

NEWSLETTER

NOVEMBER 2021

The ERN Exchange Programme is designed to share knowledge and stimulate collaboration between healthcare professionals in the European Reference Networks (ERNs). The first visits have taken place and many ERNs are now actively planning exchanges so their network can fully benefit of the opportunities provided by the European Commission. In this newsletter, we will give you an update on the current state of affairs and provide some examples of different modalities of exchanges developed by ERNs.

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

Many exchanges on the roll!

The number of exchanges is rapidly growing! The first edition of the Programme had a slow start due to the travel restrictions and heightened workload for healthcare professionals in the context of the Covid-19 pandemic. Since progressive vaccination rates and the arrival of the EU Digital COVID Certificate make travelling possible again, we see the number of planned exchanges rising. Many ERNs are preparing exchanges, and the first visits actually took place. The overview below shows to what extent each ERN has prepared or implemented exchange visits per end of October (as % of the total number of packages). We see the numbers going up every day!

ERN	Planned/used as % of total available
PaedCan	100%
RND	73%
EUROBLOODNET	55%
ERKNet	41%
RITA	38%
VASCERN	32%
eUROGEN	26%
EpiCARE	25%
CRANIO	24%
TRANSPLANT CHILD	21%
ITHACA	20%
GUARD HEART	18%
RARE-LIVER	11%
ENDO ERN	11%
EURACAN	9%
ERN Euro-NMD	7%
EYE	7%
GENTURIS	6%
SKIN	5%

Figure 1: overview of planned/used packages per ERN (per end of October 2021)



Vytis Kazlauskas, participant of an exchange from eUROGEN:

“It was a great opportunity to visit one of the ERN centers which is actively involved in the management of scientific research of rare diseases. The purpose of my visit was to improve my experience in the understanding and management of urogenital diseases by visiting another ERN center which has not only a great clinical experience in pediatric urology but also its own scientific point of view to the number of urogenital problems based on their original research. I am also glad to announce that I have finally met the main researchers of the AGORA project and discussed my further involvement in it. We could share our experience in the management of urogenital diseases. For me personally it was useful to see how the patient follow-up and treatment is organized in another ERN. It was also interesting to finally meet the people whom I have known from virtual conversations, but never seen them eye to eye before.”



Various modalities to organise exchanges

There are various ways to organise exchanges. If you examine the exchanges that are being organised up until now, we can divide them in three categories.

1. Clinical exchanges

Most of the exchanges up until now are clinical exchanges: one or two health care professionals go on an exchange to learn clinical skills. The first visitors submitted the evaluation of their exchange visit and these preliminary results are very positive. Visitors mostly value the following results:

- Gaining more specialised knowledge on rare diseases;
- Seeing considerably more patients with a rare disease than would have been possible in their own hospital;
- The opportunity to contribute to the treatment of complex cases;
- Meeting in person with colleagues in the ERN.

The visitors consider that the exchange visit will strengthen their ERN in the following ways:

- Increased compliance to medical guidelines for the disease(s) treated;
- Better diagnosis and patient care;
- Increased incorporation of patients' perspectives in treatment decisions;
- Diminishing disparities in knowledge and expertise among hospitals in the ERN.

2. Exchange offers in collaboration with specialised member HCP's

Another way of organising exchanges is to compile a programme concerning clinical programmes, that are important for every ERN member. Some examples are:

- **ERN EuroBloodNet** has developed an Exchange Programme focused on Sickle Cell Disease (SCD). Building on the opportunities offered by the ERN Exchange Programme, EuroBloodnet developed a Preceptorship programme on SCD with the objectives to **train medical residents in**

haematology in order to improve the speed and the efficiency of patients' care.

Specific objectives of the programme are to inform young physicians about the effective possibility for a RHD patient to be followed in high quality health services in Europe, to foster cross-border collaborations between ERN HCPs, to promote the best practices in diagnosis and safe clinical care, and to give students through an accredited programme an opportunity for broad experience and clinical training. Four HCP's have been selected as Preceptorship Sites. Each HCP has elaborated a detailed programme composed of sessions with different modalities such formal lectures, informal discussion, case study discussion, direct tutorial clinical activity and meetings with patients and their family. Preceptorships are carried out on HCPs sites that are centres of excellence in the ERN-EuroBloodNet and they are coordinated by ERN-EuroBloodNet experts. Preceptorships are open for 5 to 10 participants per host centre. A call for participants will be launched among ERN-EuroBloodNet members and candidates will be chosen by a jury according to: CV+ cover letter + Cross Border Health collaboration needs + follow-up with education projects and activities on medical education.

- **Endo-ERN and ERN EYE** developed a similar initiative. Both ERNs prepared exchange offers to facilitate professional exchanges within the Network. For this purpose, member HCP's 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.

