

## PRINTO PROJECTS

COUNTRIES	No. of patients with JSLE	No. of patients with JDM
Argentina	13	10
Austria		2
Belgium	2	2
Brazil	25	13
Bulgaria	7	1
Chile	5	1
Costa Rica	4	3
Croatia		
Cuba	4	2
Czech Republic	4	5
Denmark	2	
Finland		1
France	3	3
Germany	10	9
Greece	4	4
Hungary		1
Georgia		
Israel	6	2
India	2	
Italy	20	14
Korea (South)	3	
Latvia		
Luxembourg		
Mexico	3	
Netherlands		2
Norway		
Portugal		2
Russia		
Singapore	3	
Slovakia	1	1
Slovenia	1	
Spain	6	2
Sweden	4	
Switzerland	1	2
Turkey	8	1
United Kingdom	4	9
Yugoslavia	12	
USA		
<b>Totals</b>	<b>157</b>	<b>92</b>

**"Paediatric Rheumatology International  
Trials Organisation - PRINTO"**  
 IRCCS G. Gaslini  
 Pediatria II  
 Largo Gaslini, 5



MAY 2002

# Paediatric Rheumatology INTERNATIONAL TRIALS Organisation - PRINTO



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#### Senior Scientist

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

### NEW PRINTO ADDRESS!!

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VIII NEWSLETTER

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**PLEASE NOTICE  
THE NEW PRINTO SYMBOL ON THE  
COVER OF THIS NEWSLETTER.  
WE HOPE YOU WILL LIKE IT!!**

**The Annual Meeting of PRES will be held  
on June 12-15, 2002  
Stockholm, Sweden**

**The PRINTO workshop will be held on:  
Thursday June 13  
8.30-9.45 am  
Room A3 (250)**

All PRINTO members, and interested people, are invited to participate.

**The agenda will be as follows:**

- Results of the methotrexate trial (MTX): medium versus higher doses in children with Juvenile Idiopathic Arthritis (JIA) who failed on standard dose of MTX
- Update on the project: disease activity and disease damage core sets and definition of improvement for juvenile systemic lupus erythematosus (JSLE) and juvenile dermatomyositis (JDM).
- meeting of the PRINTO national coordinators.

**Membership:** We have now 170 effective

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members in 124 centres in 43 countries.

**Disease activity and disease damage core sets of outcome measures and definition of improvement for JSLE and JDM.**

Aims of this new project are to establish:

- 1 a JSLE and JDM core sets of outcome measures for disease activity and disease damage assessment. This aim has already been achieved through a consensus conference held in Pavia, Italy on April 2001.
- 2 prospective validation of the JSLE-JDM core sets with data collection among PRINTO members (see below).
- 3 JSLE and JDM definitions of improvement to be used in future clinical trials.

The prospective validation of the JSLE-JDM core sets is proceeding very well with 157 JSLE and 92 JDM patients already collected (see table next page) from 31 countries. These figures correspond to an increase of 50% compared to our March 2002 newsletter!!

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We remind you that all new onset patients, or patients with disease relapse or flare for whom there is an important change in current therapy can be enrolled.

To allow PRINTO to keep track, of all the patients enrolled in the study it will be greatly appreciated if you could send immediately the data by fax to Genova at  
Fax +39-010-39-33-24 or  
+39-010-39-36-19

**ENROLLMENT WILL CONTINUE UNTIL  
MARCH 2003**

**IMPORTANT** this time PRINTO has obtained funds from the European Union to pay approximately **400 EURO** for each of the first 500 patients received at PRINTO.

**A European information network on  
paediatric rheumatic diseases:**

Aims of this new project are to provide

- information on the paediatric rheumatic diseases for the families
- a map of paediatric rheumatology centres
- a map of associations to help families

In the next weeks you will receive a questionnaire that will allow PRINTO to

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