

Reformed WPs

- The London Meeting (June 22, 2018)
- PReS Working Parties 2.0

The reformed WPs:

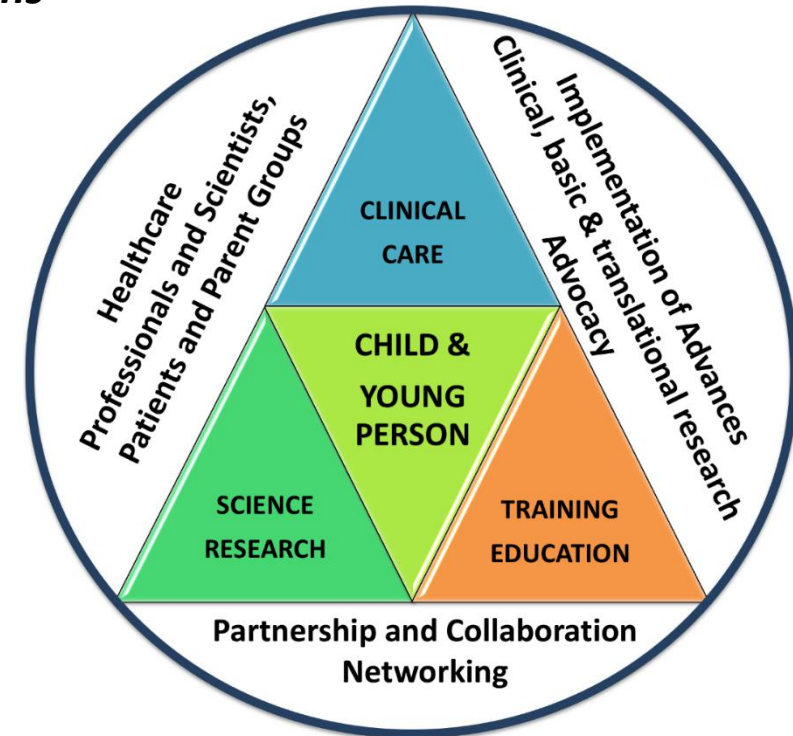
- Contribute to and advance the goals of PReS Mission
- Foster excellence in three PReS pillars (clinical care, science and research, and training and education)
- Proactively engage with EMERGE
- Chair for WP-



Athimalaipet Ramanan

PReS mission

“Dedicated to advance the care and improve the health and wellbeing of children and young people with rheumatic conditions”



Strenghts of WPs

- Forum for sharing knowledge (research) and best practices (clinical care)
- Forum for new ideas and initiatives
- Forum for developing/providing PRES-endorsed guidance/recommendations
- Foster collaboration
- Provide peer scientific advice and expertise
- Promote good clinical practice










Importance of WPs for young investigators

- Having the opportunity to get experience and be included in:
 - ❖ International research
 - ❖ Creation of guidelines
 - ❖ Organization of educational activities
 - ❖ Authorship of important publications
- Coming soon: PReS grants for research, supporting young investigator co-applicants



PReS WPs



	Autoinflammatory WP
	Imaging WP
	JDM WP
	MAS WP
	SLE WP
	Vaccination WP
	Uveitis WP
	Vasculitis WP
	Scleroderma WP

Autoinflammatory WP-1



Véronique Hentgen



Aim: To promote knowledge and international multidisciplinary collaboration among experts in the field of systemic autoinflammatory disorders (AID)

Contacts:

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- Federici Silvia (silvia.federici@opbg.net)
- Antonella Insalaco (antonella.insalaco@opbg.net)
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Autoinflammatory WP-2



Véronique Hentgen



JIR Winter School
Auto-inflammatory Disease

Switzerland, Villars
Friday 11th to Sunday 13th of January 2019



India, Mumbai
Friday 11th and Saturday 12th of January 2019



Education: JIR Winter School on AID;
www.jirws.org

Clinical affairs:

- Proposal for a common statement for the use of alternative tx in FMF

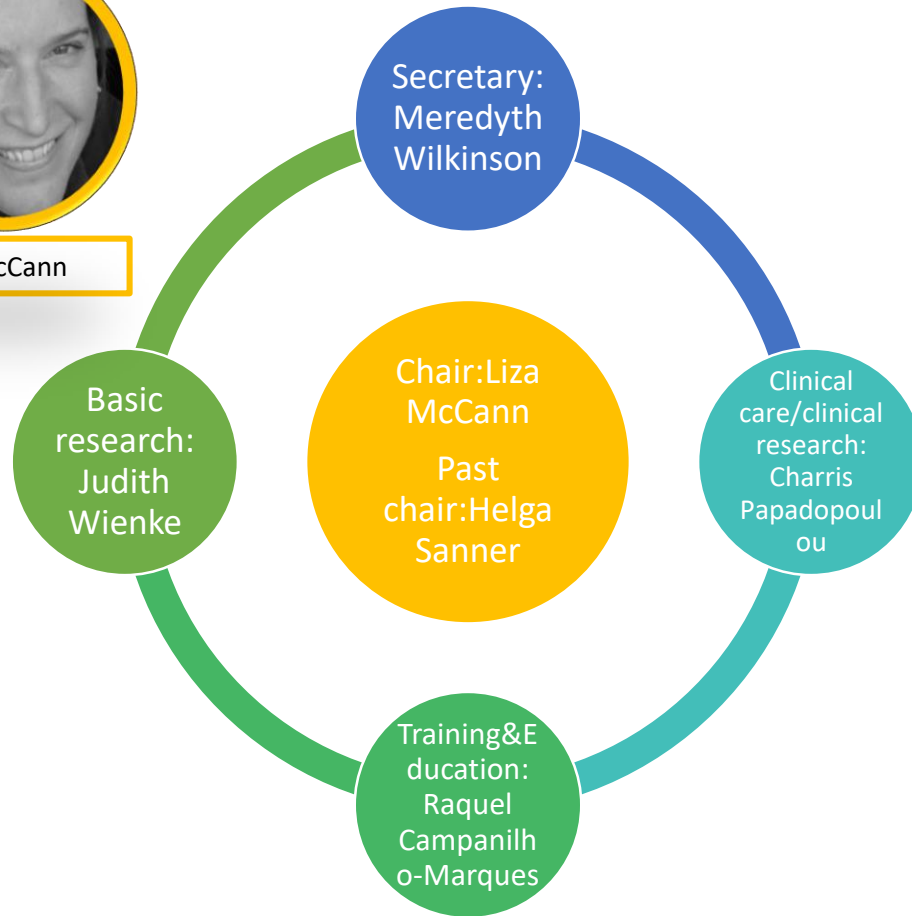
Ongoing projects:

- Validation of EUROFEVER criteria
- Activity score for AID
- Severity score and quality of life for AID

JDM WP-1



Lisa McCann

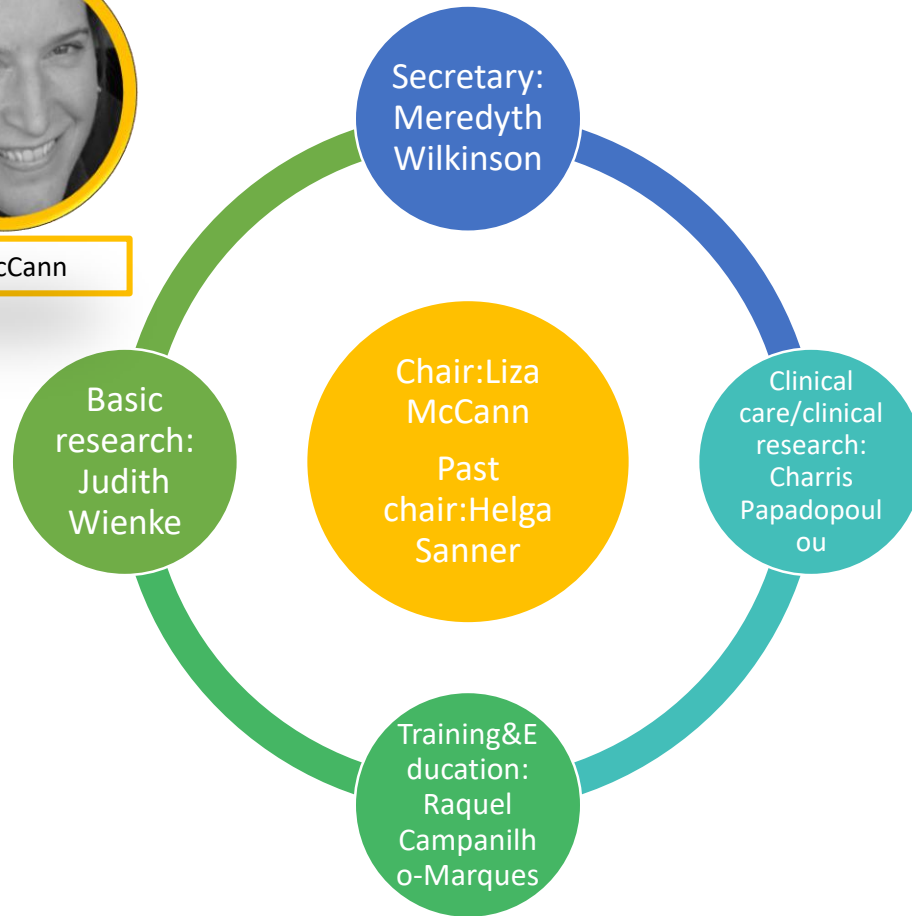


- **Aim:** To bring together clinicians and JDM researchers to formulate strategies to increase knowledge; hereby to facilitate research on outcome measures and clinical guidelines
- **Contacts:**
 - Helga Sanner
(helga.sanner@medisin.uio.no)
 - Charalampia Papadopolou
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JDM WP-2



Lisa McCann



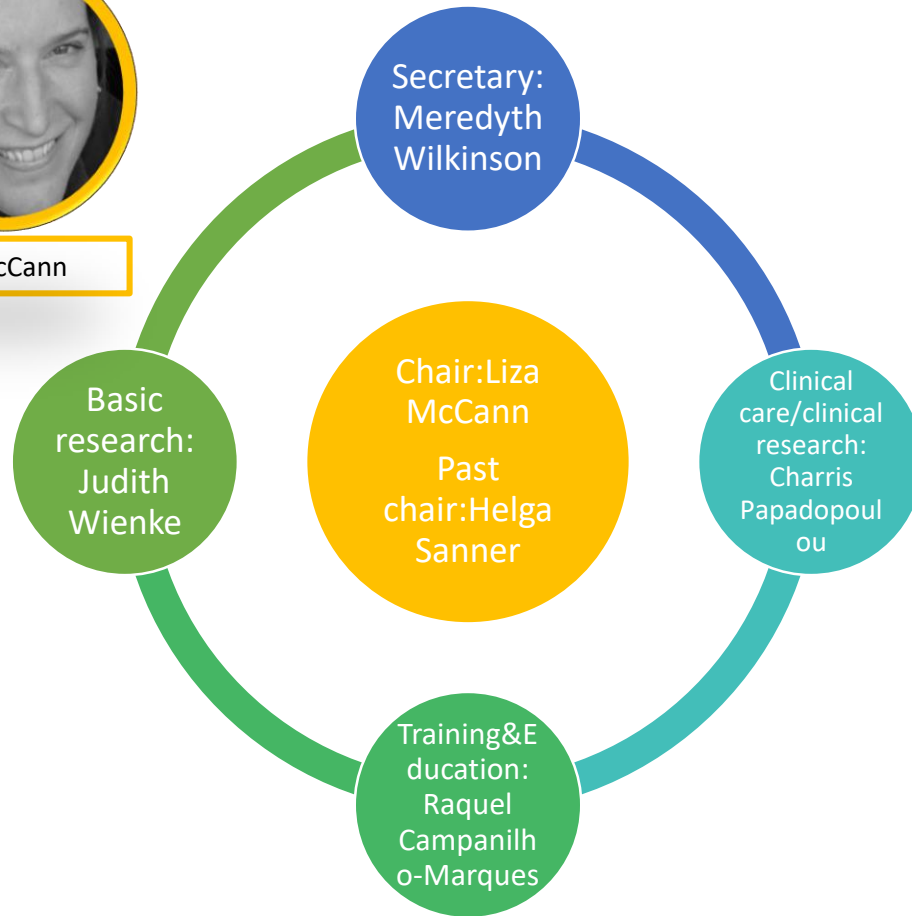
Projects achieved:

- Consensus Based Recommendations for the Management of Juvenile Dermatomyositis (SHARE recommendations) for diagnosis and treatment of JDM (Ann Rheum Dis. 2016)
- Criteria for Minimal, Moderate, and Major Clinical Response for Juvenile Dermatomyositis: An ACR/EULAR/IMACS/PRINTO Collaborative Initiative (A&R 2017)
- Development of a consensus core dataset in juvenile dermatomyositis for clinical use to inform research (ARD 2018)

