European Reference Network for Rare Immunodeficiency, AuToinflammatory and Autoimmune Diseases (ERN RITA)

RITA Members



- 1. Newcastle upon Tyne Hospitals NHS Foundation Trust
- UC Leuven, Belgium
- General University Hospital, Prague
- Hôpital Necker-Enfants malades, Paris
- 5. APHP Bicêtre Hospital, University of Paris
- 6. Cochin Hospital, Paris
- Strasbourg University Hospital, Strasbourg
- von Hauner Children's Hospital, LMU, Munich
- 9. Center for Chronic Immunodeficiency, Freiburg
- 10. University Children's Hospital, Münster 11. Istituto Giannina Gaslini, Genova
- 12. Ospedale San Raffaele, Milan 13. Ospedale Pediatrico Bambino Gesù, Roma
- 14. Policlinico San Matteo, Fondazione IRCCS, Pavia
- 15. University of Brescia
- 16. Erasmus MC, Rotterdam
- 17. Wilhelmina Children's Hospital, Utrecht
- 18. University Medical Center Groningen
- 19. University Medical Centre Ljubljana
- 20. University Hospital Vall d'Hebron, Barcelona
- 21. Karolinska University Hospital, Stockholm,
- 22. Great Ormond St. & Royal Free Hospital, London
- 23. Leeds Teaching Hospital NHS Trust
- 24. Behçets UK (London, Birmingham, Liverpool)



"From rare care to frequent cure"





RITA Network Board

Network Co-ordinator:

Prof Andrew Cant, Great North Children's Hospital Newcastle upon Tyne, United Kingdom

Network Manager:

Mrs Lydia Tropper, Dr. von Hauner Children's Hospital Munich, Germany

Immunodeficiencies:

Prof Christoph Klein, Dr. von Hauner Children's Hospital, Munich, Germany

Auto-Immunity:

Prof Mark Little, Tallaght Hospital, Dublin, Ireland

Auto-Inflammatory: Dr Marco Gattorno, IRCCS Istituto Giannina Gaslini, Italy

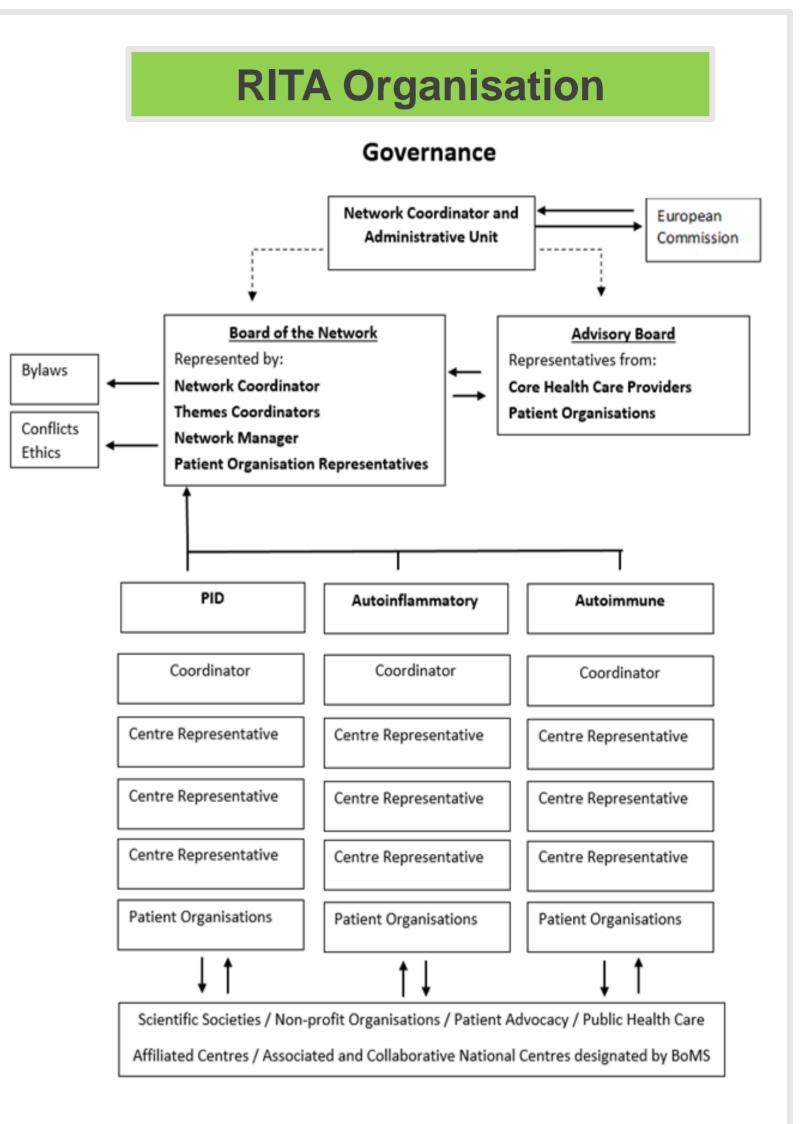
Rheumatology:

Prof Nico Wulffraat, Wilhemina Kinderziekenhuis, Utrecht, The Netherlands

Patient Organisations:

Mr Johan Prevot - International Patient Organisation for Primary Immunodeficiencies

Mr Richard West - Behçet's Intl Mr John Mills - Vasculitis Europe



RITA Mission & Vision

- Comprehensive clinical care for children and adults with rare Immunodeficiency, AuToinflammatory and Auto-Immune disorders
- Equal access to excellent expertise and care across Europe
- Sustainable alliances with European centres Improve diagnosis and therapy for children with rare immunodeficiency, auto-inflammatory and auto-immune disorders
- Train future leaders, securing international sustainability

