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## 23rd Newsletter - April 2016

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#### **PRINTO celebrates its 20th birthday with a NEW website!**

Dear Friends,

Did you know that PRINTO turns 20 in 2016?

PRINTO was founded during the "International consensus conference on defining improvement in juvenile arthritis", held in Pavia on 17-19 May 1996. Since then, 20 years have gone by and PRINTO has grown a lot, publishing 130 manuscripts and enrolling more than 35,000 patients for academic studies and about 3000 patients in sponsored trials. All this was done thanks to our invaluable PRINTO collaborators, who are the strength behind PRINTO many achievements.

To celebrate this great event, PRINTO has recently launched its brand new website, with a new look and enhanced features optimized for mobile devices, available at <http://www.printo.it/>.

In addition, PRINTO has also recently launched the new website for families available at <http://www.printo.it/pediatric-rheumatology/> (more details below).

Our goal with the new PRINTO website is to provide our members and visitors with a fresh and easier way to learn about the PRINTO network and facilitate their participation in our research projects in the field of the Pediatric Rheumatic Diseases.

The menus have been streamlined to give a quick access to the sections you are looking for. We invite you to start exploring the new homepage. It introduces the PRINTO network and provides all the links to the different sections of the website (Projects, Publications, News, Contacts), where you can find:

- constantly updated information on the PRINTO past and current activities;
- details on upcoming events around the world related to the Pediatric Rheumatology;
- the instructions on how to apply for membership;
- the link to the new PRINTO website for families recently launched.

If you log in in the website as a member, you can take advantage from several new features:

- easy access to the PRINTO studies in which you are participating with specific and customized links;
- a direct link to the feasibility studies you are involved in;

- quick download of your PRINTO certificates (Joint assessor, PRINTO membership, PRINTO enrollment and publication summary);
- internal search engine to easily retrieve specific information in the website;
- personal section where PRINTO can share with you private documents (including funding transfer from PRINTO for your participation to collaborative projects) or study materials.

The PRINTO coordinating centre is continually expanding the contents of our website and keeps you updated with the latest information on our activity, so check back often!

Your feedback and any comment on the website will be more than welcome!

Thank you and enjoy your new PRINTO website!

Alberto Martini, MD, PRINTO Chairman  
Nicola Ruperto, MD, MPH, PRINTO Senior scientist  
PRINTO research assistants and web developers.

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### **The NEW website for families is on line!**

The PRINTO website for families represents an important reference for children, adolescents and young adults affected by paediatric rheumatic diseases and their families. It provides useful information on symptoms, diagnosis, therapy and impact on the every-day life of these diseases, together with the contacts of specialized paediatric centres and family associations for each country of the PRINTO/PRES networks.

The new 2016 PRINTO website for families (launched in December 2015), with updated information and a renewed graphical user interface, is now available in more than 60 languages for 56 countries! Since then it has already about 1,700 contacts per day from 174 countries.

Click on <http://www.printo.it/pediatric-rheumatology/> to discover it!

The new website contents can be shared on the main social networks (Facebook, Twitter etc), and are accessible with all portable devices (tablets, smartphones). A dedicated APP is available for Android OS ( <https://play.google.com/store/apps/details?id=it.printo.prdsearch> ).

It is important to underline that in order for your centre to be listed, you need to complete the SHARE survey for physicians ([www.printo.it/SHARE](http://www.printo.it/SHARE)) or contact PRINTO for new family associations.

The 2016 renovation of the website has been possible thanks to a grant from the European Union named SHARE (PI Nico Wullfraat, Co-PI PRINTO, project number 2011 1202), funding from the Gaslini Hospital (Genoa, Italy) and with the invaluable cooperation of the PRINTO/PRES members and family associations. More details about the methodology to develop the website and the goals of **SHARE** are reported below.

Thanks so much again to all the contributors who made this possible!