JDM WP-3



Lisa McCann



- **Plans:**

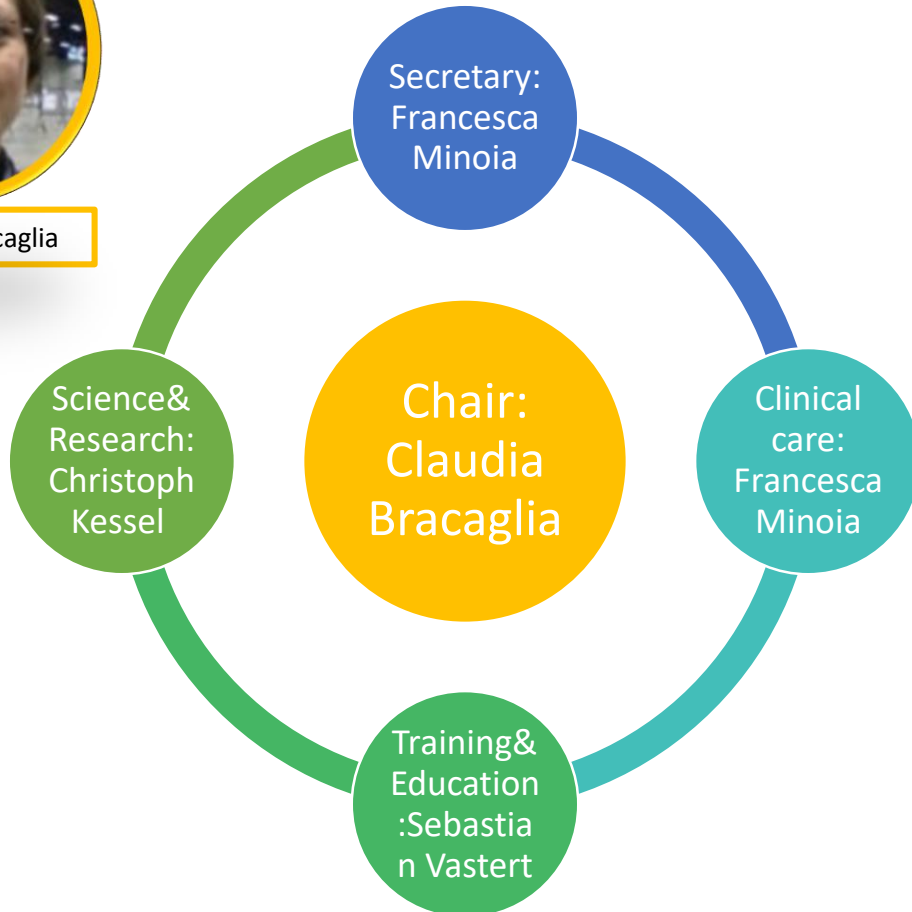
- Implementation of the SHARE recommendations

- Use of the Euromyositis database to facilitate collaboration within the WP

MAS WP-1



Claudia Bracaglia

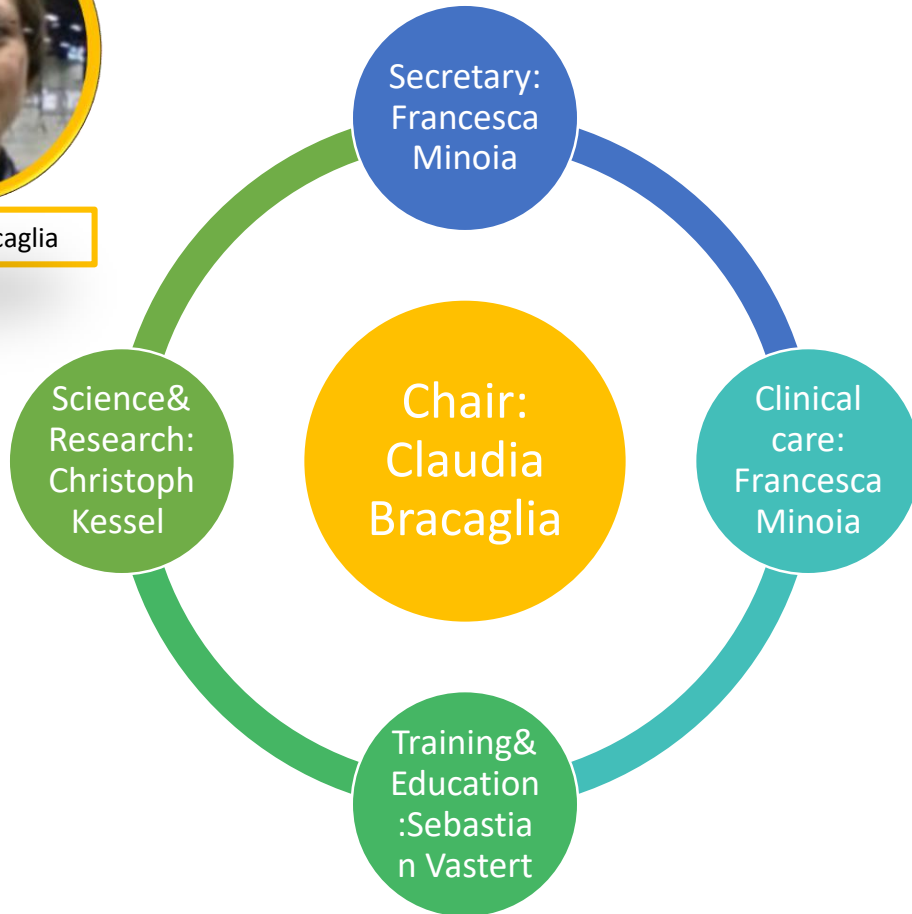


- **Aims:**
- to promote knowledge and international multidisciplinary collaboration among experts in the field of MAS
- to foster translational research in order to improve care and outcome of patients with MAS
- **Contacts:**
- Claudia Bracaglia (claudia.bracaglia@opbg.net)
- Francesca Minoia (francesca.minoia@policlinico.mi.it)
- Christoph Kessel (christoph.kessel@uni-muenster.de)
- Sebastian Vastert (b.vastert@umcutrecht.nl)

