

PRINTO PROJECTS

	No. JSLE	No. JDM	Web survey
Argentina	38	29	9
Australia	1	1	1
Austria		2	3
Belgium	2	3	6
Brasil	49	22	15
Bulgaria	7	1	1
Canada	17	3	
Chile	7	3	3
Costa Rica	8	6	1
Croatia	6	5	2
Cuba	4	1	5
Czech Republic	6	5	3
Denmark	5	1	2
Finland	1	2	
France	8	7	7
Georgia			1
Germany	23	16	16
Greece	5	5	4
Hungary	2	1	1
India	4		2
Israel	9	3	3
Italy	48	20	8
Latvia			2
Lithuania			1
Korea	5		
Mexico	11	2	2
Netherlands	1	7	3
N. Ireland	3	1	
Norway		3	2
Poland	5	4	1
Portugal		6	2
Russia			13
Saudi Arabia	2		1
Singapore	4	1	
Slovakia	3	2	3
Slovenia	2		1
Spain	14	5	5
Sweden	6		1
Switzerland	2	7	1
Tunisia	1		1
Turkey	14	4	7
Un. Kingdom	6	11	3
USA	5	5	
Yugoslavia	21	5	6
Total	355	198	145

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



JANUARY 2003

Paediatric Rheumatology INTERNATIONAL TRIALS Organisation - PRINTO



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NEW PRINTO ADDRESS!!

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IX NEWSLETTER

Dear Friends,

We are still receiving faxes and mails at the old address in Pavia. Please notice we all moved to *Genova*. Our new address is:

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We encourage everybody to visit the new PRINTO web site at

www.printo.it

You can find the following information:

- About PRINTO: members and national co-ordinators addresses, and list of PRINTO publications
- On going projects: with the latest information on PRINTO researches
- How to contact us: application form for membership

Membership: We have now 178 effective members in 128 centres in 43 countries.

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

The prospective validation of the JSLE-JDM core sets is proceeding extremely well with 355 JSLE and 198 JDM patients already collected from 40 countries (see table next page). **All**

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

Please send immediately the data collected by fax to Genova at

Fax +39-010-393324 or 010-393619

ENROLLMENT WILL CONTINUE UNTIL JUNE 2003

We remind you that **400 Euro** will be paid for the following countries from the European Union (EU): Austria, Belgium, Czech Rep, Denmark, Finland, France, Germany, Greece, Hungary, Israel, Italy, Latvia, Luxembourg, Netherlands, Northern Ireland, Norway, Portugal, Slovakia, Spain, Sweden, Switzerland, United Kingdom.

We STRONGLY encourage the above countries to enroll patients and take advantage of this great opportunity.

For all the other countries outside the EU we cannot guarantee the same amount since the European Union has granted the authorisation to spend a maximum of 20% of the received funding. Therefore non EU centres will be reimbursed proportionally to the number of patients collected (about 80-100 Euro per patients).

A European information network on paediatric rheumatic diseases:



Thanks to the 3rd EU grant we are preparing a web site for each of the countries belonging to PRINTO (EU non EU) containing the following translated information.

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

In the past months you should have received the survey that will be used to prepare the web site specific for your centre. So far we have already received 145 surveys. If you have not responded and wish to take advantage of this opportunity please download the survey at the PRINTO web site (on going project button)

www.printo.it/workforcesurvey.htm