



www.printo.it

www.printo.it/pediatric-rheumatology

25th PRINTO newsletter | May 2017

Table of contents

News

PRINTO ongoing projects

- EPOCA
- PharmaChild
- ABIRISK
- Eurofever
- SHARE
- The MYPAN trial

Patients enrolled in the PRINTO projects

Latest PRINTO papers

Membership

PRINTO Advisory council & contacts

News

PRINTO elections

In the last months PRINTO has organized the elections for the National Coordinators (NCC) for the period 2017-2021. Each PRINTO centre within a specific country had the right to apply for the role of coordinator for that country, and then vote among the candidates. Please find below the [list of the new PRINTO National Coordinators](#):

COUNTRY	TOWN	PRINTO NCC
Algeria	Alger	Maya-Feriel Aiche
Argentina	Buenos Aires	Ruben Cuttica
Australia	North Adelaide	Christina Boros
Austria	Bregenz	Christian Huemer
Bahrain	Albosaiteen	Sahar Saad
Bangladesh	Dhaka	Shahana Akhter Rahman
Belgium	Gent	Rik Joos
Bosnia and Herzegovina	Sarajevo	Velma Mulaosmanovic
Brazil	Botucatu	Claudia Saad Magalhaes
Bulgaria	Varna	Boriana Varbanova
Chile	Santiago	Benito Gonzalez
China	Beijing	Caifeng Li
Colombia	Bogota	Clara Malagon
Costa Rica	San Jose	Oscar Porras
Croatia	Zagreb	Marija Jelusic
Cuba	Santa Clara	Santa Yarelis Gomez Conde
Cyprus	Nicosia	Elpida Mina

Czech Republic	Praha	Pavla Dolezalova
Denmark	Copenhagen	Susan Nielsen
Ecuador	Guayaquil	Cristina Herrera Mora
Egypt	Cairo	Yasser El Miedany
Estonia	Tartu	Chris Pruunsild
Finland	Helsinki	Pekka Lahdenne
France	Paris	Pierre Quartier
Georgia	Tbilisi	Maka Ioseliani
Germany	Muenster	Dirk Foell
Greece	Athens	Elena Tsitsami
Hungary	Budapest	Tamas Constantin
India	Chandigarh	Surjit Singh
Iran, Islamic Republic of	Teheran	Nahid Shafaie
Israel	Kfar Saba	Yosef Uziel
Italy	Genova	Nicolino Ruperto
Japan	Kagoshima	Syuji Takei
Jordan	Amman	Adel Mohammad Alwahadneh
Korea, Republic of	Seoul	Soo-Kyung Cho
Latvia	Riga	Ingrida Rumba-Rozenfelde
Lebanon	Byblos	Rawane Dagher
Libya	Tripoli	Soad Hashad
Lithuania	Vilnius	Violeta Panaviene
Mexico	Monterrey	Nadina Rubio-Perez
Netherlands	Utrecht	Joost Swart
Norway	Trondheim	Marite Rygg
Oman	Muscat	Reem Abdwani
Paraguay	San Lorenzo	Zoilo Morel Ayala
Peru	Lima	Amparo Ibanez Estrella
Poland	Lodz	Elzbieta Smolewska
Portugal	Lisbon	Jose Antonio Melo-Gomes
Romania	Cluj-Napoca	Calin Lazar
Russian Federation	Moscow	Irina Nikishina
Saudi Arabia	Riyadh	Sulaiman M. Al-Mayouf
Serbia	Belgrade	Gordana Susic
Slovakia	Bratislava	Tomas Dallos
Slovenia	Ljubljana	Tadej Avein
South Africa	Cape Town	Christiaan Scott
Spain	Madrid	Jaime De Inocencio
Sweden	Uppsala	Lillemor Berntson
Switzerland	Lausanne	Michael Hofer
Thailand	Bangkok	Soamarat Vilaiyuk
Tunisia	El Menzah	Rym Hajri Ben Ammar
Turkey	Ankara	Seza Ozen
Ukraine	Lviv	Yaryna Boyko
United Kingdom	Liverpool	Michael Beresford

After these elections, PRINTO has put in place the election for the 6 Counsellors of the Advisory Council. Each National Coordinator had the right to apply for the role of Counselor. After the receipt of the candidatures, each National Coordinator voted for 6 candidates.

The elected Counsellors for the period 2017-2021 are:

Tadej Avcin, MD, MSc - Ljubljana, Slovenia
Michael Hofer, MD, Prof - Lausanne, Switzerland
Seza Ozen, MD, Prof - Ankara, Turkey
Pierre Quartier, MD - Paris, France
Claudia Saad Magalhaes, MD, PhD - Botucatu, Brazil
Joost Swart, MD - Utrecht, The Netherlands

Congratulations to the new Advisory Council and best wishes for a successful work!