MAS WP-2



Claudia Bracaglia

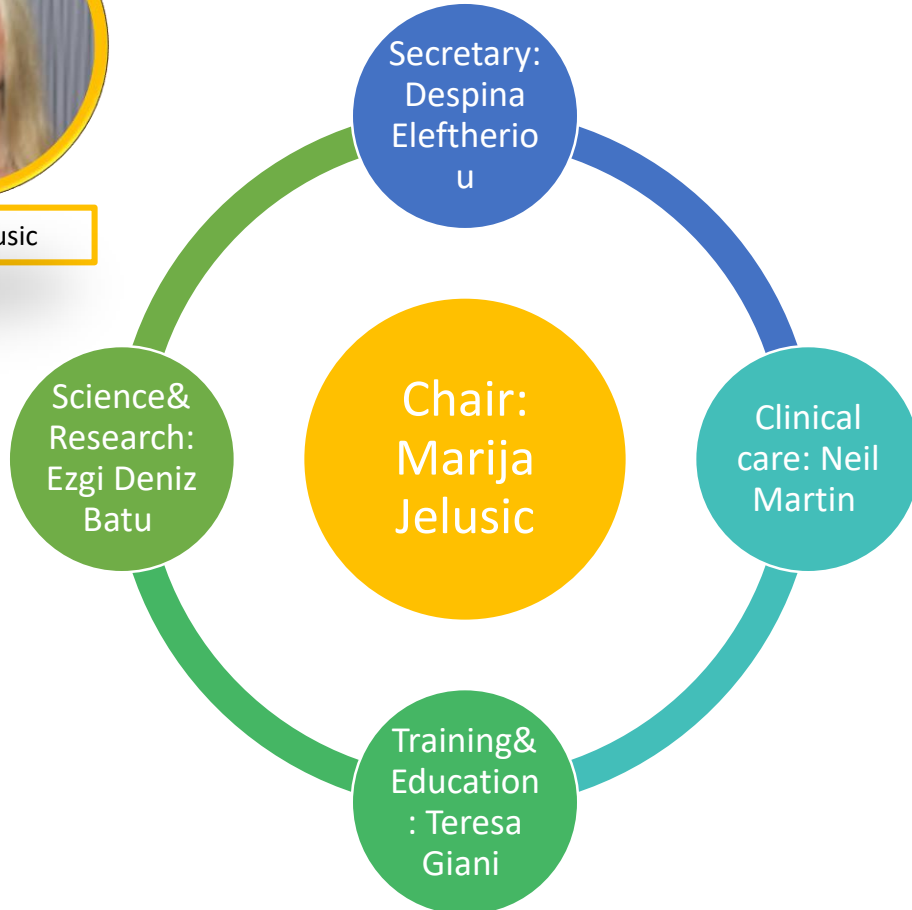


- **Ongoing projects:**
- New diagnostic criteria for primary HLH
- Validation of a risk score for MAS in sJIA patients
- Thrombotic microangiopathy in patients with MAS/sHLH

Vasculitis WP-1



Marija Jelusic

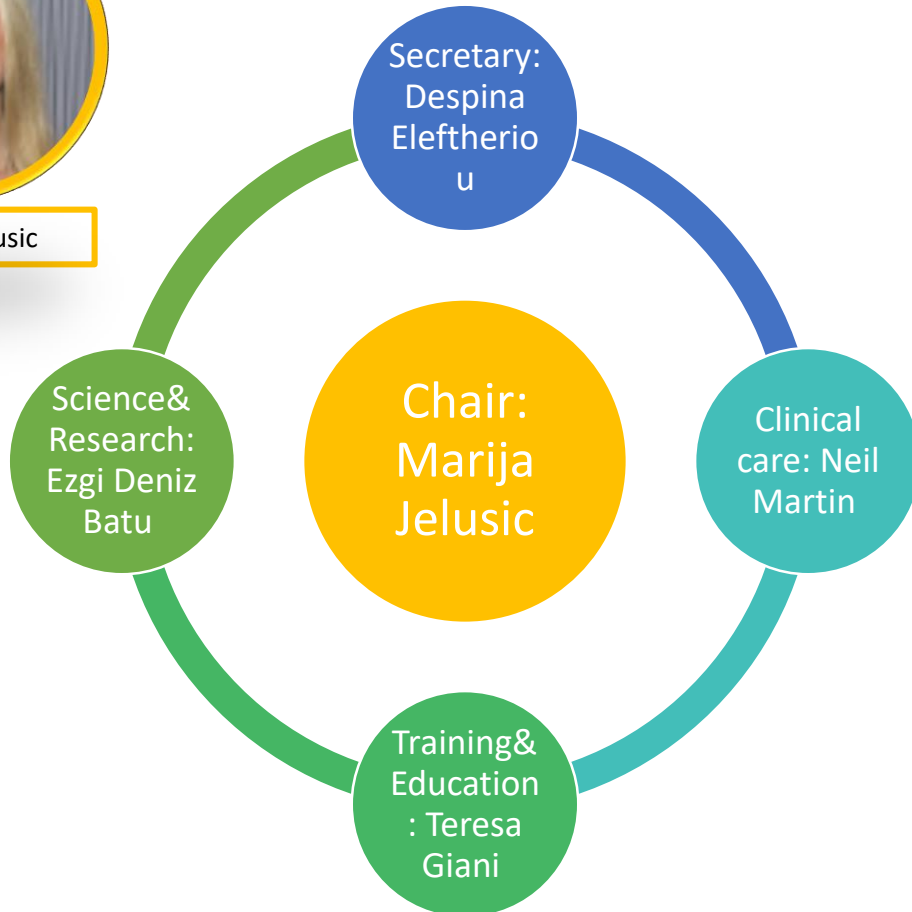


- **Aim:** To facilitate translational research in the field of vasculitis of the young
 - basic science with potential to improve patient care
 - molecular genetics
 - clinical trials (investigator led and industry sponsored)
 - clinical guidelines
- **Contacts:**
 - Marija Jelusic (marija.jelusic.drazic@gmail.com)
 - Despina Eleftheriou (d.eleftheriou@ucl.ac.uk)

