



Pædiatric Rheumatology International Trials Organisation

ADVISORY COUNCIL

Genova, May 7, 2003

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Object: **work force survey for paediatric rheumatology**

Dear Friend,

Counsellors

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Thanks to the third grant obtained from the European Union (contract 2001CVG4-808), the Paediatric Rheumatology International Trial Organisation (PRINTO) in collaboration with the Paediatric Rheumatology European Association (PRES), will establish an international paediatric rheumatic disease information network directed to families. The American Academy of Pediatrics (AAP) and the Pediatric Rheumatology Collaborative Study Group (PRCSG), have joined us to implement this effort in North America.

The main objectives of this project are to prepare a website where the following information will be available for every country member translated into their own languages.

- Updated consensus information on each of the paediatric rheumatic disease (What is it?, How to diagnose it, How to treat it...etc)
- Map of the paediatric rheumatology centres in each of the PRINTO/PRES member countries
- Map of the family help associations (charities or similar) in each of the PRINTO/PRES member countries.

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The goals of this first survey are to collect reliable information to be included on the developing web site in order:

- to characterise current practice patterns of physicians who provide care for children with paediatric rheumatic disease ,
- to characterize research and training facilities of each centre.

It will take about 20-25 minutes to complete the survey.

You can visit the **INITIAL DRAFT** of the website at

www.pediatric-rheumatology.printo.it

**IMPORTANT: ONLY BY COMPLETING THIS SURVEY YOU WILL
HAVE THE POSSIBILITY TO BE LISTED ON THE WEBSITE**

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Have a good day

Alberto Martini

Nicola Ruperto

d:\printo\ PRINTO web site survey2.doc



VISIT THE INITIAL DRAFT OF THE WEBSITE AT
www.pediatric-rheumatology.printo.it

GENERAL INSTRUCTIONS TO COMPLETE THE SURVEY

FOR THE PURPOSE OF THIS SURVEY A PAEDIATRIC RHEUMATOLOGIST IS DEFINED AS SOMEONE:

- WHO DOES 50% OR GREATER PAEDIATRIC RHEUMATOLOGY OR
- WHO IS BOARD CERTIFIED IN PAEDIATRIC RHEUMATOLOGY OR
- WHO IS RECOGNISED AS ONE OF THE HOSPITAL/REGION/STATE ACKNOWLEDGED EXPERT IN PAEDIATRIC RHEUMATOLOGY

EACH CENTRE WITH MORE THAN 1 PHYSICIAN CAN PULL THEIR INFORMATION AND SEND IN ONE FORM.

PLEASE COMPLETE THE SURVEY IN **LEGIBLE CAPITAL LETTERS** AND

- MAIL IT IN THE ENCLOSED SELF ADDRESSED ENVELOPE OR FAX AT
+39-010-39-33-24
+39-010-39-36-19
- OR YOU CAN ALSO DOWNLOAD THE SURVEY ON THE PRINTO WEBSITE
www.printo.it
- OR SEND BY E-MAIL ATTACHMENT TO
printo@ospedale-gaslini.ge.it

THE ELECTRONIC (WORD) VERSION OF THE SURVEY CAN BE DOWNLOADED AT
www.printo.it click on the button ON GOING PROJECT

IMPORTANT:

**ONLY BY COMPLETING THIS SURVEY YOU WILL HAVE
THE POSSIBILITY TO BE LISTED ON THE WEBSITE**

PLEASE REMEMBER THAT THE INFORMATION YOU PROVIDE
WITH THIS SURVEY
WILL BE USED TO PREPARE
THE WEBSITE FOR YOUR COUNTRY

BY COMPLETING AND SIGNING
THIS SURVEY IT WILL BE
YOUR OWN AND ENTIRE RESPONSIBILITY
THAT THE INFORMATION PROVIDED
DOES CORRESPOND TO THE TRUTH



Please print or type your responses and fax or mail back to PRINTO.

A. DEMOGRAPHICS:

At the moment we have in the PRINTO mailing list the address below.

**PLEASE NOTE WE NEED AN OFFICIAL ADDRESS FOR YOUR HOSPITAL
TO BE INCLUDED IN THE PRINTO WEB SITE.**

If your name, degree, address, phone, and fax numbers are correct please proceed to next page, otherwise modify on the side as appropriate.

