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## 29th PRINTO newsletter | June 2019

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### PRINTO news

#### **2019 EULAR/PReS meeting in Madrid, 12-15 June 2019**

**The joint European League Against Rheumatism (EULAR) / Paediatric Rheumatology European Society (PReS) meeting will be held in Madrid from 12th to 15th June 2019.**

In Lisbon, in 2018, PReS celebrated its 25th conference and launched a new mission and strategic programme: PReS 2025. All healthcare professionals, scientists, patients and parent groups, took together the commitment to advance the care and improve the health and wellbeing of children and young people with rheumatic conditions.

In line with previous congresses, this international event will host challenging presentations and enriching debates of the more recent scientific investigations, including new syndromes and their treatment, trials for old diseases of young people and an up-to-date of care of the more severe juvenile rheumatic diseases. On this occasion valuable abstracts will be presented by young and senior Rheumatologists from Europe and around the World and they will certainly help to advance the field of Pediatric Rheumatology both in basic science and in clinical practice.

As stated in the Welcome Letter by the President of PReS, Berent J. Prakken, "PReS and EULAR have been natural partners through years, and for a good reason: our patients also need the best possible care after their 18th birthday". To achieve their common objective, pediatric and adult rheumatologists are strong allies. Because of the importance of this alliance, this year EULAR and PReS have decided to build a truly integrated programme: ENCA (European Network for Children with Arthritis) and PARE (People with Arthritis / Rheumatism in Europe) as well as Young PARE, Emeunet (EMerging Eular NETwork) and Emerge (EMerging RheumatoloGists and rEsearchers) and scientists and health professionals from both EULAR and PReS will all meet and work together to make a difference to both adult and young patients.

**You are warmly invited to attend the PRINTO General Assembly that will take place on Friday, 14 June 2019, from 17 to 18.30 (room S17).**

For more info please go to [https://www.congress.eular.org/welcome\\_message\\_pres.cfm](https://www.congress.eular.org/welcome_message_pres.cfm)

#### **Annual PRINTO General Assembly at the 2019 EULAR/PReS Meeting in Madrid**

Dear Friends,

we are glad to invite you to the upcoming Annual PRINTO General Assembly at the 2019 EULAR/PReS Meeting in Madrid!

**The Annual PRINTO General Assembly will be held on Friday, 14 June 2019, from 17 to 18.30 (room S17).**

Below is the final agenda:

- **Introduction (A. Martini)**
- **Update on PRINTO Projects (N. Ruperto)**
- **JIA classification study (N. Ruperto, G. Giancane)**
- **STARS (A. Consolaro, M. Mazzoni)**
- **PharmaChild (N. Ruperto)**
- **The EuroFever Registry (R. Caorsi, R. Papa)**

See you soon at the EULAR/PReS meeting in Madrid!

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### **New PRINTO data collection webservice is online!**

We are proud to announce that on **25th March 2019 PRINTO launched the new data collection webservice** at the link <https://registry.printo.it/>

**This webservice will be used for the data collection of the JIA classification study, the STARS trial, the PharmaChild registry, the BMS Abatacept registry and soon also for the EuroFever Project.**

The main features of the new webservice are:

- Increased data security (GDPR)
- Improved graphic display for mobile devices (tablets, smartphones)
- Possibility to collect data for all PRINTO studies using only one webservice
- Better programming code management

All data collected within the PharmaChild registry have been transferred to the new system.

Your access to the new webservice is granted:

- Through your Member Area of the PRINTO website:  
[www.printo.it](http://www.printo.it)

or

- Through a direct link:  
<https://registry.printo.it/>

Before entering new data, we suggest the investigators to read the pdf instructions document that can be found in the Home page of the new webservice.

The PRINTO coordinating centre staff remains at your disposal for any question or if you need assistance.

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## **PRINTO ongoing projects**

### **JIA classification study**

We are glad to announce that, so far, **46 centres have been activated**. As you know, the study requires besides the central clinical data collection, the centralisation of biologic samples at the PRINTO headquarter. For this reason, we assume it is mandatory to obtain the Ethics Committee (EC) approval in all sites. PRINTO already started the EC submissions and we expect that the EC procedures for all the interested sites will last until the end of year 2019.