Vasculitis WP-2



Marija Jelusic

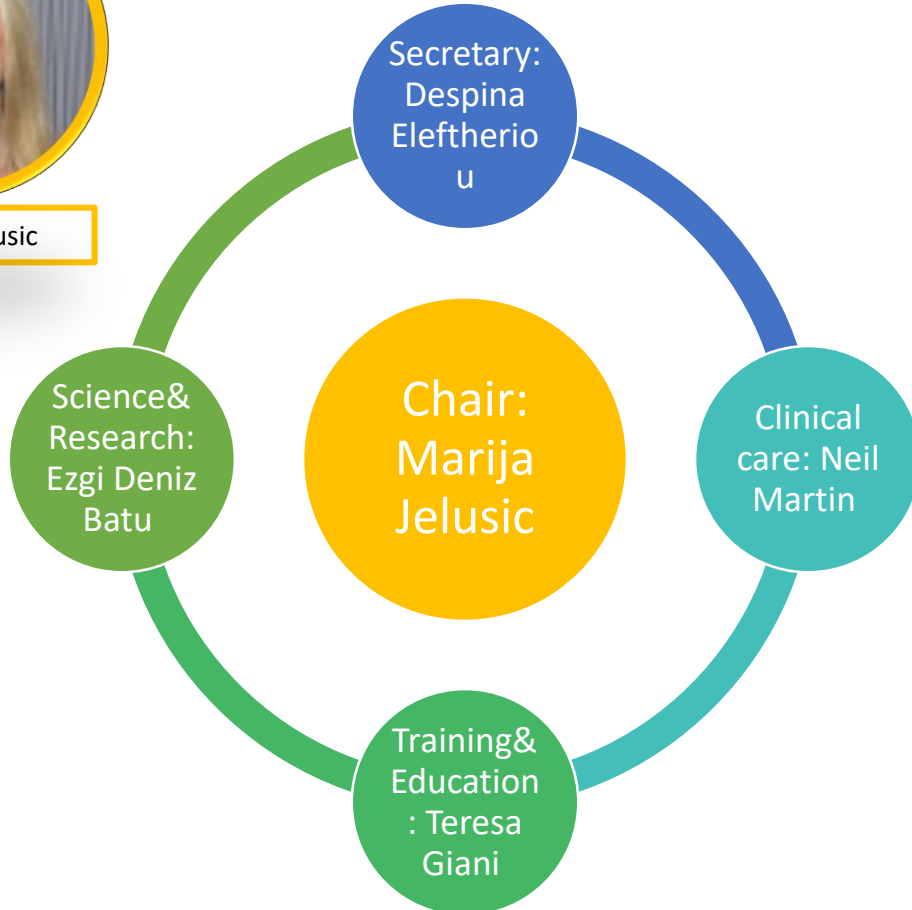


- **Ongoing projects:**
- Paediatric Vasculitis Damage Index (pVDI)
- Development and Validation of Juvenile VAsculitis Multidimensional Assessment Report (J-VAMAR)
- PEPRS "Pediatric polyangiitis rituximab study"
- MYPAN "An open label randomised controlled trial of mycophenolate mofetil versus cyclophosphamide for the induction of remission of childhood polyarteritis nodosa"
- VIP next generation sequencing panel

Vasculitis WP-3



Marija Jelusic

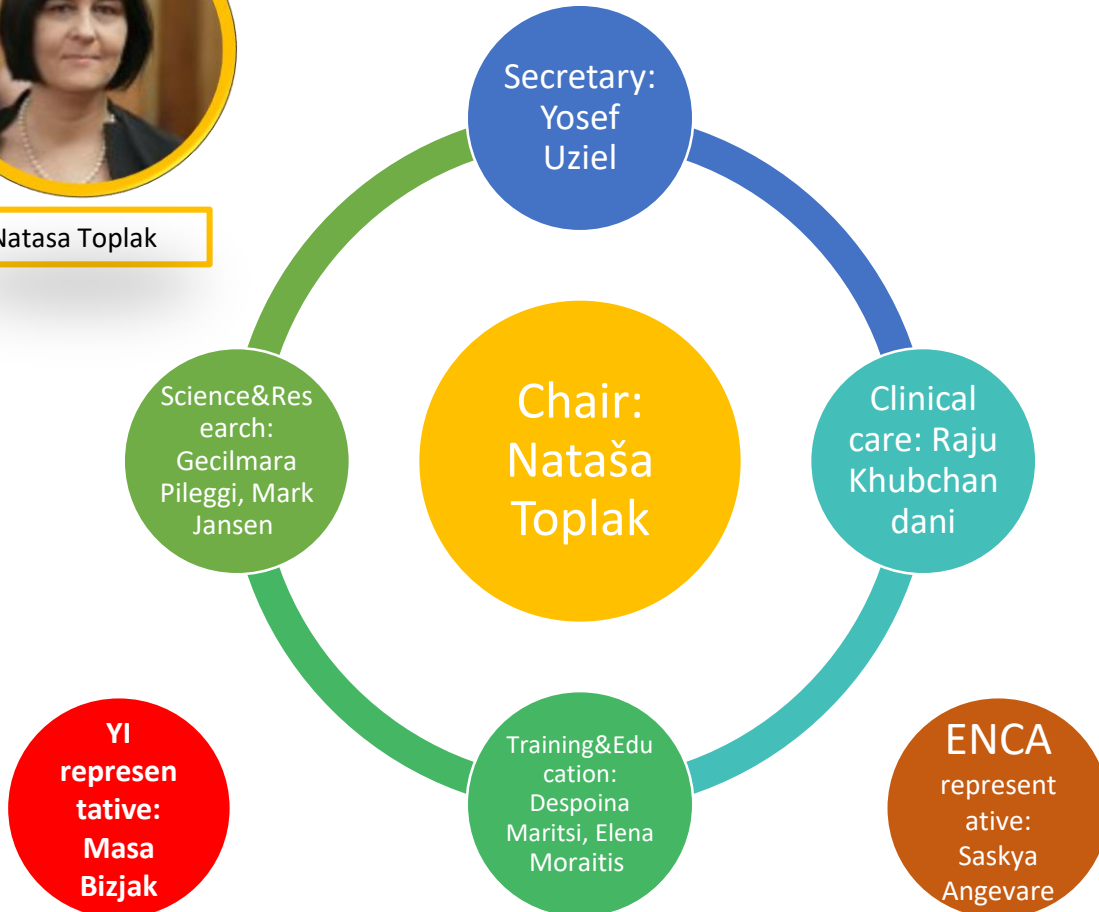


- **New trials:**
- KD-CAP (Kawasaki Disease Coronary aneurysm prevention) “Multi-centre, prospective, randomised, open-label, blinded end-point study of prednisolone plus intravenous immunoglobulin (IVIG) for prevention of coronary artery complications in acute Kawasaki disease”
- BIOVAS “A pragmatic, randomised, double-blind, placebo-controlled, modified-crossover trial of biologic therapy for refractory vasculitis in adults and children”
- Histological and clinical predictors of outcome in Henoch–Schönlein purpura nephritis
- New GPA criteria

Vaccination WP-1



Natasa Toplak



- **Aim:** to develop a platform for multicentre collaborations/ to provide high levels of evidence on vaccination recommendations for paediatric rheumatology patients