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### **23rd PRoS congress, 28 September - 01 October 2016, in Genoa!**

The Annual PRoS Meeting is a venue providing continued education, sharing of new research developments, and fostering academic collaboration, for clinicians, trainees, scientists and allied health professionals in the field of Pediatric Rheumatology.

**We are very happy to remember you that we will host in Genoa the 23rd PRoS annual congress, from the 28th September to the 1st of October 2016.**

**We are looking forward to welcoming all our friends in our beautiful town!**

The registration to PRoS 2016 is now open at <https://b-com.mci-group.com/Registration/DynamicRegistration/DynamicRegistrationPage.aspx?EventCode=PRS2016C&SiteCode=DEFAULT> .

The preliminary program is available at <http://www.pres.eu/current-pres-congress/scientific-programme.html> .

**Do not miss the PRINTO meeting on Friday 30 September at 17.30-18.30 (following the PRES AGM meeting)!**

The deadline for abstracts submission is Friday 20 May 2016. (see <https://b-com.mci-group.com/AbstractSubmission/PRS2016C.aspx> for more details).

Click on <http://www.pres.eu/> for more info about the PRoS society

**Important: Family associations can benefit of a free registration for the PRoS 2016 congress. Family associations listed on the website for families ( <http://www.printo.it/pediatric-rheumatology/> ) will receive from PRINTO a dedicated communication and the related code for free registration to PRES 2016 in Genoa.**

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## PRINTO ongoing projects

### PharmaChild

Juvenile idiopathic arthritis (JIA) is the most common chronic paediatric rheumatic disease and an important cause of short and long-term disability and quality of life impairment. Methotrexate (MTX) is the second line agent of first choice for the treatment of children with polyarticular JIA who do not respond to NSAIDs.

Patients with JIA who do not respond or are intolerant to MTX are candidates for the treatment with biologic agents such as anti-TNF, anti IL6, anti IL1, anti CTL4-IG and others currently in development. However, little information exists on the long term safety of these agents that are currently being used in children with JIA.

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.

This project is conducted by the participating centres belonging to [PRINTO](#) or the Pediatric Rheumatology European Society ([PRES](#)). As of today 7881 patients have been enrolled in about 80 centres from 38 countries (further details below).

Pharmachild start up has been funded by the European Union (EU) within the FP7 framework (contract number 260353, 2011-2014; principal investigator Dr Nico Wulffraat, co-principal investigator Dr Nicolino Ruperto).

The Pharmachild study 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.

### **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 cases, PRINTO 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 Pharmachild registry. Bristol-Myers Squibb (Abatacept in JIA) has agreed to fulfill its regulatory requirements toward FDA and EMA through the Pharmachild platform. As of today PRINTO members have enrolled 180 patients in 19 centres from 11 countries.

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### EPOCA

By involving the countries belonging to the network of PRINTO, EPOCA (EPidemiology, treatment and Outcome of Childhood Arthritis) aims to devise a new tool that enables the multidimensional assessment of the disease status in children with JIA. This new instrument, named Juvenile Arthritis Multidimensional Assessment Report (JAMAR), is simple easy to apply and multidimensional in nature. JAMAR's objectives are to foster the use of standardized quantitative outcome measures in daily care and to enable comparability of outcome data across different centers. Most clinical measures currently used to assess the disease status, particularly functional ability and health-related quality of life questionnaires, are lengthy and complex. According to agreed international guidelines JAMAR will be widely agreed upon and translated, cross-culturally adapted and validated in different languages by the PRINTO coordinators.

#### **Primary objectives**

##### **Outcome**

- To translate, cross-culturally adapt and validate the JAMAR in the language of each participating countries
- To compare the current outcomes of children with JIA across continents and countries.

##### **Secondary objectives**

##### **Epidemiology**

- To characterize and compare the frequency of the JIA categories in different countries and in different continents.
- To describe and compare the prevalence of iridocyclitis in different continents and in different countries.
- To define and compare the prevalence of ANA in the different JIA categories across diverse areas of the world.