As of today **46 sites obtained the EC approvals**, 6 are approved with objections, and 80 are in progress. **59 patients have been enrolled from 10 sites**.

We have recently delegated the Consortium for Biological and Pharmacological Evaluations (CVBF), which is a partner of the Italian National Hub for clinical trials INCIPIT (Italian Network for Pediatric Clinical Trials), to help us in managing the submission to the Ethics Committee of about 30 sites. This should speed up this lengthy process. The PRINTO staff will remain available for every need and clarification.

The sites that have been activated are strongly encouraged to try to use the new PRINTO electronic data capture system. **We have planned web**

**trainings** to explain how the websystem works.

The first web trainings are scheduled on:

- **Wednesday 12 June at 3.00 pm Italian Time (CET)**
- **Friday 21 June at 3.00 pm Italian Time (CET)**
- **Wednesday 26 June at 3.00 pm Italian Time (CET)**

If you are willing to participate, notify PRINTO by e-mail at least 2 days before the preferred webinar and we will provide you with specific instructions.

You can access the EDCS from the direct link: <https://registry.printo.it/> or from the PRINTO Member Area.

If you already accessed the Pharmachild websystem, the access data did not change. If you did not have access to the Pharmachild websystem previously, then send an email to PRINTO and ask to authorize you and send the access data.

The access occurs through:

- Username: your email address
- An individual password (computer-generated, automatically changed every 6 months). This password is user-specific (it is unique for each user).
- The center password: this password is used to encrypt the patients' data, so that PRINTO cannot see them for privacy. This password is center-specific (it is the same for all the users in one center).

We are finalizing instructions to spread out to all the Investigators, but meanwhile all the active sites are kindly invited to enter the data in the EDCS.

Biologic samples: PRINTO will provide the kits for the visits requiring samples collection and laboratory instruction containing also storage and shipment information.

For each visit with samples collection you will receive:

- 2 EDTA tubes 3 ml (2 mL of blood in each EDTA tube should be collected, if allowed by the child's weight)
- 2 Serum Vacutainer serum separator tubes (SST) 4 ml (4mL of blood in each Serum tube should be collected, if allowed by the child's weight)
- 8 cryotubes for serum aliquots for local storage
- Barcode labels for Serum tubes, EDTA tubes and cryotubes for serum aliquots
- 21G butterfly needle
- Vacutainer holder with luer adapter
- 2 Plastic envelopes for tubes (please keep one to insert the samples, once frozen, and store them)

Feel free to contact us for any issue or clarification you may need.

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### **The STARS trial**

**The comparison of Step-up and step-down therapeutic strategies in childhood ARthritis trial (STARS)** is a **new interventional trial** financed by AIFA (Agenzia Italiana del Farmaco) and by the Italian Foundation Compagnia di San Paolo that **at the moment** is **conducted** by PRINTO **only in the 26 Italian centres** that expressed their interest in the trial feasibility.

This clinical trial has the aim to investigate whether an early aggressive therapeutic intervention in children with JIA, based on the initial start of synthetic and biologic DMARDs (Step-down strategy), is superior to an approach based on treatment escalation conducted following the treat-to-target principle (Step-up strategy). The effectiveness of the two strategies will be assessed by comparing their ability to induce sustained clinical disease remission on/off treatment.

After screening of inclusion and exclusion criteria and recording of informed consent, patients will be randomized into two therapeutic arms: "Step up" or "Step down". Patients in the Step-up arm will be treated according to a conventional strategy based on treatment escalation and driven by the treat-to-target strategy. Patients in the Step-Down arm will be treated with an early, combined, aggressive therapy for 6 months.