First Name

Last Name

Title

Hospital

Department

Street

City

State

Code

Phone

Fax

E-Mail

IF YOU WISH TO RECEIVE PRINTO MATERIAL AT A DIFFERENT ADDRESS PLEASE SPECIFY

Street _____

City _____

State _____

Code _____

Phone _____

Fax _____

E-Mail _____



B. CHARACTERISTICS OF PATIENT POPULATION OF YOUR CENTRE:

If you do not have a database, then estimate

1. What percentage of your total practice is paediatric (≤ 18 yrs) ? _____ %
2. How many children with paediatric rheumatic diseases have you seen during last year at you centre? (if more than 1 physician is working at your centre please report the overall figures)

PAEDIATRIC RHEUMATIC DISEASE	TOTAL NUMBER OF PATIENTS FOLLOWED	NEW CASES (NEW REFERRAL) IN 1 YEAR
(1) Juvenile idiopathic arthritis		
(2) Juvenile systemic lupus erythematosus		
(3) Juvenile dermatomyositis/polymyositis		
(4) Juvenile systemic sclerosis		
(5) Juvenile localised scleroderma		
(6) Kawasaki's disease		
(7) Henoch-Schönlein purpura		
(8) Behçet's Disease		
(9) Necrotizing vasculitis		
(10) Rheumatic fever		
Other (specify)		

3. How many IN PATIENT (hospitalised) children with paediatric rheumatic diseases are seen in your centre in a typical week? (if more than 1 physician is working at your centre please report the overall figures)

4. How many OUT PATIENT (day hospital) children with paediatric rheumatic diseases are seen in your centre in a typical week? (if more than 1 physician is working at your centre please report the overall figures)

5. How many consultations for children with paediatric rheumatic diseases are carried out by your unit for other departments of your hospital during a typical week? (if more than 1 physician is working at your centre please report the overall figures)



C. PROFESSIONAL, TEACHING AND RESEARCH ACTIVITIES:

1. Approximately what percent of your time is spent in:

%	(1) Patient care
%	(2) Teaching
%	(3) Clinical research
%	(4) Laboratory research
%	(5) Administrative duties
%	Other (specify)
%	(6)
100 %	TOTAL

2. Approximately what percent of your time is spent in:

%	(1) paediatric (children and/or adolescents) rheumatology patient care
%	(2) general paediatric patient care
%	(3) adult patients
%	Other (specify)
%	(4)
100 %	TOTAL

3. Do you currently have general paediatrics and/or paediatric training rheumatology fellows in your department?

yes no

a) If you answered YES please specify how many **GENERAL PAEDIATRICS** training fellow:

b) If you answered YES please specify how many **PAEDIATRIC RHEUMATOLOGY** fellows:

4. Do you also have any visiting fellows from other hospitals/countries? yes no

If you answered yes please specify how many you had last year _____

From which countries? _____

5. Is **PEDIATRIC RHEUMATOLOGY** officially recognised as subspecialty in your country?

yes no



D. CLINICAL TRIALS BACKGROUND:

1) Have you performed paediatric clinical trials? yes no

If you answer **YES** then please go to question 2 continue answering. If you answer **NO**, then please go to question 6 and continue answering

2) If you answered YES to question 1 how many paediatric trials have you performed in the past 4 years?

3) Of the paediatric trials you have performed in the past 4 years how many were related to paediatric rheumatology? _____

Only for the **paediatric rheumatology trials** you have performed in the past 4 years please specify:

PAEDIATRIC RHEUMATOLOGY DISEASE	DRUG	NUMBER OF PATIENTS ENROLLED

4) Are you currently participating in any paediatric rheumatology trial(s)? yes no

5) If yes, would you be able to run more than 1 trial in parallel? yes no

would you be able to run **MORE** than 1 trial in parallel? yes no



6) Are you willing to participate in future paediatric rheumatology clinical trials if these are trials that require a minimal amount of work (collection of routine information) usually related to a drug already on the market. These are trials sponsored by individual researchers or international networks like PRINTO, PRES PRCSG, CARRA, etc.

yes no

If you answered "No" to question 6, we are interested to know why you are unable or unwilling to participate in this type of trial by answering the following question.

