

## From the coordinator

Dear reader,



I welcome you to the first newsletter issued by the new coordination team at the University Medical Centre Utrecht/Wilhelmina Children's Hospital. As the new coordinator I am honoured and delighted to lead a very much needed professional network for the wellbeing of patients across Europe.

Before I am bringing you the latest updates on the progress and activities of the RITA network, I would like to take this opportunity to thank the previous coordination team in Newcastle: Andrew Cant, Roz Scott and Lydia Tropper.

The handover from Newcastle was requested by the European Commission (due to Brexit negotiations).

Following the democratic vote by the RITA network Health Care Providers, I have been chosen as the new coordinator and will be leading the network the following three years. My team consists of a project manager and project secretary.

Previously I have been participating in the network as the lead for the Paediatric Rheumatology stream. This role is now fulfilled by Carine Wouters from the University Hospital Leuven.

Again, and also on behalf of the RITA network, I would like to thank Andrew Cant and his team and wish them the best of luck.

Nico Wulffraat

## RITA ACTIVITIES

### ■ RITA network will hold its annual meeting in 2020 in The Netherlands

In January 2020 a two-day RITA network meeting will be organised in Utrecht, The Netherlands. For the first time, representatives from all HCPs, working group chairs, patient representatives and CPMS staff will be invited to meet, share and network altogether. The overall objective will be working towards a stronger network and community as well as strengthening collaboration among all RITA network members.

### ■ June 2019: first board meeting under the new coordination team

On 26 June 2019, the first board meeting under the new coordination team took place at Schiphol Airport. Among the decisions, RITA board decided to involve four patient representatives on board, one per arm, so patients are strongly and consistently represented in the RITA network.

### ■ WEBSITE

The ERN-RITA website is in the process of being updated. One important new functionality will be an interactive map that can be consulted on specific diseases, related health care providers and contact details.

### ■ Patient Advocacy Group for RITA

RIPAG is the Patient Advocacy Group for RITA, the European Reference Network on Rare Immunodeficiencies (PID), Autoinflammatory disorders (AID) and Autoimmune diseases (AI). It represents the patient community for immune mediated diseases by participating in the ERN-RITA Working Groups, Council and Board. The mission of RIPAG is to safeguard the patient centric profile of the ERN RITA and contribute to the ERN RITA according to the critical roles patients and patient's organisations play, as experts by experience and co-producers of knowledge in all ERN activities.

[>>Learn more](#)

## FROM RITA DISEASE STREAMS

### ■ PIDs included in WHO List of Essential Diagnostic Tests

Primary immunodeficiency (PID) diagnostic tests have been included in the World Health Organization (WHO)'s Essential Diagnostics List (EDL) published by WHO on July 9, 2019. The inclusion of PID diagnostics tests follows a successful joint application by IPOPI and IUIS (International Union of Immunological Societies). RITA had granted its support to this application.

\*International Union of Immunology Societies

[>>Learn more](#)

[Visit website IPOPI Media](#)

### ■ Funding for the Kawasaki Disease clinical trial (KD-CAAP): Kawasaki Disease Coronary Artery Aneurysm Prevention trial.

The trial that had been prioritised by the ERN-RITA Research Working Group will be rolled out via the c4c national hubs, involving roughly 12 countries, and approximately 30 sites. Site selection will be done through the national c4c hubs. 262 patients will be recruited in 30 months and sites get open from April 2020 onward.

[>>Learn more](#)

[Visit website Connect4children](#)

### ■ Trinity College Dublin wins successful bid for coordination of European research network linking healthcare data for clinical benefit

HEalth data Linkage for ClinicAL benefit is a training network comprising 17 academic and 9 non-academic/industry partners for early stage researchers in the field of Healthcare Data Linkage in the GDPR era.

Using autoimmune vasculitis as a paradigm HELICAL will provide state of the art training in data analysis from large datasets for 15 PhD students.

[>>Learn more](#)

### ■ MERITA PROJECT: towards a RITA metadata registry

ERN RITA, under the coordination of its registries/biobanks Working Group, is preparing the grant application for the next European Commission call on ERNs registries.

Called MERITA, this project consists in a metadata registry whose general objective is to promote the interoperability of the RITA network registries so far identified.

The project will be funded by 3rd EU Health Programme of the European Commission.

## RITA NETWORK

### ■ New affiliated partners

RITA is very pleased to welcome new affiliated partners in its network. Three of them are from Austria (Graz, Vienna and Innsbruck) and the three others from the Baltic countries, Latvia, Estonia and Lithuania. More affiliate partners will follow.

### **What is an affiliated partner?**

An affiliated partner is an HCP that does not meet all criteria for full membership (ERN specific criteria or overall EC criteria). It establishes a link to the ERN networks for those countries which do not have a full member in a specific ERN thus addressing the concerns related to the geographic coverage of the Networks. Although it doesn't have the same rights and obligations as a full member, it can use CPMS for virtual consultations.

[>>Learn more](#)

### **How to become an affiliated partner?**

The ERN Board of Member States, governments and ERNs decide on the applications for HCPs willing to become an affiliated member.

## **ANNOUNCEMENT**

### **■ ERNs Full Members: new call**

September 2019 a new call for membership to the European Reference Networks will open. The European Commission launches the first call for new members to join the existing 24 ERNs.

[>>Learn more](#)

## **AGENDA**

### **■ 18-21 Sept. 2019, Brussels: ESID Focused Meeting on 'PID and Malignancy'**

The ESID 2019 Meeting in Brussels will be a unique meeting, focusing on the fascinating and important intertwinement between primary immunodeficiencies, infections and malignancy. Topics include PIDs with a well-known increased risk of malignancy, (such as DNA repair disorders, CVID, T cell deficiencies), the impact of viral infections on the development of malignancies, the immunology of the tumor microenvironment.

[>>Learn more](#)

### **■ 6-8 Nov. 2019, Madrid: IPIC2019, PID congress on diagnosis and clinical care by IPOPI**

The fourth IPIC congress programme, built with input from doctors, patients and key PID community stakeholders, focuses on diagnosis and clinical care of primary immunodeficiencies (PIDs). Don't miss out on your chance to benefit from this unique conference focused on diagnosis and clinical care of PIDs.

[>>Learn more](#)

### **■ 20-24 May 2020, Athens, 12th International Congress on Autoimmunity in Athens**

The International Congress on Autoimmunity is the largest multidisciplinary congress that discusses all aspects of the related diseases under one roof, offering courses and lectures by some of the world's most distinguished experts. At the same time, the Congress prides itself on providing a stage for young upcoming talents to present their research to a first-rate audience.

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