

Monday, 18 May12:30 - 13:30 *Lunch*13:30 - 14:00 **Introduction and Overview (Margaret Sleeboom-Faulkner)**14:00 - 17:30 **What patient organisations do, how and why:**

Action Duchenne - Paul Lenihan

Muscular Dystrophy Association China - Changqing Zhu

Muscular Dystrophy Association, India - M Louis Stanislas

Taiwan Muscular Dystrophy Association - Yi-Chen Sun

United Parent Projects Muscular Dystrophy - Nicoletta Madia

15:00 - 15:40 Discussion

15:40 - 16:00 *Break*

16:00 - 17:15

Aspire UK - Brian Carlin
 Halfway Home in Beijing, China - Guan Yan
 Japan Spinal Cord Foundation - Masatoshi Ito
 Korea Spinal Cord Injury Association - Eungho Ahn
 The Spinal Foundation, India - Komal Kamra
 Unite to Fight Paralysis - Donna Sullivan

17:15 - 18:00 Discussion

19:00 *Dinner: The Regency***Tuesday, 19 May**

9:00 - 10:40 **The benefits and risks of working with medics and industry**
 The format of this session involves ALL DELEGATES

10:40 - 10:50 *Break*

10:45 - 12:30 **The search for therapy: costs, results and challenges**
 The format of this session involves ALL DELEGATES

12:30 - 13:45 *Lunch*

13:45 - 14:55 **Patient groups and knowledge activism**
 The format of this session involves ALL DELEGATES

14:55 - 15:30 Introduction: What kind of knowledge activism would be useful for my country (MSF - 5 min) - Individual reflection: 30 minutes to write this down

15:30 - 15:45 *Break*

15:45 - 17:30

What can we learn from other patient groups?

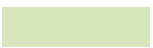
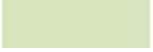
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Individual presentation on ideas for new patient group activities and Q&A

18:00

Drinks: The New Club

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