My reason(s) for not participating in future trials of the type described above (check all that apply).

- a) _____ Don't have the time to participate
- b) _____ Do not have necessary help to participate.
- c) _____ Don't follow enough patients
- d) _____ Other (please specify) _____

7) Are you willing to participate in future paediatric rheumatology clinical trials (sponsored by pharmaceutical companies)? Please notice that these trials are usually for registration purposes (Food and Drug Administration and/or European Medical Evaluation Agency) that require an extensive amount of work

yes no

If you answered "No" to question 7, we are interested to know why you are unable or unwilling to participate to future pharmaceutical companies sponsored trials by answering the following question.

My reason(s) for not participating in future trials (check all that apply).

- a) _____ Don't have the time to participate
- b) _____ Do not have necessary help to participate.
- c) _____ Don't follow enough patients
- d) _____ Other (please specify) _____



E. INFORMATION ON YOUR CENTRE:

1. Is there a web site for your hospital, department? If yes please indicate the address:

Web site for hospital: _____

Web site for department: _____

2. Your hospital is (you can reply to both)?

Children's hospital

General hospital

3. Is your hospital a tertiary level care centre?

yes no

4. Are you affiliated to a medical school?

yes no

5. Please indicate the category that describes the community (city and suburban population) in which your hospital is located

- ___ (1) 1.000.000 and over
- ___ (2) 501.000 – 1.000.000
- ___ (3) 100.0000-500.000
- ___ (4) < 100.000
- ___



LIST ONLY PHYSICIANS DEALING WITH PAEDIATRIC RHEUMATOLOGY

Please specify the number of personnel working in or for your unit including yourself

Role	Number of people
Physicians with permanent position	
Other physicians (fellows, trainees)	
Nurses	
Physical/Occupational Therapist	
Other	
Other	

Please list all **PHYSICIANS WITH A PERMANENT POSITION DEALING WITH PAEDIATRIC RHEUMATOLOGY** at your centre:

UNIT DIRECTOR
FIRST NAME
LAST NAME
TITLE
TEL
FAX
E-MAIL

OTHER PHYSICIANS WITH PERMANENT POSITION DEALING WITH PAEDIATRIC RHEUMATOLOGY

FIRST NAME	FIRST NAME
LAST NAME	LAST NAME
TITLE	TITLE
TEL	TEL
FAX	FAX
E-MAIL	E-MAIL

PLEASE ASK ALL THE OTHER PHYSICIANS DEALING WITH PAEDIATRIC RHEUMATOLOGY AT YOUR CENTRE TO COMPLETE AND SEND US BACK JUST SECTIONS A, C, D, G AND PRINTO APPLICATION FORM (PAGE 12)

DUPLICATE THIS PAGE IF NECESSARY



F. FAMILY HELP ASSOCIATIONS

1. Is there any family association (charities or similar) helping, giving support to families nearby or within your centre?

yes no

1. Can you give the complete address of the association(s)?

Name _____

Street _____

City _____

State _____

Code _____

Phone (_____) _____

Fax (_____) _____

E-Mail _____

Web site _____

DUPLICATE THIS PAGE IF NECESSARY



G. CURRICULUM VITÆ INFORMATION

1. Date of Birth (dd/mm/yy/) _____/_____/_____
2. Sex female male
3. English Knowledge basic good fluent
4. Year of graduation from Medicine/Medical school: _____
5. Specialty(ies) completed: _____

Year completed	Specialty (tick all that apply)
_____	(1) General paediatrics
_____	(2) Paediatric Rheumatology
_____	(3) Adult Rheumatology
_____	(4) physical medicine & rehabilitation
_____	Other (specify)
_____	(5)
_____	(6)
_____	(7)

6. Main field of study/research (no more than 2 lines)
7. **Years of experience in paediatric rheumatology** _____
8. Professional Experience (example: senior doctor or consultant from to, etc)
9. Honours and awards



Please list your top 5 publications:

a)

b)

c)

d)

e)

4. If you are willing to publish your colour photo on the WEB site that PRINTO will develop for your country

**PLEASE REMEMBER TO ENCLOSE A COPY OF YOUR SMILING
PASSPORT SIZE COLOUR PHOTO!!**

**I DECLARE
THAT ALL THE INFORMATION PROVIDED WITH THIS
SURVEY DOES CORRESPOND TO THE TRUTH**

Place and date

Signature



PRINTO Membership date:

If you are not a PRINTO member yet and wish to join, please send back the following letter with a 1 page copy of your curriculum vitae.