## Treatment

- To compare the treatments used in the management of children with JIA in different countries.
- To obtain information on the access to biologic medications in different countries.
- To compare the same outcomes by disease category.

## Outcome

- To promote regular use of quantitative measures, either physician-centred or parent/patient-centred, in the assessment of children with JIA in standard clinical practice.
- To foster uniformity and standardization of clinical assessment of children with JIA across different countries.

## At present...

PRINTO is currently proceeding with the publication of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) supplement on a dedicated issue on parent/patient-reported outcomes (PROs) in juvenile idiopathic arthritis (JIA) in Rheumatology International. The supplement will contain one paper for each cross culturally adapted and validated version of the JAMAR (title example: The Italian version of the JAMAR, etc.) and a general introductory manuscript with the description of the methodological approach).

The authorship of each manuscript is defined according to PRINTO policy for authorship and the ICMJE criteria and completed with local input. The supplement will be submitted this year.

At present, the EPOCA data collection has been completed by 35 countries and it is still on going in other 16. Globally, more than 8500 JIA patients and almost 4000 healthy controls from 131 centres in 53 countries have been currently collected and confirmed through the dedicated online database. The statistical analysis and the paper drafting has been already completed by the PRINTO coordinating centre for 32 manuscripts.

**If you are interested in the project, please contact the PRINTO coordinating centre for the complete set of information (material for ethics committee submission, protocol, data collection forms).**

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## SHARE

The “Single Hub and Access point for paediatric Rheumatology in Europe” (acronym SHARE, project number 2011 1202; PI N. Wulffraat, 2012-2015) aims to provide the European countries with recommendations for the care of children with rheumatic diseases. These recommendations are based on systematic literature reviews and on a dedicate SHARE surveys.

To identify the specific needs for the optimal care in PRD, PRINTO implemented an online survey, available at [www.printo.it/SHARE](http://www.printo.it/SHARE) . In March 2016, more than 220 paediatric rheumatic centres had already completed the questionnaire.

Within the framework of SHARE PRINTO has updated and renovated its website for families (previous version of 2003).

The new site [www.printo.it/pediatric-rheumatology](http://www.printo.it/pediatric-rheumatology) launched in December 2015, offers scientific information regarding the pediatric rheumatic diseases (PRD), the list of centres dealing with PRD, and the list of the family associations in more than 60 languages.

The update of the disease information texts on paediatric rheumatic diseases has been performed with the help of several experts (paediatricians and healthcare professionals of the PRINTO/PReS network) and lay members of PRD family associations. Highly specialised working groups have been formed for the update of each specific disease text, whereas the parents’ network ensured both reader-friendliness and completeness on everyday life and therapy issues. Afterwards, this final version has circulated among all the working group members for further reading and revision.

The updated English texts were then translated with the help of a professional agency in 14 languages (on the basis of national population and language diffusion). For all remaining languages, a translation process started with the involvement and volunteer contribution of all PRINTO/SHARE partners. The PRINTO national coordinators had the role to organize and lead the work process. To facilitate the translation process, the source texts in English were uploaded on a dedicated online platform implemented by PRINTO.

The new version of the website has been designed to adapt to the various portable devices, and allows all technical supports to browse easily among the contents – from a technical point of view, multimodality and user friendliness have been identified as the main characteristics to satisfy. Being a tool for families and patients, it includes customised illustrations created by professional illustrators, the possibility to share contents via the main social networks and a Search button (also available for voice search on smartphones), along with a map locating the centres and associations via Google Maps.

In order to ease the contents’ consultation for the patients and their families, PRINTO has implemented an **APP for Android operating system** .

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Its design and structure reflect the website, with three main sections. The aim is to implement the same tool also for iOS and Windows.

**Parent survey:** in order to mirror the WP4 survey for physicians and have a clear picture of the standards of care from a patient/parent point of view, a dedicated survey has been prepared in a collaborative effort between Dr Nico Wulffraat and the ENCA (European Network for Children with Arthritis) members, represented by Ms Claudia Grave. The patient/parent survey has been translated in the following languages: Arabic, Czech, Danish, Dutch, English, French, German, Greek, Hebrew, Italian, Latvian, Lithuanian, Polish, Portuguese, Serbian, Slovak, Slovenian, Spanish.

