

## PRINTO PROJECTS

	JDM trial	Vasculitis	MTX JIA
Argentina	4	35	27
Austria		2	
Brasil	1	27	33
Bulgaria			21
Chile		3	18
Croatia			4
Czech Republic	1		5
Denmark		4	2
El Salvador		4	
Estonia		5	
France		16	9
Georgia		3	2
Germany	1	5	36
Greece		3	17
Hungary			1
India		34	9
Iraq		1	
Israel		14	8
Italy	9	52	35
Kuwait			2
Latvia		20	23
Libya		3	
Mexico	1	2	2
Netherlands	3	3	47
Norway	1		
Peru		9	
Poland			1
Portugal			3
Romania		57	
Russia			2
Saudi Arabia		6	
Serbia	1	4	16
Slovakia			4
Slovenia	1		
Spain		5	16
Sweden	1		
Switzerland			4
Turkey		88	2
Un. Kingdom		35	16
USA	1		
<b>Total</b>	<b>25</b>	<b>440</b>	<b>365</b>

Paediatric Rheumatology International  
Trials Organisation (PRINTO)  
IRCCS G. Gaslini Pediatría II  
Largo Gaslini, 5  
16147 Genova - ITALY



August 2007

## Paediatric Rheumatology International Trials Organisation (PRINTO)



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*Nicola Ruperto, MD, MPH - Genova, Italy*

IRCCS G. Gaslini  
Pediatría II - PRINTO  
Largo 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@ospedale-gaslini.ge.it](mailto:printo@ospedale-gaslini.ge.it)

[www.printo.it](http://www.printo.it)

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## PReS Congress 2007 Istanbul Turkey

Sunday September 9 (8.30-9.30)

Agenda for the annual PRINTO workshop

- Update on PRINTO activities (A. Martini)
- Update on PRINTO Projects (N. Ruperto)

### New onset JDM trial:

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

As of today 25 patients have been enrolled  
A total of 73 centres in 24 countries have now obtained ethics committee approval. In 40 other centres ethics review is on-going.

**There is still time to joint the trial**

### PRES/PRINTO/EULAR vasculitides registry:

The PReS Vasculitis Working Group, in collaboration with PRINTO (EULAR support) designed the present registry to validate the recently developed "EULAR/PreS endorsed criteria for the classification of childhood vasculitides". 413 children enrolled from 131 centres in 42 countries.

**MTX withdrawal:** to determine if the time to discontinuation of MTX (6 versus 12 months) in JIA, after clinical remission, influences the time to relapse. A total of 365 patients have been enrolled (original sample 200).

**Enrollment is now over.** In September we will start the procedures related to biologic samples collection and related payment.

### JDM disease activity/damage study

The pediatric JDM provisional core set has been officially endorsed by the ACR and EULAR (paper in press) as:  
**The PRINTO/ACR/EULAR Provisional JDM disease activity core set**

### Genomics and Pediatric Rheumatic Diseases survey:

PRINTO designed the present survey to investigate if the PRINTO centres have families with paediatric rheumatic diseases 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)

**Website for families** final version in more than 50 languages available at

[www.pediatric-rheumatology.printo.it](http://www.pediatric-rheumatology.printo.it)

At the end of June 2007 reached a new hit with 11,000 people (100% increase in 1 year) per day (335.000 per month), from **130 different countries!**

**Membership:** 377 effective members in 208 centres from 46 countries.

### Recent PRINTO publications

To see the papers and ask for reprints go at [www.printo.it](http://www.printo.it) and click on papers.

- Gutiérrez-Suárez R, Ruperto N, Gastaldi R, Pistorio A, Felici E, Burgos-Vargas R, Martini A,

Ravelli A for PRINTO. **A proposal for a pediatric version of the SLICC/ACR Damage Index based on the analysis of 1,015 patients with juvenile-onset SLE** *Arthritis Rheum* 2006;54:2989-2996.

- Ruperto N, Ravelli A, Martini A/ PRINTO. **Reply to letter** by Isenberg commenting on the PRINTO criteria for the evaluation of response to therapy in juvenile SLE. *Arthritis Rheum* 2006;54:3723-3724.

- Ruperto N, Ravelli A, Martini A, for PRINTO. Evaluation of renal improvement in juvenile systemic lupus erythematosus: Comment on the articles by Ruperto et al. **Reply.** *Arthritis Rheum* 2006;55:991-992.

- Ruperto N, Ravelli A, Castell E, Gerloni V, Haefner R, Malattia C, Kanakoudi-Tsakalidou F, Nielsen S, Bohnsack J, Gibbas D, Rennebohm R, Voygiyoka O, Balogh Z, Lepore L, Macejkova E, Wulffraat N, Oliveira S, Russo R, Buoncompagni A, Hilario MO, Alpigiani MG, Passo M, Lovell DJ, Merino R, Martini A, Giannini EH, PRCSG and PRINTO. **Cyclosporine a in JIA. Results of the PRCSG/PRINTO phase IV post marketing surveillance study.** *Clin Exp Rheumatol* 2006;24:599-605.

- Gutiérrez-Suárez R, Pistorio A, Cespedes Cruz A, Norambuena X, Flato B, Rumba I, Harjacek M, Nielsen S, Susic G, Mihaylova D, Huemer C, Melo-Gomes J, Andersson-Gare B, Balogh Z, De Cunto C, Vesely R, Pagava K, Romicka AM, Burgos-Vargas R, Martini A, Ruperto N, for PRINTO. **HRQOL of patients with JIA coming from 3 different geographic areas. The PRINTO multinational quality of life cohort study.** *Rheumatol* 2007;46:314-320

- Oliveira S, Ravelli A, Pistorio A, Castell E, Malattia C, Prieur AM, Saad-Magalhães C, Murray KJ, Bae SC, Joos R, Foeldvari I, Duarte-Salazar C, Wulffraat N, Lahdenne P, Dolezalova P, de Inocencio J, Kanakoudi-Tsakalidou F, Hofer M, Nikishina I, Ozdogan H, Hashkes PJ, Landgraf JM, Martini A, Ruperto N, for PRINTO. **Proxy-reported HRQOL of patients with JIA.** *Arthritis Rheum* 2007;57:35-43.

- 2 papers in press in *Lupus* and *Arthritis Rheum*