3. Exchanges to strengthen multidisciplinary teams

A third variant of exchanges that are being organised by ERN's are collective exchanges to strengthen a multidisciplinary team in a HCP. These kind of collective exchanges contribute to improving processes and skills on various levels of expertise within a team.

An example of this type of exchange is organised by ERN SKIN. ERN SKIN has chosen to organise an exchange for three professionals: a senior dermatologist, junior dermatologist and a nurse from the dermatology department.

The goals of their exchange are:

- Improving management of patients with special skin disease;
- Improving organisation and skills of the multidisciplinary team;

- Creating strong links between HCP's of two different European countries;
- Participating in a better integration of affiliated partners within ERN SKIN activities.

This classification of types of exchanges are only to inspire ERNs in organising exchanges and is definitely not limited. Most important is that an exchange facilitates knowledge sharing and stimulates collaboration.



Ana Misir Krpan, participant of an exchange from EURACAN:

"My visit to the Neuroncology Unit, IRCCS Regina Elena Cancer Institute in Rome was an excellent and very useful experience. From the first contact and throughout the whole organization, everything worked very simply.

As an associate and relatively new member of EURACAN the goal of my trip was to create a network of contacts, meet the EURACAN representative for Domain 10 and the general representative for oncology and see what their role is, what they do, how they keep patient records, how they participate in projects, etc.

It was extremely useful to meet other colleagues and to create a network of contacts and see the differences and similarities in the daily work. The basic settings of treatment as part of evidence-based medicine are very similar to those in Croatia, but there are some minor differences. The most interesting part of the visit was the home-care system of palliative care of a neuro-oncology patient."



Exchanges offer an "invaluable experience"

SKIN organized an exchange visit from 13 to 18 September 2021. 3 dermatology specialists (1 junior, 2 seniors) from the Children's Clinical University Hospital in Riga went on an exchange visit to Ospedale Pediatrico Bambino Gesù in Rome. Purpose of their visit was to improve management of patients with epidermolysis bullosa, improve the organisation and skills of multidisciplinary teams and to create connections. The participants experienced their visit as an invaluable experience.



Gerda Petersone, participant of the SKIN exchange:

"We just came back from a visit in Ospedale Pediatrico Bambino Gesù in Roma, Italy. The purpose of this visit was to improve both our theoretical and practical knowledge about different types of Epidermolysis Bullosa (EB), the diagnostics and multidisciplinary team approach in the management of these patients. Under the leadership of Prof. Maya El Hachem we saw several types of EB patients, participated in all the daily procedures of the clinic (for example, consultations with different specialists, screening, taking care of the wounds, diagnostics etc). We also had the opportunity to meet different specialists (pathologist, pain specialist, paediatrician,

neonatologist, nurses, dentist, endoscopist, nutritionist, radiologist) and discuss the actualities in the field. We all agreed that this week spent in the clinic gave us invaluable experience for us as practicing clinicians. It was fascinating to see the great empathy and attitude in the work with the patients. We also would like to compliment the work management and logistics. Thanks to ERN Skin Exchange Programme, Prof. Maya El Hachem, Dr. Andrea Diociaiuti and all the team!"

Sanita Zigure, participant of the SKIN exchange:

"We received a very warm welcome. Doctors and nurses shared their experiences and gave useful advice. I was able to compare the knowledge gained in caring for patients in Latvia and compare how a patients meeting with counsellors is organised. It was a surprise for us that the work of nurses before the patient arrives is a good support for a quality patient examination.

Everything happens without haste, but thoroughly. Under the guidance of Professor Maya El Hachem, we saw different types of EB patients. The professor arranged an opportunity for us to meet with various specialists (pathologists, pain specialists, paediatrician, neonatologist, nurses, dentist, endoscopist, nutritionist, radiologist) and we were able to discuss current events in this field. We all say a big thank you for the week we spent at the clinic, it is an invaluable experience. We also want to compliment work management and logistics. Thank you ERN Skin Exchange Program, prof. Maya El Hachem, Dr. Andrea Diociaiuti and the whole team!"

It is great to see the ERN Exchange Programme has now really started off and the number of exchanges is rapidly growing, now that travelling between the Member States is possible again. 80% of the ERNs are now actively engaged. However, some ERNs have not proposed any visits yet. We hope and expect to see many more exchange visits of all ERNs in the coming months. At some point, remaining packages of ERNs with insufficient absorption capacity will be reallocated to other Networks. If you have ideas for exchanges that can benefit your network, please contact your coordinator. For further information, we refer to the flyer and FAQ . If you have additional questions, please contact us via ERNexchange@ecorys.com.



Consult the FAQ

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