Currently, almost 500 patients have completed the SHARE parent Survey.

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## **ABIRISK**

The introduction of biopharmaceuticals (BPs) has been a critical step forward in the treatment of many severe diseases including juvenile idiopathic arthritis (JIA). There are now several BPs for the treatment of JIA, and numerous novel molecules are anticipated in the next few years. A major limitation to the use of BPs is the development of anti-drug antibodies (ADA) in a subset of patients. ADAs may decrease the efficacy of BPs by neutralizing them or modifying their clearance, and they may be associated with BP-specific hypersensitivity (HS) reactions. The prediction, prevention and cure of anti-drug immunogenicity are thus major goals in BP drug development and patient safety.

[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 managed this project as a sub-study of PharmaChild and succeeded to collect the biologic samples (Serum and RNA) of more than 120 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 samples will be sent to the PRINTO facilities in Genoa (Italy), then transferred to the ABIRISK consortium for antibodies evaluation. The clinical data are the data collected for the PharmaChild registry.

The ABIRISK Consortium, composed of 36 partners from both academia and industry, has the chance to bring together a large network of adult and paediatric clinicians from various specialties with broad experience in the care of patients treated with BP known to develop ADA, access to clinical samples from large cohorts of treated patients, renowned academic scientists, immunologists, biologists, database experts, statisticians and leading companies of [European Federation of Pharmaceutical Industries and Associations](#) (EFPIA).

Download [ABIRISK brochure](#).

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## **Eurofever**

The Eurofever project 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 numero grant e anno). As of today Eurofever has enrolled 3303 patients from 39 countries (see enrollment table below).

**IMPORTANT: The registry is still actively recruiting and new studies will be performed.**

**The Steering Committee of Eurofever thanks you for your essential contribution to the current enrollment phase and is more than happy to receive any proposal for possible studies based on the Eurofever data.**

The general aims of the Eurofever project are to:

- sensitive pediatricians and pediatric rheumatologists to the prompt recognition of Autoinflammatory Diseases;
- provide proper information to families affected by these conditions;
- increase the knowledge on the clinical presentation, response to treatment and complications of these rare disorders.

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

**Last year a new section dedicated to Efficacy and Safety has been implemented and the registry is now able to collect also longitudinal information.**

New auto - inflammatory diseases have been added, as of today the following conditions are considered by the Project:

- Behçet disease
  - Blau's syndrome/Early onset sarcoidosis
  - Cryopyrin associated periodic syndrome
  - Chronic recurrent multifocal osteomyelitis
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- Deficiency of IL-1 receptor antagonist
- Familial Mediterrean Fever
- Mevalonate kinase deficiency (Hyper IgD syndrome)
- NLRP12 -associated periodic syndrome
- Pyogenic Sterile Arthritis, Pyoderma Gangrenosum and Acne (PAPA) syndrome
- Tumor necrosis factor receptor-associated periodic syndrome (TRAPS)
- Periodic fever, aphthous stomatitis, pharyngitis and cervical adenitis (PFAPA)
- CANDLE syndrome
- DITRA syndrome
- Schnitzler syndrome
- Majeed syndrome
- Deficiency of Adenosine Deaminase 2 (DADA2)
- STING-associated vasculopathy with onset in infancy (SAVI)
- CARD14 mediated psoriasis (CAMPS)
- Undefined Periodic fever

### The MYPAN trial in Childhood Polyarteritis Nodosa (PAN)

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 is underway (PI Dr P. Brogan). MYPAN will investigate the comparative efficacy and safety of MMF (experimental treatment) vs CYC (standard treatment) for induction of remission of childhood PAN. This will be the first ever randomized trial for childhood PAN. As of today 29 centres have shown interest in participating in MYPAN: PRINTO is currently working at the submission procedures to the regulatory authorities and ethics committees of the non-UK centres, while the first patients have been enrolled at the UK sites.