### **Objectives**

**The study is aimed to compare the effectiveness of a conventional therapeutic regimen, based on treatment escalation (Step-up strategy) and driven by the treat-to-target approach, with that of an early aggressive intervention based on a combination of conventional and biological DMARDs (Step-down strategy).**

The hypothesis tested in this trial is whether an early aggressive therapy with a 6-month course of an anti-TNF agent in combination with methotrexate or with methotrexate alone in the milder forms of oligoarthritis (Step-down arm) is more effective in inducing clinical remission on medication (i.e. at least 6-month of continuous inactive disease while receiving anti-rheumatic medications) than a conventional therapeutic approach based on treatment escalation (Step-up arm), which efficacy is maximized through the implementation of a treat-to-target approach

### **At the moment**

After obtaining the study approval from the Italian National Competent Authority (AIFA) and from the Local Ethics Committee of the coordinating centre in Genoa, PRINTO, in collaboration with the Consorzio per Valutazioni Biologiche e Farmacologiche (CVBF, <https://www.cvbf.net/it/>), has recently begun the phase of **submission of the study documents to the Ethics Committees of all participating sites in Italy**. The very **first patients** have been already **enrolled** at the coordinating centre in Genoa.

## PharmaChild

**PharmaChild is a pharmacovigilance project which aims at observing children with Juvenile Idiopathic Arthritis for 3-10 years undergoing treatment with MTX or biologic agents** in order to collect moderate, severe or serious adverse events occurred.

This project is conducted by the participating centres of the more than 50 countries belonging to the Paediatric Rheumatology INternational Trials Organisation ([PRINTO](#), certified ISO 9001-2008), or the Pediatric Rheumatology European Society ([PRES](#)). More than 200 PRINTO centres worldwide have already expressed their interest in participating to the project.

PharmaChild has been funded by the European Union (EU) within the FP7 framework (contract number 260353, principal investigator Dr Nico Wulfraat, co-principal investigator Dr Nicolino Ruperto) and has obtained the ENCePP Study Seal ([ENCePP](#)). The European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP®) is a collaborative scientific network coordinated by the European Medicines Agency and developed in collaboration with European experts in the fields of pharmacoepidemiology and pharmacovigilance. The ENCePP Study Seal means that a study upholds high standards throughout the research process based on the principles of transparency and scientific independence.

### **At the moment**

As of today **PharmaChild enrolled a total of more than 8800 subjects with JIA from 84 centres in 30 countries around the world**. In December 2018 **the first manuscript** issued by the combined dataset of the PharmaChild with other national registries (a total of more 15,000 patients) **was published in Arthritis Research & Therapy** (see the publications list below for more details). PRINTO is currently finalizing the **publication of a second manuscript** aiming at the analysis of the **opportunistic infections** in the immunosuppressed patients with Juvenile Idiopathic Arthritis enrolled in PharmaChild.

### **COLLABORATION WITH PHARMACEUTICAL COMPANIES**

The PharmaChild protocol envisages the opportunity of a cooperation with pharmaceutical companies, which may want to use the data derived from PharmaChild for regulatory post-marketing surveillance obligations related to their product towards regulatory authorities. In this case, PRINTO will MAINTAIN THE OWNERSHIP OVER THE DATA COLLECTED in order to continue to fulfill the ENCePP principles of transparency and scientific independence. All related possible revenues will be totally reinvested for the research needs of the project to support the prolongation of the registry over the planned 3-10 years. **Bristol-Myers Squibb (Abatacept in JIA) has agreed to cooperate with PharmaChild.**

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## Conect4children (c4c)

PRINTO is partner of the “conect4children” (c4c) initiative; the **collaborative network for European clinical trials for children, (c4c) is a consortium** that aims to **enhance the competitiveness of Europe as a critical region for developing medicines for children** by using existing expertise, patient access and developing common processes to be applied to disease natural history studies, registries, studies of new therapies and comparisons of existing therapies. The consortium is a novel collaboration between academic and private sectors that includes 33 academic and 10 industry partners from 20 European countries, more than 50 third parties and around 500 affiliated partners.

**The six-year project, comprised of a multidisciplinary public-private consortium, brings together key stakeholders across academia and industry.** It is a pioneering opportunity to build capacity for the management of multinational paediatric clinical trials across Europe whilst ensuring the voices of children, young people and their families are heard. Strong links with regulators will be established.

