



SHARE

The Final Conference

October 26 & 27, 2015

Zeist, the Netherlands

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 **Single Hub and Access point for pediatric Rheumatology in Europe** 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

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

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

09.00 - 09.20 hrs	Opening. To be confirmed
09.20 - 09.40 hrs	Addressing the needs in pediatric rheumatic disease throughout Europe: Pavla Dolezalova , Csech republic
09.40 - 10.00 hrs	Best practices for JIA: Bas Vastert , The Netherlands
10.00 - 10.30 hrs	Best practices for JDM: Liza McCann , United Kingdom
<i>Coffee break</i>	
11.00 - 11.30 hrs	Best practices for SLE/APS: Sylvia Kamphuis , the Netherlands
11.30 - 12.00 hrs	Best practices for rare vasculitides: to be confirmed
12.00 - 12.30 hrs	Best practices for scleroderma: Francesco Zulian , Italy and Ivan Foeldvari , Germany
<i>Lunch break</i>	
14.00 - 14.30 hrs	Advances in research ethics: the SHARE perspective: Jasmin Kummerle , 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. Bas Vastert , 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

09.00 - 09.30 hrs	Patient involvement in health care. Johan Hansen , 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. Koen Norga , 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: Anne Carine Horne , MD, PhD
11.30 - 12.00 hrs	AIM and SHARE: Menno Aarnout 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. Nico Wulffraat
13.30 - 14.00 hrs	Plenary discussion