



32nd Newsletter | September 2022

[PRINTO General Assembly at PReS Congress]

Dear Friends,

We are happy to invite all of you to the upcoming **Annual PRINTO General Assembly at the PReS 2022 Congress**, that will be held (in person, hooray!)

Wednesday 21 September from 17.30 to 18.30 CET (Terrace 2A)

Here is the **AGENDA**:

- **Introduction (Alberto Martini)**
- **The PRINTO/PReS research Grants (Fabrizio De Benedetti)**
- **Cross-cultural adaptation and validation of LoSQI in JLS (Hanna Lythgoe)**
- **Comparison of Kobayashi and Kawamet IVlg resistance scores - the KIWI study (Maria Vincenza Mastroli)**
- **Optimizing Treatment in sJIA and MAS/Secondary HLH: the METAPHOR Project (Francesca Minoia)**
- **The HyperPED-COVID Registry (Roberta Caorsi)**
- **The Eurofever Registry (Marco Gattorno)**
- **The DAISY study (Dragana Lazarevic)**
- **The STARS trial (Alessandro Consolaro)**
- **The JIA classification study (Nicola Ruperto)**
- **The CEST-JIA study (Giovanni Filocamo)**
- **Update on the PRINTO research activity (Nicola Ruperto)**

Eugenia and Elisa from the staff of the PRINTO Coordinating centre will be available at the **PRINTO booth** during the Congress and will be more than happy to meet you and discuss the network's projects and initiatives!

Thank you in advance for your participation, and see you in Prague!

**Alberto, Nicola
and the staff of the PRINTO coordinating centre**

Meet the Pls!

The Pls of the ongoing studies will be also available at the PRINTO booth on the days listed below for further clarifications on their projects and to meet already participating or potentially interested colleagues.

- Wed, 21st from 10 to 10:30 - Francesca Minoia, METAPHOR**
- Wed, 21st from 10:30 to 11 - Martina Rossano, sub-PI for CEST-JIA**
- Wed, 21st from 12:15 to 13:15 - Nicola Ruperto, JIA Classification and PRINTO activities**
- Wed, 21st from 16:30 to 17:30 - Marco Gattorno and Roberta Caorsi, HyperPED COVID and Eurofever**
- Wed, 21st from 18:30 to 19 - Maria Vincenza Mastroli, KIWI**
- Thur, 22nd from 12 to 13 - Alessandro Consolaro, STARS**
- Thur, 22nd from 14 to 15 - Clare Pain and Hanna Lythgoe, LoSQI**
- Thur, 22nd from 16.30 to 17:30 - Dragana Lazarevic, DAISY**

Do not miss your chance to meet the Pls!

Add the PRINTO GA to my calendar!



[PRINTO on going projects]



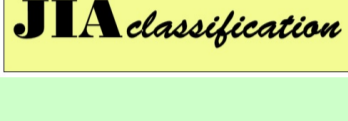
**PIs: Nicolino Ruperto,
Nico Wulfraat**

PharmaChild is a **pharmacovigilance project which aims at observing children with JIA for 3-10 years undergoing treatment with MTX or biologic agents in order to collect moderate, severe or serious adverse events** occurred. Pharmachild started in 2011 thanks to a European Union (EU) grant within the FP7 framework and has obtained the ENCePP Study Seal (ENCePP).

As of today, **more than 9,000 patients have been enrolled from 88 centres in 31 countries.**

The PharmaChild project has also a sub-study on abatacept, in collaboration with Bristol Myers and Squibb.

Enrolment is still open, although no reimbursement for data entry is provided.



PI: Nicolino Ruperto

The JIA Classification study is a translational study that aims to validate, in a **prospective collection of at least 1,000 patients at disease onset**, the proposed PRINTO consensus classification criteria for JIA. This entails also the collection of biologic samples for ANA, anti CCP, RF, HLA B27 determinations and DNA analysis.

At the moment we have 96 enrolling centres and a total of 1407 patients with at least one locked visit. **Import of biological samples to PRINTO is currently ongoing and will be ideally completed by the end of this year.**

Samples analysis is scheduled to start in September. **Enrolment will close at the end of September 2022.**



PI: Alessandro Consolaro

The comparison of SStep-up and step-down therapeutic strategies in childhood ARthritis trial (STARS) is a **new interventional trial aiming to investigate whether an early aggressive therapeutic intervention in children with JIA**, based on the initial start of synthetic and biological DMARDs (Step-up strategy), is **superior to an approach based on treatment escalation** conducted following the treat-to-target principle (Step-up strategy).

