

## **FINAL REPORT**

### 1) Statement of project aims

The aim was to promote the development of a European information network on the paediatric rheumatic diseases (PRD). This network of 21 countries (plus other 30 countries outside the EU), will provide information about this group of diseases: juvenile chronic arthritis, childhood lupus erythematosus, juvenile dermatomyositis, scleroderma, vasculitis, rare form of arthritis, and the many other rare diseases that may present with osteo-articular complaints. **OF NOTE** the PRD are the most frequent group of childhood rare diseases, highly chronically debilitating with deleterious effects on the quality of life of a growing children. This network aims at becoming a competent referent for health professionals, researchers, families and volunteer association to help patients, seeking information about the PRD not only in Europe but also outside Europe.

### 2) How does your project relate to what has already been done in the field?

This application is the joint effort of now 45 countries belonging to the “Paediatric Rheumatology International Trials Organisation” (PRINTO) and to the “Paediatric Rheumatology European Society” (PRES) that are 2 separate bodies of the same paediatric rheumatology community with common membership.

This proposal is innovative since no standardised information about these diseases is actually available to the general public. PRINTO (the applicant) has recognised competence with collaborative, multinational research networks and actually owns an extensive database containing informations like patients quality of life data, clinical trials for current drug treatment. This project has allowed PRINTO the possibility to share its informations with other health professionals, researchers, families, and association to help patients in Europe and outside Europe.

### 3) Description of tasks/sequence of work/timetable

The problem to be solved was to give to the general public a well defined and competent set of information regarding the PRD. The PRINTO network represents a 51 EU and non EU countries joint effort among leaders in the paediatric rheumatology research community to develop this set of information with reliable, scientific, and standardised methods. The Community dimension is required for the rarity of the PRD that are all children orphan diseases, highly chronically debilitating, and to create a critical mass of potential users of the released information. The resulting Community added value is forecasted to be relevant since the project involve the joint participation of almost all the European countries and also countries outside Europe, and it will ensure transfer of knowledge from clinical research centres to paediatric hospitals and to the general public strengthening the links between them.

## **RESULTS OBTAINED AT THE END OF YEAR 2 (END OF THE PROJECT)**

- identification and training of 1 full time, 2 part-time, research associates for the co-ordination of the project (with fluent knowledge of at least 2 foreign languages one of which is English) at the PRINTO international co-ordinating centre (ICC) for the overall management of the project.

Their main role has been:

- to identify all the hospitals/university, and patients/parents based health organisation etc that deal with PRD within the borders of each participating country belonging to the PRINTO network,
- to establish connection with all centres,
- to collect web site surveys in order to have reliable information on the centres dealing with paediatric rheumatology: demographics, characteristics of patient population of each centre, professional, teaching and research activities, clinical trials background, general information on each centre, information on family help associations, curriculum vita information, workforce information. As of today we have collected information on 171 centres (288 physicians) in 42 countries.
- Preparation of the consensus conference held in Genova on March 1-2, 2003. We used for the meeting consensus formation techniques (Delphi and the Nominal Group Technique), well recognised techniques in the medical literature, to combine judgements from a group of experts. At the meeting experts in the field (the supporters of the project that is one representative from each of the countries supporting the project) of the PRD plus other participants outside the EU have:
  - reached a consensus upon the content of the web page (see description of the web below);

- given rules for the preparation of documents to be released on the web;
- identified a referent for each centre participating to the project to whom the general public can address their request of information.
- Coordination of the translation from the English master documents into the languages of the countries participating to the efforts.
- identification and training of 1 full time and 1 part time computer technicians with expertise in web pages, database development and electronic means of communication employed at the ICC.

Their main role has been:

- to create the PRINTO website ([www.printo.it](http://www.printo.it)) where information about the network are available
- to prepare the final website of the project for each of the countries belonging to PRINTO. The website that is now on line at the following address: [www.pediatric-rheumatology.printo.it](http://www.pediatric-rheumatology.printo.it). It is structured as follows:
  - An home page with a flag directing to the specific country/language (48 countries are available). Of note the name of each country is translated directly into the language of that country. Once selected the specific country/language you are redirected to the specific language section where 3 kind of information can be found:
  - An up to date list of information on the paediatric rheumatology diseases translated into the language of that specific country;
  - An up to date list of all the paediatric rheumatology centres existing in that country;
  - An up to date list of all the paediatric rheumatology associations (health professionals and or patients/parents based) that deal with

parents whose aim is to solve non-medical aspects related to the burden of the PRD.

### **Dissemination:**

Brochures, either on paper and via electronic means of communication, will be disseminated among the general public, health professionals, patients, health and volunteer organisations to help families. The WEB page, paper brochures, newsletters, and if possible e-mails will be sent to all these organisations that will then provide to redirect the material directly to patients/parents based health organisations and their members. Moreover the material will be distributed on the occasion of the yearly meeting of the “Paediatric Rheumatology European Association – PRES” or of other national, and international meetings dealing with the PRD. E-mail news group will also be prepared to disseminate information among people who will have access to this mean of communication.

A manuscript is in preparation and will be sent to a medical journal.

## **ABSTRACT OF THE PROJECT FOR PUBLIC RELEASE:**

This site ([www.pediatric-rheumatology.printo.it](http://www.pediatric-rheumatology.printo.it)) is the result of a collaboration between the Paediatric Rheumatology International Trials Organisation ([PRINTO](#)) and the Paediatric Rheumatology European Society ([PRES](#)), realised with funding obtained from the [European Union](#) (contract number 2001CVG4-808).

PRINTO is an not for profit international public network established in 1996 by 14 European countries (now 51 countries in Europe and outside Europe), with the goal to foster, facilitate and coordinate the development, conduct, analysis, and reporting of studies to evaluate efficacy and safety of drug therapies, quality of life and outcome for children with paediatric rheumatic diseases. PRINTO is composed of academic and/or clinical centres actively engaged in the research and clinical care of children with paediatric rheumatic diseases.

PRES is an international scientific society for European healthcare professionals (and non-Europeans as associate members) working in the field of paediatric rheumatology. The mission of PRES is to promote knowledge of paediatric rheumatic diseases, stimulate research in the field, disseminate knowledge through scientific meetings and publications, provide guidelines and standards for good clinical practice, provide guidelines and standards for the training of doctors and allied health professionals in the practice of paediatric rheumatology. In addition, PRES facilitates co-ordination of paediatric rheumatology activities within Europe, eg. the PRINTO chairperson and the [EULAR](#) (European League Against Rheumatism) paediatric rheumatology standing committee chairperson have permanent seats in the PRES council.

The site is divided into three sections:

The first section, called “[information](#)” is aimed to inform the parents on the principle characteristics of the main paediatric rheumatic diseases (what is it?, what are the treatments?).

The second section, called “[centres](#)” gives the addresses of paediatric rheumatology centres, whose physicians are members of PRINTO and/or PRES. This list will be updated regularly and does not pretend to be exhaustive.

The third section, called “[family](#)” gives the addresses of the family help associations that you can contact. Their main purpose is to give advice with everyday problems and difficulties that the families have to cope with. Also this list will be updated regularly and does not pretend to be exhaustive.

The information provided with this web site has been gathered through a questionnaire devised by PRINTO and approved by PRES, sent to paediatric rheumatology centres in 51 countries.

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