For more info, please visit <https://conect4children.org/>

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## Eurofever

The Eurofever Steering Committee thanks all active centers that collected information of **more than 4000 patients with Autoinflammatory diseases from 116 centers in 42 countries**.

We are more than happy to receive any proposal for possible studies based on the Eurofever data. You may send your proposal to [printo@gaslini.org](mailto:printo@gaslini.org) and we will submit it to the Steering Committee.

Below the list of conditions collected by the Eurofever Registry.

### Multifactorial auto inflammatory diseases

- Behcet's disease
- Chronic non bacterial osteomyelitis/osteitis (CNO or Chronic recurrent multifocal osteomyelitis CRMO)
- Periodic fever, aphthous stomatitis, pharyngitis and adenitis (PFAPA or Marshall' s syndrome)
- Undefined periodic fever

### Monogenic autoinflammatory diseases

- Autoinflammation with infantile enterocolitis (NLRC4 – AIFEC)

- Autoinflammation, Panniculitis, and Dermatitis Syndrome (OTULIN–AIPDS)
- Blau's disease/Juvenile Sarcoidosis
- CARD14 mediated psoriasis (CAMPS)
- Chronic atypical neutrophilic dermatosis with lipodystrophy and elevated temperature syndrome/proteasome-associated autoinflammatory syndromes (CANDLE/PRAAS )
- Cryopyrin associated periodic syndromes (CAPS–CINCA/Muckle Wells/FCAS)
- Deficiency of Adenosine Deaminase 2 (DADA2)
- Deficiency of IL-1 receptor antagonist (DIRA)
- Deficiency of the IL-36 receptor antagonist (DITRA syndrome)
- Familial Mediterranean Fever (FMF)
- IL-10 deficiency-associated Inflammatory bowel disease
- Interleukin 10 receptor A deficiency
- Interleukin 10 receptor B deficiency
- Majeed syndrome
- Mevalonate kinase Deficiency (MKD or Hyper IgD syndrome)
- NALP12-related disease
- Periodic fever associated to TNFRSF11A (TRAPS11)
- PLCG2-associated antibody deficiency and immune dysregulation (PLAID)
- Pyoderma gangrenosum, acne, pyogenic arthritis syndrome (PAPA)
- Schnitzler syndrome
- STING-associated vasculopathy with onset in infancy (SAVI)
- TNF receptor associated periodic syndrome (TRAPS)

## ABIRISK

**ABIRISK** (Anti-Biopharmaceutical Immunization: Prediction and Analysis of Clinical Relevance to Minimize the Risk), whose enrollment ended on 31st March 2016, is a large **European project** funded by the [Innovative Medicines Initiative](#) (IMI) and it aims to provide an **integrated approach to investigate anti-drug antibody formation in JIA, adult rheumatoid arthritis and other conditions treated with biopharmaceuticals** .

PRINTO is the coordinator of the JIA Cohort and succeeded to collect the **biologic samples (Serum and RNA) of 147 children** with juvenile idiopathic arthritis newly treated with adalimumab, etanercept or tocilizumab at start of therapy and at 4 follow-up visits during the first year of treatment, with an extra visit between month 15 and month 18 for a total of 6 study visits.

The biologic samples, managed by PRINTO, were transferred to the ABIRISK consortium laboratories for antibodies evaluation and PK analysis. The clinical data are the data collected for the PharmaChild registry.

**As of today**, almost all the results have been obtained and will be merged with the clinical data. The information related to the patients enrolled at each site will be shared with the Principal Investigators.

For further information, you can contact the [PRINTO](#) office.

## MYPAN

The MYPAN trial is an Open Label Randomised Controlled Trial of Mycophenolate Mofetil (MMF) Versus Cyclophosphamide (CYC) for the Induction of Remission of childhood PAN, sponsored by University College London and coordinated by the Children Hospital in Liverpool and PRINTO (PI Dr P. Brogan).

**MYPAN investigates the comparative efficacy and safety of MMF (experimental treatment) vs CYC (standard treatment) for induction of remission of childhood PAN.** This is the first ever randomized trial for childhood PAN.

The enrollment period was officially closed on June 30th, 2018: **11 patients** have been globally **enrolled** and the Last Patient Last Visit is scheduled for the End of October.