At the moment we have 17 enrolling centres and a total of 124 patients in Italy.

We are now opening sites also outside Italy to increase recruitment. **Enrolment will close at the end of February 2024.**



PI: Marco Gattorno

The Eurofever registry was promoted in 2008 by the work group of autoinflammatory diseases of the Paediatric Rheumatology European Society (PRES) and was supported by the Executive Agency for Health and Consumers (EAHC).

The main objective of the project has been the creation of a registry of autoinflammatory diseases.

The registry collects information about the clinical picture, the onset of **complications**, the **treatment**, the current findings (laboratory and instrumental), **safety**, compliance to the therapy and the **quality of life**.

From 2009 to date, **the information of more than 5000 patients have been collected from 125 centers distributed in 44 countries** around the world.

Enrolment is still open, a reimbursement is being provided.

Seza Ozen is now coordinating a **new project in order to analyze longitudinally the data on FMF patients.**



PI: Marco Gattorno

HyperPED-COVID is a retrospective observational study. Its principal aim is to capture the burden of this spectrum of hyperinflammatory conditions related to COVID-19 in children and young adults.

For this reason, a **joined PReS, ISSAID, ESID, ERN-RITA and PRINTO network's effort** has been started aimed to **collect standardized clinical data** of these patients in a **common registry**.

Primary endpoint of the project is to collect information on clinical presentation, laboratory parameters, clinical outcome and response to treatment of patients with COVID-19 related hyperinflammation.

As of today we have **more than 1200 subjects enrolled in 54 sites from 22 countries.**

Enrolment is still open!



PI: Dragana Lazarevic

The DAISY study (Applicability of standardized ultrasound examination to estimate disease activity in combination with JADAS and inflammation markers in JIA patients) **aims to investigate sensitivity and predictive value of the multi-biomarker panel** and to evaluate if it could be applied in limited number of joints in patients with oligo and polyarticular JIA course as a new disease activity tool and outcome measure.

This **multicenter international study** in JIA patients involves selected pediatric rheumatology centers with expertise in the ultrasound examination of joints.

The coordinating centers are Nis (Serbia) and Genoa (Italy).

At the moment we have 8 enrolling centres and a total of 54 patients.

Enrolment will close at the end of March 2023

Enrolments in PRINTO studies



[PRINTO publications]

More than **20 peer-reviewed manuscripts accepted and published** in scientific journals with IF in the last 2 years! **A special thanks to all co-authors!**

Some titles?

- [Anakinra in patients with systemic juvenile idiopathic arthritis: long-term safety from the Pharmachild registry.](#)

Giancane G, et al, J Rheumatol 2022;49:398-407

- [Increased incidence of inflammatory bowel disease on etanercept in juvenile idiopathic arthritis regardless of concomitant methotrexate use.](#)

van Straalen JW, et al, Rheumatology (Oxford) 2022 May 5;61(5):2104-2112

- [Tofacitinib in juvenile idiopathic arthritis: a double-blind, placebo-controlled, withdrawal phase 3 randomised trial.](#)

Ruperto N, et al, Lancet 2021 Nov 27;398(10315):1984-1996

- [Definition and validation of the American College of Rheumatology 2021 JADAS cutoffs for Disease Activity States in Juvenile Idiopathic Arthritis.](#)

Trincianti C, et al, Arthritis Rheumatol 2021; Nov;73(11):1966-1975

- [Open-Label Phase 3 Study of Intravenous Golimumab in Patients With Polyarticular Juvenile Idiopathic Arthritis.](#)

Ruperto N, et al, Rheumatology (Oxford) 2021 Oct 2;60(10):4495-4507

- [Determinants of discordance between criteria for inactive disease and low disease activity in juvenile idiopathic arthritis.](#)

Giancane G, et al, Arthritis Care Res (Hoboken). 2021 Dec;73(12):1722-1729

- [Subcutaneous dosing regimens of tocilizumab in children with systemic or polyarticular juvenile idiopathic arthritis.](#)