24th Paediatric Rheumatology European Society Congress (PReS 2017), Athens, Greece, 14-17 September 2017.

The 24th Paediatric Rheumatology European Society Congress (PReS 2017) will be held from 14th to 17th September 2017 in Athens, Greece. Continuing the successful trend of past Congresses, the PReS 2017 Congress will feature presentations of some of the most recent research and trials, and will be characterized by robust debates on the clinical challenges of modern pediatric rheumatology.

Moreover, the Congress will provide unique opportunities to network with leadership in Pediatric Rheumatology and enjoy enlightened and innovative learning experiences that highlight the most up-to-date, evidence-based developments in the field.

For more details, please visit the official website of the event:

<http://www.pres.eu/pres2017/>

There you will find the welcome messages from Berent Prakken, President of the Society, (<http://www.pres.eu/>) and from Elena Tsitsami, President of the Local Organizing Committee, together with the Scientific Program of the congress and all the related practical information on the meeting.

Annual PRINTO General meeting

The PRINTO meeting at PReS will be held on

Friday 15 September at 2.00-4.00 pm

in room MC3, Megaron Athens International Conference Centre - MAICC

Vass. Sofias & Kokkali

Athens 115 21

Greece

Mark your calendars and save the date for September 14-17, 2017!

PRINTO ongoing projects

EPOCA

By involving more than 50 countries belonging to the network of Paediatric Rheumatology International Trials Organisation (PRINTO certified ISO 9001-2008, www.printo.it) 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 glad to announce that **we have just submitted to Rheumatology International the first batch of 39 papers** that will be part of a dedicated supplement of the Journal on patient's reported outcomes (PRO)s.

The supplement will contain one paper for each cross-culturally adapted and validated version of the JAMAR (for instance "The Italian version of the JAMAR") and a general introductory manuscript with the description of the methodological approach. This methodological paper is currently in draft and will include the data related to the 39 countries for which the analysis has been already completed and will be progressively updated with the data of the the remaining 11 manuscripts still in progress.

The authorship of each manuscript is defined according to PRINTO policy and ICMJE recommendations for authorship and completed with local input. The main responsible of the project in each country is listed in the first positions followed by the remaining significant authors. Additional people are listed in the acknowledgment section.

Globally, for EPOCA, **PRINTO has collected** by now **more than 9000 JIA patients and almost 5000 healthy controls from 125 centres in 51 countries** .

Thanks to all the participating centres for their effort and contribution within the EPOCA study!

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 etanercept, infliximab, adalimumab, abatacept 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 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 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.

At present...

Currently the PharmaChild registry includes the prospective data of more than 3200 patients and the retrospective data of more than 8000 patients coming from more than 60 centres located in over 30 countries worldwide.

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 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. List of companies which have agreed to cooperate with Pharmachild: - Bristol-Myers Squibb (Abatacept in JIA).

At present...

As of today the Abatacept JIA Registry sponsored by Bristol-Myers Squibb has enrolled more than 150 patients in the over 20 centres belonging to the PRCSG group in Canada and US and more than 200 patients in the 30 centres belonging to the PRINTO network in Europe and rest of the world.

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).

For further information, you can contact the PRINTO office.

Download [ABIRISK brochure](#).

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).

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

Since 2015 the registry is collecting also Efficacy and Safety information longitudinally and the newly discovered autoinflammatory diseases. The number of centers and patients are constantly increasing. As of today 111 centers from 39 countries registered 3917 patients in the web system.

CLASSIFICATION CRITERIA

During the Consensus Conference held at Villa Quartara in Genova on 15-18 March, thanks to the successful collaboration of 31 experts coming from 13 countries, we established the classification criteria for Familiar Mediterranean Fever (FMF), Mevalonate kinase deficiency (MKD), Cryopyrin associated periodic fever syndrome (CAPS), TNF receptor associated periodic fever syndrome (TRAPS) and Periodic Fever With Aphthous Pharyngitis Adenitis (PFAPA).

SHARE

The “Single Hub and Access point for paediatric Rheumatology in Europe” (acronym SHARE, project number 2011 1202; PI N. Wulffraat) 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 the surveys sent by PRINTO to individual centres belonging to its network all over the world.

To identify the specific needs for the optimal care in PRD, PRINTO implemented an online survey, available at www.printo.it/SHARE. In May 2017, more than 235 paediatric rheumatic centres had already completed the questionnaire.

