in all 24 ERN's!



Source: Flyer on EUDCC final, European Commission

EU Digital COVID Certificate

As of 1 July 2021, the EU Digital COVID Certificate became available and will be accepted in ALL EU Member States. It allows safe and free movement of citizens in the EU during the COVID-19 pandemic. You will find all information on the Certificate in **the flyers (see below)**. The website reopen.europa.eu/en offers the possibility to prepare your trip to the Member State you would like to travel to, by checking the measures in place, vaccines and tests accepted. Please note that in the unanticipated event of a cancellation due to new COVID outbreaks, **your package will not be lost and can be used at a later moment.**



First exchanges on rare kidney disease

The European Rare Kidney disease Network (**ERKNet**) took the honour of organizing the first exchange visit in the context of the ERN Exchange Programme. In the last week of June, two junior doctors, a nephrologist and a resident, from the Azienda Ospedaliera Papa Giovanni XXIII hospital in Bergamo, travelled to the Necker-Enfants Malades University Hospital in Paris for a two-week visit. The nephrologist attended activities of the ward and the outpatient clinics in order to improve experience in the diagnosis and treatment of nephrotic syndrome and complement disorders. The resident doctor engaged in knowledge sharing on genetic counselling and molecular pre- and post-natal testing as well as paediatric kidney transplantation. Please read about their experiences.

"Participating in the ERKNet Exchange Programme has been one of the best decisions I could have ever made for my education in pediatric nephrology. Since I started my residency program, I knew it was a renowned referral centre for both adults and pediatric kidney diseases, with a focus on rare kidney disorders.

I found an excellent and incredibly competent staff here, which involved me with passion in all their activities. I was involved in several multidisciplinary meetings, many frontal lectures regarding the last guidelines and the best approach to the pediatric nephrologic patient, and very interesting and educational consultations.

I had the unique opportunity to visit a huge number of pediatric patients affected by

extremely rare diseases that now I can recognize and manage.

I believe that it is a challenging experience since the visitor has to face a very different reality and organisation, but I am firmly convinced that sharing knowledge and be exposed to a diverse and stimulating scientific environment is exactly the strong point of this program.

Indeed, I am now more curious, eager to learn and open-minded. I strongly believe that all of these are qualities that a good doctor should always have."

In July, a group of four professionals – a senior and a junior nephrologist, a senior nurse and a junior nurse all specialized (or specializing) in paediatric nephrology – of the Necker-Enfants Malades University Hospital in Paris will travel together to the University Hospital of Heidelberg in Germany. They will work with their German colleagues on the comparison of clinical practice, personalised immunosuppressive therapy before and after transplantation, exchange practices before and after transplantation, peritoneal dialysis in children and diagnosis and treatment of glomerulopathies in large centres.

ERKNet has prepared three more exchange visits between hospitals in different Member States. Participants, the hosting centers and contents of the visits have been arranged. Specific dates of the exchanges will be set soon now that COVID-related travel restrictions will diminish.

"The ERKNet exchange visit in Necker is being an inspiring experience as I am having the chance to see a different working approach and to deal with very complex cases. This centre stands out for its great educational offer and for the great amount of rare diseases. I had the chance to visit different patients with extremely rare diseases and to discuss the diagnostic and therapeutic algorithms that are constantly evolving with experienced colleagues. I would suggest this exchange visit to anyone interested in expanding their point of view on rare diseases."



Consult the FAQ

For further information, we refer to the flyer and FAQ. If you have additional questions, please contact us via ERNexchange@ecorys.com.



Exchanges in preparation

The ERN for rare and complex urogenital diseases and conditions, eUROGEN, proposed 8 professionals' exchanges, between hospitals in 9 European countries. Here too, all arrangements have been made and only the dates have to be agreed upon.

ERN RARE LIVER has everything set for two exchange travels, where doctors of the Radboud University Medical Centre will go to the Medical University Centre of Warsaw, to work with their Polish colleagues on health-related quality of life in rare liver diseases.

The first exchange visit of **ERN ITHACA**, the Network for highly specialized, multidisciplinary

healthcare for patients with rare (multiple) malformation syndromes and rare intellectual and other neurodevelopmental disorders of genetic, genomic/chromosomal or environmental origin, will take place in September 2021. A French junior doctor gets the opportunity to spend a week at the Genetics Center of the University Hospital Leuven and share knowledge on the organisation of diagnostic and clinical pathways and discuss a collaborative project.

In the Network on rare endocrine conditions, **Endo-ERN**, a collaborative exchange will take place between the medical doctors of the Karolinska University Hospital from Stockholm and Ghent University Hospital. In the context of a project on disorder of sexual development, they will investigate joint case series of their archives to increase knowledge of this rare disease on pathological and genetical bases and develop a permanent platform for knowledge exchange.

To further facilitate professional exchanges within the Network, **Endo-ERN** and **ERN EYE** have also prepared exchange "offers". Hospitals with special expertise or facilities deemed of interest to their ERN colleagues, have prepared a programme for visitors. These offers are communicated throughout the Network. Professionals that are interested, can register to participate.

It is exciting to see the kick-off of the ERN Exchange Programme, now that travelling between the Member States is possible again. We hope and expect to see many more exchange visits of all ERNs in the coming months.



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