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REUMAMAMA'S EN -PAPA'S

*Info sessions for (future) parents with RMD
and
for parents with children with an RMD*



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London
8-11 June 2016



DISCLOSURES

- No conflicts of interest for this presentation/item

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European League Against Rheumatism

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Tailor made information for 2 target groups:

- **young (future) parents with an RMD**
 - Heredity, medication and pregnancy, how to take care of a child while having an RMD
- **parents of a child with an RMD**
 - Juvenile Arthritis, psychological effects, school

YOUNG (FUTURE) PARENTS WITH RMD

- **First session: Informal contact**
 - Sharing personal stories, concerns, experiences
 - Mix of young parents with RMD and young patients with a child wish
 - Session guided by a rheuma nurse
 - Session planned in Reuma Expertise Huis (neutral ground)

YOUNG (FUTURE) PARENTS WITH RMD

- **Second session: Clarification by specialists**
 - Based on quotes and questions gathered during first session
 - Gynaecologist and rheumatologist
 - Topics: heredity, medication, pregnancy, delivery, (breast)feeding, practical tips and tricks for taking care of children

YOUNG (FUTURE) PARENTS WITH RMD



PARENTS OF A CHILD WITH AN RMD

- **First session: Workshop psychological effects of having a child with RMD**
 - Sharing personal stories, concerns, experiences
 - Supported by working group ORKA (*Parents of RMD Children&Adolescents*)
 - Guided by a private psychologist
 - Mixed group: parents of ORKA and 'new' parents

PARENTS OF A CHILD WITH AN RMD

- **Second session: Clarification by specialists**
 - Based on quotes and questions gathered during first session
 - Rheumatologists, paediatrician, psychologist and parents of ORKA
 - Topics: juvenile arthritis and treatment, the impact of a child with RMD on family, school

PARENTS OF A CHILD WITH AN RMD



RESULTS

- **Both sessions were well attended:**
 - First session: 7 and 21 persons
 - Second session: 15 and 28 persons
- **More inscriptions > attendees first target group:**
 - Absence was RMD related (fatigue, pain, flare)
- **> inscriptions second sessions:**
 - Listening vs participation

RESULTS

- **Correct information regarding:**
 - Medication and pregnancy/breastfeeding, delivery, heredity, taking care of a child while having an RMD
 - The psychological impact of having a child with RMD on yourself as a parent, on family and school
 - Juvenile Arthritis

RESULTS

- **ReumaNet is working on brochures:**
 - Pregnancy and heredity
 - How to take care of children as a parent with RMD
 - Juvenile Arthritis
- Proofread by specialists and patients
- Special thanks to Reumafonds Nederland

CONCLUSIONS

- **Great need for information:**
 - Brochures + personal contact
- **Support of professionals is required and an added value during the live sessions**
- **Live sessions will be repeated every 2 years**
 - Constantly new people



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THANK YOU



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