Thanks to this project, PRINTO has updated and renovated its website for families, launched in 2003 (Ruperto N, et Al. for PRINTO/PRES Printo/Pres international website for families of children with rheumatic diseases: www.pediatric-rheumatology.printo.it. Ann Rheum Dis 2005; 64:1101-1106).

The new site 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**. Its design and structure reflect the website, with three main sections.

Parent survey: in order to mirror the 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, more than 900 patients have completed the SHARE parent survey.

The MYPAN trial

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 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 30 centres (UK and non-UK sites) have shown interest in participating in MYPAN: PRINTO is currently working at the submission procedures to the regulatory authorities/ethics committees and at the sites activation of the non-UK centres, while the first patients have been enrolled.

Patients enrolled in the PRINTO projects

Country	EPOCA	PHARMACHILD	EUROFEVER	ABIRISK Registry
Algeria	140	0	0	0
Argentina	473	123	57	0
Armenia	0	0	101	0
Australia	0	0	13	0
Austria	0	29	27	0
Belgium	199	0	13	0

Brazil	303	392	17	0
Bulgaria	300	57	0	0
Canada	355	0	8	0
Chile	119	0	5	0
China	0	0	14	0
Colombia	10	0	0	0
Croatia	200	152	11	0
Czech Republic	203	119	215	26
Denmark	402	542	135	0
Ecuador	46	23	0	0
Egypt	200	0	0	0
Estonia	210	0	0	0
Finland	273	0	0	0
France	222	297	287	20
Georgia	200	0	9	0
Germany	424	1	297	0
Greece	375	485	147	47
Hungary	297	127	24	0
India	375	119	3	0
Iran, Islamic Republic of	320	0	0	0
Israel	216	87	168	0
Italy	1400	1446	1189	28
Japan	0	0	6	0
Latvia	304	259	6	2
Lebanon	0	0	1	0
Libya	200	0	0	0
Lithuania	217	320	7	0
Mexico	199	56	0	0
Netherlands	317	657	117	0
Norway	375	362	0	4
Oman	143	16	6	0
Paraguay	151	0	0	0
Poland	248	29	9	3
Portugal	109	0	0	0
Romania	411	426	46	1
Russian Federation	298	468	62	0
Saudi Arabia	200	70	39	0
Serbia	349	276	5	0
Slovakia	208	126	1	1
Slovenia	223	53	18	0
South Africa	191	0	0	0

Spain	605	711	250	3
Sweden	144	0	1	0
Switzerland	167	490	95	1
Thailand	206	0	0	0
Turkey	563	1	206	11
Ukraine	200	0	0	0
United Kingdom	200	0	296	0
United States	413	0	6	0
Total	13903	8319	3917	147

[PRINTO overall enrollment status](#)

Latest PRINTO papers

Ter Haar NM, Jeyaratnam J, Lachmann HJ, Simon A, Brogan PA, Doglio M, Cattalini M, Anton J, Modesto C, Quartier P, Hoppenreijns E, Martino S, Insalaco A, Cantarini L, Lepore L, Alessio M, Calvo Penades I, Boros C, Consolini R, Rigante D, Russo R, Pachlopnik Schmid J, Lane T, Martini A, Ruperto N, Frenkel J, Gattorno M; Paediatric Rheumatology International Trials Organisation (PRINTO) and Eurofever Project.

The phenotype and genotype of mevalonate kinase deficiency: a series of 114 cases from the Eurofever Registry

Arthritis Rheumatol 2016;68(11):2795-2805 [PubMed](#)

Brachat AH, Grom AA, Wulfraat N, Brunner HI, Quartier P, Brik R, McCann L, Ozdogan H, Rutkowska-Sak L, Schneider R, Gerloni V, Harel L, Terreri M, Houghton K, Joos R, Kingsbury D, Lopez-Benitez JM, Bek S, Schumacher M, Valentin MA, Gram H, Abrams K, Martini A, Lovell DJ, Nirmala NR, Ruperto R for the Pediatric Rheumatology International Trials Organization (PRINTO) and the Pediatric Rheumatology Collaborative Study Group (PRCSG).

Changes in Gene Expression and Inflammatory Proteins in Systemic Juvenile Idiopathic Arthritis Patients on Canakinumab Therapy

Arthritis Res Ther 2017; Jan 23;19(1):13 [PubMed](#)

Frid P, Nordal E, Bovis F, Giancane G, Larheim TA, Rygg M, Pires Marafon D, De Angelis D, Palmisani E, Murray KJ, Oliveira S, Simonini G, Corona F, Davidson J, Foster H, Steenks MH, Flato B, Zulian F, Baildam E, Saurenmann RK, Lahdenne P, Ravelli A, Martini A, Pistorio A, Ruperto N for the Paediatric Rheumatology International Trials Organisation (PRINTO).

