

PRINTO PROJECTS

	JDM trial	Vasculitis	MTX JIA
Albania		5	
Argentina	13	69	27
Austria		5	
Belgium	2		
Brasil	11	118	33
Bulgaria		8	20
Chile		20	18
Croatia		8	4
Czech Republic	2	7	5
Denmark	2	141	1
El Salvador		19	
Estonia		5	
France	20	67	9
Georgia		8	2
Germany	3	27	36
Greece		20	17
Hungary			1
India		48	9
Iraq		1	
Israel	1	123	8
Italy	24	274	35
Kuwait			2
Latvia	1	29	23
Libya		1	
Mexico	6	12	2
Netherlands	4	10	47
Norway	2		
Peru		14	
Poland		3	1
Portugal			3
Romania		59	
Russia		7	2
Saudi Arabia		8	
Serbia	1	5	16
Slovakia	2	2	4
Slovenia	1	1	
Spain		18	16
Sweden	4	2	1
Switzerland			4
Turkey		214	2
Un. Kingdom	1	35	16
USA	1	6	
Venezuela	5		
Total	106	1399	364

Paediatric Rheumatology International
Trials Organisation (PRINTO)
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May 2009

Paediatric Rheumatology International Trials Organisation (PRINTO)



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PReS Congress 2009 Copenhagen, Denmark

Friday, June 12, 2009 at **12.00-13.15**

PRES room

Agenda for the annual PRINTO workshop

- Introduction (A. Martini)
- Update on PRINTO Projects (N. Ruperto)
- Results of the vasculitis project (S. Ozen)
- Results of the MTX withdrawal trial (D. Foell)
- The PRES EuroFever project (M. Gattorno)

New onset JDM trial:

- prednisone (PDN) versus
- PDN plus methotrexate versus
- PDN plus Cyclosporine A.

The trial is approaching the end! As of today 106 patients from 20 countries (see table next page) have been enrolled. Other 105 patients could not be enrolled due to lack of inclusion criteria (mainly referral delays).

A total of 103 centres in 31 countries have now obtained ethics committee approval.

No major safety concern identified so far

PRES/PRINTO/EULAR vasculitides registry:

The PReS Vasculitis Working Group, in collaboration with PRINTO (EULAR support) designed the registry to validate the recently developed "EULAR/PreS endorsed criteria for the classification of childhood vasculitides". The project is **NOW OVER** (see table next page) and the related 5 papers will soon be submitted.

MTX withdrawal: to determine if the time to discontinue MTX (6 versus 12 months) in JIA with inactive disease, influences the time to relapse. The project is **NOW OVER** (see table next page) and the paper(s) in preparation.

Genomics and Pediatric Rheumatic Diseases survey:

PRINTO designed the present survey to identify centres which have families with paediatric rheumatic diseases (PRD) where more cases of the same disease (e.g. JIA or JSLE or JDM etc) are present among brothers and/or sisters (affected sib pairs). A total of 382 families with JIA and other PRD have been identified. We have now collected 44 JIA families and should arrive to a total of 60 by the end of summer.

The PRES Eurofever project. The PReS Autoinflammatory Diseases' Working Group, in collaboration with PRINTO designed a survey to set up a series of Registries for the different Autoinflammatory diseases. The related data collection will start in the next few months

Study payment (Vasculitis, MTX withdrawal) the related payment are under way.

Membership: 491 effective members in 278 centres (34% increase) from 52 countries.

Recent PRINTO publications

For reprints go to www.printo.it and click on papers.

- Ruperto N, Martini A, for PRINTO. Network in pediatric rheumatology: the example of the Pediatric Rheumatology International Trials Organisation. **World J Pediatr 2008;4(3):186-191.**
- Lovell DJ, Ruperto N for PRCSG/PRINTO. Adalimumab in juvenile rheumatoid arthritis. The Authors reply. **NEJM 2008;359(23):2496-2497.**
- Bazso A, Consolaro A, Ruperto N, Pistorio A, Viola S, Magni-Manzoni S, Malattia C, Buoncompagni A, Loy A, Martini A, Ravelli A, for PRINTO. Development and testing of reduced joint counts in juvenile idiopathic arthritis. **J Rheumatol 2009;36:183-190.**
- Saad-Magalhães C, Pistorio A, Ravelli A, Filocamo G, Viola S, Brik R, Mihaylova D, ten Cate R, Andersson-Gare B, Ferriani V, Minden K, Hashkes PJ, Rygg M, Sauvain MJ, Venning H, Martini A, Ruperto N, for PRINTO. Does removal of aids/devices and help make a difference in the Childhood Health Assessment Questionnaire Disability Index? **Ann Rheum Dis 2009; Feb 16 (E-pub ahead of print).**
- Apaz MT, Saad-Magalhães C, Pistorio A, Ravelli A, de Oliveira Sato J, Marcantoni MB, Meiorin S, Filocamo G, Pilkington C, Maillard S, Al-Mayouf S, Prahalad S, Fasth A, Joos R, Schikler K, Mozolova D, Landgraf JM, Martini A, Ruperto N, for PRINTO. Health related quality of life of patients with juvenile dermatomyositis. results from the PRINTO multinational quality of life cohort study. **Arthritis Rheum 2009;61:509-517.**
- Consolaro A, Ruperto N, Bazso A, Pistorio A, Magni-Manzoni S, Filocamo G, Malattia C, Viola S, Martini A, Ravelli A, for PRINTO. Development and validation of a composite disease activity score for juvenile idiopathic arthritis. **Arthritis Rheum 2009; 61(5):658-66**