### Patients enrolled in the PRINTO projects

Country	ABIRISK Registry	EPOCA	EUROFEVER	PHARMACHILD
Algeria	0	140	0	0
Argentina	0	473	54	123
Armenia	0	0	101	0
Australia	0	0	10	0
Austria	0	0	1	24
Belgium	0	200	0	0
Brazil	0	303	9	384
Bulgaria	0	300	0	57
Canada	0	160	1	0
Chile	0	119	5	0
China	0	0	14	0
Colombia	0	10	0	0
Croatia	0	100	11	100
Czech Republic	26	203	194	119
Denmark	0	402	135	542
Egypt	0	200	0	0
Estonia	0	210	0	0
Finland	0	276	0	0
France	18	0	284	261
Georgia	0	200	9	0

Germany	0	424	268	2
Greece	40	375	73	482
Hungary	0	297	3	126
India	0	375	1	119
Iran, Islamic Republic of	0	320	0	0
Israel	0	216	149	84
Italy	24	1381	965	1284
Japan	0	0	6	0
Latvia	2	304	6	259
Lebanon	0	0	1	0
Libya	0	200	0	0
Lithuania	0	217	2	314
Mexico	0	199	0	12
Netherlands	0	317	97	586
Norway	3	375	0	355
Oman	0	143	4	16
Paraguay	0	151	0	0
Poland	2	248	8	29
Portugal	0	87	0	0
Romania	0	411	42	419
Russian Federation	0	0	45	468
Saudi Arabia	0	200	39	70
Serbia	0	349	4	266
Slovakia	0	208	0	126
Slovenia	0	223	13	53
South Africa	0	65	0	0
Spain	3	605	196	710
Sweden	0	144	0	0
Switzerland	1	100	94	490
Thailand	0	206	0	0
Turkey	11	563	193	1
Ukraine	0	200	0	0
United Kingdom	0	200	266	0
United States	0	413	0	0
<b>Total</b>	<b>130</b>	<b>12812</b>	<b>3303</b>	<b>7881</b>

### [PRINTO overall enrollment status](#)

#### [Latest PRINTO papers](#)

Minoia F, Davì S, Horne A, Bovis F, Demirkaya E, Akikusa J, Ayaz NA, Al-Mayouf SM, Barone P, Bica B, Bolt I, Breda L, De Cunto C, Enciso S, Gallizzi R, Griffin T, Hennon T, Horneff G, Jeng M, Kapovic AM, Lipton JM, Magni Manzoni S, Rumba-Rozenfelde I, Magalhaes CS, Sewairi WM, Stine KC, Vougiouka O, Weaver LK, Davidsons Z, De Inocencio J, Ioseliani M, Lattanzi B, Tezer H, Buoncompagni A, Picco P, Ruperto N, Martini A, Cron RQ, Ravelli A; Pediatric Rheumatology International Trials Organization; Childhood Arthritis and Rheumatology



Research Alliance; Pediatric Rheumatology Collaborative Study Group; and the Histiocyte Society.

**Dissecting the Heterogeneity of Macrophage Activation Syndrome Complicating Systemic Juvenile Idiopathic Arthritis.**

J Rheumatol 2015;42(6):994-1001. [PubMed](#)

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Lovell DJ, Ruperto N, Mouy R, Paz E, Rubio-Pérez N, Silva CA, Abud-Mendoza C, Burgos-Vargas R, Gerloni V, Melo-Gomes JA, Saad-Magalhaes C, Chavez-Corrales J, Huemer C, Kivitz A, Blanco FJ, Foeldvari I, Hofer M, Huppertz HI, Deslandre CJ, Minden K, Punaro M, Block AJ, Giannini EH, Martini A for the Pediatric Rheumatology Collaborative Study Group (PRCSG) and the Paediatric Rheumatology International Trials Organization (PRINTO).