## Patients enrolled in the PRINTO projects

Country	PHARMACHILD	EUROFEVER	ABIRISK Registry	JIA classification	The STARS trial
Argentina	123	57	0	0	0
Armenia	0	101	0	0	0

Australia	0	13	0	0	0
Austria	31	32	0	0	0
Belgium	0	14	0	0	0
Brazil	410	19	0	0	0
Bulgaria	56	5	0	3	0
Canada	0	38	0	0	0
Chile	0	5	0	0	0
China	0	14	0	0	0
Croatia	186	14	0	0	0
Czech Republic	143	216	26	0	0
Denmark	543	135	0	0	0
Ecuador	25	1	0	0	0
France	331	305	20	0	0
Georgia	0	9	0	0	0
Germany	0	303	0	6	0
Greece	520	179	53	0	0
Hungary	137	24	0	0	0
India	119	3	0	0	0
Israel	89	168	0	0	0
Italy	1767	1268	29	26	2
Japan	0	6	0	0	0
Latvia	256	7	2	0	0
Lebanon	0	1	0	0	0
Lithuania	320	7	0	0	0
Mexico	99	0	0	0	0
Netherlands	697	142	0	0	0
Norway	361	1	4	0	0
Oman	13	6	0	0	0
Poland	31	9	3	0	0
Romania	428	46	1	1	0
Russian Federation	491	64	0	0	0
Saudi Arabia	70	39	0	0	0
Serbia	276	5	0	0	0
Singapore	45	0	0	0	0
Slovakia	23	1	1	2	0
Slovenia	0	18	0	0	0
Spain	721	266	4	0	0
Sweden	0	1	0	0	0
Switzerland	491	102	1	0	0
Turkey	8	292	11	0	0
Ukraine	0	0	0	21	0

United Kingdom	0	296	0	0	0
United States	0	6	0	0	0
<b>Total</b>	<b>8810</b>	<b>4238</b>	<b>155</b>	<b>59</b>	<b>2</b>

## [PRINTO overall enrollment status](#)

### [Latest PRINTO papers](#)

Ruperto N, Brunner HI, Quartier P, Constantin T, Wulffraat NM, Horneff G, Kasapcopur O, Schneider R, Anton J, Barash J, Berner R, Corona F, Cuttica R, Fouillet-Desjonqueres M, Fischbach M, Foster HE, Foell D, Radominski SC, Ramanan AV, Trauzeddel R, Unsal E, Levy J, Vritzali E, Martini A, Lovell DJ; Paediatric Rheumatology International Trials Organisation (PRINTO) and the Pediatric Rheumatology Collaborative Study Group (PRCSG)

#### **Canakinumab in patients with systemic juvenile idiopathic arthritis and active systemic features: results from the 5-year long-term extension of the phase III pivotal trials.**

Ann Rheum Dis 2018 Dec;77(12):1710-1719 [PubMed](#)

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Holland MJ, Beresford MW, Feldman BM, Huggins J, Norambuena X, Silva CA, Susic G, Sztajnbok F, Uziel Y, Appenzeller S, Ardoin SP, Avcin T, Flores F, Goilav B, Khubchandani R, Klein-Gitelman M, Levy D, Ravelli A, Wenderfer SE, Ying J, Ruperto N, Brunner HI; for Paediatric Rheumatology International Trials Organisation (PRINTO) and the Pediatric Rheumatology Collaborative Study Group (PRCSG)

#### **Measuring Disease Damage and its Severity in Childhood-Onset Systemic Lupus Erythematosus.**

Arthritis Care Res 2018 Nov; 70(11):1621–1629 [PubMed](#)

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Sherman G, Nemet D, Moshe V, Consolaro A, Ravelli A, Ruperto N, Uziel Y for the Paediatric Rheumatology International Trials Organisation (PRINTO)

#### **Disease activity, overweight, physical activity and screen time in a cohort of patients with juvenile idiopathic arthritis**

Clin Exp Rheumatol. 2018 Nov-Dec;36(6):1110-1116 [PubMed](#)

