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# SHARE

# The Final Conference

October 26 & 27, 2015

Zeist, the Netherlands

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## Care for Pediatric Rheumatic Diseases in 2015 and beyond: Challenges and Opportunities.

SHARE is an European Union funded initiative that ends in December 2015. SHARE stands for **S**ingle **H**ub and **A**ccess point for pediatric **R**heumatology in **E**urope and is dedicated to improve the care for pediatric rheumatology patients throughout Europe. Pediatric rheumatic diseases are rare diseases, with an incidence of less than 1: 1000 children. To improve the care and advance in research for these children, international collaboration is essential. In the past 4 years, the SHARE project has developed and optimized collaboration in international platforms and significantly affected both the health care and the quality and opportunities for research performed across Europe. By doing this, SHARE not only advanced the field of pediatric rheumatology in Europe, but serves as an example for other orphan diseases as well.

### Project Aims:

1. To address the needs and challenges in the EU in the care for children with pediatric rheumatic diseases
2. To develop generally accepted best practices for diagnosis and treatment of these diseases.
3. To improve and link existing platforms and websites for sharing data and patient information
4. To establish best practices on ethical approval for international scientific studies in children
5. To improve the position of patients in every aspect of care and research in pediatric rheumatology

**You are cordially invited to join the final conference of SHARE on October 26-27 in Utrecht, the Netherlands, where we shall present the end terms and achievements of SHARE.**

### Location:

Congress center Woudschoten  
Woudenbergseweg 54  
3707 HX Zeist (near Utrecht)  
[www.woudschoten.nl](http://www.woudschoten.nl)

For optimal discussions and opinion making, representatives from patient organizations, national and European political parties, health care regulatory authorities (like EMA, NICE and NZA), health care insurance companies and pharmaceutical companies are invited as speaker and attendants. We look forward to meeting you in Utrecht on October 26-27th!

Please contact us for further details and for registration (no costs): [clusterb@umcutrecht.nl](mailto:clusterb@umcutrecht.nl)

*Bas Vastert and Nico Wulffraat*



## Program:

October 26, 2015

Presentation of the outcomes on each of the project aims realized by the SHARE work packages

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|---------------------|---|
| 09.00 - 09.20 hrs   | Opening. To be confirmed  |
| 09.20 - 09.40 hrs   | Addressing the needs in pediatric rheumatic disease throughout Europe: <b>Pavla Dolezalova</b> , Czech republic |
| 09.40 - 10.00 hrs   | Best practices for JIA: <b>Bas Vastert</b> , The Netherlands  |
| 10.00 - 10.30 hrs   | Best practices for JDM: <b>Liza McCann</b> , United Kingdom   |
| <i>Coffee break</i> |   |
| 11.00 - 11.30 hrs   | Best practices for SLE/APS: <b>Sylvia Kamphuis</b> , the Netherlands  |
| 11.30 - 12.00 hrs   | Best practices for rare vasculitides: to be confirmed   |
| 12.00 - 12.30 hrs   | Best practices for scleroderma: <b>Francesco Zulian</b> , Italy and <b>Ivan Foeldvari</b> , Germany             |
| <i>Lunch break</i>  |   |
| 14.00 - 14.30 hrs   | Advances in research ethics: the SHARE perspective: <b>Jasmin Kummerle</b> , Germany                            |
| 14.30 - 15.00 hrs   | Patient information for pediatric rheumatic disease: PRINTO   |
| 15.00 - 15.30 hrs   | Patient involvement in PRD: SHARED care! To be confirmed  |
| <i>Tea break</i>    |   |
| 16.00 - 16.30 hrs   | Education in SHARE. To be confirmed   |
| 16.30 - 17.00 hrs   | SHARE and beyond, the next steps. <b>Bas Vastert</b> , The Netherlands  |

*Diner*

19.00 hrs

October 27, 2015

New models for health care in Europe: discussing financial, ethical, practical and innovational issues and challenges for optimal care for orphan diseases in 2015 and beyond

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|---------------------|--|
| 09.00 - 09.30 hrs   | Patient involvement in health care. <b>Johan Hansen</b> , parent of a patient and senior researcher at NIVEL (Netherlands institute for health services research)      |
| 09.30 - 10.00 hrs   | The EMA view on orphan disease and therapies. Prof. <b>Koen Norga</b> , MD, PhD and vice-chair Pediatric Committee, EMA  |
| 10.00 - 10.30 hrs   | The Pharma perspective. To be confirmed.   |
| <i>Coffee break</i> |  |
| 11.00 - 11.30 hrs   | Value based care, the Karolinska experience: <b>Anne Carine Horne</b> , MD, PhD  |
| 11.30 - 12.00 hrs   | AIM and SHARE: <b>Menno Aarnout</b> from AIM (International Association of Mutual Benefit Societies, the European Umbrella organization of health insurance companies) |
| <i>Lunch break</i>  |  |
| 13.00 - 13.30 hrs   | Who's disease is it anyways, SHARED perspectives. Prof.Dr. <b>Nico Wulffraat</b>   |
| 13.30 - 14.00 hrs   | Plenary discussion   |