

PRINTO PROJECTS

No. JSLE No. JDM Web survey

	No. JSLE	No. JDM	Web survey
Argentina	50	34	11
Australia	1	2	2
Austria	-	2	8
Belgium	2	3	6
Brasil	63	29	33
Bulgaria	15	3	1
Canada	24	3	-
Chile	8	3	4
Costa Rica	9	6	3
Croatia	5	5	3
Cuba	7	1	5
Czech Republic	7	5	3
Denmark	6	3	4
Egypt	-	-	1
Finland	4	2	14
France	11	11	17
Georgia	-	-	4
Germany	28	20	49
Greece	7	5	23
Hungary	5	1	3
India	6	-	3
Israel	19	4	9
Italy	74	28	23
Latvia	6	3	6
Lithuania	-	-	2
Korea	5	-	-
Mexico	10	3	3
Netherlands	8	17	13
N. Ireland	3	1	1
Norway	2	5	8
Poland	5	4	3
Portugal	1	6	3
Russia	-	-	15
Saudi Arabia	2	-	1
Serbia	21	6	7
Singapore	6	1	3
Slovakia	12	3	3
Slovenia	4	1	1
Spain	24	10	10
Sweden	8	2	4
Switzerland	3	11	6
Tunisia	1	-	4
Turkey	20	6	8
Un. Kingdom	14	22	13
USA	12	13	-
Total	518	284	343

"Paediatric Rheumatology International
 Trials Organisation - PRINTO"
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Paediatric Rheumatology InterNational Trials Organisation (PRINTO)



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NEW PRINTO ADDRESS!!

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- grant no AML/B7-311/97/0666/II-0246-FI 2003-2006

X NEWSLETTER

Membership: We have now 217 effective members (+22% since last newsletter) in 152 centres from 45 countries.

JSLE and JDM disease activity and damage core sets of outcome measures and definition of improvement (EU grant QL61-CT-2000-00514).

The prospective validation of the JSLE-JDM core sets is **COME TO THE END** of the enrollment phase. We have collected 518 JSLE and 284 JDM patients from 41 countries (see table next page) with an increase of more than 40% since last time.

IMPORTANT:

enrollment is FINISHED and we will continue ONLY to collect prospective data at visit 2 (4-8 months after visit 1) DO NOT SEND ANY NEW PATIENT BUT REMEMBER TO SEND VISIT 2 WITH THE EFFICACY ASSESSMENT

(patients improved, stable, or worsened according to MD' and the parents' opinion) By the end of September all centres will receive payment from PRINTO:

- About **350 Euro** for the following EU countries: Austria, Belgium, Bulgaria, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Israel, I-

taly, Latvia, Luxembourg, Netherlands, Northern Ireland, Norway, Poland, Portugal, Slovakia, Slovenia, Spain, Sweden, Switzerland, United Kingdom.

- For all the other countries, the EU has granted the authorisation to spend 20% of the funding. Therefore non EU centres will be reimbursed about **120 Euro/patients**).

An European information network on paediatric rheumatic diseases (EU grant 2001CV64-808):

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 **with color photo of MDs**
- map of family help associations

The website draft can be seen at

www.pediatric-rheumatology.printo.it

At the home page you will see the list of all the countries (represented by flags) belonging to PRINTO.

IMPORTANT: In order for your centre to be listed on this website you have to complete the website survey that can be downloaded at the home page of the site

www.pediatric-rheumatology.printo.it

So far we have already received 343 surveys from 150 centres (61% response rate). We are **missing many photos from MDs** who have already completed the survey. If your photo is missing on the website please remember to send one passport color photo.

PRINTO-América Latina Formación Académica (Alfa) fellowship (EU grant AML/B7-311/97/0666/II-0246-FI year 2003-2006)

Thanks to the 4th EU grant PRINTO is now offering 28 scholarships for clinical and research residence up to 6 months **in Europe**.

Participating Latin American countries are: **Argentina, Brasil, Chile, Costa Rica, Cuba, and Mexico**. Participating European Union countries are: **Italy, France, Netherlands, Sweden, United Kingdom**.

For more details you can download the Alfa application module at the PRINTO website

www.printo.it

click on the **button "on going project"** and then on the **link "scholarships for Latin America"**