Genova, ITALY

Date.....

Dear Prof. Martini,

I am willing to join the Paediatric Rheumatology International Trials Organisation (PRINTO) group as Director of my hospital.

I have read and approved the PRINTO bylaws.

Enclosed is my **CURRICULUM VITAE**

Your sincerely,

Your signature

IS YOUR ADDRESS COMPLETE AND CORRECT?

YES

NO

Also include a short **CURRICULUM VITAE** (**max 1 page**) with the following information:

Name

Institution and complete address

Position title (ie MD, Prof, PhD etc)

Degree(s) and year conferred

Field of study

Years of experience in paediatric rheumatology

Professional Experience

Honours and awards

Selected bibliography



WORKFORCE INFORMATION

The following additional section is collected by PRINTO in collaboration with the Paediatric Rheumatology European Society (PRES), the American Academy of Paediatrics (AAP) and the Paediatric Rheumatology Collaborative Study Group (PRCSG) to better characterise the future development of paediatric rheumatology in your country.

1. What is the current population of the region that supplies patients for your centre in millions?

2. What is the percent children under 18 years of age in this population to your best knowledge?
_____ %
3. What approximate percentage of your patients come from more than 150 km away in your country or are international referrals from more than 150 km away?
_____ %
4. How many paediatric rheumatologists are currently working in your region/urban area? _____
(a paediatric rheumatologist for the purpose of this survey is either someone who is board-certified, does 50% or greater paediatric rheumatology, or is the region's acknowledged expert in pediatric rheumatology)
5. What are the age ranges of the paediatric rheumatologists at your centre? If your centre has more than one paediatric rheumatologist, then please indicate how many are in each category.
20-30 years _____
30-40 years _____
40-50 years _____
50-60 years _____
60-70 years _____
70-80 years _____
> 80 years _____
5. In your opinion, have paediatric rheumatologists had greater competition from other specialists (for example: paediatricians, rheumatologists, orthopaedists) in the treatment of children with rheumatic diseases in your community in the last 2 years than prior to that time?
 yes no not applicable
7. In your opinion, have paediatric rheumatologists at your centre had to modify their practice of paediatric rheumatology due to increased competition from paediatricians or rheumatologists?
 yes no not applicable



8. In your opinion, will your urban area/region need more paediatric rheumatologists in the next 5 years?

yes no not applicable

9. Will your country need more paediatric rheumatologists in the next 5 years?

yes no

If yes, please estimate how many: _____

10. Is it likely that your medical centre/medical school will be hiring more paediatric rheumatologists in the next 5 years?

yes no

If yes please estimate how many: _____

11. Has the complexity of illness of children referred to you in the last 2 years increased significantly:

yes no

12. Please check which of the following best describes your paediatric rheumatology practice or the practice of your centre:

Expanding _____
Staying the same _____
Decreasing _____

13. From your perspective in your area, are the job opportunities in paediatric rheumatology:

Increasing _____
Staying the same _____
Decreasing _____

14. In your country, which of the following best describes the job flow of paediatric rheumatologists?

More entering than leaving _____
More leaving than entering _____
Staying the same _____
Does not apply _____

If more are leaving than entering the field, why are they leaving?

Please rank the following in order of frequency that they happen (1 = most frequent cause, 6 = less frequent cause)

Retirement? _____
Entering Administration? _____
Entering another field of medicine? _____



Another career? _____
Family concerns? _____
Other?(specify) _____

15. In your opinion, how is the morale in paediatric rheumatology in your area/country?

Excellent _____
Good _____
Fair _____
Poor _____
Does not apply _____

16. In a global sense in your country, is the situation for paediatric rheumatology at the time of this survey:

Improving _____
Worsening _____
Staying the same _____
Does not apply _____

17. Do you have sufficient support from the medical administration at your centre to provide the paediatric rheumatology care that you wish to provide?

yes no

If no, what are you lacking?
