



SHARE parent survey instructions

Dear friend,

You will find below the steps you need to follow in order to complete the SHARE parent survey.

Thank you very much!

- 1) Follow the link provided by your family association. The following webpage should open.

Information on Paediatric Rheumatic Diseases

Version of 2014



You have been asked to fill in a web based survey regarding your disease or the disease of your child. This survey is part of SHARE: "Single Hub and Access point for Paediatric Rheumatology in Europe". SHARE is an European Union funded project (project number 2011 1202; Principal Investigator Nico Wulfraat, Utrecht, The Netherlands) with the main objective to improve the care for paediatric rheumatic diseases throughout Europe.

One aim of SHARE is to provide individual European countries with recommendations for the care of children with rheumatic diseases. These recommendations will be based on systematic literature reviews of medical publications and on surveys, mapping current practices, sent to both doctors and patients in pediatric rheumatology centers belonging to the PRINTO network all over the world.

The surveys for treating physicians have already been answered by more than 250 PRINTO and PRES members (doctors). In addition, a patient survey now will be performed to ensure the patient perspective is put forward in this project. For this important part of SHARE, we kindly ask for your help by filling out the web based survey. The outcome of these surveys will be used for the development of country specific recommendations and development of best practices for care for Paediatric Rheumatic Diseases in Europe.

The survey will take approximately 15 minutes.

If you have any questions regarding the survey, you can ask your treating physician or send an email to [PRINTO](#) or the coordinating team of SHARE (Dr. Bas Vastert and professor Nico Wulfraat, paediatric rheumatologists in Utrecht, the Netherlands).

Paediatric Rheumatology International Trials Organisation (PRINTO)

Tel: +39-010-382854 or +39-010-393425

Website: www.printo.it

E-mail: [PRINTO](#)

Thank you for your time and collaboration!

[Registration](#) [Login](#)

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- 2) Click on “Registration” and fill in all the mandatory fields with your details. As you can see, once you have completed correctly one field, a green sign appears. You will not be able to click on the green arrow below before all signs are green.

Remember to check the “I am not a robot” box – it will ensure all data are genuine.

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Registration


*= Mandatory fields

Email*:	<input type="text" value="printo@ospedale-gaslini.ge.it"/>	✓
Confirm email*:	<input type="text" value="printo@ospedale-gaslini.ge.it"/>	✓
Name*:	<input type="text"/>	✗
Last name*:	<input type="text"/>	✗
Country*:	<input type="text" value="Italy - Italia"/>	✓
City*:	<input type="text" value="Genova"/>	✓
Phone:	<input type="text"/>	
Address:	<input type="text"/>	
Zip Code:	<input type="text"/>	
Family association:	<input type="text"/>	✗
Center:	<input type="text"/>	✗

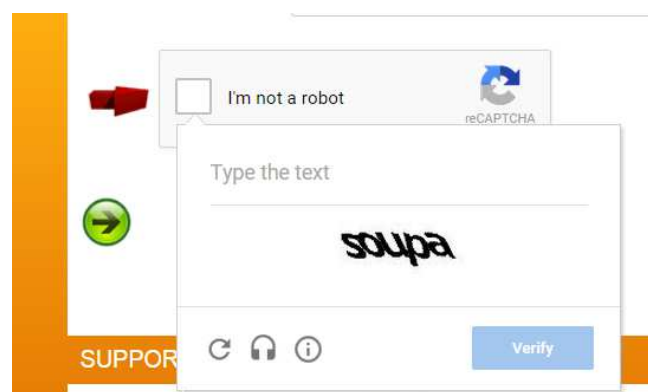
I authorize the treatment of my personal data exclusively for research purposes, in compliance with the law.*
 Yes

Do you wish to receive information from PRINTO?*:
 Yes No

I'm not a robot  reCAPTCHA
Privacy - Terms



You will be required to type the characters that appear in the box, and then click on “verify”.



3) You will receive an e-mail at the address you indicated.

Information on Paediatric Rheumatic Diseases

← Registration

 You will receive the credentials at the email indicated above and the link to complete the survey

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The e-mail will contain a link, the username and password for your SHARE survey. Clicking on the link you have received, the following webpage should open.

Information on Paediatric Rheumatic Diseases





← Registration

Enter the password you have received from PRINTO in the box below.

Password*:



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- 4) After entering your password and clicking on the arrow, the survey will start. You can see the beginning of the first section below.

Information on Paediatric Rheumatic Diseases

← SHARE parents survey

Patient personal information and Diagnosis

Country of birth

Gender
 Male
 Female

Age

Age at diagnosis

Person completing the questionnaire
 Mother
 Father
 Child
 Legal guardian

- 5) At the bottom of each survey page (there are three), you have the possibility to go back or to continue. On the final page, you can confirm your answers or modify them. Please remember to click on “confirm” if you do not want to change your answers.

99%

[Modify](#) [Confirm the survey](#)

Thank you for taking the time to fill in the questionnaire
For information or questions please contact your own doctor or:
[Claudia Grave](#), JIA parent organisation
[Prof Dr Nico Wulffraat](#), SHARE coordinator
For any technical issues you may have, contact [PRINTO](#)

- 6) For any issue, you can click on the coordinators’ names and send an email.

You will receive a reply at the e-mail address you have indicated. Always remember to tick the “I am not a robot” box.

The e-mail will be sent when you click on the green arrow.

Information on Paediatric Rheumatic Diseases

↩ Email

To: PRINTO


From (email)*:



Subject*: Family Website

Text*:



 I'm not a robot



reCAPTCHA
Privacy - Terms



- 7) Once your survey is completed and confirmed, you will receive a pdf copy at your e-mail address.

Thank you for taking the time to fill in the questionnaire



[Download](#)

PRINTO