Ruperto N, et al, Rheumatology (Oxford) 2021 Oct 2;60(10):4568-4580

- [Absence of Association Between Abatacept Exposure and Initial Infection in Patients With Juvenile Idiopathic Arthritis.](#)

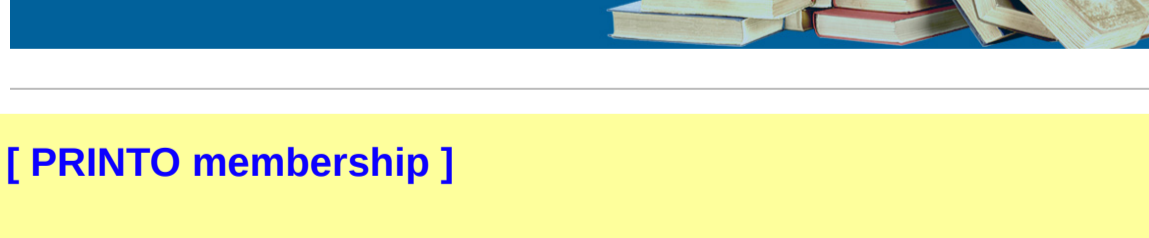
Ruperto N, et al, J Rheumatol 2021 Jul;48(7):1073-1081

- [Efficacy and Safety of Tocilizumab for Polyarticular-Course Juvenile Idiopathic Arthritis in the Open-Label 2-Year Extension of a Phase 3 Trial.](#)

Brunner HI, et al, Arthritis Rheum 2021;73(3):530-541

- [Tapering Canakinumab Monotherapy in Patients with Systemic Juvenile Idiopathic Arthritis in Clinical Remission: Results from an Open-label, Randomized Phase IIIb/IV Study.](#)

Quartier P, et al, Arthritis Rheum 2021 Feb;73(2): 336-346



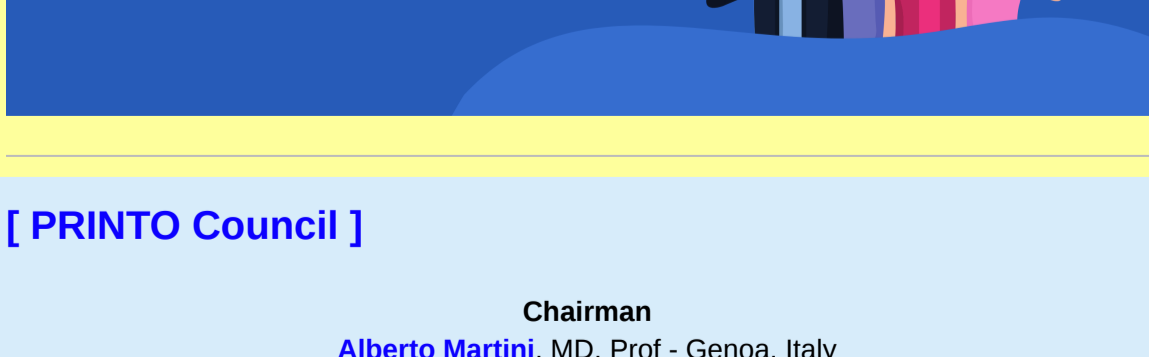
[PRINTO membership]

PRINTO has now reached **1593 effective members in 705 centres from more than 90 countries.**

If you wish to become a PRINTO member and receive regular updates and invitations to our research projects, click on the banner below or feel free to contact PRINTO.

Join the network!

Your cooperation will be more than the welcome! It is essential for the research against the paediatric rheumatic diseases.



[PRINTO Council]

Chairman

Alberto Martini, MD, Prof - Genoa, Italy

Counselors

Tadej Avcin, MD, PhD - Ljubljana, Slovenia

Michael Hofer, MD, Prof - Lausanne, Switzerland

Seza Ozen, MD, Prof - Ankara, Turkey

Pierre Quartier, MD - Paris, France

Claudia Saad Magalhães, MD, Prof - Botucatu, Brazil

Joos Swart, MD - Utrecht, The Netherlands

Senior Scientist

Nicolino Ruperto, MD, MPH - Genoa, Italy

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