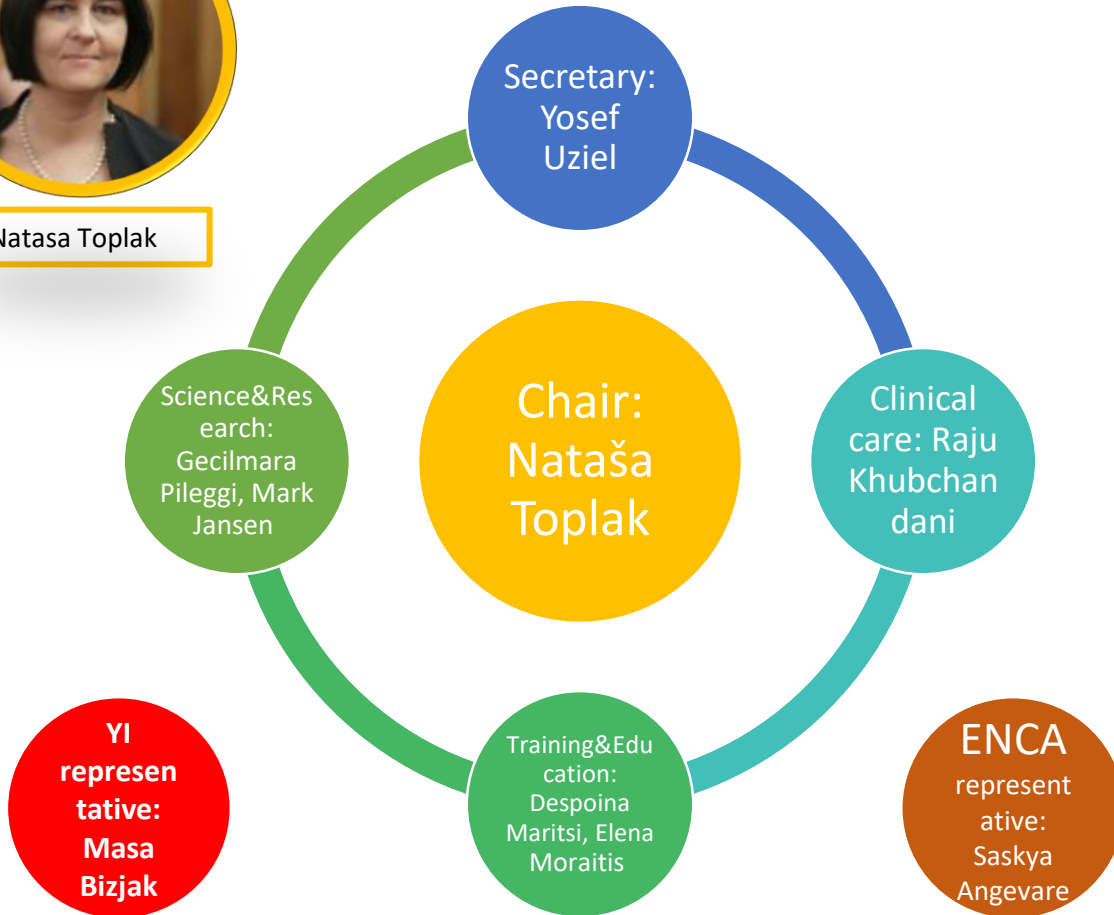
Contacts:

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Vaccination WP-2



Natasa Toplak



• EULAR / PRES congress 2019 Abstracts

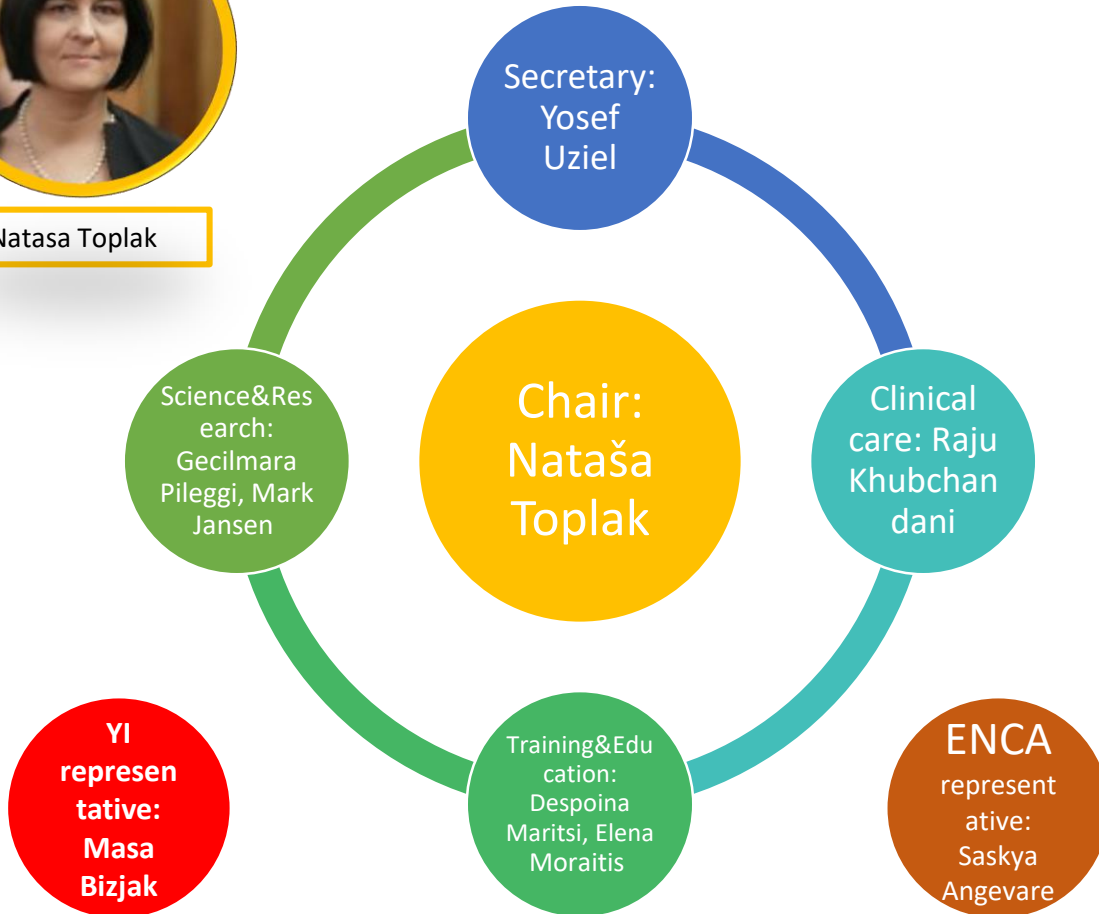
-Live attenuated vaccines in pediatric rheumatic diseases are safe: Multicenter, retrospective data collection (**in YIM**, and in the congress plenary session- Veronica Moshe)

-An international survey on approaches towards immunization in children with rheumatic diseases: a report of the PReS Vaccinations Working Group (**in YIM** and congress Poster)

Vaccination WP-3



Natasa Toplak



• Prospective and Ongoing Projects:

-Safety and efficacy of live attenuated vaccines in pediatric rheumatology patients

-Efficacy of live attenuated vaccines- MMR/V in cross sectional study

-Long term efficacy of vaccines in paediatric rheumatology patients- do we need booster doses?