**Long-term safety, efficacy, and quality of life with intravenous abatacept in juvenile idiopathic arthritis: up to 7 years of treatment.**

Arthritis Rheum 2015;67(10):2759-70. [PubMed](#)

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Levy R, Gérard L, Kuemmerle-Deschner J, Lachmann HJ, Koné-Paut I, Cantarini L, Woo P, Naselli A, Bader-Meunier B, Insalaco A, Al-Mayouf SM, Ozen S, Hofer M, Frenkel J, Modesto C, Nikishina I, Schwarz T, Martino S, Meini A, Quartier P, Martini A, Ruperto N, Neven B, Gattorno M for the Paediatric Rheumatology International Trials Organisation (PRINTO) and Eurofever.

**Phenotypic and genotypic characteristics of cryopyrin-associated periodic syndrome: a series of 136 patients from the Eurofever Registry.**

Ann Rheum Dis 2015;74:2043–2049. [PubMed](#)

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Ravelli A, Minoia F, Davì S, Horne A, Bovis F, Pistorio A, Aricò M, Avcin T, Behrens EM, De Benedetti F, Filipovic A, Grom AA, Henter JI, Ilowite NT, Jordan MB, Khubchandani R, Kitoh T, Lehmborg K, Lovell DJ, Miettunen P, Nichols KE, Ozen S, Pachlopnik Schmid J, Ramanan AV, Russo R, Schneider R, Sterba G, Uziel Y, Wallace C, Wouters C, Wulffraat N, Demirkaya E, Brunner HI, Martini A, Ruperto N, Cron RQ, on behalf of the Pediatric Rheumatology International Trials Organization, the Childhood Arthritis & Rheumatology Research Alliance, the Pediatric Rheumatology Collaborative Study Group and the Histiocyte Society

**Expert consensus on dynamics of laboratory tests for diagnosis of macrophage activation syndrome complicating systemic juvenile idiopathic arthritis**

RDM open 2016 Jan 19;2(1) [PubMed](#)

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Ruperto N, Pistorio A, Oliveira S, Zulian F, Cuttica R, Ravelli A, Fischbach M, Magnusson B, Sterba G, Avcin T, Brochard K, Corona F, Dressler F, Gerloni V, Apaz MT, Bracaglia C, Cespedes-Cruz A, Cimaz R, Couillault G, Joos R, Quartier P, Russo R, Tardieu M, Wulffraat N, Bica B, Dolezalova P, Ferriani V, Flato B, Guilaissne Bernard-Medina A, Herlin T, Trachana M, Meini A, Allain-Launay E, Pilkington C, Vargova V, Wouters C, Angioloni S, Martini A for the Paediatric Rheumatology International Trials Organisation (PRINTO).

**A randomized trial in new onset juvenile dermatomyositis: prednisone versus prednisone plus cyclosporine versus prednisone plus methotrexate.**

Lancet 2016;387:671-678. [PubMed](#)

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Demirkaya E, Saglam C, Turker T, Koné-Paut I, Woo P, Doglio M, Amaryan G, Frenkel J, Uziel Y, Insalaco A, Cantarini L, Hofer M, Boiu S, Duzova A, Modesto C, Bryant A, Rigante D, Papadopoulou-Alataki E, Guillaume-Czitrom S, Kuemmerle-Deschner J, Neven B, Lachmann H, Martini A, Ruperto N, Gattorno M, Ozen S for the Paediatric Rheumatology International Trials Organisations (PRINTO) and Eurofever Project.