Temporomandibular Joint Involvement is Associated with Quality of Life, Disability and High Disease Activity in Juvenile Idiopathic Arthritis.

Arthritis Care Res 2017;69(5):677-686 [PubMed](#)

Aggarwal R, Rider LG, Ruperto N, Bayat N, Erman B, Feldman BM, Oddis CV, Amato AA, Chinoy H, Cooper RG, Dastmalchi M, Fiorentino D, Isenberg D, Katz JD, Mammen A, de Visser M, Ytterberg SR, Lundberg IE, Chung L, Danko K, García-De la Torre I, Song YW, Villa L, Rinaldi M, Rockette H, Lachenbruch PA, Miller FW, Vencovsky J; for the International Myositis Assessment and Clinical Studies Group and the Paediatric Rheumatology International Trials Organisation (PRINTO).

2016 American Rheumatism Criteria for Minimal, Moderate, and Major Clinical Response in Adult Dermatomyositis and Polymyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.

Arthritis Rheumatol 2017;69(5):898-910. [PubMed](#)

Rider LG, Aggarwal R, Pistorio A, Bayat N, Erman B, Feldman BM, Huber AM, Cimaz R, Cuttica RJ, de Oliveira SK, Lindsley CB, Pilkington CA, Punaro M, Ravelli A, Reed AM, Rouster-Stevens K, van Royen-Kerkhof A, Dressler F, Magalhaes CS, Constantin T, Davidson JE, Magnusson B, Russo R, Villa L, Rinaldi M, Rockette H, Lachenbruch PA, Miller FW, Vencovsky J, Ruperto N for the International Myositis Assessment and Clinical Studies Group and the Paediatric Rheumatology International Trials Organisation (PRINTO).

2016 American College of Rheumatology/European League Against Rheumatism Criteria for Minimal, Moderate, and Major Clinical Response in Juvenile Dermatomyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.

Rider LG, Aggarwal R, Pistorio A, Bayat N, Erman B, Feldman BM, Huber AM, Cimaz R, Cuttica RJ, de Oliveira SK, Lindsley CB, Pilkington CA, Punaro M, Ravelli A, Reed AM, Rouster-Stevens K, van Royen-Kerkhof A, Dressler F, Saad Magalhaes C, Constantin T, Davidson JE, Magnusson B, Russo R, Villa L, Rinaldi M, Rockette H, Lachenbruch PA, Miller FW, Vencovsky J, Ruperto N for the International Myositis Assessment and Clinical Studies Group and the Paediatric Rheumatology International Trials Organisation (PRINTO).

2016 American College of Rheumatology/European League Against Rheumatism Criteria for Minimal, Moderate, and Major Clinical Response in Juvenile Dermatomyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.

Ann Rheum Dis 2017;76(5):782-791 [PubMed](#)

Aggarwal R, Rider LG, Ruperto N, Bayat N, Erman B, Feldman BM, Oddis CV, Amato AA, Chinoy H, Cooper RG, Dastmalchi M, Fiorentino D, Isenberg D, Katz JD, Mammen A, de Visser M, Ytterberg SR, Lundberg IE, Chung L, Danko K, García-De la Torre I, Song YW, Villa L, Rinaldi M, Rockette H, Lachenbruch PA, Miller FW, Vencovsky J for the International Myositis Assessment and Clinical Studies Group and the Paediatric Rheumatology International Trials Organisation (PRINTO).

2016 American College of Rheumatology/European League Against Rheumatism criteria for minimal, moderate, and major clinical response in adult dermatomyositis and polymyositis: An International Myositis Assessment and Clinical Studies Group/Paediatric Rheumatology International Trials Organisation Collaborative Initiative.

Ann Rheum Dis 2017;76(5):792-801 [PubMed](#)

Membership

As of today, PRINTO has reached 1592 effective members in 603 centres from 87 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
Joost Swart, MD - Utrecht, The Netherlands

Senior Scientist

Nicolino Ruperto, MD, MPH - Genoa, Italy

PRINTO Coordinating center contacts

IRCCS G. Gaslini
Pediatria II - **PRINTO**
Via Gaslini, 5
16147 Genova, **ITALY**
Tel: +39-010-38-28-54 or +39-010-39-34-25
Fax +39-010-39-33-24 or +39-010-39-36-19
E-mail: printo@gaslini.org