-Promotion of vaccination

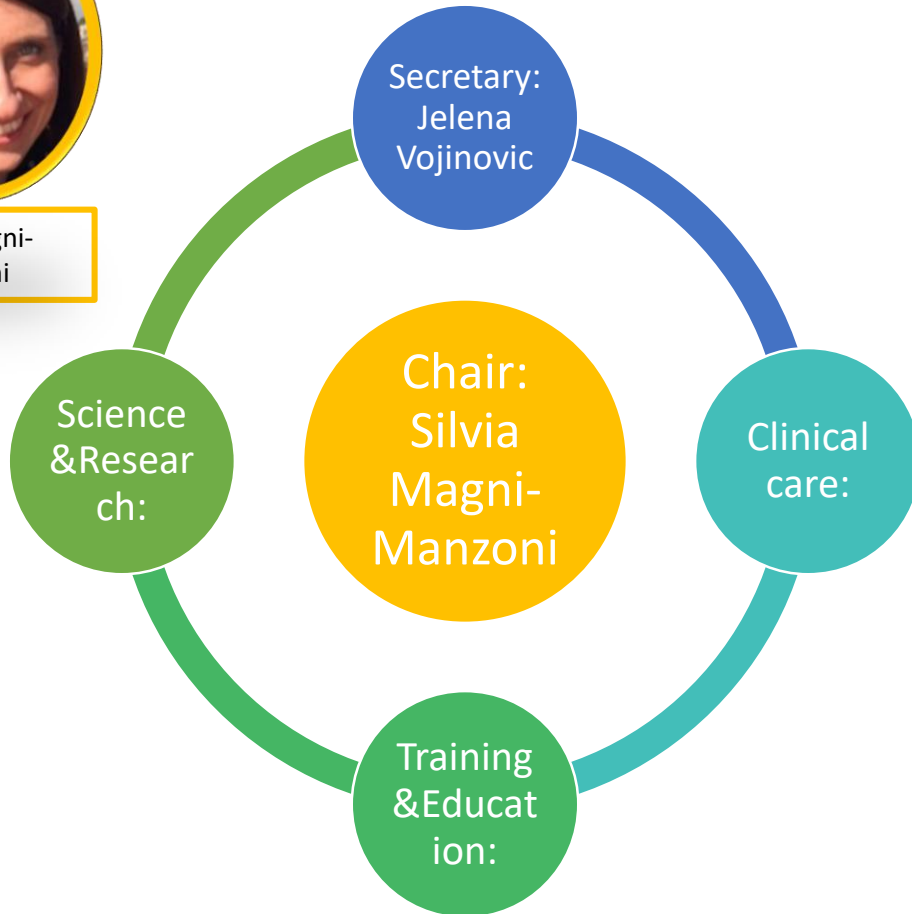
-Education for health professionals

-Communication with children and their parents (ENCA)

Imaging WP-1



Silvia Magni-Manzoni



- **Aim:** to promote knowledge, research and education on imaging in pediatric patients

Contacts:

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- Jelena Vojinovic (vojinovic.jelena@gmail.com)

Imaging WP-2



Silvia Magni-Manzoni

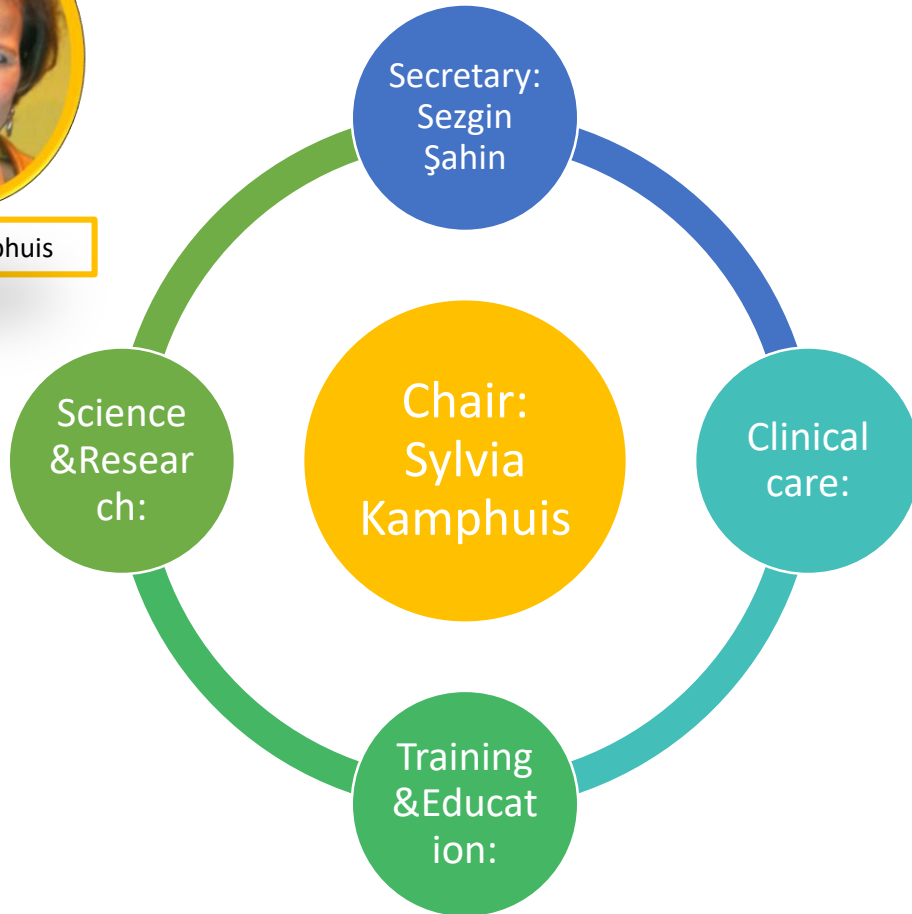


- **Education:** Prior EULAR/PReS Annual Meeting, June 2019, Madrid: Basic + Intermediate PedMSUS Courses
- **Ongoing projects:**
 - EULAR/PReS standardised procedures for US imaging in Pediatric Rheumatology (EULAR CLI087)
 - Validation of normal age- and sex-related sonographic findings of the knee and hip by comparison to patients with knee arthritis and hip arthritis
 - Applicability of standardized ultrasound examination to estimate disease activity in combination with JADAS and inflammation markers in JIA patients
 - Validation of imaging tools for use in clinical practice and as outcome tools