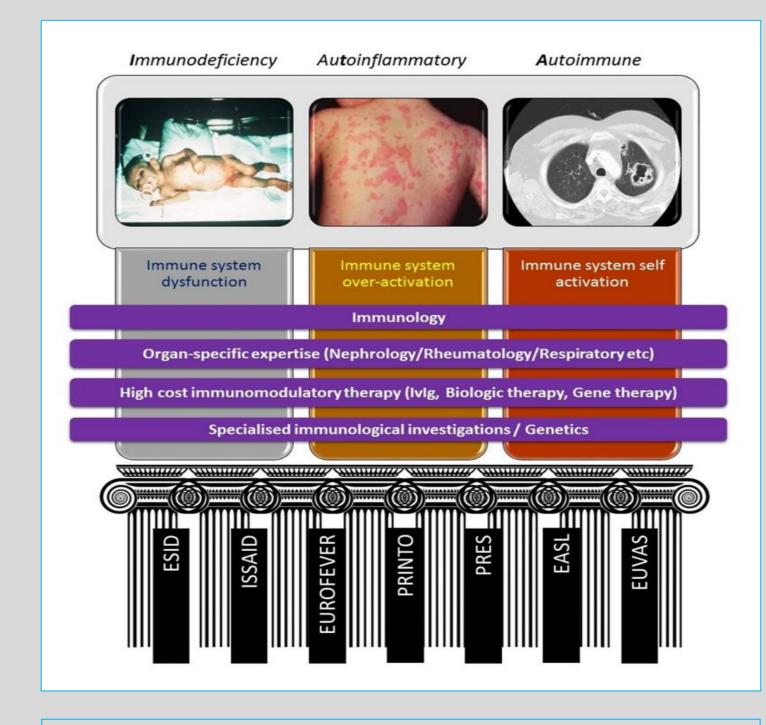
RITA Challenges

- **Getting the best from existing Networks**
- Clinic -> Lab -> Clinic
- Wide variation in centres and countries
- **Effective joined up registries Telemedicine that works**
- Meaningful patient involvement
- Accessible guidelines
- Equal access to molecular diagnostics
- **Coherent Clinical Care**
- Vibrant societies with registries
- Superb centres of excellence **Good networks and interactions - clinicians** and scientists
- Very good educational programmes

RITA Actions

- Case discussion platform; email; teleconsults
- Clinical guideline group Harmonise registries and biobanks
- **Molecular Testing taskforce RITA** education academy
- Pharmacovigilance for biologics **Prospective evaluation stem cell Rx**

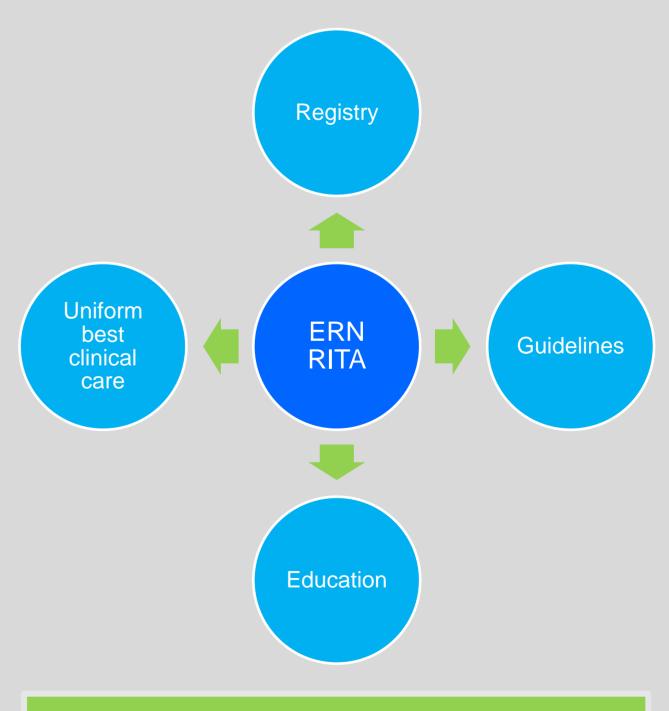
RITA Services



- Joint cross-border platform for rapid and correct diagnosis of rare immunological diseases: providing a means of navigating the directive (for patients and clinicians)
- Complementary services for all European member states (e.g. lymphoid PID Paris, innate immunity Munich, Stem cell transplant **Newcastle, European PID registry Freiburg)**
- Reduction of health-care cost (avoiding unnecessary diagnostics, avoiding wrong therapies, decreasing suffering of patients)
- Joint pan-European workforce/academy enabling education of clinical experts, sharing of best practice, knowledge transfer
- Facilitating networks of excellence for future translational science
- and development of immunological therapies Share registries- ESID, Eurofever, EUVAS, Pharmachild
- Legacy scientific / clinical organisations: ESID, EUVAS, PRES, **EUSTAR**, Myonet, EASL,
- Patient advocacy- IPOPI, Vasculitis UK, Behçet's International

RITA Goals

- Precision medicine
- Guidelines for diagnosis and therapy
- Cross-border telemedicine platforms Share clinical data
- Facilitate research activities
- European platform for subspecialty education



How to get there?

Collaborations: Clinicians, Scientists, Patients Registry based molecular, clinical & treatment studies RITA to raise standards & resources

Meeting & events that serve the exponential advances International collaborations