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Swart J, Giancane G, Horneff G, Magnusson B, Hofer M, Alexeeva ?, Panaviene V, Bader-Meunier B, Anton J, Nielsen S, De Benedetti F, Kamphuis S, Sta??vi?a V, Trachana M, Ailioaie LM, Tsitsami E, Klein A, Minden K, Foeldvari I, Haas JP, Klotsche J, Horne AC, Consolaro A, Bovis F, Bagnasco F, Pistorio A, Martini A, Wulffraat N, Ruperto N; Paediatric Rheumatology International Trials Organisation (PRINTO), BiKeR and the board of the Swedish Registry

#### **Pharmacovigilance in juvenile idiopathic arthritis patients treated with biologic or synthetic drugs: combined data of more than 15,000 patients from Pharmachild and national registries**

Arthritis Res Ther 2018;20(1):285 [PubMed](#)

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Ben-Chetrit E, Gattorno M, Gul A, Kastner DL, Lachmann HJ, Touitou I, Ruperto N for the Paediatric Rheumatology International Trials Organisation (PRINTO) and the AIDs Delphi study participants

#### **Consensus proposal for taxonomy and definition of the autoinflammatory diseases (AIDs): a Delphi study**

Ann Rheum Dis 2018;77:1558–1565 [PubMed](#)

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Consolaro A, Giancane G, Alongi A, van Dijkhuizen EHP, Aggarwal A, Al-Mayouf SM, Bovis F, De Inocencio J, Demirkaya E, Flato B, Foell D, Garay SM, Laz??r C, Lovell DJ, Montobbio C, Miettunen P, Mihaylova D, Nielsen S, Orban I, Rumba-Rozenfelde I, Magalhães CS, Shafaie N, Susic G, Trachana M, Wulffraat N, Pistorio A, Martini A, Ruperto N, Ravelli A for the Paediatric Rheumatology International Trials Organisation.

#### **Phenotypic variability and disparities in treatment and outcomes of childhood arthritis throughout the world: an observational cohort study**

Lancet Child Adolesc Health 2019 Apr;3(4):255-263 [PubMed](#)

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Federici S, Vanoni F, Ben-Chetrit E, Cantarini L, Frenkel J, Goldbach-Mansky R, Gul A, Hoffman H, Koné-Paut I, Kuemmerle-Deschner J, Lachmann HJ, Martini A, Obici L, Ozen S, Simon A, Hofer M, Ruperto N, Gattorno M; for Eurofever and the Pediatric Rheumatology International Trials Organization (PRINTO)

**An International Delphi Survey for the Definition of New Classification Criteria for Familial Mediterranean Fever, Mevalonate Kinase Deficiency, TNF Receptor-associated Periodic Fever Syndromes, and Cryopyrin-associated Periodic Syndrome**

J Rheumatol 2019 Apr;46(4):429-436 [PubMed](#)

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Martini A, Ravelli A, Avcin T, Beresford MW, Burgos-Vargas R, Cuttica R, Ilowite NT, Khubchandani R, Laxer RM, Lovell DJ, Petty RE, Wallace CA, Wulffraat NM, Pistorio A, Ruperto N for the Pediatric Rheumatology International Trials Organization (PRINTO).

**Toward New Classification Criteria for Juvenile Idiopathic Arthritis. First Steps: the PRINTO International Consensus.**

J Rheumatol 2019 Feb;46(2):190-197 [PubMed](#)

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Foeldvari I, Constantin T, Vojinovic J, Horneff G, Chasnyk V, Dehoorne J, Panaviene V, Sušic G, Stanevicha V, Kobusinska K, Zuber Z, Dobrzyniecka B, Nikishina I, Bader-Meunier B, Breda L, Doležalová P, Job-Deslandre C, Rumba-Rozenfelde I, Wulffraat N, Pedersen RD, Bukowski JF, Vlahos B, Martini A, Ruperto N; Paediatric Rheumatology International Trials Organisation (PRINTO).