SLE WP



Sylvia Kamphuis



Aims:

- To share expertise, activities and proposals for collaborative clinical studies in cSLE/paediatric APS
- To support the development of studies important for improving the care and understanding of cSLE/paediatric APS
- To foster educational initiatives in cSLE/paediatric APS

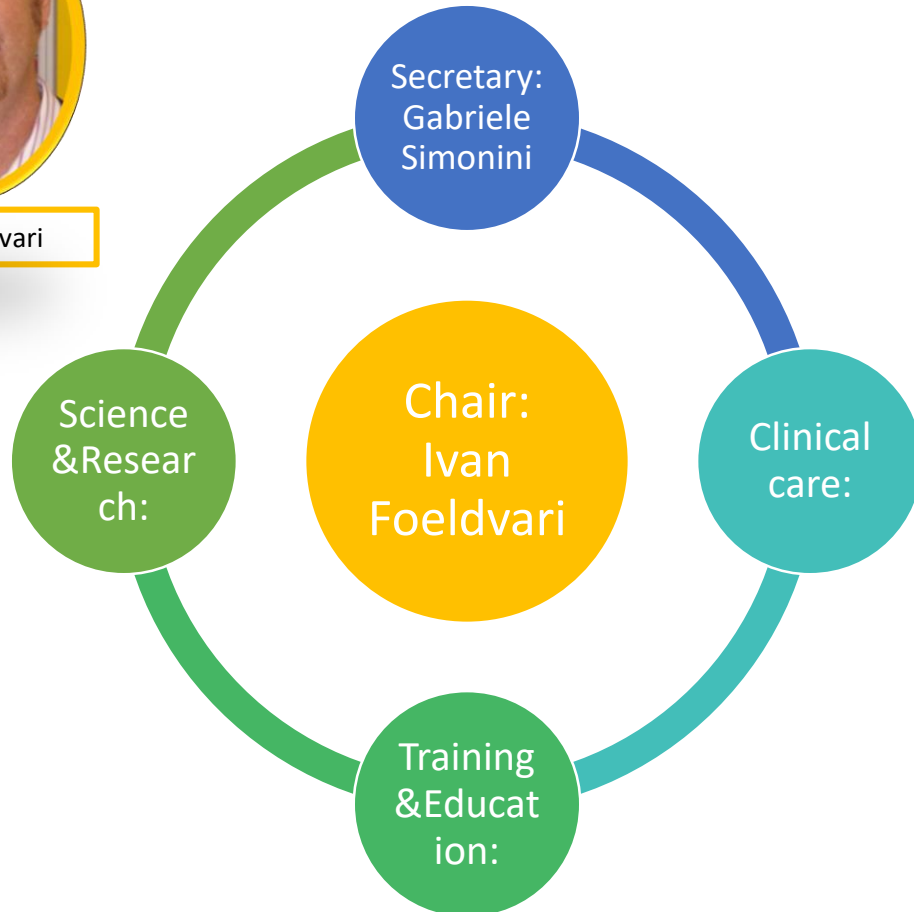
Contact persons:

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Uveitis WP



Ivan Foeldvari



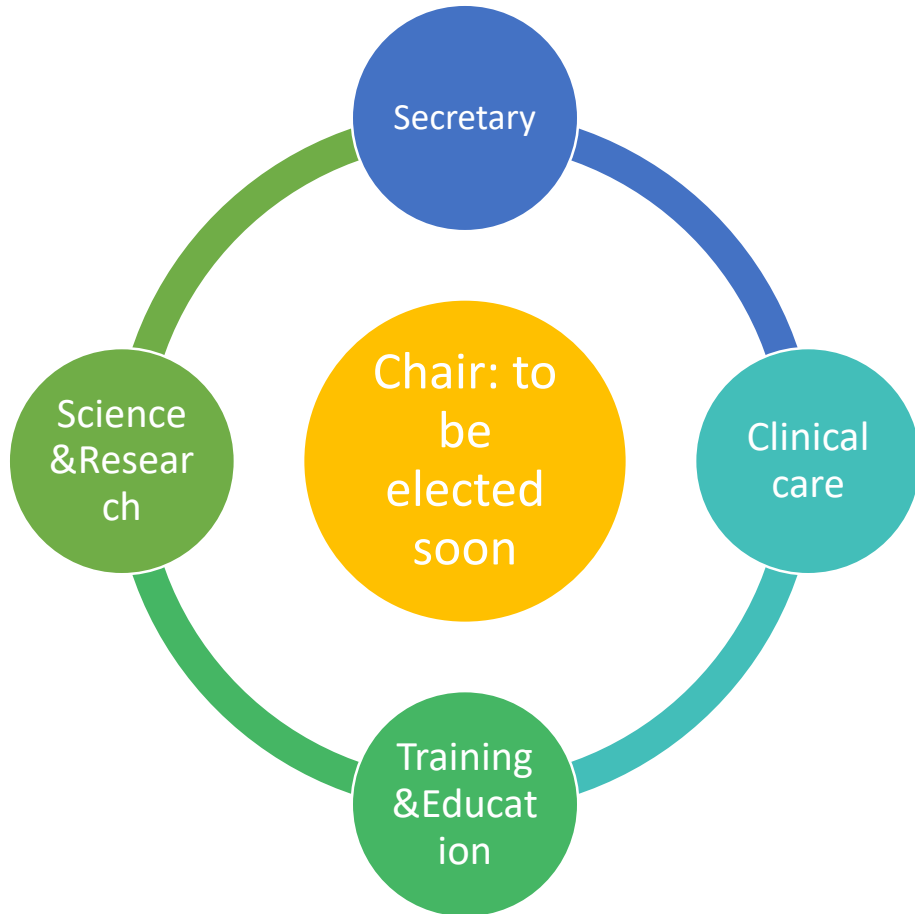
Aims:

- To set up an ophthalmologist and rheumatologist network of physicians interested in childhood uveitis
- To foster activities in research regarding JIA-uveitis
- To improve the quality of care for patients with JIA-uveitis

Contacts:

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Scleroderma WP



- Chair- Ivan Foeldvari (foeldvari@t-online.de)
- More to come