**Performance of Different Diagnostic Criteria for Familial Mediterranean Fever in Children with Periodic Fevers: Results from a Multicenter International Registry.**

J Rheumatol 2016;43:154-160. [PubMed](#)

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Ravelli A, Minoia F, Davì S, Horne A, Bovis F, Pistorio A, Aricò M, Avcin T, Behrens EM, De Benedetti F, Filipovich L, Grom AA, Henter J, Ilowite NT, Jordan MB, Khubchandani R, Kitoh T, Lehmborg K, Lovell DJ, Miettunen P, Nichols KE, Ozen S, Pachlopnick-Schmid J, Ramanan AV, Russo R, Schneider R, Sterba G, Uziel Y, Wallace C, Wouters C, Wulffraat N, Demirkaya E, Brunner HI, Martini A, Ruperto N, Cron RQ for the Pediatric Rheumatology International Trials Organization (PRINTO); the Childhood Arthritis & Rheumatology Research Alliance (CARRA); the Pediatric Rheumatology Collaborative Study Group (PRCSG); the Histiocyte Society.

**2016 Classification criteria for macrophage activation syndrome complicating systemic juvenile idiopathic arthritis. A European League Against Rheumatism/American College of Rheumatology/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.**

Ann Rheum Dis - 2016;75:481–489. [PubMed](#)

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Grom AA, Ilowite NT, Pascual V, Brunner HI, Martini A, Lovell DJ, Ruperto N, Leon K, Lheritier K, Abrams K for the Paediatric Rheumatology International Trials Organisation (PRINTO) and the Pediatric Rheumatology Collaborative Study Group (PRCSG).

### **Canakinumab in Systemic Juvenile Idiopathic Arthritis: Impact on the Rate and Clinical Presentation of Macrophage Activation Syndrome.**

Arthritis Rheum [Epub ahead of print] [PubMed](#)

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Demirkaya E, Lanni S, Bovis F, Galasso R, Ravelli A, Palmisani E, Consolaro A, Pederzoli S, Marafon D, Simianer S, Martini A, Ruperto N, Pistorio A for the Paediatric Rheumatology International Trials Organisation (PRINTO)

### **A meta-analysis to estimate the placebo effect in juvenile idiopathic arthritis in randomized controlled trials.**

Arthritis Rheum [Epub ahead of print] [PubMed](#)

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Ravelli A, Minoia F, Davì S, Horne A, Bovis F, Pistorio A, Aricò M, Avcin T, Behrens EM, De Benedetti F, Filipovich L, Grom AA, Henter J, Ilowite NT, Jordan MB, Khubchandani R, Kitoh T, Lehmborg K, Lovell DJ, Miettunen P, Nichols KE, Ozen S, Pachlopnick-Schmid J, Ramanan AV, Russo R, Schneider R, Sterba G, Uziel Y, Wallace C, Wouters C, Wulffraat N, Demirkaya E, Brunner HI, Martini A, Ruperto N, Cron RQ for the Pediatric Rheumatology International Trials Organization (PRINTO); the Childhood Arthritis & Rheumatology Research Alliance (CARRA); the Pediatric Rheumatology Collaborative Study Group (PRCSG); the Histiocyte Society.

### **Development and initial validation of classification criteria for macrophage activation syndrome complicating systemic juvenile idiopathic arthritis.**

Arthritis Rheum [Epub ahead of print] [PubMed](#)

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Constantin T, Foeldvari I, Vojinovic J, Horneff G, Burgos-Vargas R, Nikishina I, Akikusa JD, Avcin T, Chaitow J, Koskova E, Lauwerys BR, Calvo Penades I, Flato B, Gamir ML, Huppertz HI, Raad JJ, Jarosova K, Anton J, Macku M, Otero Escalante WJ, Rutkowska-Sak L, Trauzeddel R, Velez-Sanchez PJ, Wouters C, Wajdula J, Zang C, Bukowski J, Woodworth D, Vlahos B, Martini A, Ruperto N for Paediatric Rheumatology International Trials Organisation (PRINTO).

### **Two-year Efficacy and Safety of Etanercept in Pediatric Patients with Extended Oligoarthritis, Enthesitis-related Arthritis, or Psoriatic Arthritis.**

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

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## **Membership**

As of today, PRINTO has reached 1318 effective members in 516 centres from 83 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**

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Nico Wulffraat, MD, PhD - Utrecht, The Netherlands

### **Senior Scientist**

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