**Etanercept treatment for extended oligoarticular juvenile idiopathic arthritis, enthesitis-related arthritis, or psoriatic arthritis: 6-year efficacy and safety data from an open-label trial.**

Arthritis Res Ther 2019 May;23;21(1):125 [PubMed](#)

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Brunner HI, Holland MJ, Beresford MW, Ardoin SP, Appenzeller S, Silva CA, Flores F, Goilav B, Avar Aydin PO, Wenderfer SE, Levy DM, Ravelli A, Khubchandani R, Avcin T, Klein-Gitelman MS, Ruperto N, Feldman BM, Ying J for the Paediatric Rheumatology International Trial Organisation and the Pediatric Rheumatology Collaborative Study Group

**The American College of Rheumatology Provisional criteria for clinically relevant improvement in children & adolescents with childhood-onset systemic lupus erythematosus**

Arthritis Care Res 2019;71(5):579-590 [PubMed](#)

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Dolezalova P, Anton J, Avcin T, Beresford MW, Brogan PA, Constantin T, Egert Y, Foeldvari I, Foster HE, Hentgen V, Kone-Paut I, Kuemmerle-Deschner JB, Lahdenne P, Magnusson B, Martini A, McCann L, Minden K, Ozen S, Schoemaker C, Quartier P, Ravelli A, Rumba-Rozenfelde I, Ruperto N, Vastert S, Wouters C, Zulian F, Wulffraat NM; SHARE Consortium and the Paediatric Rheumatology International Trials Organisation (PRINTO) .

**The European network for care of children with paediatric rheumatic diseases: care across borders.**

Rheumatology [Epub ahead of print] [PubMed](#)

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Pardeo M, Wang J, Ruperto N, Alexeeva E, Chasnyk V, Schneider R, Horneff G, Huppertz HI, Minden K, Onel K, Zemel L, Martin A, Koné-Paut I, Siamopoulou-Mavridou A, Silva CA, Porter-Brown B, Bharucha KN, Brunner HI, De Benedetti F, for the Paediatric Rheumatology International Trials Organisation (PRINTO) and the Pediatric Rheumatology Collaborative Study Group (PRCSG)

**Neutropenia During Tocilizumab Treatment Is Not Associated With Infection Risk in Systemic or Polyarticular-Course Juvenile Idiopathic Arthritis**

J Rheumatol [Epub ahead of print] [PubMed](#)

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Rosina S, Consolaro A, van Dijkhuizen P, Pistorio A, Varnier GC, Bovis F, Nistala K, Maillard S, Civino A, Tsitsami E, de Inocencio J, Jelusic M, Vojinovic J, Espada G, Makay B, Katsicas MM, Pratsidou-Gertsi P, Lazarevic D, Rao AP, Pires Marafon D, Martini A, Pilkington C, Ruperto N, Ravelli A.

**Development and validation of a composite disease activity score for measurement of muscle and skin involvement in juvenile dermatomyositis**

Rheumatology [Epub ahead of print] [PubMed](#)

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Dolezalova P, Anton J, Avcin T, Beresford MW, Brogan PA, Constantin T, Egert Y, Foeldvari I, Foster HE, Hentgen V, Kone-Paut I, Kuemmerle-Deschner JB, Lahdenne P, Magnusson B, Martini A, McCann L, Minden K, Ozen S, Schoemaker C, Quartier P, Ravelli A, Rumba-Rozenfelde I, Ruperto N, Vastert S, Wouters C, Zulian F, Wulffraat NM for SHARE Consortium and the Paediatric Rheumatology International Trials Organisation (PRINTO)

**The European network for care of children with paediatric rheumatic diseases: care across borders**

Rheumatology [Epub ahead of print] [PubMed](#)

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## PRINTO membership

As of today, PRINTO has reached 1373 effective members in 654 centres from 90 countries.

If you wish to become a PRINTO member  
and receive regular updates about our research activity and invitations to our projects  
please go to:

<https://www.printo.it/contact/apply-membership>

Your cooperation will be more than welcome  
and your effort will be essential for the research in the field of paediatric rheumatic diseases.

**WELCOME ABOARD!**

## PRINTO advisory council & contacts

### **Chairman**

**Alberto Martini, MD, Prof - Genoa, Italy**

### **Counsellors**

**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**

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